

2017



ANNUAL REPORT



IRISH HAEMOPHILIA
SOCIETY

Cumann Haemifile Na hEireann

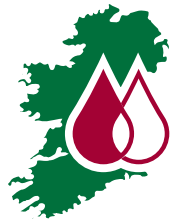


2017

Annual Report

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Traci Marshall Dowling,
Chairperson

Chairperson's Report 2017

Supports and Services



Offering support and services to our membership plays a very important role within the Irish Haemophilia Society (I.H.S.). The Society offers support to all demographics within its ranks and works with people living with bleeding disorders and their families.

In addition, we build collaborative relationships with the medical teams within the National Coagulation Centre (NCC), Our Lady's Children's Hospital Crumlin (OLCHC), Cork University Hospital (CUH), healthcare workers and others working within the field of haematology. The I.H.S. believes that building a strong informed community is the best way to support a person to live successfully and effectively with a long-term condition. We are happy to act as an advocate when needs be, our Outreach Co-

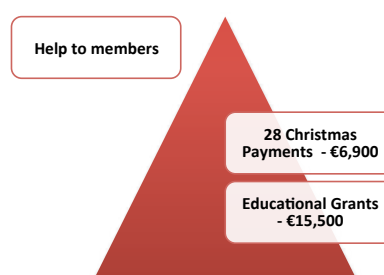
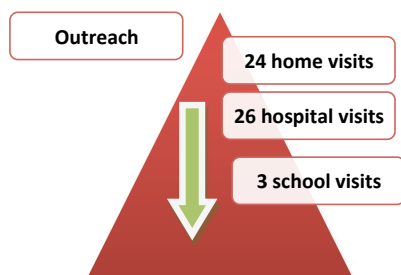
ordinator is also happy to arrange a home visit, whether it's just for a chat and a cuppa. The I.H.S. staff are also happy to assist you during your hospital visit. Often a member might have a concern they would like to raise with his/her hospital team and unsure the best way to approach it. If this is the case, give the office a call and the team will be happy to assist you.

Events & Activities 2017

During 2017 support continued to be a priority and we had 11 events and activities throughout the year.

Outreach

Although Outreach visits were down during 2017 this was due to the successful completion of Hepatitis C treatment for some members with a reduced need for outreach and support in this area.



Fundraising & Planned Giving



Each year we have members who organise events to raise money for the society. Members have run marathons, climbed mountains and in 2017, jumped out of a plane to raise money for us. Planned giving is when members sign up and agree to donate a specific amount for a 5-year period and the funds raised this are divided between our Twinning Programme with Vietnam and our apartment facility. A big thank you to all who supported us throughout 2017!



Hyde Square Apartment Facility

Our one and two bed room apartment facility was used 84 times in 2017.

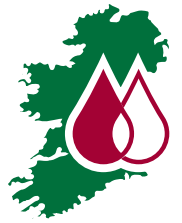
50th Anniversary Sub-Committee

With our birthday fast approaching we spent 2017 planning events and exploring ways to celebrate and remember those who have gone before us, and raise awareness about haemophilia and related bleeding disorders. A subcommittee consisting of Mary-Clare Delaney, Margaret Dunne, Debbie Greene, Brian O'Mahony and myself was formed.



50th Anniversary – Children's Project

Due to staff changes in 2016 and 2017, the in-house youth mentoring training was put on hold. Thankfully, with new staff in place the mentoring programme will resume in 2018. However, with the big 50th fast approaching we wanted to involve the many young members that attend our conferences in the celebrations. Aislinn Farrelly and I met with the Cub, Kidlink and Youth groups early in 2017 with the idea of encouraging interaction between the groups, support communication, nurture the development of intra & interpersonal skills and increase a sense of community. Together we brainstormed ideas and formulated a plan for a fitting way to mark the 50th; a time of both celebration and commemoration as we honour the past while looking toward a bright future.



Volunteers

The society has a fantastic group of volunteers. None of our conferences could incorporate the children's/youth programmes without them. I want to thank all our volunteers for their continued excellent contribution.

Educational Grants

The Society offers educational grants each year to people with haemophilia or related bleeding disorders and/or their families who wish to progress to higher education. These grants support students with the expenses involved with their studies. Traditionally there are two categories; Maureen and Jack Downey Educational Grant, available to people with haemophilia or related bleeding disorders and the Margaret King Educational Grant, available to an immediate family member of a person with haemophilia or related bleeding disorder. The amount payable varies with each grant.

Over the last number of years, the educational grant sub-committee has noticed a change in those applying for grants. This has raised a lot of discussion among the board level and membership. During the 2016 AGM members noted that some carriers, particularly obligatory carriers, may have lower clotting levels and in some instances, be classified as a person living with a mild bleeding disorder. Others pointed out that often those living with carrier status were not as negatively impacted compared to those living with moderate to severe haemophilia.

The sub-committee also noticed an increase in people applying for grants for post leaving certificate courses (PLC) at levels 5 and 6. The Society recognises the importance of further education, the many levels of ability among students and wishes to support all applicants. Whilst our aim is to empower applicants to reach their full potential, there is a marked difference in fees, workloads and commitment at levels 5 & 6 compared to levels 7-9.

Due to the extent of the discussion generated, the board reviewed the criteria for the educational grants in 2017.

Staff

Once again 2017 saw changes within the team. Paula Houlihan and Fiona Brennan departed from the staff team and Barry Healy and Robert Flanagan joined the staff. Despite the changes over the last number of years, the I.H.S. staff continue to provide a professional and efficient service. A big thanks to Brian, Debbie, Nina, Aoife, and Lyndsey (as well as our new additions) for their continued hard work and professionalism.





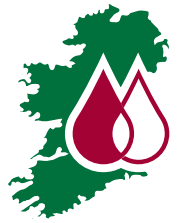
Board

2017 was also a busy year for the I.H.S. board and I would like to thank them for their hard work throughout the year. Often board members work full-time, have families or are in full-time education. In some instances, board members are juggling all these commitments at once. This has been the case for me for the past number of years. The end of 2016 brought additional health challenges within my own family. Thankfully all is back on track and normal family life has resumed, however, this coupled with a Leaving Certificate in the house, college finals and trying to finish my own Masters meant the need for a rethink, with me deciding to step down from the role of Chairperson in 2018.



Over the years there have been many who have been a great support. Often this was through words of encouragement, offering advice, guidance or highlighting areas for development and improvement, however, I will resist naming individuals for fear of accidentally leaving anyone out and causing offence. As this is my final Chairperson's Report, I want to sincerely thank you all. I have learned so much, have grown as an individual and was honoured to represent the society. The strength and inclusive nature of our community has permitted members to step in, step out and back in again when time and commitment permit. Therefore, I look forward to continuing as a committed member, to raising a glass for our 50th and to the new technologies and treatments on the horizon as we continue the journey towards the next 50 years!

**Traci Marshall Dowling,
Chairperson**



*Ms. Barbara Wynne,
Secretary*

Honorary Secretary's Report

At the 28th Annual General Meeting of the Irish Haemophilia Society (I.H.S.), which was held in the Slieve Russell Hotel on Saturday 4th March 2017, the Incoming Governing Body of the Society were elected as follows:

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

At the first executive meeting following the AGM on 13th March 2017, the following officers were elected:

- | | |
|----------------------|----------------------------|
| • Chairperson | Ms. Traci Marshall Dowling |
| • Vice-Chairperson | Mr. John Stack |
| • Honorary Secretary | Ms. Barbara Wynne |
| • Honorary Treasurer | Mr. Gerard O'Reilly |

In the period since the last AGM, nine executive board meetings took place.

The following members served on the board during 2017:



*Traci Marshall Dowling,
Chairperson*



*John Stack,
Vice-Chairperson*



*Barbara Wynne,
Secretary*



*Gerard O'Reilly,
Treasurer*



Mary-Clare Delaney



Michael Davenport



Seamus McDonald



Jim O'Leary



Aislinn Farrelly



2017

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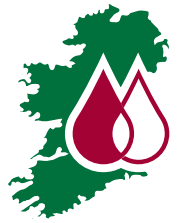
CONFERENCES & EVENTS

The following conferences and events were organised by the Society during 2017:

- 3rd to 5th March – Annual General Meeting & Conference (Slieve Russell Hotel, Cavan)
- 4th & 5th April – Member meetings regarding Factor IX Clinical Trials (Dublin & Cork)
- 6th & 7th May – Father & Sons Overnight (Lilliput Adventure Centre)
- 13th May – Hepatitis C Conference (Castleknock Hotel)
- 19th to 21st May – Ageing/Hepatitis C/HIV Conference (Hotel Kilkenny)
- 24th & 25th June – Mother & Daughters Overnight (Lilliput Adventure Centre)
- 20th to 22nd October – Members Conference (Hodson Bay Hotel, Athlone)
- 27th to 30th November – Haemophilia Camp Barretstown
- 26th November – Memorial Service (I.H.S. Office)
- 1st to 3rd December – Inhibitor Summit Barretstown
- 9th December – Christmas Party for Children (Grand Hotel, Malahide)

The Society was represented at a number of other events throughout 2017 including:

- European Haemophilia Consortium (EHC) Youth Workshop.
- EHC Leadership Conference.
- EHC Tender Procurement Workshop.
- EHC Conference.
- EHC New Technologies Conference.
- EHC Inhibitor Summit.



PUBLICATIONS AND SOCIAL MEDIA

The 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 2017 the Society produced four quarterly magazines, an annual report and two kidlink and youth magazines.

Social Media has become a part of everyday life for people. In 2017, the Irish Haemophilia Society had a strong presence online via Twitter and Facebook. Our Facebook page currently has 1119 followers. Our Twitter account currently has 477 followers. The Society continued distributing the monthly electronic eZine, which has proved to be very popular. Currently, 247 members have signed up for this monthly electronic magazine with a further 32 recipients who have signed up via our website.

The Society's website was re-launched in March 2017. The new website is easier to navigate, allows members to register online for events, renew membership, apply for educational grants and make donations.

HYDE SQUARE

The apartment facility for members at Hyde Square, which is a walk away from St. James's Hospital was used a total of 84 times during 2017.

VOLUNTEERS

The Society currently has 81 active 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.

EDUCATIONAL GRANTS AND ASSISTANCE

A total of 20 educational grants were awarded in 2017, totalling €15,500, following an application, review and selection process including a rigorous scoring system. Our hope is that this will assist in the availability of very skilled volunteers in future years.

STAFFING

2017 was again a challenging year in relation to staffing. The office was short staffed for many months.

- Paula Houlihan resigned in June 2017.
- Lyndsey Connolly completed her probation period in June 2017.
- Amy Dignam commenced working for the Society in June 2017 and was let go in July 2017.
- Debbie Greene commenced a 4-day week in September 2017.
- Fiona Brennan resigned in October 2017.
- Barry Healy joined the organisation in October 2017 and is currently on probation.
- Robert Flanagan joined the organisation in October 2017 and is currently on probation.

The staff team



Brian O'Mahony
(Chief Executive)



Debbie Greene
(Administrator &
Office Manager)



Nina Storey
(Finance & Fundraising
Coordinator)



Aoife Ni Fhógartaigh
(Events & Public Policy
Specialist)



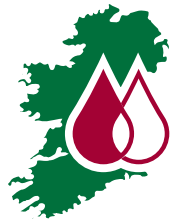
Lyndsey Connolly
(Outreach Coordinator)



Barry Healy (Publications
& Social Media
Coordinator)



Robert Flanagan
(Children's & Youth
Programmes Coordinator)



SOCIETY REPRESENTATION

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

- National Haemophilia Council – Brian O'Mahony & Debbie Greene
- Haemophilia Product Selection Monitoring Advisory Board – Brian O'Mahony & Aoife Ní Fhógartaigh
- 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
- Consultative Council on Hepatitis C – Brian O'Mahony & Debbie Greene
- Irish Haemostasis Research Foundation – Debbie Greene & Gerard O'Reilly
- Irish Blood Transfusion Service – Brian O'Mahony
- Plasma Users Group (PLUS) – Brian O'Mahony
- Governance Committee for National Audit Office for Hospital Mortality – Brian O'Mahony
- CJD Advisory Panel – 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.



Brian O'Mahony
Chief Executive

The Year in Review from our CEO

2017 was an exciting and productive year for the organisation with new frontiers reached in relation to treatment, research and Society activities.

As part of our work with the Haemophilia Product Selection and Monitoring Advisory Board, we participated in the National Tender processes for Factor IX and Factor VIII during the course of the year. The Tender process for Factor IX has resulted in a situation where all people with haemophilia B are now treated with extended half-life Factor IX concentrate. The very significant extension to the half-life of Factor IX means that individuals can benefit both from decreasing infusion frequency and increased trough levels, thereby allowing greater quality of life and greater protection from bleeding. The Factor VIII Tender process was being completed at the end of 2017 with a product change expected to take place in 2018.

The change to extended half-life Factor IX concentrate also necessitated meetings with members from Dublin and Cork where the rationale for the change was explained and people with haemophilia B were given an opportunity to become familiar with the home treatment kits for the new product. It will be of great benefit to the Society and to our members if we can measure the impact of any changes in treatment. To this end, prior to the change of treatment, the Society conducted quality of life surveys using specific tools and also brought members together in facilitated discussion groups to discuss their current experiences of living with haemophilia. These surveys and the outcomes from the facilitated groups will give us a significant amount of information which we can use to demonstrate the outcomes of treatment. This will also optimize our possibility of getting better treatments in the future as having outcome data from treatments is a very useful advocacy tool.

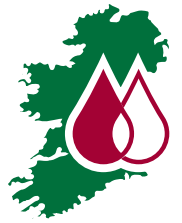
The Irish personalised approach for treatment of haemophilia (iPATH) research project was initiated in 2017. This exciting new research programme, led by the National Coagulation Centre, involves a partnership with the Irish Haemophilia Society, Our Ladies Hospital Crumlin, The Royal College of Surgeons and Trinity College Dublin. The project will involve carrying out a full genome analysis on every person with severe or moderate haemophilia who signs up for the research programme. This will then be correlated with treatment data.



The project aims to answer some fundamental questions in relation to the biology of haemophilia. Firstly, why is factor concentrate cleared rapidly from the blood in some people with haemophilia and very slowly in others? Secondly, why do some people with severe haemophilia demonstrate lots of bleeding complications while others with the same severity of haemophilia bleed very rarely? Thirdly, why do some young boys with severe haemophilia develop joint degeneration

after only a few joint bleeds, whereas other young boys with the same severity and the same number of joint bleeds have well preserved joints? Fourthly, why do some peoples develop inhibitors and others do not?

There are limitations to our understanding of the biology of haemophilia. It is our hope that this project will help to answer some of these fundamental questions and come up with some models for personalised treatment of people with haemophilia in Ireland. The current model of prophylaxis has been essentially unchanged for many years. Young boys with severe haemophilia start prophylaxis with Factor VIII or Factor IX on a fixed dose. They are observed and if bleeding occurs the dose and/or treatment frequency is changed. Essentially this method means that individuals have been bleeding until their correct prophylaxis dose is determined.



Now with the availability of extended half-life factor concentrates and with the information to be provided by the iPATH project it is our hope that this will facilitate the development of very personalised management of haemophilia in each person with the condition. This approach includes the identification of individuals who are at high risk of bleeding, tailoring factor replacement strategies for each individual and possibly develop adjunct therapies to help reduce bleeding. It should also assist with the identification of boys who are at high risk of joint disease and develop therapies to reduce this risk. We are extremely excited about this very high level centred project.



The Society have also been participating in the Lighthouse Projects which will lead to the development of a patient portal. This means that each person with haemophilia should have access to their core medical records on their smart phone, tablet or computer and people with haemophilia will be able to change appointments with many of the multi-disciplinary team.

Our conferences in 2017 were again varied and well attended. Our annual general meeting and conference in March was attended by 236 people. The programme included lectures on the new iPATH research project, an update on haemophilia care, an open forum with the comprehensive care centres, and an update on our continued work with Vietnam. The members conference in October 2017 had the highest attendance of any members conference in the 10 years of this event. A total of 250 people attended which was a 55% increase on the attendance in 2016. The programme included a comprehensive update on novel pipeline treatment for haemophilia which was followed by an interactive workshop on the future of haemophilia treatment. There were also excellent lectures on port-a-caths, vein care, tattoos and piercings and meetings of the mothers and fathers groups.

Due to the fact that the attendance of the Parents Conference in 2016 was significantly decreased we had decided that we would not run this conference in 2017. In its place we organised separate mother and daughter, and father and son events. These events were weekend trips to an adventure centre where the mothers and daughters or fathers and sons worked together over the weekend on various activities. The programme included education sessions, discussions and activities designed to increase the bonds between fathers and sons and mothers and daughters. They were extremely successful with very good evaluations.

We also organised a conference for ageing with haemophilia in 2017. Prior to 2017, this conference was held every second year. However, we had decided that for 2017 and in the future, this would become an annual conference. This is following the effective eradication of Hepatitis C in our members which means there is no longer the same requirement for us to hold a conference on Hepatitis C and HIV each year. These topics can be integrated into the Ageing Conference.

We did hold an open Hepatitis C Conference in 2017 which was open to all in the community. This conference, which was held for the first time in 2016, was the first conference to bring together state infected and state non-infected individuals with Hepatitis C. The objective of the conference was to give people updated information on treatment and treatment options which encouraging a positive attitude to treatment and living with Hepatitis C. The 2017 meeting was again successful and well

attended. We do not envisage holding this conference again in the future as we believe the requirement from the Society to organise this information meeting has now been met and the work will continue under the auspices of the National Hepatitis C Treatment Programme. The Ageing Conference was very well attended. The topics included healthy eating, physiotherapy, pain management and treatment protocols. There were also sessions on support services for those with HIV.

It is recognised that the biggest safety risk from current treatment of haemophilia is the risk of inhibitors. Approximately 20% – 30% of people with haemophilia A develop inhibitors and 1% - 3% of people with haemophilia B will develop inhibitors. The development of inhibitors, especially high titre inhibitors, has a very debilitating effect on quality of life. It generally results in a much greater number of bleeds, reduced mobility, and a significant reduction in quality of life. It is difficult for national haemophilia societies to put together meetings or programmes for people with inhibitors due to the fact that they are so small in numbers and also, they find it more difficult to travel.



In 2017, the Society was delighted to host and organise the European Inhibitor Summit on behalf of the European Haemophilia Consortium. This meeting brought together 126 people with inhibitors and their families from 27 European countries. The organisation of the event was carried out by our staff and volunteers. It was held in the wonderful Barretstown facility in Co. Kildare. The event was extremely successful and also gave an opportunity to several Irish people and their families with inhibitors to meet other people with inhibitors from around Europe.

Our work with Vietnam continues. Vietnam is now a primary target country for World Federation of Hemophilia (WFH) programmes under the Global Alliance for Progress Programme. We provide funding for micro employment and home adaptation projects to allow people with haemophilia to live safely in their homes and to work with a measure of dignity. The Vietnam Haemophilia Association have identified 12 potential patient leaders from the major cities of Hanoi, Hue, Can Tho and Ho Chi Minh, with whom we will work over the next couple of years preparing them for leadership positions in the organisation.



During 2017 we also started to prepare for the 50th anniversary of the organisation in 2018. This included gathering a lot of archive materials, digitising all of the old film archive which we have from the Society including our 25th anniversary and various advocacy campaigns and doing the preparatory work for the movie, premiered in 2018. In terms of our strategic plan, by the end of 2017 we had completed or work was ongoing on 163 of the 195 strategies or 84% of our total number of strategies to be achieved. The plan will run until the end of 2018 with I am confident that the vast majority of the strategies will be implemented and objectives achieved.

Our finances for 2017 were robust and healthy. The grant from the HSE was at the same level as 2016 and the corporate donations were increased by 74% above 2016. Total salary costs were actually slightly lower than in 2016. Changes in staff at the end of 2017 finds us in a strong position with a refreshed and renewed staff team, with new and exciting products now available to treat people with haemophilia in Ireland, with ground breaking research starting, we have exciting plans for the future in relation to conferences, events and our communications.

Brian O'Mahony,
Chief Executive



Financial Report for 2017

**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 2017 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".

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 2017 and of its deficit 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"; 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 issued by the Irish Auditing and Accounting Supervisory Authority (IAASA), and the Provisions Available for 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:

- 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.

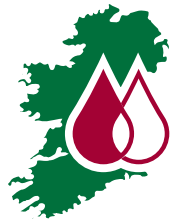
Matters on which we are required to report by exception

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.

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.

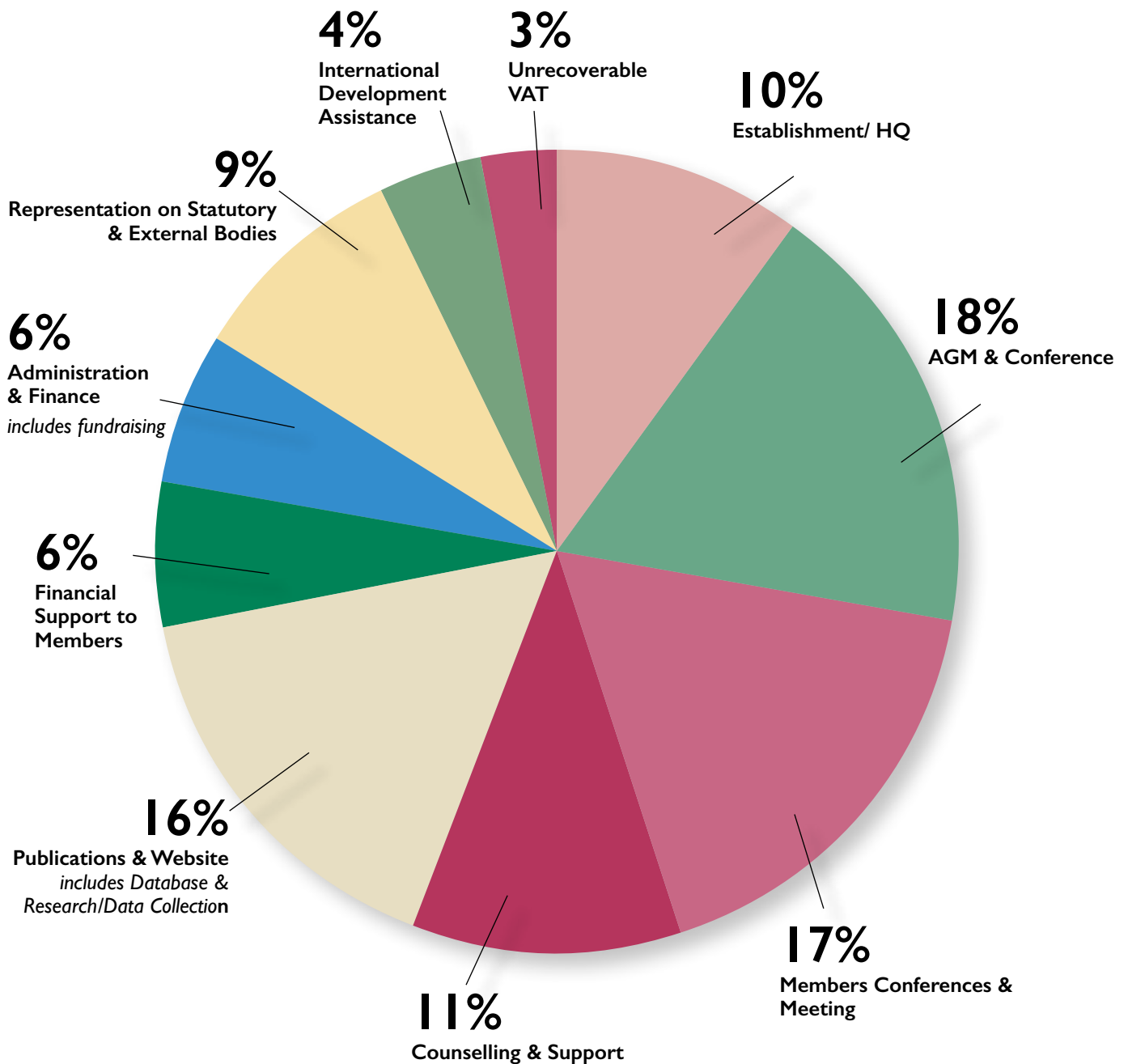
Registered Charity Number: CHY9214.

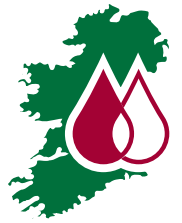


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Expenditure for 2017





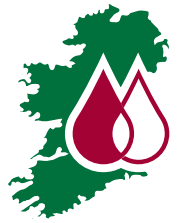
Irish Haemophilia Society

Income and Expenditure Statement for the year ended 31 December 2017

	2017	2016
	€	€
Income		
Health Service Executive	550,000	550,000
Membership	2,649	2,370
Donations - Members	19,374	22,516
Donations - Corporate	115,500	66,000
Fundraising	7,211	7,482
H.H.T Trust	3,000	9,000
Funding from EHC	10,000	1,200
Investment Income	950	2,397
	<hr/> 708,684 <hr/>	<hr/> 660,965 <hr/>

Expenditure

	2017	2016
	€	€
Wages and Salaries	281,769	291,060
Employers PRSI Contributions	30,527	31,284
Pension Costs	23,691	25,601
Service Charge & Insurance	17,541	16,397
Light, Heat & Services	11,398	11,695
Help to Members	15,628	6,518
H.H.T Trust	2,000	3,000
Subscriptions	2,228	2,011
Fundraising	656	925
Educational Grants	15,500	18,100
Twinning/Vietnam Development Work	11,910	2,191
HQ Costs	331	2,389
Office Expenses, Stationery etc.	7,542	7,339
I.H.S Members' Facility	6,102	4,532
Post, Publications & Photocopying	40,678	18,866
Telephone/Internet	5,641	6,353
Website	4,857	3,501
Computer Services	8,744	16,265
Family Meetings/Activities	6,320	-
Carriers Conference	-	6,053
Meeting Expenses	16,505	18,282
Safety/Supply Activities	596	395
A.G.M & Annual Conference	37,066	29,966
Counselling & Support Meetings	3,997	3,404
Members' Conference	43,777	19,706
HIV/HCV Conference	-	3,935
Ageing Conference	7,383	-
EHC Inhibitors Summit	1,528	-
Legal and Professional	-	1,191
Parents Conference	-	17,887
Sponsorship/Training	156	3,369
Hep C Conferences	1,724	4,101
Unrecoverable Vat	19,972	18,879
Bank Charges	1,824	2,168
General Expenses	4,127	2,530
Provision for Sinking Fund	30,000	20,000
Auditor's Remuneration	4,800	4,800
Depreciation of Tangible Fixed Assets	75,806	78,259
	742,324	702,952
Net deficit	(33,640)	(41,987)



Irish Haemophilia Society

Balance Sheet for the year ending 31 December 2017

	Notes	2017 €	2016 €
Fixed Assets			
Tangible assets	7	873,858	946,589
Investments	8	279,821	279,821
		<hr/>	<hr/>
		1,153,679	1,226,410
		<hr/>	<hr/>
Current Assets			
Debtors	9	18,172	7,951
Cash and cash equivalents		765,161	852,765
		<hr/>	<hr/>
		783,333	860,716
		<hr/>	<hr/>
Creditors: Amounts falling due within one year	10	(107,790)	(251,597)
		<hr/>	<hr/>
Net Current Assets		675,543	609,119
		<hr/>	<hr/>
Total Assets less Current Liabilities		1,829,222	1,835,529
		<hr/> <hr/>	<hr/> <hr/>
Reserves			
Capital reserves and funds		117,333	90,000
Income and expenditure account		1,711,889	1,745,529
		<hr/>	<hr/>
Members' Funds		1,829,222	1,835,529
		<hr/> <hr/>	<hr/> <hr/>

2017 in Pictures



2017 in Pictures



Corporate Sponsors

The Irish Haemophilia Society would like to acknowledge the financial contributions made in 2017 by the following companies, under our Corporate Giving Programme:

Platinum Sponsors

Roche, Shire, SOBI

Gold Sponsors

Bayer, CSL Behring

Silver Sponsors

Anylam, Merck

Fundraisers

The Irish Haemophilia Society would like to thank with gratitude, everyone who fundraised for the Society during 2017.

Volunteers

The Irish Haemophilia Society would like to acknowledge and to thank everyone who volunteered for the Society during 2017.

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 2017.

Follow the I.H.S. on our social media platforms or visit our website www.haemophilia.ie

