

Haemophilia.ie



Representing people in Ireland with haemophilia and related bleeding disorders

Magazine of the Irish Haemophilia Society

Winter 2018



The Society
at a Glance

74
I.H.S.
Volunteers

46
Planned Giving
Contributors

1187
Facebook
Followers

660
Twitter
Followers



haemophilia.ie

AGM & Conference 2019

Venue: Hotel Kilkenny

Dates: Friday 1st to Sunday 3rd March 2019

Preliminary Adults Programme

Friday March 1st

17.30 – 19.00	Registration
19.00 – 20.00	Buffet Dinner
20.00 – 21.00	Presentation: An Update on Twinning

Saturday March 2nd

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

Sunday March 3rd

10.00 – 11.30	The Future of the Society in a Changing Environment
11.30 – 12.00	Coffee Break
12.00 – 13.00	Orthopaedic Surgery
13.00 – 14.00	Lunch and Depart

AGM Packs will be going out to members in early January



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 looking forward to the Christmas festivities ahead.

It has been a memorable and nostalgic year for the I.H.S. as we marked our 50th Anniversary, and that is the topic of Brian's CEO's report on page 4, as he looks back on a year of celebration and commemoration.

As well as that, there's lots of interesting reading for you. On page 8, you will find a report from our October Conference in Sligo; we hope you all had a great weekend. On page 11, we have news of this year's recipients of the I.H.S. Educational Grants and Nina recaps on this year's super fundraising on page 14, and on page 12, Shannon Carey explains her love for Barretstown & why it's so special!

On the inside cover, you will find the preliminary programme for our AGM next year. AGM packs will be winging their way to members early in the new year! Also, if you would like further information on our 2019 events, please see page 17. On the back cover, you'll find hospital opening hours over Christmas. Why not stick it on your fridge for safe keeping!

It has been another extremely busy year in the office and one of change. I really would like to thank the staff, both past and present, the board, all the fantastic volunteers who helped us out throughout the year, those who contributed to our magazines and publications, everyone who did fundraising and who sent in donations or contributed to the planned giving campaign during 2018 and all who helped make our 50th Anniversary a year to remember!

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

Debbie Greene

In this Issue

04

CEO Report

Brian casts his gaze back over this year's 50th Anniversary of the I.H.S.

07

Our Little Blue Hero

Tralee Garda Station has a new recruit; young I.H.S. member Adam Roche.

08

Member's Conference 2018

A report from this year's Member's Conference in Sligo.

11

Educational Grants 2018

This year's recipients of the I.H.S. educational grants announced.

12

Barretstown Camp Fun

Shannon Carey explains her love for Barretstown & why it's so special!

14

Fundraising 2018: Thanks!

Nina gives a run through all the super fundraising efforts in 2018.



17

Dates for your Diary

A list of dates for our forthcoming events in 2019.

18

Noticeboard

Some updates from the I.H.S.

20

Hospital Opening Hours

Provisional hospital opening times for the Christmas period.

CEO REPORT

1968 was a profoundly difficult year in many countries. In the USA, a country embroiled in an intractable war in Vietnam witnessed the assassination of Martin Luther King and Robert Kennedy - two of the leaders who probably had the greatest potential and moral character to end the war in Vietnam and rededicate the country to President Lyndon Johnson's original vision for a Great Society.



Johnson's decision not to stand for re-election, the assassination of Robert Kennedy and the turmoil at the Democratic convention in Chicago, paved the way for the election of Richard Nixon. From that flowed, not peace with honour in Vietnam, but the spreading of the war to Cambodia and ultimately to the events of Watergate and the resignation of a disgraced President. In France, student riots seemed to usher in a new era of discontent and activism. In Northern Ireland, the first civil rights marches took place. We did not foresee the bloody and appalling carnage in Northern Ireland which would last more than 30 years until the Good Friday Agreement.

In the midst of this maelstrom of events, a letter was published in *The Irish Times* in April 1968 calling on those with haemophilia who were interested in forming an organisation, to meet. Later that year, the first meeting took place and the Irish Haemophilia Society was founded. Those of you who have attended our Annual Conferences over the past three years will be familiar with the history of the organisation as a series of lectures were delivered outlining the different eras of work since then. At this point, as I write in our last newsletter of this, our 50th anniversary year, it is worth reflecting on the impact of the Society and on our marking of the anniversary this year.

In 1968, as a child of 10 with severe haemophilia, there was no treatment available for regular and painful joint bleeds. Pain was a constant companion and it was a constant struggle to avoid missing too many days at school. Haemophilia was seen as a cross you had to bear. I was aware of the turmoil in the USA and remember the assassinations of King and Kennedy. My fondest memory of that year was linked to soccer - with the Manchester United team of Best, Charlton, Crerand and others finally winning the European Cup (for our younger readers - this is what the Champions League used to be called).

As a community, we have endured many trials and tribulations since then, on our collective and individual 50-year journey. The hope for a

better future which started to become possible due to the first clotting factor concentrates. The devastation and death caused by the contamination of many of those products with HIV and Hepatitis C which caused untold misery and death in our community, almost wiping out a generation of people with haemophilia. The strong bonds of support and empathy which formed in those difficult times. The hard, initially unwelcome but ceaseless advocacy with the media and lobbying of politicians to address these appalling tragedies in a bid to secure treatment, financial assistance and acknowledgement. The lessons we learnt as we had to bang loudly on many closed doors and force Governments to acknowledge what had befallen our community.

The achievement of treatment, financial assistance and public acknowledgement and understanding. The determination to ensure that a tragedy like this would never and could never happen again to this small community. The proactive and collaborative work with the doctors, nurses, health care professionals, treatment centres and the Department of Health and later the HSE to advance haemophilia care with the Society being a full and active partner in shaping treatment and care. The institutions established such as the National Haemophilia Council and the Haemophilia Product Selection Board which have codified the formal role for the Society.

From despair and death, a new reality was shaped. A reality that moved Ireland to the forefront of the use of synthetic recombinant products starting in 1995, to prophylaxis for children from 1997 and later for all adults. A reality which saw Ireland become the first country to effectively eliminate Hepatitis C from our haemophilia population in 2016, the first country to switch all people with haemophilia B to the new generation of extended half-life products in 2017 and the first country to switch all people with haemophilia A to extended half-life factor concentrates in 2018. A country where we have, this year, commenced the availability of subcutaneous therapy for people with FVIII inhibitors.

A country at the forefront of research and clinical trials where we expect to see the first person in Ireland treated with Gene Therapy as part of clinical trial before year end. A country where the major research project iPATH (Irish Personalised Approach to the Treatment of Haemophilia) began this year and which we hope will assist in answering fundamental biological questions about haemophilia.

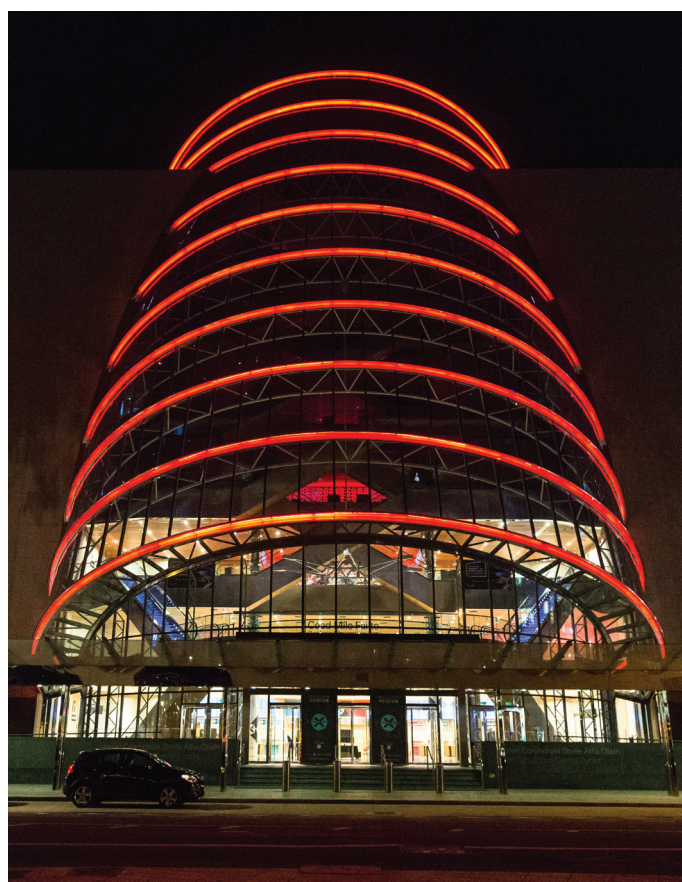
We have certainly marked this special anniversary year in many innovative ways. An increased suite of meetings and events including, not only the standard Annual General Meeting, Member's Conference and Ageing Conference but a Carrier Conference, Father and Son(s) event and specific meetings on von Willebrand's Disease, Mild Haemophilia and Haemophilia B.





Our AGM and Conference in April had a record attendance of 350 members and was a great celebration of and by our community. In retrospect, Storm Emma did us a favour as we had to move the conference to April from the original March dates - and were the beginning of an extraordinary week and month of April. At the conference, formally opened by Health Minister, Simon Harris, TD we awarded life memberships to our outgoing Chairperson, Traci Marshall Dowling and to two doctors from abroad who have been stalwart supporters of the society and our events for many years; Dr. Bruce Evatt from Atlanta and Dr. Paul Giangrande from the UK. We also unveiled a memories room which featured artefacts, old newsletters, photographs and memories for so many in our community.

World Haemophilia Day followed that Tuesday and began with Society representatives being interviewed on national breakfast television. Later that morning we unveiled a billboard on Macken Street in Dublin with a specially commissioned painting by renowned street artist Shane O'Malley. Following this, a permanent painting, also by Shane O'Malley was unveiled in the main lobby of St. James's Hospital to mark our 50th anniversary. This was an appropriate location as St. James's have journeyed with us on days of despair and of hope and progress since 1977. The day culminated with several iconic buildings – incl. Liberty Hall, The Mansion House, Dublin Convention Centre, RCSI, Stephen's Green Shopping Centre and more



- being lit up in red to mark World Haemophilia Day. The same week, I took over the @Ireland Twitter account and its 67,000 followers, to tweet about the Society's history, hopes and 50th Anniversary, among other things.

Later in April, we had a cinema premiere for our movie on the history of the society 'Facing the Rising Sun'. This movie, the product of countless hours of interviews, digitising, collating and reviewing archive footage and weaving together the story of the Society was directed by Academy Award nominated director Goran Kapetanovic from Sweden. The premiere at the restored Art Deco Stella Cinema in Dublin was a profoundly moving experience for all those present. The movie was previously premiered for all of our members at the AGM and is available free of charge to all of our members and also from our website.

In September the Society hosted a 'Gala Fundraising Dinner'. The evening included an auction which included some amazing sports memorabilia including a signed boxing glove from Muhammed Ali, a signed rugby 'Grand Slam' Ireland jersey, signed GAA county jerseys, signed ties or scarves from all our political party leaders (and a hat from a politician noted for wearing hats) and many other items.

In October, the Member's Conference included a retrospective look at the commemorative events of the year. The members were informed at the Conference that the previous week, the Society had won an Irish HealthCare Award for patient organisation project of the year for our suite of 50th anniversary programmes and commemorations. The year is not finished yet. In December, the Society will host a European Inhibitor summit on behalf of the European Haemophilia Consortium and we will round off the year with our Children's Christmas Party.

The October conference also included a debate between our new Chairperson John Stack and Shay Farrelly on whether we will need a Society in the year 2030. Shay drew the short straw having to argue against the need for the Society in the future as the audience overwhelmingly voted that the Society will continue to be not just relevant but vital. We are in an era of exciting improvements in treatment with extended half-life products being joined by subcutaneous therapies.

The promise of an effective cure, via gene therapy which has been a distant dream for 20 years, is now fast approaching. We expect to see the first gene therapies for haemophilia licenced by 2021 or 2022. The Society will remain relevant even in this changing world. There are always challenges. Currently, there are challenges relating to availability of beds and access to orthopaedic surgery even in the specialised Haemophilia H and H unit St. James's. The health service budget is in deficit again and constant challenges remain. New therapies may be available in the future but the active work of the Society will be vital in ensuring we get access to these therapies. New and improved therapies are required for von Willebrand's Disease and for rare bleeding disorders. The future is bright but only if we continue to work together as a strong, united and determined community, mindful of our shared history and working toward the best future we can achieve for all those people in Ireland with inherited bleeding disorders.

Brian O'Mahony



Our Little Blue Hero!

Criminals on the mean streets of Kerry beware, Tralee Garda Station has a new recruit; young I.H.S. member Adam Roche.

Six-year-old Adam was made an honorary Garda in early November as part of his 'Little Blue Heroes' award and he has already been out on the beat in his native Tralee.

Little Blue Heroes is a not-for-profit charitable foundation established by Garda staff which aims to support local Gardai in providing financial assistance and practical support to families in local communities who have children undergoing long-term medical treatment for critical illness – and we would like to extend our congratulations to Adam on his fantastic achievement!

As part of his award Adam received his very own Garda uniform and a Garda escort from his house straight to Tralee Garda Station - with all sirens blazing.

Adam will pick up his award at a party on December 9, as will Adam's twin sister, Grace who will be presented with a separate award by Garda staff on the night of the awards party.

Once again, we would like to congratulate Adam & Grace on their awards - what an amazing achievement!



Member's Conference 2018



The Member's Conference 2018 took place in October, in the rather relaxing surroundings of the Radisson Blu, Sligo.

A massive contingent of members were in attendance along with I.H.S. staff and our wonderful volunteers.

First off, 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!

Following registration on Friday evening, it was straight into the buffet dinner, which was followed by Ger O'Reilly's 50th Anniversary Review. It was great to look back at all the activities that have taken place throughout the year we marked 50 years of I.H.S.; Our documentary movie 'Facing the Rising Sun' on the history of the society and premiere in the Stella Cinema, Street Art Projects, expanded World Haemophilia Day activities, Twitter takeovers, a Gala Fundraising Dinner and the society winning the Patient Organisation Project of the Year award for our 50th Anniversary programme at the Irish HealthCare Awards in October.

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

session of the day was 'Understanding the Terminology of Novel Treatments' with Dr. Michelle Lavin from the National Coagulation Centre in St. James's Hospital. Dr. Lavin's presentation covered the evolution of treatments from the past to present day - standard and extended half-life products, and new novel therapies – and explained their various aspects and how they work in a very straightforward and understandable manner, while not losing the value of the information. The session concluded with member's enthusiastically fielding questions to Dr. Lavin. If you would like to view Dr. Lavin's presentation, it can be found on our website, haemophilia.ie.



Following this, Patrick Stagg from Citizens Information Service in Dublin, spoke about benefits and entitlements. He began by outlining the three-fold service they provide nationally; a national phone service for general information, citizensinformation.ie and its 7000 plus pages of in-depth information and their drop-in service, which provides face-to-face conciliation. The thrust of his presentation was that the Citizens Information Service is there to work for you and advocate on your behalf. For example, if you have had an application for carers allowance turned down the cause maybe something minor and as he noted, eighty per cent of appeals are successful. While they cannot guarantee a positive outcome, they will do their utmost on

your behalf and Mr. Stagg finished up by reminding those in attendance, that anyone wishing to contact him can do so by calling his office on 0761 07 7180. The session concluded with a lively question time from members and Mr. Stagg doing some one-on-one chats with people afterward.

After lunch, bellies suitably filled, next on the menu was a debate under the topic of 'There will not be a need for the I.H.S. from 2030' with Shay Farrelly arguing for and John Stack against, with Mary-Clare Delaney moderating affairs. It was a thrilling debate between the two who both had extremely well-conceived, articulated and passionate points of view but when put to audience for a vote, John took the victory. It was great to witness the passion and engagement, not only from the speakers but especially from the crowd; it was interesting, thoroughly entertaining and great way to get us all thinking about what the future may hold for the society.

Although it was a long day, our members know how to have fun and the Saturday evening dinner was relaxed and filled with chat and laughter. The dinner was followed by our now renowned all ages table quiz and you could feel the relaxing atmosphere ebbing away as teams prepared to do battle for the much sought-after title of I.H.S. quiz champions. It was tense and tight battle, but the Cyan team took victory – halting the volunteers three year winning streak. We think you'll agree that Rob was an excellent quizmaster; we just hope we can keep a hold of him when TV networks come calling!

While the adults were occupied at sessions 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 and a swimming lesson. The Kidlink (aged 8-12 years) and Youth (aged 13-17 years) groups had the added bonus of taking a trip to Eagle Flying Farm in nearby Ballymote.

The owner, Lothar and his colleagues, educated the children on the importance of wildlife conservation and the reintroduction of important birds back into the Irish ecosystem. The show was a real hit with all our young members and volunteers as they witnessed an array of free flying eagles, hawks and owls. After the display, some people got the chance to get up close to other animals like the fox, a racoon and numerous other farm animals. The trip was a highlight for all our young members and even the volunteers. As well as this, all the kids and young adults had educational sessions throughout the weekend, as well as the youth group taking part in the yoga session on Sunday morning.

After a night of fine food and great company, Sunday morning got underway with the opportunity to become fully informed about mindfulness; the aspects of it, how it can be beneficial in your life and how to practise mindfulness. Presented by Mel Taylor, a primary school teacher and yoga instructor, the session enlightened members that mindfulness is a natural quality that we all have. It's available to us in every moment if we take the time to appreciate it. When we practice mindfulness, we're practicing the art of creating space for ourselves - space to think, space to breathe, space between ourselves and our reactions. Mel explained several

techniques to mindfulness and how you can integrate them into everyday life. One way to do this is through different breathing techniques, Mel taught our member's to simply focus on the sensation of your breath as it goes out and as it goes in.

The second session was yoga. There were two different groups for this, family friendly yoga and chair yoga. This session was also presented by Mel Taylor. Mel was creative, attentive and fun teaching the yoga as she coached the groups through various movements. Towards the end of the yoga Mel guided our member's through meditation, comprising of a combination of music and verbal instruction. Overall the mindfulness and yoga were a massive success, enjoyed by everyone who participated. It certainly was the perfect ending to yet another excellent member's conference.

Following the popularity of the 50th Anniversary Exhibition Room at the AGM, it was once again a feature of the weekend. The room included old newsletters, publications, photographs, objects and mementos of our shared history, and this was proved exceedingly popular with members once again.

We hope that everyone who attended, enjoyed the conference and each of you gained something from the talks and sessions. We look forward to seeing you all again at our AGM in March.

I.H.S. Staff

Additional images thanks to Jay McEvoy



Sinead Farrelly & Nathan Doyle

The Kidlink Group Art Attack!



The New Quiz Champions Flaunt Their Covetted Prize



Denis Delaney Making a New Friend



Members All Set For The Conference





Educational Grants 2018

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

This year we received a total of 26 applications which is fantastic. We had a mixture of applications which were received online and in the post. The sub-group of the board met on 30th October to discuss and score all the applications.

Over the last number of years, the sub-group of the board noticed that there was a change in those applying for grants. Traditionally in the past, those with haemophilia or related bleeding disorders applied for the 'Maureen & Jack Downey Educational Grant' and those with carrier status applied for the 'Margaret King Educational Grant'.

The last number of years has shown an increase of those with carrier status applying for both these grants and those also applying for level 5 & 6 courses. Therefore a proposal for new criteria was drafted up by the then Chairperson Traci Marshall Dowling which was put to the membership at the AGM in March this year. The membership voted and we now have three main grants available.

I am pleased to announce the recipients of the main grants are as follows:

Maureen & Jack Downey Educational Grants

First Prize	Shannon Cassidy	€4,000
Second Prize	Niall Jackson	€2,000
Third Prize	Carly Wright	€1,000

Margaret King Educational Grants

First Prize	Aisling Moriarty	€2,000
Second Prize	Megan Cassidy	€1,000
Third Prize	David Moriarty	€500

Father Paddy McGrath Educational Grant

First Prize	Oran O'Neill	€500
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Congratulations to you all. I would like to encourage as many of you as possible to apply next year, it's really worthwhile and beneficial, and can really help cover the cost of perhaps travel expenses if you are studying away from home or those very expensive books!

Debbie Greene

Barretstown... A Serious Fun Camp!



If anyone knows me in the slightest, they will know how much I love Barretstown. There is even a saying in my house “That one time in Barretstown...”. Once you come to camp, you will understand why!

Barretstown is a residential camp for children and families affected by serious illnesses such as cancer, Crohn’s and haemophilia. The camps take place in Ballymore Eustace in Co. Kildare on a huge beautiful site which includes a castle, lake, horse stables, archery arena, climbing wall, fifteen cottages, and so much more!

Barretstown offers a variety of different camps such as family; where the whole family gets to go! During the summer there is sibling camp, where siblings of children who have haemophilia get to go to camp and there is one for children with haemophilia or related blood disorders.

Family camp takes place over a weekend while the summer camps last for a whole week. There is now a ‘Haemophilia Camp’ that runs during the Autumn which is fantastic, as children get to meet other children who are very like them.

This brings me back to my own story, I have Type 1 Von Willebrands and I found out about Barretstown through the I.H.S. when I was ten. At the time, I thought it was too good to be true! All these amazing things to do while staying away from home for a week while having fun? Sign me up!

I remember running to my Mam and asking her to look it up to see if I could go. For all that Barretstown offers, you would think there would be a huge bill at the end of a camp, so I remember her saying “we will see”. I understand now why she was reluctant to say yes because it does sound too good to be true, and kids that age would say anything to

have an experience like what was being offered but usually there would be a huge price tag assigned to it.

I can vividly remember standing behind my Mam in the kitchen when she phoned Barretstown to investigate what they were offering was true. I will never forget the look of shock on my Mam’s face when she was informed that yes, it was true, and it was all for free! Growing up we didn’t have a lot of money so this would be the best holiday I would have. The staff at Barretstown told my Mam that my sister Saoirse could go as well, so it ended up that Saoirse got to go first.

This is when we got to drive down the lane to Barretstown for the first time. It might sound so mediocre but the magic you feel driving down the lane for the first time, seeing the big beautiful castle and all the Cara’s waving at you is just indescribable. We dropped Saoirse off and all week I was so excited to go back to camp to see how she found it. Walking into the dining hall we saw her surrounded by girls having a blast. I remember questioning her all the way home for every little detail to see if it was real.

Finally, the day had arrived that I got to go to camp for the first time. I awoke feeling so nervous and scared to be away from home for the first time. I was only ten years old, so I never had any opportunities like this before. Once I got the camp my worries fell away. The Cara’s (Irish for friend and the volunteers at camp) welcomed me and included me into the group. What unfolded was the best week of my life. We played so many games, danced for our dinner, performed on stage where I was a baker, climbed, met so many friends and so much more. When I saw my parents on the last day I bawled and told them I didn’t want to go home. I had so much fun and in that camp, I realized what my dream would be and that would be to work in Barretstown.

Many camps later, aged 16, I did the CLP Programme at Barretstown. This is where undertake confidence and leadership training while role-modeling to the campers on site! This is where my dream to work in Barretstown started to come true.

I wrote a letter to Barretstown thanking them for all they had done for me in the years I had been attending. I gave it to the camp director Mitch and to my surprise, on the last day of camp brought me aside saying that he loved my letter, and asked if he could show it to the rest of the Cara's and workers on site? I said yes happy in the knowledge they would understand how much they had helped me!

A few months later, while I was at school, my Mam got a call from Barretstown and they informed her that so moved where they by my letter, that I was invited to give a speech on front of the board of directors. The speech went quite well, I spoke in-depth about my experience and I made a few people cry which I hadn't expected at all! Afterward we were treated to lunch in the brand-new dining hall before anyone else got to.

For me right now, I fulfilled my dream of becoming a Cara in Barretstown in late March and the months since have been the best. Seeing the magic and wonder in the eyes of the campers remind me of my own amazing experiences all those years ago. I have worked with both families and children who have shown me time and time again why this is the best place ever. I even got to travel to Scotland during the summer to do a camp like Barretstown and hopefully summer 2019 or the next, I will be flying to America to work in a camp similar to Barretstown in the US.

I would have never have heard about Barretstown if it wasn't for the I.H.S. and I have to thank them for showing me my passion in life. I urge you to go, as it is real, and you won't regret it! Maybe I just might see you there!

Shannon Carey



BARRETSTOWN
a seriousfun camp





Fundraising 2018: Thank You!

As we come to the end of 2018, we can look back on a very memorable and nostalgic year for the I.H.S. as we marked our 50th Anniversary. Since the Society was established in 1968, we have been fortunate to always have the proactive support of our members. This year, our members, their families and friends have stepped up and helped make this a truly fantastic year through their fundraising events.

On behalf of the staff and board of the I.H.S., I would like to thank everyone, we really appreciate the tremendous support of everyone who organised or took part in fundraisers throughout the year. We would also like to thank everyone who gave donations and to those who contribute to our Planned Giving Appeal.

To mark our 50th Anniversary, the I.H.S. organised a Gala Fundraising Dinner in September in the Castleknock Hotel, Dublin. We could not have held this fundraiser without the time and effort of our members who along with staff formed a committee to ensure the fundraiser was a great success. We would like to express our sincere thanks to all those involved for all their hard work and expertise.

We have had some brilliant fundraisers this year, our thanks to all our lovely ladies who took part in the VHI Women's Mini Marathon in June. We appreciate that some of you were up bright and early to travel to Dublin to take part in the race and still managed to finish with a smile on your face. Other events included the Great Limerick Run in May and big thank you to the staff and pupils of Moyle National School in Newtowncunningham, Co Donegal for organising a breakfast morning.

To mark World Haemophilia Day on April 17th, the pupils of St Brendan's National School in Blennerville, Tralee in Co Kerry had a non-uniform day, and all wore something red to raise funds for the I.H.S. and awareness of haemophilia.

The older classes undertook to do projects on haemophilia to gain a better understanding; then gave presentations to the younger classes to pass on what they had learned. Thank you to the staff and pupils for their support.

In October, Patrick Doyle took on an amazing fundraising challenge; he climbed Mount Kilimanjaro in Tanzania, Africa. Patrick climbed 5,896 metres to the summit, this was a tough trek, 6 days up and 2 days down in sub-zero temperatures. Although Patrick has haemophilia, this does not stop him enjoying his passion for the great outdoors. Until a few years ago, Patrick was never much of an outdoors person, so he truly is an inspiration for those who want to take on a challenge or just follow a dream.

Our last fundraiser of the year also took place in October, this time in the Lebanon; I was contacted by Sergeant Tommy Sheahan of the 112th Infantry Battalion. Tommy's young nephew has haemophilia and he wanted to organise a fundraising boxing event while serving in the Lebanon to raise funds for the I.H.S.; our thanks to the battalion welfare & entertainment committee for approving the fundraiser. By all accounts the evening was a huge success, the fighters were paraded into the boxing ring tent by a piper and the fighters consisted of 19 Irish, 1 Polish, 2 Finnish and 2 Fijians of all ranks. Also, on the night, there was an unarmed combat demonstration and the evening was rounded off with a band. A lot of organising went into this event and I would like to say a huge thank you to Tommy and everyone involved for all their hard work.

Thank you again for all your wonderful support in 2018, we really appreciate it. We would like to wish everyone a Merry Christmas and Peaceful New Year.

Nina Storey



World Haemophilia Day at St Brendan's National School Tralee



Gala Fundraising Dinner in the Castleknock Hotel



Sizing Each Other Up Pre-Fight



Fundraising Fight Night in Lebanon



Margret Jacob & Nicole Murphy



Nikki Clavin & Friends

A Special Thanks to our Volunteers



On behalf of the staff, board and members of the Irish Haemophilia Society, I would sincerely like to thank each and every volunteer, who dedicated their time and effort to the society this year. Our conferences and events simply would not be possible without the dedication and incredible generosity of our volunteers.

You allow us to make our conferences family friendly, super fun and very meaningful by creating a wonderful environment for the kids, that create lasting memories and friendships. Dedicating so much time to the society isn't easy with many of you trying to balance work, study, family and social life so we cannot thank you enough for the tremendous effort you put into the weekends.

With this year being our 50th anniversary we wanted as many children and young adults of the society to come and be part of celebrating with us at our AGM and Member's Conference, and again our volunteers played an absolutely imperative role. This allowed for 240 children to experience memorable weekends of fun, games, sport, laughter and learning. There is nothing like the friendships built in the I.H.S.! Along with volunteering with our kid's groups, some volunteers play a huge role in helping us with administrative tasks, lending a helping hand when needed.

So, it is with a beaming heart I say a massive thank you to all our volunteers who we would be lost without!

Best wishes and Happy New Year to all of you!

Robert Flanagan

Dates for your Diary in 2019

March

AGM & Conference

Dates: Friday, March 1st to Sunday, March 3rd
Venue: Hotel Kilkenny, Kilkenny

April

Von Willebrand's Information Day

Date: Saturday, April 13th
Venue: TBC

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, Westmeath

June

Ageing Conference

Dates: Friday June 28th & Sunday, June 30th
Venue: Killeslin Hotel, Portlaoise

July

Mild Haemophilia Information Day

Date: Saturday, July 20th
Venue: TBC

September

Newly Diagnosed Conference

Dates: Saturday 21st & Sunday 22nd September
Venue: TBC

October

October Conference

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

November

Haemophilia B Information Day

Date: Saturday, November 9th
Venue: TBC



Noticeboard



Volunteer with I.H.S.

We are indebted to our dedicated team of I.H.S. volunteers! Through their effort, generosity, dedication, creativity and optimism, our very valuable volunteers make things happen, that would be otherwise impossible.

We're always delighted to add to the ranks of our merry band of I.H.S. volunteers. We are looking for people of all ages, all backgrounds and all walks of life to volunteer with us at our events!

If you enjoy working with kids or have any skills to offer, and think you could contribute in any way, no matter how small, we would love to hear from you!

If you do not feel in a position to help out, perhaps you could pass on the information to a family member or friend who might be interested in volunteering with the I.H.S.

If you would like more information, please get in touch with Robert in the office on 01 657 9900 or by email at robert@haemophilia.ie



Home Visits for 2019

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 Lyndsey 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.

If you would like or think you would benefit from a home visit in 2019, please contact Lyndsey on 01 657 9900 or lyndsey@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 (« young adults » travel tips) of our website, haemophilia.ie.

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



Patient Organisation Project of the Year

The Irish Haemophilia Society won the Patient Organisation Project of the Year award for our 50th Anniversary programme at the Irish Healthcare Awards in October.

A lot of hard work has gone into marking the society's 50th birthday this year but the hard work has been matched by member's enthusiasm for the various event and projects in 2018.

We were thrilled to be nominated for the award and to win, we are over the moon!

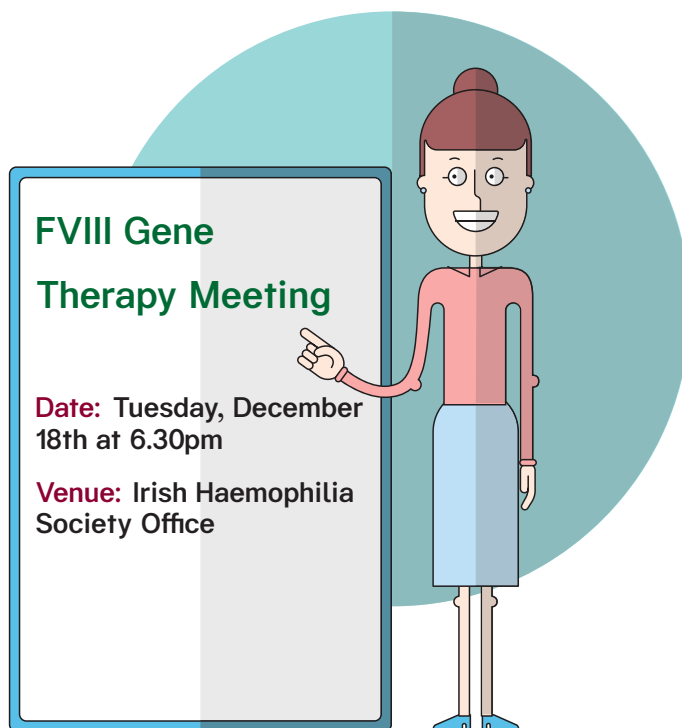


Barretstown Camp Calendar 2019

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 Lyndsey in the office on 01-6579900 or via email lyndsey@haemophilia.ie.



FVIII Gene Therapy Meeting

We are holding a meeting to discuss FVIII Gene Therapy clinical trials on Tuesday, December 18th at 6.30pm in the Irish Haemophilia Society office.

The meeting will provide information on FVIII Gene Therapy clinical trials and will be addressed by Dr. Katherine High from SPARK Therapeutics, USA and Dr. Niamh O Connell, National Haemophilia Director.

It is an excellent opportunity for adults with severe haemophilia who may be interested in participation in a FVIII Gene Therapy clinical trial to get more information, or for any person with FVIII deficiency who is interested in this vital topic.

Limited parking will be available at the Society office that evening on a first come first served basis.

If you would like to attend, please RSVP to Julia Collins at 01 6579900 or julia@haemophilia.ie

Date: Tuesday, December 18th at 6.30pm

Venue: Irish Haemophilia Society Office

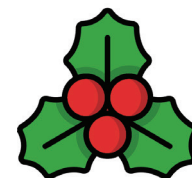
GDPR

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.



Provisional Hospital Opening Hours Over Christmas Period



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

Friday 21 December 2018 - as normal (08.30 - 5pm)
 Saturday 22 December 2018 - closed
 Sunday 23 December 2018 - closed
 Monday 24 December 2018 - closed
 Tuesday 25 December 2018 - closed
 Wednesday 26 December 2018 - closed
 Thursday 27 December 2018 - closed
 Friday 28 December 2018 - closed
 Saturday 29 December 2018 - closed
 Sunday 30 December 2018 - closed
 Monday 31 December 2018 - closed
 Tuesday 01 January 2019 - as normal (08.30 - 5pm)
 Wednesday 02 January 2019 - 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

Friday 21 December 2018 - as normal (08.30 - 1pm)
 Saturday 22 December 2018 - closed
 Sunday 23 December 2018 - closed
 Monday 24 December 2018 - closed
 Tuesday 25 December 2018 - closed
 Wednesday 26 December 2018 - closed
 Thursday 27 December 2018 - closed
 Friday 28 December 2018 - closed
 Saturday 29 December 2018 - closed
 Sunday 30 December 2018 - closed
 Monday 31 December 2018 - closed
 Tuesday 01 January 2019 - closed
 Wednesday 02 January 2019 - 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.

Our Lady's Children's Hospital, Crumlin

Friday 21 December 2018 – as normal (8am - 5pm)
 Saturday 22 December 2018 – closed
 Sunday 23 December 2018 – closed
 Monday 24 December 2018 – as normal (8am - 5pm)
 Tuesday 25 December 2018 – closed
 Wednesday 26 December 2018 - closed
 Thursday 27 December 2018 – as normal (8am - 5pm)
 Friday 28 December 2018 – as normal (8am - 5pm)
 Saturday 29 December 2018 – closed
 Sunday 30 December 2018 – closed
 Monday 31 December 2018 – as normal (8am - 5pm)
 Tuesday 01 January 2019 – closed
 Wednesday 02 January 2019 - as normal (8am - 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.



The office of the Irish Haemophilia Society will close for Christmas at 3pm on Friday December 21st 2018 & will re-open on Wednesday January 2nd 2019 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 and a peaceful New Year from the Irish Haemophilia Society board & staff.

