

# Irish Haemophilia Society



Annual Report 2011

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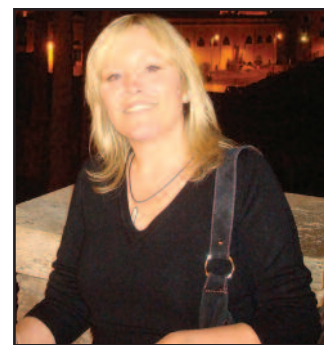
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# A Message from the Chairperson

2011 brought a New Year and with it new opportunities and challenges for the Irish Haemophilia Society. Opportunities such as the development and implementation of a new conference for young men with haemophilia aged 18 to 35 years, and the long awaited opening of the new treatment centre in Cork University Hospital. Challenges in the familiar guises relating to funding, continuation of treatment and maintaining existing services continued. A personal opportunity / challenge for me was stepping into the role of Chairperson. I would like to acknowledge the excellent work and the fantastic job Michael Davenport has done over the past 10 years. I would also like to thank him for all the support and encouragement he offered to me during 2011. If I do half as good a job as he has done I will be doing ok!



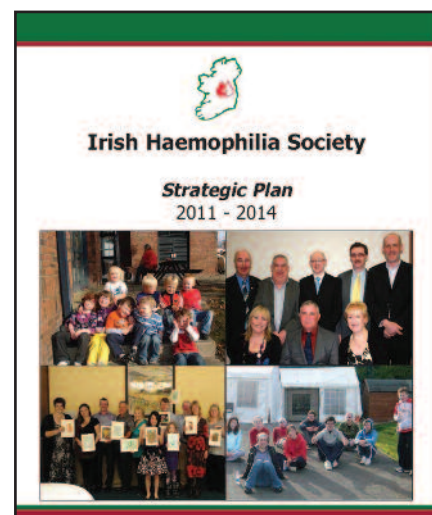
Traci Dowling,  
Chairperson

## Strategic Plan

Continuous professional development and evaluation are vital if we are to maintain our core services and secure future funding. Strategic planning is an excellent way for us to focus on selected goals, measure our progress, build on our success and improve on any weak areas.

We now have our second plan in place that will allow us to focus on four broad goals from 2011 - 2014. The plan has four broad goals;

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



A copy of the IHS Strategic Plan was sent to members and can also be downloaded from the website.



Minister for Health, Dr. James Reilly, pictured with the staff of CUH, officially opened the Haemophilia Treatment Centre in CUH

## New Treatment Centre in Cork University Hospital

After many years of pressure, lobbying and advocacy the new treatment centre was finally opened. This was a proud day for all at the Society. The centre was officially opened by the Minister for Health & Children, Dr. James Reilly T.D. in July. Staff and board travelled down to Cork to join our members for the opening. Professor John Bonnar gave a warm and moving address. In excess of 40 people attended on the day and we wish everyone at the new treatment centre the very best.

## Funding

Funding was cut again in 2011. This was despite the Health Service Executive (HSE) being impressed with the professionalism of the Society and holding our budget submission as a template for other charitable organisations to work towards. This will most probably be the pattern we can expect for the foreseeable future and we therefore need to focus on ways to meet the shortfall.

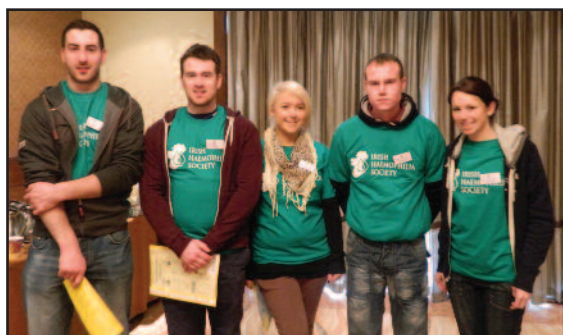


### Barrettstown

The Society has an excellent working relationship with Barrettstown. Each year we significantly raise the number of children from the Society attending both the Summer camps and family camps. It is an opportunity for children to form new friendships, become more independent and have lots of fun!

### Increased Capacity at Conferences

2011 saw a large rise in attendance at our October Conference, and an increase at all levels at each conference. It is interesting to note that we are now operating at full capacity at each of our conferences, so it is very important to book in early if you want to attend, to avoid disappointment. It is fantastic to see that each time we run an event our numbers keep on growing. This is a great indicator to us that you the members are happy with the services we are providing.



*2011 saw the IHS launch a vigorous volunteer recruitment drive to allow increased capacities in each of the children's groups.*

*A huge thank you to all the volunteers, without whom, the events would not be possible.*

### Volunteers

In addition to using our capable and willing members for volunteering, we are also having to look outside of the Society to cater for the increasing demand. An increase in numbers attending Society events means a greater need to expand our volunteer base. There is therefore a greater need to ensure that the Irish Haemophilia Society are maintaining high standards, and it is imperative that we keep abreast of current legislation and governance at all times.

In late 2011 we started a targeted volunteer drive in which we hope to add an extra 40 volunteers by the end of 2012. Those of you who are regulars at our conferences would have noticed some new faces both at our Parents and Members' conferences. It is also worth noting that all volunteers must complete training in partnership with Barnardos, and all our volunteers are Garda Vetted.

### IHS Board of Management

We have a very strong and proactive board that works very well together and who also have a good working relationship with Irish Haemophilia Society staff. We have strong representation in the majority of areas relating to haemophilia care i.e. young men with bleeding disorders, mature men with bleeding disorders, parents of young adults, and carriers. As a parent myself, I understand the difficulties that can often come with putting yourself forward at this stage of your child's life. I know for me I had conflicting feelings. I wanted to be there for my child, had work commitments on top of that and felt I would find it too difficult to balance all of that if I was on the board at that time in my child's life. This can also be a time when you and your child have started to settle into a comfortable treatment regime, and the advantages that can come with that - participation in sports, going on holidays going out, generally doing all the things that are so often just taken for granted by others not raising a child with a bleeding disorder – just living. So remember when the time is right put yourself forward for the board!

### Regional Visits

Four regional visits took place in 2011. Two in February in Kerry and Cork, and two in November in Donegal and Galway. These visits are very important as they provide members who may not get to attend our conferences with an opportunity to meet with staff and have their concerns and

issues heard if needs be. In addition to the regional visits, home visits are also made to members who have particular requirements and lack the mobility or opportunity to attend the regional meetings. This in turn allows us to keep in touch with the needs of the membership and allows us to improve existing services, develop new initiatives and bridge any gaps that exist. If you would like a home visit at any stage, give Anne Duffy a call in the office on 01 6579900.

#### European Haemophilia Consortium (EHC) & World Federation of Hemophilia (WFH)

It is very important that we continue to maintain and strengthen our links with other National Member Organisations (NMO's), on both a European and global level. This provides us with the opportunity to share valuable information, increase our lobbying and advocacy capabilities and use current best practice procedures to help strengthen both the developed and developing worlds. The EHC Conference was held in Budapest in October 2011, and was attended by Debbie Greene, Administrator and Ger O'Reilly, Treasurer. At the conference Brian O'Mahony was elected the new EHC President. Brian will be an excellent asset to the EHC and they will benefit greatly from his expertise and drive. His Presidency will also increase and strengthen our own lobbying power.



#### Website / Social Media

The website was refreshed and revamped in November 2011. You can check out our website which is consistently updated with information on all our upcoming events for the year.

#### Memorial Service

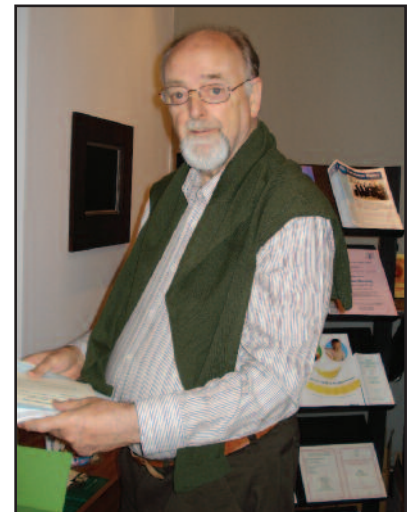
Our annual Memorial Service was held on Sunday the 6<sup>th</sup> November. As well as being a day for remembrance and reflection, it is also a day to meet up with some members that have stopped attending conferences and events as this is often the only link we have with them. This year it was especially poignant with Fr. Paddy McGrath's passing in April, and as a tribute to him we used the service that Paddy had prepared the previous year. All the prayers and hymns were some of Paddy's favourites as the staff wanted to honour the man they considered a friend. Paddy's colleague and friend Fr. Bernard did a great job on the day.

I would like to finish my report by taking the opportunity on behalf of the board to thank the staff of the Society; Brian, Debbie, Nina, Anne, Declan, Nuala and Fiona for all their hard work, dedication and commitment throughout the year.

I would also like to most sincerely thank the board for their continued commitment and passion. It is extremely rare that a board member misses a meeting.

Finally I would like to thank you, the members for your continued support at all our conferences and events. I love the fact that when all the debates, discussions and business of the day has been finished, the community spirit is still there, this is great to see. It has been a very busy year, a very interesting year, a very challenging year, but a great year.

**Traci Dowling**  
Chairperson



*The IHS lost a true friend upon the death of Fr. Paddy Mc Grath*

# Honorary Secretary's Report

At the 22<sup>nd</sup> Annual General Meeting of the Irish Haemophilia Society, which was held in the Slieve Russell Hotel in Cavan on Saturday the 5<sup>th</sup> March, 2011 the Incoming Governing Body of the Society was elected as follows:-



Traci Dowling,  
Chairperson



Michael Davenport,  
Vice-Chairperson



Gerard O'Reilly,  
Treasurer



Mary Hanney,  
Secretary

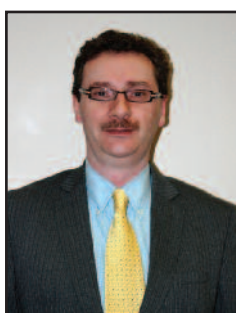
At the first executive meeting of 2011 following the AGM the following Officers were elected:-

Chairperson  
Traci Dowling

Vice-Chairperson  
Michael Davenport

Honorary Treasurer  
Ger O'Reilly

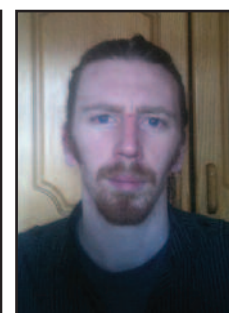
Honorary Secretary  
Mary Hanney



Pat Downey



Brian Byrne



Eoin Moriarty



Brian O'Riordan

In the period since the 2011 AGM, eleven executive board meetings were held, attended in person or by conference call by every elected member of the Board who always give their total commitment to each meeting.

## **MEETINGS ORGANISED BY THE SOCIETY**

As usual the Society had a busy schedule organised throughout the year, but I will start by paying tribute to a very dear friend of the Society who passed away during Easter week last year after a long illness. Fr. Paddy McGrath was the unofficial chaplain of the Irish Haemophilia Society, the friend, the counsellor, the source of consolation for many in times of despair. He had a great sense of humour and fun and was held in the highest esteem by everyone he knew. He will be greatly missed. May he rest in peace.

## **IN MARCH 2011 -**

The 22<sup>nd</sup> Annual General Meeting and Conference of the Irish Haemophilia Society took place over the weekend of the 4<sup>th</sup> to 6<sup>th</sup> March 2011 in the Slieve Russell Hotel, Co Cavan. There were many interesting sessions over the weekend and one of the guest speakers was Dr. Craig Kessler from Georgetown University Medical Centre in Washington, DC who delivered a lecture on the topic of "Ageing and Haemophilia". This was a very informative lecture and a very important topic as it is one that the Irish Haemophilia Society will be addressing over the coming years. The main points taken from Dr. Craig Kessler's lecture was that people with haemophilia need to be proactive in relation to their health. They should look to maintain a balanced lifestyle to include diet and appropriate exercise and should work with their health care professionals to maintain good health. There was also a very good session on the "Update from Comprehensive Care Centres" and on the long awaited hand held devices which are now in circulation to all members and seem to be working well.

The Kidlink group had a great time where they made a movie which they presented after the Gala Dinner that evening. The Youth Group also had a great time doing team building activities and swimming.

The Gala Dinner was very enjoyable after which a special presentation was made to Alison Daly who stepped down after many years running the Young Adults & Kidlink Programme. Alison will be sorely missed by everyone, but we will never forget her kindness and great sense of humour. We were then entertained by the B Sharps into the wee hours of the morning.

#### **IN APRIL 2011 -**

The Society organised two information days for women with bleeding disorders. One was in the Rochestown Park Hotel in Cork on the 16<sup>th</sup> April and the other was in the Hilton Hotel in Dublin on the 17<sup>th</sup> April. The attendance was a bit disappointing as a lot of work had gone in to reaching out to women with bleeding disorders, but those who did attend benefited hugely as the talks given by Professor John Bonnar, Dr. Paul Giangrande, Brian O'Mahony and Nurse Specialist Eadaoin O'Shea of James's Hospital were excellent.



*Alison Daly stepped down from her role as Kidlink & Youth Group Coordinator at the 2011 AGM*

#### **IN MAY 2011 -**

The Parent's Conference was held in Fitzpatrick's Castle Hotel, Killiney, Co. Dublin from May 20<sup>th</sup> to the 22<sup>nd</sup>. This was a very enjoyable weekend with fantastic talks on everything from pregnancy to bullying. There was also a session on self infusion which really benefited the children who maybe were lacking confidence in their ability to self infuse. There was very positive feedback after this weekend which was great to hear.

#### **IN JUNE 2011 -**

The ladies were out again strutting their stuff on Leeson Street by taking part in the Ladies Mini Marathon on the 6<sup>th</sup> June. There was a great turnout and everyone had a great day. The money raised was most welcome by the Society who would like to thank everyone who took part.



*Some of the ladies of the IHS who took part in the Women's Mini Marathon*

A HIV/Hepatitis C Conference took place in Kilkenny in the Pembroke Hotel over the weekend of the 17<sup>th</sup> to the 19<sup>th</sup> of June. Attendance was very good with 20 people going to the various sessions. The talks were very well received in particular the talks given by Dr. Colm Bergin, St. James's Hospital, in relation to new treatments and Michelle Tait (HSE) in relation to the HAA Card and people's entitlements. The strategy of having one conference worked well, particularly with new treatments being licenced.

#### **IN SEPTEMBER 2011 -**

On September 10<sup>th</sup> and 11<sup>th</sup>, a Conference was held in the Clarion Hotel, Liffey Valley in Dublin for young men with haemophilia aged between 18 and 35 years of age. This was a tremendous success as a lot of young men seem to lose interest in the haemophilia conferences after a certain age. The first talk was on travelling which was really beneficial as a lot of young men in this age group are thinking of travelling abroad maybe for work or holidays. The second talk was on work and college and the challenges facing them in these areas. There was a lot of positive feedback after this conference to the extent that this may very well become an annual event.

#### **IN OCTOBER 2011 -**

The Members' Conference took place from the 14<sup>th</sup> to the 16<sup>th</sup> of October in the Carlton Shearwater Hotel, Ballinasloe and everyone attending seemed to greatly enjoy the weekend. The topics covered at this conference ranged from fitness and health to dealing with and recognising depression and helping to cope with it. Again the emphasis of these talks was on the importance of leading a healthy lifestyle with plenty of exercise and a good nutritional diet which included a healthy eating presentation given by John Stack and a cooking demonstration given by the hotel chef, which I'm sure motivated everyone to start getting fit and healthy.

The Kidlink Group had lots of activities to keep them entertained and the Youth Group had a great time at the Lilliput Adventure Centre.



The IHS Memorial Statue

### **IN NOVEMBER 2011 -**

A Memorial Service was held in the Offices of the Society on November 6<sup>th</sup> in memory of our members who have passed away, but who are by no means forgotten. They were remembered for the light and joy that they brought to the lives of their loved ones.

A Number of Regional Meetings were organised for November which included Letterkenny and Galway. These Regional Meetings are a very important part of the Society's Work as it gives the members a chance to raise any issues that are of concern to them and anything that they might need assistance with.

The organising of these conferences would not be possible without the valued assistance of all our volunteers. Their help and support are really appreciated and the Society wishes to thank people who volunteered during 2011:- Liz McDonald, Erika Nasickyte, Carmel Downey, Claire Neil, Aoife Downey, Catriona Moriarty, Eoin Moriarty, Ciaran Dowling, Lucia Prihodova, Catriona Mulhall, Paul Dunne, Niamh Mangan, Barbara Guilfoyle, Aislinn Farrelly, Jane Smith, Sara Charnock, Julie McAuley, Laura McAuley, Orlaith Sweeney, Denise Maher, Cathal Rochford, Claire Moriarty, Edward Jackson, Niamh Mangan, Andrew Manifold, Teresa Howes, Deirdre Ryan, Sarah Gilgunn, Donal McCann, Daniel Carey, Ainsley Peters and Jenny Graves.

### **CONFERENCES AND OTHER EVENTS: -**

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

The European Haemophilia Consortium Conference took place in the Marriott Hotel in Budapest. Debbie Greene our Administrator and Ger O'Reilly our Treasurer represented the Society at the Conference. The lectures included topics such as "Improving Haemophilia Care in Europe", "Inhibitors" and a Debate on "Prophylaxis".

The UK Haemophilia Society AGM took place in Glasgow on the 5<sup>th</sup> and 6<sup>th</sup> of November, 2011. Nina Storey our Administrative Assistant along with Pat Downey and Brian Byrne, our elected board members, represented the Society. The topics covered at this conference included "Fit for Future Treatment & Care", "Benefits of Physiotherapy", "Advocacy" and the Benefits of "Relaxing Treatments". Again, the emphasis seemed to be on health and fitness.

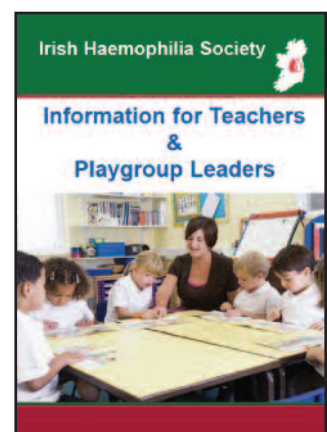
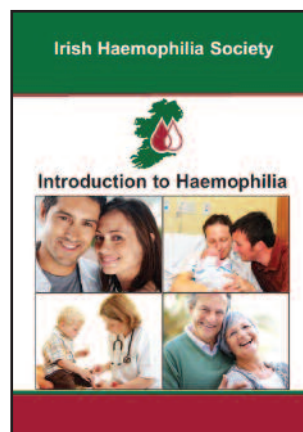
### **GRANTS AND SCHOLARSHIPS**

Our Grants & Scholarships programme is proving very successful and a total of €18,000 was paid out in 2011.

### **PUBLICATIONS**

The society had a busy year with its publications, issuing 4 Magazines, an Annual Report, an Introduction to Haemophilia Booklet, a How to Recognise a Bleed Poster & Booklet, a Hepatitis C Supplement, a Von Willebrand Disease Booklet, an Introduction Pack for Adults and an Introduction Pack for Children.

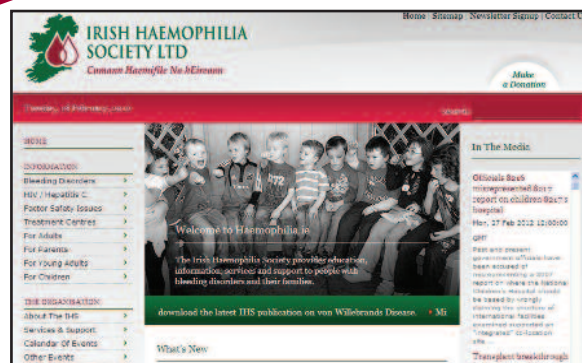
Copies of all IHS publications can be downloaded from the website [www.haemophilia.ie](http://www.haemophilia.ie) or can be obtained in hardcopy from the Office





## **WEBSITE**

The Society's Website is updated regularly with all the latest information and was recently refreshed to keep up with our super cool members.



*The new look IHS Website*

## **I.H.S. STAFF**

The Irish Haemophilia Society Staff have done a fantastic job this year keeping the show on the road with their professionalism and hard work and they are very much appreciated.

The Current Society Staff are:-



Brian O'Mahony,  
CEO



Debbie Greene,  
Administrator



Anne Duffy,  
Counsellor



Nina Storey,  
Administrative  
Assistant



Declan Noone,  
Administrative  
Assistant



Nuala Mc Auley,  
Administrative  
Assistant



Fiona Brennan,  
Administrative  
Assistant

## **SOCIETY REPRESENTATION**

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

National Haemophilia Council – Brian O'Mahony & Debbie Greene

Haemophilia Product Selection Monitoring Advisory Board – Brian O'Mahony & Declan Noone

Haemophilia HIV Trust – Brian O'Mahony & Nina Storey

Disability Federation of Ireland – Debbie Greene

World Federation of Haemophilia – Brian O'Mahony, Anne Duffy & Declan Noone

European Haemophilia Consortium – Brian O'Mahony

Consultative Council on Hepatitis C – Anne Duffy

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

We also wish to acknowledge with gratitude all donations received during the year and the efforts of our fundraisers. We understand that fundraising is very difficult in today's climate but all efforts are greatly appreciated and hopefully things will improve as we look forward positively.

**Mary Hanney,  
Honorary Secretary**



## New to the Society in 2011

The AGM 2011 saw an election for the executive board. Following a hard fought contest (which included a second vote), Brian O'Riordan was elected onto the board. Brian has been a member of the Society for over 20 years and brings a lot of energy, new ideas and experience to the board.

## Musical Chairs

2011 saw a new Chairperson for both the Irish Haemophilia Society and the National Haemophilia Council. Following the I.H.S. AGM in March, Michael Davenport stepped down from the position of Chairperson. Traci Dowling, was then elected the new Chairperson of the Society, having been Vice - Chairperson for the previous three years. Michael had served as Chairperson of the I.H.S. for ten years and to acknowledge his contribution, the Society held an appreciation evening in the I.H.S. office in July.



In July 2011 Professor John Bonnar stepped down as Chairperson of the National Haemophilia Council (NHC) having served in the role since the council was set up in 2004. Dr. Barry Harrington has since taken up the role of NHC Chair. To thank John for all his hard work and to welcome Barry onto the Council the Society held an evening in the office last year.



## Wiz Kids

The I.H.S. is dedicated to the education and involvement of children in the Society. Each group is given a programme specifically targeted to their age group. In 2011 these programmes included; swimming, team building and infusion workshops, arts and crafts, trips to adventure centres and bowling. One of the highlights of the year for the Kidlink Group was the creation of a video on haemophilia, and for the Youth Group was the production of three podcasts. The video and podcasts can all be downloaded from [www.haemophilia.ie](http://www.haemophilia.ie)



## Check us out

The IHS website [www.haemophilia.ie](http://www.haemophilia.ie) was redesigned in 2011.

## Gone Camping

The Society were very lucky to have been offered two places at a Summer camp in Hungary for boys with haemophilia aged 13 to 17. Having submitted letters of interest, two young adults were selected to attend and along with I.H.S. staff member Fiona Brennan they flew out to Hungary in July. During the 8 day camp the boys took part in canoeing, hiking, swimming, educational sessions and infusion workshops. A great time was had by all involved and we are very grateful to the Hungarian Haemophilia Society for allowing us to attend.

Fiona, Thomas and Jordan wrote reports on the camp, which can be viewed on [www.haemophilia.ie](http://www.haemophilia.ie)



## Cork takes Centre Stage

A new Treatment Centre opened in Cork University Hospital. An Open Day was held at the new centre in February and gave I.H.S. staff and members a chance to view the new facilities. The Centre was officially opened on Monday July 25<sup>th</sup> by Minister for Health & Children, Dr. James Reilly, T.D.



## Gone, but Never Forgotten

In April 2011 the I.H.S. Community was saddened at the death of Fr. Paddy Mc Grath. Members of the Society will know Paddy was a great friend and support to everyone at the I.H.S. He will always be remembered with great fondness and will never be forgotten by the I.H.S.



## The Start of a New Journey

The Irish Haemophilia Society started a twinning programme with Vietnam in 2011. A country just starting out on a journey to better care, with a community that is active and productive, with committed doctors and enthusiastic young patient leaders. A country currently coping with a very low provision of replacement therapy and difficult hospital conditions. Our work has started, and will continue for 4 years and it is hoped that we can focus on building the capacity and skills of the patient organisation.

## Daly Departure

Alison Daly was Kidlink and Youth Co-ordinator for over 10 years. Due to various commitments, Alison stepped down from this role at the AGM in 2011. IHS staff member Fiona Brennan took over the role as Children's Programme Co-ordinator. Alison' contribution to the Society was immense and she hopes to continue to be active in the Society.



## The I.H.S. Goes Green

Anyone who has volunteered or fundraised for the Society in the previous years has had the pleasure of sporting an I.H.S. t-shirt. The bright orange certainly stood out, but did not seem to be a colour of choice with most members. So when a new t-shirt was needed we let the people decide and held a vote at the 2011 AGM to find the new colour and design of the t-shirt. In June, just in time for the Mini Marathon, the results were in and the I.H.S. went green. We hope you agree that everyone looks great in the new t-shirts. We're sure other charities are **GREEN** with envy!!



## Better Together

October 2011 saw the I.H.S. launch their "Better Together" video. The "Better Together" video competition is run by The Wheel, an umbrella group for charities and helps charities fundraise and promote their profile. The video can be viewed on the IHS website. A huge THANKYOU to everyone who took part in the video and to Shay Farrelly the fabulous director; an Oscar could be on its way!

# The Year in Review from our CEO



Brian O'Mahony  
Chief Executive

We have had a very busy and productive year against the background of a difficult economic climate. We would perhaps have expected that, due to the economic situation, attendance at our conferences would decrease. In fact the opposite was the case in 2011; we saw an increased attendance at all three of the major conferences during the year. The Annual General Meeting and Conference attracted an attendance of 187, the Parent's Conference 131 and the Members' Conference 168. The Society subsidises attendance at the conferences for our members, but members still have to pay a significant sum to attend. It is therefore

encouraging that in the present economic climate, members will make the effort to attend the conferences in such large and increasing numbers. It is worth pointing out that attendance at our conferences is the highest as a proportion of membership in any of the Haemophilia Societies in developed countries. We are helped by geography and the relatively small size of the country; we are also helped by the strong sense of community we have worked so assiduously to foster. Our members vote with their feet, they are attending the conferences more regularly and in large numbers because they are clearly benefitting from them. The Parent's Conference is also having a year round impact. The Parent's Conference annually now attracts a number of new families with haemophilia to the organisations events. Many of these families benefit to the extent that they subsequently decide to attend the Members' Conference in October and the Annual General Meeting and Conference in March. The Annual General Meeting and Conference in March included sessions on prophylaxis, twinning, ageing, von Willebrands Disease and an update from the Comprehensive Care Centres.



*Attendance at IHS conferences & events increased in 2011.*

The Parent's Conference was once again organised in collaboration with the Haemophilia Care Team in Our Lady's Childrens Hospital, Crumlin. The programme included an introduction to the Parents Empowering Parents Programme, which we will be rolling out on a larger basis in 2012. This programme is designed to teach parents the skills required to raise a child with haemophilia and it includes training for parents, social workers and nurses who can then in turn deliver the learning module to other parents in the future. The Parents Conference also including sessions on bullying for both the adults and children.

The Members' Conference in October had a broad theme of taking control of your health. Proactive management of your health, both physical and mental health was emphasized. The fully inclusive programme included lectures and workshops on topics such as good mental health, exercise and diet. Practical workshops were held on exercise and healthy cooking. The conference reinforced the idea that good haemophilia care should be complimented by good general health and that good general health should extend not just to the person with haemophilia but to the entire family.



*Using Wii Fit members were shown fun ways to get active and keep healthy at the Members Conference.*

In 2011 we also again held the annual conference for members with HIV and/or Hepatitis C. A major theme of the conference this year was the upcoming availability of new therapies for Hepatitis C. New therapies look very promising and we are working with members to ensure that all of the members with Hepatitis C are fully aware of the new therapies and will consider treatment in the near future where indicated. To this end, we also produced a specific publication in relation to Hepatitis C at the end of the year and this shall become a regular feature in 2012. We also identified a need for a conference for young men with haemophilia; this conference was held for men with haemophilia aged between 18 and 35. This conference was successful and will now be repeated in 2012. A specific conference was also held for Women with Bleeding Disorders and in addition the publication we produced on this topic was circulated to every obstetrician and maternity unit in the country.



With attendances at events increasing a volunteer recruitment drive began in 2011 to increase the capacities of the childrens groups and allow them to undertake numerous activities including a popular "Teddy Bear Picnic" pictured above centre.

The major and increasing attendance at our annual conferences and the fact that we have programmes for children and teenagers in different age groups means that we have a requirement for a large number of trained and committed volunteers. Our conferences are cost effective because we rely on a large number of volunteers to organise and run programme strands at the conferences. We are fortunate that we have a volunteer driven programme and a large number of committed volunteers. However in 2011, we realised that we needed to attract new volunteers and we have started an ambitious programme of volunteer recruitment where we are targeting specific colleges, courses and groups of individuals to volunteer for the organisation. The individuals who express interest are vetted, offered induction training and then given Child Protection Training before starting their volunteer work with the Society.

### Treatment of Bleeding Episodes

#### HOW TO RECOGNISE A BLEED

Your child may experience some or all of the following:

**Head Bleed**

- \* Headache
- \* Drowsiness
- \* Nausea
- \* Vomiting
- \* Unsteady balance
- \* Irritability
- \* Confusion
- \* Seizures
- \* Loss of consciousness

**Abdominal Bleed**

- \* Bloody, black or tar-like bowel motions
- \* Red or brown urine
- \* Pain
- \* Vomiting of blood (blood may be red or black)

**Joint or Muscle bleed**

- \* Tingling/tightness
- \* Pain
- \* Redness
- \* Swelling
- \* Warmth
- \* Tenderness
- \* Reluctance to move affected limb

**FOR OFFICE USE**

Date: \_\_\_\_\_

Name: \_\_\_\_\_

MRN: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

Weight: \_\_\_\_\_

Prophylaxis: \_\_\_\_\_

Frequency: \_\_\_\_\_

Dose: \_\_\_\_\_

Review Date: \_\_\_\_\_

In 2011, we refreshed the appearance of our publications. In addition to the regular magazines we produced a number of specific publications including Information for Teachers and Playgroup Leaders, Introduction to Haemophilia, an information booklet on Taxation Issues and a poster and booklet on How to Recognise a Bleed. We also produced a dental leaflet for children with hereditary bleeding disorders. The Society also had published a number of journal articles and publications in peer reviewed journals. These included publications on Haemophilia Care in Europe, A Survey on Prophylaxis and On-Demand Treatment in 4 European countries and a monograph on Economics and Haemophilia. Our website continues to attract increasing numbers of visitors and the Facebook page was also popular.



The IHS produced 11 publications in 2011.

2011 saw the culmination of several years work with the National Haemophilia Council and with the Haemophilia Care Team in Cork, in that the new Comprehensive Treatment Centre in Cork University Hospital finally opened. The new facility was opened by Minister for Health, Dr. James Reilly in July. We are delighted that this new facility will, at last, offer people with haemophilia and bleeding disorders in Cork and the Munster region access to a comprehensive care facility of the required standard. Our service to members in the Cork region also increased evidenced by the fact that the Society had an attendance at 11 specific clinics at CUH, where we were able to meet with members who attended the clinics on those specific dates.



**Top Left:** Members of the National Haemophilia Council met before the official opening of the new Haemophilia Treatment Centre in CUH..

**Top Right:** I.H.S. staff members Declan Noone, Nuala Mc Auley and I with the Haemophilia Nurses from CUH at the Haemophilia Treatment Centre Open Day.

I also met with the Chief Executive Officer and the Hepatologist from St Vincent's Hospital in Dublin in relation to ensuring effective liaison between the Comprehensive Care Centres and the hospital for members with Hepatitis C who are undergoing assessments for possible liver transplants. There are a significant number of people with haemophilia with Hepatitis C who will almost certainly require treatment or retreatment in the coming years. There are also a significant number of older individuals with haemophilia with severe mobility problems who have to visit the treatment centres on a more frequent basis. We believed that the time was opportune for the Society to purchase an apartment close to the National Centre at St James's Hospital which can be used by members and their families. We initiated this process in 2011 and we believe that this facility which will be in use in 2012 will be very beneficial for adults with haemophilia from outside of Dublin, for parents with children attending Our Lady's Hospital in Crumlin and for in-patients of St James's and their families.

The personal level of communication and support that the I.H.S have with our members was again very evident during the year. Society staff were personally in contact with 89.2% of members by phone during the year. A number of members were also visited at home and regional meetings with members took place in Cork, Kerry, Donegal and Galway. Phone calls with members have become an integral part of our service and it allows us to keep in contact with members to ensure that we are meeting their needs, to identify any unmet needs and to get feedback on our services and support. Even if haemophilia care is centred around the three Comprehensive Treatment Centres, a supply of factor concentrates is kept for emergencies in all acute hospitals around the country. We were concerned however, following a number of specific incidents over the past two years, that if a person with haemophilia presents at a treatment centre, which was not a comprehensive treatment centre, they were subjected to inordinate delays before being treated with factor concentrates. We were very strongly of the view that a person with haemophilia attending an emergency department could wait, if required, for diagnostic tests or scans, but they cannot wait if they require an infusion of factor concentrates for a bleeding episode. To this end we produced specific Bleeding Disorder Alert Cards for the three Comprehensive Treatment Centres. The centres send these cards out to people with severe haemophilia. The objective is then that any member who attends an emergency department should immediately show this card to the Doctor or Triage nurse. The card instructs the Doctor or Triage nurse to immediately contact the relevant person at the relevant comprehensive treatment centre for advice and information on how to treat the person with haemophilia.

Once again in 2011, we awarded 16 educational grants for people with haemophilia or siblings. The standard and quality of applications was extremely high and it was a pleasure as always to see the significant number of people with haemophilia and siblings availing of third level education.



Our work on statutory bodies continues. We played an active role on the National Haemophilia Council and Haemophilia Product Selection and Monitoring Advisory Board and the Consultative Council on Hepatitis C. The Haemophilia Product Selection and Monitoring Advisory Board completed a procurement process for Factor VIII concentrates for the next two years during the course of 2011. The process, with our involvement, resulted in significant savings for the exchequer with no decrease in the quantity or quality of replacement therapy being purchased. We also decided in the course of the year to bid to host the World Federation of Hemophilia Global Congress in Dublin in 2018 and we worked with the Dublin Convention Bureau and convention facilities in Dublin to put together this bid.



**Top:** Ciaran Dowling receiving the Maureen Downey Educational Grant from Pat Downey.

**Bottom:** Sarah Gilgunn receiving the Margaret King Educational Scholarship from Michael Davenport

Financially, it was once again a challenging year. Income and expenditure levels were remarkably similar as 2010. This, in my view, was a considerable achievement considering our core funding from the HSE was reduced for the year and also donations from members were significantly reduced as indeed was fundraising income. We managed to increase funding from the corporate sector and also funding for our twinning programme. Despite the increased numbers of programmes and activities, the increased numbers of publications and the significantly increased attendances at conferences which results in greater subsidy from the I.H.S. we managed to maintain expenditure at exactly the same level as 2010. Our Income and expenditure results show a surplus of just over €84,781. However this does not take into consideration the mortgage repayments of €99,787 the vast majority of which was capital repayments – therefore in reality we had a deficit of €15,000. It is worth noting that the amount outstanding on our mortgage is €74,179, which will be paid off in late 2012. This is a very significant achievement given the fact that we took out a 15 year mortgage in 2006 as we will have paid this off in 6 years.



**Above:** Hillary O'Sullivan presenting the Bill O'Sullivan Fundraiser of the year award to Niall Jackson, Edel Jackson, Philip & Susan Clarke and Vincent Jackson.

The year was marked by the very sad passing of Fr Paddy Mc Grath. Paddy was involved with the Society for more than 20 years and first started working with us in the very dark days of the late 1980's when the full impact of HIV was becoming apparent in the haemophilia population. He was a great comfort to many people with haemophilia, many families and to the organisation as a whole. He officiated at many, far too many, funerals but also at joyous occasions such as baptisms and marriages. He will be greatly missed but never forgotten. We have instituted a Fr Paddy Mc Grath Educational grant for a person with haemophilia in his memory.

In summary, the year was challenging, but rewarding. It was very uplifting to see the increased attendance of members and engagement of members in our conferences and activities and the ever increasing number of publications being sent to our ever increasing mailing list. I want to thank the staff, board and other volunteers for their exemplary work throughout the year.

**Brian O'Mahony,**  
Chief Executive

## **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 2011, 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.

## **Respective responsibilities of directors and auditors**

As described in the statement of directors' responsibilities the company's directors are responsible for the preparation of the financial statements in accordance with applicable law and Accounting Standards issued by the Accounting Standards Board. Our responsibility is to audit the financial statements in accordance with relevant legal and regulatory requirements and International Standards on Auditing (United Kingdom and Ireland). We report to you our opinion as to whether the financial statements give a true and fair view in accordance with Generally Accepted Accounting Practices in Ireland and are properly prepared in accordance with the Companies Acts 1963 to 2009. We also report to you whether in our opinion: proper books of account have been kept by the company; whether, at the balance sheet date, there exists a financial situation requiring the convening of an Extraordinary General Meeting of the company; and whether the information given in the Directors' Report is consistent with the financial statements. In addition, we state whether we have obtained all the information and explanations necessary for the purposes of our audit and whether the company's balance sheet and its income and expenditure account are in agreement with the books of account. We report to the members' if, in our opinion, any information specified by law regarding directors' remuneration and directors' transactions is not given and, where practicable, include such information in our report. We read the directors' report and consider the implications for our report if we become aware of any apparent misstatements within it.

## **Basis of audit opinion**

We conducted our audit in accordance with International Standards on Auditing (UK and Ireland) issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgements made by the directors in the preparation of the financial statements, and of whether the accounting policies are appropriate to the company's circumstances, consistently applied and adequately disclosed. We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements. We have undertaken the audit in accordance with the requirements of APB Ethical Standards - Provisions Available for Small Entities, in the circumstances set out in note 11 to the financial statements.

**Copies of the full audited accounts for 2011 are available on request.**

### **Registered Office**

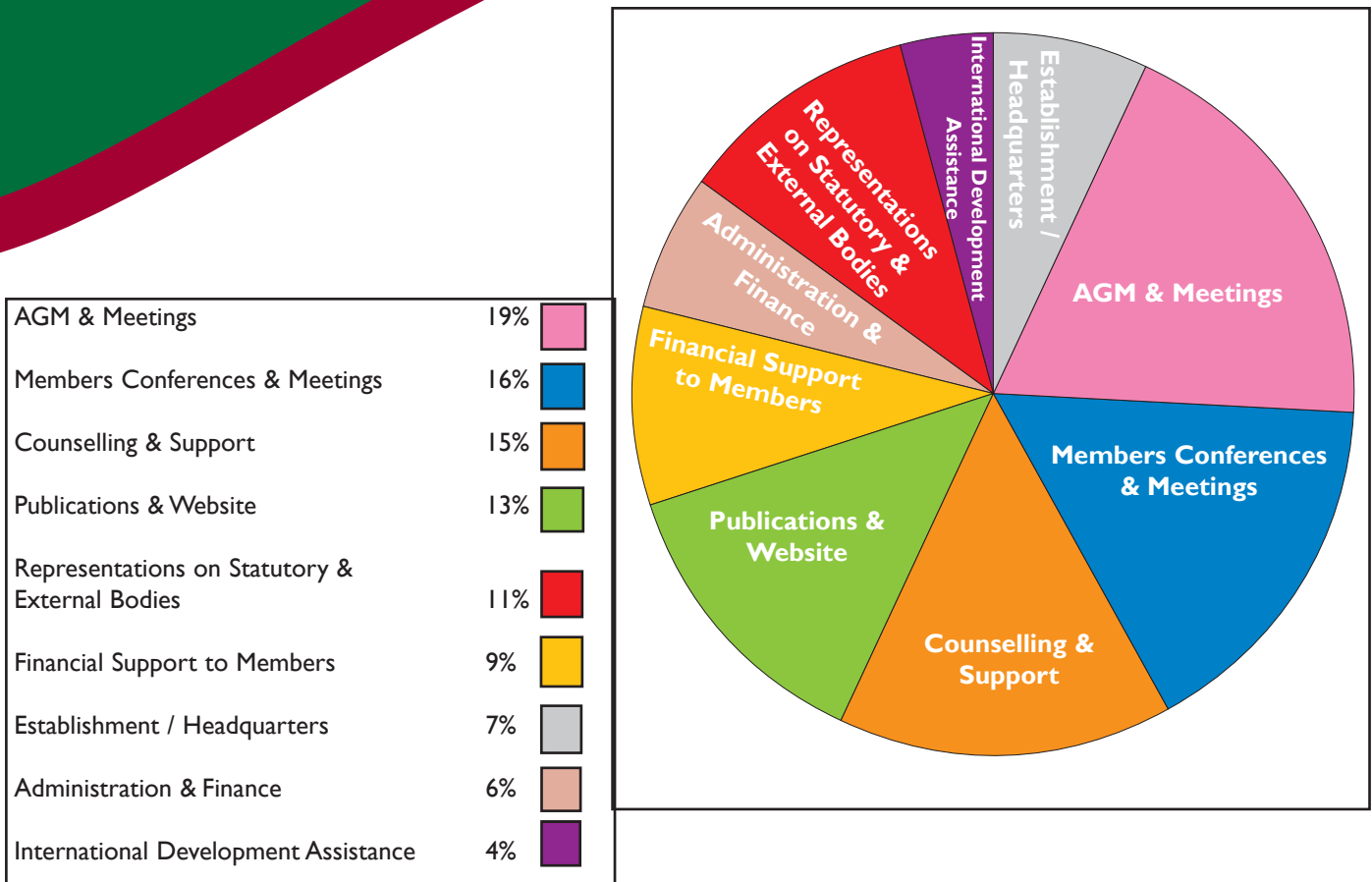
Irish Haemophilia Society Ltd., First Floor,  
Cathedral Court, New Street, Dublin 8.  
Company Number: 142834  
Registered Charity Number: CHY9214

### **Auditors**

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



# How we used the money



## Income & Expenditure Account For The Year Ended 31st December 2011

	2011 €	2010 €
<b>Income</b>		
Health Service Executive	577,396	591,523
NCHCD Educational Fund	24,000	24,000
Memberships	3,710	4,950
Donations - Members	23,820	50,044
Donations - Corporate	47,410	32,901
Twinning	10,760	-----
Fundraising	8,729	17,977
H.H.T.Trust	12,750	8,661
Investment Income	35,644	18,269
	<hr/>	<hr/>
	744,219	748,325
Expenditure as per schedule	(659,438)	(659,339)
	<hr/>	<hr/>
<b>Surplus for the year</b>	<b>84,781</b>	<b>88,986</b>





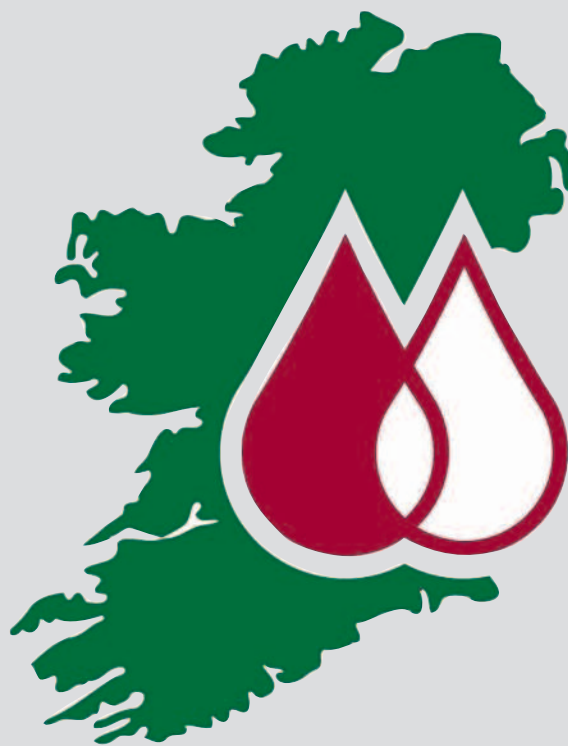
	2011		2010	
	€	€	€	€
<b>Administration Expenses:</b>				
Wages, State Insurance and Pension Costs	225,076		220,042	
Employer's PRSI Contribution	21,604		20,382	
Office Expenses & Stationery	16,618		15,603	
Telephone & Fax	9,280		8,669	
Travelling Expenses	5,019		7,386	
Overseas Travel Expenses	11,575		4,861	
Sundry Expenses	5,211		9,599	
		294,383		286,542
<b>Financial Expenses:</b>				
Bank Charges & Loan Interest	4,586		5,440	
Professional Fees	86,649		74,633	
Audit & Accountancy Fees	5,535		5,445	
		96,770		85,518
<b>Activites:</b>				
Help to Members	25,470		23,518	
Family Activities	-----		6,000	
H.H.T. Trust	6,750		7,000	
Subscriptions	1,495		1,650	
Fundraising Expenses	1,365		1,323	
A.G.M. & Meeting Expenses	35,330		31,380	
Postage, Publications & Photocopying	23,694		25,853	
Educational Grants	16,000		23,000	
Safety/Supply Activities	8,988		5,651	
Counselling & Support Meetings	14,304		15,160	
Twinning	6,283		3,319	
Website	4,509		762	
WFH GAP Program/Development Grants	7,264		14,483	
Sponsorship/Training	1,515		11,836	
Parent's Conference	17,338		18,334	
Members' Conference	21,496		19,568	
		191,801		208,837
<b>Establishment Expenses:</b>				
Service Charge & Insurance	16,056		9,343	
HQ Costs	2,200		4,124	
Computer Services	9,510		9,277	
Light, Heat & Services	13,700		11,343	
		41,466		34,087
<b>Other Costs:</b>				
Depreciation - Fixtures, Fittings & Equipment	8,736		18,073	
Depreciation - Land & Buildings	26,282		26,282	
		35,018		44,355
<b>Total Expenditure</b>		<b>659,438</b>		<b>659,339</b>

	2011	2010
	€	€
<b>ESB Mortgage Account:</b>		
Opening Balance 01.01.11	171,142	
Interest Charges	2,824	
Monthly Repayments (Capital & Interest)	<u>(99,787)</u>	
Closing Balance 31.12.11	74,179	

### Balance Sheet As At 31st December 2011

	2011		2010	
	€	€	€	€
<b>Fixed Assets:</b>				
Buildings Note 5	1,142,387		1,168,669	
Office Equipment & Fittings Note 5	----		8,736	
	<u>1,142,387</u>		<u>1,177,405</u>	
<b>Current Assets:</b>				
Davy Investment Portfolio	170,000		170,000	
Irish Nationwide Building Society-Deposit Account	----		107,184	
Educational Building Society-Deposit Account	----		180,000	
Allied Irish Bank-Current Account	296,215		143,450	
Allied Irish Bank-Planned Giving Current Account	16,771		9,508	
Allied Irish Bank-Deposit Accounts	186,476		203,540	
Permanent TSB-Deposit Account	187,560		-----	
Cash on Hand	95		332	
Sundry Debtors & Prepayments Note 6	5,275		-----	
	<u>862,392</u>		<u>814,014</u>	
<b>Current Liabilities:</b>				
Sundry Creditors & Accruals Note 7	(111,706)		(86,164)	
Net Current Liabilities	<u>(111,706)</u>		<u>(86,164)</u>	
	750,686		727,850	
<b>Long Term Liabilities</b>				
Long Term Property Loan Note 8	<u>(74,179)</u>		<u>(171,142)</u>	
<b>Net Assets / (Liabilities)</b>	<u>1,818,894</u>		<u>1,734,113</u>	
<b>Represented By:</b>				
<b>Accumulated Funds</b>				
Balance 1st January 2011			1,645,127	
Surplus for the year		1,734,113	88,986	
		<u>84,781</u>	<u>88,986</u>	
Balance 31st December 2011 Note 9		<u>1,818,894</u>	<u>1,734,113</u>	





**IRISH HAEMOPHILIA SOCIETY**

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New Street  
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