

Haemophilia.ie



Magazine of the Irish Haemophilia Society

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



SCAN ME

Summer 2025 Edition

From the Editor

By Roisin Burbridge, Publications, Website & Social Media Coordinator



Hi everyone! I hope you are all enjoying the long days and the sunshine we have had so far this summer!

We have another jam-packed edition of our quarterly magazine for you!

In his CEO report, Brian O'Mahony provides members with an update on this year's World Haemophilia Day, on which we held a memorial service for members affected by HIV and hepatitis C. He also provides an update on our upcoming events and the Society's plans to advocate for women and girls with bleeding disorders.

Sadly, our dearly loved member and previous board member, Breda Quealy, passed away earlier this year. Brian has included a lovely tribute to Breda here.

Later in this edition, IHS board member, Hannah Byrne, has contributed a fantastic article about her experience at the European Haemophilia Consortium (EHC) Youth Leadership Workshop in Brussels in April.

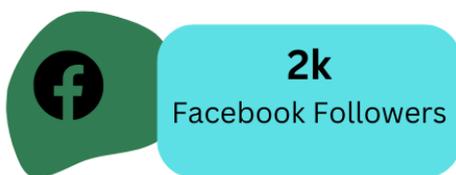
We have a focus on healthy living in this issue of our magazine. Molly O'Mahony, IHS board member and physiotherapist at St. James's, has provided us with an in-depth piece about physical activity, giving information about the different types of exercise, the various levels of exertion, things to be mindful of and more. This is well worth a read!

Following this piece, Dr. Aisling Cant, Locum Consultant in Paediatric Dentistry at CHI Crumlin, gives a rundown of all the essential information parents of children with bleeding disorders should know about taking care of their children's teeth.

As well as these main articles, we have included lots of information about the goings on of the IHS over the next few months. You can find the preliminary programme for our October Conference printed later in the magazine, as well as information about our Newly Diagnosed Information Day in September. You can also find information about our educational grants, our new WhatsApp community and much more!

We wish you happy reading!

The Irish Haemophilia Society at a Glance



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CEO Report

By Brian O'Mahony, Chief Executive

World Haemophilia Day



In April, on the week of World Haemophilia Day, the Society held a regional meeting with members in cork. The meeting was very well attended and an update was provided on the services and supports available from the Society and on upcoming events. A broad ranging discussion also took place on all aspects of haemophilia and bleeding disorder treatment and care. The following day, to mark World Haemophilia Day, the Society, in collaboration with the haemophilia care team at the Cork Coagulation Centre at Cork University Hospital, organised an information stand and also participated in a lecture with Dr. Maeve Crowley to health care professionals from the hospital, providing an update on haemophilia. It was a very successful visit to Cork for the second year in succession to mark World Haemophilia Day and one which I hope will become an annual event.

Upcoming Events

Our upcoming events this year include a parent and child overnight which will be held at the Lilliput Adventure centre in Mullingar in July. Some years in the past we organised mother and daughter events and father and son events. At this point in time we decided to organise a parent and child event which will give those present an opportunity to try different activities in an informal and fun environment. The event will include archery, orienteering, water based activities and zip lining. At the time of writing the



event has been very well subscribed and looks like it will be a major success.

Advocacy for Women & Girls with Bleeding Disorders

In November of this year the Society will organise a Women and Girls with Bleeding Disorders (WGBD) information day in Dublin. This meeting, which is planned to take place every second year, is part of one of our strategies to advance the cause of WGBD. We are in the final stages of production of a booklet on menarche for young girls, which will give age appropriate information on this important topic. We also plan to update our current publications on Women with Bleeding Disorders and Teenage Girls with Bleeding Disorders prior to the information day in November. Members will be aware that we already provide free period products at all IHS events and we will continue to do so. We will also plan some specific webinars on relevant WGBD topics in the coming year. We will be working with the centres to advocate for gynaecology services at each comprehensive care centre and access to required physiotherapy services for WGBD. We plan to produce specific information for WGBD at each stage of life including menstruation, perimenopause and menopause. We also plan to approach the Department of Education to see if we can make progress in relation to having more detailed information on menstruation made available at schools at an appropriate age point.



Breda Quealy - An Appreciation

By Brian O'Mahony, Chief Executive

We were deeply saddened by the passing in April of Breda Quealy after a long illness.

Breda was a Board member of the Society since 2022 until late last year when she stepped away due to illness. She was a determined and effective advocate for people with von Willebrand disorder (VWD).

Her personal story of years of delay before receiving a proper diagnosis was a salutary tale and Breda spoke at many of our events on the importance of timely diagnosis of VWD and of access to effective and proper treatment. Despite an initial reluctance to speak publicly, she embraced this with great passion and commitment. She was an effective spokesperson on these issues and also contributed very effectively to our VWD public awareness campaigns in 2021 and 2023. She was an inspiration to many in our community with VWD.

Breda was also a lovely human being. She was warm, caring and had a great sense of humour and fun. She had great determination and dealt with her illness with great courage and hope. She will be sadly missed by our community, her family and many friends.



HIV Memorial Service

By Brian O'Mahony, Chief Executive

On the evening of World Haemophilia Day, the 17th of April, the Society organised a memorial event for people with inherited bleeding disorders and their families. This was held at the HIV National Memorial in the Phoenix Park to give members an opportunity to see this memorial, which was unveiled in December 2023.

The event comprised of a number of readings and a selection of pieces of music. Those present congregated afterwards for some refreshments and conversation. It was a lovely event which we hope will become a more regular occurrence in the calendar.

Thank you to all those who attended and took part in our service.



Newly Diagnosed Information Day

Venue: The Grand Hotel, Malahide, Dublin

Date: 6th September, 2025

We warmly invite all parents of children recently diagnosed with haemophilia, von Willebrand Disorder or other inherited bleeding disorder to join our newly diagnosed information day. This special event is designed for parents who are navigating the early stages of diagnosis.

At the event, you'll hear from leading physicians in the field, have the chance to ask questions and make connections with other parents who have similar experiences.

Preliminary Programme

11.30am - 12pm	Arrival & Registration
12pm - 1pm	Lunch
1pm - 2pm	Bleeding Disorders in the First 3 Years of Life
2pm - 2.30pm	Questions & Answers
2.30pm - 3pm	Coffee Break
3pm - 4pm	Dental Care in the First 3 Years of Life
4pm - 5pm	Developing Coping Strategies

EHC Youth Leaders

By Hannah Byrne

Friday

I arrived in Brussels on the 5th of April for the European Haemophilia Consortium (EHC) Youth Leadership Workshop and, with my head buried in Google Maps, looked down the street of grey office buildings to find the correct one. The street was filled with people in business attire, and the hustle and bustle of a city at lunchtime. I found the building and when I went into the office. It was entirely different from the serious faces rushing around the street. It was filled with people chatting, old friends reuniting, and many people who didn't know each other introducing themselves. Within a few minutes, everyone was laughing and joking, setting the tone for the entire weekend!

After a quick bite to eat, the workshop set off with some icebreakers and introductions. Stefan Radovanovic and Fiona Brennan (who happens to be a former IHS staff member!) led the workshop. From the first session, they both put everyone at ease, creating a great environment for asking questions, learning from each other, and having a few laughs.

Friday's sessions covered volunteer engagement and strategic planning in an organisation. The conversation ranged from the principles of good governance to common problems that national member organisations (NMO's) face. I found it extremely interesting to hear from each of the participants about their NMO's set up for volunteering and planning events. It was great to be able to discuss ideas and share previous successes. Through this, we were able to take inspiration from what other organisations did, what worked for them, and what didn't.

At the end of each day, we were divided into small groups to discuss the day with the EHC Youth Ambassadors. This session was great as we were able to really break down and delve into topics that were discussed, as well as hear some advice and stories from the Youth Ambassadors.

Following a busy first day, we had our first group dinner. I really enjoyed this as we got to mingle and get to know each other. Conversations constantly circled back to bleeding disorders, with everyone sharing their personal stories. To me, these dinners and the coffee breaks were as valuable as the

programme itself. Every person there had such a different experience with their bleeding disorder based on what type they had, their medication, and the health care available to them in their home country. It was very educational to get to freely discuss these topics, for people to give advice peer to peer, and to remind us that every person has a completely different experience with a bleeding disorder.

Saturday

Saturday morning rolled around, and the sun was shining, brightening everyone's day! The day started with an icebreaker game to wake everyone up, before starting into some strategies about how to engage volunteers in an organisation. One feature of the workshop that I really enjoyed was the amount of group work. We split up, discussed scenarios, and came back to the full group with our suggestions and ideas.

The afternoon session shifted focus to the medical aspects of bleeding disorders, with Zita Gacser guiding us through every stage of the medicine licensing process - from initial discovery to market authorisation. Zita knew how to capture the group's attention by hosting the session in the form of a quiz, showing everyone's competitive side! The quiz really tested how much I had been listening to the speakers at the IHS AGM and previous conferences, but after attending these talks, I felt well-prepared! After a competitive battle, I was thrilled to win the quiz!

Our final session of the day was a discussion with representatives from the pharma industry. Both representatives had many years of experience and it was interesting to hear their take on how they felt the patient community had grown and changed with the introduction of new medical treatments. By this stage of the day, the sun was streaming through the windows, so the conference organisers swooped in with some ice creams for us all to cool down and enjoy the session!

As the day drew to a close, we went back to the hotel to get dressed up for a well-deserved meal! After the dinner, we made our way back towards the hotel... until we saw a fairground with a Ferris wheel. This impromptu decision ended up being a great one as

Leadership Workshop 2025

...e, IHS Board Member

we had a 360-degree view across the city of Brussels, which was a brilliant end to a jam-packed day!

Sunday

By Sunday morning, I was shocked we were on the last day already! We filled the morning with some more in-depth discussion on strategic planning. We then thought about some ideas of what areas we could work on to bring people together within our NMO. Ideas were flying with everyone creating plans to expand on and take back to our NMOs.

Following this, we ended the weekend with some role plays of common scenarios that may happen within

an NMO. These were equal parts educational and entertaining, with everyone getting a chance to try out their acting skills.

As the workshop wrapped up, our final task was to write a postcard addressed to ourselves to be posted to us in 6 months by the EHC. In this, we were asked to capture what we were feeling after the workshop, and when we receive this later on in the year, it will be a reminder of what we learned. I think this was the perfect ending to the workshop because the motivation and excitement in the room were palpable. Everyone was excited to go back to their NMO, to share what they had learnt, and to continue to stay involved and make a difference for members.



October Members' Conference

Venue: Mount Wolseley Hotel, Carlow
Date: 17th-19th October, 2025

Adults Preliminary Programme

Friday 17th October

7pm - 9pm Buffet Dinner

Saturday 18th October

10am - 11am **Debate: Who Should Decide On My Treatment? My Consultant or Me?**

11am - 11.30am Coffee Break

11.30am - 1pm **Panel Discussion: An Update & Personal Perspectives on Treatment**

1pm - 2pm Lunch

2pm - 3.30pm **Interactive Discussion on Treatment**

OR

Von Willebrand Disorder & Rare Bleeding Disorders

OR

Mild Haemophilia

3.30pm - 4pm Coffee Break

4pm - 5pm **Food & Nutrition**

7pm Dinner

Sunday 19th October

10am - 11am **Sports & Bleeding Disorders**

11am - 11.30am Coffee Break

11.30am - 1pm **The Sunday Game / County Colours (Fun Activity For all the Family)**

1pm Depart

Let's Get Physical! Starting a New Exercise Regime

By Molly O'Mahony, IHS Board Member and Physiotherapist

There was a story doing the rounds recently about a new machine that had been installed at the local gym. One member reported that he used it for the best part of an hour but felt sick afterwards.

"It's great though," he assured a friend, "it is packed with Mars Bars, Kit Kats, Snickers... the lot".

While it might be best to avoid machines with such distracting temptations, it's fair to say that the very thought of exercise can, at times, be overwhelming, with many questions springing to mind and, perhaps, some confusion about getting started and where it might lead.

How much exercise should I do? What type? Is this even going to be of any benefit to me?

In the past, strenuous exercise or physical activity was discouraged for people with haemophilia or other bleeding disorders due to the increased risk of bleeding and lack of available, effective treatment. Now, however, due to vastly improved treatment regimes, intense physical activity no longer poses the risk it once did.

Exercise Examples

Standing, light walking, washing dishes, doing laundry, cooking, light calisthenics

Walking at a moderate pace, bicycling 8-14.5 kph, water aerobics, weight training, dancing, recreational swimming, gardening and yard work, moderate home repair or housework

Walking briskly (>8 kph), jogging, running, bicycling, backpacking, aerobic dancing, vigorous calisthenics, circuit weight training, tennis, most competitive sports, lap swimming for fitness, heavy gardening and housework, occupational work with heavy loads



All the evidence today indicates that exercise has fantastic benefits for people with haemophilia – as well as for the general population – and it should be seen as an integral part of your life.

The American College of Sports Medicine (ACSM) – the 'gold standard' when it comes to exercise recommendations – provides guidelines for physical activity and exercise based on the latest science and insights from health professionals. These recommendations are also relevant for people with bleeding disorders.

Aerobic exercise

Intensity and duration: Exercise intensity can be graded. The ACSM recommends that healthy adults, aged between 18 and 64, should engage in 150 minutes of moderate intensity aerobic physical activity per week – this equates to 30 minutes five

days a week. Otherwise, they recommend vigorous aerobic activity for 60 minutes, which works out to be 20 minutes three days a week.

So how do you know if your exercise intensity is moderate or vigorous? One simplified way of figuring this out is by the 'sing and talk test'.

Vigorous: You can only say a few words without stopping to catch your breath.

Moderate: You can engage in a conversation but cannot sing.

Before starting a vigorous exercise regime, you should talk with a member of your healthcare team who may suggest that you undergo certain tests first. This may be the case for people with joint or muscle issues relating to bleeding disorders or those with other issues.

In general, most forms of physical activity are deemed safe for those with bleeding disorders, so long as they are on an effective treatment regime.

The type of exercise you should do depends on a number of factors. You must take into consideration likes/dislikes, cost, availability and your past medical history or previous injuries.

It is vital to remember that an activity that might be of moderate intensity for one individual may be a vigorous activity for another – for example, a brisk walk.

Strengthening

When most people think of exercise, the first type that usually comes to mind is aerobic (walking or cycling, for example) but it is important not to forget about strength training.

RPE Scale	Rate of Perceived Exertion
10	Max Effort Activity Feels almost impossible to keep going. Completely out of breath, unable to talk. Cannot maintain for more than a very short time.
9	Very Hard Activity Very difficult to maintain exercise intensity. Can barely breath and speak only a few words
7-8	Vigorous Activity Borderline uncomfortable. Short of breath, can speak a sentence.
4-6	Moderate Activity Breathing heavily, can hold short conversation. Still somewhat comfortable, but becoming noticeably more challenging.
2-3	Light Activity Feels like you can maintain for hours. Easy to breathe and carry a conversation
1	Very Light Activity Hardly any exertion, but more than sleeping, watching TV, etc

Tips to Stay Safe & Injury-Free When Exercising

- Be as active as your abilities allow
- Start slowly – with light to medium effort
- Gradually increase your pace and time spent being active
- Warm up gently and cool down at an easy pace before and after exercise
-

If concerned, please link in with your physio, GP or another medical practitioner before engaging in any exercise. If you have health worries, talk with your healthcare provider before beginning a new activity routine.

The ACSM guidelines recommend that we engage in two muscle strengthening activities for each major muscle group per week. For each muscle group, we should be completing between 8-10 exercises consisting of 2-4 sets of 8-25 reps, depending on what your goal is.

If we are looking to progress our endurance we would look towards a lower resistance for higher repetitions while power movements would encompass higher resistance for fewer repetitions.

Strength training can include the use of free weights, weight machines or resistance bands. It can also include activities that use your own body weight, such as pilates.

Intensity can be gauged by how difficult your last repetition is to complete. You want to be challenging yourself appropriately and the last repetition of each set should be very tough to complete.

Let's not forget that movement should not be confined to our allocated time for exercise and we should strive to increase our movement throughout our day.

There are huge health benefits to reducing the total time spent in stationary positions by interspersing frequent, short bouts of standing, walking and physical activity throughout the day, even if you are a physically active adult outside of work.

Try standing up and walking around the room or office every 20 minutes during your work day. This small amount of movement has huge benefits for your health.

How do I progress?

It is recommended to establish exercise as a habit, almost like taking a prescription medication.

Start at a light intensity if you are new to exercising and slowly build up to a moderate or vigorous intensity. As a general guide, aim for about a 10% increase in the amount of your activity per week for a safe progression.

Remember, physical activity is not only good for your body but it's also great for your mind as being active releases chemicals in your brain that make you feel good.

Exercise can also boost memory, improve mood and sleep and reduce stress and anxiety. Problems in these areas frequently cause or contribute to cognitive impairment.

Being active doesn't have to mean taking out an expensive gym membership or running marathons. Finding an activity that you enjoy can give you a goal to aim for and a sense of purpose.

It can also be a great way to meet people, have a break from daily life and gain confidence. It's even better if you're able to get active outdoors.

Where to start

The IHS organises a number of regular exercise classes that you can get involved in while in the comfort of your own home. The classes cater for all levels of fitness and are a fantastic way to begin your exercise journey.

Final thoughts

Think about your current fitness levels, how much time you have to exercise and what feels realistic to you. Anything you do to get active and reduce the amount of time you spend sitting or lying down is good.

Finding an activity that you like and are able to do regularly is more important than pushing yourself to do something you don't enjoy. You could try brisk walking, mowing the lawn, dancing, swimming, trying a new sport or anything that gets your body moving.

Remember that exercise isn't about losing weight or changing your body shape. If you enjoy it and it makes you feel good, that's what is important.

And one final thing to remember – you don't have to enthusiastically embrace every new machine that's installed in the local gym!

IHS Exercise Classes



The Irish Haemophilia Society organises two weekly online exercise classes to support members in staying active and healthy.

Physio-Exercise Class: Led by Mark McGowan, a Clinical Specialist Physiotherapist at St. James's Hospital, this class takes place every Tuesday at 7:30pm via Zoom.

Beginner Pilates Class: Held every Wednesday at 7:00pm on Zoom, this class is ideal for those new to pilates and is delivered by physiotherapist Emer O'Shea.

Both classes are designed to be accessible and supportive. Contact us to join a class!

Healthy Gums Don't Bleed!

Taking Care of your Child's Teeth

By Dr. Aisling Cant, Locum Consultant in Paediatric Dentistry, CHI Crumlin

Maintaining good dental care is important for everyone. People with inherited bleeding disorders should take extra care of their oral health. While dental care may sometimes fall to the bottom of a busy to-do list, if your child has a bleeding disorder, it is important to make their oral health a priority and schedule regular visits with your dentist.

What is tooth decay?

Children with bleeding disorders experience the same oral diseases as those without.

Dental caries (tooth decay) is one of the most common health problems in the world. It is caused by bacteria in the mouth which produce acids which can eat away at the tooth surface. If left untreated, tooth decay can progress causing pain and possible infection.

Children with bleeding disorders are considered at high risk of dental caries. If these children get tooth decay, their dental care can be challenging (1).

What about bleeding gums?

Bleeding gums can be a sign of gum disease. Gum disease is a common condition in which the gums become swollen, inflamed and can bleed on brushing (2). The early stage of gum disease is called gingivitis. If left untreated, this can lead to more severe gum problems (periodontitis). Periodontitis can lead to bone damage which may make your teeth loose and fall out.

If your child has bleeding gums, you should bring

Healthy Gums Don't Bleed!

If your child has bleeding gums, it may not be caused by their bleeding disorder. It could be due to gum disease which can be caused by poor toothbrushing. Bring your child to the dentist if you are worried.



them to a dentist. They may need their teeth professionally cleaned or monitored.

Which dentist should I bring my child to?

You should always let your dentist know if your child has a bleeding disorder.

Visiting your local dentist will often be the most convenient option. However, not all children with bleeding disorders can have dental treatment locally. A small number of children may have their dental care in a specialised dental centre e.g. hospital. Your child's haematology team will let you know which dentist is most suited for your child.

When should my child see the dentist?

Aim to bring your child for their first dental visit by their first birthday.

Do not wait until your child is in pain before attending

the dentist. Attending the dentist in an emergency situation may be upsetting for you and your child and could contribute to future dental anxiety.

Both dental caries and gum disease are preventable diseases. Education, routine dental visits and simple treatments by the dentist can reduce the likelihood of your child needing significant dental treatment in the future.

What if my child needs dental treatment?

If your child needs dental treatment, you should coordinate this with your child's haematology team. It is important that the dentist provides treatment in a safe setting and takes certain measures to prevent bleeding. If your dentist is unsure what to do, they should contact your child's haematology team.

References:

1. Anderson et al 2013 British Dental Journal 2013; 215: 497-504
2. HSE Gum disease (gingivitis and periodontitis) - HSE.ie (Accessed 26/03/25)

Follow these essential tips to maintain healthy teeth:

1. **Start toothbrushing as soon as the first baby tooth erupts**
2. **Bring your child to their dentist by their 1st birthday**
3. **Brush your child's teeth before bedtime and one other time during the day**
4. **Children with special healthcare needs should use a smear (rice-sized amount) of 1450ppm fluoride toothpaste. From 2 years of age, increase to a pea-sized amount**
5. **All children should be supervised with toothbrushing until at least 7 years of age**
6. **Encourage your child to spit and not rinse their mouth after toothbrushing to give the fluoride its best opportunity to work**
7. **Avoid snacking in between mealtimes. Water is the safest drink for teeth!**
8. **Attend the dentist regularly**

Essential tips for maintaining healthy teeth

Start toothbrushing when the 1st tooth appears



First dentist visit by age 1



Brush 2 times a day



Correct amount of toothpaste



Supervision



Don't rinse after toothbrushing



Avoid sugar & drink plenty of water



Attend your dentist regularly!





Apply for an IHS Educational Grant!

The Society offers annual educational grants to individuals with bleeding disorders—including carriers—and their immediate family members who are pursuing post-secondary education. The purpose of the grants is to assist students with the extra expenses of their studies.

What types of educational grants are available?

There are four categories of grants available: Maureen & Jack Downey Educational Grant, Father Paddy McGrath, Michael Davenport and the Margaret King Educational Grant.

What is the criteria for applying?

Maureen & Jack Downey Educational Grant:

For people with mild, moderate or severe inherited bleeding disorders including asymptomatic carriers

with normal levels and symptomatic carriers with levels of between 5% and 40%, who are classified as people with mild haemophilia. Degree course level: 7 to 9. Grants range from €1,000 to €4,000.

The Father Paddy McGrath Educational Grant:

For people with mild, moderate or severe inherited bleeding disorders including asymptomatic carriers with normal levels and symptomatic carriers with levels of between 5% and 40%, who are classified as people with mild haemophilia and immediate family members. PLC (or other similar course) course level 5 & 6. Grants range from €250 to €1,000.

The Michael Davenport Educational Grant:

For people with mild, moderate or severe inherited bleeding disorders including asymptomatic carriers with normal levels and symptomatic carriers with levels of between 5% and 40%, who are classified as people with mild haemophilia. For mature students

aged 24 years plus doing a Masters or PHD course. Grants range from €1,000 to €4,000.

The Margaret King Educational Grant:

For immediate family members (spouse, son, daughter, sister, brother, mother or father) of people with mild, moderate or severe inherited bleeding disorders. Degree course level: 7 to 9. Grants range from €500 to €2,000.

How much are the educational grants for?

Maureen & Jack Downey Educational Grant

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

Father Paddy McGrath Educational Grant (2 Grants)

A person with the bleeding disorder:

First prize €1,000
 Second prize €500

Third prize €250

A family member of a person with the bleeding disorder:

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

Michael Davenport Educational Grant

Grants ranging from €1000 to €4000

Margaret King Educational Grant

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

How are the applications scored and who scores them?

Once the closing date of the **3rd of October** arrives 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. Remember that even if you are eligible to apply for multiple grants, you can only apply to one each year.

Take some time to complete your application, as the more complete and detailed your application is, the higher your chance is of it being successful!



Join Our WhatsApp Community & Stay Up-to-Date on all Things IHS

We have rolled out a dedicated WhatsApp Community service to members, to make more efficient the way we share Society news and resources. Members can join the main hub and then opt into specific sub-groups that match their needs. For example: Conferences & Events, Travel, Updates from Treatment Centres, Outreach. The platform is one-way in that only Society posts are allowed. This enables updates to reach people quickly without chat clutter and allows us to moderate all content to keep it accurate. Since launching on the 17th of April, the uptake has been strong in all of the groups.

To boost engagement further, we will host a stand at the October Conference with a live display as to how it all works with a QR code so that members can join the service on the spot. We will also open a temporary, conference-specific group to share real-time schedules, reminders, and polls while our conferences and events are running, then archive it afterward. This initiative aligns with the strategic plan's goal of clearer, faster communication and is already proving an effective information channel.

Our Outreach Coordinator Robert Flanagan is managing this WhatsApp Community and is happy to answer any queries you might have about it. You can email Robert at robert@haemophilia.ie. To request to join the Community, please email Rob and provide your full name and number.

Parent & Child Overnight Event



Our overnight adventure event in Lilliput Adventure Centre is taking place on Saturday the 12th and the morning of Sunday the 13th of July, promising adventure and bonding with activities for parent and child alike.

Here is the programme:

10.00am	Archery
11.30am	Refreshments
12.00pm	Team Building Event Orienteering
2.00pm	Lunch
3.00pm	Water Based Activities
4.30pm	Zip Line
6.00pm	Free time, check into accommodation
8.00pm	Dinner
9.00pm	Games

We can't wait to see everyone there for a fun and memorable weekend!

Showcase Your Volunteer Experience on LinkedIn!

Have you volunteered with the IHS at one of our events? Whether you helped with the children's programme, supported our conferences, or assisted behind the scenes – you can now proudly reflect that on your LinkedIn profile. Adding your IHS volunteer experience not only showcases your contributions, it also helps raise awareness of the Society's work and creates a stronger professional presence for you online.

Here's how to do it:

1. Go to your LinkedIn profile and scroll to the "Experience" section.
2. Click the "+" button to add a new experience.
3. Under "Title", enter: Volunteer - Children's Programme
or
Volunteer - Youth Group / Events / Outreach
or
For Employment type, select: Volunteer.
4. In Company, type: Irish Haemophilia Society and select the official page with the logo.
5. Enter your start and end dates (or mark as "present").
6. Location: Dublin, Ireland.
7. Use this description (or tailor it to your role):



'I supported children, teens, and families at IHS events by helping to run creative and educational sessions, ensuring a safe environment, and assisting with logistics and setup. This role strengthened my communication, teamwork, and event coordination skills.'

8. Click Save – and you're done!

By linking your experience to the official IHS page, you help grow our visibility and show your meaningful involvement. If you need help, feel free to reach out – we're happy to guide you through it. Thank you again for all that you do!

Fundraise for Us!

Help support people living with haemophilia and other inherited bleeding disorders by fundraising for us! Every euro helps provide vital support, education, and advocacy.

Here are some ideas for fundraisers:

- Host a coffee morning or bake sale
- Organise a sponsored walk, run, or cycle
- Set up a birthday fundraiser online
- Hold a quiz night or raffle
- Take on a personal challenge

Big or small, your fundraiser makes a real difference to us.





Irish Haemophilia Society

First Floor
Cathedral Court
New Street
Dublin 8

Tel: 01 657 9900

Email: info@haemophilia.ie
Website: www.haemophilia.ie
Twitter Handle: [@HaemophiliaIRL](https://twitter.com/HaemophiliaIRL)

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