



SAM'S BIG SCOOT



Sam



JustGiving™

FIERES Research

#FindACureForFIERES



Sam's mum:



We couldn't save Sam, but please help us save other children.

A challenge capturing hearts and minds all over the UK...

www.samssuperheroes.co.uk

SAM'S BIG SCOOT

RAISING FUNDS FOR UK CHILDREN'S FIRES RESEARCH



JustGiving™
#FindACureForFIRES

ORDINARY PEOPLE and an EXTRAORDINARY CHALLENGE



In memory of Sam, who tragically passed away in 2021 at the age of five from FIRES (Febrile Infection Related Epilepsy Syndrome), we are taking on an extraordinary challenge. Our goal is to raise £50,000 for UK FIRES research and to increase awareness of this catastrophic and devastating syndrome.

On Friday, 20th September 2024, we will KICK SCOOT 44 MILES from Aston University in BIRMINGHAM, home of the first and only UK FIRES research, to Sam's hometown of DERBY.

OUR JOURNEY:

- Three days, two nights
- Overnight stops in Lichfield and Burton on Trent
- No electric scooters, just sheer determination!

THE TEAM:

A core team will scoot for three consecutive days, supported by a tag team joining for full or half days. On the final day, many of Sam's friends and supporters will join us as we scoot into his hometown.

SAM'S SPIRIT:

Sam is the heart and soul of this challenge. He adored his red scooter and rode it everywhere. Rachel, Sam's mum, will carry that scooter on her back throughout the challenge, ensuring he is very much part of the team!

HELP US MAKE A DIFFERENCE:

Support our mission to fund UK FIRES research and raise awareness. Together, we can fight this devastating syndrome!



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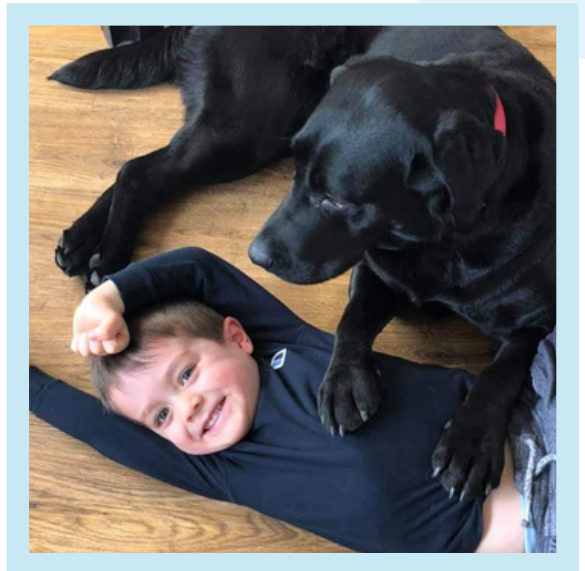
WHAT IS FIRES?

FIRES, or Febrile Infection Related Epilepsy Syndrome, is a rare and catastrophic condition that affects healthy children with no prior history of epilepsy or seizures. The seizures begin suddenly and explosively following a simple febrile infection or virus, rapidly progressing into relentless seizure activity that is exceptionally difficult to stop. Children often remain in an induced coma for weeks to months, with life-changing impacts. One in five children die during the acute stage, and those who survive often suffer significant neurological disabilities and life-long epilepsy.

There are currently children fighting FIRES in the UK; with two cases in the East Midlands during the last year.

ABOUT OUR SAM

Sam was beautiful, kind, loving, caring and joyful. He adored cuddling up to his dog Daisy and exploring the great outdoors. Shy with people he didn't know, he was articulate and had wisdom beyond his years. Sam loved superheroes and making his family and many friends laugh! He was a healthy child and rarely ill, but just after his 5th birthday, Sam and his family were catapulted head-first into a battle to save his life from the sudden onset of FIRES. After a seven-week fight in paediatric critical care at Queen's Medical Centre in Nottingham, our beautiful Sam passed away due to catastrophic and irreversible brain damage, caused by his relentless seizure activity.



OUR GOALS

The **first** is to raise awareness of FIRES to attract more research. It's not yet understood what causes FIRES, and there are no known effective treatments. Despite this, the UK's first and only FIRES research didn't start until 2023. Our **second** goal is to raise as much money as possible to help fund further research. Whilst we could not save Sam, we need to try and save other children. Support this challenge, and you could help save children's lives...**what an IMPACT!**

OUR SUPPORTERS



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#FindACureForFIRES

NHS DOCTORS AND RESEARCH FELLOWS

We are thrilled to be supported by an incredible team of NHS Doctors and Research Fellows from **Great Ormond Street Hospital (GOSH)**, London and **Aston University**, Birmingham.

These experts are at the forefront of UK children's FIRES research, with some of them pictured here on the right.



Image: Epilepsy Research Institute UK Reception 2024
Dr Marios Kaliakatsos, Dr Sukhvir Wright, Sam's mum, Dr Evangelia Ioannidou, Dr Dimitrios Champsas

Dr Ioannidou
Great Ormond Street



Hope transforms into action through charity. Together, we can turn Sam's hope for a FIRES cure into reality by supporting research with our enthusiasm and donations.

Dr Kaliakatsos
Consultant Neurologist
Great Ormond Street



FIRES patients and their families are etched in the clinician's heart forever. Scoot with us in Sam's memory to support further research. Let's make Sam one of the last children to lose their life or childhood due to this devastating disease.

BEX BAND

We are delighted to have the support of Bex Band, the renowned adventurer and founder of 'Love Her Wild,' one of the largest outdoor communities in the world. She is also a **bestselling author and blogger**, with her blog receiving over two million readers. Importantly she is a true kick scooting pro!



Bex Band, 'Kicking the States' (2019)

I'm really excited to be supporting this incredible adventure. What a great way to remember Sam's memory and to raise money for an excellent cause. As someone who has kick scooted over 1600 miles, the length of the USA, I can tell you this team is in for a real challenge – but adventure is guaranteed along the way!

Bex Band

www.TheOrdinaryAdventurer.com

OUR SUPPORTERS

THE NORSE INSTITUTE

The NORSE Institute in America is the leading global expert on FIRES. It was founded by Nora Wong, after the loss of her son, Daniel at the age of 22 in 2013 to FIRES. They work to increase awareness of FIRES and NORSE, foster community among families and doctors touched by this sudden and severe epilepsy, and build a collaborative environment for researchers to learn more about NORSE.

Sam's mum has worked closely with the NORSE Institute ever since Sam died. They have been instrumental in providing her with vital support and guidance over the past three years. We are delighted to have their support with our challenge!

Adults and children, like Sam, continue to be lost to the devastating syndrome, FIRES. We hope greater awareness and research will one day cure or prevent it. Donate today to honor Sam and benefit children like him in the future.

Nora Wong
Executive Director

www.NORSEInstitute.org

NORSE
INSTITUTE

ASHGATES

Ashgates is a progressive, proactive and friendly accountancy and advisory practice with six directors and 90 staff based at offices in Derby. They provide a broad range of expertise, support and advice to businesses and individuals, locally, nationally and overseas. Their services include accountancy, audit, tax and business advisory services, financial advice, specialist IT and HR advisory services.

The fantastic team at Ashgates have gone above and beyond to support Sam's Superheroes over the past three years. Their care and commitment to a small, local charity has been phenomenal, and we are incredibly grateful to their whole team.

www.ashgates.co.uk

ASHGATES

THE ROBIN

The Robin in Mickleover is hosting our finish line celebrations on Sunday 22 September. They are situated in the centre of Mickleover not far from the street where Sam grew up. They have a fabulous community ethos and we are incredibly grateful to have their support.

THE
ROBIN

MEET THE TEAM

Our team is diverse, from across the UK and united in #FindACureForFIRES! People are joining us daily and so far includes:

- Doctors, Researchers, Radiotherapist, GP, Accountants, Engineers, Students, IT specialists, Graphic Designer, Psychotherapist, Teachers, Retired Head Teacher plus our Therapy Dog Daisy!
- Age is no barrier, even Sam's 85 year old nana is in our back-up team, and she even wants to try some of the scooting!
- And, of course Sam's black labrador Daisy is playing a key role 🐾



SOME OF OUR TEAM



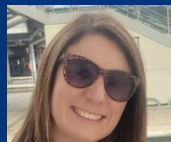
Sarah



Emma



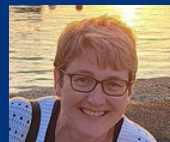
Bex



Becky



Ali



Tracey



Jasmin



Sam's Mum



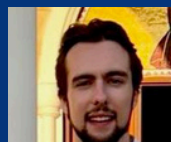
Sam's Dog Daisy



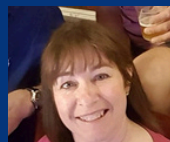
Sam's Aunty



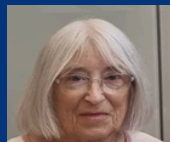
Sam's Cousin



Sam's Cousin



Sam's Aunty



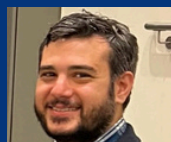
Sam's Nana



Dr Ioannidou



Dr Kaliakatsos



Dr Champsas



Dr Wright



Dr Pujar



Berni



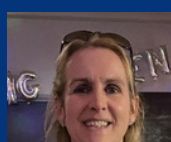
Kirstie



Jamie-Lee



Caroline



Lisa



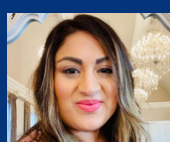
Sam's Uncle



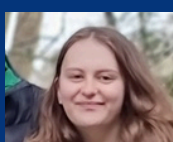
Sam's Uncle



Noriko, FIRES Mum



Nabila



Amelie



Suzie



Steve



Tash



Millie



Bex

WANT TO JOIN OUR TEAM - DROP US A MESSAGE!

- Scoot from one to the full three days, or
- Scoot the final mile with us as we go through Mickleover, or
- Join our backup team!

WORK WITH US

PRESS & PR

We are thrilled to have the support of **Penguin PR** in Derby to enhance media awareness of the challenge and provide excellent PR opportunities both locally and nationally. www.penguinpr.co.uk

FILM & PHOTOGRAPHY

We are working with the talented **Chris Newsome** who is providing professional photography for the challenge www.chrisnewsomeimages.co.uk

A short film will be created of our challenge and it will be widely shared on social media and our website.

SUPPORTING PARTNERS

It's more than just financial support. We are looking for supporting partners who can help build awareness, provide services, products, or kit such as:

Team transport between Derby to Birmingham, filming and editing, sports kits, scooters, helmets, rucksacks, merchandise and, promotional printing, finishing medals, hotel rooms around Lichfield and Burton on Trent, refreshments and meals on route...



Sam's cousin
in training

YOU CAN SUPPORT IN MANY WAYS:

- donate a raffle prize
- sponsor us
- hold a fundraiser
- provide meals or drinks during the challenge
- scoot with us for 1 to 3 days, or the final mile!
- **hold your own FUNDRAISER...**
anywhere, anytime, any distance!



Emma in training

In return we can give you
fabulous PR opportunities.

BUSINESS SPONSORSHIP

Interested in a sponsorship package? Take a look below.

BRONZE PACKAGE

Sponsorship £200

- Business named in social media post announcing Sponsorship and on Event Page

SILVER PACKAGE

Sponsorship £750

- All of bronze package **PLUS**:
- Logo on website and **one** piece of clothing, kit or marketing material
- Business named/tagged in social media posts promoting event

GOLD PACKAGE

Sponsorship £2,000

- All of bronze and silver packages **PLUS**:
- Selection of Sam's Big Scoot images/pre-agreed content for you to use on your website and socials
- Tagged in daily updates, stories and social lives during the challenge (tags/hashtags of your choice)
- Logo on **two** pieces of clothing, kit or marketing material

PLATINUM PACKAGE

Sponsorship £3,000*

- All of bronze, silver and gold packages **PLUS**:
- **CUSTOMISED OPPORTUNITIES** to align with your sponsor objectives
- Option for **SPONSOR EXCLUSIVITY**; contact us to discuss requirements and *price
- Sam's Big Scoot film with your logo featuring at agreed points, access to video content and imagery
- Sam's Big Scoot photos/other pre-agreed content for you to use
- Exclusive blog post
- **Prominent** branding/logo placement

HAVE ANOTHER IDEA HOW YOU CAN SUPPORT?
Get in contact and let's make it work!

MEET SAM'S SUPERHEROES



SAM'S SUPERHEROES

www.SamsSuperheroes.co.uk

Sam's Superheroes Foundation was founded to ensure Sam's life continues to make a difference in the world for years to come. We fund animal assisted therapies and creative activities, support FIRES research and offer grants to families affected by FIRES. We recently applied to become a Registered Charity with the Charity Commission.

A few of the activities we have recently funded for young people include: animal assisted grief workshops, horse therapy programmes, 1,800 hospital activity packs, activities for the play therapists at Nottingham's QMC Hospital, grants for two UK FIRES families and delivered therapy dog services to schools.



SAM'S DOG

Daisy, Sam's black labrador, plays a leading role in our charity through her transformative therapy dog work with young people. She came into Sam's life as a puppy, when he was two years old. It was love at first sight and they were joined at the hip from that point onwards! She is loving, kind, joyful, calm and caring - just like Sam.



Daisy makes astounding impact in her work, connecting with children in ways adults simply can't. She spreads Sam's love and energy in the world, making children smile wherever she goes. We are proud she has reached the final of BBC Radio Derby's Local Hero Awards 2024 for her work. The final is in September so watch this space!

SAM'S MUM

Sam's mother, Rachel, is committed to **#FindACureForFIRES**. Since Sam died she has been sharing Sam's FIRES story with doctors, researchers and the wider community to raise awareness and support the critical need for research.



In 2023, Rachel was a guest speaker at the NORSE Institute's International Conference, which was founded by Nora Wong who lost her son from FIRES in 2013. The NORSE Institute is the leading global expert on FIRES. This year she shared Sam's story at the UK's Epilepsy Research Institute's Reception in London where she also introduced the dedicated researchers leading the very first UK FIRES Research study.



Sam, Rachel (Sam's mum) and Daisy (Sam's dog) at Dovedale, Peak District, Derbyshire, 2019

CONTACT US:

www.samssuperheroes.co.uk

Email: rachel@samssuperheroes.co.uk or Call: 07880343416

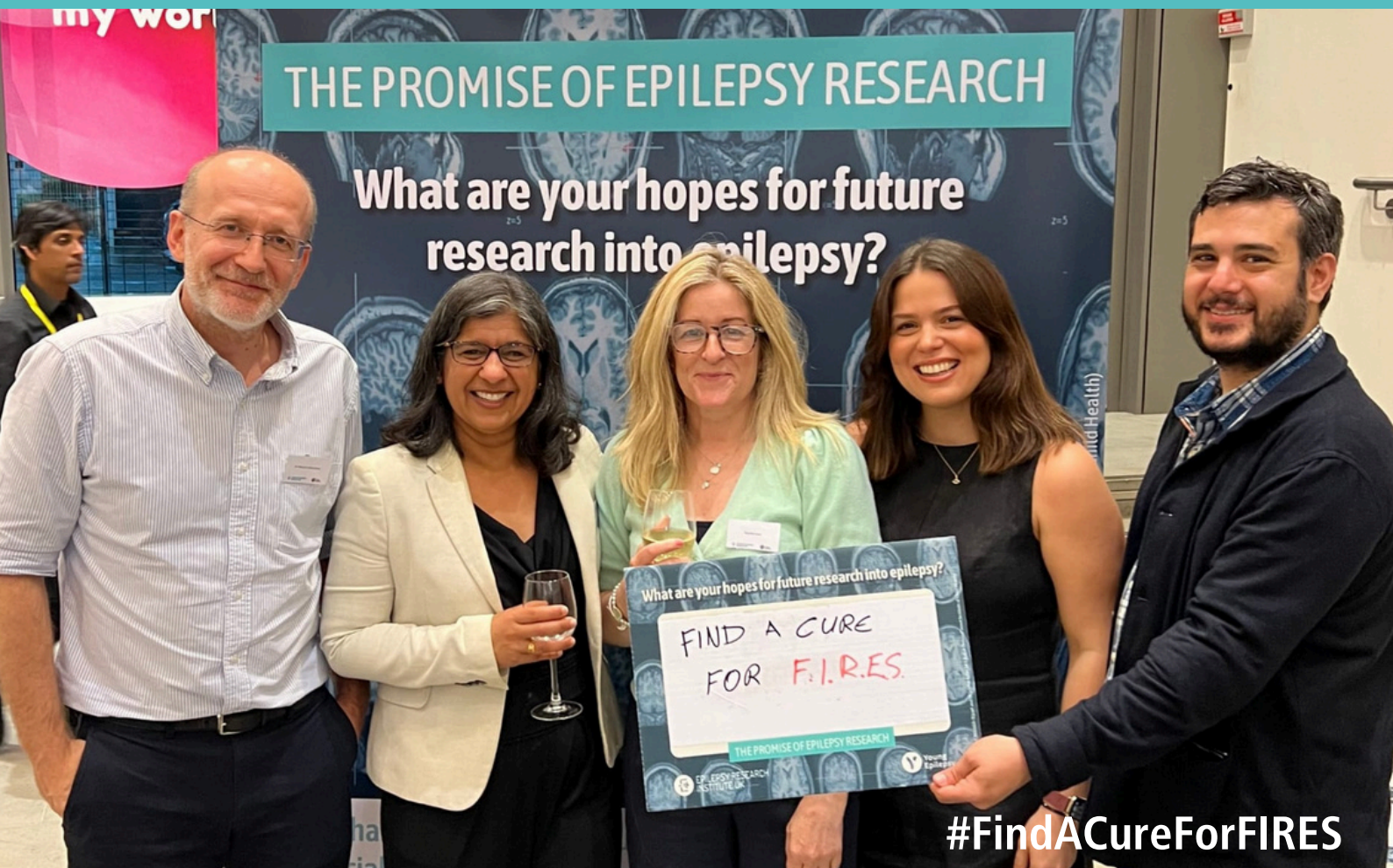


[TeamSamsSuperheroes](#)



[SamsSuperheroesTherapyDogs](#)

Press & Media Enquiries to Sarah at Penguin PR email: sarah@penguinPR.co.uk, or call: 01332 416228



[#FindACureForFIRES](#)

Image taken at the: Epilepsy Research Institute Reception London, May 2024

'Hopes for Future Research Into Epilepsy'

Left to right: Dr Marios Kaliakatsos, Dr Sukhvir Wright, Sam's mum, Dr Evangelia Ioannidou, Dr Dimitrios Champsas



JustGiving™
FIRES Research

#FindACureForFIRES

**WE LOOK FORWARD TO
HEARING FROM YOU SOON...**

www.samssuperheroes.co.uk