Haemophilia, von Willebrands & Related Bleeding Disorders

Magazine of the Irish Haemophilia Society

Summer 2021



The Society at a Glance

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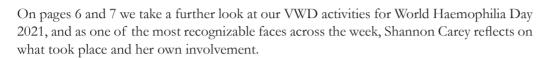
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FROM THE EDITOR

I hope you are all safe and well and looking forward to a nice summer as we begin to, hopefully, emerge from the pandemic with brighter days ahead.

On Page 3 Brian shares his thoughts on our weeklong focus on von Willebrand Disorder (VWD) for World Haemophilia Day this year, along with a look at Physiotherapy / Exercise Programme.



It is Educational Grants time of the year, you will find all you need to know on page 8, the grants are a great help to alleviate some of the financial burdens of education.

Looking after our mental health is a very important part of our overall health and helps us to manage stress and stay well and similarly, there is never a bad time to discuss mental health. Given we've all been doing our best to navigate our way through a pandemic since early last year, on page 10 we take a look at the vital importance of good mental health.

Continuing with the afforementioned theme, on page 12, we have a recap of our forthcoming Health & Wellness Programme and complimented by some useful online resources related to healthy living. And on Page 14 and 15, you will find our noticeboard with news briefs and updates from the I.H.S.

Lastly, I hope you enjoy this issue and have a great summer, if you wish to contact a member of staff between 9am and 5pm, Monday to Friday, please phone the office on 01 - 657990 or you can email us as normal too.

Barry

IN THIS ISSUE

CEO Report

Brian shares his thoughts on our week long focus on VWD for World Haemophilia Day 2021 & the physiotherapy / Exercise Programme

VWD Awareness

Shannon Carey reflects on her role Given we've been navigating through a News & Updates from the I.H.S. during our VWD activities for World pandemic since early last year, we take Haemophilia Day 2021

Educational Grants

All you need to know about the I.H.S. **Programme** Educational Grants for 2021

Mental Health

a look at the vital importance of good mental health.

Health & Wellness

A quick look at our forthcoming Health & Wellness Programme with some online resources related to healthy living

Noticeboard

CEO REPORT

Focus on von Willebrand Disorder

As part of the Society strategic plan for 2020 to 2024, we have a new focus on von Willebrand disorder (VWD). In recent years, treatment for haemophilia has been improved



immeasurably through better treatment protocols and availability of new generations of therapy including extended half-life factor concentrates and subcutaneous mimetics for Factor VIII (Emicizumab).

VWD affects both men and women and is the most common inherited bleeding disorder with approximately 1 in 1,000 of the population being affected. This would lead you to expect that there are 4,900 people with VWD in Ireland yet, at present the number diagnosed is 1,643 or 33% of the expected number. Despite the fact that only 1 in 3 of those with VWD in the country is diagnosed, this places Ireland at the higher end of the scale for VWD diagnosis internationally.

In many countries the proportion diagnosed stands at between 10% and 20%. VWD is underdiagnosed, undertreated and under-recognised. There are many reasons for this. Diagnosis is more complex than for haemophilia. Many of the initial or frequent symptoms of VWD - such as nosebleeds, heavy bruising or heavy menstrual bleeding - can occur without VWD or due to another cause. Diagnosis and management of VWD have also been hampered by the lack of internationally recognised guidelines or standards.

There is also a very wide range of severity within the VWD diagnosis from very mild to very severe. People with very severe forms of VWD, such as Type 3, would generally expect to have been diagnosed quite early in life. For those with Type 2 or Type 1, diagnosis may often have been delayed. This delay can be exacerbated by the lack of awareness among general practitioners who may not refer a person for testing for VWD when this is perhaps warranted. In men or children, easy bruising or frequent, heavy nosebleeds may be the first sign of a bleeding disorder.

The most common warning sign for women is heavy menstrual bleeding (HMB). One in 5 women will have HMB and, of these, up to 1 in 5 may have an underlying bleeding disorder. Many people with VWD have suffered through years of frequent nosebleeds, bleeding post dental care, easy bruising or HMB prior to diagnosis. There is a need to raise awareness among the general public and among GP's that frequent nosebleeds or HMB are not normal and may require investigation via referral to a specialist coagulation centre.

In VWD, the von Willebrand protein is lower than normal in the blood. Normal levels are above 50%, while in VWD, levels are below 30%. It can be difficult to tell if menstrual

Irish Haemophilia Society

VON WILLEBRAND DISORDER



bleeding is heavy. Comparing yourself to other women in the family can be misleading as they, too, may also have low vWF levels or VWD without knowing it. The following should alert a woman to a potential problem:

- Bleeding which lasts longer than 7 days, requires you to change pads or menstrual cup every two hours or passing clots larger than a €1 coin
- Unpredictable bleeding
- Menstrual bleeding which affects daily activity (needing time off work / school)

Both men and women with VWD can experience prolonged or heavy bleeding after dental procedures, surgery, or trauma. Any person who believes some of these signs of an underlying bleeding disorder apply to them should, in the first instance, contact their GP who hopefully will refer them for specialised testing at the National Coagulation Centre for adults or Children's Health Ireland at Crumlin for Children, if needed.

Thankfully, there are now newly published guidelines for diagnosis and management of VWD which have been produced collaboratively by the International Society of Thrombosis and Haemostasis, the American Society of Hematology, The World Federation of Hemophilia and the National Hemophilia Foundation (USA).

The Guidelines had extensive and formal input from people living with VWD so, for the first time, there is more international consensus developed on diagnosis and management.

Some of the key elements of management outlined in the new Guidelines include:

- The availability of long-term prophylaxis for people with VWD who suffer frequent and serious bleeding. This is welcome as the majority of people with VWD were not considered for prophylaxis in the past. This will help lead to a mindset change among treaters and also among some of those with VWD who would benefit from prophylaxis but may be initially reluctant to start. This is not entirely surprising and mimics the earlier experience where many adults with severe haemophilia were slow to embrace prophylaxis. The benefits to the individual only become apparent once you have initiated prophylaxis
- Specific regimes are recommended for the treatment of heavy menstrual bleeding with tailored treatment depending on whether or not the woman may wish to conceive
- The establishment of multidisciplinary clinics to include haematologist and gynaecologist to optimally diagnose and treat women with VWD

It is also worth noting that the first licenced recombinant von Willebrand factor concentrate has become available as a treatment option internationally in recent years which broadens the treatment options available.

With these timely developments in mind, it was opportune that the Society chose to make VWD the theme of our World Haemophilia Week events in April. Prior to this, we had made two important changes. Firstly, at the request of members with VWD, we no longer refer to von Willebrand

WORLD HAEMOPHILIA WEEK
2021 THEME:
VON WILLEBRANDS DISORDER

Join the Irish Haemophilia Society as we use World Haemophilia Week 2021 to highlight von Willebrands Disorder. We have a packed programme of digital and virtual events
Programme:

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

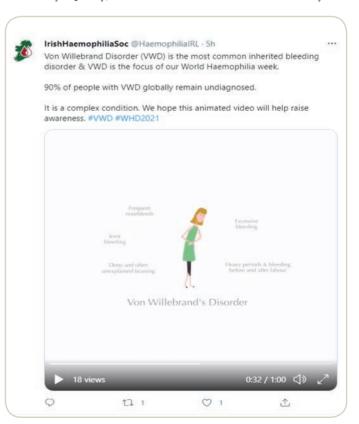
Irish Haemophilia Society
haemophilia.ie | info@haemophilia.ie | 01 657 9900

Disease but to von Willebrand Disorder. The view was expressed to us that the use of the word disease is pejorative and unacceptable. (People with haemophilia are referred to as having an inherited bleeding disorder, not disease. People with Platelet defects are referred to as having platelet disorders). The continued use of the word disease in relation to VWD is apparently important in the USA as a "disorder" may not be re-imbursed by health insurance but we have decided here to only refer to VWD as a disorder now and in the future in all of our communications.

Secondly, we were aware that many people who have VWD may not be aware that the Irish Haemophilia Society is there to provide services and support to them. We do not want to change the name of the organisation as we believe we have built up a strong brand name and reputation, but we did want it implicit that we provide services to those with VWD. Hence, we added a tagline under our name: "Representing people living with Haemophilia, von Willebrand's and other inherited bleeding disorders." In the future, depending on demand and on need, we may also set up a separate website to duplicate all of our information on VWD.

Our World Haemophilia week VWD activities had several elements.

- Re-launch of our updated VWD information booklet and specific posters on VWD for display at the treatment centres
- A clinical information webinar featuring Dr Michelle Lavin and Prof James O'Donnell for the NCC who are both widely published experts on VWD
- A patient webinar featuring 4 people living with VWD
 2 men and 2 women. We are grateful to Breda Quealy,
 Barry Quealy, Donal McCann and Shannon Carey for



- sharing their personal insights. Both webinars are now also available to view on the Society website on-demand
- Social media and website distribution of 20 short video clips featuring Breda Quealy and Barry Quealy speaking about their day to day experiences of living with VWD (available to view on website)
- A short animated video explaining VWD which was circulated on our social media platforms
- A press release which led to media coverage
- Magazine features planned in the coming weeks

We were very pleased to also significantly increase the reach of our publications and information on VWD. We have 140 people with VWD on our mailing list but, with the active co-operation of the treatment centres, our VWD booklet and campaign information went to approximately 600 additional people with VWD.

This is not the end of our work and focus on VWD but it does represent a strong beginning. We have started a Physiotherapy / Exercise class for people with VWD (on which, more information below). We plan to produce information booklets on: Heavy Menstrual Bleeding in adolescent girls, Infographics on HMB, information leaflets on treatment options including DDAVP and Transexamic acid. We will also work with Dr Michelle Lavin to optimally use her

Knowyourflow.ie website which provides information on menstruation. It is also our intention to provide free period products at future in-person Society events.

Physiotherapy / Exercise Programme

The work of Physiotherapist Megan Kennedy as part of the iPATH (Irish Personalised Approach to the Treatment of Haemophilia) Research programme has highlighted the fact that many Irish people with haemophilia and bleeding disorders are physically unfit and many are overweight. (This is also true of much of the general population but that is not much of a consolation).

In the era now of better treatment, of prophylaxis, of personalised care, the Society are keen to promote a healthier lifestyle for members and assist where possible. As part of this, we recognise that there are barriers which have prevented many people with haemophilia from taking part in exercise programmes. These include lack of confidence, fear of injury and unfamiliarity with gym equipment.

In 2020, we carried out a successful pilot programme for older adults with haemophilia. The course took place online over 8 weeks and was attended by 7 people with Haemophilia. All 7 enjoyed the course and benefitted from the exercise in a group setting which was supervised on Zoom by Sheila Roche and Mark McGowan, the specialist Haemophilia Physiotherapists from the National Coagulation Centre (NCC).

We have now commenced offering this course to members

Premium 🗸

Bruising, nosebleeds and heavy periods in women – the symptoms of an underdiagnosed inherited disease that affects one in every 1000 Irish people

Co Meath man Donal McCann suffers from bleeding disorder Von Willebrand disease. He shares what life is like with the condition, his relief at not passing it on to his daughter and why he is telling his story to raise a



Donal McCann with his 18-month-old daughter Darcy. Pic: Mark Condren

Mirror

Disorder may fight Covid & thrombosis

AN inherited bleeding disorder may lower the risk of thrombosis with Covid-19 infection.

The Irish Haemophilia Society is raising awareness of Von Willebrand Disorder for World Haemophilia Day on Saturday VWD is the most common inherited bleeding disorder with around one in 1,000 of the population being affected.

population being affected.
In men or children, easy bruising or frequent, heavy nosebleeds may be the first sign of a bleeding disorder.

The most common warning sign for women is heavy periods.

in defined demographic groups. Each course will be of 7 weeks duration. This will consist of 6 one-hour physiotherapy exercise classes on Zoom. The Society send exercise TheraBand's by post to those registered before the commencement of each course. This TheraBand, together with a chair and a mat are the only equipment required. Week 7 will consist of a session with a dietitian and lifestyle coach.

The first two groups have begun; for people with severe haemophilia aged 35 to 50 years and for those with VWD respectively.

We are now actively recruiting for groups 3 and 4: Women with Bleeding Disorders (including carriers) and those with severe haemophilia aged over 50 years.

Further groups will be started later in the year. If you are interested in joining Group 3 or 4 or indeed any future group, do let us know by e-mail to **info@haemophilia.ie**

Brian O'Mahony, Chief Executive

WORLD HAEMOPHILIA WEEK 2021: VON WILLEBRANDS DISORDER AWARENESS



Von Willebrand Disorder (VWD) is the most common inherited bleeding disorder and 90% of people with VWD globally remain undiagnosed.

Von Willebrand Disorder was the focus of World Haemophilia Week this year. We fully appreciate the need for greater education about VWD, greater public awareness and greater emphasis from the Society. To this end, VWD was the sole the focus of our events this year.

Given that we were in the midst of a pandemic our activities this year were confined to the virtual world, which provided us with opportunities as well as challenges

We had two webinars, one on 'VWD Guidelines & Research for Diagnoses & Treatment' with Dr. Michelle Lavin & Professor James O'Donnell and another on 'Living with VWD', a discussion panel with I.H.S. members Breda Quealy, Barry Quealy, Donal McCann & Shannon Carey.

Both were very engaging and informative webinars, we hope that those of you who attended thought so too. If you would like to watch them, they are available on our website / You-Tube.

We launched our new VWD booklet and an animated video on social media that we hope better explains VWD and helps raise awareness.





We also rolled out a social media campaign with Breda Quealy & her son Barry who both have VWD. In this series of video clips, they give an insight into living with VWD. You can watch the compilation of clips on our website / YouTube.

Over the course of the week we gained some excellent national coverage, one of the highlights being Shannon Carey and Dr Michelle Lavin's appearance on Ireland AM.

VWD is a complex condition. We hope our activities over the course of the week helped raise awareness. This was not a one off, we are committed to a much greater focus on raising awareness of VWD and advocating for better treatment of persons with VWD.











RSVPLIVEJE

Westmeath woman says heavy periods should 'never be ignored'

Shannon Carey, 21, was diagnosed with Von Willebrand disease when she was a baby and was...

One of the most recognizable faces across our VWD activities was I.H.S. member Shannon Carey who not only took part in our 'Living with Von Willebrands' discussion panel but also made numerous appearances across the media - so who better to reflect on the week than Shannon herself.

When I first heard that World Haemophilia day would be focusing on Von Willebrand Disorder within the Irish Haemophilia society, I was absolutely delighted. I knew it would be a great opportunity to educate people about what VWD is.

When Debbie invited me to speak at a webinar called "VWD - A Personal Perspective", I was thrilled and I was excited to share my experience as a person with Type 1 VWD. In a meeting before the webinar, Brian asked me if I was interested in doing any media coverage and I said yes. This was a scary proposition as I had never done it before, but I knew it would be a great opportunity to be a part of.

Soon afterward, I was contacted by Serena a PR expert who helped me prepare and be ready for any media appearances. Serena was absolutely brilliant and quelled all my fears. Within a few days, she contacted me to say that I had been asked to go onto Ireland AM with Doctor Michelle Lavin! This was a show I watched as a child getting ready to go to school. This was super exciting but also nerve wracking. Being on the show was an unforgettable experience, it was an amazing feeling knowing that by sharing my story, maybe some people will realize that they may have a bleeding disorder too and get tested. There were a few blips as my laptop decided to crash ten minutes I was meant to be on air. Thankfully



Inherited Bleeding Disorder May Lower Risk of Thrombosis with COVID-19 Infection

Inherited Bleeding Disorder May Lower Risk of Thrombosis with COVID-19 Infection 1 in 5 of women with heavy periods will have an underlying bleeding disorder Tuesday 13th April, 2021: Von Willebrand Disorder (VWD), an inherited bleeding disorder which affects the Read more >



however, my laptop decided to cooperate and work.

Soon after Ireland AM, Serena got in touch to let me know that I had been asked to do an article for RSVPLive.ie. I was shocked and delighted that more places wanted to put out my story, so I said yes! This led to a phone interview with a lady called Kayla, we had a great discussion about VWD and how many people do not get tested as their symptoms have been normalized, especially if they suffer with heavy periods. Following on from my RSVPLive.ie article, Midlands 103 radio station found me through LinkedIn. Within half an hour of chatting through LinkedIn, I was on the radio sharing my experience of having VWD. It was such a surreal experience, especially as I was doing an exam for college at home that day while in the process of moving house!

I have recently finished an article for the Irish Times about living with VWD which should be published by the time your are reading thing! It was a brilliant, crazy week for World Haemophilia Day, and I am so thankful that I was given the opportunity to share my experience. It is my hope now that people will be better able to recognize the symptoms within themselves or someone they know. Through my town, I have had two different women come up to me talking about their experiences and what their family members had! I felt so thankful they were able to share their experiences with me.

I have been recently accepted into the VWD Working Group within the European Haemophilia Consortium (EHC) and I'm hopeful that I will continue advocating for people with VWD across Ireland and Europe. This was an absolutely amazing opportunity to have been selected for and I hope to continue learning and supporting those with VWD and their families

Shannon Carey



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 delighted to announce that applications will be accepted from 25th June 2021 for our 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. Links to the application forms will also be available on on social media platforms.

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.

Grants Available:

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

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.

Grants Available:

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

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.

Grants Available:

A person with a 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 are the opening and closing dates for applications?

We will be accepting applications from 25th June 2021. The closing date for all applications is 24th September 2021.

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!

Debbie Greene

Please note: A receipt of payment for your college course must be submitted with your application.

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.



Looking after our mental health is a very important part of our overall health and helps us to manage stress and stay well and similarly, there is never a bad time to discuss mental health. Given we've all been doing our best to navigate our way through a pandemic since early last year, which has been a very stressful and trying time for us all, now is as good a time as any examine our mental health.

Sometimes high levels of stress may develop into a more serious health issue and if it does, it is important to remember you are not alone and there is help available. Mental health is about how you think and feel and your ability to deal with ups and downs. Your mental health does not always stay the same. It can change as you move through different life stages, or in response to difficulties in your life, such as losing your job or having money worries.

There are things you can do to look after your mental health in the same way you can look after your physical health. Stress and worry can affect your mental and physical health. We all have times when we feel down or stressed or worried. The stress of the economic downturn, losing a job or having money worries has a different effect on each of us. How to look after your mental health

To look after your mental health choose one or two steps below to start and build up to as many as you can each day.

Take it one day at a time

Focus on the here and now, and trust that you will have what it takes to cope with tomorrow. While this may feel impossi-

ble, think of times when you overcame certain situations in your life and improve your self-confidence. Plan your day so that at the end of it, you will feel you have achieved something.

Talk about it and ask for help

Talking about your feelings is a good way to cope with a problem. Speak to someone you trust such as your partner, a family member or friend. If you are feeling overwhelmed by sadness or despair, contact your GP.

If you feel there is no one to talk to, call the Samaritans on 1850 60 90 90.

Get involved

Keeping or taking up new hobbies or volunteering may help you meet people, feel less alone and more confident.

Alcohol - Watch what you drink

Sometimes people drink alcohol to deal with or forget about problems but this can make you feel worse when the alcohol wears off. Avoiding too much alcohol is important, if you are feeling down or worried.

Eat and sleep well

A healthy balanced diet and trying to get regular sleep will help your physical health and will also help you to be more positive and have more energy.

Keep active

Regular exercise will help you sleep and relax, look and feel better. A half an hour walk most days can make all the difference.

Signs of common mental health problems

Losing your job, having money problems as well as everyday stress, can make you feel alone, angry, tired or withdrawn. These feelings are normal and usually pass, but if they don't go away they can be signs of a mental health problem. The signs listed below might indicate a mental health problem.

- Feelings of sadness or hopelessness
- Withdrawing from friends, family, school, work, sports or other things that are usually enjoyable
- Excessive and undue worry
- Changes in sleeping or eating habits
- Feeling tired all the time
- Major changes in mood
- Problems paying attention or staying focused
- Apathy not caring about the things that are important to you
- Not being able to function as well at work, college or home

If you are concerned that you or someone you know might be showing signs of a mental health problem, it is important to get support. Support can range from informal support from friends or family or advice from your doctor. For more info on supports see the paragraph on Support services.

How to support someone you are worried about

Sometimes we need support to look after our mental health. Any of us can experience real distress in a time of crisis, which can make someone think of suicide or talk about suicide. This can be caused by too many strong feelings and thoughts at the one time such as stress, losing a job, money worries, health problems, the death of someone close, the breakup of a relationship or a combination of some of the aforementioned. If you are concerned about someone you can follow these steps:

Listen: Listening to someone can help them feel supported and less alone.

Reassure them, show you care: Offer support and let them know you care. Say something like: 'I'm worried about you and I want to help' 'What's up? I'm very worried about you'

Get professional help: Don't leave a suicidal person alone. Encourage them to look for help: 'Let's talk to someone who can help' 'You're not alone' 'There are people who can help you out of this situation'



Support services

If you, or someone you know, needs support, someone to talk to or is in crisis:

- Contact your local GP or family doctor
- Contact your GP out-of-hours service
- Go to or contact the Accident and Emergency Department of your nearest hospital

For details of local health services you can contact:

HSE Health Information Line

Callsave 1850 241 850 (8.00am – 8.00pm, Monday to Saturday)

Contact Samaritans Helpline on 1850 60 90 90

Contact Mental Health Ireland on (01) 284 1166

Contact **Aware** Depression support group Lo Call Helpline on 1890 303 302

For information on money and debt management:

The Money and Budgeting Service (MABS) is a free and confidential service for people in debt or in danger of getting into debt.

Helpline: 1890 283 438

For information on entitlements, retraining and employment opportunities:

Contact **Citizens Information** via citizensinformation.ie or Lo-Call 1890 777 121



Health & Wellness Programme

The programmes will be broken 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 and mental health and wellbeing.

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

If you would like more information about the programme, please email info@haemophilia.ie

While we are on the topic of health and wellbeing.....

There are lots of great resources online which are really useful, offering advice, support and inspiration across a spectrum of topics related to healthy living.

This just a brief snapshot of some favourite resources and we are always open to suggestions. So if you have a favourite that is not mentioned here, please get in touch so we can share them with others.

Eating well....





by Dr Hazel Wallace

The Food Medic

The Food Medic is an educational platform & media group founded by Dr. Hazel Wallace with the aim to educate, inspire, and to help everyone achieve better health, while bridging the gap between traditional medical advice and the latest thoughts and developments in nutrition and other areas of lifestyle. Through an array of avenues - social media platforms, podcasts, books, and website – there are loads of accessible and informative articles which are grounded in science, easy-to-follow and tasty recipes, and actionable tips and guides, helping us make informed healthy lifestyle choices.

This is a great resource.

thefoodmedic.co.uk

dietetically speaking

Dietetically Speaking

Dietetically Speaking is a platform established by Maeve Hanan, a Registered Dietitian who provides a no-nonsense guide to nutrition and eating well. Through her website and social media, Hanan shares content and information in an easy to understand way and is always really interesting, clear, and of super quality. There is a wealth of great articles, blog posts, recipes, advice and tips on dietetic and nutritional topics that are always evidence based and factual, relevant and readable.

Another super resource.

dieteticallyspeaking.com



Being kind to your mind.....

HeadSpace App

Be kind to your mind. Less stressed. More resilient. Happier. It all starts with just a few minutes a day. Headspace offers a wide variety of features, from quality meditations to daily videos, as well as sleep and exercise-specific content. The app is well-rounded, and the content is professional, and all meets a level of polish and quality.

Headspace is a brilliant choice for anyone looking to try meditation for the first time. It's affordable and easy to use.

headspace.com

SDOVITUTED WIN





We are absolutely delighted to announce two new bundles of joy have joined the I.H.S. family!

In May, Robert & Grainne welcomed baby girl Keela (left) into the world and Jay & Eimear (who you'll know from volunt-tering at our conferences) became the proud parents of a little boy called Frank (right).

Congratulations on your new arrivals, aren't they cute! Best of luck with your next great adventure!

NOTICEBOARD



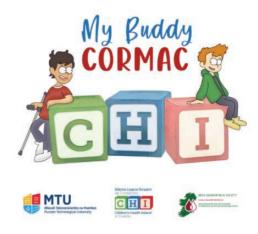
Write for the I.H.S.

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





My Buddy Cormac

We're delighted to share 'My Buddy Cormac', an animated video designed for patients & families with haemophilia in collaboration with the Creative Media Department of the Munster Technological University, Children's Health Ireland at Crumlin and the Irish Haemophilia Society.

My Buddy Cormac, an informative and positive awareness animation about haemophilia, focuses on the experience and challenges faced by children with the condition when treatment in hospital is required.

The story is told from the perspective of a child and it delivers an enlightening and creative take on events at children aged between eight and 12.

You can watch the video on haemophilia.ie

Novel Treatments in Haemophilia & other Bleeding Disorders: A Periodic Review I 2021 – Issue 1

🗓 SCAN ME

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 our website. For physical copies, please contact the office

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:

- 'Covid-19: An Update on Vaccines & Side Effects' with Professor James O' Donnell,
- Exercise and Physical Activity for Children' with Paula Loughnane, Senior Physiotherapist at CHI Crumlin
- 'Living with VWD', a discussion panel with I.H.S. members

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







Emicizumab (Hemlibra®) Booklets

We're delighted to share two new booklets on Emicizumab (Hemlibra®; one for people with Factor VIII Inhibitors and one for people with Factor VIII deficiency without Inhibitors.

They have been produced as an educational tool for members and we hope you find them useful and informative.

Digital versions are available at haemophilia.ie and if you would a physical copy, please contact the office.



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.

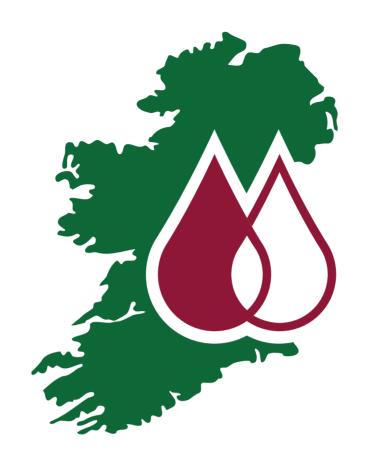
It is reproduced on our website, please download the PDF to your phone or device to bring with you to your vaccination appointment.

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



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.



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