Haemophilia.ie

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

Magazine of the Irish Haemophilia Society

Summer 2022

The Society at a Glance

626	e-Zine Subscribers
74	I.H.S. Volunteers
46	Planned Giving Contributors
1663	Facebook Followers
1226	Twitter Followers

SCAN ME

haemophilia.ie

FROM THE EDITOR

I hope you are all keeping well and you've all had a great summer so far!

We've a jam-packed issue for you, with lots of interesting articles and important updates as usual.

On Page 3, Brian gives an overview on some rather exciting developments in gene therapy, now one step closer. He also provides an update on ambulances and emergencies for people with bleeding disorders, access to H & H Ward at St. James's Hospital and new members from Ukraine.

On Page 5 you will find the preliminary programme for the Members October Conference. On Page 6, there is a report from the inaugural Gerry O'Reilly Courage Award. Elsewhere, all the details about the I.H.S. Educational Grants 2022 are on Page 8, and update on Outreach & Support on Page 13.

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

Finally, this will be my last magazine as I have moved on to pastures new. It has been a great 4 and half years here and I will definitely miss working with the society, no question! I hope the I.H.S. and community in general continues to be a strong, supportive and welcoming community for many, many years.

Barry

IN THIS ISSUE

03

CEO Report
Brian talks about Gene Therapy, Ambulance services, H & H Ward and new members from Ukraine.

06

Gerry O'Reilly Courage Award
A report from the inaugural award ceremony in CHI Crumlin

08

I.H.S. Educational Grants 2022
All you need tio know about this year's Educational Grants

10

Sports & Haemophilia
A quick overview on sports & exercise & haemophilia

13

Outreach & Support
A reminder of the outreach and support offered by the society

14

Noticeboard
News & Updates from the I.H.S.

CEO REPORT

First Haemophilia Gene Therapy - A Step Closer

On June 24th, the pharmaceutical company Biomarin announced that the European Medicines Agency (EMA) Committee for Human Medicinal Products (CHMP) had adopted a positive opinion recommending conditional marketing authorization (CMA) for their investigational factor VIII Gene Therapy, valoctocogene roxaparvovec, which will be marketed as Roctavian. This does not mean that the Gene Therapy is now licenced. It means that the CHMP are recommending conditional licencing to the EMA.

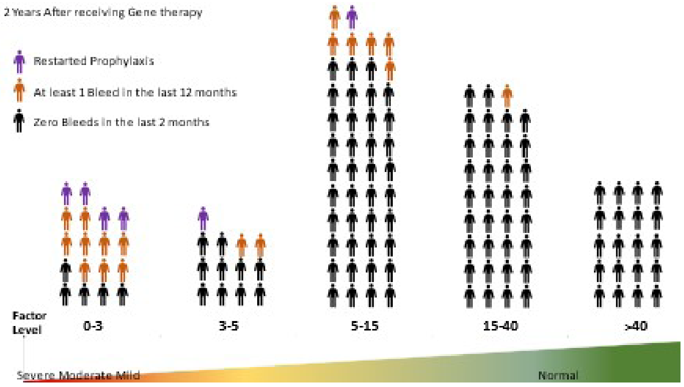
There is now an expectation that licencing may be granted by the EMA in approximately three months. A conditional marketing authorisation recognises that the benefit to public health of the immediate availability of a product on the market outweighs the uncertainties inherent to the fact that the science is still relatively new, as is the case with Haemophilia Gene Therapy. If the EMA grant a licence under CMA, the company will have to continue to provide specifically requested further data from ongoing studies within specified timelines. A CMA could then later be converted to a standard licence if the new data and information is deemed satisfactory.

There are many unknowns and uncertainties with regard to Gene Therapy for haemophilia A. The durability of the Gene Therapy in relation to the length of time that factor expression would last is unknown. At the recent WFH Congress, speakers on Gene Therapy suggested that this may be between 5 and 8 years. There is wide variability in factor VIII expression achieved.

In the Phase 3 clinical trial involving 132 people with Haemophilia A, the average factor VIII expression level after 1 year was 43% with a median point of 24%. This does not tell the full story. Normal factor VIII level is 50-150IU/Dl (50%-150%). In the trial, 38% achieved factor VIII levels above 40 IU/dl (5% of these were more than 150 IU/dl), 50% had a level between 5 and 40IU/dl, 12% had a level less than 5 IU/DL and 9% had a level less than 3 IU/dl. By year 2 on a smaller subset (for whom there is 2 years of data), the average factor VIII expression had fallen to 24% with a median point of 15%.

By year 2, 18% had a factor VIII level of more than 40IU/dl, 59% between 5 and 40 IU/dl and 24% had a level less than 5 IU/Dl. We can see from this data that approximately 1 in 10 people will not achieve a factor VIII level of more than 5%. Approximately 80% of participants had to take a course of steroids due to increased liver enzymes for an average time period of 7 months.

The annual bleed rate (ABR) decreased by 84% on average with the average ABR decreasing from 4.8 to 0.8. FVIII use decreased by 98%.



This is an exciting development which has been worked on for many years. The prospect of Gene Therapy for Haemophilia has been actively discussed and worked on for the past 30 years. Indeed, when the Society hosted the World Federation of Hemophilia Congress in Dublin in 1996, the theme was "From Care to Cure" and one of the plenary lectures was on Gene Therapy. We are not yet at the point of being able to call Gene Therapy a cure, but it certainly appears that it may at the very least offer the prospect of several years of freedom from regular prophylaxis and the reassurance for many of a significant factor level. The Phase 3 clinical trials on factor IX Gene Therapy are also well advanced and we can anticipate probable licencing in the next six to nine months.

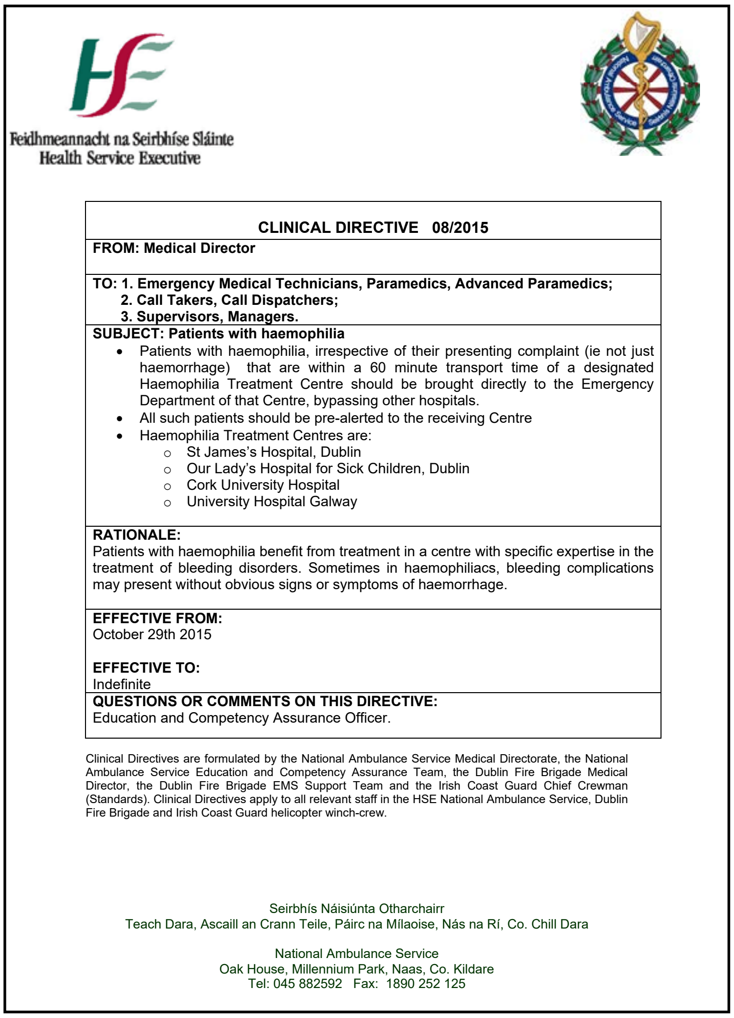
We now have to move beyond contemplating the possibilities of Gene Therapy and looking at education and awareness to ensure that, if and when Gene Therapies become a licenced and available option for people with Haemophilia, all those who may be eligible and are fully educated on the potential benefits, risks, knowns and unknowns and in a position to engage knowledgeably with the treatment services to discuss their future treatment options and set realistic expectations.

Ambulances in an emergency

If you are a person with haemophilia and you have occasion to require an ambulance to bring you to hospital in an emergency situation, there is an existing HSE directive (see below) from 2015 which instructs the Ambulance service to bring you directly to the Emergency Department of one of the four recognised Haemophilia Treatment centres: St. James's or Children's Health Ireland at Crumlin in Dublin or Cork or Galway University Hospitals. This should be the case, provided that you are within 60 minutes transport time from one of these four hospitals. This is to help ensure that you are brought to a hospital where they are aware of your haemophilia and have the specific expertise required to deal with this. We are reproducing this directive now as the result of a recent case where an individual had difficulty in persuading the ambulance to bring him to a designated hospital. (Ambulances will usually want to bring you to the nearest acute hospital). It will be easier to persuade the ambulance crew to comply with this directive if you have your Bleeding Disorder Alert Card in your wallet.

We also suggest the following:

- Keep a photo of your Bleeding Disorder Alert Card on your Phone
- Take a photo of this Directive and also store that on your phone.



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

CLINICAL DIRECTIVE 08/2015
FROM: Medical Director
TO: 1. Emergency Medical Technicians, Paramedics, Advanced Paramedics; **2. Call Takers, Call Dispatchers;** **3. Supervisors, Managers.**
SUBJECT: Patients with haemophilia • Patients with haemophilia, irrespective of their presenting complaint (ie not just haemorrhage) that are within a 60 minute transport time of a designated Haemophilia Treatment Centre should be brought directly to the Emergency Department of that Centre, bypassing other hospitals. • All such patients should be pre-alerted to the receiving Centre • Haemophilia Treatment Centres are: ○ St James's Hospital, Dublin ○ Our Lady's Hospital for Sick Children, Dublin ○ Cork University Hospital ○ University Hospital Galway
RATIONALE: Patients with haemophilia benefit from treatment in a centre with specific expertise in the treatment of bleeding disorders. Sometimes in haemophiliacs, bleeding complications may present without obvious signs or symptoms of haemorrhage.
EFFECTIVE FROM: October 29th 2015 **EFFECTIVE TO:** Indefinite
QUESTIONS OR COMMENTS ON THIS DIRECTIVE: Education and Competency Assurance Officer.

Clinical Directives are formulated by the National Ambulance Service Medical Directorate, the National Ambulance Service Education and Competency Assurance Team, the Dublin Fire Brigade Medical Director, the Dublin Fire Brigade EMS Support Team and the Irish Coast Guard Chief Crewman (Standards). Clinical Directives apply to all relevant staff in the HSE National Ambulance Service, Dublin Fire Brigade and Irish Coast Guard helicopter winch-crew.

Seirbhís Náisiúnta Otharchairr
Teach Dara, Ascaill an Crann Teile, Páirc na Mílaoise, Nás na Rí, Co. Chill Dara

National Ambulance Service
Oak House, Millennium Park, Naas, Co. Kildare
Tel: 045 882592 Fax: 1890 252 125

Access to H & H Ward at St. James's Hospital

Members will be aware that people with haemophilia have not had access to the specifically built H & H ward since the start of the Covid pandemic. The ward was initially used as a Covid treatment ward and is now being used as an assessment facticity before admitting people who may have Covid infection to general wards. The Society have been advocating on an ongoing basis both directly with St. James's and via the National Haemophilia Council to ensure that our members get access to this ward again at the earliest possible time. Some progress has been made in recent weeks and there is now one bed available again in the H & H ward which is being used for people with Haemophilia or other inherited bleeding disorder who require orthopaedic surgery. We will continue to press for full access to this facility and we will keep members updated on progress.

New members from Ukraine

There are now approximately 38,000 people from Ukraine who have moved to Ireland under the EU Temporary Protection Directive. Among the new arrivals are four people with Haemophilia (three adults and one child). All four have been assessed and offered treatment by the Haemophilia comprehensive care centres.

The Society have been in regular touch with all four and their accompanying family members. We provided letters to them before they travelled to Ireland which they could use with the Irish Red Cross to try to ensure, as far as was practicable, that they were accommodated in or close to Dublin in order to be able to attend the National Adult or Paediatric Centres as appropriate. Provision of haemophilia care in Ukraine was not at the same advanced level as in Ireland with some of the adults not able to avail of prophylactic treatment. The new arrivals will probably have to attend the National Centre more frequently than most over the next year so the plan is to provide accommodation close to Dublin has been a practical one. For one family who have been accommodated a significant distance outside Dublin, the Society accommodation facility at Hyde Square has been useful when visiting for assessment.

The Society staff are in regular touch with all four and we have also initiated a WhatsApp group which includes several of our members and the adult Ukrainian men with Haemophilia. We look forward to welcoming all our Ukrainian friends to our October Members Conference where I know you will all provide them with a warm welcome.

Brian O' Mahony,
Chief Executive.

OCTOBER MEMBERS CONFERENCE 2022

OCTOBER 14 – 16 2022 – MOUNT WOLSELEY HOTEL, CARLOW

PRELIMINARY PROGRAMME

Friday October 14th

19.00	Buffet Dinner

Saturday October 15th

10.00 – 11.30	Personal Experience with different therapies
11.30 – 12.00	Coffee Break
12.00 – 13.00	Update on Dental Care
13.00 – 14.00	Lunch
14.00 – 15.30	Adults Workshop Part 1 - Gene Therapy from Concept to Reality **OR** Parents Workshop - Selecting the Right Individual Treatment Regime for my Child
15.30 – 16.00	Coffee Break
16.00 – 17.00	Adults Workshop Part 2 - Gene Therapy from Concept to Reality **OR** Parents Workshop Part 2 - Open Forum
19.00	Dinner

Sunday October 16th

10.00 – 11.00	Insurance (Life, Mortgage, Travel, Health - Insurance Broker)
11.00 – 11.30	Coffee Break
11.30 – 12.45	Drumming Workshop for all the family
13.00 – 14.00	Lunch

GERRY O'REILLY COURAGE AWARD 2022

Members, colleagues and friends remember dearly member and former Treasurer Gerry O'Reilly. Everyone who knew Gerry remember him as being resilient, brave and courageous along with being so good humoured, with a laugh that you will never forget. Gerry was a remarkable person, given the medical burden he dealt with. He constantly bounced back with optimism and bravery. With that in mind and to honour the work that Gerry done for the organisation over the years, we are pleased to announce the 'Gerry O'Reilly Courage Award'. This yearly award will be given to children and teenagers who show courage and resilience in the face of difficulties.

We are pleased to let you know that the inaugural awards were given out to two children and one teenager in CHI Crumlin on 5th July 2022. The awards were presented by Chief Executive of CHI Ireland Ms. Eilish Hardiman and Gerry's sister Kathleen O'Reilly.

The recipients of the awards are as follows:

- Jason Rossiter – aged 16
- Adam Sygieda – aged 8
- Jacob Sygieda – aged 10

Congratulations and well done!

Hyde Square Apartments

A quick reminer 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.

EDUCATIONAL GRANTS 2022

Have you been accepted onto a post second level educational course? Are you going to college?

Do you have haemophilia or a related bleeding disorder? Are you a family member of a person with haemophilia or related bleeding disorder?

If so, why not take the time to apply for an I.H.S. educational grant?

The Society offers educational grants each year to people with haemophilia or related bleeding disorders, including a person with carrier status and/or their immediate family members who go on to do a post second level educational course.

The purpose of the grants is to offer financial support to students to assist them with the extra expenses involved with their studies. Each year applications open during the month of June and close during the month of September.

What Types Of Educational Grants Are Available?

There are four categories of grants available as follows:

- 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.

What Is The Criteria For Applying?

The criteria for the Maureen & Jack Downey Educational Grant:

This grant is made available to a person with haemophilia or related bleeding disorder, including a person with carrier status (defined as a person with mild, moderate or severe haemophilia or related bleeding disorder, or defined a carrier with levels ranging from 1% to 40%). The person must have been accepted onto a post second level educational course from level 7 to 9. The person must be registered at the National Coagulation Centre at St. James's Hospital in Dublin.

The criteria for the Margaret King Educational Grant:

This grant is made available to an immediate family member of a person with haemophilia or related bleeding disorder, be it a spouse, son, daughter, sister, brother, mother or father. 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 criteria for the Father Paddy McGrath Educational Grant:

This grant is made available to a person with haemophilia or related bleeding disorder, including a person with carrier status (carriers with factor levels greater than 40% can apply for this grant) who has been accepted onto a post second level educational course at level 5 or level 6. This grant is also made available to immediate family members be it a spouse, son, daughter, sister, brother, mother or father who has been accepted onto a post second level educational course at level 5 or level 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 criteria for the Michael Davenport Educational Grant:

This grant is made available to a person with haemophilia or related bleeding disorder, including a person with carrier status (carriers with factor levels greater than 40% can apply for this grant) 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.

How Much Are The Educational Grants For?

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.

How Are The Applications Scored And Who Scores Them?

Once the closing date arrives (which is usually towards the end of September) and all the applications have been received, a subgroup of three people from the executive board (which cannot include anyone with a family member applying for any of the grants) meet to consider and score the applications, and make recommendations to the rest of the executive 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 given 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, but remember even if you are eligible to apply for more than one grant, you can only apply for one of them.

You can apply online via our website www.haemophilia.ie. You can also download the application forms from our website, complete them and post the completed forms to the office. If you need further information please call the office on 01 6579900.

Best of luck to you all!

SPORTS & HAEMOPHILIA

Physical activity is an important part of a healthy life.

Participation in sports, games and exercise is a fun way to improve the quality of our lives – physically, mentally and emotionally. This does not change because you have haemophilia. In fact, physical activity may be even more important to someone with haemophilia, since it helps to develop strong bones and muscles that protect the joints from the traumas of daily living.

It is vital that anyone with haemophilia discuss plans for physical activity with your doctor, who is familiar with your individual situation. Together you and your doctor can assess appropriate physical activities. This discussion should also include a full discussion about how you take your treatment. Adapting your treatment appropriately for when you take part in physical activities also taking into account your lifestyle will allow you and your doctor to maximise the time spent doing the activity and minimise the risk of bleeding episodes during the activity. Depending on the severity of the condition, a physical examination may be a good idea.

It is very important to realise that bleeding episodes may occur during physical activities. If there is a suspicion that bleeding has started, either spontaneously or as a result of an injury, it must be reported and treated quickly. Numerous bleeds occurring as a result of a sport may mean the end of participation or the doctor may decide that prophylactic infusion of factor concentrate beforehand is an acceptable alternative.

30 MINUTES

HOW MUCH EXERCISE YOU SHOULD BE DOING EVERY DAY!

REMEMBER

Warming Up

Warming up the muscles for an activity usually consists of performing the activity at a much lower level of intensity for a period of at least 5 to 10 minutes. This targets the specific muscles to be used.

Stretching

Following the warm up, you should stretch for at least 5 to 10 minutes, using whole body stretching as well as concentrating on the major muscle groups you will be using; shoulders & back for swimming; calf, quadriceps and hamstrings for running and so on. Hold each stretch for at least 20 seconds and don't bounce.

For specific sports related stretching exercises, see your doctor or physiotherapist.

Cooling Down

Cool down the muscle after sport in much the same manner as you warmed them up – by doing the activity at a greatly reduced level of intensity for a period of at least 5 to 10 minutes. You should then repeat the stretches as before.

Irish Haemophilia Society

SPORT, EXERCISE & HAEMOPHILIA

This is just a quick overview on sports & exercise, for a more detailed look at sports & exercise, please our Sport, Exercise & Haemophilia Magazine. Available from the office or haemophilia.ie

INSURANCE FOR PEOPLE WITH BLEEDING DISORDERS

Insurance companies will ask questions about pre-existing health conditions, including bleeding disorders, in their policy application forms. You may be asked to provide a letter from your consultant explaining your treatment.

You will need to answer questions honestly. If you do not provide this information, the company may refuse to pay any claim on the policy where your bleeding disorder is a contributing factor. Read the insurance policies so you are aware of what is and is not covered, especially in an emergency.

To obtain a competitive rate and to reduce the amount of potential loading on your premium, shopping around is your best option. It may be useful to speak to the Irish Haemophilia Society for more information.

	Can I get?	Is there a loading?
Travel Insurance	✓	Yes, but some companies will charge an additional loading.
Life Insurance	✓	Yes, but this is changing. To obtain the minimum amount of loading on your policy it is best to shop around.
Car Insurance	✓	✗
House Insurance	✓	✗
Mortgage Protection Insurance	?	Currently no information available.

OUTREACH & SUPPORT

The Irish Haemophilia Society offers outreach and support services including home and hospital visits, regional visits and school visits to members of our organisation. The ongoing level of personal contact between the I.H.S. staff and I.H.S. members is very high.

Along with our Outreach Co-ordinator Rob Flanagan, each member of staff is trained and educated sufficiently about haemophilia and the ramifications of living with a bleeding disorder to enable them to proactively engage with and assist members. Members build relationships with the staff team from their attendance at conferences and meetings. These relationships are very helpful in allowing us to optimally help the members.

We maintain a database for member contact and each call to a member is logged. In this way, we can check to ensure that there are not a large number of members who have not been contacted.

If you need support, please contact Rob in the office on 01 6579900.

In The Case Of An Out Of Hours Emergency

In the case of an out of hours emergency, please call the office on 01 6579900. You will be directed to the answering machine, where you can obtain contact details of our emergency contact person. Contact details for treatment centres are on the home page of our website www.haemophilia.ie. Please ensure that you have your 'Severe Bleeding Disorder Alert Card' with you at all times. (A photo of your card saved on your phone would also be very useful in the case of an emergency)

Hospital & Home Visits

Meeting members in their homes allows us to integrate our understanding of the issues which specifically affect members in that area and allow us to optimise our advocacy efforts on their behalf. The I.H.S. are aware that not everyone can attend our events due to numerous reasons. However, this does not mean you do not need support. The I.H.S. can arrange a home visit to you at your convenience.

Being in hospital can be a scary and lonely time. If you or your child is in hospital and you feel like you need support, a chat or maybe a newspaper don't hesitate to contact Rob. Please contact the office on 01 6579900 if you need some support.

School Visits

If your child is starting crèche, playschool or primary school and you are a little worried, please call Rob and he can arrange to visit the school. Rob will talk to the teachers and educate them about haemophilia or a related bleeding disorder. We can also supply the school with I.H.S. publications. This service can be arranged at the school's convenience.

Remember, the staff are here for you!

NOTICEBOARD

Write for the I.H.S.

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

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

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

Webinar Catch Up

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

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

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

SCAN ME

Irish
Haemophilia
Society

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.

Irish Haemophilia Society
First Floor, Cathedral Court,
New Street, Dublin 8
Tel: +353 (0)1 657 99 00

@irishhaemophiliasociety
@HaemophilialRL

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

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

NOTICEBOARD

Staffing Update

Barry Healy

We have had lots of change in relation to staffing over the last few months. Here is an update for you all:

We said goodbye to our colleague Barry Healy in May. We thank Barry for all his work on our publications, social media and the website over the past four and a half years and wish him all the very best in his new ventures.

We would like to welcome new staff members Suzanne Fitzgerald and Roisin Burbridge. Suzanne started with us back in April 2022 and is looking after reception, Hyde square and other administrative tasks in the office. Roisin started with us in July and will be working on publications, social media and the website. Welcome aboard Suzanne and Roisin and wishing you both the best in your new roles.

Suzanne Fitzgerald

Roisin Burbridge

Join our E-zine Readership!

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

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

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:

@HaemophiliaIRL