



**Damien Foundation India Trust**

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# Activity Report

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**Damien Foundation India Trust**





## Foreword

*Amidst the present global gloom enveloping human enterprise of all nature we glimpse a pool of glimmering lights. They represent the spirited response to age-old threats. Persons working in Leprosy and TB control must take pride in the fact that they are among those reflecting the glimmer, spirit, energy and determination. Even though the time has not yet arrived for blowing the trumpet and beating the drums it need not prevent them from living it up. Their accomplishments are writ large in the smiles of those rid of the scourges. But we tend to see their exploits only in the statistics that is generated. Behind every number there is a person affected and behind every person affected there are tens of workers who have provided the support to the healing process. They are rarely acknowledged, barely praised. They are not even asterisked entries. They brush off disappointments, shrug off frustrations and rejoice in the consequence of their actions.*

*This report is dedicated to those millions of workers who continue to make a significant difference to the lives of millions of persons. Damien Foundation is proud to be associated with them and gratefully acknowledges their contribution and consequence and promises them undying partnership through the whole journey.*

*This report depicts in detail the accomplishments and the challenges, the sorrow and the triumph, from the projects and the persons affected. There is satisfaction for some, lessons for a few, information for all.*

P. Krishnamurthy

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### 1. Introduction:

Damien Foundation India Trust (DFIT) is a charitable organisation involved in leprosy and Tuberculosis control activities in India. It is also one of the nine members of the International Federation of anti-leprosy associations (ILEP) working in partnership with Government of India in leprosy control.

Damien Foundation began its leprosy control activities in 1955 in Polambakkam in Tamil Nadu. Since then it has grown in spirit and reach and now supports several projects spread in 7 States in India. Its involvement in leprosy control has evolved in 3 phases:

- hospital-based direct patient care delivery;
- field based support with referral service in defined populations;
- hospital-based direct patient care as part of referral service.

At present State-specific activities in leprosy control are implemented within the broad framework of ILEP support plan. Till March 2007 the support to leprosy control in States was provided through District Technical Support Teams and through referral centres under ILEP support. Since April 2007 ILEP support has been provided with the focus on capacity building of the District supervisory staff and also the general health staff in establishing sustainable quality leprosy services through the integrated general health set up. A representative from ILEP has been placed in major endemic states to coordinate the implementation of ILEP support activities. DFIT is the ILEP State coordinator in Bihar State. In addition DFIT has been providing referral service to persons in need in the specific areas of management of complications (reactions, ulcers) and reconstructive surgery through its hospitals. All these services are offered free of cost to Leprosy and TB patients.

Support to TB control was taken up in 1996 and it is in the form of providing diagnostic and treatment service in a population of 100000 (Microscopy centre) or 500000 population (TB Unit) or supervisory support to Government staff in 500000 population (TB Unit).

In addition support is provided to leprosy and TB control in districts. In the case of leprosy district support is provided for building the capacity of the staff in establishing Disability Prevention and Medical Rehabilitation (DPMR) and in TB it is the technical support that is provided for strengthening DOTs.

### 2. Projects and personnel:

There are three distinct categories of projects:

- NGO projects directly operated by DFIT (Delhi and Nellore) or supported by DFIT (Ambalamoola, Arisipalayam, Amda, Aundipatty, Chilakalapalli, Dindigul, Fathimanagar, Kavali, Nagepalli, Pavagada and Trivandrum);
- District Consultancy support to TB control (37); and
- NGO projects providing support to DPMR in 20 districts: (8-Amda, 5-Fathimanagar, 3-Nellore, 3-Salem and 1-Trivandrum).

The NGO projects provide Leprosy and TB care service in their hospital and field (Microscopy Centre & TB Unit for TB) or support districts (DPMR). Support exclusively to TB control is provided through consultancy teams in 37 districts (28 in Bihar, 4 in Andhra Pradesh, 4 in Karnataka and 1 in Kerala). Support to the establishment of DPMR services is provided by five projects in 20 districts. Support to NGO project in Dindigul was terminated in April 2008.

Project	Patient care: Leprosy				Patient care: TB			No. of districts supported		Special Activities
	PC	SC	TC	IP	MC	TU	IP	TB	DPMR	
Tamil Nadu										
Ambalamoola	✓	✓		✓	✓		✓			
Aundipatty	✓	✓		✓	✓		✓			
Dindigul	✓	✓		✓	✓		✓			
Fathimanagar	✓	✓	✓	✓	✓		✓		✓(5)	
Salem	✓	✓		✓	✓	✓	✓		✓(3)	
Andhra Pradesh										
Chilakalapalli	✓	✓		✓	✓					
Kavali	✓	✓		✓	✓	✓	✓			
Nellore	✓	✓	✓	✓	✓		✓		✓(3)	MDR TB project
Others										
Amda	✓	✓		✓					✓(8)	
Nagepalli	✓	✓		✓	✓		✓			
Pavagada	✓	✓	✓	✓	✓	✓	✓			
Trivandrum	✓	✓		✓	✓		✓		✓(1)	
Delhi	✓				✓	✓				
Consultancy teams										
Bihar						✓		✓(28)		UMDT (3)
Andhra Pradesh								✓(4)		
Karnataka								✓(4)		
Kerala								✓(1)		
State Coordination (National Leprosy Eradication Programme)										All 38 districts of Bihar as part of ILEP coordination

PC= Primary Care; SC= Secondary Care; TC= Tertiary Care; UMDT= Uniform Multi Drug Therapy; DPMR= Disability Prevention and Medical Rehabilitation MC= Microscopy Centre; TU= TB Unit; IP= In Patient; MDR= Multi Drug Resistant;

The project activities are implemented by the Trust through the Secretary. All the technical support is coordinated by the Director (programmes) who is assisted in the South by Chief Medical Advisor and in Bihar by TB and Leprosy programme coordinators. Administrative support is provided overall by the Chief Administrative Officer who is assisted by an Administrative Officer in Bihar. Finance management is coordinated by Chief Financial Officer. The total number of staff with Damien Foundation is 377 which include 26 doctors, 69 supervisory staff, 5 STS, 9 STLS, 9 physiotherapists, 1 Microbiologist, 2 laboratory coordinators, 67 laboratory technicians, 7 field workers, 30 hospital staff and 152 administrative staff including 78 drivers.

### 3. Activities:

The overall management of the projects is through the trust (7 members) with the Secretary being given the responsibility for execution of the mandate. The main activities of the organisation are:

- Providing direct delivery of care to persons affected by leprosy or TB;
- Capacity building of the government staff;
- Technical support to RNTCP in districts;
- Providing reconstructive surgery services to those who are eligible and willing;
- Support to the Government in establishing DPMR services in districts;
- Infrastructure support to government;
- Livelihood enhancement for persons affected by leprosy or TB;
- Community awareness generation regarding leprosy and TB disease and programmes;
- Promotion of community involvement in Leprosy and TB programmes;
- Continuing Medical Education to Undergraduate and post graduate medical students, faculty, General practitioners;
- Management of Multi Drug Resistant TB cases;
- Research;
- Coordination of the activities of ILEP member representatives in Bihar.

#### 3.1. Providing direct delivery of care (primary, secondary and tertiary) to persons affected by Leprosy or TB:

##### 3.1.1. Primary and secondary care service (Leprosy):

The thirteen NGO projects provide primary and secondary levels of care for persons affected by leprosy. They diagnose leprosy among difficult to diagnose suspects referred by peripheral health institutions and refer them back after diagnosis for treatment. They manage persons with complications (lepra reactions, complicated plantar ulcers) referred from the periphery or reporting voluntarily. Majority of these are referred back after diagnosis and initiation of treatment to the Primary Health Centres for follow up management. Persons who require intense follow up are hospitalised. Total number of cases diagnosed in these facilities in 2008 was 231 of which MB was 128. There were 14 persons among them with grade 2 disability. Total number of reactions managed by the projects in 2008 was 124. (57 Type I, 30 Type II and 37 Neuritis).

**In the race to success there is no second prize.**

- P. Krishnamurthy

### 3.1.2. Re-Constructive Surgery service:

There are three NGO projects (Fathimanagar, Nellore and Pavagada) which provide tertiary level of care also. Each of these projects has a well equipped Operation theatre, well trained Physiotherapist and hospital staff and wards for hospitalization. The surgeon located at Head office in Chennai visits the three places once in two months to perform surgery. Persons with disability referred by PHCs, District Leprosy Offices or reporting voluntarily are provided Re-Constructive Surgery service. A total of 74 persons (17 in Fathimanagar, 29 in Nellore and 28 in Pavagada) underwent 98 surgeries (hand-60; foot-19; eye-4; nerve decompression-11; and amputation-4) in 2008. All the cases are followed up (Postoperative) for five years.

### 3.1.3. Hospital admissions:

Totally 855 persons with complicated plantar ulcers, 33 with severe lepra reactions, 195 with other complications and 74 for Re-Constructive Surgery were hospitalized. Total number of bed days used was 34,829 with bed occupancy rate of 43.9% (34929 / 79205) for leprosy related reasons. The projects provided 2193 pairs of MCR footwear for needy leprosy patients.

### 3.1.4. Primary and Secondary care services (Tuberculosis):



Out of the thirteen NGO projects, one (Amda) is not involved in TB control and one (Chilakalapalli) is involved but its TB control activities are not supported by DFIT. Of the eleven projects 6 are in rural areas (Ambalamoola, Aundipatty, Fathimanagar, Nagepalli, Kavali and Pavagada). The TB management services are provided under different schemes of RNTCP. Seven projects (Ambalamoola, Aundipatty, Dindigul, Fathimanagar, Nagepalli, Nellore and Trivandrum) provide TB services

through Microscopy Centres and four projects (Delhi, Kavali, Pavagada and Salem) manage TB cases through 5 TB units. TB services in the two TB Units in Delhi project are provided entirely by its own staff and the TB control activities are implemented by them in close collaboration with the community. In Kavali the five Microscopists in 5 Government primary health centres are placed by the project and the activities are carried out by these LTs and the Government GH Staff under supervisory support (STS, STLS and MO) from the project. In Salem and Pavagada the programme in the TB Unit is primarily managed by the Government staff (LTs are from the Government and supervision of the DOT providers is done by the GH staff) with supervisory support (STS, STLS and MO) from the project. Facilities for hospitalisation of seriously ill TB cases are available in 10 of the 11 projects involved in TB control.

## The world is certainly round!



It all started when Madhavan (name changed), 23 years, from a village in Madurai in Tamil Nadu was 12 years of age. He can even remember the day. It was two days after the Tamil New year. He noticed numbness on the back of his right forearm. He told his mother about it. She looked at it and said there was nothing. Three years passed. He noticed an increase in the area of numbness. He felt rather uneasy. He told his parents that there was something wrong. He was taken by his father to the family doctor who asked him to take green leafy vegetables, prescribed some vitamin B tablets and said that it was due to vitamin

deficiency and he would be all right soon. Unfortunately, he was not. He noticed difficulty in holding objects in his right hand, buttoning his shirt and picking food from the plate. The right little and ring fingers became slightly crooked.

He went to a local skin specialist who noticed a skin patch on his back, prescribed treatment (three drugs called MDT-multidrug therapy). He did not tell Madhavan what his disease was. He was asked to come every month to collect drugs from him. The next month when he went to see the doctor Madhavan asked him about his disease and the doctor told him it was leprosy. He was shocked. Did he hear someone say that it was curable? He did not believe it. But he continued the treatment for 8 months. By then he had spent more than Rs. 1000. Madhavan's uncle when he visited them told him to go to an NGO centre nearby. He followed his advice and he was again given the same treatment. After one month he developed red, painful skin patches all over the body and pain in his right elbow. He was now given another drug and was asked to do exercise for the hand. Eight painful months later when he went to the local primary health centre for seeking treatment for cough he met leprosy worker who asked him to go to Holy Family Hansensorium, the NGO project at Fathimanagar.

He went there immediately (May 2008). He was told by the doctor that he was completely cured of the disease and therefore did not require any medical treatment for leprosy and sensory loss in the hands could not be recovered. The only recourse now was to correct the deformity through surgery. He was operated for his deformity in September. He is well on his way to complete recovery of the use of his hand. He admits that there is no discrimination by his friends in the college where he is studying Pharmacy. He proudly confesses that he has been able to refer a person from his village with skin patches and bent fingers and he is on treatment now. Madhavan may not be in high spirits, he is a happy man now.

#### *Case notification:*

The eleven projects covered a total population of 36, 16, 927 in 5 States. The number of New sputum Positive cases detected was 1917 (53/100000 population). The NSP per 100000 population in the four 5 TB units was 53 (Salem), 54 (Kavali), 76 (Pavagada), and 73 (Delhi TB unit 1) and 91 (Delhi TB Unit 2). A total of 4753 cases were registered of which 996 were Re-treatment cases, 836 were Pulmonary Negative and 1004 were Extra-pulmonary. The proportion of Pulmonary positive cases out of the total was 61.4% which is as per expectations. The NSP proportion was 40%, retreatment 21%, Extra-pulmonary 21% and pulmonary negative 18%.

#### *Outcome:*

The outcome in all the projects in general was good. Conversion was 87.9% (range 75% to 93.3%), Cure rate was 86.4% (range from 73% to 92%), Defaulter proportion was 1.7% (range from 0 to 6.5%), Failure was 3.7% (0 to 16.7%) and Death rate was 5.3% (2 to 24%). Defaulter rate was highest in Delhi, an urban area. Failure was highest in Ambalamoola (16.7%): since the number was small it is not fair to convert it into proportion. Death rate was highest in Fathimanagar because of the large number of cases with HIV co-infection. Cure rate in the 5 TB units was 83.3% (Salem), 90.8% (Kavali), 82.4% (Pavagada), and 92% (Delhi TB Unit 1) and 84% (Delhi -TB Unit 2)

#### *Admissions:*

In 10 projects with inpatient facilities 259 admissions were made for managing TB cases with complications (6 in Nellore, 89 in Nagepalli, 46 in Salem, 24 in Aundipatty, 19 in Kavali, 15 in Fathimanagar, 18 in Pavagada and 42 in Trivandrum).

All the services provided by the projects are free of cost.

### **3.2. Capacity building of the government staff:**

Capacity building can be three-dimensional: development of human resource, organisation and institutional framework. Even though the efforts of DFIT are directed at all the three elements the major focus is on human resource and organisation development. Both are aimed at providing technical or material assistance designed to strengthen one or more elements of organisational effectiveness (governance, organisational capacity, human resources, materials, service delivery). The clients are the local government, community and NGOs and private sector.

The aim of capacity building of the clients is to improve their participation in the programme, increase their problem assessment capacities, develop local leadership and strengthen links to other organisation and people. At the provider level one of the important capacity-building interventions is training.

There could be different kinds of training; on the job training with assistance from a training provider; mentoring –working alongside another employee to provide guidance; in house courses from an external trainer and external courses in institutions. Training can set right the inadequate skills of set of personnel already deployed,

sensitisation of the community will help in creating appropriate demand situation and establishing conducive environment for their participation in important health action and decision making.

Capacity building of the staff is done through several means: trainings, workshops, meetings, supervision, technical updates, and review. One of the important activities of the projects is to build the capacity of the general health staff in managing leprosy and its complications. Towards this end projects are mandated to use every interaction with the general health staff to build on their capacity to manage persons affected by leprosy and the programme.

#### *National level:*

As part of National ILEP support, officers from DFIT participated in National level workshop for State Leprosy Officers and development of training manual for NLEP.

#### *State level:*

Surgeon from DFIT trained 29 doctors in the State of Goa on DPMR. Similarly, as part of DPMR activity in Tamil Nadu, training for 31 Physiotherapy technicians was provided by the Surgeon at the NGO project in Fathimanagar.

Training for the general health staff on DPMR in Bihar was carried out in 9 districts. A periodic supervisory visit to Patna Medical College and Dharbanga Medical College in Bihar is made by the Surgeon to provide supportive guidance to the local teams. RCS facility was introduced in Jamshedpur Medical college hospital by the intensive efforts of State Leprosy Officer, Jharkhand with support from NLR. Re-Constructive Surgery team in Jamshedpur Medical college hospital was trained by the DFIT surgical team.

#### *Project level:*

Totally 246 Medical Officers, 1698 staff from General Health service, 8363 Students, and 1004 others (General Practitioners, NGOs, Community members, Self Help Groups) were trained in leprosy by the NGO projects supported by DFIT.

In Tuberculosis control, the projects trained 215 Medical Officers, 6235 General Health staff, 6588 Students and 8894 others from the community.

### **3.3. Technical support to RNTCP in districts:**

#### **3.3.1. Introduction:**

District consultancy teams have been placed in 28 districts of Bihar, 4 districts in Andhra Pradesh, 4 in Karnataka and 1 in Kerala for providing support to RNTCP. The concept of District teams for supporting the programme was originally used for supporting Leprosy control. The same concept was applied by DFIT in extending support to TB control. Each consultancy team consists of a Supervisor, a Medical Officer with mobility support. The team provides support in key areas like identification, training and monitoring of community DOT providers, ensuring follow up sputum examination, and updating of records, advocacy and community education. Two laboratory coordinators are

## The anguish of a young couple

Hirna & Dinesh (names changed) were a very happily married couple. He was a highly qualified computer engineer working with a well known computer advisory firm in a neighbouring country. They had known each other from their school days. Hirna noticed some vague patches on her body when she was 14 years old but neglected them since they were not troublesome. Years later, she married her childhood sweetheart and life was good for her.

Eight years ago she noticed small painful swellings over her upper and lower limbs with swelling of her legs. She was seen by many doctors and given various types of treatment, but nothing proved helpful. A close family friend and Physician of the leprosy programme in the country finally submitted her to a skin biopsy and diagnosed leprosy. She was put on MB MDT for 2 years. Meanwhile, she continued to get the swelling of her legs and arms with nodules frequently. For nine years she was treated with various types of steroid to combat her reaction, including 1000 mgs. of intravenous Methyl Prednesolone. She was given 2 courses of Thalidomide with a warning not to get pregnant, but her reaction never abated. The doctor then tried something none of us would have even thought of! She was exposed to 2 pulses of Cyclophosphomide (an anti-cancer drug)! Being sleepless at nights she was on regular sedatives. Exposure to all these drugs over years started taking its toll on her body. She developed severe Diabetes and within a couple of years had bilateral cataract surgery done. She became severely anaemic and was promptly started on haematinics. Then Osteoporosis set in and at the young age of 30, she acquired a stoop, the bodies of her thoracic vertebrae were giving way and she had severe backache! The Physician started her on Calcium and other supplements. Then came the news that Dinesh was being deputed to India on promotion, to set up their regional office in Chennai. There was joy within the family but anguish between them because of the uncertainties of treatment for her. They scoured the internet for some answers before starting for Chennai and came up with the ALM website. They were then directed to visit DFIT.

A stooped, small fragile-looking lady in extreme pain, supported by her husband walked into our office early this year. All unnecessary drugs were stopped, the standard treatment for reaction was started and she was referred to a local NGO leprosy hospital since there might be need for in-patient treatment for her. Now, she is free of any of those painful swellings and reaction-free. She is regaining her confidence and the couple seem to be seeing happy days again.

provided at the state level in Bihar to support the establishment of quality sputum microscopy in the State. One central laboratory coordinator placed at Chennai is involved in supporting quality assurance in sputum microscopy in all the TB projects supported by DFIT. The teams visit the PHCs, villages, patients and community volunteers to build their capacity to improve the programme. They visit the villages to ensure that the patients are on DOT, the DOT providers are functioning correctly (and arrange new DOT providers wherever needed), check community awareness by interviewing randomly selected community members and do IEC activities. They are often accompanied by the STS/STLS and DTO and MO of PHCs during the field visits. They visit PHCs during the meeting days to interact with the ANMs and relate the field problems and identify solutions, ensure that the patient cards are updated and wrong categorization is avoided. They visit the DMCs to identify problems regarding sputum microscopy and try to solve them through the supervisory visits of Lab coordinators. The Medical consultant of the team visits the District Officers to appraise them about the field problems and give them the essential support in solving the problems. The consultant tries to be present during the monthly meeting in the districts to help the district officers in resolving operational issues. All the teams meet once in two months in Bihar and once in three months in the south to discuss various operational issues, exchange best field practices and get technical updates.

The impact of the intervention is that the programme has shown considerable improvement in all areas of implementation. Quality in sputum microscopy has improved to a considerable extent- at least 80% of the DMCs are functioning properly. DOT supervision has shown a vast change- importance is now given to involving community members in DOT supervision. Involvement of the general health staff in supervising the DOT providers, updating the cards, community education has shown a sea change. Monitoring at the PHC level has improved considerably.

### 3.3.2. Bihar:

The team structure in Bihar consists of a Chief Medical Advisor at the State level who is assisted by two Senior Medical Advisors and 7 Medical Consultants. There are 47 supervisors, at least one in every one of the 28 districts supported by DFIT. Teams from the south are sent to Bihar periodically to assist the Bihar teams in building their capacity. All the team members were trained at TB Research Centre in Chennai or National Tuberculosis Institute in Bangalore. Periodic technical updates are provided to the teams by consultants from DFIT Headquarters in Chennai. The Senior Lab coordinator placed in Patna to assist the State in training STLS and LTs and in establishing



quality sputum microscopy has been trained both by National Institutes in India and abroad. There is also the Central Lab Coordinator in Chennai headquarters who coordinates quality assurance in lab services in DFIT assisted projects.

The teams are placed in Arwal, Araria, Aurangabad, Bhojpur, Buxar, Dharbanga, East Champaran, Gopalganj, Jehanabad, Katihar, Khagaria, Kishanganj, Madhepura, Muzaffarpur, Madhubani, Nalanda, Nawada, Patna, Purnea, Rohtas, Saran, Sheohar, Sitamarhi, Siwan, Saharsa, Supaul, Vaishali and West Champaran.

**Diagnosis:**



Number of districts covered is 28. One of the districts (Gaya) which had been with Damien Foundation was given to Maitri project (a project which had been supported by DFIT for leprosy control till 2005). But support to the establishment of DMCs including training of the key staff was with DFIT. It is likely that the district would be handed back to DFIT for resumption of team support from the second quarter of 2009.

Total population covered in the 28 districts (2008) was 77 172 334. There are 414 blocks, 34778 villages, 29 District hospitals, 50 referral hospitals, 356 PHCs, 787 Additional PHCs, 6669 Sub-centres, 128 TB units. There are 2816 Medical Officers (559 on contract), 359 Block / District Health Managers, 775 Multi Purpose Health Supervisors (MPHS), 10400 ANMs (2782 on contract), 276 pharmacists, 60786 ASHA and 50939 Anganawadi workers. Number of DMCs functioning has gone up from 369 to 457. The situation as for as the number of DMCs established as per the requirement has not changed. There are only 457 DMCs instead of the 1500 required for the population in the 28 districts.

Suspect referral remained has come down it was 2.6% as compared to 3.2% in 2007 (mainly due to the addition of 6 districts in 2008). Quality of smear was good in 87.6% (It was 86.4% in 2007). Single sputum examination was done in 4.2% of respiratory symptomatics (5.8% in 2007). About 77.5% of those subjected to single sputum examination were retrieved. Awareness level among the community has gone up from 50% to 57%. It was highest (79%) in Vaishali and lowest (33.2%) in Muzaffarpur.



**Out of darkness into light**



Mr. Shivadas (Name changed) from Nalanda district in Bihar was a shoe maker by profession. Two years back he went for fishing. A snail (according to him) bit him in the leg. Even though there was severe bleeding, he did not feel any pain. He was taken by his uncle to a local ayurvedic doctor who treated him for one year. He used to get medicine once a month for which he spent Rs.500/- per month. The doctor died. Three months later the village leader saw him and took

him to the PHC where diagnosis of MB leprosy was made. Patient had infiltration on the face, back of the arm and buttocks. He had thickening of both ulnar and both LPN. There was anesthesia in the sole and both the feet but no ulcers. Patient was diagnosed as MB leprosy and MDT was started at the PHC.

**All is well that ends well**

Mr. Upendra (Name changed) in Gaya district of Bihar went to Surat in search of livelihood. A few months later he noticed redness & shininess of the skin on the face, ear, back. People noticed the abnormality in the ears and told him about it. He was advised by his neighbour to go to a doctor. He refused because some body told him that if he went to a Government doctor at the PHC, his ears would be cut. When he came back to the village in Washirganj, Gaya, PHC staff living in the village took him to the PHC and got the treatment started for him. He is responding well to MDT.



**So near yet so far**



Mrs. Kamala (Name changed) belongs to Rajgir, a town in Nalanda District of Bihar. 3 years back she had a patch on the right cheek. She went to the local doctor who said it was leprosy in reaction. He treated her for four months. She did not find any improvement. Her maternal uncle who visited her told her that treatment was available for her disease at the local primary health centre. She was taken by her husband to the PHC where treatment with MDT was started. For first six

months all the three drugs (Rifampicin, Clofazimine, and Dapsone) were given and for the subsequent six months Dapsone was excluded from treatment for no apparent reason. She was released from treatment after one year of MDT. Skin smear at that time was negative. Three months after stopping MDT she had severe ENL reaction for which she was given steroids by physician at the PHC. The reaction subsided. A few month later she had the reaction second time. She went to a local dermatologist who started steroids again which was continued for one year. During this period she had consulted two dermatologists and one of them advised her to go to All India Institute of Medical Sciences at Delhi. Her maternal uncle took her to a famous private hospital in Tamil Nadu. After extensive lab investigation including skin smear which was positive (2.75) she was put on Rifampicin 600 mg once a month, Clofazimine 300 mg once a month and 50 mg daily and Ofloxacin 200 mg twice a day. She was asked to take the treatment for one year. She spent almost Rs.25000/- for this. She came to the PHC again. We saw her. She was in ENL reaction with extensive lesions on the upper limb, lower limb and the back. She had cushingoid features. Nerves were normal. The lady had 3 children, last child was five years old.

**Question : How do you manage this patient?**



Of the 1,00,13,254 adult OPD attendees (about 110 per PHC per day on an average) in the 28 districts 261885 were respiratory symptomatics (2.6%). The OPD attendance which used to be 30 to 50 per day has gone up. The number of respiratory symptomatics has gone up because of the availability of Medical Officers and drugs at the PHCs. The proportion of respiratory symptomatics among the adult OPD attendees was highest in Purnea (5%) and lowest (1.7%) in Katihar. Of the 261885 respiratory symptomatics, 257379 (98.3%) were subjected to sputum examination and 33759 (13.1%) were found to be positive. The sputum positivity rate which used to be 20 to 30% has come down to 13% on an average because of the functioning of DMCs other than the DMC at the district headquarters. The Sputum positivity rate was highest (17.7%) in Sitamarhi and lowest (8.8%) in Purnea.



Totally 61991 cases were detected. Total number of NSPs detected in the year was 25217 (it was 17675 in 2007), New Pulmonary Negative 19965, New Extra-pulmonary 4470. A total of 12339 Re-treatment cases were detected. The case notification for NSP



which was 18 per 100000 (39%) at the beginning of 2008 went up to 33 per 100000 (47%) at the end of the year (Expected is 75/10000). It was highest (48/100000) in Purnea and lowest (13/100000) in Supaul. Even though there has been improvement in case notification because of the considerable input given in the form of induction of ASHA and other community members in the programme, training of the key staff,

strengthening of the human resource for the field programme (ANMs and Medical Officers) more effort is needed. With the increased involvement of ASHA and other community members it is hoped that case notification would improve.

Whether or not you will succeed in life depends to a large extent on your capacity to transform adversities into opportunities.

- P. Krishnamurthy

#### *Treatment:*

Initial defaulter was 13.3%. It ranged from 0 to 27% (In Sitamarhi, due to floods). This continues to be a problem. With the better involvement of ANMs and the supervisory staff it is hoped that the situation will improve. Floods and their consequences are difficult to address. It needs Intersectoral coordination.



Follow up sputum examination coverage was 68.3%. It should be at least 90%. End of treatment sputum examination coverage was 77.6%. Again this should be at least 90%. Even though there has been significant improvement in the situation, further improvement is possible with improved functioning of the laboratories, better involvement of the ASHA and other community volunteers which is not difficult to achieve. About 79.4% of the cases (33328 /41957 interviewed) were on DOT. Of these cases 26177 were Cat 1, 8727 were Cat 2 and 7053 Cat 3. This is an excellent achievement which has been brought about by the excellent involvement of community volunteers including ASHA. Of the 83290 treatment cards verified 59331 (71.2%) were found to be updated. This can and will improve. About 83% of the DOT providers were from the community. One cannot ask for a better situation. Around 8.8% of the patients visited were under DOT from community members, 2.6% were under Registered Medical Practitioners, 13.7% were under Anganawadi Workers, 66.6% were under ASHA, 8.5% were under health workers and 5.9% were under supervised treatment at health facilities. And 79% of the patients were on DOT (compared to 77% in 2007). About 82% of the DOT providers (27467) visited by the teams were found to be functioning correctly which is very good. A total of 1806 out of 2596 irregular patients were made regular and 449 out of 1201 defaulters were retrieved. A total of 379 GPs were involved in suspect referral. About 2507 community members were involved in suspect referral, DOT. Conversion was 87.6% (84.3% in 2007). It was 92.8% in Nalanda 71.1% in Sheohar. Cure rate was 76.4% (71.3% in 2007). It was 89.8% in Madhepura and 55.7% in Sheohar. Defaulter among NSP was 8% (1925/23594) and among Cat 2 cases 13%. Failure rate was 3.3% and death rate 5.5%.

#### *DFIT Intervention (Infrastructure input):*

The team structure of DFIT in Bihar consisted of a Coordinator called Chief Medical Advisor at the State level who was assisted by four Senior Medical Advisors and 7 Medical Consultants. There were 47 supervisors, at least one in every one of the 28 districts supported by DFIT. A Senior Lab coordinator was placed in Patna to assist the state in training STLS and LTs and in establishing quality sputum microscopy has been trained both by National Institutes in India and abroad. There was also the Central Lab coordinator in Chennai headquarters who coordinated quality assurance in lab services in DFIT assisted projects. Secretary of Damien Foundation India Trust and Director,

Programmes, based in Chennai also made periodic supervisory and monitoring visits. Total number of personnel involved in the programme was 162 with 56 jeeps. The project was also reviewed by the project Manager and Medical advisor through their visit in February-March, through regular reports and the core group meeting in November.



The DFIT District Technical Support Teams (DTST) had their own regular monthly meetings to discuss various issues, exchange information on best practices and for technical updates. The progress was reviewed by the Director, Programme, and Secretary through regular visits and by the Project manager and Medical Advisor from Belgium through the visit in February-March and through the core team meeting in Brussels in November.

#### Personnel:

- Medical consultants-11
- TB Supervisors-47
- Laboratory coordinators-2
- Data entry coordinator-1
- STS: 2
- STLS: 7
- LTs: 39

#### Activities:

- The teams visited all the DMCs at least once in two months
- All the new cases detected in the preceding months were visited
- All the DOT providers were visited twice in a year
- New DOT providers were arranged
- Participated in PHC and District review meetings
- Community awareness survey was conducted (97637 community members were interviewed)
- Training of the STLS and LTs was carried out
- 32927 cases were contacted and interviewed to find out the treatment regularity.
- 27467 DOT providers were contacted to find out the quality of DOT

- Training:
  - ♦ 514 Medical Officers
  - ♦ 116 STLS
  - ♦ 601 LTs
  - ♦ 9715 ANMs
  - ♦ 20163 ASHAs
  - ♦ 4042 Anganawadi Workers
  - ♦ 626 RMPs
  - ♦ 307 District and block health managers
  - ♦ 774 community volunteers were sensitized
- 4 Sputum collection centres were established: one (Banjari) in Rohtas and three (Pattahi, Pakri Dayal and Madhuban) in East Champaran.
- 1483 DOT providers were arranged
- Community interaction meetings were conducted in 4333 villages covering 113302 community members
- DOT provider-patient interaction meetings were conducted- 5070 DOT providers and patients participated.
- Trained 7 STLS in maintenance and minor repair of Microscopes
- Supported 70 patients with food supplements

#### 3.3.3. South:

Support to TB control was provided in the form of District consultation teams in 4 districts in Andhra Pradesh (Nellore, Anantpur, Kadapa and Chittoor), 3 in Karnataka (Bangalore Urban, Bangalore rural and Bangalore City) and 1 in Kerala (Trivandrum).

The team for Anantpur and Chittoor consists of a Medical consultant and two supervisors in each of the two districts. The team for Nellore and Kadapa consists of a Medical consultant and two supervisors in each of the two districts. The team in Karnataka consists of a Medical consultant and three supervisors in each of the three Bangalore districts in addition to 6 LTs and 4 Health visitors in Bangalore and 3 health visitors in Tumkur. Each member of the team (consultant and supervisor) has a jeep for mobility. While the team in Anantpur has been functioning since 2001, teams in Nellore, Kadapa and Bangalore Urban have been there since 2003. The team in Trivandrum has been there since 2004 and that in Bangalore Rural and Bangalore City since 2008. The team in Chittoor was placed in March 2008.

#### Diagnosis:

Awareness among the community ranged from 42% in Chittoor to 75% in Nellore. Suspect referral in four of the eight districts was above 2%. Out of the 287 DMCs 256 were functioning. Quality of smear and microscopy was good in 186 DMCs. Percentage of respiratory symptomatics subjected to single sputum examination was about 7%. It was highest (16%) in Chittoor and lowest (3.80%) in Anantpur. There were

## Do you really want to listen to my story?

Mr. Palani, aged 41 years, from Karur in Tamil Nadu, is a contended man now. After years of ceaseless struggle he has found a new meaning to his life thanks to timely help from Holy Family Hansensorium.



His troubles started when he noticed loss of sensation in his right index finger 11 years back. He consulted a local doctor who told him that it was due to vitamin deficiency and asked him to take some pills. He took the drugs for two months and then stopped because he did not have money to continue the treatment. Two years later the sensory loss spread to the whole of right hand. He went to another doctor who treated him for two weeks. Palani was not happy. His condition was becoming worse. He developed sensory loss in both the feet also. He found it difficult to walk. His fingers became crooked. His wife left him. He had to take care of his daughter and son. Life became miserable.

He found some job as a labourer at a construction site. The assistant to staff nurse in Government hospital noticed a big patch on his back while he was working. He was advised to go to Holy Family Hansensorium. He traveled 15 kms on bicycle to reach the place. The Doctor examined him in detail and told him that he had leprosy. The world stood still for him. He could not understand why he got leprosy. He had not harmed anybody. The doctor asked him to stay at the hospital for at least 3 months. He refused. How could he? Who would take care of his children? He went to Government general hospital and took treatment. He was irregular. He developed ulcer on his right middle finger and in his feet.

Now he decided to come to Holy Family Hansensorium. He left the kids with his sister and gave her some money to take care of his children before coming to the hospital. His condition improved, the ulcers healed. While at the hospital he came to know that his children were ill-treated by his sister. The daughter was forced to work as domestic help in neighbour's house. He recounted his problems to the doctor who asked him to bring the children to the centre. He was given a job in the hospital and his children were admitted in the hostel inside the hospital campus. His wife was called to the centre and was counseled and she was convinced to live with Palani. She was also given a job. A house was constructed for them inside the campus. The family is together. They are happy. All is well that ends well.

58 respiratory symptomatics who had only one sputum sample examined and that was found to be positive. Among them 35 were retrieved. Positivity rate ranged between 4% (Trivandrum) to 13.7% (Anantpur).

Total number of new pulmonary sputum positive cases notified was 13042. It was highest (71/100000) in Anantpur followed by Nellore (65.4). It was lowest (35.6/100000) in Trivandrum followed by Bangalore Metro (40.97).

### *Treatment:*

Delay in starting treatment ranged between 0% (Trivandrum) to 22% (Chittoor). Percentage of patients on DOT was between 61% in Chittoor to 91% in Anantpur. It was above 80% in all other districts. Percentage of DOT providers functioning correctly ranged between 63% in Chittoor to 93% in Bangalore Urban. It was above 70% in all other districts. DOT providers other than General health staff constituted 98% in Nellore, 92% in Anantpur, 91% in Chittoor, 76% in Trivandrum, 28% in Bangalore Metro, 26% in Bangalore Urban, 23% in Kadapa and 18% in Bangalore rural. Treatment cards were found to be updated in 93% of the cards verified in Bangalore Metro, 90% in Bangalore Urban, 89% in Anantpur, 87% in Bangalore Rural, 82% in Trivandrum, 72% in Nellore, 64% in Chittoor and 54% in Kadapa. About 65% to 97% of the irregular cases were made regular, 207 defaulters out of 282 were retrieved.

Sputum conversion varied from 81% to 91%. Cure rate ranged between 65% (Bangalore rural) to 88% (Nellore). It was 87.5% in Anantpur, 85% in Chittoor, 81% in Kadapa and Trivandrum, 70.1% in Bangalore Metro and 72% in Bangalore Urban.

### *Personnel:*

Medical consultants-3

Supervisors-13

Health visitors-7

Laboratory Technician-6

### *Activities:*

- The teams visited all the DMCs at least once in two months
- All the new cases detected in the preceding months were visited
- All the DOT providers were visited twice in a year
- 346 New DOT providers were arranged
- Participated in PHC and District review meetings
- Community awareness survey was conducted (15079 community members were interviewed)
- 11417 cases were contacted and interviewed to find out the treatment regularity.
- 7483 DOT providers were contacted to find out the quality of DOT

- Training:
  - ◆ 418 Medical Officers
  - ◆ 3814 GH staff
  - ◆ 991 Students
  - ◆ 4463 others

### 3.4 Support to establishment of DPMR in districts:

#### 3.4.1. By DFIT projects:

Prevention of disability has been reintroduced by NLEP as Disability Prevention and Medical Rehabilitation (DPMR) with redefinition of priorities and reformulation of guidelines which were prepared with help from ILEP and provided to all the health facilities.

Damien Foundation has had extensive experience in implementation of POD activities through the general health staff. What started as an experiment in Vandavasi in Tamil Nadu about 10 years back has evolved into full-fledged and time-tested strategy. It involves establishing a coordinated relationship between a local NGO project and the Government set up and preparing a joint plan. Coordination of the whole process is done by a joint committee consisting of persons from Government health system and NGO. The process involves the following activities:

- Coordination meeting between Government and NGO;
- Formation of a core group;
- Preparation of joint action plan by Government with support from NGO project;
- Meeting with key staff with the Government to elaborate the plan, identification and sensitisation of referral centres;
- Preparation of village, sub-centre-wise list of persons with disability from the existing records;
- Preparation of training schedule, checklists for monitoring;
- Training of persons affected by leprosy disability, family member and GH staff at PHCs;
- Regular monitoring by the GH staff (concerned ANMs);
- Regular monitoring by the core group.
- Discussion of progress and problems in the monthly meetings;  
A simple report prepared by the DLO every month; and

The strategy has been successfully implemented in three districts (Salem, Trichy and Pudukottai). It is under expansion phase in Nellore district in Andhra Pradesh and initiation phase in Anantpur, Kadapa in Andhra Pradesh, Dharmapuri, Krishnagiri, Perumbalur, Ariyalur and Karur in Tamil Nadu and 7 districts in Jharkhand (East Singhbhum, West Singhbhum, Deoghar, Godda, Lohardugga, Gumla, Simdega). Salem, Dharmapuri and Krishnagiri are supported by St Mary's Leprosy Centre in Salem. Trichy, Pudukottai, Ariyalur, Perumbalur and Karur are supported by Holy Family Hansensorium in Trichy. The POD project in Trivandrum district which is in the

initiation phase is coordinated by St John's leprosy Centre in Pirappengode. The POD project in Jharkhand is supported by the Claver Social Welfare Centre in Amda in Saraikala district.



In the districts (Trichy, Pudukottai, Karur, Ariyalur, Perumbalur) supported by Holy Family Hansensorium there are 227 PHCs. While the coverage of 64 PHCs in Trichy and 52 in Pudukottai is complete, the special intervention has been initiated only recently in the other three districts. Similarly the coverage in Salem is complete and the POD programme has been initiated only recently in other districts (Dharmapuri and Krishnagiri). The progress in Anantpur and Kadapa is very slow for various reasons. Coverage in Nellore is reasonably good. In Jharkhand coverage of Saraikala is complete whereas in other 7 districts DPMR has been initiated just recently.

### “What the mind does not know, the eyes cannot see”

Dinesh (name changed) is 11 years old, the only child of poor labourer. He cannot go to school now and cannot play. He feels cheated. The parents feel wronged. There is no joy and fun in Dinesh's life. When Dinesh developed a patch on his right shoulder the parents became worried. They promptly took him to the doctor at the local ESI hospital. The doctor prescribed an ointment to be applied on the lesion and gave him an injection. This went on for 6 months. Dinesh developed blisters on the lesion and it started growing and become angry red. The parents stopped going to the hospital. After 6 months Dinesh developed swelling in the right hand, he was not able to hold a pencil. He had terrible pain. The parents were worried. They did not wish to go to



ESI hospital. Their neighbour advised them to take the child to an NGO hospital at Fathimanagar. The child had triple nerve palsy in the right hand- Radial, Ulnar and Median were paralysed. All the three nerves were considerably enlarged and tender. The skin lesion was in reaction. He was put on MDT and steroids. Incidentally when we saw the father we were surprised to see that he had cervical lymphadenitis. He said that he was taking treatment from a private doctor who had removed pus three times and given him some drugs and injection. He had TB lymphadenitis. He said that he had spent Rs.2000 till then for his treatment.



The case underscores the need to strengthen referral system where persons with leprosy, with or without complications, are correctly diagnosed and promptly treated.

Supporting NGO project	District	No. of PHCs covered	Persons with G1 disability	Persons with G2 disability	No. practicing self care/No. assessed	No. of GH staff monitoring patients / No. assessed	Footwear provided/ Needed	RCS Done / No. needing RCS
Holy Family Hansenorium	Trichy (Tamil Nadu)	60/64	13	407	208/238	73/89	327/327	8/22
	Pudukottai (Tamil Nadu)	52/52	30	496	252/294	112/128	255/368	9/24
	Ariyalur (Tamil Nadu)	4/28	1	42	NA	NA	14/72	1 / 4
	Perumbalur (Tamil Nadu)	6/20	1	152	NA	NA	19/99	0/3
	Karur (Tamil Nadu)	4/35	1	168	NA	NA	21/111	1/5
St Mary's Leprosy Centre	Salem (Tamil Nadu)	70/70	236	1596	1218/1321	350/386	735	3/3
	Dharmapuri (Tamil Nadu)	15/15	101	746	475/532	88/92	175	1/1
Damien Foundation urban leprosy and TB centre	Nellore (Andhra Pradesh)	34/62	35	503	196/340	61/83	104/230	1/38
	Anantpur (Andhra Pradesh)	6/74	128	1108	3/38	6/6	NA	NA
	Kadapa (Andhra Pradesh)	5/68	126	1004	12/52	13/13	NA	4
St John's Health Services	Trivandrum (Kerala)	86/86	30	371	324/385	145/145	161	0/5
Claver Social Welfare Centre	Saraikala (Jharkhand)	8/8	176	507	103/351	26/30	58	1/3

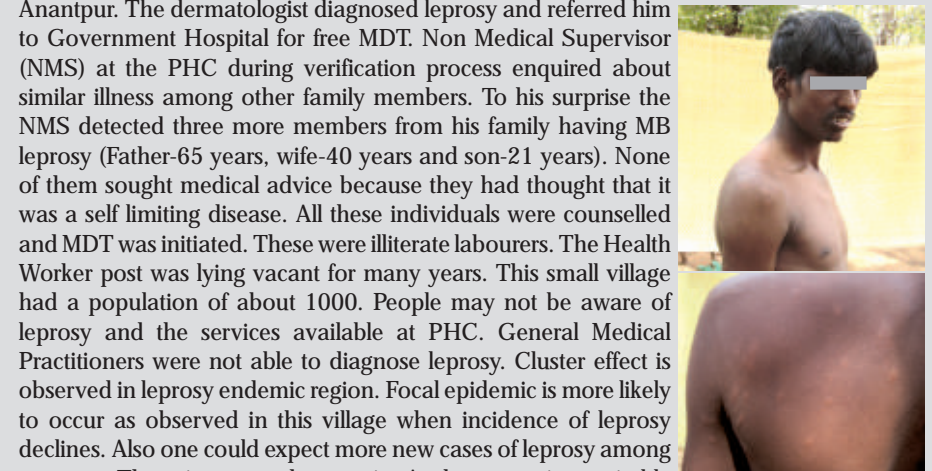
The following points emerge from the experience of supporting DPMR in districts.

- A functioning district nucleus is required for the successful implementation;
- Mobility to district nucleus is essential;
- Interface of an experienced project with expertise in DPMR and coaching is essential;
- Partnership with community based organisation and corporate bodies would certainly give fillip to the effort.
- The whole process is labour intensive. Continuous monitoring and supervision is essential for sustaining motivation and commitment;

## How many is too many?



Mr. Penchillanna (name changed) aged 45 years from a small village in Anantpur district had small swellings over the extremities since 3 to 4 years. He consulted several General Medical Practitioners including RMP doctors at a nearby town. He was treated for skin disease for which he had spent Rs.4000. One of his neighbours directed him to a skin specialist in Anantpur. The dermatologist diagnosed leprosy and referred him to Government Hospital for free MDT. Non Medical Supervisor (NMS) at the PHC during verification process enquired about similar illness among other family members. To his surprise the NMS detected three more members from his family having MB leprosy (Father-65 years, wife-40 years and son-21 years). None of them sought medical advice because they had thought that it was a self limiting disease. All these individuals were counselled and MDT was initiated. These were illiterate labourers. The Health Worker post was lying vacant for many years. This small village had a population of about 1000. People may not be aware of leprosy and the services available at PHC. General Medical Practitioners were not able to diagnose leprosy. Cluster effect is observed in leprosy endemic region. Focal epidemic is more likely to occur as observed in this village when incidence of leprosy declines. Also one could expect more new cases of leprosy among contacts. There is no need to panic. At the same time suitable modifications need to be done to the existing strategy to strengthen the health system. Such incidences should be documented and focal health campaigns could be organised to detect other existing leprosy patients at an early stage. Such campaigns would also increase the awareness on leprosy care services among the people and improve the confidence in the health system as a whole.



### Trainings:

Districts	Project	MO	GH Staff	Others
Trichy/Pudukottai	HFH	24	442	269
Nellore	DFULTC	10	97	88
Trivandrum	SJHS	90	195	0
Anantpur	DFULTC	2	26	
Ariyalur	HFH	14	0	84
Perumbalur	HFH	10	0	124
Karur	HFH	0	30	134
Saraikala	CSWC	5	270	38

#### 3.4.2. State coordination (ILEP) in Bihar:

As part of the ILEP support technical assistance is provided to NLEP in Bihar through ILEP State coordinator in establishing POD services in all the 38 districts. Training of the District Nucleus has been completed in 35 of the 38 districts. Similarly, training of 24 Physiotechnicians and 38 Laboratory technicians has been completed. Training of the General health staff has been carried out in 9 districts. A total of 104 out of 149 PHCs have been covered for DPMR training. Totally 2354 ANMs out of 3240, 844 other staff and 400 persons affected by leprosy have been trained in prevention of disability. The plan is to



equip the peripheral health workers to suspect and refer suspects and cases with complications to the Primary Health Centres and provide essential support to the persons affected in doing self care activities aimed at disability prevention and limitation. Physiotherapy technicians are available in 16 districts and they have been trained to provide supervisory support to the General health staff in prevention of disability activities. Being part of the District nucleus they are also expected to be the first referral point for persons to seek assistance from for complications.

Two government institutions in Bihar, Patna Medical College Hospital and Dharbanga Medical College Hospital, have been doing reconstructive surgery for the past four years. The surgeons and physiotherapists were trained by the Surgeon and Physiotherapist from DFIT. Other support provided by DFIT includes equipping the operation theatre (Operation table, light, surgical instruments) and supportive drugs for postoperative management. Post operative follow up of the cases is weak in these

centres. Only 28 out of 193 cases were followed up. Efforts are made to improve the situation.

### 3.5. Reconstructive surgery services

DFIT has been providing quality RCS service through its projects and has supported the establishment of RCS service in three Government Institutions. The team consists of an experienced Surgeon and a Physiotherapist.

3.5.1. NGO projects: A total of 74 persons (17 in Fathimanagar, 29 in Nellore and 28 in Pavagada) underwent 98 reconstructive surgeries (hand-60; foot-19; eye-4; nerve decompression-11; and amputation-4) in 2008. All the cases are followed up postoperative for five years.

#### 3.5.2. Government Institutions:

Two government institutions in Bihar, Patna Medical College Hospital and Dharbanga Medical College Hospital, have been doing reconstructive surgery for the past four years. In 2008 the two centres did surgery for 48 persons.

Reconstructive surgery training was given by DFIT to the staff (Surgeon and Physiotherapist) in Jamshedpur Medical College in Singhbhum in Jharkhand State. A separate ward for managing cases has been allotted by the hospital authorities. A total of 8 cases (4 each for hand and foot deformity) underwent surgery under the supervision of the DFIT Surgeon. The physiotherapist in Amda trained and experienced in pre and post op follow up of cases will be providing the necessary back up physiotherapy support.

### 3.6. Infrastructure support to government:

Institutional development is one of the key support areas that needs to be given due attention in establishing partnerships. This will enhance the effectiveness of the programme and reduce the cost. Infrastructure support to the Government is one of the key areas of involvement of DFIT.

#### 3.6.1. Leprosy:

At the government of India level support to 3 staff (DPMR consultant and two data entry operators) is provided as part of ILEP support at national level.

DFIT provided support to Medical college Hospitals at Patna and Dharbanga for establishing and maintaining RCS service. The Operation theatre was at Patna Medical College was equipped with table and overhead lamp and support to providing supplementary drugs and postoperative aids to patients (Rs 1500 per patient) was provided at Patna and Dharbanga.

PHC at Harnaut in Nalanda was constructed and Outpatient building and ward at Rudrapura PHC were renovated. Food grains, supplementary drugs and bandage materials were provided to Rudrapura PHC in Rohtas district.



## A tale of woes

Janarthanan (name changed), aged 40 years and unmarried hailing from Chennai, is living with his sister and her family. A Dermatologist in Chennai referred him to DFIT for expert opinion. His story was that he had gone to the Dermatologist for the treatment of his ulcers in both the feet which he had noticed since May 2008. He was not aware of his disease and admitted that he had not been treated for the disease before.

On examination he had multiple skin lesions over his trunk and infiltration over face and both earlobes. There were Ichthyotic, anaesthetic lesions over his limbs. He had bilaterally enlarged ulnar, median, radial cutaneous, ulnar cutaneous, lateral popliteal and musculocutaneous nerves. Sensory testing showed impairment of touch sensation over Right hand, loss of sensation over both feet and ulcers over great toes of both feet. Skin smear was positive (3+) for AFB.

He came with his sister and friend the next day. His sister was curious about his illness and was worried about spread of infection from his brother to the other members of her family. She was counselled about the disease and the treatment. He was advised about regular self care for his ulcers. The sister had an old prescription of 2007 of his, given by a Medical College Hospital. He was prescribed only Rifampicin with other Vitamin tablets for a short period and stopped, saying that the patient need not come again!

He was referred to a NGO hospital with a prescription for MB – MDT and management of ulcers.

## Back on the road

Mr. Arunachalam belongs to a town near Salem, he is an auto rickshaw driver by profession. He was a Hansen's disease Patient (MB) who had been treated with Mono and MDT. He was Released From Treatment (RFT) a few years back after treatment. The disease left with ulnar claw and ulcers on both feet. As a result of this, his wife divorced him and he was forced to live a lonely life rejected by his family and the society. Chronic recurrent ulcers forced him to dress his ulcers on his own with cotton and bandages. He was unable to concentrate on his driving job as the ulcers forced him to stop going for work frequently, but he did not lose hope. He was on look out for a ray of hope at the end of the tunnel.

He approached a Leprosy hospital run by a NGO at Salem. The NGO trained him on self care activities and Soaking, Scrapping, Oiling and Dressing (SSOD) for protecting his hands and feet. He began to practice self care regularly and made it a regular routine in his life. He was more careful on the use of his feet and gave it a lot of rest whenever possible. In six months he was totally free of his ulcers. He became a changed man. He looked forward to a life of new nerve.

He got married again and became proud father of three children. The NGO which supported his remarkable change arranged for a loan to purchase an auto under rehabilitation scheme. He paid the dues regularly and cleared the loan and became the owner of the auto.

His attitude and persevering nature was liked by his fellow auto drivers in the auto stand. He was soon elected as a leader for the auto-rickshaw owners association which boasts of 200 members in Salem Town. This social recognition was well appreciated by the local community. He got his eldest daughter married and the other two daughters are studying. He is a man with a happy family. He is a sterling example for others and especially the disabled patients that one should never give up hope and look at life with a positive attitude.



### 3.6.2. Tuberculosis:

#### National level:

Support to one Microbiologist at All India Institute of Medical Sciences (AIIMS), New Delhi

Support to two LTs and one data entry operator at IRL of State TB Demonstration Centre (STDC) in Hyderabad, Andhra Pradesh.

#### Bihar:

At the State level the laboratory training centre at the STDC in Patna was constructed. Similarly extension drug store for RNTCP at Patna was also constructed. The DMC at Harnaut in Nalanda district was constructed.

Out of the 480 DMCs in the 28 districts supported by DFIT, minor repairs were carried out in 158 DMCs for improving the laboratory facilities. Silica gel for Microscope maintenance was provided to all the DMCs. A total of 5000 slides were provided to two districts, containers for supply of reagents to DMCs were provided to three districts, immersion oil was provided to DMCs in Vaishali, Methylated spirit to Vaishali, Distilled water to two districts, Carbol fuschin to one district, sputum cups (61000) to two districts. All the DMCs were provided diamond marker pencils, lens cleaning paper, tissue roll, air blower, sticker labels.

A total of 34 Microscopes, 14 lenses (100x), 13 pairs of eye pieces and 4 heads were provided to three districts (Patna, Vaishali and Muzaffurpur).

DFIT provided 39 Laboratory technicians in 28 districts and 2 STS, 7 STLS, and 1 MO in 3 districts. Four sputum collection centres were established in Rohtas, East Champaran and West Champaran.

DFIT supplied 60000 sputum cups of WHO standard-10000 free of cost in two districts (Vaishali and Patna) and the rest at production cost.

#### South:

- Four Health Visitors and six Laboratory Technicians to Bangalore Metro district;
- Three health visitors to Tumkur district;
- Repair of 11 microscopes in Bangalore Metro district;
- Provision of one microscope to Salem district;
- Provision of sputum cups (137000 to Tumkur and 10000 to Gadag in Karnataka)

#### Construction/repair of PHCs:

Chantier Damien is a splinter group under Damien Foundation which concentrates on infrastructure development in projects that provides directly or indirectly Leprosy and/or Tuberculosis services. The support is in the form of construction of houses for the patients or for related services such as repair or construction of medical facilities. The uniqueness of the group is that it not only funds the activity but also physically participates in the construction. The visiting group comprises of people from Belgium





from all walks of life and are motivated to serve the cause of Leprosy and Tuberculosis. The Chantier group was started about 15 years back. It is getting stronger every year and the number of persons volunteering is also growing. The projects that were done during the year 2008 were: construction of 8 houses for the leprosy affected persons and their families in Salem and Fathimanagar;

construction of PHC (Primary Health Centre) at Harnout in Nalanda district in Bihar; and repair of outpatient and general wards in Rudrapura PHC at Dehri on soane, in Rohtas district of Bihar. The total expenditure for this activity in 2008 was around 4 million Indian rupees.

### 3.7. Livelihood enhancement for persons affected by leprosy or TB

The priority of DFIT which all along was prevention of disability through promotion of activities leading to early detection and treatment, has been shifted to total care for the person affected by Leprosy taking in to context the socio economic consequences of the disease on the affected persons. Although DFIT has been supporting rehabilitation on a limited scale, it has now been given renewed focus and augmented attention.



DFIT has taken up new schemes which directly support the needs of the economically disadvantaged and leprosy disabled persons in the form of Livestock support, Self employment, House repair, and educational support. A new initiative to support the poor TB patients with food grains during their period of treatment has also been taken up. Persons affected with leprosy and living with



disabilities is selected and their needs identified. Support is titred to their requirements after consultation with the beneficiaries. Initially the program was started in projects with prior experience in socioeconomic rehabilitation. It was later extended to all the projects where there was need. The programme was designated "Livelihood Enhancement Program" (LEP). The program has been implemented in 12 projects supported

## In eternal search !



The story of Rosy is the story of struggle against disease, discrimination and prejudice and of determination against all odds. Don't shed tears for her. She would be happy if you shed your prejudices and preconceived judgments!

### Shall we begin?

Born into a lower middle class family with five siblings to compete for parental attention, love and affection came at a premium for Rosy. When she was denied tenderness from her drunken father and a frustrated and busy mother Rosy naturally turned to her grandfather (mother's father) who showered her with love. Tragedy struck her at the age of ten. Suddenly she found that she was not able to lift her feet due to paralysis and there were ulcers in her right foot. It was her grandfather who took her to a local doctor who said that it was due to disease of nerves and prescribed some drugs. When there was no improvement she was taken to a bone specialist by her grandfather on the advice of one of his friends. Even after 6 months of treatment which cost him Rs. 4000 there was no improvement in her condition. The grandfather was severely rebuked by her father for wasting money and said that it was leprosy and was not curable. Treatment was stopped. She developed fever and her fingers in both hands became crooked. This time it was the turn of ayurvedic treatment. Her father started ill-treating her and her four sisters and brother avoided, ignored and rejected her. She had no one to turn to except her grandfather. One of their relatives during her visit to the family saw her and advised them to take her to Holy Family Hansensorium (HFH) in Fathimanagar.

When she came to HFH she was frail, frustrated and deeply depressed with a forlorn look permanently etched on her face. Her grandfather when he knew that she had leprosy was devastated. He died one month after Rosy was admitted at HFH. It was an irreparable loss for Rosy. She was like an orphan, nobody to turn to, nobody to relate her woes to. Gradually, she started interacting with inmates of the hospital and found willing shoulder among the sisters there. Her deformities in the feet and hands were surgically corrected. She spent a long ten years in the hospital. The Doctor and sisters in the hospital tried to get her married but no one was willing to have an alliance with her. Rosy lost interest in marriage. She was taught sewing and was given a motorized sewing machine. She began earning some income. Her father never came to the hospital to see her. The only occasional visits from her family were from her mother. When her father died due to alcoholism and none of her sisters or brother was willing to stay with her, Rosy decided to leave the hospital and help her mother.

She is not happy, but she is not dispirited. She is staying with her mother, earning a steady income for them by stitching clothes for neighbours and working in paddy field. She gets ulcers in her foot repeatedly in spite of her diligent self care. Her sisters and brother refuse to visit them; but the neighbours are kind to them. Rosy does not blame the family. She has come to accept everything as part of her life. For her the sewing machine is her companion, the mother is her solace. Everything else is meaningless to her.

by DFIT. It is heartening to note that this small help brings a sea change in the lives of the persons affected by leprosy. DFIT has so far supported 464 persons (Livestock 176, Self Employment 62, House Repair 46, Educational support to children of Leprosy Patients 30, and food grain support for TB patients 150). The expenditure made so far from the start of the program in Oct 2007 is around 3.6 Million Indian rupees.

### 3.8. Community awareness generation regarding leprosy and TB disease and programmes

#### 3.8.1. Projects:

Community awareness generation in both leprosy and tuberculosis is one of the important activities of projects supported by DFIT. Totally 39 awareness camps (population covered-8927), 17 exhibitions (2880 population covered), 32 video shows (population covered 6551), 12 rallies (4825 people covered), propaganda covering 146100 population in total, 92 school education camps covering 21806 children and 11 street plays covering 5900 people were conducted in the project areas.

#### 3.8.2. District consultancy teams:

The District consultancy teams regularly indulge in propaganda activity spreading the messages about TB and leprosy through the public address system fitted to the jeeps whenever they visit villages. Group talks are given and awareness assessment is done from a random sample of people. Priority for health education activity is given to villages with very low levels of awareness.

Totally 7 exhibitions (3450 population covered), 1 video show (population covered 350), 4 rallies (1660 people covered), propaganda covering 24630 population in total, 10 school education camps covering 2035 children and 1 street play covering 164 people were conducted in the districts.

Community awareness study was done as a routine in all the districts. It was found to be lowest in Chittoor (42%) and highest in Nellore (75%). In the other districts it ranged from 56% (Kadapa) to 71% (Bangalore Rural). It was 66% in Anantpur, 68% in Bangalore Metro and 65% in Trivandrum.

### 3.9. Promotion of community involvement in TB Control programme

It is very important to develop partnership between the Government, NGO and the community for raising the level of awareness and creating appropriate demand for quality services. Two indicators can be used to measure success in this area:

- The proportion of community members involved as DOT providers out of the total number of DOT providers of all categories.
- The proportion of TB patients under DOT supervision by community members out of total patients under DOT supervision by all categories of DOT providers

Initially community involvement in DOT supervision was very low because of the lack of faith by the Government Staff in involving the community for the task. Incessant effort by the consultancy teams in the districts has brought about favourable change in the mind set. The two indicators are showing an uptrend.



In Bihar, there were 27467 DOT providers of whom 2507 were from the community, 3875 were RMPs, 17167 were ASHA, 2399 were health workers and 1665 were health staff at health facilities. It is heartening to note that 74% of DOT providers were from the community. It was highest (95%) in Madhepura and lowest (27%) in Muzaffarpur. It was less than 50% in only 4 districts. In the South it was 92% in Anantpur, 26% in Bangalore Urban, 28% in Bangalore Metro, 18% in Bangalore rural, 91% in Chittoor, 23% in Kadapa, 98% in Nellore and 76% in Trivandrum. The urban rural difference is obvious.

Similarly proportion of patients on DOT from community members among patients on DOT from all categories of DOT providers in Bihar was found to be 60% (gone up from 47% in 2007). It was highest (96%) in Saharsa and lowest (62%) in Buxar.

### 3.10. Continuing medical education to Undergraduate and post graduate medical students, faculty, General practitioners

Damien Foundation has several programmes aimed at updating the knowledge and up scaling the skills of Medical professionals of all categories. For undergraduate students there is the endowment examination restricted to final year undergraduate medical students affiliated to Dr. MGR Medical University in Tamil Nadu. It consists of theory examination followed by practical examination in Objective Structured Practical Examination (OSPE) format. The student scoring the highest aggregate marks in theory and practical is awarded the Gold Medal by the University on behalf of which the examination is conducted by DFIT.

In 2008 a total of 133 students from 11 Medical Colleges participated in the theory examination on 5<sup>th</sup> July in their respective colleges and 19 of them were selected for practical examination at Holy Family Hansensorium in Fathimanagar, Trichy, Tamil Nadu on 19<sup>th</sup> September.

Another programme that is regularly conducted is the Seminar on leprosy for Postgraduate medical students. For lack of proper time slot it could not be carried out. A seminar for post graduate medical students in Tuberculosis was conducted at M.S.Ramiah Medical College in Bangalore.

Damien Foundation publishes technical bulletin called "UPDATE" on behalf of ILEP in India. In 2008 four issues were brought out. The topics covered were supervision, National Rural Health Mission, Community involvement, Referral services.

### 3.11. Management of Multi Drug Resistant TB cases

Damien foundation India Trust (DFIT) began its foray into Tuberculosis control in 1996 with the training of its key project staff and introduction of DOTS strategy in its NGO projects in South India. DFIT's TB control efforts expanded from the direct management of cases in its supported NGO projects in defined geographic areas to support to TB control in districts through technical support teams. The experience has given enough confidence in venturing into management of MDR TB.

Damien Foundation Urban Leprosy and TB Centre (DFUL&TBC) in Nellore town is supported by Damien Foundation India Trust. This project is catering to the needs of TB affected in a population of about 120000 and has a Medical Officer and supportive staff for hospital and field activities. It has in-patient facilities to manage those with complications. A Designated Microscopy Centre has been functioning since 1998.



A new infrastructure has been established with 20 beds for management of drug resistant TB cases and a laboratory for Drug Sensitivity Testing in Tuberculosis.

DFIT also has a technical support team consisting of two supervisors and a Senior Medical Advisor to support the RNTCP in Nellore district. The project has close collaboration with District TB Centre (DTC) in assisting training to different cadres of health staff in Nellore district. The project has capabilities in managing MDR TB programme. One STS at MDR centre is designated as Field Coordinator-MDR who is responsible for record keeping and assisting Medical Officer in coordinating field activities with hospital and DST lab.

Standard treatment regimen recommended by Government Of India (and WHO) is employed.

**RNTCP CATEGORY IV REGIMEN : 6 (9) Km Ofx Eto Cs Z E / 18 Ofx Eto Cs E**

The purpose of education is not to make a person learned but to give an opportunity to adapt oneself to the changing needs. Learning is different from education. While education gives knowledge, learning enables one to make appropriate use of knowledge.

- P. Krishnamurthy



Field supervisor visits the patient and DOT provider once a week and review regularity of treatment, side effects and follow up examinations. He will also counsel the patient and family members during his visit. He will arrange for referral of the patient to PHC or DST centre if needed. Follow up sputum culture will be done as per guideline.

The Damien TB Research Centre was inaugurated on 10<sup>th</sup> Dec 2008. Lab equipments are being installed. The lab is expected to start functioning from April 2009. The lab staff are trained at TRC in Chennai and Damien Foundation Project in Bangladesh. The Medical Consultant of the district consultancy team has been trained in Riga, Latvia. All the hospital staff and field staff were trained in MDR management procedures (two days). STS and STLS from Nellore TU also attended the training. One of the sessions was conducted by District TB Officer.

DOT Plus site committee has been constituted with District TB Officer, physician, microbiologist from medical college and treating physician as members. All baseline investigations are done and complete details are presented to DOT+ site committee. Once approved by the committee Intensive Phase is started and patients are hospitalised for at least one month after initiation of treatment. Hospitalisation can be prolonged if the patient is willing.

When the patient is initiated on treatment suitable DOT provider is selected in consultation with the patient. The DOT provider is trained for supervised treatment delivery for MDR TB patient.

Currently MDR TB patients diagnosed at TRC Chennai are being considered. Two patients have been started on MDR TB treatment on 18<sup>th</sup> Dec 2008. They were hospitalised during first month of IP. Subsequently DOT providers have been given the responsibility of supervised treatment delivery. Joint pain has been the common complaint and managed with analgesics/anti inflammatory agents. Both these patients are doing well. The centre functions in collaboration with State TB Officer and District TB Officer.



The lab services, hospitalisation and MDR TB treatment are offered FREE of cost to TB patients.

### 3.12. Research;



Field trial of Uniform MDT (UMDT) for all types of leprosy – status report Dec 2008

This study aims at determining the efficacy of short duration of Uniform Multi Drug Therapy (UMDT) regimen with three drugs to both MB and PB leprosy in comparison to presently employed standard regimen for MB and PB leprosy. It is non-randomised controlled open trial. The regimen used are as follows.

<b>UMDT: Total duration 6 months</b> <ul style="list-style-type: none"> <li>Rifampicin 600 mg once a month</li> <li>Clofazimine 300 mg once a month</li> <li>Clofazimine 50 mg daily</li> <li>Dapsone 100 mg daily</li> </ul>	<b>Standard MDT MB: 12 months</b> <ul style="list-style-type: none"> <li>Rifampicin 600 mg once a month</li> <li>Clofazimine 300 mg once a month</li> <li>Clofazimine 50 mg daily</li> <li>Dapsone 100 mg daily</li> </ul>
	<b>Standard MDT PB: 6 months</b> <ul style="list-style-type: none"> <li>Rifampicin 600 mg once a month</li> <li>Dapsone 100 mg daily</li> </ul>

Gaya, Rothas and Nalanda districts in Bihar India had a population of 4.1m, 2.9m and 2.3m respectively. Gaya district was selected for the study regimen and Nalanda district was selected for control. Rohthas district was added for study later. Patient intake was from Aug 2005 to Jul 2007 in Gaya and Nalanda districts and Jun 2007 to Jun 2008 in Rohthas district. The study areas are part of multi-centre trial by World Health Organisation. Control component was added by Damien Foundation India Trust. Status at end of Dec 2008 is given below.

Intake :

District	MB patients	PB patients	Total
Gaya	181	450	631
Rohthas	176	263	439
Total	357 (33.4%)	713	1070
Nalanda	330 (35.9%)	588	918

Study area enrolled 1070 leprosy patients and among them 33.4% was MB leprosy. Control area enrolled 918 leprosy patients (MB= 35.9%).

Treatment completion :

Outcome	Study		Control	
	No. of patients	%	No. of patients	%
Completed treatment (RFT)	936	87.5	786	85.6
Drug side effects	11	7.5	1	0.1
Migrated	56		100	10.9
Refusal	14		7	0.8
Died	Nil		4	0.4
On treatment	53	5.0	20	2.2
Total	1070	100	918	100

In the study area 936 (87%) patients completed treatment successfully. Total drop out during treatment was 7.5%. Currently 53 (5%) patients were still at different stages of treatment. Treatment completion was 85.6% in control area and 12.2% were dropouts during treatment. Migration was the major reason for dropout.

Annual follow up assessments:

Outcome	Study		Control	
	Year 1	Year 2	Year 1	Year 2
Assessed	488	196	580	173
Migrated	11	0	64	36
Not available	13	10	7	6
Died	0	0	3	0
Refusal	9	4	0	0
Other - Anti Leprosy Treatment	4	3	0	0
Not done yet	46	13	0	0
Total	571	226	654	215

All the patients included in the study and completed prescribed treatment are subjected to clinical examination for leprosy once a year. Clinical assessment at the end of first year after completion of treatment was done for 498 patients and at the end of second year for 226 patients in study area. It was 654 and 215 in the control area. No case of deterioration or relapse had been observed.

**When you follow others you belong; when you follow yourself you become.**

- P. Krishnamurthy

### Lepra reaction:

Lepra reaction	During treatment	(%)	Year 1	Year 2	Year 3	Total	%
Type 1	24	2.2	34	6	4	68	70.1
Type 2	-	-	2	-	1	3	3.1
Neuritis	10	0.9	14	2	-	26	26.8
Total	34	3.2	50	8	5	97	100

Site of Lepra reaction	During treatment	(%)	Year 1	Year 2	Year 3	Total	%
Skin	20	1.9	25	6	5	56	57.7
Skin+nerve	4	0.4	11	0	0	15	15.5
Nerve only	10	0.9	14	2	0	26	26.8
Total	34	3.2	50	8	5	97	100

Lepra reaction was observed in 34 (3.2%) patients during treatment in study area and 50 patients during first year of surveillance. In the control area lepra reaction was observed in 10 (1.08%) patients during treatment and 31 patients during first year of surveillance. Occurrence of lepra reaction was three times more in study group during treatment. All the episodes of lepra reactions were treated with Prednisolone as per protocol. Neuritis was observed in 41 (42.3%) among 97 episodes recorded in study area. It was 19 (44.2%) among 43 episodes recorded in control area.

Lepra reaction	During treatment	(%)	Year 1	Year 2	Year 3	Total	%
Type 1	7	0.7	15	-	-	22	51.2
Type 2	-	-	1	1	-	2	4.6
Neuritis	3	0.3	15	1	-	19	44.2
Total	10	1.0	31	2	-	43	100

Site of lepra reaction	During treatment	(%)	Year 1	Year 2	Year 3	Total	%
Skin	7	0.7	16	1	-	24	55.8
Skin + nerve	-	-	-	-	-	-	-
Nerve only	3	0.3	15	1	-	19	44.2
Total	10	1.0	31	2	-	43	100

The research team in each district prepare monthly visit plan and all PHCs were intimated. The team visited two or three PHC every day so that each PHC was visited twice a month. All assessment forms (intake, RFT, annual follow up and special events) were sent to NIE.

### Plan:

1. Follow up assessment would continue in all the districts.
2. Computerised data base would be created at DFIT Patna and Chennai.
3. During the annual review meeting (Dec 2008) of participating centres it was observed that patient intake was inadequate. Few centres proposed to have additional intake of about 200 patients per year. Rohtas district was considered for additional intake. Proposal had been submitted to NIE. If approved intake would commence in Rohtas district.

### 3.13. Coordination (Leprosy control) of the activities of ILEP member representatives in Bihar:

#### Introduction:

In the 90s Bihar was declared a high burden State that needed external assistance in good measure in order to implement NLEP according to Govt. Guidelines and to achieve the expected objectives and targets. Damien Foundation decided to take up the challenge and posted District Technical Support Teams (DTST) in 14 Districts in the year 1996. Each team consisted of a Medical Officer and a Supervisor with a vehicle. The DTSTs proved to be very beneficial to the Programme in the State. Other ILEP Agencies came forward to assist the State in 2001. As a result the whole State was provided DTSTs, one in every district.

On March 31<sup>st</sup> 2007 the teams were withdrawn. DTSTs provided support to the State for more than a decade. As a result complete integration of NLEP with the GHS was achieved. Case detection was through voluntary reporting. MDT was available in all Health Facilities. Once the system was in place it was expected that the State could look after the Programme on its own. However, one ILEP State Coordinator was posted in Bihar to assist the Govt. in the implementation of DPMR. The ILEP State coordinator would coordinate with the State as well as with other ILEP partners working in the State. The ILEP agencies in consultation with the State chalked out areas of support and entrusted the ILEP coordinator to facilitate and to ensure its implementation. Based on this understanding with the State objectives were formulated and activities were listed out for 2008.

#### Objectives for 2008:

1. To establish a functioning referral system
2. To ensure quality diagnosis & management of reactions/neuritis in all PHCs / District HQ
3. To establish RCS centers and follow up of RCS patients
4. To assist the State in supervision and monitoring
5. To assist the State in the implementation of DPMR services for Leprosy affected persons
6. To assist the State in annual evaluation

## Situation analysis - NLEP, Bihar

S. No.	Year	New cases Detected	Total discharged	Balance cases	PR/ 10,000	ANCDR/ 100,000	PDR	MB%	Visible Deformity %	Child %.	Female %
1	1998-99	282081	223728	145257	14.20	281.10	0.52	36.55	4.56	10.47	--
2	1999-00	172449	168726	149220	14.31	165.40	0.86	38.46	3.21	12.89	--
3	2000-01	137361	179739	106875	10.06	129.30	0.78	37.18	2.19	16.02	--
4	2001-02	120080	103711	93709	10.99	140.80	0.78	34.40	2.20	15.41	--
5	2002-03	94561	113405	74871	8.72	110.10	0.79	32.01	1.48	16.11	40.08
6	2003-04	65019	95807	44351	4.90	71.70	0.68	32.21	0.86	16.64	38.42
7	2004-05	40395	68214	16532	1.81	44.20	0.41	29.85	0.85	18.39	39.38
8	2005-06	25835	30083	12166	1.30	27.60	0.47	35.41	1.42	15.73	36.15
9	2006-07	21350	23145	10158	1.06	22.21	0.48	35.94	2.27	14.91	36.23
10	2007-08	19041	18872	10262	1.04	19.33	0.54	37.05	2.41	15.01	35.85
11	2008-09 (Dec '08)	15586	13075	12112	1.23	20.60	0.59	36.51	2	17.16	37.17

### *I. Case detection:*

Case detection which showed a drastic fall in 2002-2003 continued the sharp decline till 2006. It has been steady since then. The fall could be attributed to several factors like cessation of active case detection. In 2008 a total of 15586 cases were put on treatment till December. The state reported 27 relapses. The cases are reporting voluntarily or referred by general health staff or ASHA volunteers or community members. There is no active case detection.

### *ii. Case Holding:*

Treatment completion rate (2007-2008) for rural areas is more than 90% except in Saran District (88.5%). In urban areas in majority of districts it is more than 90%. In Saran it is 67% and Vaishali it is 47%. State average is 94.7% and 87.4% for PB and MB respectively.

### *iii. Integration:*

NLEP is fully integrated. District Nucleus is formed in 36 out of 38 districts. District Nucleus from 35 Districts have been trained in DPMR. In Kaimur there is one NLEP staff assisting the Civil Surgeon in monitoring the programme. In Kishanganj there is no NLEP staff. Mobility is a problem in all districts. Maximum number of reactions were managed at PHC (728 cases), whereas 104 reaction cases were managed at District level. Most of the Districts had stock of Prednisolone. Totally 138 cases were referred for Reconstructive surgery and 48 were operated (34 at Government institutions). Out of 771 cases fit for surgery 193 have so far been operated. Monitoring is done through zonal meeting attended by State programme Officers. The meeting takes place once in two months. But no meetings could be held in the latter half of the year because of

floods. Every month 1-2 Districts are visited by ILEP/WHO coordinator for supervision and report submitted to DDG, State and ILEP agencies.

### Activities carried out in 2008:

- Disability assessment was done in 25 districts. A total of 1003 Persons with grade 1 disability and 5725 with grade 2 disabilities were discovered. Those with hand disability were 3831 (3304 Grade 2), foot disability 3512 (2998 Grade 2) and eye disability 402 (270 Grade 2)
- Training of the District nucleus in DPMR was completed for 35 districts
- Training of 24 Physiotherapy technicians and 38 Laboratory technicians was done
- A total of 104 out of 149 PHCs have been covered for DPMR training.
- Training of ANMs (2354 out of 3240) of Purnea Zone (8 Districts) and Patna District in POD was carried out.
- 844 other staff were trained in POD and
- 400 persons affected by leprosy were trained in self care

### Future challenges:

1. Availability of State fund for the programme
2. Carrying out training activities at District /PHC level
3. Printing of DPMR formats
4. Making Prednisolone available in all PHCs/Districts
5. Strengthening of referral system
6. Training of specialists at District/State level
7. Purchase of MCR/Crutches etc for the needy patients
8. Enlist of all disabled patients
9. Involve Patients/ANM/ASHA/Volunteers etc in establishing self care groups and regular monitoring.
10. Ensure good quality RCS facilities
11. Regular follow up of patients following RCS.
12. Reduction of social stigma
13. Socio economic rehabilitation
14. Ensure regular review meetings Zonal and State level
15. Ensure sustainability

**If you wish to be a leader, speak up. The more you speak, the more accepted you become.**

*- P. Krishnamurthy*

## 4. Important visitors:

### 4.1. Ambassador from Belgium Embassy:



Mr. Jean M. Deboutte, the Ambassador from Belgium Embassy, New Delhi, visited Holy Family Hansenorium in Fathimanagar, Trichy in Tamil Nadu, on 27<sup>th</sup> of September. He was accompanied by Dr. Krishnamurthy, Secretary, Damien Foundation India Trust. He was impressed with the activities and wished the project greater success.

He had earlier visited the Office of DFIT in Chennai on 5<sup>th</sup> September to have preliminary discussion on the November visit of the Queen from Belgium.

### 4.2. Belgium Queen:



Her Majesty Queen Paola visited the DFIT supported project, Holy Family Hansenorium, in Fathimanagar, Trichy, in Tamil Nadu on 11<sup>th</sup> November 2008. The entourage accompanying the Queen consisted of diplomats and journalists. She went round the facilities at the project and interacted with persons affected by leprosy, Tuberculosis and HIV/AIDS and evinced keen interest in the activities. She was pleased with what was being done in the project and appreciated the services provided there.

### 4.3. Others:



Mr. Paul Jolie, the president of Damien Foundation Belgium, visited the project in Bihar to get an exposure to the activities of DFIT team in Bihar and also Chennai to participate in the trust meeting.

Mr. Rigo Peeters, General Secretary, Damien Foundation Belgium, visited Fathimanagar on the occasion of the visit of the Queen from Belgium and also Chennai to participate in the trust meeting.

Mr. Luc Comhaire, the Project Manager and Dr. Tine Demeulenaere, Medical Advisor, from Damien Foundation Belgium, visited various projects in the South and in Bihar for review.

Dr. Armand Van deun from Tropical Institute, Antwerp, Belgium, visited the project in Nellore to review the preparation for MDR TB project there.

Mr. Willem Gees visited Nagepalli, Ambalamoola projects for scouting for triangle visit.



## 5. Finance:

### Annual Financial Report - 2008:

The increasing global financial crisis and difficulties in cash flow reminds everyone to tighten the expenditure. It applies to a greater extent to NGO's working in various developmental activities whose finances are directly linked with the funds raised internationally. This situation necessitated more stringent arrangements for resource input and redefinition of criteria and standards. DFIT cash flow was modified to sync with priorities of DFB. Damien Foundation Belgium (DFB) continued to support Leprosy and Tuberculosis activities in 13 NGO projects including 2 directly run by DFIT (Budget 28.58%), 6 DCT (District Consultancy Team) projects in South India (Budget 7.97%), ILEP activities (Budget 4.37%) and DFIT (Budget 6.36%). As part of Co-financing, Directorate for Development Cooperation (DGDC), a Belgian Government agency, funded the DCT (District Consultancy Team) activities in Bihar (Budget 52.72%). DFIT introduced a new program Livelihood Enhancement Program (LEP) to cater exclusively to the deformed Leprosy affected persons who are poor and unable to lead a productive life (Budget Rs.10,30,000). Chantier Damien, an off shoot of DFB, finances and participates in the construction activities in India for the past several years, continued their activities during the year (Budget Rs.33,41,000). DFIT being the ILEP National Coordinator managed on behalf of ILEP, publication of ILEP Update magazine, organized meetings and SLO's conference.

In tune with changing times we have introduced electronic fund transfers through RTGS (Real Time Gross Settlement) for transfer of funds to the projects and NEFT (National Electronic Fund Transfer) for transfer of salary and imprest.

Finance - 2008	Indian Rupees
<b>INCOME</b>	
Contribution from Damien Foundation Belgium	4,95,67,039
Contribution from DGDC, Belgium	5,22,12,270
Contribution from Chantier Damien	42,94,556
Interest received on Fixed Deposit/Savings A/c	6,93,470
Miscellaneous Income	3,60,702
Opening Balance for the Year 2008	46,89,984
	<b>11,18,18,021</b>
<b>PAYMENTS</b>	
Funds Transferred to Projects	3,51,35,500
Bihar Activities - Technical Teams	5,00,49,558
Andhra Pradesh - Technical Teams	55,04,427
Karnataka - Technical Teams	32,00,546
Chantier Damien Activities	51,87,885
DFIT Office, Field, POD	80,25,022
Training / Workshop / Conference	25,13,518
ILEP Activities	20,52,374
Miscellaneous Expenses	50,412
Closing Balance for the year 2008	98,779
	<b>11,18,18,021</b>

## 6. Trainings / Meetings / Conferences / Workshops:

### Trainings:



- Training on laboratory aspects for STLS & LTs of Bihar at Patna from 1<sup>st</sup> to 11<sup>th</sup> Jan. 2008. Facilitators: Mr. Jaishankar - CLS - DFIT-Chennai and Mr. Moses Anandraj - SLC - DFIT-Patna.
- Logical framework Workshop for Delhi project staff from 12<sup>th</sup> to 14<sup>th</sup> Sep. 2008 and from 15<sup>th</sup> to 18<sup>th</sup> Sep. 2008 for Bihar DCT staff. Facilitators: Dr. P. Vijayakumaran-Director(P) and Mr. D.V. Premkumar Velu-CFO.
- Capacity Building (DPMR) for Govt. Medical Officers in Goa organized at Directorate of Health Services on 18<sup>th</sup> and 19<sup>th</sup> September 2008. Facilitator: Dr. Jacob Mathew- Consultant DPMR.
- Course on Communication skills organized by BIKASH, Nepal from 13<sup>th</sup> to 27<sup>th</sup> January 2008. Mr. D.V. Premkumar Velu-CFO.
- Training for NE states from 23<sup>rd</sup> to 26<sup>th</sup> June 2008 at Guwahati. Dr. P. Krishnamurthy, Secretary and Dr. P. Vijayakumaran- Director (P)



**Taming uncertainties in life is like losing elasticity. With it you miss the thrills and challenges. Life becomes less audacious, less exciting and less desirable.**

- P. Krishnamurthy



## Meetings / Conferences / Workshops:



- 39<sup>th</sup> World Union Congress organized by IUATLD from 16<sup>th</sup> to 20<sup>th</sup> October 2008 at Paris. Dr. Sarojini- MO-DFUL & TB C- Nellore and Dr. Ajay Kumar Pande - TB Medical Advisor- Patna.
- DFIT- NGO - Project Holders meeting on 9<sup>th</sup> Jan. 2008. All the Project Holders, Medical Advisors, Mr. Luc Comhaire, Dr. Tine, Dr. P. Krishnamurthy, Dr. P. Vijayakumaran, Dr. Jacob Mathew and Mr. D.V. Premkumar Velu.
- First meeting of Committees of Continuing Medical Education, DPMR and Livelihood Enhancement Programme on 9<sup>th</sup> Jan. 2008 at DFIT - Chennai office. All the Committee members, Secretary, Director (P) and MA (DPMR)
- Regional Meeting of SLOs on RCS in Leprosy Affected Persons organized by Govt. of India on 23<sup>rd</sup> January 2008 at Mumbai. Dr. P. Krishnamurthy-Secretary and Dr. Jacob Mathew-DPMR- Consultant.
- Regional Meeting of SLOs on RCS in Leprosy Affected Persons organized by Govt. of India on 20<sup>th</sup> Feb. 2008 at Chennai. Dr. P. Krishnamurthy-Secretary and Dr. Jacob Mathew- MA - DPMR.
- Consultation workshop for Dermatologists organized by Govt. of India on 24<sup>th</sup> January 2008 at Mumbai. Dr. P. Krishnamurthy.
- IAL Conference from 30<sup>th</sup> Jan. to 4<sup>th</sup> Feb. 2008 at Hyderabad. Participants: Secretary, Director (P), MA - DPMR, FI, CMA(N), CMC (N), ILEP Coordinator-Bihar, MO & NMS from Delhi project, Dr. Sr. Rita Adaikalam from HFH, Trichy, PT- Nellore, PT-Arisipalayam, DLO- Salem and PT (Govt.) Salem.
- NLEP Programme Review and Planning Workshop for Northern States organized by Govt. of India from on 14<sup>th</sup> & 15 Feb. 2008 at Himachal Pradesh. Dr. P. Krishnamurthy.
- TB Consortium meeting organized by World Vision India on 20<sup>th</sup> Feb. 2008 at Delhi. Dr. P. Vijayakumaran.

- Meeting of Core Partners in NLEP organized by Central Leprosy Division on 28<sup>th</sup> February 2008 at Delhi. Dr. P. Krishnamurthy
- Bihar ILEP Coordination Meeting on 8<sup>th</sup> & 9<sup>th</sup> Mar. 2008 at Patna. Dr. P. Krishnamurthy and Dr. Anne Mattam.
- Informal meeting with WHO (GLP) and ILEP members on 10<sup>th</sup> March 2008 at Delhi. - Dr. P. Krishnamurthy and Dr. P. Vijayakumaran.
- National Annual SLOs Conference at Bangalore on 2<sup>nd</sup> Apr. 2008. Dr. P. Krishnamurthy.
- Review meeting of South projects and District Consultancy Teams (S) at HFH, Fathima Nagar, Trichy from 28<sup>th</sup> to 30<sup>th</sup> Apr. 2008. Staff representatives from Projects and members of DCT(S), Secretary, Director (P), MA - DPMR, CFO, FI, CLS and Admn. Asst. DFIT- Chennai.
- ILEP State Coordinators meeting - 6<sup>th</sup> to 8<sup>th</sup> May 2008 at Hyderabad. All ILEP members
- Action Plan meeting for Bihar - 8<sup>th</sup> to 10<sup>th</sup> May 2008 at Ranchi. All team members
- NLEP review & planning meeting of Orissa 23<sup>rd</sup> and 24<sup>th</sup> May 2008 at Bhubaneswar. - Dr. Krishnamurthy
- Preliminary Action Plan meeting for District Consultancy Teams in South - 8<sup>th</sup> to 11<sup>th</sup> July 2008 at Nellore. All team members.
- Meeting of DLOs, NGO Projects & Dermatologists 17<sup>th</sup> & 18<sup>th</sup> July at Patna. - Dr. P. Krishnamurthy.
- Symposium of Leprosy for Dermatologists and Physiotherapists 22<sup>nd</sup> July 2008 at Bokaro - Dr. P. Krishnamurthy.
- Action Plan meeting for south projects - 28<sup>th</sup> to 30<sup>th</sup> July 2008 at Chennai Medical Officers and Supervisors of Projects.
- Action Plan meeting for District Consultancy Teams 31<sup>st</sup> July 2008 at Chennai. All team members.
- Review meeting of ILEP Bihar activities - 6<sup>th</sup> & 7<sup>th</sup> August 2008 at Patna. All ILEP members.
- Standardisation Workshop with Dr. Pannikar / Dr. Htoon 13<sup>th</sup> August 2008 at Delhi. - Dr. P. Krishnamurthy and Dr. P. Vijayakumaran.
- Workshop to finalise NLEP training manual - 25<sup>th</sup> and 26<sup>th</sup> August 2008 at Noida. - Dr. P. Krishnamurthy.
- ILEP Meeting - 9<sup>th</sup> September 2008 at Delhi. Dr. P. Krishnamurthy - Dr. P. Vijayakumaran
- Global Leprosy Programme Workshop organized at WHO - 17<sup>th</sup> and 18<sup>th</sup> September 2008 at Delhi - Dr. P. Krishnamurthy.
- ILEP Cooperation meeting - 1<sup>st</sup> and 2<sup>nd</sup> October 2008 at London - Dr. P. Krishnamurthy.
- Core Group Meeting 13<sup>th</sup> to 15<sup>th</sup> October 2008 at Brussels - Dr. P. Krishnamurthy
- Meeting for preparation of enhanced strategy document 23<sup>rd</sup> and 24<sup>th</sup> October 2008 at Delhi - Dr. Pannikar, Dr. Chauhan and Dr. P. Krishnamurthy.
- Meeting with SLO, Trivandrum for coordination of ILEP activities in Kerala, 9<sup>th</sup> October 2008 - Dr. P. Krishnamurthy



## Glossary

ANM	Auxiliary Nurse and Midwife Basic female health worker, one for every sub centre covering a population varying between 5000 to 10000. They are the most important staff in the General Health system and are responsible for implementing several important public health programmes especially immunization, maternal and child health and family welfare	DPMR	Disability prevention and Medical Rehabilitation. New name given to POD
APHC	Additional Primary Health Centre There are two to three such centres for every Primary Health Centre in Bihar. Generally majority of these APHCs are non functional.	DTO	District TB Officer. Programme Officer at the district level (2 to 3 million population) responsible for the TB control programme in the district
ART	Anti Retroviral Therapy	DTST	District Technical Support Team. Strategy adopted by ILEP to support leprosy control through the placement of a mobile resident team in a district. Suspended since April last
ARI	Annual Risk of TB Infection	ENL	Erythema Nodosum Leprosum
ASHA	Accredited Social Health Activist A lady volunteer from the community selected and involved in public health programmes as a link between the community and General health system under National Rural Health Mission.	EQA	External Quality Assurance. A mechanism introduced in RNTCP designed to ensure quality of sputum microscopy in the programme. The principal person involved in this is the STLS
AWW	Anganwadi Worker	GH	General Health
CAO	Chief Administrative Officer	GOI	Government Of India
CFO	Chief Financial Officer	GP	General practitioner. A medical practitioner
CMA	Chief Medical Advisor	ILEP	International Federation of Anti-leprosy associations. Has ten members. They are involved in supporting leprosy control activities in India through a coordinated mechanism designed to promote convergence of ideas and confluence of resources. The ten member organisations are  * Association Francaise Raoul Follereau (AFRF India) * Associazione Italiane Amici di Raoul Follereau (AIFO India) * Aide aux lepreux Emmaus – Suisse (ALES India) * American Leprosy Mission (ALM) * Damien Foundation India Trust (DFIT) * Fontilles-India * German Leprosy and TB relief Association (GLRA-India) * LEPRA Society (LEPRA) * Netherlands Leprosy Relief Association (NLR) * The Leprosy Mission International (TLM Trust India)
CS	Civil Surgeon. Chief of all public health programmes in a District in Bihar.	LEP	Livelihood Enhancement Programme
DCT	District Consultancy Team	LHV	Lady Health Visitor
DFB	Damien Foundation Belgium	LT	Laboratory Technician
DFIT	Damien Foundation India Trust. (One of the ILEP members in India supporting leprosy and TB control)	MB	Multi-bacillary leprosy. A person with more than 5 skin lesions with anaesthesia; bacteriological positivity; more than one nerve involved
DGDC	Directorate General for Development Cooperation. (Belgian Government Agency for providing support to NGOs)	MC	Microscopy Centre
DHS	District Health Society. The administrative body responsible for monitoring all public health programmes. District magistrate or Collector is the chairman and the Civil Surgeon is the member secretary. All the programme officers are members. Expected to meet at least every quarter	MCR	Microcellular Rubber. Rubber sheet used for insole in the footwear of leprosy affected person with anesthesia or deformity in the foot
DLO	District Leprosy Officer. Programme Officer at the district level (2 to 3 million population) responsible for the leprosy control programme in the district.		
DMC	Designated Microscopy Centre one for every 100000 population for diagnosis of TB cases through sputum microscopy		
DOT	Directly Observed Treatment. Treatment of a TB case under direct supervision by a person other than a family member		
DOTs	A package with five elements constituting the fundamental strategy of TB control adopted by all the countries including India		

MDR	Multi Drug Resistance
MDT	Multi Drug Therapy
MPHW	Multipurpose health worker. Basic health worker (male and female), one for every 5000 to 10000 population and implementing all public health programmes. The area which is covered by them is the sub centre
MO	Medical Officer Posted at every health facility or hospital in Government set up.
MO-PHC	Medical Officer- Primary Health Centre
NGO	Non Governmental Organisation
NLEP	National Leprosy Eradication Programme.
NMS	Non Medical Supervisor
NSP	New Sputum Positive case (Pulmonary TB never treated or minimally treated less than a month and found to be sputum positive)
OPD	Out Patient Department
PB	Pauci bacillary leprosy. A person with 5 lesions or less with anaesthesia; bacteriologically negative; single peripheral nerve involvement
PH	Project Holder
PHC	Primary Health Centre. The main health facility in rural area covering a population of 25000 to 200000 and responsible for implementing curative and preventive services in the designated population.
PMW	Para Medical Worker
POD	Prevention of disability. Important component of leprosy control aimed at preventing the occurrence and management of disability.
RMP	Unqualified Registered medical practitioner.
RNTCP	Revised National TB Control Programme
RR	Reversal Reaction
RCS	Re Constructive Surgery
SC	Sub Centre
SER	Socio-economic rehabilitation
SLC	Senior Laboratory Coordinator
SMA	Senior Medical Advisor
SPR	Sputum Positivity Rate
SSOD	Soaking, Scrapping, Oiling and Dressing
STDC	State TB Demonstration Centre. One in every state meant for training all the staff in RNTCP.

STLS	Senior TB Laboratory Supervisor- Laboratory supervisor in TB unit for guiding laboratory work in the 5 Designated microscopy centres.
STO	State TB Officer. Programme officer in a state in charge of TB control.
STS	Senior TB Supervisor. One in every TB unit at sub district level for 500000 population and responsible for field supervision in TB control.
TRC	Tuberculosis Research Centre, Chennai
UMDT	Uniform Multi Drug Treatment
UT	Under Treatment
WHO	World Health Organisation

## DAMIEN FOUNDATION INDIA TRUST

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Dr. P. Vijayakumaran	Director (Programme)
Dr. Jacob Mathew	Medical Advisor (DPMR)
Mr. D. V. Premkumar Velu	Chief Financial Officer
Mr. G. Kothandapani	Field Investigator
Mr. R. Jaishankar	Central Lab. Supervisor
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Mr. S. Ramesh	Junior Assistant
Mr. E. Ravi	Mechanic Cum Driver
Mr. Dursu Purthy	Senior Driver
Mr. Ram Pravesh Sharma	Driver
Mr. Dharmendar Kumar	Driver
Mr. Navin Kumar Singh	Driver
Mr. Rupan Ram	Peon

**All services to Leprosy and TB patients are FREE of cost.**