

# ALERT!

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**STOP TUBERCULOSIS WORLDWIDE**

Issue Number 6 Spring 2002



## TB Action Takes Off

Recent months have seen a noticeable jump in awareness both in Britain and by world leaders of the need for action against tuberculosis.

In the United Kingdom, the public were shocked first by the school outbreak in *Leicester* – the worst for decades, leading to over 70 active cases – and a month later by another at a private nursery in *Wandsworth*, London. National press coverage of these, plus a steady stream of local press stories of cases in places including Newport, Poole, Plymouth, Aberdeen, Barnet, and Harefield, has brought home to the general public that TB really is around, even here at home.

Globally, the July 2000 statement by the 'G8' leaders of the main industrial powers that TB, together with Malaria and HIV, is one of the three main killer diseases in the world today, has been followed by the beginnings of action.

Led by Kofi Annan, UN General Secretary, a new *Global Fund to Fight Aids, TB and Malaria* (GFATM) has been created with funds from both governments and big philanthropists. Monies pledged, including £200 million by the UK government, have reached almost \$2 billion. About \$700 million will be available in 2002 and will be mainly disbursed to high need countries for government-supported initiatives.

This is much better than nothing but the need is at least five times greater and there are three major diseases involved. Also, President Bush has put only \$200 million for the Fund in his proposed budget whereas earlier remarks by Colin Powell had implied much more.

TB work itself has been given a new focus with the *Global Plan to Stop TB* adopted at the Stop TB Partners Forum in Washington last October. Key speakers were Sir John Crofton, Honorary President of *TB Alert*, James Wolfensohn, President of the World Bank, Gro Harlem Brundtland, Director-General of the World Health Organisation, and George Soros of the Open Society Institute.

The *Global Plan to Stop TB* sets specific targets for expanding access to DOTS (Directly Observed Treatment Short-course) programmes, preventing multi-drug resistant TB, developing new TB drugs to shorten the treatment period, research for a more effective vaccine, and better strategies to treat people co-infected with HIV and TB. At its launch, Mrs Brundtland stressed that "Investing in ...TB makes sense because improving health is a concrete measurable way of reducing poverty and inequity... Investing in accelerated DOTS expansion will have a profound impact: 22 million people would be cured of TB and 16 million lives would be saved by 2005".

There is still one problem: The gap between funds needed and funds so far known to be available is \$4.5 billion. So keep those donations coming!

## Happy Birthday!

It is with very great pleasure that *TB Alert* wishes a Happy Birthday to Sir John Crofton, our Honorary President, who will be 90 on 27<sup>th</sup> March 2002, appropriately close to World TB Day.

Sir John has been a leader of work in tuberculosis since the 1940s and was Professor of Respiratory Diseases and Tuberculosis at the University of Edinburgh. One of his major contributions was the demonstration that combination drug regimens in TB are more effective and overcome problems of resistance.

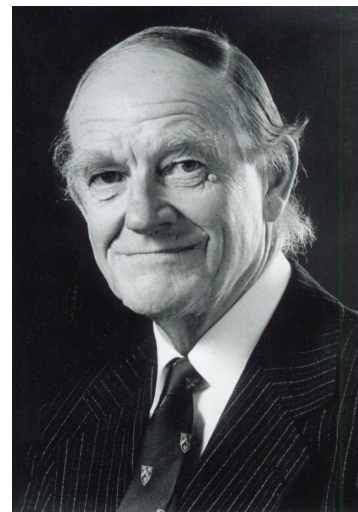
Today, he remains extremely active, and last October gave the keynote speech at the Stop TB Partners Forum in Washington. For *TB Alert* he has been done much for our fundraising and frequently attends Trustee and other meetings.

The *British Thoracic Society*, the scientific association for chest specialists, has very kindly marked Sir John's birthday by an appeal to its members, asking them, as a birthday present to Sir John, to make donations to *TB Alert*. Thank You.

## Collaboration With Ryder-Cheshire

Our last edition spoke of the growing collaboration between *TB Alert* and *Ryder-Cheshire*, another charity that has decided to orient its work toward tuberculosis. Our relationship with them has continued to grow and we greatly appreciate the considerable assistance they are now giving us. On project development, their Overseas Programme Manager, Christine Edwards, now acts in effect as Secretary to our Advisory Board and Projects Officer.

*Ryder-Cheshire* also help us with general administration – some of you may have found yourselves talking to them if you used one of the alternative numbers given when our usual number is busy or unattended. Their Director, Alastair Burt, has even drafted many of the articles for this edition of the newsletter.



In the other direction, our Fundraiser, Melanie Matthews, spends approximately 20% of her time assisting Ryder-Cheshire to develop their own fundraising capacity, and Tilak Chauhan, our Representative in India, will be available to support their projects.

*TB Alert* and *Ryder-Cheshire* are looking very closely at future collaboration. Last November a joint meeting of Trustees received a report from Kate Kirkland, an independent consultant, who recommended that merger was likely to strengthen both charities. The details are now being worked on and a further joint workshop of Trustees is planned for May, after which final decisions on whether or not to go ahead will be taken.

## Our First Employee!

Monday, 19<sup>th</sup> November 2001 was a big moment for *TB Alert*. Melanie Matthews started as our first ever employee and Fundraiser (albeit with 20% of her time working for *Ryder Cheshire*). Melanie had worked for the previous 2½ years as Manager of the Corporate, Trusts and Trading Division of *Wateraid* and before that was an Account Director for *Personal Fundraising Partnership*.



Melanie, working from home in Brighton, is quickly coming to grips with the challenge of moving *TB Alert* from limited volunteer-generated income to a flow of funds significant enough to support a range of projects and have real impact on TB work worldwide. Her professional approach has already had an impact on recent appeals. In January, Trustees adopted the fundraising strategy she proposed. So, she is now focussing on approaching trusts for a good part of the £150,000 needed for the four ambitious new projects in India and Zambia that *TB Alert* has recently committed itself to support.

## Where Were You?

*TB Alert* wants to be open and to involve supporters in its progress. So each of the last two years has seen an 'Open Day'.

The one last October took place at the London Society of Medicine in central London on a Saturday afternoon. Sir John Crofton gave the keynote address after which Peter Davies, Secretary of *TB Alert*, gave an outline of the global burden of tuberculosis, Don Carsley of Rotary International Britain and Ireland spoke about their partnership with *TB Alert*. Alastair Burt, Director of *Ryder-Cheshire*, gave a short history of the organisation and spoke of the growing links with *TB Alert*. Christine Edwards, Programme Officer, outlined the overseas projects which *TB Alert* hopes to support in the near future. Edward Sadler and Margaret Knight, both trustees, reported on fundraising. Gini Williams, Chair of the Advisory Board, introduced the latest *TB Alert* Occasional Paper, and Peter Moszynski, a freelance journalist, finished by giving a moving account of his own battle with TB.

Those who came enjoyed the programme and discussions but at only about 20, attendance was low. So, before we plan another this year *we want to hear from you*: What day of the week, time, part of the country, and content would encourage you to come? Let us know ([tbalert@somhealy.demon.co.uk](mailto:tbalert@somhealy.demon.co.uk) or 22 Tiverton Road, London NW10 3HL or 020 8969 4830).

## Thank You Madeline

For over two years the *International Union against Tuberculosis and Lung Disease (IUATLD)* – which is based in Paris – has supported the creation of *TB Alert* by asking one of their staff, Madeline Webster, to spend two days a week helping *TB Alert*. It is Madeline who was the backbone of our fundraising up to now. She, and indeed her husband John, gave much more than her official time. Without her, we could not have done nearly as much; and those of us who worked with her will miss her calm determination and professionalism. Madeline wishes Melanie success with fundraising in the future. *Thank you Madeline; Thank you IUATLD.*

## 'Tuberculosis – We Ignore It At Our Peril'

*Tuberculosis – We Ignore it at our Peril: Risk Factors in Tuberculosis Action and Care* is the latest *TB Alert* Occasional Paper. It was launched at the Open Day last October and was written by Dr Veronica White, a member of the Advisory Board, and Gini Williams, its Chair.

The paper highlights the importance of early diagnosis and treatment of TB whether in Britain or abroad; and the need for TB control programmes to be fully integrated into national health programmes. Barriers to effective treatment such as irregular supplies of drugs, the lack of practical support for patients and the overriding problems of poverty and overcrowding are examined.

This is a clear, concise and practical paper covering important aspects of TB care both in this country and overseas. If you would like to obtain a copy please contact *TB Alert*, c/o Alastair Burt at *Ryder-Cheshire*, 82 Queen's Road, Brighton, BN1 3XE Tel. 01273-821056, or download it from [www.tbalert.org](http://www.tbalert.org).

## Tilak Chauhan



Tilak starts in mid-March as our Representative in India on a half-time basis, to make us known, to help develop proposals, and to support and monitor our projects. His wide experience, including almost fourteen years as Chief Executive of *Lepra-India*, will be invaluable.

## Thank You!

Last autumn many of you generously responded to the *Development Appeal*, intended to help *TB Alert* jump up a gear and respond to heightened awareness of TB after the Leicester outbreak. Almost £6000 was given in one-off donations and, even more valuable to a charity in the long term, regular giving (Standing Order) commitments amounted to a further £1,400 a year. Claiming back tax from the Inland Revenue through Gift Aid will enhance both of these figures.



*Ringo Starr – the Beatles drummer who fronted the TB Alert Appeal on Radio 4*

Thank you too for responding to our *Christmas Appeal* and encouraging your friends to listen and respond to the *Ringo Starr Appeal for TB Alert* on Radio 4 in early December. Money is still coming in but that too looks likely to have raised around £6000. Perhaps a little less than we might have hoped for but within the usual response range for Radio 4 appeals. It has certainly also been a great boost to the public profile of *TB Alert* to have been promoted by such a well known past TB sufferer as one of the Beatles. Quite a few journalists wanting to get hold of Ringo for other stories have called us thinking we have a hotline to him!

Special appeals help a lot but we still have to increase the momentum. Regular giving through Standing Orders is especially valuable as it allows us to plan ahead and be reasonably sure of future income.

And, of course, remember that as long as you are a UK taxpayer, and you have signed a Gift Aid Declaration in favour of *TB Alert*, every £1 you contribute attracts a further 28p for the charity from the Inland Revenue at no additional cost to yourself.

A further incentive if you are a higher rate taxpayer, is that you are able to reclaim tax yourself on charity donations. If you are a 40% taxpayer, you can reclaim around 23p for every £ you donate. So, as long as you remember to mention it on your tax return, your donation to *TB Alert* costs you almost a quarter less than you thought!

## Supporting Work In Britain

*TB Alert* has become aware that although the focus of our grant giving has to be high endemic countries, there are needs with which we can help in Britain too. So, our first grant for work in this country has recently been agreed.

Around £1800 will fund the piloting of an idea to help patients know exactly when to take which capsules. The standard TB regimen involves four drugs for two months, with two of them being continued for a further four months. So it is quite a task for patients to take the right drugs, in the right numbers at the right time.

Dr. Veronica White has developed a treatment diary to help them and several TB nurses have been given the diaries to try out with patients. The Medical Illustration service at Barts Hospital assisted with the graphics and Bengali and Somali translators have given their services

free to produce the diaries. If they prove successful, such diaries could be useful overseas as well as in this country.

Trustees have also committed *TB Alert* to fundraising for another project – to undertake a survey of TB-related health education materials available in the UK. We are often surprised by the requests we get for literature aimed at the general public or patients or medical staff, and suspect there are many gaps. The survey is also likely to be the prelude to a more ambitious programme to fill gaps and develop a distribution service for TB leaflets.

## Rotary TB Awareness Campaign Begins To Bite

*TB Alert* is proud to have been asked by *Rotary International in Britain and Ireland (RIBI)* to work with them to increase public awareness of TB. Our partnership was officially launched last July and runs through the whole Rotary year up to June 2002.

The aim is to encourage Rotary clubs – there are 2000 across Britain with 65,000 members – to talk in their local communities about TB and especially to get people to *Think TB*, to be aware of the basic symptoms and to ask their GPs about TB as a possibility. The hope is that this will reduce the all-too-frequent problem in the UK of late diagnosis of TB because patient and doctor both think first of other causes of coughing, weight loss, fever, and lethargy.

A major, specific initiative like this is a new way for RIBI to work but it has caught the imagination of Rotarians. For *TB Alert* it is wonderful to have a network of thousands of community activists going out and talking about TB.

Many clubs and District Conferences started by asking *TB Alert* for a speaker. Filling all these requests in many parts of the country has been a big task. Thanks to all the TB nurses and doctors who have been drawn into speaking for us!

Clubs have then gone on to organise local action. For example, *Biggleswade* has two clubs. One arranged for a Rotary TB leaflet to be inserted in a local free newspaper, the other handed out leaflets to shoppers in the market square and supermarket. *Dingwall* club was very quick off the mark and made sure every passenger in a week last Summer on the Inverness/Thurso train line got a leaflet.

Many clubs have placed posters and leaflets in GP practices. Several clubs looked for more active collaboration with their local Health and Education Authorities, and in several areas leaflets have been actively distributed through schools.

Best of all, *Leicester de Montfort* club got their health authority to pay for translation of the *Think TB* leaflet into four Asian languages and is engaged in getting them out to local households.

Don Carsley, national Community and Vocational Service Chair for Rotary tells us his printer has filled club orders for 600,000 leaflets! Rotary are using two leaflets designed by us: One, based on our introductory *Killer*

Returns, is best for fundraising purposes; the other, *Think TB!*, is best for giving basic information about the disease.

*TB Alert* is also happy that several clubs are raising funds for TB work. A particularly generous £500 came from *Hendon* club after a 'Taste of Asia' event, and so far *TB Alert* has received altogether almost £3000 from Rotary and Inner Wheel clubs.



*Dr. Nani Nair, TB Adviser to the South East Asia Region of WHO, with the RIBI and TB Alert display at the Stop TB Partners Forum in Washington, October 2001*

## TB Alert online

We know that not all of our supporters have computers, or access to the internet. But for the growing number of those that do, you might like to know that we have a website – [www.tbalert.org](http://www.tbalert.org). Run by a volunteer, the website gives information about TB, about TB Alert's work and ways you can help. Visitors to the site can contact us by email and we have a donation form which can be downloaded – which we hope will bring new donors to our charity. But remember – if you are not a "surfer" and would like more information – all you have to do is give us a call on 020 8969 4830.

## Shop online and support *TB Alert*

If you are a keen internet user, you may be interested in UshopUgive ([www.UshopUgive.com](http://www.UshopUgive.com)) – a new shopping website which enables you to raise money for *TB Alert* when you buy products over the Internet.

The website gives you access to the websites of a wide range of online retailers including *Amazon*, *Thomas Cook*, *Comet*, and *Waitrose*. You can order a pizza on-line from *Dominos Pizza*, a ticket for a West End show from *Ticketshop*, send a bunch of flowers through *Flying Flowers*. These retailers pay sales commission (on average 5% of the purchase price) on every purchase

made when shoppers 'click through' UshopUgive to do their online shopping. At least half of that commission is passed to charities like *TB Alert*.

Shopping via UshopUgive doesn't cost you anything extra, and you will find that the website is fast and easy to use. You simply indicate that you want to support *TB Alert* prior to being linked directly to the retailer website of your choice where you shop normally.

For the first 250 people that register on the UshopUgive website during the week of 14<sup>th</sup>-20<sup>th</sup> March we will receive £1. You don't even have to make a purchase – just click the "register" button and give a few details. So please register during the promotional week – it won't cost you a thing and the total £250 could help cure 10 people of TB.

## Buy Office Supplies online and support TB Alert

UshopUgive also includes retailers such as Dell Computers, Eurooffice (Office supplies and Stationery) and the Cartridge Shop. Often there are deals available through the site that not only save you money but would result in large payments to *TB Alert* as a result of purchasing through the site. UshopUgive staff are happy to work with you, or the purchasing department of your organisation, and do the donkey work of finding out if lower prices than you currently get can be achieved through the site. Simply call TB Alert on 01273 679557 and we can put you in touch with the appropriate person. Don't worry about the fact that the orders are placed online -- most of the retailers are prepared to set up accounts and invoice your organisation for payment as with any normal supplier.

## Take up a *Charity Challenge* and raise money for *TB Alert's* vital work whilst experiencing the trip of a lifetime!

You could raise funds for *TB Alert*, whilst exploring corners of the world far from the normal tourist trail – like trekking through the Avenue of the Volcanoes in Ecuador or cycling along the shores of Lake Malawi – and many more. On a *Charity Challenge* you will find participants of all ages and from all walks of life. They are not necessarily just for the super fit; the only thing everyone will have in common is a sense of adventure, and a desire to challenge themselves by doing something a little bit different.

To take part you need to pay a registration fee (usually around £500), and then pledge to raise a minimum sponsorship amount - at least 60% of the sponsorship money that you raise will come to *TB Alert*. Or you can pay the full cost of the trip yourself, which will include a donation of £100 to *TB Alert*, and raise any sponsorship money you like on top of that. Either way you will receive support from *Charity Challenge* and *TB Alert*, helping you to be fully prepared for the event as well as the fundraising aspect of your challenge.

For more information please check the *Charity Challenge* website, at [www.charitychallenge.co.uk](http://www.charitychallenge.co.uk) – everything you need to know is there. If you don't have access to the internet, you can call them on 020 8557 0000.

If you would like a *Charity Challenge* poster to put up on your local pub, club, gym, swimming pool or shop noticeboard, please call Melanie on 01273 679557 or email [fundraising.tbalert@btinternet.com](mailto:fundraising.tbalert@btinternet.com).

## Shake, Rattle 'n Roll

*TB Alert* desperately needs volunteers for fundraising collections. Rattling tins may not be glamorous but it can be fun. It raises our profile and brings in around £15 per hour per collector - or even double that in a good spot. Most of our collections so far have been in London but others in Henley and Liverpool have done well.

So, PLEASE, could you arrange a collection in your area? We can provide tins, stickers, sashes, materials, and advice on the legalities. With just a few friends over the main shopping hours, you could bring in £300-400 for *TB Alert* in a day.

OR volunteer to do a stint on one of the collections we are already planning. The next, for the third year running, is at Harvey Nicholls in Knightsbridge, London over the week starting with World TB Day: Sunday, 24<sup>th</sup> – Saturday, 30<sup>th</sup> March 2002. This famous department store attracts a well-heeled clientele so our collection rate is especially good. But all depends on having enough collectors, each doing a couple of hours, to cover the whole time the shop is open.

By the way, we collect *inside* the entry door so you are sheltered from rain and wind!

Also we have two collections running in Brighton on 23<sup>rd</sup> and 24<sup>th</sup> March, so if you live nearby (or would like to combine a couple of hours of collecting with a trip to the seaside!) we would love to see you there. After that, the next one planned is at the Royal Academy during the 2002 Summer Exhibition – another pleasant venue. Last year, the very helpful doormen allowed some of us into the exhibition itself for free at the end of the day!

So, if you can spare a few hours, please call Melanie Matthews on 01273 679557.

## What It's All For

*TB Alert* is really worthwhile if its work means more people get good TB treatment and are cured. And that is just what has been happening.

With more funds flowing and a growing relationship with partners in high endemic countries, *TB Alert* has been able to support more work and to adopt ambitious expansion plans for growth by the local organisations we work with.

- In the midst of the joint TB/HIV pandemic in Lusaka, Zambia, *Bwafwano* ('Let's help each other') is a powerful ray of hope. Local people, out of the same community as the patients, volunteer time and effort to support individuals through the long treatment and to help the government health clinic get drugs to their patients. Our grants totalling £8300 so far have paid for two volunteer

training programmes and for a beginning to be made in extending the project to a neighbouring area. But that extension needs another £50,000!

- In Delhi, capital of the country with the most TB in the world, our first grant to *Voluntary Health Association Delhi (VHAD)* allowed them to employ a trained DOTS worker at Vikaspuri clinic. Now, we are helping them to set up five new DOTS centres in an area of the city identified by the State TB Officer as a gap in provision.

We are very happy that our recent grant of £6500 meant the first of these, Lal Kuan near Baderpur, opened its doors on 7<sup>th</sup> January this year.

- In *Theni District* of Tamil Nadu State, Southern India, we have given a first grant of £4400 to a network of eight local community organisations working together to extend DOTS treatment to the whole district (In India, a district covers a population of around 2 million). This is the TB part of a wider programme supported by our colleagues, Ryder Cheshire and Village Service Trust. We just have



to find another £36,000!

*DOTS worker supervising treatment in Theni district*

- And we have also recently given some strategic small grants: £1000 to the *Malawi Medical Journal* to publish a special edition on TB and get it to all health workers in the country; and \$5000 to *TB Net, Nepal* to bring community workers (not doctors!) to a regional TB conference.

A special trend in our grant-making is to support community outreach and the work of nurses and paramedical professions. At *TB Alert*, we believe that our particular contribution should be to build the human touch that will turn medically correct TB programmes into really good ones.

## TB in London: the Need for Action

Over two hundred people attended this conference on 3<sup>rd</sup> October 2001 aimed at raising awareness of TB in London. It was hosted by the Respiratory Section of the Royal Society of Medicine (RSM) and organised by *TB Alert* and the Communicable Disease Surveillance Centre (CDSC) for the NHS London Region.

TB has been increasing in London for the last 10 years, with an alarming 17% rise in 2000 alone, and total cases

reaching almost 3000. Although the conference heard of quite a lot that has been done, the overall message from the conference was that the disease is running ahead of these efforts. Dr. John Moore-Gillon of Barts Hospital vividly described how staff are under great pressure, and called for TB to be given much greater priority in spending decisions.

Leading decision-makers were present, including John Bacon, NHS Regional Director; Dr. Sue Atkinson, Regional Director of Public Health; Ansel Wong, Chair of the London Health Commission; and Dr. Elaine Murphy, Chair of East London and City Health Authority.

A video, commissioned by *TB Alert*, and showing four people whose lives had been affected by TB in different ways, was greatly appreciated and has since been requested for many training events. The conference ended with a global overview of TB by Dr Peter Davies, *TB Alert* Secretary, speaking in his role as President of the Respiratory Section of the RSM.

## In Memory Of Rita

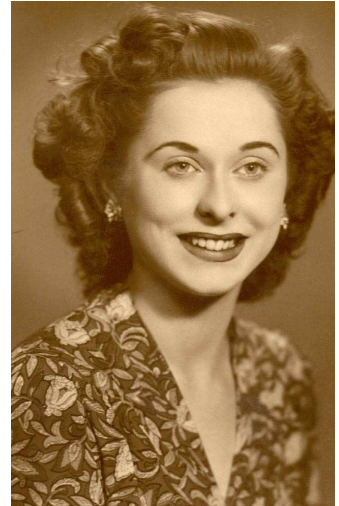
It was moving recently to receive a donation in memory of a person whose life direction had been changed by TB. Rita Fred died on 21<sup>st</sup> December 2001 and her son-in-law told us in his accompanying letter that:

“Rita was diagnosed with TB at the age of 21, in the early 1950s. She endured an aggressive, but then sadly common, treatment that involved routine collapsing of a lung and high doses of the then new antibiotic, Streptomycin. In consequence, Rita was left profoundly deaf but nevertheless maintained a full and active life right up until the day of her death.

“Rita’s experience in hospital inspired her to train as a nurse and she soon qualified as an SRN. In her later years, Rita became heavily involved in the care of children with special needs – including deafness – and continued to teach until she died.

“Rita never forgot the images of her fellow and less fortunate TB sufferers on the ward. She was acutely aware of the terrible suffering that results from the want of basic modern medical care and would appreciate the work you are doing.”

Dr. Peter Davies, Secretary of *TB Alert* adds: “The treatment probably saved her life. Deafness is an unfortunate side effect of Streptomycin that is now very rare because there are alternative drugs”.



✂ Please cut here ✂

## A Personal Gift

If you would like to make a donation, please send it, with this form to **TB Alert, 22 Tiverton Road, London NW10 3HL**

Please accept my donation of: ? £100 ? £50 ? £25 ? Other £\_\_\_\_\_ (Cheques payable to TB Alert)

? Please treat this as a Gift Aid Donation

I confirm that I will pay more in tax than my level of donations this financial year, and have given my address below for your records. If you are able to tick this box, **TB Alert** can reclaim from the Inland Revenue, an extra 28.2p for each £1 of your donation. *If you pay tax at the higher rate you may reclaim the difference between the low & high rate tax yourself.* Please let us know if your circumstances change.

Please complete your name and address details in block capitals.

Name:	
Address:	
Postcode:	
Phone:	
Email:	

I would like more information about:

- Making a regular gift to TB Alert ?
- Leaving a legacy to TB Alert ?
- Getting involved by volunteering ?
- How my company can help ?
- Fundraising at school/church/clubs ?
- Overseas Sponsored Challenges ?

TB Alert does not share its mailing list with any other organisations, but we will from time to time update you on our work and fundraising (we will not inundate you with mail!) Please tick here if you do not wish to receive **any** further mail from us ?.

Please tick here if wish to receive future **newsletters but no other mail** from us ?.

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Charity Registration No: 1071886

