

Haemophilia.ie



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

Magazine of the Irish Haemophilia Society

Spring 2020



The Society
at a Glance

74
I.H.S.
Volunteers

46
Planned Giving
Contributors

1400
Facebook
Followers

896
Twitter
Followers



haemophilia.ie

FROM THE EDITOR

Hello and welcome to the Spring issue of our quarterly magazine.

I hope you are all keep well in the strange and unprecedented situation we all find ourselves in. The whole I.H.S. team is working remotely from home but we're all pulling together to keep in touch with members via phone calls, email, e-zine and social media.

Also, 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.

Now, back to the magazine. On page 03, you will see an updated calendar of events with some changes due to Covid-19. On Page 04, Brian provides an update on Covid-19 and Gene Therapy, and a report on our recent AGM. Speaking of the latter, on Page 10 there are loads of photos from the weekend and on Page 07, there is the results from the Kidlink art competition - we have some serious young artists amongst our ranks.

There are great and really interesting articles on the Know Your Flow Campaign, an iPATH update and personal perspectives on educational grants and volunteering with the I.H.S.

Lastly, I hope you enjoy this issue - our first remotely produced and digital only magazine - and hope you are all keeping safe and well, and remember if you would like to receive news and updates via our e-zine, please email me at barry@haemophilia.ie and I will add you to our e-zine mailing list.



Barry

IN THIS ISSUE

03

Calendar of Events

Our list of events for 2020 and those that have fallen foul of Covid-19

04

CEO Report

Brian gives an update on Covid-19 and reports on the AGM & Gene Therapy

08

Know Your Flow

Aoife speaks to Dr Michelle Lavin about the Know Your Flow Campaign

10

AGM & Conference 2020

Photos & a round-up from our AGM

12

iPATH Update

Megan Kennedy, iPATH Physiotherapist, provides an update on the iPATH Programme

14

Educational Grants

Conor Birkett gives a personal perspective on educational grants

15

Art Attack

The winner and runners-up from our Kidlink art competition

16

Volunteering with the I.H.S.

Sarah Charnock & Eimear Dyer about their experiences of volunteering

18

Noticeboard

Updates and useful info from the world of the I.H.S.

CALENDAR OF EVENTS 2020

As with everything else in our lives, Covid-19 has had an impact on our events planned for this year. So far our events effected are:

Von Willebrand's Information Day

Date: Saturday, April 18th
Venue: Castleknock Hotel, Dublin

This event has been re-scheduled for August 29th.

Young Adult Conference 2020

Dates: Friday, April 24th to Sunday 26th
Venue: Radisson Blu Hotel, Athlone

This event has been postponed until further notice and will be re-scheduled for later in the year.

Women & Bleeding Disorders Info Day

Date: Saturday, May 9th
Venue: Hodson Bay Hotel, Athlone, Co. Westmeath

This event has been postponed and will be held in May 2021 instead. Apologies for any inconvenience caused.

Mother & Daughter(s) Overnight

Date: Saturday June 20th & Sunday, June 21st
Venue: Lilliput Adventure Centre

This event has unfortunately been cancelled.

So far the rest of our calendar is unaffected but we will revisit them in due course on a case by case basis.

July

Father & Son(s) Overnight

Saturday July 4th & Sunday, July 5th
Lilliput Adventure Centre

Mild Haemophilia Information Day &

Haemophilia B Information Day

Saturday, July 18th
Killashee Hotel, Naas

August

Family Day Out

Monday, August 10th
Dublin Zoo

September

Ageing Event

Saturday September 19th
TBC

October

October Conference

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

CEO REPORT

First people with haemophilia in Ireland treated with gene therapy



On March 5th, the day prior to the beginning of our Annual Conference, the Society announced that the first person with Haemophilia in Ireland had been treated with Gene Therapy. Since that announcement, a second and third individual has now been treated.

In 2014, the Society first organized a special meeting for members to inform them about the possibility of people with haemophilia in Ireland being included in clinical trials for Gene Therapy. Since that time, in collaboration with the National Coagulation Centre, we have worked assiduously to persuade companies who are undertaking clinical trials for Gene Therapy in haemophilia to consider including people from Ireland in these trials. Our case was helped by the centralized organization of haemophilia care in Ireland with a linked network of comprehensive care centres and a national patient registry.

It was also helped by the close collaboration evident between the centres and the Irish Haemophilia Society and by our ability to organize meetings attended by groups of people with haemophilia. This allowed us to inform people in a group setting, have the clinicians and experts present answer any questions and deliver detailed information and ascertain the level of interest in participation in clinical trials. These information meetings were an excellent first step in preparing those interested for the full informed consent process.

The process of initiating a clinical trial here, especially in Gene Therapy, is complex and required a lot of time and effort. Liaison with the Irish Medicines Regulatory Authority had to be carried out. The paperwork and informed consent processes were onerous. We are fortunate to have very capable and dedicated research nurses at the NCC. We are extremely fortunate that the state of the art Wellcome / Health Research Board Clinical Trial Facility (CTF) is situated in St. James hospital, ideally placed in the floor between the NCC and the inpatient H and H ward.

The first three people with haemophilia treated here as part of a Gene Therapy clinical trial are adults with severe Haemophilia B. They were treated as part of a Phase 3 clinical trial and they are part of the group of 56 people with Haemophilia B who will be treated worldwide with this particular Gene Therapy in this final Phase of the clinical trial. The therapy used an adeno-associated viral vector to deliver the Factor IX gene therapy intravenously to the liver of the individuals.

In this new era of fear relating to Coronavirus, it is ironic that a virus could now be the delivery system which offers the best hope of a practical cure for severe haemophilia.

In the earlier Phase 2B trial of this particular gene therapy, the Factor IX level in the blood increased from less than 1% to between 33% and 51% in the small number of individuals treated. This transformed their quality of life, from having severe haemophilia to mild haemophilia or no haemophilia. We do not yet know the outcome of the treatment in these individuals in Ireland. It is to be hoped that they achieve a good expression of FIX from their liver and that this persists for many years, perhaps even for a lifetime. The principal investigator for the clinical trial here is Dr. Niamh O Connell, Director of the NCC.

This is the first Haemophilia Gene Therapy trial here, but it will not be the last. There are currently plans to recruit people with haemophilia to 2 additional clinical trials - one for FIX and one for FVIII.

There is significant progress being reported from haemophilia Gene Therapy clinical trials for both FVIII and FIX. It is anticipated that the first Gene Therapy for FVIII deficiency could be licenced in the USA and EU later this year and the first licenced FIX Gene Therapy could be in 2021. We are indeed entering a very exciting time in Haemophilia treatment.

Annual Conference

The Society AGM and Annual Conference went ahead as scheduled from March 6th to 8th in the Slieve Russell hotel in Cavan. We had very good attendance from members but unfortunately, due to the escalating coronavirus situation and the requirement for health care workers to be very cautious, we were informed late on the Friday afternoon that 8 of our scheduled 11 speakers could not attend in person. This presented us with a challenge to which we immediately responded. We were able to re-organise the programme and with the assistance of technology, have three of the main speakers





deliver their presentations over the weekend remotely. The quality of the sound was excellent. The presentations were clear, and questions were answered. In fact, it demonstrated to us the benefit of using technology to have speakers contribute to a conference programme remotely. We had used this on a smaller scale in 2017 when a speaker from the US was unable to travel at the last minute. The technology has improved since then making this a more realistic option for this and perhaps future events.

Prof. Ted Tuddenham from the Royal Free hospital in the UK delivered an update on Gene Therapy in haemophilia. I complemented this with a presentation from the patient perspective on expectations from and decision drivers for Gene Therapy. Dr. Niamh O Connell and Dr. Beatrice Nolan delivered a session on Emicizumab (Hemlibra) and on the progressing plans for the new patient portal. On the Sunday, Prof. James O Donnell delivered an update on the IPATH (Irish Personalised Approach to the Treatment of Haemophilia). During the Annual General Meeting, members were updated on and approved the new 4 year strategic plan for the Society.

The entire event was very successful down to the healthier food options during coffee breaks (fresh fruit replacing biscuits).

Coronavirus

Our work and home environments have been altered and impacted very significantly by the SARS-CoV-2, the Coronavirus responsible for the Covid-19 pandemic.

At the time of writing (March 27th), we had 1,819 cases of Covid-19 in the country resulting in 19 deaths. While this is a grim statistic, the figures are not as starkly negative as projected on St Patrick's Day when we were projected to have 15,000 cases by the end of March. We may be only at the beginning of a surge of cases but even that delay gives the

health service time to prepare more fully for a large number of anticipated cases.

Hospital bed capacity has been increased. Hospital wards are being converted into Covid-19 wards. The agreement with private hospitals will add 2000 beds to the system along with much needed intensive care unit beds and beds where people can be ventilated if required. The Government, the health service and the entire population have collectively met this challenge so far. Drastic steps have been taken in temporarily closing down many businesses and requiring many people to work from home. Schools and colleges are closed. All unnecessary travel has stopped. This is all welcome.

We need to flatten the curve of infection. If we have the same number of people infected in the country but spread over a four month, rather than a four-week period, the health care system should cope. We should have enough intensive care unit beds, enough ventilators and enough proper personal protective equipment to keep our healthcare staff safe as they minister to those with Covid-19.

The new virus is called SARS-Cov-2. SARS stands for Severe Acute Respiratory Syndrome. There was an outbreak of SARS in 2003. This new virus is one of a class of viruses called Coronaviruses. It is called SARS-CoV-2. It causes severe respiratory disease and is transmitted by droplets or contact. The public health measures which include social distancing, proper cough etiquette and self-isolation where warranted are now well known and are being updated frequently by the Department of Health. I do not need to repeat them in this article. I want to provide some context from the Society for people with haemophilia, von Willebrand's or other inherited bleeding disorders.

Coronavirus and Haemophilia

There is no evidence to suggest that people with haemophilia are at any higher risk of Covid-19 infection than the

general public. If a person with coronavirus is diagnosed with coronavirus, there is nothing to suggest that it will be any more severe than if they did not have haemophilia.

However, your haemophilia may impact how your coronavirus needs to be treated. If you have been diagnosed with Covid-19 and you are being treated by a doctor or hospital outside your haemophilia centre, please ask them to contact your haemophilia treating doctor

Safety of Treatment Products

The standard treatments for people with Haemophilia A are extended half-life recombinant factor concentrates or Emicizumab (Hemlibra). The standard treatments for people with Haemophilia B are extended half-life recombinant factor concentrates. None of these products contain human blood or plasma components and therefore they cannot transmit any potentially blood borne viruses.

The standard treatments for von Willebrand's or for some of the rare bleeding disorders are plasma derived factor concentrates. The manufacture of all each these products contain viral inactivation and elimination procedures which are sufficient to very effectively destroy lipid enveloped viruses such as Coronavirus.

It is worth remembering that, with the two previous Coronavirus outbreaks (SARS and MERS), there was no evidence of, or no reports of, infection with either of these Coronaviruses through plasma derived factor concentrates.

There is no safety concern in relation to coronavirus and plasma derived factor concentrates.

Supply of Treatment Products

We are fortunate that we have in place a very efficient home delivery system for treatment products for those on prophylaxis or home treatment. In an earlier post on our website from the National Coagulation Centre (NCC), it was confirmed that from mid-March, the next two monthly deliveries of factor for home treatment would each deliver a five-week supply. This will provide individuals with two weeks of additional stock. The supply situation will be kept under constant review.

We are not aware of any current threat to the supply chain of treatment products globally. Due to the earlier potential supply risk caused by Brexit, we had increased our stock of factor concentrates in the country and we now have a national supply of four months stock.

Attendance at hospitals and treatment centres

We will be posting updated information on our website as

often as it is made available on any changes to in-patient or walk in services for people with Haemophilia, von Willebrand's or rare bleeding disorders. Services at Children's Hospital Ireland in Crumlin are continuing. Many outpatient clinics are now virtual and being conducted by telephone. Parents are asked to contact the hospital prior to attending for an emergency requiring treatment for their child but they should continue to attend in an emergency.

Many of the outpatient appointments at the NCC are now being conducted by telephone consultation. Any adult who needs to attend due to a bleeding episode should contact the service by phone prior to attending. Currently, they will be seen in the National Coagulation Centre on the 3rd floor at St. James's Hospital and not in the H and H ward which is now being used to treat people with Covid-19.

We have not been notified of any change in procedures by Cork or Galway University hospitals. Updated information has been posted on our website on emergency dental services.



For up to date information on inpatient and outpatient services, please refer to our website. We will place updated information on our website as soon as it is received. The information will also be sent out by e mail to any member for whom we have an e-mail address and, in addition to this newsletter and the website, we will be sending out an electronic newsletter (E-Zine) weekly.

We would encourage all members to provide us with your e-mail address if you wish to receive these e-mail notifications. You can send your e-mail address to Barry Healy:

barry@haemophilia.ie



Reducing your risk of transmission and staying safe

Currently, there are no known elevated risk factors to transmission of CoV-19, or an increased predisposition to the severity of the disease for people with haemophilia or inherited bleeding disorders. There is no evidence to suggest that people with inherited haemophilia who have inhibitors are at any higher risk from Covid-19.

However, there are people in our community who are immune compromised where their ability to combat an infection may be compromised. There are also people in our community over the age of 70. All of these individuals should take particular care to comply with all the public health advice. Maintain social distancing and stay away from any person who is showing symptoms. Practice good hand hygiene. Work from home if possible. Avoid all unnecessary travel. There is also some information that people with high blood pressure or diabetes may have additional problems if they develop Covid-19. If you have high blood pressure or diabetes, please make sure they are under control. Take your prescribed medications.



Please keep up to date with the precautions being proposed and get your information from the HSE, mainstream media or other reliable sources such as your treatment centre, GP or the Society. Do not pay attention to spurious information circulating on some platforms such as WhatsApp.

Services and Support from the Society

The Society staff are all working from home at present. All staff have access to their office files, and we have the ability to carry out most of the routine work. We are unable to schedule visits to members at home or in hospital at present, but we will be carrying out an enhanced service of staying in touch with members by phone. In the past 10 days, we have been in contact with a large number of members.

If you wish to contact the Society staff, call the office as normal. Your call will be automatically redirected to a member of staff. We will stay in touch. Please do contact us if you have a concern or question, or if you just want to chat.

This will be a challenging time for all of us. It is worth reflecting that this community has dealt with some unprecedented challenges in the past with issues such as HIV and Hepatitis C. We have overcome these challenges. We have prevailed. We have emerged as a stronger and more united community. Let us show the same resolve on this occasion where the entire country and indeed the entire world are being challenged. We will prevail again.

I think this country will emerge from this dark time stronger as a society, if not stronger as an economy. Economics is, and must, take second place to the welfare of all the people of the country. When this crisis ends - and it will end - we will have a deeper appreciation for many parts of our normal life which have been put on hold: shaking hands, meeting with friends, visiting family, going out for a meal or to the cinema, pub or theatre, interacting at work with colleagues. In the meantime, we must work together as a community to stay safe and stay connected.

**Brian O'Mahony,
Chief Executive**

KNOW YOUR FLOW

An Interview with Dr Michelle Lavin

1 in 5 women experience heavy menstrual bleeding, and 1 in 5 women with heavy periods who are checked for a bleeding disorder will be diagnosed with one. Despite this, only 1 in 10,000 people in Ireland are currently diagnosed with a bleeding disorder.

A new campaign funded by the Health Research Board and in collaboration with RCSI and the IHS aims to educate women to recognize if their periods are heavier than normal and when heavy periods could be a sign of a bleeding disorder. We spoke to Dr Michelle Lavin from RCSI to learn more about this project and what you should know about your flow.

Where did the idea for the Know Your Flow project come from?

It started from when we were doing our low von Willebrand in Ireland cohort study, the LoVIC study. I kept seeing a pattern emerging where women were being diagnosed in their 30's with low von Willebrand factor, but in fact, when you looked back, they'd have a long history of bleeding. From their periods being heavy to maybe having easy bruising and bleeding after a dental extraction.

Each on its own was probably manageable but when you considered it as a whole, it was clear these women had symptoms of this disorder for up to maybe 15 or 20 years before they got their diagnosis. It was emerging again and again, the same kind of pattern. We did an analysis of the first 120 women on our study and found that 89% of them had heavy periods.

It's obviously not the only symptom, but it's a very common bleeding symptom amongst people who are ultimately diagnosed with a bleeding disorder. We thought this would be a really good focus to try and raise awareness about what a heavy period is so that younger people can recognize it, and hopefully spur people to get further investigations if they

have other bleeding symptoms as well.

A lot of them didn't recognize their period as being abnormal. Also, bleeding tends to run in families, so their mother or sister may have had similar heavy bleeding. Even when they report it to doctors, doctors didn't maybe recognize it as being overly heavy or didn't take it in the context of other bleeding symptoms as well.

There's a gap in recognition, and a gap in appreciation by the medical profession, and then a gap in actually referring people onwards who need it. That's where the idea for the project came from - the recognition that we needed to do more to educate not only the public about what a heavy period is and why it's important, but also to help GPs and doctors to recognize when they need to refer people on.

How is Know Your Flow trying to get this message out there?

Know Your Flow was initially envisaged as a website, knowyourflow.ie, but in order to reach our target demographic, which is teenagers and younger women, we thought the best way to engage with people and bring them to the website would be through social media. We came up with the idea of a video of things to watch out for. We wanted to get the simple message across to the public that if you've experienced any of these symptoms that's actually heavier than you would expect for your period.

The video was really to highlight what a heavy period is and to bring you to the website. The website is to explain more about periods and other bleeding symptoms to get people thinking about a bleeding disorder if they're recognizing some of these symptoms.

What counts as a heavy period?

Signs of heavy menstrual bleeding include periods that last for 7 days or more, needing to change your pads/tampons



more frequently than every 2 hours, and passing clots of blood larger than a €1 coin.

Everyone has a different period and some people can have really heavy bleeding, but it might only last a day. A lot of people would have a three-day period or a four-day or a five-day period, but they mightn't bleed very heavily for all of those days. If you're bleeding for longer than seven days, you're probably having three to four days or even up to seven days of very heavy flow. Bleeding that lasts longer than seven days is certainly concerning for a heavy period.

Also, if you have to frequently change your pads or tampons, and you're not really able to go more than two hours without having to change, that could be sign of heavy bleeding. Changing every two hours might be fine with a regular size, but if you are using super or super plus and still need to frequently change, then that's concerning.

What should someone do if they have these symptoms?

On the Know Your Flow website we have more information if people want to read a bit more about it and are a bit nervous about going to their GP. The next thing you can do is go to your GP about it. We want to make people aware that if they also have other bleeding symptoms like easy bruising, frequent nose bleeds or if they've bled after a dental extraction or procedure, to take that on board and mention that as well to the GP. We also want to encourage people to ask, "Could I have a bleeding disorder?" As you know, public awareness of bleeding disorders is really low in the general population.

Do you think that people should be talking more about what is a normal period and what isn't?

Yes, absolutely. I think it's a huge issue not just only in Ireland but internationally. Certainly, we need to be more vocal about women's health and to talk to each other about women's health. Even in my own experience, it was only when I mentioned the Know Your Flow project to my friends that they started talking about their periods for the first time. We just realized we had never had that conversation. I think

people don't like to be open and to discuss this.

I think we really need to engage more in a conversation about it because your own experience is your normal. You only realize that's maybe not normal or maybe that's heavier than normal by talking to people. I think we have a lot to learn from the younger generations in this because I think they're more vocal and more open to sharing information than a lot of people in their 30s and 40s are.

Hopefully, things are going to change. The recent changes in Ireland between the referendum on abortion and CervicalCheck cancer controversy are all bringing women's health issues to the forefront. It's easier having that conversation now and it's a good time for people to start talking more openly and to recognize this is entirely normal. It happens to 50% of the population once a month. It shouldn't be a taboo subject.

What do you want people to take away from this project?

The most important thing is to not assume your periods are normal, and to realize that there's lots of effective treatments out there that can help regulate and normalize periods, and stop people from being chronically iron-deficient and anemic, and everything that goes with that, the poor concentration, the fatigue, the lower quality of life. They are all treatable as long as we can recognize this condition and treat it early rather than letting it run along for years for people.

The experiences that women have with bleeding disorders are different to men. If we can try and improve recognition of that, and give people effective treatment, we can really have a major impact on quality of life, not just for the women, but their families, their participation in work. There are so many different factors that can be improved if we just actually effectively treat bleeding.

For more info, see knowyourflow.ie

Aoife Kelly

AGM & Conference 2020

We hope you all enjoyed the AGM & Conference in Slieve Russell Hotel, Cavan - it was a busy but rewarding weekend. It was always going to be a big weekend given that it arrived on the back of news that the first person with haemophilia in Ireland was treated with gene therapy.

The weekend was made just a 'little' bit more hectic when 30 minutes before registration was due to open, we were informed that our clinical speakers would not be able to attend – but as the old adage goes; the show must go on.

A huge thanks to the staff at the hotel for being so accommodating, Daniel and Johnny for their brilliant AV work and to all you who made the added work worthwhile.

Here is a small snapshot of the weekend, there is more where that came from via haemophilia.ie





iPATH Update

The importance of physical activity for healthy ageing

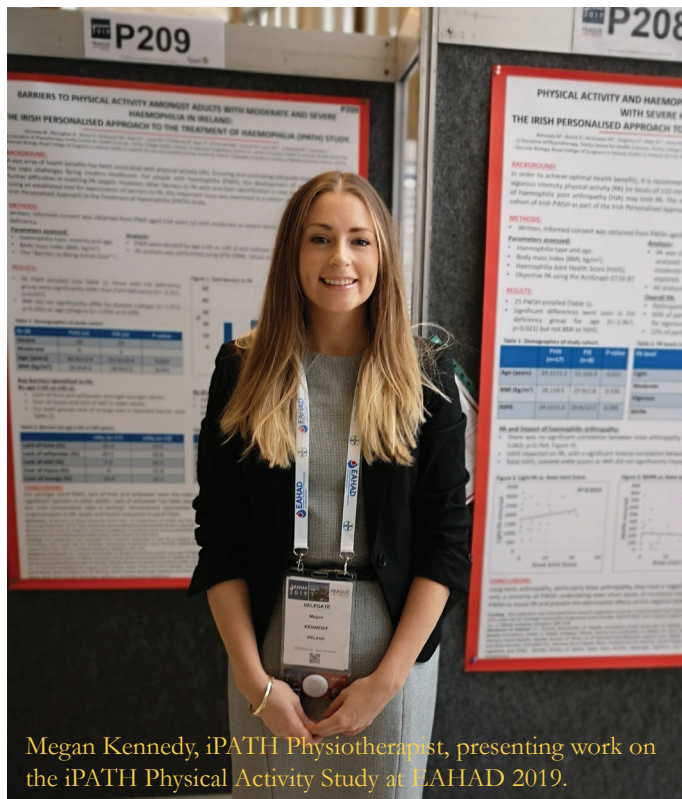
Physical activity (PA) can be described as any bodily movement our muscles generate that results in us spending energy (1). Daily PA can be classified into different domains involving what we do at work, during sport or leisure time and even how we get from A to B for travel. Exercise is a subset of PA that is planned, structured, and repetitive with the ultimate goal of improving or maintaining physical fitness (1). A lack of PA (physical inactivity) is a leading risk factor for global mortality (2). Adequate levels of PA play a major role in battling the rising rates of some cardiometabolic diseases, including cardiovascular disease and type II diabetes (2, 3).

Important aspects of PA and exercise that need to be considered are the intensity and duration of activity undertaken. Experts have recommended that adults should achieve at least 150 minutes of moderate-vigorous intensity physical activity (MVPA) per week. It is thought that exercising to this level can improve fitness levels, bone health and reduce the risk of cardiometabolic diseases. Health benefits may be even more pronounced for people who achieve longer sustained bouts of MVPA for at least 10-minutes at a time.

People with haemophilia (PWH) were previously discouraged from leading a physically active lifestyle due to the perceived increased risk of bleeding and injury in the absence of clotting factor concentrates (CFCs). In recent years the advances in medicine and the treatment of haemophilia have altered this prior belief. PA and exercise are recommended by the World Federation of Haemophilia in order to promote physical fitness and normal neuromuscular development (4). In recent years, an increase in cardiometabolic diseases and risk factors, including high blood pressure and obesity, have been found to be more common in PWH (5-8). PA has an important role in the management of cardiometabolic diseases and risk factors. PWH experience significant barriers to being more physically active, including the occurrence of painful and debilitating chronic haemophilic joint arthropathy. Establishing how physically active individuals are and how their health and fitness are affected by such barriers are key to understanding how to overcome them. This will allow healthcare professionals to personalise exercise programmes for PWH so that they can reap the numerous health benefits associated with adequate PA.

The iPATH Physical Activity Study - Personalised Health and Fitness

The aims of The Irish Personalised Approach to the Treatment of Haemophilia (iPATH) Study, which began in 2017, were to progress the understanding of factors which contribute to (i) the risk of bleeding, (ii) the risk of joint damage



Megan Kennedy, iPATH Physiotherapist, presenting work on the iPATH Physical Activity Study at EAHAD 2019.

and (iii) the risk of joint inflammation in PWH. Those who enrolled onto the study were also invited to take part in a Physical Activity and Fitness Assessment which involves a detailed examination of PA levels using an activity monitor - the ActiGraph GT3X-BT (see picture), a body composition analysis as well as a number of other health and fitness tests. Each participant receives feedback on their PA and health outcomes in a report to inform them of how they are currently doing in these areas. To date, 53 adults with moderate or severe FVIII or FIX deficiency have completed this assessment. The time and effort these participants have contributed to this research is greatly appreciated and has allowed us to identify important and insightful findings related to PA, health and fitness amongst adults with moderate and severe haemophilia. Recruitment for this proportion of the study is still ongoing and individuals who have enrolled onto the Whole Genome Sequencing element of the study are eligible to participate.

Key findings so far: Barriers to PA and PA for cardiometabolic health

Emerging findings from this study have been shared at international conferences over the past two years. In 2019, three posters related to PA and joint damage were presented at the European Association for Haemophilia and Allied Disorders (EAHAD) congress in Prague. Part of this work provided valuable insight into barriers to PA amongst a group of 36 participants with moderate and severe haemophilia. The evidence suggested that lack of time and willpower were the main challenges to exercise for younger adults with haemophilia, whilst fear of injury and lack of skill were more significant barriers in older adults. For all ages, lack of energy was identified as a barrier. These findings support the need for

personalised approaches to exercise programmes in order to identify and tackle barriers to being active. This in turn has the potential to improve the incorporation of PA into daily life for PWH so that they can benefit from regular exercise.

Further work which described PA and cardiometabolic risk profiles amongst adults with severe haemophilia was recently presented at EAHAD 2020 in The Hague and was awarded a prize for its important contribution to research in this area. The poster described that in 39 people with severe haemophilia (PWSH) high rates of overweight/obesity were found in 61.5% of the group. More detailed analysis of body composition found that waist to hip ratio (another indicator of body composition) was also highly elevated above normal values in 64.1%. This suggests an elevated risk of metabolic complications related to excess abdominal fat. Using a simple walking test, fitness levels were found to be lower than normal values for men of a similar age without haemophilia.

This finding suggests lower cardiorespiratory fitness which is a risk factor for cardiovascular events. It was also found that 66.7% of participants appeared to meet recommended guidelines of at least 150 minutes of moderate intensity PA per week. When this was looked at in more detail it appeared the total time spent in periods of higher intensity PA for at least 10-minutes at a time was relatively low, with only 17.9% of participants meeting these guidelines. This is important considering better health gains such as improvements in fitness and weight loss require higher doses of more intense PA sustained over longer periods of time. Chronic joint arthropathy may contribute to the reduced levels of more intense PA which in turn may impact on fitness or weight control. Personalised exercise programmes therefore have the potential to reduce cardiometabolic risk in PWSH by tailoring exercise to the individual's capabilities and what they enjoy doing.

estimates how efficiently your heart pumps oxygen to your muscles during exercise, and is the gold standard measurement of fitness. Participants with FVIII or FIX deficiency over the age of 18 are eligible to participate in this study.

The success of the iPATH study so far is a credit to the valuable time and effort contributed by all of the study participants, research team and partners working in conjunction with the study. We would like to thank everyone involved as this ongoing support allows us to continue our research to learn how to improve physical health outcomes and quality of life in current and upcoming generations of adults with haemophilia in Ireland.

How to get involved

For more information on the iPATH study and how you can get involved, please contact our research team at ipath@rcsi.ie.

Megan Kennedy, iPATH Physiotherapist,

References

1. Caspersen CJ, Powell KE, Christenson GM. *Physical activity, exercise, and physical fitness: definitions and distinctions for health-related research*. Public Health Rep. 1985;100(2):126-31.
2. World Health Organisation. *Global health risks: mortality and burden of disease attributable to selected major risks*. 2009.
3. World Health Organisation. *Global Recommendations on Physical Activity for Health*. 2010.
4. World Federation of Haemophilia. *Guidelines For The Management Of Haemophilia 2012*.
5. Hofstede FG, Fijnvandraat K, Plug I, Kamphuisen PW, Rosendaal FR, Peters M. *Obesity: a new disaster for haemophilic patients? A nationwide survey*. Haemophilia. 2008;14(5):1035-8.
6. Majumdar S, Morris A, Gordon C, Kermode JC, Forsythe A, Herrington B, et al. *Alarming high prevalence of obesity in haemophilia in the state of Mississippi*. Haemophilia. 2010;16(3):455-9.
7. Fransen van de Putte DE, Fischer K, Makris M, Tait RC, Collins PW, Meijer K, et al. *Increased prevalence of hypertension in haemophilia patients*. Thromb Haemost. 2012;108(4):750-5.
8. Canaro M, Goranova-Marinova V, Berntorp E. *The ageing patient with haemophilia*. Eur J Haematol. 2015;94 Suppl 77:17-22.

iPATH

IRISH PERSONALIZED APPROACH TO THE TREATMENT OF HAEMOPHILIA



Future directions for the study

At present, we are still conducting these assessments with the hope to recruit as many participants as possible to add to the data already collected. The same assessment is currently being conducted in a group of individuals without haemophilia, so that we can compare results between the two groups to see how individuals with haemophilia compare with the general population in terms of PA, health and fitness. A more detailed fitness assessment using a stationary bike fitness test is also commencing. This test will estimate the participant's maximal volume of oxygen consumption (VO2max), which

EDUCATIONAL GRANTS

A Personal Perspective



Hi there! My name's Conor and I'm a second year Arts International student in UCC. I also live with Haemophilia B. A few months ago, I heard back from the society that I had received one of their Maureen and Jack Downey grants, which I was of course thrilled about.

For those of you unsure, this grant is available to a person with haemophilia or related bleeding disorder, including a person with carrier status and consists of three prizes - €4,000, €2,000, and €1,500 - and I was lucky to have been awarded one. It meant a lot to me to get this extra funding, as university is a very expensive time. While I do still live at home, meaning I would not have the costs that others living away from home would face, I was still able to put the money to good use - I bought several (quite extortionately priced) textbooks, on top of being able to cover much of my day-to-day spending. This alleviated some of the pressure on my parents too.



I was very appreciative of this grant as the I.H.S. always try their best to help everyone out financially. While this year my costs are not huge, I appreciate every bit of help I can get, as I am currently saving hard for both my upcoming J1 trip to Chicago and then an Erasmus year to Germany. The costs of living/surviving in both will be colossal, mainly due to the fact that I have never had to pay rent or buy food for myself, so it will be a shock to the system! I am only able to work limited hours every week due to my college hours, so this grant has really aided in lifting the burden of saving for my travels.

Aside from the grant itself, I am grateful that the society we have in this country is so supportive and encouraging for trips like these. It is a daunting thing to move away from home, especially for somebody with a condition like haemophilia, which requires knowledge of your nearest centre at all times, as well as always having an emergency supply of factor on you. With the assistance of the I.H.S., I feel confident that, should any health problems arise while I'm away, I will be able to handle it without too much trouble.

I am very thankful to the board for this generous award to me, and I highly encourage others to apply for one of the grants, as it is so beneficial to your overall third-level experience.

Conor Birkett

Art Attack

At our recent AGM & Conference, Robert organised an art competition in the Kidlink Group. After intense scrutiny and discussion by a select committee in the office the result is as follows. Drum roll please.... in first place and winner of the €25 One4All Voucher is Nadine Salim! And close behind are runners up Will O'Toole & James Kelly. Congratulations!



Nadine Salim



**Runner Up
Will O'Toole**



**Runner Up
James Kelly**



We owe a huge debt of gratitude to our fantastic team of volunteers, without them, there is so much we could not do!

We're always happy to welcome new people to the team! Would you be interested in getting involved in volunteering with the I.H.S.? We are looking for people of all ages and backgrounds to volunteer with us at our events!

Do you enjoy working with kids? Are you good at arts and crafts? Are you a good photographer? Do you have a hobby or skill that you could teach to others? If so, we would love to hear from you!

If you would like to get involved or get more info, call Robert in the office on 01 657 9900 or email robert@haemophilia.ie

Who better to convince you to get involved than some volunteers themselves?

Being part of the I.H.S. has been a real positive for me; I've met new people and have had some great experiences. The families, children, staff and other volunteers have all been so welcoming and I now consider a lot of them true friends. A large group of volunteers meet up regularly outside of the I.H.S., and I love being a part of those days and nights.

I have volunteered with a couple of different age groups and therefore have been involved with a couple of different teams within the volunteering groups, but I have always felt welcome and included.



I used to be a Montessori teacher which I have since moved on from, so getting back into the swing of things with the children has been a real breath of fresh air for me. Using my experience from Montessori to help some of the younger volunteers find their feet has been really rewarding too. The younger volunteers have a real urge to make a difference, and it's obvious already that some of them will go on to become the new leaders of the volunteer groups when the time is right... although they'll have a tough group to follow with this lot!

I hope to remain involved in the I.H.S. in some capacity going forward. It's really rewarding work as well as being a lot of fun and as I mentioned already, I've made some real friends here. It's not something I want to move away from, so hopefully I can find something to offer you guys as the years go on. As the other volunteers will tell you, I'm pretty good at Giant Jenga, maybe I could run some workshops in that? Just don't ask me to pose for a band pic unexpectedly! (See image on the left)



Eimear Dyer

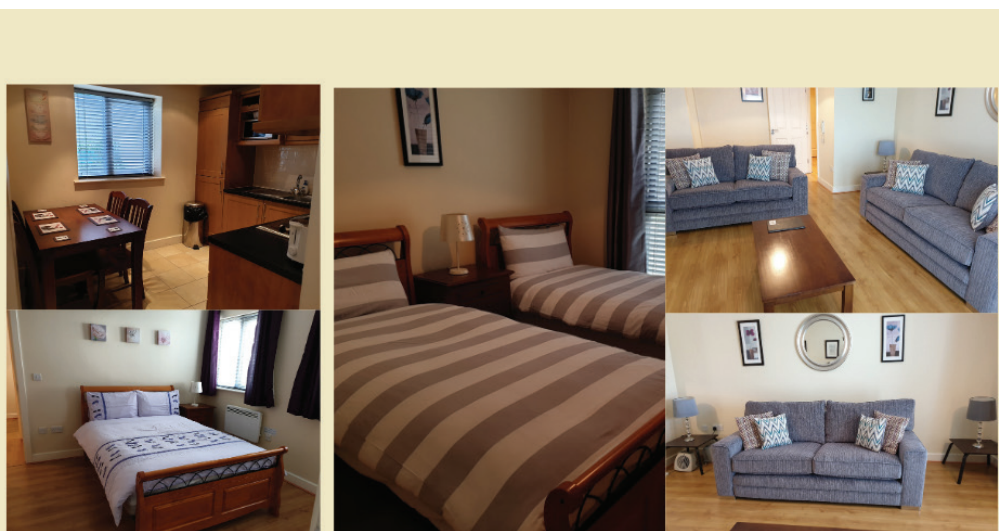
My name is Sarah and I have been volunteering with the I.H.S. for almost 10 years now. When I first started volunteering, I was almost 18 and I wasn't the most confident person but by volunteering and getting to know the families and the other volunteers my confidence has soared.

I can honestly say I love every minute of volunteering with the society. It also helped me realize how much I enjoyed working with children which then led me to my career in childcare which I've been in now for almost seven years. During my time volunteering I have met two of my closest friends and some truly amazing people. I would like to thank the I.H.S. for continuing to ask me to volunteer and I hope I can continue for many years to come.

I would encourage anyone who is interested in volunteering to get involved with this wonderful charity, they take a genuine interest in both their members and volunteers. It's been such an amazing experience being apart of such a close nit group and I will always be grateful that I was asked to volunteer with such genuinely nice people.



Sarah Charnock



Hyde Square

*Hyde Square
Apartments*



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.

Noticeboard



VHI Women's Mini Marathon Postponed

This year's VHI Women's Mini Marathon has been postponed amid the "growing threat" of the coronavirus outbreak.

The 10km run in Dublin's city centre, which attracts well over 30,000 women and raises funds for the society every year, was due to take place on Sunday, May 31.



Don't Miss out on the Latest News, Join our E-zine Crew

During this unprecedented situation in which we all find ourselves, we shall be in contact with the Comprehensive Care Centres on a regular basis, and bring you new information as speedily as possible.

We will be posting regular updates on haemophilia.ie, Facebook & Twitter.

We will be sending regular electronic e-Zines when we have updates to keep you abreast of new information. If you would like to receive this information, please send your e-mail to barry@haemophilia.ie



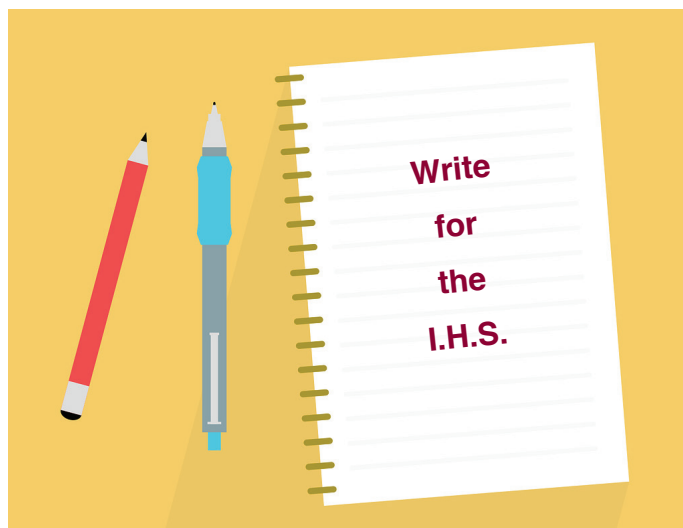
Planned Giving

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.



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



Fundraiser of the Year 2019

Congratulations to Dylan Ryan, our Fundraiser of the Year 2019.

Dylan took part in the Dublin City Marathon last October and raised an amazing €1,400 in aid of the I.H.S. Unfortunately, due to his work commitments in Cambridge in the UK, Dylan was unable to attend our recent AGM & Conference held in the Slieve Russell Hotel in Co Cavan. But we were delighted to present his award to his sister Jessica Brady who attended the conference on his behalf.

Our sincere thanks to Dylan and everyone who raised funds for the I.H.S. in 2019, we really appreciate your support.

Fundraising Draw

Every year we put the names of all those who took part or organised a fundraiser on behalf of the I.H.S. and raised over €250 into a fundraising draw, our lucky winner for 2019 was Lynn Doyle. Lynn was presented with her prize at our AGM & Conference



Bon Voyage Aoife!

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

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

Aoife will be greatly missed by us here in the office, but new adventures await in Canada, and it will be an exciting time for her as she begins a new chapter in her life in a beautiful part of the world.

Outreach & Support Update

I.H.S. staff will be contacting members by phone as normal. Home and hospital visits to members by staff are suspended until further notice.

If you wish to speak to a member of staff between 9am and 5pm Monday to Friday, please phone the office (01-6579900) as normal. Outside of normal working hours or in an emergency, you can contact staff as follows:

Brian O'Mahony 087 2515325
Debbie Greene 086 1662034
Nina Storey 085 7320069
Robert Flanagan 087 7610511



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:

