

PNH SUPPORT

England & Wales · Charity number 1161518

Details

Other names PNH SUPPORT ENGLAND AND WALES

Status Registered

Legal form CIO

Registered 2015-05-01

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

Contact

Address Blackwell House
Guildhall Yard
London
EC2V 5AE

Phone 07810352555

Email contact@pnhuk.org

Website www.pnhuk.org

Activities

Objects: (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 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.

Activities: PNH Support provides support, information and (non medical) advice to the PNH community in England, Wales and Northern Ireland as well as advocating on their behalf.

Classification

- **How:** Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Other Defined Groups

Geography

- Northern Ireland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£16,469	£12,495	-	-
2024-03-31	£13,090	£1,620	-	-
2023-03-31	£11,732	£1,446	-	-
2022-03-31	£4,642	£1,284	-	-
2021-03-31	£3,003	£1,016	-	-

Trustees

Name	Role	Appointed
Alexandra Naylor		2020-02-27
Victoria Solovieva		2025-03-07
Virginia Bertelli		2024-11-05

PNH SUPPORT

England & Wales - Charity number 1161518

Accounts

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

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
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

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

- 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) 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**.

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

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 Pigginn 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

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

- 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
Total	£16,469.00

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.

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

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 several loops and a long, sweeping tail that ends in a small hook.

Maria Piggin
Chair
PNH Support

9 August 2025
Date

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

ANNEX A

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



Receipts and payments accounts

CC16a

For the period from	Period start date 01/04/2024	To	Period end date 31/03/2025
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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	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	-
Sub total (Gross income for AR)	14,869	1,600	-	16,469	13,090
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	14,869	1,600	-	16,469	13,090
A3 Payments					
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	-
	-	-	-	-	-
Sub total	12,495	-	-	12,495	1,620
A4 Asset and investment purchases, (see table)					
Apple Air laptops	525	1,600	-	2,125	-
	-	-	-	-	-
Sub total	525	1,600	-	2,125	-
Total payments	13,020	1,600	-	14,620	1,620
Net of receipts/(payments)	1,849	-	-	1,849	11,470
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	34,690	-	-	34,690	23,220
Cash funds this year end	36,539	-	-	36,539	34,690

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	-	-
		-	-	-
		-	-	-
	Total cash funds	36,539	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

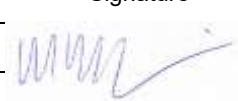
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

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

Categories	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
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	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

PNH SUPPORT

England & Wales - Charity number 1161518

Accounts

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

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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 Pigin 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



Receipts and payments accounts

CC16a

For the period from	Period start date 01/04/2023	To	Period end date 31/03/2024
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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

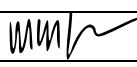
	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	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
	Maria Piggin	17 / 08 / 24

PNH SUPPORT

England & Wales - Charity number 1161518

Accounts

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

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

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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

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.

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

- 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) 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

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

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

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

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 Piggin 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.

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

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:

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

ANNEX A

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



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 £
A1 Receipts					
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	-
Sub total (Gross income for AR)	11,732	-	-	11,732	4,642
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	11,732	-	-	11,732	4,642
A3 Payments					
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	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	1,446	-	-	1,446	1,284
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	1,446	-	-	1,446	1,284
Net of receipts/(payments)	10,285	-	-	10,285	3,359
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	12,934	-	-	12,934	9,576
Cash funds this year end	23,220	-	-	23,220	12,934

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	-	-
		-	-	-
		-	-	-
	Total cash funds	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
		/ /

PNH SUPPORT

England & Wales - Charity number 1161518

Accounts

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2022



**REPORT AND ACCOUNTS OF PNH SUPPORT
FOR THE YEAR ENDED 31 MARCH 2022**

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

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2022

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REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2022

REPORT OF THE TRUSTEES (for the year ended 31 March 2022)

The trustees present this report and receipts and payments accounts for the year ended 31 March 2022. 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. Maria Piggini retired as longest serving trustee as required by paragraph 13(1) of the Constitution at the Annual General Meeting (AGM) on 3 July 2021 and was reappointed. Myra De Vries was appointed a trustee by trustee resolution on 22 February 2022 and Neil Rowntree resigned as trustee on 7 March 2022. The trustees operate within PNH Support's constitution dated 30 April 2015 (the "Constitution") as amended by member resolution on 16 May 2020 to permit the AGM to be held virtually as a result of the COVID 19 pandemic. The Constitution is an 'Association' model and has voting members other than its trustees.

PNH Support currently has 133 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 3 July 2021 and attended by 10 members at which the highlights of the patient and carer survey (undertaken for the purpose of the National Institute for Health and Care Excellence (NICE)'s appraisal of pegcetacoplan (see details below) were presented.

A general meeting of the members was also called on 15 January 2022 (and attended by 19 members) to vote on whether to merge PNH Support with the Aplastic Anaemia Trust (AAT) (a charitable company No. 1107539) in order to maximise activities for the benefit of both communities. At this meeting the membership voted in favour of an amended resolution where the trustees were to continue to explore a merger with the AAT in order to satisfy certain criteria after which the merger would be voted on again by a simple majority of members at a general meeting. The criteria stipulated were: appropriate name; appropriate number and representation of PNH patient trustees on the merged board (minimum of 3); and appropriate plan to address: PNH patients' experience including having appropriate staffing/capacity to support PNH patients and no dilution of the existing activities and actions of PNH Support; and continued representation on and participation in the PNH Global Alliance. After further discussion with the AAT, it was decided that not all of PNH Support's current national and international activities could continue to be undertaken as they currently were as part of a proposed merger. Therefore the merger did not proceed however PNH Support continues to share, collaborate and work closely with the AAT for the benefit of both communities with a view to reviewing a possible merger (if appropriate) in the future.

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.

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2022

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 2022 in order to further its charitable purposes for the public benefit:

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**:

1. maintained and moderated a closed Facebook page with 259 members open to patients and their families living in the United Kingdom and Ireland to disseminate news, events and facilitate discussion and support between members of the closed group about living with PNH.
2. provided one-on-one advice, signposting and support to patients regarding a range of non-medical advice topics
3. hosted 8 virtual patient meetings on Zoom including meetings with guest speakers including PNH physicians and an occupational therapist specialising in managing fatigue.
4. The East Anglia patient group met once face-to-face in September 2021 and otherwise twice virtually.
5. members were able to join the Aplastic Anaemia Trust's "Wellbeing Wednesdays" and other community support sessions relevant to the PNH community.

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):

6. maintained a community Facebook Page in order to raise awareness of the disease and include relevant news and updates:
<https://www.facebook.com/PNH-Support-126655011000361/>.
7. maintained and updated a 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 information re COVID guidance and information on obtaining third and fourth vaccinations/boosters.
8. held a patient and family meeting over Zoom where updates on COVID, recent research and PNH treatments in development were provided by Dr Austin Kulasekararaj.
9. Maria Piggan attended: the virtual European Haematology Association (EHA) Congress in June 2021 (and disseminated relevant information to patients);

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2022

and the virtual Health Technology Assessment involvement (HTAi) Annual 2021 meeting.

10. maintained a Twitter handle @PNHSupport in order to raise awareness of the disease, the patient group and disseminate news, information and events.
11. members were able to join the Aplastic Anaemia Trust's education sessions and webinars relevant to the PNH community.

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**:

NICE

12. participated in the NICE Single Technology Appraisal of the drug pegcetacoplan including undertaking a patient and carer survey of 76 patients and 16 carers and making a submission to NICE. Two members were supported by PNH Support to provide expert patient evidence as part of the appraisal. NICE recommended pegcetacoplan as an option for treating adults with PNH in England and Wales who are anaemic after treatment with a C5 inhibitor for at least three months. On 9 March 2022, NICE published its final guidance on pegcetacoplan following the Medicine Healthcare Regulatory Agency having provided a Great Britain Marketing Authorisation for it.

PNH National Service

13. provided advice on the redevelopment of the PNH National Service website.
14. created a report based on the results of the patient and carer survey undertaken for the NICE pegcetacoplan appraisal including unmet need and further support required by patients which was provided to the PNH National Service for relevant actions to be taken.

Kings College Hospital

15. joined the newly formed patient involvement and engagement group at Kings College Hospital, London to ensure the PNH patient voice is represented including conveying insights about attending appointments at Kings College Hospital from our community.
16. provided advice to the Kings College Clinical Research Facility regarding events and engagement with PNH patients.

Pharmaceutical companies and market research agencies

17. engaged with pharmaceutical companies developing new treatments for PNH with regard to the involvement of patients in the research and development process and research studies including providing the patient perspective on study design, reviewing study protocols and patient facing study documentation. Each engagement was subject to an agreement as required by industry codes of practice where trustees were remunerated for their time in accordance with fair market value.
18. reviewed requests by pharmaceutical companies and market research agencies to disseminate opportunities to PNH patients

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2022

NHS England

19. represented PNH Support at an NHS England annual meeting with the PNH National Service on 29 June 2021.

National Alliances

20. attended Specialised Healthcare Alliance meetings to represent PNH Support
21. participated in the “Together for Healthy Marrow Alliance (TFHMA)” comprising 7 UK rare bone marrow failure disorder patient organisations with the aim of collaboration and knowledge sharing to benefit our respective communities. This included developing a collaborative bid for the National Lotteries Community Fund to embed further sustainability and support for our respective communities.

International Alliances

22. Maria Piggin continued to:
- a. chair the PNH Global Alliance (PNHGA) comprising 11 PNH global patient organisations from 9 countries with the aim of collaboration and knowledge sharing to benefit the wider PNH community including representing the PNHGA by:
 - i. participating in the International PNH Interest Group (IPIG) PNH Registry Committee
 - ii. attending the Executive Committee meetings of the current PNH Registry
 - iii. attending the IPIG virtual 16th Annual Scientific Assembly where results of the AAT funded research on the effectiveness of COVID vaccines on PNH and aplastic anaemia patients were released
 - iv. participating in the EHA Patient Organisation Committee.
 - b. represent bone marrow failure patients in the European Reference Network for rare haematological disorders (EuroBloodNet) including advocating for patients without access to treatment and disseminating all relevant information to TFHMA members.
23. facilitated (in the absence of a formal patient group in Ireland) a submission made by Irish PNH patients to the National Centre for Pharmacoeconomics (NCPE) in Ireland for the approval of ravulizumab as a treatment for PNH patients.
24. Maria Piggin delivered a presentation entitled: “Access to Orphan Medicinal Products: the discussion around value, benefit and price from a patient’s perspective” at the virtual EHA Congress in June 2021.

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED 31 MARCH 2022

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**:

25. provided one-on-one advice, signposting and support to patients regarding a range of non-medical advice topics including by directing them to the appropriate information sources or persons (including in relation to COVID 19, participation in market research opportunities).
26. maintained a website in order to provide updated information to disseminate news and events relevant to the PNH community including in relation to COVID.
27. members were able to join the AAT's Wellbeing Wednesdays and other community webinars relevant to the PNH community.

How we have managed risk

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

Sustainability

The trustees circulated a call for additional trustees and volunteers to assist to run PNH Support and discussions are continuing with those who have been in contact. It is anticipated that the National Lottery Grant (if successful) will train a new volunteer to contribute to creation of new patient information and patient engagement in collaboration with the TFHMA communities.

Financial Review

PNH Support received the following receipts in the year:

Donations	£287
Honoraria/consultancy fees	£4,356
Total	£4,642

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.

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2022

The trustees are satisfied that PNH Support's gross income for the period is less than the £25,000 threshold and as such, there is no requirement for an audit or an independent examiner's statement.

On behalf of the Trustees



.....
Maria Piggitt
Chair
PNH Support

Date: 10 July 2022

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2022

ANNEX A

Form CC16a
Receipts and Payments Accounts for PNH Support for the year ended
31 March 2022

Receipts and payments accounts

CC16a

For the period from	Period start date 01/04/2021	To	Period end date 31/03/2022
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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	287	-	-	287	358
Fee for Services / Honoraria	4,356	-	-	4,356	2,347
Grant Funding for Zoom Licence [Apellis]	-	-	-	-	299
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	4,642	-	-	4,642	3,003
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	4,642	-	-	4,642	3,003
A3 Payments					
AGM & Conference	-	-	-	-	-
EHA Congress	-	-	-	-	-
Insurance - Zurich	364	-	-	364	-
IT Service & Fees	646	-	-	646	730
Members & Trustee Travel	-	-	-	-	-
PNH Global Alliance Membership Fee	218	-	-	218	229
PNH Support Website	-	-	-	-	-
Postage	10	-	-	10	58
Repay Fee for Services	-	-	-	-	-
Regional Patient Meetings	-	-	-	-	-
Stationary	-	-	-	-	-
Member & Trustee Expenses	24	-	-	24	-
Bank Fees	21	-	-	21	-
Sub total	1,284	-	-	1,284	1,016
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	1,284	-	-	1,284	1,016
Net of receipts/(payments)	3,359	-	-	3,359	1,987
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	9,576	-	-	9,576	7,589
Cash funds this year end	12,934	-	-	12,934	9,578

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)	12,934	-	-
		-	-	-
	Total cash funds	12,934	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets	Details	to nearest £	to nearest £	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	Unrestricted	891	-
			-	-
			-	-
			-	-
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

Maria Piggin

03/07 / 2022

PNH SUPPORT

England & Wales - Charity number 1161518

Accounts

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2021



**REPORT AND ACCOUNTS OF PNH SUPPORT
FOR THE YEAR ENDED 31 MARCH 2021**

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

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2021

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REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2021

REPORT OF THE TRUSTEES (for the year ended 31 March 2021)

The trustees present this report and receipts and payments accounts for the year ended 31 March 2021. 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 four trustees. Nelson Ekwedike retired as longest serving trustee as required by paragraph 13(1) of the Constitution on 16 May 2020. The trustees operate within PNH Support's constitution dated 30 April 2015 (the "Constitution") amended by member resolution on 16 May 2020 to permit the AGM to be held virtually as a result of COVID 19. The Constitution is an 'Association' model and has voting members other than its trustees.

PNH Support currently has 131 members. Membership is open to patients (and their families/carers) living with Paroxysmal Nocturnal Haemoglobinuria ("PNH") living in England, Wales and Northern Ireland.

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.

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 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.

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2021

PNH Support undertook the following activities during the year ended 31 March 2021 in order to further its charitable purposes for the public benefit:

1. maintained a community Facebook Page – in order to raise awareness of the disease and include relevant updates - <https://www.facebook.com/PNH-Support-126655011000361/>
2. maintained and moderated a closed Facebook page with 242 members open to patients and their families living in the United Kingdom to disseminate news and events and facilitate discussion and support between members of the closed group about living with PNH
3. maintained a Twitter handle @PNHSupport in order to raise awareness of the disease and the patient group and disseminate information.
4. maintained and updated the website (www.pnhuk.org) in order to provide information and disseminate news and events relevant to the PNH community.
5. provided support to PNH patients including by directing them to the appropriate information sources or persons (including in relation to COVID 19)
6. produced a six monthly newsletter for members.
7. held a virtual AGM (due to COVID) on 16 May 2020 attended by 17 people.
8. held regular patient and family meetings over Zoom from June 2020 to March 2021
9. attended the virtual European Haematology Association Congress in June 2020
10. advocated on behalf of members with stakeholders such as Healthcare at Home, the PNH National Service, the NHS, and NHS England
11. participated in the National Institute for Health and Care Excellence (NICE) successful Single Technology Appraisal of ravulizumab (Ultomiris) for payment including undertaking a patient and carer survey of 75 people
12. participated in the NICE Single Technology Appraisal for pegcetacoplan (ongoing) including undertaking a patient and carer survey
13. participated in a NICE scientific advice process for a confidential new therapy for PNH
14. engaged with pharmaceutical companies developing new treatments for PNH with regard to the involvement of patients in the research and development process
15. member of the PNH Global Alliance comprising 8 PNH global patient organisations from 7 countries with the aim of collaboration and knowledge sharing to benefit our respective communities
16. represented bone marrow failure patients in the European Reference Network for rare haematological disorders (EuroBloodNet).
17. member of the “Together for Healthy Marrow Alliance” for rare bone marrow failure disorder patient organisations in the UK with the aim of collaboration and knowledge sharing to benefit our respective communities.

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2021

Financial Review

PNH Support received the following receipts in the year:

Donations	£376.70
Honoraria/consultancy fees	£2,327.50
Grant funding	£299.27
Total	£3,003.47

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 £25,000 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

3 July 2021
.....
Date:

REPORT AND ACCOUNTS OF PNH SUPPORT FOR THE YEAR ENDED
31 MARCH 2021

ANNEX A

Form CC16a
Receipts and Payments Accounts for PNH Support for the year ended
31 March 2021



Receipts and payments accounts

For the period from	Period start date 01/04/2020	To	Period end date 31/03/2021
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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					
Alexion Expense Reimbursement		-	-	-	7
Christmas Cards - Receipts		-	-	-	23
Donations	377	-	-	377	1,084
Fee for Services / Honoraria	2,328	-	-	2,328	-
Grant Funding for Zoom Licence [Apell]	299	-	-	299	-
Sub total (Gross income for AR)	3,003	-	-	3,003	1,114
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	3,003	-	-	3,003	1,114
A3 Payments					
AGM & Conference	-	-	-	-	270
EHA Congress	-	-	-	-	451
Insurance - Zurich	-	-	-	-	364
IT Service & Fees	730	-	-	730	333
Members & Trustee Travel	-	-	-	-	236
PNH Global Alliance Membership Fee	229	-	-	229	-
PNH Support Website	-	-	-	-	98
Postage	58	-	-	58	7
Repay Fee for Services	-	-	-	-	300
Regional Patient Meetings	-	-	-	-	326
Stationary	-	-	-	-	61
Trustee Expenses	-	-	-	-	14
Sub total	1,016	-	-	1,016	2,460
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	1,016	-	-	1,016	2,460
Net of receipts/(payments)	1,987	-	-	1,987	- 1,346
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	7,588	-	-	7,588	8,934
Cash funds this year end	9,576	-	-	9,576	7,588

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)	9,576	-	-
		-	-	-
		-	-	-
	Total cash funds <small>(agree balances with receipts and payments account(s))</small>	9,576	-	-
		OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Details	-	-	-
	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	200
	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	03 / 07 / 2021	/ / 2021