

The newsletter for Members and supporters of Meningitis Research Foundation

Microscope



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Proteins as vaccine target?

New research projects

Welcome

from Chris Head

We are delighted with the progress in the fight against meningitis and septicaemia in the last few months.

It is our belief that quality scientific research holds the key for our vision of a world free from meningitis and septicaemia. Vaccine development plays a large part in our research funding strategy. The virtual eradication of meningococcal C disease after the introduction of the MenC vaccine over a decade ago shows the effect vaccines can have on death and disability. This is why the recent news of the impending introduction of a more broadly protective pneumococcal vaccine into the Irish immunisation schedule is so welcome.

We are also hearing that good progress is being made towards a vaccine for meningococcal group B, the main cause of disease in the UK and Ireland. However, it remains to be seen whether any vaccine on the horizon will cover all MenB strains. Allied with the fact that there will still be other types of meningitis and septicaemia

which are not vaccine preventable, it becomes clear that much remains to be done to rid ourselves of these dreadful diseases.

There have also been important developments in better understanding the genetic basis of meningitis and septicaemia. Research funded by the Foundation has begun to yield important results, uncovering why some people are more prone to the diseases and why some people are affected more than others. Read more on page 4.

With your help we are continuing to fund these genetic explorations. The St Mary's based project is one of five projects we introduce to our programme on page 3.

Of course all this couldn't be done without your support. Fundraising in tough economic times continues and your generosity never fails to amaze me. Read about one family's fundraising after their own personal tragedy on page 8 and the continuing success of our Scottish golf fundraiser Bunker to Banquet on page 11.

In this edition of Microscope you'll find a questionnaire to help us make sure the magazine meets your needs. We'd be grateful if you would fill it in and send it back in the enclosed Freepost envelope.

Thank you



Chief Executive



Chris, far right, with members of the Polish meningitis charity Aby Zyc, who visited the UK as part of a learning partnership with MRF. As well as talks at our head office, the group also visited Bristol Children's Hospital and took a tour of the research labs at the School of Medical Science at the University of Bristol, which provided the group with an insight into current vaccine trials and immunological research.

New rese

Research Officer Gill Currie introduces us to our new research projects.



MRF funded

Belfast based MRF funded researchers have won the Northern Ireland Health and Social Care Innovations award for Diagnostics and Pharmaceutical Idea of the Year.

arch projects

Five new projects have joined our research programme. This brings the number of current projects to 26 and a total of 133 projects funded since we began in 1989. The total value of our investment in research is now over £16m/€19m.

Examination of two meningococcal surface proteins as potential vaccine targets

Based at the University of Leicester and costing £184,369, this project will look at whether two proteins on the surface of the meningococcal bacteria could be a good target for a vaccine.

Development of a molecular biology tool based algorithm to improve the diagnosis in the African Meningitis Belt

Professor Samba Sow leads this project at the Centre of Vaccine Development, Bamako, Mali. The project costs £70,800 and its goal is to design an algorithm or step by step guide that allows more meningococcal infections to be classified. If successful, the algorithm will indicate how widespread each strain is and could also be applied in the UK.

Recognition and action towards meningitis amongst patients, their families and health providers

Jointly based at the Blantyre Liverpool School of Tropical Medicine and the Malawi – Liverpool – Wellcome Trust Clinical Research Programme, this project led by Professor Robert Heyderman costs £68,946.

Unlike in the UK, in developing countries, such as Malawi, early symptoms of bacterial meningitis are not commonly known and so death and disability rates are particularly high. This study will investigate the attitude towards meningitis in Malawi in both the family and healthcare setting. Understanding the possible barriers to seeking and accepting medical treatment will help to reduce the number of late presentations at hospital and so reduce the impact of meningitis as a disease.

An in-depth study of the genes involved with the susceptibility and the severity of meningococcal disease in children

Professor Michael Levin and his team at Imperial College of Science, Technology and Medicine have a £64,434 grant to continue their exciting and productive work into the genetic basis for meningococcal disease. (see page 4)

Measuring immunity to meningococcal Y and W135 bacteria in England and Wales

At the Vaccine Evaluation Unit of the Health Protection Agency North West in Manchester, Professor Ray Borrow will be leading a project costing £66,792. Meningococcal groups Y and W135 are rare compared to groups A, B and C, however, the immunity levels to these two strains are unknown.

This study aims to measure antibody levels across a wide range of age groups and compare this with carriage and disease rates. The results

Exciting and productive work into the genetic basis for meningococcal disease

will be useful in assessing how much impact the new ACWY vaccine will have compared to just meningococcal A and C vaccines.

You can find out more about these new projects at www.meningitis.org/current-projects



Fadil Bidmos from the University of Leicester examines meningococcal bacteria in one of the five new projects to join our research programme

research wins innovation award

Driven by the need to improve early diagnosis of meningococcal disease, the team has developed a new test for meningococcal bacteria.

The team developed and tested a technique based on Loop Mediated Isothermal Amplification (LAMP). This method works by recognising and amplifying a piece of the bacteria's sugar coating taking less than 60 minutes. The advantage of LAMP over traditional laboratory based PCR methods is that it is quicker and does not require specialised

equipment. As such it has potential to become a cheap and rapid diagnostic test. The team is now evaluating the test in a paediatric emergency setting.



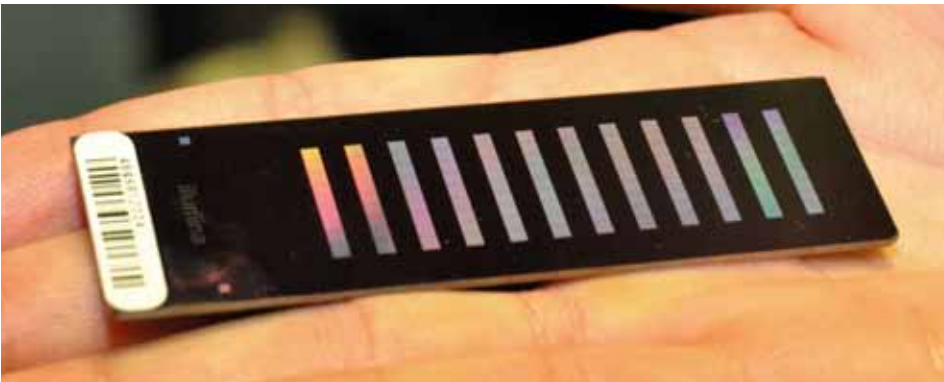


Meningitis mysteries unravel

Research supported by MRF has begun to answer two of the most fundamental questions about meningitis and septicaemia. All was revealed at our recent Members' site visit.

Given that the main disease causing bacteria live in the backs of the noses and throats of around 10% of the population why do some people develop meningitis and septicaemia, while others don't? And why is it that of those who get the disease, some get it more severely than others? The researchers believe that the answers may lie, in part, in our genes.

Over the last 15 years, international teams, led by Professor Michael Levin at the Department of Paediatrics at Imperial College London, have been scanning the whole human genome looking for factors which influence susceptibility to meningococcal infection. The study has shown that genetic variation in a group of proteins, called Factor H and Factor H



Each strip holds 48,000 genes



Professor Levin's research was the subject of our latest research site visit. Twenty-five members, along with MRF staff toured the the School of Medicine at St Mary's Hospital, Imperial College London to find out more about the Foundation funded research.

related proteins, are particularly important in determining susceptibility and resistance to meningococcal infection.

Professor Levin said: "The study highlights the power of the new genomic technologies which are now helping to unravel the basis of human disease. This is an important breakthrough in our understanding of this infection and will be important in the development of effective vaccines."

MRF Chief Executive Chris Head commented: "We are delighted that our investment in this research has helped uncover some of the reasons why some people are more susceptible to meningitis and septicaemia and why the diseases affect some people more than others.

"Since 1995, MRF has committed over £500,000 to genetic research and we hope

that our continued investment in Professor Levin's research will result in improved future treatment and, ultimately, contribute to the prevention of meningitis and septicaemia through vaccination."

Professor Levin's research was the venue of our latest Member's site visit, which was the best attended so far, when 26 members along with MRF staff had talks and a tour of the labs.

Jeffrey Pullinger, who developed W135 meningitis in 2004 at the age of 24 said "We gained an insight in to what MRF is doing and the massive difference they make through funding research. It is also clear that MRF is partly responsible for developing guidelines for treatment and awareness. An amazing achievement."

Susan Rosenberg Lazar, whose son Mark contracted bacterial meningitis in 2003 at the age of 13 said: "The presentations were excellent, and I learned a huge amount. So many people needed to speak and share their experiences of this devastating illness. The afternoon not only provided a forum for insights into research but also clearly fulfilled this need."

The next site visit is scheduled for 1st December to the NIBSC in Potter's Bar, where we are currently funding several projects into potential vaccines for MenB. Anyone who is interested in coming should email gillianc@meningitis.org or call 01454 280410.

Find out more at
<http://bit.ly/MRFgenetics>

*This is an
important
breakthrough in
our understanding
of this infection*

Why my child?

One of the first questions parents ask when their child gets meningitis or septicaemia is 'Why my child?'

Our Head of Research and Medical Linda Glennie answers:

What has emerged after 15 years of research is that susceptibility is a complex interplay between many factors, and our genetic make-up is just one of them.

Factors that might predispose a person to get meningitis/septicaemia at a particular time include:

- the virulence of the bacteria
- age
- a person's state of health
- particular immunodeficiencies: for example having no spleen or a non-functioning spleen makes you much more susceptible
- complement deficiency: this is a genetically inherited immunodeficiency we already know about which predisposes to meningococcal disease and some other bacterial infections.

Professor Levin's research, although scientifically very important, has not revealed a particular genetic deficiency that we can go to our doctor and get tested for. It simply tells us that a particular cluster of genes is associated with susceptibility.

We hope this further research Prof Levin is undertaking with MRF funding may also point the way to improved treatments and might be important in the development of a vaccine.

Do get in touch with the helpline (080 8800 3344 in UK, 1800 41 33 44 in RoI) if you have further concerns.



Meningitis Awareness W

After the under-fives, 14-24 year olds are most at risk from meningitis and septicaemia.

With cases of meningitis and septicaemia increasing in Autumn and peaking in Winter in the UK and Ireland, MRF's Awareness Week, September 20 - 26, provided an important platform to remind people of the devastating effects of meningitis and septicaemia and the measures that can be taken to protect against the diseases.

This year the campaign focused on the burden of disease in teenagers and young adults, and through the launch of two new digital resources we were urging the age group to *Get the Message*.

Ahead of the week we commissioned research to find out just how much the student population of the UK and Ireland really knew about the diseases, their symptoms and vaccinations against meningitis and septicaemia.

The research revealed that over 50% of students do not know whether they have been vaccinated. Students also ranked themselves in the second least at risk group – when in fact they are in the **second most** at risk, after babies and young children.

A quarter of students believe a rash is present in all cases of meningitis, when actually there are some types of meningitis where a rash does not appear at all. Students need to be vigilant of other symptoms including fever, vomiting, dislike of bright lights and neck stiffness, and not only look out for the rash.

As a result we have launched our meningitis symptoms iPhone app, to appeal to teenagers and young adults.

As always, we were so grateful that so many members and supporters were prepared to tell their stories of how meningitis and septicaemia have affected them and their families, helping to gain extensive media coverage for the campaign during the Week.

To help ensure that students did *Get the Message*, hundreds of thousands of wallplanners and posters were also sent to universities, colleges and sixth forms around the UK and Ireland. Whilst our Ireland office was involved in the high profile launch of mobile phone SMS messaging of symptoms which is now available in Ireland for the first time.



Campaign case study

Nicole Wilson was an MRF media representative for our *Get the Message* Awareness Week campaign.

Nicole lost both of her legs and is currently awaiting a kidney transplant after she suffered meningococcal septicaemia while on holiday, but, despite everything, knows how lucky she was to survive.

Nicole, now 18, was on holiday in Cyprus with her best friend's family and friends. She felt seriously unwell, was taken to hospital but sent back to the hotel with the diagnosis of a kidney infection.

Fortunately, one of the party was a nurse, who recognised the symptoms and got her straight back to hospital.

Week – Get the Message



Her mum and dad back home had the call to get to Cyprus straight away. With her sister they flew out, not knowing if Nicole would still be alive when they got there. Said her mum, Bev: "Nicole's health was deteriorating fast, her organs had started to shut down. I was terrified. The last call I had was to say Nicole had a 10 to 20% chance of survival."

It was 10 days before Nicole regained consciousness, but after three weeks surgeons said she would need amputations.

She was flown home for the surgery, and spent six months at Addenbrooke's Hospital where doctors removed her leg below the knee, and

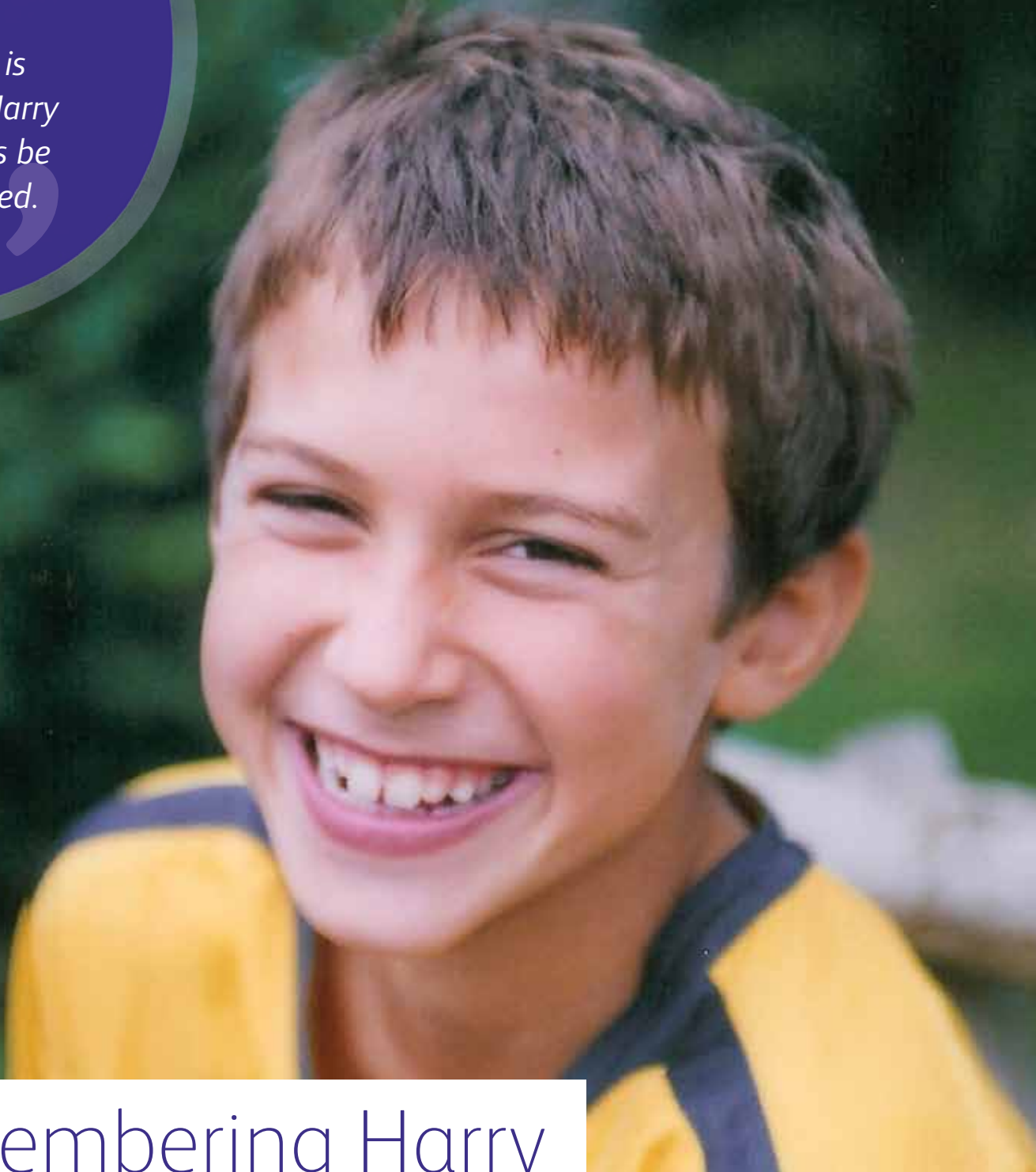
the fingers on both hands. Although plastic surgeons tried to save her left leg, Nicole bravely decided to have it amputated.

She is now on the waiting list for a kidney, and is living with the devastating after effects of meningitis and septicaemia, which is why she is passionate about working with MRF to raise awareness of the symptoms.

"I don't think people realise quite how serious it can be. If anyone has a high temperature, sickness or aching joints I'd say 'get yourself checked out'. Better to be safe than sorry," explained Nicole.

*The last call
I had was to say
Nicole had a
10 to 20% chance
of survival*

“One thing is
for sure, Harry
will always be
remembered.”



Remembering Harry

Dedicated members, Judi and Richard Mills and their family, have supported MRF for over three years now, since the death of their 11 year old son Harry.

Harry had been vaccinated against Men C ten years earlier, but it was Men B, for which there is no vaccine, that took his short life.

His family set up a tribute page 'Remembering Harry', which has had fantastic support from everyone who knew him. With the dedication of friends and family, this summer saw the total raised for charity surpass £100,000, with over £90,000 of that raised for MRF.

Money has also been raised for The Youth Sports Trust, which uses the power of sport to improve the lives of young people. Harry was a keen and very talented sportsman, and his teammates have committed to keeping his

memory alive. The Marlow Merlins under 15s rugby team recently observed a minute's silence followed by 'three cheers for Harry'.

Harry was honoured with his own memorial garden at the new Butterfly World site in St Albans last year. Harry's love of sports was reflected in his garden, with rugby posts, tennis nets and ball shaped flowers, in amongst a wild flower bank with a giant hedgehog.

On the day Harry died, his family opened the door of their home to find a hedgehog sat on their porch, which they hadn't seen before and haven't seen since. In tribute, Harry's garden was planned to include a hedgehog sanctuary

to protect and treat injured hedgehogs.

Harry's friends, teammates and family, grew sunflowers and specially sourced sweet peas called 'Our Harry' to plant in his garden, which opened in June 2009. The garden flowered as a celebration of Harry's life, to remember an energetic and much loved young man.

Friends and family have taken part in all sorts of fundraising challenges from 5km fun runs to overseas marathons, as well as parachute jumps and horse riding events. One event, Harry's Lunch, has been such a success that it has been made into an annual occasion.

Softcat, a Marlow based software company, donated £13,000 over the course of a year in Harry's memory, whilst staff at Marks and Spencer's Marlow branch have just finished 100 days of fundraising.

Marlow Town Council honoured Harry with a new Outstanding Sportsman award, which is just one of many created in his name.

Harry's family and friends are working so hard to fund research to prevent other families having to suffer a similar loss. His life may have been short but it was certainly full. One thing is for sure, Harry will always be remembered.



The Mills family with actress Emilia Fox and MRF's Iain Elliott at the opening of Harry's garden at Butterfly World

Harry's story

Judi and Richard Mills tell us about Harry.

Our son, Harry, died from meningitis on 26th April 2007, aged just 11 years old.

A much-loved boy, the youngest of our four children, Harry always had a beaming smile on his face and limitless enthusiasm for sport and life itself. Harry's short life was extinguished in a single day by this terrible disease and his loss devastated not just us, his family, but our whole community.

Sport was Harry's life. In the four days prior to his illness, he had been unanimously voted 'man of the match' in a rugby competition, played tennis and represented his school in a football tournament at the David Beckham Football Academy.

He woke the following morning feeling slightly unwell but with no obvious symptoms; we thought it was just a bug, and by the evening we even thought he was well enough to return to school the following day. It wasn't to be. During the night, he was sick and by 8.30am he was in an ambulance on his way to hospital.

The hospital staff at both Wycombe General Hospital and the John Radcliffe Hospital were wonderful – very caring and compassionate – but despite their best efforts, they were unable to save him.

The decision to agree to donate Harry's organs was an easy one – in life Harry was always keen to help others, and for us, the thought that Harry would live on in some way was of some comfort. We have since had several letters of thanks from the recipients – and this

helps us make some sense of the tremendous waste of Harry's young life.

From the moment of arriving home, we were overwhelmed by the response from all who knew Harry. There are no words to describe the love and kindness shown to us by our friends, Harry's school-friends, team-mates, coaches, school staff and even people we do not know. Harry seemed to have touched so many people's lives and the love and friendship that was his hallmark continues to live on after his death.

Read Harry's story in full in our Book of Experience and donate in his memory at <http://bit.ly/harrym>

www.harrymills.co.uk

www.justgiving.com/harrymills-meningitisresearch

www.butterflyworldproject.com

This helps us make some sense of the tremendous waste of Harry's young life

Bunker to Banquet

Over £500,000 has been raised to date from the continued success of Bunker to Banquet.

Left to right: Chris Head, Lady Helen Wood, Beverley Pace, Sir Ian Wood, Cheryl Baker, Mary Millar, Claire Coffey, Garreth Wood, Nicola Wood

Patrons Sir Ian and Lady Helen Wood hosted the 12th annual Bunker to Banquet in June in Aberdeen. A total of £55,000 was raised, bringing the grand total for the event to over £500,000.

The Championship Laird's Course at Inchmarlo Golf Club on Royal Deeside was the venue for the 13 teams competing for a range of prizes for the longest drive, nearest the pin, and that elusive hole in one. After post-match refreshments, it was time to change the golf gear for the black tie, and to head off to the luxurious Marcliffe Hotel for the gala evening and banquet.

TV presenter and former Bucks Fizz star Cheryl Baker was our MC for the evening, and did a

sparkling job. This year, part of the focus was the plight of meningitis in Africa, illustrated by a short video. Aberdeen member Claire Coffey then gave a heartfelt speech of her own experience of meningitis. Claire's son Ryan contracted meningococcal septicaemia when he was three years old. Claire had previously attended an awareness raising seminar run by MRF and her recently-acquired knowledge of the symptoms ensured that Ryan received immediate medical attention and made a full recovery. So our work truly is saving lives.

A glittering array of auction prizes was enthusiastically bid for, including trips to Wimbledon, diamond pendants, five star hotel breaks and memorabilia donated by Joanna



*This year, part
of the focus was
the plight of
meningitis in
Africa*

Lumley, JK Rowling, Andy Murray and David Tennant.

Our thanks go particularly to Sir Ian and Lady Helen for hosting the evening, and to their son Garreth for all his practical and moral support. Thanks also to the sponsors of the evening – The Wood Group, Aberdeen Journals and BP, and to all the companies in Aberdeen who entered golf teams and took tables. See you all next year!



The Purple Range



The Foundation is launching its brand new exciting Purple range of products.

The range is launched with the opportunity to buy our limited edition fashionable purple sports watch. This waterproof tubular watch is tough, cheap and great for messing around in. Perfect as a stocking filler or gift for someone

who wants to be on-trend with stars such as David Beckham and Lindsay Lohan.

These limited edition watches will be unique from other brands as they will sport the charity's logo and the name of the range so you can demonstrate your support of our cause. The Foundation is selling them for £5 to raise much needed funds. Please send cheques made payable to Meningitis Promotions Ltd or call 01454 281814 and speak to the fundraising department.



Thanks to the 225 amazing ladies who completed this year's Flora Women's Mini Marathon in Dublin for MRF, including one group of ladies who ran in memory of five year old Ruby Ayoub who died from meningitis last November. All in all the event has raised a fantastic €43,000. Well done everyone!

News in Brief

MenA

MRF is delighted with the World Health Organization's approval for a new vaccine for the meningococcal group A strain which causes so much death and disability throughout the world, particularly in the meningitis belt in sub-Saharan Africa.

Read more about the new low cost vaccine that could save thousands of lives in MRF's International Development Officer Rachel Perrin's blog piece on our site at <http://bit.ly/MenAfrica>.

NICE

We're supporting the new National Institute for Health and Clinical Excellence (NICE) guideline which says prompt recognition of the signs and symptoms of bacterial meningitis and meningococcal disease is the key to preventing the deaths of children and young people.

Linda Glennie, our Head of Research and Medical Information, is a member of the NICE

Guideline Development Group and has been closely involved in drafting the new guideline since February 2008.

Find out more at
<http://bit.ly/guidelinemrf>

New SMS Service launched in Ireland

MRF are delighted that their SMS service is now available throughout Ireland.

We hope that every person in Ireland will have this message on their phone so please text the word **TIME** to **50308** and download the video; this can then be bluetoothed to other phones free of charge. Please spread the word and download this link to your phone and send it to all your family and friends and ask them to do the same.

First aid

Over the coming months our NI office will be working on a new project to improve links with local first-aid training providers and distribute our symptoms awareness resources to first-aiders in the community. This work will be funded by a grant from the Co-operative Community Fund.

Calendar of Events

October and November



The Fire Walk Challenges – The Hottest, Shortest Sponsored Walks in the World!

Overcome your fears, increase your confidence and self esteem and raise much needed funds for us at the same time! 30 October in Dumfries, 5 November in Edinburgh, 6 November in Glasgow.

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

October onwards

Pub Quizzes

So you think you know it all? Prove it! Arrange a pub quiz, have great fun and raise vital funds. We will put together a quiz pack, along with balloons, banners and advertising posters. All you have to do is get the teams together.

For more information please contact Elaine on 01 819 69 31 or email elaine@meningitis-ireland.org

13 November

Dundrum Shopping Centre Collection

Can you spare some time to support the charity by taking part in our flag day?

Please give Elaine a call on 01 819 69 31 or email elaine@meningitis-ireland.org

18 November

Black Tie Ball

Taking place at the prestigious Inner Temple, London you'll enjoy a champagne reception, followed by a three course dinner with wine and entertainment and round off the night with dancing.

The Ball will be hosted by Norman and Beverley Pace and will be attended by other patrons including Dr Hilary Jones, Rory Underwood and Kirsty Young.

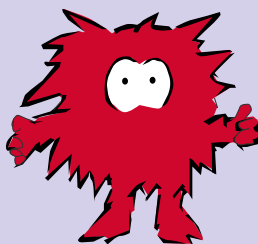
Tickets for this black tie event are priced at £125 per person and selling fast.

For further information or to reserve a ticket or table for ten, please contact Sarah Campbell on 01454 281814 or sarahc@meningitis.org

26 November

Marvin Pin Day in Ireland

Get your school, workplace or local community on board this year and be part of our Marvin Day 2010. The aim of this fundraiser is to sell as many pins as possible.



For more information please contact Wioletta on 01 819 69 31 or email vi@meningitis-ireland.org

4 December

Dublin Megaraid

From first time helpers to loyal volunteers, megaraiders are a great way to get involved in some serious fundraising. All we need is for you to come along, wear a smile, shake a bucket and help us raise thousands of euros in just one day. And if fundraising is second nature to you, you will have a great chance to receive our €150 prize.

Please get in touch with Monika on 01 819 69 31 or email monikam@meningitis-ireland.org

December

Carol Singing in Dublin

Sing your favourite Christmas Carols this Christmas for MRF.

Please get in contact with us on 01 819 69 31 or email monikam@meningitis-ireland.org

5 December



Santa Run

We need Santa Clauses for MRF causes!

Once again we are on the look out for Santas in the London 5K Santa Run. Entries are £20 each which will be donated to MRF. A free Santa suit for every runner.

For more information contact Genna on 01454 280414 or gennav@meningitis.org or book your place today by visiting <http://bit.ly/MRFSantarun>

1 January

The Loony Dook



Taking place at picturesque South Queensferry, you'll parade behind a merry band of pipers, through the town and down onto the foreshore for your dook in the Forth

for a truly invigorating start to the New Year! Fancy dress is welcome but no wetsuits allowed!

Please email alisonbaker@scotland-meningitis.org.uk or call 0131 510 2345

8 January

Bupa Edinburgh Great Winter Run

A 5km road run for all abilities in the stunning surroundings of Holyrood Park in Edinburgh.

Please register at www.greatrun.org and contact the office on 0131 510 2345 for a fundraising pack.

March

GI Jane Scotland – Boot Camp!

Taking place in Fordell Firs Scout Activity Centre, if you're aged over 16, we need you to undergo a series of both physical and mental challenges to become GI Jane 2011. You will be put through your paces by members of the Army Recruitment Team, starting the day with a warm up drill before tackling five activity zones which include, abseiling, zipline, orienteering, king swing, climbing wall, caving, and mental challenges.



To take part in this exciting, adrenalin fuelled fun filled day, please contact dawncarrie@scotland-meningitis.org.uk or call the Edinburgh Office on 0131 510 2345.

Christmas cards

You should have found enclosed MRF's Christmas card flyer for 2010. Some designs are selling fast, so get your orders in soon to avoid disappointment.

You can order online at www.meningitis.org or send back your flyer to us at the address on the back of the leaflet.

If you didn't have a flyer, please do give us a call on 01454 281811.

Freefone 24 hour helpline

080 8800 3344 (United Kingdom)

1800 41 33 44 (Republic of Ireland)

www.meningitis.org



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