

Haemophilia.ie

Magazine of the Irish Haemophilia Society

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



SCAN ME

Spring 2024 Edition

From the Editor



Hello everyone! It's been all systems go here at the IHS over the past few months. Following the Christmas break, we started making arrangements for our AGM & Conference, which took place in early March. We are now preparing for our Ageing Conference, which is approaching in May of this year.

In February just past we welcomed a new staff member, Louise Davey, who we have really enjoyed getting to know and who has been a great addition to the staff team.

This edition of the quarterly magazine covers all the bits and pieces we have been involved in over the last few months. CEO, Brian O'Mahony's address in the coming pages, highlights some of the interesting aspects of the AGM as well as the Society's plans to run gene therapy educational programmes this year. Following this, board member Seamus McDonald and volunteer Luke O'Leary (who led the children's programmes at the AGM) report back on the adults and children's

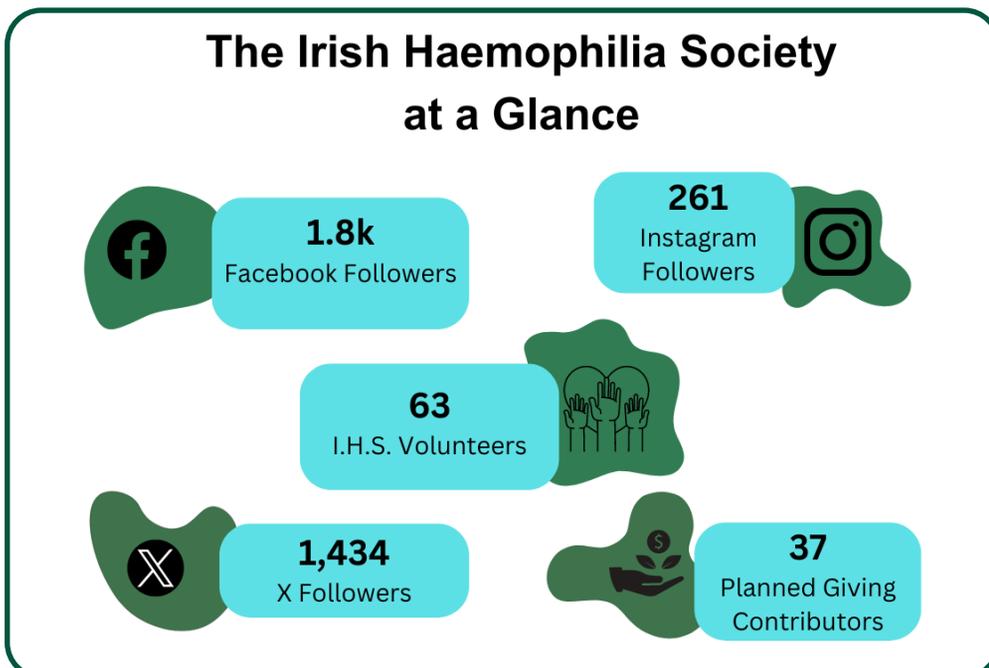
programmes. We have also included some of the fantastic photos taken by our photographer Joe Carr, who really captured the fun that was had by all attendees at the conference.

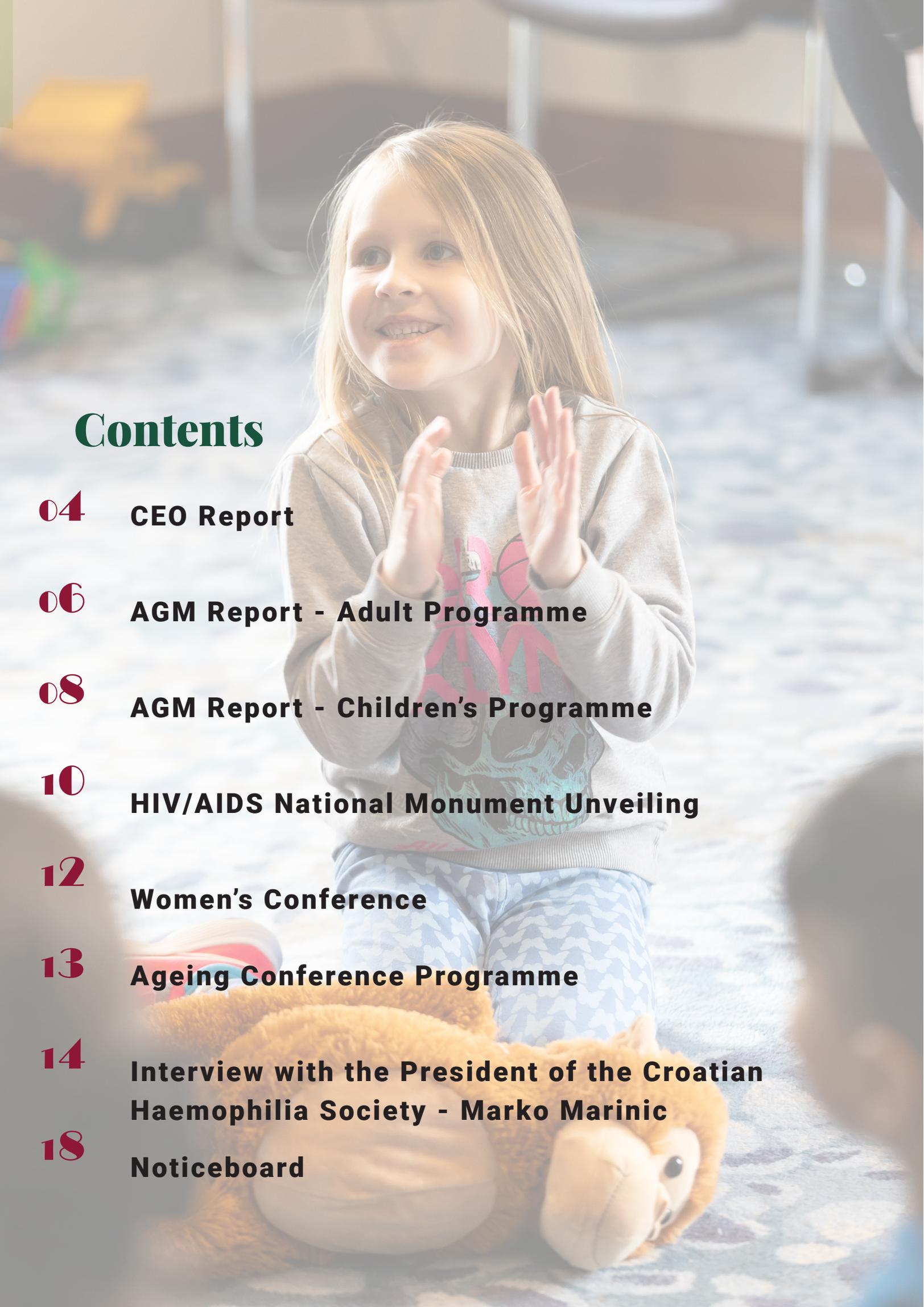
Following these pieces on the AGM, board member Jim O'Leary recounts the unveiling of the national AIDS memorial, which took place in the Phoenix Park in December 2023. Jim's piece is a highlight of the magazine, in how it eloquently sheds light on how meaningful the unveiling was to those who attended and the importance of the monument to all those affected by the HIV crisis.

After this piece is an interview I conducted with Marko Marinic, President of the Croatian Haemophilia Society. I found it very interesting to learn about haemophilia care in Croatia and also to hear about what another haemophilia society is getting up to, and I hope members do too.

Also included in this edition is the preliminary programme for our Ageing Conference and a section at the end of the magazine with some notices members may find interesting and useful.

Roisin Burbridge, Publications, Website & Social Media Coordinator





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CEO Report

AGM & Conference

We have just completed a very successful AGM & Annual Conference in the Slieve Russell Hotel in Cavan. I must admit we were somewhat anxious on the Friday morning when we saw snow on the ground and the weather forecast stating that among the places in the country worst affected was Cavan. Thankfully the snow cleared, and all of our members who were attending were able to make a safe journey. It was an excellent weekend. Lectures included an update on novel therapies by Professor Niamh O'Connell, pain management from Dr. Aine O Gara, the World Federation of Hemophilia (WFH) humanitarian aid programme by Dr. Assad Haffar, WFH Director of Humanitarian Aid, and an open forum discussion with Professor O'Connell and Dr Beatrice Nolan. A planned talk on resilience and mental health was replaced at the last minute by a panel discussion on resilience, featuring four members of the Society. I want to particularly thank the members who stepped up to take part in that panel for what was an excellent session.

For some time we have been conscious that there were no specific talks at our major conferences on von Willebrand Disorder or rare bleeding disorders. This was in a sense a catch 22 situation. As only a small number of people with von Willebrands or rare bleeding disorders attend our major conferences, we had to look at the feasibility of organising lectures for that small group in parallel sessions. On the other hand, the fact that there were no lectures for this group may have contributed to their low attendance at major conferences. This year at the AGM we had resolved to have a specific lecture on rare bleeding disorders and von Willebrand Disorder. This took place in parallel with the session update on novel therapies and was delivered by Dr. Beatrice Nolan. We were delighted with the success of this session, with over 20 people in attendance. The planned one hour session actually ran for two hours and featured lengthy discussion. It is certainly our intention to organise lectures on VWD and rare bleeding disorders at future major conferences in addition to hosting specific information days.



We are living in a country with excellent access to state-of-the-art haemophilia treatment. It was sobering for those in attendance to hear about the WFH humanitarian aid programme from Dr. Haffar. This programme started in 1996 at a small scale, where donations of factor concentrates, often close to expiry, were provided to developing and emerging countries. Given the fact that donations could not be predicted, these were often used at short notice for dental surgeries or emergency situations. Donations increased over the years and in 2015 a major step forward was taken when two companies committed significant volumes of production-run factor concentrates to the WFH for this programme. This has continued, with the addition of further companies donating products. Since the inception of the programme, over 1.7 billion international units of factor concentrate and in addition some bi-specific antibodies have been donated and provided to low and medium income countries. Since the expansion of the programme in 2015 more than 26,000 people with haemophilia have been treated, more than 6,000 are on low dose prophylaxis, more than 4,000 surgeries have been facilitated and treatment is being provided to people with haemophilia in 87 countries. Initiation of low dose, usually weekly, prophylaxis programmes in several countries has meant that the recipient children in those countries have a much better chance of growing up without severe joint damage. On a visit to Pakistan for WFH in 2019, I saw at first hand the significant impact of this programme, when a group of children with their parents came to the hospital for their weekly factor infusion, freeing them from the burden of regular bleeding episodes and fear of bleeding episodes. I have never seen children so happy to queue up to get intravenous injections. The very sad individual case studies highlighted by Dr. Haffar were sobering for the audience, who saw what the





reality of living with haemophilia is like for 70% of people in the world. The hope provided by the programme and the resolution of some of those cases show that no problem is insurmountable.

The open forum session highlighted continuing concerns from members, particularly about access to the H&H ward in St James's Hospital and the chronic parking issues at this hospital. Access for people with inherited bleeding disorders to the H&H ward was secured again last September but remains insufficient, with many cases of people with bleeding disorders unable to secure a bed there. This is an area we continue to work on and advocate for. It is clear that there are major problems for people attending St. James's in trying to park there. Lengthy queues form in the morning and afternoon to gain access to the underground car park, resulting in many people being late for appointments. This is a hospital-wide problem, one that does not only affect people with bleeding disorders. We continue to engage with the hospital on this.

At the conference dinner on Saturday evening the winners of the educational grants and the fundraiser of the year awards were announced and presented. The winner of the Brian O'Mahony Award for Outstanding Contribution to Haemophilia Care in Ireland was announced. The winner this year is Professor James O'Donnell. Professor O'Donnell has made, and continues to make, an outstanding contribution to the lives of people with bleeding disorders during his many years in St James's Hospital. At the National Coagulation Centre (NCC) and the Royal College of Surgeons, he led the innovative Irish Personalised Approach to the Treatment of Haemophilia (iPath) research programme over four years. He has published extensively on von Willebrand Disorder and is one of the world's leading experts in this condition. Professor O'Donnell could not be at the Conference and we will be arranging a presentation ceremony for him at the office in the near future.

Gene Therapies & Education Plan

Members will be aware that the first gene therapies for haemophilia A and haemophilia B were licensed in the course of the past year by the European Medicines Agency. Discussions

are taking place now and will be taking place in the coming months with the companies who produced these gene therapies in relation to reimbursement and possible availability in Ireland. Eligibility for gene therapy will be confined to those with severe haemophilia over the age of 18 who do not have current inhibitors or a history of inhibitors, who do not have antibodies to the AAV vector used to deliver the gene therapy (this is not a barrier with the haemophilia B gene therapy in most cases). Additionally, conditions such as severe unresolved liver disease will also be exclusion criteria. Ireland is a small country with a clearly defined population with severe haemophilia and a culture of education via meetings and discussions. The Society will be organising an education programme this year which will include written material, access to specific podcasts and meetings. The education programmes will be targeted to those eligible and

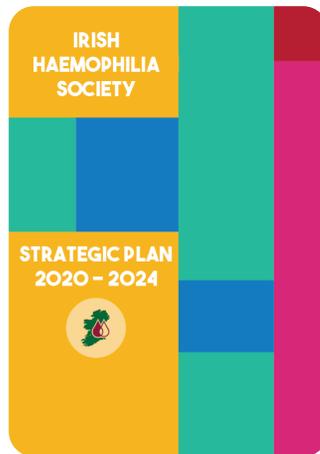
to those teenagers who may be eligible in the next three years. The decision as to whether to consider taking gene therapy is a very complex one which should not be taken lightly. Our objective is to ensure that we can provide information on gene therapy and to help every person with haemophilia who may wish to consider gene therapy to make a fully informed decision having considered the potential benefits, risks, knowns and unknowns and to ensure that people are fully aware of the monitoring and follow up requirements. Our current view is

that this can best be done by a series of small group meetings in venues around the country where individuals can get the information they require and have ample time to ask questions and explore their views on this important topic in a setting which facilitates discussion. We want to help members to prepare to engage fully and knowledgeably with the NCC and with the other comprehensive care centres if they wish to consider gene therapy. Details of our education programme and meetings will be announced at a later date.

Strategic Plan 2025-2028

Later this year, the Society will be developing our strategic plan for the period 2025 to 2028. We will be seeking your views on our future direction and activities via a survey, focus groups and through specific sessions at our October Members' Conference.

Brian O'Mahony, Chief Executive





The 2024 Annual General Meeting in the Slieve Russell Hotel almost didn't go ahead due to an unexpected snowstorm hitting the country and Cavan being one of the worst hit areas. Luckily, the weather didn't stop the IHS staff from heading off on the Friday morning to set up for what would be a very productive and enjoyable weekend.

The Friday evening buffet was well attended despite the difficult traveling conditions, and the evening was spent catching up with old friends and hopefully also some new.

The 35th AGM was opened on Saturday morning by our chairperson John Stack, followed by the adoption of resolutions and election of a governing body which saw Hannah Byrne elected to the executive board. While the votes were being counted, Barbara Wynne presented the secretary's report, Dan McIntyre presented the treasurer's report, John Stack presented the chairperson's report and finally Brian O'Mahony presented the CEO's report, before the 2024 AGM was closed.

Our first session of the weekend was broken into two groups. Professor Niamh O'Connell from the NCC in St. James's Hospital presented "An update on Current & Novel Therapies" while Dr. Beatrice Nolan from CHI Crumlin spoke on the topics of von Willebrand Disorder and rare bleeding disorders. With the ever-increasing availability of products and treatments for the bleeding disorder community, it is becoming increasingly difficult to keep up to date, but our experts both gave excellent talks which were very well received.

The second session of the day was "Pain Management", given by Dr. Aine O'Gara, consultant in pain medicine & Anaesthesia in St. James's Hospital. Dr. O'Gara gave a comprehensive talk on the types of treatments used in pain management, where and when they should be used, as well as the benefits and risks associated. I personally found the session very interesting and informative.

The final session on Saturday afternoon was an open forum with the comprehensive care teams. Professor O'Connell and Dr. Nolan answered questions from the floor ranging from queries regarding the H&H ward in St. James's Hospital and the new children's hospital to gene therapy treatments and the limited parking available for patients.





Sunday morning started off with a session on “WFH Humanitarian Aid Programme” by Dr. Assad E. Haffar, the Medical & Humanitarian Aid Director of the WFH. Treatment in the developed world has come a long way in the last 50 years, but many countries still face incredibly difficult challenges when it comes to accessing safe and effective treatments.

Due to unforeseen circumstances, Dr. Patricia Byrne, clinical psychologist for the NCC in St. James’s Hospital was unable to make it for her session, resulting in current and past board members stepping in for an impromptu panel discussion on “Resilience and Mental Health”. Although unexpected, the session was very interesting, with plenty of interaction with the audience. The discussion highlighted the psychological pressures on both patients and carers.

An IHS AGM wouldn’t be an IHS AGM without the kids’ groups. Therefore I want to extend a huge thank you to all the sensational volunteers and group leaders!! We couldn’t have these weekends without them!!

Seamus McDonald, I.H.S. Board Member

Awards Recipients



On the Saturday night of the AGM, several awards were given to their recipients. The 2023 Bill O’Sullivan Fundraiser of the Year Award was Maebh O’Sullivan from Derry. Maebh ran 100km in the month of March 2023 and raised a total of €1,577.61.

Our three educational grant recipients were Peter Walsh, Tadgh Moriarty and Aidan Clohessy, who are all doing excellently in their post-second level courses. We hope that their grants come in handy this academic year.

Finally, Professor James O’Donnell was awarded the Brian O’Mahony Award for Outstanding Contribution to Haemophilia Care in Ireland. Prof. O’Donnell is one of the excellent consultants at the NCC and is a lead expert on VWD in particular.

A huge congratulations to all award recipients.

While the adults were off getting the updates on all things haemophilia the kids were in their groups having all kinds of fun under the supervision of our fantastic and devoted volunteers.

The crèche (ages 0-3) had a ball playing with various toys and watching movies and even got to use the brilliant soft play room the hotel had to offer, which went down a treat.



Cubs (ages 4 – 7) were happy out with arts and crafts, making fantastic masks, playing musical games and even getting outside into the fresh air with a wonderful little nature walk before finishing out the weekend with a nice movie.



Our biggest group, our Kidlink (ages 8-12) had a busy and fun filled weekend. First, they unleashed their fashion potential while designing some t-shirts. Then they got to free their minds and take it all in with a mindfulness activity led by the fantastic Mel. The kids even got to let out their inner golf pro on the adventure golf course located on the grounds of the hotel and had plenty of fun in the pool.



Last but not least, the youth group (13 – 17) had a jam packed fun and educational weekend. They too had a session with Mel for mindfulness activities and got out onto the adventure golf course. They also had fun building their arguments and rebuttals while debating whether Ireland should be officially bilingual and if zoos should be banned. The youth also got to learn about health and fitness and pushed themselves with an exercise class led by our Chairperson John Stack.

Luke O'Leary, I.H.S. Volunteer





HIV/AIDS National

After a two-year project the long awaited monument to those who died from and continue to suffer from HIV/AIDS and their families, friends and carers was unveiled by Taoiseach Leo Varadkar in the Peoples Park, Phoenix park on Sunday 3rd December 2023 at 2 p.m.



Designed by artists Anaisa Franco and Michael R. Di Carlo who were in attendance, the Embraced Loop design uses an abstracted version of the HIV symbol, the red ribbon, to create an embrace of solidarity. Set in a secluded and restful part of the park, it will become a place to visit and reflect for all those whose lives were touched by HIV/AIDS in the past and present. The design was selected by open competition, judged by the Oversight committee consisting of representatives of HIV Ireland, Fast Track cities steering group, Irish Haemophilia Society (Brian O'Mahony), Ana Liffey Drugs Project, GOSHH, The Arts Council, An Office of Public Works (OPW) Principal Architect and an Art nominee.

Following our arrival at Farmleigh House on a very cold but bright afternoon we were assisted with parking and then bussed to the Peoples Park by very attentive OPW staff and very competent army drivers all of whom deserve our thanks and praise for the slick and professional manner in which the event was organised.

After an introduction and history of the project by the OPW who managed the process, Taoiseach Leo Varadkar spoke about the devastating effect of HIV/AIDS on people, families, communities and entire nations. He recognised the great advances made in prevention, treatment and care over the past 20 years especially. He thanked the oversight committee for their dedication in seeing this project realized.

Minister Roderick O'Gorman then spoke about the continuing efforts and donations by the Irish Government to fighting HIV/AIDS globally and support services at home.

The final speaker, Rory O'Neill, comedian and better known as Panti Bliss (self-proclaimed Queen of Ireland) gave a poignant but humorous account of his diagnosis of HIV at age 26 and the then bleak future he was faced with. He reminded us of the struggles with stigma and public perception which abounded at the time and the loneliness and isolation suffered by those affected and their families at that sad time in our still relatively recent past.



al Monument Unveiling



The Taoiseach then made his way from the enclosure to the monument and formally unveiled the monument and its dedication plaque. Press interviews were then allowed and photographs etc.

Approximately 150 people attended the event, including many who were affected personally and representatives of organisations who worked with and for those affected.

The Irish Haemophilia Society was well represented by both current and past board members, past employees and long-standing members of the Society.

St. James's Hospital and the NCC were ably represented by Prof. Niamh O'Connell and Prof. Colm Bergin. Old friends and supporters such as Michelle Tait (VHI and formerly HSE) were also in attendance.

After the unveiling ceremony we were again bussed back to Farmleigh House where drinks (hot and cold) and hot food were provided in ample quantities again by very attentive staff. The speakers and officials mingled with the attendees and a pleasant couple of hours were spent catching up with old friends and reminiscing about those who did not survive to be with us in person but only in spirit at this meaningful, sad but joyous occasion. May they rest in peace and forever be remembered. We went home after the event determined to make this peaceful spot and memorial a place of regular visit to meditate, reflect and remember our lost ones.

The Society plan to organise our own memorial event there, later in the year.

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



Women's Conference



Our Women With Bleeding Disorders Conference took place the 1-3 December 2023 at the Grand Hotel in Malahide, Dublin. It was very well attended by women and teenage girls with bleeding disorders and with carrier status. Despite the clear blue skies and invitingly calm waters beyond the conference window, each and every talk was well attended, with the audience too enraptured by the brilliant sessions within the conference room to think about going outside. We had an excellent group of speakers, including expert on the field of VWD and women with bleeding disorders, Dr. Michelle Lavin, Dr. Beatrice Nolan, Dr. Kevin Ryan and experts in health and fitness, Dr. Megan Kennedy and Didi de Zwarte. Topics covered ranged from treatments for women and girls suffering from heavy periods, childbirth and its aftermath, the many different symptoms of the menopause and much more. It was really inspiring to have such passionate speakers discussing women's health and the work they are doing to improve this vital area of healthcare.

While so much important information was shared at the conference, here are just a few pieces that particularly stuck with me:

- During Dr. Kevin Ryan's session, he talked about what pregnancy is like for women with bleeding disorders and their babies. He reassured those in attendance that bleeding issues are not common during the pregnancy, but that these issues may come about following delivery. He also assured everyone that natural births are generally very safe, even for babies with a severe bleeding disorder.
- Later, Dr. Michelle Lavin discussed heavy menstrual bleeding (HMB) and pointed out that the younger generations are getting better at not putting up with this issue and are seeking care for HMB, while older generations are more likely to ignore this.
- Dr. Beatrice Nolan and Dr. Michelle Lavin debunked a few myths about the pill, such as the idea that teenage girls should be on lighter pills. Instead, some may require a stronger pill due to their bleeding disorder. They also debunked the myth that people must take a break between each packet of pills. Finally, they stressed that parents should be open to considering the pill for girls with heavy periods, no matter what their age, as it can be a very effective treatment to reduce HMB and related symptoms. They explained that the image of the pill as a contraceptive method can put parents off and highlighted the importance of thinking of it as hormonal therapy instead.
- The next day was all about living and eating well. Dr. Megan Kennedy explained that the more exercise and physical activity you do the better, but also assured that even a small amount makes a big difference. Afterwards, dietitian Didi de Zwarte discussed the plate model as an alternative to the food pyramid, whereby half the plate would be salad, vegetables and fruit, a quarter would be carbs and a quarter protein. In the plate model, dairy is not included on the plate itself but is placed on the side.

We hope those who attended enjoyed the conference and we appreciate all the constructive feedback we received. It is fantastic to be able to put on an event focused solely on women's health, as women too live with bleeding disorders and yet are rarely the centre of the conversation.

Roisin Burbridge, Publications, Website & Social Media Coordinator



Ageing Conference

Date: 17 - 19 May, 2024

Venue: Meadowlands Hotel, Tralee, Co. Kerry

Preliminary Programme

Friday 17th May

19:00 Dinner

Saturday 18th May

10:00 - 11:00 **Comprehensive Care & Ageing in Ireland**
Speaker: Dr. Cleona Duggan, Consultant Haematologist, Cork University Hospital

11:00 - 11:30 Coffee Break

11:30 - 12:30 **Ageing & A Positive Mental Outlook**
Speaker: Dr. Patricia Byrne, Psychologist at the NCC, St. James's Hospital

12:30 - 14:00 Lunch

14:00 - 15:00 **Treatment Choices as You Age**
Speaker: Professor Mike Makris, Director of the Sheffield Haemophilia and Thrombosis Centre

15:00 - 15:30 Coffee Break

15:30 - 17:00 **Panel Discussion**
Panel: Professor Mike Makris, Mr. David Page, Canadian Hemophilia Society & Professor Niamh O'Connell

19:00 Dinner

Sunday 19th May

10:00 - 11:00 **Ageing & Bleeding Disorders in Canada: A Personal Perspective**
Speaker: Mr. David Page

11:00 - 11:30 Coffee Break

11:30 - 12:30 **Preparing for Ageing (Nursing Homes, Benefits & Entitlements etc)**
Speaker: T.B.C.

13:00 Lunch

Interview with the President of the Croatian Haemophilia Society, Mr. Marko Marinic

Tell us a bit about yourself.

I am the President of the Croatian Haemophilia Society and I have severe haemophilia A with inhibitors. I have a PhD in an interdisciplinary field of science, combining social sciences and the humanities. I work in the Institute of Social Sciences Ivo Pilar in Zagreb where I am a scientific advisor. My field of expertise is researching the quality of life of people with disabilities and chronic diseases, people with haemophilia and other vulnerable groups in society. I also work on bioethical issues. My master's thesis was about euthanasia from the perspective of a person with a disability and my PhD was about the value of human life in contemporary society from the perspective of a person with a disability.

Previously, I gave lectures at the University of Zagreb but since I became the President of the Croatian Haemophilia Society and have many other engagements, I have not had time to teach at the University as well. At the moment, my primary job is research. As soon as I have more time, I will return to teaching at the University. In the meantime, I give lots of lectures at different types of meetings, especially at meetings in the field of haemophilia, such as at the EHC Conference last September in Zagreb.

Do you like speaking at these meetings and events?

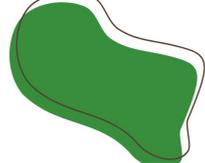
Yes, I think it is always good to share your experience as it may be helpful for someone to hear. But I also love listening to other people and their perspectives. It's only when we pool our knowledge and experiences together that we can really make changes and improve the quality of life of people with haemophilia.



What is care for inherited bleeding disorders like in Croatia?

We are happy with the level of haemophilia care in Croatia, which has improved significantly in the last 10 to 15 years. We now have all available therapies, everything that exists in Ireland, Denmark and England for example. Almost everyone with severe haemophilia is on prophylaxis. We do still struggle with all the consequences of having had a lack of adequate therapy in the past. People above the age of 40 have lots of problems with their joints. But luckily, we have all the therapy options now so we will try to fix what can be fixed.

In relation to other bleeding disorders, we share the same problems as all western countries. New therapies for other bleeding disorders, especially for the extra rare ones, lag behind the therapies for



haemophilia. We hope that the science catches up soon.

We have excellent national haemophilia centres in Croatia, both for adults and children. Our haematologists are well known worldwide and all the knowledge that is available in the field of haemophilia is available for us in Croatia, through them. Also, our nurses and physiotherapists are excellent, as is everyone else working in the centres.

What services and supports does the Croatian Haemophilia Society offer?

We try to help all our members to the very best of our abilities. We have many projects, most of them organised on a voluntary basis. Unfortunately, we do not have an office in Zagreb yet, but I am hopeful that by the end of this year we will get one from the city of Zagreb. This will make things easier.

We have lots of projects. For example, we have scholarships for university and high school students. We organise many workshops on different topics. One of our main educational projects is our summer camp. Last year a total of 280 people participated in our camp, where we organise many different lectures, workshops and exercises over the course of the four days. We always bring all participants in the care of haemophilia to the camp, from state representatives to doctors, psychologists, physiotherapists, nurses, social workers, and many other experts, to adults and children with bleeding disorders. We are all in the same place at the same time. Lots of problems can be solved when the various stakeholders of haemophilia care come together like this.

Recently, we conducted a quality-of-life survey to find out what additional work we need to do in order to improve the quality of life of patients with haemophilia here in Croatia. We published a book with the results of this research. We also publish an annual magazine "Hemofilija", which includes information on many different topics. In 2022 there was an interview published in the magazine with Brian O'Mahony, which can be read in English or Croatian on our website.

One of the results of the quality-of-life research showed that some people with haemophilia are not very physically active. Because of this, we started a project to increase the physical activity

levels of our members and to try to reduce the occurrence of diseases such as cardiovascular disease. For this, we sent blood pressure monitors to all our members, with instructions on how to measure their blood pressure and what they should do if they find that it is high. Also in 2022, we started the project of Nordic walking and sent Nordic walking sticks to all our members. Nordic walking is known to be a really good way to increase physical activity levels. We organised educational sessions in different parts of the country involving the Croatian Nordic Walking Association. After that, one of our nurses from the haemophilia centre became a Nordic walking instructor and now she is leading lots of walking activities for the Society. She gave a talk at the EHC conference on this last September.

We also conduct communication campaigns at a national level. For instance, we organise activities for World Haemophilia Day to increase the knowledge of bleeding disorders in the general public. We also have a strong media presence around this time. For instance, this year I am invited to speak on our national Croatian TV channel for World Haemophilia Day.

The Croatian Haemophilia Society also organise a lot of workshops. Recently, there was change



in the legislation around disabilities and so we will organise an online workshop to explain and discuss this.

You mentioned you don't have an office yet. Do you have employees or is everyone a volunteer?

No, we do not have employees. Actually, I am employed part-time, just for few hours a week. The biggest part of the work that is done by the Society is voluntary.

Could you tell us about your role as President of the Croatian Haemophilia Society? What's your favourite part of your job?

Well, I have been actively involved since the Society's foundation in 1992 but for the past seven years I have been the President. I try to listen to the needs of our members and fight for a better quality of life for them.

I really like the part of my work that involves communicating with others. I see all our members as a part of my extended family, and I love sharing moments with them.

Of course, we do also have a steering committee. There are seven of us on the committee. We always share out tasks and decide who will oversee which project. The committee is made up of people with different relevant connections with our community. We have people with haemophilia on the committee, parents of children with haemophilia and parents of von Willebrand Disease and other bleeding disorders. We have a youth representative and we also have people from other cities in Croatia other than Zagreb.

How often would the Steering Committee meet?

According to the Statute, it should meet four times a year, but in reality we meet much more than this. We have intensive communications and if we have a project coming up, we meet every single week if necessary.

Could you tell us a bit about your role on the Board of WFH?

Two years ago, I was honoured to be elected to the Board of Directors of the World Federation of Hemophilia. It is an exceptional organisation which has done so much good for people with bleeding disorders all over the world. WFH has many extremely valuable projects. We are truly fortunate to have such an engaged umbrella organisation. The Board decides on a lot of activities and I'm happy to be a part of this. As I mentioned already, we all have something to offer to the general story.

Is there a particular project or projects that WFH is working on that you are especially excited about?

It's difficult to choose just one or two. WFH implements many different projects and each of them is important. One of my favourites is the Humanitarian Aid Programme to reach people in countries that do not have good haemophilia care. Through this aid they can gain access to therapies they would otherwise not have had. I remember from my own past what it's like to live with haemophilia without therapy, so I know how extremely valuable this programme is and how much good it has done in low income countries.

I would also like to mention the educational mission of WFH. For example, WFH recently



developed a shared decision-making tool to help people with haemophilia choose their own therapy, particularly important as more and more therapies are now available.

I'm also really looking forward to the WFH World Congress in Madrid in April. I know there will be many lecturers who will present the latest results of new therapies but also many other topics that are important to individuals with bleeding disorders. Many of my 'blood brother' friends are attending from different parts of the world. I'm really looking forward to seeing those I already know and those I will meet for the first time there. I expect that it will be an excellent meeting.

Could you tell us about your experience in Ireland two years ago for the Inhibitors Summit?

I have actually been to Ireland several times. The last time was in December 2022. The reason I keep coming back is because I really like Ireland, and especially because of the people and my friends there with haemophilia. I'm thinking especially of Brian O'Mahony, Declan Noone, Jim O'Leary and many, many others from the Irish Haemophilia Society.

During my last visit in 2022, I had some health problems and had to be hospitalised at St James's Hospital for 6 days. I must say that even that experience, surrounded by friends from EHC and the IHS, and excellent physicians and staff, went really smoothly. I would like to take this opportunity to thank everyone for their help during this time. The staff at the IHS came to the hospital to see how I was doing. I really felt that I was part of your community.

I also want to add that the IHS is one of the leaders in haemophilia advocacy worldwide. Your NMO is doing a really excellent job and you provide a great example to NMOs around the world of how a good organisation should work. Just keep going!

Finally, I want to finish by extending my heartfelt greetings to all of my Irish friends. Stay healthy and well and I hope to see you soon!

Many thanks to Mr. Marko Marinic for taking part in this interview!





Noticeboard



New Staff Member

We would like to welcome our new Administrative Assistant Louise Davey to the organisation. Louise started with us on 19th February and will be the first point of contact when you call the office. Louise will also be assisting with logistics for events and will take bookings for our apartment facility at Hyde Square. We wish Louise well in her new role and the team in the office look forward to working with Louise.



Thank You to our Volunteers

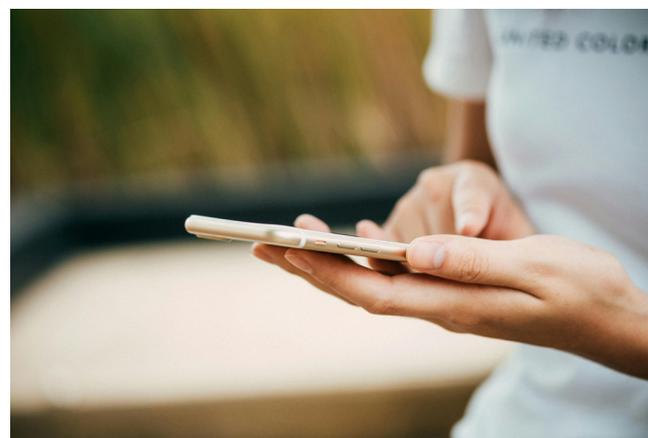
We would like to extend a huge thanks to our volunteers, who not only make our bigger conferences possible, but who also ensure that the children and teenagers have as memorable a weekend as their parents. The volunteers create a fun and safe atmosphere for the kids and really give their all to these conference weekends.

An especially big thanks to Luke O'Leary, who led the programmes at our recent AGM like a real pro and made sure everything ran smoothly.



Introduction to Haemophilia Booklet

We are publishing a new edition of our Introduction to Haemophilia booklet. The booklet provides easy-to-follow information on many important topics such as the first signs of haemophilia, main sites of bleeding, treatment and growing up with haemophilia. It is particularly useful to parents of children who are newly diagnosed with haemophilia and to those who do not have prior knowledge of the condition. We will be distributing this booklet to the haemophilia centres and it will also be available to view on our website.



My Indici

The MyIndici portal is a great way for people with bleeding disorders to access all of their healthcare records in one place, as well as other benefits. The NCC have put together a very helpful video to assist people in navigating the portal.

Find it at this web address: <https://haemophilia.ie/wp-content/uploads/2024/02/myindici-plus-messaging-video.mp4>

Photos from Our AGM





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