

Haemophilia NI

Northern Ireland · Charity number 107635

Details

Status Received

Registered 2021-01-18

Register [View on the Charity Commission for Northern Ireland register](#)

Contact

Address 51A Mullaghboy Road
Islandmagee
Co Antrim
Larne
BT40 3tr
BT40 3TR

Phone 07824777039

Email nigelhamilton@haemoni.onmicrosoft.com

Website www.haemophiliani.org

Activities

Purposes: • To relieve people with Haemophilia, Von Willbrands Disease and other bleeding disorders, their families, carers and bereaved families who would benefit from information, advocacy and support • To further the health, education, wellbeing, and the social and economic welfare of all those in Northern Ireland with a bleeding disorder and their families, in so far as is charitable

What the charity does: The relief of those in need by reason of youth, age, ill-health, disability, financial hardship or other disadvantage

How the charity works: Advice/advocacy/information,Medical/health/sickness

Who the charity helps: Carers,Children (5-13 year olds),Hiv/aids,Men,Older people,Parents,Preschool (0-5 year olds),Women,Youth (14-25 year olds)

Finances

Period end	Income	Expenditure	Assets	Employees
2025-04-04	£19,585	£10,923	£0	0
2024-04-04	£7,067	£7,745	£0	0

Trustees

Name	Role	Appointed
Miss Deborah Gowdy		
Mr Emmet Mclaughlin		
Mr Nigel Hamilton		
Mrs Amanda Hogg		
Mrs Daisy Grattan		
Mrs Mary-Anne Jess		
Mrs Rachel Olliver		
Ms Colette Maria Mcafee		
Ms Sarah Kane		

Haemophilia NI

Northern Ireland - Charity number 107635

Accounts

Independent examiner's report to the charity trustees of Haemophilia NI

I report on the accounts of the Trust for the year ended 4 April 2025, which are set out on pages 2 to 3.

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- follow the procedures laid down in the general Directions given by the Commission under section 65(9)(b) of the Charities Act
- state whether particular matters have come to my attention.

Basis of independent examiner's report

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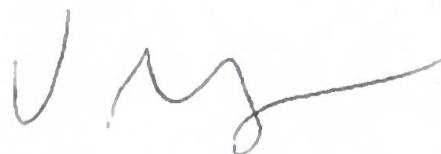
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That there is further information needed for a proper understanding of the accounts to be reached.

Independent examiner's statement

I have completed my examination and have no concerns in respect of the matters (1) to (4) listed above and, in connection with following the Directions of the Charity Commission for Northern Ireland, I have found no matters that require drawing to your attention.



Victoria Magee

Chartered Accountant Ireland Registered – membership no. 09C0172

11 April 2025

Haemophilia N.I

Statement of assets and liabilities - Year Ended 4 April 2025

	Unrestricted			
	Funds	Restricted Funds	Total 2025	Total 2024
	£	£	£	£
Receipts				
Voluntary Receipts				
Donations & Gift Aid	13,628		13,628	5,711
Grants	-	5,956	5,956	3,220
Legacy	-		-	170
Other Funding		-	-	-
Bank interest	-	-	-	-
From Charitable Activities				
Membership Fees	-	-	-	-
Other	-	-	-	-
	13,628	5,956	19,585	9,101
Payments				
Cost of Fundraising	1,193	-	1,193	291
Cost of Charitable Activities	3,764	3,158	6,922	5,291
Grants & Donations	-	-	-	200
Governance Costs	927	1,882	2,808	1,555
Asset and investment purchase	-	-	-	-
Purchase of Equipment	-	-	-	-
Total Payments	5,884	5,039	10,923	7,337
Net receipts / (payments)	7,745	917	8,662	1,763
Transfers to / (from) funds	-	-	-	-
Surplus / (deficit) for the year	7,745	917	8,662	1,763
Reconciliation 4 April 2024				
Cash at bank & in hand 04.04.2024	7,067	(150)	6,917	5,153
Surplus / (deficit) this year end	7,745	917	8,662	1,763
Cash at bank & in hand 04.04.2025	14,811	767	15,579	6,917

Haemophilia NI

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Surplus / (deficit) this year end	7,745	917	8,662	1,763
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Bank & Cash Balances				
Bank Deposit Accounts			-	-
Bank Current Accounts			15,579	6,917
Cash in hand			-	-
			15,579	6,917
Other assets (Unrestricted Fund)				
Assets			-	-
Liabilities (Unrestricted Fund)				
Liabilities			-	-

Approved by the Trustees on 27/4/25 and signed on their behalf by:

CARSON PEARCE

Printed Trustee 1 name

Carson Pearce

Nigel Hamilton

Printed Trustee 2 name

Nigel Hamilton

Haemophilia NI

Northern Ireland - Charity number 107635

Accounts

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Bank & Cash Balances

Bank Deposit Accounts	-	-
Bank Current Accounts	15,579	6,917
Cash in hand	-	-
	15,579	6,917

Other assets (Unrestricted Fund)

Assets	-	-
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Liabilities (Unrestricted Fund)

Liabilities	-	-
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Approved by the Trustees on 27/4/25 and signed on their behalf by:

CARSON PEARCE

Printed Trustee 1 name

Carson Pearce

NICK HAMILTON

Printed Trustee 2 name

Nick Hamilton

Haemophilia NI

Northern Ireland - Charity number 107635

Accounts

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Victoria Magee

Chartered Accountant Ireland Registered – membership no. 09C0172

Haemophilia N.I

Statement of assets and liabilities – Year Ended 31 December 23

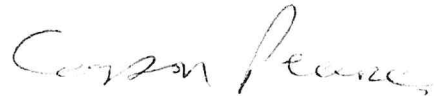
	Unrestricted Funds £	Restricted Funds £	Total 2023 £	Total 2022 £
Funds reconciliation				
Cash at bank & in hand 31.12.2022	6,427	-	6,427	7,370
Surplus/(deficit) this year end	1,070	-	1,070	(943)
Cash at bank & in hand 31.12.2023	7,497	-	7,497	6,427
Bank & Cash Balances				
Bank Deposit Accounts			-	-
Bank Current Account			7,497	6,427
Cash in Hand			-	-
			7,497	6,427
Other assets (Unrestricted Fund)				
Assets			-	-
			-	-
Liabilities (Unrestricted Fund)				
Liabilities			-	-
			-	-

Approved by the Trustees on _____ and signed on their behalf by:

NIGEL HAMILTON
Printed Trustee 1 name



CARSON PEARCE
Printed Trustee 2 name



Haemophilia NI

Northern Ireland - Charity number 107635

Annual report

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.

Haemophilia NI

Northern Ireland - Charity number 107635

Annual return

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Haemophilia N.I

Statement of assets and liabilities – Year Ended 31 December 23

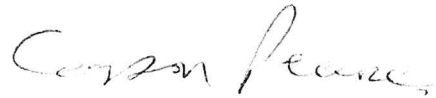
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Bank Current Account			7,497	6,427
Cash in Hand			-	-
			7,497	6,427
 Other assets (Unrestricted Fund)				
Assets			-	-
			-	-
 Liabilities (Unrestricted Fund)				
Liabilities			-	-
			-	-

Approved by the Trustees on _____ and signed on their behalf by:

NIGEL HAMILTON
Printed Trustee 1 name



CARSON PEARCE
Printed Trustee 2 name



Haemophilia NI

Northern Ireland - Charity number 107635

Accounts

CREDIT

31/01/2022		
04/02/2022		
01/03/2022		
29/03/2022		
19/04/2022		
26/04/2022	Just giving marathon sponsorship	£ 349.96
29/04/2022		
04/05/2022	Just giving marathon sponsorship	£ 24.12
06/05/2022	Cash sponsorship for marathon	£ 210.00
09/05/2022	Just giving marathon sponsorship	£ 360.57
16/05/2022	Just giving marathon sponsorship	£ 97.10
30/05/2022		
20/06/2022		
29/06/2022		
29/07/2022		
29/07/2022		
25/08/2022		
30/08/2022		
06/09/2022		
06/09/2022		
06/09/2022		
07/09/2022		
07/09/2022		
15/09/2022		
23/09/2022		
26/09/2022	Refund from Corrs corner	£ 9.45
29/09/2022		
10/10/2022		
10/10/2022		
14/10/2022		
17/10/2022		
17/10/2022		
26/10/2022	donations from AGM	£ 136.00
31/10/2022		
07/11/2022		
29/11/2022		
29/11/2022		
12/12/2022		
29/12/2022		
29/12/2022		

Opening Balance £7369.92

Jan-22

Kranken.I.O website
Wisener solutions websi
Kranken .I.O website
Kranken.I.O website
The office stationery

Kranken.I.O website

Kranken.I.O website
123 Reg Hayes
Kranken I.O
Kranken I.O
Hilton Hotel Deposit AG
Translink visit HIS
Kranken.I.O website
Wm McKeown expenses
R.Pearce expenses HIS
Taxi meeting HIS
Corporate catering HIS
Cheque000065 for room
Corrs Corner deposit for
Corrs Corner balance for

Kranken.I.O website
R.Pearce money for gift f
Tesco sundries
Hilton hotel AGM balanc
The office stationery
Argos tablet for raffle

Kranken.I.O.
The works Ballyclare stat
Kranken.I.O website
Tesco christmas cards fo
postage of christmas car
marathon entry
KrankenI.O

Closing Balance 31/12/22 £6427.30

	DEBIT	Calculated Balance	Receipt
	£ 17.51	£ 7,352.41	YES
te	£ 288.00	£ 7,064.41	YES
	£ 17.59	£ 7,046.82	YES
	£ 17.91	£ 7,028.91	YES
	£ 64.95	£ 6,963.96	YES
		£ 7,313.92	
	£ 18.72	£ 7,295.20	YES
		£ 7,319.32	
		£ 7,529.32	
		£ 7,889.89	
		£ 7,986.99	
	£ 18.62	£ 7,968.37	
	£ 40.78	£ 7,927.59	
	£ 19.12	£ 7,908.47	YES
	£ 19.48	£ 7,888.99	YES
M	£ 500.00	£ 7,388.99	YES
	£ 105.00	£ 7,283.99	YES
	£ 19.91	£ 7,264.08	YES
ISH	£ 15.99	£ 7,248.09	
	HIS £ 15.80	£ 7,232.29	
	£ 13.37	£ 7,218.92	YES
	£ 13.10	£ 7,205.82	
hire	£ 20.00	£ 7,185.82	YES
meeting	£ 75.00	£ 7,110.82	YES
meeting	£ 21.25	£ 7,089.57	
		£ 7,099.02	
	£ 22.00	£ 7,077.02	YES
for speaker	£ 12.00	£ 7,065.02	YES
	£ 10.20	£ 7,054.82	YES
ce	£ 445.90	£ 6,608.92	YES
	£ 9.57	£ 6,599.35	YES
	£ 69.99	£ 6,529.36	YES
		£ 6,665.36	
	£ 20.26	£ 6,645.10	YES
tionery	£ 6.00	£ 6,639.10	YES
	£ 19.41	£ 6,619.69	YES
r members	£ 5.50	£ 6,614.19	YES
ds	£ 22.44	£ 6,591.75	YES
	£ 144.95	£ 6,446.80	YES
	£ 19.50	£ 6,427.30	YES

Haemophilia NI

Northern Ireland - Charity number 107635

Annual report



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



Haemophilia NI

Supporting patients and families

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.



Haemophilia NI

Supporting patients and families

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.)

Haemophilia NI

Northern Ireland - Charity number 107635

Annual return

----- Forwarded message -----

From: **Mark Compton** <mimi.compton@gmail.com>

Date: Sat, 18 Feb 2023, 15:47

Subject: Accounts - 2022

To: Simon Hamilton <singlesculler50@gmail.com>

Simon,

Apologies - miscommunication as I thought from your email you were re-creating the account. I have completed and attached here for you for submission. I am happy that these accounts are satisfactory for submission.

Regards,

Mark