

The Annual Review of the Haemophilia NI 2022-2023

This proved to be a challenging and successful year and one which created growth and expansion throughout following a difficult period for every community organisation with COVID.

I have begun with our 2021 Christmas event which was an extremely successful event held at the Jungle NI in Moneymore on the 4th December. The day was well supported by families within our community with all the traditional fun for the families and lots of activities to gear into the Festive Spirit.

Prior to this event we had been advertising for our first big event in February over the weekend of 26-27th February 2022 at the Roe Valley Country Park which was well attended and proved to be a very successful event upon which to build upon.

This was a year which brought some positive progress and recognition from the Tory Government following the ongoing development of the Infected Blood Inquiry. In August one of the final decisions made by the outgoing PM Boris Johnson acknowledged the Inquiry Chair's request, Sir Brian Langstaff, for an Interim payment to those directly infected victims with a £100k payment. This was a further indication of the Government's bona fides in recognising the importance of financial compensation of the victims of this the worst NHS disaster.

Prior to this ground breaking commitment we had a very successful May Belfast Marathon and a vibrant and determined team keen to raise both awareness and funding. Special thanks to Ronan Smithson on being our star fundraiser. With a team of Ronan, Dean, John, William and Rebecca raising £500 towards our funds.

It was part of the Board's outreach and strategic development to engage with our sister societies and on the Irish Society in September in Dublin with a good attendance and an agreement to work closer together we were further encouraged in our purpose to help supporting families and patients into our immediate and long term future.

Our AGM was set for the 22nd October 2022 in the Templepatrick Hilton Hotel and the Board determined to host an Education Day with guest Speaker Brian O'Mahoney chairing our AGM and speaking to us on the concept and treatment of Gene Therapy with William McKeown talking about ageing with Haemophilia. Following the official responsibilities we sat in fellowship with those guests and members. Again we took the opportunity to raise some funds with a raffle which successfully raised £136 toward our funds. Our Chairman Simon Hamilton also gave an insight into the ongoing progress of the Public Inquiry and the engagement of HNI in both Hearings and the work of the Inquiry.

In February 2023 we held a Newly Diagnosed family weekend. This event was run in conjunction with the Haemophilia Society UK and proved to be a very successful event. This was a big endeavour at which we received considerable support from both the Adult and Children's units at the City and Royal Victoria Hospitals We had a packed conference with families coming from across NI and support from Scotland with one family and Scottish Society representative attending. Naturally the event required a Child care team and the expense and support from our funder. Gratitude also goes out to our Trustee

organisers who steered the weekend well and it proved to be a highly enjoyable get together for the families who could share their experiences.

In April we acknowledge the decision of the Dane District Council offices and the Alley Theatre lighting up to support and show solidarity with Access to all: Prevention of Bleeds as the Global Standard of Care.

The May 2023 Belfast Marathon was a greatly publicised event for our Society we had the support from a number of teams running for us from UTV teams who came out in numbers along with our committed team as a mark of respect for their Haemophiliac colleague Simon McGinnis who passed away earlier in the year. We were humbled and grateful.

The Haemophilia Centre had launched its 'My Haemophilia Centre' in May and this easily accessible service has been welcomed by our Charity and our members with our community.

May also saw International Nurses day and it helped us recognise the commitment and dedication of our local nursing team in our Haemophilia care, without whom we would find things both difficult and distant.

We celebrated World Haemophilia Day June 24th at the Ulster American folk Park, Omagh. The day involved entertaining the children before all families and guests getting together following informative we also held a self infusion session for those willing to engage. We had a great attendance and are grateful for the continued support from our funders. Our speakers were Dr Richard Gooding and Dr Charlene Neill. WE had very encouraging engagement in groups on members living with bleeding disorders.

July was a high point in the Infected Blood Inquiry with Sir Brian its Chair publishing his Compensation Report which drew continued support from the four Haemophilia Society Chairs writing a further letter to the Prime Minister to request commencement of the Compensation process to support and recognise victims both infected and affected.

The time for AGM had come around quickly and our equation of the previous year made it practical to again host the day the date 4th November at the Hilton Templepatrick was again a well attended event with our Chairman giving an impassioned speech on our activities throughout the year including outreach to our sister societies and the up to date on the Inquiry. Our guest speakers were Claire Forde Anna Wells with those present joining us for lunch and fellowship.

The 2023 Christmas event was again held at the successful Jungle's Winter Wonderland in Moneymore on the 2nd December. Again we found great support from families coming from as far as Enniskillen and south Down. This has proved to be a much welcomed event by our families and they have slotted it into their annual calendar as have we.

Christmas Day proved to be a sorrowful day for our Society with the sudden passing of our much loved Chair, Simon Hamilton. Simon was a shining light both in the development of our Charity Haemophilia NI and our broader Haemophilia family.

Simon's commitment to those with bleeding disorders and the more vulnerable in our community along with sufferers from the Infected Blood disaster was immeasurable and his loss has been very deeply felt throughout this Island and the UK.

It is a sad note to finish this report on but our existence as a charity and our foundation as a committed and open society will carry on his legacy into the long term future.