Trustees' Annual Report for the period

	Period start date				Period end date		
	Day	Month	Year		Day	Month	Year
From	01	January	2025		31	December	2025

b.

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	Graham Fiveash	Treasurer		
5	Melissa Stewart			
6	Mark Haywood			
7	Maryrose Brennan		01/01/25 – 31/7/25	
8	Julie Cooper		01/01/25 – 16/05/25	
9	Debbie Bromley		01/01/25 – 31/05/25	
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)

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.

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. Supporting research into Pitt-Hopkins syndrome.
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 the Pitt Hopkins UK mobile phone app. Construction 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 UK 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.

a. Section D Achievements and performance

Summary of the main achievements of the charity during the year

Raising Awareness/Support

The charity continued to disseminate information and provide support to parents and families via dedicated support groups (Google, Facebook), SB switch board, website, app, social media, e-mail and personal contacts. The phone line provider was changed to Switchboard following the closure of Skype.

Plans for a family weekend at Barretstown residential centre in Ireland or at a Horse Riding Centre for the Disabled in North Wales were shelved because the Barretstown centre could only cater for children, not families, and the welsh centre was not suitable for Pitt-Hopkins families.

A group of families meet at the Menphys Hub in Leicester in June 2025.

Meridian Radio interviewed a trustee family about Pitt-Hopkins syndrome and fund raising.

A digital collage was created for Pitt-Hopkins Awareness Day on 18 September and shared online to raise awareness of Pitt-Hopkins syndrome.

The Charity continued to collaborate with key rare disease organisations, including CRDN, Beacon, EURORDIS, Genetic Alliance UK and Rare Revolutionaries.

Clinicians at Amsterdam Medical Centre were contacted to provide information and support in response to questions from parents and families.

The Charity continued its collaboration with medical professionals through the Patient-Led Research Hub (PLRH) in Cambridge.

The Chair participated in the Westminster Parliamentary Lobby on Rare Disease Day (28 February 2025), advocating for improved support for people and families affected by rare diseases.

Administration

Debbie Bromley resigned as trustee for personal and family reasons and Maryrose Brennan completed her intended three year term. Jullie Cooper completed her third 3-year term and, in November, Graham Fiveash was invited to serve a second term. The need for additional trustees was discussed.

The trustees met four times during the year, the meetings being held on-line. The AGM was held (on-line) in November 2025. A face-to-face meeting was planned for April 2026.

As an ePAG advocate and elected member of the ERN ITHACA Patient Board, the Chair attended various board meetings and participated in online training courses.

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

Finance/Fundraising

The income stream in 2025 came from individual donations made through various fundraising sites which included Wonderful, Stripe, CAF etc. Additional income of £2,800 was also generated from interest on savings that the charity now hold.

An application to set up a lottery in aid of the charity was made to the London Borough of Redbridge in July 2025.

Research

The final project report from the Amsterdam research group was received in May 2025. The signing of a new contract that will provide the Amsterdam research group with a further £80,000 over the next 4 years from the start of 2026. This will further support research into breathing and digestive problems that are common with Pitt Hopkins sufferers.

The charity continued working with the PLRH who are applying for funding for research into the breathing anomalies.

a. Section D Achievements and performance

Section E Financial review

Brief statement of the charity's policy on reserves	£80,000 has now been reserved for the funding of the new research contract with Amsterdam University over the next 4 years starting with a £20,000 payment in January 2026. An administrative reserve of £5000 is held
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.	

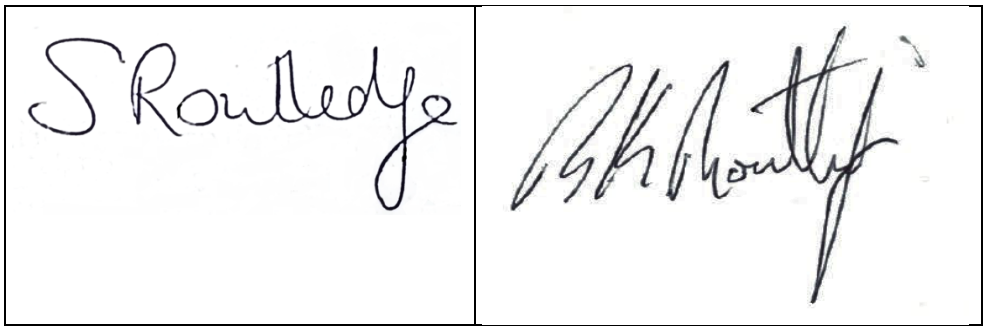
c. Section F Other optional information

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	24th September 2026	24th September 2026

Pitt Hopkins UK
Income & Expenditure Statement
1 January to 31 December 2025

Donations & Income	Jan to Dec 2025	Jan to Dec 2024	Comments on 2025 Figures
4020 - Facebook	£0,00	£1.308,14	
4030 - Give As You LIve	£0,00	£18.959,23	
4040 - Gift Aid	2.179,62	£2.128,73	Includes over £1,000 for Lila's Liga
4050 - Mirren Thompson	180,00	£240,00	
4060 - Stripe	772,62	£5.869,44	
4065 - Wonderful	9.319,00	£2.010,00	Includes over £4,000 for Lila's Liga
4075 - CAF	470,00	£0,00	Now getting more individual donations
4090 - Other Donations	6.848,47	£3.834,97	Includes over £1,000 for Lila's Liga
4110 - Interest Earned	2.804,72	£0,00	
4900 - Other income	341,09	£122,53	
TOTAL INCOME	**£22.915,52**	**£34.473,04**	
Direct Expenses			
5025 - University of Amsterdam	£0,00	£5.017,00	
5040 - Costs of Fund Raising	£269,66	£0,00	Includes Lila's LaLiga Food costs
5060 - PTHS Sponsored Events	£0,00	£420,00	
5070 - PTHS Sponsored Family Meeting Events	£501,64	£758,79	
5500 - Marketing	£0,00	£627,93	
5600 - Conference Expenses	1.681,29	£1.577,82	
Total Direct Expenses	**£2.452,59**	**£8.401,54**	
GROSS INCOME / LOSS	**£20.462,93**	**£26.071,50**	
Overheads			
7050 -Other Expenses	£0,00	£15,00	
7400 - Travelling	£325,93	£249,45	
7420 - TrusteeExpenses	£307,00	£1.768,58	
7530 - Telephone	£77,90	£202,32	
7510 - Postage and Carriage	£163,73	£8,15	
7540 - Web Site Hosting & Development	£85,18	£66,00	
7550 - Computer & Software	2.763,59	£2.528,33	Includes £1,320 for new Website 50%
7620 - Consultancy & Professional Fees	£0,00	£210,00	
7630 - Business Insurance	£307,01	£284,39	
7900 - Bank Charges and Interest	£76,71	£144,55	HSBC bank charges have reduced
8010- Office Equipment & IT Depreciation	£0,00	£29,99	
8210 - Subscriptions	£205,00	£234,20	
Total Overheads	**£4.312,05**	**£5.740,96**	
NET INCOME / LOSS	**£16.150,88**	**£20.330,54**	

In terms of the balance sheet we now have in excess of £135,000 of which £110,000 is in various savings accounts.

Pitt Hopkins UK

Finalised Assets & Liabilities Statement

To 31st December 2025

ASSETS		
Fixed Assets		
	Total Fixed Assets	**£0,00**
Current Assets		
1200 - Pitt Hopkins UK	25.464,57	
1210 - Pitt Hopkins UK - Business Money Manager	40.530,34	
1230 - Nationwide 45 Day Saver	65.546,20	
1240 - Nationwide Instant Access Account	5.000,00	
	Total Current Assets	**£136.541,11**
	TOTAL ASSETS	**£136.541,11**
LIABILITIES		
Current Liabilities		
Future Liabilities		
	Total Future Liabilities	**£0,00**
	TOTAL LIABILITIES	**£0,00**
	TOTAL NET ASSETS	**£136.541,11**