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Dear Friends,

We are, once again at the end of another year, wondering how the time flew by so quickly and thinking on all the work remaining to be done. Looking forward while learning from the past is a normal part of our lives. And so this issue brings us some of the events and accomplishments of 2012 while looking forward to the new year and future of leprosy research.

We bring you a message from Dr. Paul Saunderson, Medical Director, ALM about the new directions and priorities and ILEPs new “contact-centered strategy to reduce the transmission of leprosy.” It gives us a glimpse into the future direction of leprosy research. Jannine Ebenso from TLMI writes about experiences and major issues at the 1st. CBR Congress held at Agra in November. We also have abstracts of two papers from TLM which were published recently, and an article from Dr. Sundar Rao about choosing a research topic.

Dr. Sundar Rao is leaving TLM as Research Consultant at the end of this year, and we record our appreciation and gratitude for his work during the last 10 years, which has contributed so much to both individual and multi centric/group research in TLMTI. His association with TLM will not end and we wish him the best and will be continuing to tap his expertise for our work.

We at RRC wish you a Christmas filled with God’s Blessings of peace, love and joy and a happy and fruitful new year.

Annamma S. John

Leprosy research: looking to the future.

In recent years, there has been a lot of discussion about what should be the priority concerns for those involved in leprosy research. In general, we have viewed basic, laboratory and epidemiological research as important for the medium to long-term control and prevention of leprosy, while research into diagnosis, case management, reactions, stigma and other complications of leprosy are of more immediate concern – research in these areas could benefit current patients, if the results are applied in a timely manner. So most of us can see the value of a wide range of research topics.

As is now widely appreciated, leprosy is being categorized as one of the neglected tropical diseases (NTDs). This term comes from the fact that the Millennium Development Goals (MDGs) only mentioned HIV/AIDS, TB and malaria as important target diseases, amongst other more general health concerns – in this scenario, all other specific diseases were neglected! But recent discussion surrounding NTDs has made it clear that to compete for scarce, but potentially serious research funding, we need to be more strict in defining a clear priority target for our research effort.

ILEP recently formed a Temporary Expert Group to look into this – the group met for two days in November, under the joint chairmanship of Professors Cairns Smith and Jan Hendrik Richardus, and came up with the following priority statement:

“Our priority research goal is the development of a new, contact-centered strategy to reduce the transmission of leprosy.”

This goal accepts the view that case-finding and chemotherapy with MDT have not greatly reduced the transmission of leprosy in many areas, and that new tools are needed to... continued on pg 2
achieve this, in order to significantly reduce the incidence of the disease. The COLEP study, carried out in the TLM center at Nilphamari in Bangladesh from 2001 – 2007, showed that chemoprophylaxis with single-dose rifampicin (SDR) could reduce leprosy in contacts by over 50%. There is great interest in whether immunophrophylaxis – either with BCG, or with the new leprosy-specific vaccine being developed by American Leprosy Missions and the Infectious Diseases Research Institute (IDRI) – will give additional, and perhaps longer-lasting, protection to contacts.

This priority goal therefore contains several packages, beginning with the development of guidelines for tracing and managing contacts, which should be agreed over the coming 12 months. New diagnostic tests are also needed, especially to test for sub-clinical infection, which would help to identify those at high risk for clinical disease: one often thinks of immunological tests in this context, but other tests based on the fact the leprosy invades the peripheral nerves very early in the course of the disease could also prove useful. We need innovative thinking here! Maybe in the not too distant future, there will be genetic markers that will identify the small proportion of the population that is susceptible to leprosy, so that protective measures can be targeted to them.

Packages that help to roll out practical strategies for chemoprophylaxis and immunophrophylaxis come next, along with studies that continue to explore the epidemiology of leprosy and its transmission in the community. All the different components of this new focus should involve consultation with all stakeholders, including people affected by leprosy. What may this mean for The Leprosy Mission in India? What I think is essential is that we develop meaningful and robust collaborations, especially between the treatment centers where the patients are, and the laboratories. A good example that is slowly getting established is the sentinel surveillance for drug resistance, whereby various TLM centers around the country send specimens from relapse cases to the Stanley Browne Laboratory; molecular methods are then used to identify mutations associated with resistance. Monitoring drug resistance is currently important for the continued effectiveness of MDT, but in future it will be important if/when SDR becomes more widely used for chemoprophylaxis. Perhaps more important, however, is the model of collaboration across TLM centers, which could be expanded to study other issues.

A final point that I’m sure will be crucial in future is collaboration between TLM centers around the country and the integrated, government services for case-finding and chemotherapy. We often talk about how modern telecommunications (mobile phones, etc.) have helped patient management, but let’s also find ways to use them to strengthen the collaborative networks on which these future strategies will rely.

Paul Saunderson,
Medical Director,
American Leprosy Mission

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### Choosing A Research Topic

Research is done to answer a pertinent question or obtain clues to solve a problem. Leprosy is a ancient, chronic, mycobacterial disease, stigmatized even now, with several unresolved questions regarding its epidemiology, prevention, efficient management of complications, and continued negative social perceptions and participatory restrictions.

The Leprosy Mission Trust India is a pioneering and compassionate organization which began its work among leprosy affected persons in India more than a century ago. It still maintains more than 15 leprosy referral & community hospitals all over India with over 200 health professionals and treating more than 10,000 leprosy patients annually. With a plethora of resources, manpower, patients, state-of-the-art laboratory and abundant goodwill and public support, it has great potential to carry out significant research in leprosy, that can alleviate much suffering of the affected persons, and contribute to increasing the expertise in managing leprosy.

Sad to say, research has been a low priority for the Mission, despite stalwarts like Brand, Job, and Karat, who made significant contributions to leprosy care in earlier days. Some progress was made during the past decade in conference presentations and publications, but they are just a drop in the vast ocean of ignorance and general apathy.

The main problem seems to be a lack of active support to initiate, innovate and implement meaningful research in any of the wide range of leprosy problems: transmission, classification and early diagnosis, chemotherapy especially in managing reactions, rehabilitation and reconstructive surgery, prevention of physical and social disability, social activism and community-based interventions.

The first step is choosing the right topic for research: several parameters are necessary, the foremost being the “Relevance”. Next comes the Urgency and Significance of the research to make an impact. Avoidance of duplication, Feasibility, Applicability, Political acceptability and Ethical considerations can also be considered. Finally, the resources of financial support, dedicated time are important. None of these will help without a personal commitment and interest of the investigator. A professional is not a professional unless he/she contributes to the body of knowledge in the field, and under the present circumstances, this becomes a moral responsibility.

Once a topic is chosen, internet resources such as Google and Pubmed provide an easy access to past work done on the subject and a thorough review of literature becomes the foundation stone for new research. Computer and Information technology provides every help to design a suitable research protocol and implement the data collection, data management and preparing the report for dissemination and practice. The Research Resource Centre (RRC) was established to provide necessary guidance at every stage, including publication of research findings in accredited peer reviewed journals or to present at national and international conferences. So, choose wisely and implement relevant research on a priority basis. This is God’s will for us!

P S S Sundar Rao
Consultant, Research
1st CBR World Congress, Jaypee Palace, Agra

1200 delegates from 86 countries gathered together in Agra, India for the 1st CBR World Congress. Over 30 delegates from 6 TLM Fellowship Member Countries (Bangladesh - 4, DR Congo-1, England and Wales-1, Myanmar-3, Nepal-3, Niger - 1 and India > 20), TLMI and the TLMI Research Committee were in attendance. Delegates also included representatives from Regional CBR Networks, some National CBR Networks, International Disability Alliance (IDA), Disabled Peoples’ International (DPI), Rehabilitation International and the International Disability and Development Consortium (IDDC). The Indian government was also represented.

The congress was co-sponsored by WHO, Australian Aid, US Aid, CBM and Sightsavers.

The theme of the congress was - CBR: the key to realising the Convention on the Rights of Persons with Disabilities (CRPD).

In the opening remarks of the congress it was mentioned that, it took 20 years and 10,000 people to build the Taj Mahal. It has taken 30 years and thousands of people to build CBR to the level it is today. Along the way we have achieved many milestones – the 2004 joint position paper on CBR, the 2006 Convention on the Rights of persons with disabilities and the 2010 CBR guidelines to mention just three.

This congress gives us opportunities to take the next steps to achieving community-based inclusive development and realising the rights of persons with disabilities.

“Development is what happens when relationships are strengthened for the common good.”
- Peter Coleridge

Many times we have heard that disability and poverty are intertwined. Indeed, the most basic definition of poverty is the lack of opportunity to reach our potential. CBR is a poverty alleviation strategy exactly because it aims to help people reach their potential.

The Leprosy Mission made some presentations about our work in various countries:

- Bob Bowers (Bangladesh) presented some of the findings from his study of leprosy related disability and ultra-poverty.
- Dr Zaw Moe Aung (Myanmar) presented evidence that integrating leprosy-disabled people into a general CBR programme is very effective.

Yet again we were reminded of the relationship between disability and poverty as Chapal showed the UNDP’s map of MDG countries and compared it to WHO’s map of CBR countries – almost identical.

And so as one congress ends, we were told of the congresses to come...

2013 – Colombia (Regional Congress), 2014 – Egypt (Regional Congress), 2015 – Japan (Regional Congress), 2016 – Malaysia (World Congress)

Goodbye Agra, and thanks for having us visit you!

Jannine Ebenso.
Programme Advisor for Disability

In addition, TLM’s work was referred to in other peoples’ presentations. Peter Coleridge, a British Development worker, spoke about the importance of not just having skills development in ‘hard skills’, but also ‘soft skills’.

- TLM India’s VTCs were highlighted as good examples of where soft skills are included – a good work ethic, communication skills, building self-esteem and self worth, valuing good character and integrity etc. He said that this is one of the reasons why employers in India value the graduates of our VTCs and why we have an employment rate of over 90% in our past graduates. Congratulations TLM India!

- In his closing remarks, Chapal Khasnabis of WHO’s Disability and Rehabilitation Unit reminded us that the face of disability is changing as the world’s population changes and as the incidence of non-communicable diseases increases in the Global South.

- In addition, for the first time I heard the disability world saying that CBR should not only be focussed on disability, but also on other marginalised groups (the leprosy world has been saying that for many years).

“Christmas is not a time nor a season, but a state of mind. To cherish peace and goodwill, to be plenteous in mercy, is to have the real spirit of Christmas”.

Calvin Coolidge
Nutritional Status of Leprosy Patients in India.

**Abstract:**
A cross-sectional epidemiological study was carried out at a Leprosy Referral Hospital in Delhi to assess the nutritional status of multibacillary leprosy patients in comparison to the general population using BMI. 150 people affected with multibacillary leprosy were included in the study, of whom 108 (72%) had WHO Grade 2 disability. 100 non leprosy patients were also included as a control group. Socio-demographic and clinical details as well as their height and weight were measured and the BMI computed. The findings clearly showed that under – nutrition (BMI < 18.5) was more common in people affected by leprosy than in those without leprosy, regardless of age or sex. Presence of disability made the incidence of under – nutrition more likely. The duration of disease, number of lesions or bacterial index had no impact on the level of nutrition. There may be multiple factors working together to lead to this under – nutrition and these are discussed briefly. If, we aim to provide high quality services with a holistic approach, a mandatory BMI should be calculated for every patient and if under nourished, a qualitative diet summary should be done and suitable nutritional advice given. Further, studies are needed for a better understanding of the occurrence and progression of under – nutrition in Leprosy to find efficient ways to combat this problem.

Help-Seeking habits of untreated leprosy patients reporting to a referral hospital in Uttar Pradesh, India.

**Abstract:**
In a potentially disabling disease like leprosy, the need for prompt diagnosis and start of treatment cannot be over-emphasized. With the advent of massive Information, Education and Communication (IEC) strategies and easy accessibility of free multi drug therapy (MDT), delay in treatment is more dependent on patient initiative and subsequent health seeking habits. To study the factors contributing to delay, a random sample of 86 new untreated leprosy patients presenting to The Leprosy Mission Community Hospital, Naini, Allahabad during 2011 were interviewed in depth with the help of a check list. 61% of patients had disability at first presentation. The most common first symptom was a hypo pigmented patch. Mean delay was found to be 25.9 months. Reasons for delay varied from ignorance about the symptoms and signs of the disease, monitoring of symptoms in the hope that they would disappear by themselves and lack of vigilance among local medical practitioners in the lower levels of the health system. The authors discuss the typical sequence of events that contributed to delay at each stage before finally presenting at a referral hospital. It is necessary to outline recommendations to address delay in terms of intense health education campaigns, mass communication strategies and developing a high index of suspicion among primary health care givers.

Dr. P S S Sundar Rao

Dr. Sundar Rao joined The Leprosy Mission and took over as Research Coordinator in 2003 to encourage and develop research activities in TLM, build the capacity of Staff to undertake Research, and develop a research culture in TLM.

As we all know he is a renowned Bio-statistician and widely respected both nationally and internationally, for his expertise and extensive experience in research, having been associated with CMC Vellore, Karigiri, and many other premier organisations in very senior positions.

In the last 10 years he has facilitated the growth of research activities in TLM remarkably, which was evident by the presence and contribution of TLMTI at the last ILC held at Hyderabad in 2008, where more than a 100 papers were presented by staff of TLMTI.

He initiated many multi centric projects, both national and international, including the Azathioprine trial, community based projects on Stigma reduction (CARRELS), Population based registries (PELSI & the Urban Study), and studies on encouraging early detection and compliance and built up the relationship with IICMR. He has been a mentor to many of us and facilitated individuals and multicentric research projects and the publishing of e results in peer reviewed journals. His patience, willingness to help, along with his keen sense of humour make him an ideal teacher, mentor and friend.

Though he is leaving TLM formally he has assured us that he will continue to help us in research when ever needed. We wish him a more restful time and know that he will continue to be a support and inspiration for us.

Annamma S. John