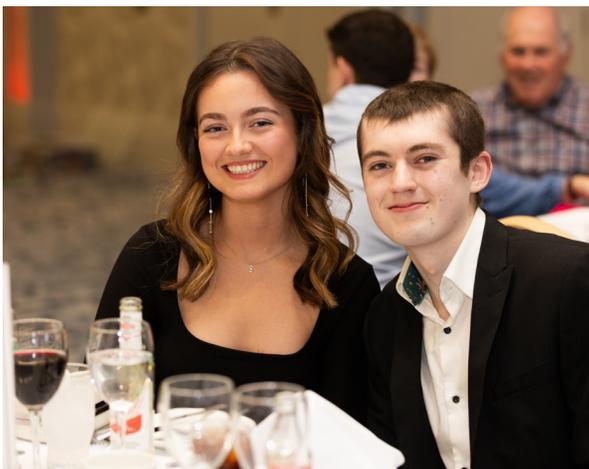


IRISH HAEMOPHILIA SOCIETY

Representing people living with haemophilia, von Willebrands & other inherited bleeding disorders



ANNUAL REPORT 2024



Haemophilia.ie

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Services We Provide

 EVENTS	 OUTREACH	 RESOURCES	 APARTMENT FACILITY	 ADVOCACY
We hold 2-3 major conferences a year, along with smaller conferences and day events.	We make regular contact with our members, aiming to call them at least once a year. We also conduct home and hospital visits.	We produce 4 quarterly magazines each year, along with other informational materials.	We have two 'Hyde Square' apartments in Dublin 8, for members coming up to Dublin for a hospital appointment at St. James's or the children's hospital.	We advocate for people with all inherited bleeding disorders.

A Message from Our Chairperson

By John Stack, Chairperson

The year 2024 was another very productive year and one where the Irish Haemophilia Society (IHS) continued to offer a wide range of services and supports to all our members with bleeding disorders.

Who We Are and What We Do

The IHS represents the interests of people with haemophilia and related bleeding disorders, by providing the following services:

- Education & Information
- Conferences and Events
- Advocacy
- Publications
- Educational Grants
- Accommodation to members attending hospital (St. James's or CHI, Crumlin)
- Outreach & Support Services
- Online exercise classes

Additionally, we collaborate with the medical teams within the health service, namely the National Coagulation Centre (NCC), CHI Crumlin, Cork University Hospital (CUH), and clinicians within the field of haematology.

Executive Board and Staff

At the end of 2024 our Executive Board comprised 7 members: Seamus McDonald (Vice Chairperson), Barbara Wynne (Secretary), Dan McIntyre (Treasurer), Jim O'Leary, Mary Clare Delaney, Hannah Byrne and myself, John Stack (Chairperson). Breda Quealy, Paul Dunne and Aislinn Farrelly stepped down during 2024. I would like to thank them for all their hard over many years on the board. The board meet once a month with eleven planned meetings throughout the year. Whilst all board members are very dedicated and committed, many work full time, have

Staff Team



Brian O'Mahony
Chief Executive



Debbie Greene
Administrator /
Office Manager



Nina Storey
Finance Coordinator



Robert Flanagan
Outreach & Children's
& Youth Programmes
Coordinator



Roisin Burbridge
Publications, Website
& Social Media
Coordinator



Lena Byrne
Administrative
Assistant

families or are in full-time education. In some instances, board members are juggling all these commitments at once.

During 2024, six staff: Brian O'Mahony, Debbie Greene, Nina Storey, Rob Flanagan, Roisín Burbridge and Lena Byrne did a tremendous job in keeping the organisation functioning.

Without the work of the Executive Board and staff, we could not have the type of Society that we do. I cannot commend, and thank them for, the work they do, highly enough.

Conferences & Events

Conference participation continued to be strong in 2024. We value and are very proud of the inclusive nature of our conferences. Details of all of our conferences and events can be found in the Secretary's Report.

Outreach

Outreach is an important function provided by the IHS. Our Outreach Coordinator, along with other staff members, are happy to give support over the phone or by arranging a home or hospital visit, be it just for tea and a chat, or advise on how best to address a particular issue that may arise for a member. Please remember to contact us if you need any kind of support.

Educational Grants Awards

We were delighted to be able to offer support to those who want to continue their education. Each year, the Society provides educational grants for students in third level education. Qualifying courses range from PLC-type courses, up to degree and post-graduate study. In 2024, we had 16 people apply for our educational grants with a total €21,000 paid out. We do hope that these grants offer support to those in college, to assist with associated costs.

Online Exercise Classes

In 2024, we continued with our online exercise and pilates classes. These are an extremely valuable toolkit for many people in our Society, particularly the older population. We would encourage you to consider signing up for these classes.

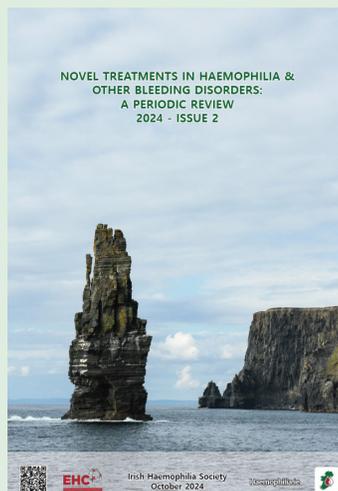
Fundraising and Donations

Fundraising, planned giving and donations are an important source of income for the Society. I cannot emphasise enough how grateful we are for the efforts people make to fundraise for the Society. Every event is important and shows a connection to the Society. No event is too big or too small and I thank each and every one of you who have supported the society through fundraising and donations. Thank you all so much for all your efforts.

Hyde Square Apartment Facility

The apartment facility has proven to be such an important service for our members, for those travelling from outside Dublin for hospital appointments. If you would like to avail of using these apartments, please contact the office and our staff can explain to you how they work.

Publication



Communications

The IHS website continues to be the main online point of information on the Society. Our publications can be viewed and downloaded from the website. In 2024, we continued to publish e-zines and to post important messages on our social media platforms, mostly using X, Instagram and Facebook.

Volunteers

I can't thank the volunteers enough for the trojan work they do at the conferences and events each year. Although we have an excellent cohort of volunteers, we could always use more, particularly as demand for our events increases. The more people who attend, the more volunteers we need. One of the main justifications for additional volunteers at our events is that it would allow volunteers to attend some of the adult programme. If you would like to volunteer for the Society, please contact the office.

I am also pleased to inform you that during 2024, a 'Volunteer Working Group' was set up with key objectives being to evaluate, improve and revamp the Children's & Teenagers programmes at our conferences, to look at and ascertain educational and training requirements for volunteers, to nurture involvement with the Society, to cultivate friendships and to encourage social activities for our volunteers.

Twinning

The twinning programme with Jordan culminated in 2024 when a delegation from the Jordanian Society, as well as some medical professionals, visited Ireland. They spent time with the Society and also with the Comprehensive Care Centre at St. James's Hospital and the Children's Hospital in Crumlin. They also visited a member's home to see how more treatment is managed in Ireland. Overall, the visit was a great success, and we wish our colleagues well in the future.

Strategic Plan

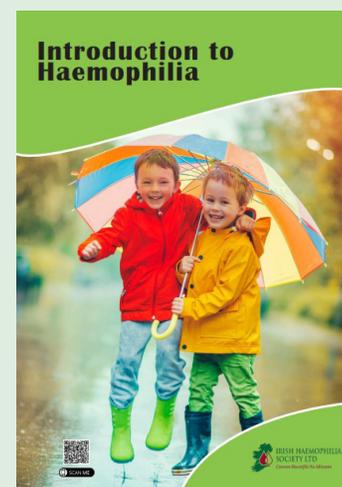
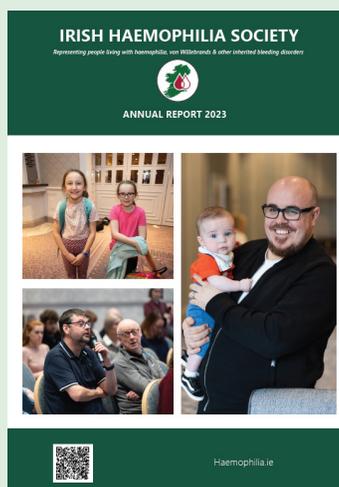
For the staff and board, 2024 culminated with a weekend at Dunboyne Castle Hotel to prepare our next strategic plan. This was a busy and intense weekend so I would like to thank the staff and board for giving up their weekend to complete it. If you would like a copy of our strategic plan, please contact the office.

Conclusion

It is a joy to be part of the wonderful community that is the IHS. Each year we seem to grow, and the standard of care remains second to none. The advocacy by the staff of the Society plays a crucial role in ensuring that we maintain that high standard of treatment. Novel therapies, including extended half-life products and gene therapy, aim to further improve the standard of treatment available to our community and improve the quality of life for everybody, both people with bleeding disorders and their carers and families. Each year the IHS staff, executive board, volunteers and members work very hard to ensure the Society delivers on its promise to provide support to all our members. The year 2024 was no exception.

Finally, I want to thank you, our related members, for continuing to engage and interact with us. Doing so ensures that the Society continues to grow and develop in the right direction, and I'm delighted that 2024 proved to be another successful year for the IHS.

ons of 2024



Thank You to Our Volunteers in 2024



Twinning with Jordan



Honorary Secretary's Report

By Barbara Wynne, Secretary

At the 35th Annual General Meeting of the Irish Haemophilia Society, which was held in the Slieve Russell Hotel in Cavan on 2nd March 2024, the incoming Governing Body of the Society were elected as follows:

- Hannah Byrne
- Paul Dunne
- Aislinn Farrelly
- Seamus McDonald
- Dan McIntyre
- Jim O'Leary
- Breda Quealy
- John Stack
- Barbara Wynne

At the first executive meeting following the AGM on 27th March 2024, the following officers were elected:

- Chairperson John Stack
- Vice-Chairperson Seamus McDonald
- Honorary Secretary Barbara Wynne
- Honorary Treasurer Dan McIntyre

On 15th May 2024, Mary Clare Delaney was co-opted onto the board.

In the period since the last AGM, eleven executive board meetings took place.

Conferences & Events

AGM & Annual Conference

The AGM & Annual Conference took place over the weekend of the 1st to 3rd March in the Slieve Russell Hotel in Cavan. The programme consisted of talks and lectures on topics such as: novel therapies, gene therapy, the WFH's humanitarian aid programme, pain management and an open forum. The conference was very well attended.

Topics Covered at Events in 2024

Treatment for Mild Haemophilia

Pain Management

Open Forum

WFH Humanitarian Aid Programme

Treatment Options As You Age

VWD & RBDs

Strategic Plan Discussion

Ageing with a Positive Mental Outlook

Novel Therapies

Personal Perspective of Getting Haemophilia Gene Therapy

Youth Debate: Life First, Bleeding Disorder Later

Ageing Conference

An Ageing Conference took place over the weekend of 17th to 19th May in Meadowlands Hotel in Tralee. The programme consisted of lectures on comprehensive care and ageing, a positive mental outlook, treatment choices and a panel discussion. This cohort of members really enjoyed this conference, in particular the peer support aspect of the event.

Von Willebrand Disorder (VWD) & Rare Bleeding Disorders (RBDs) Information Day

An information day for people with VWD and RBDs took place on Saturday 20th July in the Grand Hotel in Malahide. The programme consisted of updates on treatment and treatment expectations and a panel discussion. Professor James O'Donnell and Dr. Beatrice Nolan spoke at this event. Attendance was excellent on the day.

Mild Haemophilia Information Day

An information day for people with mild haemophilia took place on Saturday 14th September in the Grand Hotel in Malahide. Although attendance was not great, the lectures given by Dr. Beatrice Nolan were excellent and extremely informative.

October Members' Conference

The October Conference took place over the weekend of 18th to 20th October in the Midlands Park Hotel in Portlaoise. The programme consisted of workshops on travel and moving abroad, new therapies, a debate, an interactive workshop on perspectives of living with a bleeding disorder, a lecture on VWD and RBDs and an open forum session. This conference went very well.

Webinars

The Society organised a series of six clinical webinars during the final quarter of 2024. Topics and speakers were:

- An update on haemophilia A & B – Professor Niamh O'Connell
- An update on gene therapy – Dr. Radoslaw Kaczmarek
- Women and bleeding disorders – Dr. Michelle Lavin
- An update on novel therapies – Professor Flora Peyvandi
- An update on von Willebrand disease – Professor James O'Donnell
- The future of paediatric care for children with bleeding disorders – Dr. Beatrice Nolan

These webinars were a great success, and it is hoped that we can do some more in the near future.

World Federation of Hemophilia (WFH) Congress 2024

Some board and staff members attended the WFH Congress which took place in Madrid in May 2024. Staff member Roisin Burbridge attended the WFH Global National Member Organisation Training which took place a couple of days prior to the Congress. Our Chief Executive gave talks on gene therapy, real world access and economics at this event and reports on all sessions attended were published in the summer magazine.

Comprehensive Care Audits

Under the auspices of the National Haemophilia Council, peer reviewed audits of the comprehensive care centres took place in May with a team of auditors from abroad.

Twinning

Three representatives from the patient organisation in Jordan visited Dublin in July along with four healthcare workers who were part of the centre twinning programme, along with the WFH programme manager. Two separate working/training programmes were put together with involvement from all our staff and some board members. It was a very productive visit and marked the formal end of this twinning programme.

Strategic Plan

In December the board and staff met to draft a new strategic plan for the organisation for the period 2025-2028. Prior to this, surveys were carried out and collated to ensure we meet the needs of members in the plan.

Physio/Exercise & Pilates Exercise Classes

The physio/exercise and pilates classes continued last year with 25 physio classes taking place and 39 pilates classes taking place.

Outreach

Over the course of 2024, 1,117 calls were made to members to offer support and assistance. Phone calls were also made to non-members who contacted the office looking for support. During 2024, the Society continued to give support to Ukrainian and Syrian refugees with bleeding disorders.

Publications, Social Media & Website

During 2024, the Society produced the following publications: four quarterly magazines, an annual report, two novel therapies publications and an updated version of our introduction to haemophilia booklet. Social media platforms continued to work well for the organisation. The Society continued to have a strong presence online with 2,036 followers on Facebook, 1,472 on X and 316 Instagram followers. The Society continued distributing the electronic magazine e-zine, which has proved to be very popular, so much so that we have 487 people signed up for this. In 2024, a total of 34 e-zines were produced. A lot of work was also done on content for our website.

Hyde Square Apartments

The apartment facility for members was occupied as follows in 2024:

- The one-bedroom apartment was occupied for 27 nights.
- The two-bedroom apartment was occupied for 69 nights.

Fundraising

A total of €3,717 was raised through fundraising in 2024.

Donations

A total of €6,274 was donated in 2024 by members of the organisation.

Planned Giving

A total of €15,509 was raised by planned giving in 2024.

Volunteers

A volunteer working group was formed in 2024 and met twice in the last quarter of 2024. Along with our Children's Programmes Coordinator Robert Flanagan, this group set the groundwork for improvements to the children's and teenagers programmes, along with preliminary plans for training and social activities for our volunteers. We would like to thank our 56 volunteers who gave up their time to work at the AGM and October Conference in 2024. Our volunteers do very important work for the Society, and we are very grateful to them.

Grants & Awards

Educational Grants

A total of 16 educational grants were awarded in 2024, totalling €21,000. This followed an application, review and selection process including a rigorous scoring system by the sub committee.

- The Maureen & Jack Downey Educational Grant recipient - Gabriel O'Connor.
- The Margaret King Educational Grant recipient - Jessica Byrne.
- The Father Paddy McGrath Educational Grant recipient - Jake Phoenix.
- The Michael Davenport Educational Grant recipient - Abdulhakim Nazir.

Awards

- The Brian O'Mahony Award for Outstanding Contribution recipient - Dr. Michelle Lavin.
- The Gerry O'Reilly Courage Award recipients - Alex and Elayna O'Sullivan.
- The Bill O'Sullivan Fundraiser of the Year – Emma Neary, Sandra Neary, Norma Jean Kelly.
- The Dr. Barry Harrington Dental Award - Dr. Amelia Conlon Batey.

Staff

Administrative Assistant Louise Davey joined the Society on 19th February 2024 and resigned on 27th June 2024. The Society were understaffed during 2024. However, the Society staff continued to work together as an excellent team. A recruitment drive proved successful during the third quarter of 2024, with Administrative Assistant Lena Byrne joining the Society on 29th July 2024.

The current staff and roles are as follows:

- Brian O'Mahony (Chief Executive)
- Debbie Greene (Administrator & Office Manager)
- Nina Storey (Finance & Fundraising Coordinator)
- Robert Flanagan (Outreach & Children's & Youth Programmes Coordinator)
- Roisin Burbridge (Publications, Website & Social Media Coordinator)
- Lena Byrne (Administrative Assistant)

Society Representation

The Society is represented on a number of external bodies as follows:

- National Haemophilia Council – Brian O’Mahony & Debbie Greene
- Haemophilia Product Selection Monitoring and Advisory Board – Brian O’Mahony, Matthew Finnie & Radoslaw Kaczmarek
- Haemophilia HIV Trust – Brian O’Mahony & Nina Storey
- Disability Federation of Ireland – Brian O’Mahony & Debbie Greene
- Consultative Council on Hepatitis C – Brian & O’Mahony & Debbie Greene

The Board would like to express its thanks to the staff for their continued commitment and for representing the best interests of the IHS. We also wish to acknowledge with gratitude all donations received during the year and the efforts of our fundraisers, and we also wish to thank most sincerely the great work of all of our volunteers.

Thank You to Our Fantastic Fundraisers in 2024!



VHI Women’s Mini Marathon



Charleville Golf Raffle Fundraiser



Busking for the IHS



Carol Service

The Year in Review from the CEO

By Brian O'Mahony, Chief Executive

Therapeutic Innovations

The year 2024 was another year of therapeutic innovation for the haemophilia community in Ireland. In late 2024 the enhanced extended half-life factor VIII, Altuvoct, was made available for people with haemophilia A currently on prophylaxis with extended half-life FVIII concentrates. The process of switching people to Altuvoct was underway before the end of 2024. This will provide greater protection from bleeding and higher trough levels, with anticipated troughs of 40% after four days and 15% after seven days in adults. This should be a big advantage especially for those who are very physically active and participating in sports, encompassing a greater number of people than in the past. In addition, during the year, the rebalancing agents Concizumab (Alhemo) and Marstacimab (Hympavzi) were licensed. All of this innovation also leads to a requirement for more complex educational processes and shared decision-making between clinicians and people with haemophilia. The Society will play a full and active role in this process.

Centre Audits

The three comprehensive care centres at St. James's Hospital, Children's Hospital Ireland (CHI) at Crumlin and Cork University Hospital (CUH) were audited during the year using a peer reviewed audit process by a team of six auditors from abroad, including a patient expert. These external audits are an invaluable assistance in identifying and highlighting gaps in the services and in resources required for treatment and care. When these gaps and resource deficits are pointed out by an external team from abroad in a formal report, this typically adds great value to our joint advocacy with the centres and the National Haemophilia Council. The last five years has seen a record number of new patients with severe bleeding disorders in Ireland. This included six children with haemophilia who arrived from Gaza in December. We were delighted to be able to welcome these children and families from Gaza who are leaving a situation of indescribable suffering and coming to a country with first class haemophilia care. We will continue to offer them our support as they settle into living in Ireland.

Events in 2024

We ran a number of very successful events during the year. This included our AGM and Annual Conference, an Ageing Conference, information days on von Willebrand disorder (VWD), rare bleeding disorders (RBDs) and mild haemophilia and our October Members' Conference. The AGM and Annual Conference programme included updates on current and novel therapies, VWD and RBDs in the next 5 years, lectures on pain management, resilience and mental health and an open forum with the comprehensive care centre teams. It also included a very interesting lecture on the World Federation of Hemophilia (WFH) humanitarian aid programme delivered by their director of humanitarian aid. The Ageing Conference included sessions on comprehensive care and ageing in Ireland, ageing and a positive mental outlook, treatment choices as you get older, a perspective from an ageing Canadian patient and ageing perspectives around the HAA card. The von Willebrand and rare bleeding disorders information day included a treatment update on VWD and RBDs. The mild haemophilia information day included an update on treatment of mild haemophilia and separate discussions on women's issues and men's issues. Finally, our October Members' Conference included sessions on new therapies and new opportunities, travel and moving abroad, VWD and RBDs, mindfulness and a personal perspective on gene therapy. This more informal conference also included a very enjoyable youth debate on whether life should come first and bleeding disorder second or vice versa, an interactive workshop on perspectives of living with a bleeding disorder, a discussion and preparation session for our upcoming strategic plan and an open forum discussion with staff and board members.

The events continue to generate extremely good attendance and the big weekend conferences are typically booked out months in advance.

Clearly the educational model that we use which places a premium on getting face to face information and not just gleaned from booklets and publications is one which is greatly appreciated by our members. The ability to bring together the entire family and the educational approach taken from early childhood onward is also a big advantage in education and in community building.

Webinar Series

In the course of 2024 we also embarked on a new initiative where we organised six high level clinical webinars with expert speakers and professional presentations using a conference organising company. These webinars were on the topics of an update on haemophilia A and B, novel therapies, gene therapy, VWD, the future of paediatric haemophilia care and RBDs. The speakers were expert clinicians from both Ireland and abroad. The webinars were primarily aimed at a clinical audience and had clinicians, healthcare professionals and patient leaders joining from many countries including Europe and the United States. Immediately after each webinar, a specific e-zine

publication was produced with a summary of the webinar content, illustrations of some of the key slides and a link to the recording of the webinar. All six webinars are available to watch on the Irish Haemophilia Society website. This is an initiative which we hope to be able to repeat in the future if funding allows.

Twinning Programme

Our twinning programme with the Jordanian Society for Haemophilia and Thallasaemia ended in 2024. This was a challenging twinning programme for both organisations as it coincided with the COVID pandemic and the post-COVID period. Face to face meetings were difficult and therefore much of the content had to be delivered online. Our aim was to help the Jordanian society to increase their capacity as an organisation. This was greatly assisted by the fact that the main haemophilia treatment centres in their capital Amman were also twinned with the national coagulation centre (NCC) at St. James's and CHI Crumlin. We were able to work synergistically to give the best outcomes to the programme. The final activity of the programme was a visit by both the clinical and patient organisation teams to Dublin during the year. With the patient organisation, we covered topics including finance, volunteers, children's programmes, action planning, governance, publications, social media and event planning and management. We also made it clear that we would assist them with any future national tender for procurement of factor concentrate or other haemophilia medications where we have expertise in Ireland.

HIV/AIDS

A documentary on HIV and AIDS in Ireland was broadcasted by RTE during the year. The documentary highlighted the unveiling of the national HIV memorial in late 2023. The Society were involved in the selection and commissioning of that memorial. The haemophilia community was represented in the documentary by our member Colm Walsh who lost his brother to HIV, and I represented the Society perspective. We were strongly of the view that it was important that the experience and work of the Society and the impact of HIV on the community should not be forgotten in any new documentary in this area.

Strategic Plan

We also did a lot of preparation during the year for our forthcoming 2025 to 2028 strategic plan. This involved doing a strengths, weaknesses, opportunities and threats analysis with the board, the staff and also with many members and external stakeholders, including the haemophilia treatment centres. This gave us a broad range of information and feedback which we used later in the year to start putting together the strategic plan, which will be unveiled at the AGM in 2025.

Finance

In terms of finance, we had a strong year with an income of €729,528 and an expenditure of €711,388, leaving a surplus of €46,075. In reality, this surplus was €31,075 as the income included €15,000 from a one off grant of €50,000 which we received in 2019 toward the cost of purchasing an apartment for members. This funding, which was reported in the year of receipt, now also has to be released into our accounts at an annual rate of €2,500 per year for 20 years.

The high levels of IHS activities, with more than 1,100 calls made to members and various events, were carried out by a staff team of six, in contrast to the staff team of eight pre-covid pandemic. I want to thank the incredible staff team and our very dedicated Board members for all their work and commitment during the year.

Lifestyle

'My brother got the same blood treatment on the same day as me - he contracted HIV and died. I didn't'

As RTE airs a new documentary charting the spread of the virus in Ireland, Colm Walsh tells Kerry Blake-Kovacs how he developed a 'bullet' when receiving injections to treat haemophilia. His brother wasn't so lucky.



Colm Walsh, general of Haemophilia Society, and his brother Kevin had the same blood treatment in 1979, but only Colm survived.

In 1979, the first case of AIDS was reported in the US. The virus, which is now known as HIV, was first identified in 1981. It is a virus that attacks the immune system, and if left untreated, it can lead to AIDS. In Ireland, the first case was reported in 1982. The virus was first identified in a man who had received a blood transfusion in 1979. This was the first case of AIDS in Ireland. The man was named as 'Patient 001'.

Colm Walsh's brother Kevin had the same blood treatment in 1979, but only Colm survived. Kevin died of AIDS in 1982. Colm was diagnosed with HIV in 1983. He has since become a prominent figure in the haemophilia community in Ireland. He has been instrumental in the development of the Irish Haemophilia Society and has been a vocal advocate for the rights of people with haemophilia.

Colm Walsh's brother Kevin had the same blood treatment in 1979, but only Colm survived. Kevin died of AIDS in 1982. Colm was diagnosed with HIV in 1983. He has since become a prominent figure in the haemophilia community in Ireland. He has been instrumental in the development of the Irish Haemophilia Society and has been a vocal advocate for the rights of people with haemophilia.

There was no screening, there were no warnings. We didn't even know the blood was coming from American prisons.

Colm Walsh's brother Kevin had the same blood treatment in 1979, but only Colm survived. Kevin died of AIDS in 1982. Colm was diagnosed with HIV in 1983. He has since become a prominent figure in the haemophilia community in Ireland. He has been instrumental in the development of the Irish Haemophilia Society and has been a vocal advocate for the rights of people with haemophilia.

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Clinical Webinar Series

We organised six webinars from September to November in 2024. These were coordinated with the assistance of a professional conference organising company and supported by an unrestricted educational grant from Novo Nordisk. They covered a range of topics from women & bleeding disorders to haemophilia A & B and others.



First Webinar: Haemophilia A & B with Prof. Niamh O'Connell

Key points: With improved treatment for severe haemophilia A & B, severe is now moderate or mild; moderate haemophilia is the new severe, with similar bleeding patterns and hemophilia joint health scores (HJHS) but less prophylaxis; There is a need for better predictors of bleeding and joint disease.

Second webinar: Update on Gene Therapy with Dr. Radoslaw Kaczmarek

Key points: So far, gene therapy has shown marked variability of outcomes; Many candidates are not eligible for AAV gene therapy due to high prevalence of anti-AAV antibodies; RBDs could use the existing AAV platforms for expedited development of gene therapies.



Third webinar: Women & Bleeding Disorders with Dr. Michelle Lavin

Key points: Women more likely to be impacted by bleeding disorders when VWD taken into account; WGBD face difficult journey to diagnosis; Centres need to focus on WGBD as people with bleeding disorders themselves, not just as carriers; There is a massive lack of participation of women in clinical trials.

Fourth webinar: Update on Novel Therapies with Prof. Flora Peyvandi

Key points: Treatment goals should aim to normalise haemostasis; Inno8, a new FVIII mimetic, has the potential to be the first oral treatment for haemophilia A; Personalised medicine is now key, looking at a patient's needs, genetics and lifestyle.



Fifth webinar: Update on VWD with Prof. O'Donnell

Key points: New VWD guidelines are limited due to lack of evidence; Some patients with mild to moderate reductions in VWF have significant bleeding; Heavy menstrual bleeding is a huge clinical problem; Data on prophylaxis in VWD is poor but recent guidelines suggest that it should be used in history of severe and frequent bleeds.

Sixth webinar: The Future of Paediatric Care with Dr. Nolan

Key points: In the clinical trial for Altvocot, 64% of children under 12 had 0 bleeds; The availability of Emicizumab has led to discussions around the correct age to start prophylaxis; Emicizumab has led to the reduction of bleeding risk, particularly intercranial haemorrhage; It is always important to determine the level of FVIII or FIX in obligate or potential carriers.



Financial Report for 2024

Report on the audit of the financial statements

Opinion

We have audited the financial statements of Irish Haemophilia Society ('the company') for the financial year ended 31 December 2024 which comprise the Income and Expenditure Account, the Balance Sheet, the Reconciliation of Members' Funds, the Cash Flow Statement and the related notes to the financial statements, including the summary of significant accounting policies set out in note 2. The financial reporting framework that has been applied in their preparation is Irish Law and FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland", issued in the United Kingdom by the Financial Reporting Council, applying Section 1A of that Standard.

In our opinion the financial statements:

- give a true and fair view of the assets, liabilities and financial position of the company as at 31 December 2024 and of its surplus for the financial year then ended;
- have been properly prepared in accordance with FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland", applying Section 1A of that Standard; and
- have been properly prepared in accordance with the requirements of the Companies Act 2014.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (Ireland) (ISAs (Ireland)) and applicable law. Our responsibilities under those standards are described below in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the company in accordance with the ethical requirements that are relevant to our audit of financial statements in Ireland, including the Ethical Standard for Auditors (Ireland) issued by the Irish Auditing and Accounting Supervisory Authority (IAASA), and the Provisions Available for Audits of Small Entities, in the circumstances set out in note 3 to the financial statements, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the directors' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the company's ability to continue as a going concern for a period of at least twelve months from the date when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the directors with respect to going concern are described in the relevant sections of this report.

Other Information

The directors are responsible for the other information. The other information comprises the information included in the annual report other than the financial statements and our Auditor's Report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2014

In our opinion, based on the work undertaken in the course of the audit, we report that:

- the information given in the Directors' Report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Directors' Report has been prepared in accordance with applicable legal requirements.

We have obtained all the information and explanations which, to the best of our knowledge and belief, are necessary for the purposes of our audit.

In our opinion the accounting records of the company were sufficient to permit the financial statements to be readily and properly audited and the financial statements are in agreement with the accounting records.

Matters on which we are required to report by exception

Based on the knowledge and understanding of the company and its environment obtained in the course of the audit, we have not identified any material misstatements in the directors' report.

The Companies Act 2014 requires us to report to you if, in our opinion, the requirements of any of sections 305 to 312 of the Act, which relate to disclosures of directors' remuneration and transactions are not complied with by the Company. We have nothing to report in this regard.

Respective responsibilities**Responsibilities of directors for the financial statements**

As explained more fully in the Directors' Responsibilities Statement set out on page 5, the directors are responsible for the preparation of the financial statements in accordance with the applicable financial reporting framework that give a true and fair view, and for such internal control as they determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the directors are responsible for assessing the company's ability to continue as a going concern, disclosing, if applicable, matters related to going concern and using the going concern basis of accounting unless management either intends to liquidate the company or to cease operation, or has no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an Auditor's Report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (Ireland) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is contained in the appendix to this report, located at page 8, which is to be read as an integral part of our report.

The purpose of our audit work and to whom we owe our responsibilities

Our report is made solely to the company's members, as a body, in accordance with section 391 of the Companies Act 2014. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an Auditor's Report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume any responsibility to anyone other than the company and the company's members, as a body, for our audit work, for this report, or for the opinions we have formed.

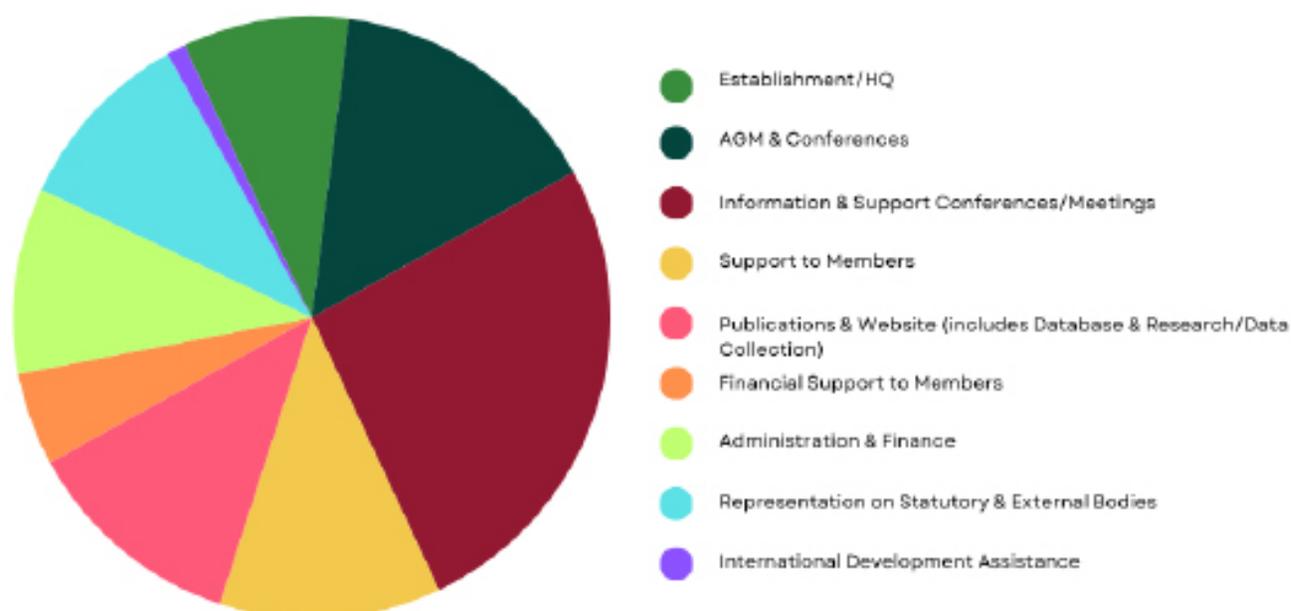
Income & Expenditure

For the year ended 31 December 2024

Income	2024	2023
Total income	729,528	724,479
Health Service Executive (HSE Grants)	575,000	595,125
Memberships	2,205	3,100
Donations - Members	21,307	27,467
Donations - Corporate	112,299	90,969
Fundraising	3,717	2,218
HHT Trust	-	5,600
Twinning	-	-
Grant Income Released	15,000	-
Overhead expenses	(711,388)	(759,412)
	18,140	(34,933)
Miscellaneous income	27,935	20,317
Net surplus/(deficit)	46,075	(14,616)
Expenditure		
Management Fee and Insurance	18,267	9,967
Light, Heat and Services	12,960	13,651
Help to Members	5,295	8,603
Educational Grants	21,000	15,550
Subscriptions	2,254	1,717
Wages and salaries	288,654	280,970
Social welfare costs	30,316	31,276
Pension Costs	48,914	43,887
Twinning - Development work	4,202	36
HQ costs	995	6,443
Office Supplies and Stationery	7,749	4,795
IHS members facility	(22,647)	(43)
Postage, printing and publications	29,720	27,939
Telephone Broadband	5,435	4,100
Website costs	3,483	5,315
Computer costs	24,660	19,057
Meeting expenses	27,526	19,194
Safety / supply activities	445	147
AGM and annual conference	52,728	50,237
Information and support events	8,298	9,919
Members conference	50,973	46,211
Ageing Conference	12,836	-
Parents conference	-	29,861
Legal and professional	935	500
Sponsorship / training	-	1,016
Unrecoverable VAT	-	27,123

Bank charges	2,204	1,931
General expenses	8,041	14,518
Women Bleeding Disorders Conference	-	8,982
IHS Clinical Webinars	16,939	-
Provision for sinking fund	-	30,000
Auditor's remuneration	7,811	6,115
Depreciation of tangible assets	41,395	40,395
Total Overhead Costs	711,388	759,412

EXPENDITURE



Balance Sheet

As at 31 December 2024

		2024	2023
	Notes	€	€
Fixed Assets			
Tangible assets	8	1,019,888	1,011,288
Investments	9	366,916	342,495
Fixed Assets		1,386,804	1,353,783
Current Assets			
Debtors	10	21,043	21,824
Cash and cash equivalents		1,144,395	1,152,837
		1,165,438	1,174,661
Creditors: amounts falling due within one year	12	(111,422)	(133,699)
Net Current Assets		1,054,016	1,040,962
Total Assets less Current Liabilities		2,440,820	2,394,745
Reserves			
Capital reserves and funds		273,220	273,220
Income and expenditure account		2,167,600	2,121,525
Members' Funds		2,440,820	2,394,745

Snapshots of 2024



Mild Haemophilia Information Day



AGM & Conference - Gala dinner



AGM & Conference - Kids programmes



Ageing Conference



October Members' Conference



Von Willebrand & Rare Bleeding Disorders Information Day

Corporate Sponsors

The Irish Haemophilia Society would like to acknowledge the financial contributions made in 2024 by the following companies, under our Corporate Giving Programme:

Platinum Sponsors

CSL Behring
Novo Nordisk
Roche
Sobi

Silver Sponsors

Biomarin

Fundraisers

The Irish Haemophilia Society would like to thank with gratitude, everyone who fundraised for the Society during 2024.

Volunteers

The Irish Haemophilia Society would like to acknowledge and to thank everyone who volunteered for the Society during 2024.

Donations and Planned Giving

The Irish Haemophilia Society gratefully acknowledges and thanks everyone who made donations to the Society and who contributed to the Planned Giving campaign during 2024.



IRISH HAEMOPHILIA SOCIETY

**FIRST FLOOR
CATHEDRAL COURT
NEW STREET SOUTH
DUBLIN 8**

TEL: 01 6579900

**INFO@HAEMOPHILIA.IE
WWW.HAEMOPHILIA.IE**

FIND US ON:

