Haemophilia.ie

Representing People in Ireland with Haemophilia, von Willebrands & Related Bleeding Disorders

Magazine of the Irish Haemophilia Society

Summer 2020

The Society at a Glance

74	46	1427	961
I.H.S. Volunteers	Planned Giving Contributors	Facebook Followers	Twitter Followers

FROM THE EDITOR

I hope you are all keep well. It has been a strange few months since the last magazine, but the country looks to be coming out the other side now.

The I.H.S. team has like many of you, been working from home but we're very proud that we've kept strong as a community and we've kept in touch through phone calls, email, social media, e-zine and our Webinars via Zoom – the latter has been a big success.

Now, back to the magazine. On page 03, you will see an updated calendar of events with a mixture of online and real world events. On Page 04, Brian provides an update on Twinning, Gene Therapy and reports on the WFH Virtual Congress and outlines plans for re-opening the office. Speaking of virtual events, Nina reports from the EHC Women & Bleeding Disorders Virtual Congress 2020 on page 07.

It is Educational Grants time of the year, you will find all you need to know on page 10, the grants are a great help to alleviating some of the financial burdens of education. On page 12 Jennie and Evan McBride offer their respective perspectives of being a parent of a child with haemophilia and being the person growing up with a bleeding disorder.

On page 14, we have the first in a series of articles on Haemophilia Care in Europe from Brian, up first is 1970s - 1980s. On page 17 we catch up with Colm Walsh to find out his new blog and on pages 18 and 19, there some notices and updates.

Lastly, I hope you enjoy this issue – a second remotely produced and digital only magazine - and are all keeping well, and remember, if you wish to contact a member of staff between 9am and 5pm Monday to Friday, please phone the office (01-6579900) as normal, or you can email us as usual too.

Barry

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DATES FOR YOUR DIARY

A mixture of virtual and realworld events coming up over the next few months:

Upcoming Webinars & Events

Gene Therapy Webinar

Wednesday July 22 @ 6pm: Gene Therapy Discussion with Declan Noone & Brian O'Mahony

Von Willebrand's Disorder (VWD) Information Day 2020

Saturday August 29, 12 Noon - 4PM
Castleknock Hotel, Dublin

To register online, please click here or if you would like to book in over the phone or would like more information, please contact the office on 01 6579900.

October Conference 2020*

Friday, October 16th to Sunday 18th
Mount Wolseley, Co Carlow

***We will have an update for members at the end of August in relation to whether this event will go ahead face to face or virtually.**

VON WILLEBRAND'S DISORDER INFORMATION DAY

CASTLEKNOCK HOTEL, DUBLIN
SATURDAY AUGUST 29, 2020

THIS EVENT IS FREE TO ATTEND, TO BOOK YOUR PLACE, CONTACT THE I.H.S. OFFICE ON 01 657 9900 OR SEE HAEMOPHILIA.IE FOR MORE INFO.

PROGRAMME

12:00 - 13:00	LUNCH
13:00 - 14:30	VON WILLEBRAND'S DISORDER – AN UPDATE SPEAKER: DR. MICHELLE LAVIN
14:30 - 15:30	LIVING WITH VON WILLEBRAND'S DISORDER SPEAKERS: MR. DONAL MCCANN AND MS. SHANNON CAREY
15:30 - 16:00	VON WILLEBRAND'S DISORDER AND THE I.H.S. SPEAKER: MR. BRIAN O'MAHONY

SPACES ARE LIMITED AND YOU MUST REGISTER IN ADVANCE TO ATTEND

Irish Haemophilia Society
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CEO REPORT

WFH Virtual Summit

Due to the Covid-19 pandemic, the WFH International Congress this year, which was due to take place in Malaysia, was organized virtually in June as a Global Summit. The event was very successful. We did lose the ability to interact face to face, to meet speakers, to discuss new information together. However, we gained the opportunity for people who would otherwise not have been able to attend due to time or finance constraints to attend. I greatly appreciated the fact that registration was free of charge. This enabled any member of the Society who wished to attend to do so. All of the staff and several members of the board attended, and the Society are producing a newsletter supplement on the Summit. Ireland was well represented among the speakers with Dr. Niamh O Connell, Dr Michelle Lavin, Prof. Alison Dougall and I all speaking at the summit.

As you would expect, the programme was varied and multidisciplinary. I was particularly focused on the sessions on Gene Therapy and on Novel current and future therapies. The scene was set for the Gene Therapy sessions by Dr. Konkle from the USA who spoke about plans for a WFH Global Haemophilia Gene Therapy registry. This is a very sensible idea which WFH have been developing over the past 2 years. With the number of people with haemophilia enrolling in clinical trials increasing and the first Gene Therapy probably being licenced for haemophilia in the USA later this year, it is wise to consider establishing a global registry which would gather core data on all those treated with Gene Therapy. If data is gathered separately from each clinical trial or for each licenced product, it will be difficult to build a complete picture of safety and efficacy. Rare adverse events or trends may be missed. A global registry would solve that problem. The proposed registry would gather core data including demographic data, gene therapy infusion details, safety data on any adverse events and efficacy data (bleeding events, factor activity levels and use of factor concentrates or other treatment). It would also gather information on quality of life and on cause of death. A separate workstream is ongoing looking at requirements for Gene Therapy education materials. I was pleased to see the paper on this topic in the journal Haemophilia, on which I was a co-author, mentioned prominently during this session.

Interestingly, the journal has now taken the unusual step of producing a separate Infographic and video based on this paper. We will share the Infographic in a future edition or in our planned specific educational booklet on Gene Therapy when published. There are currently 4 Phase 3 (the last phase prior to licencing) clinical trials ongoing for Gene Therapy in haemophilia - 2 for Haemophilia A and 2 for Haemophilia B. Several other clinical trials are in Phase 1/2. We anticipate

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REVIEW ARTICLE

Haemophilia WILEY

How to discuss gene therapy for haemophilia? A patient and physician perspective

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Abstract
Gene therapy has the potential to revolutionise treatment for patients with haemophilia and is close to entering clinical practice. While factor concentrates have improved outcomes, individuals still face a lifetime of injections, pain, progressive joint damage, the potential for inhibitor development and impaired quality of life. Recently published studies in adeno-associated viral (AAV) vector-mediated gene therapy have demonstrated improvement in endogenous factor levels over sustained periods, significant reduction in annualised bleed rates, lower exogenous factor usage and thus far a positive safety profile. In making the shared decision to proceed with gene therapy for haemophilia, physicians should make it clear that research is ongoing and that there are remaining evidence gaps, such as long-term safety profiles and duration of treatment effect. The eligibility criteria for gene therapy trials mean that key patient groups may be excluded, eg children/adolescents, those with liver or kidney dysfunction and those with a prior history of factor inhibitors or pre-existing neutralising AAV antibodies. Gene therapy offers a life-changing opportunity for patients to reduce their bleeding risk while also reducing or abrogating the need for exogenous factor administration. Given the expanding evidence base, both physicians and patients will need sources of clear and reliable information to be able to discuss and judge the risks and benefits of treatment.

KEYWORDS
Adeno-associated virus, factor IX, factor VIII, gene therapy, haemophilia

1 | INTRODUCTION

1.1 | Gene therapy for haemophilia

Gene therapy (GT) for haemophilia is being evaluated for its potential to provide long-term, potentially curative treatment for people with haemophilia (PWH) by increasing endogenous clotting factor activity. This approach could replace the current standard of care, namely exogenous factor replacement that has undergone significant improvements over the last few decades but remains suboptimal in terms of preserving joint and overall health and is associated with a significant quality of life (QoL) burden. While GT has the potential to improve physical health and overall QoL, clinical experience is still relatively limited. This article provides perspectives from a haemophilia patient advocate, with personal experience of the disease, as well as physicians involved in clinical care regarding where GT might address unmet needs and mitigate the disease burden for PWH. It should be noted that due to limitations in the available evidence, some of the expert perspectives expressed in the manuscript will necessarily reflect personal experience and are yet unsupported by published peer-reviewed studies.

1.2 | The burden of haemophilia

The introduction of clotting factor therapy in the 1960s and 1970s transformed life expectancy for severe haemophilia from under 30 years to near normal.[1] The contamination of clotting

that the first FVIII Gene Therapy may well be licenced later this year in the USA and early next year by the European medicines Agency for Europe, with the first FIX Gene Therapy probably being licenced by early 2022. Data from one of the FVIII Phase 3 clinical trials shows ongoing average FVIII expression of 10% after 3 years at the lower dose and 24% after 4 years at the higher dose of the Gene Therapy vector. There is significant variation in factor expression between individuals with some in the normal range and others with expression less than 5%. Factor levels are also falling so it in unclear how long the expression would last or would stay above 5% where the individual would be maintained in the mild haemophilia range.

The small number of individuals reported on had all been able to stop prophylaxis and their use of factor concentrates was down more than 90%. The second FVIII clinical trial reported data after 1 year with FVIII levels varying from 14% to 81%. Data presented on one of the FIX trials showed stable expression of 5% and 7.5% at 2 different doses after 4 years. This trial used the normal FIX gene. This was then replaced in a later trial by the company with an altered FIX Gene which gives higher expression. This altered Gene- the Padua mutation- is now being used in both FIX Phase 3 trials and in 1 of the Phase 1-2 trial. In this trial for which data was discussed at the Summit, data on the first 3 participants in the dose finding study showed levels of 31% to 50% after 1 year with relatively steady expression from 6 months to 1 year. This clinical trial has now completed enrolling for Phase 3 with over 50 people with haemophilia enrolled glob-

ally, including 3 from Ireland. Data on FVIII and FIX Phase 1 /2 trials also show promise with significant factor expression levels. One FVIII clinical trial showed factor levels at an average of 64% after 33 to 65 weeks. A FIX Phase 1 /2 trial showed expression in some individuals well above the normal range in one dose which would be a risk for thromosis.

Work is ongoing at a frantic pace in many Gene Therapy clinical trials. We can be very hopeful that we will see licenced effective Gene Therapies for Haemophilia becoming available over the coming years. We must also maintain a balanced view on safety and efficacy. There are questions to be answered and issues to consider. Many of the trials require individuals to take a course of steroids to deal with liver inflammation which may occur and which, without steroids, may cause the loss of some factor expression. There is a concern that factor expression is very varied and in some individuals in some trials, has increased to the point where they are at risk of thrombosis while in others the expression has not increased enough to bring them out of the range where they would no longer have severe or even moderate haemophilia. The AAV vectors used are non- integrating vectors which means that they do not integrate into the individuals own DNA.

However, it is clear that some small measure of integration does occur and the long term ramifications of this are unclear. We are, and remain, very excited about the opportunities which Gene Therapy present to our community for a functional cure for some people with haemophilia but we must await all the data from the clinical trials and closely assess this in the future. Progress must be allied to safety and efficacy. This was brought home to us with the recent announcement of the deaths of 2 children who were treated with Gene Therapy for a condition called X linked Myotubular Myopathy which we reported on our website on July 2, 2020. This condition is very different from haemophilia and the risk/ benefit ratio for Gene Therapy is also very different. Without treatment, 25% of children with this condition die in the first year of life and 10% die each year after that. This Gene Therapy is used in children. Their underlying condition also includes a pre- existing level of liver disease and the dose of Gene Therapy used was 5 time higher than the highest dose used in any Haemophilia Gene Therapy clinical trial. Nevertheless, any individual with haemophilia who is in the future considering Gene Therapy should do so having carefully considered all the potential advantages and disadvantages, the benefits and the risks and they should ask all of the appropriate questions.

This was the focus of my lecture at the Summit where I spoke about Fears, expectations and decision drivers when considering Gene Therapy. The Society will be undertaking several future educational initiatives on gene Therapy at our conferences and events, in our publications and looking at new and innovative methods of information delivery. For the present, I would recommend that any of you who are interested in this topic read the relevant sections on gene Therapy in the new update Novel products report which we have produced based on the excellent document from the European Haemophilia Consortium.

We will also be holding a Zoom education session for members on Gene Therapy on July 22nd at 6PM. Finally, on that topic, with the licencing of Gene Therapy being imminent in the USA, a presentation at the Conference looked at the economics and cost comparing Gene Therapy to other therapies and demonstrating, in their model, that Gene Therapy would be cost effective at $ 1 million per patient. It has been suggested that a price of $2 to $3 million per patient could be used in the USA. Different models would apply in Europe and in countries such as Ireland. The USA pay much higher prices for current haemophilia treatments than Ireland or most European countries. A one- off cost model would also not be the model looked at here- we would look at an annual cost model over several years and we would want to be sure that factor expression and efficacy were continuing.

The session on Novel future therapeutic approaches was fascinating. It included data on a new extended half-life FVIII currently entering Phase 3 clinical trials. This product known as BIVV- 001 is based on Elocta but increases the half- life of FVIII by incorporating an element of the von Willebrand molecule. In the Phase 1 /2 clinical trial, half-life was increased to between 37 and 42 hours which would give a FVIII trough level of approximately 10% 1 week after infusion. Ireland is among the countries where the Phase 3 clinical trial will be carried out. Various approaches to Gene Editing were discussed. This may be the future for children with severe haemophilia as children currently are not offered Gene Therapy for haemophilia as their livers are too immature and growing. A novel approach to Gene Therapy was put forward by a company called Generation Bio who are not using a virus such as AAV to deliver the dose. They are using lipid nano particles with which an individual could be re-dosed if required, unlike current Gene Therapy dosing systems where re-dosing is not possible. This approach is at

a pre- clinical trial stage of development.

An update was also discussed from Sigilon on their implantable spheres. These spheres are implanted in the gut and release FVIII, FIX or FVII, depending on what was implanted. The spheres are protected from destruction by the immune system. These are also at an early stage of development, but the theory is that they could be implanted in the gut, re-dosed if required and the factor level could be adjusted based on the number of spheres implanted.

In a review of the use of Novel Therapies, Prof. Flora Peyvandi from Milan pointed out that use of extended half- life FVIII and FIX had decreased the number of units used when compared to standard half- life factor. For FVIII, use of EHL led to a 16% decrease in units used and a 40% decrease in the number of infusions. For FIX, the decrease in units used was 39% and the decrease in the number of infusions was 51%. Updates on Fitusiran showed an impressive reduction in the annual bleed rate in those with inhibitors in the Phase 2 clinical trial of this subcutaneous therapy and new clinical trials were announced on the use of Emicizumab (Hemlibra) on infants with severe haemophilia less than 1 year of age and separately in those with mild or moderate haemophilia.

Twinning with Jordan

Our twinning programme with the Jordanian Society for Thallasemia and Haemophilia continues with interactive meetings by Zoom. In recent weeks, we have organized additional Zoom meetings with Jordan on Publications and digital media, Governance, Events and Membership. Further Zoom meetings will continue as will the separate activities being undertaken by the National Coagulation Centre and Children's Health Ireland at Crumlin with the Haemophilia treatment centres in Amman, Jordan. They have conducted a zoom meeting with Jordanian centres on Covid-19 coagulopathy and further zoom meetings are planned for July and August on Laboratory issues, dental care and Physiotherapy.

Office re-opening

The Society staff are currently working from home and delivering the best services and support we can to members given the constraints imposed by Covid-19. We shall, of course, be keeping an eye on advice and recommendations from the Department of Health and the HSE and adjusting our plans accordingly. Our current plan will see staff start back working from the office from August 20 on a phased in basis. We have put in place full plans for correct social distancing for staff in the office with some changes in work practices and arrangements. This will be subject to ongoing review as circumstances change. We do look forward to the time, hopefully in the not too distant future, when we can welcome members to visit us in the office and when we can again conduct home or hospital visits to members.

Brian O'Mahony

2020 would have been the second year for the European Haemophilia Consortium (EHC) to host a Women & Bleeding Disorders Conference following its success last year. Unfortunately, due to Covid-19 and imposed travel restrictions, the conference had to be cancelled. We hope that 2021 will see this much needed conference back again. But for 2020, EHC in its place hosted two webinar sessions on the following topics:

What does a normal menstrual cycle look like and how it is impacted by issues in coagulation?

Speaker: Dr Rezan Abdul-Kahir, Consultant Gynaecologist, Royal Free Hospital, London.

Menarche is when a young girl first starts her periods, the average age is 11 years old but can be anywhere from 9 to 16 years old. Menopause is when a women's ovaries are ageing, there is a decrease in ovulation and less oestrogen is produced, the average age of menopause is 51 years. Prior to the menopause is called perimenopause, this can last from between 3 to 10 years, and 12 months after the last menstrual cycle is post-menopausal. A typical cycle is 28 days long, however a normal menstrual cycle can range from between 23 to 32 days and even then a women's cycle can vary slightly from month to month. If ovulation does not occur, oestrogen is still produced but there is no progesterone, oestrogen causes the lining of the womb to thicken and this then leads to heavy periods, late periods and spotting before and after the period. Factors such as age, weight, exercise and if a person has polycystic ovaries can affect ovulation. But it is important to know what is normal for each individual girl, if their period is longer than 7 days and if they use more than 6 sanitary pads/tampons per day, then you need to seek help. Heavy bleeding can lead to anaemia and can impact on an adolescent/women's health and quality of life. Studies show that approximately 50-75% of women with a bleeding disorder (WBD) suffer heavy menstrual bleeding, particularly those with vonWillebrands Disease, Platelet Dysfunction and Glanzmann's Thrombasthenia because their menstrual cycle and ovulation are tissue injuries and need blood clotting to stop the bleeding. About 8-10% of WBD will require urgent medical attention due to haemorrhaging. Endometriosis is a chronic condition that affects about 10% of all women and leads to heavy bleeding, chronic pain and fertility issues and WBD's are more likely to suffer with endometriosis. All WBD should have access to a coagulation treatment centre and a gynaecology and obstetrics service as joint clinics to manage their bleeding issues.

Haemostasis impact on menstruation

Speaker: Dr Thynn Thynn Yee, Haematologist, Haemophilia Centre, Royal Free Hospital, London.

Bleeding disorders such as vonWillebrands Disease, Platelet Dysfunction and Glanzmann's Thrombasthenia can have a significant impact on menstrual bleeding. In addition to these, 30% of carriers of haemophilia A & B can have low factor levels themselves. When an adolescent/woman presents with heavy periods you need to consider an underlying bleeding disorder and you need to ask specific questions such as have you had any past bleeding problems because of a trauma or surgery? Have you had any post-partum bleeding or lost any pregnancies? Are you taking any anti-coagulation medication? In the Royal Free Hospital, they use a bleeding score, if a women scores 5 or more, they are referred on for further testing to determine if they have an underlying bleeding disorder. The Royal Free Hospital has a joint clinic where the women see both the haematologist and gynaecologist, this is the key factor in successfully treating a WBD.

Coping strategies through the eyes of a haemophilia nurse with the focus on psychological/social support

Speaker: Malin Sveenefalk, Nurse, Karolinska University Hospital, Stockholm

Preparing a girl for her first period is so important, good support early in childhood optimises good support as she approaches puberty. Early information and a positive relationship between the nurse and girl are needed to focus on a positive outcome. It is necessary to involve and educate family members, but the girl also needs the undivided attention of the nurse, she needs to feel supported and comfortable speaking with the nurse herself. The girl needs to understand her diagnoses, basic information at first and this can be increased at a comfortable pace to suit the child. In the case of carriers/possible carriers, the girl should know her own factor levels. The nurse should ensure the girl understands her own personal treatment procedure and provide emotional support. The aim is to prevent the girl from having a traumatic bleeding experience. Even mild vonWillebrands disease can cause a lot of menstrual bleeding. Treatment where possible should be available at home and contact details for emergency care to hand if the need arises. Heavy periods impair quality of life, it has a negative impact on social contact, physical activity, disrupts school and work attendance, causes fatigue and iron deficiency due to blood loss. Extra support is needed if a women is planning a pregnancy and a plan needs to be put in place for delivery. Psychological support is essential as many women worry about bleeding a lot during delivery and about having a child with a bleeding disorder. Later in life when women approach menopause, there is a growing number of patients who need support and follow up and should be linked in with a treatment centre through gynaecology.

Comprehensive Care Services

Speaker: Declan Noone, President, EHC.

Comprehensive care centres should consist of 4 key areas:

1. Support - should have 24 hr service with experience staff, hospital based medical cover with one or more whole-time equivalent doctors and designated nursing staff to coordinate treatment.

2. Expertise – should have a broad experience in haemostasis, provide people with bleeding disorders with safe and effective treatment, provide home treatment where available and adhere to consensus guidelines which should be available in each European country.

3. Diagnosis – should have labatories that provide 24 hr assay cover, acess to a genetic labatory and antenatal diagnostic service.

4. Services – should include dedicated physiotherapy, social work, rheumatology and/or orthopaedic, dental, obstetrics and gynaecology, psychological support, genetic counselling and patient and family education services.

In relation to the care of WBD, a survey was done on women who received a final diagnosis and were treated in a haemophilia treatment centre versus those who were not. The survey showed that women using treatment were 44% more likely to be prescribed replacement therapies, than if their final diagnosis was outside a haemophilia treatment centre. This goes up significantly for DDAVP at 74%, tranexamic acid at 99% and hormonal therapies at 79%. When been cared for in a treatment centre, there is greater access to services in general, the rates are still low around psycho-social support and pain management, these are areas that still need improving. The survey also showed issues such as the impact on romantic life, on physical life and on reproductive life are all significantly lower when a women received her final diagnosis through a haemophilia treatment centre and the management of her bleeding disorder is improved. Comprehensive care has been well defined in haemophilia care for years and it has had clear benefits in terms of better access to treatment, services and improved quality of life for patients. But for women with a bleeding disorder we need to include clinics such a gynaecology and obstetrics within the treatment centre.

Issues facing women to access comprehensive care services
Speaker: Naja Skouw-Rasmussen, Member, EHC Steering Committee, Denmark.

Speaker: Dr Michelle Lavin, Clinical Lead for coagulation haematology research in the Irish Centre for Vascular Biology, Royal College of Surgeons, Dublin, Ireland.

Naja and Michelle discussed the following:

- An issue experienced by some women when attending a comprehensive care centre is that you are not acknowledged as a patient who should be at the comprehensive care centres. If you go to your doctor you are often meet with disbelief that as you are not a severe haemophilia patient, why are you complaining or do you have an issue that is worth discussing?

- If you are meet with scepticism or disbelief by your GP or gynaecologist and even at the comprehensive care centre, you may start to feel you should not say anything because the doctor is not listening to you anyway. This is not the case for everyone because of course there are a lot of healthcare professionals in this area who are doing a lot to help women's health.

- There is a 'normalisation' of heavy menstrual bleeding, often women trying to access care are told your periods

can be heavy and what do you expect them to be like? This is something Michelle has seen many times. Women then don't appreciate how heavy their periods are because they have been pushed back time and time again when trying to access care earlier in life.

- Clinicians need to know the right questions to ask, because if a women is asked how her period is, she might say fine, because this is all she has known and because her mother/sisters have similar bleeding to them. There needs to be a better checklist of questions for women with a bleeding disorder to establish the level of menstrual bleeding. Many centres do not have a standarderised management plan for heavy menstrual bleeding.

- The most important thing is to improve the awareness of bleeding disorders, so that more women can be diagnosed.

- For women with a bleeding disorder the missing link in many centres is the contact between the haematologist and other specialists. Women are often attending several specialists, but they are not communicating with each other.

European Association for Haemophilia and Allied Disorders (EAHAD) Survey

Speaker: Dr Karin Van Galen, Haematologist, University Medical Centre Utrecht, Netherlands

A survey was carried out by EAHAD to specifically look at the diagnosis and treatment of women-specific bleeding symptoms in inherited bleeding disorders. Of the 136 haemophilia treatment centres (HTCs) contacted, 59 took part in the survey. The survey results showed the following:

- 33% of HTCs do not offer pre-implantation genetic diagnosis

- third trimester amniocentesis to guide obstetric management is available in only 52% of the HTCs.

- Less than 25% of women with a bleeding disorder (WBD) seek medical advice for heavy menstrual bleeding.

- Only 30% of HTCs use P-BAC, which is an instrument to quantify blood loss.

- A management algorithm for acute heavy menstrual bleeding is lacking in 42% of HTC's

- 33% offer multidisciplinary joint clinics to address heavy menstrual bleeding (HMB)

- 42% offer joint clinics to address reproductive care.

- 66% of the respondents believe that joint clinics would be beneficial to WBD.

Discrepancies exist in the model of care and range of services for WBD in European HTCs, joint clinics are not widely available due to several barriers, these barriers include lack of knowledge to set up joint clinics, funding or a belief that joint clinics are not needed. Heavy menstrual bleeding may be an underestimated issue and there is an urgent need to prioritize the improvement of knowledge and patient care for WBD across Europe.

Services for Women with Bleeding Disorders

Speaker: Debra Pollard, Nurse Specialist, Royal Free Hospital, London.

There are key professionals involved in the care of women with bleeding disorders (WBD) but we need to think about joining the care of haematologists, gynaecologists, obstetricians and nurse specialists in bleeding disorders, we also need to be involving our specialist midwives and particularly psychological support including genetic counselling. The advantages of joint clinics are having all the necessary healthcare professionals in the room at the same time or at least well contacted in some way, allowing for suitable management plans that consider the bleeding disorder and its very specific needs. The disadvantages of a joint clinic are the woman may end up relying on the expertise of a limited number of people and that might not always be available and so that expertise needs to be expanded within the HTC team and gynaecology/obstetrics teams. We need a good pathway and excellent service for accurate diagnosis and treatment for all bleeding disorders and it should not matter if you are a man or a woman. Counselling for carriers of all inherited bleeding disorders is essential because we need to counsel about inheritance and genetics, but also counselling about living with the condition. However, clinical management pathways cannot all be achieved in one clinic. A joint clinic is only part of the service for women, established pathways are needed for the management of extreme gynaecological bleeding, adapted pathways are needed for the long term follow up of gynaecological bleeding for women with bleeding disorders and pathways for early pregnancy options for WBD and carriers of haemophilia. The first point of contact for most WBD is in their community either via their GP or urgent care centres closer to home, which will have very little if any information about living with a bleeding disorder and how treatment should be accessed. Awareness needs to be raised in relation to the services available to these women, women are being diagnosed later than they should be, they are suffering in silence because they do not know who to approach and how to approach.

Nina Storey

The Society offers educational grants each year to people with haemophilia or related bleeding disorders, including a person with carrier status, and/or their immediate family members who go on to do a post second level educational course.

The purpose of these grants is to offer financial support to students to assist them with the extra expenses involved with their studies.

We are happy to announce that applications are now invited for the 2020 I.H.S. Educational Grants.

You can apply via our website 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 three categories of grants available as follows:

The Maureen & Jack Downey Educational Grant:

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

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. Carriers with factor levels greater than 40% can also apply for this grant. The person applying must be accepted on a post second level educational course at levels 7 to 9. The person with the bleeding disorder must be registered at the National Coagulation Centre at St. James's Hospital in Dublin.

The Father Paddy McGrath Educational Grant:

This grant is made available to a person with haemophilia or related bleeding disorder, including a person with carrier status and also includes immediate family members i.e. a spouse, son, daughter, sister, brother, mother or father who has been accepted on a post second level educational course at level 5 or 6. Carriers must have levels ranging from 1% - 40% to be considered as having a bleeding disorder. A scoring scale will apply to this category with points being awarded depending on the severity of the person's bleeding disorder.

How much are the Educational Grants for?

Maureen & Jack Downey Educational Grant

First prize - €4,000
Second prize - €2,000
Third prize - €1,000

Margaret King Educational Grant

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

Father Paddy McGrath Educational Grant

A person with the bleeding disorder

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

A family member of a person with the bleeding disorder

First prize - €500
Second prize - €250
Third prize - €125

What is the closing date for applications?

The closing date is Monday 28 September 2020.

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!

*Please note: *A receipt of payment for your college course must be submitted with your application. Even if you are eligible for more than one grant, you can only apply for one grant each year.*

"Helping one person might not change the whole world, but it could change the world for one person"

If you would like to make a difference to others, please consider signing up to our Planned Giving. Contributions can be made monthly, even €10 a month can make a difference or maybe you would prefer to make an annual contribution.

The choice is yours, how much and when is totally up to you, and you can cease your contributions whenever you want.

This ongoing support for the work of the I.H.S. goes a long way to help us provide and improve on the services and support we give our members.

To sign up, or for more information, please contact Nina on 01 657 9900 or email nina@haemophilia.ie.

Haemophilia Perspectives

Being a parent of a child diagnosed with a bleeding disorder presents challenges - you may feel scared, worried and perhaps even guilty. Being a child growing up with a bleeding disorder too, presents its own challenges. Rest assured that as your child grows, so will your understanding of their bleeding disorder and your confidence in how to manage it – and it will be the same for your child.

Similarly, the Irish Haemophilia Society is here to help. We offer support and advice to help improve the quality of life for people with bleeding disorders through education, publications, conferences, information meetings, regional visits, home and hospital visits and outreach.

Offering better insight into these differing views, Jennie and Evan McBride have penned their personal perspectives on being a parent and growing up with a bleeding disorder.

Being a Parent

We're at a playdate, birthday party, play centre, you name it…. Dylan, as three-year olds do, falls over, bumps his elbow or scrapes his knee. The look of sheer horror on the other parents' faces is identical every single time, and every single time I find myself saying the same thing.

"Don't worry, he's totally fine!".
"No, no, I don't need you to call anyone".

"No, he's actually not going to explode". Okay so that last one is always in my head accompanied by an internal eyeroll, but I know I'm not the only mother who thinks that.

Then I'm at home, I hear pounding on the stairs and my front door slams. Evan, as sixteen year olds do, wants to be as far away from his parents as humanly possible. The tiny twinge in my gut is identical every single time, and every single time I find myself saying the same thing.

"Don't worry, he's totally fine!".
"No, no, I don't need to call him".
"No, he's actually not going to explode". Not out loud though,

This time they're all in my head.

Three years old and sixteen years old are very different ages but they have one thing in common. They both have FIX Haemophilia. Sandwiched in the middle is six-year-old Oliver, who doesn't. A thirteen-year age gap between one person with haemophilia and the other. This means very different ways of parenting and very different worries. Haemophilia or not, that is the thing that ties all parents together, regardless of what issues, illnesses or struggles our child might have. Worry.

We worry about their health, we worry about their education, their safety, their diet, their social development and the world that we're creating for them. We worry about our parenting, our communication, the example we set for them. On top of that, when your child has a bleeding disorder, that worry multiplies infinitely. How will haemophilia affect their education, their safety, their social development? Are the treatments that are coming in the future going to make the difference that we hope they will?

One of the biggest things that plays on my mind is how do I make sure that there is balance in my family. I have two sons with haemophilia, but I have one who doesn't. I have an opinionated, outgoing

teenager and a daredevil, crazy threenager but I also have a sweet, kind, quiet little six-year-old who tries so hard to understand haemophilia and why it's a part of our family. I think that will always be one of the challenges I face as their mother. Helping them all to understand and support each other. As they grow, I hope that that is something that will grow with them and that they will become that support for each other.

This is where the Irish Haemophilia Society makes a difference in our lives. There is support for parents, children and teens with bleeding disorders but there is also support for their siblings. Every

time we go to a conference or event, all my kids are the same. They are all just boys and that means the world to me.

Every parent of a child with a bleeding disorder knows the inside of their child's treatment centre inside out, they know their child's medical team very well and they know the treatment far too well. What we don't know is what the future holds and that is the other reason the I.H.S. is part of my family. It gives us peer support. We can meet other families who have been through the next stages of life and of parenting a child with a bleeding disorder and their siblings. These other parents can give us the reassurance of advice and experience. Along with that, we can provide that same support, advice and reassurance to other families who are newer to this journey. We can open up about our struggles and our triumphs, the things we would do again and the mistakes that we learned from. The strength of the I.H.S. community comes from its members and their willingness to help and support each other, something that for us has meant lifelong friends for both us and our boys and taking away that sense of isolation that comes with a rare medical condition.

Like I said, a thirteen-year age gap between one son with haemophilia and the other and a six-year-old stuck in the middle means very different ways of parenting and very different worries. Isolation, not feeling part of a community or needing support…. These are things that thankfully, I don't need to worry about.

Jennie McBride

Growing Up With Haemophilia

What was it like growing up with Haemophilia? For the first few years of my life that I can remember, it didn't affect me that much. This is because I didn't know I had mild Factor IX haemophilia. Even though we found out that it is in my family and that my grandfather also has mild Factor IX, at the time my parents didn't know. So, when I was very young, I did karate and played hurling for a while without a problem. Once I got a little bigger and the games got a little rougher, I noticed a lot of bruises. It was around this time I was diagnosed.

After we moved away from Tipperary to Dublin and I got a little older, I became a bit more informed about the disorder. Once I knew a little bit more about my condition, you'd think I would get wiser and more cautious but no, I didn't…… like the time I went over the handle bars of my BMX and put my bottom teeth through my top lip, or the time I deliberately went down a hill on a bike with no breaks.

The first time I went to an Irish Haemophilia Society weekend conference that I can remember was 2014, and my most recent was the AGM, at the Slieve Russell hotel. Our family try not to miss the AGMs and family conferences every year.

My first conference was very informative and a bit scary because I didn't know anybody there. I didn't know that much about my condition and I was still quite young but the amazing people there, especially the volunteers, quickly made me feel right at home. I very soon grew to be good friends with the group of kids around my own age, and I'm still friends with them today.

This is particularly good right now, as we are in lockdown and have nothing else to do than annoy one another with memes and bad jokes!!! Right now, my family and I are all pent up in a small mobile home because our house was undergoing renovations when the lockdown was announced. Hopefully the builders can go back to work soon, and I can go home to my new room in the attic which is what I'm most excited about. Living with two younger brothers is not always easy so having a whole floor of the house to myself will be fantastic.

I have a three-year-old brother, Dylan who also has haemophilia. Dylan has had his fair share of bumps and bruises like me; there was the time he fell over my leg the evening we got home from a Members Conference and broke his nose. All injuries aside, people say he looks a lot like me when I was his age and he has a huge personality stuck in a very, very little body. He is a bundle of fun to be around (when he gets his way that is) but I have had to learn to be a bit more cautious when I am babysitting him as he has a habit of getting into fights with furniture, which has caused a lot of tears but a few giggles at the same time. He also has a funny little attitude and he likes to let people know when he enters a room usually by shouting something he thinks is funny.

My six-year-old brother Oliver doesn't have haemophilia but he does try to understand it and ask questions. He is a smart little kid and he already has a good grasp of what haemophilia is. He really looks out for Dylan, just like I do. He takes being a big brother very seriously. I'm glad for him that he doesn't have a bleeding disorder.

Hopefully I can guide them as their big brother, and they can learn from my life experience both with haemophilia and just with growing up.

Evan McBride

HAEMOPHILIA CARE IN EUROPE PART ONE: 1970S – 1980S

We are now in an exciting time of unprecedented innovation in relation to haemophilia care in Europe and the probability is that we will see even more innovation in treatment in the next five years. This will bring opportunities but also challenges in relation to access. To help us predict the future, it is worthwhile to examine the past. This is part one in a series examining 'Past Progress and Future Promise'.

The 1970's – Decade of Progress

Treatment for severe haemophilia progressed significantly during the 1970's. Cryoprecipitate was widely used in many countries and factor concentrates were available for the first time. The availability of cryoprecipitate enabled some measure of treatment to be provided to many people with haemophilia. It helped to break the vicious cycle whereby bleeding would occur into a joint, treatment would consist of rest and ice and perhaps rudimentary pain control and following several days or a week of pain, the joint would begin to improve. Compression would be recommended for a period of time after the bleeding episode, but the joint was very susceptible to re-bleeding for some time after the initial bleeding episode. Without access to treatment, joint damage was very common.

Cryoprecipitate enabled bleeding episodes to be treated and the pain to be controlled more rapidly. For FIX deficiency, fresh frozen plasma was used in a similar manner. Both cryoprecipitate and fresh frozen plasma were an improvement when compared to no treatment. However, they were not suitable for rapid treatment of a bleeding episode. They usually stopped the bleeding when administered and diminished the pain but they did not prevent the joint damage from occurring as the bleeding episode was usually well advanced by the time a person was treated. This was certainly the case unless the person lived close to their treatment centre.

In some countries, some people with haemophilia moved with their families to allow them to live closer to a treatment centre. I lived 300 km from the treatment centre. Following childhood years of no treatment for severe FIX deficiency, I had access from the age of 14 to treatment with fresh frozen plasma. This entailed a 300 km journey by train and taxi to receive a unit of FFP and then a return journey - a process which took 12 hours. This was not convenient, but it was a major improvement compared to no treatment. The major improvement came with the availability of plasma derived coagulation factor concentrates (CFCs). The FVIII concentrates were intermediate purity concentrates ranging in potency from 250 IU to 1000 IU. For FIX deficiency, there were no purified FIX concentrates.

Prothrombin complex concentrates were available. The availability of these concentrates meant that, for the first

time, specific factor levels could be targeted and achieved. More effective treatment could be infused without the volume constraints imposed by plasma. Crucially, these lyophilised concentrates could be used to treat the person at home rather than requiring travel to a hospital or treatment centre. This was a major advance, not in convenience, but in effectiveness of treatment. If a bleeding episode could be treated with factor concentrate at home as soon as the person felt that a bleed was starting, then the bleeding episode could, in many cases, be stopped before developing significantly. Joint damage could be significantly decreased. Pain and immobility were decreased. The person with haemophilia was able to miss less time at school or work.

The supply of factor concentrates available in the 1970's was limited. Treatment doses used were low compared to current practice. Many countries did not have a strongly established treatment centre network and there was little acceptance of the need for a significant budget for the treatment of haemophilia (1). Prophylaxis to prevent bleeding was unavailable in most countries having been pioneered in Sweden. In the 1970's, we also saw the development of haemophilia treatment centres and the beginning of some availability of comprehensive care. CFCs were typically available in designated centres and this led to the development of these as haemophilia treatment centres. With the development of centres came the concept of registries. National patient organisations also started to form.

For the first time, haemophilia started to become visible within national health systems. Despite these limitations, the availability of factor concentrates and especially home treatment were major advances in haemophilia care. Survival improved. Pain and suffering were decreased. Bleeding episodes began to be controlled. A normal life seemed attainable for the first time.

1980's - Decade of Despair

This sense of hope and optimism carried forward into the early 1980's. More people with haemophilia started to be able to avail of home treatment which improved their ability to attain an education and employment. Treatment centres were getting more organised. Prophylaxis started to be considered and used in more countries. This edifice of hope and optimism began its crash back to reality in 1982 with the first case reports of pneumocystis pneumonia in people with haemophilia in the USA (2).

From 1982, it slowly became apparent that many thousands of people with haemophilia had been exposed to HIV through contaminated blood products and large pool factor concentrates. The early CFCs were often manufactured from pools of up to 20,000 litres of plasma containing the plasma of tens of thousands of donors. The CFCs were not virally inactivated. The results were devastating. By the time it was realised that heat treatment inactivated the virus in October 1984 and virally inactivated CFCs were widely used from the beginning of 1985, many thousands of people with haemophilia in Europe and worldwide were infected with HIV.

The clinical impact was slow initially with hope prevalent that only a small minority of those exposed to HIV would go on to develop AIDS. When testing for the virus took place from late 1984, it became apparent that a significant proportion of those with severe haemophilia were infected with HIV. It was postulated that no more than one percent of those infected would go on to develop AIDS. This was unfortunately wildly inaccurate and optimistic. By 1996, when effective highly active retroviral therapies became available, up to 70 percent of those infected had died in many countries.

AIDS became the leading cause of mortality in haemophilia

Minister to hear of AIDS victims' plight

THE Minister for Health, Dr O'Hanlon, is to meet a deputation from the Irish Haemophilia Society today to hear a submission about the plight of haemophiliacs infected by HIV through blood transfusions.

Dr O'Hanlon was pressed by a number of deputies at Question Time to provide financial assistance for this category of patients, but he insisted that the Government's responsibility was to plan and provide appropriate medical and welfare services for all those who are affected, directly or indirectly, by AIDS.

Committee to administer £1m for haemophiliacs

By Padraig O Morain, Social Services Correspondent

A committee to administer a £1 million trust fund for haemophiliacs infected with AIDS is expected to be announced by the Minister for Health later this week. The move follows the apparent resolution of a dispute

two representatives of the AIDS Fund and three nominees of the Minister for Health. The committee was to have been announced yesterday, but there is believed to be a delay in finalising the ministerial appointments.

It is understood that the £1 million and the interest earned by

Dispute grows over AIDS funds

By Padraig O'Morain
Social Services Correspondent

THE DISPUTE between haemophiliacs and the AIDS Fund worsened yesterday when the fund's organisers said they would keep £250,000 allocated to it in April when the then Fianna Fail Government was trying to avoid defeat on the issue of help for haemophiliacs with AIDS.

The vice-president of the Irish Haemophilia Society, Mr Joe Dowling, said he felt as if his society had been "mugged".

The new £1 million fund for haemophiliacs, agreed in the programme for the present Government, is also to be handled by the AIDS Fund, although the Irish Haemophilia Society's president has already resigned from the fund.

It is understood that both thof AIDS Fund and the Iris Haemophilia Society accepte that the bulk of the money wou go to haemophiliacs. But la week the society's president, M Brian O'Mahony, withdrew fro the fund in a conflict over whe and how the money should b paid out.

In a further development ye terday the AIDS Fund said th because the new Government h decided to allocate £1 million haemophiliacs this year, it wou keep the original £250,000 f projects concerning other AID sufferers.

The fund's secretary, M Nicholas Kearns, said that th Irish Haemophilia Society ha said "time and time again" that it succeeded in getting a substa

tween them and people infected in other ways. Instead, it gave £250,000 to the AIDS Fund. While it was generally accepted that most of this money would go to haemophiliacs, a dispute broke out over how soon and in what amounts the money should be paid and the Irish Haemophilia Society withdrew from the AIDS

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Private Members' Business. - HIV Infected Haemophiliacs: Motion.

Tuesday, 25 April 1989

On his return to Dublin, the news of the Government's defeat on the Labour motion over an annual £400,000 State-funded trust for AIDS-infected haemophiliac sufferers found the Taoiseach in sabe-rattling form, so much so that he threatened a political earthquake here in the shape of a general election.

in many western European countries. The mortality and infection rate were lower in some central and eastern European countries due to the fact that they had not imported CFCs made from large plasma pools. The impact of this today can be seen in the fact that Hungary consistently reports the highest per capita FVIII use in Europe to the WFH Annual Global Survey. This is due to the fact that they did not use pooled CFCs in the 1970's or early 1980's and largely escaped infection with HIV in their haemophilia population. They now have more people with severe haemophilia per capita than most European countries. From being a decade where progress should have continued, the 1980's became a decade of retrenchment and despair.

The clinical and human impact of HIV became more and more apparent as the decade progressed. More people with haemophilia suffered the clinical consequences of HIV. The mortality rate increased each year. Trends toward increased factor use and increased use of prophylaxis were reversed. Many people with haemophilia were fearful about taking treatment. They had to deal with anxiety, prejudice from a population where HIV and AIDS were stigmatised and guilt where many parents had injected the CFC into their child on home treatment.

The haemophilia treatment centres had to include new expertise in infectious diseases in addition to providing counselling and other services. Haemophilia patient organisations became more active and had to advocate for those infected with HIV to assist them in coping with the clinical, emotional, psychological and financial burdens this entailed. By early 1985, virally inactivated CFCs were licenced and available. These were effective in inactivating HIV.

The vast majority of those with Haemophilia who were infected with HIV were infected prior to 1985. At this time, when further infection was largely stopped, the clinical consequences of HIV were starting to become more apparent. The number of people with haemophilia becoming ill with opportunistic infections or dying from AIDS increased every year from 1985. Many of the organisations changed to become more active and focused. Advocacy skills developed. In Ireland, a campaign by the Irish Haemophilia Society on the issue of financial assistance for people with haemophilia with HIV resulted in a defeat for the Government in the parliament in 1989 which precipitated a general election. Financial assistance funds were established in Ireland (The Haemophilia HIV Trust) and the UK (The Mc Farlane Trust).

In 1989, a new European Union Blood Directive (89/ 381/ EEC) was in preparation. There was major debate in relation to how Europe could have a secure, safe and adequate supply of blood and plasma. Many haemophilia societies were actively advocating for financial support and assistance for their members who had been affected by HIV and AIDS. Against this backdrop, the haemophilia societies from 12 European countries came together to form the European Haemophilia Consortium (EHC). The end of the 1980s saw haemophilia societies and centres working to deal with HIV and AIDS, political change with the fall of the Berlin wall presaging major political change in eastern Europe and ominously, the discovery and characterisation of yet another blood borne virus - hepatitis C.

Brian O'Mahony

[1] *E. Berntorp, "History of prophylaxis," Haemophilia, vol. 19, no. 2, pp. 163–165, Mar. 2013.*
[2] *CDC, "Morbidity and Mortality Weekly Report (MMWR): Pneumocystis Pneumonia," Morbidity and Mortality Weekly Report (MMWR). Los Angeles, pp. 30(21);1–3, 1981.*

Hyde Square

Just to remind you all, that the the Hyde Square apartments will continue to be available for members. Bookings will be taken by phone as normal and are available to:

- People with haemophilia or related bleeding disorders from outside of Dublin, when attending St. James's Hospital or Our Lady's Children's Hospital, Crumlin for treatment, for a hospital appointment or for a review clinic.

- An immediate family member, a spouse, a partner and/or child of the person with haemophilia or related bleeding disorder from outside Dublin, when attending St. James's Hospital or Our Lady's Children's Hospital, Crumlin for treatment, for a hospital appointment or for a review clinic, or while a family member is an in-patient.

If you would like more info or to make a booking, please contact Julia in the office on 01 657 9900.

A nominal fee of €10.00 per booking, per night will be levied to offset the cost of cleaning and routine maintenance.

We always like to hear from members and what they are getting up to. And with that in mind, we recently caught up with I.H.S. member Colm Walsh to find out more about his new blog, Keeping in the Moment.

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

My name is Colm Walsh. I have haemophilia, FIX deficiency and I am classed as severe. I live in Cork near the airport and I live with my partner Sinead. I am 45 years old.

What spurred you on to start blogging and sharing your life experiences with the wider world?

I decided to start my blog after Sinead suggested it. We were in quarantine for 2 weeks after coming home from holidays on March 17 and it seemed like the perfect time to get started. I had a knee replacement done on the 1st of October in St James's in Dublin and I have been in the rehabilitation phase since. The last 12 months has been a learning curve and the more I thought about it, the more it felt right to start as I have had a lot of tough experiences throughout my life and with hemophilia. With Covid-19 I felt I had a lot to give to people out there trying to deal with the pandemic.

What have you enjoyed the most so far about it?

I have enjoyed the thinking about what to write about. I try and keep it day to day and just tell people about my day and how I am dealing with my rehabilitation and the effects it is having on me. It helps me deal with stress and life issues. I have done Personal Development Courses which have help me deal with life and all that goes with it.

What has been the most challenging aspect to the blogging experience?

There were two challenging aspects:

1. Getting it started and set up and the design of the website - picking a name that I felt very comfortable and happy with, and picking colors etc that I felt happy with.

2. I have to be comfortable in my own body physically and mentally and not being afraid to write about what I feel - sometimes that can be very tough. Just knowing what I write is out there for the world to read is challenging but I am very comfortable doing it.

Have you received any feedback from people who have been reading your blog?

I have received a few comments from people I know that are reading it and they find it great. They also say you can tell it's not made up and it is all real by the way I write. That makes me feel very happy indeed.

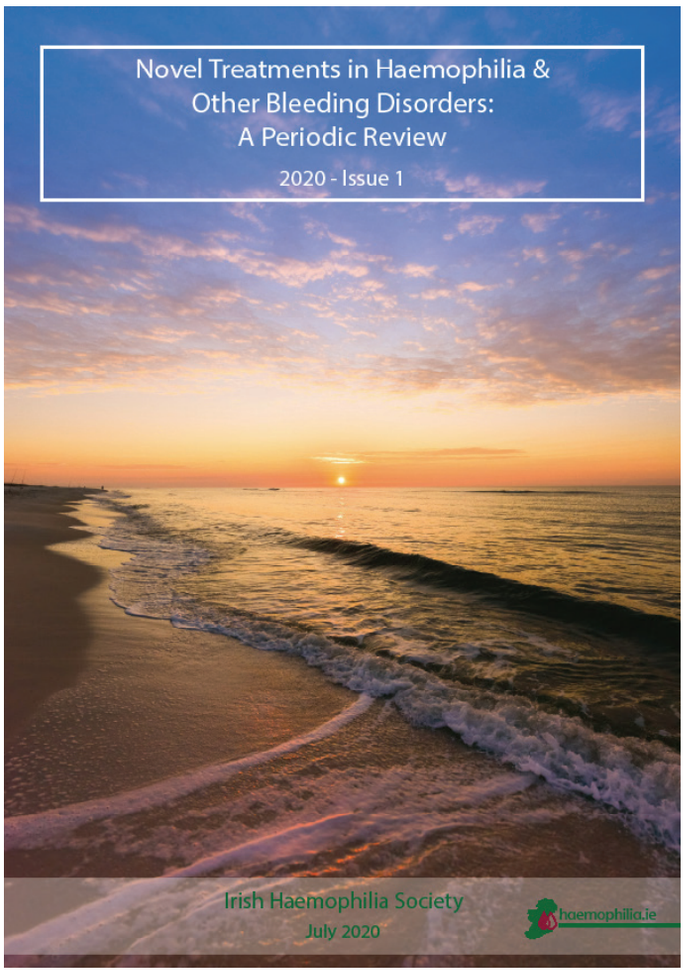
Do you have any plans to develop the blog further?

At the moment I am just enjoying writing the blog. I do not have any plans right now to develop further but as I get more knowledge with the technology side of it I will see. I am just taking One Day At A Time with it. I never know what I'm going to write about in the next blog.

How can people find the blog and get in touch with you if they want?

My Blog is www.keepingitinthemoment.com and if people want to get in touch with me, my email is colmwalsh00@hotmail.com

Noticeboard



Novel Treatments in Haemophilia & other Bleeding Disorders:

A Periodic Review I 2020 – Issue 1

The therapeutic landscape in haemophilia continues to change rapidly and it can be difficult to keep up to date.

The Society has adapted a publication compiled by the European Haemophilia Consortium to produce a comprehensive update on 'Novel Treatments in Haemophilia & other Bleeding Disorders: A Periodic Review'.

It is designed to be informative for both people with bleeding disorders and health care workers.

It is available to read / download from here.

If you missed any of our webinars over the past while, you can now catch up with them on our website and YouTube.

We are delighted with the webinars; insighful topics and great interaction with members. Some of the topics include:

- Dental Care: The New Normal with Dr Alison Dougall and Laura Parkinson
- Update on New Children's Hospital with Eilish Hardiman, CEO
- Exercise and Physical Activity for Children with Paula Loughnane, Senior Physiotherapist at CHI Crumlin
- Dental Care and Nose Bleeds in Children with Dr Kirsten Fitzgerald and Dr. John Russell

You can find the recordings on YouTube or Haemophilia.ie

We are always eager to have member's contribute to our publications.

Maybe you would like to share a story about you or your experiences with bleeding disorders, or perhaps your experience at one of our events or fundraising?

If you would like to contribute and write an article for the I.H.S. just contact Barry in the office at 01 657 9900 or via barry@haemophilia.ie

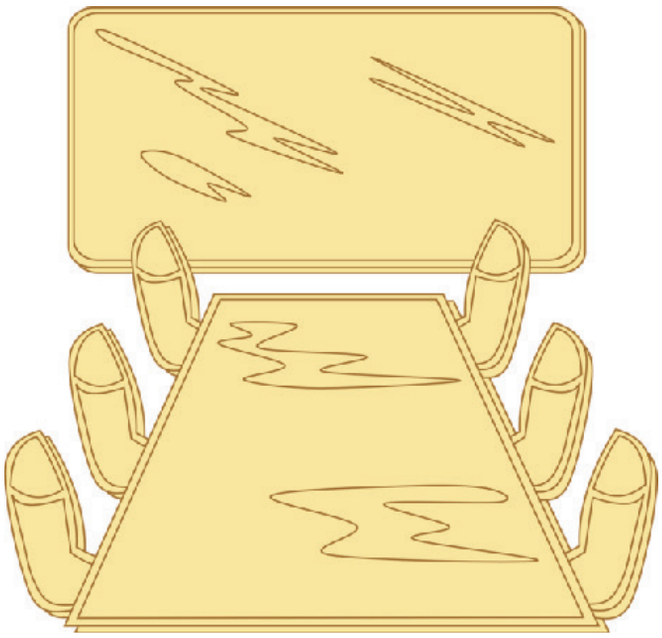
Noticeboard

Join our E-zine Readership

Our E-zine is the easiest, hassle free and most comprehensive way to keep up-to-date with all things I.H.S.

This electronic magazine is delivered straight to your inbox, providing news, event reminders, articles of interest and keeps you in the loop about what's happening in the Irish Haemophilia Society.

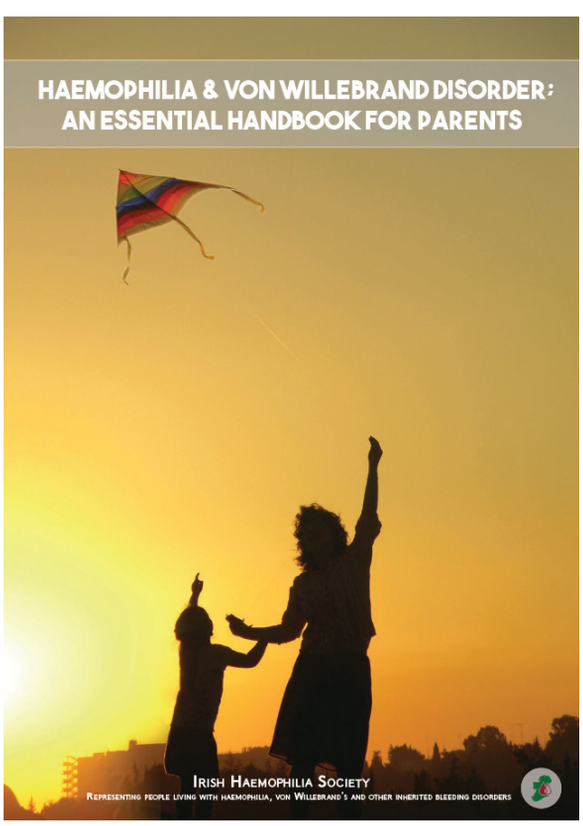
To sign up, simply email barry@haemophilia.ie or click here and fill in your details.



Board Update

We are delighted to welcome two members to the I.H.S. Executive Board; Jay McEvoy and Dan McIntyre and we are all looking forward to working with Jay and Dan over the coming months and years.

As we welcome Jay and Dan to the fold, we also say goodbye to Matthew McCabe from the I.H.S. Executive Board. We would like to thank Matthew for all his work, time and dedication in his time on the board.



Coming Soon

As a parent, when a child is diagnosed with a bleeding disorder, you may feel scared, worried and perhaps even guilty. This may be an especially hard time for those who have no family history of the condition.

It is important to remember that with good treatment the child with a bleeding disorder has every chance of growing up as an active, fit person who can participate in family, school and later working life. Because bleeding disorders are rare conditions parents may feel isolated and alone and it is very helpful to be put in touch with others in a similar position.

The Society offers support and advice to help improve the quality of life for people with bleeding disorders - and we hope that this publication is a useful, reassuring and helpful resource.

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