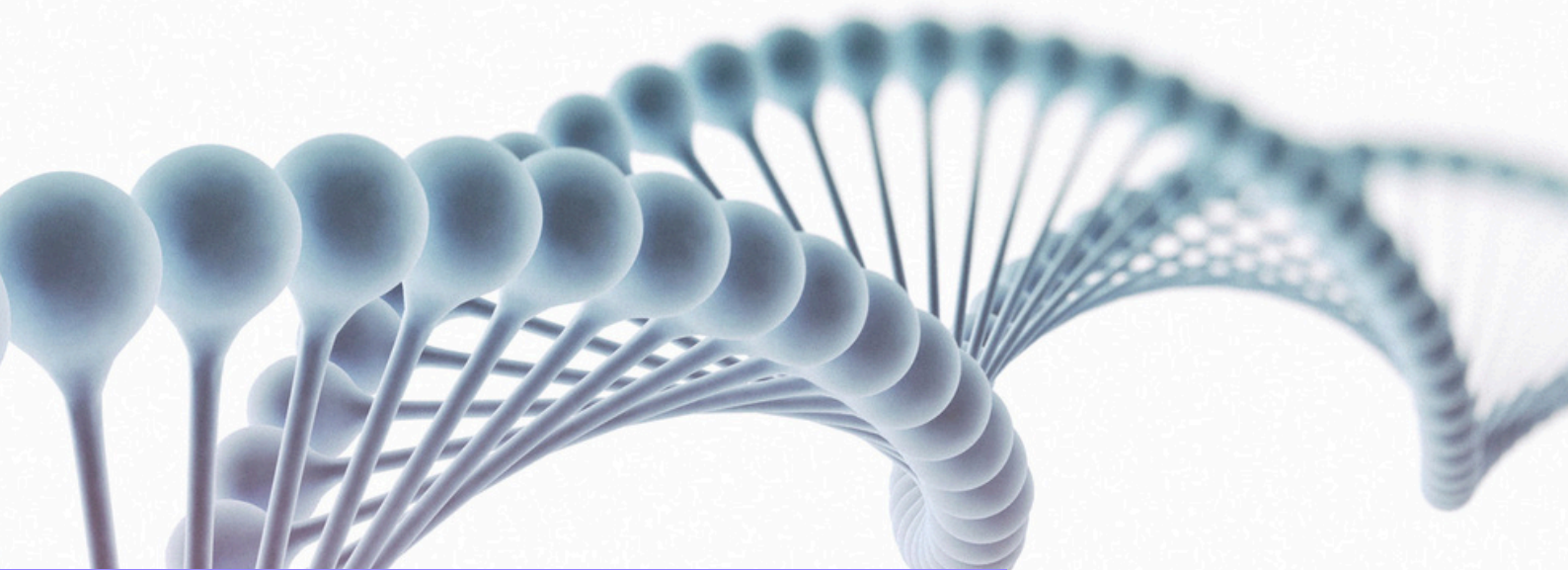




# CASK

RESEARCH FOUNDATION



# End of year trustees report

2023-2024

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## Section 1

# What is CASK?

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.

# Who are CASK Research Foundation?

**CASK Research Foundation (or CRF) is a UK-wide Charitable Incorporated Organisation (CIO) registered with the Charity Commission in England and Wales.**

It was founded in 2022 by Laura Hattersley, BSc, MSc, who is the mother to a child with MICPCH. CRF commenced work as an organisation in March 2022, setting about to create an informative network, connect with researchers and clinicians, create annual family meet ups and fundraise in order to fund scientific research to accelerate the path to treatments. CASK Research Foundation is also known informally as CASK Research UK.

## Section 2

# This annual report

This Annual Report explains our aims and how we have gone about achieving them. It has been prepared in accordance with the applicable legal requirements. It gives a balanced view of the charity's structure, aims, objectives, activities and performance. Importantly, it describes our primary sources of funding, and describes how the money was spent. It highlights the main activities we have undertaken.

## Section 3

# Meeting our legal requirements

We have still prepared our accounts on a "Receipts and Payments" basis as per our obligation. 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 period.

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;
- Achievements and performance;
- A financial review;
- Funds held as custodian trustee on behalf of others;
- Public benefit statement.

## Section 4

# Reference & administrative details

### 4.1. The Charity's Name

The Charity's name is CASK Research Foundation (informally CASK Research UK)

### 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

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

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

## 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 2023-24

1. Maintained close relations with our Scientific Advisory Board of experts in the field of neurodevelopmental disorders
2. Established the CASK Coalition
3. Established the CASK RARE-X Data Collection Programme. This is an initiative delivered by Global Genes.
4. Joined UK Rare Epilepsies Together (UKRET) network
5. Worked in collaboration with Professor Kutsche to create informative and accurate media/literature
6. Maintained and improved our website
7. Held several webinars for the international community
8. Assisted in the creation and promotion of CASK Coalition's first annual fundraiser – CASK Race for Research

## 6.2 Continued

9. Family support
10. Co-funded the CURE CASK campaign
11. Inclusion of the CASK gene into the BINGO project and GENROC study
12. Provided a grant to Bristol University
13. Attended conferences and events
14. Developed a UK CASK registry
15. Improved awareness of CASK gene disorders
16. Extended our partnership network

### 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
- Dr Mingshan Xue – Researcher, Baylor college, USA
- Professor James Hodge – Researcher, Bristol University
- Dr Isabel Zwart – Astra Zeneca

### 6.2.2 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.

### 6.2.3 RARE-X DCP

The CASK RARE-X Data Collection Programme – a patient owned, free, secure, streamlined, international registry. We now have over 120 patients registered from 21 countries. See section 7.4 for more detailed information.

### 6.2.4 Joined UKRET

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.

### 6.2.5 Dissemination of information

We identified a need for some literature to educate friends and families on CASK disorders. We offered to personalise the leaflets with a photo of their child. We created these also for our CASK Coalition partners. The scientific content was verified by Professor Kutsche.

Professor Kutsche assisted in the creation of content for an animation explaining CASK disorders to the masses. This is the only such resource currently available to families.

### 6.2.6 Website

The CRF website [www.caskresearch.org](http://www.caskresearch.org) delivers information to families and researchers. It has been updated to include more information on prognosis and more links to external charitable help as well as intensive therapy centres.



## 6.2.7 Webinars

In January we held a webinar giving updates on the global CASK registry RARE-X as well as a webinar with Professor Kerstin Kutsche about the genetics of CASK including a Q&A.

## 6.2.8 Global CASK Race for Research

CRF created the content for the CASK Coalition's annual fundraising platform. The first annual event was held in July and raised, across all members of the CASK Coalition, over £20,000.

## 6.2.9 Family support

We organised and funded the annual CASK family meet up. This year it was at Camp Mohawk in Berkshire. 9 families attended. We also host informal 'Science and Social's online which the UK and Irish community are invited to. They are able to ask questions about CASK disorders, the genetics and also meet other families and get peer support.

## 6.2.10 CURE CASK project

In January 2024 CRF donated £27,000 to UC Davis to co-fund part 1 of the CURE CASK project. This project aims to assess the possibility of X-reactivation as a potential therapeutic for CASK gene disorders in our female population.

## 6.2.11 Externally funded research projects

We have been involved in facilitating three research studies that did not require funding from CRF.

- BINGO project: This is an ongoing study by Cambridge University involving a multitude of genetic disorders. 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. We contacted Dr Kate Baker who agreed to include CASK disorders in the study and, in addition, write a stand alone paper on CASK disorders if we managed to recruit enough patients. The study involved an online survey, an online interview and an in person assessment for UK based participants. We were successful in recruiting enough individuals and await the final written report.
- GENROC: This is a study led by Bristol University that aims to see how CASK affects children's growth, development and their families. CASK is one of a number of genes being studied in this project.
- Patient studies: We linked a patient displaying an unusually mild phenotype with Professor Kutsche's lab to determine the rate of X chromosome skewing. The study was successful and the patient's family received more understanding of their child's condition.

### 6.2.12 Bristol University grant

CRF have agreed a grant of £25,000 to Professor James Hodge at Bristol University. His study included creating a robust fly model of CASK disorders in order to learn more about the gene and disorders. The money is awaiting transfer and the study starts in October 2024.

### 6.2.13 Conferences and events

- CEO Laura Hattersley attended the CDKL5 forum in November in London where she met in person with three of CRFs scientific advisors.
- Rare Summit 2023 – Laura represented CRF and UKRET at this biannual conference in Cambridge in October.
- BPNA – Laura represented CRF and UKRET at the British Paediatric Neurological Association conference. The abstract: demystifying CASK gene disorders, was presented by neurologist Dr Vlachou. The abstract used the RARE-X data to shine a light on CASK symptoms.
- Rare Disease Day Westminster Reception – Laura Hattersley attended the Palace of Westminster on February 29th to celebrate Rare Disease Day 2024.

### 6.2.14 UK CASK Registry

CRF obtained a volunteer from the company SOPHOS as part of their volunteering scheme to create a simple and secure CASK registry. There are currently 29 patients registered. This provides confirmation of known cases in the UK as well as creating a network of communication with verified families.

### 6.2.15 Improved Awareness

CRF funded the creation of 'Life with CASK', a documentary highlighting the realities of CASK gene disorders. The documentary includes interviews with Professor Hodge and Dr Tuffrey. The short film has already been viewed over 2300 times on YouTube. It aims to raise and improve awareness of the disorders as well as increase awareness of the urgent need for funding.

"Thank you so much for this video! I'm so happy to be a part of this rare disease community!"

"This is the best of humanity! Loving, caring and fighting for the most vulnerable."

"This short film will be a great step towards more funding."

"This is wonderful. So insightful"

"This is so helpful. My daughter has recently been diagnosed with CASK."

### 6.2.16 Extended partnership network

CRF are now members of:

- Eurordis
- Genetic Alliance
- The JumpStart Project
- Global Genes
- UK Rare Epilepsies Together
- CASK Coalition
- Bristol Neurodevelopment Hub

## 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. Examples of this can be seen in 6.2.10–6.2.16.

### 7.2 Our mission to support and provide advice

We have achieved this by:

- Improving our informative website.
- Holding a family meet up day in September 2023 with another planned in Sept 2024.
- Creating and facilitating the creation of information guides.
- Holding webinars and online meetings to help educate and inform parents and provide answers.
- Creating a UK registry. This acts as a formal 'free' membership system and enables us to collect more accurate and trusted data on UK disease prevalence as well as creating an additional mailing list to our Mailchimp newsletter. We use this to inform families of upcoming events and studies.
- A monthly newsletter.

### 7.3 Mailchimp

The Mailchimp account was created in June 2022. We now have 198 subscribers. We send out a monthly newsletter. This has an average opening rate of 68.4% based on information from Mailmodo (<https://www.mailmodo.com/guides/mailchimp-open-rate/>), 21% classed as a 'good' opening rate for a newsletter.

**198**

mailchimp subscribers.  
33% increase in 12 months

**68%**

Average opening rate  
for monthly newsletter

**30**

No. of UK patients  
officially registered in  
the UK registry

**133**

international members  
of the Global CASK  
Registry RARE-X

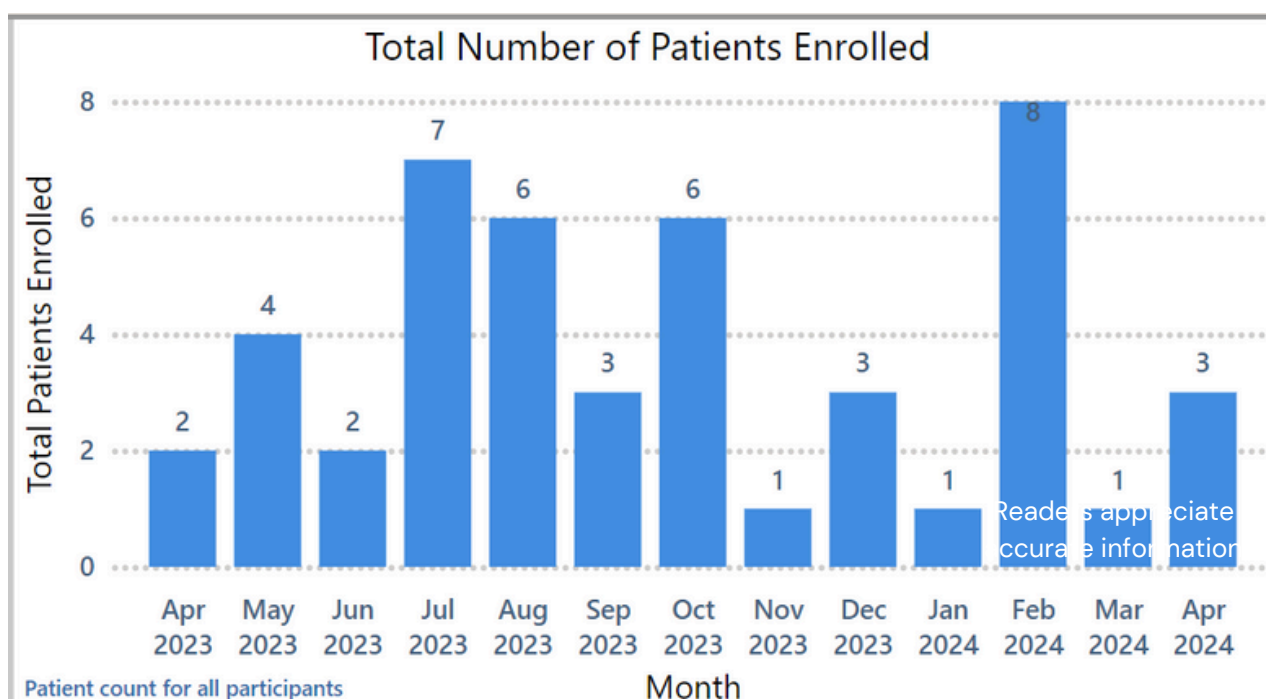


There are now four CASK non-profits working with the CASK RARE-X data collection programme: Association Enfants CASK France; Angelina CASK Neurological Research Foundations, Project CASK and CASK Research Foundation.

## 7.4 RARE-X DCP

The CASK RARE-X Data Collection Programme was officially launched in early September 2022. We now have over 126 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.



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

A webinar in February 2024 culminated in 8 more families registering. UK families currently stand at 21. We have found that by having a successful registry we are garnering interest from researchers. It led to the presentation at the BPNA conference. The data included in this abstract aims to be incorporated into a larger paper created by Bristol University.

Country	Patient Count	Percent of Global Patients
Albania	1	0.8%
Argentina	1	0.8%
Australia	6	4.8%
Austria	1	0.8%
Brazil	1	0.8%
Canada	7	5.6%
Chile	1	0.8%
France	15	11.9%
Germany	5	4.0%
Greece	1	0.8%
Ireland	1	0.8%
Italy	1	0.8%
Lebanon	1	0.8%
Luxembourg	1	0.8%
Malta	1	0.8%
Netherlands	2	1.6%
Norway	1	0.8%
Poland	3	2.4%
Romania	1	0.8%
Slovenia	1	0.8%
Spain	1	0.8%
Sweden	1	0.8%
Turkey	1	0.8%
Ukraine	1	0.8%
United Kingdom	21	16.7%
United States	49	38.9%
Total	126	100.0%

Our social media campaigns about our RARE-X registry have had international reach with patients from 26 countries enrolled

## 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 ones child.

### Example 1: Question from a parent on a Facebook group

"We had an appointment yesterday with XXs 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..."

#### Issues reported by 36 CASK respondents in Growth Survey

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

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.

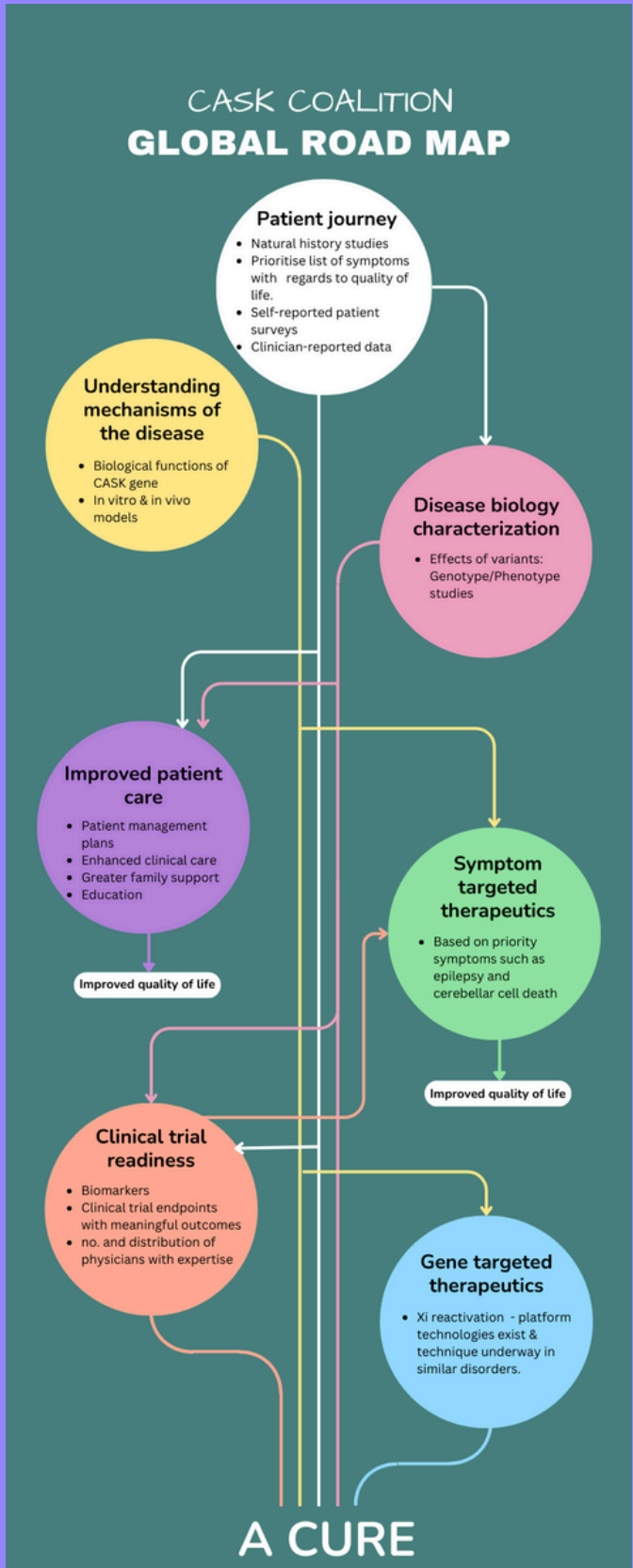
### Example 2: Epilepsy incidence

"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.

#### Issues reported by 34 CASK respondents in Brain and Nervous System Survey

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

# 7.5 CASK Coalition Road map



**CASK families**

- RARE-X Registry
- CASK Coalition patient surveys
- US patients - Citizen & CRID
- Enrollment in studies

**Understanding mechanisms**

- UK Pilot grants available
- CURE CASK campaign will result in in vivo and in vitro models, available to all

**Understanding the genetics**

- RARE-X collecting Genotype and phenotype data
- Bristol University investigating relationships

**Patient care**

- RARE-X data enabling greater understanding of symptoms and prognosis
- Cambridge BINGO study to enhance understanding of behaviour and emotions

**Targeting symptoms**

- Ongoing project with the Mukherjee lab funded by ACRNF Australia
- UK Pilot grants available

**Clinical trials**

- Detailed natural history studies using RARE-X data plus, for example, Citizen
- Physician/expertise list from Coalition countries

**Targeting the gene**

- UC Davis ready to start Xi reactivation on CASK. The CURE CASK campaign is raising money to initiate this.
- UK Pilot grants available.
- Alternative avenues yet to be elucidated due to inadequate knowledge of gene and protein.
- Platform technologies not yet established for CASK e.g. protein replacement, gene replacement, mRNA therapy.

**CASK COALITION**

United for our CASK warriors

The CASK Coalition prioritises the neglected aspects of the Roadmap. These include the longterm, detailed patient journey, improving quality of life, clinical trial readiness and gene targeted therapeutics. There is global, increasing and diverse research on the CASK gene, its mechanisms and its role in disease. What is lacking is translational research with an end point of a treatment.

The Global Roadmap was created and agreed by all members of the CASK Coalition. In 2023/24 the CASK Coalition acted on all sections of the Roadmap, either by funding projects or by improving the Patient Data Collection Programme uptake. All members are committed to the Roadmap and use it to direct their actions and funding.

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## Section 8

# Financial Review

### 8.1 The Reporting Period for this Report

The Charity's financial performance reported below is for the period from 1st April 2023 to 31st March 2024.

### 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**

**Independent Examiner's Report**

**Report to the trustees/  
members of**

CASK Research Foundation

**On accounts for the year  
ended**

31 March 2024

**Charity no  
(if any)**

**Set out on pages**

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 /03 /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 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.

**Signed:**

**Date:** 14/08/2024

**Name:**

Karen Luckman FCCA

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

ACCA

**Address:**

7 Heathdene  
Brighton Road  
Burgh Heath  
Surrey  
KT20 6AW





**CHARITY COMMISSION**  
FOR ENGLAND AND WALES

Charity Name

CASK Research Foundation

No (if any)

1197434

## Receipts and payments accounts

**CC16a**

For the period  
from

Period start date  
01/04/2023


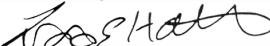
To

Period end date  
31/03/2024

### Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
<b>A1 Receipts</b>					
Sales	338	-	-	338	-
Donations	783			783	639
Donations - Fayres	133			133	2,590
Donations - PayPal	3,008			3,008	10,938
Donations - Facebook	2,991			2,991	2,176
Donations - Amazon	88			88	117
Donations - Sponsored events	9,422			9,422	1,904
Donations - Bingo	1,439			1,439	1,624
Donations - Advent Trail	803			803	728
Donations - Raffles	721	-	-	721	1,498
Donations - CAF	7,499	-	-	7,499	1,269
Donations - Open Gardens	10,377	-	-	10,377	850
Donations - Easy Fundraising	326	-	-	326	-
Donations - Merchandise	221	-	-	221	-
Donations - Wills	6,000	-	-	6,000	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>44,148</b>	<b>-</b>	<b>-</b>	<b>44,148</b>	<b>24,333</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>44,148</b>	<b>-</b>	<b>-</b>	<b>44,148</b>	<b>24,333</b>
<b>A3 Payments</b>					
Grants Given - UC Davies Cure Cask	23,373	-	-	23,373	-
Cost of Sales	269			269	324
Materials	180			180	-
Subcontractor Costs	150			150	-
CASK Meet ups	-			-	-
Documentary Costs	1,950			1,950	-
Licenses and Permits	20			20	40
Advertising and Promotion	1,710			1,710	186
Legal and Professional Fees	50	-	-	50	220
Subscriptions	604	-	-	604	82
Bank/Finance Charges	28	-	-	28	23
Insurance	96	-	-	96	96
Miscellaneous	1	-	-	1	4
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>28,429</b>	<b>-</b>	<b>-</b>	<b>28,429</b>	<b>975</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>28,429</b>	<b>-</b>	<b>-</b>	<b>28,429</b>	<b>975</b>
<b>Net of receipts/(payments)</b>	<b>15,719</b>	<b>-</b>	<b>-</b>	<b>15,719</b>	<b>23,358</b>
<b>A5 Transfers between funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>23,358</b>	<b>-</b>	<b>-</b>	<b>23,358</b>	<b>-</b>
<b>Cash funds this year end</b>	<b>39,077</b>	<b>-</b>	<b>-</b>	<b>39,077</b>	<b>23,358</b>

## Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B1 Cash funds</b>	Natwest Bank	38,574	-	-
	Paypal	503	-	-
		-	-	-
	<b>Total cash funds</b>	<b>39,077</b>	<b>-</b>	<b>-</b>
	(agree balances with receipts and payments account(s))	OK	OK	OK
		<b>Unrestricted funds to nearest £</b>	<b>Restricted funds to nearest £</b>	<b>Endowment funds to nearest £</b>
<b>B2 Other monetary assets</b>	Details			
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B4 Assets retained for the charity's own use</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B5 Liabilities</b>	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		Elizabeth Cook	7/8/2024	
		Laura Hattersley	05/08/2024	

### 8.3 Cont.

The accounts have been scrutinised by an independent accountant holding ACCA status. 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 £1500. 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 and fees promptly. It is the Charity's view that such a minimum balance would have been more than sufficient to meet our obligations. This value has been based on analysis of the previous years incomings. This is highlighted in our Finance Policy.

### 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


Below we set out that we wish to undertake the following activities in the financial year 2024/2025:

- Create a private and global community platform using the app 'Discord'.
- Continue to raise funds and create a research grant of £40,000.
- Apply to the Charities Commission to enable the charity to act as advocates between families and medical professionals.
- Achieve charity status in Scotland.
- Continue to create contacts with researchers within the UK and Europe.
- Facilitate clinical studies in collaboration with Bristol University, including a mortality study to document causes of death.
- Have the RARE-X data 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 6th April 2023 to 5th April 2024.

Signed: 

Name: Laura Hattersley

Position: Chief Executive Director, CASK Research Foundation

Date: 22/4/2024

Having been duly authorised to do so by the Trustees of the Charity.

# Acknowledgements

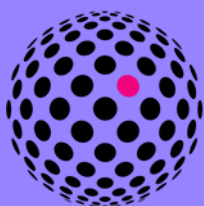
Many thanks to the following people who made this report possible and who have assisted the projects mentioned.

Our **Scientific and Clinical Advisory Board**, for guidance and support and exploring/creating research avenues

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

Our **colleagues** from [AECF](#) and [ACNRF](#)

# We thank you for your ongoing support of our programme



**CASK**  
RESEARCH FOUNDATION

**CASK Research Foundation**

33 Finchdean Road

Rowlands Castle

PO9 6DA

[www.caskresearch.org](http://www.caskresearch.org)

[info@caskresearch.org](mailto:info@caskresearch.org)





**Section A**

**Independent Examiner's Report**

**Report to the trustees/  
members of**

CASK Research Foundation

**On accounts for the year  
ended**

31 March 2024

**Charity no  
(if any)**

**Set out on pages**

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 /03 /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 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.

**Signed:**

**Date:** 14/08/2024

**Name:**

Karen Luckman FCCA

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

ACCA

**Address:**

7 Heathdene

Brighton Road

Burgh Heath

Surrey

KT20 6AW





**CHARITY COMMISSION**  
FOR ENGLAND AND WALES

Charity Name

CASK Research Foundation

No (if any)

1197434

## Receipts and payments accounts

**CC16a**

For the period  
from

Period start date  
01/04/2023


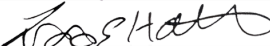
To

Period end date  
31/03/2024

### Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
<b>A1 Receipts</b>					
Sales	338	-	-	338	-
Donations	783			783	639
Donations - Fayres	133			133	2,590
Donations - PayPal	3,008			3,008	10,938
Donations - Facebook	2,991			2,991	2,176
Donations - Amazon	88			88	117
Donations - Sponsored events	9,422			9,422	1,904
Donations - Bingo	1,439			1,439	1,624
Donations - Advent Trail	803			803	728
Donations - Raffles	721	-	-	721	1,498
Donations - CAF	7,499	-	-	7,499	1,269
Donations - Open Gardens	10,377	-	-	10,377	850
Donations - Easy Fundraising	326	-	-	326	-
Donations - Merchandise	221	-	-	221	-
Donations - Wills	6,000	-	-	6,000	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>44,148</b>	<b>-</b>	<b>-</b>	<b>44,148</b>	<b>24,333</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>44,148</b>	<b>-</b>	<b>-</b>	<b>44,148</b>	<b>24,333</b>
<b>A3 Payments</b>					
Grants Given - UC Davies Cure Cask	23,373	-	-	23,373	-
Cost of Sales	269			269	324
Materials	180			180	-
Subcontractor Costs	150			150	-
CASK Meet ups	-			-	-
Documentary Costs	1,950			1,950	-
Licenses and Permits	20			20	40
Advertising and Promotion	1,710			1,710	186
Legal and Professional Fees	50	-	-	50	220
Subscriptions	604	-	-	604	82
Bank/Finance Charges	28	-	-	28	23
Insurance	96	-	-	96	96
Miscellaneous	1	-	-	1	4
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>28,429</b>	<b>-</b>	<b>-</b>	<b>28,429</b>	<b>975</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>28,429</b>	<b>-</b>	<b>-</b>	<b>28,429</b>	<b>975</b>
<b>Net of receipts/(payments)</b>	<b>15,719</b>	<b>-</b>	<b>-</b>	<b>15,719</b>	<b>23,358</b>
<b>A5 Transfers between funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>23,358</b>	<b>-</b>	<b>-</b>	<b>23,358</b>	<b>-</b>
<b>Cash funds this year end</b>	<b>39,077</b>	<b>-</b>	<b>-</b>	<b>39,077</b>	<b>23,358</b>

## Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B1 Cash funds</b>	Natwest Bank	38,574	-	-
	Paypal	503	-	-
		-	-	-
	<b>Total cash funds</b>	<b>39,077</b>	<b>-</b>	<b>-</b>
	(agree balances with receipts and payments account(s))	OK	OK	OK
		<b>Unrestricted funds to nearest £</b>	<b>Restricted funds to nearest £</b>	<b>Endowment funds to nearest £</b>
<b>B2 Other monetary assets</b>	<b>Details</b>			
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>	<b>Details</b>	<b>Fund to which asset belongs</b>	<b>Cost (optional)</b>	<b>Current value (optional)</b>
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B4 Assets retained for the charity's own use</b>	<b>Details</b>	<b>Fund to which asset belongs</b>	<b>Cost (optional)</b>	<b>Current value (optional)</b>
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B5 Liabilities</b>	<b>Details</b>	<b>Fund to which liability relates</b>	<b>Amount due (optional)</b>	<b>When due (optional)</b>
			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	<b>Signature</b>	<b>Print Name</b>		<b>Date of approval</b>
		Elizabeth Cook		7/8/2024
		Laura Hattersley		05/08/2024





**Section A**

**Independent Examiner's Report**

**Report to the trustees/  
members of**

CASK Research Foundation

**On accounts for the year  
ended**

31 March 2024

**Charity no  
(if any)**

**Set out on pages**

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**Independent  
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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.

**Signed:**

**Date:** 14/08/2024

**Name:**

Karen Luckman FCCA

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

ACCA

**Address:**

7 Heathdene

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KT20 6AW