

CASE FOR SUPPORT



CASK
RESEARCH FOUNDATION

Facilitate, Fund, Accelerate...
the path to a cure



About us

We are a Charitable Incorporated Organisation (CIO) registered with the Charity Commission in England and Wales.

CASK Research Foundation was established in 2022.

Our founder, Laura Hattersley (MSc, BSc), is the mother of a child suffering from a CASK gene mutation.

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

Our Mission: To enable medical advances to improve the lives of people with CASK gene disorders

We are: ambitious, supportive, informative, collaborative

What are CASK related disorders?



CASK is an ultra rare genetic condition that affects the brain.

As a result, 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.

In short

- The problems
- The solutions

There is no treatment for children suffering from CASK gene mutations.

International scientists are interested in studying the disease but struggle to get funding due to the rarity of the condition.

There is little information and support for parents and caregivers.

Increase awareness about the condition amongst the scientific and medical community.

Create research grants to enable research to happen.

Have online resources with information for parents and guardians.

Provide meet ups for UK families.

Our mission statement is: facilitate, fund, accelerate



The facts

There are just over 220 known cases of CASK related disorders worldwide and thirty UK cases.

We are the only organisation in the UK supporting CASK families and research.

We have a scientific committee dedicated to ensuring funds are allocated appropriately and effectively.

We have the ability to change the outcome for children with CASK.

Learning more about the CASK gene will improve our understanding of how the brain works.



Laura Hattersley, “
CEO

The foundation is a mesh of my passion for science and my first hand experience of living with the effects of a CASK gene mutation.

Knowing there are researchers out there wanting to study this disease is what drives me in my quest to put CASK on the rare disease map.

Achievements to date

Increase awareness

- Held multiple events throughout the country raising awareness
- Contacted scientists and clinicians
- Established a Data Collection Platform using the global platform RARE-X
- Taken part in the Beacon patient group
- Had multiple radio appearances

Create grants

- Held fundraising events
- Created fundraising packs
- Online fundraising
- Sponsored events

Provide information

- Successful informative website
- Collaborated with UK charity 'Unique' to publish a pamphlet about CASK for carers and clinicians

Family support

- First annual UK CASK family meet up held in June 2022
- Created map to show location of CASK families in order to facilitate support groups

How We Work



Governance

- We have seven trustees, three of whom are parents of a child with CASK.
- The organisation is 100% volunteer led and run.
- CEO has a scientific background.
- Volunteers are well experienced and include professional fundraisers and marketing, events and branding experts.



Costs

- Funding grants – we have the aim of creating our first research grant by September 2023.
- Our online support is privately funded.
- The costs of the annual family meet are covered by corporate sponsor 'The Park'.



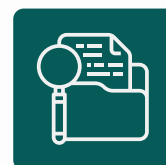
Scientific Advisory Board

- Dr Sam Amin (Consultant paediatric neurologist)
- Professor Kerstin Kutsche (deputy director of the Institute for Human Genetics, Hamburg)
- Dr Catherine Tuffrey (consultant lead for research in community paediatrics in Solent)
- Dr James Hodge (associate professor in neuroscience, University of Bristol)



Collaboration

- Our partners: Angelina CASK neurological Research Foundation USA & Australia; Association Enfants CASK France (AECF)
- Our memberships: Genetic Alliance UK; Global Genes (including RARE-X); Beacon; UK Rare Epilepsies Together



Research Review Committee

- Dr Isabel Zwart (Director Regulatory CMC at AstraZeneca)
- Dr Magda Ellis (senior analyst, THEMA consulting)
- + members of our SAB

We know Science

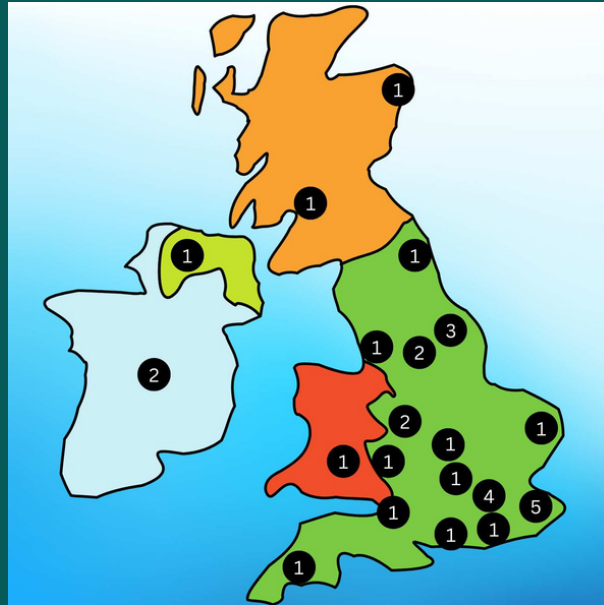
Our funds will go to the best science and the best scientists

In order to achieve this, we have a strict RESEARCH STRATEGY, summarised briefly below:

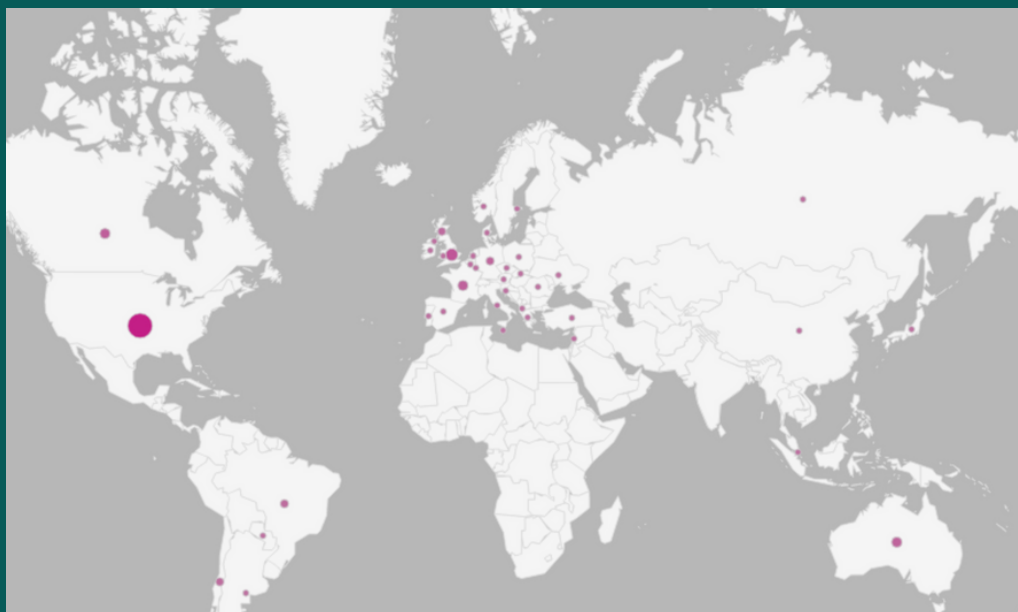
- 1 The project must be able to meet our aims as a charity: improving the lives of people suffering from CASK related disorders
- 2 Other questions include "Is the research underpinned by scientific excellence?" and "Has the right team been identified?".
3. Written peer review (for grants above £25,000)
4. Research Review Committee makes written recommendation
5. Trustees make the final decision on whether the charity should award funding to the research application.



CASK by numbers



CASK Gene Foundation have a count of at least 230 global cases of CASK gene mutations. There are over 3.5 million people in the United Kingdom suffering from a rare disease. If rare diseases are ignored and research into them is disregarded, that equates to 3.5 million people with no real hope of a cure or even effective treatments. By supporting CASK Research Foundation you are doing your bit towards ending this discrepancy and providing hope where there was none.



Our supporters

The Park, London

This award winning brand proof company supports us by providing corporate funding as well as helping us manage our branding, events and giving us business advice.

Evolve Psychological Services

They offer clinical psychological assessments and therapeutic support services for families, children and adults. 'Evolve' undertakes neurodevelopmental assessments and psychological therapy. Their founder, Dr Laura Powling, can offer advice regarding support, assessment and therapeutic services.

How can you help?

Sponsor an event

Putting on fundraising events costs money. Offering to sponsor the hire of a hall or the cost of entertainment can mean all funds raised become profit.

Match funding

Agreeing to match a particular fundraising initiative.

Volunteer a specialist skill

For example website design, social media creation or counselling.

Fundraising

Your workplace could organise a fundraising event such as a cake sale, raffle or office challenge. This will help our charity whilst also team building.

Payroll giving

Perhaps your members of staff would want to donate so they pay a donation directly out of their wage.

Be a charity ambassador

A great way to raise awareness and support for the work we do is by acting as an ambassador where you tell others about our work and how they can get involved to help.

The advantages of our small, unique charity

Minimal overheads

You know your money will go directly towards a grant.

No government funding

Without your support no grants will be created. You are this rare disease's hope.

Personal

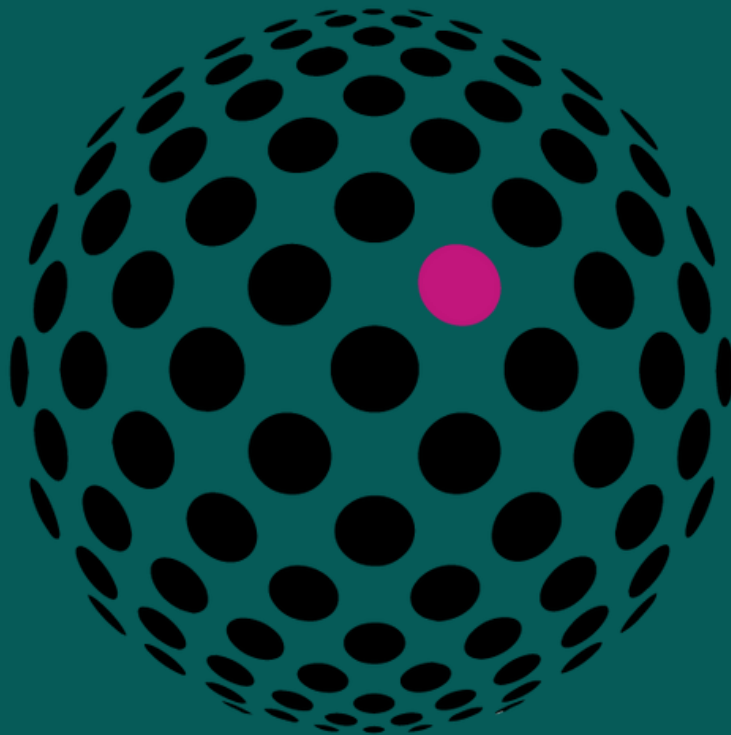
You will receive regular updates of how the research you helped fund is progressing.

Dedicated

Run by CASK parents, we have limitless drive and passion

Inspired?

Contact us at
admin@caskresearch.org



**Together let's
#conquercask**

www.caskresearch.org