

# The newsletter for members and friends of Meningitis Research Foundation Research Foundation Summer 2005

# **Scientific Conference 2005**

The Foundation has announced plans for its 2005 international conference, *Meningitis and Septicaemia in Children and Adults: Burden of Illness, Management and Prospects for Prevention.* 

The conference will bring together experts from around the world in critical care, infectious diseases, epidemiology, immunology, vaccinology and molecular medicine from both the paediatric and adult settings.

Taking place at the Royal Society of Medicine, London on Wednesday 23 and Thursday 24 November 2005, day one of the conference will examine the burden of disease and the clinical management of meningitis and septicaemia. On day two, the focus will shift to current and future vaccines.

To find out more about the conference, log on to the Foundation's website at www.meningitis.org

### Research



The search for a MenB vaccine

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# Taoiseach in major speech on meningitis

Foundation staff were delighted to meet Mr Bertie Ahern TD, the Prime Minister of Ireland, at a fundraising lunch organised by patron Liam Mulvihill and his family.



Patron Liam Mulvihill, Joanne Cronnelly, Bertie Ahern TD, Máire and Daráine Mulvihill, Diane McConnell and Denise Vaughan



Marvin makes music with the Ulster
Orchestra at the
Northern Ireland launch of our nurseries, playgroups and schools fundraising spectacular – Make Music with Marvin. Join in throughout the UK and Ireland by contacting your local office

At the event, Mr Ahern praised the inspirational courage, determination and positive outlook of the Mulvihill family when daughter, Daráine, almost lost her life to meningococcal septicaemia in 1999.

Mr Ahern went on to talk about the effectiveness of the Meningitis C vaccine campaign in Ireland in reducing cases in the country. However, he warned that vigilance against meningitis and septicaemia is still needed.

We were grateful to Mr Ahern for also praising the work of the Foundation. He commented, in relation to the annual awareness campaign in Ireland, that, "This represents just one of the important measures being taken by the Foundation who are working not only in Ireland, but in countries across the globe, to ensure that we attain a world free of meningitis."

# Support for You



The latest befriender training course

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### **Fundraising**



A big cheque from the Jenna Dempster Superstar Fund

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# Microscope | Summer 2005

# From **Denise** Vaughan



As another financial year starts, I would like to mark this milestone by thanking all our members, patrons and other supporters for your ongoing support for our

The trustees continue to give top priority to funding vital research, as this is the only way we will put an end to meningitis and septicaemia. In 2004/05 the charity again spent over £1 million on research, bringing total expenditure on this aspect of work up to over £11 million since the charity was set up in 1989. Many advances have been made, some of which are described in this issue, but more work is urgently needed.

Meanwhile our work to inform the public and health professionals about the diseases and to give support to people affected continues unabated. I hope you find the articles about recent activities of interest.

Taking part in events such as the Big Pedal (see page 7) is just one of the ways that you support our work in the fight against meningitis and septicaemia. Regular giving to the Foundation and remembering us in your will are other ways that you can

We have a whole range of regular giving initiatives to make your giving easier. Have a look at our website at www.meningitis.org for more information.

The website is also the place to go to have a look at our new section for business partnerships. We have enjoyed tremendous support from the business community over the years, and hope that many more firms will join us in our vision of a world free from meningitis and septicaemia.

You will find information with this edition of Microscope on our range of Christmas cards, notelets and wrapping paper for this year. We do hope that you'll take a look and place an order.

Vauglan

Chief Executive

# Support for You

Many members are aware of the support services that the Foundation offers to those who have been affected by meningitis and septicaemia.



Members at the latest befriender training course

But it is important that the charity continues to reach out to those who need help and support, particularly those currently experiencing the diseases.

Our Meningitis and Septicaemia: Support for you leaflet alerts families and friends to the fact that they need not be alone in coping and that we are here 24 hours a day to listen and support.

The leaflet has recently undergone a redesign and the Foundation is currently distributing it to key outlets throughout the country - such as hospitals with critical care facilities.

We were delighted to see everyone at our recent Annual Befriender Day. Feedback was highly positive, and the day is becoming an increasingly important date in the Foundation's calendar.

It may well be that at next year's Befriender Day we see new members who have taken part in the latest Befriender Training Course that ran in June and July. Many thanks to the Big Lottery Fund for all their support for our befriending initiatives.

# Richly deserved awards

It is highly gratifying when work in fighting meningitis and septicaemia is recognised by national awards.

Six pupils at Hardenhuish School, Wiltshire recently scooped the Diana, Princess of Wales Memorial Award for their hard work in raising funds for the Foundation over the last three years.

Helen Finnamore, Daisy Newsome, Jessica Sandler, Elizabeth Jones, Wendy Graham and Eleanor Gillian have raised over £15,000 since the death of their friend Kate Dutton in 2002. Their work has been inspirational to everyone at the Foundation and the award is well earned. Well done girls.



The Hardenhuish girls with their awards

Following on from her Scotswoman of the Year and Volunteer Fundraiser of the Year awards, Olivia Giles has now landed Scotland's Junior Chamber International Outstanding Young Person Award 2005.

The nomination for the award cited Olivia's 'outstanding contribution to fundraising and raising awareness of meningitis' - a sentiment that is echoed by all here at the Foundation.

# Further developments in the ongoing search for a MenB vaccine

Meningitis and septicaemia caused by Group B meningococcal bacteria (MenB) remains one of the leading causes of life-threatening infection amongst children. Unfortunately, no vaccine is yet available to protect against it.

However, much research is currently underway to develop a MenB vaccine and three important new articles on the subject have been published by Dr Chris Tang and his team at Imperial College London. The Foundation has been able to fund this work thanks to a very generous donation from Olivia Giles' Leap for Meningitis fundraising event.

### Proteins necessary to cause disease

Bacteria cause disease by growing, reproducing and producing toxins. To do this, they manufacture many different proteins which all have different roles. Scientists believe that some of these proteins could be used in the development of vaccines. Researchers on this project discovered that two proteins, previously identified in this Foundation-funded research, can protect mice against Group B meningococcal infection. Although some distance away from offering complete protection (as the MenC vaccine does), this research is another step closer to immunisation against MenB.



Research at Imperial College, London

### Bacteria need nutrients too

Bacteria need nutrients to grow, reproduce and also avoid being captured by our immune systems. Proteins (like the ones we mentioned above), manufactured by the bacteria, help them 'digest' and use these nutrients. New research has shown that if proteins of Group B meningococcal bacteria are damaged, the bacteria lose their ability to escape the immune system. Further research will determine whether vaccines to 'knockout' these proteins may be feasible. By starving the bacteria of the food they need, it might be possible to block infection.

### Discovering new genes

Meningococcal bacteria have the ability to 'pick up' new DNA (nature's blueprint for storing genetic information) from other bacteria. This allows them to adapt to changing environments and may help them to evolve to escape the effects of treatments or vaccines. The development of antibiotic resistance is an example of this. Scientists have been looking at which genes enable meningococcal bacteria to do this and further research should be able to use the discoveries they have made to develop new approaches to prevention and treatment.

# Other news from Foundation-funded projects

Findings of a confidential study funded by the Foundation have been published in the British Medical Journal.

This study looked at deaths between December 1997 and February 1999 in children under 17 years of age in England, Wales and Northern Ireland from meningococcal disease.

Researchers at the Royal College of Paediatrics and Child Health and Paediatricians at Imperial College London have discovered three main problems that increase the likelihood of death from meningococcal disease.

Children who were looked after by doctors with no paediatric training were more likely to die, as were children treated by junior doctors with insufficient consultant supervision. Cases where treatment did not follow a widely available protocol were also more likely to die.

Whilst it is distressing to discover failures in our healthcare system, identification of these failures is necessary to move forward and improve treatment in the future.

Many of the families who took part in this study are also members of the Foundation but because it is a confidential audit, we have no record of which of our member families were included. More details of the study will be released in the next issue of *Microscope* but if you feel that you would like to talk this over please contact the Foundation's helpline.

### **Diagnosis**

Meanwhile, work at Belfast City Hospital has revealed that a complex method for identifying different types of bacteria, developed previously with funding from the Foundation, is proving to be a valuable laboratory tool. It may be used along with other laboratory findings to provide a quicker diagnosis of patients with suspected meningitis.

### Neonatal meningitis

Finally, scientists at Lund University, Sweden have been investigating Group B streptococcus (GBS) bacteria, the biggest cause of neonatal meningitis (meningitis in newborn babies) in the UK and Ireland. These bacteria have proteins on their surface and rapidly increasing knowledge of these proteins should prove useful in the development of a vaccine.

# **England and Wales**

The success of the Foundation's new booklet for community nurses, *Vital signs, Vital issues*, has required a rapid reprint of the resource. The Foundation took the opportunity to update information regarding risk factors related to pneumococcal vaccinations according to new guidelines from the government.

Our new Information Officer, Arleen Flack, has been out and about speaking about recognition and prevention of meningitis and septicaemia, and promoting the Foundation's resources for health professionals. One of her destinations was Taunton, where she gave a talk at a study day organised by Somerset Health Protection Unit.

One of the key health professional audiences for the Foundation are Consultants in Communicable Disease Control

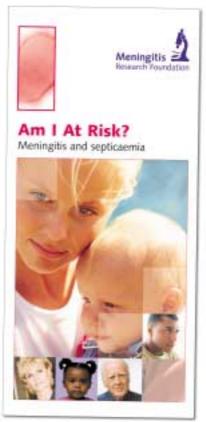


Arleen Flack at Imperial College's Child Health Surveillance GP course

(CCDCs). One of their main roles is to deliver the public health response when there has been a case of meningitis or septicaemia in their local community.

In their response, CCDCs often use the Foundation's Am I at Risk? leaflet to address concerns and to deliver the facts about the diseases. At the recent **Health Protection Agency** organised conference our Helpline Coordinator, Shirley Gieron, got to talk to many CCDCs about recently introduced or revised resources, including Am I at Risk?

Whilst in our Bristol office we were delighted to welcome Caroline Haines as the main speaker at our recent annual Learning at Work Day.



Am I at Risk?

Caroline is Consultant Nurse in the Bristol Children's Hospital Paediatric Intensive Care Unit. In a fascinating presentation, she spoke about intensive care management of children with meningitis and septicaemia.

# Northern Ireland

Although most cases of meningitis and septicaemia occur during the autumn and winter months, it's important to remind people, especially parents, that you need to be aware of the symptoms at all times of the year.

With spring just past and summer upon us, in partnership with the Northern Ireland Childminders' Association, information seminars were held with Foyle and East Belfast Childminding Support Groups.

At the seminars, supplies of Meningitis *Baby Watch* and *Tot Watch* were given to the childminders to pass on to the parents of the children they look after.

Information and Education Officer Liz Hamilton also took the opportunity to raise awareness of these devastating diseases among parents when she spoke at schools in Newcastle, Ballyoran and Portadown.

A recent Fun and Facts day organised by the Northern Ireland Pre-school Playgroups' Association proved to be a lively event at Roe Valley Leisure Centre, Limavady. Special thanks to member Sally King for looking after the Foundation's information stand.

Liz also attended the joint meeting of the Intensive Care Society of Ireland and Northern Ireland Intensive Care Society held at the Waterfront Hall, Belfast. As well as a great chance to network with this important group, Liz also ensured that Foundation's treatment protocols were included in the delegate packs.



Liz Hamilton and representatives from Orange UK as Orange announce that calls to charity and helpline numbers in Northern Ireland supported by the Telephone Helplines Association, including the Foundation's, will now be free to Orange mobile customers in the province. Up to this point, all mobile callers have had to pay to phone Freefone numbers.

# **Scotland**

Foundation member Olivia Giles was recently awarded the Evening Times 'Scotswoman of the Year 2004'.

To recognise the award, a tea party was given in her honour, sponsored by Nambarrie Tea Co Ltd and the Glasgow Evening Times. The Foundation was delighted to receive an invitation to the party, along with other major charities, health professionals, and the Scottish Health Minister Andy Kerr.

Olivia used the opportunity to talk about the fight against meningitis and septicaemia. Particular emphasis was placed on the issue of complacency since the introduction of the MenC vaccine.

Andy Kerr, while praising the enthusiasm, commitment and achievements of the voluntary sector, stressed the vital role we all have to play in continuing to spread the awareness message as widely as possible.

We were grateful to Vincent McKeown, Public Protection Nurse Specialist at the Royal College of Physicians and Surgeons, for attending the recent Glasgow members' meeting and

speaking about the public health team's involvement when a case of meningitis or septicaemia occurs.

At the meeting, we were also joined by Fran Pioli, the Foundation's Befriender Co-ordinator, who travelled from Bristol to tell us more about support for those people already



Vincent McKeown

affected by the diseases.

Information and Education Officer Rili Craig rounded off the evening by highlighting the importance of continuing to raise awareness in the absence of vaccine protection against all types of meningitis and septicaemia.

# Republic of Ireland

With the under-fives being most at risk of contracting meningitis and septicaemia, it's important to build good relationships with nurseries.

One of the most recent results of these relationships occurred when Glenone Nursery invited the Foundation to share a stand with them at the Mother and Baby Exhibition at the Royal Dublin Society's international exhibition and conference centre in May.

With visitors to the conference working with such key groups for the Foundation's awareness messages, this provided an excellent opportunity, for which we thank the staff at Glenone Nursery.

Students fall into the second most at risk group, and the Dublin office is working with all third level institutions to ensure their students are meningitis and septicaemia aware when the new academic year begins.

During the last few months, we've been working hard to ensure the move to our new premises has had the minimum effect on our provision of services in Ireland a move that has now been completed (see back page).



The Foundation's 2005 - 06 student wall planner

# Running, cycling and swimming

Of the 40,000 women who took part in the Dublin Women's Mini Marathon, over 200 were running in support of the Foundation.

Thanks to all who wore purple to raise funds and awareness for the Foundation in this popular 10k run.

We're now looking for women runners to join us at the 5k Hydro Active Women's Challenges in Birmingham, London and Liverpool on 4 September.

And all runners will be welcome at the 10 mile BUPA Great South Run in Portsmouth on 9 October. With entries closed through the official website, a Foundation place may be your best bet to take part in this event.

For the super fit, there's the London Triathlon on 6 and 7 August, if you really want to test your mettle.

For more information on any of these challenges, call 01454 280814 or email fundraising@meningitis.org



Anne McCaffrey's having the slightly surreal experience of having run over 26 miles before being greeted by a six foot furry monster, in the form of our Marvin. Anne's one of the many runners who completed April's Flora London Marathon on our behalf. So far, £14,500 has been raised

# Name that train

We've got a fabulous competition for all members and supporters.



What's its name?

Thanks to Cotswold Rail and Heartland Rail we're going to have a diesel locomotive named in honour of the Foundation.

On Saturday 24 September, the train will be running from Birmingham to Minehead, raising funds and awareness en route. One of the stops on the journey will be Temple Meads station in Bristol where the train will be named. And that's where you come in. We're looking for suggestions for the train's name and there are free tickets for the journey for the best name.

Send your suggestions by email to the Foundation at info@meningitis.org or drop a line to your local office.

And keep your eyes peeled on our website – www.meningitis.org - for more ways that you can get on board the Foundation's great train journey.



Member Gary Keanie at the Forth Rail Bridge Abseil in April which proved to be another great success, raising over £6500. Many thanks to all who helped make it such a great total. For those who are interested in getting that exhilarating feeling, there are abseils from the Europa Hotel, Belfast and the Forth Rail Bridge on 24 and 25 September respectively. Contact your local office to sign up

# Top hole

It is said that Scotland is the home of golf, and our members and supporters have certainly confirmed the point.

In last autumn's *Microscope*, we featured the story of the band of golfers who, incredibly, completed a round of 100 holes in one day.

Our Scotland manager, Jacqui Clark, was delighted to recently visit the Dumfries and Galloway Golf Club to receive a cheque from the Jenna Dempster Superstar Fund for the proceeds from the event – an amazing £16,000.

Jenna tragically died from meningitis in 2003 and the Superstar Fund was set up in her memory. The £16,000 added to an incredible total of almost £28,000 raised by the Dempster family and their loyal friends. Our sincere thanks go everyone who has worked so hard for the Jenna Dempster Superstar Fund.

### Law Society of Scotland



Douglas Mill, Alastair Thornton, John Elliot and Andrew Biggart of the Law Society of Scotland after their 18th hole at the famous Bruntsfield Golf Club

This year we are pleased to be the Law Society of Scotland's charity of the year.

Part of the fantastic total of £17,250 raised so far has emanated from the golf course. We are indebted to Douglas Mill, Chief Executive of the Law Society of Scotland, who, along with team mates made up of fellow lawyers, played a separate hole on 18 of Edinburgh's golf courses to raise funds.

Thanks are also due to Belmont Motors for providing the transport, Jody Fitchett of the Society for chauffeuring and all participating golf clubs and sponsors.

### **Bunker to Banquet**

With the recent Bunker to Banquet corporate golf event in Aberdeen on target to beat the £40,000 fundraising target, the fairways and greens have proved to be highly beneficial for our Scotland office. Our thanks everyone involved in the event, especially patrons Sir Ian and Lady Helen Wood and their family, Norman Pace and his family and friends and members John and Barbara Weir.

But the golfing action wasn't just confined to Scotland, as the fifth annual golf day in Northern Ireland raised over £5000. Many thanks to all who supported this event.

# **Band aid**

Make a statement about your support for the fight against meningitis and septicaemia with the Foundation's wristbands.



Bearing the Foundation's 'Race Against Time' slogan and our website address, these limited edition youth sized wristbands are available for £2 each (including postage & packing). Just send a cheque made payable to

'Meningitis Research Foundation', along with your name and address, to the Foundation.

Or you can purchase adult sized wristbands with the website address and words 'Spot it' on them from cmtgames. For every sale, 25p comes to the Foundation. Simply log on to http://www.iwristbands.com/?b=1 to purchase.

# Big Pedal

Despite less than perfect weather, a great time was had by all at the first two legs of our great summer of cycling – The Big Pedal.

The rain at Drumlanrig Castle, Dumfriesshire couldn't dampen the spirits, as hardy Scottish cyclists battled through the rain and mud. While at Cannock Chase, England and Wales supporters descended in numbers on this Area of Outstanding Natural Beauty.

Many thanks to everyone who helped raise vital funds and awareness for the Foundation, and a reminder that the Irish leg of the Big Pedal takes place on Sunday, 25 September.

Whether you're a seasoned pro or still have those stabilisers attached, with three courses all starting and ending in Newry, there's a route for everyone.

Entry fees for individuals are £10/€14, for families/teams it's £25/€36. Contact our Belfast or Dublin office for more information.



Bedraggled but not dispirited in Scotland

### July 28

### Garden party

Tireless Foundation supporter Janine Nolan is holding a garden party and raffle in Glascote, Tamworth between 10 and 2, with all proceeds going to the Foundation. She'd love to see you there. Give her a ring on 01827 250738.

### July 30/31 and August 1 Munro Madness

Once again, the Foundation is holding its annual fundraising quest around the beautiful mountains of Scotland. Whether you fancy a challenging climb or a gentle ramble, there's a mountain to suit everyone in this year's Munro Madness. For more information, please contact the Scotland office.

### August 6 and 7 The London Triathlon 2005

Not sure whether to run, cycle or swim to support the Foundation? Take part in the London Triathlon and do all three. Contact lain on 01454 280414 or email him at iainelliott@meningitis.org for more details.

### September

### Northern Ireland Annual House to House collection

Last year's collections across the province brought in a fantastic total of £3198. We're hoping to repeat that success this year, and we need your help to do it! If you would like to take part, please contact Dora on 028 9032 1283.

### September 4

### Hydro Active Women's Challenge

Take your pick of venues from Birmingham, London and Liverpool in these 5k challenges. 01454 281814 if you're interested.

### September 9 - 11

### Survival Challenge

The ultimate challenge for survival in the wilds of Devon. Register your interest on 01454 281814.

### September 10

**Meningitis Meanders** 

Right across Northern Ireland, people will

be setting the pace for the charity at one of five scenic locations - Roe Valley Forest Park (Limavady), Crom Estate (Fermanagh), Tollymore Forest Park (Newcastle), Drum Manor Forest Park (Cookstown) and The Ormeau Park (Belfast).

Why not get your walking shoes on and join them? Call 028 9032 1283 or email info@meningitis-ni.org for more details.

### September 18

**Great North Run** 

Wherever you come from in the UK and Ireland, you are invited to compete in the Great North Run in Gateshead. Just get in touch with your local office.

### September 25

### The Big Pedal - Ireland

Irish leg of our summer of cycling. Three courses for all abilities starting and ending in Newry. Contact our Dublin or Belfast office to register.

### October 2

### Baxter's Loch Ness Marathon

Chance to do some monster spotting along the shores of beautiful Loch Ness. Run for the Foundation and you could find yourself winning a prize for the top fundraiser. More details from our Scotland office on 0131 228 3322.

### October 9

### **Great South Run**

Portsmouth is the venue for this 10 mile run. Call 01454 281814 for one of our remaining places, but be quick as they're running out quickly.

### Various dates **Great Wall of China**



Like Sarah Downes of Impact Toyota (pictured left), journey to the Great Wall of China on one of our adventure challenges. Pick

an incredible journey and have the experience of a lifetime. Call 01454 281814 for your free brochure.

### 24 hour helpline United Kingdom Freefone 080 8800 3344

# 24 hour helpline Republic of Ireland LoCall 1890 41 33 44 www.meningitis.org

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email info@meningitis.org

### Various dates

### Parachuting

Book your flight reservation for a jump from 10,000 feet by getting in touch with your local office. Solo training and jumps now also available from selected sites.

# **Dublin** office move

There are new premises for our office in Dublin.

The Foundation first opened an office in Dublin in July 1996, in response to the high incidence of meningococcal disease in the Republic of Ireland.

With the lease coming up on the Cullenswood Road premises, the opportunity was taken to move to a more central location. The new details

Meningitis Research Foundation 63 Lower Gardiner Street Dublin 1

Tel: 01 819 6931 Fax: 01 819 6903

email: info@meningitis.org



Ireland manager Diane McConnell and Daráine Mulvihill greet Bertie Ahern at the Burlington Hotel fundraising lunch (see front page)

