haemophilia.ie

Magazine of the Irish Haemophilia Society

AGM Gallery

April 2010

ANNOUNCEMENT

Members' Weekend
Dates: 15th to 17th October 2010
Venue: Castletroy Park Hotel, Limerick

PRELIMINARY ADULT PROGRAMME

Booking forms will be going out to members during the summer. Places are limited so booking early is advisable. You will also be able to register for this event online in the 'Calendar of Events' section of our website www.haemophilia.ie

Friday 15th October

6.30pm – 7.30pm	Registration – Full group

Saturday 16th October

10.00am – 10.30am	Entitlements & Benefits
10.30am – 11.00am	Coffee Break
11.00am – 1.00pm	Positive living for the family with a bleeding disorder - Owen Hegarty
1.00pm – 2.00pm	Lunch
2.00pm – 3.00pm	Debate "Guiding the child with haemophilia: who does it better, the mother or the father"?
3.00pm – 3.30pm	Coffee Break
3.30pm – 5.00pm	Ageing and haemophilia Or Women with Bleeding Disorders & Von Willebrands
5.00pm – 5.30pm	Using Social Media

Sunday 17th October

10.00am – 1.00pm	Drama Workshop – Full group
1pm	Lunch

CRECHE

Full creche facilities will be available for the weekend.

Saturday: 09.30am to 5.30pm
Sunday: 10.00am to 1.00pm

KIDLINK

The Kidlink programme is for children aged 7 to 11 years and will be based in the hotel.

YOUNG ADULTS

The young adults programme for the weekend for 12 to 18 year olds will consist of staying in a hostel and going to an Adventure Centre in Limerick.

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

Contents

AGM & Conference 2010

Turning my front door key I fell into the hall, exhausted. It could have been the four hour drive but most likely the cause of my tiredness was the weekend I'd just spent at the Royal Marine Hotel, in Dun Laoghaire attending the I.H.S. Annual General Meeting & Conference.

Given the popularity of the weekend and the number of programmes running simultaneously finding a suitable venue has become quite a task for the Society's staff. Originally opened in 1865 the Royal Marine, with a reputation for professionalism and attention to detail, has hosted many prestigious events and can number Heads of State, royalty and numerous celebrities among its past residents. It proved to be an outstanding choice of venue, with superb facilities and excellent food.

While the adult programme didn't start until Saturday morning many of those that arrived on Friday evening took the opportunity to unwind after the journey and catch up with old friends, always an important part of any I.H.S. meeting. Meanwhile for the younger, and lets face it more energetic members, a Wii Championship had been arranged. As an older and less IT savvy member who hasn't progressed beyond Wii bowling and the Tiger Woods PGA Tour game I opted out however my spies tell me that the evening was a great success with Conor Birkett eventually being crowned King of the Wii Consol.

The business meeting took place on Saturday morning giving delegates the opportunity to hear from and, importantly, question the Officers of the Board and the CEO as they outlined the events of the past year, the financial position of the Society and future plans with an emphasis on volunteerism and fundraising. As the various reports outlined it had been a very busy year, so it was great to hear that all board members were willing to serve again next year. As the Society had also received a nomination for Eoin Moriarty to join the board an election would normally have taken place. However given the planned work load for the year ahead and the need to inject a bit of youth in to the Board, at the request of the Chairman and with the approval of the members, Eoin was appointed to the board without an election.

Following the business meeting, Evelyn Singleton from the NCHCD demonstrated the new handheld devices which when introduced will replace the pink forms that we all know and 'love'. When used in conjunction with the electronic patient records, bar-coding and the cold chain delivery service the device will allow easy recall of products, assist with stock management and help monitor treatment. By setting treatment parameters clinicians will be alerted to unusual infusion patterns which could indicate, for example, a bleed. There are two types of handheld devices currently being tested by a number of patients; one which reads the product bar-code and another which takes a photo of the code. Evelyn's colleague Laurence D'arcy showed me the bar-code reading device later in the day. It is very easy to operate and provides a final safeguard against using out-of-date, recalled or inappropriate treatment. I think everyone will love these devices from the most ardent IT geek to those of us who are more technophobic.

Following lunch Yuri Zhulyov, President of the Russian Haemophilia Association (RHA) outlined the situation facing people with bleeding disorders in his country. From Ireland it's hard to imagine the task facing Yuri, who has been President of the Association for 17 years. Russia has a population of 142 million scattered across some 6.5 million square miles and ten time zones. Naturally attending meetings in such a vast country can cause problems; one of Yuri's board members has an eight hour flight to attend meetings. It is only natural then that each of the RHA's 62 chapters, many of which Yuri helped to establish, has a large degree of autonomy. Each appoints its own board and is responsible for its own funding and expenditure. The RHA assists with, and provides training for advocacy, financially supports new chapters, maintains an informative website and provides training workshops.

Life for people with haemophilia (pwh) has improved much since the first regional organisation was founded in 1989 – the RHA was established in 2000 – but much work still needs to be done to help Russia's 7,400 haemophilia patients. Until recently very little factor concentrate was available for treatment, hospitals relying on cryoprecipitate and fresh frozen plasma. Even then there was only enough product to treat 30-40% of patients, mainly children. The use of inadequate and unsafe product has left its legacy. Ninety percent of pwh have severe joint damage, 69% have Hepatitis B and 67% Hepatitis C.

The early years of the RHA were marked with much official suspicion however 2005 saw a remarkable thawing in relations. Thanks largely to Yuri's advocacy, with the help of clinicians and other experts, in that year the Russian Federation agreed to provide factor concentrates for home treatment. The Government have so far kept to their word. In 1996 the per capita factor concentrate usage amounted to less than 0.1 iu today that figure has risen to around 4 iu. Bizarrely home treatment in many

regions of the vast Russian Federation is better than that available in hospitals where cryoprecipitate is still the norm.

The availability of home treatment has given new hope to people with haemophilia in Russia. One of his closing slides said it all. It pictured six young adults with severe Haemophilia A preparing to climb Mt. Elbrus the highest peak in Europe. Winners of a joint RHA/pharmaceutical company competition entitled, 'Say Yes to Life' the boys were inspired by Yuri to believe in themselves and realise their dreams.

Yuri also provided inspiration for our own young adults during the weekend when he addressed them as a part of their 'Learn it, Live it, Teach it' programme. The object of the programme was to give participants an opportunity to learn about haemophilia treatment in another country and then use interactive whiteboard technology to produce a presentation for the Kidlink group. Three presentations were produced; 'The Russian Royal Family & Russian Haemophilia Association'; A Day in the Life of a Russian Haemophiliac' which featured Goldilocks; and 'The Geography, Society, Culture and Economics of Russia', with Aisling Moriarty & Robert Byrne eventually being declared winners. Everyone had great fun and learnt much which in turn led to a final request to the I.H.S. Board, "Please give us a summer camp, preferably in Hawaii."

It was good of the Kidlink group to take time off from their busy schedule to judge this competition. Arts & crafts followed swimming in the morning, then the group travelled to the National Sealife Centre, in Bray where they experienced close encounters with all manner of marine life from Shrimps to Sharks and Octopuses to Eels.

Saturday as usual was very busy. While the children and young adults were enjoying their programmes older members had presentations on 'I.H.S. Support Services' from Anne Duffy; 'Prophylaxis' from Dr. Paul Giangrande and Declan Noone; and 'Haemophilia – Collaboration Towards Excellence' from Brian O'Mahony.

It's always good to see Dr. Paul Giangrande, who is an old friend of the I.H.S., at our conferences. His presentations are always informative and thought provoking. This presentation was no exception. Paul started his presentation by reminding us that prophylaxis is the optimum therapy for haemophilia, as it prevents the vast majority of joint and muscle damage and allows the child or person with haemophilia to lead a normal quality of life. He also reminded us that the practice of prophylactic treatment started in Sweden in the 1950's from where it spread to other countries.

While prophylaxis may be the norm in many developed countries there is no agreement on just what constitutes optimum prophylactic treatment. Developments in Canada, where research has shown that there is a risk of thrombosis from the long term use of Port-a-Caths or other venous access systems, are particularly interesting. Instead of the traditional thrice weekly FVIII prophylactic infusion patients are first given a single dose at 50iu/kg. If this proves to be ineffective at preventing breakthrough bleeds the treatment is changed to a twice weekly dose of 30iu/kg before finally reverting to the thrice weekly infusions. Of course the advent of longer acting factor concentrate will fundamentally change current prophylactic regimes.

Declan Noone's presentation highlighted just how effective prophylactic treatment can be. Using experiential data gathered from Ireland, the UK, France and Sweden Declan was able to show the benefits of early prophylaxis.

For example in a cohort of patients aged 20-35 years those from Sweden suffered only 3.2 bleeds per annum compared to the 16-20 bleeds suffered by those from other countries in the study. When he compared days lost from work Sweden's figure was 0-4 days; Ireland and the UK, 5-6 days; and France, whose figures were skewed by two patients, 15 days. Brian O'Mahony in his presentation highlighted the need to gather experiential data to make the argument for optimum care.

The Gala dinner, presentations and entertainment are always a special time at conferences. Each year the Society awards a number of scholarships to assist with the cost of third level education. For the current academic year a total of €16,000 in scholarships was paid out. Within this there are two special awards. The Maureen Downey Award for €4,000 for a person with haemophilia and the Margaret King Education Award for €2,000 for a family member of a person with haemophilia.

This year the Maureen Downey Award went to 22 year old Daryl Butler who has severe haemophilia. Daryl is studying medicine in University College Cork having completed his pre med in UCD. Daryl said his intention is to follow his Bachelor of Medicine degree with a one year Masters in Science. Despite his busy schedule Daryl has found time to volunteer for a number of I.H.S. events and Barretstown Gang Camp. Patrick Downey presented the award to Daryl.

The Margaret King Education Award this year went to Christina O'Sullivan. Christina is in her first year studying Applied Psychology at UCC having achieved 600 points in her Leaving Cert. She is an active supporter of the Chernobyl Children's Project, having spent some time in Belarus as a volunteer; she is a qualified lifeguard and designed our Kidlink logo. Christina accepted her award from Michael Davenport.

The Bill O'Sullivan Fundraiser of the Year Award this year went not to an individual but a group, the Castledermot Vintage Club who raised an incredible €24,000 at a vintage steam rally held in memory of I.H.S. member David Sixsmith. On hand to accept the award from Grace O'Sullivan were Rita Horan and Suzanne Corcoran.

There was one final presentation. To mark his six years as Chair of the National Haemophilia Council Brian O'Mahony presented Prof. John Bonnar with a crystal bowl.

With the formal part of the evening completed, and the younger members enjoying a disco, the B Sharps took to the stage and entertained us until the early hours. As usual they struck a chord with their audience and hit all the right notes sending us to bed with a stirring rendition of New York, New York made famous by Frank Sinatra, himself a former guest at the hotel.

On Sunday morning there were two adult sessions running simultaneously; 'Issues for Women' with Prof. John Bonnar and Dr. Paul Giangrande, and 'Dental Care' with Dr. Alison Dougall. Prof. John Bonnar's presentation focused on the use of Tranexamic Acid, which was first used in Sweden, in the treatment of heavy menstrual bleeding not only in women with a bleeding disorder but also

for other causes of heavy bleeding. He pointed out that historically the most common treatment for this problem was hysterectomy however the use of tranexamic acid had reduced the need for surgery. He added that over the last eight years Ireland had seen a 40% reduction in the number of hysterectomies being performed. Following Prof. Bonnar's presentation Dr. Paul Giangrande joined him to answer specific questions from the audience.

Dr. Alison Dougall's presentation highlighted modern dental care for pwh. She pointed out that if you have mild haemophilia it is fine to attend your own dentist for routine treatment but others should still be treated in a specialist setting. Further details on modern dental practice can be found at: www.haemophilia.ie in the publications section.

In what was a busy Sunday morning for the adults there were two other sessions; 'The Junior Programme: The Story So Far' with Alison Daly and 'The Work of the National Haemophilia Council' with Prof. John Bonnar and a number of other members of the NHC. Prof. Bonnar's session included a very informative question and answer portion which touched on many current issues.

Sunday morning for the Kidlink participants and young adults featured swimming – ever popular – and a presentation on taking care of your teeth, which received mixed reviews. Later the younger group had circle time while the young adults were given a talk on becoming the Kidlink leaders of tomorrow.

The weekend concluded with everyone, adults and children, enjoying a leisurely lunch after what most people would agree was a very successful AGM and conference.

Kevin Birkett
Honorary Secretary

AGM Gallery

An update from our Chief Executive

There are many contentious issues in relation to blood and plasma which divide the key stakeholders globally including: the question of paid and unpaid donors for blood and plasma, donor deferral measures and the relative rights of donors and patients. Over the past several years, it had become increasingly clear to me that the views of many of the key stakeholders were fixed on these issues and there was very little real dialogue taking place. From a patient organisation perspective, it was also very clear that a distinction needed to be made between the collection of blood and the collection of plasma and subsequent manufacture into plasma derived medicinal products. The amount of plasma which is required globally to make plasma derived factor concentrates and other products manufactured from plasma, greatly exceeds the amount of plasma which can be recovered from whole blood donations. Clearly therefore there is a need for, on the one hand, plasma to be collected as recovered plasma from whole blood donations, but also a very significant amount of plasma to be collected by plasmapheresis (called source plasma). In the vast majority of countries, blood donors are voluntary and non-remunerated whereas plasmapheresis donors who donate more frequently are voluntary remunerated donors. The plasma from both sectors is urgently required but, our concern as a patient organisation was that there were often calls for banning of plasma from paid donors and that many of the opinions expressed were not based on science or in the best interests of patients.

Under the auspices of the group of patient organisations who constitute the Plasma Users Coalition (PLUS), I organised a Consensus Conference for the key stakeholders which took place in Dunboyne Castle, in January 2010. I was greatly assisted in preparing all the materials for the conference by Alison Turner the Chief Executive of the National Blood Authority in Australia. The conference was attended by key opinion leaders from a broad range of stakeholders these included patient organisations (PLUS, WFH and IPOPI), National Blood Authorities (Australia, Canada and Ireland), the industry (PPTA), the not for profit sector (IPFA and EBA), the International Society for Blood Transfusion (ISBT) and the donor organisation (IFBDO). The World Health Organisation attended as observers. The 15 participants engaged in two days of constructive dialogue and discussion which resulted in an agreed consensus statement called the Dublin Consensus Statement. The Statement contains an introduction setting out broad principles and four sections relating to patients, donors, sector relationships and global utilisation of donated blood and plasma. There is recognition in the introduction that national blood transfusion systems can be based on voluntary non remunerated donors but also that an adequate supply of plasma products requires recovered and source plasma to meet patients needs on a global level.

There was a very welcome recognition that the absolute focus of the blood and plasma sectors must be the patient and a clear statement that patients whose continued health is dependant on the use of plasma products have a right, through their representative organisations, to be consulted on any issue which may have an impact on the safety, efficacy or supply of treatment they receive. These statements might seem self-evident but in the past, in many of the divisive debates which have taken place on these vital issues, it almost seems as if the interests and views of the patients were very much a secondary consideration. There is also in the consensus statement a strong section on the rights of donors and the value placed on all of those who donate blood or plasma for the benefit of patients. However, this must not obscure the fact that the primary purpose of the collection of blood and plasma is for the benefit of patients and therefore patient organisations must be proactively involved in the decisions which may impact on their vital therapy. It was vital, in my view, that this Consensus Conference was organised under the auspices of the patients' organisations which come together under the plasma users coalition. The consensus statement was agreed by all the participants with the exception of the representative of the donor organisation who none the less very much appreciated being present at the conference and contributed to the discussions. The Statement has now been sent by each of the individuals present to their respective organisations to seek their formal endorsement. Several patient organisations who constitute PLUS have already formally endorsed the Statement. The Statement will be published by the prestigious Blood Transfusion Journal 'Vox Sanguinis' in June 2010.

Of equal importance was the constructive nature of the dialogue that took place. Many of the participants at the Consensus Conference hold diametrically opposite views on several of the issues. During the constructive engagement that took place over the two days, perceptions and views were altered. The participants clearly signalled that they wish to see this becoming an ongoing process and therefore a Consensus Conference will once again be held in early 2011 to continue this vital dialogue. Our aims as patients organisations is to ensure that this dialogue and constructive engagement leads to the views of patients being front and centre in all of the major decisions taken in relation to blood and plasma in the future. In late March we discussed the outcome of the Conference with the EU Commission and we will be proactively consulted when the EU Blood Directive update reports are being prepared. The IHS have also received a letter of congratulations from the Minister for Health and Children for our leading role in organising this initiative. *[The full Dublin Consensus statement is reprinted on the following 2 pages of this magazine.]*

Brian O'Mahony
Chief Executive

Dublin Consensus Statement

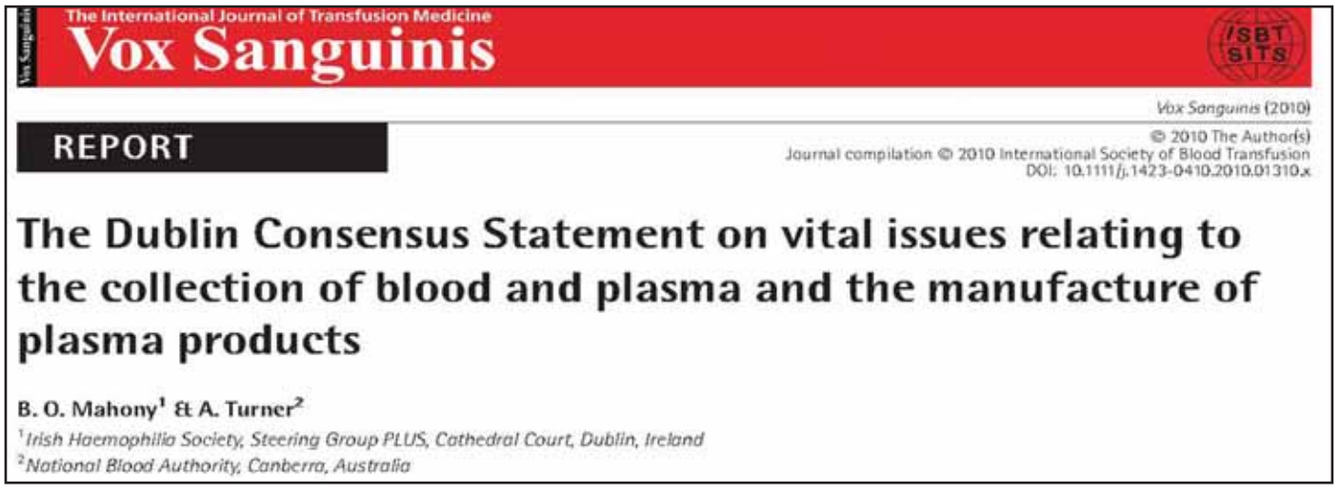
Introduction

The three major priorities for the global community in providing patients with adequate and safe blood components and plasma products are to:

a) Provide safe and sufficient blood components in all countries through the development of national blood transfusion systems based on voluntary non – remunerated donors.

b) Maintain sufficient and sustainable supplies of blood components from established blood transfusion services, based on voluntary non – remunerated donors.

c) Provide an adequate supply of plasma products from recovered and source plasma to meet patient needs on a global level.



The blood and plasma sectors comprise

• Blood establishments whose principal objective is the collection of blood for the production of blood components and in some cases plasma for further fractionation, and

• The plasma sector which collects plasma for subsequent fractionation into plasma derived medicinal products. Plasma products made from both non-remunerated and remunerated donations are currently essential to meet global health needs.

The donation of blood or plasma and its transformation into products that save and enhance the lives of patients is an invaluable contribution to modern healthcare. Respect for individuals, maintaining the health of blood and plasma donors, and providing safe blood and plasma products for patients, are of utmost importance. Countries and regions are entitled to have policies and practices on blood and plasma which reflect their political, cultural, ethical and economic contexts.The blood and plasma sectors must operate within stringent national, regional and international regulatory regimes that support the production of safe and effective products.

The following principles provide the foundation on which the blood and plasma sectors should build their operations.

Principles

1. Patients

The absolute focus of the blood and plasma sectors in health care must be the patient.

1.1 Meeting the health needs of patients through a sufficient supply of safe and effective blood components and plasma products is the principal goal of the blood and plasma sectors.

1.2 Patients are entitled to expect that all stakeholders in the blood and plasma sectors will support their need for access to safe and effective products.

1.3 Patients whose continued health is dependant on the use of blood or plasma products have a right, through their representative organizations, to be consulted on any issue which may have an impact on the safety, efficacy or supply of the treatment they receive. Health Authorities should ensure that robust mechanisms are in place to ensure that this happens.

1.4 The blood and plasma sectors must ensure that their actions do not compromise the health status of those that receive blood components or plasma products.

1.5 The blood and plasma sectors should take all reasonable steps to eliminate the possibility of adverse reactions and events including transmission of pathogens. Risks vary from product to product and each product should be individually assessed.

2. Donors

2.1 The blood and plasma sectors must respect the intrinsic dignity of all people involved in the blood and plasma donation process.

2.2 The blood and plasma sectors and society in general should highly value all those who donate blood or plasma for the benefit of patients, recognize that donors perform a good action and treat donors with respect.

2.3 There is a limit to the capacity of the blood and plasma sectors to ensure the safety of blood and plasma products through testing and processing alone. It is therefore important that measures to defer donors are based on a precautionary approach and underpinned by evidence based assessment where feasible. Donors must have donor deferral policies clearly explained to them.

2.4 All people may offer blood or plasma to the community and their generosity is highly valued. However, the blood and plasma sectors have an obligation to only accept blood or plasma where the donor selection criteria are met.

2.5 All donors must give their free and informed consent prior to the donation.

2.6 All donors must be provided with clear and accessible information prior to their donation, which should include information on:

- The potential risks to them of donating blood or plasma,
- The intended use of their donation,
- Who might benefit from their donation, including the health benefits for patients, benefits to the blood service and to any other party who facilitates the donation.

2.7 Donor information and samples will be kept private and confidential in accordance with relevant guidelines and legislation.

2.8 Donors should not be exploited by any individual or organization.

2.9 The blood and plasma sectors owe a professional duty to act in the best interests of those that donate and receive blood and plasma products.

2.10 The health of the donor should not be compromised by their donation.

2.11 Those seeking donations of blood and plasma may offer incentives for people to donate. Incentives offered will differ and reflect the social, economic, ethical and cultural environment in which the blood and plasma sectors operates. However, all incentives should be of a kind that:

- pose no risk of harm,
- do not overwhelm the capacity of the donor to make an informed decision about whether or not to donate.

3. Sector relationships

The production of blood components and the manufacture of plasma products involve different manufacturing pathways, have access to different risk mitigation measures and the products are used to treat different diseases. The co-existence of two independent collection systems, one for blood and one for plasma, in the same region or country, could create a risk of shortage in the supply of blood components. Cooperation between the blood and plasma sectors is important to ensure that the best community outcomes are achieved including sufficiency of supply for patients.

3.1 Activities undertaken to support plasma collection should not compromise the ability of a nation or a region to collect adequate supplies of blood components to meet clinical needs.

3.2 Similarly, activities undertaken to collect or promote adequate supplies of blood products should take into account the ability of those who collect plasma for fractionation to meet the requirements of patients who rely on these therapies.

3.3 Organizations involved in whole blood and plasma collection should cooperate with the goal of ensuring the health of the donor and potential blood component and plasma product recipients.

3.4 The manufacture of blood components and plasma products to treat patients with very rare diseases should be welcomed and actively supported by all those that operate in the blood and plasma sectors.

3.5 All stakeholders in the blood and plasma sectors have the right to hold and express opinions and should treat each other with mutual respect.

4. Global utilization of donated blood and plasma

The products of the blood and plasma sectors are sometimes not needed to meet the blood and plasma product needs in that particular region. This is because a number of different products can be produced from a single fresh or plasma donation. Many regions lack the capacity to collect and produce all the blood products they need, so they are reliant on blood or plasma donated in another region. Donors expect their blood or plasma to be used to benefit patients who need blood and plasma products.

4.1 The needs of patients should determine the optimal collection of blood and plasma.

4.2 The Blood and plasma sectors have an obligation to donors to make their best endeavours to use that blood or plasma for the purposes for which it was donated.

4.3 Having satisfied the principal purpose for its collection, blood components, plasma and plasma intermediates not required for that purpose should be made available to meet the health needs of others and contribute to global health outcomes where feasible. Feasibility includes whether the costs of provision are able to be met and if the regulatory regime and healthcare systems in both regions supports availability.

4.4 Regulation of the collection and use of plasma for manufacture should be based on science and the precautionary principle, and facilitate global movement of products when safe and appropriate to do so.

Hepatitis C Update

Hepatitis C Virus (HCV) is a disease that has variable rates of progression, but generally it develops slowly (Lee 1999). HCV can affect people in many ways. It can cause symptoms such as fatigue, nausea, pain and depression, which can all have an impact on quality of life (Grogan and Timmons 2009). In 1987, Interferon (mono-therapy) was available, with the introduction of Ribaviron in 2000 (combination therapy). Treatment is recommended to eradicate the Hepatitis C virus and prevent the development of severe liver disease (Posthouwer et al 2006). Many patients express anxiety and fear around starting treatment, particularly if a friend, relative or they themselves have previously experienced difficult side effects from the treatment or indeed if they have failed the treatment in the past.

With the introduction of combination therapy the response rate to treatment has increased to 50-60% depending on your genotype (Postouwer et al 2006). Your genotype is the specific strain of HCV. Patients often feel that success rates of 50-60% are not high enough, especially when dealing with lengthy and difficult treatment regimen. However, research has shown that treatment even when it has not achieved a Sustained Virological Response (SVR), which is a way of measuring treatment success, will still help decrease liver inflammation and viral load (Grogan and Timmons 2009). Throughout the treatment process there are numerous support networks available in the NCHCD, including psychology, social work and counselling for both patients and family members.

Patients are always encouraged to commence HCV treatment, but even if patients feel that it not an option at pres ent, we still encourage regular attendance to Hepatology. In all cases it is important to attend the Hepatology outpatients on a regular basis to monitor disease progression.

The introduction of a Fibroscan is a much-welcomed development in the Hepatology centre. A fibroscan is non-invasive, and similar to an ultrasound. Previously a liver biopsy was performed to determine the stage of liver fibrosis (Maor et al 2010). The fibroscan has been used to minimise the number of biopsies taken, particularly in haemophilia patients (Maor et al 2010). The fibroscan takes place in Hepatology and takes no more than an hour. It is important you discuss the option with your Hepatologist.

"If you are worried about your Hepatitis C or your health, please contact Hepatology for an appointment. Alternatively book in to the nurse-led clinic in the NCHCD for a full discussion".

In St James's Hospital a nurse-led clinic dedicated to haemophilia and HCV runs Tuesday to Thursday each week in the NCHCD. This clinic is dedicated to patients with haemophilia and Hepatitis C. Issues pertaining to HCV treatment options, relationship counselling, and HAA cards, or any other issue you have in relation to Hepatitis C and haemophilia can be discussed with the nurse specialist. Appointments can be made via reception or just drop-in.

Further to this, HCV Management guidelines have been introduced for the management of patients who are Hepatitis C PCR positive. These guidelines give clear indications on what tests should be performed and how often. It is important to study these guidelines carefully and note how frequently you should be attending Hepatology and what investigations are due. These are guidelines only, and your Hepatologist may develop a different plan during your consultation.

If you are worried about your Hepatitis C or your health please contact Hepatology for an appointment. Alternately book in to the nurse-led clinic in the NCHCD for a full discussion.

Niamh Larkin
NCHCD Team, St. James's Hospital

REFERENCES

Grogan. A., and Timmons. F. (2009) Side effects of treatment in patients with hepatitis C- implications for nurse specialist practice. Australian Journal of Advanced Nursing. 27, 70-77.

Lee. C. (1999) Hepatitis C Infection And Its Management. Treatment of Haemophilia, No 21. . World Federation of Haemophilia.

Maor. Y., Halfon. D., Penaranda. G., Morali. G., Klar. R., Bar-Meir. S., Martinowitz. U., and Oren. R. (2010) Fibrotest or Fibroscan for evaluation of liver fibrosis in haemophilia patients infected with hepatitis C. Haemophilia. 16, 148-154.

Postouwer. D., Mauser-Bunschoten. E. P., Fischer. K., and Makris. M. (2006) Treatment of chronic hepatitis C in patients with haemophilia: a review of the literature. Haemoophilia. 12, 473-478.

Hepatitis C Management Guidelines

HEPATOLOGY/NCHCD/GUIDE CLINICS
ST. JAMES'S HOSPITAL

HEPATITIS C MANAGEMENT GUIDELINES

	Non-cirrhotic or Fibrosis stage unknown	Cirrhosis, Pre-Cirrhotic or Bridging Fibrosis
Hepatitis C PCR Positive & HIV Positive	3-4 monthly review in Co-infection Clinic as directed & review in Hepatology as recommended Liver ultrasound as indicated by physician Liver function tests & blood test for alpha-fetoprotein 6 monthly	3-4 monthly review in Co-infection Clinic & review in Hepatology as recommended Liver ultrasound 6 monthly Liver function tests & blood test for alpha-fetoprotein 6 monthly OGD every 2-3 years and more frequently, if varices identified
Hepatitis C PCR Positive & HIV Negative	6 monthly review in Hepatology Liver ultrasound as indicated by physician Liver function tests & blood test for alpha-fetoprotein 6 monthly	6 monthly review in Hepatology Liver ultrasound 6 monthly Liver function tests & blood test for alpha-fetoprotein 6 monthly OGD every 2-3 years and more frequently if varices identified

Liver Ultrasound: Ultrasound uses sound waves, not x-rays, to generate images. A jelly-like substance is applied to the skin overlying your liver. Then a probe, called a transducer, is passed over the skin. The transducer sends out sound waves that pass through the body and are echoed back. The transducer receives the echoes and transmits them to a computer console, which in turn interprets the echo data as internal organs and tissues.

Alpha feto-protein: A blood test for AFP is used to help detect and diagnose cancer of the liver. It is often ordered to monitor people with chronic liver disease such as cirrhosis because they have an increased lifetime risk of developing liver cancer.

OGD: An oesophagogastroduodenoscopy (or OGD for short) is a test that allows the doctor to look inside your oesophagus (food pipe), stomach and duodenum using an endoscope. An endoscope is a tube containing a small camera and a light.

Varices: Swollen blood vessels often found in the stomach, oesophagus and intestines when there is high pressure in the liver veins, typically from cirrhosis.

Prophylaxis versus On Demand Therapy

A Survey on Prophylaxis versus On Demand Therapy in Young Adults with Haemophilia in four European Countries

A young boy from Paraguay infusing himself with factor concentrate

Prophylaxis is widely accepted as the optimum standard of care for children with severe haemophilia. However, there is still a lot of discussion and debate on the necessity of prophylaxis continuing into adulthood. Prophylaxis has been the standard of care for children and adults in Sweden for over 25 years. Therefore young adults in Sweden with severe haemophilia would, in the vast majority of cases, have been on prophylaxis since a very early age and this would have continued into adulthood. In contrast young adults with haemophilia in countries such as Ireland, UK and France would generally be treated with on demand therapy, although some would be on prophylaxis. However, in these countries prophylaxis would have been introduced some time in the last 10 to 15 years, and therefore these young adults would not have grown up with the benefits of prophylaxis and would have started their lives with on demand therapy.

Declan Noone and I undertook a survey of young adults with severe haemophilia in four European countries: Sweden, France, UK and Ireland with the co-operation of the respective countries. A total of 58 young men with haemophilia between the ages of 20 and 35 were interviewed by phone. They were asked questions in relation to how long they had been on prophylaxis, about target joints, major bleeds and mobility problems. They were also asked to answer a very simple questionnaire with five questions (EQ5D). The EQ5D questionnaire is based on questions related to mobility, self care, ability to carry out usual activities, levels of pain and discomfort, and levels of anxiety and depression. The questionnaire allowed us to extrapolate a utility value for the quality of life on a scale from zero to one. Zero would correspond to death and one would correspond to a perfect quality of life.

The results of the survey are crystal clear. The benefits to the adults in Sweden of having been treated prophylactically from an early age and continuing into adulthood were obvious. People with severe haemophilia in Sweden reported less target joints, less major bleeds and significantly lower mobility problems when compared to people with haemophilia in the other three countries. The average number of bleeds per year in Sweden was just over three whereas, in the other three countries it varied from 16 to 20 bleeds per year. Only 25% of those in Sweden had target joints, whereas 94% to 100% of those in the other three countries had target (damaged) joints. Of the 58 individuals surveyed only 16 had no target joints. Of these 16, all except one are living in Sweden. There was a very clear differential in relation to the number of days missed from work or college. In Sweden the average number of days missed per person per year was 0.5, in Ireland it was five, in the UK it was 6.6 and in France it was 15. The figure in France is very high because the French persons with haemophilia questioned for the survey included two young men with haemophilia who had recently undergone joint replacement surgery and therefore they were missing a significant amount of college or work. This is not unusual as the requirement for orthopaedic surgery

and joint replacement surgery will be there for individuals who don't have access to prophylactic therapy. There is also a dramatic difference between Sweden and the other three countries when it came to the respondents views of their quality of life as measured by the EQ5D questionnaire. The average quality of life in the UK, Ireland and France varied from 0.68 to 0.74, whereas the average quality of life in Sweden was 0.93. This Swedish score is very close to a perfect quality of life (1.0) whereas those in the other three countries have the perception that their quality of life is about 25% lower than those in Sweden.

When we looked at the data in relation to the treatment regime it was very clear that the differences were not due to nationality or other factors. They were due to the fact that the individuals in Sweden had been on prophylaxis from a very early age and this was continuing into adulthood. This study is a small scale study with a relatively small number of participants. It would be interesting to gather more data from more countries and in particular it would be interesting to look at data from countries which use different prophylactic regimes. However, the benefits of long-term prophylaxis continuing into adulthood are clear from this survey. The improvement in quality of life, in ability to take part in society, in ability to attend college or work and not be limited by bleeding episodes or joint damage in Sweden is startling. Out of the 58 patients surveyed only 16 had no target joints, 15 of the 16 are living in Sweden. We hope to extend this survey to other countries and to continue this work in the future.

At this particular time, when budgets are coming under threat, when treatment regimes are been questioned, when high cost but high value treatment regimes such as prophylaxis are under threat in some countries it is timely to have this reminder of the transformation of quality of life which can be brought about by giving a person with severe haemophilia optimum therapy on an ongoing basis. Parents of children with haemophilia in Ireland whose children are treated using prophylaxis are also perhaps getting a glimpse into the future with this survey. If your child complies with his therapy and takes his prophylaxis regularly, as a young adult there is every reason to believe that his quality of life should be near perfect and he should be able to fully participate in college, in employment and in the everyday normal activities of life with no impediment.

We greatly appreciate the participation of the 58 people with haemophilia who responded to the survey. Your participation in the collection of this type of data is vital in assisting us as a haemophilia society to make the cogent arguments required to defend, maintain or improve the high standard of haemophilia care which we will always advocate for on a national basis.

Brian O'Mahony
Chief Executive

Inga Marie Nilsson from Sweden who discovered after research that prophylaxis was the optimum form of treatment for people with severe haemophilia

Tripping around New Zealand

After an extremely busy 2009, and heading into a dark and wet winter after a beautiful Irish summer, I decided to go to New Zealand for three weeks. It has been on the list of places I wanted to go for a while after rave reviews from everyone I have ever met that has travelled there. I expected a lot but thought I would be disappointed to be honest. Not only did it live up to expectations it by far exceeded them. This is one of the most amazing and inspiring countries I have ever been to.....so far!

I arrived in Auckland, and after a few hours sleep to adjust to the time difference I picked up our home for the next three weeks, a converted Toyota people carrier. There are a number of companies that do a whole range of different camper vans, but the one I chose had a bit of character. The camper van had "Police" in graffiti on the side of the van and on the dashboard there was a sticker with a John Lennon quote,"Life is what happens to you while you're busy making other plans", which turned out to be pretty apt for the trip. From Auckland, I travelled south on the Raglan Road *(no Irish jokes intended)* to stunning black sand beaches and then to the Waitomo caves. These caves have millions of glowworm's so when you look up it's like looking at a bright starry night. Next stop was Rotorua, a fragrant town due to the volcanic area around it. There is a strong sulphuric smell in Rotorua with a lot of bubbling ponds of boiling water. For the more adventurous reader you can white water raft down the Kaituna River and over a 7m waterfall. Highly recommended and very refreshing on a hot day! You can also spend an evening with the Maori families learning about traditions, weapons, history followed by a traditional Maori feast called a hangi which is food slowly cooked over hot stones which are placed in a pit in the ground. A very interesting culture and very colourful traditions. Moving on, as you drive south out of Rotorua, you head towards the Lake Taupo, New Zealand's biggest lake. The drive down to the lake is stunning. A perfect postcard view with the sun setting behind snow capped mountains of Tongariro National Park, all reflected by the lake. Up in the Tongariro National

Park you get a concept of how it probably looks on the Moon and you get to see volcano craters and Mordor. From here the road led me to the windy Wellington, the capital of New Zealand with impressive Te Papa Museum and the ferry to the South Island. The first few days on the South Island were spent in the picturesque Abel Tasman National Park, with its stunning golden beaches and ideal conditions for sea kayaking. The companies usually bring you to the north of the park and you float/paddle down the coast through a seal colony, see the occasional penguin and go in and out of magical and pristine coves that are used as nurseries for baby seals. After Abel Tasman I drove down the west along the coast winding in and out catching glimpses of all those rock formations like a sea arch and steps that I learned in geography. Also, I found out that Irish and New Zealand west coasts have a lot in common: sheep and rain. After a while you reach the country of glaciers, with the two main ones accessible for tourists: Franz Josef and Fox. I spent a day hiking on these, moving very slowly behind a guide with a pick axe. There were thousands of shades of blue from the light bouncing off the glacier. Leaving the Alps behind, I stopped in Queenstown, which is surrounded by a mountain range *(with a very appropriate name:The Remarkables)*, that look like special effects from a movie, they are so beautiful.

Further south is the Fjordland,where I took a 2-day kayak trip through the stunning and untouched Doubtful Sound. Sheer walls of rock shooting out of deep black water to heights of 1000m and when it rains they come alive with hundreds of small waterfalls. Heading back north, I travelled to the Aoraki National Park where you can find among many other peaks also Mount. Cook and Mount Tasman. I did a few walks at the base with views on the peaks *(best view out of a toilet EVER!)* and lakes with icebergs floating in them in the middle of summer. The glaciers here also crush the rock underneath to powder which makes the water milky white but when the sun bounces off it and believe it or not it turns turquoise blue. The final destination was Christchurch.

Without doubt the best part of the city is the Antarctica Centre with many cool attractions, like travelling in Hagland *(Machine specifically designed for transport in the Antarctic*), and looking at the actual planes leaving for the Antarctic base or experience a storm at -30 degrees. These were some of the highlights of this spectacular country that has a new surprise and a hidden beauty behind almost every bend in the road. The country is practically empty and they have preserved large parks. I cannot recommend a visit to any country more highly. Getting around to every national wonder in New Zealand, even with dodgy ankles and knees, is very easy. The country is spectacular.

[Hot tip: As I said the trip was done in a camper and for this country there is no better way to do it. There are camp site everywhere. In the camper van you can wake up underneath the shadow of a snow capped mountain or 10metres from a beach.]

I suppose to be fair and balanced, there are some *(but few)* negatives. Firstly some of the beaches and wetter areas have biting insects called Sandflies and unlike mosquitoes these ones hang out with lots of their friends *(think Irish midges)*. Secondly, New Zealand has more road-kill than I have ever seen! There is something pasted to the road every couple of hundred metres. Finally, careful if you pull into a small middle of nowhere town and the sign in front of the local cafe says *"Today's Special: Headlight Delight"*. I'm sure you can guess but there is a clue to the ingredients in my second negative I will leave you with that thought. Go there, you won't regret it!

Declan Noone

An update on travelling to the USA

From the 4th of January 2010, the U.S. Department of Health and Human Services (HHS), is amending its regulations to remove HIV from the definition of communicable disease and removing references to "HIV" from the scope of examinations for people entering the United States. The HHS has stated:

"While HIV infection is a serious health condition; it is not a communicable disease that is a significant public health risk for introduction, transmission, and spread to the U.S. population through casual contact. As a result of this final rule, aliens will no longer be inadmissible into the United States based solely on the ground they are infected with HIV, and they will not be required to undergo HIV testing as part of the required medical examination for U.S. immigration."

When going to the USA, you should make sure you have health insurance. If you don't and something happens it will be a very expensive lesson. So what about haemophilia? Well, always bring your own medication and always carry it with you going on buses, planes, trains and automobiles. You will need a letter from your consultant or haemophilia treatment centre stating you are carrying medication, needles and syringes. This letter should be dated no more than six months prior to travel. The letter also needs to specifically state the brand name of the medication. If it doesn't have the brand name, U.S. Customs can legally take the medication from you. Whether they do or not is at the discretion of the Customs Officer. If you are going for an extended stay, and you are unable to bring all of your Factor with you, it can be shipped over to you. However, the following documentation should accompany the package and is a must for US Customs and the Food and Drug Administration (FDA):

• A prescription from your doctor stating the amount of factor that you use. The amount has to be less than a three month supply and the product should be licensed in the US. All Irish factor concentrates for Haemophilia A, Haemophilia B and vWD are licensed in the US.

• A copy of the recipients passport.

• A Proforma Invoice stating the senders and the receivers details, size, weight, description and value of contents. The contents should have a nominal value of USDollars20 and the description should say "Personal Use Only, Anti-haemophiliac factor – No Commercial Value".

• A letter from your haemophilia treatment centre saying the Factor has no commercial value and is intended entirely for the personal use of the recipient.

• The manufacturers certificate of analysis, for the specific batch number that is being shipped.

If you make sure you have all this information you should have no problems and the package should get through Customs quickly. However, the FDA regulations state that any package entering the country can be held for 72 hours examination, and depending on the outcome of their findings it may or may not be allowed into the country.

Declan Noone

Fundraising

Young Brandon Griffith shaving his Dad's head as a fundraiser for the Society

Enigmatic 22 year old brunette seeks outgoing, fun-loving, enthusiastic individuals. Must have good sense of humour, enjoy singing and be game for a laugh! Does this sound like you or someone you know, then phone 01 657 9900 now, because I am waiting to speak to you about FUNDRAISING!!!

In 2009 the Irish Haemophilia Society received income from fundraisers such as a Shave-a-Thon, a Four Peaks Challenge, the Women's Mini Marathon, the Dublin City Marathon and a Threshing Day. In 2010, we are looking to continue on this fundraising drive, but we need your help to do so.

At the recent AGM we launched the "Pound for Pound" Weightloss challenge. Six members have signed up to take on six members of the I.H.S. staff – Brian, Debbie, Nina, Anne, Fiona and myself to loose weight and be crowned "Society Slimmers of the Year 2010". Each participant was weighed at the AGM and their weight recorded, confidentially of course. The participants will now receive tips and advice on how to keep fit and hopefully loose weight as well as support from the staff and their team mates in their battle against the bulge.

How can you support this challenge I hear you ask? That is simple, you can sign up to sponsor either the members or the staff and at the final weigh in at the Members' Weekend in October, you match what your chosen group has lost in weight, in euros! If you are interested in supporting either of the groups or would like more information about taking part in this *"Operation Transformation"* on an individual basis then contact me at: nuala@haemophilia.ie

The Women's Mini Marathon is an important fundraiser for the Irish Haemophilia Society and we are looking to significantly increase our numbers taking part this year. Some of the I.H.S. staff will be taking part this year and we would love if you could join us. It is a 10km track that you can run, jog or walk, if needed the I.H.S. staff can pull you across the finish-line! So no matter what class of athlete you are, you can sign up. If the exercise element of the day does not entice you, then why not take part to have some fun and enjoy the free refreshments we provide on the day, not forgetting the medal you receive when you finish the race.

If you have any suggestions for fundraising, I would love to hear from you. Whether it is a sponsored silence, a bake sale or a quiz night, we would love if you could fundraise for the society and will offer you as much support as we can to ensure your fundraiser is successful. Just think of the I.H.S staff as your personal cheerleaders and motivators. Any suggestions are welcome or if you would like to volunteer to help out with fundraisers please contact me on 01 6579900 or register your interest at: www.haemophilia.ie.

Nuala McAuley

Vincent Jackson with his son Niall (our youngest ever fundraiser) who climbed 4 mountains

Dates for your Diary

MAY

HIV/Hepatitis C Conference

Dates: 22nd & 23rd May
Venue: Dunboyne Castle Hotel, Co Meath

JUNE

Ladies Mini Marathon

Date: Monday 7th June

Join the I.H.S. staff for this 10 km track across Dublin City. If you would like more information, please contact Nuala in the

office on 01 6579900. Facilities for those taking part will be provdied in Buswells Hotel from 1pm to 6pm. Looking forward to seeing you all in June!

Update Meetings on Tax for Members

Dates:
Friday 11th June in Cork
Saturday 12th June in Dublin

JULY

World Federation of Hemophilia Congress 2010

Dates: 10th to 15th July

The World Federation of Hemophilia Congress 2010 takes place in Buenos Aires, Argentina. The Congress provides the largest international meeting place for members of the global bleeding disorders community. Renowned international treatment and research experts from around the world will participate in the Congress. If you are interesting in travelling to the Congress please contact Debbie in the office for further information.

SEPTEMBER

Relatives Days

Dates:
Friday 10th September in Cork
Saturday 11th September in Dublin

Due to the success of the Relatives' Day in 2009 we have decided to organise two meetings this year in Cork and in Dublin. Please encourage your relatives to attend these excellent Information meetings where they can gain a better understanding of haemophilia & related bleeding disorders.

Official Opening of Haemophilia Centre in Cork University Hospital

Date: Friday 24th September

OCTOBER

Members Weekend

Dates: 15th – 17th October
Venue: Castletroy Park Hotel, Limerick

The venue is confirmed, we have a preliminary programme so its all systems go for our ever popular Members' Weekend again this year. Keep checking the website for updates on the programme. You will find further details on page 2.

NOVEMBER

HIV/Hepatitis C Conference

Dates: 13th & 14th November
Venue: Cork

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

Are you a fan of facebook?

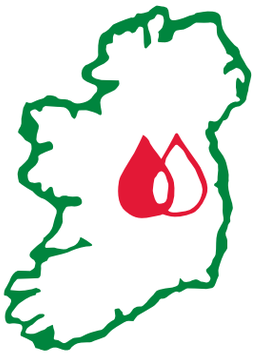
The Irish Haemophilia Society has always been committed to keeping its members up to date with information. In the past year we have revamped our website and are continuing to produce new publications in 2010. The Society have now branched out into the world of social networking.

Facebook is currently the largest social networking site, and is used by many companies and charities worldwide for communication purposes. The Irish Haemophilia Society recognises that social networking sites have become a part of everyday life for most people, in particular young adults. For this reason, we have set up our own facebook site.

We would encourage all of our members who are on facebook to become a fan of the Irish Haemophilia Society on facebook, and keep up to date with information, events and activities of the Society.

To become a fan of the Irish Haemophilia Society on facebook, simply log onto our website: www.haemophilia.ie and click on the link at the bottom of the page.

facebook The Irish Haemophilia Society is now on Facebook



Information

Founded:
1968

Website

www.haemophilia.ie

The Society provides support and advice for people with haemophilia and other bleeding disorders and their families. It carries out its work through education, publications, advocacy, lobbying and counselling.

Company Overview:
The 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. The Society has grown from an informal and voluntary group of parents of people with haemophilia who wanted a better deal for their children, to a confident and professional charity with a committed board and professional staff to deal with the challenges ahead.

Mission:
Provision of advocacy, information, education, services and support for people with bleeding disorders and their families.

Products:
Outreach Services
Youth Programmes
Counselling
Education
Parents Weekend
Members Conferences
Representation, advocacy and lobbying for people with haemophilia and other bleeding disorders in Ireland.