The newsletter for members and friends of Meningitis Research Foundation

Meningitis Research Foundation

Microscope

Autumn 2003

GPs targeted in major campaign

Over fifteen thousand GP surgeries have recently been mailed with information on meningitis and septicaemia.

Included in the mailing was a new leaflet detailing the free awareness materials for GPs and their patients available from the Foundation. As a result, the Foundation has been inundated with requests for further information, including our booklet and wall chart for GPs, front line nurses card and information for the public such as *Meningitis Baby Watch* and *Tot Watch.*

This followed the first part of our annual awareness campaign, which focused on the support that the Foundation can offer to those already affected by meningitis and septicaemia.

Radio interviews and numerous articles in local papers throughout the UK and Ireland helped promote our helpline services for people who are coming to terms with the effects of the diseases.

As regular readers know, the helpline is staffed by a dedicated team, who between them provide a 24 hour service, 365 days a year, in a cost-effective way. The team were recently successful in gaining the Telephone Helplines Association's prestigious Quality Standard.

This first wave of the campaign was closely followed by our yearly push on getting symptoms information into universities and colleges.

The ultimate aim of the campaign is to save lives as we see the seasonal rise in the number of cases of meningitis and septicaemia. This campaign has only been made possible by the funding contribution of all our supporters. Thank you all.

Ambulance card saves life

Further evidence that our awareness materials are saving lives.

Helen Horne, who is a paramedic with the London Ambulance Service, recently contacted us.

Helen told us, "I was recently given and read one of your identification and management cards for ambulance personnel. The next evening I was providing medical cover at a concert and had a patient with sudden onset symptoms that matched meningitis.

Having just read your card, the signs and symptoms were all fresh in my mind and I was able to make a fast diagnosis and arrange rapid transport to hospital where meningitis was confirmed. I don't think I would have recognised the condition so fast if it hadn't been for your card. Thanks for helping to save lives."

How did Cath the student fairy and this young lady help the Foundation raise awareness among students? *See page 4*

From Denise Vaughan

I am delighted to report that in the 11 month period ending March 2003, Meningitis Research Foundation once again spent over £1 million on scientific research, despite a drop in overall income.

We have been finding that many people think meningitis and septicaemia are no longer a problem, and this is having an impact not only on our income, but also on public awareness of the level of risk. This is why we are once again making a major push on raising awareness of meningitis and septicaemia among both health professionals and the public.

Time is of the essence when dealing with cases of meningitis and septicaemia. We hope that our mailing of *Get it Sussed* material will help with early identification of cases in the student population (see page 4).

GPs are often vital in the process of getting people with meningitis and septicaemia the treatment they need as early as possible. GP surgeries are also a great avenue to get our information to the public. Our mailing to GPs (see front page) aims to ensure that both GPs and their patients have the information they need as we enter this crucial phase of the year.

Another way of getting the message across is by presentations in local communities and businesses. We hope that many more members and supporters will consider giving talks and presentations with our new presenter pack (page 5).

Our awareness campaigns are only made possible by your generous contribution. I hope from the front page story about our ambulance personnel card and from previous articles in *Microscope* that you will see that the money you donate is being used effectively in saving lives.

Among the many ways you can help us further is by taking the trip of a lifetime on one of our Charity Challenges or shedding a few pounds or kilos in Slimathon 2004 (see page 7). I am delighted that Rosemary Conley has agreed to be the face, and body, of this year's Slimathon.

Denise Vaughan

Chief Executive

Rosemary Conley - supporting this year's Slimathon

Support for you

Foundation support services

Support for people already affected by meningitis and septicaemia is a fundamental part of the Foundation's work.

Many readers of *Microscope* will already be aware of all or some of the charity's support services.

Often our 24 hour helpline is the first point of contact when people have concerns following a case of meningitis or septicaemia.

Sometimes this initial relationship will develop further. Our website and literature can help to start provide the in-depth information about the diseases and their effects that people often need.

For those who have lost a loved one to the diseases there is the leaflet *Living with Bereavement.*

For those living with after effects of the diseases, or their family and friends, our booklet, *What Happens Next?*, provides information about the ups and downs of recovery and living with after effects.

The case studies, provided by members of the Foundation, contained in both *Living with Bereavement* and *What Happens Next?* can help people realise that they are not alone in coping with the devastating effects of the diseases.

And it is this kind of support which is at the heart of the befriender network and home visiting scheme. There are currently over 100 trained befrienders drawn from our membership – people who truly understand the effects of meningitis and septicaemia as all have experienced the diseases themselves. A unique blend of knowledge and empathy can help those more recently affected through some of the darker days.

Whatever support is required the helpline is there 24 hours a days, 365 days a year to provide a sympathetic, listening ear.

The Foundation is committed to providing the best possible services for those already affected by the diseases. As part of that commitment, we need to let people know that the help exist in the first place. To help ensure that as many people as possible are aware, earlier this year we distributed a new leaflet *Meningitis and septicaemia – Support for you* to hospitals, GPs, communicable disease specialists and health visitors.

If you wish to access any of the Foundation's support services or have suggestions as to how we could help provide better support, please get in touch with your local office or call our helpline on **Free*fone* 080 8800 3344** (UK) or **LoCall 1890 41 33 44** (Republic of Ireland).

Brothers and Sisters' Support Day

We've already had a lot of interest in our forthcoming support day for bereaved brothers and sisters, but there are still some places available.

We hope that the day will give you the opportunity to meet and share experiences with others who have also a lost brother or sister to meningitis and septicaemia.

The day is fully funded by the Community Fund, so all travel expenses will be reimbursed. If you are over 16 and want to find out more, please call Jody Blake on the UK Freefone helpline 080 8800 3344 during office hours.

Update on after effects research

Two of the Foundation-funded projects investigating the after effects of meningitis and septicaemia have reported preliminary results in the past few weeks.

Research into after effects aims to provide information that will help health professionals improve acute and long term care of patients with meningitis and septicaemia to achieve the best outcome

University College, London researchers have been looking into social, psychological and practical after effects of meningococcal disease in teenagers.

One hundred and forty-four teenagers who had the disease were compared to a control group of teenagers using confidential interviews and extensive neuropsychological tests.

Early results suggest teenagers who had the disease are more likely to experience depression and other psychological difficulties. According to their own assessment their general level of health was not as good, and they felt that support from friends and acquaintances fell short of what they needed.

The study also confirms that memory, attention and mental flexibility are affected by meningococcal disease - something very frequently reported by the charity's members. Although those who had meningococcal disease did not fare as well as teenagers in the control group in exams, overall intellectual ability did not seem to be affected. There was also no apparent difference in employment status between the two groups.

However, the researchers were concerned to find that, among the teenagers who recovered from meningococcal disease, more than half had no hospital follow up, and they are investigating this.

Doctors and therapists at **St Mary's Hospital, London** have been assessing the everyday living skills and quality of life of children and young people who have amputations from meningococcal septicaemia, aiming to provide information for health professionals involved in their acute and long-term care.

Assessment is by interview and completion of practical tasks. All participants are living with their families with minimal assistance, though many have ongoing health needs including pain, scarring, differential growth, kidney problems, and cognitive difficulties.

Interestingly, it was found the extent of amputations did not have a major effect on ability to do everyday tasks and activities or quality of life. The biggest limitations included features in their surroundings like the presence of steps and access to buildings, and the attitudes and expectations of others.

Key themes emerging from interviews include a frequently faced dilemma about whether to inform others of their disability, anxiety about their appearance in comparison with peers and a focus on achieving personal goals.

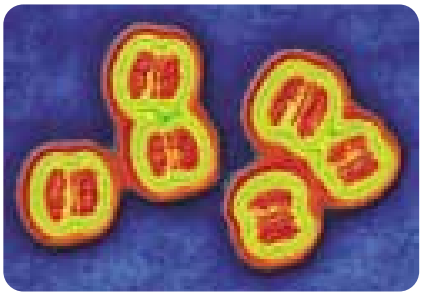
New findings on naturally acquired immunity from Bristol based researchers

Most people carry meningococcal bacteria in their nose and throat at some time in life, and yet very few get meningococcal disease.

We know there are genetic factors that influence why some people get the disease and others don't, and some strains of bacteria are more likely to cause disease than others. However, scientists believe the main reason we can carry the bacteria without getting ill is that we develop natural immunity.

Bristol researchers have found that the development of immune memory cells able to respond to the bacteria is fundamentally important, and that the capacity of immune memory cells to respond in this way is age-dependent. This may explain why Group B meningococcal vaccines tested so far do not seem to work in young children.

The research team used human tonsil tissue in their experiments, and they believe that the surfaces of the nose and throat (mucosal surfaces) are the key to the development of natural immunity. This research suggests that vaccinating using a nasal spray rather than an injection, which would mimic the natural route of immunisation, might be the most successful way to develop an effective Group B vaccine.



Meningococcal bacteria

Forward planning

Students make a huge contribution by fundraising for the Foundation. And the funds collected can be used to provide information about meningitis and septicaemia that could save their lives or those of their friends.

Students fall into the second most at risk group from the diseases. They are often motivated to work with the Foundation because they have been affected themselves, or their college or university may have had a case or cases in the past.

Last year almost £100,000 (€147,000) was raised throughout the UK and Ireland. This money has helped fund our 2003 awareness programme for students.

Timing is the key with colleges and universities. Autumn sees an increase in cases of meningitis and septicaemia and coincides with the first term of the academic year. This makes it the ideal time to alert students to the symptoms of the diseases, especially the new intake of first year students.

Posters, cards and card holders from our *Get it Sussed* range, along with materials from the Department of Health in England and the Meningitis Trust, were sent to hundreds of student unions, and, following the success of its launch last year, a big, bolder and better version of our student wall planner was distributed to students via accommodation officers.

Over 150,000 copies winged their way to halls of residence and rooms, allowing students to not only plan their academic and social year, but also have a constant reminder of the all important symptoms and action to take if meningitis or septicaemia is suspected.

And there's also a reminder of the dates of some of the Foundation's top student fundraising events, like London Loot and Flush Haggis. This keeps the circle of fundraising and production and distribution of potentially life-saving materials for young adults going.

Northern Ireland

Although most cases occur in autumn and winter, meningitis and septicaemia can strike at any time of the year.

Every year we try to get this point across by issuing a summer warning about the diseases. This year, in partnership with Mothercare, we were able to reinforce the message by holding in-store information days in Newry, Portadown and Lisburn.

Liz Hamilton, our Information and Education Officer, used the opportunity to remind parents that vaccines cannot protect against all forms of meningitis and septicaemia - therefore, knowing the symptoms of the diseases is still vital. Liz was armed with copies of *Meningitis Baby Watch* and *Tot Watch* to ensure that everyone left with the necessary knowledge.

Liz also took the awareness message to parents and carers of little ones at the Bloomin Tots Nursery in Dundrum and Inner East Belfast Sure Start.

Our relationship with Sure Start schemes throughout the province was enhanced by our attendance at a health and fun day organised by Lower Ards Sure Start. This proved to be a lively event with some very young volunteers helping to keep the literature on the Foundation's information stand tidy.

Children were also the issue at the first conference organised by the Parenting Forum NI. Key organisations concerned with parenting support and education, along with workers from many family community projects, attended. This was another wonderful opportunity to pass on our materials to those working with parents.

Scotland

As freshers across Scotland embarked on exciting new lives as students, Rili Craig, our Information and Education Officer, and her army of trusty volunteers have attended over twenty freshers' fayres, arming students with *Get it Sussed* symptoms cards for young adults.

It was very encouraging that the students we talked to had got the message that their level of risk was higher than that of other groups, and were prepared to address their concerns by means of our awareness materials.

Spreading the awareness message to students throughout Scotland is a huge and important undertaking only made possible with the support of our members. Thanks to all who helped at 2003 freshers' fayres.

The Foundation's partnership with companies through the Scotland's Health at Work (SHAW) scheme continues to develop and Rili has been travelling the country giving awareness talks to employees. Over 150 companies have requested our campaign packs this year and each has held a display in their workplace to heighten awareness of meningitis and septicaemia.

Community group work in Scotland also continues to grow; Rili especially enjoyed the morning she spent with over fifty Chinese grandparents in Edinburgh talking through a translator. Many of the group care for their grandchildren and were very keen to learn more about the symptoms of meningitis and septicaemia. The group found the session extremely helpful and all left with our Chinese symptoms information, just one of the 18 languages available on the Foundation's website.

England and Wales

Distribution of the new and improved wall planner for students has been a focus for activity.

The England and Wales office co-ordinated distribution throughout the UK. With the help of our friends at Securicor and, once again, our wonderful volunteers, our costs were kept to a minimum while distributing over 150,000 copies.

To help bolster our good relationship with the National Union of Students, who help with both the wall planner and *Get it Sussed* mailing to universities and colleges, our Medical Information Officer, Chantal Bougeard, attended the recent NUS training week. There she was able to talk to all of the newly incoming NUS officers for the new academic year, letting them know about the services that the Foundation can provide for their members.

Our helpline and membership team have been out and about in the community as well. Jody Webb has recently given a number of talks to nurseries and other childcare providers, including one of the many Sure Start projects that we are in contact with. Sarah Unsworth gave presentations to health professionals in Cheltenham and Northampton, as well as two talks to staff at an NHS Direct training day.

Conference organisers are often keen to distribute our materials free of charge to health professionals. Recently our triage card for nurses was featured at the annual Royal College of Nursing Child in A&E Conference, and our card for paramedics and ambulance personnel went down very well at the yearly Ambulance Services Conference.

Republic of Ireland

Our summer warning about meningitis and septicaemia was well publicised with many newspapers printing the Foundation's symptoms information.

We were delighted when all 41 Irish language summer colleges agreed to distribute our symptoms in the Irish language, especially as these colleges cater for 15-18 year olds, who are at a higher risk of contracting meningitis and septicaemia.

We have continued to provide *Meningitis Baby Watch* cards for inclusion in Bounty packs for new mothers. These packs reach 98% of all new mothers in Ireland. As a result, we are hoping that 57,000 new mothers will have potentially life-saving information in their possession by September 2004.

Continuing awareness work with companies has also been on the agenda in the last few months with awareness stands at both Schering-Plough in Wicklow and Pfizer in Dublin. Presently, we are distributing the Foundation's new wall planner and *Get It Sussed* literature to all 64 third level colleges. It is hoped that we can further impact on this distribution by holding awareness stands in some of those colleges.

It's not just about giving out information for our Information and Education Officers. Keeping on top of the latest advances, Evelyn Dooley recently visited the Meningococcal Reference Laboratory in Temple Street Hospital where she learnt how they collect and utilise information obtained on various forms of meningitis.

Presenter packs

Talks and presentations by staff and members to local community groups play an important role in getting the Foundation's awareness messages across.

Now anyone giving a talk or presentation can use our great new presenter pack. Consisting of guidance notes for the presenter and overheads, it's the complete kit for anyone needing to deliver a professional presentation on meningitis, septicaemia and the work of the Foundation. For those who have a liking for new technology, the pack is also available as a PowerPoint presentation.

The pack works in conjunction with the Foundation's video, *Holly's Story*, printed awareness materials and a collection box, should anyone wish to contribute towards the Foundation's work.

If you already give talks for the Foundation, or you would like to help us out in this way, get in touch with your local office or Helpline and Membership Officer Victoria Smith on 01454 280411 to add a touch of finesse to your talk or presentation.

Challenge issued following Scottish record

Fifty-three brave hearted Scots gathered at Auchterarder Airfield, Perth, to smash the Scottish Skydiving record for 2003.

Despite overcast skies, each jumper took their turn to experience this adrenalin rush, managing to raise a brilliant total of over £7,000.

Following the record, our Scotland office has really got the parachuting bit between their teeth and has issued a new Caledonian challenge - **300 miles for meningitis**. The challenge is to be part of an ongoing attempt to achieve a skydiving total of 300 miles within the next year. Each jumper participating will clock up two miles towards the total.

Scots aren't the only ones who've been throwing themselves out of planes at ridiculous heights for the Foundation. In England, Wales and Ireland, hundreds of people have taken the plunge. And it's not just a case of do as we say and not as we do, as the Foundation's Support Services Manager Paul George (pictured below) proved in June.

You too can become a parachuting star for the Foundation - contact your local office for more details.

Pulling power

Our old friends at The Battery Inn in Glenwherry's support for the Foundation over the years has been immense and continues unabated.

Proprietors Billy and Lana Ashe are forever organising a variety of events, with the highlight being their annual tractor pull. This year, by means of pulling a tractor from Sainsbury's in Ballymena to the inn, the pub's team raised another £4,000, bringing the grand total of support to over £22,000 since 1997.

On a similar theme, over the summer we've enjoyed a great deal of support from traction engine clubs throughout Northern Ireland resulting in thousands of pounds, including the Mid Ulster Vintage Tractor Club, Glenavy and District Vintage Club, Ballyronan and District Vintage Club, Co Armagh Vintage and Birches Vintage Club. Thanks to all concerned.

Member Imelda Brereton and friends after this year's Dublin Women's Mini Marathon where they raised a fantastic €5,000, contributing to the overall amount raised to date, approximately €27,000

Climb every mountain

Our Scottish supporters have been highly active over the summer. Not only have they pulled on their hiking boots as part of Munro Madness, they've also found time to take part in sponsored walks.

Over the August bank holiday weekend, 141 people were to be found over the Scottish hills for this year's Munro Madness. A huge thank you to all those who took part in this event.

Leading engineering company BAE systems raised a magnificent £2,200 through their annual charity walk in Fort William. Organisers Bob Penman and Lorraine O'Neil worked tirelessly to organise this event, which also included a pub quiz and raffle to help boost the final donation. Your efforts are very much appreciated.

Members and supporters gathered at Meadow Bank Stadium, Edinburgh to take part in this year's Great Scottish Walk. All tucked a considerable number of miles under their trainers, helping to raise an impressive £1,722 - and donations are still coming in.

Sheena Foster, Martin Beswick, Pat Foster, Dougie Potter, Gayle Richardson, Clive Allan and Sean Martin from Fife Police Constabulary HQ on the top of Braich Coire Chruinn-Bhalgain. The team raised over £800 for the Foundation as part of Munro Madness

YOUR LOSS IS OUR GAIN

If your New Year's resolution is to lose a few pounds...

...why not take part in our Slimathon?

"I am happy to be supporting Meningitis Research Foundation's Slimathon. Taking part in the event is a great way for you to support such a worthy cause and lose weight through healthy eating and exercise. Good slimming!"

Rosemary Conley

Meningitis Research Foundation

Slimathon 04

Starts 1 January

Call the Slimline for your registration form

England and Wales:
Tel 01454 281811
Fax 01454 281094
e-mail info@meningitis.org

Scotland:
Tel 0131 228 3322
Fax 0131 221 0300
e-mail info@scotland-meningitis.org.uk

Northern Ireland:
Tel 028 9032 1283
Fax 028 9032 1284
e-mail info@meningitis-ni.org

Republic of Ireland:
Tel 01 496 9664
Fax 01 496 9656
e-mail meningitis@oi.ie

Dear Supporter,

Meningitis Research Foundation

I've had a truly life-changing experience. Walking in the footprints of lost civilisations; drinking in the most intoxicating scenery; the Inca Trail surpassed my wildest expectations.

Before that, I visited a country filled with fire and ice, so alien it was like another planet, there is nowhere else in the world like Iceland. Just three hours away, this long-weekend trek took me to another world.

Colourful temples, fabulous wildlife and vast jungle landscape provided the perfect backdrop to six days trekking, rafting and elephant riding through Thailand's remarkable landscapes.

You really should experience it for yourself. Contact the Foundation for a free brochure and embark on your own challenge of a lifetime.

Best wishes,

Meningitis Research Foundation

Get Christmas wrapped up!

These are just a small selection of the delightful Christmas cards that we have - so get Christmas wrapped up and show your support.

To order, or for further information call your local office (number on back page) or visit our website at

www.meningitis.org

Meningitis Research Foundation

Calendar of events

November 1

Christmas Card Sale
Greenbank Parish Church, Edinburgh is the venue. Our Scotland office on 0131 221 3322 is the place for more information.

November 13/14

Fundraising/Awareness stand, Merrion Shopping Centre, Dublin
Come along and show your support.

November 16

Pop Concert, The Lemon Tree, Aberdeen
Re-live the hits from the past four decades - if you're still up to dancing. The Saturday Night Fever gang in the Scotland Office can tell you more.

November 21

Fundraising/Awareness stand
Blanchardstown Shopping Centre is the venue this time around. If you can give us a hand on the day call our Dublin office on 01 496 9664

December 6

Football Ground Collection
Ibrox, home of the mighty Glasgow Rangers, will, we hope, be surrounded by Foundation volunteers collecting as much money as possible. But this is only going to happen with your help. Give us a ring on 0131 228 3322 to become one of our marvellous volunteer collectors.

April 18 2004

Flora London Marathon
An early application for the Marathon will increase your chances of getting a place, for more information call our England and Wales fundraising team on 01454 281814 or email fundraisng@meningitis.org

Spotlight on ...

Iain Elliott has been a member of the fundraising team in the Bristol office for over two years.

He specialises in working with students in schools, universities and colleges in England and Wales. Iain's interest in this area of work started at Aston University and continued in a professional capacity at Hull. Following a diversion into the construction industry, Iain joined the Foundation.

As well as his work with students, Iain helps supporters with event management - from coffee mornings for a couple of friends to a ball for hundreds.

Iain's happy to work with you, giving help and support, providing awareness materials and fundraising resources, helping to get publicity and, if necessary, someone to collect that all important cheque after the event. Give him a call on 01454 280414 or email iainelliott@meningitis.org if you're in England and Wales, or call your local office.

Business cards

There's a great selection of Christmas cards in this year's brochure for UK businesses looking for personalised cards.

We've teamed up again with Powell Publishing and with the promise that 35% of the price of cards ordered will come to us, it will be a great Christmas present from you to the Foundation if your business gets involved.

To get the ball rolling and receive your free copy of the brochure, contact Hannah Duncan on 01454 281811 or get on-line at **www.charitychristmascards.com**

Well done to the MRF Challenge Crew (see last edition) who crossed the finishing line in the Fastnet Race third in their class. Over £48,000 has been pledged to the Foundation as a result of their endeavours. Many thanks to all involved, particularly Arabella Sackhett for her tremendous help in organising the challenge's launch reception at the Halcyon Gallery

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