

Epilepsy

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Paula McGowan

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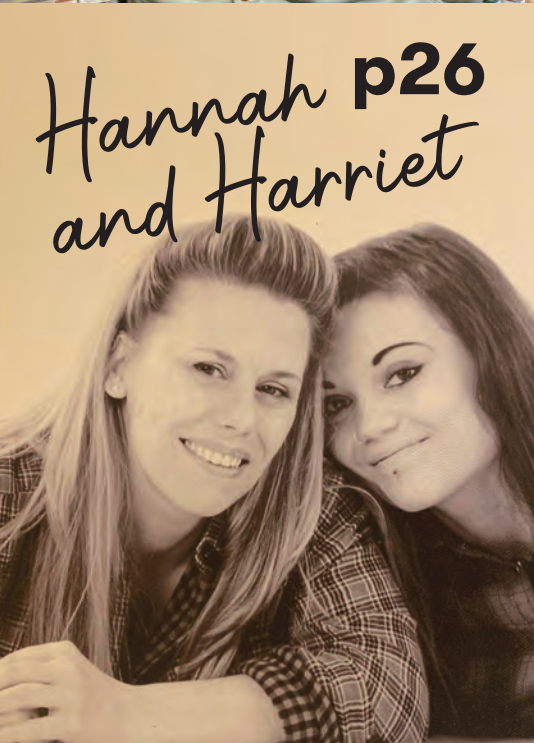
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We can be heroes

This edition's cover star Paula McGowan has become something of a hero to me. After speaking to her for this issue, I was left amazed at her spirit and her work ethic. Paula lost her son Oliver when doctors gave him medicine he didn't need. Since, she's campaigned to ensure no parent of a child with epilepsy has to go through the same thing. She now lives in Australia, which she says helps her to do this vital work. She's able to spend the daylight hours working as a school teacher and the nighttime ones on calls to doctors, politicians and leaders in the UK. Not only this, she's also been battling cancer. We were thrilled when she agreed to join Epilepsy Action as an ambassador. You can read more on pages 6 and 18.

Paula's isn't the only incredible story in this ET. On page 20 you can read about Bob Sutcliffe, whose life changed when he was diagnosed with epilepsy. He picked up a paint brush and never looked back. And on page 22 you will meet Rob Moriarty. He doesn't have epilepsy, but his friend Carla Rankin did. When she died he joined the family in fundraising in her memory. He has a high-level spinal injury that left him paralysed, but it never stopped him. Now he's written an autobiography.

Life with epilepsy can be a real challenge, but – whether you're a superhero like Paula, Bob and Rob – or an everyday hero like Star Award-winning mum Hannah on page 27, we are here for you. And we hope this month's edition of ET can offer you a little of what you need.



Grace Wood
Editor

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

Paula McGowan joins charity as ambassador

Paula McGowan OBE has become an ambassador for Epilepsy Action.

Paula is an award-winning activist who has dedicated her life to campaigning for the equality and equity of health and social care for intellectually disabled and/or autistic people.

Following the preventable death of her teenage son Oliver, Paula and her family set up Oliver's Campaign.

As part of the campaign, Paula successfully launched a parliamentary petition that meant health and social care staff in England now receive mandatory training in learning disability and autism awareness.

On 28 April 2022, learning disability and autism training became law and reached royal assent. The Oliver McGowan Mandatory Training has been designed, evaluated and is delivered alongside learning disabled and/or autistic people to meet this law.

"The family became aware of Epilepsy Action after Oliver died," said Paula, "which led to my husband and daughter running the half marathon in Bristol for Epilepsy Action. We felt we wanted to support a charity who can, and is, making a difference for our communities."

Paula is also a patron and ambassador for several charities and organisations including Health Education England, NHS England, South London and Maudsley NHS Foundation Trust, Anna Kennedy



MP Gillian Keegan and Paula after receiving her OBE

Online, DanceSyndrome and Crossroads Caring for Carers.

In May 2023, she was awarded an honorary fellowship at the University of Plymouth. She is also a member of CIDER – Cornwall Intellectual Disability Equitable Research.

Speaking about what she wants to achieve with Epilepsy Action, Paula said:

"As a charity, it is what Epilepsy Action does best – raising awareness, education, improving and saving lives. It is about making a difference for everyone who has epilepsy, their families and carers. I would like the charity to be more visible and accessible to the public and all professional services."

Read more about Paula on page 18.

Epilepsy Action certified by Helplines Partnership

The Epilepsy Action helpline has been certified by the Helplines Partnership.

The Helplines Standard is a quality mark recognised across the UK, which defines and certifies best practice in helpline work.

The charity passed its Helplines Standard Assessment in December 2023. The assessors said Epilepsy Action was providing a high-quality service and best practice for users.

The standard is reviewed every three years with an interim review within 18 months of being awarded.

The process for achieving the standard involves a written submission, a day of being observed by independent experts

and a verification procedure.

David Thornton, advice team leader at Epilepsy Action, said: “We are delighted that our helpline has been certified by the Helplines Standard.

“As a team, we have worked hard to continuously raise the standard of the service we provide and this accreditation recognises our dedication to support people affected by epilepsy in the best way possible.

“We hope this recognition will also help people to feel even more empowered when contacting the helpline, knowing that our amazing team of advisers are committed to providing a high-quality service that meets the needs of everyone

who would like to access support from us.

“To receive this news so soon after winning Helpline of the Year at the 2023 Helplines Partnership Awards makes us incredibly proud. The team has worked tirelessly over the last year to improve the service, making the experience for people affected by epilepsy the very best it can be.”

In November 2023, Epilepsy Action won Helpline of the Year at the Helplines Partnership Awards. Advice and information officer Diane Wallace was awarded the Lifetime Service Award. Advice team leader David Thornton received a runner-up award for Mentor of the Year.

Seizure-detection dog wins Crufts category

A self-taught epilepsy detection dog has won Scruffts Family Crossbreed of the Year.

Diesel, a 13-year-old Airedale Terrier-Labrador cross owned by Claire Whitehead from Derbyshire, received the award at Crufts on 9 March.

Diesel was one of four finalists in the national Scruffts competition.

Claire said Diesel had learned to bark when her friend, who has epilepsy, has a seizure, and will bring her a blanket to protect her.

On winning the award, Claire told The Kennel Club: “He’s my everything, I go nowhere without Diesel. I have a tattoo of his pawprint on my wedding finger and he is my world.”

Scruffts is a crossbreed dog competition that is held as part of the annual Crufts event that is shown on Channel 4.



The judges were Crufts TV presenter Radzi Chinyanganya, Love Island finalist Faye Winter and dog judge Paul Rawlings, who were looking for qualities such as health, good character and temperament.

On choosing the winner, Radzi said: “To find out that an untrained dog has taught itself to be a medical alert dog, that’s a superpower. It’s amazing, so when we heard that we knew it was something special.”

The Scruffts Family Crossbreed of the Year competition is run by The Kennel Club, which organises Crufts.

Seizure alert dogs are trained to detect oncoming seizures and alert you, so you have time to make yourself safe. For more information on their requirements, go to:

www.supportdogs.org.uk/pages/category/epilepsy-seizure-alert

Epilepsy news

Spring Budget 2024: government announces funds for epilepsy research

Epilepsy Action has welcomed the news in the government's Spring Budget that more money will be given to fund epilepsy research.

Speaking on 6 March, the chancellor Jeremy Hunt announced a £45 million investment into research for cancer, dementia and epilepsy.

The increased investment in "life sciences" was part of the government's annual Spring Budget.

Hunt said the money would help fund research into new medicines.

Epilepsy Action deputy chief executive Rebekah Smith said: "It's really encouraging to see additional funding

for epilepsy research being included in this week's budget announcement by the chancellor of the exchequer.

"Epilepsy affects around one in 100 people in the UK, making it one of the most common neurological conditions, yet it is rarely referred to and desperately needs more investment.

"While progress has been made in many areas of epilepsy research, there is still so much more to be done, from the effectiveness and safety of medication to new ways of treating the condition. Better treatment choices and seizure control for people with epilepsy mean better quality of life, and less limitations in so many areas of their life.

"We await more details on which key areas will be prioritised, but welcome the news of much-needed investment to improve the lives of people with epilepsy."

The chancellor also announced the government would be funding the NHS Productivity Plan, which includes £3.4 billion towards modernising IT systems. Hunt said improving NHS productivity would "save billions".

The news follows concerns earlier this year that epilepsy had been left out of the government's Major Conditions Strategy, and that there was no mention of measures to address epilepsy-specialist shortages in the NHS Long Term Workforce plan.

Cost-of-living campaigner goes to Downing Street

Disability campaigner Thomas Howard took a petition to bring back the disability cost-of-living payments – with more than 60,000 signatures – to Downing Street in February.

The petition, set up before Christmas, is one of the best performing petitions on Change.org.

The disability cost-of-living payment was dropped in November 2023 for those receiving certain disability benefits, including Personal Independence Payments (PIP). A £150 cost-of-living

payment had previously been given between 20 June 2023 and 4 July 2023.

Epilepsy Action joined Thomas' calls to reinstate the benefit. Many people with epilepsy qualified for the original cost-of-living payments because they were also receiving PIP.

Thomas travelled from his home in Suffolk to London to deliver a physical copy of the petition. He said: "It was really surreal. To actually go there was exciting and daunting at the same time."

He added: "My priority is continuing



to raise awareness and I'm going to be reaching out to all the signatories letting them know that the petition has been delivered, urging them to continue to support and share and asking them to share a copy with their MP."

‘Huge and unjust disparities’ across neurology services

London has almost four times more neurologists per person with epilepsy than the north east of England, according to new research from Epilepsy Action.

Rhys Thomas, consultant neurologist at Newcastle Hospitals NHS Foundation Trust, said patients in England face “huge and unjust disparities”.

There is just one neurologist to every 755 people with epilepsy in the north east of England (39 in total), but one to every 191 in London (326 in total).

The north east of England has the highest epilepsy prevalence rate of any area at 1.1%. In this region, 42 people out of 100,000 will be diagnosed with epilepsy every year.

Thomas added: “It doesn’t have to be like this. Good epilepsy care is dependent on helping patients access flexible and responsive service, as well as training and retaining excellent clinical staff.”

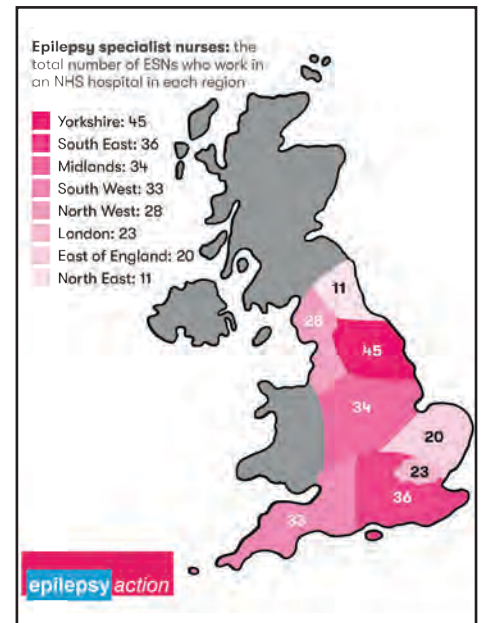
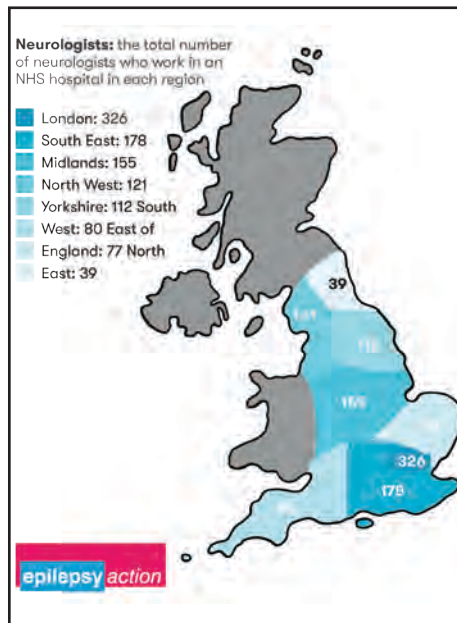
These figures come from an Epilepsy Action report into NHS workforce data across England. The charity sent Freedom of Information requests to 193 trusts across England (of which 174 responded) and then compiled the data.

The report shows that where a patient lives impacts their access to neurology services, and even the better-served areas of England are significantly more understaffed than other countries in Europe.

The research also looked into the numbers of epilepsy specialist nurses. It found there are just two epilepsy specialist nurses per 500,000 people, which is 78% lower than the NICE-recommended rate of nine per 500,000 people.

The investigation also considered England’s neurologist workforce compared to the rest of Europe. England has one neurologist per 50,000 people. In France and Germany there is one neurologist for every 25,000 people.

Thomas added: “Neurology care across the country has not been designed, but has evolved based on geography and history, and certainly not patient need. This imbalance affects some areas more



than others. Smaller teams are more vulnerable to change, whether this is retirement, ill-health or maternity leave.

“There is no minimum standard for an epilepsy service. NICE guidance is helpful, but there are no penalties for failing to follow them, so we lack the ‘key performance indicators’ for secondary care, that could be used to improve equity and access.

“And we know there are huge and unjust disparities. Some patients don’t even have access to first seizure service, which is where people who are suspected of having a seizure are seen rapidly, ideally within two weeks.

“What’s needed is a strategic drive towards addressing health inequalities, by committing to provide significant additional financial support to allow trusts to employ sufficient neurologists.”

While the data only includes figures for England, available research shows in Northern Ireland there are five epilepsy specialist neurologists and 14 epilepsy specialist nurses, a ratio of one to every 1,947 people with epilepsy. In Wales there are approximately 32,000 people with epilepsy, with 22.5 epilepsy nurses and 12 epilepsy specialist neurologists. That’s one epilepsy specialist neurologist to every 2,996 people with epilepsy and

one nurse to every 1,598 people with epilepsy.

Epilepsy Action director of health improvement and influencing Alison Fuller said: “There’s no doubt neurology services have historically been underfunded and overlooked, but our new analysis shows that staffing levels are even more inconsistent than we thought.

“This means patients don’t have access to the same levels of care, facing extremely lengthy waiting times and ultimately risking their quality of life deteriorating. But this also has a huge impact on healthcare professionals, who are severely overstretched and juggling overwhelming caseloads.

“What’s more disappointing is that epilepsy has been left out of the government’s Major Conditions Strategy, and that there was no mention of measures to address shortages in the NHS Long Term Workforce plan against condition specific workforce.

“Our calls to include neurology, and epilepsy especially, as a priority, given the unique challenges both staff and patients face, have not yet been listened to by policymakers. But we will continue to shine a light on the impact these shortages are having on both people with epilepsy and healthcare professionals until they are.”

Neurology crisis costing UK £96bn – Economist report

One in six people in the UK live with at least one neurological condition, costing the UK economy £96 billion in 2019, according to a report by Economist Impact.

The value of action: mitigating the impact of neurological disorders in the United Kingdom is a report from Economist Impact, supported by healthcare company Roche with feedback and guidance from The Neurological Alliance.

Epilepsy Action is a member of The Neurological Alliance, which is a coalition of more than 90 organisations that support people with neurological conditions.

The study considered 10 neurological conditions: Alzheimer’s disease, brain cancer, epilepsy, migraines, Parkinson’s disease, spinal cord injury, type I SMA, MS, stroke and traumatic brain injury.

The report was launched at the House of Commons on February 26.

Epilepsy Action’s deputy chief executive Rebekah Smith and director of health improvement and influencing Alison Fuller attended the launch event in London.

Epilepsy affects 937 per 100,000 people in the UK. The report focused on idiopathic epilepsy – which affects 358 people per 100,000. It said this cost the economy 0.07% of GDP in 2019 or

£1.7 billion, more than half of which is due to lost productivity.

Fuller said: “Overall, the average number of consultant neurologists in the UK is much lower compared to Western Europe.

“Delays and gaps in diagnosis and treatment can have huge repercussions on patient safety, from unplanned hospital admissions to breakthrough seizures, and even an increased risk of sudden unexpected death.”

“We know, as it stands, epilepsy costs the NHS £2 billion a year. But it is not limited to this. Lack of access to specific care means people with epilepsy are held back in so many other areas of their life, one of the most prominent being employment and economic contribution, and removing health inequalities directly reduces issues of mental health.

“With targeted access to care and treatment, people with epilepsy can thrive and contribute to society just as much as anybody else and have the quality of life they deserve. This is why we will continue to ask policymakers to listen to the thousands of people with the condition and ensure the right level of input and improvement to service provision is implemented.”

The study said that neurology and neurosurgery services were performing worse than other health services – even

amid a struggling NHS. The report’s authors said there were three challenges that stop the UK healthcare system from improving neurology services. These were a lack of overarching strategy, a lack of human resources and a lack of access.

It said there was no high-level policy to address more prevalent neurological conditions, such as epilepsy or Parkinson’s disease.

It also highlighted issues with the numbers of healthcare professionals, stating the UK has 1.1 consultant neurologists per 100,000 people. The average in Western Europe is one per 12,000.

The report added that between April 2021 and April 2023, the waiting list for neurology treatment in NHS England grew by 76% to more than 220,000 people.

Writing in the report, the authors said: “Change is necessary at both the coalface of care provision for individual conditions and at the broader, strategic level.

“To bring down the high indirect costs to the economy, much of which are borne by carers, better social care for those with neurological conditions will be essential.”

The report was produced by Ashish Niraula, Anelia Boshnakova, Rob Cook and Paul Kielstra and is available on Economist Impact.

The report launch event was followed by a debate in the House of Lords about the NHS’s resourcing and capacity for those living with neurological conditions.

Speaking to the lords, Baroness Blackwood of North Oxford said: “An epileptic seizure can cause significant disability and in the worse instances death, but only half of those living with epilepsy are seizure free. This could rise to 70% if all those with epilepsy are targeted to the right treatments.”

She then asked Lord Markham, parliamentary under-secretary for health and social care, what plans the government had to improve specialist care for people with epilepsy in the UK.

Lord Markham said: “I proudly wear the Epilepsy Action badge. It is all about trying to get that early diagnosis. Getting the right treatment and early diagnosis can make a huge difference in terms of the outcomes.”



Epilepsy medicine shortages continue

Epilepsy medicine shortages across the UK are leaving people struggling to access drugs including Tegretol (carbamazepine) and lamotrigine.

Epilepsy Action's helpline has seen five times as many enquiries on medication stock this year compared to the same time last year.

Epilepsy Action has heard from some people that they have been close to completely running out of medicine, while some have said the stress has triggered more seizures. Some have reported that doctors advised them to switch medication brands. These can

be manufactured differently. While not ideal, for most people, taking a different version is safer than suddenly stopping medicine.

The most commonly reported shortages have been of Tegretol and lamotrigine.

Epilepsy Action has contacted Tegretol manufacturer Novartis and Lamotrigine manufacturer Accord to get more information on the ongoing problems.

According to Tegretol manufacturer Novartis, all strengths of prolonged release Tegretol are in stock. The company said it is still taking time for

the stock to reach the wholesalers. They expect this backlog to be resolved by the end of the week (as of February 28).

The manufacturers of lamotrigine, Accord, have said there is very limited stock and it is currently only available to hospitals and hospital outpatient pharmacies. The company estimated a return date of April 2024 for 50mg, 100mg and 200mg. 25mg tablets made by Accord are currently unavailable long term. Accord cannot confirm when they will be back in stock.

For the latest updates, follow Drugwatch: www.epilepsy.org.uk/drugwatch

Valproate redress scheme proposed

A redress scheme for families who have suffered from exposure to sodium valproate has been proposed by the Patient Safety Commissioner.

Valproate is a commonly prescribed anti-seizure medication for people with epilepsy. It is also prescribed for bipolar disorder. It has been linked to serious developmental issues in children exposed during pregnancy. However, for many people with epilepsy, it remains the most effective drug for their treatment.

Until this year, the rules around prescribing valproate were just for women and girls. The Valproate Pregnancy Prevention Programme ensures women taking valproate are aware of the risks and using highly effective contraception.

However, the rules changed on 31 January 2024, meaning no one under the age of 55 will be newly prescribed unless two specialists agree there is no other effective or tolerated treatment, or unless there are "compelling reasons that the reproductive risks do not apply".

According to the Patient Safety Commissioner, thousands of children

have been exposed to valproate and suffered from learning and physical disabilities as result.

Dr Henrietta Hughes (*pictured right*) is the current Patient Safety Commissioner. The goals of the office are to influence government, advise on policy making and raise patient concerns to the Department of Health and Social Care.

The suggested redress scheme has two stages. The first identifies all those harmed and would "ensure patients receive long overdue financial redress quickly". The commissioner says this award would be about £25,000. This would be followed by a payout based on the individual needs of each patient.

The report also sets out non-financial redress to provide support for those affected. This includes a housing grant and improved access to education, benefits and support.

Launching the report, Dr Hughes said: "My report could not be clearer – the case for redress has been made. It highlights in detail the daily problems that impact on those who have been harmed. We found that those exposed to valproate need specialist care but must battle with every part of the system – diagnosis, treatment and support services.

"This redress programme is a crucial step towards acknowledging the challenges faced by impacted families."

Exposure to valproate in pregnancy is linked to spina bifida, facial and skull malformations, malformations of the limbs and organs, as well as learning and development problems.



Epilepsy Action deputy chief executive Rebekah Smith said: "The 2020 Cumberlege review recommended a redress scheme to meet the cost of providing additional care and support to those who have experienced avoidable harm due to sodium valproate.

"Although the government stated on a number of occasions that it was 'carefully considering' a redress scheme, the recommendation wasn't taken on board. It was instead advised that affected families could pursue clinical negligence claims. These would be costly, both financially and emotionally, and time consuming.

"Epilepsy Action has long supported the calls for compensation for the estimated 20,000 children who have been harmed by valproate. Some of these children require 24-hour care, the cost of which has been entirely on the families' shoulders for years.

"We welcome this latest call for compensation from the Patient Safety Commissioner. We hope the government listens to the calls of patients who have been harmed, providing the long-overdue financial support they need."

Epilepsy Action Cymru meets Senedd

Epilepsy Action Cymru met members of the Senedd, clinicians and patients in Cardiff Bay in January to discuss the support available for people with epilepsy in Wales.

There are more than 30,000 people with epilepsy in Wales, some of whom are having to wait a year or more to see a neurologist.

Epilepsy Action Cymru is campaigning for more Epilepsy Specialist Nurses (ESNs) to be appointed across Wales, and has introduced a counselling service to support people living with epilepsy and their loved ones.

Jan Paterson, Wales manager at Epilepsy Action Cymru, was joined by senior policy and campaigns officer Daniel Jennings and volunteer Becci Smart, *pictured right*.

Luke Fletcher, member of the Senedd for South Wales West also supported the event.

Luke, who has previously campaigned for people with epilepsy in the Senedd, said: "Epilepsy Action Cymru's research reveals a distressing reality for those managing epilepsy in Wales.

"Wales has the highest rates of incidence of epilepsy in the UK, and the extremely low specialist availability, regional discrepancies in services, and lack of investment in epilepsy resources



serves only to compound the situations of those living with epilepsy in Wales.

Becci, who was diagnosed with juvenile myoclonic epilepsy at the age of 18, said: "The challenges I face in living life with epilepsy are as emotional as they are physical, and I cannot stress enough how vital providing extra support to help people with epilepsy in Wales live safer, freer lives would be."

According to Epilepsy Action Cymru, 43% of patients aren't getting referred to any kind of specialist service following a seizure, while others wait a year or more to see a neurologist.

Wales manager Jan said: "A lot of people probably don't realise that Wales has a higher rate of incidence of epilepsy

than the rest of the UK, with 55 new cases per 100,000 each year compared to 37 in England. NICE guidelines recommend a waiting time of no longer than two weeks for patients with a suspected first seizure, which are nowhere near being met by any of the seven health boards operating across Wales."

"We are therefore calling on the Welsh Department for Health to actively support the provision of more ESNs across Wales, alongside the widespread implementation of an 'Epilepsy Service Coordinator' task force that can support the adoption of a best practice 'Open Access' model currently also only put into practice by four out of the seven health boards involved, according to our research."

Mental health treatment developed for children with epilepsy

A mental health treatment for children with epilepsy, developed by scientists at University College London, has been shown to be more effective than standard care.

The Mental Health Intervention for Children with Epilepsy (MICE) is based on recommended treatments for common

mental health difficulties such as anxiety and depression, but was modified to help children who have more than one problem.

The study was published in *The Lancet* on March 7. It found that children who went through the MICE treatment had fewer mental health difficulties than those who had the usual treatment.

It was delivered over the phone or via video call so that people did not have to travel to hospital and miss time from school or work. It was also integrated into epilepsy services.

Patients were given an initial assessment followed by weekly calls.

The study was done by researchers at UCL, in collaboration with Great Ormond Street Children's Hospital, King's College London and the University of California, Los Angeles, with funding from the

National Institute for Health and Care Research.

Lead author Dr Sophie Bennett said: "This treatment breakthrough means we have a new way to help children and young people with epilepsy who also have mental health difficulties.

"The treatment can be delivered from within epilepsy services to join up care. It doesn't need to be delivered by specialist mental health clinicians such as psychologists. This can help children with epilepsy and their families more effectively and efficiently. We were particularly pleased that benefits were sustained when treatment ended."

Researchers trialled the treatment with 334 children and young people aged three to 18. Of these, 166 received MICE treatment and 168 received the usual treatment for mental health problems.

Epilepsy Action to become Disability Confident leader

Epilepsy Action is aiming to become a Disability Confident Leader as part of the government's Disability Confident employer scheme.

The Disability Confident employer scheme has three levels: level one – Disability Confident Committed; level two – Disability Confident Employer and level three – Disability Confident Leader.

While the charity has already achieved level two status, level three will mean it has been externally and independently assessed and completed the voluntary reporting framework. This proves the charity actively supports, recruits, trains and retains employees with disabilities.

Seventeen percent of the people who work for Epilepsy Action say they have a disability. The charity also has a Disabled

Staff Network, which has supported the completion of the self-assessment and reviewed internal policies and procedures.

The Disability Confident scheme launched in 2013. There are currently about 20,000 employers signed up, which is less than 2% of employers in the UK.

Only 3% of companies in the scheme have level three status. Level three leaders include Scope, Barclays, ITV and Zurich.

Epilepsy Action's people and culture manager Steph Smith-Crawshaw said: "As an epilepsy charity, we know all too well the challenges and barriers people with disabilities and long-term health conditions face when it comes to employment. At Epilepsy Action, inclusion is at the heart of what we do. We want everyone in our community regardless of their backgrounds, identities, abilities or

circumstances to feel valued, respected and able to participate fully.

"Our recent Make Things Work campaign showed that 42% of UK managers wouldn't hire someone with epilepsy to save their company challenges. This is incredibly concerning and one of the big reasons we want to undergo an independent review as part of our level three accreditation.

"This is also why it is important that more employers become Disability Confident and go the extra mile to becoming a Disability Confident Leader."

What does Disability Confident mean if you are someone with a disability seeking employment?

The difference between the scheme levels is an important consideration for people with disabilities looking to work with a supportive and inclusive employer. Below we describe what each level means:

Level 1 – Disability Confident

Committed: There are more than 14,000 employers in the UK signed up to this and this is where a business or organisation has made the first step by signing the pledge to be or become disability confident and support and employ disabled people. However, at this level a company doesn't actually need to have employed anybody with a disability.

Level 2 – Disability Confident

Employer: There are more than 4,000 employees signed up at level two. Organisations in this group have undertaken a self-assessment and submitted it.

Level 3 – Disability Confident Leader:

With the lowest number of employers achieving this level – only 587 across the UK, these are the organisations that have gone the extra mile to support disabled people and provide robust evidence of their inclusive practises. The number is always increasing but we would like to see more organisations making the step to become Disability Confident. Organisations in this category have undergone an external assessment and committed to completing the voluntary reporting framework.

Meet Daniel

What do you do?

I am a social media and digital executive apprentice at Epilepsy Action. I began working here as part of my apprenticeship in March 2023. I manage and post content to all social media channels, supporting the organisation's digital requests. I was diagnosed with autism at an earlier age, but I was informed of my diagnosis as a teenager.

What challenges and barriers have you faced?

After leaving school, it was suggested I complete apprenticeships to gain work experience while achieving qualifications. But I wasn't provided with support during the application stages, leading to an extended period of applying to different providers and trying to understand the process on my own. I completed the Prince's Trust Teamwork Skills Level 1, and the two-week work placement. This scheme was my introduction to digital marketing. The biggest barrier I have faced is that most employers want candidates with work

experience, yet gaining the experience is part of apprenticeships. I volunteered for a local branch of a military charity to gain experience. It has been challenging at times to meet the standards and keep up with demands that are required by apprenticeship providers and employers, and during probationary periods this can cause a lot of stress as a self-critic.

How do you find working for Epilepsy Action?

I have passed my probation, which has given me the confidence to take charge of my work and experiment with best practices and content ideas. I feel my role here is career progression and even though there's challenges, they are not too overwhelming and they are important for my development. My line manager is the best manager I have had, he knows how to lead the team and has been accommodating, and my co-workers both have an extended willingness to show me the ropes.



Could Emmerdale's next character have epilepsy?

Epilepsy needs more representation on our screens. We think it's time Emmerdale had another character with epilepsy

When a member of Epilepsy Action's communications team spotted the Assistant Storyliner role at Emmerdale, we couldn't help but get excited. Epilepsy Action and Emmerdale are the perfect fit: less than eight miles from one another (an easy commute), both national institutions and devoted to

improving the lives of ordinary people.

We often hear from our members that epilepsy needs more representation on our screens – both to raise awareness and educate others, and we couldn't agree more. So, we applied.

You can see our CV and covering letter here. If you have any more ideas for Emmerdale storylines, get in touch on social media: @epilepsyaction.



Ey up,

From one Leeds institution to another, Epilepsy Action (based just a stone's throw from Esholt, the home of Emmerdale Farm) would like to apply for the Assistant Storyliner role at Emmerdale.

With more than 50 years' experience, and based just down the road from the Woolpack, we think we have everything you need for the role – and some epilepsy-themed storyline ideas to boot

Epilepsy Action's communications and digital team works with an amazing community of people with epilepsy to bring their stories to life and have expert understanding of how the condition impacts their lives and those of their loved ones.

We work hard (especially for people with epilepsy), we have strong decision making skills – evidenced by our new strategy – and award-winning communication skills.

In fact, our helpline won Helpline of the Year 2023 at the Helplines Partnership Awards.

We have excellent IT skills – having built and launched a brand new website two years ago. We're very used to working in fast-paced environments (did we mention the INTERNATIONAL airport just up the cobbles of Yeadon high street?). We also have great awareness of audience needs – you won't find any flashing images in our social posts.

What do Martin Kemp, Prince, Elton John and Maisie Adam have in common? They all have epilepsy in real-life, which shows epilepsy can really affect anyone, even everyday people like we see in shows such as Emmerdale.

In fact, we think it's time Emmerdale had another character with epilepsy.

There are 78 characters and 79 people diagnosed with epilepsy every day. In fact, there's a new diagnosis every 18 minutes meaning more than one person will be diagnosed during every episode.

But, Emmerdale is all about stories and epilepsy is about so much more than just seizures – getting a diagnosis can turn your life upside down. Here are some powerful potential epilepsy story lines we have come up with...

- Epilepsy often runs in families. Remembering that Aron's sister Liv had epilepsy, he could also discover he has the condition. Aron, being a rebel, might try to fight back against the challenges he would face with the condition: his GP might tell him he can no longer drink, he might have his driving licence revoked – which would be an extra challenge in a rural area, his medication might affect his sex life.
- Eighteen months after Marlon Dingle's stroke, he's back working as a chef. The stress of the job can't be good for his neurological health. In fact, strokes and epilepsy often go hand in hand. This would affect his employment status and how would they make reasonable adjustments for him to continue working in the kitchen?



Epilepsy Action

Comms & Creative Professionals

We're a creative communications team with more than 50 years of combined experience and a passion for telling powerful stories.

contact

press@epilepsy.org.uk
@epilepsyaction

experience

Head of Epilepsy Awareness (2023 to present)

Leading in getting epilepsy embedded in the public's conscience and creating a world without limits for people with the condition

Creative Storytelling Lead (2010 to 2023)

Shaping the conversation around epilepsy with compelling stories and creative campaigns

Epilepsy Story Assistant (2001 to 2010)

Raising awareness through powerful epilepsy stories

skills & expertise

- Creative writing and storytelling
- Proofreading
- Social media management
- Creative campaign production
- Project management
- Video production
- Graphic design

hobbies & interests

- Perfecting the art of Yorkshire tea-making
- Binge-watching TV (especially soaps!)
- Enjoying a good Yorkshire pudding

education

- NCTJ Gold Standard in Journalism
- Journalism - Master's Degree
- Renaissance Studies - Master's Degree
- Media Studies - Bachelor's Degree
- English Literature - Bachelor's Degree
- Media and Popular Culture - Bachelor's Degree

• Eric Pollard has a new diagnosis of Parkinson's. There's a huge link between epilepsy and Parkinson's. In fact a recent study found that people with epilepsy are twice as likely to develop Parkinson's disease. Older people with epilepsy face a host of different challenges. One in every four people who are newly diagnosed with epilepsy are over the age of 65. Epilepsy can have a big impact on memory as can age and both epilepsy and age can leave people feeling isolated.

• We love to see Down's Syndrome represented by Leo Goskirk, Rhona and Marlon's son. People who have Down's syndrome are more likely to develop epilepsy in their lifetime

than people in the general population. Being a child, Leo might be prescribed the ketogenic diet, which could have a big impact on the family. Specialist diets can be expensive and challenging for parents – but there are ways to make it more manageable.

• Another child whose storyline could include epilepsy is Frankie, the daughter of Tracy and Nate.

Frankie might face challenges with her epilepsy at school. If she had absence seizures, for instance, teachers might tell her off for not listening or being badly behaved when really she's having seizures because of her epilepsy.

Well, ta for reading. We hope to see you in The Woolpack soon, the team at Epilepsy Action.

What's new?



We share some recent advances in epilepsy research

Recent updates in medical research have included the development of a diagnosis tool, a better understanding of ketamine use for drug-resistant epilepsy and a new drug for rare epilepsies.



Epilepsy diagnosis tool gets MHRA approval

A technology that can help doctors diagnose epilepsy has been approved in the UK.

The clinical decision tool, which can be used as additional evidence by medical professionals, was awarded a UKCA mark in December 2023.

BioEP has been developed by a firm called Neuronostics, which says results can be produced in 15 minutes. It is listed as a Class I medical device, meaning it is low-risk.

It speeds up the diagnosis by using background EEG results to identify the likelihood of future seizures.

BioEP was awarded the UKCA mark by the government's Medicines and Healthcare products Regulatory Agency (MHRA). The mark indicates that a product meets the requirements to be sold in the UK.

The regulatory upgrade to UKCA included a thorough clinical evaluation, literature review and usability evaluations by clinicians.

Neuronostics managing director John Terry said: "I am delighted that



we have been able to deliver this key regulatory milestone.

"Our entire team has worked collaboratively towards this achievement, ensuring the Neuronostics Platform meets the robust standards laid out as part of a UKCA mark.

"This UKCA marking provides our partners, collaborators and clinicians with the confidence that we have developed a safe, effective and clinically valuable product."

The firm has also begun a prospective clinical trial of BioEP. The randomised study will measure time to diagnosis and accuracy. It will include 559 participants and conclude in February 2027.



Ketamine 'effective' for status epilepticus

Ketamine is an effective treatment for status epilepticus that does not respond to normal treatments, according to a new study from Spain.

The researchers concluded it was "an effective drug with a good response rate" and few major side effects. They also found that patients who were successfully treated had a shorter average hospital stay.

They said a "good response" was observed in 57% of patients.

Status epilepticus (SE) is when a seizure lasts a long time or when a person has one

seizure after another without recovering in between.

In the UK, ketamine is sometimes used to treat SE. It is also used as an anaesthetic. Some studies have suggested it could be used to treat anxiety and depression. However, it has many side effects – especially when taken in large doses.

It is currently also used to treat eclampsia, pre-eclampsia, head trauma, high blood pressure, brain injuries, heart attacks and strokes.

The Spanish researchers were based in Madrid hospitals: Hospital Universitario de Fuenlabrada, Hospital Universitario Clínico San Carlos, Hospital Universitario Quirónsalud and Barcelona's Hospital Universitari Vall d'Hebron.

The team studied adult patients who received ketamine for the treatment of refractory status epilepticus and super-refractory status epilepticus.

Refractory SE is when first and second treatments fail. Super-refractory is when seizures persist or recur after treatment for more than 24 hours.

Ketamine was used as an anaesthetic after an average of 37 hours of status epilepticus. Some patients were also treated with midazolam.

Previous studies have also considered ketamine as a treatment for SE. A 2023 study in the US found that ketamine was increasingly being used to treat refractory SE. In a similar study from August 2022, ketamine had a 60% success rate. This study used data collected over 10 years from 879 patients.

Despite recommending the drug, the researchers added that “clinicians should continue to be cautious when using ketamine, as it is a potent drug with numerous reported adverse effects”.



Drug developed for rare epilepsies

A new medication for rare epilepsies has reduced seizures by more than 50%

in the latest clinical trials.

Bexicaserin has been developed to treat Dravet syndrome, Lennox-Gastaut syndrome and other developmental and epileptic encephalopathies (DEEs).

DEEs are types of genetic epilepsy that usually appear during early childhood.

The epilepsy drug is currently not available to patients, but may become available if it is shown to work in larger studies.



Bexicaserin has been created and tested by American company Longboard Pharmaceuticals.

Longboard's president and chief executive officer Kevin R Lind said: “We believe bexicaserin provides us with the cornerstone to build a world-class epilepsy franchise and to explore development paths that may offer novel options to DEE patients who are vastly under served.”

The company said bexicaserin achieved an average seizure reduction of 53.3%, compared to 20.8% in the placebo group.

The threshold for a drug to be considered clinically effective is a 50% reduction in seizures.

The average seizure reduction for patients with Dravet syndrome was 72.1%, 48.1% in Lennox-Gastaut syndrome and 61.2% in other DEEs.

The results come from a small group of 52 people aged 12-65 years old. Nine dropped out. 43 participants took bexicaserin and nine took the placebo.

The studies took place at 34 sites across the US and Australia.

Only three participants reported a serious adverse event during the trial, these were ankle fracture, constipation and increased seizures. No deaths were reported. No participants in the placebo group discontinued or experienced a side effect.

All of the participants who completed the study are now taking part in the ongoing 52-week extension study.



Excellence Collective launched

Epilepsy Action has launched a project to create change and connect the epilepsy community, called the Excellence Collective.

The Excellence Collective will drive change and improvement in all aspects of epilepsy care by bringing together people with epilepsy, health and social care professionals, researchers and policy makers.

It will create and facilitate improvements by funding and supporting projects within health and social care organisations, creating an information bank, mapping support and bridging the gap between research and practice. It will also support other organisations to improve their services for people with epilepsy.

We are interested in hearing from everyone with an interest in epilepsy, whether you're a healthcare professional, researcher, policy maker, carer or someone affected by epilepsy.

If you're interested in being part of the collective, you can sign up for free at: www.epilepsy.org.uk/excellence-collective, or contact Tom Shillito by emailing tshillito@epilepsy.org.uk.



For more research stories go to: www.epilepsy.org.uk/category/research



What are we up to?

It's great to be able to see how far your support goes to help us carry out our vital work. Here's where you can see more

Epilepsy Action's aim is to improve the lives of people living with epilepsy – and that happens in a lot of ways. We are here to support through our helpline, Talk and Support groups and on social media. We are also here to campaign for a better, fairer world for people with epilepsy. Here are some of the things we've been up to.



Facebook

Our members Facebook group now has more than 250 members.

It is a place where members can share

their stories about living with epilepsy and offer support to one another. Recent conversations have focused on medicine shortages, having seizures while out and about, and looking forward to spring weather! Members have said the group is a useful place to share and be heard. You can read more and join at www.facebook.com/groups/epilepsyactionmembers

February's Facebook Challenge was to walk 50 miles throughout the month. Those who took part received a free Epilepsy Action T-shirt and fundraising pack. You can join the Facebook group and find out more here: www.facebook.com/groups/stepforepilepsy/about

Elsewhere on the internet, we put a call out for streamers to get in touch for an exciting new project on social media platform Twitch. We also celebrated International Women's Day on 8 March with a video from deputy chief executive Rebekah, which you can see here: www.twitter.com/epilepsyaction



Diffability Podcast

Epilepsy Action's advice and information officer Rosie Orford featured on the podcast Diffability.

The podcast is hosted by Paul and Michael who have two sets of twins, the eldest of whom have autism and epilepsy.

Rosie was a special guest on their episode about epilepsy. Rosie answers calls on Epilepsy Action's helpline and has epilepsy herself.

She chatted to Paul and Michael about what Epilepsy Action can offer families, including the Talk and Support group for parents. You can hear more at: apple.co/3wSYjxB Or you can watch Rosie on YouTube: www.youtube.com/watch?v=eyw9Od3tbQk



Talk and support groups

Epilepsy Action's Talk and Support groups take place in-person and online.

In every issue of Epilepsy Today, we reflect on what has been going on in the previous few months. Recent topics of discussion have included work and discrimination.

A new Talk and Support group was launched in Nottingham. There were 19 people at the first meeting. They all came together to share their experiences of living with epilepsy, or caring for someone with epilepsy.

Group development co-ordinator Leona Phillips explained how the groups are supporting members. She said: "One of our group members has been joining the virtual Talk and Support groups since 2022. They would often sit and listen to others talking and rarely engage with the conversation. As time went by, they began to play a more active role in the groups.

"Recently, at the end of a group, they stayed on to feedback that the group had changed their life. They are now more open with others and want to talk and share their experiences. They come away from the groups feeling 'really happy and bubbly!'"

There is also an exciting new plan for virtual groups. This has been led by feedback and input from the people who use our groups. It will also help us work towards our overall strategy.

If you want to find out more go to: www.epilepsy.org.uk/support-for-you/talk-and-support-virtual-groups

Turn the world purple

This year Purple Day is March 26. Here are just a few of the events going on across the country.

Kerry Smith from Lowestoft is hosting a Purple Ball, which she hopes will raise more than £3,000.

Kerry was diagnosed with epilepsy when she was 28. She joined the Norwich Talk and Support group and a year later set up her own group in Lowestoft. She now wants the money raised from her Purple Ball to help others seeking support.

The ball is being held at the Wherry Hotel in Oulton Broad, near Lowestoft, on 30 March. The event includes a band, raffle, auction and buffet, with guests

expected to include local mayoress Sonia Barker and MP Peter Aldous.

On Just Giving, 10-year-old **Lyla**, who had her first seizure last year, is raising money to “support those less fortunate than her”.

On her page, the family said: “Lyla has taken her new challenges on in the most positive, resilient way. She doesn’t let it stop her doing things she wants to do, she doesn’t believe that it makes her any different and she isn’t scared to tell people that she has epilepsy.”

Elsewhere, **Kerri-Lee Whiting** and her daughter **Ella-Rose**, who has epilepsy, are holding a bake sale and raffle to

With Purple Day coming soon, here are a few of the events taking place across the UK and Northern Ireland

raise money and awareness.

And, at Epilepsy Action HQ we will be holding a Bake Off competition and bake sale, and we are offering readers the chance to name and win our Purple Day puppy (pictured above).



To join in this Purple Day go to: www.epilepsy.org.uk/involved/fundraising/purple-day

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Reliance Technology Care Solutions is proud to be partnering with My Medic Watch to provide innovative smartwatch apps that can detect movement associated with seizures and general falls. Users can set up key contacts who are notified when the smartwatch detects an incident or when the user raises the alarm themselves. If a contact does not respond, then support is only seconds away with our 24/7/365 in-house monitoring centre and we can escalate all alarms through the emergency services if required.*

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*Reliance Technology Care monitoring service and website going live in April 2024.

Fighting *for equality*

Since her son Oliver died in 2015, Paula McGowan has been campaigning for equal treatment for people with epilepsy and intellectual disabilities. She talks about joining Epilepsy Action as ambassador



Award-winning activist **Paula McGowan OBE** has dedicated her life to campaigning for the equality and equity of health and social care for intellectually disabled and autistic people. At the beginning of the year she joined Epilepsy Action as an ambassador.

“Epilepsy is so poorly understood,” says Paula when we meet over Zoom. She’s currently living in Australia with her husband Tom who is in the RAF. She teaches at a primary school during the day and speaks to charities, health and social care organisations, and politicians in the evening. “I’m really interested in the brain and neurology, and how epilepsy affects the brain, and of course it is very personal to me.”

Paula is the founder of Oliver’s Campaign, which lobbies governments and health and care organisations to treat intellectually disabled and autistic people equally.

In April 2022, the campaign led to learning disability and autism training becoming law. The Oliver McGowan Mandatory Training has been designed, evaluated and is delivered alongside learning disabled and autistic people to meet this law.

Oliver’s story

Oliver was Paula and Tom’s teenage son. Oliver had epilepsy, autism and a mild intellectual disability, which led to diagnostic overshadowing. In October 2015, Oliver was admitted to a children’s hospital with partial focal seizures. These caused Oliver to be scared and confused.

“He’d gone in with a partial seizure – that’s all we’d taken him into hospital with,” says Paula, “because that’s what we were told to do, that’s what was in his care plan. And that’s how Oliver died – as a result of what was done to him, which was giving him anti-psychotics, when in actual fact he was just having a seizure. For him, that had devastating consequences.”

“We were just living this life until it all went wrong**”**

Over the course of a year Oliver was administered antidepressants and anti-psychotics because of a misunderstanding of his seizures and behaviours. The drugs caused changes to Oliver’s mood and increased his seizures. Paula said he would hallucinate, have up to 30 seizures a day, had problems urinating, extreme high blood pressure and sweating, all of which may have been linked to the medication. During this time, Oliver was moved to various hospitals. He was very frightened and told Paula he was scared of how staff were making him feel. In October 2016, Oliver was diagnosed with Neuroleptic Malignant Syndrome, a serious side effect of antipsychotic medications. He died a month later on November 11 .

“Oliver’s epilepsy was his biggest condition,” says Paula. “He had meningitis as a newborn baby, which caused an infarction (inadequate blood supply), which in turn led on to focal seizures. So, as a newborn he had seizures during meningitis and then – we were told it was febrile convulsions – but I think he must have been about 13 when I realized febrile convulsions don’t last more than three hours like his did.”

Oliver always remained fully conscious through his seizures. He could also



“Oliver’s doctor said he had never come across any patient who had so much insight into his own epilepsy and autism**”**

pre-empt when something was happening, which caused him to have anxiety.

Paula says: “He was aware something was going on inside his brain but he was never quite sure and it really did frighten him – so that would add to his stress. It was awful for him really, because he was very aware of himself. When one of Oliver’s doctors spoke to him, he said he had never come across any patient like Oliver – who had so much insight into his own epilepsy and autism.”

A life cut short

Oliver was part of the England development football squad and training to become a Paralympian. Paula says he was a natural leader and became a prefect at school. He attained several GCSE and BTEC examinations. He had a wicked sense of humour. He never failed to light up a room with the sound of his laughter.

“Up until that last year of Oliver’s life, life was going really well for us as a family,” says Paula. “We were just living this life until it all went wrong.”



“Oliver wanted to be the same as everybody else, but he was aware that these seizures were happening and it made him different. And he knew, because he was fully conscious, that it would affect his wellbeing. It would affect how he thought and how he spoke – and it really had such an impact on his life. The behaviors around seizures were so poorly understood – and by that I don’t mean he was aggressive, but he was anxious.”

Oliver McGowan Mandatory Training

Oliver’s Campaign is all about raising awareness and teaching health and care staff about these behaviours – that people with intellectual disabilities, autism and epilepsy can behave differently.

“People need to really understand what’s going on – and rather than seeing people as behaviour, it’s actually a part of seizure activity. I think that it is so poorly understood,” Paula says.

The Oliver McGowan Mandatory Training has now been rolled out across the NHS and Paula is campaigning to see it introduced in schools.

“I started a petition just before Christmas, which gained 70,000 signatures that was debated in parliament,” she says.

“Just before Christmas I was given about 48 hours to go in an aeroplane back to England,” she says, “because I feel so passionate about this. I went back home for a month, came back here and had another meeting with parliament over Teams.

“Our schools need training on understanding seizures, especially seizures that are less common. I would like to see training being designed and delivered alongside people who experience seizures. It is essential that teachers learn about epilepsy, directly from those who have it.”

Joining Epilepsy Action

Paula was invited to become an ambassador for Epilepsy Action earlier this year and the charity is thrilled to

“**I could feel Oliver the whole time saying: ‘Keep going mum, keep going’**”



From left: MP Gillian Keegan and Paula McGowan

have her on board. In June 2021, she received an OBE in recognition of her outstanding service to people with autism and intellectual disabilities. She is also a patron and ambassador for several charities and organisations.

Speaking about what she wants to achieve with Epilepsy Action, Paula says: “As a charity, it is what Epilepsy Action does best – raising awareness, education, improving and saving lives. It is about making a difference for everyone who has epilepsy, their families and carers. I would like the charity to be more visible and accessible to the public and all professional services.

“I would also like to see the epilepsy charities more joined up and speaking with each other – that would give a lot more strength and power.”

Paula’s work is also going international, as she uses her platform in Australia to influence leaders there. But she’s also made waves closer to home in Ireland and Jersey.

“I’ve spoken to the Australian Royal Commission,” she says. “We had a lot of similar problems over here to the inequality of people with intellectual disabilities and they asked me to be one of their main witnesses. That was massive. I’m doing my bits of meddling over here as well.”

Far from being a challenge to her campaign, living in Australia has actually allowed Paula to expand her work.

“I live in a place called Newcastle,” she says. “When I got the OBE, all the kids in the school and the teachers organized a Queen’s tea party for Mrs McGowan.

“If I had been living back home in the UK, I couldn’t have done a day job. I couldn’t have been able to teach, because as soon as the UK wakes up I’m in meetings. Because I’m here, and we’re at opposite ends of the day, I can do my job. I come home and then I do all the paperwork with NHS England and then I do all the meetings. So, it affords me to do both.”

Meanwhile, she’s also been battling cancer. “I did this all through an advanced cancer,” she adds. “I’d be sat in my chair having my treatments and I’d be still doing it.

“I believe Oliver is behind me. I feel him pushing me in the direction. Sometimes when we come across obstacles, so many people have said to me: ‘You will never get this, you’ll never achieve it, it’s never going to happen, we’ve been trying for years on years.’ And, I just kept so focused, but I could feel Oliver the whole time saying: ‘Keep going mum, keep going.’ And that’s what’s kept me going.”



Find out more about Oliver’s Campaign and The Oliver McGowan Mandatory Training on Learning Disability and Autism at www.olivermcgowan.org



Sarina Johal talks about her father Jas, and how the family are keeping his memory alive by raising money for Epilepsy Action

When Jas Johal passed away in October 2022 he was two days away from turning 60. His family were excited to celebrate and had planned some birthday surprises. They were devastated to have lost someone so dear to each of them.

“He was the heart and soul of our family and we think about him every day,” says Jas’ eldest daughter Sarina. “So, even though it’s been more than year since we lost dad, we wake up some days and it feels like only yesterday that we lost him. It’s been a really tough time.”

To remember their dad, Sarina and her family decided to do some fundraising.

“When Dad passed away we made the decision to raise money for four different charities and one was Epilepsy Action,” she says. “The charity was our first choice because epilepsy was dad’s longest illness. Due to other members in our family also suffering from the condition, it felt right to donate a charity we supported”.

In 2023, the family donated nearly £2,000 to multiple charities. For Epilepsy Action they raised £900. Jas, who was a businessman from Derbyshire, passed away from pneumonia but also suffered from other underlying health issues.

“Dad tried hard to remain positive about his epilepsy and would encourage

us all to research the illness and to support people with epilepsy. Dad always showed us that despite any illness, you have to keep fighting – which is exactly what our beloved dad did, he was strong-willed.”

The family want to keep his memory alive, but also ensure others living with epilepsy are supported.

“We want to raise awareness and share our dad’s story because we’ve had experience of epilepsy in the family, we know how challenging it can be for everyone, including the person diagnosed.”

Jas was diagnosed in his thirties after suffering from tonic-clonic seizures.

“When I was little and he would fall and have a seizure, it was very scary,” Sarina recalls. “My auntie would comfort us and say: ‘It’s okay, your dad’s alright. He will come around’,” she says. “I remember her saying to me: ‘He’s just having a little sleep, he’s tired. Once he’s had his rest you will be able to sit with him.’”

Sarina’s auntie would show the girls what to do when someone had a seizure: how to put them into the recovery position, to move everything away, let them have the seizure before you touch them and make sure the airways are clear. “Then as we got older, we learned more about the condition and what we could do to support dad. I was also interested in researching how it can impact the brain,” says Sarina.

Jas always spoke openly about epilepsy.

“He would answer any questions we had, she says, “and when his sister was diagnosed, he supported her through her journey. He was very caring.”

Sarina adds: “As difficult as it was to grow up with a parent who had epilepsy, the more dad would speak about it, it was no longer a scary illness, which I thought it was as a child. Through our family’s epilepsy journey, we have learned it is so important that loved ones of the person with epilepsy are spoken to and supported alongside the person diagnosed. You can still live a good life, despite any illness, as long as you have a supportive team around you and a good understanding of an illness and learn ways to live with it, which is what we had to learn as a family.”

To honour Jas, the family has decided to do something for charity every year.

Sarina says: “It only feels right that we take what dad has taught us and try to move forward living our lives, with our beloved dad forever in our hearts. We miss him dearly, but we are all blessed and honoured with the love and care he provided his family with,” she says.



For more information about giving in memory go to:
www.epilepsy.org.uk/donate/give-in-memory

Bob the painter



Artist, teacher and fundraiser Bob Sutcliffe tells **Grace Wood** about his upcoming exhibition and book release

“I didn’t paint when I was first diagnosed,” says artist and teacher Bob Sutcliffe.

“But my brother knew I couldn’t go through another period of illness without something to relax me. I needed to know that it was an awful thing to do to sit and watch episodes of Dallas. That is not healthy. Otherwise we’d all be getting TV therapy on the National Health Service. I knew I needed something in my life that would change it.”

And art has changed Bob’s life. When he was diagnosed with epilepsy aged 36 he was working as a landscape architect at the National Park Authority in the Lake District. During one of his first seizures he stood up during a board meeting, announced to the room he was “bored” and then “had a big seizure”. He also began to notice he was having other odd symptoms, he says.

“I knew I wasn’t right because I could drive from place to place and have no recollection of how I got there. So I went to the GP and said: ‘I know it sounds silly, but I don’t know how I got from one place to another’ and it frightened me because often it was when I was driving. My GP said: ‘I think that sounds like epilepsy.’”

In the following five years he had regular seizures and struggled to find medication to keep them under control. A specialist consultant in Lancaster told him he was unlikely to ever be able to work again.

“I was not really myself. I’m anxious for a week up to a seizure – and it took me ages to realise. My wife would know that but she wasn’t able to think: ‘Oh, that’s going to be a seizure in a few days’.”

A family friend recommended The Walton Clinic in Liverpool. “There

was an amazing doctor who I saw and he basically saved me,” says Bob. “I’ve been so blessed. I decided when I got back into work: ‘I’m going to go and do something I really want to do. I’ve been given an opportunity here’, and I’d always wanted to teach so I trained as a teacher.”

Bob became a teacher, but a heart attack and a change of medication left him struggling with anxiety.

“I can manage anxiety by reading, walking, in a light sense, but I was genuinely anxious about having seizures again and I think that was then causing more seizures so I was in a vicious circle.”

For Bob, painting became his therapy.

“I really do think that I’ve gained therapy from every minute I spend painting,” he says.



“I needed to know that it was an awful thing to do to sit and watch episodes of Dallas. That is not healthy”

“If I didn’t paint I wouldn’t have any outlet. I just know that I wouldn’t find it easy relaxing. Absolutely crucial to managing epilepsy as a life-long condition is to have some sort of outlet to reduce stress, to reduce levels of tiredness.”

Epilepsy Action supported Bob through these tricky times, and not long afterwards he decided he could use his skills to give something back.

“My mum and dad were struggling to know how to help me,” he says, “especially when I was off work. My wife was carrying on working and she wasn’t with me all the time, but my parents were and they didn’t know what to suggest. We found the Epilepsy Action helpline and I was able to do research on what might help or look at different people’s views on medication.

“I’ve always felt as if it’s part of a family really. People have been really helpful, and do know of me there, and that made a difference to me feeling a sense of worth. I wanted to say thank you. I got in touch with the fundraising team and I said ‘I’m painting’ would you like these?”

He now sells greetings cards to raise money for Epilepsy Action. His Christmas cards regularly sell out.

“The very early Christmas card range

that Epilepsy Action sold was painted with broken wrists from seizures,” he says.

And now he also raises funds for charities in his local area. They are on sale online and in Booths supermarkets.

“When I was starting to share that I was painting for charity someone said: ‘You need to get on social media’. Facebook suddenly became this place where people got in touch. And then someone who I’d gone to nursery school with remembered me and she got in touch and said: ‘My husband, who was at your school, he works for Booths and we think you should sell your cards at Booths’.”

Bob now sells up to 1,000 cards a week. He has raised more than £25,000 for Epilepsy Action by selling paintings and cards. In 2022, he received an OBE during the Queen’s Platinum Jubilee honours. The honour allowed him to set up The Creative Health Trust, which now has trustees who manage requests for funding.

“It’s only in its infancy because it’s in its first year,” says Bob, “but we’ve already handed out four grants – they’re small but they make a big difference.”

The trust often awards grants to hospices – something close to Bob’s heart.

“I went to see a hospice that had benefited from some of my fundraising

and they showed me their art therapy room and how valuable it is. The amount of work that happens at hospices is unbelievable, which is beyond the side of it that we all have an understanding of.

“We’ve part-funded an art therapist’s salary but we’ve also funded books and art equipment,” he says. “It’s so they can spend on art activities without worrying about spending money that would be best spent on medical activities.”

Bob has also written a book to raise even more money for the trust and is presenting his work in a outdoor exhibition around Cumbria.

The artworks are printed on weatherproof canvas and the giant easels are specially made to withstand the Cumbrian weather.

“The exhibition is going to be at Levens Hall near Kendal,” he says, “which has the world’s oldest topiary gardens. It’s a really interesting setting. It’s very old and my paintings are going to be outside among these world-renowned gardens and then it’s going on tour.

“People will be able to walk around and see them. They look as if they’re on their easels. Eventually it will get donated to hospices and it will go out in their gardens and stay there.”

The book, titled *Tree Therapy*, goes alongside the exhibition and was released around Christmas time. Alongside the exhibition work, it also includes some new paintings.

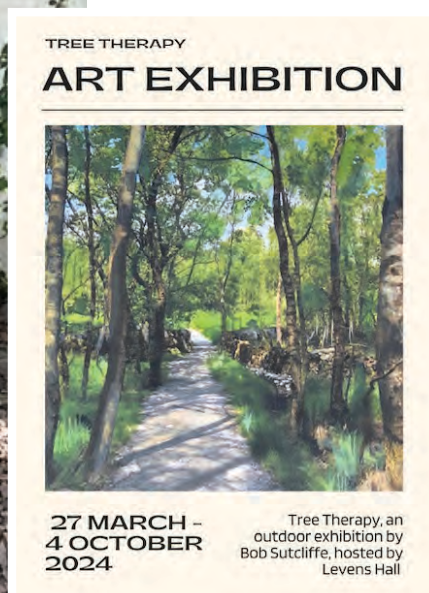
Bob says: “It’s a hardback book with pretty much all the paintings in it. It’s got a section where other people have put their work in, encouraging everyone to have a go at painting, relax and see the benefits of doing something creative.

“The book is very much about epilepsy and how I came through all that and what my life’s like now. I’m passionate about people reading what I’ve done. If you’re feeling that real sense of loss you get when you’re diagnosed with epilepsy, there is light at the end of the tunnel.

“The book is dedicated to people who live with epilepsy and the people who support them. I’d love it for people to see it as a really positive thing – that you can be successful, you can still achieve with epilepsy.”



“You can be successful, you can still achieve with epilepsy”



To buy the book and find out more about the exhibition go to: www.bobonpaintings.com/tree-therapy

Superman supporter

Fundraiser, campaigner and businessman Rob Moriarty tells ET about his new autobiography, which is raising money for Epilepsy Action

Rob and his PA at the One in a Million Ball

Rob Moriarty was the Christopher Reeve to Carla Rankin's Robin Williams.

"Her childhood hero was Robin Williams, Christopher Reeve was mine," says Rob. "And they were best friends. Reeve – who played Superman back in the 1970s and 80s – had a high-level spinal cord injury in 1995 when he was riding a horse."

Rob also has a high-level spinal cord injury sustained in 1998. Carla had epilepsy.

"I knew Carla through university," Rob adds. "Within five minutes we got on like a house on fire. We realised we had very similar attitudes when it comes to living life with any kind of disability – though neither of us particularly called it that.

We could tell we were cut from the same cloth in terms of our attitudes towards what we had to put up with every day. We clicked pretty much instantly.

"She had a seizure and passed away in 2014 and it was one of those head-turning, 'what the hell?' moments. We'd only known each other for a relatively short amount of time but I had an inkling that I had to try to do something to help if I could."

After Carla died, Rob was involved in the One in a Million Balls, which were held by the Rankin family to raise money for Epilepsy Action. The balls also gave people a chance to remember Carla and celebrate her life.

"I helped them out with the tech side of things," says Rob. "The balls were amazing. During the early days of the

fundraising campaign we had lots of different people all doing their own individual things. I came up with my own versions, because I can't do things like climb a mountain or run a marathon, nor do the ice bucket challenge because the temperature change would kill me. I did November, Dry January (quite possibly the most horrible thing I've ever done in my life) and 'Veg Feb' as I'm not a massive fruit and veg eater. I set myself the challenge of eating a different portion of fruit or veg every day. Across the three challenges I raised £1,500."

Ten years later, Rob is again raising money for Epilepsy Action. This time he has written the first part of his autobiography and is donating the proceeds to three charities. Rob's book,

“We had similar attitudes when it comes to living life with a disability – though neither of us particularly called it that”



Rob as a teenager before the accident

Rob skydiving earlier this year



Rob presenting at Huddersfield University



I'm Just in it for the Parking, is about the year he spent in hospital after sustaining a high-level spinal injury and the subsequent two years when he returned to school and got used to living his life again.

"I picked a fight with a swimming pool when I was on holiday in France with my parents and, as you can probably guess I lost quite resoundingly," he says. "You have eight spinal bones in your neck. I broke the third, fourth and fifth and was instantly paralysed from the neck down.

"They said there was a less than 5% chance I would ever move anything below my neck again, would need two years of rehab and 24-hour support for the rest of my life. Thankfully, only one of those came true. I need the 24-hour support, but I got out in 9.5 months, went back to my school and did my A levels, then came to the University of Leeds in 2001."

Rob was in the same halls of residence for the four years that he studied at Leeds and that's where he met Carla.

"I am very much still in contact with Carla's family," he says. "I've almost become an extended family member."

Today, Rob runs his own business and advises NHS England on patient experience.

"I run my own marketing-assisted-technology consultancy with my father and my main work is with NHS England. They have a strategic co-production group, which is made up of people with lived experience covering a variety of conditions and we're there to help healthcare professionals shape future policy so that it works for people."

He also does advisory and student support work for a number of universities.

“I picked a fight with a swimming pool when I was on holiday in France and I lost quite resoundingly”

"At Huddersfield University it's called the Public Partnership Group and Leeds Beckett call it Advice by Experience Leeds. We go into classes and share our experiences. It gives the students an environment where they can not only learn from us but practise with us. It's good fun and quite cathartic."

Rob came up with idea of writing the autobiography around the same time as the Rankin family balls. It has a companion piece, another book written about his accident but by his mum, from her perspective.

"Her profits are going to Spinal Research and the British Heart Foundation," he says. "I think for people who want to read both it gives you two perspectives on the same story, which doesn't happens very often."

For example, both books cover the day Rob, aged 16, was rushed to emergency services in France.

"I was taken into hospital and all of the doctors were swarming around me," says Rob. "My mum – who was a French teacher for most of my life – was translating what they were saying, she was my lifeline for what was going on.

At one point she disappeared and the doctors were getting their dictionaries out and trying to help me understand what they were saying and coming with some badly broken English. I was desperately trying to ask them where my mum was.

"But, in her version of what happened you learn they were doing tests on me. One of the tests was a reflex on the bottom of my foot, where they stroked it to see if my leg would react and it didn't. She saw that and fainted, and so that was why she disappeared. I didn't know anything about it because I couldn't feel it."

It was Christopher Reeve's autobiography, *Still Me*, that gave Rob the inspiration to get out of hospital. And, during one of his lowest moments, he received a letter from the Superman actor that said: "If you keep your belief going, you can achieve your dreams, you just have to find a different way of doing it."

"Christopher died in 2004," says Rob, "but 20 years later he still has an impact on me on a daily basis. That's one of the reasons why I do what I do. If I can do anything to make it easier for the next person going through a similar experience then I've done my job."

Rob has chosen Epilepsy Action, Cancer Research and Spinal Research as the three charities he wants to donate to. So far, the book has sold almost 100 copies and many universities have already added it their reading lists.



Rob's autobiography *I'm Just in it for the Parking* is available on Lulu.com

Tip top teacher

The first Star Award of 2024 went to teacher Helen.
Words by **Rebecca Lock**

The first star award of 2024 went to Helen Kedie, a teacher from Cambridgeshire who went above and beyond to support a student with epilepsy.

Helen teaches Zac Navarro, 15, whose mum Ruth nominated Helen (pictured) for the award.

Zac has lived with epilepsy for most of his life. He has regular seizures and occasionally they are life-threatening.

“Ms Kedie is really kind,” Zac says. “She helps me by checking in on me regularly and contacts my parents whenever they’re needed. It can be quite stressful for her, but she deals with it really well. Without Ms Kedie, I’d be pretty screwed.”

Zac’s epilepsy can often affect him at school. He says: “My seizures can happen at random times or sometimes if I’m tired. I mostly have short seizures where I ‘lag out’ for about five minutes and then have to nap for half an hour. At their worst, the seizures go on for a long time and I sometimes wake up in hospital.

“For me, having a seizure is my brain computer crashing and you can’t turn it back on again. I have to lie down and can’t do much afterwards. It can be quite annoying when I’m doing schoolwork, playing football or practising the piano. When I wake up, I can rarely carry on or do anything. I sometimes have to miss out on school, meeting up with friends or going out with family, which can be a shame.”

Zac’s mum Ruth nominated Helen because she is able to worry less knowing



that Zac is under her care. Ruth says: “I can’t tell you what it’s like when you send your son out every day hoping that he comes home. To send him into the hands of professionals who care for him as much as you do is beyond brilliant.

“Zac is a bright and brilliant boy, and he deals with an awful lot in life. Helen has leant into safeguarding him in a way that, instead of restricting the things he can do, teaches him how to look after himself and teaches people in school how to stand alongside him.

“As well as being a lovely person, she is a genius at ‘structured communication’ – she always knows how Zac is and what he’s up to because she seems to coordinate communication with everyone

who teaches him. This has allowed her to do things such as ask if he wants to come home and sleep if some teachers have noticed he’s tired. That kind of noticing can be life-saving for Zac. She also constantly thinks about and reviews policies to make sure he can maximise life, but in a way that he can feel and be safe in school.

“I wanted to nominate Helen because she’s an absolute star and makes things just that bit easier for us all.”

Helen says the whole school help support Zac. “I’m not sure I have ever won an award at school so it’s a first for me,” she says. “But I also want to emphasise that it is a group effort. Zac’s teachers are amazing. They go above and beyond for him all the time, so the award is really for the whole school and not just for me.

“When I first spoke to Ruth after Zac arrived in year nine, she was very clear that she wanted him to have the most normal experience he could, and I that has underpinned my attitude and approach ever since. Zac just wants to come in, go to lessons, play football and go to his drum lessons – he really doesn’t want a fuss.

“Zac is a lovely lad and it is a pleasure to be his tutor. Zac’s parents are amazing. There is the sense that we are all working together to make Zac’s time at school as positive and enjoyable as possible.”



For more information about the Star Awards, or to nominate someone, visit www.epilepsy.org.uk/stars.

My *amazing* mother

February's Star Award went to Hannah, a star mum. Words by **Rebecca Lock**



Hannah Murphy was nominated for a Star Award by her daughter Harriet Clare for being an unwavering source of support.

Harriet, 28, was diagnosed with epilepsy when she was three years old and says it was “a debilitating condition to cope with” when she was younger.

“I faced daily struggles at school and home during my teenage years and then had to navigate hospital appointments, emergencies, work, applying for benefits and moving out with my partner,” she says. “But my mum has always been by my side to support me.”

Hannah, 50, says she feels very privileged to have been nominated by her daughter. “I don’t think I have ever received such an award before and so was surprised when she told me that it had been accepted,” she says.

“I have always been so close with my daughter, and it feels amazing knowing that she felt the need to get in touch with Epilepsy Action to share our story. It also feels great to know that others will be able to read our story and see how far we have come over the years, despite all the struggles that living with epilepsy brings.”

Hannah was a single parent to Harriet and her two sisters, and living with epilepsy was not always easy for the family. But Harriet says her mum was always there for her.

“I have two amazing sisters who have witnessed the reality of what it’s like to

live with a loved one with epilepsy. I can’t deny that I didn’t push one or two of my mum’s buttons a few times but no matter the situation, she was always there for all of us,” she says.

“Being a 90s baby, support was often hard to reach and school was very difficult for me. Coping with bullying, a general lack of understanding towards hidden disabilities from teachers and being pulled aside from certain school activities was difficult. As I got older, one of the main things I struggled with was watching my friends get their first jobs, driving and moving out. At that point, I just saw everything as a total lack of independence and found it really hard to stay positive about anything.

“But my mum refused to watch me in this situation. She did everything she could to help me reach out to others, boost my spirits, gain confidence and show me that it’s not all doom and gloom.”

When Harriet met her partner five years ago, she took the step to move out of home for the first time. Hannah supported Harriet throughout the process.

Harriet says: “My mum has always treated him as part of the family, especially after seeing how he looks after me and supports me in any way he can.

She was even happier to know that he was the perfect person for me to start my own life with and helped us both in every way she could with moving out and applying for benefits as a couple.

“However, once I moved out, I definitely realised the reality of not having my mum and sisters right next to me. It was hard for the first few weeks, but my partner was right by my side, we adopted our kitty, and my mum and sisters are always just on the other end of the phone.”

Another big challenge Hannah faced was having to leave her job.

“I had to resign from my dream job in childcare nearly four years ago due to my health and the frequency of my seizures,” she says. “I dropped into a bad place again as the independence of work has always been so important to me. But did mum ever let that get me down? No. She was there in every way.

“It may take a long time for some people to come to terms with the reality of living with any disability, and there are always going to be bumps along the road. But if it wasn’t for my amazing mother showing me that I’m a true fighter, and how important it is to stay strong and give support to others, I honestly don’t know what I would do.”

Could you join our Council?

As Epilepsy Action prepares for this year's council elections, we spoke to chair Jane Riley about why you should get involved



As members of Epilepsy Action, every year you have the opportunity to choose your trustees or stand to become a trustee yourself. The trustees make decisions about both the everyday work and the long-term plans for the charity. Together they make up the Council of Management.

Epilepsy Action's governing rules require that a third of the Council either retires or stands for re-election each year. This year there are five positions open for election. Anyone who has been a member for more than 12 months can stand for election. The term usually lasts three years. All members can vote for the Council of Management and be nominated to become a trustee. With this year's elections around the corner, Council chair Jane Riley explains why she became a trustee...

Why did you join Council?

My son Matthew was diagnosed with

epilepsy when he was 12, which was 19 years ago now. At the time he had no neurologist or epilepsy specialist nurse. He wasn't controlled and still isn't, but at the time there was no one else to talk to and it was very isolating. I Googled to see if there was any support I could receive for myself but also ask some questions for Matthew. Epilepsy Action came top of the search and I found there was a dedicated helpline I could ring. It was the first time anybody had ever really understood what we were going through as a family, a huge relief! From that point on I became an accredited volunteer for the charity. I got involved not just for Matthew's sake but it was actually something I felt I could do to support myself – to be involved in an organisation where other people understood and were going through similar problems and issues. You feel better supported, but you also feel you're giving back. A short while later, it came through in the magazine that they were looking for

trustees. I thought: 'Well, there's probably no chance that I'll be able to do that, I just thought I wouldn't have the right skills but I spoke to Phil (chief executive) anyway and said: 'Is it something that I might be able to do?'. He really supported me and the rest is history – that was 10 years ago. It's all about having the confidence to do something that you believe in and feel that you can affect other people's lives – not just your own family's.

What have been some of your highlights?

There's been a number of highlights. I think the first highlight is that I can be influential but also have a voice and be listened to. Once you realise that you are having an influence on decision making that is useful and respected, you start to think: 'I can actually do this. It's making a difference.' But I've also learned that sometimes for change you have to be patient. One of the beneficial things I've found is that it's

great to be part of a team. It's fabulous to be among a number of people who have a similar outlook, passion and enthusiasm to make change happen. One of the other highlights is that you're with people from varying walks of life, who have completely different backgrounds and stories to tell. Central to this is that everyone is there for the same reason and that's to make a difference and to support others, to ensure that you learn from your own story and help make things better for others.

What have you enjoyed taking part in recently?

The all staff away day earlier this year was amazing! It's fabulous to see the changes with the strategy, the positivity around that, the challenge of that. I went to the Welsh Senedd in January too and I met with clinicians and others there who are all passionate to improve epilepsy care but all for different reasons. We're always on a journey together. Sometimes things happen that you might not expect.

How did you become chair?

I became an officer, and I couldn't believe it but then I became honorary treasurer and then vice chair and now I'm chair. I stand there and go: 'Am I really doing this?'. My mum would have been so proud of me. She was always proud that I was a nurse but to undertake this as well, she'd have been blown away. I'm hugely proud too of what we achieve, but we've some way to go. We need people who have that desire to make change – to have a voice, to be enthused, to bring some passion, not to stand back and let things happen but to be counted.

What makes a good Council member?

You don't need to have any major qualities. You need passion, desire and enthusiasm – you will build your confidence, you don't need to have that to start with. It's a real family-orientated place to be. You have mentors and you're guided all the way along the journey – as much or as little as you want. But you need to have the desire and to have a reason for being there. Usually, it's because you have epilepsy or a family member or someone close to you does. You might be a carer or otherwise, but you've been through something that makes you think: 'I've got a voice here and I need to let it be heard.'

It helps if you've got skills and talents or expertise in certain areas –



you might be involved in finance or health and social care services, or you might have been a carer for a long time, or you might be new to epilepsy. For whatever reason, you can bring something to the table that's new. You will be surprised by how similar yet different you are to everybody else on the Council.

What would you like Epilepsy Action to achieve this year?

It's a fabulous time to join. We're moving forward in a whole new direction. So, what I'd like to see is that we continue to

move forward to deliver the outcomes that are in the strategy. It's going to be a real challenge. It's going to need us all to pull together and for us all to lead by example, but I'd like to see that we deliver what we set out to achieve. Because without taking a risk then you never get as far as you would like to go.

Why should members apply to be trustees?

Come forward if you have desire, passion and enthusiasm, and some spare time. We need the whole epilepsy community to come together to help everyone who is affected by epilepsy. If everybody were to sit there and do nothing then there would be no change and no improvement for people with epilepsy, their families and their carers. So why not be there? Because you could be the one person who makes the difference.

“You could be the one person who makes the difference”

To apply to become a trustee, download a nomination form from www.epilepsy.org.uk/trustee.



You can request a paper form or find out more about the Council of Management by contacting Epilepsy Action chief executive Philip Lee at plee@epilepsy.org.uk.

Nominations must be supported by two other charity members, who must also provide their details. If you are not in contact with any other members, we may be able to help you.

Council of management

A t a meeting of the Council of Management held on 6 February, the following decisions were made.

- Some structure and a framework were agreed for the review of the charity's constitution and governance.
- A new environmental policy for the charity was approved.
- Initiation of a review of the providers of the charity's investment management service and the charity's audit service.
- Approval of a total return approach to the charity's investments.
- Appointment of Dr Sheila Sheppey as a member of the charity's

National Advisory Council for Wales.

- Appointment of Yasmin Ajanni and Ajeola Akanni as members of the charity's Ethnic Communities Advisory Panel.
- Approval of the following statement about the principles of good governance: 'The Council of Management has adopted the Charity Governance Code as a tool for continuous improvement towards the highest standards in governance. The principles established by the Code provide the aspirational benchmark for Council appraisal.'
- Appointment of June Massey to the vacancy on the Corporate Governance committee.

Council had a detailed discussion about safeguarding and made the following decisions:

- Council members will receive annual awareness training on safeguarding.
- Council will review the charity's policy on safeguarding at least annually.
- Council will review operational safeguarding overview reports on a regular basis.
- Council will appoint a lead trustee on safeguarding.
- All Council members will be required to pass a standard DBS check.

The next meeting of the Council of Management will be on 9 April 2024.

Did you know that another way of supporting Epilepsy Action is to leave a gift in your will?

Even 1% left would make a huge difference to people's lives.

For more information visit epilepsy.org.uk/legacy



Epilepsy Action Lottery

Play today for £1!

Our weekly lottery gives you the chance to win £25,000 while supporting the vital work we do to help everyone impacted by epilepsy.

As well as the chance to win big, 50p of every £1 allows us to continue our vital work in helping people living with epilepsy. It costs just £1 per entry then you submit your details and we will send you your lucky numbers.

Visit the Epilepsy Action website to find out more and sign up to play. bit.ly/EpilepsyLottery

A minimum of 50% of the total lottery proceeds are spent on supporting the work carried out by Epilepsy Action. 18.4% is spent on prizes and 31.6% is spent on the running and administration of the lottery.

GambleAware

Epilepsy support for you

For some of us, epilepsy can be an isolating condition that can make us feel lonely and misunderstood. But there are actually many people in the UK and around the world with the condition. One of Epilepsy Action's roles is bringing people together to share their knowledge and experiences and talk to others going through similar situations.

Join one of our virtual groups

We know many of you take comfort from connecting with others affected by epilepsy. We have face-to-face group meetings as well as online meetings using video calls instead (technical support is available). If this is of interest, you can find out more at epilepsy.org.uk/virtual-groups or by calling **0113 210 8800**.

If you previously went to a local support group, they may also be offering a chance to get together online. You can find out if this applies to the group you attended by emailing Iso@epilepsy.org.uk or calling **0113 210 8899**.

Online resources

There are many ways to be part of Epilepsy Action's online epilepsy community. You can find us on:

- HealthUnlocked (healthunlocked.com/epilepsyaction)
- Discord, (bit.ly/3vHLOkT)
- Facebook (facebook.com/epilepsyaction)
- Twitter ([@epilepsyaction](https://twitter.com/epilepsyaction))
- Instagram (bit.ly/3zSKMVM)

There are also a number of websites which can help people find pen pals, such as penpalworld.com, or ablehere.com for people with disabilities and conditions. Bear in mind that these websites are not part of or run by Epilepsy Action.

“One of Epilepsy Action's roles is bringing people together to share their knowledge and experiences”



For more information scan the QR code



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



Epilepsy Action is here for you



helpline

Epilepsy can be very confusing. Our **Helpline team** are ready to answer any questions you might have on the phone, via live chat or email.



counselling

Counselling can be really helpful when things get tough – we're ready to help in Wales and Northern Ireland. Our professional **Counselling team** can provide the support you need online or over the phone.



talk and support

If you want to talk to other people about life with epilepsy, you're welcome to come to one of our **Talk and support** groups to meet and share your experiences either on line or face-to-face.



family support
Northern Ireland

Epilepsy doesn't just affect the person with the diagnosis – that's why our **Family support** service is there for family members and carers in Northern Ireland.



befriending

Not everyone's ready for a group, though – one-to-one support through **Befriending** might be better for you. We'll connect you to a volunteer who will offer you a friendly listening ear either on the phone or online.



epilepsy.org.uk/support

“Epilepsy Action has made such a big difference in my life... they have helped me learn to live with my condition”

Epilepsy Action Helpline: freephone 0808 800 5050
email helpline@epilepsy.org.uk epilepsy.org.uk

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