



Irish Haemophilia Society

Autumn Magazine

Representing People Living With Haemophilia, Von Willebrands &
Other Related Bleeding Disorders

Autumn 2026 Edition



From the Editor

Roisin Burbridge, Publications, Website & Social Media Coordinator



Hello all! I hope everyone was able to enjoy the wonderful summer we have had! It's a busy time at the IHS and we have lots to share with you. We have two important events coming up - our Women & Girls with Bleeding Disorders Information Day and our annual October Members' Conference. You will find programmes for these events later in the magazine.

To kick off this edition, Brian provides some updates in his CEO report on our recent Parents Conference and about our upcoming publications. We are excited to launch three new informational booklets in the coming months. He also shares some interesting clinical updates about treatment products for haemophilia and von Willbrand disorder (VWD).

Following this, the team at the IHS have written an appreciation piece for our late member John O'Mahony, who passed away earlier this summer. John gave generously of his time and expertise to the Society over the years and will be sorely missed. His daughter, Molly O'Mahony, has also contributed a heartwarming tribute to John.

Afterwards, I have written a report on the highlights from our recent Parents Conference and we have included photos from the conference. Later in the magazine, you can find all the information you need to apply for one of our educational grants. There's still time to do so!

Recently, Children's Health Ireland (CHI) at Crumlin put together fantastic resources for parents and children alike to help them cope with needle procedures. We have created an infographic using their top tips for parents, which is featured later in this edition.

Finally, you can find news and other updates at the back of our magazine, in the noticeboard. Wishing you all happy reading!

The Irish Haemophilia Society at a Glance



2.2k

Facebook Followers

432

Instagram
Followers



63

I.H.S. Volunteers



1,533

X Followers



37

Planned Giving
Contributors

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CEO Report

Brian O'Mahony, Chief Executive

Parents Conference

Our Parents Conference was held in Portlaoise in July. Under our current strategic plan, we have decided to hold the conference every three years, rather than annually as was the practice up to 2016.

This change reflects the reduced amount of new information requiring an annual conference. In the past, significant parts of the programme focused on home infusion training. This is now much less relevant due to the widespread use of mimetic factor VIII (FVIII) treatments and ultra-extended half-life FVIII concentrates. As a result, fewer children now need to self-infuse intravenously, and portacath insertion is increasingly uncommon in children with inherited bleeding disorders.

This year's conference heard an update on current and future treatments, with a separate update for those with von Willebrand's disorder (VWD) or rare bleeding disorders. There was an excellent session on physiotherapy and a separate presentation on needlephobia. Diverse elements of comprehensive care were covered, areas that had been identified as important by the team at CHI Crumlin. These included nosebleeds, head injuries, dental care, treatment at home and communication with other hospitals as well as the ambulance directive and bleeding disorder alert cards. It is worth repeating that members should carry a photograph of the ambulance directive on their phone and also photographs of the front and back of their child's bleeding disorder alert card. You may not have the physical copy in your wallet when it is required so having photos of the card on your phone is a very good backup.

There was also a very good session on inheritance and carrier issues and an open forum with a panel of speakers from CHI Crumlin. On Sunday, CEO of CHI Lucy Nugent, gave an update on the new National Children's Hospital. This was a very positive and detailed overview of the new hospital and how it will function. We look forward to the hospital being open and available to our members. We finished the weekend with very



constructive mothers and fathers workshop discussion groups. The Parents Conference was evaluated as very successful by the families present and we look forward to the next one in 2029.

Publications

In addition to our autumn and winter magazines and our fortnightly e-zines, we will be producing a number of new or updated publications in the second half of this year. The Society produced a sports and exercise publication in 2019. Since that time haemophilia treatments in particular have advanced even further, allowing for greater protection from bleeding and higher trough levels. As a consequence people with haemophilia are now playing a wider variety of sports and looking at different exercise and activity options. Some people are not only playing soccer, but also Gaelic football and hurling. While these latter sports may not be highly recommended for people with severe bleeding disorders it also seems to be the case that they are no longer totally prohibited on medical advice. The content of the new publication has been put together by haemophilia specialist physiotherapists Mark McGowan from St. James's Hospital and Paula Loughnane from CHI Crumlin. We are currently finalising this publication and it will be available shortly.

We are also finalising a suite of three publications for women and girls with bleeding disorders. The first publication, "Time to Talk Periods" was published last year. With the assistance of the comprehensive care teams at St. James's Hospital and CHI at Crumlin, we are updating our existing publications on "Women and Bleeding Disorders" and "Teenage Girls with Bleeding Disorders". We will also be producing a second edition of the "Key Developments in Novel Therapies for Bleeding Disorders" in collaboration with the Canadian Hemophilia Society. The first edition which was produced in April of this year was a very welcome, succinct and readable summary of the latest developments. Our plan is to produce these publications twice per year.

Therapeutic Developments and Clinical Trials

There are now two separate rebalancing agents licensed by the European Medicines Agency (EMA). These are both anti-TFPI products which can be used for people with haemophilia A or B, with or without inhibitors. Further updates on use of these products were discussed at the recent International Society of Thrombosis and Haemostasis conference. These products will be evaluated later this year in Ireland by the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB). The Society now has four representatives on this Board - Brian O'Mahony (Vice-Chair) and Matthew Finnie as voting members and Seamus Mc Donald and Radoslaw Kaczmarek as ex-officio members. It is anticipated that, in addition to Emicizumab (Hemlibra) a second mimetic – MiM8 (brand name Denecimig) will be licensed by the EMA next year. A third FVIII mimetic, NXT-007, is currently undergoing clinical trials. These trials will also take place in Ireland at the National Coagulation Centre (NCC) and also at CHI Crumlin.

Another product which will be in clinical trials here in Ireland in the coming months is VGA-039, a monoclonal antibody developed for VWD. This is a subcutaneous therapy and particularly welcome as the therapeutic options at present for VWD are so limited. The NCC will participate in the clinical trial. Those of you with VWD who attended the VWD sessions at our recent Parents Conference or AGM/Conference in March will have heard about the many exciting therapies now being looked at in clinical trials for the condition. It is unlikely that all will survive the clinical trials process but several should, positively transforming the VWD treatment landscape in the future.

John O'Mahony An Appreciation

We were deeply saddened by the passing in June of John O'Mahony from Killarney after a short illness. John had severe Haemophilia B and was a long-standing member of the Society.

Professionally, he was a journalist. He had previously been editor of the Kingdom newspaper in Kerry as well as a freelance contributor to many national media outlets. In more recent times, John had a successful online newspaper - Killarneytoday.com and a media and public relation company, O'Mahony Media, which he ran with his wife Geraldine.

John was extremely helpful to the Society in allowing us to avail of his expertise. He assisted on a voluntary basis with all of our press releases over the past number of years and issued them to all national newspapers and radio stations. He also carried out all the media work free of charge on our national von Willebrand disorder awareness campaign in 2022 as well as providing great assistance with the organisation of our 50th anniversary gala ball in 2018.

John, together with his wife Geraldine and daughter Molly, was a very regular attendee at Society conferences for many years. His wit, storytelling ability and sense of humour were always evident. He will be sadly missed by all who knew him.

The Team at the IHS

Everyone in the IHS seemed to know John O'Mahony from regularly attending AGMs and weekend conferences, from his humorous comments and witty debates or, as he liked to describe himself, as Brian O'Mahony's more handsome brother. John had some wonderful friends in the Society who he always looked forward to catching up with at conferences and events around the country.

Everyone knew John as a friend and a great character but nobody knew him as I did – as my dad.

As an only child, my parents and I are incredibly close. The three of us often described ourselves as the three musketeers. We were a great little team and did everything together.

Growing up, my dad was a constant source of fun. The jokes, games and entertainment never stopped. I don't think an hour, let alone a day, ever went by where my dad didn't make me laugh. Even now, thinking about the mischief we got up to down through the years brings a smile to my face.

My dad had severe haemophilia B - or "Christmas Disease" as he preferred to call it. While haemophilia was a constant throughout his life, he never let it define him. He never allowed it to stop him from doing anything or from achieving his goals. He faced some huge challenges in his life because of this but he always fought through them with a brave face and a sense of humour. He was adamant that a packet of jelly babies after infusing his factor was the key to preventing bleeds. There may be no medical evidence to support this but he never skipped his jellies, just in case. My dad showed me how to be resilient in tough times and he proved



every day that you can overcome any challenge to follow your dreams.

One of the things in life that brought my dad the most joy was trying his best to make me as mortified as he possibly could. One recent example of this was a day, a number of months ago, when he was in St James's Hospital (SJH) for an appointment. For those of you who don't know, I work as a physio in SJH. I met my dad for lunch following this appointment, as I always did when he was in the area. We were standing in the middle of the hospital concourse – a very large and busy area – and my dad, as always, gave me a hug and kiss goodbye. As he did this, he proceeded to shout, at the top of his lungs, in front of patients and colleagues of mine: "best physio EVER!!" He turned on his heel and left, to head home to Kerry. Leaving everyone to think, what sort of a relationship does this physio have with her patients?

As anyone with a bleeding disorder will know, regular hospital appointments are a necessity. When I started working at St James's Hospital three years ago, I began to notice that my dad's hospital appointments were slowly becoming more frequent. He went from yearly visits, to bi-annual visits and, eventually, they were close to monthly. I was concerned until I realised the time of his appointments somehow always seemed to coincide with my lunch breaks and took place at times where I might not have been home for a few weeks. I'm pretty sure that he was making half of them up just to have an excuse to come visit me. I never complained about it either.

A number of months ago my dad was an inpatient in St. James's. Every day, I spent my breaks with him and I would sit at his bedside and eat my breakfast or lunch with him. On a few occasions, his medical team would come around as I was there so I would head out to leave them to it. After about a week of this, one of the doctors asked my dad, "how are you getting on with physio?". My dad responded that he wasn't seeing any physio as he didn't need it. This raised some eyebrows, leading the doctor to ask why there was a physio sitting with him every morning. Dad quickly pointed out that I was his daughter and I worked there, leading to huge sighs of relief from the medical team. Turns out that half the hospital had heard about this very odd physio who was going around and eating with her patients instead of doing any work.

Professionally, dad was a journalist. In 2014, he established KillarneyToday.com – a local online "newspaper" as he liked to describe it. Given the fact that his entire career for the past 12 years has been based solely online, you would imagine that he would have had the necessary skills with technology. It may have seemed that way but what the public didn't see were the numerous phone calls I would get weekly, as his unofficial tech advisor, informing me that "Facebook fell off my phone again".

It's impossible to talk about dad without mentioning his beloved golden retriever Nigel – the favourite child. Dad and Nigel had an incredible bond – Nigel would spend every day in the office with my dad, lying right behind his seat. In the days before dad went into hospital a few months ago, Nigel would not leave his side. He knew there was something wrong. They were best pals and I know that Nigel misses him so much too.

I can't begin to imagine what life is going to be like without dad but he will always be in our hearts and we will keep him with us in everything we do.

I am the luckiest person in the world to have had such an amazing, fun, caring and hilarious dad. I only wish we could have had longer together, but we will forever cherish the wonderful memories we have with him.

Molly O'Mahony, IHS Board Member



Parents Conference

Roisin Burbridge, Publications, Website & Social Media Coordinator

This year's Parents Conference brought families together on a lovely weekend in July in the Midland's Park Hotel in Portlaoise. The Friday evening started as the weekend was to go on, with lots of fun being had by the children as they were entertained by the wonderful facepainter the hotel had provided.

On Saturday morning, parents dropped their kids off into one of the four programmes, the Creche (for kids aged 0-3) the Cubs (for kids 4-7) the Kidlink (for ages 8-12) and the Youth (for ages 13-17). They then made their way to the adults talks, which promised to be information packed with a host of fabulous speakers from Children's Health Ireland (CHI) Crumlin.

The day began with parallel sessions from Dr. Saad Ahmed on current and future treatment options for haemophilia, and Dr. Beatrice Nolan on living with von Willebrand disorder (VWD). Dr. Ahmed outlined how haemophilia treatments have expanded significantly in recent years, from extended half-life products to ultra-extended products and non-factor replacement therapies. He also explored emerging treatments, including NXT007, a bi-specific antibody for haemophilia A.

Everyone then returned to the main room for Ms. Paula Loughnane's talk on physiotherapy and bleeding disorders. Her presentation focused on helping parents recognise and manage their children's bleeds, particularly by identifying early signs such as changes in movement and stiffness. She also highlighted the importance of children with bleeding disorders staying active, which is essential for developing strong bodies and healthy bones.

Following the coffee break, we had a very interesting session on comprehensive care, with input from many members of the CHI bleeding disorder and dental team. Speakers who could not attend in person sent in excellent recorded talks. Of particular note was a video put together by Dr. Mahnoor Ali on dental care, which offered an engaging and creative overview of taking care of your child's teeth as well as funny clips from many of the dental staff in CHI.



After a light lunch of soup and sandwiches, we returned to the main conference room for a talk on needlephobia by Dr. Yvonne Duane. Dr. Duane shared a range of helpful tips for parents on supporting and reassuring their children before treatment injections. She advised parents to remain calm, offer distractions and praise their child afterwards, even if things did not go as planned.

Next, Advanced Nurse Practitioner Ms. Caitriona Ferry and Dr. Beatrice Nolan delivered a joint session on carrier issues and heavy periods. This was followed by the final session of the day, an Open Forum with the team from CHI Crumlin. After an engaging session, everyone had a well-deserved break before dinner.

That evening after dinner, Jeca the Clown arrived to provide plenty of laughs and fun for both children and parents, getting everyone involved.

The following day, the CEO of CHI gave a presentation on the New Children's Hospital, showing images of its state-of-the-art medical facilities, as well as the ample outdoor spaces gardens, and dedicated art and play areas.

The final session of the day was a mothers' and fathers' group. Both groups discussed issues that were important to them, while the mothers also discussed setting up a group where they could meet a few times a year, either in person or via Zoom. We have since organised and held a Zoom call for this group.

While their parents attended the talks, the children enjoyed a range of fun activities as part of the programme. Highlights included podcasts recorded by the Youth Group exploring what it means to have a bleeding disorder, swimming, and art projects carried out by the various groups.







Women & Girls With Bleeding Disorders Information Day

Venue: Dunboyne Castle Hotel, Co. Meath

Date: Saturday 12th September, 2026

Adults Programme

- | | |
|----------------------|---|
| 11.45 - 12.00 | Registration (Cedar Suite) |
| 12.00 - 13.00 | Lunch (Restaurant) |
| 13.00 - 13.45 | Pregnancy & Childbirth (Cedar Suite)
<i>Speaker: Dr. Kevin Ryan, Consultant Haematologist, National Coagulation Centre, St. James's Hospital</i> |
| 13.45 - 14.30 | Women with Bleeding Disorders Update - Treatment & Care (Cedar Suite)
<i>Speaker: Ms. Shona Brady, Clinical Nurse Specialist, National Coagulation Centre, St. James's Hospital</i> |
| 14.30 - 15.30 | Dealing with Heavy Menstrual Bleeding (Cedar Suite)
<i>Speaker: Dr. Beatrice Nolan, Consultant Paediatric Haematologist, CHI Crumlin</i> |
| 15.30 - 16.00 | Coffee Break (Cedar Suite) |
| 16.00 - 17.00 | Menopause & Life After It (Cedar Suite)
<i>Speaker: Dr. Madeleine Daly, GP</i> |

Children & Teenagers' Programme (Ages 12 - 17 years)

- | | |
|----------------------|--|
| 11.45 - 12.00 | Registration (Drawing Room) |
| 12.00 - 13.00 | Lunch (Restaurant) |
| 13.00 - 13.45 | Dealing with Periods (Drawing Room)
<i>Speaker: Ms. Caitriona Ferry, Advanced Nurse Practitioner in Haemophilia, CHI Crumlin</i> |
| 13.45 - 14.45 | Dental Care (Drawing Room)
<i>Speaker: Prof. Alison Dougall, Dentist, National Coagulation Centre, St. James's Hospital</i> |
| 14.45 - 15.15 | Refreshment Break (Drawing Room) |
| 15.15 - 16.00 | Physical Activity (Drawing Room)
<i>Speaker: Dr. Megan Kennedy, PhD, Adjunct Assistant Professor, Trinity College Dublin</i> |
| 16.00 - 17.00 | Workshop / Art Project (Drawing Room) |

October Members' Conference

Venue: Mount Wolseley Hotel, Co. Carlow

Date: 16-18th October, 2026

Preliminary Adults Programme

Friday 16th October

19.00 Buffet Dinner (Frederick's Restaurant)

Saturday 17th October

10.00 - 10.45 **Clinical Trials (Austin Suite 2)**

10.45 - 11.30 **Personal Treatment Perspectives (Austin Suite 2)**

11.30 - 12.00 Coffee Break (Pre Conference Lobby)

12.00 - 13.00 **Debate: In 2036, will we still need the I.H.S.? (Austin Suite 2)**

13.00 - 14.00 Lunch (Frederick's Restaurant)

14.00 - 15.00 **National Haemophilia Council – Mission & Vision for the Future (Austin Suite 2)**

15.00 - 15.30 Coffee Break (Pre Conference Lobby)

15.30 - 16.15 **Sexual Health & Intimacy (Austin Suite 2)**

16.15 - 17.00 **Sports & Treatment Pathways (Austin Suite 2)**

19.00 Dinner (Austin Suite 1 & 2)

Sunday 18th October

10.00 - 11.00 **Mental Health (Austin Suite 2)**

11.00 - 11.30 Coffee Break (Pre Conference Lobby)

11.30 - 13.00 **The I.H.S. Through the Years (Austin Suite 2)**

13.00 Depart



Each year, the Society offers educational grants to people with diagnosed inherited bleeding disorders, as well as their immediate family members, who are pursuing further education after second level. These grants provide financial support to help with the additional costs associated with their studies.

There are four categories of educational grants available to apply for:

- Maureen & Jack Downey Educational Grant
- Michael Davenport Educational Grant
- Margaret King Educational Grant
- Father Paddy McGrath Educational Grant.

What is the criteria for applying?

The Maureen & Jack Downey Educational Grant:

This grant is made available to a person with a diagnosed inherited bleeding disorder. The person applying must be a member of the Irish Haemophilia Society and must be accepted onto a post second level educational degree course at level 7 to 9.

The Michael Davenport Educational Grant:

This grant is made available to a person with a diagnosed inherited bleeding disorder. The person applying must be a member of the Irish Haemophilia Society and ideally should be a mature student (aged 21 years plus), who has been accepted onto a post second level educational degree course, or a postgraduate course at level 7 to 10.

The Margaret King Educational Grant:

This grant is made available to an immediate family member of a person with a diagnosed inherited bleeding disorder, be it spouse, son, daughter, sister, brother, mother or father. The person applying must be a member of the Irish Haemophilia Society and must have been accepted onto a post second level educational degree course at level 7 to 9.

The Father Paddy McGrath Educational Grant:

This grant is made available to a person with a diagnosed inherited bleeding disorder. This grant is also made available to immediate family members be it a spouse, son, daughter, sister, brother, mother or father. The person applying must be a member of the Irish Haemophilia Society.

How much are the educational grants for?

Maureen & Jack Downey Educational Grant

First prize	€4,000
Second prize	€2,000
Third prize	€1,000

Michael Davenport Educational Grant

€2,000

Margaret King Educational Grant

First prize	€2,000
Second prize	€1,000
Third prize	€500

Father Paddy McGrath Educational Grant (2 Grants)

Grant A for a person with the bleeding disorder

First prize	€1,000
Second prize	€500
Third prize	€250

Grant B for a family member of a person with the bleeding disorder

First prize	€500
Second prize	€250



How are the applications scored and who scores them?

Once the closing date arrives and all the applications have been received, a subgroup of three people from the executive board (which cannot include anyone with a family member applying for any of the grants) meet to consider and score the applications, and make recommendations to the rest of the executive board regarding recipients. The successful applicants are then notified at the end of October by letter.

Applications are scored on the following:

- The quality of the application.
- The information given on the application form.
- Involvement in the Irish Haemophilia Society.
- Other factors.

Can I apply every year?

Yes, you can apply every year, even if you have already been successful. Remember that even if you are eligible to apply for multiple grants, you can only apply to one each year.

Take some time to complete your application, as the more complete and detailed your application is, the higher your chance is of it being successful! Remember that all grant applications must be written by the person applying.

There is still time to submit your application for one of our educational grants, with applications open until September 25th.

Tips to Help Parents Support Children with Needle Procedures

Let them know why it's happening



The test helps the doctor check how your body is working.

Tell them in advance (but not too early)



Younger children:
The day of



Older children:
A couple of days or more, depending on the child

Explain what will happen step by step



Be honest, but keep it simple



"It won't hurt."



"You might feel a quick sting. It will be over fast. You can do it!"

Before the procedure



Give them choices where you can



Practice calming techniques



Bring a comfort item to the procedure



Tell the staff if your child is nervous

During the procedure



Stay positive but acknowledge their feelings



“It won’t hurt at all.”



“It’s fine, don’t cry.”



“You are so brave giving it a try.”



“You have done hard things before, you can do this too!”

After the procedure



Celebrate effort even if the procedure didn’t go to plan



If your child is consistently having trouble with this, chat to your medical team for more support

Contact Preferences Survey

We are currently in the process of updating how we contact our members, to ensure that we are doing so in the way that best suits each member.

Therefore we ask that members fill out our Contact Permissions and Preferences Survey. This survey asks how members would like to receive event information, publications and outreach.

You can find this survey on our website, under News, or by calling Lena in the office on 01 657 9900.



School Talks

With the kids back in school, now might be the perfect time to get in touch with our Outreach & Engagement Manager, Robert Flanagan, about a visit to your school.

Robert is happy to inform teachers, principals and other staff about an individual child's bleeding disorder and what to expect. He can do this in person, on an online video call or by recording a talk and sending it over for the school to watch when suits them.

Get in touch with Robert at robert@haemophilia.ie to arrange a school talk for your child.

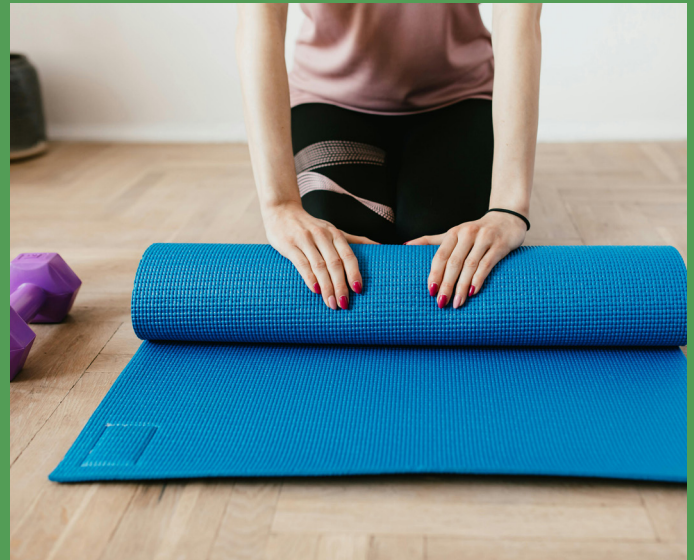


Physio Classes

Join our online physio/exercise classes and work on your fitness from the comfort of home!

We are pleased to announce that our online physio/exercise classes are back up and running for the autumn/winter period. The classes will run every Tuesday at 7.30pm and will be facilitated by Mark McGowan, Clinical Specialist Physiotherapist in Bleeding Disorders, from St. James's Hospital.

For further information, please contact Robert Flanagan on 01 6579900, or by email: robert@haemophilia.ie.



New Staff Member

We are delighted to introduce our new Administrative Assistant in Events Coordination, Haley O'Hora.

In her role, Haley coordinates the logistical arrangements for the Society's meetings and events, helping to ensure that they run smoothly and efficiently. She also provides general administrative support across the organisation, assisting with office operations, member enquiries, and a range of day-to-day activities that support the work of the Society.

We hope that Haley enjoys being part of the team!





Irish Haemophilia Society

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