

Haemophilia.ie



Representing people in Ireland with haemophilia and related bleeding disorders

Magazine of the Irish Haemophilia Society

Summer 2019



The Society
at a Glance

74
I.H.S.
Volunteers

46
Planned Giving
Contributors

1267
Facebook
Followers

747
Twitter
Followers



haemophilia.ie

October Conference 2019

Venue: Shearwater Hotel, Ballinasloe

Dates: Friday 18th to Sunday 20th October 2019



Preliminary Programme

Friday October 18th

17.30 - 19.00	Registration
19.00 - 20.00	Dinner

Saturday October 19th

10.00 - 11.00	Novel Treatments
11.00 - 11.30	Coffee Break
11.30 - 12.30	Debate: Gene Therapy vs Current Treatment
12.30 - 13.30	Lunch
13.30 - 15.00	Life Expectations (Interactive Session)
15.00 - 15.30	Coffee Break
15.30 - 16.15	Ethnographic Data
16.15 - 17.00	Travel & Insurance
17.00 - 19.00	Family Time
19.15	Dinner Followed by Entertainment

Sunday October 20th

10.00 - 11.00	Lifestyle Management
11.00 - 11.30	Coffee Break
11.30 - 13.00	Yoga
13.00 - 14.00	Lunch & Depart

Booking forms will go out later in the summer

From the Editor

Welcome to the Summer issue of our quarterly I.H.S. magazine. I hope the summer has been kind to you so far, even if the weather has been a bit, well Irish.

Now, while we can't control the weather, we can bring you this jam-packed issue. There are loads of interesting articles and reports to sink your teeth into. There are reports from the EHC Leadership Conference, Talking Red Conference in Belfast, Father & Son(s) weekend and Twinning Programme in Vietnam on pages 7, 8, 12 and 14 respectively.

On Page 4 you will find our CEO's report, where Brian pays tribute to friend and I.H.S. stalwart Ger O'Reilly - it is a fitting tribute to a cheerful, resilient and all round nice guy. There is also a PROBE update and he shares his thoughts on Dr. Barry Harrington's recent retirement as Chairperson of the National Haemophilia Council.

On Page 16, Nina provides an update on Fundraising and Planned Giving, while on Page 2, you can peruse the preliminary programme for our October Conference; we'll be sending out booking forms later in the summer so keep any eye out for them. On Page 10, you will find information on the I.H.S. Educational Grants; the grants are massively beneficial and can go some way to helping cover the cost and expense of your education, so I would like to encourage as many of you as possible to apply. On Pages 18 and 19, there is important information and updates from the society and dates for your diary on page 17.

Lastly, I hope you enjoy this issue and the rest of the summer and remember, if you would like to contribute by writing an article for a future issue 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.

Barry Healy

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CEO REPORT

The entire Irish Haemophilia community were greatly saddened by the death of Gerry O'Reilly on May 28th last. Gerry had been ill for some time and had fought strongly and resolutely against the many burdens his illness had placed upon him.



I was glad that so many of his close friends in the haemophilia family had an opportunity to see him before his untimely death and it was a tribute to him that so many attended his funeral in his beloved Freshford.

I knew Gerry for over 20 years as a fellow person with haemophilia, as a close friend, as a colleague in our work together for the Irish Haemophilia Society. Gerry faced an innumerable and bewildering number of health challenges. His haemophilia and co-morbidities led to his developing liver cirrhosis. This in turn led to not one but two episodes of liver cancer, a triple cardiac bypass, and a liver transplant. Following the transplant, Gerry had a period of relatively good health but unfortunately this was followed by a re-occurrence of cancer, several surgeries and finally an overwhelming burden of cancer which hastened his demise. Gerry bore all of these awful setbacks with resilience, fortitude and bravery. His humour never deserted him. His optimism always shone through.

We were all in awe of his constant ability to bounce back from each of these medical hammer blows and to get on with living his life with optimism and bravery. He became the by-word for bravery and resilience in our community. In the last number of years, Gerry told his story, not only to our members but to the European haemophilia community at meetings of the European Haemophilia Consortium (EHC) and at a hushed meeting organised by the EHC at the European Parliament. He also spoke about his life and experiences at a global conference of the World Federation of Hemophilia (WFH). Audiences at these meetings were

left speechless by his matter of fact recital of the sequence of health issues he had to face, one after the other. He made a very strong and lasting impression. Gerry also contributed, some months before his death, to a documentary by EHC on the impact of Hepatitis C on people with Haemophilia. This short movie, now dedicated to his memory, will be used as an advocacy tool to help persuade Governments in Europe to prioritise Hepatitis C treatment for people with haemophilia. This is, in itself, a noble legacy.

Gerry made a great contribution to the work of the I.H.S. I spent two years persuading Gerry to join the board of the Society. He was initially reluctant as he was so busy with his multi-faceted involvement in many projects in Freshford. Having said yes, he was immediately appointed as treasurer - a compliment to his probity, integrity, honesty and business sense. Gerry was treasurer for 12 years and his work was greatly valued by all at the Society. He rarely missed a meeting and always contributed wisely, honestly and constructively to discussions.

Upon hearing of his death, our colleagues and members mentioned his compassion, bravery, optimism and humour. People who knew him remember him as always smiling, always with a joke while he told in his inimitable way, bellowing with laughter at his own punchline. His humour and joie de vivre lit up rooms. It was not possible to be in his company for long and not be cheered up or in high good humour, which is remarkable given the medical burden he was constantly dealing with.

As a friend, we travelled Europe together with our friends Shay, Kieran and Frank. We share warm memories of laughter, of great company, of his joy at visiting new places and having new experiences, of his horror when we brought him to the Opera on realising how long an Opera lasts.



Gerry was a great human being with an indomitable spirit. He was one of those rare people who enriched the lives of others just by knowing him. It was an honour and a privilege to have worked with him, to have known him, to have called him a friend. He will be sadly missed but fondly remembered. He was living proof that not all heroes wear capes.

Outcome data reported by people with haemophilia

Prior to the switch from standard to extended half life (EHL) factor concentrates, the Society had asked adult members to fill out a patient reported outcomes, burden and experience (PROBE) survey. This exercise was then repeated one year after people had changed to an EHL factor. Our objective was to see if any change in outcomes or quality of life was evident. We analysed a total of 17 matched (before and after the switch) surveys; 12 from people with haemophilia B and 5 from people with haemophilia A.

The results were recently presented at the International Society of Thrombosis and Haemostasis conference, the world's biggest coagulation conference. The results showed that the switch to EHL facilitated a move from on-demand to prophylactic therapy for some members due, I presume, to the lower frequency of infusion required.

There was also a significant reduction in reported bleeds. Prior to the switch, 29% reported having more than 8 bleeds per year. After the switch, no individual reported more than 8 bleeds per year. The percentage of people reporting 1 or no bleed per year increased from 41% to 59%. A lower proportion of respondents reported the need to use mobility aids.

Acute pain also decreased and there was a very large decrease in chronic pain in patient defined target joints (damaged joints) from 67% reporting such pain down to 13%. There were reported improvements in mobility, self-care and pain or discomfort using standard measures.

Quality of life overall improved by some 6% but the real improvements came in the areas mentioned above together with a reduction in the number of activities of daily living which were adversely affected by haemophilia. This data demonstrates, albeit in a small number of people, the improvement in quality of life due to the switch to EHL FVIII and FIX. It also demonstrates the importance of proactively collecting such data to enable us to always advocate for the best treatment by being able to demonstrate the benefit of change.

National Haemophilia Council Chairperson

Dr. Barry Harrington (top right) recently retired from his role as Chairperson of the statutory National Haemophilia Council having served six years in that role. Barry had previously served for some 15 years on the Board of the Society in addition to initiating the current comprehensive care dental model in St. James's Hospital.

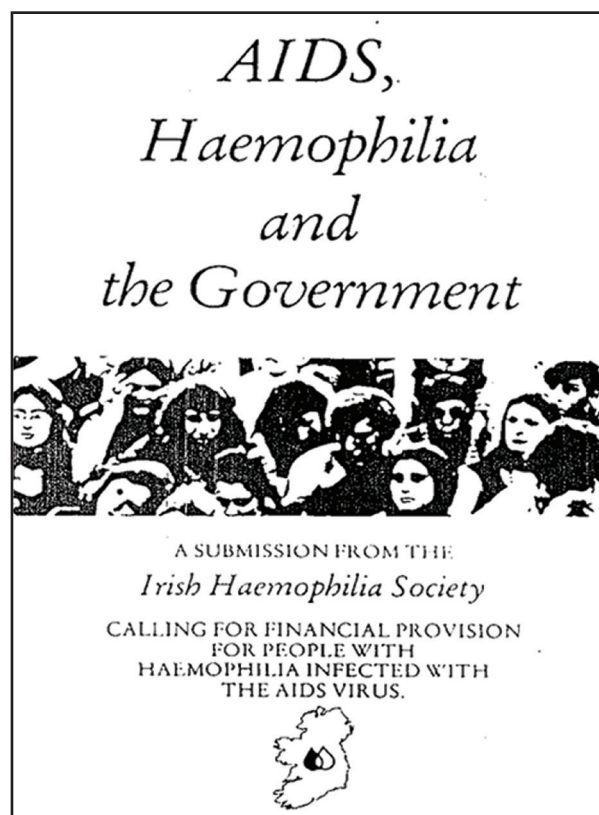
I have had the pleasure of working with Barry since he first started the dental service in St. James's in the mid 1980's. In fact, Barry and I worked together on the survey of members with HIV in 1987 which led to the advocacy document "AIDS, Haemophilia and the Government" in 1988, the

subsequent advocacy campaign and the Dail defeat of the then Government which led directly to the General Election in 1989.

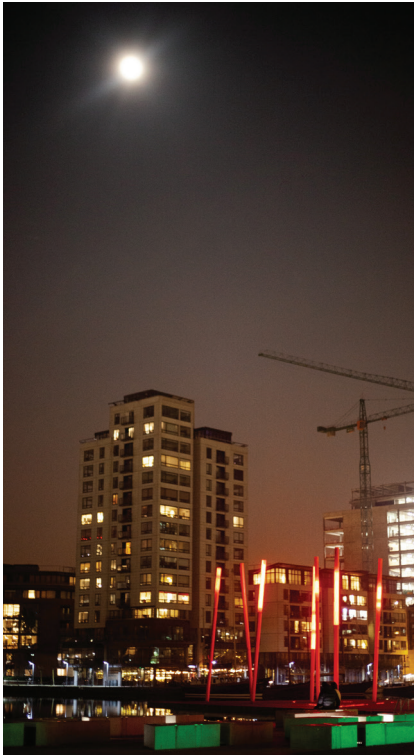


Thirty years on and Barry has continued to contribute to the haemophilia community. His hard work, empathy and direct nature have always marked him out as an effective advocate. He has been tireless in his work for people with haemophilia in Ireland and his contribution will long be remembered. We wish Barry and his wife Laura all the very best for the future in his retirement.

Brian O'Mahony



World Haemophilia Day 2019



We had a very busy but successful World Haemophilia Day this year. There was a full house for the symposium in the RCSI - entitled "Haemophilia – The Future is Now – New Approaches to an Ancient Condition" - it was very interesting and informative, and the speakers were excellent. Our World Haemophilia Day event had the added bonus of being picked up by RTE and included on the Six One News, the report also featured the Society's Jim O'Leary & Brian O'Mahony (you can watch the news segment on haemophilia.ie).

Following on from last year, a series of buildings & landmarks in Cork & Dublin lit up red for WHD, which made for quite a sight. It wasn't just us who were busy, prior to WHD some of our member's had already been out in force as Scoil Mochua in Wexford and St Brendan's National School and Claire's Slimming World in Tralee 'wore red for haemophilia' - raising funds and awareness in the process.

We would like to thank everyone involved in making WHD a success again!



EHC Leadership Conference 2019

The European Haemophilia Consortium (EHC) held its Leadership Conference in Brussels from June 20 – 23, with over 90 delegates from 29 countries, staff member Julia Collins reports from Belgium.

The EHC Leadership Conference brings together the full EHC community through different key leaders and staff from our patient community to exchange and engage on shared issues and challenges.

The weekend consisted of a series of workshops designed to improve the leadership, negotiation and communication skills of all the NMO's in Europe and to engage with each other to build a support network between countries.

The first day zoned in on the key focus areas that the EHC are working towards now. These breakout sessions helped to update all the NMO's on EHC PARTNERS programme, Inhibitor Network, Women's Committee, youth strategy, EHC strategic planning and membership. This day also educated the NMO's about the current and future treatments for haemophilia. These discussions were insightful to hear the feedback from people of different generations about the treatment they go through and their hesitations or excitements towards future treatment that is in the works. Dr. Cedric Hermans stated that "In five to ten years, patients will not be not treated the same way as they are today. Our ambitions should be to provide better treatment or even a cure to patient populations."

The Friday night had a screening of two excellent films. The first film was about Living with hepatitis C and haemophilia in Europe. The second film came from the Lithuania Haemophilia Society. It is called 'Jump Above Your Limits'; a 45-minute film that shows the strength of the human mind and determination while living with a chronic disease. They highlighted that a chronic disease does not have to limit a patient. It zoned in on their haemophilia basketball team and the international basketball camp that they have organised for a few years in a row in Lithuania.

On day two EHC CEO Amanda Bok and EHC

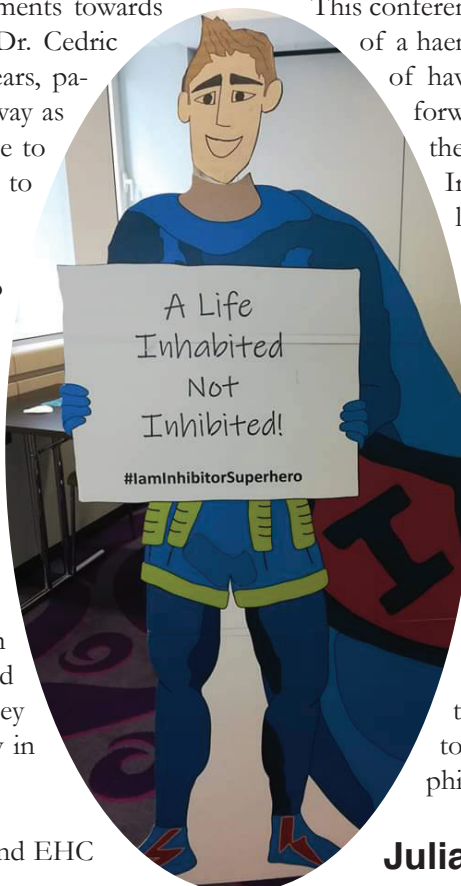
Vice-President Finance Minette van der Ven led transparent, ethical and diverse funding session. Each NMO explored the ways in which they keep their funding transparent to their members and where they source other funding; e.g donations, fundraising, legacy donations, social media, selling NMO logo products. This was followed by a workshop to build a synergy machine. This interactive session used intense real-world exercises to highlight transparency, negotiation, governance and thinking outside the box.

In the evening we had 'Know-How' sessions which provided space for exchanging good practices and experiences among the NMO's. During these breakout sessions we got to choose two themes that interested us the most. I chose youth engagement and increasing participation in the AGM's. These discussions were very knowledgeable as I took away ideas that we can work on introducing to the I.H.S.

The Sunday morning focused on social media and discussing the ways of how we use it can be adapted to the new generation.

This conference gave valuable insights into the running of a haemophilia organisation and the importance of having strong and interested youth to carry forward the work that has been achieved over the last 50 years. From this conference the Irish Society wants to end up with a streamlined or integrated programme whereby the youth programme blends into the young adult programme, as we have a good youth population at the moment, but not a good young adult population. We feel that it's important that the young adults see that they have a role to play in their society and they feel appreciated, respected and that their opinion matters. From shared experiences, skills and resources between other NMO's we believe we can achieve this goal. Working together and being able to reach out and ask for help from each other will continue to keep our Society and other NMO's to flourish and strive for sustainable haemophilia care in Europe.

Julia Collins





Women and Bleeding Disorders

The Irish Haemophilia Society in conjunction with the UK Haemophilia Society held an information day in Belfast on June 22 for women with bleeding disorders.

Haemophilia is seen as predominantly affecting male patients and women are the carriers of this bleeding disorder. However, some women are diagnosed with mild haemophilia and some are symptomatic carriers, while von Willebrand's disease affects both men and women. Many women feel overlooked and unheard when it comes their bleeding disorder, mainly because some of their symptoms vary from a man's. Women like men can bruise easily and can have prolonged bleeding following a procedure, however women can also experience heavy menstrual periods and prolonged bleeding after childbirth.

Women need to be made aware that issues with heavy menstrual bleeding is not normal even if other women in the family are experiencing the same problems, there can be several causes for this, one of which is an underlying bleeding disorder. It is vitally important for all men with a bleeding disorder to disclose their condition to the female members of their family, daughters, sisters, cousins, nieces etc. so that if these women are having bleeding issues they can have their factor levels checked.

The information day in Belfast covered several topics for women such as gynaecological issues, genetic counselling and pregnancy, oral health, mental health and a personal experience of living with a bleeding disorder.

Gynaecological Issues

Dr Joanna Davies – Gynaecologist Registrar, Royal Free Hospital, London.

The two most significant stages in the life of a woman with a bleeding disorder is when she first starts her periods and

when she begins the menopause. Post childbirth can also lead to more menstrual bleeding as the womb surface area increases following childbirth and more surface area means more bleeding.

It is important for women to know what is normal and what is excessive menstrual bleeding. The Pictorial Blood Assessment Chart (PBAC) is used to identify the level of menstrual bleeding. The 'moon cup' is a menstrual cup used as another type of feminine hygiene product. The 'moon cup' is also an effective way to measure the amount of menstrual bleeding as it can hold 10-15ml of blood and this can be charted easily. A Study has shown that approximately 13% of women who present with excessive menstrual bleeding do so because of an underlying bleeding disorder. The combined pill and the mirena coil are the two most effective treatments for excessive menstrual bleeding. However, these only target the menstrual bleeding, so women need to have their factor levels checked in the event they need to undergo a medical procedure or have other bleeding issues such as nosebleeds. Desmopressin (DDAVP) nasal spray and tranexamic acid tablets are both effective treatments and can be used combined with the mirena coil if needed.

Oral Health

Dr Lochana Nanayakkara - Consultant in Restorative Dentistry, Royal London Hospital.

Bleeding gums are only caused by gum disease, a bleeding disorder does not cause your gums to bleed. Thankfully 98% of dental problems are fixable even in patients with a bleeding disorder, so don't assume your bleeding gums are because of your bleeding disorder, it is not, visit your dentist. Patients with a mild/moderate bleeding disorder can have routine dental work such as teeth cleaning and fillings carried out by their local dentist. Just ask the dentist in your treat-

ment centre to provide a letter for you to take to your local dentist. However, tooth extraction should still be done in your treatment centre. And there is no reason that a patient with a bleeding disorder cannot get braces fitted or have dental implants. Patients think that if they have bleeding gums they need to use a soft toothbrush, this is not the cause you should be using a medium toothbrush. When you clean your teeth, spit but do not rinse, you want to keep the fluoride in your mouth after your teeth are brushed.

Genetic Counselling & Pregnancy

Dr Bethan Myers, Consultant in Haemostasis & Thrombosis, Leicester Royal Infirmary.

Firstly, it is important to note that having your factor levels checked and having your carrier status checked are two separate tests. If your factor levels show you have normal levels this does not automatically mean that you are not a carrier, you can have normal levels and still be a carrier. Genetic testing to establish if you are a carrier can be carried out from the age of 16 years, and if possible it is best to have this done prior to planning a pregnancy.

Tests are complex and usually take several months to complete. Genetic testing allows the women to plan ahead, discuss her options and if having children to put a birthing plan in place. Knowing your factor levels before you become pregnant is important as in some instances your factor levels can change in pregnancy, so it's better to know your baseline levels prior to pregnancy. Factor FVIII levels go up in pregnancy, while FIX levels do not. A woman's FVIII level drops after childbirth and if a baby's FVIII levels are tested through a cord blood sample at birth, these will need to be retested again at a later date as FVIII levels increase because of stress and labour is a stressful experience for babies.

If you are a carrier or suspect you are a carrier, it is best if your obstetricians avoids where possible the use of electro (head) monitoring on your baby and forceps delivery. In the case of women with levels over 50% an epidural can be given. Most carriers have a normal pregnancy without any bleeding, however a few women may have lower levels which will require treatment at delivery.

Thriving - Mental Health

Patricia Byrne, Clinical Psychologist/Psychotherapist, St James's Hospital, Dublin.

Looking after our mental health is as important as looking after our physical health. Daily life can be hard and having a bleeding disorder can be an added burden. Women can be their own worse critics, we are known to be multi taskers and sometimes we take on too much.

Being a carrier or having a bleeding disorder can lead to uncertainties that change from time to time because of dif-

ferent factors such as pregnancy, childbirth or having a child with a bleeding disorder. How do we thrive when faced with worry and anxiety?

We need to grow resilience and the only way to build up resilience is to face the adversity. You don't have to think positively, but you do need to find the tools to help manage a negative situation. Mindfulness is a useful tool, it can be that one hour in a yoga class or just taking a walk in the countryside to give your mind that headspace to recharge yourself. We are all so busy living our lives, but we need to make time for ourselves, take a step back to put things in context. Find your 'tribe' to help support you, this can be your family, friends or a support group, each of these can offer you different support and advice. But most of all be kind to yourself.

Introduction to Bleeding Disorders

Patricia Bell, Haemophilia CNS, Southampton Haemophilia Centre.

Bleeding disorders in women include vonWillebrands Disease, Platelet Function Disorders, Low Level Carriers of Haemophilia A & B and other rare bleeding disorders. The physical impact of bleeding in women includes anaemia, which leads to lethargy, feeling faint, pale skin and palpitations. Also, the lack of iron can contribute to further bleeding. There is also the social impact if you bruise easily, people often look and wonder why, sometimes thinking the worst.

Heavy menstrual bleeding also means that sometimes women have no choice but to withdraw from sports and leisure activities. You need to seek help when your symptoms are impacting on your life or become more severe. Your haemophilia centre can help with medication management and make necessary referrals to another specialist such as a gynaecologist or a physiotherapist.

Personal Experience

Luz Maria Heaney, I.H.S. Member

Our thanks to Luz Maria who kindly spoke to the group about her experience as a young adult living with a bleeding disorder and following her talk she was happy to answer any questions.

For more information on women and bleeding disorders, go our website haemophilia.ie and see our publications listed under 'services and support'.

We also have specific booklets on 'Women and Bleeding Disorders', 'vonWillebrands Disease' and 'Teenage Girls and Bleeding Disorders'.

Nina Storey





Educational Grants 2019

The Society offers educational grants each year to people with haemophilia or related bleeding disorders, including a person with carrier status, and/or their immediate family members who go on to do a post second level educational course.

The purpose of these grants is to offer financial support to students to assist them with the extra expenses involved with their studies.

We are happy to announce that applications are now invited for the 2019 I.H.S. Educational Grants.

You can apply via our website haemophilia.ie, or you can also download the application forms from our website, complete them and post them into the office.

What types of Educational Grants are available?

There are three categories of grants available as follows:

The Maureen & Jack Downey Educational Grant:

This grant is made available to a person with haemophilia or related bleeding disorder, including a person with carrier status (defined as a person with mild, moderate or severe haemophilia or related bleeding disorder, or defined a carrier with levels ranging from 1% to 40%). The person must have been accepted onto a post second level educational course from level 7 to 9. The person must be registered at the National Coagulation Centre at St. James's Hospital in Dublin.

The Margaret King Educational Grant:

This grant is made available to an immediate family member

of a person with haemophilia or related bleeding disorder, be it a spouse, son, daughter, sister, brother, mother or father. Carriers with factor levels greater than 40% can also apply for this grant. The person applying must be accepted on a post second level educational course at levels 7 to 9. The person with the bleeding disorder must be registered at the National Coagulation Centre at St. James's Hospital in Dublin.

The Father Paddy McGrath Educational Grant:

This grant is made available to a person with haemophilia or related bleeding disorder, including a person with carrier status and also includes immediate family members i.e. a spouse, son, daughter, sister, brother, mother or father who has been accepted on a post second level educational course at level 5 or 6. Carriers must have levels ranging from 1% - 40% to be considered as having a bleeding disorder. A scoring scale will apply to this category with points being awarded depending on the severity of the person's bleeding disorder.

How much are the Educational Grants for?

Maureen & Jack Downey Educational Grant

First prize - €4,000
Second prize - €2,000
Third prize - €1,000

Margaret King Educational Grant

First prize - €2,000
Second prize - €1,000
Third prize - €500

Father Paddy McGrath Educational Grant

A person with the bleeding disorder

First prize - €1,000

Second prize - €500

Third prize - €250

A family member of a person with the bleeding disorder

First prize - €500

Second prize - €250

Third prize - €125

What is the opening and closing date for applications?

The opening date is Friday 21 June 2019 and the closing date is Friday 27 September 2019.

How are the applications scored and who scores them?

Once the closing date arrives and all the applications have been received, a subgroup of three people from the executive board (which cannot include anyone with a family member applying for any of the grants) meet to consider and score the applications, and make recommendations to the rest of the executive board regarding recipients.

The successful applicants are then notified at the end of October by letter.

Applications are scored on the following:

- The quality of the application.
- The information given on the application form.
- Involvement in the Irish Haemophilia Society.
- Financial need.
- How many in the family are going to college.
- If the application is a first-time application.

Can I apply every year?

Yes, you can apply every year, even if you have already been successful, but remember even if you are eligible to apply for both grants you can only apply for one of them.

Take some time to complete your application, as the more complete and detailed your application is, the higher your chance is of being successful. And please do fill out the application yourself! Good luck!

Debbie Greene

*Please note: *A receipt of payment for your college course must be submitted with your application. Even if you are eligible for more than one grant, you can only apply for one grant each year.*

I.H.S. Youth Leadership Programme

The I.H.S. Youth Leadership Programme aims to facilitate young people affected by bleeding disorders to communicate with each other, share experiences and learn life skills.

The programme is open to young members aged between 12 and 17, and there are two meetings organised for August; one in Dublin and one in Limerick. The meetings will cover areas such as exercise, health, mental health, stress and anxiety, and will look at career development.

Dublin Meeting:

Venue: I.H.S. Office, First Floor, Cathedral Court, New Street, Dublin 8

Date & Time: Saturday, August 17, 2019 @ 11:30 to 13:00

Limerick Meeting:

Venue: Limerick Strand Hotel: O'Callaghan Boardroom

Date & Time: Saturday, August 24, 2019 @ 11:30 to 13:00

For more info or to book a place, please contact Robert in the office on:

01 657 9900

or

robert@haemophilia.ie





Father & Son(s) Weekend 2019

This year's Father & Sons Weekend kicked off again in Lilliput Adventure Centre at 11am sharp. Our group consisted of 16 kids, 13 parents and two volunteers; the day ahead was jam-packed with activities and the promised rain and showers, kindly held off for the day.

We began with kayaking on the lake. Kids and adults split off into groups with 2-3 per boat and we all took to the water. Some friendly competition ensued and most definitely through no fault of their own, the volunteers ended up capsizing on more than one occasion!

What better way to dry off from the lake than go bog hopping! The legendary assault course and bog run of Lilliput was up next. The kids and dads started the course through the bog of various depths and came to the giant bog pool at the end. After some cannonballs and missing shoes, all were safely out!

Once the bog had been thoroughly washed off, we took a break to relax and have some lunch before kicking off the afternoon's activities.

First up was a classic Capture the Flag in the woods. We split into two teams with each team taking one half of the forest to hide their flag. Off we went to hide our flags before swapping over to find the other teams' flag before they found ours. We had some kind assistance from local Lilliput legend, Bear the Bernese Mountain Dog!

After Capture the Flag we made our way back to the lake for Orienteering. The group was split into smaller teams and each given a map of Lilliput and the surrounding areas. Each group had to navigate their way around Lilliput and stamp their card off each location marker. The groups were set off at different time intervals and the race was on! The groups returned shortly after and the winning team had completed the course in a record breaking 18 minutes and also knocking the volunteers off last years winning spot – the challenge is on for next year!

Once the Orienteering was finished, we then moved onto

the Rock-Climbing Wall. Both the kids and dads strapped into their harnesses and began climbing. The rock climbing was a real mental and physical test with an easy abseil down once you reach the top and was enjoyed by everyone. After everybody had a few turns on the different climbs we then had a nice relaxing break and some dinner to fill all the hungry bellies after the day's activities.

When we were all suitably rested, we had one final activity for the evening. The game was called 'sardines', a twist on the classic Hide and Seek. The rules were the same, the only difference being that when the seekers found the hiders, they then joined the hiders (like sardines) so there would be less and less seekers as the game went on. Through a unanimous vote the volunteers were elected to be the hiders.

The volunteers ventured out to the woods to find their hiding place and after a whopping 40 minutes, they were only found by a few small groups of seekers before the remaining groups accepted defeat. Another Lilliput record broken this year!



When we returned, we were left to our own devices for the evening to play games, chat, relax, watch TV and get some well needed rest after the day's full schedule. We had no activities on Sunday morning but had time to enjoy a nice breakfast, relax, chat and reflect on the weekend before we hit the road.

Overall, it was another very successful Father & Sons weekend trip to Lilliput, and I think the aching bodies proved that! The activities were thoroughly enjoyed by everyone and the organisers and staff at Lilliput were extremely accommodating and helpful as always. The larger group this year proves the weekend's value and popularity and is a great opportunity for both the kids and parents to interact in a different setting.

Big thanks to those at Lilliput and I.H.S. for organising another great weekend, we're already looking forward to next year!

Sam Morrissey



Photos: Sam Morrissey & Jay McEvoy

Vietnam Report



I had been invited by Marie Ann Fernandez in the World Federation of Hemophilia to travel to Vietnam to do some workshops with the Vietnamese Haemophilia Association (VHA) in April. After leaving Dublin very early on Monday 1st April, I arrived in Hanoi on Tuesday, April 2nd.

My role on Tuesday afternoon was to do some training on skills associated with the organisation in relation to communication, publications and social media. I started with the basic methods of communicating within an organisation. I discussed the various methods of communication in our modern time and how to communicate effectively and how publications, the website and social media are excellent tools to communicate with members. I felt there was a good understanding within the group. A young man called Chan did an excellent job of translating for me. We spoke about effective leadership and communication within the organisation and how this builds an organisation, promotes education, knowledge and social activities.

We then went on to discuss publications. I was shown five excellent publications that the organisation has produced which included: 'An Introduction to Haemophilia', a short version and a full version, a 'Carriers' Booklet', a 'Dental Booklet' and a 'von Willebrand's Booklet'. It was clear that they took very good direction from the I.H.S. on these publications. They plan to produce more publications including a children's publication and a magazine.

We then discussed the website and social media. We spoke about how it is all

about connecting the user to the content and organising the information on the website. We spoke about what the user is looking for and allowing easy access to content and information. We also spoke about Ezines and the possibility of doing a monthly e-magazine. They all felt this was a very good idea. It's a great way to getting the message out to people, to educate people, to promote events, fundraising etc.

On Wednesday morning we had an early start. I met with patients to talk about their plans for World Haemophilia Day. They had a great event organised for World Haemophilia Day which included launching a short movie on haemophilia and a symposium on comprehensive care.

I was then asked to have a discussion in relation to fundraising. This wasn't planned beforehand but I gladly spoke to them about this. This was a great workshop with excellent interaction. They listened to everything I said, and I felt that some of my suggestions for very simple fundraising ideas energised them.

We spoke about what the needs are, what they want to accomplish, and we put together an action plan for fundraising. Although my brief for this trip was communication, I felt that the workshop on fundraising was needed and was received very well. I advised them to set realistic goals and to make sure it was achievable. They were interested in our fundraising events and when I informed them that the police band did a fundraising concert for us some years ago, they thought this was very funny, and they could not believe it.



Following our morning workshop, the whole group gathered for a wrap up discussion. Everyone said their goodbyes and Dr. Khanh presented everyone with a small gift. I then travelled to Ho Chi Minh City with Ms. Chao who works for the VHA.

On Thursday morning we were collected by Dr. Quang and brought to the BTH hospital in Ho Chi Minh City (HCM). Dr. Quang has haemophilia and he seems very interested and passionate. We met the director Dr. Ban Giam Doc, Dr. Hoa Nguyen, Dr. Kim and Dr. Phong. We had a good meeting. Dr. Doc updated me on what was happening in HCM. For example, they are still using cryoprecipitate, there is currently no home treatment, there is no movement on the insurance for patients and still no patient registry. However, a new hospital is being built in HCM with a haemophilia treatment centre in the plan, they are organising a summer camp and he is pushing the Ministry very hard on insurance and home treatment.

Following our meeting, we went to visit a patient in their home. We met a young 12-year-old boy and his mum. His mum explained that her first son died from a bleed. The young boy has severe factor VIII deficiency and usually has to travel to the hospital every month. His parents try their best to send him to school as much as possible. The young boy spoke about his dream to become a doctor. Dr. Quang was with us, so he spoke to him about what he had to do to become a doctor and he encouraged him to keep up with his studies. It was a lovely visit, everyone was very warm and welcoming.

We were to visit two other patients in the same area, however, both of them had bleeds and had travelled to the hospital for treatment. We therefore travelled back to the hospital and visited them in the blood transfusion ward. I met with Dr. Hao who introduced me to the two patients. Both of them were being treated with cryo when we arrived. Dr. Hao explained to me that they have put a system in place for people with haemophilia in that if they have a bleed and need to come to the hospital they do not need to go to A&E, they bypass it and come straight to the blood transfusion department for treatment. Patients have all been given a card and all they need to do is show it at A&E. This was great to hear. I was then shown around the

hospital and I was also brought into the intensive care unit to visit a patient with haemophilia who had a serious stomach bleed. It was upsetting to see him so sick and even more upsetting as he wouldn't let my hand go when we were leaving.



I then met with Dr. Quang, Dr. Phong both who assisted me with translation and two volunteers (Ngo & Hai) who have haemophilia. All four of them seem to have a great bond and it's clear that they are extremely interested in helping to bring the organisation forward and to improve everything. Both volunteers visit patients in their homes and offer support as much as possible.

The following morning, we went to the Thu Doc hospital. I met with the group of volunteers and parents (16 people) along with Dr. Quang and Dr. Phong and we had a morning of workshops. Again, I did my presentation on communication like I had done in Hanoi. We also spoke about volunteers and how to recruit more volunteers, encouraging new members to join the organisation and how to give more support to people. Those in the room exchanged phone numbers and email addresses.

This was a great workshop. We discussed priorities for the organisation and how to achieve this. Again, I reminded them to be realistic, practical and to take small steps. One parent said that the organisation needs to train volunteers on basic education about haemophilia. It was agreed that a meeting would be organised this year in HCM



inviting volunteers to come for an educational workshop. Dr. Quang and Dr. Phong agreed to do this. We also spoke about the home adaptation programme and the employment project that the I.H.S. support. Some of those in attendance had obtained grants and equipment and wanted to offer their thanks for this. I was glad to hear that people in HCM are availing of the support that the I.H.S. is giving.

Before I knew it, it was time to go to the airport to return home. It was a busy week but a great week. Everyone in Hanoi and Ho Chi Minh City looked after me so well and I thoroughly enjoyed it.

Debbie Greene

A Helping Hand

Firstly I would like to say a big thank you to all the ladies who took part in the recent VHI Women's Mini Marathon in aid of the I.H.S., which took place in Dublin on June 2nd and also to all the schools and groups who had a 'Wear Red for Haemophilia Day' so far this year.

Everyone who gives one off donations, fundraises or contributes through our Planned Giving Appeal, play a significant role in helping to provide the services and support we offer our members.

Did you know that contributions to our Planned Giving Appeal go towards two important but very different worthwhile aspects to the work of the Society?

Firstly, they help towards the running costs of an apartment in Dublin for the use of our members and their families who need accommodation linked to increased visits to treatment centres in St James's Hospital and Crumlin Children's Hospital.

Secondly, although we have completed our Twinning Programme with Vietnam, the society continues to work with them via the World Federation of Hemophilia GAP Program to provide support and education to help improve their access to treatment and improved haemophilia care to fellow patients in Vietnam. If you would like to make a difference to someone else's life, please consider signing up to our Planned Giving, you can choose to make an annual or monthly contribution, how much and what date you would like to start its totally up to you and keep in mind that you can stop your contribution at any time.

If you would like to make a one off donation to the Society, you can make a payment by cheque, postal order or card payment. Donations by card can be made via haemophilia.ie by clicking on the donate button or phone the office and we will be happy to process your contribution.

If you have more time and energy and would like to take part in a fundraiser or organise a fundraising event yourself, we are here to help every step of the way. We can provide posters, I.H.S. t-shirts, sponsor cards and more importantly help and advice. Fundraising for an organised event has become easier; the Society is registered with every-day hero, an online fundraising platform, which allows you to set up a fundraising page in a matter of minutes. It's a quick, easy and secure way for your family and friends to support you and funds raised come directly to the Society, so no more chasing people for money they promised you. Your fundraising page can be shared by email, Facebook etc., which means you can reach out to family and friends all over the world to support your fundraising efforts.

If you are looking for some ideas for the kind of fundraiser you could organise yourself, how about a table quiz, a coffee morning, bag packing in your local supermarket, rope in some family and friends to help out. We have had several schools happy to allow a 'Wear Red for Haemophilia Day' a twist on the usual non-uniform day. The pupils can wear anything, maybe a red top, red scarf or even just red socks or a red hairband. The wearing of something red also hi-lights the awareness of bleeding disorders and many schools have used the day to educate the pupils on bleeding disorders and to help them better understand the condition that affects their class mate.

If you can help us to help others, don't put things on the long finger, act today and contact me for any assistance or questions you might have. We always need your support!

For more information on our Planned Giving, making a donation or fundraising, please contact Nina on 01-6579900 or email nina@haemophilia.ie.

Nina Storey



Dates for your Diary

2019

July

Mild Haemophilia Information Day

Date: Saturday, July 20

Venue: Killashee Hotel, Naas, Co Kildare

August

I.H.S. Youth Leadership Programme

Dublin Meeting

Date: Saturday, August 17, 2019 @ 11:30 to 13:00

Venue: I.H.S. Office, First Floor, Cathedral Court, New Street, Dublin 8

Limerick Meeting

Date: Saturday, August 24, 2019 @ 11:30 to 13:00

Venue: Limerick Strand Hotel, O'Callaghan Boardroom

September

Newly Diagnosed Conference

Dates: Saturday 21 & Sunday 22 September

Venue: The Westgrove Hotel, Clane, Co Kildare

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 9

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

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.

Noticeboard



Bon Voyage Lyndsey!

Lyndsey has been our colleague and friend since she joined the I.H.S. staff in early 2017, so it is with a heavy heart that we have waved her off as she has set out for pastures new.

Many of you will have met Lyndsey on home, hospital or school visits, volunteer training or spoke to her on the phone many times, so I'm sure you will join us in thanking Lyndsey for all her hard work and dedication and of course, wishing her well in the future.

Lyndsey will be greatly missed by us here in the office, but a new adventure awaits in America, and it will be an exciting time for her as she begins a new chapter in her life.



Summer Holidays!

Are you planning on jetting off on holiday this summer???

Be sure to be prepared with all the necessary documents and of course, the I.H.S travel card.

If you would like a reminder of everything you will need, the necessary I.H.S. travel tips are available from the 'Living with Haemophilia' section (» parents » travel) of our website, haemophilia.ie.

Or if you would like to speak to us in person or need a travel card sent out to you, please just give us a call on 01 657 9900.



Sport, Exercise & Haemophilia

We are delighted to announce the arrival of a brand new specialised publication for Sport, Exercise & Haemophilia.

It is written by Paul McLaughlin, who works as a Clinical Specialist Physiotherapist in Haemophilia at the Katharine Dormandy Haemophilia Centre at Royal Free Hospital in London.

This publication aims to encourage the improvement in levels of physical activity. For some this may be as simple as using the stairs more frequently, for others it may include some degree of higher level sporting activity.

We are very happy with it and hope you find this publication a useful and interesting resource - you may also recognise some familiar faces in the magazine.

You should have received a copy in the post by now but if you have not or would like further copies, please give us a call in the office on 01 657 9900.

Noticeboard

HELPING HAND



Outreach & Support Update

As we work to source a suitable replacement for Lyndsey's outreach role, we have put some temporary measures in place with regard support and outreach.

If you are an adult and would like to talk with somebody in confidence about any concerns you have, if you would like some information or if you would like to arrange a home or hospital visit, please contact:

Brian, Debbie or Nina on 01 657 9900

If you are a parent and you would like to arrange a hospital visit for your child, a home visit or a school visit, or if you would just like a chat, please contact:

Robert on 01 657 9900



Postage Costs

As you are aware the cost of post has increased substantially of late, which of course, in turn leads to an increased cost to the Society in relation to postage.

Due to the increase, we are asking members to consider how you receive our publications. Would you to consider joining our electronic mailing list for publications instead? By doing this you will receive the quarterly magazine online via our monthly MailChimp magazine, along with other publications. Or if your household receives more than one copy of our publications, would you like to nominate one recipient for the multiple copies? Or just one copy per the household? It is entirely up to you.

However, whatever you chose, you will still receive all notifications in relation to upcoming events and conferences by post. If this is something you would like to do, please call the office on 01 657 9900.

Brian O'Mahony Award

Nominations are open from August 1 2019 for the 'Brian O'Mahony Award for outstanding contribution to haemophilia care in Ireland'.

Nominations can be proposed only by members of the Society. Members of the current board or staff cannot be nominated.

If you would like to nominate an individual who, in your opinion, has made a real difference in haemophilia care in Ireland, please send your nomination to:

info@haemophilia.ie

The closing date for nominations is September 27 2019.



Evelyn Singleton recipient of the 2018 award



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