Haemophilia NI
Supporting patients and families

Vision 2025

Strategic Plan 2023-2025

Haemophilia NI Board of Trustees

Approved September 2022

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INTRODUCTION

Haemophilia NI (HNI) seeks to support patients and families in NI affected by bleeding disorders. It is a registered charity (NIC107635) and is committed to being an open and transparent organisation. All are work is underpinned by the principles of good governance as set out in our governing documents and we are accountable to our membership. It is hoped that this document will help explain who HNI is, including our ethos and aims for the next 3 years. Our work is underpinned by the amazing fundraising efforts of our members without which none of this would be possible and to whom we are greatly indebted. Thank you for taking the time to read about our work and vision for Haemophilia NI

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Vision

“A future where all people in Northern Ireland affected by bleeding disorders can live life to the full.”

Mission statement

“Haemophilia NI aims to support people affected by bleeding disorders through:

- **Advocating** to ensure access to the best medical treatment and social support
- **Fostering Community** and support networks between those affected by bleeding disorders
- **Campaigning for Justice** for all those affected by contaminated blood
- **Equipping Patients with Knowledge** to manage their bleeding disorder and live independently

Values

“Our primary motivation at all times is the wellbeing of people in Northern Ireland who are affected by bleeding disorders. We seek to be a truly inclusive cross-community group which acts with transparency, honesty and accountability to members. Our work aims to empower the bleeding disorders community in Northern Ireland and make the lives of people affected by bleeding disorders easier where possible.”

FOSTERING COMMUNITY

Children and families

- HNI seeks to support children and families affected by bleeding disorders through a variety of educational events. This year we aim to include child and family specific workshops at our family day at the Ulster American Folk Park in 2023.

- We arrange an annual trip to see Santa, last year this at *The Jungle*. We plan to have this as an annual event on an ongoing basis.



Members meeting the Elves at The Jungle (Magherafelt) in December 2021

Please Note: HNI trustees have completed Child Protection and Vulnerable Adult Training

Youth

- HNI has developed a new youth education booklet in Partnership with SOBI (Swedish Orphan Biovitrium – a pharmaceutical company). This is due to be launched at our Family Day in 2023. We also intend to run a youth workshop as part of our members day at the Ulster American Folk Park in spring. Long term we aspire to organise residential youth weekends, but this would realistically be for 2023 and beyond.

The Haemophilia NI Youth Booklet developed in association with SOBI

Women

- HNI recognises that women are also profoundly affected by bleeding disorders and rejects the old stereotype of bleeding disorders as 'male-only diseases'. HNI wants to raise awareness that women are also affected by bleeding disorders and that this can have significant problems around issues such as menstruation and pregnancy. HNI also recognises that women without bleeding disorders are often significantly affected when partners or other family members have bleeding disorders. We plan to run a women's event for all women affected by bleeding disorders in September 2023. We try to offer ongoing support to women affected by bleeding disorders.

Partnering with other Haemophilia Societies

- The bleeding disorder community is global and Haemophilia NI actively wants to promote strong and positive links with other haemophilia societies within the UK and Ireland (the UK Haemophilia Society, The Irish Haemophilia Society, Haemophilia Scotland and Haemophilia Wales). We currently hold meetings on an annual basis with the Irish Haemophilia society. HNI has already been collaborating very actively with Haemophilia Wales and Haemophilia Scotland as part of the Infected Blood Inquiry and this partnership has certainly served to strengthen the patient voice.
- HNI has organised a newly diagnosed weekend with the UKHS in 2023 at the Roe Valley Resort.

HNI Trustees meeting with the Irish Haemophilia Society in Dublin August 2022

Keeping Members Informed

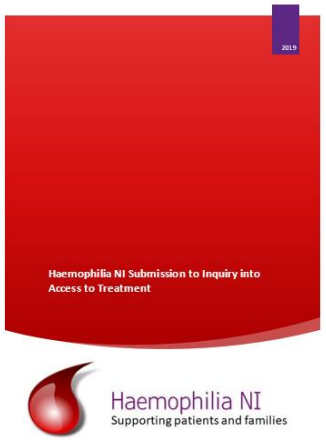
- HNI seeks to keep in touch with its memberships in numerous ways in order to foster community amongst those affected by bleeding disorders. This includes via:

  - Face-to-face meetings
  - Facebook
  - Twitter
  - Newsletters
  - Website
  - Telephone calls

ADVOCACY

Access to Treatment

- The world of haemophilia therapeutics is fast changing with multiple new treatments becoming available in recent years such as long-acting replacement therapies and Emicizumab. HNI 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 document 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. HNI is keen to promote patient involvement in national tender processes and the raising of target trough levels for factor replacement therapy. We also support having a permanent clinical psychologist attached to the Haemophilia Centre in Belfast.



Haemophilia NI submission to the All-Party Group on Access to Treatment

Pharmacy

- HNI already enjoys good links with a number of pharmaceutical companies. 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 Haemophilia NI Family Education Day and we seek to continue to partner with SOBI and others in 2023.

Raising Awareness of Bleeding Disorders in the Public Discourse

- HNI is working through social media to promote itself and bleeding disorders. This includes through the mediums of *Facebook, Twitter,* and our website.

Working with the Haemophilia Centre and Healthcare Professionals

- HNI enjoys a good working relationship with the Haemophilia Centres at the Belfast City Hospital and Royal Victoria Hospital for Sick Children. We aim to work with healthcare providers to support patients and promote Haemophilia NI events. We also aim to be able to give patient feedback to healthcare providers to help them to continue to improve the services and care which they provide. This included sending representatives to the Belfast Haemophilia centre during their last external audit in autumn 2019. We plan to hold annual meetings between the Haemophilia Centre in Belfast and HNI representatives to ensure a forum for patients voices to be heard by healthcare professionals.

EQUIPPING PATIENTS WITH KNOWLEDGE

Education relevant to patients and families throughout the life course

- HNI aims to provide patient education on an evidence based and expert led basis working with our local medical professionals from the NI Haemophilia and Thrombosis Centre coming to speak at our meetings with whom we enjoy a close relationship to help members understand treatment supporting the life course of those affected by bleeding disorders.
- HNI aims to release a new youth education booklet covering relevant topics for teenagers including dealing with bleeds, exercise, and disclosure to friends.

Self-infusion

- Self-infusion still forms the mainstay of treatment for those affected by severe haemophilia. Haemophilia NI recognises that learning this skill can present a great challenge to both patients and parents. Haemophilia NI seeks to run regular workshops dealing with this tricky issue and create a space for teenagers/children and their parents to get together and support one another.

Self-Infusion Training at Haemophilia NI Family day March 2019

CAMPAIGNING FOR JUSTICE

Stormont and Westminster

- HNI has played a strong role in advocating for and supporting local victims of contaminated blood in Northern Ireland over the past 12 months which have often been very difficult for all infected and affected. HNI wants to see an inquiry that provides justice to victims by identifying and holding to account those responsible for the biggest treatment disaster in the history of the NHS. Haemophilia NI has been a registered core participant at the Infected Blood inquiry and has been able to make free legal representation available to local people through Watkins and Gunn solicitors. In particular HNI has been working hard to highlight the disparity in payments made to affected people across the UK which has seen Northern Irish victims left less well off than those in other UK regions.

- We have made representations at the Department of Health and with the Business Services Organisation. HNI campaigned to ensure access to old medical records would be free for victims requesting access to these.

- Acknowledged for our advocacy and lobbying on behalf of victims with government and the public inquiry
- Continuing to meet and correspond with Westminster Government in Whitehall throughout the course of the contaminated blood inquiry.
- Continuing to lobby for contaminated blood victims with our Westminster MPs and NI Assembly members
- Achieving parity with other regions in scheme payments the contaminated blood inquiry to ensure NI has a strong local voice. HNI hopes to be able to work with the local executive when it is restored so that Haemophilia and other bleeding disorders in NI get priority.

HNI trustee Nigel Hamilton at 10 Downing Street with Clive Smyth (UK Haemophiia Society) and Glenn Wilkinson (Contaminated Blood Campaign) 12 July 2022

Haemophilia NI
Supporting patients and families

- ***Equipping patients*** *with knowledge*
- ***Self-help*** *workshops*
- *Updates on current and* ***future therapies***
- ***Supporting Parents*** *of newly diagnosed children*
- *Educational events led by* ***medical professionals***

- *Fighting for* ***justice*** *for victims in infected blood inquiry as core participant*
- *Advocating to ensure patients get* ***access to new therapies***
- ***Working with healthcare professionals*** *to ensure patients receive quality care*
- *Advocating to the* ***All Party Group***

- ***Fostering Community***
- *Children and families*
- *Youth*
- *Men*
- *Women*
- *Other patient organisations*

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