

CASK RESEARCH FOUNDATION

England & Wales · Charity number 1197434

Details

Status Registered

Legal form CIO

Registered 2022-01-11

Register [View on the Charity Commission register](#)

Contact

Address 33 Finchdean Road
Finchdean Road
Rowlands Castle
33 Finchdean Road
Finchdean Road
PO9 6DA

Phone 07792136772

Email Info@caskresearch.org

Website www.caskresearch.org

Activities

Objects: TO PROMOTE AND PROTECT THE PHYSICAL AND MENTAL HEALTH OF UK SUFFERERS OF CASK GENE RELATED DISORDERS THROUGH THE PROVISION OF SUPPORT AND PRACTICAL ADVICE. TO ADVANCE THE EDUCATION OF THE PUBLIC IN CASK GENE RELATED DISORDERS BY THE PROVISION OF A WEBSITE AND AWARENESS DAY DEVOTED TO CASK GENE RELATED DISORDERS. TO ADVANCE THE EDUCATION OF THE PUBLIC IN GENERAL (AND PARTICULARLY AMONGST SCIENTISTS) ON THE SUBJECT OF CASK GENE RELATED DISORDERS AND TO PROMOTE RESEARCH FOR THE PUBLIC BENEFIT IN ALL ASPECTS OF THAT SUBJECT AND TO PUBLISH THE USEFUL RESULTS.

Activities: Raise funds for scientific and medical research into the CASK Gene and its related disorders. Funds are raised via public donations. The charity is national.

Classification

- **How:** Makes Grants To Organisations, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£39,229	£73,576	-	-
2024-03-31	£44,148	£28,429	-	-
2023-03-31	£24,333	£975	-	-

Trustees

Name	Role	Appointed
Laura Hattersley	Chair	2022-01-07
Andrea LeForte		2022-01-07
Dr Charles Shawcross		2025-05-06
Elizabeth Cook		2022-01-07
Jessica Geoghegan		2025-07-31

CASK RESEARCH FOUNDATION

England & Wales - Charity number 1197434

Accounts



CASK
RESEARCH FOUNDATION



End of year trustees report

2024-2025

Table of Contents

01

What is CASK?
Who are CASK
Research
Foundation?

02

This annual
report – general

03

Meeting our legal
requirements

04

Reference and
administrative
details

05

Structure,
governance and
management

06

Objectives and a
activities

07

Achievements
and performance

08

Financial Review

09

Funds held as
custodian
trustee on behalf
of others

10

Public benefit
statement

11

Plans for the
future period

12

Signed
statement

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)

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, 2 Newtown Cottages,
George Street, Staplehurst, TN12 ORA

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 Activities Undertaken 1 April 2024– 31st March 2025

1. CASK RARE-X Data Collection Programme.
2. European expansion
3. Family support
4. Gift of £40,000
5. Completion of research projects
6. Conferences and events
7. Awareness
8. Mental health support
9. Won £21,000 worth of pro-bono work from Costello Medical
10. Creation of the Kicking CASK podcast
11. Assisting in drug discovery for cerebellar degeneration
12. Created Kicking CASK shop – raise awareness and raise funds

6.2.1 RARE-X DCP

The CASK RARE-X Data Collection Programme – a patient owned, free, secure, streamlined, international registry. This is an initiative delivered by Global Genes. We now have over 140 patients registered from 21 countries (up from 120 last reporting year). [See section 7.4 for more detailed information.](#)

6.2.2 Expanded into Europe

We currently have two Polish volunteers and 1 volunteer resident in Ireland. We have our CASK Fast Facts leaflets translated into German and Polish.

6.2.3 Family Support

We continue to offer monthly virtual socials, regular newsletters and an annual family meet up in the UK. In July 2024 we organised the first ever International CASK Family meeting where expert clinicians gave talks and answered parents' questions. This was attended by over fifty families.

6.2.4 £40,000 gift

We gifted £40,000 to University of Bristol to enable Professor Hodge's work on creating a translational platform for CASK disorders to continue. The team continue to apply for grants to help fund this. The gift has also enabled the creation of the CASK clinical registry, sponsored by University of Bristol. This will enable patient data to be collected and analysed by NHS clinician Dr Amin for at least the next three years.

6.2.5 Completion of Research

- Cambridge University completed their study on 'The neurodevelopmental spectrum of CASK-related disorder' which was instigated and recruited for by CRF. 31 patients took part. It is currently waiting publication in a peer-reviewed journal.
- Bristol University GenROC study to improve understanding of how rare genetic syndromes affect the way children grow, their physical health and their development. 11 CASK patients took part in this study.

6.2.6 Conferences and events

- Founder Laura Hattersley attended GW4 meetings on epilepsy and neurodevelopmental disorders, and presented at them.
- Founder Laura attended the CLCN4 conference in order to network and learn more about the conference process.

6.2.7 Awareness

- Improved awareness of CASK gene disorders by speaking at conferences, networking, maintaining and updating website and creating summaries of scientific papers, making complex research accessible to parents, carers and supporters.
- Our CASK Gene Awareness Day (July 15th) campaign was well supported and followed.
- We also took part in Rare Disease Day 2025 and designed conversation starting T shirts for the global community.

6.2.8 Mental Health support

·We have partnered with the charity Rare Minds to offer our community mental health support specifically designed for people living with a rare disease. With the assistance of Rare Minds we created a survey for UK families, to assess the mental health impact of caring for someone with a CASK-related disorder.

6.2.9 Costello Medical

·We won a contract to receive £21,000 of pro-bono work from the health company Costello Medical. They are creating an infographic for the community to share insights from the RARE-X data collection platform. The aim of this project is to feedback information to caregivers in visually appealing ways as well as improve uptake of the RARE-X DCP. The results will be shared with the community on July 15th,

6.2.10 Podcast creation

Laura started a podcast called the Kicking CASK Podcast as a way to easily share updates with the global community, build community and bring about more support. It is aired on YouTube and Spotify.

6.2.11 Supporting Dr Tabuchi

A Japanese scientist, Dr Tabuchi, has found out more about the cerebellar cell death (in animal models) and has found a mechanism to prevent it. We have been helping him find a way to develop this discovery into a viable therapeutic.

6.2.12 The Kicking CASK Shop

·CASK Research partnered with TeeMill, a sustainable online retailer, to deliver CASK and general additional needs merchandise to the community. Profit margins are minimal however it is bringing a regular trickle of revenue.

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 missions and aims

It is our mission to advance the education on the CASK gene and its disorders. We achieved this aim by assisting with the Cambridge university research study as well facilitating the growth of the RARE-X DCP and sharing findings with the community by our partnership with Costello Medical.

Another aim is to promote and protect the physical and mental health of UK sufferers. Partnering with Rare Minds and having monthly virtual socials enables us to provide some mental health support to families.

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 2024.
- Creating and facilitating the creation of information guides.
- Holding the family conference in July 2024. This helped educate and inform parents and provide answers.
- A bi-monthly newsletter.
- Holding a UK registry purely for collecting contact details and a patient count.

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 56% based on information from Mailmodo (<https://www.mailmodo.com/guides/mailchimp-open-rate/>), 21% classed as a 'good' opening rate for a newsletter.

222

mailchimp subscribers.
12% increase in 12
months

56%

Average opening rate
for monthly newsletter

38

No. of UK patients
officially registered in
the UK registry

144

international members
of the Global CASK
Registry RARE-X

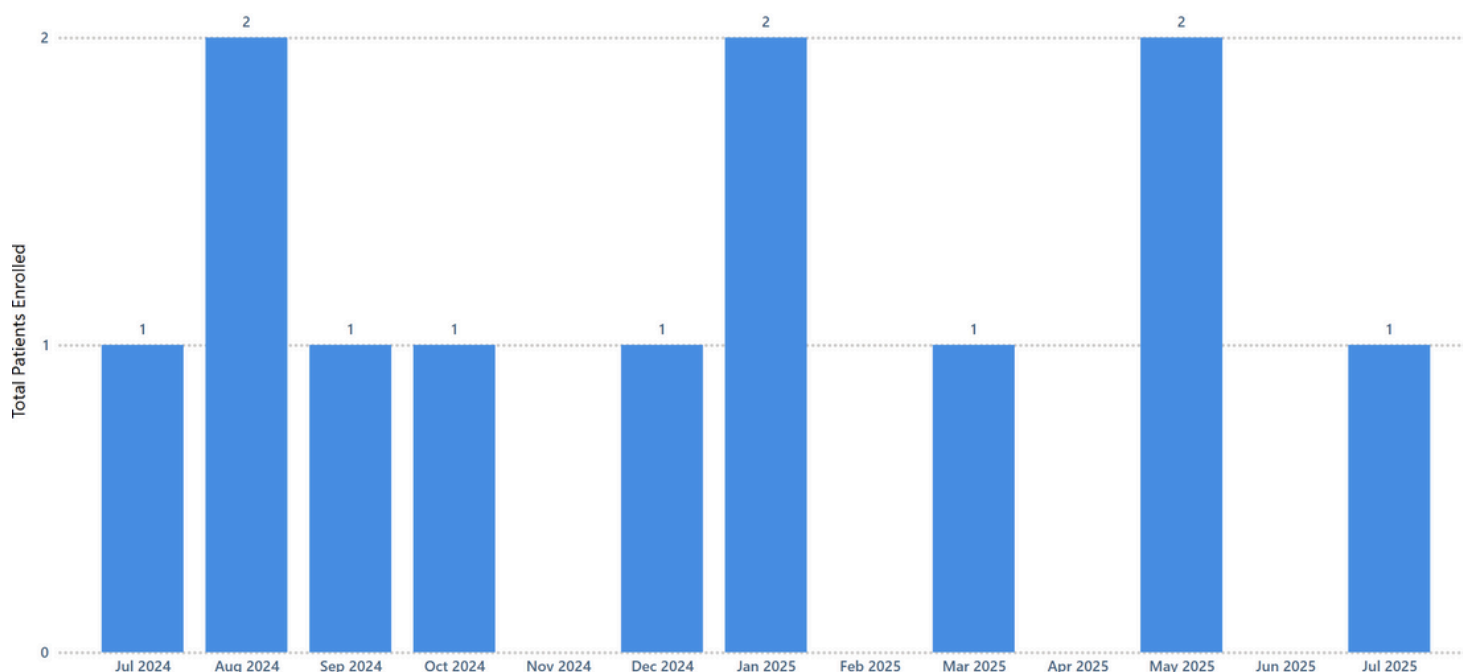


There are now four CASK non-profits working with the CASK RARE-X data collection programme: Association Enfants CASK France; Angelina CASK Neurological Research Foundations, Project CASK and CASK Research Foundation.

7.4 RARE-X DCP

The CASK RARE-X Data Collection Programme was officially launched in early September 2022 by CRF. We now have over 140 participants signed up and answering surveys.

The registry is international and RARE-X are rolling out more languages every year.



7.4.1 Quality of data

We now have a substantial registry however the completion or initiation of surveys can be very low. This is why we asked Costello Medical to look into this and create an infographic to help parents see the value in the data.

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..."

RARE X Issues reported by 36 CASK respondents in Growth Survey

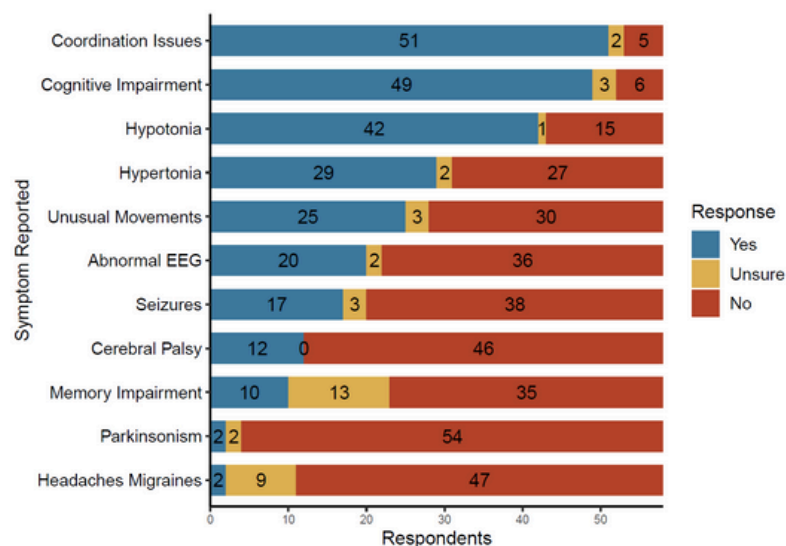
Issue Reported	Percentage reporting	Number reporting	Ages at diagnosis	Ages symptoms first appeared
Short Stature	44%	16	Range of: Before Birth- 3 years	Range of: Before Birth- 2 years
Undergrowth	44%	16	Range of: Before Birth- 4 years	Range of: Before Birth- 4 years
Growth Hormone Deficiency	14%	5	Range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

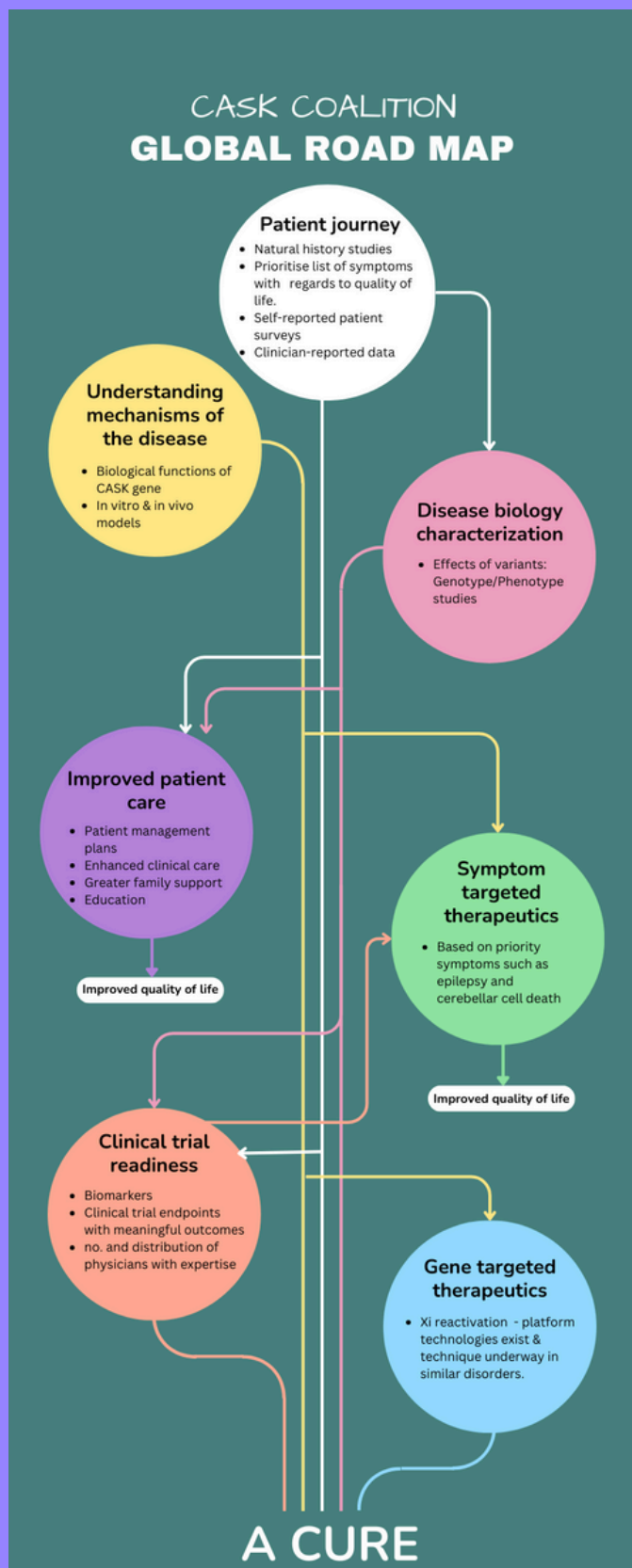
Example 2: Epilepsy incidence

"The published prevalence of epilepsy is as high as 50% (cohort of 34). Our current findings show a lower prevalence (29%). A larger data set, properly analysed, will help us understand occurrence rates better.

Issues reported by 58 CASK Gene Mutations respondents in the Brain and Nervous System Domain



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.



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.

11

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 2024 to 31st March 2025.

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").

**Independent
examiner's statement**

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.

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



Receipts and payments accounts

CC16a

For the period
from

Period start date
01/04/2023


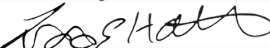
To

Period end date
31/03/2024

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
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	-
	-	-	-	-	-
Sub total (Gross income for AR)	44,148	-	-	44,148	24,333
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	44,148	-	-	44,148	24,333
A3 Payments					
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
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	28,429	-	-	28,429	975
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	28,429	-	-	28,429	975
Net of receipts/(payments)	15,719	-	-	15,719	23,358
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	23,358	-	-	23,358	-
Cash funds this year end	39,077	-	-	39,077	23,358

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 £
B1 Cash funds	Natwest Bank	38,574	-	-
	Paypal	503	-	-
		-	-	-
	Total cash funds	39,077	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	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 2025/2026:

- Continue to raise funds and create a 2nd 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.
- Assist with the creation of the UK clinical database in association with University of Bristol and the NHS
- Coordinate collaboration between European clinicians setting up their own patient databases, to ensure uniformity.
- Roll out the Global CASK Census, in collaboration with partner PAGs.

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: 16/7/2025.....

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

Acknowledgements

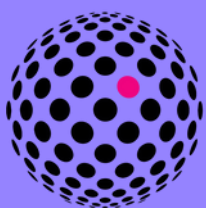
Many thanks to the following people who made this report possible and who have assisted the projects mentioned.

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

info@caskresearch.org



Receipts and payments accounts

For the period from	Period start date 01/04/2024	To	Period end date 31/03/2025
------------------------	---------------------------------	----	-------------------------------

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Sales	-	-	-	-	-
Donations	4,632	-	-	4,632	783
Donations - Fayres	-	-	-	-	133
Donations - PayPal	1,302	-	-	1,302	3,008
Donations - Facebook	-	-	-	-	2,991
Donations - Amazon	-	-	-	-	88
Donations - Sponsored events	14,356	-	-	14,356	9,422
Donations - Bingo	2,199	-	-	2,199	1,439
Donations - Coffee Morning	1,241	-	-	1,241	-
Donations - Advent Trail	-	-	-	-	803
Donations - Raffles	-	-	-	-	721
Donations - CAF	7,507	-	-	7,507	7,499
Donations - Open Gardens	200	-	-	200	10,377
Donations - Easy Fundraising	158	-	-	158	326
Donations - Merchandise	20	-	-	20	221
Donations - Wills	100	-	-	100	6,000
Donations - Art Auction	6,609	-	-	6,609	-
Donations - Golf day	905	-	-	905	-
Sub total (Gross income for AR)	39,229	-	-	39,229	44,148
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	39,229	-	-	39,229	44,148
A3 Payments					
Grants Given - UC Davies Cure Cask C	-	-	-	-	23,373
Grants Given - University of Bristol	65,000	-	-	65,000	-
Cost of Sales	7,517	-	-	7,517	269
Materials	-	-	-	-	180
Subcontractor Costs	-	-	-	-	150
CASK Meet ups	-	-	-	-	-
Documentary Costs	-	-	-	-	1,950
Licenses and Permits	-	-	-	-	20
Advertising and Promotion	379	-	-	379	1,710
Legal and Professional Fees	-	-	-	-	50
Subscriptions	581	-	-	581	604
Bank/Finance Charges	-	-	-	-	28
Insurance	96	-	-	96	96
Miscellaneous	3	-	-	3	1
Sub total	73,576	-	-	73,576	28,429
A4 Asset and investment purchases. (see table)					
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	73,576	-	-	73,576	28,429
Net of receipts/(payments)	- 34,347	-	-	- 34,347	15,719
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	39,077	-	-	39,077	23,358
Cash funds this year end	4,731	-	-	4,731	39,077

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 £
B1 Cash funds	Natwest Bank	4,681	-	-
	Paypal	50	-	-
		-	-	-
	Total cash funds	4,731	-	-
	receipts and payments account(s))	OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval
		Laura Hattersley	30/11/2025
		Liz Cook	30/11/2025



Section A Independent Examiner's Report

Report to the trustees

CASK Research Foundation

On accounts for the year ended

31 March 2025

**Charity no
(if any)**

1197434

Set out on pages

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31/03/2025**.

Responsibilities and basis of report

As the charity's trustees, 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 all 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:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did 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 this report in order to enable a proper understanding of the accounts to be reached.

** Please delete the words in the brackets if they do not apply.*

Signed:

Date:

30/12/2025

Name:

Thomas Morris

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

CIMA

Address:

c/o CASK research foundation

33 Finchdean Road

Rowlands Castle, PO9 6DA

CASK RESEARCH FOUNDATION

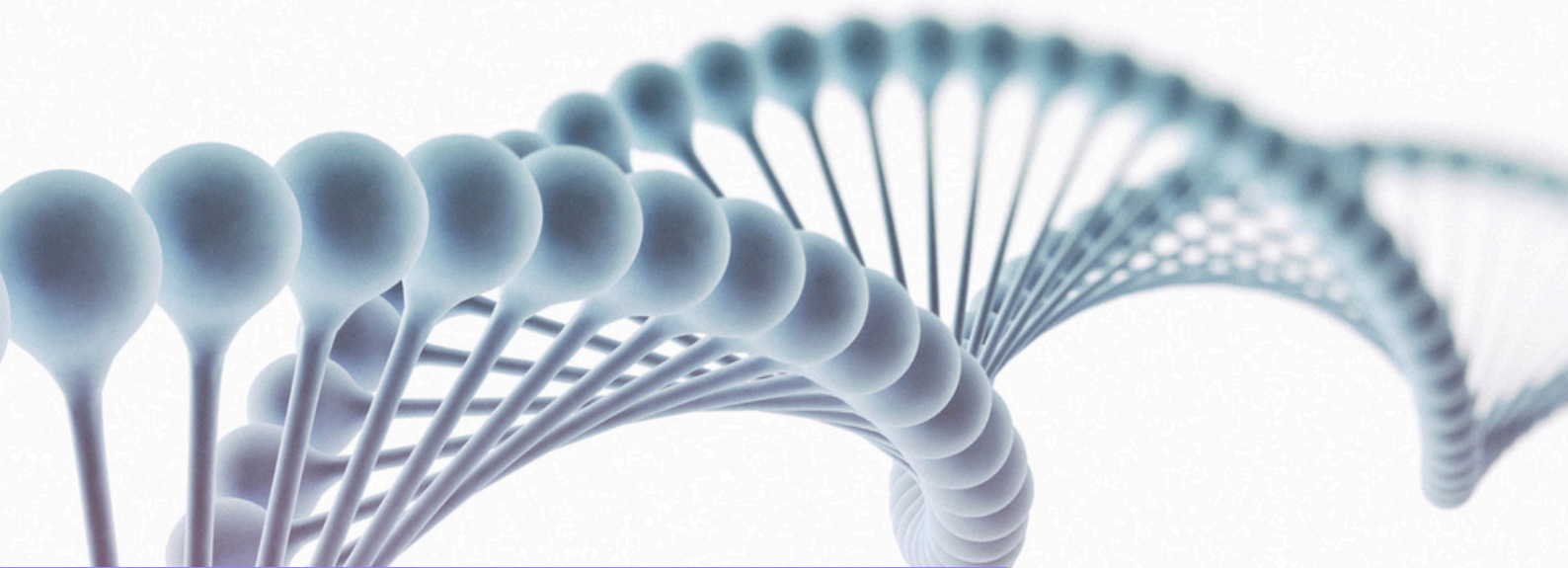
England & Wales - Charity number 1197434

Accounts



CASK

RESEARCH FOUNDATION



End of year trustees report

2023-2024

Table of Contents

01

What is CASK?
Who are CASK
Research
Foundation?

02

This annual
report – general

03

Meeting our legal
requirements

04

Reference and
administrative
details

05

Structure,
governance and
management

06

Objectives and a
activities

07

Achievements
and performance

08

Financial Review

09

Funds held as
custodian
trustee on behalf
of others

10

Public benefit
statement

11

Plans for the
future period

12

Signed
statement

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 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 You Tube. 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

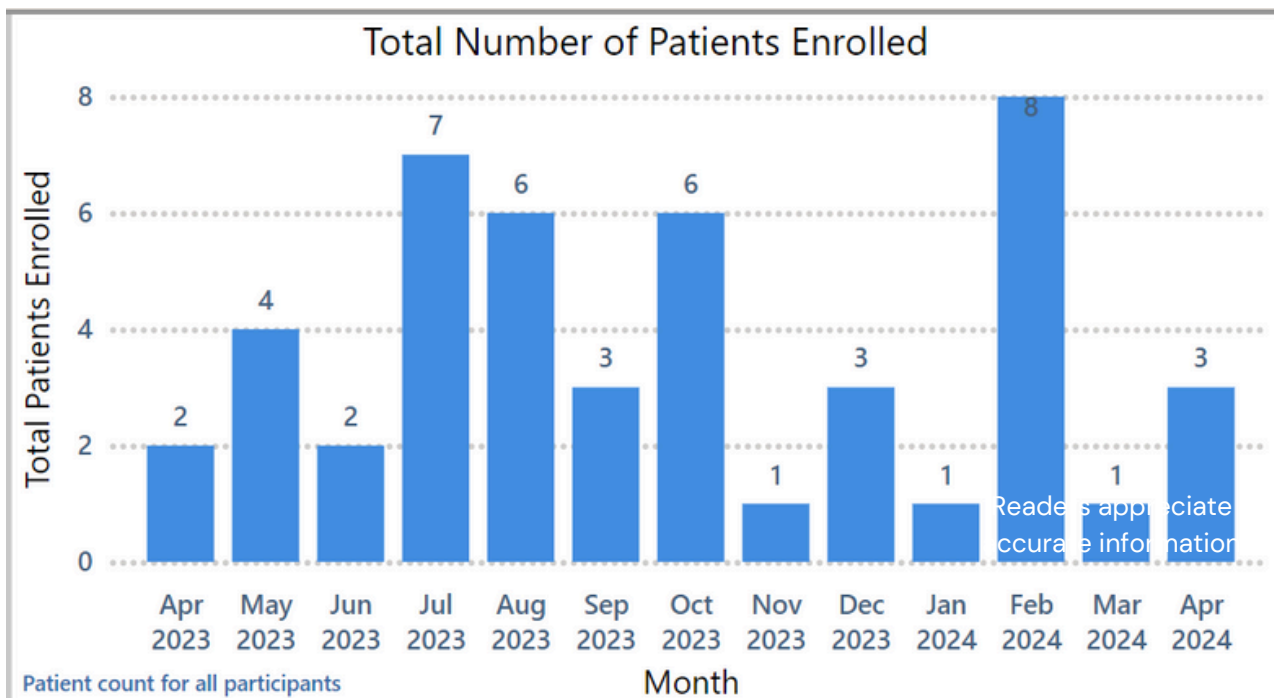


7.4 RARE-X DCP

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.

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.

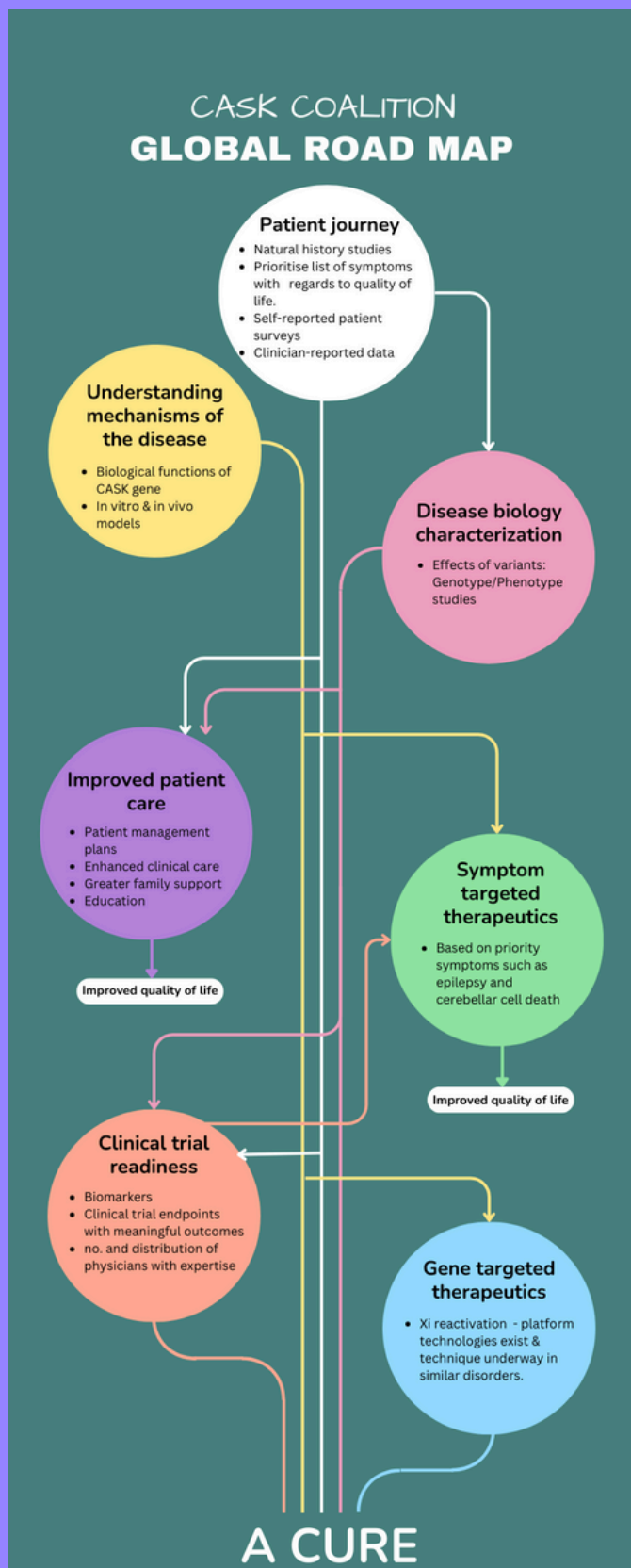
Example 2: Epilepsy incidence

"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.



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.

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").

**Independent
examiner's statement**

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.

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




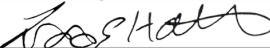
Receipts and payments accounts

For the period from	Period start date 01/04/2023	To	Period end date 31/03/2024
----------------------------	---------------------------------	-----------	-------------------------------

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
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	-
	-	-	-	-	-
Sub total (Gross income for AR)	44,148	-	-	44,148	24,333
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	44,148	-	-	44,148	24,333
A3 Payments					
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
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	28,429	-	-	28,429	975
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	28,429	-	-	28,429	975
Net of receipts/(payments)	15,719	-	-	15,719	23,358
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	23,358	-	-	23,358	-
Cash funds this year end	39,077	-	-	39,077	23,358

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 £
B1 Cash funds	Natwest Bank	38,574	-	-
	Paypal	503	-	-
		-	-	-
	Total cash funds	39,077	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
	Details	to nearest £	to nearest £	to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-
	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	
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

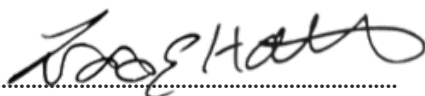
Below we set out that we wish to undertake the following activities in the financial year 2024/2025:

- 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

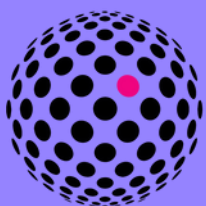
Many thanks to the following people who made this report possible and who have assisted the projects mentioned.

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

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").

**Independent
examiner's statement**

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.

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




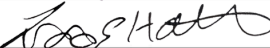
Receipts and payments accounts

For the period from	Period start date 01/04/2023	To	Period end date 31/03/2024
---------------------	---------------------------------	----	-------------------------------

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
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	-
	-	-	-	-	-
Sub total (Gross income for AR)	44,148	-	-	44,148	24,333
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	44,148	-	-	44,148	24,333
A3 Payments					
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
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	28,429	-	-	28,429	975
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	28,429	-	-	28,429	975
Net of receipts/(payments)	15,719	-	-	15,719	23,358
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	23,358	-	-	23,358	-
Cash funds this year end	39,077	-	-	39,077	23,358

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 £
B1 Cash funds	Natwest Bank	38,574	-	-
	Paypal	503	-	-
		-	-	-
	Total cash funds	39,077	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	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



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").

**Independent
examiner's statement**

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.

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

CASK RESEARCH FOUNDATION

England & Wales - Charity number 1197434

Accounts



CASK
RESEARCH FOUNDATION

End of year report

2022-2023



Table of Contents

01

What is CASK
What is CASK
Research
Foundation

02

This annual
report – general

03

Meeting our legal
requirements

04

Structure,
governance and
management

05

Objectives and
activities

06

Achievements
and performance

07

Financial review

08

Public benefit
statement

09

Plans for future
periods

10

Signed stateent

11

Your section
titles go here

12

Your section
titles go here

Section 1

What is CASK?

CASK is the name of a gene essential for healthy development of the brain. Mutations in this gene cause two disorders: 'MICPCH' and 'XL-ID with or without nystagmus'. To simplify things, we often use the term 'CASK' to describe either disorder.

CASK gene mutations are ultra rare. The brain doesn't grow as it should, giving the child microcephaly (literally meaning 'small head'). Children with CASK can suffer from 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.

Male infants with CASK generally pass away within the first few years of life. Females with CASK have an unknown prognosis but many 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 most suffer from sleep disturbances.

Many 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.

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

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;
- 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

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, 26/6/84

4.4 Cont.

Grants advisor
Rachel Manktelow, 71 New Wokingham
Road, RG45 XXXXXX

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

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
- Liased with the charity Unique to enable the first ever disorder guide to be written for families.

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
- Got the CASK gene included in 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
- Magda Ellis ???

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 (UK RET) 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 their friends and families on their child's rare disease. 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 £xxxxx

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 foreign parent whose child has unusual and alarming symptoms. We share 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 Snoozelen 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.

This culminated in the 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 on April 2024. We created a separate fundraising platform to identify funds a donor specifically wants to go towards 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.

6.3 Statement of compliance

The Trustees are in agreement that the CIO is 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 our 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 the 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
- Held a Family meet up day in 2022 with another planned in Sept 2023
- Created and facilitated the creation of information guides (see 6.2.6 & 6.2.7)
- Held webinars (6.2.12) to help educate and inform parents and provide answers
- Created a map of UK families to reduce feeling 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 with 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% is a good opening rate for a newsletter.

153

mailchimp subscribers

70%

Average opening rate for monthly newsletter

33

No. of UK patients, based on Facebook poll by CRF

82

international members of the DCP

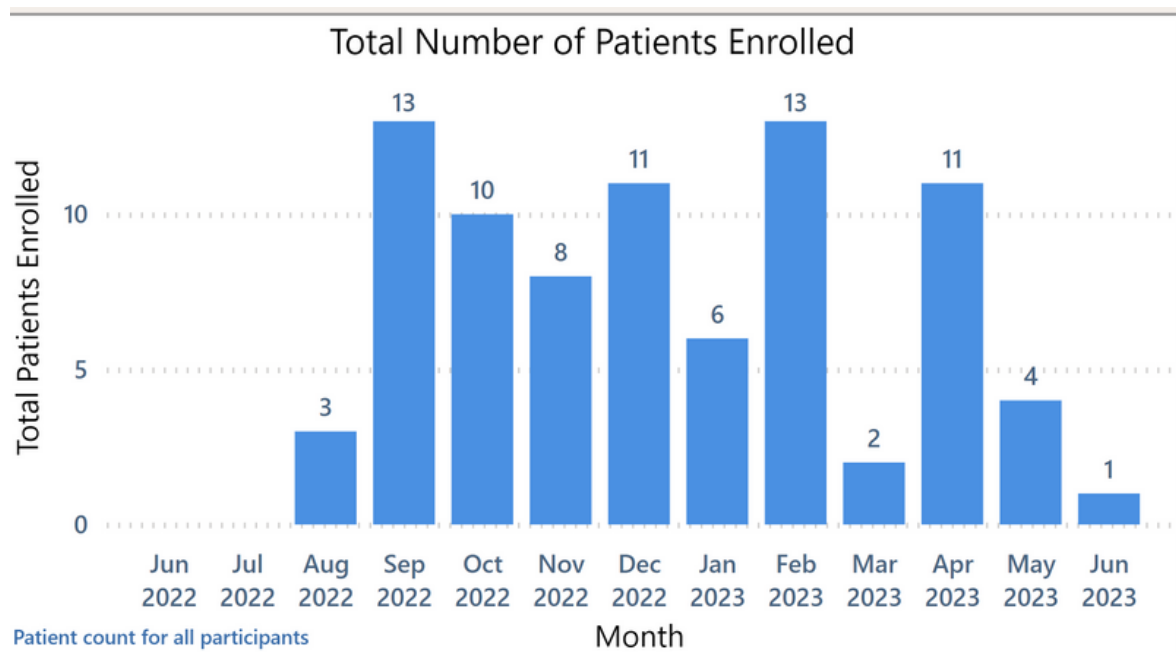


7.4 RARE-X DCP

Readers appreciate accurate information

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.



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 are garnering interest from researchers.

Country	Patient Count	Percent of Global Patients
Albania	1	1.2%
Argentina	1	1.2%
Australia	4	4.9%
Brazil	1	1.2%
Canada	3	3.7%
Chile	1	1.2%
France	8	9.8%
Germany	4	4.9%
Greece	1	1.2%
Italy	1	1.2%
Lebanon	1	1.2%
Luxembourg	1	1.2%
Malta	1	1.2%
Netherlands	1	1.2%
Poland	2	2.4%
Romania	1	1.2%
Slovenia	1	1.2%
Sweden	1	1.2%
Ukraine	1	1.2%
United Kingdom	17	20.7%
United States	30	36.6%
Total	82	100.0%

Our social media campaigns have had international reach with patients from 21 countries enrolled

7.4.2 Data obtained

Only verified researchers and clinicians are able to gain access to the entire set 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 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)*1. 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

Section 8

Financial Review

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.

References

- 1.

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
- 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

We thank you for your ongoing support of our programme

Ref 1 <https://pubmed.ncbi.nlm.nih.gov/33640666/>

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 our projects, in particular the RARE-X DCP

Our **colleagues** from AECF and ACNRF

Your **contributors**

CASK Research Foundation
33 Finchdean Road
Rowlands Castle
PO9 6DA
www.caskresearch.org
info@caskresearch.org



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name CASK Research Foundation	No (if any) 1197434
---	------------------------

CC16a

Receipts and payments accounts

For the period from	Period start date 1/11/2022	To	Period end date 3/31/2023
---------------------	--------------------------------	----	------------------------------

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Donations	639	-	-	639	-
Donations - Fayres	2,590	-	-	2,590	-
Donations - PayPal	10,938	-	-	10,938	-
Donations - Facebook	2,176	-	-	2,176	-
Donations - Amazon	117	-	-	117	-
Donations - Sponsored events	1,904	-	-	1,904	-
Donations - Bingo	1,624	-	-	1,624	-
Donations - Coffee morning	728	-	-	728	-
Donations - Advent Trail	1,498	-	-	1,498	-
Donations - CAF	1,269	-	-	1,269	-
Donations - Open Gardens	850	-	-	850	-
	-	-	-	-	-
Sub total (Gross income for AR)	24,333	-	-	24,333	-
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	24,333	-	-	24,333	-
A3 Payments					
Cost of Sales	324	-	-	324	-
CASK Meet ups	-	-	-	-	-
Licenses and Permits	40	-	-	40	-
Miscellaneous	4	-	-	4	-
Advertising and Promotion	186	-	-	186	-
Legal and Professional Fees	220	-	-	220	-
Subscriptions	82	-	-	82	-
Bank/Finance Charges	23	-	-	23	-
Insurance	96	-	-	96	-
Sub total	975	-	-	975	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	975	-	-	975	-
Net of receipts/(payments)	23,358	-	-	23,358	-
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	23,358	-	-	23,358	-

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 £
B1 Cash funds	Natwest Bank	23,176	-	-
	Paypal	182	-	-
		-	-	-
	Total cash funds	23,358	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval
		Elizabeth Anne Cook	6/10/2023
		Laura Elizabeth Hattersley	