

ALERT!

Issue Number 14 Spring 2006

ALERT!

The newsletter of *TB Alert* – the UK's National Tuberculosis Charity



What's your 'World Stop TB Day' action?

Every year World Stop TB Day on 24th March is a chance to raise awareness about the fight against TB. This year TB Alert is launching our biggest campaign yet – awareness and fundraising in health centres, community centres and supermarkets all over the country. Lots of people have signed up already but its not too late!

Could you spare 4 hours to collect donations and give out leaflets at your local supermarket on 24th or 25th March?

OR why not buy a TB Alert red wristband (£2 each) to show your support? Or commit to take 10 wristbands to sell to friends?

Whatever your action for World Stop TB Day – be part of it!
Phone Melanie NOW on 0845 223 5293.

A life saved in Delhi

This is Pooja, age 1½ years. Pooja has TB meningitis. She was referred to Ali Extension TB treatment Centre, a TB Alert funded centre in a very poor area of Delhi. Pooja had been discharged from the government hospital because her parents could not afford the cost of treatment.

The Indian Revised National TB Programme provides free treatment for infectious TB cases. But TB meningitis is not infectious. She was extremely ill though - TB meningitis is fatal if untreated and children who are diagnosed and treated too late can be left deaf, blind or paralysed by its effects.

Thankfully drugs were purchased by the DOTS centre, and Pooja's life is now no longer in the balance. We wish her all the best for a full recovery.



Children are highly susceptible to tuberculosis. The power to resist TB infection is normally poor in the first 5 years of life, and resistance can be further reduced by malnutrition, HIV, other childhood infections and worm infestations – all too common childhood conditions in poor countries.

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.

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Newsletter written and produced by Melanie Matthews and Dr Owain Tucker with thanks to Tina Harrison, Rebecca Welfare, Nicola Tregay, Nicola Cullum and Sapna Naveen.



A focus on VHAD – treating TB in the slums of Delhi



TB Alert supports five DOTS* centres in some of the poorest areas of Delhi. The centres, each staffed by a healthworker and supervised by Dr Sapna Naveen, provide an excellent way of ensuring tuberculosis patients receive the adequate doses of medication at the correct intervals and make available a number of leaflets and other sources of information about the disease for the local population. Nutritional Support, in the form of high protein biscuits and eggs was offered to children to help them endure the full course of treatment.

Leela, age 35 came to Lalkuan Dots Centre with cough and chest pain. She was diagnosed with Sputum Negative TB (not infectious). Her husband, who had earlier suffered from TB (and in all likelihood passed it on to her), decided to abandon her after he found out. Sadly it is not unusual for a woman with TB in India to be divorced or abandoned by their family for “bringing TB and shame on the household”.

Understandably, Leela became confused and depressed. She stopped taking treatment and was even ready to end her life. The health workers at Lalkuan knew that even if she didn't take her own life, it was at risk anyway since, if she didn't carry on the treatment, she could develop drug resistant TB.

The health worker visited her husband and convinced him to support Leela and the importance of Leela continuing treatment. Today, Leela is cured of the disease and has decided to fight the disease which nearly ended her life by creating awareness in her community.



An important part of the centres' activities is raising awareness of TB. Right – a TB leaflet with a picture of someone coughing and information about TB. Left - an awareness day at Harkesh Nagar. Because the people in this area are extremely poor they don't have access to television very often so showing a video ensures they get very high attendance! Its also vital as not everyone would be able to read leaflets



Plans for the future

The success of the existing centres, means that in the near future they are hoping to expand and open a new centre in the area. In addition to this there are plans to convert a room in the Harkesh Nagar DOTS centre into their own laboratory. This will speed the diagnosis of the disease by enabling them to analyse sputum samples themselves to detect the presence of tuberculosis instead of relying on the use of the laboratory department in the Nehrunagar Chest Clinic.

*What is DOTS?

There are a number of components to a full DOTS programme, including political commitment, diagnosis by microscopy, complete availability of good quality drugs, free to the patient, and systematic monitoring and accountability. All of these can be put in place but unless treatment is made convenient for patients, it will fail. This is why the heart of the DOTS programme is 'directly observed treatment' (DOT) in which a health worker, or another trained person who is not a family member, watches as the patient swallows the anti-TB medicines in their presence.

Two go to Delhi - a visit to VHAD

We are 5th year medical students at Guy's King's and St Thomas' Medical School and for our elective we chose to go to India because the country is such a diverse nation with a great contrast between the rich and poor, urban and rural communities. Having heard of TB Alert's work in India we arranged to spend a few days with the staff of the Voluntary Health Association of Delhi DOTS centres.

We took the opportunity of coming into contact with a number of tuberculosis patients to conduct some research into the relationship between smoking and the severity and the type of tuberculosis. Over the past few years there has been emerging evidence that smoking is associated with an increased incidence of pulmonary tuberculosis and taking into account age, ethnicity and sex it has been illustrated that patients with tuberculosis are 2.3 times more likely to have a 30 year history of heavy smoking than patients without tuberculosis. All evidence obtained to date suggests that the inhalation of biologically active substances, especially nicotine, in cigarette smoke prevents the body's immune system from suppressing the disease.



This photograph shows water logged areas in front of the Mithapur DOTS Centre.

Whilst we were there Sukhwinder Walia, healthcare worker at the Ali Ext DOTS centre kindly took us into the village of Badarpur, South Delhi to visit some patients in their homes. It is routine for these workers to spend some of their time following up non- attendees to preventing them from defaulting from the programme. The fact that these villages welcomed her into their homes was testament to how much these health workers are valued within the community in which they work. We were shocked by the conditions we saw. The area was very overcrowded, with poor housing and sanitation, piles of rubbish lined the street, drains were overflowing and because we visited during the monsoon season there was also plenty of flooding.

We would like to take this opportunity to thank the patients and staff for making our time at the centres so enjoyable and for aiding us in our research and we wish them every success in their continuing work.

Nicola Tregay and Nicola Cullum

TB and Smoking in India

Research indicates that about half of male tuberculosis deaths in India are due to smoking, with the mortality rate from TB about four times as great among Indian smokers as among their non-smoking countrymen. In one study, authors concluded that three-quarters of the smokers who became ill with TB would not have done so if they had not smoked.

"Almost 200,000 people a year in India die from TB because they smoked, and half of the smokers killed by TB are still only in their 30s, 40s or early 50s when they die,"

Dr. Vendhan Gajalakshmi, lead researcher with the Epidemiological Research Center in Chennai, India.

The study compared the smoking habits of 43,000 men who died of various diseases in the late 1990s in Tamil Nadu, southern India, with the habits of 35,000 men still living in the region. Results were similar in men who smoked cigarettes as in those who smoked "bidis," local cigarettes made from rolling tobacco in the leaf of another plant.

The full study, "Smoking and Mortality from Tuberculosis and Other Diseases in India: Retrospective Study of 43,000 Adult Male Deaths and 35,000 Controls," appears in the Aug. 16 issue of the Lancet (2003;362(9383):507-515).

A cup of Chai?

Swapping the windswept greyness of north central London for the humidity, dirt and smells of Kolkata may not be everybody's cup of chai, but this is what I decided to do last year.



The importance of a cup of chai, in a society where the stigma attached to TB can have enormous implications for young women, should not be underestimated. A serving of sweet, sticky brown chai in Calcutta Rescue's DOTS clinics allowed patients time to chat, share stories and support each other through treatment.

Underneath this colourful daytime chatter I was told stories, of how mother in laws refused to give them money to come to clinic, maids who had lied to their employers and worries over future marriage prospects.

The case of one teenage girl and her sandesh (Indian sweet) and the subsequent refusal of a piece by a DOTS worker highlights the deep rooted stigma attached to TB. The girl immediately associated the refusal of her sandesh as a rejection of her, because she had TB. I explained that this wasn't the case and that the DOTS worker was very busy. Unconvinced she offered me a piece, which I accepted and ate, as DOT for stigma.

Like TB, stigma crosses caste and class boundaries, TB is curable but tackling society's stigma is more difficult, however an impartial cup of chai on all occasions did facilitate conversation.

Rebecca Welfare, TB nurse specialist

About her experience, Rebecca told us.....

"Kolkata was the dirtiest, most humid, and noise polluted city I had ever been to and the poverty was in your face, it was overwhelming. In my first 2 weeks I wondered if I could stick 9 months. But then its cultured down to earth atmosphere and the friendliness of the Bengalis, not to mention the sweets, won me over! Although I was there to share my experience I also received valuable lessons from my colleagues, something they found hard to believe. They don't have all the answers neither do we but by sharing knowledge we can strive towards tackling the global burden of TB."

Calcutta Rescue needs qualified volunteers. To find out more go to www.calcuttarescue.com.

Myths and misconceptions

There are a lot of misunderstandings surrounding TB and its treatment. In Zambia some people believe that people die when they go on TB treatment, so they don't come forward for treatment. In some ways this is a self-fulfilling prophecy - because if people only start TB treatment when they are in the advanced stages of the disease and have given up on any other options, it is often too late to save them.

Because more people living with HIV in Zambia die of TB than any other cause many people think that having TB automatically means you are HIV positive. Knowing there is no cure for HIV they don't bother to seek treatment for their TB.

Perhaps the most dangerous misconceptions is the myth that sex with a child can cure AIDS.



Some people also believe TB treatment has side effects like change in skin colour and hair texture, and so everyone will know that one is on TB treatment - and they fear that they will be discriminated against.



New TB Alert Southern Africa Representative Winstone Zulu is determined to fight the stigma and discrimination against TB and HIV patients AND raise awareness and understanding of the two diseases to bust those dangerous and unhelpful myths.

We hope to bring you more news of Winstone's activities next time, which will include a campaign focused around football to try and reach young men and women who wouldn't normally see health messages.



When you need a little help..

The Hardship Fund is there to help when patients can't access benefits or are on a low income, making the extra cost of prescriptions and travel to clinic a real burden. It can also help health professionals in raising awareness about TB or to provide incentives (such as a hot meal) for patients likely to default on treatment.

We've received some very rewarding feedback - here are two examples of feedback from TB Nurses:

The Green* Family, received help with prescription pre-payment certificates and transport costs to get to the clinic once a month for six months.

"The grant made a tremendous difference to the family. Although all three were employed they have very low paid jobs and were unable to continue with overtime which they did when well. Sick pay did not cover their general living expenses. They would have found the extra burden of finding money to cover the cost of three lots of prescription charges too great (especially when drugs needed to be changed due to reactions etc) and therefore would probably not have been compliant with treatment. All were extremely infectious and the consequence of non-compliance would have been dreadful. Two of the family work in factories employing over 240 people and they both have a substantial amount of close contact with their co-workers. The other worked at two nursing homes and often did agency work as a care assistant. The consequences of any one or all of them being non-compliant would have been an infectious time bomb waiting to happen"

The Brown family*, were awarded £180 to help with their transport costs.

"Thanks so much for helping this family. Mum had TB, and two of the children had been infected (although luckily they were diagnosed before they became ill). Because dad had to give up his part time job to look after the family while mum was in hospital, there was a very small budget and the additional costs of transport would have meant that this family would have gone short of food in order to maintain both the visits to mum in hospital and making sure that the two children got to the clinic for their treatment. At a time of serious stress this was the very last thing Mr Brown* needed.

Mum is home now, continuing on treatment and well. The children have completed preventive treatment of three months and dad has found another job.

There was a bonus for me too – the ability to give practical help at such a time strengthened the relationship with the family and has made my job easier! They were immensely grateful. Mum was in hospital for around six weeks so it was really important that her children were able to see her regularly."

** patients' names have been changed for privacy*

TB Alert would like to thank diagnostics company *Oxford Immunotec* for their continued support of the fund.

Information for TB nurses and health professionals ...

New BCG Leaflet

TB Alert has now published a new leaflet "Tuberculosis and the BCG Vaccination" in which we answer many of the questions we have received over the past few months since the schools BCG programme ended. Topics covered by the leaflet are;

- About the BCG vaccine
- Who needs to have BCG?
- But I want BCG, so can I still get it?
- BCG for Travel
- What is TB?
- How is it caught?
- I didn't have BCG when I was younger - should I have one now that TB is on the increase in the UK?
- How is a BCG vaccination done?
- What happens after the BCG injection?

The full text is available to view on our website at www.tbalert.org/resources/clinical.php.

To order copies of the leaflet (£12.50 per 100 plus postage), single copies at no charge, please contact Tina on 0845 456 0995 or email awareness@tbalert.org

Mantoux Training

If you're a health professional working with TB, you'll probably have had your Mantoux training by now but, since nothing was available at the time of going to press for our last newsletter, we thought we'd pop in a quick note about the materials available from the Department of Health (DH) and Health Protection Agency (HPA).

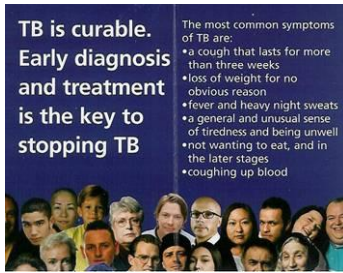
The DH has developed a flip chart, ruler and training DVD for Mantoux. To order these materials, call the DH publications order line on 08701 555 455 and ask for item numbers 269370, 270227 for the flip chart and DVD respectively. The ruler reference is simply tuberculin skin test ruler. The flip chart can also be accessed on the website at:

<http://www.immunisation.nhs.uk/files/mantouxtest.pdf>

The HPA National Knowledge Service (see page 6) has also developed a Mantoux training video which they are hoping to make available shortly on their website <http://www.hpa.org.uk/tbknowledge/default.htm>

World TB Day Materials

TB Alert is working with the Department of Health again this year to devise materials for World Stop Day on 24th March. The leaflet and poster will be re-launched with the message "TB is curable" and the pocket card will still be available to order. TB Alert also has balloons and pens available. There are almost 300 events taking place across the country, varying from stands in supermarkets, shopping centres and hospitals, to study days, pharmacy and local GP practice campaigns.



NICE Guidelines for TB

The National Institute for Health and Clinical Excellence (NICE) is to release the National clinical guideline for diagnosis, management, prevention, and control of Tuberculosis on March 22nd. Implementation guidance will also be published, which aims to provide practical advice to help NHS organisations implement the guidance. The advice will help implementers identify recommendations in the guideline that are not part of current practice and should be used alongside the costing report and template.

For further information, go to www.nice.org.uk

HPA National Knowledge Service TB Pilot

The National Knowledge Service (NKS) TB Pilot began in April 2005 and aims to bring together sources of information and knowledge on tuberculosis for healthcare professionals and patients. This will enable both professionals and patients to base their decisions on best current knowledge.

In addition to developing information or resources relevant to NICE guidelines on TB, the pilot is looking to identify gaps in knowledge and high risk areas. NKS for TB aims to raise awareness by working with charities and voluntary organisations already involved in supporting the patient and public e.g. Homeless Link and TB Alert.

Initiatives will include information resources for managers and staff of hostels for homeless people; information about Pregnancy and TB for doctors, midwives and patients; and information for parents, schools and others dealing with TB in children and school settings.

The project is working to have a website live by the end of March

<http://www.hpa.org.uk/tbknowledge/default.htm>

The Tuberculosis Survival Handbook (2nd Edition)

The highly acclaimed *The Tuberculosis Survival Handbook* has been completely re-worked and updated, and includes a new chapter called "A Clinician's Perspective" by Dr. Marcos Espinal of the Stop TB Partnership. There is also a new chapter on the growing patient movement. The book also includes handy advice for patients, or what Paul calls "TB-Tips". Another new addition to the book is a TB Treatment chart as an aid to adherence. The book is primarily aimed at patients, but health care workers will find this book equally useful too. Indeed, it offers some interesting insights from the patient perspective of TB care today.

"Paul Mayho's excellent book goes a long way to make the patient voice louder. As Paul says, "the TB treatment journey is a long one and it is not only about taking pills... Paul has important things to say, some of these things are captured eloquently in this, the second-edition of *The Tuberculosis Survival Handbook*."

Dr Richard Coker

Paul is giving 10% of his royalty to *TB Alert*. You can pre-order your copy now for £14.95 from www.amazon.co.uk or from the publishers Merit Publishing International, email: merituk@aol.com.

The Tuberculosis Survival Project

Two of the contributors to Paul's book suggested that the next natural stage of his project could be to collect the stories of other people's experience of TB/MDR-TB and this is what he now plans to do, as *The Tuberculosis Survival Project*.

"Tuberculosis and writing are historically connected; Keats, the Bronte sisters, George Orwell, Katherine Mansfield were all what was termed then 'consumptives'. Their own personal struggle with tuberculosis is well documented and reflected in their work....Having TB/MDR-TB can be very lonely and there are many stories to be told. I want to address stigma around the disease and get people talking openly about it. This is the patient-centred approach that I feel is missing at this point in time."

Paul Mayho

Paul will create a website where people can post their stories of having tuberculosis. He also intends to collect the stories of those in the most resource-limited countries of the world by other means as not everyone has access to the Internet. The culmination of the project will be a book called "*Tuberculosis in the 21st Century – A People's Diary*".

The project and website will be launched World TB Day 2006.

Questions, questions....

The newsletter item most commented on as the readers favourite in our questionnaire last time was our Questions page. We aim to please so will try to make it a regular feature. But of course to do that we need your questions so keep them coming!

I had a chest x-ray which showed that I have calcified nodules called granulomas on two of my lung lobes. My GP told me that I had a past TB infection, also I had a Heaf test done last year, it was a positive result even though I have never had a BCG vaccination. Can the disease reactivate?

You don't say whether you have received treatment previously for tuberculosis but I am assuming from the rest of the information you gave that you have not. If that is the case, the granuloma would be indicative of latent TB infection which would also give a positive reaction to a skin test. When a person breathes in the TB bacteria exhaled by an infectious person, one of three things can happen;

- their immune system fights the bacteria and no infection happens (approximately 60% of people).
- their immune system is not strong enough to fight the bacteria and they develop active TB (approx 10% of people). In adults this would be a post-primary infection and would usually develop within a few weeks.
- their immune system fights the bacteria but doesn't entirely kill them of and they remain dormant in the person (approx 30% of people), possibly to reactivate later on. This is called latent TB infection and around 10% of people with latent TB go on to develop active TB, although this could occur years, even decades later. When a person develops active TB after having latent TB it is called secondary infection. Relapse into active disease in a fit adult is very unlikely.

Even if a person has had active TB in the past, it is possible that it can re-occur, either due to ineffective or incomplete treatment or because a new infection has been contracted.

My cat has been diagnosed with Bovine TB and is now on treatment. Our children love playing with our moggie and I am worried that they are risk.

Bovine TB comes from cows but it can be passed to other animals and humans. However once on treatment animals (and humans) quickly become non-infectious and no longer pose a risk.

Normally your vet would contact the local TB nurse and ensure that humans in contact with animals with Bovine TB are tested just to be on the safe side, but it is likely that any risk there was occurred before the diagnosis.



I like a drink - can heavy drinking stop my TB medication working?

Heavy drinking does not stop the medication working, however, some of the medication can affect normal liver function so it is not advisable to drink heavily while taking the medication.



TB in the workplace

We've received several calls from employers and managers over the past few months, asking for advice regarding handling the news that an employee has been diagnosed with TB. The main concerns have been how to reduce risk to and reassure other employees. Here are some examples of the types of questions we've received and the answers given;

Who should I contact regarding having my other employees tested?

Firstly, do you know whether the person has infectious TB? Only TB of the lungs or throat can be infectious and then not always. It also depends on the working environment, usually close contact for several hours is required with an infectious person to be at risk of catching TB. TB is a disease which must be notified to the health authorities and there are protocols for health professionals to follow. If the person with TB is infectious, their medical team will talk with them to establish who they have been in prolonged contact with. The medical team will then set in place procedures for contacting those deemed to be at possible risk, usually close family and friends, more unusually close work contacts. If the team do not contact any of your employees, this means they are not thought to have been at risk of infection.

Should we have things sterilised?

No, TB is an airborne infection and can only be caught by breathing in bacteria coughed or sneezed out into the air. TB cannot be caught from cups, toilets or any other object.

How long should the employee affected stay off work?

In most cases, if they were infectious, once under treatment, people are no longer infectious within two weeks. In some cases, if a person has had TB for a long time before being diagnosed, they may have become very ill and will need longer to recover from the effects of having the infection.

Making it possible ...

Lilly chooses TB Alert as 2006 Charity of the Year.

Throughout the course of 2006, employees at Lilly UK will be fundraising across to raise money for TB Alert. A full calendar of events is planned, from raffles to bike rides, from fetes to pantomimes. TB Alert are excited to have been chosen as Lilly's charity for 2006, and look forward to getting involved and supporting their employee fundraising efforts.

TB Alert and Lilly have got to know each other over several years - Lilly UK have sponsored a leaflet for patients about MDR-TB and were delighted to have been involved in the launch of Lilly's new Capreomycin plant at its factory in Speke, as we support any initiative which helps people in developing countries get better access to effective TB treatment.

Special thanks

We would need a whole extra newsletter to thank everyone who has supported TB Alert over the last 6 months, however special thanks must go to:

Dr Vanessa Graham, Dr Muriel Buxton-Thomas and all their friends and supporters who helped to raise over £13,000 plus gift aid for our project in Zimbabwe

David Crees and his friends from the Cheltenham motor club who raised over £400 in one evening for the children of Bwafwano

And Dr Noel Snell and Mrs Carol Horner who put on a fabulous charity dinner in Henley, hosted by Boris Johnson and with special guest Stella Vaughan. The dinner and accompanying Auction raised over £3,000.



A runner reports

"Thank you very much for the chance to run yesterday - it was hot out there but the atmosphere was fantastic and I thoroughly enjoyed myself. Given the amount of



wine I drank with the friends with whom I stayed the night before I was very pleased with my time of 1:46! I have raised about £550 via my justgiving website, and with another hundred or so in cash and cheques hope to take the final total through the £1000 mark. I really would like to express once more my gratitude to you for giving

me the chance to run in one of the world's great races and my thanks to you and all your workers for the great work you do." *Simon Quantrill*

Ready, get set....run!

TB Alert has 10 charity places in this year's Great North Run but if its anything like last year they will go quickly. We ask our runners to commit to raising at least £250, and in return you will receive a TB Alert running vest (as modelled by Simon above), and our two best fundraisers will receive a copy of 'The Great North Run; the first 25 years', a book which tells the story of the world's largest half-marathon, highlighting the history of the event along with recollections of individual participants from the first twenty-five years.

The Great North Run is on October 1st 2006 but you'll need to start training soon - call Melanie on 0845 223 5293 NOW!

Thanks for your feedback!

We appreciate the responses to our questionnaire in our last newsletter. To read a report on the responses go to: <http://www.tbalert.org/about/documents/newsletterquestionnaireresults.pdf> or phone Melanie on 0845 223 5293 for a copy. You will find that many of the requests have been incorporated into this edition of our newsletter.

One request we were happy to read was that people wanted to know how to donate!

- You can: go online to www.tbalert.org and click on Donate Now to donate by credit card
OR: Phone 0845 223 5293 to donate by telephone
OR: Send a cheque or caf cheque, payable to TB Alert to TB Alert FREEPOST LON12815, London, NW10 1YS. Don't forget to include a note telling us whether we can gift aid your donation.
OR: Give by standing order – phone Melanie on 0845 223 5293 for a form. **THANK YOU!**