



Charity No: 1151919

# **Trustees' Annual Report & Statement of Financial Activity**

**for the Year Ended 1 April 2022**

## **Trustees**

Sinéad James

Christopher James

Rabia Harrison

January 2023

# Trustees' Annual Report & Statement of Financial Activity for the Year Ended 1 April 2022

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# Trustees Annual Report & Statement of Financial Activity

## for the Year Ended 1 April 2022

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## 1 Reference and Administration Details

### 1.1 Charity Name & Registration

#### CPA Research Foundation

The charity is a Charitable Incorporated Organisation, registration no: 1151919, registered with the Charity Commission on 29 September 2020.

### 1.2 Charity's Address

66 Highfield Road, Romford, Essex, RM5 3SA

e-mail: [hello@cparfoundation.org](mailto:hello@cparfoundation.org)

website: [www.cparfoundation.org](http://www.cparfoundation.org)

### 1.3 Names of the Trustees Who Manage the Charity

<i>Name</i>	<i>Office</i>	<i>Appointed</i>	<i>Resigned</i>
Sinéad James	Chair	29 September 2020	-
Christopher James	Treasurer	29 September 2020	-
Rabia Harrison		29 September 2020	-

### 1.4 Names of Advisors & Senior Members of Staff

None

### 1.5 Bank

Barclays Bank, 93 High Road, Ilford, Essex, IG1 1DE

## 2 Structure, Governance & Management

### 2.1 Type of Governing Document

Constitution – based on the Charity Commission's model governing document for Foundation Charitable Incorporated Organisations, *ie*: where the Trustees are the only Members of the charity.

### 2.2 Charitable Objects

Such purposes as are exclusively charitable for the public benefit as the trustees shall see fit.

a) For the public benefit the promotion and protection of good physical and mental health of sufferers of Cerebral Proliferative Angiopathy living in England and Wales in particular but not exclusively through assisting in the provision of funding for research into the diagnosis, treatment and management of Cerebral Proliferative Angiopathy.

b) To relieve the needs of sufferers of Cerebral Proliferative Angiopathy and their families and carers living in England and Wales by the provision of practical support and by raising awareness and understanding within the general public about Cerebral Proliferative Angiopathy.

## **2.3 Trustee Selection Methods**

There must be at least three charity trustees. The maximum number of trustees is 12.

In accordance with the Constitution, Trustees are appointed or re-appointed for a term of three years by a resolution passed at a properly convened meeting of the charity trustees.

In appointing Trustees due consideration is given to ensuring that the Trustees have, between them, the skills and experience necessary to manage the charity effectively and in accordance with charity law.

# **3 Activities, Achievements & Performance**

## **3.1 Statutory Declaration**

The Trustees confirm that they have paid due regard to the guidance issued by the Charity Commission on public benefit in deciding what activities the charity should undertake.

## **3.2 Overview**

### **About CPA**

Cerebral Proliferative Angiopathy (CPA) is an extremely rare disease. It is thought that 3.4% of Arteriovenous Malformation (AVM) sufferers are diagnosed as having CPA. Currently, there are no known research activities being undertaken to develop much needed therapies to control the disease. In addition, before CPA Research Foundation was established, CPA did not have an online support network, like many other neurological diseases. It is our mission to establish CPA Research Foundation as the number one global charity for CPA research and awareness. Over the next five years we aim to focus on our top priorities as we fund research, develop new therapies and ultimately treat and cure the disease.

## **3.3 Activities, Achievements & Performance**

CPA Research Foundation is the first of its kind. There are no other charities or organisations that have any affiliation with CPA. Because of this, things are moving very slowly in terms of setting it up and establishing itself. Currently we are waiting for ethical and institutional approval for a multicentre study between Great Ormond Street Hospital, Boston Children's Hospital and Toronto Children's Hospital. Once approved these facilities will be able to data share so that a registry of patients can be developed.

We have a fully functioning website which is updated regularly with any news we can share and where the public can make donations. We also have a social media presence (Facebook, Instagram, Twitter and LinkedIn, where people can find us). We have a small community of patients from across the globe connected via a private social media group where we can knowledge share and offer each other emotional support.

## **3.4 How the Public Have Benefitted.**

The public have benefitted by having a website to visit, social media connections and a slowly growing community of other CPA patients to connect with.

## **3.5 Trustee Development**

None to report.

## 3.6 Looking Ahead

### Priorities

- 1. Community** – Establish a registry of CPA patients. **Key areas of focus:** Build IT Infrastructure, Recruit a part time research assistant for routine maintenance.
- 2. Awareness** - Develop a rigorous, consistent definition. **Key areas of focus:** Establish a clear, consistent definition to separate CPA from large diffuse AVMs.
- 3. Evidence** – Document the natural history of CPA. **Key area of focus:** Find out what happens to patients with CPA, Look at genomic/tissue pathology of CPA.
- 4. Treatment** – Work with experts to develop effective treatments. **Key areas of focus:** Investigate revascularisation surgery and other medical treatments.

## 4 Financial Review

### 4.1 Details of Any Funds Materially in Deficit

The Charity has no funds which are materially in deficit.

### 4.2 Policy on Reserves

The Charity's policy on reserves is to generate and maintain a balance which is sufficient:

- a) to preserve the financial viability of the Charity in the event that unforeseen and/or unavoidable circumstance precipitate a short-term fall in its income;
- b) to enable the Charity, in the interests of meeting its objectives, to undertake from time to time the setting up of new and innovative projects on a pilot basis to demonstrate the viability and potential benefits of such activities as a precursor to securing the external funding necessary to maintain such projects on an on-going basis.

For these purposes the Charity will endeavour to generate and maintain reserves which are at least 50% of its annual expenditure.

### 4.3 Principal Sources of Funding and Outgoings

To date, due to Covid, the fundraising efforts have been slow. One of the Trustees has taken part in a fundraising skydive and all other donations have come in via the website, paypal giving and Facebook fundraisers.

**No funds have been spent to date.**

### 4.4 Remuneration of Trustees

All Trustees act in a voluntary capacity and receive no remuneration or other material benefits from their services to the Charity.

Out-of-pocket expenses necessarily and reasonably incurred by Trustees in promoting the purposes of the Charity are reimbursed at cost.

### 4.5 Financial Status

The charity's current resources from unrestricted and unrestricted donations are more than sufficient to meet its outgoings for at least next year.

All the indications are that this will remain the case for the foreseeable future.

### 4.6 Statutory Statements on Liabilities

The Trustees declare that:

- ✓ The charity has given no guarantees where potential liability under the guarantee is outstanding at the date of this statement (eg: any outstanding/ongoing contract or legal undertaking to buy or provide specific services);
- ✓ The charity has no debt outstanding at the date of this statement which is owed by the CIO and which is secured by an express charge on any assets of the CIO (eg: a mortgage on property owned by the charity);

Approved by the Trustees and signed on their behalf,

Sinéad James (Chair)

Date: 25-01-23

## 5 Statement of Financial Activity

### 5.1 Receipts & Payments During the Financial Year Ended 1 April 2022

	Unrestr'd Funds £	Restricted Funds £	Total £	Total £
<b>A1 - RECEIPTS</b>				
Voluntary Income	0		0	0
Income Generation	0		0	0
Investments Income	0		0	0
Charitable Income	4,094	313	3,781	3,781
Other Receipts	0		0	0
	4,094	313	3,781	3,781
<b>A2 - ASSETS &amp; INVESTMENTS</b>				
Sale of Investments	0		0	0
Sale of Assets	0		0	0
	0	0	0	0
<b>TOTAL RECEIPTS</b>	<b>4,094</b>	<b>313</b>	<b>3,781</b>	<b>3,781</b>
<b>A3 - PAYMENTS</b>				
Generating Funds	0		0	0
Charitable Activities	0	0	0	0
Support Costs	0	354	354	0
Other Payments	0		0	0
	0	354	354	0
<b>A4 - ASSETS &amp; INVESTMENTS</b>				
Purchase of Investments	0		0	0
Purchase of Assets	0		0	0
	0	0	0	0
<b>TOTAL PAYMENTS</b>	<b>0</b>	<b>354</b>	<b>354</b>	<b>0</b>
<b>NET OF RECEIPTS-PAYMENTS</b>	<b>4,094</b>	<b>667</b>	<b>4,135</b>	<b>3,781</b>
<b>A5 - Transfers Between Funds</b>	0	0	0	0
<b>NET AFTER TRANSFERS</b>	<b>4,094</b>	<b>667</b>	<b>4,135</b>	<b>3,781</b>

### 5.1.1 Summary of Receipts & Payments Accounts

	0	0	0	0
<b>Total Current Funds</b>			3,739	0
<b>Total Funds</b> <i>(net of liabilities)</i>			3,781	0

### 5.1.2 Statement of Assets and Liabilities

### 5.1.3 Disposition of Funds

The Charity has no designated or restricted funds

### 5.1.4 Approval of the Board of Trustees

The Trustees declare that they have approved the above Annual Report & Statement of Financial Activity.

Signed on behalf of the Trustees

Christopher James, Treasurer

Date: 25-01-23

## 5.2 Notes to the Accounts

a) Accounting Policies

The financial statements have been prepared in accordance with the Charities Act 2011 Section 133, using the Receipts and Payments basis available to small charities and the charity's own Simple Accounts Spreadsheet.

b) Reimbursement of Out-of-Pocket Expenses

Out-of-pocket expenses necessarily, reasonably and incidentally incurred by Trustee in the course of their duties as Trustees are reimbursed in accordance with the prevailing Financial Policies & Procedures.

c) Salaries & Professional Fees

No trustee receives any payments for the services they provide to the charity.  
In the current financial year the charity employed no staff or external contractors;

d) Fixed Assets

The charity has not purchased or disposed of any fixed assets in the current financial year;

e) Creditors

Cheques issued prior to the end of the financial year but not appearing in the end of financial year bank statement are only reported as outstanding creditors if they remain unrepresented at the time of producing the financial statements.

f) Rounding Discrepancies

All amounts are recorded to the penny, but in these accounts are shown as digitally rounded to the nearest pound. This can occasionally result in a total apparently not being the sum of its constituent amounts. All individual amounts, and their totals, are nevertheless correct.