

Haemophilia.ie



Magazine of the Irish Haemophilia Society

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



 SCAN ME

Autumn 2022 Edition

From the Deputy Editor

Hello everyone, I'm Roisin, the new Publications, Website and Social Media Coordinator! I am so excited to meet you all in the coming months and really enjoyed meeting some of you at our Newly Diagnosed Information Day and at the Ageing Conference. You have all been so friendly and welcoming. I'm very happy to have joined the I.H.S. and to be working with such a hardworking, kind and close-knit group.

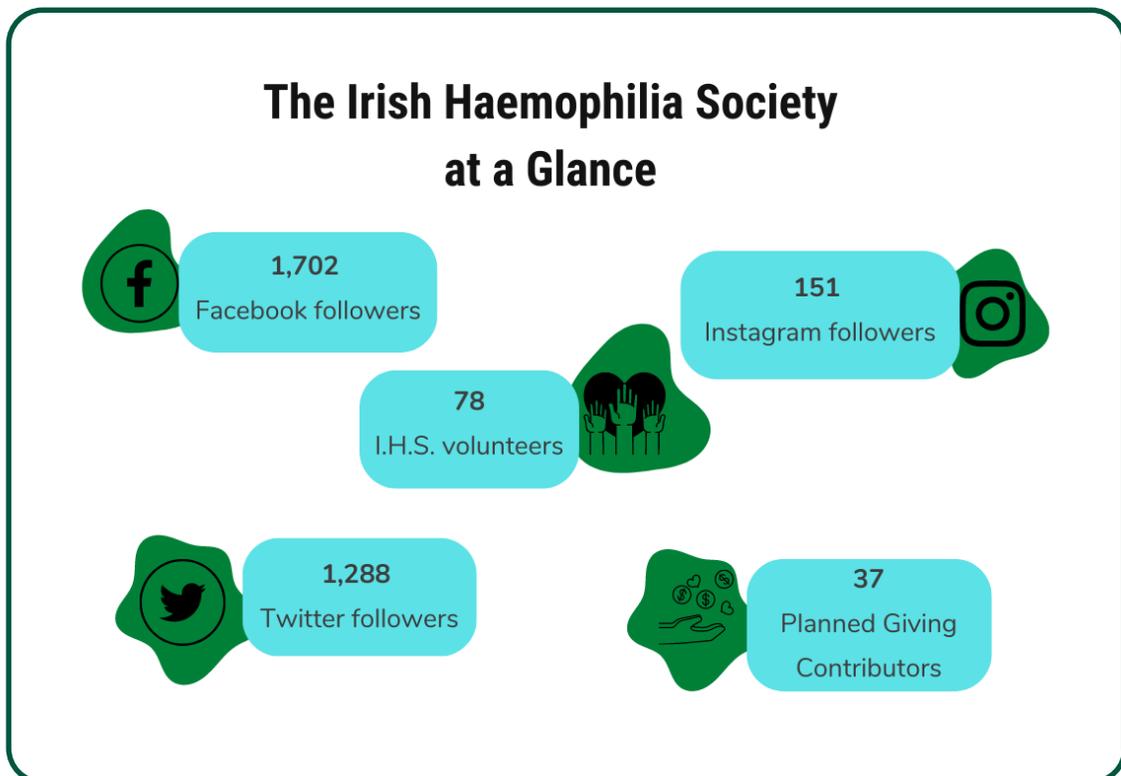


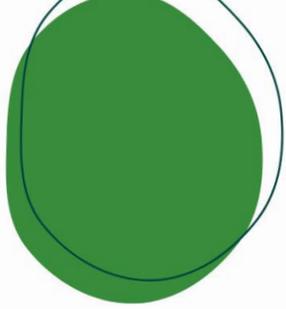
bright news on the new Gene Therapy, an update on our Ukrainian members and an overview of his trip to the Croatian Haemophilia Society, some of my own articles on the events we have held in recent months, and a report on outreach from Rob. In the coming pages you will also find information about our educational grants, some notices, a calendar of I.H.S. events for 2023 and lots of photos from our recent events.

I hope you enjoy the magazine and I'm looking forward to putting together many more in future!

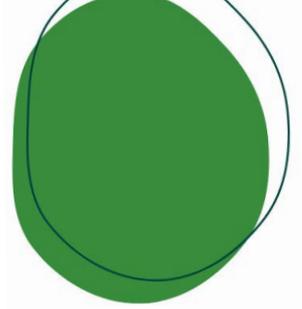
I'm very happy to put my name to my first publication as part of the team. In the following pages, you will find reports from our CEO Brian O'Mahony, sharing

- Roisin Burbridge, Publications, Website & Social Media Coordinator





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Photos from our Ageing Conference

CEO Report

First Gene Therapy Licensed in Europe

A milestone moment was reached for the haemophilia community on August 24th with the announcement by the European Medicines Agency (EMA) that they had granted a conditional marketing approval (CMA) to Roctavian - a Haemophilia A Gene Therapy manufactured by Biomarin. A CMA requires that continued information and data should continue to be supplied on an agreed basis to the EMA on the production by the company. This may then be reviewed regularly in the first 1-3 years with the objective of granting a full licence if the data is satisfactory. This is a common route for treatments with small trials in rare conditions. Roctavian has not yet been licensed by the FDA in the USA so the European community will be the first to consider prescribing of haemophilia Gene Therapy.



The licensing follows the publication of the Phase 3 (final phase) data in March of this year. The mean (average) FVIII expression level in the 132 participants in the clinical trial at 1 year post dosing was 43 IU/dl (43% with a median (half above this number/half below this number) of 24%. At year 2, the mean FVIII expression had decreased to 24% and the median to 15%. There was a wide variation in factor expression achieved from no increase (0%) in expression to supra normal levels (>150%) in some individuals. The mean and median do not tell the full story- range of expression also requires study.



At the end of year one the median FVIII expression in the 132 individuals was as follows:

- 50 (38%) of participants had a FVIII level effectively in the normal range (>40 IU/dl).
 - 66 (50%) were in the mild range (5-40 IU/dl).
 - 16 (12%) were in the moderate or severe range (<5 IU/dl) with 9% having a FVIII level of <3 IU/dl.
- At the other end of the spectrum, 5% of those with a FVIII level of >40 IU/dl had a level above normal (>150 IU/dl).

Two years of data were available on a smaller number of participants (17). At the end of year two:

- 18% had a FVIII level in the normal range (>40 IU/dl).
- 59% had a FVIII level in the mild range (5-40 IU/dl).
- 24% had a FVIII level in the moderate or severe range (<5 IU/dl).

In the 112 participants on whom they had collected bleed data and factor use data prior to the clinical trial, the annual bleed rate decreased on average from 4.8 to 0.8 (an 84% decrease) and factor use decreased by an average 98%. In terms of annual bleed rate, 75% had no bleeds in year one and 10% had more bleeds than in the previous year before Gene Therapy. Elevations in liver enzymes occurred in 86% of participants. 79% of trial participants were prescribed a course of steroids to deal with the liver inflammation for a median period of 230 days (approximately 7 months).

It is clear that Gene Therapy is an irreversible one-off therapy which may confer significant benefits to many individuals, but a deliberate consideration of benefits, risks, unknowns and uncertainties should be made by each country and indeed by each individual contemplating treatment. We celebrate the milestone of a licensed Gene Therapy and the data which demonstrates





a significant factor expression in the majority of participants in the clinical trials, which may confer very significant benefit to them in the management of their haemophilia for several years. We must also be aware of significant uncertainties with this and other potential Haemophilia Gene Therapies. The duration of expression is uncertain. For FVIII Gene Therapy, it currently appears that many PWH will achieve significant factor expression for at least 5 years. (Separately, for FIX, where there is currently no licenced Gene Therapy but where clinical trials are in a late stage, based on the latest Phase 3 data this may be for at least 10 years. There are no predictors for who may achieve high, medium or low factor expression, no predictors for individual duration of expression and no predictors for those who will not achieve any significant increase in expression. A high proportion of those on FVIII Gene Therapy may require treatment with steroids for a variable period but again there are no predictors for which individuals may require this treatment. The potential long term safety issues such as the theoretical risk of insertional mutagenesis which may

be linked to an increased cancer risk is an additional uncertainty.

People with haemophilia, clinicians, the Irish Haemophilia Society and payers will all have to deal with these uncertainties and factor them into their decision process. People with Haemophilia will need to acquire a sufficient degree of knowledge on the benefits, risks and uncertainties and sufficient self-awareness to identify their own decision drivers and their expectations. They will have to prepare for a range of possible outcomes and be comfortable with these in order to make a fully informed decision.

The Society will be undertaking a comprehensive education programme for members over the coming

months and years which will include targeted publications, infographics, meetings and workshops. The first such workshop was held at our members conference in October of last year and a further workshop for adults will take place at our October Members' Conference this year. We want to engage with every person with haemophilia who is interested in or contemplating treatment with Gene Therapy now or in the future to play our part to ensure that any decision they take will be fully informed and based on a clear understanding of the potential benefits, risks and unknowns.

Clinicians will need to ensure that every person who is eligible for and interested in Gene Therapy is provided with all the information they require to allow them to be aware of the uncertainties and make a fully informed decision. The European Haemophilia Consortium (EHC) and the clinicians organisation (EAHAD) have jointly agreed that Gene Therapy should be prescribed in countries by a limited number of Hub centres

where there is sufficient knowledge, experience and expertise. Management and follow up would then be shared between these Hub centres and local Spoke treatment centres. Selection of and agreement of these centres may be complex in many countries but in Ireland, given our well established model with 3 comprehensive care centres, 1 treatment centre and a specific research facility, the decision should be straightforward.

The Society are committed to playing a strong role in education of members, in providing information on all aspects of the therapies, in testing understanding and comprehension via workshops or other suitable interactions and in working closely with clinicians and hub and Spoke centres to ensure that people



with haemophilia enter into these momentous personal decisions well prepared with knowledge, an understanding of the benefits, risks and uncertainties and a clear understanding and commitment to the follow up and monitoring required.

As the first Haemophilia Gene Therapy was granted conditional marketing authorisation by the EMA on August 24, 2022, the focus will now move to considerations relating to affordability and possible use in Europe. Payers do not like uncertainty. Access programmes and payment models may need to adapt to ensure an element of risk sharing between the company marketing the Gene Therapy and the payer. Budget impact could be very significant and limit access or the number of people who may have access in any country.

Payers will not want to pay the full upfront cost for

a therapy which may not work or stop working for some people.

An outcome based annual payment model with defined outcomes (such as factor expression, treatment use or requirement for return to prophylaxis) for an agreed or flexible time period would deal with many of these economic uncertainties. Countries may state that they do not currently have mechanisms to achieve this but now is the time for this work to be underway.

In Ireland, we have the Haemophilia Product Selection and Monitoring Advisory Board which will have to play a major role in the reimbursement decisions for Haemophilia Gene Therapy.

We truly live in exciting times for Haemophilia treatment!



Ukraine

We have been greatly heartened by the compassionate and appropriate response of the Irish Government and people to the plight of people and families fleeing their homes in the war torn country of Ukraine. The Society were in touch at an early stage with the Irish Red Cross to ensure, where possible, that any person or family with an inherited bleeding disorder who arrived in Ireland from Ukraine or from Ukraine via another country would be accommodated in Dublin or close to Dublin. This is due to their need to be assessed initially and managed by one of the National Comprehensive Care centres. We were also in touch with the Haemophilia Patient Societies in Ukraine and in Poland and indeed we liaised with them to ensure the safe arrival of some people with haemophilia. The Ukrainian patient organisation also had a need for additional short term accommodation in Lviv in western Ukraine to help those fleeing from the areas of greater danger at that time in the

east of the country. The Society sponsored some accommodation for families transiting via Lviv to Poland for a 2 month period. At present, there are 5 people with haemophilia or other inherited bleeding disorder from Ukraine resident in Ireland. The Society have been liaising with all 5 and their family members. They have all been registered and placed on appropriate treatment regimes by the National Coagulation centre or Children's Health Ireland at Crumlin and all are doing very well. A WhatsApp group has also been started which includes several of the Society members and several of the Ukrainian people with bleeding disorders. We hope to be welcoming all of our Ukrainian friends to the members conference in October and I know that all our members will make them feel welcome and part of this great community.

Croatia Haemophilia Society Camp

I recently attended the annual camp of the Croatian Haemophilia Society, which serves as their largest national meeting. I was there to speak about Gene Therapy and the future of haemophilia therapies.

The camp was held in a large hotel about 30km from the capital city, Zagreb. Attendance at the camp was a very impressive 270 and the sessions were well attended. The activities for the children were organised by hotel staff or parents as the Society have no staff and do not have a large cohort of volunteers who manage these programmes at their conferences, as we are fortunate to be able to do. I was very impressed by their organisation and commitment.

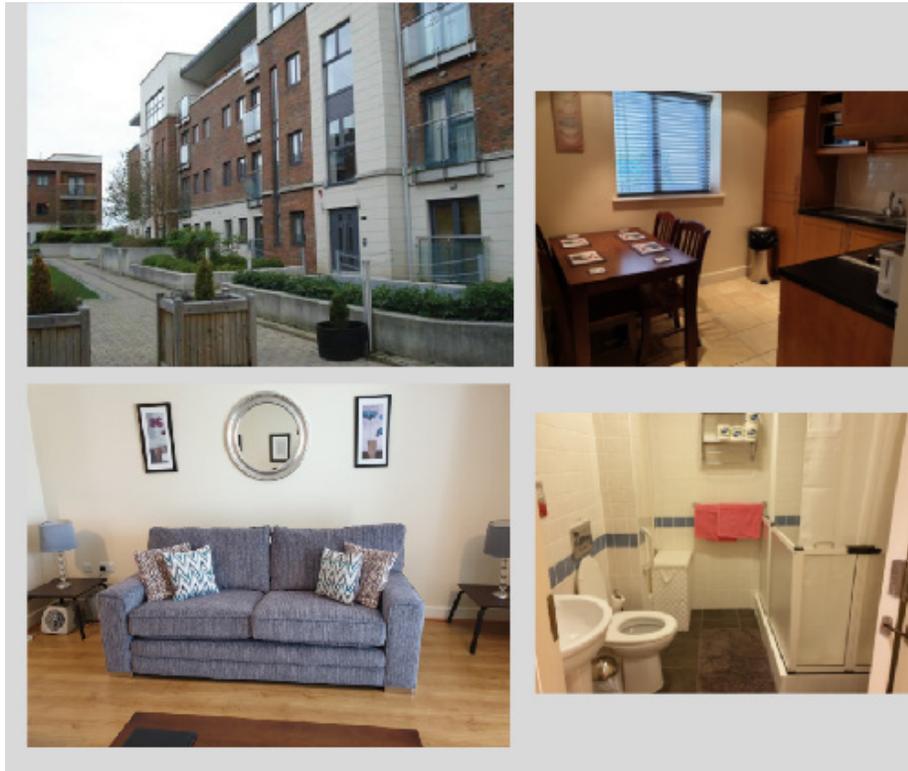
They have also introduced “Nordic walking” as a Society activity. They had a warm up session supervised by physiotherapists and then an organised Nordic walk. They are also carrying out a research project in this area where the people with bleeding disorders are monitoring their blood pressure before and after these walks for a period of 3 months. It was very interesting to participate in this activity as it parallels our efforts to increase focus on healthy lifestyle using our physiotherapy/exercise programme. Perhaps this is an activity we will look at for members in the future.

-Brian O'Mahony, Chief Executive Officer



Photos from Brian's trip to the Croatia Haemophilia Society's Camp

Hyde Square Apartments



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

- People with a bleeding disorder 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, spouse, partner and/or child of the person with the bleeding disorder from outside Dublin, when attending St. James's Hospital or Children's Health Ireland 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 information or would like to make a booking, please contact Suzanne in 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.

Newly Diagnosed Information Day

Our Newly Diagnosed Information Day was a great success. On Saturday the 16th of July, mothers and fathers met with Children's Health Ireland (C.H.I.) and I.H.S. staff to discuss the supports available to their children, while the kids played at the back of the room with Rob. Consultant Haematologist Dr. Beatrice Nolan and Clinical Nurse Specialist Imelda Kelly from the Haemophilia Centre at C.H.I. participated at the event.

The meeting opened with everyone introducing themselves and their connection to a bleeding disorder. Dr. Beatrice Nolan and Imelda Kelly then introduced the services offered by C.H.I. Firstly, they gave the parents practical information about how to contact them, their office hours, and information about emails and phonelines. They shared important information about the supports offered by their team, including those provided by the psychologist and social worker. They also stressed the importance of updating the team on the child's developments such as changes in their weight and stressed the need to touch base with the team should the child need to go to hospital.

Talk also turned to summer activities and holidays abroad, with Beatrice warning about the potential dangers of bouncing castles and trampolines, as well as the practicalities of getting through security at the airport with factor treatment. Before long, the event became an interactive discussion between parents and the C.H.I. staff, with parents asking questions related to a wide array of issues and Imelda and Beatrice carefully and thoroughly answering these questions.

After the nurse and doctor shared their knowledge, the I.H.S. team introduced themselves to the parents and Brian and staff gave information on the services we provide. The afternoon finished with a well-deserved cup of tea and coffee and delicious, freshly baked cookies.

- Roisin Burbridge, Publications, Website & Social Media Coordinator



Dr. Nolan and Ms. Kelly addressing the parents

Outreach Report



Since taking on this role back in 2019, little did I know what would be around the corner. We were all blissfully unaware of the trouble and anxiety 2020 would bring. I remember the day well when Debbie called us all into her office as the then Taoiseach Leo Varadkar was set to break

the news that our lives would be changed for an unforeseen amount of time. As always, Brian and Debbie acted quickly on not only ensuring the safety of the staff but on planning how to ensure the health and safety of the society and all its members as a whole.

We adapted our outreach services to members on all fronts by emailing, telephoning, WhatsApping and meeting via Zoom, to hear how our members were doing, if they needed assistance and most importantly to let them know we were here if they needed us, even just for a chat.

Over 2020, when we were all safe at home, I set up my home office and got to work ringing all our members. I think I spoke with someone from every county in Ireland. It was so interesting to hear how people were passing the time from walking around the garden, making bread or finally getting a chance to watch a TV show they had heard so much about. There was a lot of positivity but in the background was the worry of what the coming days and months would bring. With this I knew the importance of each call. Even if the person was doing great and had no issues it was nice to just chat. One thing I noticed from all the calls was they all finished with the similar sentence,... "All the best to the staff and I hope all the

rest of the members are keeping well". You might not have known it, but you were all thinking about each other.

The increase in outreach had proven to be a great help. We were able to get a sense of how our members were doing as a collective. Whether it was Zoom meetings to provide up to date information, Zoom exercise classes, Zoom quizzes to help people stay connected or more calls for certain members. All of this allowed us to stay in touch with our members and help in any way we could.



Since then, I have continued to call our members, but we are also planning to bring back other forms of contact such as home visits, hospital visits and school visits. With these visits I hope to meet you in person. The Society will always help and support you with any issues you may have.

If you need any help, support or even if you just need a chat, please call me on 089 6134173 or email robert@haemophilia.ie.

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



Ageing Conference

Our 2022 Ageing Conference was a great success! We were delighted to meet with members on Friday evening at a delicious buffet dinner. For Suzanne and I, it was the first time meeting many members, while the other staff were thrilled to see members again, some of whom they had not seen since before Covid.

The weekend was packed full of engaging and informative sessions led by a range of experts from Professor Niamh O'Connell, National Haemophilia Director at St. James's Hospital, G.P. Dr. Madeleine Ní Dhálaigh to Geriatrician Dr. William McKeown, Physiotherapist Mark McGowan and Hepatitis C Liaison Officer Antoinette Kelly. The talks were varied and focused on different aspects of the ageing process. Professor O'Connell shared information about how ageing in Ireland, and particularly ageing for those with haemophilia, is developing and changing. Dr. Ní Dhálaigh discussed the main illnesses that could affect ageing populations and Dr. McKeown talked about frailty and how to improve the ageing process. Each speaker hammered home the importance of physical activity, with Mark McGowan stressing the fact that a level of physical activity is always good

no matter who you are or what ailments you might have. Mark's session was particularly interesting as he went through the different kinds of activities people should aim to get through each week, from balance exercises to aerobic to strength exercises. Following his talk, we got the opportunity to run through some of these exercises with him, which got everyone's hearts beating faster and left us feeling warmer but more energised than before. The other striking aspect of the sessions was the enthusiastic engagement from the audience, as each talk closed with a long questions and answers session between the speaker and the audience. Finally, our last session was an open forum discussion in which members shared suggestions for topics to be covered in future conferences, from a session about nursing homes, to financial planning to security.

It was a thoroughly enjoyable conference and I'm greatly looking forward to the next one the year after next!

- Roisin Burbridge, Publications, Website & Social Media Coordinator



Members enjoying a coffee break



Dr. McKeown giving a presentation

Educational Grants

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

The purpose of the grants is to offer financial support to post-second level students to assist them with the extra expenses of their studies. Applications open in June and close in September.

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

We are delighted to announce a new educational grant in memory of Michael Davenport, who passed away last year. This grant will be specifically made available to a person with a bleeding disorder, going back into third level education as a mature student.

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 Centre for Hereditary Coagulation Disorders 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 registered at the National Coagulation Centre at St. James's Hospital in Dublin.
 - 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.



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.



Dara Dowling receiving the Margaret King Educational Grant in 2021

October Members' Conference Adults Programme

Friday 14th October

19.00

Buffet Dinner for the full group (Fredericks Restaurant)

Saturday 15th October

10.00 - 11.30



Personal Experiences with Different Therapies: (Austin Suite 2)

(An Interactive Workshop facilitated by Mr. Brian O'Mahony, Chief Executive, I.H.S. covering the following therapies)

- Extended Half Life Factor VIII - TBC
 - Emicizumab - Mr. David Flanagan & Mr. Jim O'Leary
 - BIVV-001 - Mrs. Úna Ó'Tuama
 - Extended Half Life Factor IX - Mrs. Mary Clare Delaney
 - Factor IX Gene Therapy - Mr. Brian O'Mahony & Mr. Luke Pembroke
- Followed by a Panel Discussion and Q&A session

11.30 - 12.00

Coffee Break (Pre Conference Area)

12.00 - 13.00

An Update on Dental Care (Austin Suite 2) *(Chair: Mr. Jim O'Leary, Board Member, I.H.S., Speaker: Dr. Alison Dougall, NCC & Dental Hospital)*

13.00 - 14.00

Lunch (Fredericks Restaurant)

14.00 - 15.30

Adults Workshop Part 1: Gene Therapy from Concept to Reality (Austin Suite 2) *(Facilitated by Mr. Declan Noone & Mr. Brian O'Mahony)*

OR

14.00 - 15.30

Parents Workshop Part 1: Selecting the Right Individual Treatment Regime for my Child (Riley 1) *(Facilitated by Dr. Beatrice Nolan, Consultant Paediatric Haematologist, CHI Crumlin)*

15.30-16.00

Coffee Break (Pre Conference Area)

16.00-17.00

Adults Workshop Part 2: Gene Therapy from Concept to Reality (Austin Suite 2) *(Facilitated by Mr. Declan Noone & Mr. Brian O'Mahony)*

OR

16.00-17.00

Parents Workshop Part 2: Selecting the Right Individual Treatment Regime for my Child (Riley 1) *(Facilitated by Dr. Beatrice Nolan)*

19.00

Dinner for the full group (Austin Suite 1 & 2)

Sunday 16th October

10.00 - 11.00

Insurance Issues (Austin Suite 2) *(Chair: Mr. Dan McIntyre, Board Member I.H.S. Speaker: Ms. Colette O'Donohue, McCarthy Insurance Group)*

11.00 - 11.30

Coffee Break (Pre Conference Area)

11.30 - 13.00

Drumming Workshop for all the Family (Austin Suite 1 & 2)
(Parents, please note that children from the Cubs, Kidlink and Youth groups will be brought to the Austin Suite by volunteers. Parents are required to supervise their children during this family workshop.)

13.00 - 14.00

Lunch for the full group (Fredericks Restaurant)



TRAVELLING OR STUDYING ABROAD?



What you need to know...

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

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

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



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

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

3 Find the nearest treatment centre
For Europe see - <http://www.euhanet.org/centrelocator/>
For the rest of the world see -
<https://www.wfh.org/en/resources-education/treatment-centre-directory>

4 Apply for the correct VISA
To find out what VISA you need and how to apply see:
<https://www.dfa.ie/travel/visas/visas-for-irish-people-going-abroad/>



5 Get adequate health insurance
A company that does provide insurance cover for pre-existing medical conditions including haemophilia is a company called Blue Insurance. They can be contacted by:
Ph. 0818 444 449 or at www.blueinsurance.ie.



6 Pack essential items
If you are carrying treatments and medications it is very important to ensure that you have a travel letter from your haemophilia treatment centre for customs. You should also carry your haemophilia card which was issued from your haemophilia treatment centre. For travelling within Europe, you should have an EHIC card (European Health Insurance Card). This entitles you to necessary healthcare in the public system of any EU/EEA member state.



Write for the I.H.S.

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

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

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

Physio-Exercise Classes

Every Tuesday from 7-8 via Zoom

Open to male members over 40

There is no charge for the classes

With Mark McGowan and Sheila Roche

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



Calendar of Events 2023

Members we are pleased to inform you that we are busy looking at dates for our Calendar of Events for 2023. We are pleased to announce that we will be organising a Parents Conference in 2023. Some planned events are as follows:

- **AGM – 3rd to 5th March – Slieve Russell**
- **Parents Conference – 7th to 9th July – Venue T.B.C.**
- **October Conference – 20th to 22nd October – Venue T.B.C.**
- **Women & Bleeding Disorders Conference – 2nd & 3rd December – Venue T.B.C.**

We are also looking at doing some information days for people with mild and moderate bleeding disorders, von Willebrand's disorder, haemophilia B and gene therapy.



Irish Haemophilia Society

**First Floor
Cathedral Court
New Street
Dublin 8**

Tel: 01 657 9900

Fax: 01 657 9901

Email: info@haemophilia.ie

Website: www.haemophilia.ie

Find us on:

