Irish Haemophilia Society

Annual Report 2010

Representing people with haemophilia & related bleeding disorders for over 40 years.

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A Message from the Chairman

Michael Davenport, Chairman

Last year was a challenging one for our Society. What impact would the recession have on our services to members as a result of a reduced subsidy from the HSE? Would our voluntary funding be reduced? Would Haemophilia services be affected in terms of treatment supply and hospital services?

Despite our representation to the HSE demonstrating our cost efficiencies and careful use of all our funding, we were cut the same percentage as other organisations thereby not rewarding us and not penalising inefficient ones, notwithstanding, our contribution to saving millions of euro via the Haemophilia Products Monitoring and Advisory Board.

However, despite reduced HSE funding, we continued to provide a full service to our members with our three main weekend conferences being fully subscribed. The development of the new haemophilia treatment centre in Cork University Hospital was delayed somewhat but was closely monitored by the National Haemophilia Council. Product supply was not affected while savings were made by closer monitoring of short dated product and reducing wastage, and we were assured that the new In-Patient unit in St. James's is still on course for commencement in 2011.

An improvement in services occurred with the appointment of an 'Outreach' nurse in Our Lady's Children's Hospital Crumlin, so it wasn't all bad news last year.

Our services to members continued to include counselling, an individual phone call to almost every member, regional meetings and home visits, representations on various government bodies, and, legal and taxation advice. We also produced quite a number of new publications. Our conferences last year included an update on HIV and Hepatitis C review, a parent's conference, a member's weekend and our AGM and Conference weekend in March.

The 29th World Federation of Haemophilia Congress took place in Buenos Aires in Argentina in July. It was the largest congress ever with over 4,300 delegates from approximately 118 countries.

Delegates from Ireland included several staff and board members, a number of clinicians and members of the Societ., So we were well represented and had sufficient numbers to continuously man our booth in the conference hall where we distributed four suitcases of our publications and literature.

We had nine posters on display during the week describing some of the activities of the Irish Haemophilia Society, and included a survey of prophylaxis, on demand and combined treatment in 20-35 year olds in four European countries by Declan Noone, Brian O'Mahony and Lucia Prihodova. Anne Duffy had two posters, one on Psychosocial Workshops in Belarus and one, in conjunction with Declan Noone, about Communication Strategies.

I.H.S. Delegates at the 2010 WFH World Congress in Buenos Aires

We looked at the congress programme and divided up the conference talks amongst staff and board which enabled us to cover as many topics as possible. There were updates on Future Factor Therapies. Since a number of companies are developing products with a longer half-life, hopefully it won't be too long before prophylaxis will consist of just one shot per week. This will dramatically improve the quality of life for families with haemophilia children. There are 130 potential treatments (or agents for treatment) for Hepatitis C in the works. A few have reached trial stage so hopefully our members, who have so far not cleared the virus, will do so in the not too distant future. Ageing and Haemophilia was also on the agenda at the congress. A lot of the attendees at this talk had greying hair but you could still see Ger O'Reilly, Brian O'Mahony and Kieran Mc Hugh in the middle of them! Our October magazine included a Congress Supplement which includes reports from our staff and board members and you can view this on our website.

Up to the 1970's effective treatment for haemophilia was not widely available in Ireland. One result of this was that many people with haemophilia lost a lot of time from school due to recurring bleeds which left them incapacitated for long periods of time. This in turn meant that a large proportion of them did not go on to college. When treatment improved and home treatment became available this made a huge difference not only to their quality of life, but they no longer had to miss so much school and the percentage of those going on to college was comparable to the general population. In response to this the Society in the late 1980's decided to offer an Educational Grant each year to a person with haemophilia or related bleeding disorder, going on to post second level education.

This is called the **'Maureen Downey Educational Grant'** in memory of one of our esteemed founders. Currently the award is in the amount of €4,000. Applications are invited from any person with haemophilia or related bleeding disorder, who has been accepted on a course at any post second level educational institution.


Daryl Butler receiving the Maureen Downey Grant from IHS Board Member, Pat Downey at the 2010 AGM

Since then, the Society has introduced a second grant in 2004 which is called the **'Margaret King Educational Scholarship'** in memory of a brilliant woman who we met originally as a haemophilia nurse in St James's and who later devoted many years to the Society. This scholarship is made available to an immediate family member of a person with haemophilia or related bleeding disorder, who has been accepted on a post second level educational course. Currently the award is in the amount of €2,000.

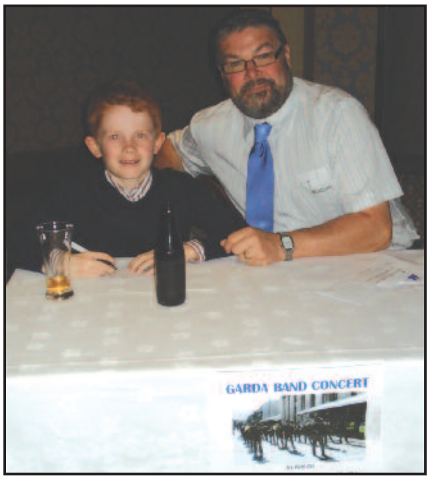

IHS Chairman Michael Davenport presenting Christina O'Sullivan with the Margaret King Educational Scholarship at the 2010 AGM

We are delighted that so many of our members are now going on to third level education and we are in position to support them. Last year we introduced an online application form which was used by most applicants for the 2010/2011 term. While a sub committee from the Board reviews and selects the winning applicants, a parent or relative of an applicant cannot be on this subcommittee. Previous award recipients can apply again and our latest recipients are a mixture of new and previous applicants with some only starting college and others completing third or fourth years.

IHS Staff Nina Storey and Fiona Brennan braved the bad weather to take part in the 2010 Womens Mini Marathon on behalf of the Society

Despite the recession, our fundraisers didn't hold back last year. Nuala Mc Auley set out a number of targets for participation in a weight loss competition. We had a great turn out also for the yearly Women's Mini Marathon. However, a certain member of staff pulled out of the mini marathon with a foot injury that healed up suspiciously soon afterwards but Fiona Brennan soldiered on with Nina Storey and our other ladies.

(L - R): Orla O'Sullivan, Laura O'Donovan, Emma Corbett, Andrea Hickey and Kate St. Ledger took part in the Cork Mini Marathon on behalf of the IHS



Niall Jackson, 10 years old, and Philip Clarke were part of a team of members who organised a hugely successful Garda Band Concert in aid of the Society.

The Clarke & Jackson families, and friends organised a concert by the Garda Band in Monaghan which was a great success.

We also had cyclists in France, participants in the Cork mini marathon and quiz nights. Fundraising not only raises money, it raises awareness of haemophilia and the work of the society so a huge thanks to all participants and contributors.

John Fitzgerald having completed the Col du Tourmalet Challenge in September 2010.

Regretfully, last year, we lost a great friend and supporter of the Society for many years. Jim Casey came to numerous AGMs and meetings and accompanied us around the world to many WFH Congresses. He was a gentleman in the truest sense of the word with, typical, dry Kerry wit. He is still missed by all who knew him. May he rest in peace.

I would like to compliment and thank the staff for the manner and enthusiasm in which they carried out their tasks last year. Many people are currently under severe pressure due to the recession and this must make it harder to make a voluntary commitment which occupies a lot of their spare time so I would like to sincerely thank our Board and all our volunteers for their continuing commitment to the Society.

Michael Davenport,
Chairman.

Honorary Secretary's Report

Kevin Birkett,
Honorary Secretary

At the 21st Annual General Meeting of the Irish Haemophilia Society, which was held in the Royal Marine Hotel, Dun Laoghaire, Co. Dublin on Saturday 6th March, 2010 the Incoming Governing Body of the Society were elected as follows;

Michael Davenport
Traci Dowling
Kevin Birkett
Gerard O'Reilly
Brian Byrne
Mary Hanney
Michael Butler
Pat Downey
Eoin Moriarty

Eight of the nine committee members at the 2010 Annual General Meeting.

At the first executive meeting following the AGM the following officers were elected:

Chairman
Michael Davenport

Vice-Chairperson
Traci Dowling

Honorary Secretary
Kevin Birkett

Honorary Treasurer
Gerard O'Reilly

In the period since the last AGM, twelve full executive meetings were held. Staff and board members also spent a weekend in November drafting 35 objectives for a new strategic plan, which reflects the challenging times we are facing.

Meetings organised by the Society

As usual the Society organised a number of meetings throughout the year.

The 21st Annual General Meeting and Conference of the Irish Haemophilia Society took place over the weekend of the 5th to 7th March in the Royal Marine Hotel, Dun Laoghaire, Co. Dublin. The conference continued the work of recent conferences by highlighting developments in haemophilia care not just at home but also abroad. The keynote speaker on Saturday afternoon was Yuri Zhulyov, President of the Russian Haemophilia Association who outlined the situation facing people with bleeding disorders in his country. As the weekend continued other speakers outlined developments in haemophilia care in Ireland.

Yuri Zhulyov provided the inspiration for the young adults who had the opportunity to learn about haemophilia treatment in another country and then use interactive whiteboard technology to produce a presentation for the Kidlink group. The Kidlink group had a busy time with arts & crafts, swimming and a visit to the National Sealife Centre in Bray on the programme. After a busy Saturday for one and all a gala dinner and music for Liam O'Sullivan and Frank O'Connor allowed everyone to let their hair down.

In April the Society again organised a conference specifically for parents of children with haemophilia. Organised in conjunction with Our Lady's Children's Hospital, Crumlin and the National Centre for Hereditary Coagulation Disorders, to give the opportunity for parents who are not members of the Society to attend, the weekend covered the many issues parents will face as their child grows and develops.

The third weekend in October saw the Society's now well established 'Members Weekend' held in the Castletroy Park Hotel, Limerick. The emphasis was on fun with a drama workshop for everyone, while the inspirational Corkman, Owen Hegarty, entertained and challenged the adults. Meanwhile the young adults enjoyed a full day of activities at the University of Limerick Activity Centre and the Kidlink members enjoyed their own busy programme.

The Society would like to thank Barbara Guilfoyle, Paul Dunne, Eoin Moriarty, Liz McDonald, Daniel Carey, Niamh Mangan, Claire Moriarty, Daryl Butler, Lucia Prihodova, Catriona Moriarty, Amy Phipps, Aisling Denieffe, Catriona Mulhall and junior leader Ciaran Dowling without whom the Kidlink and young adult programmes would have been impossible.

Some of the IHS volunteers at the Members Weekend in October. The IHS could not function without volunteers.

For those not old enough to participate in these programmes the crèche offers its own stimulating environment. We would like to thank Carmel Downey, Claire Neil, Aoife Downey, Deirdre Ryan, Sandra Phipps, Jane Smith, Jenny Styles, Julie McAuley and Laura McAuley for ensuring that our smallest members have a great time too.

A huge thank you to all the creche leaders for their hard work throughout the year.

The Society arranged a number of smaller events throughout the year many of which utilised the facilities offered by our headquarters, which is available to any group of members wishing to organise a meeting of their own.

In January 2010, under the auspices of the Plasma Users Coalition, the Society organised a conference in the Dunboyne Castle Hotel, Co. Meath to help bring consensus in relation to the collection of blood and plasma globally. Over two days the participants engaged in discussions which resulted in an agreed consensus statement called the Dublin Consensus Statement. A copy of the Consensus Statement is available on the Society's website and was printed in the April issue of the Society's magazine.

The Society organised two weekend workshops / conferences for members living with Hepatitis C and HIV, the first, in May in the Dunboyne Castle Hotel, Co. Meath and the second, in November, in Cork.

In June the Society organised meetings in Cork and Dublin to update members on tax issues. On hand to provide information on the income levy, Capital Gains Tax and Dirt Tax was tax consultant, Patricia Quigley together with Brian O'Mahony and Brian Byrne.

Also in June the Society organised a conference to develop an international policy on vCJD screening. The conference – attended by experts from Ireland, Canada, the USA and France, haemophilia clinicians from Ireland and the UK and Haemophilia Society representatives from France and the UK – resulted in the publication of the I.H.S. Policy on vCJD Screening of Persons with Haemophilia and Related Bleeding Disorders, which appeared in the October issue of our magazine and is available on our website.

On September 10th and 11th the Society organised Relatives' Days in Cork and Dublin respectively. These days are specifically aimed at the relatives of people with haemophilia and provide participants with information on the history of the Society, past and present treatments for haemophilia and basic medical and genetic information.

Regional visits continue to be an

important part of the Society's work. A series of meetings were arranged throughout the country for the weeks beginning the 9th November and, most recently, the 14th February during which members were able to raise various issues of concern to them.

Finally a memorial service took place in the offices of the Society on the 12th December in memory of our members who have passed away and the light and joy they brought to our lives. Twenty-eight members attended the service.

Conferences and other events

During the course of the year the Society was represented at a number of conferences and other events.

The World Federation of Hemophilia biennial Congress took place in Buenos Aires, Argentina from July 11th to 15th. Seven delegates attended the Congress from the Society. In addition, a large number of members and their families attended the Congress.

The Society continues to forge closer links with the UK Haemophilia Society. Both Societies send delegates to the other's AGM while families from the north attended the Parents'Conference in April. In September two families from Ireland travelled to the UK Society's Inhibitor Conference, which was held in Stratford Upon Avon.

In October a delegation from the Society attended the 23rd Annual Conference of the European Haemophilia Consortium, which was held in Lisbon, Portugal. The topics under discussion included:

- *How to diagnose Von Willebrand Disease;*
- *Pre-natal Diagnosis and Genetic testing;*
- *Bleeding disorders in EU policy;*
- *Prophylactic treatment;*
- *Experiental data collection;*
- *New development in the treatment of Inhibitors;*
- *Hepatitis C treatment;*
- *Psychosocial aspects of living with haemophilia;*

There were also workshops for haemophilia nurse specialists and for physiotherapists.

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Website / Publications

Over the past twelve months the Society has continued to develop its website and has launched two new channels for communicating with members; a 'Facebook' page and a discussion forum. The 'Facebook' page, which went live in April, provides information on upcoming events and the services the Society provides while the discussion forum – up and running since September – allows families to share their experiences and any issues that they may have.


haemophilia.ie

Magazine of the Irish Haemophilia Society

October 2010

The Society has also continued updating and re-designing its information booklets. This year we published booklets on;

- *Women and Bleeding Disorders;*
- *Rare Bleeding Disorders;*
- *Benefits & Allowances for Adults with Haemophilia;*
- *Benefits & Allowances for Parents of a Child with Haemophilia;*
- *Benefits & Allowances for Carers.*

These and other publications can be downloaded from our website or can be obtained in hardcopy from the office.

The current Society Staff are:


Brian O'Mahony
Chief Executive Officer


Debbie Greene
Administrator


Anne Duffy
Counsellor, Family Support
& Outreach Officer


Nina Storey
Administrative Assistant


Declan Noone
Administrative Assistant


Nuala Mc Auley
Administrative Assistant


Fiona Brennan
Administrative Assistant

Society Representation

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

National Haemophilia Council	Michael Davenport & Brian O'Mahony
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 Hemophilia	Brian O'Mahony, Anne Duffy, Declan Noone
European Haemophilia Consortium	Brian O'Mahony
Consultative Council on Hepatitis C	Anne Duffy

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.

Kevin Birkett
Honorary Secretary

The Irish Haemophilia Society would like to acknowledge the unrestricted financial contributions made in 2010 by the following companies under our Corporate Giving programme.

Platinum Sponsors	**Gold Sponsor**
Baxter	Bayer Schering Pharma
Pfizer	

The Year in Review from our CEO

Brian O'Mahony, CEO

This was a challenging year. We worked to implement the final strategies in our four year strategic plan against a background of budget cuts and general economic retrenchment.

Work with statutory and other bodies

Our work during the year with the National Haemophilia Council (NHC) was productive. Finally, after several years of advocacy and many meetings, work commenced on the new Haemophilia treatment centre in Cork University Hospital. This new centre, which will open early in 2011, was the culmination of several years of active lobbying by the NHC and the Irish Haemophilia Society (I.H.S.) and was a priority for the improvement of care identified by the external audits of the comprehensive care centres in both 2006 and 2008. Together with the appointment of Dr. Susan O Shea as Consultant Haematologist, this should result in a greatly improved service in Cork. Work will continue in other priority areas including the requirement for additional laboratory staff to allow for a full and comprehensive diagnostic service.

One of the treatment rooms at the new Haemophilia Treatment Centre in Cork University Hospital.

Other priority areas of work for the NHC were the provision of an additional nursing post for the centre in Our Lady's Children's Hospital Crumlin, to allow for greater outreach by the comprehensive paediatric service to the community. This post was filled in 2010. We were also pleased to see the recruitment of an additional consultant haematologist - Dr. Ruth Gilmore - to lead the haemophilia service in Galway University Hospital. The Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) completed national purchasing tenders during the year for plasma derived Factor VIII concentrate for the treatment of von Willebrands disease and for plasma derived Factor X concentrate for the treatment of Factor X deficiency. We also met with the Minister for Health and Children to press the case for St. James's Hospital to replace the Irish Blood Transfusion Service as the contract holder for the purchase of products under the remit of the HPSMAB. We strongly believe that this will be both more effective and more cost effective. Following our representations, this change will occur and will come into effect in 2011 when the necessary legislative changes have been completed. We continue to work with the Consultative Council on Hepatitis C, and in 2010 we engaged in a consultative process designed to evaluate the requirements of all members with HAA cards and optimise the provision of services to them. This work continues.

Conferences and Meetings

Attendences were very high at all the IHS conferences during 2010.

Our Conferences were very successful and well attended this year. We held four major conferences. The Annual Conference and AGM in March included lectures on Prophylaxis, Dental Care, Haemophilia in

Russia and the work of the NHC. The importance of collaboration between treating doctors and the Society was set out in the session "Collaboration Towards Excellence". The Parents conference in April focused on improving the quality of life of the child with Haemophilia, and included information on treatment in the first two years of life, getting the most from your care and the provision of handheld devices for treatment recording. Sessions were held on age appropriate communication to children and on parenting skills. The mothers and fathers workshops which had begun in 2009 re-convened and offered an excellent forum for informal discussion and peer support. The Conference for members living with HIV and/or Hepatitis C was held in Cork in June. The programme included an update on treatment, peer discussions and treatment and monitoring guidelines.

A workshop on Social Media took place at the Members Conference after the launch of the IHS facebook and discussion forum.

The Members Conference in October included sessions on Introduction to Entitlements and Benefits where we took the opportunity to launch our three new booklets on these issues. Popular sessions also included a lecture on Positive Living with a Bleeding Disorder and a Workshop on Use of Social Media. Our traditional debate between two members took place on the topic of "Guiding the Child with haemophilia: Who does it better, the mother or the father?" This enjoyable and thought provoking debate polarised the audience to the amusement of many and in my capacity of chair of the debate, I diplomatically declared the result a draw. The humour in the session actually underscored the important point that the child with Haemophilia copes best with this lifelong condition when both parents are involved in and committed to his care. Our Conferences go from strength to strength and we are working hard to come up with interesting, informative and innovative programming. In addition we continue to recruit more volunteers to assist us in running the four programme strands (adults, teenagers, kid link and crèche). These volunteers are crucial to the success of our programmes but also to the future development of the organisation as leadership begins here. One day conferences for relatives of those with bleeding disorders were also held in both Dublin and Cork.

Publications

We had a very productive year in relation to production of publications. We have been cost effective in lowering the unit cost of publications while increasing the quality. In 2010, we produced major new publications on Women and Bleeding Disorders and on Rare Bleeding Disorders. We produced three separate booklets on Entitlements and benefits for Parents, for Adults and for Carers.

Irish Haemophilia Society

A Guide to Benefits & Allowances for Adults with Haemophilia

Irish Haemophilia Society

A Guide to Benefits & Allowances for Carers

The IHS produced several publications in 2010, including benefits booklets for adults, carers and parents.

We produced a new Paediatric Dental leaflet. In addition, the number of scientific papers and posters published in peer reviewed journals hit an all time high. Society staff had papers published in the journals Haemophilia and Vox Sanguinis, a Monograph on Economic Concepts in Haemophilia for WFH and EHC(their first ever joint publication), a Book chapter on Rare Disorders Treated by Plasma Proteins and a total of nine poster presentations at the WFH International Conference which were also published in the journal Haemophilia. Our production of publications is efficient and proactive. We are working with the treatment centres to ensure that our new publications will reach all those who will benefit from them, irrespective of whether they are member of the I.H.S. All of the publications are downloadable in PDF format free of charge from the website.

Strategic Plan

In November 2010 the board and staff of the IHS worked together to create a new Strategic Plan which will run from 2010 until 2014.

Our current strategic plan for 2006 to 2011 was completed. This ambitious plan had 4 major goals, 24 objectives and 103 strategies. In auditing the outcomes, we were delighted to see that some 87% of all the strategies outlined in 2006 have been completed. The remainder are ongoing or in some cases (as with an examination of the relevance of providing services for patients with Thrombophilia), have been postponed until 2012. The Board and staff worked collectively in 2010 to draft a new strategic plan for 2011 to 2014 and this will now form the basis of our work for the coming four years.

Communication with members

The policy of making annual phone calls to as many members as possible in order to see if they are benefiting from our programmes or activities or if they require any assistance continued apace with some 68% of members personally spoken to by I.H.S. staff this year. Home visits and hospital visits to members also increased. Regional meetings with groups of members were held in nine cities and towns. The provision of meal vouchers to the parents of children with bleeding disorders attending Our Lady' Children's Hospital, Crumlin was a development welcomed by many hard pressed parents.

The website continued to improve during the year. The addition of a Facebook page and a Discussion Forum has made the site more relevant to a younger demographic group. We also hope to extend the use of Facebook to allow for meeting registration in the future. The demand for educational grants from the society is increasing and the quality of applications is constantly improving. In 2010, we awarded a total of 17 grants to young men and women with bleeding disorders or siblings of those with bleeding disorders.

Haemophilia outside Ireland

A boy with haemophilia in Vietnam.

One of the I.H.S. Strategic Goals is to assist WFH in their Goal of improving Haemophilia care worldwide. In 2010, we carried out an assessment visit to Vietnam to decide on a possible twinning programme between the I.H.S. and the Vietnam Society for Haematology and Blood Transfusion. We visited the Hospitals in both Hanoi and Ho Chi Minh city and met with the committee doctors and enthusiastic young patient leaders. It was instructive to see how they are coping with a very low provision of replacement therapy and difficult hospital conditions. We will be proceeding with a Twinning programme with Vietnam starting officially in 2011 and focusing on building the capacity and skills of the patient organisation.

The I.H.S. also continued our contribution to the WFH Global Alliance for Progress (GAP) programme which since its inception in 2003, has resulted in the diagnosis and access to treatment of more than 11,000 new people with haemophilia. A major contribution was made by the I.H.S. to the provision of factor for developing countries via the WFH Humanitarian aid programme. The WFH is in receipt of factor concentrate donations on a planned and opportunistic basis from Pharmaceutical companies. Much of this product is shipped to developing countries from the USA but the I.H.S. also plays a major role in shipping product for WFH. In 2010, some 1.4 million IU of factor concentrates was shipped to

10 countries from the I.H.S. We were also the convenors of a major international meeting in January 2010 which brought together the WHO, Industry, Blood Transfusion Services, National Blood Authorities, Patient Organisations and donors. The aim was to see if we could achieve a consensus on major areas globally relating to blood and plasma with the aim of ensuring the provision of a sufficient and safe supply of blood and plasma to patients. This unique conference was very successful, and resulted in the publication of the "Dublin Consensus Statement" in the journal Vox Sanguinis. The statement has since been endorsed by 22 patient organisations working in the area of Blood and Plasma (including for example WFH and EHC) in Europe, the USA and Canada. Due to the success of this initiative, a further conference will take place in 2011.

IHS Chairman Michael Davenport and CEO Brian O'Mahony signed a Twinning Agreement with Vietnam in December 2010.

The Society also played a role in developments in the Irish health service generally. I took part in the working groups on the Acute Medicine Programme and Accountability for Public Hospitals. I was also a member of the group which carried out the inquiry into the X ray and GP letters issues in Tallaght hospital. In addition, I took part in a Health Technology Assessment working group which examined the potential use of prion filters for red cell transfusions. Following several years of requesting the setting up of a specific vCJD Incident panel to examine clinical situations relating to vCJD and Blood products, this group was finally established in 2010 and I also participate on this group. The anticipated blood screening test for vCJD will not now be available in the immediate future so the work of this group is even more important in maintaining vigilance and in ensuring that our members are in no way unduly disadvantaged by any provisions brought in as a result of vCJD developments.

Financial Update

Financially, it was a challenging year. Core funding provided by the HSE decreased by €35,000. Despite this, we ended the year with a surplus of €89,165 not including mortgage capital repayments. When the mortgage payments are taken into account, the deficit for the year was just over €6,000. Costs were cut in many areas. We work hard to get best value in areas as diverse as printing, hotel costs for conferences and office supplies. Unlike 2009, we did not have an income from organising and hosting the EHC Annual Conference. Donations from members increased significantly and corporate donations were lower. Costs for conferences were maintained or decreased despite higher attendance. Expenditure on educational grants for members was significantly increased due to higher demand and quality of applications. Financially, it was a satisfactory year. We maintained expenditure within the constraints of our budget and managed to increase the depth and range of our activities in a challenging fiscal climate.

It was a challenging and rewarding year. The work of the board, the staff and the volunteers resulted in an increase in the quality and quantity of written and electronic communication and information. More people with Haemophilia were in personal contact with the staff. More parents, people with haemophilia and bleeding disorders and carriers attended and benefitted from our conferences and meetings. More ideas were generated for future directions and improvements in our support and services. More co-operation took place with the health care teams at the treatment centres, with the HSE and with the hospitals. In many ways, the Society acts as a beacon of light in a twilight landscape, working with and for others to illuminate a better future.

Brian O'Mahony
Chief Executive

A Look Back at 2010

Irish
Haemophilia
Society
Discussion
Forum

Find us on
Facebook

New to the Society in 2010

Fiona Brennan joined the IHS staff as Administrative Assistant in February 2010. While Eoin Moriarty was elected to the IHS Board at the 2010 AGM.

Social Networking

The IHS joined the world of social media in 2010, with our own facebook page and discussion forum.

Education is the key!

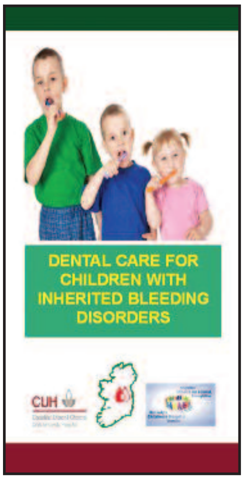
Education featured heavily in the Creche, Kidlink and Youth Programmes in 2010. The creche had a puppet show to teach them the importance of treatment. The kidlink and youth groups took part in an infusion workshop, and also had talks on dental care and learned about haemophilia in Russia and how it differs to treatment in Ireland.

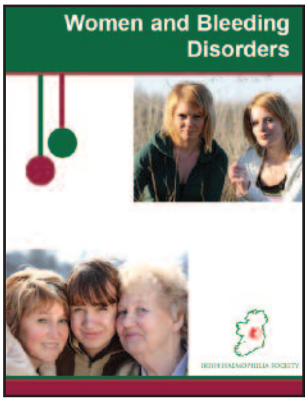
Strategy is everything!

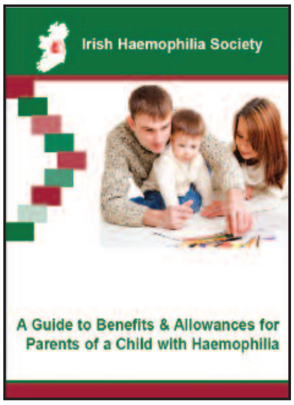
In November 2010, the board and staff of the IHS created a new Strategic Plan for 2011 - 2014. The new Strategic Plan can be viewed on the IHS website.

Parent Trap!

The debate at the Members Conference asked the question "Guiding the child with Haemophilia, who does it best, the mother or the father?"







Well Published!

The IHS Library is fully stocked. In 2010 the IHS produced four newsletters, an Annual Report, three booklets on entitlements, booklets on Rare Bleeding Disorders, Women and Bleeding Disorders and a Children's Dental Leaflet.

IHS International

The IHS continue to be well represented at international events. In 2010 IHS representatives attended the WFH World Congress, the EHC Conference, Advocacy Training in Rome and participated in a Twinning site visit to Vietnam.

Financial Reports

Independent auditors' 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 2010 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 2009. 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.

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 2010 and of its surplus for the year then ended and have been properly prepared in accordance with the Companies Acts 1963 to 2009. 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.

Copies of the full audited accounts for 2010 are available on request.

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

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

How we used the money

AGM & Meetings	**21%**	■
Counselling & Support	**17%**	■
Members Conferences & Meetings	**16%**	■
Publications & Website	**13%**	■
Financial Support to Members	**9%**	■
Representation on Statutory & External Bodies	**9 %**	■
Establishment / Headquarters	**7%**	■
Administration & Finance	**5%**	■
International Development Assistance	**3%**	■

Income & Expenditure Account

For The Year Ended 31st December 2010

	2010 **€**	**2009** **€**
Income		
Health Service Executive - Northern Area	-	130,950
Health Service Executive	591,523	495,000
NCHCD Educational Fund	24,000	30,000
Memberships	4,950	4,070
Donations - Members	50,044	19,710
Donations - Corporate	32,901	47,505
EHC Conference	-	93,787
Fundraising	17,977	32,982
H.H.T. Trust	8,661	10,286
Investment Income	18,269	9,611
Sundry Income	-	5,400
	748,325	879,301
Expenditure as per schedule	(659,339)	(648,037)
Surplus for the year	**88,986**	**231,264**

Schedule Of Expenditure
For The Year Ended 31st December 2010

	2010		2009	
	€	€	€	€
Administration Expenses:				
Wages, State Insurances and Pension Costs	220,042		225,164	
Employer's PRSI Contribution	20,382		18,667	
Office Expenses & Stationery	15,603		10,513	
Telephone & Fax	8,669		9,580	
Travelling Expenses	7,386		7,454	
Overseas Travel Expenses	4,861		11,145	
Archive Storage Fees	-		2,420	
Sundry Expenses	9,599		8,092	
		286,542		293,035
Financial Expenses:				
Bank Charges & Loan Interest	5,440		9,169	
Professional Fees	74,633		53,332	
Audit & Accountancy Fees	5,445		5,445	
		85,518		67,946
Activities:				
Help To Members	23,518		24,847	
Family Activities	6,000		6,000	
H.H.T. Trust	7,000		10,161	
Subscriptions	1,650		2,056	
Fund Raising Expenses	1,323		1,083	
A.G.M. & Meeting Expenses	31,380		35,350	
Postage, Publications & Photocopying	25,853		29,648	
Educational Grants	23,000		16,000	
Safety/Supply Activities	5,651		8,951	
Counselling & Support Meetings	15,160		8,347	
Twinning	3,319		1,008	
Website	762		3,092	
WFH GAP Program/Development Grants	14,483		20,677	
Sponsorship/Training	11,836		810	
Parent's Conference	18,334		14,363	
Member's Conference	19,568		20,821	
		208,837		203,214
Establishment Expenses:				
Service Charge & Insurance	9,343		18,805	
HQ Costs	4,124		270	
Computer Services	9,277		8,061	
Light, Heat & Services	11,343		12,351	
		34,087		**39,487**

	2010		2009	
	€	€	€	€
Other Costs :				
Depreciation- Fixtures.Fittings & Equipment	18,073		18,073	
Depreciation- Land & Buildings	26,282		26,282	
		44,355		44,355
Total Expenditure		659,339		648,037

EBS Mortgage Account

Opening Balance 01.01.10	266,725
Interest Charges	3,675
Monthly Repayments (Capital & Interest)	(99,258)
Closing Balance 31.12.10	171,142

Balance Sheet As At 31st December 2010

		2010		2009	
		€	€	€	€
Fixed Assets					
Buildings	Note 5	1,168,669		1,194,951	
Office Equipment & Fittings	Note 5	8,736		26,809	
			1,177,405		1,221,760
Current Assets					
Hibernian Spectrum Bond		-		150,000	
Davy Investment Portfolio		170,000		-	
Irish Nationwide Building Society - Deposit Account		107,184		105,206	
Ulster Bank - Deposit Account		-		170,481	
Educational Building Society- Deposit Account		180,000		-	
Allied Irish Bank - Current Account		143,450		44,109	
Allied Irish Bank - Planned Giving Current Account		9,508		31,604	
Allied Irish Bank - Deposit Account		203,540		250,000	
Cash on Hand		332		2,027	
Sundry Debtors & Prepayments	Note 6	-		620	
			814,014		754,047
Current Liabilities					
Sundry Creditors & Accruals	Note 7	(86,164)		(63,955)	
			(86,164)		(63,955)
Net Current Assets/(Liabilities)			727,850		690,092
Long Term Liabilities					
Long Term Property Loan	Note 8		(171,142)		(266,725)
Net Assets/(Liabilities)			1,734,113		1,645,127
Represented By:					
Accumulated Funds					
Balance 1st January 2010			1,645,127		1,413,863
Surplus for the year			88,986		231,264
Balance 31st December 2010	Note 9		1,734,113		1,645,127

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