Irish Haemophilia Society

Spring Magazine

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

Spring 2026 Edition

From the Editor

Roisin Burbridge, Publications, Website & Social Media Coordinator

Hello everyone!

I hope you are all enjoying the longer evenings and brighter days. We hope you enjoy this edition of our quarterly magazine.

To kick off this magazine, Brian O'Mahony highlights some key updates in his CEO report. He discusses the recent European Association for Haemophilia and Allied Disorders (EAHAD) Congress. He also provides an update about our new podcast series, as well as news about factor IX gene therapy.

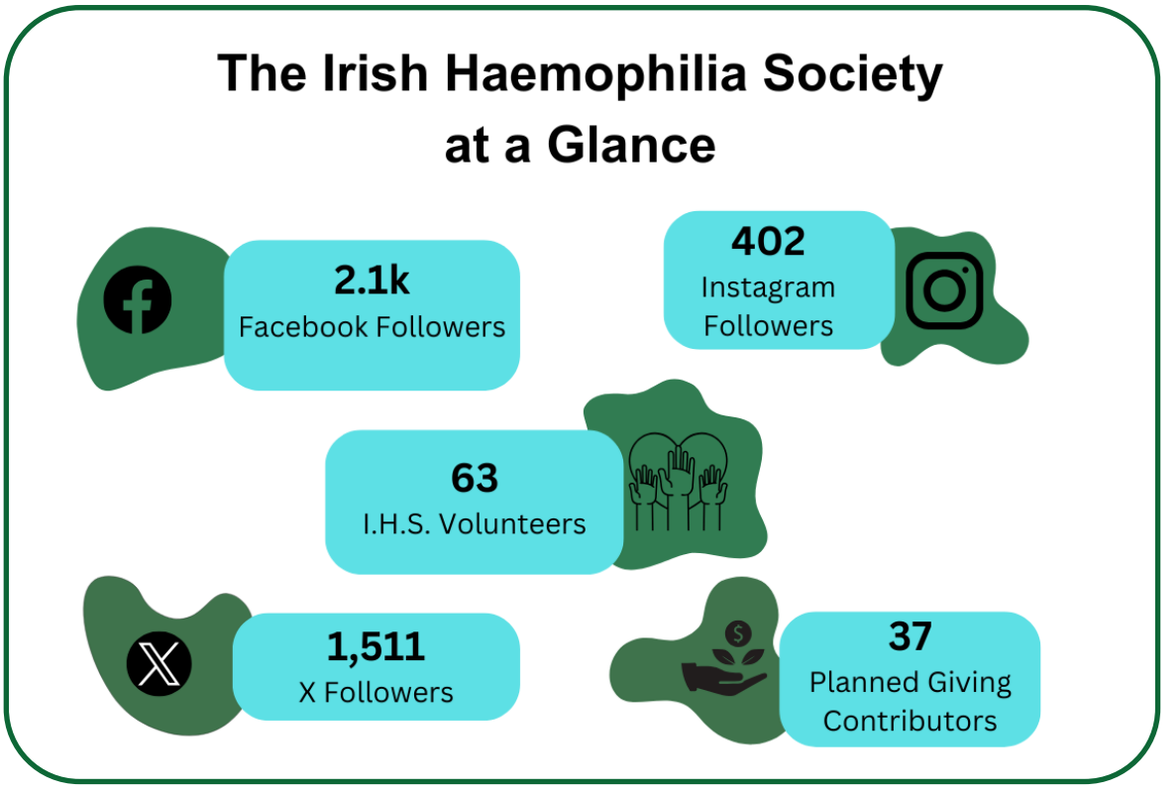
Following the CEO report, Executive Board Member and Secretary Hannah Byrne provides a thorough recount of our recent AGM and Conference. We have also included some of the best snapshots from the Conference, as well as photos of our wonderful award winners receiving their awards at the gala dinner. Congratulations to all!

Following this, the IHS staff have put together a report on the highlights of the EAHAD congress. We also have a very interesting piece by member Sinéad O'Driscoll who recently did her master's thesis on ageing in haemophilia. For this, Sinéad surveyed people with severe haemophilia in Ireland and asked them about their experiences ageing with the condition. In this piece, Sinéad discusses some of the findings from the research.

After this, we have included an interview I conducted with Prof. Cedric Hermans, the director of the centre of haematology in Brussels. In it, Prof. Hermans discusses his role as chief editor of the international journal 'Haemophilia', as well as his role on the board of the World Federation of Hemophilia and his thoughts on future treatment options for bleeding disorders.

In this edition, we share the Parents Conference preliminary programme, an infographic with tips and tricks for travelling with a bleeding disorder and other news and updates.

Happy reading!



Contents

04 An Update from Our CEO

06 Highlights from Our AGM

08 AGM Award Ceremony

10 Snapshots of Our AGM

11 Parents Conference Preliminary Programme

12 Highlights From EAHAD 2026

14 Navigating Ageing with Severe Haemophilia

16 Interview with Cedric Hermans

18 Rob's Top 10 Tips for Travelling with a Bleeding Disorder

19 Noticeboard

An Update From Our CEO

Brian O'Mahony, Chief Executive

AGM & Conference

The Irish Haemophilia Society's 37th Annual General Meeting and Conference took place March 3rd to 5th in the Slieve Russell Hotel. As usual, it was very well attended with over 200 delegates in attendance, and featured sessions on haemophilia and von Willebrand disorder treatment updates, liver health, an open forum and more. A more detailed report on the AGM and Conference is included later in this edition.

EAHAD Congress

The Annual Congress of the European Association for Haemophilia and Allied Disorders (EAHAD) took place at the Dublin Convention Centre in early February. This was the first large international haemophilia conference held in Ireland since 2018. The congress was attended by over 2,100 delegates. The vast majority were clinicians, nurses, physiotherapists, psychosocial professionals, dentists and laboratory scientists. As this conference is mainly aimed at healthcare professionals, there were only a small number of patient leaders in attendance. The Society staff were also in attendance. I had the pleasure of co-chairing the opening symposium on successful ageing in haemophilia. This began with an excellent presentation from Prof. Rose Anne Kenny from the Mercer's Institute for Successful Ageing (MISA) at St. James's Hospital. She pointed out the importance of recognising and dealing with frailty and that people's key concerns are falls, mental health and neurological disorders. This was followed by a very lively panel discussion on the same topic with audience interaction and featured a doctor, a nurse, a physiotherapist, a dentist and an occupational therapist.

At the symposium on re-imagining factor replacement for haemophilia, Astermark discussed the advantages of ultra-extended half-life (ultra-EHL) factor VIII (FVIII) compared with standard extended half-life (EHL) FVIII. He highlighted the substantially higher trough levels achieved with ultra-EHL products, resulting in greater protection against bleeding and less frequent infusions. Intravenous FVIII administration once weekly is now a feasible and effective option. He also emphasised that prophylaxis must be individualised; a uniform, "one-size-fits-all" regimen is no longer appropriate.

Prof. Cedric Hermans addressed the greater complexity of factor IX (FIX) therapy. Unlike FVIII, FIX distributes not only within the bloodstream but also into extravascular compartments such as joints and muscles. Two of the three licensed EHL FIX concentrates do not go into the extravascular space. Therefore, when comparing FIX levels between products - particularly with an EHL FIX that does distribute extravascularly - this difference must be considered. Required trough levels vary between products to achieve bleed prevention, and direct comparisons are not appropriate.

The progress in the availability of newer therapies was also discussed at the EAHAD Congress. The

The WFH team visiting the IHS office during the EAHAD Congress

mimetic MiM8, which acts in a similar manner to Emicizumab (Hemlibra), was licensed by the United States Food and Drug Agency (FDA) last October and may be licensed by the European Medicines Agency (EMA) within the year. The rebalancing agent Marstacimab (Hympavzi) was licensed by the EMA for haemophilia A and B without inhibitors in November 2024 for those over the age of 12. The rebalancing agent Concizumab (Alhemo) was licensed by the EMA in December 2024 for haemophilia A or B with inhibitors for those over the age of 12 and expanded in July 2025 to those with haemophilia A and B without inhibitors. The final re-balancing agent Fitusiran (Qfitlia) was licensed by the FDA in March 2025 but the EMA have not yet licensed this therapy - this is expected in the next 18 months. These therapies add to the list of potential treatments for haemophilia and some of them may also have utility in treating some rare bleeding disorders.

Separately, Donna Coffin from the World Federation of Hemophilia (WFH) spoke about implementing shared decision-making (SDM). The WFH have developed an excellent SDM tool which is regularly updated and can be a very valuable part of the SDM process. This process should be increasingly used in the current complex therapeutic environment.

Podcast Series

The Society, recognising that many people get much of their information from podcasts, have collaborated with the Canadian Hemophilia Society and organised a series of four podcasts on FIX gene therapy. The focus was on FIX specifically as FVIII gene therapy is not currently being marketed and will not be available in either Ireland or Canada. The first in the series featured Prof. David Lillicrap from Canada, who explained the science behind gene therapy and gene editing in an understandable way. The second in the series featured four people with haemophilia who discussed their degree of interest or disinterest in gene therapy. This included three members of the Irish Haemophilia Society with FIX deficiency and one man from Canada. The third podcast was with four people with haemophilia who had undergone FIX gene therapy. This included men from Canada, the Netherlands, the UK and myself from Ireland. The final podcast featured two clinicians - Dr. Pratima Chowdary from the UK and Dr. Davide Matino from Canada - discussing SDM with David Page from the Canadian Hemophilia Society and myself. The people with haemophilia who participated really enjoyed the group discussions and participated fully.

As in this podcast series, it has long been our experience at the Society that members meetings or small group meetings to discuss new therapies add a lot of value to individual discussions and are an excellent method of education. Someone often introduces a point or concern that others have not considered, which further enhances the depth and value of the discussions.

Factor IX Gene Therapy

Last, but certainly not least, we are very pleased that the licensed FIX gene therapy - Hemgenix - following lengthy discussions and negotiation, is now available in Ireland as a treatment option for eligible people with severe FIX. The first individual has already been treated and the treatment is now being rolled out and discussed with those who are eligible and interested. The process should involve several discussions for each individual with the National Coagulation Centre (NCC) to ensure that any person undergoing gene therapy is making a fully informed personal decision. The Society will also be rolling out more educational initiatives for relevant members in this area during the year.

At the time of writing, a delay in the availability of the FIX gene therapy has been announced due to a manufacturing issue. This is expected to be a relatively short delay and should not impact individuals' preparation or discussions with the NCC.

Highlights from Our AGM

Hannah Byrne, Secretary of the Executive Board

The 2026 AGM was held in the Slieve Russel Hotel, Co. Cavan, a beautiful hotel with acres of sprawling woodlands - and, most shockingly, it even had some sunshine! Friday night got off to a great start with a lovely buffet, followed by many members running straight to watch the tense Ireland vs Wales Six Nations Rugby match. The whole bar cheered as Ireland snatched their victory, leaving everyone in a good mood heading into the weekend of talks.

Saturday morning opened with the AGM, which saw the election of two new board members, Seamus McDonald and Colm Walsh. This meeting also signified two board members, Brian Byrne and Cian O'Sullivan, stepping down, as well as John Stack stepping down as Chairperson after eight years. John has shown true leadership throughout his tenure and was thanked for his work and dedication to the IHS.

Following lunch, the focus turned to future treatment options with parallel sessions running. Prof. Niamh O'Connell delivered a highly engaging talk about future treatment options for haemophilia, and Dr. Beatrice Nolan spoke in her session about future treatment options for von Willebrand disorder and rare bleeding disorders.

Prof. O'Connell opened her talk referencing the recent rise of ChatGPT and, as a challenge, put ChatGPT to the test asking it to predict what will happen with haemophilia care up until the year 2100. She then went on to explain her own predictions about how haemophilia care will advance compared to those ChatGPT had shown. Everyone was highly engaged with this approach and only time will tell what actually happens!

These talks were followed by Dr. Vincenzo La Mura from Milan speaking about monitoring liver health. Dr. La Mura spoke about the importance of taking care of your liver and how different lifestyle choices can have a direct affect on liver health. This session was highly valuable and of particular importance to the haemophilia community due to the effect of hepatitis C on the liver. This talk evoked many questions and led to many people taking these chats into the coffee break following the session.

Following this, the closing plenary of the day was an open forum with the comprehensive care teams. This session was chaired by Dr. Paul Browne - the newly appointed chairperson of the National Haemophilia Council. On the panel for this session were Prof. Niamh O' Connell, Dr. Beatrice Nolan, Dr. Maeve Crowley, alongside Brian and Debbie from the IHS. Each time that I attend a session like this, I am reminded about how unusual it is that we, as a bleeding disorder community, have such direct access to the centre directors and how important this two way communication is for our entire community. There was a great discussion, with many people asking a variety of questions to everyone on the panel.

As Saturday's sessions drew to a close, parents collected their children from the four children's groups, who had had an extremely busy day - from

swimming to a first aid workshop, debates to arts and crafts - all of the children left with smiles on their faces.

After a short rest, everybody reunited for the gala dinner. The night started with an awards ceremony. Congratulations to all of the deserving award recipients. The meal was enjoyed by all, followed by an evening of chats and laughter.

Sunday morning began bright and early with Dr. Saad Ahmed delivering a talk titled “Is Mild Haemophilia the New Severe?”. The session addressed the quick advancement of a variety of treatments for severe haemophilia over the last decade. It demonstrated how the treatment for mild haemophilia, although advancing, is not happening at the same speed as that of severe haemophilia. Dr. Ahmed provided a comprehensive overview which gave everyone the information and tools to mull over the title question for themselves.

The final session of the weekend was by Prof. Mike Makris entitled “Haemophilia Treatment: Past, Present, and Future”. This talk was also attended by the Youth Group. Personally, I find talks such as this particularly interesting as throughout the weekend you hear so many names of new treatments, trials and products and so it is very informative to see it all laid out on a timeline. It really showcases how far haemophilia care has come and the quality of treatment available in 2026.

Overall, I feel the tone of the weekend was hopeful - there were many updates on successful new products, trials and options. Most importantly though, it is a reminder of the community within the IHS, people reuniting with old friends, meeting new ones and bonding over shared experiences.

Roll on March 2027!!

AGM Award Ceremony

Pictured:

- **Top Left** - Jake Phoenix receiving the Maureen & Jack Downey Educational Grant 2025.
- **Top Right** - Catherine Moriarty receiving the Volunteer Certificate of Recognition 2025 on behalf of David Moriarty.
- **Bottom Left** - Catherine Moriarty receiving the Margaret King Educational Grant 2025 on behalf of Tadgh Moriarty.
- **Bottom Right** - Aoife Boylan receiving the Father Paddy McGrath Educational Grant 2025.

Pictured:

- **Top Left** - Chloe O'Sullivan receiving the Bill O'Sullivan Fundraiser of the Year Award 2025.
- **Top Right** - Jamie Finn receiving the Gerry O'Reilly Courage Award 2025.
- **Bottom Left** - John Stack receiving the Brian O'Mahony Award for Outstanding Contribution to Haemophilia in Ireland 2025.
- **Bottom Right** - Traci Marshall Dowling receiving the Brian O'Mahony Award for Outstanding Contribution to Haemophilia in Ireland 2025.

Snapshots of Our AGM

Parents Conference

Venue: Midlands Park Hotel, Portlaoise, Laois

Date: July 3rd - 5th, 2026

Preliminary Adult Programme

Friday 3rd July

19.00 Buffet Dinner

Saturday 4th July

10.00 – 10.45 **Current & Future Treatments**
An update on where we are at with current and future treatments for haemophilia.

Or

Living with Von Willebrand Disorder / Rare Bleeding Disorders
A presentation on living with a bleeding disorder, covering medical information & practical management.

10.45 – 11.30 **Physio & Bleeding Disorders**
Topics covered will include: Bone Health, Muscoloskeletal Bleeds & Vitamin D.

11.30 – 12.00 Coffee Break

12.00 – 13:15 **Elements of Comprehensive Care**
Topics covered include: Nosebleeds, Head Injuries, Dental Care, Treatment at Home, Communication with other Hospitals, Ambulance Directive, Bleeding Disorder Alert Cards & Long-term Illness Allowance.

13.15 – 14.15 Lunch

14.15 – 14.45 **Needlephobia**
A presentation covering a mix of psychological, medical issues & practical coping strategies.

14.45 – 15.30 **Inheritance & Carrier Issues**
Topics covered will include: Inheritance, Carrier Issues, Girls with Bleeding Disorders, Awareness for Dads & Prenatal Genetic Diagnosis.

15.30 – 16.00 Coffee Break

16.00 – 16.45 **Open Forum**
The Open Forum will consist of a panel of speakers from CHI Crumlin.

19.00 Dinner & Entertainment for the Kids

Sunday 5th July

10.00 – 10.30 **An Update on the New Children's Hospital**
A presentation & update on the new national paediatric hospital at St. James's.

10.30 – 11.30 **Mothers Workshop Group**
A safe space for mothers to discuss a range of issues.

OR

Fathers Workshop Group
A supportive group for fathers to discuss a variety of issues.

11.30 – 12.00 Coffee Break

12.00 – 12.45 **Self-Care & Advocacy: Supporting Your Child While Caring for Yourself**
This session explores the challenges of parenting a child with a bleeding disorder, highlighting the vital role of self-care. When you look after yourself, you are better able to look after your child.

Highlights from EAHAD 2026

Staff of the Irish Haemophilia Society

Healthcare professionals from across Europe and beyond gathered in Dublin in February for the Annual Congress of the European Association for Haemophilia and Allied Disorders (EAHAD). Held at the Convention Centre in Dublin, the EAHAD 2026 Congress brought together clinicians, researchers, nurses and allied health professionals to share the latest developments in haemophilia and related bleeding disorders.

All the staff from the Irish Haemophilia Society and Dan McIntrye from the Board attended the Congress. While aimed primarily at clinicians, we all came away with more knowledge on a variety of topics, from ageing to women and girls with bleeding disorders to treatment developments in the fields of haemophilia and von Willebrand disorder. Below are some of the main highlights from the Congress.

Ageing

The conference opened with an important session on ageing in which the founding principal investigator of the Irish Longitudanal Study on Ageing (TILDA), Rose Anne Kenny, outlined some shocking facts about the realities of ageing in 2026. Relevant to the general population as much as to those with bleeding disorders, she highlighted how while lifespan is increasing substantially, healthspan (the number of years a person lives without disability) is not keeping pace. In fact, many people live their last decade of life in sickspan. She discussed the issue of frailty, and stressed that this needs serious attention especially as the number of people living with frailty in Ireland is expected to increase five-fold over the next 15 years. One vital piece of advice she gave was for older adults to do resistance training in order to build muscle and bone density.

Women & Bleeding Disorders (WBD)

Speakers on Thursday highlighted that women frequently experience significant bleeding symptoms but remain under-diagnosed and under-recognised in clinical practice. Sessions addressed several aspects of care for women with bleeding disorders, including the evolving role of haemophilia nurses in supporting menstrual health, reproductive care and psychosocial wellbeing. These sessions emphasised the importance of multidisciplinary collaboration between haematology, gynaecology and obstetrics services to ensure coordinated care across the entire lifespan. Musculoskeletal health was another important topic discussed. While joint disease is commonly associated with severe haemophilia in men, emerging evidence suggests that women with mild factor deficiencies or carrier status may also experience joint bleeding and long-term joint complications. Early recognition of symptoms and the integration of physiotherapy and musculoskeletal monitoring are key components of comprehensive care for women with bleeding disorders.

Speakers also explored pregnancy and childbirth, particularly in the context of rare bleeding disorders such as Glanzmann Thrombasthenia. They discussed the challenges of managing bleeding risk during pregnancy and delivery, and reviewed strategies to give mother and baby sufficient support and minimise complications for both.

Digital Health

Just like in so many other areas, artificial intelligence also featured in this conference. Dr. Guido Giunti from St. James's Hospital gave a very interesting presentation on the potential role of digital health tools and artificial intelligence in improving the diagnosis of patients with unexplained bleeding symptoms. He explained that many individuals experience significant bleeding but do not meet the diagnostic criteria for a known bleeding disorder, sometimes described as a bleeding disorder of unknown cause. Dr. Giunti described how digital health platforms could support clinicians by enabling more structured bleeding history collection,

integrating laboratory data and analysing complex clinical datasets. Artificial intelligence technologies may help identify patterns within patient data that could help clinicians in recognising possible bleeding disorders earlier.

Importantly, the presentation emphasised that artificial intelligence is intended to complement rather than replace clinical expertise.

Gene Therapy for Haemophilia

During several sessions at the congress, researchers presented long-term data on gene therapy for haemophilia B and haemophilia A, highlighting both the progress made and the challenges that remain.

Professor Frank Leebeek presented five-year clinical trial results for the gene therapy now licensed as Hemgenix. The data showed lasting benefits for many participants, including a significant reduction in bleeding rates and continued production of factor IX (FIX) several years after treatment. By year five, most participants experienced no treated bleeds and maintained FIX levels high enough to reduce or eliminate the need for regular factor infusions. Additional analysis presented by Karim Miesbach showed that the majority of trial participants maintained meaningful levels of FIX expression after five years. Separate data from a gene therapy programme licensed and marketed in China also showed encouraging early results, with most participants achieving factor IX levels above 5% after one year.

Developments in gene therapy for haemophilia A were also discussed. While early increases in factor VIII (FVIII) levels are often seen after treatment, longer-term results show greater variability, with levels sometimes declining over time before stabilising. One possible explanation discussed is that liver cells, which are targeted by current gene therapy approaches, do not naturally produce FVIII. Ongoing research is therefore focused on improving the design of gene therapy vectors, promoters and transgenes to achieve more stable FVIII expression at lower doses and to reduce the need for additional treatments such as steroids.

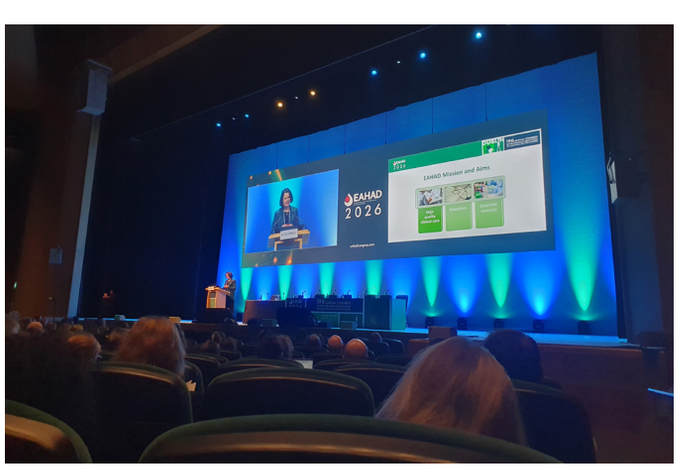
Von Willebrand Disorder (VWD)

Importantly, the sessions focused on VWD highlighted the impact the condition can have on daily life. Bleeding symptoms can be significant even when laboratory results appear only mildly abnormal. People with VWD may experience heavy periods, frequent nosebleeds, bruising and fatigue, which can substantially affect work, school and overall quality of life, and many feel their symptoms are often underestimated. There is growing recognition that blood levels alone do not tell the full story, as people with similar laboratory results can have very different bleeding experiences, making individual assessment and shared decision-making essential.

Positive developments in VWD treatment were also discussed. Dr. Hayakawa presented striking early results from a clinical trial of the therapy VGA-039. 16 people with VWD were treated, including one 50-year-old participant whose annual bleeding rate fell dramatically from 176 to 7 following treatment, illustrating the potential impact that new therapies could have for people with severe symptoms.

Taken together, the sessions throughout the EAHAD Congress demonstrated how the field of haemostasis continues to evolve. Advances in treatment, improved understanding of bleeding disorders in women, and the potential of digital technologies are all contributing to a more comprehensive and patient-centred approach to care.

As highlighted throughout the Congress, continued collaboration between clinicians, researchers and multidisciplinary teams will be essential to translate these developments into improved outcomes for people living with bleeding disorders.



Navigating Ageing with Severe Haemophilia

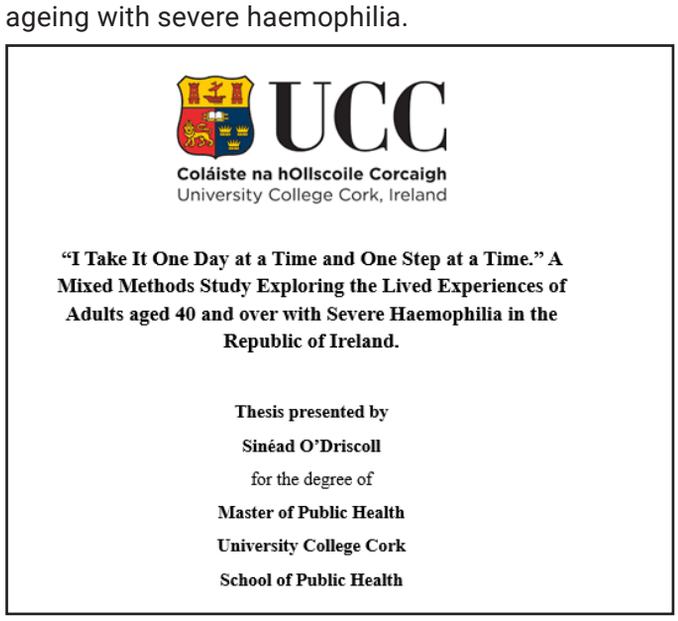
Sinéad O'Driscoll, Member of the Irish Haemophilia Society

Upon embarking on my journey of the Master of Public Health (MPH) programme at University College Cork in September 2024, I found it timely for my dissertation to focus on the lived experiences of ageing with severe haemophilia in Ireland. During my first lecture, I reflected on how public health is not complicated – it is complex. A lecturer explained that building a rocket is complicated but once it is made, it can be replicated. Ageing with severe haemophilia presents unique and complex challenges. It requires comprehensive, multidisciplinary and person-centred care to support individuals holistically. In recent times, haemophilia care has undergone remarkable changes – from historically unsafe treatments to the advanced therapies available today. Although the medical management and clinical care of haemophilia is well-established, exploring the lived experiences of this ageing cohort remains underrepresented in contemporary research. My dissertation aimed to give ageing members the opportunity to share their experiences of living with severe haemophilia. Ageing with severe haemophilia once appeared an unattainable goal; however, with the advent of safe prophylactic treatments, in addition to advanced therapies for viral-related conditions, growing older has become a reality.

Nevertheless, ageing has introduced additional challenges. It is common for ageing individuals to experience age-related and haemophilia-related health issues such as haemophilic arthropathy, resulting from repeated joint bleeds, in addition to chronic pain, arthritis, osteoporosis, fatigue, anxiety, and depression. These complex comorbidities, whereby a health condition often occurs alongside haemophilia, means that ageing can lead to unique physical, emotional and wider social challenges.

To better understand the lived experiences of ageing with severe haemophilia, I reviewed the literature and consulted Brian O'Mahony to ensure that the questions posed in the postal questionnaire would provide meaningful insights. The IHS distributed the questionnaires to members aged 40 and over living with severe haemophilia. It gave members the opportunity to share their experiences from physical and psychological perspectives, and to provide suggestions on appropriate supports and services to promote successful ageing. Twenty-two members with severe haemophilia responded to the questionnaire, including 15 diagnosed with severe haemophilia A and seven with severe haemophilia B.

A predominantly qualitative mixed methods design was used, whereby the open-ended responses allowed for deeper insights into the respondents lived experiences. The questionnaire allowed the respondents to share how living with haemophilia affected their daily routines, the adjustments they had made to manage their bleeding disorder, and its impact on their ability to remain physically active as they age. Respondents described the psychological challenges of ageing, including how they showed resilience, differing coping mechanisms, and how their attitudes toward living with haemophilia evolved throughout their lives. The main themes were predefined by the findings of existing literature and in consultation with Brian O'Mahony, which formed the basis for the structure of the questionnaire – (1) Barriers to Daily Living and Social Participation, (2) Facilitators of Effective Haemophilia Management in Later Life, (3) Living with the Psychological Impact of Haemophilia, and (4) Physical Consequences of Ageing with Haemophilia. These main themes guided the responses, and this allowed 19 subthemes to emerge. Collectively, these themes revealed the multifaced experiences of respondents, offering insights into the physical, psychological and social challenges encountered, and how they adapted to ageing with severe haemophilia.



UCC
Coláiste na hOllscoile Corcaigh
University College Cork, Ireland

"I Take It One Day at a Time and One Step at a Time." A Mixed Methods Study Exploring the Lived Experiences of Adults aged 40 and over with Severe Haemophilia in the Republic of Ireland.

Thesis presented by

Sinéad O'Driscoll

for the degree of

Master of Public Health

University College Cork

School of Public Health

Respondents shared how physical impairments arising from haemophilia-related comorbidities, namely arthropathy, made it difficult to undertake daily activities. Reduced mobility, reported mainly from arthropathy in the knees and ankles, along with pain, was reported as a significant challenge. These issues affect their ability to walk for extended periods, climb stairs, or remain standing. Arthropathy makes it difficult to remain physically active especially in individuals with inadequate pain management strategies. Some respondents expressed their frustration with the lack of access to pain management supports. Another common theme identified was the avoidance of risk-taking behaviours. Many respondents shared how they were aware of their physical capabilities. For these reasons, they avoided risky environments which may increase the risk of getting bleeds. The literature showed how impairments including arthropathy, reduced range of motion, and chronic pain are strongly linked. Such impairments result in disability which lead to barriers to engaging in daily activities and social participation. Overcoming these barriers extend beyond the medical management of haemophilia. It requires supportive environments that are responsive to physical challenges and promote ageing individuals to remain socially engaged. This includes integrated care models that connects Haemophilia Treatment Centres with physiotherapy, better screening for haemophilia-related health issues, and mental health support. Some respondents reported how flexible employment arrangements allowed them to remain in the workforce. These supportive environments allow the respondents to maintain independence, remain socially engaged, which can improve their quality of life.

Respondents offered examples of enablers to better manage their bleeding disorder. Common facilitators included adherence to prophylactic treatment, in addition to household modifications, relocating to bungalows, employment arrangements suitable to haemophilia-related issues, having support networks, and successful surgical outcomes. Interestingly, in another study, it found that marriage was a protective factor in managing haemophilia. In this study, fourteen of the respondents were married. Other sources of support such as the IHS, the National Coagulation Centre at St. James's Hospital and hired help were vital in managing their haemophilia. Orthopaedic surgeries such as joint replacements and joint fusions were important for long-term haemophilia management. These surgical interventions improve mobility, range of motion, and the ability to perform daily tasks which promoted quality of life. Environments which fail to adapt to individual's physical requirements create barriers that can limit equitable participation in daily living and social engagement.

Ageing with haemophilia is not solely about living with a chronic physical condition but also having an ongoing psychological strain. Reflecting on the substandard haemophilia treatments in the past, the respondents' experienced complex emotions that the general population does not encounter. Many respondents, nonetheless, expressed the importance of maintaining a positive outlook on life. When reading the responses, what moved me was their inspiring resilience. Many respondents came to accept their haemophilia, with some accepting it early and others developing acceptance later in life.

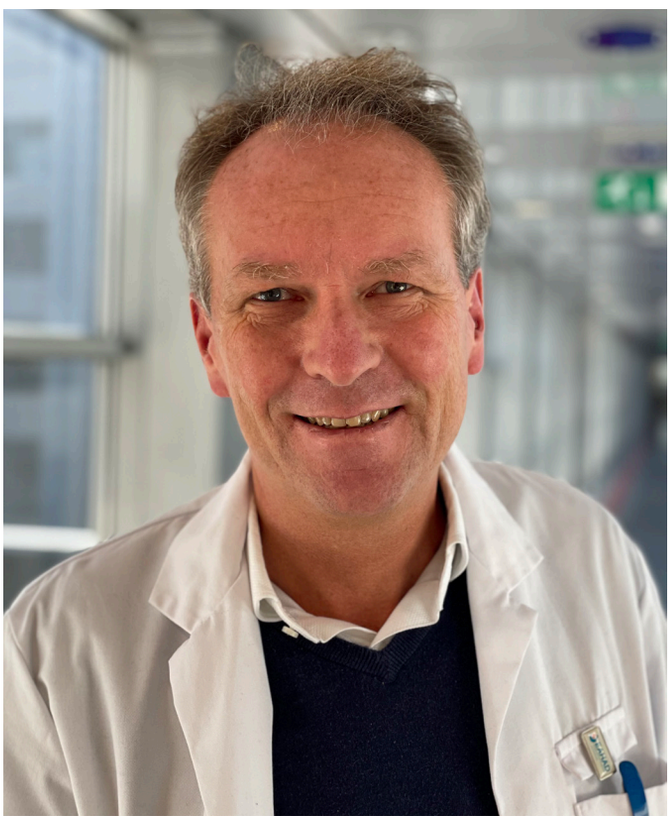
This dissertation is among the earliest mixed methods studies that explored the lived experiences of ageing with severe haemophilia in Ireland. The respondents' insights show the complex barriers and facilitators that ageing with severe haemophilia encompasses. It highlights the requirements for equitable, person-centred, comprehensive, and multidisciplinary care in accordance with Sláintecare frameworks and the World Federation of Hemophilia guidelines. I hope that future research continues to explore the experiences of individuals living with haemophilia and other related bleeding disorders, so that with appropriate supports and improved integrated care, it can enable them to live fulfilling lives across their lifespan.

I wish to express my appreciation to the IHS for their support and providing access to ageing adults with severe haemophilia, without which this study would not have been possible. I wish to extend my appreciation to the respondents who generously gave their time to candidly share their lived experiences. Their valuable contributions enriched the study's findings. This research is dedicated to the memory of those individuals whose lives were tragically taken too soon.

Session on ageing well with a bleeding disorder at our last Ageing Conference

Interview with Cedric Hermans

Professor Cedric Hermans is the head of the Division of Haematology, the Hemostasis and Thrombosis Unit and the Hemophilia Center of the Saint-Luc University Hospital in Brussels, Belgium. He was President of the European Association of Haemophilia & Allied Disorders (EAHAD) and is currently a member of the Board of Directors of the World Federation of Haemophilia (WFH) and the Editor-in-Chief of the journal 'Haemophilia'.



Can you tell us about your role as Editor-In-Chief of the journal 'Haemophilia'?

I've been doing this for a couple of years now. It's a very interesting job because we receive many submissions from all over the world. My role is to organise the peer review process. We receive numerous manuscripts, but they must be evaluated by experts.

My main task is to assign each paper to several experts, who read the manuscript carefully and provide comments. I then collect this feedback and make a decision on whether the paper should be accepted for publication or rejected. It's quite demanding, especially because the process is continuous and never really stops.

While I hold the title of editor-in-chief, the journal would not exist without close collaboration with authors and the many experts who generously agree to review manuscripts. The reviewers do not work for the journal; they contribute purely on a voluntary basis. When a paper addresses a specific treatment or complication, I identify experts - often across Europe or globally - who have clear expertise in that area. They assess originality, scientific quality, relevance, and impact. Their generosity is essential to the system.

What I really enjoy about this role is the level of interaction at a global scale. I work with people who contribute to haemophilia care in many different ways. Submissions come not only from physicians, but also from nurses, psychologists, physiotherapists, and experts in pharmacoeconomics. Doing this job requires a holistic interest in haemophilia, and I genuinely enjoy it. I've learned a great deal over the years.

It is also a major responsibility, because as editor-in-chief you decide whether submitted data are scientifically valid and whether they truly contribute to advancing the field. Haemophilia is a unique journal because it focuses almost entirely on inherited bleeding disorders, which is quite unusual in medicine. At the same time, the environment is competitive. The science of haemophilia is evolving rapidly, and many haematology journals are increasingly interested in attracting this type of research.

I've recently been invited to renew my contract with the publisher, which I am pleased to accept. The journal is now the official journal not only of the World Federation of Hemophilia (WFH) but also of EAHAD, which reinforces its role as our scientific voice.

You are also the director of the haemophilia treatment centre in Brussels. Can you tell us about this role?

My primary occupation is as a medical doctor with a strong focus on blood coagulation. I care for many patients with haemophilia, von Willebrand disease, and other bleeding disorders, as well as patients with thrombosis. I run clinics almost every day. My main scientific interest, however, is haemophilia and bleeding disorders, and this is where I invest most of

my time in research, education, and advocacy.

I trained in London in 1999 at the Haemophilia treatment Center of the Royal Free Hospital under Professor Christine Lee, which strongly influenced my approach to care. When I returned to Belgium, I worked to establish multidisciplinary care. While funding is more limited than in the UK, I've built a team that includes younger physicians, an excellent physiotherapist with a PhD dedicated to haemophilia, specialised nurses, and close collaboration with laboratory specialists, surgeons, liver specialists, and infectious disease experts.

We don't have a psychologist or social worker fully dedicated to haemophilia, but when patients need this type of support, we can identify appropriate professionals. Over the past 25 years, I've worked to make this team efficient, and the fact that over 300 of the approximately 1,000 haemophilia patients in Belgium are registered at our centre reflects the quality of care we provide.

At our centre, we care for both children and adults. Brussels is very diverse, and we see patients from all over the world, including individuals from Africa, Asia, and Eastern Europe who have had limited access to care. Belgium's healthcare system allows us, in many cases, to provide advanced treatments, including prophylaxis, to these patients. In fact, over the past decade, we've seen more new patients coming from outside Belgium than newborns diagnosed locally.

You are also on the board of the World Federation of Hemophilia. Please tell us about this position.

Well, I've been involved in several organisations over many years, including EAHAD, where I served as board member and president. I'm currently a board member of the WFH. This role is very important to me because it highlights the disparities in haemophilia care worldwide. I invest significant time in supporting WFH initiatives, particularly in low income countries, and I've been involved in training programmes in Africa.

This global interaction is essential. It allows us to appreciate the quality of care available in Europe while understanding the challenges elsewhere. I also work closely with the European Haemophilia Consortium (EHC) and benefit from being based in Brussels, near both EAHAD and EHC offices. Collaboration with these organisations adds a new dimension to medical practice.

What are your views on new therapies such as mimetics, rebalancing agents, and gene therapy?

These innovations are extremely important. Prophylaxis has significantly improved outcomes, but we are still far from providing a completely normal life for all patients. Gene therapy shows promise, particularly for haemophilia B, while results in haemophilia A have been more modest. Bispecific antibodies and next generation agents are very encouraging.

Rebalancing agents act differently by modifying the coagulation balance. They may be valuable for selected patients but must be used cautiously, with careful assessment of safety and efficacy. They are unlikely to become first line treatments, but they will play a role.

Gene therapy remains restrictive, with eligibility limitations related to age, liver health, prior inhibitors, and comorbidities. At present, it is limited to adults. While still in its infancy, advances such as gene editing and cell based therapies are exciting. The reinvestment of resources into innovation has created a positive cycle, and maintaining this momentum is critical.

The ultimate goal is not only physical freedom from disease, but also mental liberation, allowing patients to live normal lives. Innovation brings us closer to this goal, though it will not apply uniformly to all patients.

What about the future of other inherited bleeding disorders?

Haemophilia A and B are currently in a favourable position, but much work remains for other disorders. I am optimistic about advances in von Willebrand disease and rare conditions such as Glanzmann Thrombasthenia. New technologies - including antibodies, nanobodies, and aptamers - are opening promising avenues.

Blood coagulation is complex, involving many factors, and achieving equity across all disorders is challenging. Nevertheless, progress in haemophilia is likely to have positive spillover effects for other bleeding diseases. While the path may be longer and more complex for some conditions, the field continues to move forward, and there is good reason for cautious optimism.

We are very grateful to Prof. Hermans for taking part in this fascinating interview. Thank you!

Rob's Top 10 Tips For Travelling With A Bleeding Disorder

Spring is in the air, and for many of us, it's time to shake off the winter blues and explore the world. Whether it's a short break in Europe or a more ambitious adventure, traveling with haemophilia or a related bleeding disorder takes preparation and confidence. Thankfully, with some planning and the right support, the world is yours to explore safely.

Plan Ahead

Contact the Irish Haemophilia Society early for personalised advice. Book appointments with your haematologist to discuss your travel plans. Identify Haemophilia Treatment Centres (HTCs) at your destination using tools like the WFH Finder.

Insurance is Non-Negotiable

Make sure your travel insurance covers pre-existing conditions, including haemophilia. Get written confirmation from your insurer to avoid surprises.

Documents at the Ready

Carry a travel letter from your doctor detailing your condition, treatment, and emergency contacts. Apply for an EHIC card for travel within the EU and supplement it with private insurance for full coverage.

Pack Smart

Bring more treatment supplies than you think you'll need. For longer trips, plan for restocking options at local HTCs. Use insulated bags or portable coolers if temperature-sensitive storage is required.

Customs Made Easy

Inform airlines and customs about your medical supplies in advance. Translate your travel letter into the language of your destination if applicable.

Stay Connected

Register your trip with the Department of Foreign Affairs for additional support. Save the contact information for HTCs, local emergency numbers, and your insurance provider.

Be Mindful of Emergencies

Know the nearest HTC's location and have their contact details ready. Inform your insurance provider immediately if a medical emergency arises.

Research Healthcare Systems

Understand what's covered in your destination country, especially for routine treatments. Countries like the USA and Canada require extra insurance and planning due to high treatment costs.

Always Be Prepared

Check travel advisories and health alerts at your destination. Don't forget basic travel necessities like comfortable shoes, snacks, and entertainment!

Noticeboard

Save the Date for our October Conference

Our 2026 October Members' Conference is taking place in Mount Wolseley Hotel in Co. Carlow from October 16th - 18th.

We are delighted to offer an array of sessions on topics that members themselves have highlighted as being important to discuss, such as orthopaedic treatment and mental health. We will also have a debate, a session on sexual health and intimacy and a lookback of the history of the Society over the years.

We will also have a fun and engaging children's programme to keep the little (and not so little) ones entertained over the weekend!

Fundraising for the IHS

In January, Michelle McKeown and her family very kindly raised money for the Irish Haemophilia Society through an annual tractor run. This fun event, in which locals of Ballyhea, Cork and the surrounding areas, come together to drive their tractors and raise money for various good causes.

Michelle McKeown and her family donated €1,000 from this event to the Society. Thank you so much to everyone involved!

If you woud like to fundraise for the Irish Haemophilia Society, please contact Lena Byrne on lena@haemophilia.ie.

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: