

Microscope

Autumn 2004

Race Against Time

The Foundation's new awareness leaflet, *Race Against Time*, aims to dispel myths about meningitis and septicaemia.



The launch of *Race Against Time* in Scotland

Using a question and answer format, the leaflet tackles common misconceptions about the diseases, such as the idea that they only affect children and young people, or that available vaccines protect against all forms.

Opening out into a mini-poster for handy symptoms reference, *Race Against Time* also emphasises the need to act quickly if a case is suspected.

Read more about the Foundation's *Race Against Time* campaign on page 5.



Vaccine update

Children under age five who have had pneumococcal meningitis or septicaemia can now get conjugate pneumococcal vaccine.

Pneumococcal vaccines:

For some while, the Foundation has been urging governments to extend protection against pneumococcal meningitis and septicaemia, the second most common kind of bacterial meningitis.

We are therefore pleased that the conjugate pneumococcal vaccine, previously only available to under-two's with risk factors that make them prone to the disease, has been extended to at-risk under-fives in the UK.

Additionally the at-risk recommendation now includes children who have had pneumococcal meningitis and septicaemia or who have been hospitalised with pneumonia. Others

now able to get the vaccine in the UK include those of all ages who have been hospitalised with asthma, need steroids to control asthma, have shunts, have had surgery to their skull or have any other condition that might cause leakage of cerebrospinal fluid.

This is an encouraging step forward but as all babies are at risk the Foundation will continue to press for the earliest possible introduction of pneumococcal vaccination into the routine immunisation programme.

5-in-1 vaccine:

Because of changes to the polio and pertussis (whooping cough) vaccines the current 4-in-1 vaccine, which immunises against diphtheria, tetanus,

pertussis and Hib (which causes meningitis), is being replaced in the UK with a new 5-in-1 vaccine. This now includes a polio element, formerly given separately to young children as a live oral vaccine. The Hib element of the vaccine is just the same as before, but changes to other components will reduce the number of minor, but troublesome, reactions – such as soreness of the injection site.

For further information on vaccines against meningitis and septicaemia and these recent changes, contact the Foundation's helpline or log on to www.meningitis.org

From Denise Vaughan



The number of deaths from meningitis and septicaemia in the UK and Republic of Ireland went up from 329 in 2002 to 389 in 2003. This is of great concern to us at the charity, and was a major impetus to us in launching our latest autumn public awareness campaign. This rise is due to types of meningitis and septicaemia that vaccines in the routine vaccination programme do not prevent. Cases and deaths from Group C meningitis and septicaemia continue to fall.

I was very pleased to be asked to co-host the recent World Conference of Meningitis Organisations, with the Meningitis Trust and St Mary's Hospital, London, at the Runnymede Hotel & Spa, Surrey.

The Conference was supported by Wyeth Vaccines, and brought together groups from around the world who are working to combat meningitis and septicaemia. At the meeting, the Foundation was able to help share best practice with these groups, and I hope it will help towards our vision of a world free from meningitis and septicaemia.

We congratulate Wyeth on winning the prestigious 2004 UK *Prix Galien* prize in the drug innovation and health category for their pneumococcal vaccine, which is being used to protect at-risk babies and young children against life-threatening pneumococcal diseases (see front page). I would also like to thank the employees of the company for selecting us as their charity to support.

In common with many charities, we are still experiencing a difficult fundraising environment. I know so many of you already do a great deal, for which I thank you, but if you are able to help, do please consider us. This newsletter contains some ideas; or call your local office to talk through your own ideas. We'd love to hear from you.

Thank you.

A handwritten signature in blue ink that reads "Denise Vaughan". The signature is written in a cursive, flowing style.

Chief Executive

SUPPORT FOR YOU

Support offered by the Foundation to people already affected by meningitis and septicaemia takes a number of forms.

Befriending, home visits and telephone conversations help to establish and develop one-to-one relationships.

But support can also come through meetings which bring together groups of people with similar experiences.

Recently at Donnington Park, the Foundation provided a forum for bereaved parents and brothers and sisters to come together to share their experiences. Many participants

commented on the mutually supportive atmosphere that the day created. Many others appreciated the input of the guest speaker, Sarah Willis from the Childhood Bereavement Network.

Demand has been such that planning has already begun for a similar gathering in the new year.

If you are interested in attending, do give the membership department a ring on 01454 281811.

Life savers

Evidence continues to mount about the effectiveness of our awareness materials.

Chris Deering works in a further education college in Aylesbury. Therefore, with our regular mailing of academic institutions, she was well used to seeing our *Get it Sussed* material.

Little did she know that the symptoms information would be relevant to her own family. That was until her five-month-old grandson, Joshua, started feeling ill. When a rash developed, along with other symptoms Chris had seen on *Get it Sussed*, she moved quickly to get Joshua medical help. We are delighted that he has now made a full recovery.

Lynn Roberts from Bangor is a senior A & E nurse. Again, she would have expected that the Foundation resource she saw, *Vital Signs for Frontline Nurses*, would be applied to her professional rather than family life. But the card's information held her in good stead when her four-year-old son Iwan suddenly fell ill. Recognising the symptoms, Lynn got prompt medical help for Iwan, and credits the resource with saving his life.

In the last edition of *Microscope*, we mentioned jockey Errol Taylor, who arranged for the Errol Taylor Meningitis Research Foundation Stakes to be run at Doncaster. This is just part of the support that Errol has given us since he contracted meningitis a number of years ago. Part of his voluntary work has been to distribute the Foundation's

pin badges for sale in Doncaster's shops. The badges come with a symptoms card, which is good news for three-month-old Frankie Watford. His mum, Amie, bought one of the badges and it was from the accompanying symptoms card that she was able to recognise the symptoms when Frankie fell ill.



Member Amie Watford with partner Carl and son Frankie

Septicaemia and amputations

Findings from a Foundation-funded study of children with amputation following meningococcal septicaemia.



Foundation member Jake Hardcastle playing with his dog, two years after having his leg and fingers amputated as a result of meningococcal septicaemia

Having amputations due to septicaemia can cause more problems than amputations for other reasons; septicaemia often affects more than one limb, and may cause other medical problems.

Very little is known about the experience of children who have amputations after meningococcal

septicaemia, so there is a limited amount of published information to help doctors look after these patients. The multidisciplinary team treating them may not be prepared for the coordination of care needed between different health professionals, hospitals and the community.

Doctors and therapists at St Mary's Hospital in London have been studying children with amputation due to meningococcal septicaemia.

Nearly all these children developed strategies to help compensate for their amputations.

Generally they reported a good quality of life and focused on achieving their individual work, study and family goals. However, appearance was also a fundamental issue, with many unsure as to who and how much they should tell about their amputations.

The project team plans to develop a resource for families and doctors to use when young people are facing the prospect of amputation due to meningococcal disease.

Green light for septicaemia treatment

One of the main reasons why people die from meningococcal septicaemia is that extensive, catastrophic clotting can block blood flow in vital organs.

Foundation-funded research has shown that in patients with meningococcal disease, a natural substance, called protein C, which works in the body to stop blood clotting from getting out of control, is lost or used up.

These findings created a strong impetus towards international trials of a genetically engineered form of activated protein C in children with septicaemia. These trials are still underway.

Meanwhile, international trials of the drug in adults with severe septicaemia showed that it could improve survival. Activated protein C was licensed in Europe in August 2002, but implementation has been slow.

For this reason, the National Institute for Clinical Excellence (NICE), which was set up to eliminate post code prescribing, was asked to provide guidance on when activated protein C should be used.

The Foundation was involved in the NICE appraisal process, and members Helen Smith and Diane Moran took part.

NICE has now published its final recommendation, that the drug should be used to treat adults with severe septicaemia that has caused failure of two or more organs, who are being given intensive care support.

The Foundation welcomes this decision. Mortality in patients with severe blood poisoning can be as high as 50%, and we are delighted that funding early research on this topic has contributed to such a positive outcome that could save many lives.

Neonatal meningitis

Findings have been emerging from a study into long-term after effects of neonatal meningitis.

Researchers based at Imperial College London and funded by the Foundation have been studying all five year olds throughout England and Wales who had meningitis as newborns (neonatal meningitis) in 1996-97 and have been comparing the results with an earlier study which looked at the outcome of neonatal meningitis in a group of 5 year olds who had the disease in 1985-87.

Over this time period the drugs used to treat the disease have changed and there has been an increase in the use of preventative antibiotics in high risk births (e.g. low birth weight, prematurity) and there have been improvements in neonatal care. This has been reflected in a decrease in the fatality of neonatal meningitis from 22% to 6.6%. Results

from this study have confirmed the researchers' previous findings from the earlier study that neonatal meningitis is associated with a high level of long term after effects. They also found that, despite the drop in the number of deaths between the two time periods, the proportion of children who recover with severe to moderate after effects is similar. All but one of those with severe after effects had laboratory-confirmed meningitis and at least one risk factor such as low birth weight or prematurity.

Further analysis of the type of after effects experienced by the two groups has shown a smaller number of children suffering from hearing loss, seizures (fits) and neuromotor disabilities in those who recovered from neonatal meningitis in the 1990's study.

INFORMATION & AWARENESS

Get it Sussed

Students are in the second highest risk group for contracting the diseases. Once again, the Foundation targeted this population, as they began or returned to college after the summer break.

In combination with the Meningitis Trust and the Department of Health in England, all Student Union Welfare Officers were mailed with targeted materials from all three organisations, including art cards and posters from our *Get it Sussed* range of information for young adults.

Also, over 155,000 *Get it Sussed* wall planners were sent to academic institutions, mainly via accommodation officers, throughout the UK and Ireland to give students a visible reminder of the symptoms throughout the year.



The Foundation student wall planner 2004-2005

The Foundation's Get it Sussed work with students and young adults has been selected as a winner in the inaugural Community Support Programme awards, organised by Dublin Bus. Dublin office manager Anne McCoy is pictured at the awards ceremony which was attended by the President of Ireland, Mary McAleese



Scotland

The value of awareness talks was recently graphically illustrated.

Since the death of his son David, Michael Pattie has been a staunch supporter of the Foundation.

In addition to his magnificent fundraising, Michael has also been heavily involved in raising awareness of the diseases.

Michael regularly gives talks throughout the community, and last year, accompanied by Information and Education Officer Rili Craig, Michael visited a Dumfries and Galloway school.

The talk obviously lodged in the memory of the Bonn family. A few months later, when Kirsty Bonn was feeling under the weather, she remembered her mother's attendance at Michael's talk and recognised what she thought could be the early onset of meningitis. On getting herself off to hospital, the disease was confirmed. During her week in hospital, Kirsty was told that her prompt recognition of the symptoms probably saved her life.

It is always gratifying when awareness work results in the saving of a life, but it is particularly apt that after contributing so much time and effort, Michael's work

should have been rewarded in this manner.

Buoyed up by this success story, Rili continued with her programme of talks over the summer, with particular emphasis on the parents of young babies. Following an invitation from a local health visitor, she travelled west to Largs to present to an audience consisting of mothers and their babies. As all the babies were under one it made for a noisy but worthwhile experience.

And there were more babies at Mothercare in Edinburgh for an information morning. New mums snapped up the information Rili had on offer, as they eagerly placed free copies of the Foundation's *Baby Watch* and *Tot Watch* information in their shopping baskets.

As part of the Foundation's *Race Against Time* awareness campaign, Rili and Foundation members have been to Fresher Fairs across the country, talking to students and handing out *Get it Sussed* awareness cards by the box load.

Republic of Ireland

Alerting students to the dangers of meningitis and septicaemia has also been an important part of our work in the last few months in the Dublin office.

Our wall planner has proved to be a great hit. After distribution, along with *Get it Sussed* material, to all third level colleges, we were inundated with requests for further copies for student accommodation areas. We'll be following up this interest with visits to colleges to hold awareness events.

Awareness stands were the order of the day during visits to Tallaght and Blanchardstown hospitals. The days were a great

success as thousands of awareness leaflets were handed out.

New mothers are the target as the Foundation continues to supply *Baby Watch* cards for Bounty Packs. These packs reach 98% of all new mothers in Ireland. If everything goes to plan, 57,000 new mothers will have a *Baby Watch* card in their possession by September 2005.

Northern Ireland

You may know that the majority of cases of meningitis and septicaemia come in autumn and winter.

However, it is important that people are aware that the diseases can strike at any time of the year. We were, therefore, pleased that so many regional papers in Northern Ireland chose to publish articles about the potential for cases in spring and summer.

Following this, preparations for the autumn awareness campaign have taken centre stage. Once again, we are indebted to all of our members who agreed to be media representatives for the campaign. This work by our members often provides the main key to getting important information messages out.

An important element of the campaign is to make students more aware of the diseases. So, over 9,000 copies of the *Get It Sussed* art cards were distributed to Queen's University, Belfast and

campuses of the University of Ulster.

Our Northern Ireland Information and Education Officer, Liz Hamilton, recently attended the launch of a new venture called Parents and Paediatricians Together. Our good friend Dr Bob Taylor from Belfast's Royal Victoria Hospital for Sick Children is one of the patrons of the organisation, which aims to open up new opportunities for parents of disabled children to influence paediatric and child health services, an issue close to the Foundation's heart.

If you have any thoughts about how to improve services for children with additional needs in Northern Ireland, then Catherine Flannigan, the Paediatric Project Officer would love to hear from you. Contact Liz in our Belfast office for further information.

England and Wales

While preparation and delivery of the *Race Against Time* campaign has been an important focus in the last couple of months, we have also found time to get out and about.

Head of Research and Medical Information, Linda Glennie presented the new *Lessons from research for doctors in training* handbook at the Oxford Infection and Immunity Conference, where it was very well received by delegates. Meanwhile, Information Officer Chantal Bougeard updated nurses as part of East Lincolnshire Primary Care Trust's Immunisation and Vaccination study course.

Chantal also had an information stand at the Royal College of Physicians Intensive Care/A&E meeting.

Victoria Smith from our Membership and Helpline department recently visited RAF Lyneham to raise awareness of the diseases with new mums.

The Foundation has

contributed to a review of nurse prescribing by the MHRA, the UK's medicines regulatory agency. In future, nurses may be authorised to give antibiotics in suspected cases of meningitis and septicaemia.

Medical Advisory Service nurses play a crucial role in staffing the out-of-hours helpline, and the Foundation regularly updates them on current issues.

The highlight of the most recent training day was an illuminating talk from Linda Diggle, Principal Research Nurse/Manager from the Oxford Vaccine Group on the safety of multiple vaccines, and changes to the vaccine programme for children in the UK (see front page).

Autumn awareness campaign

Using our new leaflet as its centrepiece (see front page), our autumn *Race Against Time* campaign delivered crucial messages on the dangers of meningitis and septicaemia.

All GPs and other key personnel in primary care in the UK and Ireland received copies of *Race Against Time* for their patients.

England and Wales The launch of the campaign took place at Backwell school near Bristol where pupils released 370 balloons, representing the number of lives lost last year in the UK to meningitis and septicaemia.

Scotland The launch was marked with a media photo shoot at Meadowbank Sports Stadium, followed by an open day at our Edinburgh office for members and supporters.

Republic of Ireland International athlete Catherina McKiernan and her husband, journalist and broadcaster Damien O'Reilly, helped at the launch in Phoenix Park, Dublin.



Belfast Race Against Time Olympics

Our **Belfast** office held a *Race Against Time* Olympics featuring pupils from Botanic Primary School.

As launch events were happening, members and staff were giving interviews to newspapers, radio and television throughout the UK and Ireland. Coverage highlighted the free availability through our helpline of *Race Against Time* resulting in hundreds of packs being sent out.

Many thanks to all our members who were prepared to tell their stories.



Olympian Catherina McKiernan and husband Damien O'Reilly

Legends in the making

Q: What's the best way that businesses can spend lunch hours?



The answer is to begin the quest to become lunchtime legends.

Yes, our on-line quiz is back and this time it's better than ever as Scottish and Irish businesses are also invited to prove that their clogs are indeed clever by testing their midday mindpower.

This really is the chance of a lunchtime and you'll be raising money for the Foundation at the same time.

Starting in November, questions will be dispatched Wednesday lunchtimes via email and you've got your lunch hour to use all of your wit and wisdom to come up with the answers and get them back to the quizmaster.

After the four lunchtime quizzes, the highest scoring team in the Republic of Ireland will take on the mantle of that country's Lunchtime Legends and win the prestigious Once In A Lunchtime award.

In the UK, after the four lunchtime quizzes, the highest scoring teams will be invited to compete head-to-head in the UK grand finals, to be hosted in Bristol and Edinburgh in January 2005.

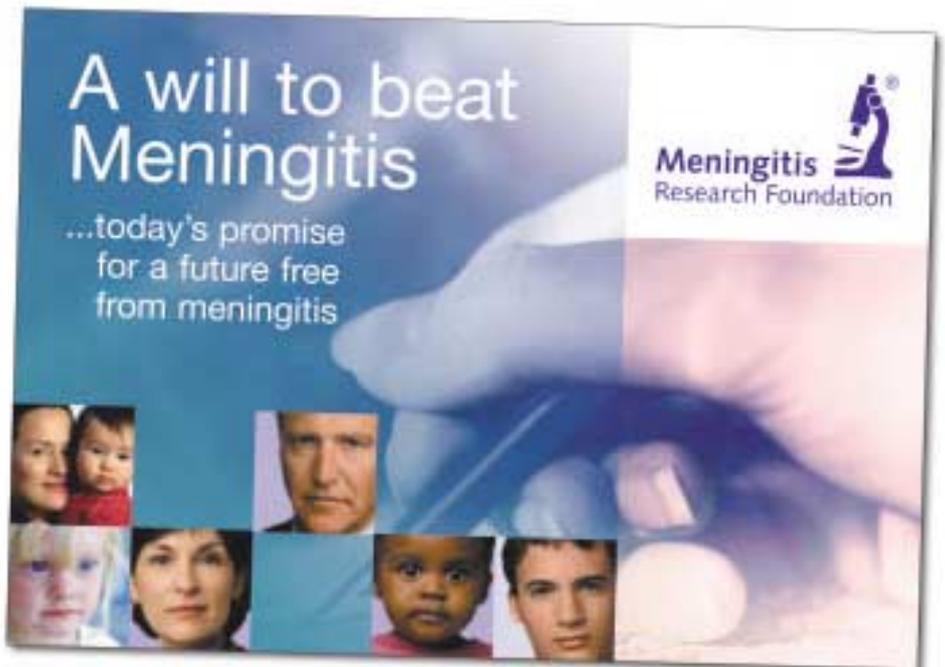
We're looking for teams of up to a maximum of five people to compete. You can enter as many teams as you like.

It costs just £60/€100 (inc VAT in UK) per team - that's just £3/€5 each per week.

Get involved by visiting our website at www.meningitis.org and downloading the application form or calling your local Foundation office.

Remember us in your will

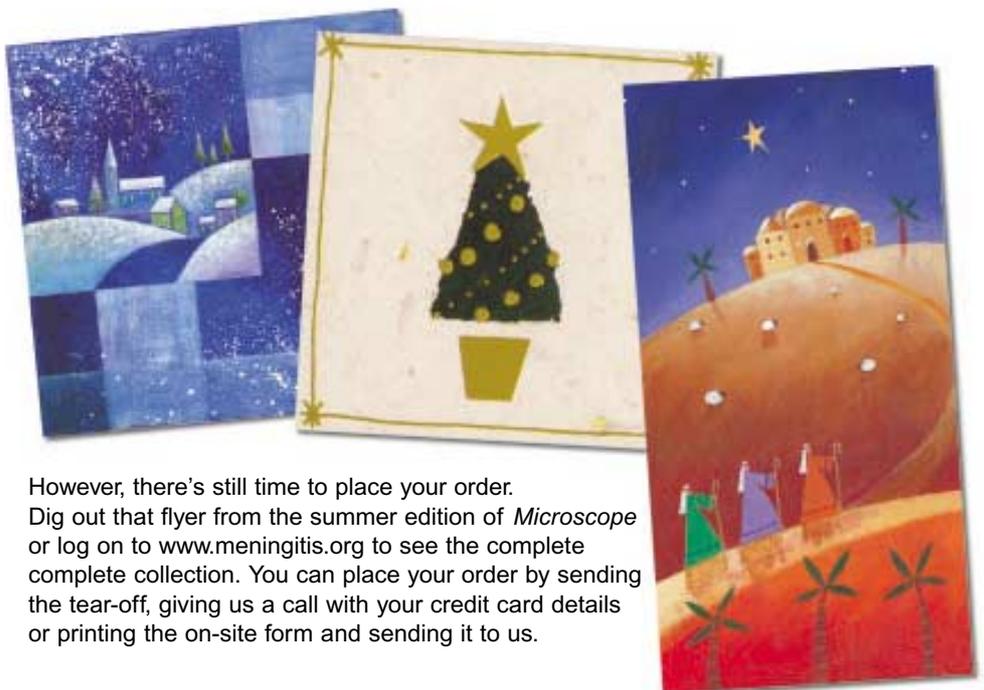
If you are making a will or reviewing your existing will, please consider including the Foundation in your bequests.



For your free leaflet on leaving a gift to support our work, telephone us on 01454 281814, and in your will make a promise today for a future free meningitis and septicaemia.

Festive cheer

This year's selection of Christmas cards is really selling well.



However, there's still time to place your order. Dig out that flyer from the summer edition of *Microscope* or log on to www.meningitis.org to see the complete collection. You can place your order by sending the tear-off, giving us a call with your credit card details or printing the on-site form and sending it to us.

Tee time

Determined supporter Robert Richardson completed a challenge of a lifetime when he played 100 holes of golf in one day to raise a magnificent £14,500 for the Jenna Dempster Superstar Fund on behalf of Meningitis Research Foundation.



As the sun rose in Dumfriesshire, Robert was already striding down the fairway, sinking balls in Sanquhar and putting perfectly in Powfoot.

Supported by a nine strong team (pictured approaching the last hole), including committee members Hugh Broadfoot and Jenna's father John, Robert continued well into the night and finished his challenge at Galloway Golf Club.

After completing his feat, Robert said, "I wanted to support the Jenna Dempster Superstar Fund and it

seemed natural for me to pick up a club and raise money by doing something that I love. The response we have received has been tremendous, with donations from local companies, friends and family. I am absolutely delighted by the final total raised and it just goes to show how well Jenna was loved and respected in Dumfries."

We would like to say a huge thank you to Robert, Hugh, the Dempster family, and all others who helped make this event such a huge success.

On a similar theme, many thanks also to Margaret O'Brien, the charity's newest trustee, for organising the fourth of her annual golf classics. A great day was had as the sun shone on over 40 teams playing the magnificent Turvey Golf course before, later that evening, local band The Pirates entertained the crowds in the clubhouse.

Dotty, spotty - and maybe slightly potty. The staff at Wyeth went one step further than your usual dress-down day to raise more than £4,000 for the Foundation. If it could be worn, it had spots on it. If it could be baked, it had spots on it, as Dotty Friday gripped the pharmaceutical company



Jump success

Many thanks to all the brave members and supporters who made National Jump Day such a success.

With the money still rolling in, over 130 jumpers took to the skies and raised over £21,000 for the Foundation.



Richard Clarke and friends from Armagh who took part in a sponsored cycle and raised £670



Five year-olds Ella Gaywood and Tom Baggott at the fourth annual youngsters walk organised by Ella's aunt and Tom's mum, Sue Baggott. Sue's hoping to raise £2,500 this year

Calendar of events

October - December Collections

Could you spare some time to hold a collection at your local supermarket or town centre in the run up to Christmas? If so call your local office for further details.

November

Trading Treasures

We don't know the exact date yet, but look out in November for ITV1's new daytime series Trading Treasures where one of the programmes features a Foundation team pitting their wits in a car boot sale challenge against representatives from another charity.

November 18 - 28

Thailand Jungle Trek

If you like it hot and steamy then Thailand's the place for you on this Charity Challenge trip. More information on 01454 281814.

November 6

Christmas Card Sales

Supporters are invited to attend card sales at Green Bank Parish Church,

Morningside and the Methodist Central Church, both in Edinburgh. More details from our Scottish office on 0131 228 3322.

November 15

Scottish Members' Meeting

Scottish members are invited to the next Edinburgh Members' Meeting, which will be held between 7.30pm and 9pm at the Edinburgh Office. Contact the office for more information.

December 4

Dublin Megaraid

Regular readers of *Microscope* will know of the continuing success of our UK megaraid. Now for the first time students from the UK and Ireland will join forces and descend on Dublin for a collecting frenzy.

January 31 - Easter

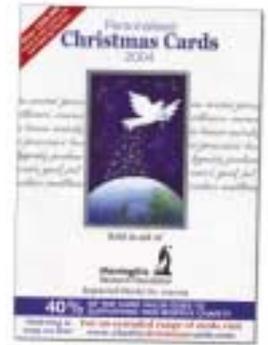
Slimathon 2005

That time of year is fast approaching, when after the Christmas cheer the pounds pile on. Fight the flab and take up our brand new Slimathon challenge. For further details contact your local office and keep an eye on the website for more information - www.meningitis.org

Business cards

Has your firm chosen its cards for Christmas?

If not, we hope you'll consider ordering from Powell Publishing's range of corporate cards, as 40% of the value of card orders will come to the Foundation.



Give the Foundation a call on 01454 281814 for your free catalogue.

Give us a dog and bone

Virtually all of us have old mobile phones hanging around we don't know what to do with.

Well the Foundation can turn those old phones into money. We've linked up with Community Fonebank who'll not only give us £5 for each phone, but will also recycle them for use in developing countries to improve communications.

So root out those old phones and send them to the Foundation's head office in Bristol.

Award reward



Congratulations to Foundation member Judy Tomlinson who won Best Fundraiser in the national Marks and Spencer volunteer awards. Judy has been fundraising for the Foundation since the death of her fourteen-year-old daughter, Natalie, from meningitis and septicaemia in 1996.

Judy's hard work has seen her raise an incredible £112,000 for the Foundation and thanks to Judy's success at the awards, Marks and Spencer are donating a further £500 to the Foundation.

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www.meningitis.org

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Charity of the year

Being nominated as a business' charity of the year can pay dividends for the Foundation both in terms of raising awareness and funds towards our fight against meningitis and septicaemia.

It's often the case that to become a charity of the year you need to be nominated by an employee. Therefore, do you know anyone who works for a major blue chip or household name company who would be prepared to nominate the Foundation for 2005?

If you can help, give Kate Guyatt a ring on 01454 281814.