

# Haemophilia.ie

Magazine of the Irish Haemophilia Society

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



SCAN ME

Spring 2025 Edition

# From the Editor

Roisin Burbridge, Publications, Website & Social Media Coordinator



Hello everyone! The days are finally getting longer and warmer. Roll on summer! This edition of our quarterly magazine is packed to the brim with very interesting content from both members and staff of the IHS!

In Brian’s CEO Report, he gives a brief recap of our recent AGM and Conference, which was a great success. He also discusses treatment updates and the news about families with haemophilia who have come to Ireland from Gaza.

Next, our newest member of staff, Administrative Assistant Lena Byrne, provides a thorough report of the AGM, accompanied by lots of fantastic photos of the conference taken by our wonderful photographer Joseph Carr. We have dedicated a spread of the magazine to the award ceremony we held at the Saturday night dinner of our AGM. The inaugural volunteer recognition award ceremony was a great addition to our yearly ceremony.

Following this, John O’Mahony chronicles the amazing

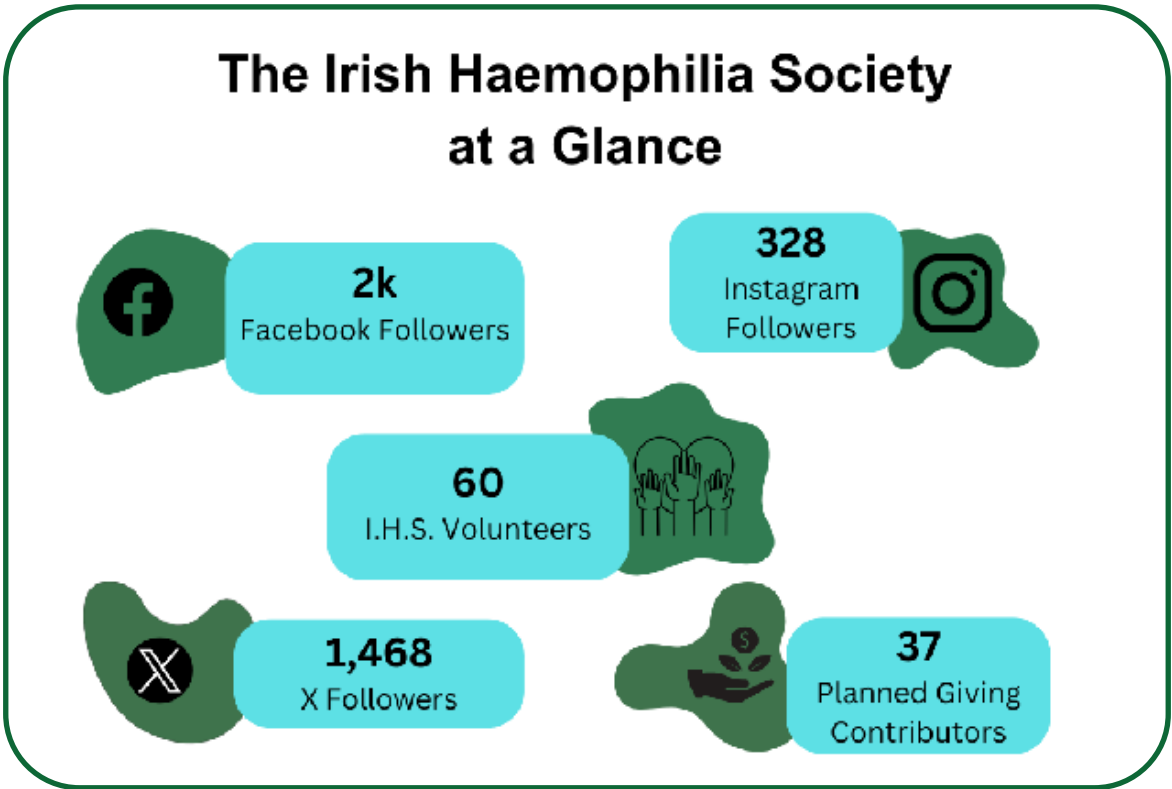
sporting achievements of IHS member Mike Murphy, who recently received the Lifetime Achievement Award at his GAA club in Kerry.

Nikki and Cian O’Sullivan from Cork have provided us with a piece about their lives with their two children who have Glanzmann Thrombasthania. This is an extremely rare bleeding disorder, where current treatment options are severely limited. This is a very eye-opening yet heartwarming article.

Next, we hear from member Abdulhakim Nazir, who is studying a masters in physics at the moment and who received an educational grant from us in 2024. Our last member piece is from Claire Sheeran, who raised a fantastic €1,688.05 for the IHS at a carol service in December.

Alongside these articles, we have also included the preliminary programme for our upcoming Ageing Conference in June, top travel tips from our Outreach Coordinator Rob Flanagan, and some news and updates in the noticeboard at the back of the magazine.

We hope you enjoy reading!





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# CEO Report

*By Brian O'Mahony, IHS Chief Executive*

## AGM & Conference



The Annual General Meeting (AGM) and Conference took place in Galway on March 7th and 8th. The conference was very successful with 250 delegates in attendance. A varied programme included an update on current haemophilia therapies by Dr. Michelle Lavin, an update on current treatments for von Willebrand disorder (VWD) and rare bleeding disorders (RBDs) by Dr. Beatrice Nolan and an update on future therapies from Professor Mike Makris.

The treatment landscape for haemophilia has even evolved over the last year, with the availability of the new enhanced extended half-life factor VIII (FVIII) Altuvoco and the licensing of the re-balancing agents Concizumab (Alhemo) and Marstacimab (Hyvampi). Altuvoco is now being rolled out for FVIII prophylaxis for those previously on extended half-life FVIII. This will provide more protection and significantly higher trough levels for longer than the previous treatment. The increase in the number of therapeutic options for haemophilia and the probable future availability of other options such as gene therapy make this a more complex environment. In future people with haemophilia will need to engage more in a shared decision-making process with their clinicians in order to look at the best treatment option for them going forward. We are moving away from a time when there was one standard treatment and treatment dose for everybody, when you would have discussions about what you could do with your life given this reality. We are instead moving to a point where a discussion should start with your life goals, ambitions and challenges and what treatment would best suit you in terms of meeting these goals and challenges.

The Conference also included an update on the audits of the comprehensive care centres at the National Coagulation Centre (NCC) and Children's Hospital Ireland (CHI) at Crumlin delivered by Professor Niamh O'Connell and Dr. Beatrice Nolan. The audits, which also included the Coagulation Centre at Cork University Hospital, were carried out late last year by an external team. This audit process is carried out approximately every four years by an expert team from abroad, and includes a patient representative. It is a very useful process which can identify gaps in services and help identify resources required, which can often be more apparent to an external team or will have more credibility with the health service if also pointed out by an external team as part of a formal process.

On the Sunday we had an update on clinical trials from research nurse Margaret Nolan, an update on dental care by Dr. Alison Dougall and a discussion

on shared care between two treatment centres by Dr. Ruth Gilmore and nurse specialist Amy Mullins from Galway University Hospital, where they discussed the organisation of care in Galway in collaboration with either the NCC at St. James's or CHI at Crumlin. During the day on Saturday we also live streamed the Ireland - France rugby match, the result of which was probably the only low point of the weekend.

## Award Ceremony

We held an award ceremony at the gala dinner on Saturday evening in which we gave out our 2024 awards. We presented Dr. Michelle Lavin with the Brian O'Mahony Award for Outstanding Contribution to Haemophilia, because of her outstanding contribution to haemophilia care in Ireland since 2011 and her particular expertise on VWD and on women and girls with bleeding disorders. The Bill O'Sullivan Fundraiser of the Year Award, Dr. Barry Harrington Award for Dentistry and the Gerry O'Reilly Courage Award were also awarded. The educational grant recipients also received their certificates. A particular pleasure this year was the initiation of a volunteer award ceremony where we recognised those who had completed volunteering at 10, 20 or 30 conferences. In total we had 24 volunteers who had volunteered at 10 events, five who had volunteered at 20 events and three who had volunteered at 30 events. These are great achievements and markers of commitment given that there are only two events each year that require volunteers, signifying up to 15 years of commitment from the volunteers. This was a very special moment for the Society and for the volunteers and we look forward to distributing these awards every year.

This was the largest attendance at any of our conferences since our 50th anniversary AGM and Conference in 2018. The event was booked out well in advance with a resulting waiting list, most of whom we were able to accommodate. Our events have now become so popular that we are looking at finding venues or hotels with increased capacity. This is not an easy task given our requirements for rooms for each of the groups, family rooms, leisure centre facilities for activities and parallel meeting rooms, but we will be working toward increasing capacity for future conferences. This will also require increased staff resources, more volunteers and more financing.

## Strategic Plan

At the AGM, we also launched our new Strategic Plan for 2025 to 2028. This lays out our planned schedule of events for the next four years. It details our planned activities and initiatives on publications and digital media, advocacy and external influence, therapeutic environment, haemophilia A and B, VWD, RBDs, women and girls with bleeding disorders, ageing, mental health, children's activities and international developments.



It sets out our objectives for board, staff, succession planning, volunteers, finance, outreach and initiatives on lifestyle and future proofing. The plan is available to view or download from our website, under resources - publications - other publications. Members can also request a hard copy from the office.

### Families from Gaza

Members may have seen reports in the media in December last on the arrival of eight children from Gaza who were brought here with medical conditions. Six of the eight children have haemophilia. They are all now under the care of the haemophilia team at CHI at Crumlin. We have already met with some of the families and we will be assisting them in any way possible on an ongoing basis.

### Treatment Updates

Recently, a number of therapies in clinical trials or licensed therapies for haemophilia have been discontinued. The rebalancing agent, Serpin PC from

the company Centessa, which looked promising in early clinical trials, has discontinued development. The second licensed factor IX (FIX) gene therapy, Beqvez from Pfizer, which was licensed by the EMA had also stopped development and will no longer be available. The first licensed FVIII gene therapy, Roctavian, from Biomarin, will for the foreseeable future be marketed only in the US, Italy and Germany. Another FVIII gene therapy jointly being developed by Roche and Spark Therapeutics has been paused for the moment while apparently, they consider changes to the FVIII variant being used. None of these were discontinued due to any specific safety event or concern. These were purely commercial decisions taken by the companies probably in light of the licensing of other competitive products in the case of rebalancing agents, poor uptake or sales in the case of FVIII gene therapy and competition from the other licensed FIX gene therapy. With so much innovation in haemophilia it was always inevitable that not all the products under development would come to the market and as we see, not even continue development or marketing post licensing in all cases.



*Pictured: Professor Niamh O'Connell & Dr. Beatrice Nolan speaking at our AGM & Conference*



*Pictured: Some of our hardworking volunteers at the weekend*



# Report on the AGM & Conference

*By Lena Byrne, Administrative Assistant*

The 36th IHS Annual General Meeting (AGM) took place on a beautiful sunny weekend in the Galway Bay Hotel. It was our first time hosting a conference in this hotel, and it was very well attended by our members, with the largest attendance we've had since 2018. With a great selection of speakers and topics, as well as the idyllic location, it's safe to say it was an enjoyable weekend for all.

The AGM was opened on Saturday morning by the IHS Chairperson John Stack. We progressed through the agenda very swiftly. There were four official nominations for new board members, and five of the current board members were standing for re-election. The membership agreed by a show of hands that there would be no election and those nominated would be deemed elected to the board for 2025, making a new board of nine members. At the end of the meeting when all board members were present, we gave a round of applause to welcome the four new members: Brian Byrne, Shannon Carey, Molly O'Mahony and Cian O'Sullivan.

Following the AGM, we had a short presentation from our CEO, Brian O'Mahony, on the strategic plan for 2025 – 2028, outlining in further detail our goals for the next four years and how we intend to achieve them. There were some suggested actions from the membership during this presentation which Brian took on board to

help us achieve our goals for the benefit of all of our members.

Across the weekend, we had great attendance from our members at all talks. Everyone seemed to enjoy the conference and learn from all the sessions that we had. We had two sessions at 11:30am on Saturday. Dr. Michelle Lavin gave a talk on current treatment options for haemophilia in the Lettermore Suite, while Dr. Beatrice Nolan gave a talk in the smaller Inisheer Suite on current treatment options for von Willebrand disorder (VWD) and rare bleeding disorders (RBDs).

Dr. Lavin discussed the wide variety of treatment options now available for haemophilia, and how quickly the options have expanded in the last 10-20 years. She discussed Altuvoco, as well as the clinical trial results for Hemlibra and who will benefit the most from their use. Dr. Lavin also discussed the licensed gene therapies Hemgenix and Roctavian. She also discussed the shared decision-making tool and how important it is to take time to research before making a decision on treatment. There were some questions at the end about VWD and women and girls and Dr. Lavin pointed out that women are generally excluded from these drug trials.

Meanwhile in the Inisheer Suite, Dr. Nolan had a group of 20 to hear her presentation, which ended with a lengthy Q&A session.





After a quick lunch in the restaurant, everyone headed back to the Lettermore Suite to listen to Professor Mike Makris's presentation on future therapies for all bleeding disorders. I personally found this presentation to be very interesting and the information was very understandable in the way it was presented. Professor Makris highlighted the importance of shared decision-making. He reminded everyone that it is important to get information from various sources before making your decision on treatment. Nowadays, people with bleeding disorders, particularly haemophilia, have a wide variety of treatment options available to them, so it is no longer just about taking the treatment that is available. There is now the possibility for personalisation and discovering the treatment that allows you to live your life to the fullest potential. Professor Makris encouraged the attendees to look at real life stories as well as the statistics from drug trials, as participants in the trials are carefully selected and won't always reflect how the treatment works in real life situations. Towards the end of the presentation, Professor Makris presented some information on intranasal desmopressin and various potential novel therapies that are in the early stages of development for VWD.

After a disappointing result in the rugby match that we broadcasted in the Lettermore Suite, we had the final session of the day, an update on the comprehensive

care centre audits, presented by Professor Niamh O'Connell.

Everyone reconvened in the Lettermore Suite for the awards ceremony and Gala Dinner at 7.15pm. With the room full to capacity and a lovely atmosphere, a great evening was had by all.

On Sunday morning we had an update on clinical trials from Margaret Nolan, followed by a talk on dental care. Ms. Nolan discussed the purpose and process of clinical trials and how they can benefit people when trying to decide between treatment options. The dental care session had been much anticipated, so there were high numbers in attendance as expected. Dr. Alison Dougall gave a great talk about the importance of oral hygiene and staying on top of dental care to give you one less thing to worry about when you have a bleeding disorder to manage. Dr. Ruth Gilmore concluded the weekend with a talk on shared care between treatment centres.

On behalf of the IHS staff, I would like to thank all of those who attended our AGM and Conference this year, including board members, guests and speakers. We look forward to seeing you again soon.





## Photos from our A



### Pictured:

- **Top left** - Dr. Michelle Lavin receiving the Brian O'Mahony Award for Outstanding Contribution to Haemophilia & Bleeding Disorders in Ireland.
- **Middle left** - Amy Dunne, Shannon Doyle & Aislinn Farrelly receiving the volunteer recognition award for having worked at 20 conferences.
- **Bottom left** - Sam Morrissey, Sarah Charnock & Paul Dunne receiving the volunteer recognition award for having worked at 30 conferences.
- **Top right** - Dr. Amelia Conlon Batey receiving the Dr. Barry Harrington Dental Award.
- **Bottom right** - Alex & Elayna O'Sullivan receiving the Gerry O'Reilly Courage Award.





# AGM & Conference

## Pictured:

- **Top left** - Abdulhakim Nazir receiving the Michael Davenport Educational Grant.
- **Bottom left** - Jessica Byrne receiving the Margaret King Educational Grant.
- **Top right** - Gabriel O'Connor receiving the Maureen & Jack Downey Educational Grant.
- **Middle right** - Emma Neary, Sandra Neary & Norma Jean Kelly receiving the Bill O'Sullivan Fundraiser of the Year Award.
- **Bottom right** - Jake Phoenix receiving the Father Paddy McGrath Educational Grant.







# Not Even Haemophilia Can Stop Kerry men From Playing Football

*By John O'Mahony, on the remarkable sporting achievements of IHS member Mike Murphy*

In Kerry, where Gaelic football is considered a religion and, perhaps at this stage, afforded even more reverence than the traditional methods of worship, it's not very often that lifetime recognition awards are bandied about for achievements on the field of play. The legendary Mick O'Connell has received one. So too have Jack O'Shea, Pat Spillane and Colm Cooper. And it's only a matter of time, one presumes, before a young man by the name of David Clifford sees his name up in lights in the GAA hall of fame.

At a more domestic level, clubs throughout the Kingdom have also been known to honour their great achievers and the latest to be presented with a coveted lifetime achievement accolade is none other than Mike Murphy from Killarney who will be very well known to Irish Haemophilia Society members.

Mike was honoured with the premier award by Killarney Legion GAA Club, a leading force in Kerry since 1929, which has numbered in its ranks GAA legends like the Lyne and Murphy brothers, Johnny Culloty, Weeshie Fogarty and, in more recent years, Kerry goalkeepers Peter O'Leary and Brian Kelly and 2014 footballer of the year James O'Donoghue.

But when one thumbs through the pages of the club's history, the name Mike Murphy is hugely prominent, particularly during the 1970s and '80s.

A powerful, athletic midfielder, sufficiently versatile to play a role at full back or full forward if required, Mike was one of the standout players in the game in Kerry for several years, with a big reputation for his magnificent fielding ability and versatility.

Over 30 years on, it remains the general consensus in local football circles that the Legion man would have been a valuable addition to the so called Golden Years squad, assembled by Mick O'Dwyer, that won eight All-Ireland titles in a glorious 11-year period.

The fact is that Mike had been invited on to the county panel on a number of occasions during that time but an all-too-familiar obstacle came in the way – injuries. Knocks and bumps, damaged muscles, severe bruising, sprains and aches were something Mike had to contend with as he rose through the ranks in the underage structure but he was determined to just get on with it. When he lined out with St Brendan's College in Killarney – a famed GAA nursery – in the All-Ireland Colleges'



Championship in 1977, he had to get three painkilling injections from his GP to allow him to play his part in a campaign that ended with a single-point defeat at the semi-final stage.

Injuries took their toll too when Mike was called into the Kerry minor team for that year's championship with team manager, Kerry legend Tom Prendergast, recognising the qualities the Legion clubman could bring.

"I had a lot of injuries, nothing too serious, but they were always niggles, mainly muscle problems," Mike reflected.

When his GP referred him further to assess what might have been at the root of his problems, Mike, then aged 20, was astonished to learn that he had been living with Haemophilia A for two decades.

It was mild – but it was a significant bleeding condition nevertheless and not the type of condition best suited for a young lad entering into direct combat with veteran footballers, at the tail-end of their playing days, anxious to prove one last point to the ambitious midfielder-in-waiting almost half their age.

"The diagnosis explained a lot. It confirmed the reason why I had been sustaining so many injuries over the years," Mike said.

Ignoring medical advice that it might be wiser to hang up his boots – a difficult ask for a talented 20-year-old to comprehend – Mike continued to play on and, memorably, he was one of the star performers on the Killarney team – the pick of the crop from an amalgamation of the Legion and Dr Crokes clubs – that won three Kerry Under 21 Championship titles in a row.

A psychiatric nurse by profession, Mike played on and played well with the Killarney Legion senior team for several years, occasionally being called into training



with the Kerry squad for league games but injuries and knocks always came in the way.

Eventually, at the age of 27, when he should have been entering his prime playing days, he was forced to call it quits.

But observers of Kerry football down through the years know and appreciate the wonderful contribution made by Mike Murphy and it was indeed fitting that his beloved club acknowledged that wholehearted commitment when honouring him with the 2025 Lifetime Achievement Award at a gala function at the end of January.

Over 230 club members leapt to their feet to afford the great stalwart a deserved standing ovation and he will feature in the sporting annals as one of the most dedicated and accomplished players to pull the famous green and white Legion jersey over his head.

Mike Murphy made his mark on the game he loved – and he defied the odds in doing so.

Haemophilia, and any other obstacle life can put in the way, will never separate a Kerryman from his football.





# Living with Glanzmann Thrombasthenia: The O'Sullivan From Cork

*By the O'Sullivan family*

*Glanzmann thrombasthenia (GT) is a very rare bleeding disorder condition that causes easy bleeding and bruising. It affects the ability of the platelets to gather around the site of a broken blood vessel. Symptoms of GT include bruising easily, frequent nosebleeds (epistaxis), bleeding gums and heavy menstrual bleeding.*

*The O'Sullivan family have kindly provided us with insight into their lives with this bleeding disorder, which we have included below.*



We are the O'Sullivan family from Cork. We are parents to Elayna (8) and Alex (5). Elayna and Alex were both born with an extremely rare bleeding disorder called Glanzmann Thrombasthenia (GT). GT for those that don't know, is a clotting disorder where the affected person's platelets do not function as expected to form a clot.

Elayna was born on the 2nd of June 2016 in Cork University Hospital (CUH) Cork. Elayna had an injection to her scalp to check oxygen levels during labour, which bled for a prolonged period of time. This was slightly alarming as it was not normal. She soaked through multiple hats, which did cause concern. Additionally, Elayna started to form random black and blue bruising all over her body a short period of time after her arrival, which heightened awareness to the fact that something wasn't quite right. Emotions were now getting the better of myself and Nikki as our minds went into overdrive. To cut to the chase, after a four month period of daily/weekly/monthly back and forth drop ins to CUH & Crumlin, clinics and phone calls with our consultants Dr. Clodagh Ryan (CUH) and Dr. Beatrice Nolan and a bad flare up of a rare skin condition, a diagnosis for Elayna's condition became apparent. We were overwhelmed, especially because of the lack of knowledge of the disorder and the lack of treatment for it. Our consultants have been fantastic and together we have developed a plan for each scenario that has presented with Elayna. Elayna suffers from nose bleeds but nowadays more so from mouth bleeds and these tend to go on continuously for up to three weeks.

Alex was born in CUH in October 2019. He was diagnosed after one month. He was bruised very like Elayna at birth. I am not saying Elayna's bleeding disorder is straightforward, but it is manageable for now compared to Alex's. Alex suffers massively with his nose – he has random spontaneous uncontrollable nosebleeds. Quite scary to be perfectly honest. Alex

has needed to get a port-a-cath for intravenous administration of Novo-Seven which he is currently on daily. For those of you not familiar with ports – they are a fantastic option for home treatment when they work but do come with some cons. People who have ports are more prone to infections – port site and blood infections. Alex is now on his third port-a-cath. This has led to numerous lengthy hospital stays which have been extremely disturbing and disruptive for him and the family. This daily administration is not a recommendation for the treatment of GT but as there is no other prophylactic treatment, we felt like we had to be doing something to try and keep bleeds at bay. When Alex gets nose bleeds, he needs to get his nose packed with a nasal packing. It proved extremely difficult for us to get our hands on this for home use as an emergency stop gap and without the help of the IHS this may still not have readily available. Alex's current treatment plan for excessive nose bleeds is to be admitted to hospital and get Human Leukocyte Antigen (HLA) matched platelet transfusions and red blood transfusions. Alex also needs to attend day clinic quite regularly for iron infusions because his concurrent blood loss leaves his levels quite low.

Apart from bleeding, there are other recognisable symptoms of Elayna and Alex's bleeding disorder which have led to a kind of social stigma that myself and Nikki are neglectful parents. This is because the kids present with significant bruising from the most innocuous of knocks which the kids themselves might not even remember happening but which can look quite sore and dramatic to others. You feel the eyes glaring while out in public and that makes you feel somewhat insecure as a parent. The kids are such happy and loving children and are so innocent, but you feel a little on edge when you feel you are being judged. This is an element we struggle with but which has gotten better over time.



This is where the IHS has played a huge part in helping to create a safe space for us to connect with people in similar situations and to allow us to find a common ground with people. The support we have received from Brian in the last number of years has been phenomenal – checking in with us and advocating for our needs. His support has been a game changer for us. The overall community in the IHS has such a feel good factor and the empowerment you feel and the energy to fight for the future is infectious at the events. Everyone has the same goal – to improve patient care and advocate for investment in haemophilia and specifically in the rarer bleeding disorders. I sincerely believe the change that the IHS made recently in adding specific talks on menstrual bleeding and focus sessions for the rarer bleeding disorders has opened the door for undiagnosed patients to come forward. There is an outreach programme to try and connect with people that are living their lives in an undiagnosed state and we need to reach these people so that the IHS can have an equal impact on others, in the same way it has had on us. Elayna and Alex absolutely love these weekends away with the IHS because they meet other children who share similarities to them and it creates a different type of bond that is magical to observe.

On a final note, we were approached to attend the European Rare and Inhibitor Network (ERIN) summit in Croatia. We were originally apprehensive about the event but after a brief conversation with Brian about the expected benefits for us a family we decided to go. I cannot emphasise enough the impact that the weekend had on us as a family. The kids were entertained from the minute we arrived to the minute we left. There were some really special people with such touching stories. We met people from all over Europe with differing stories and it really painted a picture about how advanced Ireland is in the treatment of haemophilia. We also had the opportunity to meet individuals with GT from Spain and Sweden, which was great to learn about their experiences and their personal struggles.

I want to emphasise the importance of the IHS and the benefits it can offer long-term members and also potential newly diagnosed members and to ensure we as community members continue to do our bit to support each other and to lean on each other to ensure we have an outlet as a support mechanism.

Thank you.





# My Experience Receiving an IHS Educational Grant

*By IHS member, Abdulhakim Nazir*

From a young age, I have always been interested in science and mathematics, with a particular attraction to nuclear physics. Having received the Entrance Scholar Award, I graduated from University College Dublin (UCD) with a First-Class Honours in Physics. My specialisation was in experimental physics and I received research studentships as an undergraduate in theoretical physics, namely in the fields of condensed matter physics, quantum field theory and statistical biophysics. Institutions included the School of Theoretical Physics at the Dublin Institute for Advanced Studies (DIAS), where the research involved the study of exotic Dirac-like fermions with a final paper and presentation delivered. My final year research thesis was in the field of optical physics with the UCD Plasmonics and Ultrafast NanoOptics research group, involving the experimental work of a novel adaptable lens technology. In my final year, I was offered a summer research studentship from the module 'Advanced Statistical Physics' at the UCD School of Physics, involving the statistical analysis of Streptococcus bacterial trajectories based on microscopy images of the Imaris particle tracking software, in collaboration with researchers from the UCD Conway Institute and the School of Biomolecular and Biomedical Science.

Currently, my main interests lie in the fields of nuclear physics and ionizing radiation dose calculations, Monte Carlo computational physics i.e. application of EGSnrc (Electron Gamma Shower), radiation oncology and radiobiology.

As of now, I am undertaking a CAMPEP-accredited M.Sc. in Medical Physics at UCD, which focuses on the application of physics to the diagnosis and treatment of human disease, such as diagnostic imaging physics, nuclear medicine, radiation oncology physics etc. My M.Sc. research thesis is in the area of computational physics, involving the development and validation of Kilovoltage Monte Carlo code of 3D irradiation dose distributions for the treatment planning system of superficial cancer patients at St. Luke's. During the M.Sc., I submitted an IRC application to undertake a Ph.D. at the UCD School of Physics in the field of nanomedicine, focusing on the machine learning of molecular dynamics. Upon completion of the M.Sc., an alternative pathway is to become a radiation



oncology physicist such as at a residency programme at St. Luke's Radiation Oncology Network. Through that pathway, I also aim to pursue a Ph.D. in radiation oncology to further become an expert physicist in that medical field and contribute to the clinical improvement of patient care and treatment.

As a young adult member of the Irish Haemophilia Society with haemophilia, I was fully aware of the educational grants that were being offered to students. For me, this academic year would benefit the most from receiving a grant compared to previous years since I had just started my M.Sc. in Medical Physics right after graduation, which proved significantly more expensive. Due to this, I decided to make an application for an educational grant. It was a pleasant experience to fill out since the application process itself was very straightforward and offered immense freedom to express my interests and personality through an essay style format. As I was filling out the application, I reflected numerous times on my involvement with the IHS, hoping to contribute more as a member of the Society. Having received such an award, I was delighted that more avenues could be open for engagement with other IHS members.

The Michael Davenport Grant has proved indispensable in supporting my graduate studies. The grant will be used to contribute towards funding my M.Sc. in Medical Physics, significantly alleviating additional financial stress. I was overjoyed to receive news of being offered the grant from the IHS committee and am forever truly grateful to the Society for the distinguished award.





# 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!



# Claire Sheeran's Haemophilia Journey: Family, Resilience, and Giving Back

*By IHS member, Claire Sheeran*

To start at the beginning—my dad, Joe Rabbette, had haemophilia. His mother, May Rabbette, was a carrier, and her father, Joe Saunders, also had haemophilia. My dad and mum, Marion, were members of the IHS for decades. Dad had moderate factor VIII deficiency and passed away in 2015. Our family will always be grateful to the IHS, St. James's Hospital, and especially the H&H Ward, where Dad spent four months in early 2015 before coming home for end-of-life care.

In our early 20s, my sister Noreen and I were tested—I'm a carrier, while Noreen has von Willebrand disorder.

When I became pregnant with my first child, I had to connect with St. James's Hospital and the IHS. There was a 50/50 chance of having a boy with haemophilia. A plan was quickly put in place for me to have the child at the Coombe Hospital, Dublin, with regular check-ups and scans. The care I received was second to none. At 20 weeks, I found out I was expecting a boy. We were overjoyed, but equally anxious about what his life might be like.

Joe was born in June 2005 via elective C-section. A haematology team was present, and before the cord was cut, a sample was sent to St. James's. Within the hour, we got confirmation—our little Joe had haemophilia. The care he received was outstanding, from early tests to ongoing support from Dr. Beatrice Nolan and her team, linking us with CHI Crumlin. During his early life, Joe had countless trips to Crumlin Hospital for football injuries and he always received timely and free treatment. When he turned 18, he transitioned to St. James's, where he'll be cared for for the rest of his life.

In 2007, our second son, John, joined our family. Again,

I received exceptional care, and he was delivered by emergency C-section 10 days early. We got his results in recovery—John didn't have haemophilia. To be 100% sure, he was tested for two years.

Fast forward to 2012, and our third son, Joshua, came along. That evening, we received the news that Joshua also had haemophilia. Like Joe, he's had multiple hospital visits for injuries and will transition to St. James's at 16.

As a family living with haemophilia, we couldn't manage without the IHS. Because of the incredible work they do, the continuous research into the best treatments and the information available, our children are able to live a normal life.

During Covid, I returned to work in the civil service after the music industry stalled. I was fortunate to rejoin the Department of Social Protection, working in Carers Allowance. In 2022, my manager, Frank, asked me to join the office choir for a Christmas carol service tied to a charity fundraiser. We repeated it in 2023, and for 2024, I suggested the IHS as our chosen charity.

On the day, we had donation buckets and a Revolut option for remote workers. Everyone gave so generously. Contributions from the Christmas party, a €5 draw, and various donations brought our total to €1,688.05 for the IHS.

Thank you to everyone who donated to this important cause.



Interested in fundraising for us? Contact [nina@haemophilia.ie](mailto:nina@haemophilia.ie)





# Ageing Conference

Date: 27 - 29 June, 2025

Venue: Springfield Hotel, Leixlip, Co. Kildare

## Preliminary Programme

### Friday 27th June

19:00 Dinner

### Saturday 28th June

10:00 - 11:00 The Benefits of Physical Activity  
Speaker: Dr. Megan Kennedy

11:00 - 11:30 Coffee Break

11:30 - 12:30 Benefits & Entitlements  
Speaker: Mr. Brendan Casey

12:30 - 13:00 An Update on the HAA Card  
Speaker: Ms. Ger Kane

13:00 - 14:00 Lunch

14:00 - 15:00 Wills, Probate & Advanced Health Directives  
Speaker: TBC

15:00 - 15:30 Coffee Break

15:30 - 17:00 Ageing Well with a Bleeding Disorder - Panel Discussion

19:00 Dinner

### Sunday 29th June

10:00 - 11:00 Getting the Most From Your GP  
Speaker: Dr. Madeleine Daly

11:00 - 11:30 Coffee Break

11:30 - 13:00 Introduction to Physio & Pilates, Plus class  
Speaker & Facilitator: Mr. Mark McGowan

13:00 Lunch



## Strategic Planning

In early December 2024, the Board and staff of the IHS met to put together a new strategic plan for the years 2025-2028 inclusive. This was the culmination of months of planning and gathering perspectives from the membership and also from the comprehensive care centres.

This is a comprehensive plan which considers strategies to enhance all areas of our work, from events, to publications to youth activities, succession planning and more. The plan includes an event calendar for these years, new ideas encompassing digital media such as the launching of a WhatsApp group which members will be able to join, work to promote rare bleeding disorders, von Willebrand disorder and women and girls with bleeding disorders and much more.

The Strategic Plan for 2025-2028 has been published and is available to view on our website under resources - publications.



## The New Home Treatment App is Up & Running

The new home treatment app mproHealthcare for haemophilia is up and running and available to download from the Apple App store and Google Play store.

The following are the functions of this app that were not available in the previous app:

- **Treatment recording:** New option to record treatments pre and post procedure/surgery
- **Diary function:** Set up reminders and alerts for when your home treatment is due
- **View treatment data:** View your scanned treatment data
- **For Hemlibra patients:** Keep a record of injection site locations used
- **Stock information:** View and manage your home treatment stock
- **Recording a bleed:** Distinguish between new and existing bleeds

The comprehensive care centres want to thank everyone for their patience in awaiting the launch of this new app. They are happy to help with any queries or issues you may encounter.

If you want more information about this, please contact the National Coagulation Centre on (01) 416 2142.



## Raising Money for the IHS Through Fundraising



On Sunday, 24th November 2024, Charleville Golf Club hosted a fundraising raffle in support of the Irish Haemophilia Society. Thanks to the generous efforts of Patricia Walsh, who kindly organised the event, an impressive €500 was raised to aid the Society's vital work. On top of this, Linda Curtain and Margerat Quish, from the above golf club, fundraised from the Ladies Minor Gold Alliance and raised €335 for us.

Con Walsh, working with the Ballyhea Community Council, raised a whopping €1000 for us through their recent tractor run. Thank you to all of these fundraisers for their amazing efforts and support!

## Online Pilates & Physio Classes



Our online pilates and physio classes are well under way after taking a break at Christmas. They are a fantastic way to get fit at home and to have the expert advice of experienced physiotherapists who work at St. James's Hospital.

Our physio class continues to take place every Tuesday evening at 7.30 to 8.30pm. These are run by Mark McGowan, registered physiotherapist in the National Coagulation Centre.

Our pilates classes have started afresh with a new instructor, Emer O'Shea and take place on Wednesday evenings from 7 to 8pm. These classes are at a beginner level so don't be afraid to come along even if you have no experience with pilates!



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