

Magazine of the Irish Haemophilia Society

haemophilia.ie



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



The Society
at a Glance

1052

Facebook
Followers



46

Planned giving
Contributors



74

IHS
Volunteers



6059

Website
Hits



AUTUMN 2017



haemophilia.ie



IRISH HAEMOPHILIA SOCIETY LTD

Cumann Haemifile Na hEireann

OCTOBER MEMBERS' CONFERENCE

October 20th - 22nd, 2017

Hodson Bay Hotel, Athlone

Preliminary Adults Programme

Friday 20th October

- | | |
|---------------|--------------------------|
| 18.00 – 19.00 | Registration |
| 19.00 – 20.00 | Buffet Dinner |
| 20.00 – 20.45 | Planned Giving & Vietnam |

Saturday 21st October

- | | |
|---------------|---|
| 09.30 – 10.00 | Registration |
| 10.00 – 11.30 | New Developments in Haemophilia Treatment |
| 11.30 – 12.00 | Coffee Break |
| 12.00 – 13.30 | Interactive Workshop |
| 13.30 – 14.30 | Lunch |
| 14.30 – 15.30 | Port-A-Caths
Or
Vein Care |
| 15.30 – 16.00 | Coffee Break |
| 16.00 – 17.00 | Tattoos and Piercings |
| 19.15 | Dinner & Entertainment |

Sunday 22nd October

- | | |
|---------------|--|
| 10.00 – 11.30 | Mothers Peer Support Group
Or
Fathers Peer Support Group
Or
Members Peer Support Group |
| 11.30 – 12.00 | Coffee Break |
| 12.00 – 13.45 | Wellness Workshop |
| 14.00 | Lunch |

For more information or to book this event, please contact the Irish Haemophilia Society on 01 657 9900 or visit the website: www.haemophilia.ie

**THE FINAL PROGRAMME
WILL BE POSTED OUT
TO EVERYONE WHO HAS
REGISTERED, WITH THEIR
CONFIRMATION LETTERS.**



A Note from the Editor

Hello everyone,

Welcome to the Autumn edition of haemophilia.ie.

In this edition on page two, you will find details of our adult's preliminary programme for the October Conference. For those of you who have booked in to attend the conference, a copy of the final adults and children's programmes will be sent out with the confirmation letters.

On page three our Chief Executive gives an update on what is happening in the UK with their government announcing that they will be carrying out a contaminated blood inquiry.



*Debbie Greene,
Administrator & Office Manager*

Read all about our fantastic 'Mother & Daughter Overnight' that took place recently, on page 12. Thanks to Gina Daly for writing the article and for the lovely photos.

2018 is a big year for the Society as we will be celebrating our 50th anniversary. With that in mind, we have now set dates and venues for all the main conferences and events for 2018. Why not put the dates in your diary now. For more information go to page 15.

Go to page 16 for our noticeboard which gives little snippets of information about various items of interest and important information.

We are starting to see more and more members writing articles, taking photos, volunteering and assisting us with various projects. This is most welcomed and much appreciated. If you would like to get involved in some way, please contact me in the office. I hope you enjoy reading this edition and don't forget we are always delighted to see members dropping into the office to say hello.

Debbie Greene
Administrator & Office Manager

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CEO's Report

Examining The Past To Map The Future

In recent weeks, the UK Government announced that they would be carrying out a contaminated blood inquiry. This will finally give people with haemophilia in the UK an opportunity to examine decisions that were taken in the past in relation to blood products leading to the infection of people with haemophilia with HIV and Hepatitis C. The UK Haemophilia Society have been lobbying for such an inquiry for many years and they now have a major amount of work ahead of them. In mid-August, the leadership team from the UK Society spent a day in Dublin meeting with me to discuss our experience of inquiries. The UK inquiry has been a long time in gestation. The IOM Inquiry in the USA took place in 1994, the Krever Inquiry in Canada in 1997, the Finlay Inquiry in Ireland in 1997 and the Lindsay Inquiry in Ireland in 2001.

There are many elements to be considered in such an inquiry including the type of structure for the inquiry, preparation, the gathering of data and evidence, legal representation, ongoing communication with members and ensuring that the voices of people with haemophilia are heard. I have been reflecting now, 16 years after the report on the Lindsay Tribunal of Inquiry into the infection of people with haemophilia in Ireland with HIV and/or Hepatitis C. The recommendations from Lindsay were vague and certainly not detailed. This was a source of criticism at the time from our community and others. However, prior to the finalisation of the report, we had spent a lot of time thinking about what we wanted for the future and how we could ensure that the mistakes of the past were not repeated. The answer was to ensure that the structures and processes which would be put in place following the report, would include a formal role for the Irish Haemophilia Society, in all major decisions which would have an impact on the health and healthcare of people with haemophilia in the future. To this end, we were able to take the vague recommendations from Lindsay and use them to build fully inclusive structures. Recommendation number two stated:

Brian O'Mahony,
Chief Executive



"A Co-ordinating Committee in regard to the treatment and care of persons with haemophilia should be established with representatives from the various different organisations and interest groups in relation to haemophilia care. The Tribunal does not believe that it is appropriate for it to set out a detailed structure and composition of such a committee, rather this should be a subject of discussion and agreement between the various interested parties and the Minister for Health and Children. Its remit should include all aspects of the treatment and care of persons with haemophilia including choice of blood products to be given to such persons".

This recommendation was used to structure the statutory National Haemophilia Council (NHC) in 2004. The Society was responsible for drafting the first and decisive draft of the terms of reference for the NHC and in fact, had started this work prior to the tribunal report, in anticipation of such a finding.



This Council recommends policy on haemophilia to the Department of Health and the Health Service Executive (HSE). The Council includes representatives from the Society, the three Comprehensive Care Centres and the centre in Galway, the HSE, the Department of Health and some additional experts such as nurses with specific haemophilia expertise. The Council meets six times per year and reviews care in all the haemophilia centres, meets annually with the CEO's of each of the relevant hospitals, carries out audits of the centres and the services they provide and advocates for continuous improvement in haemophilia care. Recommendation number one stated:

"The blood products supplied to persons with haemophilia should be of the highest standard and of the safest nature that are available".

This recommendation and the last section of recommendation number two (including choice of blood products to be given to such persons) has been implemented by the establishment of the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) in 2002.



Again, the Society was instrumental in drafting the terms of reference for this board. This board carries out the procurement and selection processes for all the factor concentrates used in the country. The board includes the Centre Directors from the three Comprehensive Care Centres, the Society, the Department of Health and additional experts. The board has been a great success. Ireland is now at the forefront globally when it comes to the use of the safest and most effective therapies in optimal quantities at the most cost effective prices. The presence of the clinical experts and the Society representatives is your assurance that safety and efficacy are and always will be of paramount importance when selecting products.

Over the past 15 years, as the population of people with haemophilia has increased, the children who were started on prophylaxis have grown into adulthood and treatment protocols have improved. Our factor use has inexorably increased to the point where we are now using almost three times as much factor VIII as we were using in 2002. Our factor IX use is the highest in Europe (although so is the prevalence of factor IX deficiency in Ireland). Despite these impressive improvements in treatment, the budget for replacement therapy

has not significantly increased. The HPSMAB have been and continue to be, remarkably successful at selecting and purchasing the best available products at the lowest prices in Europe. The Centre Directors, the Society and the other participants work collaboratively in a very effective manner which is now being studied in many other countries as an excellent model. In the past ten years, thanks to the cost-effectiveness of the HPSMAB process, the work of the NHC and the collaboration and relentless focus of the Society and the teams at the Haemophilia Treatment Centres, we have seen significant investment and improvement in infrastructure at a time when the health budget decreased significantly and the country was in a bailout. We have a new Comprehensive Care Centre at CUH in Cork. We have a state of the art new in-patient unit in St. James's hospital and a new purpose built National Coagulation Centre, two floors above the in-patient unit. We have state of the art electronic patient record systems and smartphone apps for the recording of treatment.

We have a new information technology investment from the HSE through the Lighthouse Project and a very exciting new research project - IPATH (The Irish Personalised Approach to the Treatment of Haemophilia) which was outlined by Professor James O'Donnell at our Annual Conference in March. Taken together, all of these initiatives, in my view, have brought us to the point where we have the best haemophilia treatment system in the world. This has been the real outcome of the Tribunal of Inquiry for the community here because we put so much thought and effort into the future when examining the past. I hope that our friends and neighbours in the UK have a similar long term positive outcome from the difficult work and process they are about to embark on.

New Therapeutic Advances

We are living in exciting times in relation to haemophilia therapies. We now have a small number of people with haemophilia A, without inhibitors, on a clinical trial with a once weekly subcutaneous treatment with an agent which mimics (or replaces) the action of factor VIII. This is one of a new generation of exciting alternatives to factor concentrates which can be used both for those with or without inhibitors. In relation to factor IX, a significant number of people with factor IX deficiency in Ireland have now had blood tests carried out to see if they may be suitable for a gene therapy trial. It is





quite possible that we may have some individuals from Ireland on a gene therapy trial by the end of 2017. For those of you who will be attending our Member's Conference in October, we will have an extended session discussing the new therapies with Dr. Glenn Pierce from the USA.

Quality Of Life Data Collection

With both current and new therapies, it has become increasingly important to ensure that we have data and evidence which we can use to support the availability of current levels and cost of treatment and advocate successfully for new and improved therapies. Haemophilia care is relatively expensive. We have been very successful in advocating for ever improving access to treatment. However, if we succeed in getting access to new or better treatment, we need to be able to measure and demonstrate the benefits of this new treatment in terms of improvements in quality of life. This will be important data to have available for the HSE, the Department of Health, the hospitals and the clinical and payer community generally. To this end, the Society is starting to systematically collect quality of life data on members who wish to assist us in carrying out our mission. We hope to collect this data annually from as many people with severe haemophilia as possible. Separate questionnaires will be used for adults and for the parents of children. In 2016, we started this process by collecting quality of life data on people with factor IX deficiency. In 2017 and in the future, we are extending this to people with factor VIII deficiency. When we have gathered this data every year, we will anonymise the data and the cumulative data will be extremely useful to the Society in looking at quality of life, at examining the impact of new or changed treatments and in advocating

with the Department of Health, HSE and hospitals for access to the best therapies available at any given point in time.

Transmission Of Hepatitis B By Blood Transfusion

In late August, the Irish Blood Transfusion Service (IBTS) announced that a recipient of a blood transfusion had been infected with hepatitis B by that blood transfusion. Hepatitis B is a common form of infectious hepatitis, causing millions of infections worldwide every year. Transmission is usually through hepatitis B infected blood and body fluids. Transmission of hepatitis B via blood transfusion is now a very rare event. There are two separate tests carried out on each donor including a very sensitive nucleic acid test (NAT) for actual virus. Following infection with hepatitis B, an individual may not produce antibodies to the virus which can be detected for up to three months after infection. By using individual donor NAT testing, the presence of the virus can be detected in the infected individual about fifteen days after infection. However, for the first fifteen days after an individual is infected, their blood will not test positive for hepatitis B antibody or virus using NAT. This is the so called "window period" when transmission via blood can occur. It is an extremely rare event with the transmission of hepatitis B having an expected prevalence in Ireland of one in every two million donations. Since the introduction of NAT testing, the IBTS have tested more than 1.2 million donations. This is the first case of a confirmed window period donation known to result in a hepatitis B infection in a blood recipient in Ireland. This is a very unfortunate event for the individual involved. All the tests and procedures appear to have been properly carried out but this demonstrates that even with the most sophisticated and up to date testing regimes, there remains a very low risk of transmission of viruses when the donor is in the brief window period, between being infected and having any signs of infection in their blood. It confirms the continued importance of vigilance, of stringent donor deferral policies and of the development and future implementation of pathogen inactivation techniques for blood, platelets and other labile components. For those people who use plasma derived factor concentrates, hepatitis B is a lipid enveloped virus which is very effectively inactivated by the current viral inactivation methods used for factor concentrates. There has not been a reported infection with hepatitis B via clotting factor concentrates since the 1990's.

Brian O'Mahony, *Chief Executive.*

Educational Grants 2017

The closing date is getting near folks! It's time to get your application into us!

Applications are now invited for the 2017 Educational Grants. You can apply online on our website www.haemophilia.ie, or you can also download the application forms from our website, complete them and post them into the office.

What types of Educational Grants are available?

There are two categories of grants available as follows:

- Educational Grants for people with haemophilia or related bleeding disorders.
- Educational Grants for immediate family members.

How much are the Educational Grants for?

The grants are broken down as follows:

Maureen & Jack Downey Educational Grant

- First prize €4,000
- Second prize €2,000
(This is called the Father Paddy McGrath Educational Grant)
- Third prize €1,500

Margaret King Educational Grant

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

What is the criteria for applying?

The criteria for the Maureen & Jack Downey Educational Grant

This grant is made available to a person with haemophilia or related bleeding disorder, who has been accepted on a post second level educational course. The person applying must be registered at the National Coagulation Centre at St. James's Hospital in Dublin.

The criteria for the 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. The person applying must be accepted on a post second level educational course, and the person with the bleeding disorder must be registered at the National Coagulation Centre at St. James's Hospital in Dublin.

What is the opening and closing date for applications?

The opening date is Friday 30th June 2017 and the closing date is Friday 29th September, 2017.

How are the applications scored and who scores them?

Once the closing date arrives and all the applications have been received, 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 consider and score the applications, and make recommendations to the rest of the executive board regarding recipients. The 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 being successful. And please do fill out the application yourself! Good luck to everyone who applies.

Debbie Greene, Administrator

Teaching Your Toddler about Haemophilia



Your child with haemophilia may go from playtime to hospitals, pain and infusions all in one day. Parents offer loving comfort and emotional support during trying times of haemophilia. Yet, it's daunting to try to help children make sense of haemophilia. You can offer solace during difficult times, but you can also use infusions, hospital visits, and comfort time as opportunities to learn how your child understands his world, and then to better explain what's happening to him.

Think of teaching your child this way: when you first learned he had haemophilia, you may have been scared, overwhelmed, and emotional. You wanted and needed comfort. After a time, however, you were ready to learn more about the bleeding disorder and craved information. It might have been scary if a doctor had taught you everything about haemophilia on the

first day of the clinic. On the other hand, it may have been frustrating not to understand at all what was going on with your son, after several clinic visits. Somewhere in between, knowledge and emotional support go hand in hand, to make you feel you have control and are capable of handling this disorder.

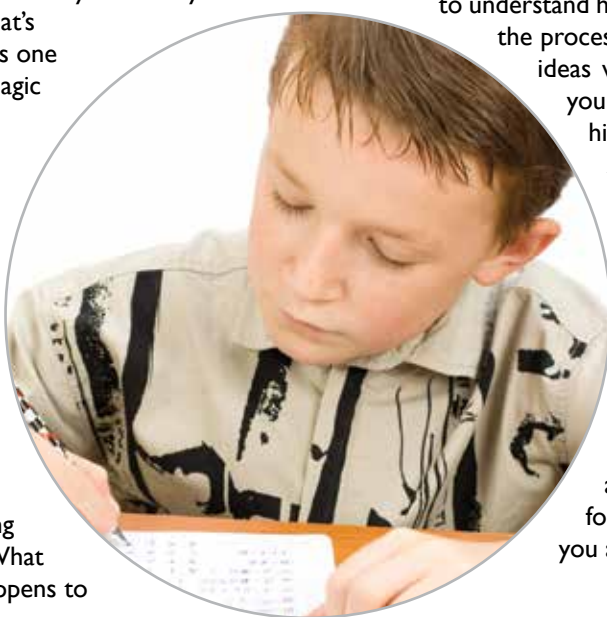
Like you, your child also needs comfort, and eventually information. But you don't want to give him too much information when he's not ready, or use inappropriate terminology or concepts. The right information, presented in the right way, may help calm him emotionally, build his confidence and sense of security, and encourage him to learn even more.



How Pre-schoolers Think

To learn how your pre-schooler understands haemophilia, it helps to know how pre-schoolers process their world in general. There are five major thinking tools that pre-schoolers use:

- Magical thinking means that a pre-schooler cannot logically figure out a missing 'casual' step in a step-by-step process.
- Perceptual thinking means that everything the pre-schooler knows about his world comes from his senses: what he sees, hears, smells, and feels. So he is very externally orientated; that is, focused on what's happening outside his body. This is one reason that pre-schoolers love magic – they believe what they see.
- Absolute thinking means that a child perceives his world in black and white, with no in-betweens or shades of grey. Now you know why many pre-schoolers are attracted to superheroes – good guys and bad guys.
- Egocentric thinking means that the pre-schooler sees the world from his vantage point only. He has a difficult time putting himself in other people's shoes. What happens to him explains what happens to everyone.



- Immediate thinking means that the pre-schooler lives in the present. He rarely perceives the past, and thinks little of the future. Ever take a long car ride with a pre-schooler, and five minutes into the ride hear him ask, "How much longer?"

You can use your knowledge of these tools to help you teach your child about haemophilia. To avoid overloading your child, both cognitively (thinking) and emotionally (feeling), it helps to know what your child thinks first. Often, the best way to begin teaching is to ask questions. Make them 'open-ended' questions, like "What do you think haemophilia means?" as opposed to "Haemophilia is a bleeding disorder, isn't that right?" Don't make your questions biased with any extra information. Just ask "How does....." or "Why is....." or "What happens next....." and see what he says.

Imagine what you would think if a doctor told you that she has moved your belly button and put it on your nose, but your belly button has always been in the same place since you were born. This is what you believe to be true. Now tell a five-year-old, whose port has been in his chest since he was ten months old, that his port has been moved to his belly. What will he feel? What will he think?

Helping our children understand the sometimes invasive procedures that come with haemophilia means taking the time to understand how they think. Do you focus only on the process of getting factor? Do you explore ideas with your child? Don't assume that your pre-schooler knows all about his port the way you understand it. Ask questions, like "What is that?" "Where did it come from?" "Why do you have that?" "How does it work?" Explore possible explanations. Let your child first attempt to figure things out and conjure answers. Finally, offer age-appropriate explanations to help him learn. Your efforts will support his burgeoning emotions and ever-developing thinking and foster a better relationship between you and your child.

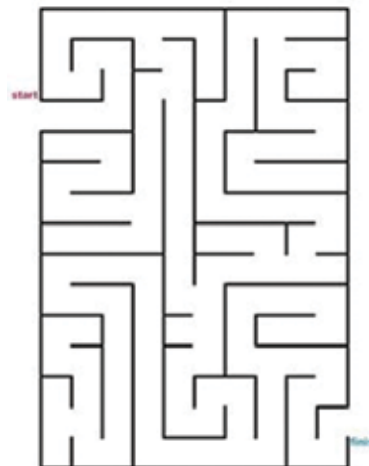
Cubs



Welcome to the Autumn Edition of the Cubs Group! We hope you are all enjoying being back in school.

If it is your first year in school we hope you are having lots of fun and making lots of new friends and if you are going back to school we hope you are having lots of fun back with your friends. We are sure you are learning lots of new things in school, so this time we thought we would play some fun games!

Can you help Brian find his way to school?



Can you find the following farm animals in the word search?!

Chicken	Cow	Donkey
Goat	Horse	Pig
Rabbit	Sheep	Turkey



Remember: It is really important when you have haemophilia or any other bleeding disorder that you tell an adult in school if you fall or hurt yourself. They can call your Mam or Dad who can show your teacher exactly what to do!

Kidlink Club



We hope you all had a fantastic summer and are excited to be back in school with all of your friends!

When the summer holidays were over we all loved going back to school here in the I.H.S. so we started thinking about some tips that might help if you are not too excited about being back to school!

- The old saying “breakfast is the most important meal of the day” is never truer than when you’re going to school. You will be more alert and ready for the day if you eat a good breakfast.
- Get enough sleep. We need at least 8 hours of sleep each night to feel rested. If you don’t get enough sleep it can be hard to concentrate.
- Do more at school and you’ll have less to do at home. When your teacher gives you a few minutes to get started on some homework if you concentrate really hard you will have less to do later in the evening!
- Get outside and have some fun on your break times – running around, playing games and laughing with friends is always our favourite part of the day! Get moving and have fun.



The I.H.S. is celebrating a very big birthday next year and we want our super creative and talented Kidlink Group to help with suggestions and be part of the preparations! Each of our kid’s groups will be getting involved and we will be taking some time to make plans at the Members’ Conference this year! We can’t wait.



Again this year, Barretstown are having a special camp for 7 to 17-year-olds with haemophilia and related bleeding disorders from Saturday 28th October to Tuesday 31st October 2017. This is a great chance to meet up with your old friends from the haemophilia weekends but also to meet lots of new friends! We are sure you have heard about all of the fun things you get to do at Barretstown, things that you might not get to do anywhere else things like archery and high ropes, fishing and canoeing! If you think you would like to go to this camp ask your Mam or Dad to call Fiona in the I.H.S. to talk about booking your a place at the camp.

Mother & Daughter Event



I was thrilled to go to Lilliput Adventure Centre for the Mother & Daughter Event as a volunteer for the Irish Haemophilia Society. During the first few minutes of arriving, I don't know who was more nervous the little ones or the Mammy's, as these kind of activities can be a little bit intimidating. However, once everyone got to know one another and started to relax, it was a fantastic way to have fun together. This is exactly what happened when our leaders from Lilliput Aoife and David joined us. They were able to make everyone feel comfortable and relaxed and it brought everyone out of their shells. Eimear (my co-volunteer) and I, were ready and willing to get stuck into all of the activities with a little curiosity regarding the bog hopping.

First up was orienteering. This then quickly moved onto crate stacking and aero ball. By the time lunch was coming up we were all relaxed, chatting away and having great fun and realising we had worked up quite an appetite!

The afternoon brought out the surprising screamers of our group, (it's always the quiet ones!) followed by rock climbing and archery. As if that wasn't enough - after wolfing down our dinner, we played capture the flag in the forest. Nothing like 'The Mammy's' V's 'The Care Bears' to bring out everyone's competitive side.



Lilliput Adventure Centre, Co. Westmeath June 24th & 25th 2017



After capturing the flag, it was time for some slightly less physical activities and games in the house and with tired bodies and happy faces we went to bed. There was lots of excited chat from the little ones about the infamous bog hopping the following morning!

Sunday started off with yet another very competitive activity in our alphabet scavenger hunt. But then it was on to the good stuff - the water activities! After the fab kayaking, we were brought through to bog hopping - I won't lie, I was petrified by the thoughts of it! But it was by far everyone's highlight of the weekend! Nothing like being up to your knees in muck to really bring a group together!

Fair play to all the Mammy's who waded through the bogs with us - with even bigger praise to those who crawled through "The Hole"! Leaving each other with massive smiles and very tired bodies, I thought an outstanding weekend was summed up brilliantly by the youngest and the smallest of us all when she said "Mammy this has been the best weekend of my life, I wish it didn't have to end". Another Irish Haemophilia Society weekend finished up and a huge success in my opinion!

Gina Daly, Volunteer

A Fitting Tribute

My dad Cormac (Nico) Meade was a person with haemophilia. He was on the liver transplant list and in hospital for five months. Dad was very optimistic about the change that a transplant would bring about for him and he looked forward to the new lease of life and energy that it would bring. He was constantly making plans and stayed positive throughout his time in hospital.

While visiting Dad in St. Vincent's Hospital I told him that I'd registered for the Women's Mini Marathon and he immediately suggested that I run it for the I.H.S. Over the five months that Dad was at St. Vincent's, he had constant communication from the I.H.S. The staff at the I.H.S. were always there when he needed them which was wonderful. In sickness, we need all the support we can get, from friends, family and even a Society like the I.H.S., whom Dad had been linked with for many years. Dad was a real character and was always laughing. The I.H.S. team brought a smile to his face. I really appreciate the kindness they showed my Dad. Another reason for me wanting to run for the I.H.S. was that I also carry the haemophilia gene, so should I have a baby boy, there's a chance he'll be affected. I can take comfort in the fact that the I.H.S. would support us.

Dad was a true warrior; right to the end. And like a warrior, he knew when to let go. Dad passed away on Friday the 26th of May and he died with great dignity. A doctor who had been taking care of Dad in ICU remarked that Dad took everything on the chin while in their care. He said that Dad had a most gentle demeanour. Mum suggested that his relaxed attitude towards hospital care was probably because he had haemophilia, he was used to hospitals from a young age. However, the doctor responded that Dad was born with such gentility, it wasn't something he developed, it was in his nature.

Dad would have wanted my family and me to keep laughing and living life to the full despite his absence, but he didn't realise the impact that his loss would make in our lives. However, it was Dad's unending optimism that inspired me to run in the Women's Mini Marathon, just days after his funeral. I decided that if I couldn't dance and sing as Dad had hoped for at his funeral, then I could at least run 10k as a tribute to him instead.



With only days to help raise money for the I.H.S., I was astounded by the response to my Everyday Hero story. I managed to raise 1,898.81 euros. I was so thrilled for Dad and the I.H.S. and I know Dad would have been delighted too. As I ran the 10k, I could hear him cheering me on all the way to the finish line.

Rest in Peace Dad.

Jenna Meade.

DATES FOR YOUR DIARY

2017

2017

October

Members Conference

Dates: 20th to 22nd October

Venue: Hodson Bay Hotel, Athlone, Co. Westmeath.

November

Memorial Service

Date: Sunday 26th November

Venue: I.H.S. Office, Dublin 8.

Haemophilia Camp Barretstown

Dates: 27th to 30th November

Venue: Barretstown, Co. Kildare.

December

Christmas party for kids

Date: Saturday 9th December

Venue: Grand Hotel, Malahide, Co. Dublin.

2018

2018

March

50th Anniversary AGM & Conference

Dates: 2nd to 4th March

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

May

Carrier Conference

Dates: 12th & 13th May

Venue: Castleknock Hotel, Dublin.

June

Ageing Conference

Dates: 22nd to 24th June

Venue: Killeslin Hotel, Portlaoise, Co. Laois.

September

50th Anniversary Gala Dinner

Date: 22nd September

Venue: Castleknock Hotel, Dublin.

October

October Conference

Dates: 19th to 21st October

Venue: Radisson Hotel, Co. Sligo

November

50th Anniversary Memorial Service

Date: 4th November

Venue: T.B.C.

December

50th Anniversary Children's Christmas Party

Date: 8th December

Venue: Clarion Hotel, Liffey Valley, Dublin.

Noticeboard

St. James's Hospital Patient Feedback / Patient Experience

It is the aim of St. James's Hospital to meet the needs of all patients and their families. They believe it is important for patients and their families to give their opinion about the services they receive. They will use feedback to continue doing what they do well and to make improvements where recommended.

There are a number of ways to give feedback as follows:

Compliments, Comments, Concerns

Hearing about the experience that patients and families have is very important because it enables St. James's Hospital to pass on feedback to the staff and to make improvements. Compliments, comments and concerns can be submitted by post, by email to patientfeedback@stjames.ie or by appointment by calling the Patient Experience Office on 01 4103361.

Formal Complaints

The hospital encourages patients and families to let those involved in their care know if they have a concern. Any concerns should be discussed in the first instance with the manager of the ward or department so that a solution can be found locally. If this is not possible or if you do not feel comfortable discussing your concern with the manager or staff member involved, a formal complaint can be submitted in writing by post to the Patient Experience Office, CEO Building, St. James's Hospital, James's Street, Dublin 8, Email: patientfeedback@stjames.ie or by appointment by calling the Patient Experience Office on 01 4103361.

Patient Representative Group

The group comprises of patients and family members who have had a personal experience in St. James's Hospital. Patient representatives work in partnership with hospital staff to:

- Advise and give feedback
- Provide the patient and family perspective for staff
- Review recommendations, quality improvement projects, service developments and information leaflets brought to the group by hospital staff
- Actively participate in the development of new facilities or refurbishments
- Keep the patient and family as the focal point of our health system

Meetings are held monthly in the hospital. If you are interested in being a patient representative or would like further information please contact: Maria Kane, Quality Manager, Person Centred Care, CEO Building, St. James's Hospital Tel: 01 4162153 Email: mkane@stjames.ie

Contact Details

Patient Experience Office, CEO Building, St. James's Hospital, James's Street, Dublin 8.

Name	Title	Telephone	Email
Nikki Deegan	Complaints Manager	01 4103361	patientfeedback@stjames.ie
Julie Sampey	Complaints Manager	01 4284248	patientfeedback@stjames.ie

Noticeboard



National Coagulation Centre Women's Clinic

In recent years, there has been a growing awareness of the needs of women with bleeding disorders. The National Coagulation Centre (NCC) team, led by Dr. Niamh O'Connell, Consultant Haematologist, initiated a clinic dedicated to women with bleeding disorders providing a wide range of medical, nursing and the support services of a social worker and clinical psychologist. For more information please call 01 416 2141.



Brian O'Mahony Award

Nominations are now open for the 'Brian O'Mahony Award for outstanding contribution to haemophilia care in Ireland'. Nominations can be proposed only by paid up members of the Society. Members of the current board or staff cannot be nominated. If you would like to nominate an individual who, in your opinion, has made a real difference in haemophilia care in Ireland, in 2017, please send your nomination to: info@haemophilia.ie by 29th September 2017.

Noticeboard



Inhibitors

People with haemophilia receive recombinant factor concentrates to help their blood to clot. However, in some people, the immune system may produce antibodies which block the effects of the treatment. These antibodies are known as inhibitors. Do you, or a member of your family, have a current diagnosis of having an inhibitor? If so, please get in touch with the Society to ensure that we can provide you and your family with the most up to date information, education and that we continue to provide the best level of support. If you have had an inhibitor in the past and it has successfully been treated, please also contact us so that we can update our records.



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



Planned Giving

We are asking members to consider committing planned monthly or annual donations to the Society at a level which they can afford. We hope that you will consider participation in this planned giving campaign to allow us to work for a better future for you and for those with haemophilia in developing countries. If you would like more information on this, please call Nina on 01 6579900.

Noticeboard



Leave a legacy

We are asking you to leave a donation or legacy to the Society in your will. A strong active and effective Haemophilia Society is essential and will continue to be essential in the future if we are to optimise the quality of life for people with bleeding disorders in this country.

We hope that you will support our endeavours by positively considering leaving a present for the future and leaving a legacy to the Society.



Post

As you are aware the cost of post has increased substantially over the last year. Due to the increased cost to the Society in relation to post, we are asking members to consider joining our electronic mailing list for publications. By doing this you will receive the quarterly magazine online via our monthly MailChimp magazine, along with other publications. However, you will still receive all notifications in relation to upcoming events and conferences by post. If this is something you would like to do, please call the office on 01 6579900.

Wedding Favours

We aim to assist everyone with a bleeding disorder to live positively, to be proactive with their health and to maximise their quality of life. Without the generosity of our supporters, we would be unable to achieve these objectives and we would sincerely like to thank those who have donated to the Society. If you would like to find out more about how you can organise wedding favours, contact Nina in the office on 01 6579900.





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