

# Haemophilia.ie



Representing people in Ireland with haemophilia and related bleeding disorders

Magazine of the Irish Haemophilia Society

Autumn 2019



The Society  
at a Glance

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

**46**  
Planned Giving  
Contributors

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# October Conference 2019

**Venue:** Shearwater Hotel, Ballinasloe

**Dates:** Friday 18th to Sunday 20th October 2019



## Friday October 18th

17.30 - 19.00	Registration (Pre-Conference Area - Plaza 3)
19.00 - 20.00	Dinner (Plaza 1 + 2)

## Saturday October 19th

10.00 - 11.00	<b>Leading The Way, Where We Stand In Europe (Plaza 1)</b> Speaker: Mr. Brian O'Mahony, Chief Executive, I.H.S.
11.00 - 11.30	<b>Coffee Break (Plaza 3)</b>
11.30 - 12.30	<b>Debate: Gene Therapy vs Current Treatment (Plaza 1)</b> Speakers: Matthew McCabe & Seamus McDonald
12.30 - 13.30	<b>Lunch (Plaza 2)</b>
13.30 - 14.45	<b>Life Expectations (Interactive Session) (Plaza 1)</b>
14.45 - 15.15	<b>Coffee Break (Plaza 3)</b>
15.15 - 16.15	<b>Novel Treatments: The Terminology Explained In Simple English (Plaza 1)</b> Speaker: Dr. Niamh O'Connell, National Director, NCC
16.15 - 17.00	<b>Hot Topic (Plaza 1)</b>
17.00 - 19.00	<b>Family Time</b>
19.15	<b>Dinner Followed by Entertainment for the Children (Plaza 1 + 2)</b>

## Sunday October 20th

10.00 - 11.00	<b>Lifestyle Management (Plaza 1)</b> Facilitator: Mr. Jay Mulligan
11.00 - 11.30	<b>Coffee Break (Plaza 3)</b>
11.30 - 13.00	<b>Yoga (Plaza 1 + 2)</b> Facilitator: Ms. Mel Taylor
13.00 - 14.00	<b>Lunch &amp; Depart (Restaurant)</b>

# From the Editor

Welcome to the Autumn issue of our quarterly magazine. I hope you all had a fine summer and are looking forward to the Member's Conference in October, we all are!

Speaking of the October conference, you can get acquainted with the programme on Page 2. On Page 4 meanwhile, you will find our CEO's report, where Brian provides an update from his recent visit to Vietnam, plans for twinning with Jordan and Brexit preparedness. On Page 9, our Chairperson John Stack updates us on what's been going on during the summer and future plans.

Then on Page 10, Jim O'Leary gives an insightful personal perspective of ageing with a bleeding disorder in 2019 and Aislinn Farrelly writes about her experiences volunteering with the I.H.S. on Page 12. The I.H.S. Youth Programme was back in action and Robert has a report about the summer meeting on Page 13.

On page 14 you will find an interview with Dylan Ryan who is running the Dublin City Marathon in aid of the I.H.S. – we caught up with him to find out more about his preparation, why he chose to raise funds for the I.H.S. and more. On Pages 18 and 19 there are some news and updates, with staff profiles on pages 16 and 17.

Lastly, I hope you enjoy this issue and if you would like to contribute by writing an article for a future edition or suggest a story or area that you would like to see covered, please don't hesitate to get in touch with me at [barry@haemophilia.ie](mailto:barry@haemophilia.ie).

**Barry Healy**

## In this Issue

04

### CEO Report

Brian reports on Vietnam, Jordan and Brexit

08

### Dates for your Diary

Events for the rest of 2019 and the two big ones for next year!

09

### An Update from our Chair

John Stack gives an update on what has been happening over the summer

10

### Ageing with a Bleeding Disorder in 2019

Jim O'Leary shares some personal perspectives on ageing with haemophilia

12

### Lending a Hand!

Aislinn Farrelly regales us with tales of volunteering with the I.H.S.

13

### Youth Programme

Robert reports on the summer youth programme meet up in Dublin

14

### Marathon Fundraiser

Getting to know Dylan Ryan who is running the Dublin City Marathon in aid of the I.H.S.

16

### Meet the Team

I.H.S. staff profiles

18

### Noticeboard

Updates and useful info from the world of the I.H.S.





# CEO REPORT

Members will be well aware that we have been working and collaborating with the Vietnam Hemophilia Association (VHA) since 2010. The World Federation of Hemophilia (WFH) has a twinning programme which encourages twinning between haemophilia societies in developed countries, with those in developing and emerging countries. Initially, our work with Vietnam was under the auspices of this programme. Following the formal ending of our twinning programme, Vietnam was included in the more ambitious WFH Global Alliance for Progress (GAP) programme. This work has just been completed.

In Vietnam in 2010, treatment was mainly with cryoprecipitate, which is a much less effective form of therapy, no longer used in Ireland. Access to factor concentrates was very limited. In 2010, 2.7 million 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 Haemophilia Association was called the Vietnam Society for Congenital Bleeding Disorders, it was run by the doctors with very little or no involvement by patients. The governing structure of the organisation was unduly complex with a very large executive committee which rarely met. They did however have 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.

Following the assessment, the twinning programme officially started at the end of 2010. This was originally a 4-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.



## 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 plan workshop was carried out as part of the board governance

## In 2012 our activities included:

- The identification and preparation of suitable publications to be translated into Vietnamese
- A workshop on organising of 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.

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

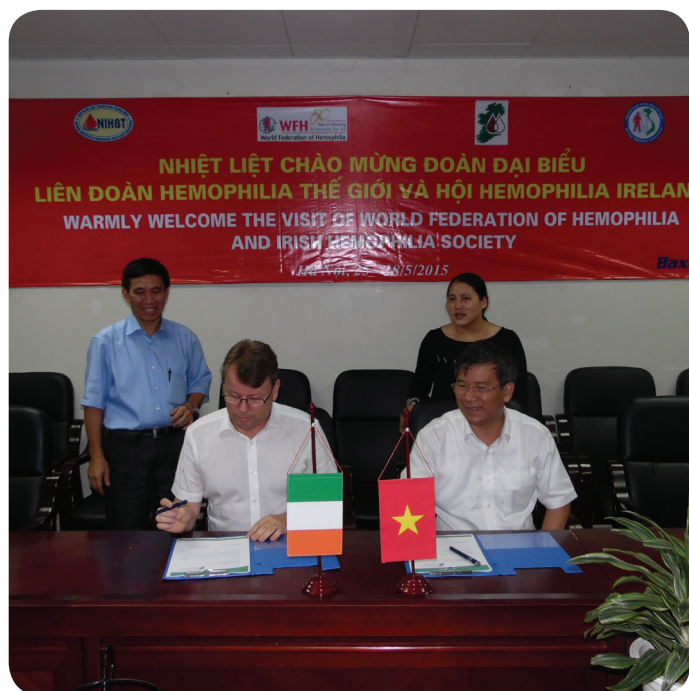
## In 2014 workshops were held for chapter leaders.

- 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 which provides small grants for people with haemophilia to allow those with limited mobility to establish a small business which they can run from home

In 2014 the Irish Haemophilia Society staff team also 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 period the I.H.S. visited Vietnam on eight occasions and the VHA visited Ireland on three 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 Haemophilia 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
- 3 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. and 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.

#### By the start of the GAP programme in 2015;

- The Ministry for Health approved treatment on demand for bleeding episodes and changed the regulations to allow for access to home therapy



They also approved, in theory, 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 were seven hospitals providing haemophilia care – two in Hanoi, three in Ho Chi Minh City, one in Hue and one in Can Tho
- The state medical insurance coverage for haemophilia medications improved with specific coverage agreed in 2012 and 2014
- The number of patients with haemophilia 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

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 in 2016 in Vietnam and continued until 2019. The major objectives were set as:

Improve care delivery in the country by strengthening the existing network of seven haemophilia treatment centres and creating satellite centres.

1. Support the development of medical expertise of HCP's in selected centres and in general in the country
2. Increase the supply of factor concentrates for patients
3. Expand the patient organisation and increase its lay leadership and the number of active volunteers
4. Develop and implement a national registry

5. 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
  6. 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
  7. 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 euro worth of free medication per year during the course of the GAP Programme
- Establishment of 10 satellite centres
  - 70% of PWH no longer have to co-pay for factor and the co-payment for the majority of the remaining 30% is 5% subject to a maximum of 8-9 million Dong per year (US\$ 320-\$400)
  - The 7 major HTS's (3 in Hanoi, 2 in HCM, 1 in Hue and Can Tho) now use factor concentrates primarily
  - Since 2015, FVIII per capita use has increased again to 0.252 per capita. This obviously remains low but represents an increase of 780% increase since 2010
  - Since 2015, FIX per capita use has increased from 0.016 to 0.042 per capita (262% increase)



**By august 2019, the following had been achieved:**

- 891 new people with inherited bleeding disorders had been diagnosed (696 with haemophilia, 50 with von Willebrand's and 145 with other rare bleeding disorders)
  - New decrees from Ministry of Health approving in principle home treatment, low dose prophylaxis, treatment at primary healthcare facilities, importation of humanitarian aid clotting factors (discontinued for a time in 2018). This does not mean they have home treatment or prophylaxis, but it does remove potential legal obstacle
  - Enhanced comprehensive care team at NIHBT in Hanoi and improved training and capacity
  - Improved comprehensive care teams in Ho Chi Minh, Hue and Can Tho
  - Improved capacity to carry out diagnostic tests, genetic tests and tests for VWD
- Core group of 12 patients/parents trained. 3 patients/parents now on Executive Board. 4 training workshops held
  - Patient clubs established in 4 of the 10 cities with satellite centres (Thai Binh, Hai Phong, Da Nang Khanh Hoa)
  - 6.975 million IU of extended half life FVIII/FIX donated by WFH
  - Pilot project on home treatment completed. (I am currently helping them prepare the paper on this for publication)
  - Centres in Hanoi and HCM participating in WFH World Bleeding Disorders Registry





### Additional Achievements of Irish Engagement

- Micro employment project has provided micro employment for individuals over past 3 years
- Home adaptation project providing wheelchairs, crutches and home aids
- Acceptance of Vietnam into Gene Therapy clinical trial, initially for haemophilia B (5 - 10 people) followed by haemophilia A. The first people are expected to travel to the USA around end of 2019 for assessment and dosing. They will stay in the US for 3 months with all costs paid
- Engagement of Irish Embassy and meeting with President Higgins for leaders of VHA during his state visit to Vietnam

Our work with Vietnam has achieved recognition. In 2012 the Twinning Programme between the Irish Haemophilia Society and the Vietnam Hemophilia Association was awarded the WFH Twin of the Year Award, in 2016, I received the Peoples Health Award from the Ministry of Health in Vietnam for our work with the VHA and in 2016, President Higgins met the leaders of the VHA in Hanoi.

We hope that the next steps for Vietnam will be the initiation of a national home treatment programme (A pilot programme took place for 6 months demonstrating clearly the advantages of home treatment) and the initiation of a national tender or procurement system for factor concentrates. This latter step would enable Vietnam to significantly increase their factor supply within the existing national budget. If these objectives become a reality, then the Society

and the clinical team from Melbourne, led by Prof. Huyen Tran, will continue to work with Vietnam to implement these much-needed improvements. In the meantime, the contact and friendships which have formed will endure and we remain humbled by their struggle, their commitment and their perseverance.

### Twinning Programme with Jordan

In 2018, the Society agreed a Twinning programme with Jordan. In September of this year, we will travel to Jordan to implement the first part of this programme. This will involve workshops on healthy living and also on Governance of the organisation. The comprehensive care centres at St. James's and Children's Hospital Ireland at Crumlin are also twinned with their clinical counterparts in Jordan so a team from both centres will also travel to Jordan in September to implement their programme. During the visit, the Health Ministry have also organised a haemophilia conference at which we will all participate. An update on our work with Jordan will be provided in the next newsletter.

### Brexit

We're in an era of uncertainty with regard to Brexit. However, we have not been idle in making the required preparations. The Haemophilia Product Selection Monitoring and Advisory Board (HPSMAB) have been working on contingency plans for several months. Arrangements have been finalised to ensure no disruption of supply to haemophilia treatment products. Additional stocks will be kept in Ireland. Supply routes have been changed to ensure that, following Brexit, no product will be imported directly from the UK or from Europe via UK land bridge. All products will be imported directly from Europe.

**Brian O'Mahony**

## Dates for your Diary



## 2019

### October

#### October Conference

**Dates:** Friday, October 18 to Sunday, October 20  
**Venue:** Shearwater Hotel, Ballinasloe, Co Galway

### November

#### Haemophilia B Information Day

**Date:** Saturday, November 16  
**Venue:** Hotel Kilkenny, Kilkenny

## 2020

### March

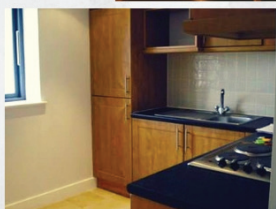
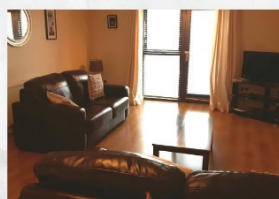
#### AGM & Conference

**Dates:** Friday, March 6 to Sunday, March 8  
**Venue:** Slieve Russell Hotel, Co Cavan

### October

#### October Conference

**Dates:** Friday, October 16 to Sunday, October 18  
**Venue:** Mount Woseley Hotel, Co Carlow



HYDE SQUARE  
Apartments

### Hyde Square

A quick reminder that the apartments at Hyde Square have re-opened & are available to:

- People with haemophilia or related bleeding disorders from outside of Dublin, when attending St. James's Hospital or Our Lady's Children's Hospital, Crumlin for treatment, for a hospital appointment or for a review clinic.
- An immediate family member, a spouse, a partner and/or child of the person with haemophilia or related bleeding disorder from outside Dublin, when attending St. James's Hospital or Our Lady's Children's Hospital, Crumlin for treatment, for a hospital appointment or for a review clinic, or while a family member is an in-patient.

If you would like more info or to make a booking, please contact Julia in the office on 01 657 9900.

*A nominal fee of €10.00 per booking, per night will be levied to offset the cost of cleaning and routine maintenance.*



## An Update from our Chairperson....

Hi everybody. I hope you had a great summer. We certainly did. Ellie and the kids did loads of camping all over the country and I joined them when I could. Camping is a great and affordable way to holiday. You do need to be well equipped with a quality tent and all the other trappings that make camping comfortable and enjoyable. And marshmallows. You can't camp without marshmallows.



But, for us, that's not all we needed to make camping, or any kind of holidaying even possible. Last year was a complete write off for us as we spent many a day and night in Crumlin. This year, thanks to a new product, we got a sense of normality back into our lives.

Hemlibra has completely transformed our quality of life, especially Fionn's. For effectively the first six years of his life, he has had daily injections as he tried to fight off an inhibitor. Last year, after a port infection, he became very ill. Life became extremely challenging, unpleasant and, sometimes, hopeless for him. He was miserable, rarely laughed or smiled, missed many days of school and his friends, and was generally very down.

Last year, when we went on holiday to West Kerry, Ellie and Fionn had to abandon it on the first night and drive back to Crumlin. This year, thanks to Hemlibra, Ellie and the kids got to travel all over the country camping and enjoying the great outdoors. Looking at the photos, and there were many, you would think it was a different person when looking at Fionn. The smiles, the childhood glee, the energy levels and no bleeds, infections or complications. He has gone from a daily injection to a fortnightly one. This new product has been huge for us. If this is the outcome of new and novel treatments, then the future for people with haemophilia is very bright indeed.

In other news, Brian is just back from Vietnam and I'm sure he will update you all on his experience there when he gets the chance. Briefly, while the twinning programme with Viet-

nam has been a huge success, it must draw to a close. I wish them well and hope that they can continue to improve the level of service to people with haemophilia in their country. I would love to see them introduce a national tender, which would pave the way for at-home treatment. If they do make progress in this area, we have made it clear we will be available to assist.

Brian and I are off to Jordan in September and I hope to see big progress since we were there last. When we meet the Jordanian Haemophilia Society, Brian is hoping to cover national tenders. I will do a session on personal well-being, quality of life, diet and exercise. While these topics would be typical here, I don't know if there is a culture of scheduled or planned exercise in Jordan. I'm looking forward to having a brainstorming session on that. We intend doing a session on governance, which, based on last year's trip, is an important topic to address early in our twinning project. We will be travelling with staff from the Comprehensive Care Centre.

Speaking of sport, exercise and haemophilia, I hope many of you are making use of the guidance document issued recently by the Society. You should have received a copy in the post, but if you haven't, give the office a shout and the staff will happily send it out to you. While exercise is very important for us all, whether or not we have haemophilia, we are more likely to stick to a plan if we do something we thoroughly enjoy. I have an aunt in her late 70s who still goes old time dancing twice a week. I know people who do yoga, sea swimming, hill-walking, mountain climbing, the gym, and/or team sports. The one thing that keeps them coming back is that they enjoy it and it is right for them at that time. Aim for 30 minutes of activity most days.

It's been five years since we did a strategic plan. We'll be starting a new strategic plan in the new year which will set out our targets and objectives for the next five years.

Don't forget that the October Conference will take place at the Shearwater Hotel, Ballinasloe from the 18th to the 20th October. There's a great

programme planned and I'm looking forward to seeing many of you there. I'm also looking forward to continuing the exercise programme with the teenagers. I feel we're making good progress there.

**John Stack**



## Ageing with a Bleeding Disorder in 2019

**We are living in a time where people with haemophilia will have to confront the challenges of ageing for the first time. This is a testament to the improvement in comprehensive care and the availability treatment over the past decades. While no one wants to dwell on the degenerative effects of ageing, and the problems they may bring, being prepared can go a long way towards alleviating these challenges. Jim O' Leary shares some personal thoughts about various issues of ageing with a bleeding disorder.**

As a 63-year-old person with haemophilia, with an inhibitor which I contracted at age 14 in 1970, I was very happy to be asked to discuss ageing because like others of my generation, I can remember a time when we would not have been expected to reach this age.

In the 1950's and 1960's growing up in rural Ireland with no treatment available for haemophilia meant survival was a lottery and life expectation was 20 years. In the late 1960's cryoprecipitate became available and was a lifeline even though it meant long drives to Dublin to access it and generally a hospital stay of days or weeks depending on the severity of the bleed. This treatment, crude as it was, increased life expectancy to around 30 years and gave hope where there had been little previously. Further improvements appeared in the 1970's and 1980's with the development of concentrates which led to greater life expectancy but also to the devastation caused to our community by the sourcing of contaminated blood for products which were meant to be lifesaving.

We must never forget our relatives and friends who lost their lives then and in the intervening decades due to a failure in care and standards and those who survived but still carry the legacy issues and future uncertainty. It is poignant and necessary to remember them when we discuss ageing issues that they never lived long enough to experience.

Our younger members who have grown up with safe recombinant product and prophylaxis regimes can now look forward to a life expectancy in the same range as the general population who do not suffer from a bleeding disorder. This is being further enhanced by extended half-life products and novel therapies replacing intravenous infusions with subcutaneous injection once per week, two weeks or even four weeks. Gene therapy, which will be licensed within five years, offers the opportunity of eliminating bleeding disorders entirely so the future is bright and a lot longer than when I was born.

So, with all this good news on the horizon why do we need to be talking about ageing?

In the past my priorities were; a) to survive the regular bleeding episodes and occasional severe bleeds that I encountered, b) to manage a career which allowed me to support my family and c) to try and keep as physically fit as possible. Now I'm retired so career does not matter, and my bleeds are being well controlled by my new novel treatment. My Average Bleed Rate has gone from one every three weeks to no bleeds in a year. Okay. I still have haemophilia and I could still suffer a breakthrough bleed and need traditional treatment for surgery or trauma, but I no longer wake up every morning wondering if I will have a problem today. However, I now experience other ailments that are not haemophilia related and I am seeing doctors in other specialties. In the past year I have seen a gastro intestinal specialist, a Rheumatologist, a renal specialist etc. This raises the question as to who is now going to coordinate my medical care?

We are used to having our care coordinated by our Comprehensive Care Centre (CCC) and our haematologist arranges any occasional visits to other specialties. Now with new treatments we are being seen less by the CCC and as we age, we are seeing more of other specialties. I see my GP far more often than previously, as she is now my first port of call for non-haemophilia complaints. Our CCC is



also struggling with this change and how to manage it in a manner, which retains some central control of our treatment but does not divert their valuable time away from their core duties of dealing with bleeding disorders.

Integration of our medical data is limited by the antiquated IT systems whereby the system used by the GP cannot be interrogated by the hospital and vice versa. Likewise, not all hospitals can interrogate each other's IT systems so centralizing control of patient care is extremely difficult and expensive where multiple treatment locations are involved. Alternative options have been discussed such as attaching a GP to the clinics at the CCC but from my point of view, it would be far simpler to integrate the IT systems and rise above the protectionism, which is preventing it happening. In the interim I try to have all of my other needs met at Saint James's Hospital where there is a good level of communication between the various disciplines.

The I.H.S. advocate for people with bleeding disorders to take control of their health needs by educating themselves about their condition and discussing their needs with the other stakeholders. In the same way I believe it is necessary to educate ourselves about ageing and the needs we might have in the future. We can do this as a planning project, firstly by establishing what areas we need to look at, find out where to get the information we need, who we need to speak with and make a preliminary plan, which we can adapt as our future needs change.

#### **Some examples of areas we need to think about:**

Is our home suitable for someone who might have mobility issues in the future?

Does it have a suitable downstairs area for sleeping and accessible bathroom facilities if we could not manage stairs?

Is our home in a location where we have access to public transport if we could not drive and is it close enough to a medical facility, which meets our needs?

Could our home be adapted now to meet future needs? With a bit of planning and some investment we can avoid the stress of relocating and there is some financial help available for essential adaptations.

Could we cope with living alone in the future if we had to?

Are there care agencies and care packages available that we could afford to access, which would help with daily living tasks such as personal care, house cleaning, garden maintenance, routine repairs, shopping etc.

Consider joining a senior's alert group if over 65 and living alone at least some of the time. This will provide a personal alarm and alert others if you need help.

If we could no longer live at home and needed care in a retirement facility, is there a suitable facility we could visit to establish its suitability, especially as we have medical needs and may need help with intravenous infusions?

What would be the cost and how would we fund it? Could we access the Fair Deal and how would that affect us?

Some facilities offer assisted living in retirement villages where we can live in a fully maintained, warden protected



Jim speaking at our World Haemophilia Day event in the RCSI

property with access to an onsite retirement facility for meals and or medical care etc. This can be a good half way house, but such facilities are few on the ground in Ireland.

Legal issues are also something to think about and make some plans. Making a will is often deferred as it can be considered morbid but in fact it is the most practical thing one can do and it can save endless problems and legal fees that are incurred if one dies intestate (without a valid will). Most solicitors charge a relatively small fee for preparing a will and giving valuable advice with it including advice about enduring powers of attorney in the event of not being capable of managing our affairs.

Looking after our spouse/partner and family is an important consideration so ensuring they have access to finance etc. if anything happens to us is a serious consideration as lack of a joint bank account etc. can prevent access to funds until after probate is granted and this can take a long time.

Preparing a living will is also a modern trend. While it has no legal standing a living will is an expression of our wishes that can be signed and dated and stored with our legal will. People use living wills for all types of wishes such as, would they wish to be resuscitated at the end of life, would they prefer to be buried or cremated and where would they prefer their final resting place to be. What type of service would they want? It can also be used to specify whom they would like to gift certain private possessions such as pieces of jewellery, paintings etc.

Having sorted all the morbid stuff and with the future plans arranged it is time to enjoy the extra years we have been given and make the most of life. Get involved and stay involved socially with people indulging whatever interests you have and exercise as much as possible while eating a healthy diet. This will ensure you get the maximum enjoyment from the maximum number of years.

These are some personal thoughts to provoke discussion about the issues and keep it on the agenda for future conferences and strategic planning purposes.

Useful sources of advice are our team at the I.H.S and their booklet on Ageing & Haemophilia (also on the website), Citizens Information offices and Government Departments.

**Jim O'Leary**



## Lending a Hand: Volunteering with the I.H.S.

I began volunteering for the I.H.S. close to 10 years ago. Fiona asked my parents if I would be interested. It sounded okay; I'd get to spend a weekend in a hotel for free, look after some kids and I'd be helping out a charity. If I'm honest, the main reason I did it was because I thought it would look good on my C.V.

I was super shy as a teenager and avoided the groups on weekends, so I was nervous the first weekend by myself, as the rest of my family weren't attending, but I was determined to put myself out there, and if I hated it I never had to go again! My first weekend was in the crèche and it was intense. It was a lot of very tiny humans to help look after, but my God they were super cute and it was actually a lot of fun! It was also really nice meeting the other volunteers and staff who made me feel so welcome, I volunteered to do the next weekend without hesitation.

Over the years I served my time in Cubs and Kidlink, but I found my volunteer home with the Youth Group. My first experience with the Youth Group was a weekend in Lilliput. It was a freezing October evening when we arrived. I was shown where we'd be sleeping and where we could hang out and then, to my horror, I was told we were going for a night time walk in the woods. In the dark, with frogs and other woodland creatures to watch out for! I swiftly grabbed my two youngest sisters arms (who were probably 13 and 15 at the time) and held on to them for dear life as I stumbled through the woods with Paul Dunne grabbing at my heels causing me to scream every time thinking it was a slimy frog or something. Needless to say all the teens, volunteers and Lilliput staff had a great laugh at my expense and we all got on extremely well from then on out. That was also the night Paul and I introduced my sisters and the other youths to the 'Five Mega-Mix' and I think it's safe to say their lives were changed for the better from that day on. Between bog jumping, ziplining, box stacking, kayaking, manhunt, laser-tag and hours and hours of 'Heads Up' and 'Catchphrase,' Lilliput was always a lot of fun, despite the freezing cold showers. And I have to also mention Bear, their amazing dog.

Getting to spend time with the Youth Group has definitely been a highlight of my time as a volunteer. They really are a fantastic group of funny, intelligent and inspiring young

people. We've done a flash mob, debates, fort building, exercise, animal impressions, Pictionary and played tons of mind games that will literally drive you crazy when you're the only one who can't figure it out – and no matter how much you beg no one will tell you the answer. These are my personal favourite games and they have been brought to the bar after to ensure we drive all the other volunteers crazy too. We've had some great outings to bowling (I got 3 strikes), reptile houses and Eagles' Farm in Sligo where an owl landed on my head and I got to pet a teacup pig and cuddle a fox!

I've also had a lot of other opportunities with the Society which stemmed from volunteering. I am very passionate about the society and the great work it does, and I also find the treatment and developments extremely interesting, so I decided to go to a WFH conference to learn more. Traci and Brian noticed this interest and asked me to become a member of the board three years ago. I've gotten to go to Lithuania and Glasgow for conferences since then and I have met people from all over the world which has been incredibly fascinating and inspiring. You really learn how lucky we are in Ireland with the standard of care we have and that is down to the stellar work the society has done over the last 50 years.

I'm very grateful that Fiona encouraged me to volunteer all those years ago because I got so much more from the experience than some volunteer work for my C.V. (even though it does look great on there). It helped me build leadership skills and grow in confidence which has helped me in many areas of my life and career. I've gone from a shy kid & teenager to treasurer of the board, and being a volunteer has definitely helped me in that journey.

I've heard many people say it, and I completely agree that the society is more of a community than anything else. I've met friends for life and we actually hang out outside of the weekends! I would highly recommend volunteering; you learn a lot about haemophilia and other bleeding disorders, treatments, gain useful, transferable skills but most importantly, it's so much bloody fun. I've had some of the most fun weekends of my life, with some of the soundest people you are ever likely to meet, all while helping a really good cause.

**Aislinn Farrelly**





## I.H.S. Youth Programme

The latest instalment of the I.H.S. Youth Programme took place in our office in Dublin 8, on August 17th.

On this occasion the topic of conversation revolved around life after the leaving cert; we chatted about results, CAO applications, third level education, apprenticeships and jobs.

Following an opening discussion, each participant began compiling a survey tailored to matching current interests and skills to a potential career path. From here we examined the CAO system in more detail and what third level options are open to young people. Alongside this, we touched on importance of researching chosen courses and institutions carefully and setting reasonable and realistic study targets with a view to successfully attaining their preferred choice. The importance of selecting second, third and fourth choice courses was discussed as well as exploring other options such as PLC courses and apprenticeships.

Next, we examined the fabric of college courses; how they are designed and what to expect from first year. We naturally

progressed further into the future and chatted about life after completing courses and seeking employment with a more detailed examination of CVs and the application processes.

In the final section we spoke about interview preparation which included:

- Researching the industry
- Researching the company
- Studying the role in-depth
- Preparation of correct attire
- Arriving at least ten minutes early

After exploring the above areas, we discussed what can happen during the interview, common questions asked in interviews etc. We closed on what happens after the interview and how to prepare for the possibility of not getting offered the job.

It was another great meetup and all the participants were very engaged in all the discussions. Yet again I was extremely impressed by their inquisitiveness, willingness to converse and the level of maturity on show.

Unfortunately, the planned Limerick meetup did not go ahead due to a lack of numbers but hopefully next time that's not an issue.

With the October Conference only around the corner, we'll have a big group together for the next part of the I.H.S. Youth Programme.

**Robert Flanagan,**  
Children's & Youth Programmes Co-ordinator





## Marathon Fundraiser for I.H.S.

We are very grateful to everyone who organises or takes part in fundraisers for the Irish Haemophilia Society every year, your tremendous support for the work of the society is really appreciated.

Fundraising events are ever so important, not only in raising funds but to raise awareness of haemophilia and other bleeding disorders, and there is a big I.H.S. fundraiser on the horizon.

Dylan Ryan is running the Dublin Marathon, his first marathon, in October and in doing so, he will be raising money for the I.H.S. and awareness of haemophilia. The Dublin Marathon is an annual 26.2-mile (42.2 km) marathon in Dublin, held each year since 1980, this year's race takes place on Sunday October 27<sup>th</sup>.

With this year's race not too far away, we decided to catch up with Dylan to find out more about what has inspired the decision to run the marathon, his preparation, why he chose to raise funds for the I.H.S. and more.

### **For those who don't know you; can you introduce yourself, please?**

Hello everyone! My name is Dylan Ryan, I'm a 28-year-old Dublin native and I work as a scientist having just recently completed my PhD in Biochemistry and Immunology in Trinity College Dublin. I'm moving to England this month with my partner Lisa to take up a new position in University of Cambridge. My number one passion is science and I'm very lucky to have the opportunity to work as a scientist.

I am also an avid reader of science-fiction, fantasy and popular science books and I'm also a self-professed cinephile. I'm also mad about football and a long-time supporter of Chelsea Football Club.

### **When did you decide you wanted to do the Dublin City Marathon and what spurred this decision?**

I decided I wanted to do the Dublin City marathon after last year's race having supported two close friends of mine Laura and Eoghan, who are both excellent runners and completed their first marathon in aid of the Dublin Rape Crisis Centre. I was only beginning my runners' journey, and this was a great source of inspiration to give it a go.

### **This is an impressive undertaking, is this your first marathon? Is running something, you've long had a passion for?**

Thank you! It is my first marathon having completed a couple of 10 km and half-marathon races before this. I actually only took up running 13 months ago but once I started, I developed a real love for it very quickly. I flirted with running and athletics in 1st year of secondary school but back then my real passion was playing football!

### **What has your preparation been so far and how are you finding it?**

I really ramped-up my training this year in preparation. I completed my first stage of training by doing a 20+ week programme for the Wexford half-marathon in April running around five times per week at an average of 60-70 km per week. I then took it handier maintaining frequent runs for May and June but at a lower intensity before starting my 18-week training programme for the Dublin City marathon. With 10 weeks to go, I'm currently on my 8th week of this programme now and covering between 80-90 km per week now doing around 6-7 runs.

It's definitely tough but I'm really enjoying it. Trying to balance finishing my PhD and planning my move to Cambridge



with the training programme is not without its challenges but it has gone smoother than expected and everything is starting to click into place.

### **What is your preparation plan for the run up to the race? If people would like to track your training and progress, how can they do so?**

I plan on continuing the programme, which was designed by the RunSMART project and uploads the programme to an app on my phone. I track my runs using Strava. If anyone is interested, they can download the app for free and search for me (Dylan Ryan) and follow me on the app. Every run I do is recorded on my watch and is directly uploaded onto Strava so you can follow my progress if you like.

### **What has been the biggest challenge so far? And what have you enjoyed the most?**

The biggest challenge so far has been trying to strike a healthy balance with work, life and an intense training programme. It's important to be flexible I feel and sometimes you have to switch days around to spend time with friends and family and if you have to miss a day occasionally for this you can't be too hard on yourself because life is for living. Trying to keep an eye on your diet can also be tough because you require a lot of calories so it's easy to gorge and not always the best food so making sure I fuel my body appropriately for recovery and good energy levels is definitely a priority.

I love going on my long runs the most as I use that time to take in some gorgeous routes along the coast in Clontarf, or around the Phoenix Park or along Sandymount towards

Dun Laoghaire. When the weather is good the views are very soothing for the soul and I enjoy taking some time to reflect on my thoughts and unwind. It is a very therapeutic experience.

### **We are very grateful that you choose to raise funds for the I.H.S., can you tell us why you selected the society as your charity of choice?**

I'm very happy to have chosen the I.H.S. and it's been a pleasure getting everything set-up, I must give a big shout-out to Nina for all the help and to my good friend Seamus for vouching for me.

I selected the I.H.S. because there are a number of people in my life that I love dearly who happen to have haemophilia and the society is a great source of support for people with haemophilia and their families. They do great work in raising awareness for people with inherited blood disorders and have ensured the standard of care is of an extremely high level here in Ireland. So, I do this for them and so the I.H.S. can continue to support my family and friends and anyone else who requires it.

### **If people would like to, how can they donate to your fundraising efforts?**

If anyone would like to donate, big or small, they can do so on my GoFundMe page:

<https://www.gofundme.com/f/1st-marathon-in-aid-of-irish-haemophilia-society>



### **A perfect gift for the readers in your life**

Buy a book, help the society!

'A Nursing Life' is the story of a Midleton-born nurse who rises to the top of her profession in the 1960s before marriage sees her having to leave her job and become a fulltime mother. Tragedy and comedy collide as tales of marital breakdown and a bullying matron mix with nights on the town and days on ever-changing wards as the health service.

The books have been kindly donated to the society by the author, Aubrey Malone.

They cost €10 (excl. P&P) – with all monies going to the society - and will be available to purchase at our forthcoming October Conference.



## Meet the Team

Currently, the Society has 7 staff in the office. Remember, the I.H.S. Staff are here for you so if you would like assistance with anything, please don't hesitate to contact us in the office on 01 657 9900 or by email.

The current office team consists of:



### **Brian O'Mahony (Chief Executive)**

Brian is the Chief Executive. He represents the Society on the statutory National Haemophilia Council and he is the Vice Chair of the Haemophilia Product Selection and Monitoring Advisory Board. Brian leads the organisation, prepares policies and plans for the organisation and oversees the implementation of the strategic plan. Brian also communicates with the Department of Health, Health Service Executive and various other stakeholders. He previously served as Chair of the Irish Haemophilia Society for 17 years from 1987 to 2003 and as President of the World Federation of Hemophilia (WFH) for 10 years from 1994 to 2004. Brian currently is the President of the European Haemophilia Consortium.

Email: [brian@haemophilia.ie](mailto:brian@haemophilia.ie)



### **Debbie Greene (Administrator & Office Manager)**

Debbie joined the Society in 2003 and since then she has had various roles. Debbie is the Administrator and Office Manager, having taken up the role in May 2009. Debbie is responsible for the day to day running of the office, supervises staff, administers educational grants, attends board meetings, oversees the apartment facility for members, supports members and prepares policy documents for the organisation. Debbie represents the Society on the National Haemophilia Council, the Irish Haemostasis Research Foundation, and is involved in the World Federation of Hemophilia twinning programme. Debbie also attends regular team meetings with the Comprehensive Care Centres.

Email: [debbie@haemophilia.ie](mailto:debbie@haemophilia.ie)



### **Nina Storey (Financial & Fundraising Co-ordinator)**

Nina began working for the I.H.S. in 1998 and since joining the Society, her role has varied greatly. Currently, Nina is responsible for the financial administration of the organisation and is the Society's fundraising co-ordinator, which includes planned giving and legacies. Nina's current role also includes updating the database and memberships, along with phone contact with members, outreach and hospital visits. Nina represents the Society on the Haemophilia HIV Trust.

Email: [nina@haemophilia.ie](mailto:nina@haemophilia.ie)





### **Barry Healy (Publications Editor)**

Barry joined the I.H.S. in October 2017 and is designer and editor of I.H.S. publications, with responsibility for producing articles, sourcing content, conducting interviews and designing flyers etc. Barry also distributes the monthly electronic newsletter to members, manages the I.H.S. website, social media as well as developing other digital media.

Email: [barry@haemophilia.ie](mailto:barry@haemophilia.ie)



### **Robert Flanagan (Children's & Youth Programmes Co-ordinator)**

Robert joined the Society in October 2017 and is responsible for the four children's programmes at I.H.S. conferences. He is also be the first point of contact for volunteers, Barretstown events, memberships database, Child protection/Garda vetting and youth mentoring. Robert has great experience working with families and people of all ages. He also has a creative eye and a passion for photography and digital media which is a great asset for our publications, social media and website.

Email: [robert@haemophilia.ie](mailto:robert@haemophilia.ie)



### **Julia Collins (Administrative Assistant)**

Julia joined the I.H.S. in May 2018 as Administrative Assistant. Julia is responsible for the general office duties every day and carries out tasks and duties assigned by the Chief Executive and Office Manager. Julia is also responsible for Hyde Square; the I.H.S. apartment facility. Julia processes all accommodation bookings the I.H.S. receives and deals with the handover of keys to people who have booked into Hyde Square. Julia also oversees the administration for conferences and events when necessary and assists with financial administration.

Email: [julia@haemophilia.ie](mailto:julia@haemophilia.ie)



### **Aoife Kelly (Events Coordinator)**

Aoife joined the I.H.S. in August 2018. Aoife is responsible for organising I.H.S. conferences and events as well as administrative duties for Chief Executive and Office Manager. Aoife is the point of contact for members when processes bookings and registration for events and conferences and handles member's queries in relation to events.

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

# Noticeboard



## November

MOVEMBER is nearly here. Time to Man Up & Grow a Moustache, all for a good cause. Grow a moustache for the month of November and fundraise in aid of the I.H.S.

Just in case you are in any doubt of what is expected of you, let me clarify. Starting from the 1st of November, you will start off clean shaven and then for the rest of the month, you can groom, trim and wax your way to a fine moustache, finishing on the 30th of November. You can set up a fundraising page on [everydayhero.ie](http://everydayhero.ie), it is very easy to do and only take a few minutes.

A fundraising page allows you to share a link through your Facebook page or just email to everyone or we can send you a sponsorship card.

We would really appreciate your support, to take part please contact Nina on 01657 9900 or email [nina@haemophilia.ie](mailto:nina@haemophilia.ie).

Thank you!



## Volunteering with the I.H.S.

### Volunteer with I.H.S.

We're owe a huge debt of gratitude to our fantastic team of volunteers & we're always happy to add to the team!

We've a fantastic team of I.H.S. volunteers but we're always happy to add to this merry band.

Would you be interested in getting involved in volunteering with the I.H.S? We are looking for people of all ages, all backgrounds and all walks of life to volunteer with us at our events!

Do you enjoy working with kids? Are you good at arts and crafts? Are you a good photographer? Do you have a hobby or skill that you could teach to others? If so, we would love to hear from you!

If you would like to become a volunteer or more info, please call Robert in the office on 01 657 9900 or email [robert@haemophilia.ie](mailto:robert@haemophilia.ie)

## A couple of updates from the NCC for members....

Firstly, the iNDICI National electronic healthcare record (EHR) for people with Haemophilia and Allied Bleeding disorders will go live on October 14, 2019. While the system has been well tested and major glitches are not anticipated, they would like to make patients aware that there may be some delays in the centres on that week.

And....

Secondly, the staff in the NCC would like to advise patients that if you are on Home Treatment and are due to have a procedure or surgery in St James's Hospital, the Haemophilia nurse will be in contact with you a week prior to your procedure/surgery so that a treatment plan is put in place regarding the days you will need to take your prophylaxis. This patient safety initiative is being undertaken to try to reduce delays on the day of surgery/procedure, for the patient.



# Noticeboard



*"Helping one person might not change the whole world, but it could change the world for one person"*

If you would like to make a difference to others, please consider signing up to our Planned Giving. Contributions can be made monthly, even €10 a month can make a difference or maybe you would prefer to make an annual contribution.

The choice is yours, how much and when is totally up to you, and you can cease your contributions whenever you want.

This ongoing support for the work of the I.H.S. goes a long way to help us provide and improve on the services and support we give our members.

To sign up, or for more information, please contact Nina on 01 657 9900 or email [nina@haemophilia.ie](mailto:nina@haemophilia.ie).



## Write for the I.H.S.

Do you enjoy writing?

Do you like sharing your experiences or feel that other people's perspectives have helped you in the past?

Maybe you had a particularly beneficial or enjoyable time at one of our conferences or maybe you would like to share a story about you and your experience with a bleeding disorder.

If any of the above are true, we would absolutely love to hear from you!

If you would like to contribute and write an article for the I.H.S. just contact Barry in the office at 01 657 9900 or via [barry@haemophilia.ie](mailto:barry@haemophilia.ie)

## Ezine

Would you like to keep up to date with all that's going on with the Irish Haemophilia Society?

Why not sign up for our monthly electronic magazine? The easiest and most comprehensive way to keep up-to-date with all things I.H.S.

This electronic magazine is sent out at the end of every month and goes straight to your inbox, providing news, event reminders, articles of interest and keeps you in the loop about what's happening in the I.H.S.

To sign up, simply go to our website [haemophilia.ie](http://haemophilia.ie) or email [barry@haemophilia.ie](mailto:barry@haemophilia.ie)





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