

Welcome

from Chris Head

The after effects of meningitis and septicaemia are a major focus of this edition of *Microscope*.



The Impact of Meningitis report, contained within, is the first result of a collaboration between MRF and the University of Bristol. This report, based on the experience of Members, helps us better understand the long-term impact of meningitis and septicaemia. The report will be used with policy-makers and opinion formers to highlight problems with diagnosis and access to aftercare, as well as the lasting effects on education, career and financial well-being of individuals and families.

We are committed to providing support if you or someone you care for has after effects as a result of meningitis or septicaemia. Providing relevant, practical information is one way we can help. The aim of our new Disability Rights and Benefits booklet, available on our website at **www.meningitis.org** in the Supporting You section, is to demystify what can be a confusing system, to open up the gateways to the financial and practical benefits you may need when coping with after effects.

Our commitment to you extends further, and includes our funding of research into after effects. One project in our current research programme is shedding more light on the intellectual and psychological effects on children. On page 10, Research Officer, Kate Rowe, reports on a Member site visit to

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Imperial College to look at this project.

And opposite you can find out how one woman triumphed over her after effects of the disease to go on to fundraise for us.

Vaccination has had a big impact on some forms of meningitis and septicaemia in recent years, and it is sometimes forgotten that there are still too many people for whom vaccination has come too late or they contract a type not covered by vaccines. Through the projects outlined above and though our Befriending Programme and 24/7 Helpline we remain committed to doing all we can to help those living with the after effects of these diseases.



MRF research and your money

We're very proud of the fact that we spend over half of our outgoings on research.

MRF Fundraising and Communications staff Sarah and Neil sat in on our annual Scientific Advisory Panel meeting in London on 25 March, to see how a group of 11 scientists and clinicians – all leaders in their fields – thrashed out how best to push our research forward over the next year and beyond.

Chaired by Christoph Tang, Professor of Infectious Diseases at Imperial College, our Panel worked through 24 applications to decide which to fund on the basis of scientific merit, compliance with the vision of our Trustees and benefit to achieving MRF's core aims.

Potential projects were discussed with a focus on MRF's longstanding aim to fight meningitis and septicaemia, particularly MenB, in the UK and the more recent priority to take action in Africa where the burden of meningitis is the greatest.

Panel members remarked that the calibre of research was excellent, with many interesting proposals. After a day's discussion, agreement was reached and a final shortlist of the best projects submitted to our Trustees.

Professor Tang closed the meeting by congratulating MRF for putting forward a budget of £750,000 at the meeting, saying "This speaks volumes about MRF and its Members' commitment to funding research – and in the current financial climate is a remarkable achievement."

Our Belfast office is celebrating another successful G.I. Jane event.

Jacqui steps out for MRF

Jacqui Pearce's world was turned on its head in March 2009 when she contracted septicaemia.



Jacqui from Glasgow remembers: "They had to put me into an induced coma. They told me later that this gave my body the best chance to fight the disease and respond to the drugs."

While Jacqui won her battle with septicaemia, it came at a price. Nearly all of her toes were amputated and she lost the soles of her feet. She resolved to keep fighting the diseases by joining MRF and raising awareness and funds for vital research.

For someone with her kind of disabilities, you would think that running would be the last thing on Jacqui's mind. But Jacqui was having none of that as she strapped on her running shoes to complete the Rouken Glen 5k last June.

Jacqui also managed to convince a number of friends to join her, and rallied support in her workplace and a number of other local businesses. All in all Jacqui's brave run raised a grand total of £1,857.

The run was not without its difficulties. Jacqui says: "My right foot was a problem because

It was all worth it. I had a tremendous feeling of achievement.

of the pressure that was being put on the remaining little toe."

However, despite the pain, Jacqui declares: "It was all worth it. I had a tremendous feeling of achievement."

Jacqui says that organising and participating in the run kept her focused all last year and helped her recovery enormously and it's given her the taste for future fundraising.

Jacqui is having a further operation in April to have the remaining parts of toes on her right foot amputated, which she says she's looking forward to as this will hopefully relieve her of remaining pain.

If you have been inspired by Jacqui's bravery and want to run for MRF, take a look at our Calendar of Events or log on to our website at

http://bit.ly/MRFRunning



Iain Elliott

It was with the greatest sadness that we learned of the death of lain Elliott on 26 March, following his diagnosis with an inoperable brain tumour last autumn.

lain, 33, joined Meningitis Research
Foundation in July 2001 and he became a
highly-valued Fundraising Manager, much
liked and respected by the supporters he
worked with and his colleagues at MRF
alike for his good humour and commitment
to the cause. Taking part regularly himself
in fundraising quizzes and challenges, and

very willing to enjoy a pint of beer as well as go the extra mile for the charity, lain's cheerful personality and appetite for hard work will leave a lasting impression on all who knew him.

All the trustees, staff and volunteers at MRF offer their deepest sympathy to lain's parents Ron and Norma, his brother Mark, and to the other members of his family and countless friends for their loss.

News in Brief

NICE Guidelines

Our Head of Research, Linda Glennie, is a member of a National Institute for Health and Clinical Excellence (NICE) guideline development group, established to produce national guidelines on the management of bacterial meningitis and meningococcal septicaemia in children. Covering issues including symptoms recognition, emergency management by GPs, diagnosis and treatment in hospital, transfer to intensive care, and management of after effects. The quideline is due to be finalised in June this year.

Pneumo report

MRF has joined forces with Pfizer and a number of other charities to develop a pneumococcal disease awareness document, the PneumoAware Report. It will be presented at meetings for public health professionals involved in implementing vaccine policy to gain their support. We hope this document will be used to raise awareness of the diseases and the benefits of vaccines, among politicians and key opinion leaders.

Student and baby aware



Belfast's Lord Mayor, Naomi Long, met up with us at Queen's University Student Crèche to help promote meningitis awareness to local families. The Lord Mayor is pictured with babies, parents and staff at the crèche.

Meet the **Team**

Laura Clark from the University of Bristol. working with MRF in collaboration with the **University of Bristol Department of Social** Medicine, tells us about her work on the Impact of Meningitis project and the 2003 members' survey.

"My role is to carry out research and collate the Impact of Meningitis project findings so that we can more effectively campaign for improvements in prevention of meningitis and care for people affected, and provide accurate information to help our Members.

"In 2003, 809 people with experience of surviving meningitis took part in a Member survey. The initial stage of this project was to



your behalf to gain the services you really need.

we are now more

able to advocate on

analyse the survey results, and the summary is contained in this edition of Microscope.

"During the MRF international conference last November I had a fantastic opportunity to talk to a range of influential people about Members' experiences of meningitis and septicaemia. I presented a poster on the key findings of the 2003 survey, which can be seen on our website at www.meningitis.org/ conference.

"The participation of Members has been invaluable for campaigning in 2010. This project has highlighted how difficult it can be to gain access to after care and support, and with the data from the Impact of Meningitis report we hope to be able to influence improvements in the future. Many people had difficulty in gaining access to after-care, and we are now more able to advocate on your behalf to gain the services you really need.

"This partnership between MRF and the University of Bristol will facilitate a further Member survey. We plan to develop an after care booklet detailing known long-term health implications and potential impact on quality of life. We are also investigating the feasibility of setting up a national register of meningitis survivors. This would provide an invaluable resource to quantify the impact that meningitis and septicaemia have."



Foundation staff and members at a private visit to Áras an Uachtaráin, the residence of President Mary McAlesse. The invitation was extended to mark the work of MRF staff and supporters in reducing the number of cases in Ireland through research funding and awareness raising.

Ask the Expert

Do we need an extra dose of a meningococcal vaccine in adolescence?

In March a new vaccine was licensed for use by the European Commission.

The Menveo vaccine protects against four of the main disease-causing strains of meningococcal bacteria – A, C, W135 and Y. The vaccine improves upon the current available protection, meaning more lives saved and disabilities averted.

In the UK it will largely be used as a travel vaccine, at least for now, but here Professor Andrew Pollard and Dr Matthew Snape discuss whether there could be another important use for the new vaccine.

"It is now almost 11 years since the introduction of the serogroup C meningococcal (MenC) vaccine into the UK in 1999, and the huge impact of this vaccine has been sustained throughout the last decade so that there were only a handful of cases in 2009. A crucial component of the success of the vaccine introduction was the

'catch-up' campaign that aimed to immunise everyone under the age of 19 years. The rates of disease were reduced among adolescents (previously a time of increased risk for MenC disease) as a direct effect of the vaccine, but the vaccine also prevented these teenagers inadvertently spreading the bacteria from their nose or throat to younger children or unimmunised adults, adding to the value of the vaccine by reducing the risk of disease for these groups too.

"It now appears from these observations that maintaining high levels of immunity among adolescents and young adults may be important, even critical, to keep MenC disease under control since it protects the rest of the population. However, from studies conducted by the Oxford Vaccine Group and the Health Protection Agency, it has been shown that immunity falls rapidly after immunisation in early childhood and the majority of children entering adolescence over the next decade, who received their dose in the original MenC campaign, will not have protective levels of MenC antibody.

"Do we need to introduce an extra dose of a meningococcal vaccine in early adolescence to maintain both direct protection in this age group and provide the broader community protection? Although there is no rush to introduce a booster today as we have so little MenC disease activity, investigation of the role of an adolescent booster is important in

the near future assuming the vaccine were needed for those immunised in the 1999 campaign before they leave school. The good news is that, unlike the situation in early childhood, protection does appear to persist for years when the vaccine is given to adolescents.

"Intriguingly, an adolescent booster could be an opportunity to provide broader protection against meningitis and septicaemia if we decided to use the newly licensed MenACWY vaccine (covers meningococcal serogroups A, C, W135 and Y) instead of the MenC vaccine that is used today. Indeed, this is the approach that has already been taken in Canada, where a booster dose of meningococcal vaccine was recently recommended for 12 year olds.

"This is an unfolding chapter in the battle against meningitis and septicaemia but for once we may be ahead of the game."

Ask the Expert is now available on our website at http://www.meningitis.
org/ask-the-expert and we welcome your questions to our experts on site or by emailing adrianr@meningitis.org

Information Officer, Claire Wright, has written a blog piece on site about the new vaccine read it at http://bit.ly/menveo

Our Experts



Andrew Pollard is Professor of Paediatric Infection and Immunity at the University of Oxford, Director of the Oxford Vaccine Group, and Honorary Consultant Paediatrician at the Children's Hospital there.

He chairs the UK's NICE meningitis guideline development committee. His current research includes clinical trials of new and improved vaccines for children, development of a serogroup B meningococcal vaccine, bacterial diseases in children in Nepal, and

studies of immune responses to vaccines. He has published over 200 articles and books. He has recently joined MRF's Scientific Advisory Panel.



Matthew Snape is a Consultant in Vaccinology at the Oxford Vaccine Group, University of Oxford, and a Consultant in General Paediatrics at Oxford Radcliffe Hospital NHS Trust. His research includes clinical trials of vaccines against meningococcal and pneumococcal disease, with a particular interest in the immunisation of adolescents against meningococcal disease.

This is an unfolding chapter in the battle against meningitis and septicaemia but for once we may be ahead of the game.

Calendar of Events

28 May

Brand NEW Skate-a-rama Event

Skate your way back into the 80s at Northern Ireland's only Roller Disco Rink.

Tickets £10.

Please contact Keli (028 9032 1283, keli@meningitis-ni.org)

31 May

Newry Marathon

If you are interested in running the full marathon, half marathon or the fun run we'd love to hear from you.

To register please go to www.newrycitymarathon.com and contact Emma (028 9032 1283, emma@meningitis-ni.org)

6 June

Forth Rail Bridge Abseil

Experience the adrenaline rush of freefalling 165ft SAS-style, from one of the world's best known landmarks.

Contact Dawn (0131 510 2345 or email dawncarrie@scotland-meningitis.org.uk)

7 June

Flora Women's Mini Marathon

This 10K run in Dublin is one of the most popular ladies' marathons.

Entries available at www.

florawomensminimarathon.ie and in The Evening Herald. For your sponsor pack and T-shirt please contact Elaine (01 819 69 31, elaine@meningitis-ireland.org)

7 June

Cork City Marathon

The Champion Sports Cork City Marathon takes place on the Bank Holiday Monday.

Online entries (www.corkcitymarathon.ie), then contact Monika (01 819 69 31, email monikam@meningitis-ireland.org)

17 June

Lisburn Half Marathon, 10K and Fun Run Whichever run you're interested in we'd love to hear from you.

Register your interest with Emma (028 9032 1283, emma@meningitis-ni.org)

19 June

'Take a Titanic Leap'

Be part of the first ever 100ft FEET FIRST free fall event in Northern Ireland. Join MRF at Titanic's Dock and Pump-House in Belfast.

Contact Emma (028 9032 1283, emma@meningitis-ni.org) or download your pack from http://bit.ly/MRFTitanic

Your child and after

In March, MRF Members and staff attended a site visit at St Mary's Hospital in London to see the scientists working on our project: 'Assessing children's memory, learning ability and stress levels following hospital admission with meningitis and septicaemia'.

MRF has a long association with St Mary's and this research group, headed by Professor Elena Garralda and Dr Simon Nadel. The programme of work that we have been funding is looking into the learning and memory development, and also the emotional after effects of schoolage children who have experienced meningitis and septicaemia.

We were very pleased to have Members Nicky and Matt McClure, Fiona Ling and Andy Williamson attending the visit with us. We started with coffee and introductions, and then Dr Lorraine Als (the scientist doing the day to day work on this grant) gave an excellent talk on the aims and progress of the project.

She explained how families of children are

Nicky and Megan

Member Nicky McClure had a personal reason for attending the latest research site visit. Her daughter, Megan, has experienced some problems following Group B streptococcal (GBS) meningitis as a baby in May 2006.

The actions
of the midwife
and my GP saved
Megan's life

Nicky says: "As Megan had meningitis in infancy I was really pleased to be invited to the site visit at St Marys. I am really interested in the after effects of meningitis studies as it has always been at the back of my mind that although Megan didn't lose any limbs and her hearing is fine, that something may become apparent at a later date.

"I had a fairly normal pregnancy with Megan, and an elective c-section. But two days after she was born, I commented to the nurses that she was pale and jittery.

"The following morning, after discharge, when I was changing her I noticed her groin area was blotchy, but her temperature was normal. The midwife arrived shortly after and decided that she wasn't happy with her colour and sent us straight down to the GP. By the time we arrived her temperature had risen so we were sent to the hospital. The actions of the midwife and my GP saved Megan's life.

"She was given a lumbar puncture immediately, and as it was Friday we were told that it was unlikely we would get the results until Monday but they would treat her for meningitis anyway to be on the safe side. I was actually woken

effects

asked to take part approximately four months after being discharged from hospital. They, their parents and/or teacher are asked to complete a questionnaire on how they are progressing following their return home and to school. The researchers also visit the children's homes, and conduct a number of tests to assess visual, spatial and auditory memory. We had a go at a few of these tests ourselves, and they were pretty challenging!

The families are also asked to participate in another part of the study, which involves collecting saliva samples from the child. These samples are sent back to the scientists and tested for Cortisol levels. Cortisol is a hormone associated with stress. This test allows the

researchers to find out whether these children have higher levels of Cortisol (and therefore stress) than children, who have not been admitted to hospital.

This visit provided some really interesting insights into the potential intellectual and psychological after effects of meningitis and septicaemia. The results from this work will help us to better explain the effects of meningitis and septicaemia to families and doctors, and to campaign for improved follow-up care for children who have been affected.

Read more about this project at www.meningitis.org/current-projects/stress-and-emotional-after-22644

this work will help us to better explain the effects of meningitis and septicaemia to families and doctors



the following morning to be told it was indeed meningitis caused by GBS, and that the next 24 hours were critical. They also told us that if we had waited any longer to bring her in we would have lost her.

"We are incredibly lucky to have a happy, healthy daughter now, although her immune system is not great, so she does pick up everything going, but we hope that will improve with time.

"And we've noticed minor issues about Megan that have also been picked up by the preschool. They have noticed she is a little clumsy (she runs like Phoebe from Friends!!) and still cannot do stairs properly (as in walking up one foot alternating steps). She also has a few slight speech issues with some letter sounds, and has a short attention span, and is not really learning her letters as well as she should be! All these are pretty normal and some other children in her pre-school have similar issues, but not all together!

"I am lucky that I have always been able to communicate with Megan's pre-school and have her monitored, and we will discuss the issues with school in September when Megan starts so that she can have some support from the start and not get left behind.

"The research being done into the after effects would be so beneficial out there in doctors' surgeries and hospitals so that there could be a protocol for annual monitoring. There are after effects for most people who have had meningitis, so it does stand to reason that infants could have some longer term issues.

"In our case I am eternally grateful to MRF, as I expect in many cases there are children who may be struggling at school who did have meningitis in infancy who's parents and health professionals have not considered the possible cause. They may be left behind academically or in some cases labeled disruptive or with ADHD, or learning

"As Megan had meningitis so young, there is no "before" to compare to, so the fact that the after effects are getting

difficulties.

noticeable now is interesting. I'm not unduly concerned, given what could have happened - she still has the occasional spectacular paddy, although that might be her age!!"



Calendar of Events

19 & 20 June

Tough Ness

A 40 mile hike and a 30 mile bike ride along the Great Glen Way and around Loch Ness. The truly stunning route will take your breath away.

Contact Alison (0131 510 2345, alisonbaker@scotland-meningitis.org.uk)

25 – 27 June

Celtic Challenge

Action men and women needed for our first Celtic Challenge. Enjoy a weekend's mountaineering on Slieve Donard, Errigal, Croagh Patrick and Lugnaquilla. Price per person is £500 which includes transport, accommodation, food, guides and sponsorship.

Contact Keli (028 90321283, keli@meningitis-ni.org)

8 August

Members' Day

Blenheim Palace is the setting for our second Members' Day of the year. Both the Palace and the Capability Brown-designed gardens exude history.

Contact Shirley or Victoria now for your reduced rate entry (shirleyg@meningitis.org or call 01454 281811)

14 August

Black Tie Ball and Charity Auction

A fun-filled evening at Cobham Hall, Kent with all proceeds to MRF in memory of Zoe Hogan-Gabell.

You'll enjoy a champagne reception, three course meal, charity auction, live music and dancing. Tickets are £65 per person, sold in tables of 12 (£780 per table).

Contact Philippa Martin (phil@comec.net)

29 August

Longford Run

Whether it's a full marathon, as part of a relay team or a half marathon run for MRF.

After online registration

(www.longfordmarathon.com/) contact the Dublin office (01 819 69 31,

info@meningitis-ireland.org)

19 September

Bupa Great North Run

We've still got places up for grabs.

Contact your local office

26 September

Cork Mini Marathon

Don't miss out the 29th Cork Mini Marathon. Run for MRFI

Register (www.corkminimarathon.com) and contact our Dublin office for your free fundraising pack and T-shirt (01 819 69 31, info@meningitis-ireland.org)

3 October

Edinburgh Kilomathon

Scotland's first Kilomathon 26.2 kilometres (16.3 miles).

Contact Alison (0131 510 2345, alisonbaker@scotland-meningitis.org.uk)

3 October

Loch Ness Festival of Running

A monster run alongside the shores of the world's most famous loch. As well as the full marathon there are a 10k. a 5k and a Fun Run.

Contact Alison (0131 510 2345, alisonbaker@scotland-meningitis.org.uk)

25 October

Adidas Dublin City Marathon

The 31st year of this run through the historic Georgian streets of Dublin.

Register (www.adidasdublinmarathon.ie) then contact us (01 819 69 31.

info@meningitis-ireland.org) for your free info pack and T-Shirt.

30 October/5 & 6November

Firewalks in Scotland

Walk across 20ft of glowing, red-hot coal beds completely barefoot. This inspirational fundraiser can offer a life-changing experience, as well as raising funds. Edinburgh on the 30th, Dumfries on the 5th and Glasgow on the 6th.

Contact Alison (0131 510 2345, alisonbaker@scotland-meningitis.org.uk)

Scotland's rare bank notes auction

Many thanks to our friends at Clydesdale and Yorkshire Bank for a donation of £1,500 to our Scottish Office.



A North of Scotland One Pound Note. Just one of the unusual auction items

The money represents a share of a great giveaway of £180,000 to 126 charities across the UK following an auction of over 300 historic and collectable banknotes.

Members of staff throughout the country were asked to nominate their charities for a share of the proceeds and we are indebted to Member Sharon Clark from National Australia Group, owners of the banks in the UK, for successfully nominating MRF.

Sharon's son Christopher had meningococcal septicaemia in May 2007. Read their story in our Book of Experience on site at http://bit.ly/christopherclark



The Belfast 'Halloween Hoolie 09' was another great success raising a fantastic £1,336.28.
A huge thank you to Queen's RAG for their continued support.

Freefone 24 hour helpline 080 8800 3344 (United Kingdom)

1800 41 33 44 (Republic of Ireland)

www.meningitis.org



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