

Haemophilia.ie



Representing people in Ireland with haemophilia and related bleeding disorders

Magazine of the Irish Haemophilia Society

Winter 2019



The Society
at a Glance

74
I.H.S.
Volunteers

46
Planned Giving
Contributors

1366
Facebook
Followers

821
Twitter
Followers



haemophilia.ie

AGM & Conference 2020

Venue: Slieve Russell Hotel, Co Cavan

Dates: 6th - 8th of March 2020



Preliminary Programme

Friday March 6th

17.00 – 19.00	Registration
19.00 – 20.00	Buffet Dinner

Saturday March 7th

10.00 – 12.30	Annual General Meeting
12.30 – 13.30	Lunch
13.30 – 14.30	Update on Gene Therapy
14.30 – 15.45	Hemlibra
15.45 – 16.15	Coffee Break
16.15 – 17.00	An Open Forum with the Comprehensive Care Centres
17.00 – 19.15	Family Time
19.15 – 23.00	Gala Dinner

Sunday March 8th

10.00 – 10.45	Twinning
10.45 – 11.30	An Update on the iPATH Project
11.30 – 12.00	Coffee Break
12.00 – 13.00	Focus on Lifestyle
13.00 – 14.00	Lunch and Depart

More details will be posted to members in the new year

From the Editor



Welcome to the Winter issue of our quarterly magazine, I hope you, like all of us in the I.H.S. office, are getting excited Christmas!

Speaking of Christmas, over on the back cover, you'll find hospital opening hours for the Christmas period - why not stick it on your fridge for safe keeping?

Elsewhere meanwhile, on Page 4 Brian's CEO report provides an update on new treatments, our next strategic plan and EHC updates. On Page 7, Robert introduces himself as the new I.H.S. Outreach Co-ordinator and outlines his hopes and plans for the future. On Page 11 there is an update on the Lighthouse Project and you can check out the recipients of this year's educational grants along with a wonderful personal perspective from Orla Fahy over leaf.

On the inside cover, you can take a look at the preliminary programme for our AGM next year. AGM packs will be winging their way to members in the new year! Also, if you would like info on all our 2020 events, please see page 17.

It has been another busy year with the I.H.S., especially with the new and exciting treatments that have arrived, and more within touching distance.

I would like to thank everyone who contributed to our publications this year - be that writing articles, sending in ideas, photos or feedback - and of course, thank you all for reading the magazines, without you, there would be no magazine!

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

Barry Healy



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CEO REPORT

New Treatment Option for prophylaxis in severe Haemophilia A



For the past several years, we have been updating members on the rapidly changing therapeutic environment in Haemophilia. In 2017 and 2018, we became the first country globally to switch all people with severe haemophilia to extended half-life (EHL) FVIII and FIX concentrates. This change has resulted in an improved quality of life for people with haemophilia.

In a report I presented at the ISTH international haematology conference earlier this year, we were able to demonstrate some of the beneficial impact on quality of life. We had quality of life survey results for 17 people with severe haemophilia where we compared some elements of their life before the change to EHL FVIII or FIX with their quality of life 1 year after the change. We did this using the Patient Reported Outcome Burden and Experience (PROBE) survey which many of you may recall filling out at some of our conferences.

The results demonstrated that in a mixed group of FVIII and FIX people, the switch to EHL had resulted in a higher quality of life, a significant reduction in acute pain and in chronic pain in damaged joints, reduced impact on their ability to do their normal activities of daily living and reduced frequency of pain medication use. We also saw a reduction in reported bleeding episodes in this group. The comprehensive care centres will be reporting further detailed data on these outcomes in the near future but there is no doubt that they have had and continue to have a significant beneficial impact on quality of life.

In September of 2018, people with high titre or serious inhibitors to FVIII were offered a new non- factor treatment called Ecmicizumab (brand name: Hemlibra). In the blood, FVIII works by binding or joining together activated FIX and FX and thereby allowing the clotting cascade to continue and the blood to clot. Hemlibra is a bi-specific antibody which binds to both activated FIX and FX and mimics the effect of FVIII in the absence of FVIII. Therefore, the clotting cascade can continue.

Hemlibra was also licenced earlier this year for use in people with severe FVIII deficiency without inhibitors. We have now reached agreement in Ireland to have Hemlibra available as an option for prophylactic treatment for any individual with severe FVIII deficiency. This agreement was negotiated by the Haemophilia Product Selection and Monitoring Advisory board (HPSMAB) which includes the centre directors from St. James's, Crumlin and Cork, the Society, the Depart-

ment of Health and the contract holder (St. James's Hospital) in addition to a clinical nurse specialist. In the past, when we have carried out a competitive procurement or tender process, the decision has been to switch all eligible people with haemophilia to the newly selected product (for example, this was the case after the switch to EHL FVIII and FIX where all eligible people with haemophilia switched). This will not be the case with Hemlibra. All people with severe Haemophilia A will have the option of switching to Hemlibra for their prophylactic therapy. The decision for each individual will be taken after a detailed consultation with their clinician. To assist with this process, the Society have organised information meetings for our members on Hemlibra in Dublin, Cork and Galway in January. Details are set out below. Further meetings may be organised as required after the initial meetings.

This is a very exciting development for people with FVIII deficiency. Hemlibra is an antibody which is injected subcutaneously (just under the skin) and not intravenously. The half-life (time taken for 50% to be eliminated from the body) is approximately 28 days compared to approximately 19 hours for our current EHL FVIII. This means that Hemlibra can be injected once a week, once every 2 weeks or once every 4 weeks. It should be emphasized that Hemlibra is a prophylactic treatment only and factor concentrate would continue to be required for bleeding episodes. Because of the long half- life, Hemlibra offers a constant level of protection thought to be equivalent to a constant FVIII level of between 10% and 15%.

We would strongly urge people with FVIII deficiency and parents of children with FVIII deficiency to attend the information meetings and engage with their comprehensive care centres over the coming weeks and months to make a personal decision on whether they would like to change to this new option or remain with their current treatment.

Hemlibra Info Meetings

Cork (New Venue):

Date: Wednesday, January 8th 2020 @ 18.30
Venue: Imperial Hotel, Cork City

Dublin:

Date: Monday, January 13th 2020 @ 7pm
Venue: Irish Haemophilia Society Office

Galway:

Date: Wednesday, January 29th 2020 @ 7pm
Venue: Maldron Hotel, Sandy Road, Galway





European Inhibitor Summit

In December, for the 4th consecutive year, Ireland played host to the European Haemophilia Consortium's European Inhibitor Summit at the wonderful Barretstown Serious Fun facility in Kildare. Some 130 people with inhibitors or parents participated from 26 European countries. The programme contained a mixture of lectures, workshops, educational sessions and community building exercises. Adults and children attended. This is the only EHC event which includes children. This was greatly facilitated by the collaboration with the Irish Haemophilia Society as we have extensive experience of conferences including adults and children of all ages. The Society were very pleased to partner with EHC and offer our help and support to this great programme. Ireland, as with all European countries, has a small number of people with serious inhibitors. Because of the relatively low numbers, it has been difficult or impractical to offer or organise any specific conferences or events for this group. This difficulty is exacerbated as it is often more difficult for people with inhibitors to travel as they have a significantly higher number of bleeding episodes annually compared to those without inhibitors. By bringing together people with inhibitors from many European countries, this summit makes the formation of a real inhibitor community for Europe possible. It is very encouraging to see the positive impact of these summits. The community is building. Isolation is decreasing. More people with inhibitors are getting involved at board level in their national haemophilia societies and care is improving. It was encouraging to meet parents of children at the summit who first heard of new therapeutic options for their children at previous summits and now have access to these therapies. We look forward to hosting the summit again in 2020.



Strategic Plan

In January 2020, the Society will embark on a new 4-year strategic plan to cover the years from 2020 to 2023 inclusive. Prior to the formal process, we will be consulting with doctors, health care professionals, industry representatives, health officials and other contacts to get their views on the current and future treatment and care landscape for haemophilia in Ireland and on the issues which will be priorities in the coming years.

We would welcome any views or thoughts that you - the members of the Society - have on our current programmes, events, activities and priorities and where you think we should be focusing our attention and work over the coming 4-year period. Please contact me at brian@haemophilia.ie if you wish to share any thoughts or ideas on what our shared future will be.



New President of European Haemophilia Consortium

In October of this year, I completed eight years as President of the EHC and decided to step down. In those eight years the organisation has become a very dynamic and effective advocacy organisation for people with haemophilia and related bleeding disorders in Europe. The staff team increased from one part-time person to a professionally led team of eight people. The budget increased tenfold and the programmes, activities and events increased in a very significant manner. I am delighted to announce that the newly elected President is Declan Noone from Ireland. Declan had been working with me at EHC for the past three years. He is currently a Society representative on the HPSMAB in Ireland and is, of course, a former member of staff of the Irish Haemophilia Society. Declan is a health economist by training, and he is ideally placed to lead EHC in to the next phase of development when access to novel therapies will be a major issue. I have left the EHC in very good hands.



A Familiar Face, New Role

Robert Introduces Himself as the New I.H.S. Outreach Co-ordinator

Since joining the Irish Haemophilia Society in October 2017 as Children's Programmes Co-ordinator, I quickly learned how great and welcoming all our members are. It has been wonderful to get the chance to meet parents and all the children which enabled me to get an overall understanding as to how the society works for all ages.

While working closely with Brian and Debbie on the day to day efforts which go on behind the scenes, I have witnessed first-hand how the society benefits each of its members.

This year the opportunity arose for me to also take on the position of Outreach Co-ordinator. I am honoured to be given the opportunity to grow within the organisation. I have spent much of my time reading and learning all the different forms of support we can offer our members and have developed a strong understanding of the systems in place.

I am now excited to begin outreach visits and calls to all our members who require support and assistance, be these queries regarding entitlements, advice, general support or a visit be it at home, in hospital or at school.

Every need is unique, and I will ensure my support is tailored to benefit the member as much as possible. I also liaise with the teams in the Comprehensive Care Centres and have developed strong working relationships with the teams.

It is very important for all of us at I.H.S. to bring support directly to our members wherever they require it. I am currently compiling my visit calendar for 2020, so, if you would like or think you would benefit from a home visit, please don't hesitate to get in touch.

You can call me on **01 657 9900** or reach me via email at **robert@haemophilia.ie** and I will be more than happy to make arrangements with you.



Robert Flanagan

Hyde Square



Hyde Square
Apartments



The apartments at Hyde Square 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.

October Conf

A close to full house witnessed a lively debate on 'Gene Therapy for Haemophilia'. Matthew McCabe and Seamus McDonald did battle with a lot of dry humour and Seamus took the spoils disagreeing with the statement. It was a lively, informative



While opening the 2019 conference, Brian announced that from next year, in memory of our great friend Ger O'Reilly, who sadly passed away earlier in the year, there will be an award named in his honour. The 'Ger O'Reilly Courage Award' will be presented to a young member of the society who has displayed outstanding courage – a fitting way to remember Ger.



While the adults were occupied on Saturday and Sunday, the volunteers were kept busy overseeing the children's programmes. The crèche group enjoyed fun and games, as you do when you are three years and under. The Cubs (aged 4-7 years) enjoyed games, arts and crafts. The Cubs, Kidlink (aged 8-12 years) and Youth (aged 13-17 years) groups had the added bonus of taking a trip to a nearby farm – which went down a treat!



Conference 2019

philosophy, do the Benefits Outweigh the Risks?'. Board member's wit, in an attempt to win over the crowd. In the end, a lively and entertaining debate – and at times extremely funny too.



The most popular event all weekend was the magician who provided after dinner entertainment for kids, teenagers and adults alike – hands down, this was my favourite part of the weekend!





Last but certainly not least, we would like to extend a huge thank you to all our incredible volunteers for their time and dedication in looking after the Creche, Cubs, Kidlink and Youth Groups over the weekend – they really do an amazing job!



National Haemophilia Lighthouse Project



The patient will see you now: Haemophilia extends the boundaries of electronic health care in Ireland

On October 14th 2019, the National Haemophilia Service in Ireland initiated a new and innovative advanced e health system for haemophilia and inherited bleeding disorders.

The new system was developed by Valentia Technologies in collaboration with the National Coagulation centre in St. James's hospital, Children's Health Ireland at Crumlin, Cork University Hospital, Galway University hospital and the Irish Haemophilia Society. The development of the system was financed by the HSE as one of three innovative Lighthouse projects which aim to optimise the use of e health technologies in the Irish healthcare system.

"Integrated electronic health records (EHRs) are critical to the delivery of safe, effective healthcare in the modern era" stated Dr. Niamh O'Connell, National Haemophilia Director.

Healthcare professionals, working in a network of Haemophilia Comprehensive care and treatment centres are able to access critical patient information in real-time to deliver truly holistic care. All people in Ireland with Haemophilia are registered on a single, national system which combines comprehensive, individualised patient health care records with a National Haemophilia register.

"We are in an era of exciting new treatment options for Haemophilia. This will be complemented by this new state of the art information system which will optimise patient experience, clinical outcomes, safety measures and resource utilisation." stated Dr. O'Connell.

Haemophilia in Ireland has long been at the forefront of the development of electronic patient record systems with a national system in place since 2006 and a smartphone app for monitoring and reporting of home treatment since 2010.

"Ireland is consistently recognised as a leading international haemophilia service and this project demonstrates our commitment to remain as an innovator" stated Feargal Mc Groarty, National Haemophilia Lighthouse Project Manager.

Phase 2 of this innovative project, due to be rolled out in 2020, will include a patient portal which will allow people with haemophilia to have access to their medical records on their smartphone or electronic device.

Phase 2 will also include the first national pilot of the Individual Health Identifier (IHI) in clinical practice. The IHI will be used to accurately identify anyone who uses a health service, allowing those who are delivering services to be assured that they have the relevant information for that person, leading to safer and better quality care.

"The patient portal will offer people with haemophilia the opportunity to see and contribute to their own medical records and to interact electronically with their health care team. This is the future." stated Brian O Mahony, Chief Executive of the Irish Haemophilia Society.

Feargal Mc Groarty,

National Haemophilia System Project Manager



Educational Grants 2019

Thanks to everyone who applied for an educational grant from the I.H.S.

This year we received a grand total of 26 applications - both online and through the mail - which is brilliant! The I.H.S. educational grants are hugely beneficial and go some way to helping cover the expense of one's education.

Who better though to explain the benefits of the grants from their first-hand experience than recipients themselves!

The sub-group of the board met in October to discuss and score all the applications so we are delighted to announce the recipients of the main grants are as follows:

Maureen & Jack Downey Educational Grants

First Prize	Shannon Carey	€4,000
Second Prize	Nicole Chun	€2,000
Third Prize	Molly O'Mahony	€1,000

Father Paddy McGrath Educational Grant

First Prize	Tara Cassidy	€1,000
Second Prize	Elva O'Neill	€500
Third Prize	Saoirse McNamee	€250

Margaret King Educational Grants

First Prize	Dara Dowling	€2,000
Second Prize	David Moriarty	€1,000
Third Prize	Megan Cassidy	€500
Fourth Prize	Hannah Byrne	€500



A Helping Hand: A Personal Perspective

My name is Orla Fahy and I'm a grateful recipient of the Margaret King Educational Grant for the academic year 2019/20. I'm a postgraduate student in UCD Smurfit where I'm currently studying on the MSc Finance programme until September 2020.

I have always had an interest in Financial Markets and Corporate Finance and having the opportunity to further my education in the area of Finance is both an honour and a privilege. I'm currently coming to the end of Semester 1, with many assignments due and Christmas exams looming.

While I've been kept busy so far with challenging modules and plenty of exams, I feel like I have learned a lot in the past 11 or so weeks. So far I have been able to expand my knowledge of topics such as Derivative Securities, Capital Markets and Financial Analysis.

The programme is really enjoyable but the travel costs and expenses involved have been astronomical. While I live in Dublin, the commute on public transport from my home to UCD Blackrock is long and costly – it takes me up to two hours each way in rush hour traffic and costs up to 120 euro a month! This is before one considers additional expenses such as purchasing textbooks, printing costs and attending any course events such as corporate presentations.

During my undergraduate course in TU Dublin, it was possible to have a part-time job and attend college simultaneously. To say the postgraduate course that I am now undertaking is intensive, is a gross understatement! With the high volume of reports and assessments due each week combined with my extended commute, working during term time would not be possible. Receiving the Irish Haemophilia Society grant has meant that I can focus solely on my studies and has enabled me to dedicate the time I need to revision and assignment completion.

The I.H.S. has worked diligently to ensure those with bleeding disorders, genetic carriers and their families are supported throughout every stage of their lives. I have witnessed firsthand the high standard and wide range of services the I.H.S. provides to members from information sessions during conferences to advocacy for increased care for haemophilia patients in hospitals and more!

I am incredibly grateful to have been one of the chosen recipients of a grant this year and wish to thank the subgroup of the board, the board and all of the society members for this educational grant, which is continuing to play a pivotal role in the advancement of my studies.

Receiving the notification that I had been allocated an educational grant was a mixture of joy and relief at a time when I was swamped with assignments and still trying to comprehend the steep level of costs I was set to incur on a weekly basis while studying at postgraduate level. I would strongly recommend applying for this grant if you are currently studying or are due to commence a course in a third level institution. For me, the Margaret King Educational Grant will help me to complete my studies before I embark on a career in the Financial Services industry.

Learning the history of the Irish Haemophilia Society and experiencing the services provided, I feel fortunate to be part of a society with so many strong leaders that have advocated for members so profoundly, including the late Margaret King who lends her name to this grant.

And finally, thank you Irish Haemophilia Society for all of the support.

Orla Fahy



Fundraising in 2019

As we come to the end of 2019, on behalf of the staff and board of the I.H.S., I would like wholeheartedly to thank everyone for their amazing fundraising efforts this year.

We really appreciate this tremendous support throughout the year, from those who organised or took part in fundraisers, those who made donations and those who contributed and continue to contribute to our Planned Giving Appeal. We rely on the support of our members and their families and friends to raise funds for the I.H.S. and more importantly raise awareness of haemophilia and other related bleeding disorders.

The funds raised in 2019 through fundraising events, our Planned Giving Appeal and individual donations allow us to continue to provide the support and services needed both at home and globally to improve the level of care for patients with a bleeding disorder. One of the services these funds help us provide is the apartment facility for members attending hospital appointments in Dublin. The apartment facility is used on a regular basis by patients and their families to have somewhere to stay, a home from home when it is needed. It has proved invaluable for members who need to travel to St James's Hospital and Crumlin Children's Hospital for outpatient or inpatient care. When you have to travel a long distance from home for a hospital stay, you can feel very isolated in hospital without family and friends around to visit you anytime. The apartment facility allows family to be able to stay close by and therefore give much needed support to their loved ones during their stay in hospital.

If you are in a position to help raise funds either through a fundraising event or personal contribution, please do so, your support goes a long way to help others. What might seem like a small amount to you, all adds up and makes a big

difference. If you are looking for a fundraising idea maybe this year's fundraisers might help you decide what to do. This year's events included participants in the VHI Women's Mini Marathon, the Dublin City Marathon, Movember, several 'Wear Red for Haemophilia' days and the proceeds from the sale of a book donated to the I.H.S.

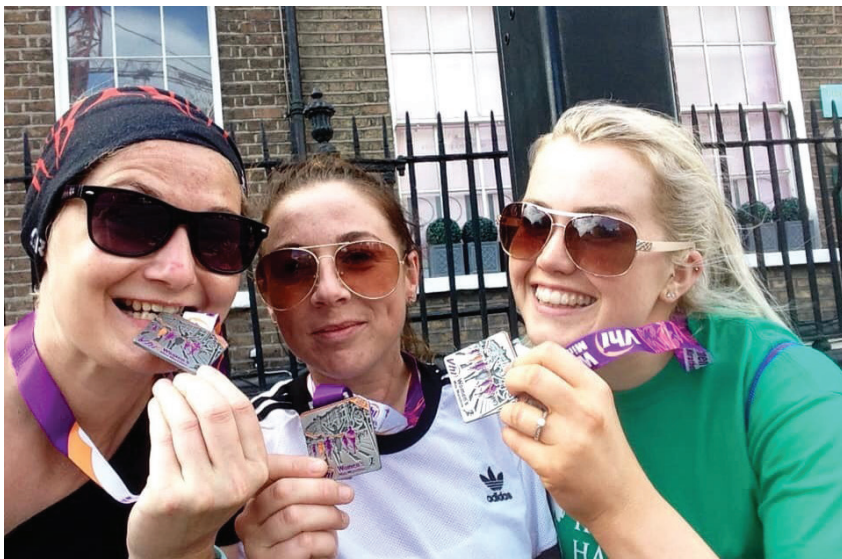
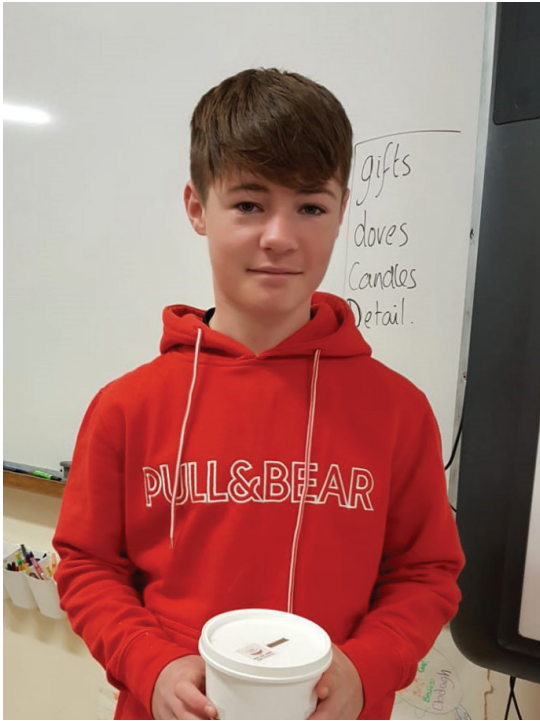
'Wear Red for Haemophilia' has become a very popular fundraising event, in schools, the workplace or groups for example Slimming World, you just wear something red, such as a football jersey, t-shirt, or even a scarf or tie and then give a donation. The I.H.S. are happy to provide posters for fundraisers such as this to let people know the day and details of the fundraiser. Or we can provide sponsorship cards and details on setting up a fundraising page for organised events such as the VHI Women's Mini Marathon.

This year we were contacted by author Aubrey Malone who kindly donated several copies of his book 'A Nursing Life, from Midleton to the Mater' a fictitious story of a nurse during the 1960's. The book costs €10 (excluding P & P) and all proceeds come to the I.H.S., so if you are looking for a Christmas or birthday gift for the reader in your life, contact the office and we can arrange for a copy to be sent to you.

For help with a fundraising event or to contribute to our Planned Giving Appeal, don't hesitate to contact me on 01-6579900 or email nina@haemophilia.ie and I will be happy to answer any questions you may have.

Again, our thanks to everyone for their tremendous support in 2019 and wishing you all a very Merry Christmas and a peaceful New Year.

Nina Storey





A Special Thanks to our Volunteers

On behalf of the staff, board & members of the Irish Haemophilia Society, I would like to thank each and every volunteer who has given up their time to work with the Society over the course of 2019.

As you have heard countless times, we could not cater to the needs of our membership without the hard work, generosity, dedication and enthusiasm of our very valuable and vibrant volunteers. We do realise it can be a huge commitment to volunteer while balancing college, work, family and a social life, (sometimes all four) while at the same time doing your bit for the society. Our volunteers not only work with our kids groups but also help with administration tasks. With the number of attendees at conferences increasing year on year this extra help is often quite necessary and very much appreciated.

It was an absolute pleasure to work alongside you all this year. Your energy, enthusiasm and good humour never fail to put a smile on my, and most importantly, the children's faces!

Best wishes and Happy New Year to all of you!

Robert Flanagan



Dates for your Diary in 2020

March

AGM & Conference 2020

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

April

World Haemophilia Day Event

Date: Friday, April 17th
Venue: TBC

Von Willebrand's Information Day

Date: Saturday, April 18th
Venue: Castleknock Hotel, Dublin

May

Women & Bleeding Disorders

Date: Saturday, May 9th
Venue: Hodson Bay Hotel, Athlone

June

Mother & Daughter(s) Overnight

Dates: Saturday June 20th & Sunday, June 21st
Venue: Lilliput Adventure Centre

July

Father & Son(s) Overnight

Dates: Saturday July 4th & Sunday, July 5th
Venue: Lilliput Adventure Centre

Mild Haemophilia Information Day

Date: Saturday, July 18th
Venue: Killashee Hotel, Naas

August

Family Day Out

Date: Monday, August 10th
Venue: Dublin Zoo

October

October Conference

Dates: Friday, October 16th to Sunday 18th
Venue: Mount Wolseley, Co Carlow

November

Haemophilia B Information Day

Date: Saturday, November 14th
Venue: Hotel Kilkenny, Kilkenny



Noticeboard



Home Visits for 2020

We would like to remind and reassure members of the support that the Society offers to persons with haemophilia, von Willebrand's disease, related bleeding disorders and to their families on any issue relating to their haemophilia, or their ability to deal with their medical condition.

Our Outreach Co-ordinator Robert is the main point of contact for all our members who need support and assistance, be this queries regarding entitlements, advice, some support or a home, hospital or a school visit.

The Society is aware that not everyone can attend our events for a variety of reasons. However, this does not mean you do not need support. The I.H.S. can arrange a home visit at your convenience - remember, the staff are here for you!

It's very important for us at I.H.S. to bring support directly to our members.

For more information or to book a home visit in 2020, please contact Robert on 01 657 9900 or robert@haemophilia.ie.



Volunteering with the I.H.S.

Volunteer with I.H.S.

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

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

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

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

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



Bon Voyage!

Are you planning on jetting off for the Christmas break or New Years?

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 of our website, haemophilia.ie.

Or if you need a travel card sent out to you, give us a call in the office on 01 657 9900 or email info@haemophilia.ie.

Noticeboard



Independent Patient Advocacy Service Launched

The Patient Advocacy Service is a new independent, free and confidential service to assist people to make a complaint about the care they have experienced in public acute hospitals.

Funded directly by the Department of Health and developed by The National Advocacy Service for People with Disabilities, this new service is for all patients of public hospitals.

The Patient Advocacy Service can provide you with the information and support you need to make a complaint to the HSE over an experience you have had.

It receives no HSE funding and is entirely independent of the HSE.

You can find out more via patientadvocacyservice.ie and the national phone line is 0818 293003.



Barretstown Camp Calendar 2019

Barretstown camps run from Spring to Autumn each year and offer a range of exciting camps for all ages - and the 'Barretstown Camp Calendar 2019' has been announced.

The calendar and details can be found at barretstown.org

If you are interested or would like more info, please get in touch with Robert in the office on 01 657 9900 or via robert@haemophilia.ie.

Camp Dates

- Spring 1 - (24th - 26th Jan) Family Camp
- Spring 6 - (28th Feb - 1st Mar) Family Camp
- Spring 7 - (6th - 8th Mar) Family Camp
- Spring 8 - (13th - 15th Mar) Family Camp
- Spring 9 - (20th - 22nd Mar) Family Camp
- Spring 10 - (27th - 29th Mar) Family Camp
- Spring 11 - (7th - 10th Apr) Brothers & Sisters (7-17)
- Spring 13 - (8th May - 10th May) Family Camp
- Spring 14 - (22nd May - 24th May) Family Camp
- Summer 1 - (12th June - 19th June) Teens Camp (13-17)
- Summer 2 - (24th June - 30th June) Children Camp (7-13)
- Summer 3 - (6th July - 12th July) Siblings Camp (7-17)
- Summer 4 - (17th July - 24th July) Teens Camp (13-17)

Buy a book, help the society!

'A Nursing Life' is the story of a Middleton-born nurse who rises to the top of her profession in the 1960s before marriage sees her having to leave her job and become a fulltime mother.

Tragedy and comedy collide as tales of marital breakdown and a bullying matron mix with nights on the town and days on ever-changing wards as the health service.

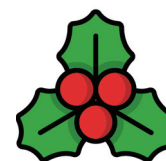
The books have been kindly donated to the society by the author, Aubrey Malone. They cost €10 (excl. P&P) – with all monies going to the society.

For more details, contact Nina in the office on 01 657 9900 or email nina@haemophilia.ie.





Provisional Hospital Opening Hours for the Christmas Period



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

Monday 23 December 2019 - as normal (08.30 - 5pm)
 Tuesday 24 December 2019 - No Clinics
 Wednesday 25 December 2019 - closed
 Thursday 26 December 2019 - closed
 Friday 27 December 2019 - closed
 Saturday 28 December 2019 - closed
 Sunday 29 December 2019 - closed
 Monday 30 December 2019 - closed
 Tuesday 31 December 2019 - closed
 Wednesday 01 January 2020 - closed
 Thursday 02 January 2020 - as normal (08.30 - 5pm)
 Friday 03 January 2020 - as normal (08.30 - 5pm)

The walk in assessment unit in H&H will operate as per out of hours and weekends with 24 hour cover.

Out of Hours Service Phone: (01) 410 3132 (after 5pm Monday to Friday, and at weekends or bank holidays).

Patients who need emergency assessment or advice should phone the H&H Ward prior to attending, or alternatively contact St. James's hospital via the main switchboard on 01 410 3000 and ask for the haematology SHO on call.

Cork Coagulation Centre - Cork University Hospital

Monday 23 December 2019 - as normal (08.30 - 5pm)
 Tuesday 24 December 2019 - closed
 Wednesday 25 December 2019 - closed
 Thursday 26 December 2019 - closed
 Friday 27 December 2019 - closed
 Saturday 28 December 2019 - closed
 Sunday 29 December 2019 - closed
 Monday 30 December 2019 - Open (8.30 - 2.30pm)
 Tuesday 31 December 2019 - closed
 Wednesday 01 January 2020 - closed
 Thursday 02 January 2020 - as normal (08.30 - 5pm)
 Friday 03 January 2020 - as normal (08.30 - 5pm)

The Haematology Registrar is on call throughout the holiday period and can be contacted through the CUH switchboard at 021 454 6400.

Children's Health Ireland at Crumlin

Monday 23 December 2019 - as normal (08.00 - 5pm)
 Tuesday 24 December 2019 - emergencies only
 Wednesday 25 December 2019 - emergencies only
 Thursday 26 December 2019 - emergencies only
 Friday 27 December 2019 - limited elective activity
 Saturday 28 December 2019 - emergencies only
 Sunday 29 December 2019 - emergencies only
 Monday 30 December 2019 - as normal
 Tuesday 31 December 2019 - limited elective activity
 Wednesday 01 January 2020 - emergency only
 Thursday 02 January 2020 - as normal (08.00 - 5pm)
 Friday 03 January 2020 - as normal (08.00 - 5pm)

FYI: The Haematology Oncology Service always remains open but the Haematology Oncology Day Unit & Service only operates Monday - Friday & closes for public holidays.

In the case of an emergency, please contact the hospital on 01 409 6100 and ask for the haematology registrar on call.



Merry Christmas

The office of the Irish Haemophilia Society will close for Christmas at 3pm on Monday, December 23rd 2019 & will re-open on Thursday, January 2nd 2020 at 9am.

In the case of an emergency, please call 01 657 9900 where contact details for our emergency contact person will be found.

Wishing you all a very Merry Christmas & a peaceful New Year from the board & staff of the I.H.S.

