Issue 168 | Autumn 2025

Epilepsy Today

EPILEPSY ACTION

75th ANNIVERSARY

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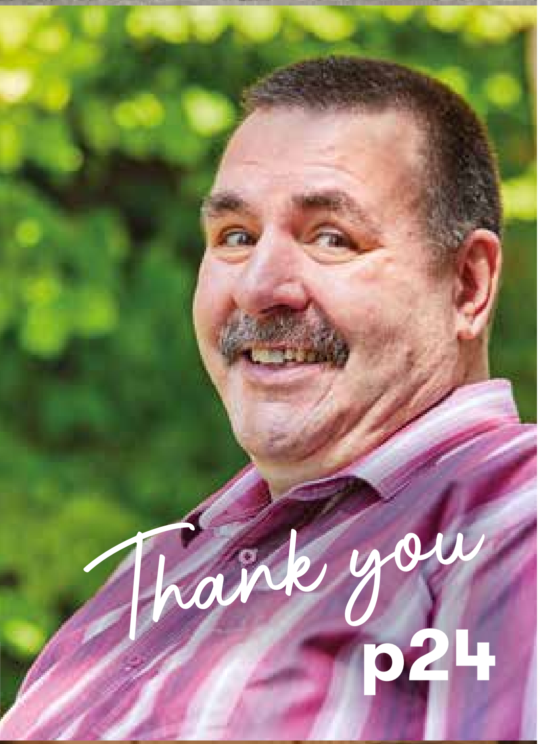


Inside

Happy 75th!

Welcome to the Autumn issue of Epilepsy Today. This issue we are celebrating a landmark 75 years since Epilepsy Action was first established.

Many things have changed in the last 75 years, but one thing remains the same, and that is our dedication to improving the lives of people with epilepsy. Read more on page 10.

We have some important information on page 4, where chair of the Board of Trustees explains the upcoming vote.

There are a lot of exciting updates on what we've been working on in your Autumn issue too – Doodle Day is turning 21 and is bigger than ever (page 20), our Christmas catalogue is ready to peruse (page 16) and we're launching our ThankFest, thanking you for your unwavering support and asking you who or what you are thankful for (page 24). You can also take an early look behind the scenes of our next awareness campaign on page 28, ane read about two Star Award-winning hero nurses on page 29.

You can also read about one-year-old Lennon batting status epilepticus (page 14), an update on the valproate scandal five years on from the Cumberlege report (page 22), and deep brain stimulation (page 26).

We hope you enjoy this issue and celebrate all you have helped to achieve over the years.

Kami Kountcheva
Editor

It's time to *vote*

Epilepsy Action chair of the Board of Trustees, Jane Riley, explains what your vote will mean

For those of you that read the article from myself and Rebekah in the last *Epilepsy Today*, you will know that the trustees are asking you to vote yes to a resolution to approve changes to the charity's governing document, the "Articles of Association,"* that have now been approved by the Charity Commission.

The details of how to vote are included in a letter you will receive with your printed copy of *Epilepsy Today*, or as a separate email from "Civica" if you receive a digital copy of the magazine.

Before we go into more detail about what we are asking you to vote for, I want you to know what is not changing:

The most important part of the Articles that govern the charity are the "Objects", or purpose of the charity. These are:

- To support people with epilepsy or those with an interest in the condition
- To raise awareness and understanding of the condition
- To promote research into epilepsy.

There will be NO changes to our purpose: this is, and will always be, what drives our strategy and ambitions.

There will also be no change to the fact that lived experience of epilepsy is at the heart of everything we do. This has been specifically written into the Bye Laws** that support the new governing document, stating that the majority of trustees must have lived experience.

What are we asking you to vote for?

We are asking you to vote on a number of amendments, two of which are key changes:

> **“There will be NO changes to our purpose: this is, and will always be, what drives our strategy and ambitions”**

Jane Riley

1. To appoint, rather than elect, the trustees of the charity.

The Council of Management, or Board of Trustees, is currently voted for by the current defined membership body. This will change to the trustees being appointed by the board and being the legally recognised members of the charity.

The trustees are recommending this change to the membership after assessing a number of different charity models to address the ongoing low voting numbers and the need to develop a more diverse board. The proposed change was agreed as the most effective to achieve the NCVO's*** recommendation to **"change the constitution to allow trustees to be selected through a recruitment process and that this process tests suitability for the role; in terms of skills and experience, commitment to the cause, and the value of lived experience."**

2. Changes to the length of office and number of trustees.

Terms of office will be a maximum of three terms of three years, rather than the current indefinite time period. This is in recognition of best practice and need for ongoing changes in skills and representation. The board size will reduce to 8-12, rather than the current 12-16, in line with the NCVO recommendation.

All other amendments to the Articles relate to changes that have been set out by the Charity Commission and are relevant to all charities.

What do you want from membership?
We've now completed two surveys to understand more about membership this year. The trustees commissioned an initial piece of research with 900 people to help understand the importance of voting. The 2nd piece of research has involved a further 2,000 current members and 2,400 non-members to look at how a new membership scheme would look.
If this Resolution is passed, a new scheme will be launched at the start of 2026.

How will we make sure members who want to get involved in appointing the trustees can still do so?

There will be a number of ways non-voting members of Epilepsy Action can still be involved. How this will work is set out in the Bye Laws, which explains the process for identifying people who are interested in supporting the recruitment and appointment process. Non-voting members will be contacted at the relevant times of the year to be part of recruitment review groups, to take part in interview panels and to attend an annual "meet the trustees" event.

What does this mean for our current membership scheme?

It means we can now look towards developing a membership scheme that encompasses our whole community, including the 400 volunteers who are not currently members, the 25,000+ regular supporters and service users and some of the 209,000 people who we have contact with.

We can create a membership that is free at the point of entry. A community focused membership that provides a whole range of different benefits, giving people a choice of what they want to be part of, hear about and pay for – and, of course, *Epilepsy Today* will remain a key part of our offer as we know how much it is valued.

Annual General Meetings will become Annual Meetings open to anyone who wants to attend, rather than the current system that is restricted to the 7,500 defined members and that very few people go to. These meetings will be more flexible in their format and will include discussions about achievements and challenges and provide the ability to ask questions of both the trustees and the senior leadership team.

Did you know about our Advisory Boards in Northern Ireland and Wales?
While they do not have decision-making authority they can submit formal recommendations to the Board. A new Bye Law will formalise the relationship between them and the Board with regular Chair and CEO contact to agree key priorities and support.

How do I find out more?

If you have a question or are unable to access the link or your security code, please contact our membership team on 0113 210 8810.

Alternatively, if you would like to receive a full paper pack of all voting documents and the opportunity to vote by post, please send a request to Epilepsy Action's membership team at membership@epilepsy.org.uk or on 0113 210 8810. The final day to request a paper AGM pack is Thursday 28th August 2025.

When you log into Civica you will see documents including the Articles of Association and Bye Laws.

Voting closes at midnight on Sunday 7th September.

* Articles of Association are the governing document for a charity and are legally binding. They are a set of rules that outline how the charity will be run, its purpose and governance structure.
** Bye Laws are the internal rules that govern how the charity operates. They add the processes and details that are not set out in the Articles.
*** NCVO is the National Council of Voluntary Organisations. Over 10,000 charities are members and they carried out the Governance Review of Epilepsy Action in 2024 which is resulting in the proposed changes.

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

Epilepsy Action celebrates Volunteers' Week 2025

Epilepsy Action celebrated Volunteers' Week from 2-8 June 2025, a week created to show appreciation for volunteers whilst inspiring more people to make a difference.

Epilepsy Action hosted a series of exciting events to celebrate the amazing contributions of volunteers.

This included the Volunteer Awards, with more nominations this year than ever before for the five exciting awards up for grabs.

And the winners are:

- New Starter: Patrick Egan
- Unstoppable Spirit: Rebecca Smart
- Positive Participator Award: Chloe Milburn, Paul Cooper
- Change Champion: Koletta Jurskyte
- Volunteer Superstar: Fay Dawes

On winning the Volunteer Superstar Award, Fay said: "I have epilepsy myself, complex and simple partial awareness seizures [now known as focal preserved consciousness and focal impaired consciousness seizures]. I chose to volunteer for Epilepsy Action because of the huge difference the Talk and Support Groups made to my life, being and talking with people who knew how I felt and sharing how we all dealt with our epilepsy."

For Koletta, volunteering has been both a boost to her skills and a way to give back. She said: "My partner has epilepsy and I realised how lonely it can be. I really wanted to give back to the community and do something new to my job in marketing. The Befriending Volunteer Role felt like a good fit – gain active listening skills and support others who might feel lonely."

Chloe is committed to raising awareness of epilepsy. She says: "I have epilepsy myself and also have family and friends who have a connection to epilepsy. I have a group to raise awareness for epilepsy on Facebook called "no cause no cure epilepsy awareness" so then people feel like they are not alone and I've gained friends all over the world."

Chloe says volunteering has given her "confidence for the possible future", explaining: "Volunteering with Epilepsy Action has changed me for the better as I feel I'm making a difference and helping people."

Marnie Hartley, volunteer programme officer at Epilepsy Action, said: "Thank you once again to all our incredible volunteers. Your commitment to volunteering is helping us create a world without limits for people with epilepsy. We look forward to working on more fun and exciting projects with you in the year ahead and beyond."

If you're interested in volunteering for Epilepsy Action, you can find available opportunities at **epilepsy.org.uk/volunteer**

VOLUNTEERS' WEEK


Fay


Koletta


Chloe


Paul

Anniversary celebration at the House of Lords

To mark Epilepsy Action's 75th anniversary, 120 people attended a special afternoon tea at the House of Lords on Wednesday, 2 July, hosted by Epilepsy Action's Honorary President Baroness Margaret Ford.

At the event, legacy donors, in-memory fundraisers, major donors, corporate partners and MPs heard from Baroness Ford, Chair of Trustees Jane Riley and Epilepsy Action chief executive Rebekah Smith. They explained why now, already a year into our six-year strategy, is a significant time to be a supporter of the charity.

Rebekah said: "Already, we've launched new counselling services in Northern Ireland and Wales, a befriending service that started in 2023, and our helpline continues to be the most used in the UK — a lifeline for so many.

"We're also embracing the power of digital. It means that wherever someone lives, they can access our trusted information and join our support groups virtually. Today, over 36,000 people regularly support us, and more than 200,000 regularly engage with us. And through partnerships — like our joint membership with the Epilepsy Specialist Nurses Association, and our role as a founding partner of the Epilepsy Research Institute — we're making sure that every advance in research can translate into real improvements in people's lives."

Rebekah championed all the policy and campaigning work achieved by the charity, including the recent successful Don't Take the PIP campaign and ensuring people with epilepsy were prioritised for vaccines during the COVID pandemic. She also highlighted the charity's efforts to break into new spaces, including working with the writers and actors of Coronation Street on storylines based on a new character diagnosed with epilepsy.

Attendees were given an early peek of a new video, featuring Geoff's story sharing how Epilepsy Action has helped him.

Thanking everyone for their support, Rebekah said: "Every experience shared chips away at ignorance, chips away at stigma, and helps us get closer to that world without limits for people with epilepsy."

Befriending service sign-ups open!

The Epilepsy Action befriending service is open for sign-ups now. If you are someone with epilepsy or a family member to someone with the condition, you can sign up to be matched with a friendly volunteer for regular chats online or by phone.

The service aims to offer a friendly ear and give people someone to talk to. Anyone affected by epilepsy living in the UK and aged 18 or over can sign up for it. The team will match you with a volunteer befriender and you will be able to have weekly calls over the course of three months to chat about anything you like.

As well as being able to chat with a volunteer and build a connection around shared interests, the service will aim to help you gain confidence and self-worth and build new social connections in your community.

Kayleigh, who completed the service, said: "I had my doubts at first, but I'm so thankful I went through with it.

"Having someone to talk to that could help me understand what was going on with my condition and the feelings I was having because of it was great for my mental health."

You can sign up by **calling 0113 831 5678, emailing befriending@epilepsy.org.uk** or by **visiting epilepsy.org.uk/befriending** and filling out the form.

PIP U-turn in welfare bill shortly before it is voted in by Parliament

The government's contentious welfare bill was voted in by Parliament on 1 July, after a concession made last minute to take out any reform to personal independence payment (PIP) until after the Timms Review of the PIP Assessment has been carried out.

The Universal Credit and Personal Independence Payments Bill stirred up controversy over the stringent cuts to welfare benefits proposed by the government.

More than 120 Labour MPs threatened to block the original bill, forcing Prime Minister Sir Keir Starmer to make a concession, allowing current claimants to remain unaffected by the cuts.

Earlier today, 39 MPs signed a fresh bid to block the bill, amid criticisms that it will create a two-tier system and an "unequal future" for people.

Shortly before this evening's vote, the government made its latest change to the bill which was debated in Parliament.

Epilepsy Action has been campaigning against the plans, highlighting that many PIP recipients are in employment and use the support to life and work safely.

Of the news, the organisation said it will push for people with epilepsy to be represented in the forthcoming PIP review.

Daniel Jennings, senior policy and campaigns officer at Epilepsy Action, said: "The government announced that it has passed its new welfare bill, but last-minute changes mean PIP will not be affected for now.

"While we appreciate the changes made to the government's initial plans and are pleased that people with epilepsy will continue to get this essential support, the last-minute climbdowns and amends have been quite a shambles and have cost people with epilepsy a lot of stress and anxiety. The opposition to the cuts to such key benefits has been strong and clear for weeks.

"Thank you to everyone who took part in our Don't Take the PIP campaign, and to the MPs who voiced their concerns in parliament over the past few weeks.

"We will now push for people with epilepsy to be represented in the Timms review around PIP, to ensure their voices are heard. As the largest hidden disability community in the UK, people with epilepsy must be consulted as part of any welfare reforms. For too long people without visible disabilities have had their PIP claims unfairly rejected.

"This isolates people both financially and socially. We must change that. It must change now."

ILAE updates how seizures are classified

The International League Against Epilepsy (ILAE) has updated the way it classifies epileptic seizures.

The new classifications include four classes and 21 different seizure types.

The four classes are: focal, generalised, unknown and unclassified.

Seizures in the focal or unknown groups are then also classified by whether the person loses consciousness (impaired) or doesn't (preserved) during the seizure. The generalised seizure group will include absence seizures, generalised tonic-clonic seizures and other generalised seizures, which will now include negative myoclonus as seizures (when the muscles stop tensing for a moment, and the person briefly loses muscular tone). Seizures can then be further classified using visible signs and movements.

The new classifications will help clinicians describe seizures more accurately, but people can still use the terms they're comfortable with.

All Wales health boards failing to meet first seizure treatment standards

Every single health board in Wales is failing to meet waiting time guidelines for treatment after a first seizure, a new report by Epilepsy Action Cymru shows.

The guidelines, set by the National Institute for Health and Care Excellence (NICE) say people should have a follow-up within two weeks of having their first seizure. However, according to the Seizing Change report, launched on 17 June at the Senedd, this standard is not being met anywhere in Wales.

Some patients, like those served by the Hywel Dda health board, are waiting up to 36 weeks to be seen – the longest waiting time on record.

The report is calling for urgent change and investment into epilepsy services.

Furthermore, more than two in five people (43%) are not being referred to any kind of specialist treatment after a seizure.

The report also warns that Wales is facing a neurology workforce shortage, with not enough specialists to give patients the care they need, Epilepsy Action Cymru says.

There are only 17 full-time epilepsy specialist nurses (ESNs) in Wales for the 36,000 people living with epilepsy. This equates to more than 2,000 patients per ESN, when epilepsy charities recommend a caseload of around 250–300 patients per ESN.

There are also only 12 specialised neurologists for that population.

Some improvements have been made since 2022, with more staff recruited at the Swansea Bay and Cardiff and Vale health boards.

However, Epilepsy Action Cymru says there is still a pressing need for investment into the workforce and improvement of healthcare pathways for people with seizures and epilepsy.

Janet Paterson, Wales manager at Epilepsy Action, said: “There is still so much to be done to reach the right level of care for people with epilepsy in Wales. We’re nowhere near where we need to be.

“Since 2022, when we highlighted the workforce crisis facing NHS neurology services in Wales, we’ve managed to get the Senedd’s attention on the issue, securing a dedicated debate.

“But while some progress has been made and some new staff recruited, it’s clear this hasn’t been fast enough or at all.

“Too many patients keep telling us they’re waiting months for an appointment, or they can’t get a hold of a neurologist because they have too many patients.

Sioned Williams MS and Becci Smart, with Epilepsy Action’s Janet Paterson and Daniel Jennings

“And the data speaks. It’s practically impossible to serve a population of over 30,000 people with epilepsy with a dozen specialists.

“Not just this, Wales has a higher rate of incidence of epilepsy than the rest of the UK and the epilepsy population is growing, but services continue to be underfunded and, very obviously, not meeting the standards. This needs to change. Now.”

Seizures on Corrie

Coronation Street has revealed new character Brody Michaelis (Ryan Mulvey) has epilepsy, after the youngster has experienced several seizures on the famous cobbles.

Brody had his first on-screen seizure in early June outside of the Rovers Return. In another episode, he had a seizure in the security training centre (STC) after his medication is taken away.

Scriptwriters received support and information from Epilepsy Action on how to represent epilepsy and seizures accurately.

Mental health and epilepsy

More than four in five people with epilepsy reported mental health challenges as a result of their condition, the latest My Neuro Survey from the Neurological Alliance.

The patient experience survey, published on 25 June, showed sustained problems with mental health for people with epilepsy, with 84% reporting this in 2025, and 83% in 2022.

The results also highlight that people with neurological conditions are not getting the mental health support they need.

You can read more on this and other stories at: **epilepsy.org.uk/news**

Padel winners donate £2,000

A dentist and founder of a cosmetic dentist surgery in Manchester has donated £2,000 to Epilepsy Action, after winning the sum at a padel tournament in February this year.

Dr Stephen Dodd took part alongside teammate Bradley Mallia in the amateur padel tournament on the 8th and 9th of February at Rockel Padel Bristol to win the platinum final. Stephen wanted to donate to Epilepsy Action as he has a family member with severe epilepsy.

He said: “The charity has been great to my family member. He’s been in touch with the helpline several times and they’ve been so supportive to him.”

Hopes for the future

As Epilepsy Action celebrates its 75th anniversary, we look forward another 75 years and ask – what do we want to see change by the year 2100?

It's quite interesting to think back 75 years. The year 1950. It sounds almost recent in the grand scheme of things, but, actually, life was starkly different. World War II had ended only five years previously. The UK was rebuilding and recovering. In 1950 the NHS – healthcare free at the point of access – was brand new, only two years since its establishment in 1948.

At that time, life with epilepsy was also vastly different. People with epilepsy often were forced to live in communes or asylums. Myths were rife. We were still on the first generation of epilepsy medications, with phenytoin and phenobarbital as some of the most commonly prescribed options. People couldn't have MRI scans for epilepsy.

In the last 75 years, we have come a long way – more so than we might even realise. Communes and asylums are a thing of the past. In that time, we have developed more than 35 new medications for epilepsy. MRIs have

> **“Together, we have worked hard to influence positive change, and help people connect and feel more empowered around their condition”**

become routinely used in epilepsy. Technology has advanced dramatically. Epilepsy surgery has come on leaps and bounds and is safer and more precise than ever before. We can monitor seizures long term. There are now wearable devices that give an accurate picture of seizure activity in a quick download. We can stimulate the vagus nerve to reduce seizures. People with epilepsy and controlled seizures have been allowed to drive. Myths and misconceptions have reduced and steadily, life has improved for people with epilepsy.

But we still have a long way to go. Even with so many advancements, around a third of people with epilepsy still live with uncontrolled epilepsy. People still face barriers with getting and staying in work and there is still an unacceptable pay gap. It's still a challenge to get essential government support and to feel understood by society.

Another thing happened in 1950. The British Epilepsy Association – now known as Epilepsy Action – was founded on 5 September. Since that time, our organisation has worked tirelessly to support and advocate for people with epilepsy. We've fought to legally and societally end discrimination and for fairer driving rules. We established the Sapphire nurses scheme to help train more epilepsy specialist nurses, we helped to set up the Children's Epilepsy Surgery Service (CESS) and we opened a free national helpline to help inform and support people with epilepsy.

None of this could have been possible without our supporters, members, fundraisers and champions to help direct us, tell important stories and raise vital funds. Together, we've worked hard to influence positive change, help people connect and feel more empowered around their condition, and build understanding and awareness of epilepsy among the general public. Now, with a new strategy of 'creating a world without limits for people with epilepsy' as our North Star, we at Epilepsy Action celebrate 75 years and look forward another 75, to many more advancements and an even brighter future.

A little understanding

To mark the anniversary, we put the question out to you, our community. The responses were heartfelt and humble. It goes to show how little people need – some compassion and understanding – to make their lives overwhelmingly better and easier.

"Not feeling excluded," one person said. "More understanding," said another. "Awareness." "Support."

With the sky as the limit of what people could hope for in the next 75 years, all people seemed to ask for was just to be treated fairly and with empathy. Things that shouldn't be out of reach in this day and age. Employment support and understanding. Help at school. Help with transport. Being made aware of sudden unexpected death in epilepsy (SUDEP). More epilepsy nurses. Better access to services. Better understanding around mental health support. Less discrimination.

A few people also had a simple hope for the not-so-distant future. "A cure, please."

Helen Buffey is a long-time fundraiser for Epilepsy Action in memory of her son, Zander, who died in 2014. Her biggest hope for the next 75 years is very much part of the chorus of the community: "awareness and education from school age onwards, so that as adults and parents, we know what to do".

She explains: "When my son was diagnosed with epilepsy, people shied away from us. He wasn't invited to friends' houses really because the parents were worried 'what happens if...'.

"So, if more people recognised and knew what to do, they (and I) would have been more relaxed and Zander might have had a better childhood.

"As he got older, it was the same really. I was forever worried that if he had a seizure out on his own, people would think he had taken something. A lot of people would walk past and not help.

"Since Alexander died, I have been fundraising to try to help in some way to enable other epilepsy sufferers get some support, both for themselves and for the family, and to hopefully contribute to the ongoing research.

"I'm not sure how things will have changed in the next 25, 50 or 75 years, but we have moved forwards from 75 years ago, so let's pray that we have more control over this horrible condition in the future."

Practical steps forward

Forging partnerships with other organisations and companies has been a key step in expanding our services and extending our reach to even more people.

Angelini Pharma UK-I Ltd supported Epilepsy Action with a grant to expand the helpline service. Marking 75 years of Epilepsy Action, Angelini general manager Fräs Anna Andersson said:

> **“I'm not sure how things will have changed in the next 25, 50 or 75 years. Let's pray we have more control over this horrible condition”**

Helen Buffey's son Zander


Rosemarie Pardington

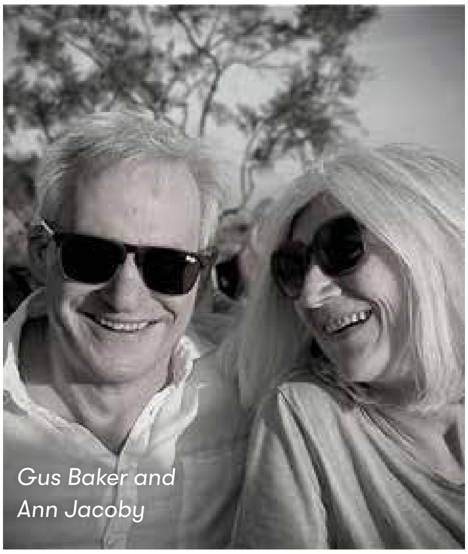
> **“In 75 years’ time, I trust we will live in a world where epilepsy is not only fully understood but entirely preventable”**

“As we celebrate Epilepsy Action’s 75th anniversary, we recognise the critical role the organisation plays in driving awareness, support and advocacy for people affected by epilepsy.

“Looking to the future, we hope to see continued investment in research that deepens our understanding of the underlying mechanisms of epilepsy, enabling earlier diagnosis and more precise, personalised interventions. We envision significant advances in data science, genetics and neurotechnology that could potentially revolutionise how epilepsy is monitored and managed.

“At the same time, we believe that stronger policy frameworks and equitable access to care must remain a priority — ensuring that innovation reaches every individual, regardless of background or geography. As a company committed to improving outcomes for people with epilepsy, we are proud to work alongside Epilepsy Action in pursuit of a future where science, society, and advocacy converge to transform lives.”

Retired professor of clinical neuropsychology and secretary general of the International Bureau for Epilepsy (IBE) Gus Baker, and retired professor of medical sociology, and former chair of the Board of Trustees at Epilepsy Action,Ann Jacoby compiled a wish list comprising advances in treatment and management, global and multidisciplinary working, greater global resources and services, and an end to stigma and equal opportunities for people with epilepsy.


Gus Baker and Ann Jacoby

They added: “It is almost impossible to predict what the landscape will look like for people with epilepsy and their families in 75 years. However, that should not prevent us from having hopes and expectations.”

ESNs Sarah and Phil Tittensor at Epilepsy Nurses Association (ESNA), added to the wish list, saying they’d love to see more ESNs to support people with epilepsy, and more coordinated services. They also championed more awareness of epilepsy through training for healthcare staff and the general public, and increased use of tech to maximise the effectiveness of epilepsy services.

Chief executive of Epilepsy Research Institute UK, Rosemarie Pardington, is thinking big and optimistic. She says: “In 75 years’ time, I trust we will live in a world where epilepsy is not only fully understood but entirely preventable.

“Due to the increased focus on research in the previous years, advances in neuroscience, genetics and precision medicine will have unlocked the underlying mechanisms of every form of epilepsy, allowing for early detection, prevention and personalised treatments.

“Alongside these long-awaited advances, with enhanced global collaboration and equitable access to care, no individual, regardless of their age, background or geography will live with the uncertainty or stigma that once surrounded the condition. I am optimistic for a future where living seizure-free is the norm, and epilepsy is a challenge of the past, overcome by the relentless united endeavours of clinicians, researchers and scientists world-wide.”

Awareness far and wide

Jane Riley, chair of the Board of Trustees at Epilepsy Action, is determined to promote more acceptance and understanding for people with epilepsy. She says progress so far has been tangible, but more is needed – and quickly – for the future. She explains: “We need rapid growth in awareness and support across the UK now more than ever, with our difficult economy and challenging, overwhelmed systems of health and social care.

“We need to educate and inform as widely as we can and be seen and heard in every corner of the country. I feel we need to ensure schools, higher educational institutions and workplaces are all ‘epilepsy-friendly’ have full understanding of the impact of seizures and the lifestyle considerations that generally need to be made. People with epilepsy, and sometimes their carers and loved ones, can suffer enormously from significant mental health conditions and psychological help needs to be readily available for all, without exception.

“These are just some of my personal thoughts as chair of the Board of Trustees, but also as a mother. We need to continue

Jane Riley and her son Matthew

our journey, deliver our strategy and make the next 75 years a time where people with epilepsy can live their lives without limits.”

Baroness Margaret Ford has been Epilepsy Action’s Honorary President since 2008, helping to represent the charity in Parliament and with launching campaigns. Thinking of the next 75 years, she is also hoping for more awareness from employers, as well as better care and support. She said: “My hopes would include more specialist clinicians who really understand epilepsy in all its complexity.

“I also want to see better understanding of the needs of parents with young children with epilepsy. Early education and support for parents and carers is essential in providing children with epilepsy with the best possible start. Parents need to know what they can expect for their child and how best to advocate for them.

“I also want to see better understanding from potential employers. People with epilepsy have so much to contribute and yet we know that stigma still surrounds the condition – especially when it comes to employers. Having a job is such an important part of wellbeing and contributes so much to healthy self-esteem that we must continue to campaign for better education and understanding from employers.”

Meanwhile, consultant neurologist and chief medical adviser of Epilepsy Action’s Epilepsy Professional magazine Rhys Thomas says: “For me the epilepsy specialist nurse (ESN) is inarguably the greatest innovation in UK epilepsy care over the last 75 years. More than just clinicians, ESNs are lifelines, providing expertise, advocacy, and a reassuring human connection at the most uncertain moments.

“Their impact is measurable: better seizure control, fewer emergency admissions, improved mental health, and empowered patients who feel seen and heard. ESNs remind us that the most powerful tool we have is expert, compassionate, consistent care.

“In [another] 75 years? No one with epilepsy should feel lost or unsupported.”


Baroness Margaret Ford


Rebekah Smith

Fulfilling our purpose

We can – and should – dream big for what the next 75 years hold. Hope for epilepsy to be as well-known and understood as the common cold. Hope for a cure, for prevention. And while we take leaps towards that, you can rest assured that we’re not going anywhere.

> **“I want to see better understanding of the needs of parents with young children with epilepsy. Parents need to know what they can expect for their child and how best to advocate for them”**

> **“Our mission is unwavering: to provide ever more personalised, compassionate support to everyone affected by epilepsy, and to empower the healthcare professionals who support them”**

Epilepsy Action chief executive Rebekah Smith has the final word: “I’m hopeful that the next 75 years will bring much greater strides in overcoming epilepsy than has happened over the last 75 years. As our knowledge of the brain deepens and technology continues to break new ground, I believe we are moving to a future where no one will have to live with epilepsy. Perhaps, in 75 years’ time, there will be no need for a charity like Epilepsy Action, because the condition itself will be a thing of the past.

“Until that day comes, our mission is unwavering: to provide ever more personalised, compassionate support to everyone affected by epilepsy, and to empower the healthcare professionals who support them. Equally vital is our commitment to ensuring the world truly understands epilepsy: breaking down misconceptions and building a society that embraces and supports those living with it. This will always be at the very heart of what we do.

“In the nearer future, we need bold leadership from the Government to invest significantly in epilepsy research, so that Epilepsy Action can turn groundbreaking discoveries into tangible quality improvements in care and support.

“If, within the next decade, people with epilepsy can say that the only limits on their lives are the ones they themselves choose, not those imposed by their condition or by society, then we will know we have truly fulfilled our purpose.”

Laps for Lennon

Jess shares the story of her one-year-old son Lennon's difficult time with his epilepsy and why she wanted to fundraise for Epilepsy Action. Words by Emily Stanley and Kami Kountcheva

Lennon was aged just one at the time when he'd been through a number of medical procedures that most people wouldn't experience in a whole lifetime.

"As of now, Lennon has had a CT scan, an MRI, two lumbar punctures, three EEGs, a multitude of blood samples taken, three prolonged states of status epilepticus, three induced comas, an intensive care stay and two allergic reactions," recalled Jessica McRae.

The 25-year-old mum from Liverpool said her son Lennon has become her "biggest inspiration in life", showing resilience through a really difficult year for the family.

Lennon had his first seizure at six months old. "It was petrifying to see him in that state," Jess said. "Still to this day, when he is seizing, my heart breaks knowing there is nothing I can do to take it away from him."

Lennon's seizures were initially diagnosed as febrile seizures, even though only his first tonic-clonic seizure happened when he had a high temperature. Then, in September last year, Lennon went into a prolonged seizure – status epilepticus – that lasted 53 minutes. None of the usual treatments for status epilepticus were working, so Lennon had to be put into a medically induced coma.

Jess said: "Seeing Lennon in these states can only be described as soul-crushing. Seeing my 10-month-old baby boy lay there lifeless, with tubes everywhere… I can't put that feeling into words. It has been horrific."

Lennon recovered and was sent home without a diagnosis or any medication, even though he continued to have seizures. What used to be tonic-clonic seizures changed, over time, to include more different seizure types including long absence seizures. In December, at just 12 months, he went into status epilepticus

> **“Seeing my 10-month-old baby boy lay there lifeless, with tubes everywhere... I can’t put that feeling into words. It has been horrific”**

again, which lasted 23 minutes. He had to be put onto breathing support and a second induced coma.

After the doctors tried to wake him up from this coma, he started having seizures again and was placed in a third induced coma. Jess and Lenon’s dad noticed that he was changing colour and looking swollen. He had an allergic reaction to one of the many medications he was on, so he had to be taken off everything – and quickly. When he woke up, Jess explained he was like a different child to the happy boy she knew.

“He was a ball of anger, clawing at himself, causing marks, constantly screaming and clearly in a lot of distress,” she said. It turned out, because of how quickly the medication was stopped, he was suffering from withdrawal. To the family’s distress, Lennon had stopped being able to move and communicate like he used to. The medical team said it could be the sedative medication waring off and to give it a few days.

Jess continued: “After Lennon did not make any improvements in the following 72 hours, he was taken for his first EEG. This is where we finally got confirmation of an epilepsy diagnosis.

“Lennon was still immobile at this point and still unable to communicate with us in any other way than a cry. This, in itself, was extremely distressing to see, as Lennon was always so advanced in his development. So, seeing his brain go back to the state of a five-month-old’s was horrific for us.

“He couldn’t sit, stand, talk, walk, he lost all mobility and communication. Lennon ended up being in hospital over Christmas and New Year. We were in for almost a month. On Christmas day, Father Christmas visited Lennon in his bed but the only thing he had the ability to do was look at him. It was heart-breaking to watch him unable to participate in the Christmas fun.”

Having been through so much already, this is when Jess began to see the amazing strength and resilience her little boy had. After another allergic reaction, more EEGs and a change in medication, Lennon began to recover and slowly gain back his mobility and communication.

“Despite this life-altering diagnosis, it has brought me and the family some relief having an answer,” Jess said. “Lennon is now on a different medication and is much more like himself.

“Lennon’s dad and I provided a blood sample to test for genetic epilepsy. If it turns out to be genetic, we will be able to test Lennon’s younger brother for epilepsy, but we are yet to hear back from this.”

Throughout this extremely stressful and confusing time, Jess and the whole family were able to access a lot of helpful information from the Epilepsy Action website. She said: “We’re still very new to epilepsy and that is why the Epilepsy Action website (www.epilepsy.org.uk) has been so helpful.

“New things are presenting in Lennon’s epilepsy all the time and this is another reason Epilepsy Action’s resources have been so helpful. The charity has also helped me to see that I am not alone, and it has inspired me to show as many families in my position as possible that they are not alone either.

“This is why I want to give back to Epilepsy Action and raise awareness of the condition.”

Earlier this year, Jess did a 10km walk with friends, family and medical professionals to raise money for Epilepsy Action, marking Purple Day. The group completed the 10km in Sefton Park.

Philippa Cartwright, director of fundraising at Epilepsy Action, said: “Lennon has been through so much, and is such an inspiration at such a young age. We are so glad that Epilepsy Action has been able to help Jessca and her family throughout this tough journey.

“We’d like to say a big thank you to Jessica and the team for supporting us and for sharing Lennon’s powerful story.”

Jess said: “I am so thankful to everyone who joined us for our 10k walk, including Lennon’s family and friends, as well as a few people who Lennon met whilst in hospital.

“The sun was shining and we even fed some geese at the end – it was a magical day from start to finish. Thank you for all the support we have received through Lennon’s journey, and I can’t wait to do some more fundraising in the future for such an amazing cause.”

Merrily on high

Take an early peek and start planning for a stress-free festive season

Welcome to Epilepsy Action's 2025 Christmas collection!

It might feel early, but there's no better time to start planning for a stress-free Christmas. Whether you're getting ahead on your Christmas cards or finding the perfect gifts, we hope you'll find everything you're looking for to help you celebrate this festive season. By choosing our cards and gifts this Christmas you are helping us to create a world without limits for people with epilepsy.

Our Christmas elves are eager to get your order to you. To ensure you receive all your items in time for Christmas, please place your order by Friday 12th December 2025.

Wishing you a joyful lead-up to the festive season!

How to order

You can place your order:

- **Online** (with more choice available): charitycardshop.com/epilepsyaction
- **By phone**: 01227 811 633 weekdays between 8.30am to 5pm (4pm on Fridays)

Post and packaging costs

- **Orders up to £15.00** - £3.75
- **Orders from £15.01-£30.00** - £4.75
- **Orders over £30.01** - Free

We dispatch all orders as quickly as possible but please allow 14 days for delivery. The last date to order is **Friday 12th December 2025**.

Christmas Essentials

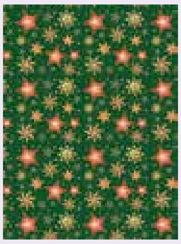
We are sure you will find everything you will need to make the Christmas period run smoothly in our Christmas Essentials collection. We have a range of designs of wrapping paper, money wallets and even some traditional picture advent calendars. You can view our full range online in the Christmas shop but we have included a few of our favourites below.

Each gift wrap comes with four sheets of 500mm x 700mm and includes four gift tags of the same design.

The Christmas gift cards come with a white envelope and are perfect for enclosing gifts like money or a lottery ticket.

A pack of gift labels comes with four sheets of 12 (48 in total) self-adhesive labels.

Christmas gift wrap - £2.75

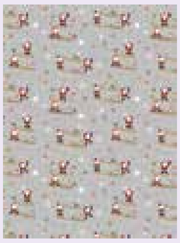

1. Red and Gold Stars


2. Stars and Crackers


3. Robins and Stockings

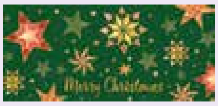

4. Neon Trees


5. Festive Food


6. Happy Santas

Gift wrap, gift cards and labels available in matching designs

Christmas gift cards – £2.00

7.


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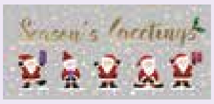

eCards

We now have an exciting range of everyday and Christmas eCards available to purchase in our online shop, which are great for helping the environment and saving money on postage costs.

eCards are easy to order and you can specify the time and date you want your friends and relatives to receive their card.

Our eCards are available to purchase with a minimum donation of £1.00 and 100% of your donation when purchasing the eCard goes directly to Epilepsy Action.

You can find more information on how to use our eCards by visiting our online shop at **charitycardshop.com/epilepsyaction**.

19. Large, traditional advent calendar with Bible text and a Christmas icon behind each window. Comes with a red envelope. Size: 220mm x 310mm.

Gift labels – £1.50

Christmas Cards

We have a fantastic range of 12 Christmas Cards available this year, with a variety of designs including lovely winter landscapes, traditional Christmas illustrations and adorable festive animals. All of our Christmas Cards come in a pack of 10 cards and envelopes unless otherwise stated.

20. Santa's Visit - £4.25
Greeting: Merry Christmas and a Happy New Year
126mm x 126mm

21. Winter Lake - £4.00
Greeting: Merry Christmas and a Happy New Year
126mm x 126mm

22. Jolly Geese - £4.25
Greeting: Merry Christmas and a Happy New Year
126mm x 126mm

23. At the Stable - £4.25
Greeting: Merry Christmas and a Happy New Year
126mm x 126mm

24. Snowy Stag - £4.50
Greeting: Season's Greetings
140mm x 140mm

25. Festive Flock - £4.25
Greeting: Season's Greetings
126mm x 126mm

26. Twinkling Tree - £4.25
Greeting: Merry Christmas and a Happy New Year
126mm x 126mm

27. We Three Kings - £4.25
Greeting: Merry Christmas and a Happy New Year
126mm x 126mm

28. Santa's Snow Wish - £4.00
Greeting: Merry Christmas and a Happy New Year
126mm x 126mm

29. Morning Service - £4.50
Greeting: Merry Christmas and a Happy New Year
126mm x 126mm

30. Stars Over London - £4.50
Greeting: Season's Greetings
140mm x 140mm

31. Dachshund Through the Snow - £4.25
Greeting: Merry Christmas
126mm x 126mm

If I told you, would you stop inviting me out?

If I *told* you

Epilepsy Action's new awareness campaign, focusing on friendships, relationships and work, aims to foster better understanding and empathy for people with epilepsy.

Words by Kami Kountcheva

> “People say they're supportive at first, but when they're faced with the realities of what it means to employ someone with epilepsy, that support can fade fast”

A new awareness campaign, launched this week, is shining a light on the discrimination people with epilepsy often face around friendships, dating and work.

Epilepsy Action's ‘If I told you...’ campaign features three short films showcasing the fear people with epilepsy can feel around how revealing their condition could affect their life.

The campaign aims to build more understanding and empathy around epilepsy in members of the public, as new survey results show this is still a problem.

The new Epilepsy Action research of around 2,000 people in the UK found that almost half of respondents (48%) said they were uninformed about epilepsy.

The findings showed that more than three-quarters of people (77%) thought people with epilepsy were a risk to themselves or others. Nearly two in five (39%) thought those with epilepsy can't handle work or responsibilities and a third (35%) assumed they need constant supervision or protection.

One in five people (20%) assumed that people with epilepsy are mentally unstable.

Rebekah Smith, chief executive of Epilepsy Action, said the data demonstrate that there is still a lot of work to do. “Too many people are still uncomfortable with epilepsy – even if it was to affect a potential partner, a friend or a colleague,” she said.

“We want to shift the conversation from fear to understanding, from avoidance to action.”

The campaign features videos focused on three key areas – work, friendships and relationships. The campaign page also

If I told you, would you see me differently from everybody else?

offers tips and information to help people better understand epilepsy and know how to respond to a friend, loved one or colleague with the condition.

Dating

Over a third of respondents in the survey (36%) said they wouldn't, or aren't sure they would, feel comfortable dating someone with epilepsy. Nearly as many (37%) said their first reaction to finding out someone they were dating had epilepsy would be feeling nervous about seeing a seizure. Nearly one in 10 (9%) admitted they would never date someone with the condition.

Twenty-nine-year-old Emma Dearling from Surrey, had to deal with the breakdown of her six-year relationship while also trying to get to grips with a new diagnosis of epilepsy. She said: "I wasn't who I used to be anymore – and he couldn't handle that.

"He also couldn't tell me the truth. It wasn't until a year after we'd broken up that I found out he'd been cheating for the last six months of our relationship – right when I was newly diagnosed and trying to get my head around this massive life change."

Emma is now forthcoming about her epilepsy straightaway, and it's led her to finding a healthy relationship. She said of her current partner: "There was no hesitation. He wasn't fazed at all. He cared about me, not my diagnosis. Going through everything together has brought us even closer."

Work

The survey revealed that nearly a quarter of people (23%) would worry about health and safety risks when hiring someone with epilepsy. More than a quarter (27%) believe the condition could impact people's ability to do certain jobs or tasks. Data from a previous survey show that 60% of people with epilepsy said they had faced discrimination at work.

Ciara Smyth, 29, from Weston-super-Mare, has had exactly that kind of experience in a previous job. She believes in being open about her epilepsy, telling her employers about it from the start. However, in a former role, despite things starting well, Ciara was then asked to work from home because some colleagues felt "uncomfortable" in case she had a seizure at work.

Despite clear reports from occupational health stating she could work safely in the office, she was excluded from normal routines and even prevented from taking part in key parts of her role.

She said: "People say they're supportive at first, but when faced with the realities of what it means to employ someone with epilepsy, that support can fade fast."

> **"There have been many events I haven't attended out of fear of having a seizure and ruining things for everyone else"**

Friendships

In the latest survey, one in five people (20%) said they would feel nervous about seeing a seizure if a friend disclosed to them that they had epilepsy. Among people with epilepsy, nearly nine in 10 people (87%) said they have felt anxiety, depression and isolation on top of having to manage their condition.

"There have been many events I haven't attended out of fear of having a seizure and ruining things for everyone else, especially on momentous occasions," said Erin Davies, 30, from Belfast.

"At this time in my life, a lot of friends are getting married, having hen parties and baby showers. As much as I want to be involved, I'm conscious of ruining these significant occasions. It's sometimes as disappointing to them as it is to me and that's not a nice feeling."

Erin has ended up withdrawing from social occasions and feeling awkward and inadequate.

She said: "I'm afraid of the fact that it seems to make people around me feel uneasy. I know it's only out of concern for my wellbeing that my friends are acutely aware of my patterns and behaviours, but I am not epilepsy. I'm Erin."

Having real conversations

Rebekah added: "In our short film, we wanted to take people inside those silent, vulnerable moments. To get them to understand how people with epilepsy feel when they're about to go into an interview and fear their condition will mean they won't get the job, even if they're fully qualified.

"When they're dating someone they really care about, but are afraid they'll leave if they reveal they have epilepsy.

"When they have to tell their friends they can't go on that night out because they've just had a seizure, but are scared they won't understand.

"Epilepsy affects one in 100 people in the UK. They should be able to talk to a potential partner, a friend, a colleague, a prospective employer about their condition. They shouldn't fear they will be discriminated against, cut off from their friendship group, broken up with or treated differently because of something they can't help. They shouldn't feel they have to hide.

"So, let's start having real conversations. Today. Let's not leave people with epilepsy wondering what would happen if they told us."

You can find out more about the 'If I told you...' campaign by visiting: **epilepsy.org.uk/if-i-told-you**.

21 years of doodles

National Doodle Day is celebrating its 21st anniversary on Friday 26th September.

Words by Michael King

National Doodle Day brings together hundreds of artists, illustrators and celebrities to create original artworks, which will be auctioned across a 10-day period from 26th September to 5th October via eBay. We are incredibly grateful to have the support of iconic names such as Sir Ian McKellen, Dame Joanna Lumley, Sir Grayson Perry and Alice Oseman getting creative to raise funds.

Last years campaign generated over £30,000 via the sale of 550 original A5 artworks, and this year we are hoping to make this even bigger – with some really exciting accompaniments to this year's event.

Although we are very grateful to have the support of so many huge names in the world of film, TV and art doodling, the continued success of National Doodle Day is only possible due to the involvement of the hundreds of independent artists and illustrators who create artworks for the auction each year. This is a project open for anybody creative to get involved, so to request a National Doodle Day pack, just email doodle@epilepsy.org.uk with your best postal address to receive one in the post.

Be sure to follow @NationalDoodleDay on Instagram to keep up to date with all the latest news about our most colourful campaign of the year!

> **“R.W. Alley will be returning to host a virtual session on Friday 26th September at 7pm to teach us step-by-step how to draw our own Paddington Bear”**

We're giving away just a little pixelated teaser of the doodles by these famous faces. To see these doodles and more, follow @NationalDoodleDay on Instagram.

Olivia Colman x Epilepsy Action

Olivia Colman stars in her best role yet… merchandise designer!

Olivia Colman CBE is an Academy Award, BAFTA, Primetime Emmy and Golden Globe-winning actress, best known for her roles in projects such as Fleabag, The Favourite, Broadchurch, Paddington in Peru, Wonka, The Crown and Heartstopper.

To celebrate Epilepsy Action's 75th anniversary, Olivia has very kindly designed a range of merchandise to raise funds, which includes a T-shirt and tote bag!

These are available to pre-order now, with T-shirts available for £25 and tote bags for £12.50, which will be dispatched beginning in September.

Everybody who pre-orders an item of the Olivia Colman x Epilepsy Action range before **15th August** will be entered into a prize draw to win a hand-signed tote bag from Olivia herself!

This range of merchandise is strictly limited edition so once they're gone, **they're gone**.

Pre-order now at: **epilepsy.org.uk/olivia-colman-x-epilepsy-action**

Doodlers Digest to launch this October

With 87% of people telling us epilepsy has affected their mental health in an Epilepsy Action survey from 2023, we've decided to create an exciting resource to help combat that. However, we also thought we'd put it out to the wider world as an excellent item to receive every month.

Doodlers Digest is a 12-page monthly puzzle book, which is full of activities all centered around mindfulness and taking some time out to focus on your mental wellbeing. These activities will feature things such as puzzles, colouring pages, drawing prompts and much more!

For a £10 per month donation, you will receive this booklet via post each month, with all the proceeds going directly to Epilepsy Action, and you can register for the first edition NOW. Visit: **crowdfunder.co.uk/p/ea-doodlersdigest**

R.W Alley will once again be teaching us how to draw the paw-fect Paddington Bear

R.W. Alley is the longest serving illustrator of Michael Bond's beloved Paddington book series, and we are thrilled to say that he will be returning to host a virtual session on Friday 26th September at 7pm to teach us step-by-step how to draw our own Paddington Bear, followed by a live Q&A.

Tickets are available via the Epilepsy Action website for just £5, and the session will be recorded for all ticketholders, so no need to worry if you aren't able to attend live.

So, grab your pens, pencils and marmalade sandwiches, for what we promise will be a wonderful evening.


Becci Smart


Susan Jamison


Susan Cole

STILL WAITING

Becci Smart, Susan Jamison and Susan Cole describe what life has been like for their families affected by the valproate scandal and why a redress is now urgent and essential

Words by Kami Kountcheva

“It was really obvious from the moment he was born that something wasn’t right,” says Becci Smart. “He was born floppy, he was jittery, he was lethargic, he was irritable. He couldn’t suckle.”

Becci had been taking sodium valproate when she fell pregnant unexpectedly with her son Zak. She was advised by her neurologist to take a higher dose of folic acid and that that would make the risks of epilepsy medication in pregnancy the same as in the general population.

However, Zak was born with foetal valproate syndrome (FVS) and a number of health challenges as a result.

Today, Zak lives with physical challenges, including malformations in his hands, hypermobility causing problems with his legs, flat feet, overcrowding of his teeth and “the classic features of someone affected by FVS.” He has also been diagnosed with autism spectrum disorder (ASD) and doesn’t like to be touched.

Thousands of families like Becci’s have been affected by the sodium valproate scandal. This medication, often very effective for managing epilepsy, carries a risk to babies if taken during pregnancy.

While this was known since the 70s, for decades it wasn’t communicated to women with epilepsy. Over the years, this omission has caused harm to thousands of babies and changed the course of life of thousands of families.

Anyone worried about valproate should continue to take their medication as prescribed and ask to speak to their specialist urgently.

The right options

Susan Jamison took valproate while she was pregnant too, without being made aware of the risks to her babies. She had three children, all affected by valproate.

Susan explains that, looking back, her eldest daughter had signs at birth, including the classic facial features of FVS. She says she was hard to settle as a baby and her learning was affected. Her son also struggled growing up and attended a range of paediatric health services.

But she says her middle daughter, Anna, is worst affected. Anna has been diagnosed with ADHD and autism, and also has epilepsy and learning difficulties.

Susan says: “I feel, actually, still to this day, extremely angry about it. I carry an awful lot of guilt, because if I had the right options, I could have made different choices.”

The gaps

Susan Cole’s younger daughter, Hannah, was also affected by sodium valproate. Susan explains: “I really distinctly remember in hospital trying to bathe her and I had to get my brother to help me hold her because she was so floppy that she couldn’t hold herself up. I know babies can’t hold their heads up, but she was like a dead weight.

“So obviously there was something wrong then and it just went on and I was never really told exactly what the problem was.

“At her first birthday party, a friend

of mine came over and I said, 'You know what, I'm a bit worried about her', and she said, 'I think you should be, I think you should see a doctor about it.'

"You can only see these things looking back, you can just see the gaps. You can just see the moments when you were in a doctor's office or you can remember these times when people could have said things, but they didn't."

Over the years, without explanations or accountability from authorities, women have had to chase answers, campaign tirelessly and deal with intense guilt over what has happened to their children.

Still waiting

Then, on 8 July 2020, the Independent Medicines and Medical Devices Safety Review was published by Baroness Julia Cumberlege. It was called 'First Do No Harm', and it looked into three medical scandals, one of which was sodium valproate.

In it, Baroness Cumberlege detailed "heart wrenching stories of acute suffering, families fractured, children harmed and much else", as well as making recommendations for the government going forward.

One of these was around a redress for the affected families. She said: "Patients have waited far too long for redress. Any scheme must be set up promptly."

It's been five years since the report was published and people affected by valproate are **still** waiting for redress.

Last year, the Hughes report was published by the Patient Safety Commissioner, setting out options for financial and non-financial (such as housing, healthcare and social security) redress.

The government has not officially responded to the Hughes report. In response to a question to the health minister, the government said it is "carefully considering" the Hughes report, but that it is "not currently able to give a timeline for a response".

Waiting for the light at the end of the tunnel

Epilepsy Action has called the lack of compensation after two reports a "scandal", adding that this has "gone on long enough".

Rebekah Smith, Epilepsy Action chief executive, said: "It is a scandal that as far back as 35 years, thousands of women with epilepsy weren't being told about the risks involved with taking valproate in pregnancy when evidence was mounting. These women have had to live with the reality of that for decades and the huge emotional and financial impact it has on their lives.

"It is also a scandal that two reports in the last five years have recommended that families be compensated for the ordeal and yet those affected are still waiting for the light at the end of the tunnel.

"These families don't have another 35 years to wait for redress to happen. With each year that passes, it costs families affected around £30,000 a year to support their now adult children, with many needing 24-hour care.

"They need closure, the acknowledgement of how they were let down and the means to be able to move on with their lives. Many families are now in their 60s and 70s and are understandably very concerned about who will be there to look after their children when they have gone.

"It's time the government really sees them now and acts on the recommendations set out five years ago."

Stability, acknowledgement and respect

After so many years since the scandal began, a redress is not just a gesture people are asking for but is absolutely essential for families affected.

Becci says: "I sit and think about Zak's future. I'm not going to be here forever. What is his future going to look like? What is his health going to look like in 10- or 15-years' time if healthcare professionals are dismissing him now when I'm sat in the room with him? How is he going to manage when I'm not here?"

"I think, for me, a redress would just mean knowing Zak would be stable in the future.

"Knowing that he's got something there for when I'm not around or for when I'm older, when I can't care for him, is really important to me."

For Susan and Anna, there's been a lot of suffering for the family due to the effects of valproate.

Susan says Anna will always have to live with her and will always need support. "Financially, for the children, they definitely need financial redress because parents are getting old. We won't be around [forever] and the children definitely need the money so they can move on in life.

"I would love an acknowledgement of somebody saying, 'Sorry, no, it wasn't your fault. You didn't get the right information. You should have got the right information, but we didn't give it to you.' And I'd love to know why they did not tell us."

Meanwhile for Susan Cole, words are empty, and all she wants to see is helpful action that will help her and her family to support Hannah. Susan founded the organisation Valproate Victims to campaign for justice for the thousands of families affected by the valproate scandal.

From starting campaigning in 2002, Susan has delved into the science and the research, raised awareness with her local GP, built a legal case, attended meetings with government bodies and protested side by side with other affected families.

She says: "What matters is what we are provided with now in terms of financial and non-financial redress. Words mean absolutely nothing to me.

"We need redress with respect and we need to be part of the process of designing any redress scheme."

You can find out more about the campaign at **epilepsy.org.uk/valproate-campaign**


Zak and Becci


Susan Jamison and Anna

Just grateful

As we begin our ThankFest campaign to show our gratitude to those who have supported us over the years, we share Geoff's story as a shining example of the good you've done.

Words by Jaimie Kay

This year marks a remarkable milestone — Epilepsy Action's 75th anniversary. And we couldn't imagine commemorating it without you, our incredible members.

As part of our celebrations, we're thrilled to invite you to our very special ThankFest — a heartfelt campaign dedicated to recognising the unwavering support of people like you. So, the first huge 'thank you' goes to you. Your generosity, passion and belief in our mission have shaped everything we've achieved. From challenging stigma to transforming care and understanding of epilepsy, our progress has only been possible because of your involvement.

To mark the occasion, we're sharing the personal story of someone who's been part of this journey for more than half of our history. Their story is a powerful reflection of how far we've come, and a testament to what we can accomplish together. It's also a reminder that when you stand with us, you stand with thousands of others who are living with epilepsy and striving for a world without limits.

We hope ThankFest gives you the space to reflect, celebrate, and feel proud of the vital role you play in our community.

As part of this celebration, we'd love for you to share what or who you're thankful for. Whether it's a friend, a family member, a healthcare professional, or simply someone who showed you kindness when you needed it most, we invite you to share your thanks.

Please write your message of thanks on the slip on the next page, cut it out and return it to us in the Freepost envelope provided. We'll bring these messages together and share them as part of a special online thank you campaign, showcasing the voices of our amazing members and supporters and the countless reasons we have to be thankful.

Four decades of courage and community

At just 15 years old, Geoff had no idea that the course of his life was about to shift dramatically. It began with a seizure — his lips went blue and he had to go to hospital.

"That was when everything changed," he recalled.

Geoff's diagnosis of epilepsy came with all the uncertainty and fear that we know all too well. Relationships became harder to build, and daily life took on a precarious rhythm of managing medication, navigating stigma and bracing for the next seizure.

But, with the support of Epilepsy Action, he never let the condition define him. It shaped him, but it did not become all he was.

Geoff explained: "With the right support and treatment, things started to get better."

That support — steadfast and transformative — came in large part from Epilepsy Action's helpline and Talk and Support groups, two services Geoff and his parents would use consistently for more than 40 years.

Knowing the support and community were there for him, while he struggled to reconcile his condition in his teenage years, was a lifeline.

"I joined Epilepsy Action (as a member) in my early teens," he said.

"They were a great source of help —

for me, and for my mum and dad. That reassurance meant everything.”

His family, especially his parents, stood by him unwaveringly. “We’re going to see this through,” they told him.

And they did — through six-week hospital visits, countless appointments, and the everyday unpredictability of seizures.

Geoff’s father often searched for resources and solutions online, frequently landing on Epilepsy Action’s website.

There, they found a guide through to new medications, difficult side effects, and what life can and should be like for someone with epilepsy.

Epilepsy made everything harder. Education, work, social life — all came with added challenges.

Geoff described exams as “twice as hard,” and job interviews as a test of not just skill, but of courage.

“How do I tell someone I’ve got epilepsy?” he would ask himself before every interview.

Thanks to the support he received from Epilepsy Action, Geoff was able to take a direct and honest approach and face his epilepsy head on.

Geoff carved a path through higher education, earning his degree in Information Technology.

Along the way, he endured injuries from seizures, confrontations with law enforcement who mistook him for drunk, and moments of deep emotional struggle. “Why me?” he asked. But again, Geoff overcame these struggles.

“No matter what happened to me, I knew I had people to talk to, whether it be through the helpline or the Talk and Support groups I attended.”

In 2000, with help from a Job Club advisor who saw potential rather than risk, he landed a trial at a retail store.

Geoff said: “The team was supportive. If I had a seizure, someone would step in. A plan B was always ready.”

That month-long trial turned into five years of steady work.

“It was a win-win,” he said. “They got a dedicated team member and I got a chance to prove myself.”

Still, prejudice, stigma and discrimination were never far. He vividly remembered the bystanders who walked past him while he was having a seizure in central Birmingham, and the ones who assumed he was intoxicated when that wasn’t the case.

But he also remembered those who helped: a lone Good Samaritan who called an ambulance, compassionate police officers who escorted him to hospital after realising the truth, and the team at Epilepsy Action.

Geoff was able to work through the stigma, prejudice and discrimination that often comes with an epilepsy diagnosis, thanks to his consistent engagement with Epilepsy Action. As well as his continuous advocacy for people like him, people living with but not controlled by epilepsy.

That partnership with the charity matured over time — from someone who needed support to an outspoken and inspirational advocate. Geoff participated in campaigns, shared his story to raise awareness, and encouraged others to seek help rather than worry in silence.

In recent years, Geoff made another decision that underscored the depth of his gratitude. While drafting his will — something he hadn’t thought about until Epilepsy Action offered free advice on the subject — he chose to leave a gift to the charity that had stood beside him for so long.

Explaining why he left a gift in his will to Epilepsy Action, Geoff said: “It was for two reasons really. “First, I’ve got a close association with them. Second, if I leave something to a charity, I know it’ll do good long after I’m gone.”

Geoff hopes that the legacy he leaves behind will help others find the same support he did. That no one will feel as alone or misunderstood as he did in those early days. That someone else’s journey might be just a bit easier because of the path he helped clear.

For over four decades, Geoff has lived with epilepsy. But just as enduring is the relationship he’s built with Epilepsy Action — a partnership rooted in mutual respect, shared purpose, and a relentless pursuit of advocacy.

“I’m just grateful for the way Epilepsy Action helped me, being a part of this community has really improved my quality of life.

“I’m also thankful to all those who’ve supported the charity across its 75 years. If it hadn’t been for them, I know my life would have been very different.”

Geoff

Family photo of Geoff and his parents

I want to say thank you:

“ ....

....

....

.... ”

Name:

Postcode/Membership number:

☐ By returning this form, you agree for Epilepsy Action to use your message for marketing and fundraising purposes. Please tick this box if you would prefer us not to.

Treatment for the *future?*

Zoe Gude, graduate from King's College London (KCL), and Dr Antonio Valentin, Reader in Epilepsy and Clinical Neurophysiology at KCL, talk about deep brain stimulation (DBS) and its potential for the future.

Epilepsy is a common neurological condition affecting around 1 in 100 people in the UK. According to the World Health Organisation, more than 50 million people have epilepsy worldwide. However, despite the prescribed use of daily medication, approximately 30% of patients continue to suffer from seizures; this is known as a condition called drug-resistant epilepsy (DRE). Seizures occur when there is a sudden, intense burst of electrical activity in the brain.

Epilepsy is usually diagnosed after a person has had more than one seizure and other tests confirm the findings. The majority of patients, (around 70%) have seizure control given the right medication. However, some people with epilepsy (about 30%) continue to experience seizures, with only partial or no control despite medication. For those resistant to antiseizure medication (ASM) alternative treatments such as brain surgery may be considered. Research shows though, that around 30-57% of patients still won't be seizure-free after surgery. For some patients, this is because it's not possible to identify a specific area of the brain where seizures start, making them unsuitable candidates for resective brain surgery. This is where other treatments, like deep brain stimulation (DBS), alongside medication, could offer hope.

What is Deep Brain Stimulation?

DBS is a surgical procedure that uses electrical currents to stimulate specific areas of the brain responsible for seizures. This involves placing electrodes at the end of a very thin lead into that region of the brain. The lead is then connected to a pacemaker-like device, implanted under the skin near the chest or in the head. This device is programmed to deliver electrical currents through a small connecting cable placed under the scalp, linking the lead to the generator.

Once the surgery is completed, a magnet (similar to a programming computer) is placed externally onto the chest or head area (where the pacemaker-like device has been implanted). This is then used to adjust the stimulation settings, including the strength and frequency of electrical currents. These settings can be adjusted to either increase stimulation to reduce seizures or decrease it if the person experiences side effects. This treatment is always used together with medication. In places where this treatment is currently approved (US, Europe, Australia and Canada), it is recommended for people with focal seizures.

Although DBS is currently approved and funded for treatment for specific movement disorders on the NHS, such as Parkinson's disease, the funding for epilepsy remains limited due to pending funding approvals or lack of supporting evidence.

DBS for Epilepsy

Pioneering research in DBS for epilepsy was conducted by Dr Francisco Velasco and his team in Mexico. They targeted several brain regions and found that patients responded very well to treatment, showing a substantial reduction in the number of seizures, particularly in patients with generalised seizures and Lennox-Gastaut syndrome (LGS), a severe form of epilepsy, when stimulating an area called the centromedian thalamic nucleus (CMN).

DBS is not suitable for everyone. In the US, the Food and Drug Administration (FDA) has only approved DBS targeting a specific section of the brain, the anterior nucleus of the thalamus (ANT), for treating focal-onset drug-resistant epilepsy. This is because DBS has only so far been found to work in certain areas of the brain. The pivotal stimulation of the Anterior Nucleus of the Thalamus for Epilepsy (SANTE) trial demonstrated that ANT-DBS greatly reduced seizure frequency in patients with medically refractory epilepsy.

Over time, patients experienced substantial seizure reductions, with some achieving more than a 50% decrease in seizures. The side effects from the SANTE trial were mostly related to the implantation site. These included, implant site pain, tingling, vibration, while other adverse effects not related to the implantation site included memory impairment, leads not within target and dizziness. The study demonstrated that adverse effects were generally well tolerated, with 73% of patients reporting satisfaction. In some cases, side effects improved or resolved over time. This shows that the benefits of DBS far outweigh the risks associated with it. Following the SANTE trial, approval for ANT-DBS for epilepsy became available in many countries.

In Australia, a prospective, double-blind, randomised study investigated the effectiveness of DBS, targeting the centromedian thalamic nucleus (CMN) in patients with LGS. The study found that CMN-DBS reduced electrographic seizures (seizures that, for the most part, can only be seen on an EEG), and 50% of participants experienced a ≥50% reduction in diary-recorded seizures by the study's end, supporting the treatment's effectiveness.

In Brazil, DBS has also been tried, targeting the hippocampus in patients with temporal epilepsy, and the centromedian nucleus in patients with genetic generalised epilepsy, with promising results.

Trials on DBS in Europe have also been carried out, particularly involving two major studies: one targeting the anterior nucleus of the thalamus (ANT) in patients with focal epilepsy, and another focusing on the hippocampus in patients with temporal lobe epilepsy. However, more trials with larger numbers of people need to be carried out. This is now happening to test the efficacy of DBS. If these trials show promising results in decreasing the number of seizures that patients have, then this could help pave the way for more patients with drug-resistant epilepsy to be treated with DBS.

In the UK, DBS has already been trialled in 36 epilepsy patients, 29 at King's College Hospital (KCH), 1 at The Walton Centre in Liverpool, and 6 at Great Ormond Street Hospital (GOSH). Different brain regions have been targeted depending on the type of epilepsy, e.g. the thalamic nuclei such as the centromedian and anterior nuclei, as well as the hippocampus and various cortical areas. Some of the patients in the UK with severe epilepsy have remained seizure-free for many years following a DBS implant. However, although DBS is included in UK clinical guidelines for adults with certain types of epilepsy, it is not currently funded by the NHS.

New UK Research in Paediatric Epilepsy

In October 2023, a new research study began at KCH and GOSH, focusing on children with LGS. As part of this project, a teenager who was the first paediatric patient with this device, presented his case on the BBC. His family showed that his daytime seizures have since reduced by 80%. So far, 6 children altogether at GOSH have received the new DBS device developed in the UK, with another 22 expected to undergo implantation at KCH and GOSH over the next few years. This offers renewed hope for paediatric patients who have not responded to conventional treatments.

Editor's note: The more treatment options we can have for epilepsy the better. Deep Brain Stimulation (DBS) treatments could help people with epilepsy that cannot be controlled by medicines or resective brain surgery. However, we need more evidence showing that DBS is effective and safe in epilepsy before it can be routinely offered in the UK – especially for children. We are pleased to be involved in helping to gather this vital evidence.

Could I count on *you?*

An early peek behind the curtain of Epilepsy Action's next awareness-raising campaign.

Words by Kami Kountcheva

The shot opens on a phone on the table. It's 3 o'clock on a Wednesday. As the image zooms into the phone, you start to hear mutterings. You hear some bumping and clattering. You can pick out a voice saying: "What's happening? Can someone help?"

We zoom in even closer, and the phone starts to buzz with notifications. "Increased heart rate: 90bpm", the Fitness Tracker announces. Another buzz: "Unsteady heart rhythm detected". "Are you working out?"

The muttering continues. It sounds urgent, nervous. Buzz after buzz, the Fitness Tracker continues. "Heart rate rhythm is irregular". "Heart rate: 120 bpm". "Most active minute".

A voice becomes clearer among the noise. "Don't worry, I'm right here. I'm staying here." The Fitness Tracker declares: "Workout complete!"

This is the video that creative agency Boldspace put together as its entry to take part in the 2025 Creative Shootout this January. With such an innovative way to allude to a seizure and give a glimpse into what it might feel like, without ever even showing it, they bought themselves a ticket to the big night.

The Creative Shootout is a one-day event, pitting creative agencies against each other to solve a problem facing a charity in order to win a prize and funding to create the campaign. The charity in question, this year, was Epilepsy Action. And the problem? Shattering the stigma that surrounds epilepsy and driving empathy.

On the evening of January 30th, at the Creative Shootout held at BAFTA London, among the other creative agencies taking part, Boldspace presented their campaign.

Elliot Payne, a member of the team, says: "We had this thought that every time someone with epilepsy leaves the house, there's so much for them to consider. It's not just their plans and responsibilities that everyone else has to deal with, it's that ever present thought of: 'What if I had a seizure today?'

"Most of the time, they're completely in control, but in that 1% when they're not, everything depends on the people around them. And in that moment, could they count on you?"

On the night, they presented this idea with a few campaign posters bringing the issue to life through a range of everyday scenarios.

Presenting their idea, the team explained they want to shift the emphasis away from people with epilepsy and onto the public to learn more about epilepsy and become someone people could rely on in an emergency. They want to reframe everyday scenarios through the eye of someone with epilepsy who has the constant worry of having a seizure in the back of their mind. They want to build understanding and empathy.

It'll come as no surprise that Boldspace walked away from the Creative Shootout having won the prize of £10,000 and the opportunity to build and realise their awareness campaign with the backing of a £350,000 media fund.

The team is now working hard behind the scenes to refine their idea and bring their winning campaign to life.

Boldspace will work to showcase different seizures through the campaign, aim at different scenarios and age groups, and open avenues for more educational offshoots using the 'Could I count on you' tagline.

Keep an eye out in September for the full campaign!

Hero nurses

The May and June Epilepsy Star Awards recognised two epilepsy specialist nurses providing brillinant and vital support to their patients.

Words by Emily Stanley

May's Epilepsy Star Award went to Julie Day from Worcester Royal Hospital, for her amazing work as an epilepsy nurse. Julie was nominated by one of her patients Katy, who says Julie has been amazing since the day they met. Katy describes Julie as her 'hero' and can't imagine how she would have coped with her epilepsy without her. Katy says:

"I was diagnosed when I was 20 years old. As I've gotten older, my medication was no longer working and my epilepsy got worse. I don't know what my triggers are.

"Julie was the second epilepsy nurse I had involved in my care, and she has been amazing ever since. She has directed me and supported me so much, that I don't really know how I would be coping without her.

"She has pointed me in the right direction for everything from tips on how to manage my condition, to financial support that I didn't even know existed.

"Julie always goes that extra mile for me, and gets things done quickly. She is my hero and I know I am very lucky to have her fight my corner and support me.

"Julie goes out of her way to contact me straight away if I've needed to contact her. I'm sure there have been many times that she has worked overtime, or on her days off. She truly goes above and beyond.

Upon accepting her award, Julie said: "I am so touched, this is so lovely. "I also wanted to say thank you so much for the amazing support given by Epilepsy Action to individuals with epilepsy and their families. We use your website to provide education and information to all our patients."

Unwavering support

June's Epilepsy Star Award was scooped by Jenny Edwards from Swansea. Jenny is an epilepsy specialist nurse and has been recognised for her above-and-beyond care for her patients.

Jenny was nominated by Epilepsy Action's Wales manager, Jan Paterson. The pair worked closely during the recent Epilepsy Action Cymru report, that revealed poor standards of care across Wales. Jan says that Jenny was her 'rock' during this time and is a role model for what real, compassionate and extraordinary care looks like.

She said: "Jenny is one of those rare people who makes an extraordinary difference, not just through her expertise, but through her kindness, compassion, and unwavering support for everyone she cares for.

"For people living with epilepsy, life can be filled with uncertainty, fear and frustration, but Jenny has a remarkable way of making those difficult days feel a little lighter. She listens without judgement, explains things in a way that makes sense, and is always there when she's needed most.

"It's not just what she does, but how she makes people feel – safe, supported and never alone. She ensures people feel seen, valued and reminds them that they are so much more than a diagnosis.

"Jenny often uses Epilepsy Action's resources, from information, to training and even awareness campaigns, to help support her patients and their families as much as she can.

"Jenny goes above and beyond every single day. She advocates fiercely for her patients and gently challenges stigma."

Board of trustees

Summary of Board meetings

13 May 2025

End of Year Accounts and Audit Report
The auditors, Saffery, presented the 2024 year end accounts. There were no significant issues raised in the audit report.

Management Accounts to 31st March
There was a surplus against budget of £35k.

Governance Review and Membership
The board discussed the ongoing governance review, membership plans, resolution and voting process scheduled for September and the first draft of the new Bye Laws.

75th Anniversary Events
Plans for 2025 anniversary celebrations were reviewed, with agreement on recognising the contributions of Epilepsy Specialist Nurses alongside other key events.

Director of Services Presentation
Ann Richardson-Greaves provided an update on the team's work, highlighting the positive impact of the counselling service in Wales and Northern Ireland, ongoing funding challenges, and new service development plans.

AI and Governance
The board considered the potential role of AI and trustee Cameron Hill is leading a review.

Farewell to Diane Hockley
The board thanked Diane Hockley as she stepped down after seven years. Her advocacy work in disability law and EDI was recognised, and she expressed appreciation for her time as a trustee.

15 July 2025

Management Accounts to 31st May
There is now a surplus against budget of £1.6m due to a legacy that was released early and is higher than expected. Discussions are underway about the impact on 2026 phasing and investment.

Governance Review
Trustees approved the new Bye Laws that will be presented to the members alongside the changes to the Articles of Association. The trustees will be recommending that the members vote in favour of the changes that will be circulated in August.

AGM
The AGM date was confirmed as Tuesday 9 September at 2pm and the voting process will be delivered by Civica.

Membership
The initial results of the Membership Matters survey were shared that included feedback from 2,000 members and 2,400 non members.

Annual Reports
Progress reports and plans for 2026 were presented for DEI (Diversity, Equity and Inclusion) and Research.

Director of Health Improvement and Information Presentation
An overview of progress against targets was presented and positive results from projects was shared, including the improvement in how our information pages perform.

Other areas that were discussed were the Lord Hastings Award nominations and the frequency and format of board meetings in 2026.

Notice is hereby given that a meeting of the Council of Management will be held on Thursday 4th September at 12pm for the purpose of considering a resolution that it is in the best interest of the British Epilepsy Association (BEA) to remove those current members of BEA who are not also members of the Council of Management, for the purpose of moving to a closed membership structure (the "Council of Management Resolution").

This is required in the event that special resolution no.1 is passed at the AGM to support the changes to the articles of association and is required by Article 3.1.5(a).

Following the engagement with the membership to date, if you would like to make any final representations to the Council of Management, please send these by email to exec@epilepsy.org.uk. Please ensure that any representations are received by 12pm Monday 1st September.

If the Council of Management Resolution is passed, this will take effect at the AGM once the resolution to adopt the new articles of association has been passed

Thank you Sheffield branch

The Sheffield Epilepsy Action branch closed at the end of last year when Epilepsy Action volunteer Duncan Froggatt, who ran the group, had to step down for health reasons. We pay tribute to a long-running and award-winning branch and the people who led it.

The Sheffield branch was founded in 1989. Over the years, the branch has provided invaluable support to people with epilepsy and their family and friends in the area and beyond. The branch met monthly, and over the years raised over £25,000 for Epilepsy Action.

The branch has championed healthcare for people with epilepsy in Sheffield and South Yorkshire. In 1990, it was instrumental in ensuring that one of the UK's first ever posts for an epilepsy specialist nurse was located in Sheffield. The branch also funded several local epilepsy specialist nurses in their studies to achieve a Diploma in Professional Epilepsy Care. In 2001, the Sheffield and District branch was named British Epilepsy Association's (now Epilepsy Action) Branch of the Year. The branch celebrated its 30th anniversary in 2019.

David Streets, one of the founders of the branch, was a longstanding volunteer and served as Chair of the branch for many years. He was committed and passionate about this work, having firsthand experience of the condition, as his son was diagnosed with epilepsy. He was also a member of Epilepsy Action's Board of Trustees (then the Council of Management) from 2003-09, serving as Vice Chair of Council between 2006-07.

David passed away in June 2020 from COVID at the age of 83. Duncan Froggatt took over running the Sheffield branch to keep this important access point of support open for people. Duncan has epilepsy and had started volunteering for Epilepsy Action in 2006.

David, Maureen and Duncan, 2018

Kathryn Hughes, services manager at Epilepsy Action, said: "I remember being with Duncan and the Streets family at one of Epilepsy Action's award ceremonies in Leeds in 2018, when Maureen Taylor and David Streets received the Hilary Figg Award for long and distinguished service.

"Duncan is a lovely man who wanted to continue the important work of the Sheffield group for as long as possible."

We want to say a huge heartfelt thank you to David, Maureen, Duncan and everyone else at the Sheffield branch who kept it going and made it a success and a place where people could feel supported and part of a community for so many years.

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- **Website –** high quality information about all things epilepsy
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