

Irish Haemophilia Society

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

Annual Report 2019



haemophilia.ie

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2019 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 at Crumlin, Cork University Hospital (CUH), and other healthcare and people within the field of haematology.

Outreach is an important part of the society's work. 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.

2019 was, as usual, a very busy year for the Society, with a large number of conferences and events as well as our second Twinning visit to Jordan.

Board and Staff

There was only one change to the Board in 2019, when Ger O'Reilly stepped down after giving many years of support, service dedication, help and commitment to the Society.

It was with great sadness that we learned of Ger's passing on Tuesday, 28th May 2019 and his absence leaves a gap in many of our lives. The attendance at his funeral is testament to how important Ger was to so many people. RIP Ger.

On the staffing front, Lyndsey Connolly left the I.H.S. in March 2019 to go and live in the USA. We wish her all the very best in the future.

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 very busy year for conferences and events, with great attendances recorded, and great interaction and

collaboration with members.

As many of you will be aware, the Society provides numerous events throughout the year and 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. This includes 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.

One event, unfortunately, did not go ahead during 2019 as there was not enough interest from members. This was the Family Adventure Overnight which was to be at Lilliput.

Having attended numerous Father and Sons weekends, I know how much fun Lilliput is so it was a pity to see this event not go ahead. There may, however, be great enthusiasm for such an event in the future.

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-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 2019, 26 applications were received and €18,350 was distributed amongst those who applied. I should point out that the standard of applications is of a very high quality. For more information on educational grants, see our website, haemophilia.ie

In 2019, the Brian O'Mahony Award for outstanding contribution to Haemophilia care in Ireland went to Evelin Singleton.

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. Members, friends and supporters of the Society organised or took part in a broad range of events, including the Dublin City Marathon, the Women's Mini-Marathon, a boxing match by the





112th Infantry Battalion, Irish Defence Forces in Lebanon, Movember, cake sales, Christmas fairs, Christmas Lunches, a 'Wear Red for Haemophilia day' event. A book, *From Middleton to the Mater*, which was donated to the Society is also available for sale and has raised some money for the Society.

Every event is important and every event that is organised shows a connection to the Society. No event is too big or too small and I thank each and every one of you who have supported the society through fundraising.

Planned Giving is another important fundraiser for the Society. The 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 for expensive accommodation when coming to Dublin for an overnight stay. If you would like to avail of the apartment, please contact the office. The apartment is so important and valuable that the purchase of a second property close to St. James' Hospital is being considered. We feel that, when the Children's Hospital is completed, there will be even greater demand for the apartment.

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 74 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. We are always looking to add new volunteers too, so if it is something that would interest you, please contact the office.

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

Twinning

The Society has been running a Twinning programme with Vietnam for a number of years now, even continuing relations when the official Twinning arrangement through the WFH ended. It has produced some great results, although there is still much work to be done. While the Twinning arrangement with Vietnam has ended, we are happy to work with them again if, for example, they decide to move to a national tender for treatment products, something that would be hugely beneficial to them.

In 2018, both the Irish Haemophilia Society and the Comprehensive Care Centres started a joint twinning programme with Jordan, with the first visit taking place in September 2018.

I visited Jordan again in September 2019, this time with a clear task at hand, namely to develop a three year strategic plan for the Society in Jordan. In parallel with my work on Jordan, a team from the Comprehensive Care Centres, comprising of Dr. Niamh O'Connell, Dr. Beatrice Nolan and Mary Byrne carried out reviews at the hospitals in Amman and met with senior officials from the Ministry in Jordan. A regional medical conference took place on the final day of our visits and Niamh, Beatrice and Mary all gave excellent presentations.

Conclusion

Under the current circumstances, last year seems so long ago but it does provide us with an opportunity to reflect and identify the things which really matter. The stand-out things for me are the importance of our health and our sense of community and need to connect with other people.

The importance of a well-funded, well-staffed and fully resourced health service is clearly critical. 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 30th Annual General Meeting of the Irish Haemophilia Society (I.H.S.), which was held in the Hotel Kilkenny on Saturday 2nd March 2019, 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 2019, 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, ten executive board meetings took place.

At the end of 2019, the following members were serving board members (inset).



John Stack,
Chairperson



Mary-Clare Delaney,
Vice-Chairperson



Aislinn Farrelly,
Treasurer



Barbara Wynne,
Secretary



Seamus McDonald



Donal McCann



Jim O'Leary



Matthew McCabe

Conferences & Events:

2019 was a busy year for the organisation. The following conferences and events were organised by the Society during 2019:

- 1st to 3rd March – Annual General Meeting & Conference (Hotel Kilkenny)
- 13th April – von Willebrand’s Information Day (Midland’s Hotel, Portlaoise)
- 17th April - World Haemophilia Day Events
- 18th & 19th May - Father & Sons Adventure Overnight (Lilliput Adventure Centre)
- 22nd June - Talking Red Information Day (Belfast)
- 28th – 30th June – Ageing Conference (Killeshin Hotel, Portlaoise)
- 20th July – Mild Haemophilia Information Day (Killashee Hotel, Naas)
- 18th – 20th October – October Members Conference (Shearwater Hotel, Ballinasloe)
- 16th November – Haemophilia B Information Day (Hotel Kilkenny)
- 28th November – 1st December – Inhibitor Summit (Barretstown)

The Society was represented at a number of other events throughout 2019 including:

- EHC Leadership Conference.
- EHC Roundtable Discussion.
- EHC World Haemophilia Day.
- EHC Women & Bleeding Disorders Conference.
- EHC Tender Procurement Workshop.
- EHC Conference.
- EHC New Technologies Conference.

Volunteers:

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 have members who also volunteer with administration at events and other projects. We would like to thank all our volunteers who gave up their time in 2019.

Publications & 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 2019 the Society produced the following publications:

- Four Quarterly Magazines
- Two Children’s Magazines
- Two Novel Treatments Magazines
- Annual Report
- Sports & Exercise Magazine
- 50th Anniversary Booklet
- Updated edition of: Information for Teachers & Playgroup Leaders

In 2019, the Irish Haemophilia Society had a strong presence online via Twitter and Facebook. Our Facebook page currently has 1,337 followers and our twitter page currently has 852 followers. The Society continued distributing the electronic magazine eZine, which has proved to be very popular. In 2019 the Society produced 12 eZines. Currently, 272 members have

signed up for this monthly electronic magazine and 113 website signups.

Fundraising:

A total of €8,028 was raised through fundraising in 2019.



Donations:

A total of €48,188 was donated in 2019.

Hyde Square:

In relation to the apartment facility for members at Hyde Square I am pleased to inform you that it was occupied for 72 nights during 2019. This is proving to be an essential service to members who have to travel for hospital appointments.

Outreach:

The Society's Outreach Co-ordinator Lyndsey Connolly resigned in March 2019 to go and live in the USA. Currently Robert Flanagan is the temporary Outreach Co-ordinator.

Educational Grants & Assitance:

A total of 26 educational grants were awarded in 2019, totalling €18,350, following an application, review and selection process including a rigorous scoring system. Applications were much improved in 2019 and our hope is that this will assist in the availability of very skilled volunteers in future years.

Staff:

The 2019 staff roles were 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 (Events & Membership Coordinator)

Society Representation:

The Society is represented on a number of external bodies as follows:

- National Haemophilia Council – Brian O’Mahony & Debbie Greene
- Haemophilia Product Selection Monitoring Advisory Board – Brian O’Mahony & Matthew McCabe
- Haemophilia HIV Trust – Brian O’Mahony & Nina Storey
- Disability Federation of Ireland – 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
- 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.

**Barbara Wynne,
Honorary Secretary**

2019 staff:



Brian O’Mahony



Debbie Greene



Nina Storey



Barry Healy



Robert Flanagan



Julia Collins



Aoife Kelly

The Year in Review from our CEO

The year 2019 was a successful year for the Society on several fronts. There was continued innovation in access to treatment, a year of successful and well attended events and a strong financial performance.

The beneficial impact of the switch to the use of extended half-life factor concentrates for FIX deficiency in 2017 and FVIII deficiency in 2018 started to become more apparent. We had collected quality of life data on a number of adults with severe haemophilia who had switched to these products and compared their quality of life before and after the switch. This data, which was presented at the conference of the International Society of Thrombosis and Haemostasis was very encouraging. We saw a reduction in the annual bleeding rate, in the frequency of use of pain medications, in acute and chronic pain and in the number of activities of daily living which were adversely impacted by haemophilia.

We are grateful to the members who agree to complete these surveys at our conferences and events. As part of our ongoing work on the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB), we also produced an internal audit of the effectiveness of the work of this group since its inception in 2003. The results are very impressive. The total quantities of FVIII purchased per head of population have increased three fold in that time due to more optimal treatment regimes and the availability of prophylaxis for all children and adults. The quality has also improved dramatically. Despite this, the budget has not had to substantially increase, and our very competitive system has helped us to avoid some €175 million in additional costs which would have been incurred if we had not changed to this system and method of selection and procurement of medications.

The year 2019 also saw the licensing of the first subcutaneous therapy for the treatment of those with FVIII inhibitors. This therapy, later in the year, was also licenced for use in those with FVIII deficiency without inhibitors. The HPSMAB negotiated the availability of this new therapy for those with inhibitors and later in the year also for those without inhibitors. By the end of 2019, a substantial number of those with FVIII inhibitors were being treated with this new therapy and it was available as an option for all those with severe FVIII deficiency. In addition to these licenced products, we had people with haemophilia on a clinical trial for another subcutaneous therapy which can be used for both FVIII and FIX with or without inhibitors. Work on Gene Therapy trials had progressed here to

the point where treatment of the first Irish people on a clinical trial was imminent at year end. This was truly an innovative year for access to treatment in Ireland.

Our events during the year were well attended. The Annual Conference and AGM and the October Conference were, as usual, the biggest events with 5 programme streams catering for the adults, teenagers, children and even the babies in attendance. I have to again acknowledge the enormous commitment of our many dedicated volunteers who work tirelessly at these events. Without their participation, the events could not be organized in such an inclusive fashion where we can cater for all ages. We greatly value our volunteers. They are one of our most precious resources and amid their number, we will also find future leaders for the organization. It is worth noting that our three youngest Board members have all come through the volunteer ranks and indeed continue to volunteer. This large group of people with haemophilia, carriers, siblings and their friends are the bedrock on which we will build the future of this organization.

The Annual conference agenda covered issues including novel therapies, an update on the innovative iPATH (Irish Personalised Approach to the Treatment of Haemophilia) Research project and a fascinating, if graphic, presentation on orthopaedic surgery. We also covered our ongoing development work programme with Vietnam which was now being finalized and our newer twinning partnership with the Haemophilia patient organization in Jordan.

The latter programme which is our sixth twinning programme, for the first time sees us twinning alongside our comprehensive care treatment centres in St. James and Childrens Hospital Ireland in Crumlin as they also twin with the haemophilia centres in Jordan. This collaborative approach will be beneficial, not only for Jordan, but also for the continuing strong working relationships between the Society and our centres. Given the fact that we will be developing a new strategic plan for the Society in 2020, it was also appropriate that we discussed the future of the Society in a changing environment. This facilitated feedback and ideas from the members as we chart our future direction. Also at the Annual Conference in 2019, the award for outstanding contribution to haemophilia in Ireland was presented to Nurse Specialist Evelyn



Singelton from the National Coagulation Centre.

The October conference included a timely debate between members on the merits or otherwise of Gene Therapy in haemophilia, an explanation on the terminology used in Novel therapies and a number of sessions on lifestyle. We organized a conference on Ageing and Haemophilia and one day information meetings on von Willebrand's Disorder, Haemophilia B and on Mild and Moderate Haemophilia.

With the continued media coverage of Brexit, we also arranged to co- host and co-sponsor two events with the UK Haemophilia Society in areas where collectively, there should be a sufficient number to warrant such meetings. These were also to demonstrate that, whatever differences may be apparent between Governments, haemophilia is no respecter of nationality or allegiance.

We have always enjoyed a close and collegial working relationship with our friends and colleagues in the UK and these events were meant to demonstrate that collaboration. The event for Women with Bleeding Disorders went ahead and was well attended by members of the Society. Unfortunately, the planned weekend conference for Newly Diagnosed families had to be cancelled as the level of interest anticipated did not materialize.

At the end of the year, we were also delighted to host, for the third successive year, the European Haemophilia Consortium Inhibitor summit which brought more than 100 people with inhibitors or their family members together for a weekend conference of lectures, workshops and discussions in the beautiful family setting of the Barretstown Camp. Once again, our pool of volunteers stepped up and helped at this great event.

We had a wonderful World Haemophilia Day event at the Royal College of Surgeons on April 17th. The theme was the future and we had discussion on Novel Therapies including Gene Therapy, research and personal stories including our youngest ever speaker, an assured performance by Oisín Stack who was aged 8. We were very pleased that the event was covered by RTE. That night, several of the iconic buildings in Dublin and Cork were lit up in red to celebrate the day.

Our publications in 2019 included two editions of the comprehensive update on *Novel Treatments in Haemophilia and other Bleeding Disorders* and a new publication on *Sport, Exercise and Haemophilia*. The latter publication is an acknowledgement that, with ever improving therapy for haemophilia, more options for sport and exercise are now available for members and lifestyle issues will be a larger part of our work and education programmes in future. We also produced a 50th Anniversary booklet and an updated publication for teachers and playgroup leaders. Sadly, the year also saw the passing of our esteemed colleague and treasurer Gerard O'Reilly who will be sadly missed by his many friends and colleagues in the Society.

Our financial position was strengthened with increased corporate contributions and a reduction in depreciation for our fixed assets allowed us to show a surplus for the year. I want to thank the Board members for their diligent work during the year and the staff team for their hard work, enthusiasm and flexibility as roles and responsibilities change and evolve.

Brian O'Mahony. CEO



Financial Report for 2019

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 year ended 31 December 2019 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 2019 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 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.

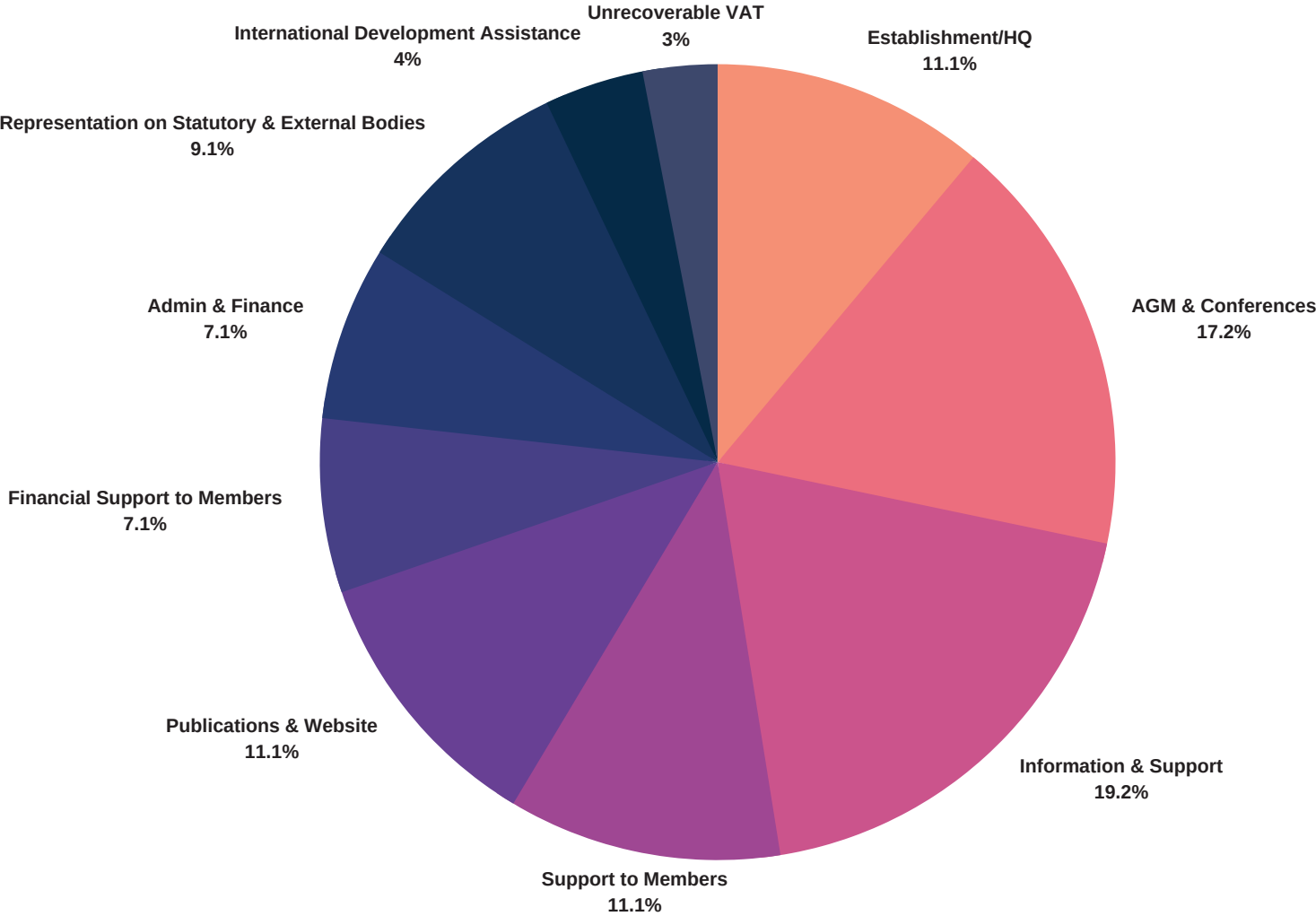
Registered Office:

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

Company Registration Number: 142834.

Registered Charity Number: CHY9214.

Expenditure for 2019



Irish Haemophilia Society

Income and Expenditure Statement for the year ended 31 December 2019

		2019	2018
		€	€
	Notes		
Income			
Health Service Executive		575,000	574,990
Membership		2,309	2,700
Donations - Members		48,073	59,741
Donations - Corporate		114,289	146,500
Fundraising		8,028	38,905
H.H.T Trust		12,077	-
Funding from EHC		10,000	33,000
Twinning		7,880	-
Investment Income		388	401
		<hr/>	<hr/>
		778,044	856,237
		<hr/>	<hr/>
Overhead expenses	1	(720,410)	(849,965)
		<hr/>	<hr/>
		57,634	6,272
Miscellaneous income	2	24,244	23,439
		<hr/>	<hr/>
Net surplus		81,878	29,711
		<hr/>	<hr/>
		2019	2018
		€	€
Expenditure			
Wages & Salaries		297,918	305,970
Employers Prsi Contributions		32,362	32,920
Pension Costs		35,453	29,763
Service Charge & Insurance		18,662	18,189
Light, Heat & Services		10,960	12,892
Help to Members		6,442	11,311
H.H.T Trust		8,077	2,000
Subscriptions		2,582	1,843
Fundraising		658	16,615
Educational Grants		18,350	18,000
Twinning/Vietnam Development Work		13,583	12,322
HQ Costs		2,881	3,918
Office Expenses, Stationery etc.		7,783	8,581
I.H.S Members' Facility		7,879	3,111
Post, Publications & Photocopying		23,355	40,035
Telephone/Internet		4,109	4,868
Website		3,573	5,781
Computer Services		13,385	13,789
Family Meetings/Activities		1,362	3,674
Meeting Expenses		19,213	19,851
Safety/Supply Activities		5,036	5,022
A.G.M & Annual Conference		45,946	72,619
Information & Support Conferences/Meetings		5,344	20,606
Members' Conference		32,812	35,614

Ageing Conference	5,736	6,661
EHC Inhibitors Summit	670	972
Legal & Professional	100	-
Sponsorship/Training	735	1,785
Unrecoverable Vat	22,387	23,856
Bank Charges	1,794	2,142
General Expenses	4,177	4,649
Provision for Sinking Fund	30,000	30,000
Auditor's Remuneration	5,046	4,800
Depreciation of Tangible Fixed Assets	32,040	75,806
	<hr/>	<hr/>
Total Overheads	720,410	849,965
	<hr/>	<hr/>

Irish Haemophilia Society

Balance Sheet for the year ending 31 December 2019

	Notes	2019 €	2018 €
Fixed Assets			
Tangible assets	7	770,546	798,053
Investments	8	327,504	303,260
		<hr/>	<hr/>
		1,098,050	1,101,313
		<hr/>	<hr/>
Current Assets			
Debtors	9	18,157	27,313
Cash and cash equivalents		1,057,922	832,176
		<hr/>	<hr/>
		1,076,079	859,489
		<hr/>	<hr/>
Creditors: Amounts falling due within one year	10	(181,650)	(80,201)
		<hr/>	<hr/>
Net Current Assets		894,429	779,288
		<hr/>	<hr/>
Total Assets less Current Liabilities		1,992,479	1,880,601
		<hr/> <hr/>	<hr/> <hr/>
Reserves			
Capital reserves and funds		169,000	139,000
Income and expenditure account		1,823,479	1,741,601
		<hr/>	<hr/>
Members' Funds		1,992,479	1,880,601

2019 IN PICTURES



2019 IN PICTURES



2019 IN PICTURES



Corporate Sponsors

The Irish Haemophilia Society would like to acknowledge the financial contributions made in 2019 by the following companies, under our Corporate Giving Programme:

Platinum Sponsors

SOBI, Roche

Gold Sponsors

Bayer, Novo Nordisk, Takeda

Silver Sponsors

Biomarin, Unique

Fundraisers

The Irish Haemophilia Society would like to thank with gratitude, everyone who fundraised for the Society during 2019.

Volunteers

The Irish Haemophilia Society would like to acknowledge and to thank everyone who volunteered for the Society during 2019.

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 2019.



IRISH HAEMOPHILIA SOCIETY

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Fax: 01 657 9901

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