

IRISH HAEMOPHILIA SOCIETY

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



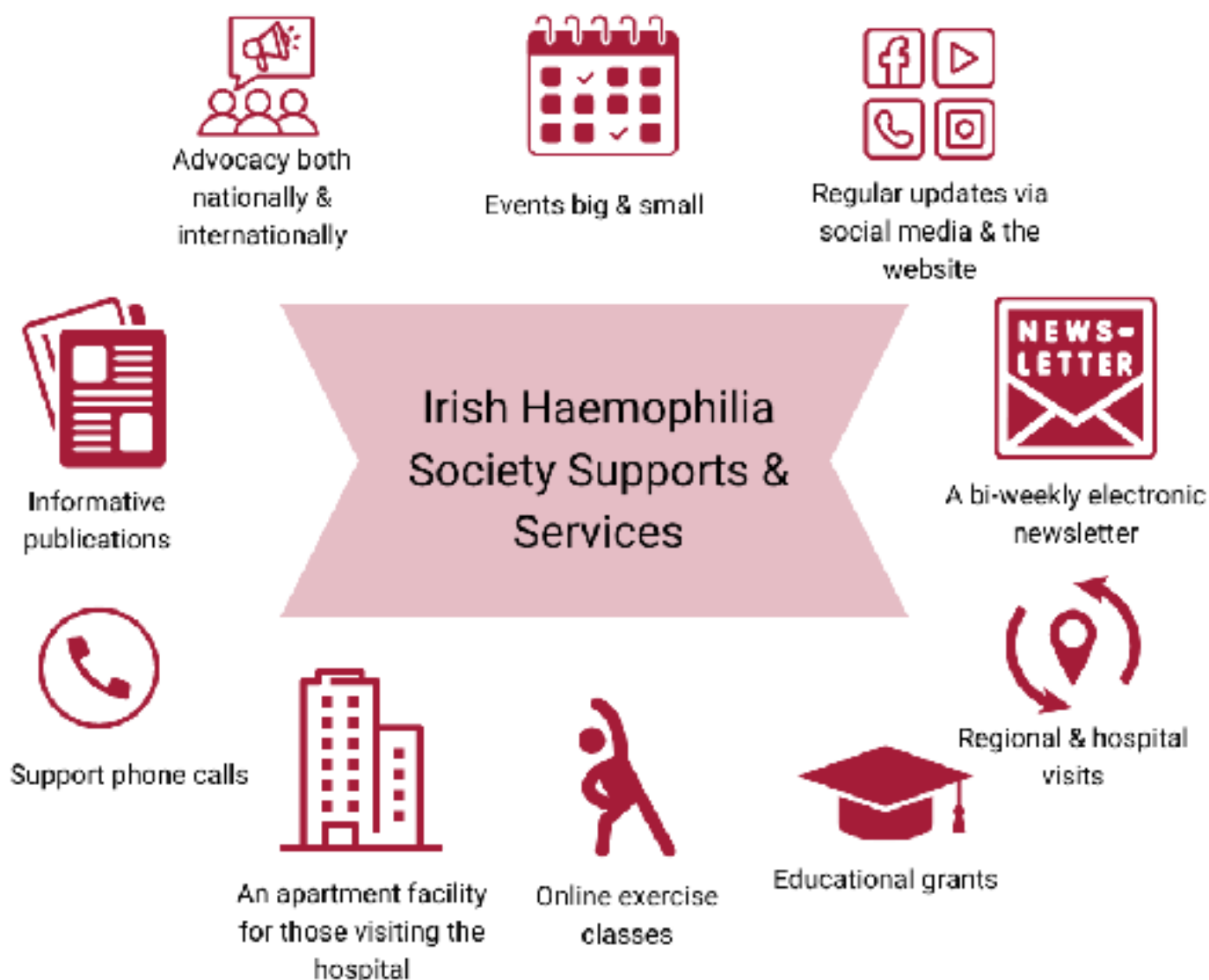
ANNUAL REPORT 2023



Haemophilia.ie

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Chairperson's Report

Who we are and what we do

The Irish Haemophilia Society (IHS) represents the interests of people with haemophilia and other bleeding disorders, providing the following services:

- Education
- Conferences and events
- Advocacy
- Publications
- Educational Grants
- Accommodation to members attending hospital (St. James' or CHI Crumlin)
- Outreach

Additionally, we collaborate with the medical teams within the haemophilia and bleeding disorders services, namely the National Coagulation Centre (NCC), CHI Crumlin, Cork University Hospital (CUH), and with other healthcare and people within the field of haematology.

Outreach is an important function provided by the IHS. Our Outreach Coordinator is happy to arrange home or hospital visits, be it just for tea and a chat, or advice on how best to address a particular issue that may arise for a member.

Board and Staff

The Executive Board for 2023 comprised of 10 members; Seamus McDonald, Barbara Wynne, Dan McIntyre, Jim O'Leary, Mary Clare Delaney, Aislinn Farrelly, Breda Quealy, Paul Dunne, Donal McCann (stood down from the board on November 2nd 2023) and I.

There were six staff members in the Society in 2023: Brian, Debbie, Nina, Rob, Suzanne and Róisín, who do a tremendous job in keeping the organisation functioning. However, Suzanne resigned in September, bringing it down to five staff.

Staff Team at end of 2023



Brian O'Mahony, CEO

- Represents I.H.S. on National Haemophilia Council, Haemophilia Product Selection Monitoring Advisory Board & the Consultative Council on Hepatitis C
- Oversees the budget and strategic plans.



Debbie Greene, Office Administrator & Manager

- Manages the day-to-day running of the office
- Oversees all events, activities & Hyde Square
- Administers educational grants & attends monthly board meetings



Nina Storey, Financial & Fundraising Coordinator

- Oversees the financial administration of the organisation
- Manages the database
- Oversees fundraising and donations



Robert Flanagan, Outreach & Children's Programmes Coordinator

- Provides members with support & information
- Conducts hospital, regional & home visits
- Manages children's programmes & volunteers at conferences



Roisin Burbridge, Publications, Website & Social Media Coordinator

- Manages the website, social media & bi-weekly E-zine
- Produces publications
- Manages stands at conferences & oversees AV

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

Conferences and Events

The year 2023 was a characteristically busy year for conferences and events for the Society. The 2023 AGM took place in the Slieve Russell Hotel, with 212 people in attendance. This number was considerably higher than 2022, when 156 people attended.

In 2023, the Society held a Parents' Conference, the first in several years. This took place in July at the Midlands Park Hotel, Portlaoise. There were 130 people in attendance, which was a great turnout, considering that it took place in the middle of the holiday period.

The October Conference, which took place at the Mount Wolseley Hotel, Carlow, had 210 attendees. The high turnout at our main events demonstrates the strong sense of community that exists within the Society.

We also marked World Haemophilia Day on the 22nd April 2023, held a Von Willebrand Disorder Information Day, which was very well attended on the 23rd September 2023, and a Women and Bleeding Disorders Conference on the 2nd and 3rd December 2023. These smaller, specific events are very important.

The quality of our events is a credit to the Society staff. It takes an awful lot of work to organise an event, regardless of the size. Traditionally, this involves identifying interest in a particular topic or area, establishing if there is interest from the members, booking a suitable venue, developing a programme, organising volunteers, managing bookings, and so on. These events are a key element of our Society as they facilitate the sharing of information and allow our members to meet, catch up and stay in touch. They ensure that new members, who may have a new diagnosis of a bleeding disorder, feel welcomed and supported.

In addition to our traditional conferences and events, four regional visits took place in 2023 (Cork, Athlone, Donegal and Galway). A busy physiotherapy/exercise and pilates exercise programme was delivered online.

Finally, our outreach programme was intensive in 2023, including 832 phone calls to members, return calls to non-members and the provision of support to our Ukrainian and Syrian friends.

Grants and Awards

Each year, the Society provides grants for third level education. Qualifying courses range from PLC-level courses, up to degree and post-graduate study.

There are three categories of grants available:

- The Maureen and Jack Downey Educational Grant
- The Margaret King Educational Grant
- The Fr. Paddy McGrath Educational Grant

In 2022, 16 applications were received and €15,200 was distributed amongst those who applied. I should point out that the standard of application is very high. For more information on educational grants, see <https://haemophilia.ie/services-and-support/educational-grants/>.

Award W



The Maureen & Jack Downey Educational Grant
Peter Walsh



The Margaret King Educational Grant
Tadhg Moriarty

The Michael Davenport Educational Grant was not awarded in 2023. It is intended to review the criteria for this adult further education award as it has not yet been granted since it was created.

The Brian O'Mahony Award for Outstanding Contribution to Haemophilia Care in Ireland was presented to Professor Niamh O'Connell in recognition for her outstanding contribution to haemophilia care over many years.

The Gerry O'Reilly Courage Award was not awarded in 2023.

Fundraising

Fundraising is an important source of income for the Society. I cannot emphasise enough how grateful we are to the efforts people make to fundraise for us.

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. In 2023, members raised €2,208 through events and activities they organised.

Planned Giving is another important fundraiser for the Society. The funds raised through Planned Giving are allocated primarily to costs associated with the apartments owned by the Society and operated for members. The apartments are a hugely valuable asset to which members have access when they are attending Dublin for a hospital appointment in St. James's Hospital or CHI Crumlin. It is a huge relief knowing that you don't need to arrange accommodation when coming to Dublin for an overnight. Once again, this was a particularly valuable asset during the pandemic as it gave assurance that people could attend their hospital appointments knowing that they could stay as safe as possible. Planned Giving raised €15,514 in 2023 and members also donated an additional €11,953. Thank you all so much.

The apartment has proven to be such an important service for our members that we purchased another apartment in the same complex in 2021. This is a vital exercise in forward planning as it will prove to be hugely beneficial to our members when the Children's Hospital moves to its new location on the St. James's site. The apartments were used over 100 times during 2023.

If you would like to avail of the apartment, please contact the office.

Communications

The IHS website continues to be the main online point for information on the Society. There were 23 ezines published in 2023 (3 more than 2022) and distributed to 467 households. If you would like to receive the ezine, please contact the office.

Social media is another important source of information on the Society, our services, supports and events. We predominantly use Twitter, Instagram and Facebook.

Winners



The Fr. Paddy McGrath Educational Grant
Aidan Clohessy



The Bill O'Sullivan Fundraiser of the Year Award
Niamh O'Sullivan

This year, the Society also issued our traditional quarterly publications, one Novel Therapies publication and our Annual Report.

Volunteers

I can't thank the volunteers enough for the trojan work they do at the conferences and events that occur each year. We currently have 63 Volunteers registered with the Society, though we could always do with more. 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.

All of the Board members are volunteers. The Board meets 11 times a year, with August being the only month in which a Board meeting does not occur. It is important to note that all Board members are working full or part time, or are studying full or part time, and have busy family lives. Having a presence on the Board is a significant commitment, but one to which we willingly sign up.

Conclusion

It is a joy to be part of the wonderful community that is the Irish Haemophilia Society. Each year, we seem to grow and the standard of care remains second to none. The advocacy carried out by the staff of the Society is crucially important 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 Haemophilia and their carers and families. The year 2024 will be an interesting year as some of these products become licensed and available to us. The Society hopes to carry out an intensive education campaign to ensure that members are as informed as possible, and have all the information they need, to make informed decisions on their personal care.

The staff and Board produce periodic strategic plans to ensure that we are working as effectively as possible for you and to ensure that we are at the forefront of haemophilia care. The current strategic plan is coming to a close and I'm happy to say that we've had tremendous success with it. The staff and Board will be convening towards the end of the coming year to set out the strategic plan for 2025 to 2028.

**John Stack,
Chairperson**



Honorary Secretary's Report

At the 34th Annual General Meeting of the Irish Haemophilia Society, which was held in the Slieve Russell Hotel in Cavan on 4th March 2023, the incoming Governing Body of the Society were elected as follows:

- Mary Clare Delaney
- Aislinn Farrelly
- Donal McCann
- Seamus McDonald
- Paul Dunne
- 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 Mary Clare Delaney
- Honorary Secretary Barbara Wynne
- Honorary Treasurer Dan McIntyre



In the period since the last AGM:

- Nine executive board meetings took place.
- Donal McCann stepped down from the board on 2nd November 2023.

CONFERENCES & EVENTS 2023

AGM & Annual Conference

The AGM & Annual Conference took place over the weekend of the 3rd to 5th March in the Slieve Russell Hotel in Cavan. The programme consisted of talks and lectures on topics such as: novel therapies, gene therapy, physiotherapy and an open forum. The conference was very well attended.

World Haemophilia Day

To mark World Haemophilia Day, the Society organised an information day for people with mild haemophilia which took place in the Grand Hotel in Malahide on 22nd April.

Parents Conference

The Parents Conference took place in collaboration with the team at CHI Crumlin over the weekend of 14th to 16th July in the Midlands Park Hotel in Portlaoise. The programme consisted of topics such as: treatment, the new Children's Hospital, inheritance, carrier issues, nosebleeds, pathways to care, sports and an open forum. This was the first Parents Conference since 2016 and it was great to see new families attending this event, who are now members.

Von Willebrand Information Day

An information day for people with Von Willebrand Disorder took place on Saturday 23rd September in the Grand Hotel in Malahide. The programme consisted of an interactive workshop, updates about treatment and treatment expectations over the next five years.

October Conference

The October Conference took place over the weekend of 20th to 22nd October in Mount Wolseley Hotel in Carlow. The programme consisted of workshops on different treatment options, a debate, a women's health survey, a talk on travelling wisely and a family quiz. This conference went very well, and we were delighted to have three Syrian families in attendance at this event.

Women & Bleeding Disorders Conference

A conference for women with bleeding disorders took place on 2nd and 3rd December in Grand Hotel in Malahide. The programme consisted of topics including menstruation, pregnancy and conception, menopause, physical

2023 Major Conferences



March 2023 AGM & Conference

Venue: Slieve Russel Hotel,
Cavan
Key topics covered:

- Novel therapies
- Comprehensive care
- Haemophilia worldwide



July 2023 Parents Conference

Venue: The Midlands Park
Hotel, Portlaoise
Key topics covered:

- The new children's hospital
- New therapies
- Nosebleeds



October 2023 October Members' Conference

Venue: Mount Wolseley
Hotel, Carlow
Key topics covered:

- Workshop on living your best life
- Travelling wisely
- Colm Walsh's Fastnet swim

activity and diet and nutrition. Overall the event was very successful.

Regional Visits

Four regional visits took place last year to Cork, Athlone, Donegal and Galway. Whilst numbers were low it was agreed that all of these visits were very worthwhile with excellent discussions taking place during the meetings.

PHYSIO/EXERCISE & PILATES EXERCISE CLASSES

The physio/exercise and pilates classes continued last year with 34 physio classes taking place and 32 pilates classes taking place.

OUTREACH

Over the course of 2023, in excess of 862 phone 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 2023 the Society continued to give support to Ukrainian refugees with bleeding disorders and also gave support to Syrian refugees with bleeding disorders.

PUBLICATIONS, SOCIAL MEDIA & WEBSITE

During 2023, the Society produced 4 quarterly magazines, one novel therapies publication and an annual report. Social media platforms continue to work well for the organisation. The Society continues to have a strong presence online with 1,851 followers on Facebook, 1,422 on Twitter and 251 on Instagram. The Society continued distributing the electronic magazine e-zine, which has proved to be very popular, so much so that we have 467 people signed up for this. In 2023 a total of 23 e-zines were produced. A lot of work has also been and will continue to be done on content for our website.

HYDE SQUARE

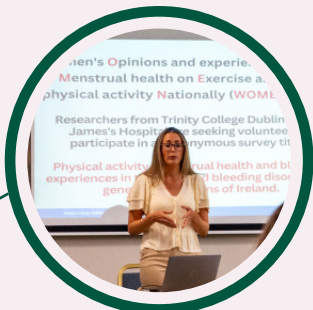
The apartment facility for member was occupied as follows in 2023:

- The one-bedroom apartment was occupied for 29 nights.
- The two-bedroom apartment was occupied for 77 nights.

FUNDRAISING

A total of €2,218 was raised through fundraising in 2023.

2023 Information Days & Smaller Events



September 2023
Von Willebrand
Information
Day

- Venue: The Grand Hotel, Malahide, Dublin
- Key topics covered:
- The future of VWD treatments
 - Struggles of people with VWD
 - Comprehensive care



- April 2023
Mild
Haemophilia
Information
Day
- Venue: The Grand Hotel, Malahide, Dublin
- Key topics covered:
- Treatment of mild haemophilia
 - Comprehensive care
 - Dental care



- December 2023
Women with
Bleeding
Disorders
Conference
- Venue: The Grand Hotel, Malahide, Dublin
- Overview:
- Pregnancy & child birth
 - Menstruation & heavy periods

DONATIONS

A total of €11,953 was donated in 2023 by members of the organisation.

PLANNED GIVING

A total of €15,514 was raised by planned giving in 2023.

VOLUNTEERS

We would like to thank our 36 volunteers who gave up their time to work at the AGM, the Parents Conference and October Conference in 2023. 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 2023, totalling €15,200 paid out to applicants, following an application, review and selection process including a rigorous scoring system.

- The Maureen & Jack Downey Educational Grant recipient was Peter Walsh.
- The Margaret King Educational Grant recipient was Tadhg Moriarty.
- The Father Paddy McGrath Educational Grant recipient was Aidan Clohessy.
- The Michael Davenport Educational Grant was not awarded in 2023, due to no applications being received, therefore the criteria for this award will be looked at for 2024.

Awards

The Brian O'Mahony Award for Outstanding Contribution to Haemophilia Care in Ireland recipient was Professor Niamh O'Connell.

STAFF

Suzanne Fitzgerald resigned on 22nd September 2023. The Society were understaffed during the latter half of 2023. Recruitment proved difficult in 2023 with two major recruitment drives proving unsuccessful. However, Society staff continued to work together as an excellent team, providing services to our members.

The staff, as of the end of 2023, 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)

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 Advisory Board – Brian O'Mahony & Matthew McCabe
- Haemophilia HIV Trust – Brian O'Mahony & Nina Storey
- Disability Federation of Ireland – Brian O'Mahony & Debbie Greene
- World Federation of Hemophilia – Brian O'Mahony
- European Haemophilia Consortium – Brian O'Mahony & Jim O'Leary
- Consultative Council on Hepatitis C – Brian & O'Mahony & Debbie Greene
- Irish Blood Transfusion Service Board – Brian O'Mahony

The Board would like to express its thanks to the staff for their continued commitment and for representing the best interests of the I.H.S. 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.

Barbara Wynne,
Honorary Secretary

The Year in Review from our CEO

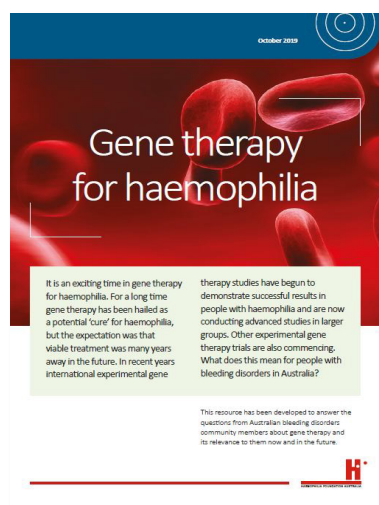
We are fortunate to be living in a time of great advances in therapy for haemophilia and other bleeding disorders. For the past several years and continuing in 2023, Ireland has been actively participating in clinical trials for new therapies. Ongoing clinical trials here include participation in the phase three trials for the FIX gene therapy Hemgenix (now licenced by the EMA), the RNA I inhibitor Fitusiran which is a rebalancing agent, the mimetic MiM8 which may be a future competitor for Emicizumab and the super extended half-life FVIII Bivv-001 (now licenced in the USA as Altuviio). Together with the existing half life FVIII and FIX products, the subcutaneous mimetic currently used in Ireland and other novel therapies in clinical trials, this adds up to a complex and exciting therapeutic landscape now and in the future.

Information about current and forthcoming therapies and all aspects of treatment or care are provided not just via our publications, but also through our events. We are fortunate that there is a strong culture of members attending our events. It is very difficult to produce a single publication on therapies that would provide information at the required level for such a diverse population: hence the importance of covering these topics at our events. We do publish two issues each year of the Novel Therapies Report, which goes into great detail on developments with all the current and future therapies. This excellent publication is based on content produced by the European Haemophilia Consortium. We recognise however that this level of detail is not required and is not particularly useful for many people with haemophilia or other family members. The publication is designed for people with a keen interest in therapies and it also performs a second vital function of being an educational tool for healthcare workers.

During the course of 2023 we covered the evolving therapeutic environment in great detail at several of our events. This included a lecture by the World Federation of Haemophilia Vice President Medical, Dr. Glenn Pierce, at our Annual Conference on therapeutic choice in the era of gene therapy, in addition to a lecture on educational approaches with novel therapies. To support this approach, we had a panel discussion at our October Conference where people with bleeding disorders spoke about their experiences with different therapies which are licenced or in clinical trials, followed by a broad discussion on selecting therapeutic options. We are strongly encouraging the approach of shared decision making in relation to choosing therapeutic options. Indeed, we used the newly developed WFH shared decision making tool at the October Conference during the workshop.

At the Parents Conference there was an update on the national experience with the use of Emicizumab and during our information days on mild haemophilia and von Willebrand disorder respectively there were updates on current and future therapeutic options.

Novel Therapies on the Horizon



Rondoraptivon pegol (BT200) – pegylated aptamer to VWF

A diagram showing the structure of Rondoraptivon pegol (BT200). It features a yellow/orange structure labeled 'BT200' and a blue structure labeled 'VWF/A1'. A green structure labeled 'PEG' is also shown. The diagram is adapted from Du S et al. J Thromb Haemost 2020.

- Synthetic molecule
- Long half-life 7-12 days
- Subcutaneous

Developed as a VWF inhibitor to use as an anticoagulant in stroke

The ISHTH 2023 logo is located in the bottom right corner of the slide.

Our events were highly successful during 2023. We organised three major conferences which, as usual, had adult programmes and separate programmes and activities for youth, older children, younger children and a creche. The programmes for youth and children are possible because of the dedication and involvement of our excellent pool of volunteers. The three major conferences were our Annual Conference in March, our Parents Conference in July and our October Members' Conference. The Annual Conference included sessions on comprehensive care, an update on the iPATH research programme and an update on haemophilia worldwide. Our October Members' Conference, which is usually more informal, in addition to the previously mentioned panel discussions on treatment, had a debate on the impact of haemophilia versus von Willebrand Disorder, and lectures on the patient portal and on travelling wisely. It also included a talk on the new Women's Health Survey which is being led by Dr. Megan Kennedy and Dr. Michelle Lavin. We took the opportunity at the conference to pilot test the survey. We had an excellent talk by member Colm Walsh who swam from Cork to the Fastnet lighthouse - an incredible swim which very few people could or have achieved.

For the first time for several years we held a Parents Conference which was very successful and included an update on the new Children's Hospital, a session on inheritance and carriers and talks on sports, an update on Society services and an open forum. Our strategic plan now calls for a parents conference every third year as we believe this is the optimum interval between these conferences to share new content with parents that would not be covered by the other conferences. Our plan also calls for a women and bleeding disorders conference one year followed by an ageing conference the following year. In 2023, we organised a very successful Women and Bleeding Disorders Conference, which included sessions on heavy menstrual bleeding, conception and pregnancy, menopause, paediatric care for girls with bleeding disorders, physical activity, and diet and nutrition. We also organised our annual information days on VWD and on mild haemophilia respectively. The VWD Information Day included an update on treatment and care and an interactive workshop where people with VWD discussed what they would like to see in the next five years. It also provided us with an opportunity to get further input on the Women's Health Survey. The Mild Haemophilia Information Day included an update on the use of Emicizumab in mild haemophilia, dental care and a very lively discussion.

We are pleased that such a high proportion of our membership attend events. Our last three major events have booked out even before the closing date. We do not presume that they were successful- this is based on extensive evaluations carried out by event attendees which are compiled and are also used to plan future events and content. As we look to the future and the availability of more complex therapies and gene therapy, the willingness of our members to attend meetings and events should mean that it will be easier for us to provide information at a level which people need and understand, in an environment where questions can be asked and where we can assist members to make fully informed decisions on therapy on all occasions.

In terms of comprehensive care, we were pleased that in late 2023, following sustained advocacy from the Society and from the National Coagulation Centre and National Haemophilia Council, access for people with haemophilia and inherited bleeding disorders to the H&H ward in St. James's Hospital was restored. A new senior nurse was appointed at the Galway University Hospital centre. The Society and the National Haemophilia Council continued to advocate for more dedicated physiotherapy time for the Children's Hospital in Crumlin - an issue which has frustratingly been on the agenda for quite a long time. We had concerns during the year about the potential relocation of the outpatient haemophilia centre in Cork away from the main campus and we made it very clear to the Chief Executive and his team that this would not be acceptable to the community. The peer reviewed external audits of the comprehensive care centres which will take place in 2024 and for which planning commenced in 2023 should assist in highlighting current gaps in the comprehensive care service and hopefully help to remedy these gaps.

Schedule of

Each year we hold

- 1. AGM & Conference
- 2. October Members' Conference

Every 2nd year we hold

- 1. Ageing Conference
- 2. Women & Bleeding Disorders Conference



The Society continued our formal participation on the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB). During the year, contracts were renewed for extended half-life FVIII and FIX, as well as bypassing agents. A new contract was issued for cold chain delivery of products which provides for the delivery to the homes of people with bleeding disorders of FVIII, FIX or Emicizumab for their home therapy. The Society representation on the HPSMAB changed this year. I remain on the HPSMAB as Vice Chair and Society representative but I have now been joined by member Matthew McCabe who replaced Declan Noone and as our external advisor we have appointed Dr Radoslaw Kaczmarek from the USA. Doctor Kaczmarek is a person with haemophilia with whom we have worked for many years and he is an expert on haemophilia care and probably the most noted patient authority on haemophilia gene therapy.

Other highlights of the year included the unveiling of the national HIV monument in December. I was on the commissioning committee for that monument during the course of 2023. I'm very pleased with the final monument which was selected and is now placed in a prominent position in the Phoenix Park.

Our weekly physiotherapy and pilates classes continued and these proved to be very beneficial to members. We have now completed more than 70 tasks which were set out in our strategic plan for 2020 to 2024 and we hope to complete many of the outstanding tasks in 2024.

In terms of finance, we had a good year with effectively a balanced budget once depreciation was accounted for. Due to the requirements for depreciation at a minimum level each year, the actual value of our office building and the apartments that the Society operates for our members, are significantly higher than stated in the audited accounts. We are delighted to have these resources available for our members. It was a successful year and I want to express my appreciation to the board for their dedication and to our small staff team for their hard work during the year, especially given the situation that we continue to be understaffed.

Brian O'Mahony,
Chief Executive



of Events

Every 3rd year we hold

- 1. Parents Conference



Information Days we hold regularly

- 1. Mild Haemophilia Information Day
- 2. Von Willebrand Disorder Information Day
- 3. Newly Diagnosed Information Day

Financial Report for 2023

INDEPENDENT AUDITOR'S REPORT

To the Members of the Irish Haemophilia Society

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 2023 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 2023 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 (IMSA), and the Provisions Available for Audits of Small Entities, in the circumstances set out in note 4 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.

A further description of our responsibilities for the audit of the financial statements is contained in the appendix to this report, located at page 9, 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.

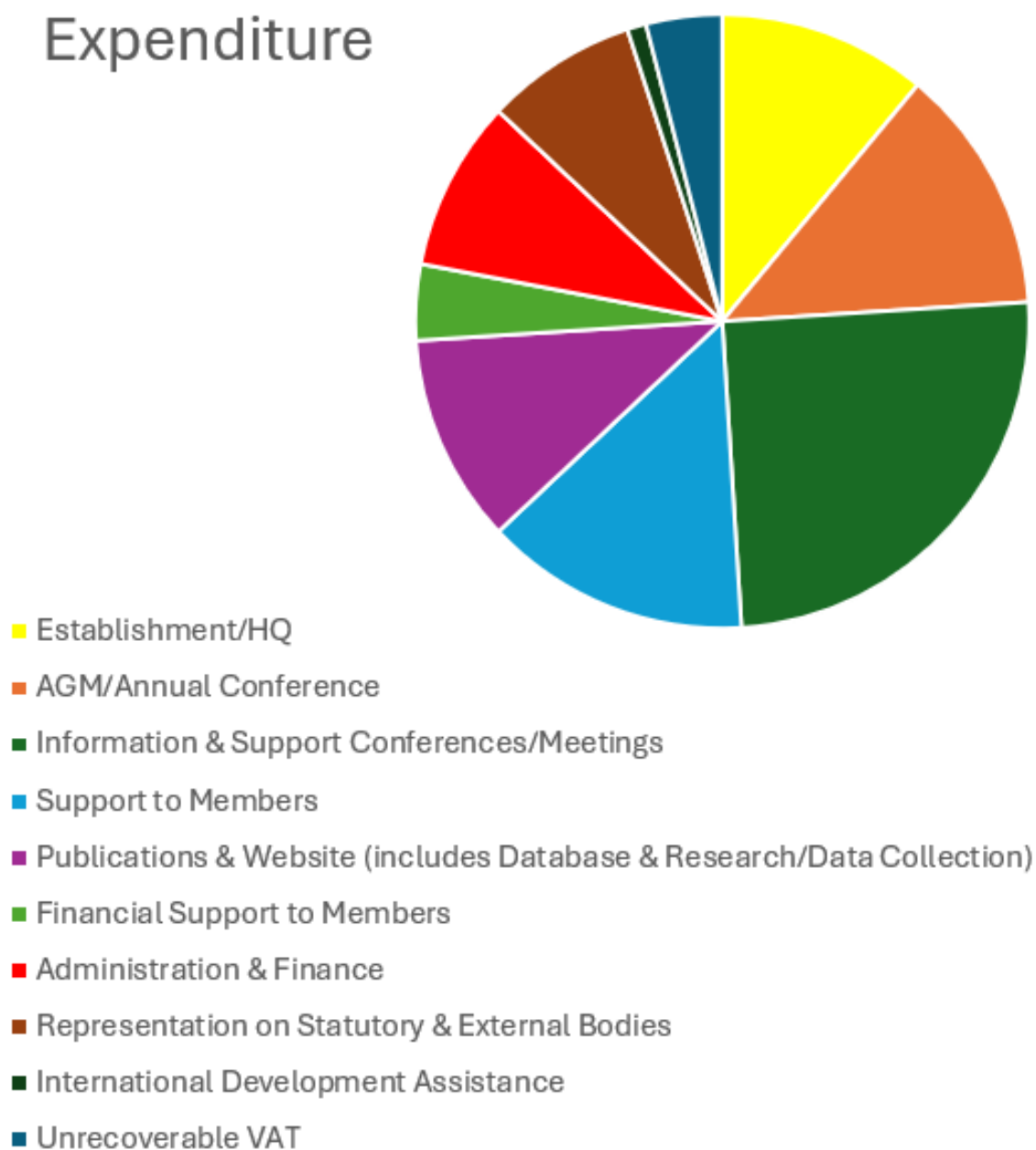
Income & Expenditure

For the year ended 31 December 2023

	Schedule	2023 €	2022 €
Income			
Health Service Executive		595,125	575,000
Membership		3,100	2,940
Donations - Members		27,467	24,174
Donations - Corporate		90,969	81,000
Fundraising		2,218	2,601
H.H.T Trust		5,600	-
Twinning		-	3,081
		724,479	688,796
Overhead expenses	1	(759,422)	(715,721)
		(34,943)	(26,925)
Micellaneous income	2	20,317	(38,928)
Net deficit		(14,626)	(65,853)
Expenditure			
Wages and Salaries		280,970	266,386
Employers Prsi Contributions		31,276	29,428
Pension Costs		43,887	42,189
Services Charges & Insurance		9,967	25,894
Light, Heat & Services		13,651	13,123
Help To Members		8,603	8,545
Subscriptions		1,717	1,781
Educational Grants		15,550	17,350
Twinning- Jordan/Vietnam Development Work		36	1,959
HQ Costs		6,443	5,605
Office Expenses, Stationery etc.		4,795	12,939
I.H.S Members' Facility		(43)	9,543
Post, Publications & Photocopying		27,939	22,928
Telephone/Internet		4,100	4,220
Website		5,315	3,154
Computer Services		19,057	21,934
Meeting Expenses		19,194	19,429
Safety/Supply Activities		147	291
A.G.M & Annual Conference		50,237	37,285
Information & Support Conferences/Meetings		9,919	7,733
Members' Conference		46,211	54,173
Ageing Conference		-	11,561

Parents' Conference	29,861	-
Women with Bleeding Disorders Conference	8,982	-
Legal and professional	500	-
Sponsorship/Training	1,016	1,613
Unrecoverable Vat	27,123	24,322
Bank charges	1,931	2,101
General expenses	14,528	4,225
Provision for Sinking Fund	30,000	26,000
Auditor's remuneration	6,115	5,615
Depreciation of tangible assets	40,395	40,395
Total Overheads	759,422	715,721

Expenditure



Balance Sheet

As at 31 December 2023

		2023	2022
	Notes	€	€
Fixed Assets			
Tangible assets	8	1,011,283	1,051,678
Investments	9	342,495	322,178
		1,353,778	1,373,856
Current Assets			
Debtors	10	21,824	10,767
Cash and cash equivalents		1,152,837	1,081,347
		1,174,661	1,092,114
Creditors: amounts falling due within one year	12	(133,704)	(86,609)
Net Current Assets		1,040,957	1,005,505
Total Assets less Current Liabilities		2,394,735	2,379,361
Reserves			
Capital reserves and funds		273,220	243,220
Income and expenditure account		2,121,515	2,136,141
Members' Funds		2,394,735	2,379,361

Snapshots of 2023



**Regional visits to Cork, Athlone,
Galway & Donegal**



**January 2023
Visit from the Scottish Haemophilia Society**



**March 2023
AGM & Conference**



**July 2023
Parents Conference**



**September 2023
VWD Information Day**



**October 2023
October Members' Conference**



**December 2023
Women & Bleeding Disorders
Conference**



**Staff CPR & Manual Handling
Training**

Corporate Sponsors

The Irish Haemophilia Society would like to acknowledge the financial contributions made in 2023 by the following companies, under our Corporate Giving Programme:

Platinum Sponsors

Biomarin, CSL Behring, Novo Nordisk, Roche, Sobi

Fundraisers

The Irish Haemophilia Society would like to thank with gratitude, everyone who fundraised for the Society during 2023.

Volunteers

The Irish Haemophilia Society would like to acknowledge and to thank everyone who volunteered for the Society during 2023.

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 2023.



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