Haemophilia.ie

Magazine of the Irish Haemophilia Society

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

SCAN ME

Winter 2022 Edition

From the Deputy Editor

I'm delighted to introduce this jam-packed edition of our quarterly magazine filled to the brim with photos, stories and more. We have pieces written by members and non-members alike, as well as sections the staff put together. Brian O'Mahony starts the magazine off with an update on gene therapy, a few of the highlights from the October Conference, a piece about the advocacy groups who were at our offices in November and an introduction to our von Willebrand Disorder awareness campaign, which I have been happy to work alongside him on.

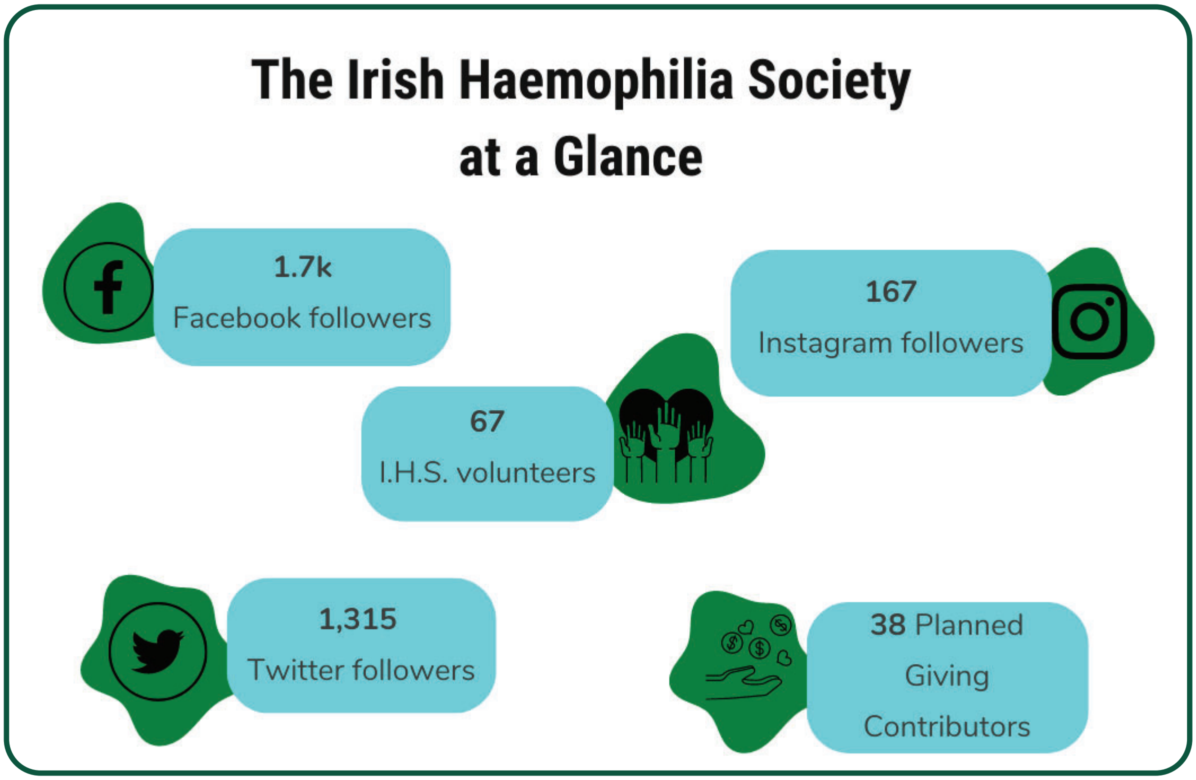
After Brian's report, I give a more in-depth run through of our October Conference, followed by announcements of the recipients of this year's educational grants.

One of the recipients, Hannah Byrne, gives an update on how the grant is helping her so far and we learn about her exciting college experiences.

We have two other personal accounts in this magazine, one a funny yet heartfelt story of a strong friendship and how it led a group of young people to do a skydiving fundraiser for the I.H.S., and another of courage, resilience and impressive sporting achievements.

Besides these accounts, you will find lots of information in this magazine such as our programme of events for 2023, hospital Christmas opening hours, and information about volunteering with the I.H.S.

Roisin Burbridge, Publications, Website & Social Media Coordinator



The Irish Haemophilia Society at a Glance

1.7k Facebook followers

167 Instagram followers

67 I.H.S. volunteers

1,315 Twitter followers

38 Planned Giving Contributors

Contents

CEO Report

Gene Therapy Update

In the last edition of our magazine, I outlined that the first hemophilia A gene therapy - Roctavian - was licensed in August by the European Medicines Agency (EMA). Following on from this, the first factor IX gene therapy - Hemgenix - was licensed this month by the Food and Drug Administration (FDA) in the USA. It is anticipated that this gene therapy will be licensed by the EMA in early 2023.

In November, I participated as a patient expert in the US economic assessment of gene therapy for both hemophilia A and B carried out by the Institute for Clinical and Economic Review. They compared factor VIII gene therapy with both factor concentrate and emicizumab and factor IX gene therapy with standard and extended half-life factor IX. The company manufacturing the gene therapy had to provide an indicative price in order for the comparison to be made. For factor VIII therapy the indicative price was $2.5 million and for factor IX gene therapy the indicative price was $4 million. The factor IX gene therapy has since been launched in the USA with a list price of $3.5 million. This very high price must be placed in context with the US healthcare system where the prices paid for the current therapies, including factor concentrates, extended half-life factor concentrates and Emicizumab, are far in excess of prices paid in the vast majority of other countries. The indicative prices for the USA cannot be used as a guide to the likely cost in European countries. This will be a matter of negotiation and discussion over the coming months in each country.

October Members' Conference

Gene therapy was also the theme of one of our workshops at our October Members' Conference. We organized a lengthy workshop entitled "Gene Therapy- from Concept to Reality", where we explored many issues relating to gene therapy including durability, factor expression, safety and monitoring requirements. Over the coming year the Society plan to roll out a comprehensive education programme for members who may be interested in gene therapy as a treatment option. We shall not be advocating for or against gene therapy but we will be doing our utmost to ensure that members who are interested in gene therapy are in the position to make a fully informed individual decision. The October Conference also included a workshop with Dr. Beatrice Nolan on treatment choices for children, which was very well attended. The range of different therapies now available for haemophilia was illustrated by our symposium on personal experiences with different therapies. This interactive workshop included parents who spoke about their children's experience with extended half-life FVIII, extended half-life factor IX and the ultra-extended half-life factor VIII BIVV-001, which is currently in clinical trials.

Brian speaking at the Gene Therapy workshop

There were contributions from adults on emicizumab including an adult with severe FVIII deficiency and an adult with FVIII inhibitors and there were two speakers who were currently participating in clinical trials for factor IX gene therapy. Their experiences were contrasting and the contributions of the entire panel led to a very good discussion. Following this excellent symposium, there was a reality check for the audience when they heard from several adults and parents with haemophilia from Ukraine about their experience of hemophilia in Ukraine. We were delighted to welcome our new members from Ukraine to the conference, to the Society and to the community.

AFFIRM and SURO training programmes

In the past month, we also had groups of young leaders with bleeding disorders visiting the Society's office as part of the AFFIRM and SURO training programmes. These training programmes provide young haemophilia leaders from around the world with training in areas such as advocacy, therapeutic developments, volunteering and organizational governance.

The groups of young men and women who visited the office came from India, Nepal, Bangladesh, United States, Netherlands, Romania, Pakistan and Colombia. During the course of the AFFIRM group visit, they heard lectures on the work of the Irish Haemophilia Society, the Irish model of care, and they also had an opportunity for a tour of the Irish Blood Transfusion Service headquarters and main processing facility.

AFFIRM group in our office

SURO group meeting in the board room of the I.H.S.

Awareness raising about von Willebrand Disorder

On the last week in November the Society launched a major awareness campaign on von Willebrand's Disorder (vWD) culminating in an information day in Dublin on December the 3rd. The information day program included an update lecture on vWD by Dr. Michelle Lavin, an outline of the supports the Society offers, and a panel discussion featuring three people with vWD. The awareness campaign included professional videos featuring three members with vWD, outlining their stories and their experience and a clinical video featuring Dr. Lavin. It also included a press release, social media posts, the launch of a bleeding assessment tool, and specific information materials for general practitioners. This campaign follows on last year's awareness campaign on vWD and we are doing our utmost to bring people with vWD into the community and to help them to optimise services and support for their condition. The campaign videos are available to view on our website.

Brian O'Mahony, Chief Executive Officer

Panel Discussion at the vWD Information Day

Listening to Brian O'Mahony speak at our vWD Information Day

Back to Full Capacity at our 2022 October Members' Conference

On a mild weekend in mid-Autumn, staff, board members and members came together for the first time in the same kind of numbers as we had pre-pandemic. Everyone was thrilled to see each other again after a long and arduous few years. For Suzanne and I, as the newest staff members, the October Conference was our first opportunity to meet and get to know a large cohort of members.

Ukrainian members sharing their experiences

Discussion on experiences with different treatments

The Conference was jam-packed with informational talks and workshops. We started the weekend with a panel discussion on treatment options, where individuals discussed their own experiences on various treatments, or their children's experiences. What was particularly interesting about this discussion was how it highlighted how individuals think differently about their condition, particularly depending on which generation they come from. Following this, our Ukrainian members shared their own personal stories with bleeding disorders in Ukraine, reminding us of how lucky we are in Ireland to have such good treatment options.

Next there were two separate workshops, one for parents and one for anyone interested in gene therapy. The parents workshop was particularly interactive. Dr. Beatrice Nolan chaired the discussion and took part by answering any questions the parents had, while parents talked openly about any issues their children were having with taking their medication, discussing these with each other and brainstorming solutions together. At the gene therapy workshop, Brian O'Mahony and Declan Noone gave an in-depth presentation about this new form of therapy. At the start of the workshop members filled out a detailed questionnaire which was used later to determine whether or not gene therapy would be of interest to each individual. To start the gene therapy workshop, members filled out a detailed questionnaire to help focus on what is important to consider if gene therapy may be of interest to an individual, such as the time needed to dedicate to hospital visits for checkups.

After the workshops, we were all free to enjoy the hotel's amenities or relax until dinner time. The next morning we had our last 'serious' session, where Colette O'Donoghue discussed different types of insurance, from life to serious illness cover. It was a very informative session.

Kidlink group meeting the boa constrictor

Getting to know the Australian Water Dragon

While a lot of the conference was information packed, there was also lots of time for lightheartedness and fun. On Sunday afternoon before lunch, kids from Cubs, Kidlink and Youth all came together with their parents to take part in a drumming workshop, held by a Samba group based in Dublin. Each person was given one of a wide variety of percussive instruments, ranging from bass drums, to bodhrans to the triangle. Leading the session was Dave, who aptly gained and held the attentions of countless children and their parents throughout the hour. It was delightful to hear how the performance came together in the end. It was a wonderful way to finish off the weekend and gave us all a good appetite for lunch before our departure that afternoon.

The children's and young people's programmes were a great success this year, with lots of positive feedback coming from our evaluation forms following the event. A particular highlight was the visit from National Reptile Zoo in Kilkenny. Volunteers and children met exotic creatures such as the Australian Water Dragon, Emperor Scorpion, a tortoise and a boa constrictor. They had to be careful as the boa constrictor started shedding its skin during the meeting!

Sarah Charnock working in the creche

Thank you to all who helped make the 2022 October Conference a possibility, particularly to the volunteers, without whom we would not be able to hold such events. Thank you as well to all the members who attended. We are really looking forward to seeing many of you again at our AGM, our smaller information day events and at our next October Conference next year!

Roisin Burbridge, Publications, Website & Social Media Coordinator

Arts and Crafts

Meeting with the National Reptile Zoo

Educational Grants 2022-2023

Thanks to everyone who applied for one of our educational grants!

This year we received a total of 22 applications, which we received both in the post and online. The sub-group of the board met on 27th October to discuss and score the applications.

We are pleased to announce the recipients of the main Grants as follows:

Maureen & Jack Downey Grant

First Prize	Gabriel O'Connor	€4,000
Second Prize	Peter Walsh	€2,000
Third Prize	Eimear Farrelly & Molly O'Mahony	€1,000 each

Margaret King Grant

First Prize	Tadgh Moriarty	€2,000
Second Prize	Hannah Byrne	€1,000
Third Prize	Aaron Flanagan	€500

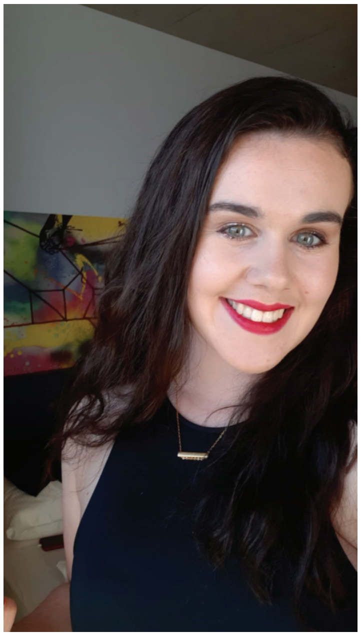
Father Paddy McGrath Grant

First Prize	Danniel Hanney	€1,000

While the full Michael Davenport Educational Grant for an adult with a bleeding disorder returning to higher education was not awarded this year, a grant worth €1,000 was awarded to Nicola Pentland in memory of Michael Davenport.

Congratulations to everyone who received a grant and best of luck with your studies this academic year!

Educational Grant Recipients: Hannah's Story



My name is Hannah Byrne, and I am a grateful second place recipient of this year's Margaret King Educational grant. I am in my final year of studying a Bachelor of Arts International degree in Drama and English at University College Dublin.

I have loved attending University and being given the chance to delve into learning subjects I am passionate about. Unfortunately, like many other students, a large portion of my university education has been online due to the pandemic. I was in UCD for just under 6 months before my classes were moved to zoom for the next year and a half. This was very challenging, but due to my love of the subjects, I was able to continue with my course.

I was lucky enough to be offered the chance to go on Erasmus for my third year. This enabled me to alter my standard Bachelor of Arts degree and I will graduate with a Bachelor of Arts International degree, which is valuable for job opportunities post university. I attended Utrecht University in the Netherlands, and I had the time of my life, learning about different cultures, mixing with people from all around the world, and finally attending in-person classes again. As this year was optional it extended my degree from three to four years. Due to this my fees also increased. I am very grateful to receive this grant to offset some of these fees. As well as this, commuting into Dublin each day and materials such as textbooks, adds to the cost of each year. This grant will enable me to put some money towards my fees and some toward my textbooks and transport to make my final year at university less financially stressful and more enjoyable.

I am currently working part-time at the Liffey Champion newspaper as a journalist around my university studies. After university I hope to pursue journalism as a career. Over the last few months, I have been working two jobs which have taken a lot of time away from my study. However, this grant has enabled me to leave one job. Due to this, I will be able to put more time into my studies, journalism and learning from the team around me before I look to full time jobs after university.

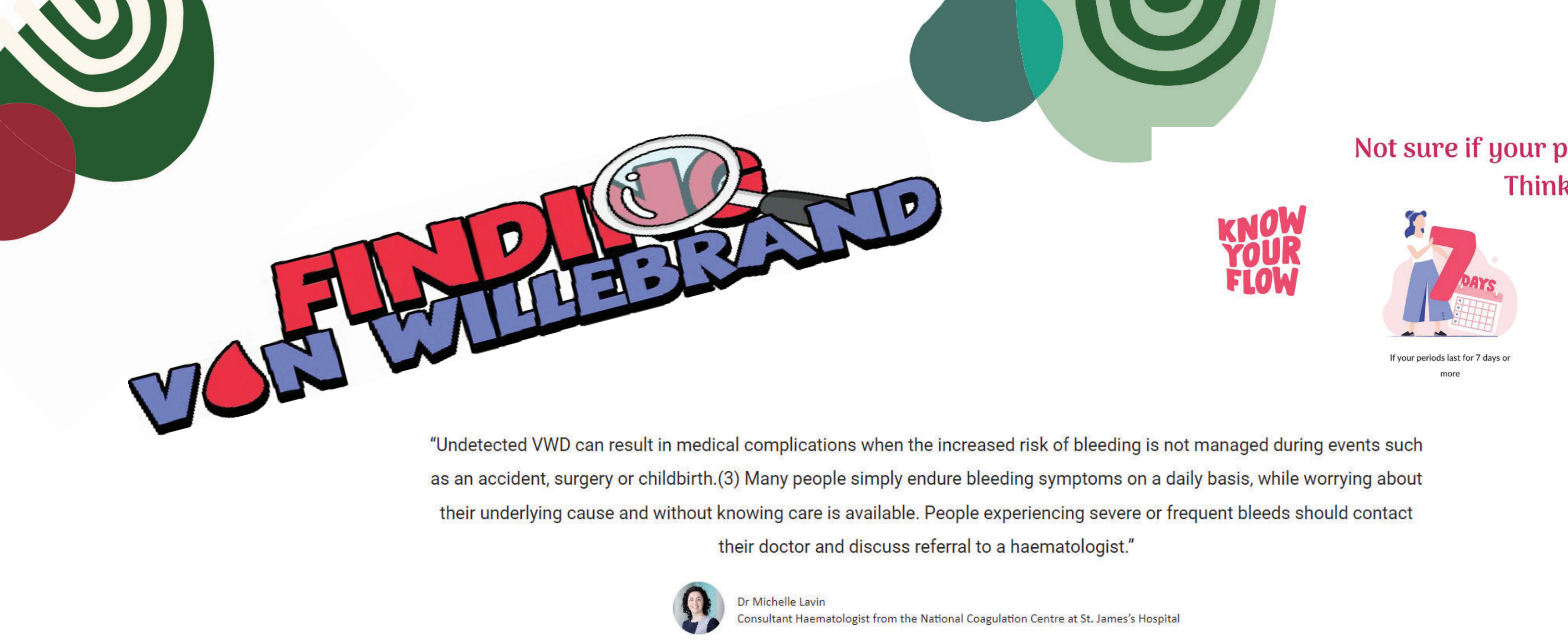
The Irish Haemophilia Society has always been a source of joy and support for me and my family. The AGM and October Weekend are a highlight of our calendar. With many of my family members, including myself, having volunteered and attended the children's programmes, the weekends are filled with such joy and great memories. As well as this, the Irish Haemophilia Society has always been on hand for any questions or support needed for my medical treatment. They were particularly helpful during the period that I was told that I am a carrier of Haemophilia.

The grant programme allows so many people to pursue education they may not have been able to without it, and I am incredibly grateful to receive it.

Hannah Byrne, Member & Educational Grant Recipient

Utrecht City where Hannah studied

Utrecht University



"Undetected VWD can result in medical complications when the increased risk of bleeding is not managed during events such as an accident, surgery or childbirth.(3) Many people simply endure bleeding symptoms on a daily basis, while worrying about their underlying cause and without knowing care is available. People experiencing severe or frequent bleeds should contact their doctor and discuss referral to a haematologist."

Dr Michelle Lavin
Consultant Haematologist from the National Coagulation Centre at St. James's Hospital

Finding von Willebrand Campaign

The I.H.S., with the support and collaboration of PR agency Wilson Hartnell and Takeda, have launched an informational campaign entitled Finding von Willebrand. The purpose of this campaign is to raise awareness about the symptoms and prevalence of von Willebrand Disorder as there are a high number of people undiagnosed with the disorder, with very little known about it among the general population.

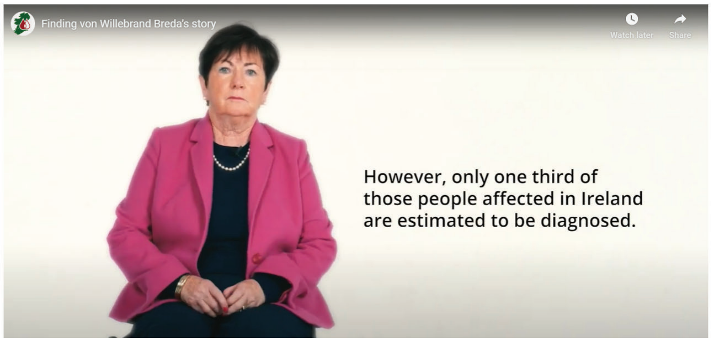
Another area that we want to highlight through this campaign is the fact that heavy periods are often a sign of an underlying bleeding disorder in women. One in five women have heavy periods, while up to 20% of these women may have an underlying and undiagnosed bleeding disorder such as von Willebrand.

As part of the campaign, our members, Shannon Carey, Donal McCann and Breda Quealy have all shared their stories about living with von Willebrand and how it has impacted their lives. Each story is unique and gives good insight into how the disorder can affect people differently.

If you are interested in sharing your own experiences with von Willebrand Disorder by writing an article for a future magazine or for our bi-weekly e-Zine, please email roisin@haemophilia.ie.

To view our Finding von Willebrand campaign, please find the 'Finding von Willebrand' webpage, or go to our homepage and scroll down and you will see it there.

Finding Von Willebrand: Breda's Story



However, only one third of those people affected in Ireland are estimated to be diagnosed.

IrishHaemophiliaSoc @HaemophiliaIRL · Nov 30

People with von Willebrand Disorder often don't know they have it.

If you get heavy nosebleeds or bleed for longer than normal you could have VWD.

Learn more through our #FindingvonWillebrand campaign.

Von Willebrand Disorder Information Day

On Saturday 3rd December, our von Willebrand members from all over Ireland met to learn and discuss all matters related to their medical needs, care, treatment, and concerns. Although the number of members attending this meeting was not where we would like it to be, the von Willebrand community was well represented and heard loud and clear.

Brain O'Mahony opened the day with a talk from the I.H.S. that covered all the supports and services around von Willebrand Disorder (vWD). He began with an overview of where the vWD community is currently at and how the I.H.S. is trying to grow it through publications, social media, and mainstream media. He also looked at a new campaign called 'Finding Von Willebrands', a new initiative to target GPs, healthcare workers and the general public in an effort to improve healthcare workers' overall knowledge of vWD.

We then had an extremely informative talk and presentation from Dr Michelle Lavin. She gave us an in-depth update on vWD from the point of view of the National Coagulation Centre, St James's Hospital. She opened her talk with an explanation of von Willebrand Factor and von Willebrand Disorder and how in each case it affects the body. Dr Lavin went on to explain how there is a need for improved vWD guidelines to standardise diagnosis and improve management for people with vWD.

We then looked at receiving a diagnosis of vWD and the management of the condition as we age. Dr. Lavin also explained the use of the bleeding assessment tools (BATs) and specific lab tests for vWD at the initial diagnosis and how genetic testing in the diagnosis can be optimal in some subtypes.

From that, we looked at the management of vWD for different patient groups. This covered the use of prophylaxis and other treatment option and patients undergoing surgery. The second part of this section covered women with vWD with heavy menstrual bleeding and women with vWD during labour and in the postpartum period.

The final part of Dr. Lavin's talk gave us an insight into the number of people diagnosed throughout Europe and how these numbers don't reflect the predicted number who are yet to be diagnosed.

The meeting was closed with an open and honest panel discussion with four people with von Willebrands. They spoke out about their experience of receiving a diagnosis, how they have managed life with vWD and their experience with different treatments. And to close they explained what they would like to see implemented to improve the support and services for people with vWD and for undiagnosed people throughout Ireland. Overall, the information day was a great success.

Robert Flanagan, Outreach & Children's & Youth Programmes Coordinator

Panel discussion on vWD

Dr. Beatrice Nolan

Brian O'Mahony, Decl
discussin

Youth group exercise class

Suzanne Fitzgerald &
Roisin Burbridge greeting members

n Noone & Luke Pembroke
gene therapy

Meeting the reptiles from the
National Reptile Zoo

Ciaran Dowling holding
an emperor scorpion

Enjoying the
excersising equipment

Skydiving for the Irish Haemophilia Society

We decided to raise money for the Irish Haemophilia Society as a close friend of ours, Ciaran, is affected by the bleeding disorder. Myself (Aaron), Elliott, Jack, Aideen, Daniel, Keith and Sean jumped out of a plane in honour of Ciaran.

I have always known that Ciaran has had haemophilia. Ciaran had always played down the seriousness of it but earlier in the year I was genuinely afraid that I had lost one of my best mates. I gave Ciaran a call about going to see the Red Hot Chili Peppers in Marley Park. His response was that he was in hospital and had nearly croaked it from food poisoning. With this being Ciaran I thought he was only having a laugh but as he continued to talk I knew it wasn't a joke. The food poisoning had caused him to get sick and this resulted in a small tear in his stomach, causing him to throw up blood, and was taken to hospital. At the time of talking to him he had spent a couple nights in hospital, in a stable condition and recovering which was a relief to hear. I still felt panicked and worried. I have yet to meet someone like Ciaran, a caring, empathic, hilarious guy. He is genuinely one of the funniest people I have ever met in my life and even after the call I had to take a few minutes to get over the shock of what had happened. I hope he knows this but there's a whole lot of love out there for you brother and we are all glad a takeaway didn't take you down.

Thank you to everyone who shared the donation link and who donated. Thank you to everyone who entered our competition where all funds raised went to the fundraising fund! For those who don't know, we raffled off two tickets to Kendrick Lamar and a ticket to Bicep next year. Thank you to the instructors at the Irish Parachute Club who getting us to the ground safely. Massive thanks to the crew who jumped who were the main drivers for the fundraising. Stay away from the 4in1s Ciaran, we love you brother.

Aaron Elliot, I.H.S. Fundraiser

The group raised a grand total of €2,446 for the

Society! Thank you all so much! If anyone is interested in fundraising for us, please contact nina@haemophilia.ie.

Callum Andrews: A Story of Adversity and Success

I want to share my son Callum's story, as he is a wonderful example of someone with haemophilia who has had a rough start in life but is now thriving through sports.

Callum was diagnosed with severe factor VIII deficiency at three months old in 2004. I am a carrier and my two cousins, now in their 40s, have the same strain of haemophilia.

Callum's early years were very traumatic. He had several large bleeds, reluctant injections via a port-a-cath, 3 bone breakages (which thankfully did not involve any major bleeds), a twisted port-a-cath that was removed and replaced and a severe needle phobia.

When Callum's port-a-cath was successfully removed, I started doing his intravenous injections. Many months were spent travelling to Dublin for vein training with huge support from all the nursing staff at Crumlin.


Callum playing football for Boyle Celtic

Callum was still very reluctant at this stage to do his own medication. However in 2017 I broke my shoulder and physically could not help him. Callum faced the difficult journey of learning to inject himself, which he succeeded in doing with the help and further encouragement from nursing staff and my own friend who is a nurse.

What I believe pushed Callum to succeed with his injections was his love of and desire to play sports. While he never 100% got over his needle phobia, he knew that the least worrying and least painful way to receive his treatment would be to do it himself.


Callum climbing Mount Snowdon, Wales with his 75 year old grandfather!

Throughout his life, Callum has always loved sport. From a young age he enjoyed swimming, playing football and climbing mountains with his dad. In 2017, he also started Gaelic football. At first, we weren't very keen on this. While we always encouraged him to try whatever he wanted, even though we knew that haemophilia would always be in the front of our minds, Gaelic was the one thing that we did discourage. Callum, however, was determined to try it out. At this point he was taller than me and I wasn't going to argue! At least he plays as a goal keeper and therefore he is not in the main line of fire!!

Callum signed up for the U18's Fenagh St Cailins Gaelic team as a goal keeper and he worked very hard for them. Callum was super proud to play as captain in their championship game and to raise the Championship Cup. He is now playing with the senior team as a substitute goal keeper.

Callum is also a keen soccer player. He was a valued player for Boyle Celtic U18 football for a couple of years and as he approached 18 he signed up for the Senior team. Both teams had some huge achievements and Callum was very much involved and is very proud of this. He plays the important position of striker and has scored many goals for the team. While as a striker he is really in the thick of it, with all his hard training routines he is not afraid at all.

With very few injuries Callum has proved that with the correct medication and a healthy lifestyle everything is possible for young people with haemophilia today.

Sara Andrews, Member


Callum holding up the cup after winning the U18 championship in 2022

A Special Thank You to All Our Volunteers!

On behalf of the staff, board, and members of the Irish Haemophilia Society, I would sincerely like to thank each and every volunteer, who dedicated their time and effort to the Society this year. Our conferences and events simply would not be possible without the dedication and incredible generosity of our volunteers.

You allow us to make our conferences family-friendly, super fun and very meaningful by creating a wonderful environment for the kids, that creates lasting memories and friendships. Dedicating so much time to the Society isn’t easy with many of you trying to balance work, study, family and social life so we cannot thank you enough for the tremendous effort you put into the weekends.

With this year moving on from Covid-19 we wanted many children and young adults from the Society to come and be part of celebrating with us at our AGM and Members’ Conference, and again our volunteers played an absolutely imperative role. This allowed for 132 children to experience memorable weekends of fun, games, sport, laughter and learning. There is nothing like the friendships built in the I.H.S.! Along with volunteering with our kid’s groups, some volunteers play a huge role in helping us with administrative tasks and lending a helping hand when needed.

So, it is with a beaming heart I say a massive thank you to all our volunteers whom we would be lost without!

Best wishes and Happy New Year to all of you!

Robert Flanagan, Outreach & Children’s & Youth Programmes Coordinator

IRISH HAEMOPHILIA SOCIETY

Preliminary Programme of Events 2023

AGM & Conference
March 3-5, 2023, Slieve Russel Hotel, Cavan

Parents' Conference
July 14-16, 2023, Venue TBC

October Members' Conference
October 20-22, 2023, Venue TBC

Women & Bleeding Disorders Conference
December 2-3, 2023, The Grand Hotel, Dublin

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.

NOTIC

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 call Rob in the office on 01 657 9900 or email robert@haemophilia.

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.

We will be resuming our home visits service in the new year. We are aware that not everyone can attend our events or conferences, so please do let us know if you would like us to give you a home visit. 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 or to book a home visit, contact Rob on 01 657 9900 or email robert@haemophilia.ie.

Bon Voyage!

Are you jetting off for Christmas this year?

Make sure to have all the necessary documents with you along with 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 by emailing info@haemophilia.ie.

EBOARD

BRIAN O'MAHONY AWARD

FOR OUTSTANDING CONTRIBUTION TO HAEMOPHILIA CARE IN IRELAND

Nominations are now open for the Brian O'Mahony Award For Outstanding Contribution to Haemophilia Care in Ireland.

Nominations can only be proposed by members of the society and members of the current board or staff cannot be nominated.

If you would like to nominate someone who, in your opinion, has made a real difference in haemophilia care in Ireland, please send your nomination to info@haemophilia.ie.

The deadline for nominations is January 31, 2023.

Write for the I.H.S.

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

Share a story about your experience living with a bleeding disorder, your experience at one of our events, fundraising, volunteering, or something entirely different!

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

Physio-Exercise Classes

Every Tuesday from 7-8 via Zoom

Open to male members

There is no charge for the classes

With Mark McGowan and Sheila Roche

For more info call the office on (01) 657 9900

BARRETSTOWN
a seriousfun camp

Barretstown in Co. Kildare run a range of exciting camps run from Spring to Autumn each year for all ages. We have enclosed the camp calendar here. You can also visit barretstown.org to view this online.

If you are interested or would like more information, please get in touch with Rob in the office on 01 657 9900 or email robert@haemophilia.ie

Hospital Opening Hours for the Christmas Period

National Coagulation Centre & H&H Assessment Unit - St. James's Hospital

NCC opening hours

Friday 23 December 2022 - Open (as normal) (8.30am - 5pm)
Saturday 24 December 2022 - Closed
Sunday 25 December 2022 - Closed
Monday 26 December 2022 - Closed bank holiday
Wednesday 28 December 2022 - Open
Thursday 29 December 2022 - Open
Friday 30 December 2022 - Open
Saturday 31 December 2022 - Closed
Sunday 1 January 2023 - Closed
Monday 2 January 2023 - Closed bank holiday
Normal services from Tuesday 3 January 2023

H&H Assessment Unit opening hours

Friday 23 December - Open 8am to 5pm – phone 01 4103130 to speak to the nursing team – (*Out of hours support from 5pm to 8am*)
Saturday 24 - 27 December – Closed
Wednesday 28 - 30 December - Open - 8am to 5pm
Saturday 31 December- 2 January – Closed

For out of hours support please call 01 410300 (St James main hospital number) and ask to speak to the Haematology SHO or Consultant on call.

Merry Christmas from the I.H.S.!

The office of the Irish Haemophilia Society will close for Christmas at 3pm on Friday December 23rd 2022 and will reopen on Tuesday January 3rd 2023 at 9am.

In the case of an emergency, please call 01 657 9900 where contact details for our emergency contact person will be found.

The I.H.S. Board and Staff wish you all a very Merry Christmas and a happy and peaceful New Year!

Cork Coagulation Centre - Cork University Hospital

Friday 23 December - Open (8am-1pm Half day)
Saturday 24 December - Closed
Sunday 25 December - Closed
Monday 26 December - Closed
Tuesday 27 December - Closed
Wednesday 28 December - Closed
Thursday 29 December - Closed
Friday 30 December - Closed
Saturday 31 December - Closed
Sunday 1 January - Closed
Monday 2 January - Closed
Normal services from Tuesday 3 January 2023 (8am - 5pm)

Should anyone need to contact the haematology services in CUH over the Christmas period, there is a registrar on call 24 hours. Please contact the CUH hospital switch on 021 4546400 and ask for the haematology Registrar on call.

Children's Health Ireland, Crumlin

Friday 23 December 2022 – Open (as normal) (8am to 5pm)
Saturday 24 December 2022 - Closed
Sunday 25 December 2022 - Closed
Monday 26 December 2022 - Closed
Tuesday 27 December 2022 - Closed
Wednesday 28 December 2022 – Open
Thursday 29 December 2022 – Open
Friday 30 December 2022 – Open
Saturday 31 January 2022 - Closed
Sunday 01 January 2023 - Closed
Monday 02 January 2023 - Closed
Normal services from Tuesday, January 3, 2023

The Haematology Oncology Service always remains open but the Haematology Oncology Day Unit & Service only operates Monday - Friday & closes for public holidays.
In the case of an emergency, please contact the hospital on 01 409 6100 and ask for the haematology registrar on call.