Magazine of the Irish Haemophilia Society

haemophilia.ie

Representing people in Ireland with Haemophilia and related bleeding disorders.

The Society at a Glance

908 Facebook Followers

50 Planned giving Contributors

74 IHS Volunteers

5924 Website Hits

Irish Haemophilia Society Hoodies

Our comfy I.H.S. hoodies are now available to purchase at all of our events and conferences. They come in a range of different sizes and are priced from €20 to €25. If you are interested in purchasing a hoodie, please give the office a call to place your order. We can have your hoodie available for collection at the next event or conference, that you attend.

Sizes Available

Children sizes:	2-3, 5–6, 7-8, 9-10, 11-12, 12-13
Adult sizes:	S, M, L, XL, XXL

Cost

Adult Hoodies:	€25.00
Children Hoodies:	€20.00

A Note from the Editor

Hello everyone,

Welcome to the Autumn edition of haemophilia.ie.

In this edition on page 4, our Chief Executive gives an update on what is happening in Europe in relation to new recommendations and regulations around haemophilia treatment. It's definitely worth a read.

A huge thank you to all those who have been fundraising for the Society this year. It is very much appreciated. For an update on this, go to page 8.

We now have set dates and venues for all the main conferences and events for 2017. Why not put the dates in your diary now. For more information go to page 9. We will be kicking off 2017 in style by travelling to the Slieve Russell in Cavan for the AGM and Conference in March!

If you are interested in reading about our Parents Conference that took place in Athlone, look no further. Go to page 12 where you will find a report from members Karla and Iain Ellis and some lovely photos from the weekend.

On page 15 you will find some information on what's involved in relation carrier testing.

Go to page 18 and 19 for our noticeboard which gives little snippets of information about various items of interest.

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. If you need assistance, support, advice, information, a home visit, a hospital visit or just a chat, call Nina, Brian or myself in the office on 01 6579900 and we will be more than willing to help in any way we can.

HAPPY HALLOWEEN!

Debbie Greene
Administrator

Contents

CEO's Report

Brian O'Mahony, Chief Executive

The European Directorate for the Quality of Medicines and Healthcare (EDQM) is an official Council of Europe body, which makes recommendations every three to four years on the optimal use of blood and blood products, including recommendations on treatment of haemophilia.

The EDQM previously made recommendations in 1999, 2009, 2013 and most recently in May of 2016. The recommendations are then circulated at a meeting attended by approximately 150 expert clinicians, scientists and a small number of patient leaders. The importance of the recommendations is that they come from an official body of the Council of Europe and in 2013 they were also formally endorsed by the Council of Europe. This lends weight to the recommendations as these are then effectively standards, often minimal standards, which any country can use to advocate for improved care with their Government, given the fact that they are endorsed by the Council of Europe. In 2009, 2013 and 2016, the European Haemophilia Consortium (EHC) played a large role in the discussions and the formulation of the recommendations. Our influence on this process was partially due to the extensive data we collect every three years on every aspect of treatment and care in Europe.

The cumulative data we collected in late 2015, from 37 European countries, on standards of care, helped to provide evidence for many of the recommendations. This year, a total of 12 recommendations were agreed at the meeting following a discussion and workshop co-chaired by Professor Paul Giangrande and I. In many cases, you are looking at deficiencies or gaps in care and outlining minimum requirements or standards. These are often currently exceeded in many more economically resources western European countries, but remain aspirational goals for many other countries in central or eastern Europe.

It is instructive to look at some of these new recommendations in relation to the current reality of treatment and care in Ireland. There is currently a system of certification of haemophilia centres in Europe where centres are categorised as either European Haemophilia Comprehensive Care Centres (EHCCC), who treat a minimum of 40 people with severe haemophilia regularly or European Haemophilia Treatment Centres (EHTC), who treat a minimum of ten people with severe haemophilia regularly (this is one of many criteria for certification).

The first recommendation stated: *"Hospitals providing clinical care for people with haemophilia and related disorders are strongly recommended to seek formal designation as either EHCCC or EHTC".*

In Ireland, the centres in St. James's Hospital, Our Lady's Children's Hospital, Crumlin and Cork University Hospital have already been designated as EHCCC with the centre in Galway University Hospital designated as an EHTC.

The second recommendation stated: *"There should be agreed national protocols or guidelines on management of the ageing patient with haemophilia. Treatment centres are encouraged to include an appropriate general physician in the comprehensive care team".*

This is still under discussion in Ireland but it is increasingly accepted that a general practitioner should work with the centre and possibly be added to the comprehensive care team to advise on normal complications of ageing (i.e. high blood pressure, risks of cardiac or renal disease or cancer among other possible conditions). In terms of factor usage, this is expressed as units per capita (total number of units used divided by total population. For example, if a country with a population of 10 million uses 30 million international units of factor VIII, their usage is 3 I.U per capita). The minimum recommended usage of factor VIII (FVIII) has increased from 1 in 1999 to 2 in 2009, to 3 in 2013 and to 4 in 2016. This is important for many European countries who treat sub-optimally. Ireland currently uses 8.5 IU per capita. In terms of factor IX (FIX), a minimum use figure was agreed this year for the first time at 0.5 IU per capita. Ireland has the highest per capita FIX use in Europe at 2.37 IU per capita. This is partly a reflection of the fact that a higher proportion of our haemophilia patients have FIX deficiency that in any other European country. We have been very concerned about the lack of access to hepatitis C treatment for people with haemophilia in many European countries. Given the fact that hepatitis C in haemophilia was a consequence of the provision of unsafe blood products in the past, we were of the view that European governments have a moral obligation to offer treatment to people with haemophilia with the new direct acting antivirals on a prioritised basis. This was agreed as a recommendation. In Ireland, we have aggressively and effectively advocated for priority for treatment for people with haemophilia over the past four years. The result is that there are now, to our knowledge, less than five people with haemophilia who have not completed, commenced or have a start date for treatment. We anticipate hepatitis C being effectively eradicated in the haemophilia population in Ireland in 2016. The very small number of people with haemophilia who have not cleared the virus have been offered re-treatment. We expect to be the first country in Europe, and to our knowledge, the world to achieve this in people with haemophilia.

There were two recommendations on inhibitors, setting out the requirement for people with inhibitors to have access to immune tolerance therapy (currently available in approximately 60% of European countries) and access to elective surgery. Both of these are available in Ireland. The EHC will host the first ever European summit for people with inhibitors in Barretstown, Co. Kildare in December of this year. This novel event will be attended by 120 people with inhibitors or family members from most European countries, including Ireland.

In our European survey of methods of purchasing and selecting factor concentrates in 2014, only 19 of 38 European countries surveyed carried out a tender process to select factor concentrates. Several countries consulted the national haemophilia organisation during their tender process, but in only two countries (Ireland and Serbia) were the Haemophilia Society formally represented on the Tender Board, which selects the factor concentrates. A recommendation was agreed that national or regional tenders for factor concentrates are encouraged and should always include both haemophilia clinicians and national haemophilia patient representatives. Ireland has led the way in this vital area. The availability of extended half life factor concentrates has the potential to change, individualise and improve treatment. Current prophylaxis regimes are predicated at maintaining the FVIII or FIX level at greater than 1% (trough level) at all times. This is designed to prevent most spontaneous bleeding episodes. It is now increasingly recognised that this 1% level does not confer sufficient protection against bleeding episodes especially in those who are very active, those with damaged or target joints, those with a low individual factor half life and also may not prevent micro bleeds. There is increasing discussion of the need to increase minimum trough levels and therefore increase protection

from bleeding. The meeting could not agree a specific targeted higher trough level but the principle was agreed with a recommendation that treatment with extended half-life factors should be individualised and protection against bleeding should be improved by increasing trough levels.

Finally, the recently published SIPPET study which looked at the relative risk of developing inhibitors using recombinant FVIII as opposed to plasma derived FVIII containing von Willebrand factor demonstrated a significantly higher risk of FVIII inhibitors when using recombinant FVIII. This has led to the need for discussion of the best treatment option for newly diagnosed previously untreated patients with severe FVIII deficiency, especially for the period of their first 50 exposure days. This led to a recommendation stating that there is increasing evidence that the incidence of inhibitors amongst previously–untreated patients (PUP's) varies between products. Steps should be taken to understand and minimise this risk. (Patients, or their parents, should be involved in discussions related to product choice). In Ireland, the decision has been taken to not change treatment practice across the board but the results of this study will be discussed with parents of newly diagnosed children with severe FVIII deficiency by the clinicians and a decision taken on a case by case basis.

As should be evident from these recommendations and the current reality of care in Ireland, we are fortunate to have standards of treatment and care which greatly exceed the minimum and in most cases approach the optimum level of care. There are improvements to be made and gaps to close but it is useful to be able to benchmark our care with the current reality in Europe and against the new recommendations.

Brian O'Mahony
Chief Executive

TRAVEL

Before travelling abroad identify the nearest haemophilia treatment centre at your destination.

Talk to your Haemophilia Treatment Centre and the Irish Haemophilia Society before travelling for information and advice.

Travel insurance should be checked well in advance of departure as it can be difficult to obtain for a person with haemophilia. Full disclosure is required and there will be some loading on your premium. However, this should not be a significant amount.

You will require a letter from the your Haemophilia Treatment Centre for airport security/customs. The letter should be on headed paper and confirm that you are carrying treatment, needles, syringes etc, as well as relevant information on any metal implants (such as knees or hips) that may set off the security scanners. The letter should not be more than six months old and should be updated as necessary. This letter should be signed by a consultant doctor. To allow for some delays you should pass through security as early as possible.

6 months

How often you should update the letter required from the NCHCD for carrying your treatment abroad.

Always carry your own treatment including syringes, needles etc. in your hand luggage (preferably in a small cooler bag). When packing factor, you should bring your regular dose for the duration of your trip plus sufficient factor for at least one extra 100% rise.

It may be useful to pack one medication information insert and one box cover. In the event that you cannot treat yourself, or if there is a language barrier, this would be useful for the treating doctor.

If you are planning a long haul flight it may be useful to take some treatment before you leave.

USEFUL SITES:

www.haemophilia.ie **www.wfh.org** **www.ehic.ie**

The Irish Haemophilia Society

Tel: 01 657 9900 **Web:** www.haemophilia.ie **Email:** info@haemophilia.ie

VHI Women's Mini Marathon

It was another successful year for the VHI Women's Mini Marathon that took place in Dublin on the 6th June 2016. This event is in its 34th year and remains the biggest single-day charity fundraiser in Ireland. This year saw just under 35,000 ladies take part in the 10km race and according to organisers the youngest entrant was 14 years of age and the oldest was over 70 years. A staggering 800 charities benefitted and almost €200 million has been raised since the event began in 1983. We would like to thank all our amazing ladies who took part to fundraise for the I.H.S. We really appreciate your fundraising efforts and support and hope you all had a fantastic day.

If you would like to support the I.H.S. and organise a fundraising event, remember we are here to offer you any help we can. You may be taking part in an event which is already organised and want to raise sponsorship. We can provide I.H.S. t-shirts, print posters and tickets, sponsorship cards or apply for Garda permits if needed. Maybe you would just like some advice on how to get started? If so please contact the office on 01-6579900 or email nina@haemophilia.ie. We would really appreciate your support!

Car Boot Sales are becoming very popular. Why not have a de-clutter, get rid of unwanted books, DVDs, clothes or that Christmas gift you never liked. Then rope in family and friends to do the same and have a car boot sale to fundraise in aid of the I.H.S. To check out when and where car boot sales are on around the country log onto www.collectireland.com/car-boot-sales.

Everyone enjoys a ***Table Quiz.*** Many local pubs will be happy to reserve tables' mid-week for a fundraiser. You will need some family and friends to help out on the night and the I.H.S. would be happy to prepare posters and anything else you might need.

A good place to start when you are organising a ***Bake Sale*** is your local bakery. They will often be happy to contribute to a good cause.

Check out events in your area where you might be able to set up a stall or contact your local school or community centre or clubs.

Nina Storey

Dates for your diary for 2017

AGM & Conference
Dates: 3rd to 5th March 2017
Venue: Slieve Russell Hotel, Co. Cavan

Ageing Conference
Dates: 12th to 14th May 2017
Venue: Kingsley Hotel, Co. Cork

Parents Conference
Dates: 16th to 18th June 2017
Venue: Killashee Hotel, Co. Kildare

October Conference
Dates: 20th to 22nd October 2017
Venue: Hodson Bay Hotel, Co. Westmeath.

Welcome to the Cubs Club Autumn Edition!

We hope everyone is settled back into school. Brian always loves going back to school to see all of his friends after the summer holidays!

Last week Brian was playing football in the yard with his friends at break time and hurt his leg – he didn't want to tell his teacher because he wanted to keep playing. In the afternoon his leg got really sore, because he didn't tell an adult when it happened Brian thought he would get in trouble, so he didn't tell anyone he was in pain!

When Brian went home from school he pretended that he was fine, but later that night before going to bed, when his leg was really sore, he had to tell his Mammy what had happened!

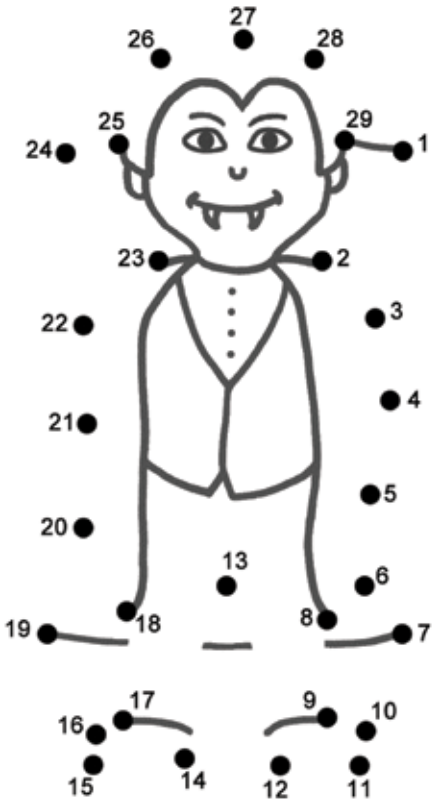
Brian's Mammy was a little cross at first because he didn't tell her earlier, but she was really happy that he told her before the bleed got worse and she gave him his factor so that Brian wasn't in pain anymore! Brian can't play football for the rest of the week leg but he is looking forward to playing next week. ☺

What do you think Brian should do if he hurts himself in school?

When you have a bleed it is very important to look after yourself. You should always tell an adult, so that they can help you take your factor and make sure you are ok. Remember there are four simple steps to keeping healthy and safe:

REST, ICE, COMPRESSION AND ELEVATION (R.I.C.E.)

Dracula – *join the dots*



Jokes

Why is Dracula so unpopular?

Because he is a pain in the neck ☺

What do witches get in hotels?

Broom service ☺

Why didn't the skeleton cross the road?

Because he had no guts ☺

Kidlink

Barretstown Haemophilia Camp

Barretstown are having a special camp for 7 to 17 year olds with haemophilia and related bleeding disorders on the 3rd – 6th of November. This is a great chance to meet up with your old friends from the haemophilia weekends but also to meet new friends! You probably know already but in Barretstown you get to do lots of activities 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 you a place at camp.

Whats New!

Have you heard your parents or doctors talking about Longer Acting Factor? Are you getting less injections than you did before? Do you know why?

Brian wasn't so sure why he was getting fewer injections than he did before – let's find out why!!

Why do we need to take factor for haemophilia?

When you have haemophilia it means that your blood doesn't form a clot properly. Your blood needs to be able to form a clot to stop bleeding after an accident or an injury. When you get an injection to replace the factor you are missing from your blood, a clot can then be formed and you should not get any bleeds!

What is Longer Acting Factor?

When you get your injection, the factor works in your body to help form a clot. However, the factor in your blood doesn't last for long. That's why you need to take regular injections of factor during the week to make sure you have enough factor in your blood to keep you safe. **BUT NOW** with Longer Acting Factor products the factor will last longer in your blood, than it did before. This means you might be able to have less injections and still be safe from having a bleed or you might have the same number of injections each week but have higher factor levels in your blood, which will give you more protection from having a bleed, especially if you are very active in school or at home.

Parents Conference

We had the pleasure of attending this year's Parent's Conference in the lovely Sheraton hotel in Athlone. This was our 8th year attending this conference. The Parent's Conference or as we like to call it "The Family Conference" is our favourite, as not only do we learn about all the new and exciting developments in the world of haemophilia, we also get to reconnect with the families we have got to know throughout the years. Personally, it is like a "family reunion!". It's also a great way to meet the new families who have joined the Society.

We arrived at the hotel on the Friday evening. After checking in and registering we went for a family swim, then back to the room to get settled and ready for the weekend ahead. However, as is with many families, when we stay in any hotel, sleep is not great.

Saturday morning arrived nice and early. We all made our way, half asleep, down to the restaurant. After filling up on a lovely breakfast, (Iain had a moan about the fruit salad), we brought Leo to the crèche and Adam to the Kidlink group. The first session we attended was the 'Home Infusion Demonstration Workshop" and we were very proud parents as Adam was one of the kids doing the demonstration. It was a truly enjoyable time with mum Barbara and son Callum and our son Adam answering all the questions asked of them. We were very impressed with both boys having the confidence to self-infuse in front of a room full of grown-ups! What an achievement. We, personally, would have liked to have seen some of the younger members who are about to start home treatment or taking an interest in home treatment attend this demonstration, however afterwards we were informed that the Society have an educational programme in place in conjunction with OLCHC. We feel it is important for younger members to see someone of their own age group self-infusing. We can definitely see Adam and Callum on the Board in the future! After lunch, we attended the Mothers and Fathers workshops. These are, in our opinion, the most important talks to attend over the

Parents Conference

weekend. Seeing the changes in the mother attitudes and confidence levels growing over the past 8 years proves how well and how far we have come. The experience and advice given from the "seasoned" mothers is very different from when I joined! The fear of talking about haemophilia, talking to doctors, family and friends is no longer there. The support is unprecedented and Fiona, also, did an excellent job as a mediator. Regarding the Father's workshop it was very good as all the fathers had children at different stages, which gives the advice and support for what comes next in their child's life. While we were attending our meetings Leo was being spoilt by the girls in the Crèche. But, unfortunately, this time, Adam found the Kidlink not for him as he was a lot older than the majority of the kids. Next year he will be in the youth group and hopefully will have a much better time.

Saturday night was, unfortunately, another broken night's sleep. However, after another lovely breakfast and dropping the boys off, we attended the 'Extended Half-Life treatment – Experience to date' talk. It was chaired by Brian O'Mahony with Barbara Wynne and John Finn on the panel. As usual, Brian was full of knowledge and up to date information. This meeting was very important to us as Adam would be starting the treatment a few weeks later. It was brilliant to hear how well the treatment is working for both factor VIII and factor IX. We also heard the amazing new developments regarding Gene Therapy. It was very exciting to find out that it has been successful for factor IX patients and it is on the verge of being as successful for factor VIII patients. It is obvious that there is a long way to go. But the fact it has started is incredible. This is something we have been hearing about for the last five years plus and now that it is happening its mind blowing. The information was almost too much to take in!

With the extended half-life treatment, the future for children with haemophilia is looking very positive. It just goes to show that the haemophilia of past years is a different world to the haemophilia of now.

The conference ended with lunch and the Ireland V France football game, but we shall say no more about that!

We are looking forward to the Member's Conference in October and what it has to offer.

Iain and Karla Ellis.

Parents Conference

Carrier Testing

Inherited bleeding disorders such as haemophilia can have an impact on daily life and psychological wellbeing not only of the affected individual but also on carrier mothers and other close family members. Before embarking on parenthood, known carriers or those who have the possibility of carrying haemophilia should be given the opportunity to consider the implications for their children and themselves.

Carrier testing in haemophilia is dependent on the accurate taking of family history and confirmation of family relationships. A woman can be defined as an obligate (definite) carrier of haemophilia if; her father has haemophilia or she has two children with haemophilia or she has a child/grandchild with haemophilia and a maternal relative with haemophilia. It is important to remember that in 30% of women who are carriers of haemophilia, there is no family history of the disorder and it has occurred in the family as a result of a spontaneous mutation.

The genetic abnormality (mutation) that causes haemophilia occurs on the X chromosome which is passed from parents to their children. The inheritance pattern of haemophilia if the man has haemophilia is illustrated in figure 1. In general, all the daughters of a man with haemophilia will be carriers and none of the sons will be affected. The inheritance pattern of haemophilia if the woman is a carrier of haemophilia is illustrated in figure 2. In general, there is a 50% chance that any daughter will be a carrier and a 50% chance that any son will have haemophilia.

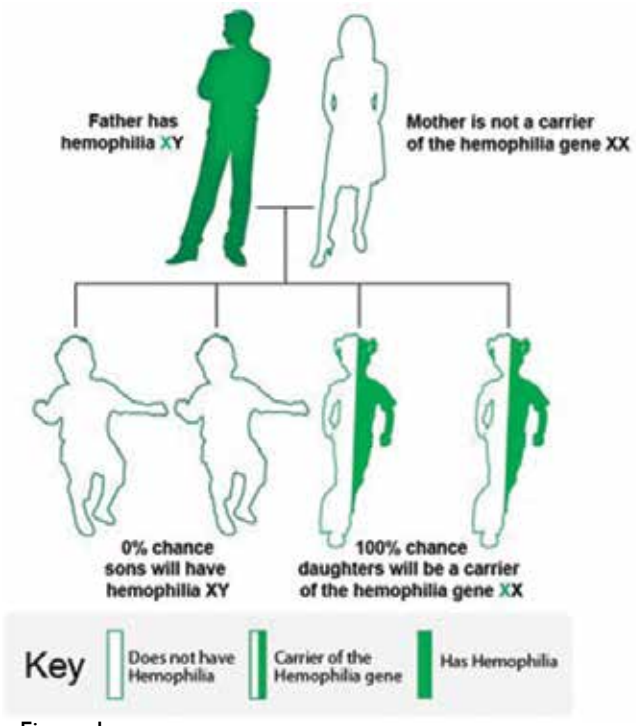


Figure 1

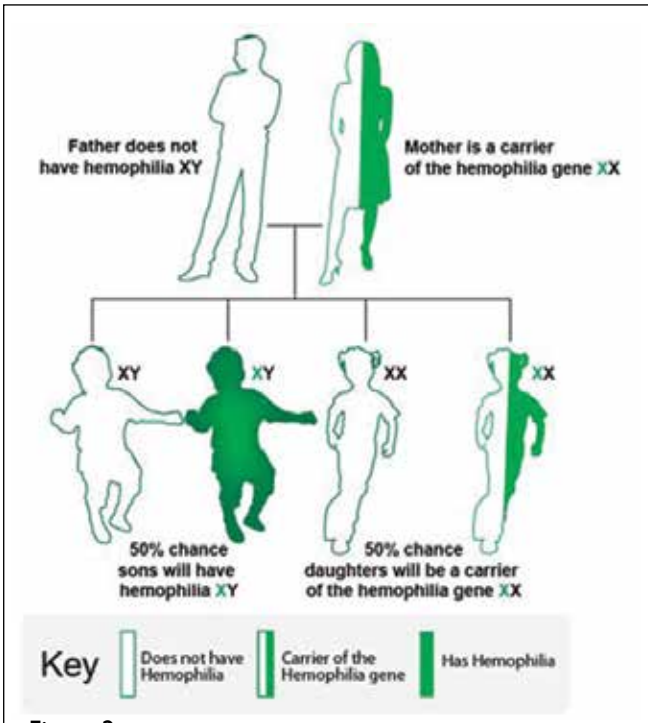


Figure 2

Genetic testing can be done to determine carrier status. These tests are complex. However, results are more reliable if DNA from a family member with haemophilia is also available.

In Ireland, the policy is that a possible carrier must be old enough to understand the implications of the test results before genetic testing is carried out. This is usually after 16 years of age. The sooner a girl is tested after this age, the more time she has to come to terms with being a carrier. It also prepares her for eventual decisions about pregnancy and childbirth.

People cope in different ways when they are faced with new information. This depends on age, reasons for seeking the test and on any previous experience they might have with the condition. Carriers can receive this diagnosis at a young age due to health problems, or as adults after the birth of a child with haemophilia in the family. A girl or woman can experience a wide range of emotions when she finds out that she's a carrier. She may be afraid of what it will mean for her, her relationships and any children she may have. She may feel a sense of loss that she is different from everyone else and may even fall into a pattern of denial and refuse to acknowledge the diagnosis. When a son is diagnosed with haemophilia and there is no family history, parents also have to deal with the possibility that his sisters are carriers. A person's decision to progress with carrier testing can affect the extended family. Genetic counsellors can provide suggestions on how to inform other at-risk female relatives such as sisters, daughters or nieces.

For more information, please contact

The National Centre for Hereditary Coagulation Disorders (NCHCD) at St. James's Hospital on 01 4162141 / 01 4162142 or Cork University Hospital on 021 492 2278 for advice and an appointment.

F.A.Q.

How is carrier testing carried out?

The method that is used at present to determine carrier status is direct mutational analysis. A blood sample is first required from an affected male in the family and from the female requesting testing. There are many different genetic mutations that result in haemophilia and the most common of these are carried out first. The identification of more unusual mutations might be time-consuming and could take up to two years for results to be available.

What does it involve for me if I want to be carrier tested?

An affected male in the family needs to attend with you in the clinic or at an earlier date to give a blood sample. You will have an opportunity to discuss the genetic inheritance of haemophilia and the consequences of being a carrier with haemophilia with one of the specialist nurses. You will be asked to sign a consent form and a blood sample will be taken. You will be contacted when the results of your carrier testing are available and asked to attend to discuss these results and to give a confirmation sample of blood.

If I am a carrier of haemophilia with a low factor level, can I bleed?

Females who are carriers of FVIII or FIX deficiency may have reduced levels. Approximately 10% of carriers will have a level below 30% (normal is 50 – 150%). Carriers with reduced FVIII or FIX levels are managed in the same way as men with mild haemophilia. They will have a bleeding tendency which will be problematic at times of surgery, childbirth, dental work or after an accident or fall.

If a girl has a normal factor level does this mean that she is not a carrier?

No. It is very important to note that most carriers of haemophilia will have a normal factor level.

I am a carrier of haemophilia and have one child who has haemophilia. Does this mean that the next child will not have haemophilia?

No. The risk of having a child with haemophilia is the same for every pregnancy.

Noticeboard

New Staff

Paula Houlihan

Paula Houlihan joined the I.H.S as an Administrative Assistant in August 2016 and will be working in the area of social media and publications. Paula will also be looking after the logistics of the apartment facility for members at Hyde Square in Dublin. Paula was born and raised in Canada to Polish parents before relocating back to Poland. At the age of 16 Paula moved once more with her parents and found herself here in Ireland. Since then she has worked within many healthcare settings including a nursing home, GP and dental practice, chiropody centre and a dermatology clinic. Paula is looking forward to getting involved and joining the team at the Irish Haemophilia Society and is extremely excited for this new chapter in her busy life.

Educational Grants

The closing date for applications for educational grants was Friday 30th September 2016. Everyone who applied, will be notified in writing at the end of October in relation to recipients for 2016/2017.

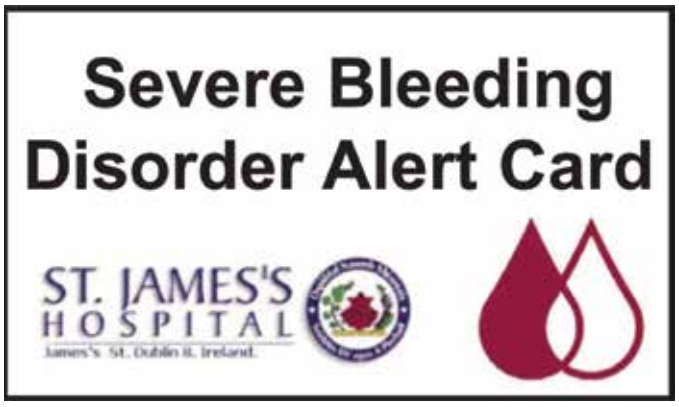
Hyde Square

The Hyde Square apartment facility for members is available to people (who must be 18 years of age) with haemophilia or related bleeding disorders, and accompanying family members, travelling from outside of Dublin to attend hospital appointments or when an in-patient. You will be asked to confirm the date and time of your hospital appointment or in-patient admission. If you have an appointment coming up and are travelling from the country, please contact Paula or Debbie in the office on 01 6579900 to make a booking.

Planned Giving

We are asking members to consider committing planned monthly or annual donations to the Society at a level which they can afford. Of the funds raised, 75% will go to defray the cost of the apartment and 25% will go to our overseas development fund.

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.



Severe Bleeding Disorder Alert Cards

A reminder to you all to make sure that you carry your 'Severe bleeding disorder alert card' with you at all times. It is so important that people with haemophilia are treated promptly if they need to attend an Emergency Department in any hospital. Your consultant haematologist at your treatment centre will provide you with a card, so if you have not already received same, please ask for one when next attending your treatment centre.

Brian O'Mahony Award

If you would like to nominate an individual (be it a member of the I.H.S., a health care professional, or a person from abroad) who has made an outstanding contribution to haemophilia care in Ireland, please send your nomination to Debbie Greene (Email: debbie@haemophilia.ie)

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.

Ezine

If you would like to sign up for our monthly electronic Ezine magazine, please contact Aoife in the office on 01 6579900. (Email: aoife@haemophilia.ie) This electronic magazine gives reminders of events, articles of interest other up to date things that are happening in the I.H.S. and is sent out on the last Thursday of every month.

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