

Irish Haemophilia Society



Annual Report 2013

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A Message from the Chairperson

During 2013 the Society continued to work on behalf

of its members with particular focus on development in many areas including, services to members, fundraising, educational grants and conference attendance. These developments form part of our commitment of supporting IHS members with diagnosis, bleed recognition, educational programmes, information programmes, counselling and home & hospital visits. In particular our education and information programmes are important as they support all the membership. In

2013, we delivered a total of 7 conferences; AGM & Conference, HCV / HIV Conference, Parents Conference, HIS Meeting, Members' Conference, Ageing Conference and Parents Empowering Parents (PEP) Programme.



*Traci Marshall Dowling,
Chairperson*

Support to Members

A lot of support to members and peer support happened throughout 2013 in particular relating to Hepatitis C treatments. These treatments offer new hope and can lead to a cure. However, treatment can be very gruelling on the patient, their partners and families. Having access to others who have experienced the treatments is invaluable.

The apartment facility for members at Hyde Square has been a great success and an excellent addition to the services the Society offers. It is encouraging to see members getting optimum use from them now, as often both apartments are fully booked.

Home and hospital visits continued to be a priority throughout 2013. These are vital as it is often over a cup of tea that you get to hear the real issues and discover what's working for the members and the areas that need improvement. The Society continues to maintain and strengthen relationships with the hospital and haemophilia care teams at the comprehensive care centres.

The quality and standard of our publications continue to go from strength to strength.



IHS Administrator Debbie Greene with Haemophilia Nurse Specialist Eadaoin O'Shea and IHS staff person Declan Noone in the Haemophilia In Patient Unit in St. James's Hospital.

Fundraising

2013 was another excellent year for fundraising and we really want to say a big thank you to all those who continue to raise money for the Society. A total of €46,696 was raised during 2013 thanks to the Malin to Mizen Head Cycle, the Mini Marathon, Swim a Mile, Church Collection, an 80/90's night, a 3 Run Challenge, Movember and a Sky Dive.



Far left: An 80s & 90s fundraiser took place in Bray in May 2013.

Left: The 2013 Mini Marathon Team IHS

Planned Giving

Members of the Society continue to play an active role in the organisation's future. 2013 saw an increase in members now supporting the 'Planned Giving Campaign' with the numbers of members donating rising from 38 to 41. The funds from this campaign continue to be divided between the cost of the apartment facility for members and the Twinning Programme with Vietnam.

Educational Grants

The Educational Grants were discussed in detail at our AGM in March 2013 and a clear process and assessment criteria was presented during the Chairperson's address. It is important that our members are aware of the different grants that people with haemophilia and related bleeding disorders and their families can apply for and how the successful applicants are chosen.

There are two categories, one for people with haemophilia or related bleeding disorders, and the second for immediate family members of people with haemophilia or related bleeding disorders. In order to qualify for the first category (the Maureen & Jack Downey and Father Paddy McGrath Educational Grants) the following criteria must be met by the person applying:

- * **Must** be a person with haemophilia or related bleeding disorder.
- * **Must** be accepted on a post second level educational course.
- * **Must** be registered at the National Centre for Hereditary Coagulation Disorders at St. James's Hospital in Dublin.

If the immediate family members of people with haemophilia or related bleeding disorders wish to be considered for the second category, the Margaret King Educational Grant applicants, the following must be met by the person applying:

- * **Must** be an immediate family member of a person with haemophilia or related bleeding disorder.
- * **Must** be accepted on a post second level educational course.
- * Related person **must** be registered at the National Centre for Hereditary Coagulation Disorders at St. James's Hospital in Dublin.

Applicants can apply each year, online or by post; they can apply from June onward and the closing date is usually the end of September. The selection group consists of three board members. The IHS Administrator is present to answer any queries they may have.

The following considerations apply when reviewing the applications. The quality of the application, the information provided, the involvement in the Irish Haemophilia Society, the financial need of the applicant, how many in the family are going to college and finally whether or not the applicant is applying for the first time. All who adhere to the assessment criteria receive a minimum grant of €250. In 2013 a total of €18,250 was awarded to individuals with Haemophilia, related bleeding disorders and their immediate family members.

Conference Attendance

Another area that generated a lot of debate and discussion amongst you was attendance at our conferences. A new attendance policy was introduced and agreed by the membership at the AGM in March 2013. The policy is working extremely well with notable increase in attendance at specific talks and sessions at our conferences. We take the continued excellent evaluations as a sign that the members are happy with the new policy.

New Categories of Membership

During the 2013 AGM the different categories of membership currently available within the IHS was discussed during the business meeting. The IHS have several membership categories including ordinary, honorary and associate membership and it was discussed whether or not all categories continued to offer the best options to our members. This topic evoked a lively debate and it was proposed that the IHS staff and board would review all options and present a new proposal to the membership for discussion and ratification at the AGM in March 2014.

The image shows a sample application form for the Margaret King Educational Grant. The form is titled 'Irish Haemophilia Society EDUCATIONAL GRANT In memory of Margaret King APPLICATION FORM FOR YEAR 2013 / 2014'. It includes sections for 'Background', 'Contact Details', 'Post 2nd Level Course Details', and 'Further Information'. The form is designed to collect personal and educational information from applicants.

Above: A sample application form for the Margaret King Educational Grant.

Below: Attendances at IHS Events continued to grow in 2013.



I.H.S. Board

Each board member brings with them various levels and areas of expertise. The current board works well together and are very committed; it is very rare that a board member misses the regular monthly meetings. I would like to thank the board for their continued commitment, support and hard work. I look forward to working with them again in 2014.



Right:

The current IHS Staff.

Far Right:

The IHS Board for 2013.



I.H.S. Staff

Brian and his team continue to be a valuable and much appreciated resource for the Society. The staff offer excellent support and services to our members such as travelling to England with members in need of assessments, developing and improving publications, data collection and analysis and initiating volunteer training. Their skill sets are changing and developing constantly and it is important for members and the board to recognise the efficient, loyal and hard working staff we have. Therefore I would like to thank Brian, Debbie, Anne, Nina, Declan, Nuala and Fiona for their energy, dedication, professionalism and commitment in 2013.

45 Years and Still Going Strong!

The Society reached its 45 year milestone in 2013. It was fitting that newsletter reports throughout the year included the history of the Society which mapped the path that led us to where we are today and also remembered and acknowledged past staff members who played such a pivotal role in our journey. The essence of Margaret King was captured so beautifully that it is hard to believe that some staff had never had the pleasure of working with Margaret. (Well done Nuala!)

Finally, over the last 45 years we've had laughter, tears, battles and better treatments. We've witnessed the development of comprehensive care and the arrival of an excellent home delivery system. With new treatments, longer acting factor and gene therapy now a distinct reality I am really looking forward to what the next 45 years will bring and look forward to continuing that journey together!

Traci Marshall Dowling
Chairperson



2013 was the 45th year of the Irish Haemophilia Society. The occasion was marked throughout the year in various ways. A video showcasing the Society's 45 year journey was showcased in The Better Together Campaign and can be viewed online at www.haemophilia.ie

Honorary Secretary's Report

At the 24th Annual General Meeting of the Irish Haemophilia Society, which was held in the Osprey Hotel in Naas, Co. Kildare on Saturday the 2nd March, 2013 the Incoming Governing Body of the Society were elected as follows:-



Traci Marshall Dowling,
Chairperson



Brian O'Riordan,
Vice-Chairperson



Gerard O'Reilly,
Treasurer



Mary Hanney,
Secretary

At the first executive meeting following the AGM the following Officers were elected:-

Chairperson

Traci Marshall Dowling

Vice-Chairperson

Brian O'Riordan

Honorary Secretary

Mary Hanney

Honorary Treasurer

Gerard O'Reilly



Eoin Moriarty



John Stack



Sarah Gilgunn



Michael Butler

In 2013, 11 executive meetings were held in person or by conference call, with very few apologies. The board always give their total commitment to each meeting.

MEETINGS ORGANISED BY THE SOCIETY



Delegates at the Gene Therapy session at the 2013 AGM & Conference.

The 24th Annual General Meeting and conference of the Irish Haemophilia Society took place over the weekend of the 1st to the 3rd of March in the Osprey Hotel in Naas, Co. Kildare.

This weekend was a great success with an attendance of 236 people. It was the best attended AGM to date thanks to the implementation of a new attendance policy. It is also worth noting that the evaluation forms that came back following the AGM were excellent.

Sessions on Saturday included "The Future is Here" which included gene therapy, longer acting factor and clinical trials. There was an "Open Forum" in the afternoon with the three Haemophilia Treatment Centres, chaired by Dr. Barry Harrington and Dr. Barry White, Director of the NCHCD, who received the Brian O'Mahony award later in the evening. On Sunday morning there were sessions on travel, vein care and an update on the twinning programme with Vietnam.

There were four Children's Programmes organised for the weekend. (Creche, Cubs, Kidlink and Young Adults).

The Gala Dinner was very enjoyable with entertainment provided by the B-Sharps.

A HIV/Hepatitis C conference took place over the weekend of the 10th to the 12th of May in the Pembroke Hotel, Kilkenny. Along with staff and speakers from St. James's Hospital 21 members (including some spouses) attended the conference which was a great success. The programme was packed with excellent talks including 'Review of Treatments', 'Future Treatments', 'Treatment Experiences' and workshops for spouses or partners.

The Parent's conference was held in the Johnstown House Hotel from June 14th to the 16th. This was a very enjoyable weekend with a fantastic programme which included a Mother's and Father's workshop, a session on self infusion, an update from OLCCH, and the PEP Programme. This conference was attended by 143 members.

Right: The Cubs Club enjoy some sports day activities at the Parents Conference.



Far Right: The Kidlink Group strike a pose at the Parents Conference!



Twenty four ladies took part in the 'Ladies Mini Marathon' on the 4th of June. The Society had a room in Buswell's Hotel for members to leave bags and get a cup of tea afterwards. Everyone had a great day and the money raised was most welcome by the Society who would like to thank everyone who took part. I would like to see more ladies taking up the challenge this year.

On the 21st of September a conference was held in the Clarion Hotel, Liffey Valley in Dublin for young men with Haemophilia aged between 18 and 35 years of age. The programme for this conference included sports, disclosure and longer acting factor.

The Member's conference took place from the 11th to the 13th of October in the Bloomfield House Hotel, Mullingar, Co. Westmeath and everyone attending seemed to greatly enjoy the weekend.

The programme for this conference included a debate on adherence, sessions on individualised treatment, travel and an interactive session on disclosure of haemophilia. There was a treasure hunt for all the family on Sunday. The attendance for this conference was 206 members.



The Mother's Group at the Disclosure Workshop at the 2013 Members' Conference.



The facilitators for the 2013 Parents Empowering Parents Conference included parents, IHS staff and staff from OLCCH and NCHCD.

A PEP Programme was held in the Clarion Hotel, Liffey Valley, Dublin from the 8th to the 10th of November.

This Programme which is called 'Parents Empowering Parents' was described as fantastic. This was about parents sharing their experiences, advice and what worked for their families. It was about parents who share the same worries and problems in their lives supporting and encouraging each other. The attendance at this conference was 13 members and 9 facilitators some of which included members.

On the 15th to the 17th of November, 2013 an Ageing Conference was held in the Sheraton Hotel, Athlone. The programme for this conference included vein care, pain management, changing bleeding patterns, cardiac issues, home adaptations and coping skills. Overall this conference was a great success with a lot of questions, discussions and excellent presentations. It is very important to start taking care of yourself early in life to ensure good health in the future. The attendance at this conference was 43 members.

HOME AND HOSPITAL VISITS

During 2013 the focus was more on home visits rather than regional visits. Counsellor Anne Duffy assisted by staff members Brian O'Mahony, Debbie Greene and Declan Noone made 150 home and hospital visits last year. The IHS is aware that not everyone can attend events so these visits are a very important way of keeping in touch with members who may need information or just a friendly chat.



With the continuing increase in attendance the number of volunteers required for events has risen. The Society now have a database of over 45 volunteers who assist at the various events throughout the year.

The organising of conferences would not be possible without the valued assistance of all our volunteers. Their help and support throughout the year on various projects is really appreciated.

CONFERENCES AND OTHER EVENTS

During the course of the year the Society was represented at the following: The Annual European Haemophilia Consortium (EHC) Conference took place in Romania on the 4th to the 6th October, 2013. Two board members, Traci Marshall Dowling and Sarah Gilgunn, and three staff members, Brian, Declan and Anne represented the Society. Traci Marshall Dowling was voted onto the EHC Steering Committee.

WEBSITE

The Society's Website is updated regularly with all the latest information including events and what is happening in the Society. During 2013 a small revamp took place on the homepage. We now have rolling images on the homepage which are changed on a monthly basis. The 45th year logo was also new on the website during 2013 as was the Mother's and Father's group on Facebook which is a private forum for parents.

PUBLICATIONS

The following publications were produced during 2013: Spring Magazine, Annual Report, Travel App (For Phones), Two Positive News Magazines, Summer Magazine, Autumn Magazine, Ageing and Haemophilia, How to Treat a Bleed Leaflet and a Winter Magazine.



Copies of all the IHS publications can be downloaded from the website or obtained from the IHS office. The travel app can be downloaded free from I-Tunes and the Google Play Store.

All IHS publications can be downloaded from our website or can be obtained in hardcopy from the office.

GRANTS AND SCHOLARSHIPS

Our Grants & Scholarships programme is proving very successful and a total of €18,250 was paid out in 2013.

Right: Joanna Keniry accepts the Margaret King Educational Grant from Ger O'Reilly on behalf of her sister Shauna Keniry.

Far Right: IHS Chairperson Traci Marshall Dowling presents Irene Clarke with the Maureen and Jack Downey Educational Grant.



I.H.S. STAFF

The Irish Haemophilia Society Staff have done a fantastic job this year keeping up with an ever increasing work load. They carry out their duties with true professionalism and hard work and I wish to state emphatically that they are very much appreciated.



Brian O'Mahony,
CEO



Debbie Greene,
Administrator



Anne Duffy,
Counsellor



Nina Storey,
Administrative
Assistant



Declan Noone,
Administrative
Assistant



Nuala Mc Auley,
Administrative
Assistant



Fiona Brennan,
Administrative
Assistant

SOCIETY REPRESENTATION

The Society is also represented on a number of external committees 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 & Traci Marshall Dowling
- Consultative Council on Hepatitis C – Brian O'Mahony & Anne Duffy
- Irish Haemostasis Research Foundation – Debbie Greene & Gerard O'Reilly

The Board would like to express its thanks for their continuing commitment and for representing the best interests of the Society.

We also wish to acknowledge with gratitude all donations received during the year and the efforts of our fundraisers. We would like to especially acknowledge the outstanding fundraising efforts of David Curtin who raised over €32,865 for the Society in 2013. We understand that fundraising is very difficult in today's climate but all efforts are greatly appreciated and hopefully things will improve as we look forward positively to the rest of 2014.

**Mary Hanney,
Honorary Secretary.**

2013 In Pictures

Happy Birthday IHS!



We may not look a day over 21, but in 2013 the Irish Haemophilia Society celebrated their 45th anniversary.

The Society began as a voluntary organisation to provide services and support to people with haemophilia and their families. Now the Society is a professional charity with a staff of seven and a membership of over 1,000.

The Year of the Fundraiser

2013 may have been the year of the snake, but for the IHS it was the year of the fundraiser.

A total of 7 fundraisers took place throughout the year, including the Malin to Mizen Head Cycle, a Swim-a-Mile sponsored swim, a sky dive and an 80s & 90s night. We also had our annual fundraisers, the Mini Marathon and Movember.

A huge thank you to everyone who took part in and supported the IHS fundraisers. GO TEAM IHS!



IHS International

In 2009 the Irish Haemophilia Society produced a travel card to provide relevant information to people with bleeding disorders in a convenient manner.

Following a review of the needs of members, in 2013 the IHS launched an app "IHS Travel Safe". The app contains up to date information for people with bleeding disorders and important reminders for travelling. The app can be downloaded from itunes or the google play store free of charge.



Video Stars

For the third year in a row, the Irish Haemophilia Society took part in the Better Together Video Campaign organised by The Wheel, an umbrella group for charities.

The video for the 2013 campaign focused on the Society's journey throughout its 45 years in existence.

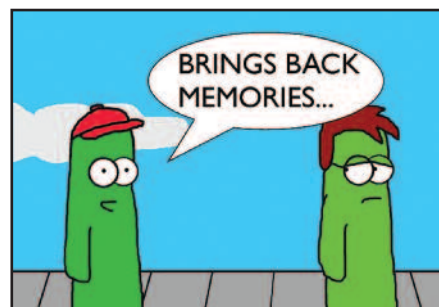
We were looking to equal, if not better our top 10 place of 2012 and we did! Finishing overall in the competition in 6th place.



Conor's Cartoon Creation

IHS Youth Group Member Conor Birkett introduced "The Slobs" in 2013.

The Slobs comic strip features in every edition of haemophilia.ie. The comic has amassed quite the fanbase, the question is are you a Slob?



Respect Your Elders

As part of the Irish Haemophilia Society's Strategic Plan, the society focused on an emerging demographic of the membership, the ageing community. This is the first generation of people with haemophilia who will experience the challenges of ageing.

In 2013 the Society produced an "Ageing & Haemophilia" publication and held an Ageing Conference for members aged 45 years and over. The conference focused on the practical side of ageing with a bleeding disorder; vein care, pain management and home adaptations, as well as the psychological aspects such as coping skills.

We're Moving In!

2013 was a great year for haemophilia care in Ireland as a new In-Patient Unit opened in St. James's Hospital, Dublin 8.

Located on the first floor of the clinical research unit in the main hospital building in St. James's Hospital, the new unit contains twelve single rooms, two isolation rooms and a six bed assessment bay.

The In-Patient Unit will make hospital stays more comfortable for people with bleeding disorders.



PEP in their step!

For the second year in a row, the Parents Empowering Parents Programme was held by the IHS. However, the 2013 course was different, because it was facilitated by IHS members and staff from the IHS, OLCHC and NCHCD.

The programme was full to capacity and to meet the demand, will take place again in 2014!

The Year in Review from our CEO



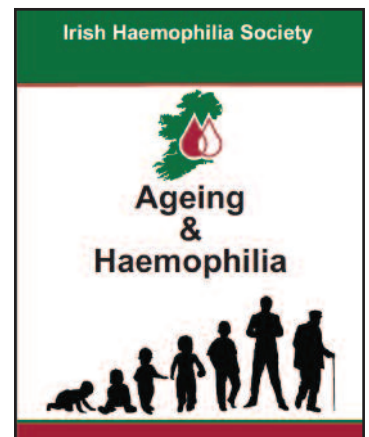
Brian O'Mahony
Chief Executive

The year 2013 was an exceptionally busy and productive year for the Irish Haemophilia Society. Our policy of continuous education of members on all aspects of haemophilia and bleeding disorders continued with a record number of conferences. A total of seven conferences for members were held throughout the year. Four of the conferences are now well established on our calendar - the Annual General Meeting in March, the conference for members with Hepatitis C / HIV in May, the Parents Conference in June and the Members' Conference in October. In addition, other conferences for specific demographic groups of members were held for young men with haemophilia (HIS IHS), for training of parents (Parents Empowering Parents Conference) and for members over the age of 40 who attended a conference on Ageing and Haemophilia. The numbers attending the conferences were exceptional. The accumulative attendance of the three largest conferences was 585 people, a 21% increase since 2011. Just as significantly, the numbers attending lectures and symposia at the conferences also significantly increased. This was greatly assisted by the policy which was endorsed by the Annual General Meeting in 2013 of subsidising conference attendance for members only when they attend lectures and symposia at the conferences. The large attendance at the conferences together with the multiplicity of topics covered gave a very strong sense of vibrancy and progress in the community.



As part of the IHS Strategic Plan, a publication on Ageing & Haemophilia was produced in 2013.

Following the publication, a conference on Ageing and Haemophilia was held in the Sheraton Hotel, Athlone.



The conference on Ageing and Haemophilia was particularly noteworthy. This conference was initially envisaged under our strategic plan as a one off event following on from the publication of the Ageing with Haemophilia Booklet by the Society. However, the conference was so successful and the evaluations were so positive that we are now considering organising this conference every second year. This is also rational given the increased level of clinical knowledge and awareness in relation to all aspects of ageing and haemophilia. We are fortunate that we are living at a time when the first generation of people with haemophilia can look forward to ageing. We must take into consideration, however, that many of the normal diseases which can occur in an ageing population will have additional ramifications for individuals with underlying bleeding disorders. This requires education, information and prevention. With the publication on Ageing and Haemophilia and the specific conference in 2013 we have made a good start in this process.

Information meetings also took place during the course of the year for members with Factor IX deficiency in relation to the potential initiation of a clinical trial in Ireland for gene therapy. The Society were closely involved with the National Centre for Hereditary Coagulation Disorders (NCHCD) in the application process for a clinical trial for gene therapy with the Irish Medicines Board. Gene therapy was a major topic at the Annual General Meeting in 2013 and there is now every prospect that a gene therapy clinical trial will commence in Ireland for individuals' with Factor IX deficiency. The Society also collaborated during the course of the year with the NCHCD in the establishment of a Chronic Disease Self Management Course. Staff from the Society and the centre were trained to deliver this course and going forward, this will be of major benefit to persons with haemophilia and related bleeding disorders as the course assists people with chronic long term conditions such as haemophilia, to develop the coping skills and strategies required to optimise their quality of life and self management of their condition.

Our one to one outreach to members continues and in the course of 2013 phone calls were made to 634 members and just over 150 visits were made to members at home or in hospital.

In 2012, the Society had identified Hepatitis C as a major priority. The quality of life for people with haemophilia now is very good, life expectancy is near normal with modern optimum treatment. Treatment for those with HIV has improved dramatically since the introduction of highly active anti-retroviral therapy in the 1990s. Where we have seen mortality among people with haemophilia in the last number of years, it has generally been from Hepatitis C. With the availability of a new generation of therapies for Hepatitis C in 2012, the Society wanted to ensure that we gave every support possible to members in relation to accessing this treatment and coping with treatment. Our objective was to ensure that all members were aware of the need to engage with the Hepatology services and actively manage their Hepatitis C and to ensure that they were aware of the treatment options that may be available to them. We wanted to ensure that they were fully supported before, during and after treatment.

The support provided to members included;

- * A specific newsletter, Positive News which gave up to date information in an understandable format on treatment and all other issues relating to Hepatitis C. Two issues were produced in 2013, with the latter issue at the end of the year focusing on the next generation of treatments which should become available in the coming months and years.
- * Information meetings were held for members with the clinicians who treat members with Hepatitis C and with Hepatitis C and HIV Co-infection.
- * Specific and regular phone calls were made by Society staff to members with Hepatitis C to ensure they were getting all the information and support that they required.

A lot of individual and specific support was delivered to members through the course of the year who were undergoing treatment for Hepatitis C and from this also grew a network of peer to peer support among those on treatment, where they supported each other. Assistance with accommodation when visiting the hospital and also with coping with the additional financial burden of regular attendance for treatment was provided to members.

The results of this proactive approach by the Society are clear. The new treatments for Hepatitis C licensed in 2012 were designated for people with a particular genotype. People with haemophilia constitute just over 1% of those with this genotype in Ireland, but they constitute over 9% of those treated. In addition, to date 15% - 20% of individuals on these treatments stopped taking the treatment due to adverse effects or an inability to tolerate the side effects. Of those with haemophilia, not a single individual ceased treatment due to an inability to tolerate the side effects. The Society also carried out a detailed survey among our members on treatment and meetings with the people on treatment and their partners to ascertain what were the factors which influenced their treatment decisions and which supports were the most valuable. It was found that the information meetings organised by the Society were the most valuable source of information to those who were starting treatment.



Positive News, an information magazine for people with Hepatitis C and HIV.



The IHS Apartment had a high occupancy rate in 2013.

This type of outcome based research, together with the evaluations conducted at each of our conferences are very useful in ensuring that we can prioritise the services and support which work best in the interest of members.

The apartment which the Society purchased close to St. James's Hospital has been more widely used during the course of 2013 and has been invaluable for some members who travel long distances to Dublin for treatment.

The Society's involvement in statutory bodies continued and expanded in 2013. We continue to work as part of the National Haemophilia Council (NHC) to progress issues such as the provision of the National Treatment Guidelines and the opening of the new haemophilia in-patient unit in St. James's Hospital.



IHS staff member Declan Noone with Consultant Haematologist Dr. Niamh O'Connell in the Haemophilia In-Patient Unit in St. James's Hospital.

The Society worked closely with the National Haemophilia Council, the National Centre for Hereditary Coagulation Disorders and St. James's Hospital in planning the new unit which opened in late 2013.

The Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) carried out a procurement process during the year for Factor X deficiency. The Society were very aware that there is a new generation of haemophilia therapies currently under development. These longer lasting factor concentrates have the potential to transform haemophilia care for many people with haemophilia in the future. These products will not be available in Europe before 2015 / 2016. However, it is vital that we are prepared for the proper evaluation of these products. To this end, the Society organised a conference in late 2013 for clinicians and experts from abroad who were joined by members of the HPSMAB looking at the clinical aspects of all the longer lasting factor concentrates. We have taken the lead in ensuring this information is fully considered before the products are even licensed in Europe. We want to be fully prepared for the scientific, clinical, patient and economic parameters which will form part of the discussion when new products become licensed and potentially available.

The Consultative Council on Hepatitis C was reconstituted during the year and the Society now have two members on the Council, which recommends policy to the Minister for Health on all aspects of Hepatitis C treatment and care for persons who were infected through blood and blood products.

The Society are also formally represented on the NCHCD Patient Panel and I serve on the vCJD Incident Panel and on the board of the Irish Blood Transfusion Service.

Our contribution to the development of haemophilia care worldwide continues. Our Twinning programme with Vietnam had a very successful year. Additional training was carried out for volunteers and chapter leaders in Vietnam and agreement was reached on the parameters for a micro-employment project, a home adaptation project and the provision of English classes for people with haemophilia in Vietnam. The success of this twinning programme was recognised by the World Federation of Hemophilia (WFH), who awarded the Ireland-Vietnam partnership, the Twin of the Year award. The Society also continues to donate and to participate in the WFH Global Alliance for Progress (GAP) Programme. The Society has also helped in the shipping of humanitarian aid factor concentrates donations. In 2013, the Society was responsible for shipping factor concentrates to 13 countries with a value of over €1.1 million. We also made a specific donation to the haemophilia patient organisation in the Philippines following the typhoon in that country.



In July 2013 we welcomed Professor Tri and Dr. Mai to Ireland. The IHS made two trips to Vietnam in 2013.

In terms of finance, the income for the Society was substantially increased in 2013. This was partially due to an additional grant from the Health Service Executive (HSE) towards the cost of legal fees for the Hepatitis C Insurance Scheme.

It should also be noted that fundraising income more than doubled from 2012, this was due to the efforts of many members who fundraised for the Society, which we greatly appreciate. I must give specific mention to the Malin to Mizen Head Cycle which was organised by David Curtin and undertaken by a group of 11 people. The cycle raised in excess of €32,000 for the Society. In addition the fact that a person with haemophilia, with a relatively high public profile, cycled from one end of the country to the other, gives a very strong message about the physical capabilities of people with haemophilia. This is a strong and productive message.



Some of the volunteers and participants who supported and took part in the Malin to Mizen Head Cycle which Raised over €32,000.

Donations from members were significantly decreased in the course of 2013. This change was primarily due to some very significant individual donations in 2012.

Our expenditure in 2013 was also higher and this includes significant provision being made for legal fees for the Insurance Scheme.

There were several controversial episodes in the media in relation to the funding of charities. The Society greatly welcomes the appointment of a charities' regulator. We have made it clear that as a registered charity of long standing in receipt of state funding, we are fully compliant with the requirements placed upon the organisation. The Society has very strong financial governance and accountability in place, overseen by our board of unpaid volunteers. We agree an annual detailed business plan with the Health Service Executive (HSE) and we were the first organisation receiving funds from the HSE in the area of Hepatitis C to sign a Service Level Agreement (SLA). Our funding from the HSE has been governed by Service Level Agreement's since 2009 and we have been fully compliant with the requirements of the SLA. The Society utilises the funding received from all sources in a prudent, accountable and transparent manner to provide the maximum support and services to all those with inherited bleeding disorders. This has been acknowledged in 2013 in writing by the HSE. In addition, the Society's innovative work on medication procurement with the haematologists, the HSE and Department of Health on the Haemophilia Products Selection and Monitoring Advisory Board, has resulted in savings to the exchequer in excess of €180 million from 2002 to 2013. The savings we have achieved for the country are a multiple of the funding received by the Society.

We remain committed to ensuring the provision of the safest and most efficacious treatment for haemophilia while achieving this at the lowest possible cost to the country. The Society remains committed to continued proper, ethical and transparent use of all the funding received. The audited accounts of the IHS are published each year in the Annual Report and these are available on our website.

Finally, I want to acknowledge the excellent work carried out by the staff team at the Society, the dedication and commitment of our Board who meet on a monthly basis and contribute greatly to the Society and the large network of excellent volunteers who make it possible for our events to take place in a fully family inclusive manner.

Brian O'Mahony
Chief Executive

www.haemophilia.ie

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 31st December 2013 which comprise the income and expenditure account, the balance sheet, the cash flow statement and the related notes. These financial statements have been prepared under the accounting policies set out therein.

This report is made solely to the company's members, as a body, in accordance with the requirements of the Companies Acts 1963 to 2013. 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 auditors' 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 described in the statement of directors' responsibilities the company's directors are responsible for the preparation of the financial statements in accordance with applicable law and Accounting Standards issued by the Accounting Standards Board. Our responsibility is to audit the financial statements in accordance with relevant legal and regulatory requirements and International Standards on Auditing (United Kingdom and Ireland). We report to you our opinion as to whether the financial statements give a true and fair view in accordance with Generally Accepted Accounting Practices in Ireland and are properly prepared in accordance with the Companies Acts 1963 to 2013. We also report to you whether in our opinion: proper books of account have been kept by the company; whether, at the balance sheet date, there exists a financial situation requiring the convening of an Extraordinary General Meeting of the company; and whether the information given in the Directors' Report is consistent with the financial statements. In addition, we state whether we have obtained all the information and explanations necessary for the purposes of our audit and whether the company's balance sheet and its income and expenditure account are in agreement with the books of account. We report to the members' if, in our opinion, any information specified by law regarding directors' remuneration and directors' transactions is not given and, where practicable, include such information in our report. We read the directors' report and consider the implications for our report if we become aware of any apparent misstatements within it.

Basis of audit opinion

We conducted our audit in accordance with International Standards on Auditing (UK and Ireland) issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgements made by the directors in the preparation of the financial statements, and of whether the accounting policies are appropriate to the company's circumstances, consistently applied and adequately disclosed.

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements. We have undertaken the audit in accordance with the requirements of APB Ethical Standards - Provisions Available for Small Entities, in the circumstances set out in note 11 to the financial statements.

Opinion

In our opinion the financial statements give a true and fair view, in accordance with Generally Accepted Accounting Practice in Ireland, of the state of the company's affairs as at 31st December 2013 and of its surplus for the year then ended and have been properly prepared in accordance with the Companies Acts 1963 to 2013.

We have obtained all the information and explanations that we consider necessary for the purposes of our audit. In our opinion, proper books of account have been kept by the company. The financial statements are in agreement with the books of account. In our opinion the information given in the directors' report is consistent with the financial statements.

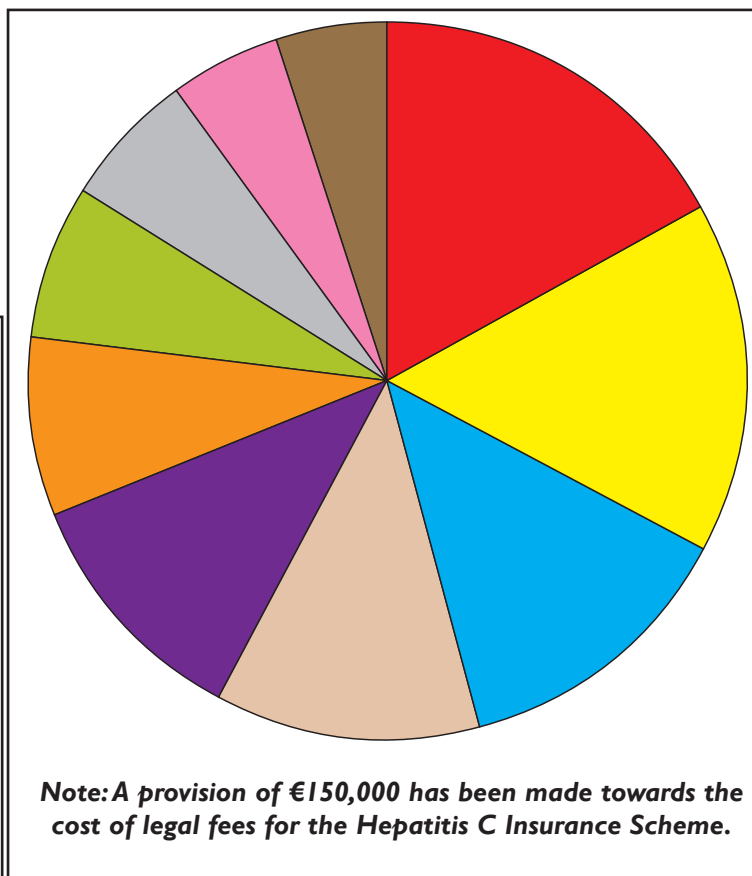
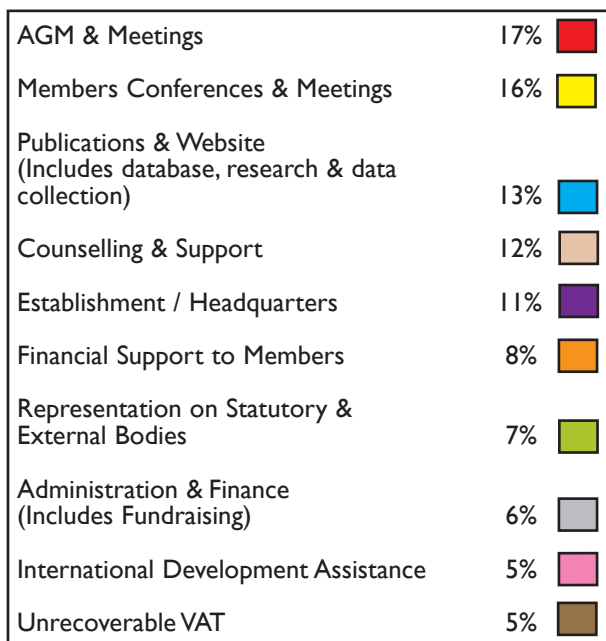
Registered Office

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

Auditors

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

How we used the money



Income & Expenditure Account For The Year Ended 31st December 2013

	2013 €	2012 €
Income		
Health Service Executive	532,966	549,448
Health Service Executive-Re: Legal Fees	100,000	-----
Irish Haemostasis Foundation	84,000	-----
Memberships	3,120	3,980
Donations - Members	25,529	75,282
Donations - Corporate	61,485	69,279
Twinning	6,345	6,015
Fundraising	42,696	19,792
H.H.T.Trust	12,083	-----
Research	9,000	-----
Investment Income	12,882	13,236
Sundry Income	-----	1,000
	<hr/>	<hr/>
	890,106	738,032
 Expenditure as per schedule	 (867,374)	 (732,836)
	<hr/>	<hr/>
Surplus for the year	22,732	5,196





	2013		2012	
	€	€	€	€
Administration Expenses:				
Wages, State Insurance & Pension Costs	223,015		225,986	
Employer's PRSI Contribution	23,164		23,672	
Office Expenses & Stationery	7,050		9,933	
Telephone & Fax	6,111		9,510	
Travelling Expenses	5,080		5,643	
Overseas Travel Expenses	7,484		6,654	
I.H.S. Members' Facility	5,411		2,234	
Sundry Expenses	2,515		7,137	
		279,830		290,769
Financial Expenses:				
Bank Charges & Loan Interest	1,935		2,332	
Professional Fees	58,515		85,913	
Provision for Legal Fees	150,000		-----	
Audit & Accountancy Fees	4,500		5,535	
Unrecoverable VAT	33,086		-----	
Provision for Sinking Fund	30,000		-----	
		278,036		91,780
Activites:				
Help to Members	15,455		22,569	
H.H.T.Trust	8,948		9,500	
Subscriptions	1,889		1,777	
Fundraising Expenses	9,102		1,285	
A.G.M. & Meeting Expenses	27,749		37,298	
Postage, Publications & Photocopying	20,512		41,681	
Educational Grants	18,250		17,750	
Safety/Supply Activities	11,292		1,669	
Counselling & Support Meetings	6,607		4,455	
Twinning	11,293		13,440	
Website	746		2,799	
WFH GAP Program/Developing World Grants	9,352		17,804	
Sponsorship/Training	1,577		5,060	
Research	3,220		-----	
Parent's Conference	16,839		17,075	
Members' Conference	22,311		24,775	
HIV/HCV Conference	4,279		4,699	
PEP Conference	4,171		6,531	
HIS Conference	804		2,350	
Ageing Conference	7,304		-----	
		201,700		232,517
Establishment Expenses:				
Service Charge & Insurance	12,087		15,534	
HQ Costs	1,742		489	
Computer Services	6,983		12,858	
Light, Heat & Services	9,474		11,367	
		30,286		40,248
Other Costs:				
Depreciation - Fixtures, Fittings & Equipment	3,068		3,068	
Depreciation - Land & Buildings	74,454		74,454	
		77,522		77,522
Total Expenditure		867,374		732,836

Balance Sheet As At 31st December 2013

	2013		2012	
	€	€	€	€
Fixed Assets:				
Buildings	<u>1,168,479</u>		<u>1,242,933</u>	
Office Equipment & Fittings	9,203		12,271	
		1,177,682		1,255,204
Current Assets:				
Davy Investment Portfolio	170,000		170,000	
Allied Irish Bank-Current Account	270,546		82,706	
Allied Irish Bank-Planned Giving Current Account	50,028		32,083	
Allied Irish Bank-Deposit Accounts	277,881		194,200	
Permanent TSB-Deposit Account	187,560		187,560	
Cash on Hand	72		263	
Sundry Debtors & Prepayments	<u>11,485</u>		<u>8,772</u>	
		967,572		675,584
Current Liabilities:				
Sundry Creditors & Accruals	<u>(298,432)</u>		<u>(106,698)</u>	
		(298,432)		(106,698)
Net Current Assets / (Liabilities)		<u>669,140</u>		<u>568,886</u>
Net Assets / (Liabilities)		<u>1,846,822</u>		<u>1,824,090</u>
Represented By:				
Accumulated Funds				
Balance 1st January 2013		1,824,090		1,818,894
Surplus for the year		<u>22,732</u>		<u>5,196</u>
Balance 31st December 2013		<u>1,846,822</u>		<u>1,824,090</u>



Please note that copies of the full audited accounts for 2013 are available on request.

CORPORATE SPONSORS

The Irish Haemophilia Society would like to acknowledge the unrestricted financial contributions made in 2013 by the following companies under our Corporate Giving programme.

Platinum Sponsors

Baxter, Pfizer.

Gold Sponsors

Bayer, CSL Behring, Novo Nordisk, Swedish Orphan Biovitrium.

Silver Sponsors

MSD.

FUNDRAISERS

The Irish Haemophilia Society would like to acknowledge and thank with gratitude everyone who fundraised for the Society during 2013, as follows:

Amy Dunne, Beth Mallard, Brian O'Regan, Carmel Ward, Charlotte McCallum-Mallard, Clair McEvoy, Colm O'Driscoll, David Curtin, Diarmuid Clancy, Fintan Treacy, Garry Mannion, Garry Donohue, Ian Kingston, Jackie Wright, Jacqueline Reid, Jennifer Andrews, Joey Marrinan, John Clarke, Johnny Kenny, Jonathan Touhey, Linda Eagers, Lucia Prihodova, Lynn Doyle, Martin Kenny, Mary Hanney, Matt O'Sullivan, Monica O'Connor, Noel Horan, Pallavi Phoenix, Paul Griffiths, Paula Doyle, Rebecca Roche, Sandra Byrne, Sarah Gilgunn, Sarah Griffin, Shane Ryan, Shannon Doyle, Sheena Mc Donnell, Sinead Usher, Veronica Dunne.

VOLUNTEERS

The Irish Haemophilia Society would like to acknowledge and thank everyone who volunteered for the Society during 2013. Their help and support are very much appreciated.

EVENTS

Aisling Moriarty, Aislinn Farrelly, Amy Carroll, Andrew Manifold, Aoife Carey, Aoife Conway, Carley Byrne, Carmel Ann Galligan, Cathal Rochford, Catriona Moriarty, Ciaran Dowling, Claire Moriarty, Claire Neill, Deirdre Ryan, Denise Maher, Donal Glackin, Donal McCann, Eoin Moriarty, Erika Nasickyte, Jay McEvoy, Jessica Dolan, Judith Persse, Lucia Prihodova, Mary Flanagan, Paul Brophy, Paul Dunne, Sam Morrissey, Sarah Charnock, Sarah Gilgunn, Seamus McDonald, Shannon Doyle, Shauna Keniry, Stephen Boylan, Tara Lehman, Teresa Howes, Tracey Byrne, Tricia Moran.

PUBLICATIONS

Conor Birkett, Cora Marshall, Jennifer Andrews, Joanna Keniry, John O'Mahony, Lucia Prihodova, Michael Davenport, Niamh O'Sullivan-Costa Pinto, Saoirse Carey, Shay Farrelly.

PLANNED GIVING 5 YEAR APPEAL

The Irish Haemophilia Society gratefully acknowledges and thanks the following people who donated to our 'Planned Giving 5 Year Appeal' during 2013.

Marcus Beresford, Anne Brennan, The Campbell Family, The Cox Family, The Crowe Family, The Davenport Family, The Farrelly Family, The Fay Family, The Friel Family, Nodlaig Griffin, The Guilfoyle Family, The Hanney Family, Ann McCabe, Stephen, Daniel & Joyce McEvoy, Brendan McGuinness, Kieran McHugh, The Moloney Family, Dolora Monaghan, Brian O'Mahony, Gerard O'Reilly, Brian O'Riordan, The Sheerin Family, The Stack Family, The Wynne Family.

In memory of Richard & Paul Costello, In memory of Andrew Finlay,
In memory of George Marshall, In memory of Sheila O'Mahony,
In memory of Patrick Owens, In memory of Donal Twomey.

Eighteen anonymous members also donated to our 'Planned Giving 5 Year Appeal' during 2013, for which we are very grateful.

IRISH HAEMOPHILIA SOCIETY

First Floor
Cathedral Court
New Street
Dublin 8

Tel: 01 6579900

Fax: 01 6579901

Email: info@haemophilia.ie

Website: www.haemophilia.ie

