Irish Haemophilia Society

Annual Report
2025

Representing People Living With Haemophilia,
Von Willebrands & Other Related Bleeding Disorders

Haemophilia.ie

Table of Contents

Services We Provide

Events

We arrange 2 - 3 major conferences each year as well as information days and other events.

Outreach & Supports

We offer support to members, on a variety of issues. We also offer educational grants for students.

Resources

We produce quarterly magazines, informational booklets and other leaflets and publications.

Advocacy

We advocate for all people with an inherited bleeding disorder in Ireland.

Website

Our website contains extensive information on all bleeding disorders.

Apartment Facility

We have an apartment facility for our members travelling to Dublin for hospital appointments.

A Message from the Chair

John Stack, Chairperson, Executive Board

Hello everybody.

As I reflect on 2025, I am reminded of the extraordinary journey that has brought the Irish Haemophilia Society to where it is today. For more than five decades, this organisation has been shaped not by buildings or budgets, but by people: families who refused to accept isolation, clinicians who pushed boundaries, advocates who demanded better, and individuals living with bleeding disorders who showed courage in the face of uncertainty.

Our history is one of resilience. We have faced challenges that tested us deeply, and we emerged with a stronger voice, a clearer mission, and a community bound together by trust. We are responsible for carrying this legacy forward.

We are now in another period of profound change in the world of bleeding disorders. Advances in treatment are reshaping what it means to live with haemophilia, von Willebrand disorder and other bleeding disorders. These developments bring hope, but they also bring complexity. In response, we have strengthened our education programmes so that every member can make informed decisions about their care. We have produced numerous publications throughout the year, some general in nature and others more specific or medical in nature. We continue to develop our website, and our social media platforms are busy and active.

We continue to foster deep partnerships with clinicians, researchers, and international organisations to ensure Ireland remains at the forefront of best practice. For example, we've recently produced webinars with renowned speakers from all around the world. We are working out another twinning programme for the coming years.

As we look to the future, I see the Society moving in three clear directions. Firstly, we will be focusing on supporting people across a much longer lifespan. Our programmes will increasingly reflect all the experiences of living with a bleeding disorder: mental health supports, transition pathways for teens to adult care, women's health, ageing with haemophilia, and peer networks that ensure no one feels alone at any stage of life.

Secondly, the next decade will bring choices that previous generations could not have imagined. Our role is to ensure that every member has access to independent information, that treatment decisions remain patient-centred, and that the health system is ready for the opportunities and responsibilities of advanced therapies.

Finally, advocacy remains at the heart of what we do. We will continue to advocate for all bleeding disorders. We will invest in youth leadership, empower families, and ensure that our collective voice remains strong, informed, and respected at national and international levels.

I would like to express my sincerest thanks to the team in the office who effectively run our organisation, to the volunteers without whom we couldn't have our major events, and to our fundraisers who illustrate how strong our community is. Thank you all so much for everything that you have done in 2025.

Who We Are

The Irish Haemophilia Society (IHS) is the national representative body for people with haemophilia and other inherited bleeding disorders in Ireland. Established in 1968, we advocate for individuals and families living with conditions such as haemophilia, von Willebrand disorder and other rare bleeding disorders. We work to ensure access to comprehensive care, safe treatment products, and appropriate support services across the Irish healthcare system.

A central function of the Society is patient advocacy. The IHS have played a significant role in shaping haemophilia care in Ireland, particularly in relation to ensuring safe products, following the long-term consequences of contaminated blood products in previous decades. The Society continues to monitor emerging therapies, including extended half-life factor concentrates and gene therapy, to safeguard patient interests.

Beyond advocacy, we provide our members with practical and social support. We pride ourselves on maintaining close contact with members, offering support through phone calls and visits. We organise educational conferences and information days to build awareness, as well as to enable individuals and families to socialise with other members of the community. Through these activities, the Society fosters a structured community network while promoting informed, evidence-based care.

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

Executive Board

The Executive Board of the Irish Haemophilia Society in 2025, consisted of nine members, who met 11 times during the year both online and in person. The Executive Board plays a central role in strategic leadership, governance and the overall direction of the organisation.

The 2025 board was:

John Stack

Chairperson

Mary Clare O'Sullivan

Vice-Chairperson

Hannah Byrne

Secretary

Dan McIntyre

Treasurer

Jim O'Leary

Board Member

Cian O'Sullivan

Board Member

Shannon Carey

Board Member

Molly O'Mahony

Board Member

Brian Byrne

Board Member

An Overview of 2025

Brian O'Mahony, Chief Executive

Events

2025 was a highly productive and active year for the Society. Our conferences and events were very well attended and featured diverse, engaging programmes.

The Annual General Meeting and Conference in March included sessions on current treatment options for haemophilia, von Willebrand disorder (VWD) and rare bleeding disorders (RBDs). We also had a session related to the comprehensive care centre audits that took place recently, clinical trials, dental care and shared care between the National Coagulation Centre (NCC) and Galway haemophilia treatment centre.

The October Members' Conference, as is customary, had a more informal format, incorporating debates and discussions in addition to lectures. A central feature was a well-received debate on whether treatment decisions should primarily rest with the consultant or the patient. The debate highlighted the importance of shared decision-making between consultant and patient. A general treatment update was followed by members sharing personal experiences with different products, both licensed and in clinical trials. This approach, now used regularly, has proven highly effective in educating members about current and future treatment options, ensuring they are well informed ahead of new therapies becoming available. This is one of the reasons Ireland has been at the forefront of clinical trials in recent years, with members well attuned to ongoing developments.

Additional sessions covered food and nutrition, as well as sports and bleeding disorders. Parallel sessions were also held on von Willebrand disorder and rare bleeding disorders, and on mild haemophilia. This integrated format has become a key feature of our major conferences, replacing separate information days and helping to bring members with these conditions more fully into the mainstream of Society activities.

A very successful Ageing Conference was also held during the year. It included practical sessions on wills, probate, and advanced healthcare directives, as well as benefits and entitlements, updates on Health Amendment Act (HAA card) provisions, guidance on getting the most from your GP, and an introduction to physiotherapy and pilates. We also had a very interesting panel discussion with a number of members who discussed ageing well with a bleeding disorder.

A dedicated information day for women and girls with bleeding disorders included sessions for adults and for girls over the age of 12. It also provided an opportunity to promote our new booklet, 'Time to Talk Periods: A Guide for Young Girls with a Bleeding Disorder'. In addition, a newly diagnosed information day allowed us to welcome and engage with several new families.

We also organised a parent and child event featuring a range of enjoyable activities, including opportunities for children to try experiences they might not otherwise have access to, alongside their parents. Finally, a poignant and well-attended memorial service was held in remembrance of those who had passed away. This took place at the National HIV Memorial in the Phoenix Park.

Communications

We continue to communicate with our members through a number of different channels: publications, social media, e-zines and our new WhatsApp Community. We produced eight publications in 2025. As is usual, we produced four editions of our quarterly magazine, a novel products review, and last year's annual report. We also produced two new informational publications - 'Time to Talk Periods: A Guide for Young Girls With a Bleeding Disorder' and 'Dental Care for Children with Inherited Bleeding Disorder: A Guide for Parents'. The former is part of our efforts to raise awarness about the issues that affect women and girls with bleeding disorders. The latter is a collaboration between the Society and CHI Crumlin.

We continue to update members on a regular basis through our e-zine and social media channels. We use these channels to update members on news from the comprehensive care centres, our events and other activities. In March, we set up a WhatsApp Community, a quick and effective way of sharing information with members through various groups in the community. Members can join groups relevant to them and get updates in this way.

Our communications programme also included a series of six clinical webinars. While primarily designed for healthcare professionals, these were also attended by members of the Irish Haemophilia Society and participants from other societies internationally. The webinars featured expert international speakers and covered a range of important topics, including new therapeutic options for VWD, monitoring liver health in haemophilia, rebalancing agents, gene therapy and gene editing, mimetics, and global access to treatment.

This was our second year organising this webinar series, and it is intended to become a regular feature of our work. All registered participants received a dedicated e-zine the day following each webinar, summarising the webinar and providing a link to the recording for later viewing. Recordings of all webinars are also available on our website.

140,000

Reached through Social Media

430

Joined WhatsApp Community

6

Webinars held

Outreach & Support

Outreach and offering support to our members remains at the very heart of what we do. Outreach during the year addressed a wide range of needs, including treatment guidance, travel planning, support for newly diagnosed children, and assistance with social welfare benefits and entitlements. We conducted several school visits throughout the year, providing information on haemophilia and other bleeding disorders, and responding to questions from school staff. There was also targeted outreach to international families from Ukraine, Syria, and Gaza who have moved to Ireland within the past few years. We continue to support these families as they integrate and adapt to living with a bleeding disorder in Ireland.

Our Hyde Square apartments continue to be a vital resource for members travelling to Dublin for hospital appointments in St. James's or Crumlin Children's Hospital. This accommodation will be even more convenient when the new children's hospital, located in the St. James's campus, opens. This is located less than five minutes drive from the apartment and a 15 minute walk.

We continue to offer educational grants to members who are in or going into post second-level education. We have four different grants that are aimed at individuals with a bleeding disorder and/or their immediate family members. The grants aim to take some of the financial burden off students. In 2025, a total of 25 educational grants were awarded, amounting to €16,750. The first prize recipients were Jake Phoenix for the Maureen & Jack Downey grant, Tadgh Moriarty for the Margaret King grant and Aoife Boylan for the Father Paddy McGrath grant. The Michael Davenport grant was not awarded. Congratulations to all who received a grant!

Advocacy

Internationally, I worked as part of a team with the World Federation of Hemophilia (WFH) to advocate for changes to the World Health Organization (WHO) Essential Medicines List for haemophilia.

In 2023, the WHO had listed pathogen-reduced and untreated cryoprecipitate as part of the core essential medicines list for haemophilia. Meanwhile, safer and more effective plasma-derived factor concentrates were placed on the complementary list, and recombinant factor concentrates and the mimetic Emicizumab were not included. This was widely regarded as a regressive and potentially harmful decision.

Following a series of engagements with the WHO, the WFH submitted three separate proposals, all of which were successful. As a result, pathogen-reduced and untreated cryoprecipitate were removed from the 2025 Essential Medicines List for haemophilia and VWD. Plasma-derived factor concentrates were moved to the core list and were joined by recombinant factor concentrates, Emicizumab, and Desmopressin (DDAVP).

This represented a significant advocacy achievement. The inclusion of untreated or inadequately treated cryoprecipitate could have allowed governments in developing and emerging countries to justify continued reliance on outdated and less safe therapies. Ensuring the list reflected modern, safe, and effective treatments was therefore essential, and this objective was successfully achieved.

Finance

In financial terms, the Society had a strong year. Income exceeded budgeted projections, while expenditure was lower than anticipated. As a result, the overall deficit was less than 50% of the level originally forecast.

Securing funding from pharmaceutical companies continues to be challenging. This is largely due to the limited number of programmes available for sponsorship, as well as the Society's policy of not accepting sponsorship for events and most publications.

We want to sincerely thank everyone who fundraised for us in 2025, as well as those who gave through planned giving and donations. We are very grateful for your contributions to the Society.

Thank You to Our Volunteers!

The Society extends our heartfelt thanks to the 68 dedicated volunteers who generously contributed their time, energy, and expertise to support our conferences and events throughout 2025. Their commitment has been instrumental in helping us to continue to deliver engaging and meaningful programmes for children and young people at our conferences.

We are also pleased to report that the Volunteer Working Group met twice during 2025, fostering valuable discussion and collaboration. Working closely with the Children's Programmes Coordinator, the group has laid a strong foundation for upcoming enhancements to our programmes.

To mark the exceptional dedication of our volunteers, we launched a volunteer recognition programme in 2025, presenting awards at the AGM to those who attended multiple conferences.

The volunteers bring enthusiasm, fun and their own individual skills to the conferences and events and continue to enrich our Society in countless ways. Their contribution is deeply valued. Thank you!

Financial Report for 2025

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 2025 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 2025 and of its deficit 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 6, 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.

Further information regarding the scope of our responsibilities as auditor

As part of an audit in accordance with ISAs (Ireland), we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.

- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the company's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the directors.
- Conclude on the appropriateness of the directors' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our Auditor's Report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our Auditor's Report. However, future events or conditions may cause the company to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

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 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.

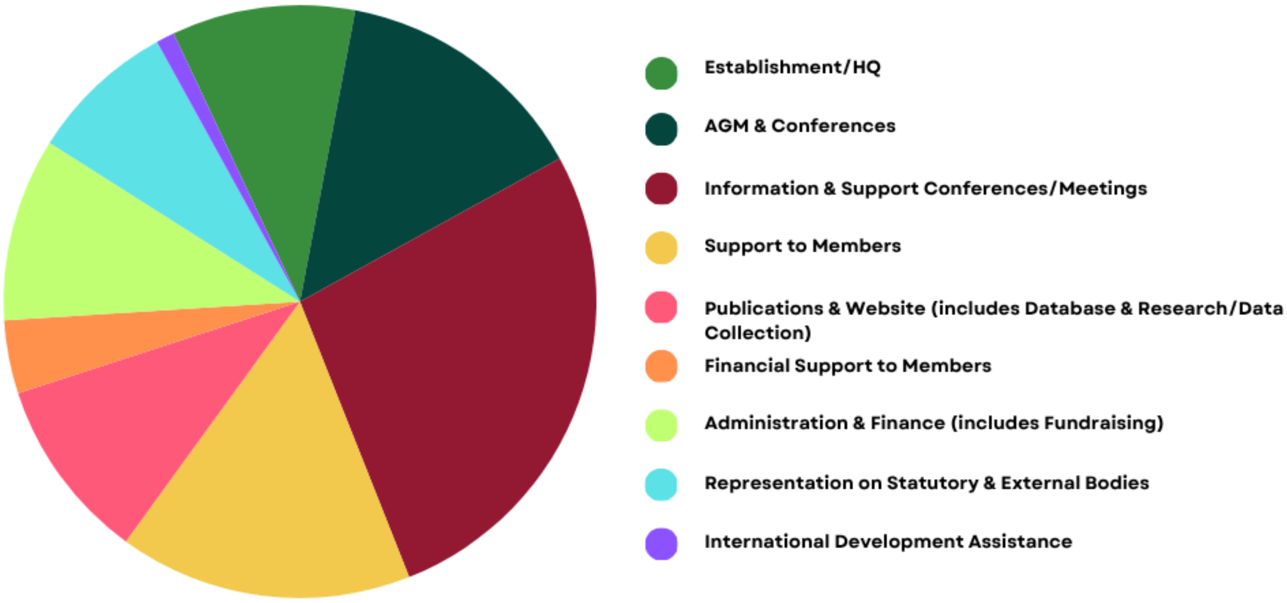
Income & Expenditure

For the financial year ending 31 December 2025

Schedule	2025 €	2024 €
Income		
Health Service Executive (HSE grant)	**575,000**	575,000
Fundraising	**11,184**	3,717
Memberships	**2,870**	2,205
Corporate Donations	**87,969**	112,299
Members Donations	**19,698**	21,307
HHT Trust	**1,000**	-
IHS Members Facility	**36,410**	-
Grant Income Released	**2,500**	15,000
	736,631	729,528
Overhead expenses	**(832,234)**	(711,378)
	(95,603)	18,150
Miscellaneous income	**29,408**	27,935
Net (deficit)/surplus	**(66,195)**	46,085

	2025 €	2024 €
Overhead Costs		
Wages and salaries	**313,613**	288,654
Social welfare costs	**35,471**	30,316
Pension Costs	**58,811**	48,914
Twinning - Development work	**-**	4,202
HQ costs	**6,446**	995
Office Supplies and Stationery	**4,426**	7,749
IHS members facility	**15,437**	(22,647)
Postage, printing and publications	**28,208**	29,720
Telephone Broadband	**5,947**	5,435
Website costs	**5,167**	3,483
Computer costs	**42,003**	24,660
Meeting expenses	**17,508**	27,526
Safety / supply activities	**908**	445
AGM and annual conference	**65,753**	52,728
Information and support events	**9,853**	8,298
Members conference	**61,997**	50,973
Ageing Conference	**14,418**	12,836
Women & Girls with Bleeding Disorders Conference	**1,638**	-
Legal and professional	**135**	935
Bank charges	**2,564**	2,204
General expenses	**9,281**	8,031
Family Activity	**2,762**	-
IHS Clinical Webinars	**27,407**	16,939
Auditor’s remuneration	**8,180**	7,811
Depreciation of tangible assets	**39,582**	41,395
Management Fee and Insurance	**18,307**	18,267
Light, Heat and Services	**12,698**	12,960
Help to Members	**5,016**	5,295
Educational Grants	**16,500**	21,000
Subscriptions	**2,198**	2,254
Total	**832,234**	711,378

EXPENDITURE



Balance Sheet

For the financial year ending 31 December 2025

	Notes	**2025** **€**	2024 €
Fixed Assets			
Tangible assets	**8**	**980,306**	1,019,888
Investments	**9**	**384,446**	366,916
Fixed Assets		**1,364,752**	1,386,804
Current Assets			
Debtors	**10**	**33,902**	21,043
Cash and cash equivalents		**1,099,009**	1,144,395
		1,132,911	1,165,438
Creditors: amounts falling due within one year	**12**	**(123,038)**	(111,422)
Net Current Assets		**1,009,873**	1,054,016
Total Assets less Current Liabilities		**2,374,625**	2,440,820
Reserves			
Capital reserves and funds		**273,220**	273,220
Income and expenditure account		**2,101,405**	2,167,600
Members' Funds		**2,374,625**	2,440,820

Members' Contributions in 2025

€15,753

Raised through planned giving

€11,184

Raised through fundraising

€3,945

Raised through member donations

The Year in Photos

AGM & Conference

Parent & Child Overnight Event

October Members' Conference

Memorial Service

Ageing Conference

Newly Diagnosed Information Day

Women & Girls With Bleeding Disorders Information Day

Corporate Sponsors

The Irish Haemophilia Society would like to acknowledge the financial contributions made in 2025 by the following companies, under our Corporate Giving Programme:

Platinum Sponsors

CSL Behring, Novo Nordisk, Roche, Sobi

Gold Sponsors

Takeda

Fundraisers

The Irish Haemophilia Society would like to thank with gratitude everyone who fundraised for the Society during 2025.

Volunteers

The Irish Haemophilia Society would like to acknowledge and to thank everyone who volunteered for the Society during 2025.

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 2025.

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