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

Magazine of the Irish Haemophilia Society

Spring 2022

The Society at a Glance

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74	I.H.S. Volunteers
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FROM THE EDITOR

I hope you are all keeping well and 2022 has been good to you so far.

We've a jam-packed issue for you, with lots of interesting articles and important updates.

On Page 3 Brian looks back at our recent AGM & Conference, outlines some fabulous new awards honouring the memories of Gerry O'Reilly and Michael Davenport. Brian also talks about our plans for World Haemophilia Week and the 20th Anniversary of The Lindsay Inquiry Report, and an update on the society's work with Ukraine and Syria.

Elsewhere, there are personal stories about the I.H.S. Educational Grants from recipients Dara Dowling and Aoife O'Connor on Page 7. There are photos from AGM 2022 on Pages 8 & 9. On Page 10 the iPATH Physiotherapy Research Team have provided a piece on Physical Activity during the Covid-19 Pandemic.

The Irish Haemophilia Society is pledging its support for the HSE Rainbow Badge, winner of the 2020 Equality and Diversity Irish Healthcare Award, an initiative that aims to make a positive difference by promoting a message of inclusion for patients and staff who identify as LGBTQ, read all about it on page 12.

Lastly, I hope you enjoy this issue, if you wish to contact a member of staff between 9am and 5pm, Monday to Friday, please phone the office on 01 - 6579900.

Barry

IN THIS ISSUE

CEO REPORT

Annual Conference 2022

It was a great pleasure to see almost 170 members attend our in-person annual conference and AGM at the Slieve Russell Hotel in Cavan on the first weekend in March, exactly two years after our last in-person Annual Conference at the same venue.

The entire conference went exceptionally well. Our guest speakers from abroad - Prof. Flora Peyvandi from Milan and Prof. Mike Makris from Sheffield - presented outstanding lectures on Novel Therapies and Gene Therapy respectively. The Irish presenters - Dr. Beatrice Nolan, Niamh Larkin and Mark McGowan also did an outstanding job. Beatrice and Niamh presented - on the Irish experience to date with Emicizumab and Mark presented an update on our innovative and successful physiotherapy /exercise on-line programme. Ireland has extensive experience on the use of Emicizumab with a total of 76 children and 51 adults now being treated.

The programmes for the children and teenagers also went very well. It was a very positive experience for them to meet up with their friends with bleeding disorders and their siblings again after two years. We were also very pleased to see our volunteers back working with us The post event evaluations from members were uniformly positive and members will be glad to know that we shall be returning to the Slieve Russell hotel again next year for the Annual Conference.

New Awards

We were particularly pleased at the Annual Conference to announce new awards in memory of two members who had contributed so much to the Society.

The Gerry O'Reilly Courage Award will be presented annually to a teenager or child who has demonstrated courage and resilience. The award is named for long time member, Board member and former treasurer Gerry O'Reilly who sadly passed away in 2019. Gerry was the embodiment of courage and resilience and his humour and can do attitude in the face of serial adversity was an inspiration to all.

We were also very pleased to announce the Michael Davenport Education Grant which will be an annual grant for up to three to four years for an adult with a bleeding disorder returning to higher education as indeed Michael did when he did a BA degree in his 50's. Michael was a former Chairperson and long time Board member who made a great contribution to the Society.

Lindsay Inquiry Report Anniversary

This year marks the 20th anniversary of the publication of the Report of the Tribunal of Inquiry into the Infection with HIV and Hepatitis C of Persons with Haemophilia and Related Matters (the Lindsay Inquiry report).

There were a total of 106 people with haemophilia who were infected with HIV and 255 with Hepatitis C via contaminated blood products supplied by the state. To date, 114 have died.

Gerry O'Reilly

Michael Davenport

The recommendations of the Lindsay Inquiry called for the establishment of a co-ordinating committee to look at all aspects of the treatment and care of haemophilia care including the choice of blood products. They also called for formal co-operation between doctors and patients.

As a result, 2 separate bodies were established:

The national haemophilia council is a statutory body established in 2004 to advise the minister for health and the HSE on all aspects of treatment and care. The council includes the directors of the 4 haemophilia treatment centres in Dublin (2), cork and Galway, the Irish Haemophilia Society, the Department of Health and an independent chair - Mr. Brian Fitzgerald. The Society are represented on the NHC by Debbie Greene and I. The work of the council has been vital in developing a true national outlook on the service requirements. Development of care has been greatly assisted by peer reviewed independent audits, organised by the council, which provide a roadmap for dealing with deficiencies in the service.

HPSMAB meeting circa 2012

The Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) was established on a non-statutory basis in 2002. The HPSMAB members are the Directors of the 3 comprehensive care centres, 2 representatives from the Irish Haemophilia Society, a representative from the Department of Health, a nurse specialist and a representative from the contract holder - St. James's Hospital. The HPSMAB is chaired by the National Haemophilia Director, Dr. Niamh O'Connell and I am the vice Chair representing the Irish Haemophilia Society.

Declan Noone also represents the Society on this board. The HPSMAB has provided the expertise to allow for the procurement of the safest and most effective treatments for haemophilia since 2002. in that time, the quality and quantity of treatment has increased markedly and Ireland has been at the forefront in the introduction of the latest and most effective therapies. We were the first country in the world to introduce extended half life FVIII and FIX for all people with severe haemophilia A and B and one of the first countries to provide Emicizumab as an option for all with severe or moderate FVIII deficiency. We have always selected the safest and most effective treatments using a rigorous and scientific analysis of each product in each procurement cycle. The quantity of treatment purchased has also increased very significantly over the years from 3.7 IU per capita in 2002 to the equivalent of 11 Iu per capita by 20021. Remarkably, this has been achieved with a budget which has not increased since 2002. The HPSMAB has proven itself to be an exceptionally effective and cost effective board in the provision of haemophilia therapies. When the board commenced their work in 2002, Ireland were paying prices which were 26% above the EU average. Now, we are paying prices which are 60% below the EU average.

Procurement of haemophilia medications in Ireland through the HPSMAB is now seen as the most effective model globally in haemophilia care. The Irish Haemophilia Society has provided training on haemophilia procurement to doctors, patient organisations and health officials in over 30 countries since 2010.

The formal involvement of people with haemophilia through the Irish Haemophilia Society in decision making on haemophilia policy and procurement is now well established at a national level and indeed is widely recognized as best practice. The achievements in the organiation of haemophilia care have been built on a model of collaboration and partnership between the haemophilia treaters and the Irish Haemophilia Society with key input and engagement from the department of health. It is our belief that a similar system of organisation and formal involvement of doctors and the relevant patient organisation in care and in procurement of medications could benefit many other rare or indeed chronic diseases in Ireland.

From the tragedy of the past, we have built a system where the interests of people with haemophilia and other inherited bleeding disorders are protected and represented by the Society being formally involved at policy level and in the choice and selection of therapies. This is patient empowerment and we must continue on this path and build on it for the future.

World Haemophilia Week

World Haemophilia Daty on April 17th this year falls on Easter Sunday. As in previous years, we shall be designating a World Haemophilia week which will run from April 17th to April 22nd (and we may even have some activities the previous week). The theme that the World Federation of Hemophilia (WFH) is promoting for World Haemophilia Day this year is the importance of patient involvement in

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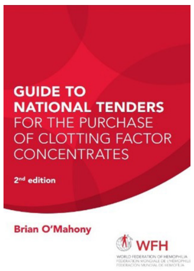
Haemophilia (2015), 1–8 DOI: 10.1111/hae.12720

ORIGINAL ARTICLE

Survey of coagulation factor concentrates tender and procurement procedures in 38 European Countries

B. O'MAHONY,*†‡ D. NOONE*† and L. PRIHODOVA†§

*European Haemophilia Consortium, Brussels, Belgium; †Irish Haemophilia Society; ‡Trinity College, Dublin,Ireland; and §School of Psychology, University College, Dublin,Ireland

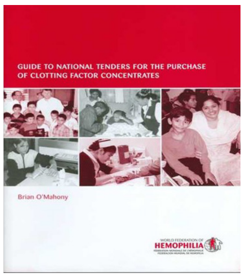


GUIDE TO NATIONAL TENDERS FOR THE PURCHASE OF CLOTTING FACTOR CONCENTRATES

2nd edition

Brian O'Mahony

WFH



GUIDE TO NATIONAL TENDERS FOR THE PURCHASE OF CLOTTING FACTOR CONCENTRATES

Brian O'Mahony

HEMOPHILIA

Concepts
In
Factor Replacement
Therapy

Irish Haemophilia Society
2014

decision making. As seen above, the outcome of our work following the recommendations of the Lindsay tribunal are an excellent example of patient empowerment. We shall be highlighting this work during the week and hopefully by the time you are reading this, we shall have achieved some media coverage and increased public awareness on these important issues.

There are also additional events planned for World Haemophilia Week.

We are launching a new and improved website for the Society. The existing website has been totally redesigned with a new layout, a new look and new content. We hope that members and visitors to the website will appreciate the new more modern look and the more user friendly navigation on the site

We will be awarding the Gerry O'Reilly Courage award to three children or teenagers with Haemophilia who have demonstrated courage and resilience over the past year. The award is named for long time member, Board member and former treasurer Gerry O'Reilly who sadly passed away in 2019. Gerry was the epitomisation of courage and resilience and his humour and can do attitude in the face of serial adversity was an inspiration to all. The awards will be presented by the Society at a ceremony in Children's Health Ireland, Crumlin on April 21st.

A fourth event during the week will be the launch of a video produced by the National Coagulation Centre in collaboration with Children's Health Ireland, Crumlin on transitioning from the paediatric to the adult service. This will be jointly launched by the NCC, CHI Crumlin and the Society.

Ukraine and Syria

The invasion of Ukraine and the consequent human suffering and devastation has appalled all right thinking people. Ireland, in collaboration with the other EU countries, have responded with help and support. At the time of writing (March 30th) some 14,611 refugees from Ukraine had arrived in Ireland and may stay for up to 3 years. It is anticipated that Ireland may have 30,000 refugees from Ukraine by the end of April. The red cross have received 22,657 pledges of accommodation. If there are any Irish families or people with haemophilia or other inherited bleeding disorder who have pledged accommodation through the red cross, we would appreciate if you would let us know. In an ideal scenario, it would be great to place refugees with bleeding disorders with familied or individuals who have experience of living with a bleeding disorder. We are in the process of assisting with the placement of one refugee at present with a family with a bleeding disorder.

The Society have also reached out to the Haemophilia Societies in Ukraine, Poland, Hungary, Slovakia and Romania offering our help and support. The organisation in the Ukraine has been moving people and families with bleeding disorders from war torn eastern Ukraine further west to Lviv and then on to Poland and further west. They requested assistance with hotel accommodation costs in Lviv as they were running out of accommodation for desperate families arriving there who needed to rest for a day or two before moving on. The Society have funded hotel accommodation which will cater for up to3 families at a time for a period of 2 months. I have been heartened by the solidarity and sense of community displayed by European haemophilia Societies. The Polish Haemophilia Society have assisted a stream of people arriving from Ukraine as have the Societies in Slovakia, Hungary and Romania. Many of the refugees with haemophilia

Engaging your government, integrating inherited bleeding disorders into national policy.

APRIL 17
2022
WORLD
HEMOPHILIA DAY

arriving in Poland then move further west and as of yesterday there were 20 people with haemophilia from Ukraine in Poland. Germany and Lithuania in particular have stepped up. Thera re now 30 people with haemophilia from Ukraine in Germany and 14 in Lithuania and the haemophilia societies there are offering them every help and support.

I know that if and when people with haemophilia and other inherited bleeding disorders arrive in Ireland from Ukraine, our members and our Society will respond generously with the required help and support.

Just prior to the invasion of Ukraine, agreement had been reached with the Department of Foreign Affairs for 3 Syrian families with Haemophilia who are currently refugees in Jordan to move to Ireland. Syria has over the past number of years been devastated by war and many Syrian families are currently refugees in Jordan. The Irish Government has agreed to take a defined number of Syrian people into Ireland and , thanks to the tireless efforts primarily of Dr. Beatrice Nolan, they have agreed to admit three families who each have a child with Haemophilia. Accommodation for these families will be provided by the state and, as with Ukrainian refugees, health care will be provided. We are working with Dr. Nolan and the Department of Foreign Affairs at present on arrangements for the families and we look forward to welcoming them into our country and into our community.

Brian O'Mahony,
Chief Executive

NEWLY DIAGNOSED INFORMATION DAY

DATE: SATURDAY JULY 16 2022
VENUE: CASTLEKNOCK HOTEL, DUBLIN

In conjunction with by Children's Health Ireland at Crumlin, the I.H.S. is delighted to announce a Newly Diagnosed Info Day in Castleknock Hotel on Saturday, July 16.

The programme will consist of a clinical overview of haemophilia, support, fears, physiotherapy and activities and some personal stories.

If you are interested in attending, contact the office on 01657 9900 or info@haemophilia.ie

Preliminary Timings

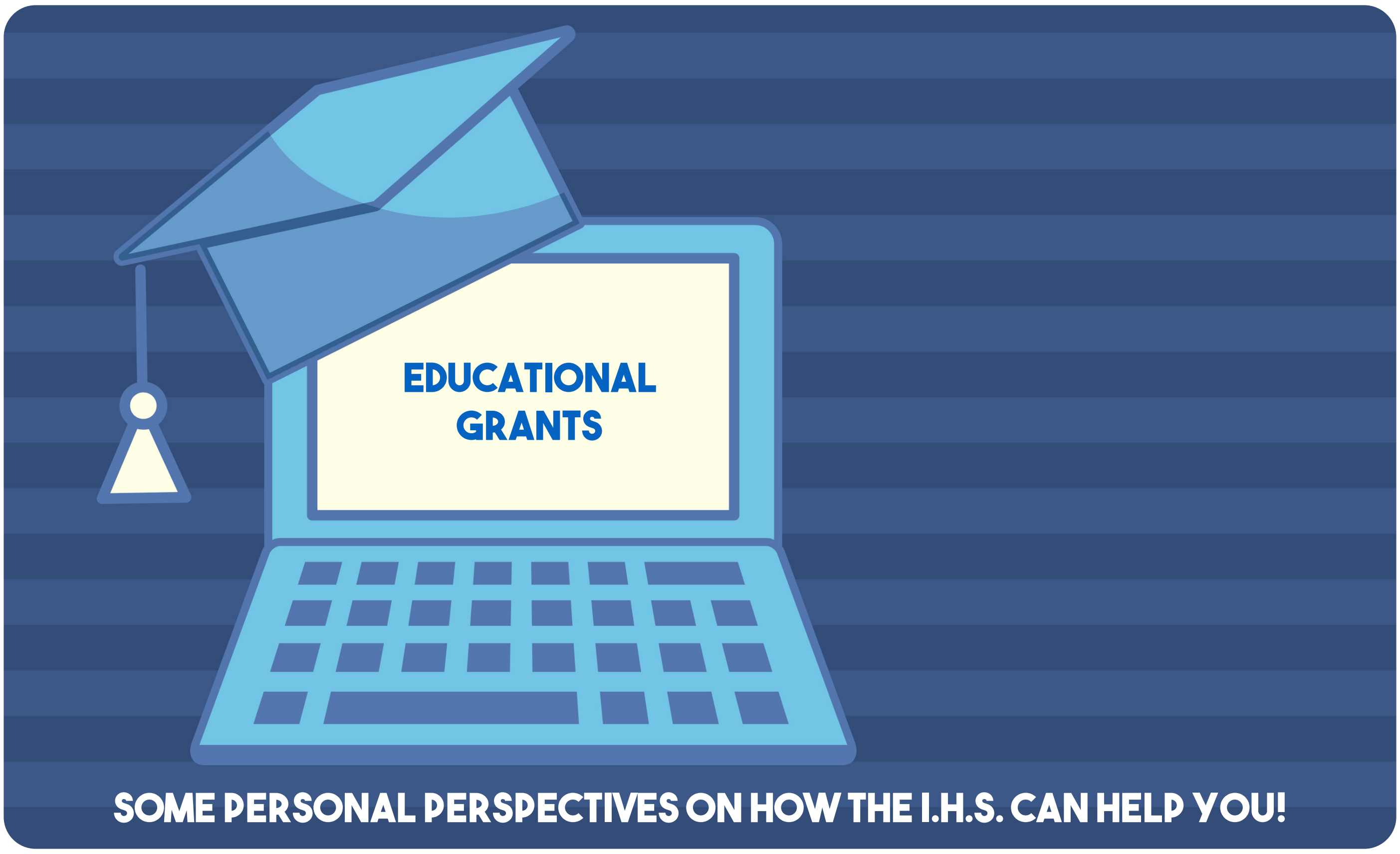
11.00 – 12.00 Registration

12.00 – 13.00 Lunch

13.00 – 17.00 An Afternoon of Talks

Sláinte Leanaí Éireann
ag Cromghlinn
CHI
Children's Health Ireland
at Crumlin

IRISH HAEMOPHILIA
SOCIETY LTD
Cumann Haemifile Na hEireann



EDUCATIONAL GRANTS

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

Hi there, my name is Aoife O'Connor and I'm a first year Home Economics and Religious Education student teacher In St Angela's College, Sligo. I'm honoured to be awarded the 2021 Margaret King Educational Grant by the I.H.S.

This contribution is deeply appreciated as I'm from Dublin so I will be using the funds to go towards my travel expenses, and essential course equipment required, such as a culinary set, a culinary uniform and a sewing machine.

This year has brought many changes in my life including the move out of home for College, to new surroundings and people that has taken a lot of adjusting too. It has always been my dream to be a Home Economics teacher and I'm very grateful to have the support of Irish Haemophilia Society backing me all the way. I hope in the future I can give back to the society for what they have done for me and inspire young member to follow their dreams whatever they may be.

Once again I would like to thank the I.H.S. for this award.

Aoife O'Connor

Hi, I'm Dara Dowling and I'm a final year Business Studies student in Dublin City University specialising in Human Resource Management. I have been involved with the society since I was born and progressed from the crèche through to the youth group and decided to begin volunteering in 2017. I enjoy volunteering as I remember all the fun I had attending the conferences growing up and hope that I can give that experience to other members who are going through the programmes. I would encourage anyone who is considering volunteering to do so as I have made friends for life and it has brought me so many amazing opportunities. The past two years of the pandemic have been difficult for everyone and covid has highlighted how much I enjoy attending the conferences and events hosted by the I.H.S.

This academic year I was awarded the Margaret King Educational Grant. The grant helped me cover the costs of textbooks which can be costly at 3rd level. It also allowed me to update my technology as college this year is hybrid meaning many of my classes are still online. Additionally, it covered the costs of printing my assignments and slides and other general expenses throughout the year.

I would recommend others to apply for the grant as I found the application process easy and seamless as there is plenty of information available on the website that is very useful when filling in your application. If there is anything you are unsure of or have any questions you can reach out to the wonderful staff who I'm sure would be more than happy to help with your queries.

I would like to thank the society for awarding me with this grant as it has allowed me to focus on final year without the worry of the financial costs surrounding it. I am looking forward to attending another conference and returning to volunteering, something I have greatly missed during the pandemic.

Dara Dowling

AGM & CONFERENCE 2022

It was a brilliant to see almost 170 members attend our in-person Annual Conference and AGM at the Slieve Russell Hotel in Cavan on the first weekend in March, exactly two years after our last in-person Annual Conference at the same venue.

It was especially nice to have our children and young adults programmes back. Here are some photos from the weekend and we hope to see more of you at our events throughout the year and beyond.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Cumann Haemifilia Na hÉireann
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CELEBRATING 50 YEARS


IRISH HAEMOPHILIA SOCIETY
THE MARGARET KING EDUCATIONAL GRANT 2021
DARA DOWLING


THE BOSS

Physical Activity during the Covid-19 Pandemic: Insights from the Irish Personalised Approach to the Treatment of Haemophilia (iPATH) Study

The impact of the Covid-19 pandemic on the physical health and well-being of the global population has certainly shed light on the importance of maintaining a physically active and healthy lifestyle. Aside from a reduction in all-cause mortality and in the risk of developing a vast array of chronic health issues(1), regular participation in physical activity (PA) has been strongly associated with a reduced risk of severe illness and death from Covid-19(2). PA has also been associated with lower levels of depression and anxiety during the Covid-19 pandemic(3), which highlights an important role for PA in helping people to deal with stress and mental health issues during these difficult times. Lockdowns and stay at home orders during the pandemic have presented challenges in achieving a physically active lifestyle, and thus, reaping the numerous associated health benefits. Limits placed on leaving the house, working and schooling from home policies in conjunction with the closure of gyms, swimming pools and sports clubs, have all impacted on daily PA.

Studies from some countries have suggested that compared to pre-pandemic times, PA declined during the initial periods of lockdown. Other studies however, report no changes and even increases in PA throughout the course of the pandemic(4,5). In Ireland, a large survey of the general population during the initial Covid-19 restrictions, found that the majority of people were more active than usual, with a minority being less active(6). More time for PA and a greater belief in the importance of PA for health and wellbeing were predictive of being more active than usual(6). A lack of access to usual means of exercise, being advised to stay at home and working more than usual were predictive of being less physically active(6). In the pre-pandemic era, a busy work, family and social life may have contributed to certain barriers to PA for some individuals, including a lack of time and motivation for exercise. These barriers may have become less of a burden during the pandemic due to reduced time spent commuting to work, doing the school run or generally socialising with family and friends. Certainly, opportunities to take up new forms of exercise were a lot more accessible due to an increase in online exercise platforms, including online exercise classes for strength and aerobic training, yoga and Pilates(6-8). Equally, barriers to PA for others compared to the general public may have increased, due to the need for the elderly and medically vulnerable to self-isolate and restrict their social movements. Furthermore, increased caregiver demands on families, working demands on frontline workers, and staffing shortages across a variety of sectors may have resulted in less time to engage in regular leisure time PA.

At the beginning of the pandemic, ongoing research for the iPATH Physical Activity Study was affected, alongside many other aspects of general healthcare treatment, management and research. The iPATH research team wanted to know if the Covid-19 pandemic had impacted PA and physical health in adults with moderate and severe haemophilia. Fortunate-

ly, after a period of adaptation it was possible to conduct the study on a remote basis. A number of previous participants of the study agreed to a follow-up assessment of PA and health using a questionnaire which was posted to them. Some participants also agreed to wearing the ActiGraph PA monitor (see picture) again for one week, to compare their previously measured activity levels with current PA. The study was carried out after the third lockdown phase of the pandemic, providing interesting insights to how PA was impacted across the three main waves of lockdown in Ireland. Approximately three years after the original research assessment, emerging results from 24 participants revealed that the majority of participants (45.8%) reported no differences in their PA compared to normal during the first lockdown, although 33.3% reported to be less active. A similar trend was found during the second lockdown, but during the third, longest lockdown, the majority (45.9%) reported to be less physically active compared to normal. Only a small proportion of adults reported increased PA throughout the various waves of lockdown (17-25%). The ActiGraph monitor revealed that objectively measured moderate-vigorous intensity PA (i.e. exercise which increases your heart rate such as brisk walking or cycling), was similar between the pre-pandemic period and after the third lockdown period. However, guideline recommended levels of moderate-vigorous PA of 150 minutes per week were achieved by 75% of participants during this assessment, compared to 63% in the pre-pandemic assessment. Based off these findings to date, it would appear that PA was not overall negatively impacted by lockdown for the majority of adults with moderate and severe haemophilia in the study. The fact that a higher percentage of participants achieved recommended PA after the most recent lockdown, may indicate that PA has increased since the original iPATH research assessment.

These results are encouraging, yet ongoing analysis of this study is currently underway. These emerging findings are due to be presented at the World Federation of Hemophilia Congress in May 2022. The iPATH research team continue to be extremely grateful to all of the participants who have taken part in this research. Without their ongoing support and contribution, this research would not be as rich and informative as it has been to date. Results of the entire iPATH study are currently undergoing final analyses, and the iPATH research team look forward to sharing these findings with the haemophilia community in Ireland in due course.

As Ireland continues to emerge from Covid-19 restrictions, pre-pandemic barriers to PA may resume for people who have become more active throughout the pandemic, as people return to the workplace and busy social lives. Additionally, barriers may be further heightened for the elderly and medically vulnerable who may be required to continue to restrict their movements due to high levels of Covid-19 variants continuing to circulate in the community. Future research must continue to assess and monitor changing patterns in PA behaviour in all populations, in order to continue to address the burden of physical inactivity on long-term health. This will also continue to inform interventions and services which will promote and enable a more physically active lifestyle for all.

Megan Kennedy and John Gormley, iPATH Physiotherapy Research Team

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THE HSE RAINBOW BADGE

The Irish Haemophilia Society is pledging its support for the HSE Rainbow Badge, winner of the 2020 Equality and Diversity Irish Healthcare Award, an initiative that aims to make a positive difference by promoting a message of inclusion for patients and staff who identify as LGBTQ+ (lesbian, gay, bisexual, transgender, queer; the + simply means inclusive of all identities, regardless of how people define themselves).

1 in 2 Irish LGBTI
young people experience anti-LGBTI bullying at school
The LGBTIreland Report (2016)

2 in 3 Irish LGBTI people
do not feel respected by their health care professional
Maycock et al, GLEN and BeLonGTo (2009)

LGBTI young people have 4 times
higher levels of severe stress, anxiety and depression than their peers
My World Survey: National Study of Youth Mental Health in Ireland (2012)

Almost 1 in 2 Irish LGBTI
people seek out LGBTI-friendly healthcare professionals because of previous bad experiences
Maycock et al, GLEN and BeLonGTo (2009)

Why does it matter?

Despite improving attitudes towards LGBTQ+ people in Ireland, negative attitudes (such as homophobia, biphobia, transphobia) are still prevalent. Many people are afraid to disclose their sexual or gender identity and to 'come out' to healthcare staff – being unable to do so often increases their risk of physical and mental health problems.

Research has shown that negative attitudes towards LGBTQ+ people are prevalent within the HSE; 27% of Irish doctors have witnessed homophobia or transphobia towards patients. Members of the LGBTQ+ community in Ireland feel healthcare providers lack knowledge and sensitivity to LGBTQ+ issues, with almost half seeking LGBTQ+ friendly clinicians because of bad experiences (Maycock et al, 2009). Additional barriers to accessing health services include fear, lack of understanding of LGBTQ+ issues and lack of appropriate language. These barriers lead to marked inequalities in healthcare for this vulnerable group of people.

People who identify as LGBTQ+ experience additional emotional and psychological stresses when compared to non-LGBTQ+ people. This can be attributed to having to manage a stigmatised identity, being faced with heteronormative and gender norms within society and experiencing discrimination. As a result, LGBTQ+ are at increased risk of mental health issues such as depression and anxiety. It's a real problem for children and young people: more than half of Irish LGBTQ+ young people self-harm; 2 in 3 seriously consider suicide; and tragically 1 in 3 have attempted suicide. The average age of first attempt is just 15. The statistics are similar for older LGBTQ+ people in Ireland, with levels of attempted suicide three times the national average (LGBTIreland Report, 2016).

The report 'Visible Lives' (2011) details stigma, marginalisation and discrimination that older LGBTQ+ people have faced in their lives and the social and emotional impacts this adversity had on their lives. Older people who identify as LGBTQ+ also encounter difficulties in healthcare, experiencing high levels of poor-quality service from healthcare professionals with 40% considering these poor experiences as a result of their LGBTQ+ identify (Higgins et al. 2011).

What is the initiative?

The Rainbow Badge is a small enamel badge worn on a lanyard or lapel, a simple visible symbol that can make a big difference for those unsure of both themselves and the reception they may receive if they disclose their sexuality and/or gender identity. As advocates, people who work in healthcare can play a key role in making things better. We know that simple acts of visual representation and basic frontline training are something which members of the LGBTQ+

community value and it is noted that this simple act can improve access to healthcare and address fear for service users. The model though is more than just the badge; it's a model that emphasises the substance behind the symbol, with the emphasis on **education for staff, responsibility and support.**

Promoting the initiative allows organisations to show that their place of work offers open, non-judgemental and inclusive care for all who identify as LGBTQ+. Wearing the badge allows individual healthcare professionals to show that they are someone an LGBTQ+ person can feel comfortable talking to about issues relating to sexuality or gender identity. It shows that the wearer is there to listen without judgement and signpost to further support if needed. The model is opt-in; wearing a badge is a responsibility; signing up to the badge means signing up to a package of basic education about the challenges that LGBTQ+ people can face in relation to accessing healthcare and learning about ways in which they, the wearer, can be an LGBTQ+ ally in health.

Where can I find out more?

More information about how to introduce the HSE Rainbow Badge in your organisation can be found on the HSE website at **www.hse.ie/HSErainbowbadge**.

The page contains an **Implementation Toolkit** and **Guide for Healthcare Professionals**. Although the badge is designed with the HSE logo, other logos can be incorporated for non-HSE healthcare organisations.

Where can I organise training?

LGBTIreland have developed a training programme for healthcare professionals who work with LGBTQ+ older people, The LGBT Champions Programme, but also tailor their training for LGBTQ+ people of all ages.

www.lgbt.ie/champions-programme, **training@lgbt.ie**.

BeLonGTo have partnered with Jigsaw to provide training for people who work with young people on the topic of supporting LGBTQ+ young people's mental health.

www.belongto.org/professionals/training.

They are planning online webinars for healthcare professionals later this year – please check their website for more information.

TENI offer Transgender Awareness Training for healthcare professionals. Contact **office@teni.ie**

HSELand 'LGBT+ Awareness and Inclusion: the basics' e-learning module training is available for HSE employees from **www.hseland.ie**

Wearing a badge is only one step towards overcoming healthcare inequalities but with increasing awareness and education we can start to overcome barriers to healthcare for LGBTQ+ people in Ireland.

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.

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**

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.

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

SCAN ME

40 YEARS OF WOMEN MAKING MAGIC

Vhi Women's Mini Marathon

VHI Women's Mini Marathon 2022

Entries are now open for the VHI Women's Mini Marathon 2022, which will be taking place in Dublin City on Bank Holiday Sunday 5th June.

In 1983, 9,000 incredible women entered Ireland's first Women's Mini Marathon in Dublin. In 2022, to celebrate its 40th magical year, #WMM will stand for Women Making Magic!

Now one of the largest women's event in the world of its kind. Over €225 million has been raised for charities, not to mention the hearts, souls and spirits raised every single step of the way. This special year, lets recognise and celebrate their magic.

We are very grateful to all the ladies who take part in the Mini Marathon for the I.H.S. every year, your support for the work of the Society is really appreciated. An event like this is so important, not only to raise funds but to raise awareness of haemophilia and other bleeding disorders.

So, if you have a bleeding disorder or if you are the mother, sister, daughter, niece, cousin or friend of an adult or child living with a bleeding disorder, now is your chance to show your support by taking part in this year's VHI Women's Mini Marathon to raise funds for the I.H.S.

For more info on VHI Women's Mini Marathon or to register, please visit **vhiwomensminimarathon.ie**.

If you would like to raise funds in aid of the I.H.S. or you would like more info about fundraising, please contact Nina in the office on **01 6579900** or email **nina@haemophilia.ie**.

NOTICEBOARD

Board Update

Jay McEvoy has stepped down from the I.H.S. Executive Board. We would like to thank Jay for all his work, time and dedication during his time on the board.

We would like to congratulate young I.H.S. member Jason Rossiter who represented Wexford Minor Hurlers on Saturday, March 26, as they went on to defeat Dublin in Parnell Park by a point!

Irish
Haemophilia
Society

TRAVELLING OR STUDYING ABROAD?

What you need to know...

If you are relocating or studying abroad there is a lot to consider before you travel. Each country has their own rules and regulations that you must follow to ensure you receive equivalent healthcare to what you receive here in Ireland.
Most countries cover emergency/urgent healthcare that is required while a person is visiting, in accordance with your health/travel insurance. However, this usually does not extend to regular haemophilia treatment and does not cover prophylaxis nor regular on demand therapy.

How do you plan your trip to ensure you will receive the equivalent healthcare?

1 **Call the I.H.S.**
Call us as soon as possible. We will help you with all of the stages and help with any queries.

2 **Call Your Treatment Centre**
They will advise you on how much factor you will need to bring. It is important to request a letter from your treatment centre which gives details of your treatment.

3 **Find the nearest treatment centre**
For Europe see - http://www.euhanet.org/centrelocator/
For the rest of the world see - https://www.wfh.org/en/resources-education/treatment-centre-directory

4 **Apply for the correct VISA**
To find out what VISA you need and how to apply see: https://www.dfa.ie/travel/visas/visas-for-irish-people-going-abroad/

5 **Get adequate health insurance**
A company that does provide insurance cover for pre-existing medical conditions including haemophilia is a company called Blue Insurance. They can be contacted by:
Ph. 0818 444 449 or at www.blueinsurance.ie .

6 **Pack essential items**
If you are carrying treatments and medications it is very important to ensure that you have a travel letter from your haemophilia treatment centre for customs. You should also carry your haemophilia card which was issued from your haemophilia treatment centre.
For travelling within Europe, you should have an EHIC card (European Health Insurance Card). This entitles you to necessary healthcare in the public system of any EU/EEA member state.

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@HaemophiliaIRL

As our lives return to some sembalance of normality, so to do possibilities for travel or study abroad.

If you are thinking about relocating or studying abroad there is a lot to consider before you do so to ensure you receive equivalent healthcare to what you receive in Ireland. With all that in mind, we have this handy infographic which can also be found on our website.

IRISH HAEMOPHILIA SOCIETY

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