

# IRISH HAEMOPHILIA SOCIETY

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



## ANNUAL REPORT 2021





# Contents

A Message from the Chairperson

Page 03

Honorary Secretary's Report

Page 05

The Year in Review from our CEO

Page 10

Financial Reports

Page 13

## 2021 in Pictures





# A Message from the Chairperson

## Who we are and what we do

The Irish Haemophilia Society (I.H.S.) 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's or CHI at Crumlin)
- Outreach

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

Outreach is an important function provided by the I.H.S. 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.

It seems like the last two years living under the Covid-19 pandemic has lasted a lifetime. Despite the difficulties of lockdown, I think the Society adapted well to the situation in which we found ourselves and did an excellent job in maintaining services to the best of its ability. I think everybody would agree with me that a huge 'thank you' is due to the staff of the Society.

## Board and Staff

In 2021 the Executive Board comprised of 9 members; myself, Mary-Clare Delaney, Aislinn Farrelly, Barbara Wynn, Jim O'Leary, Seamus McDonald, Donal McCann, Dan McIntyre and Jay McEvoy.

At the end of 2021, there were 5 staff in the Society, Brian, Debbie, Nina, Barry and Rob, who do a tremendous job generally, but did even more so during the pandemic. The Society typically retains a permanent staff of 7.

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.

## Conference and Events

As in 2020, most of the Society's events were virtual last year. The Virtual AGM was a strange experience but quite a success. It was our first experience with a large international

audience, something that I think the Society should capitalise on in the future as we spread our message about the importance of comprehensive and state-funded treatment.



Overall, the Society held over 50 different events on Zoom during 2021. Some of these were events that would have made up our traditional calendar of in-person events, others were information sessions on a broad variety of topics. A lot of them were to deliver the online physiotherapy and exercise programme, which we are continuing to run in 2022 and, hopefully, onwards.

The quality of these 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. If we have learned one thing from the pandemic, it's that online platforms like Zoom can play a very important role in the delivery of our services.

The October conference was our first attempt at an in-person event. Given the significance of the pandemic, this was limited to adults only. 33 members were in attendance and can only be described as a success. It also provided some insight into the running of larger events post-pandemic.

As the October event was an adults-only event, a trip to Dublin Zoo was organised for our younger members. The photos certainly indicate that a great time was had by all.

## 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 2021, 26 applications were received and €17,700 was distributed amongst those who applied. I should point out that the standard of application is of a very high quality. For more info on educational grants, see: [haemophilia.ie/services-and-support/educational-grants/](https://haemophilia.ie/services-and-support/educational-grants/)

## Fundraising

Fundraising is an important source of income for the Society. We are extremely grateful to the efforts people make to fundraise for the Society. The pandemic, of course, made it extremely difficult for fundraising activities to take place. 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.

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 apartment. The apartment is 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. The apartment was used 78 times during 2021.

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.

If you would like to avail of the apartment, please contact the office. The apartment is so important and valuable that we are considering the purchase of a second property close to St. James's Hospital. We feel that, when the Children's Hospital is completed, there will be even greater demand for the apartment.

## Communications

We have had to make a huge transition over to digital communications as a result of the Covid-19 pandemic and this also has been a success. Our website is currently being re-designed and will soon be launched to our members and the greater society.

In order to keep you, our members, informed, Barry created a series of e-Zines which proved to be very popular with over 600 subscribers so far. Social media has also played an important role in how the Society communicates and informs.

## Volunteers

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

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.

## 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. We are planning on returning to Jordan again in 2022 with a view to progressing the twinning programme there.

## Conclusion

When I wrote my report in 2021, I was looking forward to life post-pandemic when we would be in a position to lead normal lives again, without having to isolate from society. While 'normal' looks slightly different to what I'd envisaged, it is important that we still look out for each other and take care with sanitation, hygiene and mask-wearing in appropriate situations.

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.

**John Stack,  
Chairperson**



# Honorary Secretary's Report

At the 32nd Annual General Meeting of the Irish Haemophilia Society (I.H.S.), which was held virtually on the Zoom platform on Thursday 4th March 2021, the incoming Governing Body of the Society were elected as follows:



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

At the first executive meeting following the AGM on 25th March 2021, the following officers were elected:

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

In the period since the last AGM:

- Eleven executive board meetings took place.

At the end of 2021, the following members were serving board members:



John Stack,  
Chairperson



Mary-Clare Delaney,  
Vice-Chairperson



Aislinn Farrelly,  
Treasurer



Barbara Wynne,  
Secretary



Seamus McDonald



Donal McCann



Jim O'Leary



Jay McEvoy



Dan McIntyre

## Conferences/Events/Webinars

The COVID-19 pandemic hugely impacted our conferences and events again during 2021. However, the Society adapted very well and were able to arrange the following events and webinars during 2021.

### Virtual Annual Conference & AGM 2021

Our annual conference took place virtually over the evenings of 1st, 2nd and 3rd March 2021. Attendance was excellent at our annual event with many people attending from abroad. Our Annual General Meeting took place virtually on 4th March 2021.

The virtual AGM & Conference programme for 2021 was as follows:

### AGM & Conference 2021 (March 1-3 2021)

#### 01.03.21

Review of Novel Therapies  
An Overview of Gene Therapy

#### 02.03.21

Covid-19 & Vaccines  
The Use of Technology  
Dental Care  
Targeted Physio at Home  
Von Willebrand's Disorder (speaker/personal stories)

#### 03.03.21

Update on iPATH  
Resilience and Mental Health  
The Changing Face of Treatment in Ireland

### October Conference

In October we were delighted to be able to hold our first in person event since the start of the pandemic. The October Conference took place from 15th to 17th October in Mount Wolesey Hotel in Co. Carlow. The conference was only open to adult members with bleeding disorders. We had 34 members, 7 speakers and 5 staff attend this very worthwhile event.



Some of the topics on the programme included:

- Haemophilia Services & Support - Lessons from a Pandemic
- An Update on the Patient Portal / Lighthouse Project
- Treatment Options & Unmet Needs – The Next Five Years
- Debate: 'I Prefer Virtual Clinics/Care' VERSUS 'I Prefer In Person Clinics/Care'
- A presentation and discussion around Social Media
- Physio / Exercise Session with TheraBands



**The following Zoom Webinars which included our Physio/Exercise Programmes also took place in 2021:**

- 13.01.21 Coping during a pandemic with Dr. Patricia Byrne
- 28.01.21 An update on Factor VIII clinical trials with Dr. Beatrice Nolan
- 17.02.21 Staying Healthy at Home: Physiotherapy and Exercise Groups with Sheila Roche
- 24.02.21 Financial Support with Robert Flanagan and Pat Stagg
- 31.03.21 An update on Hemlibra for Parents with Dr. Beatrice Nolan
- 14.04.21 vWD with Dr. Michelle Lavin & Professor James O'Donnell
- 19.04.21 Personal Perspectives of living with vWD (Donal McCann, Breda Quealy, Barry Quealy, Shannon Carey)
- 28.04.21 An update from Barretstown
- 04.04.21 Physiotherapy/exercise class for PWH - Sheila Roche (Physiotherapist)
- 05.05.21 An update on COVID-19 Vaccines - Professor James O'Donnell
- 06.05.21 Physiotherapy/exercise class for vWD - Mark McGowan (Physiotherapists)
- 11.05.21 Physiotherapy/exercise class for PWH - Sheila Roche (Physiotherapist)
- 12.05.21 An update on Clinical Trials from NCC - Dr. Niamh O'Connell
- 13.05.21 Physiotherapy/exercise class for vWD - Mark McGowan (Physiotherapist)
- 18.05.21 Physiotherapy/exercise class for PWH - Sheila Roche (Physiotherapist)
- 20.05.21 Physiotherapy/exercise class for vWD - Mark McGowan (Physiotherapist)
- 25.05.21 Physiotherapy/exercise class for PWH - Sheila Roche (Physiotherapist)
- 26.05.21 Hemlibra - An update on new kits - Evelyn Singleton from NCC
- 27.05.21 Physiotherapy/exercise class for vWD - Mark McGowan (Physiotherapist)
- 01.06.21 Physiotherapy/exercise class for PWH - Sheila Roche (Physiotherapist)
- 03.06.21 Physiotherapy/exercise class for vWD - Mark McGowan (Physiotherapist)
- 08.06.21 Open Forum with Coagulation Centre in CUH - Dr. Cleona Duggan
- 08.06.21 Physiotherapy/exercise class for PWH - Sheila Roche (Physiotherapist)
- 10.06.21 Physiotherapy/exercise class for vWD - Mark McGowan (Physiotherapist)
- 17.06.21 Physiotherapy/exercise Educational Webinar for 4 groups - S Roche, M McGowan, P Byrne & Dietician
- 22.06.21 Physiotherapy/exercise class for PWH over 50 yrs - Sheila Roche (Physiotherapists)
- 24.06.21 Physiotherapy/exercise class for WBD - Mark McGowan (Physiotherapist)
- 29.06.21 Physiotherapy/exercise class for PWH over 50 yrs - Sheila Roche (Physiotherapists)
- 01.07.21 Physiotherapy/exercise class for WBD - Mark McGowan (Physiotherapist)
- 08.07.21 Physiotherapy/exercise class for PWH over 50 yrs - Sheila Roche (Physiotherapists)
- 13.07.21 Physiotherapy/exercise class for WBD - Mark McGowan (Physiotherapist)
- 15.07.21 Physiotherapy/exercise class for PWH over 50 yrs - Sheila Roche (Physiotherapists)
- 17.07.21 Physiotherapy/exercise class for WBD - Mark McGowan (Physiotherapist)
- 20.07.21 Physiotherapy/exercise class for PWH over 50 yrs - Sheila Roche (Physiotherapists)
- 22.07.21 Physiotherapy/exercise class for WBD - Mark McGowan (Physiotherapist)
- 27.07.21 Physiotherapy/exercise class for PWH over 50 yrs - Sheila Roche (Physiotherapists)
- 29.07.21 Physiotherapy/exercise class for WBD - Mark McGowan (Physiotherapist)
- 21.09.21 Physiotherapy/exercise class for PWH - programme recommenced this evening - Sheila Roche (Physiotherapist)
- 23.09.21 An Update on Clinical Trials & Hemlibra from CHI Crumlin - Dr. Beatrice Nolan
- 28.09.21 Physiotherapy/exercise class for PWH - Mark McGowan (Physiotherapist)
- 29.09.21 An update from NCC and on Clinical Trials - Dr. Niamh O'Connell
- 05.09.21 Physiotherapy/exercise class for PWH
- 12.10.21 Physiotherapy/exercise class for PWH
- 19.10.21 Physiotherapy/exercise class for PWH
- 26.10.21 Physiotherapy/exercise class for PWH
- 02.11.21 Physiotherapy/exercise class for PWH
- 09.11.21 Physiotherapy/exercise class for PWH
- 10.11.21 An update on Hemlibra for Parents with Dr. Beatrice Nolan
- 16.11.21 Physiotherapy/exercise class for PWH
- 17.11.21 Physiotherapy/exercise class for Women
- 23.11.21 Physiotherapy/exercise class for PWH
- 24.11.21 Physiotherapy/exercise class for Women
- 30.11.21 Physiotherapy/exercise class for PWH
- 01.12.21 Physiotherapy/exercise class for Women
- 07.12.21 Physiotherapy/exercise class for PWH
- 08.12.21 Physiotherapy/exercise class for Women
- 14.12.21 Physiotherapy/exercise class for PWH
- 15.12.21 Physiotherapy/exercise class for Women



## Outreach

Over the course of 2021, in excess of 962 phone calls were made to members to offer support and assistance.

## Publications, Social Media & Website

Over the course of 2021, the Society produced 4 quarterly magazines, 2 novel therapies publications, 2 Hemlibra booklets and the annual report. Social media platforms continue to work well for the organisation, as does the website. The Society continues to have a strong presence online with 1193 followers on Twitter and 1455 on Facebook. The Society continued distributing the electronic magazine e-Zine, which has proved to be very popular, so much so that we have 613 people signed up for this. In 2021 Barry produced 26 e-Zines.

## Database

The new membership database is proving an excellent investment.

## Hyde Square

With additional cleaning procedures in place around COVID-19, the apartment facility for member was open for quite a lot of 2021 with the one bed being occupied 34 times and the two-bed occupied 82 times.

## Fundraising

A total of €825 was raised through fundraising in 2021.

## Donations

A total of €23,392 was donated in 2021 by members of the organisation.

## Planned Giving

A total of €14,174 was raised by planned giving in 2021.

## Educational Grants & Assistance

A total of 26 educational grants were awarded in 2021, totalling €17,700, following an application, review and selection process including a rigorous scoring system.

## Staff

The current staff and roles are as follows:

- Brian O'Mahony (Chief Executive)
- Debbie Greene (Administrator & Office Manager)
- Nina Storey (Finance & Fundraising Coordinator)
- Barry Healy (Publications Editor & Social Media Coordinator)
- Robert Flanagan (Outreach & Children's & Youth Programmes Coordinator)



Julia Collins resigned on 8th March 2021 and emigrated to London.

## 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 & 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 Haemostasis Research Foundation – Brian O’Mahony
- Irish Blood Transfusion Service Board – Brian O’Mahony
- National Review of Clinical Audit Steering Group – Brian O’Mahony
- National Hepatitis C Clinical Advisory Group – 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 all our fundraisers.

Barbara Wynne,  
Honorary Secretary

## Staff at the end of 2021:



Brian O’Mahony



Debbie Greene



Nina Storey



Robert Flanagan



Barry Healy

# The Year in Review from our CEO

After the seismic shock of the Covid-19 pandemic in 2020, the Society had to plan and deal with a great deal of uncertainty in 2021. There was no foreknowledge of how long the pandemic would last and the degree of continued disruption to society as a whole was unknown. In reality, of course, we were all operating in full pandemic mode for the entire year. The communications pivot which we had made in 2020 toward a more digital footprint continued and increased.

During the course of 2021, we worked to keep members updated on a very regular basis with developments. The staff logged in excess of 1,000 phone calls with members where we proactively reached out to contact members in a methodical fashion to maintain a sense of in-person connection and to ensure we were aware of the concerns which were preoccupying members. Issues that arose very commonly in discussions included Covid-19 and vaccination, particularly additional information on protocols for vaccination of people with inherited bleeding disorders, benefits and entitlements, access to hospital services and the welfare of other Society members and the staff.

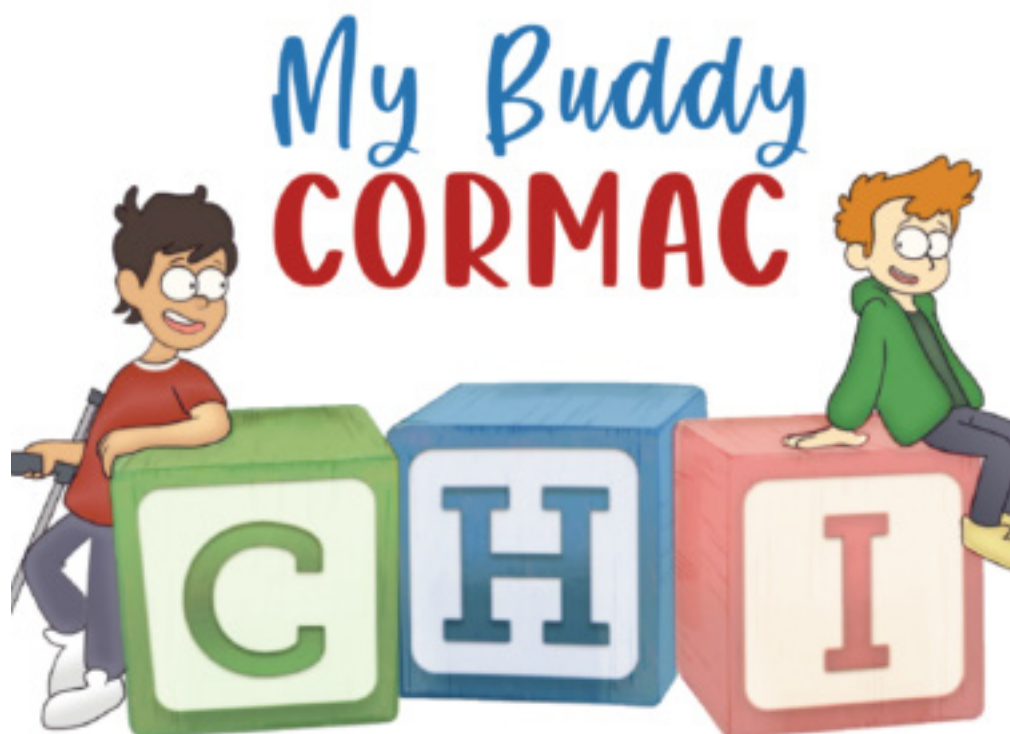
The continued phone contact with members provided us with a very useful set of issues and priorities on which we needed to communicate frequently. During the course of the year, we communicated frequently on our social media platforms, especially Facebook and Twitter. Our website was a constant source of information and we also carried out a significant amount of work on a new website which will be launched in 2022. We produced 26 e-Zines, typically once each fortnight. This enabled us to provide important up-

dated information on a regular basis on topics such as vaccination information and arrangements and access to hospital services.

We also collaborated with Children's Health Ireland at Crumlin and Munster Technological University to produce a short animated feature entitled "My Buddy Cormac" to familiarize children with haemophilia with coming to the Haemophilia centre. This was a novel venture which we would very much like to repeat and build on in the future.

We did not neglect the traditional publications route as we produced four quarterly magazines two novel therapies updates and two separate information booklets on Hemlibra - one for those with FVIII inhibitors and one for those with FVIII deficiency without inhibitors. A separate virtual initiative was the online physiotherapy and exercise classes which we initiated. Research from the Irish personalized approach to haemophilia (iPATH) study had shown that there was a significant deficit in activity and fitness among Irish people with haemophilia and that a significant proportion of people with haemophilia were overweight.

Our strategic plan for 2020 to 2024 has an emphasis on lifestyle change and improved health and fitness. As part of this direction we started online physiotherapy and exercise classes on a pilot basis with four disparate groups during 2021: men





with haemophilia aged over 50, men with haemophilia aged 35 to 50, people with von Willebrand Disorder and women with bleeding disorders. Each course was for an initial seven weeks with six weeks of online physiotherapy and exercise by zoom and the seventh week devoted to talks from a dietitian and a psychologist. The society provided TheraBands to participants and, later in the year, yoga mats to those who attended the in person physiotherapy sessions at our October conference. The only additional equipment participants required at home was a chair.

The classes worked very well. The specialist haemophilia physiotherapists from St. James's Hospital were very familiar with bleeding disorders and were able to tailor the exercises to the group and indeed to individuals. An average of 8 participants participated in each class. Following the successful pilot programmes, two ongoing classes were initiated- one for men with bleeding disorders and one for women. We expanded the group of physiotherapists to four to include also a haemophilia specialist physiotherapist from Cork University Hospital. By the end of 2021, the men's group was continuing strongly with a very good attendance on a weekly basis. The women's group was discontinued as the level of interest required to maintain the classes was not present. This initiative has demonstrated that an online exercise class is indeed feasible and beneficial for some of the community and there was a high degree of enthusiasm to continue this initiative in the men's group.

Our annual conference in 2021 took place fully online using the zoom platform. The conference was very successful and in total, we had 107 attending on Monday, 106 on Tuesday and 85 on Wednesday, including several attendees from overseas. The virtual nature of the conference also facilitated the attendance as guest lecturers of Prof. Flora Peyvandi from Milan and Dr. David Lillicrap from Canada who spoke on Novel Therapies and Gene Therapy respectively.

Our strategic plan also envisaged greater recognition and awareness of von Willebrand's Disorder (VWD). This was the theme for our World Haemophilia day and week events in April 2021. It was a great success. With the active collaboration of the treatment centres, we were able to provide our new VWD booklet not just to the 140 people with VWD on our mailing list, but also to an additional 650 people with VWD on the national treatment register. Awareness and knowledge were raised also by two webinars, the release of 20 ethnographic video clips on social media featuring members with VWD speaking about their lived experience, a short animated video and significant media coverage in newspapers, magazines and on television. The coverage featured not just clinical information about VWD but also both men and women with VWD speaking about their lived experience.

In October, following months of planning and contingency planning, we were able to proceed with our first in person event since the pandemic started in March 2020. We organized a Members Conference for adults only in Carlow at-

Premium

### Bruising, nosebleeds and heavy periods in women – the symptoms of an underdiagnosed inherited disease that affects one in every 1000 Irish people

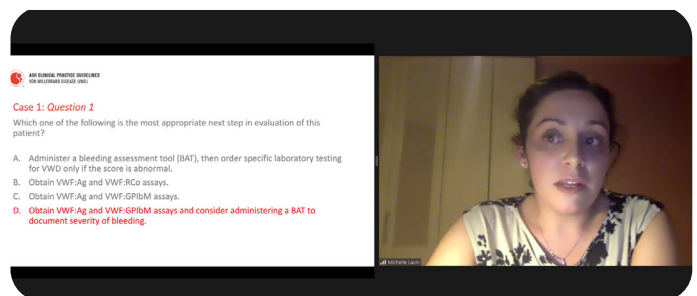
Co Meath man Donal McCann suffers from bleeding disorder Von Willebrand disease. He shares what life is like with the condition, his relief at not passing it on to his daughter and why he is telling his story to raise awareness



Donal McCann with his 16-month-old daughter Darcy. Pic: Mark Condren.



### WHD 2021 with an emphasis on VWD and below, our Virtual AGM & Conference 2021



### What have we learned?

- Efficacy in clinical trials is translating to real world effectiveness
  - Israel, UK, Ireland (HCWs)
- Vaccine may protect against asymptomatic infection as well
  - UK SIREN study
- Reduced viral load in infected vaccinated individuals
  - Reduced duration of infectiousness
- Single dose may suffice in those previously infected with SARS-CoV-2

Transmission

### rFVIII-Fc-VWF-XTEN (BIVV001)

- New class of FVIII replacement, uncoupled from endogenous VWF breaking the VWF-imposed half-life ceiling
- In Phase 1 repeat-dose study, 4 once-weekly infusion of 50 IU/kg associated with:
  - mean FVIII activity of **48% at 3 days** and **10% at 7 days**
  - FVIII mean (range) half-life was **41.3 (34.2-50.1) hours**





*Members Conference 2021*

tended by a total of 46 adults. The programme included an update on services and support during the pandemic, the patient portal, a workshop on treatment options and unmet need and an in person physiotherapy and exercise class.

The workshop took a novel approach where the members and their partners were asked to consider the different types of therapies now available and in clinical trials including extended half life factor concentrates, bi-specific antibodies re-balancing agents and gene therapy. There was a full discussion and consideration of each type of therapy and the potential benefits and risks in the context of the remaining unmet needs of individuals. It was an excellent exercise which demonstrated to the members the complexity of thought and decision making which will be required in the future as we take an individualized approach to treatment.

The physiotherapy and exercise class was very well attended with 26 members joining and enjoying the session. The conference was a great success and those present really enjoyed the opportunity to meet old friends and make new acquaintances in person after eighteen months of virtual interaction.

Despite the pandemic, the comprehensive care centres managed to switch a significant number of both children and adults to the licenced bi-specific antibody therapy for FVIII deficiency. In addition, the Society, working with Prof. Niamh O'Connell from the National Coagulation Centre and Brian Fitzgerald, Chairperson of the National Haemophilia Council produced a comprehensive Gene Therapy business case which we submitted to the Health Service Executive and Department of Health. We hope this will pave the way for gene therapies, when they are licenced to be available as options for people with haemophilia who may be eligible to receive gene therapy.

Financially, the Society had a strong year with a surplus of €267,000. This was a great help in enabling us to purchase



a second apartment for the use of members in the Hyde Square development very near to St. James's Hospital. This will become even more valuable to the Society and the members when the new children's hospital opens in 2024 or perhaps 2025. At that stage, it may become prohibitively expensive to purchase property in the area. By purchasing now, we are able to ensure we can provide the accommodation assistance required for members attending for out-patient appointments or in patient procedures into the future.

Finally, I want to acknowledge our Board who continued to meet virtually on a monthly basis during the pandemic, our volunteers whom we did not get a chance to see in person apart from a Christmas lunch we hosted for those available and our excellent hard working and adaptable staff team who all pulled together in what was another challenging yet ultimately innovative year.

**Brian O'Mahony,  
Chief Executive**



# Financial Reports 2021

## 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 2021 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 2021 and of its surplus for the financial year then ended;
- have been properly prepared in accordance with FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland", applying Section 1A of that Standard; and
- have been properly prepared in accordance with the requirements of the Companies Act 2014.

#### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (Ireland) (ISAs (Ireland)) and applicable law. Our responsibilities under those standards are described below in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the company in accordance with the ethical requirements that are relevant to our audit of financial statements in Ireland, including the Ethical Standard for Auditors (Ireland) issued by the Irish Auditing and Accounting Supervisory Authority (IAASA), and the Provisions Available for Audits of Small Entities, in the circumstances set out in note 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 informa-

tion. 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.



**Auditors:**

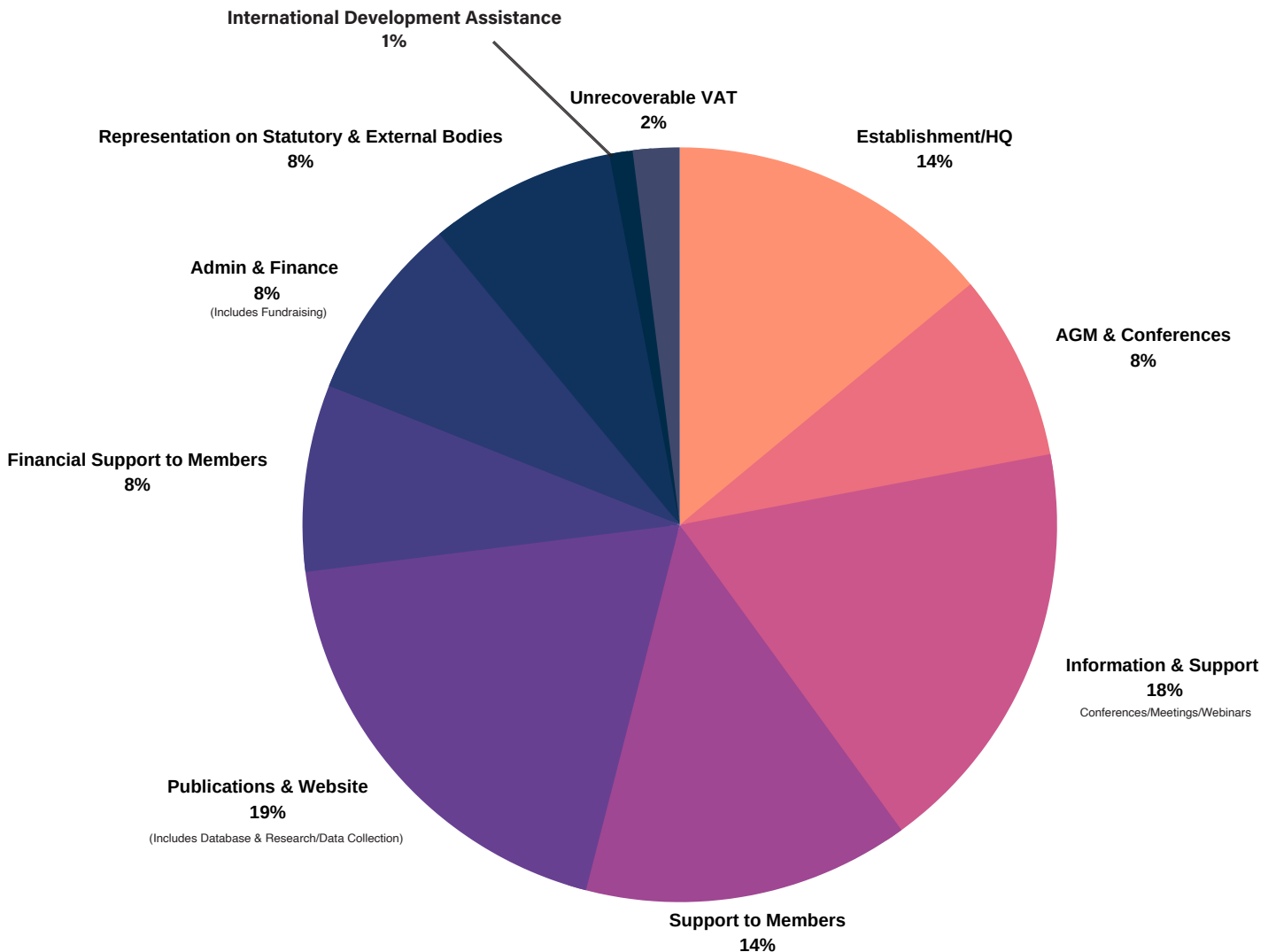
Howlin O'Rourke & Co.,  
Certified Public Accountants & Registered Auditors,  
4 The Seapoint Building, Clontarf, Dublin 3.

**Registered Office:**

Irish Haemophilia Society,  
First Floor, Cathedral Court,  
New Street South, Dublin 8. D08 VH64.

Company Registration Number: 142834.  
Registered Charity Number: CHY9214.

# Expenditure for 2021



Irish Haemophilia Society

Income and Expenditure Statement for the year ended 31 December 2021

	Schedule	2021 €	2020 €
<b>Income</b>			
Health Service Executive		575,000	575,000
Membership		2,050	1,929
Donations - Members		137,566	19,344
Donations - Corporate		121,268	99,754
Fundraising		825	6,828
H.H.T Trust		3,500	-
Twinning		2,249	-
Bank Interest Received		47	133
Sinking Fund Allocation for Works on HQ		-	5,780
		<u>842,505</u>	<u>708,768</u>
Expenses	1	(595,883)	(610,479)
		<u>246,622</u>	<u>98,289</u>
Investment Gains		20,824	12,778
		<u>267,446</u>	<u>111,067</u>

**Expenses**

Wages & Salaries	251,235	269,535
Employers Prsi Contributions	27,762	29,784
Pension Costs	39,676	36,401
Service Charges & Insurance	19,698	18,872
Light, Heat & Services	7,981	7,078
Help To Members	13,178	12,970
H.H.T Trust	3,500	2,000
Subscriptions	1,435	1,507
Fundraising	-	152
Educational Grants	17,700	18,250
Twinning- Jordan	475	901
HQ Costs	120	5,995
Office Expenses, Stationery etc.	4,462	13,595
I.H.S Members' Facility	5,574	5,948
Post, Publications & Photocopying	28,488	20,935
Telephone/Internet	4,281	4,655
Website	37,317	4,105
Computer Services	17,117	19,811
Family Meetings/Activities	2,949	-
Meeting Expenses	2,672	7,855
Safety/Supply Activities	39	66
A.G.M & Annual Conference	444	38,857
Information & Support Conferences/Meetings	5,335	1,686
Members' Conference	11,726	261
Legal and Professional	217	-
Sponsorship/Training	1,289	150
Unrecoverable Vat	12,494	15,686
Bank Charges	1,639	1,268
General Expenses	3,064	6,689
Provision for Sinking Fund	30,000	30,000
Auditor's Remuneration	5,100	4,900
Depreciation of Tangible Fixed Assets	38,915	30,567
	<u>595,883</u>	<u>610,479</u>
<b>Total Expenses</b>	<u>595,883</u>	<u>610,479</u>

## Irish Haemophilia Society

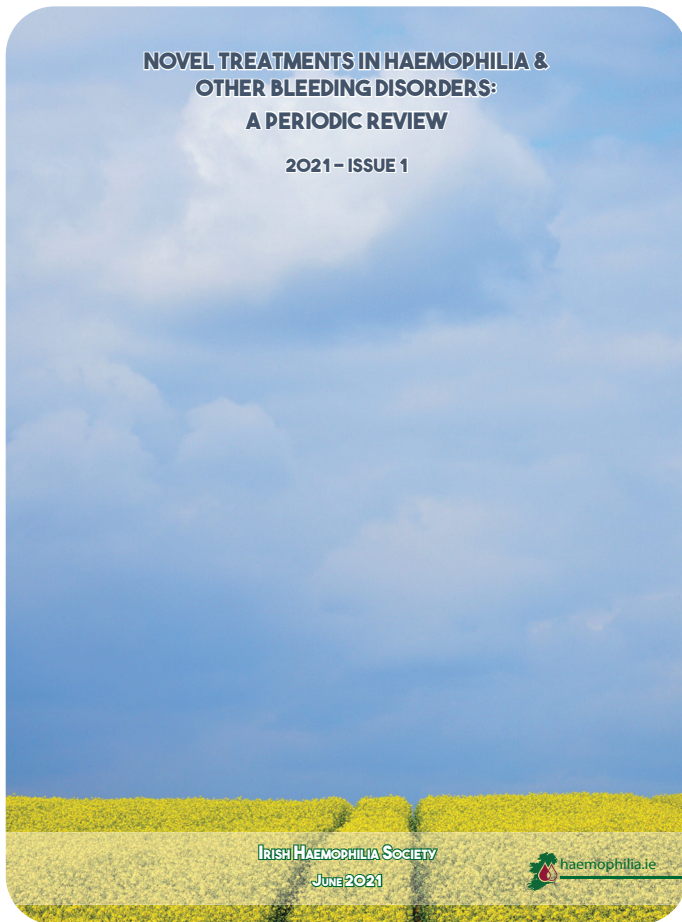
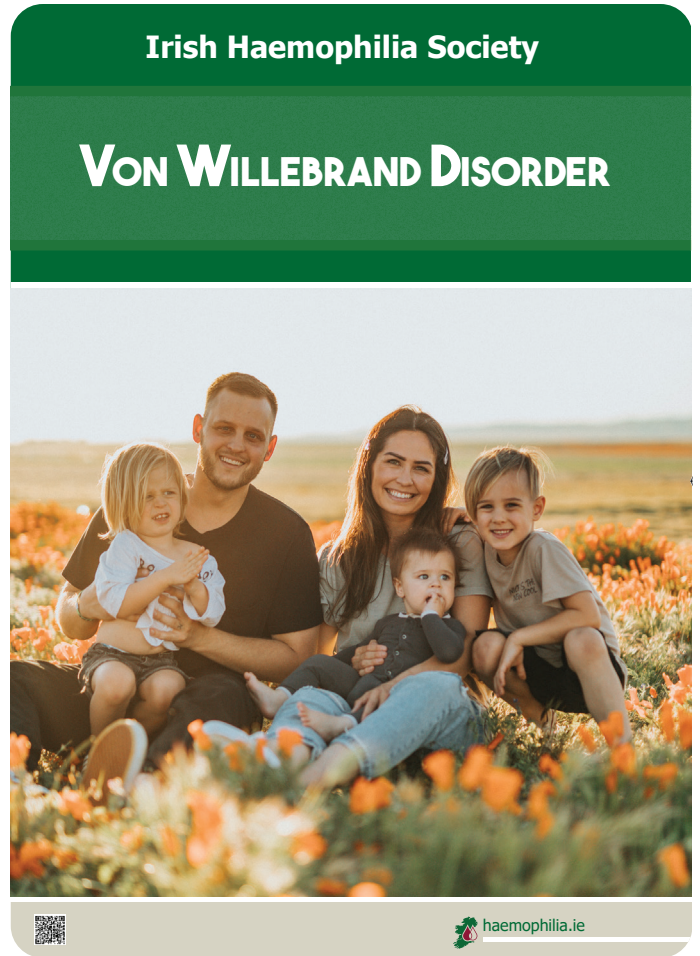
### BALANCE SHEET

as at 31 December 2021

		2021	2020
	Notes	€	€
<b>Fixed Assets</b>			
Tangible assets	8	1,081,593	739,980
Investments	9	361,106	340,282
		<u>1,442,699</u>	<u>1,080,262</u>
<b>Current Assets</b>			
Debtors	10	10,194	12,433
Cash and cash equivalents		1,053,736	1,175,155
		<u>1,063,930</u>	<u>1,187,588</u>
Creditors: amounts falling due within one year	11	(81,416)	(140,083)
<b>Net Current Assets</b>		<u>982,514</u>	<u>1,047,505</u>
<b>Total Assets less Current Liabilities</b>		<u>2,425,213</u>	<u>2,127,767</u>
<b>Reserves</b>			
Capital reserves and funds		223,220	193,220
Income and expenditure account		2,201,993	1,934,547
<b>Members' Funds</b>		<u>2,425,213</u>	<u>2,127,767</u>



# A LOOK BACK AT 2021



# WORLD HAEMOPHILIA WEEK 2021 THEME: VON WILLEBRANDS DISORDER



Join the Irish Haemophilia Society as we use World Haemophilia Week 2021 to highlight von Willebrand's Disorder. We have a packed programme of digital and virtual events

#### Programme:

- Wednesday, April 14 @ 6pm: Webinar on 'vWD Guidelines & Research for Diagnoses & Treatment' with Dr. Michelle Lavin & Professor James O'Donnell.
- Thursday, April 15: Launch of New vWD Booklet & Social Media Campaign
- Friday, April 16: Launch of New Animated vWD Video
- Monday, April 19 @ 6pm: Webinar on 'Living with vWD', Personal Stories from I.H.S. members Breda Quealy, Barry Quealy, Donal McCann & Shannon Carey



SCAN ME

Irish Haemophilia Society  
haemophilia.ie | info@haemophilia.ie | 01 657 9900



## PRESS RELEASE



IRISH HAEMOPHILIA SOCIETY

### Inherited Bleeding Disorder May Lower Risk of Thrombosis with COVID-19 Infection

Inherited Bleeding Disorder May Lower Risk of Thrombosis with COVID-19 infection 1 in 5 of women with heavy periods will have an underlying bleeding disorder Tuesday 13th April, 2021: Von Willebrand Disorder (VWD), an inherited bleeding disorder which affects the [Read more >](#)



**IrishHaemophiliaSoc** @HaemophiliaIRL · 5h  
Von Willebrand Disorder (VWD) is the most common inherited bleeding disorder & VWD is the focus of our World Haemophilia week.

90% of people with VWD globally remain undiagnosed.

It is a complex condition. We hope this animated video will help raise awareness. #VWD #WHD2021

Von Willebrand's Disorder

18 views 0:32 / 1:00

**Ireland AM** @IrelandAMTV · Apr 16  
Also on Saturday's show:  
It's World Haemophilia Day tomorrow. We'll be meeting a 21 year old living with a rare bleeding disorder, hoping to raise awareness of her condition.  
[#IHAM](#) @HaemophiliaIRL

**Westmeath Woman Warning Others To Get Tested For Chronic Disease**

Monday, April 26th, 2021 1:32pm



A Westmeath woman with a genetic bleeding disorder is encouraging others to get tested instead of living in pain.

Von Willebrand disease can cause bruising, nosebleeds and lead to more serious discomfort for women once they reach puberty.

VWD is the most common inherited bleeding disorder with around one in 1,000 of the population being affected.

In men or children, easy bruising or frequent, heavy nosebleeds may be the first sign of a bleeding disorder.

The most common warning sign for women is heavy periods.

## IRISH Mirror

### Disorder may fight Covid & thrombosis

AN inherited bleeding disorder may lower the risk of thrombosis with Covid-19 infection.

The Irish Haemophilia Society is raising awareness of Von Willebrand Disorder for World Haemophilia Day on Saturday



### Corporate Sponsors

The Irish Haemophilia Society would like to acknowledge the financial contributions made in 2021 by the following companies, under our Corporate Giving Programme:

#### Platinum Sponsors

Roche, Sobi

#### Gold Sponsors

Bayer, CSL Behring, Takeda

### Fundraisers

The Irish Haemophilia Society would like to thank with gratitude, everyone who fundraised for the Society during 2021.

### Volunteers

The Irish Haemophilia Society would like to acknowledge and to thank everyone who volunteered for the Society during 2021.

### 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 2021.



## **IRISH HAEMOPHILIA SOCIETY**

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

**TEL: 01 657 9900  
FAX: 01 657 9901**

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

**FIND US ON:**

