Haemophilia.ie

Magazine of the Irish Haemophilia Society

Representing People in Ireland with Haemophilia, von Willebrands & Related Bleeding Disorders

SCAN ME

Autumn 2025 Edition

From the Editor

By Roisin Burbridge, Publications, Website & Social Media Coordinator

Hi everyone! The brilliant summer we had is now over and we are on our way to the spooky season and all the cosy things we can enjoy in the cooler months!

The IHS have been busy over the summer with a number of great events and we are excited to share plans for more! Read on for more information about these.

In Brian's CEO report, we learn about exciting new developments in haemophilia treatment. He also shares good news about changes made to the World Health Organisation's (WHO) Essential Medicines List (EML), which he and others have been working tirelessly to change over the past couple of years.

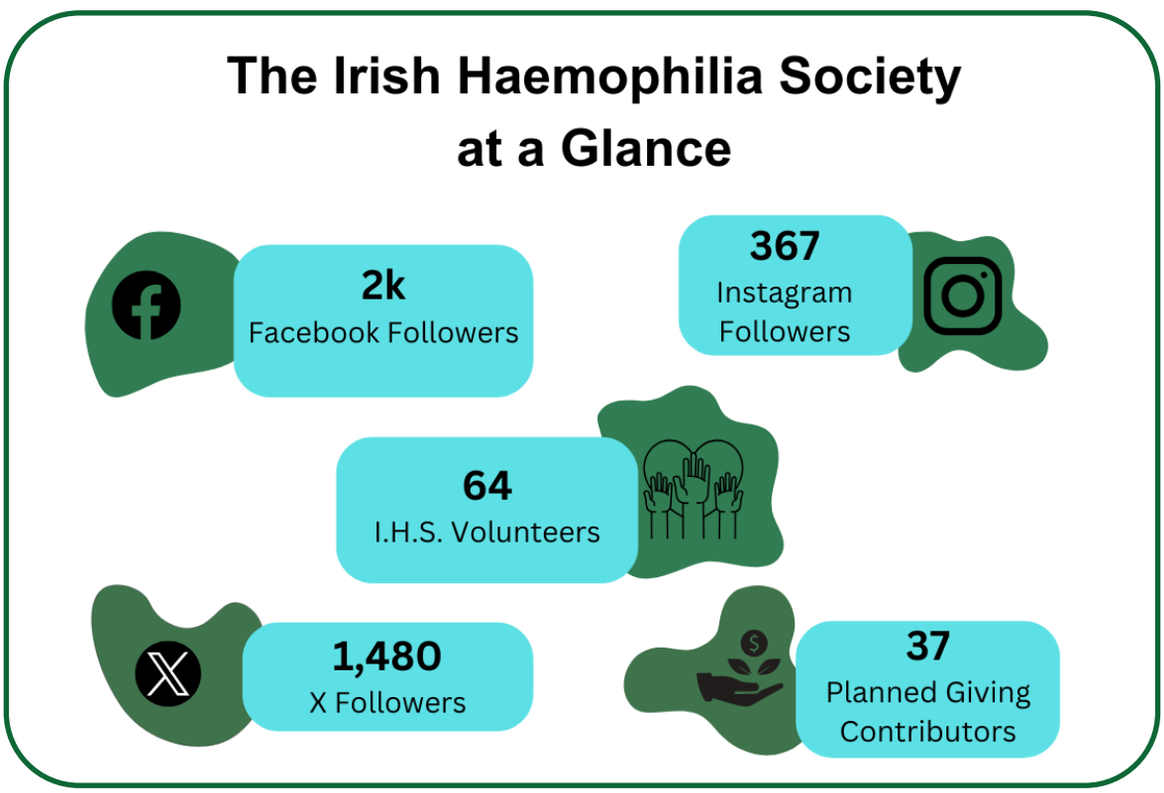
Following his report, Brian shares an interesting piece about the much-awaited new National Children's Hospital, along with some images that demonstrate how modern and state-of-the-art the new hospital will be.

After Brian's updates, we have articles on our recent events, from the Ageing Conference which took place in June, our parent/child overnight event in July and our recent Newly Diagnosed Information Day which took place earlier in September. For those attending our upcoming October Members' Conference, we have also included the final programme here.

We are happy to share updates about our efforts to bolster the cause of women and girls with bleeding disorders (WGBD) and include information about our WGBD Information Day in November of this year. We hope this will be a well attended event with both women and girls (10 years of age and older). Continuing this theme, Caitriona Ferry of CHI Crumlin shares some top tips for managing heavy periods, particularly useful for the younger cohort of members but also for anyone struggling with heavy periods.

Nearing the end of this edition, we have information on our services and supports, educational grants, and our news bulletin.

We hope you enjoy this edition of our magazine!



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CEO Report

By Brian O'Mahony, Chief Executive

Treatment Updates

We are living in very exciting times for haemophilia treatment. The ultra extended half-life (EHL) factor VIII (FVIII), Altuvoct, is now being routinely used here in Ireland, as well as the mimetic Hemlibra. There are other mimetics in clinical trials and licensed gene therapies for haemophilia A and B (although the haemophilia A gene therapy is currently marketed only in Italy and Germany in the EU).

We have been talking to members for several years about the new range of products in clinical trials which seek to re-balance coagulation, not be increasing FVIII or factor IX (FIX), but by inhibiting naturally occurring anti-coagulants. These are now becoming available. Concizumab (brand name Alhemo) and Marstacimab (brand name Hympavzi) have recently been licensed by the European Medicines Agency (EMA) for people over 12 years of age, while Fitusiran (Qfitlia) is expected to be licensed by the EMA in the next 18 months. All three are subcutaneous with injection frequency ranging from daily to once every two months. These products can be used by people with haemophilia A and B, with and without inhibitors (Concizumab) or without inhibitors only (Marstacimab), Eventually, we expect all three to be licensed for all four indications (haemophilia A or B with/without inhibitors). It is also our hope that some of the re-balancing agents or mimetics may be effective in treating rare bleeding disorders such as Glanzmann Thrombasthenia and indeed a clinical trial is underway using the mimetic, Hemlibra, in type 3 von Willedrand disorder (VWD).

We look forward to reviewing these products with the clinicians and continuing education with members.

WHO Essential Medicines List

In a previous newsletter, I spoke about the danger to haemophilia treatment from the World Health Organisation (WHO) Essential Medicines List (EML). The list contains core medicines which are the most important and complementary medicines which can be used if core medicines are unavailable. The last EML published in 2023 had pathogen-reduced cryoprecipitate on the core list with non-virally inactivated cryoprecipitate as a backup. These products are not safe and efficacious. Non-virally inactivated cryoprecipitate continues to have the potential to transmit bloodborne viruses. Safe and effective plasma derived factor concentrates were relegated to the core list. In addition, safe and effective recombinant factor concentrates which have been on the market since the mid-1990s and the mimetic Emicizumab (Hemlibra) which has been on the market since 2018 were not mentioned on the list at all. It is unlikely that this would have had any impact on people with haemophilia in Ireland but it had the potential to have a major impact on people with haemophilia in developing and emerging countries. The governments in these countries could use the preference for cryoprecipitate on the WHO EML to treat people with haemophilia with cryoprecipitate as opposed to safe and effective plasma derived, recombinant factor concentrates or mimetics.

It was our strong view that that this list was misguided and wrong. I was part of the team with the World Federation of Hemophilia (WFH) who raised the alert about this issue and worked on three separate submissions over the past two years for the 2025 WHO EML. We wanted untreated cryoprecipitate and pathogen-reduced cryoprecipitate to be removed from the core and complementary lists. We wanted safe and effective plasma derived and recombinant factor concentrates added to the core list. We wanted prothrombin complex concentrates, which contained FIX and several other factors, to be removed from the list for haemophilia B as they have a thrombosis risk. We wanted Emicizumab added to the core list.

We were extremely pleased when all of these recommendations were accepted by the WHO in their just published 2025 EML. This was an important landmark for the haemophilia and VWD community globally. This greatly reduces the risk of morbidity and mortality from the use of these unsafe products.

Society Events

In July, the Society organised an overnight parent and child event at the Lilliput Adventure Centre in Westmeath. This was very well attended by approximately 30 adults and children. It featured a lot of water based and land based activities. We were very pleased with the attendance and we look forward to organising further such events in the future.

In September we organised a newly diagnosed information day for parents of children with inherited bleeding disorders three years or younger. There have been a significant number of newly diagnosed children with haemophilia in recent years and we were delighted to be able to organise this event for these families. Dr. Beatrice Nolan and physiotherapist Ms. Paula Loughnane from CHI at Crumlin discussed the normal developmental milestones in the first three years of life followed by a discussion on bleeding disorders in the first three years of life. Dr. Aisling Cant, who was a paediatric dentist at CHI at Crumlin, talked about dental care in the first three years of life. The event was very well attended with approximately 30 people including several children. The children obviously did not attend the lectures but they were kept busy by our Children's Programmes Coodinator Robert Flanagan and several volunteers. This is an area where we hope to do further meetings in future and depending on demand this may become an overnight event.

Publications

The Society are currently putting the finishing touches to two new publications. The first is a booklet targeting young girls between the ages of 10 and 14 called "Time to Talk Periods". This is a Society publication based on a booklet produced by the European Association for Haemophilia and Allied Disorders and authored initially by Dr. Michelle Lavin from St. James's Hospital. When available, we hope this will be of great interest to young girls and their parents. The new booklet will feature at our women and girls with bleeding disorders information day in November.

The second publication is a dental leaflet aimed at parents of children with bleeding disorders and provides a lot of basic but important information about caring for the teeth of a child with a bleeding disorder. This will be available from the Society on our website and at each of the treatment centres.

National Haemophilia Council

There will be significant change at the statutory National Haemophilia Council in the coming months. The current Chairperson, Mr. Brian Fitzgerald, has completed his mandate and is stepping down from the council after three years. The current Chief Officer Ms. Grainne Leach, is also stepping off the council later this year after 11 years as Chief Officer. I want to thank both Brian and Grainne for their commitment to haemophilia and to the council. Their contribution will not be forgotten.

New Children's Hospital

By Brian O'Mahony, Chief Executive

I had the opportunity in June to do a tour of the new National Children's Hospital at the St. James's Hospital campus. Many of you will have seen the impressive view of the hospital from outside the building. Once inside the building it is even more impressive. It is laid out on six levels with clear functionality for each level. The inpatient ward for people with haemophilia and other inherited bleeding disorders will be on level four. The layout is very deliberately organised to enhance patient flow throughout the hospital. A lot of thought and planning has gone into this.

The inpatient rooms are spacious and comfortable and many look out onto a garden. The gardens themselves are very pleasant and overlooking them is a futuristic part of the hospital, pictured below.

The workings of the hospital will be built around a strong information technology system. Nurses and doctors will use tablets and cell phones for patient information. When the nurse handover is being carried out at the end of a shift this will be done using tablets and not on paper. It's also interesting that parents will be able to attend their child's handover. The television in each single room will also be an information portal. In addition to TV, video streaming and movies on demand will be available. Meals can be ordered via the TV with flexible meal times. There will also be school content available on the TV in addition to a school in the hospital. There will be a patient portal called MyChart which will allow patients and their parents to access key health information online. This will include clinic letters, after visit summaries and discharge summaries including patient instructions and access to specific material.

Much of the work internally has been completed although clearly work remains to be done. There are constant media stories about timelines and delays in completion. Once the hospital is handed over (currently planned for November 2025) there will be a nine month commissioning period. This will be to ensure that people, department services, technology and digital infrastructure, and facilities, are operationally clinically ready to provide safe and effective patient care when the hospital opens.

My understanding is that the sequence of moving children from the existing Children's Hospital will be that children from Tallaght, Temple St and Crumlin will move in that order over a relatively short period of time. I do not know when this will take place. Currently it looks as if this may well be in late 2026 but I would not be surprised if this becomes early 2027 as their there may be difficulties in moving children during the winter. I understand the plan is that they will try to allow as many children in hospital go home and to minimise elective surgery for a period of time before the move so that the number of children to be moved will be manageable.

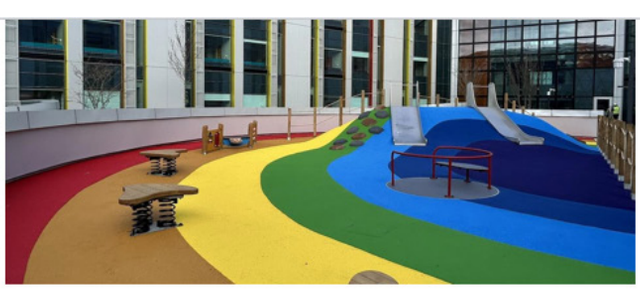
There are no further tours of the facility at the moment but if and when tours are available for parents we will of course let members know.

#ourchildrenshospital

Departments & Clinical Areas in NCH

Sláinte Leanaí Éireann
CHI
Children's Health Ireland

Level 6	**Ward 64A (24 Bed)** Respiratory/CF, Metabolic Medicine, Endocrine, Diabetes, Dermatology **Ward 63C (24 Bed)** Infectious Diseases/Immunology, Rheumatology, General paediatrics > 72 hours Neurodisability > 1 year, Complex care		**Ward 64B (24 Bed)** Neonatology, Transitional Care Patients, Neurodisability < 1 year **Ward 63D (24 Bed)** Orthopaedics
Level 5	**Wards 54A & 54B (2 x 24 Bed wards)** Acute General Paediatrics **Ward 53C (24 Bed)** Surgical including: Burns, Plastics, ENT, CranioFacial, Maxillo-Facial, Dental, Gynaecology, Ophthalmology		**Ward 53D (24 Bed)** Neurosciences (Neurosurgery, Neurology, Neuro-rehabilitation)
Level 4	**Ward 44A (20 Bed)** Nephrology, Haemodialysis, Transplant & Urology Gastroenterology & Hepatology		**Ward 44B & 43C 34 Bed** Oncology & Malignant Haematology Benign Haematology, BMT(Bone marrow transplant)
Level 3	**Therapies Floor (HSCPs)**	**Pharmacy**	**Education Centre**
Level 2	**Operating Theatre**	**Ward 25A (24 Bed)** Inpatient General Surgery	**Day Care & Clinical Trials** 61 SDU/MDU beds 6 Clinical Trials Beds
Level 1	**PICU / CICU / NICU**	**Ward 17A (30 Bed + 6 day bed)** Cardiology & Cardiothoracic Surgery	**Ward 13A (20 Bed)** CAMHS
Level LG & 0	**OPD** **Laboratories**	Level 0	**ED (Includes SSOU - Short stay Observation Unit)** **Radiology (Includes 15 day bays)**



Importance of play and outdoor space

Ageing Conference

By Dan McIntyre, IHS Board Member

Of all the conferences that the IHS arrange I certainly feel the Ageing Conference is the one I look forward to the most. It was held this year in Leixlip, Co. Kildare.

It's not that I don't look forward to our other conferences. March's AGM and the October Conference are mainstays in my calender of Society events. But the intimacy of the Ageing Conference, (41 attendees this year) allows you to chat with almost everyone. It was great to meet a fellow person with haemophilia who was attending his first Ageing Conference and a couple whom I had never met before. These opportunities don't arise as easily at the larger events due to the sheer volume of people in attendance, which can exceed over 300. There, we have a tendency to drift towards people we are familiar with, but small events can have you sharing a table with people you don't already know and, fortunately, I am not too shy to chat with anyone. That would be a big problem as a taxi driver!

The hotel was a little outside Leixlip but unfortunately, the weather was not great, which meant no touring took place for me. The programme, however, was unmissable. On the Saturday alone we covered Wills/Benefits/HAA Card/Physical Activity, as well as a discussion on Ageing Well.

The session 'Wills, Probate and Advanced Health Directives', which started the morning off, was very well presented by Ms. Sinéad Byrne. Advanced Health Directives specify medical treatment wishes if you lose capacity, and help professionals respect your wishes through those you nominate. We all have a bit of knowledge about wills and probate but Sinéad laid it out well and gave us some added bits of information. One piece of advice that stood out to me was that people should consider writing percentages rather than specific amounts into their wills, as their assets might change.

Mr. Brendan Casey, who gave the next presentation on Benefits and Entitlements, did not leave any doubts as to how important this topic is to anyone nearing retirement age! He advised that everyone get their information from the Department of Social Protection as early as possible, because the department can make mistakes. He also advised that if you retire before age 66, you should claim Job Seekers Benefit because even if you are not entitled to payments you will be awarded credits, which are counted towards your pension.

During lunch and coffee breaks is always a good time to chat with your peers and relive past experiences both with bleeds and hospitalisations. I heard some great stories that won't be put to paper!

Our last session on Saturday was a panel discussion with a few ageing men with haemophilia which centred around how to age well and live a good life now that the pension is on the horizon. (None of us are any the wiser!)

On Sunday morning, Dr. Madelaine Daly, who is well known within the haemophilia community, gave an open question and answer session. She advised us that we don't get enough sun to make enough vitamin D between October and March and that we should take vitamin D tablets during this time.

Following a question from Brian as to how often one should visit the GP and get a full blood count, Dr. Daly advised a 6 monthly or at least 12 monthly visit for our age group. This can help flag something early but also builds your relationship with your GP, which may be to your advantage. Most importantly, this session gave our members the opportunity to ask questions to a GP in a relaxed environment, which is rare these days.

We finished the day with Mark McGowan, a physiotherapist who is very familiar with people with haemophilia and leads online exercise classes hosted by the Irish Haemophilia Society, which many of our members have signed up to. Mark did a talk on the importance of exercise and then led us all to a big room and made us sweat for 45mins! It was fun though.

The next Ageing Conference will take place in two years, as agreed in the recent strategic plan. I hope I will still be around when it gets held in the Canaries - after all vitamin D is good for us oldies!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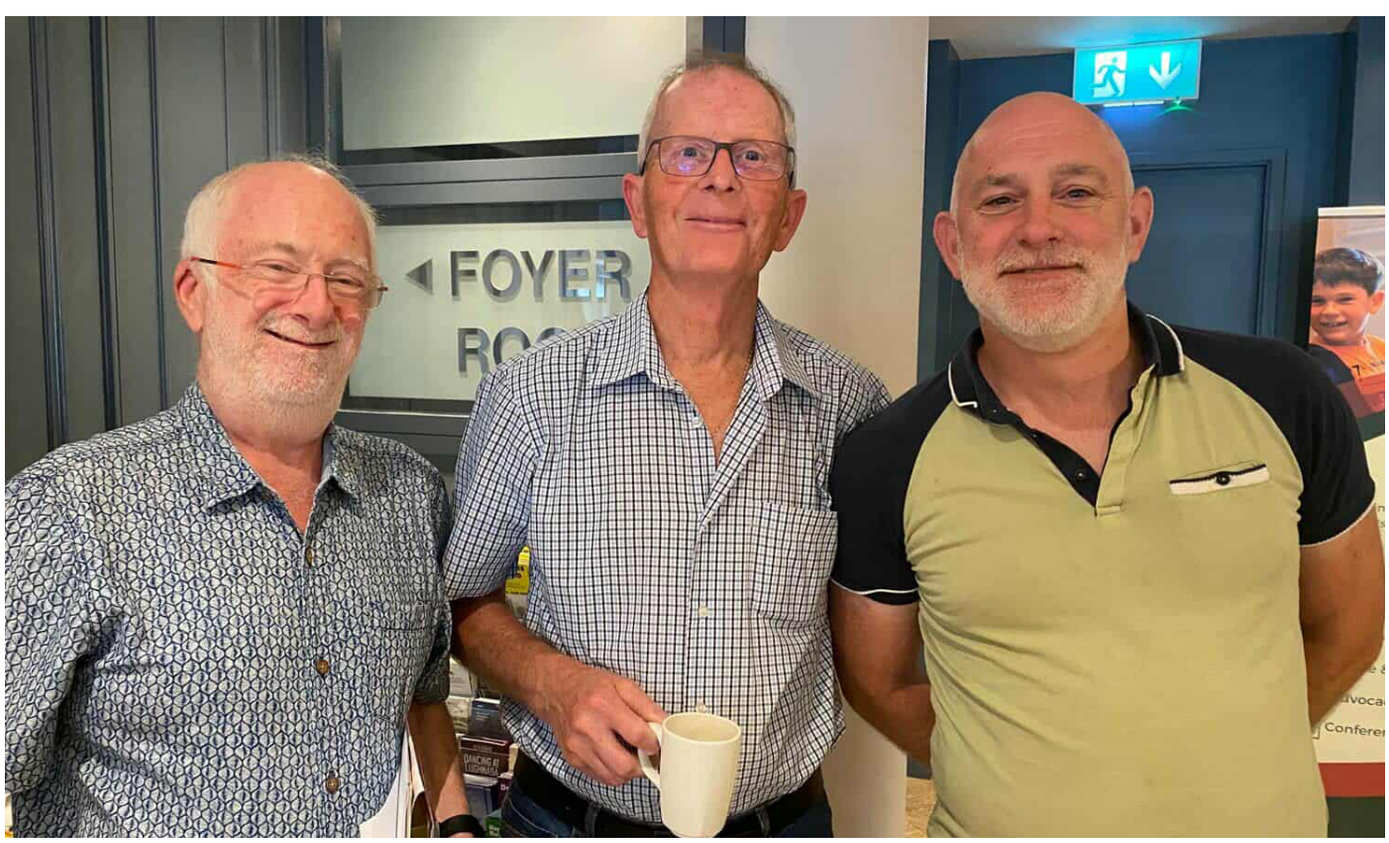
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Lilliput Adventure Centre

The Parent & Child event in July at Lilliput Adventure Centre was a great success, filled with energy, laughter, and muddy fun from start to finish.

The day kicked off with an orienteering challenge, giving families a chance to explore the scenic grounds and work together as a team. After a quick break for refreshments, the afternoon ramped up with trampolining and rock-climbing — two favourites among the kids (and a few brave parents!).

A well-earned hotdog lunch refuelled everyone just in time for one of the most talked-about parts of the day: bog hopping and water activities on the lake. Wet, messy, and brilliant fun, these sessions brought out plenty of smiles and even a few heroic splashes.

Before dinner, families took part in a lively game of rounders, which saw parents and kids facing off in good-natured competition. The evening meal hit the spot, and after checking into their bunks, families had the chance to relax, unwind, and enjoy the peaceful surroundings.

The day wrapped up with a well-deserved pizza feast and plenty of chats and laughs before bed.

A huge thank you to all the families who came along and to the team at Lilliput for helping us create a weekend of unforgettable memories!

Newly Diagnosed Information Day

By Lena Byrne, Administrative Assistant

The IHS held a Newly Diagnosed Information Day in the Grand Hotel Malahide on September 6th. The aim of this event was to provide support for parents of young children who have been recently diagnosed with a bleeding disorder and make them aware of the services and supports we can provide, as well as providing some useful information for navigating the first years of life with a bleeding disorder. To help us with this, we had Ms. Paula Loughnane, Clinical Specialist Physiotherapist, Dr. Beatrice Nolan, Consultant Paediatric Haematologist, and Dr. Aisling Cant, Paediatric Dentist. The event was very well attended by both new and existing members.

The day started with a quick lunch in the Hospitality Suite where all the members had a chance to get to know each other. At 1pm, Paula Loughnane started off her talk on normal motor development, discussing the expectations for a child in their first three years of life, and briefly mentioning the typical milestones from three up to the age of 12. Paula went on to talk about recommended activities and activity levels for kids at different ages, mentioning that children with haemophilia should be able to do most activities now thanks to the advances in treatment.

After a short Q&A at the end of Paula's talk, Dr. Beatrice Nolan began her talk 'Bleeding Disorders in the first three years of life'. Over the next hour, Beatrice gave an overview of the role of the comprehensive care centre, and how it differs from that of the haemophilia treatment centres. Beatrice also explained very clearly the inheritance of haemophilia, how inhibitors are developed, and the variety of treatment options available for haemophilia with and without inhibitors.

At 3pm we had a coffee break before Dr. Aisling Cant's talk on the importance of dental care for children. I think it was beneficial that Aisling could give advice from a parent's perspective as well as from a dentist's as it made her content more relatable for the rest of the parents in the room, for example with the struggles of teething and introducing your child to a toothbrush and making it part of the bedtime routine.

To finish up we had a short Q&A session with Beatrice and Paula where they shared some helpful advice about travel, pregnancy, the bleeding disorder alert cards and the ambulance directive. Overall, the talks were very informative, and everyone seemed to be engaged with the speakers, which was great.

On behalf of the IHS staff, I would like to thank all of those who attended our Newly Diagnosed Information Day, especially our speakers and the volunteers who looked after the children for the day. We look forward to seeing you again soon.

October Members' Conference

Venue: Mount Wolseley Hotel, Carlow
Date: 17th-19th October, 2025

Adult Programme

Friday 17th October

7pm - 9pm — Buffet Dinner for Full Group (Frederick's Restaurant)

Saturday 18th October

10am - 11am — **Debate: Who Should Primarily Decide On My Treatment? The Consultant or the Patient? (Austin Suite 2)**
Moderator: Mr. Dan McIntyre, Treasurer, I.H.S. Board.
Debaters: Mr. Patrick Browne & Mr. Colm Walsh, I.H.S. members

11am - 11.30am — Coffee Break **(Pre Conference Lobby)**

11.30am - 1pm — **An Update on Treatment, Followed by Personal Perspectives on Treatment (Austin Suite 2)**
Speaker: Dr. Maeve Crowley, Consultant Haematologist, Cork University Hospital.
This session will start with an update on treatment from Dr. Maeve Crowley, followed by a panel discussion on various treatments from the following IHS members:

Aprolix - Mr. Conor Birkett / Altuvoct - Mr. Tony McAfee / Hemlibra - Mr. Jake Phoenix / Fitusiran - Mr. Nathan Doyle / Gene Therapy - Mr. Brian O'Mahony / MiM8 - Mr. Richard Lowe

1pm - 2pm — Lunch (Frederick's Restaurant)

2pm - 3.30pm — **Interactive Discussion on Treatment (Austin Suite 2)**
Facilitators: Mr. Brian O'Mahony, CEO, I.H.S., & Dr. Saad Ahmed, Consultant Paediatric Haematologist, CHI Crumlin.
A facilitated interactive workshop with members split into groups for a discussion.

OR

Von Willebrand Disorder & Rare Bleeding Disorders (Riley Suite 1)
Speaker: Dr. Beatrice Nolan, Consultant Paediatric Haematologist, CHI Crumlin

OR

Mild Haemophilia (Healy Suite)
Speaker: Dr. Maeve Crowley

3.30pm - 4pm — Coffee Break (Pre Conference Lobby)

4pm - 5pm — **Food & Nutrition (Austin Suite 2)**
Speaker: Ms. Didi de Zwarte, Registered Dietician
A broad and engaging session on everyday nutrition for people with bleeding disorders.

7pm — Dinner for the full group (Austin Suite 1 & 2)

Sunday 19th October

10am - 11am — **Sports & Bleeding Disorders (Austin Suite 2)**
Speaker: Ms. Paula Loughnane, Clinical Specialist Physiotherapist, CHI Crumlin
An overview on sports and activities suitable for people with bleeding disorders.

11am - 11.30am — Coffee Break (Pre Conference Lobby)

11.30am - 1pm — **County Colours Line Dancing: Interactive Activity for all the Family (Austin Suite 1 & 2)**
Facilitator: Mr. Declan Flanagan.
A fun interactive activity for adults & children. We would encourage you to wear you county jersey for this entertaining class. Parents, please note that children & teeangers from the Kidlink & Youth Group will be brought into the Austin Suite by volunteers, to allow them to participate in this class. Parents will be required to supervise their children during this class.

1pm — Depart

Women & Girls with Bleeding Disorders

The issues facing women and girls with bleeding disorders (WGBD) have often been overshadowed by those facing men. The IHS recognise the importance of tackling this imbalance and the need for better education and support for WGBD. This is a key aim of our strategic plan for 2025-2028.

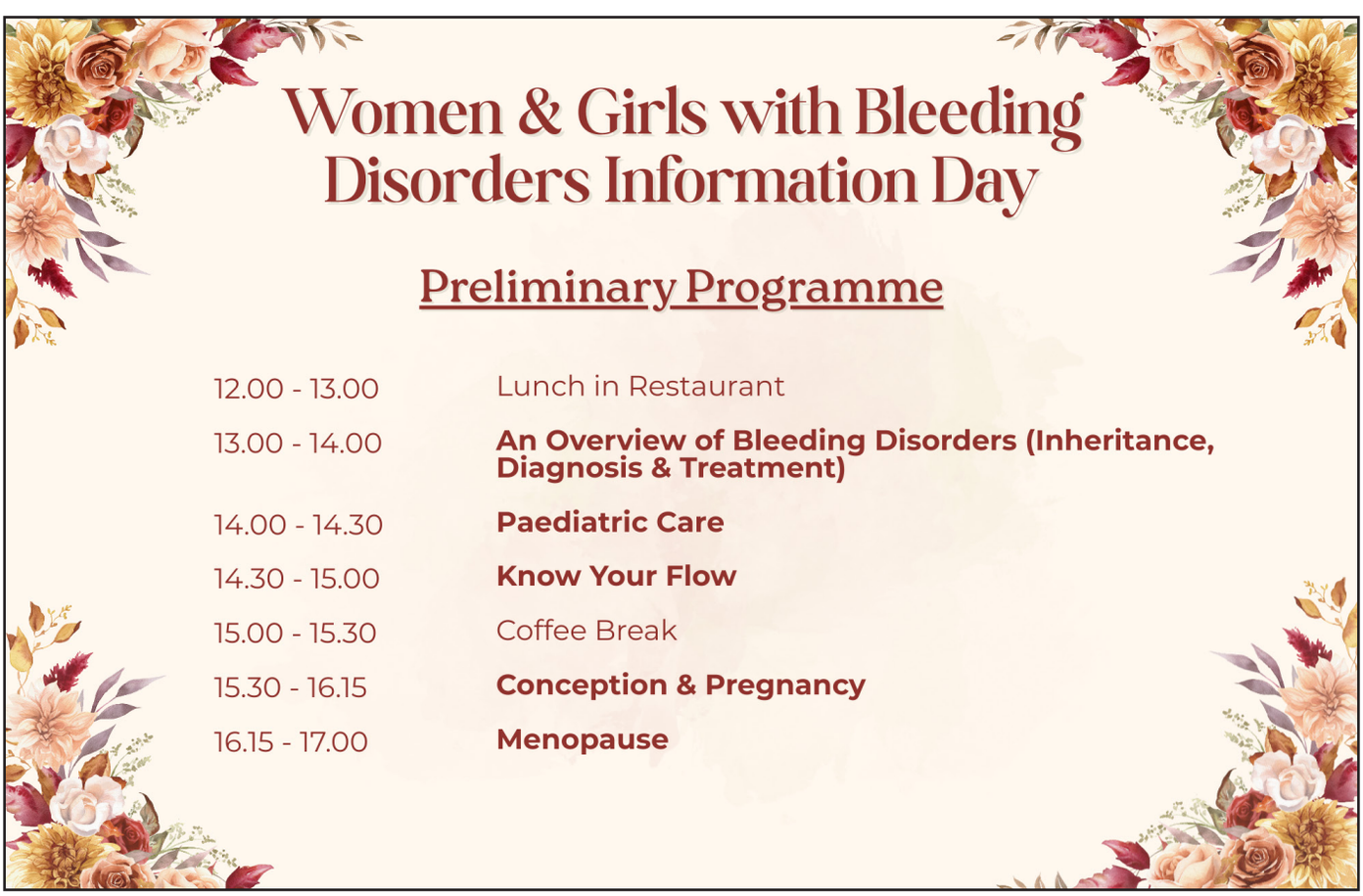
As part of our strategic plan, we are producing a booklet about periods for older children and young teenagers. We are also updating our Teenage Girls booklet and Women with Bleeding Disorders (WBD) booklet in the near future. For these projects, we are working closely with the comprehensive care centres and experts such as Dr. Beatrice Nolan and Dr. Michelle Lavin.

Our other committments include organising webinars on relevant topics, continuing to provide free period products at all of our conferences and advocating for a gynaecology service at each comprehensive care centre.

One key channel through which we share information is a WGBD information day or conference, which we are committed to holding every second year. This is a dedicated event focusing on issues related to WGBD. At these events there are plenty of opportunities to ask questions of the speakers and to get to know other members.

This year, we are holding this information day on November 8th in the Grand Hotel in Malahide. This will be an ideal opportunity for women and girls to learn about issues related to their bleeding disorders. Some of the sessions will focus on adult issues, while others will be targeted at girls 10 years of age and older. We are hoping in particular that the sessions for the younger cohort will spread awareness about periods and help to break the stigma so that girls feel comfortable discussing this with their family, teachers or friends.

Registration for this event is free of charge. You can register now by filling in the form sent out to relevant members, on our website or by calling the office on 01 657 9900. The closing date is October 29th.



Periods & Bleed
Understanding & Man

By Caitriona Ferry, Advanced Nur

Hello! I'm Caitriona Ferry, an Advanced Nurse Practitioner specialising in Haemophilia and Allied Bleeding Disorders at the Paediatric Coagulation Centre, Children's Health Ireland at Crumlin.

I run a specialised clinic dedicated to supporting teenagers who have heavy periods, whether they are new patients or have a known bleeding disorder. Our clinic offers expert care tailored to your needs in a welcoming and supportive environment.

New patients are referred by their GP to the haematology service to check if their heavy periods are caused by an underlying bleeding disorder. In adolescents, the most common gynaecological cause of heavy periods is anovulation, which means irregular or absent ovulation. However, an underlying bleeding disorder is found in about 30-40% of referred teenagers.

For those already diagnosed with a bleeding disorder and experiencing heavy periods, we provide ongoing personalised care.

Our goal is to educate and empower you and your family to recognise heavy periods early so that you can manage them effectively—helping to prevent periods from interfering with your daily life, school, or sports.

Heavy periods and bleeding disorders: what should you know?

If you have a bleeding disorder, it's common for your periods to be heavier or last longer. One study showed that 78% of teenagers with a bleeding disorder had heavy periods. Always remember, you're not alone, and there are ways to help manage this.

How long should a normal period last and how much should I bleed?

Typically, a period:

- Lasts 3 to 7 days
- Requires changing pads or tampons every 3–4 hours

If your period lasts longer or is heavier, especially with a bleeding disorder, please talk to your doctor or nurse.

What are signs that my period is too heavy?

- Bleeding lasting more than 7 days
- Changing protection every 2 hours or less
- Passing clots larger than 1 euro coin
- Flooding episodes/leaking through to your clothes
- Needing to change products during the night
- Feeling tired, dizzy, or weak
- Low iron levels or anaemia

To understand whether your periods might be heavier than normal, visit www.knowyourflow.ie and remember the 7, 2, 1 rule —7 days, changing pads or other form of protection every 2 hours, and passing clots bigger than a 1 euro coin.

Can heavy periods cause low iron or anaemia?

Yes. Heavy bleeding can lower your iron levels, leading to anaemia, which can cause:

- Tiredness
- Dizziness or light-headedness
- Shortness of breath
- Trouble concentrating

A simple blood test can check this, and iron supplements or dietary changes can help.

eding Disorders: naging Heavy Bleeding

Nurse Practitioner in CHI Crumlin

Will my period be painful?

Some cramps or discomfort is normal. Having a bleeding disorder doesn't always mean more pain, but heavy bleeding or large clots can make cramps feel worse. If pain keeps you from going to school, playing sports, or sleeping, please tell your healthcare team.

How can I manage heavy periods or cramps?

For pain relief:

- Use heat packs or take warm baths
- Try gentle movement or stretching
- Take paracetamol (usually safe but always check first)

To reduce bleeding:

- Tranexamic acid (Cyklokapron) – helps slow bleeding
- Desmopressin (DDAVP) – boosts clotting for some conditions
- Hormonal treatments – like the pill, patch or an intrauterine device (IUD/ coil) to regulate bleeding
- Clotting factor treatments – for certain bleeding disorders
- Iron supplements – to prevent or treat anaemia

Your healthcare team will help find the best option for you

What period products should I use?

Pick what feels comfortable and fits your lifestyle:

Products	Best For
Pads	Easy to use, good for heavier flow
Tampons	Discreet, great for swimming or sports
Menstrual Cups	Reusable, holds more blood
Period Underwear	Comfortable, perfect as back up to prevent leaking
Panty Liners	For light days/spotting

Mix and match period products, such as tampons and period underwear, to find the level of protection that works best for you.

Who should I talk to if I'm having concerns regarding my period?

Don't hesitate to reach out. You can talk to:

- Your GP
- Your haematologist (blood doctor)
- Your haematology team nurse
- A paediatric and adolescent gynaecologist
- A trusted adult

Your concerns are valid, and support is available.

How can I keep my period from affecting school or sports?

- Use a period tracker app to know when your period is coming
- Pack extra pads, tampons, or underwear
- Wear dark clothes if that helps you feel confident
- Combine products for extra protection
- Let teachers or coaches know if you need extra bathroom breaks
- Follow your treatment plan to keep symptoms under control

With the right support, your period shouldn't stop you from doing what you love.

Final reminder!

You deserve to feel well, confident, and supported. Heavy periods aren't something you just have to live with.

We're here to help you manage your symptoms, protect your health, and enjoy life to the fullest.

Need help tracking your period? Ask us for a period diary template or try a period tracking app like:

- Clue - 13+
- Period Tracker Period Calendar - 12+

Other Resources

- Time to Talk Period - EAHAD
- Heavy periods - Overview - HSE.ie
- Home | Know Your Flow

IRISH HAEMOPHILIA SOCIETY
Cumann Haemifile Na hEireann

IHS Services & Supports

At the Irish Haemophilia Society, we provide a variety of services and supports for our members, including:

Call us for more info
01 657 9900

Events

We hold 2-3 major conferences a year, along with smaller conferences and day events.

Outreach

We make regular contact with our members, aiming to call them at least once a year. We also conduct home and hospital visits.

Publications

We produce 4 quarterly magazines each year, along with other informational materials.

Apartment facility

We have two 'Hyde Square' apartments in Dublin 8, for members coming up to Dublin for a hospital appointment at St. James's or the children's hospital.

Education & Information

We provide extensive information about different bleeding disorders on our website & at conferences and events.

Advocacy

We advocate for people with all inherited bleeding disorders both nationally and internationally.

Educational Grants

Our 2025 Educational Grants are open until the 3rd of October. We encourage students with a bleeding disorder and their immediate family members to apply. The purpose of the grants is to assist students with the extra expenses of their studies.

What types of educational grants are available and what is the criteria for applying?

Maureen & Jack Downey Educational Grant:

For people with mild, moderate or severe inherited bleeding disorders including asymptomatic carriers with normal levels and symptomatic carriers with levels of between 5% and 40%, who are classified as people with mild haemophilia. Degree course level: 7 to 9. Grants range from €1,000 to €4,000.

The Father Paddy McGrath Educational Grant:

For people with mild, moderate or severe inherited bleeding disorders including asymptomatic carriers with normal levels and symptomatic carriers with levels of between 5% and 40%, who are classified as people with mild haemophilia and immediate family members. PLC (or other similar course) course level 5 & 6. Grants range from €250 to €1,000.

The Michael Davenport Educational Grant:

For people with mild, moderate or severe inherited bleeding disorders including asymptomatic carriers with normal levels and symptomatic carriers with levels of between 5% and 40%, who are classified as people with mild haemophilia. For mature students aged 24 years plus doing a Masters or PHD course. Grants range from €1,000 to €4,000.

The Margaret King Educational Grant:

For immediate family members (spouse, son, daughter, sister, brother, mother or father) of people with mild, moderate or severe inherited bleeding disorders. Degree course level: 7 to 9. Grants range from €500 to €2,000.

How much are the educational grants for?

Maureen & Jack Downey Educational Grant
First prize €4,000
Second prize €2,000
Third prize €1000

Father Paddy McGrath Educational Grant (2 Grants)
A person with the bleeding disorder:
First prize €1,000
Second prize €500
Third prize €250

A family member of a person with the bleeding disorder:
First prize €500
Second prize €250
Third prize €125

Michael Davenport Educational Grant
Grants ranging from €1000 to €4000

Margaret King Educational Grant
First prize €2,000
Second prize €1,000
Third prize €500

How are the applications scored and who scores them?

Once 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.
- Financial need.
- How many in the family are going to college.
- If the application is a first time application.

Can I Apply Every Year?

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

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Congrats to our Amazing Fundraisers!

We want to extend a massive thanks to this summer's fundraisers. Three sepearate parties raised funds for us as part of the VHI Women's Mini Marathon in June.

Vicky Murphy raised €1,380 with the help of her friends Rebecca Mooney, Niamh Quinn and Sorcha Burke.

Norma Jean Kelly raised a whopping €2,465, which is much appreciated.

Anne Brady raised €275, which we're also very thankful for.

We also want to wish Chloe O'Sullivan and her friends luck in the upcoming Cork Mini Marathon and everyone taking part in the Dublin Marathon in October.

Hyde Square Apartment Facility

The IHS have two apartments located in Dublin 8, used to accommodate members travelling to Dublin for hospital appointments. The facility consists of a two bedroom apartment and a separate studio apartment, which are next door to each other. Located on South Circular Road, these apartments are located just 5 minutes from St James's and 15 minutes from Crumlin's Children Hospital.

Members of the IHS can book in at a rate of 10 euro per night. To book in, please contact Lena in the office on 01 657 9900.

eboard

A Reminder to Join Our IHS WhatsApp Community

Our WhatsApp Community has been up and running for a few months now and offers us a more efficient way to share Society news and resources. Members can join the main hub and then opt into specific sub-groups that match their needs. For example: Conferences & Events, Travel, Updates from Treatment Centres, Outreach. The platform is one-way in that only Society posts are allowed. This enables updates to reach people quickly without chat clutter and allows us to moderate all content to keep it accurate. Since launching on the 17th of April, the uptake has been strong in all of the groups.

To boost engagement further, we will host a stand at the October Conference with a live display as to how it all works with a QR code so that members can join the service on the spot. We will also open a temporary, conference-specific group to share real-time schedules, reminders, and polls while our conferences and events are running, then archive it afterward. This initiative aligns with the strategic plan's goal of clearer, faster communication and is already proving an effective information channel.

Our Outreach Coordinator Robert Flanagan is managing this WhatsApp Community and is happy to answer any queries you might have about it. You can email Robert at robert@haemophilia.ie. To request to join the Community, please email Rob and provide your full name and number.

IHS Exercise Classes

We continue to hold exercise classes for adult members each week. On Tuesday evenings, physiotherapist Mark McGowan, leads a physio-exercise class on Zoom. Mark is highly experienced working with people with haemophilia through his work in the National Coagulation Centre.

On Wednesday evenings physiotherapist Emer O'Shea runs a pilates class via Zoom. This class is aimed at beginners, and no previous experience with pilates is requierd.

We invite all adult members to join one of our classes. It's a great way to get fit from home! Contact Rob at robert@haemophilia.ie for more information or to register.

Irish Haemophilia Society

First Floor
Cathedral Court
New Street
Dublin 8

Tel: 01 657 9900

Email: info@haemophilia.ie
Website: www.haemophilia.ie
Twitter Handle: @HaemophiliaIRL

Find us on: