

# Haemophilia.ie



Magazine of the Irish Haemophilia Society

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



SCAN ME

Autumn 2023 Edition

# From the Editor



Hello everyone! We are approaching a busy time of year in the IHS! In early September, we are holding our final regional visit for the year, taking place in Galway. In mid-September we have our annual von Willebrand Disorder Information Day in Dublin and

in October, our much-loved Members' Conference returns, back to full capacity for the second year since the pandemic. Details of these events can be found later in this edition, as well as interviews and articles that we hope you find informative and enjoyable to read.

As is customary, Brian O'Mahony starts this edition with an update on recent developments in the bleeding disorder world, including the current debate around replacing the word 'haemophilia' with a broader term to represent other bleeding disorders as well and the issues that could arise as a result. Afterwards, I give a quick run down of our Parents Conference in July.

I also contribute an article about the EHC Leadership Conference I attended in Brussels earlier in the

summer where I learnt a lot about how other organisations are run and the advocacy work they are doing.

Following this, members will find an in-depth interview with Professor Niamh O'Connell, exploring her personal journey as a medical professional as well as the role of the Product Selection Board and the collaboration between the NCC and the IHS.

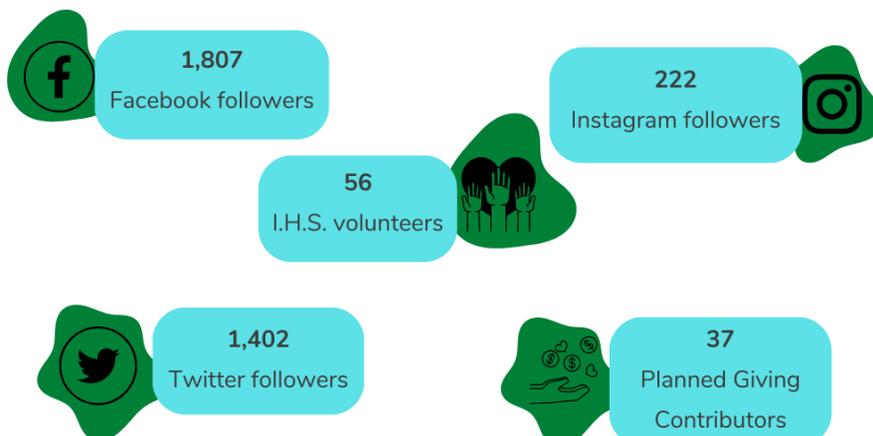
Afterwards there is a very different interview with a Spanish man called Fabio Blasco who took on the extraordinary challenge of travelling to Switzerland from his home in Spain by bike in spite of joint problems he had as a result of his haemophilia.

Also in this edition are details about our 2023 educational grants, which close later this month, a news bulletin members should find interesting and details about our apartments in Dublin 8 for members travelling from outside Dublin for appointments in St. James's or Crumlin's Children's Hospital.

I hope you enjoy this edition!

Róisín Burbridge, Publications, Website & Social Media Coordinator

## The Irish Haemophilia Society at a Glance



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# CEO Report

## The National Bleeding Disorders Foundation, USA

The National Hemophilia Foundation, the US haemophilia patient organisation, have just announced that they are changing their name to the National Bleeding Disorders Foundation. They are doing this as a recognition of the fact that they also serve those with other blood and bleeding disorders such as von Willebrand disorder (VWD), rare bleeding disorders (RBD) such as deficiencies in factor II, V, VII, X, XI, XIII, platelet disorders and others. Their desire is to be more inclusive and to ensure that people with VWD and RBDs understand that the organisation exists also for them. Interestingly, they also talk about evolving even further in the future to assist families with other blood disorders.



This issue is not a new issue and this debate is not a new debate. The possibility of changing the name of haemophilia organisations to be more reflective also of the other inherited bleeding disorders has been discussed for many years, including here in Ireland. This was an issue that we discussed during our strategic plan of 2014 to 2018. Following that discussion we decided not to change the name of the organisation but to add a new tagline under the name: Representing people living with haemophilia, von Willebrands and related bleeding disorders. We are fully cognisant of the requirement to be more inclusive. As therapies for haemophilia become more and more advanced, the pace of innovation has lagged far behind for people with von Willebrands and for many RBDs and platelet disorders. In our work and in our strategic planning, we strive to be inclusive, to raise awareness of and promote better diagnosis and treatment of VWD and rare bleeding and platelet disorders. We work to increase the attendance of people and families with VWD, RBDs and platelet disorders at our events. We have organised national von Willebrands

awareness campaigns in 2021 and 2022 assigning significant time and resources. We hold annual VWD information days and plan to organise a rare bleeding disorders awareness day in 2024. Booklets and information cards have been distributed to the treatment centres to make it clear that we also cater for other bleeding disorders and the centres are encouraged to make these available to the affected families who may not be on our mailing list.

Let us look at some of the advantages and disadvantages of changing the name of the organisation. A clear advantage is that it would be more inclusive and if you were starting the organisation now you could probably call it the Irish Society for Inheritable Bleeding Disorders (as opposed to inherited as many diagnosed are as a result of new mutations). That may attract more people with VWD, RBDs or platelet disorders - despite the fact that their conditions are not actually named. You could argue that a good tagline, similar to that which we now use, teamed with search engine optimisation and proactive information from the centres where they are diagnosed would achieve even more. It would be quite an unwieldy name so you could use Irish Society for Bleeding Disorders or Bleeding Disorders Ireland. That is an attractive name and is the approach now taken by the US organisation.

This causes a different problem. The term bleeding disorders covers a very wide area. It obviously includes haemophilia, von Willebrands, RBDs and platelet disorders - all of whom come under our current mandate. It also covers idiopathic thrombocytopenic purpura (ITP), disseminated intravascular coagulation (DIC), people on anticoagulants and people with liver disease. People with haemophilia, VWD and RBD would be a small minority of bleeding disorder patients. We would be in danger of diluting or dissipating our work and focus into too many disparate areas.

NHF is now the  
National Bleeding  
Disorders  
Foundation (NBDF)

[Learn More | >](#)





Another disadvantage would be the loss of a well recognised brand. Due to the tragic history of HIV and Hepatitis affecting and devastating this community in the past, the organisations advocated strongly and effectively to the point where Haemophilia has strong name recognition with politicians, journalists, health care administrators and the general public. This enables our organisations to be more impactful advocates for our entire inheritable bleeding disorders community. In marketing terms, you do not replace a successful and well recognised brand name and start again. It is relatively easy to decide to change a name. It is very difficult to come up with an alternative which meets your stated purpose and does not negatively impact on your ability to effectively advocate for your community. Many of the national haemophilia patient organisations have been in existence for many years - 75 years in the US and 55 years here in Ireland. The names may be viewed primarily as historical. However, in 2008 when the European Treaters Group was being established, there was discussion about a name which would include all the bleeding disorders. They chose the name "European Association for Haemophilia and Allied Disorders" probably due to the strong name recognition. This is a debate which will continue and I look forward to engaging with you on this topic.

**Parents Conference**

We were delighted to host the Parents Conference again this year after an absence of several years. Our strategic plan now calls for a parents conference to be held every third year and this was the first parents conference since 2016. The very well attended conference included lectures and discussions on future treatment, the new Children’s Hospital, inheritance and carrier issues, sports and pathways to care. It was especially motivating to see several new families and the ease with which they mixed with and communicated with other families with haemophilia and other bleeding disorders.

**“Tainted Blood” Newstalk Documentary**

A Newstalk documentary by journalist Kelly Crichton entitled “Tainted Blood” was broadcast on August 6th and 12th and is also now available as a podcast on Newstalk, Spotify and Apple Podcasts. It is important that we as a community remember the trials and tribulations which have been beset this community in the past and the appalling impact of HIV and Hepatitis C on our community from the 1970s onwards. This is a story that many people in the country will not be familiar with. In this era of new and novel therapies for haemophilia, it is sobering to reflect on the tragic consequences of unsafe treatment in the past. We must ensure that there is awareness of this history within the healthcare system and to ensure that our voice is heard and continues to be heard on the selection and use of the safest therapies for people with haemophilia and bleeding disorders in the future. He who does not learn from history is condemned to repeat it. We are absolutely committed to ensuring that people understand our history and learn from this to allow people to live a safer future.

**New Members**

In addition to the many new members of our community from Ukraine, we now have three families with haemophilia from Syria living in Ireland. This was achieved as part of the Irish government’s commitment to the resettlement of some Syrian refugees following the appalling civil war in Syria. These families were among the more than one million Syrian refugees living in Jordan which we became aware of during the twinning partnership between Ireland and Jordan. Particular thanks has to go to Dr. Beatrice Nolan for her indefatigable efforts with the Department of Foreign Affairs in ensuring that these families were able to come to Ireland. We look forward to welcoming them at our conference in October.

Brian O’Mahony, Chief Executive Officer



# Parents Conference Update

Our Parents Conference took place on the 14th-16th July in the Midlands Park Hotel in Portlaoise. Though the weather was highly questionable for the middle of July, we all managed to have a fantastic time staying inside and learning from the team at Children's Health Ireland (CHI) Crumlin, while the kids had a great time playing and doing activities with the volunteers.

Our last Parents Conference took place several years back, in 2016, and much has changed in terms of treatment and care since then. This was an opportunity for parents who used to come to the parents conferences to come back and learn about the developments in treatment and care. It also attracted many newer members with newly diagnosed children, and offered them a glimpse into how our events run.

The adults programme focused on some of the areas most relevant to parents of children with bleeding disorders. Ms. Eilish Hardiman, CEO of Children's Health Ireland, gave an update on the much-awaited new children's hospital which is nearing the completion of construction in the St. James's site. Ms. Hardiman shared ways in which CHI planned to transform children's healthcare, such as through digitalising healthcare and establishing a Paediatric Academic Health Sciences Centre and Network.

Following this session, Dr. Saad Ahmed shared a detailed presentation outlining the future of treatment. He talked about new therapies and their complexity and choice, sharing that there are no longer only factor concentrate options, but also mimetics, new mimetics, rebalancing agents (whereby the blood clotting cascade is approached in a complementary direction) and gene therapy.

A highlight of the adults programme was Dr. Beatrice Nolan's presentation, which was, as ever, funny, easy to understand and engaging. She focused on the important topics of inheritance and carrier issues. She clearly explained the difference between obligate and possible carriers, and she discussed some of the increased childbirth risks people with bleeding disorders might have, such as the risk of intracranial and extracranial haemorrhage. She explained that birth can be well managed as long as the mother knows she is a carrier, goes in with a birth plan and is in close contact with her haematologist at the birth stage.

Another highlight was the update on a recent survey on emicizumab from nurses Ms. Ruth Hunter-Nolan and Ms. Brídín Brady. The survey has gathered a lot of information about the way children and young people have responded to switching to emicizumab. The survey found many positive effects of the changeover, such as needing to use less medication, not being invasive and not having bleeds. It also pointed out some negatives of the drug, such as the difficulties of giving it to very young children.

Throughout the sessions, parents engaged with speakers by asking questions and voicing concerns. For instance, in the Open Forum session with the team at CHI Crumlin, there was some discussion around the backlog in accessing dental care at the centre in Crumlin. Parents were encouraged to take their children





to their local HSE or private dental clinic every six months from age one. The dentist in CHI Crumlin sees children with moderate and severe haemophilia every two years.

Ms. Paula Loughnane's session focused on sport and exercise and Ms. Loughnane stressed that no sports bar heavy contact sports should be off limits but that children and parents should come to herself and her colleagues in Crumlin to discuss increasing treatment and changing the treatment routine to ensure that the child is able to participate safely.

While the adults were learning from CHI Crumlin, the children were having a great time doing various activities, such as swimming, races and exercise challenges with Paula Loughnane, a photography class with our Children's Programmes Coordinator Rob Flanagan and dancing.

Saturday night proved particularly fun, not just for children but for adults and teens alike. Clown Jeca was our entertainer. He was full of energy and good-naturedly roped parents into taking part in the fun and games (much to the delight of their children). Before long, practically the whole room had gathered round to watch and cheer on the participants. Rob actually won the main challenge, where a number of men were called upon to pick up a plastic ring with the fake elephant trunk they were wearing.

We are looking forward to seeing everyone again in October for another conference weekend!

Roisin Burbridge, Publications, Website & Social Media Coordinator





Irish Haemophilia Society

# OCTOBER MEMBERS' CONFERENCE

20th – 22nd October 2023, Mount Wolseley Hotel, Co. Carlow

Preliminary Adults Programme

## Friday 20th October

7:00 pm **Buffet Dinner**

## Saturday 21st October

10:00 am – 11:30 am **Different Treatments Options: Personal Experiences**  
*(This session will involve a panel of speakers discussing various treatment options)*

11:30 am – 12:00 pm **Coffee Break**

12:00 pm – 1:00 pm **Debate: von Willebrand's Disorder 'Versus' Haemophilia – Which is the toughest bleeding disorder to have?**

1:00 pm – 2:00 pm **Lunch**

2:00 pm – 3:30 pm **Workshop: Treatment Options & Living Your Best Life**  
*(An interactive workshop with members being split up into different groups for a discussion)*

3:30 pm – 4:00 pm **Coffee Break**

4:00 pm – 5:00 pm **An Update on Dental Care**  
*(An update on dental services & best dental practices for people with bleeding disorders)*

7:00 pm **Dinner**

## Sunday 22nd October

10:00 am – 10:30 am **Women's Health Survey Project**  
*(A talk to explain the background of this survey, followed by time to complete the survey)*

10:30 am – 11:00 am **Travelling Wisely**  
*(A session for members where important information & tips will be shared around travelling wisely with a bleeding disorder)*

11:00 am – 11:30 am **Coffee Break**

11:30 am – 1:00 pm **Family Quiz**  
*(A family quiz to include adults & children & teenagers from cubs, kidlink & youth group)*

1:00 pm – 2:00 pm **Lunch**





The European Haemophilia Consortium (EHC) Leadership Conference took place in Brussels on the 15th-18th June. I attended the conference with board members Jim O’Leary and Paul Dunne and really enjoyed getting to know them more over the weekend. This was my first European conference and I was warmed by how close-knit the wider bleeding disorder community is and how friendly people were together. I learnt a lot from the conference, both in terms of which topics and workshops make for a great conference and in terms of what we can glean from other EHC National Member Organisations (NMOs).

The conference was a very nice blend of interactive and lecture-style sessions, a perfect set-up for an event so focused on advocacy. The EHC organisers incorporated varied workshop ideas to get us all thinking. We sat in groups of eight and took part in activities such as a ‘sustainable relationships’ game, in which we considered how NMOs can maintain good working relationships with various stakeholders, including the haemophilia treatment centres (HTCs).

Another useful activity that really got us using our thinking caps was a think tank related exercise known as the ‘systems thinking iceberg exercise’ whereby we considered an issue the bleeding disorder community is facing and unpacked the many layers contributing to this issue. We considered patterns and trends, structures and systems and embedded mindsets. Our table chose the issue of why women with bleeding disorders are diagnosed later than men with bleeding disorders. Through the layer technique, we unveiled various pertinent factors, such as the fact that women and girls often do not know what constitutes a heavy period and how this could signify a bleeding disorder, a deep-rooted religious mindset which makes discussing periods difficult, the fact that bleeding disorders (namely haemophilia) are generally associated with men and boys, and more. We came to the conclusion that it is the responsibility of schools and health care professionals to disseminate information about bleeding disorders to teenage girls. I found this exercise particularly effective in really delving



into the issue and thinking about it from so many different angles.

Learning from the other NMOs was perhaps the best part of the conference for me. The group exercises were particularly good because they enabled the members of the NMOs to share their stories and experiences. This helped me to think about issues that may not be relevant for us in Ireland but are interesting to know about. For instance, one participant who is both a doctor and a person with haemophilia, shared about the importance of good communication between the NMOs and health care professionals, as often the latter can feel like their voices are not really heard in patient advocacy. Another thing that surprised and impressed me was the fact that so many NMOs are run on a voluntary basis. It made me realise how lucky we are in Ireland to have a staff team, but also how dedicated the bleeding disorder community is to their cause.

Over the course of the weekend, we discussed issues relevant to all NMOs, such as the issue of youth engagement. As a group, we considered the fact that as haemophilia treatment has become so good, many young people feel they do not need to be active in their organisation. Another interesting point that was discussed was the possibility that the topics covered at NMO events do not capture the interests of young people and that if discussions were held on issues such as sex, tattoos or needle-phobia, there may be better engagement. A final point that struck me as being vital, is the fact that people with rarer bleeding disorders often feel left behind, as developments in their treatment lag far behind those of haemophilia, and so patients with these disorders continue to struggle with bleeding symptoms.

Overall, there were many intriguing discussions throughout the Leadership Conference, and I’m looking forward to meeting our European friends again in the future!

Roisin Burbridge, Publications, Website & Social Media Coordinator





# Interview with Professor Niamh O'Connell

*Professor Niamh O'Connell is National Haemophilia Director at the National Coagulation Centre (NCC), St. James's Hospital, Dublin. Professor O'Connell joined the NCC as Consultant Haematologist in 2010 and took on the role of Director of the NCC in 2018.*

*Her research interests include clinical trials in novel therapies for haemophilia, clinical outcomes in haemophilia and application of information technology solutions in the management of haemophilia.*

*Below is an interview Roisin Burbridge conducted with Professor O'Connell earlier this year.*

## **Can you outline your career to date?**

Firstly, I studied medicine in University College Cork. It was a great university to attend because Cork is a small city and the university is very compact. But then I wanted to spread my wings a little bit. I'd lived at home all through my college career, so I think it was time to move out at that point. I applied for Senior House Officer (SHO) schemes in Dublin. The SHO schemes involve two years of rotations through different disciplines. One of the reasons I chose the scheme was because it included six months

of haematology. When I came to Dublin my first rotation was in the Mater Hospital, in haematology.

I had a number of other rotations following this. I worked in Wexford Hospital and I had a wonderful six months there. My final six months were in the Cleveland Clinic in Ohio, which was a very interesting experience. The Clinic loved having the Irish trainees come over because we had so much experience of hands-on medical care. For my part, when I was in Wexford, even though I was quite junior, I had a lot of responsibility. This was because it is a small hospital and it didn't have loads of doctors. So I just had to do what needed to be done. By the time the other trainees and I had got to Cleveland it was as if we could do anything! The Cleveland Clinic thought we were very well trained and loved having us from that perspective. From our perspective, our time at the Clinic showed us what the future of medicine could be. The Clinic had new computerised systems and they had a really in-depth knowledge of the patients they looked after. You were expected, even if a patient had come in at two in the morning, to know every single thing about their medical history by the time rounds happened at eight o'clock. There was an expectation of excellence.

Before I left for Cleveland, I had interviewed for a haematology registrar training post in Ireland and so I came back to that in 1997 and did my first rotation in St. Vincent's Hospital, with a wonderful consultant who really guided me and mentored me there. I worked in Beaumont for the second six months and then I went to St James's. At that time, the Coagulation Comprehensive Care Centre was basically one big room with one nurse, one receptionist, a registrar and a part-time consultant.

Later, I moved to London, as a research fellow in the Royal Free. The Royal Free Hospital at that time had a long-standing comprehensive care centre and it really is the model for the comprehensive care centres that we have now in Ireland. The comprehensive care centre at the Royal Free had all the various specialties, including things like physiotherapy and clinical psychology. The laboratory was very closely connected with the clinical service. I did my PhD thesis at this hospital on a rare bleeding disorder called factor XI deficiency.

But then, as often happens for Irish people, I needed to get back home. At the time there wasn't a role in the haemophilia centre. I felt I had a choice to either come back to a general job in Dublin or stay in London, and I decided to come back and take up a general post in Tallaght University Hospital. I worked there for six years as a consultant haematologist.

I kept in touch with my coagulation interest and later a post came up in St. James's in the haemophilia centre. I couldn't believe it. So I applied for it and joined the team in St. James's in 2010. I've been there ever since as a consultant haematologist in the NCC, and since 2018 as the Director of the Centre. I feel like the luckiest person in the universe.

### **Could you tell me a bit about the various functions of the NCC and how it is structured?**

The primary function of the NCC is to deliver holistic care to people and families with bleeding disorders. In order to do so, we take the best practices from centres around the world. We want to ensure that firstly, we are reaching the highest standards possible and also, we are watching what is on the horizon so that we can set standards rather than just respond to them. At the NCC, we look after the patient and their families. This involves much more than just a consultant haematologist alone. In fact, we have a whole multidisciplinary team, including a physiotherapist, psychologist, specialist nurses and social worker. Our social worker, for example, gives support to young people who are putting down their course choices for the CAO or trying to decide which career path they should follow. She also helps people with housing and with benefits applications. We have a wonderful dentist and a dental team who provide care for people with particularly complex dental needs. Professor Alison Dougall (our dentist) is also very innovative around training the trainers, meaning that she wants the community dentist to feel comfortable dealing with the common dental issues of people with bleeding disorders.

We also have a role in the procurement of treatments and in making sure that the platforms we are using to manage haemophilia are up to date, such as the electronic health record. There is also a huge international dimension to what we do. Because bleeding disorders are such rare conditions, there are only a few of us in a country as small as this who have an understanding of and an interest in bleeding disorders. Because of this, our peer group stretches beyond Ireland, incorporating our European colleagues and further afield - the EHC, the ISTH and the WFH.

Finally and importantly, this is a system that is co-designed with the patient community. They tell us what they need and we give them some ideas about what we think might work. And together we make it happen. I couldn't do my job without the support of the patient organisation.

### **You've already discussed a bit about your role as the NCC director, could you expand on this a bit more?**

I feel like I'm conducting an orchestra and the team are all experts in their own areas. I need to trust in their expertise as they know what they're doing. My role is to facilitate what they're doing and at times give a little bit of steer here or there, a little nudge.

I also liaise with other people and departments within the hospital, the CEO and hospital management team, the Admissions Office and other consultants. I've also learnt, in the past few years particularly, that as the Director of the Centre my role is also to advocate on behalf of our patients and team.

I also work with the patient organisation and other haematologists nationally and with the HSE on various projects.



### **Could you talk a little about the new patient portal?**

Yes! Those who are 16 and over can now apply to the NCC to be able to access the patient portal. One of the reasons this particular system, called Indici, was chosen, is because it was already a portal in New Zealand. We wanted to innovate but didn't necessarily want to trial something completely new. We had confidence in this system as it was already working well in New Zealand.

The first step was to put the electronic health record into being and we went live with that in October 2019. The intention was to go into the next stage of the patient portal but we needed a few months to allow the main Indici system to bed in with our clinical teams. And of course we all know what happened in March 2020...

We did a lot of background work around the user agreement and around the privacy statement. In the midst of this, the cyber attack occurred, which

affected the HSE enormously. This incident really underlined the importance of making sure that the necessary security and privacy elements were in place.

At this time, we were also having a lot of discussions and conversations with our fellow comprehensive care centres in CHI Crumlin and Cork University Hospital. We did a lot of research about how we could try to facilitate paediatric patients and their families having access to their records. But this is a much more challenging process than it is for an adult, as children cannot consent for themselves. Along with that issue, CHI Crumlin were tendering for and developing their own electronic healthcare record for their move to their new site in St James's. They have made a decision that they don't want multiple portals for kids and families.

The patient community have been brilliant in testing the portal for us. We had a group of committed patients who helped us with the first developmental stage last year and their feedback was essential. They let us know that the limited functions we had at first were simply not enough. We took that on board and developed the messaging function and we plan to keep improving the functions available.

We have a very good partnership with the Innovation Value Institute at Maynooth University. They are a group of researchers who are very interested in getting feedback from consumers about electronic platforms. They're going to help us to survey both the users of the portal and the healthcare professionals who are operating it from the NCC. I anticipate that we'll get important feedback which will enable us to make changes to improve the portal, both for the person using it and for the healthcare professional.

### **It looks great! It's great that patients can schedule appointments.**

Scheduling is not quite like Ryanair yet, where you can go and map out which slots are free. This is, however, ultimately where we hope to go with it. The

portal currently allows patients to send a message saying that they have an appointment and would like to reschedule it. It means patients don't have to sit on the phone, waiting for hours to try to get through to a team member. Patients can send in their message and we can deal with it in the background for them.

### **I'm sure that'll save time for a lot of people. Now, can you tell me about the Haemophilia Product Selection Monitoring Advisory Board (HPSMAB) and your role as Chair?**

The role of the HPSMAB is to advise St. James's, who procure the treatments on behalf of the whole country. That's a function that was assigned to St. James's as a statutory instrument in 2012. In a very forward-thinking action, the statutory instrument states that we can procure biological treatments, as well as clotting factors. This means that in the era of new treatments, these all come under the umbrella of the procurement process. This is brilliant because it means we could procure emicizumab, and that we can procure gene therapy. It also means that the expertise for procuring treatment stays within a group of experts, including members of the patient community.

We have a number of people on the Board with enormous experience of procurement. It was a steep learning curve for me when I joined as Chair, although I had been involved in some procurement previously in my role in the laboratory and therefore did have some background knowledge. Additionally, I've been lucky enough to have a good grounding in things like legal documents.

### **What is your favorite aspect of your job?**

I get a real buzz out of my patient clinics. They're intense, because I see a lot of people and have a lot of meaningful and in-depth conversations. My absolute favourite clinic is the young adult clinic. It does my heart good to see those young people and how much maturity they have, especially with everything they have gone through in such short lives. It's a big change for them, coming for the first time to a new hospital and having to speak for themselves.

The concept of the young adult clinic is that we have a little more time. We try not to over-schedule so that we have plenty of time with each young person. For the first clinic, we deliberately keep the number of people that each young person meets to a minimum because we don't want to overwhelm them with hundreds of new faces. At their first clinic, the young person tends to meet one consultant and one of our specialist nurses. At their second



visit they will meet others like the physiotherapist, dentist or social worker. In the waiting room when they come, obviously because it's the young adult clinic, they see lots of other young adults who are also attending. We want them to see the NCC as a place where people of their age come - I don't want them to feel they're the only young person in the whole service.

One of our patients made a brilliant video on our website about his experience coming to St. James's for the first time. I think it's really inspiring. It's about how he felt coming over from CHI Crumlin and what that process meant to him. Not only was it about moving location, but it was also a marker of new-found independence and of taking ownership of his own life and his choices. He was brilliant to give us his time. His is a really positive experience.

### **That's wonderful. Finally, what is your view on the collaboration between the NCC and the IHS?**

Well, I think the relationship is unique in Irish healthcare to be honest. It does not seem that colleagues in other specialties have as close a working relationship with their patient organisation as we do in haemophilia.

There are two main areas where the collaboration has been really effective. The first is in clinical trials. When I first came to the NCC in 2010 there was a clear message coming from the patient community that they placed great value in treatments that were tried and tested and they did not want to go into the space of clinical trials of treatments. And I can understand why that was. They had been hurt by things that had occurred in the past and they really valued safety. But as the 2010s progressed, there was a lot of development in the world of haemophilia around novel therapies. Little by little, we were able

to build up a clinical trials team in the NCC. We now have a clinical trials coordinator, a research nurse and we're shortly to have another staff nurse to assist us. We have a pipeline of clinical trials that we think are useful for people to consider. We believe that clinical trials are really beneficial. They give access to new treatments earlier, allowing us to gain an understanding of these treatments so that when it comes to rolling them out to more patients we know what to expect. From the perspective of the person who participates in the trial, the huge additional bonus is that they get really great clinical care.

The patient organisation helps us with this. I talk to the team in the IHS about the studies that are coming up and they facilitate my participation in patient meetings to inform people about the clinical trials that are available. There are real advocates within the patient community and organisation who tell those considering participating that it is a positive and worthwhile experience. This really helps to reassure people who are considering a clinical trial and give them confidence that they will be well looked after.

The other area where we work closely together is in our twinning with Jordan. Though the IHS had taken part in twinning before, this was our first time. The IHS's long experience of twinning helped enormously in this first relationship. We learnt a lot from their knowledge and experience. Even though twinning was disrupted by Covid as everything was, we have the final year of that programme this year. We were delighted to hear from WFH recently that the treatment centres in Ireland and Jordan have been awarded "Twins of the year" for 2022. This was a great boost and I'm looking forward to planning the next visit in November with the IHS.

*Many thanks to Professor O'Connell for taking part in this interview!*





# Educational Grants

The Society offers annual educational grants to people with haemophilia, von Willebrands and other related inherited bleeding disorders, including to a person with carrier status and/or their immediate family members.

The purpose of these educational grants is to offer financial support to post-second level students to assist them with the extra expenses of their studies. Applications opened on 23rd June 2023 and close on 22nd September 2023.

### Types Of Educational Grants

There are four categories of grants:

- Maureen & Jack Downey Educational Grant
- Margaret King Educational Grant
- Father Paddy McGrath Educational Grant
- Michael Davenport Educational Grant

### Criteria For Applying

#### The Maureen & Jack Downey Educational Grant:

- Available to a person with a bleeding disorder, including to a person with carrier status.
- The person must have been accepted on to a post second level course from level 7-9.
- The person must be registered at the National Coagulation Centre at St. James's Hospital in Dublin.

#### The Margaret King Educational Grant:

- Available to an immediate family member of a person with a bleeding disorder, such as a spouse, child, sibling or parent.
- Carriers with factor levels greater than 40% can also apply for this grant.
- The person applying must be accepted on a

post-second level educational course at levels 7 to 9.

- The person with the bleeding disorder must be registered at the National Coagulation Centre at St. James's Hospital in Dublin.

#### The Father Paddy McGrath Educational Grant:

- Available to a person with a bleeding disorder, including to a person with carrier status who has been accepted onto a post-second level educational course at level 5 or 6.
- Also available to immediate family members who have been accepted onto a post-second level educational course at level 5 or 6.
- The person with the bleeding disorder must be registered at the National Coagulation Centre at St. James's Hospital in Dublin.

#### The Michael Davenport Educational Grant:

- Available to a person with a bleeding disorder, including to a person with carrier status who has been accepted onto a post-second level educational course at level 7 to 9.
- The person must be a mature student going back into third level education.
- The educational grant will be a bursary for 3 to 4 years with 4 years being the maximum term of the grant.
- The person applying must prove they are staying in college for the 4 year period and must provide receipts.
- The person with the bleeding disorder must be registered at the National Coagulation Centre at St. James's Hospital in Dublin.





### Award Amounts

#### Maureen & Jack Downey Educational Grant

- First prize €4,000
- Second prize €2,000
- Third prize €1000

#### Margaret King Educational Grant

- First prize €2,000
- Second prize €1,000
- Third prize €500

#### Father Paddy McGrath Educational Grant (2 Grants)

##### 1) A person with the bleeding disorder

- First prize €1,000
- Second prize €500
- Third prize €250

##### 2) A family member of a person with the bleeding disorder

- First prize €500
- Second prize €250
- Third prize €125

#### Michael Davenport Educational Grant

€2,000 will be paid per year, with a maximum of €8,000 being paid out over a 4 year period.

### Process of scoring applications

Once the closing date arrives, towards the end of September, a subgroup of three people from the

executive board (which cannot include anyone with a family member applying for any of the other grants) meet to consider and score the applications, and make recommendations to the rest of the board regarding recipients. The successful applicants are then notified at the end of October by letter.

Applications are scored on the following:

- The quality of the application.
- The information provided on the application form.
- Involvement in the Irish Haemophilia Society.
- Financial need.
- How many in the family are going to college.
- If the application is a first time application.

### Can I apply every year?

Yes, you can apply every year, even if you have already been successful. Please remember that you can only apply to one grant each year.

You can apply online via our website at [www.haemophilia.ie](http://www.haemophilia.ie). You can also download the application forms from the website, complete them and post the completed forms to the office. If you need further assistance, call the office on 01 6579900.

## Hyde Square Apartments



Hyde Square  
Apartments



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

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

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

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





# An Inspiring Journey from Spain to Switzerland

*Mr. Fabio Blasco is the Vice-President of the Spanish Federation of Haemophilia. Though, Mr. Blasco has suffered with ankle pain due to*

*severe haemophilia, in 2021 he embarked on a spectacular journey from his home city of Zaragoza, Spain, to Switzerland, by bike.*

*Below is an interview Roisin Burbridge conducted with Mr. Blasco this summer.*

## **Fabio, would you tell us a bit about yourself and your story growing up with haemophilia?**

It has been difficult for me living with haemophilia because I love sports and being active. I love hiking, but as my haemophilia has gotten worse over the years, this has become harder. My ankles particularly have caused me a lot of problems. I have severe haemophilia B and I use long-acting factor, but I need to take it every four days because my factor levels go down really quickly.

## **Did you have a really active lifestyle as you were growing up?**

Yeah, I always liked taking part in new sports and activities. But I got injured a lot and unfortunately when I was a kid I was not very strict with taking prophylaxis. This was really bad for me and I had a lot of bleeding problems because of it.

## **Before we start talking about the bike ride, could you tell me what haemophilia care is like in Spain?**

In the public system everything is accessible and free. The only issue is that when a new treatment comes out, it can take some time to reach the public system. In Spain we have patient associations who

provide other kinds of care, such as psychological supports and physiotherapy. These services are free.

I work in the Spanish Federation for Haemophilia (FEDHEMO). As part of the Federation, we organise projects and studies, make guidelines and give support to different regions of the country.

## **Tell us a bit about your bike journey and why you made the decision to embark on this journey.**

I made this decision because I wanted to teach society at large about haemophilia. To do so, I filmed my own documentary during the journey. I wanted to talk about how I manage my life with haemophilia, how I find ways to stay balanced and how I work to improve my health.

It was also a personal project. I wanted to stay active while also respecting my haemophilia and my joints. It was a great way to test my limits.

For me, cycling is the perfect activity. I use my bike all the time in my daily life, going to work, going out, moving around my city. I can't walk properly because I have a lot of pain and I limp.

## **Had you gone on a big bike ride before?**

No, I had done some weekend routes, 60 or 70km a day, but this was the first big one.

## **What was the journey like?**

Well, I was following the EuroVelo routes, which are a network of cycling routes around Europe. Before the trip I planned a lot about where I would sleep etc., but I ended up not following this. As I was travelling with my tent, I could stop anywhere. Some days I rode more than I had expected, other days less. I rested when I was tired. I slept on beaches, in the forest, in the desert, on mountains, beside a house. Sometimes I also slept in hostels or hotels when I needed more rest.

## **What time of year did you go?**

I went from the beginning until the end of October. I got really lucky with the weather. France is a really rainy country but it only rained two days. It was 15-25 degrees everyday.

## **What challenges did you face along the way?**

The biggest challenge for me was psychological.

I had a lot of fear that I wouldn't reach my goal of getting to Switzerland. I feared I would have an accident and that my body would not be able to manage the trip. This was the worst part. Even until I crossed the border of France, I didn't think I would complete the trip. But my body worked really well because I had trained a lot.

Another challenge was learning how to manage my haemophilia if I had a problem or an accident, especially when I was cycling a lot. I had to stretch a lot and massage my ankle to relax the muscles and joints. Some days I had to rest a few days because I had swollen ankles.

I had a few bleeds along the way. Towards the end of the trip I fell off my bike, twice. The second time I got an elbow bleed and I had to stop and take a higher dose of my factor. But the next day it was much better.

### **You mentioned that you trained a lot beforehand. How did you train for this trip?**

I try to be really active in my daily life. I practice a lot of sports, ones I can do with my ankle the way it is. I practice callisthenics, which is a bodyweight exercise using a bar to do pull ups and other exercises. This is really focused on strength-building. I also practice yoga, which is great for flexibility.

### **What was it like going over the mountains? Did you have to sleep on the mountain?**

I slept for many nights on the mountains. I love mountains so it wasn't a problem for me. Actually, it was the best part of the trip. I do remember once it was so cold, but I had a really good sleeping bag. When I reached Switzerland it was nearly November and it was getting really cold. My tent was completely frozen on those mornings.

### **What were the highlights of your trip?**

One of my highlights was crossing the border with France, by crossing the Pyrenees. It was really

intense and hard. My bike weighed 50 kilos with everything on it, so pushing that up the mountains was very difficult. During that time, I really felt like I wouldn't be able to finish the trip. But as I came to the border with France I started really believing I could do it. It was easier after that, I listened to my body and knew when to bike and when not to bike and to rest.

Of course, reaching Switzerland was also a huge highlight. When I reached Switzerland I really felt like I could do anything. I was really proud of myself. I had pushed my limits, while being respectful of my ankles and haemophilia.

Another highlight was a year ago when I presented the documentary in Spain. I showed it to people from the Federation who came from all around Spain, patients, doctors and others. They were so moved by the documentary. Sharing with the community was so beautiful for me.

### **What was it like making the documentary? Did you film everything yourself?**

Yes I did. Before the trip, I thought a lot about what kinds of shoots I would do.

I wanted to focus on three main points during the course of the documentary. The first was about how haemophilia affects my daily life and how I manage with it, the second was how I can still do everything I love even with my haemophilia and the third was how people can and should push themselves and change their lives for the better.

### **Do you have any other adventures planned?**

After that trip I did many more cycling trips. I love travelling, so I have now bought a camper van and who knows, maybe my life will continue on the road!

*Many thanks to Mr. Fabio Blasco for taking part in this interview! The documentary is available to watch in Spanish on YouTube.*





## VWD Information Day

Following our Von Willebrand Disorder Information Day in 2022 we are holding another information day to bring people with VWD and those interested or connected with the disorder together. This Information Day is taking place Saturday 23rd September in the Grand Hotel in Dublin.

During the information day, Professor James O'Donnell, Consultant Haematologist at St. James's Hospital will share updates about the treatment for VWD. There will also be an interactive workshop to allow attendants to discuss what they would like to see in VWD treatment and care over the next five years.

Please call the office on 01 657 9900 if you are interested in registering for this event.



## My Indici Patient Portal

The NCC's 'MyIndici' Patient Portal is up and running. The Portal provides those who are registered with the NCC the ability to have more control over their healthcare and a compact space in which to view healthcare records, hospital letters, past appointments etc. The system means that patients can access their own healthcare records in the one place.

The Portal also allows patients to change appointments without calling the NCC, as they can send messages to the team and request a change of appointment this way.

To register for the patient portal, visit the NCC website and download the Patient Portal Access Request Form.



## WFH Twins of the Year

The World Federation of Hemophilia (WFH) 2022 Twins of the Year have been announced! The NCC and CHI Crumlin have been named the Haemophilia Treatment Centre Twinning (HTC) Programme Twins of the Year with Al Bashir Hospital in Amman, Jordan.

Many activities were held over the year which moved the level of care forward in Jordan for people with bleeding disorders (PWBDs). Medical, nursing and physiotherapy trainers from Ireland visited the haemophilia treatment centre in Al-Bashir, as well as the haemophilia treatment centre in Zarqa to work with specialists to help optimize the processes.

Congratulations to the NCC and CHI Crumlin for this achievement!



## Long-term Illness Scheme

Oral contraceptives and progesterone containing intrauterine devices are now available to women with haemophilia through the Long-Term Illness Scheme, to manage heavy menstrual bleeding caused by a diagnosis of haemophilia.

Anyone with a diagnosis of haemophilia is eligible for the Long-Term Illness Scheme. The scheme covers certain medications and equipment for people with haemophilia. A list of medications and equipment covered by the scheme can be found on the HSE's website.

The initial prescription for these contraceptives should come from your Haemophilia Comprehensive Care Centre and subsequent prescriptions can then be obtained from your GP.



## Pilates & Physio-Exercise Classes

Our physio-exercise and pilates classes stopped briefly during the Summer but are back up and running in September.

On Tuesdays, we have physio-exercise classes for adult male members with registered physiotherapist Mark McGowan. These classes take place on Zoom from 7-8pm.

On Wednesdays, we have a new pilates class for all adult members with registered physiotherapist Carly Blackburn. These classes take place on Zoom from 7-8pm.

Please call the office on 01 657 9900 if you are interested in registering for one of these classes.

## Newstalk's 'Tainted Blood' Documentary



Newstalk recently ran a radio documentary entitled 'Tainted Blood', which shares the story of the haemophilia community during the HIV crisis and the actions that had to be taken to secure justice for the community.

The documentary includes the voices of those impacted and those involved in seeking justice for the community. One of our members, Colm Walsh, whose brother contracted HIV and eventually died, features on the documentary.

Also featuring on the documentary are Brian O'Mahony, who shares information about the Irish Haemophilia Society's role in offering support to the community during the crisis and Margaret Dunne, former Office Administrator of the IHS.





Irish Haemophilia Society

First Floor  
Cathedral Court  
New Street  
Dublin 8

Tel: 01 657 9900

Email: [info@haemophilia.ie](mailto:info@haemophilia.ie)  
Website: [www.haemophilia.ie](http://www.haemophilia.ie)  
Twitter Handle: @HaemophiliaIRL

Find us on:

