Haemophilia.ie

Representing people in Ireland with haemophilia and related bleeding disorders

Magazine of the Irish Haemophilia Society

Spring 2019

The Society at a Glance

74	I.H.S. Volunteers
46	Planned Giving Contributors
1285	Facebook Followers
701	Twitter Followers

haemophilia.ie

Ageing Conference 2019

Venue: Killeshin Hotel, Portlaoise
Dates: June 28th to 30th 2019

Preliminary Programme

Saturday 29th June		Sunday 30th June	
10.00 – 11.45	Lifestyle Choices	10.00 – 11.30	New Approaches to Exercise & Activity
11.45 – 12.15	Tea & Coffee Break	11.30 – 12.00	Tea & Coffee Break
12.15 – 13.00	HAA Issues	12.00 – 13.00	Mindfulness
13.00 – 14.00	Lunch	13.00 – 14.00	Lunch
14.00 – 15.15	Benefits & Entitlements		
15.15 – 15.45	Tea & Coffee Break		
15.45 – 16.45	Specific Services from the I.H.S.		

Talking Red Conference

Venue: NICVA, Belfast
Date: Saturday June 22nd 2019

We are delighted to be collaborating with the UK Haemophilia Society for two events in 2019, the first of which is the 'Talking Red Information Day' and takes place in the NICVA, 61 Duncairn Gardens, Belfast BT15 2GB on Saturday June 22.

We will have speakers from Ireland and the UK and topics will include menstruation, pregnancy, treatment options, genetic counselling, family support and the emotional impact of living with a bleeding disorder.

Please note, there is no charge to attend this event.

If you are interested in attending, please contact Aoife in the office on 01 6579900 or via email at aoife@haemophilia.ie

Talking Red Conference

THE HAEMOPHILIA SOCIETY

IRISH HAEMOPHILIA SOCIETY LTD
Cumann Haemifile Na hEireann

22 June 2019, Belfast

Tens of thousands of women across the UK and Ireland are living with a bleeding disorder without even knowing it.

For everyone affected by a genetic bleeding disorder

This event is being jointly run by the UK Haemophilia Society and the Irish Haemophilia Society. To find out more about this free event:
UK Society: Email services@haemophilia.org.uk Tel: 0044 20 7939 0780
Irish Society: Email: info@haemophilia.ie Tel: 00353 1 6579900

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thehaemophiliasociety

Charity no. 288260 (England & Wales) SC039732 (Scotland) UK company 1763614
Charity Number: CHY9214 (Irish Haemophilia Society)

From the Editor

Welcome to the Spring issue of our quarterly I.H.S. magazine. You may have already noticed something different and yes, I have taken on the role of editor from Debbie and I aim to maintain the high standards she set at helm of publications over the years.

I would like to thank Debbie for all her assistance and I look forward to bringing you this and future issues of the I.H.S. magazine.

There are lots of interesting articles to be found in this jam-packed issue. On Page 4 you will find our CEO's report, whereby Brian shares his hopes for our new twining project with Jordan and insight on the development of care and treatment for people with bleeding disorders in the next five years. On Page 6, you will find an in-depth update on the iPATH project from Professor James O'Donnell. On Page 8, there is a report from this year's AGM & Conference in Kilkenny; we hope you all had a great weekend. On Page 11, there are details about the VHI Women's Mini Marathon and on Page 12, Dr Dómhnall O'Connor gives an account of his Kilimanjaro experience having climbed Africa's highest peak with I.H.S. member Patrick Doyle last year.

On Page 14 you will find some very interesting testimonies from recipients of the I.H.S. Educational Grants and on Page 16, Margaret Dunne shares a personal perspective of the I.H.S. through the generations of her family. 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 reading this issue and if you would like to contribute and write an article for a future issue or suggest a story or topic that you would like to see covered, please don't hesitate to get in touch via *barry@haemophilia.ie.*

Barry Healy,
Editor

In this Issue

CEO REPORT

2018 was a momentous year for the Society as we celebrated our 50th anniversary and remembered the challenges and achievements of the past. Now, in 2019, as we prepare for the development of a new strategic plan for the Society we need to look forward to the next five years.

Treatment Development

The transformation in the treatment landscape in the past five years has been remarkable. In 2014, people with haemophilia were treated with standard prophylaxis regimes which did not take account of individual variation in half-life or pharmacokinetics. Since then, we have seen a move toward individualised prophylaxis regimes based on individual pharmacokinetic profiles, individual half-life and individual levels of activity or pre-existing joint damage. The vast majority of those with severe haemophilia are now on prophylaxis. These changes have been assisted by the availability of extended half-life (EHL) factor concentrates which offer the twin advantages of higher trough levels (giving greater protection from bleeding) and less frequent infusion. The possibility of less frequent infusion has led to a greater uptake of prophylaxis. Much lower annual bleed rates are now possible and have become a reality for many people with haemophilia.

The availability of a subcutaneous therapy - Emicizumab (Hemlibra) - for people with FVIII inhibitors in the past year has been a major improvement in quality of life for the group within our community who had the most bleeding episodes and where there had not been any major therapeutic advances for many years. In the last month, Emicizumab has also been licenced by the European Medicines Agency for the treatment of people with FVIII deficiency without inhibitors. This offers an intriguing treatment possibility going forward. There is already clinical experience here in Ireland with this product for this indication as a number of adults here with FVIII deficiency have been on a clinical trial over the past two years.

The pace of transformation in treatment is not slowing down. It is highly probable that the next five years will see more innovation, and more change in the haemophilia treatment landscape than in the past five years. Other subcutaneous therapies such as Fitusiran and anti TFPI products will come to market offering new possibilities for treatment of those with FVII or FIX deficiency, with or without inhibitors. Some of these products may also be suitable for treatment of those with rare bleeding disorders such as deficiencies in Factor V, VII, X, XI or XIII.

A recombinant von Willebrand factor will shortly be a potential treatment option. New and improved EHL factor concentrates, including a FVIII concentrate with a significantly longer half-life are in clinical trials. In less than five years, I am convinced that Gene Therapy for FVIII and FIX deficiency will be licenced therapies.

Novel Treatments in Haemophilia & Other Bleeding Disorders:
A Periodic Review
2019 - Issue 1

Irish Haemophilia Society
February 2019

haemophilia.ie

In Ireland, we have been at the forefront of development as we have participated in clinical trials for the EHL factor concentrates, Emicizumab, Fitusiran and soon Gene Therapy. The atmosphere of innovation here is also assisted by the innovative iPATH (Irish Personalised Approach to the Treatment of Haemophilia) research project which is seeking to answer basic biological questions about haemophilia. The pace of change has already been reflected in our educational materials where we have published two reviews of Novel treatments in the past year (both available from the office or the publications section of haemophilia.ie) and have made available five short educational videos on Gene Therapy on the news section of our website.

These have been possible thanks to the excellent work of the European Haemophilia Consortium who compiled the content. Our next strategic plan will be drafted in the light of these probable developments and the changes in life, in quality of life, in educational requirements, in coping skills which more advanced treatment options may lead to. We truly live in interesting times.

Brexit

We have been conscious of the concern of many members about possible disruption to factor supply due to Brexit. We have been working diligently through the Haemophilia Product Selection and Monitoring Supply Board to ensure there are no disruptions to supply whatever happens with Brexit. Companies will now be maintaining in Ireland a minimum of five months' supply of the major products used here and supply routes have been altered to ensure that factors are imported directly from Europe and not from the UK or by UK land bridge.

Twinning with Jordan

The Society this year formally commences a Twinning programme with the Haemophilia Society in Jordan, under the auspices of the WFH Twinning programme. Following an assessment visit last September, we agreed a work plan with the Jordanian Society for the next four years. The work in 2019 will include identification of key volunteers in Jordan who will work on their social media and publications, providing training on production of electronic newsletters, increasing and broadening their social media presence and provision of training in event planning. We will also work with Jordan to re-examine their governance structure and assist in organising an educational meeting in the capital, Amman.

Over the next there years, we will also provide training in advocacy and lobbying and work to double the number of members in their organisation in addition to identifying potential new board members and volunteers. The comprehensive care centres at St. James's and Crumlin have also twinned with their counterparts in Jordan. Their work will include working on a better national registry, national treatment protocols and training of members of the comprehensive care team. We will work jointly with the centres on the development of a national procurement system for factor concentrates or other haemophilia medications in Jordan.

We very much look forward to working with the Haemophilia Society in Jordan. This will not detract from our ongoing development work with Vietnam where training of young leaders with haemophilia and parents continues and where we hope to be in a position to assist them with a national procurement programme for haemophilia treatments in the near future.

Brian O'Mahony

iPATH Update

While all people with severe haemophilia have factor levels <1%, not everyone will have the same experience of the condition. For example, even within families, a difference in severity of bleeding and joint damage may be evident. Consequently, other influences can clearly impact upon the course of haemophilia. For many years, the recommended treatment approaches in haemophilia are based mainly on the body weight of the individual. However, recent research has demonstrated that this "one size fits all" approach is not ideal. In particular, it fails to take into account important difference's that may exist between people with haemophilia. For example, it seems likely that the ideal trough factor level will differ between different subjects, and will even vary in a given individual through the course of their life.

In order to provide new insights into the condition, the iPATH study was established in 2017 with the aim of personalising care for people with haemophilia. In partnership with the Irish Haemophilia Society, this study is addressing the important clinical questions that need to be answered in order to enable treatment in the future to be given that is specifically tailored for each individual patient. The iPATH study is supported in part by a research grant from Science Foundation Ireland (SFI) under the SFI Strategic Partnership Programme Grant (16/SPP/3303) and research support from Shire US Inc., a Takeda company, Lexington, MA, USA.

Our iPATH partners include the Irish Haemophilia Society; clinical partners from St. James's Hospital and Our Lady's Children's Hospital Crumlin; world class scientists from the RCSI and Trinity College Dublin; and colleagues in Takeda. Together we are working to progress the understanding of factors which contribute to (i) risk of bleeding, (ii) risk of joint damage and (iii) risk of joint inflammation in people with haemophilia.

Pushing forward the boundaries in care of people with haemophilia

In the iPATH study, clinical information about the lived experiences of people with haemophilia (number of bleeds per year, amount of factor replacement used, degree of joint damage) combined with specialised genetic and laboratory tests will provide a personalised approach to treatment for each participant. In addition, all participants can avail of a fitness assessment by the physiotherapist involved in this study, Ms. Megan Kennedy.

iPATH

IRISH PERSONALIZED APPROACH TO THE TREATMENT OF HAEMOPHILIA

For people with haemophilia, changes in your code (genes) for factor VIII or factor IX result in low factor levels and bleeding. Genetic testing in haemophilia is already established in routine care, but only focuses on the factor VIII and factor IX genes. The iPATH study is taking a different approach, looking at your entire genetic code to understand what other genes also influence bleeding, inflammation and joint damage in haemophilia. This approach is called Whole Genome Sequencing and is performed on a single sample of an iPATH participant's blood, taken as part of routine clinic bloods at regular review.


Professor James O'Donnell speaking at our AGM & Conference 2019

Complimentary to the genetic testing being performed, our research teams based in the RCSI and Trinity College Dublin will perform specialised laboratory testing, with the aim of identifying new tests to identify early signs of inflammation, joint injury, bleeding and clotting. Using the information from the study, we hope to identify new targets to help reduce joint damage associated with haemophilia, ultimately leading to improved treatment approaches.

Involvement in the iPATH study

In 2018, we continued to recruit adults with moderate and severe haemophilia to the iPATH study through the National Coagulation Centre (NCC) in St. James's Hospital. There are now over 100 Irish adults involved in this exciting project. In 2019, Our Lady's Children's Hospital, Crumlin will also start recruiting, so that children with moderate and severe haemophilia will now have the chance to join the iPATH study.

Almost 50 adults on the iPATH study have now completed a physical activity assessment with our research physiotherapist, Ms. Megan Kennedy. From this assessment, information is combined from an activity monitor, your weight, height, grip and balance assessment, to make a fitness assessment, sent out to each person who completes the test. Taking part can be linked with your appointment and takes approximately 30 minutes.

In the last 12 months, important new data protection legislation for clinical research, the General Data Protection

Some of the iPATH team with Brian O'Mahony & Minister for Health, Simon Harris, TD at our AGM & Conference in 2018

Regulations (GDPR) and Health Research Regulations, have been introduced. In keeping with these regulations, all data and results from each person enrolled in iPATH are coded so that no personal names, addresses or hospital numbers are used in the research. Due to the changes with the introduction of GDPR, we will have new consent forms for each participant to ensure your data protection rights are further explained and, as before, absolutely protected at all times.

What are the key findings so far?

2018 saw the first results from the iPATH study, with posters presented both the prestigious American Society of Haematology Congress in San Diego, USA in December 2018 and the Haematology Association of Ireland annual conference in October 2018. The iPATH research team has recently returned from the European Association for Haemophilia and Allied Disorders (EAHAD) congress in Prague, where three posters on physical activity and joint damage were selected for presentation.

A large focus of our work to date has been how your body breaks down Factor VIII (FVIII) treatment – your FVIII half-life or pharmacokinetics (PK). Looking at PK results from all people with Haemophilia A on this study, we have shown that blood group, age and Von Willebrand Factor all affect FVIII half-life. FVIII treatment will last for shorter times in people with blood group O, those who are younger or who have lower Von Willebrand Factor levels.

To better understand how PK could help shape prophylaxis, we reviewed the prophylaxis routines prescribed in response to bleeds for the last 5 years and related this information to each person's PK results. We showed, for the first time, that the amount of prophylaxis prescribed was strongly related to an individual's PK results. These results suggest that rather than people with haemophilia "bleeding their way" to their optimal prophylaxis schedule, a person's FVIII half life could instead be used to plan prophylaxis at the outset.

Examining joint damage and physical activity in people with haemophilia, we have shown that joint damage (as measured by Haemophilia Joint Health Scores, HJHS) increased with age, with ankles the most severely and frequently affected joint. Although ankle damage occurred earlier in life, with age elbow damage was surprisingly just as severe. When physical activity was monitored in 25 patients (using an Actigraph device worn for a week), the majority of time was spent in light physical activity, with 60% of people doing the recommended amount of moderate physical activity but only 8% involved in vigorous activity. Examining reasons for this level of physical activity using a special activity questionnaire, we identified key barriers that limit activity in people with haemophilia. For younger adults, a lack of time and willpower were the main barriers, whilst fear of injury and lack of skill were more significant barriers in older adults. This information will help us build towards our future goal of personalised approaches in physiotherapy and exercise.

As we now look to the future; encouraged by the results of the iPATH study thus far; we thank our partners for their continued contribution and ongoing support, without which such research, could not be sustained and we acknowledge that by working together we are closer than ever to enhancing the quality of life for people with haemophilia.

How to get involved?

More information on the iPATH study can be obtained by contacting our research team at *ipath@rcsi.ie*

Professor. James O'Donnell

AGM & Conference 2019

Our AGM & Conference 2019 took place over the first weekend of March in Hotel Kilkenny with a huge number of members were in attendance along with I.H.S. staff, invaluable volunteers and invited guests – making it our second highest attended AGM ever, with numbers just shy of last year's 50th Anniversary AGM.

First off, we would like to extend a massive thank you to all our brilliant volunteers for their time and dedication in helping with registration and looking after the Creche, Cubs, Kidlink and Youth Groups over the weekend – without their help, so much wouldn't be possible.

Registration took place on Friday evening in the hotel lobby, which worked well, and everyone was in good form despite the inclement weather – to put it mildly.

Following registration, it was time for dinner, which was followed by Brian's 'Update on Twinning'. Brian outlined the valuable work undertaken in Vietnam which among other things, has seen an increase of 300% in factor use since 2010 but there is still much to be done.

Factor is available for major bleeds but not all of the time and not in all cities and Cryoprecipitate is still used. A pilot home treatment project, previously not permitted, has been completed in Hanoi by 60 people with haemophilia, receiving the treatment for 6 months. The WFH Humanitarian Aid Programme has been the main source of Vietnam's EHL FVIII and FIX supply but recently introduced regulations blocking aid, prevented its import but the good news is that this issue was circumvented in August 2018.

Brian also outlined some specific I.H.S. project work funded directly by members from the Society's Planned Giving Campaign. These projects include a micro employment project; small grants given to 10 people each year to set us small business at home or nearby. Home adaptation grants, wheelchairs, crutches, accessible toilets and handrails. With the Vietnam Programme due to finish soon, the focus is now on working with key volunteers – pwhs and parents – to provide culturally appropriate training for respectful advocacy, action planning, outreach, and volunteering, organisation and factor concepts, and ensuring patient leaders are prominent in hospital meetings.

Brian moved on to talk about the 'Ireland-Jordan Twinning 2019-2022'. The I.H.S. will twin with Jordanian Society for Thalassemia and Haemophilia (JTHS) and St. James's Hospital and Our Lady's Children's Hospital, Crumlin will twin with two hospitals in Amman; Al Bashir and Royal Medical Services, with joint outreach to other cities. The Centre Twinning objectives are to develop and update the National Registry, improve supply of factor (and help with tenders), improve Lab. Diagnostic capability, upskill members of the team - nurses, physio, dental etc. and development of updated National Treatment protocols.

The objectives of the Society Twinning are to increase membership and participation in JTHS, increase publications and communication, organise Educational events, build capacity of JTHS to organise meetings, organise Educational events and increase advocacy and Lobbying activity. Brian concluded by speaking enthusiastically about the potential for this new twinning programme and his hopes for the future of the programme – and with that, Friday was over.

Saturday began with the volunteers ensuring that all the children and young adults were registered in their relevant groups for a weekend of fun and learning, leaving adults free to attend the AGM and various sessions.

The Annual General Meeting kicked off at 10 am and was extremely well attended. The Chairperson Mr. John Stack opened the meeting, welcomed members and called for the adoption of the minutes.

Next up was the Secretary's Report. Ms. Barbara Wynne provided details of the events and activities of the Society during 2018, along with information on publications, the website, social media, home visits, educational grants and staff. Treasurer Mr. Gerard O'Reilly presented the Audited Accounts for 2018 and outlined the Society's finances.

The Chairperson addressed the membership and spoke about supports and services available to members, including the 'Youth Leadership Programme' re-launched in 2018. John gave an overview of the various fundraising efforts undertaken throughout the year and ran through the events and 50th Anniversary celebrations of the previous 12 months. The Chairperson thanked the board, staff and volunteers for their dedication and hard work and in particular Gerard O'Reilly, who was stepping down after 14 years on the board and received a rapturous round of applause.

Next up was the Chief Executive; Mr. Brian O'Mahony who went into more details on publications produced, events organised in 2018 and how the 50th anniversary was marked throughout the year by the society. Brian recapped on twinning, informed member's that a new strategic plan will be drafted this year and revisited the 2015-2018 Plan, explaining that of 41 objectives, 39 were achieved and 92% of 195 strategies have also been achieved. Brian finished up with an overview of current and future haemophilia treatment and outlined the strong and formal role the society has on product selection board.

The first session following lunch was Dr. Michelle Lavin's presentation on 'Novel Therapies'. Focusing on Gene Therapy, it was an excellent adjunct to Dr. Lavin's 'Understanding the Terminology of Novel Treatments' at our October Conference last year. Dr Lavin explained the various aspects of Gene Therapy, what it is and what it is not (it is not gene editing!) and how it works in a very straightforward and understandable manner, while not losing the value of the information. Basically, it involves taking the shell of Adeno-associated virus (AAV) and using it as a vehicle to get the genetic material into your body, with Dr. Lavin equating it to someone borrowing your existing tools to perform a DIY job in your home.

The results from published data shows an impressive decline in bleed rates and the findings are promising. Dr. Lavin showed numerous slides explaining the current studies before taking questions from members and recommending people check out 'Novel Treatments in Haemophilia & other Bleeding Disorders: A Periodic Review 2019 – Issue 1' recently published by the EHC & I.H.S.

Following a coffee break, Dr. Barry Harrington from National Haemophilia Council then chaired an 'Open Forum' with Dr. Niamh O'Connell, National Director, National Coagulation Centre, St. James's Hospital, Dr. Beatrice Nolan, Consultant Haematologist, Our Lady's Children's Hospital, Crumlin and Dr. Alison Dougall, Assistant Professor, Dublin Dental Hospital & National Coagulation Centre. It was an interesting and enlightening session and it was very encouraging to see members getting involved and fielding question to the representatives from the Comprehensive Care Centres.

Next on the agenda was 'An Update on the iPATH Project' with Professor James O'Donnell and Ms. Megan Kennedy. Professor O'Donnell began by explaining that until quite recent, treatment for young boys with haemophilia hadn't changed for 30 years; it essentially entailed a pwh "bleed their way to the 'correct' prophylaxis dose". The original rationale was about trying to convert severe haemophilia to moderate and to prevent spontaneous bleeds but there a still big gaps in knowledge with the current approach i.e. we don't know why bleeding varies so widely in pwhs.

Professor O'Donnell explained what we need is personalised treatments for patients, as "people are not all the same" nor are pwh, so one size fits all doesn't work - this is at the core of iPATH; an innovative and collaborative research programme to provide the answers required to optimise every aspect of future treatment for each individual with haemophilia.

So far 105 adults with haemophilia have been recruited, with the enrolling of children to begin soon. While the iPATH programme continues, both Professor O'Donnell and Ms. Megan Kennedy presented some interesting preliminary data on the activity study and on FVIII clearance data. The session concluded with a number of questions before we broke for the day. If you would like a more in-depth look at iPATH, Professor James O'Donnell's excellent iPATH update can be found on pages 6 & 7.

Later on, before we all sat down to a well-earned dinner, the Awards Ceremony took place. First up were the Educational Grants, which were awarded to Shannon Cassidy from Monaghan (Maureen & Jack Downey Educational Grant), Aisling Moriarty from Killarney (Margaret King Educational Grant) and Oran O'Neill from Carlow (Fr Paddy McGrath Educational Grant). Evelyn Singleton was presented with the 'Brian O'Mahony Award for Outstanding Contribution to Haemophilia Care and Nikki Clavin was named Bill O'Sullivan Fundraiser of the Year Award. Nikki raised €1,805 from the Women's Mini Marathon in June 2018.

While the adults were occupied at sessions on Saturday and Sunday, the volunteers were busy with the children's and young adult's programmes. The crèche group enjoyed fun and games, as you do when you are three years and under. The youth programme on Saturday morning focused on Exercise and Nutrition; the benefits of being physically fit and strengthening joints and muscles and eating a balanced diet. The Cubs (aged 4-7 years) enjoyed games, arts and crafts, parachute games and joined the Kidlink (aged 8-12 years) and Youth (aged 13-17 years) groups for a trip to a nearby Reptile Zoo on Sunday.

The first session for adults on Sunday was 'The Future of the Society in a Changing Environment' Mr. Brian O'Mahony, I.H.S. CEO and Ms. Mary Clare Delaney, I.H.S. Vice-Chairperson. Unsurprisingly, this was a very well attended session with members enthusiastically getting involved in the discussion with a vast array of subjects and areas of focus being raised, including psychosocial counselling, succession planning, exploring ways for volunteers to attend the talks, retaining a focus on the history of I.H.S, an emphasis on carriers and a mothers group, and researching suitability of retirement homes / nursing homes for people with haemophilia. Despite it being Sunday morning, this was an energised session and was really hearting and encouraging to witness the vocal and passionate display from our members.

On Sunday, to conclude this year's AGM, there were two options as we hosted sessions on 'Orthopaedic Surgery' and 'Gene Therapy Videos'. The former was presented by Dr Niall Hogan, Consultant Orthopaedic Surgeon in St. James's Hospital. There was a lot of interest from members in what Dr Hogan had to say, with massive numbers attending this session. Dr Hogan designed his presentation with simplicity, he explained every aspect of orthopaedic surgery in an understandable manner going through step by step about what members should expect when they have to undergo orthopaedic surgery. To bring his presentation to a close, he gave members a broader awareness into knee replacement surgery. He showed the members several images of his orthopaedic surgery team carrying out knee surgery. It is safe to say after hearing and seeing Dr Hogan's presentation that the orthopaedic surgeons in St. James' Hospital do a phenomenal job for their patients.

Simultaneously, meanwhile, in the Orchard Suite, was the premiere of the 'EHC Conversations' five easy to understand videos on gene therapy. Gene therapy is complex and not always easy to communicate but these videos from the European Haemophilia Consortium, featuring a number of experts, are insightful, informative and offer an understanding of the topic in a more digestible manner. If you would like to watch (or re-watch) these videos, you can access from the news section of our website haemophilia.ie.

We hope that everyone who was in attendance, enjoyed the conference and each of you gained something from the talks and sessions. We look forward to seeing you all again throughout 2019.

Lastly, I.H.S. AGM's are becoming synonymous with snowy conditions and we hope everyone got home safe and sound, and with the least amount of disruption.

I.H.S. Staff


The trusty volunteers of the I.H.S.


Ger & John share a joke prior to the AGM


Evelyn Singleton gets the Brian O'Mahony Award for Outstanding Contribution to Haemophilia Care


Some young members of the society enjoying the Gala Dinner on Saturday night

VHI Women's Mini Marathon 2019

One of the biggest fundraising events in Ireland is the VHI Women's Mini Marathon. This year's race will take place in Dublin on the Bank Holiday Sunday, 2 June 2019 at 2pm.

This is a great event to be involved in and there is a wonderful atmosphere on the day; with plenty of banter, laughs and stories from the other ladies taking part. It is quite a sight to see the array of different coloured t-shirts worn on the day for the many worthy causes and in memory of many loved ones.

The first Women's Mini Marathon took place in 1983 and since then, over 1 million women have taken part. It is an event renowned for its fundraising efforts and we would ask you to consider taking part and fundraising in aid of the I.H.S. With your support, we can offer more services and support to our members. So if you, your mum, sister, aunt, niece, cousin, friend, neighbour or work colleague (remember ladies only) would like to do your bit for charity, please take part in aid of the I.H.S. It is a 10k race, which you can walk, jog or run, so is suitable for all fitness levels. All participants must first register with the event organisers (see details below) and then contact the I.H.S. to obtain your I.H.S. t-shirt, sponsorship card and details on setting up a fundraising page. Setting up a fundraising page is not obligatory, but it only takes a few minutes and funds raised online come directly to the I.H.S. It is quick and easy to set up a fundraising page and is a great way to let friends and family at home and abroad know you are fundraising, your page can be shared by email or on social media.

Below is some general information on the event, but for more details go to *vhiwomensminimarthon.ie/faq*.

How do I enter?

Online entries via *vhiwomensminimarathon.ie* from the 28 February 2019 or forms will be in the *Herald* Newspaper in March

How much is it to enter?

The cost of entry is €25 per person.

What distance is the VHI Women's Mini Marathon?

The mini marathon is a 10km event – walk, jog or run – it's up to you!

What is the minimum age to enter the event?

The minimum age is 14 years, but you must be 18 years or older to participate and start in the under 60 minute wave e.g. complete the event at a runner's pace (This is an AAI ruling).

Can I get my race number posted to me?

Yes but you need to apply early. The postal option will close on the 30 April or sooner if demand exceeds capacity. There is limited availability. You will need your Eircode to select this option and the cost is €2.90 per person.

Can I enter a group?

Yes, you can enter up to 25 people using the Online Entry System.

How can I fundraise for the I.H.S.?

If you would like to fundraise for us, please contact Nina on 01-6579900 or email *nina@haemophilia.ie*.

'Being the Fence and the Ambulance'

An Expedition Doctor's Kilimanjaro Experience

In October of last year, I.H.S. member Patrick Doyle climbed Mount Kilimanjaro in Tanzania – Africa's highest peak, the summit is 5,896 metres high, roughly two thirds the height of the world's highest mountain; Everest.

Patrick undertook the tough 8-day trek, 6 days up and 2 days down with temperatures that can hit -20C, raising very welcome funds for the society in the process.

Patrick was not alone on his endeavours, he was accompanied by a group of fellow mountain climbers from Earth's Edge, an Irish Adventure Travel Company who are the only Irish company of their ilk to send a practising doctor on all of their trips.

The expedition doctor for this trip was Dómhnall O'Connor whose report from the trip has been reproduced below with the kind permission of Earth's Edge.

Kilimanjaro with an Expedition Doctor

I recently travelled to Arusha, Tanzania with a group from Earth's Edge to summit Kilimanjaro and stand on 'the roof of Africa'. As a recreational hiker it was a fantastic personal challenge and an unforgettable experience but as a doctor, the trip had much more to offer. Earth's Edge is the only Irish adventure company to send a qualified, practising doctor on all their trips and I don't think I truly appreciated what that means to people until we arrived at the mountain.

Over the course of the fortnight, I spent time getting to know each of the group and as time went on and we all settled into familiarity, people started to tell me why having a doctor on the trip mattered to them. For many, it was an extra insurance policy, a sense of security or peace of mind. For a few though, it meant that their age or medical history (both things that we all accumulate with time) didn't exclude them from something they always wanted to do.

So many people want to challenge themselves, to set goals, to train hard and all they want is to be given a chance. For many of our group that's what made Earth's Edge different; they are in the business of giving people a chance and for our clients, the expedition medic was part of that.

Fences and Ambulances

In his 1895 poem, Joseph Malin wrote: "Better put a strong fence 'round the top of the cliff than an ambulance down in the valley".

His wisdom holds merit, but from my experience of being an expedition doctor, it's probably best to have both. When it comes to realising goals at altitude there are plenty of fences to build and you want a pretty decent ambulance parked in the valley.

On our trip, there was no better example of fence building than in the case of Paddy Doyle, an avid climber and hiker from Wicklow. Paddy was born with haemophilia, a condition where blood does not clot as effectively as normal.

In many cases, people manage to live normal lives, but even minor bleeding can become critical. Having summited most of the major peaks in Ireland and the UK, Paddy had set his sights on the highest peak in Africa.

Planning for Kilimanjaro

The terrain of Kilimanjaro and the altitude is not for the faint-hearted but in the case of a person with haemophilia, being many miles away from a hospital, in locations not easily vacated, means planning and prevention are essential. Plans were laid out by myself, Paddy and his consultant so that we would be travelling with specialised drugs that Paddy could take himself, or that I would administer to improve blood clotting in the case of a fall. Additional stock was also arranged to deal with nosebleeds, broken bones, lacerations and any causes of bleeding on the mountain. Finally, to prepare for the worst-case scenario, we reviewed evacuation plans and all helicopter landing sites along the expedition.

As a doctor, it was fantastic to have such a thorough plan for accident prevention and management before we set off. Even more fantastic is the fact that it was entirely redundant and on the 22nd of October 2018 Paddy Doyle became one of an elete few Irish PWHs to summit Kilimanjaro!

Medical Supplies for Kilimanjaro Trek

If our planning and prevention was the 'fence' from Malin's poem, then the 'ambulance' was the Earth's Edge medikit for dealing with accidents when they happen.

A few months before we departed, I was sent a list of the medical equipment that we would have with us for the expedition. Having a background in hospital medicine, I didn't have high hopes for the expedition equipment and had visions of myself doing 'MacGyver' medicine with bits of tree bark and string! I couldn't have been more wrong.

The Earth's edge medikit has everything except the kitchen sink. Its stocked to treat everything from headaches to heart attacks, dehydration to delirium, infections, insomnia, fractures, nausea, a minor surgery kit and a load more besides. After reading the extensive list I was relieved and admittedly a little worried… How was I going to carry all that stuff?

I needn't have worried though as I was introduced to an energetic and cheerful Tanzanian man named Thomas, who was to be the medical porter, on the first day of the climb. As with all medical porters, Thomas was one of the more experienced and stuck with me throughout, always keeping an eye for anyone struggling and quite literally running uphill if he was needed.

Being an expedition doctor is a totally different world to everyday medical practice. It's about starting out with someone who is physically well, taking on a great physical challenge and supporting them to overcome it. The rewards from doing a major summit transcend the physical and bring about changes in people within themselves. It was a privilege to be part of so many people's journeys and I'll definitely be back to do more.

If you are interested in experiencing Kilimanjaro with an expedition doctor for yourself, you can find out more info from www.earths-edge.com

Dr Dómhnall O'Connor


The Summit of Kilimanjaro


The Group that Scaled Kilimanjaro with Patrick (back row, right)

Educational Grants

We believe the I.H.S. educational grants are hugely worthwhile and beneficial in helping cover some of the cost of someone's education. Who better though to explain the benefits of the grants from their first-hand experience than recipients themselves! You will have to wait to apply for the 2019 grants but we have insightful testimonies from Nicole Chun and Róisín Horan.

Nicole Chun - Margaret King Educational Grant 2017

I am currently a third-year student in the University of Limerick (UL) where I study psychology and sociology. I love studying here but it can be tough when you have to worry about paying accommodation, travel and living costs. I think that the educational grants are an excellent idea as they really do help. I am extremely grateful to be chosen by the society as a recipient of the I.H.S educational grants.

Since my family home is in Kerry and I study at UL, I live in student accommodation in Limerick. I also travel home every now and then, so these costs tend to stack up. There is also the expense of textbooks and it is easy to forget that you need money to pay for living costs. I have found the grant very helpful with all of these things. The grant has also helped when I did work experience placement in Vietnam and a semester studying abroad. Both of these were compulsory for my course and so I had to find a way to provide for myself during these months, which the grant helped me with.

Last January I travelled to Vietnam for my co-op placement and I stayed there for five months, working in an English centre, teaching English to students aged 3 to 16. I loved working in Vietnam as I was able to meet so many incredible people from around the world and I learned so much about their cultures. I worked in both English centres and state schools in small towns and rural villages where I enjoyed working with both the teachers and students, the latter were so happy and grateful to learn English all the time and I would like to go back someday.

Although it is not an expensive place to live, the price of flights more than makes up for it. The educational grant I received last year helped me to pay for the return flights to Vietnam. I made such amazing friends and memories; it would be a shame to think that I may not have been able to do all that if it wasn't for the grant.

I also had to take a compulsory semester out of UL to study abroad. I decided to go to the University of Skövde in Sweden for my Erasmus placement. Compared with flights to Vietnam, the prices to fly to Sweden wasn't as expensive but it is actually the cost of living that you have to watch out for in Sweden. Everything is a lot more expensive than in Ireland.

In Sweden, the classes are more specialised than in bachelor's programmes in Ireland, so I was able to learn about certain topics in psychology in more detail. The classes I took were evolutionary psychology, neuropsychology of consciousness, various states of consciousness, and basic neuroscience. Even though these classes were more difficult as some of them were at a masters level, I still enjoyed them very much. I was able to learn about topics I wouldn't get the chance to in UL.

I had such a great time in Sweden and I am so grateful that the I.H.S. was able to help make the experience even more enjoyable and less stressful. I made lots of friends and my time in Sweden made me realise that I would like to travel more in the future, and maybe work abroad. I was able to learn so much about myself as a person and about different cultures too.

I love my course in UL; the classes are extremely interesting, and the lecturers are very helpful. I am so glad that I chose this course because of the compulsory co-op placement and Erasmus semester. I found that I learned a lot about myself and my course while on these placements. I also was able to figure out what I want to do after I graduate.

I would just like to thank the I.H.S. for thinking of me for the educational grant. It has helped in many more ways than you could think of and I am very grateful for that.

Róisín Horan - Maureen and Jack Downey Educational Grant 2018

My name is Róisín, I'm originally from Co. Kildare and I'm a Business Student in my final year at Trinity College Dublin. I am due to complete my degree in May, and with some exciting summer plans ahead, I can finally see the light at the end of the tunnel! I have enjoyed my time as a student, despite the many challenges I have encountered. This year has been particularly tough given that my final year is worth 100% of my degree. Hopefully, with a bit of luck, the hard work will pay off! I have a keen interest in my studies and enjoy wider college engagement with societies and social clubs. This year I am the Treasurer of the Finance and Investment Society in Trinity – a welcome distraction from the studies. I am, however, very much looking forward to moving on and pursuing further accounting qualifications, while working full-time.

This year I was one of the recipients of the I.H.S. Educational Grants. I received word that I was a successful recipient at the start of this academic year, just as college expenses were beginning to mount. I was delighted to receive this grant and put it to immediate use, buying text books I required for the year. The grant also ensured that I could pay for all 'back to school' supplies – many of which were required given the busy year I have had! This grant also enabled me to cover all of my travel expenses over the first term in college. Easing the pressure from my parents was indeed much appreciated with three girls in school and college.

I recommend that others apply for this grant, as it contributes in easing the burden that is associated with the cost of third level education in Ireland. After four years in Trinity, and with two younger sisters coming behind me, I can see from my parents the hefty costs and sacrifices in sending children to college.

I would like to thank the Irish Haemophilia Society and the sub-group of the board for choosing to offer me this grant. Your support is much appreciated.

FATHER & SON(S) OVERNIGHT

Saturday May 18th & Sunday May 19th

Lilliput Adventure Centre in Mullingar, Co Westmeath

We are pleased to announce details of our Father & Son's event at Lilliput Adventure Centre which will take place over the weekend of the 18th & 19th of May 2019 in Lilliput Adventure Centre in Mullingar, Co. Westmeath.

This event is open to:

- **Fathers who have sons with haemophilia. (Please note that male siblings who do not have haemophilia may also attend this event).**
- **Fathers with haemophilia with sons who do not have haemophilia.**

Please note children must be aged between seven to seventeen.

The cost for the overnight will be subsidised by the Society at €50 per adult and €25 per child. This will include all activities, accommodation on Saturday evening, lunch and dinner on Saturday and breakfast on Sunday. The total must be paid in full at the time of booking.

In relation to accommodation, please note that Lilliput Adventure Centre operate a shared sleeping facility in a dormitory type setting. All bed linen and duvets are provided. More information in relation to what you will need to bring (for example: an old pair of runners, clothes etc.) will be given in the confirmation letter.

The closing date for registrations is April 30th - If you have any questions or queries about this event, please contact Rob in the office on 01 6579900.

The Generation Game

So, there I was chatting to my granddaughter Hannah about her experience volunteering as a leader in the junior programme at the family weekend in Sligo last year. It is very special to me to see the third generation of our family volunteering for the Society. My son Paul has just stepped down this year having been the longest serving leader in the junior programme.

Hannah and her siblings have attended many of the weekends over the years and have always enjoyed the experience. She said she loved working with the Cubs Group and enjoyed the whole weekend. She was very impressed with how Rob had organised the programme and all his support for the leaders. She told me about the activities and loved them all especially the visit to the Eagles Flying Farm - her standout moment!

There was one special moment at the weekend that stood out for her. There were two young boys sitting talking on Sunday morning. They were discussing that they both had ports and talked all about their haemophilia. She thought it was lovely to see them so engrossed and happy to talk to someone else who actually understood what it was like to live with haemophilia.

Rewind – Almost exactly 20 years to an AGM in Killiney.

I was sitting at the registration desk while the delegates attended a lecture. There were two young boys sitting near me waiting for their parents. They started talking and they eventually realised that they both had haemophilia. I listened to them comparing their experiences and it became fairly clear that neither of them knew anyone else with haemophilia except those they met at the hospital. I was amazed at how animated they became and how well they understood each other. I think that was the moment when a very small seed was implanted in my brain.

The following year was the first time we had children at the AGM. Alison Daly came on board to organise activities and my daughter Pamela organised the Crèche Group activities for the younger ones. I loved working with Alison over the following years to develop the junior programmes. It was great to see friendships developing and seeing the young members come up through the programme some of whom went on to volunteer as leaders. A number even went on to serve on the board where their experience volunteering was surely a great help. There were many challenges along the way. We had to avoid just providing a childminding service and try to provide an environment for education and a place where the younger members felt they were an important part of the wider haemophilia family.

Now in our Golden Jubilee year we all know the Society has a superb junior programme run over four age ranges, Crèche, Cubs, Kidlink and Young Adults. Lots of them keep in touch with each other throughout the year on WhatsApp etc. The amount of work that goes into the junior programmes was very clear to everyone at the AGM this year from the brilliant 'Madhatter's Tea Party' (how good was that?) to the excellent film the Youth Group put together with the help of Kieran Dowling who himself came up through the programme and later volunteered as a leader.

There are many challenges in providing this excellent programme not least ensuring that there are enough volunteers to cover all the events. I think it will continue to evolve as needs change and like all activities, changes will be made in response to those changing needs. It is now almost ten years since I was involved personally, and I love to keep up with what is happening. There is no doubt that what has been achieved with the junior programme would never have been possible were it not for the full support of the Board, the hard work put in by the staff and of course the large numbers of volunteers many of whom have come up through the programme. May it continue for many years to come.

Margaret Dunne

Dates for your Diary in 2019

April

Von Willebrand's Information Day

Date: Saturday, April 13th
Venue: Midlands Hotel, Portlaoise, Co Laois

World Haemophilia Day Event

Date: Wednesday, April 17th
Venue: TBC

May

Father & Son(s) Overnight

Dates: Saturday May 18th & Sunday, May 19th
Venue: Lilliput Adventure Centre, Co Westmeath

June

Talking Red Conference

In conjunction with the UK Haemophilia Society

Date: Saturday June 22nd
Venue: NICVA, Belfast BT15 2GB

Ageing Conference

Dates: Friday June 28th & Sunday, June 30th
Venue: Killeshin Hotel, Portlaoise, Co Laois

July

Family Adventure Overnight

Dates: Saturday 13th & Sunday 14th July
Venue: Lilliput Adventure Centre, Co Westmeath

Mild Haemophilia Information Day

Date: Saturday, July 20th
Venue: Killashee Hotel, Naas, Co Kildare

September

Newly Diagnosed Conference

Dates: Saturday 21st & Sunday 22nd September
Venue: The Westgrove Hotel, Clane, Co Kildare

October

October Conference

Dates: Friday, October 18th to Sunday, October 20th
Venue: Shearwater Hotel, Ballinsloe, Co Galway

November

Haemophilia B Information Day

Date: Saturday, November 9th
Venue: Hotel Kilkenny, Kilkenny

AGM 2019 Photos

Noticeboard

Fundraiser of the Year 2018

Congratulations to Nikki Clavin, our Fundraiser of the Year for 2018!

Nikki took part in the VHI Women's Mini Marathon in Dublin and raised a staggering €1,805 in aid of the I.H.S.

We were delighted to present Nikki with her fundraiser of the year clock at our recent AGM & Conference in Kilkenny.

Our thanks to Nikki and everyone who raised funds for the I.H.S. in 2018, we really appreciate your support.

EHC
european haemophilia consortium

Gene Therapy Videos

A major area of development in Haemophilia is in Gene Therapy. Several clinical trials are underway for both FVIII and FIX. Indeed, it is our clear expectation that some people with haemophilia here in Ireland will have an opportunity to participate in some of these clinical trials.

We understand that the science of Gene Therapy is complex and not always easy to communicate. We are delighted to be able to share a series of short professionally produced videos commissioned by the European Haemophilia Consortium available on the I.H.S. website.

The speakers were carefully selected, not only for their understanding of the topic, but for their clear ability to communicate this information.

We hope you enjoy these short presentations. We would very much welcome your feedback and comments.

The videos are available in the Newsfeed section of our website.

Novel Treatments in Haemophilia & Other Bleeding Disorders:
A Periodic Review
2019 - Issue 1

Irish Haemophilia Society
February 2019

haemophilia.ie

Novel Treatments in Haemophilia & other Bleeding Disorders: A Periodic Review

2019 – Issue 1

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

The Society has adapted a publication compiled by the European Haemophilia Consortium to produce a comprehensive update on 'Novel Treatments in Haemophilia & other Bleeding Disorders: A Periodic Review'.

This document, a first issue of 2019, is designed to be informative for both people with bleeding disorders and health care workers.

It is available to download from the publications section of our website, haemophilia.ie.

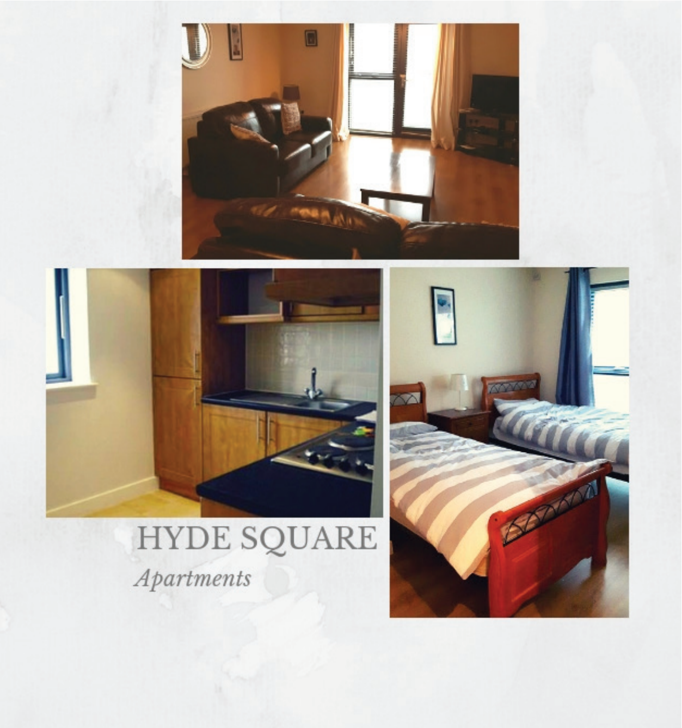
If you would like a hard copy, please get in touch with us on 01 657 9900.

GDPR

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

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

Noticeboard



Hyde Square

We're are delighted to announce that the apartment facility for members in Hyde Square has now re-opened.

Just to remind you all, the apartments 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 6579900.

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

World Haemophilia Day 2019

The I.H.S. will once again be active in celebrating World Haemophilia Day (WHD) on April 17th.

This year, the I.H.S. has joined with Royal College of Surgeons (RCSI) in Dublin for a symposium in the RCSI, entitled 'Haemophilia – The Future is Now - New Approaches to an Ancient Condition'.

Following the success of the 'Light Up Red' last year, a series of prominent buildings and landmarks in Ireland will join others across the globe in lighting up red for WHD.

This year, buildings lighting up will include Cork City Hall, The Capitol Building in Cork City, The Dublin Convention Centre, and The Mansion House, the Civic Offices on Wood Quay and Smithfield Square in Dublin.

Board Update

Following a meeting of the I.H.S. Board in March, Ms. Aislinn Farrelly has assumed the role of Treasurer, following Ger O'Reilly stepped down from the board after 14 years.

Thanks to Ger for all his work and we wish him the best of luck in the future.

We'd also like to wish Aislinn all the best with her new role.

IRISH HAEMOPHILIA SOCIETY

First Floor
Cathedral Court
New Street
Dublin 8

Tel: 01 6579900
Fax: 01 657 9901

Email: info@haemophilia.ie
Website: www.haemophilia.ie