

IRISH HAEMOPHILIA SOCIETY

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



ANNUAL REPORT 2020



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2020 AGM 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, Crumlin)
- Outreach

Additionally, we collaborate with the medical teams within the health service, namely the National Coagulation Centre (NCC), Children's Health Ireland, Crumlin, 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.

2020 was, without doubt, a very challenging year for the country due to the Covid-19 pandemic. 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

There were a number of changes to the Board in 2020, with Matthew McCabe stepping down. We co-opted two new members onto the Board, Mr. Dan McIntyre Mr. Jay McEvoy.

It was intended to recruit a new member of the staff last year. Interviews were held and a successful candidate identified. However, it was not possible to complete the recruitment due to the pandemic.

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

The Society had scheduled another great year of, mostly in person, events. However, the vast majority of these had to be cancelled due to the pandemic. In fact, the only in-person

meeting that took place in 2020 was our AGM. In order to circumvent the potential loss of many of our speakers for the event, we arranged a live link so that they could attend the conference remotely. This experience was such a valuable lesson for the Society that it became the template we applied throughout the entire year as we moved most of our events to the online platform Zoom.

Overall, the Society held 45 different events on Zoom. 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. We even held some casual events, such as quizzes, to help members stay connected.

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. I think that we can all agree that, without online meeting platforms like Zoom, it would have been impossible to deliver our calendar of events in 2020.

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 2020, 27 applications were received and €18,250 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 our website haemophilia.ie.

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, but some very dedicated and determined people were not to be put off!

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.

Planned Giving is another important fundraiser for the Society. The funds raised through Planned Giving is divided between the twinning programme 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 2020.

The apartment has proven to be such an important service for our members and the society is looking to purchase another apartment in the same area. 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.

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. We had 26 volunteers helping out at the AGM in 2020, the only in-person event we could hold. We look forward to seeing our volunteers helping out at in-person events again as soon as we can.

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 due to the pandemic. In addition to the annual visit by

Brian and I to meet our counterparts in Jordan, it had been arranged that Society staff would visit Jordan in 2020 to help with the establishment of certain services for the society in Jordan.

As these visits could not occur, we again relied on Zoom on which we held four workshops dealing with e-newsletters and publications, event planning and memberships, governance and strategic planning.

Having the Twinning programme on Zoom, once again, proved useful as it allowed a broader range of people from Jordan to attend these meetings, with some directly contributing and some observing. We scheduled these meetings for times that would suit most of the people with whom we wished to engage.

Conclusion

It seems like it's been a very long year since I wrote my Chairperson's Report 12 months ago. There has been a sense of putting everything on hold or treading water until we can resume some sort of normal lives post-pandemic. Many of us may have lost loved ones, and our worlds were, and continue to be, turned upside down. The lockdown, while inconvenient, did give us an opportunity to reflect and identify the things which really matter. As I wrote last year, our health, our sense of community and our need to connect with other people really matter. The importance of a well-funded, well-staffed and fully resourced health service is clearly critical. We owe a huge debt of gratitude to all of our frontline staff, regardless of where they work.

When all of this is over and we adapt to our new normal, whatever that will be, we may have a different outlook on life and on what is important. The need to retain social distancing measures may impact how our events take place and how we deliver our services, but we will adapt to this. The delivery of the vaccination programme indicates that there is light at the end of the tunnel, and the end of that tunnel is appearing closer with every passing day. It seems that we are 'nearly there'. I think most of us are looking forward to the simple things in life, like dining out, meeting family and friends, getting the hair done, or going on a holiday. Regardless of the environment we find ourselves in, both social and economic, you can rest assured that the Society will be there to provide our services to you, our valued members.

**John Stack,
Chairperson**



Honorary Secretary's Report

At the 31st Annual General Meeting of the Irish Haemophilia Society (I.H.S.), which was held in the Slieve Russell Hotel Kilkenny on Saturday 7th March, 2020, the incoming Governing Body of the Society were elected as follows:

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

At the first executive meeting following the AGM on 20th March 2020, 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:

- Matthew McCabe stepped down from the board on 26th March 2020.
- Dan McIntyre and Jay McEvoy were co-opted onto the board on 23rd April 2020.
- Eleven executive board meetings took place.

At the end of 2020, 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 during 2020. However, the Society adapted very well and were able to arrange the following events and webinars during 2020.

Face to Face Event:

- March 6th to 8th – Annual General Meeting & Conference (Slieve Russell Hotel, Cavan)

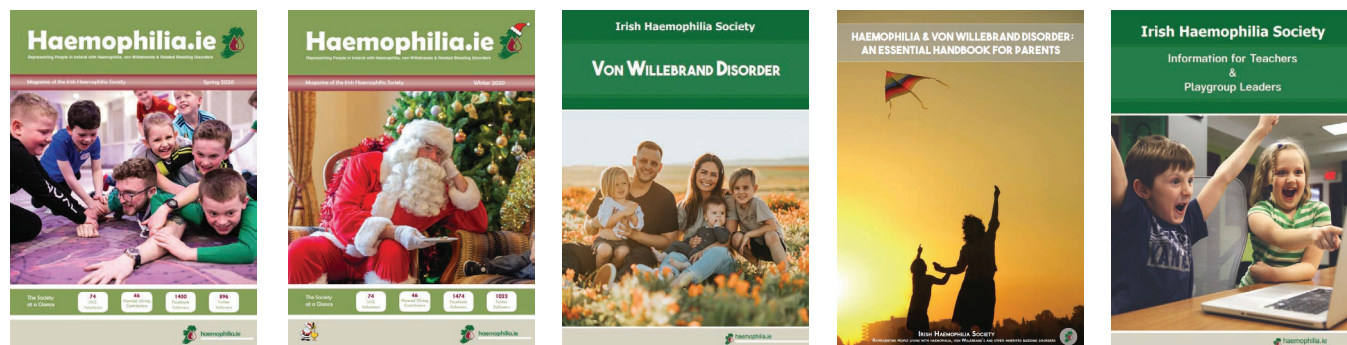
The following Zoom Webinars took place in 2020:

Date	Topic	Speaker(s)
1. 14/04/20	Update from CHI, Crumlin	Dr. Beatrice Nolan
2. 17/04/20	COVID-19 Update, National Coagulation Centre (NCC)	Dr. Niamh O'Connell
3. 22/04/20	Haemophilia Care in Europe	Mr. Brian O'Mahony
4. 24/04/20	Family Quiz	Mr. Rob Flanagan
5. 29/04/20	Hemlibra Information for Parents, CHI, Crumlin	Dr. Beatrice Nolan
6. 01/05/20	Mothers Peer Support Group	Ms. Nina Storey
7. 01/05/20	Family Quiz	Mr. Rob Flanagan
8. 06/05/20	Physiotherapy talk for adults, NCC	Mr. Mark McGowan & Ms. Sheila Roche
9. 08/05/20	Physiotherapy & gym work for adults, NCC	Mr. Mark McGowan & Ms. Sheila Roche
10. 13/05/20	Resilience & coping for adults during the pandemic, NCC	Dr. Patricia Byrne
11. 15/05/20	Physiotherapy & gym work for adults, NCC	Mr. Mark McGowan & Ms. Sheila Roche
12. 15/05/20	Mothers Peer Support Group	Ms. Nina Storey & Mr. Rob Flanagan
13. 19/05/20	Resilience & coping for children during the pandemic, CHI, Crumlin	Dr. Yvonne Duane
14. 21/05/20	An update on the Lighthouse Project, National Coagulation Centre	Mr. Fergal McGroarty
15. 22/05/20	Physiotherapy & gym work for adults, National Coagulation Centre	Mr. Mark McGowan & Ms. Sheila Roche
16. 27/05/20	An update on Hemlibra for parents, CHI, Crumlin	Dr. Beatrice Nolan & CHI Team
17. 03/06/20	Exercise & Physical Activity for children, CHI, Crumlin	Ms. Paula Loughnane
18. 05/06/20	An update on the iPath project, National Coagulation Centre	Professor James O'Donnell
19. 15/06/20	An update on the new Children's Hospital, NCH	Ms. Eilish Hardiman
20. 19/06/20	Haemophilia Care in the year 2030	Professor Mike Makris, UK
21. 22/06/20	COVID-19 & Economics Consideration	Mr. Jamie O'Hara, UK
22. 24/06/20	Dental care: The new normal, National Coagulation Centre	Dr. Alison Dougall & Ms. Laura Parkin
23. 26/06/20	Heavy Menstrual Bleeding in Adolescent Girls	-son Dr. Geraldine Connolly
24. 29/06/20	Dental Care & Nose Bleeds in Children, CHI, Crumlin	Dr. Kirsten Fitzgerald & Dr. John Russell
25. 01/07/20	An update from the National Coagulation Centre	Dr. Niamh O'Connell
26. 03/07/20	Family Quiz	Mr. Rob Flanagan
27. 08/07/20	Treatment choice in an era of change	Mr. David Page, Canada
28. 22/07/20	Gene Therapy	Mr. Brian O'Mahony & Mr. Declan Noone
29. 27/08/20	The Role of the Advanced Nurse Practitioner, NCC	Ms. Niamh Larkin
30. 02/09/20	The Future Role of the I.H.S. – Have your say	I.H.S. Staff
31. 29/09/20	Von Willebrand's Disorder, National Coagulation Centre	Dr. Michelle Lavin
32. 17/10/20	October Virtual Conference – Gene Therapy	Professor Mike Makris, UK
33. 17/10/20	October Virtual Conference – Hemlibra	Dr. Niamh O'Connell & Dr. Beatrice Nolan
34. 17/10/20	October Virtual Conference – Treatment Panel Discussion	Mr. Brian O'Mahony, Mr. David Flana -gan, Mr. Colm Walsh
35. 18/10/20	October Virtual Conference – Eating Healthy	Ms. Didi De Zwart
36. 18/10/20	October Virtual Conference – Exercise Class	Mr. Mark McGowan, Ms. Sheila Roche & Ms. Paula Loughnane
37. 21/10/20	An update from the National Coagulation Centre	Dr. Niamh O'Connell & Team
38. 28/10/20	An update from CHI, Crumlin	Dr. Beatrice Nolan & Team
39. 04/11/20	Ageing and haemophilia	Professor Mike Makris, UK
40. 07/11/20	Kids Virtual Event – Cubs Group	Mr. Rob Flanagan
41. 07/11/20	Kids Virtual Event – Kidlink Group	Mr. Rob Flanagan
42. 07/11/20	Kids Virtual Event – Youth Group	Mr. Rob Flanagan
43. 17/11/20	Coping during the pandemic	Dr. Patricia Byrne
44. 18/11/20	Q&A on Hemlibra for parents	Dr. Beatrice Nolan
45. 09/12/20	Update on clinical trials for parents	Dr. Beatrice Nolan

Outreach

Over the course of 2020, in excess of 1,642 phone calls were made to members to offer support and assistance.

Publications & Social Media



Over the course of 2020, the Society produced 12 publications. Social media platforms continue to work well for the organisation, as does the website. The Society continues to have a strong presence online with 1056 followers on Twitter and 1477 on Facebook. The Society continued distributing the electronic magazine e-Zine, which has proved to be very popular, so much so that we have 523 people signed up for this.

Database

A new membership database is proving an excellent investment.

Hyde Square

With additional procedures, the apartment facility for member was open for quite a lot of 2020 with the one bed being occupied 18 times and the two bed occupied 60 times.

Volunteers

The organising of our conferences would not be possible without the valued assistance of all our volunteers. We would like to thank all our volunteers who gave up their time at our AGM in 2020.

Fundraising

A total of €6,833 was raised through fundraising in 2020.

Donations

A total of €4,763 was donated in 2020.

Planned Giving

A total of €14,581 was raised by planned giving in 2020.

Educational Grants & Assistance

A total of 27 educational grants were awarded in 2020, totalling €18,250, following an application, review and selection process including a rigorous scoring system.

Staff

At the end of 2020, 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 (Personal Assistant)

Aoife Kelly who was our Events & Membership Coordinator resigned on 11th March 2020 and emigrated to Canada.

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
- 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 – Debbie Greene
- Irish Blood Transfusion Service Board – 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 2020:



Brian O'Mahony



Debbie Greene



Nina Storey



Barry Healy



Robert Flanagan



Julia Collins

The Year in Review from our CEO

In the 15 years for which I have been CEO of the Society this has, without doubt, been the strangest year. The Covid-19 pandemic has impacted the way we work, the way we live, the way we communicate. It has made it extremely difficult for individuals and families in this strong and vibrant community of people with inherited bleeding disorders to meet and to interact. Every person in the country has had to adapt to this new situation where socialising has become social distancing, where meeting in rooms has been replaced by Zooms, where many aspects of daily life which we took for granted have had to be re-engineered.

We were fortunate that our Annual General Meeting and Conference in the Slieve Russell Hotel in Cavan went ahead as planned on the first weekend in March. Even then, the storm clouds were gathering. On the Friday afternoon of the Conference, we lost most of our health care worker speakers who had to attend and deliver their lectures by Zoom. In retrospect, our ability to re-configure the Conference at very short notice to accommodate several speakers by Zoom to a live audience was a portent of the adaptability required during the year. In the days immediately after the Conference, the country went into the first national lockdown. It remains the last in-person event we were able to host in 2020.

From March to the end of 2020, we adapted our work model to fit in with the public health restrictions. Staff worked primarily from home. Coming closer to the summer months, we started to make tentative plans and schedules to resume working from the office or at least a blended approach. This did not happen as the country swung back into more restrictions and another lockdown. We have been primarily working from home from March to year end with staff attending the office in the smallest number required when specific tranches of work, such as mailshots were required.

Our culture over many years was based on provision of information and education via publications, website and events with ten to twelve in-person events being organised in a typical year. Our culture of outreach to members was based on regular phone contact together with home and hospital visits to members. The culture had to be adapted in 2020. We pivoted to virtual events using Zoom with the 10 to 12 regular events being replaced by 46 educational Zoom webinars between March and December. We covered a very wide range of topics and worked to bring good speakers and up to date information to members.

We continued to produce high quality publications during

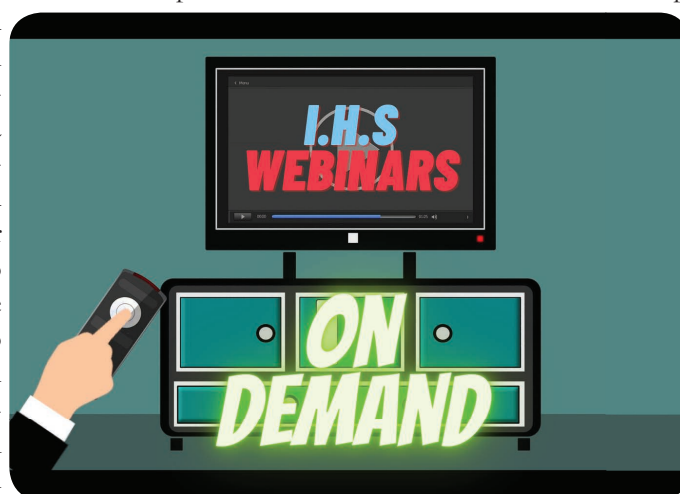
the year but we also saw a significant increase in the number of members who were now also interested in receiving our information in a digital format. With the ever changing landscape with Covid-19, there was definitely a requirement for more up to date information on a more regular basis. Quarterly magazines, while very useful and being a useful method of conveying complex information, are not suited to rapid updates. We started a weekly, then fortnightly electronic magazine: E-Zine. 523 members had subscribed to the e-Zine by the end of 2020.

We were more active on social media and increasing our reach on Facebook, Twitter and Instagram account, the latter we initiated in 2020. The e-Zines are an excellent method of communicating changing information quickly to a large number of people. This was especially useful in communicating information from the Centres with the National Coagulation Centre at St. James's and Children's Health Ireland at Crumlin using the medium of our e-Zines to get updates to many people quickly on many occasions during the year. Changes in clinic arrangements, in-patient arrangements, contact details, Covid restrictions and other clinical changes were all disseminated via our e-Zines.

Webinars were also organised to update members on therapeutic changes and clinical trials. This included webinars on the availability of Efficizumab as a treatment option for FVIII deficiency, the beginning of Gene Therapy clinical trials in Ireland and webinars on the pipeline products available via clinical trials in both the adult and paediatric centres.

The treatment centres also pivoted to offering virtual consultations including with dentists and physiotherapists in addition to nurses and haematologists. We organised, with the haemophilia physiotherapy team from St. James's, a virtual 6 week physiotherapy/exercise programme at home for older adults with severe haemophilia. Basic and inexpensive exercise equipment was sent to attendees homes by the Society and the course demonstrated that a lot of benefit can be derived from

the use of basic equipment in the home with the advice and guidance of expert physiotherapists. This programme was so successful and well regarded by attendees that we plan to repeat this course for other demographic groups.



Vaccination against COVID-19: Rationale, modalities and precautions for patients with haemophilia and other inherited bleeding disorders

Radoslaw Kaczmarek¹ | Magdy El Ekiaby^{1,2} | Daniel P. Hart^{1,3,4} | Cedric Hermans^{1,5} | Mike Makris^{1,6} | Declan Noone^{1,6} | Brian O'Mahony^{1,7,8} | David Page^{1,9} | Flora Peyvandji^{1,10,11} | Steven W. Pipe^{1,12,13} | Thomas Sanné^{1,6,14} | Uwe Schlenkerich^{1,15} | Mark W. Skinner^{1,16,17} | Alok Srivastava^{1,18} | Amanda Bok⁶ | Glenn F. Pierce^{1,19} | the World Federation of Hemophilia (WFH), European Association for Haemophilia, Allied Disorders (EAHAD), European Haemophilia Consortium (EHC), U.S. National Hemophilia Foundation (NHF)

¹Coagulation Product Safety, Supply and Access Committee, World Federation of Hemophilia, Montreal, Quebec, Canada

Our publications in 2020 included 4 magazines, 2 issues of the Novel Therapies Review, updated information for Teachers and Playgroup Leaders an Information Handbook for Parents and an updated booklet on von Willebrand Disorder. Home and hospital visits were not possible but our telephone outreach service continued and increased with our Outreach Co-ordinator, Robert Flanagan, personally contacting the majority of members during the year and identifying issues where we could assist members or provide information, guidance or support. We carried out a survey of members on our service during the year and we found that they greatly valued the Webinars, the telephone contact and increased information on lifestyle and wellbeing.

Financially, it was a stable year. Costs were lower as we were also operating with a smaller number of staff. Aoife Kelly left the Society just before the lockdown to move to Canada so for the remainder of the year, we operated with a team of 6 staff. Income was €70,000 less than in 2019 but expenditure was also lower by €110,000, leading to a surplus of €111,067 for the year. This was especially welcome as the Society need to plan for the purchase of an additional property near St. James's and the new National Children's Hospital for members use in the near future.

It was a year which held many challenges for people with haemophilia and inherited bleeding disorders. We were challenged to respond to a pandemic and pivot to a new working environment and new methods of communication and interaction. I believe we have met those challenges successfully. We have become more adaptable, responsive and proactive with the need for more regular digital communication while maintaining in parallel the classic hard copy publications. We have worked seamlessly with the treatment centres and served as an adjunct communication system for busy health care teams.

I have no doubt, that as we look back on 2020, we will realise that some of the new modes of work and methods of communication we have utilised will become a routine and welcome part of our work. While we look forward to returning to in-person events, I have no doubt that webinars will form an important part of our future education strategy. They are convenient for many people and do not require travel, either for attendees or indeed speakers. I am also of the view that the thirst for regular up to date information will require a continuation of our e-Zines and increased social

Telehealth for delivery of haemophilia comprehensive care during the COVID-19 pandemic

Mairead O'Donovan^{1,2} | Catherine Buckley¹ | Julie Benson¹ | Sheila Roche¹ | Mark McGowan¹ | Laura Parkinson¹ | Patricia Byrne¹ | Gloria Rooney¹ | Catherine Bergin¹ | Deirdre Walsh¹ | Rachel Bird¹ | Feargal McGroarty¹ | Helen Fogarty¹ | Elizabeth Smyth¹ | Saad Ahmed¹ | James S. O'Donnell¹ | Kevin Ryan¹ | Brian O'Mahony³ | Alison Dougall¹ | Niamh M. O'Connell^{1,2}

¹National Coagulation Centre, St James's Hospital, Dublin, Ireland

²School of Medicine, Trinity College Dublin, Dublin, Ireland

³Irish Haemophilia Society, Dublin, Ireland

Abstract

Introduction: The COVID-19 pandemic caused an unprecedented impact to haemophilia healthcare delivery. In particular, rapid implementation of telehealth solutions was required to ensure continued access to comprehensive care.

media presence. The planned patient portal, on which we continued working with the centres during 2020, will provide an additional vehicle to increase communication between the centres, the Society, and those with inherited bleeding disorders. The great realisations during the year, I believe, were the absolute need for regular communication, the success of digital meeting platforms in enabling at least digital face to face communication (and incidentally the total demise of conference calls) and the unrealised longing in the community to meet up again when we will have a greater appreciation of simple pleasures such as meeting for a coffee at our events, the children seeing each other again at our events and meeting friend and colleagues at a distance of less than 2 metres.

Finally, I want to express my appreciation to the Board for their commitment and work during a challenging year and to the staff team: Debbie Greene, Nina Storey, Barry Healy, Robert Flanagan and Julia Collins for their exemplary work, for their adaptability and commitment during a difficult year. Last but not least, a massive thanks to the health care teams at the Centres at St. James's, CHI Crumlin, CUH Cork and GUH, Galway for their dedication, perseverance and sheer hard work and dedication in such a difficult and challenging year. They could not work from home. They were never in lockdown - they kept the show on the road, and we salute and thank them.

**Brian O'Mahony,
Chief Executive**



Financial Report for 2020

INDEPENDENT AUDITOR'S REPORT to the Members of the Irish Haemophilia Society (A company limited by guarantee, without a share capital)

Report on the audit of the financial statements

We have audited the financial statements of Irish Haemophilia Society ('the company') for the financial year ended 31 December 2020 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 a 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", 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 2020 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 further described 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 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

We have nothing to report in respect of the following matters in relation to which ISAs (Ireland) require us to report to you where:

- the directors' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the directors have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

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 entity's ability to continue as a going concern for a period of at least twelve months from 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. In connection with our audit of the financial statements, 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 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

Based solely on the work undertaken in the course of the audit, we report that:

- in our opinion, 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
- in our opinion, the Directors' Report has been prepared in accordance with the Companies Act 2014.

We have obtained all the information and explanations which we consider 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. 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 disclosures of directors' remuneration and transactions required by sections 305 to 312 of the Act are not made. We have nothing to report in this regard.

Responsibilities of directors for the financial statements

As explained more fully in the Directors' Responsibilities Statement, the directors are responsible for the preparation of the financial statements and for being satisfied that they 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, as 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 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.

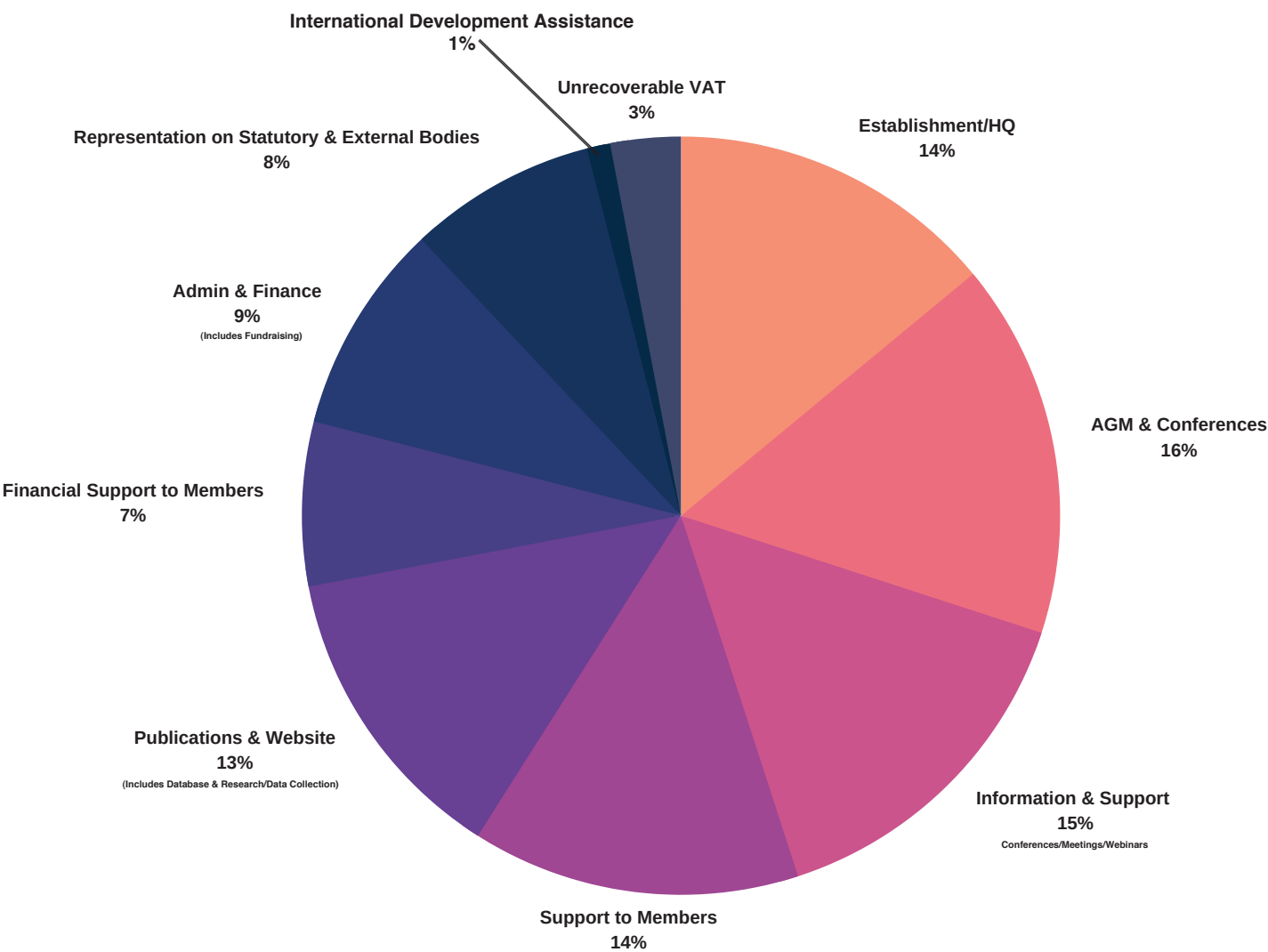
Registered Office:

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

Company Registration Number: 142834.

Registered Charity Number: CHY9214.

Expenditure for 2020



Irish Haemophilia Society

Income and Expenditure Statement for the year ended 31 December 2020

		2020 €	2019 €
	Notes		
Income			
Health Service Executive		575,000	575,000
Membership		1,929	2,309
Donations - Members		19,344	48,073
Donations - Corporate		99,754	114,289
Fundraising		6,828	8,028
H.H.T Trust		-	12,077
Funding from EHC		-	10,000
Twinning		-	7,880
Investment Income		133	388
Sinking Fund Allocation for Works on HQ		5,780	-
		708,768	778,044
Overhead expenses	1	(610,479)	(720,410)
Miscellaneous income	2	98,289 12,778	57,634 24,244
Net surplus		111,067	81,878
		2020 €	2019 €
Expenditure			
Wages & Salaries		269,535	297,918
Employers Prsi Contributions		29,784	32,362
Pension Costs		36,401	35,453
Service Charge & Insurance		18,872	18,662
Light, Heat & Services		7,078	10,960
Help to Members		12,970	6,442
H.H.T Trust		2,000	8,077
Subscriptions		1,507	2,582
Fundraising		152	658
Educational Grants		18,250	18,350
Twinning- Jordan/Vietnam Development Work		901	13,583
HQ Costs		5,995	2,881
Office Expenses, Stationery etc.		13,595	7,783
I.H.S Members' Facility		5,948	7,879
Post, Publications & Photocopying		20,935	23,355
Telephone/Internet		4,655	4,109
Website		4,105	3,573
Computer Services		19,811	13,385
Family Meetings/Activities		-	1,362
Meeting Expenses		7,855	19,213
Safety/Supply Activities		66	5,036
A.G.M & Annual Conference		38,857	45,946
Information & Support Conferences/Meetings		1,686	5,344
Members' Conference		261	32,812
Ageing Conference		-	5,736
EHC Inhibitors Summit		-	670

Legal and Professional	-	100
Sponsorship/Training	150	735
Unrecoverable Vat	15,686	22,387
Bank Charges	1,268	1,794
General Expenses	6,689	4,177
Provision for Sinking Fund	30,000	30,000
Auditor's Remuneration	4,900	5,046
Depreciation of Tangible Fixed Assets	30,567	32,040
Total Overheads	<u>610,479</u>	<u>720,410</u>

Irish Haemophilia Society

Balance Sheet for the year ending 31 December 2020

	Notes	2020 €	2019 €
Fixed Assets			
Tangible assets	8	739,980	770,547
Investments	9	340,282	327,504
		<u>1,080,262</u>	<u>1,098,051</u>
Current Assets			
Debtors	10	12,433	18,157
Cash and cash equivalents		1,175,155	1,057,922
		<u>1,187,588</u>	<u>1,076,079</u>
Creditors: Amounts falling due within one year	11	(140,083)	(181,650)
Net Current Assets		<u>1,047,505</u>	<u>894,429</u>
Total Assets less Current Liabilities		<u>2,127,767</u>	<u>1,992,480</u>
Reserves			
Capital reserves and fund	12	193,220	169,000
Income and expenditure account		1,934,547	1,823,480
Members' Funds		<u>2,127,767</u>	<u>1,992,480</u>

Corporate Sponsors

The Irish Haemophilia Society would like to acknowledge the financial contributions made in 2020 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 2020.

Volunteers

The Irish Haemophilia Society would like to acknowledge and to thank everyone who volunteered for the Society during 2020.

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 2020.



IRISH HAEMOPHILIA SOCIETY

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Dublin 8**

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Fax: 01 657 9901**

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www.haemophilia.ie**

Find us on:

