A Chronicle of

Indian Leprosy

(Commemorating 21st International Leprosy Congress 2022)

Editors:

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Foreword

Leprosy has been an integral part of the history of India over millennia. While India was known across the world from ancient times for its riches -cultural, spiritual and economic- later it also became infamous for its mystics, snake charmers, poverty and misery. One of the reasons for the swathes of poverty and misery could be that, India missed the benefits of industrial revolution and modernization for many centuries as it was reeling under the yoke of invasions, plunder and colonial rule.

Of many diseases prevalent at those times in the Indian populace, the malady leprosy attracted special attention of the medical fraternity due to its inherent nature of progressing to disfigurement. Unfortunately, India held and still accounts for a major chunk of global leprosy burden.

Indian leprosy over the last two centuries received generous munificence and compassion from the west. For these benefactors, India has been a fertile and readily available ground to test various extracts, oils, potions, medicaments and drugs through diverse trials for leprosy; be it Chaulmoogra oil, dapsone or clofazimine. These efforts ushered in improvements in the management of leprosy greatly, not only in India but across the world. The contribution of leprosy patients who were subjects of these trials, some successful and many just human experiments with hope, need to be remembered with humility. At the same time, we also need to reminisce with respect all those researchers, workers and doctors, some native and many from abroad, who toiled in this country and contributed to the cause of Indian leprosy.

While there are many documents which chronicled the tribulations of Indian leprosy, few discuss its accomplishments. Many wonder if India contributed to the growth of knowledge of leprosy at all, apart from being a passive receiver of largesse! But it is often not realized that while receiving the benevolence of donors and patrons, India too contributed to the the understanding of leprosy and its management. However, the story of how it contributed to the cause of leprosy has apparently not been documented or told in an orderly manner for posterity.

While working for this chronicle, to our delight we realized that there is more to the story of Indian leprosy than being assumed. There were great thinkers and philosophers, brilliant researchers, self-less workers, generous benefactors from India and abroad, who contributed to the growth of leprosy knowledge & welfare in substantial ways. Some of them started important institutions which till today continue to serve the cause of leprosy.

This handbook attempts to bring out an account of Indian leprosy in all these facets, may not be in full measure, but meaningfully, with contribution from a wide array of members who worked for leprosy over decades. We have endeavored to chronicle the work, done essentially over the last two centuries, detailing some milestones and contributors in a story-like fashion. Our intention was to design this chronicle for easy reading by a casual reader, while keeping the leprosy aficionados interested. We understand limitations of our

attempt and hence lay no claim to the completeness or comprehensiveness of information. Many important contributions of researchers and events must have been missed, in defense of which we can only plead of our limitations and constraints. Only thing I vouch for is that our intentions were sincere!

I take a bow to all the members of IAL & academy who encouraged, supported and contributed to this venture. Bringing out this Chronicle of Indian leprosy, commemorating the 21st International leprosy Congress 2022 has been a very gratifying exercise I have been a part of as President of this venerated association.

In the hope that this book will make an interesting reading to all….

P Narasimha Rao, MD, PhD,

President, Indian Associaiton of Leprologists

Message from the Academy

Leprosy research in India is an indispensable and constitutive part of leprosy. Many a thing were identified, documented in this part of the world both by Indian researchers and the foreign researchers working on Indian soil. A Chronicle of Indian Leprosy is an effort to bring out the work of these researchers and institutes in this hand book in a readable way. Thanks to the IAL president Dr P Narasimha Rao and Secretary Dr Sujai Suneetha for conceptualizing this idea and visualizing its need. On behalf of IAL Academy, we are grateful to them for providing an opportunity to be a part of this beautiful compendium.

A Chronicle of Indian Leprosy is not a scientific journey through the history of leprosy, but a kaleidoscopic view of the happenings in leprosy in India. The editorial team has made lot of efforts to collect and compile these works. We tried our best to include as many as possible, but we know that there will be definitely several shortcomings and the list may not be complete. The omissions were not intentional. We tried to bring together some facts and facets how, we as citizens of India tried to overcome the disease and its after effects. Our sincere gratitude to all those researchers, working for decades in this field of leprosy and contributed to this book with their rich experience.

We wish the information provided in this book about the contributions of various researchers in India, and can be a guide for future generations.

Have a happy reading.

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SECTION I

LEPROSY IN ANCIENT AND COLONIAL INDIA

01

Leprosy In India—Ancient knowledge and wisdom

P Narasimha Rao

Leprosy has afflicted human populations for millennia, whose importance and influence on civilizational growth is recorded both in scriptures as well in the history of mankind. We may not be in complete agreement as to where leprosy first appeared, but one thing is perfectly clear that the disease has been known in Africa and India for 3000 years at least.

Statue of Sushruta in Royal Australia College of Surgeons, Melbourne

Three religions are regarded as the oldest having come down to us from pre-historic times. They are Hinduism, Zoroastrianism and Judaism. In the earliest sacred writings of the world, there are allusions to a number of diseases which had evidently impressed ancient peoples. But one disease stands out more than all others by its gravity and terrible nature is leprosy, which as a malady has stamped itself on the popular imagination. From the most ancient literature downwards to the present time, there is an unbroken chain of references to this disfiguring and terrible scourge which came to be termed leprosy, from the Greek word lepra. Good number of references to leprosy are present in these literatures.

Leprosy is referred to in several places in the Avesta, the primary collection of religious texts of Zoroastrianism and in the Old Testament, the holy book of Jews. However, in the records of many ancient literature descriptions of leprosy are usually so vague that it is very difficult for us, in most instances, to identify it as known and classified at present times; and the descriptions of disease in the Bible form no exception to this rule. On the contrary, the ancient Indian literature provides the most vivid description of leprosy, while theorizing wildly about its cause.

Let's examine some of these details of relevance to India. Hinduism also known as 'Sanaatana Dharma' has the largest collection of ancient religious texts and scriptures, which are considered holy by its followers and passed on to generations over millennia. They can be broadly classified as Vedic literature, Puranas and Itihasas and others. In addition, Buddhism, an important world religion, has originated from India between the 6th and 4th centuries BCE and Indian thought greatly influenced it. Added to these, there are numerous

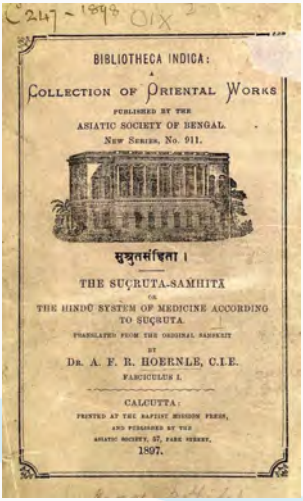
texts of ancient Indian medical literature, under Ayurveda, the Indian system of Medicine.

Fruit and leaves of Chaulmoogra plant

Of ancient India, Vedic scriptures are considered the oldest recited texts of humankind. Vedic Sanskrit is the language of the Vedas consisting of Samhitas, Brahmanas and Upanishads. The metrical hymns of the Rig Veda Samhita, the oldest of Vedas are regarded as the earliest compositions of man. Western historians and experts date Rigveda as created around the year 1500 BCE, while many Indian researchers believe them to be much older, near to 3000 BCE.

Rigveda Samhita mentions Kushtha, a term covering leprosy, as well as some other skin afflictions. (The etymology of the Sanskrit word "kus- tha" is "kusnati iti kustham", from root "kus" + suffix "kthan" meaning 'that which tears asunder'). Atharvaveda, which is the fourth of the of the Vedas, also has a reference to pathogenesis of leprosy and its cure by a plant extract of Kushtham, which goes like this- 'Leprosy which has originated in the body and upon the skin, the white mark begotten of corruption, I have destroyed with my charm'.

Of ancient Indian scriptures, Puranas contain stories and folklore of remote times. They describe the times, troubles and triumphs of those periods while presenting philosophical truths and precious teachings in an easier manner for common people. There are 18 main Puranas – all written by Veda Vyasa. There are an equal number of Upa-Puranas (Sub- Puranas). Number of them have references to Kushtha or leprosy. The Padma Purana, Garuda Purana, Ganesh Purana and Bhavishya Purana have mention of leprosy afflicting certain personalities. However, most times it is a curse inflicted on persons who do not follow their injunctions or a divine retribution for their misdeeds.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सुश्रुतसंहिता ।

THE SUÇRUTA-SAMHITÁ

OR

THE HINDU SYSTEM OF MEDICINE ACCORDING TO SUÇRUTA.

TRANSLATED FROM THE ORIGINAL SANSKRIT

BY

Dr. A. F. R. HOERNLE, C.I.E.

FASCICULUS I.

CALCUTTA:

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Itihasa 'traditional accounts of past events' refers to the collection of written descriptions of important events in Hinduism. The Sanskrit term itihāsa was derived from the phrase iti ha āsa which means 'so indeed it was'. Ramayana and Mahabharata are important itihasas and the reference to leprosy is present in both of them. "Kustha" finds mention in Santiparva and Anusasanaparva of Mahabharata. In addition to mention in these ancient scriptures, Kushtha as a disease is also mentioned in Bhartruhari Sataka (CE. 650) and Somadeva's Katha saritsagara (CE.11th century).

The history of leprosy is interwoven with civilization of India itself. It was supported by the recent anthropological evidence reported on the analysis of a 4000-year-old skeleton from India bearing earliest evidence for human infection with *Mycobacterium leprae*

in the world and the first evidence for the disease in prehistoric India. This skeletal evidence for leprosy was unearthed from the BCE 2000 site of Balathal located 40 km northeast of Udaipur in the contemporary state of Rajasthan, India, which had two phases of occupation at early Historic period (BCE. 760 - CE. 380) and a large Chalcolithic settlement (BCE. 3700–1820). The Chalcolithic people of Balathal lived in stone or mud-brick houses, made wheel thrown pottery, copper implements, and practiced dry field agriculture focused on barley and wheat, demonstrating Harappan influences, which was an advanced civilisation of that period.

What about the ancient Indian medical works and mention of leprosy? Before going into it, let us first briefly know about them.

Ancient India had a rich inventory of medical texts and treatises. For example, nine treatises by eleven different authors are mentioned in the ancient Hindu literature, viz., Athri, and Charaka Samhitas, Bhilatantra, Jatukarna Tantra, Parasara, Bharadwaja, Harita, and Karpara Samhitas, and Sushruta Samhitas; composed respectively by Athri, Charaka and Agnivesa, Bhila, Jatukarna, Parasara, Bharadwaja, Harita, Karpari, Dhanwantari and Sushruta. Of these five can be found at present, namely, Harita Samhita, Charaka, Sushruta, Bharadwaja, and Atri Samhitas ; and the remaining are supposed to be irrecoverable. Several commentaries are available on the existing Samhitas, each of which has two or three commentaries. Besides these ancient works, there are many relatively recent treatises on medicine that can be found in India, such as the Ashtanga-hridaya Samhita of Vagbhata, Sarngadhara Samhita and various others. At any rate medicine in India is of a very great antiquity.

Sculpture of Surya Deva (Sun god) at Konark Sun temple, Odisha

In order to understand their ideas and theories relevant to leprosy, a few prefatory remarks may not be out of place here. According to Ayurveda (centuries old Indian system of medicine) all maladies are considered to be produced by the derangements of the humours of the part, and by the peculiar diseases of that part. The entire system is supported by three humours/(or doshas), viz., vayu (air), pitta (bile), and sleshma (phlegm). If deranged they are the cause of disease and death; and with the blood they retain and eventually destroy the body. Without these three humours and the blood the individual could not exist. (Some way these are similar but more profound than the four temperaments or concept of 'humors' or bodily fluids that affect human personality traits and behaviours, proposed by Greek physician Hippocrates, and described as Sanguine, Choleric, phlegmatic and melancholic personalities.) With the essential parts of the body and the appendages and impurities, they form the fabric of the body. Their derangement leads to

illness and disease, which under these assumptions were divided into 11 classes and Kushtha stands as the 10th of the 15 orders of diseases under class II, which includes General diseases or diseases affecting the general system.

Coming back to the medical treatises, the most popular of these is the Sushruta Samhita which was probably compiled about 600 BCE, but it embodies traditional knowledge from even more ancient times. Charaka's work is considered to have been compiled even earlier, while VagBhata's compilation is of a little later date. References to leprosy are found in all of these ancient medical writings, but most detailed can be found in the Sushruta Samhita. Referring to the description of leprosy in the Sushruta Samhita, Lowe (1942) in his article "Comments on the History of Leprosy" states that 'this is actually the most valuable ancient reference which I have been able to trace, and it is also in many ways the most accurate and complete of the old descriptions. Under different heads it describes most of the signs and symptoms of leprosy, even in its milder form, with which we are familiar today.'

Sushruta Samhita has a clear description of leprosy. Under terms "Vat-Hakta" and "Vat-Shonita" there is mention of hyperesthesia, anaesthesia, formication and deformities. Under the designation Kushtha there were two kinds of skin lesions. In one the prominent symptoms and signs were local anaesthesia and deformities. In the other, the features were ulceration, falling off of fingers and sinking of the nose. It was described that the expansion of Kushtha from skin to the remaining elements of the body is compared with the gradual expansion of the roots of a tree in the earth. This text considered Kushtha to be a highly contagious disease transmitted from the diseased to healthy persons by the touch or breath of the patient, by sharing the same bed and by eating and drinking out of the same vessels with him, or by using the wearing apparel, garlands, etc., previously used by the patient.

Further, it was mentioned that Arun-Kushtha, a sub-type of Kushtha which appears to refer to leprosy more than other types, was described as characterized by the appearance of slightly vermillion coloured spreading patches; a sort of pricking pain is experienced in the affected parts which lose all sensibility to touch. Two sub-types of Arun-Kushtha are described; in one the prominent symptoms are anaesthesia and deformity of the limbs, while in the other type the prominent symptoms are suppuration of the affected part, breaking down of local skin, falling off of fingers, and sinking of nose. Paradoxically, while describing the disease as highly contagious, it was also mentioned as having a strong hereditary predisposition.

A reference to Kushtha is also found in other important books of edicts, for instance in the Manu Smriti (Laws of Manu), which accordioning to European scholars to have been written sometime from 500 to 1300 BCE., but in India is popularly regarded as of greater antiquity. One cannot be sure that the term mentioned there refers to leprosy alone, since it was seen as a general term to indicate many skin ailments, including leprosy. The context, however, makes it very probable that the term Kushtha in the Manu Smriti refers to a serious disease as Manu forbids marriages into families whose members are subject to certain diseases and defects, and Kushtha is one of them.

Reference to leprosy, are available in Buddhist literature. Vinaya-Pitaka mentions that men and women suffering from "kutta" (Sanskrit "Kushtha") were not eligible to get "upasampada" or admission into the order of monks. "Pabbaja" or going abroad was also prohibited for them.

Vinaya-pitaka (Maha- vagga) records that this was one of the five diseases prevalent among the people of the Magadha empire. Jain texts, "Acaranga" (CE. 6th century) and Vipaka-Sutra (CE.12th century) also mention leprosy. The holy scripture of Sikhs Sri Guru Grandh Sahib relates leprosy to sins like allurement or attachment and reprobation.

Treatment of Kushtha has been prescribed by the application of various herbal extracts and oils in ancient medical treatises of India with varying grades of relief. And what is noteworthy was that it was not considered incurable. Most important of them is the Chaulmoogra plant.

The use of Chaulmoogra (*Hydnocarpus wightianus*) plant extracts for their medicinal values, has a long history in Asian countries such as India, China and Burma. It entered Western medicine only in the nineteenth century, through the efforts of British physician Frederic John Mouat in 1854. In India even today it grows in tropical forests along western Ghats, along the coast from Maharashtra to Kerala, Assam, Tripura, often observed along roadsides in hilly areas.

Both Chaulmoogra extracts & oil and the purified esters of this oil have been used in the East against leprosy and various skin conditions for many hundreds of years with varying results. Traditionally it has been a part of repertoire Ayurvedic medicine against leprosy in Indian subcontinent and was used as an external application through massage.

In addition, emetics were recommended to be administered in the manner prescribed. For example, a decoction of Kutaja Phala, (fruit of Wrightia antidysenterica), Madana, (fruit of Randia dumetorum), Madkuca, (fruit of Bassia latifolia), Patola (fruit of Lagenaria vulgaris) and others were suggested as beneficial for patient of Kushtha.

In addition to these medicaments, penance, austerity, Sun worship were also mentioned as approaches to get relief and cure from this malady, not so much in medical treatises but in Purana-Itihasas. Samba, the son of Lord Krishna, who contracted leprosy due to a curse, supposed to have got relief from it after a prolonged penance and Sun worship. It has already been stated the word Kushtha encompasses a number of skin diseases, some scaly and other with pigment alteration, including leprosy. And with advances in understanding of medical science, now we are aware that sunlight certainly has beneficial effects on some of the scaly disorders (e.g. psoriasis) and pigment dilution (e.g. Vitiligo) of skin.

World leprosy in 1891

From the above descriptions of Kushtha in various Hindu religious books and medical writings of ancient India, some of them older than 2500 years, one could conclude that leprosy was well known disease in this part of the world. At the same time, we can also note that it was a much-dreaded disease, which made the affected ineligible for a number of social functions, responsibilities or

status. The references to Kushtha in some of the ancient literature of India stand out as a very honest clinical description of the disease, including sensory changes and deformities, and one can therefore feel sure that it actually refers to leprosy as we know it today. In these scriptures we find a mention of treatment of leprosy with chaulmoogra (hydnocarpus) oil which have been globally accepted in the management/treatment of leprosy, till the discovery of Dapsone. Ancient medical literature of no other country contains such a near complete description 'of leprosy, which also points to its prevalence in this part of the world consistently over the last few millennia. Dispassionate reading of these ancient treatises provides us a window to have a peek at the distant past and would make one wonder how tirelessly efforts were made to record the varied presentations of this disease, albeit imperfectly. The dogmas which prejudiced their thinking in putting forward a panacea for the management of this distressing malady with the available knowledge, resources and societal influences of those challenging times need to be contemplated before brushing them off as irrelevant to the present.

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"If we are to make progress, we must not repeat the history but make new history. We must add to inheritance left my our ancestors."

-Mahatma Gandhi

02

Management of leprosy during the colonial era (1850–1947 CE) in India

Santoshdev P Rathod, Arwinder Brar

Introduction:

Colonial India was the part of the Indian subcontinent that was under the jurisdiction of European colonial powers during the 'Age of Discovery'. It is believed that the colonial era in India started with the establishment of a Portuguese trading centre at Quilon in the year 1505 CE and lasted till the Indian Independence in the year 1947 CE. The history regarding the origin of leprosy is wrought with questions and is still debated. Western literature often depicts a pattern of trying to establish the spread of leprosy to their civilization as a direct result of colonization. However, this has proved futile as various ancient religious scriptures from around the world document leprosy much before colonization. It is interesting to learn how different countries were managing this great malady and what ultimately put us on the correct path of disease elimination which we are now on.

At the beginning of the chapter, I must thank the editors of this book for conceiving the idea of a book on 'The Chronicle of Indian leprosy'. It is important to note India's contribution to the science and knowledge of leprosy. As we delve deeper into the details and past publications during the colonial era, we quickly learn that at a time when the understanding of leprosy and its management was naïve and rudimentary, the population of Indian patients affected with leprosy proved to be a fertile ground for experimentation and drug trials, both topical and systemic, by the western physicians. This is clearly reflected by the numerous treatment experiments carried out on Indian patients in the 19th century documents. (Report of the Leprosy Commission in India, 1890-91) At least till the advent of Dapsone in 1940s, it is safe to say that India can claim to fame in the knowledge that the treatments tried by their ancestors for leprosy, e.g. Chaulmoogra oil, were one of the better options for the effective management of leprosy across the world.

We shall attempt to describe how leprosy was managed during the British colonial era (1850 – 1947) in India. Here it is important to note the view of traditional systems of medicine which were deeply rooted in the Indian 'natives' and certain management decisions which were imparted on them by the then 'administrators'.

Treatment of Leprosy according to traditional Indian systems of medicine: In the Vedas, natural elements such as Sun, Fire, Water, Air, Moonlight, etc. have been considered as panacea for various diseases. The seven rays of the solar spectrum was considered curative and are mentioned to be effective treatment for Leprosy.

Various texts of the ancient Indian system of medicine have indicated 'Samshodhan Karm' (purificatory measures) with great stress in the treatment of 'Kushthas' (skin diseases including leprosy). These measures have been prescribed not only before the administration of specific drugs, but also to be repeated several times in between the actual drug therapy. This particular procedure consists of several different processes, one of which for the treatment of leprosy is 'Snehana' (oleation), which was carried out in two steps namely, inunction of 'Tubarak Taila' (Hydnocarpus oil) mixed with equal parts of 'Nimb Taila' (Azadirachta indica oil), followed by 'Vamana' (emesis), 'Virechana' (purgation) and 'Raktamokshana' (blood-letting). Bloodletting was usually not performed for leprosy patients as they were considered anemic.

This concept of 'Snehana (Oleation) brought about the utility of vegetable oils for treatment of leprosy. Two predominant oils used for the management of leprosy included gurjon oil and chaulmoogra oil. Chaulmoogra/Chaulmoogra oil (also called Hydnocarpus oil) was preferred over gurjon oil because patients regarded its action as milder and because it left the skin softer. Gurjon oil, commonly known as gurjon balsam or wood oil, was derived from the Dipterocarpus turbinatus tree (perfected by Surgeon Dougall of the Madras Medical Service). Four-drachm dose (1/2 oz /14g) of gurjon oil and lime water mixed in equal portions was also given.

The Chaulmoogra oil was introduced into Western medicine by British physician Frederic John Mouat in 1854. He was a professor at Bengal medical college and wrote a paper about favourable results of chaulmoogra oil in leprosy patients in the Indian Annals of Medical Science in 1854. He had tried chaulmoogra oil as both topical formulation in the ulcers of leprosy patients as well as in the form of a tablet, both forms being effective. As the use of Chaulmoogra oil and its derivatives became more widespread, the demand for the oil increased globally. The downfall of Chaulmoogra came about through the introduction of the sulfones to treat leprosy in the 1940s.

Influence of administration on the management:

The report of the leprosy commission 1880 is a good document to study and understand the thinking of researchers and writers of then prevalent times. It includes a census of the Indian population and compares the findings of three censuses that took place over years (1st census 1867–1872, 2nd census 1881 & 3rd census in 1891). The specific imperial request was made to calculate the leper population of India with the objective being to gauge how much the 'British Empire' was at risk of leprosy as leprosy was considered an 'Imperial Danger'.

This report was a very meticulous and methodical study akin to currently conducted epidemiological studies. The report studied the prevalence of leprosy across Indian provinces which varied from 4–15 per 10,000 population. and its relation to soil, climate, race and other factors like cleanliness, income, and eating habits. Most common age of presentation was between 26–30 years of age. It mentions that the mean duration of taburculated form of leprosy was nine and half years while that of anaesthetic form (which later become to be known as neural leprosy) was eighteen

and half years. It also examined the possibility of hereditary mode of transmission of leprosy among family members and conclusively refuted the possibility of the same. Findings of the report suggest that the disease is caused by an organism (bacteria) which has low infectivity and it doesn't spread by heredity or by specific eating habits like fish eating which was a belief prevalent both in orient and Europe as a cause of leprosy, was investigated across India.

The report also highlights the then prevalent leprosy management in India. The important message coming from the report of the commission was that treatment was mainly palliative and it recommended against the segregation of the leprosy patient, due to its low infectivity. It divided management into mainly three forms; hygienic, medicinal and surgical. The medicinal management consisted mainly of the application of various vegetable oils externally and the use of mercury and arsenic internally.

Missionary interest in leprosy:

During this period, missionary interest in leprosy developed greatly, which contributed to sustaining public concern. In 1874 Wellesley Bailey founded the Mission to Lepers in India, which was to become the major Indian organization concerned with leprosy. By 1893 the Mission to Lepers had 10 asylums and supported 8 others; in 1899 it maintained 19 asylums, and aided many others. Missionary publications on leprosy drew on Biblical representations, and Wellesley Bailey's comment is typical of this discourse: "The utter helplessness and dependence of these folks on others is a continual picture of the way sinners have to come to God and get His blessing".

In 1889, shortly after Father Damien's death, after contracting leprosy at a leprosy colony in New World, the contagion theory gained ground. A National Leprosy Fund was instituted under the patronage of the Prince of Wales, whose activities included the appointment of a Leprosy Commission for India. At the all-India level, a draft bill on confinement of lepers was circulated for comments to a wide cross section of the population, including colonial officials, European and Indian medical men. This resulted in the Lepers Act of 1898, the major legislation on leprosy of the colonial period of India, which represented a typically colonial solution to a health problem which did not touch colonial interests. Here the medical definition of leprosy was equated to vagrancy and ulceration with contagion. The Act went against the grain of the Leprosy Commission, whose report the government had accepted previously.

Description of various modalities of treatment in a chronological order during the colonial era:

Timeline: Important events with regard to development of leprosy management in India

1853	Professor F J Mouat of the Bengal Medical Service introduced chaulmoogra oil to Western medicine for the treatment of leprosy (Feeny Ch 12).
1857	Successful use of chaulmoogra oil in Bengal (Mouat) International Journal of Leprosy: Centennial Festskrift, 1 1873-1973.

1869	Use of Hydnocarpus oil in the treatment of leprosy by Dr Bhau Daji Lad in J J Hospital, Bombay.
1873	After meeting Dr Hansen, Dr Henry Carter demonstrated *M. leprae* in J J Hospital, Bombay, to other colleagues.
1874	Irishman Wellesley Cosby Bailey founded in 1874 'The Mission to Lepers' in Ambala, India, which later subsequently became 'The Leprosy Mission 'in 1973.
1924	The British Empire Leprosy Relief Association (BELRA) was inaugurated by The Prince of Wales (later King Edward VIII) at Mansion House, London, which operated in Indian subcontinent.
1945	R G Cochrane principal of Christian Medical College at Vellore in South-East India - given DDS in pure form to use (Dr Molesworth, Head of Ghanian leprosy service) (P S Narayanaswami published results in International Journal of Leprosy)
1946	'Promin', first sulphone compound brought into use as treatment of leprosy at the Acworth Leprosy Home. 'Dapsone' therapy, however, started by 1950. Reconstructive Surgery Unit opened. (Bhatki, Report on Anti-Leprosy Activities in Mumbai)

Segregation as management strategy and advent of Leprosaria:

It is important to note here that the concept of isolating leprosy affected people was widely prevalent in Europe before it was brought to India by the colonisers. First leprosy asylum was built in Portugal in the year 1000 & 1067 in Spain while the first leprosaria in India too was established by Portuguese in the year 1587 at Madras with rent money. Now while this Chronicle is getting ready in time for the 21st International Leprosy conference and advocating inclusiveness, it can be noted with a tinge of irony how the First International Leprosy Conference, held in Berlin in 1897 had adopted segregation as the global response to the renewed threat of leprosy. In fact, the 1909 second international Congress Bergen, reaffirmed recommendation for control by isolation and segregation; and further recommended removal of children from leprous parents as soon as possible. Those were different times, indeed! This medical edict had resonated religiously and led to establishment of leprosy colonies. This also shows the distance we have traveled along in the past 125 years and how our thinking and knowledge evolves over time. Nonetheless, as a legacy, we still have more than 700 leprosy colonies across India.

Conclusion

It is difficult to ascertain whether the management strategies employed were primarily the Indian way of thinking or reflective of their rulers. As we see, most of the medical institutions in India were headed by the foreign faculties and it is safe to conclude that management of leprosy in India during Colonial times, while marked by the influence of Indigenous medicine and beliefs, the decisions were made based on the Western way of thinking and interpretation. The early history of the Mission to Lepers in India is a good example of such

interplay between politics, religion, and medicine in the context of British imperialism. The Mission pursued the dual but inseparable goals of evangelization and civilization of natives, advancing not only a religious program but also a political and cultural one. These activities and their consequences were multi-faceted because while the missionaries pursued their religious calling, they also provided medical care to people and in places that the colonial government was unable or unwilling. Because it symbolized Christian charity, leprosy care drew donations and support for the missionary movement of the nineteenth century.

While the British brought techniques of surgery and modern medicine including Dapsone in the management of Leprosy to India, a great deal of Western medicine for leprosy during the 19th century was based on Chaulmoogra oil and its derivatives till the advent of Dapsone in 1940s. The concept of isolation of leprosy patients doesn't bear Indian basis. However, persons affected by leprosy from India were the major contributors towards the development of evidence based medicine in leprosy.

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03

Ridding the Empire of Leprosy: Sir Leonard Rogers and Chaulmoogra Oil, 1915–1924

Shubhada Pandya

When a physician boasted of his success with this drug or that electric cabinet, Gottlieb always snorted, "Where was your control? How many cases did you have under identical conditions, and how many of them did not get the treatment?'

Sinclair Lewis and Martin Arrowsmith

Note: The use of the term 'leper' in this article is in historical context, not in a pejorative sense.

Introduction

Leprosy presented a formidable therapeutic challenge to 19th Century British colonial medical men in India. They were unfamiliar with plant-based remedies recommended in Ayurvedic medicine. One such, the oil of chaulmoogra, came to general notice after a favourable report published in 1854 by F. J. Mouat (1816-1897) of the Calcutta Medical College.

The present article examines the experimentation on chaulmoogra oil which led to the first formal campaign to "eradicate" the disease in colonial India. Underpinning the campaign were clinical trials conducted by Sir Leonard Rogers(1868-1962) of the Bengal cadre of the Indian Medical Service (IMS), Professor of Pathology at Calcutta Medical College. (Fig 1)

Rogers was a renowned member of the IMS. Unlike his peers who made their name in tropical medicine by discovering causative organisms or disease vectors, Rogers's fame rested on tropical disease therapeutics, e.g., emetine in amoebic dysentery, hypertonic saline in cholera, tartar emetic and pentavalent antimony in kala azar, antidotes to snake venom. Understandably, he was attracted to an opportunity to close his almost 30-year India career with another therapeutic triumph -- the successful treatment of leprosy. Rogers's tangible legacy in India is the "Calcutta School of Tropical Medicine" which materialized in 1921, by which time he had retired. The school was the nerve-center of leprosy clinics and field work till Independence.

Traditional Plant Oils

It was stated in Ayurvedic texts that the oils expressed from the seeds of Taraktogenos kurzii ("chaulmoogra", from North-East India) , and Hydnocarpus wightiana, ("kowti", "marotti", from coastal West and South-West India) were reliable remedies for skin diseases including

leprosy. Unfortunately, the oil taken by mouth induced severe nausea and vomiting and patients refused to persevere with the treatment.

It was the United States of America, an emerging colonial power in the late 19th century which scientized traditional knowledge. The putative active principle in chaulmoogra oil was identified and administered in an injectable form to by-pass the oral route. American organic chemists worked chiefly with the ethyl esters of the fatty acids of chaulmoogra oil. Rogers was urged into leprosy therapeutics in 1915 by Victor Heiser, Director of the Rockefeller Foundation, who insisted that he postpone retirement to work on the problem of "a swift-acting leprosy treatment".3 Rogers consented, for he was a demon for hard work – not for nothing was his autobiography titled Happy Toil.

Medical Knowledge on the Natural Behavior of Leprosy Relevant to Treatments

The observation that leprosy showed spontaneous remissions and exacerbation, and even self-healed in some sufferers, had a direct bearing on objective assessment of experimental therapies. Two authorities who were surely known to Rogers advocated skepticism regarding hasty claims of cure.

"… All reports as to recoveries [after treatment], such as have been brought forward recently, should be accepted with caution. They all are open to the reproach that they were observed for too short a time after the supposed recovery, and too little consideration has been given to the fact that leprosy without any treatment occasionally comes to a standstill for several years, and even a retrogression of the symptoms may occur."

Sir Patrick Manson, the "father of tropical medicine" virtually echoed the caution. 'One is very apt to be deceived in estimating the value of a drug in leprosy…. In the natural course of events, and without treatment of any description, especially if the patient be placed under favorable hygienic these acute manifestations tend to become quiescent, and the disease temporarily to ameliorate. Observers are too apt to attribute this natural and temporary amelioration to whatever drug the patient may happen to be given at the time. Moreover, in judging the value of any drug in leprosy, it must be remembered that the disease may be arrested spontaneously, or even be recovered from, without the use of any drug. Others also cautioned against premature jubilation regarding putative remedies. It is impossible that Rogers was unaware of these limitations. Blinded therapeutic trials as we know them today were still of the future, but the importance of objectivity and avoidance of personal bias by randomization of experimental subjects was rigorously followed by a medical researcher in India in the late 19th century.

Rogers and Leprosy Therapeutics

Rogers turned to organic chemists Chunilal Bose and Sudhamoy Ghose to obtain soluble derivatives of chaulmoogra oil. Unlike American chemists who used ethyl esters, Rogers and the chemists set their sights on the soluble sodium salts -- sodium chaulmoograte and sodium hydnocarpate (the latter referred to as "sodium gynocardate A") which caused negligible local irritation when injected sub-cutaneously and advertised them. (Fig 2)

Within a year of commencing his clinical trials Rogers reported interim results with the sodium salts, thereafter, updating the numbers in reputed medical journals as more (unselected) patients were recruited. Successive publications were peppered with phrases such as "most encouraging", without "ill-effects beyond temporary giddiness and headache and occasional localized clotting in the vein", "substantial advance", "a most remarkable and encouraging discovery", "unparalleled in any human disease of bacillary origin". It was claimed in one update that subcutaneous injection to nine patients for "six months and over" resulted in restoration of sensation and muscle power in some.

In 1917, Rogers published a tabulated summary of "Two years' experience" with the injection of sodium salts in 26 patients. The paper's title itself was a good example of his facility in manipulating the idiom -- withholding specific details of results. He reported that subcutaneous route for sodium gynocardate, though non-irritating locally, was less effective therapeutically than the intravenous. He employed intravenous gynocardate extensively, noting no ill-effects beyond "temporary giddiness and headache and occasional localised clotting in the veins and the results have been most encouraging. All the patients have shown improvement. The lesions have disappeared and become bacteriologically negative in 50% of the cases treated within 3 years of the onset of the disease, including cases treated from only 3 to 12 months; while in cases from 3 to 15 years' duration, 25% have cleared up under treatment." Contrary to what he wanted his readers to believe from the title of his paper, only 2 patients had been administered the chaulmoograte injection treatment for two years!

By 1919, Rogers replaced chaulmoograte with sodium hydnocarpate (hydnocarpus oil being cheaper and easily available). By 1920, his last year in India, his patient tally from 5 ½ years observation for "upwards of a year" was 51 patients. But of these, only 13 had had the injections for "upwards of a year". As for his dismissal of "occasional localized clotting in the veins", a young physician from Britain who spent a few months with Rogers in 1917 recalled that on each visit by a patient Rogers had to search for a new vein; eventually he was forced to use veins in the hand and even the foot because the previously injected vessels were thrombosed due to irritant chemical action of sodium hydnocarpate solution."

In 1920, Rogers attended a gathering of leper asylum missionaries and presented before them a new paradigm based on his claimed successes with hydnocarpates and chaulmoograte and suggested that our leper asylums can be converted into leper colonies and hospitals, to which earlier cases will be attracted by the prospect of receiving beneficial treatment.

Nobel Prize Nominations

Rogers was a nominee for the Nobel Prize in Physiology or Medicine in 10 nominations from 1907 to 1940 for contributions to tropical disease therapeutics. Leprosy found a mention in 6 Nominations post-1929. Among the Nominators were three IMS officers connected with the School of Tropical Medicine and the Medical College.

Post-Retirement Leprosy Work

On return to Britain after 1921, Rogers spoke before august medical bodies such as the Royal Colleges of Physicians of London and Edinburgh respectively about the 51 patients treated

for 'upwards of a year' and wrote in respected medical journals such as Edinburgh Medical Journal.

In 1924 as a member of the Medical Board of the India Office he initiated an ambitious campaign to "stamp out leprosy in the British Empire, probably within three decades" It was Britain's imperial duty, declared Rogers, to provide "our lepers" with the benefits of the latest treatment. The organisation which Rogers headed was the British Empire Leprosy Relief Association (BELRA). With Rogers at the helm of BELRA affairs in London, the British Empire entered an era of 'chaulmoogrification'. [Figure 3] Hydnocarpus wightiana saplings were distributed throughout leprosy-affected countries. The Indian Council of BELRA (IC-BELRA) despatched saplings from Kerala to all leper asylums. The trees still survive in some old asylum compounds. IC-BELRA, head-quartered in Calcutta, was responsible for the country-wide "Propaganda-Treatment-Survey" (PTS pattern) of control utilizing chaulmoogra oil derivatives.

Conclusion

Rogers lived long enough to see India independent and to introspect on the value of his chaulmoogra oil studies. Despite the final bursting of the Chaulmoogra therapy balloon, he remained steadfast on its supposed therapeutic efficacy. In 1948 when the sulphones, a new class of chemotherapeutic anti-leprosy agents appeared on the scene, he tried desperately not to be forgotten by posterity by resorting to a re-print of his 30-year old newspaper article. "Conquest of the Leprosy Scourge: How I Found a Cure for the World's Most Dreaded Disease". Post-Independence IC-BELRA was transformed into Hind Kushta Nivaran Sangh, (HKNS) and its PTS Scheme into "Survey-Education-Treatment" (SET) based on the sulphones.

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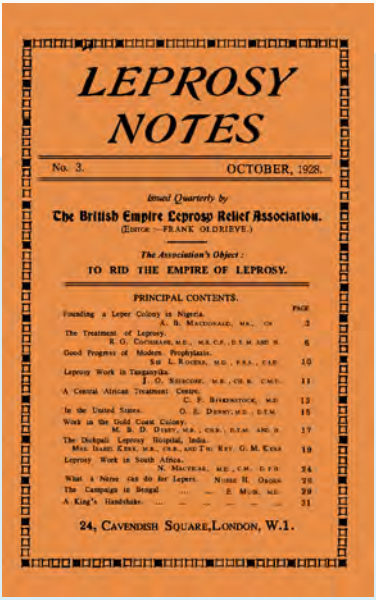
04

Leprosy Census & formation of BELRA (British Empire Leprosy Relief Association)

Kiran Katoch

During the British rule, leprosy in India achieved visibility in the second half of the nineteenth century, following the take-over of the administrative services by Britton from the East India Company. In 1852 the first leprosy census was undertaken by the Royal College of Physicians in wake of the West Indies leprosy epidemic. They estimated that about 99,073 persons were suffering from leprosy in British India. Their study drew considerable criticism as they concluded that the disease was hereditary and non-contagious. However, In 1874, Armauer Hansen discovered the bacillus, *Mycobacterium leprae*, in the tissues of leprosy patients and, established it to be the causative organism of the disease. Hansen rejected the concept of heredity, and held leprosy to be a contagious disease. He advocated confinement of patients as the preventive measure. Similarly, during the same period, a legislation was enacted in Norway in 1885 for the compulsory confinement of patients who did not conform to a strict regimen of isolation in their homes. Amid growing acceptance of the communicability of leprosy, in 1887 and again in 1889 the Royal College of Physicians recommended another investigation. The medical concerns were increased by fears of a leprosy epidemic in Hawaii, and following the death from leprosy of Father Damien de Veuster, a Belgian priest who worked for and with leprosy patients isolated on this island. To many his death proved that leprosy was indeed contagious, and this led to panic reactions, which called for compulsory confinement of patients as the only means to stem the onslaught of the disease. Shortly after Father Damien's death, a National Leprosy Fund was instituted and also the appointment for leprosy Commission in India. under the patronage of the Prince of Wales. This Leprosy Commission was formed to investigate the aetiology and epidemiology of leprosy. The Leprosy Commission concluded that leprosy is a disease *sui generis* caused by a bacillus having striking resemblance to tuberculosis. It is not a hereditary disease; it may spread by contagious means although the chances for that are very small. However, its spread is influenced by poor sanitation and malnutrition. The Commission suggested that segregation might not be fruitful in India. It suggested a prohibition on the sale of food articles, prostitution, and other occupations involving direct interference with people like barbers or watermen by the infected people. It insisted on the improvement of sanitary and living conditions. However, the 1st International Leprosy Congress at Berlin (1897) concluded that "every leper is a danger to his surroundings" and recommended segregation; it also declared leprosy to be "virtually incurable". Efforts by Indian elite groups in Bombay, working with Dr Henry Vandyke Carter, an officer of the Indian Medical Services (IMS), resulted in the establishment of several leprosy asylums in the



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(Editor:—FRANK OLDRIEVE.)

The Association's Object:

TO RID THE EMPIRE OF LEPROSY.

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24, Cavendish Square, London, W.1.

Leprosy notes printed by BELRA in 1928

region. The British Government of India passed the All-India Leprosy Act in 1898 and Leper Asylums were established in major parts of the country with forcible segregation of leprosy patients. Various surveys, surveillance and research was carried out on the distribution of lepers, hereditary transmission, predisposition possibilities, contagiousness, and relation of disease with sanitation and diet. It was also reported during this period, that, leprosy patients in India had decreased to 102,000 in 1821 from 120,000 and 110,000, as reported in 1881 and 1891 respectively.

Establishment of asylums and segregation of leprosy patients from society did offer scope of experimentation on these patients with newer modes of treatment. However, the sufferings of gender segregation, separation from families, difficulties in following the religious rituals and teachings by individual inmates of asylum, and lack of medical facilities for self-care, wound dressings, care of eye and surgical care were the main difficulties of the inmates as well as asylum administrators and workers. These asylums were in all parts of the India from Travancore, Adoor , Almora, Agra, Champa, Purulia, Manicktala, Supathu, Ramachandrapuram etc. There were also some unrests in some of the asylums and homes due to the segregation and shortcomings. In some asylums some medical services were made available by the intervention of Dr E Muir in 1920's, who was from the Calcutta school of Tropical Medicine. However. the problems persisted in several State run as well as Missionary run asylums.

On 31 January 1924, the British Empire Leprosy Relief Association (BELRA) was officially founded, with the financial support of Sir Frank Carter, a Calcutta businessman & philanthropist, The Association was inaugurated by the Prince of Wales (later King Edward VIII) at The Mansion House in London. Major General Sir Leonard Rogers, an ex-Indian Medical Service doctor and Rev. Frank Oldrieve decided to work together for the Association. Sir Rogers had earlier also treated leprosy patients with Chaulmoogra oil and had reported good results. As a head of a Medical Organization he shifted the focus to treatment of leprosy cases rather than segregation.

Some salient milestones achieved by BELRA:

In 1928, a pamphlet entitled 'Leprosy Notes' was begun to share information on the disease, its communicability and possible treatment. This contained news of leprosy related activities in various countries ruled by the British as well as some treatment modalities being observed on leprosy patients which included the Chaulmogra oil being investigated by Dr E Muir in School of Tropical Medicine, Calcutta, India.

In the year 1929, Dr Robert Cochrane took over the work in BELRA from Rev Oldrieve and began his long association with BELRA by becoming its Medical and General Secretary of the Society. He also published his work and thoughts in the "Leprosy Notes". In 1930 'Leprosy Notes' becomes 'Leprosy Review' a more scientific journal to encourage and disseminate evidence-based work on people affected by leprosy. This was widely circulated on the Empire states and Europe and was well accepted. In 1931 with ardent, huge follower, subscribers and growing popularity of the "Leprosy Review", the organizers and delegates at the International Leprosy Congress in Manila, recognized BELRA as the 'First leprosy Prevention Organization.

As a substantial amount of funds and manpower was needed to run the asylums, Journal as well as leprosy related research, the British Government started raising funds from philanthropists, public as well as students to keep the leprosy related activities moving and growing. In 1935, a Child Adoption Scheme was launched as a method of raising funds for treatment of children who were in-patients at leprosy hospitals and asylums. The child patients are connected with a particular UK sponsor for his/her upkeep, treatment and education. This scheme was launched by the Prince of Wales in London. The Royal family adopted children through BELRA's Child Adoption Scheme in 1948.

BELRA is also credited as one of the first organisations to methodically start a trial of use of Dapsone as a treatment for Leprosy and record its impact, This study was launched in 1947. Observations in the studies lead to introduction of this cheap, relatively safe drug in the armamentarium for treatment of leprosy.

Taking into consideration the enormous effort as well as the compassion and upliftment of leprosy patients and their families, Dr Robert Cochrane was appointed as the Advisor to the UK Ministry of Health. After the Queen Victoria became the patron of the Association in 1952, the organization continued to work in India, Bangladesh and Africa. BELRA is also credited with the development of Clofazimine (B663) as an anti-leprosy drug in 1961. It became an important member of the International Federation of Anti-Leprosy Associations (ILEP) and supported the Government in its anti-leprosy campaign and National Program. It changed its title from BELRA to LEPRA (Leprosy relief Association) in 1964.

"References to various skin diseases resembling leprosy are found in ancient Indian texts like Atharva Veda (2000 BC) and the Laws of Manu (1500 BC). The Sushrita Samhita (600 BC) recommended treatment of leprosy with oil derived from the Chaulmogra tree."

05

Discovery of *Mycobacterium leprae* and its impact

Mallika Lavania

I was asked by my lecturer "Who was the first to discover lepra bacilli?" when we attended our first class of post-graduation in the National JALMA Institute of Leprosy and other Mycobacterial Diseases, Agra [also known as JALMA]. One of us fumbled 'Hansen'. Sir was pleased with the response and insisted on hearing more from his students than simply their names. However, as much as we tried to connect a few disconnected phrases like Norway, leprosy, and bacilli to this moniker, none of us had a thorough understanding of the history. The remainder of the course concentrated on molecular, clinical skills and leprosy fundamentals during the degree programme. But Hansen's hidden story lingered in the back of my mind, and the enormous painting on the wall was like a bookmark, urging me to turn the pages of history every time I went past him in the canvas. As I dug deeper, I discovered a fascinating narrative about a brave heart scientist who was rightfully recognized for discovering the leprosy bacilli, and a guy who spent a lifetime of scientific research turning one of humanity's greatest scourges into a treatable disease.

History of *Mycobacterium leprae* discovery:

The discovery of leprosy bacillus was a pioneering venture and the result of an interaction between medical research and public health work. However, this discovery was based on many frameworks that existed long before Gerhard Armauer Hansen began his work, and influenced them in a very different way. Against the background of these assumptions and results, discoveries are particularly exciting and must be understood in a broader sense from that context.

The story begins in Bergen, a tiny town in western Norway, in 1841. On July 29, that year, Gerhard Henrik Armauer Hansen, the eighth of fifteen children born to Mrs. Elizabeth Concordia Schram and Mr. Claus Hansen was born. In 1859, this destiny's child went to the University of Christiania to study medicine after a mischievous upbringing controlled by his strict father in a middle-class household. In 1866, this outstanding researcher earned a bachelor's degree with honours. After acquiring his medical degree in 1866, he joined as an assistant physician in a leprosy hospital in Bergen. He worked as a community doctor in Lofoten, a tiny Norwegian fishing village in northern Norway, for a year after finishing his internship. However, as fate would have it, Hansen returned to his hometown of Bergen in 1868.

Norway, which was already combating leprosy by the middle of the nineteenth century, was perhaps the worst-affected country in Europe, and it was in Bergen that the leprosy research centre and three other lepra hospitals were built. In the 1850s, it was estimated that two out of every thousand people in Norway had leprosy, while the frequency in Bergen was as high as 25 out of every thousand. Hansen met Dr. Daniel Cornelius Danielssen and Dr. Carl

Wilhelm Boeck, two famed stalwarts of old leprosy study, who were responsible for the well-known "Om Spedalskhed" (On Leprosy) book, as well as a wealth of researched knowledge. Dr. Danielssen was regarded as the world's foremost expert on leprosy scientific research and the driving force behind all public health initiatives to combat the disease, not only in Norway but across Europe. He, on the other hand, was a firm believer in the concept of hereditary leprosy, which was backed up by the rest of the medical community at the time. Because of the protracted incubation time, which disguised the trail of interaction, an infectious aetiology was not clear. But, as we all know now, history was yet to be written, and it was to be written in a different way.

No one can deny Dr. Daniel Cornelius Danielssen's contribution to the fight against leprosy, no matter how ludicrous the hypothesis of hereditary transmission of leprosy sounds now. Bergen became the centre of leprosy research thanks to his efforts. While working for Dr. Danielssen, a young and inquisitive Hansen accompanied him all over Norway to study the disease, collect pathological samples from lepers, and research relentlessly until he arrived at a revolutionary conclusion that contradicted Dr. Danielssen's theory of hereditary transmission. He felt the disease was transmitted from person to person by an organism and emphasised the hypothesis of contagion, ruling out inherited causation. It was a bold hypothesis at a time when the concept of contagion was still a mystery. By declaring this theory, Hansen ran into a professional conflict with his superior but he stood firm in his belief in his findings. Despite the negative feedback and opposition to such a difficult concept, he persisted in his investigation to verify his theory.

He described the pathological changes in leprous tissue in his first published study in 1869. However, his staining technique was extremely crude, and his lack of equipment impeded his work, so it would be unreasonable to expect him to provide a more accurate description of the lepra bacilli than he did. Hansen realised he needed to strengthen his pathologic anatomy skills, notably in microscopy. Dr. Hansen received a grant in 1870 to travel to Vienna for advanced training in staining and histopathology, which allowed him to improve his research technique, and a more determined Hansen began his search for that infectious substance, a culprit yet to be captured and produced in front of the world. He would sit for days on end, focussing the microscope and peering through stained tissue slides of leprous tissue. He finally finished his successful attempt at identifying the infectious ingredient in leprous material and published his historic work in 1873, when he was only 32 years old. He was hired as chief medical officer for the leprosy disease and worked as a leprosy physician for the rest of his life.

His conviction of belief and an unstinted devotion to a lifetime of scientific research changed the way leprosy was approached as a disease. It was the fruit of his untiring work that the amended act of 1885 was passed, which resulted in steady decline in leprosy burden in Norway. An experiment with a patient, without consent, led to Armauer Hansen being stripped of his position as a hospital doctor in 1880.

On a research trip to Norway to study leprosy in 1879, a young German bacteriologist named Albert Neisser (who later became famous for identifying the causative organism of gonorrhoea), a student of Robert Koch, had the opportunity to visit Hansen and see his research work. He received preparations manufactured from lepra nodes from Hansen. When he returned to Germany, Neisser made every effort to stain them better in order to produce

more convincing results, and he was successful because of his sophisticated staining processes and the fact that he was a bacteriologist himself. Neisser went on to publish his scientific discovery in 1880, without providing full recognition to Hansen, and claimed credit for identifying the organism that caused the disease. Fortunately, the truth was revealed, and the controversy was officially handled in a lepra convention in Berlin, where Hansen was acknowledged as the true discoverer of the lepra bacilli. Armauer Hansen represented Norway internationally in a number of contexts and received numerous honors and awards. He remarked "There is hardly anything on the earth, or between it and heaven which has not been regarded as the cause of leprosy; and this is but natural, since the less one knows, the more actively does his imagination work."

Gerhard Henrik Armauer Hansen (1841-1912)

Hansen depiction of leprosy bacilli

When it comes to his personal life, he had his share of ups and downs. He wrote his autobiography, "The Memories and Reflections of Dr. Gerhard Armauer Hansen," when he was in his seventies. Coming from a low-income family, pursuing medical education was a challenge he took on, working as a schoolteacher in a ladies' school and later as a prosecutor in anatomy to help pay for medical school. In February 1912 he breathed his last in Florø, a little town on the western coast, leaving behind an inspirational story of a brave heart scientist who fought against all odds to unveil the truth for the benefit of humankind. Armauer Hansen is the Norwegian doctor best known internationally and especially in India, where he is still regarded as one of humanity's great benefactors.

Impact of discovery of *M. leprae* on control of leprosy:

Assessing the greatness and importance of a scientific discovery can easily become subjective. Nevertheless, it must be established that Armauer Hansen's discovery of the lepra bacillus is unique in many ways. At this time, no chronic disease was shown to have an infectious etiology. The discovery showed that prioritization and concentration of resources, even under difficult general framework conditions, can lead to scientific breakthroughs in the international research front. Norway's name was on the medical world map for the first

time. In addition, its discovery helped humanity to fully comprehend the infectious nature of leprosy and discarded the old belief surrounding it. The discovery also led to implementation of measures that resulted in the disease becoming extinct in Norway, and many other countries of the world.

Our understanding of the course, pathogenesis, presentation, and therapy of this chronic infectious disease has grown dramatically during the last century thanks to the discovery of *M. leprae*. During that time, Dr. Guy Faget and Dr. Robert Greenhill Cochrane introduced the sulfones and dapsone, respectively, as the first effective medicines against *M. leprae*. The present treatment for Hansen's illness is based on a combination of medications that has proven to be effective in eradicating the infection, and new research is focusing on early detection and prevention.

An important milestone in the understanding of the disease was the demonstration of multiplication of *M. leprae* in the mouse footpad by Dr. Charles Shepard of Centers for Disease Control (CDC), US in an experiment in 1959. Later in 1968, the Gulf South Research Institute's Dr. Eleanor Storrs and Dr. Waldemar Kirchheimer infected a nine-banded armadillo with M. leprae, which led to the animal developing disseminated leprosy.

The discovery of *M. leprae* represents a link in a chain of development in international medicine that was influenced by two main concepts, namely, that germs may be causes of disease and that social conditions can be related to disease as causes, consequences, or both. One of the first complete genomes to be sequenced was that of *M. leprae*, and the results of this new information are now showing. For instance, molecular microbiology has started to explain M. leprae's fastidious nature and preference for an intracellular environment.

Once *M. leprae* genome has been sequenced in the year 2001, it unraveled that this organism can generate significantly less proteins than M. tuberculosis, the other main human-pathogenic mycobacterium. While *M. leprae* cannot yet be grown in artificial media, the newly developed molecular capability to evaluate its capacity to transcribe and synthesize a variety of proteins in response to various environments and stresses, will probably soon provide important clue about its mechanisms of how humans are infected and its pathogenesis.

PCR testing of tissue samples for *M. leprae* DNA now offers a useful method for diagnosing this pathogen. DNA analysis is anticipated to replace current methods for identifying mutations in the *M. leprae* genome that are linked to resistance to certain medications used to treat this infection. Leprosy is treatable with a number of potent antimicrobial medications, and this infection is curable. Today, a number of mutations in *M. leprae* associated with antibiotic resistance can be found using molecular techniques. These methods support devising appropriate type and duration of treatment as needed.

To summarize, the most significant historical events related to *M. leprae* are:

- The discovery of the bacillus by Dr. Armauer Hansen of Norway in 1874;
- The use of the sulfone drug by Dr. Guy Faget of Carville in 1941; Dr. Robert Greenhill Cochrane for the treatment of leprosy.
- The discovery of the bacillus multiplication in the mouse footpad by Dr. Charles Shepherd of the Center for Disease Control in 1959;

The demonstration of susceptibility of nine-banded armadillo to develop disseminated *M. leprae* infection after inoculation by Dr. Waldemar Kirchheimer of Carville and Dr Eleanor Storrs of the Southern Gulf Research Institute in 1968. Complete sequencing of genome of *M. leprae* in 2001.

Conclusion:

Leprosy is an age-old disease which can be considered as a symbol for social injustice and the historical influence of societal stigma. Only when we consider the state of investigative medicine in 1873 when the leprae bacillus was discovered, can we fully appreciate Hansen's contribution to medicine in general, and to bacteriology in particular. He suffered the same fate as previous great minds who worked ahead of their time and were confronted with hostility, stinging criticism, and a lack of acknowledgment. The leprosy community will ever remain indebted to his efforts in discovering this bacterium which defies most attempts to multiplication in artificial medium even now. The discovery of *M. leprae* will remain as a seminal event in the history of leprosy and will always be remembered as an epochal episode in medical history. Researchers must work hard to eradicate disease completely from endemic regions, and humanity as a whole must fight against prejudice and put an end to all forms of discrimination.

We hope that in the extremely long history of Hansen's disease, the final act will see not only the eradication of the illness but also the suppression of a misguided attitude toward those who are ill and their societal role.

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06

A Legal Overview of Leprosy in Pre-Independence India

Sridhar Potaraju , Ankita Sharma, Rajat Srivastava

Introduction

Leprosy has impacted mankind for millennia. The sickness takes its name from the Greek word (léprā), from (lepís; 'scale'), while the expression "Hansen's illness" is named after the Norwegian doctor Gerhard Armauer Hansen. Leprosy has generally been related to social disgrace, which became an obstacle to self-announcing and early treatment. World Leprosy Day is observed globally on the last Sunday of January every year and in India Anti-leprosy day is observed on 30th January every year on the anniversary of Mahatma Gandhi's martyrdom day to draw awareness to those affected by leprosy.

Leprosy as social stigma from customary law perspective

In its onslaught on mankind, leprosy has left a trail of pain and suffering that dates back thousands of years. Researchers believe leprosy has existed since at least 4000 BC.

Leprosy is one of the most misunderstood diseases. Throughout human history, leprosy is feared; a whole host of myths and misconceptions surround the disease since time immemorial. As far as mistaken beliefs are concerned, many believe that leprosy is a hereditary disease, a curse, or a punishment from God. Even after the discovery of the germ that causes the disease, leprosy patients are stigmatized and shunned. They are disparagingly called 'lepers' and many of them are forced to live as outcasts in leprosy colonies. The popular mis-perception is that leprosy is an ancient disease that has been eradicated many years ago, but the reality is that leprosy is still prevalent, with more than 200,000 people being diagnosed every year worldwide. Even though leprosy is completely curable, the disease is one of the world's most stigmatized diseases, and people affected by the disease are considered social outcasts in many parts of the world. They are often denied basic human rights, discriminated against, and forced to live sub-human lives. Leprosy is completely curable now with multi-drug therapy (MDT).

The Bible's depiction of 'leprosy' is not harmonious with present leprosy, and hence the connection between this illness, tzaraath, and leprosy has been questioned. As per the biblical culture, each of the skin diseases would make a person culturally impure. According to the above, biblical leprosy was defined as "a comedy of errors," and other authors suggest that a more appropriate translation of tzaraath would be "sign of impurity" or "spiritual

uncleanliness," and they postulate that in modern Bible translations, the term leprosy should be replaced again by the term tzaraath, which should prove that we do not know what this term meant, or use the literary term "plaque," which indicates an infectious disorder of great concern for the person, for his or her clothes, and home.

The ancient Hindu texts apparently base the exclusion on the ground of the incapacity of the sufferer to perform the funeral and other obsequial rites of the deceased. So far as leprosy is concerned, the later Hindu books generally lay down grounds for exclusion, it must be of the disabling or ulcerous and not of the anesthetic type. There is no explicit mention of leprosy as a ground for exclusions under ancient Hindu texts. There is no complete destruction of the rights and interests of a person who becomes a leper subsequently. The Hindu law did not deny rights for a person on being diagnosed but kept his rights in abeyance until he could recover.

Leprosy in British India

Leprosy in India achieved prominence in the second half of the nineteenth century, largely due to its greater visibility internationally. This coincided with an overall concern about the status of public health in India following the take-over by Britain of administrative authority from the East India Company. During the 1860s, the first leprosy census took place, which estimated that there were 99,073 persons suffering from leprosy in British India.

Later a National Leprosy Fund was instituted, under the patronage of the Prince of Wales, whose activities included the appointment of a Leprosy Commission for India. This Commission had one member each from the Royal College of Physicians, the Royal College of Surgeons, and the Executive Committee of the National Leprosy Fund and was sent to India. The Commission arrived in India in November 1890, and prepared a report which was signed on August 21, 1891, the English members of the Commission being Dr. Beaven Rake, Dr. George A. Buckmaster, and Dr. Alfred A. Kanthack, and the members appointed by the Indian Government Surgeon-Major Arthur Barclay and Surgeon-Major Samuel J. Thomson, of the Bengal Medical Service. The first aim of the Commissioners was to acquaint themselves with the features of the disease as it appeared in the empire, directing their attention more to etiological factors than purely clinical aspects. This could only be done by traveling from center to center and from asylum to asylum, and by personally inquiring into the histories of as large a number of lepers as possible. It was, therefore, decided to take full advantage of the cold season and to spend about five months examining asylums and lepers in various localities. Subsequently, the Commissioners were to assemble at some hill station in order to supplement their inquiries by pathological and bacteriological researches. This plan was faithfully carried out, numerous places were visited, over 2000 lepers were personally examined, and the bacteriological investigations were carried out at Simla. The Commission's report in 1891 concluded that "the amount of contagion which exists is so small that it maybe disregarded"

Meanwhile, during 1873-1874, missionary interest in leprosy developed and the general public was targeted for subscriptions, which contributed to sustaining the public concern. In 1874, Wellesley Bailey founded the Mission to Lepers in India, which was to become the major organization concerned with leprosy; by 1893 the Mission to Lepers had 10 asylums

and supported 8 others; in 1899 it maintained 19 asylums, and aided many others. Missionary publications on leprosy drew on Biblical representations, and Wellesley Bailey's comment is typical of this discourse: "The utter helplessness and dependence of these folks on others is a continual picture of the way sinners have to come to God and get His blessing". Gussow has commented: "To a mind attuned to the Old Testament, leprosy is an abomination, a matter of ritual uncleanliness. For those who believe in the New Testament, the stories of Christ miraculously curing the lepers become metaphors for divine salvation". Missionary activity imprinted the specifically Christian representation of leprosy in the public mind, and Gussow has discussed how historically "this care and the treatment evolved into a separatist tradition."

In 1889, the British Government in India drafted a bill for confinement and circulated the same for comments from the population, including colonial officials, medical men both Indian and European, native chiefs, and several intellectual societies. The feedback suggested that partial confinement was insufficient to control leprosy transmission. However, in order to appease the urban elite, The Lepers Act of 1898, significant legislation on leprosy of the colonial period was enacted.

The Lepers Act of 1898 was framed for the segregation and medical treatment of pauper lepers. Section 2 (1) of the said Act provided the definition of the leper as follows "any person suffering from any variety of leprosy in whom the process of ulceration has commenced".

The historical legacy and societal stigma toward leprosy are evidenced by various laws of British India containing discriminatory clauses against leprosy patients.

1. The Indian Lepers Act, 1898 - The entire Act is discriminatory. It was framed for the segregation and medical treatment of pauper lepers.
2. Banaras Hindu University Act, 1915 has provided under clause 1(a) of section 12(B) that a person shall be disqualified for being chosen as, and for being, a member of any of the authorities of the University if he is suffering from a contagious form of leprosy. The said Act has also provided under section 32 (1)(a) that an employee other than a teacher may be removed if he or she is suffering from a contagious form of leprosy.
3. The Chennai City Municipal Corporation Act, 1919, has provided under sub-clause (2) of section 52 that a person shall be disqualified for election as a councilor if such person is at the date of nomination or election is a leper and under section 53 of the Act, a person shall cease to be a counselor if he becomes a leper. As per section 308(B), the person-in-charge of a marketplace shall have the power to expel any person suffering from leprosy in whom the process of ulceration has commenced or from any infectious or contagious disease who sells or exposes for sale there in any article or who, not having purchased the same handles, any articles exposed for sale therein.
4. Madras University Act, 1923 has provided under section 5 that the university shall be open to all classes and creeds. However, clause 2(a) of the section states that no person shall be qualified for election or nomination as a member of any of the authorities of the University if he or she is suffering from a contagious form of leprosy. Also, section 40 gives the Senate the power to remove a person suffering from contagious leprosy from the membership of any authority of the University.

5. Dissolution of Muslim Marriages Act, 1939, 2 (vi) Grounds for decree for dissolution of marriage. A woman married under Muslim law shall be entitled to obtain a decree for the dissolution of her marriage on any one or more of the following grounds, namely: "That the husband ..... is suffering from Leprosy.

6. Bengal Vagrancy Act 1943 under Clause 3(a) of section 9 has provided that, the Collector had to ensure homeless persons suffering from leprosy are segregated from other homeless people at vagrants' homes.

Contemporary legal position

Even the post-independence legislation also continued the discrimination against persons suffering from leprosy similar to the above-mentioned pre-independence laws. The provisions gave sweeping powers to various governing bodies under the act such as to dismiss or disqualify from employment and membership of universities; disqualify individuals from getting elected into public bodies such as Panchayats and Municipal bodies as well as into committees and management of places of worship and professional associations; to segregate beggars and prisoners suffering from leprosy from other beggars and prisoners respectively and for their indefinite detention. These post-independence laws also prevent leprosy patients from accessing certain places such as schools, colleges, slaughterhouses, public transport, etc.

In this regard, attention is drawn to the Supreme Court judgment "Dhirendra Pandua v. State of Orissa", (2008) 17 SCC 311 wherein the Hon'ble Supreme Court upheld the disqualification of an elected representative under the ground that he was suffering from leprosy and upheld the discriminatory provision in the Orissa Municipal Act, 1950. However, the court taking cognizance of the changed concept and knowledge gained about the disease of leprosy leading to the repeal of the leper's Act 1898 and other similar state legislations observed as below:

"Before parting with this case, we deem it appropriate to point out that having regard to the changed concept and knowledge gained about the disease of leprosy, on the recommendation of the Working Group on Eradication of Leprosy, appointed by the Government of India, many State Governments and Union Territories have repealed the antiquated Lepers Act, 1898 and subsequent similar State Acts, providing for the segregation and medical treatment of pauper lepers suffering from infectious type of disease. Therefore, keeping in view the present thinking and researches carried on leprosy as also on tuberculosis, and with professional input, the legislature may seriously consider whether it is still necessary to retain such provisions in the statutes."

On 21st February 2019, the President of India gave his assent to the Personal Laws (Amendment) Bill, 2018 which consequently became the Personal Laws (Amendment) Act, 2019. The Act aims to exclude leprosy as a ground for divorce for married couples from all religions across the country in order to eradicate the prejudicial treatment experienced by the patients of this disease.

The Hon'ble Supreme Court also while considering a Writ Petition filed challenging the constitutional vires of several states and central enactments which are discriminatory against

persons suffering from leprosy observed as follows in its Order reported as "Pankaj Sinha v. Union of India, (2020) 20 SCC 428"

"We will in due course deal with the constitutional validity of the laws and the steps taken for repeal by the Union of India and the State Governments. There can be no doubt that a person suffering from leprosy has the right to live with human dignity. His/Her status in society cannot be bereft of humanness. Needless to emphasize, there is no reason to discriminate against such persons in any vocation or profession, or for that matter, in the exercise of any civic rights or entitlements under the Constitution or law. It has to be understood that treating persons suffering from leprosy in a stigmatic manner denudes them of humanness."

The National Human Rights Commission (NHRC) advisory dated 14.01.2022 wherein the NHRC has recommended amending 97 laws that discriminate against leprosy-affected persons in a time-bound manner while annexing the list of those 97 laws to the advisory.

Conclusion

Leprosy is one of the foremost misunderstood diseases of the world and distinct challenges are faced in its management and elimination. The physical manifestations of Leprosy had a deep impact on the social seclusion of the person suffering. Legal discrimination continues in various statutes referred herein above which unfortunately leaves the persons affected by leprosy with civil disabilities even though the disease now is curable with the progress of medical sciences.

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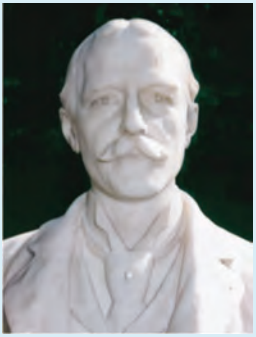
07

The Acworth Leprosy Hospital and Museum, Mumbai: In the Fight Against Leprosy

Shubhada Pandya, Pratibha Kathe

The Acworth Municipal Hospital for Leprosy was established at Matunga (currently Wadala) on the outskirts of Bombay, presently Mumbai, Maharashtra in 1890. It was originally named 'Homeless Leper Asylum'. The important reason mentioned for its establishment was the distress and annoyance caused to the public by vagrant and deformed leprosy patients crowding the streets of this major colonial city.



Mr. H.A. Acworth

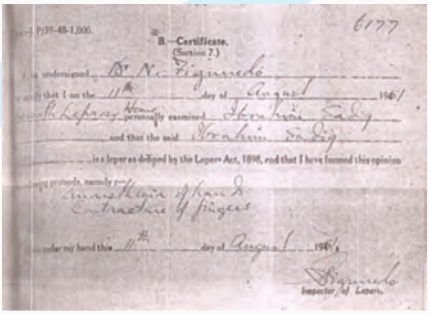
A unique, non-sectarian Institution for Care, Treatment and Rehabilitation of such outcasts, it was the tangible outcome of funds donated by Mumbai's philanthropic citizens of every community and the energetic efforts of Harry Arbuthnot Acworth (1849-1933), who was in Indian Civil Service (ICS) as City's Municipal Commissioner. In recognition of Acworth's signal role, the Asylum was named after him in 1904.

Acworth obtained the services of Dr. Nasarwanji Hormasjee Choksy, (1861-1939) an infectious diseases specialist as the first Superintendent. The value of the institution as a fertile location of study was recognised by the visits of the British Leprosy Commission in 1892, and scientists Robert Koch (1843-1910) and George Sticker (1860-1960) of the German Plague Commission. Sticker demonstrated Mycobacterium leprae in patients' nasal discharges. The Asylum was also a location for X-ray therapy for skin lesions, injections of bacillus-derived "Nastin", and plant-derived Hydnocarpus (Chaulmoogra) oil. Not to be overlooked are pioneering neuropathological researches of Vasant R. Khanolkar (1895-1978), and Darab K. Dastur (1924-2000) and bacteriological studies of Raghavendra Row (1871-1953) who were associated with this institute.

Once a shelter for 500 inmates, the Acworth Municipal Hospital for Leprosy today accommodates 120 patients. In addition to inpatient care, the Hospital provides comprehensive services on an outpatient basis. It is a part of the National Leprosy Elimination Programme.

Acworth Leprosy Museum

The possibility of establishing a Museum on the history of leprosy in Mumbai arose from the suggestion by late Mr. Sharad. S. Naik, (1940 -1999), Hon. Secretary of the ALH-RRE



B.—Certificate.
(Section 7.)

6177

I, undersigned Dr N. Figueredo

certify that I on the 11th day of August 1901

at Leper Home, personally examined Ibrahim Sadiq

and that the said Ibrahim Sadiq

is a leper as defined by the Lepers Act, 1898, and that I have formed this opinion

on grounds, namely:—

Anesthesia of Hand &
Contracted fingers

Given under my hand this 11th day of August 1901.

N. Figueredo
Inspector of Lepers.

Certificate signed by Medical Superintendent N. Figueredo that inmate Ibrahim indeed has Leprosy'

First page of Minutes book-Homeless Leper Asylum,1890

Society. The Museum is a joint project of the Acworth Leprosy Hospital Society for Research, Rehabilitation and Education in Leprosy (ALH-RRE Society) and the Hospital.

The Museum, opened on 9th June 2009, is the only one of its kind in India, not just about a disease. It holds a mirror to Indian Society of pre-colonial, colonial and contemporary times by depicting how it interpreted leprosy, once considered an apparently incurable deforming, loathsome disease

The Museum has a broader aim of informing the public about a disease which is still a serious problem in India. Plentiful documentary material available in the Museum serves as a resource for scholars who are welcome. It is substantially supported by the Sasakawa Memorial Health Foundation (SHF), Japan.

The Museum exhibits comprise two parts: (a) the history of the Hospital; (b) Modules devoted to multiple facets of the disease, namely: 1. Leprosy—The disease; 2. Timeline of developments in treatment; 3. Institutions for leprosy-affected, leprosy self-settled colonies and first-hand testimonies titled 'Victims Speak'; 4. Literature & leprosy; 5. Leprosy under the legal gaze; and 6. Health education. Acworth leprosy museum also showcases persons who have variously contributed to the fight against leprosy. An upcoming new exhibit will depict the very successful pioneering work on Sewage Disposal at the Homeless Leper Asylum carried out by Carkeet James, (1863-1942) Executive engineer, drainage, Bombay municipality, in the early 20th century as India's first bio-gas plant which was recognized worldwide.

There was a wealth of historical material available at the Hospital itself and at the State Archives. The Municipal Corporation of Mumbai has recognized the Hospital and Museum as heritage sites, and will continue their services to affected persons and the Leprosy Elimination Programme.

Inmates at the Leper Asylum,1890

SECTION 2

INDEPENDENT INDIA
Pre-MDT era

08

A note on National Leprosy Eradication Programme (NLEP), India

Kiran Katoch ,P Narasimha Rao

Leprosy management during the first few years post-independence after 1947, consisted of providing some relief and institutionalization of patients in leprosy homes and Institutions. Dr Wardekar who graduated from the Grants Medical College in Mumbai, created a system of health education, case detection and "domiciliary treatment" in 13 centres throughout India. His methods became an accepted practice throughout India and was also acknowledged by **World Health Organization**, which also began using his approach. After Mahatma Gandhi's death a Trust was set up for leprosy relief at the Gandhi Memorial Leprosy Foundation (GMLF) by Dr Sushila Nayar. Dr Wardekar became the Director of this hospital in 1952 and established the principles of Survey-Education-Treatment (SET) for bringing relief to leprosy patients and scientifically addressing the problem of leprosy control. He is also known as the father of Leprosy control in India and was awarded the Padma Shri for his contributions to work in leprosy in 1973. His approach covered all aspects, medical, social, economic and psychological aspects of the disease and its effects.

In 1955, when the National Leprosy Control Programme (NLCP) was formulated by the Govt. of India. Dr Dharmendra was its first Director appointed by the Government. NLCP was based on Survey, Education and Training, (SET) which included training of doctors and health staff. Treatment with Dapsone which was given as domiciliary treatment, through vertical units, implementing the SET activities. Due to poor resource mobilization, fund allocation, lack of understanding of the requirements of the affected population and uncertain response of patients to Dapsone, its impact on leprosy control was not significant during the 2nd and 3rd five-year plan periods of Govt of India. NLEP was supported by the voluntary agencies, and even studies on chemoprophylaxis to contacts of LL cases was initiated with CIBA 1966, Fandisil (long acting sulphonamide), treatment of ulcers and disabilities was initiated with support from GMLF. During the fourth 5-year plan (1969–74). More priority and funds were allocated to leprosy control, specific targets were set for all states, and the program became performance oriented in this plan period. Following the recommendations of the Swaminathan Committee in 1982, the Government of India reoriented the National Leprosy Control Programme into the National Leprosy Eradication Programme (NLEP). Multi Drug Therapy (MDT) for leprosy was introduced in India from 1983 onwards.

The exact numbers of leprosy patients in India during this pre-MDT period is difficult to ascertain. However, as per WHO estimates of 1965, the global leprosy load was 10,786,000.

We can safely presume that of this, more than half of leprosy patients would have been from India, which works out to be little more than 5 million. During the same time, to support the leprosy activities across India, four Research & Training Institutes were conceived and established directly under Director General Of Health Services (DGHS) Govt of India; namely Central Leprosy Training and Research Institute Institutes (CLTRI) Chengalpattu, Regional Leprosy Training and Research Institute (RLTRI) at Raipur, Gauripur and Aska. In addition, a Training Centre for doctors, and health staff was established at Agra under ICMR (JALMA). Remarkable progress has been achieved in reducing the disease burden in the country with the help of these Institutes and other National and international leprosy stakeholders.

The strategy of NLEP post-MDT introduction was based on controlling the disease through reduction in the quantum of infection in the population and reduction in infectious source, thus breaking the chain of disease transmission. The programme was initially taken up in endemic districts and was extended to all districts in the country from 1993-94 with World Bank Assistance. All the districts in India could be covered by MDT only by the year 1996.

NLEP continues to be a centrally sponsored Health programme of the Ministry of Health and Family Welfare, Govt of India. While NLEP strategies and plans are formulated centrally, the programme is implemented by the States and Union Territories. The programme is also supported by partners, by WHO, ILEP and few other NGOs. At present (year 2021) the estimated number of leprosy patients in India is less than 100,000, which showcases a remarkable reduction in leprosy load. Nonetheless, India still holds more than 55% of global leprosy patients. In the next few chapters we will know more about how such improvement was made possible by the collective efforts of all agencies and stakeholders.

09

Dapsone in leprosy: A story

Lalit Kumar Gupta, Manju Meena

Dapsone is one of the most widely used drugs by dermatologists, primarily for leprosy but the drug has shown promise in treatment of many disorders of inflammatory origin as well. Although it had been synthesized in 1908, it took researchers years to prove its role in various diseases, especially leprosy. Dapsone was the first established therapy for leprosy and remained the gold standard treatment for around three decades. It still forms the backbone of the treatment of leprosy in the MDT era. This article essentially focuses on historical aspects pertaining to research and use of dapsone, in leprosy.

Discovery of dapsone

Eric Fromm and J. Wittmann, chemists at the University of Freiburg, announced the synthesis of dapsone in a paper published on June 15, 1908. The German chemical industries were expanding at the beginning of the 20th century. To discover novel compounds for industrial usage, several concurrent experiments were being conducted. Dapsone, an azo dye, was one such finding in that series. This was regarded as a scientific breakthrough in the dye industry. No one considered its medicinal potential at that time.

Establishment of efficacy of dapsone

The therapeutic potential of dapsone was not known for nearly three decades of its synthesis until the increasing popularity of sulfa drugs focused scientific attention on the therapeutic benefits of sulfur-containing compounds. The first effective sulfonamide was subjected to clinical trials in 1933 and commercialized as Prontosil in 1935. After prontosil, chemically similar molecules, such as dapsone, attracted researchers' attention as potential additions to this family of drugs. In 1937, for the first time dapsone was investigated for its antibacterial effect by two research groups, Buttle et al. in England and Fourneau et al. in France. Dapsone showed promising antibacterial results and soon it gained worldwide recognition for treating leprosy. It is a competitive inhibitor of dihydropteroate synthetase leading to reduced production of tetrahydrofolic acid, an essential component for nucleic acid biosynthesis in M. leprae.

Dapsone as an anti-leprosy drug:

Leprosy has existed since biblical times without any hope of cure and has historically been a topic of research on a global scale because of its profound consequences on patient's lives and the stigma it causes. Until 1940, only remedy available for leprosy was "chaulmoogra oil" which was thought to slow down the disease process but was ineffective in cure of leprosy. Researchers all over the world were engaged in many trials to find an effective anti-

leprosy drug. Tuberculosis, another disease caused by mycobacteria, was one of the leading causes of death in the early twentieth century and worldwide therapeutic trials were going on in search of its cure. Promin, a non-toxic derivative of dapsone synthesized in 1937, demonstrated successful inhibition of tuberculosis. Since leprosy was caused by the same bacterial family, Promin was investigated in leprosy as well. In march1941, Faget began the first clinical human trial of promin at Carville Leprosarium in Louisiana, U.S. Promin's efficacy in treating leprosy was unexpectedly high. This miraculous drug had to face two challenges - First, it was expensive, and second, it was to be administered intravenously.

Robert G Cochrane who was chief medical officer at the Lady Willingdon Leprosarium in Chengleputtu, Madras, who later became adviser in leprosy to the State of Madras, in 1945, began studies with sulfone derivatives, and was the first to use dapsone in the treatment of leprosy, laying the groundwork for treatments still used today. Dapsone was examined in treatment of leprosy by Cochrane in Indian patients in 1949 and reported that dapsone is very effective in halting disease progress. He also used dapsone through subcutaneous route but the effectiveness of oral dapsone was proven in the next few years.

Safety of dapsone was also established by further studies which revealed that anaemia and methemoglobinemia can be avoided with the right dosage. Table 1 shows the historical milestones in development of leprosy treatment and dapsone

Table 1: History of Dapsone development and use

1873	Mycobacterium leprae identified in 1873 by Gerhard Henrik Armauer Hansen
1908	Fromm and Wittmann synthesized dapsone, recognized it as chemical dye
1937	Dapsone first time investigated for its antibacterial properties
1941	Faget conducted first clinical trial of promin in leprosy patients at Carville Leprosarium in Louisiana.
1949	R G Cochrane with his assistant tested dapsone in leprosy treatment in India. They found that dapsone is very effective in halting disease progress.
1955	Indian National leprosy elimination Programme (NLEP) launched based on Dapsone domiciliary treatment
1964	Petit et al reported first case of secondary dapsone resistance and confirmed it with mouse foot pad technique.
1976	First secondary dapsone resistance from India documented by Taylor at Schieffelin Leprosy Research & Training Centre, Karigiri.
1977	First record of primary dapsone resistance i.e. newly diagnosed leprosy cases that failed to respond to dapsone
1977	Toman K emphasised the role of persisters in clinical relapse of leprosy
1978	Giridhar BK investigated three patients to have primary dapsone resistance and one of them was found resistant.
1981	WHO recommended MDT as first line treatment of leprosy with Dapsone being part of it.

Dapsone monotherapy in leprosy

Chaulmoogra oil was formally discontinued in 1947, and sulfones were approved as the standard treatment for the condition at the Fifth International Congress on Leprosy in 1948. For over 3 decades dapsone formed the cornerstone and norm of care to treat leprosy globally till 1980s with reasonable success. The advantage of dapsone was that it could be administered orally, was inexpensive, widely accessible, and nontoxic at the low dose. Therefore, it very quickly became the drug of choice for leprosy worldwide. It was shown to halt the disease progression and also to prevent deformities caused by nerve involvement. However, since dapsone is a weak bactericidal drug, it took several years to cure leprosy patients, a factor that prevented satisfactory patient compliance. The Government of India launched the National Leprosy Control Programme (NLEP) in 1955, based on dapsone domiciliary treatment and implemented survey, education, and treatment activities through vertical divisions.

Dose and duration of dapsone monotherapy

Although the role of dapsone had been proved in leprosy, its optimal dose was yet to be known. Several dosing schedules were tried in order to establish a uniform understanding of the standard dose of dapsone.

Low dose dapsone: Clinicians treating lepromatous leprosy patients before and after the introduction of Dapsone as specific therapy have gained the impression that both the incidence and severity of Erythema Nodosum Leprosum (ENL) reactions in leprosy have greatly increased. There have been reports of the beneficial effects of low dose Dapsone in reducing the incidence of these reactions in lepromatous leprosy. Dapsone was tried in various dosages such as 5 mg daily; 10mgdaily; or 50/ 100mg daily. However, fortunately, this experimentation lasted only a few years.

- Before1971, dapsone was also given in gradually increasing doses (from 5 mg a day) up to a maximum of 300 mg per week.
- From 1972 this practice of gradually increasing the dose was stopped and the maximum dose was increased to 400 mg per week
- Maximum dose was further increased to 700 mg (100mg/ day) from 1975 onwards
- Likewise, the duration of dapsone monotherapy was not fixed and was given for a period varying from one year to more than 20 years. Lepromatous patients were usually given lifelong treatment

Impact of dapsone on leprosy:

Dapsone was the first effective anti-leprosy drug of modern era. After being introduced dapsone effectively decreased the burden of leprosy globally as well as in India. It also reduced the load of deformities due to leprosy and its transmission by decreasing bacterial load treated patients. Dapsone monotherapy was the main stay of leprosy treatment for over four decades world-wide.

Relapse, resistance and persistence:

After years of prolonged therapy with dapsone some patients, particularly multibacillary cases started showing clinical signs of relapse. Such reports started to be documented globally. Two reasons for relapse in leprosy cited were: drug resistance and bacterial

persistence. Prolonged, interrupted and inadequate use of dapsone monotherapy was said to be the factor in development of dapsone-resistant cases. Two types of resistance were identified; Primary dapsone resistance and Secondary dapsone resistance. Dapsone resistance is attributed to the mutations in the gene folP1, which encodes the synthesis of dihydropteroate. This enzyme is a member of folate synthesis. The resistance to dapsone was established to be a multistep mutation.

In the late 1970s, mono-therapy with dapsone lost its reputation as an adequate and effective treatment of leprosy due to the emergence of resistant strains. With the introduction of multi drug therapy (MDT) in 1981 dapsone mono-therapy became gradually obsolete, however dapsone still remains an important component of MDT. Dapsone had also been tried as a chemoprophylactic agent in contacts of leprosy patients. Its use in leprosy chemoprophylaxis was also being studied by many researchers in order to decrease case load and to increase the chances of disease eradication. Dharmendra et al investigated dapsone in chemoprophylaxis and found that dapsone has a definite protective value against the disease. It was given in weekly or biweekly doses for 2 to 3 years to leprosy contacts, with variable benefits.

Dapsone the wonder drug:

Dapsone truly is a wonder drug, as apart from leprosy it is also very useful in many inflammatory dermatoses of skin, particularly that involve the role of neutrophils in the inflammatory cascade, such dermatoses include dermatitis herpetiformis, bullous pemphigoid, neutrophilic vasculitis, Sweet's syndrome, granuloma faciale among others.

Conclusion:

Dapsone has been the first effective modern drug in the management of leprosy and which revolutionised its treatment. Its introduction has changed the management outlook of leprosy globally and brought the much needed hope of cure for the leprosy patient. While the advent of MDT for leprosy saw the end of the dapsone mono-therapy era, it still remains an important component of leprosy therapy and management. Dapsone continues to be the ever dependable foot soldier of leprosy management.

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10

National JALMA Institute for Leprosy & Other Mycobacterial Diseases, Agra

DS Chauhan

This national Institute came into existence on 1st April,1976 when the India Centre of JALMA was officially handed over to the Govt. of India and subsequently to the Indian Council of Medical Research (ICMR). This was named as Central JALMA Institute for Leprosy in 1976 and has been renamed as "National JALMA Institute of Leprosy and other Mycobacterial Diseases" in 2005 to reflect its broader research areas. This Institute was originally established as "India Centre of JALMA" in 1966 and was managed by a Tokyo based voluntary organisation -JALMA (Japanese Leprosy Mission for Asia). This Institute is one of the fine examples of international human links and compassion for each other.

The Institute has completed over four decades of its existence under ICMR. The Institute has a major thrust on leprosy (40%), relevant areas of tuberculosis and other mycobacterial diseases (40%). It also focuses on HIV and Filariasis research.

During its existence as a research Institute under ICMR the scientists of the Institute have contributed on almost all aspects of leprosy, several cutting edge areas of tuberculosis (DNA fingerprinting methods, drug resistance etc), selected areas of HIV-AIDs and has now made forays in to related problems like filariasis. At present, Dr. Abdul Mabood Khan,

Scientist 'G' is the Director-in-Charge of ICMR-National JALMA Institute for Leprosy & Other Mycobacterial Diseases, Agra.

The Institute has state of the art facilities like BSL-3 labs, DNA chip lab, Proteomics Lab, all well-equipped laboratories, modern hospital and well set Field Programmes at Ghatampur as well as Agra. The main focus of the research of the Institute is on Leprosy which covers several themes such as: Using electrophysiological, immunological and molecular tools for better understanding of the disease; developing newer technologies for diagnosis using in-situ methods; viability determination using mouse foot-pad, ATP and molecular methods; drug resistance studies using molecular methods; studies on transmission using epidemiological and molecular approaches and improving the therapeutic aspects of the diseases by using various modalities of drug combinations and immunotherapy.

The Institute has established its leadership in all important aspects of leprosy and mycobacterial research in India. The Institute is participating in and co-coordinating several multi-centric studies on Leprosy and Tuberculosis.

11

Regional Leprosy Training & Research Institute, (RLTRI) ASKA

V Santaram

Introduction:

The Regional Leprosy Training & Research Institute (RLTRI), Aska, was started by 'Danish Save The Children' a voluntary organization of Denmark in 1968 for doing Leprosy control work. The Institute was taken over by the Government of Orissa in 1972 and later by Govt. Of India in 1977. Since then, the Institute has been functioning under the Directorate General of Health Service (DGHS), Ministry of Health and Family Welfare, Govt. of India.

It is located in Babanapur village, Aska block of Ganjam district, Odisha, at a distance of 170 kms south of Bhubaneswar city (Capital city & nearest airport) 45 kms from Berhampur (nearest railway station) and 05 kms form Aska bus terminus. The Institute is spread over an area of 10 acres accommodating a 50 bedded hospital along with training and administration block.

The Vision and Objectives:

The vision of the institute is to establish itself as a national center of excellence for leprosy and to work towards making 'Leprosy free India'. The objectives are a) To provide basic and specialized diagnostic, therapeutic, rehabilitation and referral services to leprosy affected patients. B) To train manpower necessary to implement National Leprosy Eradication Programme (NLEP). C) To monitor and supervise the NLEP implementation. D) To undertake research in basic & operational aspects for eradication of Leprosy. E) To function as a nodal center for promoting anti-leprosy activities in the country, in collaboration with government and non-government organizations.

Activities:

A. Contribution to NLEP at National/State Level (Outreach Activities)

- Faculty are members of TRG (Technical Resource Group) at National Level.
- Part of JMM (Joint Monitoring mission) for NLEP of states.
- National Trainer for NLEP and State level Trainer for NLEP
- Member in Preparation of various "Training Manuals for Medical officers/Paramedical

Staff" and TNA (Training Need Assessment) Guide in Collaboration with CLD and CLTRI.

- Involved in the preparation of various National Guidelines of LCDC, SPARSH etc., being a part of CLD.
- Member of State co-ordination committee of NLEP of Odisha for planning and Imple mentation of NLEP.

B. Training:

Faculty are involved in various National/State level Trainings of SLOs/DLOs/MOs in different States in the past several years. (Delhi, Tripura, Patna, Bhubaneswar, Gwalior, Lucknow, etc.). Participated in "Training video modules" on NLEP developed by WHO and CLD. Training of M.O/MO (Ayush)/BNLWs (Block Nodal leprosy worker)/LTs of different districts of Odisha.

Sensitization & Training to Faculty of SKIN & VD Department Of MKCG Medical College; and training of MSc, BSc Nursing students, CHO (Community Health Officers) in various batches at the Institute and at the Medical College.

Virtual training during Covid times to DLOs/PG Students in NLEP in collaboration with CLTRI. Virtual training in NIKUSTH to various districts of Odisha.

NIKUSTH Training to MOs of several States like Gujarat, Uttarakhand, Punjab, Tripura, etc. In the past long term PMWs/NMS trainings were organized for several years for different states at the Institute to develop manpower for NLEP.

C. Treatment:

The institute is a referral **centre** having a Hospital with outpatient services and inpatient facilities with 50 Beds for patients. It is involved in diagnosis, treatment and management of leprosy and its complications. In addition it provides Surgical and Physiotherapy services to the needy, as well as having expertise to manage patients and Recurrent reaction cases, including the use of Thalidomide for Recurrent ENL reaction Cases. During Covid period,

a part of Hospital Building & Training block were used as Covid Care Center & Quarantine Center respectively by State Authorities.

D. Monitoring and supervision for NLEP (Outreach Activities):

Faculty are involved in past several years in various National/State level monitoring and supervision of NLEP Activities (Last year at AP and Dadra Nagar Haveli) as well as Special campaigns like MLEC/LEM/LCDC/SPARSH etc. in different states/districts on different occasions under guidance and direction of CLD. Faculty also involved in routine NLEP monitoring and supervision of several districts of Odisha.

E. Research & publication:

Faculty are involved in Field based research projects, Epidemiological investigation etc. as per direction of CLD. In this regard the institute is involved in the a) Development of service delivery model by WHO for providing comprehensive leprosy services in the hard to reach high endemic blocks of Chhattisgarh and Odisha (Boudh & Sambalpur districts). B) Descriptive study of high leprosy endemic pockets and exploring occurrence factors of multi-case families in the village of Salaunikhurd of Chhattisgarh (Published int J Med Public Health 2021;11(2):113-7).

Thus RLTRI, Aska being a part of CLD, DGHS, MOHFW, GoI is actively Involved in all components of NLEP towards Achieving vision of **"Leprosy Free India"** in near future.

12

CLTRI, Chengalpattu

Vijay Bhagat, Vivekanand Giri, Shubhangi Baviskar

Sowing the seedling:

The existence of Tirumani hospital at Chingleput dates back to 1864, later renamed as Lady Willingdon (the First Lady of Madras Presidency) leprosy sanatorium (LWLS). In 1924 the lepers were shifted (under the single asylum) at LWLS. The emergent need of a dedicated institute for research and training for leprosy sowed the seedling for establishment of **Central Leprosy Teaching and Research Institute (CLTRI)**. Accordingly, the LWLS was handed over to the Governing Body (GB) under the chairmanship of Health Minister Rajkumari Amrit Kaur in 1954. On 3-3-1956, the GB appointed Dr. Dharmendra as the First Director of CLTRI. Since 1-4-1974, CLTRI has been functioning as a subordinate office of the Directorate General of Health Services, Ministry of Health and Family Welfare Govt. of India.

The Legacy:

Some of the pioneering work by Dr. Dharmendra, were Dapsone for the treatment & chemoprophylaxis of leprosy, Dharmendra's antigen, Comparison of Ridley's scale and Dharmendra's scale of calculation of Bacterial Index etc. The books authored by him still guide the researchers as lighthouses. Dr. S.K. Noordeen, former Deputy Director-Epidemiology, legendary visionary leader, accomplished the milestone of Multi-Drug Therapy in leprosy which stood as a cornerstone for treatment of leprosy since last fifty years. Dr. H. Srinivasan former Director of CLTRI has done pioneering work in surgical rehabilitation of leprosy patients.

For their indebted contribution to humanity Dr. Dharmendra, Dr. Srinivasan and Dr. Noordeen were bestowed with one of the country's highest civilian award 'Padmashri' in 1966, 1984 & 2009 respectively. Meanwhile in 1998 CLTRI received the 'National Award for Rehabilitation of disabled people' by the Ministry of Social Justice & Empowerment, Govt. of India. It is customary to note here that the seeds for MDT were sowed by none other than CLTRI through its THELEP trials conducted at Bamko (Mali), CLTRI (India) & NIMR (England) which tested five regimens for efficacy in leprosy. The 12 year Field trial of ROM, Validation of leprosy elimination, monitoring of MLEC, LCDC, SLAC are a few more examples of contribution of CLTRI.

The operational research of Dr. Ashok Kumar and colleagues has witnessed elimination of leprosy. Dr. Iyer, Dr. Balakrishnan, Dr. Ramanujam, Dr. Mohmed Ali, Dr. Desikan, Dr. Bhatia, Dr. Neelan, Dr. Sheshadri, Dr. Roy, Dr. Elangeshwaran, Dr. George, Dr. Kar, Dr. Rao,

Mr.Vinod Kumar, Mr Sirumban, Dr. Krishnamoorthy, Dr. Ramu, Dr. Mukherjee, Sh. Namasivayam, Dr. Oommen, Dr. Padma, Dr. Subramanian, Dr. Reddy, Dr. Sekar, Dr. Siddalingaswamy, Dr.Vijayaraghavan, Dr. Showkath Ali, Dr. Chadha are among some of the eminent alumni of CLTRI.

The technology:

Currently CLTRI hosts the largest Govt. exclusive leprosy hospital in more than 100 acre land, with its 124 beds inpatient capacity. The operation theatre witnesses all major and minor surgeries, with its attached digital X-ray unit. The Physiotherapy building complex besides its traditional exercise facilities such as wax bath, plain-ramp-stair walking platforms, stationary cycling etc. also provides electrical, ultrasonic and infra-red muscle stimulation facilities. CLTRI is among only a few government agencies having indigenous Micro-Cellular Rubber production unit. The footwear unit manufactures the customized footwear and also houses speciality facilities of orthotics and prosthesis. Laboratories separate sections, Clinical pathology (including slit skin smear), Hematology-Serology (through automated counter), Biochemistry & Microbiology sections. The molecular biology-histopathology section is involved in both real-time & traditional PCR and also processes the skin biopsy for histopathology. CLTRI's separate building of animal house, the legacy of Dr. Shephard's mouse footpad inoculation is still carried forward. The Division of Epidemiology and Statistics conducts training, monitoring and statistical activities, and plays a crucial role in NLEP monitoring under the direction of the Central Leprosy Division. With the support of National Informatics Centre (NIC), CLTRI started the country's first regular online training programme on Bharat VC platform. With more than 12500 books, scientific journals, periodicals, 154 reprints and 187 Microfilms, the Central Library of CLTRI houses one of the largest & oldest leprosy archives. The state of art academic facilities such as the auditorium, conference halls, clinic halls, AC hostel and

canteen facilities are also hallmark of CLTRI, which are always ready to receive a full range of trainees (village to state level and UGs to speciality level).

The institute has a busy Institutional Ethics Committee and an Institutional Animal Ethics Committees. 'Feasibility of Antimicrobial Resistance surveillance in leprosy', 'Assessment of delay in diagnosis and treatment of leprosy', 'Mathematical modeling in lepra reactions (Funded by CSIR)' etc. are a few ongoing research activities in the institute. Recently CLTRI concluded research in 'Quality Assurance of SSS microscopy in Tamil Nadu', ' Operational yield of hot spot surveys' and 'Monitoring & Evaluation of LCDC activities'. Training Manuals for Medical Officers, Laboratory Technicians, Health Supervisors and Physiotherapists, National Training Need Assessment and Implementation Guide' are a few latest publications of CLTRI.

13

Regional Leprosy Training and Research Institute (RLTRI), Gouripur, West Bengal

MK Kundu

Introduction:

National Leprosy Control Programme (NLCP) was launched in India in the year 1954-55 when survey, education and treatment (SET) was the main stay and Dapsone was the only therapy available. It was doing well till 1960 when Dapsone resistant cases in India and other parts of the world were found. To combat this, the World Health Organization in 1981 recommended a new type of therapy known as "Multi Drug Therapy" (MDT) to treat such leprosy problems. After the success of the project, the Govt. of India launched the National Leprosy Eradication Programme (NLEP) with MDT from 1983.

Birth of RLTRI, Gouripur:

With a view to implement NLEP effectively throughout India and to produce suitable trained man-power to combat the growing menace of leprosy, Govt. of India then decided to set up, in early part of 1984, three new Regional Leprosy Training and Research Institutes (RLTRIs), in West Bengal, Orissa and in Madhya Pradesh, in addition to the CLTRI, Chengalpattu, Tamilnadu which was already in existence.

Thus, RLTRI, Gouripur, Bankura, West Bengal was born in June, 1984 in the location as under with the following objectives: a) To create sufficient trained man- power of different categories including Medical Officers, for implementation of NLEP in different Indian states ,especially, in the North-Eastern states including WB to eradicate leprosy. B) To develop a research programme gradually on leprosy.

Location: RLTRI, Gouripur is established at the village Gouripur of Bankura district under West Bengal state, taking a part of the existing government Gouripur leprosy hospital. Initially, it started working in the existing buildings, wards and staff quarters, which were scattered but still in use, in a total area of 43.17 acres. The new Administration Block is established on SH-8. The institute is well connected with the district town Bankura (12 kms), Kolkata city, Ranchi city, Durgapur and Kharagpur railway stations both by road and rails.

Activities of RLTRI, Gouripur:

Gouripur has the following activities and sections for management of leprosy. Since inception in 1984, the institute had been focusing its attention on long term training courses of field

workers of different categories (Medical Officer, NMS, PMW, Lab. Technician etc.). This way, a number of sponsored candidates from different states had been trained from the institute to implement NLEP in their respective areas and helped their concerned states to achieve the goal of NLEP. To make the training programme more effective and meaningful, treatment of leprosy patients at OPD & at Indoor Ward for complicated cases (Ulcers and Reactions) along with providing laboratory, physiotherapy services on a regular basis were also started. Field activities in the allotted areas were started with a view to carry out research work.

Now, in the changing scenario of NLEP management, presently, the institute has been conducting short duration course trainings on NLEP since the year 2011-12 for different categories of medical / para-medical personnel e.g. TOT Programme on NLEP for DLOs, NLEP training of three days duration of Medical Officers, NLEP training course of PMW as per yearly training Calendar schedule in batches. NLEP short training course for MPH/DPH/MD (CM) students, DHP&E students of AIIH&PH, Kolkata and orientation training on NLEP is arranged for MSc/ BSc. and GNM nursing students and to students from AYUSH when it is requested.

In addition, catering OPD services mainly referral, 03 days a week, for the public, afflicted with leprosy and running a 30 bedded indoor ward towards management of complicated ulcer and reaction problems of recurrent nature are done regularly. Furthermore, towards diagnosis of difficult cases and for providing quality care to disabled /complicated leprosy patients, the institute runs one laboratory, one physiotherapy unit.

At present, the institute is managing a significant number of new leprosy cases, some of them in advanced infectious stages. Most of these newly detected leprosy patients are found belonging to SC/ST categories of people as per our record. It speaks of hidden cases existing in society. However, G2D cases are observed to be decreasing. This institute has the potential to be an ideal place for clinical & epidemiological studies in leprosy considering its patient flow and location, by the necessary up-gradation of the existing buildings and man-power by the authorities.

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Regional Leprosy Training and Research Institute (RLTRI), Raipur & ICMR-National Institute of Epidemiology, Chennai

Compiled by editors

Regional Leprosy Training and Research Institute (RLTRI), Raipur

Regional Leprosy Training and Research Institute (RLTRI), Raipur established in the year 1979, is one of the 3 RLTRIs in the country, established with the aim to provide specialized care to the leprosy cases, undertake research in the field of leprosy and develop specialized manpower by imparting training to vertical leprosy staff, deployed all over the country. The institute has a fenced campus with a land area of 14 acres with an Administrative block, a Hostel Block and a Hospital block.

After being involved in the concerted and dedicated efforts to bring down the case load to a level, enabling India to achieve elimination in 2005, the programme became integrated with General Health System (GHS) and implementation of NLEP came under the preview of State health system, with RLTRI primarily as supportive institute. During the crucial pre and post integration period (2000-2010) the institute has undertaken Operational and Health System research and nation wise evaluation of leprosy control acuities (LEM & MLEC etc.).

Current role of the institute is of referral institution to provide support and specialized quality services to difficult to manage complicated cases of leprosy. Institute continued to impart training to various health functionaries viz. Regional Directors, State Leprosy Officer, District Leprosy Officers, Block Medical Officer, and Para Medical Personnel, Laboratory staff, Physiotherapist and other categories of staff from general health care system of various states.

As a subordinate office of Central Leprosy Division (CLD) it is involved in special case detection drives awareness drives (LCDC & SPARSH) with the aim of achieving elimination at subnational, regional and state level.

In the year 2005, the institute has been designated as Regional Office of Health and Family welfare for the State of Chhattisgarh for monitoring various national Health programmes including NVBDCP, RNTCP, RMNCHA+, HIV, AIDS, NPCDCS, NBCP, IDSP, Disaster Management. Thus, the institute at present is holding the dual responsibility of RLTRI & ROHFW, Chhattisgarh.

In addition to Epidemiological and training wings, the institute also has a hospital including OPD, 57 bedded indoor wards, a laboratory to undertake Microscopy

confirmation of M Leprae by skin smear examination and an OT to undertake reconstructive surgeries for leprosy related deformities which is closed for over 3 years and is now under the process of renovation/repair. Presently the Institute is undertaking RCS surgeries in camp mode in various districts of the state. DPMR services are also provided to PAL.

During the ongoing Covid-19 pandemic, under the guidance of the DGHS, the institute has played an important role in supporting the state. It has assessed the Covid hospital and health facilities, made recommendation for improvement of functioning, doing daily reporting of hospitalised cases. The hospital complex is currently working as Isolation Centre / dedicated Covid Health Centre. Covid diagnostic lab with TrueNet facility, with capacity of undertaking about 150-200 has also been developed in the hospital complex of the institute.

The institute is committed to Goal of Leprosy free society, by empowering the health manpower and the community through competency based training and IEC, undertaking need based research and providing quality care to Person effected with leprosy (PAL).

ICMR-National Institute of Epidemiology, Chennai

The ICMR-National Institute of Epidemiology (ICMR-NIE) is a permanent premier institute of Indian Council of Medical Research (ICMR) established on July 2, 1999 by merging the Central JALMA Institute for Leprosy (CJIL Field Unit), Avadi with the Institute for Research in Medical Statistics (IRMS), Chennai. Its vision is to be a catalyst for a vibrant national health system through responsive research, education and training in epidemiology and public health.

The broad objectives of the Institute cover conducting epidemiological studies, development of human resources in epidemiology and biostatistics, networking of the various ICMR and non-ICMR Institutes at the national level for epidemiological purposes, and consultancy. The Institute has the distinction of being the WHO Collaborating Centre for Leprosy Research and Epidemiology, especially under the tenure of director Dr Mohan D. Gupte, between 1999–2008.

The Institute carries out a variety of research activities, which include areas such as interventional studies, health systems research, evaluation of health schemes and disease control programmes, statistical methodology, epidemiological investigations and outbreak science.

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The Calcutta School of Tropical Medicine (CSTM)

Rathindra Nath Dutta, Santanu Tripathy, Shambo Samajdar

The Calcutta School of Tropical Medicine (CSTM) was the only institution in India which dealt exclusively with tropical diseases. It offered postgraduate courses, undertook research and provided patient care. Sir Leonard Rogers came to India in 1893 with the intention of doing research in tropical diseases. He outlined his scheme of establishing a school of tropical medicine in the Englishman and British Medical Journal (April 1910). Lord Carmichael, the then Governor of Bengal, laid the foundation stone of the school on 24 February 1914 and of the Carmichael hospital for Tropical Diseases on 25 February 1916. The school was planned for both teaching and research and every detail of its design was personally supervised by Sir Leonard. However, failing health compelled him to give up his work and he left India on 26 February 1920. The School of Tropical Medicine opened in 1921, with Lt. Col. J. W. D. Megaw as its first director at 8, Chittaranjan Avenue, Calcutta (presently Kolkata). An account of its work is given in a paper by one of the staff, Major Knowles. This teaching and research institution had a laboratory with four floors with 220 feet of north light and a shorter wing at right angles to the main front, while the special hospital for tropical diseases has more than 100 beds, both having been constructed and partially endowed at a cost of about Rs 120,000.

Special laboratories and investigators were provided for kala-azar, dysenteries, ancylostomiasis, leprosy (for which a separate institute was planned to be built opposite the school), diabetes and filariasis, all in addition to the teaching staff of the school. Later the number of departments grew to seventeen. Three or four departments were commonly combining for research under one director. Col. J. W. D. Megaw, thus furnished the team work so essential to success. Due to multiple factors like interdepartmental difference of opinion, political interests, waning interest among Britishers joining IMS (Indian Medical Service) etc. the plan of a separate Leprosy Institute was postponed and later did not fructify.

The Indian Council of British Empire Leprosy Relief Association (IC-BELRA) was founded on 27th January 1925. (This later became Hind Kusht Nivaran Sangh (HKNS) after independence in 1949) At that time BELRA had two headquarters, one located at Indian Red Cross Society Office, New Delhi functioning as Administrative Office and the other headquarter working as Technical Office situated at the Department of Leprosy, School of Tropical Medicine and Hygiene, Calcutta under the leadership of Dr Ernest Muir. Dr. Muir spent 15 years as a medical missionary among Bengal lepers, another 15 years as a research worker in leprosy in CSTM.

Dr. Dharmendra, who was a doyen of Indian leprosy research, joined the School of Tropical Medicine in Calcutta as an Assistant Research Officer of the erstwhile Indian Research Fund Association (now the Indian Council of Medical Research) in 1928. In this institute he developed the chloroform and ether extraction of *Mycobacterium leprae* from human lepromatous tissue and used the bacillary suspension, called Dharmendra lepromin, for skin testing. In addition, eminent researchers like Sir UN Bramhachari, Sir Ronald Ross, Prof. RN Chopra, Prof JB Chatterjee, Prof AB Chaudhury, among others did fundamental research in this institution on various tropical diseases and are remembered globally for their inventions. The Researchers and Faculty of the institutions are now holding the flagship to continue with world class fundamental research.

At CSTM, a six-week special leprosy training course is held twice a year for medical graduates and a special leprosy training course once a year for non-medical technical assistants. Prof RN Dutta, one of the authors of this chapter had taken this training in the early 1980's when Prof Sachin Sen was the Chair of Leprosy Department.

Calcutta School of Tropical Medicine (CSTM), is one of the seven such Institutions dedicated to research, care and cure of tropical diseases, across the world. It is the only institution in India engaged exclusively in research, Post-graduate education and healthcare for tropical diseases. Basically, the objectives have remained unchanged and the school provides facilities for research, postgraduate teaching, training, investigation and treatment in tropical diseases. Presently the institute is under West Bengal University of Health Sciences that governs all the medical colleges in the state of West Bengal. The hospital section of the institute is known as Carmichael Hospital for Tropical Diseases. The Institute possesses a Centre of Excellence where advanced research is going on HIV/HBV Co-infection and Hepatitis B antiviral therapy. This prestigious institution has just completed its 100th year and the centenary year is being celebrated appropriately.

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SECTION 3

POST 1983: INDIAN LEPROSY AFTER INTRODUCTION OF MDT

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Implementation of multi-drug treatment of Leprosy in India: Progress and future

VM Katoch

Leprosy or Hansen's disease has been a debilitating and feared disease since time immemorial. India has been among the most affected countries since the beginning of recorded history of disease, some studies even linking us to its origin and spread. With the discovery of effectiveness of chaulmoogra oil hope of its treatment came. Sulphones helped millions including a large number from India. With the positive outcomes from sulphones many considered and tried it an additional tool for chemoprophylaxis of leprosy and thereby attempt its control. However, these hopes were guarded because of lifelong requirement of treatment of extensive multibacillary disease, increase in secondary and then primary resistance to sulphones, then to rifampicin which was observed to be rapidly bactericidal and promising in treatment. Designing and recommendation of combinations of rifampicin (RFP), clofazimine (CLF) and dapsone (DDS) by WHO– all three for multibacillary (MB) forms and RFP & DDS for paucibacillary (PB) forms was a revolution which changed the course of treatment of leprosy forever (WHO 1982). These combinations, referred to as multi-drug treatment (MDT), have benefitted several millions in India and other parts of world. Recently WHO has recommended an uniform MDT (UMDT) comprising of same combination of RFP, CLF and DDS for 6 months for PB and 12 months for MB leprosy (WHO 2018). However, this article will deal with earlier combination used during the last four decades.

WHO recommended MDT for leprosy was introduced in the treatment of leprosy in 1982 (WHO 1982). Since then, more than 15 million leprosy affected persons have been cured of the disease. It is estimated that MDT has contributed to prevention of disabilities in about 3 million individuals. MDT was in India in year 1982 and impact has been tremendous on all major indicators – prevalence and incidence of disease, disabilities, drug resistance and social health. Trends of last 20 years plus are available on NLEP website. Pre-MDT era has been very well captured in various chapters of Dharmendra (1978).

Impact on Leprosy Burden

Numbers of leprosy affected persons have always been big in India. Though the data is available 1872 onwards, estimates from 1941 onward are considered to have included all leprosy cases. Before that mainly self-reporting cases with disabilities are believed to be the major proportion. Dharmendra estimated the number of leprosy as 1.5 million in 1941 (in a population of 32.5 crore) which increased to 4 million in 1981 and 5 million in 1991(Gupte).

It was also observed that during the decade of 1990-2000, number of registered cases were reduced by 85% globally. Important landmarks for India associated with progress and impact of MDT on leprosy are:

(i) Estimated prevalence at the time of introduction of MDT in 1980 was around 58/10,000, it was almost the same (59/10,000) in 1991.

(ii) By December 2005, prevalence came down to 0.89/10,000 (reduction of 98.5%)

(iii) Thereafter the decline in prevalence was slower. By 2010, the prevalence had reduced to 0.69/10,000

(iv) In 2016, prevalence of leprosy in India was 0.66/10,000

(v) In 2019-20, estimated prevalence was ---/10,000

(vi) Active case search led to detection of more cases in some years which is expected.

Above summary shows that India achieved spectacular success in first 15 years of active case detection and treatment with MDT during 1990 to 2005. This massive reduction in active leprosy cases was a success story of efforts led by NLEP- vertical programme of Govt of India, implemented by states and valuable support of various national / international agencies including NGOs.

Drug resistance:

While monotherapy with DDS benefitted a huge number of leprosy patients, rise in dapsone resistance became a worrying issue. This problem was more with low dose regimens, however, this was happening even with full dose regimen more so in cases with high bacillary load. Cases acquiring resistance (secondary resistance) became source of infection leading to primary resistance. Problem was observed with monotherapy rifampicin and other drugs also. Various studies from India showed MDT certainly controlled the situation of this increase in resistance. Though follow up data from same field areas is very scanty, yet the institution-based studies like from JALMA showed clear reduction (around 80%) in dapsone resistance in post MDT era in cases voluntarily reporting to this tertiary care centre. Through there was no data to compare for rifampicin, after initial post 1990 increase (may be monotherapy impact), resistance to rifampicin came down tremendously – no rifampicin resistant case detected between 2005 to 2009. There have been several studies on this aspect from India. Even though some recent studies from TLM institutions specially Purulia have reported molecular evidence of rifampicin resistance, there is no evidence that it is due to failure of currently used MDT. However, there is need for continued surveillance of drug resistance in leprosy and development of newer improved easy to use molecular tools specially for drugs like CLF.

Deformities/Disabilities:

Leprosy has been a feared disease due to disabilities. Earlier publications mention about 20-25% leprosy cases getting disabilities (Srinivasan 2001). Though exact year is not mentioned, data appears to be from pre-MDT years. After MDT use expanded to entire country there was significant reduction in grade 2 disabilities (G2D) which decreased to 2.31% in 2001 and 1.89% in 2006 (NLEP). After the programme was merged with general health services, there was increase in grade 2 disability rates (4.6% in 2016) which might have been due to late diagnosis in self reporting mode and inadequate treatment. 13.9% in new cases in leprosy case survey in 2010-11 had G2 disabilities (Katoch et al 2017). After NLEP restarted active case

detection surveys, disability rates have been coming down (2.41% in 2019-20).

G2D in children have been an indicator which no one nationally and internationally likes and zero disability in children is the target. Unfortunately, the data from the tertiary care hospitals in India shows that child leprosy cases have been coming with G2 disabilities. Recent data shows that this may be coming under control. In 2019-20, 0.8% of child cases has G2 disability compared to 2.41% overall figures. We can hope to achieve this target in near future if massive health education, active case detection campaigns continue with present speed and coverage.

Success of MDT in terms of consequences (deformities/disabilities) is also linked to access and proper management of reactions (Kar & Gupta 2016), neuritis and other complications (Kumar & Dogra 2016) and also surgical & after care (Shah & Shah 2016). A critical appraisal of the tools/techniques/ strategies used so far and their access to needy persons is required to comment on impact of these management practices individually and collectively.

Stigma-Social dehabilitation :

Social stigma is leprosy has been an important problem from the beginning. This has been seen all over the world, perhaps among all major religions and has been largely due to deformities/disabilities due to leprosy. Disfigurement of face and limbs not only resulted in fear and ostracization of leprosy affected persons (LAPs), but it also led to mental/ psychological distress to LAPs and their families. It also caused functional handicaps to many of such persons due to sensory and motor damage to their peripheral nerves. There are hardly any systemic follow up studies in the same population groups to determine as what has been the impact of MDT coverage on deformities/ disabilities. As MDT resulted in rapid reduction in the number of LAPs, it is expected to have impact on the absolute number of new cases with G2 disabilities. The impact on individual/ personal stigma and social stigma is likely to be different in different areas depending upon the beliefs and education of population concerned. Published literature available shows the positive impact. While qualitative and quantitative impacts can be determined by proper studies, experience is largely positive. In our institute JALMA, Agra the scenario was changing very rapidly in MDT years of1990s, 2000s. Profile of patients rapidly changed. While waiting hall of OPD used to be full with persons with visible nasal/ hand/ feet deformities/disabilities, patients in mid and late 2000s were just like any other normal person with some skin lesions. While in pre-MDT and early MDT years the persons de-habilitated and thrown out by families (mostly women faced the brunt) was frequent, it gradually became lesser and lesser frequent even when a huge number of self-reporting cases were still coming. It is likely that subtly the fear is reducing in the community and resultant social stigma is diminishing. It will be nevertheless important to study these aspects systematically in the current scenario.

Problems

Analysis so far shows a positive impact of MDT on leprosy situation and leprosy affected persons in India. However, several challenges remain which have been nicely captured in reviews (Narsimha Rao & Suneetha 2018). Some of these challenges are :

- **Pockets of endemicity:** When one looks at national programme data, it is observed that we still face the problems of some areas/ districts still having high endemicity. High endemic pockets persist in several areas with low as well as high endemicity. Obviously

this has nothing to do with effect of MDT because its success rate remains the same in these groups as well. Epidemiological investigations on continued transmission in these areas will provide the answers and solutions.

- **Late reporting:** Access to services and timely diagnosis are important for favourable outcomes to any treatment for any disease. This will hold true for MDT in leprosy also. Active case detection done all over the country during 2010-11 at the direction of Parliament showed that there is – fold difference between self-reported cases and cases detected by active survey by same system (Katoch et al 2017). It has been observed that in some of low endemic areas disability rates are very high. While the proportion of cases who report late and their reasons (perception, ignorance, compulsion, health system related factors) will vary, nevertheless whenever we analyse the reports from medical colleges/ other tertiary care specialized centres – this emerges as a common issue all over the country. Number and proportion may be small but the consequences are tremendous to those affected, their families and society. Participation and knowledge improvement of community as well as health care workers needs improvement and deserves special attention.
- **Inadequate surveillance/ follow up:** NLEP has created a system for persons released from treatment to report their problems and get redressal. However, there are gaps as late reactions continue to be observed for a long time. These are being reported from several tertiary care centres. Many end up with silent/ painful neuropathy resulting in disabilities. What is exact gap and what to do should be determined based on evidence. Many experts feel that current guidelines and strategy is inadequate for adequate follow-up for late reactions and relapses. It will not be fair to pass general comments, however, urgent need to study these problems and suggest practical measures is the need of the day.
- **Fixed duration of treatment (FDT):** FDT for paucibacillary (PB) and multibacillary (MB) disease was operationally necessary and useful for the programme. It appears to be quite successful too. However, such fixed durations are not optimum for some PB and also MB cases. Wrong classification (too simplistic based on counting of lesions) also contributed to these problems of improper/ inadequate treatment in some. Cases left with clinically active lesions, persistent bacillary positivity (experience of those who continued to do slit skin smears), reactions and relapses continue to bother affected persons, their treating doctors who are neither themselves convinced nor find reasons to convince their patients that have been adequately treated. Fears about this contributing to drug resistance are unfounded as persisters in such cases have always/ mostly been found to be sensitive to the drugs in MDT and those who relapse respond well to current MDT.
- **Poor response of MDT in some patients:** Over the years publications have come out from important institutions like PGIMER, Chandigarh which show that MDT and even modified regimens may not show desirable results in a section of leprosy cases.

Search for improved MDT regimens:

Since the roll out of MDT in 1980s there have broadly two kinds of attempted modifications.

1. Investigators who designed combination and tried these to reduce the duration of treatment further. While initial response was positive, long-term problems like higher relapses dampened the progress on this front.
2. Many investigators reported the above problems of persisting clinical activity, persistence of live bacilli in some and problems of reactions/ relapses. Attempts were made to modify the regimens by extending the duration of treatment – dapsone treatment in PB, entire MB regimen in highly bacillated cases of MB leprosy, use of other drugs like minocycline, ofloxacin and clarithromycin and immunotherapy using BCG /MIP), adding the clofazimine to PB regimen (the present UMDT), other drugs like ethionamide/prothionamide (Katoch et al 1999; Katoch 2016, Saunderson 2016). Initially clofazimine was added in JALMA studies to PB regimen of six months and showed many benefits in terms of reducing the persistent clinical activity and better recovery of sensory deficit. However later this was tried as uniform MDT for a common duration – global trial results have been positive and this has been recommended. However, uniform MDT common duration is contested by many and a consensus is yet to emerge. These studies have been done both in India and other countries. It is needless to say that over the last four decades several possibilities and approaches to modify currently used MDT have emerged. These need to be considered for the apparent benefits to improve the therapy further.

Future perspective:

It is desirable that we learn lessons and improve. It is a matter of debate whether the current MDT needs replacement – clearly the experience of more than 30 years in India shows that current MDT regimens are robust even today and take care of majority of leprosy patients. Timely access remains a priority which should be strengthened by locally relevant evidence. NLEP led programmes like SPARSH and ABSULS have shown impact on improving the access. Molecular diagnostics, thanks to tuberculosis and Covid 19, have reached the periphery. Genetic platforms like TrueNat need to be made available in the periphery and all medical college hospitals for diagnosis of atypical leprosy cases and cases missed by health care professionals with limited training in leprosy. Strengthening the clinical expertise at all levels is a necessity for better public health outcomes of MDT.

Addition of clofazimine and immunotherapy with MIP are clearly beneficial – these reduce the activity, reduce (MIP)/ manage reactions (CLF), how and how much are the issues that need more debate and decision. Alternate drugs including minocycline, ofloxacin, bedaquilline (Saunderson 2016) can be used to improve the therapy specially for a small number of non/ poor responders who need also appropriate alternatives. Cases infected with drug resistant strains, though not a significant public health problem as of now, need appropriate regimens.

Grade 1 disabilities (G1D) need more attention. They should be properly identified, timely captured and managed so that these do not progress to G2D. Research needs adequate focus on improving the management of neuritis and reactions specially in field resource limited settings.

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India reaches global leprosy elimination target in 2005

P Narasimha Rao

In 1981, WHO took a monumental decision and recommended Multi Drug Therapy (MDT) for leprosy globally. In India the MDT for leprosy was introduced in a phased manner from 1982 onwards, initially in high endemic districts, later to cover all the states of the country. It was only in 1995-96 whole of India was covered by it, the last state covered being Jharkhand.

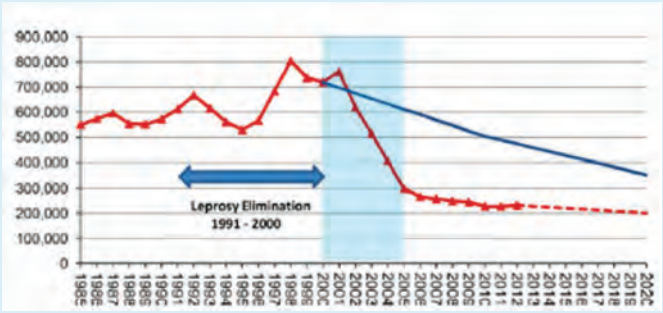
There is clear evidence that the elimination strategy is sound and effective and within the first two decades of its introduction, the global prevalence has fallen by almost 90% and more than 14 million patients have been treated successfully. Nevertheless, since its introduction the timelines and schedules of MDT of leprosy have been a subject of debate and discussion, which led to significant changes in terms of duration of treatment and the criteria for therapeutic classification. Within a decade of introduction of MDT, the World Health Assembly Resolved in 1991 to "eliminate leprosy as a public health problem" defined as a reduction in prevalence rate below 1 per 10,000 population (PR <1) , by the year 2000. One need to note that by this year, the MDT was not yet made available across all districts states of India. While that being so, this resolution galvanised extraordinary international support to program activities leading to a significant fall in the point prevalence of leprosy at global level.

However, the selection of this number (1 per 10,000 population) for elimination target was arbitrary and not supported by mathematical modeling of leprosy data. This cut-off point was chosen because within the WHO it was thought that when this point was reached, the disease would 'die out'! Critics remarked that there was no evidence that this would occur and the whole idea of the hypothesis that at a prevalence of < 1 case per 10,000 population would disrupt the transmission of leprosy in the community was epidemiologically not tenable.

Be it as it may, as a part of the Global Leprosy Elimination initiative, the 'Final push' leprosy strategy was initiated by WHO in November 1999 with an objective to achieve the target of prevalence rate < 1/10,000 by 2005, the extended target year for global leprosy elimination. This was because by that year, of total 122 endemic countries, 21 countries including India could not reach the WHO elimination target. Because of these 'final push' initiatives and activities, all but six countries reached the elimination target by 2005,

including India. While it was an occasion to rejoice, many workers and researcher were left wondering if it was real or a make-believe achievement!

Figure 1: Graph showing the influence method adopted to reach global elimination targets on Annual case detection numbers between 1985-2022 (red dotted line). The extreme reduction observed (highlighted in blue) between 2000-2005, during the extended period of global elimination target. The continuous dark blue line is indicative of predictive normal rate of fall.



To unravel the reason, we need look at the background and methods followed for achieving this elimination target by India.

In 1991 the World Health Assembly (WHA) passed a resolution to "eliminate leprosy as a public health problem" by the year 2000 and encouraged detection of new cases globally and treat them with MDT. The number of leprosy cases detected globally rose significantly from 566,567 in 1996 to 622,110 in 2002. In India too, more new cases were being detected by Leprosy Elimination Campaigns (LECs), where active block level search for new cases was being done, which were recommended and promulgated by WHO towards the end of the last millennium in order to intensify elimination of leprosy in India. This LEC strategy not only detected new cases but also mobilized resources and political commitment to leprosy across India. However, the problem faced by the program managers was that LECs were very effective. For example, in West Bengal, 8,181 new cases were detected in an 8-day period in a district by LECs. This was going against the intended purpose of leprosy elimination and reduction in case numbers!

Meanwhile WHO proposed a strategic Plan for Elimination of Leprosy 2000-2005, (also known as 'The Final Push'), to encourage the commitment of 21 countries who failed to reach the desired global leprosy target by year 2000. But this target could be reached only by reporting fewer patients! When it was clear that leprosy transmission continued and new cases were being detected in many countries including India, the appropriate response should have been to redefine the campaign rather than cling on to it. But how the global program managers perceived the increase can be gauged by the opening speech of Maria Neira, the then head of the Communicable Disease Programme - WHO, during the Asian Leprosy Congress 2000, who accused Indian leprosy workers of over-diagnosing leprosy so as to keep their jobs! As a fallout measure to control and report on LECs, WHO introduced the

'Leprosy Elimination Monitoring groups' (LEMs). These LEMs developed standard protocols for the validation of leprosy diagnosis and classification of newly detected leprosy cases. Of course, as was desired and expected, validation of the diagnosis of new leprosy patients in India led to a conclusion that indeed, there was a marked over-reporting of new leprosy cases, including incorrect diagnosis, re-registration and registration of non-existing patients. And the registers were cleaned and realigned to 'corrected' numbers! Are the LEM findings accurate and impartial? What is not mentioned while reporting the findings of LEMs was that similar validation was not conducted in the previous years. In the districts where new cases were assessed by LEMs, the LECs were conducted by the same experienced staff who were involved in leprosy work over the last few decades, with similar infrastructural facilities and techniques. How have they become suddenly less competent remains a mystery. Moreover, not all evaluators found the LECs to be the cause of over diagnosis or re-registration. Some evaluation teams actually diagnosed additional new cases missed by the LEC teams.

On the whole, as intended these measures brought about a significant fall in the numbers of cases being reported from India. The leprosy case prevalence which at beginning of 2004 was 265,781 (PR =2.6), dropped down to 148,910 (PR =1.4) by the beginning of 2005, a decline of more than 1 lakh cases in a year! To bring it further down to <1 by end of the target year 2005, WHO organised a meeting of 'National Program managers for leprosy elimination' at Kathmandu, Nepal in January 2005, with the main objective of taking an overview of the progress of leprosy elimination in the South east Asian Region countries and come out with recommendations. The meeting came out with India and Nepal specific recommendations. (Box 1) This meeting was chaired by representatives of WHO and number of national program managers from 7 countries, including DDG-Leprosy, Govt of India. The outcome was that 'Kathmandu recommendations' were implemented in toto and more, all over India in the year 2005 (Box 2).

Road to declaration of elimination target: Questions still remain about 'Final push":

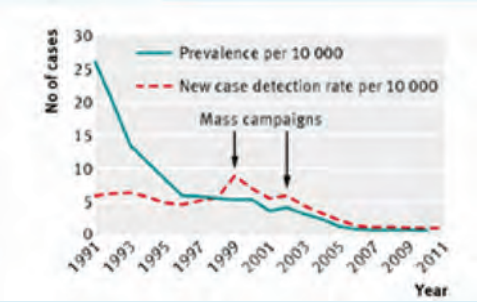
As detailed above, the 'Final push' as a leprosy strategy was initiated by WHO and the measures pursued to achieve the target in India by 2005 were subject of debate and issue of concern even today. Some of the most infamous instructions given to Indian leprosy workers and field staff to achieve these highly ambitious and improbable targets and goal were known as 'Kathmandu recommendations' (Box 2). They included such orders as to 'stop the search for new cases' to the field staff which are astounding and cannot be justified, as the whole leprosy program of leprosy elimination till that time was based on the detection and cure of new cases. The extent of influence of such dubious instructions, including 'cleaning of registers' in engineering the decrease in the leprosy numbers of India during this period was immense.

Implementation of these recommendations and methods led to the achievement of prevalence to less than <1 by the 31st December 2005; and the news of India reaching the elimination target was announced on 30th January 2006, the Mahatma Gandhi martyrdom and Anti-leprosy day observance day. The leprosy point prevalence of India reported for

year 2005 was only 95,150 (The number of new cases reported for the same year were 161,457!). This was an improbable and drastic reduction of about 65% compared to leprosy point prevalence of 265,781 at the beginning of 2004. It was also documented that India experienced an phenomenal and insanely drastic reduction in annual new cases detected from 473,658 in 2002 to about 160,000 by 2005, a fall by about 65%. The impact of reduction in Indian leprosy was so great that the global leprosy figures fell by 27% for the year 2005.

Altogether, due to these measures the annual leprosy new case detection between 2002-2005 in India declined over 30% per year. Such a large, sudden fall in transmission and number of new cases seems biologically implausible given the long and variable incubation period in leprosy. The only explanation could be that the Indian leprosy programme adopted measures that ensured that fewer patients were registered, including not registering single lesion cases and no tracing of household contacts, even though this is not a good public health practice.

Figure 2: Incidence and prevalence of Leprosy in India (1991-2011) and influence of Leprosy detection campaigns.



Can the leprosy statistics be trusted?

What makes India so different from all the other endemic countries in being able to achieve a consistent annual decline in case detection at a rate which is believed to be not epidemiologically possible? (Figure 1) Some felt that due to a deadline and hurry to reach the global elimination target, by encouraging repeated changes of definitions of leprosy classification, ascertainment procedures, and diagnostic registration conventions, it had in effect eliminated our ability to monitor and understand what has actually happened! Others opined that, the fall of numbers were a result of lax case finding activities and dubious registration procedures, based on Kathmandu recommendations. Yet another group judged that the concept of elimination itself, and the choice of prevalence as an indicator to measure the progress of the WHO-orchestrated campaign, were scientifically devoid of significance, as was the 2005 deadline; and that over the last few years of the campaign, the elimination target had become more a political target, rather than an epidemiological or program quality target.

Even the present scenario of new case detection globally in 2021-22 corroborates that there is no evidence that the WHO global initiative of leprosy elimination 1991-2005 has led to the disappearance or local eradication of infection or disease from any population, as leprosy continues to appear throughout Africa, Asia and Latin America, southern Europe and even in the US. And it has come close to eliminating leprosy research, while most of the basic questions remain unanswered. With dwindling research and leprosy funding sources, one of the very consequential event which happened was the closure of an important leprosy journal of the past 70 years, the *International Journal of Leprosy and Other Mycobacterial Diseases* in the year 2005.

Leprosy scenario in India in the aftermath of India reaching elimination target:

The number of leprosy patients in the registers in India by the end of 2005 were about 110, 100 and the number of new cases detected in the year 2005 was 160,000. While India reached the elimination target at national level, however at sub-national level many states and Union territories (UTs) have not achieved elimination target. By the end of August 2006, 27 states/ UTs have reported to have achieved elimination status and while the other 6 states/UTs had PR > 1. The states which were important were Bihar, Jharkhand and Chhattisgarh. Leprosy prevalence was also found higher in UTs such as Delhi and Dadar & Nagar Haveli and this was attributed to the migrating population which hampers case detection and follow-up. What is of concern is that these states and union territories still in the year 2022, have higher caseload compared to other states and with many districts with PR>1.

Integration of leprosy in to general health services - A policy change-post 2005:

In 2005, the Government of India took another major step towards expansion of the NLEP and the leprosy work, which had been carried out so far as a vertical programme, was integrated into the general health services. There were no more special leprosy clinics. All hospitals, dispensaries and PHCs had to treat leprosy patients. By integration, it was expected that leprosy becomes an "ordinary" disease, discrimination against leprosy can be set to be removed and the patients have access to the services of ophthalmologists, surgeons, physiotherapists, and general physicians.

As a result of this move, leprosy services got integrated into general health services at district and PHC level whereas, at State and Central level, leprosy has retained its vertical nature. Post integration, hitherto leprosy workers have been inducted as multipurpose workers engaged in other public health activities such as TB and HIV. However it brought in some negative aspects such as, deterioration of the quality of care and leprosy work became lax as worker's focus had shifted away from leprosy. At the same time, with the elimination target reached, public information campaigns regarding leprosy has decreased significantly in print and audio visual media, such as TV and/or Radio/FM programmes. Coupled with this was a general decline in leprosy activities following the declaration of elimination as a public health problem globally, resulting in reduced intensity and drive in case detection & community awareness activities and training.

Conclusion:

Global leprosy eradication may have been a politically desirable aspiration but the scientific case for such a strategy cannot be justified. Moreover, a target to eliminate a disease should be set only if it is realistic as workers and government servants strive to reach targets and find unexpected ways of doing so, particularly if incentives or pressure is exerted on them from higher authorities. And importantly, such targets given to reach in a limited time can disrupt the focus and quality of services.

The lessons of leprosy show that monitoring of targets must be realistic and transparent, and unfortunately, it was not the case with the Indian leprosy elimination campaign of 2000-2005. Based on the evidence and experience, some opine that the leprosy elimination concept might have been actually detrimental to public health, as the distinction between eradication and elimination is widely misunderstood. Moreover, the rhetoric that 'leprosy is eliminated' had led to the impression in some quarters that leprosy no longer exists. On the whole, although the target of leprosy elimination was achieved at national level in 2005, even today a very large proportion of leprosy (58%) cases reported globally still come from India and leprosy still remains a serious problem in the high-endemic districts and blocks of many states of India. These regions often have very large populations, many of them in tribal regions. There is a need to employ innovative and inclusive methods, including retrenching of efforts to achieve sub-national level elimination of leprosy in India.

At the same time, it is true that the WHO global leprosy elimination campaign 1991-2005 had definitely mobilised the global leprosy community to the possibility of containing and probable eradication of leprosy. Nonetheless, as already pointed out, there was an orchestrated undue haste in drafting and implementing specious recommendations and directives, forcing the field workers to reach unreasonable and insincere targets to push India to reach the elimination target by year 2005, for political reasons.

Fortunately some remedial efforts and actions were initiated, both by WHO and Indian government agencies, though deliberations and discussions for course correction post 2006. In 2007, WHO abandoned the elimination target for leprosy programme and instead set a target based on disability rates with the aim of improving focus on prevention of disability. Of course, it is an another topic for discussion.

National Programme Managers for Leprosy Elimination Report of an Inter-country Meeting Kathmandu, Nepal, 6-8 January 2005. WHO Project: ICP CPC 600.

The purpose: To take an overview of the progress of leprosy elimination in the South-East Asia (SEA) Region and in countries and come out with recommendations, (also known as the 'Kathmandu Recommendations'). Twenty-six participants from 8 Member States and national programme managers from 7 countries attended, including Dr G.P.S. Dhillon, DDG (Leprosy), Government of India.

This meeting identified that SEA Region continues to be the only WHO region that was yet to achieve the goal of leprosy elimination and that within it, India accounted for 91% of new cases detected in 2003. Moreover, three countries, namely India, Nepal and Timor-Leste were yet to achieve their national elimination target and that they need to make concerted efforts to achieve the goal by December 2005.

The main objectives were to a) discuss implementation of country plans of action for the biennium 2004-2005, and b) to make appropriate recommendations for acceleration of national/sub-national-level elimination.

Specified recommendations for India and Nepal were as follows:

(1) The most critical and priority activities for 2005 should be:

1. Routine case confirmation prior to registration;
2. Monthly up-dating of registers
3. Capacity building of health staff in order to minimize the 'operational factors' influencing prevalence and new-case detections.
4. These activities can be done through focal teams like District Nuclei/District Technical Support Teams/NGO Support Teams and WHO consultants.

(2) In order to ensure quality of new case detection, programmes should ensure:

1. Case finding is mainly focused on promoting self-reporting and that

   a) Active case finding activities are not employed at any level;

   b) Instructions should be issued to discontinue active case detection activities which seem to accentuate the problems of wrong diagnosis and re-registration of cases;
2. Strict adherence to case definitions as per WHO and national guidelines;
3. Confirmation of new cases by competent health staff/MO prior to registration and initiation of MDT,
4. Considering the history of previous treatment and ensuring that previously treated cases are not registered as new cases, even if they require MDT.

Based on the Kathmandu recommendations, State governments of India issued these guidelines at the beginning of 2005 in an effort to reach the elimination target by the year end.

New instructions to the field staff ***(Named 'Kathmandu recommendations).***

1. To stop all active search for case detection.
2. No registration of cased to be done before reconfirmed by experienced staff (Routine case confirmation only by a member of validation team).
3. Declare patients as RFT (released from treatment) and delete names of the patients from registers as they receive the last pulse. (Monthly updating of registers or 'Cleaning' of registers) *
4. Do not register single lesion cases for now.

The first three instructions are thorough official documents and office orders to the field workers. The last instruction is the verbal communication / instruction.

*Comment: Previously patients were made RFT and names removed from registers after end of completion of last month of therapy.

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"I tell politicians, if you want to demonstrate India's progress, you can't afford to have a disease like leprosy,"

-S.K. Noordeen, Head, WHO's global leprosy elimination program (1984–1999)

18

Post elimination era and remaining challenges

Sujai Suneetha

Introduction

The introduction of multidrug therapy (MDT) by the World Health Organization (WHO) in 1982, along with the shortening of therapy over the years resulted in a dramatic reduction in the prevalence of leprosy in India. It is estimated that over 5 million were successfully treated and cured of the disease in the country. That was a great success for India which needs to be lauded. Meanwhile, the WHO set the goal of 'elimination of leprosy as a public health problem' with less than 1 case per 10,000 population as the target and India was able to achieve this goal at a national level in December 2005. Once it was announced that India had reached that figure it was considered a significant and grand achievement and India in 2006 moved into the 'post-elimination era'.

'Post elimination era' – an inapt idiom:

Along with the announcement of 'Elimination', the country took a few measures which included disbanding of the vertical system, (from a dedicated program only for leprosy) and integrating leprosy into the general health care system at the district level. The objective of this measure was that access to leprosy diagnosis and treatment would be expanded to the whole health care system in the country thereby widening the net to identify and treat all cases in the country. As a fallout, the practice of 'active case finding' (health workers actively searching out new cases in the community) was given up and leprosy patients had to seek diagnostic and treatment services from the general pool of health services in the country. This required that all staff needed to be trained and oriented to recognize and treat leprosy. However, there were a number of challenges – the interest to get involved in the care of a stigmatized disease like leprosy was low; as well as the addition of a new disease was resented by an already overburdened general health care system; whereas the existing trained leprosy staff had to take up responsibilities as multipurpose workers, with less time for leprosy related work. This resulted in a dwindling pool, rather than a larger pool that was envisioned of clinical expertise in diagnosing and treating leprosy. Cases were missed and there were delays in diagnosis resulting in continued spread of the disease and new cases in communities. Concomitant was an increase in MB leprosy proportion, leprosy in children and disability even at first diagnosis. Pockets of high endemicity were found in the country

especially in hard-to-reach and in tribal communities.

Slit skin smears which was for years considered a gold-standard lab test for leprosy was given up in the post-elimination era. The rise in HIV/AIDS during the same period was another excuse for giving up skin smears, as a relatively invasive lab test. The diagnosis of leprosy then was only based on clinical skills and on skin lesion count alone as nerve palpation was not a skill widely prevalent or promoted among health care staff.

The announcement of 'elimination of leprosy' meant to most ordinary people that there was no more leprosy in India. In most conversations people would say "Is there still leprosy in India? I thought it was eliminated". Many medical professionals assumed as well that there was no more leprosy in India and there was a general decline in interest about this disease. Funding for research and for leprosy programmes saw a dip. This led to closure of leprosy programs or integration/initiation of HIV services into these institutions as the HIV epidemic was on the rise in India. This also resulted in fewer centres for providing specialized leprosy services like skin smears, biopsies, physiotherapy, reconstructive surgery etc., across the country.

Nonetheless, in the post elimination era India saw a gradual decline in the prevalence of the disease (number of patients on treatment). But the reduction in the incidence or new cases detected remained more or less constant post elimination. Each year over 110,000 new cases were consistently being reported in the country. It was also observed that India continued to contribute about 60% of the world's caseload. This raised an alarm that leprosy was still a problem in India and that efforts were needed to identify the sources of infection in the country. The NLEP (National Leprosy Eradication Programme) identified sub-nationally that many districts have the prevalence above the global elimination target of 1 per 10,000 population and efforts were focused on these districts.

Having given up active case finding as a means to identify new cases in the community, the NLEP initiated an innovative campaign mode of 'Leprosy Case Detection Campaign' or LCDC's in high endemic pockets from 2015. States like Bihar, Chhattisgarh, Jharkhand, Madhya Pradesh, Maharashtra, Odisha and Uttar Pradesh were selected for LCDC. This proved to be very effective and the campaigns yielded many new cases. This indicated that there was continued transmission of the disease from 'hidden cases' in the community and LCDC campaigns were a good way of flushing out these hidden cases who were spreading the disease as well as the fresh new cases. Multiple LCDC's were conducted all over the country and they yielded over 35,000 new cases in a very short period of time. The LCDC's also highlighted the value of the good old 'active case finding' approach. Other new approaches that were implemented were ASHA-based Surveillance for Leprosy Suspects (ABSULS) where the dynamic work force of ASHA workers were roped in; and Active Case Detection and Regular Surveillance (ACDRS) which are presently being conducted from 2019 with the goal of stopping the spread of the disease in the community.

The World Health Organization (WHO) through its country office in India has continued to support the NLEP through ensuring uninterrupted supply of MDT in the country. Besides this, the WHO continues to provide strategic inputs into the leprosy programme.

Meanwhile, an important study was carried out in one of our neighbouring countries on the value of a Single Dose of Rifampicin (SDR) which is a potent antibiotic, to household and neighbour contacts of an index case of leprosy. The study showed that SDR produces an over 50% reduction in new cases among the contacts over a 4-year period. This led to India adopting this strategy initially in a pilot mode and then as a wider strategy. This widened the approach to a three-pronged strategy of early diagnosis, effective MDT and chemoprophylaxis with the long-term goal of wiping out leprosy from our country.

Remaining challenges

While it is important to celebrate the successes of the MDT era and the milestone of achieving elimination at a national level, a few challenges have emerged in the post-elimination period which need to be addressed.

1. Bringing down the new case numbers: As mentioned earlier there has been a very slow, almost negligible drop in the new cases in the country, with the figure remaining over 100,000 since 2006 except for the years affected by COVID. This points to continued transmission of leprosy in the community. There is a need to identify all cases; fully treating them; identifying all the family and neighbourhood contacts; treating any of them if having the disease; administering preventive treatment with SDR; and continued surveillance in the area for at least 5 years. There is a need for continued awareness about leprosy in schools and communities to promote self-reporting of cases, as well as training of health care workers on the early signs of the disease so that they do not miss the diagnosis.

2. Stopping further spread of leprosy (Interrupting transmission): The above-mentioned efforts are effective means of interrupting human to human transmission from an index case of leprosy. There are suggestions from basic research in the country that there could be extra human reservoirs of the leprosy bacteria *M. leprae* in soil, water and even in other animal carriers. Improvement in environmental sanitation and even personal hygiene could contribute to stopping the spread. 'Swatch Bharat' or 'A Clean India' is a very positive national effort in that direction and will most likely yield positive results in terms of contributing to bringing down an age-old disease like leprosy in India. The more recent recognition of the value of sufficient and clean water for families and communities in the 'WASH (Washing, sanitation & Hygiene) program' initiatives is also a step in the right direction.

   Note: Leprosy can also spread through 'droplet infection' like COVID-19. People are more aware now of the benefits of personal hygiene, social distancing and nutrition in preventing the spread of COVID. The same is most likely to be true for the spread of leprosy. Better housing with more ventilation, less overcrowding in communities, better nutrition, personal hygiene and poverty eluviation can be game changers in stopping the spread of leprosy (as well as COVID, tuberculosis (TB) and other air borne diseases) in India.

3. Reducing leprosy in children: Much significance is attributed to identifying new cases among children. It is the harbinger of active spread of disease and every effort needs to be taken to bring this down. An active case of leprosy within the household of the

child is the most likely source of infection. Tracing the index case and identifying their contacts especially children can help to protect the other children in the household. Another approach is the thorough examination of all children in the house of a newly diagnosed adult patient, which will ensure early detection of children and prevention of disability among them. School and community surveys are also two other effective means to detect new child cases early and prevent disability among children which can have disastrous ramifications for the child and the community.

4. Better management of leprosy and specially patients with high bacterial load: Research has shown that Multi bacillary (MB) leprosy patients have a 3-5 times higher risk than Paucibacillary (PB) patients of transmitting leprosy to others. In the MB group there is a sub set of patients with a higher load of bacilli. These high bacterial load patients have a greater potential of transmitting the disease as well as take longer to become non-infectious to their families and community. These patients may need a different approach of treatment – longer course of Multi Drug Therapy (MDT) or an alternate course of treatment with stronger anti leprosy drugs. This will undoubtedly help in reducing leprosy in India.

5. Effective management of post treatment problems: Leprosy patients who complete their course of treatment are 'Released from Treatment' or RFT. Leprosy is a slowly progressing illness when it begins and takes an equally long time as well to recover. As a result, many of them have multiple problems during the post RFT period, especially in the first few years (2-5 years). These include lepra reactions, damage to nerves, ulcers and sometimes recurrence or relapse of the disease, all of which lead to worsening of disability and further spread of disease. There is no clear mechanism in place for the care of these problems, and patients often turn to private practitioners, dermatologists and specialized centres for their care. There are limited centres however for these post RFT problems, especially wound care and surgical rehabilitation. There is a definite need to plan resources so that patients are well taken care of even during the post treatment period. Delay in treatment of leprosy can lead to development of deformities or disability. Disability is one of the key causes for the stigma associated with the disease. One of the effective ways of ensuring that patients under treatment and RFT patients do not develop disability is to give proper health education to patients on ways to prevent ulcers through proper care of hands and feet and simple physiotherapy exercises to prevent deformities.

6. Actively look for new leprosy patients in the community (Restoring active case finding): A key contributor to the success of the MDT era was the tool of active case finding. Active search for new cases was carried out and communities combed successfully to flush out all cases early. The value of active search was revalidated by the LCDC's done in 2016. With India still sharing 60% of the worlds leprosy there is a need to bring back active search for new cases of leprosy. A recent finding from Mumbai shows that there are still huge pockets of leprosy in the cities probably in the slums and in the villages and they need to be actively searched out and treated.

7. Reinstating Slit Skin Smears service as a lab test for leprosy: Research from specialized institutions and medical colleges have shown a rise in smear positive MB patients. This was possible because in these centres skin smears are still routinely being done.

Whether this is because leprosy is still actively spreading in the country or this is part of a phenomenon where before it dies down there is a short burst of MB leprosy is a matter of debate. Skin smears are still a valuable tool for diagnosis, choice of treatment and follow up in leprosy. It can also help identify the sub group of high BI patients so that they are properly treated.

8. Moving from a public health approach to an Individualized approach of care: When India was battling large numbers of leprosy patients a public health approach was needed and was effective in bringing down the numbers. But the numbers of new patients now is more manageable and there is great benefit in using a personal approach to treat each new patient. Each individual has different needs and responds differently to the medications and needs individualised care which is better and more effective.

Conclusion

India has made great strides in its attempt to tackle leprosy. The proofs of success on many fronts is undeniable. Program managers have left no stone unturned in their efforts to contain leprosy. However, many solutions have eluded us, some obvious and some not so obvious. Some of the obvious ones need to be tackled and they have been highlighted above. Continued basic, clinical and operational research in leprosy needs to be the thrust for the days ahead. India has proved its mettle in the way it handled Polio and more recently COVID-19 pandemic. It will no doubt succeed in wiping out leprosy, if not before 2030, at least in the near future. We all need to stand shoulder to shoulder and join hands with the government in our fight against leprosy and we will surely succeed. Mera Bharath Mahaan!

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Efforts towards repealing of laws of discrimination against leprosy

Nikita Sarah, Subhojit Goswami

Introduction

Leprosy, to this day remains a dreaded disease due to prevailing misconceptions about its causation, transmission, and curability. Although leprosy may lead to irreversible disabilities in some cases, advances in treatment ensure that it is completely curable, and a person affected by it can be rendered non-infectious in the early phase of treatment with multi-drug therapy. Exaggerated fear of leprosy, which stems from ignorance and misinformation, promotes exclusion and discrimination against people affected by/cured of the disease. It creates barriers to their participation as equal members of society and violates their rights.

Besides societal misconceptions, some provisions in Central and state laws also encourage discrimination against persons affected by leprosy. For long, many laws and acts of India interpreted leprosy as an 'incurable and virulent' disease, allowed it to be a legitimate ground for divorce or separation, earmarked people affected by leprosy as lunatics, and provided for their detention for an unspecified duration. The Life Insurance Corporation Act 1956, for example, has a provision of charging higher premium rates from persons affected by leprosy on account of higher risk to their lives as understood through past notions. Several other Acts prohibit them from holding or contesting for civic posts and deny them certain rights and concessions.

India is a member of the UN General Assembly, which, in 2010, unanimously adopted a Resolution on the Elimination of Discrimination against persons affected by leprosy, along with the Principles and Guidelines, which listed out measures to improve their living conditions. India has also ratified the United Nations Convention on the Rights of Persons with Disabilities, 2007 (UNCRPD), which promotes, protects, and ensures full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities.

While the need for reforming some of the archaic laws was evident, momentum was lacking to give this issue its due prominence. The Leprosy Mission Trust India (TLMTI) took lead in building awareness on misconceptions and prejudiced practices that do not allow persons affected by leprosy to live in dignity. It has been sensitizing different networks about discriminatory treatment meted out to people affected by / cured of leprosy with no legal implications on the perpetrator. As a ripple effect, some of the networks came forward and initiated actions in their own capacities. In 2014, it took it upon itself to explore the depths of the problem pertaining to existing discriminatory laws. What followed is a series of activities—research, collaboration, communication, and advocacy, targeted towards sensitizing and mobilizing stakeholders—legislative, judiciary and civil society—who would then throw their weight into the issue.

Efforts towards repealing discriminatory laws

When the Union Ministry of Law & Justice, in June 2014, announced its decision to do away with all obsolete laws, TLMTI connected with the then Union Law Minister Shri. Ravi Shankar Prasad with a request to repeal The Lepers Act, 1898, which had discriminatory provisions. It marked the beginning of an eventful journey towards creating awareness and galvanising efforts for repealing several other discriminatory laws. The 20th Law Commission of India, which, under the Chairmanship of Justice (Retd.) A.P. Shah had undertaken the task of identifying obsolete laws that can either be repealed or modified, came up with a series of reports (Report No. 248-251) to that end.

In its Second Interim Report No. 249 on 'Obsolete laws: Warranting immediate repeal', the Law Commission recommended the repeal of The Lepers Act (Act 3) of 1898, recognizing it as "completely out of sync with the modern understanding of the disease and its treatment". The Commission considered it "unconstitutional for being violative of Article 14 of the Constitution because it legalises forcible segregation of people affected with leprosy." The Commission also acknowledged that the Act was against the spirit of the UN resolution on the elimination of discrimination against persons affected by leprosy and their family members.

After the release of the Second Interim Report in October 2014, the Law Commission sought help in stepping up action on other obsolete laws applicable to persons affected by leprosy. With research and documentation support from ILEP International and ILEP India, TLMTI made a submission before the Law Commission in 2015. Following this, the Commission held a series of deliberations with stakeholders working in leprosy domain, and in April 2015, it came up with Report No. 256—'Eliminating Discrimination Against Persons Affected by Leprosy'.

The Report not only recommended repealing and amending discriminatory laws, but also framed a new comprehensive legislation dealing with all aspects of rights of persons affected by leprosy and their family members Elimination of Discrimination against Persons affected by Leprosy (EDPAL) Bill, 2015. The Bill—which the Law Commission thought "will ensure coherence and send out a strong signal of resolve of the Government of India to tackle discrimination faced by persons affected by Leprosy"—was submitted to the Ministry of Law and Justice, Government of India, for further action. The Law Commission

recommended that the proposed law, besides covering the repeal/modification of specified statutes, must also contain principles of non-discrimination and equal protection before law, and enabling provisions regarding affirmative action. It called upon the government to undertake affirmative actions related to health, social welfare, education and employment, participation on policy decisions, and security of tenure, title, and ownership of property of persons affected by leprosy. 'All persons affected by leprosy and members of their family shall be entitled to the recognition, enjoyment, and exercise, on an equal basis, of all human rights including freedoms guaranteed by the Constitution of India,' the Report 256 observed.

One of the first signs of positive development following the drafting of the EDPAL Bill was the introduction of a Private Member Bill on leprosy titled, 'The rights of persons affected by leprosy and members of their family (Protection against Discrimination and Guarantee of Social Welfare) Bill, 2017' by Mr. KTS Tulsi, the then Rajya Sabha MP and a Senior Advocate of the Supreme Court of India. TLMTI and the Vidhi Centre for Legal Policy supported Tulsi's office in drafting the Bill, which was introduced in the Parliament in December 2017. It was partially structured on the lines of EDPAL and raised questions on discriminatory provisions in various laws, and social, economic, and cultural discrimination meted out to persons affected by leprosy and their family members.

With the private member's bill managing to garner attention of different stakeholders, individuals and institutions initiated advocacy efforts towards sensitizing judicial bodies for relevant interventions. In 2018, Pankaj Sinha, a senior advocate, filed an instant writ petition in the Supreme Court, drawing attention to discrimination meted out to persons affected by leprosy. Based on the petitioner's argument, the apex court issued directions to the Centre and state governments to ensure the rehabilitation of leprosy patients and end discrimination against them, especially in hospitals and schools. Another writ petition was filed in the Supreme Court in the same year by the Vidhi Centre for Legal Policy. The petition challenged discriminatory provisions in 119 Central and State laws. In response to the petition, the Supreme Court asked the Centre and states to delete from statute books all laws

that discriminated against people suffering from leprosy. "Delete from statute books all such laws. We are sure Centre and states will rise to the occasion to remove the provision relating to disability. We are conscious that leprosy is absolutely curable," the court observed.

The Supreme Court order put the government machinery on active mode with Shri Ravi Shankar Prasad presenting The Personal Laws (Amendment) Bill, 2018 in the Lok Sabha and getting it passed in February 2019. The Bill amended the following Acts: (i) the Divorce Act, 1869, (ii) the Dissolution of Muslim Marriage Act, 1939, (iii) the Special Marriage Act, 1954, (iv) the Hindu Marriage Act, 1955, and (v) the Hindu Adoptions and Maintenance Act, 1956. With this, it became illegal to use leprosy as a ground for divorce or separation.

Few months later, the UN Committee on the Rights of Persons with Disabilities also rallied behind the issue and urged upon the Government of India to "repeal all discriminatory legislation against persons affected by leprosy in all areas, including provisions in the Hindu marriage rules and the family court rules and provisions restricting their freedom of movement or preventing them from participating in public life, and be guided by the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members".

Within months of this development, the then Union Health Minister Dr Harsh Vardhan wrote to the then Union Minister of Law & Justice, Union Minister of Social Justice and Empowerment, and Chief Ministers of 23 States/UTs, seeking amendment to existing discriminatory laws against persons affected by leprosy. He also urged upon them to expedite the process and introduce the EDPAL Bill. In early 2020, the Ministry of Health & Family Welfare requested TLMTI to redraft the EDPAL Bill to give it more teeth. TLMTI, with support from the Vidhi Centre for Legal Policy, had a series of deliberations with the government and organizations of persons affected by leprosy and other disabilities and prepared the revised draft. It defined terms such as barrier-free access, discrimination, etc., and included specific provisions on:

- Protection of women, children and other vulnerable section affected by leprosy;
- Formulation of government schemes to provide appropriate assistive aids, medicines, diagnostics and surgery free of cost to persons affected by leprosy;
- Ensuring access to safe drinking water, sanitation, and drainage in leprosy colonies;
- Making it a mandate for employers to provide reasonable accommodation for employees affected by leprosy;
- Prescribing penalties for any contravention of the provisions of the Act.

TLMTI engaged and advocated for representation of leprosy-related concerns to the National Human Rights Commission (NHRC) core committees, including the impact of discriminatory laws by involving people affected by leprosy and disseminating their stories. In early 2022, the NHRC, headed by Justice Arun Mishra, issued a detailed Advisory to the Centre, States and Union Territories, calling for timely identification, treatment and elimination of discrimination against persons affected by leprosy. The advisory listed discriminatory provisions against persons affected by leprosy in 97 laws (as on January 2022) in the country and called for their removal.

Progress Made

Since May 2016, the Centre and nine states have taken decisive steps towards ending discrimination of people affected by leprosy. Ten states—Chhattisgarh (1), Gujarat (1), Karnataka (2), Madhya Pradesh (3), Maharashtra (1), Odisha (3), Rajasthan (1), Sikkim (2), Tamil Nadu (3), and Uttar Pradesh (1)—collectively repealed 22 discriminatory laws between 2016 and 2020. Most of these laws considered leprosy a valid reason for dissolution of marriage, prohibiting someone from attending schools and colleges, holding a responsible position in academic institutions, and getting nominated as a member of governing bodies such as district councils, village panchayats and municipalities.

Sl No	State	No of laws repealed
1	Central Govt	4
2	Odisha	3
3	Maharashtra	1
4	Rajasthan	1
5	Madhya Pradesh	3
6	Tamil Nadu	3
7	Gujarat	1
8	Sikkim	2
9	Karnataka	2
10	Chhattisgarh	1
11	Uttar Pradesh	1
	TOTAL	**22**

Summary of laws repealed as on June 2022

As mentioned before, the government took a landmark decision in 2019 by passing The Personal Laws (Amendment) Bill, 2018 in the Lok Sabha, making way for the removal of leprosy as a ground for divorce in four personal laws. Soon after, the then Union Health Minister Dr Harsh Vardhan urged upon several ministries and chief ministers to speed up amending and repealing discriminatory laws and introduce the EDPAL Bill.

As inter-ministerial deliberations on the revised EDPAL Bill continue, various organisations working in the field of leprosy in India are training and guiding state consultants under the NLEP to take forward the work of advocacy in their respective states. Persistent follow ups with the concerned departments started showing results in 2021, when the Tamil Nadu government took up the issue. Under the guidance of the State Disability Commissioner, TLMTI and Vidhi Centre for Legal Policy drafted the Tamil Nadu Barring Of Laws Discriminating Against Persons Affected By Leprosy Bill, 2022 'to declare void existing legal provisions in Tamil Nadu that discriminate against persons affected by leprosy and to prohibit the enactment of any laws that discriminate against such persons'. The Bill is scheduled to be tabled at the state legislative assembly by the end of 2022.

Road ahead

So far, a sustained effort of persons affected by leprosy and NGOs has ensured significant progress in repealing of discriminatory laws. In fact, both the States and the Centre have demonstrated their intent to include and integrate persons affected by leprosy into the

mainstream. Repealing these laws will go a long way in changing social perceptions about the disease and addressing concerns over social exclusion and rights violations. The leprosy community in India is grateful to various NGOs working in the field of leprosy and their partners for taking up these issues and for apprising the government of the challenges these laws have been posing to them. The task ahead for the leprosy organizations is to partner with more relevant organisations, mobilise resources and sustain their efforts towards the passage of the EDPAL Bill.

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Leprosy Vaccines: Immune-prophylaxis and immunotherapy, Indian Experience

Kiran Katoch

Leprosy is caused by *M. leprae*, which was discovered by Dr Gerhard Armauer Hansen in 1873, however, it still cannot be grown in any artificial media. Its genomic structure has been deciphered and available in public domain. The clinical manifestations of leprosy depend to a large extent on the immune response of the host to *M. leprae*. In fact, the majority of individuals exposed to the organism do not manifest the disease, and/or in a few cases self-heal.

However, as a result of immunological alterations, some patients also suffer and present with 'reactions' which may lead to disabilities if not diagnosed and optimally treated, not only because of live pathogens but also due to the presence of the dead bacilli and/or its products. Leprosy reactions are reported to occur before, during and also after completion of MDT and release from treatment (RFT).

With the successful implementation of MDT, the prevalence of disease has come down substantially. Nonetheless, new cases continue to be reported with disabilities and reactions, including in children which is a cause of concern. The present-day fixed duration MDT (FDT) kills most of the susceptible live organisms but 'persistors' which remain dormant in various situations in the host for a variable duration are usually the cause of relapses, as well as probably for continued transmission of the disease.

For these reasons, besides Multi Drug Therapy (MDT) which primarily targets the infecting live organism, immune modulators are required to modulate the aberrations in immune response to prevent damage to the nerves which is the principal cause of morbidity. This can also help to arrest the transmission of the disease. Several of these immunomodulators have been tried as well as developed in India and are discussed below.

Immuno prophylaxis

Prophylaxis is an intervention which enables the host to effectively deal with the infecting organism and protect from disease, Vaccines are generally inactivated/killed/ or attenuated organisms or their components which are antigenically similar to the pathogen and are capable of evoking an immune response in the host. These are part of the ideal core interventions to reduce the burden of the disease and positively impact the population health.

Other factors which influence the protective effect include: route of administration; age of the recipient at the time of vaccination; vaccination overage of the population; duration of follow-up; nutrition status of the vaccinated persons; endemic diseases in the population; environmental bacteria present in the environment and geographical location of the population.

Immunotherapy:

The present-day MDT, has helped in reducing the prevalence and incidence of the disease and achieving the elimination goal at the national level. However, some problems do remain which are briefly summed up:

- Relatively long duration of treatment schedule and non-adherence to the treatment;
- Persistence of disease activity after completion of MDT/stoppage of therapy;
- Occurrence of reactions and nerve damage before, during as well as after successful completion of treatment.;
- Relapses, disabilities and recurrences are being reported after stoppage of therapy.
- Transmission of leprosy continues to occur as seen by the very modest decline in new case detection rates and occurrence of new childhood cases.

These call for better, efficient and optimum management modalities with multi pronged approaches. The addition of immunotherapy to chemotherapy aims at achieving more efficient killing of viable bacilli, including the persistor organisms; rapid clearing of dead bacilli and their components from the tissues without sequelae; reducing the incidence as well as severity of reactions during and after completion of treatment; arresting the transmission of the disease; and restoration of effective immunity in the host so that relapses/re-infection can be prevented.

The immunomodulators being used to achieve the above benefits are related mycobacteria which share antigens with *M. leprae*; drugs and other miscellaneous agents and/ or components of *M. leprae* which mount an immunogenic response in the host.

The vaccines/agents found to be useful against leprosy as immuno-prophylaxis and immuno-therapeutic agents can be broadly classified into the following sub groups:

- Live attenuated organisms that evoke a protective response in the host against the pathogen, but do not cause disease per se, e.g. BCG.
- Killed organisms that have lost its infectivity but has retained its 'protective' antigens, and can provoke a immune response; e.g. killed *M. leprae*. In leprosy it was used in combination with BCG.
- Antigenically related mycobacteria: Mycobacteria which share some antigens / or show cross reactivity with *M. leprae* and have been tried as immunotherapeutic agents: *Mycobacterium indicus pranii* (MIP), ICRC bacillus, *M. vaccae* and *M. habana*.
- Use of immunogenic 'subunit(s)' of the organism. These are usually prepared by recombinant DNA technology, which evoke a protective response in the host; e.g. recombinant BCG vaccines and other subunit vaccines.

Drugs and miscellaneous agents.

Let's look at some of them and their relevance and usefulness in the leprosy management.

BCG vaccine: The Bacille Calmette-Guérin (BCG) vaccine has existed for over 80 years and is one of the most widely used of all human vaccines, BCG is a live attenuated strain of M bovis and has been used worldwide as well as in India for the prevention of tuberculosis and leprosy. It was first described by Calmette during the early 20th century for its use in cattle. BCG also protected against experimental *M. leprae* infection in mice. The results of BCG protection against pulmonary tuberculosis, although varied in different population groups, but, has been recommended to be used in both tuberculosis and leprosy by WHO.

BCG as an anti-leprosy vaccine was tried in Karinaul, Papua, New Guinea and was reported to be efficacious. Immunoprophylactic trials with both, BCG alone, as well as BCG + killed *M. leprae*, demonstrated that the combination provided greater protection against leprosy. However, this was not pursued further due to the inability to get killed M. leprae in sufficient amounts. In the comparative leprosy vaccine trial of South India, four vaccines, namely BCG, BCG + killed *M. leprae*, Mw (now named as *Mycobacterium indicus pranii*, MIP), ICRC vaccine and normal saline as placebo was administered to about 1,71,000 population.(can we have the year please). The protective efficacy after 5 years post vaccination follow-up are based on examination of more than 70% of the original cohort population, in both the first and the second resurveys, the protective efficacy was 27% for BCG. Interestingly, the placebo group too, showed a significant decline in leprosy incidence during the three re-surveys from 23.6 per 10,000 during the first, to 12.8 per 10,000 during the second and 6.1 per 10,000 during the third re-survey.

Varying results of BCG in different populations are probably because of exposure to different environmental mycobacteria in different areas which may be modulating the immune response of the inhabitants, type of BCG strain used, nutritional status of the population etc.

A working group report of WHO stated that BCG is effective in preventing leprosy with an overall pooled RR of 0.45 (95% CI: 0.34 to 0.56). In randomized controlled studies greater effect of BCG was observed when given at birth or <15 years of age. All these factors and others could be influencing the outcomes of the prophylaxis rendered.

BCG + killed *M. leprae*: The addition of killed *M. leprae* to BCG was postulated to increase the effectiveness of BCG vaccination. However, the reports of its benefit were not consistent. reported after release from treatment (RFT).

Shepard et al in1980 studied the protective effect of BCG + killed *M. leprae* in mice and its use in humans was studied by Convit et al. They reported beneficial immunological changes in Indeterminate leprosy patients, Mitsuda negative contacts and lepromatous leprosy patients. Several other investigators also reported beneficial histological upgrading in patients receiving this therapy along with MDT. In the South India vaccine study, the protection provided by this combination was 70.7% which was significantly higher than the use of BCG alone. Nonetheless, it was observed not to provide significant additive effect over the use of BCG alone in studies done at Papua New Guinea and Africa, However, it needs to be noted that killed *M. leprae* was no longer available in sufficient quantities and hence subsequent further studies were not undertaken.

ICRC bacillus: (Indian Cancer Research Centre bacillus) This is a leprosy derived cultivable mycobacteria, belonging to *M. avium* intracellulare complex. It also shares antigenic cross reactivity with *M. leprae* . It was prepared in 1979 at the Cancer Research Institute in Mumbai and is known by this name since then. ICRC bacillus strain (C-44), a candidate vaccine against leprosy is cultured in vitro in Dubos medium enriched with amino acids and human serum. It was administered as a killed vaccine, as a single dose intradermally. It has been observed that when ICRC vaccine was administered to lepromatous patients along with MDT, reversal reactions and lepromin convertibility were observed, in addition to a significant and rapid fall in BI of these patients.

Large scale field studies were launched in the South Eastern part of Maharashtra, India to house-hold contacts of active leprosy cases. However, the results of this are not readily available in the literature. In the South India Vaccine study, it was administered as one of the arms to the general population. The protective efficacy observed after the 2nd re-survey was 65.4% with a p value of <0.01 in the general population. Unfortunately, despite the promising results it is not available commercially, and its use for immune-prophylaxis did not progress further.

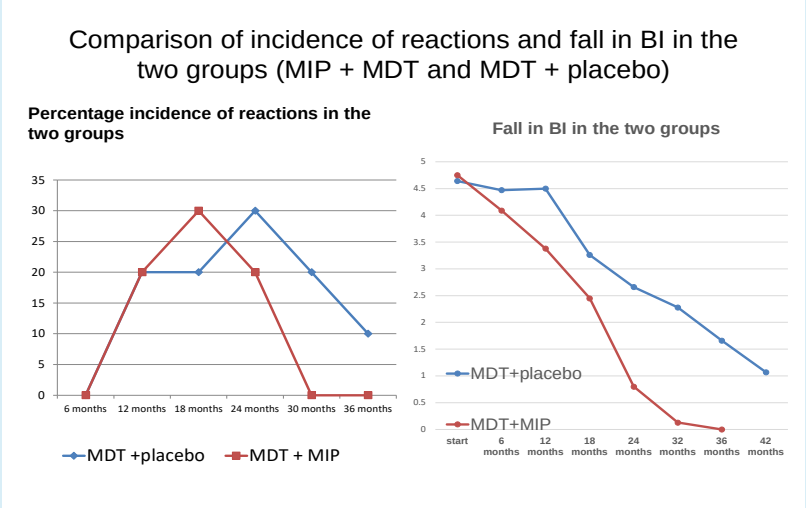
Mycobacterium indicus pranii (MIP; formerly known as Mw):

Mycobacterium. w, which is renamed as *M. indicus pranii* is a non-pathogenic, rapidly growing cultivable atypical mycobacterium. It was developed by Dr GP Talwar & his group at National Institute of Immunology, New Delhi, with funding from Department of Science and Technology, Government of India in1990s. MIP shares several antigens with *M. leprae* and *M tuberculosis*. It is administered as a killed vaccine and there are several studies of its immunotherapeutic use in all types of leprosy patients. It is well tolerated in all types of leprosy disease, and safe with blister/nodule formation at the local site of inoculation. The blister/nodule appears in 3 -4 weeks and heals of its own in another 6 to 8 weeks.

A large field based, double blind placebo-controlled field based clinical study was undertaken in family healthy contacts of index leprosy cases funded by Department of Biotechnology, Government of India at Ghatampur, Kanpur. Two doses of killed MIP administered at day zero and 2nd dose at an interval of 6 months. On follow-up of the household contacts, a protective efficacy of 68% and 60% was observed after a follow-up of 3-4 years and 7-8 years post vaccination, respectively. However, the efficacy decreased to 39.3%, 9-10 years after vaccination. This waning of protection probably indicates a need for a second booster around 8-10 years.

In the South India vaccine study, it was given as single dose in one of the arms, in the general population. The protective efficacy was 30.9% after the 2nd re-survey (5-6 years post vaccination) in the general population. However, when the results in contacts of leprosy patients was recalculated, the PE observed, using the MH test was 50-60% in household contacts after 9 years of vaccination. These study findings therefore indicate that the protective efficacy is significant in contacts of leprosy patients, at least up to 5-6 years post vaccination.

The results from other studies in multibacillary leprosy cases have shown an earlier achievement of smear negativity, a more rapid bacterial clearance. Histologically also there was rapid granuloma clearance by Mukherjee et al. The summary results of the use of MIP in highly bacillated BL/LL patients where MIP was given along with MDT every 6 months till 24 months, indicate that it was well tolerated with no side effects except for blister/nodule formation at the local site of injection, which appeared in 2 to 4 weeks and regressed within the next 1 to 2 months with a small scar. The fall in BI and incidence of reactions in the MIP + MDT and MDT + placebo group is shown in the following Figure 1 below:



The fall in BI was as a result of both killing of viable bacilli (as measured by mouse foot pad inoculation and measuring the ATP in the tissue biopsies of these patients), as well as clearing of dead bacilli from the tissues. Besides, the granuloma fraction also decreased more rapidly and there was more lymphocytic infiltration in the MIP group as compared to MDT+ placebo group. The incidence of reactions (both reversal and ENL), stopped earlier in the MIP + MDT group as compared to MDT + placebo group.

In another study undertaken at JALMA Institute Agra, Borderline cases (BT, BB, and BL cases) were given MIP combined with MDT in a serially allotted manner every 6 months with their respective FDT. The results indicated a more rapid clinical improvement in terms of decrease in size and decrease in erythema in lesions, regaining of sensations in a substantial number of patients, faster granuloma clearance histologically, and decreased incidence of reactions in the group receiving MDT + MIP as compared to those receiving MDT + placebo (Figure 2). The time line of both type 1 and 2 reactions as observed in these patients is shown in Figure 3.

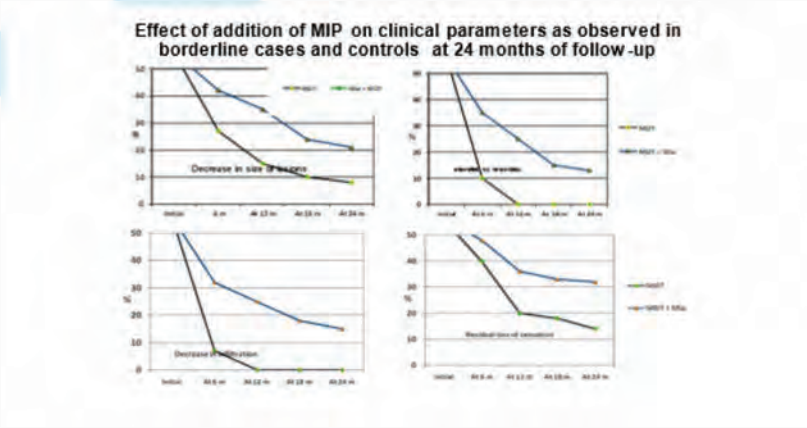


Figure 2: Figure showing the clinical response of the patients in both the groups

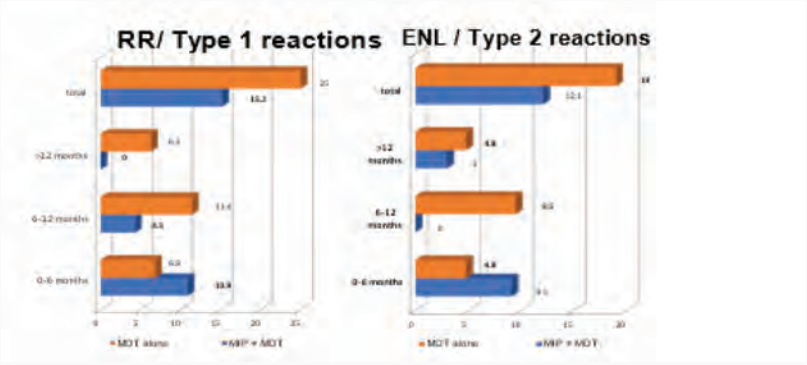


Figure 3 showing the timeline and incidence of both Type 1 and 2 reactions occurring in the 2 groups.

Over all, MIP as an adjunct to MDT helps in reducing the time duration of achieving BI and MI negativity, reduces severity and frequency of reactions, during as well as after release from treatment, along with and subsidence of signs and symptoms of the disease and to some extent also return of sensations.

MIP is approved as an immunomodulator both by FDA and DCGI, and is commercially available. MIP is an immunomodulator approved by Drugs Controller General of India (DCGI), India and the US FDA. It has received approval of the NLEP, India and has introduced MIP vaccine for leprosy in a project mode in India from the year 2016 in five highly endemic districts. Both patient and his contacts will receive two doses of MIP 6 months apart. Nonetheless, it is unfortunate MIP is not being widely used for leprosy patients in India, as it is yet to be recommended by NLEP for routine use in all leprosy patients. At the same

time, it is also not much used in private clinics too for leprosy patients, one important reason being its high-cost and the other, it is that it is not being promoted well for leprosy at present.

However, while MIP was initially tried almost exclusively for leprosy and found effective, it is at present being used extensively as immunomodulator in other diseases like tuberculosis, genital warts, cancers like melanoma, non-small cell carcinoma of lung and bladder cancer. Its benefits are being tried in diseases like COVID septicemia etc. At present MIP is manufactured commercially by Cadila Pharma in India.

***Mycobacterium vaccae*:** This rapidly growing, non-tuberculous mycobacterium, is generally not a human pathogen and was isolated from cow dung and soil in several countries of Africa and India. It is administered as a killed vaccine, and has shown immunotherapeutic properties when administered singly or when combined with BCG, has been shown to induce in vitro and in vivo immune reactivity in leprosy patients and their contacts. It was reported that pain & temperature sensations significantly improved in leprosy patients, (as measured using doppler flux, vasomotor reflexes, blood flow measurements), when MIP was administered along with MDT. It was tested in children of leprosy contacts for its immunoprophylactic effect alone as well as in combination with BCG, in areas around Mumbai, India in partnership with Acworth Leprosy Foundation.

Besides the above related mycobacteria, a few more mycobacteria also have shown some antigenic similarity and cross sensitization with *M. leprae*. These include *M. habana*, *M. phlei* and *M. gordonae* . These candidates have not been adequately investigated / promoted as immunotherapeutic agents.

Immunogenic subunit vaccines: Various sub unit vaccines against leprosy are still in the evolutionary phase, and experimental evidences show that immunization with select antigens of M. leprae-Ag85B and ESAT6 as hybrid recombinant proteins formulated with GLA-SE hold some promise. It has also been reported that ML2028, ML2055 and ML2380 as single antigens, or combinations of antigens could limit *M. leprae* infection in animal experiments. These in combination with a synthetic GLA-SE as an adjuvant, (LepVax) is undergoing evaluation. This, when used as a prophylactic immunization, provides protection against *M. leprae* challenge in mice as well as in armadillos. Human studies are to begin soon.

Drugs used for immune modulatory/ therapeutic benefits:

Levamisole: This is a broad spectrum anti-helminthic drug which acts by influencing the host defenses and modulating the cell mediated human response as seen in vitro and in vivo experiments. It is believed to have an immunomodulatory effect on defective T lymphocyte function and has been tried in lepromatous leprosy patients. Sher et al administered Levamisole, daily for 2 consecutive days each week for 6 weeks in a group of lepromatous patients with a positive response. Beneficial effects have also been reported by the use of Levimizole in persistently skin smear positive BL and LL patients by Ramu G et al at JALMA Agra; Bora DK and Sen PC from Varanasi. The use of Levamisole as an adjunct to MDT has been reported to be beneficial by Kar et al. with bacteriological improvement and increase in the EAC rosette counts were found at the end of one year. No adverse effect due to it was encountered. Its further use with MDT, however, has not been reported.

Zinc: Zinc has also been tried as an immunomodulator in treatment of lepromatous leprosy. When given in therapeutic dosages it inhibits the complement dependent immune complex formation and polymorphonuclear leucocyte chemotaxis. It has also been tried in recurrent ENL reaction and it was observed that, after giving zinc therapy, steroids could be withdrawn completely, and the duration and severity of reaction could be reduced. Cases treated with Zinc showed faster clinical improvement, re-growth of the eyebrows and rapid fall in BI of the skin and in the granuloma as seen histologically. However, the effect of Zinc with MDT is not documented.

Other drugs: Various other drugs like Corticosteroids, Thalidomide, Clofazimine, Colchicine, Cyclosporin, Methotrexate etc are being used for treatment and modulating the host response specially in neuritis and ENL reactions.

Other immuno modulatory factors used as immunomodulators in leprosy:

Transfer factor: Hastings and CK Job, injected its preparation locally, in lepromatous patients, and reported lepromin conversion, granuloma formation and increased influx of lymphocytes, locally. However, these effects were short lived and were not seen systemically.

Cytokines/Interleukins: The use of gamma interferon (IFN-γ) has been shown to activate macrophages and cause intracellular killing of *M. leprae*. Intralesional injections of recombinant IFN-γ have demonstrated a distinct fall in the bacteriological index at the local site, formation of epitheloid granuloma and occurrence of reversal reaction in some cases. However, the results were confined locally and for a short period and repeated injections were required to sustain the effect. Enhanced bacterial clearance at the local site has also been observed by the use of the recombinant interleukins. However, the major limitations of Transfer factor, IL-2, IFN-γ and interleukins, are that the beneficial effects are seen locally at the site of injection and last for a limited period only.

In summary, of all the agents summarized above, MIP as an immune modulator stands out. MIP is a good immunomodulator, is available and developed in India, has been extensively tried, safe, well tolerated, in addition is FDA and DCGI approved. It can be used both as immunotherapy with MDT as well as immune-prophylaxis. It is very effective when given to all newly diagnosed cases and their contacts, with the cost for vaccination coming to less than 1% of GDP (Gross domestic Product) of India. There is a need to improve its availability and to promote & popularize its wider use for leprosy in India.

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Contribution of Indian leprosy researchers in immunology and diagnostics

Utpal Sengupta

Introduction

Both Immunology and Diagnostics are very important aspects of the disease leprosy. Immunology describes the host response and reaction to the disease-causing bacilli, *M. leprae* and Diagnostics are the procedures those could be used to diagnose the disease by any laboratory based or field-based techniques. This chapter will detail the names of the Indian Scientists who discovered and developed techniques and assays which have helped to understand the disease, host immune response to the pathogen and in identification of the disease early which has ultimately helped in better understanding the host parasite relationship.

1. Contribution towards Immunological aspects of leprosy

i) Work on Dharmendra Antigen to evaluate status of Cell Mediated Immunity (CMI) in leprosy

The first research on determining the immune status of the host was initiated by Dr. Dharmendra way back in 1942 at the School of Tropical medicine, Calcutta by developing an antigen named, Dharmendra antigen (DA). This antigen was then standardized by chloroform and ether extraction of lepromatous nodules, rich in M. leprae, obtained from lepromatous leprosy (LL) patients. The tissue extracted defatted air-dried powder (10mg) was then suspended in 100 ml of 0.5% carbol-saline solution. DA is injected in 0.1 ml volume intracutaneously to determine an early delayed type of hypersensitivity (DTH) reaction (lepromin reaction) at 24 and 48 hours. Tuberculoid [tuberculoid (TT) and borderline tuberculoid (BT)] types of leprosy having a high level of cell mediated immunity (CMI) evoke a strong early reaction to DA. On the other hand, lepromatous [borderline lepromatous (BL) and lepromatous leprosy (LL)] having very low CMI evoke a negative reaction. The early reaction is measured by recording the diameter of the skin reaction in millimetre (mm) by a calliper.

As batches of DA standardized by Dharmendra method were noted to contain variable number of acid-fast bacilli (AFB) and evoked variable results, DA was further standardized by Sengupta and his group (1979) by fixing the AFB number to contain 107/ml in the preparation. This standardized antigen not only evoked an early skin reaction but also the

late DTH reaction at 3 to 4 weeks. Further, using this standardized DA a sequential histological study of lepromin reaction was carried out later by Desikan and associates (1983) at National JALMA Institute for Leprosy & Other Mycobacterial Diseases (NJILOMD) and indicated that while erythema was more predominant in early reaction, induration was mostly noted in late reaction. Histologically, while early reaction was manifested by infiltration of large numbers of polymorphs along with lymphocytes, late DTH reaction was exhibited by lymphocytes and epithelioid cells and Langharans giant cells.

ii) Work on Immunological Aspects of Leprosy

First research work on CMI response in leprosy was published by Dr. Kunal Saha and his group (1970-1978) from GB Pant Hospital, Delhi. In 1970 it was noted that LL patients failed to evoke any inflammatory or granulomatous reaction after intradermal allogeneic normal lymphocyte inoculation. From the above observation later in 1975 they attempted transferring immunity to leprosy patients by intravenous inoculation of lymphocytes and Lawrence's transfer factor from lepromin positive and tuberculin positive normal individuals. Although some LL patients evoked Mitsuda skin reaction at the lymphocyte inoculated site, the histological picture of lepromatous lesions remained unaltered. Further attempt was made in 1978 to repair the CMI of LL and ENL patients by transferring mitomycin-treated allogeneic lymphocytes obtained from lepromin and tuberculin positive individuals. However, no change in the disease pattern was noted except that the severity of ENL was reduced. They also noted clearance of bacteria, resolution of skin lesions and return of several immune deficits without the return of lepromin positivity in some indeterminate, BL and LL patients by transplantation of human foetal thymic grafts indicating a permanent loss of lepromin reactivity in BL/LL patients. Considering some beneficial effect to LL patients the group in 1982 further attempted repeated transfusion of fresh blood from lepromin and tuberculin positive normal individuals to seriously ill LL patients and noted histological reversion and immunological responsiveness and clearance of M. leprae in some patients.

Research work on immunological aspects of leprosy was further established by Dr. Indira Nath and her group at the All India Institute of medical Sciences (AIIMS), Delhi. The first publication with sheep RBC-rosette forming T cells showed that there was a significant reduction in peripheral blood T cell population in highly bacillated LL patients (Nath et al, 1974). Further, the group also noted that there was lower T cell response to M. leprae and PHA indicating lowering of CMI in LL patients (Nath et al, 1977). In addition, M. leprae antigens have been shown to suppress PPD and PHA induced lymphocyte proliferation of leprosy patients and healthy contacts (Nath and Singh, 1980). It was later noted that phenolic glycolipid-1(PGL-1) of M. leprae induced suppression of T cell response across the leprosy spectrum (Prasad et al, 1987). However, later they have shown that LL patients may generate a T cell response to certain peptides of M. leprae (Nath et al, 2015). Narayanan et al (1983) noted gradual reduction in the number of T cells in the granuloma of leprosy patients from TT to LL. It was also noted that the CD4/CD8 ratio which ranged from 1.2 to 5.0 in tuberculoid leprosy was reduced to 0.5 to 1.0 in lepromatous type. Narayanan et al (1984) investigated the population of Langerhans cells in skin lesions of leprosy patients and noted that while these cells were present in abundance along with mononuclear and epithelioid cells in TT/BT granulomas, in LL these cells were hardly present in the lesions. The group further worked on the cell types in the granulomas of reactional patients and observed that there is a rise in T

cell numbers during reaction and suppressor/cytotoxic cells remained in the periphery with central presence of helper/inducer T cells in BT reactional lesions. In lesions of BL and ENL also there was an increase in helper/inducer cells and both the cell types remained scattered in the granuloma (Narayanan et al, 1984). Later in 1983 the group reported on the release of monocyte -derived T cell suppressive factors from LL patients (Sathish et al, 1983). Nath et al (1984) further reported on the presence of M. leprae reactive T cells in some patients of LL. Later Lal et al (1985) reported on the emergence of antigen reactive T cells during the acute episode of reactions in ENL. It was observed that pooled LL sera identified a fusion protein named LSR2 (leprosy serum reactive 2) from γgt11 expression library of M. leprae (Lal et al, 1991) and these proteins were able to stimulate T cell responses in leprosy patients across the spectrum. It was noted later that three distinct regions of peptides were associated with antibody response with acute episodes of ENL (Sathish et al, 1994). In continuation to this a hierarchical responses in lymphoproliferative assays with selective response in anergic LL patients (Chaduvula et al, 2011) has been established. Dr. Nath after her superannuation from AIIMS, Delhi continued her research as Emeritus Scientist and Raja Ramanna Fellow at the National Institute of pathology, ICMR from 2009. Here, her group showed for the first time that besides Th1 and Th2 type of cells there are Th0 types of non-polarized T cells and their association with Th17 pathway factors (Saini et al, 2013). Later they showed that TGF-β secreting CD4+CD25+FOXP3+ T regulatory cells are associated with lepromatous leprosy (Saini et al, 2013).

Dr. D. N. Rao's group at AIIMS worked on reversal of T cell anergy in LL patients in vitro culture using murabutide and trat-peptide along with M. leprae antigens in liposome preparations (Sridevi et al, 2003). It was further shown that liposomal delivery of murabutide and trat peptide along with M. leprae antigen led to inhibition of Fas-induced apoptosis of peripheral blood lymphocytes in LL patients. Upregulation of antiapoptotic protein Bcl-X(L) was also noted in LL patients Chattre et al (2007). Further understanding on the T cell anergy in LL was found to be due to disruption of HLA-DR raft and deregulation of Lck-Zap-70 in T cells (Kumar et al, 2011). The E3 ubiquitin ligase Cbl-b is an established non-redundant negative regulator of T-cell activation. Overexpression of Cbl-b with high level of TGFβ have been noted in LL. High T cell proliferation and IL-2 production in PBMC cultures treated with anti-TGF-β and siRNA reverted the T cell hypo-responsiveness by downregulating Cbl-b expression in vitro culture in leprosy and indicated the existence of Th3 type of immunity in LL (Kumar et al, 2011). Further work with T cells revealed that CD4+CD25+ Treg cells with acetylated FoxP3 are associated with immunosuppression in LL (Kumar et al, 2013). The group further showed that both alpha beta αβ+ and gamma delta γδ+ T cells are involved in T cell response and proportion of γδ+ T cells are more in LL and are responsible for immune suppression and disease progression (Tarique et al, 2017, 2018).

Dr. Alpana Sharma's group from AIIMS further showed that γδ+ T cells are associated with inflammation and immunopathogenesis in Type 1 and Type 2 reactions in leprosy (Saini et al, 2018). In addition to the above, they further noted that a distinct IL-17A+/F+ T helper cells induced inflammation leads to IL17 producing neutrophils in type 1 reaction in leprosy (Saini et al, 2020). Recently, it has been further noted that IL-21 cytokine plays an important role in the development and maturation of Th-17 cells in an autocrine manner and plays an important role in Type 1 reaction in leprosy (Saini et al, 2022).

Dr. V. R. Muthukkaruppan and his group established research work on Immunological aspects of leprosy in the Immunology Department of Madurai Kamraj University at Madurai in 1976. Their initial attempt was to understand the defect in the CD2 receptor of the T cell . They hypothesised that as M. leprae is modulating the T cell receptor for sheep RBC (CD2), T cells are hyporesponsive. They noted that while anti-CD3 monoclonal antibody is able to activate T cells anti-CD2 monoclonal antibody (MAb) fails to activate the T cells in LL indicating that there is a defect in this receptor which is modulated by M. leprae (Muthukkaruppan et al, 1987, 1988). Further experiments indicated that the non-responsive function of CD2 molecule could be restored by addition of IL-2 along with anti-CD2 MAb in culture (Malarkannan et al, 1989).

The other prominent group working on immunological aspects of leprosy was from the then ICMR institute, JALMA (Japanese Leprosy Mission for Asia) and later renamed as the NJIL&OMD. Dr. U. Sengupta established the Immunology laboratory at JALMA in 1976. Initial research carried on the estimation of quantum of immunoglobulin showed that LL patients have hyper-γ-globulinemia. It was shown that PHA induced lymphocyte transformation was low in LL patients (Ghei et al, 1980). It was also noted that DDS intake suppressed the lepromin induced DTH skin reaction (Ramu et al, 1980) and it also suppressed the PHA induced lymphocyte transformation in in vitro culture (Ghei et al, 1981). Study on the differences in peripheral blood T cell population, blastogenic response to M. leprae and in levels of immunoglobulins between fresh and MDT treated TT/BT patients did not show any significant difference (Mackay et al, 1982). A serological test for leprosy based on competitive inhibition of monoclonal antibody binding to the MY2a determinant of M. leprae was developed (Sinha et al, 1983). Many LL patients were found to secrete immunoglobulins in the urine (Sengupta et al, 1983). Dr. VD Ramanathan et al (1984) demonstrated high levels of circulating immune complexes (CICs) in reactional (R) patients of both BT and LL. While CICs in BTR mainly contained IgG and C3, CICs, LLR patients also contained IgM, CRP and rheumatoid factor. Later it was noted that CICs play an important role in precipitation of reactions in leprosy (Ramanathan et al, 1985) and persistence of reduced solubilization of CICs by complement led to precipitation of reactions (Ramanthan et al, 1991).

These ICs were shown to contain *M. leprae* antigens (Patil et al, 1986). Using *M. leprae* specific MAb serum, urine and cerebrospinal fluid were shown to contain *M. leprae* antigens (Patil et al, 1990, 1991). Further, these ICs were shown to be responsible for M. leprae specific immunosuppression in LL (Tyagi et al, 1991).

Cellular infiltrates from skin granulomas revealed that higher percentage of lymphocytes were expressing pan T cell markers and Ia like antigens, helper T cells in TT/BT patients compared to that in LL. On the other hand, LL granulomas contained a higher percentage of suppressor cells (Narayanan et al, 1986). Lymphocytes obtained from skin and nerve granulomas of tuberculoid patients contained rosette forming activated T cells with HLA-DR positivity. Lepromatous infiltrate contained a lesser number of T cells (Kumar et al, 1989). Later a similar DTH response with similar helper suppressor T cell ratio was noted between Standard Dharmendra antigen and leprosin -linked-liposome (Narayana et al, 1987). Further, autologous inoculations of peripheral blood in skin showed significantly more number of CD1 positive Langerhans cells and lymphocytes in TT/BT as compared to LL and ENL patients indicating an active immune response in tuberculoid leprosy (Narayanan et al, 1989).

Mycobacteria species, mycobacterial antibody and phenolic glycolipid-1 (PGL-1) of *M. leprae* were found to activate alternative pathways of complement (Parkash et al, 1987, 1988; Ramanathan et al, 1990). It was shown that soluble M. leprae proteins linked- liposomes could be used to understand late DTH reaction in leprosy (Sengupta et al, 1990).

Synthetic high affinity HLA-DR permissive peptides of 35kD of *M. leprae* proteins evaluated in a peripheral blood T cell proliferative assay showed responses to the peptide pair 206–224 was involved both in species-specific and cross-reactive T cell response. IFNγ production was negligible and IL10 production was more pronounced both in controls and patients to 241-255 peptide indicating a cross sensitization due to environmental mycobacteria. It was further shown using several recombinant antigens of *M. leprae* that regulation of immune response is a complex one. The intermediate immune phenotype of the healthy controls heavily exposed to leprosy indicates that, although a polar type 1 response is clearly associated with a reduced bacillary burden in tissues, it may also contribute to the immunopathology characteristic of tuberculoid disease (Wilkinson et al, 1999).

Further research in long-term treated and cured LL showed that while these patients remain negative to lepromin, response to *M. leprae* with IFNγ response in vitro culture in a few patients indicate that there is a tendency of return of immunogenicity to *M. leprae* with time (Joshi et al, 2001). Later it was shown that in these long-term treated cured patients, the immunity to *M. leprae* could be recalled by challenging them with higher concentrations of lepromin (Mitra et al, 2009). Ultrastructural study on Schwann cells of nerve and endothelial cells of blood vessels revealed that M. lepraeforms a niche in these cells for their growth and M. leprae growth from the ruptured endothelial cells maintain bacteraemia in patients (Kumar et al, 2003). In addition to the heightened T cell response, high levels of antibodies to heat shock proteins were noted in Type 1 reactional patients (Mohanty et al, 2004). Further M. leprae antigens were shown to alter TCR/CD8 signalling for inducing T cell unresponsiveness and early biochemical events for T cell proliferation (Joshi et al, 2006). Later both PGL-1 and Lipoarabinomannan were found to alter earlier events of TCR-CD8 signalling in leprosy (Dugar et al, 2012). Leprosy specific B cells were shown to be present in BT granuloma and might be responsible for presentation of *M. leprae* antigens to T cells for their activation and maintenance of granuloma for a long time in BT leprosy (Iyer et al, 2007). Autoimmunity in leprosy was noted against host-self proteins and revealed that keratin, neural proteins and tropomyosin have similarities with *M. leprae* components and host responds with antibody response to these mimicking peptides (Singh et al, 2012; Singh et al, 2014; Singh et al, 2018). Recently, significantly high levels of antibodies to mimicking epitopes have been reported in type 1 reactions in leprosy (Singh et al, 2021).

Research on Immunological aspects of leprosy was later initiated at the Stanley Browne Laboratory (SBL) of The leprosy Mission Trust (TLM) India, Delhi. High levels of cortisol and proinflammatory cytokines were found to be associated with type 1 reactions in leprosy (Chaitanya et al, 2012, 2013). Collaborative research between AIIMS and TLM reported on reciprocity between regulatory T cells and TH17 cells and its relevance to polarized immunity in leprosy (Sadhu et al, 2016).

2. Work on Diagnostics

Initially a test named Fluorescent Leprosy Antibody Absorption (FLA-ABS) test developed by Abe et al (1976) was established at JALMA for early diagnosis of leprosy. This test was further established by Bhardwaj et al (1981). Early meaningful diagnostics based on serology was established at NJIL OMD based on 35kD MAb based serology (Sinha et al, 1983). This test was developed initially as a competitive inhibition radioimmunoassay and later as a competitive ELISA. This MAb based assay and PGL-antibody assay were compared for their efficacy in diagnosing leprosy and for monitoring chemotherapy (Sinha et al, 1989).

Further work using *M. leprae* specific gene- based PCR assays were developed at NJILOMD under the leadership of Dr. V.M. Katoch in the Microbiology Department. In situ PCR assay in formalin-fixed tissues using suitable protocol was developed at NJILOMD (Dayal et al, 2005; Singh et al, 2004).

At SBL (TLM) a comparative analysis of blood samples employing RLEP, 16SrRNA, RpoT and Sod A gene- based PCRs showed maximum positivity of 53% in bacteriologically negative patients by RLEP PCR (Turankar et al, 2014). Recently, in the Biochemistry Department at the Institute Post Graduate Medical Education and Research, Kolkata using multiplex PCR it was shown that detection of leprosy could be performed better (Banerjee et al, 2010). Using 3 pseudogenes of *M. leprae* 75.6% of indeterminate leprosy could be diagnosed at Schieffelin Institute of Health Research & Training Centre, Karigiri, Tamil Nadu (Chaitanya et al, 2017). Further, a recent multiplex PCR (16SrRNA, RLEP and soda genes) 100% of MB and 93% of PB leprosy was possible to diagnose at SBL of TLM (Pathak et al, 2021).

The above account has chronologically placed some of the important research studies and activities that have been conducted by the Indian and Foreign scientists on the immunological and diagnostic aspects of leprosy in India. The above research studies in India has helped in understanding the immunobiology and host pathogen interaction and early disease diagnosis in leprosy.

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Role of Leprosy Case Detection Campaign (LCDC) in revitalizing National Leprosy Programme of India

Anil Kumar, Vijay Dhange

Introduction

The major source of leprosy infection in the community is because of untreated cases, i.e., a hidden case of leprosy lying undetected in the community, who transmits the disease agent to other people in the community. Early detection will help in containing the source of infection in the community, interrupt the active transmission of disease, reduce the complications of case management, and reduce the disability. Leprosy Case Detection Campaign was introduced specifically for high-endemic districts, by the Central Leprosy Division in 2016 which is a unique initiative of its kind under National Leprosy Eradication Programme (NLEP). Each campaign is carried out for a period of 14 days in the specified districts in which house-to-house visits are conducted by trained search teams comprising one ASHA and one male volunteer in each village to enable physical examination of male by male volunteers and female by female volunteers considering person's privacy and proceed in a well illuminated room with minimum clothing on person. Suspects are referred to nearer health facilities for confirmation of leprosy cases by Medical Officer, PHC, CHC, etc. The teams are expected to conduct screening of the entire village population in the given period of 14 days.

Objectives of the LCDC

- To detect the hidden leprosy cases and interrupt the transmission of the disease agent in the community.
- To effectively supplement IEC activities in the programme.
- To draw attention of policy makers towards leprosy.

Rationale behind the introduction of LCDC

The trend of Prevalence Rate (PR) and Annual New Case Detection Rate (ANCDR) per 10,000 population from 2001-02 to 2015-16 is shown in Figure 1.

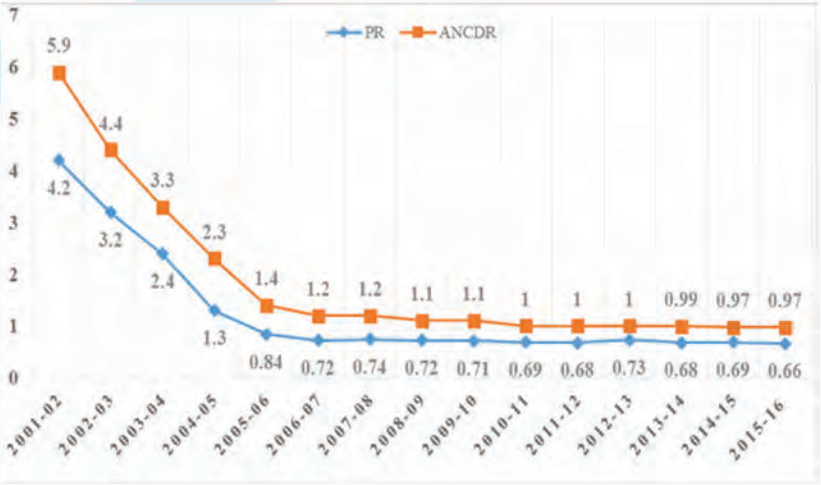


Figure 1: Trend of Prevalence and Annual New Case Detection Rate per 10,000 populations, 2001-02 to 2015-16

It was observed that trend of the two indicators of NLEP, India i.e. PR and ANCDR are almost static since 2006-07 till 2015-16. The main objective of the programme was to prevent the disability due to leprosy. When one more important indicator under NLEP i.e. the percentage of grade II disability among new leprosy cases detected has shown increasing trend from 3.10% (2010-2011) to 4.61% (2014-2015), which was the main alarming sing for the programme, which indicated that the cases are being detected late in the community and there may be several cases which are lying undetected or hidden. These hidden cases are the obstacles in achieving elimination as untreated Leprosy affected persons are an active reservoir in the community which transmit the disease to susceptible.

The trend of Gr. II disability cases amongst new leprosy cases from 2005–06 to 2015–16 is shown in Figure 2.

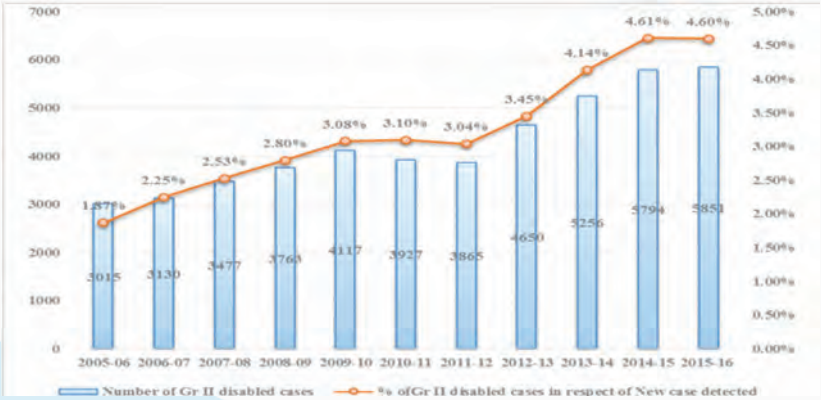


Figure 2: The trend of number of Gr. II disabled cases and % of Gr. II disabled cases among new leprosy cases from 2005-06 to 2015-16

It was clear that there are cases occurring in the community and detection capacity is not exactly matching the level and intensity of disease occurrence. There was presumptive and scientific evidence that the number of cases detected is less than the number that occur. Periodic active case detection campaigns were a priority for the programme. The major source of infection in the community is an untreated case, and in order to detect the hidden leprosy cases, Leprosy Case Detection Campaigns (LCDC), on line with Pulse Polio Campaign were introduced specifically for high endemic districts. Various committees were formed at each level i.e., National, State, District, Block to plan & implement the LCDC. Through intensive IEC activities, awareness was generated in various media during and before the LCDC. Under this, focused training was given to all health functionaries, from District to Village level. The teams were trained to suspect the leprosy patients through physical examination of each and every person of house visited. Micro-plans are the important part of the campaign; those are prepared for local areas. Supervision of house-to-house search activities are done through identified field supervisors. Central Monitors nominated by the Central Leprosy Division are directly monitoring the activities. Continuous, systematic collection and compilation of reports was done through the formats designed for this purpose which were filled by search teams and supervisors. After the completion of the campaign the post LCDC evaluation was also carried out through independent evaluators.

Impact and results of LCDC

LCDC was introduced in 2016 thereafter the progress made under NLEP is very much fillip to an active leprosy case finding.

Impact at Global Level: The burden of new cases detected in India were 58.8% and G2D cases burden were 41.2% in 2014 this trend of grade 2 disability burden to 41.1% (2015) which is almost constant trend. After the introduction of LCDC in 2016 the G2D burden has started declining from 40.2% (2016) to 25.5% (2019). As in the current situation despite having 56.6% of new cases burden India contributes 21.8% in Grade 2 disability at global level. Which indicates these has been a drastic decline in G2D burden in the country and prevented disability at the right time.

Results of LCDC

Leprosy Case Detection Campaign in high endemic districts have detected a total of 1,13,819 confirmed leprosy cases and registered for treatment till March 2020. The new cases detected with LCDC were almost 22% of the new leprosy cases detected during the year. Even though the LCDC is conducted for only 14 days, the hidden cases are detected promptly by this campaign. LCDCs were conducted in 165 districts in 2016-17, 255 (2017-18), 270 (2018-19), 300 (2019-20).

Year	Total no. of States covered	Total no. of Districts covered	Population covered	Suspect Identified	Suspect Screened	Total new Cases detected	Percentage of New Cases Detected through LCDC
LCDC-2016-2017	20	163	33.6 cr.	–	–	34,672	25.59%

Year	Total no. of States covered	Total no. of Districts covered	Population covered	Suspect Identified	Suspect Screened	Total new Cases detected	Percentage of New Cases Detected through LCDC
LCDC-2016-2017	20	163	33.6 cr.	–	–	34,672	25.59%
LCDC-2017-2018	23	255	38.8 cr.	711832	644035	32,714	25.93%
LCDC-2017-2018	19	270	33.8 cr.	475469	405443	23,356	19.41%
LCDC-2017-2018	23	300	47.5 cr.	772212	711702	23,077	20.16%

Table 1. Leprosy Case Detection Campaign (LCDC) from 2016 to 2020

Percentage of Grade 2 Disability among new cases was 3.04% (2011-12) increased to 4.61 (2014-15) in increasing trend, later in 2016 after the introduction of LCDC grade 2 disabilities has decreased from 4.60% (2015-16) to 2.41% (2019-20). The introduction of innovative campaigns like LCDC has prevented many disability cases during the last six years. If not intervened at the right time with innovative activities the G2D percentage would have been 7.32% (2019-20).

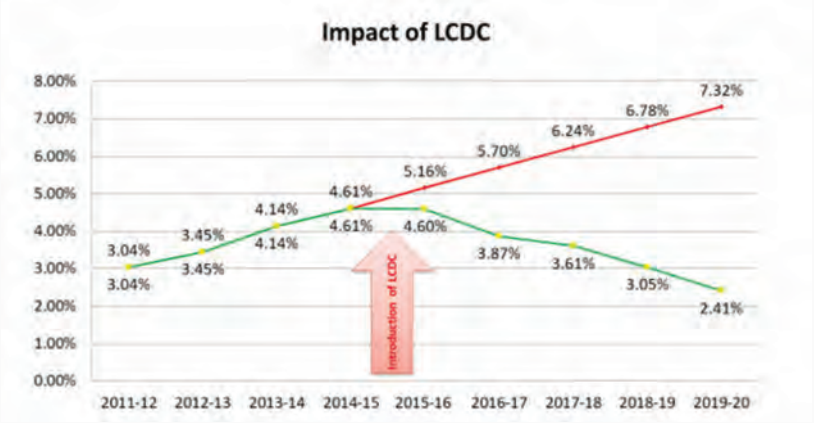


Figure 3: Impact of LCDC

LCDC role in revitalizing NLEP.

Inter-alia, the report of Midterm Evaluation of the National Leprosy Eradication Programme, India 10th–21st November 2014, DGHS, MoHFW and WHO joint initiative stated that "It is clear that there are cases occurring in the community and detection capacity is not exactly

matching the level and intensity of disease occurrence." It was also mentioned that "There is presumptive and scientific evidence that the number of cases detected is less than the number that occur. The exact magnitude of the gap cannot however be known" and recommended that "Periodic active case detection campaigns should be undertaken in priority areas with focus on detection of backlog cases as well as new cases.

The COVID-19 pandemic had a significant impact on the health care system and national health programmes in India. The case detection activities under the National Leprosy Eradication Programme are hampered. A drastic decline in new cases in the past two years may not be interpreted as an epidemiological shift but it is because of operational factors during COVID-19 pandemic. The field level staff were engaged with COVID Surveillance and management. Health facilities were over burdened with the COVID-19 cases. But during this crisis the Central Leprosy Division has released advisory to States/UTs regarding uninterrupted services for leprosy patients. MDT drugs and treatment to leprosy patients were ensured. However, it is a fact that case detection activities were hampered because of human resource crunch in pandemic situations.

Grade 2 disability rate among new cases is considered as a key indicator to assess the situation of leprosy disease in the country. The graph clearly indicates that in 2014-15 G2D rate among new cases was 4.61%. after the intervention of LCDC in the year 2016. Active case detection was strengthened and new cases were promptly detected and reported, and as a result of early case detection the G2D rate among new cases has declined during the time course from 2016 to 2020. But during COVID-19 pandemic the efforts to detect the new cases were not sufficient enough to detect all the backlog cases. 2020-2021 (2.41%) to 2021-22 (2.47%) rising trend is suggestive and in urgent need of strategic intervention.

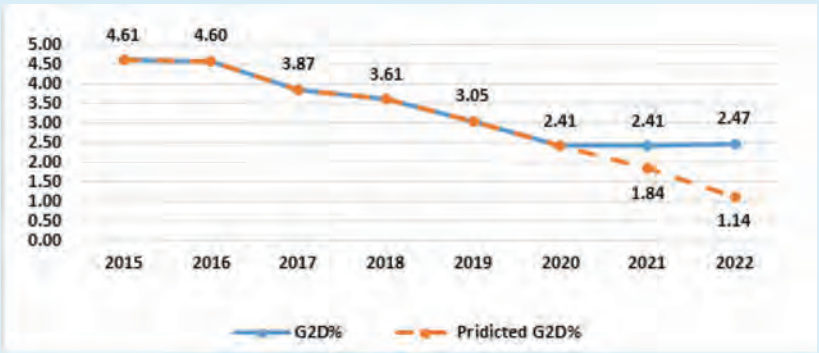
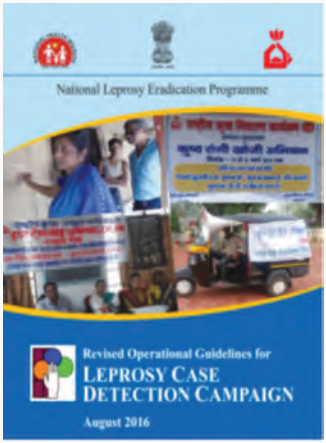


Figure 4: Grade 2 Disability % among new cases FY: 2015-2022

After the detailed analysis of the data, the Central Leprosy Division has suggested the list of districts on the two criteria 1) districts with more than 40% reduction in new cases from 2019-20 to 2020-21 and having more than 20 cases in F.Y 2019-20. 2) District with less than 40% reduction in new cases from 2019-20 to 2020-21 but having G2D% more than 2% and new cases more than 20 in 2020-21. Total of 379 suggestive district names are given to States/ UTs to conduct LCDC.

Conclusion



LCDC Revised Operational Guidelines

Although leprosy, as a public health problem, was eliminated at the national level in 2005, the agenda of eliminating leprosy at the subnational level is still unfinished. With decreasing prevalence and incidence worldwide, adequate capacity and competence building in leprosy control is essential for making the world free from leprosy. However, sustainable quality anti-leprosy services would be a challenge, as the problem gets reduced in number when compared to other public health issues in the country.

Already approaching the year 2023, With a view to accelerate the progress under NLEP, there is a felt need to strengthen active case detection, treatment compliance, quality surveillance, routine monitoring, and supervision in order to ensure 100% reporting and management of leprosy-affected persons in the country. Now, in the current scenario, NLEP is adopting one of the best innovative campaigns like LCDC to detect hidden cases and prevent the disability cases in the community. The objective of leprosy eradication has now shifted from reducing the prevalence of registered cases to reduction in the absolute number of new cases detected and to reduce the G2D percentage among them. LCDC is not only helping in case detection but also generating awareness about leprosy in the community, as LCDC committee meetings at each level provides inter-departmental coordination.

However, due to many reasons including the COVID-19, significant decline in leprosy case detection has been observed during 2020-21 and 2021-22. If cases are not detected early, it leads to progression of leprosy disease into Grade 2 disability. Case detection in campaign mode (LCDC) will accelerate the efforts of NLEP towards achieving Zero transmission of leprosy in India.

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SECTION 4

CONTRIBUTIONS OF NON-GOVERNMENTAL AGENCIES

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Schieffelin Institute of Health-Research and Leprosy Centre (SIHRLC) – Karigiri

Jerry Joshua

Leprosy had been a problem in Tamil Nadu for decades and Dr. Robert Cochrane and Dr. Paul Brand had started treating people with leprosy, in the early 1940s in Christian Medical College (CMC) Hospital in Vellore. Dapsone had been introduced as a promising drug by Dr. Cochrane and reconstructive surgical procedures in leprosy were being conducted by Dr. Brand. However, there was very little place, time and personnel allotted for the work in leprosy, because of the stigmatizing nature of the ailment.

The then administrators of CMC Vellore began looking for a separate place to treat people with the disease of leprosy and its sequelae. The Collector of North Arcot district offered a large stretch of wasteland near the Karigiri village near a hill ("Kari" meaning, elephant and "giri" meaning, hill) for a leprosy sanatorium and research centre, and in 1948, the land was handed over to Christian Medical College. The Mission to Lepers (now The Leprosy Mission (TLM)) and the American Leprosy Missions (ALM) provided funds for setting up the institution. Funds came in the memory of W.J. Schieffelin of ALM. The buildings were built under the personal supervision of William Bailey the then secretary of TLM and Ms. E. Lillelund, superintendent of a leprosy home and hospital in Vadathorasalur. The institution began functioning from June 20th 1955. Dr. Herbert Gass, a dermatologist from CMC served as its first Medical Superintendent.

Research was the priority of the institution. Dr. Herbert Gass, Dr. Robert Cochrane, Dr. Paul Brand, Dr. Ernest P. Fritschi, Dr.C.K. Job, Dr. A.B.A. Karat, Dr. Shakuntala Karat and Dr. R.H. Thangaraj were some of the pioneers who worked here and helped Schieffelin Institute blossom into a training and research centre.

Schieffelin Leprosy Research Sanatorium (SLRS) was how the institution came into being in 1955 and functioned under The Leprosy Mission till 1972. It then became an autonomous institution and in 1976 began functioning under the name of Schieffelin Leprosy Research and Training Centre (SLRTC).

Many drug trials, such as Multi drug Therapy trial, Ofloxacin trial, were all tried here in collaboration with the World Health Organization (WHO) and the National Leprosy Eradication Programme (NLEP). Reconstructive surgery in leprosy was pioneered here and many new procedures were introduced into the armamentarium, to deal with deformities and disabilities in leprosy. The laboratory for the diagnosis of the disease and for the study of the disease-causing organism, *Mycobacterium leprae* was set up here with the then state of the art facilities. Epidemiology in leprosy was honed here in the three blocks of Gudiatham, Katpadi and K.V.Kuppam. Path-breaking work in the management of leprosy, prevention and management of the sequelae of leprosy and laboratory investigations pertaining to the disease and leprosy control activities were meticulously planned, carried out and documented here. Work on foot care involved setting up a customized footwear making unit, with equipment and personnel specially trained for this. Microcellular rubber (MCR), an important component of customized protective footwear was needed in large quantities and an MCR manufacturing unit was also set up in the Karigiri campus.

Many publications stand as a testament to the work done by the institute. Simultaneously, during this period, the barren landscape at the foot of the Karigiri hill blossomed into one of an ecology park, boasting beautiful flowering trees and bushes between buildings and gardens.

As leprosy began to be less of a public health problem and interest in funding leprosy work waned, SLRTC had to take on managing non-leprosy health problems and become a training centre of allied health sciences and nursing, to augment its income to continue its work in leprosy. The available skills and experience in dermatology, ophthalmology, disability prevention and deformity correction, community health and disease control and laboratory technology came to its aid in maintaining its viability while shifting its focus to general health care (while continuing to retain its skills and ability to manage leprosy and its sequelae). So, in 2006, in keeping with its current work as a post graduate training institute, SLRTC changed to Schieffelin Institute of Health-Research and Leprosy Centre (SIHRLC).

It has continued to work in general health care as a hospital, a nursing school and a college of allied health sciences. Still, after undergoing all these changes, SIHRLC has not lost sight of its vision of a world free of leprosy.

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Reputed Leprosy institutions of India

Complied by editors

Bharatiya Kushtha Niwarak Sangh (BKNS)

Khatre Nagar, Chhattisgarh

Bhartiya Kushtha Niwarak Sangh, Katre Nagar a place of holy service for leprosy situated 8 km from Champa-Nagar, Chhattisgarh, India. It was established by a great human, Shri Sadashiv Govind Katre, who himself was a leprosy Patient. Katre Ji though came from a very distinguished family and was a Railway official in Jhansi, became a victim of leprosy unfortunately. As a leprosy patient, he had to face social boycott, humiliation and mental agony. For the treatment of leprosy, he went to Baitalpur, in a centre run by Christian missionaries. There he opposed the act of religious conversion in the pretext of service and was on strike for two months. Katre Ji met Shri Madhavrao Sadashivrao Golvalkar (Shri Guruji), who directed him to initiate leprosy cure service on his own and asked him to meet and work with volunteers, Balihar Singh, Chhotelal Swarnkar, Jivanlal Sav, Vaidya Godavarish, who were involved in contact and service work of the disease in leprosy affected areas.

Inspired by Shri Guruji, he established "Bhartiya Kushtha Niwarak Sangh" on 5th April 1962 with a noble objective that each leprosy victim must get self-respect during life and a dignity during death, with three patients to start with. Though the institution (Sanstha) got established but further path was very difficult. Katre ji learnt cycling at the age of 55 to travel to meet leprosy affected people in the nearby villages. When he asked for support, he was ridiculed saying, "now-a-days leprosy patients are begging on bicycles". However, impressed by Katre ji's dedication and hard work toward his objective, Shri Sadhram Sav Kesharwani from village Lakhurry donated a house with a water well for this noble cause, which became 'Dharamshala' for the patients of BKNS.

In 1974, Katre ji handed over full responsibility of the leprosy centre to Dr. Damodar Ganesh Bapat. On 16th may 1977 Sri Katre ji took his last breath. To realize the dream Sri Bapat, through his sustained efforts and simple behaviour added new well-wishers in the institute, and provided continuity in the monetary support for the work. For his tireless work he was awarded with Padma Shri by Govt of India. After serving this institute for over four decades, Shri Bapat ji expired in the year 2019.

At present, at BKNS treatment is being provided in a 20 bed hospital along with lodging and boarding facility to the inmates (both for ladies and gents). Apart from this, 300 patients living in the villages are also taking treatment. Institute has 60 acres of agricultural land at present. Approx. 1000 quintal rice is being produced in it. Wheat is being produced in 35

acres and Horticulture is being done in 3 acres. All this is being done by leprosy patients only.

Shri Sudhir Dev is the present secretary of this institute, who is devotedly involved in giving impetus to this mammoth work.

Maharogi Sewa Samiti, (Anandvan, Warora)

Maharogi Sewa Samiti (MSS), Warora, also known popularly as Anandvan, is a non-profit organisation in the Chandrapur district of Maharashtra, India. It was established by Shri Baba Amte to help socially disadvantaged people enhance their livelihood capabilities through self-discovery and empowering them to contribute to society.

Murlidhar Devidas Amte popularly known as Baba Amte was born to an affluent Hindu Brahmin family on the 26th of December 1914 in Hinganghat, Wardha. He Established MSS in 1949 with a fund of Rupees 14, with 6 leprosy patients and a lame cow. Later, MSS Warora has spread its work all over Maharashtra. Baba chose to call this place 'Anandwan', meaning 'Forest of Bliss'. He became internationally renowned as a human rights activist for his work to better the plight of the marginalized leprosy afflicted and people with disabilities through treatment, training and active inducement in self- managed communes.

MSS, Warora has been a pioneer in medical treatment and rehabilitation of leprosy patients in the world. Till date, more than 2.6 million people have benefited from our services. Our work spans a wide spectrum of activities ranging from the provision of basic healthcare and rehabilitation, development of land and water resources, enhancement of income and sustainable livelihoods, imparting formal and vocational education and sensitization of youth on environmental and socio-economic issues. MSS strives to couple innovative tools and technology with these activities for environment-friendly means of coexistence. It is fast becoming a focal point from where the quintessence of new paradigms of social work and developmental activities is spreading far and wide. The institution has grown over the last six decades to become an internationally renowned institution and perhaps the largest community of leprosy afflicted and people with disabilities in the world. The legacy of Dr Baba Amte continues to this date through the various projects of MSS, Warora.

Healthcare spearheads all the activities of MSS. What began as an attempt to provide holistic healthcare to the people affected by leprosy, has today expanded into a large-scale project providing healthcare to all the marginalized sections of society. Treatment of disease is the primary focus, however, preventive healthcare and comprehensive attention to the patient's socio- economic and psychological welfare which enables the individual to lead a healthy, productive and confident life forms a major portion of MSS's healthcare philosophy. The impact of Baba Amte and MSS across the world is immeasurable and many organizations have taken inspiration from Baba's work and are working for the downtrodden across the India and the world.

Sivananda Rehabilitation Home (SRH, Hyderabad)

Sivananda Rehabilitation Home (SRH) was established as a charitable institution in 1958 by Rani Kumudini Devi in over 51 acres of land in Kukatpally on the outskirts of Hyderabad, India. What was initially planned to be a small home for the destitute suffering from leprosy,

soon expanded into a centre of excellence for the care and treatment of leprosy patients. Rani Kumudini Devi, by her perseverance, hard work and devotion, made this institution the centre of excellence in the field of treatment and rehabilitation of leprosy patients. She also inspired a number of people to join her in her endeavours for improvement of the conditions of the unfortunate victims of leprosy. Today, SRH has grown into a large well known institute dedicated to the treatment, care and rehabilitation of patients suffering from leprosy and tuberculosis (TB).

In 1976 the AP state government handed over to SRH the responsibility of taking care of the nearly 900 patients in the leprosy home run by the Municipal Corporation in Hyderabad. Cottages for their housing were built and two sick wards with 20 beds were established. A laboratory, a physiotherapy department and a footwear section were also started.

Since 1978, the German Leprosy Relief Association (GLRA), which funds anti-leprosy projects across the world, has generously been providing financial assistance to SRH in its fight against leprosy. They funded an Urban Leprosy Control Project to survey and detect early cases of leprosy and provide prompt treatment to people living in the slums of Hyderabad. A population of about 1.5 million were surveyed and more than 11,000 cases were detected and treated by SRH. Detection and treatment by SRH drastically brought down prevalence levels below WHO criteria and the programme was therefore discontinued.

With GLRA funding, a 200 bedded referral hospital was constructed and inaugurated on 05 Feb 1985, with facilities for reconstructive surgery, physiotherapy, x-ray, clinical laboratories, orthopaedic and cobblery workshops. Dr.August Otto Beine, an internationally known orthopaedic surgeon from Germany has been working with SRH as Chief Medical Officer since the past three decades.

In 2006, SRH was established as a nodal centre, for the DPMR (Deformity Prevention and Medical Rehabilitation) covering 6 districts in Andhra Pradesh. SRH has broadened the scope of its activities to include other communicable diseases. In order to control tuberculosis in the area, SRH worked in collaboration with the Government of India, under the Revised National Tuberculosis Control Programme to detect and treat sputum positive patients. The Directly Observed Treatment Short Course (DOTS) programme started in the year 1998, covering a population of 0.5 million people in Hyderabad. SRH runs a Tuberculosis Unit with five Microscopic Centres for direct sputum testing.

In October 2005, SRH started a 20 bed orphanage for HIV+ orphans, funded by A.P. State Aids Control Society (APSACS). In 2009, the orphanage was upgraded to a 50 bed Community Care Centre for HIV+ children, one of only six in the country and had been funded by National AIDS Control Organisation (NACO). The children are given Anti-retroviral therapy (ART) as well as a highly nutritious diet. A primary school is run on campus while the older children study at the local government school, followed by vocational training. NACO has withdrawn its grant from 31 Mar 2013 as it is stopping funding of all HIV/AIDS projects. SRH has been unable to get alternate source of support to continue to run the Children's home and so had to close the Children's home. The children have been placed in an orphanage in Warangal, Telangana. The Chudamani Vrudhashram, a home for aged women was established in 1993 by Rani Kumudini Devi in memory of her mother, with accommodation for 15 inmates.

To cater to the needs of the poor and disadvantaged sections of society, Ramdevrao Hospital, a "not for profit" hospital, was started in 2002 with 30 beds. It is now a 100 bedded Hospital which provides quality health care at an affordable cost for middle and lower income groups. Dr Ananth Reddy, a trained leprosy reconstructive surgeon, is the Chief Administrator of this important institute at present.

Truly, Sivananda Rehabilitation Home embodies the spirit of selfless service to the destitute, the deprived and the disadvantaged by bringing hope to lives.

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FAIRMED (FM) India

John Kurian George

FAIRMED India is working towards a world in which no one suffers from leprosy and other neglected tropical diseases (NTDs), discrimination because of disease or handicap. Since 1960, FAIRMED India has spearheaded the efforts to eradicate leprosy in India by supporting the NLEP as well as providing services at 3 (primary, secondary, & tertiary) levels of health care system and in the community. FM's projects are aligned to Sustainable Development Goals (SDG) which aims to ensure 'health for all'.

Since initiating work in India, FM has committed itself to working in collaboration with the government at all levels so as to increase its reach and enhance its impact. Historically, programs implemented at the state, district, or sub-district levels have been in consensus with the government and towards further strengthening the government systems to implement its leprosy control program seamlessly and effectively. FM India works directly with the NLEP in various capacities. FAIRMED India is presently supporting 4 tertiary leprosy care hospitals where out-patient and in-patient services are provided, including reconstructive surgeries, reaction management, and disability care services. These facilities are recognized by the Central Leprosy Division (CLD), Government of India. Through its work in the last five years, FAIRMED successfully provided 1,54,273 services across the cascade of care to around 30,906 people registered in its tertiary care hospitals.

Following is the list of FM supported tertiary care hospitals:

S. No.	Name of the hospital	No. of beds	Location
1	Gretnaltes	40	Guntur District, Andhra Pradesh
2	Hubli Hospital for the Handicapped	30	Hubli District, Karnataka
3	Rural India Self Development Trust	50	East Godavari District, Andhra Pradesh
4	Sacred Heart Leprosy Hospital	300	Thanjavur District, Tamil Nadu

FM India annual budget is INR 62 million. In addition to providing medical & social rehabilitation through its supported tertiary care hospitals, FM India implements special projects such as the Migration in Leprosy project across 4 states in India, namely Bihar & Uttar Pradesh, Chandigarh & Delhi. While the former 2 states contribute to the highest

number of out-migration the latter account of the highest numbers of in-migration. The main goal of the study is to understand the impact migration on people affected by leprosy & their contacts pertaining to treatment, continuum of services including disability care & management, other health seeking behaviour, and social support.

FM India also extends technical support to 4 north Indian states including Haryana, Punjab, and Chandigarh with a NLEP Consultant rationalizing his time between these 3 states.

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Bombay Leprosy Project (BLP)

Vivek V Pai and S Kingsley

Introduction

Bombay Leprosy Project (BLP), founded by Padma Shri Late Dr R Ganapati, a renowned leprologist and WHO Consultant in 1976, transformed leprosy control work in Mumbai from institution based to community-based approach. Vision - Accelerating towards achieving a "Leprosy Free India" and a 'World Without Leprosy'. Mission – Improving quality of life of persons with leprosy through sustained quality leprosy services. First NGO in India to initiate, strategize concept of urban leprosy work and published more than 450 scientific articles over last 46 years. Partnered with several medical, public health, rehabilitation and research institutions globally including WHO.

Chronology of work of BLP:

BLP administered MDT (3 drugs) to leprosy cases at field clinics in slums of Mumbai from 1976. Mass scale delivery of WHO MDT to leprosy patients from slums and leprosy colonies in 1980 even before WHO recommendations in 1981. Leprosy treatment centers established in 1981 integrated with Skin and STD Department at General Hospitals in Mumbai. 'Grip-aids' on tools and utensils using epoxy resin developed for leprosy patients with gross hand deformities in 1982. Thalidomide for leprosy patients with Type II reactions not responding to steroids and with recurrent reactions in 1984. Audio-visual aids (video tapes & 35mm slides) used for leprosy teaching to medical students in 1984. Standardized pre-fabricated splints for hand deformities in leprosy field tested in 1985. Reconstructive surgery camps conducted for leprosy patients at public and private hospitals involving plastic and orthopedic surgeons in 1989. Computer based 'Central Registry' of leprosy patients designed and maintained in 1990 to prevent multiple registration and monitor treatment response in Bombay.

Integrated vocational training to leprosy patients along with physically challenged at Rehabilitation Institutions in 1991. Clinical trials with Rifampicin + Ofloxacin daily for 28 days in multibacillary smear positive leprosy patients in 1992. Pilot study with M vaccae, an immunotherapeutic vaccine done in 1993 to hasten clinical and bacterial clearance in MB leprosy patients on MDT. Started field-based Prevention of Disability (POD) programme for leprosy patients with disabilities in slums and rural areas adjoining Mumbai in 1994. Integrated Community Based Rehabilitation (ICBR) model initiated in urban and rural areas utilizing local resources in 1995.

Interferon alpha-2B, immunomodulating intervention along with MDT in 1996 for treatment of MB leprosy patients to hasten bacterial clearance. Clinical trial with single-dose Rifampicin + Ofloxacin + Minocycline (ROM) therapy for PB leprosy cases with single skin lesion (SSL) and for two to five skin lesions in 1997.

Clinical trials based on short course chemotherapy (SCC) with 'intermittent regimens' using combination of Rifampicin along with second line drugs Ofloxacin & Minocycline in monthly doses for smear positive leprosy patients in 1998. Standard schedule of Prednisolone for treatment of acute neuritis with or without nerve function impairment in leprosy in 1998. Pilot study on effect of Pentoxifylline in treatment of chronic and recurrent ENL reactions not responding to Prednisolone in 1998. Leprovac an intra dermal vaccine, as immunotherapy in multibacillary smear positive leprosy patients in conjunction with WHO-MDT for bacterial clearance and control of ENL reactions in 1999. Thalidomide as primary line of treatment to treat severe ulcerative ENL Type 2 reaction in 2002. Clinical trials with monthly regimens comprising Rifampicin + Moxifloxacin + Minocycline/Clarithromycin + Clofazimine for all MB leprosy and PB cases in 2009. Clinical trial with Montelukast leukotriene receptor antagonist along with Prednisolone in 2009 for treatment of Type 1 Reaction.

Seminal events

Clofazimine (1975) as standard therapy to treat moderate to severe ENL reactions in leprosy cases. Started leprosy treatment centers (1977) in public (Govt. & Municipal) and private hospitals in Bombay. Fixed Duration Therapy (FDT) for MB leprosy (1984) with WHO-MDT for 12 and 24 months. Demonstrated initial 21 days intensive therapy with Rifampicin (1986) had no added advantage over WHO MDT pulse therapy. 'Wall Journal' a new stimulating concept for education of UG and PG medical students on leprosy (1991) - monthly edition - displayed in 6 public and private medical colleges in Bombay.

Digital technology like Mobile phones and pagers (1998) first used by community health workers to seek instant expert medical advice on management of leprosy and field follow up. Hosted an interactive and academic oriented web site (2000) for benefit of medical students in India and abroad. Initiated a network of Referral Centres since 2005 for delivering quality leprosy services to patients from Maharashtra and adjoining States.

Contribution to Indian Leprosy

Practising integration of leprosy services with general healthcare system in urban context since 1977 that became a strategy of NLEP recommended in 2002. Orienting and engaging medical students and faculty in various aspects of leprosy including guidance on PG thesis and dissertations since 1981 leading to sustained utilization of health resources for leprosy control in urban areas.

Contribution to global leprosy / patients

Trials with FDT and intensive therapy has led WHO to redefine and rationalize the duration of MDT for MB leprosy from 24 months to 12 months in 1998. Integrated approach towards

rehabilitation of people with leprosy along with other physically challenged helped to eliminate stigma and discrimination and empowerment of people affected reinforced initiatives of WHO so crucial for achieving Universal Health Coverage.

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Hind Kusht Nivaran Sangh (HKNS)

Compiled by editors

Hind Kusht Nivaran Sangh (HKNS), the Indian Leprosy Association, is an old and prestigious body of people committed towards treatment, rehabilitation of leprosy patients and elimination of leprosy from India. It is the successor of the British Empire Leprosy Relief Association (BELRA), which was founded well back in 1925 with the objectives of serving leprosy afflicted individuals. The Indian Council of BELRA (IC-BELRA) was established by His Excellency the Earl of Reading and; then Viceroy and Governor-General of India with offices in Delhi and Calcutta, as an Indian wing of BELRA, which had its headquarters at London.

After the independence of India, the IC-BELRA was renamed as Hind Kusht Nivaran Sangh (Indian Leprosy Association). It came into existence on the 19th of August 1949 but was registered in 1950 under the Registration of Societies Act (XXI of 1860) with the President of India as the President of the Sangh and by its constitution, the Chairman, Honorary Treasurer and Organizing Secretary all being nominated by the President. Late Rajkumari Amrit Kaur, the then Health Minister of India was nominated by the President as the first Chairman of HKNS. Prof T. N. Jagadisan, was the first Secretary of HKNS. It was his pioneering and painstaking efforts that the HKNS (Indian Leprosy Association) spread throughout India to become the foremost association of leprosy researchers and activists in India. After the inception of the National Leprosy Eradication Programme (NLEP) in India, HKNS (Indian Leprosy Association) has done a commendable job to achieve the dissemination of information about the NLEP through its 18 State branches and sub- branches. The HKNS and its auxiliary branches acted as catalysts in accelerating the pace of public health awareness programmes and rehabilitation of dislocated leprosy patients. It was through the office of HKNS that the first International leprosy Congress (ILC) to be hosted in India was organised in New Delhi in the year 1984.

Principal activities of HKNS are; production and distribution of health education and publicity material on leprosy; publication of quarterly *Indian Journal of Leprosy*, a bi-monthly journal, production and distribution of leprosy seals to create awareness about leprosy and observance of Anti-Leprosy Day on the 30th January every year to create mass awareness about leprosy.

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The Leprosy Mission Trust India (TLMI)

Compiled by editors

The Leprosy Mission was founded in 1874 as 'The Mission to Lepers' by an Irishman named Wellesley Cosby Bailey, in Ambala, India. Later it was renamed as The Leprosy Mission international (TLMI). The Leprosy Mission International (TLMI) is a leading international non-denominational Christian organization with over 130 years of experience in leprosy work. TLMI is a worldwide partnership, active in 34 countries, with a vision for a world without leprosy and a passion to eradicate the causes and consequences of leprosy.

In India, The Leprosy Mission Trust -India (TLMTI) was registered as a Society in 1973. TLMTI is the largest leprosy-focused non-governmental organization in India and is headquartered in New Delhi, India. The organization works with people affected by leprosy and other neglected tropical diseases (NTDs), people with disabilities, and marginalized communities, especially women.

TLMTI has a diverse set of programmes – Healthcare, Sustainable Livelihood, Community Empowerment, Advocacy, and Research and Training. These programmes are implemented through 15 hospitals, six vocational training centres, four residential care homes for elderly persons affected by leprosy, nine community empowerment projects, and a research laboratory, spread across 9 states of India – Andhra Pradesh, Bihar, Chhattisgarh, Delhi, Karnataka, Maharashtra, Tamil Nadu, Uttar Pradesh, and West Bengal.

Stanley Browne Laboratory (SBL) of TLMTI is involved in national and international collaborative research studies on various aspects of leprosy. SBL works as a referral lab with the World Health Organization, Government of India and the ICMR in a 10-year project on global surveillance of drug resistance in leprosy. SBL seeks to address the need for research in different aspects of leprosy concerning basic science, such as immunology and molecular biology, to help answer questions and solve problems of this disease.

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LEPRA, India

Prasant Naik

Since the last 33 years LEPRA (registered as LEPRA Society) has been in the forefront in the fight against Leprosy – a disease which is over 6000 years old and is still surrounded with age-old myths. It is a disease which does not cause death to the person affected, but has the potential to destroy a life due to the mental and emotional trauma and isolation it causes. LEPRA was established in 1989 with a core focus of making Leprosy a disease of negligible or little consequence by way of providing end to end holistic services to the people, families and communities directly and indirectly affected by Leprosy.

Prevention and Treatment

LEPRA's main strength are the field teams who work at grassroot level in some of the remotest and hard to reach places across 8 states, where we provide end to end services by way of Referral Centres (RCs) and mobile health facilities. The RCs and mobile health facilities provide a wide range of Leprosy care services related to areas of Prevention, Treatment & Follow-up; Physical, Psychological, Social and Economic (PPSE) needs of the affected people including activities related to Morbidity management, disability prevention, eye care services, SER (Socio – Economic Rehabilitation) and Mental health assistance etc.

LEPRA is committed to spreading the message that Leprosy is curable and ensuring that those affected have access to free Multi Drug therapy (MDT) and support services where necessary. LEPRA was one of the first organizations to use MDT to treat Leprosy. Through our work we try to alter misconceptions of the disease, ensure access to early and appropriate treatment, educate families, local communities about the disease and how to support the affected people. We also follow up with those who have been diagnosed, making sure that they are receiving adequate support from their family and community. By focusing on early detection and early treatment, we strive to lessen, or entirely avoid serious, life altering disabilities often associated with Leprosy.

People affected

Due to misunderstanding, lack of information and incorrect beliefs, people affected by Leprosy can experience severe prejudice and discrimination when they show symptoms, or when a diagnosis is confirmed. Therefore, we work to find, treat and rehabilitate the hidden cases / affected people, promote their rights and do our best to prevent Leprosy related disabilities. We debunk the myths associated with the disease and work for the people affected through activities related to health education, improving livelihoods, providing disability aids like customized protective footwear and restoring a person's dignity. We conduct health education activities in villages to educate people about maintaining good health and teaching them about the symptoms of Leprosy and where to seek treatment. We also visit schools to teach children the signs of Leprosy so that they may be able to recognise symptoms not only on themselves, but also on their families. And we screen any children with suspected symptoms and train teachers so they are able to send children for treatment. Since Leprosy has a profound prejudice attached to it, during school visits we drive out myths about Leprosy through talks, films, health information leaflets and encourage children to be more accepting of their classmates who are affected by Leprosy. Some of our key impact numbers are shown below.

Rights of the people

People affected by Leprosy are often deliberately overlooked and excluded from government grants and schemes and it can be exceptionally difficult for them to secure constant, reliable employment, regardless of disability. LEPRA in addition to assisting them through various projects, outreach programmes, active case finding, etc. also lobbies / advocates so that the affected are entitled to the same benefits and standard of life as anyone else. Since our advocacy is evidence – led, the Research component is an important part of our organization.

LEPRA's research centre – BPHRC (Blue Peter Public Health Research Centre), one of the leading authorities on Leprosy, was established in 1999 following a highly successful campaign on the children's BBC TV programme - Blue Peter. Today BPHRC combines scientific expertise and state of the art facilities and works with close contact with communities affected by diseases. This direct contact with communities enables us to improve quality of care, and techniques for treating and managing disabilities. It furthers our knowledge of Leprosy, provides evidence led interventions and helps in our advocacy efforts. Our research on the impact of disease on the economic and social well-being of those affected, helps us to identify the wider needs of people and communities affected by disease and design projects to respond to community needs in more appropriate and effective ways.

Through our efforts, we envision to reduce the incidence and impact of Leprosy, enable the affected people to transform their lives, overcome poverty and prejudice and lead a life of dignity and empowerment.

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SAKSHAM

S Sivasubramanian

SAKSHAM, Samadrishti Kshamathavikas evam Anusandhan Mandal is a service oriented All India organization, established in the year 2008 having its headquarters at Nagpur. It serves for the welfare of 21 types of Differently Abled persons including Leprosy Cured but Deformed Persons (LCDPs). SAKSHAM believes that disability is an integral part of nature's law of diversity and the differently abled people are not burden to the society but assets of the nation.

SAKSHAM in the Field of LCDPs

Vision: To serve LCDPs with a principle that each individual is divine and has to bring a paradigm change in the attitude of society towards LCDPs. Mission: To create viable socio-economic, cultural and spiritual environment for bringing LCDPs to the national mainstream and enable them to become contributors to their family and growth story of humanity through leading a life of self-reliance and dignity.

SAKSHAM Savita

Understanding all the perspectives associated with leprosy and being a responsible organization wishing for a prosperous country, SAKSHAM took up service activities for LCDPs. Savita, one of the wings of SAKSHAM, initiated serving LCDPs in the year 2013 based on the inspirational ideals of Shri Sadashiv Govind Katreji, who established Bharatiya Kushta Nivarak Sangh (BKNS) during 1960, at Champa of Chattisgarh State. Around 30,000 LCDPs have been benefitted by sustainable community rehabilitative services of BKNS in the last 6 decades. Savita is the offspring of BKNS with a mission to serve LCDPs across the nation. Prior to founding of SAKSHAM, its volunteers had established a rehabilitation center, namely Vivekananda Maharogi Arogya Kendram at Bommur of Andhra Pradesh in 1980. The centre has independent houses for hundreds of LCDPs, well equipped hospital, Gowshala, and Surya Mandir. As LCDPs themselves manage the project, begging is stopped naturally. The notable achievement of the centre is bringing a change in the attitude of people residing in nearby villages. Every year, the Ratha Sapthami festival is celebrated by the villagers. Around ten thousand people visit the Surya temple to offer prayers and receive the food cooked and distributed by LCDPs. The notable outcome of rehabilitative activities of the above two organizations inspired SAKSHAM to initiate services to LCDP through its Savita wing.

Community Based Rehabilitation (CBR)

SAKSHAM envisages to develop CBR which facilitates integrating LCDPs in society and empowering them through social, economic and medical rehabilitation. A successful CBR,

with 1700 LCDP beneficiaries, has been in practice at Sri Ramakrishna Math, Chennai since 1988. SAKSHAM plans to implement this model across the nation to benefit lakhs of LCDPs through networking voluntary service organizations.

National Convention on Leprosy

SAKSHAM jointly with Sri Ramakrishna Math and CSIR-CLRI organized a "National Awareness Convention on Leprosy" on 2016 in which the then Union Minister for Health & Family Welfare Shri. JP Naddaji had participated. This program resulted in two important events a) implementation of MIP leprosy vaccination trials in endemic hot spots and b) initiation of Leprosy Case Detection Campaign (LCDC). Through LCDC, NLEP detected more than 90,000 hidden leprosy cases in high endemic districts in years 2016, 2017 and 2018.

The Chief Guest Shri. JP Nadda, Dr Soumya Swaminathan and other dignitaries at National Awareness Convention on Leprosy 2016

SAKSHAM Team with Shri. Ravi Shankar Prasadji

Efforts to amend Discriminatory Acts

Efforts have been put since the last 5 years to take the legal challenges to the notice of Govt of India. Its team met Shri. Ravi Shankar Prasadji, the then Union Minister for Law and Justice, during Jan, 2018 in this regard. Due to incessant efforts of SAKSHAM, six discriminatory acts in which leprosy was one of the reasons for divorce were repealed in the year 2019.

Efforts to strengthen the Rights of Persons with Disabilities (RPWD) Act, 2016

SAKSHAM Team met Shri. Sushil Modi, The Chairman of Parliamentary Committee (Ministry of Law) and Smt. Ramadevi, Chairman of Parliamentary Standing Committee (Ministry of Social Justice and Empowerment) Feb and Apr, 2022 and explained them about the various discriminatory acts and how the existing RPWD can be strengthened to support LCDPs.

Other Activities

- SAKSHAM conducts monthly online series of "Awareness and Knowledge Transferring" sessions on various aspects of leprosy.
- It also conducts Leprosy Awareness Fortnight programs across the nation with several organizations.
- SAKSHAM along with Artificial Limbs Manufacturing Corporation of India (ALIMCO) conducted a camp on distribution of assistive aids and appliances for LCDPs during 2022.
- In efforts of integration of LCDP in to the Indian main stream and abate stigma, Sri Ramakrishna Math, with the support of SAKSHAM organized 3 holy pilgrimage visits to Kashi, Ayodhya, Prayagraj, Gaya, Kanyakumari and SriRangam. LCDPs undertook the yatra without any discrimination.

Expansion of activities to serve LCDPs

- To create awareness on leprosy through conferences, workshops and camps regionally, state level and national wide
- To promote CBR model to address socio-economic and physical challenges
- To motivate LCDPs and family members to engage in education, jobs or business and support them through various schemes
- To identify and honor the achievers among the LCDPs and bring out publications on those who served them. In these efforts, it has published a book that focuses on the life and LCDP services of Shri Sadasiva Kovinda Katreji in Tamil
- To engage in advocacy on protecting their rights, liaison with Government machinery in policy making and in implementation of benefits given in various acts

SAKSHAM is committed in efforts to resolve the challenges LCDPs face and empower them to lead a dignified life free of physical, mental and social agonies.

Ashok Agarwal

until No Leprosy Remains (NLR) – India

NLR India is a forerunner in the fight for a leprosy free India since its establishment in the country in the year 1999. We were part of the Global Leprosy Post Exposure Prophylaxis (LPEP) pilot study that was carried out in 2015-2018 across eight countries including India (Dadar Nagar Haveli), to demonstrate the feasibility of using single dose rifampicin (SDR) as leprosy post exposure prophylaxis (LPEP), under the routine national leprosy control programs. Based on hard evidence generated out of the study in Dadar Nagar Haveli (DNH), the Govt. of India adopted SDR-PEP as a national policy and rolled it out nationally in October 2018. We work in 129 districts and 150 leprosy colonies across seven states of India namely Bihar (10), Delhi (11), Jharkhand (16), Rajasthan (33), Uttarakhand (13), Uttar Pradesh (35) and West Bengal (11). We provide technical assistance to the National Leprosy Eradication Programme (NLEP), Govt. of India in achieving the three "ZEROs" – Zero Transmission, Zero Disability and Zero Exclusion. Since 2019-20, NLR India, in accordance with the three strategic programmes of the NLR Alliance: Zero Transmission, Zero Disability, and Zero Exclusion, had restructured our priority programmes to deal with leprosy & its consequences. The 3 Zeroes underlines our vision of an India free of leprosy & its consequences.

Under Zero Transmission of leprosy, we combine years of NLR's experience in leprosy control with promising innovations that help to prevent leprosy, diagnose and treat patients as early as possible. NLR India supports the seven state governments in implementation of NLEP components such as leprosy case detection campaign (LCDC), leprosy post exposure prophylaxis (LPEP) with SDR, urban leprosy program, disability prevention and medical rehabilitation (DPMR), etc. We undertake innovative research for stopping the transmission of leprosy, which is the enhanced post exposure prophylaxis (PEP++) using multiple drugs to demonstrate the effectiveness of the enhanced preventive therapy in reducing risk of transmission by 80-90% in the study districts, as part of the larger global study that is being carried out in 5 countries.

Under the Zero Disabilities programme, NLR India undertakes disability care and rehabilitation through 'combined self-care' and 'comprehensive socio-economic rehabilitation (CSER)'. We aim to prevent persons affected by leprosy developing new disabilities during or after treatment with multi-drug therapy (MDT) and to improve the

general impairments of persons affected by leprosy and lymphatic filariasis (LF). We have been successful in imparting knowledge of self-care techniques and skills to persons affected and general health care (GHC) service providers. We facilitate in delivery of necessary assistance especially MCR footwears, crutches and logistics for self- care camps. As a sustainability approach, we developed master trainers to conduct and promote self-care activities in their respective communities in the block/district and state where we work. The trained master trainers were able to train the persons living with disabilities (PWD) on self-care. One of the notable success is that the state governments of Bihar and Jharkhand has adopted the self-care model piloted by NLR India, for implementation across all districts, and this was a result of our advocacy with the state governments. In West Bengal, we have assisted in developing and implementing home-based self-care (HBSC). On pilot basis, we envision to create disability friendly villages and communities in Bihar.

Under the Zero Exclusion programme which consists of two major interrelated components - disability care, and disability inclusive development (DID); we had been successful in empowering the "change agents" who are mostly adolescent boys and girls including youths living in leprosy colonies of the seven states through capacity building initiatives on several relevant issues such as life-skill education (LSE) and sexual and reproductive health (SRH); the LSE intervention has been particularly successful in West Bengal where we have ensured zero drop out of students in our leprosy colonies due to effective community and students' engagement. We facilitate in forming new self -hep groups (SHGs) and facilitate in strengthening existing SHGs, towards empowerment of persons living with disability due to leprosy and LF etc. Another highlight under zero exclusion program is the contributions by NLR India to vitalize a good movement for repeal of discriminatory laws along with other NLEP partners. We partner with academic institutes to conduct stigma related studies and strengthen our research capacity. One of the notable successes is demonstration of effectiveness of basic psychological support (BPS) based intervention through peer supporters in reducing stigma and improving the mental well-being of persons affected by leprosy and LF in Bokaro district of Jharkhand. The district authorities have adopted the intervention through an order passed on 22 July 2022. The annual turnover of NLR India is around 8.2 crore (INR).

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German Leprosy and TB Relief Association (GLRA), India

Debajit Sarkar

GLRA India was founded in 1966 and has been working with the core objective of care and support to people affected by Leprosy, Tuberculosis and Disabilities. Besides the medical care for the affected, GLRA also promotes their empowerment and participation through social rehabilitation. Over the past five decades, our support reached out to 2.5 million people affected by the above diseases and conditions. GLRA has more than 55 years' experience in development sector in effectively engaging with multiple stakeholders, including government health services and non-profit organizations.

GLRA works independently through direct initiatives, coordinating with the governments for implementing National programs and also in collaboration with like-minded NGOs across the country. GLRA has been working with the socio-economic pyramid base to improve the quality of life by enhancing access to health services while ensuring the participation and social inclusion of the poor. GLRA has successfully implemented over 382 health and social development projects. In 2021 alone, GLRA extended its work in 62 districts in 12 Indian states through 6 thematic areas ie; Leprosy, TB, Disability Inclusion, WASH, NTDs and Humanitarian Aid – COVID response by implementing 14 projects.

GLRA India is a secular, non-profit organization registered under the Trust Act, having its registered office in Chennai, head office in Delhi and divisional offices in Kolkata, Lucknow and Mumbai. We collaborate with the National Leprosy and National TB programs and also with several bi-lateral/multi-lateral agencies such as Global Fund, BMZ, MISEREOR, DBS (Germany) and with several Indian corporates under their CSR initiatives. We are proud to be a part of our parent organization DAHW Germany and continue to enrich the association for leprosy free world.

GLRA works with a vision to create ***"A world in which no one suffers from Leprosy, Tuberculosis and other poverty-related diseases/conditions and the consequences they bring such as social exclusion and disability".***

GLRA has comprehensive experience in implementing various Leprosy projects successfully in close collaboration with State and district leprosy offices and also with NGO hospitals. A total of 2.3 million people affected by leprosy have been identified and treated successfully by working through our NGO partners and in collaboration with the National Program,

covering more than 38 million population. In the post integration phase, GLRA has shifted its focus to strengthen the secondary and tertiary care leprosy hospitals located in low resource settings and also in promoting hub and spoke model care besides organizing outreach campaigns for early case detection. The core areas of our work ranges from diagnosis, treatment, hospital care, reconstructive surgeries, physiotherapy, protective footwear, aids & appliances, social rehabilitation and facilitation for accessing social welfare schemes.

GLRA is a member organization of ILEP India, continued to support NLEP (National Leprosy Eradication (Program) at the national level and currently supporting the state NLEP program in West Bengal. Recently we started a project on PPM leprosy in four districts of Madhya Pradesh as a pilot. In the past GLRA coordinated with NLEP by deploying 10 State Technical Support Teams (STST) and 32 District Technical Support Teams. The state level coordination team at West Bengal assist the state leprosy office in implementation of routine programs and special campaigns. The state coordination aims to build the capacity of government health staff in early detection, validation, management of complications besides providing monitoring supervision at the districts.

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GRECALTES

Gitanjali Saha

In seventies during 1974-75, West Bengal in eastern India was a very high endemic state. Prevalence of leprosy in Kolkata was 19 per 1000 population. Deformity rate and Child Case Rate were also very high. Many leprosy patients were severely disabled. The stigma affected not only leprosy affected persons but leprosy workers as well.

GRECALTES (Greater Calcutta Leprosy Treatment & Health Education Scheme) came into existence in the year 1975 by the efforts of Dr. D.S. Chaudhury, with financial and technical support from German Leprosy Relief Association (GMLF). The opening and functioning of this leprosy clinic was an herculean task and a big challenge. Nonetheless, this organization pioneered urban control of leprosy, attempted or organized never before in Kolkata.

Control of leprosy in the community was a difficult proposition. Dr. D.S. Chaudhury's association with GMLF gave him much needed inspiration to team GRECALTES to work with the leprosy patients among the slum dwellers and marginalized destitute of Kolkata, who were left alone for their fate. It was observed that there were many dropouts due to false identities which hindered a lot in controlling the disease. GRECALTES started clinics with follow-up in the community and brought back the defaulters and drop- outs through persuasion.

GRECALTES contacted the then Director of Health Services Late Dr. K.C. Basu Mallick, who gave lot of encouragement. GRECALTES started their field of operation at Khidderpore, the entire location was a collection of slums and Thika Tenants system, with predominantly Muslim population. Late Father Subir Biswas, the pastor of St. Paul's Cathedral and lady vaccinators of KMC lent their help to recruit a few Volunteers of the locality to assist GRECALTES in making enumeration of the residents with full details of addresses so that they could be followed up. Next hurdle was to locate the clinics. Leprosy clinics where leprosy ulcers would be dressed among other services were not accommodated willingly. GRECALTES approached local youth clubs, isolated rooms in different parks of Kolkata. In fact all available facilities had to make use of even when not entirely suitable. GRECALTES recruited local men and women of different faiths, Hindus, Muslims and Christians, gave them the para medical training in Gandhi Memorial Memorial leprosy Training Centre at Wardha, Maharashtra. With their help screening of the community particularly the slum dwellers in congested localities was done systematically and recorded.

In 1976-78 area of work extended to Behala, Parnasree, Dhapa, Goragacha, Tiljala and Beniapukur and one clinic at Sudder street for out of the project area patients

In 1977 main office of GRECALTES at 35/1A, Old Ballygunge 1st lane, Kolkata-19 was constructed for providing services for control of leprosy. In 1980 own Training Centre was built at 23, Market Street for training activities, comprehensive laboratory facilities, operation theatre and sick bay. Trainees from adjoining states of India and also from other countries like Bangladesh and Sri Lanka came for PMW training. GRECALTES started special clinic meant for limb protection related activities at Goragacha, Kolkata.

The Sisters and Brothers of Missionaries of Charity were being trained on a regular basis. GRECALTES had the extreme privilege of blessings of Mother Teresa who visited the centre on several occasions.

Dr. D.S. Chaudhury, in 1981, on behalf of GRECALTES visited 'Bharat Sevashram Sangha' in Jamshedpur and helped them start Leprosy work there. At that time, he met Dr. R.N. Dutta, MD (past National President IAL -2017 to 2021 and Vice Chairman, GRECALTES) was the first Medical Officer of Bharat Sevashram Sangha, Jamshedpur who devoted himself fully for leprosy work. In the Eighties MDT was available to our patients. GRECALTES worked in Kolkata covering one third of KMC area to run programs like survey, education and early detection of leprosy affected persons, their treatment and rehabilitation.

Now the goal of India is eradication of Leprosy. GRECALTES pledges to continue its support to eradicate leprosy from the community and country as a whole. GRECALTES regularly conducts research under ICMR, Govt. of India, New Delhi and with Govt. of West Bengal, India. Moreover, National Workshops on "World without Leprosy" were organized in the gracious presence of the then His Excellency, Governor of West Bengal, Sri Gopal Krishna Gandhi and the then Director, ICMR and Secretary to Health Research, Govt. of India, Dr. Vishwa Mohan Katoch.

GRECALTES will continue its services to the leprosy affected persons with the active support from Governing Body of GRECALTES and other stakeholders till India is made leprosy free which devastated the lives of so many affected persons.

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Sasakawa-India Leprosy Foundation (S-ILF)

Vivek Lal

Stigma against leprosy results in discrimination and social-economic deprivation of not only those affected, but also their families including children, who themselves may not be affected by the disease. This is especially true of those residing in marginalised leprosy colonies. Apart from lack of land ownership and basic civic amenities, residents of colonies continue to be discriminated against and lack educational and employment opportunities. More than 800 such colonies exist in the country.

While India celebrated the achievement of elimination of leprosy as a public health problem in the year 2005, Mr. Yohei Sasakawa, the WHO Goodwill Ambassador for Leprosy elimination and Chairman of the Nippon Foundation was quick to realize that his mission of eliminating leprosy would not be over unless stigma against people affected by leprosy was eradicated and they were reintegrated into society. He therefore took two visionary steps: facilitating the setting up of the National Forum of Leprosy Affected People (now renamed Association of People Affected by Leprosy)- an association of persons affected by leprosy living in colonies across the country so that they could work together to lead the fight for acceptance in society and their inclusion in the welfare schemes of the government; and two, setting up of a foundation that would facilitate the economic empowerment of persons affected by leprosy so that they could move out of the demeaning dependence on alms and begging and begin to earn their livelihood with dignity. The latter, Sasakawa-India Leprosy Foundation (S-ILF) was instituted in November 2006.

S-ILF works towards mainstreaming persons affected by leprosy and their families through socio-economic empowerment, thereby restoring dignity to their lives. Ensuring equal social, economic and cultural opportunities for those affected by leprosy is a means of combating stigma and discrimination against those affected by the disease. The major areas of focus are:

- Providing grants and technical support through training for setting up micro-enterprises for self-employment and empowering persons affected by leprosy to access government welfare schemes
- Providing access to vocational training and higher education through scholarships
- Addressing water, sanitation and hygiene (WASH) issues in leprosy colonies for improvement in overall quality of life and healthcare activities such as provision of customized MCR footwear and ulcer care services

- Creating awareness about leprosy among all sections of society to fight stigma and discrimination
- Engaging with opinion and policy makers for the rights and inclusion of persons affected by leprosy

Economic rehabilitation through income generation support

Educational opportunities through scholarships (picture depicts beneficiaries of S-ILF's scholarship during alumni meet)

S-ILF has been able to reach out to more than 3,200 beneficiaries through its livelihood initiative across 18 states in the country; provided opportunities for higher professional education to more than 300 scholars; skilling in retail, electrical and hospitality for 800 youth and more than 400 children benefit through after school learning centres (ASLCs), which run from within the colonies across 11 locations in the country. Through these ASLCs, children are provided opportunity for studies, sports and other extra-curricular activities such as dance and music. With more than 1,100 scholars having been supported, an alumni network has been formed to enable peer-learning as well as inculcate leadership roles to emerge as Champions for the cause of leprosy. In order to create an enabling environment, S-ILF has entered into partnership with Confederation of Indian Industry (CII) thus raising awareness about leprosy among corporate leaders. Through its various awareness campaigns around leprosy, it has reached out to more than two million people. Active participation of persons affected by leprosy at all levels of program implementation is vital for success and sustainability of activities. For the implementation of its programs, S-ILF works in close collaboration with the Association of People Affected by Leprosy (APAL).

S-ILF has its head office in New Delhi and zonal offices in Nashik (for the states of Maharashtra and MP), Jamshedpur (Jharkhand and Bihar), Raipur (Chhattisgarh and Odisha), Delhi (Delhi and UP) and Vijayawada (Andhra Pradesh and Telangana).

Socio-economic rehabilitation through such endeavours has positively impacted the life of persons affected by leprosy and their families, enabling dignity, demonstrated through improved quality of life and weaning from begging. Dignified living is an important means of combating stigma and discrimination through ensuring mainstreaming. The United Nations 'Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members' state that such persons who have been empowered and who have had the opportunity to develop their abilities can be powerful agents of social change.

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Gandhi Memorial Leprosy Foundation (GMLF), Wardha

Prabha Desikan

It was the early fifties, the beginning of the decade. Dr. Sushila Nayar, a close associate of Mahatma Gandhi, was looking for help with leprosy work in Sewagram, Wardha, in Central India. She was the secretary of the Gandhi Smarak Nidhi Kushtha Nivaran Samiti, a committee mandated to start and support leprosy work, in keeping with Mahatma Gandhi's constructive work programme. Dr. Sushila Nayar, already a member of the Delhi state assembly, was moving to Delhi as Health Minister of Delhi state. This would leave her with hardly any time for leprosy work. She, however, was committed to Mahatma Gandhi's vision for leprosy work, and was keen that the work be continued. Dr. Wardekar, a pathologist, who gave up a lucrative practice in Bombay to follow Mahatma Gandhi's vision, was made the secretary of the Gandhi Smarak Nidhi Kushtha Nivaran Samiti. Deeply influenced by Gandhian ideals, Dr. Wardekar worked out of a small room in his house in Wardha, which doubled up as his office. Dr Desikan joined Dr. Wardekar in 1952. They were joined by a small group of dedicated workers, including a social worker, and assistants. The organization was now renamed as the 'Gandhi Memorial Leprosy Foundation' (GMLF), with Dr. Wardekar as its first Director.

Stigma against leprosy was rampant at that time. Treatment protocols were in nascent stages. The standard management of leprosy patients was to either send the patients to leprosy homes, or treat lesions with intradermal injections of hydnocarpus oil on an outpatient basis. Dapsone had just been introduced. In this scenario, Dr. Wardekar had envisaged an ambitious strategy. He had identified 35 villages within a 25 km radius from Sewagram for a leprosy control initiative. His proposal involved visiting each of these villages regularly. The plan was to spread awareness and knowledge about leprosy, identify cases, and treat them. Three villages among the 35 were strategically chosen for establishment of three clinics in each respective village. None of the other villages would be more than 4 to 5 km away from a village with a clinic. Dr. Wardekar and Dr. Desikan embarked upon the world's very first Survey, Education and Treatment (SET) programme for diagnosis and management of leprosy. The SET programme, as pioneered by GMLF, was a milestone in the management of leprosy as a public health programme. It would eventually become the basis for the very successful National Leprosy Eradication Programme (NLEP).

After the Sewagram Leprosy Control Unit had been established, GMLF had established a Leprosy Control Unit at Chilakalapalli, a semi-tribal village in Srikakulam (presently

Vijayanagaram) District, in the Northern part of Andhra Pradesh. With an estimated prevalence of 25 per 1000 population, leprosy was a major public health issue in the area. Dr. Desikan moved to Chilakalapalli in 1957 to take over and strengthen the work of the unit there. The unit had a mandate to cover nine villages, with a cumulative population of around 30,000. With no leprosy treatment centres elsewhere in the district, patients from other villages too, began to attend the unit in Chilakalapalli. The numbers burgeoned to an OPD footfall of almost 15000 per month. To manage these patients, Dr. Desikan set up OPDs in other villages as well, with the support of GMLF.

The GMLF Balarampur Leprosy Control Unit in Purulia District in West Bengal was established in 1977. It covered a population of 9,00,000 in 668 Villages in the tribal and underdeveloped blocks of Balarampur, Baghmundi, Barabazar, Jaypur, as well as the municipalities of Purulia & Jhalda.

In addition to surveys, diagnosis, treatment and rehabilitation of leprosy patients, GMLF had a mandate to provide training to medical officers, and paramedical workers. Awareness programmes and educational lectures were also conducted. Over the years, GMLF grew into an institution of repute. Many government doctors, as well as doctors from private organizations were deputed for training to GMLF and its leprosy control units.

At present GMLF, in Wardha has houses wards, OPDs, a training centre, a resource library, patients' records dating from 1951. It actively supports social science research on leprosy. Presently, GMLF is under the administrative control of the Kasturba Health Society, Sewagram. Doctors from the Mahatma Gandhi Institute of Medical Sciences, Sewagram, provide services, not only to leprosy patients, but also to the general public. Healthcare services in the specialties of Surgery, Medicine, Obstetrics and Gynecology, Pediatrics, Ophthalmology, ENT, Orthopedics and Dermatology are provided. Such integration of leprosy work with regular health care services is a true realization of the Mahatma's vision.

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ALERT- INDIA

Antony Samy

In 1978, ALERT – India was established with a focus to combat leprosy in the urban slums of Mumbai, Maharashtra. It initiated leprosy control work under the 'Survey Education Treatment (SET) Strategy' of the National Leprosy Eradication Programme (NLEP) and adopted three large municipal districts with slums as its control area including 205 municipal and 271 private schools to address leprosy incidence among children. Its administrative office is located at Mira Mansion, Sion (West), Mumbai, India..

With this initial push for a decade, ALERT multiplied its efforts, from 1991 to 2004 by incorporating actions such as a) Advocacy and policy dialogue; b) IEC development and publication; c) Public sensitization, education, and awareness; d) Establishing Microcellular Rubber Footwear (MCR) & Splint unit, and e) Importantly, public participation and resource mobilization to sustain initiatives.

This was the time when a gradual reduction in new leprosy cases was witnessed and India unfortunately hastened to announce the 'Elimination of Leprosy' - and declared it no more a public health problem in year 2005.

NLEP post-elimination policy shift created gaps in the program and put people affected and leprosy services at stake. To bridge the policy gaps, ALERT initiated a stakeholder analysis to evolve practical solutions. In 2005, ALERT launched a comprehensive strategic program called the 'Leprosy Elimination Action Programme' (LEAP). The LEAP aims to strengthen the integration of leprosy services in the General Health care System (GHCS) by creating Leprosy Referral Centers as a signpost for the affected and the public at the secondary level as a core strategy, organically linked to initiatives such as i) Selective special drives (SSD) in endemic blocks; ii) Continuing Medical Education (CME) for the public health functionaries; and iii) Advocacy for policy change.

ALERT's, Leprosy Referral Centers is a pioneer intervention with a focus on greater access to leprosy services. ALERT established 149 Leprosy Referral Centers (LRC) in Maharashtra and Chhattisgarh at the secondary level within GHCS providing services such as; diagnostic, therapeutic, management of complications (lepra reactions/neuritis), nerve assessment, physiotherapy, counseling, etc. NLEP Maharashtra endorsed the ALERTs LEAP initiative and collaborated across Maharashtra.

Selective Special Drive (SSD) was initiated as a key link between the LRCs and the local community. It includes identification, orientation, training, and engaging volunteers from the community to create leprosy awareness, case detection, referrals, and spokespersons

within the community. As an outcome 31,500+ community volunteers reached out to 1.4+ million rural/ tribal populations in 15 Maharashtra districts, which resulted in the identification and referral of 41,000+ leprosy suspects with approx. 10% (4000+) confirmed leprosy.

Continuing Medical Education (CME): ALERT ensures resources for critical aspects of medical education to sustain leprosy referral services. It focuses on creating a cadre of skilled leprosy service providers (medical and para-medical professionals & students). In the last 15 years, ALERT trained 36,000+ medical / frontline health workers including ASHAs through 1,200+ training.

For advocacy and policy dialogue, ALERT established a 'Knowledge Management Unit' to periodically undertakes a) Epidemiological Monitoring & Evaluation; b) operational research; c) validating leprosy trends; d) developing educational and publications & Audio-visual material; e) disseminating findings/results at state / national and international platforms. It conducted eight National level Workshops (2004 to 2015) to disseminate the program outcome and impact including 40+ publications, research papers, and presentations.

With these interventions, ALERT has reached out across 15 endemic Maharashtra districts to address the risks of NLEP policy changes in sustaining leprosy control measures and improve accessibility for quality care in collaboration with GHCS including promoting the 'right to health and social inclusion of persons affected.

Since 2010, for wider reach and impact initiated 'LRC Out-Reach Camps' (LORC) and 'Disability Prevention and Deformity Care Camps' (DPDCC) linked at the primary level resulting in the identification of 45,000+ new leprosy cases and 17,000+ at the risk of nerve damage including prevention from developing disability and in 25,000+ people it prevented deterioration of disabilities.

In 2016, ALERT evolved a Community-led Human Rights Based Approach (HRBA) under LEAP and piloted it in two districts. This has resulted in empowering people affected within the tribal community, including the establishment of a people affected by leprosy-led organization named Saksham Kushthanteya Swabhimani Sanstha (SKSS).

In 2022, we still strive for a fresh approach to strengthen the National Leprosy Eradication Programme priorities by collaborative action based on decades of knowledge, expertise, and experience, to reach still remaining vulnerable communities.

ALERT as a core member of GoodBye Leprosy, a collaborative action to eradicate leprosy and enable the inclusion of people affected by leprosy in India, aimed to launch a pilot program, especially on leprosy incidence-based surveillance using 'Advance Technology'. It also intends to initiate New Cadre training and replication of established, based on the successful HRBA model, engaging affected people with ensuring a continuum of care in the remote tribal and rural neglected geographical areas. ALERT India can be contacted at antony@alertindia.org (Website: www.alertindia.org).

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The Foundation for Medical Research (FMR), Mumbai

Vanaja Shetty

The Foundation for Medical Research (FMR) was established in 1975 In Mumbai, India for conducting basic laboratory research in leprosy in the fields of neurology, immunology and microbiology.

The decision to dedicate this foundation to the laboratory aspects of research in leprosy by the Godrej and Seth families was a result of their foresight and fortuitous circumstances. Bombay then with its more than 1,00,000 leprosy patients, presented ample clinical material for investigation and FMR was also the largest center for scientific research in the developing world. Commencing with meager resources then became a well-established, well-equipped institution, operating largely on externally funded research projects. Dr NH Antia a renowned plastic surgeon under whose leadership and guidance pioneering work was undertaken in the major thrust areas of basic research leading to identification of mechanisms of nerve damage, mechanisms of pathways of immunological unresponsiveness and cultivation of leprosy germ. This knowledge has been applied to prevention and treatment of deformities in leprosy.

Development of screening tests for conventional and potential anti-leprosy drugs and formulating immunological approaches to anti leprosy treatment and devising of immunodiagnostic tests. Institute has been recognized both for its original contributions in the field of leprosy research and for the training of several talented young scientists through the university of Mumbai. This has enabled it to attract substantial project fundings from both national and international agencies like the ICMR, DST and DBT of the Government of India, Sir Dorabji Tata trust, Government of Maharashtra etc. The Wellcome Trust (UK), British and German leprosy relief association, NORAD, WHO and NLR. It is affiliated to Mumbai University for post-graduate/doctoral degrees

Work highlighting the hidden burden of leprosy and issues related to access to health care in the public health facility across Maharashtra, are instrumental in questioning the government's claim and rethinking over leprosy elimination in India.

FMR possesses equipment for biomedical research and facilities such as upgraded P-2 level containment rooms for advanced work with infectious agents, animal house, library, histopathology & electron microscopy, tissue culture and good clinical back-up. It has over 285 peer-reviewed publications to its credit. The senior faculty have been recipients of several national and international awards and hold professional/advisory positions including Planning Commission, Ministry of Health & Family Welfare, AYUSH, PHFI, University of

Mumbai, ACTREC, Dabur, Leprosy Mission. The Foundation is a referral institute for clinical research in leprosy. FMR is expanding its skillsets in technologies for both laboratory and field-based research. Dr Vanaja P. Shetty is currently the Emeritus Senior Scientist of the Foundation for Medical Research looking after leprosy related work.

A sister institute, the Foundation for Community Health (FRCH) was also established by Dr NH Antia in Poona, Maharashtra, that conducted community-based research probing into the ground level health issues and means of countering the same at the community level.

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Association of People Affected by Leprosy (APAL)

Maya Ranavare

Background

Association of People Affected by Leprosy (APAL) is a National Organization spread across 16 states and covering 800 leprosy colonies with a major community-based network and effectively managed by people affected by leprosy. It was initiated by its patron Shri Yohei Sasakawa, the WHO Goodwill Ambassador for Leprosy elimination as "National Forum of Leprosy Affected People' which was later renamed and fully functional in 2013as 'Association of People Affected by Leprosy', a registered Society of persons affected by leprosy living in leprosy colonies across the country so that they could work together for a common cause and interest.

Core objective of APAL: **To work for the Socioeconomic empowerment & welfare of persons affected by leprosy, their families & persons with disabilities.**

Motto: **Support & Strengthen US to Sustain Ourselves**

Specific areas of work of the organization: Community Mobilization, Awareness, Empowerment, and Advocacy, with Government and other stakeholders.

APAL has focused on the Regionalization-Institutionalization of approach for services utilization. The major turning point was the Multipurpose Integration. Integration of existing resources and Leadership based Advocacy, especially in terms of extension and provision of services has been the goal. APAL has have been a pioneering organization for People Affected by Leprosy in advocacy and peer support mobilization.

The innovative approaches and the community and mobilization have helped an umpteen number of dependent families and homeless individuals of persons affected by leprosy. The effects were recognized which led to parliamentarians visiting the leprosy colonies to interact with the inhabitants for support and synergetic development. Shri. Sasakawa and The Nippon Foundation (TNF) have been long-standing supporters of the effective implementation of the APA activities. The efforts have shown a considerable change in the perceptions of the general community and the health officials. Sustained advocacy has helped to achieve the envisioned emancipation from stigmatized perceptions to a supportive fraternity in the eyes of the government and non-Government offices and communities.

Fear of discrimination is one reason why people may hesitate to seek treatment, which means they may be transmitting the disease to others. This is why initiatives such as the strengthening, empowering, and community-led approaches are being actively promoted by TNF. These efforts are important to raise awareness and reduce discrimination and remove barriers in the way of people seeking medical help and also empower and economically sustain themselves.

Consistent support of TNF and partnership with APAL has been a community-focused approach to initiate the action of programs that are planned by the community. Our patron is Shri. Yohei Sasakawa, has been leading us in our endeavors and with the extensive support and encouragement provided by him, APAL's activities are expanding and our network is playing an important role in bringing about change in the lives of leprosy-affected persons;

The present annual report is a compilation of the year-long activities undertaken by APAL with the support of The Nippon Foundation.

Current Activities

Coordination with other country associations of Persons affected by leprosy such as ENAPAL, IDEA Nepal, and HANDA. Networking among leprosy colonies and sustaining Strengthening capacity of State Leaders and Team of colony members for effective working in the states. Women & Youth Empowerment workshops Capacity Building Training programs for state leaders, colony members and youth.

Human rights issues of people affected by leprosy. Work with the Government, WHO, NGOs,

and National & International agencies for mainstreaming of people. Working in Collaboration with SILF for vocational training, higher education, and coaching to school-going children of people affected by leprosy. Awareness of Leprosy, RPWD Act, Supreme Court Judgment, precautions of COVID-19, and prevention of disabilities. Working for the UDID cards, social entitlements, aids and appliances, livelihood and land issues of Persons affected by leprosy.

Achievements accomplished till today by APAL or the successful episode of the APAL's activities

The petition was filed before the Rajya Sabha Petition Committee of Parliament and the Government has taken action on the recommendations of the committee. Civic amenities are being provided to leprosy colonies on the intervention of the Human Right commission. Public Interest Litigation (PIL) APAL was submitted to the Supreme Court of India, seeking amendments in the provisions of the derogatory Acts. Amendment of Local Panchayat Election Act by Odisha Government. Participation of People affected by leprosy in the Government decisions making to leprosy-related policies and programs. Translation of WHO guidelines in the Hindi Language on strengthening the participation of people affected by leprosy services. Advocacy for Housing and land rights of the leprosy colonies. Involvement of youth to work for the empowerment of persons affected. Worked for the social entitlements like disability pension, ration cards, Railway Concession, etc.

During the COVID-19 pandemic, with the support of Sasakawa Health Foundation, APAL has conducted COVID-19 awareness programs in 25 leprosy colonies in 6 states and chosen the youth of the colonies to work voluntarily in the implementation of the awareness program. The board members and state leaders have also contributed their services by supporting the volunteers.

SECTION 5

LEPROSY TEACHING, JOURNALS, AND ASSOCIATIONS IN INDIA

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Leprosy Teaching in Medical Universities of India

Hemanta Kumar Kar

Introduction

The new competency based medical undergraduate curriculum for medical education in India has been modified and implemented recently from 2021/2022 at undergraduate i.e. MBBS with changing health needs of India under National Health Commission (NHC). New competency based post graduate training programme (MD and MS) have also been implemented in all medical teaching institutes of India in 50 specialities including post graduate course (MD) in Dermatology, Venereology and leprosy from 2022.

Updating and reorganization of the undergraduate and postgraduate curriculum focussing on competency was carried out by the Academic Cell of NHC earlier known as Medical Council of India (MCI) with the help of subject experts and members of its Reconciliation Board. Leprosy teaching has been given high level of importance both at undergraduate and post graduate levels in the teaching curriculum at university level.

I. Undergraduate Medical Teaching (MBBS)

Objective: At the end of the undergraduate training program, every freshly qualified MBBS doctor should be able to recognize "health for all" as a national goal and should be able to fulfil his/her societal obligations towards the realization of this goal.

Goal: This undergraduate medical curriculum is supposed to produce a clinician, who understands and is able to provide preventive, promotive, curative, palliative and holistic care to his patients. The student should be trained to effectively communicate with patients and their relatives and community as a whole in a manner respectful of the patient's preferences, values, beliefs, confidentiality and privacy and to this purpose.[1]

Competency based teaching in leprosy for MBBS students: The new curriculum provides for early clinical exposure, electives and longitudinal care. Skill acquisition is an indispensable component of the learning process in medicine. The curriculum reinforces this aspect by necessitating certification of certain essential skills. Therefore, exposure to clinical materials is must immediately after 1st professional examination is over in para-clinical subjects (Anatomy and Physiology). The students get opportunity to see leprosy patients in outpatient department (OPD) of Dermatology,

Venereology and Leprosy for history taking, clinical examination and learn OPD based laboratory procedures like skin slit smear examinations as well as techniques of skin biopsy using disposable punch biopsy needles. Under graduate teaching program has been divided into 1. Theory lectures, 2. Clinical posting, 3. Practical, tutorial, seminar and integrated learning (PTSI).

For each subject in UG course including dermatology, venereology and leprosy the outcomes (competency) is outlined - the learning domains (Knowledge, Skill, Attitude, Communication) are identified. The expected level of achievement in that subject is identified as – [knows (K), knows how (KH), shows how (SH), perform (P)]. As a rule, 'perform' indicates independent performance without supervision and is required rarely in the pre-internship period. The outcome is a core (Y - must achieve) or a non-core (N - desirable) outcome. The suggested number of times a skill must be performed independently for certification is normally provided in the learner's log book. The following UG courses for leprosy (competency, domain, level, core, suggested teaching methods, suggested assessment methods, vertical integration and horizontal integration) are enumerated in the table below.

Subjects Leprosy	COMPETENCY: The student should be able to	Domain K/S/A/C	Level K/KH/ SH/ P	Core (Y/N)	Suggested Teaching Learning method	Suggested Assessment method	Number required to certify	Vertical integration	Horizontal Integration
DR9.1	Describe the epidemiology, etiology, classify, microbiology, pathogenesis, clinical presentations and diagnostic features of Leprosy	K	KH	Y	Lecture, Small group discussion	Written/ Viva voce		General Medicine	Microbiology, Community Medicine
DR9.2	Demonstrate (and classify based on) the clinical features of leprosy including an appropriate neurologic examination	S	SH	Y	Bedside clinic	Bedside clinic/ Skill assessment		General Medicine	
DR9.3	Enumerate the indications and observe the performance of a slit skin smear in patients with leprosy	S	KH	Y	Bedside clinic, DOAP session	Written/ Viva voce			Microbiology
DR9.4	Enumerate, describe and identify leprosy reactions and supportive measures and therapy for the reactions	K	KH	Y	Lecture, Small group discussion	Written/ Viva voce		General Medicine	Pharmacology

Subjects Leprosy	COMPETENCY: The student should be able to	Domain K/S/A/C	Level K/KH/ SH/ P	Core (Y/N)	Suggested Teaching Learning method	Suggested Assessment method	Number required to certify	Vertical integration	Horizontal Integration
DR9.5	Describe the treatment of Leprosy based on the WHO guidelines	K	KH	Y	Lecture, Small group discussion	Written/ Viva voce		General Medicine	Pharmacology, Community Medicine
DR9.7	Enumerate and describe the complications of leprosy and its management, including understanding disability and stigma.	K	KH	Y	Lecture, Small group discussion	Written/ Viva voce		General Medicine	Pharmacology, Psychiatry

Abbreviations used in table for understanding the competency level:

Domains of learning

K	KNOWLEDGE
S	SKILL
A	ATTITUDE
C	COMMUNICATION

Levels of competency

K	Know	A knowledge attribute - Usually enumerates or describes
KH	Know how	A skill attribute: is able to identify or demonstrate the steps
S	show	A skill attribute: is able to identify or demonstrate the steps
SH	Show how	A skill attribute: is able to interpret/ demonstrate a complex procedure requiring thought, knowledge and behaviour
P	Perform (independently or under supervision	Mastery for the level of competence - When done independently under supervision a pre-specified number of times - certification or capacity to perform independently results

Vertical integration indicates that competency can be integrated in subjects of next phase (professional)course to increase relevance and improve basic understanding where as in **horizontal integration (above table)** it is integrated in other subjects of the same phase (professional) to allow a more wholesome understanding. **Under column "Number required to certify "P"** is the number of times a skill needs to be done independently to be certified for independent performance mainly in PG course, rarely in UG course.

Competency based post MBBS internship training in leprosy

After completion of four and half year MBBS course, each student undergoes internship in all subjects for one year out of which the students are posted in dermatology, STDs and Leprosy department for seven days for clinical and practical learning. While posting under Community medicine, it is mandatory to work in both Primary Health Centres and Community Health Centres (Urban and Rural) to take active participation in the field and to enable him/her to diagnose and treat common medical illnesses and recognize the importance of community involvement related to various National Health Programs including Leprosy (NLEP) as recommended by the Ministry of Family and Health Welfare, Government of India.

II. Postgraduate Medical Training (MD in Dermatology, Venereology and Leprosy)

Post graduate course in all medical subjects have a duration of three years, competition based admission is offered once in a year except few national institutes i.e. All India Institute of medical sciences etc. where there are admission facilities twice a year.

A. Subject specific objectives:

At the end of the three years training in Dermatology, Venereology and Leprosy,

1. Students should have knowledge of basic sciences like anatomy, physiology, biochemistry, microbiology, pathology and pharmacology as applied to Dermatology and Leprosy.
2. Students should have acquired practical and procedural skills to the subject
3. Students should evaluate, initiate investigations and clinically manage the cases
4. Students should learn and advise measures for prevention and rehabilitations.
5. Students should be able to ensure implementation of National Health Programme in Leprosy and STDs and HIV infections
6. Students should acquire training skill in research methodology, professionalism, attitude and communication skills.
7. Students should have developed teaching skill in subjects, basic methodology of teaching and develop competence in teaching medical/paramedical students
8. Students should have acquired problem solving skills.

B. Subject specific competencies:

Competency based post graduate training programme for MD in Dermatology, Venereology and Leprosy is now implemented in all universities of India with an objective as mentioned above recognizing the health needs of community, developing competency to handle effectively the medical problems and aware of recent advances pertaining to the discipline. The post graduate student should require basic skills in teaching medical/ paramedical students. The students should able to counsel patients and relatives in infectious diseases like HIV/AIDS, sexually transmitted diseases, curative **leprosy** and tuberculosis and any event of serious illness or death.

By the end of the course the student must gain knowledge (cognitive domain), professionalism (affective domain) and skill (psychomotor domain) as below

a. Cognitive domain:

At the end of course the student should acquire following theoretical competencies like describing structure, function, and development of skin, basic pathologic patterns and reactions of skin and can describe clinical features, reactions and management of leprosy including rehabilitation, acquire knowledge of laboratory stains and procedures used in histopathological diagnosis, basic concept of research methodology and interpretation of data in medical literature/publications, skilled as a self-directed learner, recognize continuing educational needs, use of appropriate learning resources and critically analyze relevant published literature in order to practice evidence-based leprosy

b. Affective Domain:

At the end of the course, the student should acquire the attitudinal competencies: like behaviour and emotional stability, motivation and initiative, honesty and integrity, inter personal skills and leadership qualities. The students should recognise the emotional and behavioural characteristics of patients and keep these fundamental attributes in focus while dealing with them. The student should demonstrate empathy and humane approach towards patients and their families and respect their sensibilities, The students should identify social, economic, environmental, biological and emotional determinants of patients and institute diagnostic, therapeutic, rehabilitative, preventive and promotive measures to provide holistic care to an individual and community level against skin, leprosy and sexually transmitted infections. The students should be part of a team, develop an attitude of co-operation with colleagues and interact with patients and clinician or other colleagues to provide the best possible diagnosis or opinion. Finally, students must adopt ethical principles and maintain proper etiquette in dealing with patients, relatives and other health personnel and respect right of patients including the right to information and second opinion.

c. Psychomotor Domain:

A student at the end of three years of study must acquire the following practical skills: 1. General medical skills as learnt in MBBS to be maintained including basic and advanced life support (BSL and ASL)), recognize conditions outside his/her areas and refer them to other specialities. The student must develop skill in history taking, physical examination, diagnosis and management of patients with leprosy, the students must be able to diagnose and classify leprosy and differentiate from other skin and neurological diseases. He/she is able to perform systemic examinations (chest, cardiac, abdomen, neurological, genital, oral, eye and gynaecological examinations) relevant to leprosy. The student is able to plan and advise measures for prevention of leprosy to family members, contacts and community as a whole. He/she is able to plan for rehabilitation of patients suffering from leprosy, especially after treatment and special need for disabilities with leprosy. Finally, he/she should be perfect in documentation of case details, morbidity/ mortality data relevant to leprosy.

Under laboratory skill the students should able to perform skin slit smear for acid fast bacilli(AFB), fix, stain and examine slides under microscope for AFB and calculate BI and MI. The students must be familiar with other recent investigations relevant for diagnosis, monitoring of leprosy. Finally, he/she should be competent enough to do skin and nerve biopsies and interpret skin and nerve histopathology of leprosy in all spectrums including reactions, neuritis and nerve lesions.

Syllabus course contents in Leprosy:

A. 1st year MD students: Basics as applicable to leprosy

1. Bacteriology of leprosy
2. Immunogenetics of leprosy
3. Immunological aspects of leprosy
4. Biochemical aspects of leprosy
5. Pathogenesis of leprosy
6. Structure, electrophysiological and ultra-sonographic studies of peripheral nerve
7. Pathomechanisms of nerve damage
8. Basic history taking and examination (peripheral nerve examination and sensory testing with SW filaments)

B. 2nd year MD students: clinical as applicable to leprosy (lecture, seminar, group discussion, etc.)

1. Approach to a patient with leprosy
2. Classification of leprosy
3. Immunology and molecular biology aspects
4. Histopathology and laboratory diagnosis (serological and molecular techniques)
5. Differential diagnosis of leprosy
6. Systemic and ocular leprosy
7. Leprosy in HIV
8. Leprosy in pregnancy and children
9. Neuritis
10. Leprosy reactions
11. Chemotherapy of leprosy (including WHO-MDT packs and newer drugs)
12. Immunotherapy of leprosy (chemoprophylaxis and vaccines)
13. Disabilities, deformities and rehabilitation
14. Relapse and drug resistance
15. Prevention, education and counselling in leprosy
16. NLEP and future challenge

C. 3rd year MD students case presentation

1. Case presentation:
    a. Of different types of leprosy patients (as short cases and spot case) by the students.
2. Recent advances in leprosy:
    a. This is covered in the form of discussion of journal, both national and international articles, review articles, and case reports with weekly assessment.

III. Examination System

In **MBBS** due importance is given in leprosy subject at all professional levels, 1st professional (anatomy, physiology and biochemistry), 2nd professional (pathology, pharmacology, microbiology, forensic medicine), and 3rd professional (Part 1- ophthalmology, ENT, PSM and Part 2- Medicine, Surgery, Pediatrics, Obstetrics and Gynecology, Orthopedics, Anesthesia, Dermatology including leprosy, Radiology, Psychiatry) in the form of case presentation, lab investigations, and viva.

In **MD (DVL)** The examination is conducted internally every year and final at the end of 3rd year. The thesis has to be approved by the internal and external examiners before final examination with publication of research papers from the thesis. The final examination includes four theory papers, first paper on basic science as applied to Dermatology, STDs and Leprosy, second paper on dermatology, third paper on leprosy and STIs, fourth paper on recent advances in the field of dermatology, STDs and leprosy. Practical examination is taken to assess the competency and skill of methodology, techniques, procedures of patient's examination (one long case and two short cases and ten spot cases, normally one short case in leprosy is must in addition to spot cases in leprosy. During oral/viva examinations students are evaluated on histopathological examinations of skin slides including leprosy, instruments, drugs including MDT blister packs, newer anti-leprosy drugs and radiological, ultra sound/ CT /MRI findings etc.

Conclusion

The competency based undergraduate, internship and post graduate training program in relation to leprosy is quite robust at present in India. PhD program in leprosy of any specific aspect is also an innovative attraction for research scholars in many universities for those who want to peruse their research carrier in leprosy and related branches. Finally, refresher training programs are being carried out from time to time for the medical officers and specialists during their posting in peripheral primary and community health centers, district /tertiary care hospitals by the government and NGOs to refresh, upgrade the knowledge and skill in leprosy particularly for successful national leprosy eradication program of India.

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Indian Association of Leprologists (IAL)

Vitthal Jadhav, Meenal Jadhav

Indian Association of Leprologists (IAL) was formed as professional organization in 1950 during the Third All India Leprosy Workers Conference at Madras now known as Chennai. It was established with the objectives of promoting the study and research in leprosy, creating a public opinion in matters relating to its cure, prevention and rehabilitation of patients afflicted by it and collaborating with medical and other institutions at regional and national level having similar objectives. Its Ordinary membership is open to all medical professionals who are interested or engaged in leprosy work and are registered with Indian Medical Council under its Act of 1956 and those with neighbouring countries registered with equivalent medical councils, those non medical personnel with active involvement with leprosy work of 5 and 2 years standing, possessing post graduate degree or doctorate in science from recognized institute and university respectively. The full time non medical staff members engaged with leprosy work having post graduate degree in basic sciences and medical practitioners registered with other authorised medical councils or boards engaged in leprosy work for more than 2 years, can obtain Associate membership on recommendation of Central Council of IAL. Given the multisystemic nature of the disease, its potential for complications causing disabilities and deformities with social stigma, its once highly prevalent endemic nature prompting its inclusion in one of the first national programs of India, imparts this organization a multidisciplinary nature. Its members encompass general clinicians, dermatologists and leprologists, pathologists and medical microbiologists, epidemiologists, general, plastic, ophthalmic, orthopaedic and neuro surgeons, general and neuro physicians and laboratory scientists. Its present member strength is around 1000 members.

The seeds of IAL were sowed in first three 'All India Leprosy Workers Conference', a post independence association of Indians working in leprosy (1947, 1948, 1950).The very basis of founding a focused professional association of Indian leprologists with medical specialities was to put leprosy control on firm and formal footing by using Dapsone chemotherapy in its management, based on scientific research. It can be loosely said that formation of IAL was the culmination of conceptual clash between those advocating Dapsone therapy versus non-medical leprosy exponents emphasizing institutionalized isolation of patients as almost the sole measure for control of leprosy.

As has been aptly described once by Late Dr R Ganapati, 'the Indian Association of Leprologists (IAL) is the only professional body in the country totally dedicated to maintain

high standards of deliberations needed to guard the interest of science of leprology and sustain the interest of medical profession'. The association does this by organizing biennial conferences, mid-term national symposia, innumerable continuing medical education programs and workshops for undergraduate and postgraduate medical students, medical officers and health care workers. IAL has started nationwide CME cum orientation training on 'Current scenario of Leprosy in India: In search of the ideal ways to keep up the status of elimination' in medical colleges of each state since January 2015. This aims at sensitizing young medicos, general practitioners, budding dermatologists, orthopaedic and plastic surgeons, ophthalmologists, neuro-physicians and otorhinolaryngologists about the current day understanding of the disease. Given the nature of multi-system involvement by leprosy, this initiative of the association is noteworthy.

IAL has been a major force in fight against leprosy in India and is also involved in tackling the post elimination emerging problems. It works in close collaboration with National Leprosy Eradication Program (NLEP), in implementation, policy making and training the healthcare workers. IAL stands out amongst all other professional organizations in its fervour in maintaining the strong interest in national effort in fighting the disease. In doing so it does not merely act as a professional body but goes beyond that. IAL perhaps is the only professional association so closely and actively associated with national and international health programs.

The path finding contribution of IAL is that it devised a Consensus Classification of Leprosy based on clinical patterns of the disease in India in 1980, with clinical variations in view and based on immunologic and histological findings. This was after suggesting and working on user friendly classifications based on clinical grounds, suitable in Indian scenario in 1955. Besides this, IAL devised its own MDT regimen in 1984.

IAL in collaboration with Hind Kust Nivaran Sangh (HKNLS) publishes a quarterly journal 'Indian Journal of Leprosy', abbreviated as Indian J Lepr (IJL). IJL is one of the oldest peer reviewed journals of India, dedicated to publishing best comprehensive research in the field of leprosy in the form of review and original articles and brief communications, encompassing fundamental and applied aspects of leprosy along with other mycobacterial diseases. It is one of the highly referred and cited journals with extensive viewership. It is considered one of the finest publications in leprosy which has served as a voice of Indian anti leprosy movement. It was previously named as 'Leprosy in India' and was renamed as Indian Journal of Leprosy in 1984 by Dr Dharmendra. He has been its editor for almost 40 years in its both forms till 1989. IAL was later edited by Dr H Shrinivasan (1990- 2001), Dr SK Noordeen till 2007. Dr VM Katoch is editing it till date. IAL publishes proceedings and abstracts of research presentations of its conferences. It has published IAL Textbook of Leprosy edited by Bhushan Kumar and HK Kar and IAL Handbook of Leprosy authored by Bhushan Kumar, Tarun Narang, VV Dongre and Swapan Kumar Samantha.

The first conference of IAL was organized in 1953 at Puri, Odissa. Dr Dharmendra, a genius researcher, hero and crusader of anti leprosy movement in India, untiring exponent of Indian view point of leprosy, revered as authority on all aspects of leprosy, who with his humongous contribution in science and practice of leprology is considered as Father of leprology was its founder president. Since then 31 biannual conferences have been organized by IAL at

various institutes with themes ranging from chemotherapy, immunotherapy, plastic surgery, epidemiology, urban leprosy, classification, lepra reactions, vaccines, immune-prophylaxis, molecular epidemiological tools, recent advances and so on and so forth. The IAL conferences were held jointly with All India Leprosy Workers Conference till 1976 which was a silver jubilee conference of IAL. IAL members participated in organizing International Leprosy Congress thrice, once in Delhi and twice in Hyderabad including the present one.

Number of post-office bearers and members of IAL were honoured with Padma awards which are India's highest civil awards for their contribution to leprosy. Many other members received other national and international awards like International Gandhi and Damien - Dutton awards (Elaborated elsewhere in this Chronicle).

IAL in the year 2021 formed IAL Academy as its academic and research wing working under its executive committee to further knowledge and expertise of its members. It formed Leprosy focus groups to work on its sub-specialities. It is looking forward to collaborate and work in alliance with Asian and Latin American Leprosy association. With its rich heritage and future plans IAL has a great future in field of Leprosy.

Presidents and office bearers of IAL have worked relentlessly in field of leprosy. Their contributions include extensive clinical and epidemiological work, undertaking research in all fields of leprosy including clinical presentation, epidemiology, transmission, pathogenesis, pathology, organ affection, immunology, immune-prophylaxis, chemoprophylaxis, undertaking experimental studies, establishing research and training institutes, undertaking large scale vaccine and drug trials, innovating plastic surgery & physiotherapy techniques, experimenting with drug regimens and duration of therapy, modifying classifications and devising the user friendly ones suitable for the national need and implementing them in the field, developing epidemiological molecular and other diagnostic techniques, setting up specialized lab services, undertaking community based comprehensive leprosy work, developing community based rehabilitation models, planning and implementing field programs in rational manner, innovating them with health education strategies, undertaking physical and occupational rehabilitation of leprosy cured persons, fighting against the social stigma and uncivilized laws, writing books on theory and practice of leprosy for medical and non-medical workers, editing journals, participating and guiding leprosy control program which turned out to be the first and one of the most successful national health programs of India ; working in various capacities and representing India on Expert, Action Plan and Program Assessment committees of WHO. Following table summarizes an account of biennial conferences and contribution of its presidents held so far

Table: Summarization of IAL conferences with contributions of its presidents

Serial number of the IAL Biennial Conference - Year – Host City – Hon. Secretary of IAL	President of IAL – Affiliations – Brief list of Contribution & Awards
1 1953 Puri, Odisha **Dr P Sen** 4,5 1959, 1962 Mumbai Hyderabad **Dr H. Shamarao**	**Dr Dharmendra** (Medical Microbiologist),Founder Director NLCP, CLTRI Chingleput, Emeritus Scientist ICMR, , WHO Advisor, Member expert committee. Research & teaching in all aspects of leprosy including the transmission of the disease, extraction of M leprae from human lepromatous tissue invented Dharmendra lepromin, established research & training institutes, groomed researchers, participated & guided National Leprosy Control program (NLEP), authored Textbook Notes on Leprosy, Leprosy, Editor: Leprosy in India, Indian Journal of Leprosy (IJL) Padmashree, International Gandhi Award, Damien – Dutton award
2, 3 1955, 1957 Gorakhpur, UP Jamsedpur **Dr K.R. Chatterjee**	**Dr S.N. Chatterjee** (Research Officer Calcutta School of Tropical Medicine, Clinical work, extensive research in clinical manifestations including ocular involvement, nerve damage in maculo-anaesthetic leprosy, neuropathology of leprosy, histopathology of lesions & nerves, vascular pathology, clinico-bacteriological features, therapy with Chaulmoogra oil & DDS.
6 1965 Chennai, Tamil Nadu **Dr H. Shamarao**	**Dr R.V. Wardekar** (Pathologist), Founder Director Gandhi Memorial Leprosy Foundation (GMLF), Member of expert committee GOI, ICMR, WHO. Considered as Father of Leprosy Control, introduced idea that leprosy needs to be dealt as public health problem, initiated systemic utilization of paramedical workers in control program & devised their training programs, developed SET model, started case detection system & domiciliary line of treatment, Initiated Dapsone treatment in leprosy control & for its prophylaxis, introduced participation of NGOs in NLEP. Recipient of Padma Shree, International Gandhi Award
7, 8 1967, 1969 Agra, New Delhi **Dr H. Shamarao** **Dr V.K. Sharma**	**Dr Victor Das** First Indian Secretary South Asia Leprosy Mission Transformed leprosy Mission at Poladpur as an exemplary leprosy institution, as a secretary of Southern Asia leprosy Mission was responsible in bringing out a change in policies & implementation in India & abroad, modernised & transformed system of leprosy control & inpatient care
9 1971 Bhopal, Madhya Pradesh **Dr V.K. Sharma**	**Dr C.K. Job**, Director SLRC Karigiri, Professor Pathology, Medical Supt & Principal CMC Vellore, Chief of Pathology, National Hansen's Disease Centre, Carville USA, Hon.Vice President International Leprosy Association. Extensive research & publications in transmission, pathology, immunology, pathogenesis of nerve lesions in leprosy, contribution in service, education and training programs Life Time Achievement award, Damien – Dutton award
10, 1973 Wardha, Maharashtra. Centennial celebration of Dr Hansens bacillary discovery **Dr K.V. Desikan**	**Dr K. Ramanujam**, Head of clinical division CLTRI Chingleput, SLRC Karigiri, India. Undertook clinical work , research on leprosy affected children, leprosy in twins, therapy, prophylaxis with Dapsone, treatment of leprosy reaction

Serial number of the IAL Biennial Conference - Year – Host City – Hon. Secretary of IAL	President of IAL – Affiliations – Brief list of Contribution & Awards
11 1976 Baroda, Gujarat Silver jubilee conference **Dr S.K. Noordeen**	**Dr A. G. Selvapandian,** HOD Orthopaedics & Reconstructive Surgery for Leprosy, CMC Vellore Invented reconstructive surgery techniques for facial deformities, foot drop &claw hand, surgical decompression of nerve, established mobile units for reconstructive surgery. Established physical & occupational rehabilitation facilities. Conducted health education programs and demonstration programs in reconstructive surgery& physiotherapy. Recipient of BC Roy National Award
12 1979 Chennai, Tamil Nadu **Dr S.K. Noordeen**	**Dr P. Kapoor,** State Leprosy Officer Maharashtra , Member of Expert Committee of ICMR, Instrumental in introducing treatment of leprosy in Govt & municipal hospitals, research in epidemiology, introduced sample survey techniques for monitoring ongoing programs, authored a practical book on Leprosy & Leprosy Control
13 1981 Agra, UP **Dr R. Ganapati**	**Dr N.H. Antia,** Plastic Surgeon, Founder of first Plastic Surgery centre, Research laboratory in JJ group of Hospitals Mumbai, Plastic surgery facility of Bandorwala Leprosy Hospital (BLH) Kondhwa, Founder director FMR, member of ICMR, ICSSR, Planning Commission & Ministry of Health GOI Pioneered plastic surgery & RCS for facial deformities of leprosy, research on neuropathology and immunology, Developed a model of training rural women for early detection of leprosy. Recipient of Padma Shree, G D Birla International award for Humanism
14 1983 Mumbai, Maharashtra **Dr V P Bhardwaj**	**Dr K.V. Desikan,** Pathologist, Director CJIL, Emeritus Professor Pathology, Member, Institute of Tropical Diseases,MGIMS Wardha, Chairman, Medical Consultant Lepra India. Contributed in medical care, education, clinical, epidemiological, work. Established mouse foot pad model and developed an Autopsy Lab at CLTRI, established Leprosy Histopathology centre at MGIMS, Authored a book History of Leprosy in India, topic on Leprosy in Tropical Neurology Recipient of Damien-Dutton award
15 1986 Jabalpur, Madhya Pradesh **Dr B.K. Girdhar**	**Dr R.H. Thanjaraj,** Surgeon & Supt. Philadelphia Leprosy Hospital& Surgical Research & Training Centre, Vice president HKNS, Member of Working Group on Leprosy, of Swaminathan Committee of Health ministry GOI, Director Leprosy Mission Southern Asia, Asian Secretary General of International Leprosy Association. Worked in clinical leprosy, Plastic surgery, rehabilitation, leprosy control, devised surgical technique for foot drop &lagophthalmos, authored 3 books on leprosy
16 1987 Vishakhapatnam, Andhra Pradesh **Dr V.V. Dongre**	**Dr R. Ganapati,** research officer, founder secretary of ALH- RRE Society, Bombay Leprosy Project (BLP), Member of Maharashtra State Leprosy Council, NLEP, WHO consultant for assessment of MDT & training centres Recipient of Padma Shree.

17 1989 Trichur, Kerala **Dr V.M. Katoch**	**Dr H. Srinivasan ,** Orthopaedic Surgeon, Director JALMA, CLTRI Chingleput Developed reconstructive surgical techniques, conducted workshops in medical colleges, institutes in India, Brazil, under WHO & other programs , Research on surgical procedures for nerve damage and its response to steroid treatment, Reported Quiet Nerve palsy, authored books on reconstructive surgery commonly used in Leprosy & Prevention of disabilities in leprosy, Contributed Chapters on leprosy in various textbooks including IADVL textbook of dermatology, Editor IJL Recipient of Padma Shree, International Gandhi award
18 1992 Bhilai, Chhattisgarh **Dr J.A. Ponniah**	**Dr V. K. Ekambaram**, State leprosy officer for TN, secretary of Damien Foundation India, AIFO Led MDT program in Andhra Pradesh, set up urban leprosy unit in Banglore Recipient of International Gandhi Award, IAL Life time achievement award
19 1994 Chennai, Tamil Nadu **Dr P.S. Rao**	**Dr M.D. Gupte**, Epidemiologist, Founder Director NIE (ICMR), Researcher in leprosy prevention (ICMR), Epidemiologist for first MDT trial, Indian coordinator WHO UMDT trial , Member NLEP evaluation teams, working group of Medical health Research & development: Planning Commission, 8th five year plan, Chairman WHO Technical Advisory group on elimination of leprosy Research in epidemiology, Authored chapters in Textbook of IADVL Recipient of International Gandhi Award
20 1995 Pune, Maharashtra **Dr B.N. Reddy**	**Dr B.R. Chatterjee,** Member , Governing body GMLF, scientific Advisory Committee CLTRI Chingleput, JALMA, Action group of leprosy, Expert Committee ICMR Worked in Clinical leprosy, Edited a book Window on Leprosy. Recipient of Padma Shree
21 1997 Bhopal, Madhya Pradesh **Dr D. Porichha**	**Dr J.A. Ponniah**, Director SLRTC Karigiri, India. Officer I/C Leprosy Training & Leprosy Control Program Nigeria, Worked in clinical leprosy, training & research
22 1999 Chandigarh, (UT) **Dr Sreevatsa**	**Dr S.K. Noordeen**, (Epidemiologist) Program Officer Leprosy unit WHO, Director WHO, Action Program for Elimination of Leprosy, Global Program for Elimination of leprosy, President, International Leprosy Association (ILA), Founder Chairman, Sasakawa India Leprosy Foundation & Leprosy Elimination Alliance, Member NLEP Technical Resource Group, Editor IJL. Pioneer of Leprosy Research in India & globally at WHO, promoted leprosy control by implementing MDT. Padma Shree, International Gandhi award,
23 (Golden Jubilee) 2001 Patna, Bihar **Dr D. Porichha**	**Dr Bhushan Kumar,** Dermatologist, Former Professor and HOD, PGI Chandigarh Involved with Clinical, Teaching, Research , Edited IAL Textbook on Leprosy and IAL Handbook of Leprosy. Recipient of International Gandhi Award.
24 2004 Haldia, West Bengal **Dr Swapan Samantha**	**Dr Vitthal Jadhav,** (Dermatologist) Medical Suptd. BLH Kondhawa, Pune, DLS under DGHS Leprosy GOI, Chief facilitator training MLEC Govt. Maharashtra Principle investigator Isoprodian R (GLRA), UMDT(WHO). Recipient of IAL Life Time Achievement Award

Serial number of the IAL Biennial Conference - Year – Host City – Hon. Secretary of IAL	President of IAL – Affiliations – Brief list of Contribution & Awards
25 2005 Agra, UP **Dr K. Venkateshan**	**Dr V.M. Katoch,** (Medical Microbiologist) Director JALMA, Director General ICMR, Founder Secretary Health Research Ministry of Health GOI, Chairman Lepra society, Editor: IJL Research :Molecular diagnostic methods for rapid diagnosis, molecular basis of drug resistance & pathogenesis, Functional genomics & epidemiology Recipient of Erwin Stindl Memorial Oration Award, GLRA
26 2007 Kanpur, UP **Dr K. Venkateshan**	**Dr H.K. Kar,** (Dermatologist) Officer Regional Leprosy Training & Research Institute Raipur, HOD KIIT University, Director ABVIMS & RML Hospital Contributed in research in therapy, prophylaxis & reaction, Edited IAL Textbook on Leprosy
27 2009 New Delhi **Dr Swapan Samantha**	**Dr Atul Shah,** (Plastic Surgeon) Director Novartis Comprehensive Leprosy Care Association Undertook reconstructive surgery for deformities, developed newer techniques, authored chapters in IAL Textbook on Leprosy, Principles & Practice of Wound Care Recipient of International Gandhi Award
28 2012 Mumbai, Maharashtra **Dr Swapan Samantha**	**Dr Kiran Katoch,** (Physician) Former Director, JALMA, Agra, Principal investigator UMDT WHO project, Collaborator Leprosy Project 2: the foundation for Medical Research, ICMR. Research in immunotherapy, immunodiagnostics, clinical, translational matters. Contributed to IAL Text book of Leprosy
29 2014 Chandigarh (UT) **Dr R. N. Datta**	**Dr Swapan Samantha,** (Opthalmic Surgeon) Professor, Burdwan Medical College West Bengal, Visiting faculty for ocular leprosy in India & abroad. Undertook clinical work, teaching, research in ocular leprosy & community ophthalmology, aligned NLEP with NPCB for ocular leprosy. Instrumental in organizing nationwide IAL CMEs in state medical colleges for sensitizing young doctors.
30th 2017 Digha, West Bengal **Dr Mrudula .P. Save**	**Dr R. N. Datta,** Dermatologist, Professor & HOD IPGMER Kolkata Involved with clinical work, teaching, research, training programs in leprosy, Vice-president, National IADVL.
31 2021 Hyderabad, Telangana **Dr Sujai Suneetha**	**Dr P. Narasimha Rao,** Dermatologist, Professor Bhaskar Medical College, Hyderabad. President, National IADVL, 2019 Involved with clinical leprosy, teaching, research in therapy & post elimination challenges. Authored a chapter in IAL Text book of Leprosy, IADVL text book of Dermatology. Organizing Secretary, International Leprosy Congress 2022, India.

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IADVL & Contribution to Leprosy

K A Seetharam

Indian Association of Dermatologists, Venereologists and Leprologists (IADVL) is the second large dermatology association in the world. Initially it was association of dermatologists and venereologists of India in 1947, and later evolved into Indian association of dermatologists, Venereologists and Leprologists on 28th January 1973 including leprosy in its name, showing its commitment and dedication to leprosy. IADVL is now an official partner of National Leprosy Eradication Program (NLEP) in the fight against leprosy.

IADVL and anti-Leprosy Day

IADVL organizes anti- leprosy day on 30th January, commemorating Mahatma Gandhi's death anniversary. On that day, the association through its state branches participates in various programmes, like CMEs, educating the health workers, medical students, leprosy awareness walks, addressing issues of leprosy patients, visiting leprosy colonies and sharing and solving their issues.

IADVL and Leprosy Research

Dermatologists always prided themselves on being qualified leprosy specialists. This pride is based on the fact that they are they only medical specialists who study leprosy in detail as a part of their curriculum. Added to this, many medical college hospitals have leprosy clinics as an extension of the dermatology OPD. They also teach leprosy to students, nurses and paramedical workers. Many postgraduate students take up leprosy as the subject for their dissertation too.

With this background and keen interest to contribute to the cause of leprosy, in 2010 IADVL formed a Special Interest Group (SIG) to promote research and to identify lacunae and to recommend solutions. Number of leprosy works were funded through the initiative of this group. One of the important leprosy activity this SIG has undertaken was the pan-India DermLep Survey, funded by IADVL research grant. It involved 201 dermatologists across 20 states in India, including both institutions and practitioners and studied 3701 patients. This study has brought out unregistered leprosy patients (about 40%) seen by dermatologists as the missing numbers of the government statistics. This survey has also brought out the facilities available with the dermatologists and the issues faced by patients after released from treatment. This apart, number of research projects on leprosy were funded by the IADVL over the years. IADVL also promotes young researchers by funding leprosy projects and providing thesis grants to postgraduates who are doing thesis work, many of which were for work in leprosy. Some of these completed works were published in indexed journals later.

IADVL and Leprosy Symposia

IADVL organized national symposiums in association with IADVL Academy and SIG leprosy at Delhi in 2018 and 2019. Dr P Narasimha Rao, the then president elect and IADVL president for the respective years and Dr Sujai Suneetha, SIG leprosy coordinator (2018-19) have concerted these symposiums. The first symposium was held in August 2018 with a theme of 'Accelerating towards a leprosy free India' and three major objectives: To discuss the efficacy and value of implementation of Uniform-Multidrug Therapy (U-MDT); To examine the efficacy, value, limitations and administrative aspects of administration of Single dose Rifampicin (SDR) as a chemoprophylaxis tool; and To discuss the efficacy, value, availability and implementation of MIP vaccine and other vaccines in the Immuno-prophylaxis of leprosy. The second National symposium was held in November 2019 with a theme of "Research priorities for Leprosy-Free India". Various issues like progress made in leprosy control in India, Genetics in leprosy and relapse in leprosy, were discussed through lectures and panel discussions. These symposiums paved the way to appraise various issues with the concerned government authorities and the leprosy organizations. Representatives from different national and international organizations/ groups participated in these symposiums. These included representatives from the Central leprosy division (CLD), Government of India, & National Leprosy Elimination Programme (NLEP); Representatives of the World Health Organization, (WHO-SEARO) New Delhi ; Indian Association of Leprologists (IAL); Indian Association of Dermatologists, Venereologists and Leprologists (IADVL); and all other major leprosy stakeholders of India, including Association for People Affected by Leprosy (APAL).

IADVL National Leprosy symposium, 24th August 2018,New Delhi

IADVL and Leprosy Session in conferences

IADVL organizes special sessions on leprosy during their State conferences (CUTICONs), Zonal conferences (DERMAZONEs) and National conferences (DERMACONs and MID-DERMACONs). It disseminates the knowledge and updates about leprosy at these conferences and try to bring out various issues faced by leprosy patients and endeavours to list out the research priorities and opportunities. There is also a special prize for the best paper presented at DERMACON by young dermatologists on leprosy.

IADVL and Leprosy books

IADVL dedicated a full section on leprosy in IADVL textbook of Dermatology, which has gone through five editions now. It also has the IADVL Concise textbook of Dermatology which has leprosy as one of the chapters. At present it is also in the process of bringing out a "Practical Manual of Leprosy" in association with SIG leprosy. IADVL SIG leprosy had brought out newsletters periodically with the updated scientific knowledge. IADVL brings out two journals (IJDVL & IDOJ) and review articles, editorials and original research papers and case reports on leprosy get published in them regularly.

Thanks to all the IADVL executive committees for their focus on leprosy and supporting Indian leprosy.

IADVL National Leprosy symposium, 2nd August 2019, New Delhi

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Leprosy and Journals of India

Bhavya Swarnkar, M Ramam

Despite the national-level elimination of leprosy in 2005, India still holds almost 60 percent of the world's leprosy cases. Moreover, in certain districts and states of India the incidence of new cases is observed to be on raise as reported by NLEP in the year 2021. At the same time efforts are on to achieve the vision of 'leprosy-free India' through activities like Leprosy Case Detection Campaigns, ASHA-based surveillance for leprosy suspects, 'Sparsh' leprosy awareness campaign, single-dose chemoprophylaxis, etc. across India. With these efforts the prevalence of leprosy has decreased reported new cases, child cases, multibacillary forms, and deformities are still being reported indicating active transmission of disease.

While this disease is already considered a neglected tropical disease, fortunately due its social and epidemiological importance and varied clinical presentations, research in the field of leprosy diagnostics, therapy, relapse, reactions and development of potential vaccines is still taking place across the world. To publish these observations, there are two dedicated journals for leprosy with world-wide readership. These are the Leprosy Review, a UK-based open access quarterly journal, and the other, the Indian Journal of Leprosy published from India, both of which are open assess journals. Besides these the Japanese Journal of Leprosy also deals only with leprosy and is published by the Nippon Foundation, Japan. Unfortunately, two very popular journals dedicated to leprosy The International Journal of Leprosy and Other Mycobacterial Diseases published from the US [1933- 2005] and Acta Leprologica published from Switzerland discontinued their publications and are presently closed.

In addition to these, the work on leprosy is also published in various other international journals and Indian medical journals. Some of them are are Indian Journal of Dermatology, Venereology, and Leprology, Indian Dermatology Online Journal, ICMR bulletin, Indian Journal of Medical Research, Indian Journal of Public Health, The National Medical Journal of India, and Journal of Postgraduate Medicine, International Journal of Mycobacteriology, PLOS Neglected Tropical Diseases, Clinical Dermatology, Science, Tropical Doctor, Lancet, Epidemics, Parasites & Vectors and Vaccine.

The immense good quality literature published in these journals continuously provides robust data to practice evidence-based medicine in leprology. Here, we are going to discuss some of the Indian journals and their contribution to Indian and global leprosy.

Indian Journal of Leprosy (IJL): Indian Council of British Empire Leprosy Relief Association (IC-BELRA) was founded on 27th January 1925. This journal was first published by Dr. Ernest Muir, an eminent leprologist, leading to the birth of Leprosy in India in July 1929 with the name "Leprosy in India".

After Independence, IC-BELRA was renamed Hind Kusht Nivaran Sangh (Indian Leprosy Association) in 1950. With the rapid generation of data on anti-leprosy work in India, the journal Leprosy in India, became the official publication of Hind Kusht Nivaran Sangh (Indian Leprosy Association) and grown further as a means to disseminate information and share experiences related to leprosy and bridge the gap between the leprosy workers and researchers in India. Over the years, this became highly cited and renamed as Indian Journal of Leprosy (Indian J Lepr) in January 1984. The list of eminent leprosy scientists and workers who served as Editors of this highly reputed journal is given in Table 1.

Editors of Indian Journal of Leprosy	
Duration	**Name**
1929 to 1935	Dr Ernest Muir
1935 to 1939	Dr John Lowe
1939 to 1940	Dr Dharmendra
1940 to1943	Dr John Lowe
1943 to 1955	Dr Dharmendra
1955 to 960	Dr N Mukherjee
1961 to 1970	Dr Dharmendra
1970 to1972	Dr CGS Iyer
1973 to 1989	Dr Dharmendra
1990 to 2001	Dr H Srinivasan
2001 to 2007	Dr SK Noordeen
2008 to till date	Dr VM Katoch

The contributions made by Dr Dharmendra in building its reputation as a global scientific level of the journal will be written in golden words. It was during his tenure that the journal Leprosy in India was renamed as Indian Journal of leprosy.

It is a peer reviewed journal and all Life members of the Indian Association of Leprologist get a free hard copy. It is listed in Scopus and publishes review articles, original research articles, case reports, letters to the Editor, Conference/Symposia reports, and brief communications dealing with various aspects/branches of leprosy and other mycobacterial diseases. While in the earlier days of its publication, the journal mainly published leprosy surveys, from 1934 onwards, the scope of the journal widened to include other aspects of leprosy research.

Over the years, this journal became the voice of the Indian anti-leprosy movement and took an exceptional position in the Global Scientific community within a decade. It is considered to be one of the best publications on leprosy published quarterly in four issues.

Dr. VM Katoch is the present Editor-in-Chief.

Indian Journal of Dermatology, Venereology, and Leprology (IJDVL): It is an official publication of Indian Association of Dermatologists, Venereologists, and Leprologists (IADVL). IJDVL is an open-access bimonthly peer-reviewed journal committed to publishing high-quality articles in the field of Clinical and Experimental Dermatology, HIV Medicine, Sexually Transmitted Diseases and Leprosy.

It reaches as a hard copy to all members of the Indian Association of Dermatologists, Venereologists, and Leprologists (IADVL) free of charge. It also reaches more than 200 medical colleges in India. In addition, it has a good number of international individual and institutional subscribers. Importantly, it has a large online readership, as a free open access journal and a respected dermatology journal. IJDVL publishes editorials, CME articles, case reports, studies and letters, and photo quizzes.

The inclusion of leprosy as important part of this journal was gradual. The IJDVL, before acquiring the present name, was first published as Indian Journal of Venereal Diseases in 1935-36, and edited by Dr. U. B. Narayan Rao. Later, in 1940 the name was changed to the Indian Journal of Venereal Diseases and Dermatology, and it was published quarterly. In 1947 it was once again renamed the Indian Journal of Dermatology and Venereology. Finally, in 1973, at a conference held in Udaipur, the name of the Indian Journal of Dermatology and Venereology was changed to the Indian Journal of Dermatology, Venereology, and Leprology (IJDVL), with the inclusion of name 'leprosy' in the title of the journal. Since then, Dr. S. C. Desai, Dr. Bhaktavizam, Dr. (Mrs.) Rachel Mathai, Dr. J. S. Pasricha, Dr. S. G. Deshpande, Dr. Gurmohan Singh, Dr. K. Pavithran, Dr. Uday Khopkar, Dr. D. M. Thappa and Dr. M. Ramam have been the Chief Editors of the IJDVL. Dr. Saumya Panda is the current Editor-in-chief. IJDVL is one of the highest-rated scholarly journals published in India. The Journal Impact Factor of 3.030 was achieved in 2018. According to the JCR 2021, the 5-year impact factor is 3.25 which is considered very good. As per Clarivate JCR 2021, the total number of citations of IJDVL in the past 5 years is 10,675.

IJDVL regularly receives and publishes high-quality articles, editorials and informative case reports on leprosy. It has a dedicated team of section editors and reviewers for leprosy. A study by Moorthy et al on clinico-histopathological correlation in leprosy is one of the highest cited articles on leprosy. It has the highest readership globally among all Indian journals on dermatology and leprosy.

Indian Dermatology Online Journal (IDOJ): It is a bimonthly open access print journal of the Indian Association of Dermatologists, Venereologists, and Leprologists (IADVL). This journal was first published in 2010 with Dr Shyam Verma as the founding editor. The Indian Dermatology Online Journal (IDOJ) is a bimonthly journal. While the title includes the term 'online journal', it is actually available both in print and online versions. It was introduced with the main objective of showcasing clinical dermatology from India and worldwide. This journal encourages articles on pure clinical dermatology including leprosy and aims to sensitize dermatologists across India and the world to the importance of documentation. Because of this spirit and its raison d'etre of encouraging sharing of dermatology in India, IDOJ is steadily growing in its stature, content, and readership. The immediate past editor was Dr. Sunil Dogra. The current Editor-in-chief of this journal is Dr. K.A. Seetharam.

IDOJ publishes regularly a good number of editorials, reviews, original articles, case reports, and opinions on leprosy. This Indian journal exhibits great promise in terms of readability, teaching, and learning dermatology & leprosy in India and across the globe. Review articles published in this journal on psychosocial aspects of leprosy by Singh GP, which highlighted the importance of early diagnosis and management of psychiatric issues on Current Situation of Leprosy in India and its Future implications by Rao PN and Suneetha S, which reviewed the global and Indian leprosy scenario, effects of LCDC and benefits of chemo and immune-prophylaxis are some of the most cited articles on leprosy.

Indian Journal of Medical Research and ICMR Bulletin: IJMR was established in 1913, it is one of the oldest journals in Asia. It is published monthly from the Indian Council of Medical Research. Landmark studies (parts I,II,II) on immunological skin tests by Dharmendra and Lowe were published long back in the 1900s mentioning the process of extraction of lepra antigen and three different clinical types of lepra reaction. The important results of the National Sample survey of Leprosy, undertaken by ICMR with financial support from the Ministry of Health and Family Welfare, Government of India, in all states and six Union Territories of India by Dr Kiran Katoch and team, was published in this journal in 2021.

Other journals like the **Indian Journal of Dermatology, Indian Journal of Public Health, The National Medical Journal of India, and Journal of Postgraduate Medicine**, etc., have also contributed immensely to the field of leprosy by publishing a number of good quality authentic work done in the field of leprosy from India and aboard.

Indian medical journals are known for their indulgence in prioritising reports and articles on leprosy, by having dedicated section editors for leprosy. In the last 10 years, approximately 65 articles in IJDVL and 40 articles in IDOJ were published covering various aspects of leprosy including pathogenesis, clinical presentation, resistance, vaccine, and therapeutic options for reactions. Our PubMed search showed that IDOJ published 3 out of 19 and IJMR published 10 out of 174 editorials on leprosy in the last 10 years, highlighting the emphasis being given to this disease by our authors, editors, and reviewers. Various editorials in Indian journals have also focussed on leprosy. This is quite important because leprosy is a disease of great concern to India even now considering the high child infection rate, deformity rate, relapse rate, and increasing cases of drug resistance. Editorials in IJMR by various authors mentioned how far we have come since the launch of a leprosy control program and how far we need to go. These provides clarity on various aspects of the disease like epidemiological trends, social stigma, empowerment of persons affected by leprosy, and the effect on the quality of life of leprosy patients. It also forms the backbone of evidence-based medicine-based prevention and management of the disease.

Through these contributions, these Indian journals are playing an extremely important role in updating the knowledge on leprosy, while bringing to attention the issues which need to be addressed for achieving the goal of leprosy-free India.

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International Leprosy Congresses held in India

P Narasimha Rao

While twenty international Leprosy Congresses were already held across the world from 1897 onwards, when the first congress held in Berlin, India was host to only to two International leprosy Congresses till now. They were; the 12th International Leprosy Congress held at New Delhi in 1984 and the 17th International Leprosy Congress held at Hyderabad in 2008. The present 21st ILC 2022 would be the third congress to be hosted by India. A brief detail on 12th and 17th ILC is given below.

XII International Leprosy Congress – (12th ILC 1984)

New Delhi, India.

20th-25th February 1984

The 12th (XII) International Leprosy Congress was the first ILC to be held in India. It was held at Vigyan Bhavan, New Delhi, India from 20 -25 February 1984, Dr Dharmendra was the Chairperson of this congress and Dr Thangaraj was the organizing secretary.

Dr Dharmendra who was the Chairman of the congress elaborated in his own words below in an interview, on how it was brought to India: "When I went to the Havana Congress in 1948, I had invited ILA on behalf of India for the next congress to be held in India. The Central Council of the International leprosy Association (ILA) very much liked the idea. But the next Congress was already fixed for Madrid in 1953. India's invitation was accepted for holding the Congress in 1958. But somehow it so happened - the reasons into which I will not go here - that only three months before the congress was to be held, the Government of India withdrew its invitation. That embarrassed me very much and embarrassed the international Leprosy Association. Fortunately Japan (which also wanted to hold the Congress in 1958, but India was given preference) came to our help. Within two or three months they organized the Congress in a very good way and I had sent all the papers which I had collected as a Secretary of the Conference to Japan. With the help of those papers they could go ahead and hold the Conference on the day it was to be held in Delhi.

From that very date I was looking for the opportunity to invite the Congress to India again. But I kept silent for some time because I knew the mood of the International Leprosy Association about [the previous] invitation being withdrawn only a few months before. So I just waited for a sufficient time and then began to move for Congress to recall in Delhi in 1983. At my request, the Secretary of Hind Kusht, Nivaran Sangh, wrote to the Government of India to invite the Conference. They agreed to hold the Congress. After all, I went to Mexico Congress to invite the Congress to India for 1983. Actually accepting this they asked me a few questions. Whether this invitation is from the Government of India and whether it will not be withdrawn as it was done in 1958. They took my assurance that it is really the Government of India which has approved of it and they have just asked HKNS to organize the Conference and the second question I answered that I can assure you that there will not be the same experience which we had in 1958. It was very gratuitous of them that the Central Council of the General meeting of the members of Association, my request was unanimously accepted. Although there were some of the other countries that were in the field, but because so much work has been done on leprosy in India, they were very happy to accept our invitation. Specially because I had gone to Mexico Congress only for this purpose. My ambition was that the congress in India in Delhi should surpass all the previous congress, scientifically in providing amenities to delegates etc. and as soon as I came back we found we established a local organising committee for which the Minister of State for Health was the President. I was the working chairman and Dr. Thangaraj was elected as Organising Secretary. With the spirit of teamwork, we all worked together and ultimately the Congress was a big success in all aspects. We had 1400 delegates from all the different parts of the world. The congress was of a very high standard and we looked after their hospitality and their transport from the Hotel to the Vigyan Bhavan, New Delhi where the Congress was held. The cultural programme and reception which were given by a number of Embassies. After the congress was over and the delegates had gone back to their countries, several letters of appreciation were received of the way in which the Congress was organized".

This congress was a great success and received national and global attention. The then President of India, Late Shri Zail Singh, inaugurated the Congress, while the late Mrs Indira Gandhi - then Prime Minister of India- gave the keynote address, which brought focus on to leprosy in a big way. It was very happening period for leprosy, as MDT was introduced only a year before (1982-83) globally and in India and there was hope all around that it would bring down the prevalence and probably the incidence of leprosy in India and across the world.

Indian Post and Telegraph department released a commemorative stamp on occasion of XII international Leprosy Congress being held in India. Indeed, it was an seminal event which was widely celebrated!

17th International Leprosy Congress, (17th ILC 2008)

Hyderabad, India

30 January-4 February 2008

The 17th International Leprosy Congress was organized by the International Leprosy Association, under the auspices of the Government of India, through a National Organizing Committee. The theme of the congress was "Towards a world without leprosy."

The Congress is being organized by the International Leprosy Association, under the auspices of the Government of India, through a National Organizing Committee located at New Delhi, with Dr CS Walters as its Chairman and Dr Jaykumar Daniel as its Organizing Secretary. It was co-sponsored by the World Health Organization (WHO), International Federation of Anti Leprosy Associations (ILEP), The Nippon Foundation (TNF) and Novartis. It is supported by a number of leprosy organizations in India, including International Leprosy Union (ILU), Hind Kusht Nivaran Sangh (HKNS), Indian Association of Leprologists (IAL) and IDEA – INDIA.

While it was Dr Noordeen, who was also the president of International Leprosy Association (ILA) at the time, who took lead in bringing the congress to India and the initial planning, he could not take active part in the actual conduct of the congress due to health reasons. It was Dr VM Katoch, the Director of ICMR- JALMA, Agra at that time, who took charge of the planning of scientific programme of the congress and oversaw it as a very successful conference.

It was held at the Hyderabad International Convention Centre (HICC), Novotel, Hyderabad, which provided excellent facilities for more than 1000 ILC delegates, representing more than 50 countries, who attended the 17th ILC. While the congress was held form 30th January to 4th February 2008, the pre-Congress Workshops were held on 29th and 30th of January. For the congress inauguration the chief guest was the Governor of Andhra Pradesh, N.D. Tiwari, who stressed the need for all those involved in combating leprosy to remain vigilant and avoid complacency.

The scientific sessions were held for more than 150 hours, which included pre-Congress workshops, plenary and free paper sessions. Training sessions on topics as diverse as diagnostics and legal issues were also available to delegates.

The 17th ILC was eagerly awaited by all leprosy enthusiasts in the wake of the Govt of India announcing on 30th January 2006 that India had reached the elimination target - of less than one case per 10,000 population. It provided a unique forum for the leprosy community to share ideas and develop common goals.

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SECTION 6

STALWARTS OF LEPROSY IN INDIA

44

Mahatma Gandhi and Leprosy

Sanjiv Kakar, Vishwa Mohan Katoch

Mahatma Gandhi's involvement with leprosy was spread over much of his life and shaped by a great many people and events. Leprosy was visible and a matter of concern in Kathiawar, where Gandhi spent his childhood. Leprosy was then regarded by western medicine as a hereditary condition: at the local level, stigma was prevalent, but it was not uniform. The discovery of the leprosy bacillus by Armauer Hansen, and its acceptance by the international medical community was spread over 1873-1882: henceforth leprosy would be viewed as a contagious disease. Gandhi imbibed the ideas of modern medicine during his residence in London in the late 1880s. He had his first experiences of nursing leprosy patients in South Africa, which he described in his Autobiography, and he later added that "my interest in the leper work is as old as my

Mahatma Gandhi serving Shri Parchure Shastri, a scholar and person affected by leprosy at his Sevagram Ashram.

residence in South Africa." Following his return to India in 1914, there is abundant anecdotal evidence by contemporaries on the compassion he exhibited for the leprosy affected: most notable was his caring for Parshure Shastri, social activist, freedom fighter and leprosy patient.

Most studies have focused on the aspect of nursing, though Gandhi's involvement with leprosy was much wider. Gandhi intervention with leprosy took a new turn following his visit to the Purulia Leprosy Asylum, where he encountered an entire new understanding. (Young India, 24 September 1925) Leprosy was no longer regarded in terms medieval. The newest treatment was of injections of the active agent of Chaulmoogra oil, an ayurvedic medicine. Microscopic examination could determine which patients did not harbour bacilli, were no longer infectious and could be released from the leprosy asylums. Shubhada Pandya has pointed out that the leprosy bacillus was first exhibited at Grant Medical College in 1883, but this understanding was slow to penetrate across India, due to the apathy of both the colonial state and of the Indian elites. In the 1920s, during his visit to several missionary leprosy homes, Gandhi saw a package: a new approach to leprosy and a new hope, to which he was drawn; but also the aspect of proselytizing, which he contested. On the policy of segregating male and female patients, prevalent in missionary institutions for leprosy, Gandhi initiated a debate (Harijan, 14 September,1935).

In the 1930s, this modern understanding of leprosy began to penetrate outside of the leprosy asylums and into the rural areas, and Gandhi interacted with many Indian leprosy specialists. In 1934, during his tour of Orissa, he met with Dr Isaac Santra, an eminent leprosy expert: the prevalence of leprosy was now estimated at over 1 million, far in excess than the decennial Census returns, which estimated about 120,000 patients. Despite his personal commitment to nature cure, Gandhi now made public his endorsement of the approach of modern medicine towards leprosy(Harijan, 7 September 1934).

Another phase in Gandhi's involvement with leprosy began with his shift from the Sabarmati Ashram to Sewagram in Wardha (1936), where in some villages the prevalence of leprosy was as high as 5 to 8%. Close associates like Vinoba Bhave were engaged in leprosy relief, and in 1936 Manohar Dewan founded the Maharogi Seva Mandal in Wardha, the first Gandhian leprosy institution. Gandhi now had a hands-on engagement with modern medicine. In 1945, the Kasturba Gandhi National Memorial Trust began its activities with leprosy work with the Kasturba Kushtha Nilayam, in Malavanthangal. Also in 1945, Gandhi included leprosy in his Constructive program, where he wrote of the leprosy affected: "they are as much a part of society as the tallest amongst us." Gandhi now had a much-enlarged team of advisers, including leprosy patient and activist T N Jagadisan, and he turned to the medical authority of Dr R G Cochrane, regarded as one of the foremost leprosy experts in the world. With the convening of the All- India Leprosy Workers Conference at Wardha in 1947, Gandhians had in place dedicated activists to take this vision forward.

Gandhi's life straddles the entire range of notions about leprosy, from the hereditarian beliefs to the bacteriological understanding. He spoke against stigma, rejected calls to sterilize patients, and in prayer meetings he called for an end to the use of the word "leper." (24 October 1947). Analysis of various historical events associated with Gandhi's life and leprosy shows Mahatma Gandhi contributed significantly to the modernization of attitudes towards scientific understanding and management of leprosy in those critical years from 1925 to1948

(Sanjiv Kakar in M.K.Gandhi, Media, Politics and Society - New Perspectives, Edited by Chandrika Kaul, Palgrave Macmillan). After his death, the Gandhian commitment was taken forward by the Gandhi Smarak Nidhi, the Memorial Trust founded to perpetuate his values, and by the Gandhi Memorial Leprosy Foundation. Dr R.V. Wardekar, the founder Director, had worked at the Kasturba Hospital in Sevagram with Dr Sushila Nayyar, personal physician to Gandhi. Wardekar has recounted how Dr C G Pandit, suggested the use of sulphone drugs for a leprosy prevention and control program. The first such experimental control unit was in Sevagram (1951). Gandhi's spirit continued to guide, in both his life and after-life. His life inspires many in present and will certainly inspire future generation of leprologists to continue the fight against leprosy by modern scientific tools and strategies.

Leprosy work is not merely medical relief; it is transforming frustration of life into joy of dedication, personal ambition into selfless service."

–Mahatma Gandhi

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International leprosy researchers/ workers of repute, who did their work in India

Rakesh Kumar Bahunutula

Wellesley C. Bailey

Wellesley Cosby Bailey (1846–1937) was the founder of international charity 'Mission to Lepers' which later became The Leprosy Mission (TLM). In the 1860s he witnessed the severe consequences of leprosy and decided to dedicate his life to their care. Wellesley Bailey saw a huge need when he first visited the leprosy huts in Ambala and set about raising awareness of the plight of those with leprosy. The Mission he established all those years ago is still active today.

Wellesley Bailey, born in Ireland, set out to find his fortune in the goldfields of Australia in 1866 before he eventually departed for Faizabad, North East India, in 1869. He joined work with the American Presbyterian Mission under the leadership of Dr J H Morrison and was introduced to leprosy patients for the very first time here. Wellesley was deeply moved seeing the pathetic state of these patients and upon returning to Ireland described his work with leprosy affected people and the problems faced by them. Wellesley's talks were also produced in booklet form, entitled Lepers in India, and was successful in raising funds for leprosy work in India through the 'Mission to lepers' for which he was appointed as the secretary.

In 1886, Wellesley set out on a tour of India which highlighted the dire need for the support and success of The Mission to Lepers and he started providing financial support through the funds raised. Services of the mission extended beyond India to Burma, China etc. In view of his vast knowledge and experience of leprosy work, in 1893 he was invited to Chicago to speak at the World Congress of Missions. In 1913 Wellesley toured through China, New Zealand, Australia, the Philippines, Japan, Korea, Malaysia, Singapore and India during which he gave number of addresses, met with many government officials and visited leprosy homes everywhere. It is fair to say that before the birth of the Mission to Lepers, support for leprosy work in India was not very high on the agenda of Church or Christian charities. He had spent the best part of 50 years dedicated to serving those with leprosy. By the time of his retirement in 1917, the Mission to Lepers was working with over 14,000 leprosy-affected people in 12 countries, including India.

Subsequently in 1973, the Mission to Lepers became The Leprosy Mission (TLM). TLM trust-India (TLMTI) at present is the largest leprosy-focused non-governmental organisation in India and has its headquarters in New Delhi, India.

Dr Robert Greenhill Cochrane

Dr Robert Greenhill Cochrane (1899-1985) was a renowned British leprologist who devoted his entire life to the study and control of leprosy. He initiated epidemiological surveys of leprosy, was instrumental in the introduction of sulfones for the definitive treatment of the disease and contributed significantly to the development of rehabilitation programmes for patients affected with leprosy.

Dr Cochrane, born in Pei-Tei-Ho, China, completed his medical qualification from the University of Glasgow in 1924 and obtained a Diploma in Tropical Medicine from the London School of Hygiene and Tropical Medicine. He was then appointed as Medical Secretary to the Mission to Lepers (later The Leprosy Mission) and relocated to India. He spent three months with Dr Ernest Muir at the leprosy research laboratory and clinic at the Calcutta School of Tropical Medicine in Kolkata, after which he had to work in Purulia in Bihar State from 1925 to 1927, and then as Medical Superintendent of the Leprosy Mission Hospital at Bankura in Bengal from 1927 to 1929. He returned to Glasgow and obtained his MD in 1928 and became a Member of the Royal College of Physicians of London.

He travelled to all the leprosy institutions in India and Burma, contributing to a world leprosy survey. On 24 June 1929, he became Medical and General Secretary of BELRA (now LEPRA), and continued in this role until 1935. He attended the Leonard Wood Memorial Conference on Leprosy in Manila in 1931, where the International Leprosy Association (ILA) was established and Cochrane was made the first Secretary-Treasurer of the newly formed ILA.

From 1935 to 1944, Cochrane was chief medical officer at the Lady Willingdon Leprosarium in Chengalpattu, Madras and later became adviser in leprosy to the State of Madras. As the head of the Leprosy Campaign in Madras State, he travelled throughout the state, stimulating systematic diagnosis, survey and control of the disease. He strongly fought against the segregation of leprosy patients and set an example by employing in his own home two ex-patients as cook and gardener. He later worked in the General Hospital, Madras, as Principal, Professor of Medicine and Dermatology, and Director of Rural Medicine at Christian Medical College and Hospital, Vellore. Here, he laid the foundations for making it a centre of excellence. During his stay at Vellore, Dr Cochrane was instrumental in introducing Dr Paul Brand, who did pioneering work in correction of leprosy deformities. In 1945, Cochrane began studies with sulfone derivatives, and was the first to use dapsone in the treatment of leprosy, laying the groundwork for treatments still used today.

In 1951, Cochrane returned to England and resumed the role of Medical Secretary of BELRA. He founded the Leprosy Research Trust (later renamed the Leprosy Study Centre), with support from the Welcome Trust. A collection of 16,000 histopathological slides assembled by the Leprosy Research Trust is now located in the Hospital for Tropical Diseases, London.

Cochrane was President of the ILA from 1965 to 1968 and presided over the Ninth International Leprosy Congress in London in 1968. In 1966, Cochrane returned to India, where he worked in Vadathorasalur, Madras and later moved to Tanzania where he continued his work on leprosy.

He received many honours for his work, including Companion of the Order of St Michael and St George; India's Kaiser-i-Hind medal in gold, first class; and the Damien-Dutton Award in 1964. The Robert Cochrane Fund for Leprosy, administered by the Royal Society of Tropical Medicine and Hygiene, was established to provide bursaries to young leprosy researchers in his honour. The Cochrane Annex at the Slade Hospital, Oxford, is also named after him.

Dr Paul Wilson Brand

Dr Paul Wilson Brand (1914–2003) was a pioneer in developing tendon transfer techniques for use in leprosy patients with deformities. He was one of the first physicians to appreciate that leprosy is not a disease of the tissue but of the nerves.

Dr Brand completed medical school at London University, becoming a Fellow of the Royal College of Surgeons. Together with his wife Dr Margaret, whom he met at medical school, he returned to India in 1946 to teach surgery at the Christian Medical College (CMC) and Hospital in Vellore, where he was motivated to explore the reasons for the development of deformities in Hansen's patients. After careful observation and research, he came to understand that leprosy attacks chiefly the nervous system and that most injuries in Hansen's disease patients were a result of the pain insensitivity they experienced, and not due to inherent tissue decay directly caused by the lepra bacilli. In 1950, with a donation from a missionary woman, Brand established the New Life Centre, Vellore, as a model rehabilitation center for leprosy in CMC campus which helped dispel the stigma that was so prevalent even among medical professionals.

In the late 1940s, he became the one of the first surgeons in the world to use reconstructive surgery to correct the deformities of leprosy in the hands and feet. As a skilled and inventive hand surgeon, he pioneered tendon transfer techniques in leprosy patients, and opened up a whole new world of disability prevention and rehabilitation for those affected by leprosy. Drawing on his experience of treating injured hands of wartime casualties in the UK, and those paralyzed through poliomyelitis, Dr Brand developed procedures for the repair of ligaments to restore mobility to the hands and feet of patients with leprosy. Brand also popularised the technique of serial casting for the flexion contractures of fingers, a technique that is even now widely used to treat contractures from many different hand injuries.

In 1965, after doing more than 3000 operations at the CMC vellore, he became chief of rehabilitation at the National Hansen's Disease Centre in Carville, Louisiana, the only leprosy hospital in the United States and worked as professor of orthopaedic surgery at the Medical College at Louisiana State University. Dr Brand retired in 1984 and moved to Seattle, where he became emeritus clinical professor of orthopaedics at the University of Washington. Over his long career, Dr Brand served on the expert panel for leprosy of WHO and as president of Leprosy Mission International, based in London. He was co-founder of the All-Africa Leprosy and Rehabilitation Training (ALERT) Centre in Ethiopia and was one of the main architects for the Schieffelin Leprosy Research and Training Center (SLRTC) at Karigiri, India.

He was the author of 100 scientific papers and seven books on reconstructive surgery and rehabilitation, including 'Clinical Mechanics of the Hand', a standard reference work for hand surgeons, physical therapists, and other hand specialists. In one of his best known books, Pain: The Gift Nobody Wants (1993), republished in 1997 as The Gift of Pain, his appreciation of the importance and value of pain is well described. Dr Paul Brand is also the subject of Dorothy Clarke Wilson's biography, 'Ten Fingers for God'.

During his career, Dr Brand received many awards and honors. He was awarded the title of the Commander of the Order of the British Empire in 1961. In 1977, he was given the Damian-Dutton Award for outstanding contributions in prevention of disabilities due to leprosy.

Dr Lykle Hogerzeil

Dr Lykle Hogerzeil (1927 – 2011), born in Arnhem, Holland, influenced many people in leprosy through his work in Nigeria, India, and South East Asia. He studied medicine at Leiden University, qualifying in 1954, after which he worked as a missionary doctor in eastern Nigeria from 1955-1963. Later he became medical superintendent of Uzuakoli Leprosy Settlement, which had a research unit attached to its hospital.

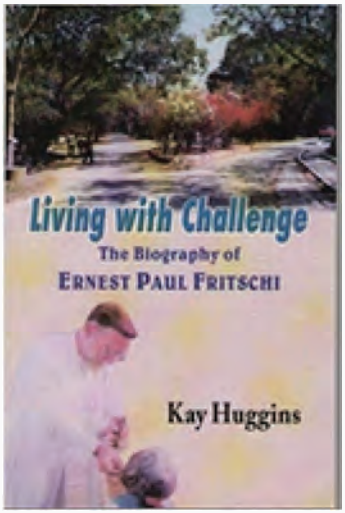
In 1962 Dr Hogerzeil and Dr Stanley Browne, published the first report on the use of Clofazimine as an effective antibacterial for Mycobacterium leprae. This soon became adopted by the World Health Organization as a part of the multi drug regimen for leprosy and has now been used for over 50 years as an anti-leprosy drug.

Dr Hogerzeil returned to the Netherlands and spent four years at the University of Utrecht carrying out research into dermatology and gained a medical doctorate in 1971. Upon being invited by Dr Frank Davey, he worked as a doctor and director for The Leprosy Mission in the Victoria Hospital at Dichpalli, near Hyderabad, India. Here, Dr Hogerzeil and Dr Frank worked on developing effective drug combinations for treating leprosy. In association with Dr Rex Barton, an ENT surgeon, they also worked on studies on the transmission of leprosy, showing that the nasal mucosa was an important exit route for *M. leprae*. Dr Hogerzeil also

took a compassionate interest in the ex-patients living in the leprosy villages and promoted self-care. He also initiated primary health care from Dichpalli as an early model of integrating leprosy and non-leprosy services.

From 1985 to 1990 Dr Hogerzeil served as South East Asia regional director of The Leprosy Mission, which is an international Christian development organization, during which he travelled widely, teaching and training staff in the region. His contribution to leprosy work was recognised in Holland with the award of a Knighthood of the Dutch Royal Household.

Dr Ernest Paul Fritschi



Pual Firtschi (1924–2011) is an internationally acclaimed leprosy reconstructive surgeon. He completed his MBBS from Madras Medical College and was the first resident surgeon at Karigiri. Trained by Dr Brand in reconstructive surgery, Dr. Fritschi worked as Head of the Reconstructive Surgery Unit of the Christian Medical College Hospital, Vellore and as Superintendent of the Leprosy Mission Hospital, Vadathorasalur. He served as Director of the Schieffelin Institute of Health Research and Leprosy Centre, (SLRTC) Karigiri, for two terms, from 1956 to 1959, and from 1974 to 1987. Under his leadership, training courses in different fields of leprosy were systemized and organised into a syllabus, which was later recognised by the government and SLRTC became an internationally acclaimed teaching and training centre.

During his service in the above organisations, he not only provided reconstructive surgical and rehabilitative service to innumerable leprosy patients, but also personally trained hundreds of medical personnel in leprosy not only from India but also from other countries. His book 'Reconstructive surgery in leprosy' published in 1971 was the sole guide and inspiration for nearly two decades to people who aspired to learn and practice this super speciality. It was under Dr Fritschi that the greening of Karigiri and the ecology project was started, MDT was introduced as the cure for leprosy and roots for the Care after Cure Project were planted. He, along with his wife, late Mrs. Manorama Fritschi, were instrumental in setting up 'Shanthigramam', a home for the aged, destitute and deformed leprosy patients near Karigiri.

"Living with challenge" is the biography of Dr Fritschi written by Kay Huggins which is concrete description of his creativity and all-round personality. For his selfless services to people on the fringe of society, Dr Fritschi was awarded the Damien Dutton Award in 2006 one of the highest awards given to persons who have contributed immensely to leprosy work. Even after retirement, Dr. Fritschi was very active and continued to be recognized as one of the leading authorities in reconstruction and rehabilitation in leprosy.

Others

In a country faced with a large leprosy load, many international workers dedicated themselves in serving the cause of leprosy affected in India. Above mentioned is just a small segment of a long list of such wonderfully dedicated people. Henry Vandyke Carter, Sir Leonard Rogers, Ernest Muir, Ridley DS, John Pearson, August Baine, Isaac Santra are examples of some of the eminent workers who came to this country and did significant contributions to leprosy, not only in understanding the pathogenesis but also spreading awareness regarding the disease. It was only through the efforts of many such selfless workers that leprosy has evolved from a disease of isolation to a disease with effective management and drug therapy.

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Doyens of Indian Leprosy

Bhumesh Kumar Katakam, P Narasimha Rao

Dharmendra (1900–1991)

Dharmendra was born in undivided India in the province of Lahore on 1st February 1900. He graduated in medicine from the King Edward Medical College, Lahore, in 1928. He had a distinguished career as a student. He had discontinued his studies for 2 years as a protest against the Jallianwala Baugh massacre and joined the noncooperation movement launched by Mahatma Gandhi.

He joined the School of Tropical Medicine in Calcutta as an Assistant Research Officer of the erstwhile Indian Research Fund Association (now the Indian Council of Medical Research) in 1928. There he found that senior workers engaged in leprosy research were all foreigners. Therefore, leprosy research offered a challenge to him, which he took up against the wishes of his family. The stigma which was attached to leprosy patients was also attached, to some extent, to doctors working in leprosy. He derived help from Dr. Lowe, who was at that time head of the department.

During those early days at the Indian Research Fund Association, a leprosy researcher's work encompassed several disciplines, such as clinical, epidemiological and bio scientific. Dr. Dharmendra's name is associated with all of these disciplines in which research was carried out at this center. He is especially known for the chloroform and ether extraction of *Mycobacterium leprae* from human lepromatous tissue and the use of the bacillary suspension, called Dharmendra antigen/ lepromin, for skin testing. As early as 1941, he had observed that the positive response evoked by Dharmendra lepromin was due to its protein content.

When he was asked to say something about the history of development of Dr. Dharmendra's antigen, here is an excerpt in his own words.

'I was interested in [the] lepromin test to find out the active principle, because protein solution could not be available and I just tried to isolate the bacilli from the tissue by my own method called Chloroform Method. I isolated the bacilli, dried them in vacuum and prepared the vaccine in carbol saline. This vaccine, because of some personal reasons, was

called Dharmendra's antigen. But now it is normally referred to as Dharmendra's lepromin. I was standardising this lepromin by the weight of the dry powder of the leprosy bacilli. But Dr. Utpal Sengupta found that to get constant results it is better to count the number of bacilli rather than standardize the vaccine by the weight of the dry powder of the leprosy bacilli. I have gladly accepted this modification and I am grateful to Dr. Sengupta and his co-workers for this.'

While about to retire in 1955, Dharmendra was asked by the Government of India to head the National Leprosy Control Programme as its first director. There he laid the foundation for one of the most successful health programs of the country.

In 1957, he was assigned the task of organizing the pioneering institute exclusively devoted to leprosy research and teaching in Chengalpattu, Chennai (Madras), India. He collected together a band of young medical men and groomed them into productive scientists. At Chingleput he found Dr. Ramanujam and Dr. Ramu were very friendly and very helpful and they had a great love and respect for one another.

The investigation of the effect of dapsone prophylaxis in preventing leprosy among the contacts of lepromatous patients is a fine example of his planning of a scientific experiment with the population as the laboratory.

In 1967, he retired from the post of Director, Central Leprosy Teaching and Research Institute, but continued to work there as an emeritus scientist of the Indian Council of Medical Research until 1970. He received the prestigious Damien-Dutton Award in 1970.

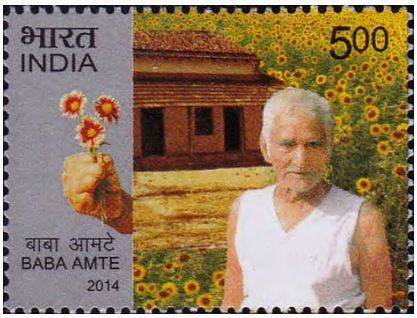
He was a founding member of the Indian Association of Leprologists and was its president for four terms. Dr. Dharmendra had been the Editor of the quarterly scientific journal "Leprosy in India," later renamed "Indian Journal of Leprosy," more or less continuously from 1939 to 1989, with breaks for three short periods totaling 10 years. It was his persuasive efforts that have led to a continuous flow of scientific articles from medical and non-medical Indian scientists. He authored the textbook Notes on Leprosy in 1960, and brought out a revised edition in 1967. Its popularity among leprosy workers led him to edit the monumental work Leprosy, the first volume of which was published in 1978, the second in 1985.

Dr. Dharmendra was revered as an authority on all aspects of leprosy, and his advice was sought by many. Consequently, he was a member of several committees set up by the Government of India, the Indian Council of Medical Research and the Hind Kusht Nivaran Sangh. The Government of India honored him by conferring Padma Shri. He was on the advisory panel of the World Health Organization, and had been a member of some of the expert committees. The International Gandhi Award was presented to him in 1986.

His austere life and outlook gave him a rough exterior behind which was a person full of compassion for the patients and workers alike. Dr. Dharmendra owed the placid course of his long life in no small measure to the loving care of his devoted wife.

He passed away on 10 March 1991, the world of leprosy lost one of its original stalwarts.

Baba Amte (1914–2008)



Murlidhar Devidas Amte, popularly known as Baba Amte, was an Indian social worker and social activist known particularly for his work for the rehabilitation and empowerment of people suffering from leprosy. He was an Indian social activist who has been an inspiration to millions of leprosy workers across India.

Born in 1914, at Hinganghat, Wardha, Maharashtra,Murlidhar grew up in an affluent Hindu Brahman household and became a lawyer. As a young man, he had a taste for good clothes, movies and fast cars; but he also had a social conscience, which caused him misgivings about India's caste-ridden society and the state of poverty and oppression in which so many lived. However, attempts to reach out to his fellow man met with stiff resistance from his father and the high-caste circles in which he moved.

Influenced by the likes of Mahatma Gandhi, with whom he spent some time, and by Vinoba Bhave, Gandhi's spiritual successor, Murlidhar eventually turned his back on the comfortable life and began organizing the downtrodden into unions and fighting for their rights. He even lived and worked among them to experience their plight.

One day, while working as a scavenger, he stumbled upon a man so terribly afflicted with leprosy that what little remained of his body barely suggested he was once human. At first, Murlidhar fled in fear; later, he returned, realizing that the only way to mitigate the fear he felt was to replace it with love. It was a turning point in his life. Aged 34, he decided to devote himself to the care and rehabilitation of leprosy patients.

After spending some time acquainting himself with leprosy and its treatment, he set out with a young wife, two infants, a lame cow, four stray dogs, six people affected by leprosy and a handful of Rupees for 50 acres of scrubland donated by the Maharashtra government. Amte, who was now called 'Baba' (father), named the place ***Anandwan, or Garden of Joy,*** which he described as "an outcast land for outcast people." Together, they turned these barren acres into a successful example of rural development and community living.

Baba's wife, Sadhna Tai, deserves special mention. Raised in an orthodox Hindu tradition by a family of Sanskrit scholars, she relinquished all caste prejudices upon her marriage to Amte, and worked alongside him in even the most difficult circumstances. In 1949, their untiring efforts led to the foundation of Maharogi Sewa Samiti (MSS), an organization for curing and rehabilitating the leprosy affected. It was registered in 1951.

This was also the year that Vinoba Bhave inaugurated Anandwan. Bhave noted: 'Its name 'Anandwan' is most appropriate. This is not a lepers' colony, not a home or settlement for leprosy patients. Here a new epic of service and labor is being written.' More patients began

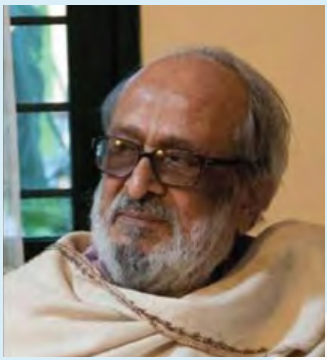
to arrive, medical services were started, and within a couple of years it was self-sufficient in everything.

Today, Anandwan has grown to 450 acres, and is a thriving community of people affected by leprosy as well as others with disabilities. It is a testament to the power of Amte's motto, "Charity Destroys, Work Builds." Baba did not rest with Anandwan. In addition to establishing two more rehabilitation centers for leprosy-affected persons. Ashokwan in 1955, and Somnath in 1967. He also diversified into other areas, beginning projects for tribal peoples and persons with disabilities. He also became actively involved in the protest movement against the construction of big dams in India.

His highness Shri Dalai Lama, wrote in a book that 'in creating Anandwan, Amte provided a practical opportunity for people even with crucial disadvantages to show that they could regain dignity and come to be recognized as productive members of society." In his words, Amte was a man "who has consistently put others before himself; a living example of true compassion in action."

Baba Amte's relentless work for the neediest of his countrymen was acknowledged worldwide in the form of prestigious awards and aides, both national and international. He was awarded the Padma Shree in 1971 and the Padma Vibhushan in 1986. He was a proud recipient of the Jamnalal Bajaj Award in 1979 for his work with leprosy patients and Welfare of the disabled award in 1986 for his endeavors in Anandwan. He won the Ramon Magsaysay Award in 1985 for his humanitarian activism and the Templeton Prize in 1990. Both these international awards brought him worldwide acclaim. He was awarded the Gandhi Peace Prize in 2000 along with cash reward which he directed towards his projects.

H. Srinivasan (1929–2015)



Dr. Hariharan Srinivasan was born on September 7, 1929, Vellore, Tamil Nadu, India. He studied medicine at Madras Medical College, Chennai and later went to the UK and did double FRCS. He worked in the UK in various capacities before returning to India. He was a trained orthopedic surgeon who worked primarily with leprosy patients.

Dr. Srinivasan's contributions to the field of leprosy as leprologist, reconstructive leprosy surgeon, researcher and mentor are of immense value and span several decades. He authored/co-authored numerous studies on nerve damage, surgical procedures and disability. Citations in PubMed of his published articles date back to 1966. He identified and reported "Quiet Nerve Paralysis" and the benefits of steroid therapy for it in his most widely cited paper published in Leprosy in India (previous name for Indian J Lepr) in 1982.

He developed innovative techniques in reconstructive surgery and conducted workshops in medical colleges and other institutes. He used his orthopedic and reconstructive skills for the benefit of poor leprosy patients in India, Brazil and other countries. For decades, he shared his knowledge and experience of leprosy reconstructive surgery with a number of plastic and orthopedic surgeons under World Health Organization-sponsored programs. He furthered the cause of leprosy in India as the director of Central JALMA Institute for Leprosy, Agra, and as the director of Central Leprosy Teaching and Research Institute, Chengalpattu. He was editor of the prestigious Indian Journal of Leprosy from January 1990 to June 2001. After the age of 60, he worked largely doing free reconstructive surgeries, traveling around the world.

Dr. Srinivasan was a recipient of the "Padma Shri," a prestigious civilian award given by the Government of India in 1984 for his "distinguished contribution in the sphere of medicine." He also received Doctor of Science (Honoris Causa) from Medical University of Tamil Nadu (2004), International Gandhi Award (2007) and Pioneer of Hand Surgery (2007) by the International Federation of Societies for Surgery of Hand.

He contributed to the knowledge of leprosy by authoring important books including "Corrective surgical procedures commonly used in leprosy" and the World Health Organization publication, "Prevention of disabilities in patients with leprosy." He contributed chapters on leprosy to various textbooks including the "IADVL Textbook of Dermatology."

Apart from being a leprosy reconstructive surgeon, Dr. Srinivasan was a philosopher and a prolific writer in Tamil, his native language. According to people close to him, he described himself as a pure scientist and a skeptic agnostic. He wrote under five pseudonyms in Tamil one of which was Charvakan. His stories and novelettes are about the vagaries of common life and the philosophy behind living a life in peace with oneself. He was also a contributing editor of a finely compiled 1328-page Tamil-English dictionary.

Srinivasan passed away on December 21, 2015. He died due to complications of end-stage renal disease and chronic obstructive pulmonary disease at Chennai. With his demise, the world of leprosy has lost an authority on leprosy rehabilitation and nerve damage.
Dr. Srinivasan leaves a legacy of surgical reconstruction and rehabilitation techniques to the world of leprosy. May his soul rest in peace.

Mother Teresa (1910–1997)

Mother Teresa was born Agnes Gonxha Bojaxhiu in Skopje, Macedonia, on August 26 1910. Her family was of Albanian descent. At the age of twelve, she strongly felt the call of God and had to be a missionary to spread the love of Christ. At the age of eighteen she left her parental home in Skopje and joined the Sisters of Loreto, an Irish community of nuns with missions in India. After a few months' training in Dublin she was sent to India, where on May 24, 1931, she took her initial vows as a nun.

Work In India: From 1931 to 1948 Mother Teresa taught at St. Mary's High School in Calcutta, but the suffering and poverty she glimpsed outside the convent walls made such a deep

impression on her that in 1948 she received permission from her superiors to leave the convent school and devote herself to working among the poorest of the poor in the slums of Calcutta. Although she had no funds, she depended on Divine Providence, and started an open-air school for slum children. Soon she was joined by voluntary helpers, and financial support was also forthcoming. This made it possible for her to extend the scope of her work.

On October 7, 1950, Mother Teresa started "The Missionaries of Charity", whose primary task was to love and care for those persons nobody was prepared to look after. In 1965 the Society became an International Religious Family by a decree of Pope Paul VI.

The Society of Missionaries has spread all over the world, including the former Soviet Union and Eastern European countries. They provide effective help to the poorest of the poor in a number of countries in Asia, Africa, and Latin America, and they undertake relief work in the wake of natural catastrophes such as floods, epidemics, and famine, and for refugees. The order also has houses in North America, Europe and Australia, where they take care of the shut-ins, alcoholics, homeless, and AIDS sufferers.

The Missionaries of Charity throughout the world are aided and assisted by Co-Workers who became an official International Association on March 29, 1969. By the 1990s there were over one million Co-Workers in more than 40 countries. Along with the Co-Workers, the lay Missionaries of Charity try to follow Mother Teresa's spirit and charisma in their families. Under Mother Teresa's guidance, the Missionaries of Charity built a leper colony, called Shanti Nagar ("Town of Peace"), near Asansol, India.

Mother Teresa's work has been recognized and acclaimed throughout the world and she has received a number of awards and distinctions, including the Pope John XXIII Peace Prize (1971) and the Nehru Prize for her promotion of international peace and understanding (1972). She also received the Balzan Prize (1979) and the Templeton and Magsaysay awards.

However, there are certain controversies surrounding Mother Teresa, her books and her work. It is said that her Missionaries of Charity had done no substantial work – neither in Calcutta nor anywhere else. Having said that, the real significant impact of Mother Teresa was more in terms of changing the way in which society and its charitable organizations work for leprosy, which is highly commendable.

Mother Teresa once said that 'Being unwanted is the worst disease any human being can ever experience'. By moving into the colonies and treating lepers, what she did was a simple act which revolutionized the way in which society perceived leprosy. She and her nuns showed the world that all people, whether they were diseased, old or poor, were their own people. During the last two decades of her life, Mother Teresa suffered various health problems, but

nothing could dissuade her from fulfilling her mission of serving the poor and needy. She died on September 5, 1997. In 2016, Mother Teresa was canonized by the Roman Catholic Church as Saint Teresa.

S K Noordeen (1933–2021)

Dr. Shaik Khader Noordeen was a visionary who worked vigorously to translate the concept of global leprosy control into a successful programme in all the countries endemic for leprosy. Noordeen was born in Keeranur, Tamilnadu, India and had his early medical education in Chennai, followed by postgraduate education in public health in Calcutta, India and Michigan, USA.

Based on his strong interest in leprosy, he joined the Central Leprosy Teaching & Research Institute (CLTRI), Chingleputtu, India, in the year 1958 and served there for more than two decades where he initiated research in epidemiology, clinical leprosy, prevention, and rehabilitation. He was closely associated with Dr. H. Srinivasan, Dr. M. Christian, Dr. P. Neelan and Dr. D. G. S. Iyer, among others during this period. The South India BCG leprosy prevention trial, Multi-arm Leprosy Vaccine Trial and WHO chemotherapy studies done in India and other leprosy endemic countries had his imprint.

Based on his contribution in India, the WHO invited him in 1979 to join its Leprosy Programme in Geneva where he served as Medical Officer, Chief Medical Officer and later as Director of the Global Programme for the Elimination of Leprosy. In 1991, Dr Noordeen had played a crucial role in the adoption of World Health Assembly Resolution 44.9 which reaffirmed WHO's commitment "to attain the global elimination of leprosy as a public health problem by the year 2000'. He took a key role in developing the concept of Leprosy Elimination. Dr Noordeen, became the director of the WHO's Action Programme for the Elimination of Leprosy from 1994 to 1998 – during the crucial years that saw the global roll-out and implementation of multidrug therapy (MDT).

During later years, Noordeen provided leadership to the leprosy world as the President of Indian Association of Leprologists (IAL) form 2000–2002 and of the International Leprosy Association (ILA) from 2002–2008. He also served as editor of the prestigious Indian Journal of Leprosy from 2000 to 2010. He was a Founding Trustee and Chair of the Sasakawa-India Leprosy Foundation and a Member of the Technical Resource Group of India's National Leprosy Eradication Programme.

He received several international and national awards and recognitions, the most important were, the International Gandhi Award and Padma Sri. Dr Noordeen was passionate about leprosy and contributed to transform a disease of neglected people into a solvable public health problem. Through his work he has left an indelible mark in the field of Indian and global leprosy.

V R Khanolkar (1895–1978)

Vasant Ramji Khanolkar, M.D., D.Sc., (1895-1978) better known as V. R. Khanolkar, was an Indian pathologist. He studied medicine at the University of London and obtained his M.D. in Pathology in 1923. He was a Professor of Pathology in Grants Medical and Seth G. S. Medical Colleges. In leprosy his contributions relate chiefly to an understanding of the pathogenesis of nerve involvement and to the elucidation of the characteristics of dimorphous leprosy. He is famously cited for the colourful quote on M. leprae 'swimming like fish up a stream' to travel proximally within the nerve. He was director of the Indian Cancer Research Institute in Bombay from 1952 to 1963 served as director of laboratories and research and Vice-Chancellor of the University of Bombay. He was also the founder president of the Indian Association of Pathologists. He published three books on cancer and leprosy and more than 100 scientific papers. He received Padma Bhushan in 1955 from the Government of India. Dr. V. R. Khanolkar Oration was established in 1987 by the National Academy of Medical Sciences, India, in his memory.

Dr. Dinkar D. Palande (1929–2020)

Dinkar Dattaraya Palande, pioneering leprologist in the field of reconstructive surgery, rehabilitation and disability prevention. His repertoire of expertise ranged from chief surgeon for years at Sacred Heart Leprosy Hospital, Kumbakonam in Tamil Nadu, to teaching and inspiring young surgeons internationally, setting up rehabilitation centres in tribal areas of Odisha state, while serving as Surgical Consultant to Lepra - India.

Remembered as a compassionate, perspicacious, and visionary physician and humanitarian, Dr. Palande's expertise embodied a remarkable long service in the field of leprosy: he contributed both generously in the sphere of reconstructive surgery and in non-surgical, preventive strategies. In his editorial in Leprosy Review (1994) 'Nerve Involvement in Leprosy. Prevention and Management of Deformities: Need for a Paradigm Shift' he stated that 'without first achieving the change of perspective, of approach, any number of pamphlets, articles, and books published and distributed is not going to have much practical impact.' What was remarkable was that in that 4-page editorial written by a maestro surgeon, does not once reference the word 'surgery' nor 'surgeon' while he cogently argues his point! He had a number of publications and books on RCS ,and many of them with Dr H Srinivasan.

Dinkar wa a teacher and mentor to many, but he didn't want him to be called sir or dada. He cheerfully encouraged cultivation of critical reasoning during individual and group conversations. He also composed poetry, a book of which was published on his 88th birthday.

PK Gopal (1941–2021)

Born in Tamil Nadu, India, Dr. Gopal was diagnosed with leprosy at the age of 12. After being cured, he devoted his life to helping others affected by the disease. In 2005, he founded

the National Forum, the first organization in India formed by and for persons affected by leprosy. The National Forum is known today as Association of persons affected by Leprosy (APAL). He is also credited with a 2006-07 survey, under the aegis of IDEA India, to identify and document the leprosy homes in India, a survey which brought to light 850 leprosy colonies in the country.

He was a very kind-hearted person who always worked for the good of everyone. He was an ardent social worker who became known both nationally and internationally as a great social activist. He received the Padma Shri award, one of the highest civilian awards in India, in recognition for his distinguished contributions to social service. He received many other awards as well. Gopal passed away on March 18, 2021.

R Ganapathi (1930–2011)

R Ganapathi was born in 1930 in Tirunelveli town of the former Madras Presidency in a middle class family. He began his leprosy career at Acworth Leprosy Hospital, Wadala, Mumbai, on October 1, 1963, as Assistant Medical Officer.. Opportunity for intensive field work was possible by the establishment of "RRE Society" along with courageous colleagues like Mr. S. S. Naik and Dr. V. V. Dongre. In order to widen his work, he founded the Bombay Leprosy Project (BLP) in September 1976. He demonstrated effectively the importance of field work in leprosy control especially in in the urban situation.

The Government of India bestowed upon him the coveted title of "Padma Shree" in 1983. He published more than 100 research papers on different aspects of leprosy. Dr Ganapathi was concerned about the 'care after cure' of leprosy patients with deformities & disabilities and promoted Community-Based Rehabilitation (CBR). He breathed his last on November 13, 2011, while undertaking anti-leprosy work till the very end.

G Ramu (1924–2003)

Dr Gopal Ramu (1924-2003) was a noted Indian leprologist. He played a key role in building up research at CLTRI (Central Leprosy Teaching and Research Insititute) from 1962-76 and the Central JALMA Institute for Leprosy Research (CJIL) from 1976-86. He has been the Resource person in several WHO Workshops conducted in various parts of India. He was keenly interested in the reactional states of leprosy and authored more than 250 scientific publications.

R E Thangaraj (1930–1991)

A surgeon, trained in orthopaedics and plastic surgery, his main contributions to the field of leprosy have been in surgical rehabilitation and control. As Director of the Leprosy Mission in Southern Asia, started many control programmes in India, Bhutan, Bangladesh, Burma and Nepal. The high point in his career was the organizing of the International Leprosy Congress in 1984 along with Dr. Dharmendra. He authored and co-authored number of books on leprosy.

Dr. Virendra Nath Sehgal (1936–2020)

Prof VN Sehgal was a teacher and administrator who established medical specialties in various medical colleges across India and who worked tirelessly for medical education for over 5 decades. He authored a book on 'Clinical Leprosy and contributed immensely for the understanding of Histoid leprosy. Prof. Sehgal was a thinker, philosopher and guide to many students of Dermatology and leprosy. He was honoured with the Dr B.C. Roy National Award.

This list is only representative of the large number of Indian researchers & workers who did yeomen service to leprosy across India. We fold our hands in supplication to all those un-named legends and silent workers.

"In spite of tremendous advances made in the academic sphere, leprosy is still in isolation. The protagonists of the cause of leprosy eradication themselves seem to fall a prey unwittingly to this phenomenon"

-R Ganapathi

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Padma awardees for work in leprosy

Keshar Kunja Mohanty

Introduction

Service to mankind is service to God. In the journey of life millions believe this and pursue their endeavour. Padma Awards, the coveted series of three civilian awards by Government of India bestowed on the persons who dedicated their life for the society and upliftment of the under-privileged as a token of recognition of excellence. Among these noble souls Padma awardees are twinkling stars in the sky of the human race who cared and impacted the life of the persons affected with leprosy.

They are the harbour of knowledge having the depth of sea for mitigating the evil forever; they are Researchers, Doctors, Social workers and Policy makers to eradicate the pangs from the populations afflicted with leprosy.

Padma Awardees for their work in the field of Leprosy and Chronology

Padma Vibhushan Awardees:

- Murlidhar Devidas Amte (1914-2008) popularly known as Baba Amte who was named as Abhay Sadhak by Mahatma Gandhi, filled him with fear when encountered with a living corpse and leprosy patient Tulshiram. Later, he had a strong view that leprosy patients can be truly helped only when a society is free of "Mental Leprosy"-fear. To wipe out the wrong understanding that leprosy is not highly contagious he got injected with bacilli from a leper. He was awarded with Padma Shri (1971) to overcome the taboo and fear of leprosy and Padma Vibhushan in 1986 'for exceptional and distinguished service', the highest among three Padma awards series.

Padma Bhushan Awardees:

- **Dr Vasant Ramji Khanolkar (Padma Bhushan, 1955)**- He is often referred to as the "Father of Pathology and Medical Research" in India. In addition to cancer, he contributed in the understanding of leprosy diagnosis and published three books and more than 100 scientific papers.
- **Dr Jal Minocher Mehta (Padma Bhushan, 1982)**- A surgeon, social worker and philanthropist, made effort toward the leprosy eradication programme through rehabilitation, organizing self-help of the leprosy patients and creating social awareness about the disease through documentaries.

- **Dr Gursaran Pran Talwar (Padma Bhushan, 1992)**- A national and internationally famous medical researcher, his notable research contribution have led to an understanding of the nurture of immune deficit in leprosy patient and to the development of an immune-prophylactic cum immune-therapeutic vaccine against leprosy, Mycobacterium indicus pranii (MIP) which is approved by the Drugs Controller General of India (DCGI) and US FDA.
- **Dr Jacob Cherian (Padma Bhushan, 1999)**-Popularly known as Ayya, was a surgeon, educationist and social worker, the founder of Christian Fellowship Community Health Centre Society, an NGO. He took initiative to establish a 25 bedded hospital in Ambilikkai in 1966 for TB and Leprosy patients, which was later transformed to a 175 bedded multidisciplinary NABH accredited facility, the first such recognised facility on leprosy started by an Indian. Apart from this he established a leprosy rehabilitation school to transform the lives of leprosy patients from social outcasts to socio-economically productive people.

Padma Shri awardees:

- **Dr Isaac Santra (Padma Shri, 1956)**: A Physician, known for Leprosy eradication efforts.
- **Shri Thakkadu Natesasastrigal Jagadisan (Padma Shri, 1957)**: He was the secretary, Hind Kusht Nivaran Sangh, was also Honorary Publicity Secretary to the British Empire Leprosy Belief Association, Madras. He believed that leprosy is not so much a public health problem is a social problem.
- **Dr Shivajirao Patwardhan (PadmaShri 1959)**: He did remarkable work for treatment, and rehabilitation of leprosy patients in tapovan at Amaravati.
- **Mother Mary Teresa Bojaxhiun (Padma Shri, 1962)**: She founded the Missionaries of Charity, a Roman Catholic religious congregation. The congregation later extended its work to manage homes for people who are dying of HIV/AIDS, leprosy and tuberculosis. She opened a hospice for those with leprosy, calling it Shanti Nagar (City of Peace). **Mother Teresa** was awarded India's highest civilian award, the **Bharat Ratna** on January 25, 1980, for her humanitarian work.
- **Dr Dharmendra (Padma Shri, 1966)** had a long career in leprosy research including early development of refined lepromin and chemical analysis of M. leprae contributing understanding of many aspects of leprosy.
- **Dr Natteri Veeraraghavan (Padma Shri, 1967)**: A physician, microbiologist and medical researcher, known for his contributions to the understanding of diseases like rabies, and tuberculosis and leprosy.
- **Dr Dorothy Woodworth Dunning Chacko (Padma Shri, 1972)**: A Physician, instrumental in establishing the lepers' colony, Bethany Baptists Village Leper Colony, at Ganaur, in Sonepat district in Haryana.
- **Dr Ramchandra Vishwanath Wardekar (Padma Shri, 1973):** The founder of Gandhi Memorial Leprosy Foundation and considered "the father of leprosy control" in India.

- **Dr Claire Marie Jeanne Vellut (Padma Shri, 1981)**: A Belgian born naturalized Indian leprologist, the founder of the Damien Foundation India Trust, conceptualized and established, the Clinic Under the Trees, the Mobile Clinical Services.
- **Dr R Ganapati-(Padma Shri, 1983):** He established a research oriented field project called [the] Bombay Leprosy Project (BLP) in 1976. He helped to reduce the management cost of the leprosy control programmes.
- **Dr Hariharan Srinivasan (Padma Shri, 1984)** spent most of his working life in correcting the deformed hands and feet of leprosy-affected persons. His research work in the management and prevention of deformities and disabilities in persons with insensitive and paralysed hands and feet in general and the leprosy-affected in particular.
- **Dr B.R. Chatterjee (Padma Shri, 1985)** joined the Gandhi Memorial Leprosy Foundation (GMLF) and through the GMLF, he organised the widespread administration of multi-drug combinations on a large scale in 1979-80.
- **Dr Noshir Hormasji Antia (Padma Shri, 1990)**: A plastic surgeon and social worker, known for his pioneering contributions to the treatment and rehabilitation of people afflicted with leprosy.
- **Dr Govind Narain Malviya (Padma Shri, 1991)** is known for his efforts in the treatment and rehabilitation of Leprosy patients.
- **Dr Indira Nath (Padma Shri, 1999)**: Her major contribution in medical science includes the understanding of mechanisms underlying reactions and nerve damage in leprosy and a search for markers for the viability of the Leprosy bacillus. She believed that it is the nerve damage and the deformities you see on the body frightens patients.
- **Dr Prakash Amte (Padma Shri, 2002)** following the footsteps of his father Sri Murlidhar Devidas Amte, he contributed immensely to overcome the taboo and fear of leprosy.
- **Mrs Gladys Staines (Padma Shri, 2005)**: She transformed the leper house she served at into a full hospital in her award money.
- **Dr Shaik Khader Noordeen (Padma Shri, 2009)**: He was passionate about leprosy and contributed to transform a disease of neglected people into a solvable public health problem. He strongly supported global efforts to reduce stigma and social exclusion associated with leprosy by disseminating information on the effectiveness of treatment, and by making it available for free to all those in need through large-scale donations made to WHO.
- **Mr P. K. Gopal (Padma Shri, 2012)** is an Indian social worker and a co-founder of International Association for Integration, Dignity and Economic Advancement (IDEA), an international advocacy group, known for his services towards eradication of leprosy, especially in India. He is reported to have established a rehabilitation centre, known to be the first of its kind in India, for the leprosy-affected people of the region. Gopal has been associated with Yohei Sasakawa, the Chairman of Nippon Foundation, and together they are reported to have succeeded in passing a resolution at the United Nations Human Rights Council in 2003 towards ending discrimination against leprosy-

affected people. The United Nations General Assembly adopted the resolution on 21 March 2011. He is also credited with a 2006-07 survey, under the aegis of IDEA India, to identify and document the leprosy homes in India, a survey which brought to light 850 leprosy colonies in the country.

- **Dr Kiritkumar Mansukhlal Acharya (Padma Shri, 2014)**: A dermatologist, known for his services for the eradication of leprosy. He runs the Mahatma Gandhi Leprosy Society.
- **Shri Damodardas Ganesh Bapat (Padma Shri, 2018):** Contributed immensely for eradication of leprosy, rehabilitation, education and improvement in health of leprosy patients and making them self-reliant served as secretary at Bhartiya Kushta Nivarak Sangh (BKNS).
- **Smt Shanti Devi (Padma Shri, 2021)**: A follower of Vinoba Bhave, a social worker, set up an ashram for leprosy patients in Jabarguda in the Rayagad district of Odisha.
- **Dr Dillip Kumar Singh (Padma Shri, 2021):** Relocated, treated & rehabilitated 382 lepers and involved as a member of National Leprosy Organization.
- **Mr Prem Singh (Padma Shri,1922)**: A social worker, his involvement in community based rehabilitation of leprosy affected persons, revival of human rights and elimination of leprosy from the country is noteworthy.
- **Swami Sivananda (Padma Shri, 2022)**- He served leprosy affected beggars in Puri .
- **Dr Vijay Kumar Vinayak Dongre (Padma Shri, 2022)** Implementation of survey, Education and treatment along with Rehabilitation, repealing outdated acts violating the human rights of leprosy patients .

Acknowledgements

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Post script: Concerted efforts were made to include all the names of Padma Awardee worked for leprosy, however, if names of some awardee has been left, it is unintentional. The recognition and awards received by the above listed needs to be appreciated, as they represent the efforts of several workers and researchers who toiled silently for the cause of Indian leprosy.

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International Gandhi Award

Rakesh Kumar Bahunutula

Gandhi Memorial Leprosy Foundation (GMLF), a pioneering organization established in 1951 in the field of leprosy in India, has instituted the award titled "International Gandhi Award" in 1986 to commemorate Mahatma Gandhi's service and scientific approach towards leprosy. The award is presented to individuals/institutions making outstanding contributions in leprosy resulting in the amelioration of the suffering of leprosy patients and enabling them to lead normal lives.

The award is presented once in two years and consists of Rs 2 lakhs cash, a medallion and citation. Two awards are presented either to individuals or institutions fulfilling the eligibility criteria for the award.

Eligibility:

The award is given to a leprosy worker/leprosy institution having worked for a period of not less than ten years and having made significant contributions to improve the quality of life of leprosy affected persons and helping them to lead normal and useful life in the society.

The award is open to medical, paramedical or non-medical and social workers in the leprosy field. The candidate has to be nominated by a person of prominence in the field of leprosy. Posthumous nominations are not accepted.

In-service staff and committee members of GMLF as well as those who retired within a period of 5 years prior to the year of the award are not eligible for nomination for this award.

SELECTION PROCEDURE: The nominations received by GMLF are referred to members of an International Panel of Experts nominated by the GMLF Committee. The members of the panel will not nominate any individual/institution/or any member of the panel, for this award. The Award Committee, under the Chairmanship of the Hon'ble Vice-President of India, meets to consider and finalise the names of two awardees.

REQUIREMENTS: The nominating agency/person must provide complete bio-data of the nominee with detailed description of anti-leprosy work done by the nominated person or institution. The significant contribution to leprosy work should be supported with documentary evidence/publications. It should include confirmation from the nominee that she/he or the institution is willing to accept the award if selected.

Recent Recipients Of The Award: Sahyog Kushtha Yagna Trust and Dr Bhushan Kumar for the year 2021, Leprosy Mission Trust and Dr N S Dharmashaktu for 2019, Dr M D Gupte and Dr Atul Shah for 2017, Dr R K Mutatkar and Dr Arturo Cunanan Jr for 2015, Dr Vijaykumar Vinayak Dongre and Prof Guocheng Zhang for 2013, Dr Claire Velut & Dr J D Samant for 2011 are the recipients of this prestigious award in the last decade.

SECTION 7

LEPROSY IN INDIA AND FUTURE PROSPECTS

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Rehabilitation of people affected by leprosy and the way forward

Mannam Ebenezer

Leprosy is a disease that primarily affects the peripheral nerves and skin. As a result of nerve damage, individuals affected with the disease develop impairments (disabilities & deformities) of hands, feet and eyes. Being affected by disease poses many challenges for the person affected. Physical disabilities render them unable to carry out their daily work and earn a living making them dependent upon another. Psychological problems like lack of self-esteem, self-confidence and depression coupled with stigma associated with the disease further lead a patient into a downward spiral called 'de-habilitation'.

'Rehabilitation' is a word that stems from the Latin word 're' meaning again and 'habitare' that means "make fit". Rehabilitation of a person affected by leprosy aims at reversal of physical, psychological, social and economic disadvantages. The main goal of rehabilitation is to enable "holistic restoration" of a person affected by leprosy to live with dignity through healing, inclusion and independence.

The role of the health team in rehabilitation is to involve not only the affected persons but also their families in making decisions that progress to restoration. The affected person's background, impairments, religious beliefs, social support and psychological status must be taken into account before prioritizing the needed interventions.

The overall rehabilitation of a person affected by leprosy can be divided into four major areas

1. Physical rehabilitation: This aims at helping a person either to reverse physical impairments or through surgical correction, aids and appliances to enable him/her to return to some form of vocation to be able to support himself/herself
2. Psychological rehabilitation: Through counseling this helps patient and their support system to cope with the psychological challenges of disability and stigma
3. Social rehabilitation: Education of family and community about disease and need for inclusion of affected individual is paramount in diminishing social stigma associated with leprosy
4. Vocational rehabilitation: Support and training of affected individuals in their present or new jobs are essential to support them to gain economic independence.

Physical Rehabilitation

As mentioned above, impairments of hands, feet and eyes occur as a result of damage to peripheral nerves in leprosy. The most common groups of nerves involved are the major peripheral nerve trunks in upper and lower limbs as well as two cranial nerves. Involvement of peripheral nerves results in loss of their sensory, motor and autonomic functions.

Motor function of hand

The nerves affected in the upper limb are Ulnar and Median nerves. The Ulnar nerve innervates muscles of the hand involved in grasping of objects. The median nerve innervates muscles of thumb involved in holding objects in a pinch grip. Damage to these nerves leads to loss of two basic functions of the hand – 'Grasp' and 'Pinch' required for holding objects. Fine movements of hand are also affected. In addition to loss of function, nerve damage results in impairments of "Claw Hand" and "Ape Thumb"

Motor function of foot

Lateral popliteal nerve and the posterior tibial are two major nerves of lower limb that are damaged in leprosy. The lateral popliteal nerve functions to keep the foot in extension during swing phase of gait thereby allowing one to clear the ground while walking. Damage to this nerve results in 'foot drop' leading to gait abnormality known as "high stepping gait". The posterior tibial nerve damage results in claw toes that lead to inability to grip footwear while walking.

Motor function of eyes

Muscle supplied by facial nerve enables closure of the eye lids in blink reflex. Trigeminal nerve supplies sensation to cornea and protects it from external stimuli. Damage to these nerves leads to inability to close the eye (Lagophthalmos) and drying up of cornea with subsequent loss of vision.

Sensory loss

Loss of sensory function of ulnar and median nerves results in loss of sensation over the palm. Loss of sensory function of posterior tibial nerve results in loss of sensation over the sole of foot. These may result in injury and damage to palmar or plantar skin due to external stimuli. Such damage can lead to ulceration, infection and damage to the foot even leading to amputation sometimes.

Aims of Physical Rehabilitation

Physical Rehabilitation of a person affected with leprosy is largely dependent on the stage of disease that person presents.

Prevention of disability

To prevent disability in leprosy, early detection, prompt, complete treatment with Multi Drug Therapy (MDT) and regular follow up are the key. This would depend upon good awareness about leprosy among community for early reporting and health education of person affected for regular complete treatment. Along with this, it is imperative to educate affected person as well as family about signs and symptoms of nerve function damage so that early reporting will enable to prompt management and prevention of disability.

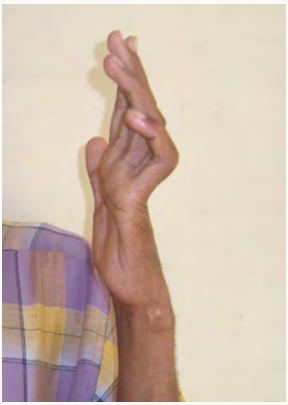
Reversal of nerve damage

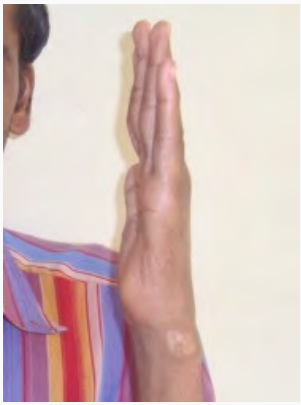
In persons who present with clinical features of nerve damage, treatment can reverse nerve function damage and prevent further damage. Corticosteroids are the mainstay in the treatment of neuritis. Corticosteroids reduce inflammation and oedema of the nerve. Rest to the nerve, passive exercises of hand and foot to keep the joints supple and electrical stimulation of paralyzed muscles, support treatment.

Leading Institutes of India involved with leprosy rehabilitation:

Prominent leprosy institutions like CLTRI, Chengalpattu, SIH-R & LC, Karigiri and Dr Hemerijckx Government Leprosy Centre, Polambakam established leprosy control programs in early 1950s and 1960s. These centres implemented Survey, Education and Treatment (SET) of National Leprosy Control Program of India (NLEP) , which has largely helped build awareness among public, improved voluntary reporting for diagnosis and completion of treatment that brought down the numbers of patients with nerve damage and deformity.

These healthcare facilities developed, tried and tested treatment modalities for neuritis. Leprologists (Dr Ramanujam, Dr Arunthathi and others) worked along with histological support from pathologists (Dr Job, Dr Iyer and Dr Desikan) in establishing neuritis treatment protocols which are followed even now.





Work on Correction of impairments through reconstructive surgery:

Reconstructive surgery improves motor function by rebalancing available muscle power through tendon transfers. Reconstructive surgery corrects impairments and thereby improves cosmesis. It also prevents further damage to the impaired part.

Dr Paul Brand was the pioneer in conceptualizing, developing, implementing and establishing principles of correction of impairments in leprosy through tendon transfers in paralytic hands, feet and eyes. He worked at SLR&TC, Karigiri, CMC Hospital, Vellore and CLRTI ,Chengalpattu to perfect these techniques. Dr Fritschi (Karigiri), Dr Selvapandian

(Vellore), Dr H Srinivasan (Chengalpattu), Dr Palande (Kumbakonam) and Dr Antia (Bombay) then popularized these reconstructive surgical techniques which benefited thousands of persons giving them hope.

The common reconstructive surgeries include, claw hand correction, restoration of opposition of thumb, foot drop correction, wrist drop correction and correction of lagophthalmos (lid lag) .

Centers for innovation in Physiotherapy, appliances and footwear:

It is important to protect impairments from damage and deterioration while enabling useful function.

Creating awareness among affected persons about risk of further damage to impairments through health education and impressing upon them the need for self-care are critical. Imparting skills to maintain integrity of skin, soft tissues and skeletal structure of impairments through self-care, exercises and usage of splints is the key.

At SLR&TC, Karigiri and CMC, Vellore, Mr. Kolumban, Physiotherapist and others developed physiotherapy techniques to protect and enable functioning of hand and foot through exercises, static and functional splints. Dr. Premkumar, Occupational therapist from Karigiri was instrumental in developing indigenous protective devices, functional splints, training for safety, occupational assessments and vocational modifications for safe, improved function.

Dr Brand articulated and established principles of protective footwear for insensitive feet. He fashioned footwear for intact and deformed insensitive feet. He used the principle of redistribution of pressure from high pressure areas of paralyzed foot through padding, moulding and rigidity in designing the footwear. The four essential features of these footwear are soft insole, hard undersole, heel back strap and with no nails in the footwear. He in collaboration with the Madras Rubber Factory(MRF) produced Micro-Cellular Rubber (MCR) insoles for insensitive feet in 1962. MCR insole footwear are very effective in preventing plantar ulcers and are in use not only among patients affected by leprosy but in patients with insensitive feet due to other causes like diabetes mellitus as well.

Life style Modifications

Life-Style Modifications necessary to prevent injury and/or worsening of impairments are walking slow with short steps and for short distances and avoiding sharps/hot objects to prevent damage both at home and at work.

Psychological Rehabilitation

Leprosy as a disease not only damages the body, but affects the mind also leading to psychological problems. Irrespective of which walk of life the person affected belongs to, no one is immune to these problems. From the moment a patient is told that he/she has the disease, it begins a flurry of emotions like anger, denial and fear. Fears are centered around transmitting disease to loved ones, fear of deformity and inability to earn a living and fear of exclusion due it stigma associated with the disease. The rehabilitation of psychological problems should be done with sensitivity towards persons affected and their families. Psychological problems if unresolved can lead to mental illness later.

Psychological rehabilitation starts with counselling from the time a patient is diagnosed with leprosy. It involves counselling of the family as well. Psychological support will be required in following situations

- At diagnosis all persons need psychological support to deal with negative emotions
- Persons with unresolved negative emotions who find it difficult to accept a diagnosis of leprosy will need continued counselling
- Stressful events that may occur during treatment period or later because of consequences of leprosy will need psychological support to cope during those events.
- Persons who progress to mental illness with stress of leprosy or its consequences will in addition need medication

Patient counselling

Persons affected are first encouraged to express their fears and concerns freely. Based on this, counselling is planned addressing each aspect. Persons must be counselled in a positive, truthful and gentle manner about realities of the disease. They must be reassured that they will receive needed support. Follow up counselling sessions may be required to improve self-esteem and self-confidence both of which go a long way in protecting against stigma of the community.

Family counselling

Counselling of family is paramount to psychologically support the affected person. The three key issues that require a discussion with family include, less infective nature of disease, need for regular treatment both medications or self-care and need for acceptance and inclusion into the family.

Social Rehabilitation

The word stigma is most commonly used with leprosy which is a big misconception. Stigma stems from ancient India where most diseases of skin were considered 'leprosy'. Laws were brought about that prohibited contact with such individuals and punishment was given to

those who married into their families. In the present day, with development of medicines to cure leprosy, reconstructive surgeries to correct impairments and rehabilitation, quality of life among persons affected has improved significantly and stigma has reduced to some extent. However, stigma still persists in some life domains and to varying degrees in different countries. The major determinants of stigma on part of the person affected are transmission concerns, fear of deformity and exclusion. Important determinants on the part of family and community are – lack of knowledge, attitudes generating from historical beliefs and myths and fear of infection. Economic independence and sufficiency diminish stigma significantly.

There are various tools available to measure stigma: Participation scale that measures experienced stigma, Jacoby stigma scale: Anticipated stigma and Explanatory Model Interview Catalogue (EMIC)

The following interventions will help to reduce leprosy stigma

Health Education and Counselling

Health education plays a vital role in diminishing leprosy stigma. The two main objectives of health education are to give factual knowledge about leprosy and to put to rest the myths and mis-beliefs associated with the disease and clarify such doubts. NLEP in its recent guidelines suggests Information, Education and Communication (IEC) and social marketing to enhance leprosy awareness and reduce blame among community. It recommends one to one counselling. It supports advocacy, lobbying and legislature to improve acceptance and inclusion of affected persons into the main stream.

Empowerment

The process of empowerment improves identity of a person, enhances value of life, promotes independence and potential for productive future. Empowerment can be done through imparting skills in self-care, vocation, economics and social standing.

Social skills

Through social skills training self-esteem, self-confidence and social interaction skills of person affected can be improved. These skills will enable the person to deal with situations at job, in the family and community.

Vocational Rehabilitation

Leprosy disabilities and stigma may cause unemployment. Vocational rehabilitation aims to ensure continuation of present job with modifications or help create opportunities for new jobs for persons affected. Vocational assessment is essential to see which kind of work affected person is most suited to perform based on a careful anatomical, functional and occupational examination. The person's previous job must also be taken into consideration. This enables person to be comfortable in their vocation promoting confidence and self-image. It is also important to choose vocations that are safe for these persons.

Institutions like CMCH Vellore, SIH-R & LC, Karigiri, WORTH Industries,Vellore and Sivananda Rehabilitation Home, Hyderabad, took initiative in early years providing vocational support

to leprosy affected. Training and opportunities for weaving, candle, mat making etc.. were enabled at home (Domiciliary rehabilitation) and at institutions (Institutional rehabilitation). WORTH industries trained and employed affected persons to manufacture machine parts and make certain equipment (Industrial Rehabilitation). In the latter years, Community-based rehabilitation was introduced which included Health, Education, Livelihoods, Social and Empowerment aspects.

Vocational training centres of Government and Leprosy Mission played an important role in training scores of affected persons over the last 50 years, providing Vocational rehabilitation. NLEP through Ministry of Social Justice and Empowerment, Govt of India, has also enabled access to six National Disability Institutes and District Rehabilitation centres for medical services, aids/appliances and employment.

Way forward

India has been at the forefront of progress achieved in care of leprosy. Government of India and many institutions that have been doing work exclusively for leprosy with many dedicated health workers over the past 75 years must be greatly appreciated. However, there is a lot more that needs to be done in rehabilitation. Following are few of them.

Empowering person affected family & Community

Person affected and family has to be empowered to take responsibility for acceptance, inclusion and home based disability care. Awareness should be improved about leprosy in the community and community empowered to take responsibility for early case detection, for stigma reduction and economic upliftment of person affected through community based approaches.

Tools to detect early nerve function impairment

Presently nerve function impairment can be detected clinically only after nearly 30% of the nerve is damaged. Tools are urgently required to detect nerve function deficit much earlier.

Optimize Nerve Function recovery

Present nerve function recovery rates with steroids of 60% must be improved through alternative drug regimen. Surgical nerve reconstruction can be revisited. Bypassing damaged part of nerve electrically through implanted bio circuits and stem cells for nerve regeneration can be considered.

Reconstructive surgeries

Reducing post-operative physiotherapy period to improve acceptance rates for RCS admissions and alternative surgical reconstruction methods for correction of impairments should be explored. Uniform objective criteria to assess surgical outcomes must be used in all RCS centers.

Better offloading measures for healing plantar ulcers:

Alternatives to offloading POP casts for healing plantar ulcers are urgently needed. Light weight, indigenous offloading shoes, with insole modifications for plantar ulcer healing can be tried. Cost effective, aesthetic, effective, affordable and acceptable footwear must be developed.

Enabling Government Health Institutions further:

Government Health institutions at Block, District and Tertiary levels are involved in managing complications of leprosy (reactions and ulcers), providing footwear, aids and appliances, carrying out RCS and training in vocations and placement. It is critical that all government health facilities should be enabled in a similar manner to cater to large number of persons affected requiring such care.

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Progress made in the Surgical Techniques of Re-Constructive Surgery (RCS) in India

Atul Shah

Introduction

My teacher Dr Antia summed it as "it has been observed that as the layperson considers deformity synonymous with leprosy, he will also readily reaccept the patient once the deformity is corrected. No certificate of bacteriological negativity will achieve the same result. It is hence true that for total social and economic rehabilitation of a leprosy patient, surgery is essential to correct residual deformities."

Evolution

Dr. Brand in 1946 at CMC Vellore found that damage to hands and feet was caused by injuries as patients could not feel pain sensation. This was a completely new finding that would change the lives of many people. His further work on deformities of hands showed that the chief disability is the loss of the grasp due to intrinsic paralysis and the loss of pinch owing to the loss of abduction and opposition of the thumb. He started with Stiles Bunnell's' operation of using FDS as motor but later observing undue pull-on extensor expansion described ECRB and ECRL transfer. All were extended with tendon graft. About opponens-plasty he agreed with Littler and White that the flexor sublimis to the ring finger gives a far better result than any wrist flexor, or palmaris longus, both because of its better range of excursion. Even today Brand's opponens-plasty using FDS of ring finger is considered a standard operation.

Dr Brand trained Dr Fritschi and Dr Sakunthala Karat. The greatest contribution of Dr. Fritschi besides training surgeons was publication of book on "Reconstructive Leprosy Surgery" describing pathophysiology of deformities and types of reconstructive procedures. Dr. Fritschi also started the care and cure of ulcer primarily based on giving 'rest' to ulcer to heal by 'offloading' devices like double rocker plaster for "healing while walking." In his biography he says his main contribution was to make SLRTC a training institute. Author had a chance to interact with Dr. Samuel Solomon and Dr. Fritschi operating at Karigiri. Dr. Vijay Kumar invited him along with surgeons like Dr. Fritschi, Srinivasan and Palande to demonstrate his 'One in four lasso" operation where nearly 30 surgeons were trained.

Writes Dr. Desikan, "Just as Dr. Brand and Dr. Fritschi pioneered hand and foot care. Dr. Antia, as a cosmetic surgeon, gave a fresh look to those patients who were disfigured. These two surgeons changed the lives of leprosy patients from being subjects of charity to becoming useful citizens with dignity and a social status."

Surgery on face

Gilles described postnasal epithelial inlay for syphilitic nose, which was adopted by Antia for leprosy. The other operation to provide lining was nasolabial flaps inserted through side incisions. It was a blind technique. That is when Dr. Atul Shah used an unconventional "inverted U-shaped" incision to turn down the nose from the root to the two third of the length leaving arterial supply from the ala intact. Dr. Fritschi even suggested taking it down as much as possible to fit in nasolabial flaps from both sides of the face. Since then, it has established itself as standard operation leaving PNI for extreme cases. Later, when silicone implant came in plastic surgical correction of depressed nose. Dr. Atul Shah became the first surgeon to insert it in a leprosy patient at a leprosy colony. Of course, like other silicone implants it did extrude after five years but the patient was happy and did not ask for another operation.

For correction of lagophthalmos Temporalis Musculo-facial sling has been widely practiced. There are two ways in which this operation is performed. One is detaching the part of insertion and attaching palmaris or fascia Lata graft to it and then rerouting the two slips on the upper and lower eyelids to get attached to medial canthus. This is an excellent and small operation but requires operating at another site, in the leg to harvest fascia Lata. This was used by Dr. Fritschi and others in South India extensively. The other technique is to open the temporalis muscle with a longitudinal incision in line of temporal vessels, detaching the temporal fascia from the bone in such a way that it remains attached to temporalis muscle and two slings made from this fascia is detached from temporalis insertion to reach to medial malleolus. It avoids operation at another site and takes longer time than the former. Results are similar in both techniques. Dr. Antia and the author used to practice this operation. Further progress in correction lagophthalmos was made possible with the advent of lid loading, preferably with nonallergic twenty-four carat curved gold implant. Dr. Atul Shah and Dr. Narayan from Nanavati Hospital even carried it out at Gujarat mega-camps. In the follow up of ten patients only one case needed its removal due to chronic irritation. Today, at many places internationally, lid loading is the operation of choice for any etiology of lagophthalmos.

The loss of eyebrow resulting from infiltration is corrected by either free hair graft (Gilles 1935) or Temporal Artery Island scalp flap or Transposition flap without arterial pedicle (Antia). On face, by regression of the infiltration, the skin loses its normal elasticity and hangs as loose folds and wrinkles, giving the appearance of premature ageing. While traditional face lift can be offered to young patients (Shah), naso-labial face lift (Antia) has been described as more satisfactory.

Surgery on Nerves

Besides its indication as biopsy for diagnosis or for abscess it is conducted for relief of pain and in anticipation of sensory motor recovery.

There are two procedures described for neurolysis - external neurolysis i.e., only deroofing of the external fibrous tunnel and internal neurolysis by hemispherical epineurotomy which also decompress the nerve, release the internal pressure of edema and allow the axonal flow to occur. The advent of operating microscopes and magnification loupes made it possible to get funicular decompression. Late Dr. Salafia showed particularly satisfactory results of micro-

surgical decompression. While simple release of posterior tibial nerve decompression did not offer any significant result Arolkar postulated that release of the entire tibialis posterior neurovascular complex including the artery offers satisfactory results in healing of ulcers.

One question remains is its timings. Whether to start a course of steroid therapy initially or decompress first and follow it up with steroid therapy is a dilemma. Author proposed at IAL conference at Kerala that if a surgeon is available then to start steroids after decompression calling it "Anatomico-physiological decompression". This proposition has limitation of availability of surgeon and hence of limited value. Sajid et al concluded that surgical decompression of the nerve together with steroids treatment, is a better option to prevent the progression of deformities due to median nerve involvement, than steroids alone. Comparable results from Brazil states the 80% patients had interruption in nerve damage worsening and improvement took place. Dr. Virmond, former President of International Leprosy Association suggested a multi-centric study to confirm the results. The progress in nerve transfer and nerve anastomosis in trauma made it possible to study it in leprosy. Dr. Pawan Agarwal and others have demonstrated that saphenous nerve transfer to posterior tibial nerve can be performed for regaining the sensation on feet.

Surgery of hand

The commonest deformity is called claw hand. The indications for surgery can be summarized as for function or re-ablement, for cosmetic correction and for both. Reconstructive surgery of the claw hand is an ever-evolving subject. The main points to consider in choosing the technique are which donor muscle is suitable, whether tendon graft will be required and point of insertion.

Flexor digitorum superficialis will reach the insertion without need of the graft (Stiles Bunnell) while palmaris longus for lumbrical replacement (Lenox, Antia) or Extensor carpi radialis longus (Brand) will need to be lengthened with the plantaris tendon or fascia lata graft. All these get inserted into the extensor expansion lateral band. Palande modified the insertion point into intrinsics at Metacarpophalangeal joint level for reactivation, which the author found difficult. Dr. Srinivasan has designed an Extensor by-pass operation based on splitting the force of long extensors passing graft below the fulcrum of the MP joint.

The greatest advancement in simplification of correction of claw deformity was made after Dr. Atul Shah (1986) described correction of ulnar claw hand of ring and little finger with "lasso" procedure and followed it up with his modification "one in four (1:4) flexor superficialis lasso" by dividing tendon in to four slips for ulnar and median claw hand, which till date remains the standard procedure. He also described the Transverse Arch Correction (TRAC) operation for ulnar claw hands. In this operation ulnar slip of FDS of ring finger is inserted in the base of little finger at the insertion of hypothenar muscles to bring about protraction and retraction of transverse arch with satisfactory results but is not required in all cases. Nadkarni et al employed Shah's lasso in detail in 18 cases with a follow-up of one to three years and reported the results as excellent in 22.7 %, good in 68.2 %, and fair in 9.1 % of the cases.

Malviya used FDS of middle or index finger and found reliable results in 60% cases with FDS middle finger while Shah uses FDS ring finger. When one does not want to sacrifice

the sublimis of any finger, indirect lasso can be done using palmaris longus as a motor muscle as described by Malviya. Contraindication for lasso would be PIP joint stiffness. In such cases, it is better to insert the transferred tendon slip into the extensor expansion. Nevertheless, there are cases with suboptimal results and known for correcting such deformities Dr. August Beine from Sivananda Leprosy Hospital used to find a resolution to problems faced by patients. He was joined in his work with equally devoted Dr. Ananth Reddy, who was awarded by IAL last year with the oration. Dr. Beine also used to correct thumb with abductor pollicis longus displacement. While Brand's opponens-plasty remains the standard operation for thumb paralysis, Premal Das mentioned Extensor Indicis Proprius transfer (after George Anderson) as an alternative to Brand's opponens-plasty where one would like to preserve the FDS tendon for better strength of the hand.

Progress in newer techniques have helped long standing muscle contracture cases. The adaptive shortening of long flexors described by Anderson was overcome by division of deep fascia in the forearm by Dr. Santosh Rath. When fascia release is found insufficient on operation table, Dr. Atul Shah does release all white tendinous fibers of long flexors at the elbow to help extend the fingers. Satisfactory results have been obtained with this technique.

To add to application of recent advances ICMR under Dr. V M Katoch permitted the study on "Active mobilization of fingers after claw correction" as proposed by Dr. Santosh Rath. One of the centers was TLMI-Naini under Dr. Premal Das. The publication is awaited.

In the feet, though there are three main deformities – foot drop, claw toes and ulcers, maximum progress has been in ulcer prevention and care in recent times. In the foot drop correction, tibialis posterior tendon transfer to extensors of the foot is the procedure of choice with some variance like including evertors peronei if there is tendency to inversion. Insertion is in Tibialis Anterior with some people preferring only extensors of great toe and digits to get better dorsiflexion. Another route is the interosseus through the membrane between tibia and fibula at the distal end. It was meant to be inserted in the bone primarily so that dorsiflexion is forceful, however in leprosy rarefaction of bones preclude its use. In claw toes, where there is danger of distal phalanx developing ulcers at the tip of the toes or if a patient is uncomfortable in walking and hitting the ground with bent toes the operation for correction is indicated. The flexor digitorum longus is divided and inserted in the extensor tendon over the proximal phalanx which will then extend the distal phalanx and prevent ulceration.

Plantar Ulcers

Greater the problem, the greater the progress and advances. Since the days of Dr. Brand, who demonstrated that walking causes shearing stresses and paralysis of the posterior tibial nerve, the contraction of intrinsic muscles decreases to lift the MTP region upwards subjecting these areas to pressure and friction while walking. These factors lead to localized ischemia, traumatic inflammation and loss of padding of fat. Thus, ulcers occur due to external injuries as well as internal factors. The common sites of ulcerations on the sole of the foot are heel, MTP heads and lateral border of the sole of the foot.

All simple ulcers will heal, if given sufficient rest. Dr. Fritschi on this principle devised the offloading equipment like double rocker POP application which will allow "healing while walking." Microcellular rubber (MCR) was also introduced as chappals or insoles to distribute weight following Dr. Brand's pioneering work on materials suitable for distributing body weight and shearing stresses. However, it has also been advocated for primary prevention in cases where there is a high degree of pressure point and/or increased temperature in a localized area. Antia went on to research chappal with a hard iron bar in the sole made by a commercial manufacturer. Neela Shah suggested commercial designs, remote made custom footwear with drawings of the size sent from leprosy colonies, which still boils down to the fact that local repairer is required after MCR sandal delivery. Dr. Premal Das, Executive Director of the Leprosy Mission informs that using non-stigmatizing, colorful, cheaper and lightweight TPE/polyurethane silicon is an especially useful substitute to MCR. Nevertheless, the majority of ulcer cases need only self-care at home.

Atul Shah and Neela Shah have detailed their work over a decade in obtaining healing with a "self-care kit" designed by them. A typical self-care kit contains scraper to scrape thick margin of the ulcer, an antiseptic cream, an antiseptic solution to pour into water at the time of soaking the feet, sterile gauze pieces to cover the ulcer after ointment application, a bottle of Vaseline, or any oil or cold cream, which is used to hydrate the skin or retain hydration in the skin, bandage with scissors and sticking plaster. Giving away "self-care kit" or materials is the simple thing, but the important thing is to empower patients in its use with group therapy. Its inclusion in NLEP has increased its reach to eighty thousand patients.

Though 40 percent will heal, and 85 percent will improve, the cardinal rule is if an ulcer does not heal in 4 months' time it needs surgery. Recently, PRP or fibrin matrix dressings have been tried to promote wound healing. Some of the publications from Hyderabad dermatology department by Dr. Kurre under Dr. Narsimha Rao Netha have shown encouraging results.

Surgery in plantar ulcers

A patient with an uncomplicated ulcer who has no response to home care may need a split skin graft as an outpatient or as Indoor patient. On examination, if the structures like bone, joint or tendon are exposed the ulcer will need the flap cover. Transposition flaps from nearby skin to cover metatarsal head ulcer or heel ulcer is the choice if limited expertise is available. Where there is need to interpose some tissue flexor digitorum brevis myo-cutaneous flap (Shah and Pandit) may be required. At metatarsal head Shah has described "neurovascular island flap" (Kotecha) which also carries sensations. The advances in arterial/nerve pedicle flap have enabled plastic surgeons to apply it to large ulcers on the heel. Dr. Jerry Joshua, (Currently, Director & Surgeon SIH-R & LC, Karigiri) the only plastic surgeon in TLM was performing the "sural artery pedicle flap" and all types of advanced flaps on the sole of the feet. He is one of the best trainers in RCS.

Outreach of RCS

To reach almost half a million estimated deformity cases needing RCS Government of India's progressive step was to increase the recognition to RCS centers of the NGOs and provide incentive to each patient and hospital. Moreover, CLTRI Chengalpattu and RLTRI at Raipur

were made the main government centers performing hundreds of operations in house or as outreach. Dr. Kamble from RLTRI has been doing excellent outreach programs comparable with NGOs. Major NGO conducting RCS through visiting surgeons is TLM. Dr. Premal das, Dr. Vijay Kumar, Dr. Vaz, Dr Jalaz and Dr Elkana cover 13 TLM centers and four non-TLM centers, continuing even under pandemic of COVID and performing two to three hundred operations annually.

Government of India also recognized mega-camps at Gujarat where under the leadership of Dr. Atul Shah more than 7500 operations were conducted and GoI asked other states to follow the example and make a sustained campaign approach for outreach services. Currently, all medical college in Gujarat as well as other states perform the RCS without any prejudice and admit the leprosy patient like any other patient.

Thus, it can be said that tremendous progress has been made in the Surgical Techniques of RCS in India with evolution of simpler techniques, integration of RCS into medical colleges and providing outreach services by NLEP and NGOs together. Note that progress in RCS techniques would not have been possible without concurrent progress in orthotic and prosthetic devices and their pioneers to whom surgeons will ever remain grateful.

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6. Atul Shah, Neela Shah: Deformities of Face, Hands, Feet, and their Management -IAL Textbook of Leprosy

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Research priorities in leprosy and work in progress

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Introduction

After the declaration of elimination of leprosy as a public health problem, the perception that leprosy was no longer a problem led to a loss of political commitment to leprosy control, resulting in reduced funding and loss of expertise. Over the last 10-15 years the annual new case detection rate and childhood leprosy rate have not decreased significantly which means that the transmission of leprosy is continuing unabated. In addition to this, we are witnessing an increase in multibacillary cases, drug resistance, relapses and more cases with recurrent and chronic reactions. The WHO GLP (World Health Organization- Global Leprosy Programme) envisions a world free from leprosy by 2030, however, the current scenario in leprosy endemic countries raises a lot of doubt if we will be able to achieve this target of zero disease, zero disability and zero stigma or discrimination.

Fundamental gaps in knowledge continue to impede progress and thwart our dream of a leprosy-free world. We need research priorities for the next few years which will help us in accelerating our progress toward the different targets of WHO GLP. However, this requires the integration of different disciplines to work across traditionally divided fields in order to make breakthroughs. The key target areas for the next decade are given in Table 1.

Table 1: Key research areas
Diagnostic tests for disease and infection (PCR based molecular/ immunological diagnostic tests with promise).
Improved understanding of transmission including host, agent and environmental factors and zoonotic transmission/ extra human reservoirs of infection
Improved understanding of the mechanism of leprosy reactions
Optimised case detection through integration, especially in low-endemic settings
More effective drugs or drug combinations, or shorter regimens, to treat leprosy and leprosy reactions
Improved preventive approaches including chemoprophylaxis and immuno-prophylaxis or vaccines
Effective models of care throughout the patient journey
Digital health applications in leprosy.
Inclusive approaches in community-based rehabilitation and stigma reduction.

There has been interesting research in the field of leprosy diagnostics, immunogenetics, biomarkers for the disease and reactions, chemoprophylaxis, vaccines, and treatment, but they have not been implemented on a large scale and the leprosy transmission still continues unrelenting. In this chapter, we will discuss the research priorities for the next few years which will accelerate our progress towards interruption of transmission, zero disability, zero stigma and discrimination and also report on the work in progress.

Early diagnosis and prevention of transmission

The best way to stop the transmission of leprosy is early case detection and treatment. Besides clinical examination, other methods for leprosy diagnosis include slit skin smear (SSS), histopathology, antigen-antibody assays, biomarkers, and tests based on molecular diagnostics. SSS and skin biopsy are two conventional and reliable methods for diagnosis as well as assessment of bacillary load in patients. However, they are not universally available and not done in most of the countries and even SSS has been discontinued after WHO goal of leprosy elimination was achieved. We should revive SSS for diagnosis of doubtful cases, diagnosis of relapse cases and even monitoring of response to treatment.

We need sensitive point-of-care tests for early diagnosis, the currently employed serological tests like NDO-LID or PGL-I are not sensitive enough to detect paucibacillary cases. Besides, the presence of these antibodies is not predictive of disease. Detection of blood-based cytokines by POC lateral flow assays seem to have more advantage and should be further evaluated in larger study designs. For serological assays, some strategies can be used to achieve specificity and higher sensitivity. There is also an unmet need for assays that can detect antibodies/ cytokines from saliva as it is less invasive and may be acceptable to leprosy contacts as well.

Biomarkers:

Studies on the immunopathogenesis of leprosy and leprosy reactions have given useful information about the various cytokines and genes which are upregulated or downregulated and can prove helpful in identifying who will develop the disease/ the spectrum of disease (paucibacillary vs multibacillary) or who is more prone to reactions.

Based on the cytokine profile on infection with M.Leprae, scientists have tried to identify potential universal biomarker-type cytokines. It has been reported that in the ex vivo context, raised levels of CD4+IL-10+ cells and in vitro, increased levels of NEUTLR4+ appear as common biomarkers universally observed in all leprosy patients. Jorge et al. identified a combination of four miRNAs (miR-101, miR-196b, miR-27b, and miR-29c) after screening 377 miRNAs using TaqMan low-density (TLDA) in skin lesions from TT and LL patients with 80% sensitivity and 91% specificity. Also, it has been observed that the combination of multiple miRNAs serves as a more powerful biomarker than the use of a single one. Another study by Tio-Coma et al for the first time has identified a prospective transcriptional 4-gene signature in blood, designated RISK4LEP (MT-ND2, REX1BD, TPGS1, UBC) using extensive translational development approaches based on genomics and transcriptomic approached. This gene signature can act as a diagnostic tool for the prediction of leprosy, 4 to 61 months prior in leprosy suspects with a sensitivity of 87.5%, and specificity of 72.3%. The main focus should

not only be on the development of biomarkers but the application of these in clinical setups or point-of-care facilities. In this regard, various studies have identified signature biomarkers such as αPGL-I IgM, IP-10, CRP, ApoA1, and S100A12. Amongst these, ApoA1 has been considered the prime biomarker for PB leprosy patients while increased levels of αPGL-I IgM, IP-10, and CRP levels were directly associated with MB leprosy patients. Out of these ApoA1 and S100A12 can be used for the diagnosis of patients from both groups. The study used one single strip format for MBT (Multi-biomarker test) combination of six biomarkers on a single MBT device to avoid running six individual tests which is a remarkable step towards POC applications. A test protocol analysis revealed the effectiveness of combining cytokine and chemokine assays with *M. leprae*-specific antibodies to identify both PB and MB leprosy. To evaluate whether identified biomarkers may be used for diagnosis, more research is required. To determine how successfully these tests foretell the emergence of overt leprosy in contacts of leprosy patients, longitudinal investigations are required.

Tests based on Molecular Diagnostics:

PCR has proved to be a vital molecular diagnostic test in early case detection of leprosy. The advantage associated with this technique is that it can be applied to a variety of specimens including skin smears, urine, nerve, oral, blood, or nasal swabs, and ocular lesions.

When compared to other targets, the RLEP assay has been found to be the most sensitive at 87.1%. However, these assays still need to undergo clinical validation, and we need assays that can differentiate between infection and disease. A multiplex PCR using different genes where the sample can test both the bacilli and the host's response may be able to provide an answer. However, as of now, there is no PCR-based test that has been approved for leprosy diagnosis. The establishment and use of molecular assays is no longer a problem even for developing countries. For the diagnosis of TB programme, a large number of Microscopy Centers are already using real-time PCR for TB and recently also for Covid 19. A good number of such centers are present all over India and the world due to the COVID pandemic. The same platform can be used for more than 20 other diseases. Technicians doing microscopy for TB could easily start using real-time PCR with 48 hrs of training.

We need to develop a duplex or triplex qPCR also targeting the most frequent resistant SNPs in rpoB and other genes which can detect drug resistance. Molecular tests for direct detection and estimation of molecular bacilli viability in fresh or fixed clinical samples would help improve the management of relapse cases (live mycobacteria) by distinguishing them from reactional states (dead mycobacteria).

Research priorities for Diagnosis

1. Development of immunological and molecular markers for infection with *M. leprae* and disease.
2. (Further) development of a field-friendly point-of-care test for leprosy infection or Subclinical disease.
3. (Further) development of *M. leprae* viability assays which may be used to monitor treatment outcome/success).
4. Development of markers to detect relapse.

The use of loop-mediated isothermal amplification (LAMP) in leprosy molecular diagnosis is a relatively new DNA amplification technique that can be used for molecular diagnosis of leprosy but needs extensive validation based on the simplicity, low cost, and easy technique as well as interpretation.

Improved understanding of transmission:

Research should also continue on the non-human reservoirs which may maintain the transmission of leprosy in endemic areas. Armadillos and red squirrels were reported as natural hosts that also develop the disease after infection with *M. leprae* or *M. lepromatosis*. A study by Turankar et al found the presence of viable *M. leprae* in soil and water samples collected from areas of leprosy patients. These viable bacilli might survive in the environment and may cause leprosy infection (disease) in a susceptible host. Similar genotypes in clinical and environmental samples indicate that environment could possibly act as a source of infection. SNP and VNTR combination showed *M. leprae* strain similarities and their differentiation in certain blocks of Purulia, West Bengal. Such studies with the combination of genetic markers may provide a tool to track transmission link in the community."

Prevention of leprosy

Contact tracing, followed by administration of chemoprophylaxis, BCG vaccination, or both is currently the most promising approach to halting *M. leprae* transmission. However, tracing contacts of index leprosy patients has operational and ethical challenges as compared to population-based screening which may not be economically feasible. Skin camps for NTDs or joint screening camps for leprosy and tuberculosis seem good options that are cost-effective. Hence we need to work on increasing awareness and removing the stigma, develop better tools for screening of contacts, and more effective vaccines for prophylaxis as the effect of chemoprophylaxis last a few years but the protection offered by a vaccine is long term and induces an immunological memory. Mycobacterium indicus pranii (MIP), is being studied as immunoprophylaxis to contacts of leprosy patients in selected endemic districts in India but its effectiveness and safety need to be examined. LepVax has been found to be safe, well tolerated and immunogenic when administered as intramuscular injections at 28-day time intervals amongst healthy adult subjects. Mice studies have also shown that it prevents nerve injury which would be something which none of the vaccines has exhibited so far. However, complete clinical trials, international registration, and the establishment of safety monitoring must still be completed for both MIP and LepVax.

Priorities for leprosy prevention

1. Defining and implementing optimal post-exposure prophylaxis strategies and regimens (chemoprophylactic/immunoprophylaxis).
2. Development of new leprosy vaccines and RCTs to determine the safety and efficacy of potential new leprosy vaccines.
3. Modelling studies to predict and map the effect and impact of PEP interventions.

Priorities for reactions and neuritis

1. Continue research on pathophysiological/immunological mechanisms of nerve in jury in leprosy and type 1 or type 2 reactions
2. Research into genetic susceptibility for the development of reactions and impairments.
3. Identifying risk factors for the development of reactions and impairments.
4. Development of diagnostic tools for the detection of nerve function impairment and reactions.
5. Identification and efficacy trials of novel drug treatment of NFI and reactions.
6. Monitoring the adverse effects of steroids in patients with reactions and neuritis.
7. Research into financial and psychosocial burden of reactions

Treatment

There are reports of increasing cases of relapse/ recurrence as well as drug-resistant cases which may further slow our progress toward leprosy eradication. Additional agents bactericidal for *M. leprae* have been identified in the 40 years since MDT introduction and these could now be considered in new MDT regimens. Effectiveness of newer regimes and second-line drugs for leprosy patients need to be studied in those who are not responding to WHO MDT. There is a need to develop management guidelines for patients with high bacillary load and polar lepromatous leprosy for better management of this epidemiologically important subset of leprosy.

Priorities for treatment and management

1. Development and field testing of alternative MDT regimens.
2. Research into the effectiveness of immunotherapy for highly positive patients (borderline lepromatous leprosy (BL) and lepromatous leprosy (LL)).
3. Studies assessing the effectiveness, feibility, and impact of reducing MDT treatment duration (e.g. uniform-MDT)
4. Finding optimal regimes for management of patients with higher bacterial load
5. Strategies and operational research to improve treatment adherence

Drug resistance

Drug resistance is a potential disrupter of any communicable disease control/ eliminationprogram. Although the current data suggest that drug resistance is not currently a serious threat to leprosy control. However, surveillance measures are urgently needed to recognize drug resistance and enable immediate treatment to prevent its spread and reduce its impact on efforts to attain zero leprosy. Basic research is needed for improved methods of testing for drug resistance, especially for methods that can be used in peripheral settings, such as district hospitals or health centers, as have been established with tuberculosis. Another research need is the development of a test for resistance for other drugs like clofazimine, minocycline and clarithromycin. Whole genome sequencing will also be useful

to identify further variations between drug-resistant and sensitive strains of *M. leprae* that may be useful as molecular signatures for drug resistance under routine conditions. Research could also be initiated to identify relevant genetic mutations in other genes such as rpoA, rpoC, and other mechanisms of drug resistance.

Operational research is needed in two key areas: first, the development of improved sampling procedures from new cases to properly monitor the rate of primary resistance to rifampicin; and second, improved monitoring of treatment outcomes in cases showing rifampicin resistance to determine the efficacy of second-line drug treatments for resistant cases.

Priorities for tackling drug resistance

1. Studies assessing the prevalence of rifampicin resistance.
2. Research into the prevalence of relapse in field settings.
3. Development of easy to handle animal models or axenic media for drug resistance testing.
4. Rapid molecular assays to detect drug resistance
5. Continued research to develop more drugs which can be used as second line or third line management

Digital health applications in leprosy

Rapid development in digital technology has significant potential effects on how leprosy programs are carried out. The use of mapping and cluster identification technologies are used PEP++ leprosy. The use of mobile app helps to collect data on index cases and contacts, enabling data analysis and clear visual representation. It also helps in recording and graphical display of personal and diagnostic data of leprosy patients. GPS-tracker devices may help to trace mobility, assess health-seeking behaviour and support rationalized contact tracing. Digital tools also help in training health care workers about the diagnosis, identifying reactions, and detecting neuritis early which helps in giving a better quality of care to leprosy patients. Digital health apps can be developed and used in various aspects like digital diagnostics, surveillance, disease mapping, e-Learning, policy and digital strategy, and monitoring and evaluation. Digital innovations are being made in the NTD and NCD fields through physician aids, eLearning and mapping which can be adopted by the various national programs to improve and increase the health care coverage.

More AI-based tools are required for early detection of leprosy, planning management and rehabilitation. Mobile phone-based technology would prove to be handier and more convenient and it will save time. Artificial intelligence can also be used to screen skin biopsies using hematoxylin and eosin (H&E) stains or slit skin smear slides for unrecognized patterns to help detect tissue patterns or bacilli to improve diagnosis. Cutaneous thermography may also be used as a complementary diagnostic method, with or without ultraviolet photography to screen for leprosy. It would also make it possible to remotely perform leprosy diagnosis in the most prevalent and poorest areas of the world by sending images to reference centers.

Disability Prevention:

Early diagnosis, prompt treatment of leprosy reactions and injuries to neuropathic limbs, and teaching life-long self-care prevent disabilities due to leprosy down towards zero disability. Defining, implementing and assessing optimal strategies for the prevention of disabilities is an urgent need for more than 30 million people living with disability. There is a need for investigations to detect subclinical neuropathy or silent neuritis and prognosticate neuritis so that nerve impairment can be managed early and subsequently help in the prevention of irreversible nerve damage. There is also a need for investigations to monitor patients with nerve function impairment to guide the tailoring of oral steroids and immunosuppressants. There is a necessity for implementation strategies to educate patients and family members regarding self-care, physiotherapy, occupational therapy, and combined approaches. Operational research is required for combined approaches for the prevention of disabilities (POD) in leprosy, diabetes, and other skin conditions (e.g. self-care groups for leprosy and diabetes).

Priorities for disability prevention and management

1. Operational research to determine best practices for post-MDT surveillance.
2. Operation research into the feasibility and effectiveness of self-monitoring/self-care on early nerve damage.
3. Innovative approaches for the treatment of secondary consequences by ophthalmologist and reconstructive surgeons.
4. Effectiveness, feasibility and acceptability of new orthopedic methods and aids to help patients with disability
5. Identifying and testing novel treatment approaches for trophic ulcers.

Community-based rehabilitation (CBR) and stigma reduction:

Leprosy stigma exists on three different levels: among patients (self-perceived stigma), among family, and throughout society. There has been research on interventions to lessen stigma, but no standardization has been done. There is a need for test interventions to reduce stigma and, improve mental wellbeing. Examples include support groups that give peer counseling, peer-to-peer network facilitated by local specialists, socioeconomic development, and including those afflicted in leprosy services. In order to identify standardized methodologies, such interventions need to be evaluated in various situations and scale-up needs to be investigated.

Apart from physical impairment, there is also an impairment of quality of life (QoL) and mental health due to social stigma and discrimination. There is also a need for leprosy-specific, quick, simple, and validated tools to assess the QoL and mental well-being in leprosy-affected individuals. Leprosy patients also require emotional support in order to maintain family relationships, support treatment plans, and hasten leprosy recovery and we need to train our leprosy staff to identify and help the patients with their emotional needs.

Priorities for stigma reduction

1. Operational research into the feasibility, acceptability, and impact of stigma reduction activities.
2. Assessing the role of community/religious leaders in generating or maintaining stigma and in stigma reduction activities.
3. Assess the (local) implementation and impact of the UN guidelines on leprosy dis crimination.
4. Studies into approaches on capacity building/empowerment for persons affected by leprosy.
5. Studies on mental health and wellbeing of persons affected by leprosy.
6. Studies into the attitude of families and contacts of persons affected by leprosy.
7. Studies into the perceptions and behaviour of health staff towards leprosy.

Conclusion

Although MDT had a significant impact on leprosy, particularly in the 1990s, the number of reported cases stayed constant over the past ten years, and worries are mounting that a sizable number of cases may go unreported and untreated. New methods and innovations are required in addition to conventional public health strategies like active case finding; which call for creative, high-quality research and an active scientific community that is devoted to solving important research goals. Research on new diagnostics, new drugs, shorter regimens, better prophylactic measures and interventions to improve the quality of life of people affected by leprosy must be continued to improve leprosy control and services. It is equally important to prioritize further, align partners, mobilize resources, plan, and coordinate how to carry out that research agenda. Investments are needed from both current and new partners at every level of the process, from discovery through implementation, in order to achieve zero leprosy. The creation of the necessary tools for intervention and diagnosis requires technological innovation. Further, to standardize those tools and integrate them into nationwide programs, a high-quality implementation research with a good evidence base is required.

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Prioritizing leprosy by National Health Mission, Govt. of India

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Background

Government of India (GOI) started the Leprosy Control Programme in 1955. Subsequently, with availability of multi drug therapy (MDT) as a cure for leprosy, the National Leprosy Eradication Programme (NLEP) was started in the year 1983. Since then, through different plan periods, it has achieved various milestones. To enhance the process of elimination, the first World Bank-supported project on NLEP was started in the year 1993–1994, where the project supported the vertical program structure formulated by GOI for the high-endemic districts, while in the moderate- and low-endemic districts, mobile leprosy treatment units (MLTUs) were established. The project was completed on March 31, 2000, with further extension of 6 months to complete the preparation of proposal for second-phase project. During this phase, against a target of 2 million cases, 3.8 million new leprosy cases were detected and on the whole, 4.4 million leprosy cases were cured with MDT. The global target of leprosy elimination by the end of the year 2000 was attained, although PR in India in March 2001 remained at 3.7/10,000 population. The Second World Bank supported the National Leprosy Elimination Project for a period of 3 years from 2001–2004.

Prioritizing leprosy by National Health Mission

The National Rural Health Mission (NRHM) has been launched in 2005 with a view to bringing about dramatic improvement in the health system and the health status of the people, especially those who live in the rural areas of the country. NHM has provided the Central and the State Governments with a unique opportunity for carrying out necessary reforms in the Health Sector. The reforms are necessary for restructuring the health delivery system as well as for developing better health financing mechanisms. The strengthening and effectiveness of health institutions like SHCs/PHCs/CHCs/Taluk/District Hospitals have positive consequences for all health programmes [TB, Malaria, HIV/AIDS, Filaria, Family Welfare, Leprosy, Disease Surveillance etc.]

Under the NRHM, institutional mechanisms have been created at each level to support national health programs and improve delivery of healthcare services. At the village level, there are multi stakeholders—village health and sanitation committee to decide the health priorities in the village and also their appropriate solution. There is also an accredited social health activist (ASHA) for every village. She is a female volunteer belonging to the same village, selected by the community. Services of ASHA could be utilized for early detection of

suspected cases of leprosy and referral of such cases should be made to the nearest health center for confirmation and completion of treatment. Rogi Kalyan Samities at PHC, CHC, and district hospitals are autonomous registered bodies constituted at each level to facilitate in the management of hospitals and delivery of quality care to patients. The NLEP will be benefited by working in coordination with other programs under the NRHM. District Health Mission, which is chaired by the president of Zila Parishad, may be helpful for advocacy of the program

The NRHM [now National Health Mission (NHM)] issued guidelines to the states/UTs regarding decentralized planning through district health plans. To make the NLEP plan more compliant to the NRHM guidelines, the states/ UTs are advised that annual plans should be prepared as a result-based plan. The results to be achieved at the end of the 12th five-Year Plan are:

- Improved early case detection and case management
- Reduced stigma
- Research supported evidence-based program practices
- Improved monitoring, supervision, and evaluation system
- Increased participation of PAL in society

The funding for the NLEP activities are being released by NHM based on the States/UTs PIP and ROP. Many initiatives have been prioritized under NLEP since 2016 are as follows:

Three-pronged strategies were introduced in 2016–2017. This strategy includes— Leprosy Case Detection Campaigns (LCDC), Focused Leprosy Campaign (FLC), and special plans for hard-to-reach areas.

Leprosy Case Detection Campaigns (LCDC): The major source of infection in the community is an untreated case, i.e., a hidden case of leprosy lying undetected in the community, who transmits the disease agent to other people in the community. campaign is carried out for a period of 14 days in the specified districts in which house-to-house visits are conducted by a team comprising one ASHA and one male volunteer in each village.

Focused Leprosy Campaign (FLC): The village or urban area where a G2D case was detected is considered a hotspot. It indicates that the case was detected (very) late and that there can be several hidden cases in the community. In such hotspots in low-endemic districts, which were not selected for LCDC, close contacts of index cases are screened for leprosy where a case of G2D may be detected in regular surveillance. FLCs target 300 surrounding households in urban areas or the entire village in rural areas.

Special plan for hard-to-reach areas: States/UTs were directed to identify hard-to-reach areas or hard-to-reach populations where routine NLEP services cannot be provided in a usual manner. States/UTs are to make special area-specific plans for carrying out leprosy control services through community participation as per the local needs of States/UTs.

ASHA-based surveillance for leprosy suspects (ABSULS) were introduced in 2016 in districts, which are not covered under LCDC, with the objective to expand community-based leprosy surveillance at the village level on a periodic (monthly) basis, wherein ASHA who is the representative of the community to the health system and accountable for the health conditions of people of approximately 200 households will detect and report suspected leprosy cases in the community.

Grade-2 disability investigation: Epidemiological investigation for the causes of occurrence of visible deformity of eachcase of G2D

Post Exposure prophylaxis (PEP): GOI decided to launch PEP across India wherein single dose of rifampicin (SDR) prophylaxis is administered to all the close contacts of existing cases as part of preventive treatment (adults and children aged 2 years and above).

Sparsh Leprosy Awareness Campaigns: In order to address the issue of stigma and discrimination associated with the disease, a year-wise theme-based mass awareness campaign named SLAC is being conducted across the country on Anti-leprosy Day on January 30, since 2017. Since then, every year, nationwide Gram Sabhas in villages across the country are being organized in cooperation and coordination with allied sectors of the health department. Appropriate messages from district and appeals from Gram Sabha Pramukh (heads of village councils) to reduce discrimination against persons affected with leprosy are read out, pledge is taken by all Gram Sabha members to reduce the burden of disease in the community, and felicitation of persons affected with leprosy is done.

Further scale up the leprosy screening in a holistic way, leprosy screening has been strategically converged with Rashtriya Bal Swasthya Karyakram (RBSK), Rashtriya Kishor Swasthya Karyakram (RKSK), and Comprehensive Primary Health Care under Ayushman Bharat at the health and wellness centers (Box 1).

- Convergence of leprosy screening under Rashtriya Bal Swasthya Karyakram (RBSK) and Rashtriya Kishore Swasthya Karyakram (RKSK) for screening of children (0-18 years).
- Dedicated mobile team of RBSK visit school for health checkup during which children leprosy screen is also being carried out by the team.
- Comprehensive primary health care package under Ayushman Bharat at the health and wellness centers for leprosy screening: Community- based assessment checklist (CBAC) for early detection of communicable diseases (tuberculosis and leprosy) - suitably modified inter alia to ensure a comprehensive screening of 30+ years population for leprosy.
- Five questions related to early signs of leprosy have been added in the CBAC checklist to identify the suspects of leprosy by ASHAs at the community level. The five signs are as follows:
    1. Any hypo-pigmented patch(es) or discolored lesion(s) with loss of sensation, thickened skin, or nodules on skin
    2. Recurrent blistering / ulceration on palm or sole or/and tingling/numbness on palm(s) or sole(s)
    3. Clawing of fingers or/and tingling and numbness in hands and/or feet
    4. Inability to close eyelid.
    5. Difficulty in holding objects with hands/fingers or weakness in feet that causes difficulty in walking.

These are some of the welcome initiatives from NHM and the Government of India to strengthen the early new case detection, needed for speeding up the eradication of leprosy from India.

Notes

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