

Epilepsy

Today

‘Epilepsy
makes
my music
unique’

ARTIST VC PINES, P14

‘Getting in
touch with
Epilepsy Action
saved my life’

CHRISTMAS APPEAL, P18

ALSO IN THIS ISSUE...

Dennis and friends: the cartoon
dog educating children **p20**

Meet Jennifer who had her first
seizure while scuba diving **p24**



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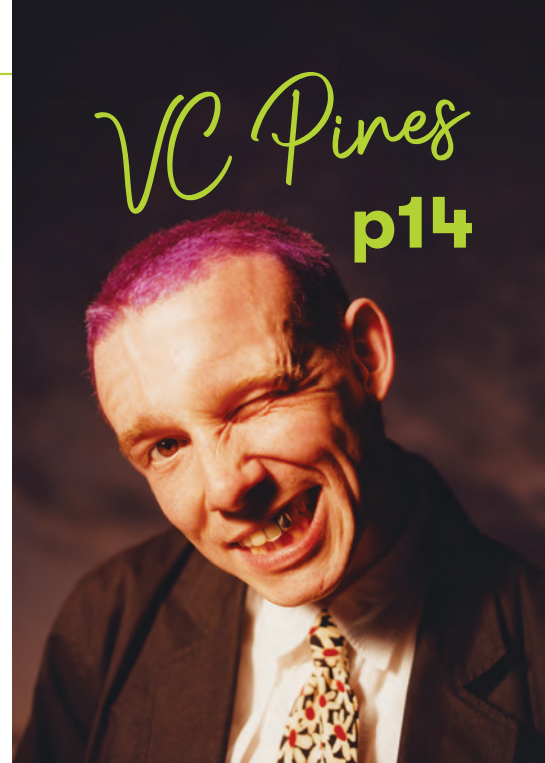
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Support for all

This season's cover star VC Pines – also known as Jack Mercer – released his debut solo album MRI this month, which is all about living with epilepsy (p14-16). Jack says his condition has made him creative "in a way that's different to other people". While epilepsy can be difficult to live with – and for some it's debilitating – some people find positives to their condition.

Star Awards winner Jennifer Constant (p24-25) was travelling around the world when she began having seizures – she's had them scuba diving in Thailand, in a hotel in Bolivia and in the rainforests of Costa Rica. Now, closer to home, she uses her experiences to support people through one of the most important days of their lives – their wedding.

For Jennifer and Jack, epilepsy didn't stop them living, but for Rhys (p18-19) it nearly did. After being diagnosed, school, friendships and relationships became difficult for Rhys. He shut himself away and came close to taking his own life. But finding Epilepsy Action turned things around – talking to our expert advisers saved his life.

We want to help people like Rhys, whenever and wherever they need us, as you will see on our map (p13) and online (p17). So, thank you for supporting us and if you have anything extra to give this Christmas, please do consider our appeal: www.epilepsy.org.uk/stick-it



Grace Wood
Editor

Parents: low-histamine diet reduced son's seizures

Parents from Croatia claim they have reduced their son's seizures, and improved his behaviour and wellbeing, by reducing histamine in his diet.

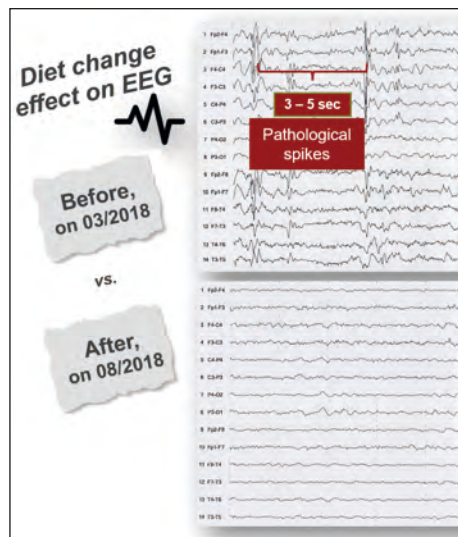
Histamine is a chemical your immune system releases, but it is also present in many foods and drinks.

At two and half months old, Ana and Goran Dumic's son was diagnosed with epilepsy. He had up to 10 seizures a day. Anti-seizure medications had severe side-effects and adverse events, such as liver failure.

Their son's seizures were often triggered by infections such as cold and flu, which blocked the his nose. He had a sleep disorder, with cycles of 10-minutes sleeping then waking. He also suffered from serious gastrointestinal issues, frequent vomiting and general food sensitivity.

After all regular epilepsy treatments had been exhausted, being data analysts, the parents embarked on an extremely thorough diary. They used an app called Baby Daybook to record seizures and

“We logged everything: sleeping, playing, eating, screaming, even air temperature”



side effects, recording their son's diet in great detail.

Goran said: “We tried to see if we could understand what sequence of events lead to seizures.

“We logged everything. From everyday events: sleeping, playing, eating, crying, screaming, his temperature, medications, symptoms, and even the air temperature.”

The family had a “gut-feeling” that they were doing “something right on some days and something wrong on others”. As time went by, they began to see some patterns.

The patterns particularly appeared in his diet. They distinguished between “good” and “bad” days as days with high or low seizure rates. Certain combinations of food appeared in each of the days.

By adjusting their son's diet, one ingredient at the time, the parents began to see positive changes in their son's behaviour and seizure rates.

After analysing these results they concluded that their son was histamine intolerant, which was confirmed by extreme low-levels of DAO enzyme.

Histamine intolerance is a sensitivity to histamine, a disorder associated with an impaired ability to digest histamine. Almost all foods and drinks contain some histamine, but some contain much higher levels than others. A suspected imbalance of gut flora is also considered to impact histamine levels.

The family believes the intolerance has led to their son's seizures, as putting their son on a low-histamine diet has greatly reduced seizures and the related symptoms.

The family says it has seen other children benefit from their research but would like to see it help more children.

Goran said: “It's all about motivation and dedication. And even though you can't issue a patent on tracking whether the carrot your child just ate a few hours ago is triggering seizures, I believe personalisation in treatments will become more of a thing than it is now, especially with the rise of ever-more accessible artificial intelligence models and other technologies. Perhaps even pharma companies might want to utilize data analytics to help patients with protocol-resistant conditions.”

Great North runners raise more than £20,000

Sixty eight runners took part in this year's Great North Run for Epilepsy Action, raising more than £20,000.

The event on September 10 saw more than 60,000 runners take part in total – running 13.1 miles around Newcastle, Gateshead and the North East.

Among those running for Epilepsy Action was Daniel Bedeau (pictured right), who has had epilepsy since he was seven. In 2009, Daniel had epilepsy surgery, which reduced his number of seizures.

Daniel said: "I decided to take part as I really enjoy running and setting myself challenges. I enjoy running because it's therapeutic. It's good for stress levels and wellbeing."

He added: "Epilepsy Action does great work to help raise awareness and support those living with epilepsy. And running the Great North Run helps to add to the great work they do."

You can sign up for next year's event at: bit.ly/GreatNorthRunEA



Epilepsy first aid rolled out in Lincolnshire

Inspired by Epilepsy Action's CARE campaign, a volunteer from Lincolnshire – Andy Jackson – has organised an epilepsy first aid training programme.

Andy arranged for a trainer from LIVES first aid to teach general and epilepsy first aid to 12 people. The LIVES qualification lasts three years.

The training was funded by community

group the Horncastle and District Lions.

All 12 participants passed the one-day course, which included an exam and first aid demonstration.

All aspects of first aid were taught, including what to do if someone has tonic-clonic or absence seizures.

Taking part were participants from local clubs including Nancy Byrne Theatre Arts, Spartans Taekwondo, Walking

Tennis, Age UK Lindsey and U3A – a Horncastle group for people who are no longer in full-time employment or raising a family.

Andy said: "I think everyone was quite shocked to hear how complex epilepsy is and it's good that the teenagers who attended now have this knowledge as they are around others at school and college."

Honorary president appointed Gatwick chair

Epilepsy Action's honorary president Baroness Ford has been appointed chair of Gatwick Airport.

Margaret Ford (pictured right) is a Scottish business woman and non-aligned British peer. She became honorary president of Epilepsy Action in 2008.

Baroness Ford was appointed a Labour peer by Tony Blair in 2006,



but since 2009 she has sat as a crossbencher.

She said: "Gatwick is an important piece of our national infrastructure and has exciting plans for the future."

Baroness Ford is a parent of a child with epilepsy. She has previously campaigned for better services for people with epilepsy in the House of Lords.

Epilepsy news

Documentary about sisters with epilepsy premieres at Raindance

The story of two sisters with epilepsy has been made into a documentary that follows Chelsea and Tamsin Leyland.

Called *Sisters Interrupted*, the film will premiere at London's Raindance Film Festival on 1 November. It is directed by Caroline Sharp and produced by Sophie Daniel. It will be distributed by production company Fremantle.

The makers described the documentary as "the story of two sisters, one condition and hundreds of years of stigma".

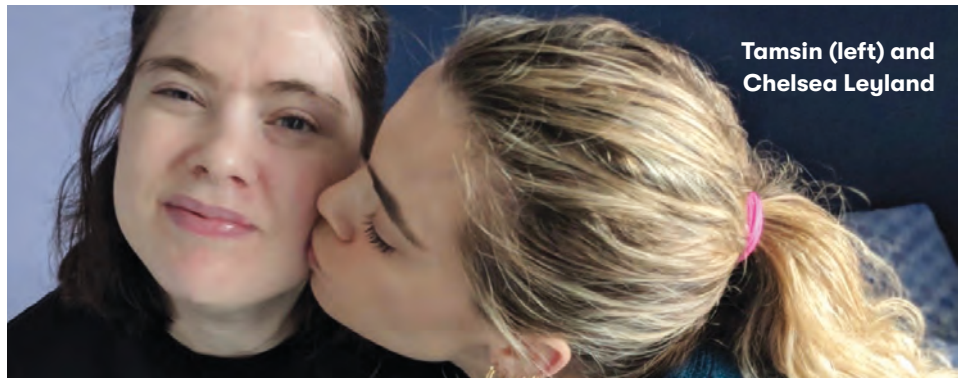
Chelsea is a model and DJ who lives with her own family in New York. Her sister Tamsin has a more severe form of epilepsy and mild autism – she lives at the Epilepsy Society's residential care facility in the UK. They both have drug-resistant epilepsy.

In New York, Chelsea gained access to medical cannabis eight years ago and has been seizure-free for six years. In the UK, Tamsin often has up to 70 seizures a day and is unable to access medical cannabis.

On making the film, Chelsea said: "Tamsin loved it. She felt like a movie star. My dad loved it. He's a larger than life personality and he's really had to fight for Tamsin. The hope for this project is that it somehow touches the lives of other people and helps influence policy."

Director Caroline said: "Our mission was to create a beautiful, human and relatable piece of film that spoke to wider themes of family love, human fear and loving support, while also highlighting the condition."

She added: "I hope an effect of the film



Tamsin (left) and Chelsea Leyland

“The hope for this project is that it somehow touches the lives of other people and helps influence policy”

will be that people run towards a seizure, not away from a seizure. I'd like to kick off a real movement that can develop like the cancer awareness movement."

The team hope the film will both raise awareness around epilepsy and help address the situation in the UK where cannabis medicines are legal but extremely difficult to access.

Chelsea said: "My sister deserves to try this medicine. I'm not saying that this is going to be the right medicine for her but it's worth us trying. We've had two second opinions, both from neurologists who believe that my sister would be a very suitable candidate given my own situation and response to the drug."

Caroline added: "We hope that this film draws attention to the serious nature of these medicines and their potentially profound effects."

"We are not advocating for use of cannabis without medical support, but we are advocating for the medical community to take its potential impact, public support and irrefutable results as seriously as any other medicine."

Currently there is one cannabis-based medicine that has been approved for treating epilepsy in the UK, called Epidyolex.

In time, the team hopes the film will be available more widely across the UK.

Producer Sophie said: "The most imminent aim is to get it on to a UK broadcaster and have as many people see it locally in the UK as possible, to try to have education and people associate with the theme, which is love within a family. We'll start with the UK, but we think the film has a global reach."

Caroline added: "This is such a labour of love. And it's such a passion beyond 'this is a film we made about this'. It's so much more about the cause."

Prisoner who died of SUDEP received 'inadequate' care

A coroner has ruled that “insufficient and unacceptable management” of care contributed to the death of Trevor Monerville (pictured right), who died in prison from sudden unexpected death in epilepsy (SUDEP).

In her report, assistant coroner Rachel Redman said: “The lack of systemic observations... alongside no care plan and no seizure diary, contributed to the insufficient and unacceptable management of Trevor Monerville’s care”.

Trevor had seizures caused by epilepsy and non-epileptic attack disorder for a number of years. He was detained at HMP Lewes from 30 November 2020 until his death on 18 April 2021, aged 33.

Trevor had been prescribed and administered medication, but 40 days’ worth, unused, was found in his cell after his death.

Epilepsy Action’s senior policy and campaigns manager Daniel Jennings said: “Prison staff ignored Trevor Monerville’s family’s concerns around his seizures, especially his nocturnal ones, and failed to monitor them. They also failed to put measures in place to keep him safer, like moving him to a shared cell where he wouldn’t be alone in the night should he have a seizure.

“Not only this, but the inquest into his death found prison staff didn’t carry out a morning check as they were meant to, on the day Mr Monerville passed away. Prior to this, officers hadn’t been fully briefed

about his condition, and practically didn’t know what to do.”

According to the charity Inquest, the prison officer who worked on the night shift in the week leading up to Trevor’s death, said the only night checks were at 9pm and at 5am. CCTV shown to the jury of the 5am check showed that it lasted only a second and was inadequate for confirming signs of life.

Jennings added: “All of this is completely unacceptable and shows an appalling lack of understanding of epilepsy and its risks, on top of miscommunication between healthcare and prison staff around the nature of Mr Monerville’s condition.”

According to The Independent, Trevor was sent to HMP Lewes on recall over allegations of criminal damage.

The coroner’s inquiry was held at Hastings Coroners Court in September.

Redman said: “The communications between all the organisations involved, the monitoring systems, the sharing of medical documentation and the engagement with Trevor’s family, were inadequate for his individual needs.

“We have considered HMP Lewes staff shortages and the pandemic, however, we note there were, and still are not, systems in place to have oversight of vulnerable people in Trevor’s position, who do not warrant having an ACCT in place.”

An ACCT is an Assessment, Care in Custody and Teamwork plan for someone in prison who is at risk of self-harm or



suicide. According to Inquest, Trevor had a long history of mental ill health.

Redman added: “We have considered Trevor refusing to take his medication and his refusal of food a matter of his personal choice. The evidence confirmed there was no system in place to monitor and document Trevor’s seizures in the absence of a care plan and seizure diary.”

Jennings added: “Mr Monerville’s death could have been prevented. What happened can’t be changed, but action can be taken to stop anything like this from happening again. This is through safeguarding policies, and with epilepsy training for prison officers across the country. We have called for evidence on the level of training police forces currently receive for conditions such as epilepsy, and we will extend this to UK prisons and prison officers, to ensure the right measures are in place and inmates with the condition aren’t running the same risk.”

The Trevor Monerville Campaign run by his family can be found at @TrevCampaign on Twitter and @Trevor.monerville_campaign on Instagram.

CBD limit lowered by Food Standards Agency

The Food Standards Agency (FSA) has said people consuming CBD from food “should limit their consumption to 10mg per day”.

This is about 4-5 drops of 5% CBD oil. Previous advice, from 2020, set the limit at 70mg per day.

It said the advice was based on the average lifetime exposure to food products containing CBD, such as drinks,

oils, sweets, bakery items or drops. All food products containing the compound must apply for authorisation before they can be sold legally in the UK.

FSA senior communications manager Jessica Finlay said: “Medicines are regulated under a different regime to foodstuffs and are prescribed as controlled drugs in very specific circumstances by trained clinicians. Our

ADI is a recommended acceptable daily intake for CBD as a foodstuff.”

The organisation said the advice is based on research from the Advisory Committee on Novel Foods and Processes and the Committee on Toxicity.

Medical CBD products are available on prescription in the UK for people with some forms of epilepsy and these will not be affected by the new advice.

Sanofi sells epilepsy drug to Pharmanovia

Sanofi has sold the epilepsy medicine Frisium, along with 10 more of its central nervous system (CNS) medicine brands, to Pharmanovia.

Frisium, a brand name for clobazam, is a treatment used alongside other epilepsy medicines. It is a benzodiazepine, which works by slowing down the body and brain's functions.

Pharmanovia is a global healthcare company with headquarters in Basildon, Essex.

Pharmanovia MSL director Fernando Osorio reassured people who take the medicines that very little would change.

He said: "We'll be working very closely with Sanofi to make sure there is no disruption."

Pharmanovia added that it intends to keep the same branding for Frisium, with the only likely change being the packaging.

"Patients will ask for Frisium, get Frisium, but it will have our logo", said Osorio.

The acquired medicine brands also include Sentil, Urbanyl, Urbanil, Urbanol, Urbanan, Noiafren and Castilium, Phenobarbital (Gardenal), Cyamemazine (brand: Tercian) and Prochlorperazine (brand: Stemetil).



Gardenal is an anti-convulsant, used to treat all forms of epilepsy except absence seizures.

Pharmanovia associate vice president, communication, Alison Dyer said: "Both ourselves and Sanofi are focussed on ensuring a smooth transition of the portfolio of products, including Frisium from Sanofi to Pharmanovia and we're working closely on this transition."

"We fully understand that these are critical medicines and that there are patients in need who are not easily switched to alternative medicines."

She added: "Ensuring we maintain a regular supply of products is critical for Pharmanovia and Sanofi and both companies are prioritising this."

If you have any concerns about your medication contact our helpline: www.epilepsy.org.uk/support-for-you/the-epilepsy-action-helpline

NHS updates medicines guidance

The NHS has updated guidance for trusts around optimising medicine use, including advice on sodium valproate, anti-depressants and polypharmacy.

Polypharmacy is when patients are taking many medicines simultaneously.

The "optimisation opportunities" ask integrated care boards (ICBs) to focus on 16 priorities. It asks ICBs to choose at least five "medicine optimisation opportunities" to focus on. ICBs are responsible for planning and funding NHS services.

One "optimisation opportunity" is around improving the safety of the epilepsy medicine sodium valproate.

Taking valproate during pregnancy can cause problems with a child's learning and development. The guidance asked ICBs to ensure people only take valproate in line with a Pregnancy Prevention Programme.

Epilepsy Action's health improvement and influencing research manager Tom Shillito said: "For some patients, sodium valproate is the most effective medication overall to control their seizures. If they were to come off it, they might have to be prescribed multiple anti-seizure medications to have the same effect, which could work against the aim to reduce polypharmacy."

Charities urge government to act on time-critical medication

Epilepsy Action has joined charities calling for improvements to time-critical medications.

The charities are asking the UK government to keep patients safe in hospital by making sure no one misses a dose of medication.

According to Parkinson's UK, only 52% of NHS trusts in England require staff responsible for prescribing and administering medication to have training on time-critical medication.

People with conditions such as epilepsy often have to take medication when they need it and at a specific time (time-critical).

The campaign was launched by Parkinson's UK with support from Epilepsy Action, Diabetes UK, National Aids Trust, Rethink Mental Illness and the Richmond Group of Charities.

Epilepsy Action's senior policy and campaigns manager Daniel Jennings said: "Almost half (48%) of people with epilepsy already struggle to control

their seizures with medication.

"Not getting their medication on time can impact on people with epilepsy's seizure control. This can lead to breakthrough seizures, which could have a huge impact on their ability to drive, or, in extreme cases, increase their risk of sudden unexpected death in epilepsy."

According to Parkinson's UK, only 42% of people with Parkinson's admitted to hospitals in England last year always got their medication on time every time.

Northern Irish legislative assembly meets Epilepsy Action

Members of the Northern Irish legislative assembly (MLAs) met with Epilepsy Action and volunteers on Monday (September 11) to discuss what they can do to support people living with epilepsy.

The event took place at Parliament Buildings on the Stormont Estate in Belfast and was attended by MLAs from Sinn Féin, the Ulster Unionist Party and the Alliance Party.

A number of people with epilepsy and those who care for people with epilepsy shared their stories, including Paul Strain, Kerry Watkinson, Shauneen Simpson, John Scott, Samantha Campbell and Monica O'Neill.

It was organised by Epilepsy Action's Northern Ireland policy and campaigns officer Jack Morgan and Northern Ireland manager Carla Smyth.

The MLAs heard directly from people living with epilepsy and people caring for



Epilepsy Action volunteers Paul Strain and John Scott

them. Epilepsy Action also repeated its call for the Northern Irish parties to work together to restore Stormont and begin addressing these issues.

MLAs have agreed to work with Epilepsy Action on some of the issues raised by the speakers.

Jack said: "Today was a great opportunity for MLAs to hear directly from



MLAs Colm Gildernew, Jemma Dolan and Robin Swann

people with epilepsy. Those in attendance shared their heartfelt stories and struggles, such as access to healthcare, mental-health provision, challenges with employment and accessing benefits and education. We hope that the MLAs in attendance now have a good understanding of the condition and are better able to assist their constituents."

Epilepsy ignored in government's major health conditions strategy

The government has left epilepsy out of its strategy for major health conditions.

The Department of Health and Social Care's Major Conditions Strategy is a five-year plan for the main causes of ill health and early mortality.

The government has selected six conditions to focus on: cancer, chronic respiratory disease, dementia, cardiovascular disease, musculoskeletal disorders and mental ill health.

It claims that together these six groups drive more than 60% of mortality and morbidity in England.

With epilepsy affecting 1 in 103 people, and about 1,000 people dying every year in the UK from causes related to epilepsy, Epilepsy Action is disappointed that the condition has been ignored.

Senior policy and campaigns manager

Daniel Jennings said: "The government has ignored pleas from various epilepsy charities to include epilepsy in the Major Conditions Strategy. This is despite it being one of the most common and serious neurological conditions.

"With epilepsy not being included in the strategy, it is likely that epilepsy services will not get the same level of input or improvement as those that are included. This comes as existing epilepsy services are already understaffed and under-resourced."

Led by Epilepsy Action, a number of charities wrote to health secretary Steve Barclay to request it be amended "to include neurology as a seventh priority, with a focus on epilepsy".

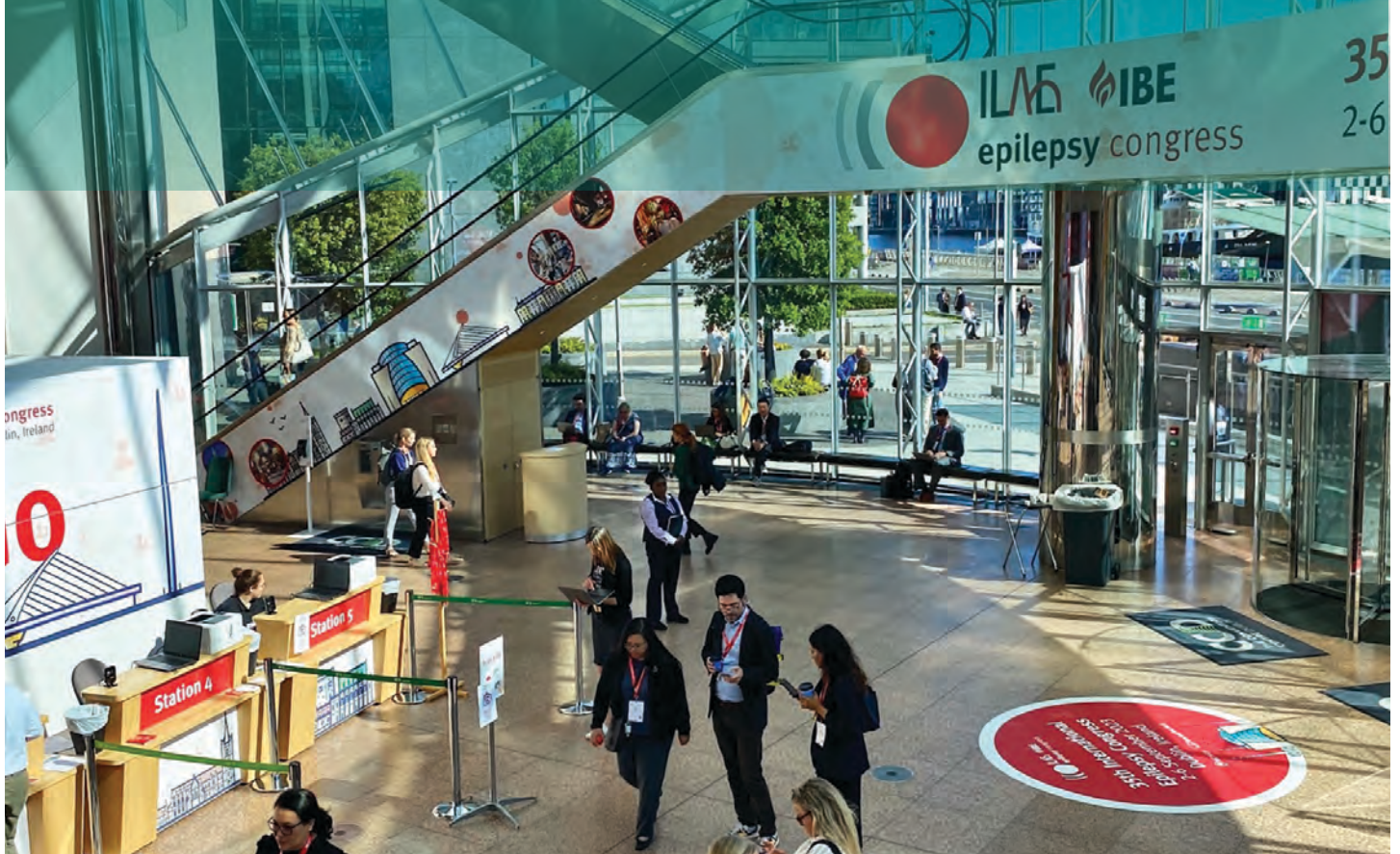
The letter said: "Given the unique and specific challenges facing epilepsy

services, and people with epilepsy, it is an opportunity to revisit the Major Conditions Strategy and include epilepsy as a focus within a neurological priority."

The charities included Epilepsy Action, Epilepsy Research UK, Young Epilepsy, the Epilepsy Society, SUDEP Action, Behçet's UK, Roald Dahl's Marvelous Children's Charity and more.

In response, health minister Will Quince said: "Focusing on these groups of conditions will allow us to identify the key actions that are needed to achieve our ambitions to increase healthy life expectancy, reduce pressures on the NHS and tackle labour market inactivity. The actions we take have the potential to benefit patients living with other conditions beyond the scope of this strategy."

What's new in research?



We went to Dublin to see the latest epilepsy research from doctors, patient groups and academics

The International League Against Epilepsy held its annual international congress from September 2-6, in Dublin. Epilepsy specialists, patient groups and academics met to discuss the future of research, patient care, treatment and diagnosis. The event was chaired by ILAE president J Helen Cross and International Bureau for Epilepsy president Francesca Sofia.



Presidential Symposium

Opening the symposium was Amber Freed, the founder of SLC6A1 Connect – a patient organisation she set up to find a cure for her son Maxwell's rare epilepsy caused by a genetic disorder. She explained how the organisation had grown into a national body in the USA that supports researchers with genetic testing and patient registries.

James Mitchell from the University of Liverpool spoke about outcome measures in research. His studies showed that the outcomes patients and doctors wanted to see from research were sleep quality, impact on driving and fertility.

Next to speak was Scott Demarest, professor of Pediatrics and Neurology at Colorado University, he covered the topic: are all epilepsies the same? "Of course not!" he said. He discussed the differences between anti-seizure medication (ASM) trials and disease modifying treatment (DMT) trials adding that seizure frequency need not always be the top measure.

Colin Josephson from the University of Calgary, Canada, joined the congress online, to discuss how artificial intelligence (AI) can help predict the outcomes of



epilepsy surgery. He discussed whether AI could replace or assist clinicians when deciding whether to send patients with temporal lobe epilepsies for surgery. Josephson concluded that while the computer program was about as good as a specialist at predicting outcomes, we would not be seeing it replace experts any time soon.

The last person to speak was Action Amos. Having travelled from Ghana, Amos spoke about engaging national governments and healthcare providers with epilepsy professionals. He said just 2.5% of research budgets globally went to low and medium-budget countries.



Could AI diagnose and treat epilepsy?

“Artificial intelligence is a tool for epilepsy professionals, it’s all about using it with regulation”, according to a panel of experts.

The panel included Sandor Beniczky from Aarhus University in Denmark, Stefan Wolking from Aachen University Hospital, Germany, Katia Lin from the University of Santa Catarina in Brazil, and Jacqueline French from New York University.

The first topic of debate was artificial intelligence (AI), with Lin arguing that AI in neurology could lead to reduced costs and higher efficiency. She said that in some instances, AI had managed to interpret EEGs with 80% accuracy – a similar rate to trained clinicians.

French then countered her argument, claiming that, while AI-decision support

“Everybody should be making sure their kids are out and not just playing video games”

tools might work for many patients, they don’t account for everyone. Both French and Lin agreed that artificial intelligence needed to be overseen by humans.

Wolking and Beniczky then debated seizure detection systems. They considered the increased use of seizure detection devices, with Wolking arguing that they could be more reliable than patient evidence – especially where the seizure left a patient with poor memory. However, Beniczky added, these devices often have high false alarm rates. They agreed there was potential in these systems but that more work was needed for them to be reliable.



Epilepsy and exercise

Should epilepsy specialists be prescribing exercise? This was the question debated by an expert panel.

Ricardo Arida from the University of Sao Paulo in Brazil presented his research in animal models, which suggested that exercise could be a protective factor against seizures.

Elinor Ben-Menachem from the University of Gothenburg in Sweden discussed exercise self-management programmes. Her work on men in Sweden found that low-cardio fitness in childhood was associated with an increased risk of epilepsy in later life. She concluded that “everybody should be making sure their kids are out and not just playing video games”.

Halley Alexander from Wake Forest University in North Carolina, USA, talked about how people with epilepsy can optimise the effects of exercise.

“Physical medicine is medicine,” she said, citing studies that suggested training with weights may reduce seizure frequency. She also suggested that programmes of combined cardio and strength training might be the best way forward.

“Some activity is better than nothing”, she said, adding “it is partially true that sitting is the new smoking”.

Finally Jane Allendorfer from the University of Alabama, USA, discussed how to improve patient engagement with exercise. She said stigma was a major factor for people with epilepsy as well as travel and safety fears.



Plant-based therapies

Patients need the same access to medical cannabis as any other ASM, according to Yvonne Cahalane, the mother of Tristan Forde, the first person in Ireland to be legally allowed access to medicinal cannabis.



“People with anxiety are at an increased risk of developing epilepsy”

differing methods of extraction, and that natural compounds cannot be patented by pharmaceutical companies.



Epilepsy and anxiety

“People with anxiety are at an increased risk of developing epilepsy”, and people with epilepsy are at an increased risk of developing anxiety, according to researchers.

The panel comprised psychologists and neurologists, chaired by Milena Gandy from Macquarie University, Sydney, Australia, and Heidi Munger Clary from Wake Forest School of Medicine in North Carolina, USA.

Gandy discussed tools for differentiating between normal anxiousness and an anxiety disorder. She said “anxiety becomes a disorder when it affects day-to-day functioning”, is disproportionate to the situation a patient is fearful of, and becomes a challenge for the patient to manage.

Coraline Hingray from the Centre Hospitalier Universitaire de Nancy, France, discussed the increased risk of people with pre-existing mental health conditions developing epilepsy, including anxiety and post-traumatic stress disorder.

Gaston Baslet from the University of Illinois, Chicago, USA, discussed how anxiety can lead to worse seizure control and impact a patient’s quality of life.

Sophie Bennett from Great Ormond Street Hospital, London, then discussed anxiety in children with epilepsy. She reiterated the importance of personalisation when treating these patients.

Finally, the panel discussed medication and anxiety. They spoke about how anti-depressants and ASMs impact one another and emphasised how understudied the field was.

For more information about the ILAE go to: www.ilae.org

Cahalane was speaking on a panel discussing the benefits of plant-based therapies for epilepsy.

Tristan, who has Dravet syndrome, had his first seizure aged five months and Cahalane said none of the prescribed medicines would work. He was first given access to cannabis in 2016 after spending time on a research project in Colorado, USA.

The family saw improvements in weeks. After three months of treatment, his seizures were greatly reduced. However, the family faced stigma, with schools refusing to administer the drug and many doctors unwilling to prescribe.

The panel also included Elizabeth Thiele, a neurologist at Massachusetts General Hospital, USA; Cecilie Johannessen Landmark, a senior researcher from Oslo University Hospital; Finbar O’Callaghan from University College London and Great Ormond Street Hospital; KP Vinayan from the Amrita Advanced Center for Epilepsy in Kerala,

India, and neurologist Siegward Elsas from Arlesheim, Switzerland.

Thiele argued that other plant-based therapies had become common medicines, such as Aspirin, which was found in the bark of the willow tree, and morphine, which is based on the poppy plant.

O’Callaghan – who was a member of the UK Home Office expert panel on cannabis-based medicines in 2018 – said the medicine had been effective against a range of seizure types and could be used for more than the treatment of Dravet Syndrome, for which it is permitted in the UK. However, he emphasized that more randomised control trials were needed.

Vinayan discussed traditional Asian medicine. He said 70% of people in India prefer natural systems for treating epilepsy, such as Ayurveda.

Finally, Elsas discussed his research into plant-based medicines. He said the difficulties of plant-based treatments included that the concentration of ingredients changes seasonally, the

What's happening *where* you are?

Members are integral to Epilepsy Action's work across the UK and Northern Ireland. We round up what's happening and how you can get involved

Northern Ireland

On 14 November it is International Men's Day and Epilepsy Action Northern Ireland is hosting a men's mental wellbeing session – it is available to men across the UK. There will also be a therapeutic support group for men held over three weeks, starting 21 November.

On 29 November, the Northern Ireland team is holding an understanding anxiety and epilepsy session online to give tips to young people. And, on 13 December, there will be a webinar called Caring for yourself at Christmas. Talk and support groups continue in Belfast and Fermanagh.

Wales

Cardiff Half Marathon took place on 1 October, with five runners taking part to raise money for Epilepsy Action.

September's winner of the Epilepsy Star Award was Katie Davies, 23, from Caernarfon, North Wales. She was recognised for her awareness raising and commitment to the epilepsy community. Katie was diagnosed with epilepsy in 2008 following an inflammation on the brain, which is known as encephalitis, and has lived with the condition since. Working alongside Epilepsy Action, Katie shared her experiences in a documentary called 'Epilepsi a Fi' for S4C. She said: "Awareness is everything for me and it's important for me to be a voice for people with this invisible condition."

Talk and support groups continue in Aberystwyth, Caernarfon, Pembrokeshire and Swansea.

North of England

The Great North Run in Gateshead raised £20,000 for Epilepsy Action (see p5). You can sign up now for 2024. A new Liverpool talk and support group was launched and groups continue in Bradford, Huddersfield, Leeds, Manchester, Sheffield, Teesside and Wigan.

Midlands

NHS Midlands and Lancashire's project with Epilepsy Action, aimed at reducing mortality in people with learning disabilities and epilepsy, was shortlisted for a Health Service Journal Patient Safety Award.

Elsewhere, talk and support groups continue in Birmingham, Coventry, Leicester and Stoke on Trent.

South of England

There are still spots available for the London Marathon on 21 April, 2024.

Talk and support groups continue in Basildon, Bournemouth, Bristol, Chelmsford, Chichester, East London, Exeter, North London, Lowestoft, Norwich, Romford, Saffron Walden, Thurrock, Torbay, Truro, Weymouth and Witham.



For more go to epilepsy.org.uk or scan the QR code

Songs

about seizures

Musician VC Pines released his debut solo album MRI last month. He tells us how living with epilepsy has made his music unique



“If someone said take this pill and you’ll wake up tomorrow and you won’t have epilepsy anymore I wouldn’t take it,” says VC Pines.

In September, VC Pines – the stage name of Jack Mercer – released his debut solo album MRI, focusing on his experience of living with epilepsy. He says the album is inspired by living with temporal lobe epilepsy and that living with the condition has given his creative output a unique style.

“Epilepsy has made me different. I’m not the best musician in the world, I can’t just shred on my guitar and do all of that but it makes me create in a way that’s different to other people.”

The sound of an MRI (magnetic resonance imaging) is on the album’s opening track, Chamber, and in the video for the song Running, he is in a hospital gown linked up to an EEG. “I wanted to start with a brain scan taking place, which symbolises the EEG scan I had,” he says.

To Jack, his epilepsy makes him unique. “I’m fortunate enough with my condition that it’s not completely debilitating and it’s something I try to harness and use as a tool. It’s a part of me. It’s something that I turn around on myself,” he says.

Utilising his symptoms

Epilepsy is present throughout the new album with song titles such as Colours, Damn Different and No One’s Gonna Save U speaking to this inspiration.

“It’s affected the way that I write,” Jack says. “I think my condition makes me very sensory.”

“I have lots of memories and stuff that gets triggered by senses, by sounds, smells and sights, and they’ll trigger nostalgic episodes, which can turn into a seizure. So, I try to use the senses when I’m making music – in my writing. All of the songs themselves, they burst from nostalgia. So they’re memories that have been blown up and turned into song.”

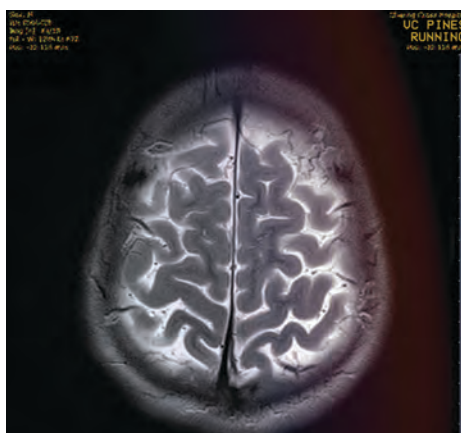
The heightened senses and flashbacks of memories that come with his epilepsy have all fed into his work.

“Synaesthesia is one of the symptoms,” he says, adding: “When I’m making the music part of it, chord sequences and stuff, there are colours in my head.”

“The stuff I’m most happy with is always violet or purple in colour. VC Pines is violet-coloured pines. I try to kind of paint the songs in my head using senses and memories.”



“I try to paint songs in my head using senses and memories



The Pines part of his name comes from a trip to New Hampshire when Jack was a child. There were huge pine trees all around the town, which resurfaced as a memory when he was having seizures as a teen.

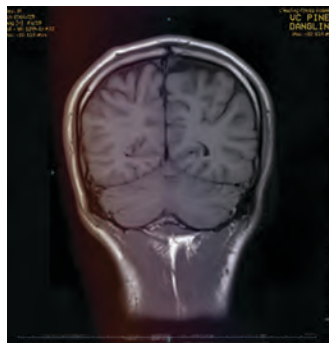
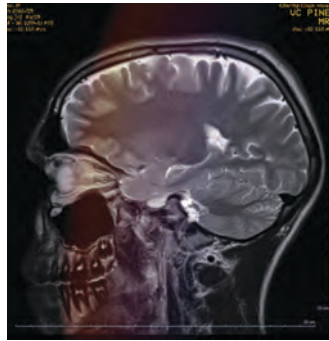
Epilepsy and memory are strongly linked, with many people reporting memory loss around the time they have seizures.

For Jack, his creativity is connected to his memory. And while the inspiration he draws from nostalgia helps him write, the memory difficulties he faces because of his epilepsy can create problems day-to-day.

He says: “I feel like my long-term memory is good. My senses will trigger memories that I wouldn’t otherwise remember, but my short-term memory is dreadful. I will think: ‘When I leave, I have to take this out with me’ and I’ll leave it by the door. I just don’t register anything and completely forget.”

Discovering his epilepsy

Seizures remain a present in Jack’s life, and he has been living with epilepsy since he was 17.



“I started having simple partial seizures and then I had a couple of focal seizures as well and I had no idea what was going on. I just thought I was going mad and losing my mind at 17. So, I went to the neurology department in Charing Cross (London) and got scanned and diagnosed from my symptoms.

“They put me on lamotrigine and I had a really bad time with it. I would be a completely different person. I fell out with a lot of friends and it completely changed me. It’s put me off medication as a whole. I was still having seizures, so I was like: ‘I would rather be myself and have seizures than not be myself.’”

Epilepsy has also had an effect on his mental health.

“I’m much more prone to seizures when I’m depressed,” he says.

“Epilepsy can give me sharp mood swings that are always hard to navigate. My mood will rapidly change just before I have a seizure and it’s not something that I necessarily notice. There’s loads of daily things that come with epilepsy

that you have to navigate as well as the seizures – there’s a million other things that are all emotional and mental, and things that happen every day.”

Going solo

Jack began his music career with The Carnabys, an indie-pop band from south London. The band toured around the world with many artists, including Bruce Springsteen. When the band released its second album, all the pre-sale and first-week profits went to Music Venue Trust, a charity for grassroots venues. But working in a band made living with epilepsy more challenging for Jack.

“Everything was fun and exciting, but I didn’t look after myself the way I should have when we were touring. It really did take a toll. Adrenaline would always get me through the shows and then after the gig, that’s when whatever was coming for me would happen, straight after.”

Being a solo artist has made it easier to live with his condition. “I’ve started telling myself nothing good happens after 3am.”

he says. And now he sees his epilepsy as a positive influence.

“I feel like because of the niche it’s given me and my work, it’s given me a sense of confidence because there’s a uniqueness and I guess that’s something that could help other people.

“I know how fortunate I am for my condition to not be as life-changing as other people’s, but, if you can, try not to see your epilepsy as a bad thing, try to see it as something that’s for you to use to create things that no one else could create or see things that no one else could see from that perspective.”

To find out more about VC Pines and listen to the album go to: vcpines.com

If you experience any problems with your epilepsy medication, it’s important you do not stop taking it without speaking to a medical professional as this could cause breakthrough seizures. Please talk to your doctor or epilepsy specialist before changing or stopping any medication.



What are *we* up to?

Your support helps us carry out our vital work online as well as in person. Here's where you can see more

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



Facebook

In September, Epilepsy Action launched a membership Facebook group. It is for members to meet others in

the community and share their experiences of epilepsy. In just a couple of days, the group had more than 100 people join.

The group has been described as a "safe space for members to chat and share their experiences, as part of Epilepsy Action's mission to improve the lives of everyone affected by epilepsy".

One user said: "Thank you for letting me join the group. It will be interesting to hear from people who have also been affected by this condition. Having only been diagnosed recently I am finding it difficult to make sense of all the emotions and the variety of symptoms each person has."



Instagram

On Instagram Live, we've spoken to Imogen Cauthery about her experiences abroad – she answered

questions about travelling with epilepsy. We also spoke to Letizia Mollinedo about being a university student with epilepsy. Letizia spoke about living away from home and managing the challenges of uni life. We also chatted to musician VC Pines (p14-16), and about air tags and GPS tracking – are they useful safety devices or an invasion of privacy?

Elsewhere on social media, Epilepsy Action asked its followers: have you been told to do CPR because of a seizure? And discussed the cost and availability of medicinal cannabis prescriptions.



Talk and support groups

In August, Epilepsy Action launched a New to Epilepsy group. And, in September,

an online group especially for men was formed. This group is open to any man affected by epilepsy, including family or carers of those living with epilepsy. A new Manchester Talk and Support group has also been launched and starts on 2 November. The weekly groups across the UK and online are running as normal.



Doodle Day

Doodle Day was a success, raising more than £25,000 – the most the event has ever raised.

The top selling pieces

were created by Heartstopper author Alice Oseman whose artwork sold for £2,000, artist Grayson Perry whose two pieces went for £1,209 and £960, and Paddington illustrator RW Alley whose drawing raised £910.

In 2024, Doodle Day will celebrate its 20th anniversary – so watch this space for more information about what we have planned or scan the QR code.



Facebook challenges

In October, Epilepsy Action ran two Facebook fundraising challenges. These are sponsored events

taking place online.

The skipping challenge involved skipping for 16 minutes a day – the average length of a call to Epilepsy Action's helpline. Participants received a free skipping rope. For those worried about the risk to their knees, there was also a reading challenge. Fundraisers were asked to read for 30 minutes every day and received a free bookmark.

To take part in November's Facebook challenges scan the QR code above.

The chat that saved a life



Rhys' journey with epilepsy was tough until, at his lowest point, he reached out to Epilepsy Action. **Jaimie Kay** tells his story

**STICK IT
TO EPILEPSY**

Rhys was 14. His life was great. He was enjoying school. Everything was going well. Then everything stopped and his life was turned upside down.

This is his journey with epilepsy.

Dealing with the life-changing moment so many face when diagnosed, Rhys was isolated and cut off. The life he once knew had disappeared.

School was a difficult time. His attendance dropped to the point where he was at home more than he was in the classroom. He worried what people thought: was he just not bothering to come in? Would he fall behind?

As it is for so many people, a diagnosis of epilepsy was life-changing and, at one point, Rhys began to feel that things might be better if he wasn't around anymore. He struggled to keep his friends, hold down a job or do well at school. The condition began to take over.

He says: "Unfortunately epilepsy has affected my life a lot. It was annoying people thinking I was having days off, but I would take being in the classroom everyday over being at home in a downwards spiral."

As Rhys got older, he deserved to experience what any 18 year old should, meeting with friends and finding relationships, but his epilepsy made him feel like he wasn't good enough. He missed out. He still lives with that feeling to this day, the fear of a seizure and

feeling that his epilepsy will cast a shadow over him.

Rhys says: "I had and still have that feeling that no one wants me. I have no problem speaking to girls, in fact some of my closest friends are girls, but I never thought I was good enough for anyone, even to this day."

Rhys' friends slowly started to disappear. He felt he couldn't do the things other people his age were doing. His epilepsy began to bring him down, his mental health took a hit and over time he found himself missing from life.

"Some friends couldn't understand, so I lost a good few of them," he says.

"I would rather lose friends than have a seizure in front of everyone."

For Rhys, epilepsy meant he couldn't get out of bed, he was emotionally worn out and he was worried he was becoming a burden to his family and friends.

"I was mentally drained. While my friends and people my age were progressing in life, I felt I was regressing – and not just mentally draining, also physically draining. I was down. I lost a lot of hope. I didn't have any control of my life. It was scary."

At his lowest point, Rhys called 111. The operator referred him to Epilepsy Action. Rhys spoke to an operator via the webchat. He knew then there was hope.

"I got a lot of help from Epilepsy Action, which I'm so grateful for," he says.

"Speaking to the helpline made me feel that I wasn't alone anymore. I got a sense they understood my situation. I felt I could

66
I lost a lot of hope. I didn't have any control of my life

breathe and met people who had been through similar experiences, which helped.

"From then, I knew that taking my life would be a bad thing. It had been a very lonely and dark time. I felt I was a burden to my family and friends and thought everyone would be better off without me. If it wasn't for speaking to someone, I would have ended it altogether."

Today, Rhys has found a new normal. He still has worries, but he is happier having support from Epilepsy Action.

He says: "I'm feeling better and I have been at my current job for two years, which was unimaginable not long ago. I want people to know there is support and you are never alone."

Chatting to Epilepsy Action saved Rhys' life. He says: "Getting in touch with Epilepsy Action really did save my life and it has changed my life for the better.

"It does get better. You should reach out for the help, because it could change your life completely."

Rhys is now on a better path. He has been living seizure free for two years and although epilepsy still remains a huge part of his life, he has started using his story to inspire others.

He says: "I'm doing more things that make me happy. There are a lot of things Epilepsy Action does for you to make you feel included, make you feel better about yourself. And I'm very grateful for that, because it has supported me and helped me in so many different ways – ways I couldn't imagine when I clicked on the Epilepsy Action logo for the first time."

Donate to support people like Rhys at Christmas, and together let's end the loneliness and isolation that epilepsy brings. For more information: www.epilepsy.org.uk



Rhys

Head in a book



After being inspired by her daughter's books, Ibbly Brown decided to write her own children's book to teach young people about epilepsy and hidden disabilities – she explains how it came about

Ibbly Brown's three-year-old daughter Niamh is probably more knowledgeable about epilepsy than most adults.

"Epilepsy is something that I want my daughter to be aware of from an early age," says Ibbly.

The secondary school teacher from Nottinghamshire was diagnosed with epilepsy five years ago after having a number of absence seizures. Three years ago, while pregnant with Niamh, she also began to have tonic-clonic seizures.

"My epilepsy is fully controlled now," says Ibbly, "but it's horrible really. Just before a seizure, it felt as though somebody had turned the dimmer switch up.

Everything would get very sharp and bright and I'd feel an intense pang in my stomach so I knew I was about to have a seizure."

Surrounded by colourful children's books, Ibbly decided a book would be the perfect way to teach her daughter about her condition.

"My little girl knows that mummy has epilepsy and that mummy takes tablets but other than that she wouldn't really understand it.



Ibbly (far right), her husband and their daughter Niamh

"In a lot of the books that we read, particularly since I was growing up, there is a lot more inclusion with ethnic diversity and physical disability. There's at least one character on Postman Pat and Fireman Sam in a wheelchair. There's a Peppa Pig character in a wheelchair and that really encourages positive conversation.

"I wanted the message to get across to children that there isn't anything to be embarrassed about and there are so many hidden disabilities that people aren't aware of."

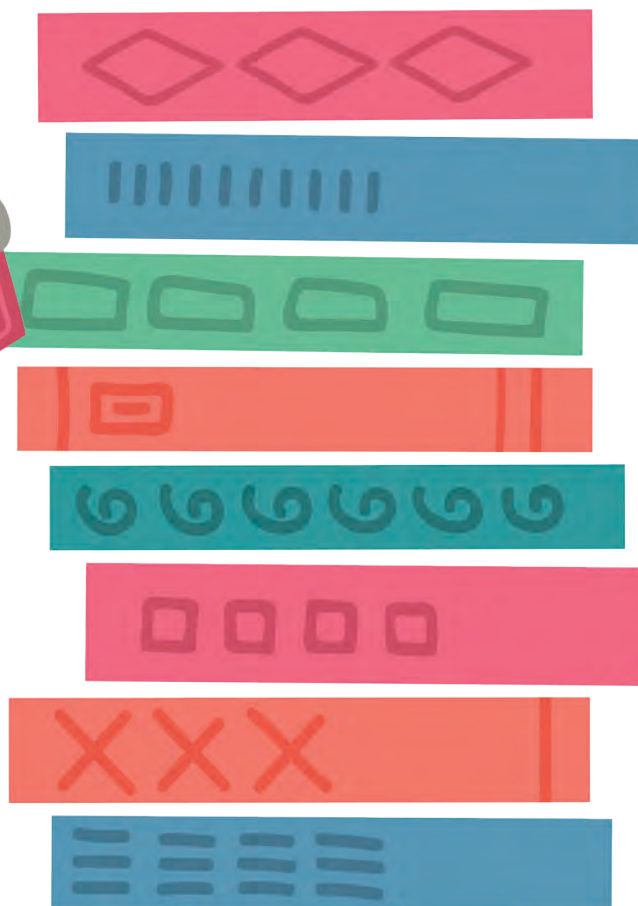
In Ibbly's book, Dennis is a dog who has epilepsy but is too embarrassed to tell his friends. He has absence seizures and is reluctant to tell anyone.

Then one day, he's playing at the park and begins to feel funny. He desperately tries to ignore it and pretend he's fine. But what happens when he has an absence seizure right at the top of the slide?

Dennis' experiences are partly based on Ibbly's own.

"I had never in a million years heard of an absence seizure," she says.

"With me not being diagnosed until I was 33, and not experiencing my first



absence until that age, I definitely can relate to the character's feeling of real embarrassment and feeling a need to hide it."

Although lbby wasn't at the top of a slide when she began having absence seizures, she was teaching a class of teenagers – something that showed her the importance of educating children about epilepsy.

"Having an absence seizure in front of a class of students was mortifying," she says. "I felt excruciatingly embarrassed and completely disorientated as I stared at a sea of teenage faces. Some students were laughing, some looked concerned

and anxious. I was the teacher. I was the person who was supposed to be in control."

Now pregnant with her second child, lbby believes it's important to educate children at a young age.

"I thought it was a good opportunity to open up conversations with that age group.

"I would love this book to start conversations about epilepsy: how it feels to have the condition, how embarrassed people may feel to tell others, how other people feel so much better knowing about it and knowing what to do, as well as giving children with the condition a character they can relate to. There is definitely a gap in the market for stories that introduce and explore hidden disabilities."

But the book isn't just for children who have epilepsy or have a sibling, parent or family member who does. lbby is also hoping it will appeal to children who might never have heard of it.

"When I've looked on Amazon or googled other children's books about epilepsy, or any other condition, there are

some, but not many, and they don't seem to be very popular or mainstream," she says.

So to reach a wider audience, she chose a rhyme scheme and decided to make it "quite jolly and quite fun to read".

"I've put in things that are designed to be quite funny," she says, "like when your bottom's being pricked. I have a joke about when you're in your brother's room, your brain says: 'Oh, that stinks' – things that young people find humorous. I was really determined for it to be relatable to everyone – because even if you haven't got epilepsy you've got a brain and you can smell, you can feel."

lbby says she still regularly has to teach adults, too, about her condition – which can be more difficult than explaining it to children.

"I still can get quite wary telling people, because it's very evident that some people aren't comfortable, particularly if I might be in the car with somebody and it's only me and them. You can almost feel them praying that I won't have one.

"Tonic-clonic seizures can be very frightening for people to witness. And,

“There is a gap in the market for stories that introduce and explore hidden disabilities”



Ibbby and her daughter Niamh



Ava's Doodle Day Paddington

obviously, anyone new that I meet, I have to say: 'This is the condition that I've got, it's controlled with medication but if I have a seizure this is what you need to do.'

So, in Ibbby's house, seizure first aid starts young.

"I know that my husband knows exactly what to look out for with my absence seizures, which are now fully controlled with medication.

"He knows what I look like if I'm having a seizure and he'll say: 'Are you having one?' and if I respond straight away he obviously knows I'm not. So sometimes he'll just look at me and he'll say my name, repeat my name and ask: 'Are you having one?'. My daughter will sometimes repeat that question and say: 'Are you having one Mummy?', especially if I'm quiet for a little bit and I'll say: 'No, don't worry, I'm not having one.'"

But, Ibbby adds, epilepsy doesn't stop her from living her life. It's not her condition that's the problem – it's the lack of education.

"Yes, I have a condition and it is unpredictable, but you can't live your life forever thinking: 'What if I have one right now?'. If I lived like that, I'd never boil the kettle or stir a pan of spaghetti! It makes you more determined to live harder and do all the things that you have been putting off. It also makes you so grateful for everything you can do easily: see, hear, walk."

And so, her goals for the book are big. She's got more ideas in the pipeline and she wants to

use those ideas to raise money to support other people with epilepsy.

"My proposal was to find an illustrator who also had a connection to epilepsy. We could then work together to complete the picture book. The next step would be to publish the book, with the idea that some money from every sale would be donated to Epilepsy Action.

"With children's books the images are absolutely fundamental to bringing the words to life. I thought it would be amazing if the illustrator also had the condition or experience of it," says Ibbby.

Then, during Epilepsy Action's

Doodle Day earlier this year (see p17), Ibbby connected with illustrators Ava Sheriff and Laura Farnsworth. Now, Ava will be illustrating Ibbby's book and together they are looking forward to starting work on the project.

Ava is Laura's daughter. On Doodle Day she took part in the Paddington workshop held by Epilepsy Action and run by the illustrator RW Alley. Her auntie, Laura's sister, was diagnosed with epilepsy as a teenager.

Laura said: "As a family we all support Epilepsy Action. We were delighted to have met Ibbby through the charity."

Ibbby does have ideas for what Dennis might look like, but she's open to experimenting with new ones.

"I would love the images to be – like the images from the Gruffalo, the Axel Scheffler illustrations – really bright, colourful, friendly characters. I can imagine it with the images really bringing it to life."

"At the end of the book," Ibbby says, "Dennis' mum says to him: 'Your friends will be far more upset not knowing', it's frightening for people when they don't know". And, in the end, he does tell his friends about his epilepsy – and they support and reassure him.

Dennis Dares to Share is aimed at children aged 2-6. If you are an illustrator, publisher or interested more in the book, please email: ibbybrown@hotmail.co.uk



Epilepsy Action is here for you



helpline

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



counselling

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



talk and support

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



family support
Northern Ireland

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



befriending

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



epilepsy.org.uk/support

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

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

Registered charity in England and Wales (No. 234343)

Adventure of a lifetime

Jennifer had seizures scuba diving in Thailand, in Bolivia and in the rainforests of Costa Rica. Now she's using her experiences with epilepsy in her work as a wedding celebrant. Words by **Rebecca Lock**

“ was unconscious. My wetsuit had to be cut off and I was resuscitated. Everyone thought this was it, but it wasn't my time to die.”

Jennifer Constant (pictured right) had her first seizure during a scuba diving session in Thailand. More than 10 years later, she's set up three successful businesses and has now won an Epilepsy Star Award.

Her husband, Terry, who witnessed that first seizure, nominated Jennifer, 38, for her inspiring attitude and incredible dedication to people with epilepsy and other disabilities through her work as a wedding celebrant.

Jennifer and Terry's trip to Thailand was the adventure of a lifetime, but it was also the start of Jennifer's epilepsy journey.

“I wasn't always a fan of the ocean. I was always seasick on boats and afraid of what was beneath. So when Terry sat beside me on a beach in Thailand and said: “Let's do scuba!” I said: “Heck no,” says Jennifer. “Soon enough, I'm there in the practice pool, wetsuit on, learning about respirators and gas tanks.”

“Terry and I started our backpacking journey after university, travelling the world together. We had so many adventures. And scuba diving, while it wasn't on the top of my list, was on





Terry, Jennifer and their children

“My wetsuit had to be cut off and I was resuscitated. Everyone thought this was it, but it wasn’t my time to die”

Terry’s. I surprised myself as I loved it. I thrived under water and loved sitting at the bottom of the ocean floor watching another world of marine life go by.

“We went under, excited to be filmed and show off our skills. The video panned to us. Terry did a spin in the water and I copied. Then the story ends. Well for me.

“Terry on the other hand witnessed something he will never forget. He looked left and right and couldn’t see me. I’d disappeared. He looked behind and another dive buddy with wide eyes pointed downwards, as if he’d seen the biggest shark ever. However it wasn’t a shark, it was me floating down into the darkness from 25 feet, to 60, to 70... respirator out, mask off, having a seizure.

“Unusually the dive school had an additional dive master with us that day. Before Terry looked back up for help, the dive master caught me and we ascended to the top with no other considerations but to get me to the surface.

“I spat out the water, slowly came back to earth and after about five hours, I remembered who and where I was. Something only those of us with epilepsy can understand.”

For Jennifer, this seizure was the first of many, but the shock of being diagnosed was difficult to come to terms with.

“This was just the beginning for me. We continued to travel, unaware that this was epilepsy, but two years later in Bolivia, I walked out of my hotel, fell to the ground and had another seizure. We headed to Argentina for a scan and were sent back to the UK. This is when my epilepsy story began.

“When I found out I needed to take medication every day, potentially for the rest of my life, I went into denial. How could it be that I had two seizures, two years apart but I was stamped with this label of having epilepsy. I started to stop taking my medication but every time I did, I had a seizure.”

Since being diagnosed with epilepsy, Jennifer has gone on to set up three

“Having epilepsy drove me to make experiences better for others”

successful businesses and explored more of the world with her family.

“Since diagnosis, I’ve had many seizures,” she says. “Many during and at the end of pregnancy. Some in front of my children. Some when exploring the rainforests in Costa Rica. They aren’t nice but I don’t let them stop me.”

In 2010, Jennifer set up a celebrant business and became a wedding celebrant, officiating hundreds and hundreds of wedding ceremonies. Combining her experience of living with epilepsy and her passion for officiating weddings, Jennifer embarked on helping couples with epilepsy or other disabilities, who may have extra considerations, to have the perfect wedding day.

“I often stood in front of hundreds of people, all looking directly at me. There was one ceremony where I stumbled. My mind went foggy and I had to stop and take a break. I never let epilepsy embarrass me or hold me back. I took a drink and started again. We’re all human.

“This gave me extra motivation to start talking directly to couples who have the same condition or similar disabilities. I started to officiate ceremonies for couples who needed the extra support, or even the confidence that it was okay to have a wedding with a disability.

“Having epilepsy drove me to make experiences better for others.”

Jennifer’s husband, Terry, who nominated her for the Epilepsy Star award, said: “Jennifer is a true inspiration to people with epilepsy and does not let any challenge overwhelm or stop her.

“She deals with epilepsy on a daily basis and is a pioneer for others who want to take control of their own lives by starting their own business. Literally nothing stops this inspirational woman from taking charge of her condition.”



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

Council of management

The Council of Management met by remote video conference on 3 October.

The main item of business was the consideration of the draft of the new long-term strategic plan for the charity. This was the culmination of months of review, consultation, analysis and modelling. The strategy has now been finalised and approved by the council and a comprehensive communication plan will soon begin to advise everyone about the charity's future (see more in January's edition).

In other business, Domini Wood was appointed as the latest member of the charity's ethnic communities advisory panel. Council also reviewed and were



content with the charity's current financial position and the progress being made with this year's business plan. It also confirmed a set of guidance for staff for the preparation of the 2024 revenue budget and business plan.

Finally, council approved recommendations submitted by its finance and strategic policy committee to revise and update the charity's corporate risk register and its policy and process for strategic risk management.

The next meeting of the council is scheduled for 5 December, 2023.

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

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

For more information visit epilepsy.org.uk/legacy



Epilepsy Action Lottery

Play today for £1!

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

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

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

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

GambleAware

Epilepsy support for you

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

Join one of our virtual groups

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

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

Online resources

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

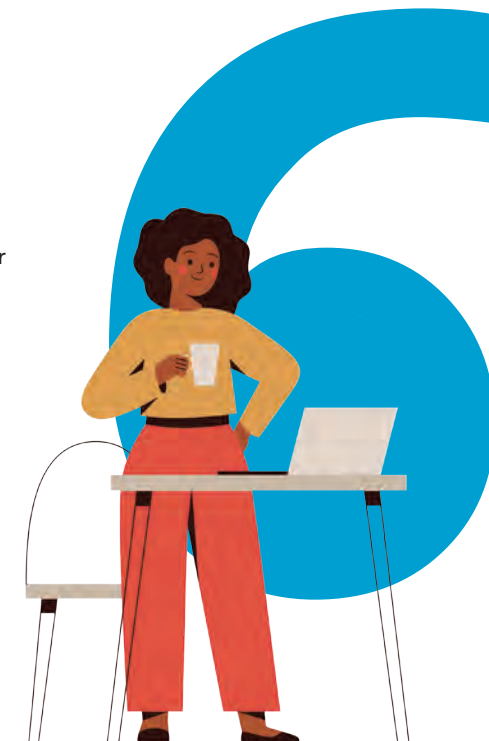
- HealthUnlocked (healthunlocked.com/epilepsyaction)
- Discord (bit.ly/3vHLOkT)
- Facebook (facebook.com/epilepsyaction)
- Twitter ([@epilepsyaction](https://twitter.com/epilepsyaction))
- Instagram (bit.ly/3zSKMVM)

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

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



For more information scan the QR code



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



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SUPPORT
AND YOU ARE
NEVER ALONE**



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