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

Magazine of the Irish Haemophilia Society

Autumn 2020



The Society
at a Glance

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I.H.S.
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FROM THE EDITOR

I hope you are all keep well in these strange and unpredictable times.

The I.H.S. team is continuing, like many of you, to work remotely but we are very proud of the work we've achieved in these trying times; especially how our community has remained strong - a theme running through Brian's CEO Report.

On Page 4 Brian gives an overview on how our communications and outreach have morphed in the new reality we find ourselves in, and looks at the provision of haemophilia care also.

On Page 7, Chairperson John Stack provides us an update from his end while on Page 8, Dr Michelle Lavin offers us an insight to the 'Know Your Flow' project and campaign.

On Page 10, Brian continues with part two in a series examining 'Past Progress and Future Promise' of haemophilia care in Europe, followed by an update on Tele-Dentistry in 2020 from Laura Parkinson on page 12, and Niamh Larkin explains what her new role as Advanced Nurse Practitioner Haemophilia on Page 14

Lastly, I hope you enjoy this issue – a first physical copy of 2020 - and are all keeping well, and remember, if you wish to contact a member of staff between 9am and 5pm, Monday to Friday, please phone the office (01 - 6579900) as normal, or you can email us as usual too.

Barry



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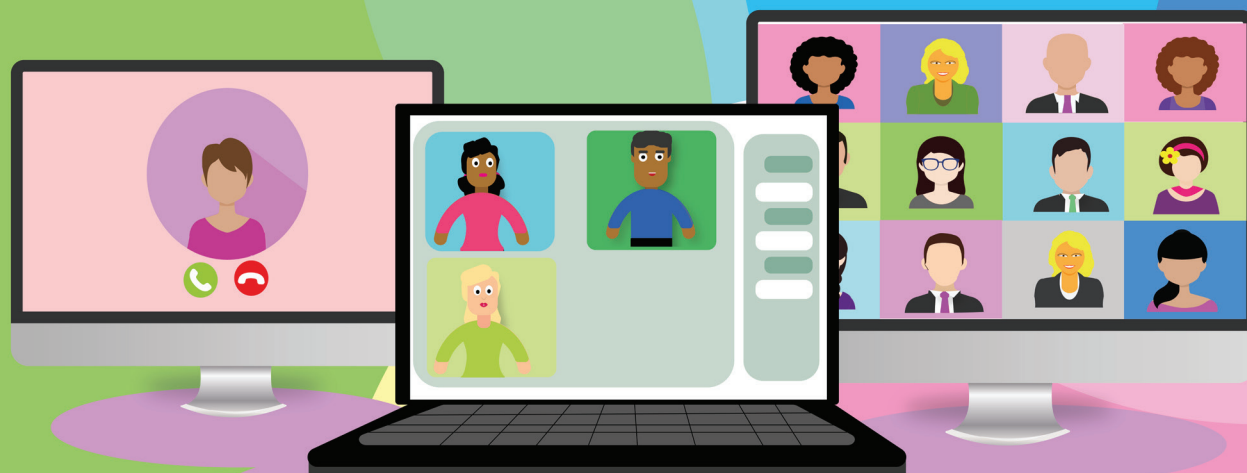
Noticeboard

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



VIRTUAL OCTOBER CONFERENCE

OCTOBER 17 & 18, 2020



The Irish Haemophilia Society is delighted to announce a Virtual October Conference 2020. The conference will take place via Zoom on Saturday, October 17 & Sunday, October 18; between 10AM & 1PM both days.

The event is free to attend but you must register beforehand. To register your place for the I.H.S. Virtual October Conference 2020 please contact the office on 01 657 9900 or info@haemophilia.ie, or to book your place online, please see haemophilia.ie

PROGRAMME

Saturday, October 17: 10:00 - 13:00

- 10.00 - 11.00 **Gene Therapy Update & Discussion**
Speakers: Prof. Mike Makris and Mr Brian O'Mahony
- 11.00 - 11.45 **Hemlibra**
Speakers: Dr Niamh O Connell & Dr Beatrice Nolan
- 11.45 - 12.15 **Break**
- 12.15 - 13.00 **Treatment Discussion Panel**
Gene Therapy - Mr. Brian O'Mahony
Hemlibra - Mr. David Flanagan
EHL Factor - Mr. Colm Walsh
Plasma derived VWF - Ms. Luz Maria Heaney

Sunday, October 18: 10:00 - 13:00

- 10.00 - 11.00 **Healthy Diet in a Pandemic**
Speaker: Ms. Didi de Zwarte, Registered Dietician
- 11.00 - 11.30 **Break**
- 11.30 - 13.00 **Exercise & Health**
Speakers / Facilitators: Ms. Sheila Roche, Mr. Mark McGowan & Ms. Paula Loughnane

CEO REPORT

Communication in the new reality – Provision of Haemophilia care



We live in interesting and challenging times. The reality of the ongoing Covid-19 pandemic has altered our lives in many ways; how we work, how we live and how our haemophilia and bleeding disorder health services are organised. The situation has also led to innovation and fresh thinking and the introduction of measures which had been spoken about for a long time but finally implemented.

The provision of health services for people with haemophilia and related bleeding disorders was, of course, affected by Covid-19. The infrastructure in St. James's Hospital was the most affected. Access for people with inherited bleeding disorders to the purpose built H and H in-patient ward was stopped as the ward was initially used as a Covid-19 ward and is currently being used as an isolation ward for suspected cases of Covid-19, or for those requiring isolation or single rooms. Members can be assured that we are fully aware of the importance of access to this ward for people with inherited bleeding disorders. We fully understand the rationale for the temporary lack of access, but both the Society and the National Haemophilia Council are working to ensure that the hospital management are fully aware of the importance of this ward to our service. The staff are specially trained in bleeding disorders and we had worked for many years to have this facility established. Work is underway also at present to provide a separate entrance to the assessment bay in the H and H ward so that this may be available earlier than the main ward. The number of dental suites available for treatment of those with bleeding disorders in the National Coagulation Centre has also been temporarily reduced from 2 to 1. The Dental team have done a great job dealing with emergencies during the pandemic to date, but the second chair will be required to ramp the service back up to near normal levels. We will work with the team at the NCC and the Dental team to advocate to ensure that optimum access is again restored. There have not been similar infrastructure challenges reported to us by the Centres in Crumlin, Cork or Galway.

The provision of services for out-patients has been innovative and successful. Virtual consultations have been offered as a replacement for many scheduled visits. Telephone consultation visits had been used prior to the pandemic for many with mild haemophilia. We were also fortunate that we are relatively well advanced in the use of technology compared to the rest of the health service. A haemophilia electronic health record has been in place since 2006 and indeed a new and upgraded system – Indici - was introduced in the last year. The home treatment app which has been in place since 2011 has also allowed real time clinical management

of treatment remotely and finally the start of the rollout of the patient portal has focused minds on virtual and novel methods of communication. Since the start of the pandemic in March, virtual consultations or so-called Telehealth have replaced the majority of outpatient visits. Consultations were offered either by phone or by video with about a 50% preference for each method. Virtual consultations were in place with haematologists, clinical nurse specialists, physiotherapists and psychologist. The only area where this was not feasible was a visit where blood tests were required. By the end of May, the NCC had reviewed 731 patients using telehealth consultation - including 601 return patients and 130 new patients. About 50% were from the Dublin area and 50% from the rest of the country. This was so effective that by the end of May, consultations were at a greater number than in the equivalent month in 2019. Given the captive audience of people at home, it was not entirely surprising that the percentage of missed appointments also decreased significantly from 15% to 6%.



The NCC carried out a survey of the impact of Telemedicine. The majority of those who responded felt that the telehealth consultations improved access, reduced inconvenience, were easy to use and allowed for good communication with the team. Respondents felt that their healthcare needs were met by a virtual consultation, the technology was user friendly and the fact that travel or trying to find parking were not required was also a major bonus. A significant number of emergency dental procedures were also carried out – many of them virtually. This included talking people through how to insert a temporary filling from kits available from local pharmacies and issuing of prescriptions for pain medications. The Society also supported the Dental service in advocating for the availability of a fogging machine which allows rapid decontamination of the dental suite and allows

for faster turnaround time when in person dental care is required. An interesting aspect was the provision of virtual consultation with the Physiotherapy team and again the number of virtual consultations by May 2020 had increase to a level which exceeded actual consultations in May of 2019.

An exercise Gym class was also organised over a 6-week period for a group of older people with haemophilia. This pilot project was initiated prior to the pandemic as an in-person class and this was then moved to a virtual Zoom class facilitated by the Society. The activity worked very well and was greatly valued by those who participated. This is an activity we plan to organise with the physiotherapists for other groups of members and indeed an exercise class will form part of our virtual conference in October. A separate survey with the health care workers providing the consultations was also carried out. This showed a wide degree of satisfaction with the service and 88% of those surveyed would recommend to colleagues that they use telemedicine. Interestingly, a significant number of the health care workers reported that the virtual consultations took longer than face to face consultations as the patients liked to chat. This surely demonstrates a level of comfort with the process. I have no doubt that, even in a post pandemic future, Telemedicine and virtual consultations will form a core part of the service to people with inherited bleeding disorders. A blended approach will probably be most realistic for those with a severe bleeding disorder, rather than the past experience of an outpatient visit twice annually, perhaps a once annual visit would suffice which would include phlebotomy and a second visit would be organised virtually. For those with a mild bleeding disorder, where annual phlebotomy may not be a requirement, perhaps a face to face visit every second year with a virtual visit on the other year would work. It will be important to review all of this when the pandemic is, hopefully, winding down. We should not just return to the old normal. We should integrate lessons learned and design a new system for a world where communication is faster and often virtual. If this is the case, it will be important that the centres and staff are provided with the appropriate technology and IT support to allow for an optimised service

Communication from the Society

The communication strategy from the society also had to change during the pandemic. Our normal programme of home and hospital visits to members was no longer possible and remains impractical for the most part. In an emergency or where there is a requirement for a face to face meeting, we will of course facilitate this where possible. Our individual outreach to members has been primarily through our regular phone calls to members to see how you are all coping and to deal with any issues that arise where we can be of assistance. Our outreach co-ordinator, Robert Flanagan has to date made in excess of 1,200 phone calls to members since the start of the pandemic. This allows us to keep in touch and also to identify issues proactively. Our in-person meet-

ings have also been cancelled or postponed and indeed we were fortunate to be able to hold our AGM and Annual Conference in March just before the pandemic struck. We have been monitoring the situation closely and in late August, we reached the conclusion that our October conference this year would also be a virtual event. Many of the older members would have been understandably nervous about travelling to and attending an in-person event and attending would not have been feasible for many parents as we would have been unable to organise programmes for young members.



A sample of what we have uploaded so far:

- Dental Care: The New Normal with Alison Dougall and Laura Parkinson
- Heavy Menstrual Bleeding in Adolescent Girls with Dr Geraldine Connolly
- Update on New Children's Hospital with Eilish Hardiman, CEO
- Exercise and Physical Activity for Children with Paula Loughnane, Senior Physiotherapist at CHI Crumlin
- Dental Care and Nose Bleeds in Children with Dr Kirsten Fitzgerald and Dr. John Russell
- Gene Therapy Discussed with I.H.S. CEO Brian O'Mahony & EHC President, Declan Noone
- The Role of the Advanced Nurse Practitioner in Haemophilia with Niamh Larkin, cANP

We are planning an exciting virtual event which we hope many of you will attend and it will include an exercise / physio session on the Sunday morning where all you will need will be a chair and a TheraBand which will be mailed to all those who register for the sessions. Other events planned for the remainder of this year include a von Willebrand's virtual Information day in late September and webinars on Mild Haemophilia and on Haemophilia B to replace the information days on those topics which had to be postponed from July.

Our communication strategy during the pandemic, in addition to the phone calls, has focused on regular webinars / information lectures for members, digital publications including a regular electronic update and selected hard copy publications. The webinars using Zoom have been very successful to date with 28 organised up to the end of August. We

worked to ensure that there were topics of interest generally as well as catering for topics of specific interest to adults or to parents of children with bleeding disorders. Attendance at the webinars was generally good with a maximum attendance at any 1 webinar being 52 people.

As time went on, it became more difficult for many members to attend webinars during the working day as more and more people went back to working outside their home. In the last two months, we have generally held the webinars at 6pm and we have also posted many of the webinar lectures now on the website where they can be watched on YouTube.

Our publications editor Barry Healy has been circulating a weekly (and more recently fortnightly) E-Zine where we can circulate up to date news and information. The pandemic has seen a significant increase the number of members signing up for the E-Zine thus allowing us more rapid, real time and regular communication. This is the ninth publication produced this year to date and I hope you have noticed and have used the e-reader / flip page reader feature on the website. We have also produced and mailed to members copies of selected publications. We have posted more information on our social media platforms and regularly updated content on our website.

Our communications have evolved during the pandemic. In terms of the future, we obviously will return to hosting at least some in-person events with social distancing and precautions as required when this is in line with public health guidelines. This will not be before start of 2021. We will continue with zoom webinars also in the future to replace some information events and to supplement the information provided with additional meetings or virtual events. The virtual webinar events allow members to attend free of charge, to receive the information they require without the need to travel and with a minimum time commitment. We will of course continue with publications, both digital and hard copy but we will also continue to roll out more content on social media and with podcasts. Virtual lectures on our website may enhance our ability to communicate complex information on treatment updates using carefully selected speakers twinned with good graphics or infographics and possibly podcast voiceover on slides. Virtual events also allow us to invite eminent speakers from abroad without incurring significant cost for travel or accommodation.

The pandemic has been and continues to be a challenge, but we will use this challenge innovatively and constructively to reimagine, redirect and renew our communication in the future.

Brian O'Mahony



An Update from our Chairperson....

Hi everybody. I hope you are all keeping well. When I wrote the article for the August 2019 magazine, I started with “I hope you had a great summer”. Well, it’s been very different this year, but I still hope you had a great summer or, at least, the best summer you could have had, all things considered.



Life has been transformed for everybody as a result of Covid-19 and we will all have to adapt to a new normal. Any idea of reverting to what we did in the past is gone, at least for the short to medium term. It is in all of our interests to do our utmost to control the spread of Covid-19. I’m writing this as Kildare, Laois and Offaly return to a more prescriptive lockdown, which only illustrates the potentially catastrophic consequences of complacency. I’m sure I’m not alone when I say I hate wearing a mask, but I wear it anyway. It’s a small price to pay to help reduce the risk of community spread. The more of us who implement the guidelines, the greater likelihood of controlling the virus.

As a community relying on a continuous and uninterrupted supply of medication, we all had additional concerns when the country went into lockdown. I would like to take the opportunity to thank all the people in TCP, and everybody else involved, for their very competent handling of this. I know our supply was not interrupted and I hope yours wasn’t either. I would also like to acknowledge and thank the staff at the various Comprehensive Care Centres – Crumlin for us – for adapting to the crisis and maintaining services.

Since lockdown, I’ve tried to take every opportunity to make positive change where I can. In fact, there are a number of practices to which I do not want to return, like commuting at 10 kph for 2 hours a day. On the other hand, there are some practices that I definitely want to retain, like having the flexibility to work from home and making use of technology to simplify my working life.



When we all went into lockdown, the Board and staff of the Society, like everybody else who could, switched to working from home. Zoom became the primary method of communicating in groups. We’ve now had several Board meetings on Zoom and the staff also regularly utilise Zoom. We do have a protocol in place for when we can return to working in the office but will obviously follow government advice on that. I believe that technology has allowed the staff and Board of the Society to work more efficiently and in a way that improves work-life balance.

We have continued our Twinning programme with Jordan during the lockdown, again using technology. We held several Zoom meetings with our colleagues in Jordan and I think they were a great success. Hosting the meetings online allowed more people to attend than would otherwise have been possible. I think this is because the meetings were held in the evenings when people were at home and had time. The more people in Jordan we can get involved in the Twinning programme, the better.

You’ll be well aware that we held many webinars all through the first part of the year. This included moving some previously scheduled mini conferences to a virtual option, again using Zoom. The feedback from those who attended was very positive overall. What was striking is that attendance at some virtual mini conferences was higher than we had expected at the physical event.

There is definitely a case to be made for virtual conferencing! While we are all very focused on staying safe during what is now just generally referred to as ‘Covid’ or ‘the Covid’, it is also important to stay healthy, both in mind and in body. Getting some daily exercise is very important, as is access to green space, as is access to other people. I think we have all learned to appreciate just how important it is to be able to access nature on a daily basis. Exercising outdoors is great, even in Ireland when the weather doesn’t often suit. I was once told that “there is no such thing as bad weather, just the wrong clothes” and, for the most part, that’s true.

We’ve done some ‘staycationing’, mostly camping, in the last few weeks and it’s been a lovely experience. Ellie and the kids are in Mayo at the moment and I’ll join them next weekend. They went to a falconry today that also seemed to have a collection of sports and vintage cars. Here are Fionn, who loves nature and animals, and Naoise, who loves cars, enjoying the day out from their own personal perspectives.

I’ve included these photos in my report to simply highlight the strength of the human spirit in the face of adversity. That’s Fionn after a year on Hemlibra! Humans are adaptive and resilient. Let’s all remain positive and hopeful.

John Stack

KNOW YOUR FLOW

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. Dr Michelle Lavin from RCSI is the project lead and explains the project in more depth.

Many people with a bleeding disorder experience a long delay in diagnosis, despite bleeding symptoms that may stretch from childhood. For women and girls with bleeding disorders (WBD), teenage years can be particularly challenging for bleeding as heavy periods may be problematic. In all teenage girls, periods may be heavier as the hormones that control bleeding are still maturing. Girls with an underlying bleeding disorder may experience particularly heavy or longer periods and these may have a major impact on participation in sports and/or school as well as their social life.

While effective treatments to manage heavy periods are readily available, the major hurdle is often recognition of abnormal or heavy bleeding. Periods remain a taboo issue and women often fail to discuss their periods openly. As a result, many women may not be aware when their periods are heavier than normal. Even if they talk with their mother or sisters, as bleeding disorders may run in families, their perception of a normal period may also be impacted. It is not uncommon in the clinic to see women on their first visit for

workup of a possible bleeding disorder who describe heavy periods since menarche (the first period) whose mother had an early hysterectomy (surgery to remove the womb) to treat heavy periods.

We have also seen similar patterns in our research for people with bleeding disorders. As part of the Low Von Willebrand in Ireland Cohort (LoVIC) study we asked patients about their journey to diagnosis of a bleeding disorder. 89% of the 120 women in this study described symptoms of heavy periods but only 60% of women had ever attended their GP about heavy periods. Even for those women who had complained of heavy periods to their GP, a bleeding disorder was not considered at an earlier stage. In fact, 33% of 120 women described seeing 2 or more specialists about bleeding symptoms before being referred to the NCC and the average age at diagnosis was 33 years old.

It was clear from our research that two major problems existed; not only women but doctors also may fail to recognize heavy menstrual bleeding related to a bleeding disorder. The Health Research Board (HRB) funded our initial LoVIC study so in July 2018 we approached them with a suggested programme to improve public awareness of heavy periods (heavy menstrual bleeding) and bleeding disorders in general. This programme would be developed with the Irish Haemophilia Society and focus on development of a website and social media awareness campaign. This proposal was successful and using the HRB funding the website, knowyourflow.ie was developed.



This campaign focused on simple messaging and attractive visuals to engage with younger women and girls. The aim was to educate on the key signs of a heavy period using the “721” approach – bleeding longer than 7 days, changing pads / tampons more frequently than every 2 hours and passing clots >1 euro coin.

For women experiencing these symptoms they were prompted to read more and brought to information on bleeding symptoms and bleeding disorders. There is also an option to link to the “Self-BAT”, an online tool that will calculate a printable bleeding score so people can bring it to their GP if concerned.

In order to publicize the website, we ran a social media campaign, focused on Instagram. This campaign targeted 13-33 year old females living in Ireland. The campaign was a huge success, with 695,147 impressions with a reach of 150,048 unique Irish female users. This campaign reached 21.3% of all Irish females aged 13-33 years old in the first four weeks. The findings of the campaign were analyzed and presented as a poster at the recent ISTH Virtual Congress 2020.

This website is the first step of improving awareness of bleeding disorders for women in Ireland, but there remains a lot of work to do. The majority of people with bleeding disorders remain undiagnosed. Heavy menstrual bleeding remains a key early symptom of a bleeding disorder; focusing on promoting awareness of heavy periods may help identify women earlier. The scale of the challenge is daunting – when we consider women with bleeding disorders it is useful to think of “1 in 5”. Based on Central Statistics Office data, approximately 1 in 5 of our population are women of men-

struating age and 1 in 5 women will experience heavy periods at some stage. We know from research data that among women with heavy periods, 1 in 5 will have an underlying bleeding disorder. This equates to a possible 45,000 women in Ireland with a bleeding disorder; today we have less than 4000 people (male & female) diagnosed.

Looking to the future, we look forward to working with the I.H.S. to continue to promote awareness and understanding of bleeding disorders, both in Ireland and worldwide. Our next series of campaigns will focus not only the public, but GPs and hospital physicians to help improve understanding of when specialist referral for bleeding disorders is necessary. In this way we hope to shorten the time to diagnosis and improve care for people with bleeding disorders.

Dr. Michelle Lavin



HAEMOPHILIA CARE IN EUROPE PART TWO: 1990S - 2000S

We are now in an exciting time of unprecedented innovation in relation to haemophilia care in Europe and the probability is that we will see even more innovation in treatment in the next five years. This will bring opportunities but also challenges in relation to access. To help us predict the future, it is worthwhile to examine the past. Brian continues with part two in a series examining 'Past Progress and Future Promise', an expanded version of an article published in the *Journal Haemophilia* in August 2020.

The 1990's - Decade of Progress & Promise

The 1990's were a decade of promise and progress. Coagulation Factor Concentrates (CFC) use started to increase and there was greater willingness by haemophilia centres to begin the initiation of prophylaxis for some individuals. The supply constraints and limitations on use of CFCs caused by changed treatment protocols due to lower yield per litre of plasma due to viral inactivation of CFCs remained a consideration. Treatment with CFCs was conservative. In 1992, a European White Paper (3) discussed rational use of Factor VIII and concluded that rational use was 1.9 IU per capita. This is low compared to current use in Europe but reflects the reality that use had been depressed by HIV and bleeding episodes were treated, but not aggressively in many countries. Viral inactivation of CFCs since 1985 had greatly di-

minished further infections with HIV but the heat treatment regimens initially used were of limited efficacy in inactivating Hepatitis C.

It was not until 1988 that effective viral inactivation against Hepatitis C in the form of solvent detergent was available. Europe continued to see transmission of Hepatitis C to people with haemophilia until 1990 or 1991 (Report of the Lindsay Tribunal of Inquiry, Ireland) when adequate supplies of optimally inactivated CFCs were available. Infection continued to occur in many European countries where treatment was inadequate or unsafe after 1991. The impact of Hepatitis C on the haemophilia population was not initially appreciated. This virus, which had been characterised as non-A non-B hepatitis since the late 1970s did not generally cause acute illness. Its impact was more insidious with a large proportion of those infected failing to spontaneously clear the virus and go on to develop chronic Hepatitis C infection and varying degrees of liver fibrosis or cirrhosis. Early treatments for Hepatitis C in the 1990's with interferon monotherapy had a very low success rate in achieving a sustained virological response.

The clinical and human problems associated with Hepatitis C became more pronounced in the 1990's, exacerbated by the fact that almost all of those who had been infected with HIV were now co-infected with hepatitis C. In 1994,

the first recombinant FVIII was licenced. This development along with the development of other recombinant FVIII and Factor IX products helped to break the cycle of dependency on plasma derived FVIII and FIX in many countries. Up to that point, the mantra of self-sufficiency in blood and plasma had been widely promulgated based on a WHO Recommendation from 1975. This was seen as a potential route to prevent further blood borne viruses from very large pool imported CFCs.

In reality, in several countries, this developed into a mindset where the amount of FVIII or FIX CFC which could be used in a country was dependent on the amount of plasma the country could collect for fractionation, either nationally or by contract fractionation with a pharmaceutical company. The view was also expressed at the WFH Congress in 1994 that as recombinant CFCs could be manufactured in a large scale without the need for human plasma, they could be available in very large quantities at a relatively low cost. The quantities did increase over the years but the cost remained high. Initially recombinant CFCs were priced at a premium compared to plasma derived CFCs probably due to the perception of greater safety they conferred. This price differential was widely maintained until recent years and was changed then only by competition from extended half life CFCs.

From 1990 to 1996, the mortality rate of people with haemophilia from HIV continued to increase year by year. This was changed from 1996 in many countries with the availability of highly active anti-retroviral therapy (HAART). From that point onward, mortality from hepatitis C was greater than from HIV. As one blood borne infection came under some measure of control, the old threat of non-A non-B hepatitis in its new guise of Hepatitis C claimed an increasing number of lives. This was joined by a third threat from 1996 with the threat of variant Creutzfeldt Jacob Disease (vCJD) linked to Bovine Spongiform Encephalopathy (BSE) in cattle. This led to major fears linked to the potential exposure of many people with haemophilia to this prion via plasma derived CFCs. The worst-case scenarios envisaged many thousands of clinical cases in the UK alone and the later mathematical modelling led to several thousand people with haemophilia in people in the UK being categorised as at risk of vCJD for public health purposes. Plasma from UK and Ireland was no longer used for manufacture of CFCs. Blood donor restrictions were imposed.

The stoic initial response of many people with haemophilia and haemophilia societies to the threat imposed by Hepatitis C (which was widely viewed as slowly progressing) was not matched by the response to vCJD where clinical cases always resulted in death. As it transpired, the number of clinical cases of vCJD were a very small proportion of the worst case scenario with no clinical case of vCJD being reported in haemophilia, albeit there was one individual in the UK who had prions in his spleen at autopsy but his death was not due to vCJD (4). The 1990's also saw the licencing of recombinant FVIIa for the treatment of people with inhibitors.

Following the political changes in Europe, the decade saw the emergence and greater activity levels among haemophilia patient organisations in many eastern European countries and the development of a real European haemophilia patient community.

The 2000's - Decade of incremental progress but limited innovation

The first decade of this century saw very little innovation in haemophilia treatment but incremental progress in many areas. We saw the development of second and third generation recombinant CFCs manufactured without the addition of human or animal proteins. This was partially a response to the fears linked to vCJD and the presence of bovine components in some of the earlier manufactured recombinant CFCs. The concern relating to vCJD peaked in 2004 which saw the publication of a risk assessment in the UK. Treatment for Hepatitis C improved with the availability of pegylated interferon with ribavirin. SVR rates increased generally to 40% and up to 70 % for Genotype 1.

The European Principles of Haemophilia Care were published by a diverse group of haemophilia clinicians (5). This led to effectively, a set of ten principles which could be aspired to and progress measured against. This exercise also led to the formation of the European Association for Haemophilia and Allied Disorders (EAHAD) in 2009. That year also saw the first systematic data collection by the EHC looking at the development of haemophilia care in Europe and the extent to which the principles of haemophilia care were reflected in the reality. In this first survey, data was collected from 19 countries (6). Meetings held under the auspices of the European Directorate of Quality and Medicine in Healthcare (EDQM) to look at optimal use of blood and plasma were first held in 1999 and produced a limited set of general recommendations. A second meeting was held in 2009 again resulting in recommendations on optimal use of clotting factors. This process under the auspices of EDQM and including significant input from both EAHAD and EHC grew in importance from the end of that decade.

Brian O'Mahony

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- [4] L. Eaton, "Haemophilia patient had variant CJD agent in spleen," *BMJ*, vol. 338, no. feb18 3, pp. b705–b705, Feb. 2009.
- [5] B. T. Colvin et al., "European principles of haemophilia care," *Haemophilia*, vol. 14, no. 2, pp. 361–374, 2008.
- [6] B. O'Mahony, D. Noone, P. L. F. Giangrande, and L. Pribodova, "Haemophilia care in Europe: A survey of 19 countries," *Haemophilia*, vol. 17, no. 1, 2011.



Tele-Dentistry in 2020

I have travelled to Dublin from Laois every day for 15 years to work as a dental nurse at the Dublin Dental Hospital and NCC. If someone had told me this time last year that it was possible to do anything useful in dentistry without having the patient in the chair or even in the building or do that journey every day by train I would have scoffed. But over the last 3 months I have learned that tele dentistry has been a crucial part of assuring our patients wellbeing at this difficult time. Prior to the Covid pandemic, to me the term 'tele dentistry' probably meant searching the web for information that might help patients or for perhaps partaking in online continuing education. I could never have imagined that it would become the cornerstone of our dental services for patients with bleeding disorders and that we would have an urgent need to adopt it almost overnight.

I am not so very fond of change if I am honest, but I learned that several dentists had died in Spain and Italy from contact with asymptomatic patients during routine dental treatment as it's impossible to social distance doing dental work and due to the high concentration of virus in saliva. However, when the New York Times listed dental nurses as the highest risk of all professions due to our additional role in decontamination in the dental surgery between patients I realised that I had to embrace the redesign of dental services for a few months and the NCC formal tele dentistry service was borne.

I learned that the term "tele dentistry" was not a new concept and was first used in 1997, when it was defined as "...

the practice of using video-conferencing and other communication technologies to diagnose and provide advice about treatment over a distance'

My initial job was to offer patients who had had their dental appointments cancelled, the opportunity to have a dental consultation with Dr Alison Dougall either by phone or by video. We were advantaged over many other countries or centres relying on tele dentistry because of The Lighthouse Project* and the availability and easy access to a confidential electronic record. This meant we had access to everything we required to give advice and record careful clinical notes and crucially we have been able to carry out those consultations every day from various locations offsite, even when we were not due to be at the centre. This also allowed us to make multi-disciplinary decisions together with the haematologists and specialist nurses and plan care...sometimes each working from a variety of locations.

I always enjoy speaking to patients, many of whom I have known for years and my role was to assure all patients that there was a service available should they have an urgent problem and answer any queries they had about looking after their teeth or about preparing for an online consultation. I also was the first responder to any dental emergency calls that came into the centre. Before any booked emergency consultations via tele dentistry patients were asked to photograph any dental problems and send them to us and to this day we continue to be blown away by the quality of photographs that have been possible using a mobile cell phone. This is

a practice we will continue with long after the pandemic is over. We have realised that this is a really valuable way to plan in advance what is likely to need to happen – whether a tooth can be saved or whether it needs to come out, whether someone has an abscess and needs antibiotics or whether a persistent ulcer was something to worry about...this has opened new horizons.

So, was the tele dentistry service useful? I can say a resounding yes. During the first 6-week period, 89 telephone or video consultations were conducted with patients with bleeding disorders from all over Ireland. 18 patients recorded pain scores of 7 or above with half of those reporting maximum scores of 10. 26 people indicated their dental problems were impacting significantly on relationship, sleep, nutrition or mood. 29 scripts were issued for patients who were not managing their dental pain adequately. 7 patients were tutored on self-placement of temporary fillings using kits from local pharmacies. Dental extractions were arranged for 22 patients. These were not all done at the NCC. For the first time we undertook remote ‘tele mentoring’ of dentists who were nervous or unsure of how best to manage a patient with bleeding disorder. We literally talked them through all of the required details, so they were confident to proceed. There was no incidence of bleeding from the mouth requiring admission during the 6 weeks of our data collection. This is again something that we can continue in future for people living in remote areas of Ireland.

So, in conclusion I can say that during the pandemic dental problems impacted on quality of life. We provided care for people with bleeding disorders that we had never ever met in the last 10- years of working, in fact regular dental patients had very few problems. We have realised that tele-dentistry enabled urgent dental problems to be identified and addressed efficiently, effectively and safely using a patient centred team approach. Tele-dentistry has the possibility to reduce many barriers to care and although it can never replace a face to face treatment, it has a future in our service, and I am all for it.

Our challenge now is about how we start to slowly open up dental services. Dentistry is going to look a bit different for the time being. We have even more personal protective equipment than before, with upgraded masks and visors. We have to be careful with anything that produces an aerosol so are still very limited in our ability to provide fillings and cleanings. But slowly, slowly, the new normal of dentistry will emerge and risks will be reduced, and we look forward to seeing you all soon should you need us...be phone, by video and soon enough we hope in person.

Laura Parkinson

** The Lighthouse project refers to the information technology project for Haemophilia in Ireland. It included the new electronic patient record system and a patient portal*






KIDS VIRTUAL CONFERENCE 2020

SATURDAY NOVEMBER 7, 2020

- PROGRAMMES FOR THE DAY -

Cubs (Ages 4 – 7) 11:00 – 11:55 <ul style="list-style-type: none"> • Draw What You Hear • Wildlife Adventure • Crazy Quiz • Lets Talk About Teeth 	Kidlink (Ages 8 - 12) 12:00 – 12:55 <ul style="list-style-type: none"> • Draw What You Hear • Travel The World From Your Couch • Crazy Quiz • Making A Movie! • Name That Veg • Time To Exercise 	Youth (Ages 13 - 17) 13:00 – 14:30 <ul style="list-style-type: none"> • Draw What You Hear • Travel Ireland From Your Couch • Crazy Quiz • Making A Movie! • Guest Talk • Time To Exercise
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FOR MORE DETAILS, PLEASE CONTACT ROBERT ON 01657 9900 OR ROBERT@HAEMOPHILIA.IE

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info@haemophilia.ie
haemophilia.ie

Advanced Nurse Practitioner, Haemophilia. What is this role all about?

Niamh Larkin has been appointed Advanced Nurse Practitioner, Haemophilia in The National Coagulation Centre (NCC). We would like to take this opportunity to congratulate Niamh on her new appointment

As the position is a totally new creation, we decided to get Niamh to explain her new role in more detail, and what it is all about.

The National Haemophilia Council (NHC) is a statutory body and is an advisory to the Minister for Health, Department of Health and the Health Services Executive and who advice on the design and operation of haemophilia services in Ireland. The National Coagulation Centre (NCC) is internationally recognised as a leading haemophilia service. An external audit of the NCC by an international team of clinical experts in haemophilia, including physicians, nurses, scientists and patients recommended the development of an Advanced Nurse Practitioner (ANP) in Haemophilia.

The development of an ANP post in Haemophilia has been a priority for the NHC and the National Coagulation Centre (NCC) over the last few years. Finally, in late 2019, following many routes of enquiry and applications for funding, the ANP Haemophilia post was approved in St James's Hospital.

The Nurses and Midwifery Board of Ireland (NMBI) describe the role of ANP as a group of advanced practitioners who are experienced skilled senior decision makers and autonomous practitioners who work independently to provide skilled competent care to patients. To register as an ANP in Ireland requires multiple qualifications and vast experience in your speciality. The candidate requires a qualification to Masters level, to hold a post Certificate in Advanced practice and be registered as a nurse prescriber. This qualification process involves commitment to the field of experience and commitment to continued education over time (Neville & Swift, 2012). Following completion of this, a portfolio which is evidence of qualifications and supervised practice are presented to the NMBI for consideration for registration.

I applied for the role as ANP Haemophilia when advertised and commenced my new role in late February 2020. The ANP Haemophilia is a whole new role which will continuously evolve. The initial aim of the role is to:

1. Develop and manage Haemophilia rapid access clinics. These clinics will allow for direct access to the ANP who can provide these assessments either directly in the NCC or via video link.
2. ANP Haemophilia nurse led clinics. These clinics are delivered in a combination of tele clinics and face to face clinics.
3. Co-ordination of product switches and providing post switch clinical reviews.

The main benefits of the ANP Haemophilia are the ability to improve continuity of care for people with haemophilia in Ireland (PWH). PWH will have improved access to expert care in a more prompt and streamlined way through tele clinics and rapid access clinics. The ANP Haemophilia nurse led clinics will aim at key indicators to optimise health and patient outcomes, targeting patient education, optimising treatment regimens and health promotion in view of optimising treatment regimens for managing chronic conditions. The ANP Haemophilia has the skills to assess bleeding episodes, decide on treatment schedules, prescribe medications and radiological investigations, refer to other disciplines and support PWH with issues relating to their haemophilia.

Contacting the ANP can be done via email nlarkin@stjames.ie or mobile on 087 9010301. In the event of a bleeding episode or urgent care please contact the NCC directly on 01 416214.

Niamh Larkin



Noticeboard



Fundraising Update

Congratulations to Elva O'Neill, one of our young members for her recent fundraiser in aid of the Irish Haemophilia Society. Elva kindly wanted to donate some of her hair to a fantastic charity called the Rapunzel Foundation that makes wigs for people suffering from Alopecia and raise funds for the I.H.S. at the same time.

So on the 4th August, hair appointment made and facemask on, Elva had 14 inches cut off her hair to help others and she also looks great with her new hairstyle. Elva raised a total of €303 in aid of the I.H.S., so a big thank you to Elva from everyone in the I.H.S. for her wonderful support.

HAEMOPHILIA & VON WILLEBRAND DISORDER: AN ESSENTIAL HANDBOOK FOR PARENTS



Parents Handbook

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

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

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

If you would like a physical copy, please contact the office on 01 657 99 00. For a digital copy, see haemophilia.ie or scan the QR Code





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