

Haemophilia.ie



Magazine of the Irish Haemophilia Society

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



SCAN ME

Spring 2023 Edition

From the Editor



Hello everyone! We're finally leaving the winter season behind us and coming into the brighter, warmer months of the year! I hope you are all as excited for this time as I am.

We have lots of interesting articles packed into this edition of our quarterly magazine and I hope you really enjoy reading it.

Firstly, Brian gives his CEO Report, in which he details information about the novel treatments that were discussed at the European Association for Haemophilia and Allied Disorders (EAHAD) Conference in Manchester in February. Next, I give a run-through of some of the key takeaways from our 2023 AGM and Conference just past. We have some programmes and dates for your diary sprinkled throughout so you can start reserving future weekends and days for learning and connection with other I.H.S. members.

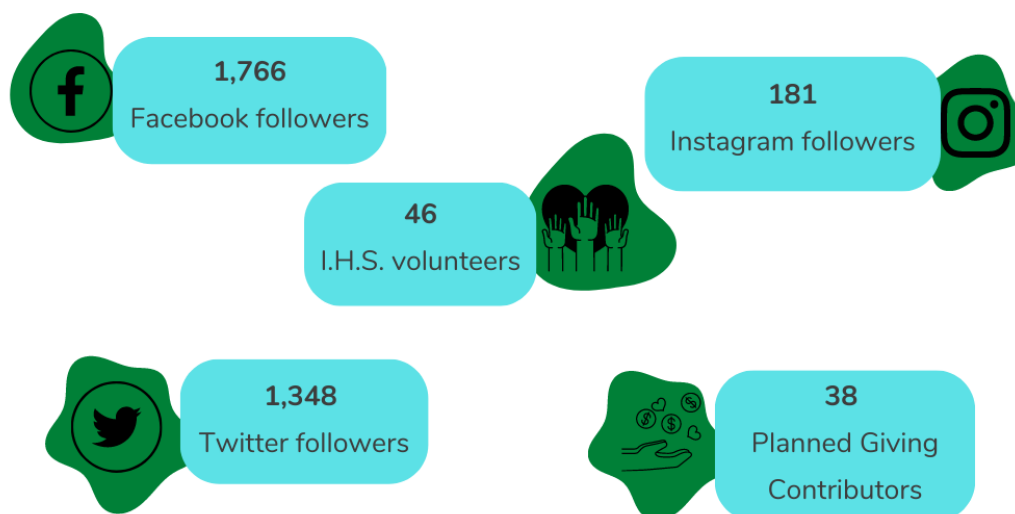
Particularly interesting in this edition are the two interviews which I conducted with Consultant Haematologist, Dr. Michelle Lavin, and Molly O'Mahony, one of our longstanding volunteers. I want to thank both individuals for taking the time out of their busy schedules to speak with me over Zoom and for their insight and enthusiasm. I learnt a lot from each interview and I hope readers do too.

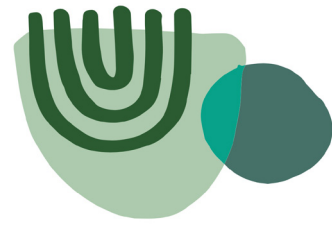
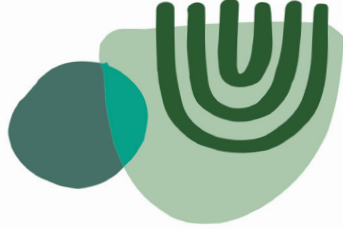
Sprinkled throughout this edition are photos from previous conferences and events and many photos from our recent AGM and Conference, which will give members who were not there a taste of what we got up to over the weekend and will remind members who did attend of the weekend's highlights. Readers will also find information about Outreach, travelling or studying abroad and a few other bits and pieces in the Noticeboard at the back of the magazine.

Wishing you happy reading!

Roisin Burbridge, Publications, Website & Social Media Coordinator

The Irish Haemophilia Society at a Glance





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CEO Report

AGM

The AGM and annual conference held in the Slieve Russell hotel in early March was a great success. It is worth noting that hotels are now looking for final rooming lists several weeks in advance so we encourage members to book as early as possible for future conferences and events in order to ensure that they will have a place.



The conference programme was varied and interesting. Dr. Glenn Pierce, Medical VP of the World Federation of Hemophilia (WFH), delivered an excellent overview on therapeutic choice in the era of novel therapies and gene therapy. This was particularly appropriate timing given that we now have licenced gene therapies in Europe for both FVIII and FIX deficiencies. In relation to whether these licenced gene therapies meet the minimum criteria for a cure, his view was that this may be the case for Haemophilia B but not for Haemophilia A. In relation to whether the licenced gene therapies have a positive risk benefit ratio in high income countries such as those in Western Europe his view was that for Haemophilia B gene therapy the answer would be a qualified yes and for haemophilia A gene therapy there are many alternative therapies. This is a complex and dynamic area which will require intense education, shared decision making models and informed decision making by any person in the future who is considering gene therapy.

Simon Fletcher from the UK outlined different educational approaches focusing on knowing who you are, what you're looking for from a treatment, know what you are willing to live with and taking as much time as you need to make an informed decision. Professor Niamh O'Connell from the National Coagulation Centre (NCC) gave an update on comprehensive care at the centre and also launched the new MyIndici patient portal which has been long awaited and is very welcome.

A number of members at the meeting raised serious concerns about the continued lack of access to the H & H ward in St. James's hospital for people with haemophilia. There is access at the moment for orthopaedic surgery for one person per week but it is a priority for the Society and indeed for the National Haemophilia Council to regain access routinely to the H & H ward for people with bleeding disorders in the course of 2023.

Dr. Beatrice Nolan gave an entertaining, perceptive and novel lecture on comprehensive care in CHI Crumlin. Dr. Pierce also gave an update on haemophilia worldwide, pointing out that the many new exciting therapeutic advances are really only going to be available to 17% of the world's population with haemophilia, individuals who live in high income countries. He spoke about the wonderful WFH humanitarian aid programme which is providing ongoing treatment to more than 20,000 people with haemophilia worldwide. There was also an opportunity for the Society board to introduce themselves to members during a specific symposium and outline their work on the board. All in all, the conference was a resounding success.

Following the Conference, Dr. Pierce and I attended the NCC and Dr. Pierce gave a talk on therapeutic choice in the era of gene therapy, going into more technical detail than at the Conference. The talk went down very well.

European Association for Haemophilia and Allied Disorders (EAHAD)

At the recent conference of the European Association for Haemophilia and Allied Disorders (EAHAD), there were important updates delivered on many of the novel therapies under development or in the process of being licenced.



Members will be aware that the first FVIII gene therapy- Roctavian- was licenced by the European Medicines Agency (EMA) in recent months. Updated results from the phase three clinical trial data showed factor expression over a four year period - starting at an average of 43% in year one and falling to just over 15% in year four. There is clear medium to long-term FVIII expression but there is also a clear decrease in expression each year. This has been associated with significant reduction in bleeds and improvements in quality of life.

In relation to FIX Gene Therapy, updated results were presented from the Hope – B trial which is the Phase three trial for the first FIX Gene Therapy now licenced by the Food and Drug Administration (FDA) in the USA and with imminent licencing expected to be granted by the EMA. This is the clinical trial which also had three participants from Ireland. The average FIX expression after 18 months was 36.9% and after 24 months was 36.7% showing a very encouraging stability of expression. This was also associated with a significant decrease in annual bleeding rate. A second FIX gene therapy from Pfizer/Spark also reported encouraging 15 month data, averaging FIX expression of 27.5% with 80% of participants having a FIX expression > 5%.



Plenary lectures on gene therapy were delivered at the conference by three people with haemophilia: Dr. Radoslaw Kaczmarek from Poland, now working in the USA (who is a new addition to our Haemophilia Product Selection and Monitoring Advisory Board as an external advisor nominated by the Society), Dr. Glenn Pierce and myself. I gave a presentation on what patients and payers will expect. In relation to patients' expectations, I reiterated our view that a comprehensive and tailored approach must be taken to gene therapy education to ensure that every member who might be interested in looking at gene therapy as a current or future treatment option will be given the education required to allow them to make a fully informed decision, which is optimised for them individually. We are planning a multi-stage education process in collaboration with the centres. This approach to gene therapy education will also be useful in a modified form for education on an ongoing basis for the wide range of new and novel therapies currently in clinical trials or being planned.

There were also updates at the meeting on progress with other novel therapies including the new mimetic Mim8, the anti TFPI's Concizumab and Marstazimab, the anti thrombin inhibitor Fitusiran and the activated protein C inhibitor, Serpin PC. The clinical trials for Mim8 and Fitusiran include Irish participants. Mim8 will be a direct competitor to Emicizumab and the other novel therapies are all re-balancing agents which work by decreasing or interfering with naturally occurring anti-coagulants. Rather than replacing the missing factor or mimicking the role of factor (as with Emicizumab or Mim8), the re-balancing agents increase clotting by interfering with proteins which prevent excess clotting in people without bleeding disorders.

There were also encouraging developments in the treatment of von Willebrands disorder (VWD) with two new molecules in clinical trials which increase the existing amount of von Willebrand factor (VWF). There was also limited data on the potential use of Emicizumab for Type 3 severe VWD. Dr. Michelle Lavin lectured on low VWF levels and pointed out that there is a distinct difference between having a low VWF level (30-50%) and having a bleeding disorder. For an actual diagnosis of VWD, the individual would need a low VWF levels and a history of bleeding. A presentation on the monitoring of liver disease raised the question of the possible need to restart regular monitoring of people who have cleared hepatitis C via treatment and who do not have cirrhosis. For some of the people in this category, regular monitoring by fibroscan or ultrasound may be required depending on other risk factors. My expectation is that EAHAD and the EHC will look at developing guidelines on this in the near future.

There was a very strong input from Irish speakers at the conference with six speakers in total. For those

members who would like more detail on all the new therapies- I refer you to our latest edition of the novel products newsletter.

World Haemophilia Day & More

Our World Haemophilia Day theme this year will be "Mild/Moderate Haemophilia" with a series of awareness activities from April 17th to 22nd culminating in a Mild Haemophilia Information Day on April 22nd in the Grand Hotel, Malahide.

In recent months, we were also very pleased to play host to leaders from Haemophilia Northern Ireland and Haemophilia Scotland. Both organisations were very interested to learn more about our programmes and activities and to meet with the staff and some of the Board members. We will continue these very worthwhile engagements and, certainly with Northern Ireland, we will be jointly examining possible synergies including organising joint meetings in some areas in the future.

Brian O'Mahony, Chief Executive Officer



The Scottish Haemophilia Society visiting our offices



Dr. Glenn Pierce at the NCC





Our AGM & Conference took place over the weekend of the 3rd-5th March at the Slieve Russell Hotel in Cavan, a perfect location for our conference. We as I.H.S. staff want to thank the big group of people who made this weekend so successful: the hotel staff who were so efficient and friendly throughout the weekend, the speakers who gave such engaging talks, the Board who not only spoke in the symposium 'Meet the Board' but also helped staff out at the sign-in desk, chairs of sessions and volunteers, without whom the weekend would have been impossible.

Following set up on Friday, I was honoured to get to interview Dr. Glenn Pierce for a future I.H.S. quarterly magazine. Dr. Pierce grew up with severe haemophilia at a time when there was no adequate treatment, has been at the forefront of the development of a number of major treatments for haemophilia (such as Elocta and Alprolix), and is the Vice President Medical of the World Federation of Hemophilia (WFH). It was a real treat to listen to his story and his expert opinions, and I'm sure members will also greatly enjoy the interview when it comes out in a future magazine.



Mr. Brian Fitzgerald, Chairperson,
National Haemophilia Council

The AGM kicked off on Saturday morning at 10am with our Chairperson Mr. John Stack welcoming members. Following the approval of the minutes of the previous AGM, the Honorary Secretary Ms. Barbara Wynne gave her 2022 report, after which the Treasurer Ms. Aislinn Farrelly gave her presentation on the audited accounts for 2022. The Chairperson was the next speaker who gave a great presentation and our Chief Executive Mr. Brian O'Mahony was the last speaker. The AGM went by efficiently, the reports and presentations were excellent and following a few short questions from the members, it was time to break for lunch.

After a lunch of soup and sandwiches the talks were underway. The first speaker welcomed to the podium was Dr. Pierce, who gave an in-depth presentation on therapeutic choice in the era of gene therapy. Dr. Pierce

provided his audience with a history of treatments and discussed the long process that eventually resulted in the recent licensing of the first two gene therapies. He shared his own opinions of where we are at with gene therapy for haemophilia A and B respectively.

The next topic was a real treat with two excellent and highly charismatic speakers: Professor Niamh O'Connell and Dr. Beatrice Nolan. Prof. O'Connell discussed how comprehensive care is evolving and used this as a lead into a soft launch of the new haemophilia patient portal, which is a great step forward in the area of digital health. The platform 'MyIndici' is open to patients over 16 who are registered with the NCC. It is a fabulous resource which enables individuals to view health records, manage appointments and view clinical letters. Most importantly perhaps is the messaging feature, which enables individuals to contact the centre without having to phone and spend lengthy time waiting to speak to a member of staff. Prof. O'Connell did stress that this feature is for non-urgent matters only - no broken legs!!

Dr. Nolan's presentation was a very humorous, informative and effective outline of haemophilia comprehensive care. Dr. Nolan compared haemophilia care with Tesco products and services. One analogy I found particularly funny was her comparison of novel therapies with a number of bizarre new Heinz products such as 'Hanch' 'Tarchup' and 'Wasabioli'. Dr. Nolan's dry delivery made the presentation even more impressive and she had the audience in stitches laughing throughout the talk.

Following the coffee break, Professor James O'Donnell provided an update on the iPATH Research Programme and the benefits of the study, such as training young people to become more involved in coagulation and bleeding disorder work. He also outlined some of the major areas where iPATH has made a difference, including in gathering more data on physical activity and in the development of new mouse models to study the impact of haemophilia on the immune system.



Dinner that evening was accompanied by the awards ceremony in which recipients of 2022's educational grants received their official awards and Prof. O'Connell received the Brian O'Mahony Award for Outstanding Contribution to Haemophilia Care in Ireland. A huge congratulations to each of our award winners!

The following morning the I.H.S. Board introduced themselves and told members a bit about why they had joined the Board and about their own backgrounds. Following this, Simon Fletcher from the UK outlined his approach to haemophilia education. He encouraged anyone considering a new therapy to reflect on their expectations of the new treatment and to make sure they understood the risks and benefits of the treatment. He also encouraged individuals to consider activities their condition prevents them from doing at present and whether a new treatment would make a difference in this.

After this, Dr. Pierce gave a talk about haemophilia worldwide, which was both harrowing and inspiring. He emphasised the level of inequity in treatment that persists to this day, pointing out the fact that while Africa makes up 17% of the world's population by region it uses only 1% of the world's FVIII IU, while Europe, which makes up only 10% of the world's population, uses 35% of the world's FVIII IU. More positively, he also talked about the great milestones the W.F.H.'s humanitarian programme has reached, such as in treating 25,000 patients with haemophilia and carrying out over 4,000 surgeries.

Over the course of the morning, I took some videos for Instagram and TikTok with a few volunteers and then was lucky enough to be able to interview Prof. O'Connell for one of our future magazines. It was particularly interesting for me to learn about the inner workings of the NCC and all that goes on behind the scenes to make patient care the excellent level that it is in Ireland, such as through the work of the Product Selection Board.

The weekend finished with a carvery lunch before members, staff, board members and volunteers parted ways. Until next time!

Roisin Burbridge, Publications, Website & Social Media Coordinator



Vice-Chairperson Mary Clare Delaney presenting the Margaret King Educational Award to Tadhg Moriarty



Chairperson John Stack presenting the Maureen Downey Educational Award to Gabriel O'Connor



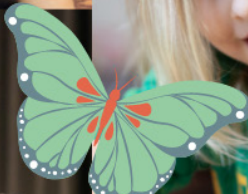
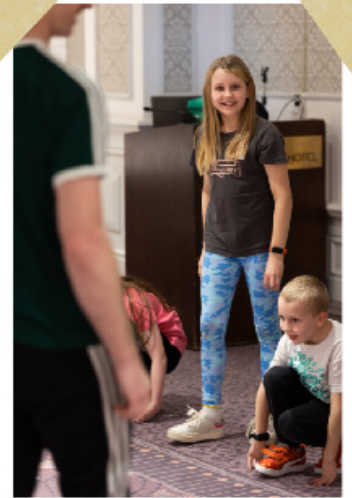
Honorary Secretary Barbara Wynne presenting the Fr. Paddy McGrath Educational Award to Daniel Hanney



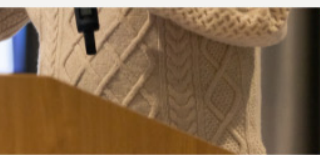
Professor Niamh O'Connell receiving the 'Brian O'Mahony Award for Outstanding Contribution to Haemophilia Care in Ireland'







CONFERENCE



Interview with

Below is an interview Roisin Burbridge conducted with Dr. Michelle Lavin on February 14, 2023. Dr. Lavin is a Consultant Haematologist at the National Coagulation Centre in St. James's Hospital and also lectures in the Royal College of Surgeons.

Can you tell us a bit about your background, what you studied in university and how your career has progressed so far?



I studied medicine in Galway as an undergraduate. Even in medical school I loved haematology. At first I was more interested in the malignant side because you don't tend to learn that much about coagulation in college. It was really only when I started working as a specialist registrar in Cork with Dr. Susan O'Shea that I realised that coagulation was definitely for me.

I specialised in haematology and when I came towards the completion of my scheme I did my PhD with Prof. James O'Donnell in the NCC and focused on haemophilia and von Willebrand Disease (VWD). It's really just grown and grown from there. It's such a privilege to work in an area I love so much.

Why did you choose to specialise in haematology? What is your specific interest in inherited bleeding disorders?

I love that there are so many different aspects to haematology, which incorporate looking after our patients and also looking after the laboratory. It's great to be able to talk to somebody, take blood samples, bring them to the laboratory, be responsible for running and interpreting those assays and actually go back to the person with a diagnosis. And that diagnosis is something that you've seen through from start to finish.

So you're involved with the whole process?

Exactly, and this is also why I like research, because the story from the patient drives our research questions. When we're hearing the same problem again and again it shows that there is something we could be doing better. It means that we can take the patient's question to the lab and hopefully come back to the patient and be able to say that we have solved or addressed the question in some way.

Would that be different in other areas of medicine?

Yeah, in other areas of medicine you rely a lot on diagnostic imaging, so things like CTs or MRIs and you're not in control of those so you can't control how quickly they'll be performed or interpreted.

Is there an area of your work that you find most rewarding?

What I find most rewarding is dealing with patients and making a difference in terms of their care. Even simple things like managing someone's iron deficiency can make such a huge difference to someone's life and I love being involved in this.

I really love that my work is so focused on the patient. It's the person's story in front of you that shapes your decision making. For instance, the person's history is so important when determining if they have a bleeding tendency. I love that I get to listen and interact with the patient like this.

"I really love that my work is so focused on the patient. It's really the person's story in front of you that shapes your decision making."

What does a day in your work life look like?

It's very varied! My husband is a GP and has a very set schedule, whereas for me everyday is different, which is fantastic. On a clinical day, I go in and meet with the multidisciplinary teams about any issues our patients may be having. I do a round of the ward and day centre and also deal with anyone coming in with an urgent issue. There's also quite a lot of admin behind the scenes. This is because we're always trying to improve services in the centre, which takes a lot of planning. Ultimately the admin makes things quicker but it takes time at the outset.

There's other days where I could be working with the hospital thrombosis committee, looking at where we can optimise care for all the medical and surgical in-patients. We also look at education and how to improve awareness of bleeding or clotting disorders among nurses and doctors. I also meet with patient societies and I do a lot of work on advocacy internationally with the World Federation of Hemophilia (WFH), with the International Society of Thrombosis and Haemostasis and with the European Association for Haemophilia and Allied Disorders (EAHAD). Trying to slot all those things around the general clinical workload is always fun.

Do you travel a lot with these committees or is it mostly on Zoom now?

One of the major benefits of covid has been the availability of doing things over Zoom, which makes it easier and more flexible to connect with people. There's only so much you can do when you are stepping away from your clinical workload to travel all the time. You can fit a lot more in when the meetings are online. I try to pick two or three main meetings each year to attend in person.



Dr. Michelle Lavin

You are the Clinical Lead for the iPATH study. Could you tell us about this study?

We completed the first phase of the study, and it was really exciting to be involved in. The study was looking at trying to understand why people's experiences of haemophilia are so different. Patients with severe or moderate haemophilia often have different prophylaxis needs, meaning some on standard half-life products would have needed alternate day treatment while others only needed it every four or five days. We are using genetic analysis to try to understand the variability between people, and this is still ongoing in the background.

There were a number of different strands to the study. The first was a very basic science strand in which we tried to develop models in the laboratory that could mimic haemophilia, which we could work on to better understand changes. Another was the physiotherapy study, for which Dr. Megan Kennedy, who did her PhD in this area, was our research physiotherapist working with our clinical physiotherapy team. This looked at joint health, pain and pain management in people with haemophilia. It was led by Prof. John Gormley in Trinity. The other strand was the clinical phenotype, which looked at people's joint health scores over time, their factor usage, and how they had got to their prophylaxis dosing.

The study has really been very insightful. We have a recent paper that's been accepted and may be coming into print now, looking at pharmacokinetics.

We are always hoping to do more research, with a new project coming focused on carriers and women who have mild haemophilia and how their joint health could be affected. So that'll be a really exciting programme as well.

"The study has not only benefited patients in Ireland but has changed care for patients internationally, as the findings have translated into international guidelines."

The LoVIC study is the largest dedicated study of patients with low von Willebrand Factor in the world. What is the LoVIC study and what are its goals?

This has been a hugely successful project because of high patient engagement. We're hugely thankful to the Irish patient community for their enthusiasm in getting involved. The aim of the project was to try to understand how having a low von Willebrand factor (VWF) influenced bleeding and how it could best be managed and treated. The study has not only benefited patients in Ireland but has changed care for patients internationally, as the findings have translated into international guideline recommendations.

One of the changes to our care brought about by the results of this study is that we no longer bring people in for DDAVP trials. This is because the study showed that if you're an adult with low VWF you will have a very predictable response to the treatment. While patients used to have to spend a whole day in the centre getting their bloods taken at hourly intervals, they now only need their first dose of DDAVP when they are getting a surgery or procedure.

At the time we started the project, it was suggested that maybe low VWF didn't result in any bleeding, but our study has shown that some people have quite significant bleeding and do need closer follow up and that the levels of bleeding vary hugely between people. We're working on a further study within that to try to understand why some people experience more bleeding than others.

I'm interested in how people get diagnosed with VWD if they don't have bleeding symptoms. Is it because of their family history?

Yes, people can be referred to us because they have a positive family history of the disease. I think you've touched on a key aspect - we should only be diagnosing people if they do experience bleeding. Low VWF levels, those levels in the 30-50% range, actually overlap with the normal population. So we don't want to tell people who are healthy and normal that they have a bleeding disorder and then complicate their future surgeries or life assurance or mortgage protection. There are quite a lot of long-reaching impacts of having a new medical diagnosis. We need to be careful not to over diagnose.

It can be difficult to diagnose people who have never had surgery or haven't had a tooth out, as you can't say for certain whether or not they will have bleeding problems in future. You really have to wait and let things evolve over time. It's important for people to have our contact information and know to contact us if they have bleeding of concern. We're always happy to reassess things.



So I suppose it might be easier to diagnose a woman because of her heavy periods than it would be to diagnose a man who hasn't had surgery?

It can definitely be easier with women but even just having heavy periods on its own isn't enough to say that you have a bleeding tendency. This is usually combined with other bleeding like nosebleeds, bruising or bleeding with surgery. But if you're a woman coming in who has never had heavy periods then that shifts the balance towards you not having a bleeding disorder.

What inspired you to create the Know Your Flow tool?

I had so many women come into me who had a diagnosis of a bleeding disorder and had very definite bleeding symptoms and when I first asked them if they had heavy periods they would say no. However, when I asked them to describe their period, it could be torrential. But because it was their normal they never perceived it as heavy, even if they were bleeding for 8 or 9 days or having to restrict what they were doing during their heaviest days of flow. Their family members might have all experienced the same kinds of periods. It really comes down to the problem that we don't have open conversations about periods. There is still a lot of stigma around menstruation and we need to tackle this so that women know if their periods are heavy and know to speak to someone if so.

I wanted to spread awareness about heavy periods, so I brought this as a challenge to the students at RCSI Summer School. I asked them how we could best reach that younger demographic of women to really highlight the issues regarding heavy menstrual bleeding. It was actually the students themselves who came up with the campaign name Know Your Flow, and 7:2:1. One of the students stayed on with me afterwards and did research with me. It's great that I not only gain so much from the students but they also gain research experience with me.

What are your predictions for treatment and care for haemophilia/VWD/women with bleeding disorders in the next 5 years?

I think the rate of progress in haemophilia has been just astounding, phenomenal over the last decade. Internationally, I do feel there's a real risk that the improvements we have made in higher income countries just further the gap between these countries and lower and lower-middle income countries, where people aren't even getting a diagnosis. We have to be careful not to forget those boys that are living and

dying prematurely with haemophilia in other parts of the world. So while we're funnelling costs towards improvements in care here, we should also be trying to always advocate for those who cannot advocate for themselves. I do worry that we are widening that gap immeasurably and we risk leaving people behind permanently if we don't take care.

Within Ireland I hope that we will have broader availability of gene therapy and better treatments for everybody. I do miss my patients with haemophilia - I hardly get to see them anymore, so hello to everybody reading the magazine! This is of course a great complaint. I think we need to look at how we evolve our haemophilia centres now because our models of care are so completely different to what they used to be. We're no longer seeing people come in with recurrent bleeds, but coming in for corrective orthopaedic surgery, or for long-term physiotherapy needs.



Unlike haemophilia, our other bleeding disorders don't have as much opportunity in terms of access to drug development or to novel therapeutics. VWD and women and bleeding disorders are falling far behind haemophilia care because they are underrepresented in clinical trials in comparison. We are trying to encourage drug development in these areas so that we can have

better treatment for women and girls with haemophilia who currently aren't included in most trials for new haemophilia agents, but also for people with VWD and other bleeding disorders. While improvements will be slower, we know from haemophilia that if we really target resources towards a particular disease we can really improve care dramatically.



To mark World Haemophilia Day 2023 we are holding a

Mild Haemophilia Information Day



When?: Saturday April 22, 2023



Where?: The Grand Hotel, Malahide, Dublin

Preliminary Programme

11.30 - 12.00	Registration
12.00 - 13.00	Lunch
13.00 - 14.00	An Update on Mild Haemophilia and the Use of Hemlibra in Mild Haemophilia (Speakers: Professor Niamh O'Connell & Dr. Beatrice Nolan)
14.00 - 14.45	Dental Care (Speaker: Dr. Alison Dougall)
14.45 - 15.15	Coffee Break
15.15 - 15.45	I.H.S. Services & Supports (Speaker: Mr. Brian O'Mahony)
15.45 - 16.30	Q & A and Discussion

Hyde Square Apartments



Hyde Square
Apartments



A quick reminder that our apartments at Hyde Square are available to:

- People with haemophilia or related bleeding disorders from outside of Dublin, when attending St. James's Hospital or Children's Health Ireland, Crumlin for treatment, for a hospital appointment or for a review clinic.
- An immediate family member, a spouse, a partner and/or child of the person with haemophilia or related bleeding disorder from outside Dublin, when attending St. James's Hospital or Children's Health Ireland at Crumlin for treatment, for a hospital appointment or for a review clinic, or while a family member is an in-patient.

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

A nominal fee of €10.00 per booking, per night will be levied to offset the cost of cleaning and routine maintenance.



Interview with Molly

Below is an interview Roisin Burbridge conducted with Molly O'Mahony on March 1, 2023. Molly has been a volunteer with the I.H.S. for six years and counting. She is in her final year of physiotherapy at Trinity College Dublin.

When did you start thinking about volunteering with the I.H.S.?



The Society has always been part of my life and, as such, you could say that it is an extension of the family. I have been attending AGMs, conferences and other events with my parents for much longer than I could possibly remember, graduating through the ranks of the cubs, kidlink and the youth group, so volunteering was a natural progression.

Did all your friends move up from Youth at the same time?

Yes, we all moved up at the same time which was really nice. We still get to see each other two or three times a year which is really great.

What motivated you to become a volunteer?

I have always loved the camaraderie in the Society, the friendships made that have stood the test of time and I am a great admirer of the work the Society does and how those involved go about the tasks at hand in such a friendly and good-humoured manner.

I have received such wonderful benefits, support and encouragement from the I.H.S. over the years that I am only chuffed to be able to give something back and I intend to continue to do so for as long as they want me!

What age were you when you started volunteering?

When the great days of attending the kidlink and the youth group ended, I attended the AGM and other conference events and sat in on the meetings because they were very informative and, for obvious reasons, the subject matters were of interest to me.

I was 19 when I first volunteered and although Covid put paid to a few years, I've been an ever-present volunteer since.

For how many years have you been volunteering with us?

2023 will be my sixth year and I aim to be around for many more to come. Any long service medals going?

"There's always a great spirit of adventure and it's fabulous to be volunteering alongside many of those I was friendly with when attending the various clubs and groups myself."

Can you tell us a bit about what is involved in volunteering with us?

First and foremost, the priority is to make sure the events are fun and that the children and teenagers get as much enjoyment from the activities as possible, in a safe environment.

We always try to come up with new ideas and if the schedule we had planned is not working as well as we or the participants would like, it's important to be able to switch activities as soon as possible to keep it interesting and interactive.

It's important too that the children and teenagers have their say and that we listen to them because, when it comes down to it, it's all about them and making sure they enjoy themselves and want to return.

What goes into planning the activities?

The volunteers are amazing! Every weekend people have different ideas for activities. We come up with a few ideas in the Whatsapp group chat before the Conference and then on the Friday night we usually meet up and get chatting about our various ideas for the weekend. We definitely try to change it up each time while also keeping some of the old stuff that the kids love.

On the Saturday morning we talk to the kids to see what they'd like to do for the weekend. They always have even more creative and better games than we have!



Have you moved around to the different groups or have you mostly been with one of them?

I'm mostly with Kidlink, which is great because they're really good fun. I've also been with the Youth group a few times. The I.H.S. is really accommodating - you can always put in a request to be with a particular group if you like.

What are your favourite aspects of volunteering?

There's always a great atmosphere and a great spirit of adventure and it's fabulous too to be volunteering alongside many of those I was friendly with when

attending the various clubs and groups myself.

The days can be challenging and tiring and you're certainly kept on your toes and it's always important to ensure that



Molly O'Mahony

the quieter children are every bit involved as the more vocal characters.

Essentially, it's great that the parents can attend the meetings and workshops and spend the days with friends and other delegates, secure in the knowledge that their children are safe and enjoying themselves and that they are not very far away.

What's your own career path?

When I was smaller I set my heart on becoming a princess but, alas, that opportunity now seems to have passed me by. But who knows – someday my prince might come! It's funny, I really loved maths and applied maths in school and I always thought I'd pursue a career in that direction but by the time the Leaving Cert came, I had other ideas. I studied medicine for two years but, after some deliberations and uncertainties, I decided to pursue a career in physiotherapy and I am currently close to completing my fourth and final year of a BSc Physiotherapy degree in Trinity College Dublin.

Why did you decide to go into physiotherapy?

It is one health science subject that I always thoroughly enjoyed. It's great to be able to combine the science of the discipline with the interaction with patients and it's great to witness the sometimes immediate benefits that they enjoy. No two days are the same and it's great that there is so much variety and so many options in physiotherapy.

Whenever I get home at weekends, I have no shortage of "volunteer patients" to practice on – no such thing as a free lunch!

What do you hope to do after you qualify as a physiotherapist?

One of the great advantages of the four-year degree course is that we are sent on various placements for six weeks at a time and you learn so much from the hospital environment, working alongside so many skilled physios and other medical teams who have years of valuable experience and are really on top of their game.

I have been on placement in St James's Hospital, the National Rehabilitation Hospital in Dún Laoghaire, Peamount Healthcare and Tallaght University Hospital, experiencing the various disciplines involved in physiotherapy – including musculoskeletal, respiratory, orthopaedics, paediatric, hydrotherapy, neurology and stroke recovery.

When I finish college I hope to secure a position in one of the acute hospitals where the sharp learning curve will continue before, eventually, choosing a discipline that I think would best suit me and best suit potential patients.



What are your hobbies and interests?

Being from Kerry, obviously GAA is the big passion and, thankfully, there is never a season lacking excitement when you follow the green and gold. Being from a football mad household, I've travelled the country to watch inter-county teams, at all grades, and I take in as many club games as I can. (Note to the Kerry GAA: If you're looking for a team physio a few years from now, I might know someone).

Apart from that, I walk my dog (a two-year-old Golden Retriever named Nigel) at every possible opportunity. Holding Nigel back from chasing deer, squirrels and golfers is great for building upper-body strength.

I have always loved drama and attended classes for about a decade during my school years and, actually, it really helps with some of the I.H.S. volunteering activities.



Dates for your Diary in 2023

April

Mild Haemophilia Day

Date: Saturday, April 22

Venue: The Grand Hotel, Malahide, Dublin

May

Athlone Regional Visit

Dates: Monday, May 15

Venue: Radisson Blu Hotel, Athlone

July

Parents Conference

Dates: Friday- Sunday, July 14-16

Venue: Midlands Park Hotel, Portlaoise

Donegal Regional Visit

Dates: Monday & Tuesday, July 24 & 25

Venue: TBC

September

Galway Regional Visit

Dates: Monday & Tuesday, September 4 & 5

Venue: TBC

Von Willebrand Disorder Information Day

Dates: Saturday, September 23

Venue: The Grand Hotel, Malahide, Dublin

October

October Members' Conference

Dates: Friday - Sunday, October 20-22

Venue: Mount Wolseley Hotel, Carlow

December

Women's Conference

Dates: Saturday - Sunday, December 2-3

Venue: The Grand Hotel, Malahide, Dublin

Photos From Previous Events





**IRISH HAEMOPHILIA
SOCIETY**

Parents Conference

Dates: Friday 14 July - Sunday 16 July, 2023
Venue: Midlands Park Hotel, Portlaoise

Telephone: 01 657 9900
Email: info@haemophilia.ie



We are pleased to announce details of our Parents Conference, which is being organised in collaboration with the team at CHI Crumlin. We are hoping to encourage as many parents as possible to attend this very worthwhile and informative conference. We hope you find the programme interesting and take this great opportunity to meet other parents to discuss common concerns you have for your child/children with bleeding disorders. At the conference, you will receive up-to-date information from the haemophilia care team at CHI Crumlin, build long lasting friendships with other parents, and enhance the personal growth of your child. The event will be a two night package for parents and children with bleeding disorders. We will provide 4 children's programmes to allow parents to attend the various lectures and talks. Conference packs will be going out to members at the end of March, however, in the meantime if you are interested in attending, please do call the office for more information.

Preliminary Programme

Friday 14th July:

19.00 Buffet Dinner for the full group

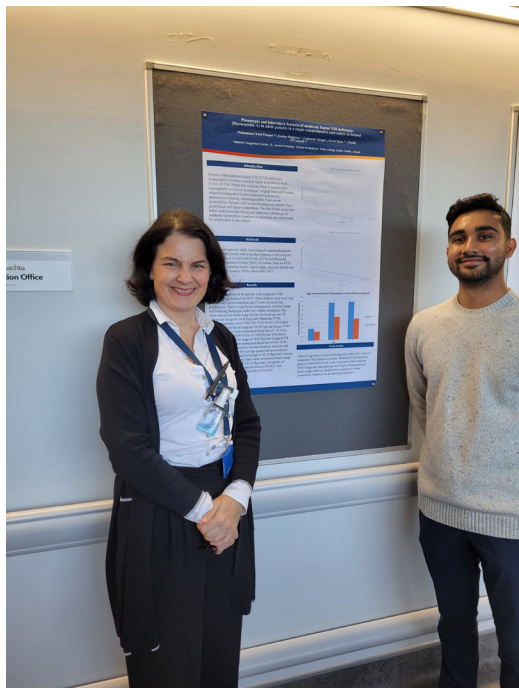
Saturday 15th July:

10.00 - 11.00 The Future of Treatment
11.00 - 11.30 An Update on the new Children's Hospital
11.30 - 12.00 Coffee Break
12.00 - 13.00 Inheritance & Carrier Issues
13.00 - 14.00 Lunch
14.00 - 15.00 An Update on Factorials/Hemifilia
15.00 - 15.15 Dealing with Nosebleeds
15.15 - 15.30 Coffee Break
15.45 - 17.00 Pathways to Care
19.00 Dinner

Sunday 16th July:

10.00 - 11.00 Bleeding Disorders and Sports
11.00 - 11.30 Coffee Break
11.30 - 12.30 Open Forum with CHI Crumlin Team
12.30 - 13.00 Society Services & Supports
13.00 - 14.00 Lunch





In 2022 the Society and the centres gave bursaries to medical students to carry out short projects on bleeding disorders. The longterm objective is to encourage their interest in a career in haemophilia and bleeding disorders.

The above photo shows Prof. Niamh O'Connell with medical student Saad Furqan and a poster of his project entitled "Phenotypic and Laboratory Features of Moderate Factor VIII Deficiency (Haemophilia A) in Adult Patients in a Single Comprehensive Care Centre in Ireland". He is hoping to present his work at an upcoming scientific conference.

Fundraise for the I.H.S.!



We really appreciate all efforts to raise funds in aid of the I.H.S. Everything raised goes towards ensuring that we are providing our members with the best possible supports and services that we can. If you think you can help raise funds in aid of the Society, let us know what fundraiser you have in mind. We will be more than happy to help you in any way that we can, such as in organising tickets, sponsorship cards, posters and t-shirts.

To find out more about fundraising for the I.H.S., please contact Nina on nina@haemophilia.ie



Are you jetting off to warmer weather this Spring?

When travelling, make sure you have all the necessary documents with you. Don't forget to also bring the I.H.S. travel card, which includes useful information such as phrases translated into a number of different languages, space to fill out personal information and some travel tips.

Find out more by visiting our website, under the Living with Haemophilia section.

If you need an I.H.S. travel card sent to you, give us a call in the office on 01 657 9900 or email info@haemophilia.ie.





Outreach Services

We would like to remind our members of the supports we offer to members with a bleeding disorder and to their families.

Our Outreach Coordinator, Rob, is the main point of contact for all our members who need support or assistance, such as queries related to entitlements, advice, or other supports.

The I.H.S. offers home and regional visits for members. Brian and Rob have a number of regional visits planned for 2023. In February they visited Cork. In May they will visit Athlone, in July they will visit Donegal and in September they will visit Galway. Keep an eye on our website and social media for updates.

We also offer school visits, so if your child is starting school feel free to contact Rob for a school visit to educate the teachers on your child's bleeding disorder.

For more information email Rob on robert@haemophilia.ie.



Volunteering with the I.H.S.

We have a fantastic team of I.H.S. volunteers but we are always eager to add to our numbers!

Would you be interested in volunteering with us? We are looking for people of all ages, all backgrounds and all walks of life to join us at our events!

Do you enjoy working with kids? Are you good at arts and crafts? Are you a good photographer? Do you have a hobby or skill you could teach to others? If so, we would love to hear from you!

If you would like to learn more or would like to sign up to become a volunteer, please email Rob on robert@haemophilia.ie.

Write for the I.H.S.

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

Share a story about your experiences with a bleeding disorder, your time at one of our conferences, or about any other relevant topic! If you prefer, you could also do an interview with us about your experiences, instead of writing an article.

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





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