It's time to put pen to paper and apply for an I.H.S. Educational Grant!

See inside pages 12/13
**OCTOBER MEMBERS CONFERENCE 2016**
**FRIDAY 14th OCTOBER - SUNDAY 16th OCTOBER**
**Radisson Blu Hotel, Sligo**

**Preliminary Adults Programme**

**Friday 14th October**

18.00 - 19.30  Registration

**Saturday 15th October**

09.30 - 10.00  Registration
10.00 - 11.30  Interactive Workshop: Communicating with Healthcare Workers
11.30 - 12.00  Coffee break
12.00 - 13.00  Debate: Extended Half-Life Recombinant versus Current Recombinant
13.00 - 14.00  Lunch
14.00 - 15.30  Interactive Workshop: Disclosure
15.30 - 16.00  Coffee break
16.00 - 17.00  Mindfulness
19.15  Dinner

**Sunday 16th October**

10.00 - 11.00  Cooking Demonstration - Fast Nutritious Meals
11.00 - 11.30  Coffee break
11.30 - 12.45  Awesome Games
13.00  Lunch
Hello everyone,

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

On the inside cover you will find a preliminary programme for the Members Conference in October. Booking forms won't be going out till 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 new developments in haemophilia. These new developments make it a very exciting time for haemophilia care and treatment. Go to page 4 for to read his article.

It's that time of year again when applications are open for our Educational Grants. You will find information on pages 12 & 13. The deadline is towards the end of September so there are no excuses, you have plenty of time to apply.

On page 8 you will find important updates from the NCHCD.

On page 15 you will find a report from our Carrier Conference that took place in May in Dublin and on page 18 you will find a report from the European Haemophilia Consortium Leadership Conference that took place in Brussels recently.

Why not update your diary with our calendar of events on page 16 and take a look at our noticeboard on page 17.

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

See you all at the next conference, enjoy the summer and enjoy the read.
New Therapeutic Developments in Haemophilia

Extended Half-Life Factor VIII

In November 2015, the first extended half-life (EHL) factor VIII concentrate was licenced in Europe by the European Medicines Agency (EMA). In April 2016, the first two EHL factor IX concentrates were licenced by the EMA. Half-life is the amount of time it takes for factor to decrease its circulating concentration by half, or 50%. It is calculated by taking a series of blood samples over a specified time span after infusing clotting factor, and then measuring how much factor remains in each sample. When graphed, these measurements are called pharmacokinetic (PK) curves and they show how rapidly your body eliminates factor. The half-life of factor may vary from product to product, and from person to person. It is, therefore, important to know how long a particular brand of factor lasts in your body, which may be significantly different from the average half-life of that brand, due to high variation from individual to individual. By knowing how quickly you eliminate factor from your blood, your haemophilia centre team can tailor a prophylactic dosing schedule specific to your needs.

For instance, if you want to achieve a 50% factor VIII level in a man weighing 80 kg, you would infuse 2000 IU of factor VIII. Immediately after the factor VIII is infused, the level of circulating factor VIII in the body is at 50%. If the product has a 12-hour half-life, then about 12 hours later, the factor VIII level will be at 25% (half has been eliminated) and 24 hours (or 2 half-lives) after the original injection, 12.5% is left. Thirty-six hours after the infusion, 6.25% is remaining and two days after the initial injection, the factor VIII level is at 3.125%.

How does this work for a prolonged half-life product? If the half-life is on average 50% longer than 12 hours, say 18 hours, then 36 hours after the original injection (which resulted in a factor VIII level of 50%), factor VIII levels are reduced by two half-lives, so 12.5% is left. Three days after the initial dose, factor VIII is at 3.125%. In other words, when using a prolonged half-life factor VIII product, with an 18-hour half-life, you may be able to go an extra day between infusions, as compared to a standard product with a 12-hour half-life. In clinical practice, EHL factor VIII can be utilised to reduce the frequency of factor VIII prophylaxis from three times per week to twice a week. Alternatively, it can be used at the current frequency of infusion (i.e. three times per week) resulting in a higher trough level (the level below which the factor VIII does not fall) and therefore conferring greater protection from bleeding.

The first EHC factor VIII licenced in Europe is Elocta, developed in the USA, by Biogen and marketed in Europe by SOBI, based in Sweden. This product was licenced in the USA about 18 months ago. Elocta harnesses one of the body's natural mechanisms to prolong the half-life of factor VIII. Clotting factors such as factor VIII are proteins, and each protein that circulates in the blood has a different half-life; some proteins last for a few hours, and others last for several weeks. Two proteins, in particular, albumin and an immune antibody called IgG, both last for a long time, more than 21 days. Many proteins in the blood are absorbed and broken down by endothelial cells, the cells that line the blood vessels. IgG usually manages to escape this process. There is an area on the protein, called Fc, which allows the protein to bypass the breakdown process and causes the endothelial cell to eject the protein back into circulation. Scientists at Biogen took advantage of this fact and developed a recombinant form of factor VIII fused to an Fc molecule. With the Fc molecule attached to the factor, the endothelial cells treat the factor as if it were IgG, and eject the factor back...
into the bloodstream, extending its half-life (by effectively, recycling the factor VIII fused to Fc). The half-life of Elocta, and of the other EHL factor VIII products under development is approximately 50% longer than standard recombinant factor VIII products. Several children with haemophilia in Ireland participated in the phase 3 clinical trial for this product and the product is now being introduced for routine use for some children and adults in Ireland. Several other EHL factor VIII products are under development and in late stage clinical trials. Baxalta (now part of Shire), Bayer and Novo Nordisk are developing EHL factor VIII products where the factor VIII is linked to polyethylene glycol (PEG). This is a petroleum derivative which is found in a variety of products from cosmetics to food. (PEG will be familiar to some people with haemophilia, as in the past, one of the standard treatments for hepatitis C, included injections of Interferon fused to PEG, so called Peg Interferon). Another approach to prolonging the half-life of factor VIII involves making a slight change in the structure of the factor VIII molecule. Normally, factor VIII is synthesised in the liver as a single long protein, called a single-chain. When secreted from the cell, the single-chain factor VIII molecule is broken into two parts, or two chains. Factor VIII travels in the bloodstream as a two-chain molecule. In the approach used by CSL Behring, the two chains of factor VIII are bonded back together to form the more stable single-chain molecule. All of the EHL factor VIII products extend the half-life by approximately 50%.

Extended Half-Life FIX
The EMA licenced two EHL factor IX products in April 2016: Alprolix from Sobi and Idelvion from CSL-Behring. Alprolix utilises the same Fc fusion technology as Elocta. This significantly extends the half-life of factor IX from about 19-24 hours for standard factor IX products to 86 hours. Idelvion fuses the factor IX to another protein with a long half-life. Idelvion increases the half-life of factor IX very significantly to 104 hours. Both of these products can be used, to significantly decrease the required frequency of infusion of factor IX, or to increase the trough level or achieve both these objectives. Current factor IX concentrates are typically infused twice a week in a prophylaxis regime. Alprolix can be infused for prophylaxis once a week and in some people with haemophilia once every ten days to every two weeks. Idelvion can be used weekly or once every two weeks in many patients. The half-life increases with these EHL factor IX products can significantly alter the treatment pattern for people with haemophilia B, allowing for less frequent infusion combined with higher trough levels and greater protection from bleeding episodes. Novo Nordisk are also developing an EHL factor IX fused to PEG. This is not yet licenced.

New Approaches with New Types of Products
There are a number of novel products currently undergoing clinical trials, which offer new and innovative possibilities for the treatment of haemophilia as follows.

Emicizumab (ACE-910)
This is a bi-specific antibody which mimics the role of factor VIII. Factor VIII works in the clotting cascade by bringing factor IX and factor X together and activating them. These activated factors, in turn, activate other clotting factors, eventually resulting in the formation of thrombin and then fibrin, the stringy protein necessary for a strong clot. In the absence of factor VIII or IX, little fibrin is formed. This results in weak clots that easily break down, causing prolonged bleeding in either haemophilia A or B. Roche and its subsidiary Genentech are developing a new antibody drug (ACE910) to replace factor VIII. Antibodies are Y-shaped proteins produced by the immune system; they have two arms that usually bind or stick to one target, such as an infectious agent like a virus, to eliminate it from the body. Through the process of recombinant DNA technology and genetic engineering, scientists have been able to develop a bispecific antibody that binds to two different molecules. In this case, one arm of the genetically engineered bispecific antibody binds to factor IX, and the other arm binds to factor X. The antibody latches onto factor IX and factor X in the bloodstream and brings them together, essentially, the bispecific antibody is doing the job of factor VIII. In early clinical trials, this bi-specific antibody was effective in preventing bleeding in factor VIII deficient patients with and without inhibitors. This product can be used to treat factor VIII deficiency and also used to treat people with inhibitors to factor VIII. (It cannot be used to treat people with factor IX deficiency). It does not require venipuncture; it is administered as a weekly subcutaneous injection. In these trials, patients were protected from most bleeding
episodes with ACE910 alone, without the need for prophylactic factor VIII. ACE910 has generated a lot of interest in the haemophilia community and larger scale clinical trials are under way now. The next phase of clinical trials will be carried out on people with factor VIII deficiency in several countries, including Ireland. We expect these trials to commence later in 2016. This product looks like a potentially exciting therapeutic option for people with factor VIII deficiency, including those with inhibitors.

A number of other new products under development work on the premise of preventing the breakdown of thrombin, which is essential for clot formation. In addition to clotting factors like VIII and IX that participate in forming a blood clot, our bodies also have naturally occurring inhibitors that keep the clotting cascade in check by shutting it down. This is necessary to prevent unwanted clotting, possibly resulting in a stroke or heart attack. Perhaps these naturally occurring inhibitors could be neutralised to allow the clotting process to proceed with little or no factor?

**Fitusiran (ALN-AT3)**

Naturally occurring Anti-Thrombin breaks down thrombin and prevents excessive clotting in people without inherited bleeding disorders. This seems counterproductive in those with bleeding disorders, where you would like to prevent excessive clot breakdown. Alnylam Pharmaceuticals has made a completely different type of molecule to inhibit production of Anti-Thrombin 3 (AT3). It is called an RNA interference therapeutic (RNAi) and currently is being developed under the name Fitusiran. This binds to and eliminates AT3 RNA, preventing the liver from making AT3 protein (so called gene silencing). Clinical trial data on humans suggest that RNAi is effective in preventing bleeding when patients are given a subcutaneous dose sufficient to block the production of most AT3 protein. Bleeding was prevented in patients without the use of any clotting factor. Fitusiran will be tested in larger studies in haemophilia A, haemophilia B, and all inhibitor patients. Again, this will be a subcutaneous injection eliminating, for this product, the need for intravenous infusion. Fitusiran could be used not only in those with factor VIII deficiency, factor IX deficiency, but also those with factor VIII or factor IX inhibitors, von Willebrand's type 3, factor V, factor X or factor XI deficiency. Clinical trials with this product are continuing and we expect Ireland to participate in these trials.

If their potential is confirmed, both ACE-910 and Fitusiran may offer a meaningful advance for both inhibitor and non-inhibitor patients.

Research is also focusing on another naturally occurring inhibitor: tissue factor pathway inhibitor (TFPI). Both Novo Nordisk and Bayer have made antibodies that can bind to and eliminate TFPI in the bloodstream. These are being tested now in early human clinical trials, to see if they can improve clot formation in patients with haemophilia and patients who have inhibitors, by reducing the negative effect of TFPI on clot formation. No data on effectiveness is available yet.

**Gene Therapy**

Over the past five or six years, a small number of severe haemophilia B patients, in a successful clinical trial at University College London (UCL) and the Royal Free Hospital London have been successfully treated with gene therapy using a viral vector developed with St. Jude Children's Research Hospital in Memphis. This work was carried out by Professor Amit Nathwani and Professor Edward Tuddenham (who lectured on his groundbreaking work at the I.H.S. AGM & Conference in March of this year). People with haemophilia B on this gene therapy clinical trial have achieved a constant expression of factor IX activity from 1% to 6%, some of whom continue to express this level of factor IX up to 5 years after a single injection. They have seen a significant reduction in the requirement for prophylaxis in these individuals and very few or no bleeding episodes. Their work has inspired many others and currently, multiple haemophilia B gene therapy clinical trials are being conducted in addition to one factor VIII gene therapy clinical trial.

Among the other factor IX gene therapy trials are those being carried out by Baxalta, Uniqure and Spark. In the Baxalta and Spark trials, researchers are using a super-active form of factor IX, called factor IX Padua; that was first discovered in 1998 and identified in 2009 in a man in Italy who was experiencing excessive clotting. This factor IX variant is being evaluated for gene therapy by several groups, because it might solve one of the current problems with gene therapy—low “expression” rates; in other words, low factor levels produced as a result of gene therapy. The factor IX
Padua variant might solve this problem because it has about seven times the activity of normal factor IX. So an expression of 2% using a normal factor IX gene would be equivalent to an expression of 14% using factor IX Padua. In the Baxalta trial, some of those who have been treated with the gene therapy vector have lost any factor IX expression they gained, but others are expressing factor IX ranging from 7-20%. In the Spark trial, three people with factor IX deficiency have been infused. They are now expressing factor IX at levels of 16%, 28% and 30% respectively. In the Uniqure trial, (which does not use the Padua mutation) four people with factor IX deficiency were infused. Two of these are now expressing factor IX at levels of 4-5%.

In the factor VIII gene therapy trial, carried out by Biomarin, early results are available on eight patients infused with a factor VIII gene therapy vector. The first two individuals who were treated at the low and medium doses, achieved a factor VIII expression of less than 1% for the low dose and 2% for the medium dose. When they infused six people with the higher dose, the levels achieved were very varied at 57%, 60%, 8%, 4%, 21% and 10% respectively. It should be borne in mind that these are all preliminary results and expression has only currently been for a matter of weeks or months (when compared to up to five years for the initial group in the Royal Free in London). However, these results are very encouraging and gene therapy definitely seems to be heading in the right direction, after many years of trials and setbacks. The steady and incremental progress being made by scientists brings our community closer to the goal of a permanent cure. All of these developments, new therapies and potential new therapies make this the most exciting time in haemophilia in the past 30 years. I expect there to be more change and more new and innovative therapeutic options available in the next five years, than in the last 30 years combined.

Brian O’Mahony
Chief Executive

[Acknowledgement: Some of the information in this article is based on an article written by Dr. Glenn Pierce MD, PhD, which previously appeared in PEN]
National Centre for Hereditary Coagulation Disorders (NCHCD) Update

Re-location of NCHCD

The NCHCD is relocating to the main hospital. We will be located on the top floor of the current H&H building. We are hoping to be moving in late September 2016 or early October. All patients will be notified in writing once we have a final date confirmed.

NCHCD Staff

There have been lots of staffing changes in the NCHCD over the last few months.

- In February Eadaoin O’Shea retired after 27 years in St James’s Hospital.
- Currently, the physiotherapist position has been divided between two physiotherapists Emma Sherlock and Sheila Roche.
- In June we had 3 new nursing appointments as follows:
  - Niamh Larkin has taken over as Clinical Nurse Specialist.
  - Noreen Boland has taken over as Clinical Nurse Specialist.
  - Julie Benson started as Clinical Nurse Manager.

Cristin Leavy
Centre Manager

Image of the new NCHCD in St. James’s Hospital.
Planning Permission has been granted for the new children’s hospital in St. James’s Hospital

The Irish Haemophilia Society are very happy that planning permission has been granted, for the new children’s hospital project. This is great news for children, young people and their families. The project will bring together the three existing children's hospitals (Temple Street Children's University Hospital, Our Lady's Children's Hospital, Crumlin and the National Children's Hospital, Tallaght).

There has been much controversy in relation to the suitability of the site. An Bord Pleanála has granted permission, subject to 17 conditions. No major changes have been sought on the original planning application. Chief Executive Ms. Eilish Hardiman of the Children’s Hospital Group said: “This truly is a watershed day for children, young people and their families. These buildings are a significant catalyst for how the new national model of care will be delivered. We are now firmly on our way to making this long awaited children’s hospital a reality”.

The building will be seven storeys high in places with 380 single in-patient rooms, 42 beds in a critical care unit and 18 neonatal critical care units.

It is expected construction will start this summer with the hospital opening in 2020. The project has been described as “the most significant capital investment project ever undertaken in healthcare in Ireland”.

Debbie Greene
Welcome to another edition of our Cubs Club!!

Welcome to the I.H.S. Summer Magazine. Hope you are all enjoying your summer holidays and getting outside to play fun games and explore nature. You may have already met Brian. Brian loves to play outside on his holidays. His favourite activity is building a fort and his favourite game to play is hide and seek. Brian has to take his factor to make sure that if he falls or gets a bang, when he is outside playing with his friends, he won’t get a bleed. Brian gets bleeds in his ankle, so he has to be extra careful when he is running and jumping. If Brian gets hurt, he must tell his mom, dad or an adult who is there. Once, Brian continued playing and didn’t get his factor in time and his ankle got very hot, sore and swollen. Now Brian always tells an adult. He gets his factor on time and he sits in his favourite chair and reads his favourite comic, while he rests his ankle. Do you get bleeds? Where do you get them?

What did the pig say on a really hot day?
I’m Bacon

What does the sun drink out of?
Sunglasses

Join The Dots & Colour the Butterfly
Welcome to the Kidlink page!!

My Summer Holiday Plans

What do you call a fish with no eyes?
A fsh!

Why do bananas wear sun cream?
Because they peel!

Enjoying the summer holidays?
What have you been doing on your break? I’m sure you have loads of plans. Why not jot some of your plans down on above and tick them off as you do them. It is so important that you have fun when you are taking part in activities. Exercise and activities help to keep your muscles strong and flexible. Exercise and sports can be whatever activity you enjoy but it is important to get out and get moving. Keep yourself strong and fit. Some sports that are great for people with haemophilia are cycling, swimming, fishing, tennis, athletics and hiking. But there are some sports that are not recommended for people with haemophilia. Some of these are rugby, hurling, rock climbing and karate. These sports can be more physical and may cause bleeds. If you do get a bleed while doing an activity make sure you take your factor straight away and rest up. While it is important to have fun, it is also important to take care of yourself so that you can have fun more!!
Educational Grants 2016

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?

Applications are now invited for the 2016 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

It’s time to put pen to paper and apply for an I.H.S. 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.

When is the closing date for applications?
The closing date is Friday 30th September, 2016.

How are the applications scored and who scores them?
Once the closing date arrives and all the applications are received a subgroup 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
Thank You for the Educational Grant

I cannot begin to thank the Society enough for awarding me with this year’s Educational Grant in memory of Margaret King. I am currently in my first year of a BA course in Drama and Theatre Studies in UCC. I began studying drama at a very young age, and it has always been my favourite hobby. Despite considering many other courses, it felt like a natural progression to take something I love so much to a degree level. It is compulsory to study two arts subjects in the first year of my course, so I chose English and Sociology, as these have ties to some of the work I do in drama.

I applied to many drama courses due to the high competition, and I was extremely lucky to get a place in UCC. Not only am I able to live at home during my studies, but I have the opportunity to work with experienced lecturers that know everything about the theatre industry, and I get to work with extremely talented classmates every day. My grant has allowed me to travel and to gain invaluable industry experience, as I have attended workshops with directors and industry professionals. I have also worked in theatres such as the Granary and the Everyman theatres in Cork, and the Abbey Theatre in Dublin. The costs of these trips quickly build up, but my grant from the Society has allowed me to take up all of these great opportunities.

Without doubt, my favourite part of college so far has been the work I have done with Dramat, UCC’s drama society. I have learnt so much about working in theatre here in only a few months, and I have made friends for life that share my love of drama. I have already worked as part of a backstage crew and played a part in a short play. This semester I am lucky enough to have a main role in a big production, which I am extremely excited about! Between rehearsals and other work with Dramat, I have absolutely no spare time to take up part-time work, something which I had planned on doing in college. Luckily, my grant has given me the freedom to work on projects that I enjoy without having to worry about how I will fund my ridiculously busy day-to-day life.

The I.H.S has always been hugely important to my family, and knowing I have their support in my studies is wonderful. I know I would not benefit as much from my course if I had to worry about how to fund myself all the time, but thanks to the Society, this isn’t an issue. Again, thank you to the Society for awarding me this grant and for giving me the chance to fully enjoy and learn from my college experience.

Niamh Birkett

This is me back in 2007 at the opening of the I.H.S. office in New Street with President McAleese.
I was aware of haemophilia growing up, my dad was very active in the Society and this had knock-on effects for my sister and I. He brought us to as many activities as possible, these ranged from Christmas parties to trips on a jumbo jet. I was also lucky enough to accompany him to a World Conference in Vancouver, Canada. However, this level of involvement ended in 2008 when he passed away and I threw myself headfirst into that river in Egypt (denial) and haemophilia suddenly ceased existing. This all changed in April this year when Nina rang me to ask about attending the Carrier Conference. I was invited last time too but still hadn’t felt ready. However, I turned 30 this year and felt it was about time to embrace being a carrier and ask all the questions that had built up in my mind (I also teach leaving cert biology, so there really is no getting away from genetics).

That’s how I ended up in the Castleknock Hotel in May, wandering through the front door and seeing people whom I hadn’t seen in years, like Anne, Margaret and Debbie, and about to begin what ended up being one of the best and most informative weekends I’ve had.

The talks were very well organised, ranging from carrier testing and the issues that surround this, to a positive living session taken by Anne on the Sunday. These, along with the family planning talk and one dedicated to the child with the bleeding disorder, as told first hand by two mums, ended up becoming a platform for all the questions I had long stored up inside. The talks were all well-presented and the deliveries so open and honest, that I personally spent the whole conference feeling totally at ease.

The sessions were interspersed with things such as a fabulous afternoon tea-esq lunch, a dinner to die for and to top it off a makeup demo by a fellow Carolvian Anne Hutton (filled us in on all the tricks of the trade whilst giving one lucky girl a stunning makeover). The days passed almost too quickly. If I had to pick my favourite moment, it has to be the talk on dental care....... it was a fabulous way to end the weekend! I went from feeling like I never wanted to know anything about the ins and outs of being a carrier, to forming new connections (and seeing old friends) and suddenly feeling a lot more comfortable in my own skin, now that I was so much more informed.

I was so impressed with the Society for organising this event and the people I met there, that I’ve already pencilled myself in for the Members conference, hopefully I’ll see some of you there!

Ali Bird

Over the weekend of the 7th & 8th May a Carrier Conference took place in Castleknock Hotel in Dublin. Although the conference, was not as well attended as expected, for those who did attend and from evaluations it appears that members did get a lot out of the conference. Some of the positive comments made were: it was informative, good to hear new speakers, nice to hear personal experiences. Some suggestions that came up was to include talks on piercings and tattoos and on dual clotting disorders at a conference in the near future, which we will certainly look at. It was also clear that although the current treatment for haemophilia is excellent, and most families cope extremely well these days, for some it can be still quite difficult and frustrating at times. Below you will find an article written by Ali Bird. I hope you enjoy the read.

Debbie Greene
Dates for your Diary

Hepatitis C / HIV Conference
Date: Saturday 17th & Sunday 18th September
Venue: T.B.C.

October Conference
Date: Friday 14th to Sunday 16th October
Venue: Radisson Hotel, Sligo

Barretstown Haemophilia Camp
Date: Thursday 3rd to Sunday 6th November
Venue: Barretstown

Haemophilia B Information Day
Date: Saturday 12th November
Venue: Offices of the I.H.S.

AGM & Conference 2017
Date: Saturday 3rd to Sunday 5th March
Venue: Slieve Russell Hotel, Cavan
Staff Update
Leah Cawley, who has been working for the Society for the past year and four months, decided to move back home to Mayo and left the organisation in mid-June. We would all like to wish Leah the very best of everything in the future and to thank her for her hard work.
With best wishes from all the staff and the board Leah!

Outreach Update
If any HAA Card holders 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 event just a chat, please contact Fiona Brennan on 087 9361621.

Hoodies
I.H.S. hoodies are available to buy at our events and conferences. Adults sizes cost €25 and kids sizes cost €20. If you would like to order your hoodie in advance, please call the office on 01 6579900 and we would be happy to take your order and prepare same for you for the next conference.

Brian O’Mahony Award
Nominations are now open for the ‘Brian O’Mahony Award for outstanding contribution to haemophilia care in Ireland’. Nominations can be proposed only by members of the Society. Members of the current board or staff cannot be nominated. If you would like to nominate an individual who, in your opinion, has made a real difference in haemophilia care in Ireland, please send your nomination to: Debbie Greene (Email: debbie@haemophilia.ie) The closing date is Friday 30th September 2016.
The second standalone EHC leadership conference took place in Brussels from the 9th to 12th of June, 2016. The conference brought together volunteers, staff and board members from each EHC National Member Organisation (NMO), in order to discuss common goals and challenges that countries face in their bid to achieve sustainable haemophilia care. The weekend consisted of a series of workshops designed to improve the leadership, negotiation and communication skills of all the NMO’s in Europe and to engage with each other to build a support network between countries.

The first day began with a series of workshops that approached the theme of both internal and external communication. Discussions regarding internal communication highlighted the need to encourage members in each NMO to be more engaging with each other.

“There is too much one-way communication,” said Fred Cuipers of the Dutch Hemophilia Society. “Personal involvement within the NMO is very important to keep a dialogue between its leaders and members.” It was established that there is a constant need for interactions within NMO’s and that surveys, media and questionnaires, are a good way of keeping the activities, ideas and goals of the organisation fresh.

External communication is something that all NMO’s find themselves trying to master, whether it is with their country’s health board, government, the media or with pharmaceutical companies. Gaining respect and legitimacy with policymakers can be difficult and different tools and tactics can be used to tackle this. Sessions on

the Friday afternoon, focused primarily on the use of I.T. and social media skills, in order to improve the transmission of information and to advocate for the main goals within an NMO. Kristine Jansone of the EHC ran an informative session on all the online platforms, that can be used to run an NMO in a smooth, transparent and organised way. This was followed by a social media workshop, which encouraged NMO members to publicly inform, engage, report and voice opinions to the larger community. It was also recognised that social media can be an important resource to use within NMO’s, providing private platforms for members, patients and family members to share experiences and advice. It was established, that peer to peer support as opposed to medical practice can be equally, and sometimes more beneficial to members. The increased use of apps was also an indicator of how technology is having an increasing impact on haemophilia care in Europe. Haemophilia apps have the potential to provide a range of services such as tracking haemophilia treatment centres (HTC’s) while abroad, providing key statistics regarding half-life, sending reminders for factor infusions, sending updates and messages from your NMO, how-to information, interactions with medical professionals and much more. Some countries already have or are in the process of creating these apps, which will promote independent care and improved knowledge in dealing with their disorder.

Friday night saw the official launch of the film entitled ‘Haemophilia Stories’ produced by Goran Kapentanovic. The film documented individuals with haemophilia in France, Ireland, England, Sweden, Bulgaria and Romania, explaining what haemophilia is, how it impacts the daily lives of the individuals affected by it and also the stark difference between
haemophilia care in these countries. The personal stories made for a very touching film and the screening was followed by a discussion with Goran and two of the featured participants in the film: Boyan Boyanov from Bulgaria and Christian Dragusin from Romania, who shared their personal views and experiences while featuring in the film.

The second day introduced the concept of external relations with pharmaceutical companies and funding practices. Dr. Paul Giangrande, Chairperson of the EHC Medical Advisory Group, outlined the important factors that need to be considered, when dealing with pharmaceutical companies such as funding, clinical trials, company’s influences and publications. Funding is crucial but we also need to have a constructive dialogue with pharmaceutical companies based on mutual trust and respect. Companies need to know patients’ needs and this is a fundamental issue in many countries, where neither the patient nor the NMO has any input, in the quality or quantity of the medication given to them. Patient confidentiality should be respected, and all relations between NMO’s and pharmaceutical companies should be carried out with complete transparency. All interests should be declared honestly and openly from the beginning.

A negotiation workshop followed which was chaired by Kristine Jansone of the EHC. Kristine outlined some key points for useful preparation strategies such as the importance of separating the people from the problem and preparing the best alternative to the negotiated agreement. Negotiation strategies were discussed such as using the correct language, using positive phrases, agreeing with the opposition when possible and most importantly, aiming for and accepting a mutual satisfaction between both parties. A communications lecture by Danish expert Arjen Mol also highlighted how it is often useful to assess the personality of the people you are dealing with to build relationships - if the negotiating experience is positive for decision makers, it will likely open doors for further discussions. Case studies revolving around tenders and procurement put the theory of each of these topics to the test and allowed delegates to emulate scenarios they would be faced with in reality.

With just six months experience as a staff member of the Irish Haemophilia Society, I approached this conference as an opportunity to learn more about treatment for bleeding disorders, the contrast of haemophilia care in European countries and of course, all the communities involved. It would be an understatement to say I was blown away by the drive and strength in the people who are advocating and often struggling for an improved access of treatment for the people with haemophilia in their individual countries.

Collectively and individually - what can we do? It is vital to encourage younger generations to constantly challenge and question the way NMO’s, health boards and tender boards are managed and to always strive for improvement. In order to do this, we need to take the skills we have learned and build on them both within our individual NMO and also alongside our fellow European NMO’s. The EHC and conferences like these are vital to maintain a continued standard of haemophilia care as they offer the tools, resources, assistance and support needed to give NMO’s a platform and the encouragement to approach their governments and policy makers. Along with the help of the EHC, we can also learn from each other with the positive or negative experiences we may have had. The main take-home message after the weekend was to ensure that the learning process did not stop when everyone returned home. Contacts were shared and alliances were made, skills were learned and it is with these resources that NMO’s will be able to reach out and ask for help from each other and continue to strive for sustainable haemophilia care in Europe.

Aoife Ní Fhógartaigh