HAEMOPHILIA.IE

Magazine of the Irish Haemophilia Society

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

Wishing you all a very Merry Christmas and a Happy New Year.

SCAN ME

Winter 2023 Edition

From the Editor

Merry Christmas to everyone! I hope everybody has a nice break from work, school or college ahead of them.

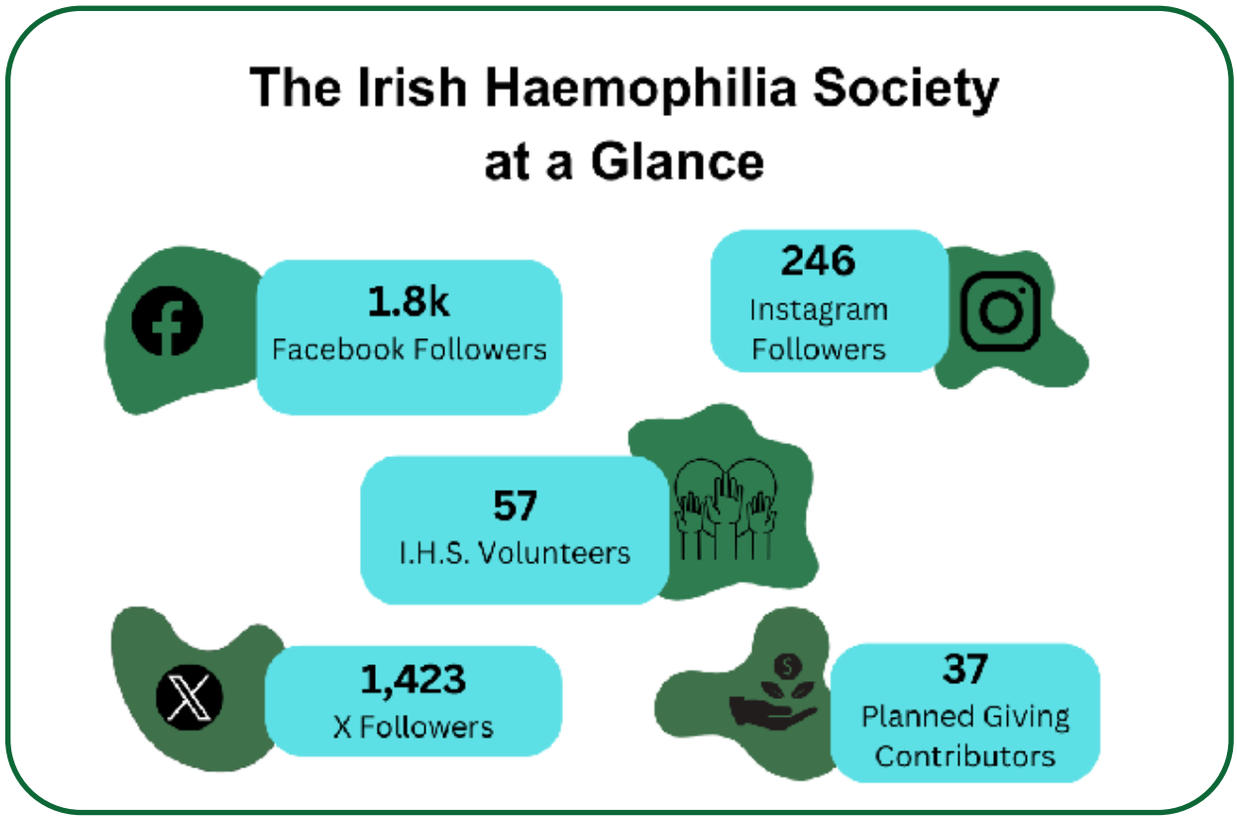
Another year has come to a close. It has been a busy year here at the IHS, with lots of conferences, information days and regional visits having taken place throughout the year. In Brian O'Mahony's CEO Report, he gives a rundown of these events and of some of the plans for 2024. He also discusses some developments that have taken place over the course of 2023, such as the return of the H&H ward in St. James's Hospital to patients with bleeding disorders and the unveiling of the HIV/AIDS Memorial in the Phoenix Park. Following Brian's update, Rob Flanagan and I give some insight into our October Conference, from the perspectives of the adults and children's programmes.

Next is the highlight of this season's edition - Colm Walsh's piece about his extraordinary experience and accomplishment of swimming the Fastnet Swim. Colm's personable writing style takes us through the whole journey, which proves to be just as emotional a challenge as it was a physical one. I have to admit that I did tear up a bit when I read the end of his story - he truly is an inspiration!

Another highlight of this edition is the interview I conducted with board member Jim O'Leary. Jim speaks openly of life before treatment and the considerable added burden of living with an inhibitor before the advent of Emicizumab. It was a pleasure to hear about Jim's busy life and the positive change he has helped to bring about for people with inhibitors and rare bleeding disorders through the European Haemophilia Consortium (EHC).

Later in the edition I give an update on how our von Willebrand Disorder Information Day went and on the EHC Conference in Zagreb. There are other bits and pieces throughout the magazine that I hope you find useful.

Roisin Burbridge, Publications, Website & Social Media Coordinator



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CEO Report

2023

As we near the end of 2023, we can reflect on a very busy and productive year. We returned fully to in person events and we were delighted with the attendance at our conferences during the year. In addition to the major conferences, the AGM / Annual Conference and the October Members' Conference, we also organised the Parents Conference this year for the first time in several years.

Our intention is to organise the Parents Conference every third year. We believe this is the correct interval to meet the needs of members as every three years, there should be sufficient new information to justify the meeting. In addition to the regular meetings this year we also had a von Willebrand Disorder (VWD) Information Day which had excellent content, while unfortunately the attendance was less than we had hoped. We had organised major national VWD awareness campaigns for each of the past two years. We will have to reflect on our approach to VWD in the future to try to optimise the involvement of people with VWD in our events and activities.

Members will have noticed that there were practically no zoom webinars organised by the society this year. Toward the end of 2022 we had detected a definite amount of zoom fatigue among members and, as evidenced by the attendance at our conference this year, their strong desire for in person meetings. Following the isolation of members during COVID we also organised regional meetings this year in Cork, Galway, Athlone and Letterkenny. These were generally well attended and we will review the necessity for regional meetings again in 2024. Our last in person event of 2023 was our Women with Bleeding Disorders Conference in Malahide in December. Again, we were very pleased with the numbers booked in for this conference.

Plans for 2024

Plans are already well advanced for the AGM and Conference in March 2024 in the Slieve Russell Hotel in Cavan, the October Conference in the Midlands Park Hotel in Portlaoise and the Ageing Conference in the Meadowbank Hotel in Tralee. Our current strategic plan calls for the Women with Bleeding Disorders and the Ageing conference to be held every second year in rotation.

Despite what I said about zoom fatigue in 2022, we are planning a series of six high level webinars on clinical issues with renowned clinicians for 2024 on topics including VWD, women and bleeding disorders, an update on novel therapies. These webinars will be targeted not just at members but also at clinicians and people with bleeding disorders in Ireland and abroad.

While we review the requirement for regional meetings next year, we are also putting in place preliminary plans to hold gene therapy meetings in several venues around the country in addition to Dublin. Gene therapy for factor VIII deficiency and factor IX deficiency are now licensed by the EMA and we are currently beginning the process of evaluating these and looking at reimbursement. If the gene therapies are available in 2024 as a treatment option for people with hemophilia, we are fully cognisant that this is a very significant decision for individuals to make and will require a very informed decision and a shared decision between the clinician and the person with haemophilia. We believe that the Society has a strong role to play in this process. We plan to organise meetings to update members on basic facts of gene therapy, eligibility, comparing gene therapy with other therapeutic options available to them and information on the monitoring and follow up requirements. The decision as to whether or not to take gene therapy is an irreversible one off decision which members have to fully consider. We believe that part of our role is to educate members to the point where they can engage fully and constructively with their treatment center. There is also an excellent shared decision making tool on the World Federation of Hemophilia website: https://sdm.wfh.org/, which I would urge members to take a look at.

To date, since the gene therapies have been licensed, four people with haemophilia B have been treated in the USA with the licensed factor IX gene therapy and two people with haemophilia A have been treated in Germany with the licensed FVIII gene therapy. The low numbers are reflective of the seriousness of the decision, the time it takes to come to a decision and the complexity of payment models and contracting for a one off therapy when there is uncertainty about the exact durability of the gene therapy. The shared decision making tool and approach are ideal for gene therapy but in fact can and should be used for all therapeutic decisions and for other aspects of care such as surgery, discussions on sports and activities and exercise programmes. The very exciting therapeutic landscape for haemophilia means that there may well be several treatment options in the future which people will have to navigate. In the past people with haemophilia tended to be told what treatments they were getting and then they would have a discussion about what quality of life this would give them and what activities or sports or exercise that

would allow them to participate in. A new approach is required with the advances made with new therapies. The person with haemophilia or parent can perhaps think of what restrictions hemophilia currently places on their quality of life, what sports or activities they would like to participate in reasonably, what career or travel options they would like to undertake and then, in this context, which treatment option might best serve their needs in the future. We are hopefully getting to a time when you can look to have the treatment that will suit your lifestyle and aspirations rather than tailoring or minimising your lifestyle or aspirations around the treatment you can get.

This was the subject of an excellent workshop at the October Conference when members discussed exactly those questions. This followed on from a symposium where parents and people with haemophilia or VWD spoke about their experience or their child's experience with various therapies including the currently licensed therapies and several products in clinical trials. Ireland is now and has been for the last 10 years proactive in looking at and seeking participation in clinical trials for haemophilia products. This helps place us in the forefront of innovation and gives real world experience of these products before they come to market so that we can make the best informed choice for the country when it comes to procurement.

H&H Ward

In September, we regained access for people with bleeding disorders to the H&H ward in St. James's Hospital. While this is excellent news, the lingering impact of the pandemic, hospital waiting lists and staff shortages have led to some other deficits in comprehensive care in the centres around the country. The comprehensive care centres in St. James's Hospital, Children's Hospital Ireland at Crumlin and Cork University Hospital will be externally audited by a team including an external patient representative in May of next year. This is done every three to four years and it has always been very beneficial in terms of highlighting the areas where improvement is needed. Indeed the very fact that the audits are taking place often leads to proactive action being taken to make sure some of these improvements are implemented around the time of the audits. We hope this will be the case in 2024.

HIV Memorial

It is now 40 years since we first raised concern about the potential for a new disease to be caused by a bloodborne virus. I am of course referring to HIV and AIDS. We have come through a long and arduous journey as a community to get to a point where we now have very safe and effective treatment. We have lost many good people along the way. I'm particularly pleased that finally after 40 years, a National HIV Memorial was unveiled in Phoenix Park on December 3rd by an Taoiseach, Leo Varadkar. I represent the society on the committee which commissioned the memorial and chose the successful artist. At an appropriate time and date in 2024 we will plan to host our own memorial event at the new National HIV Memorial.

Syrian families

Ending on a happy note, members will be aware that some years ago the Irish government committed to bring in a number of refugees from Syria into Ireland. As part of the Society and NCC twinning programme with Jordan, we identified a number of families with children with haemophilia from Syria who were refugees in Jordan and who were not getting access to any decent level of haemophilia treatment or care. Following many representations to the Department of Foreign Affairs and thanks largely to the persistence of Dr. Beatrice Nolan, the government included three haemophilia families among the limited number of Syrian refugees who were allowed to move to Ireland in 2023. Each of the families have one son with haemophilia. Their quality of life and treatment have been transformed since they moved to Ireland and we were delighted to meet the three boys with their fathers at the October Conference. Their future certainly looks brighter than a year ago.

Brian O'Mahony, Chief Executive

Takeaways from the 2023

As the Children's Programmes Coordinator for the Irish Haemophilia Society's 2023 October Conference, it is with immense pride and joy that I reflect on the success of this year's programmes. With a focus on inclusivity and age-appropriate engagement, we crafted programmes catering to four distinct groups: Creche (0-3 years), Cubs (4-7 years), Kidlink (8-12 years), and the Youth Group (13-17 years). At the October Conference, a total of 59 children embarked on a journey of enrichment, guided by the caring hands of 28 dedicated volunteers.

The Creche, for babies and children up to 3 years of age, was a haven for our youngest participants. It was filled with an array of toys, a designated nap corner and was full of laughter and exploration.

Recognising the importance of outdoor activities, the decision to take the Cubs, aged 4 to 7, into the fresh air after a week of rain was met with resounding success. The playground became a oasis for their boundless energy. The indoor activities, which included arts and crafts, parachute games, and musical madness, facilitated by our incredible volunteers, brought a balance of fun and learning.

The Kidlink, our largest group comprised of 25 enthusiastic children aged 8 to 12, was truly a dynamic force. The exercise session, led by our Chairperson John Stack, and the swimming session added a physical dimension to which is always good.

Those who attended the Youth Group, for teenagers aged 13 to 17, experienced a lovely reunion with friends. Along with attending the debate with the adults, they engaged in a spirited debate of their own, tackling topics such as school dress codes and the merits of homework, demonstrating their interest in participating in meaningful discussions.

The success of the Children's Programmes at the October Conference is a testament to the collaborative efforts of our staff, our wonderful volunteers, and the unwavering spirit of the participating children. It is not merely an event; it is an opportunity for babies, children and teenagers to reconnect.

I would like to thank all our fantastic volunteers who gave up their time during 2023 to volunteer at our three large conferences: AGM & Conference, Parent's Conference and our October Conference. Thank you, we wish you a very Happy Christmas and we look forward to working with you again in 2024.

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

23 October Conference

While the kids and teenagers had a fantastic time participating in the various groups, the adults enjoyed a conference full of varied talks and workshops. The weekend started with a session that has proven worthwhile the past two October Conferences - 'Different Treatment Options: Personal Perspectives'. During this, members shared their experiences (or their children's experiences) with various therapies. This included the perspectives of a member who is on a clinical trial for a new therapy for factor VIII, MIM8, known for its long half-life and expected to be licensed soon.

The debate which followed attracted an audience old and young. Volunteers and the Youth Group also attended this session. The debate considered which is the toughest bleeding disorder to have - VWD or haemophilia and was important as it highlighted the individual and shared struggles faced by people living with VWD and haemophilia.

Following this, there was an interactive workshop in which members broke out into groups and discussed four questions relating to how their bleeding disorder impacts their quality of life and their ability to live their best lives. The groups discussed sports, travel, work and what treatment option they feel would be best for them in future. Those with haemophilia were generally positive about their treatment and their ability to live their lives the way they wish to, while the rare bleeding disorder (RBD) and VWD cohort reported struggling more with their treatment options.

After the coffee break we learned about the new patient portal My Indici. Professor Niamh O'Connell shared some insight into feedback the team at the NCC have received on the Portal so far. Following this, Colm Walsh took us through the highs and lows of his astonishing achievement of swimming out from Baltimore pier to the Fastnet Lighthouse, an over 20km swim! Colm's resilience thoroughly impressed the audience and sent some to the verge of tears as he shared how much it meant to him to achieve this feat.

Sunday brought further informative and interactive sessions. The first session brought together many of the women of the conference (and some of the men) as Dr. Megan Kennedy asked the female members of the audience to fill out the Women's Opinions and experiences of Menstrual health on Exercise and physical activity Nationally (WOMEN) survey, which asks questions about pain and the menstrual cycle. She also shared some of the findings of the iPATH study. This study measured physical activity in people with haemophilia, finding that this group scored lower on tests of aerobic fitness, upper body strength and balance than people without haemophilia. On the other hand, the research showed similar rates of being overweight and obesity in people with haemophilia as in the general population.

After this session, Rob Flanagan gave a fantastic presentation on travelling with a bleeding disorder. He highlighted the need to carry a copy of the Ambulance Directive and to have a Bleeding Disorder Alert Card when travelling within Ireland and the importance of reaching out to the IHS when travelling abroad. He also stressed the need to have an EHIC card and travel insurance when visiting other countries.

Finally, our Conference weekend closed with a fun and competitive family quiz, which tested parents and children's knowledge of areas from music and history to movies and geography. It was a thoroughly enjoyable way to end the weekend!

Roisin Burbridge, Publications, Website & Social Media Coordinator

My Fastnet Swim

Adapted from the full article, which will be available to read on the IHS website.

As some of you will remember, I do a lot of swimming. It keeps my body in relatively good shape following the bleeds and accidents I have had to my legs. After getting into open water swimming and doing distances of 5km and 10km I started considering longer swims, of 20km plus. I had heard about the Fastnet swim and when I researched about it all I can say is that it really drew me in. The swim itself is between 20-22km. You either start at Baltimore pier and swim out to the Fastnet and touch it, conditions pending, or you start out at the Fastnet and swim into Baltimore pier. You swim with the tide. In March 2022 I signed up for this legendary swim. My life for the months before the Fastnet Swim were spent training in the sea or in the pool when weather conditions didn't suit. My invalidity pension allowed me the time to swim when it suited me best.

My swimming window for the Fastnet Swim was between the 6th -14th of September. This is when the neap tide occurs, meaning that the least amount of water is moving between tides. I got a call from Nathan on the Fastnet Team on the 4th to let me know to be ready to do the swim the following day, but the next day the phone rang again to inform me that conditions were not great and that the 7th looked better. On the Wednesday I got a call to tell me that we were a go for the next day and to be on the pier in Baltimore at 9am. I was to be in the water at 10am swimming from Baltimore pier to the Fastnet Lighthouse.

With the date set, I got in touch with my crew, Alex and Adrian, and they were all set. Sinead was also going to join to help out. I got my feeds made up and I did an injection just to give myself cover for the swim, as discussed with Dr. Duggan and the nurses from the Coagulation Centre in C.U.H.

The next morning I met the crew of Radiance (the boat that was going to sail alongside me) Nathan and skipper Kieran, Alex and Adrian. Everyone was set to go. Feeds and gear were put on the boat, sun cream was lashed on, lanolin was lashed on, goggles were de-fogged and my sleeveless wetsuit was done up. Nathan filled out some necessary forms as he was my observer and would be making notes on the time of feeds, the amount of feed taken and on my stroke rate for the ILDSA ratification. Down I walked to the slipway with Sinead by my side, holding my hand to steady me as I entered the water. I gave Sinead a kiss and she went away after wishing me luck. I stood there alone in the water up to my ankles, looking out of Baltimore pier and waiting for the hooter to sound to start my swim. I just thought of all the hours and kilometers I had swam to work up to this point. I thought, let's go for it. Kieran sounded the hooter and I slowly got down into the water and started to swim. My Fastnet Swim was on.

The water in the bay was lovely and calm and I was getting into my stroke and just taking it easy as I knew it was not going to be this easy once I got out to open water. I breathe to my right so Kieran was on my right hand side, as we had discussed before the swim. He was going to take me close to the rocks on my left as we left the bay and past the iconic beacon. As I looked up while passing the beacon, what I was doing suddenly hit home – it was such a special moment. I was passing this stunning view of the beacon above me that not a lot of people see, while swimming in lovely calm 17.2 degree water and heading out to the Atlantic Ocean. Far away was my destination of the Fastnet Lighthouse.

I swam past the beacon and the swell started to build, as there was a small bit of wind from the east blowing from my left to right. As I breathe to my right, this would theoretically stop me from swallowing water. Little did I know what was in front of me. My stroke is breathe once, take a stroke, breathe again and then two strokes. However, this was not working, so I had to switch to breathe after every stroke. This is not my normal stroke, and I was not comfortable. The swell

was getting bigger and I was going up and down, and I could see the boat beside me starting to move up and down a lot, with my crew holding onto the rails and watching me. They knew I needed to settle and get into my groove.

The waves were getting bigger but were at a constant pace, which helped a tiny bit. I could judge when to breathe and stroke. I told myself to just go with it and see. It would get better and easier as I kept going. This did not happen. As Adrian put on his high visibility vest to signal feed time, I was glad to know I had one hour done. The feed bottle was thrown out to me on a long dog lead, and I tried to get some of it into me. I was bobbing up and down in the swell, treading water with the bottle in my hand trying to go on my back to get some nutrition into me. I got some in and off I went again. I knew there was another feed in 30 minutes. My goal was to go feed to feed. I knew not to think of time or distance.

My crew were settling in and watching my stroke and how I was doing. I did not feel good at all and after the next feed they said to me to try to swim on the other side of the boat, as it would give me shelter from the swell. They put a weighted ribbon in the water so I could sight directly underneath me. I tried this but unfortunately it was not going to work. The diesel fumes from the boat were too much, and I was not going to be able to stick at it. I moved back over to the port side and got back into the swell coming from my left to right. I was all over the place but making good headway despite the conditions.

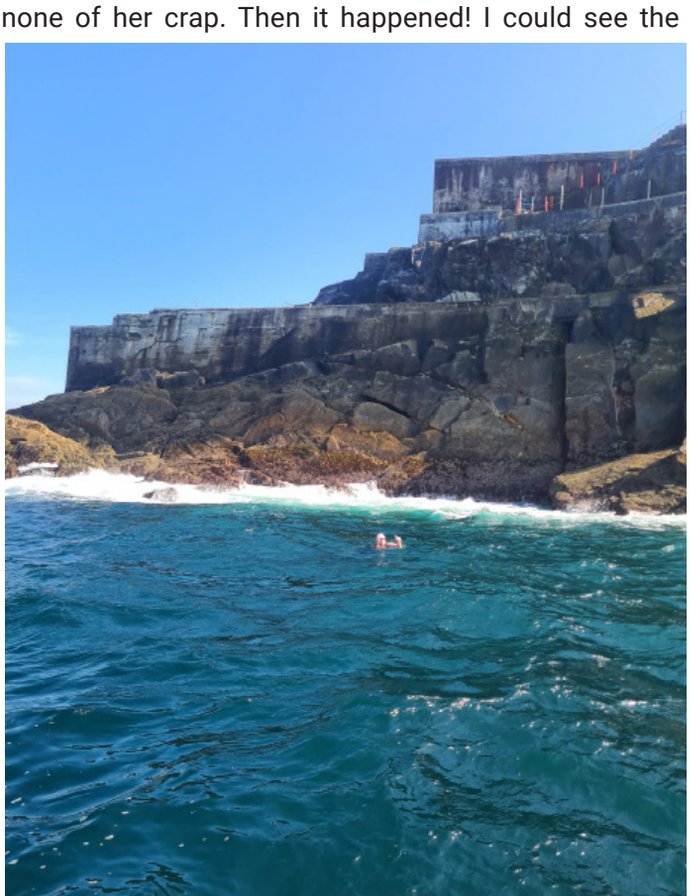
Alex put on the high visibility vest and Adrian and Sinead got the feed ready. I got some of it down into me but not all of it. The crew asked how I was feeling, and I said I wasn't the best. Because of the swell my feeds were not settling in my tummy and that was making me feel uncomfortable and nauseous. We passed Sherkin island and made our way to Cape Clear with no ease from the swell. We were roughly 90 minutes in and I was starting to doubt myself. My mental wall was getting bigger and bigger in front of me.

I could not get my stroke going in a comfortable way and my tummy was getting worse with the up and down of the sea. I was out in the Atlantic Ocean and she was not going to make this easy for me. As I was just about to take my third feed a wave hit me and really annoyed me. Why was I doing this to myself? Nathan yelled over to me to slow down and just take it easy. I said I would try. I swam for another bit but the feeling in my tummy was just awful. Everything was going wrong, and I let out a yell and hit the water with my hand out of frustration. I stopped and shouted, 'I am done, finished! Get me out!' Sinead insisted, 'No, you can do this'. Alex said 'Come on you got this'. Nathan said, 'Keep going!' I did, but that wall was huge at this stage, and every fibre in my body was telling me to get out. I knew that my fifth feed would be roughly around the half-way mark. I told myself to just get to the next feed, which was number four. I did get to the fourth feed but I still felt awful - my stomach was not good, my head was not in a good place and I was dealing with a sea that was not making it easy for me at all. I got a tiny bit down for my fourth feed and went on a bit but I stopped and said 'Right, that is it, I am done!' Nathan said 'How badly do you want this? Just keep going!' I knew my half-way feed was close and that I just needed to get to it. I went on again and the wall rose up in front of me and I said to myself, Colm, you are not going to do this. I was at my wits end. My tummy was doing somersaults with the swell. The feed bottle was thrown out to me and I got very little into me. Adrian shouted over to me to give myself 10 more minutes. I said, 'I am done.' Then it happened.

I looked over at Cape Clear and saw the chimney stacks. Brian, who had crewed for another swimmer earlier in the year, had said that once you see them you are halfway to the Fastnet. I had to stop and look again to make sure I was not seeing things. Then it finally happened - all the liquid feed I had taken decided it was not staying in my tummy any longer! I vomited up everything that I had taken in. It was just like a sea of purple Miwadi in front of me! I just kept getting sick. This felt awful but wait! My tummy was feeling better. The crew were looking at me and watching what was going on. I started to swim and thought, right let's try this again. Off I went a small bit and got sick once more and then I knew there was nothing left inside me to come up. This was the turning point. I could see the crew hustling on the boat and after three minutes they called me over and just said get this into you, no questions.

This was a critical point - if I did not get something down me in the next 10 minutes I was done. Adrian, Alex and Nathan were marathon swimmers themselves and knew how important this feed was, so I said nothing. They threw me a bottle with very little Lucozade in it and I drank it down in two gulps. What I didn't know, although Sinead assures me that they all shouted it to me, is that there were two Panadol tablets crushed into the Lucozade. My bad elbow was a bit sore but all ok, this drink helped it. And now, this was it. Colm was about to be unleashed on the Fastnet and was not going to take NO for an answer!

Feeling a lot better now after taking the small amount of feed and paracetomal, I started to swim like I knew I had in me. I was still breathing every stroke, but I felt like the fire was after being lit inside me and this was my time to show the Atlantic Ocean what I was made of. Head down and ass up and swim, as they say, which is a term Rob, a fellow Sandycove swimmer, uses to say get going and show what you are made of. I was swimming and making good progress. Alex put on the high visibility vest and the feed came and I took what I wanted and off I went swimming again. Now I felt I was in a good place and as Alex was having a sandwich I gave him the thumbs up and he smiled back and gave me the thumbs up back. Sinead was doing a bit of social media for my swim buddies and telling them how I was getting on. Adrian was keeping an eye on my stroke rate, and Nathan and Kieran were up at the top of the boat keeping course and also monitoring me. I was swimming and I was going for it. The swell was after dying down a bit and the sun was out and I was swimming in the Atlantic Ocean and I was taking none of her crap. Then it happened! I could see the



outline of the Fastnet lighthouse just on my right, just in front of the boat and this really got me going. I said, 'NO WAY are you going to beat me - I am going to get to you!'

At this point Adrian was going to join me for a small bit of company - this is allowed in ratified marathon swimming. He pulled to my left and off we swam. I was going at a steady pace and unknown to me, making real progress. The tide and wind were pushing me along and I was swimming strong. My body was feeling ok, and my elbow was ok. Adrian swam with me for 30 minutes and then got out. I had my next feed and all was ok. Alex gave me the thumbs up and told me to keep going. I could see Nathan was filling in forms and Sinead was videoing and taking pictures. Everything was running well and I was swimming well.

Then that little outline of the Fastnet I saw earlier was after getting a lot bigger and I was getting closer and closer.

Next feed Kieran the skipper shouted over to me to look, as it was there for me. He said to go and get it. They were all cheering for me to go on. The image was getting bigger and bigger and I was feeling good and my body was firing on all cylinders. I was enjoying my swim now even though it was still tough. Everybody on the boat was doing what they were supposed to do and I was swimming. Then Alex said the words every swimmer wants to hear - LAST FEED. I could barely believe it. I kept the head down and then as I looked up, there she was, around 1km away - the Fastnet Lighthouse, The Rock. It was there and I was swimming towards it. What a sight it was. There was a boat of tourists out there with us looking at the lighthouse. My crew got them to cheer as they passed me, as I was on the home stretch. What they must have been thinking seeing this man swimming out to the lighthouse - he must be mad!

As I got closer to the Fastnet I could not believe it was going to happen. I was going to get there. Oh this is a big rock out in the middle of the sea with nothing around it whatsoever. I swam and followed my boat crew. They were shouting at me to keep going and to swim to a certain point. I swam and approached the rock and was careful as there was a nice swell hitting off the rocks and the lighthouse towering in front of me. I was mindful and could see rocks underneath me. I had to get close enough to maybe touch the rock, but that was not going to happen today because of the swell. My crew knew that I could not risk banging any part of my body off the rocks, especially my leg. They shouted at me to turn and look up, and there it was - the Fastnet Lighthouse towering above me. Then Kieran sounded the hooter, and I had done it. They told me to put up my two hands and thumbs to signal I had finished. That was the moment that I had waited for and trained for the past nine months.

In that moment I had achieved something not many people can say they have done. I had swam 20.3km in 5 hours 53 mins and completed a swim that is in the Irish Triple Crown of swims, the other two being the North Channel and Galway Bay. Plus, the Fastnet swim is one of 'The Toughest Thirteen' swims in the world. I swam back to the boat and all the crew were cheering for me. I was going up and down with the swell and just flapping around a bit.

My arms were done and my whole body was in a state of shock with what I had just put it through. As I got to the back of the boat the ladder was lowered into the sea for me. All the crew were clapping. I swam towards the ladder and the crew got ready to help me onboard. Nathan lay down on the floor of the boat and Alex was there to guide me up. My last hurdle was climbing up the ladder with one bad knee and a bad hip on the other side. I put one foot on the step, grabbed a rail with one hand and put my other foot on the same step, and Nathan was able to grab me by the shoulder. Alex had my other shoulder, and I just took it one step at a time, climbing very slowly onto the boat. Nathan and Alex helped me hobble to a seat and I sat down, and my Sandycove swim club towels were draped over me. Everyone was patting me on the back. Sinead sat beside me; Nathan said 'You did it!' Adrian and Alex hugged me and Kieran came down and shook my hand, hugged me and said 'Well done!'

The tears started to flow from me as I could not keep it in anymore, what I had worked so hard for, what I had trained for was now done. I had overcome so much during the swim to get here. I had to just let it out somehow and tears were the way. We all looked up again and there it was, the Fastnet Lighthouse towering above us all and saying to me - Colm, well done, you did it - YOU SWAM THE FASTNET!

As I sit here writing this the sun is out and it is Saturday the 9th of September. We are having a heat wave and my body is feeling ok. I am going to go for a paddle later this evening with Sinead in Sandycove, where I have trained so much for my swims.

I would like to thank Dr. Duggan and all the staff and nurses in the Coagulation centre in C.U.H. for all their help and support in preparing me for the swim. My GP Dr. Dillon for the medical and her support. I also want to give my thanks to the Fastnet Swim team of Skipper Kieran, Observer Nathan and Noel who never hesitated to take me on, even with my medical history and small mobility problems. I thank my crew of Alex, and Adrian who were there with me through it all. Thank you also to my family who always support and encourage me with my swimming.

I also want to thank my Sandycove Island swim club buddies who are always there supporting, giving advice, helping out, sharing knowledge and just an inspiring bunch of people I am so, so proud to call my friends.

Finally two people who have supported me through this whole journey of 18 months. My swimming buddy Brian was there for me through the long training swims and small swims and was always there to throw ideas at me and have chats after a swim. Brian THANK YOU for everything.

Sinead, you were there for me getting up those early mornings in the winter heading to the pool and always asking how was my swim and how I was feeling. You were there when I doubted myself and just needed someone to talk to. You were there to help me when I needed help changing out of my gear after a long swim. You fed me well and always had my back when I needed to eat well and just kept me on the right track. You were also there on the boat on the day of the swim, going above and beyond your duty, helping with feeding and anything else that needed to be done during the swim. A HUGE THANK YOU TO YOU.

I do not know what my next swim will be or even when it will happen, but I have the Fastnet done. She did her best to stop me and she nearly succeeded but I dug deep and broke down that wall brick by brick, and just BELIEVED in myself, and that is all any of us can do.

BELIEVE ANYTHING IS POSSIBLE AND YOU CAN ACHIEVE ANYTHING YOU WANT.

Colm Walsh, Fastnet Swimmer, 20.3km 5hr 53 mins.

Interview with Mr. Jim O'Leary

Mr. Jim O'Leary is a member of the Executive Board of the IHS and is currently an advisor to the European Rare and Inhibitor Network (ERIN) at the European Haemophilia Consortium (EHC).

The following is an interview Roisin Burbridge conducted with Mr. Jim O'Leary in Autumn 2023.

Could you tell me a bit about growing up with haemophilia in the 60s and 70s?

It was a different time totally. I was born in the mid 50s as the first person in my family to have haemophilia. I was diagnosed when I was two, which was quite early for the time. My GP was sharp. He noticed all the bruising I was having and referred me to a paediatrician in Limerick, who ran some tests and made the diagnosis of haemophilia. Having been diagnosed, there was still nothing they could do about it. There was no treatment for haemophilia in those days. The norm if you had a bleed was ice packs and bed rest. I went through a lot of sleepless nights, due to the very severe nature of arthropic pain.

I was lucky in that my parents weren't overprotective, and I was still allowed to cycle and kick a ball when I wanted to even though it caused lots of ankle bleeds. I spent a good bit of my time in bed and missed about 50% of my schooling because of bleeds. One of the benefits I suppose was that I became a voracious reader. I read everything I could lay my hands on, up to six books a week was not unusual for me in those days.

In 1968 cryoprecipitate became available and that was a big breakthrough. It was administered at the National Children's Hospital in Harcourt Street. I had my first treatment in 1968/1969. This was an infusion where you had to be put on a drip for two or three hours in the hospital. Because I lived so far from the hospital, I would have to stay in.

After being on cryoprecipitate for about a year I developed an antibody, an inhibitor. This meant I couldn't have the cryoprecipitate anymore because it would shoot my inhibitor level up and my inhibitor would consume the product, rendering it worthless. Because of this, I went through a period where I wasn't having regular treatment and would only receive cryoprecipitate if I had a very serious bleed.

Even when they started developing some of the more modern-style refined products – anti-clotting agents, my inhibitor denied me having access to those unless I had a very serious bleed. Inhibitors were a major stumbling block. About one in four would develop an inhibitor in those days.

The first real support effort for people with haemophilia was the founding of the Irish Haemophilia Society in 1968, as previously there was no information available and no single contact point for families to use. I wasn't aware of any other haemophiliacs when I was a kid.

Did you only really start meeting other people with haemophilia when you started going to the hospital?

Yes, I met one or two others with haemophilia at the Children's Hospital and realised that there are other people out there with the same problem as me. As I moved from the Children's Hospital into the adult facility, which was in the Meath Hospital in those days, I got to know a lot of people because everyone had to come into the hospital to get their cryoprecipitate. We had a four bed room so there were generally three or four staying there plus the guys living locally who could come in and get their infusion and then go home. We got to know each other and built up a good community. A lot of stuff went on in that little ward when we were in our late teens/early 20s. All night poker games and things like that.

That sounds fun! At what stage were you able to go on regular treatment?

I was 28 years of age before they brought out a product which bypassed the inhibitor, known as an APCC. This was the first effective treatment. At that stage, I'd moved to the UK and had started on home treatment. That made a huge different - I could treat as soon as I had a bleed.

At that stage I was travelling a lot for work. I had a busy work life, working for an American multinational as

their European accountant. I travelled a lot to Germany and France. My responsibilities expanded until I was looking after nine offices in Europe. I was also travelling to the States for meetings. The by-passing agent I was using required large doses, you had to give 120mls for one treatment, so if you wanted to carry three or four treatments you would need an extra suitcase, which was not really practical. I tended to travel with a briefcase and an overnight bag and that was it. So I made the decision not to bring the product with me and to take my chances. If I was in Germany or France or somewhere like that, I figured I could always catch a flight home if I had a bleed. It was a risky strategy but it was forced by the practicalities of travel, and business travel especially. Hotels in those days didn't have fridges and treatment centres were few and not well known.

That was on demand treatment. When did you start on prophylaxis?

I didn't. I never took prophylaxis, until 5 years ago when I started on Emicizumab, the product I'm on now. My inhibitor is a pretty vicious one and trying to get rid of it was always difficult. Because of my lifestyle, I could never commit to doing Immune Tolerance Induction (ITI) or one of these intensive therapies to try to get rid of it, because it would take up so much time. I still have the inhibitor, but I don't have the bleeds anymore because of Emicizumab. I haven't had a bleed in five years.

What is it like for people who develop inhibitors today?

Most inhibitors develop within the first 50 exposures to the factor VIII or factor IX and those who develop them today will almost always be placed on ITI. Haematologists agree that getting rid of the inhibitor is the most important thing to do. While the inhibitor can go and come back again, ITI has a 60/70% success rate of eliminating the inhibitor.

The Newstalk documentary 'Tainted Blood' about the HIV crisis recently aired. Can you tell us a bit about what this period was like for you?

I moved to the UK in April 1984 with my job. I was just married the year before and my wife was pregnant with our first child. It was just before that time that we started hearing a lot about this virus that was affecting haemophiliacs. There were a lot of stories coming from the US especially. No one really knew a lot about it and no one was getting much information about it. But when I moved to the UK and registered with the treatment centre in Birmingham they said they were starting to test everybody for this. There was only one laboratory in the UK, situated in London, that could handle the testing, so everybody's tests went there. Unfortunately, it took three months to get results back. That was horrendous. There was a big stigma around AIDS. In the public mind it had become linked to haemophilia, partially because the haemophilia associations were making a lot of noise about it. So if you said you were a haemophiliac people often assumed you were an AIDS victim and tended to back off from you. Because of that you tended not to tell anyone you were a person with haemophilia. If you were looking for a job and said you had haemophilia you wouldn't even get an interview. Luckily I was already established in my job. Being told what HIV entailed, that there was no cure and that it was a death sentence and then being told that you were going to be tested for it and that it was going to take three months to get the results, that's a tough three months. I couldn't discuss it even with family. You're waiting three months to find out if you are positive and trying to work and carry on normal life, knowing this is happening.

My inhibitor probably saved me from getting HIV, since I wasn't receiving much treatment. I avoided the worst of the batches that were coming through. So yes, it was an awful time and as a community we all lost family, friends, people we looked up to, due to failures in our care which need never and should never have happened.

It sounds very isolating to have to deal with all that on your own. When did things start getting better?

As I said, because of my inhibitor I was in a different world to the rest of the haemophiliacs. Once the products were heat treated they started being safe again. As more products became available, such as extended half-life products, it gradually improved for them. For me, and others with inhibitors, the by-passing product I started in the 80s was a blood product and remained the exact same until I started on Emicizumab in 2018. It was a bit of a mystery product with nobody knowing exactly why or how it worked to bypass the inhibitor. There was a new recombinant product that came out in the 90s. I trialled it but clinically I didn't respond as well to it as I did to the other bypassing agent, so I stayed with APCC.

Since then, what has your adult journey with haemophilia been like?

It's been a roller-coaster because of the inhibitor. Over the years I've had several serious bleeds that could have killed me. I had a brain bleed and a failed knee replacement that I had to have removed, which was a huge issue. I had a big abdominal bleed. I had an eye bleed behind my right eye and in 2020 during Covid I had successful oesophagectomy surgery. I came through all of those and survived them by, I believe, pure stubbornness.

Having a bleeding issue meant needing to take time off from work, which was always an issue for me because my job was so busy. There were even times when my employer would have brought work into me in the hospital because deadlines had to be met. It was a case of well yeah you might be ill but we have to get these accounts in before the deadline. I have worked from a hospital bed on more than one occasion.

So when did you retire?

I retired in 2015 when I was almost 59. At that point I'd done 40 years of work and I was developing other health issues. I knew that when I would retire I wanted to move back to Ireland. I had only planned on trialing the UK for 2 years and ended up spending 32 years there. My kids were brought up there and educated partially in England, one of my sons went to UCD for third level and the other one went to Keel and Cambridge.

Have you enjoyed retired life?

Absolutely. I had retired with a plan. I had wanted to give up the financial work I was doing but also to reinvent myself and do something else. My plan was that I would get involved with something to keep my brain active and stay involved with people because that's what I like. For a few years before I retired, I had been coming back to Ireland for IHS meetings and I'd reconnected with Brian and others that I knew. I hoped to find something helpful that I could do for the bleeding disorder community once I retired, as I was feeling guilty that I hadn't had time to advocate for bleeding disorders for many years. I had been involved in the 70s with the IHS, I was on the committee for 2 years while I was a student. We spent our time trying to raise money for the Society at that point.

I was co-opted onto the Board in 2016 after coming back to Ireland in 2015. There was no one on the board with inhibitors at that point and we, the inhibitor community, were feeling quite left out at conferences. The inhibitor group is a very small community within a small community. I felt that we needed to be doing more.

Brian introduced me to the EHC and I went with him to a few meetings in Brussels. They were talking about setting up a European Inhibitor Network at the time. I saw that as an avenue in. I was actually turned down on my first attempt to join the network because nobody knew who I was. In 2016, the following year, I was added. Advocating for inhibitors has given me a new lease of life.

What is the general role of the inhibitors network?

Because most countries only have a small population of inhibitors, the EHC wanted to pool all of the populations in Europe together and build a big community. We got it up and running in 2015 and started by organizing a summit, an annual get together. Barretstown was chosen as the venue so that families could get involved. This was probably the best thing that we could have done since meeting others who have similar problems is always so helpful for people.

The inhibitors network also set up online peer-to-peer sessions every three or four months. These sessions are basically an open forum for people to talk about their problems and what they need. We have also produced a lot of information and we advocate at the European Parliament. We have had minimum standards of care developed for inhibitors and other things like that. We have done quite a bit in terms of advocating and because of this we're pretty well known now. We're also the first subcommittee of the EHC. Since then, the EHC have set up subcommittees for VWD, Youth and Women with Bleeding Disorders.

Since the advent of Emicizumab, there was the feeling that a lot of the treatment issues for people with inhibitors had been resolved. We started looking at other rare bleeding disorders (RBDs) who have even smaller communities than the inhibitor community. Some of them are very isolated and have a lot of issues.

It was decided to use the European Inhibitor Network model and expand it to add RBDs. It was renamed ERIN (very subtle!). European Rare and Inhibitor Network. We had a combined summit in Barretstown last December for inhibitors and RBDs where a manifesto was set up for rare bleeding disorders, stating the things we need, why we need them and what our plan is. There was a new board appointed for the ERIN committee in February. We had our first meeting in July in Brussels. The ERIN committee have some planning done for the next year and through the end of 2024.

The committee plan to achieve some important things in this period, starting with data collection. Currently there isn't a proper data registry with information about where people with RBDs are based and what their issues are. We're trying to gather this information by issuing surveys through the NMOs and hopefully get these back completed by the end of this year. ERIN are also hoping to have a summit in 2024, though it has not yet been decided where this will be held. This will be for RBDs and inhibitors. We want to keep the

existing community active and so we're carrying on with initiatives we had set up, such as the national inhibitor ambassador initiative. I am the ambassador for Ireland, meaning that I work both ways between the EHC and the IHS to try to solve issues faced by people in Ireland with inhibitors. We may in the future look to see if the ambassador role will work for RBDs.

ERIN are basically going back to the beginning again to see if we can build something similar to what was built for people with inhibitors. The EHC wants to build a home for people with RBDs so they feel there is somewhere they can turn to.

What challenges do people with rare bleeding disorders face?

People with RBDs face a lot of similar issues to people with inhibitors. One is isolation, because it's such a small community. A lot of people don't know anyone else who has their condition. The idea of a European community puts those people in the same room. We've already put people in contact with others with their condition, from across Europe.

Lack of access to information is another thing. Because these are such rare bleeding disorders, there isn't a lot of available information and so people turn to Google and we know Google isn't always the best source of information. We're hoping to beef up useful information and put this on our website.

Lack of access to good treatment is another issue. There are no treatments for a lot of these RBDs, like there was no treatment for inhibitors. But there are now research programmes for some of these RBDs. There are trials going on and products in development. We're trying to put that information in the public domain for people through the Novel Product Reviews we put together at the EHC.

We hope that by pooling our medical resources in Europe and by pushing our advocacy work we can raise the profile of these bleeding disorders and provide that home for people so that they have somewhere to turn for information and support.

I've enjoyed being able to give something back. I'd like to think I've contributed to the Inhibitor Network. I've seen some positive outcomes from it. I'm no longer an official member of the committee but I'm acting as an advisor to the ERIN committee. It's a new role created by the EHC for someone with experience in the European Inhibitor Network. We'll hopefully get a blend of old experience with new ideas. We have a whole bunch of new people on the committee who are very enthusiastic.

What does your role on the Board of the IHS involve?

I was co-opted onto the Board because I have inhibitors and we try to have a blend of people on the Board. We have parents of kids with haemophilia, people with VWD, myself with inhibitors, one parent who is a nurse.

One of the main reasons we exist is the governance of the organisation. We're directors of the limited company and because of this we have a legal role. Good governance is very important, especially with charities. We have monthly meetings in which we scrutinise the monthly accounts. We make decisions and plan policy. Brian reports to the Board as CEO and if he has a major decision to make he refers it to us and we make a decision. We do the five year plan, and review it every year.

Most importantly, we represent members. We are their voice. There have been occasions where members have come to me with issues they have had and I have brought these up with the Board and assisted them with their issues. I really enjoy working with the Board and hope to continue to do so for many more years.

Many thanks to Jim for taking part in this interview.

2024

Upcoming Events

1-3 MARCH
AGM
Slieve Russell Hotel, Co. Cavan

17-19 MAY
Ageing Conference
Meadowbank Hotel, Tralee, Co. Kerry

18-20 OCT
October Members' Conference
Midlands Park Hotel, Portlaoise, Laois

VWD Information Day

As well as educational campaigns and information booklets, the IHS holds an annual von Willebrand Disorder Information Day to raise awareness and increase knowledge about VWD. This year's Information Day took place in the Grand Hotel in Malahide, Dublin on the 23rd of September.

Professor James O'Donnell, Consultant Haematologist and specialist in VWD at St. James's Hosptital, gave the primary presentation of the day. He shared some really important and useful information in easy-to-understand language. Professor O'Donnell explained that while VWD is the most common type of bleeding disorder in the world, it is still not well known. Unlike with haemophilia, unfortunately, VWD can be hard to diagnose, and requires multiple tests to properly measure von Willebrand factor (VWF) levels. Professor O'Donnell discussed the fact that heavy menstrual bleeding is very common in women with VWD, noting that it is probably more common in VWD than in other bleeding disorders. He raised two important and thought-provoking questions which need to be answered. The first referred to why people with VWD are more prone to post-partum haemorrhage, particularly when VWF levels tend to go up during pregnancy. The other question he raised was what happens as patients with VWD get older? He pointed out that while more than half go from having low VWF levels to normal levels, it is still unclear as to whether their bleeding symptoms go away.

Following this, Professor O'Donnell turned to the more positive topic of future treatment and discussed several new treatment options which are on the horizon. He talked about BT200, which is a synthetic molecule given by subcutaenous injection, a drug which was developed for stroke but was found to increase VWF levels 3/4 fold. He observed that Emicizumab, which is used to treat factor VIII deficiency in haemophilia, has been seen to successfully treat bleeding in Type 3 VWD. He also mentioned platelet nanoparticles which have been found to stop bleeding in mice with no VWF levels. It is hopeful that these new therapies will improve the lives of people living with VWD, who have had far fewer improvements in their treatment options as those living with haemophilia.

During the panel discussion after this opening presentation, several other issues were raised about care, treatment and attitudes. The first was that comprehensive care outside of Dublin sometimes falls below expectations, with patients waiting for extended periods for appointments. Another issue patients struggle with is delays in having other medical procedures undertaken due to having to wait for VWD treatment for these procedures to go ahead. A comment was also made that VWD is often not considered as serious a condition as haemophilia and that while haemophilia is known to cause joint bleeding, many people do not realise that VWD also causes this type of bleeding.

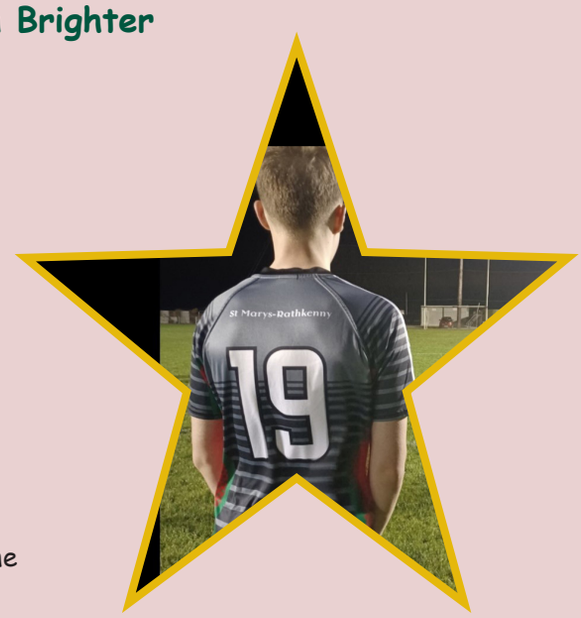
Dr. Megan Kennedy introduced the WOMEN (Women's Opinions and experience of Menstrual health on Exercise and physical activity Nationally) survey and gave the female members of the audience the opportunity to fill it out. The survey aims to uncover the impact of the menstrual cycle on women's daily lives and on their levels of physical activity, asking questions about pain and exercise in and around the time of menstruation. The survey is open to women with and without bleeding disorders and can be found on our website under 'News' and in 'Women With Bleeding Disorders' under 'Living with Bleeding Disorders'.

Overall the Information Day gave a lot of food for thought and was a very interactive and productive event.

Roisin Burbridge, Publications, Website & Social Media Coordinator

The Future is So Much Brighter

Members, we hope you enjoy this little article writen by a parent (who preferred to stay anonymous) of a young man with severe haemophilia. We hope it gives you a small insight into their lives.



Dear fellow members of the Irish Haemophilia Society,

Sixteen years ago this fella literally had his cot in the Coombe Hospital wrapped in cotton wool. Nurses were almost afraid to pick him up as not knowing anything about haemophilia, they were afraid they would hurt him. My wife was from a haemophilia background and we were very prepared but even still the 1st night in ICU spooked us.

Over the years at many parents and general conferences, it has been very normal to talk to a new family or two attending their 1st conference after a recent diagnosis. Those with no haemophilia background are obviously the most wide eyed and unsure of what the future holds. Myself and others would always try to allay any fears and give an honest guide as to what to expect and of course praise the IHS for being such a fabulous resource to us.

Anyway, back to the 16 year old in the photo. He has just won a County Minor Championship medal with our local club in a game that could easily grace any pitch in Brian O'Mahony's Homeland. 2-18 to 4-11 after extra time. This will be added to the league medal that was won earlier in the year. He attended almost all training sessions and played in almost all games with zero issues. All this despite the fact that he has severe haemophilia, a feat that all previous generations could only have dreamed of.

So, for any newbies joining our little group. There will of course be problems and its not all plain sailing but the future is so much brighter than what Doctor Google would sometimes let you believe.

Staffing Update

We said goodbye to our colleague Suzanne Fitzgerald in September of this year. Suzanne was the first point of contact when some of you may have called to book in to attend a conference or to book the apartment facility at Hyde Square. We would like to thank Suzanne for all her work over the past year and a half. We wish Suzanne all the very best in her new role.

Rob's Marathon

A huge congratulations to Rob Flanagan, our Outreach and Children's and Youth Programmes Coordinator, for his fantastic achievement of running the Dublin Marathon this year!

Rob has been training hard all year, running the challenging Achill Half Marathon during the summer and building up the miles in preparation for this race. His dedication and commitment to running longer and longer distances greatly impressed his fellow IHS colleagues. Rob has demonstrated the real mental determination and physical fitness needed to run such long distances.

We wish him the best of luck with all his future challenges and are excited to hear what he plans to do next!

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EHC Annual Conference

On Thursday 5th of October, Jim O'Leary, Breda Quealy and I flew over to Zagreb, Croatia to attend the EHC Annual Conference. As well as meeting and reconnecting with members of other National Member Organisations and enjoying an evening of Croatian traditional song, dance and food, there was a varied programme, ranging from highly scientific talks to patient stories to interactive light-hearted sessions. While the highly scientific presentations did, admittedly, go over my head, there was so much to learn from the speakers and their perspectives.

There were sessions relating to ageing with a bleeding disorder and the issue of frailty which tends to be higher in the bleeding disorder population, while the focus on haemophilia in this session in turn drew attention to the lack of data on VWD and women ageing with a bleeding disorder. There was a wonderful session on haemophilia care in Croatia in which Marko Marinic, the head of the Croatian Haemophilia Society, shared data on the life quality of people with haemophilia in Croatia, including data on whether married or unmarried people report to be happier. (It was found that married people are supposedly happier!) Another entertaining session was the youth debate in which Brian O'Mahony shamelessly feigned youth again, but unfortunately lost his side of the debate!

This was a fabulous conference and I hope to go back in future!

Roisin Burbridge, Publications, Website & Social Media Coordinator

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Educational Grants

We are delighted to announce the main recipients of this year's educational grants:

Maureen & Jack Downey Educational Grant
- **Peter Walsh**

Margaret King Educational Grant
- **Tadgh Moriarty**

Father Paddy McGrath Educational Grant
- **Aidan Clohessy**

Congatulations to everyone who received an educational grant this year and we hope that these grants are useful to all who received them.

Hospital Opening Hours for the Christmas Period

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

NCC opening hours

Friday 22 December 2023 - Open
Saturday 23 December 2023 - Closed
Sunday 24 December 2023 - Closed
Monday 25 December 2023 - Closed
Tuesday 26 December 2023 - Closed (bank holiday)
Wednesday 27 December 2023 - Open (08.30 am - 5pm)
Thursday 28 December 2023 - Open
Friday 29 December 2023 - Open
Saturday 30 December 2023 - Closed
Sunday 31 December 2023 - Closed
Monday 1 January 2024 - Closed (bank holiday)
Normal services from Tuesday 2 January 2024

H&H Assessment Unit opening hours

Walk-in and urgent planned treatment during 27th, 28th and 29th December. Normal hours resume on 2nd January.

Haemophilia clinics:

No clinics on 27th and 28th December. They will recommence on 2nd January.

Dental care:

Open for emergencies on 20th and 21st December. Will reopen for clinics from 3rd January and aim to see post-Christmas emergencies on this date.

In the case of emergencies, please call 01 4103000 (St. James's 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 22nd 2023 and will reopen on Tuesday January 2nd 2024 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 a very Merry Christmas and a happy and peaceful New Year!

Cork Coagulation Centre - Cork University Hospital

Friday 22 December, 2023 - Open (8 am - 1pm)
Saturday 23 December, 2023 - Closed
Sunday 24 December, 2023 - Closed
Monday 25 December, 2023 - Closed
Tuesday 26 December, 2023 - Closed (bank holiday)
Wedbesday 27 December, 2023 - Closed
Thursday 28 December, 2023 - Closed
Friday 29 December, 2023 - Closed
Saturday 30 December, 2023 - Closed
Sunday 31 December, 2023 - Closed
Monday 1 January 2024 - Closed (bank holiday)
Normal services from Tuesday 2 January 2024

The Haematology medical team is on call throughout the Christmas period and can be reached through the main hospital phone on 021- 4546400 for any urgent issues.

Children's Health Ireland, Crumlin

Friday 22 December 2023 - Open
Saturday 23 December 2023 - Closed
Sunday 24 December 2023 - Closed
Monday 25 December 2023 - Closed
Tuesday 26 December 2023 - Closed (bank holiday)
Wednesday 27 December 2023 - Open
Thursday 28 December 2023 - Open
Friday 29 December 2023 - Open
Saturday 30 December 2023 - Closed
Sunday 31 December 2023 - Closed
Monday 1 January 2024 - Closed (bank holiday)
Normal services from Tuesday 2 January 2024

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.