

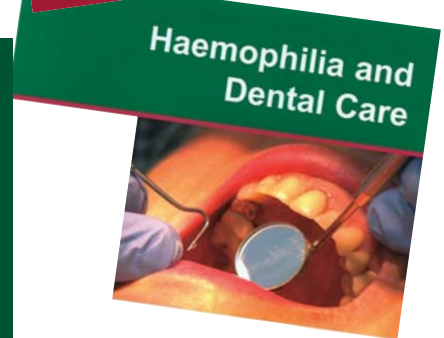
Irish Haemophilia Society

Annual Report 2009



Representing people and families with haemophilia and related bleeding disorders

New Publications in 2009



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A Message from the Chairman



Michael Davenport, Chairman

2009 was a superb year for our Society due to the number of our extremely interesting, and well attended meetings. We had a consolidation of newly scheduled events but also the end of a career that served us so well. We had new members join us but sadly we also lost some old friends. Some of our hopes didn't materialise but others worked out better than expected.

Our first event of the year, as usual, was our AGM which was held in Ballinasloe. We had the pleasure of being addressed by Dr. Mammen Chandy, from Vellore in India, who is doing amazing work in the area of haemophilia with totally inadequate replacement factor. He gave us the history of what is now a 1,700 bed hospital and explained how he manages haemophilia with very limited resources. He is a very eloquent and engaging speaker and it was a privilege for us to have him at our conference. Dr. Chandy also addressed our younger members as part of the

Kidlink programme which also included movie making. Our High School Musical troupe could give the kids in 'Glee' a run for their money.

Another interesting speaker was Dr. Evelien Mauser-Bunschoten from Utrecht who spoke about ageing and haemophilia. This is a relatively new area of consideration for those with haemophilia, as replacement therapy and improved surgery means life expectancy has improved dramatically over previous generations. So hopefully my golfing partners will have to put up with me for a lot longer than they would like!

A very successful new event in 2009 was the 'Parents' Conference'. This was a weekend event held in April and organised in conjunction with the clinical teams from St James's and Our Lady's Children's Hospital in Crumlin. Forty-four parents and thirty-six children gathered to discuss issues particular to raising a child with haemophilia. These issues included prophylaxis, sibling issues, self infusion, needle phobia, physiotherapy and so on. Our youngest ever speaker, Gary Butler, aged 10, from Cork, spoke about self infusion from a personal perspective. Mary O'Sullivan and Traci Dowling gave their perspectives on raising a child with haemophilia.

All parents need extended family support, but when there is haemophilia in the family the in-laws, aunts or uncles can be wary of getting involved due to fear. So with this in mind, we held our first 'Relatives' Day' in September to give extended family members an opportunity to learn from their peers and medical experts, and be in position to better support their son or daughter. The meeting was addressed by Dr. Clodagh Ryan, a Paediatric Haematologist, and Clinical Nurse Specialist Norma Collins, both from Cork, who explained genetic inheritance, how bleeds occur, the damage they can do to joints and how they are treated. Brian O'Mahony outlined the role our Society plays in supporting those with haemophilia and their families.

The attendance and feedback from both of these new initiatives convinced us that there is a need for more of these conferences so we have scheduled them again for 2010.

Although the new centre in Cork University Hospital (CUH) didn't proceed as planned during 2009, we are extremely optimistic that it will go ahead in 2010. However, progress was achieved in that Consultant Haematologist Dr. Susan O'Shea was appointed to lead

haemophilia services in CUH. Clerical assistance has also been added but an increase in laboratory services is also required in order to bring the centre up to the standards of a comprehensive care centre, as highlighted in the last external audit.

Another major project we are anxious to see commencing is the building of the new 12 bed Hepatology and Haemophilia Inpatient unit in St. James's Hospital. The Board of St. James's is committed to this project and we are very hopeful that building will commence around the summer of 2010. This will be a major improvement to inpatient services. I was going to say I am looking forward to using the new unit but that would require my being ill enough to be admitted! But you know what I mean.

Our fundraisers excelled themselves this year (Where do they get the energy?) Noel Wynne certainly had enough energy as he ran over 26 miles in the Dublin City Marathon. He did it in under four hours which was a great achievement, particularly as it was his first marathon. Most people never even climb one mountain but some people think if you climb one you might as well go up another three while you're at it! Nine year old Niall Jackson and his Dad, Vincent, climbed a total of

3,577 metres (are they mad?) to raise money for the I.H.S. and Barretstown, well done lads! Paul Griffiths decided not to pay a barber in April, but have people pay him for losing his hair instead! His son Brandon happily took the shaver to his Dad's head and their friends and supporters happily (we think!) handed over one thousand euros to the Society. Our loyal and intrepid ladies once again took to the streets on our behalf on Mini Marathon Day in June. Thanks ladies.

An amazing exhibition of vintage farm machinery was on display at the Castledermot Threshing and Vintage Working Day in September. Also on display were traditional crafts and demonstrations such as hand weaving and tool making. As the late David Sixsmith was a highly regarded member of the Castledermot Vintage Club, proceeds from this year's event were presented to us at a gala night. Over €24,000 was donated for which we are extremely grateful. I would like to most sincerely thank everyone who took the time and energy to raise money for the Society, as well as our Planned Givers. Not only are you funding the Society's programmes, you are raising public awareness of haemophilia and the Society as a representative organisation.



Our first ever Parents' Weekend - 'The Creche'



Honorary Secretary Kevin Birkett accepts a cheque for €24,000 from the Castledermot Threshing & Vintage Club



*The I.H.S. Board from top left: Kevin Birkett, Gerard O'Reilly, Brian Byrne, Patrick Downey, Michael Butler,
From bottom left: Traci Dowling, Michael Davenport & Mary Hanney.*

After 20 years of involvement in the Society as a volunteer and as an employee, Margaret Dunne retired as Administrator in April. I first met Margaret in the car park of the Addison Lodge where she was running a fundraising sale of work for the Society. She was a volunteer for a number of years before becoming an obvious choice when we needed part time, and later full time, employees. No one knows more members, their children, who is related to whom, and where they live, than Margaret. She was instrumental in reforming our AGM's into a weekend event for all the family. She has represented the Society at

many international events and has made many friends abroad who have been welcomed by her and Jim into their home. Margaret has left in place a dedicated, well trained and organised office team, to continue the excellent work. Thanks a million Margaret and happy retirement.

I would like to acknowledge the commitment made by our eight Board members. Although we have a schedule of monthly board meetings, as matters arise we frequently need to consult them between board meetings. We also have strategic planning reviews, training days and representation at external events,

both home and abroad. So altogether, quite a lot of their time is volunteered to the Society throughout the year. They never complain and on our members behalf I would like to thank them for their invaluable contribution to the successful running of our Society.

Other volunteers we could not function without are our Crèche ladies: Carmel, Deirdre & Claire. Alison Daly did her usual excellent job on the Kidlink & Young Adults programmes ably assisted during the year by Eileen, Paul, Amy, Barbara, Eoin, Mark, Lucia, Sandra, Aoife, and Catriona. Thanks guys, you are

so good we wouldn't dream of asking anyone else!

Last, but certainly not least, I would like to commend Brian O'Mahony and the office team for their superb work during the past year. Although it is a challenge to tolerate Brian's jokes, the team were certainly up to the challenges set by Brian to improve on old tasks and take on new ones. With our additional programmes, the workload has increased for the team but their enthusiasm and commitment means that (almost) everything gets done on time.

With the full support of our members, plus all the previously mentioned volunteers and employees, I have no doubt that 2010 will be another great year for our Society.

Michael Davenport
Chairman

Honorary Secretary's Report



Kevin Birkett, Honorary Secretary

At the 20th Annual General Meeting of the Irish Haemophilia Society, which was held in the Carlton Shearwater Hotel in Ballinasloe, Co. Galway on Saturday 7th March, 2009 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

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

Chairman

Michael Davenport

Vice-Chairman

Traci Dowling

Honorary Secretary

Kevin Birkett

Honorary Treasurer

Gerard O'Reilly

In the period since the last AGM, eleven full executive meetings were held. In November the executive and staff held a review of our strategic plan to monitor progress and ensure that its objectives remain relevant.

Meetings organised by the Society

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

The 20th Annual General Meeting and Conference of the Irish Haemophilia Society took place over the weekend of the 6th to 8th of March in the Carlton Shearwater Hotel in Ballinasloe, Co. Galway. The conference continued the work of the 19th Conference by highlighting developments in haemophilia care not just at home but also abroad. The keynote speaker on Saturday afternoon was Dr. Mammen Chandy who spoke of his work at the Haemophilia Centre in Vellore, India. As the weekend continued other speakers outlined developments in haemophilia care in Ireland.

In the meantime participants in the Kidlink programme were busy making a superb movie which premiered on Saturday night and which, together with the gala dinner and music from Liam O'Sullivan and Frank O'Connor made for a great evening's entertainment. Also

on Saturday night Margaret Dunne was presented with an Honorary Life membership to mark her years of sterling service to the Society.

In April the Society organised its first 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 art and Tai Chi classes for everyone, while the inspirational Corkman, Owen Hegarty, tried to help the adults balance their lives. Meanwhile the young adults enjoyed a full day of activities at the University of Limerick Activity Centre and the Kidlink members went swimming and played Unigolf.

The Society would like to thank Eileen Prenderville, Barbara Guilfoyle, Aoife Downey, Mark Dwyer, Paul Dunne, Amy Carroll, Lucia Prihodova, Catriona Moriarty, Eoin Moriarty, Sandra Phipps

and junior leader Ciaran Dowling without whom the young adult and 'Kidlink' programmes would have been impossible. We would especially like to thank Alison Daly for keeping all these willing volunteers in order and for ensuring that our young adults and 'Kidlink' participants have an entertaining, stimulating and safe time.

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, Deirdre Ryan, Marie Fay, Julie McAuley and Laura McAuley for ensuring that the 'smallies' have a great time too.

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.

On the 12th of February 2009, the I.H.S. office was the venue for a Polish evening where members of the Polish community were given details of the services that we offer. Later that month two meetings were held, one in Cork and the other in the office, to give members an update on vCJD.

On the weekend of the 19th to 21st of June the Society

organised a HIV/Hepatitis C Conference in the Park Plaza Hotel, Tyrellstown, which was attended by 13 people including two members of staff. A further HIV/Hepatitis C Conference was held in the Kingsley Hotel, Cork on the weekend of the 14th November. As a result of these conferences two HIV/Hepatitis C peer groups have been organised. The first meetings of these peer groups have taken place, one in the office and the other in Cork.

In early September the Society organised a Relatives' Day specifically aimed at the brothers, sisters, aunts, uncles and or grandparents of people with haemophilia. The meeting, which was held in the office, provided 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 8th February during which members were able to raise various issues of concern to them.

Finally a "Service of Light" took place in the offices of the Society on the 29th of November in memory of our members who have passed



Alison Daly with the Kidlink Group and Young Adults at the Parents' Weekend

away and the light and joy they brought to our lives. Over 30 members attended the service.

Conferences and other events

During the course of the year board and staff members of the I.H.S. represented the Society at a number of conferences and other events.

The third Consultative Council on Hepatitis C International Conference was held in Dublin Castle on the 18th & 19th of June. The title of the conference was 'The Third Decade and Beyond' and featured two programmes entitled 'Clinical Research Perspectives' and 'Living with Hepatitis C'. Once again the Society played a prominent role, taking an exhibition stand for the duration of the conference while three members – Brian O'Mahony,

Margaret Dunne and Declan Noone – chaired sessions.

In September a delegation from the Society attended the 22nd Annual Conference of the European Haemophilia Consortium, which was held in Vilnius, Lithuania. The programme included Hepatitis C Compensation and physiotherapy workshops; two symposia on Prophylaxis; and sessions on the Management of Carriers, Health Technology Assessments, Pre-Natal Diagnosis, Genetic Testing and Ageing. Undoubtedly though the most important aspect of the weekend was the opportunity it presented to exchange ideas and experiences with other delegations.

Web-site / Publications

Over the past two years the Society has revamped its newsletter and its website. This year work commenced

on updating and re-designing our information booklets to reflect the latest developments in haemophilia care and our new corporate image. So far we have published a 'Haemophilia & Dental Care' booklet and an 'I.H.S. Travel Card'. Further booklets will appear in the coming year.

I.H.S. Staff

Last summer Margaret Dunne left the Society. As a result of Margaret's departure duties within the office were reassigned to give staff members an opportunity to develop new skills while Debbie Greene was appointed to the position of Administrator.

In January the Society advertised for an Administrative Assistant. Following a rigorous selection process Fiona Brennan was appointed to the position.

The current Society Staff are:



Brian O'Mahony, CEO



Debbie Greene, Administrator



Anne Duffy, Counsellor



Nina Storey,
Administrative Assistant



Declan Noone,
Administrative Assistant



Nuala McAuley
Administrative Assistant



Fiona Brennan
Administrative Assistant

Society Representation

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

National Haemophilia Council

Haemophilia Product Selection Monitoring Advisory Board

Haemophilia HIV Trust

Disability Federation of Ireland

World Federation of Hemophilia

European Haemophilia Consortium

Consultative Council on Hepatitis C

Michael Davenport & Brian O'Mahony

Brian O'Mahony & Declan Noone

Brian O'Mahony & Nina Storey

Debbie Greene

Brian O'Mahony

Brian O'Mahony

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

IHS CORPORATE GIVING PROGRAMME

We would like to acknowledge the following companies who contributed unrestricted and restricted funding to the Irish Haemophilia Society as part of our Corporate Giving Programme in the course of 2009.

Platinum Sponsors:

Baxter

Wyeth (Pfizer)

Gold Sponsors:

Bayer Schering Pharma

Novo Nordisk

The Year in Review from our Chief Executive



Brian O'Mahony, CEO

Nationally and internationally the year was characterised by recession, depression and bad economic news on all fronts. Thankfully that did not extend to the Irish Haemophilia Society, once again we had a busy and productive year with tight monitoring of expenditure and the optimisation of income ensured that we had a good financial year for the organisation.

One of the highlights of the Annual Conference in March was the attendance and lecture by Professor Mammen Chandy from the Christian Medical College Centre in Vellore, India. Professor Chandy's lecture was a thoughtful and evocative portrayal of the reality of living with haemophilia in India. This contrasted starkly with the thankfully, excellent reality of living with haemophilia in Ireland at this point in time, which was set out by Dr. Barry White. Professor Chandy also spoke to the teenagers separately in relation to haemophilia care in India and I know that his presence at the Annual Meeting

and his lecture were very much appreciated. When a person with haemophilia or a parent is troubled by particular problems with a joint or bleeding tendency in themselves or in their child they can get pause for thought and reflection when they hear about the reality of living with haemophilia in a country such as India.

At the Members' Conference in October the concept of having separate lectures and activities for the different groups and then bringing all of the families together for some of the sessions worked very well. The evaluations from both conferences were extremely positive. In what has become traditional, we also had a debate between two members of the organisation on the topic of "Are

there limits to my life activities?" These debates allow members to reflect on various aspects of living with haemophilia and bleeding disorders in a challenging environment.

In our strategic plan and in our consultations with the haemophilia treatment centres we had identified a definite requirement for a conference for parents of young children with haemophilia. Together with the haemophilia treatment centres in Our Lady's Children's Hospital Crumlin (OLCHC), the NCHCD in St. James's and Cork University Hospital (CUH), we organised a conference for parents of children with haemophilia. The conference was attended by parents of children of all ages right up to the age of eighteen.

Several aspects of haemophilia care were discussed including prophylaxis and compliance, needle phobia, sports and transition issues. A very important aspect of the weekend was the interaction between the parents and the discussion on various aspects of raising a child with haemophilia. Positive messages were reinforced and it was clearly evident that some parents who were running into problems with particular areas received assistance in solving those problems by discussing them with other parents who had gone through similar situations in the past.

The Parents' Conference was also attended by a small number of parents from Northern Ireland who were made very welcome. The conference was a great success. We will



Kidlink Children at the Members' Weekend in October

certainly be repeating this conference in 2010. We also used the occasion of the conference to carry out a survey among the parents in relation to prophylaxis.

Additional meetings organised during the year also included a Relatives' Day, a meeting for the Polish community and Regional meetings. The Relatives' Day was held at the I.H.S headquarters in September. The purpose of this day was to give basic information about haemophilia and related bleeding disorders, and about the services offered by the Society to grandparents, aunts, uncles, siblings and those family members who would not have had direct involvement in having haemophilia or in raising a child with haemophilia or related bleeding disorder. The

relatives who attended the meeting, I believe, left with more up to date and correct knowledge in relation to haemophilia. We were surprised that there were quite a few misconceptions in relation to the severity of symptoms which could be expected in a child with mild haemophilia and we were happy to correct those misconceptions.

We also organised an evening meeting for persons with haemophilia from Poland who are now residing in Ireland. This meeting, which was attended by Dr. Barry White was valuable in assisting them in integrating into the community and encouraging them to attend our other programmes and activities.

A number of specific meetings

were also held to support our members living with HIV and/or Hepatitis C. In June, a number of members attended the International Conference on Hepatitis C, organised by the Consultative Council on Hepatitis. In the week immediately after that conference, we organised a separate weekend conference where members received an update on treatment and monitoring of Hepatitis C and HIV. This weekend conference also had a psychosocial element to it and following discussions among members at the weekend, it was decided that there was a requirement for an additional peer support mechanism. Consequently, two peer support groups have now been established, one in Dublin and one in Cork. The group in Dublin, which is being facilitated by the psychologist

from the NCHCD, meets regularly at the I.H.S office. Following this conference we had a separate psychosocial workshop in Cork late in 2009, which again was of benefit to those who attended and had led to the setting up of a peer support group for members living with HIV and Hepatitis C in Cork. This group will meet regularly and will be facilitated by Anne Duffy, the nurse counsellor from the Irish Haemophilia Society together with an external psychologist. We also organised meetings in Dublin and Cork during the year in relation to taxation issues for members with HIV and Hepatitis C. An additional focus in this area in 2009, was assisting members who were attending St. Vincent's Hospital in Dublin for assessment of their liver disease.



Creche children having fun at the October Weekend in 2009

The I.H.S. counsellor, with the agreement and encouragement of the team at St. Vincent's Hospital, has been attending appointments at the hospital with a number of the members and has assisted the members in their understanding of the implications of their clinical situation. In addition, we have been providing logistical support in relation to arrangements for travel, accommodation and coordination of appointments and in assisting members deal with the inevitable fears and anxieties. A major role of the Society is in advocating for optimum services, care and treatment for persons with haemophilia and related

bleeding disorders. To this end, we have been working very closely as part of the National Haemophilia Council (NHC) and also with the Haemophilia Treatment Centre teams. The degree of constructive engagement and cooperation between the Society and the Haemophilia Treatment Centres has increased markedly over the last number of years and this was very evident in 2009. We worked closely with the treatment centres in relation to topics and speakers for our conferences, in relation to encouraging persons with haemophilia and bleeding disorders who are not members of the Society to attend the conferences, in publications and in provision of services. We worked closely with the NHC throughout the course of the year to make progress in relation to the deficiencies in the haemophilia service identified during the external audit of the centres in September 2008.

During the course of 2009, a Consultant Haematologist, Dr. Beatrice Nolan was appointed to lead the haemophilia service in OLCHC. The in-patient treatment unit in St. James's Hospital remains on the capital plan for the hospital. We were greatly encouraged during our meeting with the Chief Executive of St. James's Hospital, to see the level of commitment the hospital has to this project. We also attended several meetings at CUH in relation to the planned provision of a new

haemophilia treatment centre. Work was progressed on the plans for this centre and on the funding and the centre is due to open in 2010. We were also delighted to see that Dr. Susan O'Shea was appointed as lead consultant for the haemophilia service in CUH. In addition, a part time data manager and secretary's post were also granted to the



Members Open Forum Meeting at AGM 2009

haemophilia service in the hospital. I must pay tribute to the work of Professor John Bonnar, Chair of the NHC, who was very effective during the course of the year in working to ensure that the deficiencies identified in the haemophilia service at the various centres were rectified and that the optimum service was provided for people with haemophilia. With the NHC, the Society also attended meetings during the course of the year with the Chief Executives of the three treatment centres, and with the



National Haemophilia Council meeting in the I.H.S. Headquarters

haemophilia care teams in all three centres. The Society separately hold meetings with the teams at the NCHCD and Our Lady's Children's Hospital Crumlin on a regular throughout the year. These meetings give us the opportunity to discuss issues of mutual concern and to raise any issues or queries in relation to the haemophilia service. During the course of the year, progress was made on a number of other issues in relation to treatment of Hepatitis C and HIV. The Fibroscan machine for which the Society

lobbied for is now available and in use at the Hepatology Centre in St. James's Hospital and is being availed of by a number of people with haemophilia. We had a concern in relation to the regular monitoring of persons with haemophilia who were infected with HIV and/or Hepatitis C. We wanted to ensure that there was a degree of agreement in relation to the frequency at which tests and scans should be carried out. Consequently we worked with the NCHCD, with the infectious diseases consultant and with the hepatologist in St. James's and by the end of 2009 agreed guidelines were produced in relation to the monitoring of persons with haemophilia with Hepatitis C and HIV. These, we believe, will be of great assistance to our members in ensuring that their health is monitored at the appropriate intervals. We



*Press Conference on vCJD
From left: Prof John Bonnar,
Dr. Barry White, Brian O'Mahony
& Dr. Willie Murphy*

also worked closely with the team at the NCHCD and with Dr. Barry White in relation to ensuring that the use of Factor Replacement Therapy was optimised in relation to the clinical requirements. The Society worked with the centre to put forward a number of proposals to ensure that Factor Replacement Therapy was always appropriately used, that wastage was kept at an absolute minimum and that procedures would be looked at to ensure that no product was allowed to expire.

We had a very busy year in relation to publications and communication. Those members who use our website on a frequent basis will have noticed that the website was given a major upgrade and new look in 2009. We redesigned the entire website, the content and the architecture. We believe that the new website is now much more user friendly, responsive to



*From left: Dr. Beatrice Nolan, Olwen Halvey-Social Worker, Nurse Ann O'Sullivan,
Carol Carr-Social Worker & Nurse Mary Kavanagh at the Parents' Weekend*

members needs and more easily navigated to find the information you require. In addition, members can now book for our conferences and events online. We also revamped the visual identification of all of our publications and we now have a standard and much improved layout and colour scheme to our publications. During the course of the year in addition to the regular Annual Report and magazines we produced a Kidlink supplement for our younger members. We also produced a travel card, a wallet sized booklet giving basic

information on what you need to do prior to travelling. It also gives the key phrases in relation to haemophilia in five languages. In conjunction with the Dublin Dental Hospital and Dr. Alison Dougall we produced a specific leaflet on dental care and haemophilia which is designed for use by community dentists and gives basic information on what to

do and what not to do in relation to treating persons with a bleeding disorder. A paediatric version of this leaflet is also being produced. The I.H.S supplied specific publication stands at two of the treatment centres at the NCHCD and OLCCHC, where society publications can be stocked, displayed and made available to those visiting the treatment centres.

During the course of the year the number and quality of applications for our educational grants was very heartening. A total of 11 grants

were paid and we are clearly in a situation now where we are developing a pool of young, healthy and very well educated persons with haemophilia and carriers. This bodes well for the future of people with haemophilia in Ireland and hopefully also with the future of the organisation. Our counselling and support services for members continued. Practical help included home visits to a number of members. Regional visits were also made by the society on eleven occasions with visits to Cork (on two occasions) Limerick, Galway, Waterford, Sligo, Letterkenny, Killarney, Cavan, Carlow and Thurles. These meetings are invaluable in enabling the I.H.S to keep members up to date with developments, programmes and activities and are an invaluable source of feedback to the I.H.S on the operation of services at a local level and in identification of any concerns or problems encountered by members in accessing services on a national basis. Phone calls were also made to members to ascertain their level of engagement with the society services and to check to see if there are any services or support we could be providing which would be of assistance to them. Some 67% of the members of the society were individually contacted by staff by phone during the course of the year. Contact had the additional benefit of increasing the uptake of counselling services from the Society and the counsellor also visits

members who are ill in hospital, assisting in liaising with hospital staff if required and provides members with any assistance required from the I.H.S. During the course of 2009, twelve members were visited in hospital by the counsellor, many on several occasions.

We continue to be active on the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB). The Society holds two positions on the HPSMAB including the position of vice chairman. Work was ongoing throughout the year in relation to preparation for future tenders and in keeping up to date with current developments. We also made available to the HPSMAB an international expert to speak to them in relation to future developments with replacement therapy for haemophilia. The Society continues to play an active role on the Consultative Council on Hepatitis C, and on the working groups for that Council including the working groups for the database and international conference.

The staff responsibilities were realigned and expanded in 2009 following the retirement of Margaret Dunne as Administrator. A very pleasant evening reception was held at the Society offices for Margaret on the occasion of her retirement and we wish her and Jim all the very best in the future. The current staff continue to develop their skills and work for the

Society, and it is especially notable that our publications and website are now laid out and managed internally by the staff. We continue to support the World Federation of Hemophilia Global Alliance for Progress which to date, since the inception of the programme in 2003, has identified and diagnosed 10,930 persons with haemophilia in 15 countries.

In relation to our strategic plan we are currently completing the strategic plan for 2006 to 2009. The original strategic plan for that period had four goals, twenty three objectives and ninety seven strategies. By the end of 2009, eighty three strategies have been completed, seven remain to be carried out and seven had been dropped. The implementation of the strategic plan was reviewed at a joint meeting of the staff and board

in November 2009 and we will be developing a new strategic plan in 2010.

During the course of 2009 we also had a constructive engagement with the Health Service Executive and we signed a service level agreement with the HSE in relation to the funding that the society receives from the HSE on an annual basis.

The financial report for the year was very satisfactory. Expenditure on conferences and meetings for members and for publications and the website increased marginally. Income was lower than in 2008 due primarily to a very significant bequest in 2008. Expenditure was also lower, and a successful effort was made to lower costs across all areas where possible. We maintained the mortgage payments on the headquarters

at the current high level which, if maintained, will lead to the mortgage being fully paid by late 2012. Income this year was boosted by the large surplus we generated from organising the EHC Conference in Dublin in 2008 and by an increase in corporate donations.

In summary, it was a very satisfactory year in a challenging external environment. I would like to thank all the volunteers, staff, members and donors who contributed significantly to our progress this year.

Brian O'Mahony
Chief Executive



Brian O'Mahony presenting Margaret Dunne with a commemorative photo album at her retirement reception

Photo Gallery.....



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 2009, 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.

Auditors 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 2009 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 2009 are available on request.










Auditors

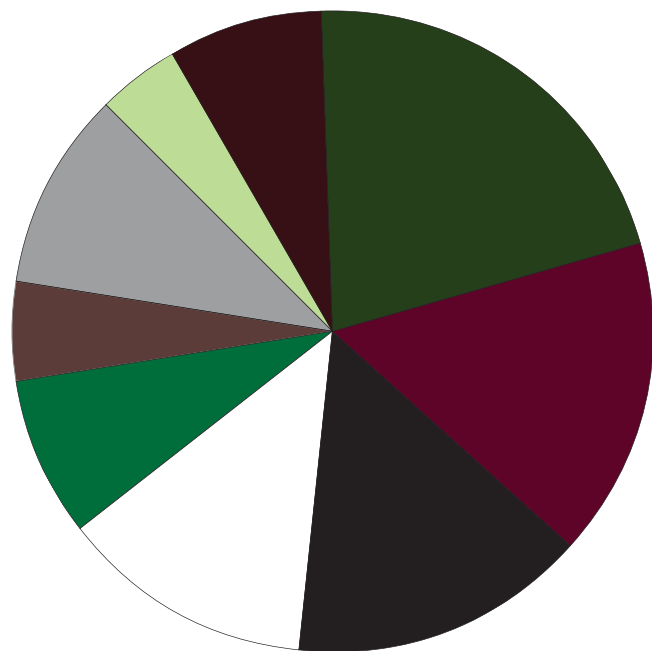
Howlin, O'Rourke & Co.,
Certified Public Accountants &
Registered Auditors,
4, The Seapoint Building,
Clontarf,
Dublin 3.

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 %	
Members Conferences & Meetings	16 %	
Counselling & Support	15 %	
Publications & Website	13 %	
Representation on Statutory & External Bodies	10 %	
Establishment / Headquarters	8 %	
Financial Support to Members	8 %	
Administration & Finance	5 %	
International Development Assistance	4 %	



Income & Expenditure Account For The Year Ended 31st December 2009

	2009 €	2008 €
Income		
Health Service Executive - Northern Area	130,950	135,000
Health Service Executive	495,000	535,000
NCHCD Educational Fund	30,000	30,000
Memberships	4,070	3,120
Donations - Members	19,710	46,855
Donations - Corporate	47,505	25,700
Bequests	-	182,476
EHC Conference	93,787	28,016
Fundraising	32,982	13,873
H.H.T.Trust	10,286	12,912
Investment Income	9,611	10,753
Sundry Income	5,400	-
	879,301	1,023,705
 Expenditure as per schedule	 (648,037)	 (766,776)
 Surplus for the year	 231,264 =====	 256,929 =====

Schedule Of Expenditure

For The Year Ended 31st December 2009

	2009		2008
	€	€	€
Administration Expenses:			
Wages, State Insurances and Pension Costs	225,164		205,824
Employer's PRSI Contribution	18,667		18,229
Office Expenses & Stationery	10,513		13,222
Telephone & Fax	9,580		9,853
Travelling Expenses	7,454		7,927
Overseas Travel Expenses	11,145		11,061
Archive Storage Fees	2,420		3,990
Sundry Expenses	8,092		5,572
	<hr/>	293,035	<hr/>
			275,678
Financial Expenses:			
Bank Charges & Loan Interest	9,169		30,434
Professional Fees	53,332		140,259
Audit & Accountancy Fees	5,445		5,468
	<hr/>	67,946	<hr/>
			176,161
Activities:			
Help To Members	24,847		18,025
Family Activities	6,000		6,000
H.H.T.Trust	10,161		8,500
Subscriptions	2,056		1,589
Fund Raising Expenses	1,083		1,311
A.G.M. & Meeting Expenses	35,350		52,151
EHC Conference	-		13,690
Postage, Publications & Photocopying	29,648		30,669
Educational Grants	16,000		16,500
Safety/Supply Activities	8,951		3,359
Counselling & Support Meetings	8,347		11,310
Twinning	1,008		3,090
Website	3,092		11,063
WFH GAP Program/Development	20,677		20,398
Sponsorship/Training	810		3,313
Memorial Event	-		8,913
Parent's Conference	14,363		-
Member's Conference	20,821		21,317
	<hr/>	203,214	<hr/>
			231,198
Establishment Expenses:			
Service Charge & Insurance	18,805		18,776
HQ Costs	270		1,353
Computer Services	8,061		8,949
Light, Heat & Services	12,351		10,306
	<hr/>	39,487	<hr/>
			39,384

	2009		2008	
	€	€	€	€
Other Costs:				
Depreciation- Fixtures.Fittings & Equipment	18,073		18,073	
Depreciation- Land & Buildings	26,282		26,282	
		44,355		44,355
Total Expenditure		648,037		766,776
		=====		=====
EBS Mortgage Account				
Opening Balance 01.01.2009	359,776			
Interest Charges	7,423			
Monthly Repayments (Capital & Interest)	(100,474)			
Closing Balance 31.12.2009	266,725			
	=====			

Balance Sheet As At 31st December 2009

	2009		2008	
	€	€	€	€
Fixed Assets				
Buildings Note 5	1,194,951		1,221,233	
Office Equipment & Fittings Note 5	<u>26,809</u>		<u>44,882</u>	
		1,221,760		1,266,115
Current Assets				
Hibernian Spectrum Bond	150,000		150,000	
Irish Nationwide Building Society	105,206		100,000	
First Active Deposit Account	170,481		166,137	
Allied Irish Bank - Current Account	44,109		158,060	
Allied Irish Bank - Planned Giving Current Account	31,604		23,961	
Allied Irish Bank - Deposit Account	250,000		3,989	
Cash on Hand	2,027		1,399	
Sundry Debtors & Prepayments Note 6	620		-	
		754,047		603,546
Current Liabilities				
Sundry Creditors & Accruals Note 7	<u>(63,955)</u>		<u>(96,022)</u>	
		(63,955)		(96,022)
Net Current Assets/(Liabilities)		<u>690,092</u>		<u>507,524</u>
Long Term Liabilities				
Long Term Property Loan Note 8		<u>(266,725)</u>		<u>(359,776)</u>
Net Assets/(Liabilities)		<u>1,645,127</u>		<u>1,413,863</u>
		=====		=====
Represented By:				
Accumulated Funds				
Balance 1st January 2009		1,413,863		1,156,934
Surplus for the year		<u>231,264</u>		<u>256,929</u>
Balance 31st December 2009 Note 9		<u>1,645,127</u>		<u>1,413,863</u>
		=====		=====



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