

Magazine of the Irish Haemophilia Society

# haemophilia.ie



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



The Society  
at a Glance

**994**  
Facebook  
Followers



**50**  
Planned giving  
Contributors



**75**  
IHS  
Volunteers



**5999**  
Website  
Hits



SPRING 2017



haemophilia.ie

# VHI Women's Mini Marathon



It's that time of year again when we are looking towards the summer and planning for the VHI Women's Mini Marathon on 5th June 2017. The event takes place every year in Dublin city centre, attracting thousands of women to walk, run or jog and raise awareness for a charity of their choice, along with raising funds.



## Race Information

**Date/Time:** Bank Holiday Monday 5th June 2017 at 2.00pm

**Distance:** 10 kilometres

**Start Line:** Fitzwilliam Square, Dublin 2.

**Finish Line:** Baggot Street, Dublin 2.

**Fee:** €20.00 entry fee

## How to Enter

You can enter the VHI Women's Mini Marathon by signing up online via the official website [www.vhiwomensminimarathon.ie](http://www.vhiwomensminimarathon.ie).

Alternatively, you can enter through the official entry form which appears in the Herald newspaper every Wednesday and Saturday from 1st March, 2017. You must register to ensure you have your race number to allow you to take part on the day and to receive your medal. We would like to remind you this is a FEMALE ONLY event and that the minimum age for walkers, joggers and fast joggers is 14 years and for runners and elite runners is 18 years.

We are very grateful to all the ladies who take part in the Mini Marathon for the I.H.S. every year, but due to the decrease in numbers of those that avail of the room we provide in Buswells Hotel on the day, we will not be in a position to provide this facility this year. Don't worry ladies, t-shirts will be posted out in advance to those taking part.

If you would like more information about fundraising, please contact Nina in the office on 01 6579900.

# A Note from the Editor

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 very exciting new developments in haemophilia care, the new factor IX recombinant coagulation factor concentrate, the iPATH research project and an update on vCJD. This article is definitely worth a read.



*Debbie Greene,  
Administrator & Office Manager*

2017 is a busy year with various conferences and events. On pages 2, 8, 9, 10 and 11 you will find information on the upcoming events to the end of 2017.

For our younger members check out the Cubs & Kidlink club on pages 12 & 13 and also information about our Junior and Youth Membership programme on page 15.

You will find an interesting article and photos from the recent AGM from page 16 to 19. Thanks to everyone who attended the AGM and to everyone who helped out and made it a great weekend, in particular, to 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 and what a positive conference it was, with so many fantastic things happening in the world of haemophilia care now and in the future.

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 2.

For those of you who are unsure of the various staff roles in the Society, you will find an introduction to staff and staff roles on page 22 & 23. Now you will be able to put a face to the name. We would like to welcome on board our newest staff member Lyndsey Connolly who is our new Outreach Co-ordinator. If there is anything that any of us can do to help you, please do not hesitate to contact any one of us. That's what we are here for.

**Debbie Greene**  
*Administrator*

## Contents

- 2 VHI Women's Mini Marathon
- 4 An update from our Chief Executive
- 8 Information on upcoming events
- 14 F.A.Q. on Barretstown
- 16 AGM review and photo gallery
- 20 Fundraising
- 21 New look website
- 22 An introduction to staff and staff roles



# CEO's Report

## New Factor IX Recombinant Coagulation Factor Concentrate

The Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) recently completed a tender process to choose a product for the treatment of people with factor IX deficiency. The group included the directors of the three Comprehensive Care Centres and representatives from the Irish Haemophilia Society (I.H.S.). The major selection criteria used in evaluating the products submitted for tender were safety, efficacy, quality, supply and cost. The product which scored highest in the tender process was an extended half-life factor IX (FIX) called Alprolix. Consequently, from the beginning of May, the FIX recombinant coagulation factor concentrate used in Ireland will be the extended half-life product Alprolix. This product has a half-life of approximately 77 hours, compared with a half-life of approximately 23 hours for the currently used product Benefix. It is anticipated that the vast majority of people with FIX deficiency, who are currently on prophylaxis will change from prophylaxis twice a week to prophylaxis once a week, while simultaneously maintaining higher trough levels and being provided with increased protection from bleeding. Ireland, to the best of our knowledge, is the first country in the world to switch all FIX patients to an extended half-life factor concentrate. Two extended half-life FIX concentrates came on the European market in late 2016, one of the products Alprolix has been on the US market for the best part of two years, so there is significant clinical experience with this product in the US.

**Brian O'Mahony,**  
Chief Executive



The Society in collaboration with the Comprehensive Care Centres organised information meetings for people with FIX deficiency and their families. These took place on April 4th in Cork and April 5th in Dublin and gave people with FIX deficiency and their families an opportunity to hear more information about the new product as part of their individual change to this product.

## Research Project



At the recent Annual General Meeting and Conference of the Society, Professor James O'Donnell and Dr. Michelle Lavin from St. James's Hospital, outlined the new exciting and innovative research project on haemophilia in Ireland. This new project is called the Irish Personalised Approach to the Treatment of Haemophilia (iPATH). The research project, which will be led by Professor James O'Donnell, involves a partnership between the National Coagulation Centre in St. James's Hospital, Our Lady's Children's Hospital in Crumlin, the Irish Haemophilia Society, The Royal College of Surgeons



and Trinity College Dublin. It will be funded jointly by Science Foundation Ireland and by Shire. The research project will take place over a four-year period. The objectives are to answer some fundamental questions in relation to haemophilia and to more fully understand some issues which have an impact on treatment and care. The project aims to develop a greater understanding of the biology underlying haemophilia.

There are fundamental questions to which we still do not have answers. If you take a group of people with severe haemophilia, despite the fact that they all have factor levels of less than one percent, some of the individuals will bleed far more frequently than others. Why is it that some patients get more spontaneous bleeds than others, despite having the same low factor level in their blood? Similarly, if you look at several boys with severe haemophilia who have had a similar number of bleeds into a joint over a period of time, some will develop much more serious joint damage than others. Others will have well-preserved joints, despite lots of bleeds into that joint. We do not understand the biological difference which causes this.

Ireland has a number of advantages when it comes to carrying out research projects such as this. We have a small homogenous population. People with haemophilia are all registered at the National Coagulation Centre (NCC) and attend one of the small number centres regularly. We have extremely good and relatively complete data on the use of factor concentrates

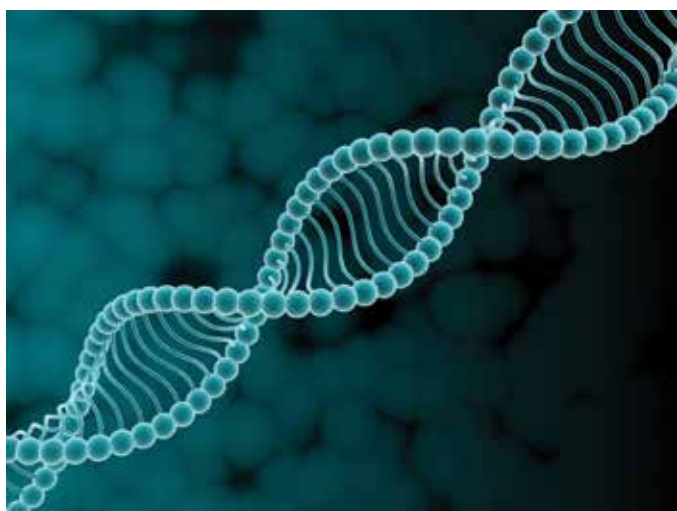
and bleeding rates from the home treatment app on people's smartphones. Consequently, we have a lot of information about the clinical impact of haemophilia in each individual.

Part of the project will involve doing a full genome analysis of every person with severe or moderate haemophilia who signs up to take part in the research project. Interestingly, in the United States, a full genome analysis has been carried out on some five thousand people with haemophilia. However, the US does not have the same level of information about bleeding rates and factor use. By looking at treatment records and joint assessments, the research project can identify groups of individuals who bleed less often than others with severe haemophilia and can identify groups of individuals who have less joint damage, despite having a significant number of bleeds into particular joints. They can then look for specific genetic sequences in the genome of those individuals and hopefully may identify genetic sequences which are linked to preventing bleeding or helping to prevent joint damage. This, in turn, may lead the project in the direction of developing biomarkers or tests which can be used to reliably stratify bleeding risk and/or the risk of developing joint damage in people with haemophilia. It is also highly probable that some of the differences in bleeding rates and in the developing of joint arthropathy are due to the variations in individual immune responses. This research project could conceivably identify those differences and develop targeted immuno-modulated therapies which



could assist in optimally protecting joints against joint damage. The research project will also allow the development of knowledge of individual pharmacokinetic profiles of each person with severe haemophilia. The half-life of factor VIII (FVIII) which averages at approximately 12 hours, varies from 6 hours to 29 hours in particular individuals. The impact of this variation in the half-life of the individual can be identified during the course of this research project. Once we have a greater understanding of the biological basis underlying the variation in bleeding and joint damage in people with severe haemophilia, we can more clearly design optimal personalised treatment regimens for each person, in addition to potentially developing adjunctive therapies, which can help to prevent joint damage or specific biomarker assays, which can help to identify variations in bleeding patterns.

The I.H.S. are delighted to be involved as a partner in this very exciting innovative research project. The National Coagulation Centre is already well known internationally for research work on von Willebrand's Disease. We believe that this research project will now place the haemophilia community in Ireland at the very forefront of global research in relation to haemophilia. It should provide a significant amount of valuable information which will assist the clinicians here in optimally treating people with haemophilia in the future and may help to answer these fundamental questions in relation to bleeding patterns and joint damage, which will be of benefit to people with haemophilia globally.



## Changes to Blood Donor Deferral Criteria



On 16th January 2017, a number of changes in blood donor deferral criteria took effect. There has been a long-running public discussion regarding the advisability of any change in the lifetime deferral as blood donors of men who had sex with men (MSM). The Irish Blood Transfusion Service (IBTS) organised an international conference on this subject in April 2016. I attended that conference and spoke on behalf of the haemophilia patient community and other patients who rely on blood or blood products. Our view at that time was that any change from a lifetime deferral should only be countenanced if this did not result in any increased risk to blood recipients. Our concern was not regarding the transmission of currently well-known viruses such as HIV or hepatitis B or C, for which there exist rigorous tests. Our concern was centred around the potential for a newly emerging virus, which could be transmissible via blood and which would potentially be present at a higher prevalence in the MSM population. Those at risk for such an emerging virus among the MSM community would have been more likely to have been exposed to sexually transmitted infections (STI). Therefore, the decision taken by



the IBTS to decrease the lifetime deferral of MSM donors to a 1 year deferral after last having sex, when linked to a new 5-year deferral for several common STI's (in addition to the existing lifetime deferral already in place for some STI's notably, syphilis and gonorrhoea) is a proportionate and reasonable decision in our view, which will not negatively impact the safety of the blood supply.

On the same date, following representations from the Society and haemophilia clinicians, a donor deferral question referring to haemophilia which was outdated, was removed. Up to that date, potential donors were asked several questions referring to their sexual history in the past 12 months. These included:

**In the past 12 months, have you had sex with:**

- Anyone who has HIV or hepatitis?
- Anyone with haemophilia or other blood clotting disorders, who has ever been treated with clotting factor concentrates?

Since the last transmission of HIV to a person with haemophilia in Ireland occurred in 1987 and the last transmission of hepatitis C took place in 1991, this question is now redundant. Sexual partners of people with haemophilia are no longer deferred as blood donors unless the person with haemophilia has HIV or hepatitis, in which case the earlier question applies. Consequently, there is no requirement for this question relating to haemophilia and we are pleased to see it removed.

## vCJD and Access to Surgical Procedures

In 2004, following a UK Risk Assessment, people with haemophilia who had been exposed to UK plasma-derived factor concentrates between 1986 and 2001 were designated at risk (for public health purposes) of having potentially been exposed to vCJD. This was due to the fact that a number of plasma pools in the UK used to manufacture plasma-derived factor concentrates contained a donation (among thousands of donations in a pool) from a donor who later developed vCJD. This was and remains a highly precautionary step. No person with haemophilia has ever developed clinical vCJD. A significant number of people with haemophilia from Ireland had used some plasma-derived factor concentrates from the UK between 1986 and 2001 and therefore this was noted in their medical charts. The practical ramifications were that, if they required certain surgical procedures, disposable surgical instruments would be used and if they required endoscopies (a not uncommon procedure in our members) the endoscope used would be quarantined and retained for their sole use or destroyed. This was due to the theoretical risk of transmission of prions, the abnormal proteins which cause vCJD.

This risk assessment has been kept under review and changes have now been made based on an updated risk profile and the absence of any cases of vCJD. The applicable years where people will be designated at risk has been narrowed to 1990 to 2001. Further changes have been made to procedures for endoscopy and surgeries. Endoscopes used for people with haemophilia who are designated at risk will no longer require quarantine or destruction. They will be decontaminated using the normal procedure for endoscopes and returned to general use. Less severe restrictions will also apply to some surgical instruments which have undergone repeated cycles of decontamination. These new guidelines may prevent any delay in access to surgery or endoscopy for our members designated as at risk.

**Brian O'Mahony.**  
**Chief Executive.**



# Irish Haemophilia Society

## Father & Son(s) Overnight

### Dates:

Starting at 11am on Saturday 6th May 2017

Finishing at 1pm on Sunday 7th May 2017

### Venue:

Lilliput Adventure Centre



We are pleased to announce details of our first Father & Son(s) Overnight, which will take place over the weekend of the 6th & 7th May, 2017 in Lilliput Adventure Centre in Mullingar, Co. Westmeath. This event is open to:

- Fathers who have sons with haemophilia. (Please note that male siblings who do not have haemophilia may also attend this event).
- Fathers with haemophilia with sons who do not have haemophilia.

*(If you have any questions or queries about eligibility to attend this event, please contact the office on 01 6579900).*

Please note children must be aged between seven to seventeen.

The cost for the overnight will be subsidised by the Society at €50 per adult and €25 per child. This will include all activities, accommodation on Saturday evening, lunch and dinner on Saturday and breakfast on Sunday. The total must be paid in full at the time of booking. If you and your son(s) would like to attend, please return this booking form by Monday 17th April, 2017.

In relation to accommodation, please note that Lilliput Adventure Centre operate a shared sleeping facility in a dormitory type setting. All bed linen and duvets are provided. More information in relation to what you will need to bring (for example: an old pair of runners, clothes etc.) will be provided in your confirmation letter, which will be sent out to you two weeks prior to this event.



Activities: Kayaking, Assault Course, Rock Climbing, Abseiling, Archery, Night Line, Open Canoeing, Orienteering (Day & Night), Laser Tag, Bivouacking, Hill-Walking, Raft Building, Man-Hunt, Gorge Walk, Stack 'm' High, Team Building.





# Hepatitis C Conference



**Date: Saturday 13<sup>th</sup> May 2017**

**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, to receive updates on treatment, on how to access treatment and what happens after treatment.

**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**

11.30hrs – 12.00hrs Registration

12.00hrs – 13.00hrs Lunch

13.00hrs – 14.15hrs Hepatitis C Treatment

*Speaker: Dr. Omar El-Sherif, St. James's Hospital, Dublin*

14.15hrs – 15.15hrs Treatment Experiences & What Happens After a Sustained Virological Response (S.V.R.)

*Panel of speakers*

15.15hrs – 15.45hrs Tea/Coffee Break

15.45hrs – 16.45hrs Accessing Treatment: The National Hepatitis C Programme

*Speakers: Ms. Michele Tait, National Hepatitis C Programme Manager*

*Ms. Nicola Perry, Programme Advisory Group*

16.45hrs - 17.00hrs Final Remarks & Conference Closing

# IRISH HAEMOPHILIA SOCIETY

## AGEING CONFERENCE

Dates: Friday 19th to Sunday 21st May 2017

Venue: Hotel Kilkenny, College Road, Co. Kilkenny.

### PRELIMINARY PROGRAMME



### Saturday 20th May

10.00am – 11.00am Healthy Eating - Is it too late to change the habits of a lifetime?  
*Speaker: Ms. Ellen Roche, Dietitian & Clinical Nutritionist.*

11.00am – 11.30am Tea & Coffee Break

11.30am - 12.30pm Physiotherapy  
*Speaker: T.B.C.*

12.30pm – 1.30pm Lunch

1.30pm – 2.30pm Health Amendment Act (HAA) Card  
*Speaker: Ms. Ger Kane, Health Service Executive.*

2.30pm – 3.00pm Tea & Coffee Break

3.00pm – 5.00pm Benefits & Entitlements  
*Speaker: Mr. Patrick Stagg, Citizens Information Centre.*

7pm Dinner

### Sunday 21st May

10am – 11.30am Ageing, Pain Management & Treatment Protocols  
*Speaker: Dr. Michelle Lavin, St. James's Hospital.*

11.30am – 12.00pm Tea & Coffee Break

12.00pm - 1.00pm Hepatitis C - Sustained Virological Response - What's next?  
*Speaker: Dr. Omar El-Sherif, St. James's Hospital.*

1.00pm - 1.30pm Support Services for those with HIV  
*Speaker: Mr. Brian O'Mahony.*

1.30pm - 2.30pm Lunch

This conference is open to members aged forty years and over who have haemophilia and for members with Hepatitis C and/or HIV.

# Calendar of Events for 2017

## MAY

### Father & Son(s) Overnight

**Dates:** 6<sup>th</sup> – 7<sup>th</sup> May

**Venue:** Lilliput Adventure Centre

### Hepatitis C Conference

**Date:** 13<sup>th</sup> May

**Venue:** Castleknock Hotel

### Ageing Conference

**Dates:** 19<sup>th</sup> – 21<sup>st</sup> May

**Venue:** Hotel Kilkenny, Co. Kilkenny.

## JUNE

### Mother & Daughter(s) Overnight

**Dates:** 24<sup>th</sup> – 25<sup>th</sup> June

**Venue:** Lilliput Adventure Centre

## OCTOBER

### Members Conference

**Dates:** 20<sup>th</sup> – 22<sup>nd</sup> October

**Venue:** Hodson Bay Hotel, Athlone

## NOVEMBER

### Memorial Service

**Date:** Sunday 26<sup>th</sup> November

**Venue:** I.H.S. Office

### Haemophilia Camp Barretstown

**Dates:** 27<sup>th</sup> to 30<sup>th</sup> November

**Venue:** Barretstown

## DECEMBER

### Christmas party for kids

**Date:** Saturday 9<sup>th</sup> December

**Venue:** Grand Hotel, Malahide, Co. Dublin.





## Welcome to the first edition of our Cubs Club for 2017



Being active by playing games and sports is an important part of a healthy life and Brian thinks cycling his bike is great fun! Brian gets to play all sorts of sports and games in school and he knows that because he has a bleeding disorder, it is really important to stay active so that his bones and muscles are strong and they can protect his joints from any damage! Brian's favourite sports are swimming and cycling! Can you think of 3 sports that are good sports to play when you have a bleeding disorder and 3 sports that are not good to play when you have a bleeding disorder?

### Good sports

1. ....
2. ....
3. ....

### Bad sports

1. ....
2. ....
3. ....



### Fun Facts about Bones

- A human newborn baby has approximately 270 bones in his or her body. As the person ages and develops, some of the bones fuse together to make larger bones.
- The adult human body has 206 bones.
- There are 26 bones in the human foot.

## JOKE CORNER

**Why didn't the skeleton go to the party?**

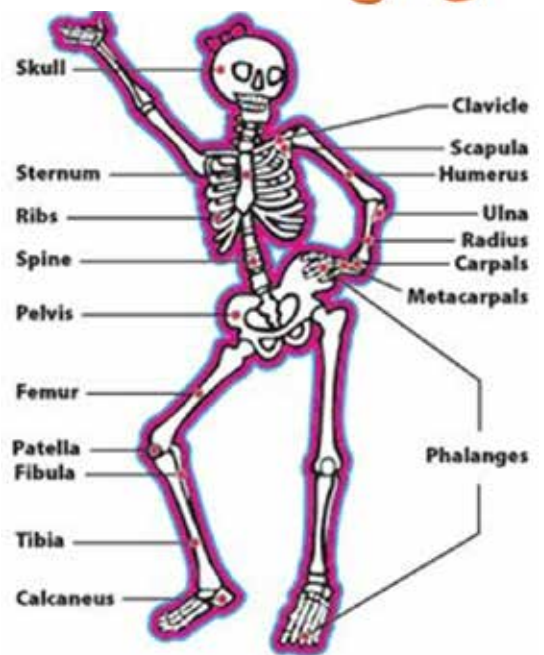
He had no body to go with ☺

**How did the skeleton know it was going to rain?**

He could feel it in his bones ☺

**What do you call a skeleton who won't get up in the mornings?**

Lazy bones ☺



# Kidlink Club

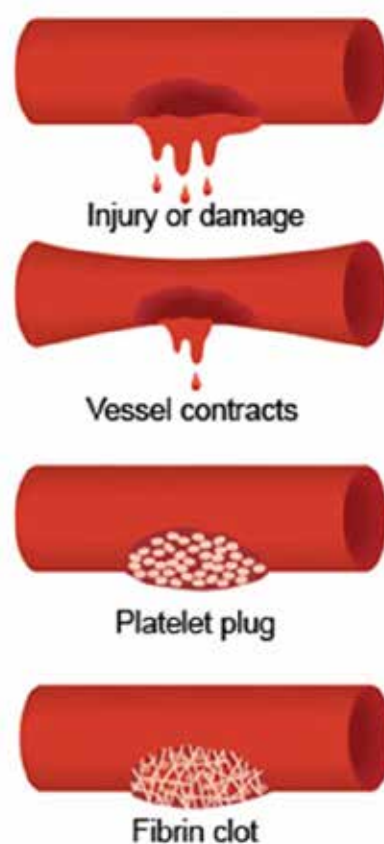
## Welcome to the first edition of our Kidlink Club for 2017

**H**aemophilia is a rare bleeding disorder which occurs when a person has a deficiency of either clotting factor VIII or factor IX in their blood, but did you know there are lots of other types of bleeding disorders? Clotting factors are proteins in the blood that stop bleeding. When a blood vessel is injured, the walls of the blood vessel contract to limit the flow of blood to a damaged area. Then, small blood cells called platelets stick to the site of injury and spread along the surface of the blood vessel to stop the bleeding. There are 13 clotting factors in the blood and each one has a unique role!



Did you know that von Willebrand's Disease (vWD) is the most common type of bleeding disorder? vWD affects a protein in the blood called von Willebrand's Factor (vWF) that helps control bleeding. People with vWD do not have enough vWF, or it does not work the way it should. It takes longer for blood to clot and for bleeding to stop. vWF helps cells in the blood, called platelets, mesh together and form a clot to stop the bleeding.

Now we know how normal bleeding is stopped. Take a look at the way it works below:



### Interesting Facts

- vWF also travels around the body linked to factor VIII!
- Factor IX is also sometimes called Christmas Disease – after Stephen Christmas the doctor who first spoke about factor IX deficiency!

# Barretstown 2017

**D**o you know all about the magic that is a Barretstown Camp? Many of our members attend the Barretstown Camps annually, as a family, as a child with a bleeding disorder, or as a sibling. For anyone with questions regarding the camps, here are some frequently asked questions, which you might find useful:



## What is Barretstown?

Barretstown is a place where you can leave normal life behind and enjoy every activity you can imagine including horse-riding, arts and crafts, camping, creative writing, canoeing, fishing, pottery, drama, music and loads more! Barretstown is a completely complimentary service. Barretstown always revolves around FUN. Children reflect on their experiences and make discoveries about themselves which helps build a child's self-esteem, independence and forges friendships.

## How can I apply for a place at camp for my child?

Each year we post out a copy of the dates for the Barretstown Camps to all eligible families. If your child has a bleeding disorder you will need to get a 'Physical Information' sheet filled out by your child's haematologist. This ensures that Barretstown

has all of the necessary information about your child so that the camp can run smoothly and children are totally safe. This form is then returned to Barretstown to the Family Liaison Co-ordinator and then they will contact you directly to offer you a place at camp.

## What if my child needs treatment?

When you are at Barretstown safety comes first. Barretstown has a full medical centre, staffed 24 hours a day by doctors and nurses experienced in paediatric specialities. All activity areas are carefully designed and are supervised by at least one carer (volunteer leader) for every two children.

If you have any queries please do not hesitate to contact me on 01 657 9900 or email me at [fiona@haemophilia.ie](mailto:fiona@haemophilia.ie)

**Fiona Brennan,**  
**Volunteer & Children's Co-ordinator**



# Youth and Junior Membership

The Society is fortunate that the children and teenagers who attend our conferences and events play an active and vital role in the organisation now and hopefully in the future. Giving the children and teenagers an opportunity to become members of the Society in their own right, in our view gives them a great sense of ownership of the organisation and increases their participation in the organisation.

Junior Membership is for children between the ages of 7 and 12 years, and Youth Membership is for teenagers between the ages of 13 and 17 years. Parents can sign up their child/teenager at I.H.S. events only.



## Some of the benefits include:

- A sense of belonging to the organisation.
- Encourages involvement in the Society.
- Education about bleeding disorders.
- Taking part in activities and events.
- Newsletters.
- Friendship.
- Community Spirit.

## Junior and Youth members will receive a membership pack including:

- A welcome letter.
- The latest newsletter.
- A membership card.
- An I.H.S. bookmark.
- Haemophilia Heroes Workbook.
- Sibling Superstars.
- Self-infusion reward information sheet (Junior members only)
- Dental care tips leaflet.
- How to become a junior volunteer information sheet (Youth members only)

## During the year Junior and Youth members will also receive:

- A birthday card.
- Newsletters.
- A self-infusion certificate and gift voucher for Smiths Toy Store, when you start self-infusing (Junior members only).
- Educational information.

If you would like more information about this, please call me on 01 6579900 or email at [paula@haemophilia.ie](mailto:paula@haemophilia.ie)

**Paula Houlihan**  
**Administrative Assistant**

# AGM 2017



*Members discussing issues at the Open Forum on Saturday afternoon*

When I started working at the Irish Haemophilia Society, the office was in a state of AGM fever. It was five and a half weeks away and there was so much to do.

Being completely honest, I was a bit like a duck out of water, to begin with. Everyone had lists as long as their arms. I don't like being idol and while I wanted to get stuck in, I had to be rained back in and firstly become more equipped with everything haemophilia. There was a lot of reading, which has given me a solid foundation for my new role. In the led up to the AGM, the girls shared their stories of past AGM's. It gave me a good sense of what to expect when March 3rd finally crept up.

In my head, I expected the office to be mental (and I'm talking about the abundance of coffee, lack of sleep, having the shakes type of mental!). It was super busy but everything and everyone was cool, calm and collected. I feel this speaks volumes for the

abilities of this fantastic team I find myself part of.

The day arrived, we were all packed and ready to go. As we neared the Slieve Russell, I started to get so nervous. It sort of felt like I was going on a first date. What would I say? What would I wear? Would everyone like me? It is quite overwhelming being the newbie, the one no one knows. On Friday evening as I sat at the youth group registration desk, the minutes were ticking by, my mouth was getting dry, my palms were sweaty, as we waited for people to start arriving. I have no idea why I was so terrified! It was so lovely to put faces to those I had spoken to on the phone and to meet everyone else. Everyone was so welcoming and friendly. I appreciated that more than you could know. It made the whole weekend less daunting.

Throughout the weekend I spent the majority of my time in the Cranaghan Suite at the various talks and sessions. I'm not



*The Annual General Meeting on Saturday morning*



*Dr. Michelle Lavin and Professor James O'Donnell following their presentation on the iPATH project.*



*Dr. Barry Harrington, Dr. Barry White, Ms. Ruth Hunter Nolan and Ms. Evelyn Singleton during the Open Forum on Saturday afternoon.*



*Members asking questions during the Annual General Meeting.*



*The Chairperson addressing the membership on Saturday morning*

going to lie, I'm a complete nerd, so having the opportunity to sit in on all the talks was fantastic. I found the history session on Friday evening extremely insightful and a really nice way to start the weekend. I enjoyed getting to go to see two of the children's groups during the weekend. It was evident how much the children enjoy themselves, how much they get from taking part and the friendships they have formed. I firmly believe these friendships will be the biggest asset to them in dealing with their haemophilia or bleeding disorder, or their sibling's haemophilia or bleeding disorder. I was completely blown away by all the developments in haemophilia care. My

background is Public Health. During my masters, it was part of the core curriculum to study different diseases, one of those being haemophilia. From learning about it in a lecture hall in UCD, I would never have imaged the vast advancements made in haemophilia treatment and care, in such a short space of time. It's incredible. I was particularly enthralled in the iPath research, it's absolutely fascinating. I also thoroughly enjoyed the inhibitors session. Inhibitors are something I am aware of but I didn't know a lot about, so it made for a great learning opportunity. Another particular interest of mine is international health. I have always been the person who wants





*Our fantastic volunteers.*

to go to developing countries. I was amazed to hear from Dr. Nam from Vietnam on how far haemophilia care in Vietnam has come since the twinning programme commenced with the Irish Haemophilia Society. It goes to show how a partnership built on a solid foundation of friendship, support and understanding can improve the lives of those with haemophilia.

Something that really struck me, over the course of the weekend, was the level of interaction from members. I have been to more conferences than I can count over the years, when the floor is open to questions and comments and you can see the fear people have asking questions. It was so refreshing to see so many people voice concerns and ask questions. This especially stood out to me at both the AGM and Open Forum. Seeing members take both ownership of decisions regarding their bleeding disorder was inspiring. You might not know it, but you all were great teachers over the AGM weekend.

As the main part of my role will be interacting and being the point of contact for members on a daily basis, my favourite part of the weekend for me was the mingling and chatting with everyone. I could have spent the entire weekend sitting down with copious amounts of tea having the chats. I am such a talker! For those of you who I had the pleasure of talking to, I hope it was as beneficial for you as it was for me. For those I didn't get the opportunity to talk to, I'm always at the end of the phone if you need anything at all. I hope going forward

that I either get to meet you all for a chat at some point, be it a hospital or home visit, or at least have a natter on the phone.

Overall, I really enjoyed my first ever Irish Haemophilia Society event. It was extraordinary to see the comradery, support and sense of community between each and every one of you. I am so delighted I get to be a part of that.

**Lyndsey Connolly,  
Outreach Co-ordinator.**



*Members discussing items during the Open Forum.*

## AGM 2017 Gallery



*Fun and games at the crèche and cubs clubs*



*Treasurer Ger O'Reilly presenting the Margaret King Educational Award to Barbara Wynne*



*Chairperson Traci Marshall Dowling presenting the Margaret & Jack Downey Award to Daniel Hanney's dad Michael Hanney*



*Chief Executive Brian O'Mahony presenting Dr. Beatrice Nolan with the Brian O'Mahony Award for outstanding contribution to haemophilia care in Ireland*



*Dr. Beatrice Nolan and Dr. Alison Dougall during the Open Forum*



*Chief Executive Brian O'Mahony presenting Dr. Nam from Vietnam with a gift*



*The Youth Group at the gym*



# Fundraising

*'Great things are done by a series of small things brought together' - Vincent Van Gogh*



**A**s a family, we look out for each other and help each other. The I.H.S. is a family and our members want to support one another. One way to provide this help is through fundraising, to allow us to improve services and support to our members. Raising funds and at the same time raising awareness of haemophilia and other related bleeding disorders doesn't have to be a monumental feat.

Raising funds can be as simple as taking part in an organised event and getting sponsorship, such as the upcoming VHI Women's Mini Marathon on the 5th June 2017 (see page 2 for details on the VHI Women's Mini Marathon), or you may want to do a fundraiser in your own school, workplace or community. Some fundraisers we have had in the past include bake sales, raffles, table quizzes and bring & buy sales. These are all things that can be organised in your local area with the help of a few family and friends and of course with our support.

We can provide posters, I.H.S. t-shirts, sponsorship cards etc. as well as advice on any fundraising event. The I.H.S. is registered with 'everydayhero' an online fundraising platform, which makes raising funds even easier, as your family and friends can go online and make their contributions. These funds come directly to the I.H.S. Setting up a fundraising page on 'everydayhero' takes just a few minutes and is a great way to advertise your fundraiser, as you can share your page on social media and by email to family and friends anywhere in the world.

If you want to be part of this support group and make a difference to people's lives, please think about fundraising for the I.H.S. Your contributions no matter how small will go a long way and will make a big difference to help someone else.

If you would like to take part in the Women's Mini Marathon or would like to organise your own fundraiser in aid of the I.H.S., please contact me on 01-6579900 or email [nina@haemophilia.ie](mailto:nina@haemophilia.ie).

**Nina Storey,**  
**Financial & Fundraising Co-ordinator**





# New Look Website!



We hope you are enjoying our new look website. We think it's a great improvement. It has been completely re-structured and we hope you are finding it easy to navigate. It's efficient and visual with a thoughtful user interface and meaningful content. Why not take a look at it and let us know what you think. Go to:

**[www.haemophilia.ie](http://www.haemophilia.ie)**

# An Introduction to I.H.S. Staff



Brian O'Mahony



Debbie Greene



Nina Storey



Fiona Brennan



Aoife Ní Fhógartaigh



Paula Houlihan



Lyndsey Connolly

Currently, the Society has 6 full-time staff and 1 part-time staff. If you would like assistance with anything, please do not hesitate to contact any of the staff by phone on 01 6579900 or by email.

## The current office team are:

---

### BRIAN O'MAHONY

---

*(Chief Executive)*

**Email:** [brian@haemophilia.ie](mailto:brian@haemophilia.ie)

Brian is the Chief Executive. He represents the Society on the statutory National Haemophilia Council and he is the Vice Chair of the Haemophilia Product Selection and Monitoring Advisory Board. Brian leads the organisation, prepares policies and plans for the organisation and oversees the implementation of the strategic plan. Brian also communicates with the Department of Health, Health Service Executive and various other stakeholders. He previously served as Chair of the Irish Haemophilia Society for 17 years from 1987 to 2003 and as President of the World Federation of Hemophilia (WFH) for 10 years from 1994 to 2004. Brian currently is the President of the European Haemophilia Consortium.

---

### DEBBIE GREENE

---

*(Administrator & Office Manager)*

**Email:** [debbie@haemophilia.ie](mailto:debbie@haemophilia.ie)

Debbie joined the Society in 2003. Since joining the Society she has had various roles. Debbie is the current Administrator and Office Manager, having taken up the role in May 2009. Debbie is responsible for the day to day running of the office and headquarters. Debbie oversees event management, is the designer and editor of publications, oversees social media and the website, supervises staff, administers educational grants, attends board meetings, oversees the apartment facility for members, supports members and prepares policy documents for the organisation. Debbie represents the Society on the National Haemophilia Council, the Irish Haemostasis Research Foundation, and is involved in the World Federation of Hemophilia twinning programme. Debbie also attends regular team meetings with the Comprehensive Care Centres.

---

## NINA STOREY

---

*(Financial & Fundraising Co-ordinator)*

**Email: [nina@haemophilia.ie](mailto:nina@haemophilia.ie)**

Nina began working for the I.H.S. in 1998 and is employed on a part-time basis. Since joining the Society, her role has varied greatly. Currently, Nina is responsible for the financial administration of the organisation and is the Society's fundraising co-ordinator, which includes planned giving and legacies. Nina's current role also includes updating the database and memberships, along with phone contact with members, outreach and hospital visits. Nina represents the Society on the Haemophilia HIV Trust.

---

## FIONA BRENNAN

---

*(Volunteer & Children's Programmes Co-ordinator)*

**Email: [fiona@haemophilia.ie](mailto:fiona@haemophilia.ie)**

Fiona joined the I.H.S. in February 2010. Currently, Fiona is the Volunteer & Children's Programme Co-ordinator. Fiona organises the four children's programmes at I.H.S. conferences. Fiona also co-ordinates and oversees the volunteers for all of our conferences and looks after event management, assists with publications and co-ordinates the yearly Barretstown camps.

---

## AOIFE NÍ FHÓGARTAIGH

---

*(Administrative Assistant)*

**Email: [aoife@haemophilia.ie](mailto:aoife@haemophilia.ie)**

Aoife Ní Fhógartaigh has been working in the I.H.S. since December 2015. Aoife has recently joined the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) which chooses the products used in Ireland for the treatment of haemophilia and other related bleeding disorders. Aoife is involved in event management and updates the Society's website. Aoife also distributes the monthly Mailchimp/Ezine electronic magazine to members.

---

## PAULA HOULIHAN

---

*(Administrative Assistant)*

**Email: [paula@haemophilia.ie](mailto:paula@haemophilia.ie)**

Paula Houlihan joined the I.H.S. as an Administrative Assistant in August 2016. Paula's main task is to look after the reception area including answering the phones, greeting visitors and typing. Paula also works in the area of publications and is developing the Society's social media platforms. Paula also looks after the bookings for the apartment facility for members.

---

## LYNDSEY CONNOLLY

---

*(Outreach Co-ordinator)*

**Email: [lyndsey@haemophilia.ie](mailto:lyndsey@haemophilia.ie)**

Lyndsey joined I.H.S. in January 2017 as an Outreach Coordinator. Lyndsey provides a variety of support to members and is now the main point of contact for all our members, who need assistance. Lyndsey makes phone calls to members, visits members in their homes and also in hospital. Lyndsey also assists members with any questions or queries they have around social welfare entitlements, the HAA Card and liaises with healthcare workers in the three Comprehensive Care Centres.





### IRISH HAEMOPHILIA SOCIETY

First Floor  
Cathedral Court  
New Street  
Dublin 8  
Tel: 01 6579900  
Fax: 01 6579901  
Email: [info@haemophilia.ie](mailto:info@haemophilia.ie)  
Website: [www.haemophilia.ie](http://www.haemophilia.ie)

