

haemophilia.ie

Magazine of the Irish Haemophilia Society

Edition: July 2014

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



The Society at a Glance

Parents
Conference
Attendance

166

Followers
on
Facebook

567

Mini Marathon
Participants
2014

37

Junior & Youth
Members

16

Website Hits
(March - May)

5,351

WHAT'S INSIDE:

- * An update on Twinning. * Memories from the 2014 Women's Mini Marathon.
- * Remembering a couple of Founding Members. * Parents Conference Report.



Carrier Conference

Date: September 27th & 28th 2014

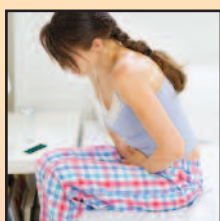
Venue: Clarion Hotel, Liffey Valley,
Dublin

Carriers of haemophilia not only carry the condition, but have their own symptoms and emotions to deal with. The Carrier Conference is an event just for carriers. The conference will feature information from diagnosis to family planning, from dental care to emotions.

Preliminary Programme

Saturday September 27th

11.30am – 12.00pm	Registration
12.00 pm – 1.00pm	Lunch
1.00pm – 2.30pm	Carrier Testing & Inheritance



2.30pm – 4.00pm	Menstruation
OR	
	Family planning & pregnancy
4.00pm – 5.00pm	Guest Speaker: Emma Quinlan
7.30pm	Dinner & Girls' Night

Sunday September 28th

10.00am – 12.00pm	Positive Living
12.00pm – 1.00pm	Dental Care
1.00pm	Lunch

As if that wasn't enough, join us for the Ultimate Girls Night, where you will receive your very own Goody Bag!



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Debbie Greene
Administrator

A Note from the Editor

Hello,

Welcome to haemophilia.ie, the magazine of the Irish Haemophilia Society. I hope you are all enjoying your summer break abroad or in Ireland.

The annual Parents Conference took place recently in Dublin. Feedback from members was very positive. The programme was really good and it was also great to have members of the IHS along with healthcare professionals from OLCHC & NCHCD participating in the programme. This year we had so many children booked in for the crèche we had to facilitate an extra crèche group for the weekend; otherwise we would have had many disappointed members and children. If you would like to read about this conference you will find photos and a report on page 15.

Fundraising has been going really well over the past couple of months with many events taking place. At the start of June a great day was had by all the ladies who did the Mini Marathon on behalf of the Society. A big thank you goes to everyone who raised funds for the Society. For more information, read Nina Storey's article on page 18.

On the inside cover you will find the preliminary programme for the Carrier Conference. We hope that the conference, targeted for teenagers and women between the ages of 16 and 35 years, will get a good response, as it is hugely important that women have relevant information, in relation to all carrier issues. On page 10 you will find an advert for the Members' Conference in October, a firm favourite with IHS members and with such a variety of sessions on the programme, no doubt we will have a high attendance again!

On page 19, you will find all the information you need in relation to applying for our Educational Grants. The deadline is towards the end of September so there are no excuses you have plenty of time to apply!

Maureen & Jack Downey were founding members of the IHS, and on page 20, Nuala Mc Auley has written a piece on the couple and their involvement with the Society. This is a lovely tribute to Maureen and Jack, and I would strongly recommend you read this piece.

See you all at the next conference and enjoy the read.

Debbie Greene,
Administrator

CEO'S Report



Brian O'Mahony
Chief Executive

In the special IHS supplement reporting on the proceedings at the recent World Federation of Hemophilia (WFH) Congress, there are updates on progress with the development of longer acting factor concentrates. Several companies are making steady progress in their clinical trials with these new and novel products using three distinct and separate methods to modify the FVIII or FIX protein to allow for a longer duration of effective factor levels in the blood. The first longer acting FIX product called Alprolix was licenced in the USA in March by Biogen, and the first longer acting FVIII product called Eloctate was licenced in June also by Biogen. Further longer acting products will be licenced in the coming months and years. In Europe, there will be a delay in licencing of these new products due to the requirements of the clinical trial guidelines of the European Medicines Agency (EMA). These guidelines mandate that clinical trials in previously treated children must be completed prior to licencing of the products for use in adults, in contrast to the USA and other countries outside the EU where products can be licenced for use in adults, once the clinical trial of the products in previously treated children has commenced. The motivation of the EMA was to ensure that new products are not used to treat children "off label" (outside the licenced parameters) before they are specifically licenced for use in children. The practical result of these guidelines is a 2 to 3 year delay in the licencing of these new products in the EU compared to the rest of the world. It is likely that the first longer acting FVIII product will be licenced in the EU in late 2015 or early 2016 with the first longer acting FIX being licenced shortly thereafter.



Longer acting factor concentrates for haemophilia are on the horizon.

The new products have led to a re-examination of the utilisation of the current generation of products and a re-evaluation of current treatment regimes and attitudes. With current treatment, with prophylaxis three times a week for FVIII and twice a week for FIX, the relative importance of treatment peaks at those intervals in addition to the trough level of 1% (which has always been the main objective of prophylaxis - to keep factor levels above 1% at all times to prevent spontaneous bleeding episodes) are being re-examined. Longer acting factors hold out the promise of maintaining a trough level of 1% with less frequent infusions, but by definition this will also result in fewer peaks in factor levels. More frequent peaks in factor levels may be important in those who are very active (for example with sports). In addition, with both current treatments and the new longer acting products, the validity of a target trough level of 1% must be questioned. This trough level does not prevent all spontaneous bleeds or offer adequate protection to joints. It will certainly not prevent bleeds in joints which have already suffered substantial damage in the past (target joints) or protect them from further bleeding episodes or damage. There is substantial clinical evidence that a trough level of 3% would offer much better protection to joints and result in a substantially lower annual bleed rate in many people with haemophilia. Individualisation of treatment based on pharmacokinetics, individual bleeding pattern, degree of pre-existing joint damage and activity levels, is almost certainly the route to optimum treatment in the future.



Studies in pharmacokinetics are ongoing, this allows haemophilia care to be designed for the individual.



Currently, the national centre for hereditary coagulation

disorders in St. James's are measuring the individual pharmacokinetic profile of people with severe FVIII deficiency. This will allow for tailored treatment suitable for each individual. The companies who manufacture and market the current generation of recombinant factor concentrates will have to respond imaginatively to offer therapeutic choices when the longer acting factor concentrates come to the market in Ireland. The entire business model may have to change. We look forward to these developments with profound anticipation as we enter an era where the worst consequences of haemophilia, bleeding episodes, may be on the verge of being minimised and currently unforeseen improvements in quality of life seem possible.

We are at the beginning of a very exciting time for the treatment of haemophilia and for the treatment of hepatitis C. The revolution in the treatment of hepatitis C will be even more profound. In the current edition of "Positive News", the Society's magazine on hepatitis C and HIV, we report in detail on the proceedings from the European Association for the Study of the Liver conference. A veritable abundance of new therapies for hepatitis C are under development and several are already licenced in Europe. These new therapies offer the realistic hope of a cure for all with hepatitis C. The current triple therapy regimes have been successful in approximately 75-80% of people with haemophilia. However, for several people with haemophilia, these therapies have failed and for the majority the course of treatment was long and harsh with many side effects. The majority of people with haemophilia treated had to undergo 48 weeks of treatment. The new therapies offer a 90-100% cure rate with a treatment regime of 12-24 weeks with a very significant reduction in side effects. There are many new drugs available and becoming available in different combinations capable of treating even the most clinically difficult to treat patients, those who are pre liver transplant or post liver transplant with recurring hepatitis C or those with advanced cirrhosis. HIV co-infection does not appear to be a barrier to success with these new treatments. The therapeutic future looks very promising for our members who still live with chronic hepatitis C infection or HIV and hepatitis C co-infection.



The latest edition of Positive News.

While clinical developments look very promising, the main obstacle we may face will be economic. These new treatments will be expensive. We are working to try to minimise this in dialogue with the companies who provide these products and we will be working both with and on the health authorities to ensure that people with haemophilia have continued access to the safest and most effective therapies for haemophilia and for hepatitis C in the future.

Brian O'Mahony
Chief Executive

Brian O'Mahony Award - Call for Nominations

At the AGM & Conference of the I.H.S. in March 2012, it was announced that an award would be considered and presented on an annual basis to an individual who, in the opinion of the Society, has made an outstanding contribution to haemophilia care in Ireland. The Award is in the name of Brian O'Mahony in recognition of his 30 year contribution to the Society.

Nominations can be proposed by members or by the board of the Society. Current members of the Society board may not be nominated.

If you would like to nominate an individual who, in your view, has made an outstanding contribution to the Society, please send in your nomination and reasons for nominating the individual to Declan Noone (declan@haemophilia.ie).

Nominations should be received by Friday, September 26th.

From Then, Until Now.

Progress Report of IHS and VHA

Fiona Brennan and I travelled to Vietnam in early May to spend some time working with our twinning partners. After a very long day travelling we were met at the airport by the smiling face of Ms. Anh who kindly brought us to our hotel for some rest. Later in the evening we met Ms. Anh and Ms. Bing for some dinner. The food was delicious, fresh vegetables and a mixture of traditional Vietnamese food including an unfamiliar dish 'pigeon porridge'. It wasn't long until we were exhausted and back at the hotel for a much needed 8 hours sleep.

The following morning started early. We arrived at the hospital and were greeted by Professor Tri, Dr. Khanh, Dr. Van, and Dr. Mai. They had erected a huge banner outside the hospital welcoming us, and in the board room where we had our welcome meeting the Irish Flag was flying high. We chitchatted; exchanged gifts and Professor Tri thanked us for our visit.

We then went to our first workshop, but before it started, Dr. Mai informed us about the guidelines for diagnosis and treatment of haemophilia in Vietnam that the Ministry for Health had agreed on, just a few weeks previously which included approval for prophylaxis and home treatment. Dr. Mai explained that once a patient is registered at the treatment centre they will be assessed in relation to their condition, including an assessment of overall muscle function in their joints and physiotherapy. Oral health will be routinely checked every 6 months and additional factor will be made available for any surgical interventions required. Genetic counselling will be offered to family members and patients will be given a one month's supply of factor for home treatment.

At present people with haemophilia in Vietnam have to pay 20% of the cost of their treatment, with insurance paying the remaining 80%. This is impossible for most people. If the person is classified as poor, they do not have to pay but the threshold is very low. For example, if you own a television or some furniture you are not classified as being poor. However, for children up to 6 years of age treatment is covered 100%. Dr. Mai informed us that they have been pushing very hard on this situation over the past few months with the Ministry, and they are hoping to get some good news back very soon in relation to this. We were only an hour into our work and already it had been a worthwhile trip, hearing this excellent news!

We then discussed publications. We had been collaborating on a dental leaflet for adults and for children, which is nearly finalised. They are hoping to launch both these publications very soon. (Dr. Mai mentioned she recommends to her patients to see a dentist at least twice a year; however in Vietnam some dentists will not treat people with haemophilia because of a lack of training. Therefore, last year they put together a training workshop for dentists. Many dentists attended from around the country, and this has proved to be very useful). We also discussed 7 publications planned for the next few years. The organisation is also very keen to start looking at producing a magazine, and we will of course assist in any way we can with this. The plan is to launch the first magazine at the start of the Lunar year in January 2015.



IHS Staff member Fiona Brennan and IHS Administrator Debbie Greene arrive at the hospital in Vietnam for the first day of workshops. The VHA had a sign erected welcoming the IHS on their Twinning Visit.



The VHA and IHS collaborated on many workshops during the visit. Most importantly the IHS received updates on the improvements in haemophilia care in Vietnam.

After a very interesting lunch with Professor Tri in the hospital canteen, which consisted of pork, cabbage, rice, fruit and believe it or not silk worms (don't be shocked, yes, Fiona and I tried one and it didn't taste too bad), we met with the hospital accountant to discuss the accounting procedures involved in relation to the logistics of the I.H.S. donating funds to the organisation regarding the home adaptation programme, whereby handrails and various equipment will be put into members homes, and the employment programme. It was good to hear that they have clear guidelines and procedures in place for same. We agreed criteria and how we can support these projects, and the simplest way that this can be organised. Ms. Hanh and Ms. Anh have done a lot of research in relation to the home adaptation programme with suppliers and we can really see that this programme will kick off very well indeed. This discussion took up most of the afternoon and is now ready to be rolled out.



After a full day of workshops and meetings Professor Tri and Ms. Anh led the IHS staff on a cultural tour which included trips to the Ethinc Museum and a stop off at a food market.

The VHA were, as always, gracious hosts and we thank them for their hospitality.



Before dinner we took a quick visit to the Ethnic Museum which was really interesting, followed by a visit to a food market, followed by dinner with Professor Tri and Ms. Anh in our favourite fish restaurant (you would think we were locals!) in the city, followed by ice cream in a café overlooking the beautiful lake.

We started early again the following day with a meeting on the employment project. Dr. Mai had invited some of those members who had applied for a grant to this discussion. It is hoped that by giving some people with haemophilia a small grant to help them start up their own business, that it will encourage them to have appropriate jobs to suit their specific needs, and will make more jobs in the long run. We had already agreed criteria and assisted the organisation with application forms etc. however Professor Tri and Dr. Khanh felt that perhaps a little more research is needed on this project as maybe it would be more effective if small groups were supported instead of individuals. We agreed with this suggestion, and this will be looked at in the coming months.

In the afternoon we discussed the starting up and development of English classes for people with haemophilia and some staff. We agreed to financially support some of this project. The aim is to give people with haemophilia and some of the staff at the hospital the opportunity to learn basic English. We discussed the practicalities of this project and it was good to see the organisation wanting to take ownership of this project in relation to sourcing members, tutors, and organising the logistics of the project. Dr. Mai and her colleagues had sent out a survey, and as the response was not as good as we thought, it was agreed that they would discuss this project further in the coming months. Everyone agreed that if this project goes ahead, 100% commitment would be needed. There is definitely an enthusiastic interest in these classes, but it just needs to be looked at a little more before it is finalised.

We left the following day but before that and after a great few days working with our Vietnamese friends and colleagues it was time to conclude and finish up our discussions. During our conclusion meeting a final agreement was reached in relation to the publication schedule and the first magazine for the organisation which Professor Tri is very keen to get started. The home adaptation programme which the I.H.S will support financially through a €5,000

donation is now firmly agreed. However Professor Tri made a very valid point that this needs to be rolled out all over the country and not just in Hanoi. We agreed with this 100%. The employment project is now going to be researched a little more before it is rolled out, as is the English classes programme.

We managed to get through a lot of work in very little time thanks to the efficiency of the organisation and keeping to the schedule. It is always a pleasure to visit our twinning partners not to mention the humbling feeling we always have leaving this beautiful country. Listening to stories from people with haemophilia here can be very hard but now there is great hope for the future for people with haemophilia. Our visits to Vietnam never disappoint, and even though our twinning programme with Vietnam finishes this year, we have agreed that our work will continue for the foreseeable future.

Debbie Greene
Administrator

The IHS and VHA have worked closely together over the past four years and at the 2014 WFH Congress, they were awarded Twin of The Year, (right).

The organisations will continue the Twinning Programme for another 2 years.



The main goal of both organisations in relation to the twinning programme was to improve the strength and organisation of the haemophilia community in Vietnam and the knowledge of the haemophilia communities in both Vietnam and Ireland. It was the hope that after the twinning programme, the necessary knowledge; skills and experience would be developed to contribute to improving haemophilia care in Vietnam and that the Irish haemophilia community would gain a greater understanding into haemophilia care globally.

Vietnam has over 89 million inhabitants. It would be expected for them to have approximately 7,000 people with haemophilia, but in 2010 only 1,600 had been diagnosed. Many of those with severe haemophilia may have died without proper access to treatment. The main treatment centres are in Hanoi – National Institute of Haematology and Blood Transfusion and Ho Chi Minh - Blood Transfusion Hospital, Nhi Dong hospital and Cho Ray hospital, there is also a hospital in the city of Hue which can treat patients with haemophilia.

In 2006, the Government started to provide some cover for haemophilia treatment under their social insurance scheme. Under this scheme, the Government pay some of the cost and individuals are liable for the balance. For children under 6 years of age the government will cover 100% of the cost of treatment. Those certified to be poor, also get 100% of their treatment costs, although it is



A new haemophilia hospital ward.

Due to overcrowding in the hospital, patients are often two to a bed. In a country where haemophilia care is so expensive, many patients endure lengthy hospital stays.

difficult to achieve this status.

In some cases where there is 95% reimbursement for poorer people, the additional 5% can be waived.

Since 2011 the Irish Haemophilia Society have completed workshops and training with the VHA on strategic planning with regards to board structure and selection, governance, budget and accounts, publications, fundraising, volunteer training, workshops on how to live positively with haemophilia, chapter leadership and many more. In total to date the Irish Haemophilia Society members have raised €2,467 for the VHA.



Since the Twinning Programme between the IHS and VHA began in 2010, the VHA have recruited over 20 volunteers who help the organisation provide services and supports to its members by taking part in hospital visits.



There are so many areas where the VHA are making incredible progress in such a short space of time. In Hanoi they now have over 20 volunteers who work regularly visiting patients and playing games with children who are in-patients in the hospital. Their new volunteer recruitment drive and the training, which was developed in conjunction with the IHS, was selected as an example at the National Member Organisation training in Melbourne this year.

The VHA now have a new governing body made up of 11 members including clinician's, patients with haemophilia and parents of children with haemophilia. They now have a structured governance procedure in place and the ability to share their experience from various demographics, which will hopefully broaden the scope of their work. The VHA now also have developed two new chapters (branches) which are doing great work in their own locations of Hai Phong and Ho Chi Minh City. This is hugely beneficial as people who cannot get to Hanoi now have a place to go if they have concerns or need advice. The two chapters are actively trying to reach out to members in their location and connect patients together. There are now also 3 new clubs which encourage interaction between members locally. These clubs in Hung Yen, Hai Duong and Thai Binh are proving to be really successful with 3 peer groups now established – a youth patient group, a father patient group and a mother patient group. These groups meet regularly and help one another with finding appropriate jobs, identifying new patients, schooling and living positively with a bleeding disorder in Vietnam.

In relation to publications, it is hoped that three publications will be published by the VHA in 2014 – these will include Dental, Genetic Testing and von Willebrands, which the VHA have identified as their priority. There are also 5 other publications which they will work on during the course of 2015. During 2015 the VHA are also planning to publish a newsletter for patients with haemophilia with information on health care and treatment, how to live with haemophilia and the activities of their chapters and clubs.

Most importantly however, in May 2014 the Ministry of Health in Vietnam approved the use of prophylaxis and home treatment. Although the situation regarding factor use has not really improved very much over the past number of years, this will improve the situation very quickly. The organisation has worked so hard to change the situation. We were also informed that they are waiting on a decision from the Ministry of Health regarding co-payment in relation to those who cannot afford to pay the 5% for the cost of factor; they are hoping it will be good news.

Members' Conference

Date: October 10th - 12th 2014

Venue: Carlton Shearwater Hotel,
Ballinasloe,
Co. Galway

PRELIMINARY PROGRAMME

Friday 10th October

6.00pm – 7.30pm Registration

Saturday 11th October

9.30am – 10.00am Registration

10.00am – 10.30am Introduction to Self-Management Course

10.30am – 11.30am Debate - Are women with bleeding disorders relatively neglected in comparison to men with bleeding disorders?

11.30am – 12.00pm Tea & Coffee Break

12.00pm – 1.30pm Longer Acting Factor; Future treatment options

1.30pm – 2.30pm Lunch

2.30pm – 4.30pm Interactive Workshop - Is haemophilia a disability?

4.30pm – 5.00pm 20:20 Vision – Part 1

7.15pm Dinner & Quiz

Sunday 12th October

10.00am – 10.45am 20:20 Vision – Part 2

10.45am – 12.45pm The Crystal Maze – Full group activity

1.00pm Lunch



***Attend the conference,
Join the community!***



*We hope to see
you there!*

Calendar of Events

JULY

Dates: 18th - 20th July
Event: Hepatitis C / HCV Conference
Venue: Pembroke Hotel, Co. Kilkenny

AUGUST

Dates: 15th - 17th August
Event: PEP Conference
Venue: Clarion Hotel Liffey Valley, Dublin



SEPTEMBER

Dates: 27th & 28th September
Event: Carriers' Conference
Venue: Clarion Hotel Liffey Valley, Dublin

** See page 2 for more details.*



OCTOBER

Dates: 10th - 12th October
Event: Members' Conference
Venue: Carlton Shearwater Hotel, Ballinasloe, Co. Galway

** See page 10 for more details.*



OCTOBER

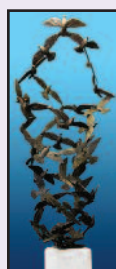
Dates: 30th October - 2nd November
Event: Haemophilia Camp
Venue: Barretstown

** See page 14 for more details.*



NOVEMBER

Dates: 2nd November
Event: Memorial Service
Venue: IHS Office, New Street, Dublin 8



Cubs Club

Welcome to
Cubs Club!

What is a blood clot?

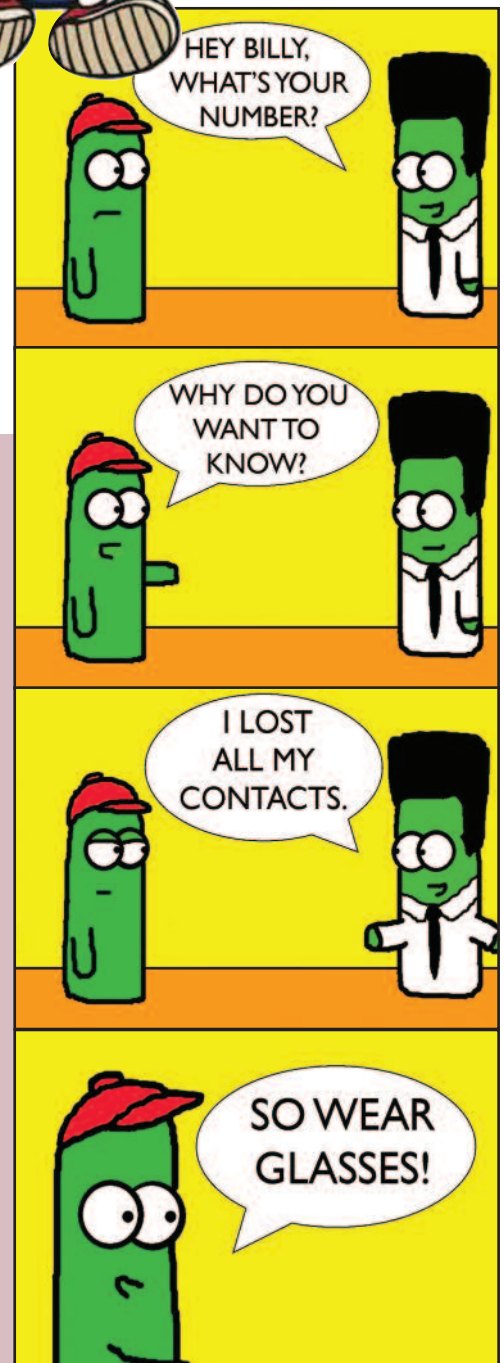
Your blood is made up of different kinds of cells but there are also 13 clotting factors in your blood and when you get a cut they all work together to form a clot to stop you bleeding.

Clotting factors work together like a chain linking one factor to another in the same order every time - all of the factors are needed to form a clot. If you have haemophilia, either factor 8 or factor 9 is missing. Without one of these factors the chain cannot finish and make a blood clot. That's why your Mam or Dad give you the factor you are missing to help make your blood clot and stop bleeding.



The Slobs

by Conor Birkett



SPOT
THE
D
I
F
F
E
R
E
N
C
E

Picture 1:



Picture 2:



Above, are two pictures of Captain Clot.

Can you spot the 5 differences between the two pictures?

Find out the correct answers on
www.haemophilia.ie, but ask
your parents permission!



Do you have a computer at home?

Do you use a computer in school?

Do you have a smart phone or use your parent's tablet?

Then you have probably used the internet a lot! The internet can be great for doing homework, school projects and for playing games but why do you think you need to be careful online?

What could be dangerous online?

Accepting people online to become your friend that you do not know.

Telling people that you do not know personal information e.g. where you live or go to school.

Some people use the internet to bully other people.

Why should I think before I post something?

It's searchable: Anyone, anytime, anywhere can find it.

It's forever: Anyone can find it today, tomorrow, 30 years from now.

It can be copied: If someone finds it, they can copy it, share it and change it

How can I stay safe online?

Only accept people that you know as friends.

Stay on websites that you know and are allowed to use.

Know how to 'escape' - hit control-alt-delete if a website will not allow you to leave it.

If something or someone online makes you feel uncomfortable, you have the right to not respond or to delete a post.

What should I do if something goes wrong?

It's simple:

If you have a bad experience on the Internet, or if you feel uncomfortable with any situation don't be afraid to tell someone.

Talk to an adult you trust who can help!



There are lots of really good things about using the internet, you can learn lots of new and exciting things, you can play games with your friends, you can watch cartoons and movies!

Don't forget you can also visit www.haemophilia.ie to check out the Fun Zone section for kids!

Barretstown

What do you think of when you hear of Barretstown? We asked the children who attended the IHS Parents Conference and they said; friends, fun, food, games, laughter, smiles, adventure and friendship.

Barretstown is a specially designed camp that provides programmes and activities of fun, adventure and support for children with medical conditions. Barretstown also provide family camps where parents and children can take some time out of the routine of daily family life to relax and have fun together in a safe and caring environment. All of the children and families come to Barretstown free of charge. Everything, including accommodation, food, and transport are provided at no cost to families. Barretstown is supported by donations and the fundraising efforts of corporate supporters, individuals and community groups.



Barretstown is a great opportunity for the young members of the I.H.S who are affected by haemophilia and related bleeding disorders, either directly or by having a sibling with a bleeding disorder. It is a safe, caring and encouraging environment which plays to everyone's strengths, bringing out the best and happiest version of each person who takes part in camps. It is a place where a child has the opportunity to be around other children going through similar situations, whether that's a camp for families, siblings or for children with bleeding disorders.

Barretstown base their camp programmes and activities on a Therapeutic Recreation programme which allows campers to experience a fun, activity based process of challenge, success, reflection and discovery. Children take part in entertaining, exciting challenges; they experience success in overcoming these challenges; reflect on their experiences and make discoveries about their confidence, self-esteem, independence and friendships. So although their medical condition may affect certain aspects of their lives, they can still get the most out of their childhood. Most importantly however, every step in the process is designed to be fun!



The programmes are jam packed with activities such as fishing, archery, theatre, high ropes, horse riding and canoeing to name but a few – there is never a dull moment for the campers and definitely no time to feel homesick!

As if that wasn't enough we have been given some very exciting news from Barretstown! This year, Barretstown are hosting an exclusive camp for children with haemophilia and related bleeding disorders from Ireland and the UK. The camp will begin on the 30th of October – 2nd November and is open to children aged 7 – 17 years with a bleeding disorder. The camp will include all of the regular Barretstown favourites; food, activities and an incredible amount of fun. This is a fantastic opportunity to have been given by Barretstown and we are very lucky to have been picked to benefit from this exclusive camp. It will give the children who know each other from our weekends, or who have met in Crumlin or Barretstown previously, to have another brilliant weekend of adventure together.

However, it will also be so beneficial for some children who may not know other children with haemophilia. It is an excellent option for parents to send their children to Barretstown for the first time, not only will some of their friends from our weekends be there but Anne Duffy and I are volunteering with Barretstown that weekend so there will be lots of familiar and friendly faces around!

I would encourage as many parents as possible to take advantage of this fantastic opportunity. As always Barretstown is fully supported by a medical team so you can be assured that your children will be in the safest of hands.

If you have any queries in relation to Barretstown or more specifically, the haemophilia camp, please do not hesitate to contact me on 01 657 9900 or you can email fiona@haemophilia.ie

Fiona Brennan



Reflection on the IHS Parents Conference

As a father of a child with severe haemophilia, attending an Irish Haemophilia Society weekend is greatly anticipated by all members of our family. As a parent I attend three weekends a year with the Society; the AGM, Parents Conference and Members' Conference, and each weekend brings something different to the adult programme.

On the Friday we arrive at the hotel which is always of the highest quality. After check in there is great excitement by the children to find the room, with the winner choosing their bed location. We organise ourselves, and head to the pool for a family swim, where we bump into other members, and their children. Following the swimming frenzy, we register for our weekend, followed by a sit down to have something to eat and family time.

We meet up with members, and individuals who have bleeding disorders travelling from all over the country at the hotel, as children and adults rekindle strong friendships formed over many previous weekends. There is an incredible sense of comradeship and bonding between the parents and older members alike, and the sense of belonging experienced when greeted by Debbie, Anne, Nuala, Declan, Brian, Fiona and the many volunteers involved with our family at registration, and throughout the weekend.

On Saturday morning the excitement begins as swimwear and caps are thrown into a bag. There are high jinks, as we rush to get breakfast which is the highlight of my weekend. The arrival to our table may be delayed by excited children, or parents greeting and hugging friends not seen since the last weekend. Many a time tables are pushed together, to make way for children excitedly catching up with the latest news, and the Daddies discussing football.

With the children signed into the Kidlink programme a sense of calm descends, and the adults move on to their activities. The morning and afternoon progress with a variety of talks and focus groups discussing various topics related to bleeding disorders, and other relative topics.



166 adults and children attended the Parents Conference.

The programme began on Saturday with an Open Forum with Crumlin. This served as a great opportunity to ask questions which you may feel uncomfortable asking directly. However, I know it can be just as beneficial listening to other people ask their questions.

Although no one can deny the educational value of topics discussed at the meetings, as a father it is at the coffee break, where the parents and members meet at the interval, that I find most beneficial.



Bridin Brady and Carol Carr from Crumlin and Anne Duffy during a role play for the session on Communication.

With the coffee break over it was time to return to the programme. The afternoon sessions included a workshop on "Communicating with Health Care Workers", which saw IHS counsellor Anne Duffy take on the role of a bold child and moody teenager in some role play exercises! The workshop led to some interesting discussion amongst the group about how to keep young children entertained at appointments and engage teenagers to become involved in their treatment and care.

Following lunch there was an introduction to the Parents Empowering Parents (PEP) Programme, an Infusion Workshop and Mothers' and Fathers' Workshops. Although I have already taken part in the PEP Programme I attended the session to encourage other fathers to become involved.

However, I was happy to take a back seat in the infusion workshop, as Mary and Eibhlin looked for a volunteer to demonstrate an infusion. A huge well done to the brave mother who stepped up for the role. Not to be outdone during the workshop, Mary Kavanagh then demonstrated self infusion. Questions and comments were encouraged throughout the session which ended with parents dividing into groups for training on identifying veins, positioning the needle and set up for infusions.



Eibhlin Mc Laughlin from Crumlin demonstrates an infusion during the Infusion workshop.

All the sessions were well attended, which was great to see.

Unlike some of the other IHS Conferences, the Parents Conference programme is made up of more workshops than talks. This, in my opinion, works well because it allows parents to interact and share their experiences.

The knowledge that mothers, fathers and grandparents share with each other is the true wealth of the Society. Lived experiences help to educate all members that haemophilia care has improved, and continues to improve all the time. Coping mechanisms and similar experiences are shared. This produces a sense of not being alone for parents who may be at the beginning of understanding and unable to see an end to their current situation. In my opinion this is the gem of the weekend, and symbolic of what the Irish Haemophilia Society is about, one big family working towards a common goal.

Saturday evening is let your hair down time, quizzes, family fortunes, dancing, raffle are all part of a fun Gala evening. Sitting at whatever table you like, is a good opportunity to meet new people and forge new friendships. The craic is ongoing all through the night. From young to old new groups of friends can be found at times huddled together learning lullaby songs from other kids or trying out the latest Nintendo or iPad game with a good night ensured to all.



There was murder on the dancefloor after the Saturday night dinner as children and parents alike danced the night away. After a full day of activities the children showed no signs of tiredness as they outdanced the adults!

The Sunday comes too fast, with the usual dash to breakfast. The children are both excited for the day's events and a little bit sad for its end. Following registration the children attend Kidlink and the adults clear their room, check out, and move to attend workshops, and meetings.

The adult programme on Sunday began with a session on IT for parents. IHS staff member Nuala McAuley led the session which was eye opening, scary and informative all at once. There were lots of parents taking notes in relation to privacy settings, game console controls and web browser advice. Carol Carr, Social Worker OLCCHC, facilitated a session on siblings. As a father of two children, one son with haemophilia and a daughter, I am always interested to hear about issues relating to siblings. Bleeding disorders can effect the whole family not just the child with, Carol explained very well the need to listen and communicate with all members of the family. The programme ended as it began, with an Open Forum, but this time with Dr. Beatrice Nolan.

Before we knew it we were collecting the kids from group and heading to lunch. One by one sad farewells were made, with some tears by the children for friends who live too far to visit. Yet the bonds made are lifelong friendships and only a phone call away if you have a need. Once in the car heading for home, the kids regaled us with stories of the weekend and how much fun they had, which was evident by how tired and satisfied they were once home.

Although my son's haemophilia is new to our family tree, it has been an incredible learning experience. I have met some wonderful courageous people who have inspired me to embrace the experience and promote it as an adventure. As a family we have evolved and embraced haemophilia as our story, and part of my son. Haemophilia is what he has, not who he is. My name is Anthony O'Connor I have a son with haemophilia, my family and I are members of the Irish Haemophilia Society.

Anthony O'Connor



Cool Kids at the 2014 Parents Conference



Top (L to R): The Kidlink & Youth Group enjoyed a trip to Dublin Zoo! IHS Creche Leader Claire Neill joining in with the fun & games!

Middle (L to R): Mary Kavanagh from Crumlin helping the Cubs Club find their veins.

The Kidlink and Youth Group had so much fun at Dublin Zoo, they wished the weekend would never end.

Bottom (L to R): With over 70 children in attendance, the creche was divided into 2 age groups. Double the trouble, but double the fun!

Mini Marathon 2014

The Flora Women's Mini Marathon is the biggest all female event of its kind in the world. It has grown from strength to strength since the first race took place in 1983 with almost 9,000 participants to just over 40,000 participants this year, which is amazing. The renowned success of this event is a tribute to the amazing women of Ireland who fundraise year in and year out for so many worthy charities.

We had a great response to this year's Mini Marathon and I just want to thank everyone for taking part and raising funds for the I.H.S. An event like this is so important, not only to raise funds but to raise awareness of haemophilia and other bleeding disorders.

The race took place on Monday 2nd June at 2pm. This year a new course had been put in place by the organisers as a lot of the city is under construction for the new Luas line. We had our usual room in Buswells Hotel on the day for everyone to meet up before the race to collect their green I.H.S. t-shirts before the race and again after the race for some well deserved refreshments and a bit of banter.

The winner of the race may have completed it in 37 minutes but our very own Ellie Heffernan (aka Supermom) completed the race in just over 51 minutes. Our youngest participant was Dara Dowling, aged 15 years. I asked Dara what made her decide to take part this year and she said she had been with us in Buswells Hotel on the day of the Mini Marathon last year and when she watched everyone heading off, she decided she wanted to do the race herself this year. So let's hope this is the first of many for Dara.



Above left: IHS Chairperson Traci Marshall Dowling, with her daughter and the youngest member of Team IHS, Dara Dowling.

For some people it was their first time to take part in the race but our annual supporter Jacqueline Reid, has only missed one race since 1985, which is a great achievement. All our lovely ladies did great on the day, congratulations to you all. We even had two 'ladies' in full female attire and high heels taking part. Thanks Niall and Tim for your support, you both looked only gorgeous!

Above right: The longest serving member of Team IHS, Jacqueline Reid with 2014 Team IHS Mini Marathon Victor, Ellie Heffernan

The atmosphere on the day was fantastic and even though I couldn't take part this year as I was holding the fort in Buswells Hotel with Debbie, we both really enjoyed catching up with old and new friends. There were lots of new faces this year, which is great to see and it was obvious that everyone had a great day and you can't help but get caught up in the spirit of things. Many of our ladies finished off the day with a lovely meal and I know one or two of them enjoyed a well-deserved cocktail to round their day off.



Just some of the 37 "women" who took part in the 2014 Mini Marathon, GO TEAM IHS!

I hope to see you all again next year, don't forget the Mini Marathon is held every June bank holiday Monday, so it's an easy date to remember, put it in your diary for next year.

Nina Storey



Educational Grants 2014

Applications are now invited for the 2014 Educational Grants. You can apply online on our website www.haemophilia.ie, or you can also download the application forms from our website, complete them and post them into the office.

There are two categories of grants available as follows:
Educational Grants for people with haemophilia or related bleeding disorders.
Educational Grants for immediate family members.

The grants are broken down as follows:

Maureen & Jack Downey Educational Grant

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

* * **(Called the Father Paddy McGrath Educational Grant)**

Margaret King Educational Grant

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

What is the criteria for applying?

The criteria for the Maureen & Jack Downey Educational Grant

This grant is made available to a person with haemophilia or related bleeding disorder, who has been accepted on a post second level educational course. The person applying must be registered at the National Centre for Hereditary Coagulation Disorders at St. James's Hospital in Dublin.

The criteria for the Margaret King Educational Grant

This grant is made available to an immediate family member of a person with haemophilia or related bleeding disorder be it a spouse, son, daughter, sister, brother, mother or father. The person applying must be accepted on a post second level educational course, and the person with the bleeding disorder must be registered at the National Centre for Hereditary Coagulation Disorders at St. James's Hospital in Dublin.



THE CLOSING DATE FOR APPLICATIONS IS FRIDAY 19th SEPTEMBER 2014.

Once the closing date arrives and all the applications are received a sub group of three people from the executive board (which cannot include anyone with a family member applying for any of the grants) meet to consider and score the applications, and make recommendations to the rest of the executive board regarding recipients. The successful applicants are then notified at the end of October by letter.

Remember, you can apply every year, even if you have already been successful. However, it is important to note that even if you are eligible to apply for both grants you can only apply for one of them.



TIPS FOR APPLYING

- 1. Be thorough with your application**
- 2. Ask for help**
- 3. Do a spell check**
- 4. Apply on time**
- 5. Answer all the questions**

Take some time to complete your application, as the more complete and detailed your application is, the higher your chance is of being successful. And please do fill out the application yourself! Good luck to everyone who applies.

Debbie Greene
Administrator

The Downey Duo!

As the application process for Educational Grants draws near, haemophilia.ie spoke to the family of Maureen and Jack Downey to find out more about the first family of the Irish Haemophilia Society.

They say opposites attract and perhaps there has never been a truer example of this than Maureen and Jack Downey. Maureen was a 5 foot outgoing, charitable, risk taker with great faith. While Jack was a 6 foot 1" shy, supportive business man. The differences in their personalities (and height) served as the perfect combination as together they made a formidable team.

Jack Downey was the eldest of a large family. When his father passed away suddenly, Jack, who was still quite young himself, assumed the role as man of the house and helped his mother raise his siblings and keep the household running as in those days widows received very little assistance from the state.

Maureen was a spirited woman. A hairdresser by profession, she believed in showing her best face to the world no matter what was going on in her life.

Maureen and Jack began dating when they were 16, but did not marry until they were in their late 20's, Miriam recounts;

"Mam always said Dad had two families, because his siblings were like his children as he had helped raise them. As was custom in the 1950's, a couple had to have a house before they could be married. Dad had to wait until his siblings were grown up before he could get married, which is why it was over 10 years before our parents wed."



Jack and Maureen Downey, opposites in height and character, but together an incredible team.

Married in 1954, Maureen and Jack welcomed their first child, into the world in 1955, a son called Aidan. They went on to have two more children, a daughter named Miriam and another son named Pat. However, their family was not the only aspect of their life which was growing, as Jack's business went from strength to strength and soon he had several garages to his empire.

When she married, Maureen gave up her career to become a stay at home wife and mother, as was customary for women at the time. A creative and caring individual, Maureen was soon looking after others as well as her family as she began a meals on wheels service for the elderly living in the city centre which included providing dinners on Christmas day, something which the whole family became involved in.

"We never had Christmas Day dinner at home, we would work out of the kitchen in Temple Street Children's hospital making food and deliver food to the elderly." Miriam said.

"I would often go with Mam when she would do her rounds visiting the old people. A lesson she thought me, was take people as you find them and it has stuck with me all this time. She would always tell us to accept anything we were offered as these people had very little, but were sharing with us what they could." Pat continued.

The couple understood boom and bust and were very aware of others financial state, as well as their own families.

As life was coming together for the Downey's, Pat was diagnosed with haemophilia at 1 years of age. The diagnosis was a shock for the family and indeed was not an easy time, as Pat recalls;

"My mother brought me to Temple Street Hospital with bruising. Once there, the Reverend Mother took me in, told my mother she would never see me again"

and closed the door on her. They thought Mam had hurt me. Luckily, our GP, who was also a family friend explained the situation to the hospital and cleared everything up, but my mother was shaken."

Not only was there was no family history of haemophilia, but there was little information about the condition available. Any information the family did receive came from the medical staff and was difficult to understand. So the Downey's set about finding other people with haemophilia and families of people with bleeding disorders to gather more information on the condition. Not an easy task, as Aidan explained;

"Haemophilia was seen as a blight on the family so people hid away."

Undeterred, the family spent weekends travelling to counties where they heard there was someone with a bleeding disorder.

"They would get a call from someone saying they heard there was person with haemophilia in a particular area, then we would all hop in the car to try and find them. Without a name they would knock on several doors trying to locate the person." Miriam recalls.

"I remember one of our Sunday outings it was near Slane, they had heard there might be a person with haemophilia in the area. They eventually found him, but what they had assumed would be a child with haemophilia was actually a man in his 30s who was totally bed ridden from bleeds into his joints. This visit shocked them, but left them more determined to try and get support and a voice for people with haemophilia in the future."

Although Maureen and Jack travelled the country seeking people with haemophilia, it was a chance meeting with fellow founding member Bill O'Sullivan as Aidan explained;

"Dad was working in the garage when Bill came in to get his car serviced. Dad noticed Bill had some trouble getting out of the car and asked what was wrong. Bill explained he had trouble with his joints due to haemophilia, and that was that."

From my time working in the Society, I was aware that Jack was a founding member, but had assumed Maureen played a supporting role. However, the truth is both were involved in setting up the organisation. In fact, it seems Maureen may have been the driving force behind it.



Jack Downey, left, with fellow founding member Bill O'Sullivan, whom he met by chance.

"They were a team. Dad supported Mam, he did things, but wouldn't be a front man" Pat explained.

"The irony is he did end up being the front man, people remember him" Miriam added.

I was keen to find out why they felt the organisation was needed and the answer was clear, people with haemophilia needed three things; support, information and their own ward. To supply these services to people an organisation was needed and so the Irish Haemophilia Society was born. However, a Society needs members. Luckily Jack kept records of all the families with haemophilia he had met on his travels. Links were developed with hospitals and soon word spread.

With the organisation established, Jack and Maureen took on different, but equally important roles. Jack continued his cross country adventures visiting people with haemophilia, on occasion even driving people from the country to the hospital in Dublin. A hospital stay for patients with haemophilia was a long, arduous experience, but for people from the country it was often lonely too as their families were at home. Jack often visited the wards with a supply of magazines and comics

as well as a friendly ear. However, his care for people with haemophilia extended beyond the hospital walls;

“Dad rented the CRC pool every Saturday for Pat and some of the other children with haemophilia. He would collect them on Saturday morning and drive them to the pool, Aidan and myself would tag along. Dad knew how important exercise was, especially swimming so it was good for us to have this time in the pool. However, there were no lessons it was just us having fun.” Miriam told me.

While Jack worked with the patients, Maureen was busying herself with fundraising, which, in a time when haemophilia was not discussed, must have been difficult. However, with sheer determination, Maureen organised various fundraisers from raffles to knit-in's, collections to club nights. Her giving nature came with specifications, as Pat explained;

“Mam was specific with her fundraisers, she would go to the hospital and ask them what they needed, then she would go with a list for where the money was to be spent. It sometimes meant she wasn't popular, but she was determined that the money would go where it was needed.”

However, the fundraising and support was nothing without a specific unit. Pat, Aidan and Miriam recall how their parents and the other founding members fought hard to get a haemophilia unit included in the redevelopment of St. James's Hospital. When I asked why the unit was important, the answers both saddened and shocked me as I discovered that children with haemophilia were put on surgical wards where people were recovering from surgery, in a bid to stop them moving around. How one ward was above the nurse's station and if they heard a patient out of bed they would order them back to bed immediately as they were afraid they would hurt themselves further. For children, who by nature are active and sociable, this must have been very tough. However, there was far worse situations as Pat explained;

“I was often on wards with leukaemia patients, this again was orchestrated to ensure we weren't too boisterous and would not get hurt. However, as a child this was very tough. Hospital stays lasted weeks”, Pat continued



Jack Downey, front row far left, pictured at a meeting on haemophilia with several board members and members of the Society in Cork. When the Society was established, they lobbied for a dedicated haemophilia unit in St. James's Hospital.

“After several stints in hospital you would recognise the signs that someone was dying, from the medication they were given to the physical condition of the patient. It got to a stage where I wouldn't interact with anyone else on the ward, because I knew it was only a matter of time before they died.”

Miriam explained further the impact this had on the family;

“Children were not allowed on the wards so often we would be left in the waiting room or outside the hospital and would wave to Pat through the window if we could. I remember Mam would be very upset having visited Pat, because he was just sitting in the corner zoned out and would not talk to people. It was tough for a parent to see their child in that situation and even harder to leave them there.”

Pat spoke about sitting his Inter Cert in hospital;

"I was put in a room by myself for my exams, but it was an isolation room where people were brought to die. Being left in a room knowing that was distressing."

I was keen to find out how haemophilia impacted on the family and how Maureen and Jack coped, which it turns out was exceptionally well. Pat was never discouraged from doing or taking part in any activity. The couple were insistent that Pat went to a main stream school, which was a struggle. However, they got their way and although Miriam had to miss yard time to sit with Pat, who was not allowed in the yard for fear of injury, he attended a main stream school. Aidan did recall his father's garage sponsoring the school, but for his son to receive a standard education, we were sure this was a small price to pay.

Aidan and Miriam were educated about haemophilia, as much as possible, growing up. Despite witnessing their brother having bad bleeds and often going weeks on end without seeing him because of hospital regulations, they do not feel haemophilia impacted too much on their lives. However, Miriam quickly remembered the reason she was not allowed a pet;

"We were told we could not have any pets until Patrick was old enough to protect himself, so I had to visit my dog at my uncle's house. However, when Pat was old enough, our house turned into a small zoo!"

To which Aidan recalled another incident;

"I loved cars when I was younger. If I got a present of a car or any toy which had sharp edges, it would discreetly disappear as it was a hazard for Pat."

A comical conversation followed in which we all agreed Pat owed Aidan a lot of extra presents!

When I asked Aidan, Pat and Miriam to describe their parents in one word, they chose survivors. From listening to the stories I could not think of a more apt word, because they dealt with, not only the issues in their own lives, but gave up their time to help others. Help, which I'm sure helped many other people survive through tough times.

It is apparent from talking to the three siblings that their parents were a great couple who wanted the best for their children. Pat's words from earlier stuck with me;

"A lesson Mam taught me was take people how you find them."



Jack and Maureen Downey, founding members of the Society and leading advocates for better haemophilia care in Ireland, will always be remembered fondly by the members of the Irish Haemophilia Society.

From my meeting with Maureen & Jack's children, I found them to be friendly, caring and charitable people. Traits which I have no doubt they inherited from their parents, who would be extremely proud of the people they have become. The stories I heard over the hours spent conversing were interesting, amusing and astonishing and there was simply too much to fit into one article, a book would be more appropriate. One thing is for certain, if a book is ever written on Maureen & Jack Downey, I will be first in line to buy it.

Nuala Mc Auley
Irish Haemophilia Society



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