

| Trustees' Annual Report for the period |  |                   |                  |              |                 |                   |
|--|--|-------------------|------------------|--------------|-----------------|-------------------|
| From                                   |  | Period start date |                  |              | Period end date |                   |
|  |  | Day<br>01         | Month<br>January | Year<br>2023 | b. Day<br>31    | Month<br>December |

## 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   |  |  |
|                                    | <div style="display: flex; justify-content: space-between;"> <span>a.<br/>P</span> <span>b.</span> </div> |  |  |

### 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 |                 |                                   |   |
| 7  | Graham Fiveash   | Treasurer       |                                   |   |
| 8  |                  |                 |                                   |   |
| 9  |                  |                 |                                   |   |
| 10 |                  |                 |                                   |   |
| 11 |                  |                 |                                   |   |
| 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)

| b. Type of adviser | Name | Address |
|--------------------|------|---------|
| c.                 |      |         |
| d.                 |      |         |
| e.                 |      |         |
| f.                 |      |         |

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

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## b. Section B Structure, governance and management

#### Description of the charity's trusts

|   |                       |
|---|-----------------------|
| Type of governing document<br>(eg. trust deed, constitution)        | Written constitution  |
| How the charity is constituted<br>(eg. trust, association, company) | CIO                   |
| Trustee selection methods<br>(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.

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## Section C Objectives and activities

**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. Encouraging 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)**

Face to face contact in November with Professor Smidt, Amsterdam.

Continuing work on producing a simple parent-friendly booklet to the recommendations of the 2018 consensus statement.

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 e.g. RAREsummit 2023.

Improvement of charity governance.

Two newsletters were published

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 with input from the chair

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 continued on producing a simple parent-friendly booklet to the recommendations of the 2018 consensus statement.

An informal gathering of some families took place in Nuneaton in May 2023.

For Pitt-Hopkins Awareness Day (18<sup>th</sup> September), Facebook Profile photos were prepared. An Awareness Day campaign slideshow was also produced.

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

Chat magazine had an article on the sibling of someone with Pitt-Hopkins syndrome.

Two newsletters were produced.

Banners and business cards designed and purchased.

**Administration**

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

The charity policy on Finance was further reviewed and agreed.

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.

Planning for a face-to face meeting of trustees in Spring 2024 was started.

**Finance/Fundraising**

**a. Section D****Achievements and performance**

The income stream in 2023 came from Gift Aid, individual donations and Facebook and Give As You Live re-imbursements generated by numerous fundraising efforts including long distance running, (Manchester 10K, London Half Marathon, iRun Gatwick 10K, Cardiff Half Marathon), cycling and walking events and sales of T-shirts.

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

**Research**

The 2022 report from the Amsterdam research group was received in January 2023

Work with the PLRH on the anonymised data from the family registry, which was launched in 2021, continued.

**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 GDeclaration

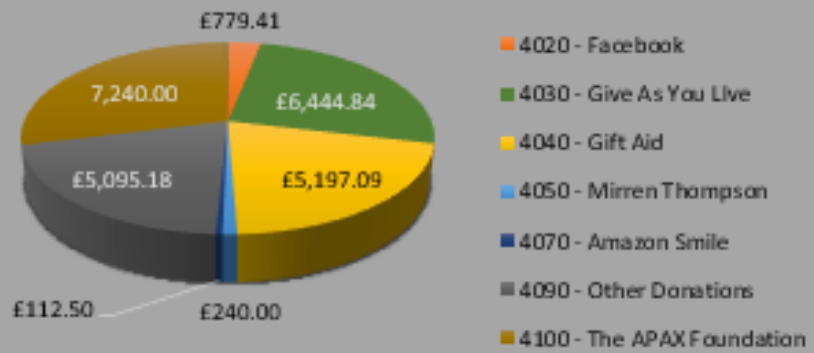
The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

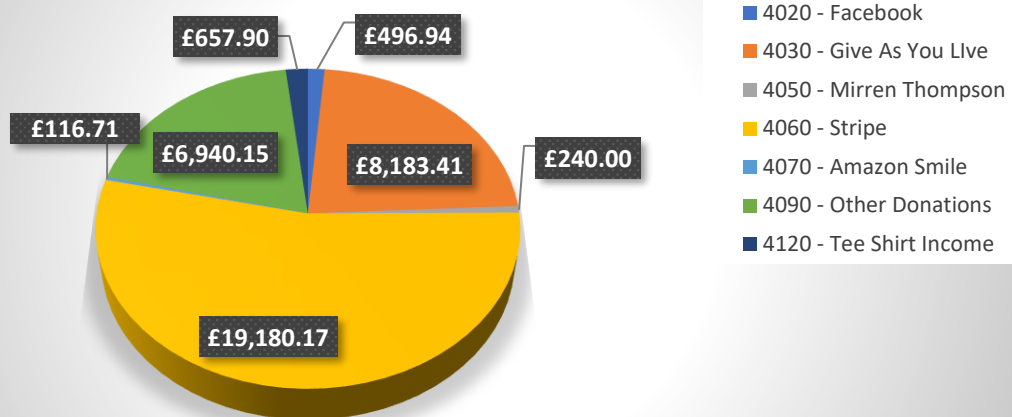
|                                     |   |   |
|-------------------------------------|---|---|
| Signature(s)                        |  |  |
| Full name(s)                        | Susan Routledge   | Brian Keith Routledge   |
| Position (eg Secretary, Chair, etc) | Chair   |   |
| Date                                | 08 October 2024   | 08 October 2024   |

| <b>Pitt Hopkins UK</b><br><b>Final Income &amp; Expenditure Comparison Statement</b><br><b>January to December 2023</b> |                        |                        |
|---|------------------------|------------------------|
| <b>Donations &amp; Income</b>   | <b>Jan to Dec 2023</b> | <b>Jan to Dec 2022</b> |
| 4010 - Virgin Money   | £0.00                  | £0.00                  |
| 4020 - Facebook   | £779.41                | £496.94                |
| 4030 - Give As You Live   | £6,444.84              | £8,183.41              |
| 4040 - Gift Aid   | £5,197.09              | £0.00                  |
| 4050 - Mirren Thompson  | £240.00                | £240.00                |
| 4060 - Stripe   | £0.00                  | £19,180.17             |
| 4070 - Amazon Smile   | £112.50                | £116.71                |
| 4080 - Pears Grant  | £0.00                  | £0.00                  |
| 4090 - Other Donations  | £5,095.18              | £6,940.15              |
| 4100 - The APAX Foundation  | 7,240.00               | £0.00                  |
| 4120 - Tee Shirt Income   | £0.00                  | £657.90                |
| 4900 - Other income   | £46.25                 | £0.00                  |
| <b>Total Income</b>   | <b>£25,155.27</b>      | <b>£35,815.28</b>      |
| <b>Direct Expenses</b>  |                        |                        |
| 5005 - Virgin Fees  | £0.00                  | £0.00                  |
| 5008 - Stripe Fees  | £0.00                  | £0.00                  |
| 5030 - Cost of PTHS Tee Shirts  | £90.00                 | £717.76                |
| 5040 - Costs of Fund Raising  | £0.00                  | £328.82                |
| 5060 - PTHS Sponsored Events  | £220.00                | £0.00                  |
| <b>Total Direct Expenses</b>  | <b>£310.00</b>         | <b>£1,046.58</b>       |
| <b>GROSS INCOME / LOSS</b>  | <b>£24,845.27</b>      | <b>£34,768.70</b>      |
| <b>Expenditure - Overheads</b>  |                        |                        |
| 6000 - Marketing  | £62.47                 | £0.00                  |
| 7400 - Travelling   | £222.97                | £0.00                  |
| 7400 - Conference Expenses  | £114.32                | £0.00                  |
| 7420 - Hotel and Accommodation  | £150.00                | £0.00                  |
| 7500 - Printing   | £74.99                 | £0.00                  |
| 7510 - Postage and Carriage   | £21.68                 | £0.00                  |
| 7530 - Telephone  | £202.32                | £0.00                  |
| 7540 - Web Site Hosting & Development   | £275.03                | £75.98                 |
| 7550 - Computer & Software  | £153.98                | £1,457.40              |
| 7620 - Consultancy & Professional Fees  | £385.00                | £4,673.00              |
| 7630 - Business Insurance   | £273.18                | £273.18                |
| 7900 - Bank Charges and Interest  | £88.31                 | £98.26                 |
| 8030 - Office Equipment and IT Depreciation   | £0.00                  | £1,212.16              |
| 8210 - Subscriptions  | £135.00                | £115.00                |
| <b>Total Overheads</b>  | <b>£2,159.25</b>       | <b>£7,904.98</b>       |
| <b>NET INCOME / LOSS</b>  | <b>£22,686.02</b>      | <b>£26,863.72</b>      |

## Donations & Income 2023



## Donations & Income 2022



| Pitt Hopkins UK                          |                                  |                   |
|--|----------------------------------|-------------------|
| Finalised Assets & Liabilities Statement |                                  |                   |
| To 31st December 2023                    |                                  |                   |
| <b>ASSETS</b>                            |                                  |                   |
| <b>Fixed Assets</b>                      |                                  |                   |
|  | <b>Total Fixed Assets</b>        | <b>£0.00</b>      |
| <b>Current Assets</b>                    |                                  |                   |
| 1200 - Pitt Hopkins UK                   | 29,277.56                        |                   |
| 1230 - Nationwide 45 Day Saver           | 65,546.20                        |                   |
| 1240 - Nationwide Instant Access Account | 5,000.00                         |                   |
|  | <b>Total Current Assets</b>      | <b>£99,823.76</b> |
|  | <b>TOTAL ASSETS</b>              | <b>£99,823.76</b> |
| <b>LIABILITIES</b>                       |                                  |                   |
| <b>Current Liabilities</b>               | £5,000.00                        |                   |
|  | <b>Total Current Liabilities</b> | <b>£5,000.00</b>  |
| <b>Future Liabilities</b>                |                                  |                   |
|  | <b>Total Future Liabilities</b>  | <b>£0.00</b>      |
|  | <b>TOTAL LIABILITIES</b>         | <b>£5,000.00</b>  |
|  | <b>TOTAL NET ASSETS</b>          | <b>£94,823.76</b> |

| <b>Pitt Hopkins UK</b>                      |                        |
|---|------------------------|
| <b>PROPOSED BUDGET</b>                      |                        |
| <i>January to December 2024</i>             |                        |
| <b>Income</b>                               | <b>Jan to Dec 2023</b> |
| Donations                                   | £12,000                |
| 4040 - Gift Aid                             | £2,000                 |
| 4110 - Interest Earned                      | £2,000                 |
| 4120 - Tee Shirt Income                     | £150                   |
| <b>Budgetted Income</b>                     | <b>£16,150</b>         |
| <b>Expenditure - Overheads</b>              | <b>Jan to Dec 2023</b> |
| 6000 - Marketing                            | £1,200                 |
| 7400 - Travelling                           | £250                   |
| 6012 - Conference Expenses                  | £150                   |
| 7500 - Printing                             | £100                   |
| 7510 - Postage and Carriage                 | £100                   |
| 7530 - Telephone                            | £100                   |
| 7540 - Web Site Hosting & Development       | £200                   |
| 7550 - Computer & Software                  | £200                   |
| 7620 - Consultancy & Professional Fees      | £500                   |
| 7630 - Business Insurance                   | £300                   |
| 7900 - Bank Charges and Interest            | £100                   |
| 8030 - Office Equipment and IT Depreciation | £100                   |
| 8210 - Subscriptions                        | £200                   |
| <b>Budgetted Expenditure</b>                | <b>£3,500</b>          |



Section A

Independent Examiner's Report

Report to the trustees

Charity Name  
Pitt Hopkins UK

On accounts for the year  
ended

Dec 31 2023

Charity no  
(if any)

1167153

Set out on pages

1-2

(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 31/12/2023.

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

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination [REDACTED] which give 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:

26/08/2024

Name:

Michael Waters

Relevant professional

C.Eng., FIMMM

qualification(s) or body  
(if any):

|  |
|--|
|  |
|--|

Address:

22 Willowmead Drive, Prestbury SK10 4BU

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## 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.

The two Nationwide accounts containing the bulk of the charity's funds were only available for inspection up to 1/10/23 and 21/7/23 respectively.

The accountant has explained to me that statements are only issued once per year on these accounts so the balance shown in October on the 45 day account and the balance in July on the instant saver account are the same as the December year-end balances. I have taken this statement on trust.