haemophilia.ie

Magazine of the Irish Haemophilia Society

Winter 2008

Announcing AGM 2009

6th - 8th March

The Carlton Shearwater Hotel, Ballinasloe, Co. Galway

Preliminary AGM 2009 Programmes

ADULTS

Friday 6th March

5.30pm – 7.00pm	**Registration**

Saturday 7th March

10.00am – 12.30pm	**Business of AGM**
1.00pm – 2.00pm	Lunch
2.00pm – 3.00pm	**Haemophilia in India** Dr. Mammen Chandy
3.30pm – 5.00pm	**Update on Haemophilia Services in Ireland** Dr. Barry White Dr. Beatrice Nolan
7.00pm	**Mass**
8.00pm	**Gala Dinner**

Sunday 8th March

10.00am – 11.30am	**Von Willebrands, Carriers & Women's Issues** Dr. Paul Giangrande **No Country for Old Men, Ageing & Haemophilia** Evelien Mauser Bunschoten
11.30am – 1.00pm	**Open Forum**
1.00pm – 2.00pm	Lunch

KIDLINK

Friday 6th March

5.30pm – 7.00pm	**Registration**
7.00pm – 10.00pm	**Games**

Saturday 7th March

10.00am – 11.30am	**Swimming**
12.00pm – 1.00p.m.	**Interactive Information Session** **Age 7 to 11 years** The story of the two boys with haemophilia **Age 12 to 17 years** Comparative look at haemophilia care: India & Ireland
1.00pm – 2.00pm	Lunch
2.00pm – 5.00pm	**Make a Movie**

Sunday 8th March

10.30am - 11.30am	**Age 7 to 11 years** Arts n Crafts: Postcards **Age 12 to 17 years** Video Message
11.30am – 12.30pm	**Age 7 to 11 years** Circle Time **Age 12 to 17 years** AGM Memories: Photo Collage
1.00pm - 2.00pm	Lunch

CRECHE

For children up to 6 years of age, our experienced creche supervisors will organise all activities for the 2 days.

Creche Opening Hours

Saturday **09.30am to 5.00pm**
Sunday **09.30am to 12.30pm**

Parents, please remember to bring a change of clothes for your child.

Contact Details

Irish Haemophilia Society,
First Floor,
Cathedral Court,
New Street,
Dublin 8.

Phone: 01 6579900
Fax: 01 6579901

Email: info@haemophilia.ie

Website: www.haemophilia.ie

Editor: Debbie Greene

Email: debbie@haemophilia.ie

Executive Board:
Chairperson
Michael Davenport

Vice Chairperson
Traci Dowling

Secretary
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Debbie Greene
Declan Noone
Nuala McAuley

Youth Group/Kidlink Co-ordinator
Alison Daly

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Memorial Sculpture

12 - 17 Read all about the October weekend. From a members perspectives Pat Downey writes about the Adult programme. Paul Dunne gives his account of the Young Adult programme which took place in Birr Adventure Centre. Declan Noone writes about the fun packed exhausting Kidlink programme and Carmel Downey writes about her little darlings in the creche......

18 Members update yourself on Safety and Supply issues on page 18....

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20 Grants, Scholarships, Christmas Greetings, find this and more on our Noticeboard pages 20 and 21....

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Mens Pilates Session


Kidlink Girls 'Its my turn now'.

Message from the Chief Executive

The Kidlink Group

October Conference

For the third year in succession the Society organised a conference in October. This year the conference was held in Birr in Co. Offaly and was very well attended by sixty three adults, nine young adults, nineteen kidlink children and fifteen creche children.

A full report on the conference is contained in the newsletter. For me the highlights of the conference were the participatory events on the Saturday afternoon. For the ladies, there was a belly dancing workshop which was hugely enjoyed by all in attendance. Unfortunately my efforts to provide a photographic record of the belly dancing workshop were foiled when my camera was confiscated at the entrance to the workshop. For the men there was a session on physiotherapy and hydrotherapy. This session was very well attended. The physiotherapy session took the form of a modified version of pilates with additional stretching and flexibility exercises. The session was accompanied by an audible soundtrack of moans and groans by all of the participants. The hydrotherapy session was equally vigorous and beneficial. On the Sunday morning, there was debate between two young men with haemophilia. Declan Noone and Colm O'Sullivan debated the topic *"Are there limits to my life activities?"*. Following their presentations and an interactive discussion with the audience, the audience voted that there are not limits to the life activities of a person with haemophilia. This conference is now very much part of the calendar and will take place again next year from 16th -18th October.

40th Anniversary and Memorial

This year is the 'Fortieth Anniversary' of the Irish Haemophilia Society. We have come a long way in the last forty years. In 1968 a small group of parents and healthcare workers got together to form the Irish Haemophilia Society. Initially the work was targeted at identifying people with haemophilia around the country and the setting up of a treatment centre in Dublin. Over the course of the past forty years many people with haemophilia, parents, family members and healthcare workers have worked tirelessly for and with the Irish Haemophilia Society to improve the quality of life for all people with haemophilia and their families. As an organisation and as a community we have come through many periods where it was easy to become discouraged, where improvements in care and treatment were slow in becoming a reality and of course we went through the horrific trauma of the infection of so many people with HIV and Hepatitis C, and the devastating impact on people with haemophilia and their families. Nietsche said *"that which does not destroy us,* serves *to make us stronger"*. I believe that this is very much the case with the haemophilia community in Ireland. We have not only survived the traumas, trials and tribulations of the past twenty years but have emerged stronger, more united, more focused as an organisation and as individuals. Lessons have been learned from the past and the reality that people with haemophilia and parents of children with haemophilia need to be educated about the condition and the need to be proactive in ensuring that they and their children get the best care is firmly embedded. The formal involvement of the community, through the Society's role on the National Haemophilia Council, the Haemophilia Product Selection and Monitoring Advisory Board and the Consultative Council on Hepatitis C ensure that the views of the haemophilia community are not just considered but are formally incorporated and embedded in the decision making process in relation to the future development of haemophilia care in Ireland.

A historical timeline of the development of the Society is contained in this newsletter. To mark the fortieth anniversary of the Society, and to commemorate the many people with haemophilia who have died over the course of the past forty years, the Society commissioned a special Memorial Sculpture from the sculptor Jarleth Daly. The sculpture which is bronze with a granite plinth is a representation of forty doves. In the words of Father Paddy McGrath:

"This sculpture represents loss, achievement and hope. It represents all members of the I.H.S, living and deceased. It respectfully recalls those whom we have known and loved and have died before their time. It honours all the living members as well as their families and providers of care who trust that the future may be marked by excellence of service and good quality of life *for us all".*

This sculpture was unveiled at a Memorial Service at the I.H.S office on Sunday the 9th of November. This moving and poignant Service was attended by eighty members of the Society, including many of those who have lost family members, and including some whom we have not had the pleasure of seeing for a number of years. We greatly appreciated their attendance. We invite any member who has not had an opportunity to see the Memorial Sculpture to call into the office, where a Remembrance Book is available, and we do plan to hold a Memorial Service on an annual basis at the I.H.S. headquarters.

Memorial Sculpture

New Hospital Posts

In the last newsletter in September, I reported on progress which had been made in relation to additional staffing posts for the comprehensive haemophilia treatment centres in Dublin and Cork following meetings with the Minister for Health and Children, and with the Director of the National Hospitals Office. Further progress was made prior to the external audit of the treatment centres in September. A new consultant haematologist has been appointed in Our Lady's Childrens' Hospital, Crumlin. The post has been filled by Dr. Beatrice Nolan who has worked for the past number of years in the National Centre in St. James's Hospital and Our Lady's Childrens' Hospital, Crumlin and we wish Dr. Nolan all the best in her challenging new post. The National Haemophilia Council met with the Chief Executive Officer and the Consultant Haematologist in Cork University Hospital at the end of November to discuss proposed plans for a modular haemophilia treatment centre for Cork University Hospital and the appointment of the new consultant haematologist. A report on the external audit of the centres will appear in the next edition of the newsletter.

Website

We are currently in the planning stages of a major overhaul of the Irish Haemophilia Society Website. We hope that the overhaul will lead to a website that has more readily accessible information, more relevant articles and additional information for specific groups, parents of young children with haemophilia, young men with haemophilia and a special children's section. If you have any ideas or suggestions in relation to content for the website please contact Debbie at the Irish Haemophilia Society headquarters.

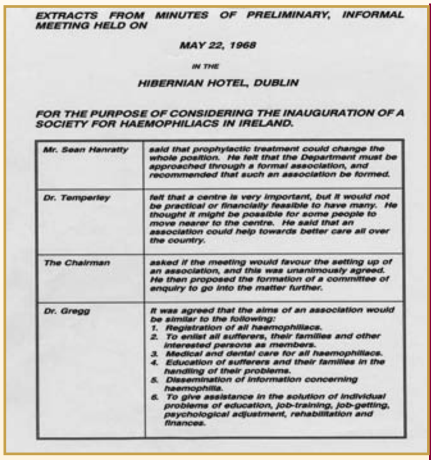
Finally, on behalf of the staff and board of the Irish Haemophilia Society may I wish you all a happy, healthy and peaceful Christmas season.

Brian O'Mahony

I.H.S. The First Forty Years...

To all our members who have journeyed with us over the past forty 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 forty 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.......



EXTRACTS FROM MINUTES OF PRELIMINARY, INFORMAL MEETING HELD ON

MAY 22, 1968

IN THE

HIBERNIAN HOTEL, DUBLIN

FOR THE PURPOSE OF CONSIDERING THE INAUGURATION OF A SOCIETY FOR HAEMOPHILIACS IN IRELAND.

Mr. Sean Hanratty	said that prophylactic treatment could change the whole position. He felt that the Department must be approached through a formal association, and recommended that such an association be formed.
Dr. Temperley	felt that a centre is very important, but it would not be practical or financially feasible to have many. He thought it might be possible for some people to move nearer to the centre. He said that an association could help towards better care all over the country.
The Chairman	asked if the meeting would favour the setting up of an association, and this was unanimously agreed. He then proposed the formation of a committee of enquiry to go into the matter further.
Dr. Gregg	It was agreed that the aims of an association would be similar to the following: 1. Registration of all haemophiliacs. 2. To enlist all sufferers, their families and other interested persons as members. 3. Medical and dental care for all haemophiliacs. 4. Education of sufferers and their families in the handling of their problems. 5. Dissemination of information concerning haemophilia. 6. To give assistance in the solution of individual problems of education, job-training, job-getting, psychological adjustment, rehabilitation and finances.

Minutes from the first meeting on the 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 Haemophilia 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 Childrens' Hospital, Harcourt Street the following year.

Founder Member: Eithne Scanlon

1970 Ninety patients were registered with the National Haemophilia Centre, sixty five with haemophilia A, twenty one with haemophilia B and four 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 television because in this pre-home treatment era, many people spent significant amounts of time as inpatients.

Founder Members:
Jack Downey & Bill O'Sillivan

1975 to 1982 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 sixty and life was becoming normal for many members of the Society.

Home treatment

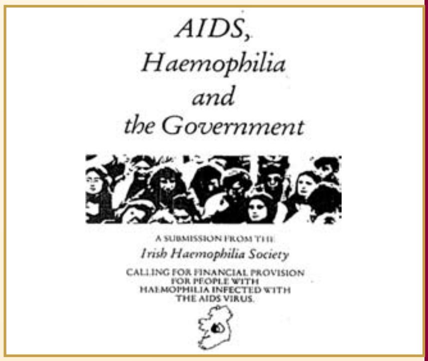
1980s The period from 1983 was a very active, traumatic and emotionally difficult time for the Society with the realisation that the blood products which had at last promised a normal quality of life had resulted in the infection of one hundred and six members of the Society with HIV. It was a devastating blow for the entire haemophilia community. As a direct result of infection with HIV and Hepatitis C, some ninety one 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 but no staff, no resources and no office.

The Meath Hospital

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.

Forever Friend: Margaret King

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.



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.

First submission to government

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.

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 General Election in 1989. This culminated in the setting up of the Haemophilia HIV Trust (HHT). The HHT has provided 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.

I.H.S. team – 1990's

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.

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 haemophiliacs' 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 haemophiliacs', 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 haemophiliacs' in this dreadful situation. It is time for our Government to do likewise".

1991 Concerned by the mounting death toll from HIV and tortuously slow progression of the legal action, the Society once 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 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.

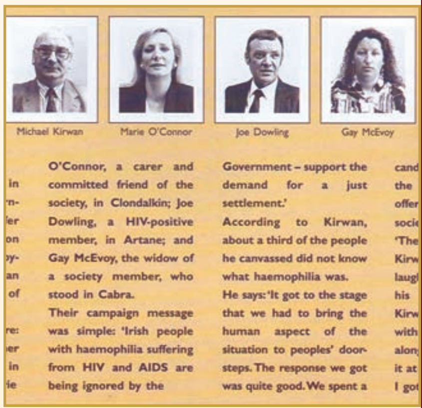
1992 The Society turned its attention to seeking improvements in the provision of comprehensive haemophilia care and monitoring developments with blood products. The Society drew up a Blood Product Policy which was communicated to the Department of Health and the National Haemophilia Treatment Centre. 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.

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.

Rosemary Daly & Brian O'Mahony host a press conference



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' doorsteps. The response we got was quite good. We spent a

Four members stood in local elections

Haemophiliacs accept new £8m offer

Irish Independent, 1 June 1991

Curb on blood imports

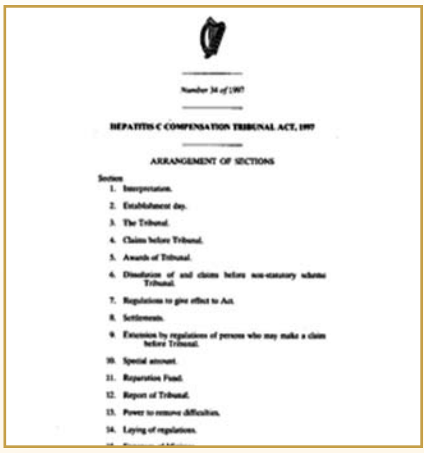
Abdication

Local election campaign by haemophiliacs

Government defeated twice

Campaign Newspaper cuttings

President Mary Robinson at 25th anniversary AGM



Number 34 of 1997

HEPATITIS C COMPENSATION TRIBUNAL ACT, 1997

ARRANGEMENT OF SECTIONS

Section
1. Interpretation.
2. Establishment day.
3. The Tribunal.
4. Claims before Tribunal.
5. Awards of Tribunal.
6. Dissolution of and claims before non-statutory scheme Tribunal.
7. Regulations to give effect to Act.
8. Settlements.
9. Extension by regulations of persons who may make a claim before Tribunal.
10. Special account.
11. Reparation Fund.
12. Report of Tribunal.
13. Power to remove difficulties.
14. Laying of regulations.

Hepatitis C Compensation Tribunal Act

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.

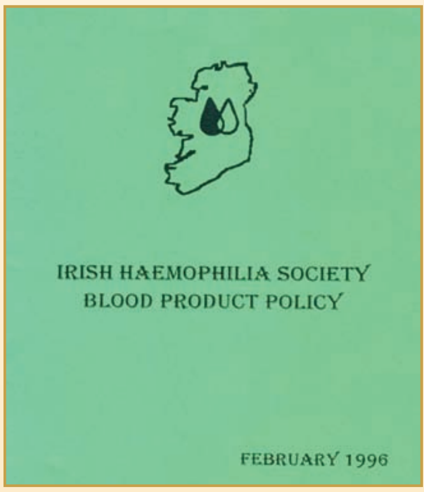
1995 The Society negotiated a Compensation Scheme with the Irish Government for people with haemophilia infected with Hepatitis C and agreed that members would attend the newly established Hepatitis C Compensation Tribunal.

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

WFH Congress 1996 - Dublin

1996 The International Congress of the World Federation of Haemophilia was held in Dublin. Some two thousand, four hundred delegates from seventy 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.

1996 The Society published a new Blood Product Policy, setting out our goals for 2000, including our aspirations for recombinant products for all, and prophylaxis for all children and teenagers.



IRISH HAEMOPHILIA SOCIETY
BLOOD PRODUCT POLICY

FEBRUARY 1996

Blood Product Policy 1996

1997 Seminars for Women with Bleeding Disorders were held in Dublin and Cork, and were attended by a large number of women, many of whom were attending such meetings for the first time. This broadened membership of the Society. The numbers of women joining the Society continued to increase. Following meetings with the Minister for Health, recombinant products were provided for all persons with haemophilia A.

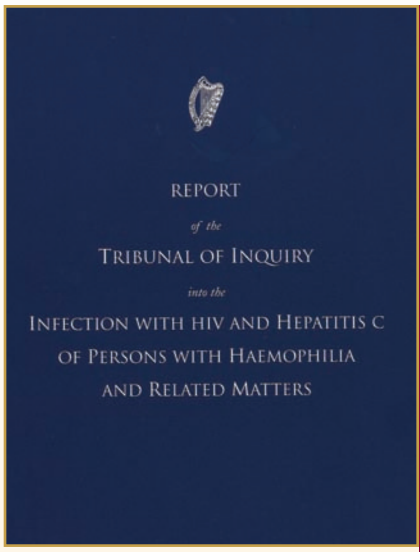
1997 The Society withdrew from the Finlay Tribunal of Inquiry into the Blood Transfusion Service as the tribunal was not dealing in any substantive way with the issues relating to the infection of people with haemophilia.

President McAleese officially opens Headquarters in Smithfield

1997 to 1999 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. Recombinant products were provided for all persons with haemophilia B.

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 moved to a new Headquarters in Smithfield.

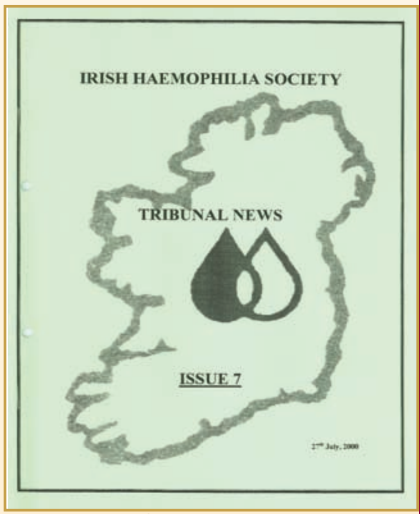


REPORT
of the
TRIBUNAL OF INQUIRY
into the
INFECTION WITH HIV AND HEPATITIS C
OF PERSONS WITH HAEMOPHILIA
AND RELATED MATTERS

Lindsay Tribunal of Inquiry

1999 to 2001

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 one hundred and ninety six days of evidence, the Society presented its final submissions and recommendations for the future on days 189-191 of the Lindsay Tribunal.



IRISH HAEMOPHILIA SOCIETY
TRIBUNAL NEWS
ISSUE 7
27th July, 2000

I.H.S. Tribunal News

2001

The Product Selection Group (now the Haemophilia Product Selection and Monitoring and 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 in the list of selection criteria. To date, the board has completed eight National Tenders resulting in the purchase of some two hundred million units of factor concentrate.

NHC National Haemophilia Council

National Haemophilia Council

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.

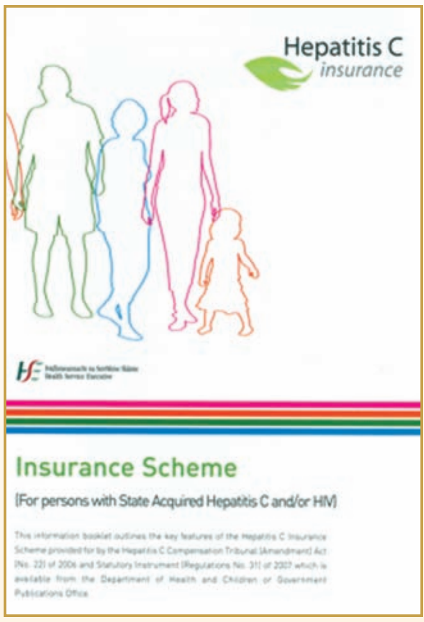
2003

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

Kidlink Group

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 teenagers, young adults, a childrens programme and crèche facilities.



Hepatitis C insurance

Insurance Scheme

[For persons with State Acquired Hepatitis C and/or HIV]

Insurance Scheme

President McAleese opening our brand new Headquarters

Memorial Sculpture

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 commenced. 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, forty percent 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 celebrates 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, 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. This year 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.

October Conference:
‘Adult Programme: A Wonderful Formula’

As most of you will know I am a regular at the October weekend. This, now annual event, is a fantastic opportunity to meet old friends from the greater haemophilia family and learn, experience, or debate together new issues, treatments or therapies that are coming on stream. It is wonderful that a formula has evolved to deliver in a casual family friendly manner, a forum to expand members’ knowledge and understanding of current or future issues. This years’ event took place in The County Arms Hotel, in Birr, Co. Offaly. Below you will find my report:

On Saturday morning talks began with Lisa Cantwell and Carmel Egan giving us a wonderful simplified explanation in plain English of the horrendously complex issue of diet and supplements. Basically best practice is to try to eat a more healthy diet of all the major food groups, therefore you should get in your diet an adequate intake of all the required carbohydrates, fat, proteins, water, vitamins and minerals. Lisa went on to explain the role of various supplements and vitamins which have always been a mystery to me. Printouts of her powerpoint presentation are available from the office if you require further clarification. Remember that a good diet will help you maintain a healthy body weight, aid wound healing and prevent micronutrient deficiencies.

The next presentation came from Brian O’Mahony. Brian gave an overview of the forthcoming plans to celebrate the Society’s Fortieth Anniversary together with recollections of past events and members. We are a vibrant forward looking organisation but we can never forget our sometimes difficult past which has made the Society the principal voice for people affected by bleeding disorders in Ireland today.

Saturday Morning Session ‘Health Supplements’

Michael Walsh & Declan Dunford

Noreen Carey, Joan Carey & Marie Griffiths

Mens Session: Some members attempting the pilates session!

Barretstown is a specially-designed camp for children with serious illnesses from Ireland, Britain and throughout Europe, and their families. Ainslie Peters from Barretstown gave a great presentation into the workings of the camp. The camp provides a unique programme of adventure, activities and fun. This of course is backed-up by on site medical care. The various programmes help children regain their confidence and self-esteem and has become internationally recognised as having a profound and positive impact on their lives. Members and their families who have taken part in programmes have nothing but praise for the high standards of the organisation. The medical world calls their programme 'Therapeutic Recreation', but like the campers, we know it as 'Serious Fun'. After taking part in the programmes, children go home with more confidence, self-esteem and more importantly, the reassurance that happiness is not just for healthy children. Barretstown also recognises the impact of serious illness on the rest of the family. That's why they also run sessions for siblings and for the whole family.

In the afternoon Adeline O'Dowd a Chartered Physiotherapist and Hydrotherapist based in Celbridge Co. Kildare gave a two part practical demonstration focusing on getting people with haemophilia of all ages and abilities to become more active. The first session consisted of trying to get sixteen lads to exercise on large balls and attempt to perform some basic pilates exercises. I have to give all involved a clap on the back for attempting this most difficult, yet rewarding exercise technique. It still brings tears to my eyes at the thought of us all bouncing and falling off our pilates balls in hysterical laughter. The second session was in the pool where Adeline gave all involved an introduction to basic exercises suitable for all. Some of the participants had specific problems and Adeline gave good advice on an individual basis for exercises suitable for these specific problems.

Everyone left this session with some exercises that can be incorporated into their next visit to their local swimming pool.

While the men were busy exercising the ladies attended an excellent workshop facilitated by Anne Duffy entitled 'Time for You'. This workshop gave the ladies the opportunity to speak about any concerns or issues they had. Following the workshop the ladies had a 'belly dancing class' which I believe was fantastic, and I heard it through the grapevine that they even put a short routine together in such a short space of time. The funniest part of this was the fact that the ladies had sellotaped black plastic bags to the windows to prevent any of the men from looking at them belly dancing.

On Saturday evening as usual Jim Dunne and his extended family did an excellent job overseeing this year's quiz that focussed on a musical theme. The dinner was followed by chat and singing late into the night.

On Sunday morning Colm O'Sullivan and Declan Noonan two young members of the Society took part in a vigorous debate on the topic of "Are there limits to my life activities?" They raised and debated the point that even if you are on prophylactic treatment that at best you are still a mild haemophiliac and you should always bear this in mind when you are considering physical activities. The point was also made that even if you are compliant with your prophylaxis and feel on top of the world all it takes is one serious breakthrough bleed to undo the benefit of years of treatment and leave you with serious long term effects in a problem joint. Colm won the debate by convincing the audience that you must be realistic and place some limits on your activities!

The weekend was a great success. The team of I.H.S. staff and volunteers deliver a consistently high standard programme that appears to be truly professional, but we all know that this is down to hard work, dedication and team spirit. I would highly recommend members to consider going on the next members weekend as I am sure they will find something of interest for all the family on the multiple options that will be available. I would highly recommend you to consider going to the next October weekend.

Pat Downey


'You said turn right!'


Margaret Dunne & Instructor Adele De Bruin


'Funny Bunnies' - Winners of the quiz on Saturday night

Young Adults Programme:

'Birr Adventure Centre'

David Carey & Ciaran Dowling

Although Alison was not able to take part this year the programme was led by Barbara who was ably assisted by Amy, Daryl and of course myself. This year the Young Adults programme was held in the Birr Adventure Centre in Co. Offaly. The past two years the programme has been in the Lilliput Adventure Centre which was brilliant so Birr had a lot to live up to.

After a four hour journey by car from Dublin I finally arrived in the Birr Adventure Centre, and found myself climbing around on an indoor rock wall which was great fun. Judging by the amount of time a lot of the guys spent hanging off the wall they enjoyed it too.

Friday night saw the usual playing of silly games and the new idea this year was to create our own style of phonejacker (you would need to have been there for that one). As per usual we ended up having a very late bed time that night. Saturday morning I was the first one up so I figured the best thing to do was really annoy people by flicking all the lights on good and early. After our breakfast we went out for some absailing and rock climbing and I have to say that was the highlight for me, most likely because I don't have a fear of heights. Not everyone felt the same and even though some of the group did have that fear they tried it. We then went back to the centre for some lunch before heading straight back out to do some canoeing, which was a good long drive away, but you can't beat a bus journey with a good sing song to make the journey seem shorter. When we got to our destination we got changed into rather fetching wet suits. The canoeing itself didn't last that long but we had a lot of fun trying to turn the canoes over and wrestle each other out of them. We then had some fun pier jumping which ended up with us trying to throw one another off despite the fact that the water was totally freezing. Maybe it was the cold that made us so mad. After all that fresh air it was good to spend Saturday evening playing Catchphrase which is quite easy but can be very noisy. And to help us all sleep soundly we ended up with some really bad ghost stories.

After breakfast on Sunday morning we joined the full group in the hotel for a debate between Declan and Colm who both obviously had prepared very well on the question "Are there limits to my life activities"? On a show of hands the result was very close with Colm just getting it.

After a good lunch with fantastic desserts it was time to say goodbye until the AGM.

Paul Dunne

Hazel Byrne & Aisling Moriarity

Kidlink Programme:

'Off Roading - Tug O War - Sumo Wrestling'

Kidlink Group getting ready to head of to Little Haven

This year the under twelve's Kidlink programme was off site and the group were accompanied by Lucia and myself for all their activities, in Littlehaven Adventure Centre.

Saturday morning started off with chatting and some intense "Revo" competitions, while we were waiting intensely (mostly me) for the safari jeep to arrive to take us all away for the day. A giant green and yellow jeep pulled up outside the hotel and we climbed in, strapped ourselves into our seats and set out for the day. A few people who sat at the back commented that as they looked down at the road flying past the bottom of the jeep it was a little scary, which I happen to agree with, but all thought it was a lot of fun. Due to the weather we had to start the day inside for a little while before we fully got into the swing of things, but once it dried up the fun could begin! We headed off to the main area for the day where there were two buses and a small track for Off-Roading. The jeep zoomed around the track twisting and turning with all of us in the back, bouncing up and down and thrown left and right (Dads, you missed out on that one!).

We were split into teams and were given challenges throughout the day. The first test of the day was one of accuracy and power with penalty shots on a target. Everyone was very good and achieved high scores for their respective teams. Another challenge was an egg and spoon relay race. This required a cunning use of tactics, speeding and stopping or a continuous slower pace. A lot of fun was had during this event however there was some illegal interference and a slight hint of cheating by a crazy man and some rogue kids.

Come on pull harder!

After lunch the next challenge was the water balloon carry which produced some excellent team performances. The day finished with a treasure hunt and the ultimate Tug-O-War. Kid versus machine! Eighteen kids pulled a half ton jeep over the line for a victory to prove that size really doesn't matter.

There is no way Declan is going to win this race!

On Sunday there was more fun and even more challenges. Driving was first up. Everybody had to drive a forklift around, pick up a wooden pallet and then move it to a specific area. Pretty tough but everyone did really well. I suppose I should mention it was a remote control forklift but with the skills shown some of them should have licences already.

The final game of the weekend was the Super-Sumo Challenge where the boys and girls came face to face in a battle to the edge of……. the table! Mini-Remote control sumo wrestlers were placed on the table and the first to push the other off was the winner. Although the boys were doing really well it was the girls who finally triumphed in the final match-up where the boys leader let them down. Finally we had a prize giving for the different events won by each team.

Overall it was a great weekend and a lot of fun was had by all and I know that after this weekend I am not the only one asking for a 4X4 from Santa this Christmas. Thanks for all the fun guys and we hope to see you all again soon.

Declan Noone

Creche Programme:
'A Fun Packed Two Days'

Hello Everyone! For those of you who don't know us, we are the 'Three Musketeers' Deirdre, Claire & myself Carmel. For the past five years we have run the I.H.S Tots Club, (A.K.A. The Crèche). We are fully qualified experienced crèche supervisors, and cater for children up to six years of age. We know people think we are crazy for giving up our time to look after the tots but it is something we really love to do and as a team we work very well together. We have watched our babies grow and then before we know it they are leaving us and heading of to the next step of the ladder which is the 'Kidlink'.

You may think because they are so young that they don't have a programme but they have a fun packed two days of singing, learning and making things and weather permitting, we go out for outdoor activities as well, as fresh air is very important!

We had a fantastic weekend in Birr at the October weekend with fifteen children attending the crèche. The children had a wonderful time. It was great to see our newest little members join the crèche Adam Byrne who was one in September and Denis O'Sullivan who was born in March this year.

Some parents are a bit nervous leaving their child in the crèche especially for the first time. But never fear as the 'Three Musketeers' are here, we have all your details and if your child doesn't settle we will contact you straight away. Failing us reaching you we have our back up yes you've guessed it we call '911 Nanny Nina'. She will track you down, hunt you out until she gets you back to your little one!


Denis Delaney born in March!


Adam Byrne aged one!

The Three Musketeers: Claire, Deirdre, Carmel with children from the Creche

There are some things that you must always make sure you bring along with you when you are leaving your child into the crèche. They are the following: made up bottles, labelled if possible, baby food if needed, nappies, creams etc., and most importantly 'A CHANGE OF CLOTHES'. We all know accidents happen so it's always handy to have something to fall back on. Well I hope this gives you some insight into the 'I.H.S Tots Club'. We look forward to seeing you all in March 2009 in the Carlton Shearwater Hotel in Ballinasloe.

Bye for now!

Carmel Downey

Safety & Supply Update

Recombinant Factor VIII Concentrate

A tender for the provision of Recombinant Factor VIII concentrate for the next two year period was recently completed by the Haemophilia Product Selection and Monitoring Advisory Board. The majority of the contract will be for the purchase of Advate from Baxter. Some fifty two million units of Advate will be purchased over the next two years. This will require no change in treatment as this is the product which is currently used for FVIII deficiency by the majority of persons with haemophilia. A smaller amount of Kogenate from Bayer will also be purchased under the contract (approximately four million units over the two year period) and it will be used for treatment of specified individuals with FVIII deficiency.

Scottish Transfusion Service Rejects MSM Donor Appeal

The Scottish Blood Transfusion Service has rejected calls from gay men's groups to lift the ban on MSM (men who have sex with men) donors from donating blood. The Transfusion Service told the Scottish parliament petitions committee that HIV is rising in gay men and donor selection is the only way to keep blood products safe. It pointed out that the measure it was taking was not discrimination but a realistic recognition of behaviour risks. Campaigners for a change in the regulations said that heterosexuals posed just as much of a risk if their behaviour was unsafe.The issue of MSM donors and their blanket rejection as blood donors has come up in several countries over the past couple of years, including the Netherland's, Canada, Australia and Ireland. In the vast majority of countries MSM donors are permanently deferred as blood donors. The position of the Irish Haemophilia Society which is the same as the position as the World Federation of Haemophilia and the European Haemophilia Consortium on this issue, is that MSM donors should be permanently deferred until such time as the science supports a change in blood transfusion policy. Any such change should be based on scientific evidence and not on the basis of political ideology or perceived discrimination.

Draft Directive on Patient Mobility in the European Union

The EU commission has published a proposal for a directive on the application of patient's rights and cross border health care. The directive is said to clarify the right of patients to seek health care in another EU country while being reimbursed by their national system. This proposed directive was the subject of a lecture at the EHC Conference in Dublin in September, by Pronsias De Rossa MEP.The directive proposes that if an individual within the European community travels to another EU member state for health care they will be reimbursed at the equivalent cost of the health care in their own country. For example if a patient from Romania travelled to France for a knee replacement and the cost of the knee replacement in France was €50,000 including factor replacement therapy and the equivalent cost of the procedure in Romania was €20,000, then theoretically the patient would be expected to fund the difference of €30,000 himself. This directive is still at the proposal stage.

Forthcoming European Parliament Events Focus on Haemophilia

On the 2nd December 2008, an information meeting for members of the European Parliament took place in the European Parliament in Brussels. The topic of the meeting was improving care for rare plasma protein disorders. I presented the patient organisation viewpoint as I spoke on improving access to care for patients with rare plasma protein deficiency disorders. Several disorders including Haemophilia, von Willebrands, and Primary Immune deficiency are treated with plasma proteins. Even though these are different conditions, they are all relatively rare disorders with a commonality of treatment and common issues in relation to collection and use of blood and blood products. On January 27th 2009 at a meeting jointly co-hosted by the European Haemophilia Consortium and the European Association of Haemophilia and Allied Disorders (the doctors group) proposed European standards of care for haemophilia will be unveiled and discussed to an audience to include members of the European parliament, haemophilia organisations and clinicians. These are based on the proposed European standards of care which were published in the journal of Haemophilia earlier this year and which are based on ten key principles of haemophilia care. These are:

1.Haemophilia co-ordination organisations with supporting local organisations in each country.

2.National Haemophilia patient registry.

3.Provision and maintenance of comprehensive care centres and haemophilia treatment centres.

4.Partnership and delivery of haemophilia care between clinicians and patient organisations.

5.Access to safe and effective factor concentrates at optimum treatment levels.

6.Access to home treatment and delivery.

7.Access to prophylactic therapy.

8.Access to specialist services in emergency care.

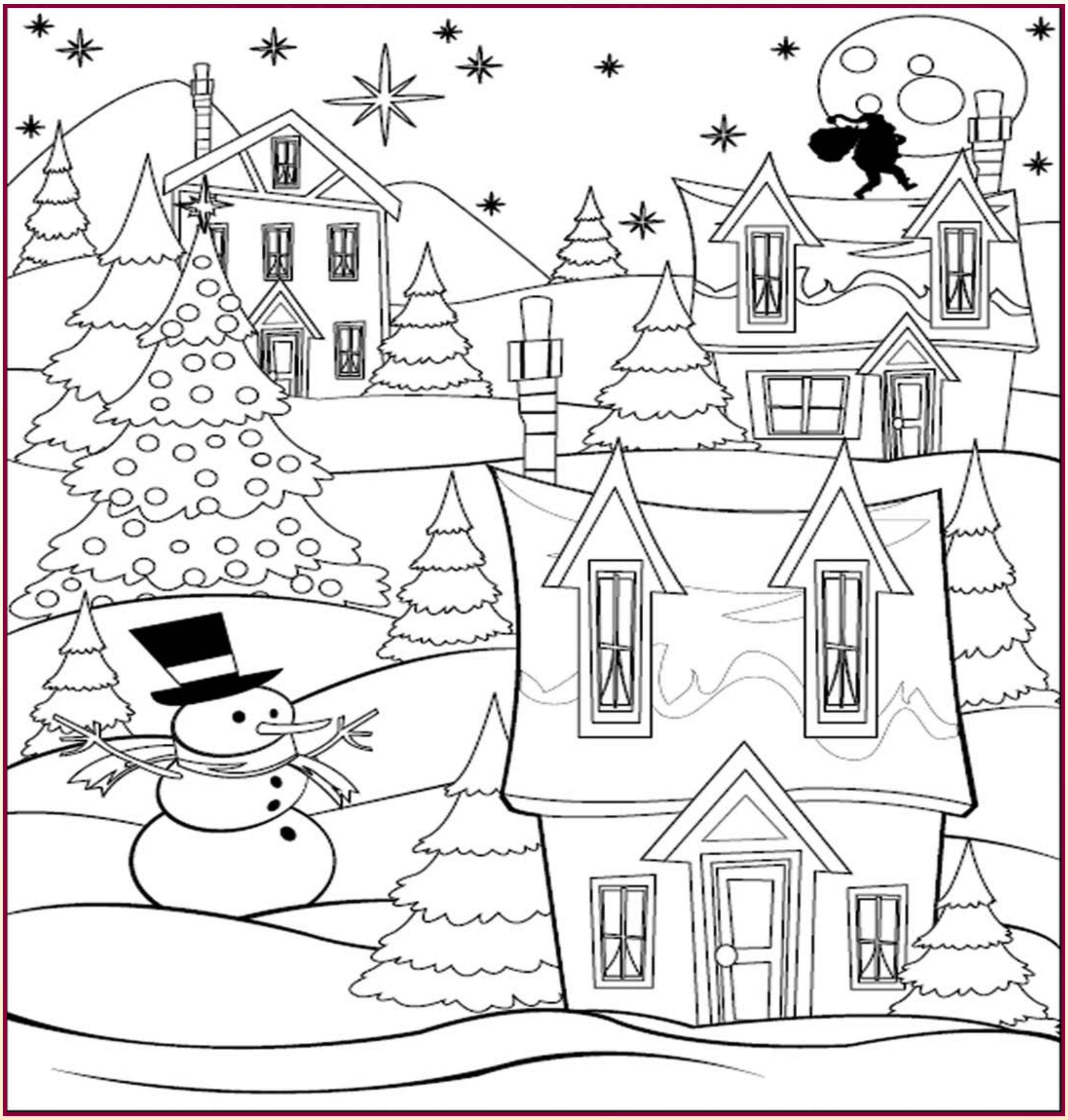
9.Management of inhibitors.

10.Education and research.

It is hoped that the principles can be of particular use in many European countries in formulating, introducing or optimising the standard of haemophilia care and perhaps in assisting EU countries in achieving a standard of haemophilia care which is closer to the optimum.

Brian O'Mahony

Kidlink Christmas Colouring Page



What do you get when you cross a snowman with a vampire?
Frostbite!

What do you call an old snowman?
Water!

What do elves learn in School?
The elf-abet!

What's white and goes up?
A confused snowflake!

Why was Santa's little helper depressed?
He had low elf esteem!

What does a cat on the beach have in common with Christmas?
Sandy Claws!

Noticeboard

Mini Marathon Draw

Members you will be pleased to know that to date we have raised €7563.00. For those of you who have returned sponsorship and who raised over €150, a draw for a weekend away for two will take place early in the New Year. The winner will be announced at our AGM in March.

Grants & Scholarships

As most of you will know, each year the Society makes Educational Grants and Scholarships available to help with the cost of third level education. We would like to thank everyone who sent in applications this year, and we are now pleased to announce winners and recipients as follows:

Maureen Downey Memorial Grant

Daryl Butler	€4,000
Lorcan Friel	€2,000
Colm O'Sullivan	€1,000
Adrian Egan	€1,000

Educational Scholarship

Catriona Moriarty	€2,000
Liz McDonald	€1,500
Richard Butler	€1,500
David Murphy	€1,000
Maura Fitzgerald	€1,000
Kathleen Fitzgerald	€1,000

Congratulations to all of you especially Daryl and Catriona, and don't forget to send us in an article for the newsletter in the Spring! For those of you who were unsuccessful, you can re apply next year.

SANTA AND THE CREDIT CRUNCH

It was the week before Christmas and all through
the nation,people were facing credit stagnation.
Everyone thought just of themselves,without a thought
for poor Santa's elves. Working so hard and without any
pay, the North Pole bank was to be bailed out that day.

Distraught economists, predicted doom and gloom, but
Santa was determined to bring joy to each room.
"Recession and belt tightening" said George Lee with
dismay, but Santa arrived with Rudolf and a full sleigh.

He checked the sleigh Sat-Nav on Christmas Eve night.
He told all the reindeers and they all got a fright. They
got a surprise that would perplex a jury. The entire population was heading for Newry.

So he sent out a message to Lenihan, Cowen &
Harney,'Tell them all to go here from Donegal to
Killarney'. Forget the stock market, the banks
and the dread. Relax, send all the children
directly to bed.
"I am on my way with toys in my sleigh".

Season's Greeting to all our Members from the board and the staff of the I.H.S.

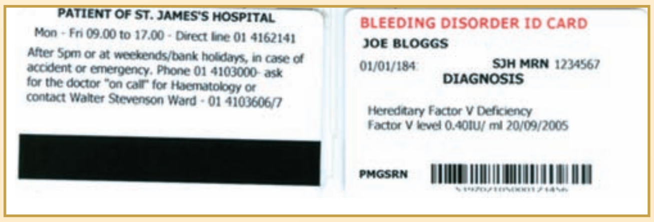
Noticeboard

Remembrance Book

To coincide with the unveiling of the Memorial Sculpture a Remembrance Book has been prepared. The Remembrance Book will remain in our office at all times and you are welcome to call in to see it. At the moment the book contains the names of all of our members who have passed away.

Space is available in the book for any family member who wishes to record their personal message or favourite verse in memory of their loved one. If you do have something you would like included in our Remembrance Book please contact Margaret who will organise it for you.

Notice from National Centre Bleeding Disorder ID Card



PATIENT OF ST. JAMES'S HOSPITAL

Mon - Fri 09.00 to 17.00 - Direct line 01 4162141

After 5pm or at weekends/bank holidays, in case of accident or emergency. Phone 01 4103000- ask for the doctor "on call" for Haematology or contact Walter Stevenson Ward - 01 4103606/7

BLEEDING DISORDER ID CARD

JOE BLOGGS

01/01/184 **SJH MRN** 1234567

DIAGNOSIS

Hereditary Factor V Deficiency
Factor V level 0.40IU/ ml 20/09/2005

PMGSRN

Credit Card style Bleeding Disorder ID Cards are now available. These cards replace the old style green card. Please ask a Doctor or Nurse for a new card at your next attendance to your Haemophilia Treatment Centre. The cards are processed through the National Centre for Hereditary Coagulation Disorders, St James's Hospital and will be sent to you by post. On receipt, please ensure you check the details are correct. Always carry your Bleeding Disorder ID Card in case of medical emergency.

Thank you!

We would like to acknowledge and say a big thank you to everyone who helped raise funds for the Society during the year, and to all our volunteers who gave up their time, your support is very much appreciated.

Our loyal fundraisers

Volunteers: I.H.S. board 2007 - 2008

Our creche volunteers Carmel, Claire, Deirdre

Thank you and a very Merry Christmas to you all!

Calendar of Events 2009

FEBRUARY

Regional Visits

Michael Davenport & Anne Duffy

We are looking forward to meeting you at another round of Regional Visits which will take place during the week of 2nd to 6th February 2009.

This is an ideal opportunity both for new and existing members to meet each other and exchange ideas and concerns. We value this opportunity to meet you and to hear about your needs, which in turn helps us in planning future programmes.

Members have all your 'Compliments, Comments and Complaints' lined up!

We will be writing to everyone in the New Year confirming venues and dates.

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

Contact Us
Cathedral Court
New Street
Dublin 8
Tel: 01 6579900
Fax: 01 6579901
Website: www.haemophilia.ie
Email: info@haemophilia.ie

MARCH

Annual General Meeting

Dates:
Friday 6th to Sunday 8th March

You will find details of the Preliminary Programme for our AGM 2009 on page 2 of this magazine.

The venue for our AGM 2009 is:

The Carlton Shearwater Hotel
Marina Point
Ballinasloe
Co Galway

Tel: 090 963 0400

MAY

** NEW FOR 2009**
Parents Weekend

Dates:
Friday 8th to Sunday 10th May

Venue:
Dublin (hotel to be confirmed)

Preliminary Programme

Friday
Registration

Saturday

10am	Sports and haemophilia
12pm	Phobias
2pm	Prophylaxis
4pm	Letting go

Sunday

10am	Relationships
11am	Self Infusion
12pm	Open Forum

Calendar of Events 2009

JUNE

Mini Marathon

Date:
Monday 1st June

The Women's Mini Marathon will take place in 2009 on Monday 1st June. Over the past number of years this has proved to be a very enjoyable day out as well as an opportunity to raise funds.

As usual we will be providing changing facilities and refreshments in Buswells Hotel, along with a free t-shirt and commemorative scroll.

Staff from the office will be in attendance on the day, so if you have any queries, questions or would like some information, a staff person will be happy to help you.

Sponsorship cards and information will be sent out to members in the Spring.

SEPTEMBER

Regional Visits

The Society will organise another round of Regional Visits during the month of September. Dates and venues will be confirmed during the summer months. Keep checking the website for further information.

OCTOBER

Member's Weekend

Dates:
Friday 16th to Sunday 18th October

It's hard to believe that we are in the process of planning a fourth annual October weekend in 2009. It's such an enjoyable weekend for everyone. Although we do not have a venue confirmed as yet, dates are confirmed as above and we are hoping that we can secure a hotel in the Midlands area of the country. Further information will be available in the New Year.

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IRISH HAEMOPHILIA SOCIETY
First Floor
Cathedral Court
New Street
Dublin 8
Tel: 01 6579900
Fax: 01 6579901
Email: info@haemophilia.ie
Website: www.haemophilia.ie