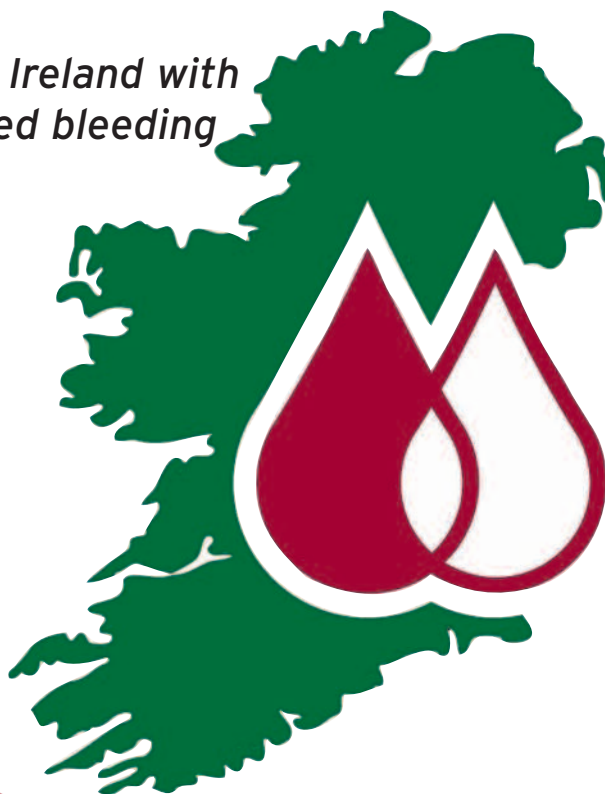


haemophilia.ie

Magazine of the Irish Haemophilia Society

Edition: April 2013

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



The Society at a Glance

AGM 2013
Attendance

→ **240**

↑ Followers on
Facebook

↑ **341**

↑ Registered
Volunteers

↑ **45**

↑ Publications
produced in 2012

↑ **14**

↑ Website Hits
(Jan - Mar)

↑ **4,771**

WHAT'S INSIDE:

- * A report from the AGM.
- * Interviews with the board of the IHS.
- * The IHS Calendar of Events for 2013.
- * Puzzles for the Cubs & Kidlink.



PARENTS CONFERENCE

14th to 16th June 2013

Johnstown House, Enfield, Co. Meath.

PRELIMINARY ADULTS PROGRAMME

Saturday 15th June

- 09.30 – 10.00 Welcome & Introduction
- 10.00 – 12.00 Mothers and Fathers Workshops
- 12.00 – 1.00 An Update from OLCHC
- 1.00 – 2.00 Lunch
- 2.00 – 3.30 Communicating with your children
- Interactive workshop focusing on family communication and bullying.
- 3.30 – 4.00 Coffee Break
- 4.00 – 5.30 Self Infusion Workshop (Adults only)
- 5.30 – 7.30 Family Time
- 7.30 Dinner



Sunday 16th June

- 9.30 – 10.30 Parents Empowering Parents
- 10.30 – 11.30 Don't exclude the siblings!
- 11.30 – 1.00 Parents Forum



PRELIMINARY CHILDREN'S PROGRAMME



Crèche

- Story Time
- Teddy Bear Picnic
- Arts n' Crafts
- Movie Time
- Playground
- Games



Cubs:

- Arts n' Crafts
- Playground
- Movie Time
- Treasure Hunt
- Haemophilia & Us!!!
- Games



Kidlink:

- Games
- Arts n' Crafts
- Swimming
- Sports Day Extravaganza
- What am I made of??
- Haemophilia Educational Session



Youth:

- Swimming
- Games
- What am I made of??
- Outdoor Team Challenge
- Mirror, Mirror on the Wall

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A Note from the Editor



*Debbie Greene,
Administrator*

Hello Everyone,

Welcome to the Spring edition of 'haemophilia.ie', and what a jam packed edition we have in store for you.

In our CEO's report on page 4 read all about the new National In-Patient Unit in St. James's Hospital which is scheduled to open in April 2013. Some of the staff and the board were delighted to visit the new unit a few weeks ago. Also in this report you will find updates on longer acting factor and gene therapy, and the interaction the Society had with the various bodies in relation to the availability of new treatments for hepatitis C for our members.

From epic bicycle rides (678 kilometres) to half marathons, take a look at what's happening in relation to fundraising on page 8.

For our younger members check out the Cubs Club and Kidlink Group on pages 12 & 13, featuring a new comic, "The Slobs, by Conor Birkett". Well done Conor, looking forward to the next cartoon!

You will find important dates for your diary on page 14, and as you can see there are many events taking place between now and the end of the year, perhaps one of these events might interest you? Keep checking the website for further updates on all our events.

Read a review from our recent AGM on page 16, which was written by member Cora Marshall. (Thanks Cora!) It was a fantastic conference. Thanks to everyone who helped out and made it a great weekend, in particular all our volunteers who I am sure were exhausted on Sunday night.

I am sure sometimes some of you wonder or might ask yourself who are the eight individuals who sit on our board? Well, if you go to page 20 you can find out in our special feature, "Introduction to the Board".

Finally, please do not hesitate to contact the office on (01) 657 9900 if there is anything we can assist you with or if you fancy dropping in for a cup of tea and a chat.

**Debbie Greene
Administrator**

CEO'S Report

At the
AGM
& Annual

Conference at the beginning of March, we had a symposium on the programme entitled "The Future is Here". On several occasions over the past five years, we have been updating members on potential new developments with factor replacement therapy. These exciting developments which include the availability of longer acting factor concentrates and the availability of gene therapy are now closer to realisation, than at any time in the past. It was therefore an appropriate time to have a discussion on these issues more in the present tense. A number of longer acting Factor IX and Factor VIII concentrates are currently undergoing late stage clinical trials. Indeed, there are a small number of children in Ireland now participating in phase 3 clinical trials for a longer acting Factor VIII and a longer acting Factor IX product.

When these products are available for routine use in the future they will open up several exciting possibilities. Firstly, as the products will have a longer effective half life, there is the possibility that infusion frequencies can be decreased. This could mean for example that prophylaxis for Factor VIII could be once or twice per week, as opposed to the current three times a week, and prophylaxis for Factor IX could be once every 7 to 14 days, as opposed to the current, twice per week. This may be particularly important for some individuals with poor venous access.

Secondly, the concentrates could be used to achieve higher trough levels. Current trough levels for prophylaxis are based on maintaining the factor level above 1% at all times. While this is sufficient to prevent spontaneous bleeding in most cases, it will not prevent all bleeding episodes. Higher trough levels will lead to better clinical management of haemophilia, which will mean less bleeding episodes and less joint damage in the future.

Of course with these new products

there will also be a need to individualise therapy. I certainly envisage a situation, when these new products are available, that each person with haemophilia would have an individual pharmacokinetic study carried out. This would determine their individual half life with the new product, so that their treatment can be prescribed according to their individual needs / requirements.



Brian O'Mahony,
CEO



Dr. Paul
Giangrande, Ms.
Sarah Gilgunn and I
spoke on gene
therapy and longer
acting factor
concentrates at the
IHS AGM.

These longer acting factor concentrates should start to be available as licensed products in the United States and Canada in late 2013 or early 2014. I do have a concern however, in relation to their availability in Europe. In the past when new products were undergoing clinical trials, the clinical trials in the adults were completed and once the clinical trials in previously treated children had begun, the products could be licensed for use in adults. There is now a divergence in policy between the European Community and the United States and Canada. Under the new European Medicines Agency Guidelines on Clinical Investigation of Recombinant and Human Plasma Derived Factor VIII and Factor IX Products, both the adult and paediatric data has to be available before companies can file for licensing of the products, even for use in adults. This could effectively mean a delay of 2 to 3 years in the availability of some of these products in Europe, as opposed to the United States and Canada. We are currently addressing this situation at a European level and have meetings arranged with the European Medicines Agency and the key committees in this area.

In 2012, we had a number of information meetings for individuals with Factor IX deficiency in relation to the potential participation of Ireland in a clinical trial for Factor IX gene therapy. There was a high degree of interest expressed by people with Factor IX deficiency in relation to possible participation in these clinical trials. The process is currently undergoing legal and regulatory approval and we anticipate that within the next 3 - 4 months an active process of full and informed consent and potential recruitment for a Gene Therapy Factor IX Clinical Trial may take place in Ireland. Therefore we face the potentially exciting prospect that by the end of this year, we may have individuals in Ireland being treated with both the longer acting factor concentrates (currently a reality - on clinical trial) and with gene therapy for Factor IX (on an early phase clinical trial basis).

New National In - Patient Unit in St. James's Hospital

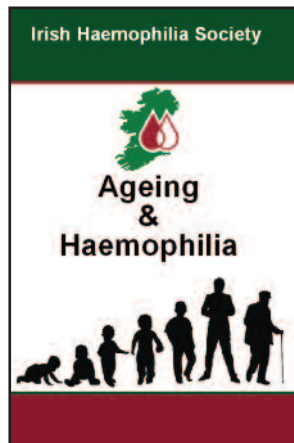
Provision of optimum care for haemophilia does not begin or end with factor concentrates. The comprehensive care model also requires optimal provision of Out-Patient services, monitoring of home treatment and optimum provision of In-Patient facilities. We are delighted that the new haemophilia / hepatology In-Patient unit in St. James's Hospital has been progressing so well and is now scheduled to open in April 2013, with a formal opening to take place in May. The unit will have 12 beds – six haemophilia beds and six beds for hepatology, with a further six assessment bays.

The IHS Board & Staff visited the new In-Patient unit in St. James's Hospital in March 2013.



The Society have been working with St. James's Hospital from a very early stage on the planning and design of this new unit. I believe we have the possibility to see a remarkable improvement in the In-Patient experience for persons with haemophilia and related bleeding disorders. To this point in time, when people with haemophilia have been admitted to St. James's Hospital, it has never been possible to ensure that they will be admitted into the same ward. Having a specialised unit with specialised staff, who are fully trained on haemophilia and will have, or will develop, the necessary expertise and knowledge should optimise the In-Patient experience and should also optimise the use of factor concentrates and the provision of all of the care associated with being an In-Patient.

I have visited the unit on a number of occasions at various stages of building together with Dr. Barry White, and our suggestions have been integrated into the design. Each of the 12 rooms will be a single patient room with disability access, and en-suite bathrooms. Each room will have a couch or chair which will be suitable for a family member to stay, if required. We are also involved in the selection of the entertainment systems and there will be wireless internet access, where patients will be able to bring in their I-Pad, laptop, or notebook when they are an In-Patient. We have also been working with the Chief Executive of St. James's Hospital and Dr. Barry White to ensure that the availability of beds for people with haemophilia in the unit when required and that this availability is always optimised.



The latest IHS publication, Ageing & Haemophilia.

Ageing and Haemophilia

Among the new publications from the Society is a new booklet on Ageing and Haemophilia. Thankfully, we are now living in a time when people with haemophilia have an extended life expectancy compared to the past. Many people with haemophilia can expect to live into their seventies or eighties, this is very

reassuring and is a testament to the improvement of comprehensive care and the availability of factor concentrates for people with haemophilia over the past decades. However, it also means that for the first time, people with haemophilia are going to have to confront the normal challenges and illnesses associated with ageing, these include; cardiovascular disease, cancer, kidney disease, diabetes and arthritis (in addition to possibly pre-existing haemophilic arthropathy). The publication we have produced is user friendly and I believe it gives excellent information. However, we are also organising a separate conference in late 2013 on Ageing and Haemophilia. In the interim we will be working with the NCHCD and with the Comprehensive Care Centres to look at pathways for optimal monitoring, diagnosis, and treatment of people with haemophilia who develop conditions associated with ageing.

There are a number of different opinions internationally in relation to dealing clinically with the challenge of Ageing and Haemophilia. These range from the opinion that all conditions should be dealt with by the Comprehensive Care Centre, to the opinion that the Comprehensive Care Centre should have a role in monitoring & diagnosis, but not necessarily in treatment of additional conditions, to the opinion that all of the conditions associated with ageing should be dealt with by the person's general practitioner.

the Minister for Health who approved the new hepatitis C therapies, and these were then subsequently approved by the HSE for reimbursement in June. The surprising element is the large number of advocacy meetings and interactions we then subsequently had to undertake in order to actually get treatment available to our members. Between April and September of 2012, I personally had 44 meetings, phone calls or interactions in relation to the availability of the new treatments for our members.

This whole area will result in significant additional challenges to people with haemophilia. It is generally the case that men do not attend doctors with any great frequency or confidence. People with haemophilia, I would submit, are an exception. They have, for the most part, developed long term relationships with their doctors and healthcare workers at the Comprehensive Care Centres and are well used to attending centres. On the other hand, many of them will not regularly attend general practitioners and indeed, some people with haemophilia do not have a general practitioner. In my view, we need to look at this whole situation very carefully. I accept that it may not be possible or even realistic to expect the Comprehensive Care Centres to manage every additional condition associated with ageing. However, I think it is entirely reasonable to expect the Comprehensive Centres to take a number of steps. This could include ensuring that screening tests (such as cholesterol, lipid profile, blood pressure, blood glucose levels etc.) are integrated into the routine tests carried out on the annual or biannual clinic visits. The follow up of abnormal results, could be carried out by the centre or by consultants whom the individual will be referred to by the centre, or could be carried out in consultation with the person's general practitioner. As an example, in the past number of years a small number of people with haemophilia have been referred to a cardiologist. It makes perfect sense, in my view, for people with haemophilia to be referred to the same cardiologist so that the cardiologist develops an expertise and experience in dealing with people with an underlying bleeding disorder. The same principal applies to other specialities. This is an important area and one which we will be exploring with the Comprehensive Care Centres in the course of 2013.

Advocacy and availability of treatment

A feature of the past year has been the extent of which the Society have had to actively advocate for the availability of treatment in a particular area (Hepatitis C). The Society had to advocate actively with the Minister of Health, the Department of Health, the Department of Health and the HSE in relation to the availability of the new therapies for hepatitis C. In April 2012, we met with

A press conference was held in the IHS office with Professor Colm Bergin and Professor Suzanne Norris in February in relation to the availability of treatment for people with Hepatitis C & HIV.



Fortunately, a number of our members have now had access to treatment through the hepatology unit in St. James's Hospital and in the near future a number of our members with hepatitis C and HIV co-infection will have availability of treatment also through St. James's Hospital. Again, more worryingly, despite the fact that the medications were approved in April 2012 and approved for reimbursement in June 2012, the roll out of treatment in the other hospitals around the country including Cork University Hospital, Galway, Kilkenny, Mater, Beaumont and St. Vincent's Hospital has been delayed by the actions of hospital pharmacists in refusing to dispense the medications. The use of a group of patients as a political football to try and get more resources from the HSE for the hospital pharmacy units was indefensible in our view and this was the subject of specific advocacy by the Society in January of this year. Since then I have also met with the Irish Hospital Pharmacy Association, their trade union and with their regulatory body.

This area is an indication of a changing trend in the availability of healthcare. Because of the current economic situation, I believe that in the future when we are looking at improved access to therapy or access to new therapies, we are going to have to not only advocate for the availability of the therapies, but put a lot of work into working with healthcare workers, the Department of Health and the HSE on the ground, to make sure that positive decisions are followed through on in a timely manner.

**Brian O'Mahony,
CEO**

Noticeboard



New Criteria for Educational Grants

As most of you will already know, the Society offer Educational Grants each year to people with haemophilia and immediate family members. For 2013, we are revamping the forms and changing the criteria slightly to make these grants broader, more straightforward and feasible for people. Don't worry there is plenty of time, and we will be advertising all you need to know in the next magazine, but in the meantime here are some of the new guidelines:

- * The opening date will be Monday 1st July 2013, and the closing date will be Monday 30th September 2013.
- * There will be new application forms for 2013, with extra questions to be completed.
- * You will be able to apply online, or download the application form, complete it and post it back to the office.
- * There will be a first, second and third place award for both grants in the following amounts:

Maureen & Jack Downey Educational Grant

First €4,000, Second €2,000*, Third €1,500

* (Second place will be called the Father Paddy McGrath Educational Grant)

Margaret King Educational Grant

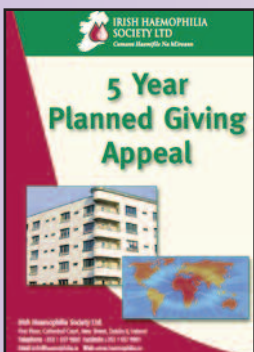
First €2,000, Second €1,000, Third €500

Everyone who applies and submits an adequate undamaged application, with sufficient information, will receive a minimum grant of €250. If an application is received and it is felt it needs improvement, or is inadequate or damaged, the person will be contacted and given a second chance to improve the application, to be submitted to the I.H.S. within 7 days. Otherwise no minimum grant will be given. Keep an eye on the website and the next newsletter for more information.

5 Year Planned Giving Appeal

The Irish Haemophilia Society 5 Year Planned Giving Appeal was launched at the AGM in 2012. Since last March, 38 members of the Society have signed up to the appeal. A sincere thank you goes to all of you who have signed up, it is very much appreciated. We are however, hoping that in 2013 more members will sign up.

It's now just over 6 months since the apartment was purchased and fitted out in Hyde Square, and I am delighted to tell you that it is really starting to take off, a lot of members and their families have used the excellent facility. As you all know 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 GAP Programme. This 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, and it is fantastic that we can allocate some of the funds raised towards this programme.



Members we are asking you to please consider, if you can, to commit to a planned monthly or annual donation to the Society at a level that you can afford for a five year period, even if it is only €10 per month. All amounts are very much appreciated.

Donation Levels

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

Of the funds raised, 75% is being allocated to the cost of running the apartment at Hyde Square and 25% is going towards our overseas development fund which we will use to fund our developing world programmes and contributions.

Thank you for considering making this donation.

Fundraising News

Fun ways to get your fix!

Fantastic and challenging fundraising ideas!

From bike rides to marathons, take a look at what's happening, and see how you can raise funds for the Irish Haemophilia Society.

JAFFA THAI FIGHT NIGHT

A Big Thank You to David Curtin



David Curtin, pictured below with IHS Treasurer Ger O'Reilly & IHS Vice Chairperson Brian O'Riordan, organised a hugely successful white collar boxing event, pictured top, and will take part in a fundraising cycle for the IHS.

On Saturday February 2nd, a boxing fundraising event was organised to benefit the Irish Haemophilia Society and the Irish Heart Foundation. The event took place in the Wright Venue in Swords, Co. Dublin. The event was organised by Society member David Curtin, who played inter county hurling for Dublin. David and his team of workers, who included his sister, his father and National Haemophilia Council Administrator, Gareth Presch, did a superb job in organising the event.

On the night there were 13 sets of six minute boxing matches in the so called "White Collar" Boxing event. This type of event has become increasingly popular in the last number of years, where individuals will undertake a period of training and then take part in a boxing event for charity. Among the boxers on the night were; a Kilkenny hurler and ex-Dublin footballer, Shane Ryan. The event was superbly organised, extremely well attended, was great fun and raised much needed funds for the Society. David raised €7,900 for the Society on the evening.

We would like to extend our appreciation to David and his team for a remarkable job.



CHARITY CYCLE - MALIN TO MIZEN HEAD CHALLENGE – A UNIQUE OPPORTUNITY

As if he hasn't done enough the next challenge that Society member David Curtin is organizing is a 4 day cycle from Malin Head to Mizzen Head, to raise funds for the Irish Haemophilia Society. David and a team of friends, family, fellow and former team mates are undertaking this truly inspiring cycle.

Details of the cycle are as follows:

Thursday 30th May – Malin Head to Sligo

Friday 31st May – Sligo to Kinvara

Saturday 1st June – Kinvara to Killarney

Sunday 2nd June – Killarney to Mizzen Head



David and his team of 15 cyclists are tirelessly training for the cycle which covers 678 kilometres. If you would like to sponsor David log on to the MyCharity.ie website or why not give your support and encouragement by logging onto their facebook page 'The Malin to Mizzen Challenge'. We will have a representative of the Society at the various stop off points, and we would like to take this opportunity to wish David and his team the best of luck!



FLORA WOMEN'S MINI MARATHON

Ok ladies, it's that time of the year again. Do you want to do something good for yourself as well as for a good cause? Then register for the Women's Mini Marathon which is due to take place on Monday 3rd June 2013 at a new starting time of 2.00pm. Don't forget the race is for walkers, joggers and runners, so it is for all ages and all fitness levels.

We appreciate all the support we have received in the past and hope that we will have old friends and new to participate this year in aid of the Society. We know that times are difficult for fundraising and just want to assure you that any amount raised is greatly appreciated. As well as raising funds we want to raise awareness of haemophilia and the services and support offered by the Society. Raising funds is not always easy, so another way to raise sponsorship for the race is to set up your own personal fundraising page on MyCharity.ie. This will allow you to receive support from friends and family no matter where they are in the world. All you need to do is go to the I.H.S. website and click on the MyCharity.ie icon on the bottom of the home page, select 'Raise Money for Charity' and then select 'Create a Page'.

Again this year, we will provide a room in Buswells Hotel on Molesworth Street for those taking part on the day. The room will be manned by I.H.S staff so you can be sure your belongings will be well looked after and following the race you will receive a certificate along with a well-earned cup of tea/coffee and a sandwich.

To confirm if you will be taking part in aid of the IHS and to receive your sponsorship card contact Nina on 01-6579900 or email nina@haemophilia.ie



The lovely ladies of the IHS who took part in the 2012 Flora Women's Mini Marathon



ON HER MARKS!

As if the Mini Marathon isn't enough, member of the Society Lucia Prihodova (pictured left) has given herself a challenge to do two other runs to help raise funds for the Society. Lucia has been training quite a lot, and is aiming to raise a minimum of €15 for every kilometre she runs. Lucia has also set up a fundraising page on the 'mycharity' website, so if any of you are interested in sponsoring Lucia, click on the 'mycharity' icon on the homepage of our website.

Details of the 3 runs are as follows:

- Women's Mini Marathon – 3rd June, 2013 (10 kilometres)
- Rock 'N' Roll Dublin Half Marathon – 5th August, 2013 (13.1 miles)
- Frank Duffy Run – 24th August, 2013 (10 miles)

Thank you Lucia for your efforts and the very best of luck.

P.S. How about this for a challenge! Lucia has said that if she raises over €700 she will run a 4th half marathon on behalf of the Society!

On Your Bike!

High-profile hurling star David Curtin didn't allow his haemophilia to prevent him from pursuing his chosen sport but he has opted for a safer option to raise funds for the Irish Haemophilia Society. John O'Mahony reports:

David Curtin sat in a treatment room in St. James's Hospital, looked Dr. Barry White in the eye and assured him he had taken his advice to give up hurling. But the experienced consultant haematologist remained unconvinced and before the week was out, his doubts were officially confirmed, courtesy of the back page of the Evening Herald. Brilliantly capturing the white heat of battle, a stunning action photograph showed Curtin, in the blue and white of his beloved Ballyboden St. Endas, rising for the sliotar in a no-holds-barred club championship match the previous day.

Dr. White's abiding memory of the said snapshot, however, wasn't the high-fielding prowess or the athletic agility of the Ballyboden midfielder, but the ominous presence of three hurleys, wielded by opponents, in the alarmingly immediate vicinity of Curtin's trademark yellow helmet.



At the next scheduled haemophilia clinic at the NCHCD, David again assured his specialist that his competitive hurling days were well behind him but he felt the colour rapidly draining from his cheeks when Dr. White casually flipped open his patient file and whipped out the Evening Herald evidence. The gifted hurler, who had represented the Dublin senior hurlers for 11 years and the Ballyboden St. Endas club since he was big enough to hold a hurl, could do nothing but hold his hands up, taking little consolation from the fact that he wasn't the first sportsman to have his cover blown by a tabloid newspaper.

"In fairness to Barry he was brilliant about it and, of course, I knew full well where he was coming from," David now reflects. *"I had suffered so many injuries playing hurling that Barry sat me down and said it just couldn't continue. I knew he was right, but I just loved the game and it was too hard to walk away."*

Dr. White wasn't the first haematologist to fail to persuade the true blue to put away the hurl and sliotar as Dr. Beatrice Nolan and Dr. Owen Smith had previously tried everything, from smiling charm to frowning threat, in ultimately unsuccessful attempts to convince him to pursue a less hazardous sporting code.

The fiercely combative and physically high-risk nature of hurling was never going to be a sensible sport of choice for a young lad born with haemophilia. But when David Curtin discarded the rule book and went chasing his dreams in GAA stadia around the country, his parents and the medical team that cared for him had little option but to offer whatever support and back-up they could.

Constantly by the side of his Kilkenny born father at club and inter-county games, it came as no surprise that the young David fell in the love with the game that was to shape his life and see him develop into one of hurling's household names who enjoyed many golden moments during the course of his long playing career.

He honed his skills at school in St. Colmcille's Knocklyon – where he now teaches – and he quickly developed into one of the most accomplished and influential Dublin hurlers of his generation. His early exploits on the field of play – and in the competitive training ground arena – led to several unplanned visits to the centre treatment couch, initially in Harcourt Street, later in Crumlin and eventually in St. James's Hospital, as David sustained a variety of knocks and strains that led to bleeds and required factor replacement.

"I'd always have an excuse made up and I'd be very slow to tell the doctors that I was injured playing a game or in training. I'd go in and try to convince them that the hurl marks on my body were caused by my sister hitting me or by falling off a wall. I'm sure though that they knew what I was up to," David said.

One of the darker days occurred in 1998 when he shattered his left elbow playing at minor level for the Dublin colleges' side, necessitating the insertion of six pins in a complex surgical procedure complicated even further by the unwelcome arrival of inhibitors in his life. That double whammy hurdle successfully negotiated, and with prophylaxis home treatment revolutionising his life, David returned to his chosen playground and went on to enjoy a glorious career in the sky blue jersey, enjoying National League glory at both Division 1 (2011) and Division 2 (2006) levels and savouring the honour of captaining his county for the 2005 league and championship campaigns. He was also the guiding hand in Ballyboden's push for glory which reached a peak with an unprecedented five Dublin SHC titles in a row. *"I knew from the very start that hurling was a risk and I realised that I would be injured quite a lot but I just got on with it and accepted that when the bleeds came then they came and I just had to deal with them,"* he said.

Despite the obvious risks involved, David remained as cautious and sensible as the circumstances allowed, taking treatment before key games and vigorous training sessions and allowing sufficient rest time to recover from bleeding episodes. He didn't give a second thought to administering factor replacement in the dressing rooms in the immediate build-up to games and, as time wore on, his team-mates didn't even cast a second glance at their colleague in the corner with a tourniquet on his arm and a needle in his vein.

"I'm sure a few of the younger lads just coming into the panel would have wondered what the hell was going on but the fact is it helped to prolong my playing career and it kept me as well as possible," he said.

David also wore specially adapted padded under-shorts, favoured by basketball players in Chicago, which successfully helped prevent against the constant threat of thigh injury.

"What it meant was when I got a belt of a knee in the thigh I might still get a bleed but it wouldn't be as severe," he explained.

Although he is still playing regularly with his club, David retired from inter-county hurling this year and immediately turned his thoughts to giving something back to the Irish Haemophilia Society which helped and encouraged him throughout his playing career. He will spearhead a team of 15 volunteers that will undertake a marathon cycle, from Malin Head in Co. Donegal to Mizen Head in Co. Cork, to raise funds for the IHS with an initial cash target of €20,000.

With his parents, Maurice and Christine, and fiancée Sheena McDonnell – who he will wed in December – leading the back-up support team, David and his fellow volunteers will depart from Malin Head early on May 30th and, following overnight stops in Sligo, Kinvara and Killarney, they are due to cross the finish line in Mizen Head on Sunday, June 2nd.

"All through my life the Irish Haemophilia Society and the team at the NCHCD have been a fantastic support to me and I'm delighted that I'm able to give something back," he said.



David and his charity cycle colleagues – including Dublin hurler Shane Ryan – are currently embarking on gruelling training sessions three times a week and they plan to step up their preparations in the coming weeks.

"I'm really enjoying it and I'm going to keep up the cycling when the event is over. It's great for the joints and it's a super sport for a person with haemophilia to be involved in," he said.

Chances are, Dr Barry White would concur.

Cubs Club

Hello all and welcome to the first Cubs Club of 2013! With a new year comes a new feature, introducing "The Slobs" a comic by former cubs club member Conor Birkett. I hope you enjoy it!



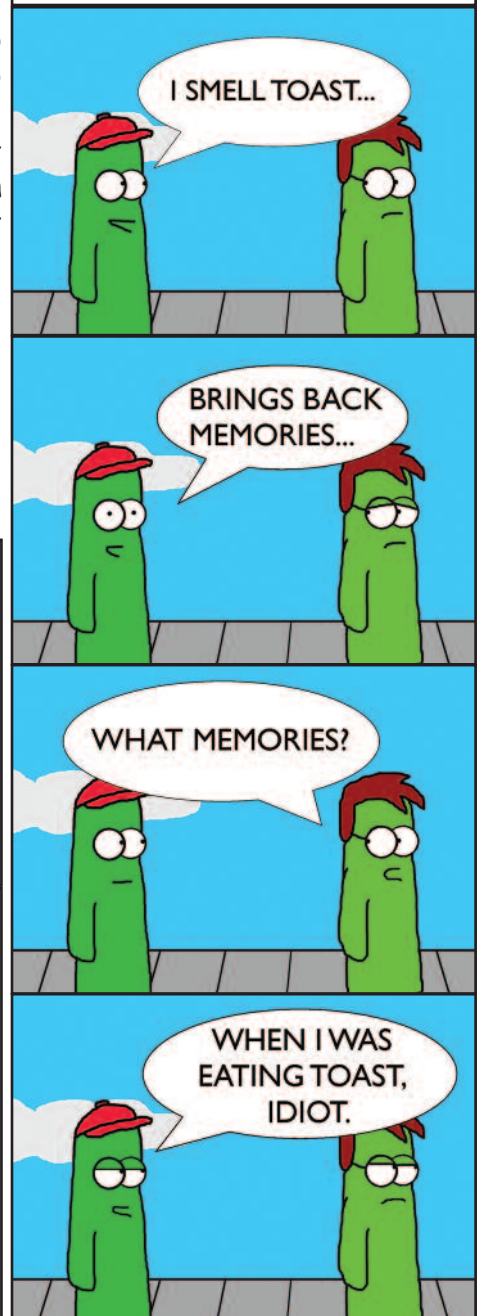
In this issue we are talking about the heart. Your heart is the strongest muscle in your body, it is about the size of your clenched fist. It never stops working, even when you are asleep - you don't have to think about how to make it work because it never stops beating! Your heart has a very important job, it pumps all of your blood around your body - so we need to keep our hearts healthy....how can you keep your heart healthy??

From the list below, list the healthy things with the active heart and the unhealthy things with the tired heart in the boxes on the bottom! Log onto www.haemophilia.ie to see the answers, but don't forget to ask an adult for permission and help.

- | | | |
|---|--------------------|---------------|
| * Skipping breakfast | * Snacking all day | * PE class |
| * Playing football | * Skipping lunch | * Running |
| * Playing on the computer for hours | | * Dancing |
| * Helping your Mam or Dad in the garden | | * Swimming |
| * Laying on the couch watching TV | | * No exercise |

The Slobs

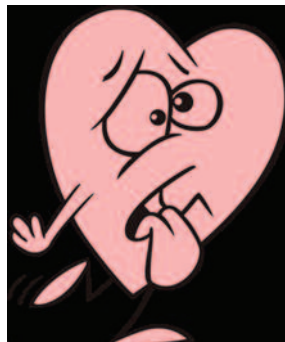
by Conor Birkett



GOOD FOR YOUR HEART

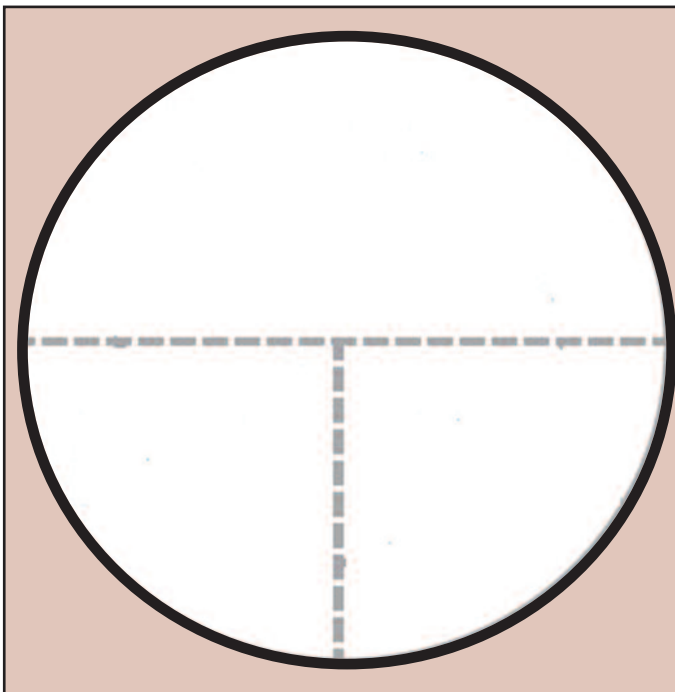
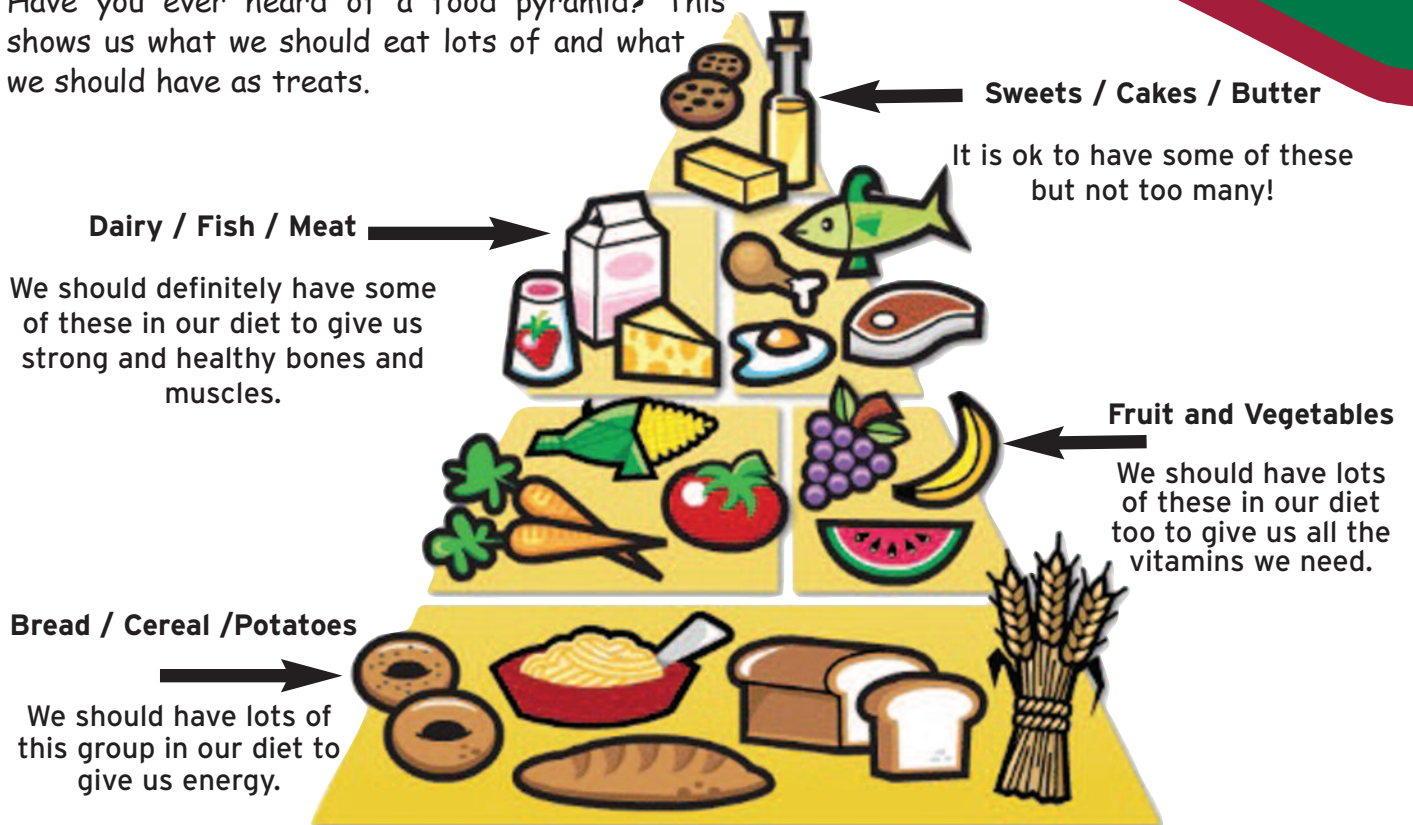


BAD FOR YOUR HEART



We all know that staying healthy is important - for our heart, brains, bones, muscles and teeth. There are lots of ways that we can stay healthy but a diet with lots of fruit and vegetables and exercise are two of the best ways!!

Have you ever heard of a food pyramid? This shows us what we should eat lots of and what we should have as treats.



Portion sizes are just as important as food choices.

Do you think you can make a tasty dinner on this plate to include all of the food groups?

Remember your portion sizes!

Dates for your Diary

MAY

Date: 10th - 12th May

Event: HCV / HIV Conference

Venue: The Pembroke Hotel, Kilkenny



JUNE

Dates: 3rd June

Event: Mini Marathon

Venue: Buswells Hotel, Molesworth Street



JUNE

Dates: 14th - 16th June

Event: Parents Conference

Venue: Johnstown House Hotel,
Enfield, Co. Meath



OCTOBER

Dates: 11th to 13th October

Event: Members Conference

Venue: Bloomfield House Hotel,
Mullingar, Co. Westmeath

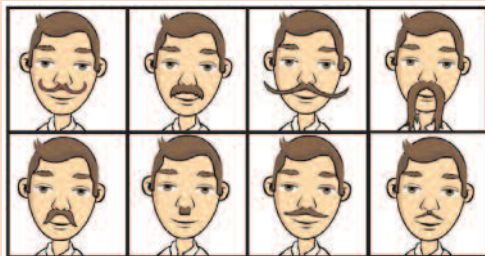


NOVEMBER

Date: 1st - 30th November

Event: Fundraiser

Venue: Everywhere



NOVEMBER

Date: 15th - 17th November

Event: Ageing Conference

Venue: The Sheraton Hotel, Athlone





On the first weekend of last November, Barretstown organised their first brother and sister camp at Barretstown Castle.

My brother, Jack and I travelled by train to Heuston station in Dublin. When we arrived we were greeted by lovely Caras (the helpers) and they brought us to their own Barretstown bus. On the way we collected more children from Crumlin hospital.

In about an hour and forty minutes we were at Barretstown! Whoo hoo! Lots of Caras were waiting for us to bring us up to our cottages. Everybody met lovely friends and then we went for a delicious hot meal!

Jack stayed in a different cottage to me, but we were in the same activity group.

The activities we did were brilliant. It was my first time to try archery and high ropes. My favourite activities were:-

* Dancing * Archery * Canoeing * Arts and crafts * High ropes

Jack and I and the other great kids were so lucky to have such a great opportunity as this. It was nice to see everybody with big smiles on their faces. It was nice too, to get away from our family for a little while!

I didn't have any concerns at Barretstown at all because everyone was so well looked after by all the staff. Secretly, I didn't want to go home for another month!

When we got home Jack and I still had smiles on our faces. I can't wait to go back to Barretstown.

In my opinion Barretstown is the best camp in Ireland!

Joanna Keniry



Barretstown run a variety of activities including high ropes, archery & fishing. All activities are adapted to suit the children attending the camp.

AGM Review

In early January a letter dropped through my letter box informing me that the Annual General Meeting of the Irish Haemophilia Society was taking place on the weekend of the 1st to the 3rd of March 2013.

My first thought was it cannot be that time of year again so soon! But it was! This year's gathering took place at the Osprey Hotel in Naas, Co Kildare. The Society celebrates its forty fifth anniversary this year. Started in 1968 by a handful of parents with children affected by what was then, an incurable rare bleeding disorder, it has grown over the years into a vibrant organisation jam packed with innovative ideas and forward thinking.

The Annual General Meeting is the most important meeting of the year. This is where the business of the organisation takes place. The nuts and bolts if you like, of who we are and what we are about. It is where we look back over the last twelve months to see if the goals we had set ourselves the previous year had come to fruition. How had we fared? How much of what was aspired to was achieved?

This year two hundred and forty members gathered for a weekend of work and fun. The agenda for the weekend promised something for everybody. It was very heartening to see such a well attended and lively A.G.M. The reports from the Committee, the governing body of the Society, were very well presented. The various addresses by Mary Hanney (Secretary), Ger O'Reilly (Treasurer), Brian O'Mahony (Chief Executive Officer) and Traci Marshall Dowling (Chairperson), were all expertly delivered and very well received by the attending delegates. It was clear that we had indeed met the targets that we had set ourselves the previous year. Our twinning with Vietnam continues for the present and we were honoured by being named Twin of the Year for 2012.



The 2013 IHS AGM took place in the Osprey Hotel in Naas. 240 people, including adults and children attended the weekend, which was regarded by many as the best AGM in many years.

Talks and Lectures

There were two sessions held on Saturday and three on Sunday. The lectures and talks were varied and had something for everyone. One of the most exciting and promising topics was "The Future is Here" delivered by Dr. Paul Giangrande and Sarah Gilgunn. This covered Gene Therapy, Longer Acting Factor and Clinical Trials. Dr. Paul Giangrande is a very personable and eminent Haematologist from the UK. He has visited and lectured many times at our A.G.M. Ms. Sarah Gilgunn is a PhD student and is also a board member of the Irish Haemophilia Society. Sarah came up through the ranks as a member of our Society. It is great to see her putting her expertise to our advantage. The lecture brought real hope for the future and the eradication of genetic diseases.

For it is only through the study of genetics that a complete cure for haemophilia and other genetically inherited disorders will come about.



A varied and interesting programme ensured that attendances at the various sessions were high.

The second session on Saturday was an Open Forum with the Comprehensive Care Centres and included lectures by Dr. Barry White, Consultant Haematologist, Dr. Beatrice Nolan, Consultant Haematologist, Biologist Vince Jenkins and Nurse Eibhlin Mc Loughlin. The session was chaired by Dr. Barry Harrington, Chairperson of the National Haemophilia Council. Dr. Harrington is a valued friend of the Irish Haemophilia Society. He was the resident dentist for people with haemophilia at St. James's hospital for many years and a very good dentist. It is nice to see him keeping contact with us. I had thought that there would have been a contribution on Comprehensive Care from the Haemophilia Treatment Centre in Cork. Perhaps next time?

Meeting and Greeting

The A.G.M. important though it is, was not all business. It was also the setting for old friends coming together again. On Friday evening members, delegates and guest speakers checked in and registered. Then everyone caught up with each others news over dinner and a few drinks. Many guest speakers were on return visits and were delighted to be asked back.

The Gala Dinner on Saturday night was the highlight of the AGM. Over an excellent meal people talked about the topics of the weekend, and one could feel the genuine delight that the guests felt on being asked to our conference. Some of them joked about seeing different parts of Ireland through the locations of the A.G.M. The Youth group and the Kidlink club always provide a little entertainment after dinner on Saturday night. This year the Youth Group did a song and dance and the smallies from the Kidlink Club performed a drama outlining the difference in what happens to patients when they have a bleed in Ireland and in Vietnam. They were very good and their performances were cheered to the rafters!



A feature on the Children & Young Adults programmes titled "IHS Got Talent" saw the Youth Group perform a flash mob and the Kidlink Group perform a play on the difference of life with a bleeding disorder in Ireland & Vietnam at the Gala Dinner.



Dr. Barry White was presented with the Brian O'Mahony award for Exceptional Service to Haemophilia at the Gala Dinner.

Afterwards the Annual Awards were presented to the recipients. These awards have grown over the years. They cover educational grants under various categories and awards for fundraiser of the year and are all named after people who have given exceptional service to the haemophilia community over the years. People who have sadly passed on, but whose memory will always stay alive in the hearts of those of us privileged to have known them.

The highlight of Saturday night was the dancing. Led as always by the B Sharps, they provide the music into the wee small hours of Sunday morning. The fact that Liam O'Sullivan of the B Sharps is the son of Bill O'Sullivan one of the original founders of the Society, and that his mother Hilary is a lifelong member, is testimony to the commitment of our members.

Workshops and Talks

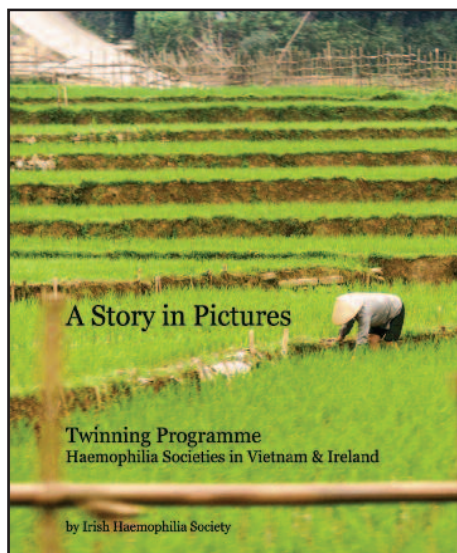
After a great day and night on Saturday, everybody was up early on Sunday for more sessions, which included information workshops on Travel and Vein Care and a talk on the IHS Twinning Programme with Vietnam.

Regarding travel, a minor miracle in itself is the ease with which people with haemophilia can now travel the world without trauma. Just the inconvenience of carrying out a few sensible precautions and taking the necessary paraphernalia with them. Now to make things even easier, modern technology and the advent of Smart Phones is changing the way we look at things. Applications or Apps for short is the new buzz word. There seems to be an App for almost everything and haemophilia has not been forgotten! A new App was announced at the weekend for all those with smart phones (and who hasn't a smart phone these days?) which will help travellers with haemophilia to find their nearest treatment centre in whatever country they are visiting, should the need arise. This is brilliant news for people with haemophilia with a wanderlust to travel.



The IHS travel card, pictured above, is currently being turned into an app for phones. The app will allow people to have the information they require at the touch of a button.

I left the lecture on vein care before it finished because needles are not my favourite topic.



The last talk on Sunday was an update on our Twinning with Vietnam. This was one of my favourite talks of the weekend and a project close to my heart.

It is sobering to realise that in the twenty first century that there are still parts of the world where people with haemophilia still have no access to modern treatment for bleeding episodes. People are still dying or being crippled from bleeds that we, in more privileged parts of the world, do not experience any more. The treatment is antiquated by our standards and is so expensive that one has to live without any comfort in order to be poor enough to qualify for free treatment.

We have so much to be thankful for on this side of the world and we owe much to the World Federation of Hemophilia (WFH) for initiating the Twinning Programme and for bringing our attention to the plight of the Vietnamese people.

Copies of "A Story in Pictures" a photobook produced by the IHS on the Twinning Programme, pictured left, can be ordered through the IHS.

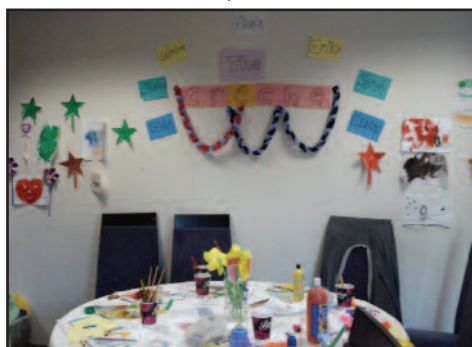
The Hotel

The Osprey Hotel was the venue for this year's conference and it was a beautiful hotel. Circular in design with linked corridors, it proved to be very unusual. Hotel guests had free access to the spa area without having to book a treatment. If you wanted access to the conference centre, however (where some of the talks were held) you had to go outside the main building and go to another area. Very puzzling, it was a bit like being in a crystal maze. The unusual design notwithstanding, the hotel bedrooms were very beautiful, the bathrooms gorgeous and the staff were outstanding in friendliness and efficiency.

Finally a huge vote of thanks must go to the IHS staff for organising the AGM. The logistics involved in bringing in effect the office to the hotel was no mean feat. The tables chock full with publications, posters, photo boards, information on world conferences, European conferences etc. took an awful lot of doing. The staff are fantastic, because coordinating everything so that it appears to run so effortlessly takes a lot of behind the scenes work.



The Cubs, pictured above, showed off their creative flair at the AGM, while the Creche showed their artistic abilities, pictured below.



Thanks also to the volunteers who give up their weekends to organise and run the programmes arranged for the younger members of the Society. Without them it would not be possible for both parents to attend the AGM. Many of the volunteers have haemophilia themselves, others are the siblings of those with haemophilia.

The Youth Group is one of the most important groups that the volunteers work with. Unconsciously the kids they are mentoring are learning valuable life skills and are imbibing the values that the Society stand for. These kids will become the future volunteers and committee members of our Society.

Hopefully the days are long gone when the brother who had haemophilia was the “different one” and their illness was something that they had no real understanding of.

I really enjoyed my weekend and look forward to the next event on the haemophilia calendar.

Cora Marshall



Happy Birthday to the IHS!

2013 is the 45th year of the IHS.

The history of the IHS can be viewed on the IHS website www.haemophilia.ie

Introduction to the Board

The IHS board is made up of eight volunteers, all of whom are members of the Society and have a connection to haemophilia. The board of the IHS act on behalf of the members of the IHS, are involved in the Strategic Plan and help to ensure the Society is providing the best services and support to members. So who are these eight individuals? Lets find out...



Name: Brian O’Riordan.

Age: 40.

Occupation / Studying:
English Language Teacher.

What is your connection to haemophilia?

I have severe haemophilia A.

How long have you been involved with the Society?
5 or 6 years.

When did you join the board of the I.H.S.?
2011.

Why did you join the board?

Having benefitted greatly from the hard work of others over the years, I was keen to make a contribution, however small, myself. I am also interested in health policy, advocacy and strategy.

Where do you see the Society in 10 years?

I’m confident it will remain a vibrant, flexible organisation. The needs of today’s children are very different to those of ten years ago. The same will be the case in a decade. We have to adapt to our members needs as we always have.

Sum up the Society in one word.
Strengthening.



Name: Eoin Moriarty.

Age: 27.

Occupation / Studying:
BA in Applied Psychology in UCC.

What is your connection to haemophilia?

I have mild haemophilia, factor IX deficiency.

How long have you been involved with the Society?

I have been attending meetings with my family since the mid to late 90’s and I have been volunteering for approximately 5 years.

When did you join the board of the I.H.S. ?
2010

Why did you join the board?

I felt that as a person with mild haemophilia, it was a demographic that I could represent in the membership.

Where do you see the Society in 10 years?

It’s difficult to say but with the recent developments in treatments, and the likelihood the effects of the economic depression will still be impacting on us, I believe the role of the Society will be more concerned with ensuring the quality of care is maintained.

Sum up the Society in one word.
Efficient.





Name: Gerard O'Reilly.

Age: 53 yrs old.

Occupation/Studying:
I consider myself semi-retired.

What is your connection to haemophilia?
I have severe haemophilia A.

How long have you been involved with the Society?
35 - 40 years.

When did you join the board of the I.H.S.?
Approximately 2006.

Why would you encourage people to become members of the Society?
There are many benefits to being a member. You will receive all the publications, newsletters and up to date information. Also subsidised rates for the various information weekends, including the AGM, for individual and families organised by the Society.

What do you see your involvement in the Society being in the future?
Even when my time is up as regards being a board member, I would still like to be of some service to the Society in any regards that they feel I can help. The one area in particular that I would like a role in, is the area of ageing with haemophilia.

Sum up the Society in one word.
Dedication.



Name:
John Stack.

Age: 37.

Occupation / Studying:
Engineer. I'm also a Strength and Conditioning Specialist.

What is your connection to haemophilia?
I have 2 sons have severe Factor VIII deficiency.

How long have you been involved with the Society?
2 years.

When did you join the board of the I.H.S.?
2012.

As a member what do you think is the best service/support the I.H.S. offers?
Understanding. Everybody in the Society knows what it is like.

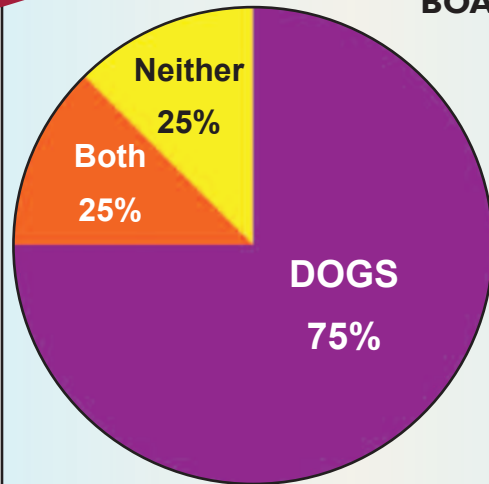
What do you see your involvement in the Society being in the future?
I would like to be more involved in the therapeutic aspect of things, particularly in the area of exercise. Modern medication has made it possible for people with haemophilia to exercise and exercise subsequently adds quality of life.

Sum up the Society in one word.
Awesome.

WHAT THE BOARD THINK
Is it a Rice Krispie Cake or Rice Krispie Bun?



WHAT THE BOARD THINK



Cats
or
Dogs?



Name: Mary Hanney.

Age 51.

Occupation / Studying:
Finance Officer.

What is your connection to haemophilia?

I have two sons with severe haemophilia A.

How long have you been involved with the Society?

Since 1994.

When did you join the board of the I.H.S.?

2009.

Why would you encourage people to become members of the Society?

It is important to have support when you might be having a hard time living with haemophilia. The information from all the publications is extremely beneficial and meeting up with other families who are having the same issues as you, and realising that everyone is going through the same thing as you, is very helpful.

2013 is the 45th year of the I.H.S. Share a memory of your time as a member of the I.H.S.

The memory that stands out for me is the day that I met Margaret Dunne in Harcourt Street Hospital. I was so worried because I didn't know anything about haemophilia and Margaret gave me such support and good advice that I never looked back.

Sum up the Society in one word.

Inspirational.

Name: Michael Butler.

Age: 55.

Occupation / Studying:
Manager of Services in HSE.

What is your connection to haemophilia?

I am a parent of two lads with haemophilia.

How long have you been involved with the Society?

Since 1986.

When did you join the board of the I.H.S.?

2008.

Why did you join the board?

To give back something to the Society who had been very supportive of us in our early years of parenting.

What do you find most enjoyable about working with the Society?

The sense of community and positive attitude to the work undertaken.

As a member what do you think is the best service/support the I.H.S. offers?

One to one support, with the required expertise to assist individuals.

Sum up the Society in one word.

Responsive.





Name:
Sarah Gilgunn.

Age: 27.

Occupation / Studying:
PhD Student – Cancer Research.

What is your connection to haemophilia?

I am a factor IX carrier.

How long have you been involved with the Society?

3 years.

When did you join the board of the I.H.S.

May 2012.

What do you find most enjoyable about working with the Society?

The people – both staff and members.

Why would you encourage people to become members of the Society?

Because it is a great community environment and members can gain a lot of important information about haemophilia. Plus they can make lots of new friends.

What do you see your involvement in the Society being in the future?

Hopefully I will still be on the board! Teaching the kidlink and cubs about genetics, haemophilia and other bleeding disorders.

Sum up the Society in one word.

Fun.



To read the full interviews with the board log on to www.haemophilia.ie



Name:
Traci Marshall-Dowling.

Age:
Old enough to know better!

Occupation / Studying:
Facilitator / Trainer and also studying B.SC in Education & Training in DCU, evenings and weekends.

What is your connection to haemophilia?

I am a carrier and have a son with severe haemophilia A.

How long have you been involved with the Society?

21 years.

When did you join the board of the I.H.S.?

2008.

2013 is the 45th year of the I.H.S. Share a memory of your time as a member of the I.H.S.

It is hard to think of one memory or one person as I have met so many wonderful people and sometimes saints in my eyes, over the years. Yet when I think of the Society and what it has meant to me over the years the words fun, laughter, tears, strength, support and friendship always spring to mind.

Attendances at events have increased in the past number of years. In your opinion, why is this?

A number of reasons; newly diagnosed children, new treatments, developments in relation to HIV / Hepatitis C treatments and factor development. I also think the fact that conferences and programmes are held in excellent hotels with excellent rates helps in these recessionary times.

Sum up the Society in one word.

Family.



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