News and Notes

Update from Africa

The following article appears on LEPRA’s website (www.lepra.org.uk).

A representative from LEPRA recently attended the Annual National Leprosy Elimination Programmes Review Meeting in the WHO African Region, held in Harare, Zimbabwe. Other participants included national programme coordinators from countries with high leprosy prevalence (Angola, Madagascar, Mozambique, Republic of Central Africa, Democratic Republic of Congo, Tanzania), countries where leprosy has been eliminated (Benin, Burkina Faso, Cameroon, Zimbabwe) and countries where leprosy services have been integrated in the primary health care service (Mali, Nigeria and Zambia). Despite the different country scenarios, all countries share common difficulties with the availability of trained staff and quality and quantity of supervision.

The presentation on the experience of leprosy volunteers in Mozambique provoked the most discussion and there was much interest in sustainability issues. Both Benin and Mali also reported on the key role local communities play in their leprosy programme activities.

In small working groups, participants were able to incorporate their views into a regional leprosy post elimination strategy to sustain quality leprosy service after 2005, when the elimination target is expected to be reached. Key concerns reflected include the need for advocacy to ensure continued political commitment, the need for referral structures at the appropriate sub national levels and the increased relevance of partnerships.

23rd Biennial Conference of Indian Association of Leprologists (IAL)

The Indian Association of Leprologists is a national body with around 700 life members. It is an association with a strong scientific forum influencing the policy of leprosy control not only at home but also globally. The 23rd Biennial Conference of IAL was held this time at Haldia, a busy port city in West Bengal. It was organized under the patronage of Mr. Laxman Seth, the sitting Member of Parliament, East Medinapole district.

The venue this time was far away from the din and bustle of a metro and for some an unheard of city, in the emerging port city of Haldia.

To reach the registration counter the delegates this time had to pass through the Chatterjee, Sen and Ramu gates, named after Dr K. R. Chatterjee, P. Sen and Gopal Ramu, the legendary figures in leprosy work in India. Passing through these gigantic gates, the delegates reached Dharmendra Nagar, the conference village. Dharmendra is popularly regarded as the doyen of leprosy in the country. His life represents half-century leprosy work in India with his thought and action influencing the entire policy on Indian program of leprosy control. The delegates then found themselves in the ‘Swarna Jayanti Auditorium’ renamed Ekambaram’ shall for this conference. Dr V. Ekambaram often referred to himself as a humble worker, though he was a person with a wealth of experience, wisdom and life-long dedicated service. This gesture of honouring the pioneer leprologists by the organizers is not only a befitting tribute to these stalwarts, but is also a reminder of the rich history of leprosy work in the country.
Though the total registration was around 140, it did not affect the scientific content in terms of the abstracts. A total of 80 abstracts were received by the scientific committee, which functioned from the Central JALMA Institute of Leprosy with Dr V. M. Katoch, Director as the Chairman. Dr K. Venketesan, Secretary and other members of the Scientific Committee took care to design a two and half day scientific programme, interesting enough to keep the audience captive and active.

The deliberations started with an oration in honour of Dr Jal Mehta. Dr Mehta, an internationally famed surgeon in reconstructive surgery, was also the Honorary President of the Poona District Leprosy Committee (PDLC) and managed Dr Bandorawala Leprosy Hospital, a premier institution looking after an average of 425 inpatients at any one time. His contribution is not confined to surgery; he has also contributed significantly to the rehabilitation of leprosy patients. The awards and accolades he has received run into pages if listed. The Mehta Cooperative Rehabilitation Model and its documentary brought him the ‘Summa Cum Laude’ gold medal at Parma in Italy as early as 1955.

The oration was delivered by Dr D. Palande, another surgeon with a long career in leprosy. Dr Palande has to his credit more than 35 publications. He is author of a couple of books on reconstructive surgery. More importantly, he not only shares the specialty with Dr Mehta, but also his ideals and goals. Dr Palande spoke on ‘Rehabilitation in leprosy: a personal perspective’. The function was presided over by Dr S. K. Noordeen, President of the International Leprosy Association and Chairman of LEA.

There were special session on eye complications, initial trends of integration of leprosy with General Health Services and management of reaction: an update on alternative to steroids, and a symposium on ‘Current face of leprosy’ mainly focusing on the disease profile, therapy, vaccines, host parasite relationship and legal reforms. The speaker were Drs V. V. Pai, N. K. Mehra, Kiran Katoch, M. D. Gupte and V. V. Dongre. There were eight free paper sessions covering clinical and related aspects; microbiology, therapy of leprosy, immunology; prevention and management of deformities, molecular biology genomics, and epidemiology and social aspects. Altogether there were 16 lead papers and 41 free papers and 39 poster presentations.

This biennial conference was unique in the sense that in spite of the comparatively remote venue, as many as seven former Presidents and Secretaries of IAL attended the conference and were congratulated by the organizing committee. There were several awards to encourage young scientists. The Acowrth R. R. Society award for the best publication by a scientist 40 years went to Dr Deena Vardhini for her publication ‘Comparative proteomics of the M. leprae binding protein: its implication in leprosy and other neuro-degenerative diseases’. The two awards for two best posters went to Dr Tarun Narang, PGIMER, Chandigarh for his poster ‘Comparative evaluation of immunotherapeutic efficacy of BCG and M w vaccines in MB patients and to Dr V. P. Agrawal of FMR, Mumbai for his poster, ‘Use of 14C-palmitic acid in detecting M. leprae viability from skin biopsies’.

Regarding the IAL business session, in the evening of 28th February 2004 IAL had its General body meeting under the Presidency of Professor Bhushan Kumar. The function started with a condolence meeting to pay homage to the members of the association who passed away during the tenure of preceding two years. After 2 minutes silence, the gathering remembered the life and work of Drs J. A. Ponniah, P. R. Mahadevan, G. Ramu, V. Ekambaram, A. N. Chakraverthy, P. Kapoor and Paul Brand. Then details of the activities in the last 2 years, along with the audited accounts of the association, were presented. At the end there was election of new office bearers of the association, for which Dr K. V. Desikan acted as the Presiding officer and Dr K. Venketesan as his assistant. The new officer bearers are President: Dr V. H. Jadhav, Vice-Presidents: Drs D. Porichha and H. K. Kar, Secretary: Dr Swapan K. Samanta, Treasurer: Dr V. V. Pai. In addition a total of nine central council members were also elected.

The organizing committee was aware that the delegates do not come for the sake of only sharing experience and deliberate on science. A conference also needs to be a source of relief from the monotony of their professions and the brain taxing deliberations. Accordingly, there was enough site seeing and cultural events to ease their fatigued nerves and strained muscles. Dr Swapan Samanta with his team deserves appreciation for the variety in the Haldia conference, which was memorable in several ways. Those who were unable to attend have missed a great experience.
WHO tackles intellectual property rights, innovation and public health

The following article is taken from the June 2004 issue of TDR News. Access to health products by poor people, especially in developing countries, is often inadequate. The drugs, diagnostics or vaccines that could make the difference to their lives are too expensive or not available. Therefore solutions to guarantee access to existing products are needed. However, equally important is the stimulation of innovation to address the existing gaps in our knowledge and the lack of tools to address diseases of poverty. This issue is particularly acute for tropical diseases and other diseases of poverty where there is little market incentive. WHO has therefore set up a Commission to produce an analysis of intellectual property rights, innovation, and public health, including the question of appropriate funding and incentive mechanisms.

The Commission met for the first time in April 2004 to consider its priority areas of work. It decided to focus on the following issues: how to stimulate the creation of new medicines and other products for diseases that mainly affect developing countries; how intellectual property rights can promote innovation relevant to public health; and how funding and other incentive mechanisms can contribute to this. Another focus will be on traditional medicine and capacity building.

Ultimately, the Commission will produce a global framework to ensure the invention of new medicines for diseases mainly affecting developing countries.

American Leprosy Mission helps children from leprosy village

The following article is adapted from a news item on the ALM website. The American Leprosy Mission is supporting a tutoring project for children in one of the largest leprosy ‘colonies’ in the world. The children about 1200 of them, come from among the most impoverished families anywhere on earth. They have leprosy affected parents, and they know the experience of stigma and poverty. Many of their parents eke out their living by begging on the streets of Addis Ababa.

The project is under the direction of Sister Senkenesh Mariam. For years Sister Senkenesh has worked in the leprosy village, helping leprosy patients to develop skills and resources to cope with their crippled lives. Through this ministry, she learned that the leprosy ravaged parents had one single, abiding dream: help our children do better, and to reach for lives beyond a leprosy village. They knew that for their children to escape shame, stigma, and helplessness, they must become literate.

The few ill-equipped, indifferent schools in their neighbourhoods had no money for classrooms, materials, or teachers; but with coaxing and encouragement from Sister Senkenesh, they came up with a plan: they would enlist older students, young men and women who had completed some high school, to tutor the young children. With fingerless hands, blind eyes, and crippled feet, they constructed humble shelters for the children. Then they recruited the older children.

Today, the programme has 120 tutors. The tutors are rewarded with small stipends and scholarships to continue their own education. The high school tutors have gained a place of honour in their villages. The pride they experience is lifting them far above any dreams they could have imagined. Both the tutors and the tutored children are experiencing the excitement that comes with education and with hope.

Andhra Pradesh Counsellors Project

LEPRA India has taken on 240 new counsellors to help in the fight against HIV/AIDS in Andhra Pradesh as part of the Frontier Prevention Project (FPP) of the international HIV/AIDS Alliance. This work is being undertaken in partnership with the Andhra Pradesh State AIDS Control Society, UNICEF and the District Coordinator of Health Services. With an estimated 400,000 cases of HIV/AIDS in Andhra Pradesh, the State has one of the highest prevalence rates in India and, as with leprosy, the stigma and discrimination attached to the disease are enormous.
Using its existing infrastructure, LEPRA India has established Voluntary Counselling Testing Centres in all the Government medical colleges, large district hospitals, and area hospitals, offering counselling services on a one-to-one basis. There are also Prevention of Mother-to-Child Transmission Testing Centres which offer information and counselling services to attendees, advising them for instance on the most appropriate medication to take in order help prevent mother-to-child transmission. This new initiative is a further example of LEPRA India using its facilities and knowledge base to benefit people suffering from diseases other than leprosy.

Japanese team visits Bombay Leprosy Project

A group of Japanese musicians under the leadership of Ms Yuri Nishimura, visited the Training and Research Centre of Bombay Leprosy Project (BLP), situated in Bhakti Park, Wadala, Mumbai on 12 February 2004. Dr R. Ganapati, Director, BLP gave a brief audio-visual presentation to the team members on the involvement of Japan in leprosy relief work in Mumbai through BLP. He narrated the various ways in which BLP has initiated a collaborative effort with the organizations and people of Japan. This approach has helped BLP to overcome the barrier of distance and come closer with the people of Japan to work towards the common cause of not only eliminating the disease, but the stigma associated with it and the efforts towards reaching the goal of a ‘World Without Leprosy’. Later, the team visited the BLP’s Vocational Rehabilitation Centre at Pratiksha Nagar, Sion, Mumbai where leprosy cured and handicapped persons are receiving vocational training on computer science and tailoring. The members of Japanese team interacted with the trainees and shared their views. Exchange of experience of members of the Japanese team with the staff of BLP brought better understanding and friendship between the groups.

Seminar on ‘Alliance and Hope’

Bombay Leprosy Project (BLP) organized a seminar on February 12, 2004 at the Conference Hall, PSM Department, Urban Health Centre, Dharavi, Mumbai. Dr Ganapati, Director of BLP, welcomed the gathering and introduced Ms Yuri Nishimura and Ms Makiko Egami, both the guest speakers from Japan. Ms Nishimura spoke on ‘History and current situation referring to leprosy in modern Japan’. She mentioned that although the long-term isolation of leprosy affected persons in Japan has come to an end, there has been little progress in rehabilitation efforts. She also outlined the purpose of Sur-Deep’s project and its future plans based on building strong bond between the people of India and Japan and to strengthen the relationship by offering educational support for leprosy cured and disabled children living in slums of Mumbai.

Ms Makiko Egami, a nurse at Kawagoe Psychiatric Hospital, Japan, made a poster presentation on the ‘Importance of Social Action Program in Psychiatric Day Care’. She compared the discriminatory laws in force since 1900 against leprosy and mental disease. She told the success story of patients following the initiation of a planned Day Care Programme and the social action movement that has brought about new hope among the patients in the hospital, who are seeking a change in their life. The seminar was attended by several nursing staff from various medical colleges and NGOs as well as by professionals like psychologists and psychiatrists from the city medical colleges. Dr V.V. Pai, Assistant Director, BLP, proposed the vote of thanks.

News wanted!

If you have any items of news, conference reports or personal stories that you believe would be of interest to other readers of Leprosy Review, please e-mail them to susan@boobis.freeserve.co.uk, for publication in News and Notes.