



Haemophilia NI  
Supporting patients and families

ANNUAL REPORT 2021-2022

Charity no. NIC107635

Haemophilia NI is a small charity run exclusively by unpaid volunteers and operate with small turnover of approximately £6500. We have a charity email address and receive post through a PO box address. We currently have 8 trustees: Simon Jonathan Hamilton, William McKeown, Carson Pearce, Rebekah Pearce, Colette Maria McAfee, Rachel Olliver, Nigel Hamilton, Sarah Kane. All of our trustees have regard to the Commission's guidance on public benefit and through this annual submission will report on the activities the charity has carried out to further its purposes for the public benefit.

Our purposes are:

- To further as a primary objective the health, education, wellbeing, and the social and economic welfare of all those in Northern Ireland with a bleeding disorder and their families.
- To further the health, education, and the social and economic welfare of the haemophilia and bleeding disorders community in Northern Ireland. And in furtherance thereof:
- To bring together individuals and organizations that share such interests.
- Where possible, to cultivate reciprocal relations with organisations that have similar aims, relevant health, social welfare and educational objectives or which may otherwise support or benefit Haemophilia NI.

Haemophilia NI received its recognised charitable status on 18/01/2021. It was formed to support the 'bleeding community' in Northern Ireland. We aim to advocate for people with inherited blood disorders and their families, provide information and education on issues relating to bleeding disorders and support on health-related issues. The society also advocates for and provides support for infected and affected victims of the contaminated blood scandal who have been recognised in the Infected Blood Public Inquiry (2017-2023) which was sponsored by the Paymaster General (Cabinet Office) and is in its currently awaiting the inquiry chairman's final report (expected in the autumn).

Haemophilia NI's charitable purposes have families and sufferers at the centre of their activities. However, with the impacts and risks associated with the Covid-19 pandemic, a number of our planned activities were severely curtailed and number of planned events had to be postponed until 2023 due to the significant risk of infection exposure that was caused to members. This included a newly diagnosed family weekend planned for February 2021 and run in conjunction with Haemophilia UK to be hosted by Haemophilia NI in the Roe Valley Resort. This was intended as an education and support weekend for families of children newly



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diagnosed with haemophilia, (we have also included a family from Haemophilia Scotland). Due to the infection risk we postponed the event for families and our clinical and medical speakers until February 2023 when it will be held at the same venue.

In order to continue to function the board of trustees held its regular monthly meetings through the medium of Zoom. We have now reverted to holding some meetings face-to-face. During 2022 the board of trustees met several times to prepare a business plan which would help guide our work and ensure our purposes and activities would benefit our members. The culmination of that work was the completion of our Vision 2025 Strategic Plan. The document helps explain who we as a charity are, including our ethos and aims for the next 3 years. It has been a useful practice to review and revise how we operate following the social and interactive stalemate of Covid-19.

Haemophilia NI communicates and co-operates with its fellow haemophilia charities both in the UK and in Ireland. During the year we continued to develop cooperation and collaboration with Haemophilia NI leading to several meetings with colleagues in the UK society by Zoom and agreement to work together to provide opportunities for sufferers and families. The board of trustee also visited Dublin in August to meet with the Irish Haemophilia Society and agree ways of cooperating for the mutual benefit of our members. Colleagues in Dublin provided us with a range of publications we could use and rebrand to help inform our members on different aspects of haemophilia and von Willebrands.

During 2022, Haemophilia NI continued to promote our charity and bleeding disorders through the media of Facebook, Twitter and our website. We communicated with our members and agreed to return to holding public events after summer 2022. Subsequently, we held a Patient Information Day and AGM at the Hilton Hotel in Templepatrick on 22nd October. This event was exclusively for Haemophilia NI members. The day included talks on gene therapy for haemophiliacs given by Brian O'Mahoney, chair of Haemophilia Ireland and a talk on ageing with bleeding disorders given by our secretary Dr William McKeown. Tea/coffee/lunch was provided. The event was free to attend. The event was well attended by just under thirty members after which the election of board of trustees took place. Three members were elected to the existing board of trustees and are undergoing induction and ACCESS NI training.

As part of our role of advocacy, Haemophilia NI continued to represent our infected members through our participation and the work of our legal team Watkins and Gunn to ensure effective core participation at the infected blood inquiry. (We enlisted Watkins and Gunn to represent and advise us since the society was a core participant at the infected blood inquiry). Subsequently we met with Watkins and Gunn on a six-weekly basis in Belfast when they can to review progress at the inquiry and discuss the quality and nature of evidence. Through this activity we have directly advocated for some of our members with the DoH NI and regarding other social and financial needs.



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Following our advocacy with government here in the Northern Ireland Assembly and at Westminster where we carried out a number of lobbying activities including meeting and corresponding with the Cabinet Office and NI Health Board of trustees and local MPs across different parties and raising ministers' questions (through our local MPs and MLAs), we helped to ensure ministerial support for parity in scheme payments for our infected and affected members. In addition, Haemophilia NI representatives sat on a guidance board of trustees with DoH civil servants responsible for providing guidance to the Minister enhancement scheme for NI victims. These advocacy activities led to concrete benefit to our infected members.

Haemophilia therapeutics is fast changing with multiple new treatments becoming available in recent years such as long-acting replacement therapies and Emicizumab. Haemophilia NI seeks to advocate for patients to be able to access new therapies wherever their healthcare professional feels it would benefit their care. We have made a submission to the APPG at Westminster looking into treatment access and will be involved as a report is compiled and recommended at the start of the next parliament. We are keen to promote patient involvement in national tender processes and the raising of target trough levels for factor replacement therapy.

Some of our younger members participated in research with a youth education booklet covering relevant topics for teenagers including dealing with bleeds, exercise and disclosure to friends. We released the publication at our October family education day. We already enjoy good links with a number of pharmaceutical companies and we are keen to ensure that pharmaceutical companies develop therapies with patients at the centre of the process. We are also keen to see that pharmaceutical companies give back to the haemophilia community through support of educational patient events. We have worked with SOBI on several projects such as the 2019 Haemophilia NI Family Education Day and we seek to continue to partner with SOBI and others in 2023.

In conclusion, in line with our aims, we have not charged for participation in any events or activities since we began our charitable work in 2017. This is something we continue to reflect on as we try to put any income into providing benefit to our members through the information and events we hold.

(This report is provided as part of our annual submission in compliance with NI Charities Commission requirements.)