

# 2015

## ANNUAL REPORT



IRISH HAEMOPHILIA  
SOCIETY LTD

Cumann Haemifile Na hEireann



# 2015

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## A Message from the Chairperson

### What Do We Do?

The Irish Haemophilia Society provides a range of services and support to a wide demographic and works with adults and children with haemophilia, people currently undergoing treatment for hepatitis C, people living with HIV and/or hepatitis C and the families of those who have died from HIV or hepatitis C. We also support people with von Willebrand's disease, people with related bleeding disorders, with rare bleeding disorders such as factor VII, factor X and factor XIII deficiency; women with bleeding disorders and carriers of haemophilia. Over the years, we have built collaborative relationships with the medical teams, healthcare workers and others working within the field of haematology.

### How Do We Do It?

Our outreach strategies and initiatives keep us in touch with the needs of our members and areas that are causing concern for them, identifies support needs and helps build relationships with staff. Over the past year, we have continued to offer and provide huge support to members undergoing hepatitis C treatment. We also try to contact as many members as possible by telephoning each member on a yearly basis and visiting members in their home. We continue to collaborate and work with the Comprehensive Care Centres (National Centre for Hereditary Coagulation Disorders (NCHCD), Cork University Hospital (CUH) and Our Lady's Children's Hospital Crumlin (OLCHC). During 2015, we strengthened our links and increased attendance at CUH clinics, where staff had the opportunity to meet with individual members who attended the clinics.



We also held a series of conferences and workshops such as the Annual General Meeting, the Parents Conference, the Members Conference, an Ageing Conference and an HIV/Hepatitis C conference. We held educational & information days and training and peer support events that help support members to incorporate their bleeding disorder into their lives.



We also provided regular updates throughout the year through a series of publications, newsletters and bulletins and represented our members at National, European and International conferences and events. We currently have in excess of 1168 individuals and families on our mailing list and 319 people on our electronic list.

### Strategic Plan 2015 - 2018

Following a series of members surveys, meetings with members, meetings with the Comprehensive Care Teams and a strategic planning weekend for the board and the staff, a new 'Strategic Plan' was agreed in late 2015, with four board goals. The broad goals are the same as the previous Strategic Plan. However, the objectives and strategies, to allow us to achieve the plan are all new.





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## Goals:

1. The provision of optimum support and services for all people with haemophilia and related bleeding disorders and their families.
2. To represent the interests of people with haemophilia and related bleeding disorders with all external bodies and agencies.
3. To ensure the viability and development of the organisation in the future.
4. To ensure that the Society plays a full and active role in the development of haemophilia care globally.

## Youth Leadership

During 2015, the Society ran a 'Youth Leadership & Mentoring Programme'. The target group was boys with severe haemophilia aged 16 to 18 years. The programme ran throughout 2015 for six days in the Society's office and the aim was to work with these teenagers to encourage them to be their own advocate. Five teenage boys attended from Dublin, Cork and Tipperary. The programme focused on the information necessary for the boys to equip themselves to make positive decisions in relation to their medical condition. The programme also focused on inheritance, genetics, longer acting factor, trough levels, PKA tests, gene therapy and dental issues. Every effort is made by parents, staff in the hospitals and the Society to educate children on haemophilia. However, often this information may seem irrelevant and unnecessary to children. It was also important to include psychosocial information as it has become increasingly important for children with haemophilia to realise that they do not need to define or limit themselves due to their medical condition.

Another area that needed attention was the transition of care from paediatric to adult services. Transition can be rejected during adolescence as part of the separation from parental control and can take several years. The process of transitioning to the adult services was discussed and explained to the teenagers and they also met with Nurse Ann O'Sullivan from the NCHCD who deals with transitioning to the National Centre at St. James's. The teenagers also received a tour of the NCHCD and the H & H Ward. During the programme, practical information was covered such as school/college, future careers, sport and travel. As a patient organisation these are topics which are frequently questioned and indeed in this particular age group these topics are extremely relevant and important. Board member and Personal Trainer John Stack spoke to the boys about the importance of strength and conditioning training and Physiotherapist Emma Sherlock spoke about the importance of physiotherapy in relation to recovery from bleeds. The programme was deemed a great success, based on feedback received from the boys themselves and from their parents. They all felt it was extremely worthwhile. The boys took a lot of helpful and practical information from the programme.



## Hyde Square

Our accommodation facility continued to be a great support to members during 2015 with 95 members using the one bedroomed and two-bedroomed apartments. This was up on the numbers using it during 2014. A nominal charge of €10 per night is applicable and bookings can be made via the office by contacting Leah Cawley or Debbie Greene.

## Fundraising & Planned Giving

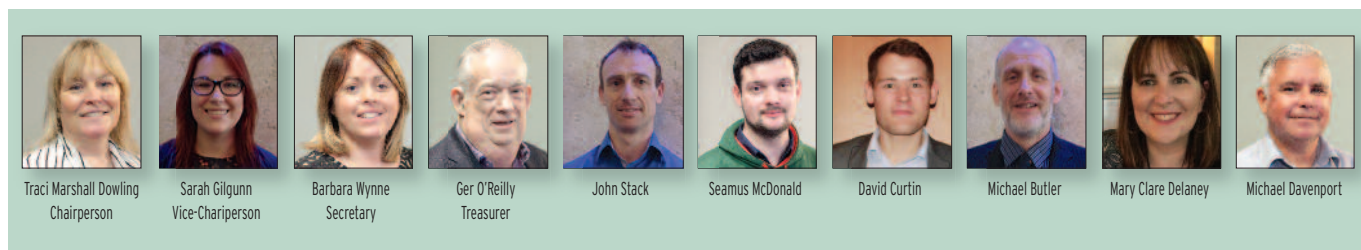
Each year, members fundraise for the Society and 2015 saw many activities organised by members and their friends who raised a total of €11,941. There has been a drop in fundraising and we recognise that this can be for varied reasons. However, if you have any ideas or projects that you think may support fundraising feel free to drop into the office or telephone us with your ideas! Fifty members also donated to our Planned Giving Campaign. Money raised from Planned Giving is divided between our work with Vietnam and the apartment facility for members and we are delighted and grateful for all fundraising efforts. If any of you want to get involved or design an event, contact Nina Storey or Debbie Greene and be in with a chance to win our fundraiser of the year award.





### The Board

Board members attended eleven meetings in 2015 and are represented at all of our conferences and events. It is a big commitment and the board work very hard. Demographics are well mixed with carriers, parents, young and older members of the community represented on the board. All board members are very dedicated. However, life can impact on the board; people welcome new children into the world, work commitments can impact and it is not always feasible to have succession. The year 2015 also saw changes of the guard for the board and while we were sorry to lose three very hardworking board members we were delighted that we had four new additions: Barbara Wynne, David Curtin, Michael Davenport and Seamus McDonald. Often change brings a new dynamic and it was a relief to discover that all new members are an excellent addition to the board. On behalf of the board I would like to thank them for all their hard work and support over the year. Members of the Executive Board for 2015 were as follows:



### Volunteer, Recruiting and Training

We are delighted with the continued hard work and dedication of our volunteers. Each volunteer receives Child Protection Training and is Garda Vetted. We also welcomed new faces during 2015 and continue to look at ways to maintain and increase volunteer numbers. We would like to thank all volunteers for their continued support that enables us to continue to deliver excellent programmes and weekends for all our membership.

### Members

Each year our members continue to engage with the services offered and inform us of areas for development, support needs and advocacy. During our yearly contact we continued to ask if we are meeting the needs of our membership, or if there are any gaps in the services offered. I am heartened to see that member engagement throughout 2015 was as strong as ever and wish to thank you for your continued support and commitment to the Society.

### Staff

In early 2015, we announced a new addition to our team. Leah Cawley (Administrative Assistant) started working for the Society in February. Leah replaced Nuala McAuley who left in December 2014. During the latter part of 2015, we had another new arrival: Aoife Ní Fhógartaigh (Administrative Assistant). Staff work as a fantastic team and each has their own way of working, i.e, some will go around an issue or challenge; some will go over it and some will charge straight through a problem! Each member is an asset and an important part of the team and on behalf of the board I would like to thank Brian, Debbie, Anne, Nina, Declan, Fiona, Leah and Aoife for continuing to steer the Society in the right direction.

**Traci Marshall Dowling**  
Chairperson



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## Honorary Secretary's Report

At the 26th Annual General Meeting of the Irish Haemophilia Society (IHS), which was held in Hodson Bay Hotel in Athlone on Saturday 7th March 2015, the incoming Governing Body of the Society were elected as follows:-

- Michael Butler
- David Curtin
- Mary-Clare Delaney
- Traci Marshall Dowling
- Sarah Gilgunn
- Gerard O'Reilly
- John Stack
- Barbara Wynne

At the first executive meeting following the AGM on 24th March 2015, the following officers were elected:-

- Chairperson                      Traci Marshall Dowling
- Vice-Chairperson              Sarah Gilgunn
- Honorary Secretary          Barbara Wynne
- Honorary Treasurer          Gerard O'Reilly
- On 19th May 2015, Michael Davenport was co-opted onto the executive board.
- On 16th June 2015, Seamus McDonald was co-opted onto the executive board.

In 2015, eleven executive board meetings were held, with the January meeting taking place in Cork.

### EVENTS ORGANISED BY THE SOCIETY

The year 2015 was an extremely busy year for the IHS in relation to conferences, events and activities.

#### FEBRUARY 2015

An open Hepatitis C Conference took place in Castleknock Hotel in Dublin on Saturday 7th February. There were 139 delegates in attendance. The conference was opened by the Minister for Health Dr. Leo Varadkar and included talks on new hepatitis C treatments and the supports available.

#### MARCH 2015

The AGM and Conference took place in the Hodson Bay Hotel over the weekend of 6th - 8th March 2015. The attendance comprised of 265 delegates. Attendance at the various programme sessions was very high. This has been assisted by the fact that we subsidise the cost of attendance at the conference for members and the subsidy requires attendance at one session on Saturday and Sunday, to avail of the subsidised rate. Post-conference evaluation showed that satisfaction with the conference in 2015 was very high.

#### APRIL 2015

On Friday 17th April, a Coffee Morning took place in the offices of the IHS to mark World Haemophilia Day. The IHS were also in attendance in the main foyer of St. James's Hospital to promote awareness of haemophilia, throughout the afternoon.

On Monday 27th April a hepatitis C meeting for members took place in Cork, which was well attended.

#### MAY 2015

An Ageing Conference took place over the weekend of 15th - 17th May in Hotel Kilkenny. A total of 54 delegates attended. The programme covered a variety of issues in relation to people with haemophilia who are now ageing.







### JUNE 2015

Twenty-two people took part in the Mini Marathon on the 1st June. Numbers were down from the previous year. The Society had a room in Buswell's Hotel for members to leave bags and get a cup of tea afterwards. Those who participated seemed to have a great day and the money raised was most welcomed by the IHS. Our thanks goes to everyone who took part.

On 6th and 7th June, the Society organised a European Conference on Hepatitis C and Haemophilia, in the Grand Hotel in Malahide, which was attended by doctors and haemophilia organisations from 20 countries.



The Parents Conference took place in the Sheraton Hotel in Athlone over the weekend of 19th to 21st June. This conference, organised for the seventh time in 2015, was again a great success.

The total attendance was 181 delegates. The evaluations were positive with parents enjoying particularly the sessions on exercise and social welfare.



### SEPTEMBER 2015

In September, a Hepatitis C/HIV Conference took place in the Kingsley Hotel in Cork over the weekend of 25th - 27th September. A total of 36 delegates attended this conference.

### OCTOBER 2015

The October Members Conference took place over the weekend of 16th to 18th October in the Heritage Hotel in Portlaoise. The attendance was 199 delegates. The evaluation forms filled in by participants were again very positive. (However, there were some issues with the hotel that have since been addressed.) Members see this as a less formal conference with more proactive participation by members as speakers and it is correctly seen, as complementing the Annual Conference.

A haemophilia camp in Barretstown took place over the weekend of 30th October - 1st November. Sixty-seven children attended this camp.

### NOVEMBER 2015

A PEP Conference took place in the Clarion Hotel, Liffey Valley in Dublin from the 20th to 22nd November. This programme is called 'Parents Empowering Parents' and it was described as a very positive and worthwhile experience. As numbers were down substantially in 2015, this conference will now take place every second year.



### PHONE CALLS / HOME AND HOSPITAL VISITS

In 2015, the Society carried out 44 home visits to members throughout the country with 74 visits made to members in hospitals, and 74.37% of members contacted by phone during the year.

### VOLUNTEERS

The IHS 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 71 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.





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## PUBLICATIONS, WEBSITE AND SOCIAL MEDIA

IHS 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 IHS website and are downloadable in PDF format. In 2015, we produced the following publications:

- Spring Magazine
- Summer Magazine
- Autumn Magazine
- Winter Magazine
- Annual Report
- Positive News Magazine (two)
- Junior and Youth Members Newsletter
- Bleeding Disorder Alert Cards for Moderate and Mild Haemophilia

Our electronic mailing list consists of 261 members.

Hits on our website have substantially increased with over 5,000 quarterly hits in 2015. The website includes a media feed of regularly updated and relevant press cuttings, relevant presentations on haemophilia and bleeding disorders, articles on various issues from needlephobia to stress management and information on Society activities including fundraising and events. The website also allows members to register online for membership and events and apply online for educational grants. We are now seeing more than half of registrations for events come via online registration.

Social Media has become a part of everyday life for people. In 2015, the Irish Haemophilia Society had a strong presence online via Twitter and Facebook. Our Facebook page has 848 followers. In addition, in 2015, the Society initiated a monthly electronic magazine called: Mailchimp, which is distributed to a specific electronic mailing list and has proved to be very popular. Currently, 165 members have signed up for this monthly electronic magazine.

## EDUCATIONAL GRANTS AND ASSISTANCE

A total of 24 educational grants were awarded in 2015, totalling €16,000. (Eleven grants were awarded to people with haemophilia and related bleeding disorders and thirteen were awards to siblings and parents.)

## STAFFING

The IHS nurse counsellor Anne Duffy, went part time in June 2015 and will retire in August 2016. The position will be filled and staff roles will also be reallocated to make maximum utilisation of the knowledge and experience of current staff in relation to outreach in addition to their specific roles. In late 2015, the Society employed new staff person Aoife Ní Fhógartaigh to cover the shortfall in event organisation and general office duties to allow more Family Outreach to be done by staff person Fiona Brennan.

Staff roles in 2015 were as follows:

- Chief Executive. (Brian O'Mahony)
- Administrator/Office Manager. (Debbie Greene)
- Finance & Fundraising Co-ordinator. Part-time (Nina Storey)
- Nurse/Counsellor. Part-time. (Anne Duffy)
- Data and Public Policy Specialist. (Declan Noone)
- Outreach Co-ordinator. (Fiona Brennan)
- Volunteer & Events Co-ordinator. (Leah Cawley)
- Administrative Assistant. (Aoife Ní Fhógartaigh)



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### 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 & Declan Noone
- Haemophilia HIV Trust - Brian O'Mahony & Nina Storey
- Disability Federation of Ireland - Debbie Greene
- World Federation of Haemophilia - Brian O'Mahony, Anne Duffy & Declan Noone
- European Haemophilia Consortium - Brian O'Mahony, Declan Noone & Traci Dowling
- Consultative Council on Hepatitis C - Brian O'Mahony & Anne Duffy
- 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 Incidents Panel - Brian O'Mahony
- National Hepatitis C Clinical Advisory Group - Brian O'Mahony & Declan Noone

The board would like to express its thanks to the staff for their continued commitment and for representing the best interests of the IHS. We also wish to acknowledge with gratitude all donations received during the year and the efforts of all our fundraisers.

**Barbara Wynne**  
Honorary Secretary





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## 2015 in Pictures



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## The Year in Review from our CEO



AGM 2015

The Society organised a record number of conferences in 2015 which resulted in a record attendance. A total of eight conferences were organised which were attended by 965 people in total. That was a 42% increase on attendance at conferences in 2015, when compared to 2014. In addition to the five conferences which are held on an annual basis, three additional conferences were held in 2015. The conferences held on an annual basis include the 'Annual General Meeting & Conference', 'Parents Conference', 'Members Conference', 'PEP Conference' and the 'Conference for Members with Hepatitis C and/or HIV'. In 2015, additional conferences were held on 'Ageing and Haemophilia', an 'Open Conference on Hepatitis C' and a conference on 'Hepatitis C and Haemophilia in Europe'. Our Annual General Meeting included lectures on: 'The Future Model of Haemophilia Care' and on 'National Treatment Guidelines'. The Members conference included workshops on: 'The Impact of Haemophilia on Family Dynamics', 'Resilience' and 'Positive Attitudes'.

The Parents conference included presentations on: 'The New National Children's Hospital' and on 'Teenagers and Communicating with Healthcare Workers'. The Ageing conference included lectures: on 'Treatment Protocols', 'Preparation for Orthopaedic Surgery' and 'Changing Bleeding Patterns'.





Parents Conference

Hepatitis C continued to be a major priority in 2015. The availability of the new direct-acting antiviral therapies for hepatitis C, which have been resulting in a sustained virological response or cure rate of approximately 95%, have transformed the therapeutic landscape for hepatitis C. We actively advocated during the course of the year for prioritised access to these new therapies for people with haemophilia and for other state infected patients who were infected with blood and blood products. The health protection surveillance centre database report on hepatitis C, clearly demonstrates a more rapid clinical progression of liver disease in people with haemophilia and blood transfusion recipients. The leading cause of death in people with haemophilia in Western Europe for the past number of years has been liver disease due to hepatitis C. For these reasons, it was our belief that it was imperative to ensure that people with haemophilia had access to these new hepatitis C therapies as quickly as possible. Our advocacy work in these areas resulted in a firm commitment from the Minister for Health that all state infected patients would be offered treatment by the end of 2017 at the latest and ideally by the end of 2016. We have also worked with the National Centre for Hereditary Coagulation Disorders and Hepatology centres to ensure that people with haemophilia were offered treatment in 2015 and 2016. We engaged directly with our members with hepatitis C on an individual basis to ensure that they were aware of the benefits of these new treatments and assisted them in accessing treatment. In addition to our conference for members with HIV and hepatitis C, we organised two additional conferences in this area in 2015 the first being an open Hepatitis C conference.





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Hepatitis C Conference

This conference was open to all people in the country who had hepatitis C. It was attended by approximately 150 people who heard some excellent clinical lectures and importantly, real stories from a panel of people who had hepatitis C, who talked about their treatment experiences. The conference was opened by the Minister for Health. In mid-2015, we organised a European Conference on haemophilia and hepatitis C which was attended by approximately 70 people from haemophilia societies and leading clinicians from Europe. The result of our work in this area is that by the end of 2015, a large number of people with haemophilia had been offered treatment and there remained only 20 people with haemophilia who required treatment for hepatitis C. We worked with the National Centre during the year to finalise the plans for the new National Centre for Hereditary Coagulation Disorders which will be built above the existing H&H unit in St James's hospital.

The Society have been formally involved in the selection of factor concentrates for Ireland since 2002 and have developed wide expertise in this area. Through our work on and with the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB), we have ensured that the safest and most efficacious factor concentrates are purchased for people with haemophilia. In 2015, we analysed the results of the work of the HPSMAB since 2002. Prior to the establishment of the HPSMAB, prices paid for factor concentrates in Ireland were 26% above the EU average. By 2015, the prices had fallen to 60% below the EU average. The detailed analysis of the work of the HPMSAB has demonstrated that the total savings to the exchequer of our work over the past twelve years



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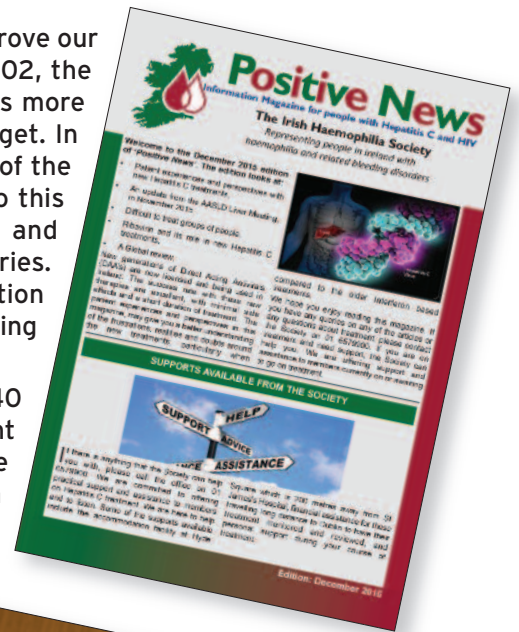


has been just over €132 million. This has allowed us to maintain and improve our access to haemophilia treatment over the past twelve years. Since 2002, the number of units of factor VIII used per head of population in Ireland has more than doubled. This has been achieved without any increase in the budget. In doing this work, it is also vitally important to ensure that we are aware of the criteria for decision making, protocols and prices in other countries. To this end in 2015, we carried out and published a survey of the tender and procurement procedures for factor concentrates in 38 European countries. In addition, we were responsible for publication of the new World Federation of Hemophilia (WFH) Guide to National Tenders for the Purchase of Clotting Factor Concentrates.

We continue to monitor and implement our Strategic Plan. A total of 40 strategies were implemented in 2015. Among these was the development of a youth mentoring programme. In addition, we assisted in the establishment of an organisation to represent people with thrombophilia and we worked to persuade the WFH to prioritise our twinning partner country, Vietnam, for future development. At the end of 2015, it was agreed that Vietnam would now be a target country for the WFH Global Alliance for Progress (GAP) programme which will bring them continued sustained assistance and resources over the next four years.

Financially, we had a very successful year. Expenditure increased by €44,000. This constituted very effective cost containment, as it must be remembered that the number of conferences we organised in 2015 increased from five to eight. Increasing expenditure was more than matched by the increase in income which increased by just over €94,000. The increase came primarily from two sources in 2015. We have received funds from the Irish Haemostasis Foundation which had not been received in 2014 and we also succeeded in receiving additional corporate donations, primarily to fund the additional hepatitis C conferences. This Society continues to be in a strong financial position and in a strong organisational position with an effective and engaged board and a committed staff team. In 2015, we also looked very much to the therapeutic future for people with haemophilia by engaging with a number of companies developing new therapies and ensuring that Ireland was included in clinical trials for these new and innovative therapies. In the course of 2015, we reached agreement that Ireland would be included in clinical trials for some of the new extended half-life factor concentrates and for gene therapy for both factor VIII and factor IX. We also reached agreement that Ireland would benefit from clinical trials for the new bispecific antibody which will be a subcutaneous treatment for factor VIII deficiency. Strong and active co-operation and collaboration between the Society and the treatment centres, the existence of an excellent national register and the organisation of care with the statutory National Haemophilia Council all assisted in persuading companies that Ireland was a good location to consider for clinical trials on new and innovative products for haemophilia. The future indeed looks exciting.

**Brian O'Mahony**  
Chief Executive



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## 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 2015 which comprise of the Income and Expenditure Account, the Balance Sheet, the Reconciliation of Funds, the Cash Flow Statement, the Accounting Policies and the related notes. The financial reporting framework that has been applied in their preparation is the Companies Act 2014 and accounting standards issued by the Financial Reporting Council (Generally Accepted Accounting Practice 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 Statement of Directors' Responsibilities, 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 3 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 31 December 2015 and of its results for the year then ended and
- have been properly prepared in accordance with Generally Accepted Accounting Practice in Ireland and in particular with 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 in 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.



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#### **REGISTERED OFFICE**

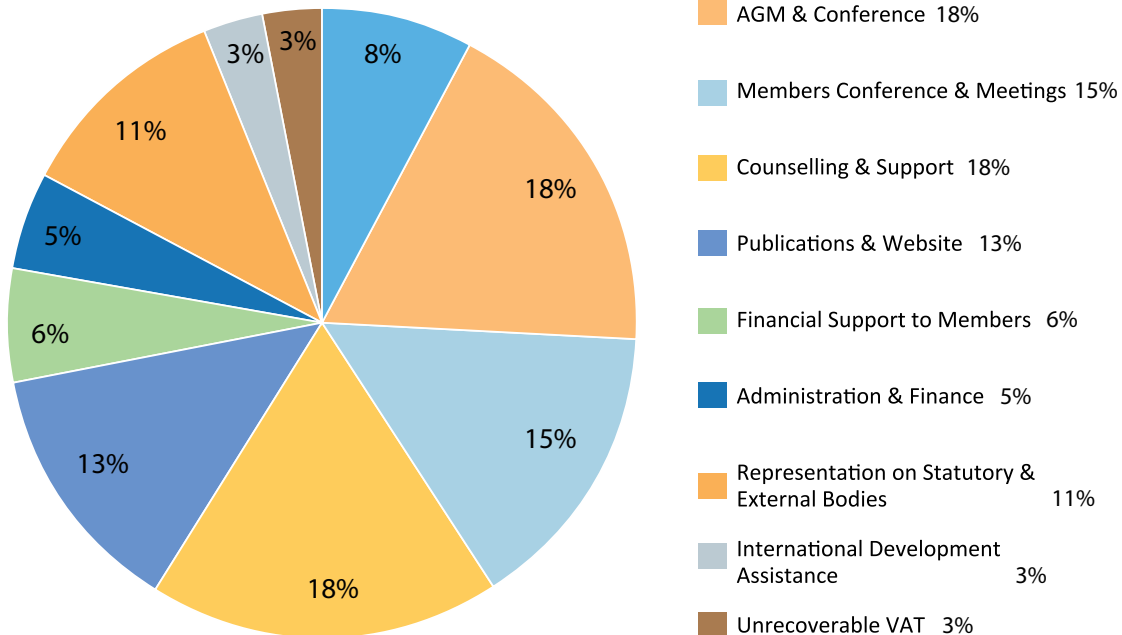
Irish Haemophilia Society,  
First Floor, Cathedral Court,  
New Street South, Dublin 8.  
D08 VH64  
Company Registration Number: 142834  
Registered Charity Number: CHY9214

#### **AUDITORS**

Howlin O'Rourke & Co.,  
Certified Public Accountants & Registered  
Auditors,  
4 The Seapoint Building,  
Clontarf, Dublin 3.



## Expenditure 2015



\*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 Statement for the year ended 31 December 2015

Schedule	2015 €	2014 €
<b>Income</b>		
Health Service Executive	550,000	532,966
Membership	2,630	2,730
Donations Members	34,244	28,917
Donations - Corporate	163,170	112,642
Irish Haemostasis Foundation	37,500	-
Funding from EHC	6,550	-
Fundraising	11,892	14,888
H.H.T Trust	-	15,006
Twinning	-	5,316
Investment Income	5,276	4,614
	<b>811,262</b>	<b>717,079</b>
<b>Overhead expenses</b>	<b>(815,858)</b>	<b>(771,789)</b>
<b>Net (deficit)</b>	<b>(4,596)</b>	<b>(54,710)</b>





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## The Irish Haemophilia Society

Schedule 1: Expenditure for the year ended 31 December 2015

	2015 €	2014 €
Service Charge & Insurance	15,729	16,265
Light, Heat & Services	11,594	12,406
WFH GAP Program	-	8,142
Help to Members	17,829	16,494
H.H.T Trust	5,000	10,058
Subscriptions	2,816	1,699
Fundraising	1,142	1,550
Educational Grants	16,000	17,750
Wages and salaries	293,398	275,442
Social welfare costs	31,078	29,151
Pension Costs	26,374	21,939
Twinning	7,990	9,105
HQ Costs	344	905
Office Expenses, Stationery etc.	13,788	8,095
I.H.S Members' Facility	6,297	5,011
Post, Publications & Photocopying	20,384	21,466
Telephone	7,387	6,556
Website	8,027	5,239
Computer Services	7,151	13,762
Carriers Conference	-	4,561
Meeting Expenses	28,578	20,243
Safety/Supply Activities	4,546	7,345
A.G.M & Annual Conference	32,134	43,568
Counselling & Support Meetings	6,249	6,461
Members' Conference	23,897	20,576
HIV/HCV Conference	4,035	5,616
PEP Conference	3,353	3,127
Ageing Conference	6,827	
Legal and professional	-	20,789
Parents Conference	21,082	23,049
Sponsorship/Training	9,055	2,198
Hep C Conferences	54,591	
Unrecoverable Vat	21,385	26,619
Bank charges	2,118	2,017
General expenses	2,552	1,826
Provision for Sinking Fund	20,000	20,000
Auditor's remuneration	4,869	4,500
Depreciation of tangible fixed assets	78,259	78,259
	<hr/>	<hr/>
	815,858	771,789
	<hr/>	<hr/>
<b>Total Overheads</b>	<b>815,858</b>	<b>771,789</b>



**The Irish Haemophilia Society**  
Balance Sheet as at 31 December 2015

	2015 €	2014 €
<b>Fixed Assets</b>		
Tangible assets	1,024,848	1,103,107
Investments	279,821	170,000
	1,304,669	1,273,107
<b>Current Assets</b>		
Debtors	9,341	10,737
Cash and cash equivalents	813,250	843,439
	822,591	854,176
<b>Creditors: Amounts falling due within one year</b>	(339,744)	(335,171)
<b>Net Current Assets</b>	482,847	519,005
<b>Total Assets less Current Liabilities</b>	1,787,516	1,792,112
<b>Reserves</b>		
Income and expenditure account	1,787,516	1,792,112
	1,787,516	1,792,112





# 2015

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## Corporate Sponsors

The Irish Haemophilia Society would like to acknowledge the unrestricted financial contributions made in 2015 by the following companies under our Corporate Giving Programme:

### Platinum Sponsors:

AbbVie, Baxalta, Bristol-Myers Squibb, Gilead, MSD

### Gold Sponsors:

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

### Silver Sponsors:

Janssen

## Fundraisers

The Irish Haemophilia Society would like to thank with gratitude everyone who fundraised for the Society during 2015.

## Volunteers

The Irish Haemophilia Society would like to acknowledge and to thank everyone who volunteered for the Society during 2015.

## Planned Giving & Donations

The Irish Haemophilia Society gratefully acknowledges and thanks everyone who made donations to the Society and who contributed to the Planned Giving campaign during 2015.