

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

**CONTENTS**

	<b>Page</b>
Trustees report for the year ended 31 March 2022	3
Annex A: Form CC16a - Receipts and Payments Accounts for PNH Support for the year ended 31 March 2022	6

## 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 Piggin 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](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 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 Piggin 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 16<sup>th</sup> 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
<b>Total</b>	<b>£4,642</b>

### 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 Piggin  
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	To	Period end date
	01/04/2021		31/03/2022

### 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	287	-	-	287	358
Fee for Services / Honoraria	4,356	-	-	4,356	2,347
Grant Funding for Zoom Licence [Apellis]	-	-	-	-	299
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>4,642</b>	<b>-</b>	<b>-</b>	<b>4,642</b>	<b>3,003</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>4,642</b>	<b>-</b>	<b>-</b>	<b>4,642</b>	<b>3,003</b>
<b>A3 Payments</b>					
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	-
<b>Sub total</b>	<b>1,284</b>	<b>-</b>	<b>-</b>	<b>1,284</b>	<b>1,016</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>1,284</b>	<b>-</b>	<b>-</b>	<b>1,284</b>	<b>1,016</b>
<b>Net of receipts/(payments)</b>	<b>3,359</b>	<b>-</b>	<b>-</b>	<b>3,359</b>	<b>1,987</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>9,576</b>	<b>-</b>	<b>-</b>	<b>9,576</b>	<b>7,589</b>
<b>Cash funds this year end</b>	<b>12,934</b>	<b>-</b>	<b>-</b>	<b>12,934</b>	<b>9,576</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 £
<b>B1 Cash funds</b>	Cash at Bank (HSBC)	12,934	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>12,934</b>	<b>-</b>	<b>-</b>
	(agree balances with receipts and payments account(s))	OK	OK	OK
<b>B2 Other monetary assets</b>	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
<b>B4 Assets retained for the charity's own use</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
	Apple Air Laptop	Unrestricted	891	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B5 Liabilities</b>	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 Pigginn

Maria Pigginn

03/07 / 2022