Magazine of the Irish Haemophilia Society

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The Society at a Glance

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Edition: July 2015

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I.H.S. Services & Support

OCTOBER MEMBERS' CONFERENCE

FRIDAY 16TH - SUNDAY 18TH OCTOBER 2015
HERITAGE HOTEL, PORTLAOISE

PRELIMINARY PROGRAMME

Friday 16th October

18.00 – 19.30	*Registration*

Saturday 17th October

09.30 – 10.00	*Registration*
10.00 – 11.30	*Factor Concentrates - clinical & patient perspectives*
11.30 – 12.00	*Coffee break*
12.00 – 13.00	*New National Centre for Hereditary Coagulation Disorders*
13.00 – 14.00	*Lunch*
14.00 – 15.30	*Impact of haemophilia on family dynamics*
15.30 – 16.00	*Coffee break*
16.00 – 17.00	*Resilience and maintaining a positive attitude*

Sunday 18th October

10.00 – 11.15	*I.H.S. Carnival - Full group activity*
11.15 – 11.45	*Coffee break*
11.45 – 12.45	*Exercise for all – Full group activity*
12.45	*Collect children from programmes*
13.00	*Lunch*

Contact Details

Irish Haemophilia Society,
First Floor,
Cathedral Court,
New Street,
Dublin 8.

Phone: 01 6579900
Fax: 01 6579901

Email: info@haemophilia.ie

Website: www.haemophilia.ie

Editor: Debbie Greene

Executive Board:
Chairperson
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Chief Executive Officer
Brian O'Mahony

Administrator
Debbie Greene

Counsellor
Anne Duffy

Office Team
Nina Storey
Declan Noone
Fiona Brennan
Leah Cawley

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A Note from the Editor

Debbie Greene,
Administrator

Hello everyone,

Welcome to haemophilia.ie, the magazine of the Irish Haemophilia Society.

The annual Parents Conference took place recently in Athlone. The programme was really good and it was also great to have members of the I.H.S. along with healthcare professionals from OLCHC participating in the programme. This year was our biggest ever attendance. 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 20.

On the inside cover you will find a preliminary programme for the Members' Conference in October. Booking forms won't be going out until early September. It looks like it will be a good weekend so why not think about joining us.

In this quarter's CEO Report Brian O'Mahony updates us on the product selection board, the tender procurement systems for factor, hepatitis C treatment and a European conference that recently took place in Dublin on hepatitis C.

It's that time of year again when applications are open for our Educational Grants. You will find an article, snippets and all the information you need on pages 14, 15 & 16. The deadline for applications is Friday 25th September so there are no excuses you have plenty of time to apply.

The Ageing Conference went extremely well again this year and if you would like to read a report on this please go to page 10.

Brian O'Mahony recently travelled to Vietnam for a GAP (Global Alliance Programme) assessment visit with delegates from the World Federation of Hemophilia. If you would like to hear about what's happening with the twinning programme with Vietnam, you will find an update on page 18.

Don't forget members if you would like to sign up for our monthly electronic eZine magazine, contact Leah in the office on 01 6579900.

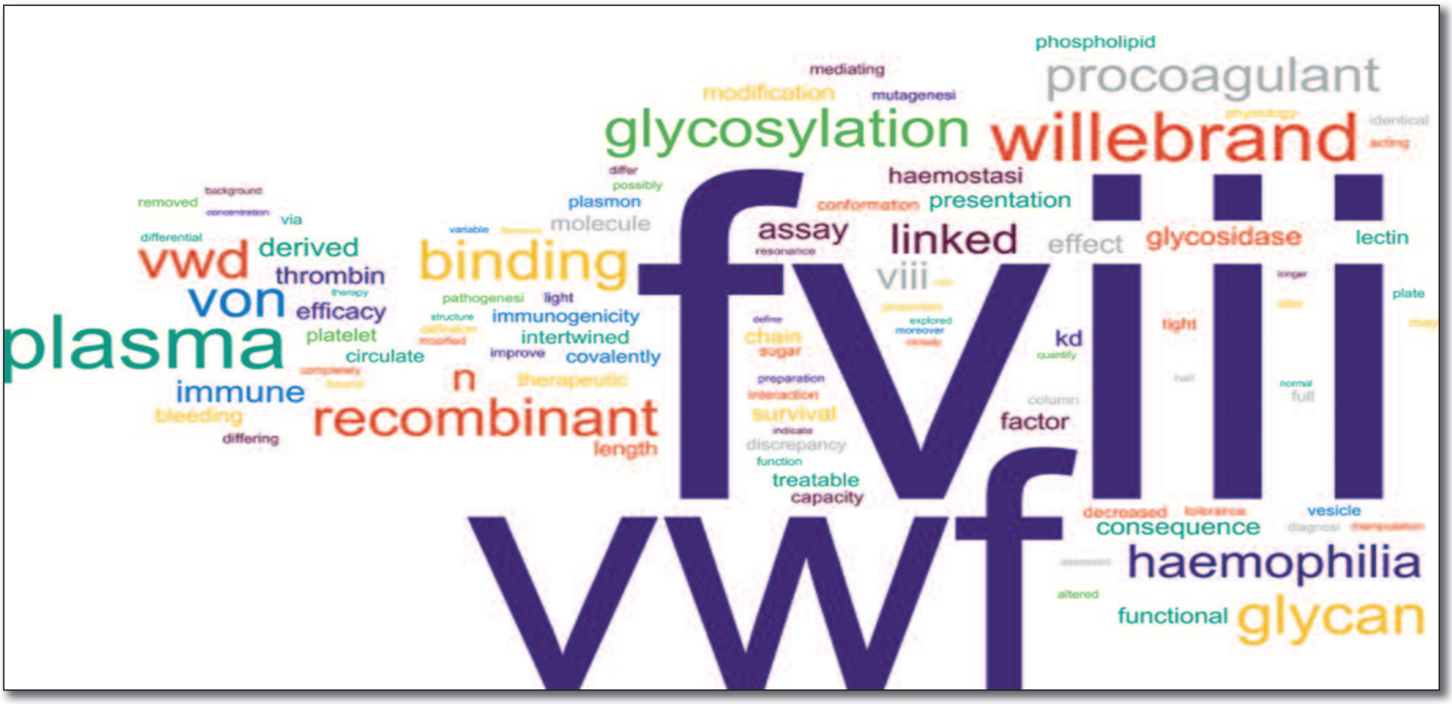
See you all at the next conference and enjoy the read.

CEO's Report

The Society has been formally involved in the tender and procurement process for factor concentrates since the establishment of the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) in 2003. The Society has two representatives on the HPSMAB and the board also includes the centre directors from the three comprehensive care centres in St. James's Hospital, Our Lady's Children's Hospital Crumlin and Cork University Hospital. The board is completed by the addition of representatives from the Department of Health, Health Service Executive, a blood transfusion expert, a virologist and a haemophilia nurse specialist. The work of the HPSMAB has resulted in the purchase of the safest and most efficacious factor concentrates for people with haemophilia, von Willebrands and related bleeding disorders over the course of the last 12 years. During that period of time usage of factor concentrates has increased dramatically in Ireland. In 2003 our factor VIII use per capita was about 3.7 and in 2014 it was 8.2 national units per capita. This effectively means that the usage of factor VIII in Ireland increased from about 15 million units per year to 36 million units per year between 2003 and 2015. This increase reflects more aggressive and optimal treatment of bleeding episodes; also the fact that all of the children and majority of adults are now optimally treated using prophylaxis and it also reflects a larger number of people living in Ireland with haemophilia. A very significant achievement of the HPSMAB has been the fact that despite the more than doubling of the use of factor VIII concentrate, the total cost of these medications has not increased. This is due to negotiation of lower unit prices and the elimination of any handling and distribution fees which were there in the past. Ireland now uses optimal treatment, has one of the highest per capita uses of factor VIII in Europe but also pays one of the lowest prices for factor VIII concentrate in Europe.

Brian O'Mahony,
Chief Executive

In late 2014, we carried out a survey of the tender procurement systems for factor concentrates in 38 European countries. The results of that survey have now been published in the 'Journal of Haemophilia'. Of the 38 countries, 19 of the countries use a tender process and 19 use an alternative procurement process. Clinicians and patient organisations are more involved in the tender process than in the alternative procurement process. In terms of involvement on tender boards, Ireland is one of only two European countries where the haemophilia organisation is formally involved in all aspects of the process. The other European country is Serbia. Portugal, Slovenia and the United Kingdom are involved only in the scientific and technical aspects of the process. Hungary, the Slovak Republic, Bosnia and Herzegovina, Ukraine and Moldova are informally involved or have observers status. Many other countries are not involved. The results of our survey clearly demonstrate that the involvement of the



haemophilia clinicians and the patient organisation representatives from the haemophilia societies are crucially important in getting the best outcome of the tender process. In countries where both the clinicians and the haemophilia organisation are involved in the tender process the prices paid for factor concentrates are significantly lower. I believe there are a number of reasons for this; clinicians on a national tender board tend to be among the leading haemophilia clinicians in their countries and experts in haemophilia; furthermore the haemophilia organisation representatives tend to be knowledgeable and committed to the best standards of haemophilia treatment. Where both the patient organisation and the clinicians are involved, the knowledge and judgement that they can collectively bring to the process usually means they show a better selection criteria initially and a better, more knowledge based analysis of these criteria. Including the clinicians and the patient organisations also demonstrates a commitment by government and the health authorities to an open, transparent and optimal process. These processes normally have a legal framework, written terms of reference, published call for tenders and a clear and precise decision framework. Having a National tender process also increases competition among the pharmaceutical companies. Clearly they will expect to get a lower unit cost for factor concentrates when you purchase for an entire country when compared to individual hospitals, health authorities or insurance companies purchasing. The costs have also been decreased in the last number of years by the change of contract holder from the Irish Blood Transfusion Service to St. James's Hospital. Handling fees which had previously been paid to the Irish Blood Transfusion Service are not paid to St. James's Hospital. These fees previously, had the effect of increasing the actual cost of haemophilia care.

Over the past number of years we have defined very clear selection criteria for recombinant factor concentrates and plasma derived factor concentrates for the treatment of von Willebrands. These selection criteria are never static and change each time we do a tender. The changes are reflective of the up-to-date scientific and clinical information available. We are now entering a new and more challenging era where

I.H.S. CEO Mr. Brian O'Mahony speaking during the EHC World Haemophilia Day Event in Dublin

Participants from the EHC World Haemophilia Day Event in Dublin with the Minister for Public Expenditure and Reform, Mr. Brendan Howlin

we are going to have to examine the possibility of purchasing longer acting factor concentrates at the same time as looking at the purchase of the current generation of recombinant factor concentrates. For the first time a unit of one factor concentrate will not be equivalent to the unit of another factor concentrate as the half-life will differ. We are currently in the process of examining options for future tenders for factor concentrates. In the past we have always compared a unit of one product with a unit of another product. In the future in addition to doing this we may also be looking at new and novel methods of pricing by comparisons such as, outcome based pricing based on defined annual bleed rates, the total cost of all the clotting factor requirements for the country, the average annual cost per patient with severe haemophilia or the cost of treating to a defined clotting level which would give greater protection from bleeding episodes. This is a very interesting time in haemophilia care, with the longer acting factor concentrates which we have been speaking about for some years likely to start becoming available on the European market later this year.

Our work on tenders and procurement in Europe was the subject of a World Haemophilia Day event organised by the European Haemophilia Consortium and hosted by the Irish Haemophilia Society in Dublin on April 16th, the day before World Haemophilia Day. The event was attended by a large number of doctors, patient organisations and regulators and during the event the participants had a photo call with the Minister for Public Expenditure and Reform, Mr. Brendan Howlin, outside government buildings.

The tender and procurement survey is also the subject of a European round table organised by the European Haemophilia Consortium which took place in Brussels on June 15th. The Society also organised a 'Coffee Morning' in the office on April 17th which was well attended and a stand in the main concourse of St. James's Hospital to promote awareness of haemophilia.

The Society have also been very active in relation to advocacy on hepatitis C treatment and at a recent National Haemophilia Council meeting with the Minister for Health Mr. Leo Varadkar. We stressed the need to have all people with haemophilia and others who were infected with hepatitis C through blood products supplied by the state treated as expeditiously as possible. The treatment landscape on hepatitis C is very exciting and innovative and the new national treatment programme has now commenced. In

Minister for Health, Mr. Leo Varadkar speaking at the conference for people with hepatitis C in Castleknock Hotel in Dublin

December 2014, the early access programme allowed treatment to be made available to those with decompensated cirrhosis or very severe liver disease by defined tentative criteria. People with haemophilia were treated under the early access programme. Treatment is now being rolled out under a multi euro national treatment programme to all people with hepatitis C and cirrhosis of the liver. We are working to ensure that people with haemophilia are fully informed and aware of the new treatments and are treated in a short time frame as is feasible. We have also been doubling our educational efforts in this regard. A new edition of 'Positive News' is currently being prepared and our annual conference on hepatitis C and HIV takes place later this year.

Professor Colm Bergin, Professor Suzanne Norris, Mr. Brian O'Mahony & Dr. Diarmuid Houlihan

In February of this year we organised a conference for people with hepatitis C, open to all groups in society. This conference was officially opened by the Minister for Health. In June we organised a hepatitis C conference for haemophilia organisations in Europe. This was organised and hosted by the Irish Haemophilia Society. It was an excellent conference which was attended by hepatologists, haematologists and patient organisation leaders from 27 European countries. Sixty five people in total attended the conference including several delegates from Ireland. The conference programme included an overview of haemophilia and hepatitis C in Europe, a very detailed update on current and future treatment options and workshops on access to treatment in several European countries. In terms of haemophilia and hepatitis C in Europe we have information on 29 countries. (Twenty countries in the E.U. and nine countries outside the E.U.) In these countries there are 41,142 people with haemophilia of whom 10,467 have hepatitis C. There are a further 29,585 people with von Willebrands disease of whom 491 have hepatitis C. In Ireland there are currently 140 people alive with hepatitis C infection with haemophilia. We estimate that 53 of these still require treatment. The other 87 have either been successfully treated or spontaneously cleared the virus. There are very large numbers of people with hepatitis C in other European countries. The U.K. has 1,298, Italy has 1,501 and France had 1,730. It is interesting to also put this scale of the hepatitis C problem in perspective in various European countries. Ireland has 12,365 with hepatitis C, Spain has 688,000 and Italy estimates that they have 1,000,000 people with hepatitis C. The availability of the new generation of hepatitis C treatments varies across Europe, as indeed do the prices being paid for these medications. Success rates with the new treatments are very high. We have seen good outcomes even in the people with the most advanced liver disease and all of the regimes now currently being marketed and licenced have a treatment success rate in excess of 90 per cent. At the conference Professor Mike Makris from Sheffield also alluded to the latest figures in the European Haemophilia Adverse Events Surveillance System (EUHASS) data demonstrated that the most turbulent cancer in people with haemophilia is liver cancer and the biggest single cause of death in people with haemophilia in Western Europe is now liver disease. This demonstrates the absolute imperative of clearing the hepatitis C virus in people with haemophilia. With the new treatments it should be entirely possible to now look at the eradication of hepatitis C in our community.

At this conference the latest report from the Health Protection Surveillance Centre on hepatitis C was previewed. This report is now being finalised and will have been published by the time this newsletter goes to print. This database looks at the progression of hepatitis C in people in Ireland who were infected by blood products supplied by the state. This includes people who were infected through anti D, blood transfusion, kidney dialysis or treatment for haemophilia. The database includes information on 1,320 individuals including 165 with haemophilia. There are still quite a few people with haemophilia who have not agreed to allow their information to be included in this database. We would urge them all to allow their information to be anonymously included in this database as it gives us an excellent source of information on the clinical progression of hepatitis C and in fact it is an important tool to advocate for access to the best treatment in the optimum time period for people with haemophilia. The database demonstrates as indeed did previous reports from the database that in people with haemophilia and those infected with blood transfusions the clinical progression of hepatitis C is more rapid and severe. A higher proportion of individuals have clinical signs of serious liver disease, cirrhosis or have developed liver cancer. It is interesting to know that FibroScans have replaced liver biopsies. For the vast majority of people it requires an ongoing monitoring process for liver disease. The new report covers the time period from 2009 – 2013. It shows a clear clinical progression of hepatitis C especially in people with haemophilia and those affected by blood transfusion. It also demonstrates one of the factors involved in more rapid progression of liver disease is high alcohol intake. Individuals who have high alcohol intake are at more than five times greater risk of having signs of serious liver disease and five times higher odds of having cirrhosis of the liver. On a positive note the database also shows that the progression of liver disease can be greatly reduced by successful treatment for hepatitis C and by lowering or ceasing alcohol intake.

Professor Colm Bergin speaking at the conference for people with hepatitis C

There has been a significant amount of discussion regarding hepatitis E over the past several months. Hepatitis E is not a new virus, it was discovered in the 1980's but it has only recently emerged as a potential cause of significant disease in developed countries. There are four genotypes of hepatitis E. Genotype 1 and 2 are human viruses and have caused outbreaks of hepatitis in the developing world through poor sanitation and contaminated water. Genotypes 3 and 4 are swine type viruses which infect pigs and other species of wild boar as well as human beings. Over the past decade we have seen increasing numbers of case of hepatitis E in wealthy countries. These tend to be genotype 3 which is associated with infection through consumption of under cooked pork. The vast majority of transmission of hepatitis E is through the consumption of under cooked pork but it is also transmitted through blood. The routine testing of our blood donors for hepatitis E is currently being considered. In terms of transmission through factor concentrates this is extremely unlikely as the viral inactivation methods are very effective against hepatitis E. However, it is a consideration in relation to the safety of blood and non-viral inactivated products such as plasma. Hepatitis E is resolved without any serious clinical consequences for the vast majority of people exposed to it. It does pose a particular risk to people who already have been compromised or for those who have had solid organs transplants such as liver transplants. People with haemophilia who have been infected with HIV in the past or those who have had liver transplants should ideally be tested for hepatitis E on regular basis, at least annually. If chronic hepatitis E is present in an individual it can be readily treated using ribavirin. It is also important to avoid eating under cooked pork products.

Brian O'Mahony

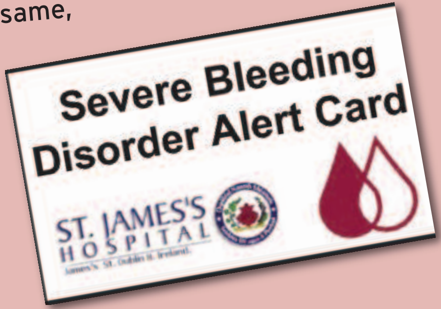
Outreach update

If any HAA Card holder would like to avail of a home visit or feels they could do with some support please contact Anne Duffy in the office or on 087 2320255.

If your child is in hospital and you would like a visit, or even just a chat, please contact Fiona Brennan on 087 9361621.

Severe bleeding disorder alert cards

A reminder to you all to make sure that you carry your 'Severe bleeding disorder alert card' with you at all times. It is so important that people with haemophilia are treated promptly if they need to attend an Emergency Department in any hospital. Your consultant haematologist at your treatment centre will provide you with a card, so if you have not already received same, please ask for one when next attending your treatment centre.



Severe Bleeding Disorder Alert Card

ST. JAMES'S HOSPITAL

eZine magazine

Our newest staff member Leah Cawley is sending out a monthly electronic eZine magazine to members. This is not replacing our quarterly printed magazine. The monthly magazine will include reminder of events, and snippets of information and articles of interest. If you would like to sign up to receive this electronic magazine, please contact Leah in the office on 01 6579900 –
or by emailing Leah (leah@haemophilia.ie)

Brian O'Mahony Award

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 25th.

Ageing Conference

The second Ageing Conference held by the Irish Haemophilia Society took place in Hotel Kilkenny on 16th and 17th of May. The two day conference was a great success with a lot of discussion in each of the sessions.

The first speaker at the conference was Dr. Niamh O'Connell, who discussed Ageing and Treatment Protocols. She pointed out that people with haemophilia with access to good treatment are living to the same live expectancy as the general population. However, there are haemophilia related issues that begin to become apparent with ageing such as arthropathy impact and increased incidences of infections and osteoporosis. Arthropathy can increase pain and reduce mobility. As a result there is a greater need for focussed physiotherapy and exercise. Osteoporosis is the loss of bone density as we get older. With most people the foundations to remove the effects of this were laid when they were in their teens and 20's with active sports. The effects of this cannot be undone due to damaged joints and limited access to treatment as they were growing up. However, the effects can be reduced with weight bearing or resistance exercises but due to damage in the joints over time this should be done with a specific programme that could include factor adjustment. In the general haemophilia population we have the first cohort of ageing people who have their own teeth. Dr. O'Connell talked about the importance of continued monitoring of your teeth and getting to know your dentist. Dr. O'Connell also highlighted the importance of sourcing a G.P., especially as people age and become increasingly susceptible to the various conditions and issues that we all know about as we get older.

Dr. Bill Cuddihy G.P., discussed the non-haemophilia specific issues that arise as we all get older, such as cancer, diabetes, heart disease and dementia. He made an excellent point that "If you want to live well when you are 60, you don't start when your 59". All of these conditions are best tackled throughout your life by staying active and reducing risk factors such as smoking and alcohol and he placed importance on eating a balanced diet and good weight management.

Dr. Amanda Clifford from University of Limerick, talked about preparation for orthopedic surgery and prevention of falls. One of the key things that improves ones recovery after surgery is the time spent prior to it building up muscles as much as

Dr. Niamh O'Connell during the treatment protocols session at the recent Ageing Conference

Dr. Bill Cuddihy discussing non-haemophilia specific issues at the Ageing Conference

possible around the specific joint being replaced or fused. This "Pre-Habilitation" helps improve ability to tolerate surgery and minimises deterioration with regard to the functioning of the joint. Again exercise before and after surgery is a recurring theme in this session.

Other sessions from the day included "Changing Bleeding Patterns" as we get older and "Pain Management". Both of these sessions were presented by Dr. Kevin Ryan. The first part of the talk on "Changing Bleeding Patterns" covered already troublesome joints. With each bleed over your life time, further damage to the joint will occur and rehabilitation at this stage is often more difficult with an increased risk of fractures. Keeping the joints mobile and muscles strong is key. This can be achieved with physiotherapy, pain medication, prophylaxis and potentially synovectomy. He also discussed the increased risk in the general population of intracranial bleeding. This obviously poses a greater risk to people with bleeding disorders; hence it is something that is noted as we get older. He also explained in detail how pain is felt, the management of these symptoms by medications and the best way to use them. A very interesting discussion ensued on the acute pain you get when you have a bleed versus the long term chronic pain of arthropathy, including other management techniques and assistance from an occupational therapist and psychologist.

On Sunday Ms. Miriam Coghlan, a pharmacist at St. James's Hospital, spoke about the challenges of taking multiple medications. She highlighted that in St. James's, patients are taking on average five medications per day, including over the counter and herbal medications. With all of these potential interactions it is very important to monitor what we take, how long we are taking it for and why we are taking it. She also mentioned the importance of keeping a list on your phone, in your wallet or simply bringing all the medications you are on with you to hospital appointments, to make sure that you are only taking what you need and that none of them are counteracting the others. She also provided very good tips on how to monitor taking medications by working them into a routine such as leaving them by a toothbrush, phone reminders, putting extras in your car or at work as well as the good old fashioned pill box.

Mr. Greig Blamey, a Physiotherapist from Canada, was the final speaker at the conference and he specifically focused on what seemed to be a running theme throughout all the sessions over the weekend. Being fit and exercising is important but the gap between being and getting can be a tough one to cross. This session focused on the little things we can do to become more mobile. He advised to start small and making sure that no harm is done to joints or other damaged areas and then slowly building up through work with the physiotherapist and maybe even a personal trainer to improve movement in a sustainable and relatively pain-free way. He also discussed the importance of balance and improving this by standing on one leg, trying to balance and when this has been managed closing your eyes.

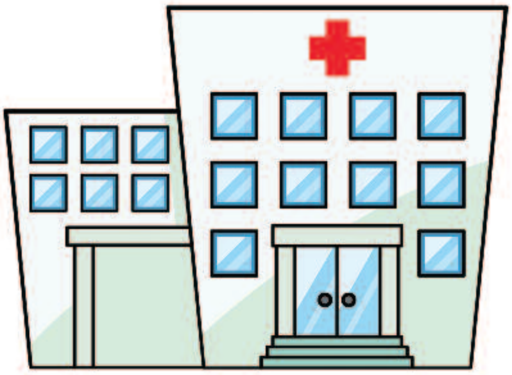
This conference, like the last one, was full of wonderful, pertinent discussion between speakers and members and members with members throughout the entire weekend. It is a great conference to meet old friends, make new friends, discuss new ideas and have great conversation. It was great to see everyone and looking forward to many more with all of you.

Declan Noone

Welcome to another edition of our Cub's Club!!

In our last magazine we met Brian who is 7 years old and has severe haemophilia. Sometimes Brian gets really cross on the days he has to get his injection. Brian has to get his factor three times a week and even though Brian doesn't think his injection is sore he hates how long it takes to get his factor through his port. He always tells his Mum that he wants to be outside playing with his friends instead.

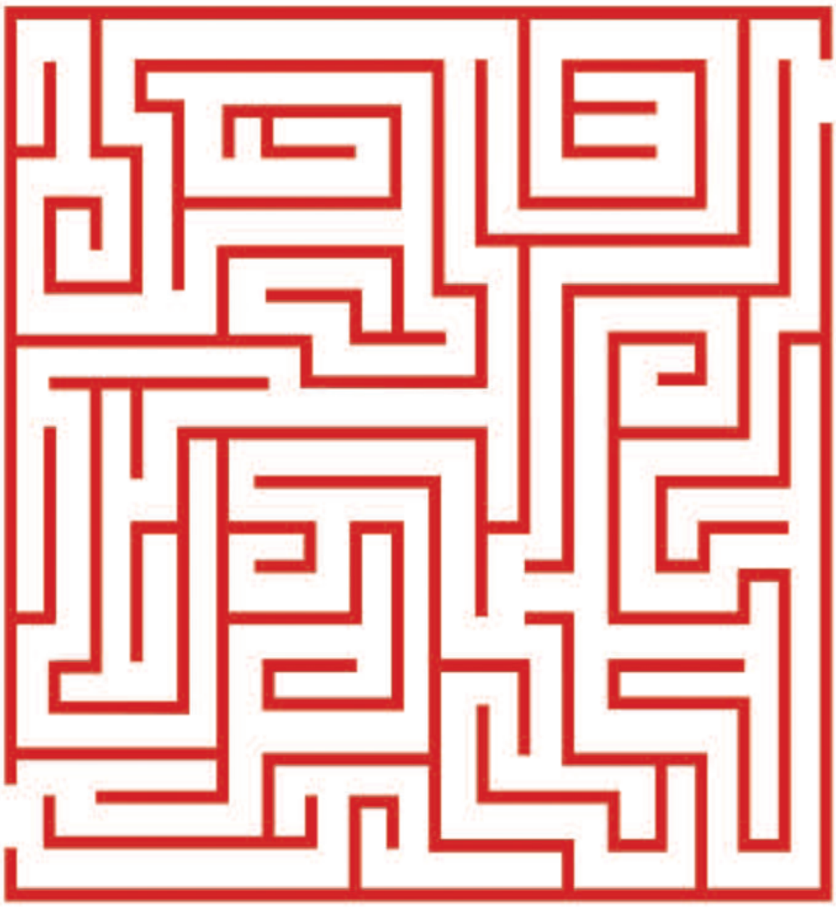
Brian's doctor said that getting his factor through his veins is going to be much quicker and that Brian's veins are now big enough to start trying to use his veins. Brian is going to the hospital to learn next week and wants to know what it will be like! Do you know what it will feel like to get factor through your veins? Why don't you tell us why you think getting your factor through your veins is a good idea?



Can you help Brian get to his doctor's appointment?!

We'll help you get started!!

1. *You will be able to do it yourself and that's pretty cool*
2. *You will be able to give yourself factor as soon as you hurt yourself so that you don't have to get too sore or rest up for too long*
3. ______________________
4. ______________________
5. ______________________



Welcome to the Kidlink page!!

In this issue we want to teach you all about haemophilia and some of the important things you need to know. Do you know what the two different types of haemophilia are? Do you know why people with haemophilia need to take factor? Do you know what causes a bleed? Let's find out!

What are the two types of haemophilia?

The two types of haemophilia are haemophilia A & haemophilia B. Our bodies have 13 clotting factors that work together in the blood to form a clot if you get a cut or a bang. If a clotting factor is missing then a clot cannot form. Haemophilia A is when there is not enough factor 8 in your body to make a clot and haemophilia B is when there is not enough factor 9 in your body.

Why do you need to take factor when you have haemophilia?

When you have haemophilia, if you have less than 1% of factor 8 or 9 in your blood then you must take factor so that you can get more of the missing factor in your blood. If you have less than 1% of the missing factor in your blood you will get bleeds into your joints and muscles which can cause a lot of pain. Increasing the amount of factor in your blood will stop you getting bleeds because your blood will be able to form a clot.

What causes a bleed?

A bleed happens when blood escapes from a blood vessel and enters a joint or muscle where it is not supposed to be. Blood outside of a blood vessel can cause damage to the surrounding areas so it is important to treat with factor.

Can you think of any questions you have about haemophilia. Let us know by emailing Fiona on fiona@haemophilia.ie

Don't forget to ask an adult for permission!

Education never really ends

I have always loved education. I was that kid in school who did very well academically but was very shy and couldn't kick a ball to save my life! My dad was very interested in education as he had to leave school at 12 to work on the farm. He always told me to stay in school, to make something of myself. He had severe haemophilia but still worked as a building labourer getting up at 5 o'clock every morning to work all day mixing and carrying cement and blocks. He walked with a limp as a result of a bleed in childhood when the medication wasn't as readily available as it is today. He was a great role model and very much encouraged me to do well in school. I didn't like school but I liked the subjects. I was very good at history, maths and English. A teacher there showed an interest in my studies and was always on to me to go to college. The school had very little resources, there was no guidance counsellor so you had to decide yourself what you wanted to do. Unfortunately my dad died in the summer before I started 6th year and the leaving certificate.

I wanted to make my dad proud and got a pretty decent Leaving Certificate. I also received a scholarship from Guinness's on my academic achievements for 2,500 punts. This was 1996 by the way! I very much struggled in college. In my school, I'd always been top of the class and won student of the year a couple of times. In DCU, however, it was the brightest kids from all over the country. I dropped out in 2nd year. I had been doing a degree in applied chemistry as I wanted to work in forensics but it wasn't for me. Soon after leaving college I realised that having a good leaving cert doesn't really make you suitable for many jobs, that in this world you are paid for what you know. I worked a lot of minimum wage jobs for £3 an hour. I was a security guard, general operative in a factory, I made salads for 4 years. When I was 25 I decided to become a nurse. I went back to college, this time to Trinity and over 4 years I finished a degree in general nursing. College is not cheap. While fees are paid for one degree by the government, registration is almost €3,000. Also with living expenses and rent, it all adds up.

I was a theatre nurse for years in a large Dublin hospital. I enjoyed it there, even though it was very stressful. I enjoyed helping people and I knew my dad would have been proud as he did a lot of charity work in the community with the church and with St. Vincent de Paul in his spare time. I was a theatre staff nurse for 7 years when I realised what I enjoyed most about the job was communicating with patients. I worked in the recovery room so I'd chat to patients, allay their fears and listen to their experiences. I realised that I wanted to move into really talking to people as a job. I'd been thinking about becoming a psychologist for a while. I had some money saved so I made the decision to change careers. I went back to Trinity again to do a conversion degree in psychology at 34. I was one of the oldest in my class and many times I asked myself "are you insane? You left a job and a pension to study again". It was a very tough course but I kept going as I love psychology and if you want something bad enough then you can do it. You just have to put in the hard work. In the last year in Trinity I also took a night course in NUI Maynooth to boost my CV. I passed my degree and applied for the higher level courses again to become a psychologist.

I applied for the Margaret King Educational Grant to help get me through the final course I had to finish before becoming a psychologist. I began a doctorate in counselling psychology in September. I hadn't been long in the course when I received a letter informing me I had won a grant! I was delighted as I love education but it's not cheap. The doctorate cost a lot of money and it's an unfortunate fact of college life that many people who deserve and could do very well in college just cannot afford to go. I love psychology and hope to be qualified in 3/4 years. The grant is so important to me for so many reasons. In every course you need textbooks. You can often borrow from the library but some core books you need to buy. Books for secondary school are expensive, books for university cost real money. Some of the new editions will set you back €80-€90 . That's just one book. The grant helped me to buy books, and enabled me to really focus on my course. As a full time student money is everything. It helped pay the bills, the rent, registration etc. It enabled me to continue pursuing my dream of one day being a psychologist. It's been a tough journey but I wouldn't change a thing. I'm almost 37 and I was in college for the first time at 17! Grants like the Margaret King Educational Grant are what kept that dream alive. I'd encourage anyone reading this to do what your heart wants you to do. Go to college, get an education, meet amazing people, have amazing experiences. If you want something badly enough there is always a way. Keep working hard and you'll get there eventually. Don't let anything hold you back, be it illness or anything else. I'd like to thank the Irish Haemophilia Society for helping me get that bit closer!

Stephen Curtin

Educational Grants: Past Recipients

Ms. Sarah Gilgunn – past recipient of the Margaret King Educational Grant

I am delighted to be writing this article to extend my gratitude to the Society having been awarded the sum of €2,000 for the Margaret King Educational Grant at the start of this college year.

For those of you who don't know me I am the Queen of the Science nerds (well, I like to think I am anyway!) I love every aspect of science, particularly biology, and have always been very inquisitive and have a constant hunger for learning more and more!

Originally, I studied a BSc. in Biomedical Science and then continued with an 'add on' degree in Pharmaceutical Science, both in Sligo Institute of Technology. Following several years working with Baxter Healthcare, I was keen to further my interest in scientific research. I decided to return to University to complete a Master's Degree in Molecular Medicine in 2011. I was very proud to graduate from Trinity in 2012 with my MSc. This course opened me up to so many opportunities and allowed me to gain the knowledge necessary for me to take the next step in my scientific career....completing a PhD and becoming an academic research scientist.

Following a very rigorous selection process from a large number of national and international applicants from leading universities, I was awarded a scholarship from the Irish Cancer Society to complete a PhD. This research is part of a multi-institutional consortium, the Prostate Cancer Research Consortium, which is the leading group in cancer research in Ireland with many international links. My PhD project is a multidisciplinary project with the aim of improving current approaches for detection of prostate cancer.

In October 2011, I registered as a postgraduate research student in Dublin City University and embarked on my PhD journey. It has been a long journey, with quite a lot of blood, sweat and tears but I am happy to say I am almost at the end of the road! The results obtained from my body of work provide significant insight into novel-approaches that can potentially deliver a much sought after cancer-specific biomarker analysis for improved prostate cancer diagnosis.

This is my final year of my PhD studies and as I wind down my days in the lab I have the task of writing my thesis! All going according to plan I hope to submit my thesis this summer and graduate in November of this year.

I have been heavily involved with the I.H.S. for a number of years. Since I was 16 I have completed several Mini Marathon's to raise money for the I.H.S. and following receiving the educational grant in 2010 I started volunteering with the Cubs/Crèche which I thoroughly enjoy.

In May 2012, I was co-opted onto the board of directors of the I.H.S., and this March I was elected to the position of Vice Chairperson on the board. I was so proud to be asked to join the board and hope my addition is as beneficial to the I.H.S. as it is enjoyable for me.

I really can't thank the Society enough for the grant I received and would strongly encourage others to apply for the many grants that the I.H.S. so kindly provides.

Sarah Gilgunn

Ms. Carly Wright – current recipient of the Maureen & Jack Downey Educational Grant

First of all I'd like to thank the board for awarding me with the Maureen and Jack Downey Educational Grant. To say it has changed my situation is an understatement.

I'm currently in my first year of Applied Social Studies in Social Care in Limerick Institute of Technology. I have always had social care as a career choice since I started secondary school. Social care interested me because it is so broad as a career, meaning you can work in many different areas helping people in all kind of circumstances and situations.

As I said before I'm currently in first year and I love it. The course and the modules have made me even more excited to work in this area. At this moment I'm considering my options for placement this September so it's an exciting time.

I'm so grateful to have gotten the opportunity to attend third level education. My choice to go to college last September was very sudden and last minute as I had decided before hand to stay local and complete a PLC course for the year. Money was tight and there was huge pressure on my parents to provide money for college fees and rent at such short notice. They managed to come up with the money for my first year but we all had the worry about how I was going to get through the rest of the three years.

When I applied for the educational grant I had no idea I would be awarded with it because I knew there was going to be a huge number of applicants. I was away in college when my parents got the letter in the post that I had received the grant. That phone call from my parents changed my situation completely. I now have the worry of college fees behind me for the next three years and I can comfortably continue with my studies. To know that I don't have to worry as much about money and my future when I'm away in college is a wonderful feeling.

Once again I'd like to say a huge thanks to the executive board for providing and helping me with my current studies. It is greatly appreciated!

Carly Wright

Educational Grants 2015

Have you been accepted on a post second level educational course?
Are you going to college?
Do you have haemophilia or a related bleeding disorder?
Are you a family member of a person with haemophilia or related bleeding disorder?

Put pen to paper, it's time to apply!

Applications are now invited for the 2015 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.

What types of Educational Grants are available?

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.

How much are the Educational Grants for?

The grants are broken down as follows:

Maureen & Jack Downey Educational Grant

- First prize €4,000
- Second prize €2,000 (This is called the Father Paddy McGrath Educational Grant)
- Third prize €1,500

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.

What is the closing date for applications?

The closing date is Friday 25th September, 2015.

How are the applications scored and who scores them?

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.

Applications are scored on the following:

- Quality of application.
- Information given on the application form.
- Involvement in the Irish Haemophilia Society.
- Financial need.
- How many in the family are going to college.
- If the application is a first time application.

Can I apply every year?

Yes you can apply every year, even if you have already been successful, but remember 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

Dates for your diary

SEPTEMBER

HCV/HIV Conference

Saturday 26th September &
Sunday 27th September
Kingsley Hotel, Cork

OCTOBER

Members Conference

Friday 16th – Sunday 18th October
Heritage Hotel, Portlaoise

Barretstown Camp

Friday 30th October to
Sunday 1st November

NOVEMBER

PEP Conference

Friday 20th – Sunday 22nd
November
Clarion, Liffey Valley

MARCH 2016

AGM & Conference

Friday 4th – Sunday 6th March
Hotel Kilkenny

Visit to Vietnam

The four year twinning programme between the Irish Haemophilia Society and the Vietnamese Haemophilia Association (VHA) was officially completed at the end of 2014. However, due to the success of this programme and the great strides that have been made and continue to be made by the haemophilia team in Vietnam, the Society have committed to working with the Vietnamese Haemophilia Association for a further four years outside the scope of the World Federation of Hemophilia Twinning Programme. We continue to work to assist them in developing their capacity as an organisation and we also continue to work on specific programmes including the 'Home Adaptation Programme' and the 'Micro Employment Project' which I have spoken about in previous newsletters.

It is our belief that the optimum route forward for haemophilia care in Vietnam would include a more strategic programme from the World Federation of Hemophilia (WFH). The WFH has an all-inclusive programme called the Global Alliance Programme (GAP). This involves working with a country on several levels including increasing government commitment to haemophilia care, providing increased training for the doctors, health care workers and laboratory scientists in helping to further increase the capacity of the patient organisation and provision of factor concentrates.

In May, I visited Vietnam along with a very high level team from WFH to assess Vietnam for possible inclusion in the WFH GAP programme for 2016. The delegation comprised of the WFH President Mr. Alain Weill, the interim Chief Executive, Ms. Elizabeth Myles and the Regional Programme Manager for Asia, Mr. Robert Leung. We visited the blood transfusion hospital and the Cho Ray Hospital in Ho Chi Minh city where they were able to see the reality of haemophilia care in Vietnam in 2015. We then visited some patients at home and followed this with a meeting with the southern branch of the Haemophilia Association. The southern branch of the V.H.A. have greatly increased their capacity over the last year and now have a large number of active volunteers willing to work

From left – President of the WFH Mr. Alain Weill with his colleagues Mr. Robert Leung and Ms. Elizabeth Myles visiting the hospital in Ho Chi Minh city

From left – Ms. Hang, Dr. Mai, Mr. Brian O'Mahony, Professor Tri, Mr. Alain Weill, Ms. Hanh, Mr. Robert Leung and Dr. Khanh in the National Institute of Haematology and Blood Transfusion

to improve the quality of life for people with haemophilia. Following our visit to Ho Chi Minh we then flew to Hanoi where we worked with the National Institute of Haematology and Blood Transfusion (NIHBT). The WFH delegation were given a detailed presentation on the reality of haemophilia in Vietnam. A country of 90 million people, which should have at least 6,000 people with haemophilia but where there are only 2,200 diagnosed. Factor VIII use in Vietnam is 0.07 international units per capita. Vietnam uses 6 million international units for a country with a population of 90 million people whereas Ireland is using 39 million international units per country with a population of under 5 million. There is a long way to go to improve care in Vietnam but they're clearly making constant and incremental improvements. In 2009, factor VIII was covered by the health insurance scheme. In 2012, factor IX was covered by the health insurance scheme and in 2014 they also achieved coverage for factor VII A. In Vietnam, individuals must also pay 20 per cent of the cost of their treatment including the cost of their factor concentrates. This is beyond the capability of most people to achieve. If an individual is categorised as poor then they do not pay 20 per cent, the government pays 95 per cent and the individual is liable for 5 per cent. This 5 per cent is often waived; however this does not generally apply to a large number of the patients. In Hanoi, the NIHBT and the Association have now managed to achieve coverage without a co-payment for 60 – 70 per cent of people with haemophilia. This is a very significant improvement in access to treatment. It is important to note that even though the use of factor concentrates in Vietnam is very low, it is still more than doubled since 2009. The Vietnamese Haemophilia Association with headquarters in Hanoi now has three branches in the south in Hai Phong in the southwest and three haemophilia clubs in Hai Phong, Hung Yen and Tai Bin. There are also three peer groups for young men with haemophilia, for mothers and for fathers and they have 30 active volunteers who provide education, support members, and carry out fundraising and advocacy. Our work with the Association over the past number of years has borne fruit in terms of a more efficient system of governance, a higher number of recruited volunteers and an increased number of publications.

The delegation then met with the executive board of the Vietnamese Haemophilia Association and carried out a detailed discussion in relation to the prospects of a GAP programme in Vietnam. Following this, we had a lengthy meeting with the Vice Minister for Health and at that meeting the Vice Minister asked Professor Nyugen Anh Tri, the President of the VHA to write a national haemophilia programme and submit it to the Ministry. It was a very successful meeting and visit and I am confident that the WFH will approve Vietnam as a GAP country for 2016. This four year commitment to Vietnam would further boost their continued efforts to improve haemophilia care.

While in Vietnam I also signed the formal agreement for the employment project whereby the Irish Haemophilia Society will support individuals with haemophilia and related bleeding disorders by giving small grants to people with haemophilia to start up small businesses such as repairing computers or mobile phones at home or other such appropriate employments. In addition to this, I was able to see at first hand the impact of the Home Adaptation Project when we visited a family in Ho Chi Minh City. The family have a 12 year old child

Mr. Brian O'Mahony visiting the family of a 12 year old child

Professor Tri and Mr. Brian O'Mahony during the ceremony to seal the 'Employment Project'

with severe haemophilia who has been confined to bed due to bleeding into his back. On the day we visited his wheelchair arrived. This wheelchair was funded by a grant from the Irish Haemophilia Society through our Home Adaptation Project and excitement ensued as the wheelchair was assembled and he was able to move around in the wheelchair. In Hanoi, we also saw a delivery of a large number of wheelchairs, crutches and portable toilets for people with haemophilia funded through the Home Adaptation Project. These might seem relatively simple devices which we would have taken for granted here for several years but they will make a significant difference in the mobility and quality of life for people with haemophilia who benefit from these in Vietnam.

Yet another successful trip to Vietnam.

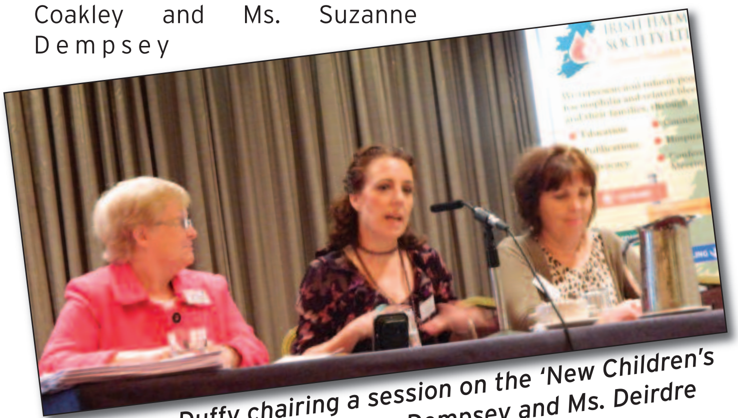
Mr. Brian O'Mahony and Dr. Mai overseeing the delivery of home adaptation equipment

Brian O'Mahony

Parents Conference

This year's Parents Conference took place in the Sheraton Hotel in Athlone over the weekend of 19th to 21st June. We had 71 adults and 78 children booked in for the weekend, along with 36 volunteers, staff and speakers. We left the office early on Friday morning to make our way to Athlone to set up. With everything organised, we were ready for registration at 6pm. As members registered with their children it was obvious how excited the children were to meet up with their friends again, and they were all so looking forward to the weekend.

On Saturday morning the adults programme started with a session on the 'New Children's Hospital'. Ms. Deirdre Coakley and Ms. Suzanne Dempsey gave excellent presentations on the new state of the art plans for the hospital which will be located in St. James's Hospital. The new hospital will bring together in one entity the 3 existing children's hospitals; Our Lady's Children's Hospital Crumlin, Temple Street, and the National Children's Hospital at Tallaght. The new hospital will be a world class facility providing paediatric services and specialist services for the country as a whole. Children who need to stay in hospital will have their own room. Every room will have an en-suite bathroom and facilities



Ms. Anne Duffy chairing a session on the 'New Children's Hospital' with Ms. Suzanne Dempsey and Ms. Deirdre Coakley from NCH

Fun and games with the children in the cubs group

The Kidlink group

The Youth group

for parents to stay overnight, and there will be free Wi-Fi. There will be 32 different specialities in the new hospital. The attendance at this session was excellent and there were plenty of questions from the floor.

Although the attendance wasn't great at the next session on the adults programme "Teenagers communicating with health care workers", the interaction between parents and Dr. Yvonne Duane, Psychologist from Our Lady's Children's Hospital Crumlin was excellent. Dr. Duane was able to simplify parents' concerns and give them tips on how to encourage their children to communicate with health care workers. More education for teenagers on relationships and sex also came up during this session and we agreed going forward that this is something that parents, Crumlin and the I.H.S. could all work on together.

While the parents were at the talks on Saturday morning the children were enjoying all sorts of activities. Haemophilia Nurse Specialist Eibhlin McLaughlin spoke to the children's groups about self-infusion, although from what I heard I am not sure if the 4 to 7 year olds in the cubs group were very interested. They were more interested in finding out what time they were going swimming! The crèche was full to capacity and they enjoyed a morning of arts and crafts. The kidlink group enjoyed indoor party games and the youth group put together a magazine.

Liam & Leah Jennings taking a break

After lunch the adults programme started with a session on "Steps to Self-Infusion" which was chaired by Mr. Declan Noone. The format for this session was a less formal approach with plenty of interaction from members who attended the session. Declan put questions to the panel which consisted of Haemophilia Nurse Specialist Eibhlin McLaughlin, and members Mr. Tony McAfee, Mr. Keith Grainer and Ms. Karla Cox. It was very interesting to see the different stages of the steps to self-infusion. Members spoke honestly and openly about their experiences with their children and Eibhlin encouraged members to contact Crumlin about training for their children.

The last two sessions on Saturday for adults were the mother's and father's workshops which always prove to be an invaluable session for members, as they feel they are able to talk at ease about their worries and concerns in a supportive environment and also gain valuable tips and advice from other parents.

The children's groups had an action packed afternoon, and to say they ran the volunteers ragged is an understatement and yet at dinner on Saturday evening most of the children still had plenty of energy. The hotel served a lovely dinner, after which

The children enjoying the magician on Saturday evening a magician entertained the children (and adults) with tricks and jokes. The children were in stitches laughing, as were some of the adults. The children were extremely well behaved on Saturday evening and it was really a very enjoyable evening.

Sunday morning started for the adults with a session on "Exercise and Sports" which was chaired by Mr. Declan Noone. Board member Mr. John Stack gave an interesting presentation and emphasised the importance of strengthening exercises for children with haemophilia. Clinical Specialist Physiotherapist from Crumlin Ms. Paula Loughnane also gave a very good presentation and answered lots of questions from the floor, in particular in relation to children with haemophilia playing hurling. Young adult Mr. Thomas Burnell spoke about his experience growing up around sports. Thomas has severe haemophilia and is a keen golfer and loves athletics. He encouraged parents to allow their children to play sports, and spoke passionately about this subject, so much so he got a huge round of applause at the end of his talk, not to mention me filling up at the back of the room!

Ms. Anne Duffy chairing the social welfare session on Sunday morning with Mr. Patrick Stagg from Citizens Advice and Ms. Traci Dowling, Chairperson of the I.H.S.

The last session on Sunday morning was on "Social Welfare and I.H.S. support". This session was chaired by Ms. Anne Duffy. Mr. Patrick Stagg from Citizens Advice gave an overview to the audience in relation to the services he offers and encouraged any parent with any query they might have, be it big or small to get in touch, and pointed out to everyone that the service is strictly confidential. Pat has been working with the Society now for many years, has excellent knowledge about social welfare and I know that Anne has been in touch with him on numerous occasions about member's issues and has always received great assistance from Pat. Chairperson Ms. Traci Marshall Dowling then spoke to parents specifically about children with haemophilia reaching the age of 16. Traci wanted to make parents aware that Domiciliary Care Allowance stops at this age and that Disability Allowance is available from this age.

I.H.S. volunteers Michelle and Rebecca with James and Christopher in the crèche

Traci gave plenty of information to parents about this and also explained to members that we now have a system in place in the office that once a child with haemophilia reaches the age of 15 that the Society will contact them to offer support if they want to apply for Disability Allowance. Some parents in the audience have already been successful with this process. Again there was plenty of interaction from the floor in the questions and answers section and Pat gave some invaluable advice to members.

I.H.S. volunteer Ashlie with Alex in the crèche

Before long it was time to pack up and go. The weekend went by in a flash. A huge thank you to all the volunteers who gave up their time at the weekend, and for taking such great care of the record number of children who attended.

It was also lovely to see new parents and new babies attend their very first I.H.S. conference. We hope you all enjoyed it and hope you all received lots of information, shared ideas and peer support from other parents. We certainly enjoyed it.

Debbie Greene

Bake Sale and Raffle in aid of Irish Haemophilia Society

Hannah and her friends getting organised for the bake sale

In my school all second years must take part in an action project for our CSPE class as part of our Junior Certificate course. My friends and I came up with the idea to support the Irish Haemophilia Society and to raise awareness about haemophilia and bleeding disorders particularly in girls, as I attend an all-girls school. This event was very important to me as my brother has haemophilia and I wanted to help with fundraising for the Society.
Photo: cake sale
My class decided that a good way to do this would be to have a bake sale and a raffle. In preparation for this, we put up posters around the school halls and went into each class announcing when and why the bake sale was taking place and requesting baking contributions. The class was split into different groups to organise the event. I was in the research group and gave a presentation to my class on haemophilia. The class all contributed to making four large hampers for the raffle. All week people volunteered to sell raffle tickets at lunch-time.
On the day of the bake sale and raffle, we spent the morning collecting cakes from everyone who had baked and before lunch we went down to the hall to set up. We had hundreds of cakes and Nina in the office had given me lots of haemophilia literature to give out to everyone.
The bake sale and raffle was a huge success. Hundreds of raffle tickets were sold and all the cakes were gone by the end. The hall was crowded with girls and staff and everyone was admiring the hampers. After lunch we pulled the tickets for the raffle. The people who won were delighted. When the money was counted, we found that we had raised €600. We were delighted with this amount and were so glad we could help the Society and educate girls in my school about bleeding disorders. Overall it was a huge success and I'm glad we got the chance to do it.
As part of our project is to raise awareness and to provide information, my nanny Margaret Dunne visited the school to give a talk to my class on haemophilia and the work of the Society. It was very successful and everyone had lots of questions. Hopefully people understand more about the condition now.

Hannah Byrne

Mini Marathon 2015

Some of the ladies who took part in the Mini Marathon for the I.H.S.

The gale force wind and rain on the June Bank Holiday Monday did nothing to deter the 37,000 brave women who took to the streets of Dublin to take part in this year's Women's Mini Marathon, which took place on the 1st June. Instead of sunglasses there was a rainbow of multi-coloured rain jackets, but the dreadful weather did not dampen the good spirit with plenty of laughs and banter along the way. Many women took part to fundraise for charities close to their hearts and there was a wonderful feeling of camaraderie among everyone. The route is marked at every kilometre with bands playing to encourage you along and it was great to see so many people on the side lines who had braved the weather to cheer us on. I will be honest and say the 5km to 6km stretch was the hardest as we travelled up and then back down the Stillorgan dual carriageway, with the wind and rain at its worst, but we ploughed on. Thankfully the sun came out as we reached the finish line, just in time for us to receive our well-deserved medals!

We would like to thank everyone who took part on the day to fundraise for I.H.S. We really appreciate your support for the work of the Society. And personally I would like to thank all the members who sponsored me to take part for the Society. I had set a target of €200 and was overwhelmed to raise a total of €598.

So a big thank you to everyone!

Nina Storey

IRISH HAEMOPHILIA SOCIETY
First Floor
Cathedral Court
New Street
Dublin 8
Tel: 01 6579900
Fax: 01 6579901
Email: info@haemophilia.ie
Website: www.haemophilia.ie