

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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74
IHS
Volunteers



5978
Website
Hits



WINTER 2016



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AGM 2017

Dates: 3rd– 5th March **Venue:** Slieve Russell Hotel, Cavan

Preliminary Programme

FRIDAY 3RD MARCH

5:30pm – 8:00pm **Registration and Buffet Dinner**
8:00pm – 9:00pm **Debate**

SATURDAY 4TH MARCH

10:00am – 12:30pm **Annual General Meeting**
12:30pm – 1:30pm *Lunch*
1:30pm – 2:30pm **Research and Haemophilia**
2:30pm – 3:00pm *Coffee Break*
3:00pm – 4:00pm **Lecture: New Developments in Treatment**
4:00pm – 5:00pm **Open Forum: Haemophilia Treatment Centres**

SUNDAY 5TH MARCH

10:00am – 11:30am **Workshop: New Developments in Treatment**
11:30am – 12:00pm *Coffee Break*
12:00pm – 1:00pm **An update on Vietnam**
Or
Inhibitors
Carriers
1:00pm – 2:00pm
2:00pm – 3:00pm *Lunch and depart*



The I.H.S. 2016 Annual General Meeting



A Note from the Editor

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

Take a look on the inside cover where you will find the preliminary programme for our AGM next year. AGM packs will be going out to everyone in early January! Also, if you would like further information on our calendar of events for next year, please see page 14.

In this edition, you will find some interesting articles on new developments in haemophilia care, information on the new National Coagulation Centre in St. James's and the Lighthouse Project, an update from Vietnam, 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 of the magazine and put it up on your fridge!

It has been another extremely busy year in the office and I really would like to thank the staff, 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 2016.

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

Merry Christmas

Debbie Greene
Administrator



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dose did not achieve any significant rise in expression, the individual treated at the medium dose achieved an expression of 2% and seven individuals were treated at the higher dose. Of these seven, one achieved an expression of 10% and 6 achieved an expression of more than 50% with 2 of the 6 now reporting levels in excess of 200%. While these levels in the last two patients are certainly higher than you would expect or hope to see, it is clear proof that Factor VIII gene therapy should work. Work is ongoing in all of these trials and we anticipate people in Ireland with haemophilia having an opportunity to participate in some of these gene therapy clinical trials in 2017 and 2018.

The companies are working to continuously improve their gene therapy delivery systems, to decrease the risk of an immune response to the gene therapy vector and to use new variants of the Factor VIII or Factor IX gene, which will provide higher expression without necessarily having to give a higher dose of the vector. The vector delivery system used for the current gene therapy trials are Adeno-Associated Virus (AAV) vectors. These AAV vectors enter the liver cells and cause the liver cells to start producing the Factor VIII or Factor IX respectively. They are not however integrated into an individual's DNA. A separate type of vector called a lentiviral viral vector is also being looked at for future clinical trials. This vector would be integrated into the DNA and it was stated that these types of vectors may be an option for future gene therapy in children. The current vectors are not ideal for children as in growing children the liver cells turn over more rapidly and therefore the expression gained through the gene therapy could be lost. Another advantage of these type of vectors is of course that they would not exclude the approximately 40% of people who have existing antibodies to the AAV vectors, which means they cannot be treated with gene therapy using a specific AAV vector. The conference also discussed future funding for gene therapy. This is going to be a challenge. The two gene therapies for other conditions which have currently been launched on the market are priced at \$1 million and €650,000 respectively. Governments and paying authorities will want certainty in terms of budgets. In my view, for countries with a national healthcare system including Ireland, the UK, Canada, Australia and many European countries, the most likely future model for making gene therapy available would be an amortisation system where the cost of gene therapy would be spread over several years and the payment of that fee over several years would be contingent on continued expression of the Factor VIII Factor IX level. This will be an interesting economic and scientific area and we will watch developments carefully.

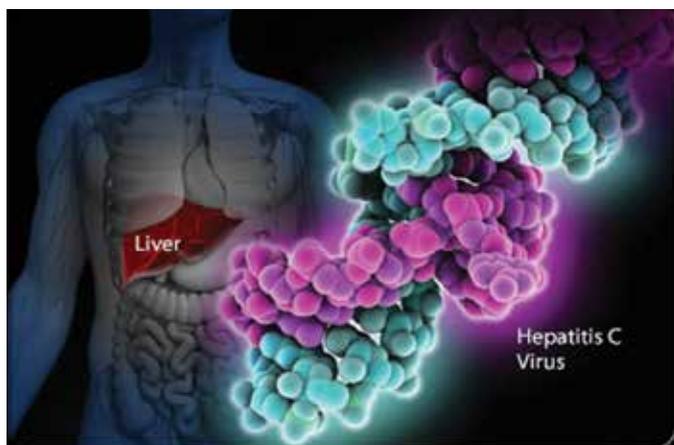
In addition to gene therapy, advances are being made in relation to gene editing. There are now techniques under development which can be used to cut DNA sequences of an individual at specific points and to add, change or delete specific gene sequences in the gene and therefore apparently modify the person's genetic code. These techniques which were referred to as "molecular scissors" could be used within the body or cells could be manipulated outside of the body and then re-inserted. There are promising technologies which now look as if it may be possible to edit, insert or delete specific parts of the gene to deal with Factor VIII / Factor IX.

There are now three Extended Half-Life (EHL) concentrates licensed in Europe, comprising of one Factor VIII EHL product and two Factor IX EHL products. The EHL Factor VIII product (Elocta) is already being used for treatment in Ireland by a number of children and adults. There are further EHL FVIII and FIX products coming down the pipeline which should be available and licensed in the next year. However, development of EHL factors will not stop there. At the conference, there were a number of significant updates in relation to potential future developments. One company is developing a FVIII product which will double the FVIII half-life to 24 hours. Probably the most significant barrier to increasing the half-life of EHL of FVIII is the fact that when FVIII enters the body, it couples with von Willebrand Factor (VWF) and this limits the half-life. One company is fusing an EHL FVIII product to a protein sequence which is derived from a specific region of the VWF. This product when infused, will not couple with the VWF and therefore this would remove the limiting factor to increasing the half-life. They anticipate increasing the half-life from the current EHL FVIII of 15-19 hours up to 39 hours allowing for once per week FVIII prophylaxis. EHL FIX when fused to this protein sequence will potentially increase the half-life to the extent that it would allow for FIX prophylaxis once a week subcutaneously rather than intravenously.

The conference also heard about a number of significant developments and research in relation to inhibitor treatment. There is a version of the Recombinant Factor VIIa product being developed which will increase the half-life from 1.7 hours to 5.1, a 3 fold increase. Other groups are working on antigen-specific immune therapies which may neutralise inhibitors. One very unusual approach was taken by an American company who have been attempting to orally induce tolerance for haemophilia B inhibitors using lettuce. They encapsulate the FIX gene in lettuce cells. In this format, it is protected from acids and enzymes in the stomach and it can be delivered

orally. When this product was given to dogs with haemophilia B it succeeded in tolerising some of the dogs (3/4 dogs were tolerised). In these dogs following the ingestion of this lettuce containing the FIX gene, these dogs when exposed to human FIX concentrates did not develop inhibitors. Control dogs who were exposed to FIX without the ingestion of lettuce prior to exposure did develop high titre FIX inhibitors. This is a novel concept for oral tolerance. It would be more difficult to do this for FVIII, as the large size of the FVIII protein makes this harder. Interestingly, the dogs were encouraged to eat the lettuce by engineering bacon flavoured lettuce. It is highly unlikely that all of these developments will succeed, but it is very likely that many of them will succeed and I am confident that the therapeutic landscape for haemophilia will be completely transformed in the next 5 – 10 years.

Hepatitis C and Haemophilia



In mid-November, the Society met with the new Minister for Health, Simon Harris to brief him on the haemophilia landscape. We had a very constructive discussion where we pointed out the very positive impact of the Society's involvement in the haemophilia product, tender and purchasing process over the past 12 years. We also briefed the Minister on the new haemophilia treatments which will be available in the coming years and we discussed the haemophilia organisation model and how this may be applicable to other chronic or long-term conditions. We also briefed the Minister on the major progress made in relation to access to hepatitis C treatment for people with haemophilia. Over the past 10 years, the major cause of death for people with haemophilia in Ireland has been hepatitis C. The Society made it our major objective as far back as 2012, to ensure that every person with haemophilia was offered hepatitis C treatment as quickly as possible.

By early 2012, there was a total of 54 people with haemophilia who required treatment for hepatitis C. On April 17th, 2012, the Society met the then Health Minister, James Reilly and sought reimbursement for the first group of protease inhibitor hepatitis C treatments - Telaprevir and Boceprevir. This was granted and over the course of the following 18 months, a total of 20 people with haemophilia were treated with these new drugs in combination with pegylated Interferon and Ribavirin. This was a particularly harsh and difficult 48-week course of treatment. However, the Society assisted each of our members both individually and collectively to persevere with this treatment regime. Of the 20 who were treated, all except one individual completed the course of treatment. The one individual who did not complete the treatment passed away during the treatment. As a result of this very high compliance rate (compared to a 67% compliance rate generally), a total of 16 individuals cleared the virus achieving a sustained virological response (SVR) or effective cure rate of 80%. This success rate of 80% compares favourably with the national rate of 51%.

In late 2014, the Society were involved with the Department of Health expert group on hepatitis C which established the early access programme for the new direct acting antivirals (DAA's). A further two individuals with haemophilia were treated under this programme. We then secured a commitment from then Health Minister, Leo Varadkar that all state infected patients would be treated with DAA's no later than the end of 2017. Given the serious morbidity and mortality consequences for our members, we worked with those who still required treatment and with the treatment centres to access treatment as expeditiously as possible. To date, 27 people with haemophilia have been treated with the new DAA's. We have now spoken individually to each person with haemophilia who required treatment. There are a very small number of individuals remaining who, despite being offered treatment, have decided not to avail of treatment. Consequently, all persons with haemophilia in the state who were infected with hepatitis C have now been treated or offered treatment and hepatitis C in the Irish haemophilia population is effectively eradicated. This is a major achievement. We are the first country in the world to have achieved this for people with haemophilia.

Brian O'Mahony
Chief Executive

New National Coagulation Centre



New National Coagulation Centre

Demolition work has commenced on the St James's campus in Dublin to allow for the building of the new National Children's Hospital on that site. As part of this, the National Centre for Hereditary Coagulation Disorders (NCHCD) and the Hepatology units will both be demolished in the coming months to facilitate this. The NCHCD has now moved to a new location in the main hospital building, two floors above the existing haemophilia H&H ward. The new facility, now renamed as the National Coagulation Centre (NCC), is an excellent addition to the haemophilia care infrastructure in Ireland.



I.H.S. staff visited the new National Coagulation Centre recently

The unit is bright, spacious and purpose built. There is an extremely nice waiting area, a sufficient number of consultation rooms, a phlebotomy suite and two beautifully appointed dental suites. The dental suites boast state of the art new dental chairs, x-ray machines and an in-mouth camera for demonstration and teaching and also the ability to stream soothing music wirelessly while having dental procedures carried out. There is also a seminar room for the haemophilia comprehensive care team and sufficient office and administration space for the consultants, nurses and other health care professionals. We are delighted that this new facility is open and that

we have avoided a scenario whereby the haemophilia service would have to transfer to temporary accommodation while the new facility was being built. It will also save transit time for the haemophilia care team and for people with haemophilia. The new outpatient NCC unit is located directly above the H&H ward and for any person with haemophilia participating in a clinical trial, the clinical trial unit is located between the NCC and H&H ward. We do have some concerns in relation to access to the new NCC. The main hospital underground carpark is right underneath this building but it is a not insignificant walk from the carpark elevator to the new unit. For people with haemophilia with severe mobility difficulties, there is an entrance to the new NCC at the side, which has a small one person elevator and also a drop off point to allow people with severe mobility difficulties to be dropped off. This space has been there since the building of the main unit but has never been utilised as it was used as a fire corridor. We are now working to ensure that this can be utilised by people with haemophilia with severe mobility difficulties where drop off is required. I must stress however that this is not disabled parking. If and when this becomes available, it will only be available for drop off. We are also working to ensure that the doors in the corridor leading to the new unit are easy to open. Many of you will be visiting the new NCC over the coming months for outpatient appointments, dental care or for other reasons. We would appreciate any feedback on the new unit, the facilities and access. We look forward to hearing from you.

Brian O'Mahony
Chief Executive

Haemophilia Lighthouse Project



eHealth Ireland is working to deliver an Electronic Health Record (EHR) for Ireland. As part of this, in 2016 eHealth Ireland is investing resources into 3 project areas known as the 'Lighthouse Projects' to build an understanding of the benefits of an EHR in the Irish healthcare system. These projects are in the clinical disciplines of Epilepsy, Haemophilia and Bipolar Disorder.

The haemophilia Lighthouse project will be led by Dr Barry White who is the National Haemophilia Director on behalf of the National Haemophilia service of Ireland. This service is based in the National Coagulation Centre (NCC) at St. James's Hospital and includes two other Comprehensive Care Centres; Our Lady's Children's Hospital Crumlin (National Paediatric Service for Haemophilia) and Cork University Hospital (which provides a comprehensive service for adults and children).

The NCC is seeking to implement an integrated care solution on the basis that the deliverables will be openly shared. This integrated care record solution could /should illustrate both the challenges and potential of such change to underpin both healthcare service transformation and related EHR strategy/development across St James's Hospital, the Dublin Midlands Hospital Group and indeed the wider health system across Ireland.

Aim

The project is aiming to achieve improvements across the key domains of healthcare delivery; quality and safety, patient experience and cost effectiveness.

Vision

The purpose of the haemophilia Lighthouse project is to leverage the existing haemophilia infrastructure to deploy an

advanced e-health platform for haemophilia which will:

- Improve haemophilia care
- Provide an exemplar to demonstrate the benefits of full e-health deployment
- Provide generic learning that can be deployed to services within the Irish Health System.

Key components of the solution

The key components of the e-health solution will be:

- A patient portal to radically improve self-management (online choose and book, access to electronic record, advanced inpatient and home educational modules, ability for patients to report outcome measures in the home setting).
- Deployment of full paperless EPR including diagnostic coding, medication management, clinical notes, order sets, integrated electronic care pathways, real-time performance reports, provider approval and reminders.
- Data repository and analytics. A data repository will be deployed to collect data from all relevant sources and provide a base for data analytics. An advanced analytics platform will be deployed to provide state of the art patient and populations analytics including predictive analytics addressing the key domain of healthcare patient experience, clinical outcomes, safety measures and resource utilisation.

Ruth Hunter Nolan

Quality Assurance Officer
National Coagulation Centre

For updates on all Lighthouse Projects go to:
<http://www.ehealthireland.ie/Lighthouse-Projects/>

An update from Vietnam



Dr. Mai and Professor Tri meet President Michael D Higgins on his recent visit to Vietnam



The official ceremony of the signing of the GAP programme

The Irish Haemophilia Society (I.H.S) have been working with and collaborating with the Vietnam Hemophilia Association (VHA) since 2010. Back then, haemophilia treatment in Vietnam, was mainly with cryoprecipitate, which is a much less effective form of therapy. Access to factor concentrates was very limited. In 2010, 2.7 billion international units (iu) of factor concentrates were used. This equates to a meagre 0.032iu per capita (as a comparison in 2010 Ireland used approximately 6.5iu per capita or some 200 times more per head of population than Vietnam). In 2010 the Vietnam Hemophilia Association was called the Vietnam Society for Congenital Bleeding Disorders, it was run by the doctors with very little or no involvement by patients. Their organisation was run by a very large executive committee. They had key leaders, empathetic and caring doctors and a good pool of people with haemophilia and parents who were willing to get involved in the organisation. The twinning programme officially started at the end of 2010. This was originally a four-year programme which was to run until the end of 2014. Each year the Irish Haemophilia Society made two visits to Vietnam and some of the leaders of the haemophilia organisation in Vietnam visited Ireland. We defined action plans for each year and set objectives as follows:

2011 Activities:

In 2011 our activities with Vietnam included:

- A board development workshop attended by 50 people.
- A volunteer development workshop attended by 30 volunteers in Hanoi – a roster of volunteers was established whereby volunteers committed to one full day per month working with the centre and assisting patients in the hospital.
- An action planning workshop was carried out. Mr. Garvan Mc Cann from the Irish Embassy attended the closing of the volunteer workshop.

2012 Activities:

In 2012 our activities included:

- The identification and preparation of suitable publications to be translated into Vietnamese.
- A workshop on organising events for the association.
- Task lists for volunteers.
- Workshops for chapter leaders.
- Task lists for newly appointed staff at the newly renamed VHA.
- At the end of 2012 a new governance structure was approved with a streamlined executive board and the renaming of the organisation to the VHA.

2013 Activities:

In 2013, a further action planning workshop took place with the new executive board of the VHA and visits were made to Hai Duong and Hung Yen.



The VHA organised their first haematology conference in 2016

2014 Activities:

In 2014 workshops were held for chapter leaders.

- A workshop was held on fundraising.
- A visit was made to the chapter in Hung Yen.
- We started a home adaptation project which was to be rolled out in Hanoi, Ho Chi Minh, Hai Duong and Hung Yen.
- We also initiated a micro employment project.

In 2014 the Irish Haemophilia Society staff team provided training to the new VHA staff member. New publications on dental care for adults and children were produced in Vietnamese. New treatment guidelines were agreed by the Ministry of Health in May 2014. By the end of 2014 which was the original date for completion of the programme, the partnership between the Irish Haemophilia Society and Vietnamese Hemophilia Association had been very successful. During that time the I.H.S visited Vietnam on 8 occasions and the VHA visited Ireland on 3 occasions. Close collaboration and close relationships were established between the doctors and patient organisation leaders in Vietnam and the I.H.S.

The key outcomes included the following:

- The structure and governance of the VHA was strengthened.
- The organisation was renamed the Vietnam Hemophilia Association with a new streamlined executive board structure comprising of 13 members representing Hanoi, Hue and Ho Chi Minh and includes doctors, people with haemophilia and parents.

- New branches of the VHA were established in HCMC and Hai Duong.
- Three Haemophilia Clubs / Chapters were established in Hung Yen, Hai Duong and Thi Binh Province.
- A large number of volunteers were trained in Hanoi and HCMC to work with the hospitals and the VHA.
- Additional staff were appointed to the VHA and trained with the assistance of the I.H.S.
- Training was provided to the patients who lead the chapters.
- Peer groups were established for mothers, fathers and young men with haemophilia in Hanoi.
- The VHA were successful in obtaining additional funding for activities from pharmaceutical companies.
- The National Institute for Haematology and Blood Transfusion in Hanoi now has a roster of more than 20 volunteers who work with them on a regular basis.
- Specific publications were provided.
- Strategic planning and action planning workshops were carried out with the VHA board.
- Training was provided on fundraising and event management.
- Specific task lists were agreed for volunteers and chapter leaders and VHA staff.
- A home adaptation project was funded by the I.H.S. This allowed for the purchase of a small number of adaptive toilets and a large number of crutches and wheelchairs.

- The I.H.S also funded a micro employment project – given the fact that many patients in Vietnam have severe joint problems due to inadequate treatment in the past, many of them could not leave their home to go to work. Therefore, we looked at situations where some assistance could be given to them to work in their home environment. The micro employment project included the purchase of sewing machines, assistance in opening an electric repair shop, assistance in opening a tailor shop and a grocery store.

Clinically, thanks to the strong leadership of Professor Nguyen Anh Tri, Director of the NIHBT, treatment for people with haemophilia in Vietnam continued to improve.

- The Ministry for Health approved treatment on demand for bleeding episodes and some access to home therapy. They also approved the provision of prophylaxis for the treatment of severe haemophilia for people who are less than 15 years old. This is not yet a reality but it has been approved.
- There are now seven hospitals who provide haemophilia care – two in Hanoi, three in HCMC, one in Hue and one in Can Tho.
- The state medical insurance coverage for haemophilia medications has improved with specific coverage agreed in 2012 and 2014.
- The number of patients with haemophilia now managed by the NIHBT in Hanoi has increased from 830 in 2010 to 1,236 in 2014.
- Factor Concentrate use, despite still being low, doubled between 2009 at 0.032iu per capita to 0.073iu per capita in 2013.

In 2015, the I.H.S persuaded the WFH to consider Vietnam for their Global Alliance for Progress Programme (GAP). This comprehensive programme aimed to build sustainable care in a country for haemophilia care focuses on six areas:

1. Increasing government support.
2. Care delivery.
3. Medical expertise.
4. Provision of treatment products.
5. Improvement in the patient organisation.
6. Data collection and outcomes research.

We visited Vietnam with the WFH President and CEO in 2015 and had a successful meeting with the Deputy Minister for Health, Nguyen Thi Xuyen. The Deputy Minister declared the Ministries support for the national haemophilia programme and their support for Vietnam becoming a GAP country. The GAP Programme started this year in Vietnam and will run until at least 2019. We will work with WFH and the VHA on the implementation of this programme to the completion of the programme. The main objective of the GAP are as follows:

- Ensure continuation of Government support for national haemophilia care programme.
- Improve care delivery in the country by strengthening the existing network of seven haemophilia treatment centres and creating satellite centres.
- Support the development of medical expertise of HCP's in selected centres and in general in the country. Increase the supply of factor concentrates for patients.
- Expand the patient organisation and increase its lay leadership and the number of active volunteers.
- Develop and implement a national registry.
- A minimum of 10 additional centres will be developed during the course of this programme. The core team and services will also be strengthened and developed at centres in Hanoi, HCMC, Hue and Can Tho.
- The expertise of the I.H.S. will be utilised in establishing a national tender procurement system for factor concentrates for Vietnam so that they can access these expensive medications on a more cost effective basis for the whole country.
- Of note is the fact that due to their acceptance of the GAP Programme that Vietnam are now in receipt of several million international units of the latest longer acting factor concentrates free of charge under the WFH Humanitarian Programme – we anticipate that they will receive approximately 5 million euros worth of free medication per year during the course of the GAP Programme.

The inclusion of Vietnam in the GAP Programme, the continuing work with the Irish Haemophilia Society and the dedication, empathy and expertise of the haemophilia treaters in Vietnam will in my view greatly improve the level of haemophilia care in Vietnam over the coming years.

Brian O'Mahony,
Chief Executive



Cubs



We would like to wish all of 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 Brian went to visit the dentist, Brian's sister hates going to see the dentist but Brian doesn't really mind because he takes really good care of his teeth and the dentist is always so proud of him!! Can you think of three ways you can look after your teeth?



1.
.....
2.
.....
3.
.....

JOKE CORNER

What do you call an old snowman?

Water 😊

What do you get when you cross an apple with a Christmas Tree?

A pineapple 😊

Who hides in the bakery at Christmas?

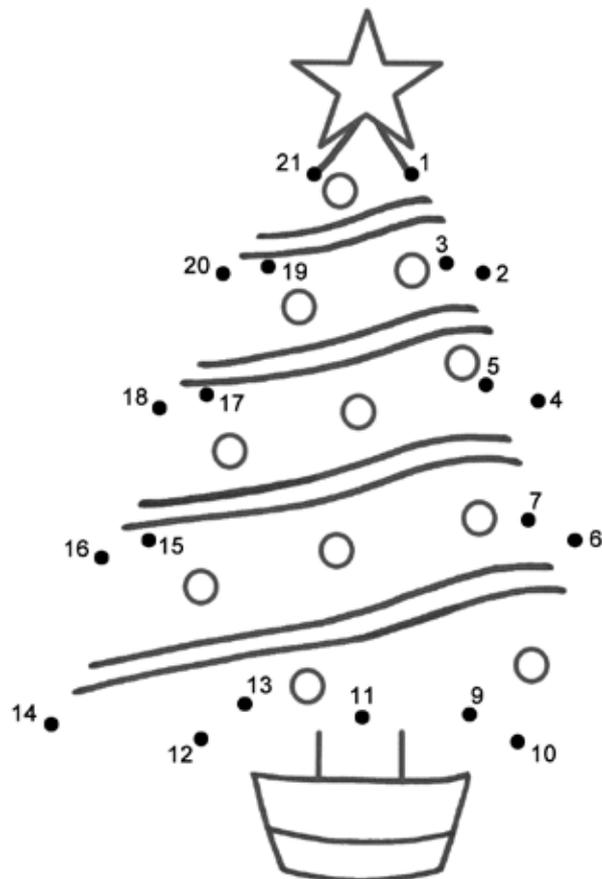
A mince spy 😊

Fun Facts about Teeth:

Dogs have 42 teeth, cats have 30 teeth, pigs have 44 teeth, and an armadillo has 104 teeth!!!!

Giraffes only have bottom teeth.

Like fingerprints, everyone's tongue print is different!





We would like to wish all of 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?

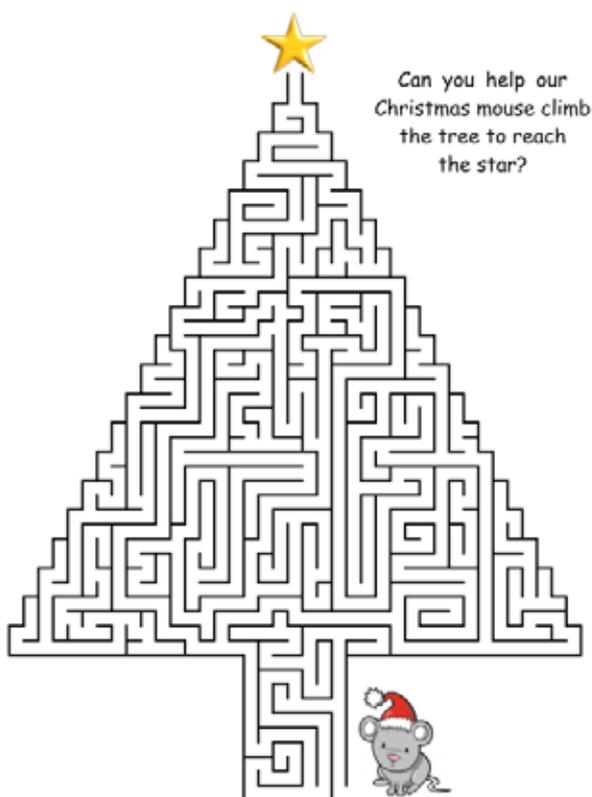
1. The tallest Christmas tree ever displayed was in Seattle Washington in 1950. The Christmas tree was 221 feet tall!
2. Did you ever wonder where X-Mas came from? X means Christ in Greek so to shorten the word Christmas we sometimes use X-Mas.
3. If you received all the gifts from the song "The Twelve Days of Christmas" you would have 364 presents!

Staying Safe Online!

There are lots of different things we can use the Internet on - computers, laptops, tablets and gaming devices and there are lots of different reasons for using the internet from catching Pokemon's, downloading apps, doing research for projects and listening to music!!

While it is super quick and easy to use there are some things we need to remember while using the internet on any device:

1. If you accidentally come across something inappropriate shut it down immediately and tell an adult!
2. Whatever you post is permanent, even if you delete - someone could have saved it or taken a screenshot before you delete it!
3. Make sure you have privacy settings so people you don't know do not have all of your details!
4. Only talk to or accept people that you know in real life as friends!



Calendar of Events for 2017

MARCH

Annual General Meeting & Conference

Dates: 3rd – 5th March

Venue: Slieve Russell Hotel, Cavan

We will start off the weekend with registration and an informal buffet dinner on Friday evening, followed by a debate. The weekend will be jam-packed with the annual general meeting, lectures, workshops and updates. Instead of finishing at 1pm on Sunday, we will continue until 2pm and finish off with lunch from 2pm to 3pm.

MAY

Father & Son(s) Overnight

Dates: 6th – 7th May

Venue: Adventure Centre

A new endeavour for the I.H.S. in 2017. This night away in an adventure centre will be open to father's and sons from 7 to 17 years of age. More information on this exciting overnight will be available in the new year.

Ageing Conference

Dates: 19th – 21st May

Venue: Hotel Kilkenny, Co. Kilkenny.

Our third Ageing Conference will take place in May next year and will cover areas including orthopaedic surgery, pain management, cardiology with separate streams on the programme on HCV/HIV.

JUNE

Mother & Daughter(s) Overnight

Dates: 24th – 25th June

Venue: T.B.C.

Another new venture for the I.H.S. in 2017. This night away in will be open to mother's and daughters from 7 to 17 years of age. More information will be available in the new year.



OCTOBER

Members Conference

Dates: 20th – 22nd October

Venue: Hodson Bay Hotel, Athlone

We will start off the weekend with registration and an informal buffet dinner on Friday evening. The programme for the weekend will include a mothers and fathers workshop, a session on new developments in haemophilia treatment in simple English and some interactive workshops. Instead of finishing at 1pm on Sunday, we will continue until 2pm and finish off with lunch from 2pm to 3pm. A residential weekend away for teenagers will also take place, providing we get the numbers.

NOVEMBER

Memorial Service

Date: Sunday 26th November

Venue: I.H.S. Office

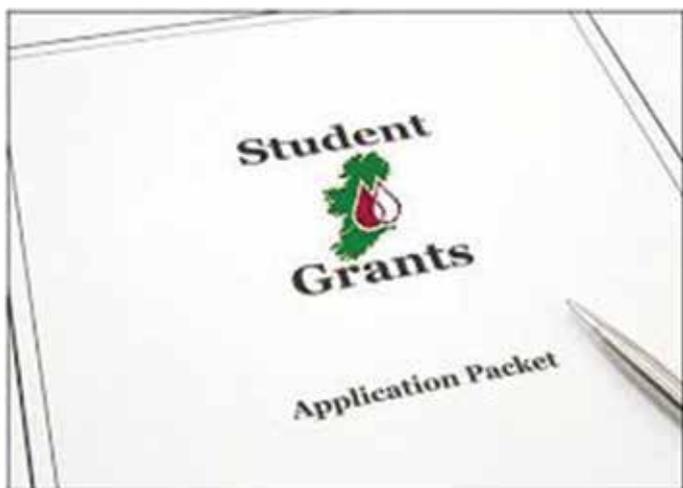
DECEMBER

Christmas Party For Kids

Date: Saturday 9th December

Venue: Grand Hotel, Malahide, Co. Dublin.

Educational Grants 2016



Thanks to everyone who applied for an educational grant from the Irish Haemophilia Society. This year we received a total of 26 applications which is fantastic. 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 €18,100 was paid out and the two main recipients are as follows:

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

Daniel Hanney from Dublin

Daniel who has severe haemophilia A is in his first year of college in the Institute of Technology in Blanchardstown. Daniel is studying engineering, enjoys going to the gym so much so that he has seen a good improvement in vascularity. Daniel previously played football and his family have been involved with the Society for many years.



Margaret King Educational Scholarship (€2,000)

Barbara Wynne from Dublin

Barbara has just started her second year in Trinity College Dublin and is studying nursing (children's and general integrated). Barbara got first class honours in her junior freshman year and is enjoying college a lot. Barbara has two sons with haemophilia and has been a member of the organisation for many years. Barbara is hoping to further her studies when she qualifies and complete a postgraduate in haematology nursing.

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

Members Conference Report



Seamus McDonald, Ger O'Reilly and Jim O'Leary during the debate

Last October saw another I.H.S. Members conference which took place in the Radisson Blu Hotel in Co. Sligo. The weekend was a huge success and proved entertaining and educational in equal measure for both staff and members. As this conference is for members by members, the atmosphere in the hotel was friendly and inviting, with an emphasis on communication and patient and members' involvement with a plentiful dose of laughter and silliness too.

Friday evening saw the Youth group set off to Lilliput Adventure Centre for a weekend of outdoor activity. After the Crèche, Kidlink and Cubs were firmly established into their groups with the volunteers on Saturday morning, an interactive workshop on communication started off the weekend for the adults. This session allowed members to share any concerns they may have, any improvements they feel necessary with their haemophilia treatment centres (HTC's) and medics, and to even get in touch with their artistic side by doing a bit of drawing! (When the blindfolds emerged, everyone knew there was interesting activity in store.) Facilitated by Chairperson of the I.H.S., Traci Marshall Dowling, these activities were useful in bringing people together to share experiences and to practice their communication skills on one another. A common viewpoint among members was the lack of age-appropriate information provided by medical staff and the need for increased communication between specialists, the HTC's and patients. This workshop was useful for promoting communication from the patients end and was demonstrated by dazzling role-play performances from Shay, Lorraine, Ger and Brian. Useful tips included writing down what you have been told by your doctor during and after an appointment – it will be extremely useful to refer back to it when necessary and for your next visit.

Next up was the debate, a session I was particularly looking forward to over the weekend. Jim O'Leary and Seamus McDonald showed no mercy when arguing their points over what was better – current recombinant factor or extended half-life (EHL) factor. On the side of the latter, Seamus made a very convincing argument for extended half-life products, explaining that not only would they give a higher trough level to patients and fewer breakthrough bleeds, but also fewer infusions which would lead to improved vein care and decreased infections. Jim approached the topic with an 'if it ain't broke, don't fix it' viewpoint, outlining the success of current recombinant factor to date and of course the expense that would be involved in EHL factor. With advanced gene therapy products and the bispecific antibody, ACE910, coming on the market in the next couple of years, Jim would prefer to bypass EHL factor altogether and wait for the elite products to emerge. As a Clare man, Jim used a hurling analogy to stress this – "As a hurling team, would you rather stay at Clare level, rise to Tipperary or aspire to be Kilkenny?" However, after a vote, it was clearly established that EHL factor was the winning side as it provides a lot more benefits for patients and was ultimately the preferred choice among members.

Saturday afternoon saw the screening of the European Haemophilia Consortium (EHC) film entitled 'Haemophilia Stories' produced by filmmaker Goran Kapentanovic. The film documented individuals with haemophilia in France, Ireland, England, Sweden, Bulgaria and Romania explaining what haemophilia is, how it impacts the daily lives of the individuals affected by it and also the stark difference in haemophilia care between these countries. The personal stories made for a very touching film and the screening was followed by a discussion with Brian O'Mahony.

A new aspect to this conference was the workshop on mindfulness with facilitator Nollag Cullinan. In a time where people are constantly on the move, aiming to fill each moment of their day with productivity, it can be difficult to allow yourself to reflect. This has proven to lead to a build-up of stress, rumination, anxiety, sleep deprivation and depression. A point that stuck with me from Nollag's presentation was the concept of acceptance. When we are happy, and everything in our life is going smoothly, we don't tend to over analyse it. We accept our emotions because we are content. However, when we are sad or angry, we tend to overthink and over analyse because we are uncomfortable with this feeling. It is important to allow feelings of negativity as well as positivity to wash over us and to allow them to pass because thoughts and



Fun and games in the cubs club

feelings are transient and unavoidable. They come and they go, and ultimately, we have a choice about whether to act on them or not. It was a useful session for all in my opinion because it can be attributed to everyone at every stage in their lives.

No I.H.S conference would be complete without a Saturday night dinner and entertainment, bringing all members, staff, children and volunteers together. This year, a table quiz roused everybody's competitive side and tested member's knowledge with rounds on music, sport, film, history and most importantly, haemophilia. I'd like to give a particular shout out to the 'Bleedin Chancers' who, despite having nobody under the age of 40 on their team got 10 out of 10 for the kiddies round! However, the team that was most victorious after an intense tie breaker was the team 'Mayo for Sam'. Now if only their football team could match such skill... I will say no more.

Sunday was a day of fun for all. The morning started with celebrity chef Joe Shannon doing an entertaining cookery



Celebrity chef Joe Shannon cooked up a storm with his quick and easy meals



Jenga on Sunday morning

demonstration and showing us all how easy it is to whip up a soup, pasta dish, and Eton mess dessert all in the space of an hour. After a quick coffee break the games began and the meeting room was transformed into an area of fun for all. Poker tables, Jenga, Pictionary, Catchphrase, face paint for the kids and lots of other team games topped off the weekend for members. This final gathering rounded up the weekend for everyone and the atmosphere was relaxed, friendly, fun and informal. It is amazing how much members (and staff members!) can get out of a conference that is run virtually by no haemophilia medical staff, professors or academics. Shared experiences, knowledge and most of all, understanding are the drivers of the I.H.S Members' conference and what makes it so unique and beneficial for people with bleeding disorders and their families.

Aoife Ní Fhógartaigh

A Special Thanks to our Volunteers!

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 2016 for the incredible and contagious effort and enthusiasm displayed by you all this year!

In 2016, the Society had 147 children attend our 3 main conferences and this was only possible because of our amazing group of volunteers! A total of 40 volunteers helped out over the course of 2016 and in each and every one of those, dedicated their free time to ensure that the I.H.S members could attend educational talks and adult sessions and most importantly ensure that the children had an amazing weekend!

It is down to you that we can say our children's groups enjoyed another absolutely incredibly successful year. We could not make these weekends happen without the effort, generosity, dedication, creativity, optimism and sparkle of our very valuable, vivacious volunteers.

As they say, it is so easy to make a euro, it's a lot tougher to make a difference and I really do hope you are proud of the impact you have all made this year! I know I've said it to you all many times, but I am so thankful to work alongside such a fabulous volunteer team!

So from all of us – huge, endless thanks! Looking forward to another successful year in 2017.

Fiona Brennan



Fundraising

“Alone we can do so little; together we can do so much” – (Helen Keller)

These words are so true, without your support, there is only so much we can do. On behalf of the staff and board of the I.H.S., I would like to thank everyone for their amazing fundraising efforts in 2016. We really appreciate the tremendous support of everyone for organising and taking part in fundraisers throughout the year and for all the generous donations and contributions made through our Planned Giving Appeal. We know how lucky we are as a Society to have the support of our members, family and friends, to allow us to continue to maintain and improve on the services and support we provide.

We currently have fifty members who contribute to our Planned Giving Appeal, either on a monthly or annual basis. This regular support is fantastic and it allows us to plan ahead with our services and support. Some of the funds raised from the Planned Giving goes towards the provision of the apartment facility for members, which is within a few minutes walk to St James’s Hospital and only a few minutes drive to Crumlin Children’s Hospital. The apartment can be used by members travelling to Dublin for early morning hospital appointments in either hospital. It can be used by family members who need to remain close to St James’s Hospital if a member is an inpatient or by mum or dad if a child is staying in Crumlin Hospital. The apartment is put to good use and with the New Children’s Hospital planned for St James’s Hospital campus, it will no doubt be in even greater demand. If you are interested in signing up to the Planned Giving or would like more information on it, please contact us. The contributions can be for any amount, whatever suits your budget and they can be stopped at any time. The I.H.S. can also claim a tax refund from Revenue on annual contributions of €252 or more, so your support goes even further.

Again our sincere thanks to everyone who raised funds in 2016, through fundraising events. We really appreciate the time and effort that goes into this, but we also know how much fun and satisfaction everyone gets from it as well. Our fundraisers this year included a Darts Night, Sober September, a Table Quiz, a Bucket Collection, Movember and the Women’s Mini Marathon.



If you would like information on fundraising or our Planned Giving Appeal, contact me on 01-6579900 or email nina@haemophilia.ie. Every contribution made and funds raised no matter how small is greatly appreciated. Wishing everyone a Merry Christmas and Peaceful New Year.

Nina Storey



EHC Conference



European clinicians and I.H.S. delegates attending the EHC conference recently

The European Hemophilia Consortium (EHC) held its 29th Annual Conference this year, from the 7th – 9th October in Stavanger, Norway. The conference provides the European bleeding disorder community with the latest medical and scientific information relating to haemophilia and other bleeding disorders. Some of the topics covered included haemophilia care in Norway, dental care, von Willebrand's treatment, a US study on haemophilia B, gene therapy, mild haemophilia, acquired haemophilia, inhibitors and caesarean sections.

Day one started bright and early when we welcomed the delegates from the Dutch Association of Haemophilia Patients (NVHP), who had cycled a staggering 1,000 km from Utrecht in the Netherlands to Stavanger in Norway to raise funds as well as awareness of haemophilia and other rare bleeding disorders. It was an amazing achievement and a challenge at times as all the cyclists have a bleeding disorder, but due to their training, there was only one bleed during the challenge.

Then it was down to business, the conference started with the General Assembly (GA) for National Member Organisations (NMO's). During the GA, Professor Paul Giangrande (EHC Medical Advisory Group) gave a presentation on the EDQM (European Directorate for the Quality of Medicines) 2016 recommendations for the standard of care for people with haemophilia and related disorders.

Professor Giangrande also spoke about inhibitors guidelines, as this has been the EHC's main focus in 2016. He explained that a series of meetings with senior members of the EAHAD committee had taken place as part of the EHC inhibitor project. Another meeting was due to take place in October, at which a draft document would be reviewed, aiming to agree on key principles of care for the clinical management of patients with inhibitors.

The highlight of the conference for me was the three 'Youth Debates'; Young Patients versus Doctors.

Debate 1 - 'Adults need prophylaxis' versus 'Adults don't need Prophylaxis'.

Debate 2 - 'We don't spend enough time on inhibitors Patients' versus 'We spend too much time on inhibitors patients who are a small % of our community'.

Debate 3 - 'Access to hepatitis C treatment should be a priority for NMO's' versus 'It should not be a priority for NMO's'.

Professor Cédric Ungureanu, Professor Paul Giangrande and Professor Mike Makris were given the task of speaking against each topic, and I must commend them on excellent presentations, which were not their personal view points. Young patients, Stefan Tasic, Cristian Ungureanu and Stephan Meijer definitely held their own in the debates and put



Brian O'Mahony presenting the NMO organiser of the conference with a bouquet of flowers

forward great arguments in favour. When put to the floor I am delighted to say that the young patients speaking in favour of each topic won unanimously. The debates really opened up the topics for discussion and were a learning experience for the young patients.

Dawn Rotellini (USA) presented the results of a US Study into the new insights on the impacts of living with haemophilia B. The study consisted of 299 patients and 150 caregivers and looked at the impact on people with haemophilia and caregivers in relation to their work, participation in recreational activities for adults, the intensity and duration of participation in physical activities for adults and children.

Professor Paul Giangrande gave a talk on mild haemophilia. He explained that one stage assay testing can misdiagnose mild haemophilia and that two stage assay testing or chromogenic assay testing gives a more accurate diagnosis. He feels it's important to genotype all patients, not just those with severe haemophilia. He recommends treatment for mild haemophilia to start with DDAVP as a trial initially before treatment with Factor VIII concentrate to avoid the risk of inhibitors.

Professor Giangrande then spoke about EHL (extended half-life) factor. He stated that EHL factors will not become the standard of care for haemophilia. This is due to several things, it is an expensive product, and there will be major cost issues because of increased trough levels.

There was a debate on elective caesarian sections for carriers, yes or no? Professor Rezan Khadir (UK) spoke in favour and Dr Danijela Mikovic (Serbia) spoke against. Professor Rezan stated that one-third of intracranial bleeds occur at birth and there is a 43% higher risk for a baby with a bleeding disorder. However, the risk can be reduced by two-thirds if the baby is delivered by C-section as compared to a vaginal delivery. Also, a C-section causes no more risk to the mother than a vaginal delivery, the risk only increases if there are three or more C-sections. She stated that C-sections should be offered to all mothers. Dr Mikovic stated a planned vaginal delivery is best, but an abnormally prolonged labour and difficult and instrumental delivery should be avoided. Also, there is only a 50% chance of a boy being born with haemophilia, so you can't plan for this. The mother's factor levels have to be considered as there is a risk of post-partum haemorrhage, and this risk increases after the first C-section due to the C-section scar. At the end of the debate, Dr Mikovic commented that she would have a C-section if it was her, but she had been asked to debate against it.

Overall I really enjoyed the conference. The selection of topics discussed was excellent and there is always something new to learn.

Nina Storey

Noticeboard

Anne Duffy Retires



We would like to wish Anne Duffy all the very best of everything on her recent retirement. Anne worked for the Society for over 15 years as a nurse/counsellor. Anne visited many of you over the years at home and in hospital and was empathetic, effective and diligent in her work, in particular if any member needed support or assistance.

Anne was involved in bringing the 'Parents Empowering Parents' programme to Ireland, represented the Society on the Psychosocial Committee of the World Federation of Hemophilia and also represented the Society on the Consultative Council on Hepatitis C.

We wish Anne well with her new venture in college life and thank you Anne for all your hard work over many years.

Severe Bleeding Disorder Alert Cards

A reminder to you all to make sure that you carry your 'Severe bleeding disorder alert card' with you at all times. It is so important that people with haemophilia are treated promptly if they need to attend an Emergency Department in any hospital. Your consultant haematologist at your treatment centre will provide you with a card, so if you have not already received same, please ask for one when next attending your treatment centre.



Planned Giving

We are asking members to consider committing planned monthly or annual donations to the society at a level which they can afford. Of the funds raised, 75% will go to defray the cost of purchasing the apartment and 25% will go to our overseas development fund.

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.



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.

Ezine

If you would like to sign up for our monthly electronic Ezine magazine, please contact Aoife in the office on 01 6579900. (Email: aoife@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. and is sent out on the last Thursday of every month.



Sarah Gilgunn



Congratulations to ex-board member and member of the Irish Haemophilia Society Ms. Sarah Gilgunn who has been awarded the Dublin City University Chancellor's Medal for achieving outstanding academic success linked to considerable industrial experience. Sarah commenced her work for a Ph.D. in 2011 under the supervision of Professor Richard O' Kennedy in the School of Biotechnology. The research was part of a multi-institutional collaboration, funded by the Irish Cancer Society, which looked at improving current approaches for the detection of prostate cancer. Throughout her career, to date, Sarah has published extensively, presented at numerous national and international conferences and has won several science communications awards.

In 2014, Sarah was awarded a prestigious Short-Term Fellowship from the European Biology Organization (EMBO) to work at Monash, one of the leading Universities in Australia. Her contributions to healthcare have also been recognised by DCU's Faculty of Science and Health and in 2015 she was named 'Outstanding Graduate Researcher 2014-2015'. Since completing her PhD Sarah has commenced work in the Protein Oncology Department at Immunicore Ltd, an Oxford-based biotechnology company, and is directly translating the skills she obtained in DCU in an effort to develop novel cancer biologics.

Hospital Opening Hours over Christmas Period

Our Lady's Children's Hospital, Crumlin



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

In case of an emergency please contact the hospital on 01 4196100 and ask for the haematology registrar on call.

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



Thursday 22nd December 2016 - as normal (8.30am - 5pm)
Friday 23rd December 2016 - as normal (8.30am - 5pm)
Saturday 24th December 2016 - closed
Sunday 25th December 2016 - closed
Monday 26th December 2016 - closed
Tuesday 27th December 2016 - closed
Wednesday 28th December 2016 - as normal (8.30am - 5pm)
Thursday 29th December 2016 - as normal (8.30am - 5pm)
Friday 30th December 2016 - as normal (8.30am - 5pm)
Saturday 31st December 2016 - closed
Sunday 1st January 2017 - closed
Monday 2nd January 2017 - closed
Tuesday 3rd January 2017 - as normal (8.30am - 5pm)

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

Thursday 22nd December 2016 - (8.30am - 5pm)
Friday 23rd December 2016 - 8.30am - 1pm
Saturday 24th December 2016 - closed
Sunday 25th December 2016 - closed
Monday 26th December 2016 - closed
Tuesday 27th December 2016 - closed
Wednesday 28th December 2016 - closed
Thursday 29th December 2016 - closed
Friday 30th December 2016 - closed
Saturday 31st December 2016 - closed
Sunday 1st January 2017 - closed
Monday 2nd January 2017 - closed
Tuesday 3rd January 2017 - 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 23rd December 2016 and will re-open on Tuesday 3rd January 2017 at 9am.



In case of an emergency, please contact Brian O'Mahony on 087 2515325

Wishing You All A Very Merry Christmas And A Peaceful New Year From The Board And Staff Of The Irish Haemophilia Society.

