The 19th International Leprosy Congress was held in Beijing, China during September 2016. The theme of the Congress was the ‘unfinished business’ for leprosy of stopping transmission, preventing disability and promoting inclusion. The Congress had many important sessions and included 4 Plenary Sessions focusing on the critical challenges facing leprosy today. The content and the key issues of these plenary sessions are reported here.

1. A Global Strategy fit for Purpose

The first plenary session was chaired by Marcos Virmond, the President of the International Leprosy Association. The focus of the session was the new global leprosy strategy for leprosy 2016–2020 which had been developed with extensive consultation during 2015 and published in 2016 (http://www.searo.who.int/entity/global_leprosy_programme/documents/global_leprosy_strategy_2020/en/). The Strategy is now available in English, Spanish, French and Portuguese, the Chinese version would be available soon too. The strategy and the background were presented by Erwin Cooreman who is the leader of the WHO Global Leprosy Programme based in the South East Asia regional office of the World Health Organisation in New Delhi, India. The Strategy built on previous strategies on leprosy and recognised related policy documents such as the London Declaration and the NTD roadmap. The context of the current leprosy situation had recently been reported in the WER (2016; 91: 405–420) which also identified trends in new case detection and the key countries reporting more than 1000 new cases each year, although there were a number of important countries that had not reported, such as Angola and South Sudan.

The strategy had a set of guiding principles and 3 pillars. The long term vision was zero disease, zero disability, zero stigma and zero transmission as well as shorter term targets for 2020 based on children with disability and new cases with disability per million population. Pillar 1 was strengthening government programmes, ownership and partnerships. Pillar 2 was to stop leprosy and its complications. Pillar 3 was to stop discrimination and promote...
inclusion. The Strategy was supported by an operational manual and monitoring indicators. A composite index based on incidence, prevalence, children and Grade 2 disability had been used to identify 22 priority countries.

A number of discussants were invited to comment on the strategy from their own perspective. Narsappa from India welcomed the strategy and stressed the importance of involvement of people affected by leprosy on the basis of ‘nothing about us without us’ concept. People affected by leprosy should be equal partners in developing and implementing policy on leprosy. He identified lack of awareness of leprosy in many health care staff and the need for training in leprosy. Tanya Woods from LEP considered the strategy from a non-governmental (NGO) perspective. A strong civil society was needed and NGOs were innovative and flexible, listening to and connected to communities, and working to connect policy with practice. ILEP had developed a strategy aligned to the global strategy including indicators for monitoring progress. ILEP was working to translate the strategy into actions such as the 3 zero campaign: zero transmission, zero disability in children and zero discrimination. The view of national programme managers was presented by Magda Levantezi from Brazil. National programmes needed to adapt the global strategy to national needs and health systems, as well as adapting to local circumstances within countries.

Finally, the strategy was considered from the NTD perspective by Emmy van der Grinten based in Ghana. NTDs used two approaches; preventive chemotherapy (also referred to as mass drug administration) and case management. Leprosy was in the case management group along with NTDs such as Buruli Ulcer, Yaws and Leishmaniasis. NTDs also have global strategies such as the London Declaration and roadmap and were aligned to the Global sustainable development goals by 2030. Regional approaches to integrate case management using mapping had been successful in the Africa region where leprosy strategies were well aligned to NTDs. There was the potential of exchange of ideas between individual NTDs such as leprosy and trachoma where programmes could learn from each other. There were common issues in integrated approaches such leadership, advocacy, training, logistics and service delivery. However challenges remained such as separate administrations and structures, separate reporting and over-burdening of local health workers. There were many potential gains from integration such as increased reach of programmes, accessibility of services and cost-effectiveness.

The plenary session endorsed the new global strategies. The discussants added important reflections on the strategy from particular stakeholder perspectives such as people affected by leprosy, NGOs, national programme managers and NTDs.

2. Advances in the Clinical Management of Leprosy

This plenary was chaired by Shyamala Anand, a clinical ophthalmologist from The Leprosy Mission India Trust in New Delhi, India. There were four presentations from leading leprosy clinicians on a range of clinical topics.

David Scollard gave an interesting presentation on the pathology of nerve injury in leprosy starting with a series of sequential histological slides showing *M. leprae* in nerves reducing in numbers up to 6 years although the evidence was these were no longer viable bacilli. The next stage was that of progressive demyelination and a method developed by Sergio Atunes was presented to assess demyelination. The next stage was that of fibrosis, with the end point of nerve injury with increasing fibrosis and reducing nerve tissue. The armadillo
animal model has proved useful in the study of nerve injury. One exciting development is the observation when testing the safety of the IDRI vaccine that the vaccine delayed nerve injury and it was much reduced compared to control animals. These were preliminary and unexpected observations and were based on nerve conduction studies but had interesting implications for the use of this novel vaccine in humans.

Zhang Fu Ren presented on three separate clinical issues. First the importance of early diagnosis. Diagnosis becomes easier as the disease progresses and early diagnosis is challenging when examination of skin and nerves is inconclusive. PCR methods proved more sensitive than traditional methods and could be used to exclude the diagnosis of leprosy as well as to confirm a positive diagnosis. PCR could be positive when slit skin smears were negative and a number of case studies were presented. Use of PCR in China had led to less disability in new cases. The second issue presented was on the management of severe Type 1 reactions in which very high doses of steroids are needed. A number of cases were presented. The third issue presented was the occurrence of dapsone hypersensitivity syndrome which occurred in 0.5%–3.6% in China and was an occasional cause of death. HLA-B 13:01 had been identified as a predictor of hypersensitivity to dapsone. New patients were now being screened for HLA-B 13:01 before starting MDT and dapsone was substituted by another drug in those found to be positive. Again, the presentation included a number of case studies.

Diana Lockwood reported that reactions in leprosy were common and associated with disability. The standard treatment for Type 1 reactions was 30–60 mg prednisolone for 12 to 24 weeks. The trial evidence of effectiveness was reviewed and second line drugs considered. Steroids remained the first line treatment for Type 1 reactions. She reported that up to 50% of LL patients experienced ENL. The clinical features had now been reviewed. It was a complication with significant burden of morbidity. A global consortium (ENLIST) had been created to study ENL and its clinical features, severity and impact on quality of life. The consortium was developing a RCT in ENL treatment. She also noted that neuropathic pain was common after MDT completion.

Linda Lehman presented on the development of integrated approaches to prevention of disability across NTDs. Leprosy, in common with other NTDs, was associated with poverty and aggravated poverty through its impact of economic development, stigma and mental health. In general, disabilities due to NTDs were inadequately managed and many NTD related impairments were similar. Integrated approaches to disability prevention and integration with diagnosis and treatment were recommended. However there were a number of challenges including the measurement of disability, cross cutting indicators and integrated care across NTDs in areas such as vision, wounds, movement limitation, self-care and education; a 10 step basic guide was recommended. Further challenges included psychological support, integrated morbidity management, capacity building, self-help and collaboration across organisations.

3. Innovation to Reduce Transmission

This plenary Session was chaired by Ann Aerts from the Novartis Foundation based in Basel, Switzerland.

The first presentation by Joseph Kawuma from Uganda focused on U-MDT (Uniform MDT). The concept originated in 2002 to explore a shorter, simplified treatment regimen for leprosy which could also abolish classification of leprosy for treatment purposes. The
approach would also simplify drug supply logistics. The protocol for the trial of U-MDT was a single arm, open field trial of 6 months MB MDT for both PB and MB patients. The trial was conducted in India and China and the primary outcome was clinically assessed relapse. The preliminary findings suggest that the relapse rates were very low; however, events such as reactions and disability occurring after 6 months required continued monitoring in primary care. Programmatic adaptations would be required for the implementation of this short regimen. The trial as yet has not been published and the final study will require critical review. A similar study was conducted in Brazil looking at equivalence with WHO MDT, and a cohort study in Bangladesh used historical controls. There remain different opinions about the use of U-MDT around use of clofazimine in PB cases and the shortened regimen for MB. Exceptions would be needed for those with a high initial BI and patients receiving steroids over a prolonged period of time. No effect of U-MDT is expected on transmission. U-MDT is a potential alternative to WHO MDT which would be shorter but not less efficacious and would facilitate integration of leprosy services into general health care. The evidence needs to be examined further and the implications for implementation under programmatic conditions considered.

Peter Steinmann from the Swiss Tropical Institute noted the lack of evidence that MDT reduced transmission and the lack of a specific vaccine. He then reviewed the evidence for the use of post-exposure prophylaxis with either single dose or multiple dose regimens to prevent disease in apparently healthy contacts. Contacts were at varying levels of risk depending on the nature of the contact: for example household, neighbour, social contact or the general population. Systematic reviews of historical evidence of the effectiveness of dapsone, acedapsone, rifampicin and combinations of rifampicin, minocycline and ofloxacin had shown their effectiveness. The findings of the large COLEP randomised trial in Bangladesh using single dose rifampicin were presented in detail. Priorities for current research were examining the effectiveness of combined BCG and single dose rifampicin, new prophylactic regimens and the impact of post-exposure prophylaxis when used in low endemic situations. Ongoing studies of LPEP (Leprosy Post Exposure Prophylaxis) are developing approaches for the use of chemoprophylaxis under routine conditions and to evaluate its impact on leprosy incidence, with early case detection and contact tracing as essential components of LPEP. In the discussion, concern was expressed about the creation of rifampicin resistance but reassurance was provided on the negligible impact of a single dose in selecting drug resistant bacteria. It was noted that the single dose rifampicin was given at least one month after the index patient had started MDT.

Fareed Mirza, head of healthcare and outcomes research at the Novartis Foundation, noted that global new case detection had remained static over the last decade. Development of a test for infection was important to complement the LPEP approach to reduce transmission. The current position was that diagnosis was based on clinical approaches. A number of methods had been explored including antibodies, T-cell tests and PCR. ELISA methods have been shown to be good for MB leprosy but not PB disease. PCR was increasingly used but there was no agreement on standardisation. A set of criteria had been developed for the target test profile and the Global Health Group at the EPFL in Lausanne has been commissioned to develop a prototype molecular diagnostic test. In discussion it was noted that one challenge was the validation of the test in people with no clinical disease.

Steve Reed from IDRI (Infectious Disease Research Institute) in Seattle, USA reported on progress with developing a vaccine that induced long lasting immunity and was safe in uninfected and infected individuals. The vaccine being developed is based on a fusion protein
and an adjuvant. The fusion protein had been selected after many years of work, and the
adjuvant was a critical component to the vaccine to facilitate a rapid, Th1 immune response.
LepVax was being validated in animal models including the mouse foot pad and the
armadillo. One very promising preliminary finding was that the LepVax appeared to delay
and reduce nerve injury in the armadillo studies. Phase 1 studies were beginning in the USA
and Brazil. In discussion, the findings were viewed very positively by the audience and the
timing of moving on to the next phase of the vaccine trials in the next year was considered.

4. Promoting Inclusion of People Affected by Leprosy

The plenary session was chaired by Anwei Law, the International Coordinator of IDEA, who
is based in the USA. The session began with a personal introduction by Rao Shuqiong, a
woman from Yunnan, China, who has experienced leprosy.

Cassandra White from the USA described a number of factors that contributed to the roots
of social exclusion including beliefs and perceptions, changes in appearance, physical
disability, living conditions and occupation as well as other discriminatory issues such age,
gender and race. There existed relationships between stigma, delay in treatment and
disability. Reduced ability to perform tasks as well as stigma contributed to loss of income.
There were many examples where the media generated stigma. Social networks were
important in inclusion. Participatory action research was recommended as a research method
that protected human rights and social justice.

Ruth Peters from the Netherlands presented the SARI project (stigma assessment,
reduction and impact) from Indonesia. This was a project which involved society and
included exploratory studies with narratives of women about concealment. Pilot studies were
developed along with new measurements such as the SARI social distance scale and the SARI
stigma scale. These scales were used to assess the impact of the interventions. There were
three interventions: contact at community level, counselling at an intra-personal level and
socio-economic development at an inter-personal level. The study design was a cluster
randomised control trial with before and after analysis to assess the effectiveness of the
interventions. The qualitative and quantitative assessments showed that all three
interventions were effective. The next steps were to use mixed methods, test the efficacy
in different countries and assess sustainability.

Michael Chen from HANDA in China reflected on the various policy and strategy
documents that had been disseminated over the last decade. In 2006 the Convention on
Human Rights of People with Disabilities was followed in 2010 by the UN resolution to
eliminate stigma and discrimination against those affected by leprosy and their families.
WHO produced guidelines to strengthen participation in 2011, which were re-enforced by the
Bangkok Declaration in 2013. In 2014, ILEP established a temporary expert group on
strengthening participation by people affected by leprosy. These were all policy documents,
but what is the reality? National programmes rarely implement participation and there are few
reports of implementation of these policies. A survey was conducted to assess practice and 20
centres, reporting from six countries. A few organisations of people affected by leprosy were
involved in leprosy services with a wide range of activities, many initiated by NGOs or
through volunteers. Much is at the level of tokenism and participation is at the level of service
receivers and not as agents of change in the Arnstein ladder of participation. Road blocks
include paternalism, resistance to delegation of power, and the lack of knowledge and
experience amongst people affected. There is a need to believe in people, create opportunities, invest in people, build capacity and create trust.

Mathias Duck from Paraguay continued the theme of the disparity between policy and practice. What does inclusion actually mean? With colleagues on the ILEP panel of people affected by leprosy, he had developed a survey tool based on the UN principles and guidelines which form a comprehensive policy document. They conducted a survey based on the UN document and received 265 responses from 20 countries. The survey found little information on state involvement and in decision making. Discriminatory practices were reported with regard to place of residence, work, marriage, public transport and use of discriminatory language. There is clearly a long way to go to implement the policy aspirations of the UN document.