# Haemophilia.ie

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

Magazine of the Irish Haemophilia Society

**The Society at a Glance**

607 e-ZIne Subscribers

74 I.H.S. Volunteers

46 Planned Giving Contributors

1590 Facebook Followers

1172 Twitter Followers

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# FROM THE EDITOR

I hope you are all well and like all the I.H.S. staff, are looking forward to Christmas!

2021 has been another trying year but when compared to 2020, there is much more cause for optimism.

Looking to next year, over on Page 3, you can see the provisional programme for our AGM & Conference 2022, which will take place in the Slieve Russell Hotel, Cavan in March.

In his CEO Report on Page 4 Brian looks back at our October Conference and provides updates on Gene Therapy and revamping of our website, haemophilia.ie. Also, on Page 12, Brian recalls when Dublin hosted the WFH World Congress in 1996.

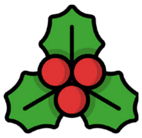
Elsewhere, on Page 7 there is news of educational grants awards for 2020, a report from the October Conference, our first in person event since the AGM in March 2020 on Page 8 and on Page 10, Feargal Mc Groarty provides an update on the National Haemophilia Lighthouse Project and Patient Portal.

On page 14 and 15, there are useful updates and news, and over on the back cover, you'll find hospital opening hours for the Christmas period. I would like to thank everyone who contributed to our publications this year - be that writing articles, sending in ideas, photos or feedback - and of course, thank you all for reading the magazines, without you, there would be no magazine!

Wishing you all a very Happy Christmas and a healthy and prosperous New Year.

Barry

## IN THIS ISSUE



# AGM & CONFERENCE 2022

MARCH 4 – 6, 2022 I – SLIEVE RUSSELL HOTEL, CAVAN

## PRELIMINARY PROGRAMME

### Friday March 4th

| | |
|---|---|
| 20.00 | Buffet Dinner |

### Saturday March 5th

| | |
|---|---|
| 10.00 - 12.30 | Annual General Meeting |
| 12.30 - 13.30 | Lunch |
| 13.30 - 14.30 | Update on Current and Novel Therapies - The Next 5 years |
| 14.30 - 15.30 | Gene Therapy - Yes or No |
| 15.30 - 16.00 | Coffee Break |
| 16.00 - 17.00 | The I.H.S. Physiotherapy/Exercise Programme – A Year of Experience |
| 20.00 | Gala Dinner |

### Sunday March 6th

| | |
|---|---|
| 10.00 - 11.00 | Experience with Emicizumab in Children and Adults in Ireland |
| | Parallel Session |
| 10.00 - 11.00 | von Willebrands Disorder - Treatment in the Next 5 Years |
| 11.00 - 11.30 | Coffee Break |
| 11.30 - 12.30 | Open Forum |
| 13.00 | Buffet Lunch and Depart |

More details will be posted to members in the New Year

# CEO Report

## October Members Conference

It was wonderful to meet up with members in- person at our recent October members conference. This was our first in- person event since the start of the pandemic and our Annual Conference and AGM on March 6 to 8 2020. By necessity, the October event was limited to adults - we were unfortunately unable to facilitate the attendance of children, teenagers and the large number of volunteers we would have required to run these programmes. A total of 33 members, 8 speakers & 5 staff attended. All were fully vaccinated and all the relevant Society and hotel Covid policies were complied with.

The sessions were very well attended and the Physiotherapy / Exercise class on the Sunday morning was a great success with 26 people participating. This particular session was also meant to be a taster for our on-line Physiotherapy / Exercise class and indeed several attendees signed up that day for either our men's and women's classes on-line. What was particularly comforting was to see how quickly members slipped back into animated conversation with each other, how they interacted and how they clearly enjoyed each others company. We are planning to host the AGM and annual conference on March 4 to 6 2022 as an in-person event. We fervently hope to be in a position to have adults, teenagers, children and babies all attend with our excellent volunteers. Prudent planning requires that we also plan a virtual conference as a back up option but I know we all hope to be seeing all of you in person next March.

## Society Website

The Society have been working with a specialist company over the past months on a total re-design of our website. As part of this, we are also auditing and updating all of the current content. We plan to roll out the new website early in 2022 and certainly prior to the Annual Conference and AGM.

Watch that space.

## Gene Therapy

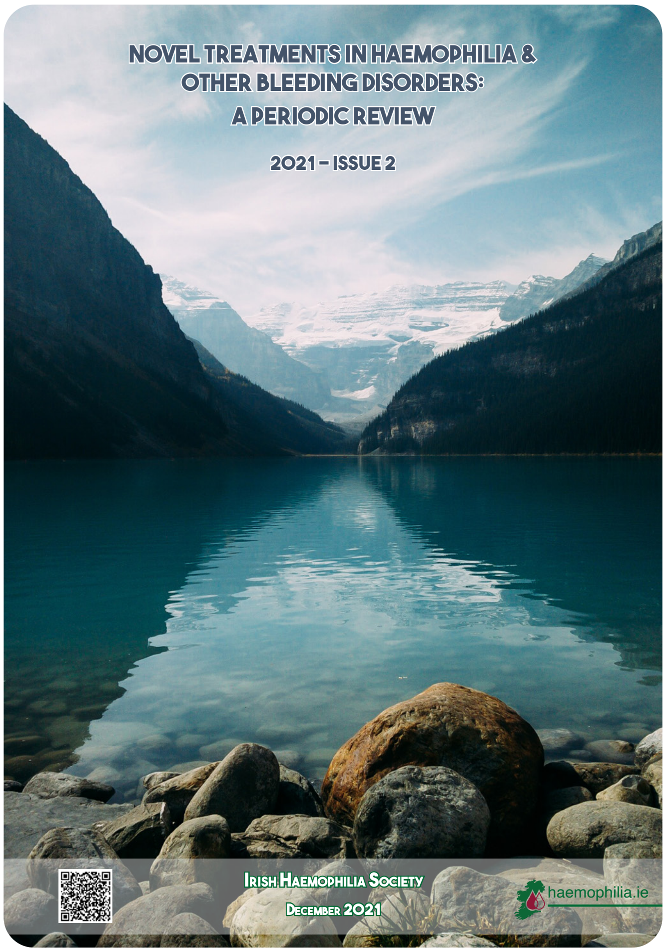
Members will be aware that much progress has been made with Gene Therapy clinical trials for people with haemophilia in the past number of years and indeed we have 3 people with Haemophilia B in Ireland who have been participating in a Gene Therapy clinical trial since early 2020. It is anticipated that the first Gene Therapies for Haemophilia A and Haemophilia B may well be licenced by the European Medicines Agency in late 2022 or early 2023. Unlike other haemophilia treatment options, Gene Therapy will be a one-

off treatment. The Gene is delivered in a viral vector delivery system. This means that anyone receiving the Gene Therapy will develop antibodies to the viral vector used to deliver the Gene, thereby preventing re-treatment on a future occasion. Gene Therapy may be a treatment option for a proportion of people with severe haemophilia. It will not be suitable for children, for those with pre-existing antibodies to the viral vector being used or for those with serious liver disease or inhibitors.

These obstacles may be overcome in the future. This does mean that, as a treatment option, some 40% to 50% of those with severe haemophilia may be theoretically eligible. At the recent October members conference, we organised a very productive information session and workshop where those in attendance had to think through some of the issues they would look at when examining Gene Therapy as a future personal treatment option. We will be keeping a very close eye on the ongoing clinical trial results as they edge closer to licencing. This is an exciting therapeutic area with significant progress reported and significant uncertainties remaining including what factor level one can expect after Gene Therapy and how long that factor expression may last.

A major issue will be how Gene Therapy is paid for. Gene Therapy will be a one time infusion with a degree of uncertainty on how long an individual may derive a beneficial therapeutic impact. A one time payment model may not be ideal in this scenario and may also have significant potential budget impact.

Other payment models, spread over several years and including specific outcomes or measures are also being examined. The Society have commissioned a Gene Therapy Business Case which we have forwarded to the Department of Health and the Health Service Executive. The business case was drafted by the Society CEO Brian O' Mahony, Health Economist Declan Noone, NCC Director Dr Niamh O' Connell and Chair of the National Haemophilia Council, Brian Fitzgerald. We are keen to be innovative, forward thinking and timely in looking at the financial viability and options for availability of Haemophilia Gene Therapy in Ireland.



NOVEL TREATMENTS IN HAEMOPHILIA & OTHER BLEEDING DISORDERS: A PERIODIC REVIEW

2021 – ISSUE 2

Irish Haemophilia Society

December 2021

haemophilia.ie

## Novel Products and Inherited Bleeding Disorders

A new edition of the Novel products report has just been produced by the Society.

Copies have been forwarded to some members and the full report is also available from the publications section of the website. If this is a publication you would like to receive a hard copy of, now or for future editions, please let us know. This is a publication produced twice annually by the European Haemophilia Consortium (EHC) with input from a working group including EHC President Declan Noone and Society CEO, Brian O'Mahony. Other contributors include Prof. Flora Peyvandi from Milan, current President of the European Association for Haemophilia and Allied Disorders (EAHAD) and the past President of EAHAD, Prof Mike Makris (both of whom will present at the Society conference next March). The range and depth of new products under development for haemophilia, von Willebrand's and other inherited bleeding disorders is breath-taking. If we look back 10 years, new products under development could have been easily summarised in a 2 page document. Now, we need a 36 page report to give an overview of the products under development and updated information on real world use of new products used for the first time in the past 5 years (including extended half life factor concentrates and Hemlibra).

The new products under development include:

- New improved extended half- life factor concentrates
- New bi-specific antibodies
- Rebalancing types of agents which decrease the natural anti- coagulants in the coagulation system and assist in blood clotting from the opposite direction to factor concentrate infusions
- Gene therapy
- Implantable spheres which can theoretically be implanted in the gut and release FVII, FVIII or FIX
- Gene editing

Not all of these products or concepts may make it to market as licenced products but many will. Where there are limitations or problems, these are being worked on. We have seen a lot of change in the treatment of haemophilia in the past 5 years with the availability of extended half life FVIII and

FIX and the bi-specific antibody, Hemlibra for FVIII as an option. I have little doubt that the next 5 years will see even more innovation with many of these novel products, including the first Gene Therapies being licenced.

Progress has been slower for von Willebrand's and for rare bleeding disorders. We do now have the first licenced recombinant von Willebrand factor as an option. At the recent National Hemophilia Foundation workshop on Novel Technologies and Gene Transfer in the USA, an invited audience of scientists, researchers, clinicians and patient leaders had 2 days of enthralling discussion on current and future developments in addition to detailed discussions on solving the problems hampering developments in these therapeutic areas.

There was a heavy focus on solving issues such as pre- existing immunity to the Gene Therapy viral vectors which of course limits the number who may avail of this therapy, optimising production of the viral vectors, targeting the vectors more accurately to optimise response and using next generation non-viral vectors such as lipid nano particles to deliver gene therapy. There was also discussion on early but promising work on Gene Therapy for von Willebrand disorder and on how existing viral vector models could potentially be adapted for use with rare bleeding disorders.

The horizon for future treatments is very bright but this does require that people with Haemophilia or other bleeding disorders need to develop a sufficient understanding of the different treatments or options in the future to assist them to make an informed therapeutic choice in collaboration with their haemophilia treater as part of a shared decision making model. The Society is determined to play a key role in assisting all of you to become more familiar with these future options especially as they come closer to licencing and becoming available on the market. We will have the responsibility to produce information for you which is both comprehensive and comprehensible for different levels of prior knowledge. We will use tools including publications, website, infographics, videos, apps and other media to get the information to you to assist you in making the best decisions possible for you or your child in the future.

Brian O'Mahony,
Chief Executive

# EHC Educational App EHCucate

The new educational app from the EHC, EHCucate, has gone live and you can download it to your device from the iOS App Store and Android Google Play.

With the sheer volume of information on rare bleeding disorders and novel therapies, looking for answers can feel overwhelming, complex and confusing!

This is why the EHC has processed years of research and publications from reliable and specialized sources to create EHCucate – an educational and dynamic app tailored to you!

The App provides info in an accessible and engaging way with easy navigation and comes with an extensive glossary of terms.

You can bookmark elements you want to add to your library, improve your knowledge and test your understanding with many quizzes, explore a variety of in-app media, track your progress, check our suggestions for further exploration on your topics of interest.

EHCucate is the ultimate resource repository and educational tool for patients, patient advocates and anybody interested in novel therapies for rare bleeding disorders.

You can now download it on your device from the iOS App Store and Android Google Play.

# Educational Grants 2021

I am delighted to announce that the recipients for the Educational Grants for 2021 have been chosen. Thanks to everyone who sent in applications. This year we received a total of 26 applications. The sub-group of the board met in October to discuss and score all the applications, after which a final decision was reached. A total of €17,450 was paid out.

The recipients of the main awards are as follows:

### Maureen & Jack Downey Educational Grants

| | | |
|---|---|---|
| First Place | Peter Walsh | €4,000 |
| Second Place | Molly O'Mahony | €2,000 |
| Third Place | Eimear Farrelly | €1,000 |

### Margaret King Educational Grants

| | | |
|---|---|---|
| First Place | Dara Dowling | €2,000 |
| Second Place | Aaron Flanagan | €1,000 |
| Joint Third Place | | |
| | Aoife O'Connor & Elva O'Neill | €500 each |

### Father Paddy McGrath Educational Grant

| | | |
|---|---|---|
| First Place | Daniel Hanney | €1,000 |

We were also delighted to be in a position to give some additional smaller grants to those who applied. I would like to encourage as many of you as possible to apply next year, it's really worthwhile and beneficial, and can really help cover the cost of perhaps travel expenses if you are studying away from home or those very expensive books!

Debbie Greene

# October Conference 2021

Our Member's Conference took place over the weekend of October 15 to 17 in Mount Wolseley Hotel, Carlow. It was a much smaller event this year which made for an intimate, more casual and relaxed vibe. It was just fantastic to finally do an in person event after so long - our first since our AGM in March 2020, which is hard to believe.

Attendance was limited to adults who were fully vaccinated. A total of 33 members were in attendance together with the Society staff and our guest speakers. The weekend was a great success and it was wonderful to see members engage in conversation, debate and participating in the sessions.

The programme began with a discussion on lessons learned from the pandemic with Dr Beatrice Nolan, Dr Alison Dougall, Declan Noone and Brian O'Mahony. Among the lessons learned were the benefits of telemedicine and virtual consultations, the ability to deal with some dental emergencies virtually and the success of the Society organized virtual Physiotherapy/Exercise programme.

Following on the same theme, we then had a presentation of the patient portal from Fergal McGroarty and Rachel Bird from the NCC at St. James's Hospital. The talked us through the project thus far and spoke of their hopes for its future. The portal is ready for testing by a small group of people with haemophilia and will shortly be more widely rolled out. Several constructive proposals on future content and use were made by members during the discussion that followed. (You can read a detailed update on the Lighthouse Project on Page 10.

After a spot of lunch, Declan Noone and Brian O'Mahony then facilitated a session where members were brought through all the potential treatment options in the next 5 years and they had to look at which treatment they would choose based on their experience of haemophilia, their current and desired activity levels and their quality of life. This was a very interactive session which those present really enjoyed. It was the start of a process of interactive education we will continue as the treatment landscape for the future is varied and exciting.

Saturday finished with a robust debate between members Jim O'Leary and David Flanagan on which was best; virtual or in-person clinics. Both made a strong case for their preferred option but the resulting vote was a tie which perhaps demonstrates that a hybrid world of virtual and in-person clinics and consultations will be the future.

Sunday kicked off with an update on the Society communication strategy and social media from Brian O'Mahony. It was interesting to take stock of how the society's digital communications have grown in recent years, a trend accelerated by the pandemic. This was followed by an in-person Physiotherapy/ Exercise class with Haemophilia Physiotherapists Sheila Roche and Mark McGowan from the NCC. This was an in-person version of the virtual classes that Sheila and Mark have been facilitating for members for the past several months.

Yoga mats and TheraBand's were provided for those attending and they went through a 45 minute class. The attendance was excellent and indeed following the class, a number of members expressed their interest in joining the online sessions.

As well as the engaging and informative sessions over the weekend, it was great to catch up with members and staff over the weekend – something that the smaller number facilitated very well -it was really nice to see our community back engaging in person.

In saying that, we missed all of you who couldn't attend but we really hope to see you next year. The same goes for our invaluable volunteers and the Children's & Youth Groups; we are planning the return of the Children/Youth Programmes for the AGM in 2022.

All in all, it was a great weekend and we hope that everyone who attended felt so too. We very much look forward to seeing the entire community back at our AGM and Conference in March 2022.

I.H.S. Staff

# Update on the National Haemophilia Lighthouse Project and Patient Portal

The National Haemophilia services have always been at the forefront for delivering innovative care to our patients. Since 2002 we have been building a connected service using technology as a tool to improve how we deliver care to you in the best way possible.

Building on from the implementation of a gold standard CFC delivery service from TCP, as well as the introduction of the first national Electronic Health Record (also known as an EHR) in Ireland and a barcode medication scanning App, which was the first in the world, the National Haemophilia Service was selected by the HSE to develop and showcase further advancements on care delivery

## "The Patient will see you now"

Having completely rebuilt the electronic health record, which is called "indici", the next natural step for us was to work with the haemophilia community to develop a Patient Portal called "Myindici Patient Portal". This online tool is focused on giving patients a window into their own health by providing access to healthcare data anytime, from anywhere in the world. We have had fantastic support and help from the IHS, and a focus group of members has worked with us to bring this exciting initiative to life.

## What is a Patient Portal?

A Patient Portal is a secure personal health record. It is used to empower you to play an active role in your health and wellbeing, you can use it to view key information directly from your electronic health record as well as access information that is relevant to your condition, such as education articles, videos, and links to other websites. Not all features on the portal will be available to all patients initially but, in general, you will be able to view health information such as:

- Diagnosis
- Treatment of Choice
- Clinic letters (including travel letters)
- Patient educational material and videos
- Appointment history (if your coagulation treatment centre is using indici for scheduling)
- Any immunisations you received in your treatment centre.

As time goes on, and with your help and feedback, our intention would be to introduce more and more features that will improve the Portal.

## Is my information safe?

Data protection is a challenging for every organisation, but no more so in healthcare. In general, hospitals have tried and tested methods for giving healthcare providers access to data, but giving patients routine access to and control over data is new, and the repercussions from any mistakes could be be daunting.

For that reason, from the very start of this initiative, we engaged with the HSE and the Data Protection Officers from all the Treatment Centres. We proceed slowly and carefully to make sure we were compliant with all Data Protection legislation.

Similarly, we worked with the Patient Portal provider to ensure that the website was secure and that it couldn't be hacked. The website has been fully tested and has been certified as being secure and we will continue to test the system periodically.

## What happens next?

At the initial launch of the portal we will be contacting a small representative group of patients to ask for their help by downloading the Myindici Patient Portal and trialling it for a number of weeks and then giving us their feedback using a patient survey questionnaire.

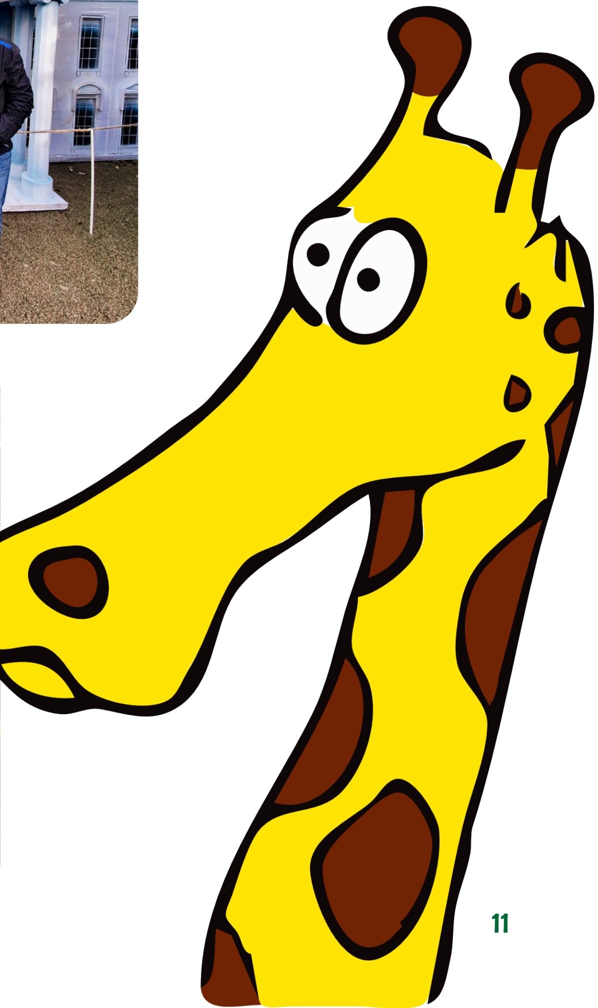
Based on that feedback and as the portal project advances, more patients will be invited to sign up and new features and functionality will be added. It is hoped that in the future portal users will be able to use their portal account as a "health vault" to store and add their own health information from other sources. Again, we will need to make sure that all data protection and website security measures are in place before we do that, so please bear with us.

We are really excited to be working with you on this cutting edge initiative and as the project continues we'll keep you updated as we progress. Wo look forward to your feedback on what we're doing so that the national coagulation service can continue to be regarded as a national and international leader on the provision of quality healthcare to our patients.

Feargal McGroarty
Project Manager
National Haemophilia System

# FAMILY TRIPS TO DUBLIN ZOO

We were delighted to be able to provide members free family passes for Dublin Zoo earlier in the year and we hope you all enjoyed your visit - judging by the photos, you had a great time!



# THE WEEK THE WORLD CAME TO DUBLIN:

## 25TH ANNIVERSARY OF THE WORLD FEDERATION OF HEMOPHILIA (WFH) CONFERENCE IN DUBLIN, JUNE 23–28 1996

It is hard to believe that it is now 25 years since the Society hosted the WFH International Congress in Dublin in 1996. The Congress was awarded to Ireland after a competitive bidding process held during the WFH Congress in Athens in 1992. We lobbied hard and were successful in getting the votes to bring WFH to Dublin in 1996. Fortunately, we had a four year lead in as this was a huge undertaking and the largest haematology conference ever to be held in Ireland.

We set up a very small organising committee with dentist and board member Dr. Barry Harrington, the then Administrator Rosemary Daly and the then Chairman of the Society Brian O Mahony. The small group meant we could meet and communicate frequently and take decisions quickly. This, together with the input from the excellent Conference Organising company allowed us to promote the conference optimally, achieve sponsorship greater than any past WFH Congress and build momentum toward a great event. I was especially pleased that, for the first time ever, we were successful in getting sponsorship to allow us to sponsor travel grants for delegates from many developing and emerging countries.

The Conference – with the theme of "From Care to Cure"- was a major success. The attendance was a record 2,200 people (the previous record was approximately 1,400) with doctors, scientists, nurses, physiotherapists, psychosocial professionals, people with haemophilia and industry all present in large numbers. The scientific programme was excellent with all sessions being very well attended. The conference was held on the University College Dublin campus which also afforded us the opportunity to use student accommodation for some delegates who could stay on- site at a relatively low cost. I do recall we had a large delegation of people with haemophilia from India who were attending a WFH Congress for the first time. The student accommodation also meant that people with haemophilia from many countries were able to meet socially during the week and form friendships and contacts, many of which endured.

The General Assembly of the WFH where the official delegates meet and vote on global WFH policies met on the Wednesday in Dublin Castle and it was a thrill to see all the national flags arranged around the table and see the representatives of all the National Haemophilia patient organisations globally here in Dublin. We were delighted that then President Mary Robinson agreed to open the Conference and after her opening remarks, she met informally with the delegates from the National Haemophilia Societies.

It was an unforgettable week in so many ways. The science, symposia and lectures were first class. The atmosphere was wonderful. The social events were great- including an early performance of Riverdance at the opening ceremony. The attendance set a new high bar for the WFH and indeed, our organisation of the Congress became the playbook for future WFH Congresses. The financial aspects were also very rewarding for the Society. We controlled costs very well and maximized income. The led to a significant profit for the WFH and also for the Irish Haemophilia Society. We invested the profit from the Congress and then in 2007, this was used as the main funding for the purchase of the Society offices at Cathedral Court. In many ways, the congress contributed to our future.

I have strong and vivid memories of all the work, meetings, presentations and organisation leading up to the Congress. Not least was the difficulty of hosting a conference in a venue which was not a purpose built conference centre and dealing with all the bureaucracy that entailed. Ironically, given all the work that went into the organisation, I suffered a recurrence of Malaria the evening before the conference began and had to work on auto pilot for the first three days. (I contracted malaria three months prior to the Conference as a result of a trip for WFH to Zimbabwe and Zambia). I had recovered sufficiently by day three to really enjoy the rest of the conference. The conference formally closed on the Friday with a Congress gala dinner the previous evening attended by 900 delegates. (That also happened to be my wedding anniversary so it was a memorable anniversary).

We had proposed to Bord Failte and others at that time that Dublin needed a purpose built conference centre. Sadly, that took many years to materialize and the new Dublin Convention centre as finally built is too small to now accommodate a WFH Congress again with numbers trending up to 5,000 delegates. We had expressed an interest and bid to host WFH in 2018 but the Conference Centre did not have the capacity.

In a Covid and post covid era, that may change as Conferences move to a hybrid model with some virtual attendees and some in- person. Who knows? Perhaps in the future we can host another WFH Congress. It is promising that with Gene Therapy now firmly on the horizon, although not a cure, we are getting closer to a cure and to perhaps fulfilling the theme of our Conference, now 25  years in the past, but which seems like yesterday

Brian O'Mahony

XXII International Congress of the World Federation of Haemophilia
"From Care To Cure"
*University College Dublin, Ireland June 23-28 1996*

XXII INTERNATIONAL CONGRESS

**Patron**
*Mary Robinson President of Ireland*

**Congress President**
*Ian Temperley*

**Vice Presidents**
*Elizabeth Mayne*
*Brian O'Mahony*
*Ian Peake*

**Organising Committee**
*Barry Harrington (Chairman)*
*Rosemary Daly*
*Brian O'Mahony*

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SCIENTIFIC PROGRAMME

**Plenary Papers**
Blood Product Provision
The Future of Recombinant Factors
Haematologic Management - Treatment in the Developing World
Orthopaedic Management
Modern Concepts of Haemostasis
The Genetics Basis of Inhibitors
VWF & Platelets in Haemostasis
Molecular Genetics of Haemophilia

**Symposia**
Transfusion Medicine
Advances in Orthopaedic Care
Management & Prognosis of Blood Borne Viruses
Management & Control of Inhibitors
Recombinant Products
Von Willebrands Disease
Gene Therapy & Animal Models
Transfusion Transmitted Disease
Behavioural Sciences
Reproduction and Bleeding
Economics of Health Care

**Psycho-Social Programme**
Meet the Experts Session
Venous Access
Exercise and Sport
Stress Management
HIV - 15 Years On
Pain
Partnerships in Care
Communication Skills
Coping with Loss

National Members Organisation Sessions:
  Skills Manual
  Developing World
  Future of Societies
  Meet the NMO's

Patient Discussion Groups:
  Ageing
  Newly Diagnosed
  Adolescents
  Coping with HIV & Hepatitis

CALL FOR PAPERS

The official Call for Papers will be included in the next Announcement scheduled to be issued in November '95, which will include full information regarding submission of abstracts including the official Abstract Submission Form. The deadline for receipt of abstracts for Free Communications, both oral presentation and poster display will be January 15, '96.

CONGRESS VENUE

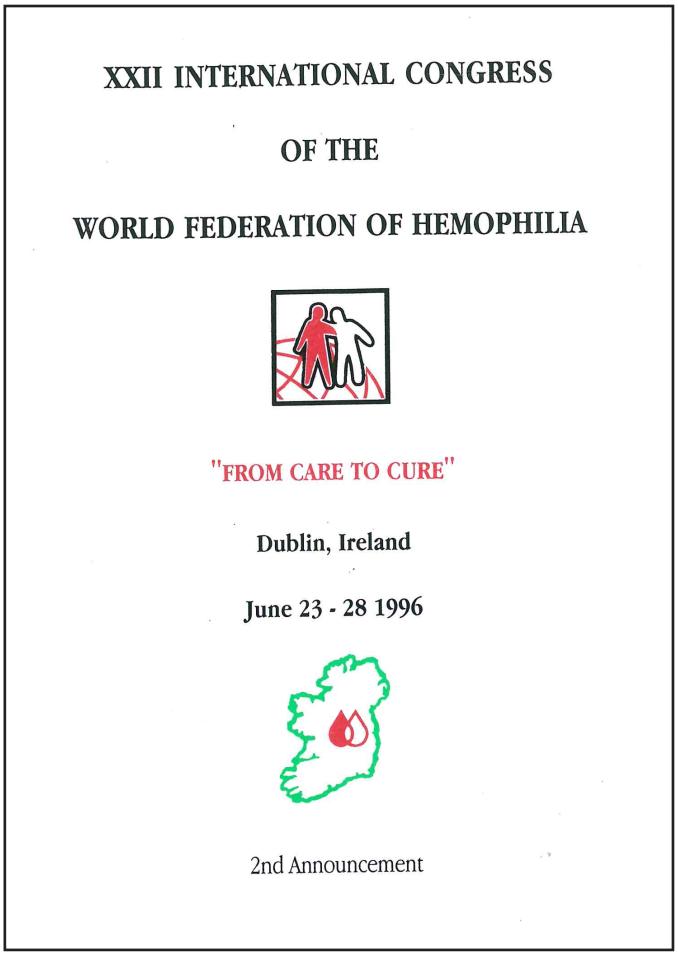
The Congress will be held on the University College Dublin's campus at Belfield, located about 8km from the centre of Dublin, the capital of Ireland. Accommodation, including wheelchair accessible rooms, will be available on campus.

COMMERCIAL EXHIBITION

There will be an exhibition of pharmaceutical products related to Haemophilia, as well as medical and laboratory instruments, at the Congress site in conjunction with the Congress.
Special Trade Symposia will also be held.

FURTHER INFORMATION

This may be obtained from the:
**Haemophilia Congress '96 Secretariat**
**c/o Conference Management Services**
**26 Temple Lane, Dublin 2, Ireland**
Tel: (+353) 1 6797655
Fax: (+353) 1 6792469
Email: 73173.1245@CompuServe.com



XXII INTERNATIONAL CONGRESS
OF THE
WORLD FEDERATION OF HEMOPHILIA

"FROM CARE TO CURE"

Dublin, Ireland

June 23 - 28 1996

2nd Announcement

# 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**

## Join our E-zine Readership!

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

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

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.

**Irish Haemophilia Society**
**First Floor, Cathedral Court,**
**New Street, Dublin 8**
Tel: +353 (0)1 657 99 00

@irishhaemophiliasociety
@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.

# NOTICEBOARD

Nominations are now open for the Brian O'Mahony Award for outstanding contribution to haemophilia care in Ireland.

Nominations can only be proposed by members of the society and members of the current board or staff cannot be nominated.

If you would like to nominate someone who, in your opinion, has made a real difference in haemophilia care in Ireland, please send your nomination to info@haemophilia.ie

The deadline for nominations is January 21, 2022.

## Congrats Jason!

Jason Rossiter has added to his already impressive collection of medals!

Jason was captain of the winning Oulart The Ballagh U15 Premier Division 1 hurling team on Sunday 10 October. Jason and his teammates have won four county titles; two U13s and two U15s premier titles.

In the words of his Mam, not bad going for someone with severe haemophilia.

## 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 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 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 Debbie 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.*

# Provisional Hospital Opening Hours for the Christmas Period

## National Coagulation Centre & H&H Assessment Unit – St. James's Hospital

Thursday 23 December 2021 - as normal (8.30am - 5pm)
Friday 24 December 2021 - closed
Saturday 25 December 2021 - closed
Sunday 26 December 2021 - closed
Monday 27 December 2021 - closed
Tuesday 28 December 2021 - closed
Wednesday 29 December 2021 - closed
Thursday 30 December 2021 - closed
Friday 31 December 2021 - closed
Saturday 01 January 2022 - closed
Sunday 02 January 2022 - closed
Monday 03 January 2022 - bank holiday service

**Normal services from Tuesday, January 4, 2022**

*The walk in assessment unit in H&H will operate as per out of hours and weekends with 24 hour cover. Out of Hours Service Phone: (01) 410 3132 (after 5pm Monday to Friday, and at weekends or bank holidays).*

*Patients who need emergency assessment or advice should phone the H&H Ward prior to attending, or alternatively contact St. James's Hospital via the main switchboard on 01 410 3000 and ask for the haematology SHO on call.*

## Cork Coagulation Centre - Cork University Hospital

Thursday 23 December 2021 - as normal (8am- 4pm)
Friday 24 December 2021 - closed
Saturday 25 December 2021 - closed
Sunday 26 December 2021 - closed
Monday 27 December 2021 - closed
Tuesday 28 December 2021 - closed
Wednesday 29 December 2021 - closed
Thursday 30 December 2021 - closed
Friday 31 Decemeber 2021 - closed
Saturday 01 January 2022 - closed
Sunday 02 January 2022 - closed
Monday 03 January 2022 - closed

**Normal services from Tuesday, January 4, 2022**

*The Haematology Registrar is on call throughout the holiday period and can be contacted through the CUH switchboard at 021 454 6400.*

## Children's Health Ireland at Crumlin

Thursday 23 December 2021 - as normal (8am- 5pm)
Friday 24 December 2021 - closed
Saturday 25 December 2021 - closed
Sunday 26 December 2021 - closed
Monday 27 December 2021 - closed
Tuesday 28 December 2021 - limited elective activity
Wednesday 29 December 2021 - limited elective activity
Thursday 30 December 2021 - limited elective activity
Friday 31 Decemeber 2021 - limited elective activity
Saturday 01 January 2022 - closed
Sunday 02 January 2022 - closed
Monday 03 January 2022 - bank holiday service

**Normal services from Tuesday, January 4, 2022**

*FYI: The Haematology Oncology Service always remains open but the Haematology Oncology Day Unit & Service only operates Monday - Friday & closes for public holidays.*

*In the case of an emergency, please contact the hospital on 01 409 6100 and ask for the haematology registrar on call.*

The Irish Haemophilia Society office will close for Christmas at 2pm on Thursday, December 23 2021 & will re-open on Tuesday, January 4 2022 at 9am.

In the case of an emergency, please call 01 657 9900 where contact details for our emergency contact person will be found.

Wishing you all a very Merry Christmas & a peaceful New Year from the board & staff of the I.H.S.