

Haemophilia.ie



Magazine of the Irish Haemophilia Society

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



SCAN ME

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

Winter 2024 Edition

From the Editor



Merry Christmas to everyone! I hope everybody is looking forward to a break from work and a time for fun and relaxation!

We have a packed edition for you. As always, our CEO Brian O'Mahony will give an update on various bits and pieces including new therapeutic developments regarding the new enhanced extended half-life factor VIII, Altuvoct and the rebalancing agents Concizumab and Marstacimab. He will also update members on other IHS activities including our strategic planning preparation and our recent medical webinar series.

Following this, I will give an overview of some of the highlights of this year's October Members' Conference and Jim O'Leary will share some insights from the parallel session we held during the conference on von Willebrand and rare bleeding disorders.

Later, Hannah Byrne, our newest board member,

has written an article for us about her own background and her experience so far sitting on the executive board. This is well worth a read.

I conducted an interview with member Timothy Persse, who recently won the 2024 World Skills Ireland competition in Industrial Mechanics. A massive congratulations to him on this impressive achievement!

We have also included the first prize recipients of our educational grants, the AGM preliminary programme and some news in the noticeboard. We have also included a few Christmas puzzles for the kids to fill out!

We wish you all a very lovely Christmas and a happy new year.

Róisín Burbridge, Publications, Website & Social Media Coordinator

The Irish Haemophilia Society at a Glance



1.8k

Facebook Followers

313

Instagram Followers



63

I.H.S. Volunteers



1,463

X Followers



37

Planned Giving Contributors



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CEO Report



New Therapeutic Products

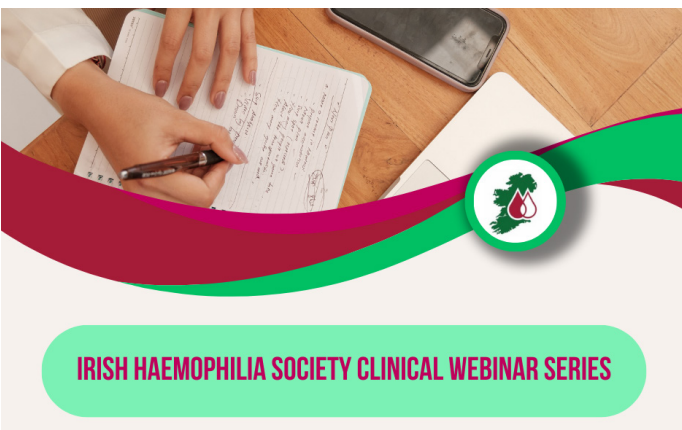
A new enhanced extended half-life factor VIII (FVIII) has recently been licensed by the European Medicines Agency (EMA). This product, with the brand name Altuvoct, is based on the currently used extended half-life (EHL) FVIII in Ireland - Elocta. The half-life of EHL FVIII products were generally limited up until now by the fact that they are linked to von Willebrand factor (VWF) in the circulation. Altuvoct gets around this by including in the product a number of fragments of the VWF molecule which frees Altuvoct from having to link to VWF in the circulation, thereby increasing the half life. There are also a number of additional proteins added to further increase the half life which in adults is extended from an average of 19 hours with Elocta to 47 hours. This means that the product can be used prophylactically once per week and at day four after infusion in adults, the FVIII level should still be in excess of 40%. At day seven post infusion the FVIII level should be approximately 15%. In children the half life extension is less and in those between six and 12 years, the FVIII level at three days post infusion is approximately 41% and at seven days 7%. In children under the age of six years, the FVIII level at three days post infusion is approximately 34% and at seven days is 6%. The overall estimated mean annual bleed rate in the clinical trial was 0.71, with 72% of adults or adolescents having zero joint bleeds and all target joints noted before the study commenced were resolved. In children 64% in the clinical trial had zero bleeding episodes, 84% had zero joint bleeds and 88% had zero spontaneous bleeds.

This product has the major advantages that it can be used less frequently than the current EHL FVIII

products and it also provides significantly higher protection against bleeding. The product comes in six potencies from 250 IU to 4,000 IU and can be stored in a refrigerator for up to four years and at room temperature for up to six months. This is a very welcome addition to the therapeutic options available for haemophilia A in Ireland. This product will replace Elocta for those currently on Elocta FVIII prophylaxis in the coming months. Individuals currently treated with Hemlibra will also have the possibility of considering a change to Altuvoct. This is an exciting development and our members will be aware that we have been tracking the development of products such as this one for several years. We also organised an information webinar on Altuvoct on November 14th which was well attended. The recorded video is available to view on our YouTube with a link. Please email roisin@haemophilia.ie to receive this link.

Members will also recall that we have been discussing the development of rebalancing agents for some time at our conferences and events and in publications. Four rebalancing agents, each of which inhibits a naturally occurring anticoagulant, were under development. These products should be capable of being used to treat haemophilia A or B with or without inhibitors. Two of these products have now been licensed by the EMA. Concizumab, with the brand name Alhemo, was licensed by the EMA in October for the treatment of haemophilia A or B with inhibitors in those aged 12 years or older. This product is a daily subcutaneous injection using a prefilled pen.

The second rebalancing agent, Marstacimab, under the brand name Hymravzi, has been licensed for the prophylactic treatment of haemophilia A or B without inhibitors in those at least 12 years old who weigh at least 35 kg. This will be a weekly subcutaneous injection. We anticipate that Concizumab will be licensed for haemophilia A and B without inhibitors and Marstacimab will be licensed for haemophilia A or B with inhibitors in the near future. These products are not yet available in Ireland, but will be looked at very carefully now for the future. Marstacimab and Concizumab are also the first licensed subcutaneous therapies for haemophilia B without or with inhibitors respectively. It is exciting to see several of the novel therapeutic options that we've been discussing with members at conferences and events for the last number of years finally becoming available. Another rebalancing agent, Fitusiran, remains in an ongoing clinical trial.



IRISH HAEMOPHILIA SOCIETY CLINICAL WEBINAR SERIES



The fourth rebalancing agent, Serpin PC, has just halted development due to the expected high cost of proceeding to the late stage clinical trial and competition from the already licensed rebalancing agents.

Strategic Plan

The Society has begun a new strategic planning process for the years 2025 to 2028 inclusive. To date, we have carried out a detailed analysis of all of our programmes, events, activities, publications and advocacy with the entire board and staff teams. We have surveyed members for their views in relation to our programmes, activities and thoughts on where our focus should be in the future. We were very pleased that more than 60 members responded. I've also met with the teams of each of the three comprehensive care centres to seek their views on potential synergy between the work of the Society and the work of the centres as we approach the next four years. The board and staff will meet for two days in early December to begin the process of drafting a new strategic plan and we hope to unveil this exciting plan at the AGM in March 2025. I would like to thank the members who took the trouble to complete the survey. This will be very useful in helping us to formulate our plans for the organisation.

October Members' Conference

Our October Members' Conference, held in the Midlands Park Hotel in Portlaoise, was very successful and well attended. As usual with this conference, the programme was a mixture of lectures, workshops and a debate. Lectures included one on new therapies and new opportunities from Dr. Beatrice Nolan, a lecture on VWD and rare bleeding disorders from Dr. Michelle Lavin and a lecture on travel and moving abroad from Robert Flanagan. There was also an information session

on the Society's strategic plan. There was a very interesting session and discussion between groups of members on different perspectives of living with a bleeding disorder. There was a very enjoyable debate between members and volunteers Gabriel O'Connor and Jake Phoenix on whether life should come first and bleeding disorder second or vice versa. The conference ended with an open forum which included board and staff members, who took part in a lively discussion and Q&A session.

Clinical Webinar Series

The Society hosted a series of clinical webinars primarily aimed at healthcare professionals both in Ireland and abroad from September to November. The webinars were also attended and enjoyed by Society members. A series of six webinars were held with state of the art lectures on the topics 'Update on Haemophilia A and B'; 'Update on Gene Therapy for Inherited Bleeding Disorders'; 'Women and Bleeding Disorders'; 'Update on Novel Therapies'; 'Update on von Willebrand Disease' and 'Future of Paediatric Care for Children with Inherited Bleeding Disorders'.

We were very pleased to host this excellent series of webinars featuring renowned clinical speakers from Ireland, Italy and the USA. We are grateful to Novo Nordisk for providing an educational grant for this activity. After each webinar, we compiled a specific e-zine which was sent to all those who had registered and to all members on our e-zine mailing list. We also provided a link to each recording in the specific e-zine which was greatly appreciated by those who were unable to attend on the evening of the webinars. The recordings are also available on our website. The number of people registered for each webinar varied from 74 to 92 and the links are also being utilised by other national haemophilia organisations.

Brian O'Mahony, Chief Executive

I am writing to express my sincere gratitude for the incredibly educational webinars by the Irish Haemophilia Society on blood clotting disorders. As a caregiver to my two-year-old son, who has haemophilia B, these sessions have been invaluable in enhancing my understanding and approach to managing his condition.

Timothy Makori, parent of child with haemophilia B from Kenya



October Members'

This year's October Members' Conference took place on a wet and windy weekend towards the end of October. This year, we congregated in the Midlands Park Hotel in Portlaoise.

One very positive aspect of this conference that stood out to me was how involved the youth group and young adult members were. In the first session of the conference two young members and active volunteers battled it out in a debate entitled 'Bleeding Disorder First, Life Second?' Gabriel O'Connor argued in favour of the motion and Jake Phoenix argued against. Both arguments were persuasive with Jake arguing that he has always taken part in the physical activities he wanted to and has not let his haemophilia stop him, while Gabriel indicated the importance of factoring in your bleeding disorder when making any kind of decision.

The Youth Group attended several of the talks of the adults programme as part of our initiative to incorporate more educational elements into their programme. They attended the youth debate, travel and moving abroad and later, they participated in our workshop session. For the workshop, participants were divided into relevant groups and asked to discuss a number of areas of their lives, from treatment to travel to career choices. The Youth Group and volunteers discussed these topics in their own group and came forward with many pertinent points and insights into their own experiences, shared by Darragh Lane, who, at a very young age, gave excellent contributions.

This was the first conference that we had the Youth attend several of the adults talks and we found it went down very well. We hope to keep up this momentum in future conferences. We have a new volunteer working group to ensure that young members' voices are heard and to revamp the children's programmes.



Two other sessions that went down particularly well were given by staff members of the IHS - Robert Flanagan and Brian O'Mahony. Rob's talk on travel and moving abroad was relevant to a wide cohort of members. He discussed short term travel and the importance of initiating contact with the closest haemophilia treatment centre (HTC) in the area you are travelling to. He also discussed longer term travel, relevant to young people who may decide to go to live in Canada, Australia or another similar country for a period. Rob encouraged everyone to contact him in the Society before going on a trip and he will do some important research for them on local HTCs and on anything else they might need.

The following day Brian O'Mahony gave a very insightful talk on his own personal haemophilia gene therapy journey. He went through his thought processes before making his decision, why he decided it was a good idea for him, what was involved, including the regular hospital visits and checkups and the positive consequences he has seen from the therapy. Brian was keen to point out that though it was the right decision for him, it may not be for someone else and it is vital for every interested person to engage fully with the Society and their doctors before making a decision on this.

Along with these more varied sessions, we also had two which really focused on developments in treatments. Dr. Beatrice Nolan of CHI Crumlin gave a detailed talk around new therapies and the new opportunities they bring. Simultaneously we ran a session on von Willebrand disorder and rare bleeding disorders. We are determined to run these at all our major events (October Conference and AGM) as it is essential that we give enough time and attention to bleeding disorders that aren't haemophilia. Jim O'Leary provides an update on this on the following page.



Conference Report

Along with the learning of the adults talks, there was the usual fun and games in the children's programmes, along with some educational elements. The Creche and Cubs played and danced. The kidlink had a particularly dynamic programme, with everything from arts and crafts to exercise and swimming. Holistic life coach Mel Taylor gave a Mind and Body Session where the group did meditation and learnt about wellness. Later on the Saturday they let off some of their boundless energy swimming in the pool and doing various races with board member John Stack during the exercise and nutrition session. The next day they showed off their artistic skills by creating 'Irish Haemophilia Society hats', as pictured on the left below. A group of Kidlink girls took their creative talents to a new level when they took to decorating some of the volunteers' t-shirts and

transforming the volunteers' runners into bright and colourful shoes worthy of a Nike vintage collection. Both Kidlink and the Youth group enjoyed learning about photography with volunteer Amber Kelly and it is through these workshops that the picture on the left was created!

Another memorable and fun aspect of this year's members' conference was the entertainment provided by Clown Jecca on Saturday night. Jecca engaged both adults and kids with potato sack races and various other competitions.

It was an informative and memorable conference!

Roisin Burbridge, Publications, Webiste & Social Media Corodinator



I had the privilege of attending this, our second ever combined session for members with von Willebrand and/or Extremely Rare Bleeding Disorders and again we were validated by the interest in the session and especially by the Q&A session which for the second year running meant we had to extend the time allotted for the session.

We were lucky to have the combined expertise of Dr. Michelle Lavin from the NCC and Dr. Beatrice Nolan from CHI Crumlin as speakers. Both are internationally recognised in their fields and we cannot thank them enough for their personal time on a busy Saturday.

Michelle outlined the current treatment landscape for VWD and in very understandable language defined the diagnostic process and difficulties encountered by medical professionals who have little training and inadequate follow up education on VWD or indeed on all bleeding disorders.

Dr. Nolan then gave an outline of the different ultra rare bleeding disorders whether they be factor deficiencies, platelet disorders or fibrinogen deficiencies. It is a vast subject which can take a lot of time to understand properly but Beatrice managed as usual to make it both informative and entertaining in her inimitable way.

We had persons with VWD, Glanzmans Thrombasthenia and a bleeding disorder of unknown cause in the room and they were very grateful to have the opportunity of connecting with others who have shared issues and the ability to question such great speakers.

The Q&A session which followed was full on and the time had to be extended to deal with the level of interest. Many issues were raised about young girls facing puberty, heavy menstrual cycles, fertility issues, menopause etc. This highlighted the need to have sessions such as this at all of our main conferences and where possible to reinstate some form of peer to peer spaces where people can exchange views on needs and hopes for the future.

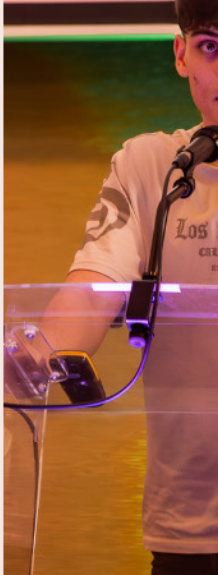
A big thank you to all participants, two great speakers and Seamus McDonald who kindly stepped in to chair the session.

Jim O'Leary, I.H.S. Board Member





October Conference Photography





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2024 EDUCATIONAL GRANT RECIPIENTS

A huge congratulations to all our educational grant recipients this year! Below are the recipients of the first prize in each grant.

Maureen & Jack Downey Educational Grant

Gabriel O'Connor €4,000

Margaret King Educational Grant

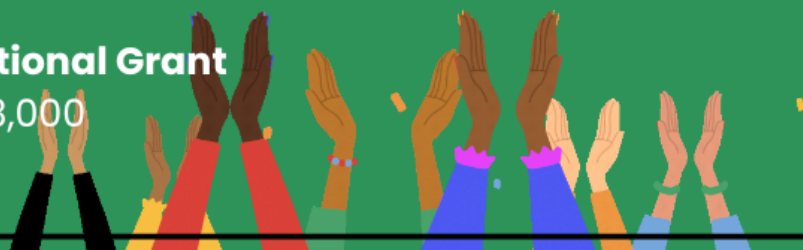
Jessica Byrne €2,000

Fr. Paddy McGrath Educational Grant

Jake Phoenix €1,500

Michael Davenport Educational Grant

Abdulhakim Mohd Nazir €3,000



Hyde Square Apartments



Hyde Square
Apartments



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

- People with haemophilia or related bleeding disorders from outside of Dublin, when attending St. James's Hospital or Children's Health Ireland, Crumlin for treatment, for a hospital appointment or for a review clinic.
- An immediate family member, a spouse, a partner and/or child of the person with haemophilia or related bleeding disorder from outside Dublin, when attending St. James's Hospital or Children's Health Ireland at Crumlin for treatment, for a hospital appointment or for a review clinic, or while a family member is an in-patient.

If you would like more info or to make a booking, please contact the office on 01 657 9900.

A nominal fee of €10.00 per booking, per night will be levied to offset the cost of cleaning and routine maintenance.



AGM & Conference 2025

Venue: Galway Bay Hotel

Date: 7-9 March

Preliminary Adults Programme

Friday 7th March

19.00 Dinner for full group

Saturday 8th March

10.00 - 12.00 Annual General Meeting

12.00 - 12.30 Strategic Plan 2025 - 2029

12.30 - 13.30 Lunch

13.30 - 14.30 Current Treatment Options for Haemophilia

OR

Current Treatment Options for von Willebrand Disorder & Rare Bleeding Disorders

14.30 - 15.30 Future therapies – An Update for People with Bleeding Disorders

15.30 - 16.00 Coffee Break

16.00 - 17.00 Update on Comprehensive Care Centre Audits 2024

19.15 Dinner & Awards Ceremony

Sunday 9th March

10.00 - 11.00 An Update on Clinical Trials

11.00 - 11.30 Coffee Break

11.30 - 12.30 Shared Care Between Two Treatment Centres

OR

Dental Care

12.30 Depart





My First Year On the

My earliest memory of the IHS is of a Sunday afternoon at the AGM - my parents had appeared to collect me from the kid's group and I was distraught. I had spent a weekend with my new friends, the leaders who I idolised, running around finding all the nooks and crannies to hide behind in a big hotel - and I had to go home?? It is safe to say I was not impressed!

Although over the years I have dialled back the dramatics of tears while leaving the hotel on a Sunday afternoon – I still have the same feeling every time I leave an IHS event. Except now, instead of missing the fun and games, I leave feeling inspired by the people that I spoke to, educated by the talks I attended, and privileged to be a part of such a great society. It was this reason and this feeling that kept me going back, and ultimately led me to wanting to be more involved in the Society.

I am a carrier of mild haemophilia - factor IX, and my younger brother, Adam, has haemophilia. My family has always been involved in the IHS. My nanny, Margaret Dunne, worked as office administrator of the IHS for many years, and from then on – they haven't been able to get rid of us! For as long as I can remember, I have been attending IHS events, with so many memories, particularly from being part of projects with the kids groups - from juggling scarves for our clown school performance to taking part in Kidlink's movie musical lipsync version of High School Musical.

Something that I have always been very passionate about, and what drove me to apply for the board, is education around the topic of bleeding disorders. Whenever I spoke to peers in school about my brother's haemophilia, they never knew what it was. In secondary school I distributed leaflets about women with bleeding disorders, and this passion followed me through to university.

I studied English and drama in college and for one of my final year assignments, we were given the task to write an excerpt from a play focusing on a painful moment in the past. While deciding what to write about, the infected blood tribunal in the UK was taking place, and was being spoken about on

TV. It struck me that this is the topic that I needed to write about. Watching the coverage of this encouraged me to become more educated and to read the documents from the Lindsay Tribunal. It was reading these documents, and understanding the history of the IHS through this, that motivated me to stand for the board the following March.

I was absolutely delighted when I was elected onto the board and am very grateful to be given the opportunity to help to shape the Society and ensure that it is always striving for the best for its members. Since I joined the board in March, I have enjoyed all of the meetings thoroughly, and feel very lucky to get to learn from my fellow board members, the IHS staff and the members.

The most insightful event that I attended this year was our meeting with Haemophilia Northern Ireland (NI). They are at a very different stage of development to the IHS. Being able to listen to their plans for the future, what their members needs were and where they needed support was very insightful and showed great promise for their organisation. Listening to the advice being shared between the two groups was a true testament to the ethos of the IHS. The IHS was open and willing to share any resources and advice with Haemophilia NI, which in turn will help to create a strong bond between both societies. The meeting was highly productive and I look forward to meeting the organisation again and sharing more ideas.

Being on the board has also allowed me to see how important it is to ensure the Society continues to cater to all members. With such a wide range of members there are many different needs and perspectives to look at. We are extremely lucky in the IHS to have a varied board with members who have all had different experiences with bleeding disorders or with family members who have bleeding disorders. Having this range of opinions and life experiences is extremely helpful in ensuring that all decisions made are looked at with a wide lens.

At the end of this year, we will be sitting down with the staff to create a strategic plan for 2025-2028.



the Executive Board



I am looking forward to helping to create a plan that reflects the Society as it is in 2024 and going forward. With haemophilia landscapes changing, new and better treatments becoming available, a new focus on ageing with haemophilia, rare bleeding disorders being studied, and more, the IHS and its role in peoples lives is constantly changing.

I hope I can help to contribute to the new strategic plan that will be reflective of this modern IHS, and will lead to many more years of families attending

events, people having access to the supports they need and an ever growing IHS community.

I look forward to seeing you all at the AGM in March...that is...if I make it through Brian's strategic planning in one piece!!

Hannah Byrne, I.H.S. Board Member



Interview with Me



I'M A
worldskills
Ireland2024
FINALIST

TIMOTHY PERSSE
INDUSTRIAL
MECHANICS
CO. MONAGHAN



Below is an interview with Timothy Persse, longtime member of the IHS and winner of the 2024 World Skills Ireland competition in Industrial Mechanics!

Can you tell us a bit about yourself and your connection to the IHS?

My name is Timothy Persse. I'm from County Monaghan. I have severe haemophilia B and I've been a part of the IHS for my entire life. I've been to lots and lots of the meetings over the years. I'm an apprentice engineer at the moment in phase three of the course Mechanical Automation and Maintenance Fitting.

Can you tell us about what it's like to do an apprenticeship?

The apprenticeship differs from a university qualification in that there's more time spent doing on the job training than in classes. It's a four year course with forty weeks in college and the rest in work full-time. It's paid at an apprenticeship wage and the time in college is also paid. For the college part of it I was in Dublin and the rest of the time I've been working at a local engineering firm called Gilmour Engineering. In the company we work with agricultural equipment, but we also work for the construction industry with concrete products and for the manufacturing industry with the likes of forklifts.

Is the work very physical?

Yes it would be quite physical. I'm on my feet from nine o'clock in the morning until six in the evening.

Did your bleeding disorder have an impact on the career you chose?

No, I don't think it did have an impact on it. I just chose to do what I liked and accepted that if there were consequences then I might have to change. With my factor being so good, I haven't had any problems with my work. I've had a few injuries but nothing major.

Why did you decide to study engineering?

Well I've always been interested in working with my hands. I started off doing construction but I didn't see myself going anywhere in that area. Then I did a level five course in engineering in conjunction with a local manufacturing company called Combilift - they make forklifts here in Monaghan. We have a farm at home and so after obtaining this level five I went on to get a green cert, which is basically how I got into the firm I'm in now. I went to college for two years in Ballyhaise Agricultural College and I did a level five in general agriculture and then a level six in advanced mechanisation. That was all fixing farm machinery and fabrication and things like that. In the second year of that course I had to do a placement in industry and I chose Gilmour Engineering and did four months there. I got on well doing everything I was put to and I enjoyed it. I asked my boss if he would be interested in taking me on as an apprentice and he was happy to.

How did you find living in Dublin for college?

I found it quite different because here at home we're out in the countryside and the next house is a five or ten minute walk away! I enjoyed my time in Dublin though. I stayed in a cabin in Santry on my own. I picked up climbing while I was there! I would go to Gravity in Inchicore twice a week and do bouldering with friends.

Could you tell us about your involvement with the World Skills Ireland Competition?

I was put forward for this while I was in college during my apprenticeship and I was accepted onto the preliminary stage where I had to go and do a



Member Timothy Persse

preliminary competition in June of this year. It was four hours over one day. I had to wait a while to see if I had got through to the main competition, which I did.

The main competition was held in the RDS Simmonscourt over three days. There were all different kinds of skills competing from car mechanics to carpentry to art design to hair and beauty. We had our own section where we had 16 hours to do everything and four hours to do each section.

I had to work in a number of areas, starting with hydraulics and pneumatics. I was given a drawing of a hydraulic circuit and I had to build it and get it to work properly. The judges then put a fault into it and I had to find the fault and fix it. Following this section, we had welding and fabrication. I had to make a frame, weld it up and drill holes in heavy plates and tap them so that a bolt would thread into them. When that was all done I had to do some pipe bending - bending the pipes to the specifications of the drawings. I also had to disassemble, inspect and rebuild a gearbox. The fabrication and pipe bending all came together in an assembly - the final part of the competition. It all had to fit together as per the drawing.

It was a tight competition between the six of us taking part but I managed to pull through and win!

**That's an amazing achievement!
Congratulations! That will be fantastic for your career and on your CV.**

I do think it looks good to prospective employers that I can produce quality work in competition settings.

So what are your plans for the future?

My plan at the moment is to finish my apprenticeship and to keep working where I am. There would also be lots of opportunities to work abroad when I have my full qualifications. Everywhere needs maintenance engineers.

Just one last question! Can you tell us about your farm?

We have horses at home and some cows. It's a very small farm - more a hobby than anything else.

We used to do a lot of horse riding. I don't have much time for it anymore because I'm working all day and it's quite late by the time I get home.

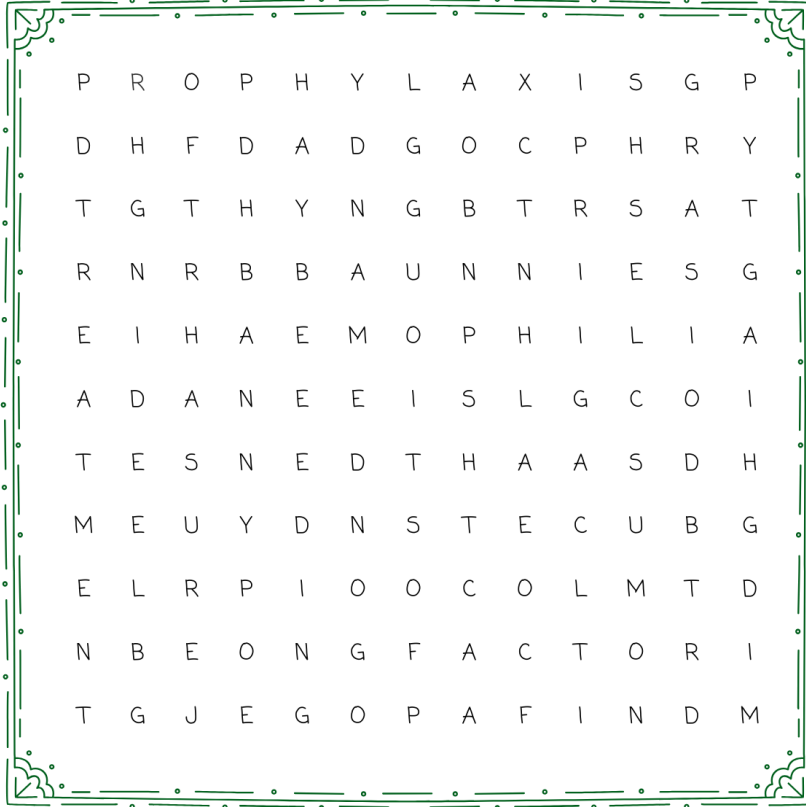
Thank you to Timothy for taking part in this interview and congratulations from all at the IHS for his amazing achievement.





Christmas Pu

IHS WORDSEARCH



Find and circle the words.
They go up, down, across and diagonal.

- haemophilia
- bleeding
- factor
- treatment
- joints
- muscles
- prophylaxis
- on demand

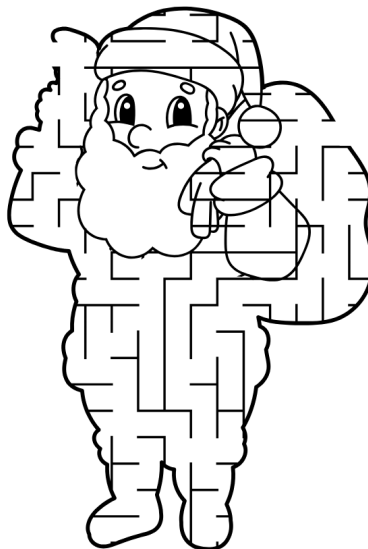


CHRISTMAS PUZZLES

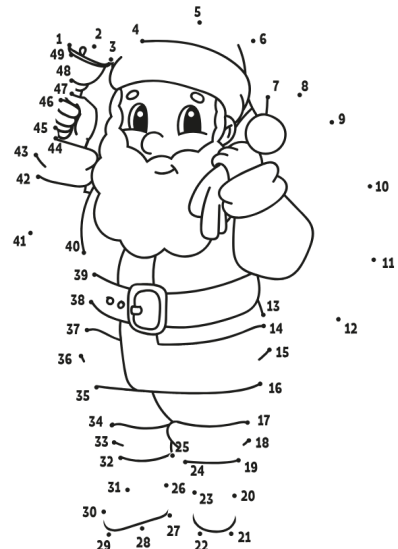
TRACE AND COLOUR



COMPLETE THE MAZE



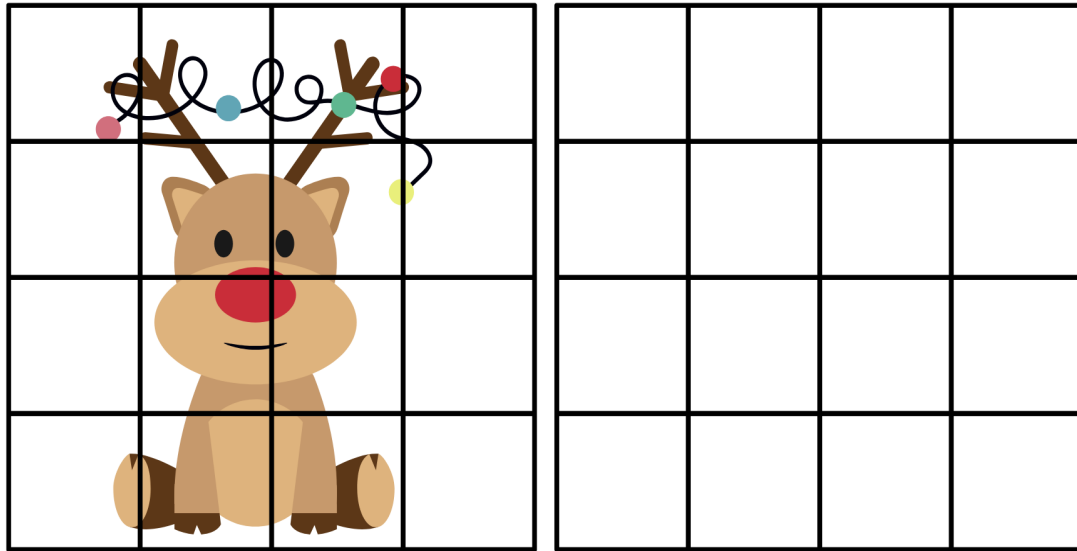
CONNECT THE DOTS





REINDEER DRAWING

Copy and draw the reindeer starting from left to right.

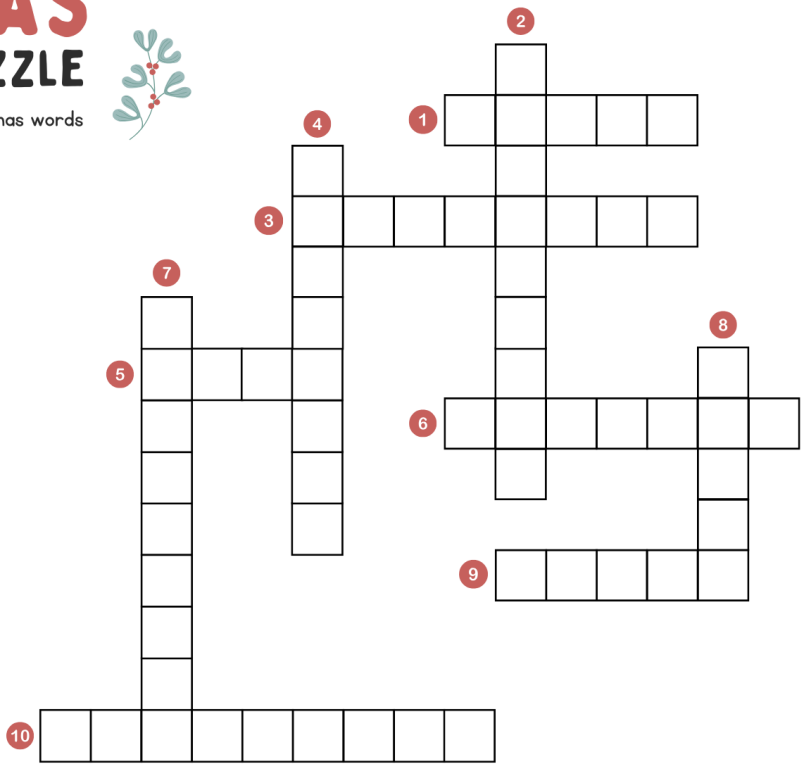


CHRISTMAS CROSSWORD PUZZLE

Look at the clues and write the Christmas words



- 1 
- 2 
- 3 
- 4 
- 5 
- 6 
- 7 
- 8 
- 9 
- 10 





Pilates & Physio Update

January marks a fresh start for our pilates and as the classes are starting at beginners level with a new instructor, this is the perfect time to join in! More information will follow but the classes will most likely take place on Wednesday evenings as before.

Our last physio class before Christmas will be on Tuesday 10th December. The classes will then continue with Mark McGowan every Tuesday evening from 7.30pm to 8.30pm after the Christmas break. Members, please note that these classes are open to men and women.

You can register for either of these classes by calling the office on 01 657 9900.



Volunteer Working Group: A Strong Start

On Friday, the 11th of October, our newly formed Volunteer Working Group held its very first meeting, setting the groundwork for a series of exciting changes to the Children's and Teenagers Programmes at our upcoming conferences and looking at other areas for improvement. This meeting marked an important step in ensuring our young members enjoy safe, educational, and enriching experiences during these key events. A second meeting took place on Friday, 29th November to look at the programme for our AGM next year.

Our working group is made up of six dedicated volunteers—Jess Byrne, Shannon Carey, Gabriel O'Connor, Meadhbh Laherty, Luke O'Leary, and Aoife O'Connor— with myself as children's programme coordinator, chairing and overseeing the group. We discussed our initial priorities and action plans. Both meetings have been fantastic and everyone is keen to contribute their ideas on improving the programmes to better suit the needs of all participants. Our discussions also focused on making our sessions more educational, creative, and inclusive for every young person involved. We brainstormed a wide range of activities, including arts and crafts, storytelling, interactive educational workshops about haemophilia, and much more. We also considered physical activities that will be inclusive, ensuring all children, regardless of ability, can participate. Safety and accessibility were highlighted as top priorities. The group discussed ways to enhance accessibility and outlined steps for a thorough risk assessment for each activity. We are committed to making these events welcoming for everyone, ensuring all activities are safe, fun, and inclusive. The group also began outlining training requirements for volunteers, ensuring they are well-prepared for their roles, covering areas such as child protection, emergency procedures, and adapting activities to suit individual needs.

Overall, our first two meetings have been a great success, filled with enthusiasm and fresh ideas. They set a positive tone for what's to come, and we can't wait to see these plans come to life in future conferences! Stay tuned for more updates as we move forward with this exciting journey. We are incredibly grateful to all the volunteers who are stepping up to make a difference. Together, we are creating experiences that educate, support, and bring joy to our young members and their families.

Robert Flanagan, Outreach Coordinator & Children's Programmes Coordinator





HIV/AIDs Documentary on RTE



RTE recently filmed and aired the documentary 'HIV/AIDs - The Story of HIV/AIDs in Ireland'. There is a section of this documentary on the haemophilia community and how HIV/AIDs affected them. Brian O'Mahony is interviewed in this part, discussing the devastation caused by the poor response to unsafe treatment in Ireland and the subsequent Lindsay Tribunal. Colm Walsh, IHS member, shares his own personal story of losing his brother Brendan to AIDs and the suffering this brought to his whole family and to himself.

The documentary also features the stories of those from other communities affected by the crisis, including the gay and transgender communities. It is available to watch on the RTE player.

A Special Thank You

On behalf of the staff and board, we would like to thank most sincerely each and every volunteer who helped out during 2024. Our conferences and events would not be possible without the dedication and support of our fantastic volunteers. We would also like to thank all those our did fundraising during 2024 and everyone who sent in donations to the Society. A special thank you goes to you all. Merry Christmas!





Hospital Opening Hours for the Christmas Period

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

NCC opening hours

Friday 20 December 2024 - Open
 Saturday 21 December 2024 - Closed
 Sunday 22 December 2024 - Closed
 Monday 23 December 2024 - Open
 Tuesday 24 December 2024 - Open
 Wednesday 25 December 2024 - Closed (bank holiday)
 Thursday 26 December 2024 - Closed (bank holiday)
 Friday 27 December 2024 - Open
 Saturday 28 December 2024 - Closed
 Sunday 29 December 2024 - Closed
 Monday 30 December 2024 - Open
 Tuesday 31 December 2024 - Open
 Wednesday 01 January 2025 - Closed (bank holiday)
 Thursday 02 December 2025 - Open

H&H Assessment Unit opening hours

The HHAU is closed on 25th and 26th December and 1st January.

Haemophilia clinics:

No clinics 24th December - 1st January. They will recommence on 2nd January.

Dental care:

Open for emergencies on 18th and 19th December. Also open for emergencies 2nd January.

In the case of emergencies, please call 01 410300 (St. James's main hospital number) and ask to speak to the Haematology SHO or Consultant on call.

Children's Health Ireland, Crumlin

Haematology/Oncology Day Unit

The day unit will operate as normal until Christmas Eve and is closed 25th and 26th December and 1st January.

Haematology/Oncology Outpatient Department

The outpatient department will operate as normal up until Christmas Eve and is closed 25th and 26th December. There will be skeleton staff then up until Thursday 2nd January. Normal hours resume from 2nd January.

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 23 December, 2024 - Open (8am - 5pm)
 Tuesday 24 December, 2024 - Closed
 Wednesday 25 December, 2024 - Closed
 Thursday 26 December, 2024 - Closed
 Friday 27 December, 2024 - Closed (bank holiday)
 Saturday 28 December, 2024 - Closed
 Sunday 29 December, 2024 - Closed
 Monday 30 December 2024 - Closed (bank holiday)
 Tuesday 31 December 2024 - Closed
 Wednesday 1 January 2025 - Closed (bank holiday)
 Thursday 2 January 2025 - Open (8am - 5pm)

Normal services from Tuesday 2 January 2024

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.



Merry Christmas from the I.H.S.

The office of the Irish Haemophilia Society will close for Christmas Friday December 20th 2024 and will reopen on Thursday January 2nd 2025 at 9am.

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!

