Irish Haemophilia Society

Annual Report 2008

1968 - 2008

Celebrating 40 Years of Service to People with Haemophilia

Irish Haemophilia Society

Cumann Haemifile na hEireann

We represent People and families with
Haemophilia,
von Willebrands Disease,
Rare Bleeding Disorders

Programmes
Education
Publications
Counselling
Family Support
Advocacy
Conferences

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Michael Davenport, Chairman

Kidlink Group performing 'Clown School' at AGM 2008

2008 was a milestone year for the Society in that it was our 40th year. From very humble beginnings in 1968 when Jack Downey, Bill O'Sullivan, Eithne Scanlon and Mary Buckley got together to try and improve the lives of people with haemophilia; with no funds, with little or no treatment, and no communication between hospitals. Compared to what we have now, although it has taken some time, we have come from the cave to the castle and our present standing as a nationally and internationally recognised organisation is a testament to the dedication and commitment of many volunteers and staff over the intervening years. [In this Annual Report you will find a chronology of our history.]

It was appropriate therefore, to invite the Minister for Health and Children, Mary Harney, to open our 40th AGM & conference in the Park Plaza Hotel, in March. It was understandable that some of our members were unhappy with this decision, given our recent history; nevertheless, by a show of hands and the warm reception you gave her, you fully endorsed her attendance. We hope her commitment to the In - Patient Unit will be fulfilled and we have reminded her, since then, of that commitment.

It was also appropriate that the theme for the AGM was 'The Past, Present and Future'. Brian O'Mahony presented a slide show and recollections from the past. I think he remembers most of our history since he joined the board when he was nine years old or thereabouts! The CEO of The World Federation of Hemophilia, Ms. Claudia Black presented the present picture of haemophilia services worldwide, and the Director of the National Centre for Hereditary Coagulation Disorders (NCHCD) Dr. Barry White presented his views on future developments on haemophilia services in Ireland. Perhaps it was because it was a milestone year that I felt our 2008 AGM had a great buzz about it. The kids seemed to have a great time learning to be clowns and put on a great show at the gala dinner, which was attended by over 200 members and guests.

Another highlight from 2008 was the World Federation of Hemophilia Congress in Istanbul. It is an amazing ancient and historic city of palaces, mosques, markets and towers set on both sides of the Bosphorus. 2008 was the 45th anniversary of the founding of the WFH by Frank Schnabel, and as current president Mr. Mark Skinner said in his address; 'Hemophilia and bleeding disorders have now been diagnosed in 219,000 people in 101 countries' and 'Daily the work of the WFH is making a difference to the lives of individuals with bleeding disorders around the world'. A large contingent from Ireland attended the Congress, not only IHS members and their families, but health care workers from our treatment centres. It bodies well for our future that clinical and nursing staff are keeping themselves updated on the various aspects of bleeding disorders covered by the Congress symposia. Gerard O'Reilly attended the Pre-Congress National Member Organisation training, and

Anne Duffy contributed to the psychosocial programme including charing a session. We had a number of posters on display about haemophilia services in Ireland including; *'Changing Perceptions of Haemophilia using a DVD'*, *'Comparative Data on Persons with Haemophilia from Irish Hepatitis C Database'*, *'Statutory Entitlements's to Prioritised Health Care for persons with Haemophilia affected by Hepatitis C or HIV'* and *'Initial Participation Rates in Government Funded Insurance Scheme for Persons with HIV and Hepatitis C'*. Brian O'Mahony gave a presentation on dealing with the media entitled *'Getting Heard without Screaming'* and Margaret Dunne was our representative at the General Assembly and voted for holding the 2012 Congress in Paris. Hopefully many of you will attend a World Congress sometime in the future as it is a great experience and eye opener to the wider world of haemophilia. The next Congress is in Argentina in 2010 so watch the magazine and website for information about that.

Another important event during 2008 was the unveiling of our Memorial Sculpture in November. We had wanted a memorial for some years but we needed a permanent home, which we now have. This is a unique piece commissioned to reflect 40 years of the Society and to remember those who have died in that time. As well as the sculpture we have opened a Remembrance Book which contains the names of deceased members. Family members are welcome to include a personal message or memory, perhaps a verse or a photograph, in this book. Please contact Debbie or Anne in the office if you would like to do so.

Our annual Regional Visits programme took place again in February and September. We find these visits very useful for meeting members as we appreciate that many people living throughout the country cannot call into the office or attend centralised meetings, so it's a great opportunity for us and them to meet in small groups or individually. These meetings are informal so when we are in your area we would be delighted to meet you.

Creche boys & girls with Claire, Deirdre & Carmel - Members Weekend 2008

The Consultative Council on Hepatitis C Annual Information Day in February held in Croke Park was very well attended by members of all four groups whose members are affected by Hepatitis C and/or HIV. Talks included a report on the database and workshops on problems that can arise within families when someone is struggling to cope with Hepatitis related issues. A recent welcome development for those affected by Hepatitis C and/or HIV was the establishment of a Travel Insurance Scheme. Brian O'Mahony continues to represent us on the Haemophilia Product Selection Monitoring and Advisory Board. However Declan Noone has successfully replaced me on this Board and was straight into the deep end as there was a tender contract for Factor VIII to be considered during 2008.

Volunteers continued to play a huge part in helping the Society last year. As well as the board and many others, we could not have managed without the services of Carmel Downey, Claire Neil and Deirdre Ryan who continue to look after the creche at our conferences.

Mini Marathon Ladies - June 2008

Trish Cox and Declan O'Mahony volunteered and helped organised our Mini Marathon runners on very short notice for which we are very grateful. Declan O'Mahony also volunteered at the European Haemophilia Consortium (EHC) conference in Dublin Castle with Des, Jack and five young ladies from Transition Year at Mount Sackville School in Dublin. Other volunteers during the year were Paul Dunne and Amy Carroll, Daryl Butler and Lucia Prihodova who were involved with running the Young Adults and Kidlink programmes.

A special thanks also goes to Alison Daly and Eileen Prenderville who co-ordinate the Kidlink & Young Adult Programmes, and to Liam O'Sullivan and Frank O'Connor who entertain us with great music at the AGM's.

As you know, each year we make Educational Grants and Scholarships available to help people with haemophilia, and their siblings, with the cost of third level education. The recipient of the 2008 Maureen Downey Memorial Grant was Daryl Butler. Catriona Moriarty was selected for the Margaret King Educational Scholarship. We wish them well in their respective college courses and look forward to hearing how they are getting on.

Our fundraisers also played their part last year. Our Mini Marathon runners and walkers turned out in force again and raised over €7,500. Stephen McEvoy jumped out of a plane at ten thousand feet to raise funds for us. Fortunately he remembered his parachute. Other fundraisers include Bina Harris, the Hospitals Saturday Fund, our Planned Giving donors and anonymous individual donations during the year. Apologies to anyone I haven't mentioned but we appreciate each and every contribution and thank you.

Staff changes during the year included Patricia O'Connor moving to pastures new. Nuala McAuley and Declan Noone have now joined the stafff team. In addition to Declan and Nuala I would like to thank Margaret, Nina, Anne and Debbie for the tremendous work they put in last year for the benefit of the members of our Society.

Our Chief Executive, Brian O'Mahony, played a blinder again last year. His leadership, organisational skills, enthusiasm and energy means we don't have to employ three other people!

I would also like to acknowledge our board. Although we have about 11 scheduled committee meetings for the year we usually end up having quite a few more than this including conference calls, reports to be considered or reports to be submitted, so quite a bit of their time is taken up. However, each committee member is closely involved with haemophilia either having a factor deficiency or as a parent, so all are familiar with the issues confronting the Society members. I would like to thank them most sincerely for their work during 2008.

Michael Davenport
Chairman

Honorary Secretary's Report

Kevin Birkett, Honorary Secretary

At the 19th Annual General Meeting of the Irish Haemophilia Society, which was held in the Park Plaza Hotel, Tyrrelstown, Dublin on Saturday 1st March, 2008 the Incoming Governing Body of the Society were elected as follows;

Michael Davenport
Traci Dowling
Kevin Birkett
Gerard O'Reilly
Barbara Guilfoyle
Declan Noone
Michael Butler
Pat Downey

In the period since the last AGM, ten full executive meetings were held. At the first executive meeting following the AGM the following officers were elected:

Chairman
Michael Davenport
Vice-Chairman
Traci Dowling
Hononary Secretary
Kevin Birkett
Honorary Treasurer
Gerard O'Reilly

Following the departure of Declan Noone from the executive, in July Brian Byrne was co-opted as his replacement.

In September the executive and staff held a day-long 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 19th Annual General Meeting and Conference of the Irish Haemophilia Society took place over the weekend of the 29th February to 2nd March in the Park Plaza Hotel, Tyrrelstown, Dublin. The conference, which was opened by the Minister for Health and Children Mary Harney, marked the 40th Anniversary of the Society. To highlight this significant landmark the theme chosen for the weekend was 'Past, Present and Future.' Guest speakers made a number of presentations focusing on the past challenges the Society has faced, the current situation for people with bleeding disorders worldwide and the future development of services within Ireland.

There was an exciting programme for our younger members the highlight of which was Saturday afternoon's Clown School, while on Sunday there was career advice, 'arts & crafts' and basic facts about haemophilia. Older members were not neglected, with a gala dinner on Saturday night followed by entertainment from the inimitable 'B-Sharps.'

On the 17th-19th October the Society held its third 'Members Weekend' at the County Arms Hotel, Birr, Co. Offaly. This event, which is now a well-established part of the Society's annual activities, is much less formal than the AGM with the emphasis on fun. This year's programme included advice on healthy eating, a presentation on the work of Barretstown, a belly dancing class for the women and, for the men, a pilates class. One of the highlights of the week-end was Sunday morning's debate. Colm O'Sullivan and Declan Noone bravely raised their heads above the parapet and debated the question, 'Are there limits to my life activities?' For the record the result was a narrow victory for Colm who maintained that you should not place limits on your activities.

There was a full programme for our younger members with the young adults and kids visiting the Birr and Littlehaven Adventure Centres respectively, while the tots were royally entertained in the crèche.

The Society would like to extend its thanks to Alison Daly, Eileen Prenderville, Amy Carroll, Barbara Guilfoyle, Lucia Prihodova, Daryl Butler and Paul Dunne without whom the 'Young Adult' and 'Kidlink' programmes would not have been possible. We would also like to thank the girls in the crèche, Carmel Downey, Claire Neil, and Deirdre Ryan, for providing a stimulating programme for the tots.

The Society arranged a number of smaller events throughout the year. These included, Benefits meetings, Insurance meetings, Tax & Investment meetings, a 'Hepatitis C and HIV Update' meeting and a Peer Support/Post Tribunal Workshop. Many of these meetings utilised the facilities offered by our headquarters, which is available to any group of members wishing to organise a meeting of their own.

It had long been the ambition of the Society to purchase a permanent home. The purchase of an office suite in Cathedral Court has enabled the Society to realise another ambition; the commissioning of a memorial sculpture to commemorate the many people with haemophilia who have died over the course of the past 40 years. The sculpture, which represents loss, achievement and hope, was unveiled during a moving Memorial Service at the office on the 9th November, and was attended by 80 members.

Regional visits continue to be an important part of the Society's work. A series of

Young Adults at Adventure Centre - Members Weekend 2008

meetings were arranged throughout the country for the weeks beginning the 29th September and 2nd February during which members were able to raise various issues of concern to them. These visits also allowed representatives of the Society to meet with clinical teams at treatment centres.

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.

On the 16th February 2008, the Annual Hepatitis C Information Day organised by the Consultative Council on Hepatitis C was held in Croke Park. Eight members attended the event, which was a great success. Among the topics discussed were the National Hepatitis C Database, the affect of Hepatitis C on family life and the use of the new Fibroscan machine.

The World Federation of Hemophilia biennial Congress took place in Istanbul, Turkey from June 1st to 5th. Eight delegates attended the Congress from the Society. In addition, a large number of members and spouses attended as well as many health care workers from Ireland.

In September the Society hosted the annual conference of the European Haemophilia Consortium, which was held in Dublin Castle on the weekend of the 12th-14th. This annual event is an opportunity to keep in touch with developments within the European Union and beyond. Many members of the Society attended, taking the opportunity to familiarise themselves with developments on the rest of the continent.

The Society would like to thank Paulene McKeever and her team for their professional assistance before and during the weekend; Shay Farrelly for acting as official photographer during the weekend; and the nurses from St. James's who gave up their time to man the treatment room. We would also like to extend a very special thank you to the 7 teenage volunteers who assisted delegates during the weekend.

Web-site / Publications

In the summer of 2007 Debbie Greene revamped the Society's newsletter. Debbie has continued to tweak the magazine since then. If you have any suggestions of how further improvements can be made I know that Debbie would be delighted to hear from you.

This year it is the turn of the website for a face lift. Debbie and new staff member Nuala McAuley have been working with a professional web design company to improve the lay-out and ease of access on the site. The new site was launced at our AGM in March 2009. You can check it out by logging on to: www.haemophilia.ie.

I.H.S. Staff

Last summer Patricia O'Connor left the Society to take up a role at the Blackrock Clinic. As a result of Patricia's departure, and of planned expansion in our programmes, in June we advertised two positions.

Following a lengthy interview process those positions were subsequently filled; the first by Declan Noone and the second by Nuala McAuley, who joined us from St. Patrick's Athletic where she worked in administration.

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

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 and Monitoring Advisory Board	**Brian O'Mahony and Declan Noone**
Haemophilia HIV Trust	**Brian O'Mahony & Nina Storey**
Disability Federation of Ireland	**Nuala McAuley**
World Federation of Hemophilia	**Brian O'Mahony**
European Haemophilia Consortium	**Brian O'Mahony**
Consultative Council on Hepatitis C	**Anne Duffy**

I would like to express our 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.

Kevin Birkett
Honorary Secretary

A year in review from our Chief Executive

Brian O'Mahony, CEO

The year 2008 was an exceptionally busy and productive year for the Society. The 40th Anniversary Annual General Meeting and Conference in March was very well attended and the conference was officially opened by the Minister for Health & Children, Mary Harney. The October Members Conference was again a sell out event, and was greatly enjoyed by all of the members who attended. The other major conference event during the year was our hosting of the Annual European Haemophilia Consortium Conference in Dublin Castle in September. The conference was attended by some 270 delegates from 40 European countries representing Haemophilia Organisations, Clinicians, Scientists and Industry. It was an ideal opportunity to showcase haemophilia care in Ireland, and to bring together all the leading European experts in an environment conducive to discussion. The conference was also of major financial benefit to the Society, with the major financial income to the organisation from the conference being finalised in early 2009.

Member meetings

A number of specific meetings were held with our members living with HIV and Hepatitis C infection. These included update meetings on treatment, taxation, financial advice and insurance issues.

The specific Insurance Scheme for persons with haemophilia who had been exposed to HIV and Hepatitis C through the use of blood and blood products provided in the state commenced in September 2007. We were anxious to ensure that we optimised participation by eligible members within the first year of the Scheme as the benefits to the members were maximised if they took part in the first year. By the first anniversary of the introduction of the scheme in September 2008 some 60 persons with haemophilia had availed of life insurance under the Scheme, or approximately 40% of those eligible to take out life insurance. This is in contrast to about 6% of the eligible persons from the other organisations whose members were eligible for inclusion in the Scheme. We put a lot of time and effort in during the course of the year to ensure that members were fully cognisant of the benefits of the Scheme, and either participated in the Scheme or at least gave it serious consideration. We are gratified that so many members have now signed up for life insurance under this Scheme and thereby made provision for their families and dependants in the event of their untimely death.

Late in 2008 the Travel Insurance Scheme for persons with haemophilia with HIV and Hepatitis C was also launched. Eligible members are now able to obtain travel insurance at a very competitive rate. As a result of the introduction of the specific Insurance Schemes, I believe there was an opportunity to educate insurance companies in relation to haemophilia generally. I have held further discussions with one particular insurance company with a view to assisting them in providing policies to persons with haemophilia without HIV or Hepatitis C, at competitive rates with no unnecessary loadings. I am hopeful that this work will come to fruition over the course of 2009.

Many members and their families who have gone through the legal process in relation to Hepatitis C/and or HIV Compensation have also found the process to be traumatic. This year we also organised a specific workshop for members who had completed the legal process, and we believe this was very beneficial to the members who attended as they were able to recount their experiences, in a supportive and peer group environment, and hopefully the weekend assisted them in relation to moving on with their lives.

The Regional Visits to members down the country were also an important feature of the year. In February we made Regional Visits to Cork, Limerick, Galway, Sligo and Letterkenny. In each of these venues we met groups of members who had specific issues to raise in relation to access to haemophilia care from the localities where they lived. In October we held further Regional Visits in Waterford, Cork, Limerick, Galway, Sligo and Letterkenny. These Regional Visits are very important for a number of reasons. Firstly they give us an opportunity to update the members around the country on the services provided and activities organised by the Society. They also give us an opportunity to update them on any developments in relation to medical services for people with haemophilia and related bleeding disorders. They give members in each regional area an opportunity to raise their specific concerns on an individual basis and also to raise any treatment concerns which apply to people living in a particular area. They give us very good feedback in relation to their experiences in accessing medical services and services provided by the Society. Last but not least they give members an opportunity to meet each other in small groups in a supportive environment. They encourage peer support and contact inbetween meetings. They also give us an opportunity to communicate with and access the needs of members who would generally not attend AGM's or conferences. The Regional Visits would typically include a number of home visits to members who have difficulty in mobility, illness or other factors in attending Society meetings.


Kyle Wynne, Nathan O'Hagan Doyle, & Peter Walsh

Communication
You will have noticed that the newsletter had undergone a major facelift during the course of the year. Our newsletter editor Debbie Greene had been experimenting with various formats and colour options, and by the end of the year we reached a point where we had a consensus on a consistent colour scheme for the magazines which will be carried through to our publications and other communications.

During the later part of 2008 we also worked on a major re-development of the website. The homepage will now feature sections on: Bleeding Disorders, HIV/Hepatitis C, Treatment Centres, Information for Adults, Parents, Young Adults, and Children. The architecture of the site is being greatly improved to allow easier navigation and hopefully faster accessing of the particular information you require. The new website which has the same address www.haemophilia.ie was launched at the Annual General Meeting and Conference in March 2009.

Representation on External Bodies
The Society is represented on the statutory body: The National Haemophilia Council (NHC), by Chairman Michael Davenport and myself. We are represented on the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) by Declan Noone and myself and we are represented on the Consultative Council on Hepatitis C by Anne Duffy. Following a 2 year mentoring and training programme Declan Noone replaced Michael Davenport on the HPSMAB this year, and his scientific knowledge and hard work have quickly made him an asset to the board.

This year was the most productive year yet for the NHC since its inception in 2004. Under the auspices of the NHC external audits were carried out of the three Comprehensive Haemophilia Centres in St. James's Hospital, Our Lady's Children's Hospital Crumlin, and at Cork University Hospital. The external audit team was composed of 3 members, Dr. Mike Makris a Consultant Haematologist from Sheffield, Chris Harrington a Haemophilia Nurse Specialist from the Royal Free Hospital in London, and David Page a person with haemophilia and the Chief Executive of the Canadian Hemophilia Society. David Page was nominated to be an external auditor by the Irish Haemophilia Society. The audits were a follow up to the 2006 audits of the same centres which were conducted by Dr. Makris and Ms. Harrington. Prior to the audits, the major deficiencies

Opening Ceremony EHC Conference Dublin Castle, September 2008

which had been identified in 2006 audits, and had not yet been rectified were the subject of intensive work by the Council. In July the Council met with senior officials from the HSE including the head of the National Hospitals Office. We also met with the Minister for Health and Children Mary Harney. As a result of this work agreement was reached on dealing with the major deficiencies identified in both Our Lady's Children's Hospital Crumlin (OLCHC) and Cork University Hospital (CUH). The major requirements for Our Lady's Children's Hospital Crumlin were the appointment of a new consultant haematologist to lead the haemophilia service. This post was advertised and a new haematologist was appointed before the end of 2008. The newly appointed haematologist Dr. Beatrice Nolan will take up her full time post in Crumlin in 2009. An additional Haemophilia Nurse Specialist was also approved and for OLCHC. The major deficiencies identified in Cork University Hospital were the need for a new consultant haematologist to lead the service and provision of an actual physical treatment centre. Up to this point in time people with haemophilia who attend CUH have to be treated in casualty. As a result of the discussions and as a result of the audits, funding was made available by the HSE for a new haemophilia treatment centre in CUH. The building is expected to commence in early 2009. The new consultant haematologist post to lead the haemophilia service has been advertised. Discussions are ongoing in relation to the provision of a secretary for the haemophilia service, and a part time physiotherapist, social worker and dentist for the service in CUH. When the new consultant is in place, and when the new centre is open, we fully expect to see substantial improvements in the haemophilia service in Cork, thereby bringing it closer to the standard expected of a Comprehensive Care Centre. The NHC will continue to closely monitor the situation. I want to express my appreciation to Professor John Bonnar, and to all the members of the NHC for their work and commitment during the course of the year.

The NHC is now working to a Strategic Plan where we will look at achieving key objectives on an annual basis. The NHC will also meet formally with the Chief Executive's of each of the hospitals on at least an annual basis, in addition to meeting with the haemophilia care teams in those hospitals.

During the course of the year the Haemophilia Product Selection & Monitoring Advisory Board (HPSMAB) met on several occasions to monitor developments in relation to factor replacement therapy internationally. We also completed new tenders for the provision of recombinant Factor VIII and Factor IX for two year period. In the course of the year we also liaised with the haemophilia care teams in NCHCD, CUH, and OLCHC. Among the achievements were assisting the Hepatology Unit at St. James's Hospital in making a case to the HSE for the provision of a Fibroscan machine for non invasive diagnostic procedures for persons with Hepatitis C. We had ongoing discussions with the Infectious Diseases Team in St. James's Hospital for the provision of a HIV/Hepatitis C Clinic for persons with haemophilia to ensure that a unified approach to haemophilia, and the infectious complications could be taken.

Communication with members

The Society staff which includes counsellor Anne Duffy are in constant contact with members. Members call into the office, they contact us by phone, or by email. They are assisted with any situation they find themselves in, which can have an impact or has been impacted by their haemophilia, or infection with HIV or Hepatitis C. In addition we now have an objective of making an annual phone call to members where we ascertain where possible their situation, assist them, and receive feedback on our programmes and activities. These phone calls also give us an opportunity to gather specific information in relation to the future requirements for our programmes and activities. Our contact with members for the first quarter of 2008 (extrapolated to the full year) meant that we had approximately 4,840 contacts with members during the course of the year. A constant theme which emerges from communication with members is the strong bond they feel with the Society.

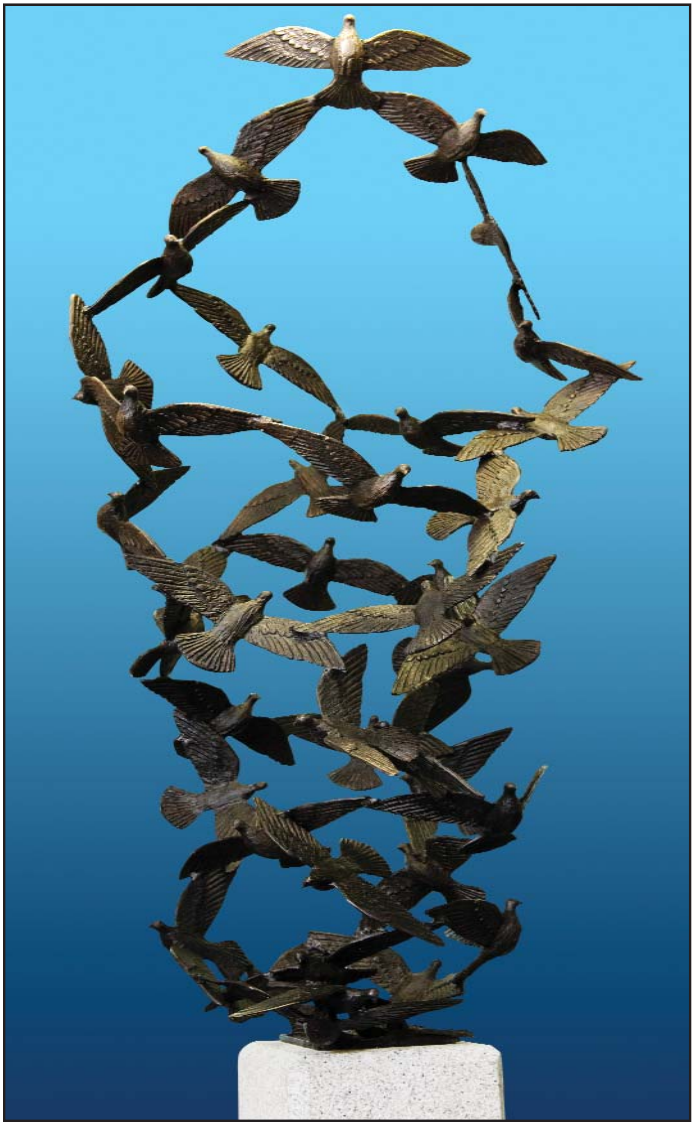
Financial Report

As you will see from the Audited Accounts, we had a very successful year financially. Thanks to the provision of additional capital funding our grant from the HSE increased by a total of €50,000 in 2008. The funding from the N.C.H.C.D. Educational Fund was unchanged from 2007. The Corporate Giving Programme, which we unveiled at the AGM in 2007, resulted in an increase in corporate donations from €7,000 to €25,700 during the course of the year. Donations from members increased from €30,297 to €46,855, and we are extremely grateful to the members who made generous donations.

The largest single reason for the successful financial outcome for the year was a specific bequest of €182,476, which was donated by the family of a member who had passed away some years ago. We were very grateful for this generous bequest and we hope that it will encourage other members to consider adding the Society as a beneficiary in their will. With the assistance of the bequest, the increased donations, and the increase in corporate donations, we had a record income for the year of €1,023,705. Our budgeted income for the year was €796,000. Our budgeted expenditure for the year was €797,000 and our actual expenditure was €767,184.

The interest payment on our mortgage decreased due to falling mortgage interest rates. On the other hand professional fees were higher than budgeted as we had significant costs during the course of the year for expert advice on taxation issues including the production of a tax booklet for members, actuarial advice on the Insurance Scheme, and expert advice on the Travel Insurance Scheme for members. Expenditure on the Annual General Meeting was also higher due to the fact that it was the 40th Anniversary AGM, and the number of additional features increased the cost. However, the budget was controlled tightly and expenditure came in at €30,000 under budget. What is not evident from the Schedule of Expenditure is the fact that in addition to paying the interest on the mortgage for the Headquarters, we are also paying capital off the mortgage at an acelerated rate. We had originally taken out the mortgage over 15 year period, and in addition to the interest payments, we paid an additional €78,369 in monthly capital repayments during the course of the year.

Brian O'Mahony, Ajdin Hacimic, Margaret Dunne & Debbie Greene receiving the WFH Twin of the Year Award at the WFH Congress in Istanbul June 2008



Memorial Sculpture

We also took a decision to apply the bequest received in the amount of €182,476 and the single largest donation during the year of €20,000 as further capital repayments on the mortgage. Therefore in addition to the monthly capital payments of the mortgage, we paid an additional €200,000 off the mortgage in 2008. At the beginning of the year the amount outstanding on the mortgage was €638,145, and at the end of the year the amount outstanding was €359,776. We were delighted to be able to apply the full bequest and donation to the mortgage which has served to reduce the term further. We are maintaining our monthly mortgage payments at the same level as 2007. The consequence of this is at the beginning of 2008, the term remaining on the mortgage was seven years and three months and at the end of the year the term remaining on the mortgage was three years and eight months. This is a very significant positive outcome considering that we initially took out a mortgage of €1,100,000 over a fifteen year term in 2006. We now expect to have the mortgage paid off fully by September 2012.

Staffing

During the course of the year Patricia O'Connor left the Society, and we were joined by two new staff members Declan Noone and Nuala McAuley. We are delighted to have both Declan and Nuala join the Society team. I want to pay tribute to all of the staff team, Margaret Dunne, Anne Duffy, Debbie Greene, Nina Storey, Declan Noone and Nuala McAuley for their hard work, application, enthusiasm, and genuine concern for the members demonstrated during the course of the year.

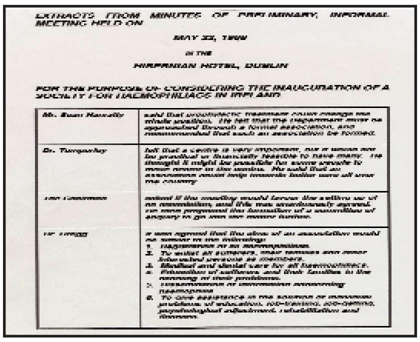
I also want to pay particular tribute to the board of the Society. The governing bodies or boards of most National Haemophilia Organisations, meet on a quarterly basis. The board of the Irish Haemophilia Society meet on a monthly basis, which is quite a commitment. During the course of 2008, the board had a total of ten meetings, including three meetings by conference call. I greatly appreciate their volunteer commitment on behalf of all of the members. I want to pay particular tribute to Gerard O'Reilly our Treasurer who has taken to the financial role with great enthusiasm and application. I also want to pay tribute to our Chairman Michael Davenport. Michael's time commitment to the organisation is very extensive and perhaps not appreciated by many of the members. In addition to attendance at the board meetings, meetings of the National Haemophilia Council, many meetings by conference call in relation to the statutory bodies, and other issues, Michael has also been a constant presence at the Regional Meetings around the country where he has taken the opportunity to meet members. We are fortunate to have such a committed Chairman.

At the end of 2008 we were clearly facing difficult times for the country and for the economy, and a difficult outlook for the future both nationally, and globally. I believe we are in an excellent position to deal with future challenges. We are located in our own Headquarters, financially we have managed to clear two thirds of the outstanding debt on the Headquarters in a two year period. We have a committed and able staff team, and an excellent board. The attendance at our conferences is being maintained at a high level, and I am particularly encouraged by the attendance on a regular basis of so many children and teenagers, as they are the future of the Society.

Brian O'Mahony
Chief Executive

I.H.S. The First 40 Years

To all our members who have journeyed with us over the past 40 years, and to those who joined the journey along the way, we acknowledge and thank you for your support and friendship, without which we could not have achieved all that has been achieved. The value of the programmes we organise is reflected in the attendance of so many of you at Society events, and we will continue to rely on your feedback and support as we endeavour to respond to the changing needs of all our members. As the Society celebrates 40 years, we remember all those who have died, we realise our strength is in our unity, and we look forward with realistic hope to a bright future. Below you will find a historical timeline of the first forty years.



Minutes from the first meeting on 22nd May 1968

1968 The Irish Haemophilia Society was founded in 1968 by members of the medical profession, people with haemophilia, their families and friends, who felt the need to provide support and advice for members and to improve the quality of life for people with haemophilia.

1969 A meeting of the World Federation of Hemophilia was held in Dublin, at which Society members were addressed by international experts for the first time. The Society produced its first newsletter in August 1969. The Government announced that it was setting up a National Haemophilia Centre at the Meath Hospital for adults, and for children at the National Children's Hospital, Harcourt Street the following year.

Founder Members: Jack Downey & Bill O'Sullivan

1970 Ninety patients were registered with the National Haemophilia Centre, 65 with haemophilia A, 21 with haemophilia B and 4 with von Willebrands Disease. Throughout the 1970's haemophilia progressed from being a severely debilitating disease to a manageable one. The quality of life for people with haemophilia improved, along with the knowledge and expertise of the organisation. The Society offered support to members who were hospitalised in the Meath & Harcourt Street hospitals. Support included visits, provision of games and access to a television because in this pre-home treatment era, many people spent significant amounts of time as In-Patients.

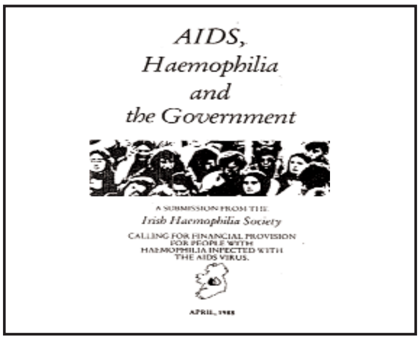
Founder Member: Eithne Scanlon

1975 In 1977 a new centre opened in St. James's Hospital. Home treatment was on the increase, a normal quality of life seemed attainable and the Society offered support to members with home visits, newsletters, and other services. At this stage the committee met at the headquarters of the Irish Cancer Society on a regular basis. By 1982, life expectancy had increased to 60 and life was becoming normal for many members of the Society.

Forever Friend: Margaret King

1980 The period from 1983 was a very active, traumatic and emotionally difficult time for the Society with the realisation that the blood products which had at last promised a normal quality of life had resulted in the infection of 106 members of the Society with HIV. It was a devastating blow for the entire haemophilia community. As a direct result of infection with HIV and Hepatitis C, to date some 91 people with haemophilia have died, and the lives of many individuals and families have been decimated. The Society had to face into this immense challenge as a small organisation with a number of dedicated volunteers with no staff, no resources and no office.

1983 The Society produced a report on the need for a new National Treatment Centre. The Society also funded research into the immune system of people with haemophilia in an early response to the spectre of Aids.



AIDS,
Haemophilia
and
the Government

A SUBMISSION FROM THE
Irish Haemophilia Society
CALLING FOR FINANCIAL PROVISION
FOR PEOPLE WITH
HAEMOPHILIA INFECTED WITH
THE AIDS VIRUS.

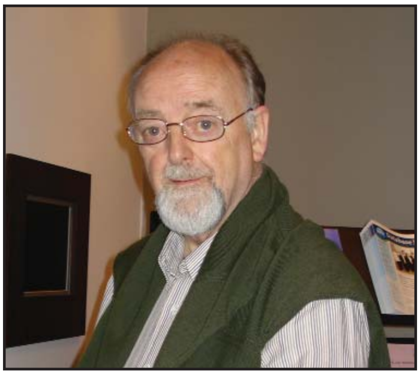
APRIL, 1988

First submission to government

1985 Following reports that the Aids virus could be transmitted sexually, the Society took the initiative and began to distribute condoms directly to members. This resulted in the very low rate of transmission of HIV to spouses and partners in Ireland when compared to the haemophilia population in other countries.

1987 The Society undertook a comprehensive survey of the needs of all of the members who had been infected with HIV.

1988 Based on the results of the survey, the Society drafted a booklet called "Aids, Haemophilia, and the Government", which called for a concerted response from the Department of Health and State Agencies.



Our friend Father Paddy McGrath

1989 When this was not forthcoming, the Society organised a political/media campaign for recompense for people with haemophilia infected with HIV. The campaign led to a parliamentary defeat for the Government and a National Election in 1989. This culminated in the setting up of the Haemophilia HIV Trust (HHT). The HHT has performed invaluable service to those with HIV and offers ongoing financial assistance for services for people with haemophilia and HIV and their families. Two members of the I.H.S. continue to represent the Society on the HHT.

1990 The Society offered assistance to members who were suffering from the clinical consequences of HIV and Aids, and provided a critical illness service, home support and nursing service for members. This service continued throughout the decade. Support and assistance was also provided to members who were pursuing legal action in relation to their infection with HIV. At the AGM of the Society, we commissioned a lecture on Hepatitis C, an ominous new threat to the community.

Haemophiliacs accept new £8m offer

Curb on blood imports

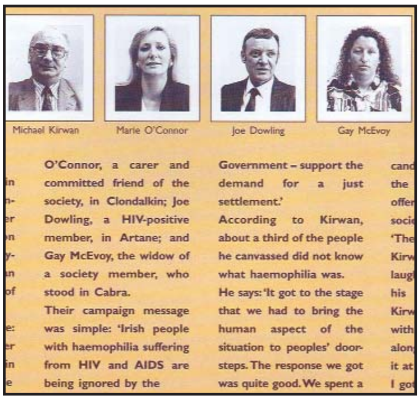
Local election campaign by haemophiliacs

Government defeated twice

Newspaper cuttings from Media Campaign

1990 Irish Press Article, 19th December 1990

"Haemophiliacs who have been infected by the Aids virus through blood transfusion are victims on the double and their plight should command the most serious attention of the Government. Yesterday it was revealed that since the famous Dail motion on their behalf in June of last year fifteen such hemophiliacs' have died and another fifteen to twenty will have died by the time legal actions on their behalf have begun at the end of next year. This is not a situation which either the Government or general public can contemplate with anything but the gravest disquiet. It is profoundly sad that these hemophiliacs', through no fault of their own, should have to face the long slow agony of death by Aids. But it is nothing short of disgraceful that they should go to their graves plagued also by the gnawing worry that their families might not be secure. In many cases, these unfortunate victims or their wives have had to give up their jobs because of the constant care which this condition demands. The British Government, not exactly celebrated for its caring attitude, recently recognised its moral duty towards hemophiliacs' in this dreadful situation. It is time for our Government to do likewise".



Michael Kirwan Marie O'Connor Joe Dowling Gay McEvoy

O'Connor, a carer and committed friend of the society, in Clondalkin; Joe Dowling, a HIV-positive member, in Artane; and Gay McEvoy, the widow of a society member, who stood in Cabra.

Their campaign message was simple: 'Irish people with haemophilia suffering from HIV and AIDS are being ignored by the Government – support the demand for a just settlement.'

According to Kirwan, about a third of the people he canvassed did not know what haemophilia was.

He says: 'It got to the stage that we had to bring the human aspect of the situation to peoples' door-steps. The response we got was quite good. We spent a

Four members stood in local elections

1991 Concerned by the mounting death toll from HIV and tortuously slow progression of the legal action, the Society again was compelled to mount a media and political campaign to negotiate a HIV compensation settlement with a reluctant government. Four members of the Society stood in local elections. Following

Rosemary Daly & Brian O'Mahony host a press conference

several months of campaigning, a political settlement was reached. This resulted in payments ranging from IR£77,000 to IR£101,000 to each individual with HIV. A payment of IR£20,000 was paid to the families of those who had died as a result of their HIV infection.

1992 The Society turned its attention to seeking improvements in the provision of comprehensive haemophilia care and monitoring developments with blood products. The Society drew up a Blood Product Policy which was communicated to the Department of Health and the National Haemophilia Treatment Centre. The policy set out the Society's objectives for haemophilia replacement therapy for the next five years. All of the objectives set out in the Blood Product Policy were achieved. The Policy was updated in 1996.

President Mary Robinson at 25th Anniversary AGM

1992 The Annual Conference of the European Haemophilia Consortium was organised by the Society in Dublin. The Society engaged in a Twinning Programme with Hungary. The death toll from HIV continued to increase and the Society continued to offer a high level of service to those affected and their families. Infection of members with Hepatitis C through contaminated blood products emerges as an issue of increasing concern.

1992 The Society moved to a new Headquarters in Eustace Street.

1993 The Society celebrated its 25th anniversary. The AGM was attended by President Mary Robinson.

1994 The Society initiated discussions with the Department of Health in relation to provision of treatment for members who had been infected with Hepatitis C.

WFH Congress 1996 - Dublin

1995 The Society negotiated a Compensation Scheme with the Irish Government for people with haemophilia infected with Hepatitis C and agreed that members would attend the newly established Hepatitis C Compensation Tribunal.

1996 The Health Amendment Act is passed with the provision of additional health benefits for members with Hepatitis C.

1996 The International Congress of the World Federation of Hemophilia was held in Dublin. Some 2,400 delegates from 70 countries attended, which was a record number. The Society's Patron the then President of Ireland Mary Robinson, attended the Congress and addressed the delegates. The Congress was a major success scientifically, socially and in terms of attendance as well as being a major financial success.

I.H.S. team - 1990's

1996 The Society worked on a new Blood Product Policy, setting out goals for 2000, and on a new Policy on recombinant products for all, with aspirations for prophylaxis set out.

1997 Seminars for Women with Bleeding Disorders were held in Dublin and Cork which were attended by a large number of women, many of whom were attending such meetings for the first time, which broadened membership of the Society. The numbers of women joining the Society continued to increase. Following

President Mary McAleese officially opens Headquarters in Smithfield

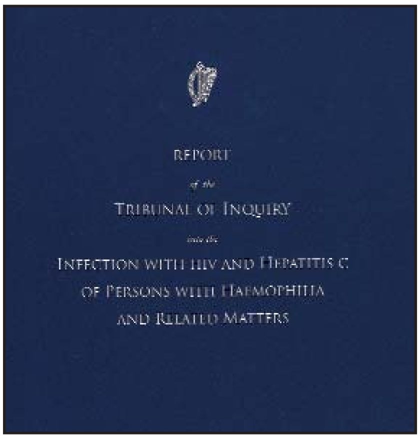
IRISH HAEMOPHILIA SOCIETY

TRIBUNAL NEWS

ISSUE 7

27th July, 2000

I.H.S. Tribunal News



REPORT
of the
TRIBUNAL OF INQUIRY
into the
INFECTION WITH HIV AND HEPATITIS C
OF PERSONS WITH HAEMOPHILIA
AND RELATED MATTERS

Lindsay Tribunal of Inquiry

NHC National Haemophilia Council

National Haemophilia Council

meetings with the Minister for Health, recombinant products were provided for all persons with haemophilia A.

1997 The Society withdrew from the Finlay Tribunal of Inquiry into the Blood Transfusion Service as the tribunal was not dealing in any substantive way with the issues relating to the infection of people with haemophilia.

1997 The Society was involved in negotiations with the Department of Health and the Attorney General regarding the Terms of Reference for a new Tribunal of Inquiry into the infection of people with haemophilia with HIV and Hepatitis C.

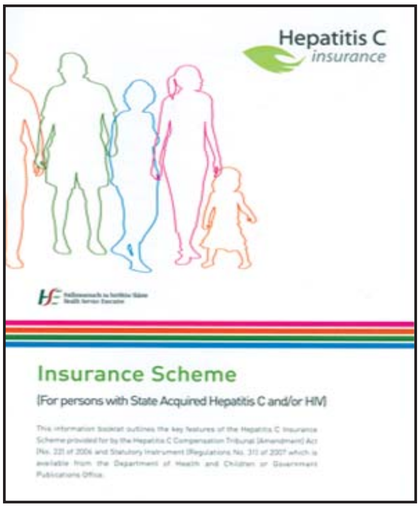
1998 To mark the 30th anniversary of the Society a publication was produced covering the history of the first 30 years of the Irish Haemophilia Society.

1998 The Society moves to a new Headquarters in Smithfield.

1999 Following protracted negotiations and many delays the Terms of Reference for a Tribunal of Inquiry, into the circumstances of infection of people with haemophilia with HIV and Hepatitis C, was finally agreed and the Lindsay Tribunal began hearings on 2nd May 2000. Because of the great importance and significance of the Tribunal to our members, and due to the fact that many members would not be in a position to attend the hearings, it was decided to produce the 'Tribunal News' which would synopsise, in layman's language, the daily proceedings at the Tribunal. The Tribunal News was distributed to the membership of the Society on a weekly basis throughout the hearings of the Lindsay Tribunal of Inquiry. Following 196 days of evidence, the Society presented its final submissions and recommendations for the future on days 189-191 of the Lindsay Tribunal.

2001 The Product Selection Group (now the Haemophilia Product Selection and Monitoring Advisory Board) was established. The Society presence on this board gives the organisation a formal role in the selection of factor replacement therapy for people with haemophilia, von Willebrands and related bleeding disorders for the first time. The formal involvement of the Society and key clinicians means that safety, efficacy and quality are, and will continue to be, foremost on the list of selection criteria. To date, the board has completed eight National Tenders resulting in the purchase of some 200 million units of factor concentrate.

2002 In September 2002 the report of the Lindsay Tribunal was published. During the Dail Debate which followed the publication of the report, the Minister for Health made a commitment that people with haemophilia in Ireland will always have access to the safest and most efficacious products available. In line with the recommendations in the report the Minister for Health agreed that; a National Haemophilia Council (NHC) should be set up as a Statutory Body to advise the Minister, the Department of Health, (and later the HSE) and hospitals on all aspects of haemophilia treatment and care.



Hepatitis C
insurance

Insurance Scheme

(For persons with State Acquired Hepatitis C and/or HIV)

Insurance Scheme

President Mary McAleese opens our brand new Headquarters

Memorial Sculpture

2003 Although HIV treatment was much better and had improved since 1996 the clinical impact of Hepatitis C was an increasing problem.

2003 Participation by young people and children at AGM's and conferences increased to the point where the Society initiated a new format for our conferences. We introduced four strands to each of our major conferences; the main programme of lectures, a programme for young adults, a childrens programme and crèche facilities.

2004 The National Haemophilia Council became a Statutory Body with formal involvement for the I.H.S. in recommending policy and priorities on haemophilia.

2004 The National Haemophilia Council managed a vCJD risk assessment based on the risk to members who had used plasma derived concentrates from the UK in the past. This was the first major example of proactive collaboration between the Society, the clinicians and the Department of Health.

2006 The Hepatitis C & HIV Insurance Scheme was signed into law. A members conference was organised in October and was successful to the extent of becoming an annual event.

2006 The Society set out a new Strategic Plan designed to ensure that optimum levels of support and services were provided to all members, that the Society is effectively represented on all external bodies and agencies, and ensuring the long term viability of the Society.

2007 The Insurance Scheme started. The Society worked with individual members to optimise their participation, and availability of the Scheme. By the end of the first year of the Scheme, 40% of eligible members had availed of Life Insurance which was a multiple of the take up from other eligible organisations.

2007 Finally, our own new headquarters. The Society moved to a brand new Headquarters in New Street in Dublin 8. The new Headquarters was officially opened on 14th June 2007 by President Mary McAleese. A DVD was produced by the Society and features several members of the Society, who explained the development of haemophilia care in Ireland over the past forty years, by telling their personal stories.

2008 The Society celebrated forty years. To mark this occasion a service was held in our Headquarters to mark the unveiling of a sculpture which represents a time of tragic loss, achievement and hope for the future. Today the Society is vigilant on safety and availability of treatment and is thankfully maintaining a strong and united organisation. We produce various publications and DVD's, organise Information Meetings, Annual Conferences, Family Weekends, Regional Visits, and updates on treatment. In 2008 we again proudly hosted the European Haemophilia Consortium Conference in Dublin Castle which was attended by delegates from 35 European countries. We have an excellent board and staff, young enthusiastic members, and are working in a strategic and planned manner. We contribute effectively to the National Haemophilia Council, Product Selection Board and Consultative Council on Hepatitis C. We have a permanent headquarters, and provide services for all categories of members. We remember those who have passed away. We remember and have learned from the tragedies which have befallen our community and we look to the future with confidence and hope.

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 2008 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 2006. 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.

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 2008 and of its surplus for the year then ended and have been properly prepared in accordance with the Companies Acts 1963 to 2006. 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.'

Respective Responsibilities of Directors and Auditors

The Directors are responsible for preparing the Director's report and financial statements in accordance with applicable Irish Law and accounting standards generally accepted in Ireland. Their responsibility is to audit the financial statements in accordance with relevant legal and regulatory requirements and auditing standards issued by the Auditing Practices Board applicable in Ireland. This report and its opinion has been prepared only for the company's members as a body in accordance with Section 193 of the Companies Act, 1990 and for no other purposes.

Statement by the Board of Directors

The summarised financial statements are not the statutory accounts but a summary of information relating to the Statement of Financial Activities and the Balance Sheet.

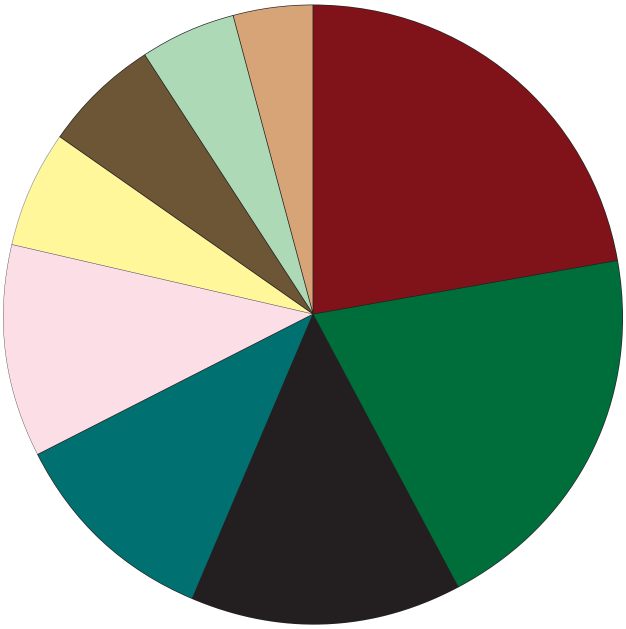
Copies of the full audited accounts for 2008 are available on request.

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	**23%**	🟥
Counselling & Support	**18%**	🟩
Establishment/Headquarters	**14%**	⬛
Members Conference & Meetings	**11%**	🟦
Publications & Website	**11%**	▨
Financial Support to Members	**8%**	🟨
External Representation	**7%**	🟫
Administration & Finance	**5%**	🟩
International Development Assistance	**3%**	🟧



Income & Expenditure Account

For The Year Ended 31st December 2008

	2008 **€**	**2007** **€**
Income		
Health Service Executive - Northern Area	135,000	125,000
Health Service Executive	535,000	495,000
NCHCD Educational Fund	30,000	30,000
Memberships	3,120	4,650
Donations - Members	46,855	30,297
Donations - Corporate	25,700	7,000
Bequests	182,476	-
EHC Conference	28,016	-
Fundraising	13,873	8,624
H.H.T. Trust	12,912	9,220
Investment Income	10,753	7,289
	1,023,705	717,080
Expenditure as per schedule	(766,776)	(725,362)
Surplus /(deficit) for period	256,929 =======	(8,282) ======

Schedule Of Expenditure

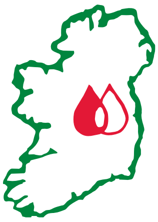
For The Year Ended 31st December 2008

	2008		2007	
	€	€	€	€
Administration Expenses:				
Wages, State Insurances and Pension Costs	205,824		198,608	
Employer's PRSI Contribution	18,229		17,270	
Office Expenses & Stationery	13,222		12,726	
Telephone & Fax	9,853		10,787	
Travelling Expenses	7,927		10,616	
Overseas Travel Expenses	11,061		9,689	
Archive Storage Fees	3,990		4,356	
Relocation Expenses	-		4,549	
Sundry Expenses	5,572		7,986	
		275,678		276,587
Financial Expenses:				
Bank Charges & Loan Interest	30,434		44,546	
Professional Fees	140,259		80,184	
Audit & Accountancy Fees	5,468		5,445	
		176,161		130,175
Activities:				
Help to members	18,025		10,225	
Family Activities	6,000		6,219	
H.H.T. Trust	8,500		10,000	
Subscriptions	1,589		1,948	
Fund Raising Expenses	1,311		1,356	
A.G.M. & Meeting Expenses	52,151		39,404	
EHC Conference	13,690		-	
Postage, Publications & Photocopying	30,669		31,650	
Educational Grants	16,500		18,000	
Safety/Supply Activities	3,359		3,352	
Counselling & Support Meetings	11,310		6,488	
Twinning	3,090		1,931	
Website	11,063		2,905	
WFH GAP Programme	20,398		18,832	
Sponsorship/Training	3,313		1,621	
Memorial Event	8,913		-	
Member's Conference	21,317		22,803	
		231,198		176,734

	2008 €	€	2007 €	€
Establishment Expenses:				
Service Charge & Insurance	18,776		3,997	
HQ Costs	1,353		85,484	
Computer Services	8,949		3,419	
Light, Heat & Services	10,306		4,611	
		39,384		97,511
Other Costs:				
Depreciation- Fixtures. Fittings & Equipment	18,073		18,073	
Depreciation- Land & Buildings	26,282		26,282	
		44,355		44,355
Total Expenditure		**766,776**		**725,362**
		======		======

Balance Sheet As At 31st December 2008

	2008 €	€	2007 €	€
Fixed Assets				
Buildings	1,221,233		1,247,515	
Office Equipment & Fittings	44,882		62,955	
		1,266,115		1,310,470
Current Assets				
Hibernian Spectrum Bond	150,000		150,000	
Irish Nationwide Building Society	100,000		-	
First Active Deposit Accounts	166,137		255,461	
Allied Irish Bank - Current Account	158,060		122,928	
Allied Irish Bank - Planned Giving Current Account	23,961		16,001	
Allied Irish Bank - Deposit Account	3,989		3,912	
Cash on Hand	1,399		518	
		603,546		548,820
Current Liabilities				
Sundry Creditors & Accruals	(96,022)		(64,211)	
		(96,022)		(64,211)
Net Current Assets/(Liabilities)		507,524		484,609
Long Term Liabilities				
Long Term Property Loan		(359,776)		(638,145)
Net Assets/(Liabilities)		**1,413,863**		**1,156,934**
		========		=======
Represented By:				
Accumulated Funds				
Balance 1st January 2008		1,156,934		1,165,216
Surplus / (Deficit) for the year		256,929		(8,282)
Balance 31st December 2008		**1,413,863**		**1,156,934**
		=======		=======



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