News and Notes

FIND: finding new diagnostics

The following article was taken from TDR News, September 2003.

An independent non-profit foundation based in Geneva and known as the Foundation for Innovative New Diagnostics (FIND) was launched in May 2003 by TDR and the Bill and Melinda Gates Foundation.

FIND represents an expansion of TDR’s ongoing efforts to find and develop new diagnostics for neglected infectious diseases; in particular it builds on the former TDR Tuberculosis Diagnostics Initiative (TBDI). With funding from the Gates Foundation (US$30 million for the first 5 years), FIND will be able to quickly turn methods into products, untested products into evaluated products, and promising tests into tools with demonstrated impact and feasibility.

Tuberculosis (TB) was chosen as the first target for FIND because of the magnitude of the TB problem (TB kills one person every 15 seconds) and because, once detected, cases can be ably treated by existing health systems. Ultimately however, other neglected diseases will be the focus of attention.

FIND and TDR have a jointly elaborated workplan on TB diagnostics, which will be carried out through managing a portfolio of focused research activities rather than through open requests for investigator-initiated proposals. However, some investigator-initiated proposals will be funded each year, and two joint FIND/TDR requests for applications have already been issued, calling for research towards 1) an antigen detection system for case-finding or follow-up, and 2) improved sputum microscopy (this being the most widely available diagnostic test for tuberculosis, which has been in use for more than 100 years).

FIND will be directed by Giorgio Rosigno, the founding director of the Global Alliance for TB Drug Development, while TDR’s own Mark Perkins will become FIND’s scientific director. The FIND offices are located next door to TDR’s new premises.

‘The recent outbreak of SARS illustrates the need for easy-to-use and accurate diagnostics to aid in the control of tropical diseases’ says TDR director Carlos Morel. ‘Great strides have been made in developing drugs and increasing patient access to good medicines, but diagnosis remains a stumbling block in public health. Public health needs can only be met by partnerships at all levels’.

Leprosy crusaders remembered

It was a refreshing and a bold change in the theme chosen by Bombay Leprosy Project (BLP) for its 27th Anniversary Commemoration Seminar held at the LT Memorial College, Sion in collaboration with Indian Association of Leprologists (Maharashtra Branch) on 10th October 2003. Moved by the tragic demise of three veteran Scientists (Drs Paul Brand, V. Ekambaram and G. Ramu) recently within a short span of time, BLP asked five PG students of city medical colleges to study the history of leprosy. The students were provided guidance to look back into the life-time contributions of nearly 30 eminent personalities, who have created an impact in changing the scenario of leprosy. Life histories of 20 stalwarts (which included living legends such as Shri Baba Amte and Dr N. H. Antia) were presented in great detail to entertain the medical audience consisting of teachers and students of preventive and social
medicine, dermatology and basic sciences. A reference was made even to the political will shown by Mahatma Gandhi and Indira Gandhi, which galvanized leprosy eradication movement in India.

Dr R Ganapati, Director of the BLP, observed that it was surprising and reassuring that the students who normally excel in reviewing exam-oriented subjects took extraordinary pains to study an unusual theme revolving around leprosy scientists and social workers. He announced that a panel exhibiting the photographs of several such personalities would soon adorn the BLP Training and Research Centre in Bhakti Park at Wadala. A book based on their biographies will be published, provided financial support is forthcoming. Dr V. V. Pai, Deputy Director of BLP, who proposed the vote of thanks, expressed BLP’s gratitude to Bank of Baroda for the support received to conduct the seminar.

LEPRA’s CE honoured as national pioneer

Terry Vasey, LEPRA’s Chief Executive, was among 400 distinguished guests invited to Buckingham Palace to celebrate their contribution as ‘Pioneers to the Life of the Nation’. The reception on Monday 13 October recognized the outstanding contribution that LEPRA has made in the field of leprosy. LEPRA pioneered field leprosy control programmes and developed and tested the medicines that are now used to cure the disease. It was a triple event for LEPRA as Her Majesty the Queen is LEPRA’s patron, and its President, Sir Christian Bonington was also honoured for his contributions to Mountaineering.

Before joining LEPRA, Terry was the Coordinator of the British volunteer programme in Brazil. The volunteer nurses and physiotherapists worked in the leprosy control programme in the most remote regions of the Brazilian Amazon. He said: ‘It was an honour and very exciting to be invited to the Palace. The Queen is very committed to the eradication of leprosy, having first visited a leprosy colony in Nigeria in 1947. The invitation to the Palace was a delight for me, but more importantly it is wonderful to know that leprosy and those affected by it were recognized in this way’.

Mrs Prunella Scarlett, Chairman of LEPRA, said: ‘I am thrilled that LEPRA’s work has been recognized. Terry has made an outstanding contribution to the advances in the fight against leprosy’.

Brazil steps up leprosy fight

The following story comes from the BBC News website (http://news.bbc.co.uk/go/pr/fr/-/1/hi/health/2966888.stm).

Health chiefs in Brazil have launched a major public awareness campaign telling people how to spot early signs of the disease. They are also training doctors and nurses to diagnose the condition early.

Brazil has one of the highest rates of leprosy in the world, and continues to suffer despite the fact that leprosy can be cured by giving patients a powerful cocktail of antibiotics.

Brazil is not alone. Figures from the World Health Organization show that 524,000 people in 103 countries were diagnosed with leprosy last year. The longer the disease is left undetected, the more likely it is that the deformities, so often associated with leprosy, will occur. For that reason, health chiefs in Brazil have stepped up their efforts to spot the disease early on. ‘The earlier it is diagnosed, the easier the treatment,’ said Dr Mauricio Nobre, a skin specialist in Rio Grande. ‘The main thing we have to do is diagnose the disease in the early stages so that the nerves are not damaged. A big part of our work is running education campaigns telling people about the signs of leprosy. It is a silent disease.’

Health chiefs are also targeting those with advanced leprosy, not least because they believe they are the source of many new infections. ‘If we can diagnose every case then we can stop the spread of leprosy,’ said Dr Nobre. He believes living conditions in Brazil are contributing to the spread of the disease. ‘We have a lot of people living in slums in and around the big cities. They live in crowded situations. They don’t have a lot of food and their immune systems do not develop as they should. These are things we think are contributing to the high prevalence rates in Brazil,’ he said.
‘It is more common to diagnose the disease in people who live in crowded situations. If you have one person with the disease and 10 people living in the same house, the chances of them getting the disease are quite high.’

Angola update

The following article is taken from LEPRAs website.

LEPRAs representative in Angola has recently written from the field where she is overseeing LEPRAs support for the leprosy and tuberculosis work in Moxico Province in the remote south east of the country.

Moxico Province has been neglected during a long period of civil conflict. This only recently came to an end and because of land mines, many areas are still difficult to reach. Certainly there has been little in the way of basic health provision for many years.

Our representative has recently been carrying out training in TB management in the provincial centre, Luena and accompanying supervision visits to some of the remoter villages. Some extracts from her letters help to give an idea of how challenging an environment this is for LEPRa to work in.

January 30th

‘The photocopier has arrived—now we just need to restore the electricity! The hospital has not had light for the week since I arrived. Prices have also gone up so the budget for the training course is slightly higher. I will also need to arrange to buy one steer each month to ensure the TB patients are fed.’

February 3rd

‘I am off to Cazombo and Luau in a few hours. The health supervisor from there has just arrived and it appears there is still fighting between two local groups. I have no great expectations of the situation there as they also report that they are expecting an influx of refugees. Sixty percent of these refugees are likely to be HIV positive and each of the community health centres has an inpatient capacity of only four beds.

I have just had malaria so life has been a bit fuzzy of late but the training seminar on TB management has been very good.’

February 12th

‘Have had an amazing trip. The huge contrasts and surprises people throw up make me marvel again and again. We found much grace and many problems of all sizes.’

She signed off a recent letter, ‘I would really value your prayers for renewed strength. It is hard work at present.’

New recommendations for India

The following article is taken from ILEPs website.

A Joint WHO/NLEP-India Meeting, attended by ILEP Representatives, was held in Myanmar 5 February 2003. The following recommendations were made.

1. Since India has endorsed and accepted the policy of integration of leprosy services into the general health services, concrete plans for integration should be formulated and implemented and the process of integration accelerated.

2. The plans and processes of integration should include phasing out vertical structures, within a definite time frame.
3. It is recognized that factors of ‘over-diagnosis’ and ‘re-registration’ of cases are responsible for static reporting of high level of new case detection in the country. The following measures are recommended to prevent these factors: case definition as laid down by WHO should be strictly and uniformly applied to all Member Countries; promotion of self-reporting cases should continue to receive the highest priority and all active surveys, except family contact examination, should be discouraged; updating of leprosy registers should form part of routine activity; Leprosy Elimination Campaigns (LEC) and Special Action Projects for Elimination of Leprosy (SAPELS) should be restricted to only the unreached and the known under detected areas; setting of case detection targets should be replaced by performance targets such as achieving 100% cure rates; case detection should be evaluated through a validation exercise on a sample basis; high risk and hard-to-reach areas should be identified and closely monitored.

4. Under special and specific circumstances, Accompanied MDT should be considered.

5. In order to accelerate the elimination of leprosy as a public health problem in India (at national and sub-national levels), the following activities should receive high priority: 100% MDT coverage and accessibility; high treatment completion and cure rates; involvement/strengthening of partnerships; inclusion of leprosy in the training curricula of the general health staff of all categories.

**BLP observes World Disabled Day**

Bombay Leprosy Project (BLP) has been pioneering the importance of the concept that leprosy programmes should observe World Disabled Day in addition to World Leprosy Day. In tune with this concept, the World Disabled Day was celebrated by BLP at a function organized on 3 December 2003 at its Vocational Rehabilitation Centre, Pratiksha Nagar, Sion, Mumbai. Dr J. Chimalgi, Medical Superintendent, Acworth Leprosy Hospital, Wadala, presided over the function as Chief Guest. He mentioned that physically challenged persons with different abilities do a lot more justice to the work, when given equal opportunities.

The ninth course of computer training for young people with physically challenged was launched, and the highlight of this training is that the trainees will be trained by a physically challenged person. About 25 disabled trainees of the present and past courses assembled to observe this day. The integrated approach practiced by BLP for offering vocational rehabilitation services to the leprosy affected persons along with the physically challenged persons living in slums of Bombay has been fruitful in minimizing stigma and helping them to lead a productive life.

**Discrimination is alive and well**

The following article is taken from the BBC News website (http://news.bbc.co.uk/1/hi/world/asia-pacific/3228200.stm).

Japanese former leprosy patients have rejected the apology of a hot springs resort on the southern island of Kyushu which denied them access. The hotel had questioned whether ‘other guests could be comfortable’ around the ex-lepers. The Ministry of Health has filed a criminal complaint against the resort and told its management to train employees in human rights issues.

Japanese lepers were forced to live in isolated communities until 1996. Over 3700 patients, whose average age is 76, continue to live such institutions and have spent little time in the outside world. The hotel, in Kumamoto prefecture, had booked in a group from one of these centres. However, on discovering its members had once suffered from leprosy, it cancelled their reservation. Current law prevents hotels from refusing custom except from those who have contagious diseases. Leprosy is, of course, not communicable once treated.

Seven years ago Japan repealed an 89-year law under which leprosy victims could be forcibly secluded. The Japanese authorities have also apologized to leprosy patients who suffered human rights abuses as a result of government policy.
World Aids Day—1st December 2003

December 1, 2003 marked World Aids Day, as the growing epidemic continues to devastate communities across the world. During the year 2003, the global HIV/AIDS epidemic will have killed more than 3 million people, and an estimated 5 million more will have acquired the human immunodeficiency virus (HIV). This brings the estimated number of people living with the virus around the world to 40 million people (UNAIDS 2003).

The disease is most prevalent in sub-Saharan Africa, where over 3 million adults and children were newly infected with HIV/AIDS in 2003. Anti-retroviral medication can slow the disease in its tracks, but effective and intensive health education activities are also needed alongside this. Stigma and fear of discrimination still prevents many from seeking treatment.

Information on CD-ROM

The following information comes from TALC’s website.

To support TALC’s continuing work in providing low cost health information TALC has initiated a pioneering project to provide free information to health workers in the developing countries on CD-ROM. Although availability of computers is still limited in the developing countries it is growing fast, while access to the Internet is still very poor, due to cost and poor telephone systems.

CD-ROMs can store large quantities of high quality information. They can be produced and distributed at low cost. This service is designed to achieve the following:

- Production of CD-ROMs with search engines, containing copyright free information. The CD-ROMs are easy to use and have the potential to be interactive (e.g. for training purposes).
- The CD-ROMs will provide free access to up-to-date and appropriate health and development information and training materials for health workers.
- A low cost method for health workers, libraries, government and non-governmental organizations to distribute health information and training resources.
- A vehicle for the exchange of ideas.

The CD-ROMs will allow users to select, adapt and tailor materials to meet local needs and develop their own Library of materials at very low cost. Information on the CD-ROM can be downloaded, e-mailed or printed and freely reproduced and shared.

The project has already met with a great deal of interest, and TALC is developing partnerships with a number of major organizations that wish to use the service. TALC would also like to hear from organizations from developing countries that have appropriate material which would benefit from wider circulation via the e-TALC CD-ROM.

If you would like more information or would like to receive a copy of the CD-ROM or are interested in putting material on it please contact us at: e-TALC, c/o PO Box 49, St Albans, Herts AL1 5TX, UK. e-mail: e-talc@talcuk.org; website: www.e-talc.org.

TDR video library

The following information is taken from the WHO website (http://www.who.int/tdr/media/video/default.html).

A unique and specialized catalogue of video material is available from TDR, covering all aspects of the TDR programme, including, target diseases, sponsored projects, institutions and individuals. The material includes B-rolls/videobite tables with disease-specific, original footage and sequences with natural sound, copied from original camera tapes; Public Service Announcements produced by TDR and distributed in collaboration with TDR partners; and Productions, which are complete, edited videos
produced by TDR Communications, covering a wide range of topics, and for a diverse range of audiences and uses.

Video sequences and footage may be used for any non-commercial purpose, provided the source is clearly acknowledged, but not for promotion of any specific company or product. Copies of sequences in the on-line TDR Library can be obtained (in either .mov or MPG-1 form, or BETACAM copies of tapes for broadcast outlets) from: Communications Unit, Special Programme for Research & Training in Tropical Diseases (TDR), World Health Organization, 1211 Geneva 27, Switzerland. Telephone: +41 22 791 3725; Fax: +41 22 791 4854; e-mail: tdr@who.int.

Bhai Ghanaiya Award 2003

The following information comes to us from the Bombay Leprosy Project.

Dr R Ganapati, Director of Bombay Leprosy Project was awarded the Bhai Ghanaiya Award for 2003 on 12 January 2004, at a function organized by the Red Swastik Society, in recognition of his selfless service in leprosy and health services. Dr Jagannath Hegde, Sheriff of Mumbai, the chief guest at the function, gave the award. Dr Ravindra D. Bapat, Vice-Chancellor, Maharashtra University of Health Sciences, presided over the function. Dr Hegde complimented Dr Ganapati on his lifetime achievement, consistently working in the neglected field of leprosy disabled patients for over 4 decades. Dr Ganapati, in his response, referred to the need for enormous resources to take care of the huge number of disabled leprosy patients, still needing services. He said that in his experience as the Head of an NGO, this problem deserves support from all sources.

The Red Swastik Society was established on 6 January 2001. Mr T. S. Bhal, Deputy Commissioner of Police, Mumbai, is the Chairman of the Society, which has as its mission to provide a holistic approach to serve poor people, without any discrimination on the grounds of caste, creed or nationality. It has regional branches across the country and renders a valuable service to humanity, focusing on health related issues. Its most significant activity has been to provide a fleet of ambulances for the Highway and Railway Accident Service.

Eighty years of caring and curing

This article is taken from LEPRA’s website.

This year marks the 80th anniversary of the formation of the organization that today we know as LEPRA. Back in 1924 the world had no cure for leprosy, only the ability to care for those it destroyed. Thankfully the vision of two men, Sir Leonard Rogers, a Major General in the Indian Medical Service, and Reverend Frank Oldrieve, Secretary for India of the Mission to Lepers (now known as the Leprosy Mission), changed all that. Sir Leonard had just completed research at Calcutta on chaulmoogra, which opened up a new era in leprosy treatment, giving hope for the first time that the disease might be cured. At an historic meeting on 29th March 1923, the idea of a new, non-sectarian organization dedicated to the eradication of leprosy was mooted, and when Sir Frank Carter, also recently retired from India, offered to organize the financial side, the British Empire Leprosy Relief Association (BELRA) was born on 31 January 1924, under the patronage of the Prince of Wales. From the outset BELRA, and later LEPRA as the organization became known, has been at the forefront of leprosy work.

Cured leprosy patients participate in solidarity rally for human rights

The Fourth World Social Forum met for the first time in Bombay from 16 to 19 January 2004. Participants came not only from India but from other countries to exchange their views and to form a
common forum to fight for human rights. Their objectives included the betterment of disabled as well as the down-trodden.

A large procession took place on the first day to focus attention of both ordinary citizens and Government officials on the day-to-day problems faced by the disabled. The rally started from Gateway of India and terminated at Churchgate. About 1000 disabled patients of all categories participated in this rally.

Bombay Leprosy Project also joined the rally and took an active part. The highlight was that for the first time leprosy affected and cured persons walked alongside other disabled people. The problems faced by the leprosy affected are much more serious than those of other disabled people, due to the added stigma. The rally has gone some way in achieving the aim of the Bombay Leprosy Project to integrate the unwanted and less fortunate people in society.