

**ALERT!****ALERT!****STOP TUBERCULOSIS WORLDWIDE**

This picture below shows an infant with advanced TB meningitis. This form of the disease affects the child by attacking the coverings of the brain and spinal cord. The disease is invariably fatal unless treated with anti-TB drugs which have a high rate of cure. Children who are diagnosed and treated late in the course of the disease may be left with permanent damage to sight or hearing. However, with good treatment this baby could be cured.

## TB and children in developing countries

**TB is a major killer of children – killing more young people than any other single infectious disease. Every minute two children die of TB worldwide.**

**Tuberculosis in children can be neglected.** Paediatric TB does not have a high priority in many developing countries as fewer children than adults have the disease and children are not usually infectious, and often, limited resources mean that infectious cases have priority.

**Vaccination is not 100% effective.** The TB vaccine, BCG, does limit some of the severe forms of tuberculosis which are unique to young children, but by no means prevents them all. Tens of thousands "immunised" children in the developing world still suffer from tuberculosis meningitis and other forms of disease.

**Children are highly susceptible to tuberculosis.** The power to resist TB infection is normally poor in the first 5 years of life. The resistance can be further reduced by malnutrition, HIV, other childhood infections and worm infestations – all too common childhood conditions in poor countries. It has been estimated that as many as one third of the world's population is infected with TB, and an estimated 20-50% of children who live in households where an adult has active tuberculosis become infected. Children are especially vulnerable to infection from household contacts as they are often held close and breathed on. The risk is particularly high in the developing world where family size is large, living quarters



are crowded and more than half the population are children.

**Traditional diagnosis of TB in children is ineffective.** A vast number of children infected remain undiagnosed – creating a reservoir of future adult disease. Diagnosis is difficult in children, and often fatally delayed – early symptoms and signs of tuberculosis in children are common and easily missed. Lung TB is particularly difficult to diagnose early as children's lungs react differently than adults, and they have little or no cough (thus not being able to provide sputum for testing) and, even if produced, microscopical examination only occasionally reveals the characteristic tubercle bacilli.

**TB can have devastating long term effects on children** who can be left deaf, blind and/or totally paralysed from TB meningitis, even after it is cured. Spread of infection to the bone can cause deformities of the spine (hunchback) or other permanent disabilities.

**TB exacerbates poverty** – it makes the patient and their family poorer because they may have to pay for treatment themselves, and even if TB drugs are free there is often a cost of travelling to clinics. If they cannot afford this they may default from treatment – leading to the added complications of MDR-TB<sup>†</sup>. Children with TB lose out in the vital years of their education, which can affect their future wage-earning capacity.

**To read about some of TB Alert's work with children see page 2**

† Multi drug resistant TB

## IN THIS ISSUE

TB & Children	1
Our work continues	2-3
The story of M	
TB and women in Bangladesh	
TB and Poverty in Zimbabwe	
UK Fundraiser meets Asia representative	
Resource file	3
Patient resource	
TB leaflets	
Feedback on TB treatment diaries	
Making it possible	4-5
Exclusive book offer	
Thanks to Barts Rag	
Volunteers take to the pub	
From the pub to the House of Lords	
Christmas card success	
Calling accountants	
Discussion time	6-7
RSM meeting on HIV	
TB in Parliament and beyond	
World TB day conference 24 <sup>th</sup> -25 <sup>th</sup> March	
Hyderabad workshop gets NGOs and government talking	
Your questions (focus on BCG)	
Special Appeals	8
World TB day Fundraiser	
Where there's a will	

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Charity Registration No: 1071886

## Our work continues ...

### M's Story

*TB Alert* is working to make sure children are not missed out in the worldwide fight against tuberculosis. We are supporting a project in Blantyre, Malawi, at the Queen Elizabeth Hospital Paediatric Ward where specialist nurses have been taken on to investigate and improve cure rates for children. Our financial input along with the expertise of our Advisors aims to improve the service at the hospital, and set an example to other government and non-governmental health services in Malawi. In this way, this project will provide benefits far wider than simply to the children treated at the Queen Elizabeth Hospital.



"M is eight years old. Two years ago M's uncle stayed with the family and during that time the uncle was found to have sputum positive TB.

For 6 months M had a growing ulcerated area on his nose. He was too miserable and embarrassed to go to school. He lost weight and became very thin.

His eyes were red and sore and he constantly rubbed them. His mother had tried various medicines recommended by the local clinic and pharmacist, but nothing helped and last month he was sent to us with a diagnosis of 'tumour of the nose'.

We decided to do a Mantoux test (which checks for TB). The test confirmed our suspicion of TB, and we started him on treatment. Within weeks the sore started to get smaller. As he gets older the scarring will fade. Without treatment the sores would have caused him great pain and disfigurement, and the infection could have spread, eventually leading to death."

*Professor Elizabeth Molyneux, Queen Elizabeth Hospital*

### A perspective on TB and women from Bangladesh

According to the World Health Organisation, **TB is the single biggest killer of young women**, accounting for 9% of deaths among women between the ages of 15 and 44. In comparison: war accounts for 4% of deaths of women in that age-group, HIV 3% and heart disease 3%. Women of reproductive age are more susceptible to develop active TB disease once infected with TB than are men of the same age.

*We asked Dr Mark Pietroni of LAMB hospital about the situation of women in Bangladesh, and how their TB work affects women particularly:*

Maternal mortality is high in Bangladesh, female participation in civil society is very limited and education of women, though actively encouraged for girls by government subsidies, still lags behind males at the higher levels. Women have a literacy rate 20% than average in a community where average literacy is only 40% – and this judged by the most minimum of criteria.

Crimes against women are widely reported, and domestic abuse is commonplace – a report by the Center for Health and Gender Equality in the USA in 1999 noted that 47% of women

in Bangladesh have been physically assaulted by their husband or partner. The Dowry and a patrilineal marriage system are common causes of abuse, discord, divorce, and increased poverty, as well as being a primary reason for a preference for male children and the neglect of girls.



LAMB's work is providing a vital service for women and their families – if the rural population of Bangladesh have access to health care facilities and can work, they are much less likely to feel the need to move into the cities such as Dhaka, leading to family break-up, loss of community, increased pressure on urban services and even greater poverty.

With regards to TB, case finding among women is much lower than men. This may be due to exclusion from wider society and hence decreased exposure to the disease, or this exclusion may inhibit access to TB services. It is not uncommon for a man to leave his wife if she develops TB, and if she is not already married the stigma attached to TB may prevent a woman from finding a husband. TB can lead to isolation and abandonment by the woman's family members too. This may hinder women's presentation for diagnosis and treatment because of (rightly) perceived increased stigmatisation resulting from the diagnosis of TB.

These intangible burdens result in depression, anxiety and lower life satisfaction, further adding to the burden of TB. Involving women in the strategy to reach women, especially as volunteers, and as trained community health educators (especially those who have been cured of the disease) has proved effective in the field of leprosy locally, and LAMB aims to use these methods in regard to TB. LAMB's awareness-raising work not only improves self-referrals and early case-detection, but also aims to change attitudes to the disease, breaking down the barriers of discrimination and stigma.

*TB Alert* is supporting LAMB clinic to impart a holistic perspective, medically, socially, economically and spiritually, to the provision of TB treatment in four Thanas (districts) of northern Bangladesh. LAMB aims to provide treatment for everyone who needs it irrespective of class, gender or creed, and central to their approach will be the activities that raise awareness of the disease, allowing early diagnosis and treatment and thus preventing the disease from escalating.

## TB and Poverty in Zimbabwe

In our newsletter of Spring 2002 we included an article about TB and poverty, explaining why Poverty increases the risk of TB, whilst TB impoverishes its victims. Recently we received a report from our most recent project, Murambinda Hospital, which highlighted this important issue:

*Dr Monica Glenshaw writes ...*

"The people in our region are very poor – the average daily wage of most people in Buhera district [being the second poorest district in Zimbabwe] is a difficult figure to estimate as most of the people are subsistence farmers, but the figure is less than 50 US cents.

"Severe poverty means that patients will often default treatment if they cannot afford the bus fare to the treatment centre in Buhera. There are 27 satellite clinics, and these act as treatment centres, but diagnosis, testing and final reviews occur at Murambinda hospital. The Ministry of Health does have a travel warrant system for TB patients but often bus companies do not accept these as the delays in payment are so long! Fortunately the supply of TB drugs in Zimbabwe (they are supplied free by the government to the hospital under the National TB Programme) remains good and constant. However, the current collapse in the economic situation, compounded by drought in Zimbabwe has led to a serious food deficit and the result [is] that people in general and the poor in particular are increasingly hungry and suffering from poor nutrition, and thus it will be expected that there will be an upsurge in the already rapidly rising prevalence rate of TB."

*TB Alert* has made a small grant to enable Murambinda hospital to purchase sputum pots and, crucially, to improve patient nutrition, ensuring patients recovering from TB receive sufficient protein in their daily diet to make a full recovery. Although the initial grant was small (£720), we are impressed with the information and feedback we have received from them. We know the hospital desperately needs more funds and we have asked that they put forward a further request which will be considered by the Advisory Board as soon as possible.

*Dr Julie Lethaby, Programme officer*

## Getting to know you



At the end of last year, I heard that Tilak Chauhan, *TB Alert's* Asia representative, was visiting the UK to spend some time with his son, and I was keen to meet him and find out more about him.

Tilak comes from the Himalayas, in the part of India which borders Nepal, and now lives in Hyderabad. He says that this, the capital city of Andhra Pradesh state, is a city of contrasts. It is full of history, with beautiful old

architecture, but also a growing high tech service industry (like me, you may have spoken to someone from a Hyderabad call centre when phoning your bank or other customer service office!) – and it is a very beautiful city, but scarred by the devastating poverty of the slum areas.

This visit was his first time in England – I was surprised that Tilak didn't find it strange, but he said that he has a love for the English classical literature, and felt that he recognised the countryside from the descriptions in books such as "Far from the Madding Crowd".

Tilak told me that he has spent 42 years working in Leprosy, which is a highly stigmatised disease, caused by a member of the same group of bacteria that cause TB, but mercifully not a killer. He has always been very aware of TB (India has the greatest burden of cases in the world), and during his career had been involved in joint Leprosy/TB projects. Retiring from his full-time post of Chief Executive of Lepra, India, Tilak wanted to spend more time with his wife, but was keen to continue some form of work part-time. He was delighted to make contact with Paul Sommerfeld of *TB Alert* and find a way that he could use his semi-retirement to make a contribution to TB work within India, and thus to saving lives.

Tilak is very confident that *TB Alert's* projects in India are making a vital difference to communities in the areas where they work. He feels that *TB Alert* is well placed to make an impact on TB in his country, through advocacy work, and networking with Government departments and good NGOs (Non-Governmental Organisations). Money goes a long way in India, and small grants along with advice and support from *TB Alert's* Advisory Board can create centres of excellence which can be replicated elsewhere.

*Melanie Matthews, UK Fundraiser*

## Resource file

### A new patient resource

*Mywavelength.com* is a free worldwide health resource incorporating all sorts of health issues – where both patients and carers can communicate and support each other. Patients with TB who would like to email others in their situation, can register on [www.mywavelength.com](http://www.mywavelength.com).

### TB leaflets – your feedback needed!

If you work in the medical profession, you should by now have received samples of nine Tuberculosis information leaflets which cover a range of subjects relevant to TB patients. If not, please contact Angela (see front page for contact details).

We have approximately one year's supply of these leaflets, and will be reprinting them after taking into account your feedback and comments. I am sure you will also be delighted to know that we intend also to make these leaflets available in the major ethnic minority languages used by TB patients in the UK, as well as to develop other materials, such as posters. However we cannot do this without your help. PLEASE complete the feedback form (on the back of the order form which came with your sample leaflets) which will help us to develop these future materials. We need this information to ensure that we can direct our limited funds to developing the right information – 5 minutes of your time will help us to provide the information YOU need for your patients.

### Feedback on the Treatment diaries:

*Just a short note as a sort of feedback on the patient diaries you sent us. We are finding them to be of great value to the patients, especially the newly diagnosed patients on the wards, as they give them something visible to take home with them and to which they can refer to at any time. Diaries make it easier for the nurses to explain what the tablets look like and also help reduce confusion with all the different tablets during the course of treatment. The patients can also carry them with them and in any emergency or even planned appointments they can be used as guides by any professionals treating them. Keep up the good work.*

Connie Richardson, TB Team Administrator, University Hospital Lewisham Chest Clinic

If you haven't ordered your treatment diaries yet, call or email Angela (see details on front page).

## Making it possible ...

### Exclusive book offer for *TB Alert* Supporters

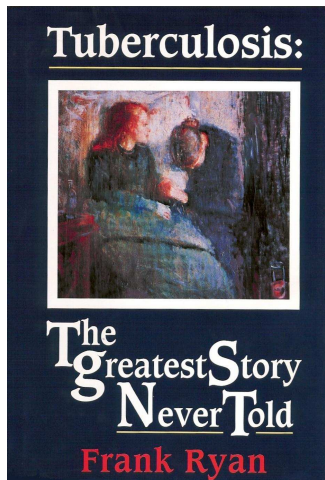
**Author Frank Ryan says of his book "Tuberculosis: The Greatest Story Never Told":**

"Tuberculosis is the greatest infectious killer in history. In this century and the previous one it killed an estimated thousand million people. Half way through this century, experts and the public alike thought the cure would never be found. In fact it was found by the most unlikely group of heroes, none of them tuberculosis experts and only half of them medically qualified. Their discovery of the cure changed history. You might imagine how surprised I was to discover that their story had never been told. I traveled about the world talking to the people who had played their parts in it – and what an incredible story it proved to be. Then, while I was writing it, the plague came back to haunt both the developed and developing world." [The last section of the book goes on to tell of the new outbreak of tuberculosis, linked with the AIDS epidemic, that now threatens the world again].



"As exciting as a detective novel ... Dr Ryan tells an important and moving story." *Anthony Daniels, The Sunday Telegraph.*

#### Author's Offer to *TB Alert* Supporters



*TB Alert* would like to thank Frank Ryan, not only for highlighting the issue of Tuberculosis to the world, and in such an entertaining way, but also for being a keen and active supporter of *TB Alert*.

Frank has offered all of our supporters the chance to buy this, and any of his other books (signed personally) with **all authors profits\*** coming to *TB Alert*.

And don't be put off if you are not a scientist – Frank's books

are intended for general readers, doctors and scientists alike. But if you are more interested in fiction, science fiction or mystery thrillers, check out some of his other books – every single one will raise money for *TB Alert*!

If you have internet access have a look at [www.fprbooks.com](http://www.fprbooks.com) where you can see reviews of all of the books on offer (the offer includes those published by other authors on this website\*).

**Please ignore the order page on the website – to take advantage of this fundraising offer contact Melanie at *TB Alert*** (see front page for contact details). If you don't have the internet, but would like to know more about his books, please contact Melanie and we can post you details.

Finally, if you are a regular book purchaser don't forget that you can buy any book on [Amazon.co.uk](http://Amazon.co.uk) with a small donation

going to *TB Alert* if you buy through [www.ushopugive.com](http://www.ushopugive.com) and choose *TB Alert* as your preferred charity.

\*Supporters will be charged cover price for the books, with no extra charges for p&p. Frank owns FPR Books, which publishes many of his books as well as those by other authors. For FPR published books (including those by other authors), *TB Alert* will receive all of the publishers profits, and for all the books he has written (including those published elsewhere), we will receive his profits as author. So for the TB book we actually receive everything you pay, except for p&p costs.

### Thank you Bart's Rag!

We'd like to thank the students of *Bart's and the Royal London Hospital*, for raising £1500 for *TB Alert* through last years Rag events.



The two medical students shown in this picture were preparing for an evening of collecting in central London, and money was also raised through events at the Student Union including Toga parties, beer races, scavenger hunts and a Rag Ball. The Rag committee selected a number of charities to benefit from their efforts, including *TB Alert*. Although many of the charities they support are based locally they felt that *TB Alert* was important because the highest rates of TB in this country are found in the East End of London.

Most Universities have active RAG committees, and some schools also nominate charities to benefit from their fundraising events and activities. Our thanks also go to the students of *Cardinal Vaughan Memorial School* for choosing us as beneficiary charity for a second time. We have yet to find out their total raised, but last time were delighted to receive a cheque for £1750! If any of our supporters have contacts within schools or universities, please let us know. Sometimes all we need is an introduction from someone for them to consider our charity as one for their potential support. We have lots of information and posters, and our network of volunteers around the country means that we can provide a speaker in most areas with a little notice.

## Volunteers take to the pub!

*TB Alert* has a dedicated little team of volunteers in Brighton, and it's not unusual, on a Friday night, to find them sampling the organic beers in their local pub. However, after one such evening last Autumn, not only were they all still sober, but *TB Alert* was over £160 better off!



In a variation on the normal tin-rattle collection, Brighton volunteers telephoned their favourite local pubs to gain their permission (some have their own charities and do not allow collectors), sent the landlords leaflets in advance to tell them more about *TB Alert*, and worked out a route. The collection took the three volunteers just 2 hours (with an extra 2 hours for one volunteer on telephone calls) – meaning that it was one of our quickest and most efficient collections yet!

If you live in an area with a high density of pubs, and you or anyone you know could spare a few hours for a *TB Alert* collection – please let us know. We will apply for a licence to your local council, and give you everything you need for a successful collection.

## From the Pub to the House of Lords

*From the Pub...*

*TB Alert's* supporters are a convivial bunch, and so it was entirely appropriate that this year's "Open Day" was held in a pub – not, it is admitted, in the bar, but in a private room at the Two Chairmen pub in Westminster. The event was held on the evening of 4 December 2002, to coincide with the Winter Meeting of The British Thoracic Society, many of whose members are supporters of *TB Alert*.

In all over 30 people came to enjoy the wine and to see and hear what has been happening in *TB Alert* over the last 12 months. It was a friendly and relaxed evening, introduced by our President, Sir John Crofton, and with a short report on our achievements over the past year by our Chairman, Paul Sommerfeld. One of the projects we support is the TB work of the Calcutta Rescue Mission, and Cathy Hall, a voluntary worker with the Mission, spoke about its work and the desperate need in Calcutta to combat TB. It was encouraging to hear at first hand about this vital work which could not happen without funding from *TB Alert*.

*...to the House of Lords*

Well a pub was fine for 2002, but in *TB Alert* we are ambitious. So for our 2003 "Open Day", to be held on the evening of Tuesday 2 December, we are moving down the road from the pub to the House of Lords. And not just the House of Lords. We have been selected to enjoy the hospitality of the Lord

Chancellor's private apartments. Everyone will remember *That Wallpaper*. When the Lord Chancellor's apartments were refurbished at great cost (and the amount spent on the wallpaper caused a particular sensation), the LC decided to invite charities to use his apartments. Now we have the chance to see what all the fuss was about – and to benefit *TB Alert* at the same time.

This will be our first prestige event, and we will be planning to use this unique occasion in the very best way for *TB Alert*. More details, and formal invitations, will follow over the next few months, but we hope that many of our supporters

will be able to join us for what will be a memorable evening, so put the date in your diary now. And if you're thinking that you might redecorate the sitting room this year, why not wait to see how the Lord Chancellor did up his place – you might get some ideas from him!



## Christmas card success!

Thank you to all of our supporters who bought *TB Alert's* first ever Christmas card. We thought you might like to know that you not only helped us to raise over £1100 when all the costs were taken into account, but, because 4500 cards with a message about TB were in circulation to your friends and family, you helped us to raise awareness too. Next year, we hope to have two new Christmas cards, one of which will be an exclusive design from one of our projects in India. Samples and order forms will be issued in our Autumn newsletter.

## Calling Accountants – or other Financial Wizards!

*TB Alert* has a dedicated group of trustees and advisors, with a wide range of skills and experiences. We still only have 2 part-time members of staff in this country, so we rely on our trustees and advisors along with other volunteers to undertake many of the tasks that keep the charity running. Our current Trustee Treasurer is looking to hand over the mantle, due to the birth of his first child, and we wondered if any of our supporters, or your friends or family would be able to help.

Don't worry – the bookkeeping is under control. What we need is someone to keep tabs on our overall financial picture, pull together financial information to help trustees take management decisions, make sure we have proper controls in place, and deal with regular financial tasks such as preparation of the annual accounts and liaison with auditors.

Whoever takes this on should be able to attend Trustee meetings which take place every two months, usually on a Wednesday afternoon in Euston. Being based near London would also help for contact with the Chair, Administrator, Fundraiser and others.

If you or anyone you know would be interested in finding out more, please contact Paul Sommerfeld (see front page for contact details).

## Discussion time – meetings, advocacy and questions

### Meeting on HIV treatment of TB patients – October 2002

One of the great tragedies of looking after patients with TB in Africa is that many of them will also be infected with HIV. This virus makes them uniquely susceptible to TB so that the signs of tuberculosis are often the first signs that they are also HIV positive.

These patients can usually be cured of their tuberculosis, provided they complete the 6 month course of antibiotics. This will actually slow the progression of HIV and give them some years of healthy life. But eventually the HIV will progress to AIDS and they will die from a recurrence of their TB or some other "opportunistic" infection.



*Boy from South Africa with TB and HIV. The distended tummy is because of an enlarged liver and spleen caused by the presence of the two diseases.*

Doctors and other medical workers looking after these patients have begun to call for the treatment of their HIV using the so called Highly Active Anti-Retroviral Drug Therapy (HAART) now available to HIV sufferers in developed countries. This raises potential problems. Firstly the cost, which even with locally manufactured drugs is almost \$300 a month. This is in marked contrast to the cost of a full course of TB drugs which is now only about \$10. Secondly treatment is lifelong, not 6 months as with TB. Thirdly medical services are stretched to provide even basic treatments. Can they be expected to supervise the giving of many tablets a day for ever?

The meeting at the Royal Society of Medicine brought together experts in the field to discuss the pros and cons of affording HAART for the poorest countries. It was pointed out that \$300 dollars a month would provide clean water for several villages and so probably save many more lives by preventing diarrhoeal diseases in children.

On the other hand, by killing young adults, the most

economically active members of the rural societies of Africa, AIDS is devastating national economies. By giving a relatively healthy life to these people economies might be revived. It must be said that no clear conclusions were reached. This is a debate, which will run and run. We have only just begun to air the problems.

### TB in parliament and beyond

On 4<sup>th</sup> December last year tuberculosis came to Parliament when a special Briefing took place in one of the grand committee rooms of the House of Commons, hosted by Ian McCartney, MP and Minister of Pensions, who spoke movingly of his personal experience of having TB when already an MP about ten years ago.

Working with *Stop TB* (the TB advocacy partnership based in the World Health Organisation) and *Results, TB Alert* told the MPs, Peers, and journalists present of the links between TB worldwide and TB in Britain – TB rates in some London boroughs such as Brent and Newham are now as high as the national rates in China or Brazil. That Britain cannot be isolated from the global TB crisis, and that its control here depends on its control worldwide, was underlined by the presence of another Minister, Sally Keeble MP of the Department for International Development. *TB Alert* was well represented by Paul Sommerfeld who chaired the event, Dr. Peter Davies who outlined the UK situation, Sir John Crofton our Honorary President who stressed the need for global action, as well as other trustees and supporters who handled particular questions.

The event gained more publicity for TB than any other since the Leicester school outbreak two years ago. Notably, it served to underline to politicians the need for action both in Britain and in the high-load countries of Asia, Africa, Latin America and Eastern Europe.

Worldwide, the situation remains deeply worrying. At the conference in Montreal last October of the *International Union against Tuberculosis and Lung diseases* (of which *TB Alert* is an Organisation Member), the central theme was that as HIV spreads, the TB epidemic will increase. There was great fear of what could happen to global TB numbers as HIV spreads in Asia with its traditionally high TB rates.

In Britain, the Department of Health has long seen TB as a matter for concern. Now, as numbers remain stubbornly high, it is about to publish a National Action Plan for TB. So far the disease has kept ahead of investment against it. Hopefully, the new Plan will be given the political priority, resources and the sense of energy that are necessary to ensure the tide is turned.

### World TB day conference – please come along!

*TB Alert* is collaborating with *Stop TB* (The TB advocacy partnership based at the World Health Organisation) and the North-East London TB network to mount, in Newham, both a general conference on World TB Day itself (Monday, 24<sup>th</sup> March) and a more clinically oriented workshop the following day.

The conference on 24<sup>th</sup> March will be one of half-a-dozen lead events around the world that day through which, with press coverage, it is hoped to focus public attention on the global challenge of tuberculosis. The day centres on the theme chosen by the World Health Organisation, "Patients and TB". Anyone concerned about TB will find this an interesting event, including professionals like social workers, housing officers, and police who need some awareness of TB but are not health specialists. The workshop on the second day will take place in Stratford Town Hall and be of more particular interest to researchers, clinicians, TB nurses and others with a professional involvement in TB.

For more details or to attend either day, please check our website where you can download information and a booking form ([www.tbalert.org](http://www.tbalert.org)) or call Paul Mayho on 0208 430 4406.

## TB Alert gets Indian NGOs and government talking

*TB Alert* has taken a lead in building better links between non-governmental organisations (NGOs) and government TB services in the Indian State of Andhra Pradesh (AP) which has a population of 80 million people and over 100 000 cases of tuberculosis every year – as against Britain's 60 million population and 7300 cases.

Our Workshop on 10-11 February 2003 in the State capital, Hyderabad, took place at a crucial moment as the Indian Government is on the point of rolling out its Revised National Tuberculosis Control Programme (RNTCP), to ensure DOTS (the World Health Organisation recommended TB treatment regimen) coverage for the whole State. Up to now it has only been available on a pilot basis in 6 of the 23 Districts. This is part of the ambitious programme to make DOTS available throughout India by the end of 2004.

We initially planned a low-key initiative to bring together NGOs in AP and encourage them to get involved in the RNTCP at this historic moment. But so many major players, from WHO and the heads of the RNTCP to the State Health Secretary and the State TB Officer saw our initiative as just the right thing at the right moment that it became a high-profile gathering of both NGOs and the District TB Officers (DTOs – the main government TB officials on the ground) with the active presence of many leading lights from national and State level.

Participation, that we had thought might reach around 60, ended up at about 110. Of these around a third were from NGOs right across the State, many of whom had long journeys to reach Hyderabad. Some were already involved in the RNTCP but crucially, many had come with a view to learning more and then deciding whether to get involved. The real measure of success of the workshop and our continuing efforts will be whether the number of NGOs committing to the RNTCP rises so that more patients are treated under the scheme.

The State TB Officer, Dr. Mohan Rao, was there pretty much throughout. All 23 DTOs were active participants. There was a real sense that people were working beyond the usual NGO/Government tensions, towards some appreciation of each other's contribution and of possibilities for cooperation.

The workshop which was supported financially by pharmaceutical company, *Astra Zeneca*, was also notable for cooperation from other donor NGOs active in AP. *World Vision*, who are involved in TB in 8 districts, saw our event as a perfect vehicle for them too and helped with the costs. *LEPRA-India* gave practical help with staff and logistical support and sent speakers on their TB work, as did *Damien Foundation* from Belgium, and *German Leprosy and TB Relief*.



Dr. L.S. Chauhan, Deputy Director General TB, conducting the lighting the lamp ceremony at the start of the Workshop.

Our Representative in Asia, Tilak Chauhan, did an exceptional job in setting all this up and will now make sure that there is

follow through with the recommendations that came from the discussions.

This was our first major event in India and has set the scene for *TB Alert* to play an increasingly important role in helping with TB work in the country with the greatest number of TB cases. A nice touch was that all participants got one of our lapel pins – which look very good on a sari!

## Have you got a question?

Thank you to everyone who has sent in a question by post or by email since our last newsletter. We hope that the answers provided by our medical and scientific advisors have helped you take the right course of action, put your mind at rest or clarified some information for you. Over the last six months many questions have been asked about BCG, with these two recurring most often:

### ***Wouldn't TB Alert's money be better spent on mass vaccination to prevent anyone from getting TB in the first place?***

Unfortunately the BCG vaccine is just not effective enough to make a significant impact on the incidence of tuberculosis in a community for the following reasons:

- The efficacy of BCG varies enormously from region to region – from around 80% to 0%!
- Even in those regions in which it has been shown to be effective, the protection is largely restricted to childhood tuberculosis which is rarely infectious.
- BCG has little impact on the prevalence of the infectious adult tuberculosis, responsible for the spread of the disease in the community.
- BCG would have no impact on the increasing burden of HIV-related tuberculosis as the immunosuppression from HIV would annul any immunity conferred by the vaccination.

Mass BCG vaccination campaigns would, in terms of both effectiveness and cost-effectiveness, be inferior to the World Health Organisation recommended DOTS strategy in reducing the incidence of infectious cases of tuberculosis in a community and transmission of the infection. Having said that, BCG vaccination in children should certainly be encouraged as it prevents serious and life-threatening forms of childhood tuberculosis, even though they are rarely infectious. Anyone who has seen, as I have during my time in South Africa, the devastating and tragic consequences of tuberculous meningitis – children left deaf, blind and/or totally paralysed – would want to ensure that all children were protected as far as possible.

*Prof. John Grange, TB Alert*

### ***I didn't have a BCG vaccination when I was younger – should I have one now that the disease is on the increase in the UK?***

Most of us would have had a BCG jab when we were at school to protect against dangerous childhood forms of the disease. Usually it's given between the ages of 10 and 14. If you haven't had the vaccine, and 30% of us generally haven't, there's really no point in having it now. The BCG only really protects us when we are children, and is only effective for about 15 years. The risk for most people is small and TB is generally fully curable with antibiotics. The best way to prevent TB is to cure people who have it, then there will be fewer people to spread the disease.

*Dr Peter Davies, TB Alert*

If you have any questions, please contact Melanie (see front page for details).



### World TB Day Fundraiser

World TB day this year focuses on the patients who have been cured through DOTS (the recommended treatment regime for TB). Worldwide the aim is for cured patients to raise awareness of the disease, its symptoms and its cure, and to highlight how other people can access the lifesaving treatment too. This World TB day, we have decided to use the same principle with our fundraising – not patient-tell-patient, but donor-tell-donor.

All of our individual supporters should find with this newsletter, about half a dozen little envelopes. Please will you use these envelopes to help us reach this year's World TB Day Target of raising £10,000, which will enable us to use DOTS to cure another 400 people.

You may be aware that for any charity, the cost of finding new donors to support their cause is one of the most expensive bills they face. For a small, relatively unknown charity like *TB Alert*, it is especially tough. Yet without new supporters, volunteers and friends it is impossible for us to grow, and to increase the number of people around the world we can help to cure.

This World TB Day, you can help us raise funds and awareness for our cause. It's very simple and it won't take up much of your time, so please, please don't put it aside. All we are asking is that you give these envelopes to friends, relatives, work colleagues or members of your church or other community group. Ask if they would be willing to take an envelope, read the information on it, and give us a donation of whatever they decide. The donation can be completely private – the envelope has a Freepost address to send it directly to us so you won't know how much they give. Of course if they would rather give you cash there and then, you can just collect the cash and send us a cheque yourself.

Please stress that we are not asking for a lot of money – if each one of our supporters could find five people to give £5 each, then that £25 total will cure another person of TB, and help us reach our £10,000 target.

We have deliberately kept the numbers small, to keep our costs low, and to make sure it is not too daunting a task for our supporters. But of course, if you would like more envelopes we would be delighted to send them – just ring Angela (see front page for details).

We do realise that some of our supporters may not be able to help us in this way. If you are not able to use the envelopes to fundraise for us, please consider sending them back to us so that we can use them again. We have kept the printing costs as low as possible, but every penny counts!

**Please help us reach our £10,000 Target with just a few minutes of your time!**

### Where there's a will ...

*TB Alert* is working towards a world where everyone, however poor, can access the lifesaving anti-TB drugs and receive effective treatment. Since 1999 our supporters' gifts have enabled us to work with some excellent programmes, saving the lives of hundreds of people who would otherwise not have had access to TB treatment. But, we can't solve the problem overnight. As the World Health Organisation states, a good tuberculosis programme must continue for more than 10 years to have a lasting impact on new incidence and for more than 50 years to have a chance of eradicating the disease. Unfortunately we won't all still be around then to help *TB Alert's* programmes to continue for that long.

#### A Lasting Gift for Long Term Change

There is a way that *TB Alert* supporters can make a lasting gift that will go on fighting tuberculosis long after their own lifetime. After you have provided for family and friends, please consider making a gift to *TB Alert* in your will. This can be a specific gift, a percentage of your estate, or a request for gifts to *TB Alert* instead of flowers, depending on your circumstances. Your support could help us work towards a future where TB can finally be confined to the history books where it belongs. If you decide to give a gift to *TB Alert* in your Will, we can promise you that your donation will be looked after well and be put to good use, ensuring that treatment is accessible to everyone, not just those who can afford it. Your gift will be appreciated for generations to come. Your gift will save lives.

#### What you need to know to help *TB Alert* with a gift in your will ...

If you are writing your will or adding a codicil to leave a legacy to *TB Alert*, please use the following wording:

1. *A residuary Legacy (a portion of the remainder of your estate):* "I give devise bequeath and appoint to *TB Alert* whose Registered Office is situated at 22 Tiverton Road, London, NW10 3HL, Registered Charity No.1071886 .....% of the residue of my estate and I direct that the receipt of the Treasurer or other authorised officer for the time being will be sufficient discharge to my Executors."
2. *A specific sum:* "I give the following pecuniary legacy absolutely and free of all taxes to *TB Alert* whose Registered Office is situated at 22 Tiverton Road, London, NW10 3HL, Registered Charity No.1071886: the sum of ..... (words) (£.....) (figures) for the general purposes of the Charity, and I direct that the receipt of the Treasurer or other authorised officer for the time being will be sufficient discharge to my Executor."

#### A note from a *TB Alert* supporter

*In my will I have requested that instead of flowers, I should like donations to go to TB Alert. Having spent a large part of the last 24 years working with TB, I felt it only right that my lifelong interest be remembered. TB is a preventable and treatable disease if the resources are available. I should like to think that in some small way I can contribute to programmes around the world by providing funds towards either equipment, drugs or staff.*

Biomedical Scientist, Liverpool