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The Society
at a Glance

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Edition: December 2015



haemophilia.ie

AGM 2016

4th to 6th March
Hotel Kilkenny

PRELIMINARY PROGRAMME

Friday 4th March

6.00 p.m. - 7.30 p.m. Registration

Saturday 5th March

9.00 a.m - 10.00 a.m. Registration
10.00 a.m. - 12.30 p.m. Annual General Meeting
12.30 p.m. - 1.30 p.m. Lunch
1.30 p.m. - 3.30 p.m. New Developments in Haemophilia
3.30 p.m. - 4.00 p.m. Tea & Coffee Break
4.00 p.m. - 5.00 p.m. Open Forum with Treatment Centres
7.15 p.m. Gala Dinner followed by awards and entertainment

Sunday 6th March

10.00 a.m. - 11.00 p.m. Vietnam: GAP Programme
Or
10.00am - 11.00am Inhibitors
11.00 a.m. - 11.30 a.m. Tea & Coffee Break
11.30 a.m. - 12.45 p.m. The History of the Irish Haemophilia Society
12.45 p.m. - 2.00 p.m. Lunch



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A Note from the Editor

Debbie Greene,
Administrator

Hi everyone, and welcome to the December edition of haemophilia.ie. I hope you are all getting organised for the Christmas festivities.

It has been another extremely busy year in the office and I really would like to thank the staff for all their hard work during the year. I would also like to thank the volunteers, those who contributed to our magazines and publications, everyone who did fundraising for us during the year, and who sent in donations or contributed to the planned giving campaign during 2015.

It's hard to believe, but we have already started working on our preparation for the AGM next year. Take a look on the inside cover where you will find the preliminary programme. AGM packs will be going out to everyone in early January! If you want further information on all of our main events next year, please see page 6.

In this edition, you will find some interesting information from our Chief Executive in relation to new technologies around haemophilia care.

On page 18 John Stack has written his second article on strength and conditioning which is very interesting.

On page 11 you will see important details on hospital opening hours over Christmas. Why not tear this page out of the magazine and put it up on your fridge!

In this edition, you will find reports on the 'Members Conference' that took place back in October and the 'European Haemophilia Consortium Conference' which took place in Serbia in October.

The recipients for our Educational Grants for this year have been announced. Congratulations to everyone!

And finally, don't forget we are always delighted to see members dropping into the office for a chat and a cuppa, so drop in if you are in the area. If you have any questions or queries, or would like to talk to somebody in confidence contact us on 01 6579900 and we will do our best to help.

Wish you all a very Happy Christmas and a healthy and prosperous New Year.

Debbie Greene



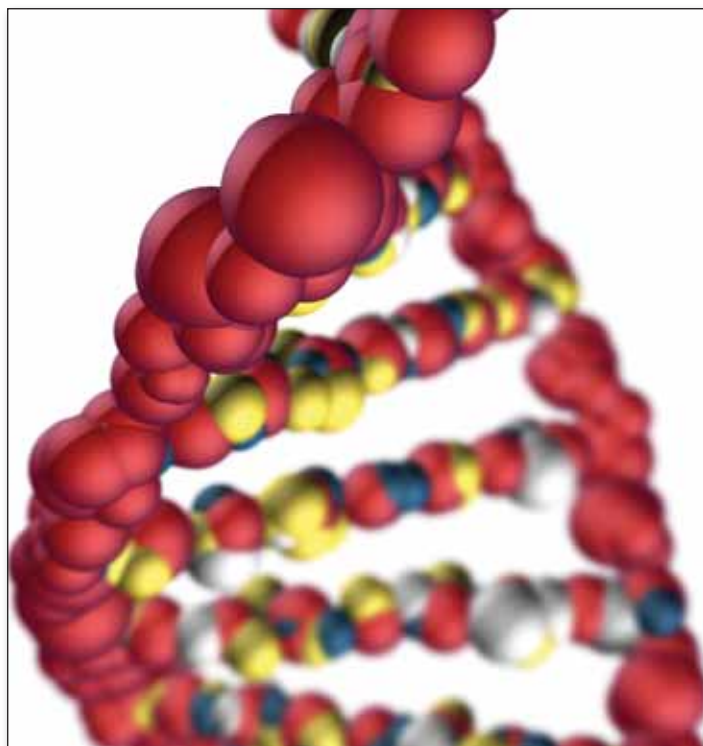


In November, the European Haemophilia Consortium organised a conference on 'New Technologies' in haemophilia which brought together patient leaders, doctors, scientists and payers. The therapeutic landscape in haemophilia care, has never been as innovative or exciting. The limitations of current treatment include short half-life of the factor concentrates, the requirement for frequent intravenous infusion and difficulties with venous access and the risk of inhibitors. The new extended half-life (EHL) factor concentrates will offer new therapeutic possibilities as they can be used to decrease the frequency of infusions or increase the trough level (or both) and deliver greater protection from bleeding. The relative risk of developing inhibitors with the new EHL concentrates compared to current recombinant factor concentrates is as yet unknown. This will require extensive post-marketing surveillance over the course of the next several years. Defining the real risk of inhibitors with a product or class of products in reality requires the collection of data on very large numbers of patients, over many years, in many countries, as you are looking for the relative risk of a rare event in an already rare disease. The EHL factor VIII concentrates which will become available in the coming years, in Europe, will extend the half-life by 1.4 to 1.6 fold.

The first EHL factor VIII concentrate was licenced by the European Medicines Agency in November, which means it can now be prescribed in Europe. This product has already been used by several children in Ireland as part of the product clinical trial over the past two years. The EHL factor IX concentrates will increase the half-life of factor IX by 2.5 to 5 fold. The first EHL factor IX concentrates are expected to be licenced in Europe in late 2016. There are currently four EHL factor VIII products and three EHL factor IX products under development with two EHL factor VIII products and one EHL factor IX product already licenced in the USA and one EHL factor VIII product licenced in Europe. An EHL



*Brian O'Mahony,
Chief Executive*

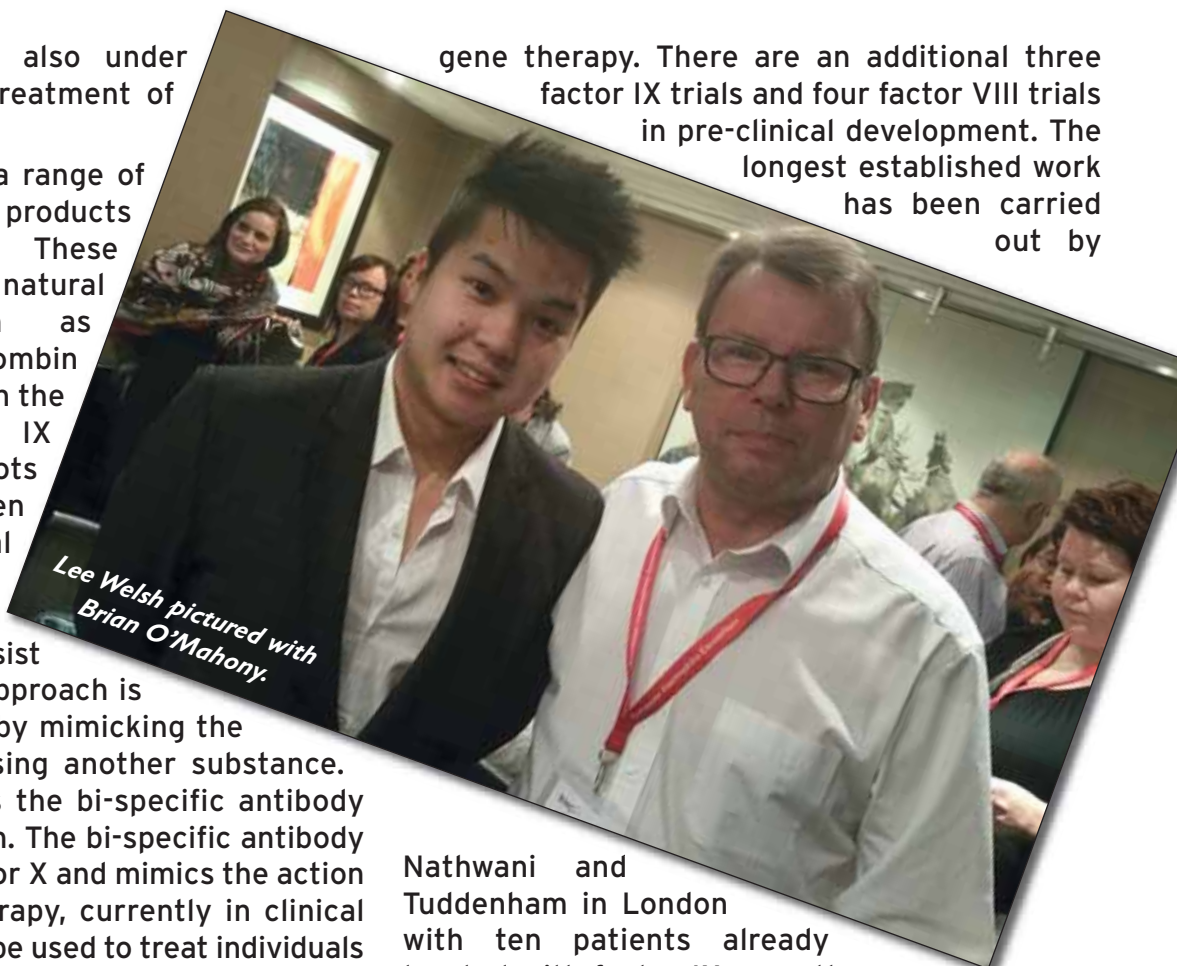


factor VII product is also under development for the treatment of inhibitors.

In addition, there are a range of novel non-replacement products under development. These include inhibitors of natural anticoagulants such as inhibitors of antithrombin which may have a role in the treatment of factor IX inhibitors. When clots form, they are broken down by natural anticoagulants. The theory is that if you can prevent this, you assist coagulation. Another approach is to help clot formation by mimicking the effect of factor VIII using another substance. Such a development is the bi-specific antibody first developed in Japan. The bi-specific antibody binds factor IX and factor X and mimics the action of factor VIII. This therapy, currently in clinical trials, could potentially be used to treat individuals with factor VIII deficiency including those with factor VIII inhibitors. The treatment would be a subcutaneous injection probably weekly but possibly as infrequently as once per month. Results from the early clinical trials are encouraging and there is a possibility that the next phase of the clinical trial will include people with factor VIII inhibitors from Ireland.

The other major area of innovation, of course, is gene therapy. There are currently at least four clinical trials underway for factor IX gene therapy and one trial underway for factor VIII gene therapy, with a second factor VIII trial due to commence in 2016. At the conference in London, we met with and spoke to a very happy young man, Lee Welsh who several weeks ago became the first person in the world to be treated with factor VIII

gene therapy. There are an additional three factor IX trials and four factor VIII trials in pre-clinical development. The longest established work has been carried out by



*Lee Welsh pictured with
Brian O'Mahony.*

Nathwani and Tuddenham in London with ten patients already treated with factor IX gene therapy.

The first of these was treated about five years ago and all ten patients are demonstrating long-term expression of factor IX with levels of up to 5-6%. We hope to be in a position to commence gene therapy clinical trials in Ireland in the coming year.

At our Annual Conference next March, there will be a symposium on new developments which will include lectures on gene therapy and the bi-specific antibody delivered by leading experts. This is an exciting time in the development of haemophilia care and we look forward to being in the forefront of development.

Brian O'Mahony

Dates for your diary 2016

March

AGM

4th - 6th March
Hotel Kilkenny

May

Carrier Conference

7th - 8th May
Castleknock Hotel, Dublin

June

Parents Conference

24th - 26th June
Sheraton Hotel, Athlone

October

Members Conference

14th - 16th October
Radisson Blu, Sligo

November

PEP Conference

12th - 13th November
Clarion, Liffey Valley





I am delighted to announce that the recipients for the Educational Grants for 2015 have been chosen. Thanks to everyone who sent in applications. This year we received a total of 25 applications which is an increase from last year. We had a mixture of applications which were received online and in the post. The sub-group of the board met on the Friday evening of the October Conference to discuss and score all the applications, after which a final decision was reached. A total of €16,000 was paid out and the two main recipients are as follows:

Maureen & Jack Downey Educational Grant (€4,000)

Carly Wright from Tipperary

Carly is in her second year of college in the Limerick Institute of Technology. Carly is studying Applied Social Studies of Social Care.



Carly Wright

Margaret King Educational Grant (€2,000)

Niamh Birkett from Cork

Niamh is in her first year of college in University College Cork. Niamh is doing a BA in Drama and Theatre Studies with English and Sociology.

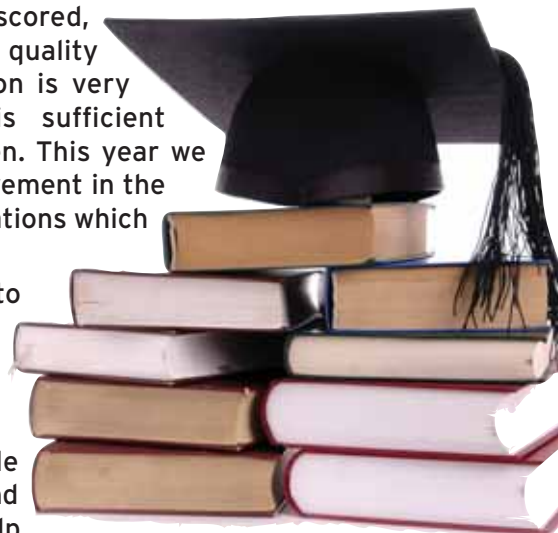


Niamh Birkett

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 great.

I would like to encourage as many of you as possible to apply next year. It's really worthwhile and beneficial, and can really help cover the cost of perhaps travel expenses if you are studying away from home or those very expensive books!

Many congratulations to you all!



Debbie Greene

European Haemophilia Consortium

EHC Leadership Conference

In October, just before the annual conference, the EHC held its first ever Leadership Conference which hosted 70 delegates from 38 countries. The aim of the conference was to bring together the current leaders from each of the National organisations, as well as some of the leading youth from the organisations. The conference looked at a number of topics that gave the youth attending a better understanding of the different aspects required for a successful organisation, as well as demonstrating the strengths and capabilities of new leaders in the haemophilia community. The programme covered areas such as good governance, strategic planning, succession planning, funding of the organisation, pharmaceutical relationships and tenders and procurement.

The first session covered the area of good governance and looked at the key elements for organisations such as, what is the purpose and strategy of the organisation? What internal and external policies affect its work? The session looked at the sustainability of the organisation focusing primarily on volunteers and staff and the importance of good communication.

The second session looked at strategic planning and how important it is. It helps us to clarify priorities and changes our way of working from reactive to proactive. In an exercise we found out that 86% of European organisations have a strategic plan in place, 46% of them are looking one-two years into the future and 54% are looking at a longer time span of three-five years. Essentially across all organisations all strategic plans were developed by a combination of the board, the staff, the members and any other committees that represent the community.

There was a very interesting session on funding which was co-chaired by our own Chairperson Ms. Traci Marshall Dowling and Dr. Paul Giangrande. Traci presented findings on the funding survey carried out by the EHC. It looked at the different aspects of funding that each of the haemophilia organisations receive and focused on issues of receiving funding from single sources and the increasing difficulty in some countries to get access to non-restricted funding.

The final session of the Leadership Conference was on tenders and procurement. The session looked at the importance of clinician and patient involvement in the purchase of factor concentrates. It also showed that



EHC Leadership tender workshop.

patient and clinician involvement also lead to a more cost effective model of haemophilia care. The session finished with delegates being split into groups for an exercise on how to assess products with the appropriate criteria. Interestingly, while there were many components to the criteria such as safety, quality and efficacy, there was a clear understanding that price was an important consideration for the purchase of factor concentrates. However, it was never going to be more important than safety, efficacy or quality criteria.

This conference gave valuable insights into the running of a haemophilia organisation and the importance of having strong and interested youth to carry forward the work. It also showed that there are capable, strong and enthusiastic youth in our community and between the leaders of today and those of tomorrow, we have to work together to maintain the strength of the haemophilia community in Europe into the future.

EHC Conference

Following the Leadership Conference, the 28th EHC Annual Conference took place where over 300 participants from 42 countries attended the event. The first session of the conference was a very interesting introduction to haemophilia care in Serbia. Dr. Miljic said *"Comprehensive care should be like a well organised orchestra in which different services work together and collaborates in order to provide optimal care for people with haemophilia."* One of the areas that this is very evident in, in Serbia, is in the inhibitor community, where once a year the adult patients with inhibitors (14), the haematologist, orthopaedic surgeon treating haemophilia, the dentist, two haemophilia nurses, a social worker and a physiotherapist all go on a three day camp to cover every aspect of care and improve the communications between patients and the team. The session also looked at the work done in Serbia in rare bleeding disorders and the development of their registry for this cohort of patients as well as how these patients were diagnosed. Professor Peyvandi from Milan, gave a presentation on gene therapy. She looked at the different delivery

systems that are being assessed. She also looked at the issues that are still remaining such as factor levels are still not high enough to free some patients from additional infusions, the expression on the factor VIII or factor IX is short lasting in some trials and the fact that inhibitor development is still an unknown and innate immunity to the delivery system for the factor VIII and factor IX gene. She finished by focusing on the current reality. Gene therapy is emerging as a viable way to treat factor IX deficiency and encouraging results have been achieved in patients. However, despite many efforts in factor VIII gene therapy is more problematic.

In the session on women and bleeding disorders, Dr. Oirion looked at the genetic and bleeding risk in carriers of haemophilia. Dr. Oirion spoke about the need for improving testing for carriers. This will require more effort from families, patient organisations and haemophilia treaters. She talked about the different stages and the care needed for carriers as they age.

- In early childhood: they need to assess bleeding risk for low levels.
- In pre-adolescence: there needs to be follow-up of periods.
- In adolescence/young adult: preparation and support for carrier testing needs to begin.
- As a young adult: with or without a partner, counselling and discussions on pregnancy and delivery become important.
- For the ageing carrier: planning for premenopausal periods, surgeries other co-morbidities needs to be considered.



EHC Conference.

Professor Khadir then spoke about pregnancy and menorrhagia and about the need for a multi-disciplinary approach and the need for close collaboration between obstetrics/gynaecology and the haemophilia team. There also needs to be more awareness of current evidence for treating menorrhagia and pregnancy protocols as well as the variety of options for treatment that are currently available. She emphasised the need for further research and the potential need for specialist clinics for severe and complex cases.

On the second day of the conference, the first session looked at ageing and cardiovascular health. In people with haemophilia life expectancy has increased to almost that of the normal population. This is for number of reasons such as more widely available and safer treatment, comprehensive care in specialised centres, prophylaxis, improved treatment of inhibitors and improved antiviral therapy for HIV and Hepatitis C. However, as a result, cardiovascular disease is starting to appear in the haemophilia community. It is relatively rare but is an increasing problem in elderly patients with haemophilia. There is currently little evidence or treatment guidelines. These will be needed in the future and will require close cooperation between cardiologists and the haemophilia treatment centres.

The last session was on long-acting factors. This was a comprehensive look at the different considerations with the impending release of these products in Europe. Dr. Carcao spoke about his clinical experience so far with the new products. Going forward there will be no "one size fits all" regimen. Treatment will be individualised and it will be easier to ensure that trough levels of above 1% are achieved. He also noted that other outcomes are also equally important and the lifestyles of individuals needs to be considered. Compliance with therapy will also be important to fully prove the benefits of long-acting products. Furthermore, as these products are new and are as such altered from their original state there needs to be good monitoring.

The EHC also held two workshops on 'Developing a European Inhibitor Network' and 'Women in the bleeding disorder community'. Finally, on Sunday, delegates from the various National Member Organisations took part in the EHC General Assembly. EHC members re-elected Brian O'Mahony as their President for the next four years (2016-2020) and decided that the EHC 2017 Annual Conference will be held in Vilnius, Lithuania. This event had the highest attendance rate yet for any EHC Conference.

Declan Noone

Bleeding Disorder Alert Cards

A reminder to you all to make sure that you carry with you at all times your 'Severe bleeding disorder alert card'. This is very important. Your consultant haematologist at your haemophilia treatment centre will provide you with a card. If you have not received same, please ask for one when you are next attending your treatment centre.

If an individual with haemophilia presents at an emergency department with a bleeding episode that requires treatment with factor concentrate, a number of delays can occur. Firstly, the triage nurse may not be familiar with haemophilia and may not be aware of the fact that factor concentrates should be given without delay. The doctor seen at the Emergency Department may be similarly unfamiliar with haemophilia and may order tests, x-rays or scans to confirm a bleeding episode is present before ordering factor concentrate. There may be a delay in locating the factor concentrate that is stored in the hospital. There may be a delay if a consultant haematologist in the hospital has to sign off before the factor concentrate is to be used.

For the person with haemophilia, the most important piece of equipment in a non-specialist centre is the telephone and the instruction to the Emergency Department staff to call your haemophilia treatment centre immediately.

Debbie Greene

Severe Bleeding Disorder Alert Card



This person: _____

MRN: _____

Date of birth: _____

has a severe bleeding disorder. If he / she presents at your hospital the Triage Nurse or Doctor must immediately contact the Coagulation Centre in CUH on 021 4922545, and appropriate treatment must be given within 30 minutes. (After 5pm and on weekends, call 021 4546400 and ask for the doctor on call for Haematology.)

Severe Bleeding Disorder Alert Card



This person: _____

MRN: _____

Date of birth: _____

has a severe bleeding disorder. If he / she presents at your hospital the Triage Nurse or Doctor must immediately contact the Haematology Registrar on call at Our Lady's Children's Hospital Crumlin on 01 409 6100, and appropriate treatment must be given within 30 minutes.

Severe Bleeding Disorder Alert Card



This person: _____

MRN: _____

Date of birth: _____

has a severe bleeding disorder. If he / she presents at your hospital the Triage Nurse or Doctor must immediately contact the H&H Ward in St. James's Hospital in Dublin on 01 410 3129, and appropriate treatment must be given within 30 minutes. (After 5pm and on weekends, please call 01 410 3132.)

Hospital Opening Hours over Christmas Period

**ST. JAMES'S
HOSPITAL**
James's St., Dublin 8, Ireland.



National Centre for Hereditary Coagulation Disorders - St. James's Hospital

Monday 21st December	08.30hrs to 17.00hrs
Tuesday 22nd December	08.30hrs to 17.00hrs
Wednesday 23rd December	08.30hrs to 17.00hrs
Thursday 24th December	CLOSED
Friday 25th December	CLOSED
Saturday 26th December	CLOSED
Sunday 27th December	CLOSED
Monday 28th December	CLOSED
Tuesday 29th December	08.30hrs to 17.00hrs
Wednesday 30th December	08.30hrs to 17.00hrs
Thursday 31st December	08.30hrs to 17.00hrs
Friday 1st January	CLOSED
Saturday 2nd January	CLOSED
Sunday 3rd January	CLOSED
Monday 4th January	08.30hrs to 17.00hrs

H&H Unit - St. James's Hospital

Out of Hours Service

Phone: (01) 410 3132 (After 5pm Monday to Friday,
and at weekends or bank holidays)

Patients who need emergency assessment or advice
should phone the H&H Ward prior to attending, or
alternatively contact St. James's hospital via the main
switchboard on 01 4103000 and ask for the
haematology SHO on call.

The H&H unit will be closed on:

Friday 25th December
Saturday 26th December
Sunday 27th December
Monday 28th December
Friday 1st January

The office of the Irish Haemophilia Society will close for
Christmas at 3pm on Wednesday 23rd December and
will re-open on Monday 4th January at 9am.

In case of an emergency, please contact Anne Duffy on
087 2320255.

*Wishing you all a very Merry Christmas and a Peaceful
New Year from all the board and staff of the I.H.S.*

Cork University Hospital



Monday 21st December	08.30hrs to 17.00hrs
Tuesday 22nd December	08.30hrs to 17.00hrs
Wednesday 23rd December	08.30hrs to 17.00hrs
Thursday 24th December	CLOSED
Friday 25th December	CLOSED
Saturday 26th December	CLOSED
Sunday 27th December	CLOSED
Monday 28th December	CLOSED
Tuesday 29th December	CLOSED
Wednesday 30th December	CLOSED
Thursday 31st December	CLOSED
Friday 1st January	CLOSED
Saturday 2nd January	CLOSED
Sunday 3rd January	CLOSED
Monday 4th January	08.00hrs to 17.00hrs

In case of an emergency please contact the
haematology registrar on call through the main
hospital switchboard on 021 4546400.

Our Lady's Children's Hospital, Crumlin



Monday 21st December	08.00hrs to 17.00hrs
Tuesday 22nd December	08.00hrs to 17.00hrs
Wednesday 23rd December	08.00hrs to 17.00hrs
Thursday 24th December	Closing at 12.00hrs
Friday 25th December	CLOSED
Saturday 26th December	CLOSED
Sunday 27th December	CLOSED
Monday 28th December	CLOSED
Tuesday 29th December	08.00hrs to 17.00hrs
Wednesday 30th December	08.00hrs to 17.00hrs
Thursday 31st December	08.00hrs to 17.00hrs
Friday 1st January	CLOSED
Saturday 2nd January	08.00hrs to 17.00hrs
Sunday 3rd January	08.00hrs to 17.00hrs
Monday 4th January	08.00hrs to 17.00hrs

In case of an emergency please contact the hospital
on 01 4096100 and ask for the haematology registrar
on call.



Welcome to another edition of our Cubs Club!!

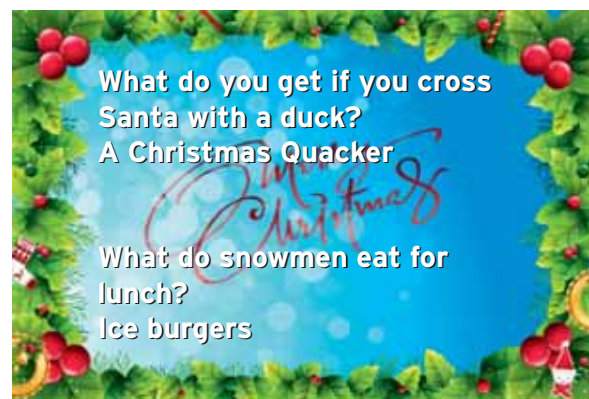
Hi everyone, you have all met Brian before. He is 7 years old and has severe haemophilia. Brian loves Christmas time with presents and all the nice food, but he especially likes the snow. He loves building snowmen and throwing snowballs with his brothers and sisters. But Brian's mom is not so excited when the snow comes because the paths can be icy and dangerous. Sometimes Brian slips and falls over. Most of the time he can see the cut on his hand or the graze on his knee but sometimes he can't see where he hurt himself, he can only feel it. He has to be very careful and take his factor but he also has to know what getting a bleed feels like. Do you know the signs of a bleed?



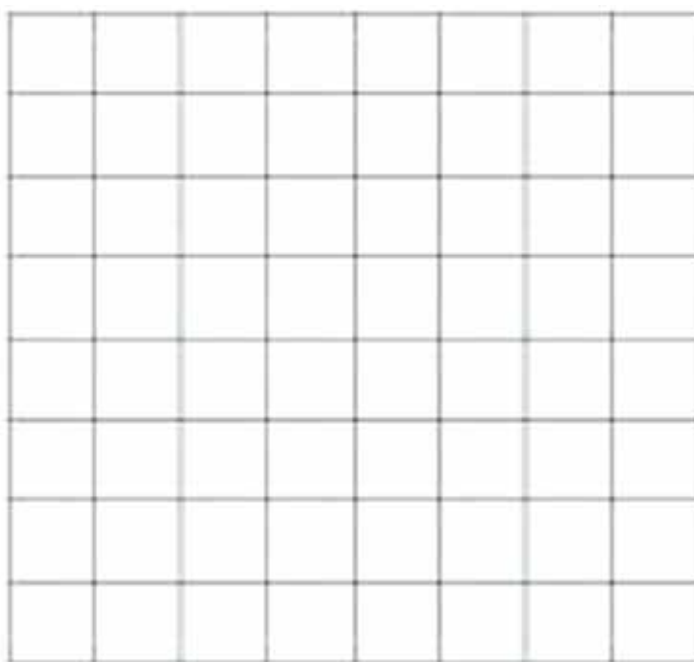
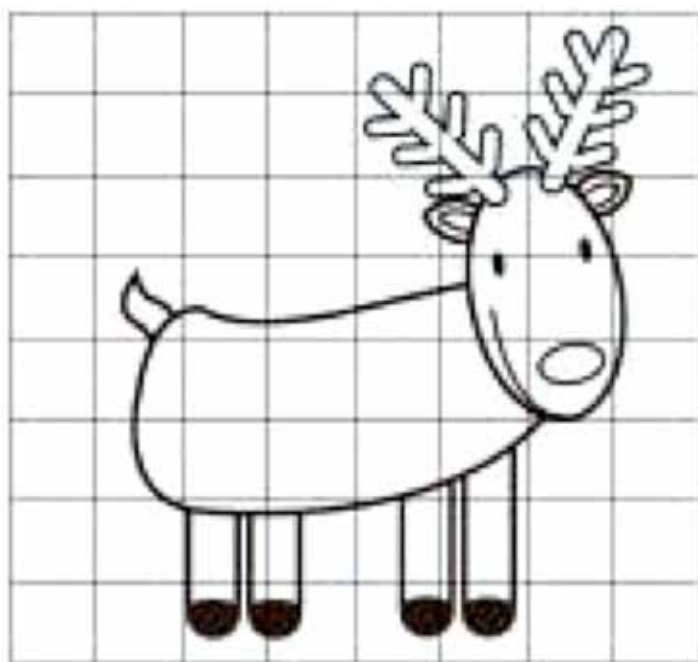
You may feel

1. P _____
2. H _____
3. S _____

Did you know
that the Germans invented the first artificial Christmas tree by dyeing goose feathers?



COPY THE REINDEER



Copy the picture using the grid lines as a guide. You might find it easier to copy one square at a time. Count the squares carefully!

Answers to signs of a bleed: - 1. Pain; 2. Heat; 3. Swelling.

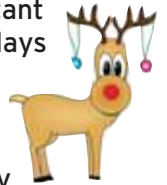
Welcome to the Kidlink page!!

We are going to talk about R.I.C.E. and looking after yourself when you have a bleed. It is really important to mind yourself. Obviously protection and prevention are key but this can be hard over the holidays especially when the weather is bad and when the snow and ice arrives! When you have an internal bleed it is really important to R.I.C.E. Do you know what R.I.C.E. stands for?

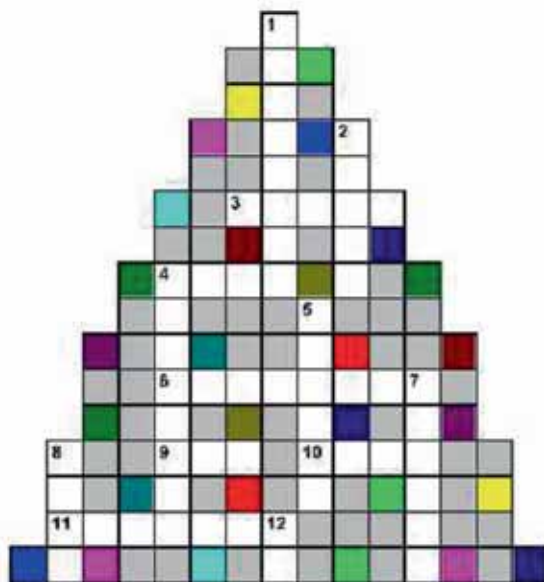
R stands for rest, I stands for ice, C stands for compression and E stands for elevation.

When you have a bleed it is best to rest and not move your joint or muscle at all. It is also really important that you try to reduce swelling by wrapping an ice pack in a tea towel and putting it on the joint or muscle for 20 minutes every 2 hours, this will help with the pain too. If you put an elasticated bandage

on it, this will help to reduce swelling by compressing the joint or muscle and finally put your feet up (in line with your heart, you may need plenty of cushions) and relax. Elevation helps to reduce swelling, so basically do R.I.C.E. and enjoy the rest!!



CHRISTMAS CROSSWORD



Across:



Down:



Did you ever wonder where X-Mas came from? X means Christ in Greek so to shorten the word Christmas we sometimes use X-Mas.



Did you know that Jingle Bells was originally called 'One Horse Open Sleigh' and was written by James Pierpont sometime between 1853 - 1857?



Members Conference

On Friday the 16th of October the O'Connor family set off to the Portlaoise Heritage Hotel. The haemophilia weekends, as we refer to them are always met with great expectations by both adults and children alike. The social aspect of the weekends are important for all the family. Questions of who will be there, what group am I in, or be old enough to get into, and what volunteers the children will pester, fill the conversation in the days prior. The parents are busy phoning friends who live in different counties to plan the weekend.

We had attended a conference in this hotel previously and had enjoyed our stay so this was not new. On arrival we checked in, our family room was very

comfortable, and the central location of Portlaoise town made it an ideal location to dine out, and to explore a bit after the drive.

Registration took place on Friday evening at 18.00hrs, where we meet up with the IHS staff, and checked out what's happening. It is always a pleasure to meet the IHS team. The children have grown up with their presence in their lives due to the weekends, so they are very comfortable to chat with them. After we had eaten, we returned to the hotel to meet up with friends. This is a great opportunity to reconnect with individuals that are not normally in our locality. We have made so many connections due to our attendance at the haemophilia weekends. Our friends come from all areas of the country, so it provides a great opportunity to get together and to have a good catch up.



Saturday morning was no effort to get the gang out of bed as they decided in the bedroom what they were going to eat for breakfast. Pancakes appear to be the craze for the kids at present for breakfast, as they ate with their eyes as the pancakes rolled down the machine. Breakfast is always the favourite meal on these weekends for all members of our family, mostly due to the large choice, as we all like different foods. There is much talking, waving hello to people we hadn't seen the night previous, with a general sense of occasion about the breakfast room, much chatting and kids laughing with parents, and friends.

After breakfast we went down to sign the children in, after which the parents gathered for an interactive workshop for mothers, fathers, individuals with haemophilia, and relatives. This type of session is normally seen in the afternoon lectures, but was switched to facilitate a guest speaker. The outcome of this change produced a more relaxed connected atmosphere as individual members that were new to the weekends, got the opportunity to make connections with individuals in the same position, and the veterans like ourselves got to enjoy the company of like-minded people we already connected with, without having to sit beside our partners. The subjects discussed were difficult in that it was hard to find cons with but we played devil's advocate. A slagging opportunity was taken by the dads around what better parents they were than the mums, which continued during the coffee break!

This interactive session resulted in a more relaxed audience participation for the sessions following. At the resilience session my husband Anthony was giving a father's perspective. I was most keen to hear this as he refused to write it down, and I wondered if he knew what he was going to say. As luck would have it I got a tap on my shoulder from Nina asking if she could have a word. My first reaction was "I hope she doesn't want me on the stage as well". Gabriel (our son) had got a



bang on the head while swimming with his friends. Off I went down to the pool. The volunteers and Fiona were brilliant with him and after a big hug we set off for Freddy in the bedroom. Freddy done, cup of tea on board for Gabriel and myself along with a chocolate bar for shock, and Gabriel was back in the pool dressing room ready to go for lunch with his pals. I returned to the lecture but alas I missed Anthony's moment, but reports say he was good. I did get to hear the end of Ger O'Reilly speech on obstacles he overcame. I have the greatest of respect for him and it is great for Gabriel and children with bleeding disorders to have such a positive and resilient individual to measure up to. I then took a bit of down time after this lecture as the session on the adult haemophilia centre is not at present my main concern, and I am only able to deal with one scenario at a time.

The dinner on Saturday night is always a great event. I had met a relative who travelled from Australia to visit

her young grandsons who have haemophilia, and she reported to me that she was impressed by the Society's positive comradeship, which was lovely. I am sure it is a worry being so far away, so the weekend provided an opportunity for that lady to observe what the Society is all about. I met parents of children with newly diagnosed haemophilia, as we were in 2005 with Gabriel. It struck me how important it is to connect with people at the next stage. I recalled the individuals we met when we first joined the IHS; these people helped us to find our own balance in processing Gabriel's diagnosis by their presence at the weekends. This is the real message the weekends offers. Although there is a lot of learning, processing, and adapting with haemophilia there is a future for your child that is positive.

The Sunday sessions were again unusual. A carnival was organised for the first session. This was great fun, all the groups were together.



Poker games, giant Jenga, and puzzles were the order of the day. There was serious competition between the dads and the mums for the games. Pat and Anthony know who won the Jenga!

This was followed by an exercise for all session by John Stack, who is one of the board members. This of course involved more competitions with losers and winners, resulting in an appetite for lunch. Following a lovely meal

much goodbyes were said and some tears from the young ones on the way home. This was partially due to saying goodbye to good friends and partially due to fatigue from late nights and too much sugar. On the way home the conversation came to the next haemophilia weekend. Where is it? Who will be there? Everyone is looking forward to the A.G.M next year, see you there.

Lorraine O'Connor

Youth Group – At Share Discovery Centre

I have been volunteering with the IHS for almost five years now and I have worked with all the different age groups. I look forward to volunteering at these weekends just as much as I did when I was in the groups myself. It's amazing to see how much the kids clubs have grown and evolved since I was a child and even since I started volunteering.

For this past member's weekend the youth group went to the Share Discovery adventure centre in Fermanagh. It was a new destination for the kids, and for me, my first time as a leader with the youth group. I was excited to work with the older kids as I hadn't worked with this age group before or been on an adventure centre weekend since I had been a member of the youth group myself. All of the kids were excited for the weekend's activities and catching up with their friends. We arrived late to the centre on the Friday evening, so it was straight to bed for the kids and leaders to rest up for the next day's activities. Both the kids and leaders participated in a number of activities the next day such as rock climbing, archery, canoeing and swimming. The kids attempted everything with a positive attitude and did each activity full of energy and enthusiasm. The whole weekend flew by and it wasn't long till we were boarding the bus back to the hotel.

Over these last few years as a volunteer, there has never been a day when I didn't enjoy



it. It is a very rewarding and worthwhile experience. The kids are always eager to do the activities or participate in the learning sessions. I really hope that the kids enjoy the weekends as I know the leaders always do. I look forward to the next weekend and seeing you all there!

Aisling Moriarty



World Federation of Hemophilia Congress 2016

The XXXII International Congress of the World Federation of Hemophilia (WFH's) takes place in Orlando, Florida from 24th to 28th July 2016. This congress is expected to be the largest in the WFH's history with more than 6,000 delegates expected from 125 countries. The National Hemophilia Foundation of the USA are honoured to host the largest international meeting dedicated to haemophilia, von Willebrand's disease and rare bleeding disorders for the first time in over 25 years. If you would be interested in attending or would like more information please click on the following link: www.wfh.org/congress



Congratulations

Many congratulations to Ellie Heffernan and John Stack on the recent arrival of their little boy Naoise who was born on 20th November. We would also like to send congratulations to Karen and Alan Whelan on the birth of their first child Amelia May.

Noel receives Gaisce Medal

Noel O'Brien from Portlaoise who has haemophilia received the Gold Gaisce Medal from President Michael D. Higgins recently. Noel has worked hard over the past two years to achieve this level of award. Noel trained and took part in sport events such as; athletics, shot put, discus and javelin as part of the Gaisce Programme. While training in these sports, Noel achieved a number of bronze, silver and gold medals and played for his county team. As part of his community involvement Noel worked with the Irish Wheelchair Association. On behalf of the Irish Haemophilia Society we would like to say congratulations to Noel on his wonderful achievement and determination. We are looking forward to hearing about your future successes.



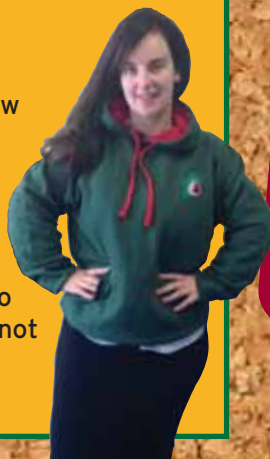
Ezine

If you would like to sign up for our monthly electronic Ezine magazine, please contact Leah in the office on 01 6579900. (Email: leah@haemophilia.ie) This electronic magazine gives reminders of events, articles of interest other up to date things that are happening in the I.H.S. (Please note that this is not replacing our quarterly printed magazine.)



Hoodies

We are delighted to let you know that we now have Irish Haemophilia Society hoodies for sale in various adults and children's sizes. Adults cost €25 and children's cost €20. Hoodies will only be available to purchase at I.H.S. events. Why not treat yourself at the AGM in March!



The essential components of a good strength programme

I hope you enjoyed the last article and found it useful. I always welcome feedback. I hope it opened your eyes and your mind to a powerful tool that can add quality to your life, regardless of age or ability.

This time, I want to talk about the components of a strength programme and try to bring clarity to things. Very little of what I am talking about in this article is mine or my creation or 'secret' system guaranteed to deliver results. There is nothing new to this, everything has been done before and there is no point in reinventing the wheel. Those things that made people strong throughout history are the same things that make people strong today.

Let's quickly mention Milos of Croton. He was a famous Greek wrestler from the 6th century BC. He won everything. Legend has it that, in order to get strong,

he got up one morning, selected a calf from his father's herd and carried it on his shoulders for a while. He did this every day. As the calf got bigger, it was more challenging to carry it. To tolerate the increased weight of the calf, Milos's body adapted by getting stronger. Eventually, the calf grew into an adult bull and Milos was still able to

carry it. Today, we call this 'progressive overload', an important element in a strength programme. It means that, in order to get stronger, we have to lift heavier things.



Strength is not complicated, but we've made it so. We need to simplify or, in the words of Dan John, an elite coach, bring clarity to our workouts.

So, let's get down to business.

First, a couple of clarifications:

- We're not talking about elite athletes in this article
- We are talking about people who want to improve their lifestyle by getting a bit stronger and adding some muscle mass

- We are talking about people with haemophilia who want to train in a safe and effective manner in order to add quality to life and excel at sports/physical activities
- If you want to get strong, you have to lift 'heavy' things
- 'Heavy' things are relative to the individual. What's heavy for you might be light for me and what is light for you might be heavy for somebody else.

Monday is bench day

If you walk into a gym any day of the week, lots of people are doing lots of stuff. If you walk into the gym on a Monday, however, you can be guaranteed that almost everybody is benching. The question of 'how strong are you' between two men is almost universally expressed as 'how much do you bench'. You'll rarely get asked how much you squat, deadlift, clean, snatch, how many chin ups can you do or what size kettlebell you use for Turkish Get Ups. You won't get asked about technique either, or whether the amount of weight you do in other lifts is proportional to what you're benching. Oftentimes, the people with the biggest bench are those with hunched shoulders and skinny legs. Fact of life.

Why am I saying this?

Balance!

A person who is truly strong and who is training to improve his health has a balanced training programme. This is the first piece of 'clarity' I want to bring you. If you bench, you must train your back too and your legs. When you train, you must consider your body as a single unit and train it thus, training muscles in isolation doesn't make you strong, rather training the whole body simultaneously does. The second piece of clarity is to train your body as a unit.

It is now generally accepted that, because of the sedentary nature of our lifestyles, we are becoming immobile. We sit for hours so our hips get tight. Tight hips are a major cause of lower back pain. We stare at screens for hours, tilting our heads which overworks the muscles of the upper back (note: I'm avoiding using scientific terms here for the sake of simplicity; not everybody knows what rhomboids are and, as for the sternocleidomastoid... you get the picture). Our



lifestyles impact on our posture. Trying to get strong without improving posture is a recipe for disaster and injury. This is another piece of clarity. Fix your posture and you'll be stronger without doing anything else. You'll also look slimmer/leaner because you're not slouching. Posture is not fixed in the gym. Stuff you do in the gym can help, but ONLY if you practice good posture all day long, whether you're sitting at a work station, watching TV, or if you're mobile and moving about. Think tall!

Now, let's combine balance and posture. Traditionally, to balance a training programme, there needed to be an equal amount of work done for the back of the body as the front. Nowadays, however, we need to do 2 to 3 times as much work on the muscle you can't see (i.e. all the muscles at the back of body) as the muscles you can see (i.e. the muscles you see when you look in a mirror). This is very important.

There is one more piece of clarity that I want to mention in this article and it is perhaps the most important.

SIMPLIFY!

The most effective training programmes are simple (note I said 'simple' as opposed to 'easy'). They tend to consist of a main lift for the day, some accessory work and perhaps a finisher. If there are 20 exercises to be completed in a single workout, I suggest you review things.

Putting it all together

So, let's describe a really simple strength programme in a way that brings clarity and simplicity. There are 6 movements that should be included in your programme and I'm going to lay them out in the order they should be done in. There are many variations of each movement.

Movement	Example
Squat	<ul style="list-style-type: none"> • Counterbalance squat • Goblet Squat (the best option for most people) • Barbell Squat <ul style="list-style-type: none"> ○ Front Squat ○ Back Squat ○ Overhead Squat
Hinge	<ul style="list-style-type: none"> • Deadlift • Romanian Deadlift • Kettlebell/Dumbbell Swing (the best option for most people)
Upper Body Push	<ul style="list-style-type: none"> • Vertical <ul style="list-style-type: none"> ○ military/shoulder press • Horizontal <ul style="list-style-type: none"> ○ Push Up (the best option for most people) ○ Bench Press
Upper Body Pull	<ul style="list-style-type: none"> • Vertical <ul style="list-style-type: none"> ○ Pull Ups ○ Chin Ups • Horizontal <ul style="list-style-type: none"> ○ Inverted row ○ Barbell bent row ○ Dumbbell row
Loaded Carry	<ul style="list-style-type: none"> • Farmer's Walk • Suitcase Carry • Waiter Walk • Combination Walks
Floor Work	<ul style="list-style-type: none"> • Foam rolling • Planks • Turkish Get Up • Rolling/Tumbling

There is a LOT of information in that table and I'll talk about each category in subsequent articles (you could write a whole book on each of them) and it serves to demonstrate why things can become complicated. Here's a suggestion - pick one movement from each category and do it each time you go to the gym for two weeks. Then pick a different movement from each category for the next two weeks and so on. The

content of the table raises another issue. Not only will you not know how to perform many of these movements, you may well have never even heard of them. You need a good coach who can do the following:

- Identify any mobility and postural issues
- Correct mobility and postural issues
- Teach you excellent exercise technique

Sets and Repetitions

One performance of a movement is a 'repetition' and a 'set' is a group of repetitions. So, '3 sets of 10 repetitions' means that you perform 10 continuous repetitions, have a rest, perform 10 more repetitions, have another rest and, finally, perform 10 more repetitions. This is standard terminology in all programmes.

How many sets and repetitions you should do is a complex issue and depends on your goals. There are thousands of programmes out there and they are all

good at achieving specific things. It is best left for a separate article. However, 3 sets of 10 repetitions is not a bad place to start. Or do each exercise for 30 seconds at a time.

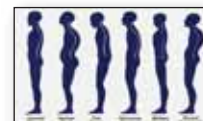
Getting Started

A sample beginner programme might look something like the following circuit. A circuit is where you move from one exercise to the next until you've done all exercises. You can repeat a circuit as many times as prescribed or required.

John Stack

Exercise	Repetitions
Goblet Squat	10
Kettlebell/Dumbbell Swing	25
Push Up	10
Chin Up	5
Inverted Row	10
Farmer's Walk	50 metres
Plank	30 seconds

The next table is a summary table containing the issues of clarity raised in this article and some recommendations.



Clarity	
Balance	Your training programme must be balanced.
Body as a unit	Train your body as a single entity.
Posture	We all have to work on maintaining good posture all the time.
Simplify	The easier your training is, the better.
Recommendations	
Have a plan	Know in advance what you're going to do. Walking in to a gym will almost certainly result in a poor workout.
Get a coach	A good coach can teach proper movement patterns and iron out any mobility issues you may have.
Everything works	Any activity you add to your life will yield some kind of result. Every training protocol you follow will deliver results – for about 6 weeks. After 6 weeks, you need something else.
<i>Festina Lente</i>	This means ' <i>make haste slowly</i> .' You don't improve your posture overnight and you don't get strong in a single session. Make it a part of your life and celebrate the tiny successes you achieve.

Fundraising in 2015

On behalf of the staff and board of the I.H.S., I would like to thank everyone for their fundraising efforts in 2015. We really appreciate the tremendous support you all gave organising and taking part in fundraisers throughout the year and for all the generous donations and contributions made to our Planned Giving Appeal. The effectiveness of our work depends on our supporters, not only to raise funds but to raise awareness of haemophilia and other related bleeding disorders.

The funds raised in 2015 through fundraising events, our Planned Giving Appeal and individual donations allows us to continue to provide the support and services needed both at home and on a global level. The Planned Giving Appeal allows us to provide the apartment facility for members, attending hospital appointments in Dublin and we are also actively involved with Vietnam and contribute to the development of haemophilia care globally through the World Federation of Hemophilia GAP Programme.

Our thanks to everyone who took the time and effort to organise and take part in fundraisers, which this year included a Raffle/Cake Sale, sale of CD's by The Twigs, a Fight Night, a Pink Hair Dye, London to Paris Cycle, a Bucket Collection, the Cork Mini Marathon, the Women's Mini Marathon, Movember and the Comedy Night in the Laughter Lounge.

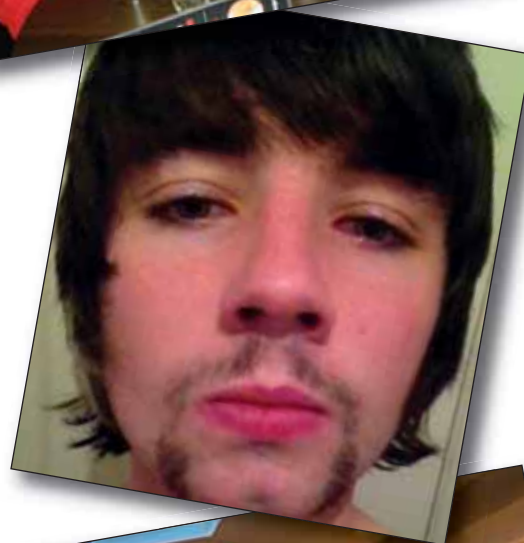
We are so proud of the wonderful support for the work of the I.H.S. and we would love to see this going from strength to strength. If you would like information on fundraising or our Planned Giving Appeal, then contact me on 01-6579900 or email nina@haemophilia.ie. Every contribution made and funds raised no matter how small is greatly appreciated.

"Nobody made a greater mistake than he who did nothing because he could only do a little"

Edmund Burke

Thank you for the tremendous support in 2015 and wishing everyone a Merry Christmas and Happy New Year.

Nina Storey



THANK YOU

A special word of thanks!

On behalf of the staff, board & members of the Irish Haemophilia Society, I would like to thank each and every volunteer who worked with the Society over the course of 2015.

As you have heard countless times, we could not cater to the needs of our membership without the hard work, generosity, dedication and enthusiasm of our very valuable and vibrant volunteers. With three main conferences annually, we do realise that it can be a huge commitment to volunteer while balancing college, work, family and a social life, (sometimes all four) while at the same time doing your bit for the organisation! Our volunteers not only work with our kids groups but we also have some volunteers who help us with administration tasks. With the

number of attendees at conferences increasing year on year this extra help is often quite necessary and very much appreciated.

This year alone saw 223 children aged from 0 - 17 years, have fun together, laugh, learn and make friendships. We had 46 volunteers who gave up their time to create fun and memorable weekends for all of these kids!

As always it was an absolute pleasure to work alongside you all this year. Your energy, enthusiasm and good humour never fail to put a smile on my and most importantly the children's faces!

Endless thanks,

Fiona Brennan





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