



CASK

RESEARCH FOUNDATION



End of year trustees report

2025-2026

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Section 1

What is CASK?

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

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

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

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

Who are CASK Research Foundation?

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

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

Section 2

This annual report

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

Section 3

Meeting our legal requirements

We have still prepared our accounts on a "Receipts and Payments" basis as per our obligation. This means that our accounts contain a statement summarising all money received and paid out in the financial year, and a statement of our assets and liabilities at the end of the period.

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

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

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

Section 4

Reference & administrative details

4.1. The Charity's Name

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

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

Director

Laura Hattersley, 33 Finchdean Road, PO9 6DA

Treasurer

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

Charles Shawcross, 2 Newtown Cottages, Rowlands Castle, PO96DA

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 Statement of compliance

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

6.3 Activities Undertaken 1 April 2025– 31st March 2026

- 1.New research projects initiated
- 2.Research projects completed
3. Family support
4. Conferences and events attended
- 5.Awareness generated
- 6.New resources created
- 7.Grants received
- 8.CASK Coalition expanded
- 9.Ongoing research

6.3.1 New Research Projects initiated

- Instigated a PhD study at **University of Portsmouth** starting in Oct 2026: Generation of **Zebrafish Models** for CASK Related Disorders
- Convened the first **global CASK Scientific Round Table**, bringing together more than 30 researchers, clinicians and charity leaders to accelerate international collaboration, including discussions on gene therapy, clinical registries and Centres of Excellence.
- Supported research at the **University of Bristol**, where the CASK fruit fly study generated new insights into the role of the CASK gene and disease mechanisms.
- Launched the **CASK Patient Research Priorities Survey** in collaboration with the Patient Led Research Hub, enabling families to directly influence the future direction of CASK research and support services.
- Undertook the first global '**Counting CASK**' **Census**, a multilingual survey to better understand how many patients make up the worldwide CASK community. To date, 192 individuals from 25 countries have registered.
- Led the development of a **Europe-wide CASK Clinical Registry** initiative, bringing together clinicians from across Europe to create harmonised national databases that will support international research and improve understanding of CASK-related disorders.
- Partnered with the **Australian FaceMatch project**, helping to improve diagnosis for people with rare genetic conditions by matching facial features with those of diagnosed individuals.

6.3.2 Research projects completed

- Completion of the **CASK Activation study** at UC Davis, USA: This groundbreaking gene therapy research successfully demonstrated that reactivating the healthy 'backup' copy of the CASK gene in human brain cells is possible—an important milestone towards a potential future treatment.
- Advanced **drug repurposing research** for CASK-related cerebellar degeneration: CASK Research identified three promising compounds and showed that they all reduced cell loss in laboratory studies, in collaboration with Professor Tabuchi at Shinshu University, Japan. We have selected the most clinically viable candidate and are progressing towards further preclinical development.
- Launched the **CASK Patient Passport** in partnership with CamRARE, providing families with a personalised health and care passport to communicate essential medical information during emergencies or when away from home.
- Celebrated the success of **MSc researcher Anya**, whose CASK research, supported by CASK Research, was selected for presentation at the British Paediatric Neurology Association Conference.

6.3.3 Family Support

We continue to offer monthly virtual socials, regular newsletters and an annual family meet up in the UK.

6.3.4 Conferences and events

- Raised awareness of CASK-related disorders through national advocacy, with Founder Laura Hattersley speaking at the Gene People Leadership Symposium
- Attended the Rare Disease Day Parliamentary Reception.
- Attended GW4 meetings on epilepsy and neurodevelopmental disorders, and presented at them.

6.3.5 Awareness Generated

Produced a new CASK Research charity film, showcased at the British Paediatric Neurology Association Conference to raise awareness of CASK-related disorders.

6.3.6 New Resources created

Published the first CASK Infographic in partnership with Costello Medical and RARE-X, transforming real-world patient data into an accessible educational resource for families, clinicians, educators and carers.

6.3.7 Grants secured and awarded

- Secured £5,000 in funding for family counselling through generous £2,500 donations from the Société Générale UK Foundation and a private donor, enabling UK CASK families to access specialist one-to-one counselling through the rare disease mental health charity RareMinds.
- Awarded a £1,500 grant from the Grace Trust to support Dr Sam Amin (University of Bristol) to progress the UK CASK Registry and Biobank.

6.3.8 The CASK Coalition

We welcomed two new European CASK charities, CASK Luxembourg and ProCASK Italia, to the CASK Coalition, strengthening international collaboration.

6.3.9 Ongoing research

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 162 patients registered (up from 140 last reporting year) from 30 countries . [See section 7.4 for more detailed information.](#)

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 have continued to advance research into CASK disorders as can be seen in section 6.3.1 and raise awareness by giving talks, representing the disorders at conferences and hosting scientific meetings to increase knowledge within the scientific community.

Another aim is to promote and protect the physical and mental health of UK sufferers. We partner with Rare Minds to provide families with free counselling and hold annual meet ups where families can receive peer support.

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 a infographic.
- A regular newsletter published six times a year.

7.3 Mailchimp

The Mailchimp account was created in June 2022. We now have 247 subscribers. We send out a newsletter approximately every other month. This has an average opening rate of 38%. Based on information from Mailmodo (<https://www.mailmodo.com/guides/mailchimp-open-rate/>), 21% classed as a 'good' opening rate for a newsletter.

247

mailchimp subscribers.
11% increase in 12
months

38%

Average opening rate
for monthly newsletter

40

No. of UK patients
officially registered in
the UK registry

162

international members
of the Global CASK
Registry RARE-X

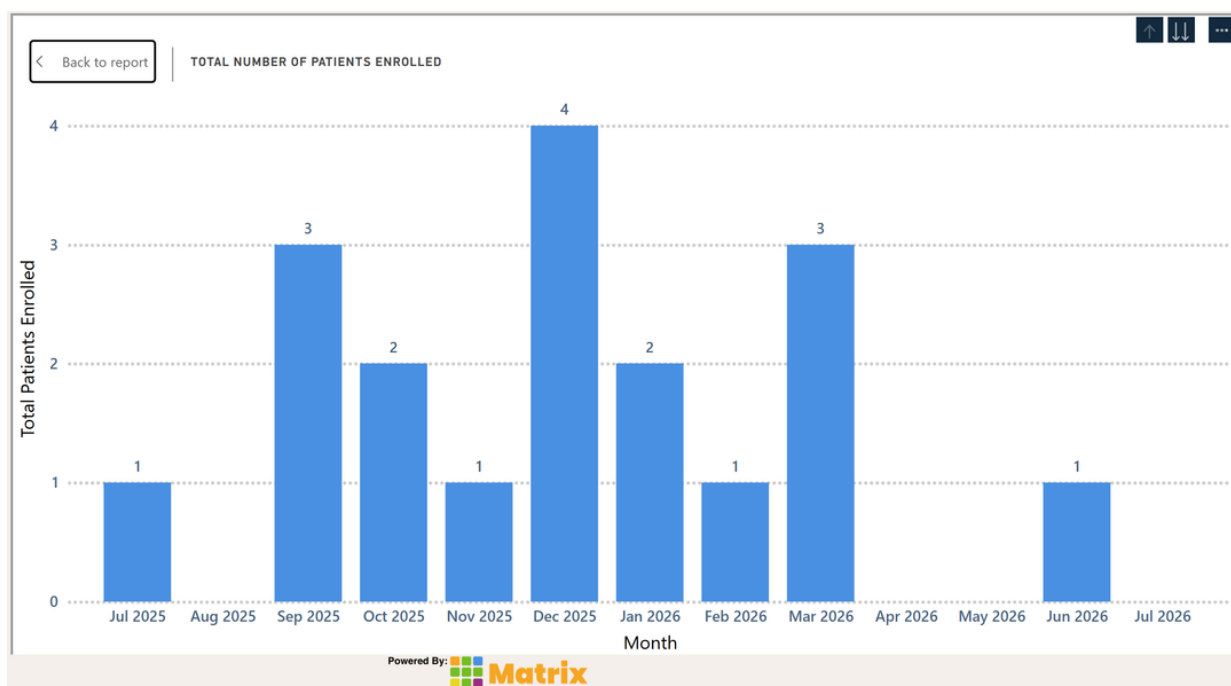


There are now four CASK non-profits working with the CASK RARE-X data collection programme: Association Enfants CASK France; Angelina CASK Neurological Research Foundations, Project CASK and CASK Research Foundation.

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 160 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..."



Issues reported by 36 CASK respondents in Growth Survey

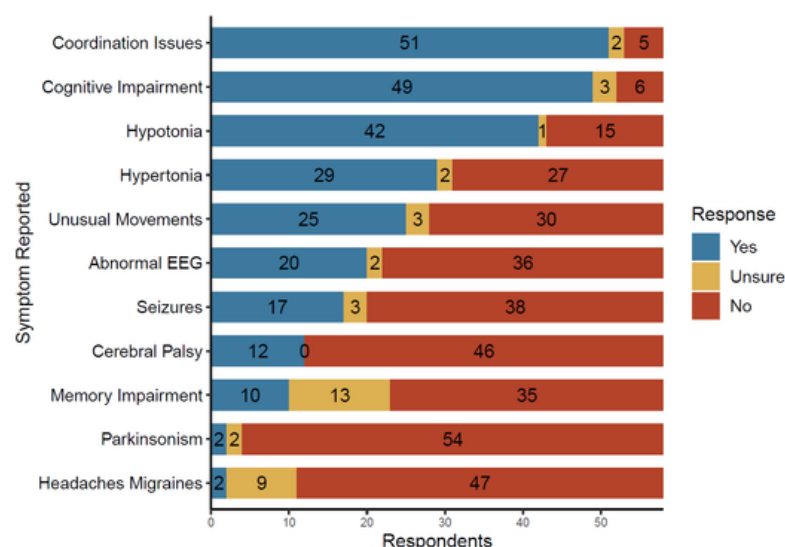
Issue Reported	Percentage reporting	Number reporting	Ages at diagnosis	Ages symptoms first appeared
Short Stature	44%	16	Range of: Before Birth- 3 years	Range of: Before Birth- 2 years
Undergrowth	44%	16	Range of: Before Birth- 4 years	Range of: Before Birth- 4 years
Growth Hormone Deficiency	14%	5	Range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

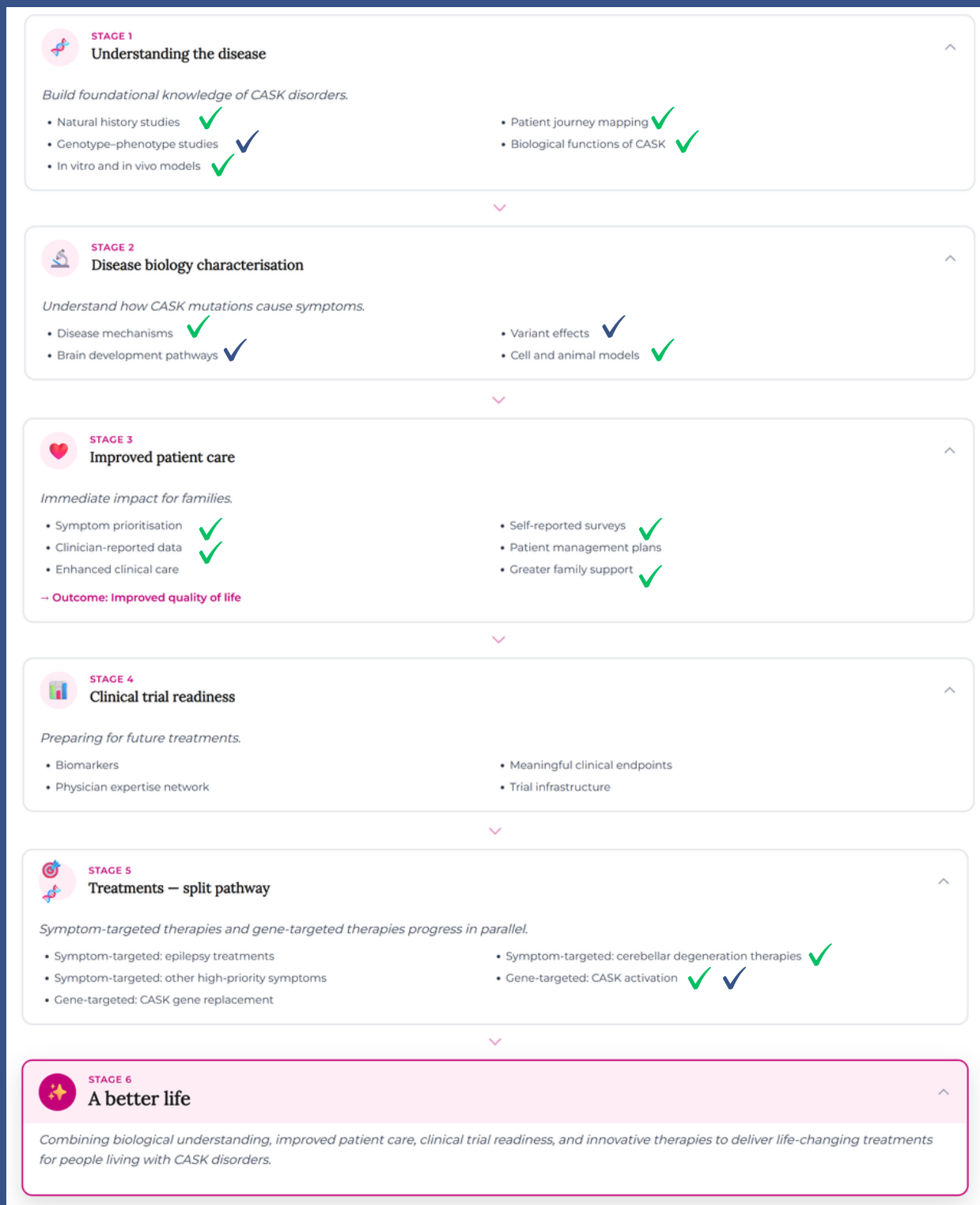
"The published prevalence of epilepsy is as high as 50% (cohort of 34). Our current findings show a lower prevalence (29%). A larger data set, properly analysed, will help us understand occurrence rates better.

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



7.5 CASK Coalition Road map to a cure

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.



Key: Green Ticks represent work done directly by CASK Research Foundation
Blue Ticks represent work done by members of the CASK Coalition

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 2025 to 31st March 2026.

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.



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name
CASK Research Foundation

No (if any)
1197434

Receipts and payments accounts

CC16a

For the period
from

Period start date
01/04/2025

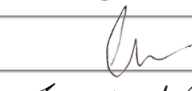
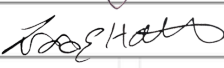
To

Period end date
31/03/2026

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Donations	£ 3,427.00	-	-	3,427	£ 4,632.00
Donations - PayPal	£ 995.00	-	-	995	£ 1,302.00
Donations - Sponsored events	£ 6,411.00			6,411	£ 14,356.00
Donations - Bingo	£ 1,958.00			1,958	£ 2,199.00
Donations - Coffee morning	£ -			-	£ 1,241.00
Donations - CAF	£ 9,572.00			9,572	£ 7,507.00
Donations - Open Gardens	£ 5,406.00			5,406	£ 200.00
Donations - Easy Fundraising	£ 250.00			250	£ 158.00
Donations - Merchandise	£ -			-	£ 20.00
Donations - Wills	£ 550.00			550	£ 100.00
Donations - Art Auction	£ 15.00	-	-	15	£ 6,609.00
Donations - Golf day	£ -	-	-	-	£ 905.00
Grant Received	£ 1,500.00	-	-	1,500	£ -
Donations - Tin Collection	£ 16.00	-	-	16	£ -
Donations Tshirts	£ 94.00	-	-	94	£ -
	-	-	-	-	-
Sub total (Gross income for AR)	30,194	-	-	30,194	39,229
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	30,194	-	-	30,194	39,229
A3 Payments					
Cost of Sales	1,807	-	-	1,807	7,517
Grants Given - University of Bristol	1,500	-	-	1,500	65,000
Advertising and Promotion	10	-	-	10	380
Legal and Professional Fees	60	-	-	60	-
Subscriptions	654	-	-	654	581
Bank/Finance Charges	15	-	-	15	-
Insurance	68	-	-	68	97
Travel	402	-	-	402	-
	-	-	-	-	-
Sub total	4,516	-	-	4,516	73,575
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	4,516	-	-	4,516	73,575
Net of receipts/(payments)	25,678	-	-	25,678	- 34,346
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	4,731	-	-	4,731	39,077
Cash funds this year end	30,409	-	-	30,409	4,731

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	Bank Account: Bu B Bank Account: Busi	30,074	-	-
	Bank Account: CAB Bank Account: CAS	335	-	-
		-	-	-
	Total cash funds	30,409	-	-
	(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	
		Liz Cook	12/07/2026	
		Laura Hattersley	15/07/2026	

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 2026/2027:

- Continue to raise funds and fund at least one UK study.
- Apply to the Charities Commission to enable the charity to act as advocates between families and medical professionals.
- Continue assisting with the creation of the UK clinical database in association with University of Bristol and the NHS.
- Continue to roll out the Global CASK Census (Counting CASK), in collaboration with partner PAGs.
- Provide mental health support to the UK community.
- Hold the annual CASK family meet up.
- Work with universities to apply for external grants.

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: 16/7/2026

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 [AECE](#) and [ACNRF](#)

We thank you for your ongoing support of our programme



CASK Research Foundation

33 Finchdean Road

Rowlands Castle

PO9 6DA

www.caskresearch.org

info@caskresearch.org