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Magazine of the Irish Haemophilia Society

July 2009

Announcing: October Member's Conference 16th to 18th October 2009

VENUE:

CASTLETROY PARK HOTEL, LIMERICK

TEL: +353 61 335566 FAX: +353 61 331117

ADULTS PROGRAMME

Friday 16th October
18.00 – 19.00 Registration

Saturday 17th October
09.30 – 10.00 Registration

10.00 – 11.15 Pain Management: Dr. James Fitzpatrick, St James's Hospital

11.15 – 11.45 Coffee Break

11.45 – 13.00 Balancing your Life: Mr. Owen Hegarty

13.00 – 14.00 Lunch

14.00 – 15.30 Entitlements & Benefits: Mr. Pat Stagg, Citizens Advice Bureau

15.30 – 16.00 Coffee Break

16.00 – 17.00 Debate: "People with haemophilia are overprotected by their mothers?"

20.00 Dinner & Quiz

Sunday 18th October
10.00 – 11.15 FULL GROUP: Adults, Young Adults, Kidlink
Art workshop
OR
Tai Chi

11.15 – 11.30 Coffee Break

11.30 – 13.00 FULL GROUP: Adults, Young Adults, Kidlink
Art workshop
OR
Tai Chi

13.00 – 14.00 Lunch: FULL GROUP

BOOKING FORMS WILL BE POSTED OUT TO MEMBER'S IN EARLY SEPTEMBER. YOU WILL ALSO BE ABLE TO BOOK ONLINE FOR THIS WEEKEND IN EARLY SEPTEMBER, ON www.haemophilia.ie

FOR MORE INFORMATION IN RELATION TO THE YOUNG ADULTS, KIDLINK AND CRECHE PROGRAMMES PLEASE SEE CALENDAR OF EVENTS ON PAGES 22 & 23

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

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Parent's Weekend Conference

In April 2009, we organised a conference for parents of children with haemophilia. We recognised that parents need support and information to allow them to deal with their child's haemophilia, the nature of the problems that they will have to circumvent, and the issues they have to deal with change as the child moves from newborn to toddler stage to older child to teenager. We also recognise the importance of having a weekend conference which would give both parents the opportunity to attend along with their children. We view this as an important educational opportunity for the parents where they could learn not only from the lectures and the healthcare workers who were present but also from each other. If there is a problem, anxiety, or concern that a parent has in relation to their child with haemophilia, they can be sure that someone has had the same problem, anxiety, or concern, and has found a way of dealing with it. This peer group interaction was fundamentally vital at the weekend.

The weekend was organised in conjunction with the haemophilia care teams at Our Lady's Children's Hospital, Crumlin (OLCHC) and the National Centre for Hereditary Coagulation Disorders (NCHCD). We were keen to ensure that parents of children with haemophilia or bleeding disorders, who are not members of the Society, and who had not previously attended Society conferences or weekends had an opportunity to attend. For this reason, the registration forms and information packs on the weekend were not only mailed to all members of the Irish Haemophilia Society but were also distributed to parents through the treatment centres in Crumlin, St. James's and Cork University Hospital. The conference which took place in the Marriott Hotel, Ashbourne was attended by 44 parents and 36 children. Speakers for the weekend were drawn mainly from the haemophilia care teams in OLCHC and the NCHCD in St. James's. Dr. Beatrice

From left: Dr. Beatrice Nolan (Consultant Haematologist OLCHC), Olwen Halvey (Social Worker, NCHCD), Ann O'Sullivan (Nurse Specialist, NCHCD), Carol Carr (Social Worker, OLCHC) and Mary Kavanagh (Nurse Specialist, OLCHC)

Members completing evaluation forms at Parent's Weekend Conference

Nolan spoke on prophylaxis and compliance. Emma Sherlock and Diarmuid O'Riain, Physiotherapists from St. James's and Crumlin respectively, spoke about sports and haemophilia. Dr. Yvonne Duane, Clinical Psychologist from OLCHC spoke on anxiety and fears about needles. The topic of letting go and handing your child over was addressed by Olwen Halvey, Social Worker from NCHCD and Ann O'Sullivan, Haemophilia Nurse Specialist from NCHCD. Mary O'Sullivan a mother of a young man with haemophilia gave a personal perspective. The sibling's perspective was discussed by Carol Carr, Social Worker from OLCHC and a personal perspective was delivered by Tracy Dowling, who has a son and brother with haemophilia. On Sunday, the focus of the meeting was independence. Relationships were discussed by Olwen Halvey and Ann O'Sullivan. 'Self Infusion, Pathway to Independence' was outlined by Mary Kavanagh, Clinical Nurse Specialist from OLCHC. Following Mary's talk Gary Butler, a ten year old boy with haemophilia, spoke about self infusion and gave his personal experience. Gary was the youngest person we have ever had addressing a meeting of the IHS but certainly not the least assured. He gave a very composed performance which I hope earned him at least an increase in pocket money from his parents! This was followed by an open disussion forum

Fun and games at the creche!

Kidlink Group enjoying arts and crafts on Sunday morning!

with a panel composed of all the speakers. The powerpoint presentations that were delivered by the speakers at the weekend can be viewed on the Irish Haemophilia Society website at www.haemophilia.ie under the 'For Parents' section.

The weekend was a great success. The evaluations which we received from the parents at the end of the weekend were very positive. The informal atmosphere, the interaction with the healthcare workers and speakers, and the opportunity to hear from a parent and a child with haemophilia from their personal experiences were very much appreciated. As we had hoped, a lot of interaction took place between the parents at the weekend, and many of them went home with food for thought having discussed haemophilia and their children with other parents. Among the comments we received on the evaluation form was one from a parent who said "What I have learned this weekend from other parents has been invaluable". This sentiment was echoed by many people over the course of the weekend. The children also benefited from the weekend, and again, especially for the small number of children who had not been at an IHS conference previously, were delighted to meet and mix with other children with haemophilia. Another parent, writing in the evaluation form, stated "My children really enjoyed the weekend. They were kept entertained and my mind was completely at ease. It was a great relief for me." We were also delighted to welcome at the weekend a number of families from Northern Ireland. This is a trend that we hope we will continue to see in the future.

Children with haemophilia in Ireland now have an excellent standard of treatment. A child born with haemophilia will have a near normal life expectancy and a normal quality of life. For parents who grew up perhaps seeing their fathers or brothers suffering greatly with haemophilia, or with the dreadful consequences of HIV or Hepatitis C infection in the past, it can take time for this new reality, and for the realisation that their child can aspire to a normal quality of life, to become apparent to them. For parents where there is no family history of haemophilia, despite all the information and education and despite the excellent treatment available, in some cases it is not until they speak to other parents and see other children with haemophilia and young adults who have grown up without major problems, that they begin to believe that their child will have a full and normal quality of life. For the children with haemophilia, getting together at these conferences and weekends breaches the isolation they can feel. Any child with haemophilia, despite good treatment, may feel different from their peers. The only real difference is that they are lacking a specific clotting protein which can be replaced on a regular basis. I believe it is very good for the children to know other children with haemophilia, to be aware that they are not the only children who have this very manageable medical condition, and to learn from each other and each others experiences as they go through life. It is certainly our intention to repeat the Parent's Weekend Conference in 2010.

Brian O'Mahony

Dunne and Dusted?

Michael Davenport, Chairman, presenting Margaret Dunne with a bouquet of flowers at the AGM in March 2009

At the end of April, Margaret Dunne retired as Administrator of the Irish Haemophilia Society. Margaret was employed by the Irish Haemophilia Society for 20 years since 1989. I have had the pleasure of working with Margaret since the early 1980's when we both became involved with the organisation as volunteers. In the early years when I was on the board of the Society, and Margaret was a volunteer, we worked together on areas such as fundraising, where we would stand outside the Bank of Ireland on College Green during Society flag days, to try to raise funds for the organisation. In the difficult years of 1987 and 1988, when the Society was engaged in a recompense campaign to try to get some assistance for our members with HIV, Margaret was a constant presence at the then Society office in assisting us to put together all of the information required for that campaign.

Margaret then became a staff member of the Society in 1989 and worked diligently over the course of the past 20 years. When we saw, in the mid 1990's, that we were starting to see many more children attend the Annual General Meeting and generally looking bored, Margaret came up with an idea to put together a programme specifically for the children. Thus, the Kidlink programme was born, and has led to a situation where we now have four established tracks at all of our conferences. The main Adult programme, the Crèche programme, the Kidlink programme and the Young Adult programmes. Margaret took an active role not only in organising but in participating in the activities for the children and young adults during the years. The fact that her sons, Derek and Paul, have haemophilia means that Margaret has a natural empathy with members, and this shone through in her work.

Margaret was enthusiastic and empathetic in her work over the course of the 20 years, and cares deeply about the welfare of all the people with haemophilia on and individual and collective basis. She will greatly missed by the staff on a day to day basis, although I know that she wil continue to be an active member of the Society.

The Dunne family, and how they have grown!

At the Annual General Meeting in March we had an opportunity to thank Margaret for her service to the organisation and presented her with an 'Honorary Life Membership'. I am sure Margaret was delighted also to see her children and grandchildren attend this very special AGM. Margaret was clearly touched by all the gestures of goodwill from members. Margaret had prepared a few words to say and spoke about being so much a part of peoples lives over the past 20 years, and of all the memories she has of that very special time.

On 30th April, we held a Retirement Reception in the Office of the Society in Cathedral Court. This was attended by approximately 70 guests and members. Many memories were shared during the evening, and those present had an opportunity to thank Margaret and to share memories of events over the past 20 years.

I.H.S. Staff at Margaret's Retirement Reception

Margaret was presented with an album of photographs covering her 20 years with the Society and also with a travel voucher and a set of suitcases. We wish Margaret all the very best in her retirement. I have no doubt that Margaret will still keep in touch with the Societyand we look forward to seeing her attend our events in the coming years.

Brian O'Mahony presenting Margaret with a photo album reflecting on her 20 years with the Society

Debbie Greene has been appointed as the new Administrator of the Society. Debbie has been with the Society since 2003. She has been responsible for our newsletters, publications and website. Debbie is already settling in to her new and expanded role with great enthusiasm and energy.

Brian O'Mahony

Consultative Council on Hepatitis C: Third International Conference

The third Consultative Council Hepatitis C International Conference was held in Dublin Castle on the 18th & 19th of June this year. The title of the conference was 'The Third Decade and Beyond'. The two day programme was a twin track programme with a 'Clinical Research Perspectives' programme and a 'Living with Hepatitis C' programme. It was possible for attendees to alternate between the two programmes. The conference was opened by the Minister for Health & Children, Mary Harney.

The first session was on the 'Discovery of Non A Non B Hepatitis', and its 'Evolution to Hepatitis C', by Dr. Harvey Alter and Dr. Michael Houghton, who discovered the virus and then created the test specifically for it. The discovery of Hepatitis C followed on the discovery of Hepatitis B. One interesting fact was that the discovery of the Hepatitis B virus started off in an aboriginal. The first name was the Red (Australian) antigen and it was found in 10% of aborigines. It was originally thought to be something to do with leukaemia. A geneticist looked at populations who had a high prevalence of leukaemia and he found that a large section of children with Down Syndrome in large institutions had this antigen. However, the appearance of the antigen was much less in smaller institutions and children that lived at home. This developed the concept that the antigen was an infectious agent and not a genetic disorder. Later, by accident, one of the laboratory technicians who was working on the Red antigen, and who was negative for the antigen became sick and jaundiced and developed acute Hepatitis and this is how the link to Hepatitis was discovered. They later connected this finding to post transfusion patients and the Red (Australian) antigen then became the Hepatitis B surface antigen. A new test was developed and applied to blood donors, and anybody testing positive was refused. This led to a massive reduction in transmission of Hepatitis B in people after a transfusion. Using this test they went back and tested stored samples of patients with acute hepatitis. Around the same time, a blood test was developed for the Hepatitis A virus and they tested the same samples for this. They found that between the two tests, there was a large portion of Hepatitis causes that tested negative for Hepatitis A and negative for Hepatitis B. Using brilliant deduction and logic; they used the term Non A Non B Hepatitis and that's where the name came from. However at this stage they still hadn't proved that Non A Non B Hepatitis was caused by a virus. Another coincidence then occurred. A man who was out hiking had a heart attack on the side of a mountain and passed out. He went to hospital for open heart surgery and afterwards developed a severe case of acute Hepatitis. After some experiments and liver biopsies they narrowed down the possibility of what the Non A Non B virus could be. Throughout the 1980's the incidence of Hepatitis B and HIV transmission started to reduce with the introduction of testing. Dr. Michael Houghton then developed a test for Non A Non B virus and called it Hepatitis C. With the introduction of this test, 1.2 million cases were prevented between 1990 and 2000. Interesting story?, I hope you agree.

'The Irish experience of Hepatitis C' was presented by Dr. Lelia Thornton. She discussed the outcomes from the National Hepatitis C Database. A lot of this information was given at the Hepatitis C Information Day in February so for further information, please look at our previous newsletter or our website at www.haemophilia.ie. Dr. Leonard Seeff discussed the 'Natural History of Hepatitis C'. He presented a number or retrospective and prospective studies, and from these he concluded that, in 6 to 12 months after initial infection with the virus, between 15 - 45% of people spontaneously clear the virus. If the virus is not cleared, the Hepatitis continues to cause fibrosis. Of the cohort that does not clear the virus, at 20 years 5 - 25% of these people develop cirrhosis. Up to 4% of people who develop cirrhosis can develop Hepatocellular Carcinoma (HCC). He reiterated the factors that influence progression and outcome of Chronic Hepatitis. The older person is at infection, the length of infection, being male, co-infection with other viruses, and alcohol, are still the main factors that cause the virus to progress.

Dr. Miriam Alter from the USA discussed the 'Global Differences in Risk Factors for HCV Infection' and the 'Implications for Screening and Prevention'. She discussed the identification of infected persons. There is an estimate that only 10 - 40% of people are aware of their infection with Hepatitis C and that there is a vast majority who are unidentified and not receiving treatment. She also said that therapy regimens are less than ideal, and even though the incidence has gone down in the last number of years, health care professionals need to remain aware of any cases and changes in epidemiology.

In the 'Living with Hepatitis C Session' in the afternoon, Professor Graham Foster spoke about what's new in Hepatitis. It now appears likely that protease inhibitors for Genotype 1 will be available with a probable launch by late 2011. Polymerase inhibitors still have side effect issues to overcome and it is estimated that it may take another 4 - 5 years to overcome these. There are 2 protease inhibitors currently in phase 3 clinical trials, Telaprevir and Boceprevir.

The problem with protease inhibitors is that, while they give a rapid decrease in viral load (the amount of the virus), they also rapidly cause resistance. In terms of the trials for Boceprevir for Genotype 1, they have seen up to a 75% sustained virological response (SVR). Although these are company trials, with carefully selected patients, they do give some very interesting results. Boceprevir would be given in combination with Interferon/Ribavirin. The other protease inhibitor, Telaprevir, would only be given for 3 months (because it is difficult to continue for longer without severe side effects, commonly a nasty skin rash) of therapy along with Peg Interferon / Ribavirin. Telaprevir, in clinical trials, has seen an SVR of 67% with 48 weeks therapy or 61% with 24 weeks therapy. If a rapid response is seen with Telaprevir, then it is possible that only 6 months of therapy in total would be needed. Telaprevir, in clinical trials, also seemed to have an SVR rate of 41% with patients who have not responded to previous treatment, and up to 73% with relapsing patients. With Polymerase inhibitors, side effects are nausea, vomiting and bone marrow suppression. Professor Foster's opinion is that, by 2011 Protease inhibitors will be available that give a 60 - 70% SVR with Genotype 1. By 2015, Polymerase inhibitors which will give a 60 - 70% SVR with genotype 1, and by 2016, a combination of Polymerase and Protease inhibitors will be available which will give an 80 - 90% SVR with Genotype 1. He also stated that, in his opinion, when Telaprevir is licensed, it might be a good idea to wait a couple of years as it often takes some time before clinical practise finds the best possible dose and treatment regimes.

Dr. Nora Tennault spoke about 'Current Therapeutic Options', such as adjusting treatment duration, depending on a response, and also altering baseline factors (Weight, insulin resistance) before treatment. She noted that the first 12 weeks of treatment are critical, and it is important to try to maintain full dose of iinterferon/Ribavirin for this time.

Session VI: Liver Transplantation which was chaired by Brian O'Mahony


Brian O'Mahony speaking to Dr. Lelia Thornton during coffee break


Meet the Experts Session which gave delegates a chance to ask questions

She discussed the relapse of patients who are virus negative towards the end of treatment called an 'End of Treatment Response' (EOTR). If EOTR patients are negative by week 4, there is a 9% relapse rate, negative by week 12, a 34% relapse rate, and negative by week 24, a 55% relapse rate. If they are still positive at week 24 there is a 98% relapse rate suggesting that, if a patient is not negative by week 24, then there is no point in continuing the treatment for a further 24 weeks. She also suggested that, if an individual was not negative at week 12, and only negative at week 24, then you give 72 weeks of treatment.

The next session 'Meet the Experts' was excellent. This session gave patients a chance to ask questions directly to the world leaders in Hepatitis C treatment. There was a large number of questions and good debate between the experts and the audience.

In the 'Individualisation of Therapy' session Dr. Thomas Berg gave his view that for relapsing patients who initially responded to treatment, 48 weeks was too short. He felt patients should have 72 weeks of treatment. He said "the faster the response, the lower the relapse rate". He questioned whether one should stop treatment if the response only occurs at week 24.

Dr. Stefan Zeuzem discussed 'Emerging therapies for Hepatitis C Treatment' for the clinical audience. He re-iterated the information on Telaprevir and Boceprevir trials and suggested possible options for how the therapies would be used in combination with Ribavarin and Interferon.

Psychologist Edmund O'Dea, from Cork, spoke about treatment and the fact that Interferon can cause manic depression, severe depression, suicidal ideation or psychosis. Depression can occur in the first 4 weeks of treatment, and is the most common cause of preventing treatment continuing. In relation to ongoing difficulties, he has seen recurrent depression, increased anxiety, unresolved hostility and panic disorder. Some of the main issues are; chronic pain and fatigue, progressive loss of function, decreased ability to partake in daily living, fear of the worst happening (with physical health), cognitive difficulties, decreased ability to deal with family crisis, and significant loss in relationships and work.

On Friday morning, in the 'Clinical Research Sessions', Dr. Colm Bergin and Dr. Barry White from St. James's Hospital spoke on HIV and Hepatitis C Co-infection. Dr. Bergin said he has treated 19 people with haemophilia who are co-infected, 11 with genotype 1 or 4, and 8 with genotype 2 or 3. Thirteen of the 19 are on HAART therapy. His overall viral negative response, for all genotypes, is 50%. Dr. White said that, in the haemophilia population, the SVR for genotype 1 was 35% (this includes some mono therapy), and for genotype 2 and 3 it was 88%. Sixty six people with haemophilia were Hepatitis C PCR positive. Twenty two had failed previous treatment and 44 had never had treatment. Of the 44, when they had been surveyed, 50% were not recommended to have treatment at the moment, as they had genotype 1 with low level fibrosis, 10% had a fear of side effects, 13% were awaiting treatment, 7% didn't have time and 10% were waiting for a better treatment to become available.

Dr. John O'Grady, from King's College hospital in London, spoke about a study he did between the years 1996 and 2002. They had 146 patients with Hepatocellular carcinoma (HCC), 103 of whom were identified prior to transplant. With an eight year follow up, 70% had survived. With HIV and Hepatitis C Co-infection, a more aggressive reoccurrence of Hepatitis C within three years occured, even if the HIV is stable and the person is on HAART therapy. In the UK they have carried out 5,435 transplants on HIV negative individuals in the last 14 years, and 33 on people with HIV positivity, 15% were transplanted because of Hepatitis C. With Hepatitis C, the one year survival was 86%, five years was 74%. With Hepatitis C and HIV the one year survival was 73%, five years was 53%.

Dr. Aidan McCormack, from St. Vincent's Hospital in Dublin, discussed the 'Irish experience of Liver Transplant and Hepatitis C'. St. Vincent's have carried out 608 transplants in 523 people between 1993 and 2008. They do approximately 60 transplants per annum. They have carried 65 transplants for people infected with Heptatits C. Forty one have had cirrhosis and HCC. The survival rates at one year are 90%, five years 77% and ten years 72%. The mean age was 50 years. Of the 65, 14 are deceased, five had multi organ failure and six have recurrent Hepatitis C. Ten patients had Hepatitis C treatment post transplant. None achieved an SVR. The older a liver donor is the faster the risk of cirrhosis in the new liver. Following this finding in 2002, they brought in new guidelines stating that, for liver transplant in a person with Hepatitis C, the person should receive a liver from a donor who is less than 40 years old where possible.

Dr. Greg Everson, from the USA, discussed 'Antiviral Therapy Post Transplant'. His findings mentioned, after five years post liver transplant 18% have Cirrhosis, ten years post transplant, 36% have cirrhosis. In relation to pre-transplant Hepatitis C treatment, many of those individuals are too ill and find it hard to tolerate treatment. In genotype 1, studies show that SVR can be 10-30% (Irish experience is 15%). In genotype 2 or 3 it can be 50%. It is a reasonably good option for genotype 2 or 3. If a person can be given an SVR before the transplant, this can prevent re-infection in 80% of cases. In post liver transplant Hepatitis C, treatment the SVR is generally 25%. In terms of living donors, these are only used in Ireland for paediatric cases.

The Irish Haemophilia Society had an exhibition stand at the conference manned by our staff. We had a large number of our publications, including our DVD, and copies of the posters on Hepatitis C issues, which we presented at the last World Federation of Hemophilia Congress. During the course of the conference, three sessions were chaired by IHS personnel. Margaret Dunne chaired a session on 'Hepatitis C: Not Just a Liver Sisease', Brian O'Mahony chaired a session on 'Liver Transplantation' and Declan Noone chaired a session on 'Hepatitis C and Associated Conditions'. The conference was attended by approximately 200 people, and the programme had an exceptional line-up of international speakers. While the 'Living with Hepatitis C' programme was very well attended the 'Clinical' programme was not so well attended. Overall the conference was excellent and gave a very good overview of current and future developments in the treatment of Hepatitis C.

Brian O'Mahony
Declan Noone

Among the speakers during this session was Dr. Colm Bergin from St. James's Hospital


Michael Davenport, Margaret Dunne & Anne Duffy

Margaret Dunne chairing the very last session on the programme entitled 'Hepatitis C: Not Just a Liver Disease'.

CJD NEWS

vCJD in the UK

On February 16th 2009 we contacted all members to inform them about a development in relation to vCJD in the UK. At that time, a man with haemophilia in the UK who was in his 70's, died from a cause unrelated to vCJD. A routine autopsy showed evidence of infection with vCJD in some of his tissues at the time of his death. It appeared most likely at that time that the man had been infected with vCJD from a batch of Factor VIII, that was known to have included plasma from a donor who later died of vCJD. This was only relevant to persons with haemophilia in Ireland who received plasma derived factor concentrates in the UK (including Northern Ireland) between 1980 and 2001.

Following the autopsy, the Health Protection Agency (HPA) in the UK, have carried out a risk assessment in relation to this man's exposure to vCJD. The risk assessment, which was published on the 9th of June, concluded that there was a very high degree of probability that this man's prion infection was caused by plasma derived Factor VIII (greater than 99% probability). More surprisingly, they reached the conclusion that the infection for this individual was more likely to have resulted from the use of a non-implicated batch. (In other words, from a Factor VIII batch that was not made from a plasma pool containing a donation from someone who later went on to die from vCJD.) The risk assessment, which is a mathematical modelling exercise, depends to a very large degree on the assumptions they make before the assessment. The major assumption which affects the outcome of this risk assessment is, the prevalence of vCJD in the UK (the number of people in the UK who are infected with vCJD). We know that, to date, there have been 168 cases of vCJD in the UK in a population of 60 million. This would give a prevalence of approximately one in 350,000. However, there was an additional study carried out in the UK where they tested tonsils and appendix's which are removed from people in the general population. (Tonsils and appendix tissues are among the tissues where you are most likely to find abnormal prions if an individual has been exposed) They found three tonsil / appendix's positive for prions in a total of 12,874 samples tested. From this they reached the tentative conclusion that the prevalence of vCJD in the UK could be as high as one in 4,225. In other words, just over 14,200 persons who may according to this risk assessment, have prions in their tissues although they may not develop vCJD. This is the most pessimistic assumption. Most risk assessments in the past have given two ranges of risk based on the most optimistic range of infection in the UK: one in 350,000, or the most pessimistic: one in 4,225. This risk assumption is based on an assumed prevalence of one in 10,000 so they are taking a very pessimistic view.

Based on this assumption, if we look at plasma derived factor concentrates which were used in the UK between 1980 and 2001, typically they would have been made from plasma pools containing up to 20,000 donations. If they assume that one in 10,000 of the population was carrying the abnormal prion, it is a fair assumption, according to this risk assessment, to assume that each pool would contain two infected donations. If we look at the implicated batches which are known to have contained plasma from a donor who later died from vCJD, it is assumed that these pools contained two infected donations plus an additional (known) donor, to give a total of three. Clearly the risk from these implicated batches was slightly higher. This man who died in his 70's, used over 400,000 IU's of Factor VIII concentrate in his life, and only 9,000 IU's came from known implicated batches. In excess of 390,000 IU's came from non-implicated batches. Therefore, they are making the assumption that (given the fact that every batch is thought to have theoretically contained two infected donations) on the balance of probabilities these prions in his tissues resulted from the use of a non-implicated batch.

It is worth re-iterating a number of points in relation to vCJD and haemophilia in the UK. Every person who lived in the UK from 1980-1996 has a continuing risk of developing vCJD. This risk is very low and there may well be less than 50 cases over the next 50 years. According to the 2004 UK risk assessment, people who received blood or blood products, including people with haemophilia, have a slightly increased risk of developing vCJD over and above this background risk (At the time in 2004, they put the increased risk as 1% above the background risk). It is important to note that this man in the UK did not develop vCJD and died from an unrelated cause. It is also important to note that to date 802 persons with haemophilia in the UK have received factor concentrate that was manufactured from known implicated batches (where a donor whose plasma went in to making the batch later died of vCJD.) To date none of these persons with haemophilia have developed vCJD. Plasma derived Factor VIII and Factor IX concentrates from the UK were never imported into Ireland, although a number of Irish people with haemophilia did receive treatment in the UK between 1986 and 2001. In addition, a number of individuals with rarer bleeding disorders used treatment in Ireland which was manufactured from UK plasma during that time. All of these people have been individually contacted in the past by the National Centre for Hereditary Coagulation Disorders, and given the information they require in relation to this issue. As a result of this latest risk assessment in the UK there is no need for any change in practise or policy in Ireland. It is also worth noting that the current generations of plasma derived factor concentrates which are used (some of which are used for the treatment of von Willebrands Disease in Ireland) in general have a much higher clearance of prions than those which we used in the 1980's and 1990's. In the meantime the Food and Drug Administration (FDA) in the U.S.A have also updated their risk assessment in June 2009, where they looked at the potential risk of vCJD for United States users of US licensed plasma-derived products. Their risk primarily comes from the number of people who were donors in the USA who may have been exposed to the BSE agent during travel or residence in the UK, France or certain other European countries. Unlike the UK, they give two sets of figures, where they base their assumptions on a very low or very high prevalence. They estimate the risk of developing vCJD to vary from one in 12,000 to one in 12 million! I believe this very broad range demonstrates the enormous amount of uncertainty in this area, and the huge affect the assumed prevalence of vCJD in the UK has on these mathematical calculations.

European Principles of Care launched at European Parliament

(MEP) John Bovis, (Chairman of EHC) Mr. Ad Veldhuizen, Ms. Sererine Trouillet (EHC), and (MEP) Miroslav Milkolasic

At a meeting in the European Parliament at the end of January the European Principles of Care which have been endorsed by a European Haemophilia Doctors Group, the European Haemophilia Consortium (EHC) and World Federation of Hemophilia (WFH) were launched. Two Irish MEP's Prionsias De Rossa and Kathy Sinnott attended the launch. The ten principles are:

1) Haemophilia National co-ordinating organisations with supporting local organisations
2) National haemophilia patient registry
3) Provision and maintenance of Comprehensive Care Centres and Haemophilia Treatment Centres
4) Partnership in the delivery of haemophilia care
5) Access to safe and effective concentrates at optimum treatment levels
6) Access to home treatment and delivery
7) Access to prophylactic therapy
8) Access to specialist services and emergency care
9) Management of inhibitors
10) Education and research

The principles of care may well be an important tool in increasing awareness of haemophilia throughout the European community and in advocacy with governments and health officials for improving care in various countries. The section on partnership in the delivery of care stresses the requirement for the national haemophilia patient organisation to be fully involved in the decision making process in relation to care in the country. As a follow on event a meeting was held in Poland in March attended by 13 countries in Western, Central and Eastern Europe. It is sobering to note that the availability of factor concentrates for haemophilia within the European community shows a 23 fold difference between the country with the highest use (Sweden) and the lowest use (Romania).

In other European developments, a coalition of the organisations who represent the users of plasma derived products (including those with haemophilia, primary immune deficiency and alpha 1 antitrypsin deficiency) in addition to other organisations was formed in March. We have been concerned for sometime now that directives and guidelines propagated by the European Union on blood, tissues and other areas, which can have an impact on haemophilia treatment, were being put forward and finalised with no input from the haemophilia community. This coalition, known as PLUS (Plasma Users), will represent the collective views of these patient organisations to the EU commission on directives, guidelines and recommendations which will effect or impact on the supply of blood, plasma and plasma-derived medications in the future. We have already responded to the Commission in relation to some potentially damaging proposals which were made in relation to restrictions on plasma donations, and we will have a formal consultation meeting with the EU Commission in October of this year. Our aim is to ensure that developments do not take place at a European level which will impact on the treatment of persons with haemophilia without the view of the haemophilia community and the other users of plasma products being taken into consideration on a proactive basis.

Other News

Swine Flu Update

In July 2009, the Irish and United Kingdom governments gave up efforts to contain the Swine Flu (H1N1 virus) after cases continued to increase. The policy is to vaccinate (which is aimed to be available in October) the population and between now and then treat severe cases with Tamiflu and recommend rest for mild and moderate cases. Recommendations for the general public are:

- Get a regular seasonal flu vaccination. It might not help against this specific strain, but it won't hurt.
- Wash your hands frequently with soap and hot running water. If hot water is not available, use an alcohol-based hand gel.
- When you cough and sneeze, cover your mouth and nose.
- Wash your hands afterward.
- Avoid being near others who might be sick.
- Stay home if you are sick, to avoid affecting others. For immune compromised individuals, a vaccination will be given as soon as it is available and try to follow the recommendations for the general public.

If an immune compromised individual does suspect they have swine flu they are advised to contact their GP immediately. If they are believed to have the virus, they will be prescribed Tamiflu. If you have further concerns you are advised to contact the GUIDE Clinic in St. James's Hospital on Tel: 01 416 2315.

Current and Future Developments in Factor Replacement Therapy

Human Cell Line Recombinant Factor VIII

Work is underway in Sweden by the company Octapharma on the development of a recombinant Factor VIII manufactured from a human kidney cell line. All the current recombinant Factor VIII products on the market are manufactured from hamster cell lines.

New Recombinant Factor VIII on market

A new third generation recombinant Factor VIII, 'Refacto AF' has now been licensed in Europe. This is a third generation recombinant Factor VIII (which means a recombinant Factor VIII without the addition of human or animal proteins). Refacto AF is a beta domain deleted recombinant Factor VIII. There was a second generation recombinant Factor VIII produced by Wyeth called Refacto, which was used in Ireland in the past. The major differences in the third generation product are:

(1) There are no human or animal proteins used in the cell culture.
(2) There is a nanofiltration step which is an additional virus removal step.
(3) The murine (or mouse) monoclonal antibodies have been replaced by a synthetic protein or ligand.

There are a number of other potential future developments in relation to factor replacement therapy which are exciting and innovative.

Longer Acting Recombinant Factor VIII

Work is progressing in relation to the development of longer acting recombinant Factor VIII concentrates. Bayer is working on a recombinant Factor VIII which will have a pegylated liposome diluent. Essentially the Factor VIII molecule will be linked to a polyethyleneglycol (PEG) molecule which in turn is linked to a liposome or lipid molecule. This effectively means that the Factor VIII will stay longer in the system as it is larger and will take more time to excrete. In early clinical trails, the number of "bleed free days" following infusion of the factor has increased from 7.2 to 13.3 when compared to a standard recombinant Factor VIII. Baxter is also working on a pegylated Factor VIII. Early studies in mice have demonstrated an increase in half life (the time taken for half of the Factor VIII to disappear from the system). Baxter is also working on a recombinant Factor VIII and vWD concentrate which could be used both for the treatment of vWD and Factor VIII deficiency. Some other approaches include working on a recombinant Factor VIII which is resistant to inactivation.

Recombinant Factor IX

The Swedish company Biovitrium are working with another company Syntonix to develop a longer acting recombinant Factor IX. This approach will work to develop a Factor IX which will bind to cells that line the blood vessels and recycle the Factor IX to increase its half life. In relation to recombinant Factor IX, another company are working on a potential nasal spray.

Recombinant Factor VIIa and developments for Inhibitors

Various developments are under way with recombinant Factor VIIa. Novo Nordisk is working on a subcutaneous recombinant Factor VIIa to prevent the requirement for constant veno-puncture. They are also working on the development of a longer acting recombinant Factor VIIa and they are looking at a version which would be fused to albumin to increase half-life. In relation to inhibitor treatment another company called Ipsen is developing a recombinant porcine (pig cell) Factor VIII which could be used for the treatment of inhibitors.

Brian O'Mahony

Travel Insurance Scheme

PLANNING A HOLIDAY? DO YOU HAVE TRAVEL INSURANCE?

Travel Insurance is now available for persons with State Acquired Hepatitis C and/or HIV who were infected by blood or blood products. The most important aspect of the Travel Insurance Scheme is that there is no financial penalty for having State Acquired Hepatitis C and/or HIV. This means that individuals who take out insurance under this scheme will only pay the standard premium to the Insurer, irrespective of existing health conditions. The Travel Insurance Scheme will be known as Emerald Travel Insurance. For more information on how the Scheme will work please see some Frequently Asked Questions below, or go to on www.hepcinsurance.ie

What is the Travel Insurance Scheme?
The Travel Insurance Scheme will enable persons, who have been infected within the State with Hepatitis C and/or HIV by blood or blood products, to take out travel insurance as if they were not infected.

What is the Travel Insurance Scheme called?
The Travel Insurance Scheme will be referred to as EMERALD TRAVEL INSURANCE.

How will it work?
Eligible individuals will take out a travel insurance policy and pay the normal premium to the insurer. Any additional premium charges are paid to the insurer by the Administrator.

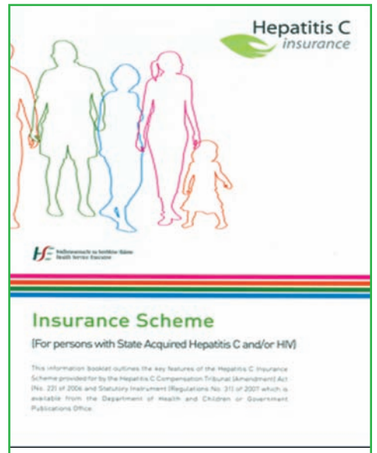
Who can take out Travel Insurance?
All eligible person's who contracted Hepatitis C and/or HIV from the receipt of blood or blood products within the State. The Spouse or partner of an eligible person. Dependents of an eligible person. Other relatives or friends whose travel arrangements are likely to be affected because of the pre-existing medical conditions of an eligible person.

How do I take out Travel Insurance?
All applications for travel insurance will be made by telephone. You telephone the contact number of the insurer and complete the application by answering the questions they ask.

Will there be any financial penalty because I have Hepatitis C and/or HIV?
No. The Travel Insurance Scheme will enable everyone who was infected with Hepatitis C and/or HIV, within the State by blood or blood products to take out insurance without financial penalty, irrespective of existing health conditions.

Do I need my Eligibility Certificate to access the Travel Insurance Scheme?
Yes. When you decide to take out travel insurance the insurer will require the number of your Eligibility Certificate.

I don't have an Eligibility Certificate how do I get one?
You must be an Eligibility Certificate Holder to avail of the Emerald Travel Insurance. To avail of the Relatives and Friends Policy, the Eligibility Certificate Holder must hold a policy. If you are unsure if you qualify, you should contact the Hepatitis C Insurance Administrator on 1850 211570. You can also download an application form to certify eligibility at www.hepcinsurance.ie

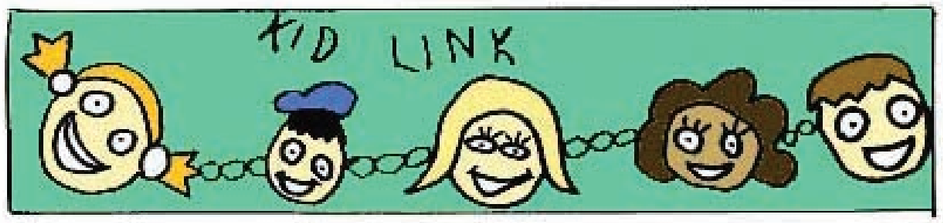


If you have your eligibility certificate and would like to arrange cover please contact the following telephone numbers:

Eligibility Certificate Holders & Immediate Family:
Telephone 0818 200113

Relatives and Friends of the Eligibility Certificate Holder:
Telephone 0818 200114

Kidlink



Sports Scene

Exercise is good for everyone, as it keeps you fit and healthy. Exercise also helps build strong muscles, this is particularly important for people with haemophilia as strong muscles help protect your joints from bleeds. It is important to keep fit and healthy during your summer holidays from school.

Everyone can enjoy sports no matter where you live or what age you are and with the warm weather there is nothing stopping you going outside and playing sports. Why don't you try to get your whole family involved in a sport?

Don't forget to talk to your Mum or Dad or the doctor/nurse at the haemophilia centre before you start a new sport.

Here are our top five outdoor activities for summer:
1. Walking *(Bringing your dog for a walk is good for you & your dog)*
2. Badminton
3. Tai Chi
4. Cycling *(Remember to wear a helmet so you don't hurt your head)*
5. Fishing

If the weather is bad, that doesn't mean you can't do exercises.
Why not try;
1. Swimming
2. Wii-Fit
3. Dancing

Unscramble the words below to identify words associated with haemophilia.

When you have finished send your answers to info@haemophilia.ie or post your answers to our offices. All entries will be entered into the mystery raffle with some fantastic prizes to be won.

1. a hi hope mail
2. hid in tree
3. being led
4. orders id
5. ice toys
6. in his orbit
7. cord to
8. for cat
9. hoax slip pry
10. cot glint

Answers to the anagrams and the winners names will be included in the next magazine, GOOD LUCK!

For more puzzles, jokes, information on haemophilia, and to look at the programme for the October weekend, check out the website www.haemophilia.ie

Did you know?
Breakfast is the most important meal of the day as it helps you concentrate!

Did you know?
You should exercise for at least one hour per day to keep fit and healthy.

What does a tree do when its ready to go home?
It Leaves!

Why wasn't Cinderella good at playing football?
She kept running away from the ball!

What bird is always out of breath?
A puffin!

SUDOKO

		3	
	4		
		1	
	2		

		1	6		
6					1
	1			6	
	5			3	
4					5
		5	4		

Grants & Scholarships

Background

Up to the 1970's effective treatment for haemophilia was not widely available in Ireland. One result of this was that many people with haemophilia lost a lot of time from school due to recurring bleeds which left them incapacitated for long periods of time. This in turn meant that a large proportion of them did not go on to college. When treatment improved and home treatment became available this made a huge difference not only to their quality of life, but they no longer had to miss so much school, and the percentage of those going on to college was comparable to the general population.

In response to this, the Society in the late 1980's decided to offer an **Educational Grant** each year to a person with haemophilia or related bleeding disorder, going on to post second level education. This is called the 'Maureen Downey Educational Grant'. Currently the award is in the amount of €4,000. This grant is made available to any person with haemophilia or related bleeding disorder, who has been accepted on a course at any post second level educational institution.

Since then the Society has introduced a second **Educational Scholarship** in 2004 which is called the 'Margaret King Educational Scholarship'. This scholarship is made available to an immediate family member of a person with haemophilia or related bleeding disorder, who has been accepted on a post second level educational course. Currently the award is in the amount of €2,000.

Applications are now invited for both awards. You can apply by downloading the application forms from our website www.haemophilia.ie, by applying online on our website, or you can contact Nuala in the office on 01 6579900 who would be delighted to post you out a form.

THE CLOSING DATE FOR BOTH AWARDS IS FRIDAY 25TH SEPTEMBER 2009.

When all applications are received and the closing date arrives a sub group of three people from the Board, (which can not include anyone with a family member applying for the grants & scholarships) meet to consider the applications and make recommendations to the Board. The successful applicants are then notified by post of their award at the end of October, and an official announcement and presentation is made to them at the following AGM.

Pat Downey presenting the Maureen Downey Grant to Etna Butler who collected this award on behalf on her son Daryl at the AGM in March 2009

Catriona Moriarity receiving the Margaret King Educational Award from Chairman, Michael Davenport at the AGM in March 2009

[Please note you may be contacted by Nuala McAuley from the I.H.S. office in the event that clarification or further information is required. Depending on the number and quality of applications received, the I.H.S. board may, at their discretion, award additional grants in lower amounts.]

Noticeboard

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

Membership Fees Reminder

If you have not yet paid your Membership Fee for 2008, we would ask you to do so as soon as possible.

The current Membership Fee is €30 per year, and Life Membership is €650.

You can pay by cheque, or if you wish, we can accept laser or credit card payments.

Jamie Meets Irish Soccer Manager!

The Irish Soccer Manager was recently speaking at Our Lady's Children's Hospital Crumlin, where he was launching a fundraising drive for the Children's Medical & Research Foundation between the Dublin facility and the Little Prince Children's Hospital, Curitiba in Brazil. The drive will centre around a visit from the legendary Pele to the Burlington Hotel on November 26 of this year, with opportunity to enjoy a Q & A session with the three-time World Cup winner. As you can imagine our young member Jamie Shannon was very excited to meet the Irish Boss!

Important Message

To enhance our magazines and website, we use photographs that have been taken at our events and activities. If you would prefer not to have your photograph included in our publications, please contact Debbie Greene in the office on 01 6579900.

Mini Marathon

Aoife Downey & Sarah Coyne giving the thumbs up!

Everything was arranged, I had agreed to participate in this years Mini Marathon so all I had to do on Monday June 1st was show up to the starting line looking pretty. Easier said than done when it was 30 degrees out! Wouldn't you know, the one day I decide to get up and do some exercise is the one of the hottest days of the year so far!

I made my way to Buswells hotel for 1pm to meet with Debbie Greene and the other ladies who had chosen the Irish Haemophilia Society as their charity to raise funds for. Arriving a good hour and a half before the race was due to start I was sure I would be one of the first ladies there, wrong! Several members had already gathered at the hotel and were raring to go. I on the other hand, having walked from Dame Street, was complaining of the heat and praying I would make it to the starting line, never mind the finish line! However, as the 3pm start time grew closer and having put on my fabulous orange I.H.S. t-shirt and joined Aoife Downey and Sarah Coyne in some pre-race stretches I left the hotel an headed towards the starting point.

Here come the girls!

Six of us left the hotel together, four arrived together to Fitzwilliam Square, but in a crowd of over 40,000 women it was inevitable that we would get separated. It felt like hours had passed as we waited for the runners, then the joggers, then the power walkers to cross the start line. The race had been underway for twenty minutes before we crossed the starting line, so then and there I had to reside myself to the fact that I was not going to win the race.

For those of you interested, the race was won by Rosemary Ryan from Limerick in an impressive time of 34 minutes and 36 seconds. Passing the 1km post, I was thanking my lucky stars that I had put sun cream on as there were a few red faces in the crowds already. The walk itself goes by quite quickly (I'm sure some will disagree), but once you start and if you have someone to chat to or an ipod to listen to, you have passed the 5km mark without a bother My topic of conversation with my fellow walkers Anita Sarah and oife was how people dressed in teddy bear and bunny rabbit costumes had not collapsed with the heat. I'm sure they were more grateful than most when people living along the route got the garden hoses out to cool down those participating, not to mention the firemen between the 7km and 8km marks who had several hoses out!

The three girls and myself crossed the finish line in 1 hour and 58 minutes (I really gave Rosemary Ryan a run for her money!). Having collected our medals, we headed back to the hotel, where surprise, surprise, we were not the first to arrive. However, realising that most of the members had beaten our impressive time did not dampen our spirits, mainly because we were so tired even trying to think about it. As we enjoyed the refreshments, we all agreed it was a great day out, some great exercise, and we will all be back next year. I hope all the ladies keep their promises and that more people will join us next year, where I will aim to finish the race in under an hour and a half!

Thank you to all those who took part on the day and who raised money for the Society and special thanks to Debbie Greene and Carmel Downey who looked after everything and everyone on the day.

Nuala McAuley

Shave-a-thon

Brandon Griffiths making a head start on his Dad's head!

"I surrender", says Paul Griffiths!

"There's more to life than hair, but it's a good place to start" and this is exactly where Paul Griffiths started when he decided to take part in a 'Shave-a-thon' to raise money for the Irish Haemophilia Society. We at the Society love when the fun is put into fundraising and backed Paul all the way.

In April 2009 Paul took a seat in his back garden and son Brandon took the razor in hand and got to work shaving Paul's beard and hair in alternative quarters. We're not sure if this look will be the next craze, but we think Brandon did a great job! Paul's 'Shave-a-thon' raised over €1,000. Thank you to Paul for all his hard work and to everyone who sponsored him.

We understand it is hard to raise money in these tough financial times, but if you have any fundraising ideas we would love to hear from you no matter how crazy they are!

Nuala McAuley

Calendar of Events

SEPTEMBER
RELATIVE'S INFORMATION DAY

Date:
Saturday 5th September 2009

Venue:
Irish Haemophilia Society Office, First Floor, Cathedral Court, New Street South, Dublin 8.

The Irish Haemophilia Society are pleased to announce a 'Relative's Information Day' which will take place on Saturday 5th September, 2009 in our offices: First Floor, Cathedral Court, New Street South, Dublin 8. This 'Relative's Information Day' will give relatives an opportunity to gain a better understanding of haemophilia. The meeting will be an ideal introduction for grandparents, uncles, aunts and any other relatives for whom haemophilia is a new experience. This will be an opportunity to get answers to all those unasked questions. Please encourage your relatives to come along.

Programme
12.00hrs - 13.00hrs
Registration followed by Tea, Coffee & Sandwiches

13.00hrs - 15.00hrs
An Introduction to Haemophilia/Living with Haemophilia

15.00hrs - 15.30hrs
Coffee Break

15.30hrs - 17.00hrs
The Child with Haemophilia

Please note that no charge is applicable on the day, however if you would like to attend please send an R.S.V.P. to Nuala in the office by Friday 30th August 2009. You can contact Nuala on 01 6579900 or by email:- nuala@haemophilia.ie or by clicking on the 'Register for Events' section of the website where you can send an RSVP to Nuala online. *[Some parking will be available on the day on a first come first served basis.]*

SEPTEMBER
REGIONAL VISITS

Dates:
28th to 30th September 2009

Venues:
To be confirmed

OCTOBER
MEMBER'S CONFERENCE

Dates:
16th - 18th October 2009

Venue:
Castletroy Park Hotel, Limerick

On Page 2 you will see details of our Adults Programme for the October Weekend. We are now pleased to give you details of our Young Adults, Kidlink and Creche Programmes

YOUNG ADULTS PROGRAMME
(12 to 18 years)

Friday 16th October

18.00 – 19.00	Registration
19.00 – 20.00	Free time with family before departing
20.00	Depart from hotel to Jamaica Inn Hostel for 2 overnight stays

Saturday 17th October

10.00 – 16.00	Full day of activities in University of Limerick Activity Centre
16.15	Depart from activity centre back to hostel for dinner and overnight stay

Sunday 18th October

09.15	Depart from hostel back to hotel
10.00 – 11.15	Full Group: Adults, Young Adults, Kidlink Art workshop OR Tai Chi
11.15 – 11.30	Coffee Break
11.30 – 13.00	Full Group: Adults, Young Adults, Kidlink Art workshop OR Tai Chi
13.00 – 14.00	Lunch

KIDLINK PROGRAMME
(7 to 11 years)

Friday 16th October

18.00 – 19.00	Registration No activity on Friday evening

Saturday 17th October

10.00 – 11.45	Swimming
12.00 – 13.00	Lunch in hotel
13.30 - 15.00	Activity to be confirmed
15.30 - 17.00	Celtic Park & Gardens Tour
17.30	Parents collect children from reception
20.00	Dinner with parents followed by quiz

Sunday 18th October

10.00 – 11.15	Full Group: Adults, Young Adults, Kidlink Art workshop OR Tai Chi
11.15 – 11.30	Coffee Break
11.30 – 13.00	Full Group Adults, Young Adults, Kidlink Art workshop OR Tai Chi
13.00 – 14.00	Lunch

CRECHE PROGRAMME
(0 - 6 years)

Friday 16th October

18.00 – 19.00	Registration

Saturday 17th October

10.00 – 17.00	Arts & Crafts Movie Play time Fun & games

Lunch served in crèche room

Sunday 18th October

10.00 – 13.00	Arts & Crafts Movie Play time Fun & games
13.00	Lunch

NOVEMBER
REGIONAL VISITS

Dates:
9th to 11th November 2009

Venues:
To be confirmed

NOVEMBER
MEMORIAL SERVICE

Date:
Sunday 29th November 2009

Venue:
Office of the I.H.S.

We would like to invite you to attend our 'Service of Remembrance', in memory of all deceased members of the Society. If you cannot attend in person, please be assured that your loved one's name will be included on the list of remembrance.

MARCH 2010
AGM & CONFERENCE

Dates:
5th to 7th March 2010

Venues:
The Royal Marine Hotel, Dun Laoghaire, Co. Dublin.

We are pleased to announce that the venue for the Annual General Meeting next year is the Royal Marine Hotel in Dun Laoghaire, Co. Dublin. More information on the programme will be available in the next edition of the magazine.

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