

ALERT!

SPRING EDITION 2001

ALERT!

STOP TUBERCULOSIS WORLDWIDE



Dramatic rise in TB cases

The annual number of cases of TB in England and Wales continues to rise, according to a report, "Tuberculosis at the end of the 20th Century in England and Wales", produced on behalf of the Public Health Laboratory Service, Department of Health and British Thoracic Society Collaborative Group. It reports on the results of a national survey to obtain detailed information on the occurrence of TB and to identify recent trends in 1998.

The report showed a 21% rise in cases since 1988 and 11% since the survey of 1993. A startling increase, from 1988, of cases in London, of 71% was observed when other regions had shown little change in numbers. The report identified a small but important rise in the cases of patients co-infected with HIV, again, especially so in London. Young adults were identified as accounting for over one third of all cases. It also highlights recent UK entrants as having a higher incidence of TB; this was particularly true of those coming from areas of the world with a high prevalence of the disease.

The report concludes that TB prevention and control measures must be based on accurate and timely information, on the occurrence of the disease. There is no doubt that the annual occurrence of the disease in England and Wales continues to rise. This has spurred TB Alert into action, along with two other charities, RESULTS, and Ryder-Cheshire, in calling on the Government to **MAKE TB A NATIONAL PRIORITY NOW!**

We are asking them to make TB a priority in the national plan (necessary if funding is to be provided for Health Authorities to upgrade the TB infrastructure) to make tuberculosis drugs free for all who need them in the UK and to commit £15m a year to support the new global TB drugs fund. Look out for more details in the press soon!

CHSS & TB ALERT appealing to Scotland

As regular readers will know, TB Alert is the only charity in the UK dedicated to raising awareness and funds for projects in both the UK and developing countries. There is also an organisation in Scotland - CHSS (Chest Heart & Stroke Scotland) that originally concentrated on tuberculosis but as with many other charities, it changed its focus (and name) when it appeared that the threat of TB had subsided. It has, however, always continued to support TB projects

abroad, through IUATLD (The International Union Against Tuberculosis and Lung Disease).

In July 1999, the two organisations met to discuss ways in which we could raise funds in Scotland, a task facilitated by the fact that our President, Sir John Crofton, has been a member of the CHSS Council for many years. Arising from this meeting the Scottish Global TB Fund was set up. Since then the fund has raised over £28,000. From this, IUATLD will be given funding to translate publications into Russian for use on training courses in Mongolia and by physicians in Russia.

We are extremely grateful to colleagues in CHSS for their help and support and we are proud of the way TB Alert strives to work in partnership with other organisations with similar objectives - to fight the global threat of tuberculosis.

Great new partnership with Rotary

TB Alert is proud to have been approached by Rotary International Britain and Ireland (RIBI) whose next national President, David Liddiatt, and Chair of Community and Vocational Service, Don Carsley, want to make tuberculosis awareness the theme of their term of office, July 2001 to June 2002. A partnership is being forged so that Rotary clubs throughout the country will be active with TB Alert in working to increase public knowledge of the TB threat and to raise funds to support work both in Britain and abroad.

There will be a variety of events over the year but the greatest burst of activity will be in the first week of October 2001 when a joint Rotary/TB Alert leaflet will be actively promoted and handed out to the public by Rotary club activists across both Britain and Ireland. For Rotary, tuberculosis is an issue that is not just of major world importance but one which will engage the enthusiasm of their members because it requires action at home as well as abroad. We are very optimistic that our partnership will do much to increase public realisation of TB and also increase the regular donors supporting our new charity so that we will be able to support much more work in future. Watch future newsletters for information on particular events and activities between July this year and June next year.

Ryder Cheshire & TB Alert travelling fellow

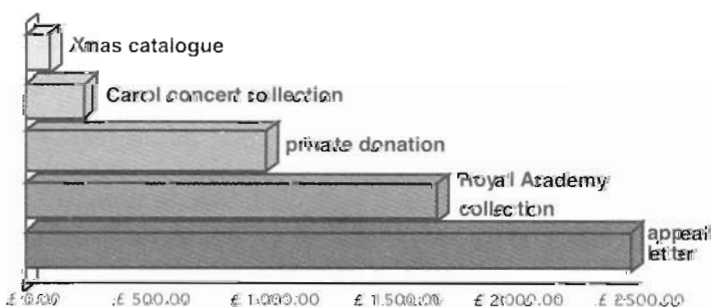
Ryder Cheshire is a UK based charity set up by Leonard Cheshire and Sue Ryder, at the time of their marriage, working overseas and with a strong interest in TB. Recent discussions on collaboration, with them, may mean more joint working in the future. Together with Ryder Cheshire, TB Alert are sharing the costs of bringing to Liverpool, Dr. Banavaliker, State TB Officer for Delhi. He was involved in identifying the five new TB clinics, to fill gaps in provision in Delhi, capital of the country most affected by TB and TB Alert has agreed, in principle, to support this project. We are also expecting VHAD's (Voluntary Health Association of Delhi) chair, Ali Baquer in London, in late April and we hope to bring you more about his visit in our next Newsletter.

Dr. Banavaliker will be attending a course to be run by TB Alert and the British Council. The course, on the clinical aspects of tuberculosis, is at the Liverpool Medical Institute from 22nd until 28th March 2001. TB Alert Secretary, Dr. Peter Davies, is the course director. To date there are 25 members enrolled from over 15 countries, as far afield as the USA, South Africa, India and Australia. Topics covered on the course will include historical aspects from fossils to present day, women's issues in TB, drug resistance, AIDS related disease and improved treatment methods.

Our first member of staff

We are very excited to be able to announce that TB Alert will soon have its first member of staff. Up until now, we have been privileged to have had Madeline Webster, seconded from IUATLD for two days a week (although Madeline has spent much more time than that) to help us out with fundraising. All other efforts have been from our wonderful volunteers. Now, Ryder Cheshire and TB Alert have joined forces to appoint a fundraiser working for two organisations but one important cause. More news on this soon, as we are in the process of appointing the fundraiser right now!

Xmas 2000 fundraising results



It's Snowing In My Bed



Many thanks to Hazel Elphick for her personal account of being a TB patient, 50 years ago.

Early in 1948, after a year at home, sleeping downstairs whilst awaiting a bed in a sanatorium, I was collected by ambulance (without springs) and taken to the Royal National Sanatorium in Bournemouth. There was another patient in the rusty, old vehicle, Bridie, who was to become a firm friend. Her sister, Ann, a nursing sister in Sutton Hospital, accompanied us to empty our sick bags and generally look after our welfare. Ann was persuaded to give up her job in Sutton in order to train in TB nursing. The reward was an earlier bed in the sanatorium for Bridie.

On arrival in Bournemouth, Bridie and I were put to bed in a 3-bed ward upstairs. The lift was ancient and had to be hand operated by one of the sisters and her staff. They pulled the massive wheel, like those found on board ship, by hand. Dora was already in the ward, having arrived earlier in the day. We were kept on strict bed rest for quite some time and this included periods during the day when we were allowed to converse, write letters or carry out any occupational therapy, which was usually embroidery. Once a week we were weighed and examined. Some people were given PAS (Para-amino-salicylic Acid), others gold. Minor surgery, such as AP (artificial pneumo-thorax) was carried out at Bournemouth but major work (e.g. thoracoplasty, like Bridie's stage 3 or phrenic crushes) was performed in a sanatorium on the Isle of Wight at Ventnor.

Many of us were very thin and no longer menstruated but the food was filling, although unimaginative, as rationing still prevailed. I must say that I am not that mad about mince to this day. Food such as bananas, grapefruit and other exotic fruit from abroad, was hardly ever seen. My parents occasionally sent me a food parcel containing fruit and chocolate (the latter still rationed). Their local tradesmen saved these luxuries for me, as they had known me from a young child. We would have a share out in the sanatorium. We used to swap fruit for chocolate and vice versa with the men downstairs by putting it in a basket and lowering it through a window to the ground floor. The men would replace the fruit with chocolate, tug the string to signal us and we would pull up the basket.

When our temperatures settled, we were allowed to go outside in huts during the day. We dressed and reclined on camp beds where we chatted, wrote letters and so on. Those of us who easily ran a temperature were not allowed to sleep in the huts at night but had to go back upstairs. I suppose this is because toilet facilities outside were almost non-existent, therefore it would be necessary to walk upstairs to reach the bathroom. Blankets were rationed to two. This was fine in the summer but it could be very cold in the winter, as all the windows in the ward were wide open. When it snowed, we scraped it off our beds in the morning. Some of us slept in our dressing gowns but kicked them down the bed before the nurse came to take our temperatures.

We were not allowed to use public transport, cafes or restaurants and had to take with us, on graded walks, little screw top bottles with which we were to contain any phlegm, expectorated. The male wards were on the ground floor. We socialised (after a fashion) at Chapel, once a week or on lighter evenings, at the beetle drive or with knock-out-whist. Tables would be set out on the lawn. Our temperatures were taken during the game, would you believe and if it was deemed necessary, one could be sent back to bed. Apart from one or two women, who had children, most of us were teenagers or in the early twenties.

A few of the men had been in the Armed Forces during the war

but they seldom talked about their experiences, as they were too recent.

Unsurprisingly, about four of the ex-serviceman had served in submarines. We tended to regard the older men as father figures and sometimes asked them for advice.

We seldom had visitors, as most of the families lived too far away. Few people had cars in those days and train fares were too dear for many people. Occasionally, my parents managed the trip by coach but it meant a very early start for them. Also, they found the Bournemouth air so relaxing that they had difficulty keeping awake!

The prolonged bed rest and starchy food produced a dramatic weight change in some patients, women in particular. They became obese with hanging breasts, in a short space of time. The rest of us stayed thin for years and were given extra milk (two pints a day), eggs and butter. After being home for a year, just prior to attempting to get a job, I was examined by the chest specialist in my own hospital. He walked around me (I was clad in pants only) and said, "Where the hell is it? You've had treatment for TB for three years and have put on just three ounces".

Before we left, we women were told that if we must get married, it was unwise to have children. Also swimming, tennis, smoking and running were out. I agreed about the smoking but nothing else. It was difficult to get used to being home and one still tired easily. When ill, it was possible to fall asleep on a short bus ride.

Getting a job was very difficult, as one automatically registered as disabled and that did not endear one to would-be employers. One wretched woman in the Labour Exchange (as it was then) phoned several firms on my behalf, in my hearing, and finished each conversation with, "of course you know she is tubercular?". In the end, I obtained my own job by lying about the three years that I had been out of work. It was bad enough being treated like an outcast by ordinary people because I was ill but it felt it was too much when I was supposed to be better. We all had similar experiences. A problem that could arise now is that too much media attention, of the wrong sort, could create fear and antipathy towards TB sufferer's and that would not be helpful. A visiting preacher, whilst I was at Bournemouth, gave us a sermon, to the effect that we had TB because we had been wicked. We could not believe our ears. The staff looked very sheepish and did not know where to look. Those of us who were ambulant walked out. Our own padre was a pet and universally popular, as he was so kind and helpful.

When I was home waiting for a bed at the sanatorium, a strange woman knocked on the door and asked my mother if I had TB. My mother replied in the affirmative, whereupon the woman pushed her way in, knelt by my bed and prayed to God to receive my soul. I thought it was funny but my mother threw her out, literally.

Bridie and Dora had to receive further treatment in other sanatoriums from time to time but I was lucky and never looked back. Six of us, we three and three men, remained friends, until now, when just two of us are left, (none of the others died of TB). We would all meet in London from time to time to have a meal out and if we could afford it, a show. We also visited one another's homes and got to know other family members. At one sanatorium where Bridie was, for a time, (probably Milford), she met two young men who became friends and late on, scriptwriters for TV. They were called Galton and Simpson, who were responsible for (among other scripts) a series about life in a sanatorium. It was a successful comedy, which I think was called "Only When I Laugh", starring James Bolan.

Three Peaks Challenge

Caris Grimes reports on a tough challenge

Six am on a cold September morning last year saw nineteen young people, lining the base of Ben Nevis, touching their toes, stretching their legs and encouraging each other for the marathon that was about to begin. As dawn rose, waved off by TB Alert's Hon. President, Sir John Crofton and Chairman, Paul Sommerfeld, we were panting up Scotland's highest peak, Lucozade in one hand, high-energy bar in the other, while our feet scabbled about in the scree for footholds. The three peaks challenge involves climbing the highest peaks of Scotland, England and Wales, (which is Ben Nevis, Scafell Pike and Snowdon, respectively), within 24 hours. We had two teams of willing, perhaps foolish, volunteers, who were keen to give it a whirl in aid of TB Alert.



Each volunteer not only had to train to get themselves into peak physical form, but they also each had to raise at least £200 for TB Alert projects. Physically, the challenge is a tough one. Morale is crucial too. This presented as a special challenge as we slogged up and down Scafell Pike in the Lake District in the dark and wet. As we came down, at 3 a.m., slipping and sliding over the wet rocks, and periodically stopping to scabble through our rucksacks for the spare batteries to our head-torches, all heroic images were shattered. We were exhausted, tired, wet, hungry... and only two thirds of the way through the challenge.

The real heroes of the adventure were our two minibus drivers who were always patiently awaiting our not so gallant return with lots of hot chocolate bubbling merrily in the back of the minibus. Many grateful thanks from all the walkers to that wonderful church that left a van of hot soup and rolls for us. May their kindness never be forgotten! We all managed to get a quick kip on the minibus ride to Snowdon. Waking up much refreshed, we warmed up for the third and final time and set off up the Miners Track. The sun burst through the cloud as we hit our final trig point and after congratulating ourselves heartily, it was into the restaurant at the top for a celebratory coffee and cake.



Many thanks to all those who supported us and took part.

COME ALONG AND MEET US AT OUR OPEN DAY!

Saturday 6th October 2001
at 2 p.m.

Medical Society of London
11 Chandos Street, London W1

Along with our Hon. President, Sir John Crofton MA MD FRCP, you can meet our officers and volunteers, as well as experts in the field and others active in TB work.

But, you don't need to be an expert to come along because everyone is welcome.

There will be short talks, an exhibition and even buy a very fetching T-Shirt! You can enter our raffle and we even promise you tea and biscuits.

We look forward to seeing you there.....

Stop Press

We are absolutely delighted to have heard that our bid for an appeal on BBC Radio 4 has just been approved and we have been allocated a slot on December 2nd. It is a great opportunity for us to raise awareness and funds. Please note the date in your diaries and, nearer the time, encourage all your friends and acquaintances to listen and to give!

Advisory Board strengthened

The size and skills of the TB Alert Advisory Board have been increased with the appointment of several new experts:

Tim Baker - TB Nurse Specialist in Newham, East London, the epicentre of TB in Britain. He also has experience of working in India.

Dr Nick Banatvala - Consultant in Public Health for Suffolk Health Authority and Advisor to MERLIN (Medical Emergency Relief International) and DfID (Department for International Development).

Dr Richard Coker - Research Fellow in Public Health at the London School of Hygiene and Tropical Medicine.

Prof Tim Cullinan - Public Health Consultant and Advisor to MERLIN.

Dr Tim Healing - Epidemiologist / Microbiologist, MERLIN.

Dr Sara Davies - Public Health Registrar in Edinburgh, recently returned from working as a health planner in Zambia.

Dr Richard de Soldenhoff - Consultant on leprosy and TB. Based in Edinburgh, who does much work in Indonesia and South-East Asia for Netherlands Leprosy Relief.

Also, **Professor John Grange** of University College London and author of the TB Alert report, "Tuberculosis: It's your problem - The Threat of tuberculosis in Britain today", has recently moved to the Advisory Board from being a Trustee.



TB Alert was established in 1998 in response to the ongoing global threat of TB. Our aims are to raise awareness of the disease and to provide financial support for operational work using the most effective treatment regimens in high-load countries.

We need your support. If you can help us, please complete and return the slip below. All gifts to charity, however small, can now attract gift-aid, making your gift even more valuable - all you need to do is, to give us your name and address, and confirm that you are a UK taxpayer by completing the form below.

Please accept my gift of £_____ I confirm that I am a UK taxpayer (delete if not applicable)

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Address _____ Postcode _____

I would also like to give on a regular basis, so please send me details (please tick)

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