

haemophilia.ie

Magazine of the Irish Haemophilia Society

Edition: December 2014

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



The Society at a Glance

Members'
Conference
Attendance

↓
158

↑
Followers
on
Facebook

650

↑
Carrier
Conference
Attendance

36

↓
Educational
Grant
Applications

19

↑
Website Hits
(Sep - Nov)

5,033

WHAT'S INSIDE:

- * Details on the Christmas Opening Hours of the IHS, CUH, OLCHC & NCHCD.
- * Reports from the Carrier Conference, EHC Conference & Members' Conference



Irish Haemophilia Society

AGM & Conference

March 6th - 8th 2015

Hodson Bay Hotel,
Athlone,
Co. Westmeath



PRELIMINARY PROGRAMME

Friday 6th March

6.00pm – 7.30pm Registration

Saturday 7th March

10.00am – 12.30pm AGM

12.30pm – 1.30pm Lunch

1.30pm – 3.30pm Symposium
Future Model of Haemophilia Care
Joined up Thinking - The New Children's Hospital
National Treatment Guidelines

3.30pm – 4.00pm Tea & Coffee Break

4.00pm – 5.00pm Open Forum with Haemophilia Treatment Centres

Sunday 8th March

10.00am – 10.45am **Group 1**
Session for Women

Group 2
Session for Fathers

10.45am – 11.15am Tea & Coffee Break

11.15am – 12.00pm Update on Twinning

Inhibitors

12.00pm – 12.45pm von Willebrand Disease

Strategic Plan



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

Sub Editor: Nuala Mc Auley

Executive Board:

Chairperson
Traci Dowling

Vice Chairperson
Brian O'Riordan

Secretary
Mary Hanney

Treasurer
Gerard O'Reilly

Eoin Moriarty
John Stack
Sarah Gilgunn
Michael Butler

Staff:
Chief Executive Officer
Brian O'Mahony

Administrator
Debbie Greene

Counsellor
Anne Duffy

Office Team
Nina Storey
Declan Noone
Nuala McAuley
Fiona Brennan

CONTENTS

- 4** CEO's Report.
- 6** 2014's Fantastic Fundraisers!
- 8** A Volunteer's Worth!
- 10** Educational Grants.
- 11** Calendar of Events.
- 12** Cubs Club.
- 13** Kidlink Page.
- 14** Christmas Opening Hours of the IHS and the Haemophilia Treatment Centres.
- 15** IHS Noticeboard!
- 16** The Carry on at the Carrier Conference!
- 18** EHC Conference Report.
- 21** Memories from the 2014 Member's Conference!



*Debbie Greene
Administrator*



A Note from the Editor

Hi everyone, and welcome to the December edition of haemophilia.ie. I hope you are all getting organised for the Christmas festivities. We have lots of interesting articles and information in this magazine and I hope you enjoy reading this issue.

Preparations are well underway for the 2015 AGM. Take a look at the preliminary programme on page 2. AGM packs will be going out to everyone in early January. Dates and venues have now been set for our three main events next year so put these dates in your diaries and make sure you all come along.

On page 14 you will see important details on hospital opening hours over Christmas, and why not tear this page out of the magazine and put it up on your fridge!

In this edition you will find reports on the Carrier Conference that took place back in September which was a huge success, the European Haemophilia Consortium Conference which took place in Belfast in October and the October Member's Conference.

With a total of €17,750 paid out on Educational Grants this year, the recipients of the grants have been announced on page 10. Congratulations to everyone!

It has been another extremely busy year in the office and I would really like to thank the staff for all their hard work during the year. I would also like to thank all the volunteers, those who contributed to our magazines & publications, everyone who did fundraising for us, and everyone who sent in donations or contributed to the planned giving campaign during 2014.

Wishing you all a very Happy Christmas and a healthy and prosperous New Year.

**Debbie Greene
Administrator**



CEO'S Report



Brian O'Mahony
CEO

In November, the Society hosted a conference on "New Technologies" in haemophilia on behalf of the European Haemophilia Consortium. The first longer acting factor concentrates have now been licenced in the USA and Canada. These products prolong the half-life of the factor VIII and factor IX by fusion of the factor protein with the Fc portion of a human immunoglobulin. The prolongation of the half-life with factor IX is a very impressive 3 to 5 fold prolongation. The prolongation of the factor VIII half-life is less extended at 1.2 - 1.6 fold due to the limiting impact of the von Willebrand factor on the factor VIII. The first longer acting factor concentrates are expected to be licenced in Europe in late 2015 or early 2016. The delay in licencing in Europe is due to the different requirements in the European clinical trial guidelines when compared to the requirements in the USA. In the USA and Canada, once the clinical trials are completed in adults, the products can be licenced for use in adults while the clinical trials in the previously treated children are ongoing. In Europe, the trials in the previously treated children must be completed prior to applying for a licence for use in adults. This explains the relative delay in licencing of these products in Europe. However, it also means that, prior to licencing in Europe, we will have available data on the real clinical use of these products from the USA and Canada. There is already significant experience of using these products in Ireland in the paediatric population as there are a total of 8 children with severe haemophilia who have been treated in Our Lady's Childrens Hospital, Crumlin as part of the clinical trial.

At the Members' Conference in October, we organised a session where members, working in groups, had to discuss 12 specific case studies where we had simulated various clinical situations (different ages, bleeding patterns, degrees of existing joint damage and degrees of difficulty with venous access) and state their collective opinions on whether these individuals would ideally be treated with current recombinant factor concentrates or longer acting factor concentrates. It reinforced their understanding that, in the future, we will be moving away from a "one size fits all" concept of treatment toward individualised care which will take into account the persons individual half-life, bleeding history, degree of joint damage, venous access and attitude to treatment. At the conference, there was also significant discussion with regard to different probable treatment regimens, their use in prophylaxis or for breakthrough bleeding episodes and the economics and cost of the new therapies.



A workshop at the 2014 Members' Conference on Longer Acting Factor, where participants were given case studies to discuss and make recommendations on, proved very successful.

In our involvement and participation with the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB), we have also met with all the major companies who are developing these new products, to discuss their product pipeline, their clinical trial results and how they see the future for their products. At European policy level we've worked to try to ensure that all of the new products will be licenced in Europe. There was a real danger that, only the first of the new longer acting factor VIII and factor IX would be licenced. We view this as completely unacceptable. We want to ensure that we have all the products available on the European market using all the different methods of extending the half-life of the protein. This would allow us to choose the product which we believe would be the safest and most efficacious and not just the first to win a race to licencing. At this point, we do not know which of these new products will be the safest or most efficacious. It may well be that all are very safe and effective. It may be that different products are optimally suited to different groups of people with haemophilia. We will not know this unless all products are available and on the market. In addition, lack of access to all the products would stymie competition, drive up prices and possibly limit our ability to access these products on a national basis. Through the EHC, we have lobbied extensively on this issue and we are currently much more confident that market exclusivity will not be an issue in the future. These new longer acting factors will realistically start to be considered for use here from 2016 with others due to come on the European market from that point. We are fully aware of the need to provide educational support and materials to members on these new products and they will also be the subject of ongoing education at our conferences and events.

The new generation of direct acting antiviral therapies for the treatment of hepatitis C will be used in Ireland from 2015. In September, the Department of Health established an expert advisory group to advise on the national strategy for delivery of these new treatments. Both Declan Noone and I were members of the expert group which completed their work in late November. The group produced a proposed broad strategy for the treatment of hepatitis C in Ireland over the next 5 years. There are currently just over 12,000 people diagnosed with hepatitis C in Ireland and probably some 15,000 to 30,000 people undiagnosed. There are some 160 people with haemophilia with hepatitis C in Ireland with approximately 60 requiring treatment. We will be working with the hepatology centres and our members over the coming months and years to eradicate hepatitis C in our members. Prior to the roll out of the new national treatment strategy in 2015, we were acutely aware that there are individuals who, because of their severe liver disease or rapid progression of liver cirrhosis, required treatment without further delay. We had advocated strongly over the past months for an early access programme where people would be treated with these new therapies in 2014. We welcomed the decision by the Minister for Health to initiate such an early access programme from late November and this programme started in the first week in December. In excess of 100 people with hepatitis C will be treated under this early access programme. It is also worth noting that the success rate for people with haemophilia in the earlier triple therapy regimens was significantly higher than the success rate in all of those treated in Ireland. In excess of 200 people in Ireland were treated with these therapies with an overall success rate of 51%. In the haemophilia group, 20 people were treated with an overall success or cure rate of 80%. We believe the difference was primarily due to the fact that no person with haemophilia stopped taking the treatment of their own volition due to the side effects. A small number had their treatment stopped for clinical reasons or lack of response. This was partially due to the high degree of preparation they had undertaken, support from the Society and very strong peer support from other members on treatment. The sense of community among those on treatment was exceptional. In contrast, a significant proportion of those with hepatitis C who did not have haemophilia stopped treatment due to inability to tolerate the side effects. We look forward to assisting all of our members who require treatment and finally eradicating this insidious virus from the haemophilia community.

At the end of November, the board and staff went through an intensive work process to develop a strategic plan for the Society, to map our work over the course of the next 4 years. This will bring us to 2018, the 50th anniversary of the Society. A detailed plan has now been drafted covering 4 main goals to achieve 41 objectives via implementation of 195 strategies. We believe we have mapped out a plan which is ambitious, yet realistic covering the real needs of our diverse and growing membership as we plan for an era which will hopefully see major steps forward in access to new and better therapies.

In a time when we will have to ensure our voices are heard and views considered on major infrastructure projects including the new national children's hospital and the relocated National Centre for Hereditary Coagulation Disorders (NCHCD). The NCHCD is scheduled to move in 2016 from the current location to a new floor built above the H&H in patient unit in St. James's hospital. Our planning process was greatly assisted by the 22 members who completed surveys on our future requirements at our members' conference and by those who took part in discussions at the 20:20 session at the conference. I also want to acknowledge the input from the comprehensive care centres with whom we discussed the future of the Society and treatment in Ireland and the services and support we all need to work together to provide. The plan will be presented to members at the AGM & Conference in March and also distributed to all members by mail.

Brian O'Mahony
Chief Executive



Above: Dr. Diarmuid Houlihan, Consultant Hepatologist and Brian O'Mahony at a press conference urging the Minister for Health to initiate an Early Access Programme for people with Hepatitis C.

Below: The staff & board working on the new IHS Strategic Plan which will run from 2015 to 2018.



Thank you for the Fundraising!

We had some fantastic fundraisers in 2014 and we really appreciate the tremendous efforts of everyone for organising and taking part in fundraisers in support of the Society. Thank you so much to everyone who organised an event took part or gave a contribution; your support means a lot to us. All funds raised, no matter how big or small, add up at the end of the day and really make a difference. Not only are you raising funds, but you are raising awareness of haemophilia and other bleeding disorders.



Some of the fundraising events which took place in 2014 were (Left to Right) A Blue Lights Fight Night in Donegal, The Women's Mini Marathon in Dublin and a Bucket Collection in Limerick. A huge thank you to everyone who fundraised for the Society in 2014!

As I said 2014 was a great year for fundraising and we really want to maintain this going forward into 2015. So if you have considered doing some fundraising in the past, but just haven't quite got around to doing anything yet, please make it your New Year's Resolution next year, take that first step and contact me. Anyone who has fundraised will tell you how worthwhile it is, but if you feel a bit daunted by the prospect, we are here to let you know that it doesn't have to be. Whether your fundraiser is big or small, we are here to help you every step of the way. The Society will provide posters, tickets, t-shirts, buckets for collections and we will apply for any Garda permits required etc. If you have a fundraiser in mind, but don't know where to start just give me a call on 01-6579900 or email nina@haemophilia.ie and I will work with you from start to finish.

Need some fundraising ideas? How about a bucket collection, bag packing, raffle, non-uniform/casual dress days or bake sale. If you prefer to take part in pre organised fundraisers, such as fun runs, cycles, half marathons etc., check out what is on near you. These types of events take place throughout the year all over the country and you don't have to be an athlete to take part, most events cater for walkers as well as joggers and runners.

Some fundraisers in support of the Society which took place this year included, the Blue Lights Fight Night in Donegal, a bucket collection in Limerick, a hunt in Kildare, an online raffle and a bring and buy sale. We have also had people take part in the Flora Women's Mini Marathon, the Galway Bay 10K Marathon, the Dublin City Marathon, the Turf Warrior Challenge, the Sean Kelly Cycle and Movember.



Pictured above are the IHS Turf Warriors - Colin Langan and Tony Mc Afee. The two men braved the elements in October 2014 to complete the challenge for the IHS!

The Fisherstown Hunt took place in Athy, Co Kildare on the 27th October and our thanks to Karen and Keith Grainger and the hunt organisers for choosing the I.H.S. to benefit from this wonderful fundraiser. We would also like to thank Mary Byrne who put a lot of time and effort into the event. Our very own Harry and Molly Grainger (ages 6 & 9 years) had the honor of officially leading the hunt to the starting point and cut the ribbon with Councillor Martin Miley Jr. The hunt started and finished at Purcells Bridge House, where everyone then gathered for a great night of prizes and entertainment. Our thanks to Gary Sheehan for providing the music and to Purcells Bridge House for providing the refreshments and to the generosity of everyone who supported this fundraiser. As the night went on a raffle and bucket collection took place, everyone gave generously and an amazing €1,758 was raised in total. Well done everyone!



Two of the most recent fundraising events for the Irish Haemophilia Society included a hunt in Kildare (above left) and a Bring & Buy Sale in Cork, (above right). Fundraising is an important source of income for the Society, so once again thank you to everyone involved!

They say that one man's junk is another man's treasure, this really was the case when a Bring & Buy Sale was organised by Nodlaig Griffin and her sister Helen Walsh. However, this Bring & Buy Sale wasn't a run of the mill sale and some fantastic contributions were made for an auction on the night. The fundraiser took place in the Cobh Ramblers Football Club, Cork on the 17th November 2014, with the proceeds from the fundraiser divided between the Society and St Joseph's School. The main event was an auction and Nodlaig's daughter Christine graciously stepped up to do auctioneer on the night. A raffle also took place with great prizes such as hampers and gift vouchers. We would like to thank everyone who made a contribution to the items on sale and the raffle prizes; we really appreciate your generosity. Our thanks also to everyone involved for all their time and effort which went into making this a very successful night. We were delighted that a total of €700 was raised in aid of the Society.

Before the end of the year a second hunt and the I.H.S. Christmas Draw will have taken place. We are really excited about the draw; we have managed to source some amazing prizes so good luck to everyone who bought tickets and thank you for your support.



To start the fundraising off in 2015, the I.H.S. has purchased tickets for a Comedy Night in the Laughter Lounge, Dublin. Tickets are €25 each, for more details check out our article on the Laughter Lounge on the page 15!

Thank you for the tremendous support in 2014, roll on 2015!

Nina Storey

A Volunteer's Worth!

On behalf of the staff, board & members of the Irish Haemophilia Society, I would like to thank each and every volunteer who worked with the Society over the course of 2014.

V is for the Very special people that you are

O is for the Overwhelming support you offer to the members of the IHS

L is for the Little things you do that make such a difference

U is for the Unspoken words that sometimes mean just as much

N is for the Need you fill when others aren't able

T is for the Time you give of yourselves on top of your own busy schedules

E is for the Enthusiasm you bring with you to every event

E is also for the Endless energy you all seem to possess

R is for the Responsibility you have taken on & never once complained

S is for the Smiles you bring to the children & their families by just being there & being you



As you all know, we could not cater to the needs of our membership at conferences without the hard work, generosity, dedication and enthusiasm of our very valuable and vibrant volunteers. With three conferences annually, we do realise that it can be a huge commitment to volunteer while balancing college, work and a social life, (sometimes all three)! Our volunteers not only work with the children and teenagers in the various groups – Crèche, Cubs, Kidlink and Youth, but we also have some volunteers who support us with administration tasks at the conferences. With the number of attendees increasing year on year this extra help is so appreciated. As if that wasn't enough, many contribute to our publications and work on other projects on behalf of the I.H.S.





Giving our members the opportunity to attend and participate in these conferences is crucial in developing the ability of both children and adults to cope positively with their bleeding disorder. This year alone saw 198 children aged from 0 – 17 years attend IHS events where they had fun together, laughed, learned about bleeding disorders and made new friendships.

As always it was an absolute pleasure to work alongside you all this year. Your energy, drive and good humour never fail to put a smile on mine and most importantly the children's faces! You may not all get the chance to stand back and take note of the difference you are making by engaging with and looking after the children at the conferences (the weekends are pretty busy!), but you do, and we hope you realise how important and valued you and your work is to the Society!



Volunteers don't get paid not because they are worthless, but because they are priceless!

If you or someone you know are interested in volunteering with the Irish Haemophilia Society in 2015, you can find more information and an application form online at www.haemophilia.ie or you can contact me in the office on 01 657 9900 or fiona@haemophilia.ie

Fiona Brennan

Educational Grants 2014

I am delighted to announce that the recipients for the Educational Grants for 2014 have been chosen. Thanks to everyone who sent in applications. This year we received a total of 19 applications. We had a mixture of applications which were received online and in the post. The sub group of the board met on the Friday evening of the Members' Conference to discuss and score all the applications, after which a final decision was reached. The three main recipients are as follows:



Maureen & Jack Downey Educational Grant - €4,000

Carly Wright from Tipperary

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.

Father Paddy McGrath Educational Grant - €2,000

Nicole Higgins from Cavan

This is a grant that the Society has named after our dear friend Father Paddy McGrath, and is given to the person who came second in Maureen & Jack Downey Educational Grant. This grant is available to a person with haemophilia, or related bleeding disorder, who has been accepted on a post second level educational course.

Margaret King Educational Grant - €2,000

Sarah Gilgunn from Sligo

This grant is for an immediate family member of a person with haemophilia or related bleeding disorder, who has been accepted on a post second level educational course.



This year we updated the application forms, and explained to everyone applying how each application is scored, for example the quality of the application is very important as is sufficient information given. We saw a big improvement in the quality of applications which is great.



I would like to encourage as many of you as possible to apply next year, it's really worthwhile and beneficial, and can really help cover the cost of perhaps travel expenses if you are studying away from home or those very expensive books!

Many congratulations to you all!

Debbie Greene

Calendar of Events

FEBRUARY

Date: 7th February

Event: Hepatitis C Conference

Venue: Castleknock Hotel, Dublin

MARCH

Dates: 6th - 8th March

Event: AGM & Conference

Venue: Hodson Bay Hotel, Athlone, Co. Westmeath

** See page 2 for more information on this event.*



MAY

Dates: 15th - 17th May

Event: Ageing Conference

Venue: TBC

Date: 28th May

Event: Comedy Night Fundraiser

Venue: The Laughter Lounge, Dublin

** See page 15 for more information on this event.*

JUNE

Dates: 1st June

Event: Women's Mini Marathon

Venue: Buswells Hotel, St. Stephen's Green, Dublin

Dates: 19th - 21st June

Event: Parents Conference

Venue: Sheraton Hotel Athlone, Co. Westmeath

SEPTEMBER

Dates: 19th & 20th September

Event: HCV / HIV Conference

Venue: TBC



OCTOBER

Dates: 16th - 18th October

Event: Members' Conference

Venue: Heritage Hotel, Portlaoise



NOVEMBER

Dates: 20th - 22nd

Event: PEP Conference

Venue: TBC



Cubs Club

Hi everyone and welcome to the final Cubs Club of 2014!



The Slobs

by Conor Birkett

We want to wish all of our Cubs Club Members a very Happy Christmas!! Looking forward to seeing you all in 2015!

Sometimes when you have haemophilia you might get hurt a little bit easier than other people. It is really important to tell an adult if you hurt yourself, so you can get treatment as soon as possible. When you get your factor soon after hurting yourself it won't hurt as much and you won't have to rest for as long!

Listed below are things that help you feel better when you have hurt yourself? Can you crack the code?

R   

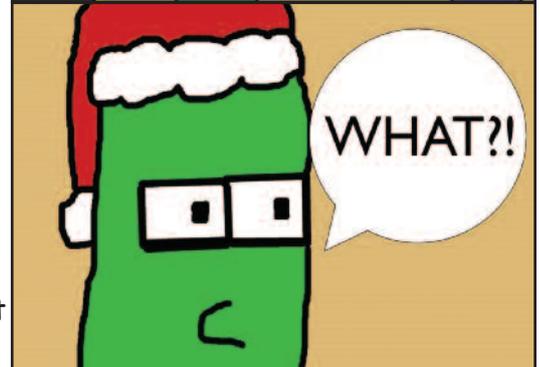
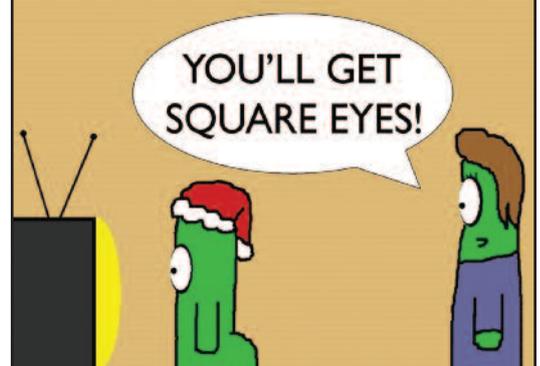
I  

C       

E      

Visit www.haemophilia.ie for the answers, but remember to ask permission first!


 What do you call an old snowman?
 Water!



MERRY CHRISTMAS
from
The Slobs!

Kidlink Group

When you were younger you were given your factor through your port because your veins were too small. Now that you are a bit bigger, your veins are big and strong enough for you to get your factor. Learning how to inject your factor into your veins yourself can be scary but there are lots of great things about doing it yourself too!

Here are some of the reasons that make self-infusion so great:

1. It is much quicker to use your veins than a port!
2. You don't have to have your Mam or Dad there all the time to do it for you!
3. You can get a voucher if you ring the I.H.S and tell us you have started to self-infuse!

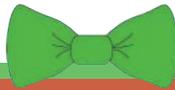
Can you think of any other reasons? _____

Log onto www.haemophilia.ie to find out more reasons or to learn more about self-infusion.



What do you sing at a snowman's birthday party?

Freeze a jolly good fellow!



What goes:
now you see me, now you don't;
now you see me, now you don't?

A snowman on a zebra crossing!

Do you like having days full of games and adventure?

Do you like trying new activities like fishing, archery or wall climbing?

Would you like to make some new friends?

If you answered yes to the questions above, then Barretstown may be for you!!

Why don't you get your Mam or Dad to ring Fiona in the IHS office to talk about a place at Barretstown Camp for you!

If you have already been to Barretstown and would like to tell everyone about your trip, please write to Fiona about your favourite things to do in Barretstown!



Christmas Opening Hours



The Irish Haemophilia Society

The Irish Haemophilia Society office will close for Christmas on Tuesday December 23rd will re-open on Friday January 2nd.

In case of an emergency, please contact Brian O'Mahony 087 251 5325.

A special thank you to everyone who volunteered for the Society during 2014, to all those who helped the Society by fundraising during the year and those who sent in donations. We value your support.

Wishing you all a very Merry Christmas and a Peaceful New Year.

*From the board and staff of
the Irish Haemophilia
Society.*

www.haemophilia.ie



NCHCD

In case of an emergency patients should contact the H & H ward on 01 410 3132. Patients must contact the ward **PRIOR** to attending.

DECEMBER

Monday 22nd	8.30 - 5.00
Tuesday 23rd	8.30 - 5.00
Wednesday 24th	8.30 - 5.00
Thursday 25th	CLOSED
Friday 26th	CLOSED
Saturday 27th	CLOSED
Sunday 28th	CLOSED
Monday 29th	8.30 - 5.00
Tuesday 30th	8.30 - 5.00
Wednesday 31st	8.30 - 5.00

JANUARY

Thursday 1st	CLOSED
Friday 2nd	8.30 - 5.00



CORK UNIVERSITY HOSPITAL

Outside of these opening hours & in case of an emergency, phone CUH on 021 454 6400 and ask for the haematology registrar on call.

DECEMBER

Monday 22nd	8.30 - 5.00
Tuesday 23rd	8.30 - 5.00
Wednesday 24th	8.30 - 1.00
Thursday 25th	CLOSED
Friday 26th	CLOSED
Saturday 27th	CLOSED
Sunday 28th	CLOSED
Monday 29th	CLOSED
Tuesday 30th	CLOSED
Wednesday 31st	CLOSED

JANUARY

Thursday 1st	CLOSED
Friday 2nd	8.30 - 4.30



OUR LADY'S CHILDREN'S HOSPITAL, CRUMLIN

DECEMBER

Monday 22nd	8.00 - 5.00
Tuesday 23rd	8.00 - 5.00
Wednesday 24th	8.00 - 5.00
Thursday 25th	CLOSED
Friday 26th	CLOSED
Saturday 27th	CLOSED
Sunday 28th	CLOSED
Monday 29th	8.00 - 5.00
Tuesday 30th	8.00 - 5.00
Wednesday 31st	8.00 - 5.00

JANUARY

Thursday 1st	CLOSED
Friday 2nd	8.00 - 5.00

In case of an emergency contact the hospital on 01 419 6100 and ask for the haematology registrar on call.



Comedy Night - Support the IHS

Not sure what to buy someone for Christmas?

How about tickets for a comedy night in the Laughter Lounge on Thursday 28th May 2015.

If you need a last minute gift why not treat someone to an evening of laughs and help support the I.H.S. at the same time? The Laughter Lounge on Eden Quay, Dublin 1 is a great venue for a night out., The evening will start with 4 comedians and will be followed by a late bar with DJ.

The show starts at 8.30pm with a free cocktail for those who arrive between 7.00pm - 7.30pm.

Tickets are €25 each and can only be purchased directly from us here in the office. All proceeds from the sale of the tickets will come to the I.H.S. For further details or to purchase tickets contact Nina on 01-6759900 or email nina@haemophilia.ie

Thank You!

Thank you to everyone who supported the Irish Haemophilia Society Christmas Draw.

Fundraising is an important source of income for the Society, but we understand that it can be tough particularly around Christmas Time. This makes your contribution even more special.

Congratulations to all our winners! Results of the draw can be found online at www.haemophilia.ie

Happy Christmas!



Nuala Mc Auley who has been working for the Society for the past six years, has decided to move on to pastures new.

Thanks Nuala for all your hard work over the past six years and for all your creativity.

The very best of luck to you in your new job.

**From all the staff in the Irish
Haemophilia Society.**

Carry on at the Carrier Conference!

I decided to go to this year's carrier conference for 2 reasons:

1. To become informed
2. To connect with people who are in a similar situation to me.

My dad has haemophilia, therefore I am a carrier. This is something I've known all my life. Dad never hid anything from us – he was always very open and honest about haemophilia and how it would affect me and my sister in the future. Being a carrier hasn't really affected me much in my life up until now. I had to have treatment when I was 18 when I was getting 8 teeth taken out, but that's been it. I've been to a carrier conference before, but I didn't really take much in. Pregnancy and babies weren't something I was thinking about at 22. I'm now 29 and hopefully getting pregnant will be something that will happen in the near future. So when I heard the conference was going to be in Dublin this year, I decided to attend.



The Carrier Conference programme included sessions on dental care, positive living & carrier testing.

Over 30 young adults and women attended the conference.



I enjoyed all the speakers at this year's event. I got a lot of information not only about being a carrier, but about being a woman. There was a lot of general information about contraception, dental care and positive living.

One of the main points was to be informed - knowing your body. I didn't realise the importance of knowing my levels as a carrier. I have had my levels checked and I know they said my levels were "border line", but I don't know the exact number. I must check that out. I was happy to hear how involved the National Centre is in your pregnancy and it's given me peace of mind. From giving counselling and information to you and your partner, to getting in touch with your GP, obstetrician and anyone else who needs to know about the fact that you are a carrier – I feel better knowing I'll have a security net when the time comes.

Something that came up that I had never thought about before, that I feel like I should have thought about, is guilt.

I've grown up just accepting the fact that I'm a carrier and that I will potentially be passing this gene on to my children. I never really stopped to think about how they might feel about it. How I might feel if I have a child with haemophilia. How my partner might feel if we have a child with haemophilia. The one saving grace I have is that treatment nowadays is second to none. People with haemophilia these days have a relatively normal life. Okay, so there's a lot of hospital trips, and there's a couple of different sports you can't take part in, but surely if you keep a positive attitude, then you won't let it get you down. That's something I've definitely learned from my parents, especially my dad. Ask anyone who meets my dad and they'll tell you he's a positive person. It's so much better than the alternative.

I spoke to my partner when I came home from the conference and I asked him how he would feel if we had a child with haemophilia. He said there's fantastic treatment nowadays and once we're fully educated, it shouldn't be a big deal. That made me so happy to hear.

I loved chatting to the other women at the event who are carriers. Whether it was women like me who haven't got children yet or women who have children with haemophilia and how it affects their daily lives. Both groups of women are very positive and well informed. We have the Irish Haemophilia Society to thank for that. I feel like they're our extended family. Having a child with haemophilia sounds tough – I'm not gonna lie. I do feel though that being positive and informed helps immensely. Having a good support system is very important as well.

I really enjoyed the talk by guest speaker Emma Quinlan. Emma's an Irish model and dancer who was on Celebrity Apprentice last year and my jaw was on the floor when she was telling us about her travels with famous bands such as Metallica, Motorhead, One Direction, to name a few. Dancing with the Moulin Rouge in Paris must have been an amazing experience as well. But Emma has Lupus. Lupus is a chronic inflammatory disease that occurs when your body's immune system attacks your own tissues and organs. Like haemophilia, it's something that cannot be cured but with treatment you can live a relatively normal life. Emma is a great example of that. Even with her condition, she doesn't let it stop her living life to the fullest.



Left to Right!

The girls night in included goody bags, a delicious meal, a wonder of woman quiz and live music. A great night was had by all. The quiz came down to a tie break question, which unfortunately my team lost. Congratulations to the winning team, pictured above! IHS Staff member Nina Storey, guest speaker & model Emma Quinlan and myself.

I'd like to thank the girls in the office for arranging such a great "Girls Night In" on Saturday night for everybody. The goody bags went down a treat and I personally felt that the quiz they put together was designed especially for me! My team "The Barton Bellas" came joint first only to lose out in the tie break situation. One word - devastated!

All in all, I had a great weekend. My sister said she would have loved to attend only my dad was too stingy to pay for her plane ticket home from Australia!

Thanks again to all the ladies in the office for all their hard work in making it a really great conference. I hope everyone else enjoyed it as much as I did and I can't wait for the next one.

Laura Davenport

EHC Report

The 27th European Haemophilia Consortium Annual Conference took place in Belfast this year. The conference took place over three days, with a slightly different format from previous years. The main track was lecture based as with previous years, where a number of excellent speakers gave talks on topics ranging from hepatitis C, physiotherapy, haemophilia centre certifications, European updates and reproductive issues. The second track was as a result of requests from haemophilia organisations for more workshop style sessions, where they could deal with specific issues and work out a solution and discuss different viewpoints. The topics discussed in these sessions were, mild/moderate haemophilia, youth engagement issues and organisation funding issues.

On Friday, in the main track of the conference, Professor Geoff Dusheiko presented on hepatitis C and the significant impact of the new generations of treatment and what this means for patients who not only have hepatitis C, but more importantly the sub-groups; who have severe liver damage and current treatments are not an option, or previous treatment resistance, or patients who relapsed after previous treatments and those who are intolerant to current treatments. He said “we are now at a watershed moment for the treatment of hepatitis C”. We have new drugs that are not toxic, and 90-95% effective, but funding streams need to be identified and a stratification of patients may be needed in order to treat those who are sickest first. For more detailed information on this topic please refer to the IHS “Positive News” newsletter.

This session was followed by myself. I reiterated the urgent need for these new drugs, but also discussed dealing with the current options for treatment in many European countries and the methods used by the IHS to help their members get through treatment. Also, what changes patients can make in their lifestyle while waiting for new treatments.

The second session dealt with physiotherapy and its benefits in haemophilia. Fionnuala Sayers from the haemophilia centre in Belfast talked about options to patients with optimum factor availability. When factor is available and prevention of bleeds is possible then physiotherapy aims to optimise the joint function and allow normal activity including participation in sports. For older men with damaged joints, factor is available for surgeries such as ankle fusions and knee replacements and physiotherapy is then used to build up the joints to maximise their function. The key challenge in this scenario is education in using prophylaxis and minimising the number of bleeds and any damage that is caused by them. Piet de Kleijn, a physiotherapist from the Netherlands, spoke about physiotherapy when there is little or no factor available. This was a very different story on how physiotherapy is used. Piet used a case study of a boy he has worked with in Indonesia as part of their centre twinning. When they arrived the boy, due to many bleeds and no factor, was unable to stand straight, his knees were permanently bent and he had very little strength in his legs so in order to get around he needed to support his movement with his hands. He was moving around on all fours for the majority of the time. It took two years, using crutches and gradually increasing them a notch at a time for the boy to walk small distances upright. On his third visit, 3 years from when they first met, the boy was able to walk unaided and managed some stairs.

This was all carried out without factor and slow and progressive physiotherapy. It is now almost 5 years later and the boy is standing and walking upright unaided and his main goal now is to have his own income, something he had never thought possible. There is a global physiotherapy initiative developed through the World Federation of Hemophilia to use the work done in Indonesia and in other countries to ensure best practice and improve the quality of life for those without access to treatment. It is always humbling and inspiring to hear talks like this.



I spoke at the EHC Conference on treatments for hepatitis C.

In the final session of the day, Dr. Paul Giangrande gave an update on an initiative to certify haemophilia treatment centres across Europe. There are 409 facilities in Europe, of widely varying size, all calling themselves haemophilia centres. There are great disparities in Europe in terms of the types and amounts of products used, the facilities available for treatment and the number of patients treated in individual centres. The project aims to set standards and criteria and ensure the same level of treatment throughout Europe for all people with bleeding disorders. So far there has been 91 applications from 29 countries submitted and 79 have been approved as haemophilia centres and the process is on-going. Dr. Gary Benson from the adult haemophilia centre in Belfast gave his experience of the certification process. Finally, Professor Cedric Hermans from Belgium and Radolsaw Kaczmerck from Poland gave their views on the cross border directive. Both pointed out that in spite of some limitations, the directive provides important opportunities for all patients within the EU, including patients with haemophilia, however its success will depend on how the directive is implemented.

The workshops for the day focused on mild/moderate haemophilia and how haemophilia organisations engage and provide services for this group. The second workshop was on youth engagement and the main question posed for the group was should a youth committee be set up or should youth be directly involved in the main board of the society. The final workshop was on fundraising for organisations and how and what policies should be in place. These workshops had restricted numbers and all of them were oversubscribed. Based on the level of discussion during the conference, they were very successful and enjoyed by all participants.



The programme for the 2014 EHC Conference featured lectures and workshops. The workshops allowed haemophilia organisations to work together on issues.



Professor Rezan Khadir spoke about Reproductive & Genetic Issues in Haemophilia Care.

On Saturday, Professor Rezan Khadir from the UK spoke about reproductive and genetic issues in haemophilia care. She spoke about the how making a decision when haemophilia was involved was very complex raising issues on; cultural or religious values, personal or family experience, severity of haemophilia, the availability or trust in medical care, too much uncertainty and what interventions were available. In a paper, she wrote in 2000, 54% of families decided not to have a child or another child with haemophilia. However, since this time there have been increasing options due to advances in technology such as prenatal diagnosis using non-invasive options as well as better knowledge, support and treatment the understanding on the mother and the family are better able to make fully informed decisions. Professor Khadir also spoke about what were the safest modes of delivery for a child with haemophilia. She said that it was important to assess each person individually for obstetric risks and then discuss with the family about spontaneous or induced labour and the benefits or risk this will have for the neonate and the mother and potential issues for future pregnancies. She pointed out the importance of avoiding a prolonged labour and difficult delivery and delivery should be carried out without instruments. She also discussed the issue of intracranial bleeds, which is 43 times higher in neonates with severe haemophilia compared to the general population.

Professor Philip de Moerloose spoke about the European Association for Haemophilia and Allied Disorders (EAHAD) and the joint work that EAHAD and EHC are working on such as communication on advocacy issues and data collection. EAHAD have also agreed to nominate clinicians to review EHC collected data when requested and will involve EHC in any revision of the European Principles of Care.

In the final session of Saturday Dr. Paul Giangrande gave an update on novel treatments explaining the details of how the products half-life were being extended and the effects on the patient's quality of life. However, there are delays in Europe around licensing and there is a 2-3 year lag behind the US getting access. He also discussed the issues around affordability and how this will be key in gaining access. Professor Claude Negreir and Dr. Beatrice Nolan spoke about the individualisation of therapy in adults and in children. Prophylaxis is not a one size fits all model. The use of longer acting treatments compared to currently available treatments will be based on bleeding rates, venous access, lifestyle, PK parameters, sport and age to give the best protection for the patients when they need it throughout their life.



Several members of the IHS Staff and Board attended the conference, here are some of the IHS delegates at the Titanic Centre, where the EHC Gala Dinner was held.

On Saturday night, our hosts treated us to a tour of the Titanic Centre with the Gala Dinner on the top floor. A great night was had by all and it was nice to catch up with old and new friends after the work of the day and before the business meeting on the Sunday.

On Sunday, the business meeting of the EHC took place where haemophilia organisations got to express their views on the work of the EHC and look at aspects of work done over the year and vote on the direction the consortium should move forward. These ranged from what the activities were for the coming year, membership fees, the statutes of the organisation, the finances and this year what the new logo for the EHC should look like.

From an Irish perspective, the IHS were well represented, with a total of 8 IHS members and staff attending the conference, five of which spoke, chaired or led a session, out of a total of 300 delegates.

So I would like to finish by saying, congratulations Belfast on a great conference, with great volunteers that made us feel very welcome and good luck to next year's hosts (Serbia).

Declan Noone

Memorial Service

A Memorial Service took place in the offices of the Irish Haemophilia Society on Sunday November 2nd. As a tribute to Fr. Paddy McGrath we used the service that he had prepared some years ago, as the hymns and readings were Paddy's favourites, and we wanted to honour him in some small way. The celebrant Fr. Bernard Treacy did a lovely service; it was reflective, respectful and focused on light.

During the service members were asked to place a red rose at the Memorial Sculpture in respectful silence. The Memorial Book which contains the names of people with haemophilia who passed away was placed on the altar. For those who were unable to attend the service, please be assured that your loved one was honoured during the service.

Afterwards light refreshments were served and everyone mingled over a nice cup of tea. Thanks to everyone who attended the service, it was lovely to meet some old friends, and a special thanks to Fr. Bernard.



Debbie Greene

Members' Conference Report

On Friday October 10th, we headed to Ballinasloe, not for the infamous Ballinasloe fair, but for the equally anticipated Irish Haemophilia Society members' conference. It was great to see some familiar faces and have a catch up that evening after a long journey. The hotel lobby had lots of space to sit and chat and room for excited kids to play and catch up with friends. At night we stood on the balcony and watched the amazing (and very long) fireworks display, but I think that was part of the fair celebrations.



Above: The children were excited to go into the creche!

Below: The adults programme included workshops on various issues.



On Saturday morning after breakfast we dropped the kids off at crèche (we were early of course as the kids couldn't wait to get in and play with all the toys!).

Afterwards we headed downstairs to the conference room for the talks. In one of the first, Brian O'Mahony was giving a talk on longer acting factor and its benefits. The most notable benefit I could see from all the charts and statistics was that the new treatment had a much longer half-life. This basically means a higher level for longer thus reducing the frequency of injections, or keep the same amount of injections, but remain at a safer level all the time. The question was how would a fair price be decided upon? Would they simply swap longer acting factor for the regular one, unit for unit, or would they increase the price considerably because it reduces the amount of injections or gives a better result? Some questions cropped up like would longer acting factor be used for treating injuries or would a young sports player prefer to have 100% protection on the days he was playing. It was pointed out that it would be phased in gradually and not everyone would be switching at once. There were some issues to be ironed out.

With all these statistics fresh in our minds, we were divided into groups. Each group had a different case study of a person with haemophilia ranging in ages from children through to older adults. We were given a few minutes to discuss our cases and then each group gave their view on what treatment should be used and why.

Declan passed the microphone and we then listened to the other cases and the views of the group and everyone was invited to contribute. I was surprised how people had such different views and how individual each case was. Everything was taken into account from lifestyle to the frequency of bleeds with some people disagreeing (very politely!) on the best course of action. It showed that longer acting factor was not suitable or the best course of action for everyone. It opened my eyes as to how individual the treatment is.

Another thing that popped up at this time that I was very interested in was teenagers, and how to deal with this difficult and self-conscious time in their lives. I wanted to know what the pitfalls were and advice on how to handle them (teenagers can be difficult at the best of times and all they want to do is fit in and be like everyone else – a bit more difficult for a person with haemophilia I would imagine). Issues that popped up were teenagers who might not be taking their factor as they forget or they might just be fed up with the whole thing. There was some interesting advice given by

people who have gone through this phase, but I think knowing some of the challenges is just as beneficial, as preparation is key. Other parents warned me about what to look out for, I think the teenage years may be the most challenging for parents and I want to be well prepared for it.

The adults weren't the only ones to receive education at the conference, the programmes for the children's groups also featured educational sessions. It wasn't all work though as they enjoyed games, arts & crafts and movie time also!



After a lovely relaxing lunch we headed back to the conference suite for an interactive workshop titled 'is haemophilia a disability?' I have to say I was a bit tired after lunch and thought I might just sit back a bit and do more listening than participating in this one. Alas this was not to be, I couldn't help but get really into this session. We were assigned to a group when you walked in – mothers, fathers, people with haemophilia and spouses. We were told to discuss the topic at hand. I took notes and let the more experienced mothers in the group do the talking. There was a definite and quick opinion that 'yes' haemophilia was a disability, something I was quite uncomfortable with (I didn't want my son to think he had a disability) but I stood back and let the more experienced mothers do the talking. They told of the limitations having haemophilia places on their son's lives, the preparation that goes into every aspect and event from holidays to football matches, the shielding, tears, traumas and the pain endured when they have a bad joint bleed. One mother told of how her son missed his first year at school because of a bad bleeding episode and another told of helping her teenage son in and out of the bathroom! I was beginning to change my mind.

The groups were then mixed up and we listened to some of the topics discussed in the other groups. The first thing I noticed was that people with haemophilia did not want to be labelled disabled. It seemed that it was the word itself and its connotations that caused the problem. Everyone agreed (and it also came from other groups in the open discussion) that the access to medication has really helped make life easier. It has made the condition more manageable and reduced long term joint damage. I think the question of disability is a changing one. For the older generation who didn't have access to the medication that's now available, the answer is 'yes' it is a disability. They have to live with the damage caused to their joints and the stiffness and limitations that goes with it. I may naively, be hoping that this is the exception rather than the rule and that this may be a thing of the past, that life for people with haemophilia will be a lot easier in the future. The question came up about car insurance forms - do you tick 'yes' or 'no' to the disability question? You may not think of yourself as disabled, but would an insurance company agree? After more open debate and discussion I was glad to hear that some of the mothers had changed their minds, as for me - inconclusive!

There was another session after this called 20/20 vision (nothing to do with eyesight as I found out). Everyone was given a form to fill out where you were asked to give ideas about what the IHS could do for you in the future and how they could improve the service - looking towards 2020. This gave us a quiet moment to talk and reflect before collecting the kids from crèche at 5pm.

After a quick swim, we gathered together for the Saturday night dinner and entertainment. Those of us with younger kids munched on bread rolls

while we waited for the feast to be brought out. My son was in his element, not only did he get chips for dinner, but dessert as well! He kept asking when the music would start, so we kept this one brushed under the carpet until bedtime - he wouldn't get quizzes! Not even this very different 'family fortunes' take on quizzes, which is great for those of us not up to speed with general knowledge, you weren't sure what the correct answer was until the answers were read out - even I had some of the answers.

Sunday morning was a challenge as we didn't go straight to bed after the quiz as we should have done. No, there were very important topics to be discussed in the bar area! After breakfast we dropped very enthusiastic children off to the crèche and strolled to the conference room, nodding in sympathy to other sleepy parents we meet on the way. I feared to think what Crystal Maze entailed. As it turned out it is great family fun and my tiredness was short lived. We had to divide up into teams of no more than six, the teenagers were back from their overnight trip to the adventure centre and the cubs were suspended for the morning so we were all back together. The object of the game was to work together and dash around various parts of the hotel solving riddles, playing games and working as a team to get things done. There was a little bit of 'you should have done this' 'I could have done that' and 'I don't believe you can do that' but it just shows how into it we got! It was great fun and had something suitable for everyone.



The youth group returned from their adventure weekend on Sunday morning to join up with the rest of the groups for the Crystal Maze, which was great fun!

After tea we headed to the conference room again to discuss the future of the Irish Haemophilia Society. It was to help the society draft a plan going forward to 2020. I listened to the suggestions, but really couldn't add much to the conversations. I am very new to all this. I think the service provided is great and the support is unreal. I love these weekends away not only for the break but for the people I meet and the advice I get about issues that I haven't even thought about yet! I feel I am getting so much help when other areas of the health system seem to be buckling. I only wish my mother had the same support in her day.

Una Uí Thuama



The final session of the Members' Conference was 20:20 Vision where members were asked for their input on the new Strategic Plan.



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