

# HNI in Focus

## The Haemophilia NI Newsletter



## Haemophilia NI AGM/Education Day - 23<sup>rd</sup> March 2019

The first Haemophilia NI Education day took place at Crumlin Road Gaol on 23<sup>rd</sup> March. Members made the effort to come from as far away as Derry and Cookstown in order to take part in what was a great day for everyone. Attendees were treated to talks from Dr. Gary Benson (NI Haemophilia Centre Director) and Patricia McGrath (NI Haemophilia Centre Lead Social Worker) about current medical and psychosocial issues affecting the world of bleeding disorders.

We were also delighted to host a range of workshops in the afternoon looking at issues such as self-infusion and aging with Haemophilia. We were particularly pleased to welcome Helen Manson (Lead Nurse NI Haemophilia Centre) and Nancy Brodie from Haemophilia Scotland who made the trip across the Irish Sea to spend the day with Haemophilia NI.

People were also treated to a tour of Crumlin Road Gaol - Which dealt with the lighter side of prison life including amazing works of art produced by former prisoners to the darker elements such as the gallows where 19 men met their deaths.

Thanks for the day must also go to SOBI whose generous grant made a wonderful day possible.

Feedback from the day has been very positive and we look forward to hosting further educational events soon. For those who couldn't make it this time, you were certainly miss but we'll make sure to catch you next time!



Infected Blood inquiry hearings opened in Belfast this week. Writing after the first day of hearings – powerful, moving and at times damning accounts were given by local persons both infected and affected. This included Paul Kirkpatrick from Londonderry who spoke about his experience of contracting hepatitis B and C and the often “confused process of passing on life-threatening information to patients”. The daughter of a local man infected with HIV and hepatitis also spoke of her experience losing her father to complications of contaminated blood and the profound effect this had on the whole family; compounded further still by deficiencies in communication from medical professionals. The inquiry also heard how financial support for victims is disparate throughout the UK, often to the detriment of Northern Ireland. Submissions were also taken from the Department of Health. The inquiry hearings continue all this week.



## Fighting Bleeding Disorders One Marathon and Abseil at a Time!



*(Above) Haemophilia NI Belfast Marathon Relay Team - Left-to-right: Ruth McKeown, Brigid Campbell, Paddy Welsh, William McKeown, Declan Campbell, Rebekah Pearce. (Below) Left-to-right: Jill Johnstone, Sarah Cairns-Johnstone and Brigid Campbell showing no fear of heights after abseiling down the Europa Hotel!*



Bleeding disorders clearly haven't been holding back Haemophilia NI over the past few months as demonstrated by our members' enthusiastic fundraising efforts.

On 28<sup>th</sup> April Jill, Sarah and Brigid bravely took the plunge off the Europa Hotel to raise money for Haemophilia NI. At an eye-watering 167ft – this was certainly not one for the faint-hearted! (See left)

On 5<sup>th</sup> May the Haemophilia NI marathon relay team did us proud by completing the Belfast City Marathon in 3:50:10 – placing a very respectable 534 out of 2215 teams.

If you have an idea for fundraising or would like to get involved by fundraising yourself we would love to hear from you. Feel free to get in touch via email or Facebook – contact details below.

## Feature Article – Attending European Youth Leadership Workshop



**William McKeown (28) from Haemophilia NI and Josh Crombie (21) from the UK Haemophilia Society discuss their experiences at the recent European Haemophilia Consortium youth workshop in Amsterdam. Both suffer from severe haemophilia A and are aspiring young leaders in the haemophilia community.**

### What made you interested in attending the youth leadership workshop?

**William:** “I have been really involved in setting up Haemophilia NI which is a new local patient group in NI, completely separate and independent to the UK Haemophilia Society. I hoped by going I would pick up skills to help grow Haemophilia NI further.”

**Josh:** “After being involved in the UK Haemophilia Society for several years and seeing what other youth leaders had been able to do at meetings; I pretty much jumped at the chance to attend the workshop! I also saw it as a chance to get more involved in a community that means a lot to me both in England and now further afield.”

### What happened at the youth workshop?

**Josh:** “The first day we arrived, the only thing I remember was meeting everyone and falling asleep almost instantly when my head touched the pillow!”

**William:** “Josh took the very early morning flight out of Manchester, I took the much more sedate afternoon flight from Belfast. Definitely a good move.”

**Josh:** “When the workshop began in earnest, after my nap, we started with the obligatory and dreaded ice-breaker, which caused me so much panic when it was mentioned, I completely forgot what anyone said and desperately tried to come up with lines that didn’t reference haemophilia because that’s always my go to! After that we were introduced to what the EHC was and how it works, led by really interesting and passionate people. We were asked to give our input and to me it felt like we were being listened to more than any other panel I’ve personally been a part of.

On the second day we got to whet our acting chops which definitely tested our improvisation skills; trying to get 4 blokes to play the role of women! We were also given the chance to listen to and ask questions of industry professionals which gave a great insight into how to get the case for NMOs into the wider conversation with pharmaceutical companies.”

### What was the best part of the workshop and what did you learn about leadership?

**William:** “For me the best part of the workshop was the people. There were young leaders from so many different places but all united by the shared bond of bleeding disorders and a genuine desire to stand up for our communities. Attendees came from all over; France, Austria, North Macedonia and even as far afield as Kyrgyzstan - I had to check that one on a map! In terms of leadership, one thing that came across was the need always to be balanced, professional and try and engage members wherever they are at. Another element that came across to me is that leadership is hard to do well and being a leader does not mean being right 100% of the time – which was a relief to hear!”

### How do you plan to use what you have learned personally for Haemophilia NI?

**William:** “I have been taking on leadership roles in Northern Ireland over the past couple of years, but this has broadened my ambition and reminded me of how important it is to work with other groups nationally and internationally. It also showed me the real need we have for young leaders – our patient organisations need to think long term and future-proof by getting more young people involved – no offence to our more mature members...”

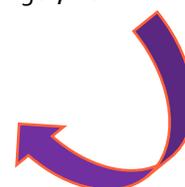
### What would you say to other young people thinking of getting involved with the youth ambassador programmes and EHC youth leadership workshops?

**Josh:** “100% go for it, don’t stop asking about them, they are brilliantly run and you make some good friends. You will have good fun and learn a lot so that you can be a more valuable asset to any programme you decide to join as well as giving you plenty of skills for jobs you might be interested in. “

**William:** “Northern Ireland needs young leaders and I totally agree with what Josh has said. If you are interested stick your neck out and get involved!”



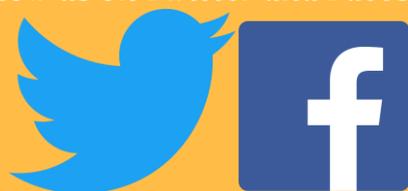
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