

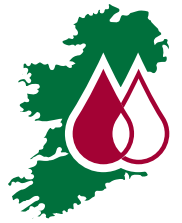


2016

Annual Report

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Traci Marshall Dowling,
Chairperson

A Message from the Chairperson

Services and Supports

2016 was another productive year and one where the Irish Haemophilia Society (I.H.S.) continued to offer a wide range of services and supports to all our members. Throughout 2016 we worked with adults and children with haemophilia A and B, families with a new diagnosis of haemophilia and families who moved to Ireland from abroad. During 2016, we continued to support our members who were undergoing treatment for Hepatitis C, persons living with HIV and the families of those who died from HIV and/or Hepatitis C. We also worked with members with von Willebrand's disease, those with related bleeding disorders, those with rare bleeding disorders such as factor VII, factor X and factor XIII deficiency, women with bleeding disorders and carriers. We also continued to build collaborative relationships with the medical teams in the National Coagulation Centre (NCC), Our Lady's Children's Hospital Crumlin (OLCHC), Cork University Hospital (CUH) and with healthcare workers and others working in the field of haematology.



We offered services and support by providing conferences, workshops and educational & information days. We also offered peer and outreach support in the guise of home and hospital visits and we also accompanied members to their clinic visits. Our members were updated regularly through our publications, magazines and eZine bulletins. We also represented our members at National, European and International conferences and events.

The Board

2016 continued to be a busy year for the I.H.S. board. The board meet once a month with 11 planned meetings per year. While all board members are very dedicated and committed, many work full time, have families or are in full-time education. In some instances, board members are juggling all these commitments at once! For some, despite their obvious dedication and passion for the Society, the timing is not right and sadly, David Curtin decided to step down in 2016. I would like to thank David for his support and commitment to the Society and look forward to working with David in the future. Due to the varied commitments of the board and to ensure a continued quorum, we decided to co-opt an additional member in 2016. We welcomed Jim O'Leary onto the board in April 2016.



In addition to our planned meetings, many board members also attend sub-committee meetings. These include meetings in relation to educational grants, our upcoming 50th anniversary celebrations in 2018 and youth mentorship programmes. Throughout 2016, board members represented the Society at our open Hepatitis C conference, various European Haemophilia Consortium (EHC) conferences and the World Federation of Hemophilia (WFH) Congress.

For the past three years, I have represented the Society at European level as an elected steering committee member of the EHC. Each term covers a three year period and elections took place in October 2016. Despite believing in and admiring the work of the EHC, I decided not to put myself forward for a second term as I wanted

to maintain a reasonable work/life balance. Whilst I thoroughly enjoyed my term with EHC and was sad to step away, I feel I was quite productive during my time on the steering committee. I was instrumental in the creation, design, development and implementation of both the EHC Youth Leadership Workshop and the Leadership Conference. These areas are vital to the haemophilia community as they support capacity building; identify future leaders and support development and sustainability. Although I have stepped down from the EHC steering committee, I was asked and have agreed to remain involved in the Youth workshops. Many of the I.H.S. youth group and youth leaders have attended and benefitted from these workshops. I plan to build on the success of these workshops and create an I.H.S. youth mentorship programme during 2017.



I also conducted research during my time with the EHC, researching the funding methodologies of the 45 haemophilia organisations in Europe and exploring how many had policies pertaining to this funding. This research was published as a Monograph and was launched at the 2016 EHC conference in Bergen, Norway.

Junior & Youth Membership & Youth Training

There was no in-house training during 2016, however, we recommenced the Junior & Youth Membership programme. Some of our youth leaders also attended the EHC Youth Leadership Workshop, the Leadership Conference and the WFH Congress.

Fundraising & Planned Giving

Members continued to fundraise on behalf of the Society throughout the year with many events organised including: Sober September, a Bucket Collection, a Darts Night, the Women's Mini Marathon and Movember. A total of €7,121 was raised.

Our planned giving campaign remained the same with 50 members donating during 2016. Funds raised through planned giving continue to be divided between Vietnam and our apartment facility.





We would like to say a big thank you to all involved in raising funds and if you have any ideas for 2017 please drop in or call the office!

Support to Members

Despite many staff changes in 2016, the I.H.S. staff and board worked tirelessly throughout the year to ensure that the needs of the different demographics within the Society were met. Support was offered to members who were undergoing Hepatitis C treatments, 66 home and hospital visits were conducted and 63% of members were contacted by phone.

Conference participation continued to be strong in 2016. We value and are very proud of the inclusive nature of our conferences. However, with the introduction of the 'Children and Vulnerable Persons Act 2012' and the 'Children First Act 2015', the Society has responsibilities and obligations that need to be met in line with both acts. All safeguarding issues have to be acted upon. Thankfully we haven't had any issues that have jeopardised the continuation of services, however, we have had incidents. If we are to continue to offer our excellent conferences we need to be mindful of the legislation in place and work together to ensure that all obligations and responsibilities are met. This has to be a collective and collaboration process and requires the commitment and participation of all our members. It was agreed by the board to facilitate an interactive session covering this area in 2017. I look forward to hearing your thoughts and feedback on this and invite as many of you as possible to get involved. If you can't attend our conferences please feel free to contact us via, phone, e-mail or call into the office.

Educational Grants

We were delighted to be able to offer support to those who want to continue their education. There are two main categories of educational grants available. The first category is the Maureen & Jack Downey Educational Grant, which is available to a person with haemophilia or related bleeding disorder, who has been accepted on a third level educational course. The person applying must be registered at the National Coagulation Centre at St. James's Hospital in Dublin. The second category is the Margaret King Educational Grant, which is available to an immediate family member of a person with haemophilia or related bleeding disorder, be it a spouse, son, daughter, sister, brother, mother or father. The person applying must be accepted on a third level educational course, and the person with the bleeding disorder must be registered at the National Coagulation Centre at St. James's Hospital in Dublin.



The selection process is quite robust and many areas are considered such as the quality of the application, the information that was given, involvement in the Society, financial need, how many in the family are going to college and whether or not the person applying is a first-time applicant. A total of 26 individuals were supported during

2016, which totalled €18,100. The selection committee has noted an increase in people applying for post leaving certificate programmes below level 7 (ordinary degree level) and an increase in the number of carriers applying for the persons with haemophilia or related bleeding disorder grant. Whilst the board do not have a difficulty with the patterns emerging, we felt they warranted further discussion and debate, to ascertain if courses and categories are still sufficient and relevant to our member's needs, or need updating.

Our Haemophilia Community

Each year the I.H.S. staff, board, volunteers and members work very hard to ensure the Society delivers on its promise to provide support to all our members. 2016 was no exception.

Despite the loss of key staff members and supporting new additions to the team, the staff ensured that the disruption to members and services was minimal. I would like to thank Brian, Debbie, Nina, Fiona, Aoife and Paula for their continued hard work and professionalism during 2016. I want to wish Anne, Declan and Leah the very best of luck in their new adventures. Whilst their experience and expertise will be greatly missed in the office, I look forward to them continuing to be valued members of our haemophilia family.

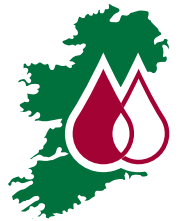
The majority of our conferences could not happen without our large team of volunteers. On behalf of the board, I thank them for their continued commitment, energy and dedication.

Likewise, the Society could not and would not exist without the time, energy and commitment of our board. Each member brings value and a different perspective to the table. I want to thank the board for all their hard work, energy and time throughout 2016.

Finally, I want to thank you, our members for continuing to engage and interact with us. Doing so ensures that the Society continues to grow and develop in the right direction and I'm delighted that 2016 proved to be another successful year for the I.H.S.!

Traci Marshall Dowling,
Chairperson.





Barbara Wynne,
Secretary

Honorary Secretary's Report

At the 27th Annual General Meeting of the Irish Haemophilia Society (I.H.S.), which was held in Hotel Kilkenny on Saturday 5th March 2016, the Incoming Governing Body of the Society were elected as follows:-

- David Curtin
- Michael Davenport
- Mary-Clare Delaney
- Traci Marshall Dowling
- Seamus McDonald
- Gerard O'Reilly
- John Stack
- Barbara Wynne

At the first executive meeting following the AGM on 15th March 2016, the following officers were elected:-

- **Chairperson** – Traci Marshall Dowling
- **Vice-Chairperson** – John Stack
- **Honorary Secretary** – Barbara Wynne
- **Honorary Treasurer** – Gerard O'Reilly
- On 11th April 2016, Jim O'Leary was co-opted onto the executive board.
- On 5th December 2016, David Curtin resigned from the executive board.

At the end of 2016, the following members were serving board members:



Traci Marshall Dowling,
Chairperson



John Stack,
Vice-Chairperson



Gerard O'Reilly,
Treasurer



Barbara Wynne,
Secretary



Mary Clare Delaney



Seamus Mc Donald



Michael Davenport



Jim O'Leary

Events organised by the Society during 2016

The year 2016 was an extremely busy year for the I.H.S. in relation to conferences, events and activities.

MARCH 2016

The AGM and Conference took place in Hotel Kilkenny over the weekend of 4th to 6th March. Attendance comprised of 221 delegates. Attendance at the various programme sessions was very high, in particular, sessions on the history of the I.H.S., new developments and an update on Vietnam. The children's programmes included educational sessions on dental care and exercise. Evaluations showed that satisfaction with the conference was very high.



MAY 2016

A Carrier's Conference took place over the weekend of 7th and 8th of May in the Castleknock Hotel in Dublin. On Saturday, 24 delegates attended and on Sunday, 22 delegates attended. Dr. Niamh O'Connell spoke about pregnancy and family planning, Professor John Bonnar spoke about menopause, Anne Duffy spoke about positive living and Dr. Alison Dougall gave dental care advice.



An open Hepatitis C conference took place in the Castleknock Hotel in Dublin on the 21st May. This conference which took place for the second year running was attended by over 50 delegates from various support groups. Speakers included Dr. Diarmaid Houlihan, Consultant Hepatologist from St. Vincent's Hospital, Ms. Michele Tait, National Hepatitis C Coordinator

and Ms. Helena Irish, Nurse Manager from the Hepatology Department in St. James's Hospital. There also was a panel discussion where people spoke about their treatment experiences. The conference was a great success.

JUNE 2016

The Parents Conference took place in the Sheraton Hotel in Athlone over the weekend of 24th to 26th June. The programme included sessions on port-a-caths and venous access, a home infusion demonstration and workshop, inhibitors, a mothers and fathers workshop, and a workshop on new developments. A total of 108 members attended this conference which was a decrease in attendance of 40% from the previous year.

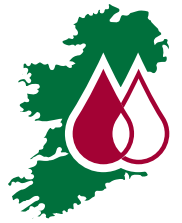


SEPTEMBER 2016

A conference for members living with Hepatitis C/HIV took place on 17th and 18th September in the Dunboyne Castle Hotel in Co. Meath. Topics covered at this conference included: sustained virological response, the Hepatitis C database, future services and support for members, investments and the HAA card. A total of 22 members attended this conference.

OCTOBER 2016

The October Conference took place over the weekend of 14th to 16th October in the Radisson Blu Hotel in Co. Sligo. A total of 161 people attended this conference. The programme included an interactive workshop on communication, a debate on extended half-life factor versus current recombinant factor, haemophilia care in Europe, a mindfulness workshop, a cooking demonstration and games for all the family. Evaluations from this conference were very positive.



NOVEMBER 2016

A specific information day on haemophilia B took place in the offices of the I.H.S. on 26th November with 18 members in attendance. Participants heard updates on the rapidly changing treatment environment for people with haemophilia B.

Barretstown held a camp for children with haemophilia and related bleeding disorders from the 3rd to 6th of November 2016. Barretstown first held a haemophilia & related bleeding disorders camp in 2014 and we have been very fortunate to have this camp as an annual event since. Over 60 children attended the camp from Ireland and the UK.

The Society was represented at a number of other events throughout 2016 including:

- European Haemophilia Consortium (EHC) Youth Workshop.
- EHC Leadership Conference.
- World Federation of Hemophilia Congress.
- EHC Tender Procurement Workshop.
- EHC Conference.
- EHC New Technologies Conference.
- EHC Inhibitors Summit.

VOLUNTEERS

The I.H.S. is fortunate in having available to us a cohort of able and enthusiastic volunteers who staff the four children's programmes. The volunteers, are educated about haemophilia and are trained using a programme developed in conjunction with Barnardos. The Society currently has 75 active volunteers who work at our conferences and events. The organising of these 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.



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 2016, we produced the following publications:

- Magazine (Spring, Summer, Autumn, Winter).
- Annual Report.
- OLCCH contact cards.

- Dental care leaflet.
- Junior member's newsletter (Autumn & Winter).
- Youth member's newsletter (Autumn & Winter).



Social Media has become a part of everyday life for people. In 2016, the Irish Haemophilia Society had a strong presence online via Twitter and Facebook. Our Facebook page has 994 followers. In addition, in 2016, the Society initiated a monthly electronic magazine called eZine, which is distributed to a specific electronic mailing list and has proved to be very popular. Currently, 250 members have signed up for this monthly electronic magazine.

charge of €10 per night per individual/couple/family is charged. Bookings can be made via the website or by contacting Paula or Debbie in the office.

PHONE CALLS / HOME AND HOSPITAL VISITS

In 2016, the Society carried out 66 home and hospital visits to members and 63% of members were contacted by phone during the year.

EDUCATIONAL GRANTS AND ASSISTANCE

A total of 26 educational grants were awarded in 2016, totalling €18,100, 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.



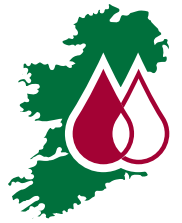
HYDE SQUARE

The apartment facility for members at Hyde Square, which is a walk away from St. James's Hospital was used a total of 76 times by members or non-members during 2016. A nominal

STAFFING

2016 was a challenging year in relation to staffing. The office was short staffed for many months.

- Leah Cawley resigned in June 2016.
- Aoife Ní Fhógartaigh completed her probation period in June 2016.
- Anne Duffy retired in August 2016.
- Rose Cotter commenced work with the Society in August 2016 and was let go on 8th September 2016.
- Paula Houlihan commenced work with the Society in August 2016 and will complete her probation period in May 2017.
- Declan Noone resigned in September 2016.



The staff compliment at the end of 2016 was as follows:



*Brian O'Mahony
(Chief Executive)*



*Debbie Greene
(Administrator &
Office Manager)*



*Nina Storey
(Finance & Fundraising
Coordinator)*



*Fiona Brennan
(Volunteer & Children's
Programmes Coordinator)*



*Aoife Ni Fhógartaigh
(Administrative Assistant)*



*Paula Houlihan
(Administrative Assistant)*

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 and Monitoring Advisory Board – Brian O'Mahony & Aoife Ni 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
- vCJD Advisory Panel – Brian O'Mahony
- National Hepatitis C Clinical Advisory Group – Brian O'Mahony
- National Office for Clinical Audit – 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.



2016

Annual Report



Brian O'Mahony
Chief Executive

The Year in Review from our CEO



2016 was a very busy year for the Society. In addition to our conferences and events, we did a lot of work during the year in relation to the potential of access to clinical trials for new and novel products for haemophilia. We worked extensively with the National Coagulation Centre (NCC) on the relocation of the centre to the new site in St James's Hospital.

The most exciting development of the year, however, came late in 2016 when we were able to publically announce the effective eradication of Hepatitis C in the haemophilia community in Ireland. Since 2012, the Society have been working nonstop to ensure access to treatment with the new generation of Hepatitis C treatments for our members

with Hepatitis C. We had succeeded in getting a significant number of members treated with the earlier protease inhibitor treatments from 2012 to 2014. In 2015, we received a commitment from the then Minister for Health Leo Varadkar, that every person with haemophilia who contracted Hepatitis C through contaminated blood products provided by the State, would be offered treatment no later than the end of 2017. We always had the ambition to achieve this by the end of 2016. We fully realised that Hepatitis C was the leading cause of mortality in people with haemophilia in Ireland over the past ten years. By December 2016, we had achieved this. Every person with haemophilia who wanted to take treatment had now been offered treatment or had commenced or completed treatment, either with the older treatments or with the new Direct Acting Antivirals. Therefore, 2016 also was the last year for us to hold the separate HIV/Hepatitis C Conference. In subsequent years, this will be rolled into an annual Ageing Conference.

Our conferences and events were very well attended during the year. The Annual General Meeting and Conference included lectures on new developments including extended half-life (EHL) factors, gene therapy and novel treatments, an open forum with the healthcare workers, sessions on dental care and our ongoing work with Vietnam.



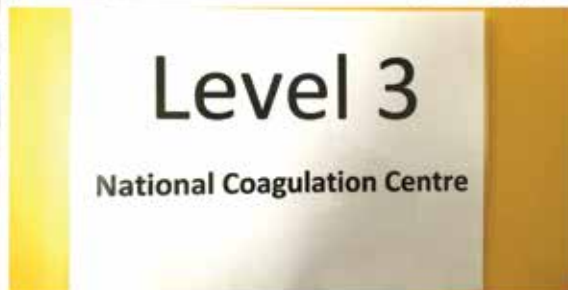


There was also a first of three lectures on the history of the Irish Haemophilia Society (I.H.S.) covering the period of time from 1982 – 2002. The Member's Conference included a workshop on communication and a debate between members on the relative merits of EHL versus standard half-life recombinant products. The conference also included sessions on mindfulness, a demonstration on healthy cooking and a screening of and discussion on the 'Haemophilia Stories' movie produced by the European Haemophilia Consortium.



The Parents Conference included sessions on port-a-caths and venous access, a home infusion workshop, a symposium on inhibitors and discussion on the experience of extended half-life factor concentrates to date. It also included workshops for mothers and fathers. A common theme running through all three of the major conferences throughout the year was sessions on the extended half-life factor concentrates. The fact is that for the past number of years a number of children with

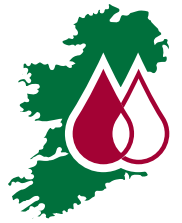
severe haemophilia in Ireland have been participating in clinical trials for extended half-life factor VIII and factor IX. These products have now become a therapeutic option for people with haemophilia. We want to ensure that people understand the relative benefits of extended half-life and standard factor concentrates and that the conferences are a continuing way of ensuring that members are informed about the therapeutic options and choices, the development of new products and the relative merits of each of the products. During the course of the year, we also had ongoing discussions, together with the treatment centres, with companies developing novel treatments such as subcutaneous therapies and gene therapy, with a view to increasing participation in these clinical trials for people with haemophilia in Ireland. During the course of 2016, we had people in Ireland on clinical trials for EHL factor VIII and factor IX products. We expect this further work to bear fruit in 2017 when we expect people with haemophilia to begin clinical trials for some of the subcutaneous trials and indeed gene therapy. Also in course of 2016, a negotiated tender was carried out for a defined quantity of EHL factor VIII concentrate and this is now being used routinely for the treatment of children with severe haemophilia.



We worked with the National Coagulation Centre (NCC) on a number of important projects during the course of 2016. The new NCC, which replaces the National Centre for Hereditary Coagulation Disorders (NCHCD) opened in November 2016 in St. James's Hospital. We had worked with the centre in relation to giving input into its design. We were delighted that the new centre opened and the fact that the centre is in the same building as the existing Haemophilia and Hepatology Units and also the Clinical Trial facility. This will greatly increase the co-ordination of haemophilia care and optimise the time of the staff and patients who attend the centre and the In-Patient Unit. Throughout the year, we also worked with the centre on the Lighthouse Project. This is an information technology project funded by the Health Service Executive (H.S.E.) which will facilitate optimal use of technology in haemophilia. The H.S.E. are interested in seeing how far technology can be pushed in terms of healthcare and haemophilia is one of the pilot projects where they are seeking to optimise this. The project will include a patient portal and will allow patients to have access to their medical records on their smartphone, tablet or computer and also to make or change appointments or clinic visits.

We also worked with Professor James O'Donnell on the development of a new research proposal called the Irish Personalised Approach to the Treatment of Haemophilia (iPATH) which will be rolled out in 2017. This project aims to answer fundamental questions in relation to haemophilia.

The Society contributed actively to the ongoing debate in relation to blood donor deferral. As a member of the board of the Irish Blood Transfusion Service (IBTS), I attended and represented the views of patients and those who rely on blood products at the consensus conference held in April 2016, in relation to blood donor deferral issues for men who have sex with men (MSM). A decision was taken later in the year to change the MSM deferral from a lifetime deferral to a one-year deferral. Significantly, however, this was accompanied by an additional new deferral of any person for five years after they have had a



sexually transmitted infection. Taken together these two measures in our view, will help to protect the blood supply. We were also pleased to achieve the removal of the specific donor question in relation to partners of people with haemophilia. There is now no longer any justification for the deferral of the partners of people with haemophilia.

I also represented the Society as the public representative on the governance committee of the National Audit for Hospital Mortality and launched the first annual report of the National Audit for Hospital Mortality in late 2016. This will in future years become a very useful tool in relation to looking at the various causes of mortality for specific conditions in hospitals in Ireland.



Our work with Vietnam continued and we were delighted that in the course of 2016 that the World Federation of Hemophilia (WFH), following advocacy from the Society, agreed that Vietnam would form part of their flagship Global Alliance for Progress Programme (GAP). This programme will provide additional resources for haemophilia care in Vietnam including the training of doctors and laboratory scientists and the provision of factor concentrates free of charge, for the next number of years.

During the course of our work with Vietnam over the past 5 years, access to factor replacement therapy has increased three-fold, albeit remaining at a very low level. We were also very pleased that in November 2016, President Michael D. Higgins, during his state visit to Vietnam met with the doctors and the Vietnamese Hemophilia Association (VHA) and thanked them for their continued work for people with haemophilia in Vietnam.

Our financial position in 2016 showed a decrease in both income and expenditure when compared with 2015. Income was 81% of the income which we received in 2015 and expenditure was 86% of that achieved in 2015. Our core funding from the H.S.E. remained unchanged, the main difference in our income related to a decrease in income due to the fact that we did not hold an International Hepatitis C Conference in 2016, similar to that held in 2015. In addition, unlike 2015, no funding was received from the Irish Haemostasis Foundation.

There was a significant amount of staff turnover in 2016 with Nurse/Counsellor Anne Duffy retiring and staff members Declan Noone and Leah Cawley leaving the organisation. We wish them all the very best in the future. We also welcomed two new staff members Aoife Ní Fhógartaigh and Paula Houlihan to the organisation.

Brian O'Mahony,
Chief Executive.



2016

Annual Report

Financial Report for 2016

Independent Auditor's Report to the Members of The Irish Haemophilia Society

We have audited the financial statements of The Irish Haemophilia Society for the year ended 31 December 2016 which comprise of the Income and Expenditure Account, the Balance Sheet, the Reconciliation of Members' Funds, the Cash Flow Statement, the Accounting Policies and the related notes. The relevant financial reporting framework that has been applied in their preparation is the Companies Act 2014 and FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" issued by the Financial Reporting Council and promulgated by the Institute of Chartered Accountants in Ireland.

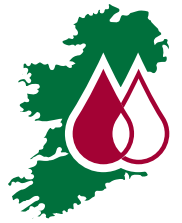
This report is made solely to the company's members, as a body, in accordance with Section 391 of the Companies Act 2014. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume 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.

Respective responsibilities of Directors and Auditors

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 otherwise comply with the Companies Act 2014. Our responsibility is to audit and express an opinion on the financial statements in accordance with Irish law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practice Board's Ethical Standards for Auditors, including 'APB Ethical Standard - Provisions Available for Small Entities (Revised)', in the circumstances set out in Note 4 to the financial statements.

Scope of the audit of the financial statements

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of whether the accounting policies are appropriate to the company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the directors; and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the Directors' Report to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.



Opinion on financial statements

In our opinion the financial statements:

- Give a true and fair view of the assets, liabilities and financial position of the company as at 31st December 2016 and of its results for the year then ended; and
- Have been properly prepared in accordance with the relevant financial reporting framework and, in particular, the requirements of the Companies Act 2014.

Matters on which we are required to report by 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.
- In our opinion, the information given in the Directors' Report is consistent with the financial statements.

Matters on which we are required to report by exception

We have nothing to report in respect of the provisions of the Companies Act 2014 which require us to report to you if, in our opinion, the disclosures of directors' remuneration and transactions specified by Sections 305 to 312 of the Act are not made.

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: I42834.

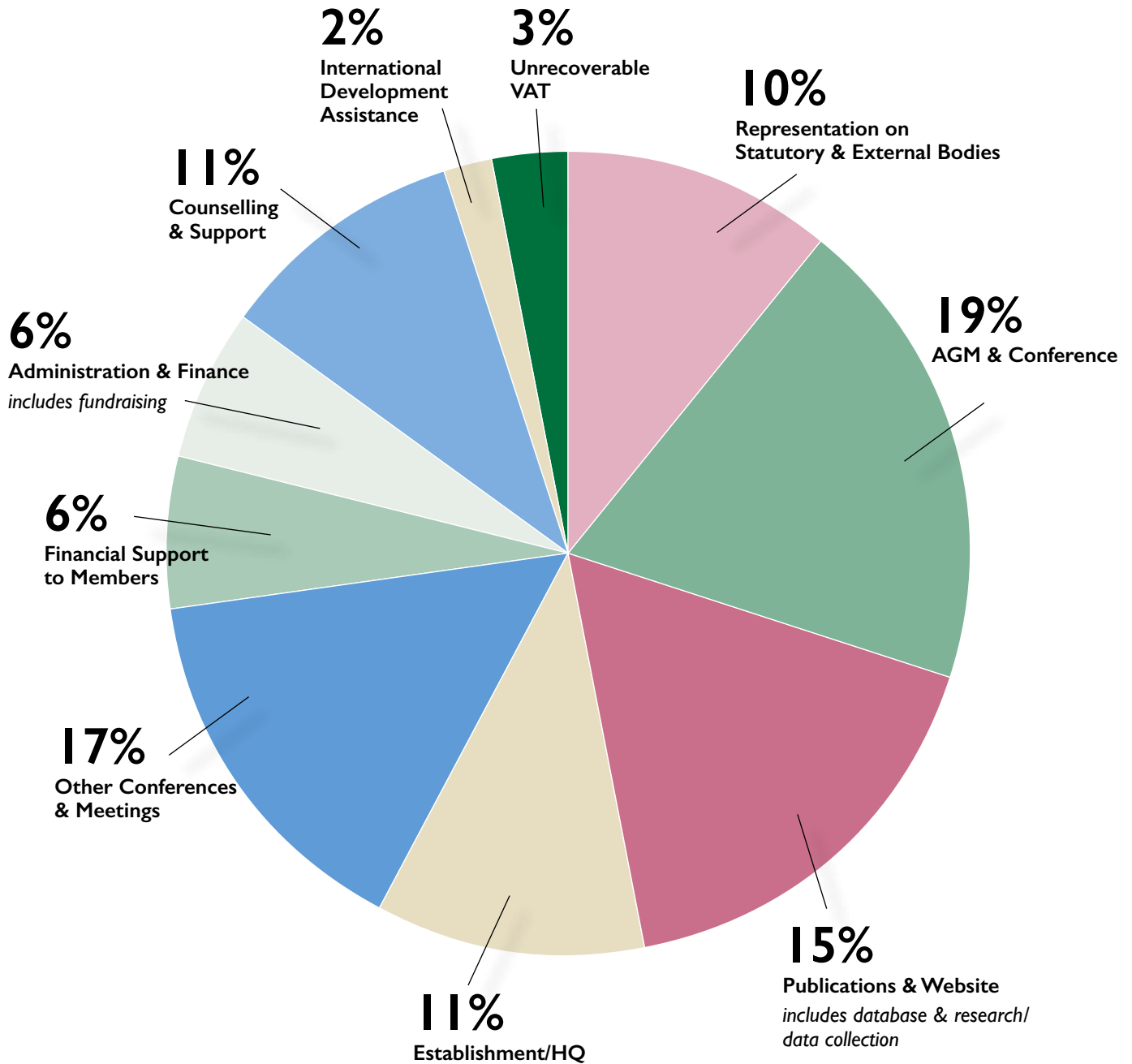
Registered Charity Number: CHY9214.



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Annual Report

Expenditure for 2016



*A provision of €150,000 has been made towards the cost of legal fees for the Hepatitis C Insurance Scheme



The Irish Haemophilia Society

Income and Expenditure Statement for the year ending 31 December 2016

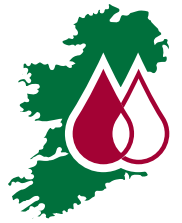
	2016	2015
	€	€
Income		
Health Service Executive	550,000	550,000
Membership	2,370	2,630
Donations - Members	22,516	34,244
Donations - Corporate	66,000	163,171
Irish Haemostasis Foundation		37,500
Fundraising	7,482	11,892
H.H.T Trust	9,000	
Funding from EHC	1,200	6,550
Investment Income	2,397	5,276
	<hr/> 660,965 <hr/>	<hr/> 811,263 <hr/>

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



Expenditure

Wages and Salaries	291,060	293,398
Employers PRSI Contributions	31,284	31,078
Service Charge & Insurance	16,397	15,729
Light, Heat & Services	11,695	11,595
Help to Members	6,518	17,829
H.H.T Trust	3,000	5,000
Subscriptions	2,011	2,816
Fundraising	925	1,142
Educational Grants	18,100	16,000
Pension Costs	25,601	26,374
Twinning / Vietnam Development Work	2,191	7,990
HQ Costs	2,389	344
Office Expenses, Stationery etc.	7,339	13,788
I.H.S Members' Facility	4,532	6,297
Post, Publications & Photocopying	18,866	20,384
Telephone	6,353	7,387
Website	3,501	8,027
Computer Services	16,265	7,151
Carriers Conference	6,053	
Meeting Expenses	18,282	28,578
Safety/Supply Activities	395	4,546
A.G.M & Annual Conference	29,966	32,134
Counselling & Support Meetings	3,404	6,249
Members' Conference	19,706	23,897
HIV/HCV Conference	3,935	4,035
PEP Conference		3,353
Ageing Conference		6,827
Legal and professional	1,191	
Parents Conference	17,887	21,082
Sponsorship/Training	3,369	9,055
Hep C Conference	4,101	54,591
Unrecoverable Vat	18,880	21,385
Bank charges	2,168	2,118
General expenses	2,530	2,552
Allocation to Sinking Fund	20,000	20,000
Auditor's remuneration	4,800	4,869
Depreciation	78,259	78,259
	702,953	815,859
Net deficit	(41,988)	(4,596)



The Irish Haemophilia Society

Balance Sheet for the year ending 31 December 2016

	2016	2015
	€	€
Fixed Assets		
Tangible assets	946,589	1,024,848
Investments	279,821	279,821
	1,226,410	1,304,669
Current Assets		
Debtors	7,950	9,341
Cash and cash equivalents	852,765	813,250
	860,715	822,591
Creditors: Amounts falling due within one year	(251,597)	(269,744)
Net Current Assets	609,118	552,847
Total Assets less Current Liabilities	1,835,528	1,857,516
Reserves		
Capital reserve	90,000	70,000
Income and expenditure account	1,745,528	1,787,516
Members' Funds	1,835,528	1,857,516

2016 in Pictures





2016 in Pictures





2016

Annual Report

Corporate Sponsors

The Irish Haemophilia Society would like to acknowledge the unrestricted financial contributions made in 2016 by the following companies, under our Corporate Giving Programme:

Platinum Sponsors

Bristol-Myers Squibb (BMS), Gilead, Pfizer

Gold Sponsors

AbbVie, Bayer, CSL Behring, Swedish Orphan Biovitrum AB (SOBI)

Silver Sponsors

Merck Sharp & Dohme (MSD)

Fundraisers

The Irish Haemophilia Society would like to thank with gratitude, everyone who fundraised for the Society during 2016.

Volunteers

The Irish Haemophilia Society would like to acknowledge and to thank everyone who volunteered for the Society during 2016.

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 2016.

