

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED  
31 MARCH 2025



**REPORT AND ACCOUNTS OF PNH SUPPORT  
FOR THE YEAR ENDED 31 MARCH 2025**

Registered Charitable Incorporated Organisation (registered no.1161518)  
Registered Address: c/o 4 Buckland Road, London, E10 6QS  
Trustees: Maria Piggin, Alex Naylor, Virginia Bertelli, Victoria Solovieva

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31 MARCH 2025

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# REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED 31 MARCH 2025

## **REPORT OF THE TRUSTEES (for the year ended 31 March 2025)**

The trustees present this report and receipts and payments accounts for the year ended 31 March 2025.

### **Structure, Governance and Management**

PNH Support is registered as a Charitable Incorporated Organisation (CIO) and is currently managed by four trustees. Myra De Vries retired as longest serving trustee at the Annual General Meeting (AGM) on 17 August 2024 as required by paragraph 13(1) of PNH Support's constitution dated 30 April 2015 (as amended by member resolution on 16 May 2020) (the "Constitution"). The trustees operate within PNH Support's Constitution which is an 'Association' model and has voting members other than its trustees.

The trustees have been appointed to ensure that the board has an appropriate level of skills to enable PNH Support to achieve its charitable objectives.

PNH Support currently has 164 members. Membership is open to patients (and their families/carers) living with Paroxysmal Nocturnal Haemoglobinuria ("PNH") living in England, Wales and Northern Ireland.

A virtual AGM was held on 17 August 2024 and was attended by 11 members.

### **Objectives and Activities**

The objects of PNH Support (as set out in its Constitution) are as follows:

1. To promote, protect and preserve the physical and mental health of those diagnosed with Paroxysmal Nocturnal Haemoglobinuria (PNH) who reside in England, Wales and Northern Ireland (either permanently or temporarily) through the provision of support, education, advocacy and practical advice.
2. To advance the education of patients with PNH who reside in England, Wales and Northern Ireland, in particular but not exclusively by the provision of advice and a point of contact for newly diagnosed PNH patients, in England, Wales and Northern Ireland.

PNH Support undertook the following activities during the year ended 31 March 2025 in order to further its charitable purposes for the public benefit:

1. Activities undertaken to promote, protect and preserve the physical and mental health of those diagnosed with PNH who reside in England, Wales and Northern Ireland (either permanently or temporarily) through the **provision of support**. PNH Support:
  - a) maintained and moderated a closed Facebook group with 346 members open to patients and their families living in the United Kingdom and Ireland to disseminate news and events and facilitate discussion and support about living with PNH.
  - b) provided one-on-one advice, signposting and support to patients regarding a range of topics (not including medical advice).
  - c) facilitated 12 patient meetings both virtually and in-person

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- d) offered 13 online courses through the Better Together collaborative project (see more below)
  - e) offered 6 webinars including through the Better Together collaborative project
  - f) offered free one-to-one advice to our community members through a specialist benefits advisor made available by the Better Together collaborative project
  - g) offered free one-on-one emotional wellbeing advice and support to community members through specialist psychologists made available by the Better Together collaborative project
2. Activities undertaken to promote, protect and preserve the physical and mental health of those diagnosed with PNH who reside in England, Wales and Northern Ireland (either permanently or temporarily) through the **provision of education** (in particular but not exclusively by the provision of advice and a point of contact for newly diagnosed PNH patients). PNH Support:
- a) maintained a community Facebook page in order to raise awareness of the disease and post relevant news and updates:  
<https://www.facebook.com/PNH-Support-126655011000361/>.
  - b) maintained and updated our website ([www.pnhuk.org](http://www.pnhuk.org)) in order to provide information and disseminate news, updates and events relevant to the PNH community, in particular regarding signposting to relevant information, guidance and information
  - c) co-hosted an online Taking Tablets session on 8 February 2025 with the PNH National Service
  - d) offered 6 webinars including through the Better Together collaborative project
  - e) was represented at the European Haematology Association (EHA) Congress in Madrid in June 2024 and disseminated relevant information to patients
  - f) maintained a Twitter and then a Bluesky handle and an Instagram account @pnh\_support in order to raise awareness of the disease, the patient group and disseminate news, information and events.
3. Activities undertaken to promote, protect and preserve the physical and mental health of those diagnosed with PNH who reside in England, Wales and Northern Ireland (either permanently or temporarily) through the provision of **advocacy**.

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***Kings College, Hospital***

- a) PNH Support attended virtual meetings of the patient involvement and engagement group at Kings College Hospital, London to ensure the PNH patient voice was represented.

***Pharmaceutical companies***

- b) PNH Support engaged with pharmaceutical companies undertaking research into treatments for PNH to provide the patient perspective on participant information forms and information about new treatments. Each engagement was subject to an agreement where PNH Support was remunerated for trustees' time in accordance with fair market value (in accordance with industry codes of practice).

***The National Institute of Health and Care Excellence (NICE)***

- c) PNH Support represented patients and carers in two NICE appraisals for PNH medicines. This involved surveying our community and providing patient organisation submissions, nominating clinician and patient experts and attending NICE committee meetings where applicable.

***National Alliances***

- d) PNH Support was represented at Specialised Healthcare Alliance meetings.
- e) PNH Support continues to be a member of Genetic Alliance UK.
- f) PNH Support is a member of the "Together for Healthy Marrow Alliance (TFHMA)" comprising 7 rare bone marrow failure patient organisations across the UK.
- g) **Better Together Project.** Six small charity partners continued to collaborate as part of a three year project (which concludes on 31 August 2025) entitled "Better Together" through funding from the National Lottery Communities Fund. As part of this project:
  - psychologists delivered mental health and wellbeing support through within a Clinical Governance and Excellence Framework including:
    - offering online webinars and courses on emotional wellbeing topics
    - providing one-to-one support where required
  - a specialist benefits advisor was made available to our community
  - our community benefitted from information and education sessions on relevant topics
  - PNH Support took part in the collaborative "Super Rare" fundraising campaign across February and March 2025
  - two of our community members sit on the Community Reference Group which feeds into the Better Together project steering group.

***International Alliances***

The Chair, Maria Piggin continued to:

- h) chair the PNH Global Alliance (PNHGA) comprising 11 PNH global patient organisations from 9 countries with the vision that 'all PNH patients globally have access to optimal care and treatment'.
- i) represent bone marrow failure patients in the European Reference Network for rare haematological disorders (EuroBloodNet) including jointly advocating for patients without access to treatment

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- j) represent the PNH Global Alliance on the European Hematology Association Patient Advocacy Committee
- 4. Activities undertaken to promote, protect and preserve the physical and mental health of those diagnosed with PNH who reside in England, Wales and Northern Ireland (either permanently or temporarily) through the provision of **practical advice**. PNH Support:
  - a) provided one-on-one advice (not including medical advice), signposting and support to patients regarding a range of topics including directing them to the appropriate information sources or personnel
  - b) maintained and updated our website in order to provide updated information and disseminate news and events relevant to the PNH community

### **How we have managed risk**

All PNH Support policies have been reviewed and updated where relevant.

### **Sustainability**

The trustees have regularly made calls for volunteers to assist PNH Support and following development of our five year strategy to 2030, we intend to recruit additional trustees with skills needed to build our resilience and capacity.

### **Financial Review**

PNH Support had the following receipts in the year:

Donations	£766.00
Fees for services/Honoraria	£7,057.00
Fundraising events	£3,150.00
Grant funding	£5,110.00
Gift aid reclaim/other	£386.00
<b>Total</b>	<b>£16,469.00</b>

Our expenditure was **£12,495**, further details of which are set out in Annex A.

### **Reserves Policy**

The trustees have established a Reserves Policy which provides a sustainable level of working capital to ensure continuity of PNH Support, contemporaneous with it achieving its objectives.

### **Public Benefit Statement**

The trustees have complied with their duty to have due regard to the guidance on public benefit published by the Charities Commission in exercising their powers or duties.

### **Responsibilities of the Trustees for the Preparation of Annual Accounts**

PNH Support's trustees are responsible for the preparation of the accounts and are required to assess whether the audit requirements of s144(2) of the Charities Act 2011 or an independent examination is required.

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The trustees are satisfied that PNH Support's gross income for the period is less than the £250,000 threshold and as such, there is no requirement for an audit or an independent examiner's statement.

On behalf of the Trustees

A handwritten signature in blue ink, consisting of a series of loops and a long, sweeping tail that curves upwards and to the right.

Maria Piggin  
Chair  
PNH Support

9 August 2025  
Date

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**ANNEX A**

Form CC16a  
Receipts and Payments Accounts for PNH Support for the year ended  
31 March 2025





CHARITY COMMISSION  
FOR ENGLAND AND WALES

PNH Support

No (if any)

## Receipts and payments accounts

CC16a

For the period  
from

Period start date  
01/04/2024

To

Period end date  
31/03/2025

### Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
<b>A1 Receipts</b>					
Donations	766	-	-	766	671
Fee for Services / Honoraria	7,057	-	-	7,057	6,366
Fundraising events	3,150	-	-	3,150	2,645
Grant funding	3,510	1,600	-	5,110	3,408
Giftaid reclaim and other	386	-	-	386	-
<b>Sub total (Gross income for AR)</b>	<b>14,869</b>	<b>1,600</b>	<b>-</b>	<b>16,469</b>	<b>13,090</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>14,869</b>	<b>1,600</b>	<b>-</b>	<b>16,469</b>	<b>13,090</b>
<b>A3 Payments</b>					
AGM, Conference & Member events	4,352	-	-	4,352	-
EHA Congress	-	-	-	-	597
Insurance - Zurich	228	-	-	228	219
IT Service & Fees	301	-	-	301	201
Member & Trustee Expenses	174	-	-	174	279
PNH Global Alliance Membership Fee	212	-	-	212	219
Bank Fees	78	-	-	78	78
Postage	2	-	-	2	6
Trustee training & meeting costs	255	-	-	255	-
Stationery and printing	95	-	-	95	21
Administrative support	1,798	-	-	1,798	-
Strategy and governance consultant	5,000	-	-	5,000	-
	-	-	-	-	-
<b>Sub total</b>	<b>12,495</b>	<b>-</b>	<b>-</b>	<b>12,495</b>	<b>1,620</b>
<b>A4 Asset and investment purchases, (see table)</b>					
Apple Air laptops	525	1,600	-	2,125	-
	-	-	-	-	-
<b>Sub total</b>	<b>525</b>	<b>1,600</b>	<b>-</b>	<b>2,125</b>	<b>-</b>
<b>Total payments</b>	<b>13,020</b>	<b>1,600</b>	<b>-</b>	<b>14,620</b>	<b>1,620</b>
<b>Net of receipts/(payments)</b>	<b>1,849</b>	<b>-</b>	<b>-</b>	<b>1,849</b>	<b>11,470</b>
<b>A5 Transfers between funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>34,690</b>	<b>-</b>	<b>-</b>	<b>34,690</b>	<b>23,220</b>
<b>Cash funds this year end</b>	<b>36,539</b>	<b>-</b>	<b>-</b>	<b>36,539</b>	<b>34,690</b>

## Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Cash at Bank (HSBC)	36,539	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>36,539</b>	<b>-</b>	<b>-</b>
	(agree balances with receipts and payments account(s))	OK	OK	OK


	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use	Apple Air Laptops	Unrestricted funds	2,125	1,998
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
	Maria Piggitt	09 / 08 / 25