haemophilia.ie

Magazine of the Irish Haemophilia Society

Edition: December 2013

Representing people in Ireland with Haemophilia and related bleeding disorders.

The Society at a Glance

Members' Conference Attendance
209

Followers on Facebook
464

Ageing Conference Attendance
55

Better Together Campaign 2013 Votes
2,707

Website Hits (Sep - Nov)
4,122

WHAT'S INSIDE:

* Reports from the EHC Conference and IHS Members, Ageing & PEP Conferences.
* Educational Grant Recipient Announcement. * Interview with Eadaoin O'Shea.

Irish Haemophilia Society

AGM & Annual Conference

March 7th - 9th 2014

Lyrath Estate Hotel, Co. Kilkenny

PRELIMINARY PROGRAMME

Friday March 7th

6.00pm – 7.30pm	Registration

Saturday March 8th

9.30am – 10.00am	Registration
10.00am – 12.30pm	AGM
12.30pm – 1.30pm	Lunch
1.30pm – 3.00pm	Open Forum with the Haemophilia Treatment Centres
3.00pm – 3.30pm	Tea & Coffee Break
3.30pm – 4.30pm	Gene Therapy
4.30pm – 5.30pm	Discussion on Developments in Clinical Trials

Sunday March 9th

10.00am – 11.15am	Sex & Haemophilia
11.15am – 11.45am	Tea & Coffee Break
11.45am – 12.45pm	Twinning Update OR Haemophilia B
1.00pm	Lunch

Contact Details

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Debbie Greene
Administrator

A Note from the Editor

Hi everyone, and welcome to the December edition of haemophilia.ie. and what an edition we have for you. From events to fundraising, to information on the new in-patient unit, this edition is packed with information and interesting articles.

Take a quick look at the preliminary programme for the AGM in March 2014 on page 2. It's hard to believe, but we have already started working on the programme. AGM packs will be going out to everyone in early January.

On page 8, you will find a report from the recent European Haemophilia Consortium conference in Bucharest, on page 20 a report from the Ageing Conference that took place in November, on pages 17 to 19 a report from the Members' Conference in October (and what a great weekend that was – thanks to everyone for the feedback), and on page 22 you will find a report from the Parents Empowering Parents (PEP) Conference that took place in November. What a year it has been for events and activities, we can hardly keep up! On page 16 you will see important details on hospital opening hours over Christmas, and why not tear this page out of the magazine and put it up on your fridge! The opening of the new in-patient unit in St. James's Hospital in October has been very much welcomed by the Irish Haemophilia Society and you will find more information on this on pages 6 and 7. With a total of €18,250 paid out in Educational Grants this year, the recipients of the grants have been announced on page 11.

I can honestly say I have never seen a year go by so quick (stop the world I want to get off). There has been an abundance of activity in the office. To say we have been stretched would be an understatement, but it has been all good. I would like to thank the staff for all of their hard work during the year, all the volunteers who gave up their time during the year at various events and those who wrote articles and helped out in other ways. I would also like to thank all those who contributed to the planned giving campaign, and everyone who did fundraising for the Society. We really do appreciate it very much, so thank you.

I would like to take this opportunity to wish you all a very Happy Christmas and a healthy and prosperous New Year.

Debbie Greene
Administrator

CEO'S Report

Brian O'Mahony CEO

HAEMOPHILIA AND DISCLOSURE

As a genetic and rare disorder, haemophilia impacts the individual and the family. A lack of public education about and awareness of haemophilia can lead to myths, stigma, isolation or discrimination against the person with haemophilia or against carriers. These factors and others, such as not wanting to be perceived as different from peers, may lead the person with haemophilia or their family to not disclose. Myths such as bleeding to death from a minor cut, stigma and isolation associated with HIV and Hepatitis C, and discrimination in employment and insurance all have led in the past to a reluctance to disclose about haemophilia.

At the Irish Haemophilia Society Members' Conference in October, we organised an interactive workshop on issues relating to disclosure and haemophilia. Following a model we used successfully last year, a person with haemophilia, a mother, a father, a partner and a grandparent were each asked prior to the conference to write out their views on disclosure and haemophilia. This was done anonymously. The participants at the conference were then divided into these same groups. The anonymous case was read out to them as a means of starting discussion on these issues.

The group with haemophilia or von Willebrands were mostly middle aged. They had no real issues with disclosing their haemophilia. Their main practical concerns related to disclosing at a job interview (would this damage an individuals chance of getting the job?) or relating to requirements to disclose for insurance. The women with von Willebrands who were present had no disclosure issues. The men felt that the biggest issues relating to disclosure were not related to haemophilia, but to issues relating to HIV and Hepatitis C. The stigma, anger, guilt and fear associated with HIV in the 1980's was recalled. The level of public ignorance and fear at that time were immense. People with haemophilia suffered discrimination and certainly could not easily disclose these issues at that time. This was replicated to a lesser extent in the 1990's with Hepatitis C. The work of the Society in highlighting the issues facing our members due to HIV and Hepatitis C were successful in gaining prioritised medical care and recompense. However, they associated haemophilia in the public mind with these viruses and this in turn left some parents feeling that they could not disclose the fact that their child had haemophilia for fear of his being discriminated against or an assumption made that he had HIV or Hepatitis C. The group also discussed that in earlier times, before treatment was available, there could have been a reluctance to disclose about haemophilia as it may have damaged the marriage prospects of a daughter who may be a carrier. This situation is still prevalent in some developing countries where treatment is rarely available. This group also felt that they were now very comfortable with their haemophilia and had no problems disclosing it (although being mostly male, they also made it clear they did not want to constantly discuss it, and especially not when they had a bleeding episode). In their view, the younger men who have grown up with prophylaxis and have very good joints do not want to discuss or disclose about their haemophilia not out of fear but because they do not want to be seen as in any way different to their peers. It was felt that there could be some dangers in not disclosing to people who need to know in case the individual is hurt or requires urgent treatment.

The Mother's Group discuss their case study in the disclosure workshop at the 2013 Members' Conference.

The mothers believed it was easier to tell your family or close friends. In the school setting, their view was that you should tell those who you want to tell and those who need to know. They also mentioned the stigma related to haemophilia in the past (again related to public linkage with viruses) and the parents being questioned in hospital about bruising on the yet undiagnosed child. We have, in the past,

recommended to Barnardos that in cases of suspected child abuse, a coagulation screen should be part of the tests carried out to rule out an undiagnosed bleeding disorder. They discussed the difficulty of getting used to infusing your child and their thoughts on having more children. They also mentioned that some boys use their haemophilia to get out of participation in activities they do not like. I personally see nothing wrong with this - I use haemophilia to avoid gardening!

The father's group discussed the anonymised case where a father felt that it "was no one else's business that his son has haemophilia". They did not agree with this. They felt it had to be disclosed to the correct people at school or it could be a safety issue. They felt that if the father hid his child's haemophilia, he was sending a negative message to his child about his haemophilia and may affect the child's confidence or self esteem. They felt it was better to discuss the haemophilia with the child's friends earlier as younger children are more accepting. Proper disclosure increased the child's confidence and garnered him more support.

The relatives discussed how IHS events help children with bleeding disorders accept their condition.

The relatives felt that disclosure was now less of an issue with optimum treatment available. Haemophilia was stigmatised in the past (as good treatment was not available and people with haemophilia had more bleeding episodes, more joint damage and missed more school or work). They believe that the openness as evident at these conferences is healing and the children with haemophilia are now more confident.

The partners and spouses stated that their husbands were open with them about their haemophilia when they met and this was important. They did not disclose to their own family until the relationship was serious. The partners of those who were looking for employment in the 1980's spoke about the stigma at that time but felt that openness with employers about haemophilia had worked well for them. In the difficult times over the past 25 years, it was mentioned that the Society was their refuge and the only place where they could be sure of getting support. They pointed out that as partners, they need support from their own families. Finally the issue was discussed as to whom they should discuss their husbands haemophilia with and the tension between their wishes and their husbands wish usually for privacy. It was felt that they should not disclose to other people without the agreement of their partner.

This was a very interesting, informative and interactive workshop. Issues about disclosure and haemophilia are relevant globally. In general, it is the case that it is easier to disclose about haemophilia with confidence when you have good access to treatment and care. Conversely, it is more difficult to disclose where there is poor or no treatment available. The family may be stigmatised. In societies where arranged marriages flourish, the marriage prospects of the daughters may be damaged. In some cultures there is a stigma associated with any genetic disease. Religion plays a role both as a potential coping mechanism in rationalising the suffering of a child ("*It is a cross he has to bear*", "*It is Gods will*" "*Insh Allah*", or in the Hindu religion, may be seen as atonement for sins in a previous incarnation).

Concerns about disclosure are, in my view, often clearly related to the degree of access to treatment and care. With inadequate treatment, the individual will have many bleeding episodes, joint damage and may have limited education and employment opportunities with a relatively poor quality of life. As access to treatment improves, quality of life, education and employment opportunities increase and confidence grows. Disclosure becomes easier. Confidence in disclosing is impacted by knowledge, understanding and perception of your haemophilia in the context of your education, religion and the country and prevailing culture where you live. However, the primary determinant in having confidence to disclose, when required, is the level of access to treatment and care.

Treatment and care have improved enormously in Ireland in the past 25 years and we can now face all eventualities including issues of disclosure about haemophilia with confidence and empowerment.

Brian O'Mahony
Chief Executive

New In-Patient Unit

H & H (Haemophilia & Hepatology) Assessment Unit

Top: A standard single room in the in-patient unit.

Middle: Clinical Nurse Specialist Eadaoin O'Shea shows Declan Noone the day ward.

We are delighted to announce that St. James's Hospital has opened a new in-patient unit called the H&H (Haemophilia & Hepatology) Assessment Unit. This is the provisional name until the official opening takes place. The H&H unit is located in the main hospital, on the 1st floor of the Clinical Research Facility. The unit contains an Assessment Unit with cubicles for patients with haemophilia and other bleeding or thrombotic conditions. The unit contains twelve single rooms, two isolation rooms, and a six bed assessment bay. People with haemophilia will be admitted to one of six beds, and out-patient treatment for bleeding episodes will take place in the assessment bay. The rooms are large single rooms with ensuite facilities, a plasma TV, a family area and wifi internet access. This brand new unit really is state of the art.

All out-patient services currently held in the National Centre for Hereditary Coagulation Disorders (NCHCD) such as out-patient clinics, appointments for blood tests and dental appointments will continue as normal.

Patients with a bleed who need to speak to a nurse urgently should contact the switch on 01 410 3000, and ask for pager 721 between the hours of 08.30 and 17.00 from Monday to Friday.

Right: IHS Administrator Debbie Greene and Declan Noone with Clinical Nurse Specialist Eadaoin O'Shea in the assessment bay.

Hours of Operation
The H&H Assessment unit will be open only from Monday to Friday from 08.30 to 17.00hrs.

Out of Hours Service: (After 17:00hrs or at Weekends and over Bank Holiday weekends)

The nursing staff on the H&H Ward will evaluate patients on arrival and arrange for a prompt medical review. Patients who require emergency assessment should contact the H&H Ward by phone on 01 410 3132 or via the main hospital switchboard on 01 410 3000 asking for the Haematology SHO on-call.

How to get there
Enter the hospital via the main entrance. Walk past the coffee shop and you will see signs for the H&H Ward along Route 3. Just past the Daffodil Centre, you will come to a set of red doors on your left. Go through the red doors and continue to follow the signs for the H&H Ward. You will come to a large foyer. The lifts are on your right hand side. The H&H Ward is on the 1st floor. On exiting the lift, there is an intercom buzzer to the right of the ward entrance to gain access.

Staff from the IHS met with members of the team from NCHCD in November to view the new in-patient unit in St. James's Hospital.

Contact details
H&H assessment unit
Opening Hours 08.30 - 17.00 Monday to Friday

Tel: 01 410 3129

H&H ward
Out of Hours Service (After 17.00hrs, at weekends & over Bank Holiday weekends)

Tel: 01 410 3132

Patients who need emergency assistance or advice should phone H&H Ward prior to attending: alternatively contact St. James's Hospital via the main switchboard (01 410 3000) and ask for the Haematology SHO on call.

NCHCD APPOINTMENT QUERIES

Tel: 01 416 2141

Patients who need to make or change an appointment should phone the NCHCD.

Further updates in relation to the new unit will be available on our website www.haemophilia.ie in the coming weeks and months.

Debbie Greene
Administrator

EHC Report

The 26th annual European Haemophilia Consortium (EHC) conference was held in the city of Bucharest in Romania from the 4th to 6th October 2013. The first day of the conference introduced four National Member Organisation (NMO) workshops, while for the remainder of the weekend there was a variety of sessions including talks on gene therapy, treatment and prevention of inhibitors and discussions on comprehensive care in both developing and developed countries in Europe.

Professor Flora Peyvandi speaking on prophylactic treatment. Other speakers on this issue were Daniel Arnberg from Sweden and IHS Chairperson Traci Marshall Dowling.

The first of the workshops took place on Friday morning and was led by Professor Flora Peyvandi of the University of Milan, Italy. This workshop was attended by over 60 NMO's and focused on treatment compliance strategies. Initially, Professor Peyvandi gave an overview talk on prophylactic treatment regimes and then Daniel Arnberg from the Swedish Haemophilia Society talked about his own experiences of compliance to his treatment plans. Daniel's talk was very interesting and brought discussion on many issues that patient's from developed countries, with great treatment plans, encounter. This then set the scene for the 'hands on' side of the workshop (the fun part!), in which Traci Marshall-Dowling from the IHS got people from the eastern and western European States to share the problems they face with adherence to treatment regimes. This workshop was executed perfectly and was a great start to the conference. The workshops were all exceptionally well received from the attendee's I met over the weekend.

The programme for the 2013 EHC Conference featured a mixture of lectures and workshops.

On Friday afternoon, there was an update on comprehensive care in developing and developed countries. Speaking from the perspective of a haematologist from an established country, Professor Mike Makris (Sheffield, UK) spoke about meeting the ranging needs of people with haemophilia and their families, while Professor Margit Serban of Romania delivered a stark illustration of how poor treatment is for the patients in Romania, where factor consumption is significantly lower than the European average. Anne Duffy of the IHS also gave a talk on how psychosocial support is an important part of comprehensive care for people with haemophilia. Anne talked in great detail about how psychosocial issues can be experienced and addressed by bringing patients and their families together in specific groups.

NMO based psychosocial support creates a sense of community where people with haemophilia can openly discuss any challenges they may be faced with. This allows peer support for adults, siblings and adolescents with haemophilia, along with support groups for parents of children with haemophilia. NMO based psychosocial support is an ideal, practical means of supporting any issues people with haemophilia are faced with.

Another point Anne discussed is the very important issue of ageing. The growing ageing population is a global concern that brings with it many economical and medical problems. People with haemophilia are now dealing with many age related illnesses and need support in areas such as geriatric care, dealing with falls, cardiology and ophthalmology.

A session on aspect's of comprehensive care of haemophilia included a talk by Professor Mike Makris on European wide safety surveillance, which monitors any adverse events from recombinant and plasma derived products since 2008, including inhibitors, transmission of infections, allergic reactions, malignancies and death, in all severities of haemophilia A and B, all types of vWD and several other coagulation factor deficiencies (Over 32,000 patients across 75 hemophilia centers were monitored in the study). From some of the preliminary results of this study, 10% of the adverse events were allergic reactions and over 20% were inhibitors. Data analysis revealed a higher incidence of inhibitors in patients with factor VIII compared with factor IX deficiency and involved 5/8 factor VIII and 3/5 factor IX recombinant factor concentrates.

Delegates at the 2013 EHC Conference in Romania.

Dr. Paul Giangrande, Consultant Haematologist from Oxford discussed the EDQM (European Directorate for the Quality of Medicines and Healthcare) recommendations for haemophilia care in Europe. One of the principle recommendations was for each country to establish a formal body to include relevant clinicians, national haemophilia patient organisations and health ministries. The EDQM recommendations also concluded that the minimum factor VIII level in a European country should be 3 international units per capita, thresholds lower than this are insufficient to guarantee access to prophylaxis for children. Paul discussed data that was compiled from a European wide study of 1400 patients in 21 countries and also detailed a recent publication from Brian O'Mahony of the IHS. This study surveyed 35 countries in Europe, highlighting the major differences in the availability of treatment and care of haemophilia across Europe.

This session also included an excellent talk by Dr. Carlos Rodriguez-Merchan from La Paz University Hospital, Madrid. Orthopeadic surgery is still a present task in haemophilia care and Dr. Rodriguez-Merchan discussed different means of improving quality of life of people with haemophilia including intra-articular injections of radioactive materials (known as radiosynovectomy) for the treatment of chronic synovitis. Up to 3 injections with 6 month intervals showed a median bleeding frequency decline of 70%. These procedures are however not recommended in children.

A session on Saturday entitled "Access to new haemophilia treatments - opportunites, challenges and barriers" included some exciting talks on longer acting factor products and gene therapy.

Dr. Giangrande discussed longer acting factors and started his talk with the statement "improving patient quality of life should drive treatment decisions, not economics". Dr. Giangrande spoke in detail about glycopegylated recombinant factor IX which is a longer acting recombinant factor IX in development that attached sugars to recombinant factor IX so it will be protected from immune responses and other clearance mechanisms. This prolongs the half-life of recombinant factor IX with the aim of reducing prophylaxis regimes to once a week. Results from this study showed a 5 fold increase in half life (when compared to current factor IX recombinant), and none of the patients in the trial

had inhibitors.

Dr. Giangrande also discussed some new data from several longer acting factor VIII clinical trials which show promising results with increased half life of factor VIII. These clinical trials for longer acting products are a step in the right direction for incrementally increasing the baseline levels of factor VIII / factor IX.

Some of the staff and volunteers from the Romanian Haemophilia Society who hosted the 2013 EHC Conference.

Professor Amit Nathwani of the Department of Haematological Research at University College London (UCL) delivered a talk with unimaginable scientific results from the factor IX gene therapy clinical trial. Gene therapy offers a potenial cure for haemophlia. Continuous endogenous expression of factor IX protein can be achieved following one single intravenous injection. An increase in plasma factor IX levels of above 1% are sufficient to improve the bleeding phenotype from severe to moderate; the results from this study show that this is now a serious possibility.

This method involves using a non-pathogenic virus, which is 'gutted' to reduce the risk of an immune response to the virus, to carry the genetic material that allows the liver to produce the factor IX protein. Ten patients have enrolled in the study to date and were followed for 1 - 4 years. Evidence of sustained factor IX expression at 1-6% in all 10 patients was observed.

The majority of these patients have stopped prophylaxis, with significant improvements to their quality of life and 4 of these patients have reported no spontaneous bleeds since treatment. These preliminary results are extremely encouraging and support further investigational studies. There were many challenges in the early stages of this trial and the timeline from the initial development to the first patient dosing was approximately 6 years. This simply means we're not there yet, but we're getting there. It takes a while so hang in there! Professor Nathwani also mentioned that there is extensive work being carried out for factor VIII gene therapy and hopes to move to clinical trials in the next 2 years.

Saturday evening became a historical day for people with haemophilia in Romania. Romania's Minister of Health, Mr. Eugen Nicolaescu, opened the Conference with a welcome speech and the onsite signature of the first tripartite agreement between the Ministry of Health, the Romanian Haemophilia Association and the EHC, Romania's first National Haemophilia Committee. Romania's State Secretary and President of the National Insurance Fund were also in prominent attendance at the Opening Ceremony.

The EHC Steering Committee as elected at the 2013 EHC Conference.

Sunday morning concluded the 26th annual EHC congress with the business meeting for all NMO's. The steering committee, which is responsible for the day to day running of the EHC was elected following speeches from all the candiates. Our own chair of the I.H.S, Traci Marshall-Dowling was elected and will hold a position on the steering committee for 3 years. The General Assembly also elected the Serbian Hemophilia Society to host the EHC Conference in 2015 in Belgrade.

Sarah Gilgunn
IHS Board Member

Educational Grants

Thanks to everyone who sent in applications for the educational grants. This year we received a total of 21 applications which is slightly up from last year. Some applications were received online, and some sent in applications in the post. We had some exceptionally well written applications, and I am now pleased to announce the recipients of the three main awards as follows:

Maureen & Jack Downey Educational Grant 2012/2013 - €4,000

Recipient: Eoin Moriarty from Kerry

(This grant is made available to a person with haemophilia, or related bleeding disorder, who has been accepted on a post second level educational course.)

Father Paddy McGrath Educational Grant 2012/2013 - €2,000

Recipient: Sean Hanney from Dublin

(This is a grant that the Society has named after our dear friend Father Paddy McGrath, and is given to the person who came second in Maureen & Jack Downey Educational Grant. This grant is available to a person with haemophilia, or related bleeding disorder, who has been accepted on a post second level educational course.)

Margaret King Educational Scholarship 2012/2013 - €2,000

Recipient: Shauna Keniry from Cork

(This grant is for an immediate family member of a person with haemophilia or related bleeding disorder, who has been accepted on a post second level educational course.)

Many congratulations to you all!

This year we updated the application forms, and explained to everyone applying how each application is scored, for example the quality of the application is very important, as is sufficient information given. This year we saw a big improvement in the quality of applications which is encouraging.

It is so worthwhile applying for these grants, and don't forget even if you did receive a grant this year, you can still apply next year.

Debbie Greene
Administrator

Fundraising - A Big Thank You

I cannot believe this year is nearly over and looking back we are delighted to say that 2013 was a great year for fundraising for the I.H.S. We are lucky to have had some amazing people organising and taking part in fundraisers in support of the Society. So, if you organised an event, took part or gave a contribution, we want to say a big thank you, your support means a lot to us.

The lovely ladies who took part in the 2013 Flora Women's Mini Marathon, just one of many fundraisers for the IHS which took place in 2013.

As we are nearing the end of 2013, we need to look forward to 2014 and that is where you come in, the I.H.S. needs you. We all like the thought of doing something for a good cause, we know it will make us feel good to do a good deed or just that we want to give something back. However, we know that for some people fundraising can seem like a daunting task. We are here to let you know that it doesn't have to be. Whether your fundraiser is big or small we are here to help you every step of the way. The Society will provide posters, tickets, t-shirts, buckets for collections and we will apply for any Garda permits required etc. If you have a fundraiser in mind but don't know where to start just give me a call and I will be happy to talk it through with you. You can email me, nina@haemophilia.ie or call me on 01 657 9900 and I will work with you from start to finish.

Here are a few fundraising suggestions that might help you take that first step….

Bucket Collections
Church gates, sport events, local shops or supermarkets. Just get a few friends to give up a couple of hours of their time for a good cause.

Bag Packing
Bag packing is a great source of fundraising and most supermarkets are happy to do their bit for charity.

Non Uniform Day/Casual Dress Day
Kids love a non-uniform day and schools are happy to teach kids about fundraising or think about organising a casual dress day in your workplace.

Fun Runs/Cycles/Marathons
The women's mini marathon is a great annual fundraising event, you don't have to run, you can walk your way to the finish line. There are always lots of fun runs etc. taking place around the country, for all levels of fitness, so there is something for everyone, why not make it a family affair.

Your Society Needs You!

Fun Run
Used Book Sale
Non Uniform Day
Donations in lieu of Gifts
Raffle
Auction
Indoor Games Evening
Sky Dive
Evening of Song & Craic
Race Night
Sponsored walk, cycle, run, ANYTHING!

If you would like to know more about the fundraisers that took place this year, go to the I.H.S. website, and click on 'Get Involved', photos can also been seen in the website gallery.

To start the ball rolling for 2014, we here in the office are already thinking about a Gala Dinner fundraiser for next year, so watch this space for further details. If you think you can help us out we would be delighted to hear from you with any suggestions or contacts for this event.

Nina Storey
Irish Haemophilia Society

Calendar of Events

MARCH

Date: 7th - 9th March

Event: AGM & Conference

Venue: Lyrath Estate Hotel, Co. Kilkenny

See page 2 for preliminary programme

APRIL

Date: 11th - 13th April

Event: Hep C / HCV Meeting

Venue: TBC

JUNE

Date: 13th - 15th June

Event: Parents Conference

Venue: Castleknock Hotel, Dublin

AUGUST

Date: 15th -17th August

Event: Parents Empowering Parents Conference

Venue: TBC

SEPTEMBER

Date: 27th & 28th September

Event: Carriers Conference

Venue: TBC

OCTOBER

Date: 10th -12th October

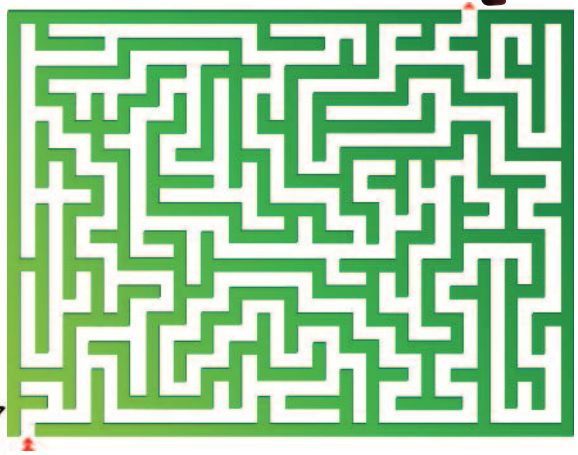
Event: Members' Conference

Venue: Carlton Shearwater Hotel, Ballinasloe

Cubs Club

Happy Christmas to all our Cubs Club members!

See you in 2014!



Work through the maze and put the star on the top of the tree!

Hi Everyone,

My name is Brian, I have severe haemophilia. I have a port under my skin and that's how I get my factor. Soon, my parents might give me factor through my veins – what does this mean?

Brian is getting bigger and stronger and that means so are his veins. It might be time to start trying to get his factor through his veins. It might seem scary but once your parents and you have tried it you will see that it is not so bad. There are lots of things you can do to help too. Why don't you help your parents find a big juicy vein in your arm?

What else could you do to help??

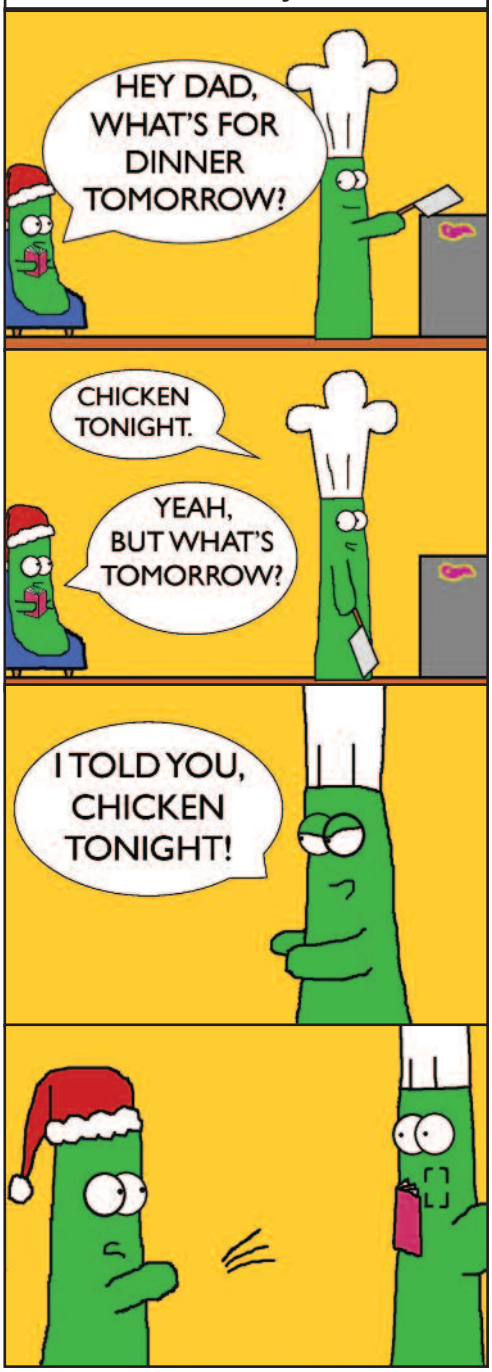
_____

_____

Ask your parents to check out www.haemophilia.ie for more ideas!

The Slobs

by Conor Birkett

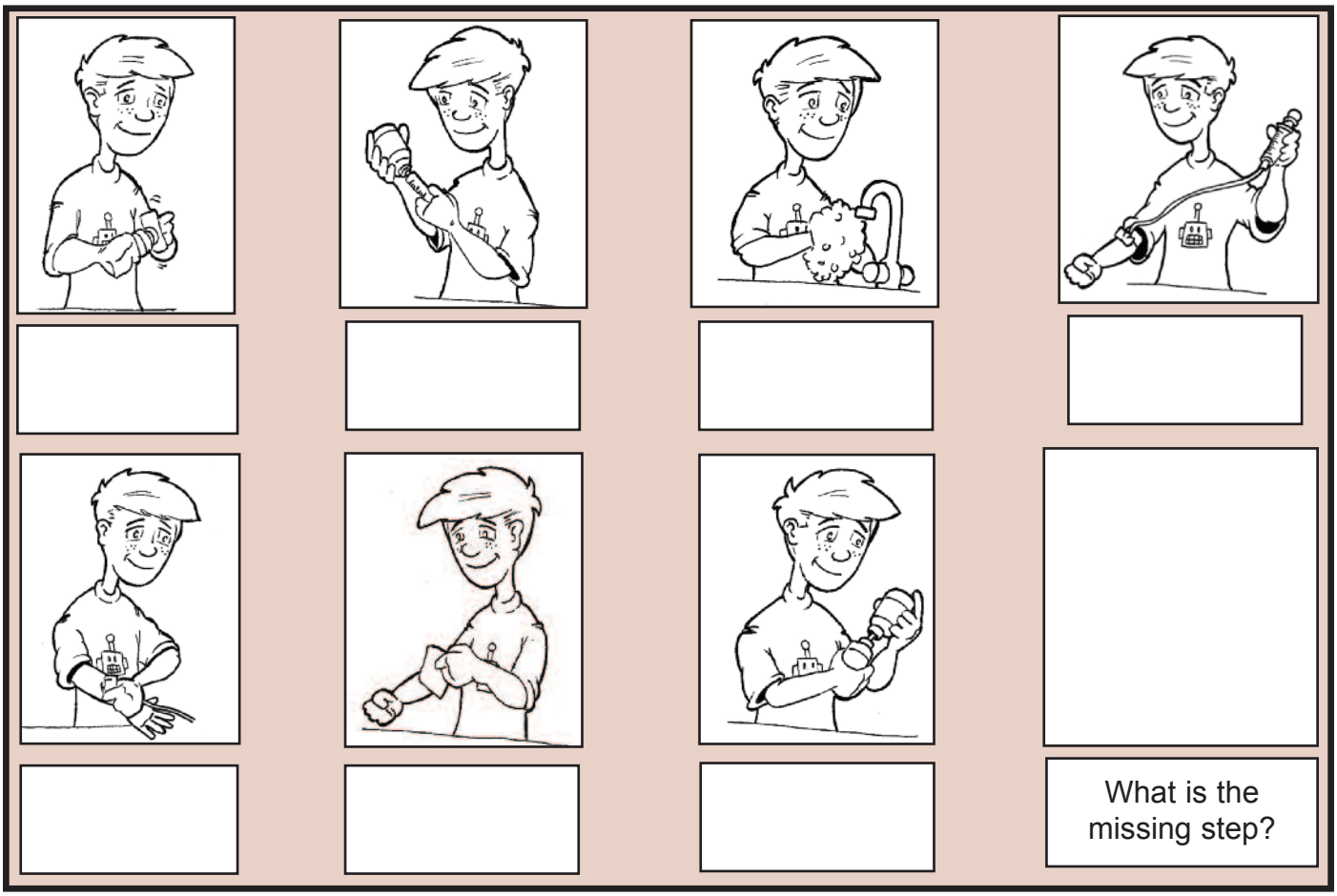


Kidlink Group

Welcome to the Kidlink Group
December Edition,

We hope you are all looking forward to your Christmas Holidays!

For most of you boys with haemophilia, you or your parents will use your veins or your port to take your factor. Do you help your parents get ready to take your factor?



We've helped Max with the steps for self infusion before, but they have become jumbled up! Can you remember what Max is doing in the pictures? Write the actions in the boxes below the pictures and number them in the order they happen.

There is also one very important step missing – can you figure out which one it is?

Log on to www.haemophilia.ie for the answers!

Wishing all of our Kidlink Group a very Merry Christmas!

Christmas Opening Hours

The Irish Haemophilia Society

The Irish Haemophilia Society office will close for Christmas on Monday December 23rd will re-open on Thursday January 2nd.

In case of an emergency, please contact Anne Duffy on 087 232 0255.

A special thank you to everyone who volunteered at various events and activities during 2013, to all those who helped the Society by fundraising during the year and those who sent in donations. We value your support.

Wishing you all a very Merry Christmas and a Peaceful New Year.

From the board and the staff of the Irish Haemophilia Society.

NCHCD

In case of an emergency patients should contact the H & H ward on 01 410 3132. Patients must contact the ward PRIOR to attending.

DECEMBER	
Monday 23rd	8.30 - 5.00
Tuesday 24th	CLOSED
Wednesday 25th	CLOSED
Thursday 26th	CLOSED
Friday 27th	8.30 - 5.00
Saturday 28th	CLOSED
Sunday 29th	CLOSED
Monday 30th	8.30 - 5.00
Tuesday 31st	8.30 - 5.00
JANUARY	
Wednesday 1st	CLOSED
Thursday 2nd	8.30 - 5.00

CORK UNIVERSITY HOSPITAL

Outside of these opening hours, phone CUH on 021 454 6400 and ask for the haematology registrar on call.

DECEMBER	
Monday 23rd	8.30 - 5.00
Tuesday 24th	8.30 - 1.00
Wednesday 25th	CLOSED
Thursday 26th	CLOSED
Friday 27th	8.30 - 1.00
Saturday 28th	CLOSED
Sunday 29th	CLOSED
Monday 30th	8.30 - 1.00
Tuesday 31st	8.30 - 1.00
JANUARY	
Wednesday 1st	CLOSED
Thursday 2nd	8.30 - 5.00

OUR LADY'S CHILDREN'S HOSPITAL, CRUMLIN

DECEMBER	
Monday 23rd	8.00 - 5.00
Tuesday 24th	Reduced activity
Wednesday 25th	CLOSED
Thursday 26th	CLOSED
Friday 27th	8.00 - 5.00
Saturday 28th	CLOSED
Sunday 29th	CLOSED
Monday 30th	8.00 - 5.00
Tuesday 31st	8.00 - 5.00

JANUARY	
Wednesday 1st	CLOSED
Thursday 2nd	8.00 - 5.00

In case of an emergency contact the hospital on 01 419 6100 and ask for the haematology registrar on call.

Members' Conference Report

The 2013 Member's Conference this year took place on the weekend of October 11th - 13th in the Bloomfield House Hotel in Mullingar, and was one of the best attended yet. With all ages catered for, there was no excuse not to participate and gain something from the weekend. In order to encourage anyone attending the weekend to participate in at least one workshop/talk, we were requested to sign in to each workshop and given a raffle ticket when leaving. Although this gave me frightening flashbacks to my working days (although the boss never gave us raffle tickets at 5 o'clock!) I thought it was a good idea, and it seemed to work as every talk was very well attended.

As usual, the Friday evening arrival and registration process is a great way to greet friends we haven't met since our last conference and catch up on what we've done or where we've been in the meantime. Some have become grandparents (Ann and I) some have moved house (Margaret and Jim) and obviously new school years have commenced for all our young members. Also, this is when our Youth Group head offsite to enjoy their own programme elsewhere until Sunday morning.

The sessions I attended on Saturday started with a talk by Dr Michelle Lavin who is commencing pharmacokinetic trials in the National Centre for Hereditary Coagulation Disorders (NCHCD) to ascertain factor VIII half life in as many 18 to 65 year old people with haemophilia as are willing to participate. While factor VIII dosage has been prescribed for many years based on age and weight this presumes an average half life, but for at least 10% of people with haemophilia this is an incorrect dose leading to too much factor VIII for some, and therefore expensive wastage, or else not enough, leading to breakthrough bleeding and permanently damaged joints. Dr Lavin explained the process to ascertaining individual half life and people with haemophilia have already been written to by the NCHCD. This is a crucial development in haemophilia treatment and the data gathered will be invaluable in the future as longer acting products become available.

Above: The 2013 Members Conference was the largest to date with high attendance at all sessions.

Below: The members were divided into groups for the workshop on disclosure.

For the first time since we began using debates as a format to explore subjects, a doctor from St. James's Hospital participated. Dr Kevin Ryan from the NCHCD spoke for the motion that 'Patients should adhere to treatment plans' or words to that effect. Declan Noone spoke against this proposal (probably selected because he seldom does what he's told anyway!) Dr. Ryan had a very entertaining presentation prepared with amusing slides and anecdotes but making the serious point that in many illnesses non compliance was a major cause of worsening conditions and long term consequences. He quoted the World Health Organisation (WHO) as stating that correct use of existing drugs would achieve far better results than waiting for new drugs, in many cases. Declan argued that, in the case of haemophilia prophylaxis in particular, people with haemophilia should not have a set down regimen but tailor their treatment to suit their weekly activities eg; if you are playing football on Sunday afternoon then taking a shot on Friday morning has very little benefit. In the counter arguing phase of the debate it was agreed by Declan and Kevin that a good treatment plan required input from the treater and the patient in order to achieve a good outcome. The debate format is an entertaining way of exploring issues of concern to us so hopefully it will continue.

After lunch we had a workshop regarding 'Disclosure' of haemophilia. We separated into groups such as partners, people with haemophilia and von Willebrands Disease, mothers, fathers, grandparents and relatives. Each group was given a written scenario regarding disclosure, discussed it

themselves for 30 minutes or so and then one member of the group reported on their discussion. It was interesting to hear varied perspectives and concerns regarding disclosure from the groups. The concerns for people with haemophilia in pre home treatment times centered around obtaining employment when there was general ignorance about haemophilia and the impact it could have in the workplace. This also applied to relationships: when should you tell a girlfriend about haemophilia? Disclosure was a worry for carriers also when in a serious relationship that could lead to children. In the 1980's when HIV was associated with haemophilia, disclosure took on another dimension; how would work colleagues, friends or extended family react whether the person with haemophilia had HIV or not? Disclosure was a concern for fathers also, especially since haemophilia hadn't previously been in their family. Wives and partners were under pressure to conform with their husbands/partners wishes regarding disclosure sometimes leaving them without their own support network or the burden of keeping a secret. Mothers also had the problem of informing playgroup leaders and schools but without alarming them, and their child being negatively treated. However all agreed that the current state of haemophilia care went a long way to alleviating what was previously a much bigger problem. This workshop was very informative.

The after dinner 'Family Fortunes' quiz was very entertaining and well hosted by Nuala Mc Auley, but who exactly did the staff survey for some of the answers? Apparently Jazz is not among the top 5 music genres? It is among the oldies that were at my table! Why is pestachio not among the top 5 icecream flavours? Well, Kieran McHugh would beg to differ! I had a grand evening of nattering and joke telling afterwards with a great bunch of people.

Right The entertainment on Saturday night was a Family Fortunes quiz, pictured are the winning team, the Griffins!

Far Right: On Sunday morning all the groups came together for a treasure hunt.

On Sunday morning, instead of a talk of some sort, a treasure hunt was organised by the staff which resulted in dozens of people, young and old, charging about the hotel and grounds looking for a written clue which took them to the next clue and so on. People who I would previously have regarded as quite sedate and friendly quite suddenly turned into marauding, charging, highly competitive beasts! Members who I have never seen even walking quickly, were now running through the hotel lounge pulling open drawers, and when finding their own teams envelope, considering taking the other teams as well so as to stop then in their tracks! Talk about dirty tricks, these were the parents not the children! Great craic though, this should be repeated.

The 'Open Forum' session before lunch on Sunday, was the best attended I have seen. We started with a number of subjects raised for consideration in the future. A major concern for parents of young children was the Saturday dinner and entertainment; how can we change and improve this especially since the volunteers are off duty after a long day? An earlier meal for children was one suggestion. Another topic was the new ward in St. James's Hospital with Brian O'Mahony giving us an update. Our website has full details.

This final session finished with an acknowledgement for the 24 or so volunteers without whom weekends like this would not be possible. The office staff also deserve fulsome praise for a job very well done!

Michael Davenport

Below: The youth group attended Lilliput Adventure Centre in Mullingar for their Members' Conference programme. Their activities over the weekend included canoeing, team building and bog diving. For a review of the youth group adventure weekend log on to ***www.haemophilia.ie***

Below: The creche was full to capacity, not to mention full of fun and games!

Above left: The Kidlink Group hard at work in Clown School.

Above right: The Kidlink kids and leaders take a break from school in the playground.

Left: The Cubs Club busy making masterpieces during the arts & crafts session of their programme.

Left: Children and adults alike had fun taking part in the treasure hunt on Sunday morning.

Ageing Conference Report

Ageing with a bleeding disorder has become a focus in the international community over the last 2-3 years as we are now seeing, in developed countries, the first generations of people with severe bleeding disorders whose life expectancy is the same as the general population. This does mean that they are also starting to face the medical issues that the general population have been dealing with for years. However, there are a number of additional considerations that people with bleeding disorders need to account for when dealing with issues. In 2013, this has been a key focus for the Irish Haemophilia Society, firstly with the publication of the "Ageing and Haemophilia" booklet and secondly with the first ever "Ageing Conference".

The conference took place in the Sheraton Hotel, Athlone on the 15th- 17th of November. There were a number of topics covered over the three days such as vein care, pain management, cardiac issues, optimising management of bleeding disorders, coping skills, independent living and occupational therapy.

On Friday evening, Eadaoin O'Shea, Clinical Nurse Specialist, discussed the importance of vein care especially as you get older as the veins become weaker and can be more difficult to locate and access. She pointed out that when accessing veins the environment is calm without interruptions. When giving the injection it is important to wash hands well and clean the skin with alcohol wipes before each injection. It is also important to allow the alcohol that is wiped on the skin to dry as it is, only then, has it sterilised the area. The most common issues that arose when discussing difficulty in accessing veins were: becoming thinner as they get older and as a result move more and have a harder wall around them, restricted elbow movement, pain, loss of confidence and obesity. There are a number of ways that improve the odds of accessing veins such as warming the area with a hot pad, squeezing the hand tightly once the tourniquet has been put on and being calm. When you cannot access the vein and you need to go to your GP or the hospital then make sure you bring the packaging with you or they will have to discard the product. Another tip that was very useful was to try and develop multiple sites to inject, which has the double advantage of having an option when you can't access one vein and rotation between multiple sites, allowing your veins to rest.

On Saturday, Dr. Ross Murphy, Consultant Cardiologist at St. James's Hospital spoke about cardiac issues. Cardiovascular disease is the biggest killer in the general population compared to any other condition. The main effects that cause cardiovascular disease are diet, exercise, smoking and high cholesterol. Dr. Murphy recommended a healthy diet, stopping smoking and 20 minutes of moderate exercise every day to reduce the risk of developing cardiovascular disease. He noted that as a doctor there is little he or any other doctor can do in relation to these risk factors and most of it comes down to the individual themselves. When talking about high cholesterol, Dr. Murphy said that although there is some connection with diet, cholesterol could be high in the thinnest of people and does need monitoring. If there is a family history of very high cholesterol, doctors may put patients on blood pressure medication (statins) to prevent problems from developing. If a blockage to the blood flow does become an issue, with a bleeding disorder, older style bare metal stents are preferable to newer coated ones as there is only a need for a few weeks of anti -coagulants with the older ones although by-pass surgery may be the best option as it does not need any anti-coagulants. It was noted that, the importance of getting fully covered for your bleeding disorder and contacting the centre before is important to plan for cardiovascular interventions.

Dr. Barry White spoke at the Ageing Conference on Pain Management & Changing Bleeding Patterns.

Dr. Madeleine Ni Dhalaigh, a GP talked about the importance of getting regular check-ups and what you need to cover when you turn 40 and every 3-5 years after this, if there are no changes. This was referred to as getting your "NCT" done. This allows the GP to give advice on changing your current lifestyle, assessment of early detection and treatment of diseases that develop as we get older. She discussed practical tips such as writing things down before you go and see your GP, mentioning any new symptoms and discussing family history. She highlighted the need for honesty regarding your lifestyle as it will only benefit you in the long run as well as being ready to change some habits. There was a whistle stop tour through the conditions that they should monitor for at your NCT such as heart disease, hypertension (blood pressure), diabetes, arthritis, osteoporosis, coeliac disease, depression, common cancers, men's health and women's health. She finished the

discussion talking about how people wait too long before mentioning problems and diagnosis is delayed as a result. So tell your doctor, don't suffer in silence!

On Saturday afternoon, Dr. Alison Dougall, Dentist at the NCHCD, gave an excellent presentation on the changing landscape of the mouth as we get older. We need 10 pairs of teeth to be able to chew. As we have 16 pairs this does leave some room for tooth loss. At any age it is important to maintain good dental hygiene to keep your own teeth for as long as possible. Bacteria in the mouth which enters the blood stream under decayed teeth has also been connected with bacteria in the lungs, heart issues and most importantly bacteria around metal implants, which a lot of older people with haemophilia and related bleeding disorders are likely to have. If teeth do have to be removed there is a number of options that are available that are suitable for people with bleeding disorders. Dr. Dougall also pointed out that any dentist should be able to treat people with haemophilia for routine work provided they have the right information.

55 delegates attended the first IHS Ageing Conference.

There was also a discussion on the optimisation of ageing and haemophilia with, Dr. Barry White, Dr. Madeleine Ni Dhalaigh, Dr. Alison Dougall and Brian O'Mahony. A study in the UK, showed that a person with 3 or more conditions can have up to 17 people monitoring their healthcare. When there are a number of people consulting on an individual's health, there should be a central contact that is over seeing this. There was a discussion on whether this should be the GP or the Haemophilia Centre. The main concerns were related to interactions between drugs, conflicting advice between consultants on medications and who makes the decisions on the balance of needing a drug in one situation where it is contra-indicated in another. One of the concerns was around pain management and the use of stronger pain medication versus how often it may need to be taken. There were also questions around the COX II inhibitors (Arcoxia, Celebrex, etc.) and their contra-indications relating to cardiovascular disease and the fact it may make blockages unstable. Whilst there are still no definite answers the conversation was very balanced and demonstrated the need for good communication between all professionals.

On Sunday, Social Workers Olwen Halvey and Anna Marie Cunningham, NCHCD discussed independent living. They covered topics such as retirement planning, making a will, enduring power of attorney, financial planning and becoming a more active member of your community. For anyone with a family making a will is extremely important. Anna Marie also mentioned that in the event of something happening, your family should know where your details are. She referred to a useful document on the citizens information website, www.citizensinformation.ie known as "Where my Possessions are Kept" which can help family members deal with a number of issues after death. Having an enduring power of attorney is recommended as it allows people you have designated to make decisions on your care in the event you are mentally incapacitated by any means. This makes it much easier for family in the event of something happening and needing to make decisions. Overall the key messages were as you get older you should be able to control and direct your own life, exercising the greatest degree of choice about where you live, with whom you live and how you live with self respect and dignity.

Michele McKevitt, Occupational Therapist, discussed adapting your environment as we get older. There are numerous assistive devices and aids that people can get to improve the usability of their home in every room from the kitchen, to the bedroom to the bathroom. These may be bathroom rails, stair lifts, shower chairs, long handled shoe horns etc. Some of these devices are large, but there are some small devices which can make an enormous difference in day to day life of people with dexterity problems. Lastly, I spoke about setting things up before this is the case. A lot of people renovate or move house in their 40's but these can be done anytime a renovation is happening and this is the time to make small differences when you are renovating that will last for a long time and will help you stay in your home for as long as possible.

Overall, the conference was a great success with a lot of questions, discussions and excellent presentations. There is obviously a need for people to start thinking about these topics and having the conversations as soon as possible, is helpful, even though at times they can be difficult. If there was a theme for the weekend it would be start early when dealing with all aspects of your life as you get older and it will make the later years a lot more enjoyable.

Declan Noone
Irish Haemophilia Society

Parents Empowering Parents Conference Review

The Clarion Hotel, Liffey Valley was the venue for the Parents Empowering Parents (PEP) programme on Friday 8th to Sunday 10th November.

Nine parents took part in the programme. The facilitators were all 'home-grown' with two nurses and two social workers, Eibhlin McLaughlin and Carol Carr from Our Lady's Children's Hospital, Crumlin and Ann O'Sullivan and Olwen Halvey from St James's Hospital; Ellie Heffernan, Deirdre McQuail, Deirdre Ryan and Barbara Wynne were the four parent facilitators, with Fiona Brennan and Anne Duffy from the IHS.

PEP was designed in the United States in 1996 by Danna Merritt, a Social Worker, to help parents become aware of how their thoughts and feelings can influence how they parent. This awareness gives parents choices about their parenting skills. The programme is made up of 10 sessions starting with the Basics of Bleeding Disorders, Child Development, Compassionate Discipline, Behaviour Management, Understanding your World View, How Thoughts and Feelings affect Parenting, Building Self-Esteem, Understanding Communication, Communication Skills and Conflict Management and finally Parenting Styles.

The facilitators for the 2013 Parents Empowering Parents Conference included social workers and nurses from OLCHC and NCHCD, IHS staff and parents of children with bleeding disorders.

The purpose of PEP is to develop a "can-do" approach to living with bleeding disorders, to provide an understanding of how to modify a child's behaviour and improve a child's self-esteem, to give parents an opportunity to deal with their feelings about having a child with a bleeding disorder, to form parent support networks, to give parents tools for improving family communication and relationships, and to facilitate learning through discussion and practice exercises.

Parents' reasons for attending PEP included: wanting to be a better parent and learn to be more understanding of their children, to gain new skills, evaluate how they interact with their children and reassurance of their parenting skills. The expectations of PEP were varied from empowering to emotional. The conference met and indeed exceeded everyone's expectations as the evaluations that came back mentioned the weekend was enjoyable, intense, emotional and beneficial.

The main results were as follows: parents got a good understanding of bleeding disorders and their genetics, while clearing up any misconceptions, an understanding of normal child development, the importance of the 4:1 rule where four positive comments are needed to balance one negative comment made to a child, the importance of the three Family Golden Rules – be kind to yourself, others and your surroundings, and being consistent as a parent. Parents learned how to tell the difference between a thought and a feeling, and how to work with both their own and their child's feelings, the importance of self-esteem for both parent and child, communication is about listening and speaking and owning one's own feelings. The concept of having family meetings, the importance of working out 'who's problem is it?' and the use of making 'I' statements; The five different parenting styles and raising the parent's awareness of which style they use.

When asked if these parents would recommend the programme to other parents they said: "I would, because I would like them to experience and benefit from it like I have…", "Yes, if even to get one change for the better it is worth it and… to meet other parents is always fantastic.", "Yes definitely, very worthwhile. If we can improve in any small way, we will have happier children."

Well readers, I could not say anything more or better than what the parents said. It was a weekend with a difference, it was challenging but was very worthwhile!

Anne Duffy
Nurse Counsellor

Behind the Scenes - Eadaoin O'Shea

2013 saw the Irish Haemophilia Society celebrate their 45th anniversary, but it also marked another big occasion for haemophilia care in Ireland. The first Ageing Conference was held in Athlone. It was a great success and we hope to hold further Ageing Conferences in the future. At the conference, Clinical Nurse Specialist Eadaoin O'Shea was presented with a piece of Waterford Crystal to mark her 25th year working in the National Centre for Hereditary Coagulation Disorders, and with haemophilia patients in Ireland. In addition to this presentation haemophilia.ie sat down with Eadaoin to talk about her career.

Eadaoin with IHS CEO Brian O'Mahony and former IHS administrator Margaret Dunne on a twinning visit to Bosnia & Herzegovnia in 1995

Eadaoin O'Shea studied nursing in Drogheda, which was the only international training available in Ireland at the time. Her reason for choosing nursing may not be what you would expect;
"I actually chose nursing because I wanted to travel. I had been abroad for a year and when I came back I was trying to decide whether I would go to college. My other big interest is music so I was going to maybe go to college and do a degree in music or do nursing and I felt nursing would give me an opportunity to travel. I enjoyed my training and I must say I have never regretted going into nursing."

Following her training Eadaoin worked in Baggot Street Hospital where she worked in various departments including ICU and coronary. During her time at the hospital Eadaoin became a ward sister, something which she is still very proud of;
"The first big accomplishment was becoming a ward sister at the tender age then of 28. Most of the ward sisters in Baggot Street Hospital were at least 40 so I felt very proud of that."

When plans to close Baggot Street Hospital were announced, Eadaoin said she saw this as an opportunity to further her career and fulfil her wish of specialising in an area.
"I always had an interest in becoming a specialist in an area of nursing and I also had a big interest in caring for people who were terminally ill so I did a course for nursing in cancer care, which was held in St. Luke's Hospital at the time. This was the beginning of the oncology / haematology course that is still being run now, but it was only the second course run at the time."

With her studies finished and Baggot Street Hospital near to closing as it was to be amalgamated with St. James's Hospital, as many hospitals in Dublin at the time were. This led to Eadaoin fulfilling her wish to travel as she moved to New York where she worked in the Sloan-Kettering Hospital, one of the biggest cancer specialist hospitals in America. When asked about her time in New York she remembers it fondly;
"I loved every minute of it and spending every dollar I earned."

So how did Eadaoin go from working in a cancer hospital in New York to becoming a Haemophilia Nurse Specialist in St. James's? After spending 2 years in New York Eadaoin decided it was time to come home and began researching nursing positions in Ireland. Upon hearing about a job in haemophilia she rang the Matron of St. James's Hospital from New York,
"I said I know nothing about haemophilia, but I do have experience working with people who are HIV positive and she said the only way you will get experience of working with haemophilia is if you work in St. James's and told me to come back for the interview. So I flew home for the interview and I got the job."

In 1988 Eadaoin began working at St. James's Hospital. Professor Temperley, the Consultant Haematologist at the time, advised Eadaoin to work in Hospital one, top floor for 3 months to gain first hand knowledge of haemophilia.

"I remember very clearly my very first time having to put a needle into somebody, I had never given an IV injection and a particular character who is still around said "Oh you could drive a bus through that vein". I still think to this day it was one of the smallest veins I have ever accessed."

After three months working in haemophilia, Eadaoin had gained the knowledge and confidence to go to the Royal Free Hospital in London, a specialist haemophilia centre. Here, under the watchful guidance of Patricia Lilly, Nurse Specialist, Eadaoin was given further training in haemophilia care.

Having spent a quarter of a century working with people with bleeding disorders in Ireland, Eadaoin has built up some strong relationships not only within the hospital teams, but with the patients whom she says she holds close to her heart. *"25 years is a long time getting to know the haemophilia community. Sadly, many have passed."*

Indeed working with the people she works with is what Eadaoin enjoys most about her job;
"I think we have a great team of people, very broad minded, very holistic and that certainly keeps me interested. I like the long term element of haemophilia care, that you're not just dealing with somebody coming to clinic and gone again, but you're dealing with the whole family and the whole life issues of the disorder."

When talking about her work and the patients she deals with Eadaoin jokes about how now she not only knows the patients and their children, but she is beginning to know their grandchildren.

Eadaoin (front row far left) has worked in haemophilia for 25 years. Pictured above is the staff of the NCHCD at the centre opening in 2001.

It is clear from speaking to Eadaoin that she is a passionate person about her work and about the haemophilia community and this is no more evident than when asked about what frustrates her about her job;
"Perhaps now it is that it is not as small a unit as it was, so I don't get to know as much about people as I did or I'm not as on top of what is happening to people as I was, because there are a lot more people involved. That frustrates me a little bit, but in general I must say I enjoy my job."

Since 1988 Eadoain has achieved a lot in her career and there have been many advancements in haemophilia care. When discussing these advancements she notes three that she thinks have made the biggest changes to haemophilia care;
"I suppose the biggest step forward was when all the anti-retroviral drugs became available for HIV positive men with haemophilia. That was huge, that was fantastic because I started in an era where there was nothing available and it was just a march to the grave. So anti-retroviral treatment was the biggest. Now we're seeing a revolution in Hepatitis C care which is a long time coming, but at last it is coming. The other thing then is because of the safety issues around the concentrate it is fabulous now to be able to talk to young mothers and talk about how haemophilia has changed so much, particularly with prophylaxis. That children can grow up without the pains and terrible suffering that haemophilia did have not so long ago, but that kids can grow up now and be perfectly normal and have a bright future."

Eadaoin with former IHS Chaplin, Fr. Paddy Mc Grath

During the course of our interview talk turns to the future and I asked Eadaoin where she envisaged haemophilia care being in 2020. This question gave us both a giggle and a fright as we realised that 2020 is only 7 years away. It seems like only yesterday we rang in the millennium, but back to the question at hand;
"I most definitely think there will be product that has a longer life so hopefully we will be looking at treating kids once a week, once a month maybe. I would hope that there will be genetic therapy available for haemophilia. When I started 25 years ago they were talking about gene therapy, they are still talking about it now, but I do think they're closer."

Eadaoin regards becoming a haemophilia Nurse Specialist as being one of, if not the, biggest accomplishments of her career.

An area of her work that Eadoain is passionate about is women with bleeding disorders and for the past number of years she has worked alongside Dr. Niamh O'Connell in the NCHCD in the women with bleeding disorders clinic. Women with bleeding disorders is an area that Eadaoin firmly believes still needs development, but she is happy with the work the NCHCD has done as there is a lot more focus on women and their needs.

Eadaoin with IHS CEO Brian O'Mahony during a twinning visit to Bosnia & Herzegovnia in 1995

Eadaoin runs the carrier testing clinic in the NCHCD and mentioned that there has been a surge in women getting tested in the past few months.
"The uptake of testing comes and goes and I think it is no different than it is internationally. Girls might know that they could be carriers, but very often they wait until they are getting married or wait until they are pregnant before they actually go and do something about it."

There are a lot more choices for carriers and / or women with bleeding disorders now in relation to management of their condition, pregnancy and delivery planning. I don't see the situation with regards to testing changing, I think putting it off until it is necessary is the case internationally so we are no different here. However, Eadaoin would like to see men with bleeding disorders encouraging their daughters and sisters to get tested early.

At the Ageing Conference Eadaoin spoke to the delegates about the importance of vein care, a message that is relevant for people with bleeding disorders young and old. I asked Eadaoin what she thinks will be the needs of people with bleeding disorders as they age;*"I think they will need to draw on their coping mechanism of which they have and appreciate how they have dealt with life and how they have dealt with everything that has happened to them and know that they have the strength to go forward."*


IHS CEO Brian O'Mahony presenting Eadaoin O'Shea with a crystal vase in recognition of her 25 years work within the haemophilia community.

Eadaoin mentioned that the legacy she wants to leave behind is the legacy of looking after the whole person and the whole family. It is clear that she cares a lot about the bleeding disorder community in Ireland and is as passionate about her job now as she was when she began 25 years ago. To the Irish Haemophilia Society and the haemophilia community Eadaoin is more than a nurse, she is a friend.

Thank you Eadaoin, here's to the next 25!

Nuala Mc Auley
Irish Haemophilia Society

A Festive Story - When Christmas was a black & white matter!

'TWAS the week before Christmas, and all through the house, not a creature was stirring... apart from the decapitated turkey embarking on a frantic final lap of honour in the back garden before keeling over, dramatically but conveniently, on the step outside the kitchen door, just feet from the makeshift festive plucking station.

The ruthless in-family exterminator, clad appropriately in sombre black overalls, emerged from the garden shed execution chamber brandishing a blood-soaked axe and a smug grin of achievement, having crudely put a stop to Big Bird's hysterical gobbling with one fell swoop.

But, quite incredibly, in a real freak of nature, jingling jangling nerve endings permitted the headless turkey to stretch its legs one last time, with a speed and agility that would have left Haile Gebrselassie trailing in its wake, before it reached life's ultimate finish line. It mightn't have been the most humane of endings but, hey, what's Christmas without a turkey?

It later formed an 18-pound centre-piece on the dining room table but, rather than dwelling on the fate of Gobbling Gabriel, the round-table chatter instead focused on who got to pull the giant wish-bone and how the Hungarian dwarf swallowing a razor-sharp sword on Billy Smart's Christmas Circus was steeped he didn't have haemophilia.

It didn't come much better than growing up - and growing out - in Kerry in the early seventies with possibilities for sheerdrama and butterfly-belly excitement reaching a dizzy peak at Christmas. It was a magical, wonderful era of action-packed, carefree days spent at play, from dawn to dusk, reluctantly breaking only to munch on sherbet pops, take in thirst-quenching slugs from the garden hose or to give that troublesome ankle joint a brief reprieve from the strain of pounding that new football off a gable wall for hours on end.

As the old crooner they called Bing reminded us in verse, it was Christmas in Killarney with all of the folks at home and, boy, was it special.

Back then, unlike now when Halloween pumpkins in Easter bonnets adorn shop windows the day after St Patrick's Day, the build-up to the festive season didn't really commence until the eighth day of December had been ushered in and the farmers hit the town with a vengeance.

The first seasonal task was the thoroughly exciting annual snapshot with Santa in a dusty corner of the local photographic supplies store and, despite the fact that his face was a motionless mask carved from hardened egg cartons, he was welcoming and cheerful and had a booming baritone voice that made Alfred Hitchcock sound like Graham Norton.

And then thoughts turned immediately to a toys for boys wish-list, inspired more by historical considerations and a limited knowledge of the contents of the North Pole assembly line than in-your-face television commercials and glossy, exaggerated toyshop brochures which, thankfully, didn't exist at a time when commercial restraint and limit recognition was the only show in town.

The Aladdin's Cave that was the solitary local toy store had a magnet-like lure and there was always something eye poppingly special to be found alongside the traditional marbles, catapults, peashooters and spud gun stocking fillers.

Every year, for several years, my letter to Santa was virtually a carbon-copy of the previous December's brief communication with a gun and holster at the top of the must-have list, complete with absolutely essential accessories of a sheriff's badge, cowboy hat, leather waistcoat and explosive powder caps with which to fell the red injuns that were known to set up camp behind the escallonia hedge in the back garden.

Once I had a gun in my holster, bristles on my wooden handled broom horse and enough spare cash to load up with extra caps from the small local bun and cigarettes shop that stayed open on Christmas day, I was as content as Marlboro Man let loose in duty free.

My Yuletide amusement needs were relatively simple, which was in sharp contrast to the yard-long wish-list proffered by a certain close relative, whose identity I shall protect but let's just call him Brian – for the sake of the story. He put his powers of persuasion to good use to ensure he got to unwrap and enjoy frightfully expensive and futuristic treats like scintillating Scaletrix tracks, intricate Meccano construction models and elaborate chemical sets, not to mention a selection of chart-topping LPs that ensured Noddy Holder and Marc Bolan got to lead the carol singing under the Christmas tree.

But the misfortunate "Brian" – again, for the sake of the story – had his domestic credit bank unceremoniously raided one Christmas night as he was determinedly attempting to split an atom, expose Bernoulli's Principal as a sham or create an antidote for chickenpox in the corner of the room. His mad scientist test tube experiment launched prematurely from the kitchen table, in a puff of black smoke, stripping paint off the wall and almost decapitating our beloved mother as she sat by the fireside wondering how Jimmy Flahive, the original TV celebrity chef, made it all look so easy as he instructed the nation to "dice it very finely."

Ahead of my time, I embarked on my own personal peace process one Christmas Eve morning in 1973 with the signing of the Back Garden Declaration with all guns and holsters decommissioned; a goodwill gesture that was generously matched by the red injuns behind the hedge handing over their bows, arrows and hatchets to be put beyond use.

In place of the cowboy attire that year came the sleekest, coolest and deadliest Batman outfit ever seen this side of Gotham City; a black cape and matching facemask with a bat motif, black leather gloves and a snug-fitting charcoal grey t-shirt emblazoned with the Pow, Zap, Wham legend that became the caped crusader's calling card.

The unsuspecting but ever obliging family dog was fitted with a plastic Mace-bag cape to become my trusted sidekick, Robin, and we set off on incredible adventures in our trusted Batmobile – two planks of wood set on the wheels from an old pram – at the first flicker of the Bat distress signal in the night sky.

Christmas was the time of year that we got to dip into bowls of Lemon's Season's Greetings and seek out chocolate Emeralds, amateurishly hidden in the goodies press. We downed enough Cidona and Taylor Keith from glass bottles to fell a small orchard, we polished off long tubes of Smarties and Toffos, tucked into boxes of Taytos and we ripped foil wrapped chocolate Santas hanging from the tree, enthusiastically beheading them without as much as a Ho, Ho, Ho.

One of my stand-out and near fatal memories of a Christmas childhood doubles as a costly and painful lesson that you should never play with fire – or electricity. Envious of the elaborate flashing light displays from Christmas trees inside neighbours' windows, and far from satisfied by our own reliably continuous but non twinkling effort, I conducted my first science experiment at the age of 10 and was taught a lesson I will never forget.

With military precision, allowing five seconds in between movements, I repeatedly pushed and pulled the plug to and from the socket to conjure up the most magnificent but short-lived display of sparkling lights witnessed since the night the three wise guys walked over the hill into Bethlehem.

I realised the error of my ways when I found myself being catapulted across the room, colliding with the facing wall, hands stinging, eyes bulging and with a Jedhead that was way ahead of its time. Try explaining the logic of that to the junior doctor who drew the short straw and was assigned to A+E for the festive season.

After the previously mentioned distant relative – whose real name is an anagram of brain – had creatively invented his own Scrabble dictionary and ruthlessly built up a Monopoly empire of hotels, apartment blocks community chest tokens sufficient to force Seán Quinn on to the dole queue, the remainder of Christmas night in the O'Mahony household always ended in front of the TV in the company of legendary double acts of the calibre of Maureen Potter and Jimmy O'Dea, Stan Laurel and Oliver Hardy and Charles Mitchel and Maurice O'Doherty.

It offered a brief if unwelcome reprieve from admiring the charisma of the Man from Uncle, witnessing the amazing self-destructing message in Mission Impossible and watching Dr Richard Kimble cleverly evading the clutches of the persistent but suspicious Agent Gerrard in The Fugitive.

Worn from the amazing adventures and filled with fabulous memories of the most wonderful day of the year, I didn't need much persuading to scale the stairs and climb between the covers on Christmas night. With a minced pie placed under the pillow a little earlier to be retrieved and enjoyed, the Beano annual on the locker to be perused and the all-action Batman cape fitting snugly over the pajamas, it was a perfect end to a perfect day.

And a good night's sleep was essential for the great adventure would continue at first light when Gotham City had to be protected from the dastardly, rampaging wrenboys and their tiny, feathered, power-hungry leader with an all-consuming ambition to be crowned the king of all birds.

Pow, Zap, Wham. Take that wrenboys.

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