2014 WFH World Congress

I.H.S. Magazine Supplement

Opening Ceremony

The official Opening Ceremony of the 31st World Haemophilia Congress took place on Sunday 11th May, in Melbourne Convention & Exhibition Centre. The ceremony featured a welcome address from the World Federation of Hemophilia (WFH) Patron Mr. Jan Willem Andre de la Porte, Mr. Robert McCabe, Congress President, Mr. Gavin Finkelstein and WFH President Alain Weill. With over 4,000 delegates from 130 countries, a lineup of plenaries, workshops, sessions presented by leading experts, and with top clinicians, scientists, people with haemophilia and related bleeding disorders, and researchers, the week ahead was surely going to be a triumph.

Entertainment came in the form of a performance of native song and dance with the hums of the didgeridoo.

The theme of 'Treatment for All' was illustrated by the presence on stage of eight people from around the world. Men and women of various ages, who are directly involved in the different WFH programmes, that have changed the lives of people with bleeding disorders worldwide, spoke about how they have impacted on the lives of people with haemophilia in their country. CEO John E. Bournas spoke about innovation, and WFH President Alain Weill closed the ceremony with a challenging question to the audience "What can you do today, to increase the number of people who have access to treatment?". With the Congress officially opened it was time to mingle with old friends and new, and look forward to the week ahead.

I hope you enjoy this magazine supplement. You will find some interesting and inspiring articles written by those in attendance at the Congress. On page 2 you will find a report from the 'National Member Organisation Training' that took place a couple of days prior to the congress, and on page 17 a report from the 'General Assembly' which took place on the last day of the congress. On pages 18 & 19 you will find two posters which were on display during the congress. Enjoy the read!

Debbie Greene

WFH Congress Opening Ceremony

Melbourne Docklands Area

WFH President Mr. Alain Weill

Global National Member Organisation Training

Global National Member Organisation Training (GNMOT) is a programme that runs for 3 days before the WFH Congress with workshops on a variety of issues facing National Member Organisations (NMO's). This year 104 delegates attended the training, which included Catriona Moriarty who some of you might know already, along with myself.

NMO Training Workshop (Catriona Moriarty second left)

At the opening session, WFH President Alain Weill, welcomed all the delegates and emphasised the importance of connections and learning from each other to strengthen organisations and the haemophilia community as we go forward. This was a good introduction to the first session on the programme on sharing best practices. Countries presented challenges, and achievements on a range of different activities. Delegates from Belgium discussed the implementation of an electronic haemophilia card that contains medical details about the individual, and a separate component within this whereby the clinicians can access the patient's history and notes. Delegates from Canada discussed two fundraising initiatives and the importance of communication and community involvement. Delegates from Serbia discussed their initiative to create advocacy training for patients to develop a strategy for the hemophilia organisation to contact politicians and regional government officials directly, but with the same messages and ability to deal with situations in a united front. It was also great to hear about a project in Uruguay which is helping to improve contact with patients particularly in the high mountainous regions of the country where access is difficult. Delegates from the Philippines talked about their recruitment of volunteers and through university programs and a Ukulele Club, which helped to improve the social involvement and self-expression of the kids when in hospital and then continued when they left the hospital.

In the afternoon on the first day there were four workshops for different groups. These workshops were then rotated between the groups. The workshops were on data and the economics of bleeding disorders, pharmaceutical relations, psychosocial support and youth leadership training. They had a distinctly Irish feel with Brian O'Mahony and I facilitating data and economics and the pharmaceutical relations workshops, respectively.

On the second day of the training, there were two excellent plenaries. The first was on 'Women and Bleeding Disorders'. Dr. Alison Street discussed issues in relation to identifying and treating women with rare bleeding disorders, von Willebrands and haemophilia carriers. Dr. Sonia Adolf talked about the Egyptian experience and some of the difficulties they faced. Culturally, many of the girls and young women have no sex education. She explained how they have used education, public awareness and screening to reduce stigma attached to these issues. Pam Wilton from Canada spoke about the Canadian Haemophilia Society programme for 'Women and Bleeding Disorders', called Code Rouge. She talked about her own experience of being a low-level carrier and going to the hospital with a bleed in her knee and being told "you are a carrier, you couldn't have a bleed". She discussed the key strategies and tactics the Canadian Society used when creating this programme such as identifying ambassadors that would talk, giving them training in how to communicate to address specific issues that may come up, developing a section on the website and putting together a conference on the topic.

During the last plenary session Dr. Alok Srivastava, Dr. Van Den Berg and Brian O'Mahony talked about clinical research in haemophilia. They pointed out some of the areas where there are gaps such as issues with inhibitor development, appropriate tools to measure outcome assessments and the need for further treatment protocols. It is clear that research is important in the development of haemophilia care. Clinicians, patients and other stakeholders need to work together to improve care as we go forward.

Declan Noone during his presentation

The final night of the training arrived and a banquet had been arranged for all participants. It was clear at that stage that the GNMOT had achieved one of things that it set out to do, to build a community among the participants. After dinner there was a recital from one of the individuals from the Philippine Haemophilia Society who is part of the Ukulele Club who then presented the Ukulele itself to the WFH. It was an appropriate way to end a fantastic few days.

Declan Noone

Delegates from 104 different countries worldwide attended the NMO training

REPORTS FROM THE CONGRESS PROGRAMME

Disclosure: when, how, and who to tell about a bleeding disorder

Brian O'Mahony was first to speak about the challenges of disclosure from a patients point of view. Brian covered areas which may affect a patient's choice to disclose their medical diagnosis such as the lack of treatment, social factors, cultural factors, religious views, potential partners opinions and marriage opportunities. Brian covered examples from various cultures and gave a broad and detailed explanation for disclosing or lack of.

Shirin Ravanbod from the Iranian Haemophilia Society was next to speak. She is the mother of a 22 year old son and she helped to build the first treatment centre in Tehran 12 years ago. She works currently in the molecular haematology laboratory in the centre. She spoke about how various factors influenced her decision to disclose to people about her son's condition. She felt that there was discrimination, at times social isolation and social stigma. However, on a more positive note she felt empowered when she disclosed, she felt a reduction in her stress levels and she also began to gain more information as she was able to speak to other people about it. She also felt as a carrier living in Tehran, there was a significant impact on carriers such as serious risk of bleeding without treatment, stigma and anxiety to name but a few.

A patient with haemophilia from Australia was next to speak and he highlighted his own personal difficulties with disclosure in the 1990's. He felt that he would have benefitted from legal advice in relation to his employment rights and could have benefitted from support from his haemophilia treatment centre at difficult times throughout his life. He felt that being upfront and honest with your partner as soon as possible would inevitably cause less of an issue and less damage in the long run. He also felt that HIV and hepatitis C changed the dynamic and willingness to disclose. He also focused on telling patients to be sure of their physical capability when applying for a job. This part of the session was a very personal life story and I found it inspiring.

Fiona Brennan

Non-Adherence: Experiences and strategies to overcome it

The first session I attended at the congress started things off with a bit of a bang. The session was on 'Non-adherence' and explanations and strategies to overcome it. The first speaker Dr. Alfonso Iorio from Canada talked about the importance of all involved and speaking the same language when we are discussing adherence. He pointed out that adherence is an outcome of a process such as taking prophylaxis on the days specified in the clinic. However, this does not necessarily mean the same for the patient as sticking to the regimen may not be the relevant outcome for them. They may consider adherence as leading a normal life and reducing the number of bleeds. He also talked about the need to understand what the reason is for taking the medications and how it works as a lack of understanding is associated with lower adherence. There is also a connection with the care team and adherence, referring to it as the 'HTC Effect'. The better the person's relationship with the clinicians, nurses, dentist, etc. the better their adherence tends to be.

Susan Cutter from the USA spoke about some the tools used at her centre to improve adherence. They first assess each individual for their preference in receiving information and then gear the education or training to them in that way. They find out what the individual feels theirs problems or barriers are and make sure they are participating in making their own choices rather than being told what to do. They also look at how the individual is coping with haemophilia separately to the physical aspects.

Kate Kahir who is a haemophilia nurse specialist from London started with a question asking the audience of about 100 people if they always took their antibiotics, inhalers, didn't smoke, and eat healthy. Only 3 people were deemed as adherent (and I am pretty sure they were lying). When asked for suggestions on how they felt support would help, the majority said being involved in patient organisations and more personal contacts between peers really helps. They also mentioned better education of the clinicians and nurses to improve the communication on how to agree on goals that are important for everyone. Finally Kate Kahir and Robert McCabe from Australia acted out a role play scenario whereby a person with haemophilia meets the nurse and it showed how many of us think we are communicating what we need to, when the reality is the conversation is actually only skirting the edges of what the discussion really needs to be about.

Declan Noone

Management with little or no factor

One of the sessions I attended was entitled "Management with little or no factor – is it possible?" The first speaker was Ricarte B. Felipe from the Haemophilia Association of the Philippines. He discussed how people with bleeding disorders manage pain. He discussed his own experience as a patient with haemophilia and his achievements. He feels that he is well supported by the patient organisation and medical professionals as they provide workshops and camps for members. He feels in the Philippines, medical professionals need to provide more education, home training, and updates on new developments in order to improve care and treatment in the Philippines. Andy Sabbour a physiotherapist from Cairo then spoke about the role of a physiotherapist and the importance of physiotherapy in people with haemophilia. He discussed the importance of exercise and physical therapy in order to improve muscle strength, flexibility and endurance. Research suggests that there are many benefits to exercise and the use of electro physical agents and hydrotherapy in particular has good benefits for musculoskeletal pain. He concluded that there is "no gain with pain".

The third speaker was Gillian Wharfe from Jamaica. She discussed treatment in Jamaica with no factor concentrates. Two hundred people have been diagnosed with haemophilia out of a population of 2.8 million, and she believes there are many people undiagnosed with bleeding disorders. There is only one diagnostic centre and four treatment centres in Jamaica. They have very little access to factor concentrates, so they focus on prevention and education. They provide education on bleeds, how to recognise a bleed early, assist and encourage academic education in order to prevent manual labour and improve their patients livelihood. They rely on the Jamaican Blood Transfusion Services to provide safe blood products to treat bleeds and they aim to have 30,000 donors per year to maintain a sufficient blood supply. They have a good relationship with the blood bank so they have a supply readily available. In the future they want to reduce exposure to blood products, increase availability of factor concentrates, increase the number of blood donations and most importantly keep the blood supply safe.

The last speaker was Daniel Hart, a lecturer in haematology in London. He spoke about the twinning perspective in Bangladesh. In Bangladesh there is a challenge in providing adequate care due to limited factor concentrates. There is poor education, little access to experts and poor diagnostic accuracy. Many people are misdiagnosed and put on the wrong treatment which can potentially have harmful outcomes. He explained that many people are undiagnosed with a bleeding disorder and one particular story struck a chord with me. A 19 year old man had surgery but unfortunately he died as he was an undiagnosed person with haemophilia. It's astonishing that in the 21st century these situations can still occur despite all the medical advancements. This session was ended with a powerful quote by Gandhi; "Your beliefs become your thoughts, your thoughts become your words, your words become your actions, your actions become your habits, your habits become your values, your values become your destiny."

Catriona Moriarty

Psychosocial workshop: Transitioning through life stages

The theme for this workshop was 'Transitioning through Life Stages'. It was an excellent workshop where professionals provided practical strategies for working with patients. Following a great 'Ice-breaker' session by Ed Kuebler (Social Worker from USA), Dr. Gringeri from Milan who is a physician spoke of the importance that the young person with haemophilia becomes independent from his parents. Factors which can affect treatment compliance were discussed as follows: - the inability of the young person to understand the potential benefits, denial, poor venous access, lack of parental commitment, interference with lifestyle and teenage rebellion. The Canadian website for adolescents and the World Federation of Hemophilia (WFH) article by Guy Young were recommended. Moana Harlen, a Psychologist, gave the psychological perspective and spoke of emotional regulation (ER) which is the ability to cope or control responses to environmental stimuli. This is considered essential for cognitive functioning. Research has shown that a child's ER is influenced by parenting skills. She suggested that parents who learn problem solving, relaxation strategies and coping skills can help to improve the child's emotional regulation.


Debbie Greene & Anne Duffy

Maureen Spilsbury, a Social Worker, spoke of the opportunities for social workers to help in family transition – from counselling, play days and parent groups, to active games, sibling groups and day camps in adolescent years. Dustin Bridges a person with haemophilia shared his experience of growing up with haemophilia and gave a sense of the social and medical challenges which face young people with a bleeding disorder. Frederica Cassis introduced the audience to her new inhibitor playing cards. These playing cards provide children with an opportunity to learn about the clotting process through play. When the programme ended there was a welcome reception for the audience which was provided by the Australian social workers group. This provided an opportunity for the psychosocial workers present to network, which was most enjoyable.

Anne Duffy

Recipe's for Healthy Living

I attended an excellent session entitled 'Recipe's for healthy living' which was extremely well attended and gave me a good understanding of the link between nutritional issues and coagulation.

Joann Deutsch from Oregon Health and Science University in the USA, who is a family nurse practitioner, spoke about healthy living and obesity management. A wonderful speaker called Andrew Selvaggi who is a person with severe haemophilia, (with inhibitors) aged 26 years old and from Melbourne, spoke about nutrition and haemophilia. He now works closely with people with haemophilia and is also an IT consultant. Andrew went back to his childhood in his presentation. He has had over 130 hospital admissions since being diagnosed with haemophilia as a young child and has had 7 major surgeries, and approximately 445 muscle bleeds. During his school years his attendance was only 30%, and because of all the bruising a district nurse was known to drop into his home unannounced at least once a week as she thought his parents were abusing him. He was a rebellious young man in his teens, and in his own words "I was very lazy, rude and very much overweight". Andrew spent his time a wheelchair a lot. Inhibitors were a big problem for him. He became very depressed about his condition. He was having bleeds a few times per week.

One day he woke up and felt something had to change for him. He started exercising as best he could, very slowly over a short period of time. Before he knew it over a couple of months he lost 35 kilos. He then decided to start looking at his diet and started to eat healthy. This sparked a passion within him, and before long he got big into nutrition. After a couple of years he became very fit, had lost a lot of weight and his bleeding decreased by 75%, which he feels was due to the 30% less weight going through his joints. He then became a personal trainer. Even though he has turned his life around some damage is irreversible, he has chronic arthritis in his ankles and elbow, has had an ankle fusion in 2012, and only last year a total knee replacement. It took him 11 weeks to recover from the ankle fusion, and 8 weeks from the knee replacement. He feels that his quick recovery was due to nutrition and fitness.

This was a great presentation, Andrew was excellent, and it struck a chord in me how important it is for people with haemophilia to have healthy muscle to support the joints, to be able to move around better.

Nutrition and exercise are important for everybody, but in particular for people with haemophilia. Andrew finished his presentation by letting us all know "You are what you eat!"

Debbie Greene

Growing up with haemophilia: The impact on the family

Silvina Grana a Psychologist from Argentina began by going through 2 case studies of children with haemophilia in Argentina. Both cases needed the intervention of a psychotherapist. Through play therapy they found that children were able to work through their issues in a child friendly way. They found that by the child socialising with peers the perception of their pathology decreased and also importantly from a psychosocial aspect, their isolation was reduced thus increasing their self-esteem and autonomy.

Dawn von Mayrhauser a Social Worker from the USA spoke next about how the diagnosis of any illness or medical condition will impact on every relationship and everyone in the family. She discussed how without a medical condition that a 'normal' sibling relationship can be extremely complicated, prone to rivalry and it can be confusing as one minute you are the best of friends and the next arch enemies. Add to this the complexity of a chronic illness and there are new issues to deal with. Although research on siblings and haemophilia patients is limited, it has been suggested with cancer based research that there can be both positive and negative effects on the siblings. Positive effects being increased maturity and autonomy for siblings, and negative effects including feelings of loss and guilt. Female siblings tend to show higher levels of depression than that of their peers with no patient in their families. In one study siblings of children with haemophilia showed double the dysfunction than that of the general population. Things that may affect this were age, gender, particulars of the illness, parental function and a history of psychopathy in the family. Dawn concluded that in order to help the siblings parents must be encouraged to deal proactively and in a positive manner with regard to their child's diagnosis. She felt that siblings need to be included in medical information and not excluded from education. She lastly stressed that the price of neglecting a sibling results in lifelong implications not only for siblings but for future generations.

Sharon Hawkins a Social Worker from Australia then spoke about the impact of diagnosis on the parents which can induce feelings of stress, guilt and helplessness, but perhaps also relief at having a diagnosis. Sharon discussed areas which greatly affect the parent's ability to cope with the child's diagnosis such as:

- Employment and financial stability
- Relationship with partner
- Unpredictability of haemophilia
- Trust in others to look after your child
- Identifying bleeds
- Product safety and many more

She felt that these areas need to be balanced by knowledge which increases the parent's self-esteem and confidence to be the best advocate for their child. She spoke about the psychosocial interventions that they provide in Perth such as education, counselling and referrals to appropriate authorities.

Crisis intervention is also provided where they make an immediate assessment of the families' ability to cope with a diagnosis and provide as much support as possible in the areas that they feel the family may benefit from. Building on this crisis intervention they will then put in place a long term plan for the family to build their resilience and provide appropriate education and support services to them in conjunction with their developing family situation. Sharon stressed the importance of social and peer support for both parents and children to encourage positive engagement regarding their bleeding disorder.

This was a really well run, well explained and to the point session.

Fiona Brennan


Sarah Gilgunn & Fiona Brennan


Volunteers from Melbourne who did an excellent job

In our backyards: Eliminating the gap in care between developed and developing worlds

This session was chaired by Cheryl D'Ambrosio and Jan Willem Andre De La Porte. Firstly Beryl Zeissink from Australia discussed the history of haemophilia in Australia and haemophilia care today. She discussed barriers to accessing treatment which include; geographical location, finance, psychosocial issues and socio-historical issues. It was highlighted that there is a high standard of care and good management in Australia as it is a developed country. Patients have access to technology, medical experts and support from their national member organisation (NMO).

Marijke Van Den Berg spoke on the topic "What could change look like?". By increasing healthcare professional's knowledge more comprehensive care can be provided to patients. More patients need to be accurately diagnosed and come in contact with specialist staff in the field of haemophilia, WFH and research programmes. The WFH aims to ensure accurate laboratory diagnosis, achieve government support, improve care delivery systems and increase product availability in all countries. However, there are many challenges that need to be overcome. In many countries there is no access to treatment and very few people are started on prophylaxis at a young age. This needs to change in order to prevent joint damage and the need for surgery so they can live normal lives.

Mr. Sathyanarayanan discussed public policy. He said there is a lack of political will and awareness about haemophilia worldwide. By involving patients and care givers the attitude of political stakeholders can be changed. Getting involved in lobbying, advocacy, training care givers and publicising in the media can all help in increasing awareness of haemophilia. Encouraging women to become involved is vital. A very good session overall.

Catriona Moriarty

Back to Basics

Angela Forsyth chaired a great session entitled 'Back to Basic'. Dr. Alison Street from Australia spoke first and her presentation was entitled haemophilia 101. She began by highlighting that 70% of people with bleeding disorders are not diagnosed. She gave some startling statistics regarding episodic v's prophylactic treatment. With a group of 90 patients on episodic treatment, with 31.1 bleeds per annum on average in comparison to patients who are on prophylaxis who only had 3 bleeds per annum on average. Dr. Street concluded that regular prophylaxis results in less target joint and chronic arthropathy problems. Dr. Street then spoke about the role of the haematologist in the comprehensive care model in relation to patients with haemophilia. The work of the haematologist it is so much more than just a haematology. In order for patients to receive the best most comprehensive care a centre must treat the patient holistically from physiotherapy, to dental, to psychology and that the team approach is key. Alison finished her presentation by highlighting what was new since Congress 2012 – she felt that there was and needed to be more of a focus on women with bleeding disorders, how low dose prophylaxis may benefit patients depending on their bleeding patterns and lastly the development and approval of new hepatitis C drugs. As always Alison was a thoroughly enjoyable speaker with a simple but inherently clear message.

Next to speak was Lize van Vulpen, a PhD student from the Netherlands who explained her study of recurrent bleeding and its effects on joint damage. Lize explained how recurrent bleeding results in iron depositions in the joints, and these iron depositions cause an inflammatory response in the joint causing the cartilage to become damaged which will result in arthopathy and osteoporosis.

Next up was Nichan Zourikian, a physiotherapist from Canada. Nichan spoke about the importance of individual physiotherapy for patients and that physiotherapy is not just about regaining the patient's range of motion but also about strength and preventing further bleeds and the resulting damage. He stressed that for younger patients physiotherapists aim to prevent damage and strengthen muscles, whereas for older patients the most important aspect is to preserve function. He also highlighted that while patients might not be experiencing pain that does not mean that damaging is not or has not occurred. Nichan focused on low impact exercise such as swimming and cycling and muscle strengthening exercises as having the optimum benefits for patients with haemophilia. He concluded that just like the future of haemophilia treatment, physiotherapy should be individualised and not one size fits all.

Nicholas Goddard, an orthopaedic surgeon was last to speak and he was an amazing speaker. He began by discussing statistically the cases that are presented to him in his hospital. He said that 50% of haemophilia patients present with knee problems and his patients are young men aged on average 37.2 years. He explained that for his patients the main issues that are causing them to seek orthopaedic consults are social effects (not being able to take part in sports and being physically active) and the quality of life (chronic pain). He then went on to explain arthopathy in relation to haemophilia how due to damage there is resulting loss of joint space, deformities and joint stiffness. He highlighted that the goals of his surgeries are – pain relief, to restore function, to reduce bleeds and to return independence for his patients. An interesting statistic which I was unaware of that after surgery in a particular joint bleeds can be reduced by 5 fold in that joint (5.5 bleeds per annum to 1.2). He then discussed various procedures such as syovectomy, debridement and arthroplasty which he had found to be most successful. He spoke of the holistic approach taken by the Royal Free Hospital in the UK including physiotherapy and counselling.

Fiona Brennan

Leadership Development Strategies: Am I ready to carry the flag?

Ed Kubler who is a Social Worker chaired this session. Mark Skinner (ex President of WFH) spoke on the importance of leadership in a national member organisation. He discussed why some people want to become involved and be leaders and how some people are happy to be followers and that all organisations need both. All national member organisation (NMO's) need to have a strong foundation in place, and be prepared for change. Succession planning is vital for continuity and to avoid disruption. The development of a leadership talent pool is essential and every NMO should plan for new leadership.

Ed Kubler then discussed leadership development strategies in the bleeding disorder community. The first step is to identify and train young leaders. NMO's need to prepare the next generation to step up and create an opportunity for future leaders. Programmes such as 'Adult Fellowship for Integrating Responsible Mentors' (AFFIRM) and 'Global NMO' training can expand leadership skills.

The flags of all the NMO's in the Convention Centre

Predrag Milkov from Serbia discussed his experiences of having haemophilia. He discussed the challenges in education and sport activities he encountered. He explained that he did not disclose his illness to his employers as he encountered discrimination on numerous occasions. He also spoke about the persistence he needed to be successful in his career and also as a leader. He was a captivating speaker and told many stories that had the whole room in fits of laughter.

Evelyn Grimberg from the Netherlands spoke of her experience of having a bleeding disorder and the difficulties she still faces. She talked about how she became involved in her NMO and how she undertook a leadership role. She was on the youth committee and is now on the board of management. She feels she was successful as she had her own goals, enthusiastic, leadership qualities and plays an active role within the bleeding disorder community.

Catriona Moriarty

Beyond Registries

I attended a presentation on the importance of registries. The first was on the UK Haemophilia Centre Doctors Organisation (UKHCDO) registry, by Dr. Dolan. He spoke about the system they have in place and how the system is a national system with access in all of the haemophilia treatment centres in the UK. The registry collects information on bleeds and joint damage and recently has added quality of life data to assess the effects of treatment.

In an assessment to try and quantify what a bleed is to improve reporting in the registry, in 15 situations where patients reported a bleed, 12 of the 15 were bleeds and 3 were due to arthritis. Interestingly, when the physicians where asked to define whether they were bleeds or not, they were incorrect in 8 out of 15. Further analysis is currently on-going. They have also used the registry to identify high and low product consumption. Dr. Mike Makris presented on the European Haemophilia Safety Surveillance (EUHASS) registry which is now in its 4th year. The registry measures adverse events in 75 haemophilia treatment centres across 32 countries and represents 32,659 patients across Europe. Over the 4 years, 18 allergic or acute reactions and 54 new cases of inhibitors have been recorded. The most common adverse event was liver cancer and the most common cause of death was hepatitis C related. This clearly shows the need for the new treatments for people with haemophilia who have hepatitis C. The registry has been so successful it is being duplicated in Canada and Australia as it is only through a large scale registry that a clear picture can be developed. Dr. Bolton-Maggs discussed the new interactive version of the WFH global survey which really allows you to look at the world and its regions in relation to identifying patients and access to treatment.

This is an extremely good advocacy tool but also a way to assess the availability of factor in a country if you were going to visit.

Declan Noone

Black 'n Blue and Golden: Ageing gracefully with haemophilia

I was very pleased to chair this session on this interesting topic. Penny McCarthy, a Clinical Nurse Specialist spoke about strategies for reducing complications related to health and living spaces. Penny highlighted the reality where the haemophilia treatment centre, while providing expert care for the person with haemophilia, can lack expertise to deal with age related illnesses, and cannot extend their services to monitoring the demands of preventative men's health care. People with haemophilia often do not see the need to have a GP and can overlook opportunities for routine screenings. Men's Health Checks for different age groups were recommended. The 5A's approach was discussed which is:

Ask:	emotional wellbeing, smoking, alcohol, physical activity, diet
Assess:	readiness to change
Advise:	brief, non-judgemental advice
Assist:	by providing opportunities to discuss health issues, educational material
Arrange:	support services and appointments

Emphasis was put on future planning and on the importance of fall prevention, taking exercise, avoiding obesity, good nutrition and vein health.

David Page, National Executive Director of the Canadian Hemophilia Society made great use of his sense of humour to deliver his presentation about coping with health and quality of life issues. He presented the results of a small research survey he did which highlighted the coping strategies which senior people with haemophilia have developed which include swimming, staying fit, being proactive about health, saying no and allowing their partner to help. The principal concerns for the future which people reported were deteriorating general health from alzheimer's, dementia, cancers, and health care affordability in retirement. Haemophilia related concerns were accessing veins for infusions, access to the treatment centre and haemophilia care in long-term care facilities.

I then introduced a video of three I.H.S. members who had agreed to be filmed and interviewed following our Ageing Conference last November. They shared their coping strategies which enhances their quality of life and spoke of their future health concerns.

Anne Duffy

Vein care

This session was aimed at nurses however, I was scheduled to attend this and felt it might be interesting. Regina Butler a Haemophilia Nurse from USA spoke about vein care challenges for nurses, and pointed out that peripheral IV access is the gold standard, is the easiest and fastest, and one of the most frequent procedures done in hospitals worldwide. However, sometimes it is so hard to find good peripheral veins. Some of the challenges are age, obesity, dark skin, drug users, low blood pressure, multiple injuries, dehydration, pain and anxiety. DVA (Difficult Venous Access) is a clinical condition. In her hospital the clinician will do an assessment with the patient regarding age, history, cooperation level, access sites, number of days of therapy, and anxiety level. Protocols for nurses that have been put in place in her hospital which includes paying attention to the sight, needle choice, nurse's experience, limiting attempts, and calling an IV nurse for assistance if necessary. Upper limbs are preferred and locating a visible vein is a good idea. They are also trained to help the patient relax. However, she mentioned that sometimes the best tips come from patients; they usually find the best vein, and that a huge percentage of missed IV's are poor traction issues. Some suggestions include the use of double tourniquets and practice, practice, practice. Regina also spoke about infrared technology which displays an image of the vein, and may help with difficult access. However, it is time consuming and costly.

Jim Munn of the University of Michigan in USA spoke about the pro's and con's of central venous devices. The reason they are used is mainly because of poor veins, the desire to maintain veins, physical limitations, and frequent infusions. These devices are ports, peripherally inserted into the central catheter; all devices can be a single or a double lumen depending on the need, and depending on individual. Some of the pro's include alleviating anxiety for the patient and allowing for more frequent infusions, and some of the con's include infection, skin erosion, it is a surgical procedure and body image. In the hospital where he works when patients are selected for this they are educated and monitored, must be non-inhibitor patients, and have no dental infections. They encourage patients to flush the device after every use and the device must only be in place for 4 years.

A very enjoyable and understandable session even it was aimed at nurses.

Debbie Greene

Family Dynamics: the ties that bind

Julia Spires is a nurse in Great Ormond St Hospital in the UK. She opened this session speaking about siblings and the affect that a diagnosis of haemophilia can have on the family. She gave a case study example of an 8 year old female sibling who was acting out particularly bad since her brother had been displaying problems with injections (her brother was 6 years old). Julia highlighted that the parent's attitude towards the bleeding disorder is often telling of the siblings personal feelings towards the child with haemophilia and the bleeding disorder itself. She explained that siblings can often be left out or neglected as the child with haemophilia takes up so much time and attention from the parents.

She also said that siblings of children with chronic illnesses tend to have high levels of empathy, kindness and emotional maturity. However, Julia did highlight that it is important for parents to maintain the involvement of the sibling and to keep in mind their emotional well-being, although Julia did explain how it can be difficult at periods where the child with haemophilia is in hospital etc.

Kuixing Li from China spoke about teenagers and the difficulty parents may have dealing with this particular age group with reference to their bleeding disorder. She spoke of the situation in China. She said that often Chinese boys act up and do not speak out. They tend to face the future negatively and parents may need to be conscious of trying to boost their self-esteem. She also highlighted the opposite problem of parents over-compensating the child with haemophilia with material goods.

Jane Latimer from Australia then spoke from a physiotherapists point of view. She said that often times due to a lack of exercise people can suffer with chronic diseases, and this is also true for people with haemophilia. They surveyed 44 boys aged 6 – 17 years and found that there was no significant difference in aerobic fitness and BMI between children with haemophilia and their healthy counterparts. A bigger survey also revealed on 104 boys aged 6 – 17 years that they spent 6.4 hours per week on moderate physical activity. 45% of all children played a competitive sport and 61% of children aged 10 years and over played in competitive sports. Positively, 43% of children met the recommended guidelines for daily physical activity, which is good to hear.

Lastly Jim Munn, a Nurse Co-ordinator from the USA spoke about ageing and the impact this may have on relationships within the family with particular focus on partners. This was an interesting part of the session partly because it reinforced a lot of the material that we would have mentioned in the Ageing Conference such as mobility difficulties, difficulties with the balance of medication for other ailments synonymous with ageing and venous access. Jim felt that planning for the future before it was on your doorstep is extremely important both from a practical and emotional sense.

Fiona Brennan

WFH Congress logo and exhibition area

AND NOW FOR THE SCIENCE BIT!

Clinical Trials, Longer Acting Factor Concentrates and Gene Therapy

The future is bright

One of the features of the programme at the World Federation of Hemophilia (WFH) Congress in Melbourne was an update on the progress in the clinical trials and development of new longer acting factor concentrates. The first longer acting factor IX concentrate Alprolix produced by Biogen in the US was licensed in the USA and Canada in the month prior to the Congress. Longer acting factor concentrates modify or enhance the factor FVIII or factor IX protein to give the factor a longer half-life in the blood, which allows for less frequent infusion and or higher trough levels, thus greater protection from bleeding. The first of these products is expected to be licensed in Europe in late 2015 or early 2016. In relation to the pegylated products Baxter is producing a full length recombinant based on their current recombinant factor VIII Advate. This product (development name BA855) has a similar recovery to Advate but with a half-life 1.5 times greater; phase 2/3 trials are ongoing and are expected to be completed at the end of the third quarter of this year and the paediatric previously treated patient trial will begin at that point. Bayer are also developing a pegylated factor factor VIII (BAY 954/9027). The phase one clinical trial with this product used 25 or 50 IU/KG every 5 days or every 7 days. In those who were treated every 7 days there was an annual bleeding rate (ABR) of 3.9 and 74% of these individuals stated that they would be happy to remain on this regimen. This session concluded that using this product treatment could be twice a week every 5 or every 7 days depending on the individual bleeding tendency, and that there was a need for individualised therapy. Novo Nordisk are producing a pegylated factor VIII (NovoN8GP) phase 2 study which has just been completed. Two hundred and seventy people with haemophilia have been treated to date in the clinical trial and the half-life shows a 1.6 fold increase over standard factor VIII. The factor VIII produced by Biogen which is now licensed in the US (Alprolix) was just in three different regimes in the clinical trials with some individuals in the trial using this every 3 days, some every 5 days and some twice a week. Early results from the Albumin infusion factor VIII produced by CSL Behring showed that greater than 9% of bleeds were treated successfully with one infusion.

The longer acting factor IX's are demonstrating a much greater increase in half-life with the half-life being increased 3 – 5 fold, depending on the product. The longer acting factor produced by Biogen (Alprolix in the US) increases the half-life by 2.5 fold. The longer acting factor produced by CSL Behring, currently under development increases the half-life 5 fold. It was stated during the conference that this could be used to allow for prophylaxis once every 2 weeks. During the clinical trial prophylaxis is used and varied from once every week, once every 10 days and once every 2 weeks. The clinical trials with all of these products are progressing rapidly, and with the first products already licensed outside of Europe, a lot of discussion is now moving towards how these products would actually be used and what prophylaxis regimes will be utilised, what individualised therapies would be required and what the implications were for the economics of factor concentrates. It is clear that in the future the concept of one size fitting all in relation to prophylaxis or treatment regimens with factor concentrates will no longer apply. Individualisation of therapies will be definitely the way forward.

Currently in Ireland there is a pharmacokinetics study where the individual half-life of people with factor VIII deficiency is being measured. It is very clearly signposted for the future that individual treatment regimens will need to be devised for people with haemophilia. Eventual treatment will almost certainly be based on their pharmacokinetic profile, their individual half-life, their bleeding tendency, the state of their joints and the degree to which they have pre-existing joint damage, their activity levels and their lifestyle. Small children or adults with poor venous access will benefit from less frequent infusion for others who have pre-existing joint damage prophylaxis regimes which allow for higher trough levels at least 3% may prevent more bleeds in these individuals in some cases a combination of less frequent infusions and higher trough levels.

I took part in a panel discussion on the rolling out of the longer acting factor concentrates and the implications for haemophilia treatment. The new products when licensed in Europe will almost certainly have to undergo a health technology assessment prior to any reimbursement decision. There is also a challenge to current National Procurement Systems including the Irish tender system where we would have to relook at our selection criteria and methodology. It would be a great shame following the development of these products

One of the many excellent sessions at the Congress

which have so much potential for improving treatment that they would not be available in many countries due to setting prices at too high a level. We have been communicating proactively with the companies developing these products to try to ensure as so far as is possible that this does not occur. A note of caution was also injected into proceedings as there was a list of some of the new product failures to date over the past number of years. Five products were listed where development had stopped, 3 of these due to a lack of efficacy or affect and 2 because of an increased rate of inhibitors. This was a confirmation of the fact that not every product under development will eventually make it to the market. In closing, this plenary session dealt with the future of prophylaxis with new novel therapies, the problems with current prophylaxis were highlighted and these include: lost venous access and adherence to the treatment regime. In reality people may miss up to 10% of their doses under their current prophylaxis regimens.

The reason for lack of adherence can be cost where the patient has to bear some or all of the cost themselves, the time required for infusion and the inconvenience and often the perceived need for prophylaxis by the person with haemophilia or the family. Allowing for less frequent infusion and more conveniently fitting in with lifestyle the new longer acting factor concentrates may increase adherence but of course this will depend on the cost of the products. Today the objective for prophylaxis has been to maintain the trough or lower level of factor of 1% at all times to prevent spontaneous bleeding. However, this does not always prevent spontaneous bleeding and certainly some individuals on prophylaxis still get bleeds more so if they have pre-existing joint damage. It was stated at the conference that if the factor level was always above 12% that people would not get bleeds even with strenuous activity. At previous conferences this level has been stated at 15%. These levels are almost certainly economically and practically unattainable as trough levels for prophylaxis at this point in time in the development of treatment but a minimum trough level increase of 1% to 3% should be attainable. In new products and the longer half-life for factor IX prophylaxis once a week, could maintain the trough levels at 10 – 15% which would be very good for active people with haemophilia.

There was also information at the congress about several new factor VIII's which are not longer acting. These included a new recombinant factor VIII from Novo Nordisk (Novo 8), a new human cell line in recombinant factor VIII from Octapharma and a new recombinant porcine factor VIII developed by Baxter which can be used in acquired haemophilia and also for the treatment of haemophilia and in gene therapy.

At the session on gene therapy the main speakers were Professor Kathy High from Philadelphia (Professor High is from the same centre which the NCHCD are collaborating with on the possible Irish involvement in a factor IX clinical trial) and Dr Amit Nathwani from the UK who has developed a factor IX gene therapy which is currently in use in the UK and has led to the first successful clinical trial in the area. Dr High spoke about the gene therapy clinical trial approach using the AAV8 vector. It is known that 30 – 50 % of individuals with factor IX deficiency have pre-existing antibodies to this vector and therefore would not be available for this trial. Methods to counteract the impact of these pre-existing antibodies were discussed including increasing the doses, delivering the vector directly to the liver via balloon catheters to decrease the circulation.

The issue of gene therapy for children was also discussed; children are not currently enrolled in the clinical trials for gene therapy, with AAV8 vectors these do not integrate into the DNA, so the expression of the gene is lost in the growing individual so therefore a lot of the potential benefit would be lost as children grow up. It is speculated that if children were to be included in the trials that children with inhibitors may be first as this would allow for a form of immunotolerance therapy without the use of needles.It was also speculated that if children were to be treated with gene therapy you could look at using the Padua variant of the factor IX gene (a very highly expressed factor IX gene named after an individual Padua who had a factor IX level of 766%) this would lead to a higher factor level in the blood even if some of the expressed factor IX level was lost it would be expected to be relatively high. For example in the current factor IX clinical trials, long term factor IX expression of 2 – 6% has been seen with a Padua variant it may be possible to get an expression range of 40% so that even if half of this was lost in children as they grow up they would be left with a factor level of 20%. The question of how long the factor expression would last after a single gene therapy infusion was discussed, and obviously the answer to this is unknown. To date in the dog model expression of the factor IX gene has lasted for more than 10 years and in the factor IX gene therapy clinical trial in people with severe haemophilia in the UK, the individuals have now maintained factor IX levels for 4 years after a single infusion. Dr Amit Nathwani pointed out that the first person in his clinical trial is now 50 months post infusion and has maintained a 2% factor level for 50 months. He is now no longer on prophylaxis and has had no spontaneous bleeds for the last 4 years and his factor IX use has decreased by 77%. To date 10 individuals have participated in the factor IX clinical trial in the UK they are now 17 – 50 months respectively from the time of infusion and they have seen no long lasting or late toxicity effects.

Dr Amit Nathwani and his team are now working on developing a factor VIII gene therapy. They will use a manipulated factor VIII gene because the current factor VIII gene is too big to fit into a vector or delivery system. The doses will be similar to those in the current factor IX trial and they expect the trial

to start in the second quarter of 2015 using a similar AAV8 vector as with the factor IX. The trial will be conducted in London with satellite sites around the world. The trial will exclude individuals with an existing family history of inhibitors, individuals who have active hepatitis B or C or HIV. He also mentioned that there may be a serious possibility for people in the future with high titer inhibitors to factor VIII who have failed immune tolerance therapy.

Indeed in discussions around clinical trials and treatment regimens it was clear that the annual bleeding rate among those on on demand therapy, even those on clinical trials was much higher than in any of the groups on prophylaxis. There is growing consensus that on demand treatment simply does not work and that prophylaxis for all children and adults with severe haemophilia is the optimum therapy. This has long been recognised as the optimum treatment for children with severe haemophilia but interestingly this year the Council of Europe under the EDQM recommended the provision of prophylaxis for adults on an individual basis based on consultation between the clinician and the patient. Several developing and emerging countries are now looking at low dose prophylaxis in situations where they will not be in a position to provide full prophylaxis economically for the time being. There was an incremental increase in the amount of information available with regard to the new long acting factor concentrates as the clinical trials progress and the first of these exciting products now come to the market. There is encouraging progress being made in gene therapy not just in factor IX deficiency but importantly the first planned clinical trial with the new vectors for people with factor VIII deficiency.

Brian O'Mahony

Inhibitor Development

I attended an excellent session on inhibitor development, which was chaired by Dr. Elena Santagostino from the University of Milan in Italy. The likelihood of inhibitor development is not just genetic and there are a variety of other factors that influence inhibitor development. These non-genetic factors can be influenced and Dr. David Lillicrap discussed the animal models they have developed to help this research. The clinical research on inhibitors towards factor VIII is challenged by the fact that this is an infrequent event occurring in a rare disease. Therefore, it is widely accepted that complementary studies involving animal models can provide important insights into the pathogenesis and treatment of this complication.

Dr. Elena Santagostino presented data to show that switching brands of factor VIII did not have any increased risk for developing inhibitors. However, the dataset's they have to date are very small and thus difficult to draw conclusions from. Dr. Santagostino emphasised the fact that prospective, controlled surveillance programmes on switching and not switching patients are required to provide robust evidence concerning the inhibitor risk related to product switching. In this respect, inhibitor testing before and after the switch as well as testing of not switching patients is a crucial element to establish the correlation with the new treatment.

The final speaker in this session, Dr. Karin Fijnvandraat discussed inhibitors in patients with mild haemophilia A (MHA). Patients with MHA are at lifelong risk of inhibitors, requiring continuous vigilance. This necessitates frequent testing for inhibitors, especially after intensive factor VIII replacement for major bleedings or surgery.

Sarah Gilgunn

Another great session at the WFH Congress

Plenary Sessions

Broad Perspectives for a new Era

Mr. Alain Weill, World Federation of Hemophilia (WFH) President gave the first of the plenary sessions of the WFH Congress 2014. Alain gave a heartfelt meaningful presentation. He believes the WFH has the power, the means and the knowledge to expand treatment products and access to treatment throughout the world. Alain showed one simple slide with three words, "Innovate, Educate, and Advocate", the three key elements necessary for obtaining the goal of treatment for all. Over the next decade the focus of the WHF will be on these three elements. Innovation in diagnostics, training methods, distribution, gene therapy, and longer-lasting factor concentrates. Education, including collecting data on specific research questions necessary for better treatment, and continued advocacy for all those in the bleeding disorders community.

Epidemiological aspects of inhibitor development

Dr. Van den Berg from the Netherlands discussed the obstacle of inhibitor development in patients with severe haemophilia A. Inhibitor development is the most serious side effect of treatment with coagulation products. Presently, 25–30% of all newly diagnosed patients with severe haemophilia A are diagnosed with inhibitors. Clinical studies in a rare disease such as haemophilia are difficult; this talk discussed the problems in diagnosing inhibitors and relationship over time between the increase in inhibitor incidence and the diagnosis of high and low-titre inhibitors. The further complications associated with the large inter-laboratory variability of the inhibitor assay was also discussed.

Inhibitors: Cellular aspects and novel approaches for tolerance

In this excellent talk Dr. Scott discussed his research on understanding the cellular and molecular aspects of inhibitor formation and how this is so critical for designing tolerogenic therapies for clinical use. Dr. Scott told the audience "Tolerance occurs in both T and B cells, and there are multiple mechanisms of tolerance that exist," The good news is that "you can teach an old dog new tricks.' You can teach the immune system to be tolerant. One can interfere by blocking or inhibiting the antibody response." He managed to keep the audience very attentive as he gave in depth details of the molecular basis of our immune system's response to FVIII, along with making very witty analogy's to a Sherlock Holmes story and inhibitor development. This excellent speaker emphasised the emerging efforts currently under investigation to reduce immunogenicity and also to prevent and/or reverse inhibitor formation. Several of these novel approaches to prevent and/or reverse antibody responses have reached the stage of clinical trials. Hopefully, these approaches will make inhibitors a thing of the past.

Haemophilia care: Beyond the treatment guidelines

Professor Alok Srivastava from Vellore, India has been working in the field of haemophilia for over 25 years and currently serves as the WFH Vice-President (Medical). This talk centred on the advances in caring for people with haemophilia over the last few decades and how prophylaxis is key to people with haemophilia living 'near to normal' lives. While prophylaxis is now considered gold standard for treating people with haemophilia it still has some limitations, mainly in the fact that there is no well-defined optimal prophylaxis protocol. Professor Srivastava put strong emphasis on the need for prophylactic protocols to be developed and also discussed issues around the limited data available on long-term outcomes in haemophilia from anywhere in the world. Professor Srivastava said "The practice of documenting specific outcomes as part of the regular evaluation of people with haemophilia needs to be established and the appropriate instruments used to assess them".

Novel products for the treatment of clotting factor deficiencies

Professor Johannes Oldenburg from Germany gave a detailed overview of all the new products that are coming to the market or are in the advanced stages of clinical trials for treatment of haemophilia and other bleeding disorders. Today, the advances for recombinant factor IX are significant with half-life extensions of up to 100 hours, allowing substitution intervals of 1–2 weeks.

For recombinant factor VIII products the effect so far is only moderate, as the half-life extension is limited to about 15–18 hours by the clearance of factor VIII through its binding to von Willebrands factor. Professor Oldenburg also detailed the exciting new products such as the bispecific antibody that mimics FVIII currently under development by a Japanese group; I think this is definitely one to watch! Some lessons that have been learned from clinical trial failures of new products over the recent years were also discussed. While there are many obstacles in developing new therapies, the new products that are now coming to/on the market will significantly improve treatment and quality of life for patients with haemophilia.

The future of haemophilia prophylaxis with novel therapies

Well the conference organisers certainly saved the best for last! Dr. Manuel Carcao from Canada delivered the last plenary of the conference and it truly was the best talk of the conference. Dr. Carcao has a brilliant ability to deliver top-notch scientific data to the audience.

The talk began with a brief history of haemophilia treatment from the 1960's when there was virtually no treatment, to the last 5 years where we have witnessed a flourish of new bioengineered longer acting factor concentrates, which are likely to be licensed within 1–2 years and which may have profound implications on prophylaxis. The issue of adherence was also discussed, the majority of patients on prophylaxis missing approximately 10% of their doses and it is thought that the use of longer acting factor concentrates, with less frequent infusions will help with patients missing doses. The issue of cost implications will affect the use of longer acting factor concentrates and also how physicians will have to consider how will they choose which longer acting factor VIII or factor IX concentrate, once these products are licensed. Should patients have higher trough levels or fewer injections? More active patients, particularly those with good venous access, might choose to receive more frequent infusions to achieve higher trough levels. There are many new questions to be considered with these new therapies but all of this leads to increased need for individualisation of prophylaxis regimens. Dr. Carcao concluded his talk with a few slides on other new therapies such as gene therapy stating it is finally becoming a closer reality.

The next 10–20 years are likely to bring a plethora of activity in the area of prophylaxis in haemophilia and hopefully will further improve the lives of people with haemophilia.

Sarah Gilgunn

WFH President Alain Weill during the first plenary session

Meetings

Twinning Meeting

We took advantage while in Melbourne to have a meeting with our twinning partners which was organised by Regional Programme Manager Robert Leung from WFH. Together with the haemophilia treatment centre staff from Melbourne, (who are also twinned with the treatment centre in Hanoi) we had a very productive meeting which resulted in an agreement to extend the twinning programme for at least another two years. Through sharing of information and knowledge and advocacy so much great work has been done on this twinning programme over the past number of years. We also had an opportunity to coordinate our joint work with Vietnam for the coming year. For more information on our twinning programme a more detailed article can be found in the summer edition of our magazine "haemophilia.ie".

Ms. Hang and Professor Tri (on the left) at the twinning meeting

Debbie Greene

EHC Meeting

I attended the European Haemophilia Consortium (EHC) Meeting that took place during the Congress which was extremely well attended. CEO Amanda Bok gave an update on what's happening in the organisation, with many meetings organised for this year including workshops on youth leadership and a conference later in the year on longer acting factor concentrates. Amanda spoke about this year's EHC conference which takes place in Belfast in October which will include workshops, scientific sessions, and a gala dinner at the Titanic Museum. President of the EHC Brian O'Mahony spoke about the tender procurement process and market exclusivity which has been a major piece of work for the organisation over past few months. Brian said that the organisation must be proactive in relation to market exclusivity as the potential consequences are a monopoly, no competition, and no potential for lower prices. Brian also went through the European principles of care recommendations. The aim is to have a formal body established in each country to include clinicians, National Member Organisations (NMO's) and the Health Ministry, with a minimum of 3 i.u. of factor VIII per capita for all countries.

The EHC is managed by a steering committee who meets on a regular basis, and the office in Brussels now has 3 staff working for the organisation which is great to see. The Medical Advisory Group (MAB) also meets regularly and assists the EHC on medical matters. If you would like to read more about the EHC why not visit the following website www.ehc.eu.

Debbie Greene

Awards Ceremony

At the last day of the Congress an 'WFH Awards Ceremony' took place to recognise the outstanding leadership and contribution of volunteers in furthering the mission of WFH which is "Treatment for all: that is, one day treatment will be available for all those with bleeding disorders, regardless of where they live".

Twinning awards were established by the WFH in 1995. These awards recognise a number of factors in the twinning partnership, including a high level of commitment to the partnership, excellent communication and teamwork, a high level of activity, achievements of objectives, and the submission of timely and comprehensive reports. Vietnam and Ireland were presented with the Twin of the year Award for 2012 and indeed the centre twinning programme between Melbourne and Hanoi was presented the Centre Twin Award for 2012. I think this is a demonstration of the high quality work both Melbourne and ourselves have been doing with Vietnam over the past number of years, and we were delighted to accept this award.

Centre & Organisation Twin of the Year Awards 2012

Mr. Alain Weill, Mr. Frank Schnabel Junior,
Mr. David Page & Mr. Brian O'Mahony (clockwise)

The WFH 'Frank Schnabel Volunteer Award' was established in 2004. This award is named in honour of WFH founder Frank Schnabel. It is given to an individual with haemophilia or related bleeding disorder, or to a family member who has contributed significantly to furthering the mission and goals of the WFH. This award is given every two years at the WFH Congress.

This year the award was given to two people the first being Mr. David Page who the National Executive Director of the Canadian Society and a person with haemophilia, and the second being our very own Mr. Brian O'Mahony, Chief Executive of the I.H.S. We were all delighted to see David and in particular Brian accept this prestigious award which is well deserved and long overdue. Congratulations!

Debbie Greene

General Assembly

Declan Noone and I were the official representatives for Ireland at the WFH General Assembly. This was my first expe-rience of the WFH General Assembly which takes place in the format of a UN style meeting with each county having their flag at their desk. A thoughtful moment began the 2014 assembly with a minute silence in memory of various National Member Organisation (NMO) members whom had passed away since the 2012 WFH Congress. The chair of the assembly was Dr. Paula Bolton-Maggs, who was more than happy to ring her bell at anyone went over their time slot and made sure the agenda was run exceptionally smooth! The first two elections were for WFH Vice-President Medical and WFH Vice-President Finance. There was only one candidate in each of these elections so there was no need to vote. Dr. Marijke Van Den Berg was elected as WFH Vice-President Medical while Eric Stolte was re-elected to his post of WFH Vice-President Finance.

The General Assembly

The next set of elections were for the medical board. There were 6 candidates who were given an allotted time to speak, after each candidate had spo-ken the voting national member organisation (NMO) was given five minutes to consult with their alternate and place their vote. Dr. Flora Peyvandi, Dr. Jerzy Windyga and Dr. Keith Hoots were voted on as medical members of the WFH board.

Our own Declan Noone had to take to the stage next as the lay person board was elected. There were some really great speakers, all of whom have great passion in advocating for haemophilia world-wide. The Irish contingent had reason to celebrate as Declan was successful in his campaign speech and was voted on to the executive board. There were 6 candidates up for 2 places which is a great achievement for Declan.

Next up was the vote (or battle!) for the chance to host the 2020 WFH Congress. There were 2 representatives from each country who had 12 minutes to convince the audience why we should visit their county for the 2020 congress. The battle com-menced as we were dazzled with facts and figures about Montreal in Canada, and Kuala Lumpur in Malaysia. The vote was cast and the 2020 WFH Congress will take place in city of Kuala Lumpur, Malaysia.

WFH President Alain Weill then presented the outgoing board members with a gift in recognition for their hard work. The General Assembly was then closed with a heartfelt speech about the 'Close the Gap' campaign; WFH will continue to do all in their power to increase the number of people who have access to treatment. What a fantastic end to a wonderful WFH Congress.

Sarah Gilgunn

On the following two pages you will find two of the posters that were on display during the WFH Congress in Melbourne.

Strategies to optimise inclusion and involvement of Young Men with Haemophilia

Authors: Mc Auley, N., Brennan, F. & Noone, D.
Irish Haemophilia Society

Introduction and Objectives:

In 1998, the Irish Haemophilia Society (IHS) created a children's programme at events. Since then this has grown into four specific children and young adult programmes. These programmes help the children build strong relationships with each other and the Society, resulting in them remaining engaged with the IHS.

Materials and Methods:

In 2010, upon review of the Society's activities and support it became apparent that young men with bleeding disorders aged 18 to 35 were disengaged from the Society as they had never had any involvement personally. Historically, parents of PWH joined the IHS when their children were first diagnosed with a bleeding disorder, but as their children moved into adulthood, they began to lose contact with the IHS. The PWH would then re-establish contact later in life when haemophilia was important in relation to planning a family.

As part of the IHS strategic plan, a programme was set up to provide optimal support and services for young men with bleeding disorders. The aim was to re-establish contact with these young men using of phone calls and social media and organise a specific conference designed around the needs of these individuals for peer support and education.

Results:

Once members fitting these criteria were identified through the IHS database, they were written to informing them of the conference and then contacted by phone from specific staff members. This was to initiate contact, increase the ease of registering and start to build relationships. As many of this age group work or attend college, it was discovered that the best option for contact was through texts, email or social media sites.

Conclusion:

Initial interest was low when comparing potential group size to the actual attendance, especially from those with mild bleeding disorders with minimal symptoms. However, a sub group did attend and following the conference have remained in contact with the IHS and fellow delegates. The group are reluctant to join the main stream conferences as they feel more comfortable in a smaller group.. Future aims for this group are to maintain contact, develop relationships and improve involvement.

Retrospective identification of factors which contribute to Hepatitis C treatment decisions in a population of people with haemophilia in Ireland

Authors: Noone D[1], O'Mahony B[1], Duffy A[1], Gallagher P[2]
1. Irish Haemophilia Society
2. Dublin City University

Introduction:
In 2012, two new protease inhibitors for Hepatitis C Genotype 1 were licensed in Ireland. In order to provide members considering and undergoing treatment with support, the Irish Haemophilia Society initiated a strategic communications plan informing members of the new treatments, through meetings, peer groups, specific newsletters, and personal stories from patients on treatment. Following the initiation of treatment we carried out a survey in an initial cohort of 11 patients with haemophilia to retrospectively identify the factors which contributed to their Hepatitis C treatment decisions.

Materials and Methods The survey was sent out to all 11 PWH who were undergoing triple treatment (100% response rate). The survey examined quantitative data based on the expectations from treatment, preparation for side effects, preparation for impact on daily life including work, daily activities and the subsequent reality of treatment. The survey was then used to form the basis of a group interview with PWH on treatment and their partners which was assessed using qualitative analysis.

Results: The results showed that the main factors influencing the decision to start treatment were

- Availability of new treatments,
- Discussions with the Hepatology Team and Clinicians
- Meetings organised by the Irish Haemophilia Society. (Fig 1)

72% of respondents rated the impact of the triple therapy treatments as severe to very severe as well as more severe or much more severe than had been anticipated. The qualitative analysis identified key challenges and protective factors in adhering to therapy (Fig 2 and Fig 3).

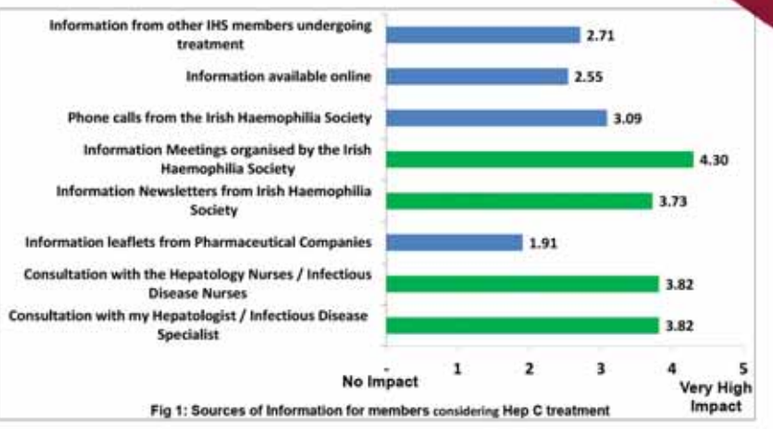

Fig 1: Sources of Information for members considering Hep C treatment

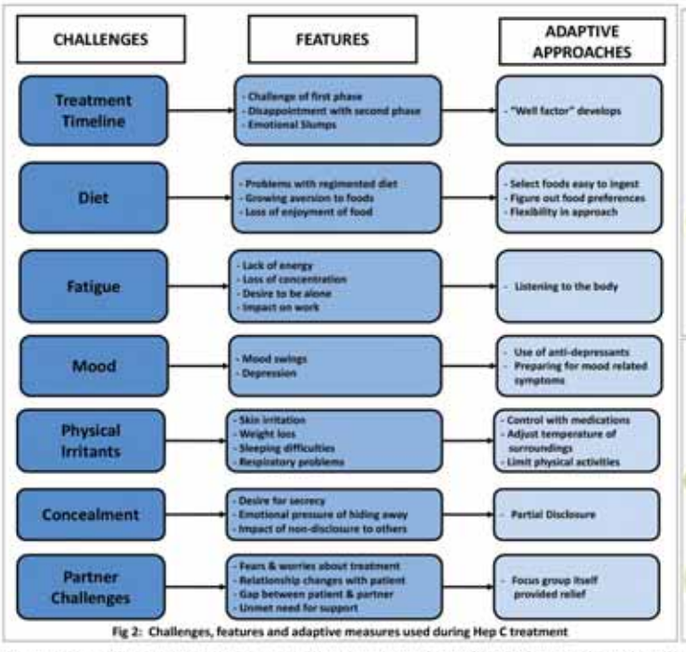

Fig 2: Challenges, features and adaptive measures used during Hep C treatment

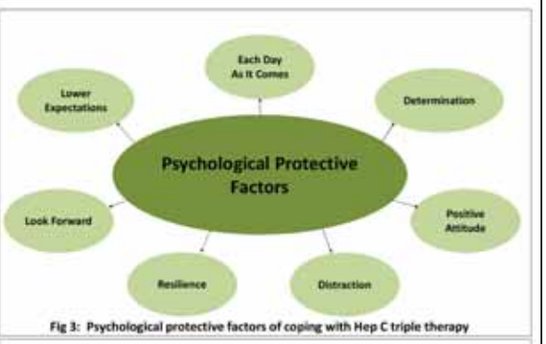

Fig 3: Psychological protective factors of coping with Hep C triple therapy

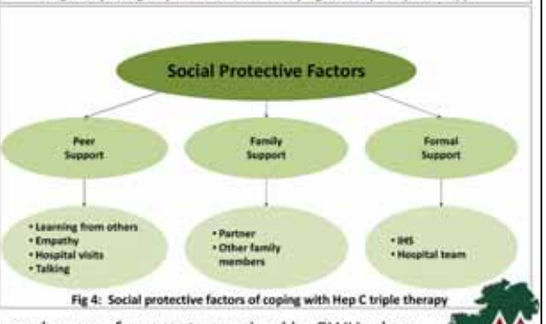

Fig 4: Social protective factors of coping with Hep C triple therapy

Conclusion: The survey and the group interview examined the major challenges and areas of support perceived by PWH when deciding to go on and undergoing treatment. Support from spouse/family member, clinical support from Hepatology clinicians and peer support from other PWH undergoing treatment were identified as having the largest impact during treatment. The members also identified the Irish Haemophilia Society as one of the key providers of additional information and support.

PHOTO GALLERY
WFH CONGRESS MELBOURNE, 2014