Issue Number 13 Autumn 2005

ALERT!

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

Christmas Special!

This year get your Christmas shopping out of the way early - ***TB Alert*** can not only solve your Christmas card needs with our two colourful new cards "The Tree" and "Adoration of the Shepherds", but we have a great idea for gifts too!

Magazine subscriptions make a wonderful and thoughtful Christmas gift that lasts all year, and this year you can buy gift subscriptions (or perhaps even one for yourself!) at less than cover price AND at least £8 will come to ***TB Alert*** for every subscription! Over 400 titles are available – something to suit everyone you know.

For information on cards and magazine subscriptions see the enclosed flyers (call us if yours are missing) or go to our website www.tbalert.org.

The beaming smile says it all!

When I visited Queen Elizabeth Hospital in Malawi earlier this year, I was shocked. Staff were doing all they could to keep the ward clean but some of the plastic covered foam mattresses were ripped, and every time the little ones wet the bed it would soak in to the foam. You can imagine that in the heat of Malawi this got a little whiffy to say the least. Not to mention the hygiene issues!

TB Alert is already helping the hospital by providing nursing staff and diagnostic resources for their paediatric TB unit, and when we asked Dr Elizabeth Molyneux if there was anything else they needed, the answer was obvious – new mattresses please! That night I phoned my boss - we quickly agreed – Genus would help ***TB Alert*** kit out the ward with new mattresses.

When we saw this picture everyone at Genus was delighted to see that our donation had made such a noticeable difference to the children's quality of life in the hospital. That beaming smile says it all!

David Crees, Genus Pharmaceuticals

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All our contact details can also be found on our web site www.tbalert.org.

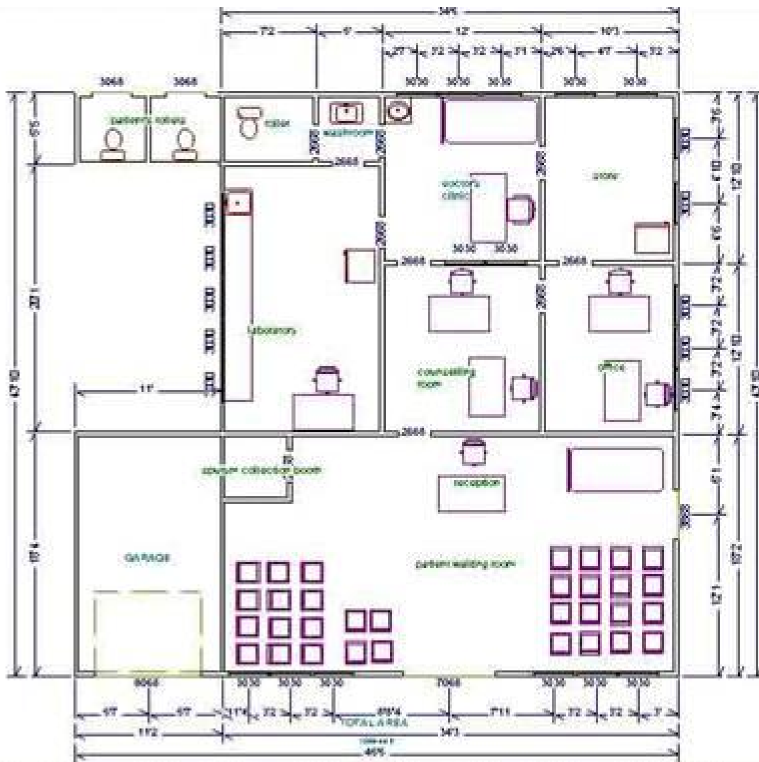
Charity Registration No: 1071886

Newsletter written and produced by Melanie Matthews with David Crees, Tina Harrison, Paul Sommerfeld, Dr Owain Tucker, Dr Noel Snell, Prof Peter Davies and Prof John Grange.

A new TB outpatients centre at Nav Jivan, India

In the last newsletter we reported that a "groundbreaking ceremony" had been held for a new TB outpatients centre at Nav Jivan hospital. The building is nearly finished and in this issue we wanted to tell you a little more about why we decided to fund this activity and show our readers more of the progress so far…

Above left and centre – These are two halves of the same room in the old outpatients department - currently there could be a patient with suspected TB visiting the doctor (picture on left) in the same room as the TB counselor (centre) is giving a talk to TB patients on treatment. In the waiting area (right) patients with infectious TB wait opposite mothers and children who do not have TB – not an ideal situation at all!



The new unit (plans left) will be solely for TB. It will have separate rooms for visiting the doctor, group counseling sessions and collecting sputum (coughing up sputum for a test can spread infection and is currently done in the doctor/counseling room).

Below - Mrs Kausalya Devi and Mr Jagmohan, two of the senior DOTS Providers from the project lay the first foundation stone.

Latest news

The outpatients centre's main construction is now complete, and work has started on the interior. However there have been some unavoidable delays. Firstly Dr Jeevan Kuruvilla, who was leading the project was seconded in January to Tsunami affected areas of the Andeman and Nicobar islands. This delayed progress while Dr Augustin Sander took over from him and got up to speed. Then the government elections in February slowed things down further, and finally, because the clinic and hospital are in such a remote area, they have found it difficult to recruit technically qualified people for the electrical and plumbing work. However things are now moving on, and we really hope to be able to show you the opening day celebration in our next issue. Watch this space!

A Motorcycle for Mzimba

A new project in Mzimba district, Malawi got underway this June with the presentation of a motorbike to the DHMT (District Health Management Team) at Mzimba district hospital. The motorbike will be used by the project co-ordinator – the best way to travel around the rural, unpaved roads of the Mzimba district.

Mzimba – approx location. Map courtesy of the University of Texas Library

The project will check household contacts of TB patients (*Active Case Finding*) to find out if they have been infected with TB. Studies in Malawi have shown that there is a much higher incidence of TB among household contacts of TB patients than the rest of the population. Most at risk are children under 5, and people who are HIV positive. Despite this evidence, at the moment new cases are generally found through *Passive Case Finding*, i.e. the hospital requesting that household contacts make their own way to the hospital for screening procedures.

Our project aims to show that by testing the contacts of TB patients, significant numbers of lives can be saved, by picking up cases of TB earlier and preventing unnecessary transmission of the disease (one infectious patient can spread the disease to 10-15 others each year) and it can be cost-effective too. The project will ensure that:

- Any household contacts who have already developed TB symptoms are identified early and started on anti-TB treatment before they become very ill.
- Children who are well and under 6 years of age will be placed on preventive therapy to prevent the development of active TB.
- Finally if the index patient is HIV-positive, the whole family will be offered voluntary counselling and HIV testing (VCT), and preventive therapy will be given to those who are found to be HIV-positive to prevent them becoming ill with TB.

The project will be a three-way partnership between ***TB Alert***, Towvirane Community Based Organisation (who will provide volunteers to undertake the home visits), and the DHMT, and we hope it serve as a model for other districts and CBOs in Malawi, eventually becoming a routine part of the National TB Programme. The motorbike has been provided with a grant from the Cotton Trust and we hope that very soon we can provide the rest of the funds needed to get this important activity underway.

TB and HIV in Malawi – a dual epidemic

According to the 2003 HIV Surveillance report it is estimated that nearly 1 million people of a population of 11.5 million in Malawi are living with HIV/AIDS. As many as 85,000 people die of AIDS related conditions each year. TB is endemic, closely linked with HIV infection, and is one of the most common HIV-related opportunistic infections and a major cause of mortality in people living with HIV and AIDS. It has also been demonstrated that one in every three TB patients is HIV infected. Over the past 20 years there has been a 500% increase in TB case notifications from 5000 per annum in the mid-1980s to over 25,000 per annum in 2003. 77% of TB patients are HIV-positive.

Raising Awareness of TB on World Stop TB Day

Krishna Project – India

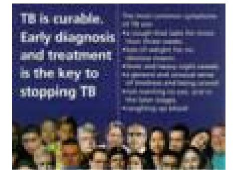
Staff and volunteers from our joint project with Lepra, based in Krishna district of Andhra Pradesh went all out for a major awareness raising drive this world TB day 24th March this year.

Posters were designed for the general public (see above – although black and white doesn't do it justice), which described the symptoms of TB and what to do if you have them; and posters for TB clinics aimed at TB patients told them of the importance of continuing their treatment, and how to prevent transmission of TB until they are no longer infectious.

100,000 leaflets were distributed in the area (along the same lines as the poster, but also listing all the TB diagnostic centres in the area) and quizzes, exhibitions at primary health care clinics and other events made for a very busy but successful day.

UK Activities

Meanwhile… this year ***TB Alert*** and the Department of Health put together the biggest ever awareness raising drive for TB so far in the UK.



Newly developed materials included the poster, leaflet and credit card-sized info card shown here, plus a TB fact sheet aimed at non-specialist health professionals. Hundreds of thousands of leaflets were distributed via high street pharmacies and GP surgeries. We now receive up to 30 calls a week from people who have seen these materials and want to know more. *Check out our questions page for some of the most common questions*.

At the same time, TB nurses all over the UK held open days, and put up stands in hospital foyers to spread the message about TB. Lambeth Community TB team held a very successful conference to increase understanding of TB within other staff in their primary care trust who work with people at risk of TB such as homeless people, refugees and drug or alcohol users.

New UK Activities underway

This year ***TB Alert*** received its first grant from the Department of Health's Section 64 (Section 64 is funding provided specifically to NGOs for activities complementing the work of the Department). The funding has allowed us to employ our second full-time UK employee, Tina Harrison. Tina joined us at the end of May as our TB Awareness Officer.

Tina will spend the next three years developing new ways to raise awareness of TB throughout the UK using the materials shown above and developing new ones, working closely with the Department of Health and other relevant government department staff.

As well as continuing to improve awareness among the general public, she will be building partnerships with voluntary and community groups working with people from countries which have high rates of TB, people living with HIV, people who are homeless or who have drug and alcohol problems to find new ways of raising awareness of TB amongst those who are most at risk What is most important is that people and their doctors recognise the symptoms of TB and know what to do if they think they might have come into contact with it.

Our work continues …

When times are hard…

Supported by diagnostics company, Oxford Immunotec, ***TB Alert***'s UK Hardship Fund continues to make small but really important grants to patients and TB services. We thought you'd like to hear more about where the money goes…

The example below, written by a TB Nurse Specialist, illustrates what a broad range of activities we're funding and how they help both the patient and others:

> "B (the patient) is an inspiration. Coming from Uganda around 18 months ago, she became ill with TB. B encountered many problems on arrival to the UK, economic, social, physical and pyschological. When I first saw her she was in considerable distress and suffering and took some time to come to terms with her TB diagnosis.
>
> Nevertheless B faced all her problems head on and with some support has 'come through' to the point that she is coping well with every day living and has attended the local college to improve her language skills. B's TB treatment is ongoing, as it is intended to last a full 12 months.
>
> She now wishes to undertake a counselling course because she feels that she can help other TB patients who have experienced similar problems to herself. I think that this is truly marvellous and would like to see if there is a way of helping her to meet the cost of her counselling course. I really think that what she will give back will far outweigh the small amount that she needs to get going."

B's grant was approved, she begins her course in September and we wish her every success.

Why patients default

When a patient is being treated for TB it is vital that they complete their treatment, which can take 6 or 8 months. If they don't carry on taking their medication the TB can return in a drug resistant form (MDR-TB) – difficult and complicated to treat in the UK, but practically a guaranteed death sentence in poor countries where the treatment is prohibitively expensive.

Yet in poor countries there may be many more reasons why patients end up not completing their treatment. When Emmanuel Manomano (the TB Clerk appointed by ***TB Alert*** working at Murambinda Mission Hospital in Buhera District, Zimbabwe) did an analysis of the patients who did default from their treatment he found there were several reasons why this happened.

- Lack of transport to and from hospital. The government supplies bus warrants, but then they don't pay the bus companies – so most bus companies ask for cash to meet immediate costs like fuel and spare parts.
- If the patient gets adverse drug reactions they may think the drugs aren't working and stop taking them.
- Sometimes local clinics run out of drugs – they tell the patients to come to Murambinda Hospital to get more but without transport they don't always come.
- TB patients lose their appetite – once on drugs they regain it. But if there is no food available they sometimes stop taking the tablets to stop feeling so hungry.
- Feeling better within a few months means patients think they are cured and stop treatment. Once they are better, family breadwinners might leave home to go to the nearest towns looking for work.
- Treatment is free but patients have to pay for x-rays - (fifty thousand dollars [yes thousand] or about £1.20). Some don't turn up because they can't afford it.

Right - Emmanuel with Dr Jack Barker earlier this year – Dr Barker was visiting on behalf of ***TB Alert*** to monitor progress of the project.

Emmanuel told us about one of the patients he visited:

> Jonah had TB but he hadn't been to the clinic for check-ups and to get his tablets for the last three months. The day I visited, he was herding cattle and it took me a while to find him. I asked him why he had stopped coming for his medicine. He told me:
>
> "Before I was diagnosed with TB I was very scared due to chest pain, having sleepless nights, shortness of breath, losing weight and loss of appetite, thinking that I was about to die. But the treatment and special care I was given from hospital staff made me feel much better. When they discharged me they referred me to a local clinic to get more drugs but they ran out and told me to go back to the hospital each month. It is too far to walk [24km each way] and I couldn't afford the bus fare. The thing is I feel fine now and I have to work to make some money, and so I don't need to come back for tablets. I have been taking them for so long I am sure that the TB is gone because I don't feel it at all."
>
> I explained to Jonah that even though he felt better, the TB was still there and could come back stronger if he didn't keep taking the medicine, and he agreed to come back if we gave him a transport allowance each time he came.

What to do about it?

TB Alert aims to increase our support over the next three years to help Emmanuel reduce the numbers of defaulters – he told us that he plans to:

- Have three days a month set aside to follow up patients who have defaulted treatment
- Strengthen health education to patients when commencing treatment and issuing of TB pamphlets.
- Provide free investigations (eg x-rays) to patients after diagnosis.
- Supply TB drugs and bus warrants to peripheral clinics on the monthly follow-up of defaulters.
- Check whether patients we transferred have been registered and if DOTS is being adhered to in clinics.
- Supply food and money for transport to patients on review dates to encourage their attendance to hospital.

Government BCG changes

On 6th July, the Government announced changes to the BCG programme, effective from September. ***TB Alert*** issued a joint press release with the British Thoracic Society and British Lung Foundation which outlined our position as broadly supportive of the government's decision to stop the universal BCG school vaccination programme and concentrate resources where they are most needed, i.e. in high TB incidence areas and at risk groups (see our website, **www.tbalert.org** for a full copy of the press release).

HOWEVER, we do feel that there are a range of issues still to be addressed, such as …
"Will the resources currently used for the universal BCG programme be fully diverted to other TB control measures, like funding more TB nurse posts?,"
"What about children who fall through the gap?"
"Will there be easier access to BCG for healthcare workers, travelers to high-incidence countries and others at risk?".

Operational guidance was released on 18th August which puts the onus on each PCT to develop a locally appropriate policy, meaning the answers to these questions may vary across the country, however we will continue to keep our ears and eyes open and let you know when we find out more.

Do you know a patient who needs our help?

We're continuing to receive an increasing amount of applications to our Small Grants and Hardship Fund to help with a variety of issues, from funding prescription pre-payment certificates and travel costs to appointments, to helping Tower Hamlets TB Service to buy a map of London postcodes to enable them to see where their increasing number of patients from out of the area are based. *See page 5 - patient B's story*.

Applications must come from a healthcare worker. If you know a patient who you feel would be eligible for a grant, please contact Tina - awareness@tbalert.org or 0845 456 0995 for details and an application form.

TB Alert is very grateful to ***Oxford Immunotec*** for supporting this very important fund.

Leaflets, posters…

The leaflet, factsheet, poster and info card which we developed jointly with the Department of Health for World Stop TB day (see page 4) has just been re-launched to take into account the changes to the BCG vaccination. Translated versions of the leaflet are available in 20 languages to download from the ***TB Alert*** website or from www.immunisation.nhs.uk . The materials should have been re-circulated to everyone who received them in March so please let us know if you haven't received them by calling Tina on 0845 456 0995, email awareness@tbalert.org.

We are in the process of arranging for the ***TB Alert*** patient information leaflets to be translated into different languages and hope to make these available to download on our website before the end of this year. Thanks for bearing with us!

Treatment Packs

Sponsored by ***Genus Pharmaceuticals***, the treatment pack, developed to assist healthcare professionals in prescribing TB medication, is a rather slick looking briefcase. It contains a *Dosage Reference Guide* which gives correct dosages of Ethambutol and Rifater (1st phase) and Rifinah (2nd phase) based on the patient's body weight. The case is then divided into colour coded sections for body weight, from which a *Patient Card* is selected. The card shows the patient what each of their tablets looks like and also helps them to track when they have taken their medication through ticking off each day in a little diary. In the back of the briefcase are *Translation Stickers* which translate the instructions on the patient card, and are available in 20 ethnic languages used in the UK.

Also in the back of the Treatment pack there is a set of Treatment Diaries …..

Treatment Diaries

The treatment diary also helps the patient to recognise and remember when to take their medication, but is designed for patients on other combinations of drugs. The nurse selects the correct drug stickers (Rifater, Rifinah 300/150, Pyrazinamide, Ethambutol 400/100, Pyridoxine, Isoniazid, Rifampicin 300/100 and sticks them on the diary in the relevant quantities. All other information (including translation stickers) is the same.

To order a full Treatment Pack briefcase, contact Kelly or Jo at Genus Pharmaceuticals on 01635 568400. The pack contains some treatment diaries but if you JUST need diaries, call Angela on 020 8998 1949 or email plbm@compuserve.com. What's more the Treatment Pack and Treatment Diaries are FREE! What are you waiting for?

Questions, questions….

Since circulating TB awareness information throughout the country we have been asked many questions about TB by patients and healthcare workers. We hope that our readers will find the small selection printed here interesting and useful. Do keep them coming!

What is "Atypical TB"?

Firstly, the term 'Atypical TB' is a misnomer, and the more correct term is ***Environmental Mycobacteria***. As suggested by the name, these bacteria are common in the environment - we all consume them in food and drink and it remains a mystery why a very small minority of people develop disease (it is more likely to affect children under the age of 6, or those who are immunocompromised). Disease due to environmental mycobacteria is not infectious, and people with disease pose no risk to others.

My wife conceived our baby while she was on TB treatment. Is the baby at risk?

Standard drugs (Rifampicin, Ethambutol, Isoniazid, Pyrazinamide all cross the placenta, but have not been associated with harmful fetal effects. Pyrazinamide, Streptomycin and similar drugs (Kanamycin, Tobramycin), Prothionamide and Ethionamide are not recommended.

Congenital TB (crossing the placenta) is possible but it is extremely rare. It could only occur if the mother had bacteraemia (TB bacteria in the blood), which would only occur in the acute phase of a primary infection or if she had disseminated (miliary) infection AND if it was then untreated. If the mother (and hence foetus) were receiving anti-TB therapy then the risk of congenital disease is negligible.

Breastfeeding while on treatment is safe, but Pyridoxine supplements for the child may be indicated as rare seizures have occurred, probably due to induced Pyridoxine deficiency caused by Isoniazid.

If TB is only diagnosed after the birth, the baby should be kept apart from the mother until she is assessed as non-contagious, or until the baby has been vaccinated against TB.

Can mycobacteria tuberculosis survive in the air? For how long? Can the bacteria survive in soil?

Basically, the tuberculosis bacteria can survive for quite long periods if kept away from ultra-violet light, to which they are sensitive. Thus they can persist in the air of dark rooms etc. Particles landing in soil etc do not constitute an infection risk. To the best of our knowledge, tuberculosis bacilli do not replicate outside the laboratory in natural conditions (i.e. except in specific laboratory culture situations).

What is the risk of TB being passed on to a doctor? Is the risk greater for surgeons, pathologists and pulmonologists?

There is evidence that health care staff are significantly more likely to be infected by the tubercle bacillus and to develop active TB than the general public. The actual risk depends on the incidence of TB in the community and the precise nature of the work of the carer. Pulmonologists are obviously at risk, but the greatest risk is found among pathologists, especially those performing post-mortem examinations.

Historically, pathologists and anatomists were at risk from developing skin tuberculosis following cuts and abrasions acquired during their work - a condition termed prosector's wart. The famous physician Rene Laenecc, the inventor of the stethoscope, developed such a lesion on his left forefinger following an injury acquired while sawing through a spine of a patient who had died of spinal tuberculosis. Pathologists also acquire pulmonary tuberculosis by inhaling tubercle bacilli liberated from infected material while undertaking various examinations, notably while performing autopsies.

A particular problem is that tuberculosis may not be diagnosed while the patient is alive, so the pathologist is unwittingly exposed to the risk of infection. In one bizarre incident, a trainee pathologist was performing a necropsy as part of her examination for Fellowship of the Royal College of Pathologists. She diagnosed disseminated tuberculosis, but the diagnosis was disseminated cancer so she failed the examination. Some months later, the pathologist developed tuberculosis and on re-investigation of the examination material her diagnosis proved to be correct!

For more information about the risk of tuberculosis among pathologists and other laboratory workers, read: *Collins CH, Grange JM. Laboratory- and autopsy-acquired tuberculosis. Communicable Disease and Public Health 1999; 3: 161-167.* This paper also gives information on precautions against infection among laboratory staff, statutory and non-statutory requirements and references to published work. Guidelines on precautions against infection of staff in clinical settings are available from the Centres of Disease Control, Atlanta, USA.

Incidentally, health care professionals other than medical staff are also at increased risk. In a study in the USA, nursing home employees had three times the rate of tuberculosis than other employed adults matched for age, race, and sex.

I had a Heaf test to test for TB and the result was Grade 1. What does this mean? Am I infectious? I am concerned because I'm going to be working with chimpanzees – could they catch TB from me?

Chimpanzees can catch TB from humans – in fact they are susceptible to many of the infections humans get. So if someone had sputum positive (infectious) pulmonary (lung) TB they should not work with chimps (or people!) until they had been on TB treatment for several weeks and been tested as no longer infectious.

Grade 1 is ***negative*** meaning that you do not have TB. If it had been *positive* this might have indicated Latent TB (which is not infectious but can turn into active TB if the immune system is compromised – and this would probably warrant preventative treatment just to be sure in a case like yours). The common symptoms which would indicate active (and possibly infectious) TB disease are a cough, loss of weight, fever and night sweats. If you are working in a country where TB is common, you and your colleagues should watch out for these symptoms and consult a doctor immediately.

Thanks to all for a great year with Bart's Choir.

Our stint as Bart's Choir Charity of the Year was a great success, and over the year we raised a grand total of £14,460 from collections at the three concerts, advertising in programmes, company sponsorship, money from ticket sales, and from a collection held at Trafalgar Square where choir members sang carols under the Christmas Tree in the Square.

We'd like to say a special thank you to Vitabiotics, Genus Pharmaceuticals and Cotto Restaurant who sponsored the programmes, to Whitbread who sponsored the reception held at the Royal Albert Hall concert, and to Shell for sponsoring the concert at the Royal Festival Hall.

But of course thank you most of all to all the members of Bart's Choir, to all of you who came along to the concerts at St George's Cathedral, the Royal Albert Hall and the Royal Festival Hall, and to all of our volunteer collectors and other volunteers – we couldn't have done it without you!

Your charity needs you!

Calling occupants of Guildford, Henley, Marlow, Brighton and London! Your charity needs you! As well as our collection mentioned above in Trafalgar Square in December, our collectors will be out in:

Guildford - on November 5th
Henley - on a Saturday in early December (tbc)
Brighton - for a collecting pub crawl in late September
Marlow - collecting on Marlow Regatta week in May
London - for Bart's Choir singing Carols under the Trafalgar Square tree on December 22nd 6pm-7pm
London - outside the Royal Academy next summer

As always – we need more collectors to help out – the more people collecting the more money we make – as simple as that! If you can help, please call Melanie on 0845 223 5293.

Cheaper Phone Calls

You may have noticed that ***TB Alert*** numbers are 0845 numbers – meaning when you call us you pay the price of a local call only (and we pay nothing). You may NOT realise that unlike BT, our phone supplier does not charge for this service, AND all the calls we make raise a commission for ***TB Alert***. If you would like to take advantage of this and change to an ethical and environmetally concerned phone supplier call Melanie on 0845 223 5293 to find out more.

Marathon Girl!

Well done Sarah! Sarah Fawcus ran the London Marathon for ***TB Alert*** this April. Whilst training for the tremendous feat of running 26.2 miles (and doesn't she look fresh at the end?), Sarah managed to find time to raise over £1,000 in sponsorship.

TB Alert does not have any Golden Bonds (charity guaranteed places) in the London Marathon, and the organisers are not giving out any more – so we are really sorry that we cannot offer places to people wishing to run for us. BUT, like Sarah, you can of course enter the ballot for an individual place. Entry forms for the 2006 Marathon are available NOW from sports shops - check www.london-marathon.co.uk for your nearest stockist.

Our thanks in advance to ***TB Alert*** runners Deirdre O'Leary, Simon Quantrill, Andrew Leonard and Elspeth O'Neill, who have undertaken to run the Great North Run (a half marathon) on 18th September this year. We hope the training and the fundraising is going well and will report back on their progress in our next newsletter.

If you'd like a place for the 2006 Great North Run let us know – we DO have charity places available for this, the greatest half marathon in the UK.

LAST CALL FOR LADIES WHO LUNCH!
Don't forget that ladies AND gentlemen are welcome to join us on our sponsored walk with a difference on 18th September. **If you want to join us (or are planning to come but haven't let us know yet), please email Melanie on helping@tbalert.org or call 0845 223 5293.**

TB Alert Gala Fundraising Dinner

Trustees Dr Noel Snell and Mrs Carol Horner are organising a Gala Fundraising Dinner hosted by Boris Johnson MP at the Remenham Club, Henley-on-Thames on Friday November 25th 2005.
Champagne reception, Dinner, Auction of Promises and Raffle - Tickets £65 – all proceeds to ***TB Alert***
If you would like to attend please email Mrs Carol Horner: horner@lineone.net with your contact details and Carol will be delighted to send you an invitation.