

# haemophilia.ie

Magazine of the Irish Haemophilia Society

Edition: April 2012

*Representing people in Ireland with  
haemophilia and related bleeding disorders.*



## The Society at a Glance

AGM 2012  
Attendance



240

Followers on  
Facebook



221

Publications  
produced in  
2011



11

Number of  
childrens  
programmes



4

Website Hits  
(Jan - Mar)



4,363

## WHAT'S INSIDE:

- \* A report from the 2012 IHS AGM.
- \* An Introduction to the staff of the IHS.
- \* An update from the NCHCD on clinics for Women with Bleeding Disorders.

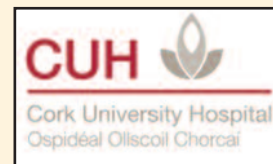




# Irish Haemophilia Society PARENTS CONFERENCE



**Dates:** Friday 11th May to Sunday 13th May 2012.  
**Venue:** The Sheraton Hotel, Athlone, Co. Westmeath.



In conjunction with Our Lady's Children's Hospital Crumlin, the National Centre for Hereditary Coagulation Disorders and Cork University Hospital, we are pleased to announce details of our Parents Conference which will take place from May 11th to 13th in the Sheraton Hotel, Athlone, Co. Westmeath. We are hoping to encourage as many parents as possible to attend this worthwhile and informative conference. We hope that you will find the programme interesting and that you will attend the conference. At the conference you will receive up to date information from the haemophilia care teams, build long lasting friendships with other parents and enhance the personal growth of your child. Here are some comments made by parents who attended the conference:

"It give parents a great chance to talk about their personal experiences, gives everybody a chance to hear other people's experiences and to know that they are not the only people dealing with this stuff on a day to day basis."

"All the talks are going to be either something that has happened to you or will happen to you. Getting to meet all the other parents and getting to know people is the other major thing, it really is just fantastic."

"At this conference everybody is on the one level and they are learning from each other so and it works really well."

## PRELIMINARY ADULTS PROGRAMME

### Saturday 12th May

9.30am – 9.45am	Introduction
9.45am – 11.30am	Self Infusion Workshop
11.30am – 12.00pm	Coffee break
12.00pm – 1.00pm	Clinical Trials Explained
1.00pm – 2.00pm	Lunch
2.00pm – 4.00pm	Disclosure / Bullying
4.00pm – 4.30pm	Coffee break
4.30pm – 5.30pm	Open Forum with Haemophilia Treatment Centres

### Sunday 13th May

9.30am – 11.30am	Mothers' Workshop Fathers' Workshop
11.30am – 12.00pm	Coffee break
12.00pm – 1.00pm	The Vietnam Experience
1.00pm	Lunch

## PRELIMINARY CHILDREN'S PROGRAMME

### Saturday 12th May

9.30am – 10.30am	Disclosure / Bullying Telling your friends about haemophilia
10.30am – 12.00pm	Swimming
12.00pm – 1.00pm	Self Infusion Workshop (The Vein Train) OR
12.00pm – 1.00pm	Siblings – My brother has haemophilia
1.00pm – 2.00pm	Lunch

### Sunday 13th May

9.30am – 10.30am	Children's Forum
10.30am – 11.30am	The Vietnam Experience
11.30am – 1.00pm	Swimming
1.00pm	Lunch

**CHILDREN WILL BE BROUGHT TO AN ACTIVITY CENTRE ON SATURDAY AFTERNOON**

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### **A Note from the Editor**

**H**ello everyone, I hope you are all keeping well and enjoyed the AGM and Conference a few weeks ago. And what a success that weekend was. The hotel was fantastic; the conference facilities were great and from evaluations received back it looks like you all got a lot out of all the talks and presentations. With 67 children attending we had 4 streams to the children's programmes with crèche, cubs, kidlink and young adults. Read all about the conference on pages 16 to 19.

On pages 4 and 5 our CEO Brian O'Mahony updates members on new treatments and the Severe Bleeding Disorder Alert Cards.

We have a very profound and reflective article written by a member of the Society on pages 6 and 7. Have a read of this article, I promise it will make you think!

The 5 Year Planned Giving Appeal was launched at our AGM in March. This initiative was launched as the Society are in the process of purchasing an apartment in Dublin. This apartment will be available for use by members of the Society who need accommodation for hospital visits. We are hoping the membership will contribute in some small way to help with the cost of purchasing this apartment. Read more about this appeal on page 14.

On pages 21 to 23 Nuala McAuley gives you an insight into the work of the staff of the Irish Haemophilia Society. Some of you I am sure might not be aware of what it is we actually do in the office on a day to day basis. I hope you find this article interesting!

Don't forget to update yourself on all our Calendar of Events for the year on page 11.

And finally, please contact the office on 01 6579900 if you have any questions, queries, would like to talk to somebody in confidence, if you have a fundraising idea, an article for the magazine, or a suggestion for a publication. And don't forget you are all very welcome to drop into the office at any stage for a chat and a cuppa! We are always delighted to see members.

**Debbie Greene**  
**Administrator**

[www.haemophilia.ie](http://www.haemophilia.ie)

# CEO'S Report

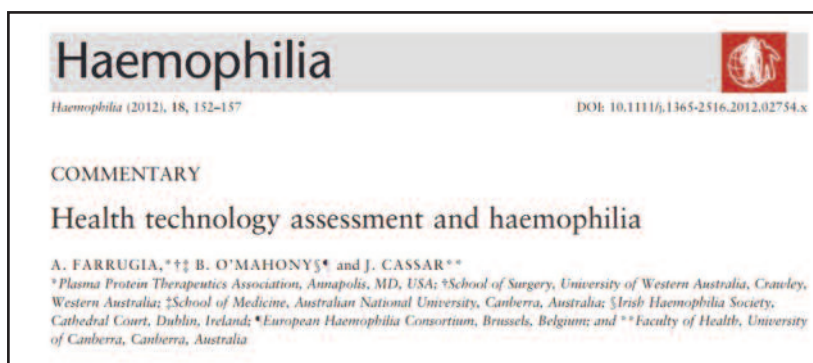
There is a Chinese saying - I am not sure if it is meant to be a

blessing or a curse - about living in interesting times.

We are currently living in interesting times in relation to treatment of haemophilia. Exciting new treatment horizons beckon. There have been encouraging preliminary results, albeit at an early stage, from the gene therapy trial on Factor IX in the UK where 6 people with haemophilia have been expressing factor levels for periods in excess of one year following one infusion. The much awaited developments with longer factor concentrates which promise extended half life, and the possibility of more effective or less frequent treatment are in various stages of clinical trials. The final phase of these trials has commenced with some of these products and it is probable that some children with haemophilia in Ireland may be treated with these products this year as part of the clinical trial. Other recombinant products are also closer to becoming available which will increase competition and choice. These developments are taking place against a European backdrop of a proposed new clinical trials directive which may have implications for the speed with which new products are available in the European Community. The grim economic situation will also undoubtedly have an impact. There is no certainty that new or improved products will automatically become available for use once licenced. It is probable that new products will be subjected to rigorous cost effectiveness analysis using methods such as Health Technology Assessments (HTA). These economic analysis will examine the additional benefit of any new products and measure the additional benefit against the probable increased cost. This is not just the case in haemophilia. The newly available treatments for Hepatitis C have also been analysed using a HTA process in Ireland. The good news is that both of the new treatments - Telaprevir and Boceprevir have been found to be very cost effective. This hurdle has been cleared and we are now working to help ensure that these much needed therapies are available to people with haemophilia who require them as quickly as possible. Exciting potential developments in treatment and economic belt tightening constitutes a difficult mix. We are, I believe, well placed to deal with this complex interaction of science and economics on your behalf.

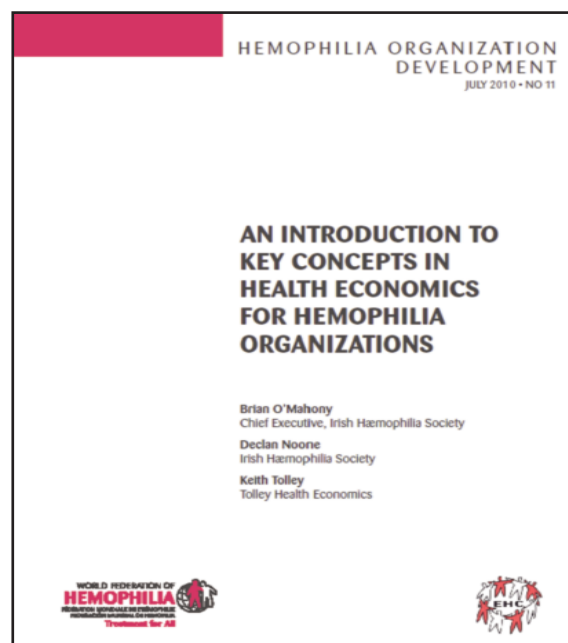


Brian O'Mahony,  
Chief Executive



**Above:** The Haemophilia Journal Paper on Health Technology Assessments and Haemophilia, which I contributed to.

**Right:** The WFH Monograph which Declan Noone and I co-authored.



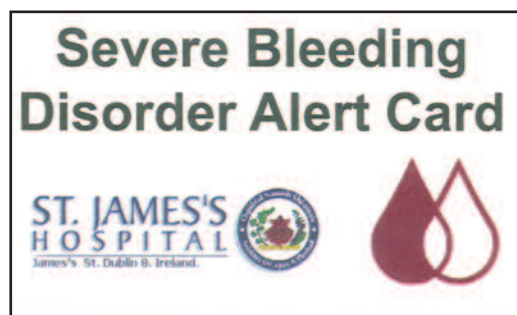
The Society have been at the forefront of research and publications on haemophilia and economics. Declan Noone and I have published a monograph on "HTA's and Economics of

Haemophilia" for the World Federation of Hemophilia and the European Haemophilia Consortium. I have also had a book chapter and scientific review paper on this topic published since the beginning of 2012.

We are in the process of completing research on the quality of life of young men with haemophilia in seven countries which clearly demonstrates the benefit of long term prophylaxis with factor concentrates. The accumulation of this experience and evidence will greatly assist us in our ongoing advocacy on your behalf to maintain and improve access to optimum care and treatment.



In the Autumn 2011 issue of this newsletter, I had mentioned the availability of the *Severe Bleeding Disorder Alert Cards*. These cards, produced by the Society, were sent from the three comprehensive treatment centres to persons with severe bleeding disorders. The cards are designed to alert staff at hospital emergency departments that the individual has a severe bleeding disorder and to stress the importance of the emergency department staff contacting the relevant comprehensive treatment centre without delay to seek expert advice on treatment. Our objective was to ensure that persons with severe bleeding disorders are appropriately treated with factor concentrate as soon as possible after presenting at a non treatment centre hospital. If you have a severe bleeding disorder and you have **NOT** received one of these cards, please contact your comprehensive treatment centre to request a card. In March, in the days leading up to our Annual Conference, we worked with the HSE to ensure that knowledge about the cards was rolled out nationally. The HSE sent an official communication about the cards to all Emergency Department Consultants, the National Nursing Service and the National Ambulance Service. The cards were also featured on the HSE Intranet site and were the subject of a report on RTE National television news on March 1<sup>st</sup>.



**Left:** Pictured at the official press launch of the Severe Bleeding Disorder Alert Cards are (L to R): Dr. Niamh O'Connell, Consultant Haematologist NCHCD, Michelle Tait, Hepatitis C National Co-Ordinator, HSE, Brian O'Mahony, CEO, IHS and Ger O'Reilly, Person with Haemophilia.

**Above:** The Bleeding Disorder Alert Card..

The Annual Conference in Kilkenny on the first weekend in March was a great success. Attendance was up an astonishing 27% since 2011 and a total of 240 adults, teenagers and children attended the weekend. An excellent programme included lectures on Orthopaedic Surgery, Clinical Trials of new products, haemophilia in our twin country of Vietnam, an Open Forum discussion with the Comprehensive Centres and a session on the future of the Irish Health Service. The conferences are becoming more popular each year. We are now stretched to capacity especially for the children's programmes given the requirement for a high volunteer to child ratio and logistical requirements for hotels. If you wish to attend our conferences and meetings, it is becoming increasingly important to book early to secure accommodation and a place in the programme stream for your child or family member.

As I write this in early March a new piece of legislation is going through the Oireachtas. This bill - the "Clotting Factor Concentrates and Other Biological Products Bill" - will give effect to the change recommended by the Society and the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) whereby the contracts for the procurement of clotting factor concentrates for Ireland will in future be held and administered by St. James's Hospital and not the Irish Blood Transfusion Services. This will, in our view, lead to a more efficient process and will also be cost effective as handling fees have been eliminated.

**Brian O'Mahony**  
Chief Executive

# Second Chances: Silver Linings and Their Clouds



*As treatments have changed and improved over the years for HIV and Hepatitis C, generally people with*

*haemophilia can now look forward to a brighter and healthier future. As a group this is a future that everyone has been looking for, however, as an individual this can cause a wide range of thoughts and emotions, some even unexpected. The following article is a thought provoking view of one individuals view on the changing tide of HIV and Hepatitis C care over the last 20 years and the change in his own perceptions over that time.*

**B**eing under the impression that one is living with a death sentence has a remarkable impact on one's thought process and approach to life. It instantly pervades all aspects of one's existence and changes everything utterly, often irrevocably. This is even more pronounced at a young age as the dreams, hopes and expectations of one's peers suddenly no longer apply. The unfairness and randomness of it are as damaging as the physical and emotional consequences. This news is often sudden and shocking; the ramifications are long-term and far-reaching.

The discovery that one then might actually have a future is mind-blowing and almost more difficult to come to terms with. The challenge is as much to do with the timing of the information, which is never merely announced but more of a slow realisation, as it is to do with the literal about turn. This gradual absorbing of said knowledge leads to a lack, and, therefore, fear, of certainty. And of course, one's approach to life has to then undergo yet another complete re-adjustment, often a more difficult one. Why is this seemingly good news more difficult? This is only my opinion and I caution against it being read as a typical experience, but the reasons may be as follows:

## **Health:**

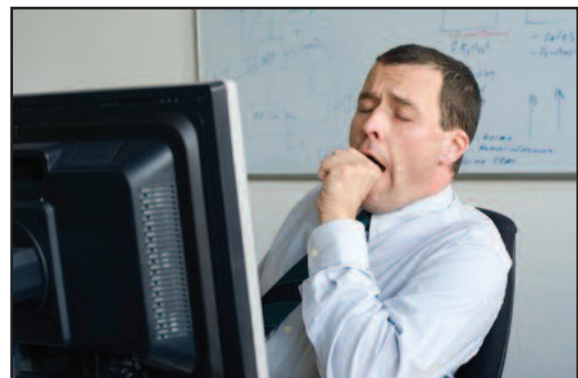
The feeling that one doesn't have long to live removes the need to manage one's long term health with any great care. Now, it would be foolish to imagine many men in their twenties taking great care of their health or living monastically in any way. But everything from diet and cholesterol to dental care and exercise can be ignored. I mean, why get fillings, refuse that slice of cake or not order another take-away or go

to the gym if there aren't that many years left in the tank anyway. More alarmingly, why not test out a few drugs or drink heavily in order to dull the pain of one's gloom? These decisions do nothing to better one's longevity but what harm? I'm dying anyway. Then, when it emerges that the individual in question has to deal with actually living for a lot longer, damage has been caused to the heart, liver, teeth, joints etc etc.



## **Career:**

While others are investing in their futures, maybe putting in the hours to impress the boss, climb the greasy pole of promotion, gain experience and develop a contacts book, it's less likely to be the route adopted by one running out of time. Expertise in a chosen field isn't the priority – what is important is enjoying what time one has left. So when the eventual good news comes into focus, the person is at an automatic disadvantage compared to his or her peers (and competitors).



### Relationships:

Committing to a relationship is extremely difficult when one sees no future. What's the point in building trust, confidence and the skills that come with these shared experiences when there's no pay off in the form of marriage, kids or growing old together? It's also not unreasonable to question how attractive such a vista might be to a prospective partner. The self - actualisation and subsequent confidence which can come from relationships, love and tenderness are not on the menu at all. Coming to terms with the notion of then actually facing decades, possibly alone, is brutal. Add the appalling and daunting variable of carrying an infectious and potentially fatal virus and relationships are no more than a pipe dream.



### Money:

Why save? Who wants to be the richest man in the cemetery? Nest-egg? Mortgage? Pension? Why would one need a bloody pension? It's all about the retail therapy. Fill the hole with possessions, clothes, CDs and books; go on holiday; see the world; be the most generous guy in the bar (there might be some love in that) but whatever, spend, spend, spend. And the shrinking bank balance comes into sharp relief at about the same time as the newly likely future does. This of course, is not helped by the years of neglected career. The fear of an early death is readily replaced with the fear of an uncertain and maybe less comfortable future.



### Friends

**and family:** The people who suffer most from the anger, resentment, mood swings, complaints and general lack of hope are usually those closest, particularly if they're aware of the circumstances and are content to indulge lest they aggravate an already horrific situation. "Let him be, he has enough to deal with". Boundaries are blurred, rules are broken and tongues are held. The dynamics in these relationships alter beyond recognition and are not easy to reassemble.



All of this is general and written in broad brush strokes. For many, the sheer gratitude of a second bite of the apple would far outweigh the difficulties in coming to terms with the upheaval. Yet, some others feel cheated. And not once, but twice.

The IHS has a nurse/counsellor who deals with member issues.

If you would like to speak to Anne in confidence call her directly on 01 6579927.



# I.H.S. Events - Are they for me?

injuries, and comparing treatment techniques, I was ill prepared for the vision that greeted me as I stepped through the function room doors. An enthusiastic Rosemary Daly was in full swing, delivering a feisty rendition of her party piece to rapturous applause and unruly shrieks of encouragement. I retreated, thinking this can't be the place, I backed for the exit, as I grappled with the door handle, this blond bombshell extended her arms in what I now know was a welcome embrace, and which I took at the time for the equivalent of a sheep being led to the slaughter. The evening was filled with introductions, (less daunting, but not less welcoming), dancing, songs, stories, long time friends and family members. It was warm, welcoming over-whelming, and wonderful. That said, my next step into what has for me become known as "the weekends", was not anticipated with any less trepidation.



David had booked us in for our first full IHS weekend together. I thought to myself, well, I've barely dusted myself down from my last tentative steps into this space, this is going to be strange and unusual and I admit, I honestly did not want to go. If I could have come up with a valid excuse, I would have ducked out of it. Realistically, I knew nobody, I didn't fully understand haemophilia, I could never fully appreciate what everybody else had already been through, what they'd learned, endured, survived, all that they had lost and experienced together. I was quite frankly terrified, and I felt like a fraud. I was out of my depth. Of course I wanted to learn about this, in my heart I had already committed to a life with David, so this was important. I wanted to understand, but I was more than a little nervous. What if I say the wrong thing, what if I ask the wrong question, or a stupid question, or the right question to the wrong person? What if my lack of knowledge or grasp of this is so poor, that I embarrass myself or David? What if I offend somebody? What if I discover things I don't want to confront? What if, what if.....what if I could find a way out of this weekend? Honestly? I was petrified. I knew there would be various meetings, talks and workshops that I should attend and get to know people. I thought I'll just sit there, I'll be quiet, say

**W**hy come along to these weekends? What's to be gained? When I first thought about what I would write in terms of why the weekend meetings are beneficial, I started to think about who would read this, and what kind of answers would they themselves give? Well, if you already attend the weekends regularly, you already know what's to be gained, so stop reading now, unless of course you just want a good excuse to have a go at me about grammar, spelling, and plagiarism! However, if you're just starting out, if all this is new, difficult, if you think it's too hard to manage learning about haemophilia without having to contend with new people and unfamiliar faces. If it seems too difficult to join in, too daunting to put yourself in an unknown environment, well then, good, this is for you.

I don't have haemophilia, or a bleeding disorder; I don't have siblings or parents with haemophilia. I have no background in medicine or counselling. I didn't grow up with it and I certainly am not qualified to comment, and yet I will! I found myself here by circumstance, and I stepped on in, so maybe my story will help you step on in too.

I hardly know where to start, well that's not strictly true, I know exactly where to start (cue nostalgic music and sepia coloured images) Jury's Hotel Ballsbridge, circa 1996. I had barely wrapped my head around the concept of haemophilia, (or the fact that it would take more than a swift, well placed elbow blow to inflict any lasting harm to my newly acquired boyfriend), when he suggests one night after a meal out, that we drop in on an Irish Haemophilia Society shin dig at Jury's Hotel, to say Hello to his family, and meet some folks that meant a lot to him. Ok, I'll bite, let's meet and greet. I had no clue what to expect, I had of course the usual pre-conceived notions, some correct, most however, were wildly incorrect. Bracing myself for a serious and sombre crowd of folk quietly discussing





nothing, take it all in....“a shut mouth catches no flies”...Yep, “do nothing”, after days of deliberation on how best to approach the weekend ahead... do nothing was the best strategy I came up with. So with that rather excellent tactic in mind I walked through the doors of the Ard Ri Hotel in Waterford!!! I can remember clearly walking in with my bags and thinking, I could still make a run for it, I’ll never fit in. Still, I stayed, we got our agenda for the weekend and I saw there was a group for spouses/partners. Okay, okay, right, ok, I’m a partner, so I’ll at least be in the right place even if I’m not saying or doing the right thing. I can do this, head down, mouth closed, firm grip on keeping cool.

There was circle of chairs in a large room, I took a seat, and thought, “Good grief, get me out, they’ll spot an imposter, and I’ll be exposed as the “know nothing” I really am...help”. I didn’t run though, I sat chewing my lip, and waiting for those who knew better than I, to begin. Now it gets hazy, I fidgeted in my chair, if I’m honest, I tuned out a bit, fully expecting to be proven correct, that this was not for me after all. Some people spoke, I didn’t really register the details, and then, the “AH HA moment”, a voice made me sit up a bit. A big man, with an even bigger heart began to speak. He gave a voice to the words already racing silently through my head. He spoke of how he wasn’t really sure of his place here, or if he was in the right place to speak, but speak he did. Softly, sincerely, he spoke with such humility and yet with such conviction. He spoke about his wife, and something in the meaning of his words struck a chord for me. While I cannot recall his exact words, their meaning and sentiment stay with me still. The affection and concern for his wife and his role in her condition were an exact replica of my own thoughts and concerns for my partner. The faces were unfamiliar, but the fears and anxieties were mine too. Others joined in, opened up, and the room was warmed with the shared honesty of fear and uncertainty, and mostly love. I knew I was in the right place. Ironically, it turned out, I had only to follow my own, once foolish sounding strategy of “do nothing”. I only had to listen and the answers came, the support came. It’s nearly impossible to quantify what that has come to mean to me.

I know when David booked that weekend, he hoped I would gain some clarity, make some connections, I don’t think he bargained on me tapping his shoulder after the mornings’ meetings with the enthusiastic announcement “I’ve met a lovely man”! This man and his wife have remained dear to us and become close to us, as are some of the many other friends we made over the years. I know that in this space, these “weekends”,

these safe havens, I can speak freely, I can ask questions, and I can relax and know I am truly among friends. Friends who need no explanation, no clarification, only the security of a shared ongoing experience. It hasn’t only been all about the haemophilia. For better or worse, the Society has been a big part of some of the important milestones in our lives. Some of the most joyful events, and some of the most heartbreaking days have been shared with our IHS friends. The advice I’ve picked up, and the lessons learned weren’t always gleaned in meetings and workshops mind you, many were picked out over drinks at the bar, or evening dinner, or strolls after lunch.

I won’t pretend that it wasn’t difficult to step into the realm of the IHS, coming as I was from the outside, with little or no knowledge of the subject matter or the emotional or physical ramifications of haemophilia, but I will be forever grateful that I did. The lesson I learned and continue to learn, is that as unlikely as it seems, there is always somebody else who “gets it”, and I am always surprised by how often I discover the benefits of that shared comfort.

So, what’s to be gained from “these weekends”? What’s in it?? Well, for me, the answers are simple and priceless all at once: - Support, information, friendship, craic, songs, stories, comfort, warmth and an inexplicable feeling of home. Sometimes joining in just takes a leap of faith, and sometimes the jump seems too great, the distance too vast, but I’ve learned that it’s not that big a leap when you have someone to hold onto.

Thank you IHS, I’ll hold on tight.

**Mary Flanagan.**



# Barretstown



**B**arretstown is a specially designed camp for children and families

affected by serious illnesses and life long conditions such as haemophilia. The Barretstown programme is based on an approach known as Therapeutic Recreation. This approach offers children and their families the opportunity to enjoy fun activities while all the while exploring 4 main areas of personal development – Challenge, Success, Reflection and Discovery.

What does this all mean?? The children or families as a whole are entertained with lots of activities these vary from Creative programmes – arts n’ crafts, drama, theatre, music, pottery, photography and Adventure activities such as high ropes, canoeing, fishing, archery and horse riding to name but a few!! Although it looks like these activities are purely for fun (which they are!!) it is through the challenge of taking part in a new and exciting activity that may push a child slightly out of their comfort zone that children have a sense of success, this encourages a child to face any further challenges in the future with strength and confidence. Through reflection the children talk about their success and how they felt when they achieved their goals – this encourages a sense of empowerment and lastly discovery – shows the child that if they could manage something they didn’t think they would, like singing a song with their group in a show, what else are they capable of!!!!



So now that the serious stuff is over – it is important to mention just how much fun children and indeed parents have when they go to Barretstown and the answer is LOTS! The camps for children ages 7 years up are eight days in length – which may seem an overwhelming amount of time when deciding to send your child to Barretstown, but what seems like an eternity for the parents absolutely flies for the children. More often than not when parents are collecting their children – the children are crying about the fact that they have to go home. Friendships are forged and serious fun is foremost.

Family weekends are 3 days in length and involve the whole family. Again, through the therapeutic recreation programme – parents and children alike take part in the various activities Barretstown has to offer in an encouraging, safe and fun environment. This gives the family time together to have fun and relax away from the pressures of everyday life.

Siblings are also offered the opportunity to attend Barretstown – there is a specific camp for Sibling’s of a child with a bleeding disorder. This allows the sibling to experience the same activities and environment as their brother / sister which is an excellent way of including the whole family.

Barretstown is a completely free service backed by a fully qualified medical team. If you think your child / children may be interested in attending a camp in Barretstown or you would like to attend a family camp please contact Fiona in the office on 01 657 9900 for further information.



# Calendar of Events

## UP NEXT!

### Parents Conference

**Dates:** 11th to 13th May

**Venue:** Sheraton Hotel, Athlone



5 Stars

As voted by the I.H.S. Members

*Fantastic Weekend*

*We made so many new friends!*

*Best weekend ever!*

[Check out the programme on page 2!](#)

### MAY - HIV/HCV Conference

**Dates:** 25th to 27th May

**Venue:** Hotel Kilkenny



### JUNE - Flora Women's Mini Marathon

**Dates:** 4th June

**IHS Base:** Buswells Hotel, Molesworth Street



### SEPTEMBER - HIS IHS

**Dates:** 8th & 9th September

**Venue:** Clarion Liffey Valley



### OCTOBER- Members' Conference

**Dates:** 12th to 14th October

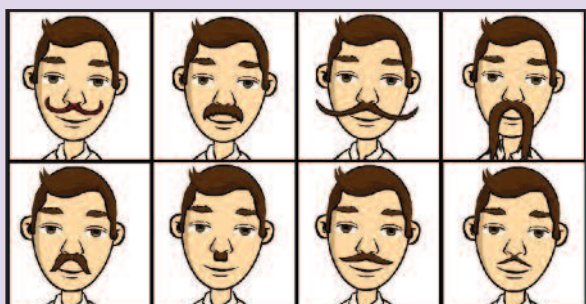
**Venue:** Heritage Hotel, Portlaoise



### MOVEMBER

**Date:** 1st - 30th November

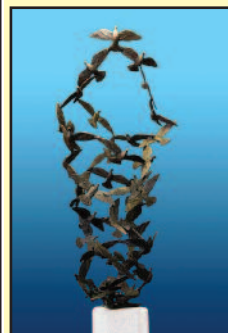
**Venue:** Everywhere



### NOVEMBER - Memorial Service

**Date:** 4th November

**Venue:** I.H.S. Office



[www.haemophilia.ie](http://www.haemophilia.ie)



# Cubs Club

**W**elcome to the First ever Cubs Club page!!

This page is just for 4 to 7 year olds to learn about haemophilia, to do puzzles and read some really funny jokes!!

The Cubs group learned a song all about haemophilia at the AGM in March. The song thought us the important steps of how to treat a bleed - telling an adult, taking factor, putting ice on the bleed and rest. Can you remember the song?

At the next event we are going to learn how blood clots, we hope you are coming to the Parents Conference!!

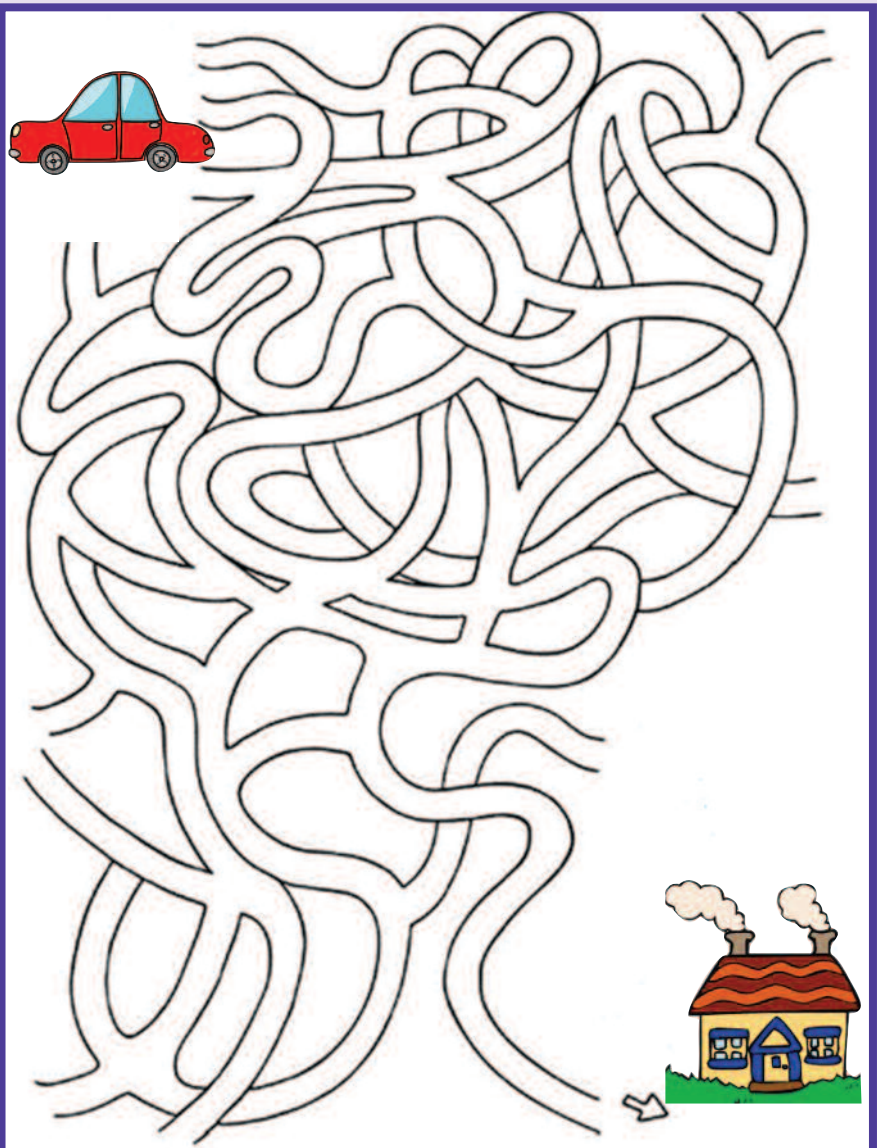
See you next time!



Hi my name is Brian, I am seven and I have haemophilia.

I am on holidays with my family, but I left my factor at home and I need to take my prophylaxis. My mam said she will drive us home so I can take my factor as it is important to take my prophylaxis.

But we are lost!! Can you help us find our way home?





Doctor, doctor, everyone  
says I'm invisible.

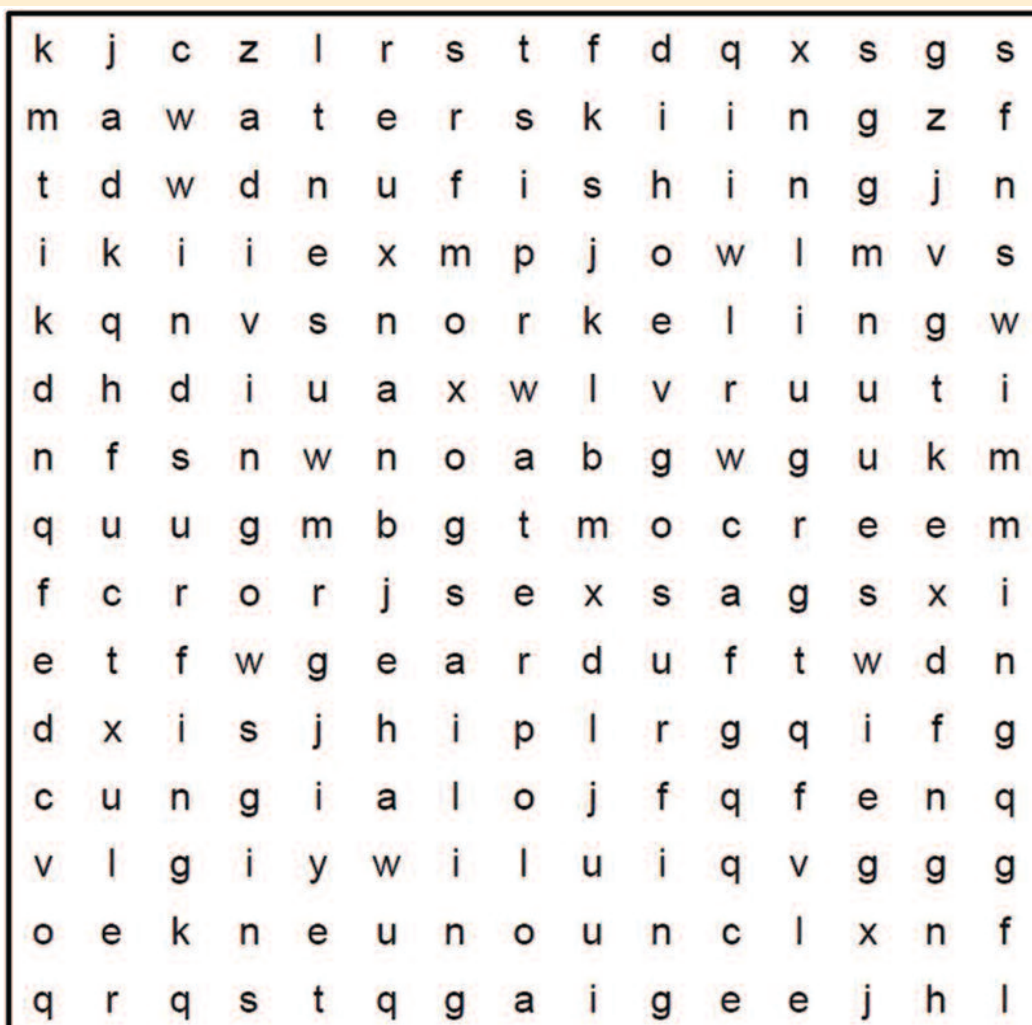
Who said that?

Doctor, doctor, I feel like a king.  
What's your name?  
Joe.  
You must be Joe King!!

## Which sports are really good for me?

You can try a lot of sports and games at school, but if a sport or game makes you have bleeds then it might be better to stop playing that one.

Swimming is a sport that is really good for you because it is good exercise, and the water acts like a cushion for your body. It is also a lot of fun - swimming is always included in our programmes at events.



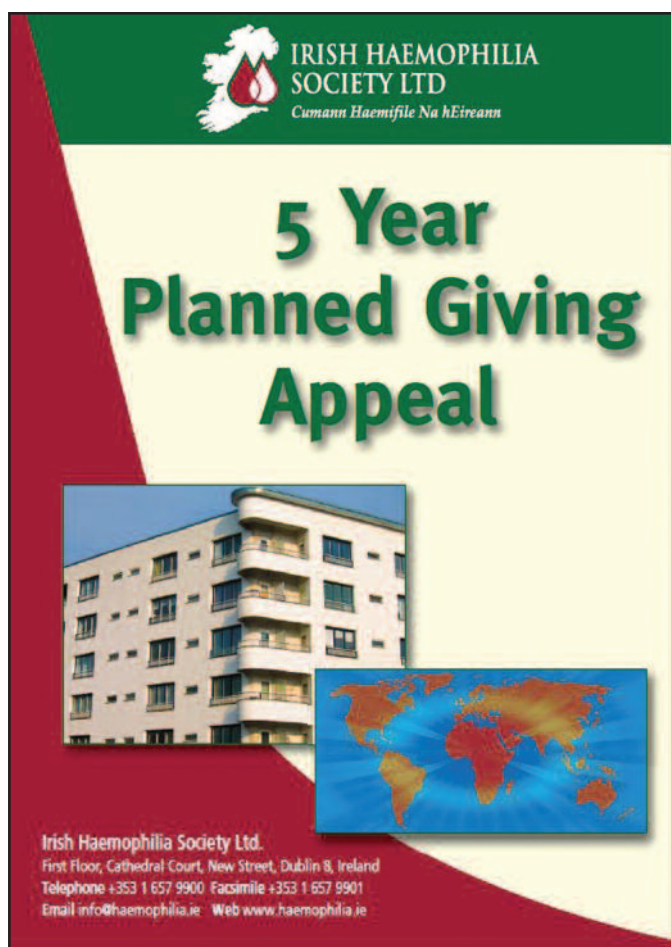
There are ten words  
hidden in this  
wordsearch - identify  
the **two words that**  
**are not in the**  
**wordsearch.**

Log on to  
[www.haemophilia.ie](http://www.haemophilia.ie)  
and see if you are right!

waterskiing	paddle	surfing	swimming
snorkeling	waterpolo	boating	windsurfing
fishing	splashing	diving	sailing

# The 5 Year Planned Giving Appeal

The Irish Haemophilia Society and other charities are facing an uncertain financial future. We continue to improve and increase our programmes, conferences, activities and publications for the benefit of our ever increasing number of members and families with haemophilia and bleeding disorders. This increased workload and requirement for additional funding is taking place amidst a backdrop of decreasing core funding from Government. In order to allow us to continue to improve our services to members, we are working to expand and diversify our funding base to include additional corporate and fundraising income. We hope that you - the members of the Society - will play an active role in allowing the organisation to thrive in the future by positively considering donating to the Society for a five year time period on a planned basis.



The poster features the Irish Haemophilia Society Ltd logo at the top, which includes a stylized map of Ireland with a red blood drop. Below the logo, the text 'IRISH HAEMOPHILIA SOCIETY LTD' and 'Cumann Haemifile Na hEireann' is displayed. The main title '5 Year Planned Giving Appeal' is in large, bold, green letters. Below the title is a photograph of a modern apartment building and a world map. At the bottom, contact information for the Irish Haemophilia Society Ltd is provided.

Irish Haemophilia Society Ltd.  
First Floor, Cathedral Court, New Street, Dublin 8, Ireland  
Telephone +353 1 657 9900 Facsimile +353 1 657 9901  
Email info@haemophilia.ie Web www.haemophilia.ie

We are currently in the process of finalising the purchase of an apartment in Dublin for the use of our members and families who need accommodation linked to increased visits to their treatment centres. We are also actively involved in a twinning programme with Vietnam and contribute to the development of haemophilia care globally through the World Federation of Hemophilia Global Alliance for Progress Programme which has resulted in the provision of diagnosis and access to treatment for over 12,000 people with haemophilia in developing countries since the inception of the programme in 2003. We are now launching a new '5 year Planned Giving Appeal' which we hope will contribute to the costs of the apartment purchase and our developing world programmes.

We are asking members to consider committing planned monthly or annual donations to the Society at a level which they can afford for a 5 year period. Of the funds raised, 75% will go to defray the cost of purchasing the apartment and 25% will go to our overseas development fund which we will use to fund our developing world programmes and contributions.

We hope that you will consider participation in this planned giving campaign to allow us to work for a better future for you and for those with haemophilia in developing countries.

## Donation Levels are as follows:

Platinum	€1,000 annually / €80 per month
Gold	€600 annually / €50 per month
Silver	€300 annually / €25 per month
Bronze	€100 annually / €10 per month

If you would like further information on this appeal, please contact Brian, Debbie or Nina in the office on 01 6579900.



# Help Us, Help You

Fundraising is very important to the Society, especially in these difficult times. However in difficult times people come into their own and it is wonderful to see people rallying around and making the extra effort to support us. We want you to know we really appreciate it. We are delighted to receive any funds raised as it all adds up at the end of the day.

So we are asking you for your support, help us to help you. If you think you can help raise funds in aid of the Society, let us know what fundraiser you have in mind and we will be more than happy to help you in any way we can, such as organising tickets, sponsorship cards, posters and IHS t-shirts. Some ideas for a fundraiser are:



Coffee Morning

Fun Run

Denim Day

Jersey Day

Payroll Contributions

Raffles

Close Shave

Bag Packing

Bake Sale

Pub Quiz

Race Night

Car Boot Sale



Fundraising can be done through your workplace, local schools, community or individuals can also take part in organised events such as the women's mini marathon or other fun runs.

The Flora Women's Mini Marathon takes place on Bank Holiday Monday 4th June, 2012. The Mini Marathon is Ireland's largest one day charity event with nearly €10 million raised for charities in 2011. The Women's Mini Marathon is a great fundraiser for the Society and the atmosphere on the day among participants is fantastic. This year we are hoping to significantly increase our numbers to help raise awareness of haemophilia, and also to raise funds for the Society. The Mini Marathon continues to be a very important source of income for the Society, so we would like to encourage as many female members as possible and their friends to participate and raise funds for the Society. We will provide facilities for those taking part in Buswells Hotel in Molesworth Street in Dublin. Staff from the office will be in attendance at Buswells Hotel from 1pm, where you can pick up a t-shirt, avail of changing facilities, a cloakroom, and refreshments before and after the event, and also receive a commemorative scroll.



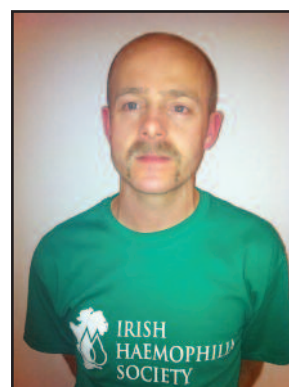
For the men out there, we have 'Movember' which is starting to take off and hopefully it will go from strength to strength.

A small selection of other races coming up throughout the year includes:

- Wexford Half Marathon, 22 April 2012
- Docklands 5km Run (Dublin), 22 May 2012
- Cork Women's Mini Marathon, 23 September 2012
- Galway Bay Half Marathon, 6 October 2012
- Dublin Marathon, 29 October 2012

We would like to take this opportunity to thank everyone who raised funds in 2011; we really appreciate all your hard work and support and hope that 2012 will be an even better year.

If you would like to help out or take part in a fundraiser for the IHS, please contact Nina or Debbie on 01-6759900 or email us on [info@haemophilia.ie](mailto:info@haemophilia.ie)



# AGM 2012 - A Sell Out

The 2012 I.H.S. AGM & Conference took place in the Lyrath Estate Hotel in Kilkenny on the weekend of March 2<sup>nd</sup> to 4<sup>th</sup>. Attendance at the weekend was the highest it has ever been with 240 people registered including 65 children!! Such high numbers meant the Society booked a second hotel to accommodate the additional delegates and arranged transport between the hotels to ensure delegates not staying in the hotel could attend the whole programme. A lot more work for the I.H.S. staff, but nothing seemed to faze them and the weekend ran smoothly and was a great success.

As well as the increased attendance the 2012 AGM saw the introduction of a fourth children's group, the Cubs for children aged 4 – 7 years. This group meant the crèche catered solely for children aged 0 – 3 years and allowed Fiona Brennan, Children's Programme Co-ordinator and the volunteers to implement an age appropriate programme. The kids groups had a jam packed weekend with trips to playground and cinema, nature walks, treasure hunts, swimming not to mention various educational sessions. The leaders for the various groups did an outstanding job, a huge thank you to everyone who helped out – I'm sure naps were had by a lot of people on Sunday!



**(L to R):** The youth group programme at the AGM included a lot of team building games - many hands make for light work!

The crèche was a hub of activity at the weekend with nature walks and trips to the playground. This nap was well deserved!

The adults programme, although not nearly as fun, was just as jam packed! The sessions kicked off on Saturday morning with the AGM where Traci Dowling gave her first Chairperson's Report and Brian O'Mahony announced the launch of the I.H.S. Planned Giving Campaign (more details on page 14). The session ran for 2 ½ hours and was very interactive. In his Treasurer's Report Ger O'Reilly informed members that the I.H.S. are looking at purchasing an apartment for members to use when attending clinics in NCHCD and OLCHC.

Following lunch the adult's programme split into two streams – stream one included an Open Forum with representatives from OLCHC and NCHCD, unfortunately CUH were unable to attend on the day, but Barry Harrington, Chair of the National Haemophilia Council noted any queries from members in relation to CUH. Following this session, Dr. Beatrice Nolan, Consultant Haematologist, OLCHC spoke to members about Clinical Trials – what is involved and what patients can expect.



Representatives from OLCHC and NCHCD with Dr. Barry Harrington, NHC at the Open Forum Session.

The second stream saw AGM regular Dr. Paul Giangrande, Consultant Haematologist from Oxford, UK lead interactive sessions with members on Mild Haemophilia, Inhibitors and von Willebrands Disease.

After a long day of sessions there was time for a rest before dinner. It was great to see so many people, all from different circumstances mixing with each other; it is hard to believe



some of the members only see each other at conferences as looking at them interacting with each other it is like looking at best friends. Following dinner the Cubs group, including the volunteers, took to the stage for their formal introduction and for one night only the Mc Curdy Suite became a platform for the superstars of the future as they sang the original score “My First Factor Song” and had the audience on their feet.

Michael Davenport had the tough task of following the Cubs group, but he succeeded in members giving a standing ovation when he announced the new Brian O’Mahony Award for Exceptional Service to Haemophilia in Ireland. Traci Dowling, Chairperson, presented Brian with a piece of crystal in recognition for over 30 years of service to the I.H.S.



**(L to R):**

*Traci Dowling, Chairperson, presenting Brian O’Mahony with a piece of crystal in recognition for over 30 years of service to the I.H.S.*

*Traci Dowling, Chairperson, presenting Lorraine O’Connor with the Margaret King Educational Scholarship.*

*Ger O’Reilly, Treasurer, presenting Patrick Browne with the Maureen Downey Educational Grant.*

Other presentations on the night included awards for the grants and scholarships; the Maureen Downey Educational Grant went to Patrick Browne and the Margaret King Educational Scholarship to Lorraine O’Connor. Although she could not attend the conference, Brónagh O’Sullivan, who raised over €2,450 by taking part in the Great Northern Run, was named Fundraiser of the Year. The final presentation of the night went to Mary Hanney who won the Fundraising Draw. With the formalities out of the way the B-Sharps took to the stage and entertained delegates into the early hours of the morning.

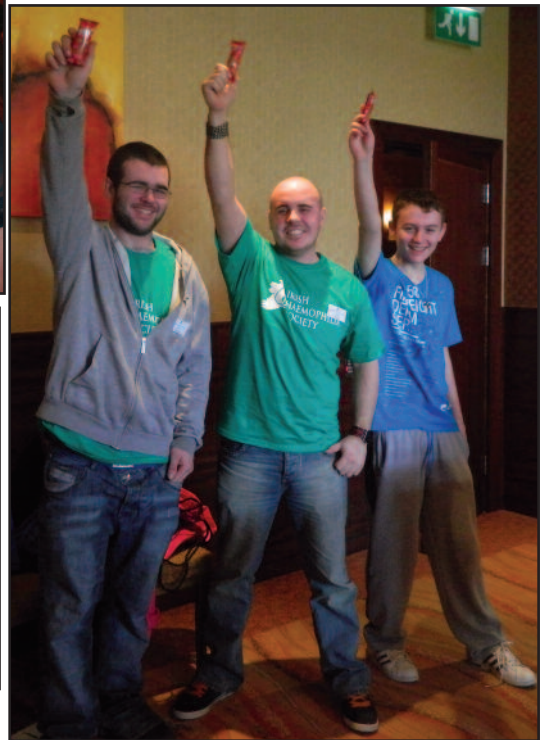
Bright and early Sunday morning guests gathered for the final day which began with an Update on Twinning talk from Brian O’Mahony. Brian outlined the hard work and constant communication the I.H.S. has with the Vietnamese Society and informed the audience of the upcoming trips between the various societies. Niall Hogan, Orthopaedic Surgeon was the next speaker in a talk that was not for the faint hearted. Niall gave an excellent (and graphic) presentation followed by brilliant advice to anyone who had questions about joint replacement or surgery. Niall’s presentation can be downloaded from the I.H.S. website [www.haemophilia.ie](http://www.haemophilia.ie) as can all the presentations from the weekend. The final session of the weekend was titled “The Future of the Irish Health Service” and included presentations by Mary Jackson, DOHC and William Murphy, HSE. The session was very open and both speakers answered questions as best they could as concerns about the level of service in the recession was at the forefront of people’s minds.

There were no signs of worry at the lunch on Sunday as the conference drew to a close. As people said their goodbyes and headed off to watch the rugby match and another conference ended, the thoughts soon turned to the Parents Conference in May. What’s the saying... no rest for the wicked!!

Attendances at I.H.S. events are increasing and although we try our best to facilitate as many members as possible attending, there are capacities on the children’s groups. We would advise anybody wishing to attend events with children to book as early as possible.



# The AGM in Pictures



240 people attend the IHS AGM, and from the smiles on everyone's faces in these photos everyone enjoyed themselves!







## THIS IS GREAT!!!

Great weekend with the Haemophilia Society in Kilkenny. When I first arrived at the hotel the first friends I met were Robert and Darragh. They were coming down the stairs.

When we were in the McGinnes Suite we built huge paper cup pyramids. Robert and I laughed when they fell down. We went swimming Robert and I tried to surf but we kept falling off. We went treasure hunting and took many pictures, real funny one's. We won and got chocolate bunny's. Robert and Darragh and I went to the game's room. We played lots and lots of games from Mario cart to Harry Potter.

It was a great weekend. Thank you very much to the people who made our weekend so cool, I can't wait for our next time with my friends at the Haemophilia Society.

**Aaron Flanagan (age 8).**



*Clockwise from Top Left:*

- \* I love the IHS weekends they are SO much fun*
- \* The volunteers help make every activity fun, thank you so much to all the volunteers. I can't wait until the next weekend.*
- \* Our group had a competition to build the biggest paper cup tower - here I am with my group and our tower!*
- \* Here are some of the guys from the Kidlink group in the playground, we did so many different activities.*

# Women's Clinics

referrals for support are arranged as necessary.

In recent years, there has been a growing awareness of the needs of women with bleeding disorders. In 2011, the NCHCD team, led by Dr. Niamh O'Connell, Consultant Haematologist and Eadaoin O'Shea, Clinical Nurse Specialist, initiated a clinic dedicated to women with bleeding disorders. This clinic provides a wide range of services to include medical, nursing and the support services of a social worker and clinical psychologist. In the future, we hope to incorporate the services of a gynaecologist at this clinic.

The most common bleeding disorders, which may affect women, include von Willebrand Disease, haemophilia (carriers), low levels of other clotting factors and platelet function disorders. Inherited bleeding disorders can be especially problematic for affected girls and women due to the monthly occurrence of menstrual periods and the effects of reproductive health. The type of bleeding reported from women with bleeding disorders includes heavy periods, bleeding after childbirth, prolonged nose bleeding, and delayed bleeding following dental surgery or general surgery. Many women are not aware of the services available for managing bleeding symptoms or are not sure whether their symptoms warrant treatment.



Heavy periods are the most common problem for women with bleeding disorders. Adolescent girls and post-menopausal women in particular may suffer the most. Chronic heavy periods may lead to a diminished quality of life

due to constant fatigue and possible iron deficiency. Women often avoid activities both at work, sport, travel and perhaps family events because of heavy periods. School attendance and participation in school activities can be compromised and some women may suffer from depression because of the impact the heavy periods have on their life. The medical management of heavy periods for women with bleeding disorders commences with the expertise of a haematologist. At our clinic, the Consultant Haematologist advises women on medical management of heavy menstrual bleeding and if necessary will refer women to a gynaecologist. We assess the impact that heavy periods have had on each individual and

Planning a family and managing a pregnancy is a very important time when it is necessary to seek the advice of a haematologist. Following previous appointments at a carrier clinic, couples will have an understanding of their chances of passing on the bleeding disorder to their children and the available choices for pre-natal diagnosis. However, this information may have been received long before actually planning a family. To avail of up-to-date information, a couple would be advised to attend prior to each pregnancy. Couples may require repeated visits to a nurse, doctor, social worker or clinical psychologist in order to seek advice and support for the decisions which they make regarding planning their family and the management of their pregnancies. In some cases, pre natal diagnosis techniques are available to couples that wish to determine if their child may have their bleeding disorder.



Generally, a pregnant woman will attend the NCHCD clinics three times throughout her pregnancy in order to monitor the coagulation changes that occur for her while pregnant and plan for appropriate management throughout the pregnancy, at delivery and post partum. Each visit is followed by correspondence with the GP, Obstetrician, local Haematologist and if the case warrants, a Consultant Paediatrician in preparation for a child who may be born with a bleeding diagnosis. Prior to the delivery of the baby, the woman is made aware of the special precautions necessary for her care and the safe delivery of her child.

A recent audit of our women's clinic in 2011, found that many women failed to attend their appointment. We recognise that women have many demands on their time which mean that visits to clinics can be difficult to organise. Therefore, we plan to write to women, who are carriers of haemophilia and who have low factor levels (<55%), to invite them to engage in a telephone consultation with a nurse specialist. The purpose of this telephone consultation is to ask some questions about their personal history of bleeding and determine if they would benefit from an appointment at our women's clinic.

Women are not obliged to participate in this telephone consultation and will be asked if they wish to proceed at the beginning of the telephone call. However, we hope that most women will avail of this convenient opportunity to assist them in the management of their bleeding condition.

**Eadaoin O'Shea,**  
Clinical Nurse Specialist, NCHCD



# Behind the Scenes of the I.H.S.

**F**our Dubs, a Kerryman, a Galwegian and a Carlovian – Ladies and Gents introducing the Irish Haemophilia Society staff.

**Have you attended an I.H.S. conference or event?**

**Have you ever called the I.H.S. office?**

Most of you may be familiar with the I.H.S. staff, but how much do you REALLY know them. The Society bases itself on a community and the staff are key members in this community so it is important you know them and feel comfortable with them. "Behind the Scenes" wants to help you feel more at home with the Society staff so that they can help you in any way.



Pictured at the 2012 AGM The IHS Staff;  
Back (L to R): Fiona Brennan, Nina Storey, Nuala Mc Auley  
Front (L to R): Anne Duffy, Brian O'Mahony, Debbie Greene, Declan Noone

## **Anne aka The Nurse**

Anne has worked in the I.H.S. since 2002. Anne provides individual counselling for members, visits members at home and in hospital, provides support to members and their families, liaises with health care workers in providing assistance and information for members and represents the Society on the Consultative Council on Hepatitis C.

## **Nuala aka The Baby**

With a background in administration, events and sales Nuala joined the Society in 2008. Her tasks in the Society include organising the logistics of events, sub-editor of publications, managing the website and volunteer recruitment.

## **Fiona aka The Big Sister**

Fiona joined the I.H.S. in 2010. The newbie of the staff, Fiona has many aspects in her role including events and social media. In 2011 Fiona took over the role as Children's Programmes Co-ordinator and Volunteer Co-ordinator. Fiona organises the programmes for each group at events and also oversees the allocation of places to Barretstown.

## **Brian aka The Boss**

Brian has been involved with the Society since 1987 (the year Nuala was born). He served as Chairperson of the I.H.S. for 17 years before taking up the role of CEO in 2003. Brian has a wealth of experience dealing with haemophilia and bleeding disorders having served as CEO of the World Federation of Hemophilia for 10 years and as the current President of the European Haemophilia Consortium.

## **Debbie aka The Godmother**

Debbie joined the Society in 2003 and took on the role as Administrator of the I.H.S. in 2009. A born multi-tasker Debbie looks after the running of the office, is editor of the publications and manages the distribution of the grants & scholarships Debbie represents the Society on the National Haemophilia Council.

## **Nina aka The Mammy**

Having been with the Society for over a decade Nina is known by many, if not all, the members. Nina's role in the Society includes accounts, fundraising and database management. Nina represents the Society on the Haemophilia HIV Trust.

## **Declan aka The Boy**

Outnumbered by females in the office Declan has a tough job, but having been with the Society since 2008 he takes it in his stride. Declan represents the Society on the Haemophilia Product Selection and Monitoring Advisory Board, distributes factor for humanitarian aid and assists with publications.

**We quizzed the staff on each other, can you guess the right answers?**

Which staff member is? 1) The quietist 2) The loudest 3) The funniest

Answers on the bottom of page 23

# In the Spotlight: I.H.S. Services &

The IHS has seven staff, a question that a lot of people ask the staff is what do you do? It has become clear that many people do not realise the range of services and support the IHS provide not just to people with haemophilia and related bleeding disorders, but also to their families. "Behind the Scenes" gives you an update on what the Society can do for you to ensure you are getting everything you need.

## Counselling

Anne Duffy is a trained psychotherapist who can provide one to one counselling to members and their families. Whether you're a person with haemophilia, a new parent, a partner or a sibling, Anne is here to listen to any questions or concerns you have and to help you move forward and accept positively your bleeding disorder.



## Barretstown

On page 10 you can read all about the services Barretstown provide to children with lifelong illnesses. The IHS work closely with Barretstown and have secured places to a number of camps for children with haemophilia, siblings and families. Fiona Brennan, children's programme co-ordinator looks after allocation of places. If you have any questions give her a call.



## Visits to school

When a child starts school it can be a nerve wrecking time – will he/she settle? Will they make friends? When your child has a bleeding disorder it can make you more nervous. As haemophilia is a rare condition a lot of teachers and educators are not aware of it. The Society can arrange to go and speak to teachers, crèche leaders and other educators to inform them of haemophilia. We have also produced a number of educational publications aimed at childcare supervisors, copies can be requested from Nuala or can be downloaded from the website - [www.haemophilia.ie](http://www.haemophilia.ie)

## Home visits

The IHS are aware that not everyone can attend our events due to numerous reasons. However, this doesn't mean you don't need support. The IHS arranges home visits to members who may not be able to attend events or visit the office and who may need information or a chat.



## Hospital Visits

Being in hospital can be a scary and lonely time. The IHS office is located in Dublin City Centre so it is easy for staff to attend St. James's Hospital and Our Lady's Children's Hospital, Crumlin. If you or your child is in hospital and you feel like you need support, a chat or maybe a newspaper don't hesitate to contact the office. In 2011 several IHS staff members attend clinics at CUH to speak to members. Remember, the staff are here for you!

## Publications

In 2011 alone the IHS produced 11 publications – these included newsletters, an annual report, an information booklet for teachers and playgroup leaders, a Hepatitis C information booklet, how to recognise and treat a bleed poster and leaflet. The publication schedule for 2012 is just as jam packed with a booklet on von Willebrands Disease and a Workbook for children with Bleeding Disorders just some of the publications in the pipeline. Copies of all the publications can be downloaded free from the IHS website where peer articles and reports from events can also be found.



# Support - How can we help you?

## Events

The IHS organise three main conferences a year – the AGM, Parents Conference and Members' Conference, but these are not the only events organised by the Society. In the past few years the IHS has organised meetings for Women with Bleeding Disorders, Young Men with Bleeding Disorders, People with Hepatitis C and/or HIV, Relatives and People with Haemophilia from Poland not to mention tax meetings, regional meetings and a memorial service. We also work with other societies – in 2010 two families from the IHS attended an inhibitors conference organised by the UK society and in 2011 two young adults with haemophilia attended a haemophilia summer camp in Hungary.



## Grants & Scholarships

There are two IHS Grants – The Maureen & Jack Downey Educational Grant for people with haemophilia or related bleeding disorder and the Margaret King Educational Scholarship for relatives. Anyone who has been accepted on a third level course can apply for these grants. The IHS know college can be an expense not only on an individual, but on a family and want to help the future generations achieve their full potential.

## Advice

Whether you are going on holiday and want to know the nearest haemophilia treatment centre or you are applying for mortgage insurance and want clarification, the IHS are here to help.

The IHS attempt to make contact with each member at least once a year, however this can be a tough task as some details have changed. If you have not renewed your membership, you can still update your contact details on our database to ensure you receive updates from the Society. To check and update your details contact Nina or Declan on 01 657 9900.

All the IHS staff have been educated on haemophilia and related bleeding disorders and work tirelessly on behalf of the members. If you would like to contact any member of staff you can do so by phone 01 657 9900 or by email; simply put the staff members name followed by @haemophilia.ie



## The I.H.S. Book & Movie Club

With the summer fast approaching, the IHS staff have some recommendations for your summer read:

Brian – The World According to Garp  
Debbie – The Charwoman's Daughter  
Nina – The Lincoln Lawyer  
Anne – Anything by Patricia Cornwell  
Declan – Darina Allen's Cookbook  
Nuala – Search Dogs and Me  
Fiona – Wuthering Heights

As the summer isn't always sunny, there may be a day you need to stay indoors, the IHS staff have also made some movie recommendations:

Brian – A Separation  
Debbie – The Piano  
Nina – Blood Diamond  
Anne – The Help  
Declan – City of God  
Nuala – Hachi  
Fiona – Breakfast at Tiffany's

**Answers:**  
The quietest - Anne  
The loudest - Nuala  
The funniest - Everyone voted for themselves, but the unanimous answer is... Not Brian





## **IRISH HAEMOPHILIA SOCIETY**

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Website: [www.haemophilia.ie](http://www.haemophilia.ie)