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

Magazine of the Irish Haemophilia Society

Autumn 2021



The Society at a Glance

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FROM THE EDITOR

I hope you are all well and had a nice summer!

It has been a summer to remember in our house as my wife Caroline and I, welcomed our son BarrÓg into the world in June. It has been a whirlwind, but to say we're overjoyed would be an understatement, he's a wee dote!



Elsewhere, on Page 3 Brian provides an update on the H & H Ward in St. James's Hospital, an additional Haemophilia Consultant Post for CHI, Crumlin & our October Conference.

Meanwhile on Page 5, Brian pays tribute to Michael Davenport, former I.H.S. Chair and board member, who passed away in June this year. Michael will be fondly remembered by his family and friends and his many friends in the haemophilia community.

We are eternally grateful to all our volunteers. We could not cater to the needs of our membership without the hard work, generosity, dedication and enthusiasm of our very valuable and vibrant volunteers – and who better to regale tales of volunteering with the I.H.S. than volunteers themselves? You can read Eve and Sam's stories on pages 6 and 7.

Then, over on Page 8, John Stack provides us with his Chairperson's update and on Page 10, I.H.S. member Colm Walsh writes about his experience in the 10k Galley Head Swim off Ireland's South Coast in July.

Lastly, I hope you enjoy this issue, if you wish to contact a member of staff between 9am and 5pm, Monday to Friday, please phone the office on 01 - 6579900.

Barry

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CEO REPORT

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H and H Ward, St. James's Hospital



Since the start of the Covid-19 pandemic in March 2020, the H and H ward in St. James's Hospital has been used as a Covid-19 ward or as an assessment unit for people suspected of having Covid-19 infection or where single isolation rooms were required. People with haemophilia have been admitted to other wards during that time period. More recently, in June and July, a specific bed was allocated to the NCC so that people with haemophilia who were on the waiting list for orthopaedic procedures could be admitted for these surgeries.

While we understand the requirement to use the H and H ward for Covid-19 admissions and assessments during the pandemic, we are adamant that this ward must continue to be available to people with haemophilia and other inherited bleeding disorders in the future. To this end, the Society and the Chairperson of the National Haemophilia Council have met the Chief Executive of St. James's Hospital on two separate occasions - in October of last year and more recently in the first week in September this year. On both occasions, we have received a firm commitment and a categorical assurance that people with haemophilia will be able to avail of the H and H ward as soon as possible. The ward continues to be used at present to deal with Covid-19. Regular meetings will now take place between the CEO and the Director of the National Coagulation Centre, Dr. Niamh O'Connell where the CEO will be updated on the evolving situation in relation to access to in-patient beds for people with haemophilia. The Society and the National Haemophilia Council will continue to actively monitor this situation and we will be seeking regular updates and advocating for access to the ward at the earliest possible time.

It is worth remembering that the H and H ward was not randomly assigned by the hospital for the treatment of in-patients with haemophilia. As the name of the ward attests, the H and H (which stands for Haemophilia and Hepatology) ward was specifically conceived, advocated for, funded, designed and built specifically to include in-patient treatment for people with haemophilia and hepatology patients. At the time of planning and design, hepatology concerns were also at the forefront in the medical treatment of people with haemophilia as many were dealing with Hepatitis C treatment and the consequences of Hepatitis C infection.

The history of the development of this ward goes back to the period immediately following the Lindsay Tribunal of Inquiry into the infection of people with Haemophilia with

HIV and/or Hepatitis C, which reported in 2002. Following the Lindsay Tribunal of Inquiry, deficiencies were identified in the Haemophilia Care system and resources were applied by the HSE to deal with these deficiencies. Several external audits of the service had as a finding a clear deficiency in the provision of designated beds for people with haemophilia and related bleeding disorders within the context of a comprehensive care service. Some 116 people with haemophilia have died to date as a result of HIV and/or hepatitis C due to contaminated blood products. Those who survive would derive a measure of reassurance from having access, when required, to a purpose designed and built in-patient facility at St. James's Hospital which is the National Coagulation Centre for adults.

The history of the development of this ward can be traced back specifically to a draft detailed specification for this ward prepared by then National Haemophilia Director, Dr. Barry White in 2003. The ward was conceived, specifically funded by the HSE and designed using evidence-based design for the purpose of being an in-patient unit which would cater, as a priority for people with haemophilia and related bleeding disorders and Hepatology. The Society were involved and consulted at every stage of design and planning of the ward. The Society and the National Haemophilia Council also discussed the proposed ward with the then health Ministers in 2005, 2008 and 2010 and there was a clear understanding of the rationale for this ward. Given the fact that the ward was to be a 12 single room ward (later increased to 14), it was clear that not all of the beds would be required at any one time for people with haemophilia or hepatology patients, but it was equally clear that they were to have priority access to the ward.

The recognition that this ward was specifically meant for people with haemophilia was also strengthened in 2015 with the relocation of the then National Centre for Hereditary Coagulation Disorders (NCHCD) to the same building two floors above, where the new National Coagulation Centre (NCC) was purposely located. The concept was to provide a cohesive and geographically proximate location where the haemophilia in-patient (including the assessment unit as well as the beds) and outpatient (NCC) facilities were very close, allowing optimal use of the staff who would work between both. St. James's sought and received funding from the HSE specifically for the building of a Haemophilia and Hepatology (H and H) in patient unit. This was approved for this purpose and €9.23 million was allocated from the 2007 HSE Capital plan budget. The specific funding for the ward was a result of many years of collaborative work between the National Haemophilia Director at that time, Dr Barry White, and the Irish Haemophilia Society. Significant savings were made for the St. James's budget due to the work of the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB). There was a clear understanding with the then hospital CEO that some of the reserves available due to these savings would be used to resource additional requirements for the new H and H ward (such as new dental equipment)

The Irish Haemophilia Society were involved at all stages of advocating for the facility, meeting with the Department of Health, the HSE and Ministers of Health with regard to the facility and were consulted formally on design and fit out. It is inconceivable that this would have been the case if the ward was not to be specifically used for people with haemophilia and inherited bleeding disorders. The nursing expertise, the orthopaedic surgery after care provided by these nurses who have been specifically trained, the disabled access rooms and bathrooms have been very welcome to our community where a disproportionate number of adults require orthopaedic surgery within the provision of a comprehensive care haemophilia service. It must also be remembered that adults with severe haemophilia can not go to other hospitals for major surgery as the specialized care has to be carried out within a comprehensive care centre for adults. This limits major procedures to St. James's or Cork University Hospital and almost all of the major orthopedic surgeries are carried out at St. James's Hospital.

The H and H ward has a long development history, but it is, and remains, an indispensable part of the infrastructure for the treatment of people with haemophilia and other inherited bleeding disorders. The Society will spare no effort in advocating to ensure that people with haemophilia have access to this ward again in the near future.



Children's Health Ireland at Crumlin

Additional Haemophilia Consultant Post for CHI, Crumlin

The Haemophilia and bleeding disorders service in Children's Health Ireland (CHI), Crumlin have been seeking the appointment of an additional consultant post for a long period of time. This is required due to the very large number of children with inherited bleeding disorders attending the hospital and the consequent workload on the single consultant, Dr. Beatrice Nolan. In March and April of this year, the Society and the National Haemophilia Council separately and collaboratively contacted the office of the Minister for Health with regard to the urgent need for an additional post. We are glad to be able to report that permission has been granted and funding allocated for this additional post and the post is now working its way through the system. We hope to be able to welcome an additional consultant to the haemophilia service at CHI, Crumlin in the coming months.

Irish Haemophilia Society



October Conference 2021

October 15 - 17, 2021
Mount Wolseley Hotel, Co Carlow

October Conference

We are very pleased that we are able to proceed with an in-person event this October. This will be the first in-person event since the AGM and Conference in early March 2020 - the week before restrictions began and the Covid-19 pandemic wrought so much change. We are conscious that many people will remain nervous about attending an in-person event. We will be taking every precaution to ensure that members attending are safe. Attendance is limited to fully vaccinated adults. Masks will have to be worn in the meeting room and social distancing will be maintained. We are sad that it is not possible for us at this time to run the children's programme and the teenage/youth programme. We understand that this, in effect, means that parents will be for the most part unable to attend this specific conference. Attendance is limited and the numbers will be well below our normal October conference attendance. This will be the first event in the new reality of masks, social distancing, and additional precautions. Many of the children and youth with bleeding disorders and their siblings have not seen their peers with haemophilia in some time. That is why we separately offered free family passes to Dublin Zoo for members. This should allow perhaps small groups of families to visit the Zoo, if they wish to do so, on the same day as other families and give the children an opportunity to meet outdoors in a relaxing and enjoyable environment.

In the meantime, we proceed with the October conference and we really look forward to welcoming all members - adults, youth, children and our greatly valued volunteers back to the AGM and Conference on March 4th to 6th 2022.

**Brian O' Mahony,
Chief Executive**



MICHAEL DAVENPORT – AN APPRECIATION

Michael Davenport, former Chairman of the Irish Haemophilia Society, passed away after a short illness on June 18, 2021. Michael initially joined the Board of the I.H.S in 2001. He was Chairman from 2003 to 2008.

Michael was Chairman of the Society in the period after the report of the Lindsay Tribunal of Inquiry when major changes were being made to the haemophilia service and to the organisation of care. Michael served on the newly formed statutory National Haemophilia Council from 2004 to 2011 and on the Haemophilia Product Selection and Monitoring Advisory Board, which advises on the selection of treatment products for people with haemophilia and related bleeding disorders, from 2004 to 2008. During that time, he was also involved in the negotiation process which led to the establishment and detailed implementation of the Insurance scheme for people with haemophilia who had been affected by HIV and/or Hepatitis C. Michael left the Board in 2008 but he was persuaded to return in 2012 and remained on the Board for a second lengthy term of service until 2018.

A dry recitation of these appointments and dates set out the record of his service to the Society but they do not capture the character of the man or his real commitment to our community. Michael was an effective Chairman of the Society Board. He sought consensus and he chaired meetings with empathy and humour - never imposing his view on others but always seeking to listen to and try to accommodate all views. Michael had a disarming but very effective style. His humour and teasing masked a seriousness of purpose and a clear commitment to the Society and to the best interests of all the members. In his second term on the Board, Michael

was able to effectively utilize his experience to always encourage others and contribute effectively to policy formulation and decision making.

When I speak to friends in our community about Michael, they mention his warmth, mentorship, humanity, commitment and dependability. They always mention his wonderful sense of humour. His humanity, humour and directness made him an effective leader and advocate. This has been restated to me since Michael's untimely passing by several people from the health service with whom we interacted over the years. They all remembered Michael with fondness. Michael was devoted to his wife Ann, his children Karen, Laura and Robert and in later years, his grandchildren. He was also devoted to his golf and often complained to me in humour that all the work we had him do was distracting him from improving his golf handicap. Since his retirement from the Board in 2018, Michael has been able to devote his time to his family and to his golf. We would have wished for him many more years to enjoy both, but it was not to be. If the memory of a life well lived is that the memory of you will endure long after you are gone, Michael will not be forgotten by this community. Michael will be remembered by his family and friends, his many friends in the haemophilia community and all those in our community whose lives he touched and added value to and who owe him a profound debt of gratitude. Michael will be fondly remembered. Rest in peace.

**Brian O' Mahony,
Chief Executive**

We are eternally grateful to all our volunteers. We could not cater to the needs of our membership without the hard work, generosity, dedication and enthusiasm of our very valuable and vibrant volunteers – and who better to regale tales of volunteering with the I.H.S., than the volunteers themselves? You can read Eve and Sam's stories below.

It all started in my first year of college. I had recently moved to the midlands from Dublin, anxious and eagerly ready to sink my teeth into any experience that would allow me to travel the beautiful Irish country, offer new challenges and give me the opportunity to make new friends. It just so happened that I was lucky enough to meet one of my most trusting, loving and adventurous friends who introduced me to the Irish Haemophilia Society. She shared with me countless stories of exciting places she had visited, the wonderful families whom she had gotten to know throughout the years of being a member and the amazing, hardworking staff and volunteer team that would plan, entertain and assist in the fun-packed weekends where everyone would come together and reunite. I instantly felt the urge to join and see with my own eyes the experiences she had told me of. I had been studying nursing for a year previously, and my decision to change courses felt bittersweet because I loved medicine. I was going to miss keeping up to date with health and advancements in treatments. When I joined the I.H.S., I knew I would have a chance to reignite my interest. I wanted to offer, above anything, my willingness to learn understand haemophilia, to listen and empathise with the people who lived with it and associated its bleeding disorders.

Before I was able to embark on my first weekend with the I.H.S., I had to undertake very important training with the staff in their main office. The thought of this almost made me break out in nervous sweats in fear of what obstacles may face me, but as soon as I stepped foot in the front door, I was instantly wrapped up in the warmest welcome I had ever received as a volunteer. In fact, the staff did not treat me as a volunteer. I was part of a team. From then on, I would be looked after as one of their own. Each member took the time to not only introduce themselves, but they wanted to get to know me. I was beyond grateful for this experience, because I grew closer with them through each event that followed.

My first weekend was mind blowing. Firstly, I would like to happily share that no other volunteer experience had the ability to feed me so many amazing meals in the space of three days! It is greatly appreciated. These weekends don't feel like work. I get to wake in the morning with my dear friends and spend the rest of the day getting to know the most fearless, intriguing and ferocious little minds that arrive with their families for the weekend. In the evening, after an exhausting and exciting day of activities and fun, we all come together for a celebration. What more could you hope for? I am continuously surrounded by like-minded people who also want to give families a meaningful experience and create



memories that will be kept and cherished for years to come.

The Covid pandemic was hard for us all, and I couldn't have begun to imagine the adversities we had to overcome during this unpredictable and incredibly challenging time. Thankfully, being able to see a hopeful glimmer of light at the end of this dark and never-ending tunnel, we will once again be reunited, and we will celebrate more than we ever have. While I have been granted a little bit of spotlight, I would like to take the chance and encourage more people to volunteer with the I.H.S. Being a volunteer is gratifying beyond words. You will learn and laugh more than you ever have in a weekend, and you will be a part of something so personal yet collective. You will be considered as a vital and important piece in a larger community, no matter what your role is, and that is something very special.

Eve Carpenter

Would you
be interested in volun-
teering with the I.H.S?
if so, get in touch with
Robert in the office



My experience volunteering with the I.H.S. has been nothing short of incredible! I started way back in about 2011 / 2012 and I don't think I have missed a single weekend since then. The organisation that goes into each weekend from the IHS staff is completely unparalleled and with the help of all the other volunteers, each weekend seems to out-do the last one. At this stage I have been a leader in all kid's groups except for Creche (they're the real MVP's!) and seeing the personal relationships form with both the kids and the volunteers has been amazing. There were kids in the groups when I started volunteering, who are now volunteers themselves, so despite making me feel old, I think that speaks volumes!!

Aside from the AGM and October Conferences, some of the other events outside of these have fantastic, like the annual Father & Son / Mother & Daughter weekends at Lilliput, the petting farms, trips to the zoo, treasure hunts etc - the Eagles Flying Birds of Prey show in Sligo was a particular highlight!

I don't have Haemophilia or any other bleeding disorder, so coming into this very tight knit group was quite daunting for me at the beginning, but the staff, members, volunteers and even the kids still made me feel welcome and part of the group. And having little to no knowledge of Haemophilia beforehand, again was quite daunting, but just from being involved I learned so much about it and it definitely helped me understand the society better and the people who make it what it is. I even went to Brussels as an I.H.S. rep with EHC and got to experience and learn about what is happening with European Societies and this really showed the collective spirit and hard work that is so prevalent in the I.H.S.

Volunteering with the society has become a massive part of my life and I have made some lifelong friends and memories from volunteering and would often meet up outside of the weekends. So much so, that a few of us got completely random tattoos one afternoon – they're gonna kill me for this, but see the damage below!!



I massively look forward to the weekends every year and it's great to see everyone and plan what's in store for the weekend ahead. Even though they can be months apart, it's as if everyone was together the week before.

For anyone reading this who is thinking of volunteering, or thinking of getting others involved, I would 1000000% recommend doing it! The society as a whole is so welcoming, and the overall experience is amazing, no matter what your skills or background are. If I can manage an hour-long group fitness session with John Stack, anyone can! There is literally something for everyone, whether its sport, crafty, games, art, music, a kids flash mob during the AGM dinner – everyone's individual skills really can bring something to the table. It's great for putting yourself out there and taking on a new experience and seeing the results at the end. You'll be in and out of your comfort zone but you'll really be glad you did it – I fully expect any newbies to be the first ones in the bog at Lilliput next year!!

So, thanks to all the I.H.S. staff for putting together these amazing weekends and for having me as a volunteer, and here's to another 10 years! I'll stop volunteering when Paul Dunne wins the volunteer raffle (which will never happen) And one last shout out to Rob for putting together such a great team of volunteers and co-ordinating the programmes – we couldn't do it without you!

Sam Morrissey

AN UPDATE FROM OUR CHAIRPERSON

Hi everybody!

I hope you all had a wonderful summer, even though our lives have been still very much governed by Covid-19. We're about a year and a half living with it at this stage, including a number of very long and very challenging lockdowns. Thankfully, though, vaccinations are giving us a glimpse of the light at the end of the tunnel. I'd like to think that the vast majority of people in the country have embraced the vaccination process, and this is clear by our high rate of uptake. I was most impressed by the uptake by people, particularly young people, on the days that you could just walk in without an appointment.



At the time of writing, I had my second vaccination coming up, although I nearly missed my first shot due to a technical glitch. I didn't get a text message with a date. By complete coincidence, I phoned the HSE one day wondering why I hadn't received a date, only to discover that I was due that day. Even though I was late for my assigned slot, they still allowed me to attend. Phew!!

While Covid-19 is obviously very prevalent in the country, the medical profession is busy treating a myriad other medical issues that people have to deal with. That, of course, includes our own community living and coping with inherited bleeding disorders. I'd like to take this opportunity to thank everybody in the health service looking after our community, particularly all the staff at the Comprehensive Care Centres and the staff at TCP who deliver medication to all of us. Our regular delivery person, Robert, has recently moved and we will miss those brief chats on the doorstep every month. I wish him the very best in whatever he does next in life. I'd also like to thank the staff and Board at the I.H.S. for keeping the show going in the Society too. It's a credit to our people how well they have adapted to these new working conditions. It is the work done by every single one of these people that gives us the high level of care that we have. So, thank you.

Technology has been a huge advantage to all of use throughout this ordeal. It's our primary mode of communication with all of you at the moment, whether that is by Zoom, e-Zine, telephone call or e-mail. We're still using traditional mail drops too of course. Earlier on this year, Oisín started self-injecting. He was signed off by Crumlin via Zoom. Isn't it fantastic that we can do things like this?

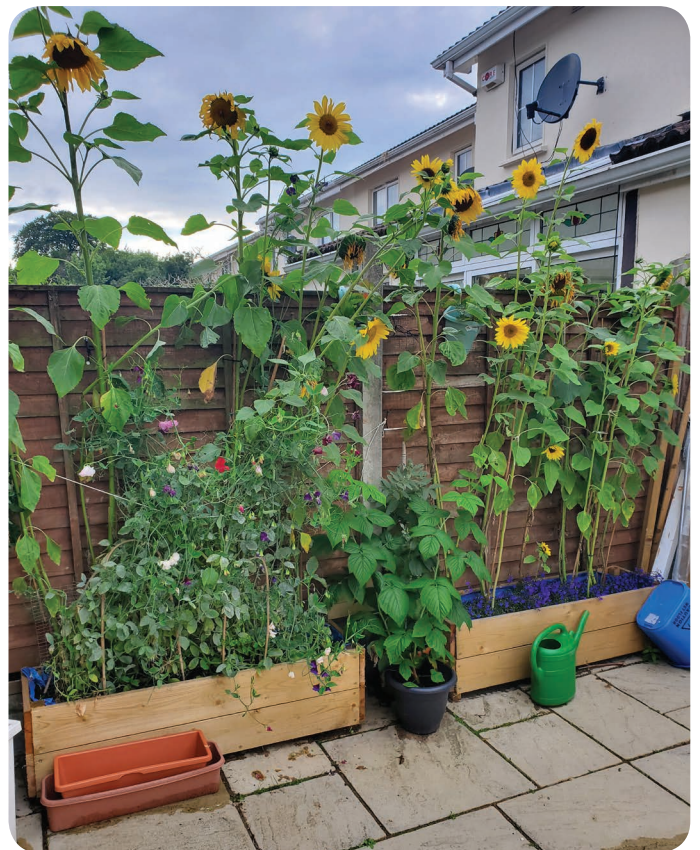
While technology has been great, I don't think it can ever replace that personal connection we get from meeting in person. With that in mind, I am really looking forward to meeting some of you for the first time since our 2020 AGM when we plan to have our first in-person event in October

2021. Fingers crossed for this!

Ellie has organised a few projects for the kids during what has now been generally termed 'Covid'. Last year, they painted this mural on our back wall.



This year it was a sunflower wall. I built the planter boxes and Ellie and the kids planted them with a mixture of sunflowers, sweet pea, some blue thing that I don't know, and some berries and vegetables. I think it looks sensational. Some of them are over two metres tall.



One day recently in the garden centre, Naoise wanted to buy a plant. He got fixated on this little plant. It was, however, a fig tree..... that would eventually grow to more than 4 me-

tres tall. Thankfully, I convinced him to get a raspberry plant instead.

While I know that we are slowly getting our freedom back from Covid-19 restrictions and we can go out and about, I want to reiterate the importance of staying fit and healthy, both physically and mentally. While things like walking, cycling, swimming (sea swimming if you're brave enough) and so on are really good for cardiorespiratory and cardiovascular health, I cannot underestimate the value of maintaining strength and having healthy joints. The Society has been running an online programme with some really great Physiotherapists in recent months. I would love to see more and more of you get involved with this. I will talk a bit more about the importance of strength, joint mobility and joint health when we meet in October.

Speaking of exercise, it's great to see sport back on our screens and on our pitches and it's absolutely fantastic to see crowds, albeit small crowds, back in our stadia. More importantly, it's great that our kids can take part in sports again. Again, exercise is very important for our children too and organised sport is a great way to achieve this.

We've had the Olympics too this summer which has proven to be a fantastic example of human spirit, resilience and, of course, community. The scenes from Portland Row this morning were a joy to watch. A huge congratulations to the whole Irish team for qualifying. Without a doubt, we're all celebrating the success of our medal winners. Hopefully, they'll get to have a proper celebration in the near future. They really lifted the spirits of the country over the last few days. What I was most impressed with was how humble and down to earth they were; Paul O'Donovan when he said they were nothing special, that they worked really hard and were just lucky, Aidan Walsh saying he'd share his medal with his sister, and Kellie Harrington in her lovely interview this morning where she even referenced her club coach. They are a credit to the nation.

Wasn't the heatwave,...well,... hot? I'm not a lover of the heat, but I suppose it was fantastic for most people, especially as it coincided with the start of the staycations for most people. I really hope you've all been able to have some sort of enjoyable break during this summer.

Ellie and the boys had a week of surfing in Dunfanahy the week of the heatwave. I joined them in Iniscrone in Sligo the following week, where the weather 'cooled

down'; in other words, 'rapidly deteriorated'. Then we went on to Achill, one of our favourite spots on the West Coast. On one of the better days weather-wise, Cian, Oisín and I cycled a section of the Great Western Greenway and followed this up with a climb to the top of the highest sea cliffs in Europe, which are at Keem Strand. It really is breath-taking here, made all the better by the fine weather.

I'm showing these pictures here because it reinforces how successful we have been at managing Haemophilia in Ireland. Without the standard of treatment that we have, things like this would not be possible. The hard work, dedication and sacrifice of previous generations has made it possible and given us all a very bright future. We won't stop trying to secure and deliver the very best of treatment to our community.

I hope to see some of you in October. Until then, stay safe.

John Stack, Chairperson





GALLEY HEAD SWIM 2021

I.H.S. member Colm Walsh swam the 10k Galley Head Swim off Ireland's South Coast in July, this is his story.....

As I sit here to write this, I think back to the day I signed up for the Galley head solo 10km swim. I remember being so excited just getting a spot to take part!

I swim around Sandycove Island in Kinsale, and I have been going there for about 8-10 years, but it is only in the past 4 years that I have really been doing a lot of swimming there. I got my first 100 lap cap on in October 2020. I try and swim everyday if I can, but I do take a day off here and there just to appreciate it even more when I do swim.

I knew from May 14 for the next 2 months I knew all that would be on my mind would be preparation for the swim, both physical and mental. In 2019, I wanted to do the second Galley Head swim but unfortunately, I fell and injured what was an already damaged knee. It was very serious, and I did not know whether I was going to be able to walk again. I had a full knee replacement in October 2019, and I am still doing physiotherapy today. I honestly did not know how well I was going to be able to get around or even swim after the surgery. I returned to swim in Sandycove was the June weekend 2020. I remember crying when I came out because I was back in the water and swimming in a place that's very special to me. Everyone was so kind to me as I was still only learning how to walk and taking things just one step at a time.

On the day I got the spot in the Galley Head swim I was after doing my 50th lap of the island this year. I knew I had

to up my distance and endurance to be able to do the swim. I was swimming with Alex Jeffers and David Conradie, and we were doing double laps. It was so nice to have people to swim with. It can get very lonely on your own and having someone with you keeps the motivation going. I also knew I had to swim in all conditions and that was going to take a lot physical and mental strength to overcome the fear of different conditions.

On May 18 I did my first 4 laps of the island which is 6.1km in 1 h 47 mins. Ned Dennison had suggested to go wide outside the marker buoys to build up my distance and I did this every lap up to the swim. The following day I did 3 laps, 4.6km, in 1h 20mins and I felt ok. On May 29 I did a 7km swim, 4 laps, with David Conradie in 2 hours and I was thrilled, and as I was coming out people on the slipway were congratulating me. I remember Adrian Healy giving me the thumbs up and saying well done. To get that from Adrian, who has done the English Channel, was a huge motivation to keep going. I did notice around the 5km mark my left hip was getting sore because of my legs being in the same position most of the time. I had to turn on my back to move my left knee up towards me and free my hip. This caused pain but once I did it, I was ok to carry on.

My goal was to do one big swim of 6-7km a week and then keep doing the double and triple laps. I was always pushing that bit harder every swim and increasing my pace. All the



time I was swimming all the swimmers and even paddlers in Sandycove were encouraging me. I found the early mornings a bit of a struggle to get up to be honest, but I knew there would be swimmers there and that helps enormously to keep you going.

The morning swimmers are a small group, but all have great experience and when I swim with them I always learn new things. On June 13 a group of us swam from the Dock Beach to Sandycove Island and this was my first big swim of the year. The weather that day was lovely. It was good to push myself out of my comfort zone and go into open water.

Killian, Grainne, Dorothy, Denise, Aideen, Ned and myself all did the swim, and I did 5km in 86mins. I was so happy, and I knew I was improving in every way. I was eating well also and getting good amount of sleep. Porridge, chicken, veg, pasta and rice were my basic foods.

Aideen mentioned her husband Eoin was helping a member of Kinsale Tri Club to prepare for the Galley Head swim, and I should contact her as it is always good to have a training buddy. Her name was Sinead Barnett. Eoin and Sinead were going to swim from the Speckled Door to Sandycove and do a lap of the island. I got in touch with Eoin and Sinead to see if it was ok to come along as it would be a good opportunity to do feeds. I needed a kayaker to act as my safety for the swim. Sinead, my partner, helped out greatly

by putting a notice up on the Kinsale Notice Board page on Facebook. Very handy to know.

June 19 was a Saturday, and the weather was looking ok at the start but was forecast to change during the swim. The south westerly wind picked up and it became lumpy, and the swell began to build. I was being tossed around a bit, but my safety kayak which had my partner Sinead on it as well, was a great comfort to see alongside me. As I could see the brown house of Sandycove in the distance I said to myself keep going you are getting there. The swell was getting stronger and as I came closer to the island it was a welcome sight. I saw Eoin and Sinead heading up the pill and I swam with them and get my distance up. Swimming in the pill was lovely, calm and warm and it was such relief to my now sore body. I did 8km in 2h 25 mins that day and it was a huge learning swim. I kept doing my doubles and triples around Sandycove but also making sure my body was doing ok. I have two legs that do not kick and just hang there while I swim. It is all upper body I use for swimming. On June 27, I did 4 laps, 6.2km, in 1h 53min. I knew I had to do a 10km swim for my own confidence. On June 30 I swam 4 laps, 6.3km, in 1h 50 mins. On July 1, I did 6 laps, and 10km in lovely conditions. I wanted to reach that 10km mark and I did it in 2h 55mins. My hip became sore twice during that swim, but I did my normal stop and just freed it out. I was thrilled and so happy. I had done 10km. I punched the water as I got and said yes! I can do this, even with my non kicking legs. That week I did 29.4km, and

the Galley Head Swim was two weeks away. The week before I did 26km, and the week before that 23.3km.

During this time the support and guidance I was getting from other swimmers was enormous. Getting advice about feeds and how best to work them out was a great help. Everyone in Sandycove was wishing me the best for the swim and encouraging me, which gave me great confidence.

Alex Jeffers and his daughter Bronwyn were going to be my safety boat and crew for the Galley Head swim. The week of the swim I had to taper down my distance so I wouldn't be burnt out for the swim. Let me just say this was harder than the swim as I was only doing 1 lap of the island a day. To make it even harder, the conditions were flat calm, and it was so tough to come in after 1 lap. Joe, who swam with me, could feel my anxiety but it had to be done.

On July 17, the day of the swim that I had waited 2 years to do and trained hard for 8 weeks, was here. Conditions were ideal. Sunny, blue skies, light easterly breeze. Karen, a swimmer from Sandycove just arrived before the start to wish me good luck. I got ready, kissed Sinead, and waited for my time slot at 11:03. I was 18th to go in. I watch as everyone before me ran in the water. My time came and I walked with a limp to the water's edge. I didn't care who saw me or what they thought. This was my time and my swim. I went in and off I started and headed for the green buoys to meet up with my safety boat. We had pre-arranged my feeds every 45 mins from the time I started. I had 250ml bottles of water with diorolyte mixed in them.

I met Alex and Bronwyn and gave the thumbs up and off we went. I was going to set the pace and Alex was going to guide me. That was the rule and I stuck to it. I breathe only on my right, and I stayed to the front of the boat as we had discussed. I was in a nice groove, and all was going ok. All went fine with the first feed and Alex said I was after passing 6 others already. That was fine and I told myself to keep it steady. As we rounded the Lighthouse on Galley Head and I looked up and I could not believe I was swimming around the Galley head. This time 2 years I was at home sitting on a chair with my right leg in a permanently straight position, and I did not know what was going to become of my leg.

It was an emotional moment to see the lighthouse towering above me and the blue sky behind it. I slowed down and took a full breath of air in and said Colm you are doing it.

I got to the third green buoy, about halfway, for another feed and I drank 2 bottles. All was going well but the easterly breeze was a bit of a slap on my face saying you are not going to get it that easy. I had to work hard, and the boat never left my side. I could feel my hip coming at me, so I just waited until I knew I had to slow down and do my normal routine. I got to the next buoy where we had to turn to the left, and Alex pointed the direction and off I went. The wind was behind me, and it gave me a great push, which felt great. All

the time I was aware of my legs just hanging there not doing anything. I could feel the extra bit of weight in my right knee and that is due to swelling and a very difficult surgery. The next feed did not go well, I got one bottle into me but could not get the second one into me.

I could see the two green buoys in the distance at the entrance to the finish. I thought OK, just keep going. My arms were feeling ok, but I hit that mental wall at around 8.5km. It was a big one, but I just kept my head in a good place. I had my safety boat alongside me, and they were willing me on. I dug down deep and remember back to the day in the hospital when I first stood up with the walking aid. The next day I took 2 steps. The following day I took 6 steps and made it to the door of my room. I was swimming now and these memories returned and gave me the power to keep going and believe in myself so that I could finish the swim. I was after coming through so much in the past 2 years. Nothing was going to stop me.

Alex signalled I was nearly there. I was nearing the green buoy and my safety crew could not go any further. As I waved to them and gestured thank you, I could not hold back the tears of joy that were running down my eyes. Only a small bit to go. They headed away and I got back swimming and I was joined by a young man on a paddle board to guide me in. As I swam the tears stopped and I could see the sand underneath. I was nearly there. Then on my left-hand side I spotted my partner Sinead swimming alongside me, and yes, I had made it. I stopped, put my hands on the sand, and felt it go in between my fingers. Brought my legs forward, bent my left knee, put my foot on the sand and brought my right leg underneath me and stood up. I got help from 2 stewards just to help me steady myself. I started walking in towards the finish line and the crowds of people were clapping and cheering for me that I had done the swim. I swam 10.45km in 2h 59min 40 seconds.

I had done it!!!!

I was third in and came 5th overall but that didn't matter, for me, completing the swim was the reward.

Karen had come to the finish also and gave me a hug and then she had to leave. Sinead and I hugged, and I started crying again but these were tears of joy. Sinead has been through all the heartache since I fell, and she has seen me at my worst and lowest but that was all in the past.

I hope my story can inspire someone to go out and set a goal for themselves no matter how small it is. On October 2, 2019, my goal was to put one foot in front of the other and just take two steps. On May 14, 2021, I set a goal to complete The Galley Head Swim and on July 17, I completed it. Believe in yourself and you can achieve anything.

Colm Walsh

I have severe haemophilia B, factor IX deficiency.



Just a quick reminder that the Irish Haemophilia Society publishes a wide variety of publications, as well our quarterly magazine you are currently reading.

All our publications are available digitally on our website, haemophilia.ie. If you would like physical copies, please contact us in the office on (0)1 657 99 00 or info@haemophilia.ie

Some of the publications available for members include:

- Novel Treatments in Haemophilia & other Bleeding Disorders: A Periodic Review (biannually)
- Emicizumab (Hemlibra) for People with Factor VIII Inhibitors / And Without Inhibitors
- von Willebrand Disorder Booklet
- Haemophilia & von Willebrand Disorder; An Essential Handbook for Parents
- Sport, Exercise and Haemophilia Magazine
- Information for Teachers & Playgroup Leaders (New Edition)
- Ageing and Haemophilia
- Dental Care for Children
- Haemophilia and Dental Care for Adults
- Haemophilia Heroes
- Introduction to Haemophilia
- Introduction to Portacaths
- Mild Haemophilia
- Rare Bleeding Disorders Booklet
- Sibling Superstar Workbook
- Teenage Girls with Bleeding Disorders
- Veincare Women with Bleeding Disorders Booklet

NOTICEBOARD



Write for the I.H.S.

We are always eager to have member's contribute to our publications.

Maybe you would like to share a story about you or your experiences with bleeding disorders, or perhaps your experience at one of our events, fundraising, volunteering or something else entirely!

If you would like to contribute and write an article for the I.H.S. contact barry@haemophilia.ie



We are absolutely delighted to announce the arrival of another bundle of joy to the I.H.S. family!

On June 30, Barry and Caroline welcomed baby BarrÓg into the world. Massive congratulations from the I.H.S. and best of luck with your next great adventure!



If you missed any of our webinars over the past while, you can now catch up with them on our website and YouTube.

We are delighted with the webinars; insightful topics and great interaction with members.

You can find the recordings on YouTube & haemophilia.ie, or scan the QR Code below.

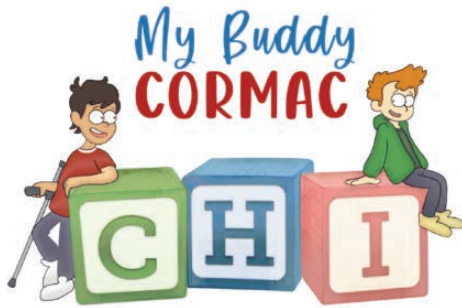


I.H.S. Office Reopening

Based on current Government guidelines and public health advice, the I.H.S. office will be reopening with a blended approach from Monday September 27, 2021.

We're all looking forward to a return of some normality!

NOTICEBOARD



My Buddy Cormac

We're delighted to share 'My Buddy Cormac', an animated video designed for patients & families with haemophilia in collaboration with the Creative Media Department of the Munster Technological University, Children's Health Ireland at Crumlin and the Irish Haemophilia Society.

My Buddy Cormac, an informative and positive awareness animation about haemophilia, focuses on the experience and challenges faced by children with the condition when treatment in hospital is required.

The story is told from the perspective of a child and it delivers an enlightening and creative take on events and is aimed at children aged between eight and 12.

You can watch the video on haemophilia.ie



SCAN ME

Join our E-zine Readership!

Our E-zine is the easiest, hassle free and most comprehensive way to keep up-to-date with all things I.H.S.

To sign up, simply email barry@haemophilia.ie or fill in your details at haemophilia.ie.



TRAVELLING OR STUDYING ABROAD?

What you need to know...



If you are relocating or studying abroad there is a lot to consider before you travel. Each country has their own rules and regulations that you must follow to ensure you receive equivalent healthcare to what you receive here in Ireland.

Most countries cover emergency/urgent healthcare that is required while a person is visiting, in accordance with your health/travel insurance. However, this usually does not extend to regular haemophilia treatment and does not cover prophylaxis nor regular on demand therapy.

How do you plan your trip to ensure you will receive the equivalent healthcare?

1

Call the I.H.S.

Call us as soon as possible. We will help you with all of the stages and help with any queries.



2

Call Your Treatment Centre

They will advise you on how much factor you will need to bring. It is important to request a letter from your treatment centre which gives details of your treatment.

3

Find the nearest treatment centre

For Europe see - <http://www.euhanet.org/centrelocator/>

For the rest of the world see -

<https://www.wfh.org/en/resources-education/treatment-centre-directory>

4

Apply for the correct VISA

To find out what VISA you need and how to apply see:

<https://www.dfa.ie/travel/visas/visas-for-irish-people-going-abroad/>



5

Get adequate health insurance

A company that does provide insurance cover for pre-existing medical conditions including haemophilia is a company called Blue Insurance. They can be contacted by:

Ph. 0818 444 449 or at www.blueinsurance.ie



6

Pack essential items

If you are carrying treatments and medications it is very important to ensure that you have a **travel letter** from your haemophilia treatment centre for customs. You should also carry your **haemophilia card** which was issued from your haemophilia treatment centre.

For travelling within Europe, you should have an **EHIC card** (European Health Insurance Card). This entitles you to necessary healthcare in the public system of any EU/EEA member state.

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@irishhaemophiliasociety



@HaemophiliaIRL

As our lives return to some semblance of normality, so to do possibilities for travel or study abroad.

If you are thinking about relocating or studying abroad there is a lot to consider before you do so to ensure you receive equivalent healthcare to what you receive in Ireland. With all that in mind, we have this handy infographic which can also be found on our website.



IRISH HAEMOPHILIA SOCIETY

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