News and Notes

Award conferred on Dr R. Ganapati

An Outstanding Community Service Award was conferred on Dr R Ganapati, Director of the Bombay Leprosy Project (BLP), at the Taj Mahal Hotel, Bombay, on 26th November 2002 by the Rotary Club of Bombay, the oldest Rotary Club (established in 1929). The Award, which is in recognition of his dedicated services to leprosy for the last 40 years, was instituted by Rtn. Taru Lalwani in memory of late Shri J T Lalwani. Dr Ganapati mentioned that the award money of Rs 10,000/- will be utilized for the rehabilitation of patients in BLP.

Sight Savers eye care link-up planned

LEPRA is looking to improve the eye care needs of people affected by leprosy, through closer collaboration with Sight Savers International.

The collaborative project is planned in three districts of Orissa where LEPRA is working. Leprosy patients, their families and the general community will all benefit from treatment and surgical interventions to prevent eye complications that can lead to blindness.

Implementation of the project will involve communities and general health staff at public health centres, which will provide eye check ups, surgical intervention where required, training of community volunteers to create awareness about eye-care, and to encourage people to self-report, and training for all those concerned with the project activities to ensure good links are set up between the project and the community, and to strengthen the competencies and expertise amongst government health staff at different levels.

Co-ordination will be carried out in conjunction with the Government, in accordance with the National Guidelines for the Control of Blindness.

Many patients worldwide are blind in one or both eyes due to leprosy. The eye can be affected in the following ways:

- Lagophthalmos, where the muscles of the eyelid may become paralysed. In such cases the patient cannot close or blink the eye to keep the eyeball wet and healthy. Then it easily gets infected.
- The outer covering of the eyeball and the linings of the eyelids may become insensitive and get damaged and infected without the patient noticing it, since he/she does not feel pain.
- Leprosy bacilli may also attack the inside of the eyeball.

ILEP Presidency handover

For the past 4 years, LEPRA’s Chief Executive, Terry Vasey, has been President of The International Federation of Anti-Leprosy Associations (ILEP). The ILEP President is elected for a 4-year period, and plays an important role internationally in representing ILEP and its members.

ILEP is an international federation of 16 autonomous non-governmental organisations who work collectively for the common goal of a world without leprosy. The ILEP co-ordination system allows
members, when required, to join forces to support major initiatives in the field of scientific research, teaching materials, training and to respond to the needs of national programmes, especially in priority countries. More importantly, this co-ordination prevents overlap of effort and ensures that there is no wastage of funds.

At the ILEP General Assembly in December 2002, the Presidency of ILEP was officially passed to Dr Sunil Deepak of AIFO, Associazione Italiana Amid di Raoul Follereau. Dr Deepak will continue the commitment to ensure that leprosy stays firmly on the international agenda, and that quality services for the treatment and care of people affected by leprosy will be available for as long as they are needed.

New ILEP Standing Committee elected

In a closely fought round, the 28th General Assembly of ILEP of 14 December 2002, elected four ordinary members of the Standing Committee. They will support Dr Sunil Deepak, who was recently inaugurated as President of ILEP, until December 2006.

The members of the new Standing Committee are:

Mr Carlos Bauverd, General Secretary of the Comité International de l’Ordre de Malte since 1998. Deputy: Mr Francis Junod.
Mr Trevor Durston, General Director of The Leprosy Mission International since 1993. Deputy: Mr Alan Gray.
Mr Max Ebstein, member of the board of Fontilles Lucha contra la Lepra since 1994. Deputy: Mr José Manuel Amorós.
Mr Rigo Peeters, General Secretary of Damien Foundation Belgium since 1987. Deputy: Ms Leslie Preudhomme.

Mosquito and malaria genomes revealed

The simultaneous publication of the sequences of the Anopheles gambiae and Plasmodium falciparum genomes in early October was reported in TDR News, no. 69. The A. gambiae sequence was published in the journal Science and the P. falciparum sequence in the journal Nature. The A. gambiae genome was sequenced by a collaboration between Celera Genomics, the French National Sequencing Centre (Genoscope) and The Institute for Genomics Research, in association with several university laboratories. The P. falciparum genome was sequenced by an international consortium of funding agencies and laboratories, including researchers at The Institute of Genomic Research, US, and the Sanger Institute, UK.

Knowledge of the two genomes and the already-published human genome will eventually lead to new drugs and vaccines and ways of interrupting transmission of malaria. First, however, there is a need for research to better understand mosquito biochemistry and physiology, and malaria epidemiology, and to identify malaria genes and biochemical pathways that are involved in transmission, pathogenicity and drug response so that targets for drugs and vaccines can be identified. Already, the knowledge has pointed researchers towards several potential new anti-malarial drugs, and towards better understanding of the evolution of drug resistance. The genome information will also be used to address issues such as how the malaria parasite evades the human immune system, to which it devotes a large proportion of its genes. Although the results of this research are still some way off, such work would eventually allow potential vaccine antigens to be identified.
Social Science and Leprosy Network

Dr Robert K. Das-Pattanayak is setting up a Social Science and Leprosy Network, coordinated by the TLM Research Resource Centre. The purpose of the network is to promote communication amongst social scientists and those interested in social science, who are caring for or concerned for people and communities affected by leprosy.

The terms of reference of the Social Sciences and Leprosy Network are as follows:

**Objectives**
1. To share ideas and information.
2. To publicise and promote the role of social sciences in leprosy.
3. To promote collaboration at the field level and at all levels within organizations.
4. To encourage and support special social science interest groups within the field of leprosy.
5. To encourage and establish links with similar groups working in related fields.
6. To encourage the development of training courses in social sciences research methods for staff at all levels.
7. To develop and maintain a public database of available training courses.
8. To develop and maintain a database of on going research projects, including postgraduate research into social aspects of leprosy.
9. To encourage the dissemination and publication of research findings.

**Activities**
1. Establishing email-based and ordinary mail communications in areas identified above.
2. Establishing a web-based forum to facilitate discussion and communication as above.
3. Inviting contributions for a monthly paper to be presented for comments and discussions on the web.
4. Compiling and providing a web-based database of training programmes.
5. Working on joint papers describing and encouraging the application of social sciences in leprosy.
6. Identifying a named contact in each region, i.e. Asia, Africa, Europe, S. America for written and verbal communication, and dissemination of information specific to individual regions.
7. Developing a brief profile of each member for circulation, including their specific interests.
8. Providing a brief summary of progress of the Network or at least acknowledgement of the existence of the Network in an established leprosy journal.

Many people have joined SSLN following the congress in August 2003 at Salvador. All are welcomed who are willing to share their areas of interest and expertise with others. Those interested in joining should write to Dr Robert at: robertp@tlm-india.org.

New leprosy cases increase

The World Health Organisation has issued statistics showing the global leprosy situation in 2001. After adjusting for Brazil and Madagascar, which have not yet reported, the figures show a 52,000, or 7% increase in the number of cases detected during the year.

A total of 771,916 new cases of leprosy were detected during 2001 and 618,000, or 80%, of the people affected live in India. The increase in India between the number of new cases found in 2001 and 2000 was 10%. In Nepal, it was a worrying 72%, with 13,800 new cases found in 2001. A major campaign was held in Nepal during 2001 to identify new cases. Given that the prime objective of any leprosy programme is early detection and treatment, it is worrying that special campaigns are still identifying so many previously undetected cases.

Leprosy agencies are now concentrating on these new case numbers as a more relevant indication of the level of the leprosy problem than the old measure of prevalence. However, whichever measure is used, the numbers are increasing.
Earliest leprosy victim Scottish?

A re-examination of 3500 year-old bones excavated from a site near Dunbar in Scotland more than 20 years ago has offered scientists a ‘fascinating glimpse’ into Scotland’s past, according to archaeology experts. The tests carried out on the skull of a child who died more than 3 millennia ago revealed signs of leprosy, a discovery which may rewrite the history of the disease.

Julie Roberts, biological anthropologist with Glasgow University Archaeological Research Division, said that although the diagnosis still has to be confirmed by DNA testing the indications are that it is a case of leprosy.

‘The child is known to have died between 1600 and 2000 BC and this would predate the previously accepted arrival of leprosy in Britain by up to 1500 years. If this is the case then leprosy took some other, unknown route, through Europe’s early societies.’

Rod McCullogh, Principal Inspector of Ancient Monuments with Historic Scotland added there was further intrigue in the find.

‘The victims of leprosy tended to be outcasts from society, yet this child seems to have been the focus of complex burial rituals, which are today thought to reflect a high social status before death. Not only is this a fascinating glimpse into Scotland’s distant past but this find may also be one of the earliest cases of leprosy in the world so far identified.’

2002 Damien-Dutton Award

On Saturday November 9, Dr Yo Yuasa, Medical and Executive Director of Sasakawa Memorial Health Foundation, Member of ILEP, received the 2002 Damien-Dutton Award in New York.

In his acceptance speech, Dr Yuasa said:

‘...For the 15th International Leprosy Congress in Beijing in 1998, Wayne, Felton and I jointly came up with a main theme of the congress, which was “Working towards a World Without Leprosy”. The term was accepted immediately and almost unanimously, and is now being used widely by many people in leprosy. But even before the closing of that congress, I have started having a doubt about the appropriateness of that goal. That term, “A World Without Leprosy”, is commonly used almost synonymously with “Elimination or Eradication of Leprosy” by most of the people. That has to be accomplished by eliminating Mycobacterium leprae from the surface of this earth. My question was, and still is, “is that necessary?” and “is that justifiable?”

‘Of course “eradication” is not possible with currently available technology, but this could change, judging from tremendous advances of scientific technologies and engineering of recent years. However, the development of tools is no guarantee for reaching the goal for which tools are created. World health statistics show that each year 3 to 4 million children are dying from diseases for which prophylactic vaccines are already available.’

‘Let us go back to the question “is eradication necessary”. My answer is “no”, because I am quite confident that with improved case detection and treatment, both of the infection itself and of accompanying nerve damages, we should be able to cure most of the patients and prevent majority of physical deformities and impairments. Thus by solving medical problems associated with leprosy, it should not be difficult for us to co-exist with M. leprae without much fear. The problems of leprosy are no longer medical ones nowadays, as most of you realize, but largely and primarily due to social ones, by which I mean extremely negative human reactions to what M. leprae does to some of the people affected by leprosy.’

‘By being preoccupied with the desire to eradicate leprosy as a medical problem, we are in great danger of neglecting social aspects of leprosy, which by the way is entirely of our own making. I am a firm believer in “what we have not created, we have no right to destroy” but “what we have created we should be 100% responsible”. What we can do medically for leprosy has already advanced quite well. It is basically dependent on brilliant minds and dexterity of hands, which we do
not lack in the world. However, on the social aspects of leprosy, which basically is an issue on human rights, dignity of individuals, equal opportunities for self expression, acceptance of individuals by the community, and others, which are matters of sensitive minds and warm hearts, which are not always in oversupply, unfortunately.’

‘... Thus, I now firmly believe that what we really need to eliminate is not leprosy as a disease or *M. leprae* as its causative organism, but the fundamental cause of the social problems of leprosy, which is one of our basic failings, all too common ‘human prejudice’ and consequent injustice which has caused, and is still causing millions of people to suffer, because certain group of people are considered to be ‘different’ for whatever the reason, including being affected by leprosy, resulting in their marginalization, persecution, or even destruction.’

‘... Thus leprosy workers now have truly unique opportunities to tackle these universal human rights problems, not by doing something for others, but by changing and improving ourselves. It is for the benefit of not only persons affected by leprosy, which admittedly is our immediate concern, but it is for ourselves and for the whole future humanity, if we set our goal right. Our task is enormous, but I trust that most of you would agree that it is our duty, worth devoting our time and energy, trying to reach that goal as closely and quickly as possible.’

**DAHW changes its name**

DAHW officially changed its name on Thursday 9 January from Deutsches Aussätzigen-Hilfswerk to Deutsche Lepra- und Tuberkulosehilfe (German Leprosy and Tuberculosis Relief Association). On this day the President of the Federal Republic of Germany, Dr Johannes Rau, honoured a delegation of DAHW with a reception.

The decision to change the name was taken by the General Assembly of DAHW after an intensive process that involved all levels of the association. The DAHW abbreviation will remain unchanged.

**Celebrity shoe auction raises almost £11,000**

The bidding in LEPRÂ’s Celebrity shoe auction, held using on-line auction house eBay, ended on Monday 25th November and was a great success. LEPRÂ received and auctioned 70 pairs of shoes in total from celebrities such as Liz Hurley, Pierce Brosnan, Rio Ferdinand, Will Young and Paula Radcliffe.

The auction raised a total of £10,941-01, with several lots being won by bidders outside the UK: the shoes belonging to Phil Collins and Pierce Brosnan are going to Canada, while the pair given by Mick Jones are heading for America along with those of Craig David. The highest bids were received for Will Young’s shoes at £830 and Dennis Bergkamp’s football boots at £800.

**City Leprosy Project completes 26 years**

Ms Jasmine Pavri, Senior Programme Officer of the Sir Dorabji Tata Trust, was the Guest of Honour and released BLP’s latest publication ‘A Glance At Leprosy 1991–2001’, a compilation of the *Wall Journal* displayed every month in the medical colleges of Bombay, towards which the Sir Dorabji Tata Trust has given generous financial support. Ms Pavri also launched the greeting cards made by disabled children under BLP’s rehabilitation programme.

Gifts were presented to the disabled children. Two older patients, now rehabilitated and absorbed into BLP, were also congratulated.

In the Academic meeting that followed, postgraduate students of Somaia Medical College and LTM Medical College, Sion, discussed the following subjects: ‘Diagnosis and Classification of leprosy’.

Ms Pavri, in her closing remarks, felt that there was need for some research in ‘Ayurveda’ for leprosy cure, not a watered down version of research but a proper scientific study of the standard and quality of Western research. She also said that though the prevalence rate and incidence rates of leprosy were going down, leprosy was still very much a health problem.

**Anglo-French Alliance for Tropical Medicine**

An initiative has been established to encourage collaboration between researchers and institutes in English-speaking and French-speaking countries within the ‘existing funding schemes’ currently available.

The Anglo-French Alliance for Tropical Medicine aims to raise awareness of current funding opportunities for tropical medicine research and publicize the extent of funding bodies’ overseas operations and policies.

Ten organizations are part of the Alliance, led by the Wellcome Trust in the UK and the Science and Technology Department of the French Embassy in London, which holds close links with the Pasteur Institute in Paris.

A bilingual web presence will provide brief summaries of key funding agencies supporting tropical medicine research, links to their relevant funding schemes and partner organizations, and details of their major overseas activities.

The Alliance comprises ten organizations: The Wellcome Trust, Medical Research Council, UK, Department for International Development, UK, Royal Society for Tropical Medicine and Hygiene, French Embassy, London, Institut Pasteur, INSERM (Institut National de la Santé et de la Recherche Médicale), IRD (Institut de recherche pour le développement), CNRS (Centre National de la Recherche Scientifique), ANRS (Agence Nationale de Recherche sur le Sida) and PAL+.

Further details on this initiative can be obtained from Hans Hagen (h.hagen@wellcome.ac.uk), Michael Chew (m.chew@wellcome.ac.uk) at the Wellcome Trust or Jacques Chevalier (j.chevalier@scientec.demon.co.uk) at the French Embassy.