2012 WFH World Congress

I.H.S. Magazine Supplement

The World Congress of Hemophilia - Paris 2012.

President Mark Skinner addressing delegates at the Opening Ceremony.

Opening Ceremony

The 30th World Federation of Hemophilia (WFH) Congress took place in Paris, from the 8th to the 12th July 2012. This years Congress was attended by 5,400 delegates from all corners of the world, a record number to date. With Paris being so near Ireland it was great to see 19 staff, board and members of the Society attend the Congress this year.

We arrived on Sunday morning and after registering we set up the Irish Haemophilia Society publications display in the Exhibition Hall. Delegates attending the Congress had access to the stand for the duration of the Congress and the stand was manned by staff and board members constantly. I was delighted to see that our publications were very popular and having spoken to many overseas delegates, we received many comments praising the publications. The biggest compliment of all was when I was told that some of our publications are being translated into other languages. We also had eight posters on display over the course of the week copies of which you will find on pages 13 to 20.

The Opening Ceremony took place on Sunday evening and when you see all the attending delegates gathered together it really brings home to you the scale of the event. Mr. Mark Skinner, President of WFH, outlined the journey of the WFH which is celebrating its 50th Anniversary, and started originally with 12 National Member Organisations (NMO's) and now has a total of 122 NMO's. Mr. Skinner spoke about the WFH Global Alliance for Progress (GAP) programme which started in 2003 and which has been a huge success worldwide. Mr. Skinner was delighted to announce that due to the previous success of the GAP programme, the WFH will undertake a second decade of the GAP programme which will continue from 2013 until 2022. The Opening Ceremony also highlighted the progress that has been made in recent times. With the Congress officially opened it was time to mingle with delegates in the Exhibition Hall, and to get ready for the first day of talks at the Congress, the following morning.

Nina Storey

Global National Member Organisation (NMO) Training

I arrived in Paris on Wednesday evening the 4th July in preparation for the Global National Member Organisation (NMO) training which took place from Thursday 5th July to Sunday 8th July, just before the actual Congress. It was my first time attending the training so I was very much looking forward to it.

The first day of training was terrific. I enjoyed it a lot. Everyone was brought together for introductions followed by an ice breaker which was great fun. The new CEO of the World Federation of Hemophilia (WFH) Mr. John Bournas and President Mr. Mark Skinner gave updates on the WFH as an organisation, followed by updates of the strategic plan and the Global Alliance for Progress (GAP) programme after which a group photo was taken. It's hard to believe there was 103 delegates from countries around the world at the training. In the afternoon I attended a workshop for established organisations on advocacy strategies. I gave a ten minute presentation on nurturing the media during this workshop. It was great to hear perspectives from other countries on advocacy strategies and a couple of very important points that seemed to come up again and again was that it is very important to have a united organisation and that education and training was key.

The second day of training started with a morning of workshops on the assessment of haemophilia organisations. The attendees were split into 4 groups and each country was asked to identify 3 challenges facing our organisation in the next 5 years. The top 4 challenges that countries seem to be facing are life cycle membership, maintaining comprehensive care, maintaining funding and political advocacy. A good discussion took place in relation to these challenges. Later during this workshop Mr. Bernard Mansen, Chairperson of the UK Society spoke about funding and how their organisation obtains funding, Mr. Val Bias CEO of the National Hemophilia Foundation, USA spoke about the use of social media and how it works for their organisation, I spoke about our volunteer recruitment plan and succession planning, and Mr. Radoslaw Kaczmarek from the Polish Haemophilia Society spoke about economics and data collection. In the afternoon there was a plenary talk on fundraising which was chaired by the new WFH CEO. He spoke about philanthropy, your case for support, networking, how it is important to tell donors how the funds are being used and how important it is to thank people. He suggested putting together a strategic plan for fundraising. Later a screening was held of the film "Bad Blood: A Cautionary Tale", which chronicles the HIV pandemic in the US haemophilia community. Following the film a discussion took place on the value of the film as a tool to raise awareness and advocate for patient involvement when decisions are being made about their treatment and care.

The third and final day of the training started with clinical research. A panel of experts gave excellent presentations on the roles and responsibilities of patient organisations and understanding the different types of research. The challenges of clinical trials was also discussed. During lunch countries bidding for the 2016 and 2018 Congress had booths set up promoting their bids. It seemed like a lot of effort and hard work was put into the booths and all 4 countries seemed very popular indeed. Dr. Paula Bolton Maggs chaired the afternoon session which included presentations on youth issues, an overview of the General Assembly and the election process, the constitution, and a questions and answers session followed by an evaluation and closing. We also got the opportunity to listen to the two Presidential Candidates, Mr. Alain Weill from France and Mr. Cesar Garrido from Venezuela. Each candidate was given 5 minutes to give a presentation to the delegates in relation to why we should vote for them followed by a 30 minute questions and answers session. Afterwards the Executive Committee of the WFH explained their roles within the organisation which was very interesting. All in all, another great day at the training.

The NMO Training was truly an amazing experience. The training and workshops were aimed to help patient organisations and leaders expand their skills and knowledge. I enjoyed it a lot, learned a hell of a lot, and met some really nice people from all parts of the world,

Le Palais De Congress here we come!

Debbie Greene

Personalised Prophylaxis

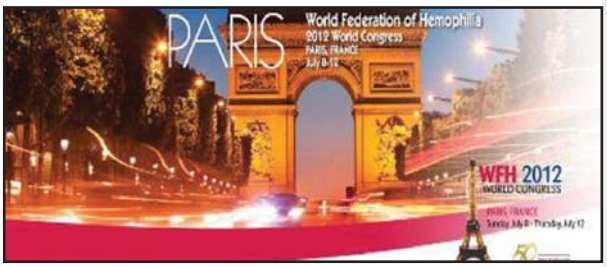
One of the best Plenary Sessions on the programme was a plenary entitled "Personalised Proplyhaxis". Dr. Peter Collins a consultant haematologist from Cardiff gave an excellent talk on the use of prophylaxis from logical point of view to prevent bleeding. He pointed out the difference in half-life's of the same product in different patients in haemophilia A from 6 to 18 hours, from kids to adults, and even the variations within families. He discussed varying options of how the peak and trough levels should be synchronised with the levels of activities and your life schedule. He discussed the importance of being able to take part in the activities giving the example of having haemophilia and growing up in Wales a rugby nation. Should there be a level of prophylaxis given for this? He also discussed longer acting factors and the possible pitfalls that may be seen. Currently there are a number of peaks and troughs on prophylaxis, reaching 1% quickly and mostly at night when your least active and peaking shortly after that. In the longer acting factor there will be less peaks and troughs but there will be a longer time occurring in the day and night where the individual will be close to 1%. What will be the affect of this? He gave a very good example of 2 brothers. The younger lighter one who was more active was on 2000 I.U. three times a week, and getting break though bleeds and the older heavier not as active brother was on 2500 I.U. 3 times a week, and not having any bleeds. By changing the dosing based on the bleeding phenotype the younger brother moved to 2500 I.U. every second day and the older less active less bleeding was reduced to 500 I.U. every second day. This resulted in a reduction in factor use from 450,000 I.U. to 90,000 I.U. whilst at the same time maintaining no breakthrough bleeds.

Debate: Seeing Both Sides

Some of the leading people in the haemophilia community provided an insight into advocating a case for care (comprehensive care and prophylaxis). This was done through a role playing mock meeting with government officials. There were 3 different role plays in the session each looking at different view points from emerged world to emerging world. The patient's side consistently had arguments prepared and was ready for any rebuttals or change of direction that the government side had to offer. They discussed their case with varying amounts of experimental data, data and well controlled emotional pleas. This session was a great success and hugely entertaining, and clearly showed how to advocate, whether it be a doctor, an organisation or a person with haemophilia, everyone needs to work together. The room was packed out, and everyone enjoyed it immensely. The issues raised were to do with preparing for a meeting, controlling emotion but also using it to give the point a personal touch, following up on the meeting, presenting solutions, and knowing the facts. I learned a lot in this session. The audience loved it, laughing out loud on more than on occasion.

Declan Noone

Mr. Brian O'Mahony during his talk.



Economics

The lectures on prophylaxis were linked to the sessions on economics, as prophylaxis is the most studied model in economic analysis of haemophilia care. In the past, studies have demonstrated that the incremental cost of prophylaxis when compared to on demand treatment varies enormously with some studies showing prophylaxis to be very cost ineffective and later studies demonstrating more cost effectiveness. All of the studies in the past have failed to take into account several relevant factors such as the impact on the individual's family and carers, the possible protective effect of prophylaxis on lowering the risk of inhibitors, and the impact over a full lifetime. At the conference, a new model for estimating the cost effectiveness was discussed. This model, to which Declan Noone and I have contributed data and analysis, demonstrates that prophylaxis is ten times more cost effective than previously estimated when looked at over the course of a lifetime. The concept of applying equity arguments was also discussed in the context that haemophilia is a rare disease and therefore concepts such as the cumulative effects of the condition and the past history of HIV and pepatitis C due to unsafe treatment mean that haemophilia needs to be given more consideration that most non rare health states when being viewed by health economists. There is a vast amount of work now underway in the area of health economics and haemophilia to which we are actively contributing.

PICTURE GALLERY

Gene Therapy

For the past 10 to 20 years, it was always being stated that gene therapy for haemophilia was 10 to 20 years away. Progress would seem to be made and then obstacles would become apparent. At the Congress, much focus was placed on the results of the latest gene therapy clinical trial for factor IX deficiency carried out by University College London. The results of the early trials are very encouraging and it now appears that real availability of gene therapy for factor IX may be less than 10 years away with a longer time period until factor VIII therapy is available. The factor IX gene was injected into 6 people with haemophilia B using a vector or delivery system known as an adeno associated virus vector. This vector(AAV-8) was injected intravenously in 3 different doses - low medium and high into 6 individuals who had a factor IX level of less than 1%. The two individuals who received the low dose now have a sustained factor IX level of 2% one year after a single injection. The first of these has been able to stop prophylaxis and now only requires treatment on demand. The second individual has stayed on prophylaxis due to his severe joint problems but he has to take prophylaxis less frequently. The next 2 individuals received a medium dose. Their factor IX levels have stabilised at 2% and 3% respectively with the latter requiring no factor injections for the past 15 months. The last 2 individuals were treated at a higher dose. In both of these some inflammation of the liver occurred as evidenced by an increase in liver enzymes. This was due to an immune response to the protein in the AAV-8 and was dealt with successfully by a short course of steroids. In the first of these, the factor IX level increased to between 5-7%, but then fell following the immune response to stabilise at 2%. In the second of these, the factor IX level rose to between 8-10%, and following timely intervention with steroids when the immune response occoured, stabilised at 5%. This individual has now had a factor IX level of 5% for over 14 months following this single injection. He has required no factor and has had no bleeds despite a high level of physical activity including soccer. This clinical trial is very encouraging. The work will continue and a further 4 clinical trials in factor IX are now getting underway. For gene therapy for factor IX, there seems to be, finally, light at the end of the tunnel.

Brian O'Mahony

HCV / HIV Setbacks and Advancements

This was an interesting session, combining the experiences of both health professionals and the patients themselves. The healthcare perspective came from two nurses, an American and an Italian, who both dealt with the best methods they have used for handling side effects from drug therapies. There presentations were general and statistical and while relevant, they talked in broad brush strokes, which, to be fair to them, is all they can do. The more interesting presentations were given by two patients, from very different backgrounds. The first was a Pakistani person with haemophilia who spoke about the social taboos associated with viral infection in his country, and how he used the negative responses to energise him in his campaign for better treatment and his work with the UN preventing the spread of HIV. It was the first of many times during the week that I realised how comparatively fortunate we in Ireland are not to be battling for basic factor treatment, much less anything else. It reminded me that we must never get complacent and always ensure the best service for our members. The final speaker was an Australian person with haemophilia, who talked in great detail and with much humour and warmth about his journey on hepatitis C treatment. He spoke about his wife, his work and himself, giving a very complete picture of the benefits of support, pragmatism and hope. The path he travelled was very much an individual one, but I sensed he may not have reached his happy destination without the help and love he received from those around him.

New approaches to the management of Hepatitis C

This was chaired by Professor Alison Street from Australia, who spoke briefly about the progress in the field of hepatitis C treatment. She then handed over to a Dr. Fabien Zoulim from France. He continued in greater detail about the recent developments in hepatitis C care. He gave an informative and accessible account of the drugs being made available (Telaprevir & Boceprevir) and the statistical strengths of each one, talking about the different genotypes and with reference to the IL28B gene pre-screening. We seem to be slightly ahead of the curve here in Ireland as most of the information presented here was made available through the Society a few months ago. Nonetheless, it is always beneficial to hear about it from a different country's perspective. Dr. Zoulim seemed very optimistic and also appeared heartened by very initial results from non-Interferon based treatments, although these may be a good few years down the line.

Questions and Answers: Sexual health

The meeting on sexual health was, rather unsurprisingly, packed out and at times not for the faint hearted. We heard from four speakers – a haematologist, a sex psychologist, a nurse and a physiotherapist – and they gave various accounts of how haemophilia and related injuries or movement difficulties may impact upon a healthy sex life. They also offered comprehensive solutions to any such problems, from both the psychological and physical point of view. The range of speciality among the speakers meant that we were given a complete picture and while the sex psychologist may have received most of the headlines, the physiotherapist was very good indeed, detailing simple and effective answers to some awkward questions. This was followed by a lively and colourful discussion!

Brian O'Riordan

Adherence

I attended a talk on adherence, which was very interesting. However, some of the content wasn't new to me as we have covered a lot of the topics at our own AGM and conferences. The main message I took with me from this session was the importance of communication. Regina Butler, a nurse from the USA asked "Is teaching enough when it comes to patient education on adherence"? Non-adherence leads to complications and lower quality of life. Patients themselves must be motivated and ready to follow treatment regimes. She described how a simple tooth extraction turned into a life threatening situation for one patient with haemophila. The speaker discussed how language barriers, assumptions, and lack of communication resulted in the person having to remain in hospital for an extended period of time with near fatal results. Whilst the speakers personal perspective was very moving it still amazes me how these type of situations can still occur in the 21st century despite all the excellent communication technologies and tools at our disposal. Thankfully the outcome was a positive one. Ms. Sylvia von Mackensen a psychologist from Germany suggested that in order to overcome barriers to adherence healthcare professionals need to be able to quantify adherence. Studies show that parents have high adherence for their children, whilst young adults and adults are less adherent. Currently, there is no unified way to evaluate adherence. Sylvia stressed the importance for professionals to work to improve this gap.

Ethical Issues

Another excellent talk I attended was one entitled "Ethical Issues". It raised many questions for me. Some which were answered and some that weren't and re-itereated again to me, those that have, and those that haven't in this world. It also drove home to me the need for organisations like ours to ensure that our members have the tools to advocate and have a full understanding of the ethical and non ethical issues that can arise, especialy with clinical trials being a real possibility for some of our members in the near future. Ethical issues are often not as clear as other kinds of issues and resolving same can be difficult. Good ethical thinking purposefully seeks out the grey in questions and concerns, in order to acknowledge the diversity and complexity of roles, situations and circumstances that arise in human life and relationships.

Traci Marshall Dowling

Inhibitors

Initially this session started with discussing the nurse's role in relation to a patient with inhibitors both from a medical side and an interaction with psychosocial support and the patient. The nurse is there to provide a medical service but because the treatment of inhibitors can be a very difficult and a long process, the nurse needs to be aware and conscious of the patient's emotional state and interact alongside the patients with any psychosocial support available. Case studies then followed:

Number 1 Paediatric Case: 3 year old boy from a developing country with a high-titre inhibitor. After Immune Tolerance Therapy (ITT) for 3 months, the response failed.

Number 2 Adolescent Case: The nurse highlighted the difficulty with this particular group not just specifically with their bleeding disorder but with all the emotional and physical changes happening to the patient at this stage. A further complication with their bleeding disorder can be very difficult to manage. The nurse must actively engage with the adolescent and give age appropriate information. Communication needs to be clear and the patients must be aware of what their particular treatment regime will mean for them from the start. A particular case they spoke of was extremely challenging because of the lack of adherence of both the patient and the parent.

Number 3 Adult Case: This case was about a patient who developed a high-titre inhibitor in his 40's. He had severe factor VIII and developed the inhibitor after prolonged exposure to factor following a car accident.

This session was extremely interesting for me as I was not well versed about inhibitors prior to the congress, so I enjoyed it and learned a lot.

Fiona Brennan

PICTURE GALLERY

E-communications

I attended a talk on "e-communications benefits and pitfalls". Developing countries seem to be very active in this area, but I found it a little worrying that some of the developing countries use Facebook, in particular for patient and physician interaction, and for advice being given through social media. I also felt there was an issue with privacy, while social media is a valuable resource and is not going away anytime soon it is something that requires a degree of privacy. There was an excellent presentation on blogging by Ms. Cheryl d'Ambrosio from the United States in which she clearly outlined the pitfalls and how to avoid them. Mr. Dan Farthing of the UK Society also gave a very informative presentation on the power of e-communication for lobbying, highlighting the speed at which information distributed but he also highlighted the need for well thought out policies in this regard as once a campaign is started it may take wings of its own.

Preparing Future Generations

The session on "Preparing Future Generations" was very interesting. The Canadian delegate Mr. David Pouliot who is the Chairperson of the National Youth Committee highlighted some of the issues they faced in their organisation. They have a separate board consisting of 25-40 year olds with their own budget and a nominated member representing them on the senior board. The biggest issue seemed to be the logistics as Canada is such a large country it is difficult to have youth committee meetings, and they have just one per year with all members in attendance. However, they manage to overcome this logistical issue through the use of technology with regular meeting taking place through Skype and in the individual provinces. The delegate from India highlighted the numerous issues they faced and the creative solutions they came up with. Some of the issues facing the Indian membership were economical, health, and geographical but it was inspiring to see how involved and pro-active the youth membership was. They organised 10 regional camps and 25 chapter state camps for children to attend last year which is terrific. At the National Youth General Assembly they organise a jobs fair, which is a major incentive for young adults who may have difficulty gaining employment, to attend. As a result the membership is growing steadily in India with more awareness of the condition, as more and more people are being diagnosed and this can only have long term benefits for the Indian haemophilia community. Ms. Dorothée Pradines from France who chaired the meeting spoke of youth involvement in France. Young people with bleeding disorders in France and in a lot of developed counties feel more "normal" as the condition thankfully is so well managed that it has such little impact on their daily lives that it is much more difficult to motivate young members to get involved.

Eoin Moriarty

Psychosocial Models Around the World

During this session we heard about three very different psychosocial models of care which are creative, holistic and comprehensive.

Ms. Frederica Cassis from Brazil gave us an overview of haemophilia care in Brazil and the psychological interventions which she started in 1994, to support the person with haemophilia and his family who receives on-demand treatment. Over the years her patients have reported an increase in their awareness and coping skills which have resulted in better self-management of their haemophilia. Frederica is a Psychologist and has been working for many years as a WFH volunteer, facilitating psychosocial workshops in many countries. The Brazilian approach which is of Primary Prevention and Psycho-education using expressive techniques like Hemoaction flashcards which has lead to an increase in awareness and coping skills, resulting in better self-management of haemophilia.

Mr. John Francis Sarmenta is from Manila in the Philippines and is doing his Masters in Psychology. John has been involved with the HAPLOS (Haemophilia organisation in the Philippines) organization for some years and presented on the holistic approach adopted by HAPLOS to care for the psychosocial health of the person with haemophilia and his family. John explained how this approach aims to encourage the individual to become physically active, mentally alert, emotionally healthy, spiritually strong and socially involved. HAPLOS has developed these programmes in the belief that focusing on the holistic development of the individual will enable him to cope with the daily psychosocial challenges which he faces with his family. This system is continuously evaluated to validate the effectiveness of the model, through surveys, interviews and observation of workshops. I found John's presentation very inspiring and one of my colleagues commented that "you could feel the love from him as he spoke". The Philippine experience which focuses on the holistic development of the person with haemophilia which enables him to cope with the daily psychosocial challenges which face him and his family.

Ms. Maureen Spilsbury is a Social Worker from Queensland, Australia who has worked at the Haemophilia Centre in Brisbane for the last 15 years with children and adults with haemophilia. Maureen told me that she feels privileged to work with this community and to have gained a whole of life perspective. Maureen loves group work and has led many weekends for the different groups within the community - couples looking at graceful ageing; men affected by HIV; couples affected by HIV; Hepatitis C and Women's issues. Maureen gave an overview of haemophilia care in Queensland and spoke about the current situation of the different levels of psychosocial support provided by the Australian Haemophilia Centres. The speaker reported on a small survey of nine Australian Centres conducted in 2009 to provide a snapshot of psychosocial services. We were given an in-depth look at the psychosocial work that is currently being conducted at the Queensland Haemophilia Centre and explored whether the high standard of service is at risk due to the current financial situation. The different levels of psychosocial support available in Australia and in particular, that which is provided in Queensland. The question was raised of what risk there may be to this high standard of care due to the current financial situation.

I thoroughly enjoyed this session, I felt it was very interesting, inspiring and its showed me how important this type of work is for people with haemophilia and related bleeding disorders.

Anne Duffy

Congratulations to Anne Duffy who was elected Chair of the World Federation of Hemophilia Psychosocial Committee for the term 2012 - 2014, during the Congress.

Some members of the W.F.H. Psychosocial Committee with Anne Duffy

Mr. Brian O'Mahony & President Mark Skinner

Delegates attending one of the many sessions at the Congress

Ageing Challenges

One of the many sessions that I attended at the conference was the Multidisciplinary session on Ageing at which physical issues, pain management and oral health was the agenda.

Ms. Megan Walsh from the Ronald Sawers Haemophilia Centre, Victoria in Australia spoke about physical and psychological issues in ageing. People with haemophilia in countries with access to safe and adequate supply of factor concentrate have a life expectancy that is equivalent to that of the general population. With this being the case, education of the haemophilia population on various issues needs to be addressed. She stressed that the need for the patient to maintain good communication with the haemophilia treatment centres on many issues such as vein health, vein rotation, physiotherapy, diet, screenings and diagnostic procedures for age related diseases. Haemophilia in itself can add a level of complexity and require a multidisciplinary approach and co-operation. These will include pain management, Cardiologist, Rheumatologist, viral infection specialists to manage HIV, and hepatitis C, to mention some. The psychological impact of ageing with haemophilia like depression, loss of mobility, early retirement and the financial impact that this has and altered family dynamics are all the extra issues to be dealt with.

Ms. Brenda Buzzard of Newcastle Comprehensive Care Centre in the UK gave a presentation on pain management in the older person with haemophilia. She said that pain is a by product of ageing and with haemophilia, joint pain can increase. The impact of chronic pain is linked with increased levels of depression, anxiety, cognitive impairment and reduced physical activity. Again education is the key and communication with the treatment centre. She suggested pain management should take the multidisciplinary approach involving your doctor, haemophilia nurse, physiotherapist and pain management team. Every individual is different and with a prophylaxis regimen and pain management programmes put in place she strongly recommended that the individual should stay active by creating a tailored exercise programme. These exercises should include improvement in flexion, strength and endurance. To encourage the individual to get involved in self-help groups and educational strategies, coping methods including cognitive behavioural therapies. Other models that help are heat/cold techniques, relaxation/breathing techniques, hydrotherapy, and pacing (not to over-do it, resting, including not standing for long periods).

Ageing and oral health was discussed by Dr. Alison Dougall, Dentist at the NCHCD, in St. James's Hospital, Dublin. Oral health is important for a good quality of life. You need 20 teeth to maintain a good nutritional diet. Oral health is also about appearance and confidence. Oral diseases need to be prevented because the effects of poor oral health into older age can be serious. It affects the individual's general health and the common issues associated with ageing like, heart disease, diabetes, those who are immune suppressed and for those taking many prescribed drugs have an impact on the mouth. Other risks of changes with age are drying of the mouth, the need to reduce plaque around the teeth, oral cancer (because of smoking, age related, immune suppressed). Also visits to the dentists sometime don't get first priority as other doctors visits do. In the past, people with haemophilia had problems with dental decay. However, today the older generation is taking more care of their teeth, and have greater expectations from a health and appearance point of view. The good news now is that a lot of dental procedures can be done without the use of factor and there are now good guidelines from the World Federation of Hemophilia on oral health and procedures.

Ger O'Reilly

Women with Bleeding Disorders

I attended a very interesting session on Women with Bleeding Disorders, where different perspectives were spoke about to the audience.

Dr. Paul Giangrande, a haematologist from the UK spoke about identifying and detecting carriers of haemophilia. He explained the patterns of inheritance and highlighted that one third of the haemophilia population occur through spontaneous mutations. He discussed that genetic testing was the most accepted way of diagnosing a carrier. He also discussed the international standard for carrier testing in that the child must give informed consent before being tested unless they are symptomatic carriers or it is necessary for medical intervention.

Ms. Debra Pollard, a haemophilia nurse from the UK spoke about the experience of carriers from an established country's perspective. She spoke about a maternal blood test which can be done from 5 weeks gestation to test foetal DNA (ffDNA). This test can check the sex of the baby in a non invasive way but it is not always accurate. Debra's main point was for the health care providers to provide non judgmental and supportive advice to the potential carrier.

Ms. Shirin Ravanbod from Iran presented on being a carrier in an emerging country. She explained that there is still a huge stigma connected with haemophilia in Iran and it is seen as a curse on the family. She spoke of the families difficulties in hiding the carrier status of their daughters from their friends and family. Ms. Shirin said that relationships would be difficult if not impossible to maintain because future in – laws would not want their son to marry a woman who is a carrier. She explained that women do not discuss menstruation as it is seen as taboo and this leads women to not realise that severe menhorrhagia is not normal.

Ms. Claire McLintock from New Zealand spoke about pre-conception counselling. Claire discussed the issue of guilt in relation to passing on the haemophilia gene that some mothers feel. She said for health care workers this is a challenging hurdle to overcome as it is a natural feeling. She felt that it should be pointed out that it is not just down to the mother and that men pass on the gene also. She highlighted that pre-conception counselling is a personal choice and that health care workers should work with the parents in a non judgmental and individual way.

Mr. Rezan Kadir from the UK spoke about the reproductive choices facing a potential carrier. He spoke about the ffDNA which if this showed a female result could mean that other potentially risky procedures could be eliminated. The main section of Rezan's presentation was based around some data comparing haemophilia and Downs Syndrome. He reported that 31% of carriers considered thepre-natal diagnosis of haemophilia to be an invasive procedure, compared with 71% for testing for Downs. A startling statistic was that only 16% of carriers contemplated a termination of pregnancy in comparison to a Downs Syndrome pregnancy. This was different to emerging countries by comparison where invasive procedures were more frequent. He explained that this may be due to a decreased quality of life in countries where management and treatment of haemophilia is not yet optimal.

Fiona Brennan

Twinning Update

During the Congress we took the opportunity to have a meeting with our partners from Vietnam. At this meeting there were representatives from the WFH, the treatment centre in Melbourne, our partners from Vietnam, Mr. Brian O'Mahony and myself. The meeting was chaired by Mr. Robert Leung, Regional Program Manager from WFH. The proposed visit by the haemophilia team from Melbourne in October, led by Professor Alison Street was discussed. It is hoped that a physiotherapy workshop for physiotherapists will take place, along with training for patients also in physiotherapy. Dr. Tran from Melbourne will also present some lectures to the doctors in relation to haematology. From an organisational perspective Mr. Brian O'Mahony will travel to Vietnam in October also at the same time to do some work with patients and key volunteers in Ho Chi Minh City and will also work with the organisation in Hanoi on a governance structure for the board. Professor Tri and Dr. Mai also hope to have a meeting arranged with the Minister for Health during the visit, and the Action Plan for 2013 will also be looked at. I think we are making good progress with this twinning programme which is very encouraging, and it was really nice to see our friends from Vietnam again in Paris.

Debbie Greene

WFH General Assembly

I was one of few I.H.S. representatives at the General Assembly and I loved it, it was like attending the United Nations. Delegates wishing to attend had to register and sit in their designated places – voting members at the tables in the middle, alternate delegates to the right of the room, and observers to the left.

The Assembly began with a minute silence in memory of various National Member Organisation (NMO) members who had passed away since the 2010 WFH Congress.

The first item on the agenda was the proposition of four countries to become full NMO's of the WFH. Cameroon, Krizickstan, Oman and Qatar were all proposed and accepted as full NMO's of the WFH. Following this Afghanistan, Mauritius, Montenegro, Uganda and the United Arab Emirates were proposed and accepted as associate NMO's of the WFH.

Next on the agenda was the acceptance of the 2010 General Assembly minutes, the presentation of the CEO's report and the President's report, all of which were accepted by the NMO's.

Then the voting began, Chair of the General Assembly, Dr. Paula Bolton-Maggs explained the process announcing the collectors and tellers of the votes, which would all be done by secret ballot. Each candidate would be given an allotted time to speak, after each candidate has spoken the voting NMO was given five minutes to consult with their alternate and place their vote. The votes on the day included votes for committee members and officers.

•President of the WFH

Two candidates ran for this position: Mr. Alain Weill from France and Mr. Cesar Garrido from Venezuela. Although this was the first vote cast, the results were one of the last to be read out with Alain Weill from France winning the Presidential race.

•Vice President Medical

Again there were two candidates for this role. Dr. Alok Srivastava was elected to the role of Vice President Medical.

The 3 Presidents; Ex President Mr. Brian O'Mahony, Incoming President Mr. Alain Weill, and Outgoing President Mr. Mark Skinner!

I.H.S. delegates at the General Assembly: I.H.S. Treasurer Mr. Ger O'Reilly, and I.H.S. Chairperson Ms. Traci Marshall Dowling

Let the voting commence!

Ms. Anne Duffy, Professor Tri from Vietnam, and Ms. Nuala McAuley at the General Assembly

•Vice President Finance

There was only one candidate for this role, Mr. Eric Stolte, current VP Finance. Chair, Dr. Paula Bolton Maggs asked the NMO's to vote on abstaining from a secret ballot and putting the vote for VP Finance to a general vote. NMO's accepted this option and then re-elected Mr. Eric Stolte as Vice President of Finance.

Next up was the vote for the venues for future Congresses. For each year there were two countries. Each country was given 12 minutes to present on why they should host the Congress, which included a video of the city and the facilities of the conference centre. Before any of the countries spoke, Mr. Craig Mc Ewen, WFH, gave some financial statistics on what the cost of holding the Congress in either country would be. Again, after both presentations voting NMO's were given five minutes to confer with their alternate and place their votes.

•2016 Congress Venue

It was the battle of the M's as Miami and Montreal went head to head to host the 2016 WFH World Congress, with Miami winning the race for 2016.

•2018 Congress Venue

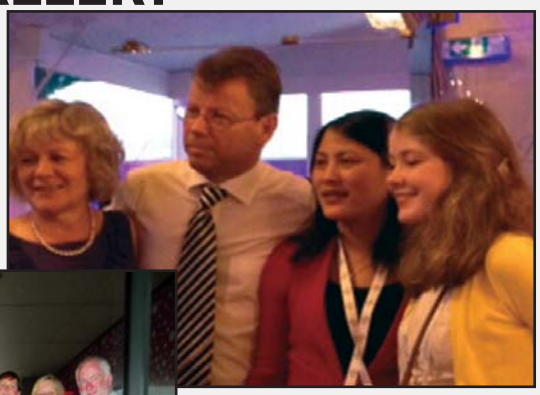
This was the last vote of the day and included a splash of colour as the Scottish presenters wore their tartan with pride and Mexico donned their sombreros. Scotland's pitch won the vote and will host the 2018 Congress.

The day finished with outgoing President Mr. Mark Skinner presenting the outgoing Committee Members with a gift in recognition for their hard work. A standing ovation was given to Mr. Skinner and the other committee members. One NMO thanked the committee and expressed concern with such big changes, but Mr. Skinner assured the NMO's that the people who they elected as committee members and officers of the WFH were more than qualified to take over and reminded everyone that the WFH is a global community to which every NMO has a part.

I really enjoyed the General Assembly. It was a fantastic experience, and one that I will remember for a long time.

Nuala Mc Auley

PICTURE GALLERY



Severe Bleeding Disorders Alert Cards

Authors: **Brian O'Mahony, Debbie Greene**
Irish Haemophilia Society

In Ireland, hospital based treatment for Haemophilia is centralised around 3 Comprehensive Care Centres:

• The National Centre for Hereditary Coagulation Disorders in St James' Hospital, Dublin,

• Our Lady's Children's Hospital Crumlin

• Cork University Hospital.

All other acute hospitals around the country carry a minimum stock of factor concentrates in case of emergencies.

There were two documented occasions when people with severe haemophilia had significant delays before being treated with factor concentrates at non comprehensive care centre hospitals. This identified, for the Irish Haemophilia Society, a policy issue with potentially severe consequences. In a normal scenario in an accident & emergency department the person is triaged, seen by a doctor, diagnosed and then treated. The difference with a person with haemophilia is that it is necessary to treat the bleeding episode with factor concentrate without delay and then follow up with diagnostic scans or other tests required.

The Comprehensive treatment centres offer 24 hour advice to all other hospitals on appropriate treatment. It is vital that a person with Haemophilia who attends at an Emergency department would be able to encourage the health care workers to contact the specialist centre for advice without delay.

This is the rationale behind the **Severe Bleeding Disorder Alert Cards.**

These cards have been produced by the Irish Haemophilia Society and distributed by the comprehensive care centres to all patients with severe haemophilia. A specific card was produced for each of the comprehensive centres and circulated by the centres to their registered patients with severe bleeding disorders. The card gives the individuals name, date of birth and unique identifier (medical record number). The cards instruct the health care worker in the relevant Emergency department to immediately contact the Comprehensive treatment centre and provide the telephone numbers for use during the day and at nights and weekends.

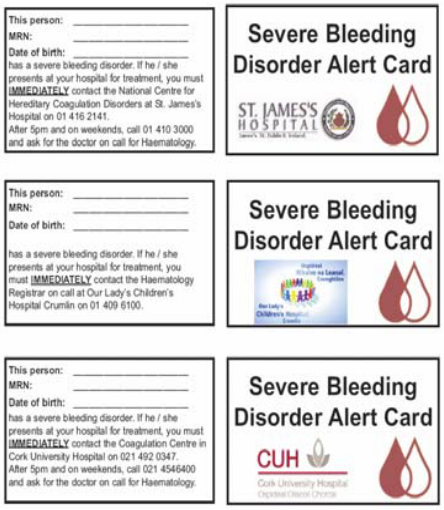
The person with Haemophilia is asked to carry this card in their wallet or on their person at all times and show the card to the triage nurse or doctor who should immediately contact the appropriate comprehensive care centre for advice on the appropriate treatment and dosage. The Cards wee issued to all people with severe Haemophilia in March 2012.

The Irish Haemophilia Society had the full support of the Health Service Executive (HSE), the organisation which operates the health service, in the introduction of the cards. The HSE wrote an official letter to every emergency department consultant and to every acute hospital in the country notifying them about the cards and instructing them to comply with the request.

An article about the cards was featured in the Staff magazine of the HSE – *Health Matters* - which has a circulation of 200,000 people.

Following the issuing of a press release by the Society ,the launch of the cards was also featured on the National television station main evening news bulletin and on the website of the main broadcaster.

For the person with haemophilia, the most important piece of equipment in a non specialist centre is the telephone and the instruction to the Emergency department staff to call the relevant comprehensive care centre may well save lives.



Treatment outcome in young adults survey of 8 Countries – Preliminary Results

Authors: Noone D[1], O'Mahony B[1], Prihodova L[2]

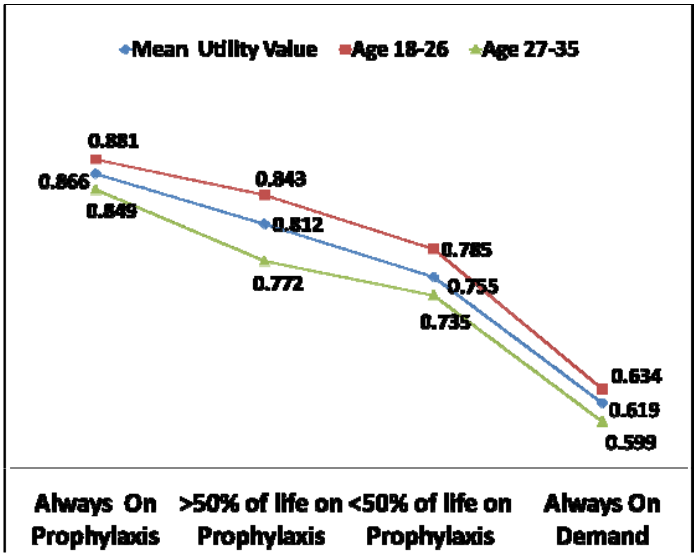
Affiliations:
1. Irish Haemophilia Society, Cathedral Court, Dublin
2. Department of Community & Occupational Health, University Medical Center Groningen, University of Groningen, the Netherlands

OBJECTIVES

In 2009, results of a survey of prophylaxis, on-demand and combined treatment in 20-35 year old men with severe haemophilia in four European countries showed that the quality of life of patients on long-term prophylaxis is significantly better than those receiving on-demand only or individuals who have changed treatment regimens over there life time (combined group). In 2011, the survey was repeated to further examine the differences in respondents who had full access to prophylaxis and those who continued entirely with varying levels of on-demand therapy. In addition countries with distinctly different prophylaxis regimes - Canada and Netherlands - were included.

METHODS

National Haemophilia organisations in Canada, France, Ireland, The Netherlands, Poland, Romania, Sweden and the UK were asked to participate by randomly selecting 20 severe haemophilia patients aged 18 to 35 years and by asking them to complete a survey. The data collection was performed by e-mail or phone interview. 124 responses were received from 6 countries. Of these, 8 respondents were moderate and 13 had a history of inhibitors and were excluded from the analysis. The data collected was sociodemographic data, medical data and responses to the EQ-5D questionnaire. The medical data collected was the type of haemophilia, severity, treatment regime (prophylaxis vs. on-demand, length of time on each regimen), current regimen, history of inhibitors, bleeds per year, target joints, serious bleeds (head or soft tissue) bleeds, mobility, recurring bleeds, surgery, pain and use of pain medication. Data on days missed from work due to haemophilia as total number of days missed from work per year was collected. We analysed the number of bleeds related to the time spent on prophylaxis. The sample was split into four groups: *Always On-demand* (N=26*), <50% of their life on Prophylaxis* (N=26), ≥50% *of their life on prophylaxis* (N=35) and *Always on Prophylaxis* (N=15). We evaluated the differences regarding the seriousness of bleeds and also the health utility value in these categories between The Netherlands (N=12), Ireland (N=16), Poland (N=20), the UK (N=12), France (N=13) and Canada (N=30). ANOVA, Correlation matrix and Chi square were used to analyse the data in PASW 18.



RESULTS

The majority of the *Always On-demand* group (61%) reported more than 30 bleeds/year. In the *Always on Prophylaxis* group, 53% of respondents reported less than 3 bleeds/year and no respondent reported more than 7 bleeds in the last year. We found significant differences regarding a greater presence of target joints, serious bleeds, recurring bleeds and surgical procedures in the *Always On-demand* group compared to the ≥*50% of their life on Prophylaxis* and the *Always on Prophylaxis* group. There were significant differences in health utility value (Figure 1) among the *Always On-demand* group (0.619) having a significantly lower (P≤0.01) health utility value compared with the ≥*50% of their life on Prophylaxis* (0.812) and the *Always on Prophylaxis* group (0.866). The *Always On-demand* group had significantly more mobility problems than those with ≥*50% of their life on Prophylaxis* (P≤0.05) and significantly more pain and discomfort than the ≥*50% of their life on Prophylaxis* (P≤0.05) and the *Always on Prophylaxis* group (P≤0.001). The Dutch cohort reported the lowest rate of target joints, serious bleeds, mobility issues, problems with recurring bleeds and lowest rate of daily pain compared to all countries, with no patients requiring invasive surgical procedures.

Poland reported the most problems with mobility and pain and also had the highest rate of early retirement due to bleeding problems with 15% of the group retiring at an average age of 32; compared to the 2.2% with an average retirement age of 30 in the rest of the group. The Netherlands had the highest health utility value with a mean of 0.915 followed by Canada (0.791), Ireland (0.786), UK (0.768), France (0.687) and Poland (0.629).

CONCLUSIONS

Prophylaxis started at an early age and continued into adulthood results in less bleeding, less damage to joints, less serious bleeds and less recurrent bleeding episodes. Prophylaxis reduces problems with mobility and reduces pain and discomfort. As a result, people with severe haemophilia who have been on prophylaxis for their entire lives to date are reporting a quality of life much closer to their peers without haemophilia.

Benefits of Individual Communications Strategy From a National Haemophilia Society

Authors: Anne Duffy & Nina Storey
Irish Haemophilia Society

The Irish Haemophilia Society has an individual communication strategy which includes annual telephone calls to their members. The purpose of this strategy is to connect with members on a personal level in order to collate updated contact details and ascertain the needs of members with regard to all aspects of information and support required from and provided by the Society. The communication strategy is implemented by designated members of staff.

Communications Strategy in 2010

First implemented in 2010, 633 of 765 (81.70%) of the membership were contacted. This personal contact with individual members proved to be an invaluable source of information. This allowed the Society to provide new and improved services and support to it's members.

Irish Haemophilia Society:
Services & Support

The Irish Haemophilia Society offers services and support to all members living with Haemophilia, von Willebrands Disease and Rare Bleeding Disorders. From the time of diagnosis there are many issues facing people with bleeding disorders. Support is offered to people with bleeding disorders, their parents, and families on issues such as how to recognise a bleed, treatment and care. Coming to terms with a diagnosis can be very difficult especially when there is no history of haemophilia in the family. Through our educational programmes, AGM & Conferences, Parents' Conference, Members' Conference, Information Meetings, and Regional Visits, we give our members as much information as possible. We also provide publications and up to date information on our website. We constantly endeavour to help members with any queries or questions they may have.

EDUCATION
The following are a list of educational meetings and conferences held by the IHS:
- AGM & Conference
- Parents Conference
- Members Conference
- Relatives Days
- Regional Meetings
- Treatment Updates
- Conference for Young People
- Women and Bleeding Disorders Information Days
- Peer Group Meetings
- Conference for members with HIV and/or Hepatitis C

Communication Strategy in 2011

Following the success of the communication strategy in 2010, 733 of 857 (85.75%) of members were contacted in 2011. Priority was given to contacting members with Hepatitis C in 2011. As a result of the communications in 2011, the following vital information relating to members with Hepatitis C was collated:

- Establishing individual's genotypes.
- Previous Hepatitis C treatment and response to treatment.
- Increase in number of members reporting that they had been diagnosed with hepatocellular carcinoma which required liver transplantation.

This information proved invaluable to the Society in ensuring that the necessary guidelines and information meetings required for this cohort of members were in place.

Information on the Health (Amendment) Act Card [HAA CARD]

Men, women and children who contracted Hepatitis C through the administration within the State of blood or blood products are entitled to a Health (Amendment) Act Card (HAA Card) under the Health (Amendment) Act 1996.

HAA Cardholders are entitled to avail of a range of services, *without charge*, including
- GP services
- prescribed drugs, medicines & appliances
- dental services
- ophthalmic services
- home support
- home nursing
- counselling services
- other services including physiotherapy and chiropody/podiatry services

In certain circumstances, terms and conditions may apply. If you have any queries about the HAA Card or the general operation of any of the services under the Health (Amendment) Act Card, please contact the Hepatitis C Liaison Officer – see list overleaf.

Any problems that arise in the course of providing a service to HAA cardholders can be resolved through the relevant Liaison Officer and not through the HAA cardholder.

Action Taken Based on Communications Strategy in 2011 relating to Members with Hepatitis C

- Collated vital information on members with Hepatitis C.
- Liaised with relevant medical specialists to optimise the guidelines for monitoring the progression to cirrhosis and to ensure early detection of hepatocellular carcinoma.
- Provided updated information on the new treatments available to members with Genotype 1.
- Encouraged members to access the home support and counselling services provided by the health authorities to enable them to maximise their chances of completing their treatments.

Other Actions

- Support to parents whose children were moving from IV access devices to peripheral vein self infusion.
- Success in encouraging members to attend conferences and meetings.
- Proactive identification of members requiring home visits and financial support.

Communication Strategy in 2012

By the end of May 2012, 394 of 887 (42.51%) of the Society's membership has been contacted. On a year to year basis new information is continually being sourced from the individual communication with members.

A Recruitment Plan for Volunteers

Authors: Nuala Mc Auley, Fiona Brennan, Brian O'Mahony
Irish Haemophilia Society

Since 1998 the Irish Haemophilia Society have provided supervision and programmes for children at our annual conferences. These programmes allow the parents to attend sessions provided at our conferences. Volunteers lead the children's programmes at conferences and assist in educating the children on bleeding disorders. Given the increasing attendance at our conferences and the requirement for a high Volunteer to Child ratio for activities the need to expand the volunteer base was apparent and an ambitious volunteer recruitment plan was implemented.

Staff roles were expanded to include the roles of Volunteer Recruiter and Volunteer Co-ordinator. Following many weeks of research and with the help of the Child Protection Officer and other volunteer organisations an official I.H.S Volunteer Policy was created. The policy was circulated to existing volunteers and is made available and utilised during volunteer induction training. With all of the tools in place the recruitment drive began. As well as targeting the existing membership of the Society, the designated staff visited colleges and attended a volunteer fair in the search for potential volunteers.

Interested people were required to submit an application detailing their experience and reasons for wanting to volunteer. Upon receipt of an application the volunteer co-ordinator would organise training which would include education on Child Protection, Haemophilia and related bleeding disorders and behavioural support. The final step in the recruitment process is to check references and also ensure that each candidate compiled with a National police check to ensure the safety and protection of the children at all times.

When the plan was first designed it was hoped to increase the number of volunteers on the database by 200%. This would allow us to use a rotation system and also to plan for the eventuality that some volunteers would not be available for every event. In less than a year we have increased our numbers of active volunteers by 60%. We hope to reach our target by 2013, but we foresee the continued development of our volunteer base for many years to come.

Staff promote I.H.S. at colleges and events.

↓

Expression of interest by potential volunteer.

↓

Potential volunteer contacted and invited to training day.

↓

Training on Child Protection, Behavioural Support and Haemophilia or Related Bleeding Disorders.

↓

Volunteer interviewed at training.

↓

References checked.

↓

Clearance obtained from Police.

↓

Volunteer works at event.

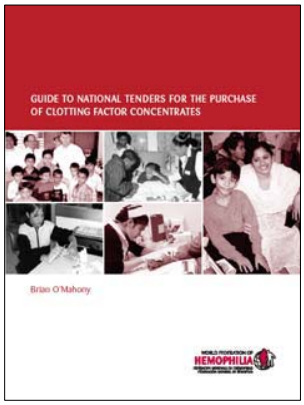
↓

Volunteer receives feedback after each event.

Economic impact of an efficient inclusive National Tender System for Factor Concentrates

Authors: **Brian O'Mahony**
Irish Haemophilia Society

A single national tender commission responsible for the purchasing of all factor concentrate requirements for a country is the method recommended in the WFH Guide to National Tenders.



In Ireland, an integrated Haemophilia Product Selection and Monitoring Advisory Board was established in 2003 on a formal but non statutory basis.

This board includes the directors of the three comprehensive haemophilia treatment centres, two representatives from the Irish Haemophilia Society, an external advisor to the Society, a virologist, a blood transfusion expert and representatives from the health ministry and the contract holding authority.

The board apply a rigorous appraisal process for products based on open competitive tendering and the use of carefully chosen selection criteria including safety, efficacy, quality and cost. The selection criteria scoresheets are published as part of the call for tender.

The largest tender is for the purchase of recombinant FVIII concentrate. In 2011, a tender for the purchase of 50 million IU of recombinant FVIII for a two year period was carried out. The selection criteria included safety, efficacy, quality, availability, technical support and cost with 30% of the total score allocated to cost.

The confidence of consumers and clinicians nationally on the products selected has increased due to the inclusive decision making process and the selection of the safest and most efficacious products.

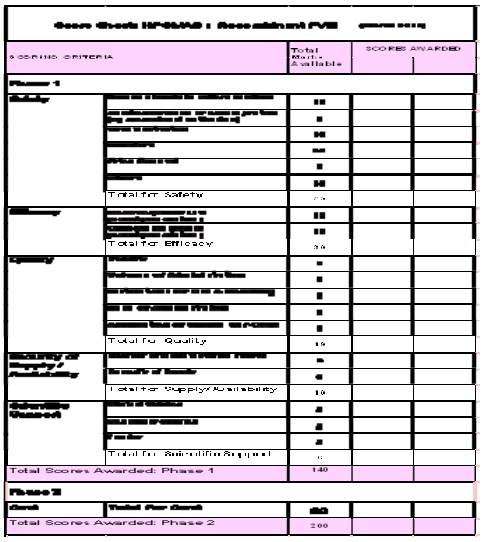
Economic benefits

The economic benefits have been very significant especially for the purchase of recombinant FVIII. With the new process and the involvement of the HPSMAB, economic benefits were attained from 2 areas. In 2012, the contract holder was changed by legislation and significant handling fees from the previous contract holder have been eliminated. Secondly, the purchase cost per international unit decreased significantly between 2003 and 2012.

Prior to the establishment of the HPSMAB in 2002, prices paid for recombinant FVIII in Ireland were 26% higher than the median prices in European countries.

The major adjustments resulted from procurement processes in 2008 and 2011 when significantly lower prices per unit were achieved from open tenders. By 2008, the cost per unit for recombinant FVIII was approximately 33%. lower than the 2002 price. In 2011 a further cost reduction of 33% was achieved. Current unit prices are 55% lower than average prices paid in Ireland in 2002 and are now 40% lower than the median price reported globally.

These cost savings have allowed the maintenance of the quality and quantity of factor replacement therapy available in the country against a backdrop of significant decreases in the national health budget over the past 3 years and have served to effectively protect and maintain Haemophilia treatment.



Score Sheet: HPSMAB : Recombinant FVIII				
Scoring Criteria		Total Marks Available	Scores Awarded	
Phase 1				
Safety	[illegible]	[illegible]		
	[illegible]	[illegible]		
	[illegible]	[illegible]		
	[illegible]	[illegible]		
	[illegible]	[illegible]		
	[illegible]	[illegible]		
	Total for Safety	[illegible]		
Efficacy	[illegible]	[illegible]		
	[illegible]	[illegible]		
	Total for Efficacy	[illegible]		
Quality	[illegible]	[illegible]		
	[illegible]	[illegible]		
	[illegible]	[illegible]		
	[illegible]	[illegible]		
	[illegible]	[illegible]		
	Total for Quality	[illegible]		
Availability of Supply / Reliability	[illegible]	[illegible]		
	[illegible]	[illegible]		
	Total for Supply Availability	[illegible]		
Scientific Support	[illegible]	[illegible]		
	[illegible]	[illegible]		
	[illegible]	[illegible]		
	Total for Scientific Support	[illegible]		
Total Scores Awarded: Phase 1		140		
Phase 2				
Cost	Total Per Cost	[illegible]		
Total Scores Awarded: Phase 2		200		

AN BILLE UM TIRCHAIN FACHTÓIRÍ TEASCITA AGUS TAIRGÍ BITHEOLAÍOCHTA EILE, 2012
CLOTTING FACTOR CONCENTRATES AND OTHER BIOLOGICAL PRODUCTS BILL 2012

Mar a Tionscnaíodh
As Initiated

ARRANGEMENT OF SECTIONS

Section

1. St. James's Hospital Board to procure and make available clotting factor concentrates and other biological products.
2. Preservation of certain contracts and adaption of references to Irish Blood Transfusion Service.
3. Revocation.
4. Short title and commencement.

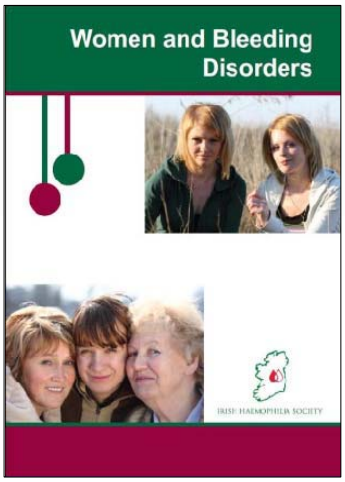
[No. 4 of 2012]

A Strategy for Women with Bleeding Disorders: The Irish Experience

Author:
Debbie Greene

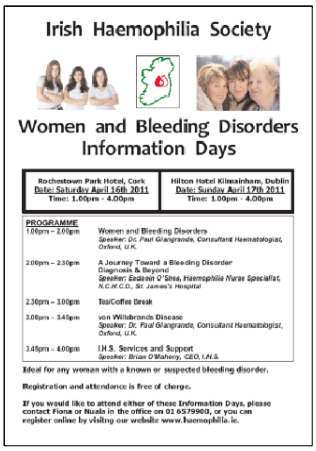
Irish Haemophilia Society

Being a women with a bleeding disorder, manifests in difficulties in relation to menstruation, fertility and childbirth. Prolonged heavy menstrual bleeding is one of the most common symptoms for a woman with a bleeding disorder. However, the biggest challenge is for women to know what constitutes "normal" or "heavy" menstruation and to seek help if needed. Women with bleeding disorders are often under diagnosed and undertreated. Many do not require therapy on a regular basis, but knowing about their bleeding disorder is essential.



There are 1,115 women with bleeding disorders registered at the National Centre for Hereditary Coagulation Disorders in Ireland. Of these, 114 are carriers of haemophilia, 578 have von Willebrands Disease, 164 have rare bleeding disorders, and 259 have uncharacterised bleeding disorders.

In 2010, we identified that this cohort of members would benefit greatly from a publication for women with bleeding disorders. We produced a publication which was circulated by the Society to members, distributed through the comprehensive care centres in Ireland, and was sent to all the maternity hospitals and obstetricians in Ireland. Following the initial distribution, additional copies were requested by several hospitals.



Irish Haemophilia Society

Women and Bleeding Disorders Information Days

Rochestown Park Hotel, Cork Date: Saturday April 16th 2011 Time: 1.00pm - 4.00pm	Hilton Hotel Kilmainham, Dublin Date: Sunday April 17th 2011 Time: 1.00pm - 4.00pm

PROGRAMME	
1.00pm – 2.00pm	Women and Bleeding Disorders *Speaker: Dr. Paul Giangrande, Consultant Haematologist, Oxford, U.K.*
2.00pm – 2.30pm	A Journey Toward a Bleeding Disorder Diagnosis & Beyond *Speaker: Eaoinín O'Shea, Haemophilia Nurse Specialist, N.C.H.C.D., St. James's Hospital*
2.30pm – 3.00pm	Tea/Coffee Break
3.00pm – 3.45pm	von Willebrands Disease *Speaker: Dr. Paul Giangrande, Consultant Haematologist, Oxford, U.K.*
3.45pm – 4.00pm	I.H.S. Services and Support *Speaker: Brian O'Mahony, CEO, I.H.S.*

Ideal for any woman with a known or suspected bleeding disorder.

Registration and attendance is free of charge.

If you would like to attend either of these Information Days, please contact Fiona or Nuala in the office on 01 6579960, or you can register online by visiting our website www.haemophilia.ie.

Our strategies resulted in two very successful meetings in Dublin and Cork attended by midwives, nurses and women with known or suspected bleeding disorders. The combination of the publication and the meetings resulted in a great degree of awareness on this issue nationally.

It is vitally important that women with bleeding disorders understand their condition, and the potential impact it may have on them during menstruation, pregnancy, menopause and surgery. Education and knowledge is power.

Participation of Children in National Haemophilia Conferences

Authors: Fiona Brennan, Nuala Mc Auley, Debbie Greene.
Irish Haemophilia Society

The Irish Haemophilia Society provides support and education to members on various issues relating to their bleeding disorder through three main conferences each year. In 1998, the I.H.S. introduced a children's programme to allow parents attend the sessions at our conferences. Starting with just four children, the programme has since developed into four age specific children and young adult's groups with an average of 52 children attending each conference, starting with our crèche group at 0 – 3 years, Cubs Group 4 – 7 years, Kidlink Group 8 – 12 years and Youth Group 13 – 18 years.

Initially, the aims of these groups were solely to provide supervision. However, as time has progressed the educational aspect has become more important. Since the introduction of the children's groups in 1998 we have seen many children progress through the different children's groups and become young adults with a clear understanding and acceptance of their bleeding disorder. These groups not only serve an educational purpose, but have also created an enhanced community where people with haemophilia and their siblings can feel comfortable discussing and sharing any issues they may have. A testament to the success of the programme is that many of the children who attended the programme are now volunteer leaders; passing on their advice and support to the younger generation. Of the 37 volunteers we now have volunteering with the society 12 previously attended the children's programmes. This is beneficial not just due to the advice and experience the volunteers can pass on to the younger children, but also adds to the level of empathy and understanding our volunteer leaders can bring to their work and foster in the children.

The programmes themselves are designed by a dedicated children's programmes co-ordinator who provides a structured yet fun approach to learning and education not only for the children with bleeding disorders, but also for siblings and children of adults with haemophilia. Each group begins the conference with team building exercises. This allows the group, who may not know each other, to bond and create a supportive environment for the various other sessions and workshops which the groups will take part in over the course of the weekend. While it is important to have an element of entertainment and fun, which will help encourage and develop friendships and social support, this is also the perfect environment to educate the children on aspects of their or their family member's bleeding disorder in an age appropriate manner. Over the past number of years some of the programme highlights have included:

- Podcasts on various aspects of life with a bleeding disorder
- Movie animation workshop on life with haemophilia
- Puppet Shows
- Team Building Exercises
- Workbook exercises with both an educational and entertaining element
- Adventure weekends for our youth group members

With regular evaluations of all the programmes it is the aim of the Society that the content is consistently relevant, informative and appealing to the target groups.

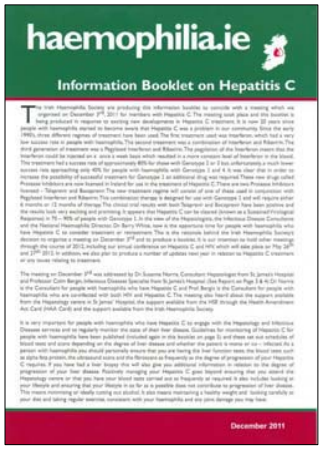
Patient Organisation involvement in the Management of Hepatitis C

Authors: Brian O'Mahony, Anne Duffy, Declan Noone
Irish Haemophilia Society

In Ireland, there are 145 persons with Haemophilia who have Hepatitis C. A further 108 have died of HIV or Hepatitis C of whom 71 were co-infected. An increased incidence of cirrhosis, hepatocellular carcinoma and requirement for liver transplant have now become apparent. Up to May 2012, a total of 10 Irish people with Haemophilia had undergone a total of 14 liver transplants with 4 of these transplants required in the 9 months to May 2012. Of the 10 recipients, 4 remain alive. In view of the deteriorating clinical situation of many of our members with Hepatitis C and the availability of new treatments for genotype 1 Hepatitis C, the Irish Haemophilia Society have prioritised the provision of information, education and assistance to members who require or are contemplating treatment. An individual phone survey was carried out on the Hepatitis C genotype of members. Provision of tests for the genetic markers IL28B and KIR-2DS3 were co-ordinated with the treatment centres.

Information

Meetings were organised in two cities in December 2011 to provide information on the new treatments available for genotype 1. The first in a planned series of specific newsletters on Hepatitis C was produced in December 2011 and the second in June 2012.


haemophilia.ie

Information Booklet on Hepatitis C

December 2011

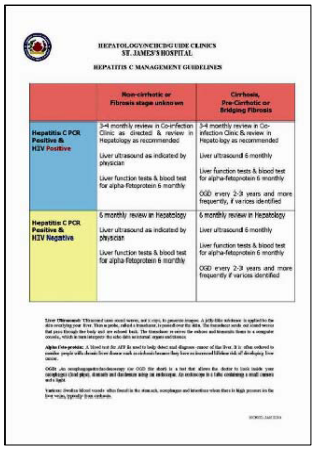
The newsletter included information on the 2 new protease inhibitors - Telaprevir (Incivo) and Boceprevir (Victrelis), information on side effects and the Guidelines for Monitoring and Managing Hepatitis C agreed with the Hepatology clinicians.

A specific Conference is organised annually for members with Hepatitis C and/ or HIV. The conference in May 2012 included sessions on the new treatments, managing side effects, psychological management of treatment and information for spouses and partners.

Advocacy

The new products were subjected to Health Technology Assessments (HTA) and the Society made a submission in relation to this assessment. Both products were found to be cost effective using the HTA process with both products demonstrating an incremental cost effectiveness ratio per QALY under €20,000.

The Society met with the Minister for Health on World Haemophilia Day and secured his agreement for the immediate approval of reimbursement for both protease inhibitors.


HEPATOLOGY/CHCHG UIDE 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 Hepato-logy 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

Practical Assistance

The Society has worked with the health authorities to arrange for assessments of each individuals requirements and provision of assistance required during treatment including counselling, assistance with domestic work, aids and appliances and access to complementary therapies. These services are available to each person with Haemophilia who has Hepatitis C via their Health Amendment Act (HAA) card which gives them access to a range of medical and support services free of charge as a result of specific legislation - the Health (Amendment) Act 1996).


AN BILLE UM BINSE CÚITIMH I aD ÁIL LE HEIPITÍTEAS (LEASÚ) 2006
HEPATITIS C COMPENSATION TRIBUNAL (AMENDMENT) BILL 2006

Mar a ritheadh ag Dáil Éireann
As passed by Dáil Éireann

The Society provides financial assistance and accommodation for members with Hepatitis C or HIV with mobility difficulties or severe side effects from treatment who have to travel significant distances to the treatment centres frequently for treatment monitoring.

Our objective is to ensure that all those with Hepatitis C genotype 1 who could avail of treatment are aware of the new therapies, actively consider treatment and receive all the support necessary to enable them to comply with the treatment regime and hopefully achieve a sustained virological response.