

Trustees' Annual Report for the period

From	Period start date			Period end date		
	Day 01	Month January	Year 2022	Day 31	Month December	Year 2022

b. Section A details

Reference and administration

Charity name

Pitt Hopkins UK

Other names charity is known by

Registered charity number (if any) 1167153

Charity's principal address

76 Auckland Road

Ilford

Essex IG1 4SF

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Sue Routledge	Chair		
2	Brian Routledge			
3	Leanne Groves			
4	Julie Cooper			
5	Melissa Stewart			
6	Maryrose Brennan		From 11-04-22 onwards	
7	Graham Fiveash	Treasurer	From 07-11-22 onwards	
8	Debbie Bromley		01-01-2022 – 15-05-22	
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

b. Type of adviser Name Address

c.

d.

e.

f.

Name of chief executive or names of senior staff members (Optional information)

b. Section B Structure, governance and management

Description of the charity's trusts

Type of governing document
(eg. trust deed, constitution)

Written constitution

How the charity is constituted
(eg. trust, association, company)

CIO

Trustee selection methods
(eg. appointed by, elected by)

Appointed by trustees

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

Debbie Bromley stepped down from being a trustee, after two three-year terms.

Maryrose Brennan became a trustee in April 2022.

Graham Fiveash took over as Treasurer in October 2022.

Summary of the objects of the charity set out in its governing document

1. Raising awareness of Pitt-Hopkins syndrome for the public.
2. Supporting families by providing information and funding to facilitate opportunities to meet.
3. Making contact with medical and social professionals.
4. Funding research

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

Continuing support of research by Professor Smidt, Amsterdam.

Preparation of a simple parent-friendly guide to the recommendations of the 2018 consensus statement started.

Ongoing maintenance and improvement of the Pitt Hopkins UK website and mobile phone app.

Participation as an elected patient advocate in the ePAG (patient advocacy group) for ERN (European Reference Network) ITHACA

Working with medical professionals with the Patient Led Research Hub (PLRH) in Cambridge

Taking part in on-going free training on running a small charity online and in-person.

Representing Pitt Hopkins UK at meetings and events.

Improvement of charity governance.

All activities have been undertaken with due regard to the guidance issued to trustees by the Charity Commission on public benefit.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

Pitt-Hopkins mobile phone app management provided by a volunteer.

Ongoing redesign of the website has been provided pro bono by one of the trustees

Nathan Routledge acted as a scientific advisor.

Summary of the main achievements of the charity during the year

Raising Awareness/Support

The charity continued to disseminate information and provide support to parents and families via dedicated support groups (Google, Facebook), Skype phone line, website, app, social media, e-mail and personal contacts.

Work started on producing a simple parent-friendly guide to the recommendations of the 2018 consensus statement.

An informal gathering of some families took place in Burgess Hill in October 2022.

As in previous years, Facebook Profile photos for use on Pitt-Hopkins Awareness Day (September 18) were prepared. An Awareness Day campaign video was also produced.

The Charity continued to work with the Cambridge Rare Disease Network (CRDN), Beacon (formally Findacure), EURORDIS, Genetic Alliance UK. Canva and Rare Revolutionaries.

Advice sought for parents from the doctors at the Dutch Pitt-Hopkins clinic via email.

Working with medical professionals with the Patient Led Research Hub (PLRH) in Cambridge

Contact was made with BNI, a networking organisation which resulted in some pro bono work on an IT problem.

Administration

The trustees met six times during the year, the meetings being held on-line. The AGM was held (on-line) in December 2022.

Charity policies on Complaints, Equal Opportunities, Finance and Safeguarding were reviewed and agreed.

A virtual assistant to support the Chair with administration tasks e.g. newsletter was found.

The Chair, as an ePAG advocate and an elected member of the patient board for ERN ITHACA participated in online training courses.

The free Pitt Hopkins UK mobile app was reviewed and updating/redesign of the website continued.

Finance/Fundraising

The income stream in 2022 came from individual donations and Facebook and Give As You Live re-imbursements generated by numerous fundraising efforts including long distance running, cycling and walking events and sales of T-shirts.

An application for a grant from Pears Foundation was not successful this year.

The charity supported a runner in the London Marathon in October.

A search for savings accounts having a better rate of interest than the present accounts was initiated.

Research

In December, the Amsterdam research group contacted the charity to say that the 2022 report of the research progress would be sent in January 2023

Ongoing work with the PLRH on the anonymised data from the family registry which was launched in 2021. Meetings with medical professionals and researchers who are experts in Rett syndrome which can be a differential diagnosis to PTHS looking at how we can apply for funding for research into the breathing anomalies.

The charity met with Aspire Biosciences.

Section E

Financial review

Brief statement of the charity's policy on reserves

£5000 held as reserve

Details of any funds materially in deficit

None

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

c. Section F

Other optional information

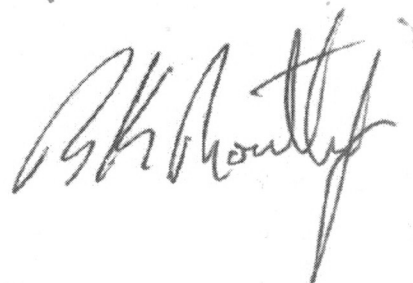
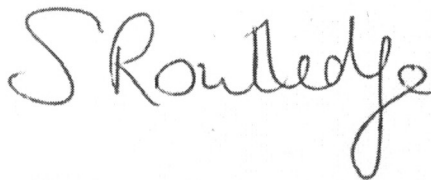
Section G

Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)



Full name(s)

Susan Routledge

Brian Keith Routledge

Position (eg Secretary, Chair, etc)

Chair

Trustee

Date

19th October 2023

19th October 2023

	Jan		Feb		Mar		Apr		May	
Cash b/f	£	28.516	£	29.811	£	28.086	£	25.186	£	26.011
Zoom	£	142								
Bank fee	£	4			£	2				
ICO	£	35								
Bank charges	£	6	£	6	£	5	£	5	£	5
Fundraising	£	50								
Wooler			£	30						
Charlotte Rastan			£	900	£	3.100				
Debbie Bromley			£	84						
Jo McPherson				230	£	69				
PolicyBee			£	546						
Appy Pie					£	57				
GAUKL								£	50	
Skype										
IT										
NRG Collective										
Workwear										
FB charges										
Diane Trill										
Texthelp										
Caroline Payne										
	£	237	£	1.796	£	3.233	£	5	£	55
	Jan	Feb		Mar		Apr		May		
Mirren Thompson	£	20	£	20	£	20	£	20	£	20
Donation	£	1.496			£	40			£	535
Give as you live	£	16					£	756	£	655
Amazon core			£	51					£	26
PolicyBee					£	273				
J Cooper										
FB										
Deposit interest							£	54		
	£	1.532	£	71	£	333	£	830	£	1.236
Cash c/f	£	29.811	£	28.086	£	25.186	£	26.011	£	27.191

NW Issue 7
NW 45 day

£ 5.000,00

Jun	Jul	Aug	Sep	Oct	Nov	Dec	2022 Total
£ 27.191	£ 30.684	£ 39.072	£ 42.743	£ 46.045	£ 51.427	£ 56.346	
							£ 142
							£ 5
							£ 35
£ 5	£ 5	£ 5	£ 5	£ 5	£ 5	£ 6	£ 63
							£ 50
							£ 30
							£ 4.000
							£ 84
							£ 299
							£ 546
							£ 57
							£ 50
	£ 202						£ 202
	£ 60				£ 16	£ 64	£ 140
			£ 65				£ 65
			£ 718				£ 718
			£ 12	£ 6	£ 6	£ 6	£ 30
				£ 244			£ 244
						£ 992	£ 992
						£ 260	£ 260
£ 5	£ 267	£ 5	£ 800	£ 255	£ 27	£ 1.328	£ 8.013
Jun	Jul	Aug	Sep	Oct	Nov	Dec	Total
£ 20	£ 20	£ 20	£ 20	£ 20	£ 20	£ 20	£ 240
£ 195	£ 65	£ 76	£ 700	£ 2.267	£ 300	£ 1.000	£ 6.674
£ 3.283	£ 8.570	£ 3.564	£ 2.415	£ 3.176	£ 4.499	£ 450	£ 27.384
		£ 16			£ 24		£ 117
							£ 273
			£ 648	£ 10			£ 658
			£ 319	£ 164	£ 103	£ 104	£ 689
£ 3.498	£ 8.655	£ 3.675	£ 4.102	£ 5.637	£ 4.946	£ 1.574	£ 36.088
							£ -
							£ -
							£ -
£ 30.684	£ 39.072	£ 42.743	£ 46.045	£ 51.427	£ 56.346	£ 56.592	£ 56.592
Gain/loss							£ 28.076

£ 5.000,00

I+E 2022		BS 2022
	b/f	£ 49.061,86
	c/f	£ 77.137,74

£ 8.012,58

£ 36.088,46

Gain	£ 28.075,88	£ 28.075,88
------	--------------------	--------------------

Current plus deposit accounts

Current plus deposit accounts

Change in cash



Section A

Independent Examiner's Report

Report to the trustees

Charity Name
Pitt Hopkins UK

On accounts for the year ended

Dec 31 2022

Charity no
(if any)

1167153

Set out on pages

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **DD /31/12/2022**.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

~~The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of [insert name of applicable listed body]. Delete [] if not applicable.~~

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination ~~(other than that disclosed below)~~ which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

** Please delete the words in the brackets if they do not apply.*

Signed:

Date:

7/9/2023

Name:

Michael Waters

Relevant professional
qualification(s) or body

C.Eng, FIMMM

(if any):

Address:

22 Willowmead Close, Prestbury SK10 4BU

Section B	Disclosure
------------------	-------------------

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

--