



CHARITY COMMISSION
FOR ENGLAND AND WALES

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	<ul 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>
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		<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>
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Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	<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>
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		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

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) to appoint trustee (if any)
1	Susan Routledge	Chair		
2	Virginia Routledge	Treasurer		
3	Leanne Groves			
4	Stewart Boraston		01-01-20 to 15-09-20	
5	Debbie Bromley			
6	Julie Cooper			
7	Julie Penniall			
8	Brian Routledge			
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Corporate trustees – names of the directors at the date the report was approved

Director name		

Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole year	

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

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Exemptions from disclosure

Reason for non-disclosure of key personnel details

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Other optional information

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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**