

Magazine of the Irish Haemophilia Society

haemophilia.ie



*Representing people in Ireland with
haemophilia and related bleeding disorders.*



The Society
at a Glance

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75

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Volunteers



6066

Website
Hits



WINTER 2017



haemophilia.ie

50th Anniversary AGM 2018

2nd to 4th March

Royal Marine Hotel, Dun Laoghaire, Co. Dublin

Preliminary Programme

Friday 2nd March

5.00pm – 7.00pm	Registration
7.00pm – 8.00pm	Dinner
8.00pm – 9.00pm	50th Anniversary Movie

Saturday 3rd March

10.00am – 12.30pm	Annual General Meeting
12.30pm – 1.30pm	Lunch
1.30pm – 2.30pm	iPATH Research Project
2.30pm – 3.30pm	History of the I.H.S.
3.30pm – 4.00pm	Coffee Break
4.00pm – 5.00pm	Perceptions of the I.H.S.
7.15pm	Gala Dinner

Sunday 4th March

10.00am – 11.00am	Memorial Service
11.00am – 11.30am	Coffee Break
11.30am – 1.00pm	Panel Discussion (Through the generations)
1.00pm – 2.00pm	Lunch

AGM Packs will be going out to members in early January.





A Note from the Editor

Hi everyone,

Welcome to the Winter issue of haemophilia.ie.

I hope you are all getting organised and excited for the Christmas festivities ahead.

If you have a look at the inside cover, you will find the preliminary programme for our AGM next year. AGM packs will be winging their way to everyone early in the new year! Also, if you would like further information on our calendar of events for next year, please see page 8.

In this edition, you will find some interesting articles on new developments in haemophilia care, plans for celebrating the 50th Anniversary of I.H.S., important updates on hospital charges and disabled parking, meet our two newest members of staff and an interview with Chris Bombardier, the first person with haemophilia to reach the summit of Mount Everest – along with reports from various conferences and our noticeboard with snippets of information for members.

Important details on hospital opening hours over Christmas are on the back cover. Why not tear this page out and stick it on your fridge!

It has been another extremely busy year in the office and one of change. I really would like to thank the staff, both past and present, the board, all the fantastic volunteers who helped us out throughout the year, those who contributed to our magazines and publications, everyone who did fundraising and who sent in donations or contributed to the planned giving campaign during 2017.

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

Debbie Greene
Administrator & Office Manager



*Debbie Greene,
Administrator & Office Manager*

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CEO's Report

Brian O'Mahony,
Chief Executive



Advances in Haemophilia Treatment

Recently, the World Federation of Hemophilia (WFH) and the European Haemophilia Consortium (EHC) organised separate conferences on advances in haemophilia treatment. At the WFH conference, clinicians, haemophilia societies, industry and regulators discussed topics such as use of extended half-life (EHL) factor concentrates, new novel therapies and gene therapy. The EHC conference included clinicians, patient organisation leaders and payers and discussed a similar broad range of topics. The conferences were an opportunity for clinicians to discuss with each other, and with patient organisation leaders, the changing treatment landscape and how they are utilising new therapies.

For the past 40 years, haemophilia treatment has been relatively straight forward - you replace the missing clotting factor in the event of a bleed or ideally prevent bleeds by means of regular prophylaxis. The availability of extended half-life clotting factor concentrates (CFC's) has increased therapeutic options.

These new products are being used by many countries for some people with haemophilia. The conferences afforded an opportunity for reflection and discussion. Which people with haemophilia should be treated with EHL products? Is

the objective less frequent infusions or higher trough levels leading to more protection from bleeding, or a combination of both objectives? Will the use of EHL CFC's result in greater adherence to treatment and improved quality of life?

The objective of prophylaxis for many years has been to maintain factor levels at more than 1% at all times. There is a clear correlation between the amount of time each week that the factor level is below 1% and bleeding risk. Ideally, the factor level would never go below 1%. More recently, with the availability of EHL CFC's, the debate has moved on.

In 2016, the European Directorate for the Quality of Medicines and Healthcare (EDQM) - an official body of the Council of Europe - formally recommended that trough levels of 1% were no longer adequate. Clinicians are debating what trough levels should be. There is no doubt that in an ideal world, trough levels of 15% or greater would almost completely eliminate bleeds. This level should be attainable in the future via gene therapy or an equivalent level of protection which may be available from some of the new subcutaneous therapies.



WFH

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOFILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

In the meantime, many clinicians and haemophilia society leaders are advocating for higher than current trough levels of up to 10%, and at least increasing trough levels to between 3% and 5%. This is more easily attainable with Factor IX (FIX) as the half-life extension is three to five-fold compared to an average 50% increase in half-life for Factor VIII (FVIII). In Ireland,



all people with severe FIX deficiency were switched to EHL FIX earlier this year. Preliminary results are very encouraging with average troughs having increased from 5% to 8% using weekly infusions or in some cases, infusion every 10 days or every two weeks.

At the conferences, there was a lot of information on changing treatment patterns in many countries. Ireland is the only country to date who have switched all the FIX people with haemophilia to an EHL factor. Canada has switched some patients, including all the children with severe FIX deficiency in some centres. The USA are switching some patients and some large centres in Germany have switched 60% of their FIX patient to an EHL factor. The UK are gradually switching some patients. The degree of switching to EHL FIX has been greater in many countries than the proportion currently switching to EHL FVIII due primarily to the much longer half-life extension



with the FIX products.

A UK clinician stated that their patients who had switched to EHL - both FIX and FVIII - expressed great satisfaction with the decreased frequency of infusions, the diminution in aches and pains and the fact that they are not having to think about haemophilia on a daily basis. People with FIX deficiency in Ireland who have switched, have expressed a broadly very positive experience. They bookmark the lower frequency of infusion, less aches and pains, the fact that their veins get a chance to recover and the increased convenience of travelling with lower amounts of factor.

There have also been reports from several countries showing a pattern of increased adherence to the prescribed treatment regime when switched to EHL. Three different centres reported adherence rates increasing from 68% to 85%, 73% to 86% and 60% to 82% respectively. We will need to monitor the impact of these new products on an ongoing basis using

many parameters including adherence, bleeding levels, physical activity, joint function, ability to participate in work, education and recreation, and impact on chronic pain.

Other therapeutic developments were also discussed and analysed. The bi-specific antibody - Emicizumab - which is being developed as a subcutaneous weekly treatment for FVIII deficiency or for treatment of those with FVIII inhibitors, was licenced by the US Food and Drug Administration (FDA) in November for the treatment of inhibitors to FVIII. This new product has demonstrated exciting results in clinical trials and will be marketed as Hemlibra. A European licence for this product for inhibitor treatment is anticipated in the next six months, with a licence for use in FVIII deficiency without inhibitors probably a year later.

The investigational drug Fitusiran, which suspended their clinical trial following a serious adverse event in September, has received a positive indication from the FDA and they hope to re-start clinical trials before the end of 2017. This product has potential for the treatment of FVIII or FIX deficiency, with or without inhibitors. It may also have potential for treatment of some severe von Willebrand cases or rare bleeding disorders.

Gene Therapy

Progress is continuing with gene therapy. University College London (UCL) now has results demonstrating long term expression of FIX following a single injection in 10 people with haemophilia. FIX levels vary from 2-7% and it is now more than seven years since the first infusion.

Spark in the USA have demonstrated FIX levels of an average of 33% more than one year post injection using a more potent FIX mutation for the gene therapy (the Padua mutation). This FIX mutation allows for the expression of FIX levels which are approximately 10 fold higher with no increased dose of the vector (injection). This mutation will also now be used by new FIX gene therapy trials from UCL in London (a trial which may well include Irish participants) and the new FIX trial from Uniqure in the Netherlands (who previously had expression of 5-6% using a non-Padua mutation).

Gene therapy for FVIII deficiency is also powering ahead with impressive results from Biomarin showing a range of FVIII expression levels from 20% to 200% with an average



of approximately 100%. Other companies and institutions, including Spark and UCL have also initiated FVIII Gene Therapy trials. I am also participating in an international process which seeks to define and agree a set of core outcomes for gene therapy. There are many gene therapy trials underway and ideally, we would get agreement from each of the companies developing the therapies that they would measure the same set of core outcomes, thereby making it a more practical proposition to properly compare the outcomes of each trial.

The process involved 48 people - clinicians, regulators, payers, gene therapy companies and haemophilia patient leaders and involved several rounds of discussion and voting. It is expected that a final list of five to ten outcomes will be agreed. There was clear consensus at this point that key outcomes, to demonstrate the efficacy of a gene therapy would have to include factor level achieved, frequency of bleeding and duration of expression (how long the increased factor level is maintained in the blood). Other outcome measures which may well make the final agreed list were degree of chronic pain, healthcare resources used, physical functioning and the perception of their health status or wellbeing by the person

who underwent the therapy.

New treatments discussed at the meetings were not solely limited to replacement therapies or novel therapies. Dr. Alison Dougall from Dublin, set out some of the new game changers in haemophilia dental care. These include the use of a low laser diode which can help reduce bleeding with gum disease and the use of a newly licenced compound called Silver Diamine Fluoride, which may greatly assist in preventing or treating caries in children, and avoid use of the dreaded drill.

The therapeutic landscape has never been more exciting or indeed more complex. There have been very few innovations in haemophilia treatment for the past 20 years (since recombinant FVIII in 1994) but we are now witnessing an explosion of new possibilities. The next five years in haemophilia treatment may well see more change than in the past 50 years, which is a nice thought with which to enter our 50th year as a society and as a community.

Brian O'Mahony, *Chief Executive.*

New Members of Staff

We would sincerely like to welcome our two new members of staff, Barry Healy and Robert Flanagan to the team! We are delighted to have them on board and looking forward to working with them.



Barry Healy, Publications & Social Media Co-ordinator

Joining us as Publications & Social Media Co-ordinator, Barry will be working with the Publications Editor in producing articles and materials, planning layout and design for all I.H.S. publications.

Barry will also be looking after the I.H.S. website, social media and distribution of the monthly electronic magazine to members. Barry will also be involved with the logistics of our events. Barry joins I.H.S. at an exciting time and brings with him much experience in both online and printed media; most recently having been editor of Council Journal.

Outside of work, Barry is passionate about music, something he has been exploring through his longstanding music blog, BarryGruff. Aside from music, Barry's other interests include football (his beloved Wrexham never fail in breaking his heart), history, reading and cycling.

Email: barry@haemophilia.ie



Robert Flanagan, Children's and Youth Programmes Co-ordinator

Robert joins us as Children's and Youth Programmes Co-ordinator. Robert will organise the four children's programmes at I.H.S. conferences. He will also be the first point of contact for Barretstown events, memberships, database and youth mentoring. Robert has great experience working with families and people of all ages.

Robert joins to the I.H.S. from the leisure industry where he was a co-ordinator for many different programs. He also has a creative eye and a passion for digital media which will be a great help for our publications, social media and the website. Robert's two main hobbies are football and photography. At 6'4 he is a tall man but don't worry he's a friendly giant.

Email: robert@haemophilia.ie

Preliminary Calendar of Events for 2018

2018

March

50th Anniversary AGM & Conference

Dates: Friday 2nd to Sunday 4th March

Venue: Royal Marine Hotel, Dun Laoghaire, Co. Dublin.

April

Father & Son Overnight

Dates: Saturday 14th & Sunday 15th April

Venue: Lilliput Adventure Centre

50th Anniversary of I.H.S. - World Haemophilia Day Event

Date: Tuesday 17th April

Venue: T.B.C.

May

Carrier Conference

Dates: Saturday 12th & Sunday 13th May

Venue: Castleknock Hotel, Dublin.

World Federation of Hemophilia Congress

Dates: Sunday 20th to Friday 25th May

Venue: Glasgow

June

Ageing & HCV/HIV Conference

Dates: Friday 22nd to Sunday 24th June

Venue: Killeshin Hotel, Portlaoise, Co. Laois.

July

von Willebrand's Disease Information Day

Date: Saturday 7th July

Venue: T.B.C. (Midlands)

August

Mild Haemophilia Information Day

Date: Saturday 18th August

Venue: T.B.C.

September

Mother & Daughter Overnight

Dates: Saturday 8th & Sunday 9th September

Venue: Lilliput Adventure Centre

50th Anniversary Gala Dinner

Date: Saturday 22nd September

Venue: Castleknock Hotel, Dublin.

October

October Conference

Dates: Friday 19th to Sunday 21st October

Venue: Radisson Hotel, Sligo

November

Haemophilia B Information Day

Date: Saturday 10th November

Venue: T.B.C.

December

Children's Christmas Party

Date: T.B.C.

Venue: T.B.C.

Celebrating 50 years of the Society

Next year will be a momentous year for the Society as it will mark our 50th anniversary. The Society was founded in 1968 by doctors, parents and people with haemophilia. At that time, treatment for haemophilia was based entirely on plasma or cryoprecipitate. Now, as we stand on the verge of our 50th anniversary, we have been using synthetic recombinant factor concentrates for 20 years and we now have longer acting factor concentrates available.

Novel therapies including subcutaneous therapies for both inhibitor and non-inhibitor patients will shortly be available and an effective cure via gene therapy looks more and more likely to be available within five years. In 1968, we were awaiting the first treatment centre - subsequently opened in the Meath hospital in 1970.

Now, as we are poised for our 50th year, we have a purpose built National Coagulation Centre, a state of the art in-patient unit and sandwiched between them, an impressive clinical trial unit which has assisted us by having the facilities to carry out and access clinical trials for new therapies, which in turn, helps to maintain Ireland at the forefront of haemophilia treatment innovation.

The Society has evolved from operating out of the homes of people with haemophilia or parents, to operating from our own office which is owned by the organisation, working with an active and engaged board and an excellent staff team, and providing a broad range of educational and assistance services for members.

Parents, people with haemophilia or families who are attending the comprehensive care centres in Dublin can avail of the accommodation facility owned by the Society and members in Cork and Munster can attend the excellent new Comprehensive Centre at Cork University hospital. We are working in collaboration with the children's hospital development board to ensure that the newly built National Children's Hospital will provide optimal services to children with haemophilia and related bleeding disorders from the entire country.

We have fought many battles, endured many tragic losses and advocated successfully on many occasions over the past 50 years. Next year will be a year of remembrance and celebration. The Annual Conference and AGM next March will be a celebratory affair. The programme will include the premiere of a movie on



the history of the society which has been filmed over the past 18 months. The children's programme will feature a series of novel activities. We will also mark the 50th anniversary with specific activities on World Haemophilia Day in April and with a gala dinner in September.

Brian O'Mahony, *Chief Executive.*



Educational Grants 2017

Many thanks to everyone who applied for an educational grant from the Irish Haemophilia Society. This year we received a total of 20 applications - both online and through the mail - which is marvellous!



The executive board sub-group met on October 25, 2017 to look at all the applications and to score same, after which a final decision was reached. The results are as follows:

Maureen & Jack Downey Educational Grant

- **First prize** – Gary Butler - €4,000
- **Second prize** – Sean Hanney - €2,000
- **Third prize** – Jordan Sullivan - €1,000

Margaret King Educational Grant

- **First prize** – David Moriarty - €2,000
- **Second prize** – Barbara Wynne - €1,500
- **Third prize** – Nicole Chun - €1,000

A number of smaller grants were also given and recipients were notified in late October - congratulations and very well done to everyone.

We would like to encourage as many of you as possible to apply next year. It's very worthwhile and of great benefit, and can go some way to helping cover the cost and expense of your education.

Many congratulations to you all!
Debbie Greene

Hospital Charges



For several months, there has been a lot of confusion as to whether people with bleeding disorders have to pay for both hospital admissions and A&E visits in St James's Hospital.

After consulting with St James's during this time, we got official confirmation that you DO NOT have to pay these fees.

If you have made payments, these should be refunded by contacting the finance department at the hospital on 01-4103000. If you receive a bill in the coming weeks or have already received a bill, contact the finance department and tell them you are a patient at the National Coagulation Centre, your bill should then be disregarded.

If you are having any issues regarding this, please contact our Outreach Coordinator, Lyndsey at the office on 01 6579900 and she can assist you with this.

Disabled Parking in St. James's

After a meeting and walk around in the grounds of St. James's Hospital with the new National Coagulation Centre Manager Deirdre Walsh, we are happy to give you information about all the disabled spaces located in St. James's as follows:

- 5 disabled spaces in the underground car park
- 5 disabled spaces at hospital 5
- 2 disabled spaces at hospital 2
- 2 disabled spaces at CPL-central pathology lab (across from the Luas track)
- 3 disabled spaces at car park 2
- 10 disabled spaces at the discharge lounge area (access can be gained to the main hospital through the discharge lounge entrance)
- 4 disabled spaces in the surface OPD pay car park

There may also be additional disabled parking at MISA/hospital 4 and these are currently being reviewed.

An information leaflet showing the location of the disabled parking spaces in St. James's Hospital is in the pipeline, and we will circulate this once we have it.



Please remember also, the National Coagulation Centre has two wheelchairs. If you need assistance, please call the National Centre and they will arrange to have a porter meet you in the underground car park to bring you up to the Centre or the H&H Unit.

Thank You!

"In the Autumn edition of our magazine we adapted an article for use which written by Laureen A. Kelly entitled "Teaching Your PreSchooler about Hemophilia". The I.H.S. would like to acknowledge this and to thank Laureen for allowing us to do so."

Cubs



We would like to wish all our Cubs Group a very Merry Christmas and a Happy New Year. We hope you all enjoy the holiday break!

Brian is really looking forward to Christmas too. After School today, a friend asked Brian what his favourite things about Christmas are. His favourites are: Christmas Cake, Christmas Lights and presents!!!

What are your favourite things about Christmas?

1. _____
2. _____
3. _____



Did you know?

- Snowflakes get smaller as the temperature drops.
- Almost 90% of snow is air.
- The longest paper airplane flight was 200 feet (61 metres).
- It would take about three years of non-stop pedalling to cycle to the moon.

JOKE CORNER

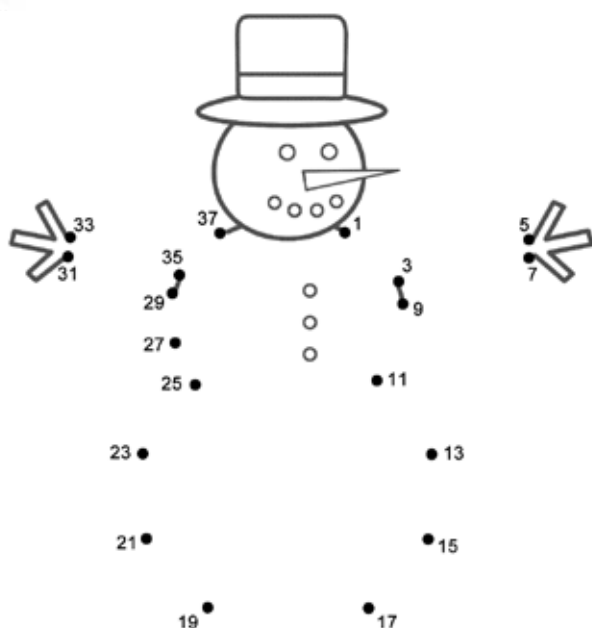
What do you get if you cross Santa with a detective?
Santa Clues!

Why does Santa Claus go down the chimney on Christmas Eve?

Because it "soots" him!

Why is it so cold at Christmas?

Because it is in DecemBrrrr





Can You Spot the 10 Differences?

We would like to wish all our Kidlink Group a very Merry Christmas and a Happy New Year. Looking forward to seeing you all for lots more fun in 2017!

Did you know?

1. In 1999, residents of the state of Maine in America built the world's biggest ever snowman. He stood at 113ft tall!
2. The largest Santa hat measures 15.47 metres (50 ft 9 in) long and 8.23 metres (27 ft) wide and was created by children from the Chill Youth Club (all Norway). The hat was presented and measured in Fredrikstad, Norway on December 9th, 2008 and took three months to complete.
3. The most Christmas trees chopped in two minutes is 27! It was done by Erin Lavoie from the USA, in Germany, on 19 December 2008.

It's good for everyone to play games and sports.

It keeps you strong and healthy. When you have haemophilia, strong muscles are particularly important because they help to protect your joints from bleeds.

While you're at primary school you will probably want to join in most of the games your friends play. Maybe you'll have the chance to go on an activity holiday and try new sports so that when you are older, you can choose a sport that you enjoy.

Some are particularly good for boys and girls with haemophilia; others it's best not to play and some may mean that you need to change which day you take your prophylaxis so you don't have problems.



Jamie loves football. He supports his local team but he likes to play football too.

The doctor said it was ok to play at school and in the park but it would be better not to join a team because proper matches can be very rough.

Jane loves to swim and she does lessons at her local pool. This is great because swimming is lots of fun and really good for keeping fit and healthy, and it also strengthens up muscles without hurting your joints.



Remember: whilst there are certain types of sport you should avoid, there are many, many others you can enjoy. So, get out there, get active and above all have fun!

Go Try: Swimming, Golf, Badminton

Be Careful: Soccer, Running, Tennis

Avoid: Rugby, GAA, Hockey

Chris Bombardier: Conqueror of Everest

In May 2017, Chris Bombardier made history when he became the first person with haemophilia to reach the summit of Mount Everest, the world's tallest mountain at 29,029 feet.



Most of us will never have the courage to climb mountains, let alone the tallest peak on the planet, but Everest was Chris' sixth summit as he attempts to complete the Seven Summits Challenge, which involves climbing the highest peak on each continent. Chris' push to conquer the Seven Summits has been to raise support for the 'Save One Life' charity, which helps sponsor children and adults living with bleeding disorders in developing countries.

This intrepid tale began while he was working at the University of Colorado Haemophilia Research Lab, and was offered the opportunity to travel to Kenya in 2011 as part of a humanitarian mission to help those with haemophilia. With the trip booked, inspired by stories of big mountain climbs from his uncle and dreams of his own epic expeditions, Chris decided to attempt Kilimanjaro; the highest peak on the African continent – it was a trip that changed his life forever.

Having witnessed the plight of those suffering with haemophilia in the developing world first hand, upon his descent from the summit of Kilimanjaro, he decided to commit himself to the goal of climbing the Seven Summits, and to help change the lives of some of his "blood brothers that struggle around the world".

Chris was diagnosed with severe haemophilia B at birth and it has played a dramatic role in who he is, and his life path.

As of November 15, Chris has scaled six of the Seven Summits; Mt. Kilimanjaro, Aconcagua, Elbrus, Denali, Carstensz Pyramid and Everest.

In late December, Chris will set out to conquer Mount Vinson in Antarctica, the final trip of his Seven Summits Challenge. It has been a long journey to get to this point. It is the culmination of many years hard work, dedication, training and a dream – which has seen Chris learn, grow and improve as a climber.

Before setting off to conquer Mount Vinson, we caught up with Chris to talk about his journey, the Seven Summits Challenge, his love of being active, haemophilia and more:

Your first sporting obsession was baseball, what sparked the transition to mountaineering?

"I transitioned to mountaineering shortly after I graduated college. I played baseball throughout my childhood and was given a scholarship to play in college but I didn't have the skills to play at the next level after college. I love being active so I started searching for something new. I started spending time with my Uncle Dave in the mountains of Colorado and he

introduced me to the incredible world of climbing and I fell in love with it!"

For you, what has been the most challenging element of your life with haemophilia? And how have you worked to overcome it?

"There have been many challenges living with haemophilia. I had several bad bleeds while growing up that were incredibly painful but I think the most challenging element has been the psychosocial impact. I remember as a kid hating that I was different. I couldn't understand why I had to deal with this condition and be stuck with needles and other kids didn't. I remember that having a profound impact on my life and I struggled with feeling sorry for myself for years. I wasn't engaged with the haemophilia community at the time and I felt incredibly isolated, but that all changed when I started going to community events and meeting others with bleeding disorders."

In May, you reached the summit Mount Everest, the sixth in your quest to conquer the seven highest peaks on each continent. What is the inspiration behind completing the Seven Summits?

"The Seven Summits challenge initially came about as a personal challenge. I listened to stories of my Uncle Dave climbing Denali, North America's highest peak, and the brutal conditions he faced and it intrigued me for some reason. In 2011, I was given an opportunity to travel to Kenya for a haemophilia project and decided to tack on a Mt. Kilimanjaro climb because of its proximity in Tanzania."

"My experience in Kenya changed my life forever and became the inspiration for my climbs. We visited a hospital the first day and saw a teenage boy dying because of his haemophilia. It was an incredibly sobering moment seeing what haemophilia can look like. I struggled with guilt for a while on that trip. I felt selfish that I was getting ready to climb a mountain and individuals with haemophilia so close by were struggling to live. When I summited Kilimanjaro, I decided that I wanted the Seven Summits to be more than about my personal challenge but an opportunity to raise awareness for haemophilia, especially globally."

What were the biggest challenges you faced in the course of conquering Everest?

"Many of the biggest challenges I faced in climbing Everest happened before even stepping on the mountain. I trained extremely hard for six months before we left for Nepal and it

was really difficult to stay focused on the training every day but I'm really glad I stayed committed."

"There were also moments that I could've let the complexities of life overtake my dream. There were instances in which we were struggling financially and I probably should've gotten a different job but that would've made this dream even more challenging. My wife was incredibly supportive throughout all of this and never let me make those decisions. She encouraged me to keep this dream and we would figure out the financial aspect some other time."

"The last two climbs are also very expensive so getting funding for those was hard. Specifically, with my haemophilia one of the challenges I continue to face on a day-to-day basis is my fear of needles. This has always been an issue for me and led to moments of non-compliance to my prophylactic treatment in the past. Having the motivation of these climbs and knowing that treatment is a must has helped me deal with that fear but it is still present every single time I infuse."

Were there times when you thought you might not make it to the summit of Everest?

"On the climb, there were a few moments that were extremely challenging. The one that stands out the most is when I was near the summit, at a feature called the South Summit. I had already been climbing for about 10 hours that day when we reached a point where the route follows this knife-edge ridge. Off to the left, you can see 9,000ft down into Nepal and Camp





Chris at the summit of Everest

2 and off to the other side, 11,000ft down into Tibet. It was an overwhelming feature and I was so tired that I thought it was too much. I actually sat down on a chunk of ice before this part of the climb began and I thought I was done."

"I was coming to grips with the fact that I might not make it to the summit but I knew the most important aspect of the climb was coming down safe. Just when I thought I was ready to turn around Tashi, the lead climbing Sherpa of our team, said "Chris, you can do this. You are here for a reason, you have a purpose, you can do this." He then walked by and clipped one of the carabiners on his harness through the one on mine and kept walking."

"This took me by surprise but it got me moving. As we started onto the ridge line it ended up not being as bad as it looked from a distance. While I was climbing through that section, I thought back to the mission and purpose that Tashi had reminded me of and I remember I was carrying a flag in my pocket. The flag was a 'Save One Life' flag and I had all the signatures of the individuals from the Nepal Haemophilia Society that I met before the climb. I remembered the immense struggle that they face every day and I remembered that they were with me on this climb. It meant the world to me to have that flag. It felt like I got a boost of strength to make it to the summit. It was one of the greatest moments of my life."

What was it like when you finally stood atop the highest peak in the world on May 22?

"It's hard to describe what standing at the top of the world was like but as I said in the above question, it was one of the greatest moments of my life. I couldn't believe that I was standing at the highest point on Earth. I tried to soak in every moment as best I could. The highlight of the summit was that I got to call my wife. My friend Rob, who works with the film crew and stayed at basecamp for the entire climb, FaceTimed with my wife and they were able to connect us through the radio. She has sacrificed just as much and maybe more along this journey, it was just incredible to be able to share that moment with her."

Your journey to the peak of Mount Everest was chronicled as part of documentary film 'Bombardier Blood', can you give us an idea of when it will be released?

"The film is going to be entered into film festivals throughout the U.S. and the world starting in the spring of 2018. We aren't exactly sure of any dates yet but we will be posting updates when we get more info on bombardierblood.com. You can also follow my Facebook page 'Adventures of a Haemophiliac' for further updates."

There's now only one of the Seven Summits to climb, Mount Vinson in Antarctica, when are you planning to tackle it?



Chris self-infusing

"I am leaving on December 25th for my climb of Mt. Vinson. I'll fly down to Punta Arenas, Chile first where I will meet up with the rest of the climbing team. Hopefully we will head down to Antarctica on December 29th to start the climb!"

What lasting legacy would you like to see left behind from your journey?

"Great question. My hope is that there are a few lasting legacies for these climbs. The first involves those living within the haemophilia community. I hope these journeys can bring them hope that despite having haemophilia, they can chase any dream that they have, so long as they approach it in a smart way. For those living with bleeding disorders in the developing world, I hope this climb also brings them hope for a life with access to treatment and a platform to lobby their government for better treatment."

"Finally, I hope these climbs and especially the documentary film, bring an awareness to haemophilia globally, especially the

drastic disparity in care that we see around the world. I want people to see that need, and want to do something about it.

And lastly, in all the interviews you've done is there anything you're eager to address but no one ever asks you?

"Thanks for this question! I really appreciate the opportunity to add something a bit extra. First, I think people forget that Everest is the sixth mountain of the Seven Summits. This has been a long journey to the summit of Everest and that I have had to develop as a climber and train extremely hard for years and years to attempt that climb. I think this an important note because I want people to realize that committing to a dream takes dedication and resilience. I think having haemophilia has taught me so much about how to be resilient but this is a huge process."

"The Second thing I would like to mention is about a program we started in Colorado called 'Backpacks and Bleeders'. The idea came to me when climbing Aconcagua in Argentina. During a rest, I looked out at an incredible view and it popped in my mind in that moment that we should be sharing experiences and views like this with our community so, with the help of our executive director Amy Board, we started the program. The goal is to teach the haemophilia community how to enjoy the outdoors in a smart way. We just kicked off a relaunch of the program a few weeks ago which is really exciting!"

For more information on Chris and his challenge, please check out: adventuresofahemophiliac.com.

Barry Healy

Photos provided courtesy of forthcoming film 'Bombardier Blood'.



Member's Conference Report



The Member's Conference took place in October, in the scenic Hodson Bay Hotel in Athlone. In addition to the I.H.S. staff and our wonderful volunteers, 122 adults and 89 children attended the weekend. We would like to thank all our volunteers who gave up their time to look after the crèche, cubs, kidlink and youth groups for the weekend, they do an amazing job. Registration had a slightly new format this year, allowing members to pay for the conference in advance and as such, registration was a lot more relaxed, which I think everyone appreciated.

Another slightly new aspect to the weekend was an information session and dinner for everyone on the Friday evening. This proved so successful at the AGM & Conference in March, we decided to follow the same format at this conference. We are delighted to say that the feedback from the members was very positive, the members really appreciated the extra time on the programme to receive updates and new information as well as an opportunity for everyone to gather together.

On Friday evening, the weekend started off with a session on 'Vietnam & Planned Giving', presented by our CEO, Brian O'Mahony. We know the members are very interested to hear about the developments and progress made by the I.H.S. to help improve haemophilia care for patients in Vietnam. The I.H.S. first became involved with the Vietnam

Haemophilia Association (VHA) through the World Federation of Hemophilia (WFH) Twinning Programme and when the programme ended, the I.H.S. continued to work with the VHA to help and support them. The I.H.S. Planned Giving Appeal is a way for our members to be actively involved and show their support for the work carried out with the VHA. Funds received go towards grants for home adaptations and micro employment projects for patients in Vietnam.



Dr Glenn Pierce, M.D., Ph.D. speaking about 'New Developments in Haemophilia Treatment'

Saturday began with the volunteers ensuring that all 89 children were registered in their relevant groups for a weekend of fun and games, leaving parents free to attend the sessions. The first session of the day began with a very informative talk by Dr Glenn Pierce, M.D., Ph.D., from the USA. Dr Pierce spoke about the 'New Developments in Haemophilia Treatment'; his presentation covered the evolution of treatment products, extended half-life products and gene therapy. If you would like a copy of Dr Pierce's presentation, it can be found at our website, haemophilia.ie.

Following on from Dr Pierce's presentation, there was an interactive workshop on the 'Future of Haemophilia Care', facilitated by members of the I.H.S. staff. The workshop was divided into four groups; parents of children with Factor VIII,



adults with Factor VIII, all parents of and adults with Factor IX and von Willebrands Disease and other rare bleeding disorders. The workshop involved frank and open discussions on the new therapies, and Dr Pierce then spoke with each individual group to address any questions they had.

Lunch was a welcome break after the morning sessions but it wasn't long before we were back on track again. The afternoon began with two sessions which took place simultaneously; one covering 'Port-a-Cath's' and the other, 'Vein Care'. Ms Imelda Kelly, Haemophilia Nurse Specialist from Our Lady's Children's Hospital in Crumlin, gave the presentation on port-a-caths. Imelda opened with an overview on port-a-caths and followed this with a question and answer session. The Q & A was an excellent opportunity for parents to voice their concerns on particular issues and gain expert advice.

In another room, Ms Shona Brady, Clinical Nurse Specialist from the National Centre Coagulation Centre in St. James's Hospital gave a talk on vein care. Shona explained the importance of looking after your veins; it's easy to become accustomed to using your 'good' vein but your veins need time to heal between infusions. Even if you don't feel that comfortable doing this, you need to vary the veins as overuse of the same vein can lead to scarring. In order to maximise venous access, it's important to make sure you are well hydrated and if possible, do your infusion shortly after a shower or bath. Shona kindly took time after her session to talk to members individually and demonstrate how to feel for a vein, which can be especially difficult for a parent who is finding a vein in a young child.

The last session of the day covered 'Tattoos & Piercings' and was presented by Ms Noreen Boland, Clinical Nurse

Specialist from the National Coagulation Centre in St James's Hospital. Noreen explained that the National Centre does not have set guidelines on tattoos and piercings, however she emphasised the importance of talking to your treatment centre before getting a tattoo or piercing. Each person with a bleeding disorder has a different bleeding pattern and first and foremost, their decision to have a tattoo or piercing should be based on this. In addition, you need to ensure the selected tattoo parlour is a reputable one. For information on how to establish you are choosing the correct tattoo parlour, the Association of Body Modification Artists in Ireland (A.B.M.A.I.) website has a section called 'Guidelines for Choosing a Body Modification Artist', which outlines the questions you should be asking. This particular session was of particular relevance to our young members and so was open to the youth group who joined us for this talk. At the end of the session everyone had the opportunity to ask questions and the youth group were very involved. The interaction between all those who attended with their own advice, stories and opinions was very welcome.

Although it was a long day, as usual our members know how to have fun and the Saturday evening dinner was relaxed and full of chat and laughter. The dinner was followed by our now renowned all ages table quiz! I would like to say the atmosphere remained relaxed, but when it comes to a quiz, it's every team for themselves. It really is good craic with lots of banter. The winners this year, for the third year in a row were our brilliant bunch of volunteers.

After a night of good food and good company, Sunday morning got under way with three separate peer support group sessions. The first group for mothers was facilitated by our Outreach Co-ordinator Lyndsey Connolly, the second group for fathers was facilitated by our CEO Brian O'Mahony and the third group, for PWH's and family members was facilitated by Anne Duffy our volunteer nurse/counsellor. Peer support is an amazing tool and without doubt these sessions are extremely beneficially. The peer support isn't confined to our sessions; you can see it everywhere you look at all our conferences. Members chatting over lunch or during the coffee breaks, giving each other advice and moral support, exchanging phone numbers and being there for each other. In order to build on this support, the I.H.S. would like to run regular peer support group meetings in 2018, aside from those included at the conferences. If you are interested in becoming involved in a peer support group, please contact Lyndsey in the office on 01-6579900 for more information.



Sunday Morning Drumming Workshop



Finger Painting in the Cubs Club



Discussion time in Kidlink

While the adults were occupied at sessions on Saturday and Sunday, the volunteers were kept busy overseeing the children's programmes. The crèche group enjoyed fun and games, as you do when you are 3 years and under. The cubs (aged 4-7 years) enjoyed games, arts and crafts and a swimming lesson. The kidlink (aged 8-12 years) and youth (13-17 years) groups had the added bonus of taking a trip to a nearby activity centre on Saturday for quasar and bowling. Other than the crèche group, all the kids and young adults had educational sessions over the weekend, as well as being involved in a 50th Anniversary Project to help the I.H.S. celebrate in 2018.

The conference ended on a high on Sunday with everyone coming together, kids and adults, for a Samba Drumming Workshop. It was great fun and everyone really got into it. You are a talented bunch but I'm not so sure about my own contribution on the maracas though. We hope that everyone who attended, enjoyed the conference and each of you gained something from the talks and sessions. We look forward to seeing you all again at our AGM in March to help us celebrate our 50th Anniversary.

Nina Storey

A Special Thank You to our Volunteers!

On behalf of the staff, board and members of the Irish Haemophilia Society, I would sincerely like to thank each and every volunteer, who dedicated their time and effort to the society this year. Our conferences and events simply would not be possible without the dedication and incredible generosity of our volunteers.

You allow us to make our conferences family friendly, super fun and very meaningful by creating a wonderful environment for the kids, that create lasting memories and friendships. Dedication so much time to the society isn't easy with many of you trying to balance work, study, family and social life, so we cannot thank you enough for the tremendous effort you put into the weekends.



This year saw five events where the volunteers played an absolutely imperative role. This allowed for 240 children to experience memorable weekends of fun, games, sport, laughter and learning. There is nothing like the friendships built in the I.H.S! Along with volunteering with our kid's groups, some volunteers play a huge role in helping us with administrative tasks, lending a helping hand when needed. So, it is with a beaming heart I say a massive thank you to all our 41 volunteers who we would be lost without!

Best wishes and Happy New Year to all of you!
Aoife Ní Fhógartaigh

Fundraising 2017

'Thank you' is a phrase used to tell someone that you are grateful because they have given you something or done something for you. These two simple words do not seem enough to express our gratitude to all those who have supported the I.H.S. throughout 2017. We would not be able to do all that we can without the support of our members. It's due to your kindness and generosity that we can maintain and provide the services and support we do.

On behalf of the staff and board of the I.H.S., I would like to thank everyone who has organised or taken part in fundraisers throughout the year and for all the generous donations and contributions made through our Planned Giving Appeal. We really appreciate the tremendous support.

Our fundraisers this year included a Sky Dive, the VHI Women's Mini Marathon, Movember and a climb up Mount Carrauntoohil in Kerry. We really appreciate the time and effort that goes into organising a fundraiser or taking part in an organised event. So as a thank you to all our fundraisers, we will start the New Year off with a draw for all those who raised over €250 in 2017, so keep an eye out in the post, you might be our lucky winner. We will also be announcing our fundraiser of the year and we hope they can join us as our guest at our AGM & Conference in March for a presentation.

But 2018 is another year, and with the I.H.S. celebrating its 50th Anniversary next year, we would love to make it a year to remember. If you have ever thought about fundraising for the I.H.S. but never quite got around to doing so, then 2018 is your year. Why not be part of our celebrations? Kicking off the fundraising in 2018 we already have someone taking on a trek up Mount Kilimanjaro in Tanzania at the end of the year, but if climbing a mountain is not for you, there are lots of other fundraising ideas to choose from. If you would like to organise a fundraiser or make a donation in lieu of wedding favours, or have friends or family make a donation in lieu of birthday gifts, just let us know. We can produce table cards for your special day or provide posters, I.H.S. t-shirts, sponsor cards etc. for your fundraiser, whatever you need we are here to help.

For information on fundraising, donations or our Planned Giving Appeal, don't hesitate to contact me on 01-6579900 or email nina@haemophilia.ie. Thank you again for the tremendous support in 2017 and we would like to wish everyone a Merry Christmas and Peaceful New Year.

Nina Storey



Making Waves



My name is Colm, I am 42 years old and I live in Cork. I have severe Factor IX deficiency. I unfortunately broke both of my legs in a motorbike accident when I was 16 years old. I spent six months in hospital, three months of which were in traction. I shattered my right thigh bone and broke my shin bone. My right knee is my target joint, so this caused a lot of problems with the healing process. I started swimming about 15 years ago because the doctors said it was the best form of exercise for me, due to my severe haemophilia and the damage I had done to my legs 26 years ago. I had always liked the water and had no problems swimming in the pool. It was a 25 metre pool and I always felt good after a swim. My legs and general fitness were always a main reason why I swam.

About six years ago, I noticed I was going further and further, and increasing my distance. One day Richie, who was a lifeguard at the pool, asked if I would consider joining him in doing the Lee swim in Cork. It is a 2km swim. He said I was more than capable. So, I increased my effort and in June 2013 I completed the Lee swim in 36 minutes and to my amazement, I beat Richie. The seed was sown. The next year I just stayed with what I was doing in the pool, I did the Lee swim again and bettered my time by roughly three minutes. In 2014 I did my first sea swim around Sandycove Island, an amazing spot down by Kinsale, Co Cork. It is a 1.8km swim. I was getting even stronger.

In 2016 the Rebel Plunge swim was announced in Cork. It is 3.8km. Tomas who is also a lifeguard at my pool asked if I would join him in doing it. I completed the Rebel Plunge in 55 minutes

and was 3rd out of the water. It got me thinking for 2017; what could I do if I trained and ate properly?

At the start of 2017 I set two goals for myself; to give it everything in the 2017 Rebel Plunge and do the 5km swim around Garnish Island in Glengarriff. I went to a personal trainer for nutritional advice which was vital for what I wanted to achieve. I also began upping my distance in the pool to 3km a session and doing between 13km to 15km a week. In March 2017 I began a nutrition plan based on what I wanted to achieve.

On a typical swim day, my food intake began with 65 grams of oats with blueberries and a banana. At 11am I ate two turkey rashers, two eggs and a cup full of mixed peppers. 30 minutes





before my swim I ate 100g of pasta with sweet corn and another cup of veg. Post swim, I drank water and ate 100g of turkey or chicken with a bagel, and for my supper I had 250g of natural Greek yogurt with protein powder mixed in. That was my food five days a week. For the two days I didn't swim, I omitted the pasta. This all made meal prep essential.

I went up to the 50 metre pool in the Sports Arena in the University of Limerick a few times. I was pushing myself to do drills in the bigger pool. These consisted of 5 x 200m as a warm up, a 2k steady swim and a 1k cooldown. This was building up my stamina and making my muscles stronger. The proper nutrition was giving me the energy I needed to keep the swimming going. I would take two days off in the week, which was very important to give my body a break and a chance to recover.

With the Rebel Plunge approaching on the June 8, I was in good shape to give it my best. The swim came and I completed it in 43 minutes with an outgoing tide which I was delighted with. All the training had paid off. The night before the swim I gave myself 8000 units of factor 9 just in case.

The following weekend I signed up for the 5 km Garnish Island swim. I increased my work rate in the pool and was doing one 4km session in the pool every week. I was swimming around Sandycove Island once every week and also in Inniscarra Lake. I was increasing my distance up and keeping my healthy eating going at the same time.

August 12 arrived and it was time for the Garnish Island swim. I completed the 5km in 1:15:28 and I was delighted with what I had achieved. This was a huge mental effort as well; to keep going and being prepared mentally is as important as being prepared physically.

I have severe haemophilia Factor IX deficiency and it has not stopped me in doing something which helps me both physically and mentally. The support of my partner Sinead was a huge help in going to swims and giving me the encouragement to go that bit extra. Also, my family are there, supporting me in every way they can.

I have enjoyed writing this on the pool deck in Italy, taking it easy after my swim, enjoying the down time and eating ice cream. If you have a goal, work damn hard for it and give it the best shot you can. Don't be disappointed if it doesn't go according to plan, once you have given it your best, that's all that matters. Pick yourself up, dust yourself off and try again. You must let life become your teacher.

Colm Walsh

Vietnam: Planned Giving and the Poverty Trap

The Irish Haemophilia Society (I.H.S.) have been working with and collaborating with the Vietnam Haemophilia Association (VHA) since 2010. In our continuing work with the Vietnam Haemophilia Association, two of the notable successes to date has been the micro employment project and the home adaptation project.

These projects, launched in 2015, have to date provided the means for 20 families or people with haemophilia to live, by giving them the essentials required for subsistence. In some cases, this was the tools required for home employment:- sewing machines, fit out for a barber's shop, and in other cases the provision of livestock such as cows for impoverished families. The home adaptation project has to date provided 56 wheelchairs, 43 pairs of crutches, 12 disability friendly toilets and three handrails for homes.

The average daily income for many people in Vietnam is less than \$1. The economic pressures on families with haemophilia in Vietnam are great, with co-payment required for their medications, that in many cases exceed their income levels. On some occasions, they have to choose to eat or treat.

Their lack of mobility diminishes their educational prospects and consequently their employment prospects. Surely the

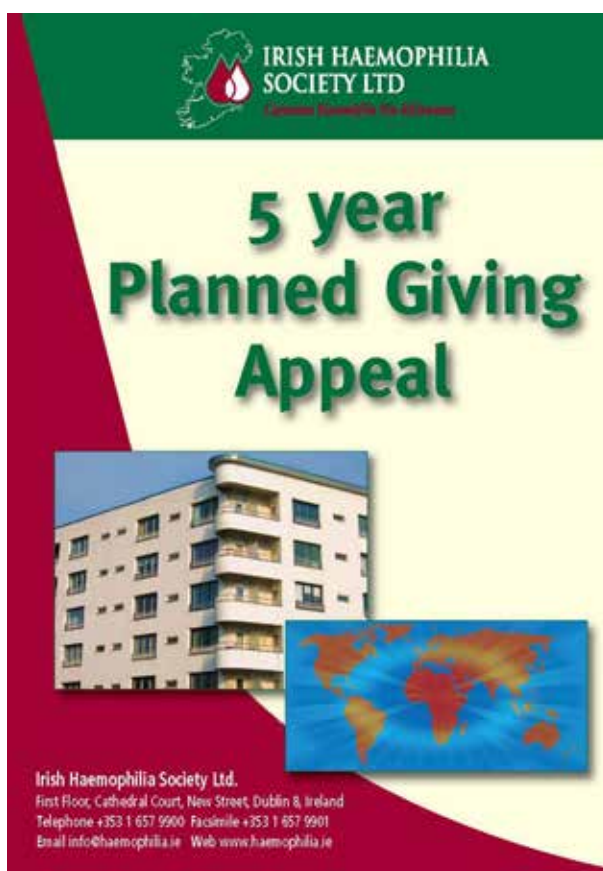
answer lies in small scale micro employment projects (such as the project run by the Irish Haemophilia Society for the past two years) which provide a sufficient level of subsistence income for a family to prevent them, in the case of haemophilia, from having to choose to eat or treat a bleeding episode.

In our work with Vietnam, in the short to medium term, it is vital that we secure the funding to continue with the micro employment project together with the home adaptation project. These are small steps which have already collectively helped some 60 people with haemophilia but they have made a big difference in the lives of the individuals.

The Micro Employment Projects and the Home Adaptation Projects in Vietnam are funded by the Irish Haemophilia Society through our Planned Giving Programme.

If you would like to make a difference, please sign up to our Planned Giving Programme.

Contributions can start from as little as €10 per month and remember if you choose to contribute €21 or more per month, the I.H.S. can benefit from tax relief, so your contribution can go even further at no extra cost to you.



Brian O'Mahony, Chief Executive.

Noticeboard

Outreach

Please contact our Outreach Co-ordinator Lyndsey in the office on 01 6579900 if you need support in any of the following areas.

- A hospital or home visit
- Support in relation to HAA card entitlements
- Support in relation to social welfare entitlements
- Educational talks to schools
- Information in relation to travel



Planned Giving

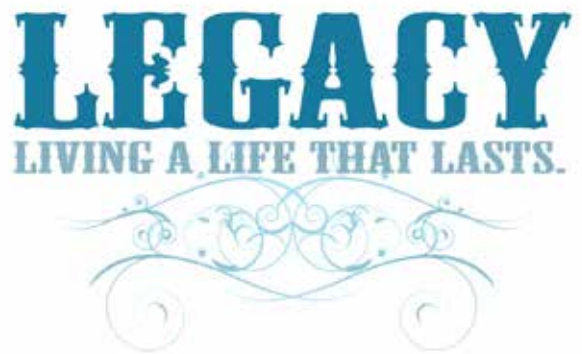
We are asking members to consider committing planned monthly or annual donations to the Society at a level which they can afford. We hope that you will consider participation in this planned giving campaign to allow us to work for a better future for you and for those with haemophilia in developing countries. If you would like more information on this, please call Nina on 01 6579900.



Leave a Legacy

We are asking you to leave a donation or legacy to the Society in your will. A strong active and effective Haemophilia Society is essential and will continue to be essential in the future if we are to optimise the quality of life for people with bleeding disorders in this country.

We hope that you will support our endeavours by positively considering leaving a present for the future and leaving a legacy to the Society.



Wedding Favours

We aim to assist everyone with a bleeding disorder to live positively, to be proactive with their health and to maximise their quality of life. Without the generosity of our supporters, we would be unable to achieve these objectives and we would sincerely like to thank those who have donated to the Society. If you would like to find out more about how you can organise wedding favours, contact Nina in the office on 01 6579900.



Post

As you are aware the cost of post has increased substantially over the last year. Due to the increased cost to the Society in relation to post, we are asking members to consider joining our electronic mailing list for publications. By doing this you will receive the quarterly magazine online via our monthly MailChimp magazine, along with other publications. However, you will still receive all notifications in relation to upcoming events and conferences by post. If this is something you would like to do, please call the office on 01 6579900.



Ezine

Would you like to keep up-to-date with things happening in the I.H.S.? The simplest way is to subscribe to our monthly electronic Ezine magazine.

Sent out at the end of each month, this electronic magazine provides reminders of events, articles of interest and will keep you up-to-date with all that is happening the I.H.S.

If you would like to sign up for our monthly electronic Ezine magazine, please contact Barry in the office on 01 6579900 or by email, at barry@haemophilia.ie.



Hospital Opening Hours over Christmas Period

Our Lady's Children's Hospital, Crumlin



Wednesday 20th December – 8am - 5pm
Thursday 21st December – 8am - 5pm
Friday 22nd December – 8am - 5pm
Saturday 23rd December – Closed
Sunday 24th December – Closed
Monday 25th December – Closed
Tuesday 26th December – Closed
Wednesday 27th December - 8am - 5pm
Thursday 28th December – 8am - 5pm
Friday 29th December – 8am - 5pm
Saturday 30th December – Closed
Sunday 31st December – Closed
Monday 1st January – Closed
Tuesday 2nd January – 8am - 5pm

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

National Coagulation Centre & H&H Assessment Unit – St. James's Hospital



Friday 22nd December 2017 - as normal (8.30am - 5pm)
Saturday 23rd December 2017 - closed
Sunday 24th December 2017 - closed
Monday 25th December 2017 - closed
Tuesday 26th December 2017 - closed
Wednesday 27th December 2017 - emergency walk in service only
Thursday 28th December 2017 - emergency walk in service only
Friday 29th December 2017 - emergency walk in service only
Saturday 30th December 2017 - closed
Sunday 31st December 2017 - closed
Monday 1st January 2018 - closed
Tuesday 2nd January 2018 - as normal (8.30am - 5pm)
Wednesday 3rd January 2018 - as normal (8.30am - 5pm)

The walk in assessment unit in H&H will operate as per out of hours and weekends with 24 hour cover.

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.



Cork Coagulation Centre - Cork University Hospital

Friday 22nd December 2017 - as normal (8.30am - 1pm)
Saturday 23rd December 2017 - closed
Sunday 24th December 2017 - closed
Monday 25th December 2017 - closed
Tuesday 26th December 2017 - closed
Wednesday 27th December 2017 - closed
Thursday 28th December 2017 - closed
Friday 29th December 2017 - closed
Saturday 30th December 2017 - closed
Sunday 31st December 2017 - closed
Monday 1st January 2018 - closed
Tuesday 2nd January 2018 - as normal (8.30am - 5pm)
Wednesday 3rd January 2018 - as normal (8.30am - 5pm)

Outside of the opening hours please contact the haematology registrar on call through the CUH switchboard at 021-4546400



The office of the Irish Haemophilia Society will close for Christmas at 3pm on Friday 22nd December 2017 and will re-open on Tuesday 2nd January 2018 at 9am.



In the case of an emergency, please call 01 6579900 where you will find the contact details for our emergency contact person.

Wishing you all a very Merry Christmas and a peaceful New Year from the board and staff of the Irish Haemophilia Society.

