

# HNI in Focus

## The Haemophilia NI Newsletter



The Grattan Family having a fun time at the Christmas Trail.

(See left)



The Fratescus tucking into some toasted marshmallows!

(See left)



## CHILDRENS' CHRISTMAS ADVENTURE TRAIL

As Christmas has been fast approaching, Haemophilia NI has been embracing the festive spirit. Belfast Activity Centre hosted 40 of our members to visit their Christmas adventure trail on 8th December. Our members were brought around a Santa Adventure trail with the opportunity to toast marshmallows, meet the elves and even Santa himself!

It was a great opportunity for people affected by bleeding disorders, young and not so young, to get together with others going through the same experiences and all had a fantastic time.

The event was paid for by Haemophilia NI, but we also managed to raise £115 from generous donations on the day to put back into more fabulous events like this.

As you can see from the photos it was hard to tell if the adults or children were having more fun!

If you were unable to make it this time, we would love to see you at are next event – see our contact details below if you would be interested.



### CONTAMINATED BLOOD INQUIRY

The contaminated blood inquiry is ongoing in London. There have been promising mootings so far from the inquiry chair, Sir Brian Langstaff, who has vowed to put the 'infected and affected' at the heart of the inquiry.

Haemophilia NI continues to provide support to local people regarding the inquiry which at times has been wrenching and emotionally difficult for all involved. We have been able to offer free legal support to victims through the Watkin's and Gunn legal team and the contaminated blood sub-group.

Haemophilia NI will be attending meetings in Whitehall to push for interim payments to victims which address the disparity in financial support across the UK. Haemophilia NI representatives also plan to meet the prime minister in the new year along with representatives from other patient groups.

Haemophilia NI plans to host further local meetings for the inquiry in 2019.

If you want any further information regarding the above please email Nigel Hamilton at [nigelphamilton@yahoo.co.uk](mailto:nigelphamilton@yahoo.co.uk)

## HAEMOPHILIA NI EDUCATION DAY/AGM 2019 – 23<sup>rd</sup> MARCH 2019

*Haemophilia NI is a patient group which is separate and independent from the UK Haemophilia Society and seeks to support and advocate for local people affected by bleeding disorders.*

Haemophilia NI is planning to host a family education day on 23<sup>rd</sup> March 2019. This will take place at the Crumlin Road Gaol Conference Centre in Belfast. If you are affected by bleeding disorders and live in Northern Ireland then please come along and join us.

A broad programme reflecting the range of people affected by bleeding disorders is planned including talks and seminars on dosing medication, bleeding disorders in women, bleeding disorders in young people, and haemophilia in later life. This will run from 9am – 3pm on the day.

*'Empowering  
People with  
Bleeding  
Disorders  
through  
Education'*

In addition to our patient education events we will be holding our AGM to update members on our progress over the past 12 months at 3pm.

Places on the day will be limited so if you would like to attend our meeting then please register via our email before 1<sup>st</sup> March 2019. Alternatively you can confirm by phone on – 07938709599.



Haemophilia NI  
Supporting patients and families

**Members' AGM - 23<sup>rd</sup> March 2019**

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Contact Us

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Phone number: 07938709599

# Feature Article - Eóghan's Story

One of our younger members, Eóghan Campbell, wrote an article about his experience with Haemophilia which was published at the World Federation of Haemophilia this year in Glasgow.

Hi, my name is Eóghan. My age is 8 and I have two sisters, a mummy and a daddy (who are very nice). My school is called Phoenix Integrated primary school and I have a friend called Jayden (he is very funny and weird). This week in school I won the class certificate for quick recall in mental maths games. I have nine cousins called: Louis, Aoife, Leo, Erin, Luke, Jude, Zach, Noah and Chloe. I have haemophilia which means that I have to get injections three days a week. Once I was born, the doctors noticed that I had haemophilia.



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*“When I was in hospital, my daddy got me the new trainers I really wanted”*

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When I was 1 they had given me an operation to put my port in...I had to get injections for 5 years on my port! Then I went back to the hospital for another operation to get my port out. I had to stay in hospital for 3 days and two nights. Before my operation the nurse done 1 final injection in my port before they took it out. When I was in hospital, my daddy got me the new trainers I really wanted. It was a big surprise for me and that's when I learnt to tie my own laces. Fionnuala my nurse is very good and she taught my mum how to do injections in my arm. My mum was only ok at the start but now she's really fast and it only takes 20 seconds.

I love sport and football is my favourite. I play every Friday night for Cookstown Youth football team. Last week I won man of the match because I done good passing and tackling. My favourite football team is Chelsea.

I like playing music on the piano and I'm doing my Grade 1 exam in May. I'm hoping to get high marks to get a distinction so I'm practicing really hard. My favourite song is 'Shut up and dance' and I like to sing it really loud. I also like telling jokes E.G. what do you do if you see a spaceman?...Park in it man. Ha ha. Hope I made you all laugh!

Goodbye and have fun reading my story.