

# haemophilia.ie

Magazine of the Irish Haemophilia Society



Ireland votes 'Yes'  
& Europe comes to Dublin!

September 2008

# Final Announcement Members Weekend | 7th - 19th October



## VENUE

The County Arms Hotel,  
Birr,  
Co. Offaly.  
Tel: 057 9120791  
Email: [info@countyarmshotel.com](mailto:info@countyarmshotel.com)

## ADULT PROGRAMME

### Friday 17th October

5.30pm - 7.00pm Registration

### Saturday 18th October

10.00am	Health Supplements
11.00am	I.H.S. 40th Anniversary
11.30am	Tea / Coffee Break
12.00pm	Barretstown Gang Camp
1.00pm	Lunch
2.00pm	<b>MEN: Being Active</b>
2.00pm	<b>WOMEN: Time for you</b>
5.30pm - 8.00pm	Family Time
8.00pm	Dinner followed by a Quiz

### Sunday 19th October

10.00am	<b>Debate:</b> "Are there limits to my life activities?"
11.00am	<b>Open Forum</b> Services & Activities of I.H.S.
1.00pm	Lunch and depart

## CRECHE

### **FOR YOUNGER MEMBERS UP TO 6 YEARS**

Our experienced creche supervisors will organise all activities for the 2 days.

#### Creche Opening Hours

Saturday	9.30am - 5.30pm
Saturday	5.30pm - 8.00pm <b>FAMILY TIME</b>
Sunday	9.30am - 12.30pm

Parents, please remember to bring a change of clothes for your child.

## KIDLINK

### **FOR CHILDREN 7 TO 11 YEARS**

#### Friday 17th October

5.30pm - 7.00pm Registration

#### Saturday 18th October

10.00am - 5.00pm Little Haven 'Just Having Fun Kids Club'  
5.30pm - 8.00pm **FAMILY TIME**

#### Sunday 19th October

10.00am - 12.00pm Little Haven 'Just Having Fun Kids Club'

## BIRR ADVENTURE CENTRE

### **FOR 12 YEARS & OVER**

#### Friday 17th October

5.30pm	Registration
6.30pm	Transfer to Adventure Centre

#### Saturday 18th October

A full day of activities

#### Sunday 19th October

10.00am Return to hotel for debate

*[Please note that this group will stay at the Adventure Centre on Friday and Saturday night]*

# Contact Details

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Alison Daly

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Robert Byrne winner of the quiz at last years Member's Weekend

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# Message from the Chief Executive



**Brian O'Mahony**  
**Chief Executive**

## Progress on the Comprehensive Haemophilia Treatment Centres

Over the course of the past year the National Haemophilia Council has worked to identify the priority areas for the improvement of services at the 3 Comprehensive Haemophilia Treatment Centres at St. James's Hospital, Dublin, Our Lady's Children's Hospital, Crumlin, and Cork University Hospital (CUH). In identifying these priorities the Council were assisted by the reports of the independent audit of the Treatment Centres, which were carried out in late 2006. These audits and the subsequent work of the Council identified improvements that were required in the service at all 3 centres. In Cork University Hospital there was a requirement for a Lead Consultant to lead the haemophilia service, additional Laboratory Scientist, part-time commitment of a Specific Physiotherapist, Social Worker & Dentist for the haemophilia service and infrastructure for an Out-Patient's clinic.

In Our Lady's Children's Hospital, Crumlin, there was a requirement for an additional Consultant Haematologist who will be the leader of the haemophilia service. There was also a requirement for an additional Nurse Specialist. In St. James's Hospital in Dublin there was a requirement for a specific In-Patient unit to deal with haemophilia and hepatology. This In-Patient unit was discussed with the Minister for Health & Children last year and the Minister gave a commitment to this unit at the Irish Haemophilia Society's AGM in March of this year.

In July, Professor John Bonnar, Chair of the National Haemophilia Council, Dr. Barry White, Director of the NCHCD, and myself, met with senior officials from the HSE, and with the Head of the National Hospitals Office. In the same week we met with the Minister for Health & Children, Mary Harney. As a result of these meetings a number of specific steps are now being taken to rectify the deficiencies in the haemophilia service. A new Consultant Haematologist will be appointed in Our Lady's Children's Hospital, Crumlin. This post has already been advertised. An additional Clinical Nurse Specialist has already been appointed in Crumlin in the past month. In Cork University Hospital the new Consultant Haematologist post will shortly be advertised. The provision of a modular Haemophilia Treatment Centre for Cork University Hospital is under active consideration by the HSE Capital Steering Committee. An additional Laboratory Scientist has been appointed. Work is on going with Cork University Hospital to look at the best way to provide the Physiotherapy, Social Work and Dental Services required. Following our

meetings in July the proposed In-Patient unit in St. James's Hospital for the treatment of persons with haemophilia has been moved up the priority list for HSE capital spending. The design stage for this unit has now been completed and the unit is currently at the planning permission stage. We expect the building of this unit to begin in the coming months with a completion date of 2010.

Further external audits will take place at the 3 Treatment Centres in late September. The audit team will consist of a team of 3 individuals from abroad, a Haematologist and a Clinical Nurse Specialist from the UK and a person with haemophilia from Canada. The person with haemophilia is Mr. David Page, Chief Executive of the Canadian Haemophilia Society. He has been nominated on to the audit team by the Irish Haemophilia Society. External peer reviewed audits of the Treatment Centres are an invaluable tool in looking at the haemophilia service provided, identifying deficiencies in the service and helping to ensure that these deficiencies are dealt with in a timely manner.

## Travel Insurance

The Insurance Scheme for persons with haemophilia with HIV and/or Hepatitis C has been in operation since September 2007. The final element of this Scheme 'Travel Insurance', was introduced on the 25th of July 2008. Letters were sent to all Health Amendment Act ( HAA ) card-holders by the HSE at that time. It has always been difficult for persons with haemophilia to obtain Travel Insurance and more particularly for persons with haemophilia who have Hepatitis C and /or HIV.

Annual Travel Insurance policies such as that provided by the Voluntary Health Insurance board were available only to existing VHI insurance holders. We are very pleased that this Travel Insurance is now available. The Travel Insurance scheme is called the Emerald Travel Insurance Scheme. Persons with haemophilia may purchase individual annual Travel Insurance, Travel Insurance for a couple or Travel Insurance for their family. The cost of individual Travel Insurance for the year is €67.50 or €135 for a couple or family. The Travel Insurance Scheme gives €5million of cover for medical expenses, €2million for personal liability, €7,500 for cancellation or curtailment and €1,500 cover for baggage. Members who are eligible for Travel Insurance under the Scheme and who wish to access the Scheme should phone 0818 200 113. Additional information can be obtained from the Insurance Scheme Administrator on 1850 211 570. This Scheme will be of great benefit, I believe, for members if they are travelling personally or with their families and perhaps taking a vacation to a country where they actually get a summer!

### Insurance Scheme Open Period Ends

By the time you will have received this newsletter the initial opening period (the first year) of the Insurance Scheme will have been completed. The initial opening period ran from the inception of the Scheme on September 12th, 2007 to September 11th, 2008. Maximum cover with no waiting period was available for members in the initial open period for Life Insurance and to this end we have worked extremely hard during the course of the year to ensure that all members who are eligible for Life Insurance and Mortgage Insurance under the Scheme were aware of the Scheme, were aware of the initial open period and

had fully considered participation in this Scheme. By the beginning of September, of the 2,000 persons who were eligible to take out insurance under the Scheme only 174 had availed of Life Insurance, 6 had availed of Mortgage Insurance and 2 had availed of equity release.

The overall participation rate for Life Insurance therefore was less than 10%. The Society was more successful in educating people with haemophilia about the Scheme and encouraging participation in the Scheme. This is demonstrated by the fact that approximately 60 persons with haemophilia out of a total eligible number of 140 had availed of Life Insurance. Therefore the participation rate by people with haemophilia in the Life Insurance Scheme to date has been 43% compared to less than 7% for the members of the other organisations whose members with Hepatitis C were eligible for inclusion in this Scheme. Interestingly to date the majority of policies taken out under the Scheme have been categorised as uninsurable by the Insurance Company. More than 80% of the individuals who have taken out Life Insurance under the Scheme have been categorised as uninsurable. This still means that they get the insurance at the same premium but it means that essentially the insurance risk is taken by the Government and not by the insurance company. Just under 20% of those who have taken out insurance have been categorised as Category 1 which means that they are insured with a loading and the loading, or additional premium, is paid by the government.

Whereas the first year of the Scheme has now passed and the initial open period has passed it is still important for those who have not yet taken out Life Insurance to consider doing so. It is worth remembering that for those who have taken out Life Insurance, they always

have the option to 'Topping Up' their policies to the maximum amount allowable under the scheme.

### European Haemophilia Consortium Conference

The Annual Conference of the European Haemophilia Consortium (EHC) took place in Dublin from 12th to 14th September. The conference was organised by the Irish Haemophilia Society. The EHC is the representative body, which brings together the Haemophilia Societies in 44 European countries. As such its remit is not just EU countries but Council of Europe countries, candidate EU countries and all the European countries who are not members of the EU including Russia and the Commonwealth of Independent States countries. Some 240 delegates attended the conference. The delegates included the leaders of Haemophilia Societies, Doctors, Scientists and Industry. The topics discussed at the conference and at the symposia tended to reflect wider European issues. These included a debate on whether or not there was a requirement for 'European Standards Of Care' and lectures on 'Setting National Treatment Goals and Standards' and on 'The Science of Reproduction and Haemophilia'. Among the speakers at a symposium on 'Patient Migration in the EU' was Proinsias De Rossa, MEP. and Dr. Barry White informed delegates about the 'Irish System of Haemophilia Care'. Following our work in organising the conference over the past year we were delighted to see such a large number of delegates registering. A full report from Kevin Birkett on the conference can be found on pages 6 - 10 of the magazine.

**Brian O'Mahony**



## E.H.C. Conference 12th - 14th September 2008 Dublin Castle

In 2008 Ireland voted 'No' to the Lisbon Treaty, but prior to this the Irish Haemophilia Society voted 'Yes' to hosting the European Haemophilia Consortium Conference in Dublin in 2008. Two years of work came to fruition from 12th - 14th September in Dublin Castle.

Situated in the heart of the capital, Dublin Castle has played a pivotal role in Irish life over the centuries. Formerly the home of the Irish Parliament and later the seat of British rule, today the Castle is synonymous with inquiries into wrongdoing by politicians. The castle though has another side. Largely overlooked by the media and public it has become home to a multitude of cultural events, exhibitions and conferences. Built to host Ireland's Presidencies of the European Union, on the weekend of September 12th the Castle's unique conference facilities played host to yet another prestigious event; the Annual Conference of the European Haemophilia Consortium.

Opening the Conference in the absence of the Minister for Health, I.H.S. CEO Brian O'Mahony gave the guests a brief

history of the Castle before recalling the very first meeting of the EHC. As he later elaborated, his abiding memory of that first meeting in the Netherlands was of the 40 or so dedicated individuals who had come together to facilitate consultation, discussion and the dissemination of information on important issues related to bleeding disorders among European haemophilia organisations. Since that first

meeting in 1989 the EHC has grown to encompass 43 member countries, who together, bring a wealth of experience to the organisation. Not only has the EHC grown but so too has its remit. Today its ongoing campaigns seek; to improve diagnostic and treatment facilities, ensure adequate supply of safe factor concentrates, promote patients' rights, raise ethical issues, stimulate research in all fields



related to haemophilia, and influence developments in European Health Policy.

Naturally such a wide ranging remit places tremendous pressure on what is essentially a voluntary organisation. One of the first to recognise this was the late Hubert Hartl who oversaw the establishment of the EHC as a legal entity in Belgium and who was instrumental in appointing the leading European corporate affairs consultancy, Interel, to promote the EHC and its policies at EU level. Much was achieved by Hubert during his time as EHC President and, as his colleague Gabriela Boehm said, "Hubert's death has left a hole in the whole community both in Austria and in Europe." His lifetime of work on behalf of people with bleeding disorders has left a huge legacy; a solid foundation on which the EHC can grow and prosper. Dublin saw the first bricks placed on that foundation when the Business Meeting adopted the EHC Strategic Plan.

During the early part of 2008 the EHC Steering Committee met on a number of occasions to formulate a Strategic Plan to take the organisation to the next level in the services it offers its members. The work of developing the Strategic Plan was lead by Brian O'Mahony who is a member of the Steering Group. At the conference Brian outlined the Strategic Plan and it was approved by the General Assembly at the conference. Key goals for the future of the EHC are; to have effective, high quality representation on external bodies, that it is viable, well-financed and organised, that its views are considered at EU and Council of Europe level, that communication, information exchange and collaboration with its members and other stakeholders is optimised, and that it continues to support and assist its members' advocacy efforts nationally. That such an ambitious and imaginative



**Anne Duffy, Uwe Schlenkrich & Catherine Hudon practising on the Bodhran**

plan can be drawn up by a voluntary organisation illustrates the extra-ordinary abilities of many within our community. Just seven strong, the EHC Steering Committee has taken it upon itself to ensure that the aims of the Strategic Plan are realised, although given the plan's scope, they are sure to need assistance from member organisations. The key changes the plan envisages over the coming years include; consultation and representation at EU level; and the establishment of a permanently staffed EHC office in Brussels.

The establishment of an office in Brussels will enable the EHC to maintain a consistently high, professional service to its members and to interact effectively with regulatory bodies regardless of personnel changes within the Steering Committee. But such continuity only comes at a price. The policy on financial support from commercial companies adopted during the Business Meeting will assist in meeting that cost. The policy clearly lays out the principles on which the EHC will establish a relationship with the pharma-

ceutical industry. The principles allow for the full independence of the EHC in deciding how to spend funding.

The Strategic Plan also envisages further development in the relationship between the EHC and the World Federation of Hemophilia. As President of the WFH Mark Skinner is an ex-officio member of the EHC Steering Committee. Speaking later he praised the work of the EHC and the lessons it's work has for other regions of the world.

"The relationship between our two organisations has continued to improve over the last couple of years. I continue to see it improving. The European Haemophilia Consortium has really matured & evolved in the last couple of years to become a very professional, dynamic organisation with a clear vision. The role that the EHC now plays in representing haemophilia organisations not just within the EU but across Europe and providing that voice to the European Union is going to be fundamentally important in helping to set the course for

care within the EU, but also across Europe and providing an example that can be used globally. We are going to learn a lot of lessons in Europe that will be transportable to the non EU countries as well as other regions of the world."

An initiative that particularly impressed Mark was the 'European Principles of Haemophilia Care' proposed by the European Association for Haemophilia and Allied Disorders (EAHAD) with input from the EHC. Steering Committee member Dr. Gabriele Calizzani briefly outlined the principles while EAHAD President Prof. Christopher Ludlam was on hand during the afternoon session to expand on them.

The objective behind the principles was; to establish a benchmark for haemophilia care, encourage improvements in countries where care is currently suboptimal, preserve and improve the level of care so far achieved in developed countries, and to act as a public relations & advocacy tool for haemophilia care issues with key stakeholders. Essentially there are ten principles covering all aspects of treatment.

- In each country there should be a central organisation for haemophilia care supported by centres operating at the local level. These organisations should

be responsible for accurate record keeping and the effective administration of haemophilia care.

- Each country should have a National Haemophilia Patient Registry administered by the central haemophilia organisations.
- Comprehensive Care Centres and Haemophilia Treatment Centres should be established to ensure that people with haemophilia need access to a number of co-ordinated services to ensure that their particular needs are met. In critical situations, people with haemophilia need immediate access to treatment as well as to skilled care through Accident & Emergency departments and to the range of specialists required to ensure their safety.
- People with haemophilia need to have access to safe and effective treatment at optimum levels.
- Home treatment and home delivery should be available in each country to facilitate immediate and effective treatment.
- Prophylaxis treatment should be available to people with haemophilia.



People with haemophilia have access to the full range of clinical specialties and appropriate laboratory services.

- Clinicians and patient representatives should be part of national and/or regional haemophilia care decision making in partnership with Ministries of Health and Social Affairs, as well as those organisations that deliver haemophilia care via a formal mechanism such as a National Haemophilia Co-ordinating Group.

- People with haemophilia who develop "inhibitors" need to have immediate access to optimum treatments. Where appropriate, immune tolerance induction therapy (ITI) and the management of bleeding should be administered by clinicians, with the necessary expertise, in hospitals with appropriate clinical and laboratory resources.

- There should be ongoing recruitment and education of physicians in the area of thrombosis and haemostasis to secure high quality care. Further

research into haemophilia is also required, with priority areas for investigation being modified Factor VIII and IX agents with longer half-life, less immunogenicity, new administration techniques, better understanding and prevention of the development of inhibitors and gene therapy.

These principles will be launched during a EHC/EAHAD sponsored meeting at the European

Parliament in January 2009. While European treaties explicitly commit the European Union to fully respect Member States' responsibilities for the organisation and delivery of health services and medical care, the EU is exhibiting increasing interest in health matters, espe-

cially in the area of patient mobility and migration. Prof. Wolfgang Schramm, Director of the Haemophilia Centre in Munich, outlined the current situation. "At present EU citizens are free to seek health care in other member states, as ruled by several cases of the European Court of Justice (ECJ). Treatment costs are reimbursed by their home country but only up to the amount covered by the home country's health care system, the difference has to be covered by the patient. There is a requirement that national authorities have to provide

information to patients, who seek cross-border treatment."

It is unsatisfactory that current practice is based on rulings of the ECJ and not regulation. The European Parliament recognises this and has requested that the Commission come forward with proposals. In July the Commission responded to Parliament's demands and came forward with a proposal for a Directive on 'The Application of Patients' Rights in

provided domestically. However, if an unpredictable surge of cross-border healthcare risks becoming a serious problem, Member States would be able to put in place a system of prior authorisation for hospital care. Patients would be guaranteed fair and quick procedures, including for the reimbursement of costs, and would have easier access to information, in particular through 'national contact points'".

It is not certain when this proposal will become a directive or even whether it will survive in its present form but it can only be hoped that it is fast-tracked. Apart from the presentations on the EAHAD principles and patient mobility there were a number of other seminars. Dr. Paul Giangrande and Dr. Flora Peyvandi gave very informative talks on 'Reproduction and Haemophilia' while

Dr. Barry White outlined the 'Irish Model of Haemophilia care'. The pharmaceutical industry played its part in a very full weekend programme, by sponsoring symposia on:

'Our Immune System & Inhibitors – How can their interactions help us?' (Octapharma), 'Evolution of Factor Manufacture: The Past, Present & Future', (Wyeth), a very interesting debate on 'Disparities of access to haemophilia care & treatment – are European standards the answer?' (Baxter) which included our



Proinsias De Rossa, MEP who spoke at the EHC conference

Cross-border Healthcare.' Proinsias De Rossa MEP outlined the proposal.

"The first aim of the proposal is to help European citizens use their rights to gain access to healthcare in another EU country, if that is the best option for them. In practise the Commission is proposing that if a treatment is provided under a national healthcare system, patients will be able to receive such treatment in another Member State, without prior authorisation, and be reimbursed at home up to the level of reimbursement

very own Declan Noone, as a speaker, and 'Haemophilia Treatment: Present & Future Challenges' (Bayer).

Over 240 delegates representing haemophilia associations, clinicians and the pharmaceutical industry attended the conference with many participating in lively discussion and debate.

All in all the conference was a huge success thanks largely to the work of the I.H.S. staff and volunteers. We had 8 young teenage volunteers who assisted delegates with clearfulness and enthusiasm. The success was also due to the professionalism of conference organiser Paulene Mc Keever and her team. The contribution of the many speakers and the industry was also appreciated.

A treatment room was set up by the N.C.H.C.D.. This was stocked with donations of factor concentrate, borrowed crutches, hired wheelchairs, and a treatment table. It was manned by friendly, professional and extremely helpful nursing staff from St. James's and a physiotherapist from O.L.C.H.C.. 16 people with haemophilia received treatment over the weekend, and the availability of treatment proved a great addition to maximising their enjoyment of this excellent conference.

I think though the final words on EHC 2008 should go to two visitors to Dublin.

"I would like to congratulate you all on the meeting, and all the people I spoke with had the same opinion"

Jane Pittadaki, Greece

"Thank you all so much, I felt very at home in Dublin"

Gabriel Lottaz, Switzerland

Kevin Birkett

For Further information see:

European Haemophilia Consortium

([www.ehc.eu](http://www.ehc.eu))

World Federation of Hemophilia

([www.wfh.org](http://www.wfh.org))

European Association for Haemophilia and Allied Disorders (EAHAD) ([www.eahad.org](http://www.eahad.org))



**'Here to help'. EHC Volunteers: Stephanie, Hannah, Sorcha, Sarah & Eileen from Mount Sackville School in Dublin**



**Des, Declan & Jack who volunteered and did a great job helping out over the weekend**

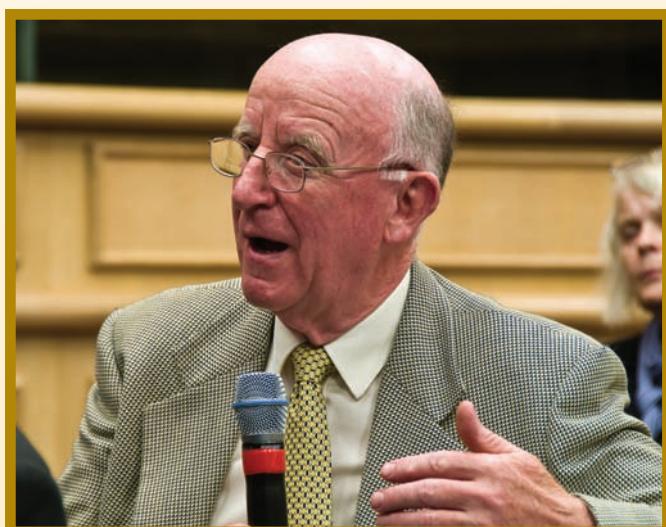
# Photo Gallery - EHC Conference 2008



Declan Noone debating  
'Are European standards the answer?'



The fantastic band who entertained us on Saturday night at the Royal Hospital, Kilmainham



Professor John Bonnar with a question for Dr. Flora Peyvandi during her session on Reproduction



Nina Storey, Brian O'Mahony, Nuala McAuley & Debbie Greene at the I.H.S. booth

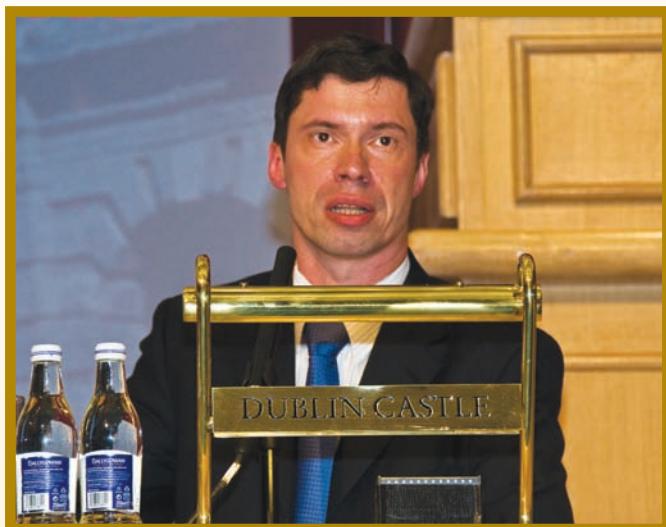


Say it with flowers! Brian O'Mahony making a presentation to Margaret Dunne



Professor Wolfgang Schramm, Director of the Haemophilia Centre in Munich

# Photo Gallery - EHC Conference 2008



Yuri Zhulyov from Russia during the debate on Saturday morning



Dr. Flora Peyvandi, from the Haemophilia Centre in Milan, talks about Reproduction & Haemophilia



Debbie Greene & Declan Noone at the I.H.S. booth in the Exhibition Hall



Dublin Castle State Apartments



Dr. Barry White, Director of the N.C.H.C.D. spoke about the Irish model of haemophilia care



Here come the girls.....  
Nuala, Nina, Margaret & Anne



## Do I, or do I not have children?

**A**s a carrier of severe haemophilia living in the developed world (UK) I know that I am extremely lucky. Who said the gene is not dominant? As a family we are riddled with haemophilia. I grew up with it as my younger brother has it. My sister is a carrier and has three haemophilia sons. Our two older sons now aged 19 and 16 are affected and our two youngest daughters 21 and 18 are carriers. Only our youngest son has "escaped".

One of the great ironies in my life and which had a major impact on me as a child and the rest of my family; is that I had an older brother. Tragically he died at the age of ten. I was nine, my brother with haemophilia eight, my sister five. The irony was that he did not have haemophilia. He died of septicaemia after contracting meningitis. This always seemed so cruel as he was the "healthy" one. It had been my younger brother

who had not been expected to live a very long life. Not him. He was "fine". Growing up it was never suggested that I would not be able to have children of my own and it was certainly something I dreamed of. This was in spite of the dominant part haemophilia played during my childhood. Looking back I recall my brother spending a lot of time in hospital with legs raised, drips in his arm. Personally, as a child, I always thought he was rather lucky being able to miss so much school.

When I was six my father was posted to Singapore. Due to my brother having haemophilia we could not go. My mother went out for a six week visit, but we didn't see our father for eighteen months. I was lucky that this huge dilemma was something I did not have to face, but my sister did. Her husband was offered a fantastic job in America. They searched all avenues, but as there was no reciprocal medical agreement with the US and with

three haemophiliac sons he felt it was impossible to take the job. I know this was a major disappointment to them all.

I was diagnosed a carrier of haemophilia at the age of sixteen. Unfortunately for my sister, my parents relied on the 'one in four genetics theory' and assumed she was not. My older brother was clear, I had tested positive, my younger brother had haemophilia; so she would be fine. When she was finally tested at 16 and confirmed a carrier it was huge shock to her. The possible implications of being a carrier were not very clear then. I have always had heavy periods, but in my teenage years just assumed that this was normal. It wasn't until a few years ago when I had to have an operation on painful varicose veins and a cruciate ligament reconstructed in my knee that I realised the full significance of my low level of Factor VIII. DDAVP didn't work and so I had to have factor; the same as the boys. Released

from hospital, I had to inject myself for five days at home.

For me I think the main issue of being a carrier was 'Do I, or do I not have children?' Growing up I didn't really give this much thought and nor did my husband when I met him. I was lucky that it was never an issue for him. We did, together, visit a haemophilia consultant. We were aware that abortion was available and that I would be offered a termination. We decided we could not contemplate the

route; nor was IVF

on the agenda then. We did not consider adoption at any stage, selfishly or otherwise we wanted our own children.

But was our desire to have a large family in fact selfish? There was a fifty fifty chance our baby was either going to have

severe haemophilia or be a carrier. Was I conveniently hiding behind the cloak of being a Catholic especially as my Catholicism is somewhat lapsed. I find abortion abhorrent, but just because I could not go through with an abortion; I was possibly subjecting our baby to a life with haemophilia and all that comes with that life. Injections, pain, hospitals etc.

I will never forget sitting next to a doctor, at a dinner with friends when I was just pregnant with our third child, Lottie and feeling rather lousy. He questioned me as to why I had not undergone

Chorion Villus Sampling. He felt that with one haemophiliac child already I should take advantage of this latest development in pre-natal testing in spite of the risks to a healthy foetus. I felt quite shocked at his judgement and it is something I have never forgotten. It certainly led me to question my conscience. Choice is one of the advantages of living in the developed world, but sometimes I wished we did not have so much. Of course I would have preferred not to have a child with haemophilia, but I didn't feel it my right to

baby kicking. I felt I could never have a termination even if both conditions proved positive. I was lucky. The amnio went well. Down's was not present and I went on to have a normal delivery. A healthy baby boy and free of haemophilia.

In our quest not to let haemophilia dominate our lives we did not consider being near a Centre though we did buy our house before our elder son was born. In hindsight I always felt this was a major mistake; being an hour and twenty from a

Centre a huge disadvantage.

My husband's job was close, but the hospital not. By the time that I realised that a limp or sore place was a bleed and managed to drop everything to get to hospital and have treatment, it would have become severe. I regret the repercussions that had.

decide, that one baby had the right to life over another. I didn't have an amniocentesis with our first four children. With our fifth it was different. I was classed, at 35, as an 'older mother'. I had an ultrasound scan at 18 weeks. A 'golf ball' or 'white dot' showed up on the baby's heart. I was warned that this was one of the signs of Down's Syndrome. The question was put to me. 'It is all very well coping with children with haemophilia, but this baby might have Down's Syndrome as well'. I was persuaded that I should have an amniocentesis. I will never forget that day. I was terrified. I could feel my

But, as I read this to my daughter last week, she is adamant I am too hard on myself. Her view is that it forced me to accept that I had to take responsibility for the boys' treatment. When they were little I was totally reliant on the haemophilia doctor and amazingly he made himself available 24 hours a day. He was fantastic and I was mortified when I learnt he was going to retire. How could I cope? It was really scary, but accepting that home treatment was the way forward gave us independence as a family.

I had to learn how to inject as soon as possible. It was a daunting prospect. It seemed, then, so unnatural certainly not a mother's job. I started on a doctor, then my husband then myself. I felt I had to be able to put a needle in my own arm before experimenting on the boys. My daughter is right. We were pioneers in home treatment. Henry was 3 years and 4 months when I gave him his first injection. This was a major achievement in my life. His younger brother 16 months. Incredibly the boys took to self-infusing as ducks to water.

Injections became as irritating to the them as brushing their teeth or making their beds!! Now we only go to the hospital for serious bleeds or check ups.

The boys attend normal schools. Initially it wasn't easy. The headmaster of one school, a Mr. Richardson, said 'How can

'How can I inflict your son with haemophilia on 'my boys'? I would be unfair on them'. We left feeling incredibly hurt and angry and with me in floods of tears. Well all I can say is that it was his loss. An area I found particularly difficult to deal with was sport. I had grown up with my brother being unable to take part in any sport. When the boys were young the school sports were rugby, football, hockey and cricket in the summer.

I hated preventing them from joining in and therefore being so obviously 'different' when outwardly so normal. Being part of the school team carried huge

kudos. I know they found it hard as did I, saying 'No'.

Prophylaxis has had a truly positive impact. Freddie our younger son, now plays squash and tennis for the first teams at his school.

My personal view, now, is we should try not to let haemophilia prevent a boy from trying any sport except perhaps rugby. I will never forget being told by our consultant that 'riding' is fine. But his idea

huge success of their education and lives so far and in many ways achieved so much more than their peers. I am sure having a disability (not that they would call it that) has, as with my brother, spurred them on. Henry is now at Edinburgh University studying Mechanical Engineering. Freddie is, as I speak, taking his GCSE's and going on to study Physics, Biology, Geography and Politics.

They do understand how lucky they are living in the developed world and the need to help others.

Four years ago Henry competed in a four day 125 mile canoe race from our home town to Westminster Bridge in London, camping overnight. He raised £4,500 which was used to train two Kenyan nurses in the treatment programme. Not content with coming

22nd he trained hard to come 2nd and win the team prize the following year.

This year with his ankle hugely improved he completed the race as a senior, non-stop in 22 hours and 45 minutes. I know this gruelling test of endurance and strength pushed him to his limit so far.

### **"The boys attend normal schools.**

**Initially it wasn't easy. The headmaster of one school, a Mr. Richardson, said 'How can I inflict your son with haemophilia on 'my boys? I would be unfair on them'. We left feeling incredibly hurt and angry and with me in floods of tears. Well all I can say is that it was his loss."**

of riding was a quiet hack or trot round an arena. Not jumping four foot hedges which is what our daughters got up to! I think, following a sport to a top level is where perhaps, even with all the benefits of living in England it gets tricky. Joint damage particularly in their ankles has been a problem for them both. For Henry, our eldest son, the pain and immobility became such a problem that last summer he had an arthroscopy. It was far more invasive and painful than we had anticipated.

At last though, eight months on he is reaping the benefit. The boys have made a

*[Our thanks goes to Fiona Dodson from the UK who allowed us to publish this article]*

# For Your Information: Updated Contact Details for Treatment Centres

## St. James's Hospital, Dublin National Centre for Hereditary Coagulation Disorders

**The Haemophilia Centre is open Monday to Friday 9.00am - 5.00pm**

Tel : 01 4162141 / 4162142 - Please ring this number to arrange the following appointments.

**Haemophilia Clinic:** Every Wednesday

**Dental Clinic:** All day Wednesday

**Carrier Testing Clinic:** Each afternoon by appointment only (please ring Eadaoin O'Shea at the above number)

**Orthopedic Clinic:** Every 3rd Wednesday contact Mr.Hugh Smyth

**Haemostasis and**

**Thrombosis Clinic:** Every Morning except for Wednesday

### **Emergencies**

Monday - Friday 9.00am - 5.00pm

If possible please inform staff you are on your way. Please ring the above numbers or 01 4103000 / 01 4103517 and ask for the Haemophilia Nurse.

### **In-Patient / Out of Hours**

Weekdays after 5.00pm / Weekends 24 hours. Contact Haematology Doctor on Tel: 01 4103000, or go to Walter Stevenson Ward in Phase IC (Main Hospital, 2nd Floor). Tel: 01 4103606, again if possible inform staff you are on your way.

### **Social Work**

Olwyn Halvey

Tel: 01 4284652

### **Clerical Staff**

Carol Finn, Manager

Tel: 01 4284649

Sinead Mahon, Secretary to Dr.Barry White

Tel: 01 4103521

Main Desk for Out-Patients

Tel: 01 4162141 / 4162142

Valerie McGill, Secretary to Dr. Beatrice Nolan

Tel: 01 4284348

Rachel Bird, Data Manager

Tel: 01 4103516

All patients should be assessed annually at the National Haemophilia Centre. If you have not been seen in the last year, contact the centre on Tel: 01 4162141 / 4162142.



## Cork University Hospital

### **Main Telephone No:**

Tel: 021 4546400

### **Consultant Haematologist**

Dr. Oonagh Gilligan

Tel: 021 4920029

### **Haemophilia Nurse Specialists**

Helen Browne / Annemarie Ruane /  
Brid Booth Flemming / Norma

Tel: 021 4922278, Bleep 228 / Mobile 087 9683246

## Our Lady's Hospital for Sick Children, Crumlin

<b>Main Telephone:</b>	Tel: 01 4096100	
<b>Consultant Haematologists:</b>	Dr. Corina McMahon, Dr. Beatrice Nolan, Dr. J Blatney	
<b>Secretary, Emma Murphy</b>	Tel: 01-4096913 Fax: 01-4563041	
<b>Appointments, Elizabeth Power</b>	Tel: 01-4282536	
<b>Clinical Nurse Specialists:</b>	Mary Kavanagh Imelda Kelly	Tel: 01-4096939 Bleep 732 Tel: 01-4096940 Bleep 733
<b>Factor Concentrate Coordinator:</b>	Bridin Brady	Tel: 01-4096647 Bleep 734
<b>Junior Doctors:</b>	Senior House Officer Registrar	Tel: 01-4096100 Bleep 542 Tel: 01-4096100 Bleep 107 & 108
<b>Physiotherapist:</b>	Diarmuid O'Riain Clinical Specialist	Tel: 01-4096100 Bleep 705
	Paula Loughnane Senior Physiotherapist	Tel: 01-4096511 Bleep 553
<b>Psychology:</b>	Dr. Yvonne Duane Dr. Rachel Brosnan Dr. Sandra Hayes	Tel: 01-4096191 Tel: 01-4096191 Tel: 01-4096041
<b>Social Work:</b>	Carol Carr Medical Social Worker	Tel: 01-4092629

### **Letterkenny General Hospital, Donegal**

**Main Telephone No:** 074 9125888

**Consultant Haematologist:** Dr. Hannah Frankova

**Haemophilia Nurse Specialist:** Rosemary Hannigan,  
Bleep 400

### **Galway University Hospital**

**Main Telephone No:** 091 524222

**Consultant Haematologist:** Dr. Margaret Murray

**Haemophilia Nurse Specialist:** Maura Sweeney,  
Bleep 673

### **Limerick Regional Hospital**

**Main Telephone No:** 061 301111

### **Waterford Regional Hospital**

**Main Telephone No:** 051 848000

**Consultant Haematologist:** Dr. Fred Jackson

**Haemophilia Nurse Specialist:** Martina Keogh

# Grants & Scholarships

## LAST CALL FOR APPLICATIONS

### **Maureen Downey Memorial Grant & Educational Scholarship**



**CLOSING DATE HAS NOW BEEN EXTENDED BY  
2 WEEKS UNTIL FRIDAY 10TH OCTOBER, 2008.**

**Applications can be posted to Margaret Dunne, Irish Haemophilia Society,  
Cathedral Court, New Street, Dublin 8,  
or emailed to: [margaret@haemophilia.ie](mailto:margaret@haemophilia.ie)**

#### **Background**

Up to the 1970's, effective treatment for haemophilia was not widely available in Ireland. One result of this was that many people with haemophilia lost a lot of time from school due to recurring bleeds which left them incapacitated for long periods of time. This in turn meant that a large proportion of them did not go on to third level education. When treatment improved and home treatment became available, this made a huge difference not only to their quality of life but they no longer had to miss so much school, and the percentage of those going on to college was comparable to the general population.

In response to this, the Society in the late 1980's decided to offer a scholarship each year to one young person with haemophilia going on to third level education. This was called 'The Maureen Downey Memorial Grant'. At that time the amount of the award was £1,000.

Applications were invited from any person with haemophilia who had been accepted for a course at any third level institute. The closing date for applications was decided as the end of September each year. Applicants were encouraged to send supporting documentation and a brief letter outlining their reason for applying and any other relevant information.

A sub group of three people from the board, which could not include anyone with a family member applying for the scholarship, was put together to consider the applications, and make recommendations to the board. The successful applicant received their award by the end of October, and an official announcement was made at the AGM, and presented with a commemorative scroll.

#### **Currently**

The Society now has two awards. The

Maureen Downey Memorial Grant is now €4,000 and in 2004 the Society introduced an Educational Scholarship which is awarded to an immediate family member of a person with haemophilia or other bleeding disorder. This award was for €2,000. The criteria for applying for and deciding on this award is similar to The Maureen Downey Memorial Grant. I work closely with the sub group. When they decide on the recipients, I am in a position to provide any extra background they may need.

This works very well, and we have not seen the need to make any major changes either to the criteria for applications, or the format for deciding on the recipients. We also like to keep up to date on how they are doing and occasionally we include an update in our magazine from previous recipients.

**Margaret Dunne**

# Noticeboard

## Mini Marathon

**Last call to get your sponsorship money in!**

Many thanks to everyone who participated and helped raise funds through the Mini Marathon in June.

**To date we have raised €5190.**

For those of you who have not returned sponsorship, please do so as soon as possible to be in with a chance to win a weekend away for two people in Ireland!



### Your Views Please!

**Dear Members,**

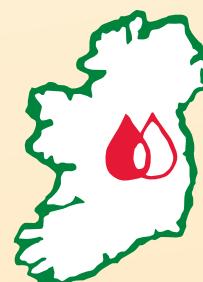
Do you have any comments to make about our magazine, perhaps you have an article which you feel might interest members, or perhaps you feel there is a topic which we should cover in a future edition?

I would be delighted to hear from you.

You can call me on **01 6579900** or email me at:  
**debbie@haemophilia.ie**

**Debbie Greene, Editor**

### Membership Fees Reminder



If you have not yet paid your Membership Fee for 2008, we would ask you to do so as soon as possible.

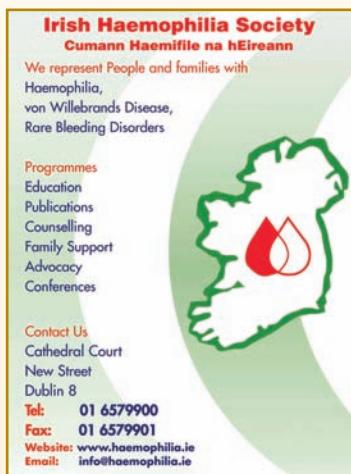
The current Membership Fee is €30 per year, and Life Membership €650.

You can pay by cheque, or if you wish, we can accept laser or credit card payments.

# Calendar of Events

## SEPTEMBER / OCTOBER

### Regional Visits



### Cork

Date: Monday 29th September

Venue: Kingsley Hotel, Victoria Cross

Time: 7.30pm to 9.30pm

### Limerick

Date: Tuesday 30th September

Venue: Castletroy Park Hotel, Dublin Road

Time: 7.30pm to 9.30pm

### Galway

Date: Wednesday 1st October

Venue: Ardilaun House Hotel, Taylor's Hill

Time: 7.30pm to 9.30pm

We have organised another set of Regional Visits to enable member's update themselves on our services and activities, and to raise any issues of concern.

We would encourage you to attend these meetings. If you would like an individual meeting, this can be arranged prior to the evening meetings.

## OCTOBER

### Members Weekend

#### Dates:

Friday 17th to Sunday 19th October

#### Venue:

The County Arms Hotel, Birr, Co. Offaly.



Following on from the success of last years Members Weekend, a similar weekend will take place in The County Arms Hotel in Birr, Co. Offaly from 17th to 19th October.

On page 2 of this magazine you will find details of the programme which I hope you will agree is a weekend not to be missed. On Saturday morning we will hear a presentation from Barretstown Gang Camp, on the excellent programmes they have provided for our younger members and their families for the last 15 years. There also will be presentation on Health Supplements and Haemophilia. In the afternoon the theme is all about being active, with Physiotherapy and Hydrotherapy for the men. For the women, Anne Duffy will facilitate a discussion on relevant Women's Issues, and this will be followed by what promises to be a lively Belly Dancing workshop.

The cost of the weekend has been heavily subsidised for members in order to allow as many members as possible attend.

# Calendar of Events

Creche Facilities for children up to 6 years of age will be provided. The Kidlink Programme is open to children from 7 to 11 years of age. And for those aged 12 years and over, we have organised a Residential Adventure Weekend in the Birr Adventure Centre, which is located right next door to the hotel. We must stress however that children who are not aged 12 or over on October 17th will not be able to attend the Adventure Weekend.



If you would like to join us, please complete your booking form and return it to us on or before 3rd October.

## NOVEMBER

### Service of Remembrance

**Date:**  
**Sunday 9th November**

**Venue:**  
**Offices of the I.H.S.**

As part of the commemoration of the 40th Anniversary of the Irish Haemophilia Society, a 'Service of Remembrance' will take place in our new Headquarters on Sunday 9th November.

We would like to invite you to attend our 'Service of Remembrance', in memory of all deceased members of the Irish Haemophilia Society. If you cannot attend in person, please be assured that your loved one's name will be included on the list of remembrance.

## NOVEMBER

### Peer Support Post Tribunal Workshop

**Dates:**  
**29th & 30th November**

We organised a Post Legal Workshop last year which was very successful. We are hoping to organise a further workshop this year.

The aim of the workshop is to bring members and their partners together who have completed the Compensation Tribunal process.

## MARCH 2009

### Annual General Meeting

**Dates:**  
**Friday 6th to Sunday 8th March**



We are pleased to announce that the venue for the Annual General Meeting next year is:

**The Carlton Shearwater Hotel,  
Marina Point,  
Ballinasloe,  
Co. Galway.  
Tel: 090 963 0400  
Fax: 090 963 0401**

We are working on a Preliminary Programme, keep checking the website for more information.



## I.H.S. Kid's Fun Pages

### Did You Know? Animal Facts



Certain Chinese and American alligators can survive the winter by freezing their heads in ice, leaving their nose out to breath for months on end !

Honeybees have hair on their eyes !

Rabbits love licorice !

Slugs have 4 noses !

The leech has 32 brains !

A rhinoceros' horn is made of hair !

All elephants walk on tip-toe, because the back portion of their foot is made up of all fat and no bone !

The placement of a donkey's eyes in its head enables it to see all four feet at all times !

Butterflies taste with their hind feet !

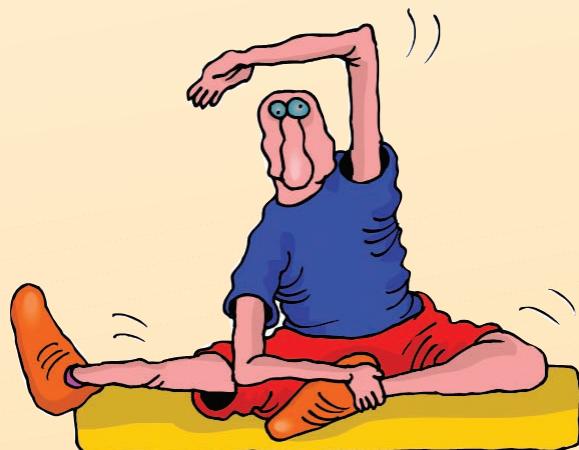
Giraffes can clean their ears with their half metre long tongue !

An adult lion's roar can be heard up to five miles away, and warns off intruders or reunites scattered members of the pride !

Cows do not have upper front teeth !

### Can You?

Can you suck your own toe or put your leg behind your head? Well keep it that way. Stretching is somethnig we all do, even with out knowing. Have you ever been sitting in one place for a long time, and you stretch with out even thinking about. Stretching is very important because as you get older, your muscles get shorther and you can't move your joints as much as you used too. Everyone can learn to stretch, regardless of age or flexibility. Try to stretch every day, whether you exercise or not. You can do them while watching TV, on the computer, or getting ready for bed. It doesn't take long and is great for you. Try this excercise and see if you can do it.



## Riddles Corner!



1. A man walks into a restaurant and the waiter says good day Admiral. So why did the waiter call the man an Admiral?
2. You are in a cabin and it is pitch black. You have one match on you. Which do you light first, the newspaper, the lamp, the candle or the fire?
3. Each day a lady gets the lift from the 12th floor to the ground level so she can go to work. When she comes home however she only goes up the lift to level 8. Why is this and it is not to keep fit?
4. Two women and two doctors walk into an ice cream parlour. They each order an ice cream cone. When their ice creams come, there is only 1 strawberry, 1 chocolate and 1 vanilla. How come they didn't complain?
5. If a Mummy Bull, Daddy Bull, and Baby Bull are in the field and Baby Bull gets scared, who would he run to?
6. I have no eyes, no legs or ears and I help move the earth. What am I?
7. You are in a house with 4 windows, which all face south, a bear walks by. What colour is the bear?
8. You are driving a bus. Six people get on, two people get off, then ten people get on and five people get off, then eight people get on and four more people get off. What colour were the bus driver's eyes?

### Answers

1. Because he was wearing his uniform.
2. You light the match first!
3. Because kidlink is a dwarf and can only reach the button for the 8th floor
4. One of the women was a doctor.
5. There is no such thing as a mammy bull, it's a cow.
6. A worm.
7. White cause your house is at the north pole.
8. Whatever colour your eyes are because you're driving the bus.

## Balls of Energy



### RECIPE INGREDIENTS:

1 small banana

1/2 cup chunky peanut butter

1/2 cup toasted wheat germ

Finely chopped peanuts, mini chocolate chips, or shredded coconut for coating

1. In a medium bowl, mash together the banana and the peanut butter.
2. Stir in the wheat germ. Roll individual tablespoons of the mixture into balls, then roll the balls in one, or a mix, of the coatings listed above. Chill until firm. Makes 14 balls.
3. Variation: For a peanut-free version, substitute sunflower-seed or soy-nut butter for the peanut butter, and omit the peanuts and chocolate chips (which can contain traces of peanut).



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