

epilepsytoday

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Step by step

**Briar Nolet's journey as
a pro dancer with epilepsy**

Also in this issue

- Living with epilepsy, autism and other conditions
- Transitioning young people into adult epilepsy services
- Epilepsy Action Awards



editor's letter

this issue...

Welcome to the March 2020 issue of *Epilepsy Today*!

I absolutely adore going to the cinema. That feeling of being immersed by a massive screen, a thumping score, a big tub of popcorn (sweet, naturally) and getting lost in a great story. For just a couple of hours, all my troubles and worries dissolve.

So I think it's a shame that many fellow cinema-goers with photosensitive epilepsy (PE) have had to miss out on the latest Star Wars movie. The Rise of Skywalker, the final part of the latest sci-fi saga, contains flashing and strobing effects in their lightsaber duels and laser battles. People have got in touch with me to say they went, spent much of it covering their eyes and didn't enjoy the experience. Or they vented their disappointment that they were missing out. Films are still being released that have these effects, and some with warnings that come too late. More concerning is that The Rise of Skywalker's director, JJ Abrams, is actually a vocal supporter of people with epilepsy. This is a disappointing situation, and more needs to be done to ensure everyone can enjoy their movies.

We have a bumper edition for you this issue. We speak to Molly, who tells of her experiences of living with not just epilepsy, but high-functioning autism and functional neurological disorder. The latter is a rare condition where the nervous system is disrupted, meaning movements can be difficult or weak. Next up is Dean, whose love of cars led him to a promising career abroad. We also speak with Dr Chinwe Ude, who talks about the state of transitioning young people with epilepsy.

Our cover feature focuses on Canadian dance sensation Briar Nolet, star of such shows as The Next Step and World of Dance. When she was younger, her epilepsy played havoc with learning routines, and almost put a stop to her promising career in showbiz.

Finally, My Journal features Lauren, artist, creator and owner of Lauren's Cows. You may have seen some of her work if you've been paying attention – one of her cow paintings fetched £596 for our 2019 National Doodle Day. Read more about how epilepsy and a single painting changed her life on p26.

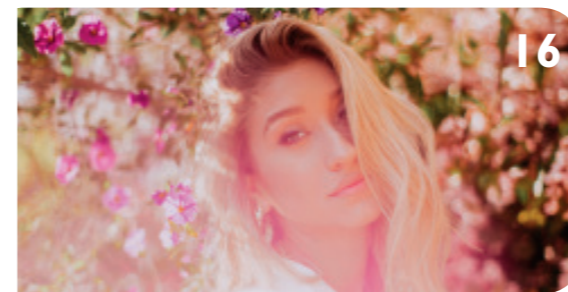
Enjoy the issue and I hope 2020 is great to you!

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People have got in touch with me to say they went to the movie, spent much of it covering their eyes and didn't enjoy the experience at all.

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Five-year-old cycles 90 miles for Epilepsy Action

A five-year-old boy has raised more than £1,000 for Epilepsy Action by completing a 90-mile bike ride.

Max McLeod, accompanied by his dad Kevin, set off from Halifax and rode to his grandparents' house in Winsford, Cheshire. The pair mostly rode on canal paths and took just five days to complete the journey. They stayed in hotels along the way.

Max wanted to raise money to help his cousin Oscar, who was diagnosed with epilepsy. Originally, he wanted to complete a parachute jump, but was persuaded by his parents to do a bike ride. He has only just learned how to ride his bike, having only had his stabilisers removed in March this year.

On his *Justgiving.com* page, Max says: "My cousin Oscar has epilepsy. It means his brain is not the same as ours."

After the ride, Max said: "There were lots of fields with mud – I tried my hardest."

Max's parents said: "Max would like to thank everyone who has sponsored him, he has loved hearing all the comments people have left him. We're really proud of the money he's raised for a worthy charity all in honour of Oscar, the greatest little warrior we know!"

For more information and to donate, visit [justgiving.com/fundraising/maxmcleod](https://www.justgiving.com/fundraising/maxmcleod)

Disney warns of seizure-risk with latest Star Wars film

Disney has advised that the latest Star Wars film could pose a seizure risk in people with photosensitive epilepsy.

The Rise of Skywalker was released in the UK on Thursday 19 December and fans turned up in droves to see it.

Fans of sci-fi will know the Star Wars movies consistently features epic battle scenes, with lasers and lightsabers lighting up the big screen. And it's possible that flashing light and strobe effects during the film could cause seizures for people with photosensitive epilepsy.

This has encouraged Disney to issue the following statement to cinemas across the world: "We recommend that you provide at your venue box office and online, a notice containing the following information: Star Wars: The Rise of Skywalker contains several sequences with imagery and sustained flashing lights that may affect those who are susceptible to photosensitive epilepsy or have other photosensitivities."

Risks of watching the film could also include headaches and migraines from the flashing and strobe effects found in the action scenes.

There have already been reports of multiple fans having seizures after watching the film. One teenager in New Orleans claimed the strobing effects were so bad, she was forced to leave the screening in the first 30 minutes. Then, she experienced a seizure outside in the hallway.

In 2018, superhero sequel *Incredibles 2* also contained strobe effects, prompting cinemas to play messages to movie-goers warning them of the risk.

Cathy Vice was looking forward to the newest Star Wars film, but now says she'll have to miss out due to her photosensitive epilepsy. "I'm a huge Star Wars fan," she said. "While many in Hollywood are making movies more accessible, Disney is going the opposite direction and their movies are becoming more and more visually intense."

Jaap Broekstra has epilepsy and got in touch with *Epilepsy Today* to describe his Star Wars experience. "I already bought my tickets when I found out about the warning," he said. "I contacted Disney, asking if they provide timestamps of the flashing sequences, so I could set

silent alarms on my phone to warn me. Unfortunately they couldn't, and now having seen it, I fully understand.

"I didn't have any seizures, however, I didn't see much either. In the very first scene the flashes are very extreme and the final 30 minutes are full of those foreboding flashes. Even with my night glasses I had to cover my closed eyes. It's extreme and my advice is not to go."

A statement from American charity Epilepsy Foundation says: "The Walt Disney Studios and the Epilepsy Foundation are working together to advise photosensitive viewers to use caution when watching Star Wars: The Rise of Skywalker. The film contains several sequences with imagery and sustained flashing lights that may affect those with photosensitive epilepsy."



Trolls target people with epilepsy in online attack

Online trolls have deliberately attacked people with epilepsy by posting seizure-inducing videos on Twitter.

In November last year, malicious users hijacked Epilepsy Foundation's Twitter account @EpilepsyFdn and hashtag to post graphics and videos containing flashing lights and strobe effects.

It's not certain how many people have been affected, but the Epilepsy Foundation has decided to press criminal charges against the users involved. The organisation has identified more than 30 Twitter accounts responsible for posting the videos.

Jacqueline French is chief medical and innovation officer of the Epilepsy

Foundation. She said in a statement: "These attacks are no different than a person carrying a strobe light into a convention of people with epilepsy, with the intention of inducing seizures."

In response, Twitter took the measure to ban certain animated graphic files from its platform. This was after the social media organisation discovered a bug that caused these types of files to autoplay when tweets were sent.

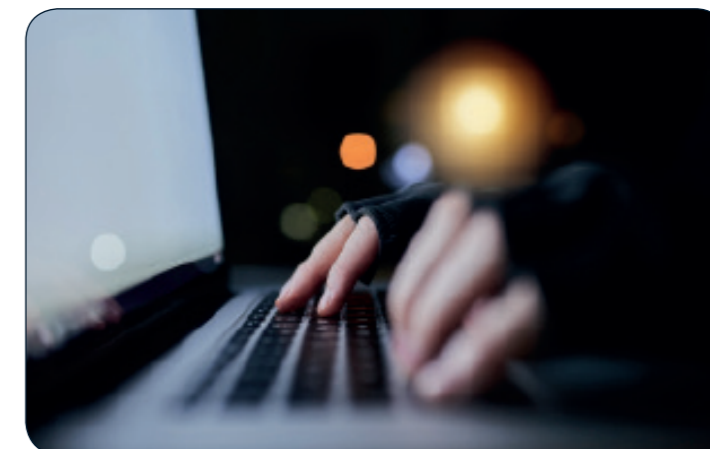
In a statement, Twitter said: "We want everyone to have a safe experience on Twitter. These graphics were fun, but they don't respect autoplay settings, so we're removing the ability to add them to Tweets. This is for the safety of people with sensitivity to

motion and flashing imagery, including those with epilepsy."

Back in 2016, a US jury decided that an animated image could be considered a deadly weapon. This was after a flashing graphic was sent to journalist Kurt Eichenwald, who has epilepsy, with the message "You deserve a

seizure for your posts". Mr Eichenwald then experienced a seizure seconds later.

Photosensitive epilepsy is said to affect around 3% of people with epilepsy. In the UK, around 20,000 people are said to be vulnerable to flashing lights or strobe effects such as those in cinemas or nightclubs.



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Cannabis-based drug fast-tracked for NHS access

Cannabis-based drug Epidyolex has been fast-tracked into the NHS, which could now help treat around 2,000 people a year.

Doctors are able to prescribe the medicine together with clobazam in adults and children aged two or over with Lennox-Gastaut or Dravet syndrome. Both are severe types of epilepsy and people with either Lennox-Gastaut or Dravet syndrome usually experience several seizures daily.

NICE has issued further guidance which states that the treatment should be reviewed every six months.

For people with Lennox-Gastaut syndrome, NICE says treatment should stop if the number of drop seizures does not fall by at least 30% after six months compared to pre-treatment. For people with Dravet syndrome, NICE says treatment should stop if the number of convulsive seizures does not fall by at least 30% after six months compared to pre-treatment.

Based on clinical trials, combined treatment with Epidyolex and clobazam was shown to reduce the number of seizures by up to 40% in some children. This news follows the NICE recommendation

in 2019, which stated Epidyolex should be covered under the NHS to help treat Dravet syndrome and Lennox-Gastaut syndrome. It's the first cannabis plant-based medicine to be recommended by NICE. In September, Epidyolex also gained approval from the European Medicines Agency (EMA) for medical use throughout the EU.

Epidyolex is an oral solution which is derived from the cannabis plant. However, it doesn't include the unapproved tetrahydrocannabinol (THC) psychoactive

ingredient, which provides the 'high' associated with cannabis products.

Many view this ruling as a step in the right direction for cannabis-based medicines. However, this hasn't stopped those affected by rare and severe epilepsies looking towards medicines that contain THC as potential treatments. The NICE guidelines on cannabis-based medicines do not advise about when and how drugs containing THC could be made available on the NHS. Instead the guidelines have made a number of research recommendations.

Epilepsy study shows link between brain activity and memory

A new study has found a link between memory and abnormal brain activity in people with epilepsy who have issues with memory.

The US research shows that in people with epilepsy, abnormal electric pulses from brain cells are linked with a brief interruption to memory. The researchers have called this transient cognitive impairment (TCI).

Understanding how this works could lead to improving treatments for

those with epilepsy, as well as understanding how memory works. The results of the research have been published online in the journal *JNeurosci*. Study lead Ueli Rutishauser is a professor within the Department of Neurosurgery at Cedars-Sinai Medical Center. "To our knowledge, our study is the first to investigate the actual mechanism of transient cognitive impairment in epilepsy," he says.

In the study, the research team looked at electrical

activity in the hippocampus, the part of the brain said to play a key part in memory. Electrodes were placed in the brains of 11 people with epilepsy, and the activity of cells in the hippocampus were recorded during a memory task.

The participants were shown 100 images. Later, a set of 50 of the same images were repeated a second time when mixed with fresh set of new images. After each image, people were asked if they had seen the image before.

Results showed that abnormal electrical pulses in the brain, known as interictal epileptiform discharges (IEDs), temporarily changed the firing of individual cells in the hippocampus. This affected people's ability to remember if they had seen an image.

Some people with epilepsy experience IEDs between seizures and report TCIs. However, it's unclear why IEDs disrupt memory in this way.

For the full study visit <https://bit.ly/382Wr3o>

'Glaring employment gap' for people with epilepsy exposed

People with epilepsy face a glaring employment gap, according to recent government figures highlighted by Epilepsy Action. Statistics show that as much as 66% of working-age people with epilepsy are not in work. This has prompted Epilepsy Action to call for fairer access to, and treatment in, the workplace.

The employment rate for people with epilepsy is far lower than for people with most other disabilities, according to data from the Office for National Statistics. The rate for people with epilepsy as their main condition is 34% compared to 53% for people with disabilities generally. This is compared to an employment rate of 81% for those without a disability. Research by the Trade Union Congress (TUC) has also highlighted that people with epilepsy in work are paid on average 11.8% less than non-disabled workers.

Some people with epilepsy are unable to work at all. But

depending on how epilepsy affects their daily life, many people can work with minimal adjustments. Despite this, they commonly report experiencing hurdles when applying for jobs or within the workplace. They say that disclosing their epilepsy at interviews can have a negative impact on their application. Many talk about experiencing discrimination from their employer or colleagues.

Philip Lee, chief executive at Epilepsy Action, said: "These figures are very worrying, yet they only skim the surface. Despite its prevalence, epilepsy is still a stigmatised condition in the workplace. From the initial application and job interview process to the day-to-day experience of working, many people with epilepsy encounter clear barriers and discrimination. This treatment can lead to fear of dismissal and even cause some people to hide their condition.

In a recent Institute of Employment Studies report, employers admitted they

were reluctant to hire people with epilepsy, largely due to safety concerns.

Neil, 57, from Oxfordshire, has been looking for work for the last two years and describes it as a demoralising experience. He went for a kitchen porter role and said the interview was going well until he mentioned he had epilepsy. This was something the Job Centre had advised him to do. Neil said the atmosphere immediately changed and the interviewer told him: "No, I want someone 100% and normal", and wouldn't

let him explain any further. He said the interviewer's comment hurt him far more than being rejected for the job did.

Philip Lee concluded: "Increased knowledge and a change in attitudes are the only ways we can start to close this inequality gap. We are calling on employers to take simple steps to help support people with epilepsy."

To access the Epilepsy Action toolkit for businesses to support their staff with epilepsy, visit epilepsy.org.uk/awarenesstraining



Researchers can 'switch off' seizures

Neuroscientists in the US have found a way to 'turn off' epileptic seizures in rats. The team have found ways to target specific sets of nerve cells, known as neurons, in the brain, depending on the type of seizure.

Finding these specific neurons suggests that epilepsy treatments can be improved. For example, deep brain stimulation could be used to more closely target cells in the brain responsible for seizures.

The study's senior investigator is Patrick Forcelli, an assistant professor in neuroscience and in pharmacology and physiology at Georgetown University Medical Centre. He said: "We have found a major choke point in epilepsy circuits in rat brains that we believe can be used to disrupt seizures or to stop their spread within the brain."

When certain neurons in the brain misfire, seizures occur. For decades, researchers have known that targeting an area of the brain known as the substantia nigra pars reticulata (SNpr) can help stop seizures. The tricky part has been following the circuits by which the SNpr controls seizures. "The SNpr is usually thought to be involved in movement and movement disorders," says Forcelli. "We knew targeting the SNpr can stop a seizure, but we didn't know how. Neurons in this area have pathways that go to many different parts in the brain."

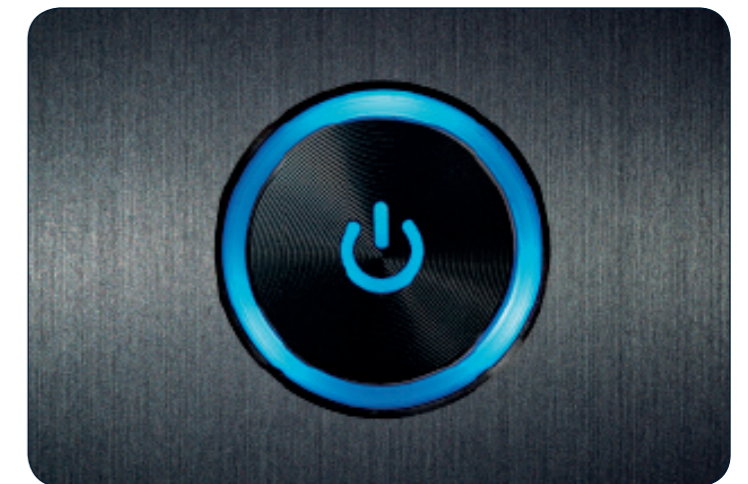
This study is built upon work which mapped out the basic neuron pathways in the brain responsible for seizures and epilepsy. The new research aims to create a more detailed version of this brain map. In this way, treatments such as brain stimulation therapy can be better targeted to specific areas.

Forcelli looked at four types of epilepsy in seizure-prone rats, to be able to analyse different seizure types. The team was able to stop seizures by placing light-sensitive ion channels (a type of gateway which only allows in certain chemicals) into neurons in the SNpr. When they were exposed to light, the neurons could be turned on or off. By silencing activity of the SNpr cells, the team were able to turn off seizures.

"For the therapy to work we need to know how the brain circuits work. Silencing one area that a SNpr sends signals to suggests we could develop better targeted therapies," Forcelli says.

The findings are now published in the online journal *Proceedings of the National Academy of Sciences*.

For the full study visit <https://bit.ly/30rKFxf>



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Online gamer calls emergency services for friend having seizure 5,000 miles away

A teenager having a seizure has been given the medical attention he needed, thanks to his friend raising the alarm despite being 5,000 miles away.

Aidan Jackson had been at home in Widnes, Cheshire, playing videogames online and chatting to his friend Dia Lathora from Texas, USA. When he started to make sounds of what she could only describe as a seizure, Dia asked if he was okay.

Aidan gave no response, so she immediately started searching for the emergency phone number for the UK. She managed to contact emergency services in the UK and thankfully had his address, so she relayed his details over the phone.

"I'm in the US, I'm currently in a call with my friend," Lathora told the emergency operator. "He had a seizure and he's not responding anymore. I do have his address."

Meanwhile, Aidan's parents were downstairs watching TV and unaware of the unfolding situation. They even assumed that the two police cars arriving outside their house were for another address.

When they received a knock at the door, the police explained they had received a call from America. The parents ran upstairs to find Aidan in a disoriented state.

"We are extremely thankful for what Dia did and shocked that we could be downstairs and not know anything was happening," Caroline Jackson said to BBC News. "Dia had our address but didn't have any contact numbers, so it was amazing she managed to get help from so far away."

Since then, Aidan has recovered and is currently undergoing tests to find the cause of the seizure.

Effects of cannabidiol on severe epilepsy studies

A new study could help explain why cannabidiol, a chemical part of the marijuana plant, reduces seizures in patients with severe epilepsy.

The effect may be due to a chemical reaction between cannabidiol and the epilepsy drug clobazam. The researchers looked at the effect of cannabidiol on reducing seizures in patients with Lennox-Gastaut syndrome. The study is published in the *British Journal of Clinical Pharmacology*.

The study author is Geert Jan Groeneveld of the Centre for Human Drug Research in The Netherlands. "The effects of cannabidiol on the seizure rate in those with Lennox-Gastaut syndrome could be explained through increased levels of clobazam in the blood," he said. "This might mean that cannabidiol alone may have limited, if any, seizure-reducing effects."

Most recently, Epidyolex has been approved by NICE for use in conjunction with clobazam in treating people with Dravet or Lennox-Gastaut syndrome.

Last issue...

In the December 2019 issue of *Epilepsy Today*, we featured an article titled Live better, life safer with epilepsy: the epilepsy-related deaths project. We would like to add that this project is being supported by the Octavia Morris Memorial Fund.

Researchers develop artificial intelligence to predict seizures

Artificial intelligence has been developed which could predict seizures up to one hour before they happen, with near perfect accuracy.

Researchers at the University of Louisiana in America looked at long-term EEG data from 22 patients to develop and test their AI model. In their trials they achieved a 99.6% accuracy rate in predicting seizures.

"Due to unexpected seizure times, epilepsy has a strong psychological and social effect on patients," said Hisham Daoud, a researcher who co-developed the model.

Hisham said that being able to predict seizures would greatly improve the quality of life for patients with epilepsy.

In addition, it would give them enough time to take action before a seizure occurs.

Previous attempts to look at brain activity to predict seizures have always been a challenge because every person has a unique brain pattern. These patterns have to be identified and then categorised using a classification system. The team designed a computer system which automatically performs both of these jobs, enabling earlier and more accurate seizure prediction. They also fine-tuned the AI system with common indications of pre-seizure activity in the brain, making the prediction process faster.

The study has been published online in the journal *IEEE*

Transactions on Biomedical Circuits and Systems.

"In order to achieve this high accuracy with early prediction time, we need to train the model on each patient," says Daoud, noting that training could require a few hours of non-invasive EEG monitoring around the time of a seizure, including during the seizure itself.

For the full study visit: <https://bit.ly/37jfgj6>



Seizures could be suppressed by gene therapy

European scientists have developed a new type of gene therapy for the treatment of temporal lobe epilepsy.

By studying mice, the team have been able to stop seizures at their source, and are now preparing the procedure for trials in humans. The study results are published in the journal *EMBO Molecular Medicine*.

For those with temporal lobe epilepsy (TLE), surgery is often the only effective treatment. However, this comes with risks to the parts of the brain responsible for perception and understanding, and may not stop seizures altogether.

The team consists of Professor Christoph Schwarzer of the Medical University of Innsbruck, and Professor Regine Heilbronn of Berlin's Charité's University. They have been working to develop a new treatment for drug-resistant TLE.

The technique looks at delivering genes to nerve cells at the site of the seizure's source. Once delivered, the gene provides cells with the information needed to produce and store dynorphins, which are chemicals which help control brain activity. When a seizure begins and the nerve cells are stimulated, the stored dynorphins are

able to quieten the seizure signals, meaning it's not able to spread.

In the mice, the team showed that this therapy could help stop the onset of seizures for several months with no obvious side-effects.

"The results from our study are encouraging, and prompts us to hope that this new therapy could be successful in humans," commented Professor Heilbronn. "Our aim is to have this gene therapy ready for its first-ever use in a clinical trial in just a few years."

For the full study visit <https://bit.ly/2TXmu8i>

Purple Day: 26 March 2020 – international day for epilepsy awareness!

Purple Day plays a huge part in raising epilepsy awareness throughout the world. It is a day dedicated to encouraging people to open up about their condition, share their stories and get talking about epilepsy.

This year Epilepsy Action is talking about how epilepsy affects people's lives, especially in terms of loss. Living with a long-term condition such as epilepsy can mean being physically or emotionally lost. It can lead to lost friendships, losing a job, or even losing your independence and confidence.

People tell us about losing valuables during a seizure or difficulties with memory loss. All too often seizures can leave you feeling like you've lost an hour, a day or even a week of your life. And we know that tragically, some people lose loved ones because of epilepsy.

People with epilepsy, and their families, often feel very lost and don't know where to turn. This can be straight after diagnosis, or maybe further along their journey. Paul (pictured) was 18 years old when he had his first seizure. That was over 20 years ago. Since then he's lost so much because of his epilepsy – several jobs, his passion for motorbikes and - ultimately - his first marriage.

Neurosurgery has failed to find the source of Paul's epilepsy. Medication can't control his seizures. Even an implant hasn't stopped them getting worse. But Paul is still positive.

"I got in touch with Epilepsy Action because I read about **Purple Day** and wanted to do something to get epilepsy out there. To make people realise what epilepsy is and how it affects you. Just because it's not always visible doesn't mean it's not there.

"If I can help just one person feel better about themselves and know they're not the only one suffering, I'll have done what I wanted."

Epilepsy Action is here to help, so fewer people with epilepsy lose precious seconds, minutes and hours from their life. From a listening ear on the Epilepsy Action Helpline



to face-to-face group support, together we can give people the information and help they need to live better with epilepsy. By joining in on **Purple Day** this year you will be helping more people get the advice and information they need to find the best possible treatment, and maybe even reduce or control their seizures.

Funds raised on **Purple Day** help Epilepsy Action to go on growing its network of local support groups across the country. That means more people supporting each other and overcoming the sense of isolation epilepsy can bring.

Your support also means more people and more employers will understand the challenges of life with epilepsy and know what to do to help someone having seizures.

Here's how you can make a difference this **Purple Day**:

- Share your story – what have you lost (or gained) from epilepsy and its impact on your life? Contact us at press@epilepsy.org.uk or call 0113 210 8870
- Order your 2020 **Purple Day** wristband and purple boppers (there's an order form on your *Epilepsy Today* address sheet, or you can order online at epilepsy.org.uk/purplegoodies)
- Donate to the **Purple Day** 2020 fundraising appeal: epilepsy.org.uk/donate
- Order a **Purple Day** fundraising pack and hold your own event to raise money and awareness of epilepsy! Call 0113 210 8851 or visit epilepsy.org.uk/purple





Moving forwards

All her life, Molly has lived with epilepsy and autism. As a teen, she also developed a rare neurological condition. She shares her story.

Where do you live?

I was born in Worcestershire and raised in Essex, where I now live.

Are you currently working?

I'm currently working for the University of Essex helping with mental health projects.

Tell me about your epilepsy

I've had epilepsy all my life. I was too young to process what was going on when I had my first seizure – I remember my mum telling me when I had them. One time I was walking home from school when I had one. My brain just followed the way of where it knew I had to go, with no regard for traffic. I was diagnosed as having temporal lobe epilepsy. I've had a wide variety of seizures since, including tonic-clonic, simple partial and complex partial.

How did your epilepsy and autism affect you growing up?

I was a very isolated child – I preferred mixing with adults rather than other children. I found them very intimidating and anxiety-inducing. I think I was scared of being bullied. So at school I spent lunchtimes inside in the library – I didn't go out to the playground. It also affected my attendance. If I was woken up suddenly it would trigger a seizure, so I couldn't use an alarm clock. I was eventually home-schooled for an hour a day for each subject.

What medications were you put on and were there any side-effects?

I was put on a lot of different drugs, mostly with no effect at all. One drug in particular was very bad for me – when I was 19 it caused me to go comatose and I ended up in hospital. They said I had a suspected stroke. It actually led to me developing a functional neurological disorder (FND), which had a major impact on my life. Very little is known about the condition, but it affects my physical ability. I lose the ability to walk, my speech is slurred and I have very little upper body strength. I've had this ever since, and I've had several relapses a year.

On top of that, I developed blepharospasm, a condition where my eyelids spasm uncontrollably. This can make me practically blind. I'm now on a new combination of drugs and my epilepsy is far better controlled – I currently experience around one seizure a month.

Was surgery ever an option?

Doctors looked at surgery when I was a child, but they decided it would have been too invasive. Now that my cognitive abilities, including my perception, awareness and learning are affected by the FND, I feel like surgeons don't want to go near me.

How did your epilepsy impact your relationships and your lifestyle as you got older?

There was very little independence. Back then I couldn't go out on my own, it always had to be with a friend. So I took it in my stride as I didn't really know anything else. I relied a lot on my mum and her friends, who also became my friends. I've never drunk alcohol or partied at clubs. I've never had the young person lifestyle. Even when I had the chance I never really wanted to, because it was never safe.

It was similar when I could learn to drive. When I was old enough to take lessons, I knew because of my condition it was out of my reach completely, so I accepted it.

Did this make things frustrating?

I always say I laugh, because otherwise I despair. I have to try and see the positive. I can spend all my time lamenting about the things I can't do, or I can concentrate on the things I can do. I choose the latter.

What's it like living with your autism?

It's a very mixed picture. Some days I will be like an average person. But most days I'm either hyper with high emotions, or feel low and in a spiral. The best way to describe it is like being a child. When they're happy, they're really excited and joyful; when they're sad they're really sad. My emotions

behave like that, and most of the time there's no in-between. That's difficult to deal with, as you have to recognise the warning signs and be aware if you're feeling too high or too low.

“So many social workers are moved around, so you don't often get one that sticks with you”

It's very sensitive to stress, anxiety and excitement. My mum says these three things are emotionally linked for me. They all impact negatively on my FND. If it flares up, I can go from being fairly mobile, to needing a wheelchair or it can even leave me bed-bound. I have no idea when it's going to come on, how long it's going to be and no idea when it's going to go away.

Do people treat you differently because of your conditions?

I felt they have with my FND. My regular neurologist takes it seriously and always has time for me. But if I see anyone else at the hospital, once they realise about my FND, they just want to send me home. Even if I couldn't walk, or it wasn't safe.

One of the biggest challenges is that this plays into both my FND and my epilepsy. Both are fuelled by my stress and anxiety. So if I'm sent home before I feel ready, then I'm going to feel very stressed, which has a knock-on effect.

You speak at events about your experiences – tell us more.

I've been passionate about speaking and raising awareness of mental health research, through presentations and workshops. I'm involved in a project called Reaching Out. This is run by the University of Essex, and aims to get more young people involved in mental health research. I've also spoken about human rights abuse and effects of the government's austerity policies. Another big project I'm working on is an app to track someone's mental health.

What's your opinion on the state of social care in the UK?

I think social care is being driven into the ground and it's really quite pitiful. Social workers do an excellent job considering they are stretched to their absolute limit. So many of them are moved around, so you don't often get one that sticks with you for a long time, in my experience.

There is not enough social housing for people who need extra support. I've had first-hand experience of that, when councils say housing can't be found in certain towns because it's so short. Social workers also don't always understand or explain things as well as they can. I think that's partly because they are so overworked. I think considering what they're working with they're working really well, but they desperately need more resources.

Finally, what's your plan for the future?

The main plan at the moment is working on the mental health app. I'd also like to take part in a university access course, and study something linked to human rights and journalism or literature.

Doctor's note

Functional neurological disorder (FND)

“This is an uncommon, but not rare condition which most commonly affects adolescent and young adult females. It has previously been called ‘conversion disorder’. It is defined as the occurrence of neurological symptoms without any recognised or known neurological condition. The most common symptoms are limb weakness, movement disorders, speech disorders, seizures and altered consciousness. The latter ranges from mild to severe, as if in a coma. Things that cause stress are known to trigger FND although these are not always identified or known. In some cases there may be no identified cause for FND. Other causes could be recent or distant (childhood) traumatic life events including emotional, physical and sexual abuse. Finally, some patients can be prone to getting FND, possibly through genetic factors.”

Dr Richard Appleton, Consultant Paediatric Neurologist and Honorary Professor in Paediatric Neurology, Alder Hey Children's Hospital

If you are experiencing any problems with your epilepsy medicine, it's important that you don't stop taking them without discussing it with your GP. Suddenly stopping your epilepsy medicine could cause you to have more, or more severe, seizures.



Transitioning

Matt Ng speaks with Dr Chinwe Ude, Paediatric Epilepsy and Neurology Services (PENS) Consultant, about her transition clinic for young people with epilepsy at Darent Valley Hospital

Where is the clinic and who can access your treatments?

The clinic is situated at the Children's Resource Centre at Darent Valley Hospital, Dartford. It's accessible to children, from 14 years of age, who have epilepsy or who are likely to still have this diagnosis by the time they are 16.

Why did you set up the clinic?

In many aspects of a child's life, apart from their health, which is a vital part of their wellbeing, transition takes place fairly effortlessly. From around 13 years of age, most children in the UK start to gain more independence over their daily lives. They go from walking to school on their own to eventually living independently... It baffles me that when it then comes to their long-lasting, sometimes lifelong health needs, we as a society can at times be 'inattentive'. Epilepsy in particular, is a long-lasting diagnosis that impacts all aspects of a young person's life. As a clinician I am dedicated to caring for children and

young people with epilepsy. So I can't imagine my job is complete without focusing on how their diagnosis affects all aspects of their lives now and into their future.

“Epilepsy is a long-lasting diagnosis that impacts all aspects of a young person's life”

Luckily, I'm not alone in this and I'm happy that transition is high on the agenda among healthcare providers across the country.

What will your service mean for you, your team, and people with epilepsy in the area?

A transition pathway means we can

fulfil our commitment to children and young people with epilepsy to provide a smooth and safe transition to adult services. For the young person and their families, I can confirm that it makes a world of difference to them. The emotional expression of gratitude we received from our first patient and their family highlighted this for me.

What challenges have you had to overcome in setting up the clinic?

As with all services within the current health economic climate, the challenges mainly revolved around resources. But like many of our other amazing NHS colleagues, we try to find innovative and sustainable ways to accomplish our goals despite these challenges.

Having an epilepsy nurse specialist on your team most certainly helps! This role is vital but the workload can be challenging as we care for nearly 300 patients. At the very least, most paediatric boards should have two epilepsy nurse specialists. The availability of consultant time, which in varying degrees requires financial commitment from the organisation, is a challenge as well.

Within my team we try to remain dynamic and flexible too, making regular adjustments to how we work. It helps if you have senior management teams who are supportive and who share your vision.

Tell us about your other activities

I have been in my role for only three

years but I set out to establish our epilepsy and neurology service. I know that campaigning, publicity and social mobilisation can make a difference to health outcomes in a very positive way. I never tire of saying this but it's about time epilepsy took centre stage in the public and health professionals' consciousness. So I use Twitter and share our activities on Facebook. Also, I invite the trust's PR team to cover our activities which they publish on the trust website.

Patient engagement is very important to us. Through our patient group Fighting Fit Paediatric Epilepsy on Facebook and @PENSTeam on Twitter, we keep our patients and their families involved. We hold support group sessions for the children regularly. Here they come to learn through play about their diagnosis and gain confidence. Parents provide invaluable support to each other too.

I also work with other organisations and charities. Roald Dahl's Marvellous Children's Charity, which funds our current nurse, is perhaps my closest affiliation. The charity helps provide nurses to children with life-limiting health conditions. Their 70 marvellous nurses are placed within in healthcare providers all over the UK. I can confirm the impact these nurses have in patient groups and service teams.

More recently, we collaborated with Cerebra who provide sleep advice and support for children with neurological conditions. We also hosted our first workshop in October 2019.

On a more fun side, we hold PENS Christmas parties where our patients and families are invited for fun activities and a treat from Santa.

Tell me about the specialists you have onboard

Our transition team consists of two paediatric consultants with expertise in epilepsy and a paediatric epilepsy nurse specialist. We also have a multi-talented support worker within our team and our secretarial team cover the administrative work. The paediatric team have very close links with the

paediatric neurologists at Evelina Children's Hospital and King's College Hospital. They support us with the care of our more complex patients. The adult services team has two consultant neurologists and an adult nurse specialist. I would also include our local GPs who are invaluable in the process.

What are the key challenges in treating children with epilepsy?

There are still a lot of misconceptions attached to the diagnosis. That life-changing moment when a child is diagnosed is a difficult one. The challenge is consistently and timely providing the right expertise, the right investigation techniques and the right information in the right format. A high level of commitment and support through their journey then needs to be sustained in the long-term.

“Many parts of their lives are taking off, and yet epilepsy casts questions over future life choices”

For all we have come to understand about epilepsy, the unpredictability of seizures and the emotional impact on the family is one thing I most empathise with. For this, we have a challenge to take every measure aimed at minimising and preferably managing seizures.

What are the challenges in transitioning to adult services?

The list of challenges is a long one but to put it simply (if that's even possible) for the young person, it is daunting! Other aspects of their lives are taking off all at the same time, and epilepsy casts questions and doubts over their future life choices.

I often say to them in my clinics that "epilepsy does not rule". I hope this adds to their courage in dealing with the process and it empowers them to live

their best life despite their diagnosis. For their parents, it is very scary. There will be many parents who will tell you the same thing. It is scary! The adult service is very different from the paediatric service they have experienced. A good transition service should help families navigate and access the systems appropriately.

Another issue is getting everyone to recognise and remember that transition is a process and not a one-stop session in a clinic. So the challenge is to encourage health services to plan both adult and paediatric services with this in mind.

What will you hope to achieve both in the short term and the long term?

In the short term, I hope to galvanise a dynamic team who are passionate and who go above and beyond. I think I have already achieved this! We are working on developing ways and means to ensure that we're efficient and safe, especially in the face of ever-increasing work demands.

Longer term, I want to see every person of transition age who accesses the services of the PENS team has had the full experience of our service. I want to ensure that their healthcare journeys are made easier because of what we do. I hope to achieve my goal to help put epilepsy in the front and centre of our healthcare services, much like we have for diabetes. One might think this is an ambitious goal, but I know there are many like me who want the same thing, so watch this space!

What's your prediction on the state of neurology services across the country?

It's hard to predict on something like this in the current social and political climate. But I have no reason to think that things will not continue to improve. I think that neurology services are getting more organised, professionals are networking better and are working together to get the best outcomes for their patients. This is a good thing for sure.

Find out more about the work of Dr Ude and her team's work on Twitter: @PENSteam



In the driving seat

Dean's passion for cars led him to a career working with an international car manufacturer. But could he control his epilepsy?

When he was growing up, Dean discovered he had a head for numbers. He decided to make use of his skills with a career in finance. "I studied the subject at university as I was always good at maths and wanted a career that would be stable," says Dean.

"I worked in a number of different industries during the early part of my career and became qualified as a chartered management accountant in 2004."

In 2009, opportunity came knocking in the form of a job opportunity at McLaren Automotive, and Dean jumped at the chance. McLaren manufacture sports cars and supercars which are sold around the world.

"I've always had a passion for cars and in 2009 when a role came up at McLaren I had the chance to combine my career and passion which was very exciting. I have been working here in several different roles since December 2009."

Despite the fast-paced nature of the industry, Dean was in his element.

"My love of cars was a key driver to my decision to work for McLaren. My passion for cars meant I understood the way our customers think. The workload is high and can sometimes be exhausting, however, the team are passionate about what we do and we work together to achieve the company's targets."

When he was 31, Dean had his first encounter with epilepsy. "My wife Iona noticed that I became vacant for a moment while sat at home, and although suspected something might have been wrong I assumed I was just tired and brushed it off."

A few weeks later, Dean and Iona were visiting at a friend's house. "I suddenly stopped talking and started crouching in an unusual way. Iona grabbed my arm and it became stiff and remained in the air where she left it."

"I wasn't aware when it happened, but after my wife explained I was very worried and confused"

Dean's wife recognised it as a focal (sometimes called partial) seizure, as she had worked with people with epilepsy before. Dean, meanwhile, had

no recollection of the event. And his focal seizures continued. "Although I had daytime seizures before I started any medication, most of my seizures took place at night. These occur usually when I'm asleep, and I'll sometimes sit up and do things without thinking or repeat common tasks. I often wander off and I'm confused for 15-30 minutes afterwards."

When Iona explained what was happening to him, Dean couldn't understand what was going on. "I wasn't aware when it had happened, but after Iona explained afterwards I was very worried and confused."

He made an appointment to see his GP, who referred him to a neurologist. Dean was told by his GP to make changes to his lifestyle. "Following the initial consultation with the GP I was told that my wife should drive my car home, and that I shouldn't drive again until I had seen a neurologist and he advised it was safe to do so. I was gutted."

Dean underwent an MRI scan, which revealed nothing out of the ordinary. He was then given a sleep EEG test, which discovered the brain activity that confirmed the suspicions. In 2012, he was diagnosed with epilepsy with complex partial seizures. These are now known as focal impaired awareness seizures.

It was a devastating blow for Dean, who felt his career might now be affected. "I didn't talk about it with my colleagues early during my diagnosis, because I was embarrassed. I could also no longer drink alcohol, as for me it greatly increases my risk of a seizure. It's not a major problem but it sometimes makes me feel a little left-out if there is a celebration or a work event."

Despite this, Dean was determined not to let his epilepsy define him. "The main challenge was adapting to taking alternative transport to get to work each day, instead of driving. But once this became my normal routine it was fine."

Iona was also there for support, even for his more unusual turns. "After a seizure at night, I'd do things like wander off while confused, squeeze her hand or pour drinks on the floor."

Dean was eventually put on a low dose of lamotrigine, which was increased over time. Thankfully, he hasn't had any side-effects. Now, his daytime seizures have all but stopped. "I haven't had a day-time seizure since 2012. But a couple of years ago I was still having around one seizure a month at night, until my neurologist upped my medication. I now have a night-time seizure every two or three months."

"After a night seizure, I'd do things like wander off while confused or pour drinks on the floor"

Thankfully, Dean's workplace was accommodating to Dean's newly-discovered condition. "If I have a seizure I typically wake up quite confused with a headache. I would describe it like having a big hangover but without the party the night before! I've sometimes had to call in sick or work from home as a result, and my work has been very flexible in allowing this when I've needed it."

Dean stayed at McLaren and worked his way up, and today he is Head of

Finance for the Asia Pacific region, which meant a move to Singapore in 2017. The company's finance department is spread across three offices, Singapore, Tokyo and Shanghai. "The finance department is responsible for all accounting activities of our Asia based companies, plus working closely with our UK colleagues, local teams, and retailers on all commercial matters. It's largely office-based; I spend a lot of time working on spreadsheets!"

Any worries Dean had about finding healthcare or medicine for his condition were also quickly eased. "Singapore's healthcare system is excellent; I had no trouble finding a neurologist. Consultations and medication are chargeable, but my company provide me with medical insurance as part of my overseas contract. Typically a consultation is around £85 and my medication is £450 per month."

Even with his condition, Dean was able to make changes to his lifestyle and find a way to make things work. He's now is planning to move back to the UK next year, and has his eyes on taking up amateur motorsports, as he can now drive again. He emphasises the importance of not dwelling on what you can't do today, but taking each moment as it comes. "Try not to see the worst in this situation, it won't stop you living a full and enjoyable life."

Dean moved to Singapore in 2017



Step by step

Briar Nolet found it all hung in the speaks exclusively with

a passion and a career in dance. But balance when her seizures began. She *Epilepsy Today* about her journey.

Briar Nolet is standing on the stage alone, poised and ready. She's about to perform on *World of Dance*, a

competitive dance TV show based in the US that's watched by millions. The lights fade to black, and the cheers of hundreds of audience members quieten to a whisper.

Golden spotlights illuminate her as the Canadian suddenly erupts into an energetic dance routine to the beat of Celine Dion's *Out of Ashes*. Her emotional performance wows the audience as she tumbles and pirouettes through the air seamlessly and effortlessly. Each spirited flip and trick makes the crowd go wild with louder and louder cheers and applause.

It's a routine that's not just technically excellent, but also packed with raw emotion, as Briar reveals her dance was inspired by five years of living with epilepsy.

The 21-year-old trained in competitive gymnastics from an early age, having

been inspired by her father, a former Olympic gymnast. However, Briar started having back problems after just a few years and was encouraged by her dad to try other sports. She decided that dance would become her new pursuit, and began lessons when she was seven years old.

"Since I can remember dance has been the biggest part of my life," she said. "I would practice from 2pm until 10pm at night. I lived for those days, dancing and learning new tricks and challenging myself, it was the best."

She discovered she had a natural talent for dance – being able to learn the routines quickly became like second nature to her. Dancing was also an escape to refresh and reset her mind. "It takes me away, balances me and puts

me in this amazing state of mind." Briar knew she had found her calling.

However at the age of 16, she started showing symptoms of epilepsy, which began plaguing her recitals. At a dance convention during a class, she started having jerks, making her forget specific moves or lose her timing. "In the middle of it I would almost trip out, like a having a blackout without the black. I would laugh it off and keep going – I knew something was weird, but I didn't think anything of it."

Briar's symptoms often meant she couldn't learn her dance routines as quickly as she once did, which puzzled both her teachers and her parents. Then one day, she found herself running late for a hip hop class. She snuck to the back of the room to try and catch up, where the blanks returned once again, and Briar struggled to focus on the instructor.

During the group routine, she suddenly forgot all her choreography and her mind went into a blur. She was having her first tonic-clonic seizure. "My right hand

started to shake, and I fell to the floor – I think I passed out for about 10 seconds."

Briar woke up on the dance studio floor, surrounded by her worried teacher and fellow students. She was taken to the hospital and was referred to a paediatric neurologist. She had tests done but everything came back clear – she was told she had a suspected concussion.

After this, the seizures kept coming back and she was having them every couple of months. "They were triggered while I was learning choreography – I never had a seizure outside a dance studio."

This was a challenging experience for Briar, who didn't want to give up dancing because of her seizures. She danced for up to 40 hours a week, so it was a huge part of her life. She'd also recently been given a starring role on Canadian teen TV series *The Next Step*, which is broadcast in the UK on CBBC. It follows the life and times of a dance group as they compete in dance tournaments and deal with drama on and off the stage. But with her seizures, her career as a dancer and actress was potentially in jeopardy.

"It was hard for me because I love to push through things. I'd thought maybe it was some kind of anxiety that was causing the seizures, because it was only happening at the dance studio. So I was thinking it was something that I could eventually control."

Her reluctance to take a break from dance was tough on her family. "It was frustrating to see how much of a toll it took on them. My mum had still never seen me have a seizure, and she was confused as to why they kept happening. My family just wanted me to stop dancing to figure it out. But I was saying no, I'll keep going at my own pace."

Briar later started seeing a psychologist to see if her dancing really did bring on stress and anxiety. But she recognised something was still off, as she knew she wasn't one to get stressed, let alone be stressed enough to have a seizure.

She decided to keep dancing, and the seizures worsened over time, getting

longer and occurring more frequently. "They used to appear when I was learning quick dance styles, then they crept in when I was learning contemporary dance, which is a lot slower." The seizures also started to affect her education, as the jerks would appear if she typed or wrote quickly.

"My mum had never seen me have a seizure, and she was confused as to why they kept happening"

When she was 18, Briar was referred to another neurologist in Toronto who gave her an EEG test. Again, the test revealed nothing. The specialist then arranged for her to have a three-day EEG test at home, which finally revealed a diagnosis of epilepsy. It was a relief for Briar, who was finally starting to get answers. She also had a big choice to make – what medication to go on. She also decided to take a break from dancing for three months to give her body the rest it needed.

After then, it was time to go back to the studio and face the music. As dance was the one activity that triggered her seizures, Briar knew she had to find out if the drugs were working. "I started back slowly, getting back into doing slower routines and making sure



I was okay, then building from there to faster hip hop dances. From then on I got more comfortable as I knew I wasn't having any of the blackouts." The medicine was doing its job, and Briar was delighted to be able to keep her dancing shoes on.

Her journey with epilepsy was something she wanted to draw from for her emotional routine for World of Dance. She'd entered the competition a year after becoming seizure-free. "Going on to the show I knew I wanted to do a dance about epilepsy, but wanted to wait for the perfect song, which I found after I got through the first round."

Before her routine, she reflected on how far she'd come – the jerks, the blanks, the tonic-clonic seizures, all in the dance studio. And as a dancer, she would usually focus on perfecting her moves at a technical level. For this performance, she let go and danced for herself. This time, nothing was holding her back. "That dance was the first time I really dug deep and expressed a story that meant something really special to me."

"I get lots of great messages from people with epilepsy, asking for advice or sharing their story with me"

Briar has now been seizure-free for two years. Thanks to her performance and her speaking about her epilepsy, her condition has opened her eyes to those living with epilepsy. "I get lots of great feedback and messages all the time from people with epilepsy, asking for advice or sharing their story with me. I love reading about them because I obviously wasn't familiar with the epilepsy community before any of this happened. Now one of the most important things for me is to stay involved and do what I can."

For Briar, she counts herself among the lucky ones, being able to come back to



do the thing she loves and forge a career with it. "I've always been grateful for dance, but I feel like when you go through something so traumatic it definitely makes you even more grateful for it. Being able to dance again was all I ever asked for when I was going through it all. I never take it for granted, as I know of a lot of people with epilepsy can't find the medication that works for them."

Briar has recently completed a global dance tour with The Next Step cast. She spoke about her love of dancing on stage and being able to see the reaction of fans. "It's incredible. It's pretty crazy looking out into the audience, hearing so many voices and seeing so many people. I get so much adrenaline and want to give them the best show possible because that's what they deserve. It's a crazy feeling."

Touring around the world took her thousands of miles from home. But Briar found she had another family she could count on to look out for her – her Next Step cast mates.

"They've been more than I could ever ask – my parents trust them so they know I'm in good hands. Jordan Clark, who plays Giselle, was there for six of my seizures and she knows exactly what

to do, how to calm me down and was there when I woke up."

Reflecting on her own experiences with epilepsy, Briar hinted that she would have probably done things differently looking back. "In my case, it was hard because I wanted to dance all the time."

"Being able to dance again was all I ever asked for when I was going through it all. I never take it for granted"

Lastly, she shares a message for those going through what she has. "Obviously your health is first, so stay safe if you know what's triggering your seizures. Taking a step back for a second is only going to drive you forward, rather than pushing yourself too hard and having to take five steps back later. Have hope, believe in yourself and know that everything's going to be okay."

Follow Briar on Twitter: @briarnolet

Epilepsy Action membership subscriptions in 2020

From 1 April 2020 the price of membership will increase from £20 to £24 a year. Professional membership will increase from £50 to £60 a year. For members currently paying £17 a year, subscriptions will increase to £20.

There will be no change for members currently paying £12 a year, or nurses paying £25 a year.

Prices have been at their current levels since 1 January 2014. We review them every year and try to keep the cost of membership as low as possible so the most people can benefit. Rising costs since 2014 mean that this year we have had to increase some prices.

Naturally we will do everything we can to make sure your membership remains great value. Members will of course continue to receive *Epilepsy Today* magazine four times a year and, for those who have chosen it, personal accident insurance cover.

You will also be able to take advantage of offers exclusive to Epilepsy Action members:

- £25 cashback on life insurance, critical illness cover and income protection from Cura Insurance
- 10% off travel insurance from specialist providers Insurancewith
- 15% discount on MedicAlert medical ID jewellery and 24/7 emergency support



For offer details and terms and conditions call 0113 210 8810 or see epilepsy.org.uk/offers

In 2020 we're also introducing regular emails for members, to keep you up to date with all the latest epilepsy news between issues of *Epilepsy Today*. To sign up for this service, simply tell us about you and your relationship with epilepsy by completing the form at epilepsy.org.uk/evenbetter

If you would like to change your membership subscription, or if you have any questions, please call the membership team on 0113 210 8810 or email membership@epilepsy.org.uk

Membership type	Current annual subscription	Annual subscription after 1 April 2020
Member	£20	£24
Member (receiving magazine online)	£17	£20
Member (in receipt of benefits, other than working tax credits)	£12	£12
Professional member	£50	£60
Professional member (nurse)	£25	£25
International member	£45	£45
International professional member	£70	£70

Getting out there

Adam, aged 37 from Bingley, found himself struggling with his fitness. Then one day he put on his running shoes and never looked back...

My first experience of epilepsy was my tonic-clonic seizure in April 2016. If it wasn't for my wife witnessing it I wouldn't have known anything about it.

The biggest impact epilepsy has had on my life was losing my driving licence - it broke my heart. Not only that, it damaged my social life and my flexibility in my job as a senior developer. My evenings used to be full of activities and without a car there was no longer time to get to them all. I felt smothered, ignored, misunderstood and dependent on others. Occasions such as beer festivals and the work Christmas party became part of a list of social events that I largely gave up.

At the time of that first seizure I'd already been struggling to lose weight and gain fitness. Every time I sat in the car my stomach protruded uncomfortably close towards the steering wheel. I knew I'd be annoyed with myself if I got back into the driving seat without more distance between my belly button and the dashboard. It was a great opportunity to get fit!

The new commute involved a short walk followed by trains then a longer walk uphill. Feeling bitter about the slower method of getting to work, I power-walked. I sweated. A lot. I walked so fast I was all but running. I started to run and shower when I arrived at work. When I say 'ran', I wobbled for perhaps 50 yards, then walked, then wobbled on again. Eventually I could run further and needed to walk less. My trainers fell apart and I had shin splints so I bought running shoes. I had more seizures and had to continue running to work through winter so I bought warmer running kit. Apparently I was a runner, sort of. I ran a total of three miles a day. After 18 months I had lost four stone and could run that final uphill mile in under 10 minutes - less than half my original time.

I decided to have a go at running 5k and accidentally ran 7k. Sometimes I ran all the way home. I'd hated every minute that I ran (I'm only a sort of runner). But I hated it more if something stopped me, because it was my fight back against epilepsy.

Then I found out about the Epilepsy Action Bradford 10k. Epilepsy was the thing which sparked my interest in running and given me fitness and health for the first time since childhood. Taking part in the 10k would be a way to give something back. It was local. The clincher was that it was on the exact date that I was due to be a year seizure-free (18 March 2018)! It was so far outside of my comfort zone, but there were too many reasons to do it.



Meanwhile, I found out about Epilepsy Action's 5k Reindeer Stampede and I took part in that too. This was my first ever sporting event - I was terrified! I had never even been running with other people. For me, running was mainly a practical way of getting to work, so I wasn't used to running with a group. Doing a warm-up had never occurred to me. My main aim was to finish in under 30 minutes without disgracing myself. There was cheering at every corner and at many points between, which broke up the run nicely, especially with bands, choirs and everyone ringing bells. For some it would be a little bit of fun, but for me it was one of my biggest challenges. I felt like a proper runner!

I completed the course in 27 minutes with a sprint finish and felt that the mince pie and chocs were very well earned! I also got a medal! I've never really been good at the kind of things that people get medals for. I've still got it, my first ever medal at the age of 35! I enjoyed it so much that it's become part of our Christmas now and the festive period wouldn't be the same without it.

For the Bradford 10k, Epilepsy Action helped encourage me with publicity including some coverage in the local press and on BBC Radio Leeds. The sponsorship I received was well beyond my target. I've found out that I know a few people whose lives have been affected by epilepsy who always encourage me! Of course, I was terrified again. I practised the course a few times and I realised that I might be able to complete it in under 50 minutes. The support was fantastic again and all the way around I kept reminding myself that it was my victory lap. This time there was a goody bag with a t-shirt and a medal, both of which I'm still immensely proud of. This was an even better medal too! I decided that after two long hard years it would be the end of my running adventures. But I'd missed the 50-minute mark by three seconds (due to accidentally hitting a button on my cheap stopwatch) - now I had a competitive edge.

I replaced my running shoes as they had holes in them and I replaced the cheap stopwatch. I was determined to beat my personal bests (PBs). Over the following year I kept training,

did two more 10ks (in 54 minutes), completed the Reindeer Stampede in 23 minutes (my 5k PB), and then smashed my 10k personal best by completing the 2019 Bradford 10k in 48 minutes. Those are still my PBs now.

In 2019, I entered the Great North Run for Epilepsy Action. Newcastle is my home city and I grew up watching the event thinking that I'd love to do it. It was a mere childhood dream, but now it was amazingly achievable. It was an extraordinary day, very hard work and an amazing privilege! I must admit that I was so proud to meet up with everyone at the Epilepsy Action marquee afterwards. We had been encouraging each other for months beforehand on the team Facebook group. It was great to see familiar faces again at the 2019 Reindeer Stampede! My competitive edge continues. I'm taking part in the Great North Run again in 2020 and then I'll run my first marathon. My wife ran her first 5k in 2019 and just missed the Reindeer

Stampede through an injury. I can't resist the challenge and it's a reminder to epilepsy that it can still be put back in its box. All the sponsorship raised is the best way that I can thank Epilepsy Action and then they can help others to fight back too.

I still get angry at the restrictions that epilepsy places on me. I can't just go out and drink with people without counting every mouthful and every tap water. Our dream of living in a rural village might always be hampered by the need to not rely on a driving licence. Epilepsy has ironically given me better health than I've had in nearly 20 years.

Less than a month ago we found out that we're expecting a baby. Less than three weeks later we found out that he's due by summer! I wonder if he'll ever have epilepsy. I wonder if he'll run!!

Below is a list of just some of the events you can get involved in if you'd like to be like Adam and challenge yourself to something outside your comfort zone. By joining the team you'll receive the full support of our dedicated events team and will be helping more people to take control of their epilepsy. For full details visit epilepsy.org.uk/events

events calendar

January Walk for Epilepsy All year - choose a date and location to suit you	February Skydive Various dates and locations available		June Ben Nevis trek (26th-28th) Kilimanjaro trek (18th-28th)	July Peak District Challenge trek (4th-5th) London to Paris Cycle Tour de France finale (15th-19th)	
March The Big Half (1st)* Purple Day (26th) London Landmarks (29th)* Epilepsy Action Bradford 10K (15th)	April Brighton Marathon (19th)* Vale of York 10 (19th) London Marathon (26th)		August Ride London 100 (16th)* Euro City Cycle (26th-30th) South Coast Challenge trek (29th-30th)	September Thames Path Challenge trek (12th-13th) Great North Run (13th)* National Doodle Day (18th)	
	May Edinburgh Half / Full Marathon (24th)* London 10,000 (25th)* Tough Mudder Various dates (May-September)*		November Inca trail trek Peru (20th-29th)	December Epilepsy Action Reindeer Stampede (6th)	

If none of these events are suitable you can also organise your own or take part in another event of your choice. Register for a fundraising pack using the following link and we'll support you all the way: epilepsy.org.uk/registermyevent Members get 20% off the entry fee for all the events marked with *, using the code MEM20, so book your place today!

Our epilepsy heroes

The 2019 Epilepsy Action Awards once again celebrated and recognised people who make a real difference to those with epilepsy in the UK.

Every year, Epilepsy Action directly helps more than two million people by offering a range of advice, information and services. For this to happen, we rely on many people for their hard work, generosity and commitment. They are the volunteers, fundraisers, schools, employers and healthcare professionals working tirelessly to improve the lives of everyone affected by epilepsy. These awards celebrate their achievements.

Early years education Willow Garden Day Nursery



Willow Garden Day Nursery supported Amelia, two, and her family, when she was diagnosed with epilepsy when she was six months old. She has prolonged focal seizures that happen around the times she is asleep which can put her at risk. The nursery staff provide amazing care to Amelia and her family. They invited epilepsy specialists to give advice about how they can give her the best support possible. The nursery management made sure that all the staff at the nursery were trained to handle Amelia's seizures safely.

The nursery was nominated for the award by Kelli and Jason Sly, Amelia's parents. Kelli said: "We are incredibly proud that Amelia can continue to thrive in the nursery setting. Without the incredible staff and management at the nursery, Amelia would definitely not be developing as fantastically well as she is. We are grateful for their support, and this is a well and truly deserved award."

Primary School Puss Bank School and Nursery

Puss Bank School and Nursery was nominated due to their support of their pupil Claire, aged nine, who has epilepsy. Unfortunately, her condition isn't controlled by medication. She has regular seizures, and experiences many side-effects from the medicines she takes.



Claire has attended the school since she was four, and Puss Bank has worked tirelessly to make sure that her needs are met. She has a one-to-one support worker who stays with her throughout the school day. Staff adapt every activity so that Claire can take part – she has never had to miss out. Beyond this, the school support her family, always checking in with her parents about how they are. Staff at the school have worked closely with Claire's epilepsy specialist nurse. They have received epilepsy training, and have developed a thorough plan about how to manage her epilepsy and seizures.

The school was nominated for the award by Jo Shuker, Claire's nurse. Jo said: "Many schools would struggle to manage Claire's needs day in, day out but for the Puss Bank staff it is their norm. They provide her with a daily routine. It is clear to see how poorly Claire is but the school never let her feel different. They do all that they can to support her and the family."

Secondary School Pontypridd High School



Pontypridd High School picked up this award for the second year running. The award recognised the work they do to support Kira-Lea Crockett, aged 12. Kira has epilepsy and can have up to 20 seizures a day, these are mostly focal. She relies on taking many different types of medicine. With all of this, Kira can feel very anxious about having a seizure in public. When she started at Pontypridd High School in September 2018, her anxiety increased and she found going to school very difficult.

School staff have been incredibly supportive. Kira can leave lessons earlier, meaning she avoids crowded corridors, which has made her feel much less anxious. The school has also helped Kira with her wellbeing and mental health with things like counselling sessions. Her epilepsy means she has to miss a lot of school, but the staff at Pontypridd make sure she is given work to do at home to help her catch up. As a result, Kira's education is thriving.

Kira's mum, Amanda, who nominated the school for the 2019 award said: "The school has shown amazing support to my daughter. Moving from primary to high school was difficult, but with their support, Kira is doing really well. She got straight As in all of her tests at the end of year seven, which is testament to how supported she is. I'm so pleased they have won this award for the second year, they truly deserve it."

Accepting the award, Laura Dober, deputy head teacher at Pontypridd High School said: "We are so pleased to have been recognised with this award for a second time. We have a number of pupils and staff at the school who have epilepsy. We have worked really hard to make sure that the school is a supportive place for them."

Volunteer Simon Privett



Simon, 37, has epilepsy and is a passionate advocate for those with the condition. He has set up and manages two extremely successful Epilepsy Action coffee and chat groups in Exeter and Torbay. More recently, he has launched a third support group at Exeter University. He knows the importance of helping people to stay in touch beyond the group meetings and runs active Facebook groups. He also delivers epilepsy training in university departments and local businesses and is a member of Epilepsy Action's research network.

Accepting the award, Simon said: "I'm completely humbled to be honoured with this award. There are so many people who work to help others with epilepsy. Therefore, to be nominated for this award was an honour in itself and I am thrilled to have won it. I would like to dedicate this award to those who I have helped and those who we have sadly lost to epilepsy. There is more work to be done spreading awareness and I am keen to continue in my work."

Lottie Pagram attends Simon's Exeter group. She describes him as someone who is very understanding about the condition and is fantastic at supporting others who are affected by epilepsy. She said: "He is dedicated to making life for people with epilepsy and their families better. He is welcoming, friendly and as someone who has epilepsy, he is very understanding. It's thanks to Simon's encouragement that I have become a volunteer for Epilepsy Action and also discovered that I am not alone."

Fundraiser Bob Sutcliffe

Bob, now 49, was shocked when he was diagnosed with epilepsy. He retrained as a primary school teacher but was struck with a



series of heart attacks caused by a virus. His brother bought him some watercolour paints to help his recovery. Soon, his dabbles with painting turned into commissions – creating an idea to raise money for charity.

Bob has since raised more than £4,500 for Epilepsy Action by selling paintings, cards and cushions of his artwork on his website Bob On Paintings. He has even been known to paint after both of his wrists were broken following a violent seizure.

Bob said: "I just hope that my determination, not just to paint but also to teach, helps others to see a way forward. Epilepsy Action has been there for me and my family when I've needed support. Fundraising means I can help it to continue to be there for people who are going through the same thing. I'd like to thank everyone who supports me by both buying my cards and asking me to paint for them. I'd also like to thank my school community for encouraging me. They have shown me it's possible to be successful in a challenging job with this condition. It's so important to show children that epilepsy is not scary or something that limits you. This award simply symbolises the power of the motto: 'Never give up!'"

His wife Jan said Bob's fundraising is about so much more than simply raising funds for charity. "I think the fact that Bob has epilepsy and desperately wants people to understand the condition makes his determination to support Epilepsy Action even stronger. He wants to show it's not just about having seizures but the wider issues they raise. He very much values the support Epilepsy Action has given him and his family. Bob doesn't just raise money – he raises his game. He raises the profile. He raises others' sense of hope and self-esteem."

Fundraising team M&S Guiseley Simply Food



The fundraising of the M&S Guiseley Simply Food store has won them the Epilepsy Action fundraising team award for 2019. M&S Guiseley chose Epilepsy Action as their charity of the year in July 2018 and again for 2019. During 2019 they have raised over £11,000. The store staff held events for Purple Day, Epilepsy Action's Tea Break and through National Epilepsy Week. They also hosted volunteers from Epilepsy Action to pack shoppers' bags, and customers have been generous with their donations.

The store chose to fundraise for Epilepsy Action because a staff member, Helen Davies, has a daughter with epilepsy. She says that the store has been very understanding and accommodating when she needs to leave work because her daughter has a seizure at school. "I am so pleased that the store has won this award. We are all very proud. My daughter, Lucy, has epilepsy and my colleagues and managers have been so supportive. It's great that they have all done so much to raise funds for a charity close to our hearts."

Local group
Truro coffee and chat group



A lifeline for people affected by epilepsy, the Epilepsy Action Truro support group welcomes a broad range of people throughout Cornwall. Set up over 15 years ago, the group is run by volunteers and local specialist nurse Mary Parrett, who was the driving force in creating the group. Up to 40 people attend monthly meetings to enjoy guest speakers and games, and the group also arranges outings such as theatre and boat trips.

Mary and the team receive great feedback about their impact. "I have made many good friends who, because they are in similar situations, understand how much epilepsy can affect your life."

"It has boosted my confidence and given me the courage to help raise awareness. I've also been able to teach others about my particular epilepsy, how not all types are the same and how it's very often not completely controllable."

"There is always something going on, from a paramedic demonstration to a quiz or hobbies evening. It's brilliant! I don't know where I would be without it!"

Julie Ford, Epilepsy Action volunteer, accepted the award. She said: "It is a pleasure to receive this prestigious award. It is a huge team effort, with many people giving up their time to make our group such a success. Our aim has always been to provide a relaxed environment offering friendship, education, fun, compassion as

well as support. It's invaluable to people dealing with an epilepsy diagnosis, and their relatives and carers, especially when their condition can become so isolating."

Healthcare worker
Malisa Pierri



Malisa's work has benefitted thousands of people with epilepsy in Wales. She has worked for over 15 years as an epilepsy specialist nurse in the Alan Richens Unit (epilepsy unit) in the University Hospital of Wales in Cardiff. Malisa supports people with epilepsy through her regular clinics and over the phone. Beyond this, she has developed and delivered a wide range of clinics and services that have improved health services for countless people with epilepsy.

Because of Malisa's work, people who go to the Emergency Unit with a suspected seizure are now assessed by specialist nurses. These help people get an earlier epilepsy diagnosis and treatment sooner. Malisa also led a project which has reduced the waiting time for someone's first specialist epilepsy appointment to two weeks. This makes a crucial difference at an anxious time in people's lives. Malisa also runs clinics for pregnant women, as well as a prison epilepsy clinic, providing support for a vulnerable group of people.

Ann Sivapatham, Epilepsy Action Wales manager, said: "Malisa is a talented, hardworking and highly motivated epilepsy specialist nurse. She is a major driving force for improving health services for people with epilepsy in Wales and a shining example of how nurses can improve the lives of their patients."

Accepting the award, Malisa said: "I am humbled to receive this award. Knowing it comes from an organisation representing patients makes it extremely special. I am so pleased to hear that the work that we do makes a difference to the lives of people with epilepsy."

Raising awareness
Derrick Kay

Derrick Kay wins this award for his uplifting and engaging media work. He has had epilepsy since he was eight years old. His YouTube channel Derrick Kay Seizure Survivor is where he shares his experiences. It's also the home of his myth-busting vlogs, such as dos and don'ts for seizures, all presented in a catchy, direct and honest way. He uses clips, drones, effects, music and captions to tell his epilepsy story. Engaging, warm and creative, Derrick loves to motivate people and dispel misconceptions too. Beyond his own channel, he featured in BBC Three's 'Things not to say to people with epilepsy' in 2017, with over 880K views.



As an Epilepsy Action media volunteer, Derrick is one of our go-to patient voices. Willing and articulate, he has done several live interviews on national TV. He has talked openly about employment, mental health and first aid to help bring Epilepsy Action media campaigns to life. The media work he does for Epilepsy Action helps to break down barriers and tell the story of many people's lived experiences with epilepsy.

Accepting the award, Derrick said: "It all started back in 2016, with me making a video and asking Epilepsy Action for expert insight. It grew from there and the media work they've involved me in has been really brilliant. I love supporting the charity and it's so rewarding to know that by sharing my own story, I'm helping others to feel more positive and less isolated by their condition."

Employer
Blackburn with Darwen Borough Council



Blackburn with Darwen Borough Council has been incredibly supportive of several employees who have epilepsy. The Council were nominated by Ben Greenwood, partnership communications manager.

He was diagnosed with epilepsy while working at the Council. The support from his managers and colleagues has been excellent. His managers made reasonable adjustments so he could continue in his job. They put measures in place so he could continue travelling as his job required. When he had his last tonic-clonic seizure, he received a message of support from the chief executive of the Council. Ben is thriving in his career, which he credits to the Council's supportive work culture. He has also worked alongside senior staff to make sure that other people are supported too. Recently, he launched a peer support group for staff at the Council living with epilepsy. Ben said: "When I was diagnosed, my head of service and

senior management made every effort to make reasonable adjustments to help me manage my condition. It has made a massive difference to me. I have felt no detriment to my career and have risen to deputy head of service. I'm able to be very open about it and senior management have actively encouraged me to raise awareness and tell my story publicly. "I'm proud that I have worked with my employer to bring in new guidance for managers on epilepsy in the workplace."

Hilary Figg Award
Beryl Sharlot



Beryl Sharlot's award was presented by Richard Chapman, chair of the Epilepsy Action Council of Management. She has dedicated the last 36 years to improving the world for people with epilepsy. Beryl was inspired to volunteer for Epilepsy Action because of her personal experiences. Her work has impacted on thousands of people with epilepsy at a local, regional and national level. She has ensured that people have the support and respect they need alongside access to good quality health services.

Inspired by the stories of people in the Warwick District Branch, she began to volunteer her time for Epilepsy Action back in 1983. Beryl has helped to run support groups for people with epilepsy ever since. Beryl was instrumental in establishing Epilepsy Action's West Midlands Epilepsy Forum in 2006. This was in response to a lack of support for people with epilepsy in the area.

Beryl has delivered hundreds of epilepsy awareness training presentations to workplaces, community organisations and schools. This has helped them gain valuable knowledge and understanding of epilepsy and how to help people. In 2019, Beryl celebrated her 30th anniversary as a member of the Council of Management of Epilepsy Action.

Will Butterworth, Epilepsy Action's central England manager, who nominated Beryl for the award, said: "Beryl will always help out wherever and whenever she can. She has provided me with constant unwavering support, advice and help with all the activities I have done across England. Thank you, Beryl, for all you have done and continue to do."

Accepting the award, Beryl said: "I am honoured to receive this award. It has been a privilege to do so much for people with epilepsy. If we don't speak up for people with epilepsy and help them amplify their voice, then who will?"



Lauren struggled to avoid stress, which was the trigger for her seizures. One day, a painting of a cow changed her life in more ways than one.



I'm Lauren, a professional artist specialising in colourful portraits of cows! And you might have also guessed, I have epilepsy.

I've been living with my condition for almost 20 years now. Many people have no idea I have epilepsy due to the fact that I have found a medication that keeps my seizures under control. I also lead a carefully managed lifestyle to prevent it from interrupting my day-to-day life.

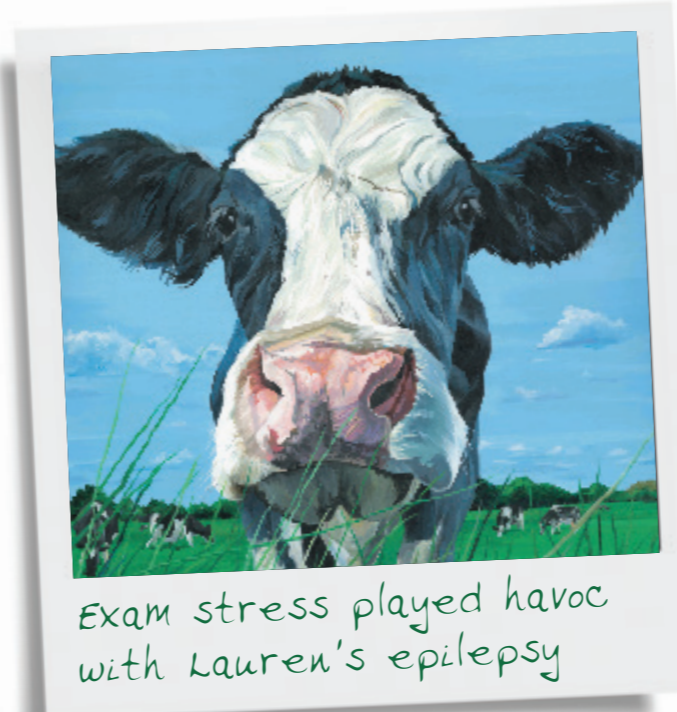
I was first diagnosed when I was 10, when I developed absence epilepsy. I would be going about my carefree childhood life and would simply go blank. They'd only last a few seconds, but in that time I'd be completely unresponsive.

If I was writing I'd maybe just move my pen in circles, or I'd stop speaking mid-sentence. But there were times when I'd stop in my tracks when crossing a road, or grind to a halt in the middle of ballet class.

There's no history of epilepsy in my family, so at first my parents simply thought it was me being away with the fairies. I'd snap back to reality after a moment or two. It would usually take me a few seconds to recall where I was or what I was doing. More often than not, I'd come round to someone telling me off for not listening!

"I'd snap back to reality after a moment or two. More often than not, I'd come round to someone telling me off for not listening!"

I was eventually diagnosed with absence epilepsy. I was terrified and I think my parents were quite taken a back



Exam stress played havoc with Lauren's epilepsy

too. But soon I was on medication and I was back to being a normal kid doing normal kid things.

Fast forward five years – GCSE time! The most joyous time of any teenager's life... Our teachers had arranged some extra revision sessions for me and my school year, to give us that last push before the exams. It was a stressful time for us all.

"My epilepsy trigger was stress... The answer was simple – don't get stressed! I wish it was that easy"

It was during this time that disaster struck and I had my first big seizure. My seizures had now developed from absences to tonic-clonic seizures. I would lose consciousness, going rigid and fall backwards to the floor. There's shaking and jerking, groaning and gurgling, and sometimes I'd even turn blue. It'll last no longer than a minute but it can take a while longer for me to regain awareness.

This is when we discovered that my epilepsy trigger was stress. So then the answer was simple – don't get stressed! I wish it was that easy. After GCSEs came A-Levels, and then it was off to university for more high-intensity studying and exams. Mix that with late nights, partying and alcohol, and you have a recipe for disaster. As an adult I recognise the mistakes I made. I wouldn't have had that fifth shot of sambuca, or pulled that all-nighter just because everyone else was. I wouldn't have woken up at 5am to cram before an exam. But

as a young adult I was damned if I was going to let epilepsy ruin my fun and unfortunately I paid the price. I even had a seizure during my A-Level music exam! That was an extremely low point as not only did I fail it, but all my peers had seen my seizure and it was the talk of the school.

I started to manage my life better. Partying less and listening to my body. However, stressful situations were never completely avoidable.

I worked as a waitress for two years at a pizzeria in Wimbledon Village. On paper this would seem to be a pretty laid-back job, after all, it's just serving pizza. That is until Wimbledon tennis tournament begins and you have a summer of non-stop tables all fighting for your attention. My absences would start creeping up on me on my shifts. I'd lose track of what I was doing and make silly mistakes, while I'm focusing all of my energy on just not having a seizure. That's when I once came around at the foot of a table covered in spaghetti, surrounded by panicked tennis fans and paramedics!

"I once came around at the foot of a table covered in spaghetti, surrounded by panicked tennis fans and paramedics!"

It seemed like no matter what I did, how careful I was, how early I went to bed, I couldn't keep my brain on track. The stress would take over and it would all unravel before my eyes.



She turned to painting to help relax



Lauren has lived with epilepsy for 20 years

People always ask me, why cows? There's something about them that just makes me smile, which is what my business is all about. Cattle that just cheer me up. They've got such a wonderful personality and a curious nature that makes for wonderfully engaging paintings that brighten any room. When I'm having a hard time and I can feel the pressure mounting, I take my camera, find a nice field of cows and chill out with them for a few hours. When I get back, things don't seem half as serious as they were. Lauren's Cows is now in its eighth year and growing every year. I love every aspect of the business, from painting commissions of prize-winning bulls, to seeing our homeware stocked on the high street and posting my cows to homes worldwide.

"When I'm having a hard time and feel the pressure mounting, I find a nice field of cows and chill out with them"

I've also been able to help raise money for Epilepsy Action with my cows! My Highland cow painting 'Violet' raised £596 in the 2019 National Doodle Day auction. We have also recently partnered up on an ongoing basis. A donation from every 'Ronnie' print goes straight to Epilepsy Action to help raise funds for those struggling with epilepsy.

To this day there's things that annoy me about epilepsy. I can't drive, I have to be very careful when drinking alcohol and I have to take many precautions when it comes to having a family. However, I've learned to love it too. After all my brain wouldn't be the same



One chance meeting led to Lauren's Cows

This is when I made a major decision that ultimately changed my life. I started to paint. I'd always had a love of art, and between waitressing shifts I began doodling and painting, just for a bit of fun. It was a great way to relax and turn my brain off. One day, by chance I painted a cow. My dad loved the painting so much he took it to be framed for me at a local gallery in Yorkshire. It just so happened that the framer, who also owned a gallery, was also very taken by the painting. He invited me to paint twenty cows so he could host an exhibition. I jumped at the opportunity and the first Lauren's Cows exhibition was held in the summer of 2012.

"Twenty years on from my first diagnosis, I've learned to respect my brain and what it's telling me"

Twenty years on from my first diagnosis, I've learned to respect my brain and what it's telling me. It's one of the reasons that I am so fortunate to have Lauren's Cows. I love the freedom it gives me. I really struggled to stay healthy in other more demanding careers, with managers breathing down my neck. Don't get me wrong, running your own business can be very stressful and I still feel swamped at times. But I've learned to listen to my brain and know when I need to put down my tools and go have some fun! I love being my own boss and am very thankful that I've built a business that pays me a monthly salary while offering me a great work/life balance.



When stress mounts, she heads out

without my epilepsy. Yes, it may not be able to handle stress and a tonne of booze but it gives me my artistry and creativity. It's the brain that loves my husband and the brain that makes me laugh hysterically with my friends. If I didn't have it then I might not have any of the things that make my life so wonderful!

A portion of sales of Ronnie go towards Epilepsy Action. Order yours now and check out the rest of Lauren's Cows at laurencows.com

epilepsy action

Your weekly chance to
Win £25,000!
Play today for just £1

The Epilepsy Action weekly lottery is part of Unity – the nation's fundraising lottery scheme. Every £1 you play is another chance for you to win a fantastic cash prize. And every time you play, you'll be helping more people living with epilepsy.

Start playing for as little as £1 a week
You can play straight away by signing-up online at epilepsy.org.uk/win
For help and further information, please call Jenny on 0113 210 8822

Write your will for free with Epilepsy Action

Epilepsy Action is pleased to offer you a free, confidential will-writing service through the National Free Wills Network.

All of the solicitors linked to the National Free Wills Network are accredited by The Law Society, so you can rest assured you're getting the right advice.

The network will provide you with a list of participating solicitors near you. All you have to do is choose one and make an appointment. There's no cost to you, and you are not obliged to remember Epilepsy Action in your will.

To take advantage of this offer, simply complete the form at epilepsy.org.uk/freewill or give Epilepsy Action a call on 0113 210 8827.



Medical files

Zonisamide (ZNS) was first licensed in the UK in 2006. It was initially an add-on treatment for focal seizures with or without secondary generalisation for people with difficult to control epilepsy.

Shortly afterwards it became available as a single treatment for those with newly diagnosed epilepsy. ZNS possesses a number of different ways of working. It affects sodium and calcium channels in the brain while delaying the release of the excitatory neurotransmitters that lead to seizures.

This probably explains its effectiveness across a range of different seizure types, including tonic-clonic, tonic, absence and myoclonic seizures. ZNS is a useful treatment for juvenile myoclonic epilepsy, which is relatively common in adolescents and usually treatable. It's also effective in treating progressive myoclonic epilepsies, which are rare and often extremely severe. The recommended starting



dose of ZNS for adults is 50-100mg daily, increasing, as necessary, up to a maximum of 250mg twice daily. Children can be treated with 2mg per kilogram of the child's weight per day, rising to 4-8mg/kg/day. Dose adjustment with this drug should always be slow and careful.

Like all anti-seizure medicines with multiple ways of working, ZNS comes with a range of side-effects. These include poor appetite, which can result in weight loss, dizziness, tiredness, sleepiness, confusion and impaired concentration. The higher the dose, the more likely are these problems to arise. A small proportion of people taking ZNS develop kidney stones. In hot countries, sweating may be reduced in children which can lead to high temperatures. Psychiatric problems, including depression, aggression, anxiety and mood swings can be associated with ZNS use. Skin rashes can also occur on starting treatment with the drug. Although skin rashes are relatively uncommon, they can be severe. In rarer cases the production of red and white blood cells in the bone marrow can be suppressed. This results in anaemia and an increased risk of infection. If this problem is suspected, a blood test should be done, and treatment with ZNS stopped under guidance from a doctor.

ZNS does not appear to cause any untoward effects in pregnancy, both

ZNS does not appear to cause any untoward effects in pregnancy, both to the mother and the unborn child

to the mother and the unborn child. There are no interactions associated with its use. However, other drugs that can increase drug metabolism in the liver, such as phenobarbital and carbamazepine, can reduce the level of ZNS in the blood by up to 50%. Overall, ZNS is an easy to use, effective and safe treatment for a range of seizure types. Like all anti-seizure medicines, it can cause side-effects in some people, so vigilance is essential, especially soon after starting treatment.

If you are experiencing any problems with your epilepsy medicine, it's important that you don't stop taking them without discussing it with your GP. Suddenly stopping your epilepsy medicine could cause you to have more, or more severe, seizures.



Council of Management 3 December

The Council of Management met on 3 December and made the following decisions.

- It approved a revenue budget and a business plan to run through 2020.
- It reviewed and renewed the charity's advisory panels covering scientific awards, research, women and health and clinical practice.
- It appointed Dr Hayley Gorton, Dr Rhys Thomas and Christine Hanson as new members of the charity's Health and Clinical advisory panel.
- It appointed Deborah McCrudden and Dr Michael Kinney as new members of the Northern Ireland National Advisory Council.
- It reviewed, updated and renewed its scheme of delegation. This is the record of how the Council manages its authority.
- It reviewed the charity's corporate risk register and ensured adequate measures are in place to manage those risks.
- It reappointed Karen Armstrong, Evan Harris, Paul Maynard,

Lord Smith and Ray Tallis as Vice Presidents of the Association when their current term of office expires at the date of the AGM in June 2020.

- It appointed Sarah Lawson as a member of the Council Corporate Governance committee.

The next meeting of the Council of Management will be on 7 April 2020.



Epilepsy support for you

For some of us, epilepsy can be an isolating condition which 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.

Local groups

Epilepsy Action puts on monthly **coffee and chat groups** around the country where you can meet other people living with epilepsy. We have groups in:

Abergele, **Amesbury**, Ballynahinch, **Basildon**, Basingstoke, **Belfast**, Bognor Regis, **Brentwood**, Bridgend, **Brighton and Hove**, Bristol, **Caernarfon**, Carlisle, **Carrickfergus**, Chelmsford, **Chichester**, Colchester, **Derby**, East London, **Enniskillen**, Exeter, **Exeter University**, Gloucester, **Grimsby**, Guildford, **Harlow**, Hereford, **Holywell**, Horncastle, **Hull**, Isle of Man, **Kingston on Thames**, Leeds, **Leicester**, Lisburn, **Liverpool**, Llandudno, **Llanelli**, Llangefni, **London**, Lowestoft, **Macclesfield**, Manchester, **Milford Haven**, North London, **Northallerton**, North West Shropshire, **Norwich**, Oldham, **Porthmadog**, Prestatyn, **Queens University Belfast**, Rayleigh, **Romford**, Rossendale, **Scunthorpe**, Sheffield, **Sleaford**, Solihull, **Southampton**, **Swansea**, Teesside, **Thurrock**, Torbay, **Trearddur Bay**, Truro support group, **Tywyn**, Walsall, **Warwick**

District, Welshpool, **West London**, Weymouth, **Witham**, Worcester.

There are also Epilepsy Action **branches** in a number of areas all over the UK, which also hold monthly meetings:


Abergavenny, Bournemouth and Poole, **Cannock**, **Cardiff**, Carmarthen, **Coventry**, Foyle, **Guildford and Godalming**, Harrow, **Huddersfield**, Mid Ulster, **North London**, Nuneaton, **Saffron Walden**, Scarborough, **Sheffield**, South West Wales, **Stoke-On-Trent**, Tendring, **Tyneside**, West London, **Wigan**, York.

For more information about these, you can visit: **epilepsy.org.uk/coffeeandchat** or **epilepsy.org.uk/nearme**. You can also get more details by calling us on: **0113 210 8800**.

Online resources

Epilepsy Action also has online spaces where people can meet others with epilepsy and exchange stories and information about their condition. This is called forum4e and can be found at **forum.epilepsy.org.uk**.

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.

A young girl with brown hair in a ponytail, wearing a brown quilted puffer jacket, black leggings, and black boots with silver studs, is riding a blue and black kick scooter on a paved sidewalk. The background shows a park-like setting with trees and a metal fence.

VNS Therapy is the #1 prescribed device for seizures in children

Early use of VNS Therapy offers proven long-term outcomes for children at a **critical time** in their development.

Children treated with VNS Therapy have been shown to have **fewer seizures**, **shorter seizures** and **improved recovery**.

Improvements in **alertness**, **concentration** and **energy** have also been reported in clinical studies.

Visit www.vnstherapy.co.uk/learn-more/stories to hear from real people with VNS Therapy

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Belgium

INTENDED USE / INDICATIONS:

Epilepsy (Non-US)—The VNS Therapy System is indicated for use as an adjunctive therapy in reducing the frequency of seizures in patients whose epileptic disorder is dominated by partial seizures (with or without secondary generalization) or generalized seizures that are refractory to seizure medications. AspireSR® and SenTiva™ feature an Automatic Stimulation Mode which is intended for patients who experience seizures that are associated with

cardiac rhythm increases known as ictal tachycardia. Incidence of adverse events following stimulation (>5%) included dysphonia, convulsion, headache, oropharyngeal pain, depression, dysphagia, dyspnea, dyspnea exertional, stress, and vomiting.

Visit www.vnstherapy.com to learn more and view important safety information. Not approved in all geographies, consult your labeling. Individual results may vary.