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# Epilepsy Today

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# Inside


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# What's new?

**Happy Spring, everyone! The sun is finally shining, and with the new season, we're bringing some novelties of our own! First and foremost, as you can see opposite, Phil Lee stepped down as Epilepsy Action's chief executive. Get to know our new chief executive, Rebekah Smith on page 4.**

Something else that's new is our brand new merchandise! From soft and comfortable beanie hats and T-shirts, to stylish water bottles and wristbands, we have lots of lovely new items with which you can show your support for people with epilepsy and help us to continue our vital work (page 22).

Shortly following International Women's Day on 8 March, we are sharing a whole host of brilliant stories from some inspirational women. Our cover star, Nic, describes her experience having focal seizures in a busy London train station (page 12) and Fathiya tells us how she's observing Ramadan while not being able to fast (page 19). On page 26, Rosemary talks changing medication and facing challenging side effects, and on page 20, Cheryl tells us about her daughter Edie and why she has signed up for the Bradford 10k.

Also, don't miss our feature on our new short film, A Place I'm Meant To Know (page 16) and our Q&A with neurosurgeon Mr Farah on laser surgery (page 24).

I hope you enjoy this issue!


**Kami Kountcheva**
Editor

# A fond *farewell*

## We say goodbye to chief executive Phil Lee and two longstanding trustees


Phil Lee

**Epilepsy Action chief executive, Philip Lee, has stepped down after more than 37 years at the organisation.**

Lee has led the organisation as its chief executive for more than 29 years. He left the organisation on Friday 29 November, 2024. Previous deputy chief executive, Rebekah Smith, has now been appointed chief executive.

In a departing message, Phil said: "After more than 37 years working for Epilepsy Action (British Epilepsy Association), and being the charity's chief executive for the past 29 years, it is time for me and the charity to move on to other things.

"Over so many years I have had the great fortune to know and work with thousands of truly wonderful, dedicated and inspiring people – be they staff, members, volunteers or trustees. Too many to name you all but you will know who you are, and to each and every one of you, I would like to say thank you for being such an essential and worthwhile part of my life. Together we have done amazing things.

"For me personally, it has always been a privilege to have been entrusted with the leadership of such a valuable and important organisation. I will always be proud of what the charity has achieved during my time and the contribution I have been able to make to improve the lives of people with epilepsy and their families.

"I take with me warm memories that will stay with me forever and I leave behind my very best wishes for the charity's future success."

Chair of Epilepsy Action's board of trustees, Jane Riley said: "After a highly successful first year of our strategy and as we progress with this new direction, Phil has decided that now is an ideal time for him to move on to a new personal challenge and pass the leadership on for the next phase of our journey.

"I want to thank Phil for his tireless dedication and long service at Epilepsy Action and to wish him all the very best for his future endeavours."

Ian Walker, a member of the Epilepsy Action board of trustees also resigned from his post in November. Ian was a trustee for 15 years, having joined in 2010, and serving as treasurer in 2012, vice chair between 2013-15 and chair between 2016-19.

Jane said: "Ian has been a pleasure to work alongside. He is well known for his sound knowledge, his commitment to Epilepsy Action, great enthusiasm to support those affected by epilepsy and his general good humour. On behalf of the trustees, we thank him very much for his relentless support and wish him well for the future."


Richard Chapman

Early this year, another longstanding trustee and previous chair, Richard Chapman, announced his retirement from the board as well. Richard said: "When I was first elected as a trustee of our charity – the youngest at that time at age 32 – I never imagined that it would be almost 38 years before I gave up the role. Whilst the decision was the right one for me personally, it has nonetheless been a bittersweet experience because, apart from having to say goodbye to some good friends and valued colleagues, it has been one of the constants in my adult life and my passion for and commitment to the charity's aims and objectives remains undiminished.

"Being a trustee is very much being part of a team, and we all take shared responsibility for the charity's successes, so it is very difficult for me looking back in retrospect to take credit for what we have done other than to say it was satisfying to be part of it. But I do look back with particular satisfaction that we managed to steer our charity successfully through the 2008 global financial crisis and the COVID pandemic, when so many other charities had to take drastic action in order to survive those financial pressures. And, of course, it has been a privilege for me to have been elected Chair of trustees by my colleagues on three separate occasions.

"Whilst I will now be cheering on from the sidelines, as supporters, we can all play a part, whether it is through raising funds, volunteering or writing to our MPs to support our campaigning work (I suspect my MP will soon be seeing an increase in his mailbag!)."

# Meet the *chief*

Meet Rebekah Smith, Epilepsy Action's new CEO. She talks strategic plans, winning an Oscar and the immeasurable value of your voice

> **"I feel so honoured to be given the opportunity to lead such a fantastic charity"**

**How lucky am I to be taking the charity forward in its 75th year! In the three-and-a-half years I've been at Epilepsy Action there has been lots of change, particularly in relation to the culture and strategic direction of the charity. My first year was the last year of COVID, so we knew our culture and ways of working had to change quickly, and that was my first focus, along with identifying funding for services which had reduced during lockdown. Within a year we had new counselling and family support services in Northern Ireland and Wales and had developed virtual talk and support groups.**

Developing the new strategy gave me the chance to talk to many of you across the UK. I attended all the 'Let's Talk About Epilepsy' sessions and from those conversations, along with our 5,000 survey responses, it was clear you wanted us to be much more ambitious in what we are achieving, as epilepsy remains an under-resourced, misunderstood condition and that needs to change. What we'll be focusing on over the next five years is providing the best possible services combined with raising the public profile of the condition, so that we can demonstrate we are making a difference to the quality of people's lives.

I'm passionate about partnership working – we can't do this on our own – and over a year ago, I joined the board of the new Epilepsy Research Institute along with the CEOs at Young Epilepsy and the International League Against Epilepsy. We are stronger together, and with the Institute leading on research, we can influence decisions, but also take that research and develop quality improvement initiatives, such as our current work in the North West improving

## let's talk about epilepsy

maternity and perinatal services and creating training for healthcare professionals working with people with epilepsy and learning disabilities.

A big focus of partnership working in 2025 will be working with other charities where epilepsy is a comorbidity, such as dementia, stroke, autism and mental health, and enhancing the relationship we have with healthcare professionals. On top of that, there are lots of big challenges for us to campaign on: from medication shortages and the issues with sodium valproate, to the continuing crisis in the NHS with staff shortages and appointment times.

Finally, I just want to say that I'm really keen to develop opportunities for you to be able to communicate with me, the trustees and other staff on a regular basis. We are only here because of your support, and I want you to be confident that we are spending the income we receive in the most effective ways we can. So, watch out for invitations to sessions to talk to us, and make sure you are signed up to receive our email communications to find out more. I feel so honoured to be given the opportunity to lead such a fantastic charity and I know that with your help we will do everything we can to create a world without limits for people with epilepsy.

## Get to know Rebekah

**What brought you to Epilepsy Action in the first place?**

I helped set up a charity after a work colleague lost her two-year-old son from a sudden, unexpected death. I knew how to run a charity, but very little on how to have an impact in the health sector. The research we did highlighted gaps in services to support families and led to real change. I realised I could really make a difference and when the role for a Deputy CEO came up at Epilepsy Action I jumped at the chance, leaving behind a 10 year career in students' unions.

**What do you love doing outside work?**

It's all the obvious things that involve spending time with my friends and family. I did lots of travelling when I was younger and last year went on my first long haul trip for many years: a holiday to Japan. I love swimming, and though I hate the cold, my favourite swim is in the sea at Scarborough followed by a sauna on the beach. And music is also a big part of my life – from festivals to gigs.


Rebekah and Epilepy Action colleagues

**What's your favourite film?**

I love lots of different genres of film, but the one that had the most impact was probably Alien. I watched it as a teenager and for the first time saw a strong, no-nonsense woman in a leading role in a major film. It also appealed to my love of science fiction which I ended up studying alongside medieval literature at university – I think I was the only person who did both!

**What's one thing you hope to do that you haven't done yet?**

Write a film script and win the Oscar for best screenwriter! I've got two films in my head and I'm hoping when I finally retire I might get to write at least one of them.


Rebekah and her sons Jude and Isaac at mount Fuji

## We want to hear from you!

We've been asking lots of questions about membership at Epilepsy Action and over 900 members and non-members have responded so far. We'd like to hear your thoughts if you haven't shared them already. This is all part of a governance review that you will hear about over the coming months.

Please either visit **epilepsy.org.uk/membership-survey** or contact us by phone if you need us to send you a paper copy to complete.

If you are interested in talking about membership in more detail, then please sign up for one of our focus groups. We are particularly keen to hear from members under 40 years of age, recently joined members and members who have been with us 10+ years. Contact **membership@epilepsy.org.uk** for more information.

# Good news

At Epilepsy Action, we want to celebrate the good things in our members' lives. If you want to be featured, email kkountcheva@epilepsy.org.uk

## Creative agency wins £350,000 fund to "shatter" epilepsy stigma

**Creative agency Boldspace has won The Creative Shootout 2025, held on Thursday 30 January at the BAFTA 195 Picadilly.**

The Boldspace team walked away with a £10,000 prize, as well as a £350,000 media fund – the shootout's largest ever – to stage and promote their winning campaign for The Creative Shootout's charity of the year, Epilepsy Action.

The campaign will be launched later this year, with the aim to "shatter the stigma" around epilepsy and make it "impossible to ignore".

Boldspace was one of six finalist agency teams selected by a high-profile judging panel in late 2024 to take part in the shootout.

Epilepsy Action's chief executive, Rebekah Smith, explained that the shootout represented an "important opportunity" for the 630,000 people living with epilepsy in the UK. She said: "We were looking for bold, ambitious thinking from the teams, and we certainly got that."

At the event in London, the six teams were briefed earlier in the day by Rebekah. The teams were asked to bring epilepsy into the cultural conversation in a way that transforms lives. As well as Boldspace, Brands4Life, Muckle Media, PHA, Propellernet and Skylark Media took part.

The finalists had four hours to work on their creative campaign and each had eight minutes to pitch their ideas back in the evening in front of a live audience of hundreds of people, as well as the judging panel.

Rebekah added: "The campaign that Boldspace presented really stood out and we can't wait to work with them to bring the campaign to life in 2025. We're also really grateful to everyone who took part."

Founder of The Creative Shootout, Johnny Pitt, said: "It's 10 years since the Shootout launched and this year's theme of 'hidden disabilities' and the cause of epilepsy made this probably our grittiest ever programme.

"The winning campaign from Boldspace will help shatter the terrible stigma of those living with epilepsy."

The media fund for the winning campaign has been donated by partners, including The Guardian, Clear Channel, JCDecaux, Google, Acast, OnePoll, 72Point and markettiers.

Epilepsy Action is celebrating its 75th anniversary this year.

### Meet the team

Embarking on their new project, Boldspace said: "While some of our wider team have personal connections to people with epilepsy, many of us knew very little when we began this journey. We quickly realised how complex the condition is – seizure types, triggers and support needs vary widely.

"What shocked us most was the level of discrimination still happening in 2025. No one should feel excluded, misunderstood, or even unsafe in public due to a lack of awareness about epilepsy. That's why we wanted our campaign to be driven by simple but powerful goals: to foster empathy, raise awareness, and create a world where those with epilepsy feel truly supported.

"Presenting after just four hours of preparation was both nerve-wracking and exhilarating. Each team brought a different perspective, reinforcing how much work remains to break down barriers and improve support.

"Since that night, we've had more opportunities to deepen our understanding of epilepsy. Our training with Epilepsy Action's Simon Privett provided invaluable insights to ensure our campaign is not only educational but also a true reflection of the diverse experiences of those living with the condition.

"Having worked with charities like MHFA England and Deaf Kidz, we understand the uphill battle for change. We're ready to stand alongside the epilepsy community and help make a real difference."

# Star Award winner Aisha interviewed on Sky News

**Star Awards winner Aisha Cox appeared with her mum, Lucy, on Sky News on Monday, 13 January 2025.**

The pair shared their story of how Aisha came to Lucy's rescue after she had a seizure with Sky News' four million viewers.

Seven-year-old Aisha was at home with Lucy, when Lucy started having a seizure while cooking tea. Aisha managed to put a cushion under her mum's head, turn off the hobs and get someone round to help.

She had been taught to ask Alexa to call her dad, but when she did, she heard his phone ringing in another room. Scrolling on the phone, she found her grandfather's number and called him for help.

Lucy said: "It makes me quite emotional to think about. I'm so proud of her! The problem-solving of a seven-year-old goes beyond my belief. It's amazing."

Aisha received the Epilepsy Star award for her bravery in December 2024, as a joint winner for the month with four-year-old Frankie, who also managed to get help for his own mum, Mair, when she had a seizure at home when the two of them were alone.

There is more on both of these stories on page 28.

# Lego sets feature hidden disabilities

**A new range of Lego sets available in 2025 for all different ages will feature figures with hidden disabilities wearing sunflower lanyards.**

Some of the sets designed to incorporate hidden disabilities include the Duplo set First Time at the Airport for ages 2+, to be released in June this year, the Lego Friends Heartlake City Airport and Airplane set for age 8+ and the Lego Icons Tudor Corner set for ages 18+.

People can also personalise minifigures with sunflower lanyards in some Lego stores and at all 55 Minifigure Factories worldwide.

The hidden disabilities sunflower is a globally recognised tool to support people with hidden disabilities, such as epilepsy.

The organisers explain it's a way to voluntarily share that you have a disability or condition that may not be immediately obvious, and that you may need a helping hand, understanding, and more time in shops, at work, on transport and in public places.

# Sea lion surgery model for humans

**An eight-year-old male sea lion called Cronutt may have been cured from seizures through surgery, and could be paving the way for similar surgery in humans.**

In 2020, Cronutt had a transplant of a specific type of braincell called GABAergic interneurons into his hippocampus. Following the procedure, he improved rapidly and could be taken off his anti-seizure medication.

Cronutt was initially found stranded, lethargic and disorientated on the California coast in November 2017. He then developed seizures and became unwell, stopping eating and losing a quarter of his bodyweight. The surgery was a "last ditch" attempt to save his life, researchers said.

While vastly different to humans, and only a single case, researchers say Cronutt could be a useful animal model into similar epilepsies in humans.

A clinical trial in the US is currently underway to test transplant of human interneurons made from stem cells as a treatment for drug-resistant temporal lobe epilepsy.

# New service launched for people harmed by epilepsy meds in the womb

**People affected by epilepsy medications while they were in the womb can now seek support from a new Fetal Exposure to Medicines Service (FEMS), available in the north of England.**

FEMS is being piloted at Saint Mary's Hospital in Manchester and Newcastle Hospitals NHS Foundation Trust. The service, funded by NHS England, will run until March 2026.

Children or adults living in the north of England who have problems that could be because of exposure to epilepsy medicines in the womb can be referred to the service by their doctor.

People will then be informed by the service whether a FEMS appointment would be of use to them.

Appointments will offer assessments and tests and offer detailed plans where needed to support people affected by medications.

Initially, people who have been exposed to the medications sodium valproate and topiramate will be eligible for a referral, but this will expand to include other medication from April.

Sodium valproate was at the centre of a health scandal, as the risks of taking this medicine in pregnancy were known but not communicated to women for decades.

In 2018, the Medicines and Healthcare products Regulatory Agency (MHRA) made the rules around the prescription of this medication much stricter, including the patient signing a risk acknowledgement form.

In June 2024, rules about prescribing topiramate became stricter too, following a review into its effects if taken during pregnancy.

From April 2025, the pilot will extend to include a much wider range of medications, including cannabidiol, carbamazepine, phenobarbital and phenytoin, as well as medications considered safer in pregnancy, such as lamotrigine and levetiracetam.

However, the FEMS services said: "It is important to be aware that not all anti-seizure medicines are thought to cause problems for the baby when taken during pregnancy."

It urged people to check the product leaflet in their medication packet for more information.

Alison Fuller, director of Health Improvement and Influencing at Epilepsy Action said: "It's certainly a positive that additional support is being offered to people who have been harmed by exposure to certain medications in the womb. These families face massive challenges day in and day out, and need all of the help they can get to navigate the complex circumstances they're in.

"As this project is only a pilot for a specific area of the country, we're hoping this will be extended to the rest of the UK to give more people the chance to access this kind of support on the NHS.

"We also can't forget that these families are still waiting for a redress scheme that could, amongst other issues, cover specialist care on a regular basis. We will continue in our work to call for its implementation until people who have been harmed get the justice they deserve."

People may also be invited to participate in research but are not obliged to participate.

There is more information about FEMS on the Saint Mary's Hospital's and Newcastle Hospitals NHS Foundation Trust's websites.

# Men taking valproate don’t need sign-off from two specialists, says MHRA

**Men currently taking sodium valproate will not need sign off from two independent specialists to continue their treatment, the Medicines and Healthcare products Regulatory Agency has confirmed.**

The update means they will also not need to sign a Risk Acknowledgement Form.

However, any new valproate prescriptions for men or for women under the age of 55 will still need two specialists to independently agree that “there is no other effective or tolerated treatment, or there are compelling reasons that the reproductive risks do not apply”, the MHRA said.

After a new prescription of valproate, women will then need to sign an Annual Risk Acknowledgement Form, while men will only need to sign a Risk Acknowledgement Form once.

These changes to the prescription guidance were introduced in January 2024, affecting men and boys for the first time. The MHRA has been tightening prescription rules around valproate for women since 2018. This followed decades of problems in babies born to mothers taking valproate without women being made aware of the risks, which became a “medical scandal”.

According to the MHRA, there is a risk that about one in nine babies born to mothers taking valproate will have birth defects and about 30-40 of 100 will have learning difficulties.

In men taking valproate, the organisation warns that there is a risk of reduced fertility.

However, no one should stop taking their medication without speaking to their doctor first, as this could result in more or worse seizures.

The MHRA has been advised on this guidance by the Commission on Human Medicines (CHM). The CHM is a public body responsible for advising on the safety, efficacy and quality of medical products.

According to the guidance, women and girls under the age of 55 currently taking valproate and who have not yet been reviewed by two independent specialists, will need a second specialist to sign off on the prescription of valproate at their next annual review.

Future annual reviews will then only require one specialist.

Specialists able to review the use of valproate, according to the MHRA, include consultant neurologists (adult and paediatric), specialist nurses in relevant disciplines and specialist pharmacists. The MHRA has posted a full list on its website.

Men currently taking valproate are advised to use effective contraception and not to donate sperm while taking valproate and three months after stopping. The MHRA says they should speak to a health professional if they are planning to have a baby.

If you have any questions or concerns, you can speak to the Epilepsy Action Helpline by calling 0808 8005050, emailing or starting a live chat with us.

## Predicting epilepsy

**A new tool that can help predict the risk of epilepsy developing after venous stroke has been created by an international team of researchers.**

A blood clot in the brain (cerebral venous thrombosis) can cause a stroke, and people can experience a seizure as part of this.

Researchers, Dr Erik Bogdanoff and colleagues, say the DIAS3 can adequately predict the risk of epilepsy (recurrent seizures) developing in these patients.

## AI tool detects epilepsy cause

**An AI-powered tool can detect 64% of brain abnormalities linked to epilepy that radiologists miss, new study says.**

Scientists from King's College London and University College London developed the MELD Graph, which helps detect focal cortical dysplasia (FCD), which can cause epilepsy.

Researchers ay the tool will speed up diagnosis times, get people surgical treatment quicker and reduce costs to the NHS by up to £55,000 per patient.

## Ketamine trial for status

**Scientists in the US have received an initial $9.3 million from the National Institutes of Health for a $30 million clinical trial into the use of ketamine for status epilepticus in adults and children.**

Previous studies have looked into the use of ketamine for status epilepticus. A study from 2022 found that ketamine had a 60% success rate, while a 2024 study from Spain found a “good response” in 57% of patients.

# Cannabis: families forced to break law to "save children's lives"

**A new report by Medcan Family Foundation reveals 382 UK families are taking a "last resort" and sourcing illegal cannabis products to treat their children's epilepsy.**

Medcan's research has revealed that families are "being pushed into criminality to save their child's life", by sourcing cannabis products from drug dealers and overseas.

This is despite medical cannabis becoming legalised in the UK in 2018 to treat some forms of severe epilepsy in children.

According to Medcan, National Institute of Health and Care Excellence (NICE) guidelines allow specialist doctors to prescribe cannabis medications if they are satisfied there is a possibility of clinical benefit.

"However, a combination of lack of understanding by decision makers, lack of funding for all but the most exceptional cases, no training within the NHS, and lack of interest from the pharmaceutical industry, means access is effectively blocked for thousands of children across the UK," Medcan said.

The full report, ' Open Secret: use of illegal cannabis by families managing childhood epilepsy ', was published on 15 January.

Aspects of the report were shared on BBC Radio 4's File on 4 Investigates on 14 January, alongside the stories of parents breaking the law to give their children cannabis medication that they say is keeping their children alive.

However, report author Alice Salisbury, highlights that this route carries big risks. She said: "It is impossible to deny that there are children who have gone from having dozens of life-threatening seizures daily to seizure-freedom using these products.

"However, there is huge variability in the quality of both products and advice that parents are being given.

"Some families have undoubtedly managed to obtain high-quality liquids supplied by people who appear able to offer responsible advice on how to use them, but we also witnessed many parents being given random products with no certainty on the content, and advice on dosing and drug interactions that is simply dangerous."

Epilepsy Action says we need short term solutions while research is underway to help families with this "life changing issue".

# Families "can't wait any longer" for valproate redress

**Families harmed by exposure to valproate during pregnancy "can't wait any longer", says charity Epilepsy Action on the one-year anniversary of The Hughes Report which set out the case for a redress scheme.**

On 7 February, 2024, Dr Henrietta Hughes published her report, 'Options for redress for those harmed by valproate and pelvic mesh', setting out her proposal for financial and non-financial redress for families harmed by these treatments.

The government has said it is "carefully considering" the options set out in the report.

However, Epilepsy Action's director of health improvement and influencing, Alison Fuller, says affected families deserve more.

She said: "For the first time, the report set out the options to provide redress for people harmed by sodium valproate, when risks weren't communicated effectively. These families are struggling immensely, not just from an emotional standpoint, but from a financial one, too. They have been for decades. They simply can't wait any longer. "

Susan Cole, founder of Valproate Victims, protested outside Parliament on 5 February, asking for the 'Care Debt' to be repaid to affected families.

**People are advised not to stop taking their epilepsy medication without speaking to a doctor first.**

# People can ask pharmacies for ‘emergency supply’ of medication

**People in the UK can request an emergency supply of medicines from a pharmacy, according to the British National Formulary (BNF), a pharmaceutical reference book from British publisher of medical journals BMJ.**

According to the publication, The Human Medicines Regulations 2012 allows for people to make a request for an emergency supply of their medication without a prescription.

This is if:

- there is “immediate need” for the medication and it is not possible in the circumstances to get a prescription “without undue delay”
- the person has previously been prescribed this treatment, and
- the dose is appropriate for the person

In a piece about the death of Charlie Marriage, his sister and special investigations editor at the Financial Times (FT), Madison Marriage, said her brother and her family had not been made aware of this by any health professionals they spoke to while trying to access epilepsy medication for Charlie in the hours before he died.

Charlie died from sudden unexpected death in epilepsy (SUDEP) on 26 June 2021. He had tried unsuccessfully to get an emergency prescription for his epilepsy medication Fycompa (perampanel) in the hours before his death, including calling his GP and NHS 111.

An inquest into his death found “a significant number of failings” and “many missed opportunities” from health services contributed to his death.

Madison wrote in the FT piece that the information that they could have requested an emergency medication supply from any pharmacy was “one of the most difficult things we discovered during the inquest”.

Madison spoke on Radio 4’s Today programme on 24 February, raising awareness of the right to request an emergency supply of prescription medication from a pharmacist. She said: “Had we known about that on that day in June, Charlie would still be here. My mum would have driven him to every pharmacist in London to find one that had the emergency supply of Fycompa that day.”

Charlie’s mum, Henrietta Hastings, is now launching a campaign to raise awareness with the public and with pharmacists about these rights. She is creating ‘Charlie cards’, which are still in development, for people who need one to carry with them to help them make a request in an emergency.

In her piece in FT, Madison also noted that the way that priority levels were set around the urgency of Charlie’s case by different call handlers he was in touch with failed to capture the way that seizures happen.

She said that call handlers asked him to get back in touch if his symptoms got any worse, which doesn’t capture the nature of seizures, which happen out of the blue for many people with epilepsy.

# Fenfluramine available on NHS for LGS

**Epilepsy medication fenfluramine will be funded for NHS patients with Lennox-Gastaut syndrome (LGS) from 20 February 2025.**

The National Institute for Health and Care Excellence (NICE) has recommended it as a treatment for seizures in LGS for people aged two years and over.

Tom Shillito, health improvement and research manager at Epilepsy Action, said it is promising to see new treatment options for such a potentially debilitating epilepsy syndrome.

“Lennox-Gastaut syndrome can be highly resistant to medication, meaning achieving seizure control is really difficult. And it’s not just this. The impact of LGS goes beyond seizures. It can include cognitive impairment, communication difficulties, sleep and behavioural challenges, and mobility problems. All of these issues significantly impact both patients’ and caregivers’ quality of life.

“There aren’t many effective medication options available for people with Lennox-Gastaut syndrome, and the existing ones can often have substantial side effects.

“We are hoping fenfluramine will represent a chance for better quality of life for people affected, where other treatments couldn’t.”

Fenfluramine is a liquid medication taken by mouth, with the dose adjusted for each person based on their weight. It works by increasing the levels of the brain chemical serotonin, which helps to reduce seizure activity, NHS England explains.

Clinical trials have shown that fenfluramine can reduce the frequency of drop seizures by more than a quarter on average.

More than a quarter of people with LGS had their number of seizures drop to less than half with this medication.

Fenfluramine can also reduce the risk of hospitalisations and needing emergency care.

# Life-changing *seizures*

Nic's seizures have disrupted her whole life – from her independence to her job. She shares her experiences and the ray of hope on the horizon. Written by Kami Kountcheva

**"I didn't know where I was," recalls Nic. "I knew I was in a train station, but I didn't know which part of the country, I didn't know what train I needed to get on."**

Nicola (Nic) Adamson, a recently appointed Epilepsy Action trustee, has had epilepsy for over 10 years. In that time, Nicola says she's tried about 10 different medications but none have been able to control her seizures, which she explains tend to come in clusters. In September 2024, she went 10 days without a seizure, but she had 21 focal seizures overall. "That's very normal for me," she says.

Having experienced a range of different types of seizures, the focal seizures are the ones that Nic says have been the worst for her. "If I have a tonic-clonic seizure, I don't know about it. I'm unconscious. They don't bother me. Afterwards the recovery bothers me. The actual seizure itself is very difficult for those around me, but for me, it doesn't bother me at all.

"Whereas some of the focal seizures that nobody can tell I'm having, except for my close family – they're really unpleasant."

At the time when she found herself in trouble at a train station, Nic was working in the NHS in a senior position, commissioning specialised (rare) services. While this started out as a job she could do working from home, it quickly turned into one where she was asked to travel to London for three or four days a week and staying overnight in hotels.

"At first, I used to travel everywhere on my own," Nic explains. "Then, I had one day when I was down in London for work and I'd had quite a bad seizure. Not

> "I think the staff just thought I was drunk. I was confused and was really struggling to talk properly and get my words out"

> “It was my absolute worst nightmare. I would happily have every seizure for her, knowing what it’s like myself”


Video EEG in 2022


Nic with daughters Katie, Lucy and Bethany in 2014 – the year she was diagnosed with eplepsy


Nic cut her hair short ahead of SEEG


Climbing snowdon with Lucy

long after that, I’d had a really bad day of seizures.

“A colleague went with me on the tube to Euston station. Then, me being me, I told them that I’d be fine from there. But I kept having lots of focal seizures and I got really confused.

“I ended up managing to speak to my husband, Jay, on the phone – I managed to ring him between seizures. It was awful for him, because he knew I was having seizures in between while he was on the phone to me.

“He was trying to explain to me where I was and what was going on and to go and get help. He told me to buy a ticket for an earlier train and that he’d meet me on the other end in Preston. He told me to find a member of staff and try to get help, but I think the staff just thought I was drunk. I was confused and was really struggling to talk properly and get my words out.

“When I went to pay for the ticket, I couldn’t remember my pin number – this was before Apple Pay, which is a lifesaver for me now! Eventually, I managed to buy a ticket, but by the time I’d bought it, I ended up missing the train anyway.

“Experiences like that – and that’s just one of many really – mean that now I’m quite anxious about even just getting the bus on my own, in case I have a cluster of seizures because I don’t know where I am.”

The reality of living with uncontrolled seizures has had quite a profound impact on Nic’s life, including disrupting her independence and having to give up a beloved job.

She explains: “Obviously, I’ve not driven now for over 10 years. Not being able to just get in the car and pop to the shops is hard.

“If I’m on public transport, I tend to always have someone travelling with me. This keeps me quite isolated at home.”

One thing Nic still feels up to doing is taking her golden retriever Murphy and her black labrador Layla for a walk. And even then, she sometimes has to rely on the goodness of acquaintances if she feels like a seizure is coming on.

“On days I don’t have seizures, I get out for a good three or four-mile walk with the dogs. I go the same route every time, so it’s very familiar. And I see all the same people each time. If I feel unwell and like I’m going to have a seizure, I just sit on the floor and they just sit with me until I’m feeling okay again. Thankfully we don’t need to do that very often.”

But even with all these challenges, giving up work has been one of the most difficult parts for Nic.

“It was heartbreaking,” she explains. “The last job that I had that I really, really loved was from 2013-2016 working at Royal Manchester Children’s Hospital. I was strategy director and oversaw projects for new developments.

“It was around the time when I worked there that my little girl had lots of health problems and she was also in Manchester Children’s Hospital for three months when she was a baby, in 2010. So, getting a job there just meant the world to me.”

Nic has three daughters, Katie, 20, Lucy, 18 and Bethany, 14. Bethany had many health problems as a baby, which she outgrew over the years. But in March 2022, she had three tonic-clonic seizures within a week, and after being admitted to hospital, she was diagnosed with epilepsy. She has been seizure free since then on medication, which is a big relief to Nic.

“Fingers crossed it stays that way for Bethany,” she says. “It was my absolute worst nightmare. I would happily have


Nic likes taking her dogs Murphy and Layla for a walk

every seizure for her, knowing what it's like myself. I couldn't imagine one of my children having epilepsy, it was horrendous. It was awful to see her having seizures, really awful."

Having loved her job and been able to work around epilepsy, helping to set up the Children's Epilepsy Surgery Service in the North of England (NORCESS), it was really hard for Nic to make the decision to give up work. She moved to different roles, looking for something without a daily commute that she could do safely, and finally made the decision to retire.

"I knew I'd got to a point where I was just having too many focal seizures at work and the tiredness of everything that was coming with that was becoming really difficult to manage. I never took time off sick, I always just used to carry on working through them. But obviously, it was the wrong thing to do. I wasn't looking after myself properly."

With this difficult decision, however, came a ray of hope. Nic had had a video EEG which showed that her seizures were coming from the left side of her brain. While she was working, she was told that operating on the left side of the brain was very high risk, as it could affect her speech and other brain functions. Now, surgery became a possibility for her.

One of the reasons it is really important for doctors to find a way to control Nic's seizures is the progression to tonic-clonic seizures, some lasting more than 5 minutes and some occurring in clusters, which comes with its own serious risks.

"The one thing I have found since giving up work is that I've had tonic-clonics less frequently. We're not sure if it's the medicines or giving up work, but it's clearly helped," Nic notes.

"Whilst I was needing to use my brain all the time so that I could work, [my doctors] were really worried about causing any further deficits to my memory or to my verbal functions. I had already had declines in memory and other cognitive functions because of the seizures. But, because I retired and gave up work, my neurologist was then happy to consider surgery again."

The next step for Nic is to have Stereoelectroencephalography (SEEG), due to take place in the next few months. This is an EEG where electrodes are placed deeper into the brain to try to try to get a more precise picture of exactly where the seizures are starting from. This will help inform if she would be a candidate for epilepsy surgery.

***Nic will share her diary of her experiences of having SEEG and what it's like in an upcoming issue of Epilepsy Today – keep a look out!***

# Year of action!

## 2025 – your year to take action and make a difference!

This year marks an incredible milestone for Epilepsy Action as we celebrate 75 years of transforming lives for people with epilepsy. But this year is about more than reflecting on how far we've come—it's about **taking action** for the future. That's why we're calling on you to join our **Year of Action** and support us to create a world without limits for people with epilepsy.

Whether you have personal experience with epilepsy or simply want to make a difference, we have an opportunity for everyone to get involved.

**Volunteering** your time is a powerful way to support our mission. From raising awareness, to becoming a befriender or joining our Action Team, your efforts can help break down barriers for people living with epilepsy. Regardless of whether you can dedicate 10 minutes, a month or even more time, we have a volunteer opportunity suitable for everyone.

If you're unable to give your time, you can still make a meaningful impact by getting involved in some **fundraising**. The opportunities are endless! Organise a bake sale, run a marathon, or host a quiz or karaoke night – there are so many fun options for you to get involved and raise vital funds for the charity.

Every pound raised or hour volunteered **WILL** make a difference!

Join us today, and together we can build a world where everyone with epilepsy has the support they need to live without limits.

Visit **epilepsyaction.org.uk** to get involved.

Let's make this a year to remember—because every action counts.


Ava, Stacey and family


Donations for the raffle


Ava and Stacey

# Proud in *purple*

Stacey and her daughter Ava share why they support Purple Day each year and their plans for this year.

Written by Emily Stanley

**Ava has had epilepsy since she was just 16 months old. Despite the challenges in her life, it's never stopped Ava from striving to achieve her dreams. Last year, Ava and her mum Stacey took part in Purple Day to raise money for Epilepsy Action, and raised over £1,700. This year, they're back and ready to do it all again.**

"Last year myself, Ava, family and friends came up with the idea of holding a Purple Day bingo and raffle evening in our local village," says Stacey. "This was hugely successful and raised £1,777 for Epilepsy Action. We were completely overwhelmed by the generosity of local businesses and companies who donated raffle prizes, the spirit of the community and the turn-out for the event.

"This year, we have a full week of events planned, starting with Ava's dance class which will be turning purple and asking for donations. Ava's entire primary school will be wearing something purple for the school day, and then I will be holding a bake sale after school full of yummy treats and a 'guess the weight of the cake'!

"Finally, we are holding another fun bingo event, alongside a massive raffle full of donations from local businesses.

"We have chosen to support Purple Day again this year as myself and Ava think it's important to spread awareness about epilepsy. There are so many different types of epilepsy, and not all seizures look the same.

"Seizures can be more than just convulsions – some can involve 'staring spells', muscle jerks or just general confusion. Recognising the different seizure types helps with early intervention, which is something myself and Ava really want to highlight this Purple Day.

"Ava was just 16 months old when she was diagnosed with epilepsy. She had her first drop seizure just three days before Christmas 2017. Since then, she's been under the amazing care of the neurological team at John Radcliffe Hospital. She's undergone so many different tests including EEGs, CTs, MRIs, genetic testing and much more.

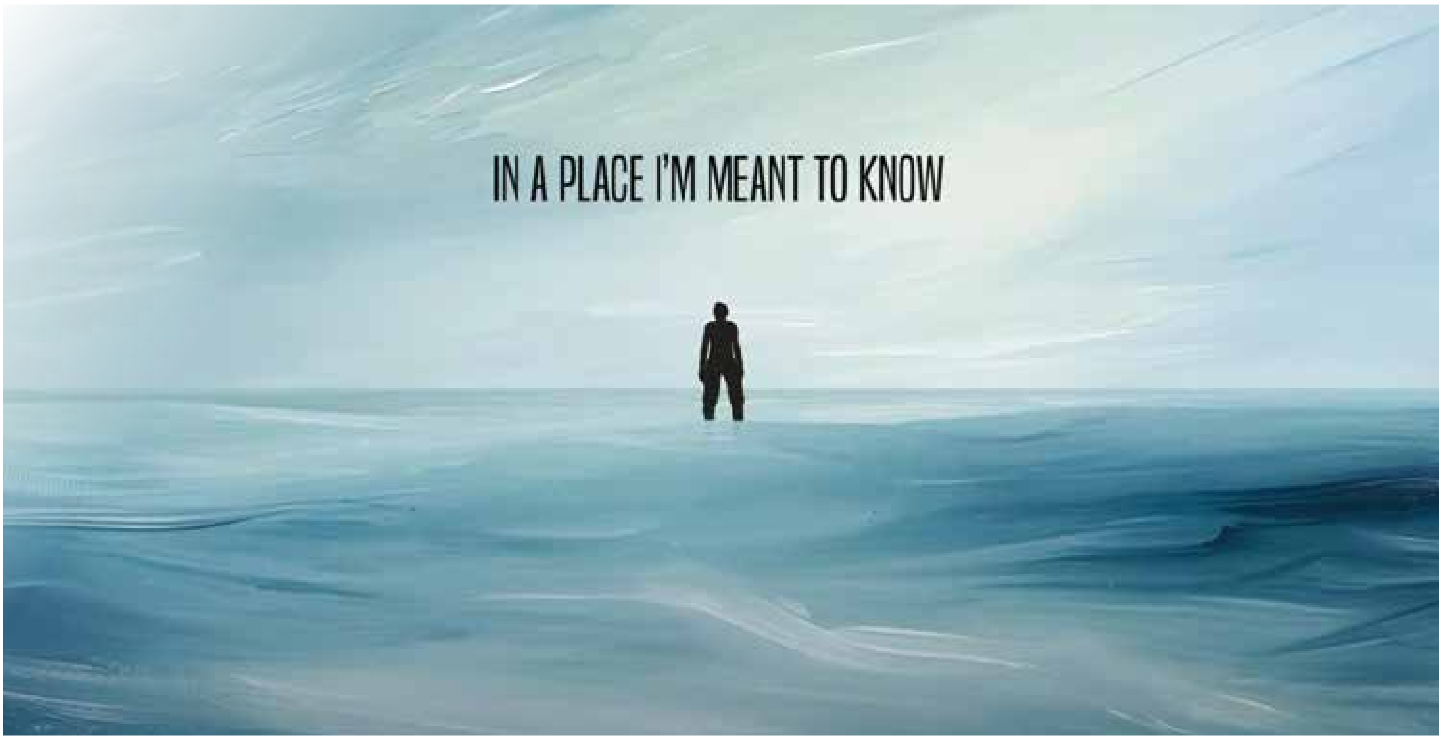
"Ava's courage, resilience and unbreakable spirit is inspirational. She has become such a strong self-advocate, explaining her condition to friends, classmates, and even teachers. She breaks stigmas and promotes understanding every day, without even realising it.

"She has now learnt to live with her epilepsy, how to balance her medical needs and daily life. She refuses to let her epilepsy stop her from pursuing her passions, whether it's excelling in school, or engaging in sports and her hobbies.

"There's never a day where I don't feel nervous or wonder if she's safe when I'm not there. There's that feeling of guilt if I don't catch her when she falls, and the feeling in the pit of my stomach if her school calls. As a parent, you know your pain will never compare to what they're going through, but you are there with them every step of the way and I am so proud to call Ava my daughter."


Ava undergoing tests in the hospital

**To see how you can support and take part in Purple Day, visit: epilepsy.org.uk/purple**



# A place I'm meant to *know*

Epilepsy Action's new short film aims to help people see through the eyes of someone having a seizure and really understand what epilepsy feels like.

**"I'm being pushed underwater. I lose vision – it goes blurry – and I lose my sense of hearing, so all the sounds merge into one as a jumbled noise.**

"I'm still conscious, I'm still standing, but I can't make sense of anything around me.

"From there, it goes into what I call a hallucinogenic nightmare, where I'm seeing things that make me panic and get stressed, so I end up sweating.

"I'm trapped. I'm trapped underwater with no escape."

This sounds like an awful nightmare, but for Katie, it's not a dream at all but a reality. Until recently, Katie used to have seizures and each would elicit those feelings for her. They would leave her exhausted and she would need to sleep for hours after coming round from one.

Seizures are something that every person with epilepsy – one in every 100 of us – has experienced. For some, it may be a regular occurrence.

But epilepsy is still misunderstood, still often undermined, and still feared and discriminated against. It's often invisible in the political sphere, invisible to policymakers, invisible in the media and invisible to the public. And yet, it is one of the most common neurological conditions in the world, with 630,000 people in the UK living with epilepsy.

In a recent survey of nearly 800 people with epilepsy, nearly two thirds (65%) said their condition is still misunderstood by most.

For someone like Fathiya, who is from Somalia, misconceptions can be even more commonplace. She has had epilepsy for 18 years, and says there is still stigma in her community. She says: "After a seizure, I feel like I've been thrown under a bus and [been] ran over by it. I feel exhausted, tired, mentally and physically.

"On top of that, I have to deal with the stigma that comes with epilepsy from my community, because they think I've been possessed by the devil, or that epilepsy is highly contagious."

The survey also revealed that epilepsy affects how people are treated. A third of people said they have been bullied or harassed because of their epilepsy. More than half (57%) of people reported feeling depressed because of their epilepsy, and a third of them even admitted they had thought about taking their own life.

### A sinking feeling

This year, Epilepsy Action is determined to help everyone to really see epilepsy. The organisation has released a powerful short film, A Place I'm Meant To Know, which transports the viewer in the centre of a seizure. This emotive and immersive project is aiming to shake up public perception of the condition.

It asks the world to stop and finally see epilepsy for what it truly is, pushing for a change in attitudes towards it.

A Place I'm Meant To Know was created using real life testimonials from people with epilepsy about exactly what it feels like to have a seizure. They shared visceral descriptions of their experiences, including "you feel very far away", "going into a dreamlike state", "a sinking feeling" and "an out-of-sync sensation between the body and the brain".

The film's emotive soundtrack, which won Best Soundtrack at the Phare International Film Festival, was composed by musician and producer Alex Marchisone, who has epilepsy. While his epilepsy is now controlled with medication, he remembers vividly what seizures feel like.

He says: "Seizures have just been horrific for me. Aside from the various physical injuries I suffered (including a broken shoulder and various spinal disc fractures and wedging) it's the sheer number of postictal symptoms that have left a scar. Long periods of ill synaesthesia, impending gloom, strong sensorial confusion."

Alex first got involved with this project after attending an Epilepsy Action Talk and Support group in London and hearing other people's experiences. "I remember I saw some real suffering there, and I thought that, amid the ever-noisy communication-driven and social media world we live in, this wasn't expressed and spoken about.

"I reached out to the wonderful team at Epilepsy Action and after a few talks, we landed on starting this project, which has been nothing short of amazing on both a human and artistic level."

### Deeply gloomy 'leftovers'

Starting the project, Alex was keen to translate all aspects of seizures into music in an accurate and honest way. He explains: "I wanted to try and convey just how powerful seizures are, and how much they affect the person experiencing them. The music needed to be powerful, as a seizure is, and convey some of the feelings that hardly can be expressed in words: sensorial confusion, synaesthesia and so on.

"I wanted to do something more unexpected, avoiding some of the composing-for-media cliches. All in all, I wanted the piece to be powerful, and I wanted it to convey some of the hard-to-communicate feelings and some of those deeply gloomy 'leftovers', while retaining an aspect of 'beauty' to the music and a sense of solace for people with epilepsy.

"The music needed to make sense on its own, too, and represent my point of view as a composer and music producer."

### Falling in slow motion

Lewis has had tonic-clonic seizures, and wishes people knew more about what it feels like before and after a seizure like that.

He says: "The best way that I can describe a seizure is that you're looking through a kaleidoscope, where you can see lots of vivid images and patterns. Then you get a similar sensation to when you've fallen in your dream, only that is in almost slow motion.

"Having epilepsy takes a big toll on the body, both physically and mentally, particularly when you're coming round from a seizure, because the brain has essentially had to reset itself.

"And this can lead to other challenges. So, for me, after a seizure, I battle with tiredness, grogginess, and even memory challenges on occasion, which can be quite upsetting.

"And people don't really see that either, they only see the physical damage from the seizures, if the individual's cut their tongue or bruised themselves when they've fallen."

Lewis, like many others, wishes that people would take the time to understand more about what having epilepsy is actually like, including the experience of seizures and what it's like to come round from one, rather than believing the misconceptions.

"I feel like people only see the seizures and assume you'll be fine when you come round from that," he says.

"But there's a lot more to it than that."

**Watch the full video on YouTube by visiting: epilepsy.org.uk/place**

# How will you be *remembered?*

## Epilepsy Action and Octopus Legacy are offering a free will-writing service

**We'll all be remembered for something – your achievements, your humour or the way you made people feel. But, we can be remembered for even more by leaving a gift in your will to Epilepsy Action.**

Having an up to date will is the only way you can be sure that your wishes are carried out when you're gone. It also ensures your loved ones are looked after.

Leaving a gift in your will ensures people with epilepsy will continue to get the relevant support they need, when they need it most. We can plan for the future and ensure the support for people with epilepsy continues. Any size of gift can transform lives for future generations.

Making a will can sometimes feel like a daunting process. But it does not need to be complicated or costly.

We are excited to announce that Epilepsy Action has partnered with Octopus Legacy to offer a free will-writing service to all our supporters. Working with Octopus Legacy can make writing your will a smooth process and can be done in a way that suits you.

You don't have to leave a gift to Epilepsy Action, but we hope you'll consider doing so after making sure your loved ones are taken care of.

To make your free will, visit **epilepsy.org.uk/legacy** and complete the simple step by step process. **Use the code EPACFREE at the checkout** to claim your free will. If writing your will online is not for you, Octopus Legacy also offers an in-person will writing service too. You can call 0800 773 4014 to talk to the Octopus Legacy Wills team and discuss your options and book a face-to-face appointment. Make sure to quote Epilepsy Action when you speak to the team.

If you feel you need more information before making your decision, you can request a free guide by visiting **epilepsy.org.uk/legacy** or contacting our legacy team on 0113 2108832.

Leaving a gift in your will to Epilepsy Action allows us to continue providing vital services for people with epilepsy in years to come. There are also other benefits to leaving a gift in your will to a charity:

- People who have left a gift in their will to a charity have said they get a huge amount of satisfaction knowing their values and beliefs will continue to be held through generations
- A gift to charity is free from inheritance tax and if you leave more than 10% of your net estate* to charity then the total amount of inheritance tax you pay reduces from 40% to 36% (* Visit gov.uk for more information)
- Many people choose to leave a gift to a charity that was important to a loved one, to keep their memory alive

Any gift you can leave, large or small, will ensure the support you have given to people with epilepsy continues after you. Leaving a gift in you will sends a powerful message – that you are committed to transforming the lives of people with epilepsy. No one should face living with epilepsy alone. With your legacy, no one will.

# Faith, epilepsy and Ramadan

## Fathiya tells us how she observs the holy month and why she is raising epilepsy awareness

**“My faith helps me a lot,” says Fathiya. She was diagnosed with generalised epilepsy 18 years ago. She has tonic-clonic and atonic seizures, and they aren’t controlled.**

Fathiya has osteoporosis from her previous medication and has ended up with a multitude of injuries as a result of her seizures.

“When you have a tonic-clonic seizure [and osteoporosis], you end up breaking your back, your face, your leg, an arm. I’ve broken about nine places in my back and eight places in my jaw and in my chin next to my ears.”

Fathiya’s past injuries mean that she is often in pain – especially when the weather is cold. And she adds that pain is a seizure trigger for her. On top of this, other previous medications have had other difficult side effects for her, including bringing on mental health struggles. But Fathiya says her spirituality really has been a source of support.

She explains: “I’m Muslim. I grew up in Somalia, but I came here to the UK when I was young. My faith helps me a lot with my epilepsy. There was a time when I was on Keppra (levetiracetam) and I would sometimes get dark thoughts.

“But sometimes you can sit down when you are overwhelmed. And we have this kind of beat, you just kind of meditate. So, faith really helps.”

Fathiya is now taking Briviact (brivaracetam), and while she is still not seizure free, she finds it is helping and she isn’t getting the severe side effects of previous medications.

### Fasting and worshipping God

Since the start of Ramadan on 28 February this year, many Muslims have been fasting. Fasting during Ramadan represents one of the five pillars of Islam, alongside faith, prayer, charity and pilgrimage.

However, some Muslims are exempt from fasting, including children, women who are pregnant, breastfeeding or menstruating, those who are travelling, and those who are ill or whose health might be affected. Fathiya explains that her condition has affected how she has observed the holy month for the last 15 years.

“During Ramadan, you dedicate yourself to fasting and worshipping God,” she says. “As I cannot fast, instead I pay Fidya. This means I give money to someone in need, who can’t afford to eat.

“I send this back home, and I sponsor one person during Ramadan, and I pay for the iftar (the fast-breaking evening meals for Muslims during Ramadan).

“It’s good to give the person the money, then they can buy what they want. It’s good if it’s someone close to you, or even your neighbour. We all have a duty to each other.”

Fathiya’s son, who is seven, can choose to fast, but only for half a day due to his age. At the end of Ramadan, they are planning to get together with family for a traditional celebration.

“At the end of the month, we have Eid al-Fitr. That’s when we have a big party, we buy new clothes, we go out, we pray, we give money and sweets to the kids and you go visit the family. And you really, really enjoy yourself – we all look forward to Eid.”

### A light at the end of the tunnel

One thing Fathiya is passionate about is raising awareness and dispelling myths within her community. While her faith helps to keep her strong, she says there is still a lot of stigma about it within her culture.

“I’m raising awareness about that through TikTok, Instagram, YouTube – and I’m getting really good feedback.

“People are surprised that I’m talking about it and advocating for it. And I’m getting so many people, to the point where I had to form a WhatsApp group, where we meet every Thursday and we just talk.

“Otherwise, there is no one to talk to, because my community can be very closed off. So, it looks like we’re opening doors and hopefully people are going to be more open to it.”

Fathiya is aiming to shatter any beliefs that people with epilepsy are ‘possessed by the devil’ or that epilepsy is ‘contagious’.

“There is no devil inside us, it’s just nerves in your brain. It’s a neurological condition, and it’s just a condition like any other. I’m hoping to achieve that – that it will be a normal subject.

“I think people are suffering in silence. But the fact that I started this, it looks like everyone can see a light at the end of the tunnel. They’re really happy about it.”

# The impact of Edie

With the return of Epilepsy Action's Bradford 10k race, Cheryl shares why she likes the event and what motivates her to keep running. Written by Kami Kountcheva

> “Running gave us a way to parent Edie, and was time out of our day when we felt like we were still able to do something for her”

**With the return of the Bradford 10k this year, people have been signing up for the iconic race to support people with epilepsy.**

Some runners do it for the love of running. Others do it for themselves, to show that their condition is not going to be calling the shots. Others do it to support loved ones. And some, like 40-year-old Cheryl, do it to feel closer to someone they've lost.

Cheryl is an administrator and mum from Pudsey. Alongside spending time with family and friends – often over a coffee – and music, she loves running.

“I started running as a way to get a bit fitter before mine and Tom's wedding in

2010," Cheryl explains. "I kept it up until mid-2012, when I found out I was pregnant with Edie."

### Edie

Edie was born in January 2013 in Halifax, and when she was nine months old, the family moved up to Scotland. "Edie was a little ray of sunshine who loved singing, dancing and playing," Cheryl says. "She had become a big sister to 'baby Annie' three-and-a-half months before she passed away, and proudly called herself 'the best big sister ever'.

"She loved Frozen and her daddy's music – especially The Cribs. She loved being read stories and playing pretend. And she absolutely loved going for a 'coffee' and a cake with mummy, daddy and baby Annie.

"She was everything a two-and-a-half-year-old should be – full of fun, cheekiness, happiness and love."

Edie hadn't been diagnosed with epilepsy when she died, but she had had seizures thought to be due to a high temperature. Cheryl explains: "Edie had what is believed to be a febrile convulsion a few months before she passed away, but never had another seizure until 10 October 2015, when she had what we thought was another febrile convulsion.

"Sadly, we now know this wasn't a febrile convulsion. Edie was admitted to The Royal Hospital for Sick Children in Edinburgh. She spent six days on life support and sadly passed away on 16 October 2015.

"During her time in hospital, the most amazing doctors and nurses treated her and after a lot of tests, they tested Edie for Hemiconvulsion Hemiplegia Epilepsy (HHE) syndrome. "Until then, we didn't know there was a possibility she had epilepsy, and we had never heard of HHE before. To be honest, it has taken us nearly 10 years to be brave enough to learn more about it."

HHE is an epilepsy syndrome that starts in children under four years of age, and starts with a prolonged focal seizure (focal status epilepticus), followed by weakness in one side of the body.

The family hadn't come across epilepsy before this. "We don't have anyone within our family and friends who have this, so our experience is limited to Edie and what we see on TV and social media."

When Cheryl and Tom felt ready, they reached out to Epilepsy Action, who were able to send over some information on the condition to help the family gain more understanding.

### 'She may have been small, but she left a huge impact'

Since losing Edie, Cheryl has run in the yearly Epilepsy Action Bradford 10k event several times to help more people understand how epilepsy can affect families.

She says: "I had always planned to get back to running once Edie was born, but it never happened.

"After Annie was born in June 2015, I set myself the target of running six 10k races in 2016 as a way to motivate me back into running.

"After Edie passed away, I was determined to keep the plans for the 10ks and 2016 became the 'year of running'. Between me and my husband, we ran six 10ks, four half marathons and a marathon together in memory of Edie. Since then, we have kept on running in her memory.

"Our youngest daughter Eilidh was born in September 2020 and following this and COVID, we are ready to do some more.

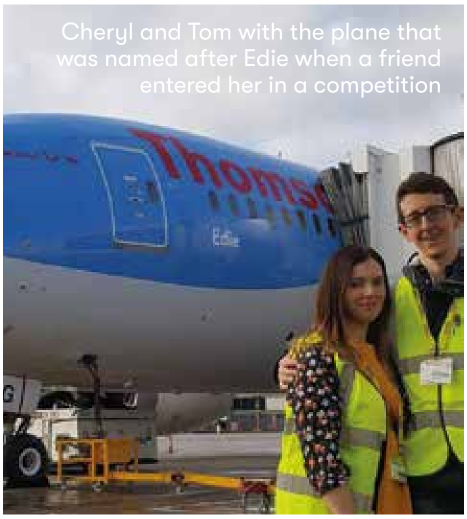
"I have done Bradford 10k a couple of times previously and really enjoyed it. It's local and very well supported.

"This year, I'm running the race with some of our amazing friends who, since Edie passed, have helped us to do lots of things in her memory and have always been there to support us.

"Running after Edie passed away gave us a focus. We had lots of genetic testing ongoing in the first few months that followed her death, but running gave us a way to parent Edie, and was time out of our day when we felt like we were still able to do something for her.

"We can't change what happened to Edie, but we hope that we can help people understand epilepsy and the impact it has on families.

"Supporting a race for epilepsy in the year that will be the 10th anniversary of her death feels really special. She may have been small, but she left a huge impact on us all and is loved and missed every day."


Cheryl and Tom with the plane that was named after Edie when a friend entered her in a competition


Edie was proudly 'the best big sister ever' to baby Annie

## Sign up now!

This year, Bradford has been chosen as the City of Culture for 2025 – only the fourth to be bestowed the title to date. This brings a lot of activities to showcase the city's highlights and boost its image, including cultural festivals, art installations, music events, comedy, workshops, opera, theatre shows and more!

As part of its many activities this year, The City of Culture is also playing host to Epilepsy Action's iconic race, the Bradford 10k. Since 2008, this running event has raised over £600,000 with the help of 16,000 runners.

You can help celebrate the 75th anniversary of Epilepsy Action at the Bradford 10k this year, whether you're chasing a personal best or conquering the 6.2-mile course for the first time.

**Sign up for the Bradford 10k at: epilepsy.org.uk/bradford**

# Brand new *merch*

Show your support in style with Epilepsy Action's new line of merchandise

**Our new branded merch has arrived!**

As you know, Epilepsy Action has undergone an exciting rebrand, and to celebrate, we're thrilled to launch our brand-new range of exclusive merchandise! Whether you're a long-time supporter or new to the cause, now is the perfect time to show your support in style.

Our carefully selected merchandise range includes something for everyone. Whether you're looking for a stylish new T-shirt or beanie to add to your wardrobe, or a practical item such as our trolley coin or water bottles to show your support, we've got you covered.

Show your support in style with our brand-new wristband, made from durable silicone and featuring the new Epilepsy Action logo. You can also pick up a branded T-shirt in a range of sizes for both adults and kids!

> **“Thank you for your support over the last 75 years!**

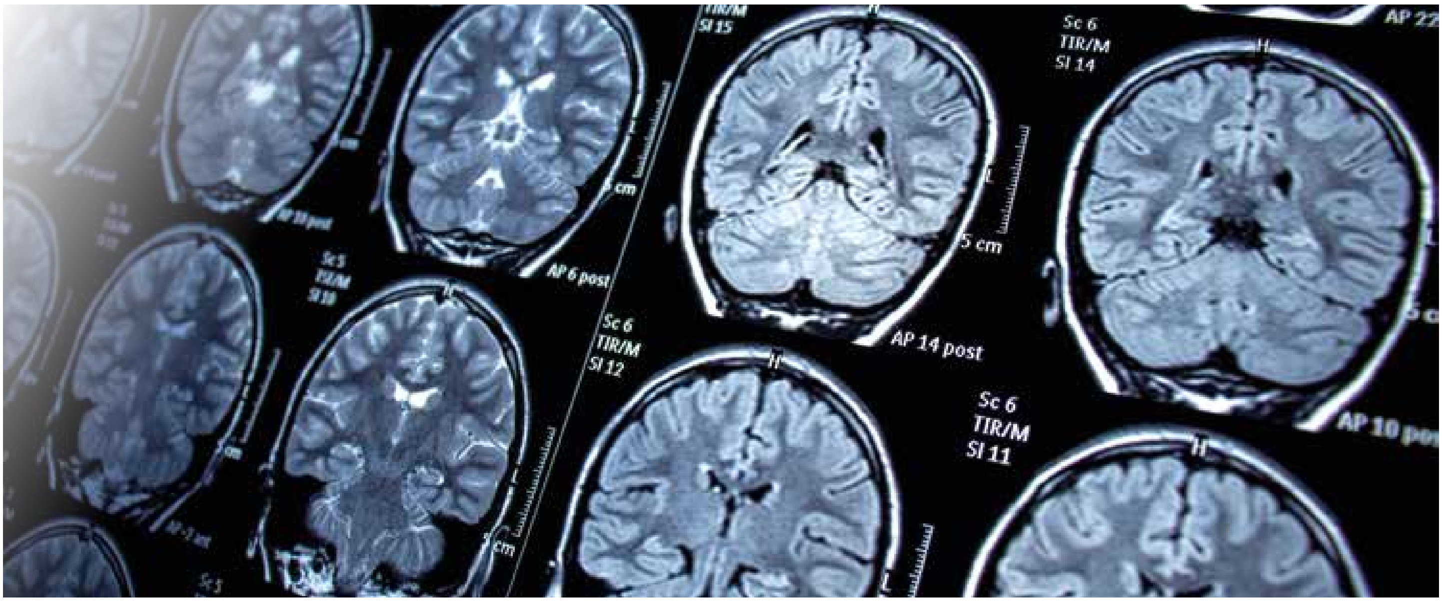
*Thank you!*

As a special thank you to our valued members we're delighted to offer you an exclusive discount code to claim you very own **free pin badge**! This special token of appreciation is our way of saying thank you for your commitment and support over the past 75 years. To claim your free badge simply visit our website today and use the **discount code MEMBERBADGE** at the checkout.

### Your support makes a difference

Every purchase you make, helps continue our vital work supporting people affected by epilepsy. And by wearing or using Epilepsy Action merchandise, you're not just showing your support, you're also helping to spread awareness, start conversations, and create a world without limits for people with epilepsy.

So, head to our shop now to place your order and claim your free Epilepsy Action pin badge **epilepsy.org.uk/shop**



# Laser surgery

Consultant neurosurgeon, Mr Jibril Osman Farah, is delivering laser interstitial thermal therapy at The Walton Centre in Liverpool. He shares some insights about this exciting new treatment.

Interview by Kami Kountcheva

**Laser interstitial thermal therapy – known as LITT, is a treatment for epilepsy that uses heat from a laser beam to destroy damaged areas of the brain that cause seizures.**

This treatment is also sometimes known as laser ablation surgery, and can be used as a less invasive alternative to open skull surgery.

The treatment promises a speedier and less painful recovery, and offers fewer cognitive problems afterwards compared to more typical epilepsy surgery.

We spoke to Mr Farah to learn more about this treatment.

**KK: Can you tell me a bit about the LITT treatment?**

**JF**: The operation is a form of ablation. Once brain tissue has been identified as a focus of epilepsy (an area where seizures start from), it is possible to burn it away with a laser probe. The probe is delivered through a twist drill and then is inserted into the focus. The laser ablation can be used in cases such as hypothalamic hamartoma (a non-cancerous tumour in the hypothalamus) in the UK.

**KK: Who is eligible for this treatment?**

**JF**: This treatment is only available for people with focal seizures, and the maximum seizure focus size that can be ablated is 3cm.

It is not used for generalised epilepsy at the moment, although there is a new way of doing a corpus callosotomy (where a band of fibres connecting the two halves of the brain are cut), but I would say that this is still experimental.

**KK: How effective is this treatment?**

**JF**: It has been proven to be as effective as surgery in suitable cases. A meta-analysis of data from 16 studies that included 269 patients with treatment-resistant epilepsy showed that MRI-guided LITT significantly reduced the frequency of seizures and reduced postoperative complications, supporting the safety and effectiveness of MRI-guided LITT in the treatment of drug-resistant epilepsy. The reported average figure was 61%, ranging between 41-88% depending on the indication (seizure cause).

**KK: What further research do we need in the UK on it?**

**JF**: In the UK, research is limited at the moment. Practically, in the UK, we need to build up the experience as our experience is mainly on hypothalamic hamartoma, which is only one indication. But looking at temporal lobe (with a seizure focus in the temporal lobe) and extratemporal lobe epilepsies (with a seizure focus outside of the temporal lobe), our experience is limited, I would say.

We can utilise the research from the

US, as they use the treatment a bit more widely. I wouldn't personally consider LITT an alternative to surgery at this moment in time, because the evidence that there is from the US is not strong enough in certain aspects. There are no specific restrictions on what can be treated with LITT in the UK. At The Walton Centre we decided to treat focal epilepsies related to conditions difficult to treat with open surgery, or linked with higher surgical risks of complication. I think that's a more appropriate approach to it.

**KK: Where is the treatment currently available?**

**JF**: This treatment is available on the NHS in Liverpool at The Walton Centre, and in London at Kings College Hospital for adult epilepsy.

For paediatric epilepsy, it's available in four centres, including Alder Hey, Bristol Royal Hospital for Children and Great Ormond Street Hospital.

However, everyone can be referred within the country, it is very much open. I encourage a referral system from epilepsy services. In other words, it's important to identify the seizure focus, and the work up to surgery in epilepsy is quite long. I think this should be done at the local unit, and any appropriate cases can be referred to us and I would be very happy to provide the treatment.

**KK: For a patient, what does a day look like coming in for this treatment?**

**JF**: This is a minimally invasive treatment, in the sense that it will substitute a full craniotomy. These cases are sometimes done as day cases, or possibly with a 24-hour hospital stay. The patient signs a consent form and undergoes general anaesthesia. I then place a static frame, I do a registration and then will place the laser probe using a robotic arm for precision. Then I will verify the position of the laser probe and after I verify the position, we go into the MRI scanner and the treatment is delivered within the MRI scanner with the patient asleep.

The ablation and the treatment probably lasts about half an hour. Then the patient has a scan to verify the ablation and then we remove the laser probe and the patient is woken up.

At the moment, we're keeping patients for 24 hours after the procedure. In the future, I think we'll go down the route of a day case and therefore we will discharge the patient on the same day.

**KK: What's the aftercare and recovery like for patients?**

**JF**: There isn't really any sort of scar and there is no hair shaving. The only thing is just a small entry point where a single suture is applied.

People are observed in recovery for a few hours and then the patient goes to the ward or goes home.

The only problem could be oedema (a build up of fluid) and swelling. The swelling is the biggest issue, and will occur post operatively within a week. Generally, this is controlled with steroids, so we send the patient home with steroids to take. It lasts between six and eight days and resolves progressively.

**KK: Can you have the procedure done more than once?**

**JF**: It can be repeated and it can be staged. There are a lot of openings on that. For example, if you want to treat a 3cm area and then you realise that you've actually only ablated 2cm, you can retreat the patient. Or, if you want to treat a 6cm area, you can stage the treatment over two LITT procedures, so you can treat a 3cm area first and then a second 3cm area next time. This is possible as well.

**KK: Can patients be weaned off their epilepsy medicines after having the treatment?**

**JF**: The same applies to patients getting LITT as with patients undergoing open surgery. On other words, you can get seizure freedom on and off medication. The best success and outcome would be seizure freedom off medication. But you can also be seizure free and stay on medication.

That means it's the choice of the patient whether to stop the medication. Several patients will not want to stop their medication, particularly adults, due to the potential risk of losing their driving licence.

The normal procedure is that we would attempt to stop the medication within one year from the treatment, because if a patient has been seizure free for one year, they would be reluctant to stop their medication and risk losing their driving licence.

From my experience, about 50% of my patients who are completely seizure free would say that they prefer to stay on medication, but the target would be to make patients seizure free off medication.

**KK: Are there waiting lists for this treatment at the moment?**

**JF**: On my books, I have about five patients waiting, so the list is not particularly long. There is a longer wait for the investigations within the epilepsy surgical programme. You need to identify a focus where seizures are coming from and all those investigations, and the epilepsy programme itself will have a longer wait time.

**KK: What are the next steps for this treatment?**

**JF**: In the longer term, possibly in the next three to five years, I would expect that each major epilepsy service within the UK will offer this treatment and I wouldn't expect that the whole of the North of England would be covered by one single centre. But I would not expect that every single new surgery unit would have this as a treatment option, I think this will depend on how big the epilepsy programme is.

**To find out more, speak to your epilepsy specialist or contact the Epilepsy Action Helpline at 0808 8005050 or epilepsy.org.uk/helpline**


Mr Jibril
Osman Farah

Rosemary with her 12 marathon medals

# Tackling *challenges*

After learning how to manage her triggers over the years, Rosemary was unexpectedly met with a new challenge when changing her epilepsy medication – unrelenting insomnia. She shares her experiences. Written by Kami Kountcheva

**“In 1988-89, I remember having a seizure at work and my employer couldn’t wait to see the back of me,” says 60-year-old Rosemary Luz. Rosemary has been diagnosed with epilepsy since before she was five years old.**

Having lived with the condition most of her life, Rosemary says she’s seen a change over this time. She’s been working freelance as an English-Spanish conference interpreter and certified translator for over 30 years, and while she no longer has a direct employer, she’s seeing improvements.

“I think there’s been some degree of enlightenment. Twice on holiday, I have had seizures and kind strangers came to my rescue, applying first aid correctly. I have had some colleagues and even a client who asked me what they should do were I to have a seizure.

“However, they’ve been few and far between. I try to be self-reliant and live as preventative a lifestyle as possible.”

Rosemary explains that she lives on her own in London (“and have done so for many years”), and while she says she hasn’t taken any special precautions, she lives her life carefully. “It’s precisely because I live alone that I have had to live as preventative a life as possible. I am not in the category of someone who has five or six seizures a day.”

Rosemary’s type of epilepsy means that she can sometimes tell when a seizure could be coming on, and she uses this to keep herself safe as well. “If I have ever felt ‘pre-seizure’,” she explains, “I lie down to prevent myself from becoming hurt from a fall. If my hand-eye coordination permits, I telephone 111 and say that I am 'pre-seizure'."

As a child, Rosemary says her first memory of a seizure was when she was around nine, holding a glass of milk and seeing it go flying up into the air. She says at the time she didn't really understand epilepsy, and her parents "weren't particularly well informed" about it either. Even so, they followed the GP's and neurologist's instructions, making sure she got enough sleep and took her medication as prescribed.

Growing up, Rosemary took an interest in her condition, learning more about it and what she can do to look after herself. Over the years, she was able to identify some triggers for her seizures.

"When I became a teenager, I started asking questions about my epilepsy, like the cause, what could affect it and so on," Rosemary explains. "I researched epilepsy and tried to find out which type of seizures I was getting."

She was experiencing absence seizures, myoclonic seizures (limb jerks) and tonic-clonic seizures, and says the road to seizure control was "very hard and slow".

"Unfortunately, I learned the hard way by having a seizure and then realising on the post-seizure or the post-limb jerk analysis that it was because I had missed out on a night's sleep, or had a very stressful day, had too much alcohol, had eaten too much chocolate or had drunk caffeinated coffee or tea.

"When I was in my teens, 20s and 30s, a seizure would leave me debilitated for three days. It felt like a bolt of lightning had gone through me."

With all her efforts to avoid her triggers, Rosemary is proud and pleased that she hasn't had a tonic-clonic seizure since 2012. She adds that her neurologist has also prescribed clonazepam as an emergency medicine, which she takes if she starts to sense a seizure coming on. "It kicks in after 20 minutes and has saved my bacon on many a day."

### Running through insomnia

In March 2024, Rosemary's neurologist suggested changing her anti-seizure medication from Epilim Chrono (sodium valproate), as she had been taking it for a long time. As well as that, Rosemary had had a wrist fracture in 2023, and browsing through the Royal Osteoporosis Society's website one day, discovered that her epilepsy medication could also be affecting her bone health. She began a plan to reduce her Epilim Chrono and start taking Keppra (levetiracetam). However, for Rosemary, this medicine came with an unbearable side effect: insomnia. Ever conscious of her triggers, she thought these might have been to blame, but writes in her blog: "It took a month for the penny to drop. I nearly had a seizure in mid-July and asked to be taken off the Keppra.

"My neurologist put me on Lamictal (lamotrigine) which gave me just as much insomnia as a side effect and made me very forgetful when I was on the full dose. I left the house without my purse. At work, I made minor mistakes. Nobody else noticed, but it was very troubling."

After months of experiencing these new side effects and seeing no added benefits, Rosemary asked her neurologist to be prescribed Epilim Chrono again.

"I have never suffered from insomnia before. It was a very frightening experience, and I can see how it can drive a person to complete despair and madness."

Once Rosemary came off Lamictal, her sleep improved, but her sleep pattern had become uneven, ranging from five to eight hours' sleep. This left her unsatisfied, so she began researching ways to improve her sleep further and found a sleep plan in a book called '4 Weeks to Better Sleep' by Dr Michael Mosley. Following this plan, she gave herself a goal she called seven x seven – seven hours of natural sleep for seven nights a week.

This was inspired by a running challenge Rosemary had taken on in May of 2024, before her insomnia reached its peak. The challenge was called 12 in 12, and involved running one half marathon a month over the year.

"I got into running in 2004. I had been dancing salsa solidly for 10 years before that, but the group of salsa friends I danced with fell out. I needed to replace it with something.

"I built up gradually from running round the local park to 5km, 10km and 20km distances.

"What I enjoy about running is that it's extremely spontaneous. I love being at one with nature. I am lucky to live near the Thames River and near a national park. Living in the moment helps me forget all about my cares. I feel much better within myself and it does help me sleep."

Starting the 12 in 12 in May and not wanting to run during autumn and winter, Rosemary had to run the 12 half marathons in five months over the spring and summer. However, she wasn't to know how much more of a challenge she was undertaking with what was happening with her sleep.

"It was a much bigger challenge than I had expected because of the insomnia."

Rosemary ran the final of the 12 marathons on 21 September. She recalls: "I had to mark the auspicious achievement with lots of photos and even if I say so myself, I was rather chuffed to have crossed the line with all the insomnia I was suffering from.

"I've now ran about 11 marathons and 17 half marathons."

Impressive as this is, that's not been Rosemary's only big achievement recently. "As of 14 December, I can confirm that the sleep plan went very well. Now, I need to embed it into my lifestyle."

> **"I have never suffered from insomnia before. I can see how it can drive a person to complete despair and madness"**

**Read more about Rosemary in her blog: gomezprofessionalservices.com/blog/**

Rosemary enjoys running for the spontaneity

# Epilepsy stars

From brave brothers and quick-thinking kids to supportive schools and defying expectations, we share star award winners' stories!

Written by Emily Stanley

Harley (left) and Louie

### Life-saver Louie

October's Epilepsy Star award has been won by seven-year-old Louie. Just a few months ago, Louie saved his older brother Harley's life, who was experiencing a sleep seizure in the night. Louie had heard Harley, 13, making 'loud noises' and immediately alerted their parents. Doctors later told the family that Louie had saved his brother's life.

The boys' mum Sophie says: "As parents, we are extremely proud of Louie for raising the alarm like he did. We will be forever grateful and I don't think we could put into words how proud we are of him. You will forever be our hero, Louie!

"We were also told by doctors that Harley is now at high risk of SUDEP (sudden unexpected death in epilepsy), which was a big shock for us. It's had a massive impact on us as parents knowing the risks, and we have decided not to talk to Harley about it just yet, as he is already very anxious after this recent event.

"My advice for other parents would be to go with your gut feeling and, if something isn't normal, call for help."

Epilepsy Action advises that 999 should be called if a seizure lasts more than five minutes, you know it's someone's first seizure, they have one seizure after another without regaining consciousness between, or they are seriously injured during the seizure.

### Superb support

November's Star Award has been scooped by Oak Lodge School in Balham in recognition of the incredible care they deliver to their students with epilepsy. The school offers support for students who are D/deaf or have SLCN (speech, language and communication needs). The school was nominated by their medical lead Ramona.

She says: "We have an incredible team at Oak Lodge School, who are amazing at dealing with seizures on-site. The team work seamlessly to ensure the wellbeing of everyone involved, including both the child having the seizure, and the other children who may have to witness it.

"We have had four students in the last three years, with no history of epilepsy, have their first seizure on-site and be subsequently diagnosed with having epilepsy. Others have been diagnosed with non-epileptic seizures. A child's first seizure can be very scary to see, especially if there is no known history, which is why the team work so hard to ensure the safety and well-being of the students in such situations.

"Epilepsy Action's online resources, particularly the videos about seizure types and symptoms, have been valuable in helping staff members better understand epilepsy.

"The team has an action plan to deal with seizures. One staff member will time the seizure, whilst another ushers the

Oak Lodge School

other students away to protect the child's dignity. Another staff member will fetch the medical lead or first aider, someone will call 999 and another will fetch the child's paperwork to attend hospital."

## Calm, cool and collected

Four-year-old Frankie and seven-year-old Aisha were joint winners of the December 2024 Star Award. Each child came to the rescue of their mum during a seizure, showing amazing bravery and quick thinking.

Frankie loves the normal things any child his age would, like board games, cards and his toy kitchen set. But young Frankie had to step up twice this year, looking after his mum during seizures, when he was on his own. In June, Frankie's mum, Mair, had a seizure whilst she was with him in the park. Then, in November, Frankie came to his mum's aid when she had a seizure whilst they were home alone.

Mair explains: "I have no memory of what happened, but I've been told that I just 'dropped' with no warning. Frankie called an ambulance and his granny Sian, again using the emergency settings on my phone.

"He then unlocked the door when the paramedics arrived and told them 'my mummy has epilepsy'. He showed them where I was and even pointed out my medication cupboard. He is only four but was able to stay calm and remember all of this!


Frankie


Aisha

"I don't think I'll ever be able to put into words how proud I feel as a parent. Frankie, you are my real-life superhero!"

Aisha loves trampolining, crafts, gymnastics, books and playing with her friends. Her mum, Lucy, has epilepsy and Aisha has witnessed Lucy having many seizures, including outside her school, and at friends' birthday parties. Aisha had been taught by her parents how to look after her mum, if she was to have a seizure when they were alone together. Unfortunately, this scenario became a reality for the mum and daughter.

Lucy said: "I was in the kitchen cooking tea, when all of a sudden I began having a seizure. Aisha's first response was to put a cushion underneath my head on the hard stone floor. She then turned off the gas hobs and oven before trying to contact her dad.

"Aisha had been taught to ask Alexa to 'call dad' and did exactly that, after she'd made sure I was safe in the kitchen. She asked Alexa the instruction, but after doing so heard a phone ring in the house... She found her Dad's phone on the hall table, who had gone to play football for an hour.

"Luckily, Aisha's clever thinking meant she started looking through his phone and managed to find a contact named 'dad' on the phone, which is Aisha's Grandad. She called him and her Grandad picked up and was able to come to the aid of both myself and Aisha. She is a real hero and it was her quick thinking that helped me get the help I needed.

"We're all extremely proud of our amazing daughter!"

## Scarlett's strength

Scarlett Mcdonagh from North London won the January Epilepsy Star award. She has spent the majority of her life advocating for people with epilepsy.

When Scarlett first developed epilepsy aged four, she was having between 120-150 seizures a day. Her mum was told she wouldn't make it past six. However, Scarlett, now 23, has defied expectations. Despite facing huge life challenges, including having nine brain surgeries, losing her mum to cancer, and battling her epilepsy, Scarlett has become a passionate advocate for people with epilepsy and is dedicated to raising awareness of the condition.

Scarlett was nominated for an Epilepsy Star award by her close friend Amber. Amber and Scarlett met at sixteen, in the bustling corridors of college, and have remained good friends ever since. Amber says Scarlett is a 'true champion'.


Scarlett (left) and Amber

She says: "Alongside living with epilepsy, Scarlett's strength was further tested when her mother was diagnosed with stage 4 cancer. Scarlett had to become her mum's full-time carer, all while managing her own health challenges, including the removal of part of her brain, and limited use of her left hand. With the support of her godmother, Scarlett found the courage to look after her mum.

"Despite everything she's been through, Scarlett has emerged as a passionate advocate for young people with epilepsy.

"I always told Scarlett that her epilepsy is her 'superpower', and after years of encouragement, she now proudly embraces it. This award is a recognition of her incredible journey and the positive impact she has had on those around her."

Scarlett has remained positive and is a role model for many, including her good friend Amber. Scarlett said: "I'm honoured to accept this month's Star award. I'm a huge advocate for epilepsy awareness – I think it's super important that people know what to do if they come across someone having a seizure.

"I'm currently doing really well in life – I'm living life in ways that I never thought I'd be able to. Having been told that I wouldn't make it far in life due to my health, I live life to the fullest."

**You can read more stories and nominate a someone for a Star Award at epilepsy.org.uk/star-awards**

# Board of trustees

**8th October**
The main agenda item was the 2025 draft revenue budget. The trustees agreed that further work was needed to achieve the three year forecast that includes a reduced deficit in 2025 followed by a break event position in 2026.

On 2024 performance targets helpline and volunteering were ahead of targets and visits to the website on target. Return on Investment for fundraising was just over £3 for every £1 spent which was on target.

The trustees approved a new carbon reduction plan for the charity.

**10th December**
The recommendations from the governance review that was carried out by the NCVO led to some initial decisions being made tat will be included in the recommendations for constitutional changes that will be presented to the members at the AGM in September. More details will be included in the next edition of Epilepsy Today.

A revised 2025 budget was approved.

**4th February**
The appointment of Rebekah Smith as Chief Executive was confirmed by the trustees. There was then a discussion about the initial results from the membership survey with a particular focus on how we can expand the membership so that it includes all of our supporters. There were recommendations from Wrigley's about the timeline needed to make constitutional changes and present them to the members at an AGM. A new appraisal process for the trustees was also discussed.

# In memory of Ruth Hall

**Ruth Hall, who ran the Epilepsy Action group in Basildon, died on 30 December 2024 at the age of 81. She had recently been diagnosed with cancer, and passed away at St Luke's Hospice in Basildon.**

Ruth got involved with Epilepsy Action as one of her three daughters, Rachael, has had epilepsy since early childhood.

Alongside her husband Albert, Ruth had been fundraising for Epilepsy Action. When she joined the Basildon group, she became secretary, acting a telephone contact for many years. Later, she took over as chair and has also held the position as treasurer.

Working with the Basildon group, Ruth helped to fundraise through fetes, street collections and applying for grants. She also helped share information through information packs sent to schools, playgroups and nurseries in the area.

The group also successfully campaigned to local health authorities to get a Sapphire Nurse for the area, and Ruth worked with local MPs to ensure it was kept as a 'full time equivalent' role.

A friend and member of the Talk and Support group, Barbara Hoare, said: "Ruth and her late husband Albert held fundraising events in Basildon for Epilepsy Action and ran the Basildon support group in the early days, with the late Barrie Gull.

"I joined the group in the early 1990s and subsequently joined the committee as secretary, and have been involved in the local group since then.

"Ruth was instrumental in organising outings, quizzes and Christmas meals for the group.

"Ruth finally 'retired' from the Talk and Support Group a couple of years ago. She has been the power and relentless driving force behind the group all these years. Epilepsy Action and I have a lot to thank her for!

"She was one of my greatest friends and I will miss her dearly."

# Epilepsy support for you

**For many people, living with epilepsy can feel isolating and misunderstood. But you're not alone. There are so many others navigating similar experiences – whether they're living with epilepsy themselves or caring for someone who is.**

At Epilepsy Action, we're here to support you and help you connect with others who truly understand. We offer a range of free, confidential services designed to make a difference:

- **Helpline**: Speak with our trained advisers who are ready to listen and help you explore possible options and solutions.
- **Befriending**: Have a friendly weekly chat with a volunteer who understands.
- **Groups**: Join others affected by epilepsy through virtual or in-person groups to share stories, experiences, and support.
- **Counselling**: Available in Wales, offering professional support to anyone affected by epilepsy.
- **Family Support**: Tailored support for families and carers in South Wales and Northern Ireland, including practical help and opportunities to connect.

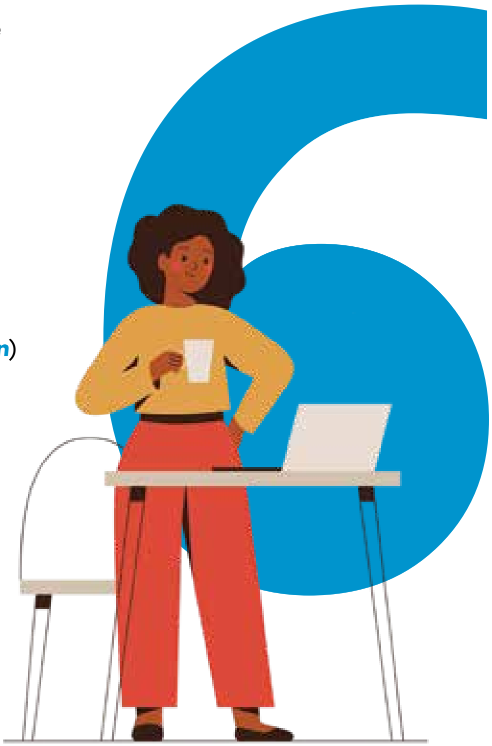
We're here to listen, support, and bring people together – because no one should feel alone on this journey.

For more information call our Helpline on 0808 800 5050 or visit ***epilepsy.org.uk/support-for-you***

You can also find us on:

- HealthUnlocked (***healthunlocked.com/epilepsyaction***)
- Discord, (***bit.ly/3vHLOkT***)
- Facebook (***facebook.com/epilepsyaction***)
- X (formerly Twitter) (***@epilepsyaction***)
- Instagram (***bit.ly/3zSKMVM***)

> **"We're here to listen, support and bring people together"**



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Epilepsy Action has revised its privacy statement (September 2022) to better reflect its activities and use of data. Please go to epilepsy.org.uk/about/our-privacy-statement to access it.

EPILEPSY
ACTION

# EPILEPSY SAYS STOP. WE SAY GO.

## Support for You:

- **Helpline –** phone, webchat or email
- **Talk and Support Groups –** online & in-person
- **Befriending –** online or phone
- **Counselling –** Wales
- **Family support –** NI & Wales
- **Website –** high quality information about all things epilepsy
- **Epilepsy awareness courses**

**epilepsy.org.uk/support**

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