Haemophilia.ie

Magazine of the Irish Haemophilia Society

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

SCAN ME

Summer 2023 Edition

From the Editor

Hi everyone and happy summer! I hope you are all enjoying the long summer days.

This edition of our quarterly magazine is packed full of interesting articles and information. As usual, we will first hear from our CEO Brian O'Mahony, who will provide an update on news regarding the H&H Ward, and on hormonal therapy for people with haemophilia, as well as other interesting topics.

Following this, I will give a run-down of our Mild Haemophilia Information Day which took place in April 2023. Next, we have included a fascinating interview with Dr. Glenn Pierce, one of the leading innovators in haemophilia care, who was at the head of bringing multiple therapies still in use today from the clinic to the market. I was honoured to interview Dr. Pierce at the AGM in March and I hope you learn as much from him as I did.

Later in this edition, Maebh O'Sullivan writes an article about her experience fundraising for us. Maebh ran a staggering 100 miles in March and we are so grateful to her for her fundraising efforts.

In this magazine, members will find the first glimpse of our October Members' Conference programme, and I would urge you all to take a look at this. The Conference is shaping up to be a memorable one, with a return of our fun debates!

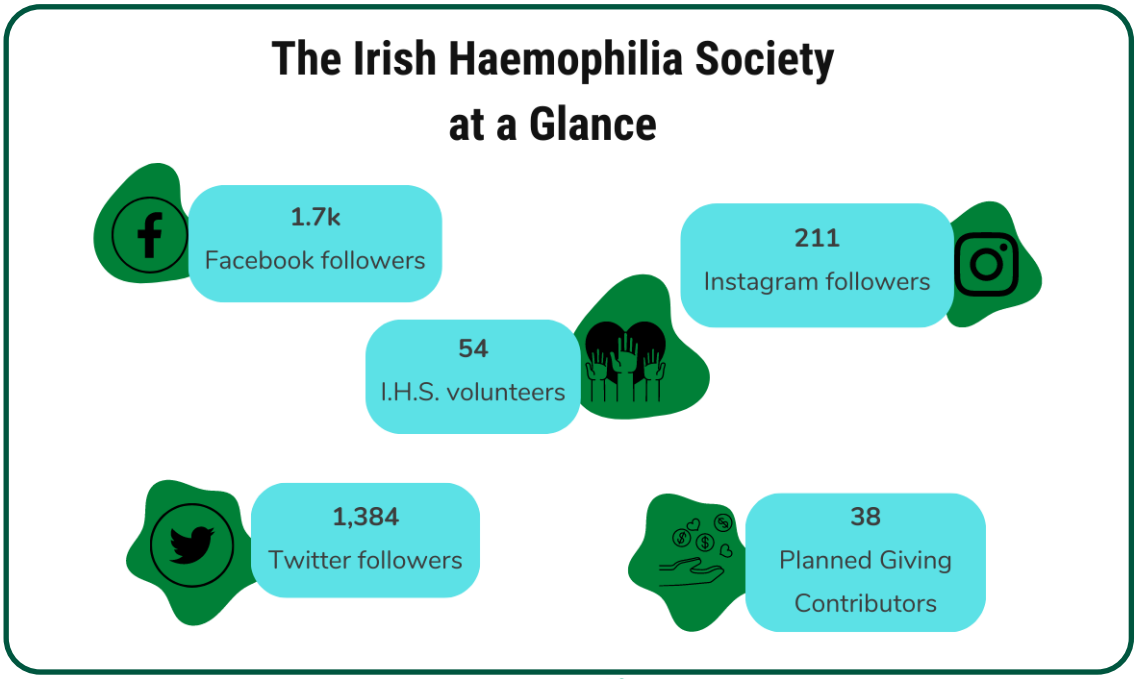
Members will also find a very interesting piece written by medical student Abdullah Zafar Khan on his research, which examined the safety of intramuscular vaccination in children with haemophilia. Later in the magazine there is an adapted press release from the National Coagulation Centre (NCC) regarding the new My Indici platform, a novel platform and app which enables patients to take control of their haemophilia care.

For those of you in third-level education or going into third-level education, we have included extensive information about our educational grants, and I would encourage students to consider applying to one of these.

Finally, scattered throughout this magazine you will find illustrations of IHS heroes, drawn by the kidlink group from this year's AGM!

I hope you all enjoy this edition.

Roisin Burbridge, Publications, Website & Social Media Coordinator



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CEO Report

H&H Ward

The H&H Ward in St. James's Hospital is a vital component of the haemophilia care infrastructure. This ward was specifically designed to include the requirements of people with haemophilia and the funding for the ward was partially available due to savings from the haemophilia procurement process in which the Society plays a formal role. It was clearly understood from the design and opening of the ward that it would be the location where people with haemophilia and those with hepatology concerns (hence the name H&H) would be admitted.

At the beginning of the COVID pandemic in March 2020, the haemophilia service lost access to the H&H Ward, which was then being used as a COVID treatment ward. This continued right through 2021 and 2022 and currently the ward is being used as an assessment unit to see if individuals are COVID positive prior to admission to other words. Indeed, the single rooms on the ward are being used by the hospital for any purposes. In 2021 we met with the then CEO of St. James's Hospital and strongly made the case for the return of access for people with haemophilia and other inherited bleeding disorders to the ward. This was not possible at the time due to the ongoing COVID pandemic, but we were assured that we would have access to the ward in the future at the earliest possible opportunity. During the COVID pandemic there was also an increase in the waiting lists for elective orthopaedic surgery in people with haemophilia. In 2022, the National Coagulation Centre (NCC) succeeded in getting access to one specific bed for people with haemophilia in for orthopaedic surgery which allowed for the resumption of elective orthopaedic procedures and this bed continues to be used for this purpose.

Progress in relation to regaining general access to the H&H Ward for people with haemophilia has been very slow. We had received testimonials from several members who were very concerned about their experiences in St. James's Hospital due to lack of access to the H&H Ward. These testimonials were discussed at the National Haemophilia Council and the lack of access to the H&H Ward was an ongoing topic over the past year and since the meeting in 2021. In April of this year, I attended a meeting together with the Chairperson of the National Haemophilia Council Mr. Brian Fitzgerald, National Haemophilia Director Professor Niamh O'Connell, with the current CEO of St. James's Hospital Mr. Noel O'Gorman and the hospital Strategy Director, Dr. Barry White. At the meeting, we received a firm commitment that people with haemophilia and other inherited bleeding disorders will now have resumed access to the inpatient beds in the H&H Ward restored from September 1st this year. From that date when people with haemophilia or other inherited bleeding disorder are admitted, it should be to the H&H Ward unless they require admission to another specialist word. We would like to thank St James's hospital for this commitment and we will also be monitoring to ensure that this commitment is honoured.

Hormonal Therapy

Hormonal therapy for heavy menstrual bleeding (HMB) due to haemophilia can now be initiated via the Haemophilia Comprehensive Care Centres for women above or below the age groups eligible for the free scheme, though GPs can continue it once the initial prescription is given. Applicants must have a Long Term Illness Card. It is not yet available for those with von Willebrand's or other inherited bleeding disorders, but advocacy and work continues in this regard. I want to acknowledge the work of the NCC in this welcome development. If you need information about applying for a Long Term Illness Card, contact the Society.

Mild Haemophilia Information Day

On April 22nd, the Society organised a mild haemophilia information day. This was very well attended and included talks on adult and paediatric developments in mild haemophilia from Professor Niamh O'Connell and Dr. Beatrice Nolan, dental care by Professor Alison Dougall and Society services and support.

Parents Conference

We are very much looking forward to our Parents' Conference in July. This is the first Parents' Conference we have organised since 2016. Prior to that year they were held on an annual basis for several years but it was then decided that they did not need to be held on that regular an interval. Our current plan is to hold the Parents' Conference every third year. It will be very interesting to see the changes in attitude and experience of living with haemophilia since the last Parents Conference. Treatment has changed very significantly since that time with every person with haemophilia now offered treatment with either an extended half-life factor concentrate or Emizicumab. Bookings for the event have been very robust and the event is totally booked out with a large number of adults, children and teenagers attending. We are very much looking forward to seeing all of the parents, the children and the volunteers in Portlaoise in July.

Shared Decision Making

With the licensing of the first gene therapies for haemophilia A and haemophilia B in recent months, the concept of shared decision making has come very much to the fore. In recent years, with the availability in Ireland of extended half-life factor concentrates and Emicizumab, people with haemophilia and parents of children with haemophilia have been engaging in shared decision making to some extent.

The decision as to which therapy to take and the intervals and doses of therapy have been matters for discussion between the individual and their clinician. This discussion would normally take into account the individual experience of living with their haemophilia including their bleeding phenotype and joint status, their lifestyle activities and barriers to their desired activities. Shared decision making is the recommended way for therapeutic decisions to be made in life long conditions such as haemophilia.

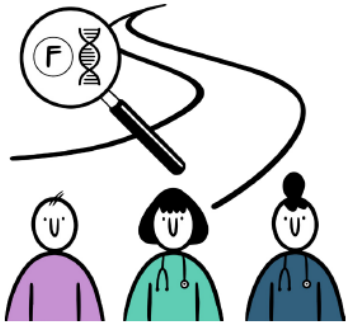
For gene therapy, shared decision making will be mandatory. If gene therapy is offered as an option in the near future, people with hemophilia who are eligible will have to consider the potential benefits, risks, knowns and unknowns and also set and manage their own expectations in the context of significant variability in outcomes. This is an exciting time in haemophilia care but decisions now being made or possibly being made in the future will require full commitment by the person with haemophilia and engagement in a shared decision making process with their clinical team, assisted by information and education initiatives from the Society. The Society will be producing educational materials on gene therapy and organising meetings for members who are interested in knowing more later in the year.

Brian O'Mahony, Chief Executive Officer

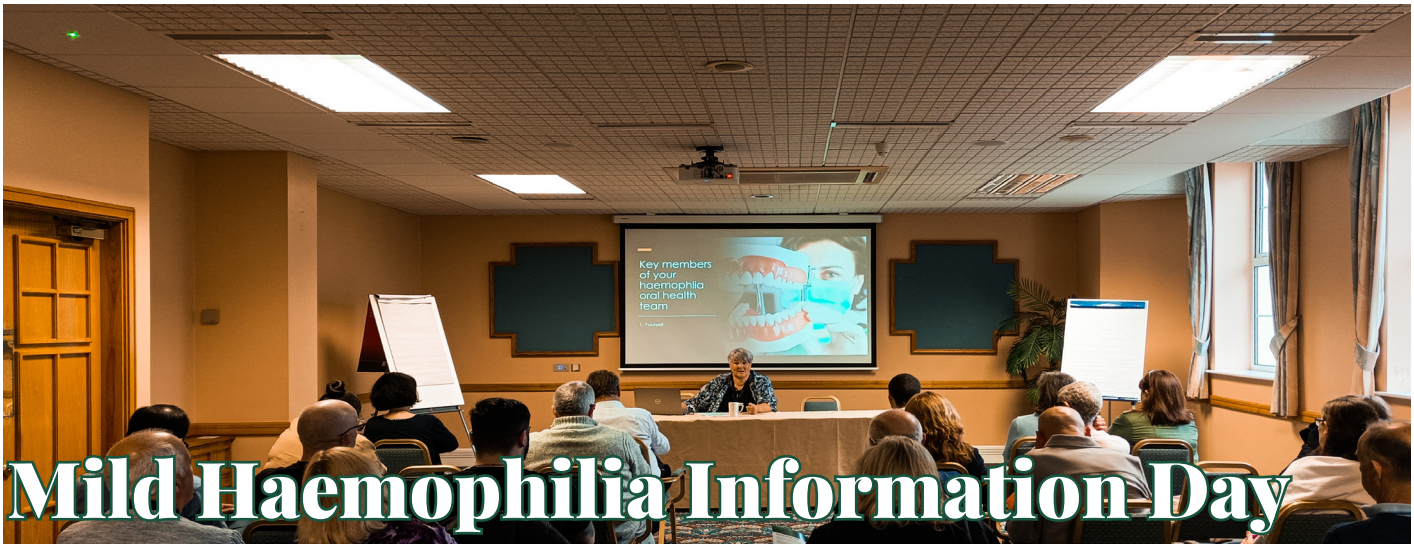
CLINICAL PRACTICE

Personalising haemophilia management with shared decision making

Leonard A Valentino, Victor Blanchette, Claude Negrier, Brian O'Mahony, Val Bias, Thomas Sannié, Mark W Skinner



The patient journey in haemophilia gene therapy is complex and multifaceted, presenting challenges to the hub and spoke model of care. Understanding these from the patient viewpoint will help ensure people with haemophilia receive the information, guidance and support they need throughout their gene therapy journey.



Mild Haemophilia Information Day

To mark World Haemophilia Day, which took place April 17th, we held a Mild Haemophilia Information Day the following Saturday April 22nd. The meeting brought together members and non-members alike and our three speakers explored various aspects of care relevant to mild haemophilia. Throughout the day, the audience engaged with the speakers with questions and comments, making it a very interactive and thought-provoking event.

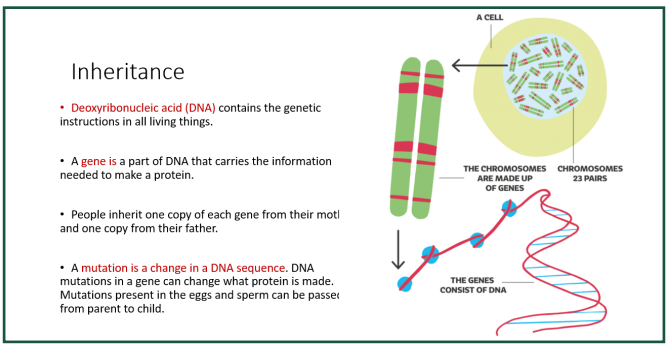
Our first speaker of the day was Professor Alison Dougall, the head of the Department of Child and Dental Public Health at Trinity College Dublin, and Consultant/Professor in Special Care Dentistry at Dublin Dental University Dental Hospital. Professor Dougall gave a comprehensive presentation on a range of topics surrounding dentistry and how it relates to haemophilia. Professor Dougall acknowledged and discussed the added fear and anxiety many members of the bleeding disorder community may feel when visiting the dentist because of their history. She stressed, however, that dental issues are avoidable with the proper care and went on to discuss some of the keys ways people can protect their teeth, such as using a medium or hard toothbrush, chewing sugar free chewing gum and taking a regular trip to the hygienist. She also shared interesting information such as the fact that healthy gums don't bleed.

Dr. Beatrice Nolan, Consultant Haematologist at CHI Crumlin, spoke next and gave a very comprehensive introduction to haemophilia, explaining inheritance patterns, carrier status, the three levels of haemophilia severity and more. She talked about the signs and symptoms of haemophilia and discussed a few of the specific bleeding patterns of people with mild haemophilia, such as the fact that they don't tend to have spontaneous bleeds like those with severe haemophilia do.

Consultant Haematologist and Director of the National Coagulation Centre in St. James's, focused her talk on Emicizumab and the Haven 6 study, which aims to assess the safety and efficacy of Emicizumab. The results of the study have generally been very positive with two-thirds of participants having had no treated bleeds. Professor O'Connell also discussed which circumstances might make it useful for a person with mild or moderate haemophilia to go on Emicizumab, such as having significant bleeds or target joints.

The afternoon closed with an excellent questions and answers session with Dr. Nolan, Professor Dougall and Brian O'Mahony, and a run through of the services and supports the Irish Haemophilia Society offers. All in all, it was a very informative and enjoyable day!

Roisin Burbridge, Publications, Website & Social Media Coordinator







October Conference Preliminary Programme

Venue: Mount Wolseley Hotel, Carlow

Friday 20th October

19.00	Buffet Dinner

Saturday 21st October

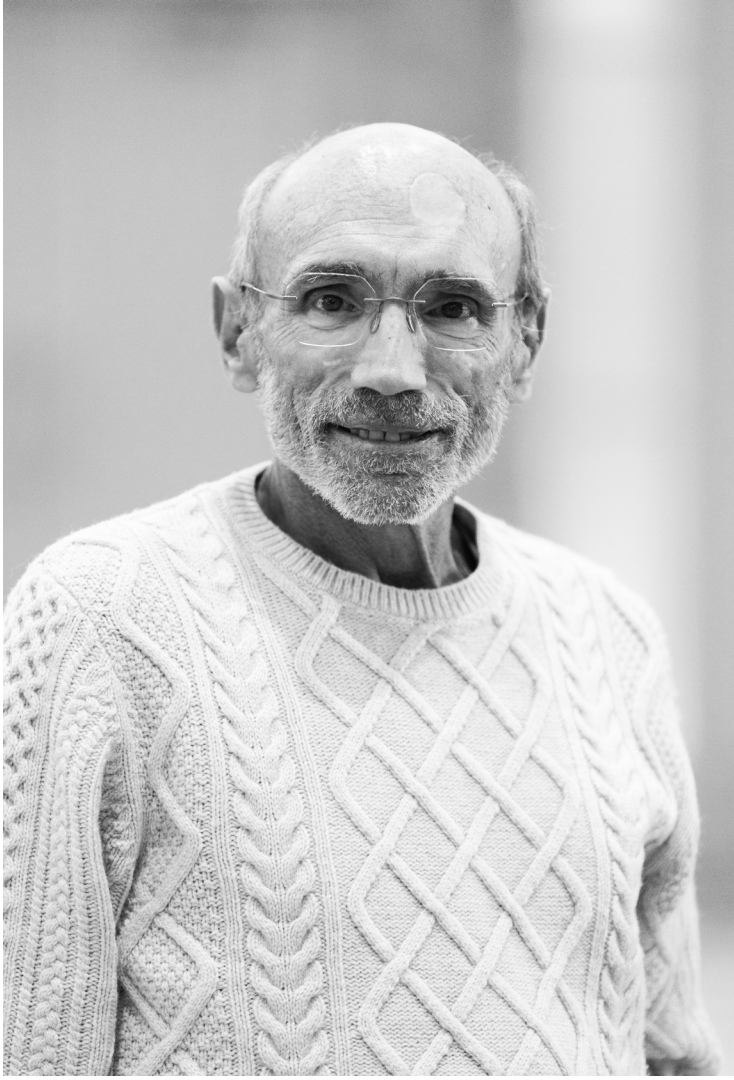
10.00 - 11.30	Different Treatments Options: Personal Experiences
11.30 - 12.00	Coffee Break
12.00 - 13.00	Debate: Which is the more challenging bleeding disorder to live with: haemophilia or von Willebrands?
13.00 - 14.00	Lunch
14.00 - 15.30	Workshop: Treatment Options & Living Your Best Life
15.30 - 16.00	Coffee Break
16.00 - 17.00	An Update on Dental Care

Sunday 22nd October

10.00 - 10.30	Women's Health Survey Project
10.30 - 11.00	Travelling Wisely
11.00 - 11.30	Coffee Break
11.30 - 13.00	Family Quiz
13.00 - 14.00	Lunch




Interview with Dr. Glenn Pierce



Dr. Glenn Pierce currently serves on the World Federation of Haemophilia (WFH) as Vice President Medical and WFH USA Board of Directors and on the National Haemophilia Foundation (NFH) (US) Medical and Scientific Advisory Council. He is an Entrepreneur-in-Residence at Third Rock Ventures, which was recently cofounded and was Chief Medical Officer at Ambys Medicines. Dr. Pierce is also a BioTech Consultant in the gene therapy and hematological areas.

The following is an interview Roisin Burbridge conducted with Dr. Pierce earlier in 2023.

As a person with haemophilia, can you outline your own haemophilia story?

I was diagnosed in 1956 when I was about one years old. As I was learning how to walk I kept falling down and getting bruises on my bottom, so I was brought to the hospital. It was difficult to make the diagnosis at that time and took the doctors a couple of days, but they found that I had severe haemophilia A. Half the doctors told my mother that I would be dead in five years and the other half told her that there would be a cure in five years. This was before the clotting cascade had really been identified, so the idea of a cure was magical thinking.

Childhood

My first 12 years of life I didn't have any effective treatments. I used icepacks, bedrest and bandages. None of that was effective in controlling bleeding. Because of this I got a lot of joint damage along the way. By the time I was 12 I was in a wheelchair full-time.

Then cryoprecipitate came along and that really was a miracle drug. It concentrated the factor VIII and meant that it was possible to get high enough factor levels to stop bleeding. Cryoprecipitate was very effective. It helped me get out of the wheelchair and lead a somewhat more normal life. I was still tied to the emergency room (every couple of weeks when I had a bleeding episode I'd have to go in to get cryo). But I was able to lead a pretty normal life in between. I still had a lot of joint damage but got along with it just like everyone else of my era did.

A few years later lyophilized concentrates became available. That really gave me a big boost of freedom as it meant I was no longer tied to the emergency room, I could take it with me. I wound up infusing myself in the bathrooms of trains, tops of mountains and all kinds of other places. If I had a bleed start I just took the factor right away to try to stop it from progressing.

Education

This freedom made a big difference in my education as well, allowing me to really pursue education non-stop.

I chose medicine as my career largely due to having spent around 25% percent of my childhood in the hospital. Doctors and other healthcare providers were my role models. As I developed into late childhood, I knew more about my disease than many doctors did. And I realised that perhaps the best way to gain control over my disease would be to know as much as I could about it. That meant studying medicine. So my disease, haemophilia, really drove me to medicine. When I was 10 years old I wrote a little autobiography and said that when I grew up I wanted to cure haemophilia. I was driven by wanting

to work on this disease, not only for myself, but for everybody else who has haemophilia.

So, I picked a medical research programme and got a medical degree and PhD at the same time over about seven years. This allowed me to get involved in research, which I enjoyed so much so that I decided to forgo clinical medicine and pursue a career in research. I also happened to get involved in work with the new biotech industry (this was back in the mid-80s). The biotech industry was just getting started and recombinant-DNA produced drugs were just being made. Leaving academic medicine to go into a biotech company was a novel thing to do at the time, but it was a great decision for me.

Haemophilia research

About 14 years into that career I decided to make a switch and move into haemophilia research full-time. I had been a volunteer in haemophilia for most of my adult life and had been President of my local chapter in Ohio, and became President of the National Haemophilia Foundation in the US on three occasions, where I really got involved in the advocacy work for the Foundation. I realised at a certain point that haemophilia work was what was driving me and I might as well do it full-time.

I began working full-time in haemophilia gene therapy research in 2002. It was an incredibly exciting time, as we were developing a haemophilia B gene therapy. We actually got to 12% factor IX levels in one patient and then he rapidly lost all of it. We spent a couple of years trying to figure out what had happened and realised that participants in the trial had experienced an immune response to the AAV virus vector that we were using to deliver the factor IX gene. This really put a damper on AAV gene therapy for haemophilia for five to six years. Later, University College London decided to do what we had done but this time they administered a steroid, to dampen the immune response. The steroid was very successful, allowing for long lasting small amounts of factor IX in patients, and ushering in the next wave of haemophilia gene therapy.

By then I had left to go back to protein engineering, a field I had been working in before switching into haemophilia research full-time. At that time I got involved in the development of Jivi, a pegylated factor VIII. Later, I worked at developing the first extended half life factor VIII and factor IX products Elocta and Alprolix. When I moved companies, my team came with me, so we were an intact unit that really knew all facets of haemophilia research and development. This helped us move very quickly and put Elocta and Alprolix into the clinic and to the market. When those two drugs got approved in 2014 two things happened – we initiated a humanitarian aid programme with the WFH and a commitment to donate one billion units of Elocta and Alprolix over a 10 year period for use in lower income countries. The second thing that happened is that I retired when those products got approved. I felt that I had done my job, moving them from the laboratory, through the clinic and to regulatory approvals. It was time to move on and do something different.

World Federation of Hemophilia (WFH)

So I gave up full-time work and became a consultant, allowing me to get involved as a volunteer with the WFH. I got involved in the WFH humanitarian aid programme and helped Dr Assad Haffar, the WFH Medical Director, get it up and running. We're now treating about 25,000 patients a year in about 74 different countries using products from six or seven different companies that are contributing products. The biospecific antibody Emicizumab has allowed us to do a much better job treating inhibitor patients as well as putting some patients on prophylaxis. We estimate that we're getting to about a third of the known population with severe factor VIII and factor IX deficiencies in low income countries. It's not the perfect situation but it's certainly making a difference in the lives of thousands and is saving lives every day.

With this programme we are also teaching the patients as well as the physicians how to treat haemophilia. We do many educational and training sessions, we get feedback on how patients are doing and on complicated cases. Teaching physicians in lower income countries how to manage haemophilia is so important because it means that these countries will have a ready-made workforce who know how to use the product when these countries are able to purchase it.

In addition, this education sets the stage down the road for utilising gene therapy to actually cure haemophilia. That's the ultimate solution for the

lower income countries of the world. The solution isn't for governments to find enough money to buy the product, as they'll never find enough money to buy sufficient product to be able to treat people the same way as patients are treated here in Europe or in North America. Gene therapy represents a "once and done" treatment. We have to find a way to pay for it of course but that's probably a lesser hurdle than getting governments to pay on an ongoing basis every year for the amount of clotting factor that would be required.

Cured of Haemophilia

Aside from work, an important personal development I should mention is that I was cured of my haemophilia in 2008 with a liver transplant. I had this transplant due to end stage hepatitis C cirrhosis which destroyed my liver over a period of 40 years. Following the liver transplant my factor VIII levels are normal.

The transplant also resulted in me becoming even more active and needing a new knee, a new ankle and then a fused ankle since these joints were so badly damaged since childhood. So I've had a number of surgeries since my liver transplant about 15 years ago now that have allowed me to continue to be active and be mobile.

That's great. Do you feel a lot better since the liver transplant?

I feel terrific. You don't realise what an insidious disease hepatitis C is because it's so gradual in its progression. But I didn't feel very well for years before the liver transplant. Then a couple of months after the transplant I felt great. Now everyday is really a good day. I appreciate that very much.

That's wonderful. You mentioned that gene therapy is a once and done treatment, but we aren't at that stage now. When do you envision we would be?

That's a good point. For factor IX it looks like it may be a once-and-done treatment. We have a lot of little pieces of evidence that point to long duration, such as no loss to date of the factor IX in patients who receive the gene therapy. As it's a first generation product there's still a lot of variability, and a few people who haven't gotten a good response. So it's still a work in progress.

But it's in a much better situation than factor VIII. Factor VIII does not appear durable at this point. It will last seven to nine years in many people. We don't understand why this is happening. We have a number of scientific hypotheses but so far it's just not clear. So if you go to the trouble of getting AAV gene therapy and all of the unknown risks that that entails, it needs to cure you for life. And that's the case in lower income countries as well. A five year holiday may not be particularly effective. The important thing to note about AAV is that it can only be given once at this point. It cannot be re-dosed if a better AAV treatment comes along.

Do you anticipate that there will be a factor VIII gene therapy that will work as well as factor IX gene therapy?

Yes, it's inevitable. Science is moving at a breathtaking pace. But I can't say when that will happen. We need some more breakthroughs. We may need to take a different kind of approach toward gene therapy such as gene editing or non-viral vectors. There are other approaches people are starting to take in preclinical work and now in clinical trials, so we'll see how those develop. At some point in time factor VIII will give us a once and done cure, I'm confident of that. But whether that's in five years, 10 years, or 20 years, I don't know.

I'm aware that gene editing is now in clinical trials.

Yes, for factor IX. Two companies are working on this. These companies are collaborating on a therapy which will place the factor IX gene directly into the chromosomes and allow permanent replacement in the liver of factor IX. Assuming that this works as it has in animal models, this will give a permanent cure for patients with haemophilia B.

The other important point is that it only goes into one place in the chromosome, making it safer than the AAV that is being used now.

Is that something that children will be given when they're born?

Well, at some point, yes. AAV therapy today cannot be given to children because their livers continue to grow and the AAV goes away as the cells within the liver divide.

But with gene editing, once it's inside the chromosome, the chromosome divides when the cell divides and so continues to contain the factor IX gene. So it really is a permanent cure. For safety, these trials start in adults but it shouldn't take long before they can move into children, assuming that they have shown to be safe and effective.

What is your view on the outlook for novel therapies for haemophilia?

Every year I say that this is a most exciting time for research into bleeding disorders and this year is no exception. We've got three new products that have been approved in the past six months – two gene therapies and a super long-acting factor VIII that is now approved in the US and will likely be shortly approved in the EU. This product looks promising, as it allows patients with haemophilia A to receive treatment once a week and at the end of the week have very high (15%) trough levels. This is going to change how haemophilia A is treated and make it a little more equivalent to haemophilia B, which is also treated once a week to once every two weeks and gives higher troughs.

Then there are the gene therapies, and there will be more coming. On top of that, we also have two new bispecific antibodies that are coming along in clinical trials to compete with Emicizumab. We don't know the characteristics of these new bispecific antibodies yet but we hope that they'll be even more effective than Emicizumab in maintaining prophylaxis against bleeding for patients. So over the next few years we'll see data coming from those as well.

It's great to hear there is so much on the horizon! You mentioned that you are the current VP Medical of WFH. What does that role involve?

The VP Medical is a volunteer elected role which runs for a four year term. I ran for re-election at the Montreal Congress last May and was elected for another 4 years.

I'm responsible for all of the medical and scientific collaborations and activities that the WFH does. For instance, I'm responsible for overseeing our research in epidemiology work with registries and databases with our Director of Research, Donna Coffin. We look at the WFH Annual Global Survey to measure the amount of people with bleeding disorders in countries around the world, as well as the amount of factor usage. We also have a World Bleeding Disorders Registry that allows over 10,000 patients to track their bleeds in a longitudinal way and then allows their physicians to be able to do research on large groups of patients from a variety of different socio-economic strata.

We are also developing a gene therapy registry at the moment. We feel strongly that persons who receive gene therapy should be monitored for the rest of their lives to look for both efficacies as well as safety signals that we may not be aware of today but which may come out in years or decades to come.

What are your aspirations for WFH in the next 5 years?

I would like to see the WFH continue to make inroads in getting better treatment for patients in lower income countries through education, advocacy, training and the humanitarian aid programme distribution of products. I'd like to see the gene therapy registry get off to a robust start and make sure that we're able to recruit the majority of patients who receive gene therapy. We have an opportunity to introduce this new technology the correct way. We just need to make sure we do that.

Many thanks to Dr. Pierce for taking part in this fascinating interview.

Educational Grants

The Society offers annual educational grants to people with haemophilia, von Willebrand's 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 open 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. 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

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.

Maebh raised a whopping €1,577.61 for the Society. Thank you so much for your dedication!

100 Miles in March

100 Miles In March

As March is haemophilia awareness month, I decided to take on the challenge of raising awareness and raising money for the amazing charity the Irish Haemophilia Society to honour my grandad Anthony O'Sullivan who sadly passed away in January 2021. Since my grandad had haemophilia, the Irish Haemophilia Society are a charity close to my family's heart, which is why I chose to show my support to them.

There were many days of this challenge which were harder than others but what made me push through it was knowing how proud my grandad would be of me. The support from others reminded me each day why I was doing this challenge and pushed me to achieve things I never thought would be possible such as my first ever half marathon.

When I first got the idea of doing this challenge, I was worried that it wouldn't be possible and the idea of failure scared me, but when I contacted the IHS they were extremely supportive and helpful which comforted me and made me even more determined to do this. As soon as I told my friends and family about my idea everyone showed great amounts of support especially through social media, which resulted in even more people finding out about it and showing their support. The support was overwhelming, and it made me ecstatic to know that so many people were backing me through the challenge and donating to such a worthy cause.

This was one of the best experiences of my life both mentally and physically, along with raising nearly £1400 which was more than 5 times my target of £250! As the Irish Haemophilia Society were so amazing to work with, I would be honoured to fundraise even more in the future with them and do more fun challenges to raise awareness.

Maebh O'Sullivan, relative of member

The Safety of Intramuscular Vaccination in Children with Haemophilia

The following is a piece written by Abdullah Zafar Khan, medical student at University College Dublin, on his study 'The Safety of Intramuscular Vaccination in Children with Haemophilia: A Single Centre Experience and Review of the Literature'. Abdullah was the winner of the 2022 National Haemophilia Council Student Bursary for Children's Health Ireland at Crumlin.

Traditionally intramuscular injections are avoided in people with haemophilia because of the concern of causing a muscle bleed. It was recommended that patients with haemophilia with factor levels less than or equal to 10% receive clotting factor concentrate (CFC) before intramuscular injection to prevent bleeding.

In Ireland, the meningococcal B (MenB) vaccine) was introduced into the Primary Childhood Immunisation Schedule for all children born on or after October 1st 2016. The MenB vaccine is given at two and four months of age with a booster dose given at twelve months. The MenB vaccine that is administered is Bexsero®, which is only licensed for administration by intramuscular injection.

This presented a dilemma. There was a risk of bleeding from the intramuscular injection but there was also a risk of bleeding from inserting a cannula to give CFC prior to the vaccine. Giving one dose of CFC at two, four and twelve months could potentially trigger the development of an inhibitor. In Crumlin, we had also noted that the majority of children diagnosed after one year of age, who had received vaccines intramuscularly before diagnosis, had had no bleeding.

We decided not to administer CFC before intramuscular vaccination in infants with haemophilia. We planned to treat with CFC if the intramuscular injection caused bleeding.

The aim of our study was to report the outcomes of intramuscular vaccination in infants with haemophilia born on or after January 1st, 2017. We also compared our findings with other existing studies on intramuscular vaccination in children with haemophilia.

In total, we considered 29 patients with mild, moderate or severe haemophilia, with factor level less than or equal to 10%, who received 64 doses of the MenB vaccine. None of the patients were on CFC or emicizumab (Hemlibra) before vaccination. None of the patients had muscle bleeding after vaccination.

We found two other studies that also examined bleeding after vaccination in children with haemophilia. Combining both studies, there were 702 doses of intramuscular vaccines given. From these 702 doses there were only 17 examples of patients experiencing bleeding after vaccination, which is equivalent to 2.4% of the total vaccine doses given. One patient required CFC for bleeding, which is equivalent to 0.14% of the total vaccine doses given. Therefore, other data also suggest that there is a low risk of bleeding in children with haemophilia when receiving intramuscular injections.

In conclusion, for administration of intramuscular vaccines it was recommended that CFC be given to patients with mild, moderate and severe haemophilia, with factor levels up to 10%. However, the outcomes from Crumlin suggest that infants with haemophilia, regardless of haemophilia severity, can safely receive intramuscular vaccines without prior CFC administration.

Abdullah Zafar Khan, winner of the NHC student bursary for CHI Crumlin

My Indici - New Patient Portal

Below is information received from the National Coagulation Centre at St. James's Hospital regarding the new patient portal. To find out more, visit the National Coagulation Centre's website, www.stjames.ie/services/hope/nationalcoagulationcentre/

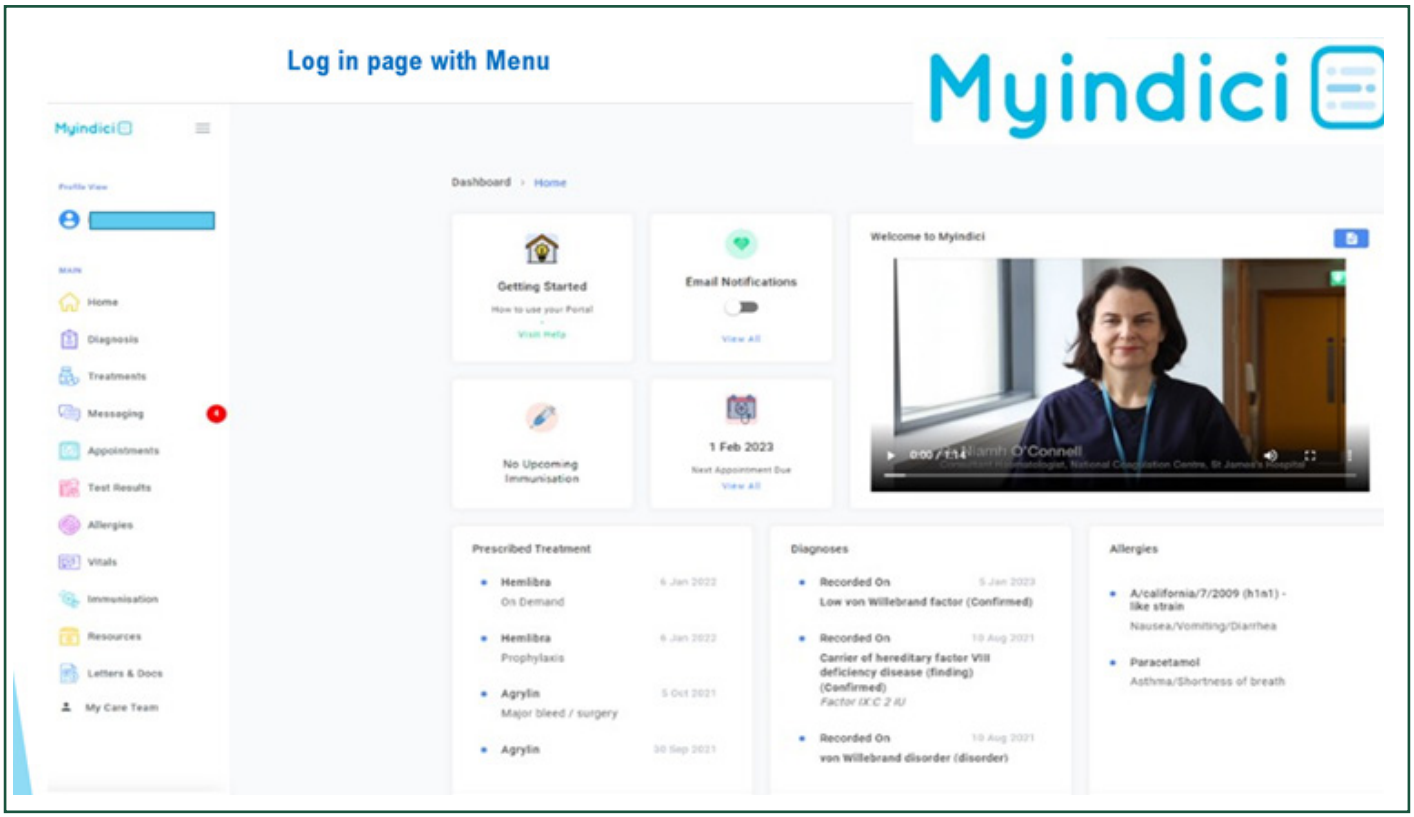
The National Haemophilia Service is proud to announce the launch of a new, fully interactive patient portal for people with bleeding disorders. Since the first national electronic record for haemophilia was implemented in 2006, ICT solutions have been a key enabler in the improvement in haemophilia services, such that the Irish haemophilia service is consistently recognised as world-class.

In 2016, the HSE Office of the Chief Information Officer chose the Irish haemophilia service as one of three National Lighthouse Projects, as part of the eHeatlh Ireland Strategy. The Lighthouse project has resulted in the implementation of a new National Electronic Health Record (EHR) known as Indici for people with bleeding disorders (go-live was successful in October 2019) and phase two of the project, to launch a patient portal, has now been completed. The patient portal (known as My Indici) has been designed in collaboration with the Irish Haemophilia Society, and with Valentia Technologies, who have provided the technological solution.

The My Indici patient portal was launched at the AGM of the Irish Haemophilia Society on Saturday, 4th March 2023. The aim of the portal is to improve self-management for people with bleeding disorders by giving them access to key parts of their healthcare records through an easy-to-use app. Reliable, curated educational resources in multiple media formats are available, along with contact details for the Irish haemophilia centres and links to the Irish Haemophilia Society website and other important patient information. In a novel development for Ireland, a secure messaging system, which is integrated into the patient healthcare record, is available to communicate on non-urgent matters with the healthcare team.

Scan and scroll over to Patient Information

Director of the National Coagulation Centre, Professor Niamh O'Connell, said: "*Access to real-time healthcare information is critical to delivering a high quality and safe service for people with bleeding disorders. Empowering people to become partners in their healthcare by facilitating secure access to their own records is a key driver for patient safety, education and timely care delivery.*"



Dates for your Diary 2023

14-16 July
Parents Conference

24 July
Donegal Regional Visit

4 September
Galway Regional Visit

23 September
Von Willebrand Disorder Information Day

20-22 October
Members' Conference

2-3 December
Women's Conference

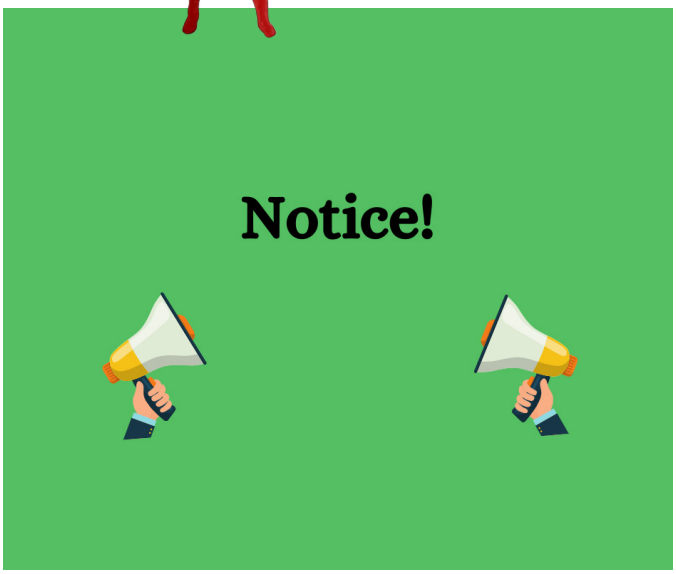
NOTICE

New Combined Care Pain Clinic at the NCC

As a part of ongoing care quality improvement initiatives, the National Coagulation Centre (NCC) held the first combined clinic with the Pain Medicine team on the 14th of June 2023.

The Pain Clinic is run by one of the St James's Hospital Consultants in Pain Medicine, supported by the NCC nursing, physiotherapy and medical team. The NCC are pleased to announce that this clinic will be held at regular intervals on Wednesday mornings in the NCC.

If you feel that you might benefit from a clinical review with a pain specialist, please speak to a member of the NCC nursing team or discuss with the NCC medical team at your next clinic review.



Bleeding Disorder Alert Card

Under a HSE Directive from 2015, if you have a bleeding disorder or are the parent of a child with a bleeding disorder, you can instruct an ambulance to take you directly to one of the four recognised Haemophilia Treatment Centres, provided you are within 60 minutes from the centre.

If you are over 60 minutes from one of the Treatment Centres, please go to your nearest hospital and contact your treatment centre on the way.

To help ensure the ambulance crew brings you directly to one of the treatment centres, please carry your Bleeding Disorder Alert Card, a photo of the card and a photo of the Directive.

Nadine Brill - VHI Women's Marathon

I took part in the VHI mini marathon to raise money for the Irish Haemophilia Society on 4 June 2023. Thanks to the wonderful generosity of friends and family I raised a total of €520. The reason I chose to raise money for the IHS is on behalf of my younger siblings, Liam (9) and Farrah (7) who both have haemophilia. Seeing how much the IHS help my family and all families who deal with rare bleeding disorders made me want to give back and raise awareness.

The women's mini marathon was an absolutely fantastic day. The atmosphere was unmatched and being able to represent such a great cause made the 10k a little easier to handle. Despite the heat, I did get the 10k done in just under an hour and a half.

Thank you to the Irish Haemophilia Society who have checked in with me and been there to answer any questions throughout the fundraising process.

Nadine Brill, relative of member

Pilates & Physio-Exercise Classes

Members, we now have two exercise classes taking place each week.

On Tuesdays, we have physio-exercise classes for adult male members with registered physiotherapist Mark McGowan. These classes takes 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 if you are interested in registering for one of these classes.

2022 Annual Report

Our 2022 Annual Report is out and is available to view on our website under Resources - Publications - Other Publications.

In it you will find reports from our Chairperson, CEO and Honorary Secretary, as well as a financial report and information.

Are you jetting off to warmer weather this summer?

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

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

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

Irish Haemophilia Society

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