

Magazine of the Irish Haemophilia Society

# haemophilia.ie



*Representing people in Ireland with  
haemophilia and related bleeding disorders.*



The Society  
at a Glance

**1163**

Facebook  
Followers



**46**

Planned giving  
Contributors



**74**

IHS  
Volunteers



**6127**

Website  
Hits



SUMMER 2018



haemophilia.ie

# Irish Haemophilia Society Gala Fundraising Dinner

SATURDAY, 22 SEPTEMBER, 2018 | CASTLEKNOCK HOTEL, DUBLIN



**As part of our activity programme for our 50<sup>th</sup> anniversary year, the Society are hosting a 'Gala Fundraising Dinner' which will take place on Saturday 22<sup>nd</sup> September in the Castleknock Hotel in Dublin.**

The evening will commence with a drinks reception at 7pm, followed by dinner at 8pm. The evening will also include an auction and music from the fantastic 16-piece brass band 'Route 66'. The host for the evening will be the actor and TV presenter Mr. Simon Delaney.

This black-tie event is open to those aged 18 years and over and is priced at €100 per ticket or €900 per table of 10 (if reserved on or before 2nd July). The event is limited to 220 people attending and promises to be an exciting and unique event, as well as a fundraiser for the Society.

If you would like to attend this event, please reserve your ticket or table by contacting Debbie or Aoife in the office on 01 6579900. You can also reserve your ticket online via our website [haemophilia.ie](http://haemophilia.ie).

A special rate for overnight accommodation will also be available from the hotel.

Official tickets will be posted out two weeks prior to the event.



# A Note from the Editor

**Hello everyone,**

Welcome to the summer edition of our quarterly magazine. I hope you enjoy reading it.

Since the last issue, our 50<sup>th</sup> Anniversary AGM & Conference took place over the weekend of 13<sup>th</sup> to 15<sup>th</sup> April 2018 at the Royal Marine Hotel in Dun Laoghaire, Co. Dublin. It was a fitting way to mark the 50<sup>th</sup>; a weekend of celebration and commemoration as we honoured the past while looking toward a bright future.

We had a much-expanded World Haemophilia Day (WHD) program this year with street art projects, a canvas unveiling, TV appearances and a series of prominent buildings lighting up red to mark the day. You can take a look at some photographs from those events, along with our movie premiere in the fabulous Stella Cinema, Rathmines on page 17.

In our CEO's report on page 4, you will find further reflection on our AGM & Conference, I.H.S. documentary movie premiere and World Haemophilia Day, and new product updates, which, as always, is well worth a read.

On page 10, you can get to know more about Patrick Doyle and his Kilimanjaro climb for the I.H.S. in October.

On page 21, we welcome our new member of staff, Julia Collins to the team and we're delighted to have her on board!

You will find important dates for your diary on page 21 and on the topic of events, on page 12 you will find a report from our 2018 Carrier Conference, and on page 8, you will find a report from our 2018 Ageing Conference also.

On page 14 you will find some important information about our Educational Grants. We believe the grants are beneficial but if you are in any doubt, who better to explain their first-hand experience of the grants other than the 2017 recipients; Gary Butler and David Moriarty. You will find their stories on pages 15 and 16.

Finally, if there is anything we can assist you with, or would like to talk to somebody in confidence, please do not hesitate to contact the office anytime on 01 6579900.

**Debbie Greene,**  
**Administrator**



*Debbie Greene,  
Administrator & Office Manager*

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# CEO's Report

**Brian O'Mahony,**  
Chief Executive



## Annual Conference, World Haemophilia Day and Society 50<sup>th</sup> Anniversary

The postponement of our AGM and Annual Conference from March to April due to storm Emma proved to be a blessing in disguise. We were able to maintain the very high attendance at the Conference which totalled 350 while integrating the conference into an entire week of events to celebrate World Haemophilia Day. This day, which falls on April 17<sup>th</sup> each year, was celebrated with extra vigour by the Society this year as 2018 is our 50<sup>th</sup> anniversary.

The Conference commenced on Friday night with a very well attended screening of the movie – 'Facing the Rising Sun - a History of the Irish Haemophilia Society'. The movie was directed by acclaimed Swedish director Goran Kapetanovic. It required filming over a period of a year with members, key stakeholders and use of archive materials. At the end of the filming process, Goran had in excess of 200 hours of film footage including archive footage of some of our public advocacy work in the past and video footage from our 25<sup>th</sup>

anniversary AGM in 1993. The movie runs to 1 hour and 15 minutes. It was extremely well received by members on the night as a very realistic and moving depiction of our history. A cinema premiere of the movie was later held in the recently restored, Art Deco Stella Cinema in Rathmines, Dublin on April 26<sup>th</sup> and was attended by some 150 members and supporters of the Society.

The movie will be uploaded on our website and copies are now available free of charge to members. Screenings of the movie have also taken place or are planned for the HSE, St. James's Hospital and Our Lady's Children's Hospital, Crumlin. We are very proud of this movie and we encourage you to view this and share it with your friends and colleagues.

The AGM continued with an update on the exciting iPath (Irish personalised Approach to the Treatment of Haemophilia) research project. This was followed by the third in a series of





*Minister for Health, Simon Harris TD with Brian O'Mahony*

three lectures on the history of the society, which I had the pleasure of delivering. At the AGM in 2016, I covered the period from 1982 to 2002. Last year, I covered the years from 1968 to 1982 and finally this year, I covered the 50-year history of the society; with an emphasis on the years from 2002 to 2018. The presentation on the history from this year's conference is available on our website.

Following this, there was a session on 'Perceptions of the Society' with external speakers including Dr Bruce Evatt, formerly from the Centre for Disease Control in Atlanta, Dr Beatrice Nolan from Our Lady's Children's Hospital and Michele Tait from the HSE. For the children there was an innovative programme of events including a 'Mad Hatter's Tea Party'. We were also delighted to welcome the Minister of Health, Simon Harris TD who officially opened the Conference and congratulated the Society on our 50<sup>th</sup> Anniversary. The Minister also took time to meet with some of the children and teenagers with haemophilia.

The gala dinner on Saturday night was a real celebration. At the dinner, we awarded Honorary Life Membership to three individuals for their outstanding contribution to the Society. These individuals were Traci Marshall Dowling, who stepped down as Chairperson of the Society that morning at the AGM



*Minister for Health, Simon Harris TD meets with Young I.H.S. Members*

after 10 years and I would like to send Traci my thanks for all her work on the board and as Chair over the last number of years. Teresa Mulvey who made a major contribution as a member of the staff team in the difficult years of the 1990's and Dr Bruce Evatt from Atlanta, who was of immeasurable help to the society during the Lindsay Tribunal of Inquiry and was a constantly available resource for us on many issues relating to blood safety from the 1980's to 2006. I would also like to mention that we acknowledged staff member Nina Storey for her 20 years service to the Society, at the AGM that morning. We also organised a memory room at the conference which included old newsletters, photographs, objects and mementos of our shared history. This was very popular with members over the course of the weekend with many spending time in the room to remember and quietly reflect.

On day two of the Conference, there was a very moving commemoration service where we remembered all of the members who are no longer with us. This was followed by a panel discussion on 'Through the Generations' where a parent and four people with haemophilia discussed their different perspectives of living with haemophilia and their experiences with haemophilia now and in the past.





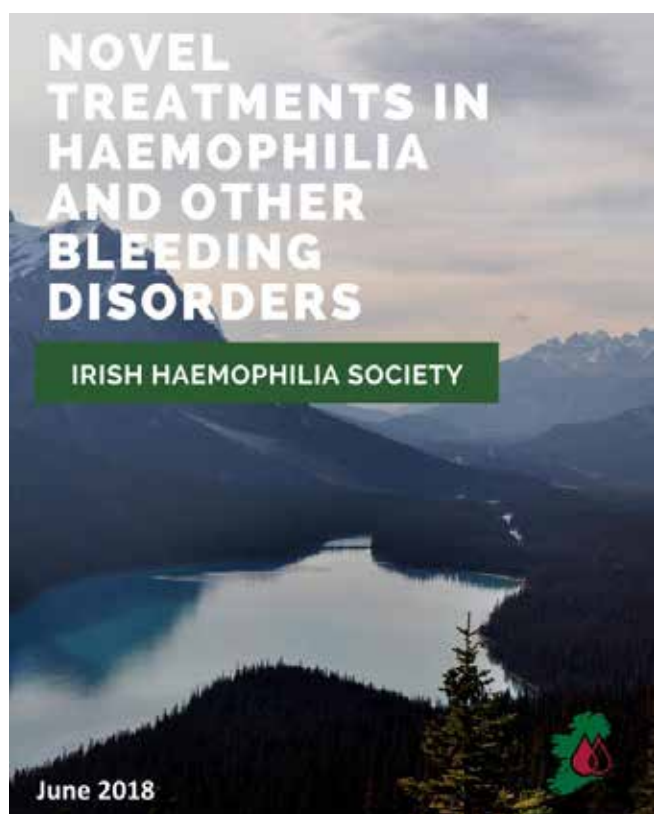
Two days after the Conference, we had an entire programme of events for World Haemophilia Day (WHD). Board member Seamus McDonald and I were interviewed live on the TV3 breakfast programme. A Billboard which had been painted by street artist Shane O'Malley was unveiled on Macken Street, Dublin in the presence of staff and a number of the Society. Later that morning, we held a press briefing in St. James's Hospital followed by the unveiling of a permanent large installation in the main lobby of St. James's Hospital. This beautiful piece of art, which was commissioned by the society and kindly sponsored, along with the billboard, by Roche, will hang in the main lobby above the main entrance as a permanent commemorative piece of art to celebrate the 50<sup>th</sup> anniversary. We are very pleased to have this installation in St. James hospital. The billboard was time limited for a month but the installation is permanent and particularly appropriate to have it installed in the hospital which has now hosted a haemophilia treatment centre for 41 of our 50-year history.

On the evening of April 17<sup>th</sup>, as the culmination of our WHD celebration, we arranged to have several iconic Dublin buildings lit up in red, including Liberty Hall, The Dublin Convention Centre, RCSI, The CHQ Building and Stephen's Green Shopping Centre.

## Society Board

At the board meeting following the AGM, John Stack was elected by the Board as the new Chairperson of the Society with Mary Clare Delaney as the new Vice Chairperson. John is a father of four boys including two boys with haemophilia. A profile of John appears on page 9.





## Novel Therapies

The therapeutic landscape in haemophilia is changing rapidly. In 2017, Ireland became the first country in the world to switch all people with haemophilia B to treatment with an extended half life (EHL) factor concentrate and this was followed this year, by a switch of all people with haemophilia A to treatment with an EHL FVIII concentrate - again a world first. Additional EHL concentrates continue to come on the market. Research is also continuing to improve the current EHL products, especially the FVIII where the extension in half life is currently limited by the fact that FVIII is linked to von Willebrand factor in circulation. One company are looking at developing an EHL FVIII using a fusion protein with VWF which, in early clinical trial results, is demonstrating a half life extension up to 33 hours. This would allow prophylaxis once per week. Other approaches under development include the possibility of subcutaneous injections for both EHL FVIII or FIX on a daily or even weekly basis.

The first subcutaneous therapy for the treatment of inhibitors - Hemlibra - was licenced by the European Medicines Agency earlier this year. This treatment, which mimics FVIII, resulted

in an 87% reduction in bleeding episodes in people with inhibitors who were previously treated on demand or a 79% reduction compared to previous prophylaxis with bypassing agents. This therapy appears to be a very exciting development for people with inhibitors. This is especially welcome as this group of people have more bleeding episodes and a marked reduction in quality of life compared to those without inhibitors. It is timely to see better treatments emerge for this greatly under-served population. Hemlibra is also expected to be licenced later this year or early next year for treatment of Haemophilia A without inhibitors.

Additional therapies under development include products which inhibit naturally occurring anti-coagulants in the blood and therefore promote blood clotting. These include Fitusiran and anti TFPI products. These products, currently in clinical trials, will be treatment possibilities for people with haemophilia A or B, with or without inhibitors. They may also be treatment possibilities for some people with von Willebrands or rare bleeding disorders. And then we have gene therapy. Clinical trials for both FVIII and FIX gene therapy are well advanced with some trials scheduled to commence in Ireland this year.

With all of these new developments, it is 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 and other Bleeding Disorders'. This document is designed to be informative for both people with bleeding disorders and health care workers. It includes a section explaining clinical trials.

It is then divided into separate sections on Haemophilia A without inhibitors, Haemophilia B without inhibitors, haemophilia with inhibitors and von Willebrand disease. The publication is designed so that individuals, if they wish, can refer to and read only the section appropriate to them. We plan to produce periodic updates to this publication as time and clinical developments dictate.

Novel Treatments in Haemophilia and other Bleeding Disorders is available to download from the publications section of [haemophilia.ie](http://haemophilia.ie).

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

**Brian O'Mahony,**  
**Chief Executive**

# Ageing Conference 2018



The fourth Ageing Conference held by the Irish Haemophilia Society took place in the Killeshin Hotel in Portlaoise over the weekend of 22<sup>nd</sup> to 24<sup>th</sup> June.

The first speaker at the conference was Dr. Niamh O'Connell, who looked at the impact of new treatments on the ageing population with haemophilia. It was interesting to look at the pros and cons of these new therapies. The pros include better bleed protection and fewer infusions and the cons included inhibitor risk, poor veins, decreased dexterity and cognitive impairment. Dr. O'Connell pointed out that people with haemophilia with access to good treatment are living with the same life expectancy as the general population. However, there are haemophilia related issues that begin to become apparent with ageing such as arthropathy, the impact and increased incidences of infections and osteoporosis. Arthropathy can increase pain and reduce mobility. As a result, there is a greater need for focussed physiotherapy and exercise. Many people ageing with haemophilia have damaged joints due to limited access to treatment as they were growing up. Dr. O'Connell spoke about bone health and encouraged members to have a DEXA scan. Dr. O'Connell also explained about the importance of continued monitoring of your teeth and getting to know your dentist. Dr. O'Connell also highlighted the importance of sourcing a good G.P, especially as people age and become increasingly susceptible to the various conditions and issues that we all know about as we get older.

Mr. Gerrard King, Senior Physiotherapist from Cork University Hospital was next up. He started with a presentation which looked at the structure of the body, the effects of ageing on the body and joint care. Mr. King spoke about how as we grow older that our bones lose density and become porous and fragile, about joints becoming thinner and more susceptible to damage and about the loss of muscle mass. Mr. King also outlined the role of physiotherapy in people with haemophilia in assisting with bleed prevention, the management of arthropathy and rehabilitation. Following his presentation, it was time to get down to the exercises. While Mr. King demonstrated basic exercises, members found an area in the room to practice the exercises. Whilst there were plenty of giggles at the start, by the end of the demonstration, everyone was getting into it and it was clear that simple exercises that are slowly built up is the way to go!

Following lunch, Hepatitis C Liaison Officers Ms. Antoinette Kelly and Mr. Larry Bathe spoke to members about the HAA Card. There were lots of queries and questions about the card and in relation to the nurse doing assessments for members. As this was the last session of the day and the weather being so nice, members took an hour to pop into Portlaoise where there was a fantastic festival taking place.

On Sunday morning the first talk of the day was from dietician Ms. Ellen Roche. Ellen spoke about how to interpret food labels, mindful eating techniques and how important a balanced diet is. I think members enjoyed this session, particularly tasting the dark chocolate!

Following this Mr. Enda Bohan from Home Instead spoke about the services that his company offers with their main ethos being enabling older people to live healthily and independently at home.

The conference concluded with Mr. Brian O'Mahony and I asking members about the services and supports they would like, with some very interesting suggestions of topics for talks for next year's conference.

In a flash, the conference was over. This, like the last one, was full of relevant discussion between speakers and members throughout the entire weekend. It was great to see so many members interact with speakers and already we are thinking about a preliminary programme for 2019.

**Debbie Greene**



# Board Update



## Meet the New I.H.S. Chairperson

Hi. My name is John Stack, and my wife, Ellie, and I have four boys, of which two have Severe Factor VIII deficiency. While our family has only a short

history with haemophilia, that history has not been short on drama. We were described as a 'new diagnosis' when we experienced our first bleed, which happened to coincide with the birth of our second child, who is now a quirky seven-year-old.

While many of you will know me from the work I do with the Society, giving talks on exercise, health and healthy eating, and I am a highly qualified and experienced strength and conditioning professional, my 'real' job is as an Environmental Engineer and Scientist working in Local Authority. Truth be told; however, I love coaching people in exercise and nutrition because I feel like I'm helping somebody or improving their quality of life.

After I gave my first talk for the society, a talk on healthy eating, Brian asked me if I'd come onto the board 'for a few months, a year at most.' "OK," said I nearly six years ago. It's a privilege to be Chairperson, and I plan to emulate the fantastic passion and commitment shown by Traci, our outgoing Chairperson.

I'm looking forward to many more years of involvement with the Society, some as Chair, but all them as a member of a vibrant community. It's an exciting time right now to be involved, especially with new treatments.

I'm a big believer in communication so please don't hesitate to talk to me if you need to.

**John Stack**



## A Message from our Outgoing Chairperson

I have been a member of the society almost 26 years. I have sat on the board for ten years and have been Chairperson for nine years. Often board members work full-time, have families or are in full-time education. In some instances, board members are juggling

all these commitments at once. This has been the case for me for the past number of years. The end of 2016 brought additional health challenges within my own family. Thankfully all is back on track and normal family life has resumed, however, this coupled with a leaving certificate in the house, college finals and trying to finish my own master's meant the need for a rethink. With the I.H.S. 50th birthday celebrations approaching, I felt the time was right for me to step down from the board and my role as Chairperson at this year's AGM. While not an easy decision, it was made easier by the fact the society has a competent and professional staff, a dedicated board and is guided, challenged and supported by a strong, vibrant membership.

Over the years there have been many who have been a great support. Often this was through words of encouragement, offering advice, guidance or highlighting areas for development and improvement. I will resist naming individuals for fear of accidentally leaving anyone out and causing offence.

The society has a fantastic bunch of volunteers. The children's/youth programmes at our conferences couldn't happen without them. I want to thank all our volunteers for their continued excellent contribution and in particular those who assisted with the 50th anniversary celebrations.

I want to sincerely thank you all. I have learned so much, I have grown as an individual and I am honoured to have represented the society. I look forward to continuing as a committed member, to raising a glass for our 50th anniversary and to the new technologies and treatments on the horizon as we continue the journey towards the next 50 years!

**Traci Marshall-Dowling**



# Kilimanjaro Climber: Patrick Doyle

**W**e are very grateful to everyone who organises or takes part in fundraisers for the I.H.S. every year, your tremendous support for the work of the society is really appreciated.

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

Patrick Doyle is going to climb Mount Kilimanjaro in Tanzania, Africa in October 2018, and in doing so, he will be raising money for the I.H.S. and awareness of haemophilia.

The summit of Kilimanjaro is 5,896 metres high, which is roughly two thirds the height of the world's highest mountain; Everest. Patrick will undertake a tough 8-day trek, 6 days up and 2 days down with temperatures that can hit -20C. Patrick is paying the cost of the trip himself so all money donated will go directly to the society.

We decided to catch up with Patrick to find out more about what has inspired the Mount Kilimanjaro climb, his love of mountaineering, passion for rock climbing, his preparation and more.

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

Hi! I'm Patrick, I'm 32 and I live in Bray, Co. Wicklow. During the week I work as a carpenter but on the weekends, I indulge in my passion for the great outdoors. I love to go rock climbing, mountain biking and very long hikes! I'm also a PWH, but that doesn't stop me!

## **When did you decide you wanted to climb Mount Kilimanjaro and what spurred this decision?**

Around two years ago I decided that I wanted to go on a once in a lifetime trip. I love travelling and I wanted to combine my passion for the outdoors and set myself a huge challenge. I watched a documentary about Kilimanjaro and started to read up on the trip. I knew this was the challenge I was looking for.

## **This is an impressive undertaking, what sparked your interest in mountaineering? And is it something you've long had a passion for?**

I was never much of an outdoors person but about five years ago I started Bouldering, which is a form of rock climbing performed on artificial rock walls without the use of ropes or harnesses. As my skills grew I slowly progressed to outdoor climbing. I took a number



*Patrick Doyle at the Summit of Lugnaquilla*

of courses and went travelling to some world renowned climbing locations including Fontainebleau in France, a huge forest region known for exceptional bouldering and more recently I've returned from a climbing trip in Squamish, Canada.

Over the last two years I've really got into mountaineering in preparation for Kilimanjaro. My goal before I set off in October is to climb to all the highest peaks in Ireland. So far, I've climbed Mount Leinster, Lugnaquilla and Carrauntoohil to name a few! I still have a good way to go but it's great preparation and it's an amazing opportunity to visit some of the most impressively beautiful landscapes around Ireland.

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

I wanted to use my trip as an opportunity to raise money for the I.H.S. as I myself am a PWH and I am aware of the amazing work that they do within the haemophilia community, and they are always there if anyone needs any information or support.

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

Since deciding to climb Kilimanjaro I have been training on and off for the last two years. I began tackling the Irish peaks last year by climbing Lugnaquilla in Co. Wicklow, Slieve Donard Co. Down and Carrauntoohil in Co. Kerry. I also travelled to Scotland and climbed Ben Nevis. It was a great experience.

I have also been taking part in mountaineering training courses and I returned to Carrauntoohil again in January during the heavy snow as part of a Winter Skills Course with Kerry Climbing. It wasn't quite as cold as Kilimanjaro will be, but hopefully it'll be good preparation! It's tough to get out every week to train but I do my best and try to make the most of it.

**What has been the biggest challenge so far? And what are you enjoying the most?**

The biggest challenges so far have been getting used to walking long distances while also going up and down mountains, and also doing this while carrying a heavy backpack. Due to the altitude on Kilimanjaro, the higher you go the heavier everything will feel so I intend to train up to carrying 15kg. The views you get from the top of each mountain is the most enjoyable part even though in Ireland sometimes you don't get a view with the weather we have.

**What are your preparation plans for the coming months?**

I recently decided I would try to climb the highest mountain in each county in Ireland before I go to Kilimanjaro. I thought this would be a good way to train, I currently have six done so there are lots more to go. I will continue regularly rock climbing indoors at The Wall (Sandyford), Gravity (Inchicore), or Awesome Walls (Finglas). I also hope to get outdoors this summer while the weather is nice.

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

If anyone would like to donate I set up an 'Every Day Hero' page:

**<https://give.everydayhero.com/ie/trekking-mount-kilimanjaro>**

Please share the link with anyone who may want to donate. No matter how big or small, all donations go to the I.H.S. where they will be greatly appreciated.

We would like to thank Patrick for choosing the I.H.S. and to wish him the very best luck!

**Barry Healy**



# Carrier Conference 2018



This year we welcomed our ladies to the Castleknock Hotel, Dublin on May 12<sup>th</sup> & 13<sup>th</sup>. This carrier conference catered for those aged 16 years and over and provided information on carrier testing, low factor levels and the emotional impact of a carrier diagnosis. The weekend had a very relaxed atmosphere, people were very open to sharing their experiences and asking questions both during, and following the sessions.

The conference began with a session on 'Carrier Testing – The why, when and where?'. Janet Cleary, Clinical Nurse Specialist from the National Coagulation Centre (NCC) in St James's Hospital presented this session and this lead onto 'Family Planning & Pregnancy' which was presented by Dr Niamh O'Connell, Consultant Haematologist also from the NCC. Both speakers gave very informative talks, generating excellent Q & A sessions.

We hope these first sessions got people thinking about carrier testing and also how important it is to know your factor levels. If you haven't thought about carrier testing in the past, please think about it now. If your father has haemophilia you are an obligate carrier; however you still need to have your own factor levels checked. If you have an uncle, brother, cousin or nephew with haemophilia, you may be a possible carrier and should have your carrier status tested. We cannot stress how important it is to know your carrier status, not just for those planning a pregnancy but for a woman's health.

30% of carriers have lower than normal factor levels, meaning treatment may be necessary for dental work, surgical procedures and after a trauma. If you want to know your carrier status, you must be aged 16 years or over. Make an appointment in the NCC, where everything around carrier testing and your own factor levels will be explained to you.

A blood test will be taken and you will have the results in approximately 12 weeks. If you are pregnant, the carrier testing and factor level results can be prioritised.

The second part of the conference examined coping with carrier status diagnosis. Dr Patricia Byrne, Psychologist from the NCC spoke about 'Positive Living', how to balance our lives following a diagnosis and the impact it has on our daily lives, and planning for the future. This was followed by a 'Peer Support Group' facilitated by Lyndsey Connolly, I.H.S. Outreach Co-ordinator. Understanding the medical dimension of your diagnosis is essential but it is equally important to know how to deal with it on an emotional level. There is support there for you and we would encourage you to contact the hospital or the I.H.S. if you have any questions.

The weekend wasn't just about providing information, we also wanted to give people the opportunity to relax, have some fun and get to know each other. I think the 'Zumba' class on Saturday certainly loosened everyone up, as did our Eurovision Song Contest sweep stake later that evening.

We ask for feedback at all our events, good or bad, we want to know what we are doing right and where we can improve. Some of the comments we received from attendees were:

- 'smaller group worked very well'
- 'lots of good interaction'
- 'very enjoyable, relaxed and informative'
- 'very interesting to hear people's views and experiences'
- 'lovely speakers'
- 'sessions enjoyable, good Q & A'

The two main suggestions we received was for more information on von Willebrand's Disease and the menopause. I'm delighted to say that we had already organised a von Willebrand's Disease information day. The second suggestion for a talk on the menopause is something we will take on board and will look to include in our next conference.

If you were unable to attend the conference and have any questions please contact the office on 01-657 9900 and we will be happy to chat to you.

**Nina Storey**

# VHI Women's Mini Marathon 2018



Margaret Jacob & Nicole Murphy



Nikki Clavin & Friends



Margaret Jacob & Kealan

Over 30,000 women took to the streets of Dublin this year to take part in the VHI Women's Mini Marathon on Sunday 3<sup>rd</sup> June. Now in its 36<sup>th</sup> year, the mini marathon has gone from strength to strength over the years and has come a long way from the first race in 1983 which had 9,000 entrants. The race is now the largest all-female event of its kind in the world. Participants from all over the country gathered to walk, jog and run this 10km race. Many women take part to fundraise for charities close to their hearts and it is brilliant to see the huge number of charities and groups who benefit from this year after year.

We would like to thank all the fantastic ladies who took part this year to fundraise for the I.H.S. We really appreciate your support to raise funds and just as importantly to raise awareness of haemophilia. Haemophilia is a rare condition and we welcome every opportunity to educate people about it. We hope that you all had a fantastic day.

Thank you again and we hope to hear from you all again next year!

**Nina Storey**

# New Criteria for Educational Grants



Applications are now invited for the 2018 Educational Grants. You can apply online or you can post the completed forms into the office.

There are three categories of grants available as follows; Maureen & Jack

Downey Educational Grant, Margaret King Educational Grant and Father Paddy McGrath Educational Grant.

## What is the criteria for applying?

### Maureen & Jack Downey Educational Grant:

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

### Margaret King Educational Grant:

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

### Father Paddy McGrath Educational Grant:

This grant is made available to a person with haemophilia or related bleeding disorder, including a person with carrier status (carriers with factor levels greater than 40% can apply for this grant) or immediate family members be it a spouse, son, daughter, sister, brother, mother or father who has been accepted onto a post second level educational course at level 5. The person with the bleeding disorder must be registered at the National Centre for Hereditary Coagulation Disorders at St. James's Hospital in Dublin.

## How much are the Educational Grants for?

### Maureen & Jack Downey Educational Grant

First prize	€4,000
Second prize	€2,000
Third prize	€1000

### Margaret King Educational Grant

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

### Father Paddy McGrath Educational Grant

First prize	€1,000
Second prize	€500
Third prize	€250

## What is the closing date for applications?

Closing date is Friday 28<sup>th</sup> September 2018.

## How are applications scored and who scores them?

Once the closing date arrives, a subgroup of three people from the executive board (which cannot include anyone with a family member applying for any of the grants) meet to evaluate the applications, and make recommendations to the rest of the executive board regarding recipients. Successful applicants are then notified at the end of October by letter.

## Applications are scored on the following:

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

## Can I apply every year?

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

Take some time to complete your application, as the more complete and detailed your application is, the higher your chance is of success.



So, now that you've got the lowdown on the changes to the educational grants, obviously, we would like to encourage as many of you as possible to apply. We believe the grants are extremely worthwhile and hugely beneficial, and can go some way to helping cover the cost and expense of your education.

If you are in any doubt, who better to explain their firsthand experience and the real-life benefits of the educational grants than the 2017 recipients of the Maureen & Jack Downey and Margaret King Educational Grants; Gary Butler and David Moriarty.

### **Gary Butler: Maureen & Jack Downey Educational Grant**



*Gary Butler at his Physics Formal earlier this year*

**M**y name is Gary Butler, and I'm a grateful recipient of the Maureen & Jack Downey Educational Grant. I am currently beginning my journey through university, having recently finished my first year of studying Physics & Astrophysics at University College Cork. Receiving this grant has been paramount in supporting my studies while living in a city of ever-growing expenses.

Studying physics at university has been an ambition of mine since a young age. This year alone I have furthered my knowledge of Newtonian mechanics, electromagnetism and the mathematics that supports this. I have glimpsed at understanding the universe at large through astrophysics, and at understanding nano-scaled systems through quantum mechanics. The course is by no means easy, but it is rewarding in its difficulty. I'm proud to have performed in my first year here, and I hope to continue this into my further years.

Upon hearing the news that I was lucky enough to be chosen, I was humbled yet also ecstatic. While the majority of the grant would be going towards living expenses, such as my student accommodation, a certain amount was put aside to purchase essentials required for my studies.

The first item I bought for university was a laptop; whether it be for receiving notes online from lectures, submitting online assignments or researching material for my physics projects, a personal laptop is now an essential piece in a student's arsenal. Until then I had been making journeys to and from UCC's public computers to make do. I am indebted that this opportunity has made a large portion of my workload more efficient, more productive and more available.

The second item of importance was getting a printer. While UCC is moving towards supporting online methods, the physics department has been a bit slower to adopt this, therefore having a physical copy of every assignment is essential for some topics. I was averaging 10 to 20 sheets a week, and sadly ink is by no means cheap.

Most importantly of all however is that the contribution toward accommodation costs will mean that I can remain in Victoria Mills for my second year. At a nearby location to UCC, Victoria Mills allows for ease of access to the campus in case of a bleed or extreme weather conditions (as we saw this year).

They often say in college that a group effort is needed to succeed. With the opportunities and support networks that I am lucky enough to avail of, I know this to be true. I'd like to thank the I.H.S. once again for this grant that has been an important aid for my education endeavors.

**Gary Butler**

## David Moriarty: Margaret King Educational Grant



*David Moriarty Receiving the Margaret King Educational Grant at our 50<sup>th</sup> Anniversary AGM*

**F**irstly, I would like to thank the board for awarding me this grant. It has been of great help to my family with my second semester tuition.

My name is David Moriarty and I am the recipient of the Margaret King grant 2018. I am currently a first-year student in Athlone I.T. and I am studying bachelor's degree in bio veterinary science.

I grew up with a brother who has haemophilia and I have always been curious as to what it was. I used to watch him take factor and the sight of a needle frightened me as it would with many young children. It wasn't long until I myself had to take medication for an illness as I was diagnosed with diabetes

mellitus, along with my other brother when I was five years old. I had to live with a long-term illness, but with it brought a new outlook on life and a new interest into the human body.

Throughout my school years the Irish haemophilia Society has been there, almost like a second family. Over the years, I made many new friends and I gained lots of information about haemophilia, and this has been useful in biology, which is my favourite subject in school and college. In the future I hope to continue learning about haemophilia and learn how the treatment for animals such as dogs can be improved. I also hope to be part of the Irish Haemophilia Society for as long as I live, and to continue to improve the lives of those who have haemophilia.

I received the grant at the AGM in April, which was our biggest turnout in the 50 years of the society, and one of the other highlights of the weekend was the movie celebrating the 50<sup>th</sup> anniversary. Although it showed some of the greatest moments for the society it also had the downsides, one of those being the HIV outbreak. I felt the emotive aspect of the movie which showcased the true meaning of our society. It was a much deeper insight of the struggles that the society had to overcome and the everyday challenges that those with haemophilia suffered in the days prior to the societies foundation.

The society is like the home we all want, compassionate, friendly, loving and comforting. It is a great honour for me and my family to be awarded this grant as it has helped with the burden of college tuition which was a relief for my parents. Lastly, I hope all future recipients of the grants can use this to help in college, so that they can go further into improving the society in years to come.

**David Moriarty**

# 50<sup>th</sup> Anniversary Celebrations

## AGM, WHD 2018 & Movie Premiere

As you're no doubt aware, 2018 is a huge year for the I.H.S. as it marks the 50<sup>th</sup> Anniversary of the society and as such, to mark the occasion, we have had an extremely busy year thus far; especially so in April.

We had a very busy but productive World Haemophilia Day (WHD), unveiling a street art project on Macken Street, Dublin 2 and in St. James's Hospital, I.H.S. pair, Brian O'Mahony and Seamus McDonald appeared on Ireland AM and a non-uniform day at St Brendan's National School in Blennerville, Tralee. WHD day concluded with a series of prominent buildings in Ireland, joining others across the globe, in lighting up red at night to mark WHD.

Following rescheduling due to the snow, our AGM & Conference in Royal Marine Hotel, Dún Laoghaire, also took place in April. It was a fitting way to mark the 50<sup>th</sup>; a weekend of celebration and commemoration as we honoured the past while looking toward a bright future. We felt it was a special weekend and hope you did too!

Last but not least, we premiered the movie on the first 50 years of the I.H.S. in the wonderful surroundings of the Stella Cinema, Rathmines. It was very moving and we think you'll agree that Goran has done an amazing job, distilling 50 years of the society into just over an hour of film, and it is an absolute triumph.

We are looking forward to seeing everyone throughout the year as we continue to celebrate the I.H.S.'s 50<sup>th</sup> Anniversary.



Movie Editing



Movie Makers



Mad Hatter's Tea Party at AGM 2018



Mad Hatter's Prep



Hard at Work Prepping for the Mad Hatter's Tea Party





AGM 2018 in Full Swing



Minister for Health, Simon Harris, TD visits our AGM



The Votes Are In!



Perceptions of the I.H.S.



Traci Marshall Dowling receives Honorary Life Membership



Teresa Mulvey receives Honorary Life Membership



Dr Bruce Evatt receives Honorary Life Membership





Stunning 50<sup>th</sup> Birthday Cake, made by Jennie McBride



Unveiling of street art project at St. James's Hospital



Unveiling of street art project on Macken Street, Dublin with artist Shane O'Malley



Street art project on Macken Street, Dublin



Nina's 20 Years with the I.H.S. Marked



Bun Times!





*The Convention Centre, Dublin in Red for WHD*



*Brian Introduces our Movie*



*National Concert Hall, Dublin in Red for WHD*



*Pre-premiere Powwow in the Stella Cinema*



*Memory Room*



*Dr Mai Makes a Presentation to Brian*



# 2018

## Dates for your Diary

### New Member of Staff

We would sincerely like to welcome our new member of staff, Julia Collins to the team and we're delighted to have Julia on board!



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

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

### August

#### Mild Haemophilia Information Day

Date: Saturday 18<sup>th</sup> August

Venue: Osprey Hotel, Naas.



### September

#### Mother & Daughter Overnight

Dates: Saturday 8<sup>th</sup> & Sunday 9<sup>th</sup> September

Venue: Lilliput Adventure Centre.

#### Haemophilia B Information Day

Dates: September 11<sup>th</sup> in Cork  
& September 12<sup>th</sup> in Dublin

Venues: TBC / I.H.S. Office



#### 50<sup>th</sup> Anniversary Gala Dinner

Date: Saturday 22<sup>nd</sup> September

Venue: Castleknock Hotel.

### October

#### October Conference

Dates: Friday 19<sup>th</sup> to Sunday 21<sup>st</sup> October

Venue: Radisson Hotel, Sligo.



### December

#### 50<sup>th</sup> Anniversary Children's Christmas Party

Date: Saturday 1<sup>st</sup> December

Venue: Grand Hotel, Malahide, Dublin

# Noticeboard



## **‘Facing the Rising Sun – 50 Years of the Irish Haemophilia Society’**

This year is the 50<sup>th</sup> Anniversary of the Irish Haemophilia Society (I.H.S.) and to mark the occasion we commissioned a 1 hr 15-minute documentary film, directed by Swedish - Bosnian writer / director, Goran Kapetanovic.

It documents the 50-year history of the I.H.S. and features fully restored archive footage, interviews with members, staff, former staff and volunteers, healthcare professionals and the people connected to this 50-year story. For those of you saw it at AGM & Conference or the screening in The Stella, we think you'll agree that Goran has done an amazing job, distilling 50 years of the society into just over an hour of film, and it is an absolute triumph.

For those of you who have yet to see it, or fancy watching it again, the movie will be available to watch on [haemophilia.ie](http://haemophilia.ie) before the end of July and physical formats are available free of charge, on request, please contact Rob in the office on 01 657 9900 or [info@haemophilia.ie](mailto:info@haemophilia.ie).



## **Bon Voyage!**

Are you planning on jetting off on holiday this summer?

Be sure to be prepared with all the necessary documents (insurance cover policy numbers & contact details) and of course, please ensure you have your I.H.S. Travel Card clearly visible in your wallet.

If you would like a reminder of everything you will need, please visit [haemophilia.ie](http://haemophilia.ie) and you will find the necessary I.H.S. travel tips under the ‘Living with Haemophilia’ section.

Or if you need a travel card sent out to you, give us a call on 01 657 9900 or email us at [info@haemophilia.ie](mailto:info@haemophilia.ie)

## **Marie Hughes Retires from NCC**

Marie Hughes has retired as Office Manager at the National Coagulation Centre (NCC) on 19<sup>th</sup> April 2018. Marie joined the Haemophilia Service in August 1998 when it was located in Hospital 1 Ground Floor, having worked in the private sector and in other healthcare sectors prior to this.

Marie has been an integral part of the development of services for people with bleeding disorders over the last 20 years, when the service moved first to the new National Centre for Hereditary Coagulation Disorders building and more recently, to the NCC. Many people attending the NCC will have met Marie, who has led the team of administrative staff and took a keen interest in ensuring that people were able to access timely appointments, especially in the co-infection clinic.

Marie will be missed by all the team in the NCC but will undoubtedly have a busy retirement, with time for family and travel. Congratulations to Marie on her long service in the NCC and best wishes for the future.

# Noticeboard



## Jason Rossiter wins Wexford Garda Youth Award

Huge congratulations to young I.H.S. member Jason Rossiter on winning Co. Wexford Garda Youth Award.

Nominated by his teacher Ms. Aoife Griffin because of his passionate love for sports, 5th Class student Jason is extremely active and an avid sportsman. His favourite sport is hurling, he is the captain of his soccer team (and has also travelled to Stoke City FC to play in their football academy twice) and plays handball too.

On the night of the awards, Jason spoke to the crowd about his haemophilia and explained his determination to not let it hold him back. As Jason's teacher, Ms. Aoife Griffin put it so eloquently; "Yes, Jason has haemophilia but haemophilia doesn't have him. Life is for living and Jason certainly lives by that motto."

Once again, we would like to take this opportunity to congratulate Jason on winning the award - what a fantastic achievement!



## Outreach

Please contact our Outreach Co-ordinator Lyndsey in the office on 01 6579900 if you need support in any of the following areas.

- A hospital or home visit
- Support in relation to HAA card entitlements
- Support in relation to social welfare entitlements
- Educational talks to schools
- Information in relation to travel

## GDPR

The introduction of General Data Protection Regulation (GDPR) came into effect on 25<sup>th</sup> 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.





**IRISH HAEMOPHILIA SOCIETY**

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