



Projektbericht Martin Heidinger

Volontariat Indien – Lepra on the Road

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Vorwort | Preamble

Durch einige Auslandserfahrungen die ich bisher schon sammeln durfte, ist mir durch jede umso mehr bewusst geworden, wie wichtig diese sind, um den eigenen Horizont, aber in Zuge dessen sowie danach auch den Horizont anderer, interessierter erweitern, und dadurch einen persönlichen aber auch gesellschaftlichen Mehrwert kreieren zu können. In diesem Sinne trauere ich keinem verwendeten Euro und keiner „verlorenen“ Zeit nach, die ich für Reisen und Auslandserfahrungen aufgebracht habe. Ich möchte mich bei Landesrat Buchmann, dem Referat für Europa und Auslandserfahrungen, sowie Frau Elßer-Eibel danken, die die Förderung für Volontariate ins Leben gerufen haben, denn, wenn ich auch keinen Euro missen möchte, ist man als Student doch über jeden solchen froh, der einem eine Erfahrung wie diese ermöglicht.

Durch die Workshops im Zuge des FairYoungStyria Projektes, und speziell auch durch das Mentoring von Michale Kvas habe ich mich nicht nur in der Vorbereitung, sondern auch in der Durchführung, und schlussendlich in meinen Plänen für die Fortsetzung solcher Projekte bestärkt, motiviert und versichert gefühlt und möchte mich dafür bedanken.

Ein großer Dank gebührt meinen Eltern, die mich so großartig unterstützen.

Schlussendlich möchte ich noch festhalten, dass ich diesen Projektbericht in Englisch halten werde, um auch die indischen Projektpartner an meinen Erfahrungen teilhaben zu lassen.

In this preamble, I therefore also want to thank Sr. Dr. Francina and her Team of the DTMC Trust, who made this experience a pleasant and my stay a medically- and research-wise very successful one. In this context, a big thank you is also reserved for my partners, including firstly Elisa Simonnet, who stayed and worked with me through day and night, Prof. Dr. Wolf Sixl, who couldn't have prepared and coached me in any way better for the challenges ahead, Anneliese and Prof. Dr. Hans Pfeifer, Prof. Dr. Andrea Grisold, Prof. Dr. Andreas Schoepfer, Dr. Claudia Wilfinger, Angelika Schirnhofner and the whole team of the Department for Global Health and Development of the Medical University of Graz.

Introduction

Salem, Tamil Nadu, Southern India is home to the Doctor Typhagne Memorable Charitable (DTMC) Trust, to the St. Mary's Leprosy Hospital as well as to the Salesian Missionaries of Mary Immaculate (SMMI) Convent, which were partnering institutions for the Medical Faculty respectively and the Medical University of Graz since 1986 when Honorary-Doctor Prof. Wolf Sixl first established the cooperation, which was last fostered by a visit in 2005. 2016 marks the continuation of this common history of joint forces as the Department for Global Health and Development (GHD) of the Medical University of Graz sent Nurses, Students and Doctors to surgically care for Leprosy patients to reduce disabilities and death from wound-infections, furthermore evaluate the work as well as leprosy-homes and their patient management through hygienic and public health measures. Survey-results on prevention of disabilities, therapy and compliance, stigmatisation and discrimination as well as wound-infections and drug-resistance shall thereafter be published and used to project future fields of collaboration. This excursion is meant to re-establish a functional and sustainable cooperation, give nurses, students and doctors the opportunity to exchange and gain experiences and finally it is a contribution to the World Health Organisation's (WHO) goal towards a leprosy-free world and reduced disease-burden.

Dr. Sr. Francina with Prof. Wolf Sixl – the Forefather of today's Department for Global Health and Development



What is special about our project is the international cooperation, which gives all participating stakeholders a rare chance for international exchange, that can be a future source of inspiration and support. Furthermore, it's a Styrian contribution to the goal of a leprosy-free world set by the WHO, the Indian Government as well as the DTMC Trust. For students, it poses an unique opportunity to experience international health collaborations and actions in development

cooperation already within medical studies, which sheds a new light and a new perspective to the objects and objectives of learning the medical profession. The Department for Global Health and Development itself insofar enjoys an outstanding status as it is relating modern medical development cooperation to a post-secondary institution's foundation. Doctors, nurses and students work together to cover the majority of medical expertise, which guarantee practical standards, whereas projects are always decisively attributed to academically interesting queries as well, to create a maximum output.



Presenting our Project-Ideas to municipal politician Lisa Rucker in Graz, Austria – FairYoungStyria 2015+

The Department for Global Health and Development of the Medical University of Graz (MUG) consists on the one hand of experienced doctors, general practitioners and specialists in general surgery, plastic surgery, pediatric surgery, orthopedics, anaesthesia, hygiene and microbiology as well as geomedicine. Furthermore, nurses coming from various medical backgrounds as far as anaesthesia to surgery, internal

medicine and nursing as well medical students complete the team, which therefore covers great parts of medical specialties.

The first partnership, established already in 1986 was carried by our Honorary-Doctor Prof. Wolf Sixl and Dr. Sr. Francina in Kerala. Initially, the work was focused on the sanitary and hygienic situation of care centers, leprosy villages and close-by living indigenous tribes until in further visits surgical interventions were carried out, whereas Prof. Dr. Johann Pfeifer, today head of the Department for Global Health and Development was already part of one excursion in 2005. This latter year also marks the last one of active cooperation of MUG and the DTMC Trust. However, contact was never lost and an intense exchange of ideas and strategies prevailed. Throughout a visit of Dr. Sr. Francina to Graz in June 2015 plans were drafted only to become reality as of October 2016.

Hygienic measures, which were taken throughout the 80s and 90s included recording the local sanitation surroundings as well as planning the creation of water wells and wastewater systems. Regarding the indigenous population, which is living close to Salem in Kolli Hills, their territories were screened and appropriate measures to improve living standards put in place. Many practical projects still function excellently today, as for example the Trichoderma-project for pest-control, vermi-compost creation, quail and rabbit breedings as well as Anthurium plantations and the continuous financing of the Kolli Hill Educational Centre.

To re-establish an already longlasting and sustainable cooperation since 1986 we plan to visit the DTMC Trust at least once per year with a medical team consisting of doctors, nurses and students to contribute to the works of Dr. Sr. Francina and her team, especially regarding the management and eradication of patients suffering from leprosy.

For our first visit in October and November we planned to elaborate the quantity of people suffering from leprosy in Salem district, Tamil Nadu, by obtaining and analyzing up-to-date data. Furthermore, we wanted to screen the procedures of the DTMC Trust in place and analyze the current status in regards to eliminating the disease and prevent as well as manage deformities. The surgical team wanted to operatively treat infected ulcers, whereas an antibiotics-resistance study was to be conducted on top of it. To start a series of research and studies adjoined to these missions a first survey on patients with deformities caused by leprosy was to be carried out.

Through our stay and analysis of elaborated numbers we hope to be able to create a further management plan of cooperation by the DTMC Trust and the Medical University of Graz. This report ought to give an insight into the achievement of these goals as well as the future plans of collaboration.

Lepra on the Road Icon created for the final presentation of FairYoungStyria 2015+



Doctor Typhagne Memorable Charitable (DTMC) Trust

The Doctor Typhagne Memorable Charitable (DTMC) Trust was founded in January 1999 under the Salesian Missionaries of Mary Immaculate (SMMI) Convent and is operating in the districts of Salem and Namakkal, which are both part of the province of Tamil Nadu in Southern India. Its head-office is located in Salem and two field-offices operate in Kakkaveri and Kolli Hills. The objectives of the charitable trust are the treatment of leprosy, tuberculosis (TB) and HIV patients, the empowerment of socially marginalized people, care for women and children in distress, protection of the environment and promotion of organic farming.

Ideology: "I came for the sick, not for those who are well" - Luke 4:31

Motto: "That all may have life in abundance"

In Salem, the DTMC Trust Headquarter is located on the Campus of the St. Mary's Hospital and the S.M.M.I. Convent Staff Quarters. Adjoined to the building is an inpatient department for male and female lepers, who are admitted for ulcer care and physiotherapy to treat deformities. Furthermore, around 40 patients are seen six days a week in the outpatient clinic and skin clinic, with lab facilities to test for leprosy, HIV and tuberculosis.

Kakkaveri, approximately 25km from Salem, hosts a 60-bed hospital, which provides general medical, surgical and obstetrical services with a focus on the inpatient treatment of HIV, TB and leprosy affected. Additionally, pharmaceutical services, x-ray, lab, ultrasound and ecg facilities are available, nursing training is provided as well as a unit for drugless and Sujok therapy. Furthermore, Kakkaveri is home to the Gertrude-Women-Training-Centre, which provides local women with educational opportunities for careers in textile and garment industries as well as one-year courses in nursing and patient management, which shows a 100% job-placement rate. In this respect the Vidivelli Community College for Women was founded. A women's shelter offers women and children a rescue-shelter and regular support groups to foster self-sustaining support, cooperation and help.

Within the district of Kolli Hills, south-east of Salem, the DTMC Trust runs organic farming with production of vegetables, fruits, bio-fertilisers and crops as part of a greater environment sanitation, an anthurium cultivation unit and a biocontrol laboratory. Here the DTMC Trust offers women empowerment units and support groups for women as well as men, further educational opportunities in form of vocational schools for trades in agriculture and textile and garment industries as well as education for school dropouts. Special about Kolli Hills are its inhabitants who partly proceed the aboriginal tribal lifestyle, which the DTMC Trust is fostering through special tribal development and education of tribal children.

Altogether the DTMC Trust runs 144 women support groups with over 1800 women participating. For men 23 groups are installed with about 270 participants.



SFS Health Centre Kakkaveri and Anthurium in Kolli Hills – by Elisa Simonnet

Since the 1960s the DTMC Trust is actively engaged in the prevention, diagnostic and treatment of leprosy and in 1981 it was respectively integrated as a non-governmental organisation into the national Anti-Leprosy Programme. Through the official elimination of leprosy funds have subsequently been cut, which makes prevention, education, diagnostic, therapy and follow-up of patients for an organisation like the DTMC Trust, that is working regionally as well as supra-regionally, extensively difficult.

Geography & History

Tamil Nadu is the South-Eastern most province of India, with a population of 7,2 Million and its capital in Chennai. The Salem district contains close to 3,5 Million people, while Namakkal, neighbouring in the south-west has a population of close to 1,5 Million. Salem City is located in the centre of Salem District. About 830.000 inhabitants are registered here, whereas the city sees a lot of commuting from neighbouring villages and towns. As a landmark it is located 186km

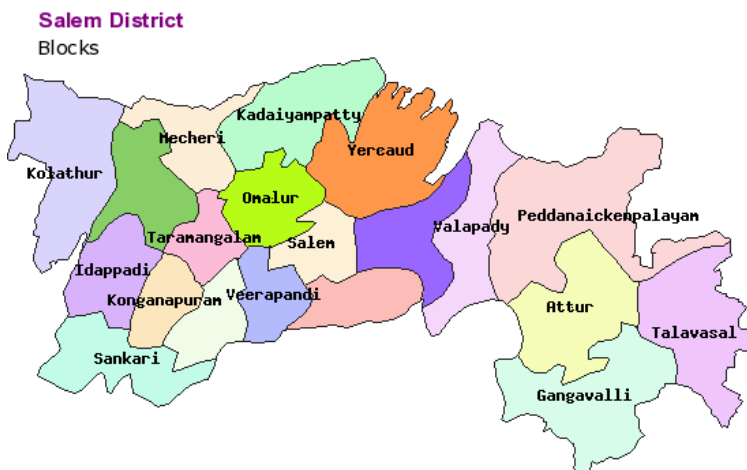


South India Illustrated Map
– by Elisa Simonnet

southeast of Bangalore. The city finds itself surrounded by dotted hills and plains, 280 metres above sea levels. Temperature highs range from 30 to 40°C all year round and lows not below 20°C. Precipitation is highest during the months of October to December, when the Eastern Monsoon arrives, however rainfall has decreased as a result of climate change within the last years and throughout our entire stay we only saw rain once. The area is mainly known for the Salem Steel plant, which uses local iron-ore to produce steel. Additionally agricultural products of the region, foremost Mango, Tapioca, Sago and Coffee are trademarks. Furthermore, the

regions imposes with mineral reservoirs as well as Sandal wood, dairy productions as well as cottage industries. Tourism mainly takes place in the surrounding hill stations of Yercaud and Kolli Hills.

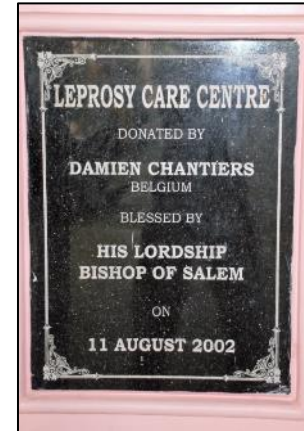
More detailed information is available at:
<http://www.salem.tn.nic.in/>



(Map Not to Scale)
Digital Map Source : TWAD Board, Chennai
Web Design : NIC, TNSC

History of Leprosy Activities

The SMMI Sisters initiated their activities in the region in 1931, focusing on education (especially for girls) and health care. Leprosy attracted a lot of attention at that time with prevalence-rates estimated as high as 130/10.000 and has been in the focus ever since. Dr. Typhagne, a French doctor and name-patron of the DTMC Trust, started the leprosy eradication work in 1960. 18 years later – 1986 not just marked the introduction of Multi-Drug-Therapy with dapson, clofazimine and rifampicin to Salem but also the integration of previous independently working institution into the National Leprosy Eradication Initiative.



January of 1999 marked the official founding-date of the Doctor Typhagne Memorable Charitable Trust, to treat leprosy, tuberculosis and HIV patients, empower socially marginalized people, care for women and children in distress, protect the environment and promote organic farming. Today the DTMC Trust is included into the Indian Leprosy Elimination Plan as a referral centre for ulcer care, prevention of disabilities through early diagnosis and patient-assistance with welfare activities. Therefore, the organisation is involved in the stages of education, prevention and diagnostics as well as treatment of complications, management of disabilities, follow-up and lifelong-care.

With over 85 years of experience in treating leprosy patients, the DTMC Trust today has an integrative and comprehensive approach to achieve its goals in the respective fields. Five permanent health-workers and medical professionals are covering the primary line of representatives together with one lab-technician, while two accountants, one Managing Director and Dr. Sr. Francina build the institutional foundation.



Leprosy

Leprosy, caused by the obligate intracellular bacterium *Mycobacterium leprae*, is a chronic granulomatous infectious disease which mainly affects peripheral nerves, skin, respiratory mucosa as well as the eyes. It is not highly infectious, has an incubation period of 5 years on average and symptoms can take up to 20 years to appear. Transmission is thought to mainly result out of close and frequent contact with untreated, lepromatous cases,(1) however, recent research suggests that environmental factors may also play a role in the geographically distinct pattern of leprosy and its transmission.(2,3) Leprosy is curable through Multi-Drug Therapy (MDT) consisting of dapson, rifampicin and clofazimine, which has been recommended by a World Health Organization (WHO) study group since 1981 and made available free-of-charge globally to persons affected by leprosy since 1995. Through this and joint efforts of international and national institutions, donors and stakeholders the elimination of leprosy as a public health problem, with a prevalence of less than 1 case per 10.000 persons was achieved in 2000.(1) However, leprosy continues to spread, with India accounting for 60% of the global disease burden and 82% of the cases in the South-East Asian Region of the WHO's cluster in 2014. Together with Indonesia and Brazil, India accounts for 81% of new cases globally.(4) The current global strategy towards a leprosy free world – “*The Global Leprosy Strategy 2016 – 2020: Accelerating towards a leprosy-free world*” - was launched in 2016 by the WHO and international organisations aiming to (i) strengthen government ownership, coordination and partnership, (ii) stop leprosy and its complications and (iii) stop discrimination and promote inclusion.(5)

Historical background

Leprosy is one of the oldest diseases known to mankind with recordings available from ancient civilisations in Egypt, China and India, and the oldest Hindu as well as Ayurvedic texts from 6 BC and the Bible referring to it. For as long as the disease has been known, discrimination

accompanied it, which makes leprosy together with the Human-Immunodeficiency Virus (HIV) the *most stigmatised disease* of all.(1,6) Since *lepers* were seen by society as contagious, in the course of the disease disfigured and therefore visible as well as distinguishable and with traditional medicines incurable they were stripped of their rights and freedoms, dispelled from their respective homes, families and societies and branded as people afflicted. The disease was seen as a curse and divine punishment for past sins.(6,7)

In 1873 Gerhard Henrik Armauer Hansen identified *Mycobacterium leprae*, an acid-fast, gram positive bacteria, which multiplies only every 20 hours by binary fission. The complete genome of *M. leprae* was identified in 2001 and showed 1.400 out of its 1.600 base-pairs similar to *M. tuberculosis*, whereas the latter one contains altogether 4.000 genes. Those base-pairs missing, mainly accounted for a lack of metabolic capacities, which explains the long doubling-time.(8)

In India, the approach of the Indian people as well as the Indian government over the decades was by Navin Chawla very pointily described as “benign neglect”.(6) The affected were physically as well as psychologically outcasted and discriminated, the only one taking care of them being voluntary institutions, which created colonies where thousands of ill were living together. Having the status of a divine punishment, it was Christian missionaries who initiated humane efforts in the caretaking of leprosy patients. In 1874 The Leprosy Mission Trust India (TLMTI) was founded as “The Mission to Lepers” still being one of the leading institutions in actions against leprosy today. The official perspective was represented in the installation of the Lepers Act of 1898, a law based on the premise that people affected by leprosy would be so for their entire life, which was true at that time due to lack of medication.

A handful of other Indian laws addressed the *incurable lepers* discriminating them directly as well as indirectly and making social stigma and inclusion acceptable from a legislative to a populist point of view. Contrary to general conception of Indian laws and also contrary to India signing the UN Resolution to End Discrimination Against People Affected by Leprosy, laws discriminating persons affected by leprosy still exists on the statute books of India today.

Besides mainly Christian missionary institutions providing relief to the thousands of affected, in multiple grand-scale non-governmental leprosy relief institutions were created in the 20th century India. One being the Ghandi Memorial Leprosy Foundation (GMLF), which based its work



on there namesake's idea of eliminating leprosy as one of his 18 Point Constructive Programme. And in 1925 the Indian Council of the British Empire Leprosy Relief Association, which was later renamed to *Hindu Kusht Nivaran Sangh*. These and numerous other NGOs lay the foundation of government initiatives, which started by the appointment of an expert committee to

evaluate the national situation in 1941. The GMLF's method – SET: Survey, Education, Treatment was adopted by the installed committee and in 1954 integrated into the newly created National Leprosy Control Programme (NLCP). Already prior to it the First Leprosy Plan was put in action, and detected 17.000 cases from 1951 to 1956. It was the start of a number of national and international plans, which continue to tackle the spread of the disease up to today.(6,9)

The medical regimen available at that time, which was introduced in the 1940s was based on dapsone, a sulfon active agent, which had to be taken over many years, sometimes up to a lifetime and to which M. leprae started to create resistance, firstly reported in the 1960s. It was not until 1981, that a WHO Study Group recommended Multi-Drug Therapy (MDT), based on dapsone, rifampicin and clofazimine, adding the two latter drugs, which were only discovered in the early 1960s. In 1982 MDT came into use but not until 1995 the drugs could be dispersed free of cost by the WHO partnering firstly with the Japanese Nippon Foundation and since 2001 through a donation agreement with Novartis.(1)

In accordance to these developments the Indian government firstly established a high power committee to deal with the problem of leprosy in 1981 and subsequently, in 1983 launched the National Leprosy Elimination Programme (NLEP) being the continuation of the NLCP as a centrally

sponsored National Health Programme. The features of this were the decentralized functioning, being funded through state health societies but functioning under the National Rural Health Mission (NRHM). The main focus was set on highly qualitative and sustainable actions, prioritizing Disability Prevention and Medical Rehabilitation (DPMR). The removal of stigma and discrimination was also to be included. Thereout 5 basic activities were scheduled, being:

1. Surveys and Case Detection
2. Case Registration for Treatment
3. Treatment Provision
4. Patient, Family and Society Education regarding Leprosy
5. Deformity-Correction through Care-after-Cure Programmes

The inclusion of districts happened in a phased manner, with full-country coverage only being achieved by the year 1996.

The epidemiological situation of leprosy at that time in India and Tamil Nadu is striking, especially compared to current data presented later in this report. At the same time we decided to present the data only from 1981, since developments at that period let us suggest, that these estimates and calculations for the first time realistically captured the burden of disease present then.(6,9)

Leprosy Indicators in India and Tamil Nadu in 1981			
Estimated No. of leprosy patients in India	Prevalence Rate per 10.000 in India	Estimated No. of leprosy patients in Tamil Nadu	Prevalence Rate per 10.000 in Tamil Nadu
3919337	57.2	733000	151.4
<p>Table 1: Estimated case load and prevalence rate in India and Tamil Nadu in 1981 Source: Chawla N. Vocational and Rehabilitation and Social Reintegration of the Leprosy Affected in India [Internet]. [cited 2016 Nov 2]. p. 114. Available from: http://eci.nic.in/ECI_Main/DJ/Vocational and Rehabilitation and Social Reintegration of the Leprosy Affected in India (Page1-Page114).pdf</p>			

It was the 44th World Health Assembly in 1991, which launched the biggest to that time, international initiative to eliminate leprosy at a global level by the year 2000 and defined elimination arbitrarily as a prevalence of 1 case per 10.000 persons. To enhance this goal, the

first phase of World Bank support to the NLEPs campaigns ran from 1993 to 2000, and made MDT available free-of-cost to all registered cases. From 1998 to 2004 the NLEP introduced its modified leprosy elimination campaigns, which were held five times in that period. This was accompanied from 2000 to 2004 by the 2nd World Bank support, during which period the NLEPs activities were decentralized and put under responsibility of the respective States and Union Territories, and which saw the Leprosy services integrated into the General Health Care System, ending the vertical approach. In December 2005 leprosy was declared eliminated as a public health problem at a national level.

While the Government of India introduced its plan of elimination in 2005 and the NLEPs 11th Plan from 2007 to 2012, it was the “Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities 2006-2010” which was launched by the WHO. The goals were set to sustain services for leprosy patients even in the official state of elimination of the disease and therefore in monetary scarcity. The services were to be integrated into the general health system, whilst sustaining quality of services, underserved communities were to be reached and partnerships were to ensure the further reduction of disease burden.(6,7,10,11) However, international as well as national focus shifted away from leprosy and new cases occurred. Incidence numbers even increased in the post-elimination era in so called “pockets” – hyperendemic areas, which led to an overall stagnation of the leprosy situation. To stop the complacency and increase political commitment the WHO together with The Nippon Foundation organized the International Leprosy Summit, in which representatives of 17 high-burden leprosy countries, amongst them India reaffirmed their commitment to eliminating leprosy by signing the Bangkok Declaration to achieve a leprosy-free-world.(12) The foundation of the declaration as well as the continuation of WHO’s programmes, namely the “Enhanced Global Strategy to Further Reducing the Disease Burden Due to Leprosy 2011-2015” were mainly based on the concept created in the Eighth Report of the WHO Expert Committee on Leprosy, which was created in 2012.(13)

Despite the great efforts and successes that were achieved during the past 35 years, from the development and integration of Multi-Drug Therapy, the drop in prevalence by 99% from 1983 to 2014 and the national elimination of leprosy in India in 2005, leprosy eradication remains a

realistic yet distant dream with new highly infectious cases being reported daily and an incubation period of years on average, which will make leprosy a challenge also in decades to come.(1,10)

**2016-2020
GLOBAL LEPROSY STRATEGY**

VISION
A LEPROSY-FREE WORLD

- Zero disease
- Zero transmission of leprosy infection
- Zero disability due to leprosy
- Zero stigma and discrimination

GOAL
Further reduce the global and local leprosy burden

TARGETS

INDICATORS	2020 target
Number of children diagnosed with leprosy and visible deformities	0
Rate of newly diagnosed leprosy patients with visible deformities	<1 per million
Number of countries with legislation allowing discrimination on basis of leprosy	0

PILLARS AND COMPONENTS

- Strengthen government ownership, coordination and partnership**
 - Ensuring political commitment and adequate resources for leprosy programmes.
 - Contributing to universal health coverage with a special focus on children, women and underserved populations including migrants and displaced people.
 - Promoting partnerships with state and non-state actors and promote intersectoral collaboration and partnerships at the international level and within countries.
 - Facilitating and conducting basic and operational research in all aspects of leprosy and maximize the evidence base to inform policies, strategies and activities.
 - Strengthening surveillance and health information systems for programme monitoring and evaluation (including geographical information systems).
- Stop leprosy and its complications**
 - Strengthening patient and community awareness on leprosy.
 - Promoting early case detection through active case-finding (e.g. campaigns) in areas of higher endemicity and contact management.
 - Ensuring prompt start and adherence to treatment, including working towards improved treatment regimens.
 - Improving prevention and management of disabilities.
 - Strengthening surveillance for antimicrobial resistance including laboratory network.
 - Promoting innovative approaches for training, referral and sustaining expertise in leprosy such as eHealth.
 - Promoting interventions for the prevention of infection and disease.
- Stop discrimination and promote inclusion**
 - Promoting societal inclusion through addressing all forms of discrimination and stigma.
 - Empowering persons affected by leprosy and strengthen their capacity to participate actively in leprosy services.
 - Involving communities in actions for improvement of leprosy services.
 - Promoting coalition-building among persons affected by leprosy and encourage the integration of these coalitions and or their members with other community-based organizations.
 - Promoting access to social and financial support services, e.g. to facilitate income generation, for persons affected by leprosy and their families.
 - Supporting community-based rehabilitation for people with leprosy-related disabilities.
 - Working towards abolishing discriminatory laws and promote policies facilitating inclusion of persons affected by leprosy.

Earlier in 2016 the WHO therefore launched its newest “Global Leprosy Strategy 2016-2020 – Accelerating towards a Leprosy-Free World”, which envisions a leprosy-free world and targets on (i) zero Grade-2-Disabilities in pediatric patients, (ii) reduction of new leprosy patients with grade-2-disabilities to less than one case per one million persons and (iii) zero countries with legislations allowing discrimination against people affected by leprosy by 2020. Key tenets include early detection of all patients before they develop disabilities, prompt treatment with a uniform MDT regimen, inclusion of persons affected by leprosy, enhancing of research especially in the area of prevention, new diagnostics, stigma reduction, and promotion of wider partnerships.(5)

Today the numbers read less tragic in terms of their quantity, yet nonetheless sad concerning an eliminated disease, which still causes around 230 newly infected just alone in Salem district each year, about half of them being highly infectious and a dozen each year already showing deformities at presentation and therefor accounting for further nourishment of prejudice, stigma and discrimination.

Prevalence Rate & Annual New Detection Rate

	Global 2015 (*)	SEAR 2015 (*)	India 2014-15	Tamil Nadu	Salem
PR per 10.000	0.29	0.61	0.69 (**)	0.38 (**)	0.32 (**)
ANCD per 100.000	3.2	8.1	9.73 (++)	4.71 (++)	4.80 (++)

(*) based on population of all countries reporting, not on world population

(**) as on 1st April 2015

(++) for 2014 - 2015

Table 2: Prevalence Rate & Annual New Case Detection Globally, for India, Tamil Nadu and Salem District

Sources: World Health Organization. Global leprosy update, 2014: need for early case detection. Wkly Epidemiol Rec. 2015;90(36):461–74.

National Leprosy Eradication Programme India. NLEP - Progress Report for the year 2014-15 [Internet]. New Delhi; 2015. Available from: [http://nlep.nic.in/pdf/Progress report 31st March 2014-15 -.pdf](http://nlep.nic.in/pdf/Progress%20report%2031st%20March%202014-15%20-.pdf)

National Leprosy Eradication Programme India. District Wise Annual New Case Detection and Prevalence as on March 2015 [Internet]. 2015. Available from: [http://nlep.nic.in/pdf/Disttwisw NCDR-Mar.15 .pdf](http://nlep.nic.in/pdf/Disttwisw%20NCDR-Mar.15%20.pdf)

NLEP, Salem District, Yearwise Epidemiological Chart

	New cases added through year			PR (per 10.000)	ANCDR (per 1 Mio)	Proportion Among New Cases			
	PB	MB	Total			Female	Child	Deformity	MB
2015 to 2016	174	101	275	0.5	7.35	38.5	17.5	7.27	36.7
Average 2010 - 2016	119	109	228	0.45	6.6	31	11.3	5.6	48.6
Median 2010 - 2016	106	105	217	0.465	6.3	31.7	11.9	5.8	50.7

Table 3: Salem District Annual Epidemiological Indicators and Average Data for 2010 - 2016

Source: National Leprosy Eradication Programme India. NLEP District wise Report of Monitoring & Evaluation of NLEP Activities in Salem District of Tamil Nadu State in August 2016. New Delhi; 2016.

My work

Of the three defined goals for this visit – surgical correction of leprosy extremities, antibiotic resistance study in ulcers of leprosy patients and evaluation of activities towards eliminating leprosy – my focus was on the latter two. Together with Elisa Simonnet, medical-student of the Université de Bretagne Occidentale Brest, France I arrived in October to conduct analyzations already prior to the team of doctors and nurses and to prepare their visit. Through a comprehensive introduction to several activities of the DTMC Trust, including visits to all three offices and facilities we got to know the magnitude of our partnering NGO. Doors were opened and we were heartily welcomed wherever we arrived, which made the time a pleasant one and the stream of information digestible yet grand. Starting on day one we found ourselves part of the project, learning the ups and downs such institutions have to face here and the challenges the team faces in trying to provide the best service possible.



As of the second week Dr. Sr. Francina and the DTMC Trust provided us with Anthony, himself Community-Health Worker and Leprosy Technician for over thirty years, as well as a car and driver, to conduct surveys I had prepared all the way from the FairYoungStyria 2015+ Workshops, through multiple hours with my mentor Prof. Dr. Wolf Sixl and finalized only in the first days in Salem. Finally, we focused on treated multibacillary leprosy patients with grade 1 and 2 disabilities, looked at their history of ulcers and usage of MCR shoes as well as their social situation, starting from Marital Status, over housing situation and addictions.



In total 127 patients were included in our survey, from 13 blocks within the district of Salem and Krishnagiri. The reason we finally chose to conduct such a study, rather than one focusing more on the epidemiology of leprosy and incidence within the district was, that government-efforts named as Leprosy Case Detection Campaigns had just undertaken such investigations prior to our stay and fresh data was available. Each patient was physically examined, interviewed and the housing situation quantitatively as well as qualitatively analyzed. Additionally, we screened those eligible for operations as well as for ulcer samples for our antibiotic resistance study.

Besides being scientifically interesting and *a first* for the two of us, to conduct a study all by ourselves, the first-hand experiences of patients affected by a disease also labelled as the “disease of the poor” was a challenging but insightful and enlightening experience. Finding living conditions that in our western setting wouldn’t even suit animals, with people living at the edge of society and personal riddance, on the edge of starvation and basic hygiene was one that up to

today is not easy to put into words. Even at earlier visits to third-world-countries I had seen poverty, but rarely in such a naked, obvious and accepted way as here.

To summarize our findings in which 127 patients were included into primary calculations, two-thirds were male and the average age was 65. Houses that we inspected were inbetween 4 and 140m² big, with 1 to 9 people living within one house. Almost 98% had no running water inside, 74% were defecating in open areas and 54% used open fire for cooking their daily meals, including a regular walk into the bushes for firewood. 38 patients presented with current ulcers and amongst these as well as patients from the inpatient as well as outpatient department in Salem 67 wound swaps were taken for further analyzation regarding germ-spectrum and antibiotic resistance.

As the Austrian team, consisting of one general surgeon, an anesthetist and anesthetic nurse, a specialist for hygiene and microbiology, a general practitioner and a clinical nurse arrived, we added the scheduled wound swaps to our programme. Firstly, during a Prevention of Deformities camp we were able to obtain over thirty samples and altogether, after including admitted patients as well as people visited in their homes we came up to 67 swaps from 52 persons.

After each visit to a leprosy home and after obtaining the wound swaps, proper documentation was the key to obtaining clean data as we are having it now.







As we covered basically all of Salem district in our rounds, we were lucky to get to know even more of southern India on weekends and through our partners at the DTMC Trust, who at times joined us or helped us organize in any way possible. Bangalore and Madurai were the cities, Kolli Hills as well as Yercaud the Hill Stations and a trip all the way to Kerala, Kumily, the Backwaters and Allepey let us even see the Arabian Sea.



Enjoyable, furthermore were nutritious delights, for which we deliberately want to thank the kitchen staff in Salem and the DTMC Trust for providing us with all meals every day, throughout our stay. Idly and Dosa gave us strength for the day, Thaliss empowered us for afternoons in the field and caramel nuts, chai or coffee made every break joyful.



Summary

Leprosy on the Road is real.

Throughout a stay in one of the best settings to learn about a disease, its far-reaching consequences, the life-long management and delicate assembly of facilitations as well as obstructions, I really had the impression of learning and getting to know practical Global Public Health, which was fascinating, frustrating, eye-opening, unbelievable and challenging at times in the same moment.



House of a person affected by leprosy – Leprosy on the Road

One of the oldest diseases known to mankind still dwells amidst us, in a lamentable situation of *less but not yet gone*, putting everyone involved in the predicament of little quantitative arguments for the necessarily highly-qualitative investments needed.



To finalize our stay in India, we were very lucky to be invited by Mr. Munish Bahl, Senior-Advisor of the Cultural Forum of the Austrian Embassy New-Delhi, to present our project and findings in a two-and-a-half-hour conversation, which was insightful for both sides and resulted in a surge for further cooperation. At this occasion, we were also able to present to him a draft-version of our “Global Health and Development Final Report – Salem 2016”.





May this *Drishti Bommai* protect all houses of persons affected by leprosy of evil
- by Elisa Simonnet

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