

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED  
31 MARCH 2023



**REPORT AND ACCOUNTS OF PNH SUPPORT  
FOR THE YEAR ENDED 31 MARCH 2023**

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 and Andy Stockley

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31 MARCH 2023

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# REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED 31 MARCH 2023

## **REPORT OF THE TRUSTEES (for the year ended 31 March 2023)**

The trustees present this report and receipts and payments accounts for the year ended 31 March 2023. The current trustees are set out on page 1.

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

PNH Support is registered as a Charitable Incorporated Organisation (CIO) and is managed by three trustees. Alex Naylor retired as longest serving trustee at the Annual General Meeting (AGM) on 18 June 2022 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. Andy Stockley was appointed as a trustee by trustee resolution on 27 June 2022. 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 143 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 18 June 2022 and was attended by 13 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 2023 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**. We
  - a) maintained and moderated a closed Facebook group with 281 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.

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- c) hosted two virtual patient meetings with guest speakers on living with COVID 19, meningitis and managing fatigue
  - d) the East Anglia patient and family group met four times (virtually and face-to-face)
  - e) co-hosted a PNH Patient and Family Conference on 18 March 2023 together with the PNH National Service and PNH Scotland. The conference had been planned as hybrid (face-to-face and Zoom) however due to a train strike and low registration numbers, it was moved online.
  - f) were able to offer our community access to webinars and events hosted by the Aplastic Anaemia Trust through the Better Together Project (see below).
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). We
- 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 (including a blood test glossary)
  - c) hosted two online patient sessions with guest speakers covering living with COVID 19, meningitis and managing fatigue
  - d) co-designed and co-delivered a monthly webinar series hosted by EuroBloodNet comprising six webinars covering aspects of PNH and aplastic anaemia
  - e) Maria Piggin, Alex Naylor and Myra De Vries attended the European Haematology Association (EHA) Congress in Vienna in June 2022 and disseminated relevant information to patients
  - f) 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) Maria Piggin authored a patient commentary piece in the Lancet journal entitled "Nothing about us should be without us"
- b) Alex Naylor co-delivered a presentation at the EHA Congress 2022 on patient quality of life

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***PNH National Service***

- c) We provided feedback on the redevelopment of the PNH National Service website and a new video about PNH for their website.
- d) Together with the PNH National Service we attended meetings with homecare services, Sciensus and Healthnet to highlight patient issues with the service and to suggest improvements

***Kings College, Hospital***

- e) We 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 conveying insights about attending outpatient appointments at Kings College Hospital and the development of a new haematology building.

***Pharmaceutical companies***

- f) We engaged with pharmaceutical companies developing new treatments for PNH about 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).
- g) Maria Piggin and Alex Naylor co-authored a paper on an ethnographic study of PNH patients, a poster for which was accepted at the European Society for Hematology European Bone Marrow and Transplantation (ESH EBMT) conference.

***NHS England***

- h) We represented PNH Support at the annual NHS England meeting with the PNH National Service on 28 June 2022.

***National Alliances***

- i) We represented PNH Support at Specialised Healthcare Alliance meetings.
- j) PNH Support continues to be a member of Genetic Alliance UK.
- k) We are a member of the "Together for Healthy Marrow Alliance (TFHMA)" comprising 7 rare bone marrow failure patient organisations across the UK.

***Better Together Project***

The partners of the TFHMA successfully secured funding from the National Lottery Communities Fund for a three year project entitled "Better Together" to enable the participating charities to build resilience and capacity. The project also aims to respond to the challenges faced by the participating rare bone marrow communities by:

- delivering mental health and wellbeing support through working within a Clinical Governance and Excellence Framework
- bringing people together through events and people-led projects
- providing better information, advice and support

As part of this project, one of our community members sits on the Community Reference Group which feeds into the project steering group. All the Better

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Together charities took part in the “Super Rare” fundraising campaign across February and March 2023.

### **National Community Survey**

The Better Together project partners also collaborated on an industry funded national survey of their communities led by the Aplastic Anaemia Trust. The next phase of the project will produce a report of the survey results together with a campaign to highlight these results.

### **International Alliances**

- l) Maria Piggini continued to:
  - a. chair the PNH Global Alliance (PNHGA) comprising 10 PNH global patient organisations from 9 countries with the vision that all PNH globally have access to optimal care and treatment.
  - b. represented bone marrow failure patients in the European Reference Network for rare haematological disorders (EuroBloodNet) including advocating for patients without access to treatment
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**. We:
  - a) provided one-on-one 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 including in response to specific requests made by patients and family members at our conference on 18 March 2023

### **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 to run PNH Support and through the Better Together project we are exploring ways in which PNH Support can build resilience and capacity.

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**Financial Review**

PNH Support had the following receipts in the year:

Donations	£1,328.00
Fundraising events	£3,525.00
Honoraria/consultancy fees	£5,161.00
Grant funding	£1,680.00
Other	£38.00

**Total** **£11,732**

Reserves Policy

The trustees have established reserves that will provide 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*  
.....

Maria Piggin  
Chair  
PNH Support

1 July 2023  
.....  
Date:



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**ANNEX A**

Form CC16a  
Receipts and Payments Accounts for PNH Support for the year ended  
31 March 2023



CHARITY COMMISSION  
FOR ENGLAND AND WALES

PNH Support

No (if any)

## Receipts and payments accounts

CC16a

For the period  
from

Period start date  
01/04/2022

To

Period end date  
31/03/2023

### 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	1,328	-	-	1,328	287
Fee for Services / Honoraria	5,161	-	-	5,161	4,356
Fundraising events	3,525	-	-	3,525	-
Grant funding	1,680	-	-	1,680	-
Other	38	-	-	38	-
<b>Sub total (Gross income for AR)</b>	<b>11,732</b>	<b>-</b>	<b>-</b>	<b>11,732</b>	<b>4,642</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>11,732</b>	<b>-</b>	<b>-</b>	<b>11,732</b>	<b>4,642</b>
<b>A3 Payments</b>					
AGM & Conference	-	-	-	-	-
EHA Congress	62	-	-	62	-
Insurance - Zurich	364	-	-	364	364
IT Service & Fees	220	-	-	220	646
Member & Trustee Expenses	375	-	-	375	24
PNH Global Alliance Membership Fee	211	-	-	211	218
Bank Fees	76	-	-	76	21
Postage	8	-	-	8	10
Trustee training	93	-	-	93	-
Other	38	-	-	38	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>1,446</b>	<b>-</b>	<b>-</b>	<b>1,446</b>	<b>1,284</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>1,446</b>	<b>-</b>	<b>-</b>	<b>1,446</b>	<b>1,284</b>
<b>Net of receipts/(payments)</b>	<b>10,285</b>	<b>-</b>	<b>-</b>	<b>10,285</b>	<b>3,359</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>12,934</b>	<b>-</b>	<b>-</b>	<b>12,934</b>	<b>9,576</b>
<b>Cash funds this year end</b>	<b>23,220</b>	<b>-</b>	<b>-</b>	<b>23,220</b>	<b>12,934</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)	23,220	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	23,220	-	-
	(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 Laptop		891	250
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

	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
<i>Maria Piggin</i>	Maria Piggin	01 / 07 / 2023
		/ /