

PITT HOPKINS UK

England & Wales · Charity number 1167153

Details

Other names PITT HOPKINS SYNDROME UK

Status Registered

Legal form CIO

Registered 2016-05-17

Register [View on the Charity Commission register](#)

Contact

Address 4 Forest Oaks
Horsham
West Sussex
RH13 6RX

Phone 02032392123

Email sue@pitthopkins.org.uk

Website www.pitthopkins.org.uk

Activities

Objects: TO RELIEVE THE NEEDS OF CHILDREN AND YOUNG PEOPLE DIAGNOSED WITH PITT HOPKINS SYNDROME, THEIR FAMILIES AND CARERS BY: 1. INCREASING THE PROFILE OF PITT-HOPKINS SYNDROME FOR PUBLIC BENEFIT BY RAISING AWARENESS OF PITT-HOPKINS SYNDROME. 2. SUPPORTING FAMILIES HAVING A DIAGNOSIS OF PITT-HOPKINS SYNDROME BY PROVIDING INFORMATION AND FUNDING TO FACILITATE OPPORTUNITIES AND MEANS TO COMMUNICATE WITH EACH OTHER AND TO EXCHANGE EXPERIENCES AND ADVICE. 3. PROMOTING UNDERSTANDING OF PITT-HOPKINS SYNDROME BY PROVIDING INFORMATION TO MEDICAL AND SOCIAL PROFESSIONALS. 4. SUPPORTING RESEARCH INTO PITT-HOPKINS SYNDROME, IN PARTICULAR NATURAL HISTORY STUDIES AND BREATHING ANOMALIES AND THE DISSEMINATION OF THE USEFUL RESULTS OF THAT RESEARCH.

Activities: Pitt Hopkins UK aims to raise awareness of Pitt-Hopkins Syndrome (PTHS), particularly among the health professionals, to support and advocate for families while delivering the latest information about PTHS. Pitt Hopkins UK also hopes to be able to fund some research one day particularly into the breathing anomalies that many of the children and adults exhibit

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Disability
- **Who:** People With Disabilities, The General Public/mankind

Geography

- Ireland
- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

| Period end | Income | Expenditure | Assets | Employees |
|------------|---------|-------------|--------|-----------|
| 2024-12-31 | £34,473 | £5,740 | - | - |
| 2023-12-31 | £25,155 | £2,159 | - | - |
| 2022-12-31 | £36,088 | £8,012 | - | - |
| 2021-12-31 | £34,383 | £10,684 | - | - |
| 2020-12-31 | £19,005 | £69,504 | - | - |

Trustees

| Name | Role | Appointed |
|----------------------|-------|------------|
| SUE ROUTLEDGE | Chair | 2016-05-16 |
| BRIAN ROUTLEDGE | | 2016-05-16 |
| Graham John Fiveash | | 2022-11-07 |
| LEANNE GROVES | | 2016-05-17 |
| Mark Lewis Haywood | | 2024-01-15 |
| Melissa-Jane Stewart | | 2021-07-12 |

PITT HOPKINS UK

England & Wales - Charity number 1167153

Accounts

| Trustees' Annual Report for the period | | | | | | |
|--|-------------------|---------|------|-----------------|----------|------|
| From | Period start date | | | Period end date | | |
| | Day | Month | Year | Day | Month | Year |
| | 01 | January | 2024 | 31 | December | 2024 |

b. 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 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 | | | |
| 7 | Graham Fiveash | Treasurer | | |
| 8 | Mark Haywood | | 15/1/2024 | |
| 9 | Debbie Bromley | | 15/1/2024 | |
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Names of the trustees for the charity, if any, (for example, any custodian trustees)

| Name | Dates acted if not for whole year |
|------|-----------------------------------|
| | |
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| | |

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 (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.

Trustee Face to Face meeting held in. April 2024 (see Section D)

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)

Continuing support of research by Dr. Simone Mesman, Amsterdam.

Ongoing maintenance of mobile phone app.

Creation of new Pitt Hopkins UK website.

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.

Pitt Hopkins UK represented at various meetings and events e.g. Genetic Alliance UK monthly online meeting, response to Downs Syndrome Act. etc

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.

The trustees explored the possibility of organising a weekend for families through the Barretstown residential centre in Ireland or at a Horse Riding Centre for the Disabled in North Wales. Further discussions about facilities and dates (2025) are ongoing.

An informal gathering, arranged at short notice, of some families took place in Solihull in October 2024.

A collage for Pitt-Hopkins Awareness Day (18th September) was constructed for use online.

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

Doctors at Amsterdam Medical Centre were contacted via email for help about questions and information wanted by parents.

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

Two trustees took part in the parliamentary lobbies on Rare Disease Day (28/02/24) at Westminster and Edinburgh.

A player at Irchester United FC was sponsored by a parent to raise awareness of Pitt-Hopkins syndrome.

Administration

Mark Haywood and Debbie Bromley joined as trustees in January.

The trustees met five times during the year, four meetings being held on-line and a face-to-face meeting was held in April 2024 in Rochester, Kent. The AGM was held (on-line) in December 2024.

The charity policy on finance was reviewed and agreed.

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

The free Pitt Hopkins UK mobile app was reviewed and design of the new website continued.

A pop-up tent and small PA system were bought for use at family gatherings

Finance/Fundraising

The income stream in 2024 came from individual donations, grants and Facebook and Give As You Live re-imbursments generated by numerous fundraising efforts e.g. Manchester 10K, Wing Walking and a mother in Ireland who climbed 40 peaks in Ireland. Funds were also generated from sales of T-shirts.

A new savings account with HSBC was opened and funds transferred.

The funding platform Wonderful was trialled.

It was agreed to investigate how to set up a lottery in aid of the charity.

Research

The Amsterdam research group contacted the charity to say that the 2023 report of the research progress would be sent in January/Early 2024. The final payment of the contract will be paid in early 2025.

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.

A statistician was helping analyse data held by the charity.

Notes on Trustee Face to Face meeting, April 2024, Rochester, Kent

Discussion on

- a) use of social media
- b) identifying geographical location, by postcode, of families to aid in organising local events and connecting families.
- c) re-assessing fund raising platforms used in view of high fees charged.
- d) ideas for use of accumulated funds
- e) merchandising of items from Simply Logo.
- f) succession planning and search for new trustees.
- g) demonstration of planned new website.

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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)

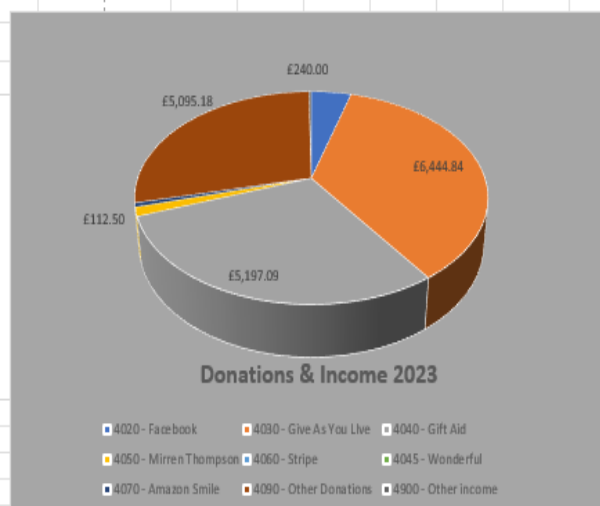
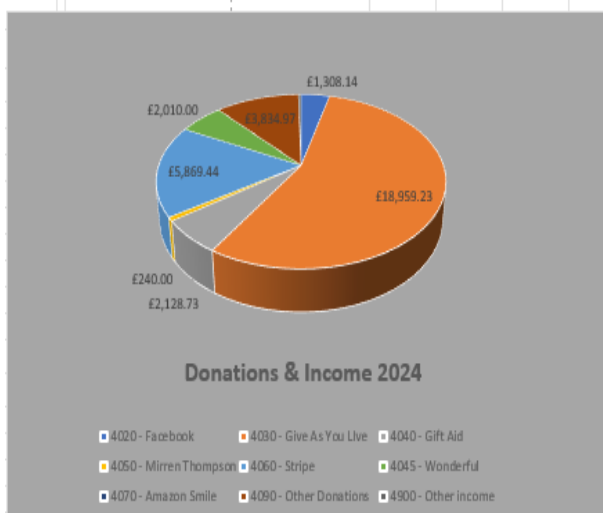
Susan Routledge

Brian Keith Routledge

| | | |
|--|-------------------------------|------------------------------|
| Position (eg Secretary, Chair, etc) | Chair | Trustee |
| Date | 11 th October 2025 | 11 ^h October 2025 |

Pitt Hopkins UK
Final Income & Expenditure Comparison Statement
January to December 2024

| Donations & Income | Jan to Dec 2024 | Jan to Dec 2023 | |
|---|------------------------|------------------------|--------------|
| 4020 - Facebook | £1,308.14 | £779.41 | |
| 4030 - Give As You Live | £18,959.23 | £6,444.84 | |
| 4040 - Gift Aid | £2,128.73 | £5,197.09 | |
| 4050 - Mirren Thompson | £240.00 | £240.00 | |
| 4060 - Stripe | £5,869.44 | £0.00 | |
| 4045 - Wonderful | £2,010.00 | £0.00 | * see note 1 |
| 4070 - Amazon Smile | £0.00 | £112.50 | |
| 4090 - Other Donations | £3,834.97 | £5,095.18 | *see note 2 |
| 4900 - Other income | £122.53 | £46.25 | |
| Total Income | £34,473.04 | £17,915.27 | |
| Direct Expenses | | | |
| 5025 - University of Amsterdam | £5,017.00 | £0.00 | * see note 3 |
| 5030 - Cost of PTHS Tee Shirts | £0.00 | £90.00 | |
| 5060 - PTHS Sponsored Events | £420.00 | £220.00 | |
| 5070 - PTHS Sponsored Family Meeting Events | £758.79 | £0.00 | *see note 4 |
| 5500 - Marketing | £627.93 | £62.47 | |
| 5600 - Conference Expenses | £1,577.82 | £114.32 | *see note 5 |
| Total Direct Expenses | £8,401.54 | £486.79 | |
| GROSS INCOME / LOSS | £26,071.50 | £17,428.48 | |
| Expenditure - Overheads | | | |
| 7050 -Other Expenses | £15.00 | £0.00 | |
| 7400 - Travelling | £249.45 | £222.97 | |
| 7420 - Trustee Expenses | £1,768.58 | £150.00 | * see note 6 |
| 7500 - Printing | £0.00 | £74.99 | |
| 7510 - Postage and Carriage | £8.15 | £21.68 | |
| 7530 - Telephone | £202.32 | £202.32 | |
| 7540 - Web Site Hosting & Development | £66.00 | £275.03 | |
| 7550 - Computer & Software | £2,528.33 | £153.98 | *see note 7 |
| 7620 - Consultancy & Professional Fees | £210.00 | £385.00 | |
| 7630 - Business Insurance | £284.39 | £273.18 | |
| 7900 - Bank Charges and Interest | £144.55 | £88.31 | |
| 8010- Office Equipment & IT Depreciation | £29.99 | £0.00 | |
| 8210 - Subscriptions | £234.20 | £135.00 | |
| Total Overheads | £5,740.96 | £1,982.46 | |
| NET INCOME / LOSS | £20,330.54 | £15,446.02 | |



Note 1 - The 2024 figures include the first donations made through the Wonderful which is free donation website i.e. No Payment or Admin fees

Note 2 - The 2024 figures includes: E.Harrison donation of £600, 4 unnamed cheques for £328.46, £629.36, £519.62 & 226.00 plus a £500 Grant that Neil Burling arranged,

Note 3 - The 2024 figures now include the final payment to University of Amsterdam for Research under the existing contract dated 20/6/2020.

Note 4 -The 2024 figures include the costs for the Solihull PTHS Family Meeting Day in October 2024.

Note 5 - The 2024 figures now include all travelling costs and entrance fees incurred by Trustees attending conferences that have previously been approved by the Charity.

Note 6 - The 2024 figures include the cost of Trustees attending the annual face to face meeting in April 2024 that took place in Rochester.

Note 7 - The 2024 figures include two annual subscription charges (2023 & 2024) for TextHelp software @ £1091 per annum.

Pitt Hopkins UK Finalised Assets & Liabilities Statement To 31st December 2024

| ASSETS | | |
|--|---------------------------------|--------------------|
| Fixed Assets | | |
| | Total Fixed Assets | £0.00 |
| Current Assets | | |
| 1200 - Pitt Hopkins UK | 49,608.10 | |
| 1230 - Nationwide 45 Day Saver | 66,854.00 | |
| 1240 - Nationwide Instant Access Account | 5,096.58 | |
| *Interest Receivable | 1,679.72 | |
| | Total Current Assets | £123,238.40 |
| | TOTAL ASSETS | £123,238.40 |
| LIABILITIES | | |
| Current Liabilities | | |
| Future Liabilities | | |
| | Total Future Liabilities | £0.00 |
| | TOTAL LIABILITIES | £0.00 |
| | TOTAL NET ASSETS | £123,238.40 |

*** Note:** This represents 9 months interest (APR to DEC 2024) on the £66,854.00 that has been earned on the Nationwide 45 Day Saver Account.

Pitt Hopkins UK
PROPOSED BUDGET

January to December 2025

| Income | Jan to Dec 2025 |
|---|------------------------|
| Donations | £12,000 |
| 4040 - Gift Aid | £2,000 |
| 4110 - Interest Earned | £2,000 |
| 4120 - Tee Shirt Income | £0 |
| Budgetted Income | £16,000 |
| | |
| Direct Expenses | Jan to Dec 2025 |
| 5060 - PTHS Sponsored Events | £500.00 |
| 5070 - PTHS Sponsored Family Meeting Events | £1,000.00 |
| 5500 - Marketing | £600.00 |
| 5600 - Conference Expenses | £1,600.00 |
| Budgetted Direct Expenses | £3,700 |
| | |
| Overheads | Jan to Dec 2025 |
| 7400 - Travelling | £250 |
| 7420 - Trustee Expenses | £1,800 |
| 7500 - Printing | £100 |
| 7510 - Postage and Carriage | £200 |
| 7530 - Telephone | £100 |
| 7540 - Web Site Hosting & Development | £1,500 |
| 7550 - Computer & Software | £200 |
| 7620 - Consultancy & Professional Fees | £300 |
| 7630 - Business Insurance | £300 |
| 7900 - Bank Charges and Interest | £150 |
| 8210 - Subscriptions | £200 |
| Budgetted Overheads | £5,100 |



Section A

Independent Examiner's Report

**Report to the trustees/
members of**

Charity Name
Pitt Hopkins UK

**On accounts for the year
ended**

Dec 31 2024

**Charity no
(if any)**

1167153

Set out on pages

1-4 of the accompanying document

(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 **31/12/2024**

**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:

16/4/25

Name:

Michael Waters

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

C.Eng., FIMMM

Address:

22 Willowmead Drive, Prestbury 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.

For administration reasons, the deposit accounts only show the balance as at 31/3/2024.

PITT HOPKINS UK

England & Wales - Charity number 1167153

Accounts

| 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 (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.

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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 (18th 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 G Declaration

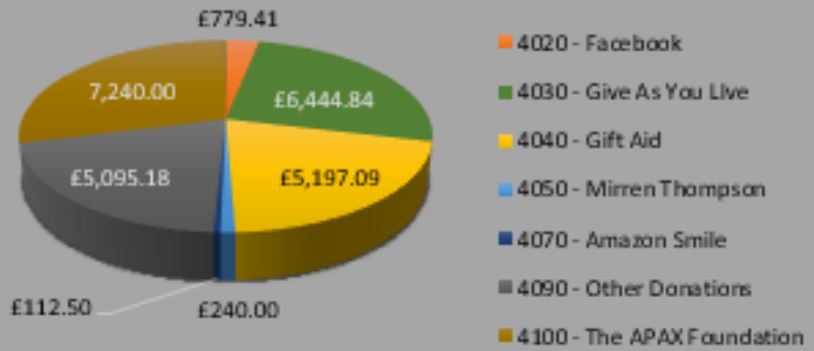
The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

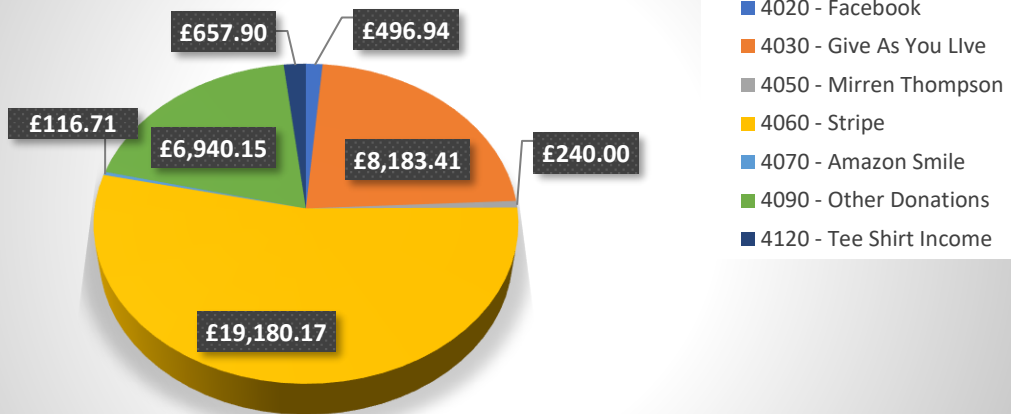
| | | |
|--|---|---|
| Signature(s) |  |  |
| Full name(s) | Susan Routledge | Brian Keith Routledge |
| Position (eg Secretary, Chair, etc) | Chair | |
| Date | 08 October 2024 | 08 October 2024 |

| Pitt Hopkins UK | | |
|--|------------------------|------------------------|
| Final Income & Expenditure Comparison Statement | | |
| January to December 2023 | | |
| Donations & Income | Jan to Dec 2023 | Jan to Dec 2022 |
| 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 |
| Total Income | £25,155.27 | £35,815.28 |
| Direct Expenses | | |
| 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 |
| Total Direct Expenses | £310.00 | £1,046.58 |
| GROSS INCOME / LOSS | £24,845.27 | £34,768.70 |
| Expenditure - Overheads | | |
| 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 |
| Total Overheads | £2,159.25 | £7,904.98 |
| NET INCOME / LOSS | £22,686.02 | £26,863.72 |

Donations & Income 2023



Donations & Income 2022



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

| Pitt Hopkins UK | |
|---|------------------------|
| PROPOSED BUDGET | |
| <i>January to December 2024</i> | |
| Income | Jan to Dec 2023 |
| Donations | £12,000 |
| 4040 - Gift Aid | £2,000 |
| 4110 - Interest Earned | £2,000 |
| 4120 - Tee Shirt Income | £150 |
| Budgetted Income | £16,150 |
| Expenditure - Overheads | Jan to Dec 2023 |
| 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 |
| Budgetted Expenditure | £3,500 |



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

[Redacted]

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

| |
|--|
| |
| |

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.

PITT HOPKINS UK

England & Wales - Charity number 1167153

Accounts

Trustees' Annual Report for the period

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

From

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-imbursments 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.

(This area is currently blank for further details.)

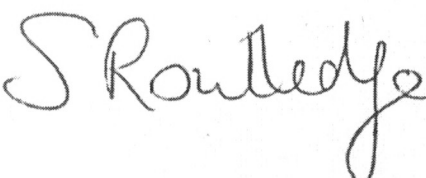
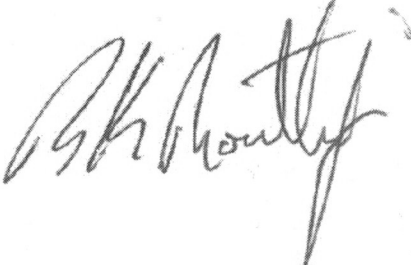
c. Section F**Other optional information**

(This area is currently blank for 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 |
| | | | £ 648 | £ 10 | | | £ 273 |
| | | | £ 319 | £ 164 | £ 103 | £ 104 | £ 658 |
| £ 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: [Signature] 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.

PITT HOPKINS UK

England & Wales - Charity number 1167153

Accounts

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 | | | | |
| 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)

| Type of adviser | Name | Address |
|-----------------|------|---------|
| | | |
| | | |
| | | |

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

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

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 patients.

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.

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.

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.

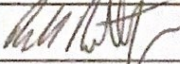

Grants, Gift Aid, donation schemes e.g., Virgin Money Giving, individual fund-raising.

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 |
|------------------------------|-------------------|
| Income | |
| 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 |
| Expenditure | |
| 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 |
| External Giving | |
| 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

| | HSBC | NWS7 | NW45 |
|-------------|-------------|-------------|-------------|
| 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~~YYYY~~.

**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:

Michael Waters

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.

PITT HOPKINS UK

England & Wales - Charity number 1167153

Accounts



Trustees' Annual Report for the period

From 01 January 2020 To 31 December 2020

Charity name: Pitt Hopkins UK

Charity registration number: 1167153

Objectives and Activities

| | SORP reference | |
|--|--------------------|---|
| Summary of the purposes of the charity as set out in its governing document | Para 1.17 | <ol style="list-style-type: none">(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 in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts. | Para 1.17 and 1.19 | <p>Signing of research contract with Professor Smidt.</p> <p>Production of information booklet based on the published Guidelines from the 2018 World Congress.</p> <p>Maintenance and improvement of the Pitt Hopkins UK website and phone app.</p> <p>Organisation of Family Day (February) and on-line hosting of smaller informal meetings.</p> <p>Participation in the European Reference Networks (ITHACA group).</p> <p>Taking part in on-going training on running a small charity.</p> <p>Representative of rare diseases at meetings and events.</p> <p>Improvement of charity governance.</p> |
| Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit | Para 1.18 | All activities have been undertaken with due regard to the guidance issued to trustees by the Charity Commission on public benefit. |

Additional information (optional)

You may choose to include further statements where relevant about:

| | SORP reference | |
|--|----------------|--|
| Policy on grant making | Para 1.38 | Grant applications made. |
| Policy on social investment including program related investment | Para 1.38 | |
| Contribution made by volunteers | Para 1.38 | Website re-design and Pitt-Hopkins app manager are provided by volunteers. |
| Other | | |

Achievements and Performance

| | SORP reference | |
|---|----------------|--|
| Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole. | Para 1.20 | <p><u>Raising Awareness/Support</u></p> <p>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.</p> <p>The major project for the year was to create an information booklet based on the parent-friendly version of the management guidelines produced during 2019 for parents which could also be given to medical professionals. The task required further re-writing of the text, lay out design and application of the branding strategy to the document.</p> <p>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 Chair took part in the Parliamentary lobby for Rare Disease Day in February just before the lockdown.</p> <p>The Charity continued to work in partnership with the Cambridge Rare Disease Network (CRDN), Findacure, EURORDIS, Genetic Alliance UK and Rare Revolutionaries.</p> |

| | | |
|--|--|---|
| | | <p>The Chair, as an ePAG advocate and an elected member of the patient board for ERN ITHACA participated in on-line training courses and gave a presentation to geneticists in December.</p> <p>A family meeting was organised in Rickmansworth at the beginning of February, just before the pandemic started. and various informal parent gatherings were held on-line during the lockdown period.</p> <p>The charity had runners in the Big Half Marathon in February. T-shirts were designed and made available for the runners, if desired.</p> <p><u>Administration</u></p> <p>The trustees met four times during the year, the meetings being held on-line. The AGM was held (on-line) in October 2020</p> <p>In September, Stewart Boraston came to the end of his three-year term as a trustee and chose not to stand again.</p> <p>The administration system was migrated to the Office 365 platform provided pro bono which will allow improved filing, access and retrieval of files as well as additional free e-mail addresses. The website host was changed from GoDaddy to Krystal.</p> <p>Policies on Finance, GDPR, Privacy, Fundraising, Equal Opportunities, Bullying/Harassment, Code of Behaviour, Grievance, Whistle Blowing, and Health and Safety were written, reviewed and agreed.</p> <p>During the year, the charity worked with two interns from Keele University and two from the University of Brighton who had become available due to the lockdown. They worked on producing a template for a newsletter, updating the website, producing instructional videos and aiding the general administration of the charity. We also had contact with an MA student from Brighton University who offered to design and conduct a study on the performance of and provision of service given by the charity.</p> <p>The grant from the National Lottery was used to purchase video and audio equipment, design and produce a banner as well as contributing to the design costs of the information booklet. A laptop and printer were purchased with a grant from the Pears Foundation.</p> |
|--|--|---|

| | | |
|--|--|---|
| | | <p>A pro bono contract was signed with Cyber Fortified to advise on GDPR and provide cyber security.</p> <p>A branding strategy was designed and produced for the charity by one of the parents pro bono.</p> <p>The free Pitt Hopkins UK app was reviewed and updating commenced.</p> <p><u>Finance/Fundraising</u></p> <p>The main income stream in 2020 came from grants from the National Lottery, Pears Foundation, Virgin Money Giving, Facebook and Gift Aid. A small amount was raised from individual donations.</p> <p>The charity joined the Amazon Smile scheme and Sustainably .</p> <p>A sub-group of the trustees was set up to focus on fundraising.</p> <p><u>Research</u></p> <p>Following further discussions and completion of due diligence, a four-year contract was signed with Professor Marten Smidt at the Swammerdam Institute for Life Sciences, University of Amsterdam.</p> <p>The charity had discussions with the Patient Led Research Hub which seeks to identify research priorities for rare disease groups, co-ordinate with researchers and explore funding sources.</p> |
|--|--|---|

Additional information (optional)

You may choose to include further statements where relevant about:

| | | |
|--|------------------|--|
| <p>Achievements against objectives set</p> | <p>Para 1.41</p> | <p>2020 has been a difficult year for all charities. The Covid-19 pandemic and consequent restrictions has impacted the ability of charities to achieve their aims and limited fundraising possibilities. As a small charity run by parents and family members, we have not had to deal with issues of staff furloughs or office space/rent and been able to make the most of the opportunities presented. Several organisations e.g. The National Lottery, offered grants to support charities during the pandemic and Pitt Hopkins UK made a number of successful applications and thanks to great efforts by the Chair, the charity was able to raise about 80% of the 2019 income total.</p> |
|--|------------------|--|

| | | |
|--|-----------|--|
| | | As the charity mainly operates on-line, the ability to give information and support during the pandemic was reasonably unaffected by the changing circumstances particularly with the grant support. |
| Performance of fundraising activities against objectives set | Para 1.41 | |
| Investment performance against objectives | Para 1.41 | |
| Other | | |

Financial Review

| | | |
|--|-----------|---|
| Review of the charity's financial position at the end of the period | Para 1.21 | The yearly balance was approx. £16,000 |
| Statement explaining the policy for holding reserves stating why they are held | Para 1.22 | The Reserve Fund stands at a balance of 6-9 months of the estimated annual running costs of the charity |
| Amount of reserves held | Para 1.22 | £5000 |
| Reasons for holding zero reserves | Para 1.22 | |
| Details of fund materially in deficit | Para 1.24 | |
| Explanation of any uncertainties about the charity continuing as a going concern | Para 1.23 | |

Additional information (optional)

You may choose to include further statements where relevant about:

| | | |
|---|-----------|--|
| The charity's principal sources of funds (including any fundraising) | Para 1.47 | Grants, Gift Aid, donation schemes e.g., Virgin Money Giving, individual fund-raising. |
| Investment policy and objectives including any social investment policy adopted | Para 1.46 | |
| A description of the principal risks facing the charity | Para 1.46 | |
| Other | | |

Structure, Governance and Management

| | | |
|---|-----------|--------------------------------------|
| Description of charity's trusts: | | |
| Type of governing document (trust deed, royal charter) | Para 1.25 | Written constitution |
| How is the charity constituted? (e.g unincorporated association, CIO) | Para 1.25 | Charitable Incorporated Organisation |
| Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees | Para 1.25 | Appointed by existing trustees |

Additional information (optional)

You may choose to include further statements where relevant about:

| | | |
|---|-----------|---|
| Policies and procedures adopted for the induction and training of trustees | Para 1.51 | |
| The charity's organisational structure and any wider network with which the charity works | Para 1.51 | Stewart Boraston ended his term as a trustee. |
| Relationship with any related parties | Para 1.51 | |
| Other | | |

Reference and Administrative details

| | |
|-----------------------------|--|
| Charity name | Pitt Hopkins UK |
| Other name the charity uses | Pitt Hopkins syndrome UK |
| Registered charity number | 1167153 |
| Charity's principal address | 76 Auckland Road Ilford Essex IG1 4SF |
| | |

Funds held as custodian trustees on behalf of others

| | |
|---|------|
| Description of the assets held in this capacity | None |
| Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects | None |
| Details of arrangements for safe custody and segregation of such assets from the charity's own assets | None |

Additional information (optional)

Names and addresses of advisers (Optional information)

| Type of adviser | Name | Address |
|-----------------|------|---------|
|-----------------|------|---------|

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

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

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

Exemptions from disclosure

Reason for non-disclosure of key personnel details

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

Other optional information

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

Declarations

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

Signed on behalf of the charity's trustees

| | | |
|-------------------------------------|--------------------|------------------------|
| Signature(s) | <i>S Routledge</i> | <i>Brian Routledge</i> |
| Full name(s) | Susan Routledge | Brian Keith Routledge |
| Position (eg Secretary, Chair, etc) | Chair | Trustee |
| Date | 02-10-2021 | |

Pitt Hopkins UK Annual Income & Expenditure Statement 2020

Income

| | | |
|-------------------------|----------------------------|--------------------------|
| 4010 - Virgin Money | 3964.18 | |
| 4020 - Facebook | 3446.59 | |
| 4030 - Give As You Live | 51.12 | |
| 4040 - Gift Aid | 1254.87 | |
| 4050 - Interest Earned | 89.27 | |
| 4060 - Stripe | 40.00 | |
| 4070 - Amazon Smile | 26.80 | |
| 4900 - Other income | 10132.92 | |
| | <u>Total Income</u> | <u>£19,005.75</u> |

Expenses

| | | |
|------------------------------|------------------------------|--------------------------|
| 5005 - Virgin Fees | 16.23 | |
| 5008 - Stripe Fees | 1.60 | |
| 5015 - Grants & Donations | 65050.00 | |
| 5060 - Other Direct Expenses | 40.00 | |
| 6012 - Conference Fees | 76.02 | |
| | <u>Total Expenses</u> | <u>£65,183.85</u> |

GROSS INCOME **-£46,178.10**

Overheads

| | | |
|----------------------------------|-------------------------------|-------------------------|
| 7400 - Travelling | 208.54 | |
| 7510 - Postage & Carriage | 34.02 | |
| 7520 - Office Stationery | 20.27 | |
| 7540 - Internet Charges | 2914.31 | |
| 7550 - Software | 307.99 | |
| 7630 - Insurance | 306.93 | |
| 7900 - Bank Charges and Interest | 39.80 | |
| 8030 - Equipment Depreciation | 28.08 | |
| 8200 - General Expenses | 156.40 | |
| 8210 - Subscriptions | 289.63 | |
| 8220 - Clothing Costs | 15.66 | |
| | <u>Total Overheads</u> | <u>£4,321.63</u> |

NET INCOME **-£50,499.73**