Dear Friends,

Looking back at the last one and a half years at The Leprosy Mission Trust India (TLMTI), I feel blessed observing, hearing and reading about the various strands of our work with the people affected by leprosy. It is indeed a unique organisation, with its rich leprosy expertise, evolving over time catering to the emerging needs of people affected by leprosy.

Leprosy has been in existence since time immemorial. We need to be committed to continuously improving the lives of people affected by leprosy by addressing a range of priorities from prevention of leprosy to reduction in stigma and discrimination. We need to question ourselves on the continuing transmission of disease, how to enhance early voluntary reporting, prevent and manage disability and complications of leprosy and greater contribution of people affected by leprosy.

The Research Resource Centre at TLM India coordinates basic science research at the Stanley Browne Laboratory, clinical and operational research through the hospitals and the field programs. This year we have made conscious efforts at training and demystifying research among our colleagues. After all, research is a systematic and objective process of gathering, recording and analysing data to aid decision making rather than use intuitive information. How do we use this evidence to influence policy and the way we work to improve the lives of people affected by leprosy?

We are happy to see this change in mind set taking root within the organisation. I hope research which aims at improving the lives of people affected by leprosy will truly become a way of life in TLM.

Wishing all our colleagues a fruitful and interesting experience as they engage in research in the field of leprosy.

Dr. Mary Verghese,  
Deputy Director, (Programmes)

Dear Friends,

We are happy to bring you the latest edition of the RRC Newsletter. The last few months have been full of activity for the people involved with research in The Leprosy Mission and you will find details of these events inside.

Dr. Mary Verghese, Deputy Director (Programmes) has conveyed to us an encouraging message for all our staff, reminding us that our research is part of our overall holistic approach to overcome the physical, mental and socioeconomic distress caused by leprosy.

The social and psychological results of leprosy are often equally or even more painful than the physical suffering and disability caused by the disease. Dr. M.S. Raju, Our Social Scientist, writes about how social science research is relevant and can be applied to all the stages of leprosy, beginning from methods to promote early detection and adherence to treatment, ways to combat stigma and right to the other end of the spectrum - evaluating the results of rehabilitation programmes.
We had the Research Skills Building Workshop which was greatly appreciated and enjoyed, the meetings of both the TLM India Research Committee and the Stanley Browne Laboratory Advisory Committee, and were in involved in developing a background document for ‘Assessment of IEC in Leprosy’ for WHO. The TLM international research committee also met via teleconferencing in August. We are full of new ideas and possibilities; and hope that many TLM staff will be enthused to join this part of TLM’s work.

Along with this we bring you four articles on variety of subjects on leprosy to show the work being done in different parts of the world. We hope you enjoy reading this newsletter and look forward to your comments.

Happy Reading!

Annamma S. John, Editor

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**Events in RRC**

17th to 20th July 2012

In July, RRC Conducted a Research Skills Building Workshop, as part of its strategy to develop a research culture in TLM and build research capacity.

Apart from the long term goal of developing a research culture in TLMTI, we also hoped that by the end of the workshop each participant would be able to prepare a suitable research proposal on a relevant topic, conduct the research, analyse the results and prepare a draft report by the end of the year.

Fifteen staff members from different TLM projects and hospitals came for the workshop which covered a range of topics including Developing Research Questions, Literature Review, Data management, Study Design, Qualitative methods and Proposal and paper writing. There was ample time provided for practical work and demonstrations. A session on laboratory research was taken by Dr. U. Sengupta and was appreciated very much. Practical Sessions on and SPSS allowed the participants to work on what they learnt and use it for their individual projects. Dr. Sundar Rao, was the main facilitator and the participants had the benefit of his vast experience. Dr. M.S Raju was the expert in Qualitative methods and there were lively participatory sessions with Focus Group discussions.

Most of the participants went back to their centres with a proposal and an aspiration to complete the project by December 2012.

The participants enjoyed the workshop and found it helpful; the feedback was very encouraging and we hope that the workshop will bear fruit in terms of improving the research culture as well as the output in TLMTI.

28th July 2012

The Scientific Advisory Committee of the Stanley Browne Laboratory was held on 28th. July 2012. It was attended by the Director TLMTI, Dr. Sujai Suneetha, Prof. Indeera Nath, Dr. Krishna Prasad, Dr. Sundar Rao, as well as the staff of SBL. It was a fruitful meeting and some new ideas were discussed and it was decided that the areas of research interest should be widened to become more visible, relevant and sensitive to the ultimate goal of a “World Without Leprosy”. The concern that research findings should be applicable in the field was felt again and the staff were encouraged to ensure the relevance and application value of the work they were doing.

4th August 2012

TLM India Research Committee

Dr V. M. Katoch, Chairman emphasized that the commitment for leprosy research in TLM is alive, but the research activities are to be translated into actions and incorporated into control programs. There should be a system in place to evaluate the outcome of the research activities and see that they have made a difference in terms of bringing about a change. Researchers are the drivers to push these changes beyond and TLM should see that their activities are visible to clinicians across different centers with similar work areas in leprosy. He also said that TLM should work on incorporating the research knowledge into applicability. This he said should feature as an agenda from the next TLM – IRC meeting onwards where details of the efforts made in application of research should be reported.
Social Science Perspectives for NLEP

The success of any health programme depends more on human behavior than availability of services, so the systematic study of health seeking behaviour, community perspectives gender issues etc., is an integral part of planning health programmes and interventions.

As such, the behavioural research is applicable for leprosy workers of different disciplines. It is broadly known as Social Science Research, since it is carried out through employment of research methodologies of various social science disciplines viz. Anthropology, Sociology, Psychology, Social Work, Economics and Political Science with branches of medical specialization and support of statistics, public health & Management Studies. TLMTI has been undertaking different projects in this field for many years and has gathered considerable experience in the field.

Given below are some important social science research projects taken up by TLMRRC during the last decade and the relevant findings that may be applicable in NLEP:

P-Scale study: Is a combination of multi-centric studies in India, Brazil, Nepal, which resulted in the development of an 18 point interview based scale to assess the nature and extent of participation restriction. This can be used as a
- A standard monitoring tool in NLEP
- To assess impact of CBR interventions in people affected by leprosy

CARRELS project: Community-based Action Research for Reduction of Leprosy Stigma (CARRELS), is a multi centric study conducted in UP, Chhattisgarh, West Bengal to find sustainable stigma reduction programs, designed and implemented by the community. Findings of the study prove that:
- Village Health & Sanitation Committee (VHSC) of the NRHM can very well perform the role of Stigma Reduction Organizing Committee, (SROC)
- Existing SROC may be integrated with VHSC
- NRHM functionaries such as ASHA & USHA can facilitate the effective functioning of the Committees.

Impact of Self-Help Groups (SHG) for empowerment of leprosy affected women: A study with an objective to understand the dynamics of empowerment in the existing Self Help Groups in Chhattisgarh state in India, especially among the leprosy affected women recommended further steps for enhancing the degree of empowerment, in terms of incorporating the following in NLEP:
- Operate NLEP as a community based activities
- NLEP is monitored by SHG (or by Village Committees)
- Ensuring the participation of leprosy affected in community based activities
- Emphasizing the specific needs of leprosy afflicted.

Prevention of defaulting of MDT in leprosy (PREDEM study): A multi-centric study addressing the problem of defaulting, aims broadly to develop, experiment and evaluate innovative strategies that promote successful completion of MDT in integrated health care system.

Findings of this study emphasizes that, prevention of defaulting needs implementation of the following through NLEP:
- Prevention of defaulting is the responsibility family/community
- Methodology designed by family/community is the most successful
- A key informant is essential for understanding of the operational processes of various contributing factors
- All the above be monitored by NLEP as a community based activity.

New Agenda: While the above studies of RRC are a few examples for behavioural research the findings of which could be incorporated in the NLEP, further applied research is needed in many aspects of leprosy care such as Community’s response to the services provided by the programme (Effectiveness of CBR), Self care practices, stigma reduction measures (Nature of the issue from community’s point of view), community participation etc.

Guidance: TLM RRC is equipped with all Social Science Research facilities and one of its priorities is to provide research assistance and capacity building any staff members interested in social science research on any aspects of leprosy. We hope you will look at your own patients or clients and be encouraged to find new methods to improve your services. Please free to contact us for any assistance.

Dr. M. S. Raju,
Sr. Social Scientist RRC

Centre for Bio Ethics

TLM has been conducting research in the field of leprosy for many years, and we have an Ethics Committee that reviews ethical Issues of any proposed study before sanctioning it. We all appreciate the need for ethical conduct and ensuring that the rights of those who are subjects or participants in any study are protected.

But more and more a need is making itself felt for a “Bio Ethics policy” – not only for research but for all aspects of medical work. There are no Christian guidelines or policy and different institutions and individuals follow what they think fit. In view of this situation Emmanuel Hospitals Association has taken the lead in trying develop a Bioethics frame work formulated with inputs from a number of Christian organisations, which will provide guidelines for practice and research.

After preliminary workshops and consultations The Center for Bioethics, which is supported 15 Christian organizations was inaugurated on 6th October 2012 at New Delhi. TLMTI is actively involved in this endeavour and Dr. Sunil Anand is the Chairman.
Abstract
Cranial nerve involvement is not common in leprosy. The fifth and seventh cranial nerves are the most commonly affected in leprosy. Herein we present a patient with Hansen disease (BL) with type I reaction who developed isolated involvement of the sixth cranial nerve leading to lateral rectus muscle palsy. He responded to timely anti-reactional therapy and it produced a good response. Careful observation of patients with lepra reaction is needed to avoid damage to important organs.

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An unusual case of isolated sixth cranial nerve palsy in leprosy

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Notice
This department requires no physical fitness program

Everyone gets enough exercise jumping to conclusions. Flying of the handle. Running down the boss. Knifing friends in the back. Dodging responsibility and pushing their luck.

Life is hard, but it’s harder if you’re stupid. Michael Crichton

Nobody can go back and start a new beginning, but anyone can start today and make a new ending. Maria Robinson