

# IRISH HAEMOPHILIA SOCIETY

*Representing people living with haemophilia, von Willebrand's & other inherited bleeding disorders*



## ANNUAL REPORT 2022



Haemophilia.ie

# CONTENTS

Chairperson's Report .....	Page 3
Honorary Secretary's Report .....	Page 7
The Year in Review from our CEO .....	Page 11
Financial Report for 2022 .....	Page 14

## The year 2022 in Photos



# CHAIRPERSON'S REPORT

## Who We Are and What We Do

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

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

Additionally, we collaborate with the medical teams within the health service, namely the National Coagulation Centre (NCC), Children's Health Ireland (CHI), Cork University Hospital (CUH), and other healthcare and people within the field of haematology.

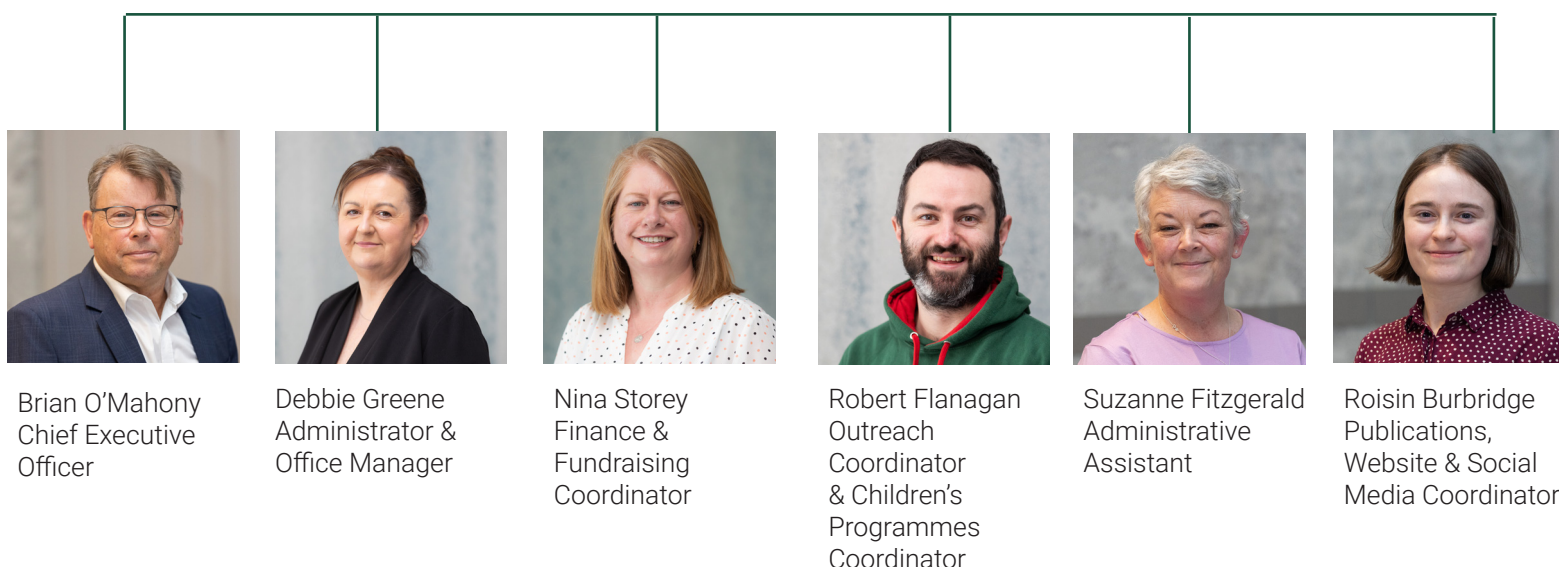
Outreach is an important function provided by the IHS. Our Outreach Coordinator is happy to arrange home or hospital visits, be it just for tea and a chat, or advise on how best to address a particular issue that may arise for a member.

## Board and Staff

The Executive Board comprises 10 members; Mary-Clare Delaney, Aislinn Farrelly, Barbara Wynne, Jim O'Leary, Seamus McDonald, Donal McCann, Dan McIntyre, Breda Quealy, Paul Dunne and myself.

At present, there are 6 staff in the Society, Brian O'Mahony, Debbie Greene, Nina Storey, Robert Flanagan, Suzanne Fitzgerald and Roisin Burbridge who do a tremendous job in keeping the organisation functioning. The Society typically retains a permanent staff of 7 and therefore, aims to recruit one additional staff member in 2023.

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



## Conferences and Events

The 2022 AGM was the first fully attended event post Covid-19 and it was wonderful to be able to meet everybody again. 156 people attended the event and it was a resounding success.

The October Conference was an even bigger success with 219 in attendance. We were delighted to have members of the Ukrainian haemophilia community in attendance, although we would have preferred had they visited under better circumstances. While the whole weekend was a great event, it is apparent that the drumming workshop was the highlight.

Throughout 2022, we had several other events, including a Newly Diagnosed Information Day in July, an Ageing Conference in September and a Von Willebrand's Disorder Information Day in December.

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 allow new members, especially those with a new diagnosis, something that is especially challenging, to feel welcomed and supported. I distinctly remember the welcome and support Ellie and I received as 'newly diagnosed' members when we attended our first conference.

## Grants and Awards

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

There are three categories of grant available:

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

In 2022, 23 applications were received and €17,350 was distributed amongst those who applied. I should point out that the standard of application is of a very high quality. For more information on educational grants, see I.H.S. Educational Grants on the website.

At the 2022 AGM, it was decided to create a new education award in honour of Michael Davenport. This award will be for people returning to education and will provide financial assistance for up to 4 years. While it was not awarded in 2022, a special merit award in Michael's honour was awarded instead.

Three young members were presented with the Gerry O'Reilly Courage Award in 2022. This award is presented to young members who overcome some significant challenges related to their diagnosis or treatment.



The Gerry O'Reilly Courage Award being presented to Adam Sygieda, Jacob Sygieda and Jason Rossiter



## Fundraising

Fundraising is 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 every event that is organised 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 2022, members raised €2,601 through events and activities they organised to raise money for the organisation.

Planned Giving is another important fundraiser for the Society. The funds raised through Planned Giving is divided between the twinning programme with Jordan and the apartments facility. The apartments are a hugely valuable asset to which members have access. 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 €14,329 in 2022 and members also donated an additional €9,845. Thank you all so much.



Pictured above are those who raised money for the Society by taking part in a skydive: Aaron Elliott, Aideen McNamara, Elliott Craig, Jack Carey, Daniel Grant, Keith Kirwan

## Hyde Square Apartments

The apartments have 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 116 times during 2022.

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

## Communications

The IHS website was redesigned in 2022 and will go through further upgrades throughout 2023.

Twenty ezines were published in 2022, which have a considerable subscription list. 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.

The 'Finding Von Willebrand's Awareness Campaign' was perhaps the most significant digital campaign of 2022. Thanks so much to Shannon, Donal, Breda and Dr. Michelle Lavin for contributing to much to this campaign and making it such a success. There have been tens of thousands of views on YouTube.

## Volunteers

I can't thank the volunteers enough for the trojan work they do at the conferences and events that occur each year.

We had 42 volunteers helping out at the AGM in 2022, and it was fantastic to see them back supporting our Society.

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 that we willingly make.

During 2022, in addition to the Board meetings, we held a Strategic Planning Review. The purpose of this was to review the current strategic plan and ensure we are on track to complete it within its lifetime and also to start to think about what may be important in the next strategic plan.

### Twinning

The Society commenced a Twinning Programme in Jordan in 2018. We had to cancel our planned visits to Jordan in 2020 and 2021 due to the pandemic. A planned visit to Jordan in 2022, unfortunately, had to be postponed. We are planning on returning to Jordan again in 2023 with a view to progressing the twinning programme there.

### Conclusion

When I wrote my report in 2022, I was celebrating the end of Covid-19 restrictions and looking forward to a freer society. Then the war in Ukraine started. The war has had a terrible impact on Ukraine, but the international outpouring of support given to the people of Ukraine has been tremendous. Hopefully, by this time next year (or long before), the war will have ended and the rebuilding of Ukraine have commenced.

Nevertheless, it is heart-warming to know that the IHS has been able to provide support to the Haemophilia community in Ukraine and to their members who have moved to Ireland.

I truly hope that, if I am writing this next year, the world will be a safer, happier place. In the meantime, let's all continue to support one another. I look forward to meeting you, our members, throughout the year at various events.

Regards,

**John Stack,  
Chairperson.**



# HONORARY SECRETARY'S REPORT

At the 33rd Annual General Meeting of the Irish Haemophilia Society (I.H.S.), which was held in the Slieve Russell Hotel in Cavan on 5th March 2022, the incoming Governing Body of the Society were elected as follows:

- Mary Clare Delaney
- Aislinn Farrelly
- Donal McCann
- Seamus McDonald
- Dan McIntyre
- Jim O'Leary
- John Stack
- Barbara Wynne

At the first executive meeting following the AGM on 28th April 2022, the following officers were elected:

- Chairperson John Stack
- Vice-Chairperson Mary Clare Delaney
- Honorary Secretary Barbara Wynne
- Honorary Treasurer Aislinn Farrelly

At a meeting of the executive board on 19th May 2022 the following members were co-opted onto the board:

- Breda Quealy
- Paul Dunne

In the period since the last AGM:

- Eleven executive board meetings took place.

## The 2022 Executive Board



John Stack  
Chairperson



Mary Clare Delaney  
Vice-Chairperson



Aislinn Farrelly  
Treasurer



Barbara Wynne  
Honorary Secretary



Seamus McDonald



Donal McCann



Jim O'Leary



Dan McIntyre



Paul Dunne



Breda Quealy

## CONFERENCES & EVENTS

### AGM & Annual Conference

The AGM & Annual Conference took place over the weekend of the 4th to 6th March in the Slieve Russell Hotel in Cavan. The programme consisted of talks and lectures on topics such as: Novel therapies and Gene Therapy, Physiotherapy and an Open Forum. The conference went very well with 113 adults and 43 children in attendance.

### Newly Diagnosed Information Day

This event took place on Saturday 16th July in Castleknock Hotel in Dublin and was put together in conjunction with CHI Crumlin. The programme consisted of topics such as: A Clinical Overview of Haemophilia, Support Available from the I.H.S., Physiotherapy and some Personal Stories. The event was informative and educational with 28 in attendance.

### Ageing Conference

The Ageing Conference took place over the weekend of 2nd to 4th September in the Hodson Bay Hotel in Athlone. Topics that were covered at this conference included: Physiotherapy, An Update from a GP, Balance and Mobility Issues, A Perspective from a Geriatrician and An Update on the HAA Card. We had 43 members in attendance at this conference.

### October Conference 2022

The October conference took place over the weekend of 14th to 16th October in Mount Wolseley Hotel in Carlow. The programme consisted of workshops on Gene Therapy and Selecting the Right Treatment, A Lecture on Insurance, Some Personal Experiences from Members and a fantastic Drumming Workshop on Sunday morning. This conference went very well with 154 adults and 65 children in attendance.

### Von Willebrand's Disorder Information Day

This event took place on Saturday 3rd December in the Maldron Hotel in Ballsbridge with 22 people in attendance. The programme included Updates on Treatment, and Overview of von Willebrand's Disorder and Supports available from the Society.

## PHYSIO-EXERCISE CLASSES

Throughout 2022, the Society continued with the weekly Zoom physio-exercise classes, with a total of 34 classes taking place in 2022. Unfortunately, we didn't get the numbers to continue with the women's classes and had to cancel same in February 2022.

## OUTREACH

Over the course of 2022, in excess of 1,065 phone calls were made to members to offer support and assistance. During 2022 the Society gave support and continue to give support to some Ukrainian Refugees with bleeding disorders.

## PUBLICATIONS, SOCIAL MEDIA & WEBSITE

During 2022, the Society produced 4 quarterly magazines, 2 novel therapies publications and the annual report. The Society launched a new website in April 2022. Social media platforms continue to work well for the organisation. The Society continues to have a strong presence online with 1,700 followers on Facebook, 1,343 on Twitter and 177 on Instagram. The Society continued distributing the electronic magazine Ezine, which has proved to be very popular, so much so that we have 450 people signed up for this. In 2022 a total of 20 Ezines were produced.

## DATABASE

The new membership database is proving an excellent investment.

## HYDE SQUARE

The apartment facility for member was occupied as follows in 2022:

- The one bedroomed apartment was occupied for 29 nights
- The two bedroomed apartment was occupied for 87 nights



## FUNDRAISING

A total of €2,601 was raised through fundraising in 2022.

## DONATIONS

A total of €9,845 was donated in 2022 by members of the organisation.

## PLANNED GIVING

A total of €14,329 was raised by planned giving in 2022.

## VOLUNTEERS

We would like to thank our 42 volunteers who gave up their time to work at the AGM and October Conference in 2022. Our volunteers do very important work for the Society and we are very grateful to them.

## GRANTS & AWARDS

### Educational Grants

A total of 23 educational grants were awarded in 2022, totalling €17,350 paid out to applicants, following an application, review and selection process including a rigorous scoring system.

- The Maureen & Jack Downey Educational Grant recipient was Gabriel O'Connor.
- The Margaret King Educational Grant recipient was Tadgh Moriarty.
- The Father Paddy McGrath Educational Grant recipient was Daniel Hanney.
- Although the newly announced Michael Davenport Educational Grant was not awarded in 2022, a special merit award in memory of Michael Davenport was given to Nicola Pentland from Northern Ireland.

### Awards

- The Brian O'Mahony Award was not given out in 2022 for 2021.
- The Gerry O'Reilly Courage Award recipients were:
  - o Jason Rossiter aged 16
  - o Adam Sygieda aged 8
  - o Jacob Sygieda aged 10

# How members raised money for the Society in 2022



## STAFF

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)
- Suzanne Fitzgerald (Administrative Assistant)
- Roisin Burbridge (Publications, Website & Social Media Coordinator)

Barry Healy resigned on 12th May 2022. Suzanne Fitzgerald started working for the Society on 20th April 2022 and Roisin Burbridge started working for the Society on 4th July 2022.

## SOCIETY REPRESENTATION

The Society was 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 & Declan Noone
- 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 & Donal McCann
- 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



This was the year when we started getting back to normal with a mixture of more in person and fewer virtual events. During the course of the year we organised 5 in person conferences or events. This was composed of our Annual General Meeting and Conference, our October conference, an Ageing Conference, a von Willebrand Disorder Information Day and a Newly Diagnosed Information Day.

The AGM and conference in March was our first such event after Covid. It was really good to see people getting back together again and it was obvious based on the interaction at the weekend that members had missed each other's company and were enjoying being part of this in person community once again. The programme for the weekend included an update on current and novel therapies, lectures on gene therapy, on experience with Emicizumab in adults and children, an update on von Willebrand's disorder, a lecture on the first years experience with our physiotherapy and exercise programme and an open forum discussion. We then had a number of smaller events during the year prior to the October Members Conference including the Ageing Conference, Newly Diagnosed and von Willebrand's Information days. At the Members Conference the programme was more interactive and included a panel discussion where members discussed their personal experiences with different therapies including several currently in clinical trials. There was also a panel discussion on haemophilia in Ukraine where the speakers were our new members from Ukraine followed by two interactive workshops on gene therapy and on selecting the right individual treatment for a child. The Newly Diagnosed Information Day was a very nice event which gave families, some of whom had no previous history of haemophilia, an opportunity not just to get information about the condition but also to meet other families in the same situation. Our von Willebrand Information Day included an update on treatment and care and a panel of speakers who themselves have von Willebrand disorder. The Ageing Conference included an update on ageing and sessions on working with your GP, on balance and mobility issues and an update from a geriatrician who, interestingly, has haemophilia himself. The events during the year were well attended and very successful. We had very few zoom webinars during the year in contrast to 2020 and 2021. There was definitely a degree of Zoom fatigue among members.

During the course of the year we also organised a von Willebrand disorder awareness campaign. This included the full involvement of three members with von Willebrand disorder and one doctor. The campaign included four videos which are now posted on our website and were made available on YouTube, a series of infographics, several newspaper articles in national and regional newspapers and a series of content on GP targeted webinars. The videos to date have had more than 60,000 views on YouTube. This was the 2nd successive year in which we carried out a von Willebrand's awareness campaign and we will be reviewing the need for this on an ongoing basis. The Society also implemented a new policy during the year whereby in order to increase awareness of issues faced by women with bleeding disorders, we are now distributing free period products at all of our conferences and events.

## About the campaign

<p>x3 videos featuring people living with VWD</p>	<p>X1 video featuring Consultant Haematologist</p>	<p>Campaign page on haemophilia.ie</p>
<p>Press release and featured interviews</p>	<p>You Tube in-feed ads</p>	<p>GP Buddy Partnership</p>

The appalling Russian invasion of Ukraine resulted in 10 people with haemophilia or inherited bleeding disorders moving to Ireland from Ukraine during the course of 2022. The Society had been in communication with the patient organisation in Ukraine and also with the haemophilia society in Poland so on some occasions we were aware of and in contact with individuals who were travelling to Ireland and were able to liaise with them. We were also in contact with the Irish Red Cross and we suggested to them that any person with haemophilia or other inherited bleeding disorder who arrived in the country should be located in or near Dublin because of the requirement for them to attend either the adult or paediatric national comprehensive care centres. The majority of those with haemophilia who arrived from Ukraine did fly into Dublin but some also flew into Knock airport in the West so we do have some people with haemophilia now located outside of Dublin. The Society has been assisting our Ukrainian friends with their orientation to Irish life including accompanying them to their first review appointments at the national centre and ensuring translation facilities were in place. We also organised for all Ukrainians with haemophilia and their relevant family members to be invited to our October Conference to meet each other and to meet members. During the conference, they spoke about haemophilia care in Ukraine. This was very educational for our members.

The Society also continued our work on and contribution to the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB). During the course of the year, the HPSMAB mainly carried out procurements for von Willebrand factor, factor X and Eficizumab. For the first time the factor X being used in Ireland is now a pure factor X concentrate. Clinical trials also continue and there are people with haemophilia now on clinical trials for factor IX gene therapy, for the re balancing agent fitusiran, for the mimetic Mim 8 and for the new extended half life factory VIII concentrate efenestacog alfa. During the course of the year the HPSMAB was also formally made a sub committee of the National Haemophilia Council.

Our publications during the year included four regular magazines, two novel therapies reports, an annual report and 20 e-zines. It was clear from feedback received from members that they appreciated the e-zines and there is clearly a need to give more regular information and updates. Consequently we will continue producing e-zines every two weeks in the future .They are a very useful method of getting current information out to members and also a vehicle for centres to give updates and information to our members on a regular basis.

The physiotherapy and exercise classes continued during the year for men with haemophilia with sessions taking place weekly. This innovative approach to lifestyle modification has been very beneficial to those participating and indeed our approach has now been taken up by centres in both Japan and Nigeria.

## The year 2022 in publications



Spring, Summer, Autumn, Winter Quarterly Magazines



April 2022 2021 Annual Report



Two Novel Products Publications



Bi-weekly E-Zines

Our twinning programme with Jordan was not very active during the year. We organised a number of events on zoom but there is no doubt that the programme requires an in person visit from the Society team and this is planned for next year to coincide with the planned visit from the centre teams.

We also welcomed the leadership team from haemophilia Northern Ireland who spent a day at our office meeting with our staff and some board members. This was a very constructive meeting in which each organisation was updated on the work of the other. Following this meeting I was also invited to speak at the AGM of Haemophilia Northern Ireland. It is clear that there is scope for increased collaboration in the area of the smaller meetings where if we were to do these jointly we would have a significant increase in potential attendees. This collaboration and dialogue will continue.

Work on the website continued during the year and this will continue into next year with new content being added. The educational grants were again awarded this year. These provide an opportunity from the Society to encourage and assist members attending third level education.

There were some encouraging developments in terms of comprehensive care and also some remaining challenges. A second consultant haematologist was appointed to the haemophilia service at Children’s Hospital Ireland at Crumlin and a new haemophilia nurse specialist was appointed to Galway University Hospital. Access to the H&H ward in St James’s Hospital remained severely constrained during the year with access only for some planned orthopaedic surgeries. The Society continued to advocate during the year for access to this ward for people with bleeding disorders to be reinstated as the ward was specifically designed and funded to include treating people with haemophilia and inherited bleeding disorders.

The finances for the year were satisfactory. There was a small deficit based on income of €688,000 and expenditure of €715,000. We saw a decrease in corporate giving from pharmaceutical companies based partly on the fact that many of them now are not allowed to give unrestricted funding and also in donations from members. The latter was due to a significant one-off donation in 2021. The Board met on 11 occasions during the year with some in person meetings but mostly meeting by zoom. It was wonderful to see our volunteers back working with the children and teenagers at our conference and events. I want to finish by thanking our board, our volunteers and our staff team for all of their work and endeavours during the year.

**Brian O’Mahony,  
Chief Executive Officer.**

## The year 2022 through events



# Financial Report for 2022

## 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 2022 which comprise the Income and Expenditure Account, the Balance Sheet, the Reconciliation of Members' Funds, the Cash Flow Statement and 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 2022 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 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 gives 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 2022

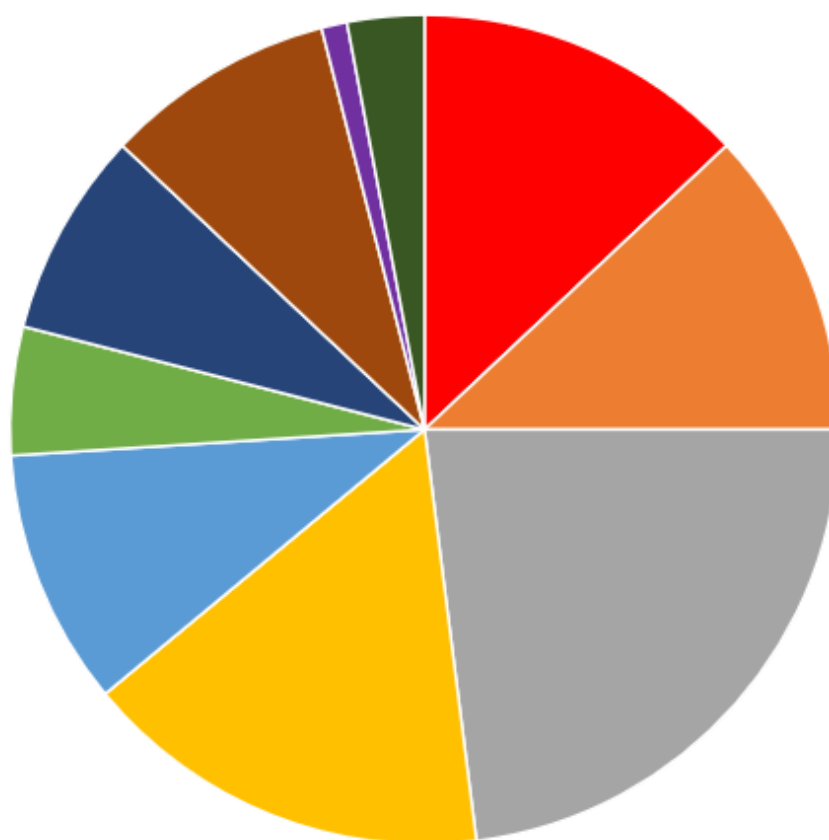
	Schedule	2022 €	2021 €
<b>Income</b>			
Health Service Executive		575,000	575,000
Membership		2,940	2,050
Donations - Members		24,174	137,566
Donations - Corporate		81,000	121,268
Fundraising		2,601	825
H.H.T Trust		-	3,500
Twinning		3,081	2,249
Investment Income		-	47
		688,796	842,505
Overhead expenses	1	(715,721)	(595,883)
		(26,925)	246,622
Investment (Loss)/Gain		(38,928)	20,824
<b>Net (deficit)/surplus</b>		<b>(65,853)</b>	<b>267,446</b>
<b>Expenditure</b>			
Wages and Salaries		266,386	251,235
Employers Prsi Contributions		29,428	27,762
Pension Costs		42,189	39,676
Services Charges & Insurance		25,894	19,698
Light, Heat & Services		13,123	7,981
Help To Members		8,545	13,178
H.H.T Trust		-	3,500
Subscriptions		1,781	1,435
Educational Grants		17,350	17,700
Twinning- Jordan/Vietnam Development Work		1,959	475
HQ Costs		5,605	120
Office Expenses, Stationery etc.		12,939	4,462
I.H.S Members' Facility		9,543	5,574
Post, Publications & Photocopying		22,928	28,488
Telephone/Internet		4,220	4,281
Website		3,154	37,317



Computer Services	21,934	17,117
Family Meetings/Activities	-	2,949
Meeting Expenses	19,429	2,672
Safety/Supply Activities	291	39
A.G.M & Annual Conference	37,285	444
Information & Support Conferences/Meetings	7,733	5,335
Members' Conference	54,173	11,726
Ageing Conference	11,561	-
Legal and professional	-	217
Sponsorship/Training	1,613	1,289
Unrecoverable Vat	24,322	12,494
Bank charges	2,101	1,639
General expenses	4,225	3,064
Provision for Sinking Fund	20,000	30,000
Auditor's remuneration	5,615	5,100
Depreciation of tangible assets	40,395	38,915
<b>Total Overheads</b>	<b>715,721</b>	<b>595,883</b>

## Expenditure

- Establishment/HQ
- AGM & Conferences
- Information & Support Conferences/Meetings
- Support to Members
- Publications & Website (includes Database & Research/Data Collection)
- Financial Support to Members
- Administration & Finance (includes Fundraising)
- Representation on Statutory & External Bodies
- International Development Assistance
- Unrecoverable VAT

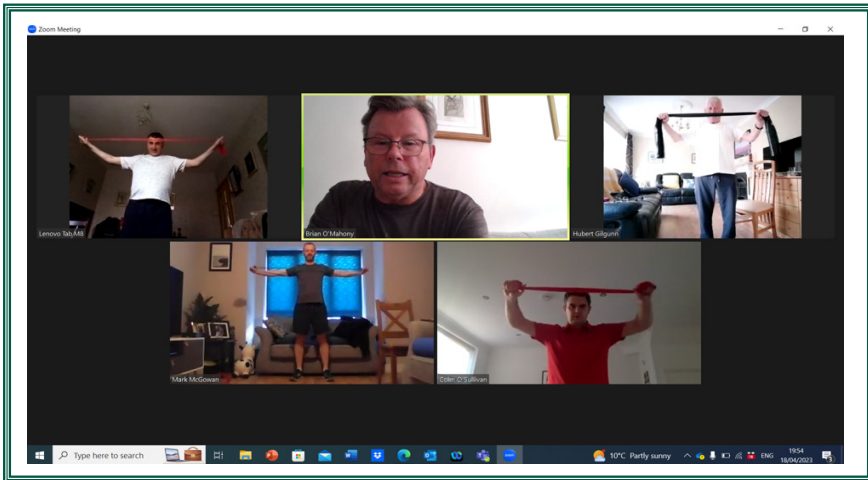


# Balance Sheet 2022

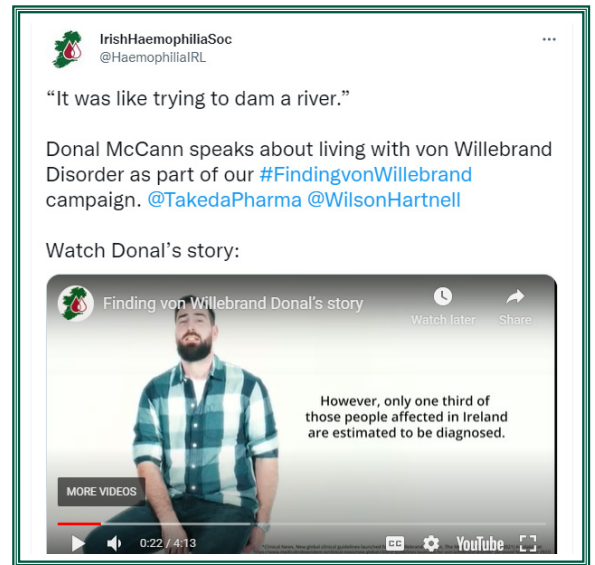
## As at 31 December 2022

		2022	2021
	Notes	€	€
<b>Fixed Assets</b>			
Tangible assets	8	1,051,677	1,081,593
Investments	9	322,178	361,106
		1,373,855	1,442,699
<b>Current Assets</b>			
Debtors	10	10,767	10,194
Cash and cash equivalents	11	1,081,347	1,053,736
		1,092,114	1,063,930
<b>Creditors: amounts falling due within one year</b>	12	(86,609)	(81,416)
<b>Net Current Assets</b>		1,005,505	982,514
<b>Total Assets less Current Liabilities</b>		2,379,360	2,425,213
<b>Reserves</b>			
Capital reserves and funds		243,220	223,220
Income and expenditure account		2,136,140	2,201,993
<b>Members' Funds</b>		2,379,360	2,425,213

# Snapshots from 2022



**Physio-Exercise**



**Finding von Willebrand Campaign**



September 2022  
**Visit from Haemophilia NI**



November 2022  
**AFFIRM group training in our office**



November 2022  
**SURO group training in our office**



December 2022  
**Strategic Planning Day**

### Corporate Sponsors

The Irish Haemophilia Society would like to acknowledge the financial contributions made in 2022 by the following companies, under our Corporate Giving Programme:

### Platinum Sponsors

CSL Behring, Roche, Sobi

### Gold Sponsors

Novo Nordisk, Takeda

### Fundraisers

The Irish Haemophilia Society would like to thank with gratitude, everyone who fundraised for the Society during 2022.

### Volunteers

The Irish Haemophilia Society would like to acknowledge and to thank everyone who volunteered for the Society during 2022.

### 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 2022.



## IRISH HAEMOPHILIA SOCIETY

First Floor  
Cathedral Court  
New Street  
Dublin 8

Tel: 01 6579900

[info@haemophilia.ie](mailto:info@haemophilia.ie)  
[www.haemophilia.ie](http://www.haemophilia.ie)

Find us on:

