EDITORIAL

Reflections on the ILA African Leprosy Congress

PAUL SAUNDERSON* & RUTH LEEKASSA**
* Leprosy Consultant, American Leprosy Missions, 1 ALM Way, Greenville, South Carolina, USA
** Executive Director, ALERT, PO Box 165, Addis Ababa, Ethiopia

Accepted for publication 19 April 2005

The recent African Leprosy Congress, held near Johannesburg in South Africa from January 31 to February 3, got off to a marvelously relaxed start when the opening ceremony was delayed for a couple of hours, while we waited for a television crew to turn up. A local choir entertained us with traditional folk songs, with enthusiastic audience participation to give an authentic African ambience! The 260 or so participants came from over 40 countries and, as the organizers had intended, there was a much bigger input from Africa than to any previous ILA Congress.

The opening session, in the presence of Dr Manto Tshabalala-Msimang, the Honorable Minister of Health, set the scene for the Congress, with the presence of about 30 people affected by leprosy, many of whom made presentations or participated in discussion throughout the 3 1/2 days of the meeting. Dr Asamoa-Baah, Assistant Director-General of Communicable Diseases, WHO, made the point that, although more than 14 million people have been cured of leprosy by MDT, they are not fully cured in the sense that disability or social stigma may still be experienced – the ‘post-elimination’ agenda will therefore be bigger than one focusing solely on the elimination target.

Human rights

The first morning focused on human rights and the removal of discrimination, with a keynote address by Mr Yohei Sasakawa, of the Nippon Foundation and a response by Professor Yozo Yokota, of the United Nations Human Rights Committee (UNHRC). Mr Sasakawa was the first person to bring the rights of people affected by leprosy before the UNHRC. In a later session it was stated that it is a human right for every leprosy patient to receive adequate and timely treatment, a challenge for those managing leprosy control programs and a stark contrast to the unexpressed, but perhaps widely held, view that once elimination is reached, the remaining cases are unimportant.

Correspondence to: P. Saunderson (e-mail: psaunderson@leprosy.org)
The remaining 3 days contained a mixture of presentations on topics familiar to those working in leprosy. One welcome feature was the lack of parallel sessions, with all the presentations and discussions being held in plenary; this was largely because the total number of presentations was small. What was lacking in quantity, however, was amply made up for in quality, with a high standard of presentation and debate throughout. The three state-of-the-art lectures were delivered by Professor Ji Baohong, on ‘The chemotherapy of leprosy’, Dr L. Bidé, on ‘Leprosy elimination in Africa’ and Dr H. Srinivasan, on ‘Prevention of deformities’.

Epidemiology and case finding

Much has been achieved in the effort to eliminate leprosy, but eight countries in Africa are still above the target prevalence for elimination (Angola, Central African Republic, Comoros, D.R. Congo, Equatorial Guinea, Madagascar, Mozambique and Tanzania) and another four countries are only marginally below it (Ethiopia, Guinea, Sierra Leone and Togo); Nigeria has a fairly low prevalence because of its large population, but is in sixth place on the continent for absolute numbers of new cases each year. In practical terms, the number of new cases is not declining and there is still a high rate of grade 2 disability, indicating that delays in case-detection remain. Continuing transmission is evidenced by the proportion of new cases under 15 years of age, which remains at around 10%.1 New and innovative strategies of case finding are needed in different situations to overcome these problems.

On a continent where control programs face significant logistical difficulties, one session was devoted to the issue of reaching hidden or unreached cases. Coverage is poor in many countries and trained staff are in short supply. One of the most encouraging developments was the involvement of community volunteers in the D.R. Congo, which has increased case detection to new levels in some areas. However, this does not obviate the need for much greater investment in the infrastructure and staffing requirements of most health services in Africa.

Training of health workers is a key issue and the importance of including leprosy in the pre-service curriculum was emphasized.

Basic science, clinical leprosy and chemotherapy

These sessions highlighted problems that remain to be solved in the fight against leprosy, including early diagnosis, the effective management of reactions and preventing the emergence of drug resistance. ALERT, in Ethiopia, and the Institut Marchoux, in Mali, remain the main centres for training and research in Africa, but it was very good to see worthwhile research coming from field programs in countries such as Angola, Cameroon, D.R. Congo, Madagascar, Mozambique and Nigeria.

A study at ALERT found cyclosporin A to be useful in treating severe type 1 reactions, although further work is needed to work out an optimum regimen. The Institut Marchoux reported 14 MB cases who had relapsed twice: fortunately, all strains remained susceptible to rifampicin and all patients responded well to repeat courses of standard MDT.
Prevention of disability, CBR, self-help groups and stigma

Often relegated to the sidelines in previous Congresses, these issues took centre stage in Johannesburg. Dr Srinivasan emphasized that people affected by leprosy remain at risk of injury throughout their lives, so they must be the main actors in the effort to prevent further disability. Many steps can be taken at home, while more complex interventions require the attention of the local clinic or hospital. The solution is a decentralized program involving the district hospital, the clinic and the home.

Community-based rehabilitation (CBR) and the formation of self-care groups are developments that are gaining momentum; there is no ‘right’ way to implement these activities and a wide range of experiences were shared. About 30 people affected by leprosy attended the Congress and several made moving presentations; many are helping to lead rehabilitation initiatives.

Worldwide it is estimated that 1.5–2 million people have leprosy related disability and only a small percentage have access to any rehabilitation services. CBR is a strategy within the field of community development for rehabilitation, equalization of opportunities and social integration. It is a strategy to increase coverage and access to rehabilitation. CBR and institution-based rehabilitation are complementary, but both require a multidisciplinary and multi-sectoral approach. CBR empowers people through its participatory approach.

Experience of self-care and self-help groups was presented from various countries, including Nigeria, Sudan and Ethiopia; involvement in planning and decision-making helps affected people to regain dignity and quality of life.

Stigma has a major impact on people, families and communities affected by leprosy. It is a violation of human rights, but surprisingly, there is no widely accepted definition of stigma. The report of a recent workshop on stigma held in the Netherlands mentioned the formation of an ‘International Consortium for Research and Action on health-related Stigma’ (ICRAS), which includes groups from Africa; there is much to be done and the group has ambitious plans.

Prevention of blindness

One highlight of the Congress was the presentation of clear guidelines for the prevention of blindness in leprosy. A new surgical procedure for correcting lagophthalmos was described, which most ophthalmologists now agree is appropriate for general use when surgery is indicated in a person affected by leprosy; it is called the ‘modified lateral tarsal strip procedure’. It is easy to do, produces a good cosmetic result, does not require physiotherapy and can be redone later, if necessary. In contrast, the temporalis muscle transfer (TMT) operation, still preferred by some, is difficult to do, requires prolonged physiotherapy for a good result and gives poor long-term control of the condition. Tarsorrhaphy should only be used as a temporary emergency procedure, never as a treatment for lagophthalmos, as the cosmetic result is so poor.

Conclusion

The conference was conducted in English, French and Portuguese, with simultaneous translation throughout, so all could participate in every session. The organization and
practical arrangements for the Congress proceeded very smoothly, thanks to the local team from the TLM South Africa office.

The Conference Centre was pleasantly situated in grounds inhabited by small groups of zebra and springbok. Serendipitously, it was some way from the nearest shopping areas, so participants were more or less forced to attend the conference sessions most of the time.

There was good participation from all over Africa. Organizations such as ILA, WHO, ILEP members, IDEA and associations of people affected by leprosy from different countries, were well represented. Many participants were impressed with the presentations and discussions concerning the social aspects of leprosy, including the issues of human rights and stigma, which have not previously been given due attention.

Reference