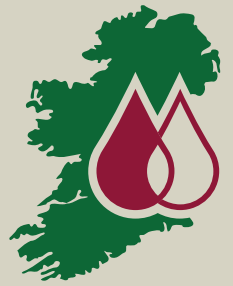


Annual Report

2018

Irish Haemophilia Society



haemophilia.ie

Contents

A Message from the Chairperson	Page 03
Honorary Secretary's Report	Page 06
A Year in Review from our CEO	Page 10
Financial Reports	Page 12
2018 in Pictures	Page 18

2018 in Pictures



A Message from the Chairperson

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 OLCHC)
- Outreach

Additionally, we collaborate with the medical teams within the health service, namely the National Coagulation Centre (NCC), Our Lady's Children's Hospital Crumlin (OLCHC), Cork University Hospital (CUH), and other healthcare professionals 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 to advise on how best to address a particular issue that may arise.

2018 was a very busy year for the Society, particularly in relation to the great events that took place to celebrate our 50th anniversary, including a Gala Dinner, the commissioning of a piece of commemorative artwork, and the making of a movie celebrating the 50 years of the I.H.S.

Support to members continued to be a priority in 2018 with a large number of conferences and events, as summarised throughout this report.

Board & Staff

2018 was a year that saw significant change to both the staff and board of the I.H.S. Traci stepped down as Chair after many years of tremendous dedication and work for the Society and I took over as Chair. Other members stepped down and new members stepped up. There were changes to staff too.

There were some changes to the Board in 2018, with a number of people stepping down after a great many years of service, and some new members joining the Board, 'for a few months' as Brian would say.

I would like to extend my heartfelt thanks and gratitude to Traci and Michael for all the years of dedication and work as Board members, and I welcome Matthew and Donal onto the Board.

There were changes to the staff also. The Society currently has 8 staff and the changes in 2018 were as follows:

- Julia Collins joined in May 2018
- Aoife Ni Fhogartaigh left in August 2018
- Aoife Kelly joined in August 2018

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 & Events

It was a busy year for conferences and events, with great attendances recorded, and great interaction and collaboration with members.

50th Anniversary

The key feature of 2018 was the 50th anniversary of the I.H.S. A variety of events took place throughout the year, including the AGM, which had the highest ever attendance at a conference. A piece of commemorative artwork was commissioned and is now proudly exhibited in St. James's Hospital. A movie celebrating 50 years of the society was premiered in newly revamped Stella Cinema in Rathmines on the April 26, and a Gala Fundraiser was held in the Castleknock Hotel on September 22.

A key objective of the 50th anniversary celebrations was that the younger generation be involved, and they were.

World Haemophilia Day 2018

World Haemophilia Day 2018 took place on April 17. Brian took over the @Ireland Twitter account, some major buildings in Dublin and Cork were turned red, and Brian and Seamus did an interview on TV3. The launch of



the commemorative artworks also coincided with World Haemophilia Day.

Fathers and Son's Weekend

This event took place at the Lilliput Adventure Centre in Westmeath at the height of the heatwave. It was a fantastic

event and everybody had a great time. Everybody was also eager to make a return trip in 2019.

Youth Leadership

This is a programme that has been developed by Robert, the Children's and Youth Programmes Coordinator. The target audience is teenagers (aged 12 to 17). The group aims to meet at least 3 times a year and key focus areas include:

- Understanding Haemophilia
- Self-Development
- Leadership

Ageing Conference

At the Ageing Conference 2018, Dr. Gerald King, Senior Haemophilia Specialist at Cork University Hospital did a hands on physiotherapy session, which was very much appreciated by those in attendance.

October Conference

At the October Conference, Dr. Michelle Lavin gave a great talk on understanding the terminology of novel products. It is important that we are all informed on these products, the pros and cons and what they mean for our members.

There was also a very interesting debate on the future of the Society, which really only scratched the surface of what will be required of the Society for the next 50 years.

Gene Therapy Talk

On December 18, Dr. Katherine High of Spark Therapeutics and Dr. Niamh O'Connell from St. James's Hospital gave a great talk on Gene Therapy at the Society Offices. It was a full house and there was great discussion following the presentations.

Other One-Day Events

A number of one-day events also occurred throughout the year, including:

- Von Willebrands Information Day
- Mild Haemophilia Information Day
- Haemophilia B Information Day
- Children's Christmas Party

The information days provided valuable, and audience specific, information relating to haemophilia and other bleeding disorders.

It was regretful the Mother's and Daughter's Weekend was cancelled but insufficient numbers expressed an interest.

Grants and Awards

Each year, the Society provides approximately €18,000 in grants for third level education. Qualifying courses range from PLC-type courses, up to degree and post-grad 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 2018, 26 applications were received. For more info on educational grants, see haemophilia.ie or contact the office.

In 2018, lifetime membership was awarded to the following people to recognise their outstanding contributions towards haemophilia; Traci Marshall-Dowling, Theresa Mulvey, Bruce Evett and Paul Giangrande.

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. Events in 2018 included:

- A boxing match took place in Lebanon by the 112th Infantry Battalion. I can confirm that no people with haemophilia were injured in the making of this event.
- The mini-marathon is always a key fundraising event. The fundraiser of the year was Nikki Clavin who raised over €1,800 taking part in the Women's Mini Marathon.



Planned Giving is an important fundraising method for the Society. Funds raised through Planned Giving are divided between the twinning programme with Vietnam 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 appointments. 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 do at the conferences and events that occur each year. At present, we have 82 volunteers assisting, without whom our conferences could not be run in the way that they are. There are other volunteers too, for example, people who help out doing admin at conferences, and people who get involved in other projects.

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 we willingly sign up for.

Twinning

The Society has been running a Twinning Programme with Vietnam for a number of years now, even continuing relations when the official arrangement through the WFH ended. It has produced some great results, although there is still much work to be done.

In 2018, a double twinning process commenced between the Treatment Centres and Societies of Ireland and Jordan. It is a great opportunity for the I.H.S. to assist in the development of an active, vibrant and successful society in Jordan, where the aspiration is that the Jordanian Haemophilia Society can provide a level of support, education, advocacy, etc. to members like that of ours. Simultaneously, collaboration between the Treatment Centres will aim to improve the level of care that is available to people with Haemophilia in Jordan. Brian and I represented the I.H.S. during a joint visit between ourselves and Dr. Niamh O’Connell from St. James’s Hospital, when we visited Jordan in September 2018.

Conclusion

As I reflect on my first year as Chair, I can only express my gratitude towards everybody with whom I have engaged during the year. That includes staff, my colleagues on the Board, and all the members I meet at conferences and events. I look forward to what 2019 brings.

**John Stack,
Chairperson**



Honorary Secretary's Report

At the 29th Annual General Meeting of the Irish Haemophilia Society (I.H.S.), which was held in the Royal Marine Hotel in Dun Laoghaire on Saturday 14th April 2018, the incoming Governing Body of the Society were elected as follows:

- Mr. Michael Davenport
- Ms. Mary-Clare Delaney
- Ms. Aislinn Farrelly
- Mr. Seamus McDonald
- Mr. Jim O'Leary
- Mr. Gerard O'Reilly
- Mr. John Stack
- Ms. Barbara Wynne

Ms. Traci Marshall Dowling stepped down from the board on Saturday 14th April, 2018. The board would like to thank Traci for all her work over the ten years as a board member and as Chairperson.

At the first executive board meeting following the AGM on April 14 2018, the following officers were elected:

- | | |
|----------------------|------------------------|
| • Chairperson | Mr. John Stack |
| • Vice-Chairperson | Ms. Mary Clare Delaney |
| • Honorary Secretary | Ms. Barbara Wynne |
| • Honorary Treasurer | Mr. Gerard O'Reilly |



Eleven executive board meetings took place in 2018.

At the end of 2018, the following members were serving board members (inset).



John Stack,
Chairperson



Mary-Clare Delaney,
Vice-Chairperson



Gerard O'Reilly,
Treasurer



Barbara Wynne,
Secretary



Seamus McDonald



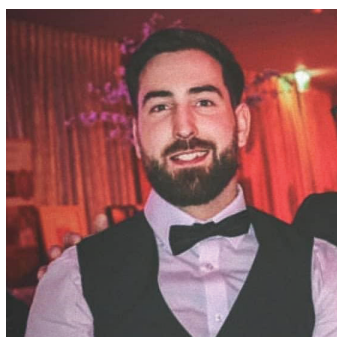
Aislinn Farrelly



Jim O'Leary



Matthew McCabe



Donal McCann



CONFERENCES & EVENTS

2018 was a very busy year for the organisation, in particular with the 50th-anniversary celebrations. The following conferences and events were organised by the Society during 2018:

- 13th to 15th April – Annual General Meeting & Conference (Royal Marine, Dun Laoghaire)
- 17th April – 50th Anniversary World Haemophilia Day Events
- 12th & 13th May – Carrier Conference (Castleknock Hotel, Dublin)
- 22nd to 24th June – Ageing Conference (Killeshin Hotel, Portlaoise)
- 7th July – von Willebrand's Information Day (Midlands Hotel, Portlaoise)
- 18th August – Mild & Moderate Haemophilia Information Day (Osprey Hotel, Naas)
- 22nd September – 50th Anniversary Gala Dinner (Castleknock Hotel, Dublin)
- 19th to 21st October – October Conference (Radisson Blu Hotel, Sligo)
- 10th November – Haemophilia B Information Day (Dublin & Cork)
- 7th to 9th December – Inhibitor Summit (Barretstown)
- 8th December – Christmas Party for Children (Grand Hotel, Malahide)

The Society also organised other information meetings in relation to gene therapy.

The Society was represented at a number of other events throughout 2018 including:

- EHC Leadership Conference.
- EHC Tender Procurement Workshop.
- EHC Conference.
- EHC New Technologies Conference.
- EHC Inhibitor Summit.
- WFH Congress in Glasgow.



VOLUNTEERS

The Society currently has 82 volunteers who work at our conferences and events. The organising of our conferences would not be possible without the valued assistance of all our volunteers. Their help and support are really appreciated and the Society wishes to thank them. We would also like to thank those who volunteer at conferences doing administration and also with other projects. We would also like to thank those volunteers who gave up their time and were involved with the 50th anniversary celebrations and events; including the sub-committee and everyone who contributed.

PUBLICATIONS AND SOCIAL MEDIA

I.H.S. publications are posted to all members and are also distributed to many people abroad by email, in PDF format. Publications are also available on the I.H.S. website and are downloadable in PDF format. In 2018 the Society produced four quarterly magazines, an annual report, two kidlink and youth magazines, a von Willebrand's booklet, and an information booklet on novel therapies.

In 2018, the Irish Haemophilia Society had a strong presence online via Twitter and Facebook. Our Facebook page currently has 1,204 followers. Our twitter page currently has 686 followers. The Society continued distributing the monthly electronic magazine eZine, which has proved to be very popular. Currently, 250 members have signed up for this monthly electronic magazine and 77 website signups.



FUNDRAISING

A total of €9,040 was raised through fundraising in 2018, excluding the 50th anniversary gala dinner.

PLANNED GIVING

A total of €16,169 was raised through planned giving in 2018.

HYDE SQUARE

The Hyde Square apartment facility for members was closed for a period during 2018 to allow structural repairs. This facility has now re-opened and is busy with bookings.



OUTREACH

The Society employs an outreach co-ordinator who meets with members on a one to one basis. The ongoing level of personal contact between staff and members is very high.

EDUCATIONAL GRANTS AND ASSISTANCE

A total of 26 educational grants were awarded in 2018, totalling €18,000, following an application, review and selection process, and rigorous scoring system. Our hope is that this will assist in the availability of skilled volunteers in future years.

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 – Debbie Greene
- World Federation of Hemophilia – Brian O'Mahony
- European Haemophilia Consortium – Brian O'Mahony & Jim O'Leary
- Consultative Council on Hepatitis C – Brian O'Mahony & Debbie Greene
- Irish Haemostasis Research Foundation – Debbie Greene & Gerard O'Reilly
- Irish Blood Transfusion Service Board – Brian O'Mahony
- Plasma Users Group (PLUS) – 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.

STAFFING

- Julia Collins joined the organisation in May 2018.
- Aoife Ní Fhógartaigh left in August 2018 to move to Australia.
- Aoife Kelly joined the organisation in August 2018.

The current staff roles are as follows:

- Brian O'Mahony (Chief Executive)
- Debbie Greene (Administrator & Office Manager)
- Nina Storey (Finance & Fundraising Coordinator)
- Lyndsey Connolly (Outreach Coordinator)
- Barry Healy (Publications & Social Media Coordinator)
- Robert Flanagan (Children's & Youth Programmes Coordinator)
- Julia Collins (Administrative Assistant)
- Aoife Kelly (Administrative Assistant)

Barbara Wynne, Honorary Secretary



Brian O'Mahony



Debbie Greene



Nina Storey



Lyndsey Connolly



Barry Healy



Robert Flanagan



Julia Collins



Aoife Kelly

The Year in Review from our CEO

2018 was a ground breaking and momentous year for the Society. We celebrated our 50th anniversary as an organisation in style.

At our Annual Conferences over the past three years, culminating this year, a series of lectures were delivered outlining the history of the Society. As a community, we have endured many trials and tribulations since then on our collective and individual 50 year journey. The hope for a better future which started to become possible due to the first clotting factor concentrates. The devastation and death caused by the contamination of many of those products with HIV and Hepatitis C which caused untold misery and death in our community, almost wiping out a generation of people with haemophilia. The strong bonds of support and empathy which formed in those difficult times. The hard, initially unwelcome but ceaseless advocacy with the media and lobbying of politicians to address these appalling tragedies in a bid to secure treatment, financial assistance and acknowledgement.

The lessons we learnt as we had to bang loudly on many closed doors and force governments to acknowledge what had befallen our community. The achievement of treatment, financial assistance and public acknowledgement and understanding. The determination to ensure that a tragedy like this would never and could never happen again to this small community. The proactive and collaborative work with the doctors, nurses, health care professionals, treatment centres and the Department of Health and later the HSE to advance haemophilia care with the Society being a full and active partner in shaping treatment and care. The institutions established such as the National Haemophilia Council and the Haemophilia Product Selection Board which have codified the formal role for the Society.

From despair and death, a new reality was shaped. A reality that moved Ireland to the forefront of the use of synthetic recombinant products starting in 1995, to prophylaxis for children from 1997 and later for all adults. A reality which saw Ireland become the first country to effectively eliminate hepatitis C from our haemophilia population in 2016, the first country to switch all people with haemophilia B to the new generation of extended half life products in 2017 and the first country to switch all people with haemophilia A

to extended half life factor concentrates in 2018. A country where we have, this year, commenced the availability of subcutaneous therapy for people with FVIII inhibitors. A country at the forefront of research and clinical trials. A country where the major research project iPATH (Irish Personalised Approach to the Treatment of Haemophilia) began this year and which we hope will assist in answering fundamental biological questions about haemophilia. To paraphrase Eugene O' Neill - A long nights journey into day.

We have certainly marked this special anniversary year in many innovative ways. An increased suite of meetings and events including, not only the standard Annual General Meeting, Member's Conference and Ageing conference but a Carrier Conference, Father and Son(s) event and specific meetings on von Willebrands Disease, Mild Haemophilia and Haemophilia B. Our Annual General Meeting and Conference in April had a record attendance of 350 members and was a great celebration of, and by our community. Storm Emma in retrospect did us a favour as we had to move the conference to April from the March dates. The new dates were the beginning of an extraordinary week and month of April. At the conference, we awarded life memberships to our outgoing Chairperson, Traci Marshall-Dowling, Theresa Mulvey, who made a major contribution as a member of the staff team in the difficult years of the 1990's, and to two doctors from abroad who have been stalwart supporters of the society and our events for many years - Dr Bruce Evatt from Atlanta and Dr Paul Giangrande from the UK. We also unveiled a memories room which featured artefacts, old newsletters, photographs and memories for so many in our community.

World Haemophilia Day began with the Society representatives being interviewed on national breakfast television. Later that morning we unveiled a Billboard on Macken Street in Dublin with a specially commissioned painting by renowned street artist Shane O' Malley. Following this a permanent painting, also



by Shane O' Malley was unveiled in the main lobby of St. James's Hospital to mark our 50th anniversary. This was an appropriate location as St. James's Hospital have journeyed with us on days of despair and of hope and progress since 1977. The day culminated with several iconic buildings in both Dublin and Cork being lit up in red to mark World Haemophilia Day. Later in April, we had a cinema premiere for our movie on the history of the society - Facing the Rising Sun. This movie, the product of countless hours of interviews, digitising, collating and reviewing archive footage and weaving together the story of the Society was directed by Academy Award nominated director Goran Kapetanovic from Sweden. The premiere at the restored Art Deco Stella Cinema in Dublin was a profoundly moving experience for all those present. The movie was previously premiered for all of our members at the Annual Conference and is available free of charge to all of our members and to any person interested from our website.

In September the Society hosted a gala fundraising dinner. The evening included an auction which included some amazing sports memorabilia including a signed boxing glove from Muhammed Ali, a signed rugby Grand slam Ireland jersey, signed GAA county jerseys, signed ties or scarves from all out political party leaders (and a hat from a politician noted for wearing hats) and many other items.

In October, the members conference included a retrospective look at the commemorative events of the year. The members were informed at the Conference that the previous week, the Society had won an Irish HealthCare Award for patient organisation project of the year for our suite of 50th anniversary programmes and commemorations. In December, the Society hosted a European Inhibitor summit on behalf of the European Haemophilia Consortium.

Our publications included four issues of our magazine, two junior magazines and the first edition of our Novel prod-

ucts newsletter which reviewed in detail all of the major developments in treatment.

Financially we had a strong year with income increased by €148,000% over 2017 and expenditure increased by 107,000%. The result was a surplus of €29,711. The increased income was primarily due to increased grant funding from the HSE, corporate donations and fundraising, including our Gala Fundraising dinner. The increased expenditure was primarily driven by higher attendance at our conferences and events which in turn results in higher accommodation and meeting costs. In terms of staffing, Aoife Ní Fhógartaigh left the Society to move to Australia. We welcomed Julia Collins and Aoife Kelly onto the staff team.

We are in an era of exciting improvements in treatment with extended half life products being joined by subcutaneous therapies. The promise of an effective cure via Gene Therapy which has been a distant dream for 20 years is now fast approaching. Despite the exciting therapeutic landscape, there are always challenges. In 2018, there were challenges relating to availability of beds and access to orthopaedic surgery even in the specialised Haemophilia H and H unit at St. James's Hospital. Deficits in comprehensive care remain. As we celebrated and commemorated the past during 2018, we also reflected on a bright potential future but only if we continue to work together as a strong, united and determined community, mindful of our shared history and working toward the best future we can achieve for all those people in Ireland with inherited bleeding disorders.

Brian O'Mahony
Chief Executive



Financial Report for 2018

INDEPENDENT AUDITOR'S REPORT to the Members of 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 year ended 31 December 2018 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 2018 and of its surplus for the 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 3 to the financial statements, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

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.

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 the 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 8, 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.

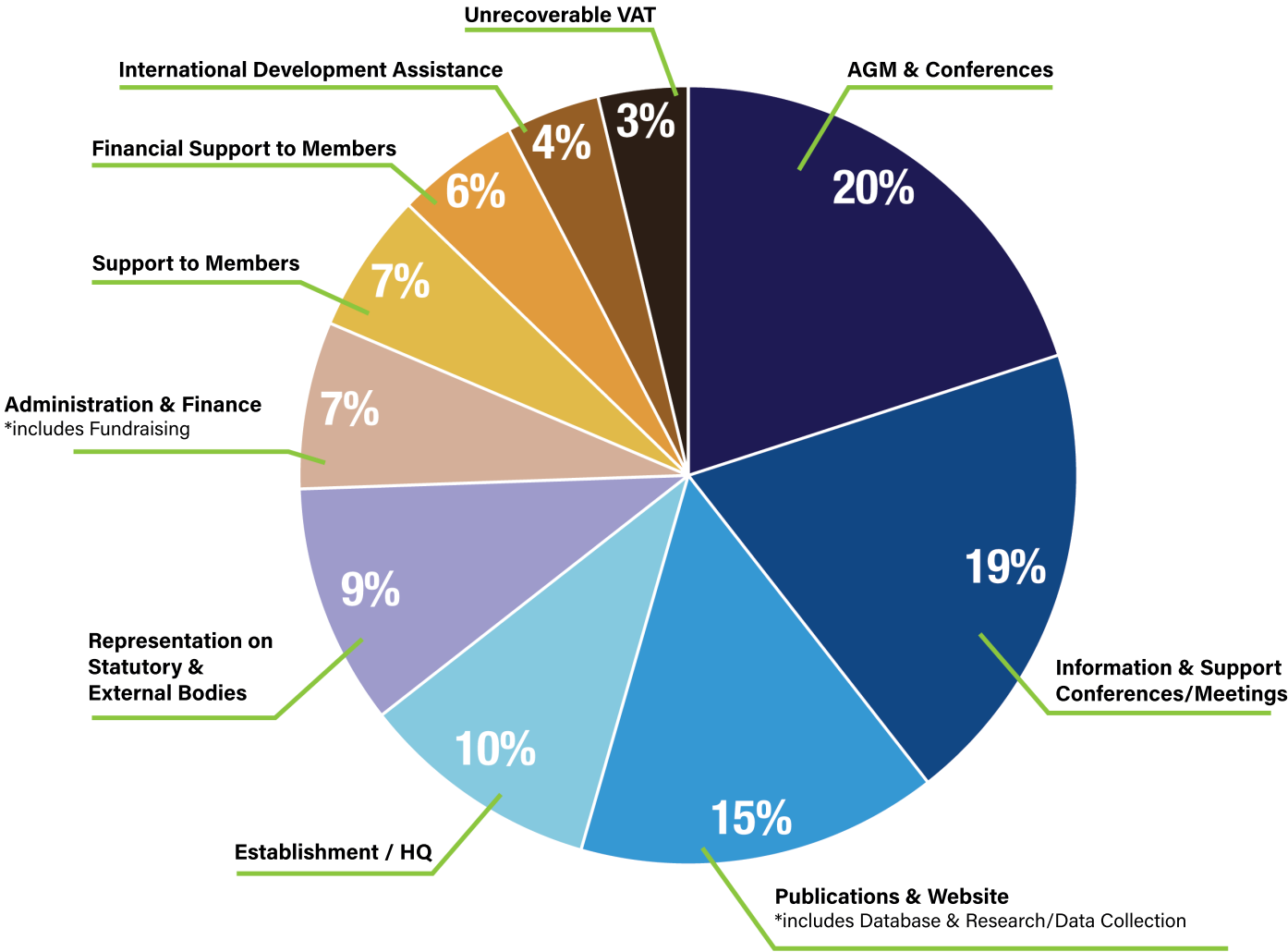
Registered Office:

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

Company Registration Number: 142834.

Registered Charity Number: CHY9214.

Expenditure for 2018



Irish Haemophilia Society

Income and Expenditure Statement for the year ended 31 December 2018

	2018	2017
	€	€
Income		
Health Service Executive	574,990	550,000
Membership	2,700	2,649
Donations - Members	59,741	19,374
Donations - Corporate	146,500	115,500
Fundraising	38,905	7,211
H.H.T Trust	-	3,000
Funding from EHC	33,000	10,000
Investment Income	401	950
	<hr/>	<hr/>
	856,237	708,684
	<hr/>	<hr/>
Overhead expenses	(849,965)	(742,324)
	<hr/>	<hr/>
	6,272	(33,640)
	<hr/>	<hr/>
Fair value gain on Investments	23,439	-
	<hr/>	<hr/>
Net surplus/(deficit)	29,711	(33,640)
	<hr/> <hr/>	<hr/> <hr/>
Expenditure	2018	2017
	€	€
Wages and Salaries	305,970	281,769
Employers PRSI Contributions	32,920	30,527
Pension Costs	29,763	23,691
Service Charge & Insurance	18,189	17,541
Light, Heat & Services	12,892	11,398
Help to Members	11,311	15,628
H.H.T Trust	2,000	2,000
Subscriptions	1,843	2,228
Fundraising	16,615	656
Educational Grants	18,000	15,500

Twinning/Vietnam Development Work	12,322	11,910
HQ Costs	3,918	331
Office Expenses, Stationery etc.	8,581	7,542
I.H.S Members' Facility	3,111	6,102
Post, Publications & Photocopying	40,035	40,678
Telephone/Internet	4,868	5,641
Website	5,781	4,857
Computer Services	13,789	8,744
Family Meetings/Activities	3,674	6,320
Meeting Expenses	19,851	16,505
Safety/Supply Activities	5,022	596
A.G.M & Annual Conference	72,619	37,066
Information & Support Conferences/Meetings	20,606	3,997
Members' Conference	35,614	43,777
Ageing Conference	6,661	7,383
EHC Inhibitors Summit	972	1,528
Sponsorship/Training	1,785	156
Hep C Conferences	-	1,724
Unrecoverable Vat	23,856	19,972
Bank Charges	2,142	1,824
General Expenses	4,649	4,127
Provision for Sinking Fund	30,000	30,000
Auditor's Remuneration	4,800	4,800
Depreciation of Tangible Fixed Assets	75,806	75,806
	<hr/>	<hr/>
	769,115	677,373
	<hr/>	<hr/>
Total Overheads	849,965	742,324
	<hr/> <hr/>	<hr/> <hr/>

Irish Haemophilia Society

Balance Sheet for the year ending 31 December 2018

	Notes	2018 €	2017 €
Fixed Assets			
Tangible assets	7	798,053	873,859
Investments		303,260	279,821
		<u>1,101,313</u>	<u>1,153,680</u>
Current Assets			
Debtors	9	27,313	18,172
Cash and cash equivalents		832,176	765,161
		<u>859,489</u>	<u>783,333</u>
Creditors: Amounts falling due within one year	10	(80,201)	(107,790)
Net Current Assets		<u>779,288</u>	<u>675,543</u>
Total Assets less Current Liabilities		<u>1,880,601</u>	<u>1,829,223</u>
Reserves			
Capital reserves and funds		139,000	117,333
Income and expenditure account		1,741,601	1,711,890
Members' Funds		<u>1,880,601</u>	<u>1,829,223</u>

2018 in Pictures



2018 in Pictures



Corporate Sponsors

The Irish Haemophilia Society would like to acknowledge the financial contributions made in 2018 by the following companies, under our Corporate Giving Programme:

Platinum Sponsors

Roche, SOBI

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Bayer, CSL Behring

Silver Sponsors

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Fundraisers

The Irish Haemophilia Society would like to thank with gratitude, everyone who fundraised for the Society during 2018.

Volunteers

The Irish Haemophilia Society would like to acknowledge and to thank everyone who volunteered for the Society during 2018.

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 2018.



IRISH HAEMOPHILIA SOCIETY

**First Floor
Cathedral Court
New Street
Dublin 8**

**Tel: 01 6579900
Fax: 01 657 9901**

**Email: info@haemophilia.ie
Website: www.haemophilia.ie**