

Magazine of the Irish Haemophilia Society

haemophilia.ie



Representing people in Ireland with haemophilia and related bleeding disorders.



The Society
at a Glance

1128
Facebook
Followers



46
Planned giving
Contributors



74
IHS
Volunteers



6127
Website
Hits



SPRING 2018



haemophilia.ie

50th Anniversary AGM & Conference 2018

13th to 15th April 2018

ROYAL MARINE HOTEL, DÚN LAOGHAIRE, CO. DUBLIN

Preliminary Adults Programme

Friday 13th April

5.00pm - 7.00pm	Registration (<i>Pavilion Suite</i>)
7.00pm - 8.00pm	Buffet Dinner (<i>Carlisle Suite</i>) An opportunity for everyone to come together for an informal buffet dinner. Parents please note that no activity will take place on Friday evening for children. We would ask you to ensure that your child/children are supervised on Friday evening.
8.00pm - 9.15pm	50th Anniversary Movie Premiere (<i>Carlisle Suite</i>)

Saturday 14th April

9.00am - 10.00am	Registration (<i>Pavilion Suite</i>)
10.00am - 12.30pm	Annual General Meeting (<i>Carlisle Suite</i>)
12.30pm - 1.30pm	Lunch (<i>Dun Restaurant/Hardy's Bar</i>)
1.30pm - 2.30pm	iPATH Research Update (<i>Carlisle Suite</i>)
2.30pm - 3.30pm	History of the Irish Haemophilia Society (<i>Carlisle Suite</i>)
3.30pm - 4.00pm	Coffee Break: 'Mad Hatter's' Tea Party (<i>Pavilion Suite</i>)
4.00pm - 5.00pm	Through the Years: Perceptions of the I.H.S. (<i>Carlisle Suite</i>)
7.15pm	Gala Dinner (<i>Carlisle Suite</i>) The evening will start with an Awards Ceremony, followed by dinner and entertainment. Parents please ensure that children are supervised and remain seated during the Gala Dinner.

Sunday 15th April

10.00am - 11.00am	Service of Commemoration (<i>Carlisle Suite</i>)
11.00am - 11.30am	Coffee Break (<i>Pavilion Bar</i>)
11.30am - 1.00pm	Through the Generations: Panel Discussion (<i>Carlisle Suite</i>)
1.15pm	Lunch (<i>Carlisle Suite</i>)

50th Anniversary Exhibition Room

This year is a momentous year for the Society as it marks our 50th anniversary. To mark this occasion, we have organised an exhibition room in the hotel. The Dunleary Suite will be open to members for the duration of the weekend. Why not pop in and take a look at some old archives and photographs, memorabilia various other documents from over the years. To access this room, take the lift beside reception and go to the 2nd floor.



A Note from the Editor

Hello everyone, welcome to this year's first edition of our quarterly magazine. I hope you enjoy reading it.

As you are all aware, due to adverse weather conditions we had to postpone our AGM & Conference. As you can imagine, the staff and board were all hugely disappointed as were lots of members, volunteers and speakers. We are very pleased to inform you that the conference has been re-scheduled and will now take place over the weekend of 13th to 15th April, 2018 at the Royal Marine Hotel in Dun Laoghaire, Co. Dublin.

In our CEO's report on page 4, you will find some updates in relation to our rearranged AGM & Conference, I.H.S. documentary movie premiere, World Haemophilia Day 2018 and new product updates, which is well worth a read.

Ladies, it is that time of year again, time to start thinking about registering for the Women's Mini Marathon. And what a great fun day out this is. For more information, please go to page 16.

You will find important dates for your diary on page 7, and as you can see there are many events taking place between now and the end of the year to make the 50th anniversary of the I.H.S. a year to remember. We hope to see you at some events throughout the year. Keep checking the website and social media for further updates on all our events.

On page 8 you will find some information about our Youth Mentoring Programme that will commence this year. Rob Flanagan, one of our newer staff members will be coordinating this excellent mentoring and leadership programme. Rob is planning to roll out the programme after the forthcoming AGM.

The great Snow of 2018 caused chaos across Ireland but our resilient young members were out in force, making the most of the untimely winter wonderland. And on page 10 and 11 you will find a wonderful gallery of images of just that.

Finally, if there is anything we can assist you with, if you fancy dropping in for a cup of tea and a chat, if you came across an article that might be useful to us, if you fancy putting pen to paper and writing something for us, if you are interested in volunteering, or would like to talk to somebody in confidence, please do not hesitate to contact the office anytime on 01 6579900

Debbie Greene
Administrator & Office Manager



Debbie Greene,
Administrator & Office Manager

Contents

- 2 – Preliminary Programme for our Re-arranged AGM & Conference
- 4 – An Update from our Chief Executive
- 8 – An Introduction to the I.H.S. Youth Mentoring Programme
- 10 – SNOWMAGEDDON Gallery
- 12 – An Interview with Artist Shane O'Malley
- 13 – Fundraising
- 16 – WHI Women's Mini Marathon
- 17 – Word Haemophilia Day Events
- 18 – Kieran McHugh's Report EAHAD Conference in Madrid

CEO's Report

Red Alerts and Lit up in Red

April 17th is World Haemophilia Day. For this very special occasion, on our 50th Anniversary year, we have arranged – thanks mainly to sterling work and persistence by our newest staff members Barry and Robert - to have several iconic buildings lit up in red that evening. This includes Liberty Hall, the Convention Centre Dublin, The Mansion House, The National Concert Hall, The Civic Offices at Wood Quay and Cork City Hall. We were looking forward to this red alert. However, we had not planned on a different and earlier red alert - caused by storm Emma.



This bad weather was disastrous timing for the Society as it forced the cancellation of our AGM and Conference scheduled for the Royal Marine Hotel in Dún Laoghaire from March 2 to 4. This was especially hard to take as the enthusiasm of members for this year's event was unprecedented with a record attendance for any Society conference, with 340 expected. The good news is that this cancellation has been changed to a postponement. Thanks to the generous co-operation of the Royal Marine hotel, the event has been rescheduled for the weekend of April 13 to 15. All members who had booked are being given the option to transfer their booking to the new dates, and for those members who were unable to attend

Brian O'Mahony,
Chief Executive



on the original dates, this may afford them an opportunity to attend. We anticipate a full house with the Society taking over the entire hotel for the weekend.

The Conference this year will focus heavily on the history and shared past of the Society and the attendees. Swedish film director Goran Kapetanovic will be present for the first showing of the movie he has directed documenting the history of the Society. This has been a mammoth project. We provided Goran with reams of documentation, press cuttings and many hours of video footage on the past work and profile of the Society. He in turn conducted interviews with a very large cross section of members, people with haemophilia, health care workers and other key stakeholders including the current and past chairs of the National Haemophilia Council and key contacts in the HSE. Goran has done a masterful job of editing over 100 hours of footage into a movie of approximately 75 minutes. As a bonus, we have many hours of extra footage and interviews which we can show at future society events and a digitised archive of all of our past footage.

The Conference will feature a memory room where we will show film footage, photo loops and copies of press cuttings, newsletters and other documents from the Society's past. I expect this to be very popular to the extent that I foresee us having to repeat this at further conferences during the year with rotation of materials. The conference will also feature the third in a series of three lectures on the history of the Society and my hope is that this final presentation will link all of the history together in a seamless continuum.

New Product Update

In late February, the European Medicines Agency (EMA) licenced Hemlibra for the treatment of patients with inhibitors to Factor VIII (FVIII). This is the first ever subcutaneous therapy to be licenced for people with haemophilia. We have been updating members through our conferences and publications over the course of the past five years on new products under development.

Finally, we now have a non-intravenous therapeutic product which can be used to treat some of our community. This product will be administered once per week for the prophylactic treatment of people with FVIII inhibitors.

This therapy is for prophylaxis only and delivers a constant level of protection against bleeding. In the event of a breakthrough bleeding episode occurring in a person with inhibitors, treatment will be required with one of the current bypassing agents. Hemlibra is currently licenced only for patients with FVIII inhibitors.



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

Clinical trials are continuing on the use of Hemlibra for FVIII patients without inhibitors. Several Irish people with FVIII deficiency are participating in this clinical trial - called Haven 3. If all goes well with the ongoing trials, it is expected that Hemlibra will be licenced for use in FVIII patients in Europe during the course of 2019. There is also a strong possibility that people with haemophilia in Ireland may participate in a clinical trial for another subcutaneous therapy - Fitusiran- during the course of 2018.

A significant number of people with Factor IX (FIX) deficiency were tested for pre-existing antibodies to the AAV virus vector being used for the FIX Gene Therapy clinical trial which will be commenced by Freeline and UCL in the UK. Other ongoing FIX Gene Therapy clinical trials by Pfizer and Uniqure, may also possibly recruit people in Ireland for their trials. Discussions and work are ongoing. We fully expect that in this, our 50th anniversary year, some people with FIX deficiency in Ireland will be offered the opportunity to commence participation in clinical trials for Gene Therapy.

This year all FVIII patients in Ireland are currently switched or switching to using extended half-life (EHL) FVIII treatment. In 2017, all FIX patients switched to using extended half-life FIX. We are the first country globally to have all people with Haemophilia A and B treated with this new generation of recombinant products. Coupled with the exciting new

developments in subcutaneous therapies and the strong and real prospect of participation in Gene Therapy clinical trials, the exciting future we have long discussed may be arriving. In fact, on the very day I am writing this, the first clinical trial for gene editing in FIX deficiency in Europe, being conducted by the company Sangamo, has just been approved.

Assessing Treatment Impact

When treatment products or treatment regimes are changed, we expect to see an improvement in the health and quality of life of people with haemophilia. In 2017, after people with FIX deficiency were switched to EHL FIX, there was an expectation that we would see higher trough levels with more protection from bleeding and less frequent infusion, for the majority of people. However, even if expected, this has to be demonstrated. This is why the comprehensive care centres measured trough levels before and after changing treatment. This is also why it is vital that all treatments infused are recorded and all bleeding episodes requiring treatment are captured on the home treatment app on your smartphone.



We need to make sure that the anticipated clinical benefits are seen in the real life clinical setting. We have seen a significant increase in trough levels (with an average trough level now at 8%, meaning that this is the lowest factor level an individual will go down to during treatment) which should confer greater protection from bleeding. This in turn should translate into a lower annual bleed rate for individuals and an improvement in joint function. The availability of EHL FIX has also made it easier to persuade those currently treated on-demand to switch to prophylaxis which again, should result in a lower number of bleeds each year.



We can also anticipate a higher trough level for those with FVIII deficiency, probably around 3%. It will be lower than the FIX trough level, as the half-life extension of the EHL FIX is significantly greater than the corresponding increase with the EHL FVIII (a 250% increase for FIX as opposed to 50% for FVIII). If we are to continue to benefit from constantly improved treatments and treatment regimes, it is vital that the doctors can collect and tabulate clinical and outcome data. Without this data, it is much harder to make a case for the increased resources required for better treatment.

The centres have also been administering specific quality of life surveys prior to switching people to EHL factors - the PROBE survey for adults and the Choklat survey for children and parents. The society has also been collecting data from members with severe haemophilia using these survey tools. I would strongly urge all people with haemophilia to cooperate fully and enthusiastically with the collection of these surveys. They give the centres and the Society the information and tools we need for several purposes.



Firstly, to allow the centres to ensure that the treatment for each individual is optimised. Secondly, to give the centres the data to show that the desired clinical outcomes are being achieved and that we will see real and measurable improvements in quality of life. I do not just mean improvements in what to many of you may seem like abstract concepts, such as joint scores or annual bleed rates. These surveys measure the impact of treatment on all of the activities of daily living from the time you get out of bed in the morning, to getting back into bed at night. Thirdly, they will give the centres and the Society the data and information we need to demonstrate the benefit of applying increased resources to haemophilia care, when discussing with budget holders, the HSE and the Department of Health.

Very often when you discuss informally with people with haemophilia, their assessment of the impact of a new treatment, you will get general indications that it is, or is not, an improvement, that they feel better or the same, that it has improved their quality of life in a vague perhaps general way. In order for us to do our jobs, to advocate always for the best available treatments, for access to new and improved treatments, for the resources for these treatments - we need compelling data which demonstrate that the changes we are making are working. We need this outcome data and in co-operating with these survey requests, you are helping the centres and the Society to help you get access to the best treatments now, and in the future.

World Haemophilia Day Events and 50th Anniversary



World Haemophilia Day (WHD) is on April 17th. This year, that will fall on the Tuesday after our re-scheduled AGM and conference. Our theme for this year will be, not surprisingly, the 50th anniversary of the Society. We will have a number of events on the day and in the following week. We have secured sponsorship for renowned Irish artist Shane O'Malley, to design and paint an abstract artwork at a prominent billboard location in Dublin, which will be unveiled on WHD. A separate large canvas painting by the same artist will be unveiled at a press conference that day and will then be permanently installed in the main lobby of St. James's hospital, with a plaque commemorating the first 50 years of the Society.

The movie on the history of the Society will be premiered at the Annual Conference on April 13th. We will also have a cinema premiere in the newly refurbished Art Deco style Stella Cinema in Rathmines, Dublin on the afternoon of April 26. Invitations will be issued to members, the media, haemophilia health care professionals and other key stakeholders, to this unique event which will also feature a short film on the making of the art project.

Brian O'Mahony, Chief Executive

2018

Dates for your Diary

April

50th Anniversary AGM & Conference

Dates: Friday 13th to Sunday 15th April

Venue: Royal Marine Hotel, Dun Laoghaire, Co. Dublin.

50th Anniversary of I.H.S.

– World Haemophilia Day Events

Date: Tuesday 17th April

For details, please see page 11.

May

Carrier Conference

Dates: Saturday 12th & Sunday 13th May

Venue: Castleknock Hotel, Dublin.

World Federation of Hemophilia Congress

Dates: Sunday 20th to Friday 25th May

Venue: Glasgow

Father & Son Overnight

Dates: T.B.C.

Venue: Lilliput Adventure Centre.

June

Ageing & HCV/HIV Conference

Dates: Friday 22nd to Sunday 24th June

Venue: Killeshin Hotel, Portlaoise, Co. Laois.

July

Von Willebrand's Disease Information Day

Date: Saturday 7th July

Venue: Midlands Hotel (Heritage Portlaoise).

August

Mild Haemophilia Information Day

Date: Saturday 18th August

Venue: Osprey Hotel, Naas.

September

Mother & Daughter Overnight

Dates: Saturday 8th & Sunday 9th September

Venue: Lilliput Adventure Centre.

50th Anniversary Gala Dinner

Date: Saturday 22nd September

Venue: Castleknock Hotel, Dublin.

October

October Conference

Dates: Friday 19th to Sunday 21st October

Venue: Radisson Hotel, Sligo.

November

Haemophilia B Information Day

Date: Saturday 10th November

Venue: I.H.S. Office.

December

50th Anniversary Children's Christmas Party

Date: Saturday 8th December

Venue: Clarion Hotel, Liffey Valley, Dublin.



Introducing: I.H.S. Youth Mentoring Programme

The Irish Haemophilia Society is ever growing and as a result, we would like to introduce our new youth programme. Our aim for this programme is to help foster the next generation of leaders in our bleeding disorder community.

Programme Vision:

Our hope is that participation in this new programme for young people with haemophilia or related bleeding disorders, and their siblings, will help develop skills and foster confidence to make positive choices for the management of their health care, recreation and personal relationships. In doing so, they can lead independent, active and fulfilling lives and participate actively in the bleeding disorders community.

The Leadership and Mentoring programme looks at ways for young people affected by bleeding disorders to communicate with each other, share experiences and learn life skills.

The programme will be for ages 13 to 17 years and will run four times a year. The programme is based around one presentation, which is broken up into six key categories. There are also many practical aspects involved, all of which will need to be completed. Each participant will take note of the work they have completed that year and we will seek to improve on that each year.



The Six Key Categories:

- 1. Haemophilia and You:** Here we will look at different types of bleeding disorders and examine exactly how they work. We will also explore how they may affect our lives presently, and in the future. Finally, we will look at how we manage the disorder and work towards being more self-sufficient.
- 2. Relationships and Social Life.** We will focus on a variety of relationships from sibling, parental and friendships. We will also look at romantic relationships and the importance staying safe, and having respect for oneself and each other. Social media will also be discussed; why people use it and examine the positive and negative aspects it can have on our lives.





3. Travel. This section will be all about self-sufficiency. We would love our members to see the world, free from barriers to hold them back. Here, we look at booking a trip from start to finish; preparing checklists to ensure we have everything we need and identifying emergency departments for any situation that may arise.



4. Health. This is the largest section of all, covering many different topics such as exercise, nutrition, sleep, addiction, self-esteem and self-awareness. We want to educate our young members on how to look after themselves physically and mentally. We will also consider feelings and emotions, and how to recognise and register them in order to improve coping mechanisms, and decrease stress.

5. Future Career Development. Finding a job can be difficult but a good strategy from an early age can make all the difference. We will begin looking at third level opportunities and how to apply for them. We will look at what skills we possess or what skills we may want to learn. From here, we will also look at how to find a job as the digital age continues to evolve and explore how best to tackle a job interview. The final part of this stage will involve talking about continual development and how we can all strive to improve.



6. The Irish Haemophilia Society. Finally, at the last stage we will talk about the society, its role and what it does. Why does the society need us? Why do we need the the Irish Haemophilia Society?

We will also discuss issues young people with bleeding disorders have and how best to make their voice heard by the society. We will explore volunteering and the difference that makes to us individually and to others. And finally, we will cast our gaze toward the future to see how we can become role models for the society, and help foster the next generation of leaders in the bleeding disorder community. The program will be rolled out after our AGM & Conference.

Robert Flanagan, Children's & Youth Programmes Co-ordinator

For more information, please contact Robert in the office on 01 6579900 or robert@haemophilia.ie 01 6579900 or robert@haemophilia.ie



No Show Like a Snow Show

SNOWMAGEDDON, The Beast From The East, the great Snow of 2018, #sneachta 18, or whatever you called it, wreaked havoc across Ireland in early March and as you are all aware, among other things, the adverse weather conditions led us to having to postpone our AGM & Conference.

As you can imagine, the staff and board were all hugely disappointed, as were lots of members, volunteers and speakers. Thankfully the 50th Anniversary AGM & Conference has been re-scheduled and will take place over the weekend of April 13th to 15th, at the Royal Marine Hotel in Dun Laoghaire, Co. Dublin.

Our resilient members didn't let the disappointment of a postponed AGM get in the way of a good time – and if you need proof, here are a selection of wonderful photos capturing I.H.S. members making the most of the untimely winter wonderland.



Twins Adam & Grace Roche Enjoying Their Snow Day



Zara-Zöe Carey Judd Making a Snow Angel!



Oliver McBride Surveys his Creation



Dylan McBride Hunts for More Snow





James & Lily O'Kane with the King of Hi-Vis



Aiden Costa Pinto & His New Pal



Syd and the Snowmen (Syd Likes Carrots!)



James O'Donoghue Ready for Action.



Aaron O'Donoghue Keeps an Attentive Eye on his Brother from inside.



Jessica and Adam Byrne and their Dapper Snowman



Getting to Know Shane O'Malley

Our theme for this year's World Haemophilia Day (WHD) will be, unsurprisingly, the 50th anniversary of the Society.

We have lots planned for the day and the following week – none more exciting than this: having secured sponsorship, renowned Irish artist Shane O'Malley, will create two artworks to celebrate 50 years of the I.H.S. – one displayed at a prominent billboard location in Dublin and the second, a large canvas painting, will be installed in the main lobby of St. James's Hospital.



Shane O'Malley visiting the NCC by Robert Flanagan.

Originally from Navan, Shane now lives in Galway city and has exhibited and painted nationally and internationally. He explores themes of identity, mental and emotional health, and essentially communicating what it is like to be human. Shane's artistic journey began with graffiti which has shaped and informed his work ever since. He has developed a unique visual language using bold colour and geometric shapes to communicate challenging concepts, through both contemporary painting and street art. As he says in his own words: "I started off with graffiti when I was 16 and then I got into painting on canvas, and working at exhibitions. In recent years it's been mostly street art and exhibitions, and I do workshops with kids, teaching art. Coming from street art has given me a different perspective, there is a sort of subversive nature to what I was doing as a teenager and now I am becoming more mainstream. I suppose, for me, it's really the colour and the form that came from studying street art and graphic design".

When it comes to the creative process, Shane isn't single minded, preferring a two-pronged approach, as he explains: "one approach is that I start off with an idea that I want to communicate. Then I draw a sketch, then bring it onto a canvas or a wall, and add colour and kind of work that way. The other way would be to work quite freely, maybe without any set idea I want to communicate and at the end, make sense of it."

One of the most striking elements of his previous work, aside from the abundance of colour, is his willingness to communicate complex issues and exploring themes of identity, mental and emotional health. Shane sees a number of similarities between his previous work and this project: "I have suffered from mental health. It was something I needed to communicate; how I felt and what it was like, to add to the conversation around mental health and help change some of the stigma attached to it, for me and other people."

These parallels, along with willingness to create a dialogue and challenge, and change preconceived perceptions that drew him to this project: "I think this project is a good fit for me as there seem to be misconceptions in some sense and I feel that it would be interesting coming in as an outsider trying to communicate and create a conversation. I want to help the dialogue and I would like to feel proud that I added in a way, and helped change perspectives. That's me as an artist."



Shane O'Malley by Julia Dunin

Shane will create two artworks, the first, will be displayed at a prominent billboard location in Dublin, and unveiled on WHD. The second, separate large canvas painting, will also be unveiled on WHD and will permanently installed in the main lobby of St. James's Hospital, with a plaque commemorating the first 50 years of the Society. Producing two pieces in, and for display in entirely different environments is something Shane is looking forward to: "While they will be quite similar in design but for me, I enjoy being in the studio so painting the one that will be displayed in St. James's Hospital is of more interesting to me because I much more enjoy the studio time. When your painting outside you've other factors like weather and being on a scaffold but it's still really enjoyable."

While in one sense it is daunting, on the other hand Shane is excited for the project and hopeful of creating something that resonates with the society, and can stand behind, while connecting with the general public.

Barry Healy

Fundraising



Giving is not just about making a donation or raising funds, it's about making a difference.

Every cent you donated or fundraised in 2017 has gone a long way to making a difference. We really appreciate all the support from our members and their families, and we would like to thank everyone who helped to fundraise or made a donation to the I.H.S. throughout the year.

Raising funds is important, but through fundraising you are also raising awareness of haemophilia and other rare bleeding disorders. Raising awareness helps to break down the barriers of the unknown and empowers people with knowledge.

We are delighted to announce our 'Fundraiser of the Year 2017' is Jason Murphy. Jason completed a Skydive last September and set up a fundraising page on everydayhero.ie called 'Jump for James'. Jason's nephew James is three years old and has severe haemophilia. Jason wrote on his fundraising page "doing a skydive on behalf of my little nephew James for the Irish Haemophilia Society. It is an organisation close to my heart and by doing the skydive I wish to help them as much as I can". Jason raised an amazing €2,806 from his skydive and is now taking part in the Great Limerick Run on May 6, 2018 to raise funds for us again. We look forward to seeing Jason at our AGM to accept his fundraiser award.

Along with Jason, we had members taking part in Movember, the month of November when you don't shave and grow a beard or moustache. We had a group of fantastic ladies take part in the VHI Women's Mini Marathon, the 10k race took

place on the June bank holiday Monday 2017 and they raised a grand total of €3,486. The winner of our fundraising draw 2017 was one of these lovely ladies, our congratulations to Margaret Jacob, who won a hotel gift card to the value of €150.

As well as these fundraising events, we had many members who made one off donations throughout the year and our Planned Giving Appeal is going strong. In 2017, we received €19,374 in donations and through monthly/annual contributions to our Planned Giving. Part of the funds raised from the Planned Giving are used to provide the I.H.S. apartment facility near St James's Hospital, this is used by members and their families. It allows members travelling long distances for early morning appointments in St James's Hospital and Our Lady's Children's Hospital in Crumlin the option to travel up the night before. This is especially helpful to parents with young children who otherwise would have to be on the road at ridiculously early hours of the morning. The apartment is also available to family members, if they have someone admitted to hospital and would otherwise would be too far from Dublin to make regular visits to their loved ones.

The above is an example of how your contributions make a significant difference to the lives of others. We are overwhelmed by your support and thank you so much to everyone for helping us, help others in 2017.

Nina Storey

Noticeboard



Peer Support

It's very important for us at I.H.S. to bring support directly to our members and in the coming months, the society will be piloting two peer support groups for mothers.

The first, well attended meeting, took place in the I.H.S. office at on March 24, with a second meeting to take place in the Kingsley Hotel, Cork on April 21, at 12 noon.

The future of the peer support groups is dependent on numbers interested - if it sounds like something that interests you, please get in touch with us.

If you would like to register your interest or would like more information on the peer support group meetings, please contact Lyndsey on 01 657 9900 or lyndsey@haemophilia.ie.



Irish Haemophilia Society Gala Fundraising Dinner

Saturday 22nd September 2018

Castleknock Hotel, Dublin.

As part of our activity programme for our 50th anniversary year, the Society plan to host a Gala Fundraising dinner in the Castleknock Hotel and Country Club in Dublin.

This black-tie event will take place on Saturday, September 22nd, 2018. The host for the evening will be the actor Mr. Simon Delaney. The event will be limited to 200 people. Tickets for the event will be priced at €100 per person or €900 for a table of 10. The evening will include a cocktail reception, dinner, an auction and music from a 'Route 66' a 16-piece brass band. This promises to be an exciting and unique event as well as raising some much-needed funds for the Society.

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

Noticeboard



Father & Son(s) Weekend

Due to the rescheduling of our 50th Anniversary AGM & Conference, the Father & Son(s) Overnight previously arranged for the 14th and 15th of April has been postponed.

The Father & Son(s) Weekend in Lilliput Adventure Centre in Mullingar, Co. Westmeath will go ahead but the new date is to be confirmed. Information packs will be going out to members after the AGM

This event is open to:

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

Please note children must be aged between seven to seventeen.

If you have any questions or queries about eligibility to attend this event, please contact the office on 01 6579900.



Ezine

Would you like to keep up-to-date with things happening in the I.H.S.? The simplest way is to subscribe to our monthly electronic Ezine magazine.

Sent out at the end of each month, this electronic magazine provides reminders of events, articles of interest and will keep you up-to-date with all that is happening the I.H.S.

If you would like to sign up for our monthly electronic Ezine magazine, please contact Barry in the office on 01 6579900 or by email, at barry@haemophilia.ie.

New Clinical Nurse Coordinator for Hepatitis C HAA Cardholder Patients

Ms Patricia Timmons has been appointed to the role of Clinical Nurse Coordinator for Hepatitis C HAA cardholder patients.

It is hoped that patients who have been waiting on an assessment of need / review of existing needs in the period since Anne Daly's departure in 2017, will be prioritised.

Following this, Patricia will be continuing to review patients as part of the HSE's overall plan to carry out the health & social care needs assessment on all HAA cardholder patients.

Patricia is based in the National Hepatitis C Office and can be contacted on 01 6201812 or by email patricia.timmons@hse.ie

Women's Mini Marathon 2018

The Women's Mini Marathon is the biggest all female event of its kind in the world. Since the first race took place in 1983 with almost 9,000 participants, it has grown from strength to strength with just over 40,000 taking part last year, which is pretty amazing. The renowned success of this event is a tribute to the amazing women of Ireland who fundraise year in and year out for so many worthy charities.

This year the race will take place on Bank Holiday Sunday 3rd June 2018. The race is for all fitness levels and all ages. You can walk, jog or run, it is totally up to you, but one thing is for sure, you will have a great day. You will be carried along by a fantastic atmosphere and between banter among all the ladies you will have finished the race before you know it.

If you are thinking of taking part this year, we would really appreciate your support and would ask you to fundraise for the I.H.S. We realise that getting sponsorship can be difficult with so many women fundraising for the same event, but no matter how little you raise, it all adds up, so please support the I.H.S.

Registration has now opened for this event. Places fill up quickly so we advise you to register as soon as possible. You must register to ensure you have your race number to allow you to take part on the day and to receive your medal. You can enter the VHI Women's Mini Marathon by signing up online via vhiwomensminimarathon.ie.

We would like to remind you this is a FEMALE ONLY event, the minimum age for walkers, joggers and fast joggers is 14 years and for runners and elite runners is 18 years.

Race Information

Date/Time: Bank Holiday Sunday, June 3, 2018 at 2.00pm

Distance: 10 kilometres

Start Line: Fitzwilliam Square, Dublin 2.

Finish Line: Baggot Street, Dublin 2.

Fee: €23.00 entry fee (incl. processing)

New Number Collection Venue: Please note, this year the Dublin Number Collection will take place at Trinity College Sports Centre, Dublin on Friday, June 1 and Saturday, June 2.



We are very grateful to all the ladies who take part in the Mini Marathon for the I.H.S. every year, your support for the work of the Society is really appreciated. An event like this is so important, not only to raise funds but to raise awareness of haemophilia and other bleeding disorders.

If you would like to take part and fundraise for the I.H.S., please contact Nina on 01-6579900 or email nina@haemophilia.ie

Entries will close on May 18, 2018 or when maximum number of entries is reached.



Debbie Greene

World Haemophilia Day Events

2018 is a momentous year for the I.H.S. as it marks the 50th Anniversary of the society and as such, we have some rather big plans for World Haemophilia Day 2018 (WHD) on Tuesday, April 17.

Over the course of the day, the I.H.S. will be organising a series of events and press conferences to celebrate the 50th anniversary of the society, and to highlight the importance of World Haemophilia Day. Below is a snapshot of some of the bigger events confirmed so far and coming on the back of our AGM & Conference, it's going to be a big week.

For more info on our WHD plans, please check haemophilia.ie, our social media or contact the office on 01 6579900.

Artworks



Shane O'Malley by Julia Dunin

Renowned Irish artist Shane O'Malley has been commissioned to create two works of art to celebrate the 50th Anniversary of the society.

Originally from Navan, now residing in Galway city, Shane has exhibited and painted nationally and internationally.

He is interested in the themes of identity, mental and emotional health, journey and self-hood and has developed a unique visual language using bold colour and simple geometric shapes to communicate challenging concepts.

The two works of art will be officially unveiled for World Haemophilia Day 2018 on Tuesday, April 17. One will be displayed at a prominent billboard on Macken Street, Dublin 2 (close to Grand Canal Dock), and the second, a large canvas painting will be installed in the main lobby of St. James's hospital.

Lighting up Red for WHD



On the evening of Tuesday, April 17, a series of prominent buildings in Ireland, will join others across the globe, in lighting up red to mark the day, these include Liberty Hall, The Convention Centre, The Mansion House, The National Concert Hall, The Civic Offices at Wood Quay and Cork City Hall.

It will make for quite a spectacle and we would like to take a moment to thank all the people and organisations involved in making this possible.

Twitter Takeover



I.H.S. CEO Brian O'Mahony will curate the @Ireland Twitter account from Monday, April 17 to Sunday, April 22. The account, with over 66k followers, is curated by a new person each week and in lieu of WHD 2018, Brian will take charge of the account for the week.

If you are on Twitter, please get involved and show your support, especially on World Haemophilia Day 2018 - using #WHD2018, #IHS50 & #Haemophilia50.

Non-Uniform Day

A Non-uniform day at St Brendan's National School in Blennerville, Tralee, Co Kerry, will take place on WHD – April 17. Staff and pupils are being encouraged wear something red to mark WHD. A big I.H.S. thank you to Rebecca Roche for organising this; helping to raise awareness of haemophilia and funds for the society.

EAHAD Madrid 2018



Along with approximately 3,000 delegates, I recently attended the European Association of Haemophilia and Associated Disorders (EAHAD) conference in Madrid.

EAHAD brings together many of the world's leading experts in haemophilia care, and the Pharma companies who research and develop new treatment options for patients with haemophilia (PWH). I was really looking forward to this event as I felt that there would be very significant medical and scientific updates. Many recognised medical persons were scheduled to give presentations on the science behind these products. These speakers shared their knowledge, stimulating debate and questions from the audience, and I was not disappointed.

The presentations were very scientific for a lay person like myself but concepts behind the science were made understandable. The most interesting presentation was on gene therapy. Gene therapy in a single vector infusion, has the potential to alter severe haemophilia to mild status, or even provide a cure. This is truly extraordinary. More trials are required as gene therapy is not always successful at present, and the cost will have to be settled upon.

There are ongoing Phase III trials to provide more data. I'm not certain as to what the cost will be but I think it is going to be expensive when licensed. The one-off cure cost will have to be assessed against the cost of prophylaxis for life. However, the cost involved may be prohibitive for many patients in different countries.

The extended half-life (EHL) products are a relatively new development. Presently, EHL products and standard factor products can produce an immune response and development of inhibitors in some patients. New bio-engineered EHL products are under development which, so far, show no major issues of inhibitors in Factor IX (FIX) patients.

Some issues for Factor VIII (FVIII) patients have still to be sorted out. Elocta is an EHL fusion technology product for FVIII patients, through which, intravenous infusions and clotting factor consumption can be reduced. The aim of EHL products is to achieve a higher trough level with a reduction of injections. The annual bleeding rate will show improvements and the treatments can be individualized and tailored for each PWH. These benefits are significant.

Dr. Flora Peyvandi gave a presentation on novel therapies. She is recognised as a world authority and investigates the science behind these products and her talk included an update on Emicizumab also called Hemlibra. The Haven Phase II Study is for 12-year-old and younger PWH with inhibitors. Emicizumab is a monoclonal antibody that mimics FVIII. Interim analysis showed that Emicizumab administered once weekly, prevented or reduced bleeding episodes in this cohort.

The Phase III Haven Study on patients 12 years and older without inhibitors also showed many patients had significant improvements in bleeding episodes and quality of life. Emicizumab is well tolerated with no adverse events. It is a weight based tailored treatment for PWH, administered subcutaneously once weekly into the abdomen. This would particularly benefit children and adult PWH with poor venous access. The aim is for zero bleeds and a normal life expectancy can be achieved - an amazing prospect!

Emicizumab has been licensed for FVIII patients with inhibitors by FDA in USA and EMA in Europe. Hopefully we shall see roll out for this cohort soon. However, suitability and costs have to be verified. Haemophilia care has now entered the era of personalised medicine, another significant milestone.

There was a poster presentation by Novo Nordisk on Concizumab. This is another novel therapy in Phase II trial stage. It looks promising but is still early days. All these developments are very exciting prospects for PWH. The future looks bright!



Dr. Carlo Martinoli discussed the use of ultrasound imaging to diagnose acute bleeding and haemophilic arthropathy. He advised that ultrasound is excellent at diagnosing joint and synovial tissue bleeding damage issues targeting especially the ankles knees and elbows. Ultrasound can be used as a primary diagnostic tool instead of radiography. Biomarkers can also be used in diagnosis of bleeding episodes. Following his session, I asked Dr. Martinoli about the differential diagnosis of microbleeds using ultrasound. He feels it may be possible as sometimes he can detect imagery that may indicate microbleeds. He referred to studies Butterfly and Lumify.

Another session was titled 'The Management of Acute Musculoskeletal Bleeding Events', a presentation given by Stephen Classey. 80 per cent of all bleeds occur within the joints and/or muscles. These bleeds result in pain, loss of mobility and loss of function issues. There has to be a method for differential diagnosis of arthropathy and/or gout which presents with similar painful symptoms as an ankle bleed but is a totally different pathology. Consequently, the treatment will be different. Chronic arthropathy and muscle weakness can result in loss of mobility and function, which can lead to permanent and long-term issues and staged rehabilitation following muscle bleeds may involve a physiotherapist.

Another session I attend was 'Can We Now Forget About Hepatitis C in Haemophilia'. Many PWH treated for bleeding episodes in the 1980s contracted HIV and Hepatitis C. Early efforts to treat Hep C involved mainly Interferon, resulting in some success. Direct acting antiviral agents or DAAs were a major improvement in the treatment of Hepatitis C. Most

PWH treated with the latest generations have achieved a sustained virologic response. This is a truly fantastic outcome for a potentially fatal disease. However patient monitoring must continue especially in the case of cirrhosis patients and development of liver cancer.

We had an extremely interesting session on the topic of 'Economics of Haemophilia'. Health economics is based on maximising the use of expenditure to maximise health benefits to society. It's finding the best possible way to utilise the resources to achieve better health and quality of life.

Dr. Evelien Mauser Bunschoten delivered a comprehensive presentation on the topic of 'Ageing'. PWH are living longer and the care of ageing haemophilia patients can be a very complex issue, presenting new issues for the patients and their treaters. Many of the older generation of PWH suffer from arthropathy, synovitis and have legacy mobility issues. Pain and disability are an increasing problem as patients get older. A significant number of these patients had no treatment for many years as children.

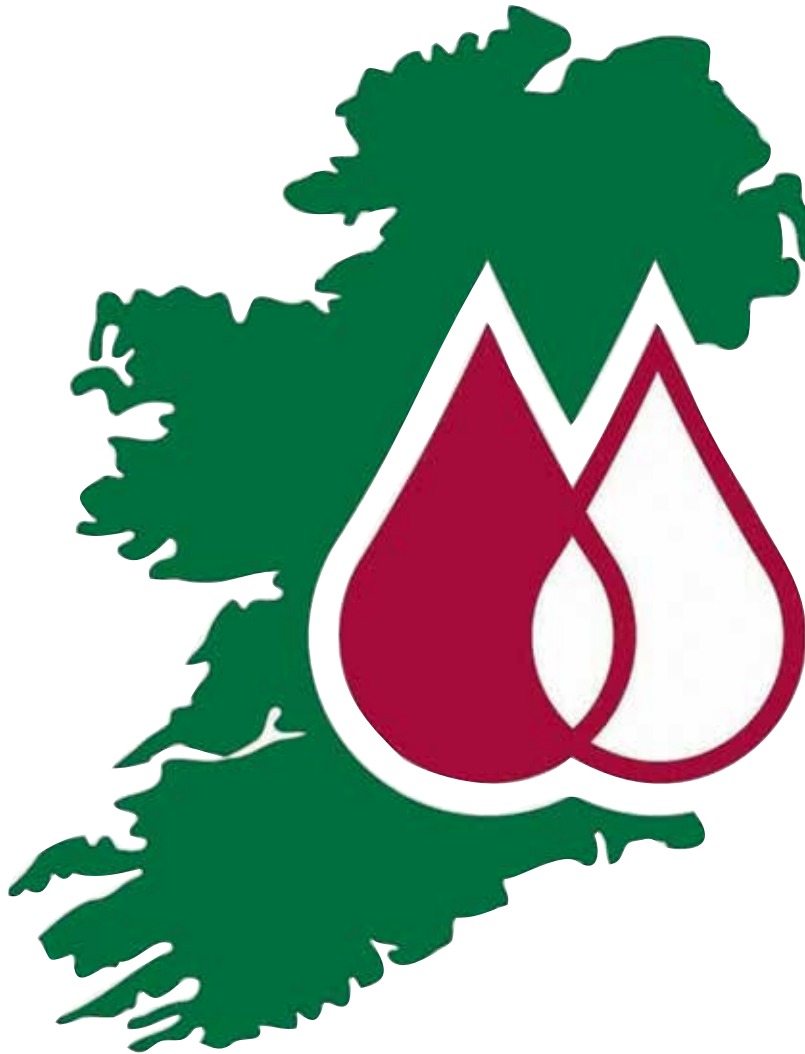
Anxiety, fear, depression can also be a problem for PWH. Quality of life is an issue as it is in the wider community. There is also a litany of diseases that may affect PWH such as cancer, raised cholesterol, cardiac issues, diabetes, obesity, hypertension, sexual dysfunction, dementia, Alzheimer's and Parkinson's disease etc.

Surgical procedures performed on some PWH require very careful attention paid to prevention and control of any bleeding episodes. The senior PWH will require to be at the centre of a comprehensive care team.

This team can include haematologist, nurses, orthopaedic surgeon, physiotherapist, dentist, hepatologist, infectious disease consultant, chronic pain specialist, renal consultant, geriatrician, psychologist, local general practitioner, pharmacist and social worker. The haemophilia community will benefit from the expertise of some or all of these specialists over time. They need to make decisions in a holistic manner.

I left EAHAD with a positive and uplifting outlook on the future for PWH although there are many challenges ahead. I applaud and compliment the efforts and endeavours to improve and transform the lives of haemophiliacs worldwide. We are living in very exciting times.

Kieran McHugh



IRISH HAEMOPHILIA SOCIETY

First Floor
Cathedral Court
New Street
Dublin 8
Tel: 01 6579900
Fax: 01 6579901
Email: info@haemophilia.ie
Website: www.haemophilia.ie

