

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2024



**REPORT AND ACCOUNTS OF PNH SUPPORT
FOR THE YEAR ENDED 31 MARCH 2024**

Registered Charitable Incorporated Organisation (registered no.1161518)
Registered Address: c/o 4 Buckland Road, London, E10 6QS
Trustees: Maria Piggin, Alex Naylor, Myra De Vries, Lucy Ellor and Andy Stockley

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2024

CONTENTS

	Page
Trustees' report for the year ended 31 March 2024	3
Annex A: Form CC16a - Receipts and Payments Accounts for PNH Support for the year ended 31 March 2024	6

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED 31 MARCH 2024

REPORT OF THE TRUSTEES (for the year ended 31 March 2024)

The trustees present this report and receipts and payments accounts for the year ended 31 March 2024.

Structure, Governance and Management

PNH Support is registered as a Charitable Incorporated Organisation (CIO) and is managed by three trustees. Maria Piggin retired as longest serving trustee at the Annual General Meeting (AGM) on 1 July 2023 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") and was reappointed. 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 156 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 1 July 2023 and was attended by 15 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 2024 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 314 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 9 patient meetings both virtually and in-person
 - d) offered 7 online courses through the Better Together collaborative project (see more below)

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2024

- e) offered 8 webinars on topics such as sleep management through the Better Together collaborative project
 - f) offered one-to-one advice to our community members through a specialist benefits advisor made available by the Better Together collaborative project
 - g) offered emotional wellbeing advice and support to community members through two 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) 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 PNH Update session on 29 February 2024 with the PNH National Service
 - d) co-hosted an online session for patients on the results of the [Rare Voices report](#) from a national survey of rare disease patients including the PNH Support community (see below for more information)
 - e) co-designed and co-delivered 3 webinars hosted by EuroBloodNet covering aspects of PNH and aplastic anaemia
 - f) offered 8 webinars on topics such as benefits and travel insurance made available through the Better Together collaborative project
 - g) was represented at the European Haematology Association (EHA) Congress in Frankfurt in June 2023 and disseminated relevant information to patients
 - h) maintained a Twitter handle @PNHSupport 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**.
- Academia**
- a) PNH Support reviewed a plain language summary for a scientific journal article on a PNH trial.

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2024

PNH National Service (PNHNS)

- a) PNH Support attended multiple virtual meetings with PNHNS and various healthcare providers with a view to improving the patient experience of at-home infusions, drug deliveries and cool bags for safe travel with medication.

Kings College, Hospital

- b) 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. This included informing insights about attending outpatient appointments at Kings College Hospital and the development of a new haematology building.

Pharmaceutical companies

- c) PNH Support engaged with pharmaceutical companies developing new treatments for PNH on the patient perspective of aspects of research and development processes and research studies. 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).

NHS England

- d) PNH Support was represented at the annual NHS England meeting with the PNH National Service in June 2023.

The National Institute of Health and Care Excellence (NICE)

- e) PNH Support represented patients and carers in three 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.
- f) PNH Support attended the NICE Annual Conference in Manchester on 7th November 2023.

National Alliances

- g) PNH Support was represented at Specialised Healthcare Alliance meetings.
- h) PNH Support continues to be a member of Genetic Alliance UK.
- i) PNH Support is a member of the "Together for Healthy Marrow Alliance (TFHMA)" comprising 7 rare bone marrow failure patient organisations across the UK.
- j) **Better Together Project.** Six small charity partners continued to collaborate as part of a three year project entitled "Better Together" through funding from the National Lottery Communities Fund. As part of this project:
- two specialist 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 advisor on benefits was available to the 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 2024

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED 31 MARCH 2024

- two of our community members sit on the Community Reference Group which feeds into the Better Together project steering group.
- k) **National Community Survey.** The charity members of the TFHMA collaborated on an industry funded national survey of their communities which resulted in a [Rare Voices report](#) which included recommendations and commitments to address the findings. The findings of this report were presented at the European Society for Hematology European Bone Marrow Transplant (EBMT) conference in Glasgow in March 2024. A specific session was also hosted to present the results to patients on 9 December 2023.

International Alliances

The Chair, Maria Piggin continued to:

- l) chair the PNH Global Alliance (PNHGA) comprising 9 PNH global patient organisations from 8 countries with the vision that all PNH patients globally have access to optimal care and treatment.
 - m) represent bone marrow failure patients in the European Reference Network for rare haematological disorders (EuroBloodNet) including jointly advocating for patients without access to treatment
 - n) 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 additional trustees and volunteers to assist PNH Support and through revising our strategy we are exploring ways in which PNH Support can build resilience and capacity. One new trustee was recruited in May 2024.

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2024

Financial Review

PNH Support had the following receipts in the year:

Donations	£671.00
Fundraising events	£2,645.00
Fees for services/Honoraria	£6,366.00
Grant funding	£3,408.00

Total **£13,090.00**

Our expenditure was £1,620, 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.

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



.....
Maria Piggin
Chair
PNH Support

17.08.24

.....
Date

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2024

ANNEX A

Form CC16a
Receipts and Payments Accounts for PNH Support for the year ended
31 March 2024



CHARITY COMMISSION
FOR ENGLAND AND WALES

PNH Support

No (if any)

Receipts and payments accounts

CC16a

For the period
from

Period start date
01/04/2023


To

Period end date
31/03/2024

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 £
A1 Receipts					
Donations	671	-	-	671	1,328
Fee for Services / Honoraria	6,366	-	-	6,366	5,161
Fundraising events	2,645	-	-	2,645	3,525
Grant funding	3,408	-	-	3,408	1,680
Other	-	-	-	-	38
Sub total (Gross income for AR)	13,090	-	-	13,090	11,732
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	13,090	-	-	13,090	11,732
A3 Payments					
AGM & Conference	-	-	-	-	-
EHA Congress	597	-	-	597	62
Insurance - Zurich	219	-	-	219	364
IT Service & Fees	201	-	-	201	220
Member & Trustee Expenses	279	-	-	279	375
PNH Global Alliance Membership Fee	219	-	-	219	211
Bank Fees	78	-	-	78	76
Postage	6	-	-	6	8
Trustee training	-	-	-	-	93
Stationery and printing	21	-	-	21	-
Other	-	-	-	-	38
	-	-	-	-	-
	-	-	-	-	-
Sub total	1,620	-	-	1,620	1,446
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	1,620	-	-	1,620	1,446
Net of receipts/(payments)	11,470	-	-	11,470	10,285
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	23,220	-	-	23,220	12,934
Cash funds this year end	34,690	-	-	34,690	23,220

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)	34,690	-	-
		-	-	-
		-	-	-
	Total cash funds	34,690	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
	Apple Air Laptop		891	250
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees		Signature	Print Name	Date of approval
			Maria Piggin	
				17 / 08 / 24