

Help transform the
future for children
with CASK gene
disorders



CASK

RESEARCH FOUNDATION

Fundraising booklet

Registered with



FUNDRAISING
REGULATOR

www.caskresearch.com

Registered Charitable incorporated
organisation, England & Wales, charity
no. 1197434

Hello,

Thank you so much for reading our fundraising pack and wanting to support CASK Research Foundation. You may have a family member who suffers from a CASK gene mutation, you may have a friend who has a newly-diagnosed child, or perhaps you stumbled across this ultra rare disease and decided to help make a difference. Whatever the reason, I can't thank you enough for wanting to spend some time and energy to help us reduce the suffering of the hundreds of children and adults who live with a CASK gene mutation across the world. We are a small community but we are a wide, friendly and hopeful one.

Laura

Founder of CASK Research Foundation



Every year a parent in the UK is told that their child suffers from a genetic condition so rare that the people who diagnose it know next to nothing about the disease. Some parents will be told their child will fail to live to adulthood, some will be left with an end-of-life care plan for their new born baby, some will be told their child will never walk or talk. Some will just be told nothing.

"The early years were really difficult, finding more and more things "wrong" with our little girl and realising our future was going to be very different from what we had planned. Each year the list of consultants involved in her care grows and we are always sleep deprived! When Annie was diagnosed the only information we received was a newspaper link to a story about another girl in the UK with CASK mutation. A Facebook CASK support group has been a great way of sharing information with other families but actually having a research foundation may enable new therapies and treatments in the future to improve our children's quality of life."



"A lot of the scientific papers on CASK make for pretty bleak reading and sometimes the fact that CASK has significantly impacted every area of my daughter's life can feel somewhat overwhelming. But Olivia is a wonderful, cheery, happy, music-loving, water-splashing, giggly ray of sunshine, who adores her sisters and is so loved by all her family."



"Me and Lisa also found great comfort in meeting other families - we weren't alone anymore! And definitely the biggest positive from the diagnosis is that we really do consider two CASK families as friends, and many others we have met along the way. Our circle of friends is probably smaller than it was, but the friends [we have] are very special to us."



Without your support, children will continue to suffer and parents will be left without hope. Money is sadly everything in the world of research. So thank you, again, for helping us make the once impossible, possible.

THE DIFFERENCE YOU MAKE

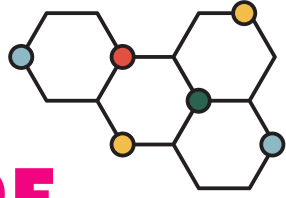
Imagine giving birth to a beautiful baby girl only to be told, when she is a few months old, that her brain isn't growing as it should be.

Imagine having all your dreams disappearing in a split second. Your child will not be the child you longed for: a child who has many friends, joins sports teams, learns to read, gets married, tells you they love you.

The majority of children with a CASK gene mutation remain non-verbal their entire lives. They have balance issues, severe learning difficulties and will never live an independent life. Forty percent have epilepsy and it's not uncommon for children to develop severe life-threatening scoliosis. Sadly, for some, their difficulties prove too much and they pass away in early infancy or in their teenage years: the years when their whole lives should be ahead of them.

Now imagine giving birth to a beautiful baby boy. It becomes quickly evident that they have complex medical issues. They start to have seizures. The doctors tell you there is no hope. There is no cure. You watch them as their seizures worsen, they grow weaker and then finally pass away.

Now imagine that science holds the answers. Imagine there are researchers offering to help your child. This is our reality and with your help we can turn an offer of help into a tangible research project with far-reaching effects.



THE WORLD OF RARE DISEASES

CASK gene related disorders are termed 'orphan' diseases. This means that drug companies aren't interested in adopting them to develop treatments because of their rarity. It is therefore up to foundations like our's to push the frontiers, peak researchers' interests and, ultimately, get drug companies involved.

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.

SCIENTIFIC GRANTS

The money you raise will be used to provide grants for scientific research. CASK Research Foundation is run by volunteers and we are determined to ensure the money goes to where it is needed – the scientists and researchers fighting to help our children.

Grants will only be awarded to the most promising research projects and the strongest proposals. With this in mind, we have an expert Research Review Committee who critique all scientific proposals and do annual reviews on current studies to ensure value for money and robustness of research. We therefore feel confident that we can tell you your money will make a difference.

FAMILY SUPPORT

Being the parent of a child with an ultra-rare disease can be isolating. CASK Research Foundation aims to support UK and Northern Irish families by facilitating and financing annual meet ups. These gatherings will enable families to physically meet one another, allow ideas and advice to be exchanged and provide the children with an accessible, stimulating and fun environment for the day.

We believe that meeting families in similar circumstances can foster good mental health.

FUNDRAISING

made easy

Here at CASK Research Foundation we recognise the challenges of every day for our families. We know you want to help so we aim to make it achievable for every family, no matter their financial and personal circumstances

See our website for step by step guidance on all our fundraising ideas. We can provide you with To Do Lists, Check Lists, promotional material and financial support (when essential).

Don't know where to start?

1. Decide how much time and effort you are willing to give
2. Choose a fundraising idea based on its difficulty rating
3. Go to our website to view the step by step guide for your chosen fundraiser
4. Contact CASK Research Foundation so we can provide you with
 - a) promotional material (posters, banners, leaflets)
 - b) information leaflets if you are holding an event or a stall
 - c) publicity on our social media platforms

NOT ABLE TO FUNDRAISE?

- Share this leaflet with your family and friends. People always want to know how they can help. Show them how!
- Share our social media posts on your own accounts and help us spread the word!

Coffee morning

Invite friends and family to your house for coffee, cake and socialising. A raffle also adds to the fun and helps raise extra funds. You could even invite someone to sell their wares at your event. They will give you a portion of their profits.

Difficulty rating: 3

Clothes sale

Ask your friends to donate their second hand clothes and then have a fun evening/day selling them on. Make an evening of it with bubbles and music and even a stall selling goods – you can take a portion of the profits! Or, if you have a little one why not sell your unwanted baby clothes and toys.

Difficulty rating: 6

READY TO FUNDRAISE?

IDEAS & INSPIRATION

Name The...

Whatever it is you choose, hold a simple guessing game at work, at your village fete, your school fair or at an after school group or evening class. Charge per entry and provide a percentage of the money raised as a prize or try to get one donated.

Difficulty rating: 1

Extreme adventure

If you're feeling adventurous or energetic, why not try running your first 10K, completing an ultra-marathon, doing an open water swim, a sponsored walk or even a horse ride and get sponsorship from friends and family?
Or even better? Get a friend or family member to do the challenge themselves!

Difficulty rating: 7



Mufti Day

Ask your child's school if they would think about holding a non-uniform day for the Foundation. Download our Fast Facts sheet and send it to them so they can understand the impact their fundraiser will have. Note that most schools only hold a few non-uniform days a year and these are decided a year in advance.

Difficulty rating: 1

Raffle stall

Write to local or national companies (we can provide you with a template) requesting a donation for a raffle prize. Once you have hit the jackpot with some (or just one) incredible prizes hire a stall at a village or school fair. Having our Fast Facts pamphlet and a banner will also increase awareness of CASK diseases.

Difficulty rating: 3

Bingo / quiz night

A fun and relatively straight forward way to raise between £1000-£2000. Hire a local venue, charge people for entry and ensure you have some great raffle prizes to increase raffle ticket sales! Selling alcohol and nibbles increases profits hugely and, of course, ensure you have a hilarious bingo caller to make for a night full of laughter.

Difficulty rating: 7

Get baking

Who doesn't like cake? Take something yummy into the office, evening class or school and ask for a donation per slice. Ensure you have our Fast Facts sheet to hand so people appreciate the great cause you are raising money for!

Difficulty rating: 2

Get crafting

If you're crafty, why not either sell your wares (always ask for a minimum donation rather than a set price) or invite your friends to learn your skills for a donation and a fun evening or afternoon!

Difficulty rating: 3-5



If you have other ideas, that is great too!
We are happy to support all types of fundraising (as long as it is safe and legal).

Remember: CASK Gene Awareness Day is held on 18th July. Please get in touch if you want to get involved in a joint fundraising event.



OTHER IDEAS

Support Cask Research Foundation

When you shop at smile.amazon.co.uk,
Amazon Donates

Visit smile.amazon.co.uk

smile.amazon.co.uk

Give by shopping

We are a registered charity with Amazon Smile. Shop and give at the same time. Don't have an account? It's easy to create one and choose CASK Research Foundation as your charity of choice. Amazon will donate 0.5% of the price of eligible purchases to our charity.

WE AIM TO SUPPORT

As well as families living directly with effects of CASK gene mutations, we aim to support their cheerleaders: you – the people who want to raise our vital funds.

Please let us know about the event you plan to hold or participate in. We'd love to know and we want to help!

What we can offer:

T-shirts

Increase your profile and raise awareness of CASK Research Foundation.

Race shirts

To wear during training and during the event

Information leaflets

Our Fast Facts sheets are perfect to display at your fundraisers. Let people know what and who they are helping!

Personalised promotional posters

Our talented volunteer graphics team are on hand to quickly whip up a poster to help publicise your event

Fundraising tins

We have a set of collection tins volunteers are welcome to use

CONTACT US

info@caskresearch.org

 [@caskresearch](https://www.facebook.com/caskresearch)

 [@caskresearch](https://www.instagram.com/caskresearch)

www.caskresearch.org



YOUR ONLINE FUNDRAISING PAGE

CASK Research Foundation is registered with gofundme, the online fundraising platform. It is easy to create your own fundraiser. Either find the link on our website (at the bottom of our 'Ready to Fundraise' page) or visit www.gofundme.com and choose CASK Research Foundation as your charity of choice.



PAYING MONEY IN

Transfer directly

Pay to CASK Research Foundation - Sort code 52-41-20. Account number 43690068. Please leave a reference with payment so we know who to contact and how the money was raised.

By cheque

Please make cheques payable to CASK Research Foundation and post to:

Finance Department, CASK Research Foundation, 33 Finchdean Road,
Rowlands Castle, PO9 6DA, UK

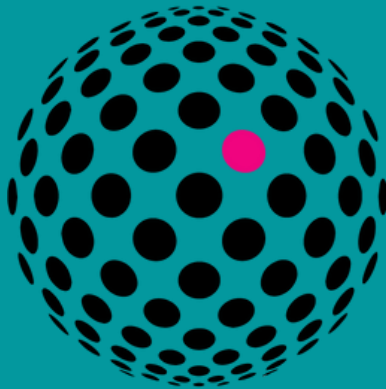
Don't forget to provide your full contact details (your full name, address, phone number and email) along with your cheque.

Please also try to provide us with details of everyone involved in donating and collecting the funds being paid in, so we can thank everyone!

THINK BIG

**NOTHING IS
IMPOSSIBLE**

**ANYTHING
IS POSSIBLE**



CASK
RESEARCH FOUNDATION