Haemophilia.ie

Magazine of the Irish Haemophilia Society

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

SCAN ME

Winter 2025 Edition

From the Editor

Merry Christmas to everyone! I hope you all have a lovely break over the Christmas period.

It was another busy season here at the IHS. Over the past couple of months we have had events, new publications, webinars and more.

To begin this edition of our magazine, Chief Executive Brian O'Mahony provides an update on the goings on of the Society since our last edition, filling members in on the clinical webinar series and podcast series we are producing and on our recent events. Following this, we have more in-depth looks at our Women & Girls with Bleeding Disorders (WGBD) Information Day and our October Members' Conference. We have also included the preliminary programme for our AGM & Conference taking place in March. Registration is currently open so don't miss your chance to book in!

As well as this you can find our calendar of events for 2026, which promises to be another busy year! We have also included a closer look at the key points covered in our first three webinars, which will give you a taste of what was discussed if you are unable to listen to the webinars themselves.

We are delighted to announce the first prize winners of our educational grants this year, as well as to give more information on a number of IHS initiatives. We have also included a few Christmas puzzles for kids towards the end of this edition. Finally, you can find the Christmas hospital opening hours at the back of the magazine. We hope you find this useful and enjoy reading this edition.

Wishing you all a very Merry Christmas and a Happy New Year!

Roisin Burbridge, Publications, Website & Social Media Coordinator

The Irish Haemophilia Society at a Glance

2k
Facebook Followers

386
Instagram Followers

64
I.H.S. Volunteers

1,497
X Followers

37
Planned Giving Contributors

Contents

CEO Report

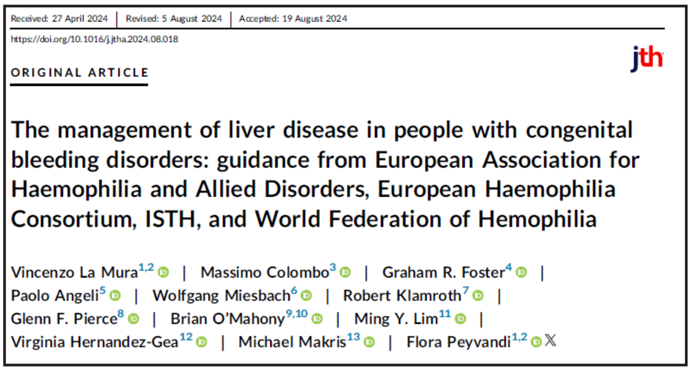
By Brian O'Mahony, Chief Executive

Webinar Series & Podcasts

The Society have been very busy in recent weeks with innovative communications including another series of clinical webinars and a new series of podcasts. We have organised a series of six clinical webinars with expert clinical speakers from abroad. The target audience are healthcare professionals in Ireland and globally and the webinars were also advertised to global and regional haemophilia advocacy organisations and to the European Association for Haemophilia and Allied Disorders (EAHAD) - the European clinical group. At the time of writing, three of the six webinars have been completed.

The first webinar was on new therapeutic possibilities for von Willebrand disease (VWD) with Professor David Lillicrap from Canada. VWD has been relatively neglected in the past when we consider it alongside the great innovations that have taken place in haemophilia in the past 10 years. It looks like this is now changing. Professor Lillicrap outlined eight potentially innovative therapies for VWD. The first two of these are already licensed - recombinant von Willebrand factor (VWF) and Emicizumab, the latter currently used for Haemophilia A with or without inhibitors, but now in a clinical trial for Type 3 VWD. The third was an aptamer - BT200 - which increases both VWF and factor VIII (FVIII) levels. Next was VGA-039 - a monoclonal antibody targeted against Protein S, which increases thrombin generation and should reduce bleeding. Ireland will be included in the clinical trial for this product. Next were HMB-002, a monovalent antibody which also increases both VWF and FVIII, KB-V13A12 – a bispecific nanobody which may be used in Type 1 VWD, platelet inspired nanoparticles and lipid nanoparticles and siRNA targeting plasminogen. Some of these innovations may not make it all the way to being licensed and available therapies but it is highly likely that several will make it to market. This, together with potential repurposing of Emicizumab for some with VWD, means that the next five years will be very exciting in VWD.

The second webinar featured Professor Vincenzo La Mura from Milan who spoke on liver health in haemophilia. There has been an understandable increase in interest in liver health in haemophilia due to liver-targeted gene therapy and this is, of course, both necessary and important. Prof. La Mura, however, concentrated more on monitoring liver health in those who have previously cleared hepatitis C. Most of these individuals may have been officially discharged from hepatology centres unless they had severe fibrosis or cirrhosis at the time they cleared hepatitis C. Prof. La Mura looked at a cohort of 119 people with haemophilia who were discharged from their hepatology service and concluded that only 2% should have been discharged. 80% had at least one risk factor for chronic liver disease. This included fatty liver, obesity, excess alcohol use or diabetes. A further 18% had advanced fibrosis, cirrhosis or liver malignancy. It is clear from this data that a significant proportion of those who cleared hepatitis C required ongoing monitoring of their liver health. This could be done with relatively simple blood tests or non-invasive screening or diagnostic tests including ultrasound and fibroscan. This important information was reiterated in recent guidance published by the major haemophilia clinical organisations globally led by Prof. La Mura. We will be following up on this with the clinicians and we have also invited Prof. La Mura to speak at our AGM and Conference in March.



Received: 27 April 2024 | Revised: 5 August 2024 | Accepted: 19 August 2024

https://doi.org/10.1016/j.jtha.2024.08.018

jth

ORIGINAL ARTICLE

The management of liver disease in people with congenital bleeding disorders: guidance from European Association for Haemophilia and Allied Disorders, European Haemophilia Consortium, ISTH, and World Federation of Hemophilia

Vincenzo La Mura[1,2] | Massimo Colombo[3] | Graham R. Foster[4] | Paolo Angeli[5] | Wolfgang Miesbach[6] | Robert Klamroth[7] | Glenn F. Pierce[8] | Brian O'Mahony[9,10] | Ming Y. Lim[11] | Virginia Hernandez-Gea[12] | Michael Makris[13] | Flora Peyvandi[1,2]

Liver health is in our hands!!

Do's

- Maintain a healthy body weight
- Physical excercise regularly
- Safe food and drink
- Get vaccinated against HBV and HAV
- Medical control if exposed to any risk facto

Dont's

- Excess alcohol
- Unsafe injections
- Unecessary drugs/herbal products/dietary supplements
- Tattooing in unregulated settings
- Unsafe sex

The third webinar in the series was on rebalancing agents in haemophilia and other bleeding disorders. Two such rebalancing agents - Concizumab (brand name Alhemo) and Marstacimab (brand name Hympavzi) are now licensed for use in the EU. Concizumab is licensed for use in Haemophilia A and B with or without inhibitors. Marstacimab is licensed for use in Haemophilia A and B without inhibitors (although we anticipate it will be licensed for inhibitors later). A third rebalancing agent - Fitusiran (brand name Qfitlia) is licensed in the US and is expected to be licensed in Europe later. These agents each inhibit a naturally occurring anticoagulant and allow the blood to clot even in the absence of FVIII or factor IX (FIX). This is a new and novel approach to treating haemophilia and it will be very interesting to see the real world evidence on its use, efficacy and safety as time progresses.

The final three webinars in the series will be updates on Gene Therapy and Gene Editing, FVIII mimetics and will finish with a webinar on access to treatment - what has been achieved and what is needed - a global perspective from Dr. Glenn Pierce, Medical Vice President of the World Federation of Hemophilia.

In addition to the webinars, the Society have organised a series of four podcasts on haemophilia gene therapy in collaboration with our colleagues at the Canadian Hemophilia Society. These will focus on FIX gene therapy. The podcasts are being recorded in November and December for transmission in January 2026. The first podcast will feature an overview of gene and cell therapies with Prof. David Lillicrap. The second will feature four people with haemophilia discussing why they are interested or not interested in being treated with gene therapy. The third will feature four people who have undergone FIX gene therapy and the final podcast will be a discussion on shared decision making featuring two clinicians and two people with haemophilia. This is a new communications departure for the Society and we are very excited about this and the potential for future podcasts.

Recent Events

Looking at more traditional communications methods, we were very pleased with the programmes, attendance and discussions at both of our recent events - the October Members’ Conference and our Women and Girls with Bleeding Disorders (WGBD) Information Day. The October Conference began with a very lively and enjoyable debate on who should primarily decide on an individual’s treatment – the consultant or the patient. This was well argued on both sides by Patrick Browne and Colm Walsh. The debates are a useful way to discuss an issue as we ask both speakers to take totally opposite views knowing that, very often, the truth or correct course of action and indeed their true opinions are in the middle. We then had an update on treatments with several members speaking about their individual experience with either a licensed therapy or as part of a clinical trial. This was followed by an interactive workshop and parallel sessions on von Willebrand and rare bleeding disorders and on mild haemophilia. The weekend was rounded off by lectures on diet and nutrition, sports and bleeding disorders and a fun session for all which involved line dancing, with many people wearing their county colours. We were particularly pleased to welcome the six families with haemophilia from Gaza who were attending their first event.

The WGBD information day was open to women and to girls aged 10 years and older accompanied by their mothers. We covered the major life events in a woman or girl’s life, with topics on paediatric care, menorrhagia and heavy menstrual bleeding, conception and pregnancy and menopause. Speakers included Dr. Beatrice Nolan, who gave an overview, Dr. Michelle Lavin, who spoke on her Know Your Flow initiative to recognise what is a normal or abnormal period, obstetrics specialist, Dr. Mary Anglim, on Conception and Pregnancy and Sallyanne Brady on menopause. The discussion was lively and interesting after all lectures. We also launched our new booklet “Time to Talk Periods”, aimed at girls age 10 to 14.

Educational Grants

In November, we also assessed the applications received for educational grants and we were very pleased to award 26 grants totalling €16,750. Congratulations to all award winners.

I would like to finish this article by wishing all of our members a very happy Christmas as we look forward to a bright and innovative new year.

Clinical Webinars 1-3: Key Takeaways

This piece provides a short overview of the first three webinars in our clinical webinar series, as mentioned in the CEO report on page four.

First Clinical Webinar: New Therapeutic Possibilities for Von Willebrand Disease (VWD) - Professor David Lillicrap

- Recombinant von Willebrand factor (VWF) is a licensed treatment and has been used for some years. It has very good potential for preventing certain types of bleeding, especially bleeding in the digestive system caused by fragile abnormal blood vessels (called angiodysplasia).
- Emicizumab has been used to treat some people with Type 3 VWD. A clinical trial is underway with this therapy.
- The drug Rondoraptivon Pegol (also called BT200) has been found to raise levels of VWF and factor VIII up to four-fold, and also increases platelet counts in people with type 2B VWD. The concern is that this may not be developed due to lack of funding.
- VGA039 is a monoclonal antibody (a lab-made protein) that targets protein S. By blocking protein S, it aims to affect the body’s clotting system. In early stage trials, this therapy has been demonstrated to greatly decrease the annual bleed rates (ABRs) of four individuals, with one individual going from an ABR of 928 to 112.9.
- While not all of the therapies are likely to come to market, the hope is that most will.

Second Clinical Webinar: Monitoring Liver Health in Haemophilia - Dr. Vincenzo La Mura

- There is a residual risk of liver disease progression after Hepatitis C clearance. The greater the damage to the liver before clearance, the higher the risk.
- A study was carried out in Milan on 119 people with haemophilia who had cleared Hepatitis C. It re-examined those who had been discharged from the hepatology service and found that only 2% could be safely discharged. 80% had at least one risk factor for chronic liver damage, among them 39% received a diagnosis of MASLD (fatty liver), and 12% had an alcohol intake putting them at risk for alcoholic liver disease. 18% had severe fibrosis, cirrhosis or liver cancer.
- To protect the liver, a person with haemophilia should limit or avoid alcohol, maintain a healthy body weight, avoid drugs and be cautious about the use of herbal products or dietary supplements which could damage the liver.

Third Clinical Webinar: Rebalancing Agents in Haemophilia and Other Bleeding Disorders

- Concizumab showed strong reductions in ABRs compared to no prophylaxis, with a median ABR of zero in several groups and 64% of participants experiencing no treated bleeds.
- Marstacimab demonstrated meaningful reductions in bleed rates for both those previously treated with on-demand or prophylactic treatment, though the results varied depending on the treament they had been using before.
- Fitusiran showed major improvements, including reductions in ABRs of up to 91%, and zero bleeds in more than half of participants in some studies.
- There is the potential to treat Factor V deficiency with Fitusiran and some other rare bleeding disorders with differing rebalancing agents.

WGBD Information Day

By Lena Byrne, Administrative Assistant

On Saturday November 8th, we hosted our final event of the year: Women & Girls with Bleeding Disorders (WGBD) Information Day. This event took place in the Grand Hotel Malahide where we have had many of our information days in the past. This event was organised with the intention of providing specified information to women and young girls with bleeding disorders on the issues they may experience and give them an opportunity to discuss their individual experiences with each other and with the speakers. The event was well attended, and we had a variety of ages in the audience. Thankfully, we had a broad spectrum of topics on the programme for the day so everyone could benefit from at least one of the talks.

As the attendees started to arrive, we met in the hospitality suite for a light lunch with tea and coffee. The first presentation of the day was by Dr. Beatrice Nolan, National Paediatric Consultant Haematologist at Children's Health Irealand (CHI) Crumlin. Dr. Nolan gave a brief overview of bleeding disorders, including inheritance, diagnosis and treatment, with some interesting facts and statistics covering VWD and rare bleeding disorders as well as haemophilia, which were appreciated by the audience. Dr. Nolan made some reference to pregnancy and the testing that can be done on a carrier or woman with a bleeding disorder while pregnant. This was later discussed in much greater detail by Dr. Mary Anglim from the Coombe. Dr. Anglim is a Consultant Obstetrician and Gynaecologist and she gave an excellent presentation on Conception and Pregnancy with a focus on women with bleeding disorders, including carriers. Dr. Anglim discussed the testing that is carried out on both the mother and the baby at various stages of the pregnancy and how the pregnancy and labour experience may differ for women with different bleeding disorders, such as the treatments that will be used during labour. Dr. Anglim also mentioned that the information is shared digitally between the NCC and the maternity hospital to ensure anyone who needs to access the notes can at any time.

During the afternoon we also had presentations from Dr. Michelle Lavin, Consultant Haematologist from the National Coagulation Centre (NCC) and Caitriona Ferry, Advanced Nurse Practitioner from CHI. Dr. Lavin's presentation discussed how and why the Know Your Flow document was created - to give women a reference guide for what's normal and what's not. This was intended to encourage women to get themselves checked if they were experiencing heavy bleeding as described in the Know Your Flow flyer. Dr. Lavin also discussed how very few women are involved in the research studies for bleeding disorders and how this needs to improve. Caitriona Ferry gave a short talk on paediatric care at CHI, what her role is and what to expect as a haemophilia patient at CHI.

The final talk of the day was nonclinical, and it was the most interactive session of the day. Sallyanne Brady, founder of The Irish Menopause, gave a great presentation on what you need to know about the menopause, what to expect and how to manage it. This session was very informative and led to a discussion of personal experiences between the ladies.

On behalf of the IHS staff, I would like to thank all of those who attended our events in 2025 and provided feedback to help us plan the next ones. We look forward to seeing you all in the new year!

October C

Adults Programme: By Roisin Burbridge, Publications, Website & Soc
Outreach Officer & Children'

Adults Programme

On a mild weekend in mid-October, approximately 220 members arrived at the beautiful Mount Wolseley Hotel for the annual October Members' Conference. After settling in with a buffet dinner on the Friday evening, members were all set for a full day of sessions on Saturday.

Saturday morning began with a well-argued debate between members Patrick Browne and Colm Walsh. The topic was 'Who Should Primarily Decide on My Treatment: The Consultant or the Patient?'. Patrick argued that consultants should primarily choose the treatment because of their superior knowledge in their field of medicine. However, he pointed out that they should do so with a patient-focused approach, while Colm argued that the patient should primarily decide because they know their own body and haemophilia. With a bit of discussion, both debaters agreed that ideally there would be a shared decision making process, in which both the patient and doctor come together to make the best decision for the patient themselves. When put to the vote, the majority agreed with Colm's side of the argument, though both debaters were fantastic.

Our next session 'An Update on Treatment, Followed by Personal Perspectives of Treatment' is one that we have repeated on several occasions at conferences such as this one because it is a great opportunity for members to hear lived experiences of various treatment options. This year, Dr. Maeve Crowley from the Cork Coagulation Centre gave a brief update on treatment and then members Conor Birkett, Jake Phoenix, Nathan Doyle, Tony McAffee and CEO Brian O'Mahony dicussed their experiences on various treatments. We heard feedback on longstanding treatments like Hemlibra and about new therapies like haemophilia B gene therapy, for which Brian was on a clinical trial.

We then had three coinciding sessions, enabling us to cover the important topics of mild haemophilia and VWD & RBDs. Our goal whenever possible is to include these topics at our major conferences. The high number of attendees at these sessions is proof that there is a major demand for these topics. Simultaneously, we had an interactive session in which parents, grandparents and people with bleeding disorders came together to discuss how haemophilia impacts their lives or their family's lives. Members sat around in a group and discussed topics such as how haemophilia has influenced their decisions around sport and activity, travel plans, career and what limitations haemophilia has had on their lives.

The last session of the day delved into the foods and dietary habits people with bleeding disorders should consider. It was an interactive way to end the day as speaker Didi De Zwarte engaged the audience, asking their opinions on whether a particular diet is healthy or unhealthy. It was a good way to learn about what is actually healthy and sustainable and what is just a fad.

After a day of lively discussions and interactive sessions, members relaxed with a three course meal and time spent with friends and family. The following morning, physiotherapist Paula Loughnane continued the theme of healthy living, discussing sports and bleeding disorders. Member, Jason Rossiter, joined her on stage to discuss his own experience as a serious sportsperson with haemophilia. Jason plays hurling for the minor Wexford team. His is a good example of shared decision making as he had worked out with Crumlin which treatment was best for his active lifestyle.

The morning finished off with a rousing session of line dancing, in which the facilitator Mr. Declan Flanagan got the whole family up and moving to various tunes from Taylor Swift to Shania Twain to Sham Rock! It was a rousing and memorable way to end the weekend!

onference

cial Media Coordinator. Children’s Programme: By Robert Flanagan,
’s Programmes Coordinator

Children’s Programmes

This year’s Children’s Programme at Mount Wolseley had a lovely atmosphere from the very start. The children arrived excited to spend time with friends they had made at previous conferences and happy to make new ones.

The little ones in the Creche were welcomed into a room full of a huge array of toys as well as cushions and a cot for nap time. It wasn’t long before they settled in, thanks to our wounderful volunteers, which allowed the parents to enjoy the adult talks.

The Cubs were bursting with energy as usual. The volunteers planned a jam packed day full of various activities for the kids to enjoy and they all went down very well, particularly the games after lunch. On Sunday, they enjoyed some time outdoors before finishing up with Arts & Crafts. Their energy was infectious, and the volunteers were kept on their toes all weekend.

The Kidlink group was the largest one at the Conference. The age range in the group allows for a diverse mix of fun, educational and challenging activities which the kids really enjoy. The debate session was the highlight in my opinion. The children spoke with confidence, made strong arguments, and even shook hands afterwards. The Haemo Hero Comic Studio on Sunday really brought out their creativity. It was lovely to see the connections the children had made in the younger groups still holding strong this weekend.

The Youth Group showed maturity, awareness, and a great sense of humour. They threw themselves into the Leadership Workshop and Team Building Exercises, and their Q&A with Brian O’Mahony felt more like an honest conversation than a formal session. It was great to include this to help bridge the gap between the youth and adult programmes, to make transition seemless and to hear the perspectives of the young adult members of the Society. The group asked thoughtful questions about the future and about treatment. We were also happy to be able to bring this group into a few of the adult sessions and hope to continue to do so in future.

Of course, the above programmes wouldn’t be possible without our amazing volunteers. They didn’t just supervise – they made the programme what it was and always made sure to include everyone. The energy that they bring to conferences creates the welcoming atmosphere that the children enjoy and look forward to at future events.

We can’t wait to see everyone at the next event and to make the programmes even more fun and exciting!

A Snapshot of Our

October Conference

AGM & Conference 2026

Venue: Slieve Russell Hotel, Co. Cavan
Date: March 6th - 8th

Adult Preliminary Programme

Friday 6th March

19.00	Buffet Dinner

Saturday 7th March

10.00 - 12.30	**Annual General Meeting**
12.30 - 13.30	Lunch
13.30 - 14.30	**Future Treatment Options for Haemophilia**
	Or
	Future Treatment Options Von Willebrand’s Disorder & Rare Bleeding Disorders
14.30 - 15.30	**Monitoring Liver Health**
15.30 - 16.00	Coffee Break
16.00 - 17.00	**The National Haemophilia Council – Mission & Vision for the Future, followed by an Open Forum with the Comprehensive Care Centre Teams**
19.15	Gala Dinner

Sunday 8th March

10.00 - 11.00	**Haemophilia: Is Mild the New Severe?**
11.00 - 11.30	Coffee Break
11.30 - 12.30	**An Update on Orthopaedic Advancements**
12.30	Depart

Calendar of Events for 2026

6-8 MAR	**AGM & CONFERENCE** SLIEVE RUSSELL HOTEL, CAVAN
3-5 JUL	**PARENTS CONFERENCE** MIDLANDS PARK HOTEL, PORTLAOISE
16-18 OCT	**OCTOBER MEMBERS' CONFERENCE** MOUNT WOLSELEY HOTEL, CARLOW

We will also be organising coffee mornings and small sessions and one-on-one sessions for gene therapy.

Christmas Pu

Name: ______________________________

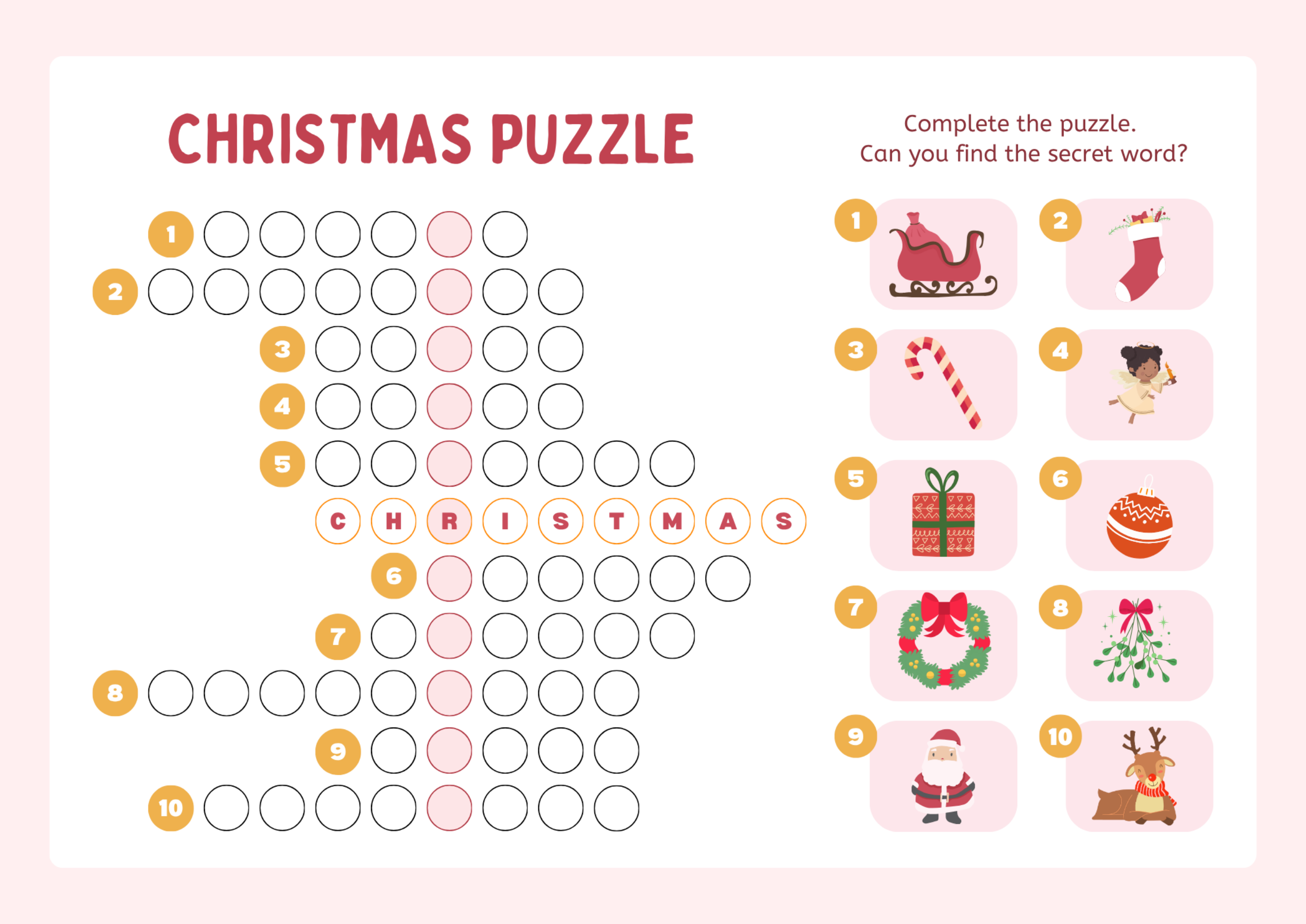
CHRISTMAS SNOW GLOBE

Draw a Christmas scene inside the snow globe.

CHRISTMAS MAZE

Help Santa reach his sledge!

uzzles For Kids



CHRISTMAS PUZZLE

Complete the puzzle.
Can you find the secret word?

CHRISTMAS COLORING

Notice

AGM & Conference

Our 2026 AGM & Conference is taking place the 6th to 8th March in the Slieve Russell Hotel in Co. Cavan. Registration opened on Monday 24th November and will close on Friday 16th January.

We have a full and engaging adults programme planned, which you can find earlier in this magazine, and the children's programme is packed with games and activities. Members will have received both programmes and a number of other documents in the post.

We are booking up fast so we recommend members who are interested in attending to register as soon as they can to avoid disappointment.

You can call the office on 01 657 9900 if you would like to register over the phone.

2026 Educational Grant Award Winners

We are delighted to announce the recipients of this year's educational grants. A big congratulations to all who received a grant! Below are the recipients of the first prize in each grant.

Maureen & Jack Downey Educational Grant
Jake Phoenix – €4,000

Margaret King Educational Grant
Tadgh Moriarty – €2,000

Father Paddy McGrath Educational Grant
Aoife Boylan – €1,000

eboard

Hyde Square Apartments

This is a reminder to members that we have apartments in Dublin 8 that are located close to both St. James's Hospital and Crumlin Children's Hospital. They are open to members with a bleeding disorder from outside of Dublin, when attending St. James's Hospital or Crumlin Children's Hospital for treatment, for a hospital appointment or for a review clinic. They are also open to immediate family members or partner of a person with a bleeding disorder when attending St. James's or Crumlin Hospital.

If you would like more information 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.

New Podcast Series: Gene Therapy - From Dream to Reality

The Irish Haemophilia Society are collaborating with the Canadian Hemophilia Society to put together a series of four podcasts, which will be available both in video and audio format. The podcast series is entitled 'Gene Therapy - From Dream to Reality' and looks at haemophilia B gene therapy from all angles. The first podcast is a clinical overview provided by Professor David Lillicrap from Queens University in Kingston Ontario. The second podcast is a discussion between four men with haemophilia who feel differently about getting gene therapy once it is available. The third is an interview with people who have already received gene therapy and the last is a discussion on the importance of shared decision making with regards to gene therapy.

Notic

Cork Mini Marathon Fundraiser

This year, myself and my family decided to take part in the Evening Echo Women's Mini Marathon in Cork to raise funds and awareness for the Irish Haemophilia Society. In September 2024, our eight month old little boy MJ was diagnosed with severe haemophilia B. It was a huge shock at the time as we had never heard of haemophilia before this, but since then the support, information and sense of community we have received from the IHS has meant so much to us as a family.

Thank you to Chloe O'Sullivan and all those who fundraised with her. They raised a whopping €3,692 for the Society!

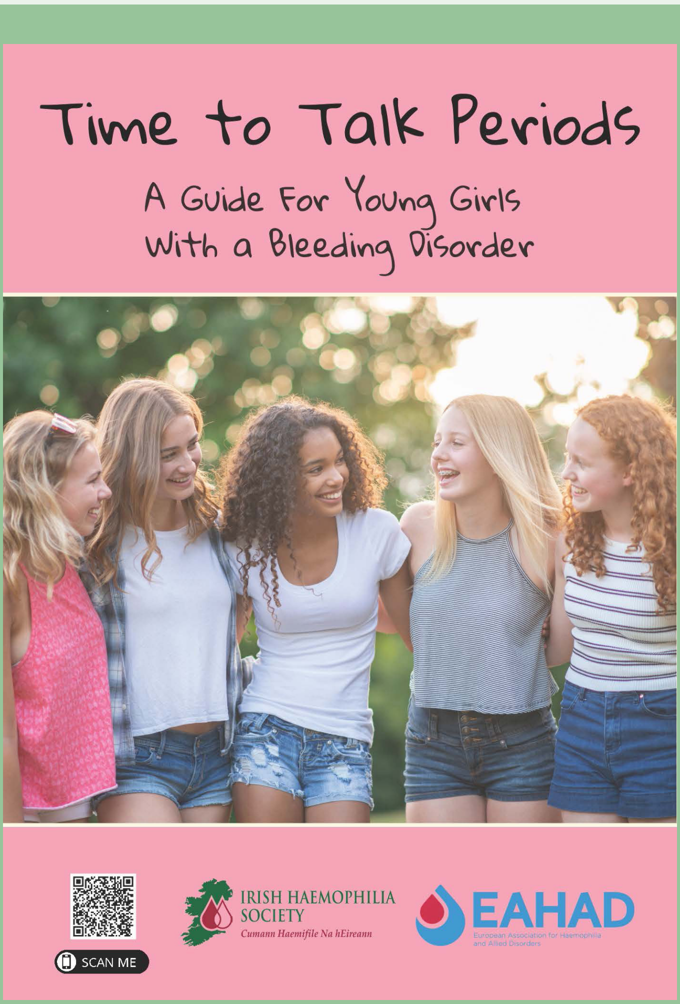
Rob Runs His Second Marathon

A massive congratulations to staff member Rob Flanagan for running the Dublin City Marathon in October!

This year, Rob ran the Dublin Marathon for the second time and he succeeded in his goal of running a sub-four hour race. Rob's time was 3 hours and 48 minutes.

Member, Traci Marshall Dowling also ran this year's marathon. Well done to Traci, Rob and anyone else who ran the marathon!

eboard



Time to Talk Periods

A Guide For Young Girls
With a Bleeding Disorder

SCAN ME

IRISH HAEMOPHILIA SOCIETY
Cumann Haemifile Na hEireann

EAHAD
European Association for Haemophilia and Allied Disorders

Hot Off the Press: New IHS Publications

We have recently produced two new publications - a booklet about periods for young girls and a dental leaflet for parents of young chidren.

The booklet is entitled ‘Time to Talk Periods - A Guide for Young Girls With a Bleeding Disorder’. It is aimed at girls and anyone who can menstruate aged 10-14 who are getting their periods for the first time. The goal of the publication is to educate girls about how their bleeding disorder can impact their periods, how to talk about any issues they may have and some tips for managing heavy periods, among other great information.

Our new dental leaflet, entitled ‘Dental Care for Children with Inherited Bleeding Disorders - A Guide for Parents’ aims to educate parents about how to care for a young child’s teeth. This leaflet was produced in collaboration with CHI Crumlin.

Thank You

The Board and Staff of the Irish Haemophilia Society would like to extend a heartfelt thanks to all of the volunteers who worked at our events this year, at our AGM & Conference, parent and child overnight event, Newly Diagnosed Information Day, October Conference and Women and Girls with Bleeding Disorders Information Day.

We would equally like to thank all who fundraised for us in 2025. You have all been a great support to us this year. Merry Christmas!

Hospital Opening Hours for the Christmas Period

National Coagulation Centre & H&H Assessment Unit - St. James's Hospital

NCC opening hours

Tuesday 23 December - Open as normal
Wednesday 24 December - Open until 1pm
Thursday 25 December - Closed
Friday 26 December - Closed
Saturday 27 December - Closed
Sunday 28 December - Closed
Monday 29 December - Open as normal
Tuesday 30 December - Open as normal
Wednesday 31 December - Open as normal
Thursday 1 January - Closed
Friday 2 January - Open as normal

H&H Assessment Unit opening hours

The HHAU will close for Christmas at 1pm on Wednesday December 24th and reopen for emergency care on Monday December 29th. There will be no service on New Years Day. Full service will resume Monday January 5th.

Haemophilia Clinics

No clinics from the December 24th to January 2nd. Clinics will resume from Monday January 5th.

In the case of emergencies, please call 01 410 300 (St. James's main hospital number) and ask to speak to the Haematology SHO or Consultant on call.

Merry Christmas From the I.H.S.

The office of the Irish Haemophilia Society will close for Christmas on Tuesday December 23rd at 3pm and will reopen on Friday January 2nd.

In the case of an emergency, please call 01 657 9900 where contact details for our emergency contact person will be found.

The Board and Staff of the Irish Haemophilia Society wish you a very merry Christmas and a happy and peaceful New Year!

Children's Health Ireland, Crumlin

Haematology/Oncology Day Unit

Closed Christmas Day and Stephens's Day.

Haematology/Oncology Outpatient Department

The outpatient department will operate as normal up until and including December 22nd. Closed the 23rd - 28th inclusive. Back open the 29th - 31st and closed on January 1st. Normal hours resume from January 2nd.

In the case of an emergency, please contact the hospital on 01 409 6100 and ask for the haematology registrar on call.

Cork Coagulation Centre - Cork University Hospital

Monday 22 December - Open (8am - 5pm)
Tuesday 23 December - Open (8am - 5pm)
Wednesday 24 December - Closed
Thursday 25 December - Closed (bank holiday)
Friday 26 December - Closed
Saturday 27 December - Closed
Sunday 28 December - Closed
Monday 29 December - Closed
Tuesday 30 December - Open (8.30am - 1pm)
Wednesday 31 December - Closed
Thursday 1 January - Closed (bank holiday)
Friday 2 January - Open (8.30am -3pm)

The Coagulation centre will reopen January 5th and resume normal opening hours 8am-5pm.

The CUH Coagulation Centre patients should contact the Haematology Registrar on call on 021 4546400 or attend ED when the centre is closed over the holiday period should they require any assistance or treatments.