

Trustees' Annual Report for the period

Period start date

Period end date

From

To

Section A

Reference and administration details

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

Postcode

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	Debbie Bromley			
6	Julie Penniall		01/01/21 -01/04/21	
7	Melissa Stewart		From 12/07/21 onwards	
8	Virginia Routledge	Treasurer	01/01/21 - 30/09/21	
9				
10				
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12				
13				
14				
15				
16				
17				
18				
19				
20				

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)

Type of adviser	Name	Address

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

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Section B Structure, governance and management

Description of the charity's trusts

Type of governing document <small>(eg. trust deed, constitution)</small>	Written constitution
How the charity is constituted <small>(eg. trust, association, company)</small>	CIO
Trustee selection methods <small>(eg. appointed by, elected by)</small>	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.

Julie Penniall passed away after an short illness in April. 2021 after having served nearly five years as a trustee.

Melissa Stewart was appointed as a trustee in July 2021.

Section C Objectives and activities

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

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

Supporting ongoing research by Professor Smidt.

Publication of the information booklet based on the published Management Guidelines discussed at the 2018 World Congress.

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

On-line hosting of smaller informal coffee meetings for patents.

Participation as a patient advocate in the ePAG. (patient advocacy Group) for ERN (European Reference Network). ITHACA.

Taking part in on-going training on running a small charity.

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 and elements of the website redesign are provided by volunteers.

Section D

Achievements and performance

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 a dedicated phone line, website, app, social media, e-mail and personal contacts.

The information booklet based on the parent-friendly version of the management guidelines produced during 2019 for parents was completed, printed and published. Interest in the booklet was received from various overseas groups.

A leaflet for fund raisers and a 'Thank You' card were designed and produced.

An online meeting for Fathers took place in May 2021.

A mailing list was constructed in preparation for a newsletter which was published in December 2021.

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 in partnership with the Cambridge Rare Disease Network (CRDN), Findacure, EURORDIS, Genetic Alliance UK and Rare Revolutionaries. Contact was made with Breaking Down Barriers.

In September 2021, in conjunction with the Swedish and Dutch groups, an online meeting for parents was held with Dr. Sylvia Huisman and Dr. Leone Menke from the Pitt-Hopkins syndrome clinic Amsterdam Medical Centre

Administration

The trustees met three times during the year, the meetings being held on-line. The AGM was held (on-line) in November 2021.

A review of charity policies was begun.

Two students from Brighton University took part in a virtual internship with the charity aiding the general administration.

Grant money was used to pay for a virtual assistant to support the Chair with administration tasks and for professional help with the website re-design

A second banner was purchased.

A laptop and printer were finally purchased with a grant from Pears Foundation

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

The charity had runners in the Virtual Vitality 10K in March and four runners in the London Virtual Marathon in October 2021.

Section D

Achievements and performance

The free Pitt Hopkins UK mobile phone app was reviewed and updating continued.

Finance/Fundraising

The main income stream in 2021 again came from grants from the National Lottery, Pears Foundation, Virgin Money Giving, Facebook and Gift Aid. 20% of income was raised from individual donations and fundraising efforts.

As the Virgin Money Giving scheme had announced it would close, Give As You Live was promoted as the method for collecting donations by fundraisers.

Research

In November, Professor Marten Smidt, by Zoom, updated the trustees and some parents of progress in the research project being co-funded by Pitt Hopkins UK.

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.

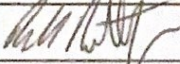

Grants, Gift Aid, donation schemes e.g., Virgin Money Giving, individual fund-raising.

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)	Brian Keith Routledge	JULIE COOPER
Position (eg Secretary, Chair, etc)	Trustee (Acting Treasurer)	TRUSTEE
Date	02 October 2022	

PHUK Income and expenditure

	2021
<u>Income</u>	
Grants	£13.483,00
Virgin Money Giving	£12.525,14
Donations	£5.894,64
Facebook	£1.453,27
HMRC	£551,40
Benevity	£144,68
Amazon Smile	£73,43
Stripe	£54,84
Give As You Live	£50,00
Everyclick	£31,72
Nationwide Interest	£121,20
Total Income	£34.383,32
<u>Expenditure</u>	
C. Rastin	£5.169,00
Software	£945,60
J.Mcpherson	£920,00
Publishing/printing	£907,16
Laptop	£798,00
Subscriptions	£437,52
Insurances	£296,24
Phones	£202,32
Printer	£183,90
London Marathon	£179,00
Banner	£146,40
Office costs	£141,52
Office supplies	£119,22
Webhosting/App	£114,40
Poster	£72,00
Seminars/webinars	£28,00
Expenses	£16,05
Fees	£8,14
Total	£10.684,47
Total surplus	£23.698,85
<u>External Giving</u>	
Grant to Professor	£0,00
Grant to research body	£0,00
Total External Giving	£0,00
Net Surplus/Deficit	£23.698,85

HSBC

Current	01/01/2021	£9.938,01
61714589	31/12-/021	£28.515,66

Year change £18.577,65

Nationwide

Saver 7	01/01/2021	£5.000,00
90162936	31/12-/021	£5.000,00

Year change £0,00

Nationwide

45 Saver	01/01/2021	£10.425,00
90162944	31/12/2021	£15.546,20

Year change £5.181,20

	<u>HSBC</u>	<u>NWS7</u>	<u>NW45</u>
31/12/2021	£28.515,66	£5.000,00	£15.546,20
01/01/2021	£9.938,01	£5.000,00	£10.425,00
Year change	£18.577,65	£0,00	£5.121,20

Total

£49.061,86
£25.363,01
£23.698,85



Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity Name
Pitt Hopkins UK

On accounts for the year
ended

Dec 31st 2021

Charity no
(if any)

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 31/12/2021.

Responsibilities and
basis of report

As the charity trustees of the Trust, 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 the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

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

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn 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:

14th July 2022

Name:

Michael Waters C.Eng., FIMMM

Relevant professional
qualification(s) or body
(if any):

Address:

22 Willowmead Drive, Prestbury Cheshire SK10 4BU

Only complete if the examiner needs to highlight 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.

Nationwide have not provided year end statements, only disclosing latest changes to the accounts, which have been taken as year end.