

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

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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.

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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.

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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
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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:

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ANNEX A

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



CHARITY COMMISSION
FOR ENGLAND AND WALES

PNH Support

No (if any)

Receipts and payments accounts

CC16a

For the period
from

Period start date
01/04/2020

To

Period end date
31/03/2021

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 (agree balances with receipts and payments account(s))	9,576	-	-
		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	200
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 / 2021
				/ / 2021