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The Society at a Glance

848 Facebook Followers ↑	**50** Planned giving Contributors ↑	**71** IHS Volunteers ↑	**5858** Website Hits ↑

Edition: April 2016

haemophilia.ie

Irish Haemophilia Society Carrier Conference

Date: Saturday 7th & Sunday 8th May, 2016

Venue: Castleknock Hotel, Castleknock, Dublin 15

PRELIMINARY PROGRAMME

Saturday 7th May

11.30am – 12.00pm	*Registration*	
12.00pm – 1.00pm	*Lunch*	
1.00pm – 2.30pm	Group 1 (16 – 24 yrs):	Carrier Testing & Carrier Issues
	Group 2 (25 – 40 yrs):	Family planning & pregnancy
	Group 3 (40 yrs plus):	Menopause & Ageing
2.30pm – 3.30pm	The Child with a Bleeding Disorder: The first two years (Full Group)	
3.30pm – 4.00pm	*Coffee Break*	
4.00pm – 5.00pm	Make-Up Demonstration (Full Group)	
7.30pm	*Dinner & Girls Night In* (Full Group)	

Sunday 8th May

10.00am – 11.30am	Positive Living (Full Group)
11.30am – 12.00pm	*Coffee Break*
12.00pm – 1.00pm	Dental Care (Full Group)
1.00pm – 2.00pm	*Lunch*

There are now many ways to keep up to date with the I.H.S. Check out the I.H.S. website www.haemophilia.ie for all the latest news and to register for events.

You can follow the I.H.S. on social media!

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A Note from the Editor

Debbie Greene
Administrator

Hello everyone,

Welcome to the April edition of 'haemophilia.ie'. I am excited to present this edition to you and I hope you enjoy the read. My gratitude goes to all those who contributed.

On page 4 our Chief Executive gives us a very informative and detailed update on the exciting new developments in haemophilia care. This article is definitely worth a read.

This year is a busy year with various conferences and events. On page 2 you will find information about our Carrier Conference that takes place in May. On page 22 and 23, you will also find the preliminary programmes for the Parents and Members Conference.

For our younger members check out the Cubs & Kidlink Club on pages 12 & 13. You will find dates for all our main events this year on page 8, and you can keep checking the website for further updates on all our events.

You will find lots of interesting articles and photos from the recent AGM on pages 14 to 19. Thanks to everyone who attended the AGM and Conference and to everyone who helped out and made it a great weekend, in particular, all our volunteers who I am sure were exhausted on Sunday night. It was also very encouraging to see so many attending the various sessions, including some of our youth group.

If any of you ladies would be interested in doing the Women's Mini Marathon in June on behalf of the I.H.S., contact Nina in the office and she will assist you with sponsorship forms and anything else you need. Further information on this can be found on page 10.

Finally, if there is anything we can assist you with, if you fancy dropping in for a cup of tea and a chat, or would like to talk to somebody in confidence, please do not hesitate to contact the office on 01 6579900.

Happy Reading!

Debbie Greene
Administrator

CEO's Report

The recent AGM and Annual Conference of the Society was a great success. Dr. Glenn Pierce from the United States delivered an excellent lecture on 'New Therapies in Haemophilia'. The lecture was delivered by Skype, as unfortunately, he was ill and unable to travel in person from the United States for the conference. Despite this, it worked extremely well and he gave an excellent overview of the new therapeutic options for haemophilia, now and in the coming years.


Professor Ted Tuddenham

Professor Edward Tuddenham also delivered an excellent update on gene therapy. The first extended half-life recombinant factor VIII concentrate was licensed in Europe in November in 2015. The 'Haemophilia Product Selection Monitoring Advisory Board' (HPSMAB) recently signed a contract to use some of the new extended half-life (EHL) factor VIII product from April 2016. This will be used primarily for the treatment of children but will also be available to some adults. The new factor concentrate is fused to the Fc portion of a normal human immunoglobulin. Fusion to the Fc protein allows the factor VIII to be recycled within the cells and therefore last longer in the circulation. The half-life of this factor VIII is approximately 1.5 times greater than the current recombinant factor VIII concentrates. Additional EHL recombinant factor VIII concentrates will be coming on the market this year and in 2017. The first two EHL recombinant factor IX concentrates are also expected to be licensed in Europe later this year. The next EHL recombinant factor VIII to be licensed will almost certainly be a product where the factor VIII is linked to polyethylene glycol (PEG), which slows the degradation and breakdown of factor VIII and also increases the half-life by approximately 1.5 fold. The EHL factor IX concentrates coming on the market this year will be a product where the factor IX is linked to the Fc portion of immunoglobulin (similar to the current new recombinant factor VIII) and a product where the factor IX is linked to human albumin.


Brian O'Mahony,
Chief Executive

The half-life extension of the recombinant factor IX is even greater where they are able to achieve a three to five-fold increase in the current factor IX half-life.

The half-life of the currently available recombinant factor VIII concentrates is typically twelve hours. For the new EHL factor VIII concentrates on the market and coming on the market, the half-life will range from 14 to 19 hours.

The half-life of the currently available recombinant factor IX concentrates is typically 18 hours. The new EHL factor IX concentrates coming on the market will have half-lives ranging between 82 and 102 hours. As these products become available over the coming years, they will add to the therapeutic options available for people with haemophilia and will certainly lead to individualisation of treatment. Currently, the majority of people with haemophilia who are on prophylaxis would be treated with a similar number of units per kilogramme, with the same frequency of infusion and little variety in treatment protocols. This will change in the future.


I.H.S. member Joe McCabe speaking during the new developments session.

With the new EHL factor concentrates available as an option, we expect to see a situation where an individual's treatment will be individually defined, based on their bleeding history, any target joints they may have, venous access, their activity levels and their lifestyle.


Brian O'Mahony speaking about the new products under development.

The people with haemophilia who face the greatest challenges in terms of current therapy are those with high titre inhibitors. There are a very small number of bypassing agents which can be used to treat people with inhibitors and their half-life is very short. There are a number of new and novel bypassing agents now under development which should greatly change the therapeutic landscape and improve the quality of life and therapeutic options for people with inhibitors. One of the current bypassing agents which is routinely used is factor VIIa. This is an effective therapy but it has a half-life of two hours. A new factor VIIa is under development which is linked to albumin and this will give a four-fold half-life extension to just over eight hours. A new antithrombin product (ALN/AT3SC), which goes under the name of Fitusiran, is under development. Antithrombin is a naturally occurring anticoagulant which activates thrombin and in people without bleeding disorders prevents too much coagulation. Fitusiran is a product which seeks to inhibit the effect of antithrombin and therefore increase the amount of coagulation. The product has had positive interim phase one results in clinical trials as a subcutaneously administered product. It dramatically reduces the levels of antithrombin in the blood and therefore allows more clotting to occur. A concern with a product like this would be that you could actually see thromboembolic events or too much coagulation occurring. This has not been seen in the clinical trials to date. To date, the clinical trials have shown a significant decrease in the annual bleed rate which seems to be linked to the proportional decrease in the antithrombin levels. The phase three trials for this product are now starting and this product may be a therapeutic option in the future for haemophilia A, haemophilia B and for the treatment of inhibitors of haemophilia A and haemophilia B. We will be meeting with this company in the near future and we hope to persuade them to include Ireland in future clinical trials for this product.

Another very exciting product under development is called an ACE 9-10 bispecific antibody. For people without haemophilia A, factor VIII promotes the interaction between activated factor IX and factor X and therefore results in coagulation and clot formation. The bispecific antibody links the activated factor IX with factor X without the requirement to have factor VIII present. The product, which would be administered subcutaneously once a week or once a month, could be a therapeutic option for prophylaxis for people with factor VIII deficiency or factor VIII inhibitors. The product, currently going under the name Emicizumab mimics the effect of factor VIII. In phase one initial clinical trials, the annual bleed rate was reduced by between 64%-96%. For the higher doses, a 93%-100% reduction in bleeds was achieved with only mild or moderate adverse effects. This product is currently going into phase three clinical trials and following our liaison and interaction with the company developing this product, we are delighted that Ireland will be included in the clinical trials for this product.

Last but not least, another major development is gene therapy. There are currently six companies developing gene therapy for factor IX deficiency and two companies developing gene therapy for factor VIII deficiency. The longest established and most successful gene therapy trial to date, is that of University College London and the Royal Free Hospital in London. They have already treated ten people with severe factor IX deficiency and achieved steady factor IX expression between 1% and 6% following a single injection of up to five years ago. Their work has prompted several other companies to begin work on factor IX gene therapy and the Royal Free Hospital in London are now starting a new factor IX gene therapy programme, which will involve a new vector delivery system, with the aim of achieving even higher long-term expression of factor IX in the region of 15%. We are delighted that the Royal Free Hospital and their development company have agreed to include Ireland in the clinical trials for their new factor IX gene therapy. They have also agreed to include Ireland in the clinical trials for their factor VIII gene therapy which will be

Members enjoying the AGM.

commencing in 2017. They are one of two organisations or companies currently developing gene therapy for factor VIII deficiency. The first two patients have been infused with factor VIII gene therapy late last year in the UK. I had the pleasure of meeting the first man who was infused with factor VIII gene therapy and he is very excited about his future prospects. Later this year, we will be organising meetings for patients for factor IX deficiency to discuss their interest in factor IX gene therapy and this will be followed by meetings on factor VIII gene therapy. The gene therapy trials will be open to adults over the age of eighteen with severe haemophilia. Gene therapy gives us the enticing prospect of an effective cure for haemophilia. If gene therapy can result in a constant expression of 15% - 20% of factor VIII or factor IX, then this will be an effective cure as factor concentrate would be required on very rare occasions or for major surgical procedures. Challenges remain with all of these therapies and in particular with gene therapy, the scale up production will not be easy. The economics of these new products and consequently their availability, will also be challenges we will have to face in the future. However, it is safe to say that with all of these new products under development, the future has never looked brighter for haemophilia therapy and there is a real possibility of transforming the quality of life for people with haemophilia in the next five to ten years.

Our advocacy in relation to the availability of hepatitis C therapy for our members continues. We are now in a position where there are only 12 people with haemophilia remaining who require treatment for hepatitis C. We are working to ensure that every person with haemophilia who requires treatment will be offered treatment in 2016. The Society are represented on the clinical advisory group established to look at treatment protocols for the new 'National Hepatitis C Treatment Programme', so we will continue working in this area. We are also organising an open conference, open to any person with hepatitis C (details on page 7). This will be held in Dublin in May and the objective of the conference is to educate people with hepatitis C in relation to why they should be treated, what the current treatment options are and to explain the new 'National Treatment Programme'. More importantly, there will be a panel of personal stories from people who have undergone treatment who will talk to an audience of those who are still facing treatment. This is the second year the Society has organised this conference. Last year, it was very well attended by approximately 150 people and was opened by the Minister for Health. We hope that the conference this year will make a further contribution to the knowledge base on hepatitis C treatment for people living with hepatitis C and their families.

Brian O'Mahony
Chief Executive

Hepatitis C Conference

Date: Saturday 21st May 2016

Venue: Castleknock Hotel, Castleknock, Dublin 15.

This one-day conference, (organised by the Irish Haemophilia Society) will be an opportunity for people with hepatitis C who are contemplating treatment now or in the future to receive updates on hepatitis C treatment options.

THERE IS NO CHARGE TO ATTEND THIS CONFERENCE BUT REGISTRATION IS REQUIRED. PLACES ARE LIMITED AND WILL BE GIVEN ON A FIRST COME FIRST SERVED BASIS.

PROGRAMME

10.00 – 11.00hrs	Registration
11.00 – 12.00hrs	**Hepatitis C – Why Treat and Treatment Options?** Dr. Diarmuid Houlihan, Consultant Hepatologist, St. Vincent's Hospital
12.00 – 13.00hrs	**The National Hepatitis C Treatment Programme** Ms. Michele Tait, Programme Manager, National Treatment Programme
13.00 – 14.00hrs	Lunch
14.00 – 14.30hrs	**Managing your Treatment** Ms. Helena Irish, Clinical Nurse Specialist, St. James's Hospital
14.30 – 15.00hrs	Coffee Break
15.00 – 17.00hrs	**Panel Discussion – Personal Treatment Stories**
17.00hrs	**Conclusion & Wrap Up**

To register to attend this conference please:

- **Complete the online booking form on www.haemophilia.ie**
- **Call the office on 01 6579900**
- **Email the office at the following: info@haemophilia.ie**

Dates for your Diary 2016

Carrier Conference

Date: Saturday 7th - Sunday 8th May
Venue: Castleknock Hotel, Dublin

Hepatitis C Open Conference

Date: Saturday 21st May
Venue: Castleknock Hotel, Dublin

Parents Conference

Date: Friday 24th - Sunday 26th June
Venue: Sheraton Hotel, Athlone

October Conference

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

Barretstown Haemophilia Camp

Date: Thursday 3rd -
Sunday 6th November
Venue: Barretstown

Haemophilia B Information Day

Date: Saturday 12th November
Venue: Offices of the I.H.S.

New Look Website!!

Coming your way soon!!!!!!!!!!

Our new website has everything going for it. It is efficient and visual with a thoughtful user interface and meaningful content. It will be so easy to navigate!

www.haemophilia.ie

Browser
Applications
Music
Email

Support the I.H.S.

The I.H.S. provides services and support to adults and children with haemophilia, von Willebrand's disease and other rare bleeding disorders. Fundraising allows us to provide education and support not just to the person with a bleeding disorder, but to their whole family. With your help, we can continue to build on this support and plan for the future, so we are asking you to please fundraise for the I.H.S. Every little you can do will go a long way to helping others.

Fundraising can be in many forms, whether you plan a fundraiser yourself or take part in an organised event. If you are planning a fundraiser, we will be happy to offer information and support, along with anything you may need such as Garda permits, posters, tickets, I.H.S. t-shirts and sponsorship cards etc. Why not consider some of the ideas listed below.

If you are taking part in an organised event, again we will be happy to provide sponsorship cards and I.H.S. t-shirts. To check out events in your area just log onto www.runireland.com and take a look at their Events Calendar. This lists all the different types of events which are taking place all around the country throughout the year. Don't be put off by the name, it is not all about running. The events include walking, orienteering and aquathlons; there is something for everyone.

Why not make your fundraising easier by setting up your own fundraising page on MyCharity.ie. It is quick and easy to set up and offers a safe and secure way for family and friends to sponsor you, no matter where they are in the world. You can then share your fundraising page on Facebook or in an email. All funds raised through MyCharity.ie come directly to the I.H.S.

As important as it is to raise funds, it is just as important to raise awareness. Every fundraiser or fundraising event helps to highlight the needs of people with a rare bleeding disorder. So make this the year that you are going to give your support and fundraise for the I.H.S.

For information or help with any aspect of fundraising and on MyCharity.ie just call me in the office on 01-657990 or email me at nina@haemophilia.ie. THANK YOU!

Nina Storey

Help Us, Help Others!

If you are taking the time to read this article, thank you. We hope that you will play an active role in allowing the I.H.S. to grow from strength to strength in the future. We would like you to help us to help others both at home and abroad.

At home the I.H.S. provides education and support to all our members, not just to the person with a bleeding disorder but to their families as well. We have many different aspects to our services in order to provide support to adults with a bleeding disorder and to young children, their parents and siblings. You will see listed some of the services we provide, but like many things these services need to be funded. One of the main services we provide are the educational conferences throughout the year. In particular the AGM & Conference, the Parent's Conference and the Member's Conference. These weekend events allow us to provide important information and support to our members. They allow our members to build relationships with each other and share experiences and practical information. All these conferences are open to families, so as well as the adults' sessions, we provide age appropriate educational talks for each of the children's groups. This encourages the children to understand and take an active role in managing their own bleeding disorder.

To find out more about the work of the I.H.S. log onto www.haemophilia.ie or just phone the office and we will be happy to talk to you.

- Educational Conferences
- Publications
- Entitlements & Benefits
- Home & Hospital Visits
- Website & Social Media
- Grants & Scholarships
- Phone Support
- School Talks
- I.H.S. Apartment Facility

Along with the services we provide for our members at home, we are actively involved in the development of haemophilia care globally. We originally twinned with Vietnam from 2010 until 2014 and during that time we were overwhelmed by their enthusiasm and work ethic to improve haemophilia care in their country. So much so that when our Twinning Programme came to an end, the I.H.S. continued its involvement with Vietnam through the World Federation of Hemophilia GAP Programme.

To help us to continue to improve and build on our services we need to your help. A quick and simple way for you to give your support is through our 'Planned Giving'. Making a monthly or annual donation is a secure and easy way to show your support. Contributions can start on a date that works best for you, for an amount that suits your budget and they can be stopped at any time. Contributions can start from as little as €10 per month (33 cent a day). However, if you choose to contribute €21 (69 cent a day) or more per month, the I.H.S. as an eligible charity can benefit from tax relief from Revenue in respect of donations. Your gift can go even further at no extra cost to you.

Dr Mai with a young patient in Vietnam.

If you would like to contribute to the Planned Giving or would like more information, please contact me on 01-6579900 or email nina@haemophilia.ie

Nina Storey

Cubs Club

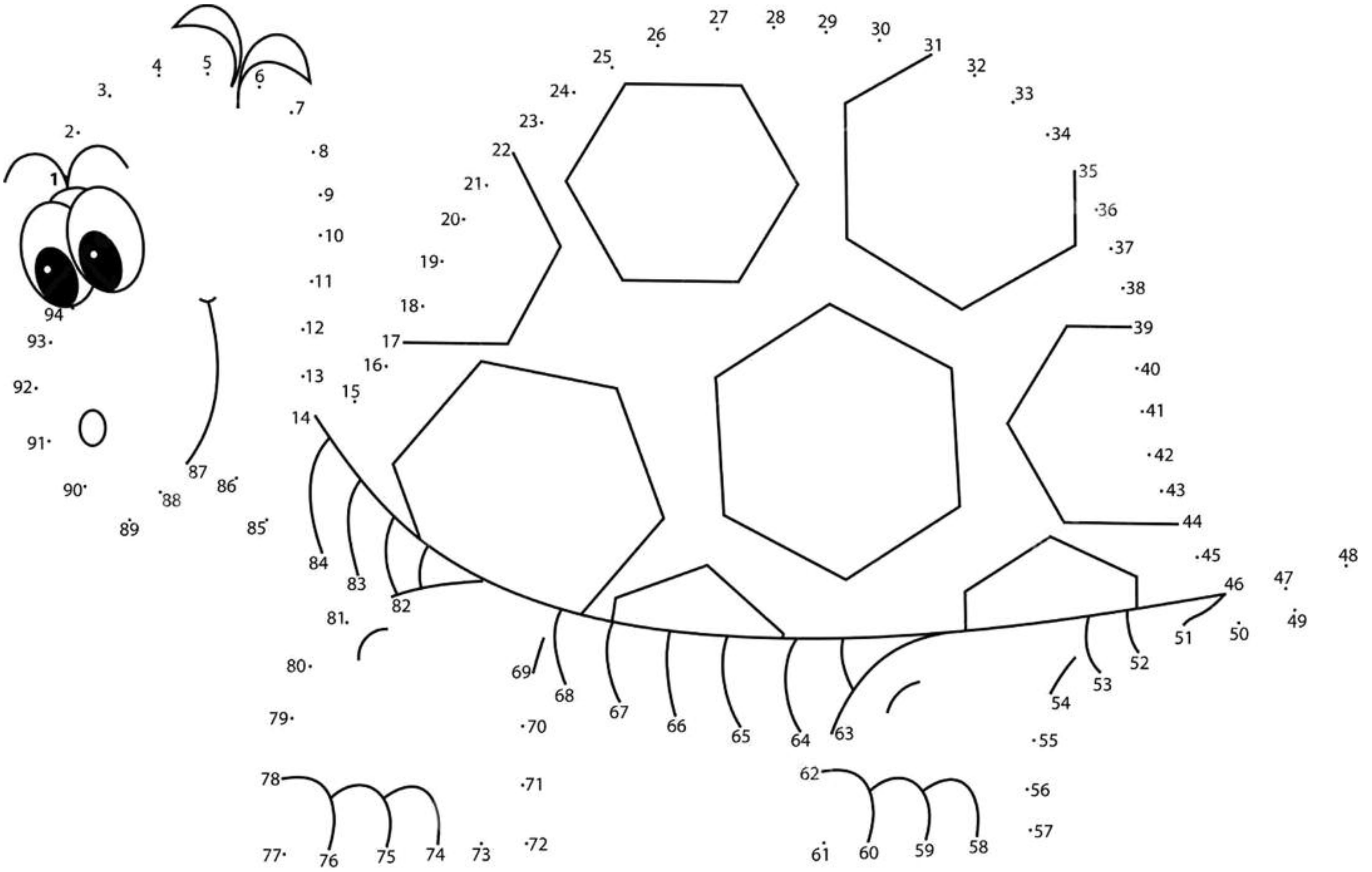
Welcome to another edition of our Cubs Club!!

This is Brian. You may have met Brian already. He has haemophilia. He was born with it and will have it for his whole life! When a boy is born with haemophilia there can be another member of their family with haemophilia, like your grandad or your uncle. This means that it is inherited (in-hair-it-did) This just means that it was in your family before you were born. Other things that you inherit from your family is the colour of your hair or eyes.

Sometimes you can be the 1st person in your family with haemophilia and this is called spontaneous (sp-on-they-knee-us) haemophilia. It is like magic!!! It is only really boys that have haemophilia but girls can have haemophilia too sometimes. Even though haemophilia mainly happens in boys, it doesn't mean you and your brother(s) will all have haemophilia.

Which letter is the coolest? **Iced T**

Join The Dots & Colour Toby the Turtle



Welcome to the Kidlink page!!

What should I do when I have a bleed?

If you think you may have a bleed or you are not really sure if you do, you must tell an adult straight away so that they can help you take your factor and make sure that you are ok. If you have a bleed and you don't tell an adult, you won't get your factor in time and you may be in a lot of pain. As you probably already know, there are two ways to get your factor – straight into your vein, or through your port-a-cath (Freddie). While your veins are still growing you can take your factor through your port-a-cath which is a device just under your skin. When you are getting your factor it is important to relax and let your factor soldiers get to work. I like to read, or watch my favourite programme on T.V. while I am relaxing. What are your favourite things to do while relaxing?

1. ______________________

2. ______________________

3. ______________________

Can you find the words on the right hidden in the letter Square?

T	Q	I	T	G	C	Z	I	N	H	E	R	I	T	E	D	I	W	J	C
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C	B	I	N	T	K	B	L	N	W	Q	S	X	C	T	N	W	C	G	C

BLEED
COMPRESSION
ELEVATION
EXTERNAL
FACTOR
FREDDIE
HAEMOPHILIA
ICE
INFUSION
INHERITED
INTERNAL
JOINT
MILD
MUSCLE
PORTACATH
REST
SELF
SEVERE
SPONTANEOUS
VEIN

AGM & Conference Review

Annual General Meeting of the I.H.S. on Saturday 5th March 2016 in Hotel Kilkenny.

Chairperson Traci Marshall Dowling addressing the membership.

After all the weeks of preparation the morning of the conference arrived, as did the bad weather. Snow, no it couldn't be, I thought! Thankfully, it wasn't too bad; it cleared up pretty quickly and our guests and speakers who were due to land on Friday morning arrived ok, so we packed the bus and off we went to Hotel Kilkenny. The afternoon was busy getting everything set up and ready for registration later in the evening. So far so good, I thought. Registration went well, as always it was nice to see members and have a quick chat with them.

Saturday morning started with the Annual General Meeting at 10 am which was extremely well attended. The Chairperson Ms. Traci Marshall Dowling opened the meeting, welcomed guests and called for the adoption of the minutes. Next up was the Secretary's Report. Ms. Barbara Wynne gave details to members in relation to the events and activities of the Society during 2015, along with information on publications, the website, social media, home visits, educational grants, the staff and finished by acknowledging with gratitude everyone who donated, volunteered and fundraised. The Treasurer Mr. Gerard O'Reilly presented the Audited Accounts for 2015 and answered many questions from the floor on the Society's finance. The Chairperson addressed the membership and spoke about supports and services available to members, the 'Youth Leadership & Mentoring Programme' that was initiated in 2015 and also updated the membership on the apartment facility. What a great facility this has been for members with a total of 95 people using the facility in 2015. The Chairperson thanked the board and staff for their dedication and hard work and in particular some of the board who were stepping down on the day. Next up was the Chief Executive; Mr. Brian O'Mahony gave members an update on where we are with hepatitis C treatment. There are only twelve members now who need treatment, and the objective of the Society is that all I.H.S. members are treated before the end of 2016. The Chief Executive spoke about new developments in haemophilia care, the new National Centre for Hereditary Coagulation Disorders (NCHCD) which will be built two floors above the H&H Unit. We also got an update on our work with Vietnam and on blood safety issues. The Chief Executive spoke about the impact of having patients and clinicians involved in the decision making in relation to factor concentrates, so much so, that a total of €132 million has been saved. Finally, members got an update on the Strategic Plan and on finance and how important it is for the Society to be economical with finance. It was then time to open the meeting to the floor and it was great to see so many members

Cora Marshall putting some questions to the board.

ask questions, get involved in the discussion and bring up issues, good and bad, that they had encountered. The business of the AGM finished at 12.30pm and the Chairperson formally closed the meeting.

Dr. Alison Dougall speaking during the 'Open Forum'.

After lunch, a two-hour symposium took place on 'New Developments in Haemophilia' and what an exciting time it is in relation to clinical trials and gene therapy. Dr. Glenn Pierce skyped in and went through his excellent presentation. This was followed by a very detailed presentation from Professor Ted Tuddenham from the UK. Chairperson of the National Haemophilia Council Dr. Barry Harrington then chaired an 'Open Forum' with the Comprehensive Care Centres and again it was very encouraging to see members getting involved and asking questions.

Later in the evening, before dinner, the Awards Ceremony took place. Ms. Carly Wright was presented with her award as recipient of the 'Maureen & Jack Downey Educational Grant', Ms. Niamh Birkett as the recipient of the 'Margaret King Educational Grant', Mr. Pat Rabbette as the recipient of the 'Fundraiser of the Year' Award and Dr. Barry Harrington was presented with the 'Brian O'Mahony Award for Outstanding Contribution to Haemophilia Care 2015-2016'. Ms. Eadaoin O'Shea was also presented with a special award for all her hard work over the years in haemophilia care as she retires.

On Sunday morning Mr. Brian O'Mahony and Dr. Mai who had travelled from Vietnam gave an updated on the 'Global Alliance for Progress' (GAP) programme and next door Dr. Alison Dougall gave members an update on 'Dental Care. The last session of the conference was 'The History of the I.H.S.' which was presented by Mr. Brian O'Mahony and for me, was the highlight of the weekend. The room was packed with members, with some of the youth group also in attendance for this talk. The work that the Society and its members has done over the years has been immense. The early 1980's was a very active, traumatic and an emotionally difficult time for the Society. Many lives of many individuals and families were destroyed. Brian's presentation was seamless, fitting and it is quite clear to me that the Society have huge strength. You could feel the emotion in the room and in fact many members filled up during this presentation and what a perfect ending when Mrs. Hilary O'Sullivan spoke so eloquently and articulately about the past, the present and the very bright future.

Debbie Greene

Traci Marshall Dowling presenting Carly Wright with the 'Maureen & Jack Downey Educational Grant'.

Grace O'Sullivan presenting Pat Rabbette with the 'Fundraiser of the Year Award'.

Debbie Greene, Brian O'Mahony, Seamus McDonald.

Gerard O'Reilly presenting Niamh Birkett with the 'Margaret King Educational Grant'.

Brian O'Mahony presenting Eadaoin O'Shea with a special award on her retirement.

Brian O'Mahony presenting Dr. Barry Harrington with his award for 'Outstanding Contribution to Haemophilia Care in Ireland'

AGM Report

Haemophilia is relatively new to our family, and we are still learning so much. It took us a few years before we started to attend any I.H.S. events despite the best efforts of the nurses in Crumlin to convince us how we'd never look back. Now we only look back and wonder why we didn't get involved sooner.

This was our second AGM. It was just as enjoyable as every other event we have attended over the last year. All of the talks are always very informative and interesting. This time around hearing about the history of the Society was one talk we did not want to end. What an amazing story and so many wonderful accomplishments achieved by such inspirational people. We are incredibly proud to be members of the Irish Haemophilia Society and so grateful to those who paved such a supportive path for our children.

The volunteers in the kids groups were wonderful, entertaining all those kids for 8 hours must be so exhausting, but there was never a hint of anything other than good humour when I saw any of the volunteers.

We had Ollie (2) in the crèche. We are always a little nervous leaving Ollie anywhere as he does like his mammy and daddy's company (24/7, 365 days a year if he had his way), but once we dropped him off and left the room (like ninjas trying not to get caught), he was grand. When we collected him, he was very happy, and we know he had a great day.

Liam (5) was in Cubs. Liam was bursting with excitement and getting to his cub's group just couldn't come quick enough. This was the topic of conversation for weeks before hand. "When are we going? What will I be doing? Who will be there? Are we going tomorrow?" He just couldn't believe when the day actually came. His excitement was clearly a reflection on how much fun he had at the previous events. We dropped him off bouncing off the walls and collected him exhausted, but he was so happy. He became very fond of the volunteers who looked after him all day.

Leah (8) was in Kidlink. This was Leah's first time in the bigger group, and she was a little nervous about going to a new group on her own, full of new people. Dropping Leah off was a lot more subdued than the boys but she toddled in quietly but happily, and one of the volunteers helped her to settle in. Collecting her was like we came back to a different child. She was dancing around without a care in the world and had settled in just fine. Again, such a credit to the volunteers in the group.

The kids learned so much over the weekend. From dental care to physical fitness to the developments being made with treatments. They came back and educated us and are still randomly pointing out various foods and stating how much sugar they contain. It's great they took so many valuable lessons home with them.

Overall, the weekend was just brilliant, and we cannot wait for the next event. The whole event was so well organised. The kids had an absolute ball and were asking on the way home when we'll be going back.

Linda & Davie Jennings

A Farewell from Eadaoin O'Shea

Dear Members,

It is with joy and sadness that I have recently retired from my nursing career. For the past 27 years I have worked in the National Centre for Hereditary Coagulation Disorders, or as I knew it 27 years ago, the "Haemophilia Centre".

As some of you know, when I came to the Haemophilia Centre, I took over from the beloved Sister Margaret King. Margaret was loved and treasured by you all. They were difficult shoes to step into.

Haemophilia nursing care in 1987 was very different to the care offered today. Sadly, then it was besieged with caring for people who had been infected with the AIDS virus. The Haemophilia Centre was located in one room on Hospital One, Top Floor. Facilities were far from adequate. Daily, I was met with distraught, sad, angry and frightened patients and their families. I found those years obviously very difficult and was often overwhelmed with grief myself, as I became close to so many patients and families.

Thankfully, since then there has been progress with anti-retroviral treatments, recombinant factor concentrates, prophylaxis and more recently, successful hepatitis C treatments. I leave haemophilia nursing in a very different place. The outcome is so positive and the care from the NCHCD is considered to be world class.

I have shed tears and also shared many joys and laughs with many of you along the 27 years of haemophilia nursing. It has been my great pleasure getting to know so many of you and I will always treasure so many warm memories. Finally, I would like to take this opportunity to wish all of you health and happiness in your futures.

Kind regards,

Eadaoin O'Shea

Volunteering for the IHS

October, 2013, sitting on my couch, Paul Dunne texts me.

"Do you fancy coming to Westmeath for an adventure weekend?"

"Absolutely. When?"

"This weekend."

"Hmm... this must have a catch... what do I have to do?"

"Mind a load of teenagers..."

"Hmmmm..."

I know Paul a long time - I thought that if he was asking he was either desperate or else he thought I'd like it - it was probably both to be fair. I said yes.

Jay McEvoy and Paul Dunne.

AGM March 2016

I've been looking after these teenagers regularly for a few years now, and I am starting to know most of them quite well. Some of them even know that my name is not "Tall Paul" now. Some of them even say hello to me when I pass them in the corridors... teenagers are delightful.

From hour one of day one the Youth Group immediately set about torturing me - brain teasers, games where you have to work out the rules as you play, puzzles. Anything that they knew I didn't know how to play, or that would take me out of my comfort zone, was the games they wanted to play. Like any true apprentices of Paul Dunne, not one of them gave me a single clue about any of the rules for the games and I was left to work these out over the course of about 3 hours. Torture. I think the group immediately felt comfortable with me because Paul told them they could relentlessly wind me up and that not only would he not give out, he'd actively encourage it. However, what I never realised until years later is that I make the kids do the exact same thing. Get out of your comfort zone, make a show of yourself, instantly tear down your defences and worries and become part of the group. It worked so well I did not even realise I was doing it – or that they were doing it to me. Being able to do that has served me well countless times in the Society and I am always grateful to Paul and my tormentors for those first few days.

Since then it has been nearly three years of pure fun. People always ask me "What got you into that?" and I always just say "Paul", but the reason I keep coming back is everything else. I've built forts, played shout-run, had eggs splattered on my head, won a treasure hunt and crystal maze, archery, climbed up a tower of milk crates that I was building as I was climbing (while attached to a harness), played laser tag in the forest at night, hummed songs at complete strangers for hours on end while they held a phone to their forehead, given and taken a fair share of slagging, sang (badly), danced (excellently), had a drink or two with amazing people and of course, ended up in a pizza shop in Northern Ireland ordering 14 large pizzas at 10pm for a group of hungry (and by definition; cranky) teenagers! I've also made friends and have genuinely been taken back by the kindness and welcoming nature of so many of the people in the Society.

Our fantastic volunteers at the 2016 AGM

The one thing that stood out to me immediately is the closeness of the Society. The Society look after everyone extremely well, and speaking purely from my own perspective; they especially look after the volunteers well. In my experience, every single volunteer that helps out is always more than happy to do so. Fiona has a great bunch of volunteers which she looks after amazingly well. In turn, every single volunteer I work with looks after their group amazingly well. No matter what group of volunteers, no matter what age group that group is given, no matter what location – the volunteers are willing to go above and beyond for this Society. It was something that struck me from day one, and still surprises me now. Not that it should surprise me – every single one of the volunteers are extremely dedicated to the Society, which is a testament to them and the I.H.S. as well. On a personal note, I would do anything I could for the Society and hope to be still helping out for years to come. Some might say that that's just because I want to retain my crystal maze trophy, and those people would be right, but I also want to win all the other competitions the Society think up too!

It's not only the fun that keeps me here though. Even now this group of people still surprise me. On the last day of the AGM, we went to a talk called "The History of the I.H.S.". The last few feedback forms had told us that some of the Youth Group were looking for something with a bit more substance than just games, and let's face it – the games are less fun when they don't get to make a show of me and drive me insane for 3 hours. From chatting to the Youth Group they told us that they wanted something more adult, and they told us that they would like to go to some of the adult classes and/or talks – so this was chosen as their first expedition – after Happy Gilmore, obviously.

As I said above, the closeness of this Society is something that always amazes me. These are more than just people who meet up two or three times a year, some of these people are genuinely close friends. You can see it everywhere you go on the weekends. From the children all the way up to the eldest members – this is a close Society. I never fully understood why until I went to that talk. To see the efforts that have gone into the I.H.S., just even to survive, blew me away. To see the politics, the sacrifices, the losses that some of these people underwent together was incredible. Seeing the Society in its early days, trying to stay afloat while fighting for basic human rights in the 80's and 90's was a humbling experience. I sat in a room with people who had carved out and shared their own little piece of Irish history, and I realised then why they were all so close. I was very proud to be part of something like the I.H.S. that day.

To say I've enjoyed my time with the I.H.S. would be a massive understatement. I can't remember ever even entertaining the thought of not going ever since the first night I spent in Westmeath – except maybe when Sam was screaming "GET UUUUUP" while banging pots and pans together on that first morning. That aside, it's been a wonderful experience and again, it's something I hope to continue in some shape or form for the foreseeable future. I should mention all the I.H.S. staff now, who have never been anything but amazing to me. They give consideration to everything and help us to do our jobs as best we can. Volunteers always get a lot of credit, and I think they should get just as much as we do.

To everyone; staff, volunteers, parents, kids and anyone else. Thanks for having me, and making me feel like part of something I think is extremely special.

Jay (Tall Paul)

Do you want to become an I.H.S. Youth or Junior Member??

There are loads of benefits for when you become a Youth or Junior Member such as:-

- Learning about bleeding disorders
- Helping to educate others about bleeding disorders
- Taking part in activities and events
- Supporting friends with bleeding disorders
- Newsletters
- Youth forum
- Competitions
- Career guidance

These are just a few of the benefits to joining. If you would like to become a Youth or Junior Member all you have to do is get your mom or dad to contact Leah on 01 6579900 or email leah@haemophilia.ie and I will send you out the consent and application form, you need to fill it in with all your details and send it back to me. **Simple as that!!**

To be a Junior Member you have to be aged between 7 – 13 years of age. To be a Youth Member you must be aged between 13 – 18 years of age.

You do not have to have a bleeding disorder to be a Youth or Junior Member, you can be a brother or sister of someone with a bleeding disorder.

Barretstown

Rebuilding Lives Affected By Childhood Cancer

BARRETSTOWN

a Hole in the Wall Camp

Year after year, we advertise the Barretstown Summer and Family Camps to our members and year after year, we have a great response with last year over 75 children and families attending either Summer or Family Camps!

Firstly and importantly, Barretstown has a fully trained medical staff with doctors and nurses attending from Crumlin and various hospitals from Ireland and the UK, so you can be assured your child is in the best medical care for the duration at camp. There is no charge for children or their parents to attend any Barretstown Camp! There is also a huge range of activities for children to try and Barretstown's unique programmes – using Therapeutic Recreation – are much more than holidays.

They are based on four main building blocks, with the emphasis always, always on FUN – Challenge, Success, Reflection and Discovery.

Why do our children go to Barretstown?

Haemophilia and related bleeding disorders are chronic conditions. While children in Ireland are extremely fortunate to have access to high quality treatment available, there can be some obstacles associated with the diagnosis of a chronic illness. Children with haemophilia have a strict prophylactic regime which can sometimes be difficult to manage. They may miss school and regular activities particularly sport due to due to breakthrough bleeds. Barretstown is and has been a place where the children are not defined by their condition and the sometimes imposing limitations it may bring. It offers the children the opportunity to focus on what they can do in a hugely positive way.

What do the children who attend Barretstown say?

Working directly with those children I often hear the difference a week/weekend at Barretstown has made to their self-esteem, confidence and outlook. While the prognosis for children with bleeding disorders is normal to their peers, they are faced daily with challenges that their peers will never experience. The opportunity to bring these children together in a place like Barretstown helps them to adopt a positive outlook that will stay with them well into their adult years and help them to live confidently with their condition.

For information on dates for camps or for how to apply for a place at camp please contact Fiona on 01 657 9900 or you can email her at fiona@haemophilia.ie

Parents Conference

FRIDAY 24th – SUNDAY 26th JUNE 2016
SHERATON HOTEL, ATHLONE

PRELIMINARY PROGRAMME

Friday 24th June	
18.00 - 19.30	Registration
Saturday 25th June	
09.30 - 10.00	Registration
10.00 - 11.30	Venous Access and Port-a-Caths
11.30 - 12.00	Coffee break
12.00 - 13.30	Home Infusion Workshop
13.30 - 14.30	Lunch
14.30 - 15.30	Inhibitors: The Chances, Risks and Policies
15.30 - 17.00	Mothers Workshop or Fathers Workshop
19.15	Dinner
Sunday 26th June	
10.00 - 11.00	Extended Half-Life Treatment – Experiences to Date
11.00 - 11.30	Coffee break
11.30 - 12.45	Siblings – Managing the Family
13.00 - 14.00	Lunch and depart

October Members Conference

FRIDAY 14th OCTOBER - SUNDAY 16th OCTOBER
Radisson Blu Hotel, Sligo

PRELIMINARY 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 Health Care 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
11.00 – 11.30	Coffee break
11.30 – 12.45	Fun for all the family
13.00	Lunch

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