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CASK is the name of a gene essential for healthy development of the brain. Mutations in this gene cause a range of inherited disorders that all affect brain function, including ‘MICPCH’ and ‘X-linked intellectual disability with or without nystagmus’. To simplify things, we often use the term ‘CASK’ to describe all disorders.

CASK gene mutations are ultra rare. The brain doesn’t grow as it should, giving the child microcephaly (literally meaning ‘small head’). Several children show abnormal brain morphology, such as a small cerebellum and pons. Children with a CASK disorder can have a multitude of problems, including intractable epilepsy, inability to feed or drink, inability to walk, low tone, poor balance, global developmental delay, vision and/or hearing loss.

Some affected males have mutations resulting in intellectual disability whilst those males with severe mutations often pass away in infancy. Females with CASK have an unknown prognosis but some are classed as having a life-limiting condition and rely on hospice care.

Most children with CASK cannot communicate other than by crying, smiling or laughing. Caring for a child with CASK is exhausting since many suffer from sleep disturbances. Often, children with CASK cannot play independently due to the inability to control their limbs effectively. The children who are less medically complex can display challenging behaviours due to their low cognitive function.
Meeting our legal requirements

Because our income lies between £25,000 and £250,000, we have prepared our accounts on a “Receipts and Payments” basis. This means that our accounts contain a statement summarising all money received and paid out in the financial year, and a statement of our assets and liabilities at the end of the year.

The detailed legal requirements for this report are set out in The Charities (Accounts and Reports) Regulations 2008 which provide a legal underpinning for many of the recommendations made in the applicable Charities SORP.

The headings used in our report follow this guidance, as follows:

- Reference and administrative details;
- Structure, governance and management;
- Objectives and activities;
- A financial review;
- Funds held as custodian trustee on behalf of others;
- Public benefit statement.

Reference & administrative details

4.1. The Charity’s Name
The Charity’s name is CASK Research Foundation

4.2. The Charity’s Registration Number
The Charity’s number is 1197434

4.3. The Address of the Principal Office
The Charity does not own any premises, but operates via a network from their own homes. The Charity’s formal legal contact is through the Chief Executive Director, whose name and address are as follows:

Laura Hattersley
33 Finchdean Road, Rowlands Castle, Hampshire. PO9 6DA

4.4 Names of Trustees

Chief Executive Director
Laura Hattersley, 33 Finchdean Road, PO9 6DA

Treasurer
Elizabeth Cook, 11 Reedsmere Walk, Comberbach, CW9 6BZ

Secretary
Nicole Poole, 47 Elm Drive, Hove, BN3 7JA

Emily Richards, 16 Magdalen Drive, Evesham, WR11 2BE
Section 5
Structure, governance & management

5.1 Particulars of the Governing Document

The Charity has a formal Constitution, which was approved by the Charity Commission in January 2022. The Charity is run by the Trustees, as a management committee. Any new Trustees will be appointed at the Charity’s Annual General Meeting.

The Charity operates by means of committee meetings, held on a video-conference basis. The minutes of the meeting are formally recorded by the Secretary.

Section 6
Objectives & activities

6.1 The Purposes of the Charity

CRF was formed in order to primarily accelerate research into CASK gene mutations and the associated conditions.

It is our mission to enable medical advances to improve the lives of people with CASK gene disorders.

Our Vision: A world where people with a CASK gene mutation have treatments and ultimately a cure.

6.2 The Main Activities Undertaken

Since our establishment, we have:
- Created a Scientific Advisory Board of experts in the field of neurodevelopmental disorders
- Created a Research Review Committee
- Established CASK Coalition in partnership with Angelina CASK Neurological Research Foundation and Association Enfant CASK France
- Established the CASK Rare-X Data Collection Programme. This is an initiative delivered by Global Genes. We currently have over eighty patients registered internationally.
- Joined UK Rare Epilepsies Together (UKRET) network and attended a conference as a member of this network
- Liaised with the charity Unique to enable the first ever disorder guide to be written for families.

4.4 Cont.

Grants advisor
Rachel Manktelow, 71 New Wokingham Road, RG45 6JG

Sarah Sanders, Cross at hand farm Cottage, Maidstone Rd, TN12 ORJ

Andrea Leforte, 12 Pitfold Avenue, Haslemere, Surrey, GU27 1PN
6.2 Continued

- Developed patient leaflets to raise awareness of CASK
- Created a website
- Raised over £25,000 in fundraising;
- Joined a charity mentoring programme led by Beacon;
- Facilitated a research study into a patient with a CASK gene mutation
- Held several webinars for the international community
- Assisted in the creation and promotion of CASK Coalition’s first annual fundraiser – CASK Race for Research
- Held a CASK family meet up
- Committed to the CURE CASK campaign
- Inclusion of the CASK gene into the BINGO project

6.2.1 Created an SAB

Our Scientific Advisory Board currently consists of:
- Dr Sam Amin – consultant paediatric neurologist
- Professor Kerstin Kutsche – Geneticist
- Dr Catherine Tuffrey – paediatrician
We are hoping to continue to expand this board.

6.2.2 Research Review Committee

Our Research Review Committee advises us on funding proposals along with any member of the SAB who wishes to.
- Dr Lucy Robinson PhD – founder of Insight Editing (handed notice in January 2023)
- Dr Jessica Tamamini (handed notice in January 2023)
- Dr Isabel Zwart – Director Regulatory CMC at AstraZeneca

6.2.3 Founded CASK Coalition

The CASK coalition was established in June 2023 in order to formalise the partnerships between three CASK research charities: CRF, Angelina CASK Neurological Research Foundation (Australia and USA) and Association Enfants CASK France. We hold shared aims and objectives and share workload and skills in order to improve efficiency.

6.2.4 RARE-X DCP

The CASK RARE-X Data Collection Programme – a patient owned, free, secure, streamlined, international registry. We now have over eighty patients registered from 21 countries. See section 7.4 for more detailed information.

6.2.5 Joined UK RET

UK Rare Epilepsies Together (UKRET) brings together like-minded charities and support groups in the UK to see how we might work more collaboratively to support rare and complex epilepsy communities on a national scale. CRF founder Laura attended the Rare Epilepsies Conference in March 2023.

6.2.6 Unique pamphlet

The charity Unique provides specialist information on rare chromosome and gene disorders. Following contact from our Director, Unique created a pamphlet that parents can be directed to following diagnosis.
6.2.7 Family leaflets

CRF’s family leaflets on CASK have proven extremely popular (over twenty personalised pamphlets created) within the CASK community. We identified a need for some literature to educate friends and families on CASK. We offer to personalise the leaflets with a photo of their child. We created these also for our CASK Coalition partners.

Flyers have also been created to go alongside fundraising pots as well as detailed fundraising booklets. All materials are created free of charge by our director using the CANVA professional software which is free for registered charities.

6.2.8 Created website

The CRF website www.caskresearch.org delivers information to families and researchers. It was created by Laura Hattersley, CRF’s director, in combination with a generous donation that allowed funding of a web developer to professionalise it.

6.2.9 Raised £24333 (gross)

CRF have been fortunate to have been the recipients of many fundraising activities during 2022-2023. We have worked hard on fundraising campaigns and our social media presence.

6.2.10 Beacon mentoring programme

Our Director Laura is currently on the Beacon mentoring scheme and is being mentored by a business manager of the charity LifeArc.

6.2.11 Facilitated a research study

We were contacted by a parent whose child has unusual and alarming symptoms. We shared their story with Professor Kerstin Kutsche who was keen to study the case. The research is ongoing.

6.2.12 Webinars

We have so far held three webinars for the international community: RARE-X and how this programme can benefit our community; UC Davis and X reactivation of X-linked genes; Kerstin Kutsche and the genetics of CASK including a Q&A.

6.2.13 Race for Research

As members of the CASK Coalition, we helped create a fundraising platform for an international fundraiser.

6.2.14 Family meet up

We held a family meet up at Worcester Snoezelen in 2022 and in 2023 we have Camp Mohawk booked for September 9th.

6.2.15 CURE CASK

Shortly after our creation we were contacted by ACNRF about a proposal from UC Davis. Their research aims to reactivate the CASK gene on the silenced X chromosome. The proposal was peer reviewed by four scientists with an understanding of either the CASK gene and/or the epigenetic technique/theory. These peer reviews were then read by our Research Review Committee who suggested to our Board that it was a project worth funding. This information was fed back to our partner organisations AECF and ACNRF. This culminated in the
6.2.15 CURE CASK cont.

creation of a memorandum of understanding stating that CRF will raise awareness of this project and attempt to raise funds for it. The success of the fundraising project named CURE CASK will be re-evaluated in April 2024. We created a separate fundraising platform to identify funds specifically designated for this campaign.

6.2.16 BINGO project

The BINGO project is run by the University of Cambridge. It brings together developments in genetics, psychology and brain sciences. The researchers want to understand the range of problems that affect individuals with neurodevelopmental disorders, after a rare genetic cause has been found. They also want to understand how genetic differences affect brain function. In future, the information they gather might make it easier to support people with neurodevelopmental conditions, because they will have a better understanding of which patterns of difficulty are associated with each cause, and why these patterns of difficulty occur. Following contact by our founder with Dr Kate Baker, it was agreed that the CASK gene could be included in this study.

6.3 Statement of compliance

The Trustees are in agreement that the CIO is a public benefit entity, complying with the definition in FRS 102.

Section 7

Achievements and performance

7.1 Our main mission and aim

It is our mission to enable medical advances to improve the lives of people with CASK gene disorders. This is a long term goal and will take some time to accomplish. Whilst we have not achieved this mission at this early stage we are making good headway towards raising awareness within the scientific community and facilitating research.

Our aim is to accelerate research into CASK gene mutations and the associated conditions. We have achieved this aim this year (see 6.2.1; 6.2.11; 6.2.16) and have a number of potential or upcoming projects to build on this including:

- an upcoming meeting with Dr Kate Baker, Cambridge University, on a CASK specific study
- meetings with Harvard/Boston’s Childrens Hospital regarding support or a collaboration
- Meeting with Andrea Cerase on X-reactivation
- Increasing our registration numbers with RARE-X
- Building our own UK contact registry
- Potential PhD (funded by Bristol University) into CASK gene disorders
7.2 Our mission to support and provide advice

We have achieved this by:
- Creating our informative website and keeping it updated
- Holding a family meet up day in 2022 with another planned in Sept 2023
- Creating and facilitating the creation of information guides (see 6.2.6 & 6.2.7)
- Holding webinars (6.2.12) to help educate and inform parents and provide answers
- Creating a map of UK families to reduce feelings of isolation and facilitate socialising.

7.3 Engaged Members

Currently CRF does not have a formal ‘membership’ structure for the charity and uses polls on the UK Facebook support group to communicate

In the next 12 months we want to create a formal ‘free’ membership system which can act as a simple registry in order to collect more accurate and trusted data on UK disease prevalence as well as creating an additional mailing list to our Mailchimp newsletter.

7.3.1 Mailchimp

The Mailchimp account was created in June 2022. We now have 153 subscribers. We send out a monthly newsletter. This has an average opening rate of 70.1% Based on information from Mailmodo (https://www.mailmodo.com/guides/mailchimp-open-rate/), 21% classed as a ‘good’ opening rate for a newsletter.
7.4 RARE-X DCP

The CASK RARE-X Data Collection Programme was officially launched in early September 2022. We now have over 80 participants signed up and answering surveys. The registry is international and, although currently in English, RARE-X are rolling out more languages. This will enable us to focus on countries where data is lacking such as Germany and Spain.

![Total Number of Patients Enrolled](chart)

**7.4.1 Patient enrollment increases when we do a big social media drive or directly contact parents.**

RARE-X held the Open Science Data Challenge which launched in May 2023. Initially there was a deadline of December to register onto the DCP. We promoted this deadline and successfully got 11 more patients enrolled. An extended deadline was then given for February 28th, which we again promoted on social media, leading to 13 more enrollments. In April we contacted a large number of families and asked them to register - this led to 11 more families.

We will be holding a webinar in September 2023 on our findings from the DCP and will use this as our next big deadline to try and reach 100 families. UK families currently stand at 17, which is 50% of known families. We have found that by having a successful registry we garnering interest from researchers.
Our social media campaigns have had international reach with patients from 21 countries enrolled

<table>
<thead>
<tr>
<th>Country</th>
<th>Patient Count</th>
<th>Percent of Global Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albania</td>
<td>1</td>
<td>1.2%</td>
</tr>
<tr>
<td>Argentina</td>
<td>1</td>
<td>1.2%</td>
</tr>
<tr>
<td>Australia</td>
<td>4</td>
<td>4.9%</td>
</tr>
<tr>
<td>Brazil</td>
<td>1</td>
<td>1.2%</td>
</tr>
<tr>
<td>Canada</td>
<td>3</td>
<td>3.7%</td>
</tr>
<tr>
<td>Chile</td>
<td>1</td>
<td>1.2%</td>
</tr>
<tr>
<td>France</td>
<td>8</td>
<td>9.8%</td>
</tr>
<tr>
<td>Germany</td>
<td>4</td>
<td>4.9%</td>
</tr>
<tr>
<td>Greece</td>
<td>1</td>
<td>1.2%</td>
</tr>
<tr>
<td>Italy</td>
<td>1</td>
<td>1.2%</td>
</tr>
<tr>
<td>Lebanon</td>
<td>1</td>
<td>1.2%</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>1</td>
<td>1.2%</td>
</tr>
<tr>
<td>Malta</td>
<td>1</td>
<td>1.2%</td>
</tr>
<tr>
<td>Netherlands</td>
<td>1</td>
<td>1.2%</td>
</tr>
<tr>
<td>Poland</td>
<td>2</td>
<td>2.4%</td>
</tr>
<tr>
<td>Romania</td>
<td>1</td>
<td>1.2%</td>
</tr>
<tr>
<td>Slovenia</td>
<td>1</td>
<td>1.2%</td>
</tr>
<tr>
<td>Sweden</td>
<td>1</td>
<td>1.2%</td>
</tr>
<tr>
<td>Ukraine</td>
<td>1</td>
<td>1.2%</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>17</td>
<td>20.7%</td>
</tr>
<tr>
<td>United States</td>
<td>30</td>
<td>36.6%</td>
</tr>
<tr>
<td>Total</td>
<td>82</td>
<td>100.0%</td>
</tr>
</tbody>
</table>
7.4.2 Data obtained

Only verified researchers and clinicians are able to gain access to the entire data sets. As a PAG leader and having completed the CITI compliance training our Director Laura has access to basic data sets that are sporadically delivered out by RARE-X. Even this simple data provides the opportunity to help improve patient care, educate and facilitate advocacy on behalf of one’s child.

Example 1: Question from a parent on a Facebook group

“We had an appointment yesterday with XX’s genetic doctor and he’s asked me if all/most of our kids have Microcephaly and are below the average weight Centile for their age. Are any of our CASK kids on any kind of steroids for their growth hormones as he is really wanting XX to start them but I am still in two minds…”

<table>
<thead>
<tr>
<th>Issue Reported</th>
<th>Percentage reporting</th>
<th>Number reporting</th>
<th>Ages at diagnosis</th>
<th>Ages symptoms first appeared</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short Stature</td>
<td>44%</td>
<td>16</td>
<td>Range of: Before Birth- 3 years</td>
<td>Range of: Before Birth- 2 years</td>
</tr>
<tr>
<td>Undergrowth</td>
<td>44%</td>
<td>16</td>
<td>Range of: Before Birth- 4 years</td>
<td>Range of: Before Birth- 4 years</td>
</tr>
<tr>
<td>Growth Hormone Deficiency</td>
<td>14%</td>
<td>5</td>
<td>Range of: 1-13 years</td>
<td>Range of: 1-13 years</td>
</tr>
<tr>
<td>Obesity</td>
<td>8%</td>
<td>3</td>
<td>Range of: 2-7 years</td>
<td>Range of: 2-7 years</td>
</tr>
<tr>
<td>General Overgrowth</td>
<td>3%</td>
<td>1</td>
<td>2 years</td>
<td>2 years</td>
</tr>
</tbody>
</table>

Rather than relying on Facebook and reporting unverified information back to a clinician, this parent could now show their geneticist this table of official results from 36 respondents.

Example 2: Epilepsy incidence

“The published prevalence of epilepsy is as high as 50% (cohort of 34). Our current findings show a lower prevalence. A larger data set, properly analysed, will help us understand occurrence rates better.

<table>
<thead>
<tr>
<th>Issue Reported</th>
<th>Percentage reporting</th>
<th>Number reporting</th>
<th>Ages at diagnosis</th>
<th>Ages symptoms first appeared</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive impairment</td>
<td>80%</td>
<td>30</td>
<td>Range of: 0-3 months-8 years</td>
<td>Range of: 0-3 months-7 years</td>
</tr>
<tr>
<td>Coordination</td>
<td>88%</td>
<td>30</td>
<td>Range of: 0-3 months-8 years</td>
<td>Range of: 0-3 months-7 years</td>
</tr>
<tr>
<td>Hypotonia</td>
<td>71%</td>
<td>24</td>
<td>Range of: 0-3 months-8 years</td>
<td>Range of: 0-3 months-7 years</td>
</tr>
<tr>
<td>Hypertonia</td>
<td>56%</td>
<td>19</td>
<td>Range of: 0-3 months-10 years</td>
<td>Range of: 0-3 months-9 years</td>
</tr>
<tr>
<td>Unusual movements</td>
<td>42%</td>
<td>14</td>
<td>Range of: 0-3 months-8 years</td>
<td>Range of: 0-3 months-7 years</td>
</tr>
<tr>
<td>Memory impairment</td>
<td>38%</td>
<td>13</td>
<td>Range of: 4-7 months-8 years</td>
<td>Range of: 4-7 months-7 years</td>
</tr>
<tr>
<td>Abnormal EEG</td>
<td>38%</td>
<td>13</td>
<td>Range of: 0-3 months-7 years</td>
<td>Range of: 0-3 months-13 years</td>
</tr>
<tr>
<td>Seizures</td>
<td>29%</td>
<td>10</td>
<td>Range of: 0-3 months-6 years</td>
<td>Range of: 0-3 months-6 years</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>18%</td>
<td>6</td>
<td>Range of: 0-3 months-4 years</td>
<td>Range of: 0-3 months-1 year</td>
</tr>
<tr>
<td>Headaches and Migraines</td>
<td>6%</td>
<td>2</td>
<td>0 years old</td>
<td>0 years old</td>
</tr>
</tbody>
</table>
Section 8
Financial Review

8.1 The Reporting Period for this Report

The organisation’s first financial transaction was on 16th March 2022. We held charitable status at this point. The Charity’s financial performance reported below is therefore for the period from 16th March 2022 to 5th April 2023, a little over a year.

8.2 Our Accounts and Bankers

The charity operates using only one bank account as follows:
Natwest Bank
Account Name: CASK Research Foundation
Sort Code: 52-41-20
Account Number: 43690068

8.3 Financial Performance: Receipts and Payments, and Assets and Liabilities

We have prepared our accounts on a “Receipts and Payments Accounts” basis, which means that we have recorded cash flows in and out during the accounting period. The data has been transferred from the Charity’s internal spreadsheet onto a standard Charity Commission Form CC16a.

8.3 cont.

The Charitable Incorporated Organisations Regulations 2012 do require the following additional information:
a) particulars of any guarantee given by the CIO, where any potential liability under the guarantee is outstanding at the date of the statement of assets and liabilities; and
b) particulars of any debt outstanding at the date the statement of assets and liabilities which is owed by the CIO and which is secured by an express charge on any of the assets of the CIO.

Section A of the form presents the receipts and payments, disaggregated into the Charity’s main areas of activity. A1 shows these receipts; A3 shows these payments.

Section B presents the Statement of Assets and Liabilities at the End of the Period. We have no fixed or material assets of any significance. We have no property assets. The financial assets of the Charity are therefore the current funds in our Natwest Account, and that is the only account we hold.

The Examiner has agreed that the Natwest account accurately expresses the assets of the Charity, as the influence of these future sums is minor in respect of the total turnover, and the profitability of the Charity.
### Section A: Receipts and Payments

<table>
<thead>
<tr>
<th>A1 Receipts</th>
<th>Unrestricted funds</th>
<th>Restricted funds</th>
<th>Endowment funds</th>
<th>Total funds</th>
<th>Last year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donations</td>
<td>639</td>
<td>-</td>
<td>-</td>
<td>639</td>
<td>-</td>
</tr>
<tr>
<td>Donations - Fayres</td>
<td>2,590</td>
<td>-</td>
<td>-</td>
<td>2,590</td>
<td>-</td>
</tr>
<tr>
<td>Donations - PayPal</td>
<td>10,938</td>
<td>-</td>
<td>-</td>
<td>10,938</td>
<td>-</td>
</tr>
<tr>
<td>Donations - Facebook</td>
<td>2,176</td>
<td>-</td>
<td>-</td>
<td>2,176</td>
<td>-</td>
</tr>
<tr>
<td>Donations - Amazon</td>
<td>117</td>
<td>-</td>
<td>-</td>
<td>117</td>
<td>-</td>
</tr>
<tr>
<td>Donations - Sponsored events</td>
<td>1,904</td>
<td>-</td>
<td>-</td>
<td>1,904</td>
<td>-</td>
</tr>
<tr>
<td>Donations - Bingo</td>
<td>1,624</td>
<td>-</td>
<td>-</td>
<td>1,624</td>
<td>-</td>
</tr>
<tr>
<td>Donations - Coffee morning</td>
<td>728</td>
<td>-</td>
<td>-</td>
<td>728</td>
<td>-</td>
</tr>
<tr>
<td>Donations - Advent Trail</td>
<td>1,498</td>
<td>-</td>
<td>-</td>
<td>1,498</td>
<td>-</td>
</tr>
<tr>
<td>Donations - CAF</td>
<td>1,269</td>
<td>-</td>
<td>-</td>
<td>1,269</td>
<td>-</td>
</tr>
<tr>
<td>Donations - Open Gardens</td>
<td>850</td>
<td>-</td>
<td>-</td>
<td>850</td>
<td>-</td>
</tr>
</tbody>
</table>

**Sub total (Gross income for AR)** 24,333

| A2 Asset and Investment Sales, (see table) | - | - | - |

**Sub total** -

**Total receipts** 24,333

<table>
<thead>
<tr>
<th>A3 Payments</th>
<th>Unrestricted funds</th>
<th>Restricted funds</th>
<th>Endowment funds</th>
<th>Total funds</th>
<th>Last year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost of Sales</td>
<td>324</td>
<td>-</td>
<td>-</td>
<td>324</td>
<td>-</td>
</tr>
<tr>
<td>CASK Meet ups</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Licenses and Permits</td>
<td>40</td>
<td>-</td>
<td>-</td>
<td>40</td>
<td>-</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>4</td>
<td>-</td>
<td>-</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>Advertising and Promotion</td>
<td>186</td>
<td>-</td>
<td>-</td>
<td>186</td>
<td>-</td>
</tr>
<tr>
<td>Legal and Professional Fees</td>
<td>220</td>
<td>-</td>
<td>-</td>
<td>220</td>
<td>-</td>
</tr>
<tr>
<td>Subscriptions</td>
<td>82</td>
<td>-</td>
<td>-</td>
<td>82</td>
<td>-</td>
</tr>
<tr>
<td>Bank/Finance Charges</td>
<td>23</td>
<td>-</td>
<td>-</td>
<td>23</td>
<td>-</td>
</tr>
<tr>
<td>Insurance</td>
<td>96</td>
<td>-</td>
<td>-</td>
<td>96</td>
<td>-</td>
</tr>
</tbody>
</table>

**Sub total** 975

| A4 Asset and Investment Purchases, (see table) | - | - | - |

**Sub total** -

**Total payments** 975

**Net of receipts/(payments)** 23,358

### Section B: Statement of Assets and Liabilities at the End of the Period

<table>
<thead>
<tr>
<th>Categories</th>
<th>Unrestricted funds</th>
<th>Restricted funds</th>
<th>Endowment funds</th>
</tr>
</thead>
<tbody>
<tr>
<td>B1 Cash funds</td>
<td>23,170</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Paypal</td>
<td>182</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

**Total cash funds** 23,358
8.3 Cont.

The accounts have been scrutinised by an independent accountancy practice. The Examiner concludes that there are no material matters of concern, and that the accounts were prepared in accordance with section 130 of the relevant Act.

8.4 Policies on Reserves

Our current position is that we seek to hold a minimum bank balance of £1000. We have minimal overheads and so this provides a more than sufficient buffer to allow us to undertake our activities, and to pay our suppliers promptly.

Because the Charity is in its first full year of operation, this policy has not been stress tested, but it is the Charity’s view that such a minimum balance would have been more than sufficient to meet our obligations. We will review this reserves policy in the light of more operational experience.

8.5 Funds in Deficit

We do not have any funds in deficit. Our only funds are, as has been described, held in the NatWest account. This is in healthy surplus, as the charity is currently saving these funds in order to pay for the projects and future plans as outlined in section 11.

Section 9

Funds held as custodian trustee on behalf of others

CRF does not hold any assets in respect of other charities.

Section 10

Public benefit statement

We believe we have complied with the duty to have due regard to the guidance on public benefit published by the commission in exercising their powers or duties.
Section 11

Plans for the future period

Although only larger charities subject to statutory audit are required to provide details of plans for future periods, we have nevertheless set out that we wish to undertake the following activities in the financial year 2023/24:

- Create a UK contact and demographic registry
- Create a global roadmap in collaboration with the other members of the CASK Coalition
- Fund a UK research project via a pilot grant for £25,000
- Continue to raise funds;
- Apply to the Charities Commission to enable the charity to act as advocates between families and medical professionals;
- Develop a fundraising and awareness video for the website and use on social media;
- Continue to create contacts with researchers within the UK and Europe
- Have the RARE-X data analysed and published

Section 12

Signed statement

I, Laura Hattersley, hereby sign this Annual Report as a true record of the activities of the Charity for the year from 16th March 2022 to 5th April 2023.

Signed: ...........................................

Name: Laura Hattersley
Position: Chief Executive Director, CASK Research Foundation

Date: 04/7/2023
Having been duly authorised to do so by the Trustees of the Charity.
Acknowledgements

Many thanks to the following people who made this report possible and who have assisted the projects mentioned.

Our SAB, for guidance and support and exploring/creating research avenues

Our Research Review Committee, past and present, for ensuring we only support the most suitable and scientifically thorough projects

Liz Cook for writing the Financial Report and doing the accounts

The Trustees for being a sounding board, providing momentum, advice and guidance

Renee Roquet for helping to promote the RARE-X DCP

Our colleagues from AECF and ACNRF

We thank you for your ongoing support of our programme