

# Haemophilia.ie

Representing people in Ireland with haemophilia and related bleeding disorders



Magazine of the Irish Haemophilia Society

Autumn 2018



The Society  
at a Glance

**74**  
I.H.S.  
Volunteers

**46**  
Planned Giving  
Contributors

**1170**  
Facebook  
Followers

**627**  
Twitter  
Followers



[haemophilia.ie](http://haemophilia.ie)



# OCTOBER CONFERENCE

**Dates:** Friday 19th to Sunday 21st October

**Venue:** Radisson Hotel, Sligo

## Preliminary Adult Programme

### Friday October 19th

17.00 - 19.00	Registration
19.00 - 20.00	Buffet Dinner
20.00	50th Anniversary Review



### Saturday October 20th

09.00 - 10.00	Registration
10.00 - 11.15	Understanding the Terminology of Novel Treatments Speaker: Dr. Michelle Lavin, N.C.C.
11.15 - 11.45	Coffee Break
11.45 - 13.00	Benefits & Entitlements Speaker: Mr Patrick Stagg, Citizen's Information
13.00 - 14.00	Lunch
14.00 - 15.00	Debate: Will there be a need for the I.H.S. in 2030?
15.00 - 15.30	Coffee Break
15.30 - 17.00	Peer Support Groups
19.15	Dinner & Entertainment

### Sunday October 21st

	Wellness Workshop (10.00 - 13.00)
10.00 - 11.00	Mindfulness and Meditation
11.00 - 11.30	Coffee Break
11.30 - 13.00	Yoga Group 1: Family Friendly Yoga (Youth Group will attend this session) Group 2: Chair Yoga
13.00	Lunch



# From the Editor

**Hello everyone,**

Welcome to the Autumn issue of our quarterly magazine, I hope you enjoy reading it!

We trust you all had a great summer and enjoyed the fabulous sunny weather, after all the snow last winter, I think we earned it. Here at the I.H.S. office we are busy getting ready for the October Conference, we are excited and hope it will be the best yet. You can take a look at the preliminary adult's programme on the previous page.

As well as that, there is lots of interesting reading for you. In our CEO's report on page 4, you will find news from Vietman and other updates, which, as always, is well worth a read. On page 10, we have a chat with the new I.H.S. Chairperson John Stack to find out more about the hopes and aims for his tenure in the role.

On page 11, we catch up with Patrick Doyle for an update ahead of his Kilimanjaro climb in October. There is also a report from the Mild Haemophilia Information Day and an update on the I.H.S. Youth Leadership Programme, which began in August. You can find these on pages 12 and 16 respectively. You will find important information on an update to the Homescan App on Page 15 and dates for your diary on page 17 as we continue mark the 50th anniversary of the I.H.S. We hope to see you at events throughout this year, and the next.

Finally, if there is anything we can assist you with, if you fancy dropping in for a chat, if you read an article that might be useful to us, if you fancy putting pen to paper and writing something for us, if you are interested in volunteering, or would like to talk to somebody in confidence, please contact the office anytime on 01 6579900.

**Debbie Greene,  
Administrator**



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# CEO REPORT

## Vietnam

The Society continues to work productively with the Vietnam Haemophilia Association (VHA).

In the past year, I carried out training sessions with selected people with haemophilia and parents from the cities of Hanoi, Hue, Ho Chi Minh and Can Tho and this continued during our visit in August.



The visit included the comprehensive care team from the Alfred Hospital in Melbourne led by Prof. Huyen Tran and the World Federation of Hemophilia (WFH) Regional Director and Director of Humanitarian Aid.

Meetings with families and people with haemophilia in Hanoi and Ho Chi Minh were augmented by fun team building exercises led by Australian Tim Mathieson who has a company called Purple Soup who carry out team building and fun events. Many of the children were shy and, in some cases, had not previously met other people with haemophilia. The team building exercises had them working and playing together in a very enjoyable manner.

Haemophilia care in Vietnam is continually improving. The work we have been doing with the VHA and the WFH over the past three years has been focusing on building up the capacity of the centres in the four cities. A further 10 satellite centres will be a priority later. We have also been working to assist the VHA in increasing their supply of haemophilia replacement therapy and we are hopeful that the Government in Vietnam will approve a national tender or procurement for factor concentrates in 2019 which would allow Vietnam to really improve their purchasing of vital medications on a centralised, effective and cost-effective basis.

In past years, Vietnam had also been recipients of significant quantities of factor concentrates through the WFH humanitarian aid programme. Due to new import regulations, this has ceased but major progress was made during the visit and I am very hopeful that these vital donations will recommence shortly. During the visit, we met with groups of people with haemophilia, parents, health care workers and also visited one family at home. I was particularly pleased by the enthusiasm and sense of community among the group of patients and volunteers in Ho Chi Minh City.

Living with haemophilia in Vietnam is not easy. Over on the right, pictured is Mr. Le Huu Hung from Ho Chi Minh who contributed very well to the meetings and the work programme.

He lost his left arm some years in the past following a bleeding episode. I met with several young men who had lost limbs or who had severe joint impairment which would not have occurred if they had access to similar quantities and quality of treatment we take for granted in Ireland. Despite this difficult past situation, they are working with others to build a better future. The home adaptation and micro employment projects funded by the Society are also continuing. We await sign off by the Vietnamese Government of the latest grant process. Once that is done, the VHA will start to process the grant applications. There are currently 20 people on the waiting list for micro employment grants and 60 for home adaptation grants. The micro employment grants facilitate the establishment of small business ventures for people with haemophilia, usually at home or close to home. This is ideal in situations where they may have limited mobility and transport is usually by motorbike. The home adaptation grants include not only items such as handrails and disability accessible toilets but wheelchairs and crutches. Our work programme with Vietnam and WFH continues and work for 2019 is already planned.



Mr. Le Huu Hung from Ho Chi Minh





Meeting people with haemophilia & parents in Ho Chi Minh (Above)

Tim Mathieson & volunteer with a child with haemophilia & his father during our visit to their home (Below)



Children playing during our meeting with families in Hanoi



Meeting with the health care workers during our visit to Tho Duc Hospital in Ho Chi Minh



## Ambulance Service

A situation recently occurred where a person with an inherited bleeding disorder was brought by ambulance to a hospital in Dublin which does not have a haemophilia treatment centre. This was despite the individual concerned making it clear to the ambulance crew that they should be brought directly to St. James's Hospital.

This was a breach of agreed protocol which is being dealt with. It is timely therefore to remind members that agreement was reached with the HSE in 2015 that people with haemophilia, irrespective of their presenting complaint, that are within a 60 minute transport time of a designated Haemophilia Treatment Centre should be brought directly to the Emergency Department of that Centre, bypassing other hospitals.

This was agreed by the HSE in Clinical Directive 08/2015- reproduced on Page 7. I would suggest that each person with haemophilia take a photo of this circular with your phone and keep it on your phone in the event that you ever require an ambulance.

## Inhibitor Treatment

A new era of treatment possibility is about to open for people with inhibitors in Ireland as the bi-specific antibody Hemlibra (known during the clinical trials as Emicizumab) will be a treatment option from this month. This product, which was licenced by the European Medicines Agency for treatment of people with inhibitors in March of this year is injected subcutaneously once per week.

Hemlibra is a therapy used for prophylaxis and cannot be used for breakthrough bleeding episodes. In the clinical trials of the product, it was associated with a 79% reduction in the annual bleed rate when compared to prophylaxis with bypassing agents. The comprehensive care centres will be discussing Hemlibra with people with inhibitors in the coming weeks. We are excited to see the first prophylactic therapy for haemophilia with inhibitors which does not require intravenous injection now become available in Ireland as a treatment option.

## Nina

Nina Storey recently celebrated 20 years of working for the Society. Nina's diligence, hard work and enthusiasm have been and continue to be very much appreciated by me and all of her colleagues. Her friendly manner and approachability has meant that she is well known by members and she is a great resource for members. We wish her all the very best in her next 20 years of working with the Society.



## Dr. Susan O Shea

Dr. Susan O Shea has left her position at Cork University Hospital and has also therefore stepped down as Director of the Cork Coagulation Centre. Susan is an extremely competent, warm and empathetic doctor who made a major contribution to the Cork centre and to improving the treatment and quality of life of many people with haemophilia.

Through her participation on the National Haemophilia Council and the Haemophilia Product Selection and Monitoring Advisory Board, she also contributed greatly to national policy decisions and haemophilia and to the selection and procurement of treatment products. Susan will be missed, and we wish her all the very best for the future. At the last Council meeting Susan attended, I presented her with an inscribed vase on behalf of the Society.

**Brian O'Mahony**



Nina recently celebrated 20 years with I.H.S.



# Clinical Directive 08/2015



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive

**FROM: Medical Director****TO:**

1. Emergency Medical Technicians, Paramedics, Advanced Paramedics;
2. Call Takers, Call Dispatchers;
3. Supervisors, Managers.

**SUBJECT: Patients with haemophilia**

- Patients with haemophilia, irrespective of their presenting complaint (ie not just haemorrhage) that are within a 60 minute transport time of a designated Haemophilia Treatment Centre should be brought directly to the Emergency Department of that Centre, bypassing other hospitals.
- All such patients should be pre-alerted to the receiving Centre
- Haemophilia Treatment Centres are:
  - o St James's Hospital, Dublin
  - o Our Lady's Hospital for Sick Children, Dublin
  - o Cork University Hospital
  - o University Hospital Galway

**RATIONALE:**

Patients with haemophilia benefit from treatment in a centre with specific expertise in the treatment of bleeding disorders. Sometimes in haemophiliacs, bleeding complications may present without obvious signs or symptoms of haemorrhage.

**EFFECTIVE FROM:**

October 29th 2015

**EFFECTIVE TO:**

Indefinite

**QUESTIONS OR COMMENTS ON THIS DIRECTIVE:**

Education and Competency Assurance Officer.

Clinical Directives are formulated by the National Ambulance Service Medical Directorate, the National Ambulance Service Education and Competency Assurance Team, the Dublin Fire Brigade Medical Director, the Dublin Fire Brigade EMS Support Team and the Irish Coast Guard Chief Crewman (Standards). Clinical Directives apply to all relevant staff in the HSE National Ambulance Service, Dublin Fire Brigade and Irish Coast Guard helicopter winch-crew.



## I.H.S. Father & Son(s) Weekend

Lilliput Adventure Centre, July 21st – 22nd 2018

Arriving at Lilliput on Saturday morning, we were greeted with the sight of hundreds of bicycles and big crowds. The local triathlon was taking place so there was already excitement and competition in the air before we even began!

We kicked off our first activity with Laser Tag in the woods. Seeing the kids and their dads doing 'Call of Duty' style tactical manoeuvres through the woods was great and everyone enjoyed it. Congrats to the kid's team for winning at the end!

After lunch we then headed back out to the woods for a game the Lilliput leaders called 'Sniper', where the leader closes their eyes for a few seconds and the participants must hide and try not to be spotted by the sniper, very similar to Kick the Can. The kids excelled here, scrambling for the best hiding places. Unfortunately for the adults, the large lunch didn't help when trying to hide behind a tree!

Once we finished up, we then prepped ourselves for the inevitable bog-hopping. Donned in our old clothes, we started the trek through the smaller bogs and obstacles until we finally got to the waist-high, thick sludge. The photos speak for themselves – everyone loved it!

After we finally got everyone out of the bog (minus a few pairs of runners), we washed off at the lake and geared up for kayaking. With two

or three people to a boat, we ventured out to the lake and things got competitive with mini races going on and some attempted boat toppling – (Dads!!!).

This marked the end of our activities for the day and we had some dinner and time to relax, play some games, chat, watch a movie and reflect on the day's activities. This was a great time for the kids to get to know each other, especially the newer ones, and for the fathers too. Putting names to faces and meeting other members was a great way to try and mask the smell of the bog!

On Sunday morning we started off with a game of Capture the Flag in the woods. It was a unanimous decision to have teams of Dads versus Kids. Despite getting lost on the way back, plus being outnumbered and having age and mobility against them, the dads remain undefeated champions of Lilliput Capture the Flag – the pressure is on for next year!



Following Capture The Flag, we split into several teams for the Orienteering. This activity involved using a map to direct your way around the entire grounds of Lilliput and surrounding areas of Lough Ennell. It was a great activity for team building, communication and decision making – something that everyone benefited from. Despite some slight bending of the rules (Dads!!) – the Volunteer group broke record time and were able to relax



while the others scrambled back to the finish line. Our last activity of the weekend was Rock Climbing. It was another great activity enjoyed by all!

Overall, the weekend was excellent and the staff at Lilliput were incredible as always. I've been to Lilliput on several occasions with the Youth Group and it always delivers. The Father & Son's and Mother & Daughter's weekend is a great opportunity for the parents and kids to bond in those situations where they might not get to at other events. The smaller, mixed-age groups mean a more personal and informal approach with the leaders and offer a great way for the kids and the parents to interact in a more relaxed setting and reconnect with friends new and old, and the opportunity to meet new members.

I think the aching arms, legs and backs proved the weekend was a success and the recovery after is well deserved! Already looking forward to next year!

Hopefully we can wash the bog off by then!

**Sam Morrissey**





# Meet John Stack, the new I.H.S. Chairperson

Earlier this year, John Stack was elected chairperson of the I.H.S. John has been a member of the society and the board for a number of years. While many of you will already know him from his involvement with the society, we thought it worthwhile sitting down with John, to discover the hopes and aims for his tenure.

We would like to congratulate John on being elected chairperson and we look forward to working with John over the coming months and years.

## **Firstly, to start things off, would you like to provide us with a little bit about yourself and your involvement with the society?**

Ellie and I have four boys and two of them have Severe Haemophilia A. As there was no history of haemophilia in Ellie's family, it came as a shock when we first discovered one of our children had haemophilia. His birth was normal and we were anticipating a quick discharge from the hospital. However, he became very ill and ended up on life support, having suffered massive internal bleeding. At the very least, it was good to get a diagnosis.

The hospital arranged for the Society to get in contact with us quickly, so we could learn about haemophilia and how to live with it. Fortunately, there was a conference coming up, which gave us the opportunity to quickly meet people and get to know the community. I was asked to speak at the next conference on nutrition and healthy eating, and I've been involved ever since. Shortly after that talk, I was asked to join the Board.

## **What was the driving force behind you to taking on the role of Chairperson?**

While most people in the Society know me as a Strength and Conditioning Coach, my background and day job is engineering....so I'm a fixer of things. The day we got the diagnosis, I wasn't particularly emotional (relieved to have a diagnosis though); rather I just wanted to know what I needed to do to help my son. That is my mindset. I want to be involved in whatever process it is that helps my son, and all other people with haemophilia, and that really is why I am involved in the Society. I'm very interested in the new treatments and what the future holds, but I also know that I have something to offer through my work in sports and sports nutrition. Having had severe health issues in my youth, I have great empathy for the haemophilia community and I genuinely care about their wellbeing.

## **How have you found the role so far?**

I'm not long in the role so I suppose I'm still finding my feet. Chairing the Board meetings has been the biggest



'challenge' to date and I think I'm doing OK! I suppose I'm in contact with the Society more now than I would have previously.

## **What are the areas you would like to concentrate on during your tenure?**

Twinning is something I am very interested in so that is definitely something I would like to focus on. Advocacy and the tendering process are two areas that I am also interested in. Finally, there is the future to look ahead to. Haemophilia care is currently going through perhaps the biggest transformation ever.

Nowadays, our young population lead very normal lives, but that luxury depends on the type of treatments available. Maintaining the very high level of treatment we have in this country is a priority. As our older population ages, their needs become different, though no less important. While the new treatments become mainstream, we must not lose sight of the needs of the older community.

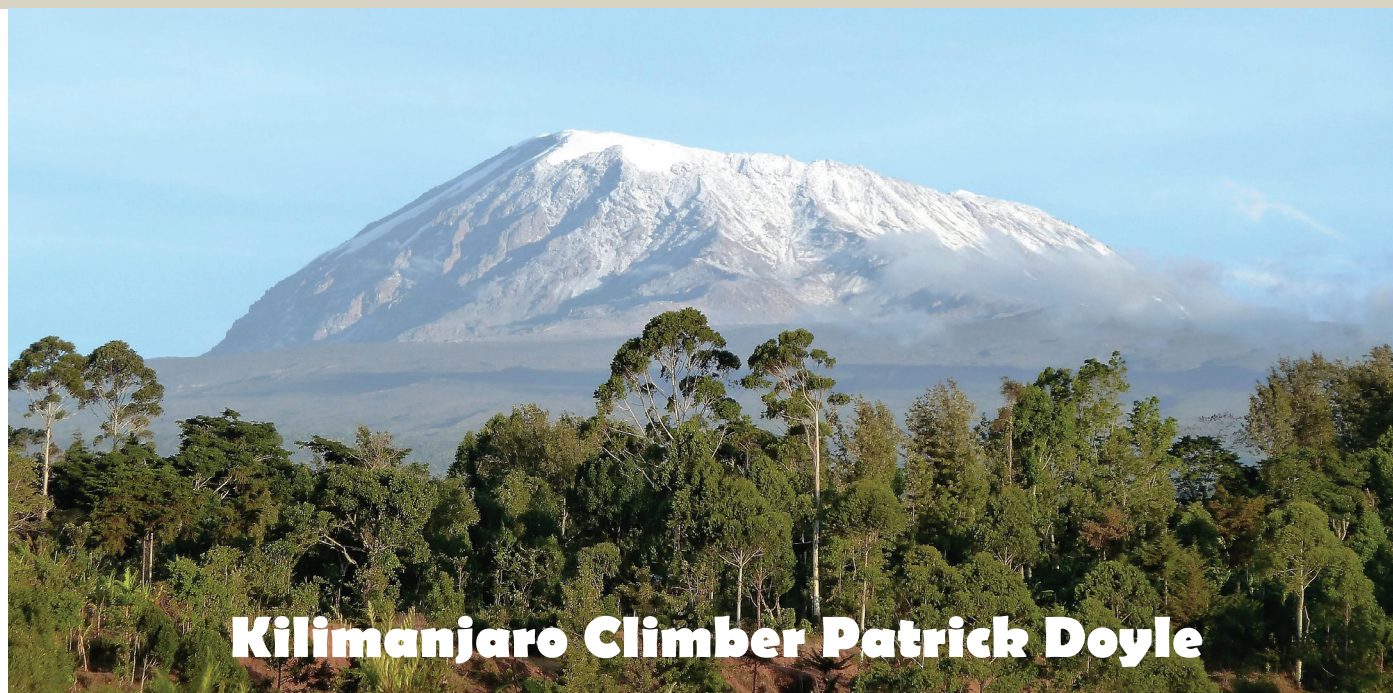
## **With so many exciting developments in haemophilia care on the horizon, how important is it that the I.H.S. is in a strong position going into this brave new world?**

I can see the role of the I.H.S. changing dramatically in the coming years. When the Society was set up, it was to fight for treatment, facilities and the standard of care that seems normal to us nowadays. What has been achieved down through the years, since the first meeting in 1968, is nothing less than outstanding. That haemophilia care in Ireland is second only to Sweden is a testament to the fantastic work carried out by those pioneers who established and made the Society a success.

While the fight to get care has been won, and the standard of care in Ireland is very high, there are still improvements to be made and, ultimately, a cure. New treatments are coming on the market at a tremendous rate at the moment, not to mention the very positive results of gene therapy research. All of them are making the lives of our community easier. One of our sons is on daily factor treatment. That means we access his port seven times a week. At the moment, we live in hope of him being able to reduce this to two or three times a week, or once a week, or once a fortnight or, and in the long term, a single injection cure. It's an exciting time, but we cannot afford to become complacent and allow these opportunities to pass us by.

It is essential the I.H.S. remains heavily involved with the process by which these products become available to our members. We have a proven track record in securing affordable prices for our community, and that will remain a huge role for the Society moving forwards.





## Kilimanjaro Climber Patrick Doyle

We are very grateful to everyone who organises or takes part in fundraisers for the I.H.S. every year, your tremendous support for the work of the Society is really appreciated, and there is a big I.H.S. fundraiser on the not too distant horizon.

Patrick Doyle is going to climb Mount Kilimanjaro in Tanzania, Africa in October 2018. The summit is 5,896 metres high, roughly two thirds the height of the world's highest mountain; Everest. Patrick will undertake a tough 8-day trek, 6 days up and 2 days down with temperatures that can hit -20C. Patrick is paying the cost of the trip himself, so all money donated will go directly to the society.

We decided to catch up with Patrick to find out how things are progressing since we last spoke, in the summer issue of the magazine.

### **How has the training and preparation been going since we last spoke?**

I've been trying to stretch out my hiking up to five or six hours at a time as well as stretching out the distance to 20+km. I've now been to the summit of 11 counties in Ireland, it doesn't look like I will get all 32 done before Kilimanjaro but I plan to finish the rest when I return from the trip.

I had a first meeting with the group I'll be trekking with. They gave us the lowdown on what gear we need, the schedule and other information about the trip.

### **So far, what have you enjoyed the most and what has been the most challenging aspect to your preparation?**

I have greatly enjoyed seeing the travelling around the Irish countryside from all the county summits. The most challenging aspect is going out two days in a row. A

long day of travelling and hiking is pretty exhausting but you just have to get up the next day and get out there again. It can be tiring but knowing each day out there will help me reach my goal is rewarding.

### **With the climb fast approaching, how are you feeling? Excited, nervous, or a bit of both?**

I feel quite relaxed to be honest, I have trained for this, so I know I'm well prepared.

### **What final preparation have you planned between now and the climb?**

My plan at the minute is to try and string at least four days hiking together, it'll be tough with work but I'll find a way.

### **What is the plan for the climb in October itself?**

The climb itself will begin on October 17. Each of the first two days will be hiking roughly 1000m up, this is similar to climbing Carrauntoohil each day. The third day is again up another 1000m this will bring us above 4000m, but we will descend below 4000m to sleep. The fourth day will again be hiking up and back down to sleep, this is an extra day to help acclimatise to the altitude. The fifth day will bring us up to 4800m where we will sleep. Our sixth and summit day will begin around midnight and will involve hiking the last 1000m to the summit of Africa, followed by a decent half way back down the mountain. This will be the toughest day of the trip and could take up to 15 hours of hiking.

*If you would like to make a donation, you can do so at the link below:*

**<https://give.everydayhero.com/ie/trekking-mount-kilimanjaro>**



# Mild-Moderate Haemophilia Information Day



On Saturday, August 18, the Irish Haemophilia Society organised a special information day with regards to mild/moderate haemophilia in the Osprey Hotel, Naas, Co. Kildare.

Mild-moderate haemophilia is not always as “mild” or “moderate” as it would seem, and persons are presented with a different set of management criteria to patients with severe haemophilia. This was essentially the theme for the day as we explored how best to treat and manage mild/moderate haemophilia, and delved into how best to cope, both in terms of mental and physical health.

Once the important issue of sandwiches, tea and coffee was dealt with, it was down to business with Professor Paul Giangrande first to speak about ‘Prophylaxis: Moderate Haemophilia – Is it time?’.

Professor Giangrande is an advocate of prophylaxis for non-severe haemophilia and believes it is unfair to deny prophylaxis treatment to all patients. Some patients bleed a lot more frequently than would be expected. Often lifestyle is curbed (by contrast with patients with severe haemophilia who are offered prophylaxis) and younger and/or more active patients in particular would benefit from prophylactic treatment

Extended half-life (EHL) factor IX preparations given once a week or fortnight by intravenous injection can certainly maintain almost normal factor IX levels throughout the week. By contrast, it is very difficult to maintain high FVIII levels with current EHL FVIII products, frequent intravenous injections are required (2-4 times week). However, Professor Giangrande also noted there is a significant risk of inhibitor development for non-severe patients with ongoing treatment.

There are many other challenges too. Some of the key

ones are; there are more non-severe than severe patients so there are significant cost implications if prophylactic treatment is extended to this group. Patients generally experience far fewer bleeds and these are typically not spontaneous, so it may be harder to advocate the cost. Diagnosis is often delayed beyond childhood and are often less knowledgeable about haemophilia as a result, and they are not trained to self-infuse. Non-severe patients are generally far less engaged with specialist haemophilia centres and NMOs.

All that being said, Professor Giangrande believes the potential benefits, especially to the quality of life, outweigh the challenges. The presentation was followed by one of many energised discussions. One of the most noticeable aspects to the day was how participants were engaging with speakers at each given opportunity with people sharing their experiences and asking questions during, and after the sessions.



Next up was Ms. Janet Cleary (left) from the National Coagulation Centre (NCC) with a session on ‘Coping Skills’. The presentation focussed on the psychological effects of mild/moderate haemophilia which, like any long-term health condition, requires ongoing management over years and decades. The Impact of living with a health condition can be felt across many domains; psychological, biological and social. And impacts on the person in numerous areas; physical, mental (stress/anxiety), fear (denial), employment, education and family.

She stressed the need to manage your own condition, have a quality of life suited to you and manage the emotional impact that may be associated with having a health condition, and being resilient to adapt and cope with change and bouncing back from difficult experiences. While it is not always easy to remember but looking after yourself is not a selfish act or something to feel guilty about – it enables you to manage your



condition or help someone else to do so.

Coping with a long-term health condition can be challenging but you cannot change the condition, but you can change how you look at it or deal with it:

- Keep connected
- Learn health habits: diet, exercise, rest.
- Accept that change is a part of living
- Nurture: your personal strengths
- Have balance & flexibility in your life.
- Take care of yourself
- Laugh
- And don't be afraid to ask for help from family, friends, professionals, support groups

Next, Dr. Kevin Ryan from the NCC presented his session 'You do not think Mild-Moderate Haemophilia is problem?'.

Mild-moderate haemophilia is not characterised by numerous spontaneous bleeds. While it may cause mild symptoms day-to-day, it can still go unrecognised and will cause increased bleeding at the time of challenges such as surgery, invasive or dental procedures, trauma or pregnancy. Do not underestimate your bleeding disorder, complacency isn't your friend.

Dr. Ryan outlined the many problems associated with bleeds; they may delay recovery and discharge from hospital, need for repeat surgery or blood transfusion

and may lead to severe disability (brain, spinal cord or nerve damage), or even death. However, there are lots of strategies to manage your bleeding disorder but first and foremost it requires recognition and knowledge of your bleeding disorder. You can reduce the risks by knowing your disorder, level, treatment, when to seek treatment and where and when/what to tell medical professionals. He also outlined the need for patients to attend the centres for regular follow-up to review any bleeding problems, medications, complications and updates on any new developments.



The day concluded with a fascinating personal insight of living with mild-moderate haemophilia by David Curtin (left), who shared his experiences of growing up with haemophilia, the challenges he encountered and overcame, and of course, his love and passion for hurling.

He began playing sports from a young age, but his love of hurling started at St Colmcille's School in Knocklyon and from there, he joined Ballyboden St. Enda's and has been hurling ever since. Throughout David's career, which included captaining Dublin, he had a lot of setbacks; injuries would occur from the knocks but with physio and rehab he'd get back on track. He also developed inhibitors twice but despite numerous setbacks it never crossed his mind to give it up.

David's story is a fascinating and inspirational tale of positivity and resilience in the face of adversity, and one that requires further attention in a future issue of our newsletter.

If you were unable to attend the conference and would like to access the presentations or have any questions, please contact the office on 01-657 9900 and we will be happy help.

## Barry Healy



Professor Paul Giangrande receives his honorary lifetime membership to the I.H.S. following his presentation.



Dr Kevin Ryan (NCC) delivers his presentation



# 50th Anniversary Gala Fundraising Dinner 2018

Our 50th Anniversary Gala Fundraising Dinner took place on Saturday, September 22nd in the Castleknock Hotel, Dublin. It was a fabulous night and we hope fun was had by all!

Actor and TV presenter Simon Delaney was a superb host and we think everyone will agree that he is one funny guy. Pat Davitt was an exceptional officiator of the auction which was a huge success, and great fun too! Rounding things off was Route 66 Big Band - a 16-piece brass band - who treated us to their famed and fabulous floor-filling sounds; meaning there would be plenty of sore feet to match the sore heads the next day!

For fear of missing anyone out, we shan't name names but needless to say we are indebted everyone involved in making the night a success – a massive thank you from the society!



Perusing some of the auction items



Simon Delaney was superb on hosting duties



The I.H.S. staff in all their finery



Volunteers, members & friends enjoying their night!



Volunteers, members & friends enjoying their night!





# New Version of Homescan App Available



A new version of the Homescan App is available to download for free from October 1st, 2018, via Google Playstore and Apple App Store. It includes new features to help better manage your care and reduce medication wastage.

There are some FAQs below and a comprehensive guide is available on the news section of our website.

## How to do I download the App?

It can be downloaded free of charge from the Apple Store and Google Play Store - all you need is a smartphone.

## Can I have the app on more than one device?

Yes – the app can be on multiple devices.

## How do I know I have the up to date version of the app?

If you try to download the app you will receive a message stating your app is up to date. You can check what version you have by opening the app, at the bottom of the first screen you will see what version you have.

## How do I log on to the app?

If you have never used the app before, contact your treatment centre who will issue you with a ID card and login details. If you have used the app before continuing to log on as normal.

## Why should I scan my treatment?

In order to make sure the treatment is safe always scan your treatment before you take it in to check:

The treatment is your treatment of choice; the treatment is in date and the treatment is not on a recall list

## I lost my card; can I still use the app?

Yes, you can manually log on using your username and password. If you can't remember these, contact your treatment centre.

## Which barcode should I scan?

Always make sure you are scanning the square barcode.



## The app is telling me I have shorter dated stock, what should I do?

**Note:** This alert is only valid if your treatment is stored in the fridge. Ignore these short-dated alerts if you keep your treatment out of the fridge. If you urgently need to take your treatment just continue. It is always best to use the shorter dated stock first, so that it is less likely that you will have expired treatment.

## I cannot scan my treatment?

If you are unable to scan the barcode before you have taken your treatment, put the treatment box aside and try scanning another treatment. If that works, continue with your treatment and contact your treatment centre with details of the box that did not scan.

In the unlikely event you have taken your treatment before scanning, please write the treatment date and reason for treatment on the box (avoid writing on or near the barcode) and contact your treatment centre with details of the box that did not scan.

## I have received an alert saying that I have scanned another patient's treatment, what should I do?

Please see 'Stock Information Alert 1' in the user guide or contact your treatment centre.

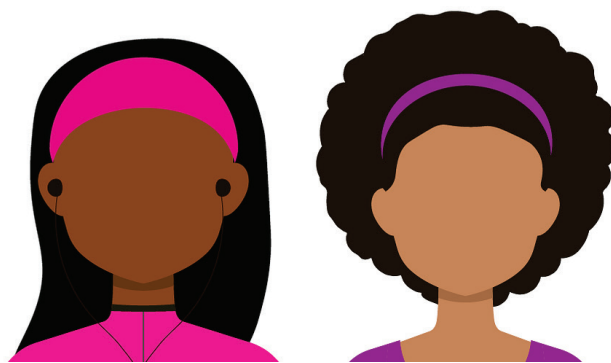
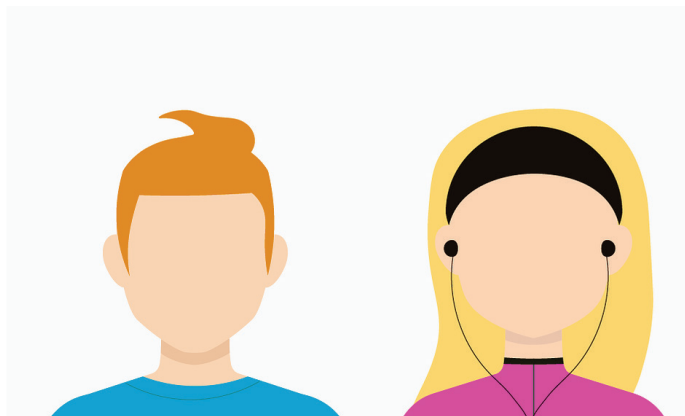
## Can I scan if I am abroad? Can I scan if I have no data or Wi-Fi connection?

Yes, you can scan as normal when abroad. If you have any queries, contact your local treatment centre before travelling.

And Yes – Your scanned information will be stored within the app until you have a data/wi-fi connection.



# The I.H.S. Youth Programme Report



The I.H.S. Youth Programme kicked off with two meet-ups in August; the first took place in the Limerick Strand Hotel on August 18th, followed by the second in the Citywest Hotel, Dublin on August 25th.

The topics discussed during these days were relationships and social media. This was broken down into three parts:

Types of Relationships, Social Media and Disclosure.

## 1) Types of relationships

In this section we spoke about healthy relationships such as family, friends, doctors, teachers etc. And how they are made up of respect, trust and communication and why it is important to have this strong network around you.

We also looked at unhealthy relationships and what can cause a relationship to become unhealthy such as pressure or abuse. We tried practical examples which were great fun and gave us another point of view. From here we talked about our life experience verses our parents and how are parents have a wealth of knowledge that we will need now, and in the future. We should always open up with our parents and ask any questions about life or our future as this only makes the relationship stronger and makes life easier.

We also briefly talked about romantic relationships and how they are also built on the say same three principles; respect, trust and communication.

## 2) Social Media

Everyone really excelled at this topic. After looking at all the main social media platforms we talked about the positives and negatives of each. This led to how to keep yourself safe and secure online. We all enjoyed this topic and it was great to hear everyone's opinion on the subject.

## 3) Disclosure

We looked at how someone could approach telling their friends that they have haemophilia or any illness. We discussed how knowledge is the key. The more someone knows about a topic the more confident they can speak about it to others.

**"It was a great start to our youth program and while there is scope to increase our numbers, the initial stage of the programme went very well. Everyone enjoyed the content and were very engaging"**

## In Conclusion....

It was a great start to our youth programme and while there is scope to increase our numbers, the initial stage of the programme went very well. Everyone enjoyed the content and were very engaging.

The locations in Limerick and Dublin were perfect with everything supplied. My hope is that at the October Conference I can speak to the rest of the youth group about how beneficial the programme is and why you should get involved. I hope to meet you soon.

**Robert Flanagan**





## New Member of Staff

We would sincerely like to welcome our new member of staff, Aoife Kelly to the team and we're delighted to have Aoife on board!



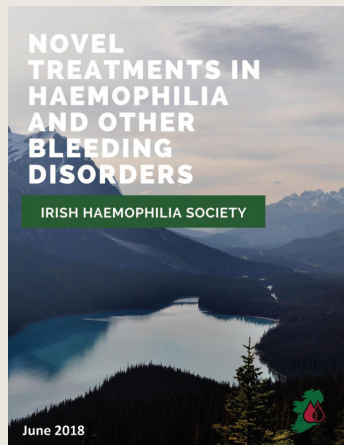
Aoife joined the I.H.S. in August 2018 and Aoife is responsible for organising I.H.S. conferences and events as well as some general administrative duties.

**Email: [aoife@haemophilia.ie](mailto:aoife@haemophilia.ie)**

## Novel Treatments in Haemophilia and other Bleeding Disorders

The therapeutic landscape in haemophilia is changing rapidly and it can be difficult to keep up to date.

The Society has adapted a publication compiled by the European Haemophilia Consortium to produce a comprehensive update on 'Novel Treatments in Haemophilia and other Bleeding Disorders'. This document is designed to be informative for both people with bleeding disorders and health care workers.



It is available to download from the publications section of our website, [haemophilia.ie](http://haemophilia.ie).

If you would like a hard copy, please get in touch with us in the office on 01 657 9900.

## Dates for your Diary

# 2018

### October

#### October Conference

**Dates:** Friday 19th to Sunday 21st October

**Venue:** Radisson Hotel, Sligo



### December

#### 50th Anniversary Children's Christmas Party

**Date:** Saturday 1st December

**Venue:** Grand Hotel, Malahide, Dublin.



# 2019

### March

#### AGM & Conference 2019

**Dates:** Friday 1st to Sunday 3rd March

**Venue:** Hotel Kilkenny, Kilkenny

### June

#### Ageing Conference

**Dates:** Friday 28th to Sunday 30th June

**Venue:** Killeslin Hotel, Portlaoise, Laois



### October

#### October Conference

**Dates:** Friday 18th to Sunday 20th October

**Venue:** Carlton Shearwater, Ballinasloe, Galway





## Noticeboard



### Planned Giving Appeal

Contributions to the I.H.S. Planned Giving Appeal have allowed us to pay for the running costs of the apartment facility for members. This apartment in Dublin was purchased for the use of our members and their families, who need accommodation linked to increased visits to their treatment centres in St James's Hospital and Our Lady's Children's Hospital Crumlin. The apartment has proved to be an excellent facility for our members and continues to be used on a regular basis.

Contributions have also helped our International Development Fund which continues to contribute to access to treatment and improved haemophilia care to fellow patients in Vietnam. As a result of our involvement with Vietnam, Vietnam has increased its factor usage by 300%. We are delighted to say that our work with Vietnam continues today and improvements of treatment and haemophilia care in Vietnam is progressing all the time.

We are asking for your support to help maintain these services and support. Contributions to our Planned Giving Appeal can start from as little as €10 per month. However, if you choose to contribute €21 or more per month, the I.H.S. as an eligible charity, can benefit from tax relief from the Revenue Commissioners, in respect of donations. Your gift can go even further, at no extra cost to you.

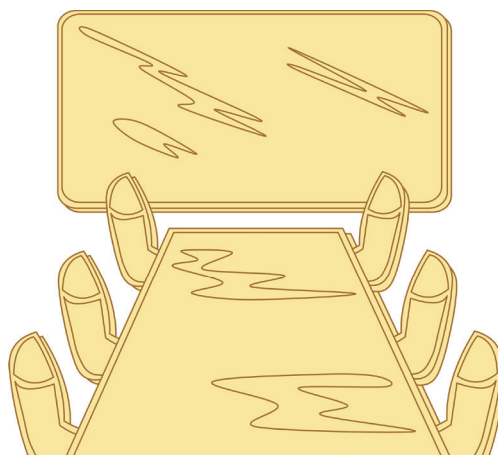
If you would like to contribute to the Planned Giving Appeal or would like more information on this please contact Nina on 01-6579900 or email at [nina@haemophilia.ie](mailto:nina@haemophilia.ie).



### Bon Voyage Aoife!

Aoife has been our colleague and friend since she joined the I.H.S. staff in December 2015, so it is with a heavy heart that we have said goodbye to her as she has left the I.H.S. for pastures new. Many of you will have met Aoife at conferences or spoke to her on the phone many times, so I am sure you will join us in thanking Aoife for all her hard work and dedication and wishing her well in the future.

We will miss Aoife but know that her new adventure will be an exciting time for her as she travels to Australia for a new chapter in her life.



### Board Update

We are delighted to welcome two members to the I.H.S. Executive Board; Donal McCann and Matthew McCabe.

With so many exciting prospects on the horizon, we are all looking forward to working with Donal and Matthew over the coming months and years.



## Noticeboard



### Movie Reminder

As this year marks the 50th Anniversary of the Irish Haemophilia Society we commissioned a documentary film, directed by Swedish - Bosnian writer and director, Goran Kapetanovic.

'Facing the Rising Sun – 50 Years of the Irish Haemophilia Society' documents the 50-year history of the I.H.S. and features fully restored archive footage, interviews with members, staff, former staff and volunteers, healthcare professionals and the people connected to this 50-year story.

For those of you who have yet to see it, or fancy watching it again, the movie is available to watch on [haemophilia.ie](http://haemophilia.ie).

Physical formats are also available free of charge on request, please contact Rob in the office on 01 657 9900 or [info@haemophilia.ie](mailto:info@haemophilia.ie).

### GDPR

The introduction of General Data Protection Regulation (GDPR) came into effect on 25th May, 2018. GDPR is the EU's new privacy law and affects every organisation using personal data including the Irish Haemophilia Society.

If you no longer wish to receive communication from us or wish to be removed from our database, please let us know and we will remove your details.



### 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



### Brian O'Mahony Award

Nominations are now open for the Brian O'Mahony Award for outstanding contribution to haemophilia care in Ireland. Nominations can only be proposed by members of the society and members of the current board or staff cannot be nominated.

If you would like to nominate someone who, in your opinion, has made a real difference in haemophilia care in Ireland, please send your nomination to [info@haemophilia.ie](mailto:info@haemophilia.ie) by October 12th, 2018.





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