

## Dr. Jonathan's Proposal for the Rural Outreach Program for Leprosy

### **Summary**

This proposal covers co-ordination of care and community based rehabilitation for non-entitled people suffering from the long term effects of leprosy and living independently in communities in Thailand near the border with Burma.

### **Background**

In and around Mae Sot there are a number of people suffering from long-term nerve damage of leprosy and its secondary effects for whom there is currently no help available.

Between 1995 and 2000 Mae Sot hospital reported 41 Burmese (including Karen) with leprosy, of whom 20 (49%) completed medication, 14 (34%) defaulted, 2 (5%) died, and 5 (12%) moved elsewhere with outcome unknown. Since then 12 more cases are known to me, of whom 2 are known to have died. These people probably represent the "tip of the iceberg" of leprosy cases.

Medical care in Burma, especially in the Karen area opposite Mae Sot, is absent or extremely limited, mostly to those in the towns who can pay and some groups favoured by the government.

The first contact for medical care for many Karen and Burmese staying in and around and opposite Mae Sot is often the outpatient department for the Mae Tao Clinic of Dr. Cynthia Maung. If a person is suspected of suffering from leprosy an initial diagnosis can be made there.

There is provision within the Thai health system for the diagnosis and drug treatment of leprosy in Thai citizens and this has been extended, by the dermatologist at Mae Sot hospital, to include non-entitled Karen and Burmese.

### **The Problem**

- Help for leprosy sufferers is limited to a hospital-based service and does not go beyond the technical medical activities of diagnosis and drug treatment.
- There is no provision in the Thai or NGO system in Mae Sot to help leprosy patients in the community or for any continuation of assistance after the drug treatment has finished.
- Staff trained to teach the ideas of preventive care of anaesthetic feet and hands and to carry out general supportive community activities do not exist in Mae Sot.
- In Mae Sot there is a lack of availability of suitable protective footwear and also specialist surgical procedures for leprosy patients. The nearest centre for these is in Chiang Mai at the Mckean Hospital.

- The stigma of leprosy is still strong in this area and limits the number of people willing to care for leprosy sufferers. The attitude of relatives and surrounding people can also be a source of difficulty.
- For Karen and Burmese in Thailand access to medical care is limited by Thai health service constraints, language barriers, lack of legal status with real fear of arrest, transport difficulties and both the direct costs of movement and of opportunities lost by the time involved.

### **The Idea**

To employ and train a suitable person based at Mae Tao Clinic outpatient department to work in the local community to assist people with nerve damage from leprosy in the prevention of disability and in limiting its effects when already present. Also to work to help sustain the dignity, psychological well-being and independent material survival of these people and to encourage family, neighbors and local people towards a realistic, positive and helpful view of the difficulties of people with leprosy.

### **The Role**

To help people with leprosy to access medical treatment, to prevent, limit or minimize physical disability, to support themselves materially, to sustain the spirit and dignity of the individual, and to achieve acceptance within the community.

### **Organization of Medical Treatment**

- Arrange for suspected leprosy patients to be seen at Mae Sot Hospital dermatology OPD for diagnostic consultation and accompany the patient to help with translation, transport, etc.
- Explain and help the patient understand the diagnosis and treatment.
- Supervise the regular supply and taking of medication.
- Ensure rapid recognition and treatment of complications, reactions, other medical problems.
- Organize with Mae Tao Clinic trauma department for treatment of skin damage and ulceration.
- Organize with Mae Tao clinic eye department and visiting eye specialists for the treatment of eye problems.
- Organize appropriate specialist surgery at the McKean Hospital in the provision of protective footwear.

### **Support at Home**

- Visit the patient at home and assess his/her living circumstances, looking particularly for dangers to anaesthetic limbs, type of work and level of income, presence of people providing support, role and acceptance within the community.
- Teach methods of skin care and ulcer prevention suitable for long term use at home by the patients themselves.

- Suggest and help arrange forms of daily living that avoid damage to anaesthetic limbs.
- Identify and support means of income generation that minimizes trauma to limbs and allows the person's material survival and increases a sense of self-worth and role within the family and community.
- Encourage the person in all aspects of life to achieve dignity and independent self-help.
- Contact and encourage family, relatives, neighbors, and community members to view and treat the person properly with acceptance and respect and to understand that fear is unnecessary and discrimination is not appropriate.

### The Person

- Probable Thai-Karen with full ID card, without limitations on movement.
- Able to speak well: Karen, Burmese, Thai, and English, in order to communicate with patients, clinic staff, hospital personnel, police, and trainers.
- Possess Thai motorcycle license and willing to ride a motorcycle in difficult weather and road conditions.
- Happy to work with leprosy patients, with suitable attitude to their illness, disability, and social circumstances.
- Happy to work in poor community surroundings and with people without legal status in Thailand.
- Able to work independently and reliably account for use of time and money.
- Able to explain work to authorities and police if questioned.

### Estimated cost:

Initial	Item	Cost		Total
	Motorcycle x 1	36,000 Bt	800 \$US	
	Helmet (European quality)	18,000 Bt	400 \$US	
	Gloves	9,000 Bt	200 \$US	
	Microscope (Zeiss binocular)	55,000 Bt	1,300 \$US	
	<b>Total</b>	69,000 Bt	2,700 \$US	<b>2,700 \$US</b>
<b>Yearly</b>	Salary (10,000 Bt monthly)	120,000 Bt	2,700 \$US	
	Insurance		5 \$US	
	Tax moto		3 \$US	
	Petrol (720 litres) 36,000km/50km = 1 liter =16Bt	120,000 Bt	262 \$US	
	Repairs (tires especially)	8,800 Bt	200 \$US	

	Stationery	1,100 Bt	25 \$US	
	Postage	1,100 Bt	25 \$US	
	Telephone	2,200 Bt	50 \$US	
	Income generation fund	2,200 Bt	100 \$US	
	<b>Total</b>			<b>3,400 \$US</b>

Thus a one time start up cost of \$2,700 \$US to buy a motorcycle, protective clothing and a microscope and an annual running cost of \$3,400 \$US each year with a commitment to 5 years is proposed.

Any savings on specified items could be transferred to expand the income generating capacity of patients and their families.

Year 1	2,700 + 3,400	6,100 \$US
Year 2		3,400 \$US
Year 3		3,400 \$US
Year 4		3,400 \$US
Year 5		3,400 \$US
<b>Total over 5 years</b>		<b>19,700 \$US</b>

## Organization

The community worker employed will answer directly to Dr. Cynthia Maung of Mae Tao Clinic, or such persons as she might specifically delegate for this role under her responsibility, who will be responsible for payment of salary and supervision of work. The person employed will be given a copy of the final version of the agreed proposal to act as a basis for his/her duties.

A short report of work and activity will be made every 3 months jointly by the community worker and the supervisor designated by Dr. Cynthia at Mae Tao Clinic. Finance will be received by the Mae Tao Clinic under the responsibility of Dr. Cynthia Maung and the community worker will be informed by the Mae Tao clinic of all such money received. In addition the donor will be requested to directly inform the leprosy worker of transfers of money to Mae Tao clinic.

Finances will be used for the support of leprosy sufferers and their families only. All expenses will be made by the community worker only (exception for protective motorcycle helmet and gloves to be purchased in Europe to ensure adequate standard). All expenses will be supported by a written receipt and when this is in Thai a translation into English will be written on the receipt. A receipt will only be accepted for a clearly identified item, with specified quantity or number of items, with date, name, and address of place purchased complete and translated into English. The receipt will be clearly

signed by the community worker. All receipts for expenditures will be kept for one year longer than the duration of activity and will be available to the donor upon request.

The motorcycle will be used by the community worker only and will be kept under his/her personal care. A record of use, expenditure on fuel, maintenance, and repairs will be kept. It will not be used for the private use of the community worker, although he may use it to travel daily between his home and work place in addition to using it for work. The motorcycle will be kept in the name of the community worker and should the activities stop the motorcycle will be transferred to the donor or sold and the money raised used for the support of leprosy patients.