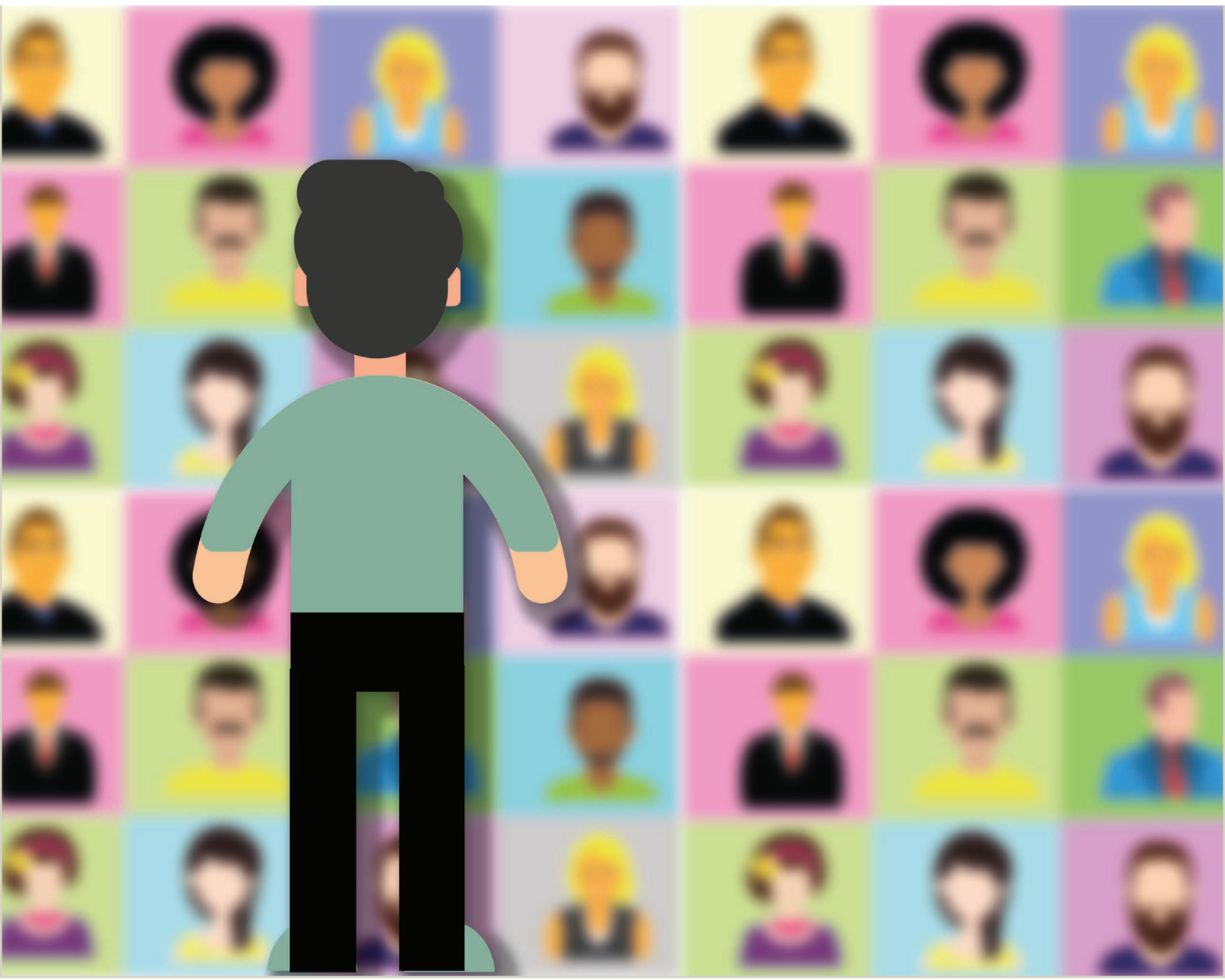
Haemophilia.ie

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

Magazine of the Irish Haemophilia Society

Spring 2021



The Society at a Glance

576	74	46	1490	1076
e-Zine Subscribers	I.H.S. Volunteers	Planned Giving Contributors	Facebook Followers	Twitter Followers

SCAN ME

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FROM THE EDITOR

I hope you are all safe and well in these continuingly strange days – however, as 2021 progresses and vaccines rollout, hopefully we can begin to see the end of the pandemic on the horizon.

The I.H.S. team is continuing, like many of you, to work remotely but we are very proud of the work we've achieved in these trying times and how our community has remained; we are especially pleased with how our Virtual AGM & Conference went.

On Page 3 Brian shares his thoughts on our Virtual Conference & AGM and outlines the new von Willebrand (VWD) guidelines and plans for World Haemophilia Day 2021, with weeklong focus on VWD.

Elsewhere, on Page 6, Robert gives the lowdown on the new I.H.S. Health & Wellness programme; a members guide to be the best you can be. On Page 8, with an update on the study's progress into 2021 and on Page 10 we are treated to some personal perspectives on the I.H.S. grants & how the I.H.S. can help you with your studies.

Then, on Page 12, I.H.S. member John O'Mahony reflects on a little adventure and the despair of encountering a total stranger at his bedside not wearing a mask – this is a very funny story! And on Page 14 we have news and updates from the I.H.S.

Lastly, I hope you enjoy this issue 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 normal too.

Barry

IN THIS ISSUE

CEO REPORT

Conference and AGM

Our annual conference this year was, for the first time ever, a virtual event. It was held over three consecutive evenings on March 1, 2 and 3 with the Annual General Meeting for members taking place on March 4.

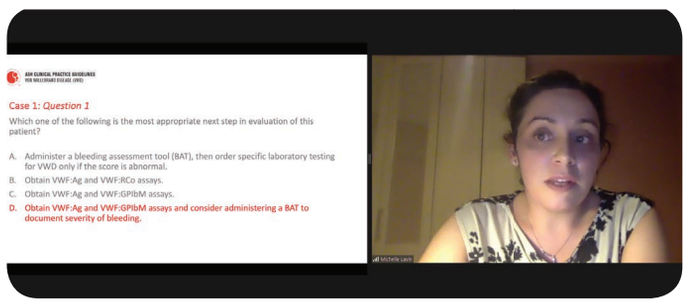
Obviously, we missed seeing all the members in person and it was sad that the children and teenagers could not get together and enjoy the activities and varied programmes which are always supervised so well by our trained and committed volunteers. Hopefully, our annual conference in 2022 will be an in person event and we also hold out hope of hosting an in-person Members Conference in October this year, depending on developments with Covid-19.

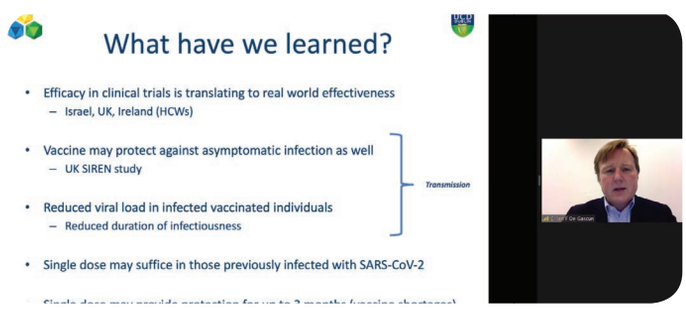
We were very pleased with the Conference outcome. The fact that it was virtual made it feasible for us to invite expert speakers from abroad (Italy and Canada) at no cost to the Society and with minimum disruption to their lives. It also made it possible to expand registration to the haemophilia community abroad and we had attendees from all across the globe, including; USA, Canada, Iceland, New Zealand, Netherlands, South Africa, Switzerland, Belgium, Austria, Brazil, UK, Turkey, Jordan, Finland, Germany, France, Spain, Armenia, Croatia, Vietnam and Denmark. We also welcomed additional representatives from several of the pharmaceutical companies who manufacture treatments for haemophilia and related disorders. In total, we had 107 attending on Monday, 106 on Tuesday and 85 on Wednesday.

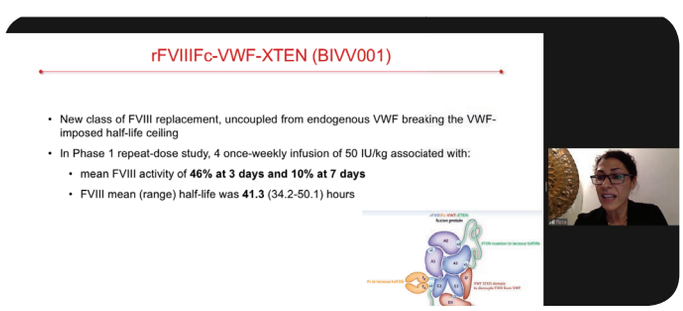
On the Monday evening, we had excellent updates on Novel Therapies and on Gene Therapy from Prof. Flora Peyvandi from Italy and Prof. David Lillicrap from Canada respectively. Flora and David are global authorities on these topics and their presentations were very comprehensive. Tuesday began with a very comprehensive look at Covid-19 and vaccines from Dr. Cillian de Gascun, Director of the National Virus Reference Laboratory and a key member of NPHET. This was followed by updates on the Use of Technology including the Lighthouse project and Patient Portal from Dr. Niamh O Connell and Feargal Mc Groarty, an Update on Dental Care from Dr. Alison Dougall and Targeted Physiotherapy at home from Mark Mc Gowan- all from the team at the NCC at St. James's Hospital.

We ran a parallel track on Tuesday on von Willebrands Disorder with a comprehensive look at the new VWD Guidelines from Dr. Michelle Lavin from the NCC followed by a discussion on their personal experience of living with VWD from Breda Queally and Donal McCann. Wednesday began with an update on the innovative iPATH research programme from Prof. James O'Donnell from NCC, followed by a talk on Resilience and Mental Health from Dr. Patricia Byrne from the NCC. This was followed by a panel discussion between Dr. Niamh O'Connell, Dr. Beatrice Nolan from CHI, Crumlin, Declan Noone, President of the EHC and I. We discussed the future direction of treatment, haemophilia comprehensive care, treatment for VWD and patient engagement.

We were very gratified by the number and quality of questions submitted during the conference. After the two hour session each evening, we opened a separate networking room which gave members and speakers an opportunity to chat and communicate in a less formal manner. We are very grateful to all of the speakers who shared their time and expertise with us for the conference. For those who were unable to attend the conference or for those who attended and would like to listen again to some of the excellent pre-







sentations, all of the lecture based presentations (with the exception of the iPATH presentation, which contained as yet unpublished data) are available to watch on our website, **haemophilia.ie**

The Annual General Meeting of the Society then took place by Zoom on the Thursday evening with a total attendance of 53 members.

Von Willebrand Disorder

New International Guidelines have just been published on von Willebrands Disorder (VWD). These were the result of more than two years work and collaboration between the

World Federation of Hemophilia (WFH), International Society of Thrombosis and Haemostasis (ISTH), American Society of Hematology (ASH) and the National Hemophilia Foundation (NHF) in the USA. It is a measure, perhaps, of the degree to which VWD is under-recognised that the collaboration is between 4 organisations - two of which have Hemophilia in their name but no mention of VWD in any of the organisation names - (we are maintaining the name of the Irish Haemophilia Society but the tagline under the name on all our publications and communications now states "Representing people living with Haemophilia, von Willebrand's and other inherited bleeding disorders").

VWD is the most common inherited bleeding disorder and yet it is comparatively underdiagnosed clinically and unknown by the public and most doctors and health care professionals who would have some basic knowledge of Haemophilia. VWD also affects both men and women. A lack of awareness of the difference between normal and abnormal bleeding symptoms coupled with the limited availability of specialized laboratory testing makes the diagnosis of VWD challenging. The clinical complexity of VWD and the absence of extensive evidence to guide decision making means that there is considerable variability in the clinical management of the disorder.

These guidelines are very comprehensive, and it is particularly encouraging that people with VWD made up approximately a quarter of both the Diagnosis and Management Panels who agreed the guidelines. The clinical manifestations of VWD may touch every aspect of an affected person's life. Thus, these guidelines are relevant to their interactions with all healthcare professionals, not just those specializing in the diagnosis and management of bleeding disorders. General practitioners, emergency department staff, dentists, surgeons, gynaecologists, obstetricians, anaesthetists, and many more will do well to familiarize themselves with these guidelines. The guidelines cover both diagnosis and management of VWD.

The 11 diagnosis recommendations cover:

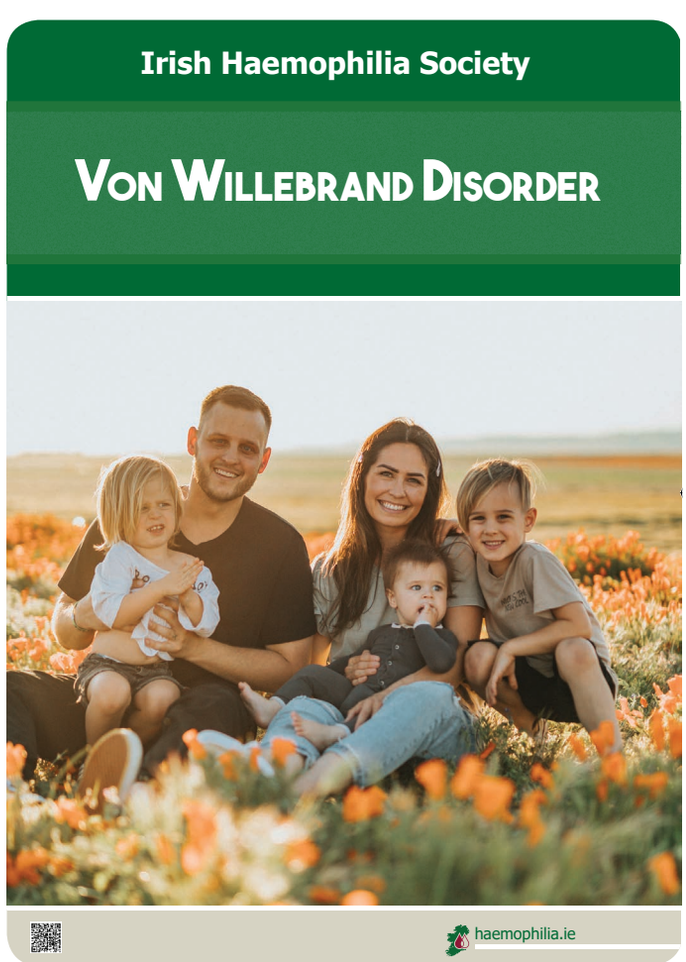
- The role of bleeding assessment tools (BAT) in the assessment of patients suspect-ed of VWD
- Diagnostic laboratory cut offs for type 1 and type 2 VWD
- The role of genetic testing for types 2B and 2 N
- The reconsideration, rather than simple removal, of a type 1 VWD diagnosis, should VWF levels normalize over time

The eight management recommendations cover:

- Prophylaxis for severe and frequent bleeds
- Desmopressin (DDAVP) trials to determine therapy
- Use of antithrombotic therapy (antiplatelet agents and anticoagulant therapy)
- Target VWF and factor VIII activity levels for major surgery
- Strategies to reduce bleeding during minor surgery or invasive procedures
- Management options for heavy menstrual bleeding
- Management of VWD during labour and delivery
- Management in the postpartum setting

The Management Guidelines also place a consistent emphasis on seeking optimal outcomes for individuals affected by abnormal bleeding. The recommendation of prophylaxis for frequent and severe bleeds does not specify a VWD subtype, and the recommendations on the management of heavy menstrual bleeding point out that some women and girls may need prophylaxis to control bleeding. While VWD is inherited equally by men and women, women are disproportionately impacted by menstrual and postpartum haemorrhage. The particular need for guidance on issues specific to women's health was highlighted in the responses (of both men and women) to the stakeholder clinical question prioritization survey and is re-flected in the multiple recommendations devoted to heavy menstrual bleeding, epidural anaesthesia and postpartum management.

We were very pleased to host a parallel session on VWD at our Conference on March 2nd. Dr. Michelle Lavin from the NCC, who is one of the authors of the Guidelines outlined the Guidelines. This was followed by a panel discussion between Breda Queally and I.H.S. board member Donal McCann - both of whom live with VWD.



Von Willebrand Disorder is the focus of World Haemophilia Day this year. We fully appreciate the requirement for greater education about VWD, greater public awareness and greater emphasis from the Society. To this end, VWD will be the focus of our World Haemophilia Day (WHD) events this year. WHD is on April 17 and we plan almost a week of VWD activities. This will include:

- A webinar of VWD Guidelines and Research on April 14th with Dr Michelle Lavin and Prof. James O'Donnell from the NCC
- A webinar on April 19 where we will hear about the lived experience of living with VWD from four people with VWD: two men and two women

Between April 14 and 19, activities will include:

- The public launch of our VWD Booklet
- Launch of our newly developed VWD animation
- Launch of 15 ethnographic clips on living with VWD featuring Breda Queally and her son Barry on our social media accounts (Facebook, Twitter and Instagram
- Launch on our website of the panel discussion session from our conference on VWD

Our hope is that these tools will also lead to some media coverage and increased aware-ness about VWD. Complete Information will be sent, prior to that week, to all of our members with VWD and to many others in the country diagnosed with VWD. The information will also be made available through the 4 treatment centres. We see this as the beginning of increased awareness and focus on VWD.

Brian O'Mahony

WORLD HAEMOPHILIA WEEK 2021

2021 THEME: VON WILLEBRANDS DISORDER

Join the Irish Haemophilia Society for World Haemophilia Week 2021 as we focus on von Willebrands Disorder (VWD). We fully appreciate the need for greater education about VWD, greater public awareness and greater emphasis from the Society. To this end, VWD will be the focus of our events this year and we plan almost a week of VWD activities ncluding;;

- **Wednesday, April 14 @ 6pm: Webinar on 'VWD Guidelines & Research for Diagnoses & Treatment' with Dr. Michelle Lavin & Professor James O'Donnell.**
- **Thursday, April 15: Launch of New VWD Booklet & Social Media Campaign**
- **Friday, April 16: Launch of New Animated VWD Video**
- **Monday, April 19 @ 6pm: Webinar on 'Living with VWD', Personal Stories from I.H.S. members Breda Quealy, Barry Quealy, Donal McCann & Shannon Carey**

To join us please visit haemophilia.ie or email info@haemophilia.ie for more details.

You will be pleased to hear that we have started the process of developing a new Health and Wellness programme for members. The programmes will aim to help all our members improve overall health, fitness, and wellness. These programmes can be used as a reference from time to time to keep you on track with your goals. We have decided to break up the programmes into three different age groups.

- Children (4-17)
- Adult (18-55)
- Senior (Over 55)

Each programme offers different advice, tips and tricks to get you started on the right path and to keep you motivated and focused to improve your overall health and wellbeing.

Children (4-17)

The Children's programme covers the benefits of healthy food for kids and how to encourage healthy eating habits. We also look at making mealtimes about more than just healthy food and how to limit sugar and refined carbs in your child's diet. The programme should give readers an overall understanding of what foods are made up of and how different foods affect children. As well as this there is some guidance on encouraging exercise.

Adults 18-55

The 18-55 programme targets exercise, healthy eating, and mental health. We help you answer such questions as, what's keeping you from exercising, how much exercise do you need, how hard do I need to exercise, among others. We also bust the biggest exercise excuses, get you started on your exercise journey safely and provide tips on how to make it a habit.

The Healthy Eating portion of this program includes all aspects of nutrition to give readers advice on what foods we should consume, what they are made up of and how much we should aim to eat. There is also guidance on how to eat healthy on a budget, the importance of staying hydrated and the effects of alcohol.

The final aspect of the 18-55 programme focuses on mental health. Readers will gain a better understanding of good mental health, what characteristic people who are mentally healthy have and why are we often reluctant or unable to address our mental health needs?

We also look at the importance of making social connection a priority - especially face-to-face with tips for connecting to others. Another area covered is learning how to keep your stress levels in check and managing your emotions to relieve stress. The final part of this programme covers sleep and tips on how to get the best sleep, so you feel refreshed and revived.

Adults 55+

The 55+ programme is more extensive and covers the same

topics as the 18-55, exercise, healthy eating, and mental health. We start by looking at what are the benefits of exercise for older adults in terms of physical health and mental health benefits.

This programme will also help you get started exercising by overcoming obstacles to getting active as you age even if you hate to exercise. It will advise you on building a balanced exercise plan, with examples of activities beneficial to older adults and how to stay motivated even if your routine changes. From there we will look at getting started safely and addressing issues such as an injury, disability, weight problem, or diabetes.

The healthy eating section looks at the benefits of healthy eating as you age and how to create a healthy senior diet. There is also guidance on the importance of vitamins and minerals as you get older and cope with your changing dietary, physical and lifestyle needs that may affect your diet. The final part of the healthy eating section covers many different issues such as:

- Understanding malnutrition
- Boost a low appetite
- Cope with difficulty chewing
- Deal with a dry mouth
- Don't like healthy food?
- Meals on Wheels
- Eating well on a budget
- Alcohol

Mental Health

The final aspect of the 55+ programme focuses on mental health. Much like the 18 to 55 readers will gain a better understanding of good mental health, what characteristics people who are mentally healthy have and why are we often reluctant or unable to address our mental health needs?

We also look at the importance of making social connection a priority - especially face-to-face with tips for connecting to others. Another area covered is learning how to keep your stress levels in check and managing your emotions to relieve stress. The final part of this programme covers sleep and tips on how to get the best sleep, so you feel refreshed and revived.

We hope to roll this out soon so keep an eye on our website, social media and e-Zine for details.

Robert Flanagan

Hyde Square Apartments

A quick reminer that our apartments at Hyde Square are available to:

- People with haemophilia or related bleeding disorders from outside of Dublin, when attending St. James's Hospital or Children's Health Ireland, 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 Children's Health Ireland at 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 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.

IPATH STUDY UPDATE 2021

Following on from Prof James O'Donnell's presentation at our recent Conference & AGM, the iPATH Partnership provide us with an update on progress with the innovative Irish Personalised Approach to the Treatment of Haemophilia (iPATH) research programme.

Although all people with severe haemophilia (PWH) have factor levels <1%, there are significant differences in how they are affected by the condition. For example, some people develop frequent spontaneous bleeding episodes, whilst other people may have very little bleeding. In addition, some PWH develop joint damage despite the fact that they have had few joint bleeds. In contrast, some individuals have quite a number of joint bleeds but appear to develop minimal joint damage. The reasons behind these important inter-individual differences remain poorly understood. However, understanding these differences is of paramount importance in terms of developing improved care for PWH.

For many decades, recommended treatment for haemophilia has been based on using factor concentrates, the dose of which was based only on the body weight of the individual. This "one-size-fits-all" approach continues to be widely used in many countries where factor concentrates are available. However, there is an inherent flaw with this standard approach in that it completely ignores the fact that individual patients are all different. What we need in the 21st century is to strive towards a personalized approach, where treatment dosage and frequency are specifically adapted for each individual patient. For example, young and active teenagers with haemophilia who are playing sports will require their treatment to be timed so that peak clotting factor levels are present when they are most active. In contrast, older less active PWH may not need such high factor levels in order to prevent spontaneous bleeding. Finally, it is evident some PWH may be more at risk of developing bleeding and joint damage. For these individuals, once again it makes sense to consider targeting higher factor levels to prevent them experiencing long-term complications. In summary, the idea of developing personalised treatment for people with haemophilia is no longer just a concept, it should become a standard of care for PWH.

Objectives of iPATH

Before we can move towards personalised treatment for haemophilia, there are a number of key questions that we need to consider:w

1. How should factor treatment be adjusted based upon physical activity?
2. Why do some PWH develop more bleeding than others, despite the fact that their factor levels are the same?
3. Why are some PWH more susceptible to developing joint damage than others who seem relatively protected?
4. Why does the survival of clotting factor in the blood vary widely between PWH?

In order to gain new insights into these questions and push towards personalised therapy for PWH, the iPATH study was established in 2017. A key aspect of the study is that it comprises a multidisciplinary team and involves close partnership with the Irish Haemophilia Society. The iPATH study is supported in part by a research grant from Science Foundation Ireland (SFI) under the SFI Strategic Partnership Programme Grant (16/SPP/3303) and research support from Shire US Inc., a Takeda company, Lexington, MA, USA. In addition to the clinical team within the National Coagulation Centre (NCC) in St James's hospital, iPATH also includes basic scientists working in the Royal College of Surgeons in Ireland (RCSI), Trinity College Dublin and within Takeda.

iPATH progress

The iPATH programme has faced a number of obstacles. As discussed in previous I.H.S. AGMs, these have included the introduction of Irish regulations regarding data protection in clinical research. Of course, more recently we have also all faced the challenges associated with the COVID-19 pandemic which has certainly restricted access to the NCC and to our various research laboratories. Nonetheless, significant progress has been achieved towards all of our original goals. In December 2019, the progress of the iPATH partnership was reviewed by an independent external panel of renowned haemophilia experts. This panel were extremely complementary about the results to date and highlighted the fact that iPATH was not only important for Irish PWH, but also that it carried great significance for PWH around the world. One particular aspect of the review panel report that was particularly pleasing was that it emphasized the close relationship that exists between all the members of the iPATH partnership, including the active role played by

the IHS in helping to design and promote the study. A number of insightful recommendations from the review panel have already been implemented and have led to some changes in the iPATH research programme.

With respect to specific findings from the iPATH research partnership, these were discussed in m greater detail the I.H.S. Conference & AGM presentation by Prof O'Donnell. Briefly, some exciting examples include:

1. Cardiometabolic risk factors including increased body weight, reduced fitness and reduced physical activity (PA) levels have been identified amongst adults with severe haemophilia.
2. As measured by Body Mass Index, 60% of participants were classified as overweight or obese. Similarly, waist to hip ratio (another indicator of body composition) was also elevated in 64% PWH.
3. 67% of participants appeared to meet recommended PA guidelines of at least 150 minutes of moderate intensity PA per week. However the total time spent in periods of sustained higher intensity PA was relatively low, with only 18.9% achieving this target.
4. Age-dependent barriers to PA have been identified amongst adults with moderate and severe haemophilia. Lack of time and willpower were more common amongst younger adults, whilst fear of injury and lack of skill were more significant for older PWH.
5. PWH who clear clotting factor rapidly from their blood are more likely to have bleeding complications and require more factor to prevent bleeding.
6. Factor VIII treatment is cleared more rapidly in PWH who are blood group O and is regulated by plasma von Willebrand factor levels.
7. A new cell surface receptor has been shown to regulate FVIII clearance.
8. Novel assays have been developed to identify determinants of different bleeding tendencies between PWH.
9. A new laboratory model of severe haemophilia A has been established that develops spontaneous bleeding and haemophilic arthropathy. This model is being used to explore immune mechanisms associated with bleeding, arthropathy and inhibitor development.

iPATH – what is happening next?

The iPATH partnership was originally planned to run for four years in the first instance (2017-2021). However, we are pleased to announce that it has recently been confirmed that the partnership has been extended and will now continue through until Sept 2022. This excellent news means that despite the limitations associated with the COVID-19 pandemic, we will now positioned to build upon our progress to date. In the next 6 months, we are optimistic that many of the new findings that have been generated through the iPATH programme will be published in international peer-reviewed journals. The extension will also enable us to complete our whole genome sequencing studies which have been delayed because of GDPR regulations. Importantly, a new clinical fellow has joined the iPATH team (Dr Einas Elsheikh). She will take over the position that was previously occupied by Dr Michelle Lavin.

Another important update is that we are planning a follow-up study of physical activity and quality of life. It has been over two years since the original iPATH Physical Activity research assessments were carried out. Upon completion, individual feedback reports were given to all participants about their PA and health. The research team are interested to discover whether PA and lifestyle habits have changed for those who participated in the original assessment and whether they found the personalised feedback beneficial. Furthermore, the COVID-19 pandemic has affected the lives of everyone over the past year. The team are also keen to discover if the pandemic has had any impact on PA and quality of life in adult PWH. For people who are interested, we plan to do a further study to see whether PA habits have changed compared to their first assessment. Unlike before, people will not have to attend the hospital research facility in person in order to participate in the follow up study. Instead, this study is being conducted on a remote basis and the ActiGraph activity monitor (worn during the original assessment) will be delivered to anyone who participates in the follow up study. The research team will also arrange to have the monitor collected once the data has been collected. An optional questionnaire will also be sent which will ask for more detail on PA, as well as the impact the past year. If you participated in the original assessment you may be contacted again in future in relation to this follow-up study. Again, participation is fully voluntary and a detailed information leaflet about the study will be sent to anyone interested in taking part.

As we now look to the future; encouraged by the results of the iPATH study thus far; we thank our partners for their continued contribution and ongoing support, without which such research, could not be sustained and we acknowledge that by working together we are closer than ever to enhancing the quality of life for people with haemophilia.

I.H.S. EDUCATIONAL GRANTS

SOME PERSONAL PERSPECTIVES ON HOW THE I.H.S. CAN HELP YOU!

Hi there, my name's Conor and I'm a final year college student. I am currently working towards a BA in Economics and German in UCC. This year I received the Maureen and Jack Downey Educational Grant from the I.H.S., a gesture that was deeply appreciated.

There is more information about the I.H.S. grants on haemophilia.ie, but essentially this particular grant is for people with haemophilia or a related bleeding disorder, while there are others that facilitate immediate family members of people with a bleeding disorder, and for people with a bleeding disorder that are enrolled in a level 5/6 educational course.

I found this grant extremely useful, due to the nature of this college year: all lectures and extra-curricular activities are virtual, and so I found it necessary to upgrade my technology to handle my transition into a purely online entity. I purchased a new laptop, which is proving thus far to make my year more bearable; I can type up assignments fluidly, I can participate in classes with Microsoft Teams, and I can easily access course materials for my studies. Without this help from the I.H.S., I would have found college much more difficult this year than I currently do.

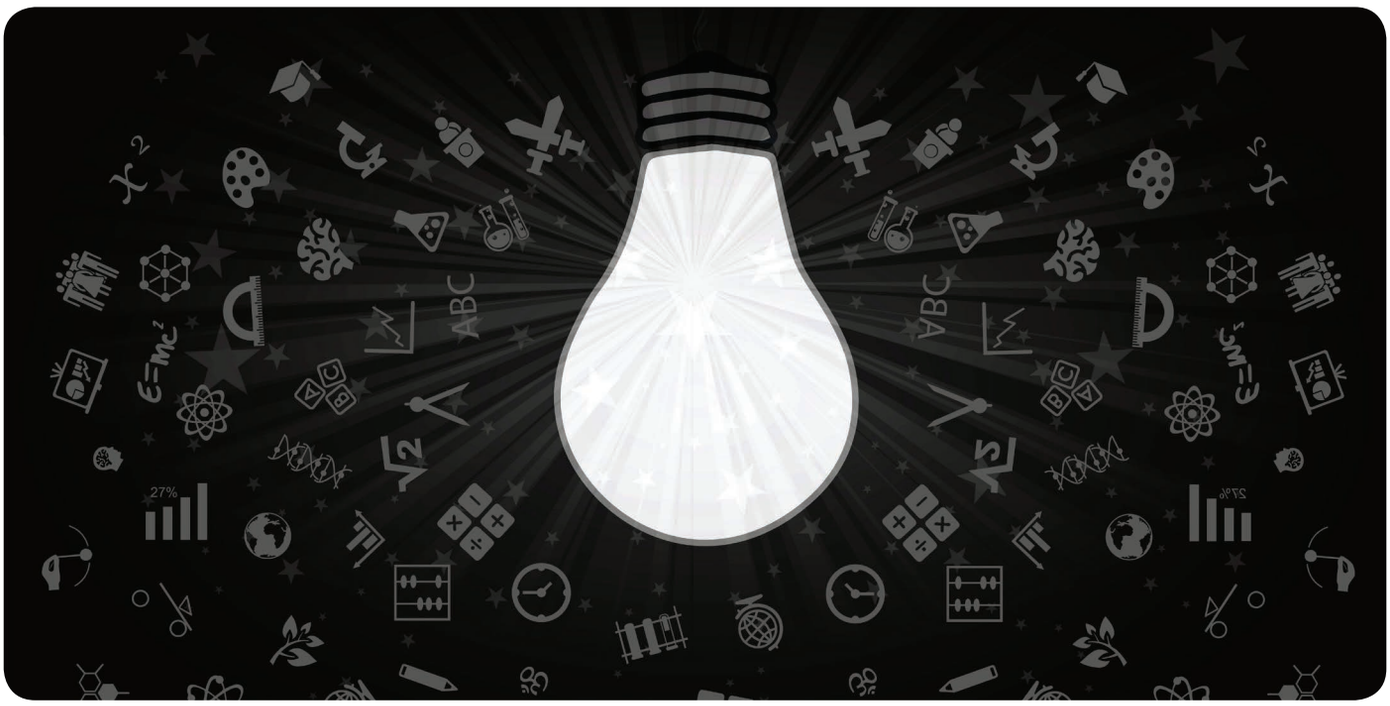
Of course, the social aspect of college can't be overlooked. In a year in which everyone's lives have increasingly began to resemble that of a Shaolin monk's, having a fast laptop has enabled me to stay in touch with friends. This has helped to curb the loneliness and sense of isolation that comes with a pandemic, as we have been forced to become more inventive in meeting our social needs. I do feel it necessary, on a vaguely related note, to thank the I.H.S. for their check-in services during the last 12 months: at my lowest, I found great comfort in the support I received from members of the society, as they all were willing to bend over backwards to help me feel relatively normal. This encouragement went a long way in making me feel that I wasn't all alone in this world.

This grant has also provided me with a great sense of security. I feel the pandemic has revealed to people the lack of control they have in their lives, as we see the reality of our autopiloted existence and the illusion of having any real grasp on the direction our lives are going in. For fear of becoming more existential, the point I'm making is that this grant has helped me personally, providing some well needed solidity and a feeling the future is brighter, once I graduate.

It isn't easy in the best of times to finish your studies and figure out where to go next in your life, and this is doubly true now, with me and my compadres facing entering the working world with a global recession on our hands. For me, I would love to travel for a while. I had previously planned to go on Erasmus to Germany this year, and my drive to live there still lingers. I plan on moving to Germany or another German speaking country, in order to perfect the language skills, I have been developing since secondary school. This will then, naturally, boost my employability, not just in Ireland, but around the world.

The feelings of security I have from receiving this grant are felt every day. I cannot recommend for people to apply to one of these grants enough. The Irish Haemophilia Society show time and again their generosity, as they try to help as many members as possible going into further education. The application is quite a simple process and easy to complete, and if you qualify for a grant, you shouldn't hesitate in putting your name forward (I'm trying really hard not to quote the National Lottery's slogan). I am extremely thankful to the board of the I.H.S. for providing me with this grant, and I hope that prospective applicants do not hesitate in throwing their name into the mix.

Conor Birkett



Hello! My name is Belen Fernandez. I am an Early Years Practitioner. I'm qualified in Early Childhood Education and Care. I worked for three years in community childcare services. During that time, I had an advantageous experience and a unique opportunity. However, I found the need to acquire some knowledge to improve the practice to assist the children.

In August 2020, aware of the continuous changes and challenges resulting from the current restrictions due to the pandemic, I decided to move forward and go back to study. I found the course of my interest, applied to enter, and started to look for financial support to pay the fees. I was very optimistic about the idea of returning to study and my social responsibility in the future.

At this point, as luck would happen, I read the Irish Haemophilia Society Summer Magazine, and to my delight I found lots of useful information including financial support to students, so I didn't hesitate to contact the organization. Julia helped with my inquiries, and I completed my grant application.

I succeeded in admission for B.A. Early Childhood Studies and Practice at NUI Galway a few days later, I received the news that my application for the Educational Grants 2020 was approved! I was profoundly moved and grateful because of all the support I have received from The Irish Haemophilia Society in many aspects.

Now, I am in my first year of studies. Despite the academic year 2020-2021 is entirely online, I am very committed to advance. It can be different from attending presential classes and spending time with your classmates. Still, the resources are useful and accessible all the time. The academic tutor is very supportive. I am learning about the safeguarding, health, nutrition, and wellbeing of children.

I am enhancing my skills through theory, policy, and research in the early years' environment. I am gaining an understanding and knowledge, and it is building my confidence to support children's needs. I am looking forward to the next modules and complete the degree.

The process of applying for grants is straightforward. I highly recommend others to apply because it is of great help and benefit.

Belén Fernandez

John O'Mahony reflects on a little adventure he had to embark on and the despair of encountering a total stranger at his bedside not wearing a mask

PUBLIC enemy number one came in the form of a jagged, stubbornly attached and brutally painful 8mm kidney stone that was deemed too formidable to pass through a narrow 4mm tube along a route best not thought about.

Given the measurement imbalance and the little matter that eight into four doesn't usually go, Isaac Newton himself or even the brilliant rock and roll scientist Luke O'Neill would probably struggle to determine a practical extraction method.

But where there's a will….

And so, Covid checked and cleared 24 hours in advance, I presented myself for admission at the surgical ward where one of the country's great urologists awaited, scrubbed, gowned and, hopefully, refreshed after a good night's sleep, to boldly go where nobody ever went before.

It was, I was assured by the charming member of his team, a routine, straightforward, everyday procedure but that didn't really explain why, if it was that simple, a general anaesthetic was required at all.

Probably opting to spare me the anguish the specifics would bring, no great detail was volunteered so quick check with Dr Google briefed me on all I needed to know.

And don't mind what the medical professionals will tell you, Dr Google is great – and there's never a fee or a packed waiting room.

But, in this instance, given the gory details, I wished I hadn't consulted.

When being discharged the following day, there was one small, lingering issue that remained to be tackled – the procedure didn't work.

The Rock of Cashel was still hugging my right kidney for no other reason than eight into four just doesn't go, unless a little help is provided. And the less spoken about that the better – just don't ever mention the words 'temporary stent' to me again.

With the procedure rescheduled for six weeks later, it was a case of second time lucky and although success brought with it a share of discomfort for a week or so, the nasty 8mm boulder had been blasted into oblivion.

And I had the photographic evidence to prove it, courtesy of one of the theatre team's uncanny knack of being able to double job with a surgical instrument in one hand and a smartphone in the other.

I share this tale of personal woe for a particular reason and it is this: Days before admission I was instructed to wear a face mask on my arrival at the front door of the hospital and not to remove it, at any stage, until told that it was safe to do so.

The security man at the door wore his, the lady behind the admissions desk did too and all along the long and winding corridors, and right through to the next day's discharge, almost every member of staff was adhering to the golden rule.

I say almost because there's always one. In every facet of life, there's always one that will veer left when told to turn right and stand up when advised to sit down.

This particular member of staff obviously felt it was perfectly adequate to have the mask dangling from one ear or tucked in under the chin.

"Would you not wear the mask properly?" I enquired.

"I hate them," came the fast as you like reply, "they're very hot and itchy".

"Might be better to be hot and itchy than ending up in a bed with more serious matters to concern you," said I.

"Yerra look," came the retort, "I could be killed by a bus crossing the road".

The staff member's supervisors were either entirely oblivious to the situation or there was nothing they could do about it but it was hardly acceptable that anybody not wearing a mask properly could be let loose in the wards of a hospital where people were vulnerable, petrified about contracting Covid and not there by choice.

Irked somewhat by that particular episode, I've been on what could only be described as some sort of super mask watch alert since returning home, frowning when I see them dangling, tut-tutting when they are being pawed and shoved any which way into trouser pockets and throwing my eyes skywards in despair when I listen to those moaning about how much of an inconvenience they are.

I've walked out of a supermarket because a staff member on a till was not wearing a mask. I refuse point-blank to frequent business premises where a visors-only approach is accepted. I have turned on my heels and walked out anytime I encounter sanitiser dispensers drained dry and if looks could kill the chap that never heard about the two metre rule and stood on my shoulder at the shop counter would be six feet under and counting.

You could say I am a now a fully paid up subscriber to the 'if you find a mask uncomfortable try a ventilator' brigade.

So what do you think happened to me?

On a quick dash to a local shop, I was rather puzzled when one of the two staff members behind the counter threw me a look that could kill, adjusted her mask and kept her distance while I processed my contactless payment.

It was only on my return to the car when I found only an ear and no string when I went to remove my mask that the horror dawned on me.

I can imagine the two ladies behind the shop counter complaining that there is always one. And there always is so maybe we are all a bit too quick to pass judgement.

The only consolation was that I was in the shop less than 90 seconds and there was a protective glass separating the staff member from the idiot outside the counter.

It won't happen to me again. Of that I'm certain.

In the meantime, let those without sin cast the first stone – even if it is as big as the Rock of Cashel.

John O'Mahony

NOTICEBOARD

Covid-19 & Vaccination

We have no current information on when and where people with haemophilia and other inherited bleeding disorders will be offered one of the licenced Covid-19 vaccines. Some work has been completed on guidance on giving the vaccine, bearing in mind that these vaccines must be injected by the intramuscular route.

A guidance document for health care workers on vaccination of people with haemophilia, von Willebrands and other inherited bleeding disorders has just been produced by the National Coagulation Centre at St. James's Hospital.

It is reproduced on our website, please download the PDF to your phone or device to bring with you to your vaccination appointment.

It can be found on haemophilia.ie or via this QR Code.

SCAN ME

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

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

Write for the I.H.S.

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, fundraising, volunteering or something else entirely!

If you would like to contribute and write an article for the I.H.S. contact **barry@haemophilia.ie**

We are very pleased with how the conference went and are thrilled that so many of you could make it. We hope all of you who attended enjoyed the conference and found the sessions informative, engaging and thought provoking.

We've uploaded the sessions from conference to the website so you can watch them at your ease, when time allows.

You can find the recordings on YouTube & haemophilia.ie, or scan the QR Code below.

SCAN ME

NOTICEBOARD

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:

- Update on New Children's Hospital with Eilish Hardiman, CEO
- Exercise and Physical Activity for Children with Paula Loughnane, Senior Physiotherapist at CHI Crumlin
- The Role of the Advanced Nurse Practitioner in Haemophilia

You can find the recordings on YouTube & haemophilia.ie, or scan the QR Code below.

SCAN ME

Bon Voyage Julia!

Julia has been our friend and colleague since joining the I.H.S. team back in 2018 and it is with a heavy heart that we bid farewell as she sets out for pastures new.

Lots of you will have spoken to Julia at our events or on the phone many times, so I'm sure you will join us in thanking Julia for all her hard work and dedication, and of course, wishing her all the very best in the future.

Julia will be greatly missed by all the I.H.S. team but new and exciting times await as she sets out on a new chapter in life.

Coming Soon....

Two booklets on Hemlibra

1) For people with Factor VIII Inhibitors
2) For people with Factor VIII deficiency without Inhibitors

IRISH HAEMOPHILIA SOCIETY

First Floor
Cathedral Court
New Street
Dublin 8

Tel: 01 657 9900
Fax: 01 657 9901

Email: info@haemophilia.ie
Website: www.haemophilia.ie

Find us on: