Irish Haemophilia Society

Summer Magazine

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

Summer 2026 Edition

From the Editor

Hello everyone! I hope you are all having a lovely summer and getting to enjoy some sunshine.

This season's edition of our magazine is packed full of interesting material from staff and members alike.

To kick off, Brian O'Mahony shares some key updates in his CEO report, including information about the now available gene therapy for haemophilia B, upcoming events, the World Federation of Hemophilia World Congress and more.

Following this, member and keen volunteer Jake Phoenix shares some insight into the European Haemophilia Consortium's Youth Leadership Workshop which he attended in April. Jake was representing the Society at this workshop.

Later, we have a very interesting interview I conducted with member Callum Andrews, who is a successfull sportsperson living with severe haemophilia. It was great to hear how dedicated he is to the sport of football and how his bleeding disorder has not held him back in pursuing his dreams. Callum is an inspiration for all young people who want to get involved in sport. This interview will also be available to watch online.

It's the time of year again to apply for one of our four educational grants, and we have included all the important information you need to do so in this edition. Applications opened June 19th and close September 25th.

Rob has done up some top outreach tips for members, and you can check these out later in this edition. It's coming up to a busy time of year for events and we have information about our upcoming Parents Conference in July, our Women and Girls with Bleeding Disorders Information Day in September and our October Members' Conference in October.

Finally, check out the Noticeboard at the back for IHS news. Happy reading!

The Irish Haemophilia Society at a Glance

2.2k
Facebook Followers

414
Instagram Followers

63
I.H.S. Volunteers

1,522
X Followers

37
Planned Giving Contributors

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CEO Report

Brian O'Mahony, Chief Executive

FIX Gene Therapy

The licensed factor IX (FIX) gene therapy, Hemgenix, is now available as a treatment option in Ireland for severe FIX deficiency. This is a one off infusion and the objective is to have the individual's own liver cells produce FIX from the infused FIX vector. Hemgenix performed well in clinical trials. After a single infusion, more than 90% of recipients show stable FIX expression in the mild haemophilia range (5% to 40%) or normal range (greater that 50%) starting several weeks after infusion and currently lasting for a period of at least 5 years. These participants have stopped requiring FIX prophylaxis. Ireland had three people with haemophilia B in the Phase 3 clinical trial and, to date, one person with severe FIX deficiency has now been treated with the licensed gene therapy.

The infusions are carried out at the research centre in the building housing the National Coagulation Centre (NCC) at St. James's Hospital. The expectation is that up to four additional people will be treated with gene therapy this year with more to follow as required from 2027. Gene therapy is for adults over the age of 18. It is not suitable for those with FIX inhibitors or those with severe liver disease. The evaluation process includes liver ultrasound and fibroscan tests. If these show severe fibrosis or fatty liver, the person may not be suitable. Another exclusion criteria is if the individual has a pre-existing high level of antibodies against the adeno associated viral (AAV) vector used to deliver the gene therapy to the liver. If the person is negative for these AAV antibodies or has a low level of antibodies, this will not affect their eligibility.

Gene therapy is a very exciting development but any person with severe haemophilia B who is interested must be aware that this is a one off irreversible therapy requiring a fully informed decision making process by the individual. It is also worth noting that, in the event the gene therapy does not work or does not produce a significant increase in the FIX level, the previous extended half life FIX therapy can continue to be used. Any person who is interested should, in the first instance, contact Niamh Larkin at the NCC (NLarkin@stjames.ie). This would begin a process of engagement, information and eligibility testing. During the process, each person being considered for gene therapy will also have a discussion with two consultant haematologists. Members who are interested are also encouraged to contact the Society and we will provide information and support. You can contact me at brian@haemophilia.ie.

Events

In addition to our regular members conference in October, the Society have organised two additional events - a Parents Conference in July and a Women and Girls with Bleeding Disorders (WGBD) Information Day in September. Our current plan is to organise a parents conference every third year. This allows sufficient time between conferences to take account of new therapies and new developments in comprehensive care. We are excited to hold the conference this year as the last one was held in 2023. The programme was devised in collaboration with the haemophilia team at Children's Health Ireland (CHI) at Crumlin. The conference will feature an update on current and future therapies, von Willebrand disorder (VWD) and rare bleeding disorders, self care and advocacy. Specific elements of comprehensive care will be highlighted including dealing with nosebleeds, head injury, dental care and needlephobia. There will be sessions on physiotherapy and on inheritance and carrier issues. Mothers and fathers workshops will give parents an opportunity to discuss issues in a supportive environment. Finally, we will have a presentation on the new children's hospital from the Chief Executive of CHI.

The second event is our WGBD information day in September. The event is open to women with bleeding disorders and their daughters aged from 12-17, who will have a separate programme. The women's programme will include treatment and care, heavy menstrual bleeding, pregnancy and childbirth

and menopause. The programme for the 12 to 17 year old girls will include dealing with periods, dental care, physical activity and an art project. We will also be using the opportunity to launch updated versions of our publications on Women and Bleeding Disorders, Teenage Girls with Bleeding Disorders and re-launch our Time to Talk Periods booklet. This will be an excellent programme with great speakers and we look forward to seeing everyone there.

World Federation of Hemophilia & World Health Organisation

In May, I spoke at a World Federation of Hemophilia (WFH) event linked to the World Health Organisation (WHO) World Health Assembly in Geneva. During that week WFH succeeded in having a resolution passed by the assembly (which represents the health ministeries of all WHO member countries). The resolution was entitled "Global action to enhance health equity for people with haemophilia and other bleeding disorders". It calls on the WHO and member states to address gaps in care for haemophilia and other bleeding disorders, and strengthen the implementation of policies to improve treatment and care. It particularly focuses on underdiagnosis and undertreatment in WGBD. Actions taken on foot of the resolution have to be reported on during the World Health Assembly in 2028. It also gives global recognition by WHO to World Haemophilia Day each year on April 17th. In future, this day should be promoted by WHO as well as by WFH and all the national haemophilia societies.

WFH World Congress

The WFH World Congress took place in April in Kuala Lumpur. Attendance was decreased by the situation in the middle east with many flights being cancelled. Despite this, WFH organised an excellent meeting. There were incremental updates on many of the new therapies and on many currently in clinical trials. Prof. David Lillicrap from Canada gave an excellent overview of new therapies for VWD, listing several therapies. Prof. Lillicrap had also delivered an excellent lecture on this very topic at one of the Society organised clinical webinars late last year. This can be viewed on our website at https://haemophilia.ie/educational-resources/webinars. There were updates on the now licensed re-balancing agents Concizumab (brand name Alhemo), Marstacimab (brand name Hympavzi) and Fitusiran (brand name Qfitlia).

Alhemo is now licensed by the European Medicines Agency (EMA) for people with haemophilia A or B with or without inhibitors. Hympavzi is licensed by the EMA for people with haemophilia A or B without inhibitors (licensing for those with inhibitors will follow). Qfitlia is not yet licensed by the EMA but it is licensed by the US Food and Drug Administration (FDA) for haemophila A and B with or without inhibitors. These are all subcutaneous therapies with infusion frequencies varying from every day to every week to every second month. The Haemophilia Product Selection and Monitoring Advisory Board will be considering the EMA licensed products in the second half of this year.

During the congress, I delivered a number of lectures, primarily on health economics, pricing and procurement. There are very significant differences in the pricing of therapies not just between high income, upper middle income, lower middle income and low income countries, but within each economic category. The most cost effective prices tend not to always be in the lower income countries but in countries who have a well organised, effective and efficient procurement process on a national basis with procurement for more than one year.

I also had the opportunity to catch up with our colleagues from Vietnam with whom we worked from 2009 to 2018. Access to home treatment in Vietnam has improved, with the government providing certificates to patients to allow this. There are remaining difficulties with access to prophylaxis due to a lack of factor. Vietnam will be participating in a clinical trial for FIX Gene Therapy next year. It was also very heartening to meet a young man, Ha Duc Hai, who was their alternate delegate at the General Assembly. I previously met him in 2014 when he was in hospital in Haiphong and encouraged him to get active in the organisation as he grew up. This he has certainly done. See the photos below.

Jake Phoenix Attends the EHC Youth Leadership Workshop

Jake Phoenix, IHS member & volunteer

Attending the European Haemophilia Consortium (EHC) Youth Leadership Workshop in April was an experience that gave me a much deeper understanding of bleeding disorders and the importance of young people becoming involved within their National Member Organisations (NMOs).

The conference brought together young people from 14 different European countries, all with varying experiences, healthcare systems and perspectives. Although we came from different backgrounds, everyone shared a common interest in learning more about bleeding disorders, advocacy, and leadership within the community. Being able to meet and speak with people from so many countries was one of the most valuable parts of the experience for me. It gave me a much broader understanding of the challenges different countries experience in terms of care and support, as well as the progress they have made.

Throughout the conference, we took part in workshops, educational talks, and group discussions focused on leadership, advocacy, and education around bleeding disorders. The sessions covered a wide range of topics, including different bleeding disorders, treatments, medications, and the role NMOs play in supporting patients and families. I learned far more than I expected to, particularly about conditions and treatments of which I had little previous knowledge. One of the most interesting aspects of the conference was hearing directly from other delegates about how their NMOs operate and how bleeding disorders are managed within their countries. Some countries have strong systems of support and access to treatment, while others still face significant difficulties in awareness and healthcare access. It was clear how much emphasis is being placed on encouraging younger people to become involved and help shape the future of their organisations.

Outside of the educational sessions, the workshop also gave everyone the opportunity to socialise and build connections with one another. Spending time with people who understood many of the same experiences created a strong sense of community very quickly. Even though we all came from different countries, there was a shared understanding that made conversations feel easy and genuine.

Personally, I came away from the conference with far more confidence and knowledge than I had beforehand. It helped me better understand my own NMO and showed me how important youth involvement can be within these organisations. The conference encouraged participants to contribute ideas, ask questions, and think about how we can positively impact our own communities going forward.

What stood out most to me was how much there still is to learn within the bleeding disorders community. The conference highlighted not only the medical side of bleeding disorders, but also the importance of communication, advocacy, education, and leadership. It showed how valuable it is for young people to engage with these topics early and become active within their organisations.

Overall, the EHC Youth Leadership Workshop was an extremely worthwhile experience. I returned home with a much greater understanding of bleeding disorders across Europe, a stronger connection to my own NMO, and new friendships with people from across the continent. Most importantly, I left feeling motivated to use what I learned to make a positive contribution within my own organisation and within the wider bleeding disorders community.

Parents Conference

Venue: Midlands Park Hotel, Portlaoise, Co. Laois

Date: July 3rd - 5th, 2026

Adult Programme

Friday 3rd July

19.00 Buffet Dinner **(Maryborough Suite)**

20.30 Face Painting for Children **(Hotel Lobby)**

Saturday 4th July

10.00 – 10.45 **Current & Future Treatments** **(Maryborough Suite 1)**
An update on where we are at with current and future treatments for haemophilia.
Speaker: Dr. Saad Ahmed, Consultant Paediatric Haematologist, CHI Crumlin

Or

Living with Von Willebrand Disorder / Rare Bleeding Disorders **(Maryborough Suite 2)**
A presentation on living with a bleeding disorder, covering medical information & practical management.
Speaker: Dr. Beatrice Nolan, Consultant Paediatric Haematologist, CHI Crumlin

10.45 – 11.30 **Physio & Bleeding Disorders** **(Maryborough Suite 1)**
Topics covered will include: Bone Health, Musculoskeletal Bleeds & Vitamin D
Speaker: Ms. Paula Loughnane, Physiotherapist, CHI Crumlin

11.30 – 12.00 Coffee Break **(Pre Conference Area)**

12.00 – 13.15 **Elements of Comprehensive Care** **(Maryborough Suite 1)**
Topics covered include: Nosebleeds (Zoom recording from Dr. Alanna Quinn), Head Injuries (Dr. Saad Ahmed), Dental Care (Zoom recording from Dr. Mahnoor Ali), Treatment at Home & Communication with other Hospitals (Clinical Nurse Specialist Bridín Brady), Ambulance Directive, Bleeding Disorder Alert Cards & Long-term Illness Allowances (Dr. Beatrice Nolan).

13.15 – 14.15 Lunch **(Triog Restaurant)**

14.15 – 14.45 **Needlephobia** **(Maryborough Suite 1)**
A presentation covering a mix of psychological, medical issues & practical coping strategies.
Speaker: Dr. Yvonne Duane, Principal Clinical Psychologist

14.45 – 15.30 **Inheritance & Carrier Issues** **(Maryborough Suite 1)**
Topics will include: Inheritance, Carrier Issues, Girls with Bleeding Disorders, Awareness for Dads & Prenatal Genetic Diagnosis.
Panel: Nurse Specialist Caitriona Ferry, Dr. Beatrice Nolan

15.30 – 16.00 Coffee Break **(Pre Conference Area)**

16.00 – 16.45 **Open Forum** **(Maryborough Suite 1)**
The Open Forum will consist of a panel of speakers from CHI Crumlin.

Children must be collected from children's programmes. Family time - volunteers off duty.

19.00 Dinner & Entertainment for the Kids with Jeca the Clown at 20.30 **(Maryborough Suite)**

Sunday 5th July

10.00 – 11.00 **An Update on the New National Children's Hospital** **(Maryborough Suite 1)**
A presentation & update on new national children's hospital on the St. James's campus.
Speaker: Ms. Lucy Nugent, CEO, Children's Health Ireland

11.00 – 11.30 Coffee Break **(Pre Conference Area)**

11.30 – 12.45 **Mothers Workshop Group** **(Maryborough Suite 1)**
A supportive group for mothers to discuss a variety of issues.
Facilitator: Ms. Orlagh Fagan, Psychotherapist and Coaching Facilitator

Or

Fathers Workshop Group **(Maryborough Suite 2)**
A supportive group for fathers to discuss a variety of issues.
Facilitator: Mr. Brian O'Mahony, Chief Executive

12.45 Depart

Women & Girls with Bleeding Disorders Information Day

Women and girls with bleeding disorders are an important part of our community, facing unique challenges. We have been working to raise awareness and provide education to this cohort, especially as this is a key area of our strategic plan for 2025-2028.

As part of this educational campaign, we recently produced a supportive booklet for young girls about periods. We are in the process of updating our Women with Bleeding Disorders booklet, as well as our Teenage Girls booklet and we hope to launch them in the coming months.

We also provide free period products at all of our major events.

In November of 2025, we held an information day for both women and young girls with bleeding disorders. The sessions were aimed at both groups. In September, we are holding another information day. This time, however, we are holding two parallel tracks, which we believe will enable us to better share information relevant to each group. The children's and teenagers track will involve workshops and creative activities to keep the young people engaged throughout the day.

This event is taking place September 12th in Dunboyne Castle Hotel. Registration to attend will open at the end of July.

Adults Preliminary Programme

12.00 – 13.00	Registration & Lunch
13.00 – 13.45	Pregnancy & Childbirth
13.45 – 14.30	Women with Bleeding Disorders Update - Treatment & Care
14.30 – 15.30	Dealing with Heavy Menstrual Bleeding
15.30 – 16.00	Coffee Break
16.00 – 17.00	Menopause & Life After It

Children & Teenager's Preliminary Programme

12.00 – 13.00	Registration & Lunch
13.00 – 13.45	Dealing with Periods
13.45 – 14.45	Dental Care
14.45 – 15.15	Refreshment Break
15.15 – 16.00	Physical Activity
16.00 – 17.00	Workshop / Art Project

October Members' Conference

Venue: Mount Wolseley Hotel, Co. Carlow
Date: 16-18th October, 2026

Preliminary Adults Programme

Friday 16th

19.00	Buffet Dinner (Frederick's Restaurant)

Saturday 17th

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

*Registration will open at the end of July

Interview with Callum Andrews

Tell us about yourself?

My name is Callum Andrews and I'm 22 years old. I grew up in lovely Leitrim and I have severe haemophilia.

Could you tell us about your football career to date?

I started playing football from a really young age. My dad had me straight into football — there wasn't much choice really. If he had a son, he was going to play football.

Growing up with haemophilia made things a bit more challenging when I was younger, so I had to be more careful. My dad used to chuck me out on the wing and tell me, "Don't get into trouble, don't kick anybody, and don't get kicked." Somehow, I managed that for about ten years.

Then I had my port-a-cath removed, and that was probably the point where I started thinking seriously about football. I was watching fellas on TV and thinking, "I want to do that." Up until then, I never really thought haemophilia would stop me. It was only as I got older that I started realising the challenges that could come with it.

I moved from my local team to Boyle Celtic to get closer to clubs like Sligo Rovers and Longford Town. I had a few trials along the way but never quite made the cut. Still, I kept playing and enjoying it, and then I had a breakout season when I was 19.

I was playing first-team football, recording all my clips and sending them off to agencies and clubs without really expecting much to come from it. Then I got the chance to move to Sweden and play in the fourth tier over there. It was semi-professional, but there were professional teams in the same division, so it was a big challenge.

At the time, I had just finished studying to become a personal trainer. Three days after finishing the course, I moved to Sweden. Looking back, I probably didn't have a clue what I was doing, but I went for it anyway.

I spent four months there, helped keep the team in the league, scoring a couple of goals and getting a few assists. After my contract ended, I moved back home and started working in the personal training industry while also playing football part time in Dublin, which brought a whole new set of challenges.

In Sweden, football was very technical and focused on ability. In Dublin, it was much more physical — you'd spend more time getting pushed around and ending up on the ground than actually dribbling the ball, which obviously isn't ideal when you have haemophilia.

Still, I adapted and did well. A lot of that comes down to mindset. I don't try to ignore the fact that I have haemophilia, but when it's time to play, I almost switch into football mode and deal with any consequences afterwards.

I've carried that attitude throughout my career, even when I broke my foot last year. That was tough. I needed surgery and now I've got a rod in my foot holding everything together. But coming back from that injury has probably made me fitter, faster and stronger than I've ever been.

I've had a really good season with the reserve team this year, and now I've got trials lined up for the new third tier of the Irish League. I made it through the first round and now I'm heading into the final stage, so I'm feeling sharp and ready to go.

At the moment, I'm working full-time while still chasing the dream and trying to balance the three things that matter most to me — football, earning a living and being happy.

That sounds great, and best of luck with the trial. Who are you playing for at the moment?

Right now I'm playing with my local side, Boyle Celtic, trying to build up more clips and keep my CV updated. I've been back with them since January after recovering from my injury.

I've also been in and around places like Sligo Rovers and Longford Town, training and keeping myself in that environment where you're surrounded by good players and constantly improving. I never want to become stagnant or settle at a level I don't want to stay at.

What position do you play?

I'm a striker. My job is to score goals and make everyone else look good — or at least try to.
It can be difficult because you're up against big centre-halves who want to push you around, kick you and stamp on you, but I enjoy that challenge. Most people don't even realise I have haemophilia. There's no sign above my head saying, "Don't touch me." You just learn how to deal with the bumps and bruises in your own way and keep going.

Have you had many bleeds from playing?

I've had a few, but overall I've been fairly lucky. The worst was probably three or four years ago when I ruptured my quad. That was a spontaneous bleed and, looking back, it probably came from overtraining and not taking care of myself properly.

At the time I was playing both Gaelic football and soccer, training every day and pushing my body too hard. Since then, I've become much more focused on recovery and looking after myself. Now I treat my body like a temple because I want to keep doing this for as long as I can.

There's nothing worse than being stuck sitting at home with a bleed, knowing you can't do anything except rest. Anyone with haemophilia understands that feeling.

I've had my share of joint and muscle bleeds, but I've also had seasons where I've gone all the way through without injury, so overall I consider myself lucky.

What's your treatment regime at the moment?

I take treatment once a week, every Friday. I was part of a medical trial for Altuvoct for two years, starting when I was in Sweden. That was a huge turning point for me because it gave me the freedom to train like a professional footballer for the first time in my life.

Before that, I was doing intravenous treatment two or three times a week. Since starting Altuvoct, I've been able to gradually push my body more and learn exactly what my limits are.

At this stage, I know how to manage my workload, training and recovery. If I push too far, my body lets me know pretty quickly, so I've found a rhythm that works for me.

Could you describe a typical training week?

When I was in Sweden, football was basically my whole life. You'd get up, go to the gym, come home, eat, recover, maybe go for a walk, and then train again in the evening. Doing that every day allowed you to see constant improvement.

That environment was incredible, especially for someone with haemophilia. I was training with players who've since gone on to play at really high levels, even in the Champions League.

Ever since coming home, I've tried to keep that same mindset. Every day I'm either pushing my body or recovering properly — whether that's running, gym work, ball work, sprinting or focusing on nutrition. When I was in Sweden, I'd usually train four hours a day between gym work and football sessions. I still try to keep close to that now, usually doing weights before work and football training later on.

Were you encouraged or discouraged from playing sport growing up?

Mostly encouraged, especially by my family. Football was always part of our family. My uncle actually played in the Tottenham Hotspur academy years ago alongside players like Glenn Hoddle, and my cousins played semi-professionally as well.

Have attitudes towards contact sports and haemophilia changed over your lifetime?

Massively. I remember being sent into school football tournaments wearing a helmet, elbow pads and knee pads because everyone was so worried about injuries.

As I got older, attitudes changed and treatments improved at the same time. Around the peak years of my football career, these newer medications became available, and they allowed me to push my body in ways I never could before.

Without those treatments, I honestly don't think I would have had the opportunities I've had in football. It's incredible how far things have come. I feel lucky to have access to treatments that older generations of haemophiliacs never had.

Where would you like to be five years from now?

Honestly, I'm pretty happy already. I've got a good job as a personal trainer and swim teacher, and I'd love to keep building my reputation in that area while hopefully playing at an even higher football level.

I know there are probably limits I can't push past without consequences, but if I can help other people achieve goals that maybe I couldn't reach myself, that would mean a lot too.

More than anything, I just don't want haemophilia to dictate my life. I want to stay healthy, keep pursuing my goals and help others do the same.

Whenever I volunteer or speak with younger people with haemophilia, I'm always happy to encourage them and share my experiences because the opportunities available to them now are incredible.

What would you say to children who want to get involved in sport but have a bleeding disorder?

I'd absolutely encourage them to give it a go.

Obviously everyone's situation is different, and I've been fortunate in many ways, but I think it's so important for kids to stay active and experience being part of a team.

People hear "contact sport" and immediately think of injuries, but there's so much more to it than that. Sport gives you friendships, confidence, memories and life experiences that stay with you forever. Some of the friends you meet through sport could end up being friends for life.

For me, football was one of the best things I ever did, and I'd never want haemophilia to stop someone from at least trying to follow something they love.

Thank you so much to Callum for taking part in this interview with us and we wish him all the best in his football career!

Apply for an IHS Educational Grant!

Each year, the Society offers educational grants to people with diagnosed inherited bleeding disorders, and/or their immediate family members who go on to do a post second level educational course. The purpose of these grants is to offer financial support to members to assist with the extra expenses involved with their studies. We have four categories of educational grants available for application.

These are:

- 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.

The closing date for applications is September 25th.

Hyde Square Apartments

This is a reminder that our apartments at Hyde Square are available to:

- People with haemophilia or related bleeding disorders (with their immediate family members) from outside Dublin, when attending St. James's or Children Health Ireland, Crumlin, for treatment, a hospital appointment or a review clinic.

If you would like more info or to make a booking, please contact Lena in the office on 01 657 9900.

A nominal fee of €10 per booking per night will be levied to offset the cost of cleaning and routine maintenance.

Rob's Top 10 Outreach Tips

Robert Flanagan, Outreach & Engagement Manager

Living with a bleeding disorder in Ireland comes with its own set of challenges, and over the years I've seen the same questions, worries and frustrations come up repeatedly from members. Some regular questions that I get relate to treatment, benefits, travel, school and work. This article is a collection of the ten things I think all our members need to know. I hope it will assist you and make life that little bit easier.

Pick up the phone and give me a call

If something is concerning you, give me a call. Don't wait until the issue gets worse. So many people start a conversation by saying, "I wasn't sure if this was worth ringing about," and almost every time, it is. Whatever the issue, I'm happy to talk it through with you. That's what I'm here for. Call me on 01 657 9900.

Know what you're entitled to

A lot of members are not aware of what they could be claiming. For example: The Long-Term Illness Scheme covers your medication. The Drugs Payment Scheme caps what you pay each month. Medical cards, GP visit cards, Disability Allowance, Carer's Allowance, the HAA Card, are there for those who are eligible. If you're not sure what applies to you, give me a call and I will go through it with you.

Keep your records together

A simple folder at home with your factor records, recent letters from your treatment centre, prescriptions, and a list of emergency contacts is one of the most useful things you can have. If you ever end up in an emergency department where they don't know you, that folder does half the work for you. Please also remember to have your bleeding disorder alert card and the ambulance directive printed out or on your mobile phone. Have everything in one place and you'll thank yourself later.

Talk to your treatment team about everything

The teams at St. James's, Crumlin, Cork and Galway are not just there to look after your treatment. They're there for the pain you've been ignoring, the joint that's been niggling for months, the worry about starting a family, the question you didn't think was important enough to ask.

Don't tough it out at home

A bleed that gets treated quickly heals quickly. A bleed that you sit on for two days because you didn't want to make a fuss can cause damage that takes much longer to recover from and sometimes doesn't fully recover at all. If you think you have a bleed, treat it. If you're not sure, ring your comprehensive care centre. Nobody on the other end of the phone is going to be annoyed with you for checking.

Look after the rest of your health too

A bleeding disorder is one part of your health, but not all of it. Get your blood pressure checked. Keep your weight in a range that's kind to your joints. Move your body in whatever way works for you. Swimming, walking and cycling are great. Strengthening work, if done properly, protects your joints rather than damaging them. Your physiotherapist can guide you on what's safe and what's not.

Plan your travel properly

Going on holiday with a bleeding disorder is possible, but it needs a bit of thought. Order your IHS Travel Card from the office. Get a letter from your treatment centre for customs. Bring more factor than you think you'll need. Have your European Health Insurance Card if you're in the EU. Check that your travel insurance covers your condition. If you're going somewhere with limited haemophilia care, give me a call before you go and I'll help you find the nearest treatment centre at your destination.

Get involved

The IHS is more than an office and a phone number. We offer conferences and events for all the family, which includes four different groups for children and teenagers. We have online exercise classes, and a WhatsApp community where members can keep up-to-date on all things IHS. Some of the best feedback we get is from people who weren't sure about coming to their first event and then couldn't believe how much they got from the event, particularly being with people who understand. If you've never been, this is the year to try!

Talk to other members

A parent whose child has just been diagnosed will get something from another parent that no professional can give them. A teenager working out how to talk to friends about their condition will get more from another teenager than from any leaflet. An older member adjusting to retirement and ongoing joint issues will find their own kind in the room at our adult events. We can put you in touch. Just give me a call.

Look after your mental health

Living with a bleeding disorder can be hard, and there's no medal for pretending otherwise. The frustration of repeated bleeds, or the worry about your children or grandchildren. We all have busy lives these days. All of these things take their toll. If you're struggling, please tell somebody: your GP, your treatment team, or give me a call. There are supports available, and you don't have to manage on your own.

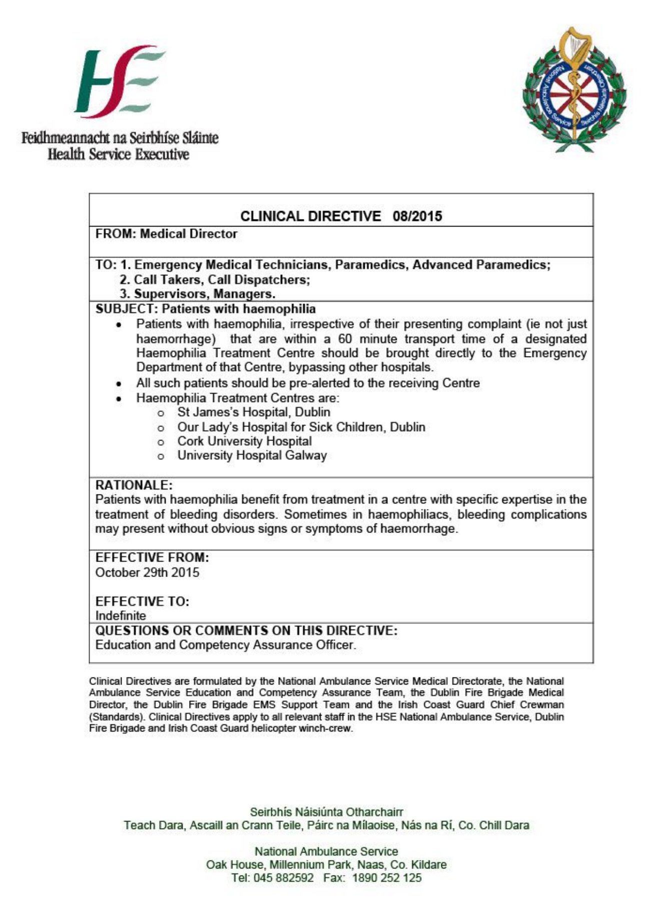
The IHS has been here since 1968, and the work continues because of the trust members place in us. If there's anything we can do for you or your family, the door is always open. Don't hesitate to get in touch. You can reach me at robert@haemophilia.ie or on 01 657 9900.

Key Developments Booklet

In the rapidly changing treatment environment for inherited bleeding disorders, it can be difficult to keep up to date with all the information from clinical trials and updates on licensed therapies. We have teamed up with the Canadian Hemophilia Society to produce a short summary document on major developments in novel therapies. The content is based on published data and congress presentations and abstracts. The plan is to produce this publication twice per year. You can view this publication on our website.

Please contact our communications coordinator roisin@haemophilia.ie if you would like a PDF copy sent to you.

The 2015 Ambulance Directive



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

CLINICAL DIRECTIVE 08/2015
FROM: Medical Director
TO: 1. Emergency Medical Technicians, Paramedics, Advanced Paramedics; **2. Call Takers, Call Dispatchers;** **3. Supervisors, Managers.**
SUBJECT: Patients with haemophilia • Patients with haemophilia, irrespective of their presenting complaint (ie not just haemorrhage) that are within a 60 minute transport time of a designated Haemophilia Treatment Centre should be brought directly to the Emergency Department of that Centre, bypassing other hospitals. • All such patients should be pre-alerted to the receiving Centre • Haemophilia Treatment Centres are: o St James's Hospital, Dublin o Our Lady's Hospital for Sick Children, Dublin o Cork University Hospital o University Hospital Galway
RATIONALE: Patients with haemophilia benefit from treatment in a centre with specific expertise in the treatment of bleeding disorders. Sometimes in haemophiliacs, bleeding complications may present without obvious signs or symptoms of haemorrhage.
EFFECTIVE FROM: October 29th 2015 EFFECTIVE TO: Indefinite
QUESTIONS OR COMMENTS ON THIS DIRECTIVE: Education and Competency Assurance Officer.

Clinical Directives are formulated by the National Ambulance Service Medical Directorate, the National Ambulance Service Education and Competency Assurance Team, the Dublin Fire Brigade Medical Director, the Dublin Fire Brigade EMS Support Team and the Irish Coast Guard Chief Crewman (Standards). Clinical Directives apply to all relevant staff in the HSE National Ambulance Service, Dublin Fire Brigade and Irish Coast Guard helicopter winch-crew.

Seirbhís Náisiúnta Otharchairr
Teach Dara, Ascaill an Crann Teile, Páirc na Milaoise, Nás na Rí, Co. Chill Dara

National Ambulance Service
Oak House, Millennium Park, Naas, Co. Kildare
Tel: 045 882592 Fax: 1890 252 125

The 2015 Ambulance Directive states that a person with a bleeding disorder should instruct an ambulance to take them to one of the four haemophilia treatment centres in Ireland - the National Coagulation Centre, Cork Coagulation Centre, CHI Crumlin or Galway University Hospital, provided they are within 60 minutes of one of the centres.

Members should keep a copy of this directive on their phone so that they can show the ambulance crew, as the crew may not already be aware of this directive.

If you would like more information on this, please contact our Outreach & Engagement Manager, Robert Flanagan at robert@haemophilia.ie.

IHS Patron

We are delighted to announce that President Catherine Connolly has agreed to be the new patron of the Irish Haemophilia Society. We are looking forward to our future interactions with her. President Connolly is the fourth president of Ireland to be patron of the Society.

Write for Us

We are always eager to have members contribute to our publications!

Share a story about your experiences with a bleeding disorder, you child's experiences, or about any other relevant topic! If you prefer, you could do an interview with us.

If you would like to contribute or would like more information, email roisin@haemophilia.ie.

Dr. Barry Harrington Award

A big congratulations to dentist Dr. Louise Barry who received the Dr. Barry Harrington Award 2025 from Brian O'Mahony in May.

Dr. Barry worked as one of the dental team for people with bleeding disorders in CHI Crumlin.

This award is named after Dr. Barry Harrington, who made a huge contribution to haemophilia care in Ireland. He was the head of the dental service in St. James's in the 1980s at a time when many dentists feared treating patients with haemophilia. He broke down myths and found that patients could be treated safely without factor concentrates.

Following his death in 2024 we set up the Dr. Barry Harrington Award to honour his memory and award dentists who have made a difference in the field of inherited bleeding disorders.

Irish Haemophilia Society

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Find us on: