Meningitis Research Foundation

Working to defeat meningitis and septicaemia

Meningitis Research Foundation Annual Review 2006

Meningitis Research Foundation's vision is a world free from meningitis and septicaemia.

Meningitis and septicaemia can affect anyone of any age, but most cases are in babies, toddlers and young adults. These diseases are the major infectious cause of death in children in the UK and Ireland.

Out of every ten people who get bacterial meningitis and septicaemia, one will die. One in four survivors lives with after effects as severe as brain damage, deafness and amputations.

The charity's objectives are to:

- promote research into the causes and treatment of all forms of meningitis and associated infections;
- promote the dissemination of the knowledge gained by such research;
- advance the education of the public in the causes, treatment and prevention of meningitis and associated infections;
- help relieve distress to individuals and families caused by death and damage through meningitis and associated infections.

Beverley Pace

This has proved to be a year of great progress in our fight against meningitis and septicaemia, culminating in the announcement of the introduction of a vaccine against pneumococcal disease into the UK childhood immunisation schedule.

In 2005, pneumococcal meningitis accounted for in excess of 250 of over 3225 cases of bacterial meningitis and septicaemia in the UK and Ireland, and more than one third of the cases were in children under the age of five years – by far the highest incidence. The introduction of this vaccine promises to save young lives and stop others having to live with the often devastating after effects of infection.

The introduction of the vaccine is something for which the Foundation has been campaigning for many years, and we will continue to lobby for this life-saving measure in the Republic of Ireland.

The trustees also welcome the news of a Hib/MenC booster vaccine in the UK which will ensure that protection against these deadly diseases is maintained at the highest level.

However, much work remains to be done before we have finally defeated the diseases.

Group B meningococcal disease, for which there is no vaccine for most strains in the UK and Ireland, continues to cause the majority of cases, and showed an increase on the previous year. This is why, within our strategy to defeat meningitis and septicaemia through research, we place particular emphasis on research into the prevention of Group B.

In 2006/07, we will be looking to commit another £465,000 to research. This brings the overall total invested in this top priority area since the formation of the charity to over £11m.

I understand how devastating these diseases can be, as my daughter Holly had meningitis as a baby and lives with the after effects. I also understand how important support can be for people coming to terms with the consequences of the diseases, both for those who have lost a loved one and those individuals and families coping with the after effects of meningitis and septicaemia.

I thank all of our members and other supporters in helping to raise well over £2m during the last year working with us on our three-pronged attack on the diseases through research, support and awareness programmes. I do hope that you will continue to back our efforts to help make our vision of a world free from meningitis and septicaemia a reality.

Beverley Pace
Chair of Trustees

Chief executive's report

Picture courtesy of Liz Pitman

During 2005/2006 the Foundation maintained its position as the largest research-funding meningitis charity.

Over most of the year, the charity continued to support 21 scientific research projects with an overall value of more than £2.5 million.

The income of the charity during the year was £2.34m, and I am happy to report that this was above target. Voluntary income again accounted for the majority of funds, and I would like to thank all of our members and supporters for their magnificent contribution.

Expenditure was £1.62m. This was below budget, mainly as a result of changes to accounting policy.

During the year, the Foundation-organised international conference, *Meningitis and Septicaemia in Children and Adults: Burden of Illness, Management and Prospects for Prevention*, provided a focus for communicating knowledge about the latest developments in combating the diseases throughout the scientific and health professional communities.

As part of our awareness programme, up-to-date information was sent to health professionals in primary care, hospital and public health environments. In addition, from more than half a million visitors to our website, our dedicated section for health professionals received over 65,000 visits. We also distributed almost one and half million leaflets, booklets, symptoms cards and posters to the public.

We continued to give support to thousands of members who have already been affected by the diseases, ranging from a listening ear provided by our **Free***fone* 24 hour helpline, to home visits and a telephone befriending service.

We continue to provide all our services free of charge, and I thank all those who so generously help us, enabling us to keep overheads low and maximise our charitable spending.

Thank you.

Denise Vaughan

research

Searching for a Group B vaccine at Imperial College, London

We believe that research into prevention, detection and treatment will lead to the elimination of meningitis and septicaemia and the suffering they cause.

In our research strategy, priority is given to the funding of projects that promise to produce results in immediate problem areas, including:

- prevention of all forms of meningitis and associated infections;
- improving treatment and outlook for patients;
- improving the speed and accuracy of diagnosis.

Within that strategy we place particular emphasis on research into the prevention of Group B meningococcal infection, the cause of most cases of meningitis and septicaemia in the UK and Ireland.

The charity invites applications for project grants from researchers throughout the world. Applications are looked at on the basis of a strict peer review process - just one of the ways that we adhere to the principles of the AMRC (Association of Medical Research Charities), of which, along with the Irish Medical Research Charities Group, we are active members.

At least two independent referees and the Foundation's Scientific Advisory Panel assess the merits of applications, before the Panel makes its recommendations for funding to the charity's Board of Trustees.

It is important that the results of Foundation-funded research are shared with researchers, health professionals and, where appropriate, the general public. For instance, information on the 'red flag' symptoms (see case study opposite) was first published in The Lancet and will be highlighted in all of the Foundation's publications on recognition of meningitis and septicaemia.

In total, findings and outcomes from 26 projects funded by the charity appeared in 35 peer-reviewed scientific journals during the year.

Presentations at conferences are another important way to bring research findings to a wider audience. International conferences saw 16 presentations of research supported by the Foundation, with many more at UK conferences. And the Foundation's own conference, *Meningitis and Septicaemia in Children and Adults: Burden of Illness, Management and Prospects for Prevention*, attracted experts and delegates from around the world.

Find out more about Meningitis Research Foundation's research programme by logging on to **www.meningitis.org**

The pneumococcal bacteria - the second biggest cause of meningitis and septicaemia in the UK and Ireland

Case study

One piece of research that has produced immediate results is a study of the pre-hospital symptoms in children with meningococcal meningitis and septicaemia.

The researchers at Imperial College, London and the Royal College of Paediatrics and Child Health, in collaboration with the University of Oxford, found in their Foundation funded study that three particular symptoms of septicaemia were likely to appear five to eight hours earlier than the more well known symptoms. These 'red flag' symptoms - limb pain, cold hands and feet, and pale or mottled skin - could help both the public and health professionals in spotting the diseases earlier, resulting in earlier treatment – often essential with these diseases which can kill in hours.

Actor Richard Wilson supporting the Know About Pneumo campaign

Case study

Progress towards a Group B meningococcal disease vaccine has been made in a project funded by the Foundation with funds arising from Olivia Giles' Leap for Meningitis event. In the project, the Imperial College, London research team has identified proteins that could form the basis of a vaccine to protect against Group B.

Case study

As part of a nationwide study of bacterial meningitis in the Netherlands, researchers at the University of Amsterdam, funded by the charity, found that nearly one in three adults with pneumococcal meningitis die of the disease. This fatality rate is much higher than in children, and the researchers also found a higher rate of severe permanent brain damage and deafness in this large adult study than has been shown in children.

In a companion piece in the New England Journal of Medicine, the authors made far-reaching recommendations for the treatment of bacterial meningitis in adults, highlighting the use of steroids, to reduce death and disability. For the future, the authors emphasise the potential for prevention through vaccines as the best approach to defeating adult bacterial meningitis.

Therefore, during the year the Foundation promoted and distributed the adult meningitis treatment protocol it has produced with the British Infection Society, and worked with Help the Aged and the British Lung Foundation to promote pneumococcal vaccine for older adults - Know About Pneumo.

Case study

Work at Belfast City Hospital has revealed that a complex method for identifying types of bacteria is proving to be a useful laboratory tool for earlier diagnosis of patients with suspected meningitis when used with other lab findings.

awareness

Picture copyright Bristol United Press

Foundation supporters round off Meningitis Awareness Week by taking a Great Train Journey

It is vital that everyone has information to recognise meningitis and septicaemia.

Early recognition of the diseases, followed by prompt, effective treatment give the best chances of a good recovery.

The Foundation aims to provide free access for as many people as possible to our life-saving range of symptoms publications, and materials for health professionals to both diagnose and treat the diseases.

The charity's website – www.meningitis.org – plays an important part in achieving that aim. Unique visitors to the site during the year almost doubled to 570,000, with symptoms information and more in-depth knowledge of the diseases and their causes being the most popular areas of the site.

The Foundation continued to distribute printed symptoms information, particularly for the most at risk groups – *Baby Watch* and *Tot Watch* for parents and other carers of the under-fives, and *Get it Sussed* for students and young adults. And our new symptoms poster was mailed to all GP surgeries in the UK and Ireland as part of our autumn awareness campaign. The *Am I at Risk?* leaflet also helped public health teams and others dealing with cases in the community allay unnecessary fears about the diseases.

As with our information for the public, our materials for health professionals are all written in collaboration with experts in the field, and are endorsed by relevant professional bodies. Our booklet for UK community nurses, *Vital signs, Vital issues*, was adapted for the Irish health care system and received the endorsement of the Irish Nurses Organisation. Additionally, our treatment protocol for adults was updated during the year.

The range of media in which information is being provided in is ever expanding. Therefore, much work was carried out during the year translating our Junior Doctors' handbook, *Lessons from research for doctors in training*, into a digital, interactive format which will be available on disk and through our website. Our educational video, *Holly's Story*, is now also available in DVD format.

Whilst funding research remains the Foundation's top priority in combating meningitis and septicaemia, the charity will continue to focus on providing life-saving symptoms and treatment information to as many people as possible in a form that is most accessible to them, until all forms of the diseases are vaccine preventable.

Case study

Chris Doughty is a Senior Resuscitation Officer at Worcestershire Royal Hospital who contacted the Foundation to say:

'Very many thanks for your recent sample of the information booklet *"Lessons from research for doctors in training: recognition and early management of meningococcal disease in children and young people"*. I have shown this booklet to a number of my colleagues and junior medical staff who all agree it is a most useful and powerful education tool.

Again, very many thanks for producing this most useful publication.'

Vital signs Vital issues - the booklet for community nurses

support

The helpline is there at any time for anyone who has a concern about meningitis and septicamia

The Foundation offers befriending and support to people already affected by meningitis and septicaemia. This support is tailored to the needs of the recipient.

Central to the Foundation's support services is our **Free***fone* 24 hour helpline. The helpline, the only meningitis helpline awarded the prestigious Telephone Helplines Association Quality Standard, is always there to provide information on meningitis and septicaemia. During the year, the helpline dealt with 11,160 calls.

Many of those calls came from people who have already experienced meningitis and septicaemia, and primarily the helpline provides a sympathetic, listening ear.

Further in-depth support is offered through our telephone befriending scheme. The Foundation has trained 141 befrienders, all drawn from the charity's membership. Befrienders are matched with others based on shared experiences of the diseases, and the Foundation has facilitated over 300 relationships.

The Foundation also provides support days for members with shared experiences, with 2005/06 seeing the first day for members who have had amputations as a result of septicaemia.

Anyone who has been affected by meningitis and septicaemia can become a member of the charity. There are now over 5,500 member families of the Foundation, and membership provides a way to work with the charity to fight back against the diseases.

Members contribute to all aspects of the Foundation's work. For instance, they provide much information for researchers looking into the effects of the diseases. Members provide case studies for inclusion in awareness material and tell their stories to the media to raise awareness, particularly during the Foundation's autumn awareness campaign. Members also provide support for others through the telephone befriending scheme, and their drive and enthusiasm is evident in their commitment to raising funds for the charity.

The Foundation is also supported by a committed band of volunteers working in the charity's offices in Bristol, Belfast, Dublin and Edinburgh and in the community raising awareness and funds, and representing the charity at many events.

Thomas and Michelle Grattan

Case study

Michelle Grattan called the helpline when she was worried about her son:

'Thank you for keeping me calm in a situation where I was beginning to panic. I don't know what I would have done if I hadn't had your helpline number to hand. Also thank you for your support afterwards in answering all my questions and queries as I was struggling to understand what had happened to my son Thomas.'

fundraising

Support for the Foundation's work comes from all sections of society in the UK and Ireland.

Each of the Foundation's offices has a small, dedicated team who work with our supporters to raise funds for our programme of research, awareness and support as a way of combating meningitis and septicaemia.

Our members are incredibly committed fundraisers. Having had experience of the devastating effects of the diseases, fundraising for the Foundation provides a way to fight back against the diseases.

Members are joined by increasing numbers of people who have not been touched by the diseases themselves, but recognise the progress that the Foundation is making in tackling meningitis and septicaemia and choose to support our cause.

The energy and ingenuity of members and other supporters in raising funds for the Foundation is fantastic. As well as an astounding range of self-organised events, thousands of members and supporters took the Foundation's challenge and journeyed to far off lands in search of adventure, ran and walked in some of the world's most famous events, got on their bikes for the Foundation's Big Pedal, drove, chipped and putted their way around golf courses, dropped from 10,000 feet attached to a parachute, bought raffle tickets, answered quiz questions, attended children's musical concerts, lost weight and collected on the streets, at home and work, and door to door throughout the UK and Ireland.

Our thanks go to all our generous members and other supporters, including: Paul Baines in memory of Elaine; Craig and Anthea Berry in memory of Ethan; Moira and Jim Brough in memory of Alistair; Emma and Darren Cowey in memory of Jamie; Sylvia Dunlop in memory of Michelle; Stephen Greene; Bryn Griffiths in memory of Eleri Jacks; Sam and Brenda Hynds; Bethan and Christopher King in memory of Keelan; Jonathan Jordan; the Justice family in memory of Barbara; Nicola Keane with Marks and Spencer; Alison MacGrath in memory of Christina; the Maidment family in memory of Kai; the McQuillan family in memory of Roisin; Kathleen Mills in memory of David; Michael and Lyndsay Pattie in memory of David; Margaret Pelosi; Maria and Robert Penfold in memory of Dan; Pennthorpe School in memory of Andrew Sillett; John McPolin in memory of Ashlene; Michael Rosen in memory of Eddie; Ian and Emma Ryan in memory of Evan; Joanna and Roger Shenfield in memory of David Farmer; Paula and Declan Strain and the Brady family in memory of Rhys; Adrian Swift; Hugo and Lucy Vaux, family and friends in memory of Ellie; Ian and Irene Wardrop in memory of Andrew; John and Barbara Weir; Garreth Wood, and many, many more.

A big cheque for a great cause. The results of a fundraising lunch at the Burlington Hotel Dublin, organised by patron Liam Mulvihill and his family and attended by the Taoiseach Bertie Ahern

Supporters take to the streets of Dublin

We are also indebted to the many charitable trusts who supported the Foundation during the year, including:

Agnes H Hunter Trust; Billingsgate Christian Mission Charitable Trust; Bryan Guinness Charitable Trust; Cooper Gay Charitable Trust; Garfield Weston Foundation; Haymills Charitable Trust; James Weir Foundation; John Coates Charitable Trust; Lloyds TSB Foundation for Scotland; Maureen Boal Charitable Trust; Padraig Harrington Charitable Foundation; The Peacock Charitable Trust; The Rosetrees Trust; Sovereign Healthcare Fund; W and M Morris Charitable Trust; the Willie and Mabel Morris Trust; and Mrs Waterhouse Charitable Trust.

Businesses, both large and small, provided great support for the Foundation during 2005/06 and included:

Boots the chemist, who ran their sixth awareness campaign with the charity in the Republic of Ireland; Brahm in memory of Stuart Hocknell; Chiron Vaccines; Diageo NI; Deltex Medical; Dublin Airport; Gallery Loft Conversions; The Gallery Dental Practice; GlaxoSmithKline; Law Society of Scotland; Lilly; Mothercare; sanofi pasteur MSD; Scottish Equitable/Aegon; Signature Pubs; Wyeth Vaccines.

In addition grants to support our work were received from:

The Big Lottery Fund, DOHSS and PS in Northern Ireland, and the Department of Health in England.

Case study

Ken and Brenda Robinson have worked with the Foundation since 1997, when their youngest son Glenn tragically died of meningococcal septicaemia.

Since then Ken and Brenda's fundraising for the Foundation has been outstanding. Last year alone, they raised over £2,600 through different events and a network of collection boxes, forming part of a magnificent total over £45,000 raised in less than ten years.

Glenn, who was only 16 when he died, was a very promising young cricketer and big fan of Sunderland FC. So, much of Ken and Brenda's fundraising has been sports related, such as cricket and football matches, usually followed by dinner with guest speakers which have included test match umpires and Premiership footballers.

We are extremely grateful to Ken and Brenda for their support.

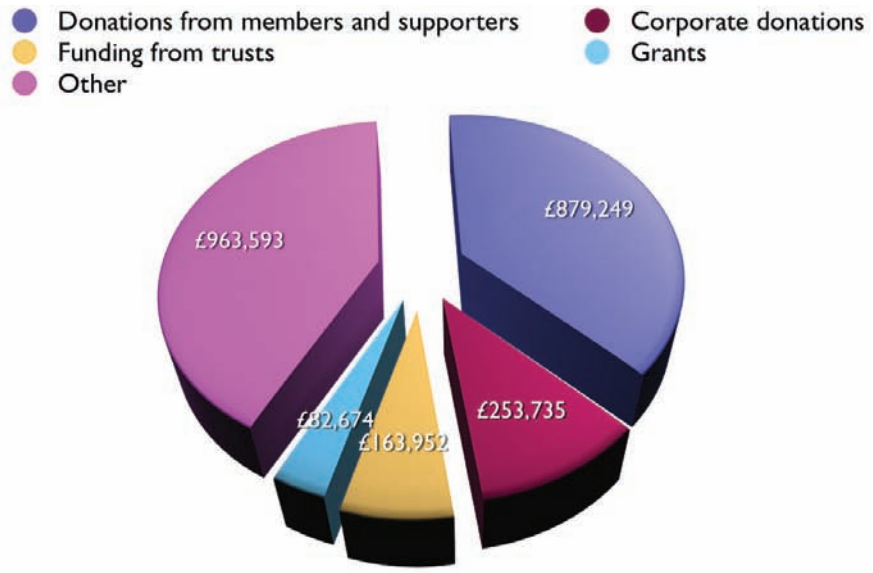
Brenda and Ken (far right) Robinson and local supporters

finance

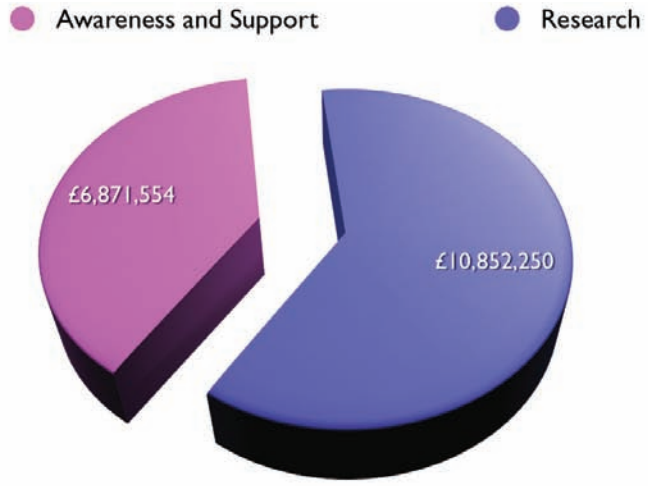
Overall income for the Foundation in 2005/06 topped the £2m target set at the start of the year.

This excellent performance was only made possible by the hard work and dedication of all the Foundation's supporters.

How the money was raised in 2005/2006



Charitable expenditure 1989–2006



Copies of the 2005/06 annual report and accounts, drawn up following the Statement of Recommended Practice (SORP) 2005 - Accounting and Reporting by Charities, are available on request from the Foundation's registered office in Bristol.

who we are

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Meningitis Research Foundation

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