epilepsy action

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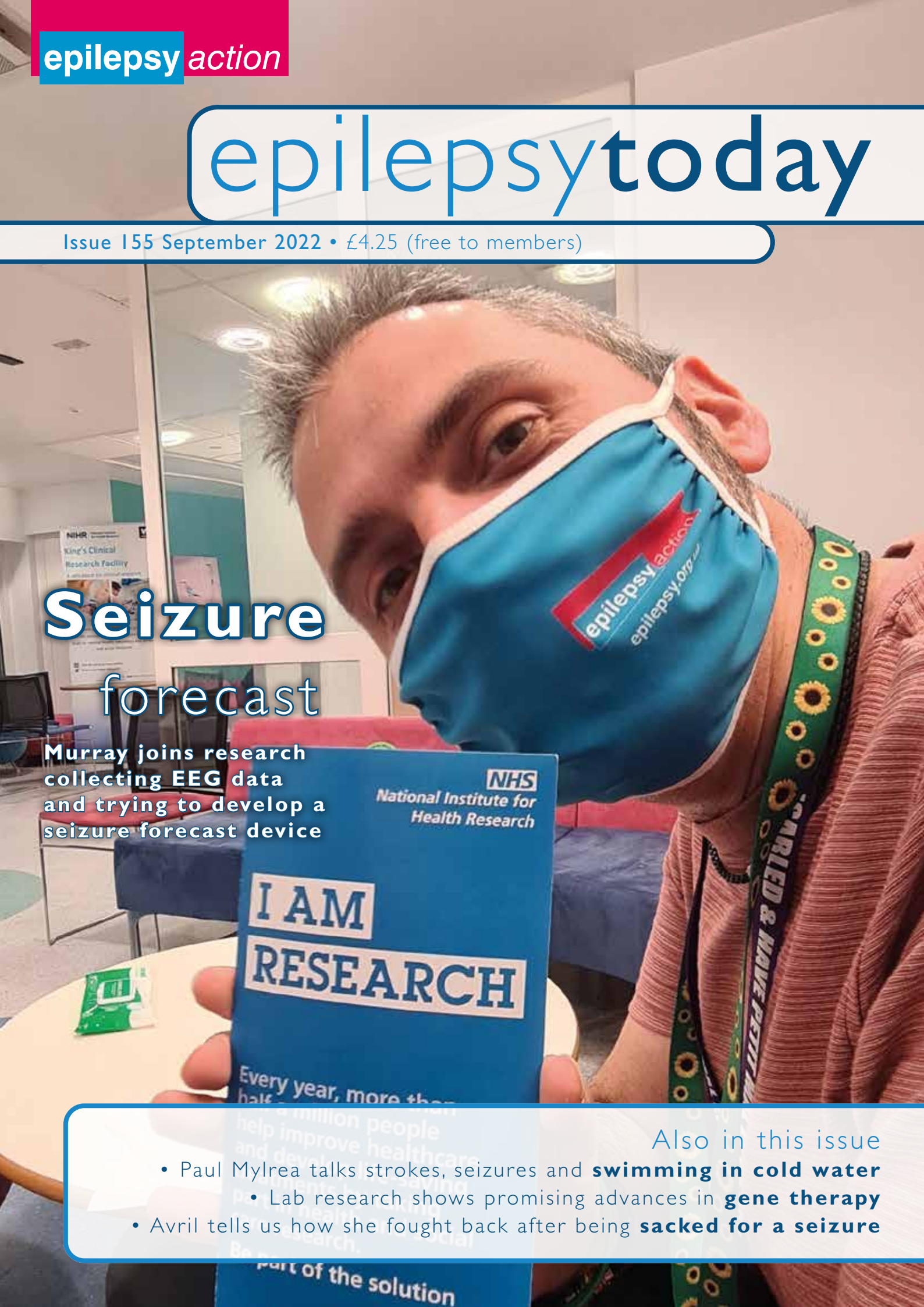

Seizure forecast

Murray joins research collecting EEG data and trying to develop a seizure forecast device

Also in this issue

- Paul Mylrea talks strokes, seizures and **swimming in cold water**
- Lab research shows promising advances in **gene therapy**
- Avril tells us how she fought back after being **sacked for a seizure**

editor's **letter**

Welcome to the September 2022 issue of *Epilepsy Today*.

This summer was quite something. We clocked the hottest temperatures on record in the UK, football 'came home' when the Lionesses won the Euros, and Westminster commenced a leadership changeover. But this was not all that the last few months have held. In May, Epilepsy Research UK held its Shape Network Conference. On page 16 you can find the lowdown from the first of three conference sessions, talking about what lab research is looking into, particularly genetic therapy. This could be an exciting new form of treatment that is working to deliver treatment exactly where it's needed and avoid side effects.

What's more, we held our Jog 30 Miles in June challenge. So many of you took part and raised vital funds for epilepsy, which was a joy to see. On page 24, we share Hayley and Alex's stories about the reasons they took part in the challenge and what it was like for them.

After all the excitements of summer, we're heading towards a golden autumn. So it probably feels like it's an odd time to think about going out swimming in lakes or in the sea, isn't it? Not for Paul Mylrea. He shares his story of getting Covid-19, followed by strokes and a diagnosis of epilepsy. He is a wild swimmer, and he and his doctors believe his swimming in cold water year round helped him during some touch-and-go moments. Read his incredible story on page 8.

This issue, we also bring you some stories around topics that are always a big issue for people with epilepsy. We know employment is one of the biggest problems people face. On page 12, we share an empowering story from Avril, who tells us about the time she was fired for having a seizure, and how she fought back. Another issue people face is having their seizures mistaken for things like drunkenness or daydreaming. On page 20, read what other behaviours or conditions you told us on Facebook your seizures have been mistaken for.

Last but not least, don't miss our cover star Murray on page 26. He's taken part in a trial of a long-term EEG device, and tells us first hand what this has been like for him, what the device is like, and what it was like being filmed for TV alongside one of his music heroes, Martin Kemp.

I hope you enjoy this issue and all the variety of stories we have for you!

Kami Kountcheva
Editor

Editor
Kami Kountcheva kkountcheva@epilepsy.org.uk
Publisher
Epilepsy Action epilepsy@epilepsy.org.uk
New Anstey House, Gate Way Drive, Yeadon,
Leeds LS19 7XY, UK
Tel: 0113 210 8800 Fax: 0113 391 0300
Freephone Epilepsy Action Helpline:
0808 800 5050
www.epilepsy.org.uk

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this **issue...**

MHRA launches topiramate safety review

The Medicines and Healthcare products Regulatory Agency (MHRA) has launched a safety review into the epilepsy medicine topiramate, announced on 21 July. The review comes after a study has reported an increased risk of problems with development to babies exposed to the medicine in the womb.

The study in the journal *JAMA Neurology*, which triggered the safety review, has shown that topiramate may increase the risk of autism and problems with learning and development in children whose mothers took it during pregnancy.

The researchers, Marte-Helene Bjørk and colleagues, found that topiramate and valproate, when taken on their own, are associated with a 2-4 times higher risk of autism and learning and development problems. This was also found to be the case with some combinations of epilepsy medicines.

The MHRA review will look at all available information about the safety of topiramate and decide if more needs to be done to increase awareness and reduce the risks posed. It will also look at what future research is needed to fully understand the impact of the medicine, and offer recommendations to the Commission on Human Medicines (CHM). This is expected to happen in October this year.

Last year, the MHRA published updated safety advice around many epilepsy medicines, after a review by the CHM into the safety of epilepsy medicines in pregnancy. This found topiramate could increase the risks of major problems at birth, as well as cause babies to be born smaller. Concerns were raised then about the medicine's effect on development, but there were not enough data at the time to reach a conclusion.

Epilepsy Action has said in a statement: "We are pleased to see the MHRA is reviewing the available safety data on topiramate. We will monitor the progress of the review and keep everyone updated on the results."

The organisation is pushing for this information to be quickly circulated to doctors and nurses so they can help people make informed decisions about their healthcare.

Epilepsy Action has added it is crucial that women do not stop taking their epilepsy medicines without talking to their doctor first. Stopping medicines could be harmful to them, and if they're pregnant, their unborn babies. Anyone taking topiramate who is pregnant or planning a pregnancy, should contact their epilepsy specialist nurse or doctor for urgent advice about the safest medicine for them and their baby.

There is more information on the safety review at ***bit.ly/3PXI9Im***.

There is also more information on epilepsy and pregnancy at: ***epilepsy.org.uk/medicines-pregnancy***.

Sulthiame reduces seizures in myoclonic atonic epilepsy

Add-on use of the medicine sulthiame may reduce seizures in children with myoclonic atonic epilepsy, according to a new study from Argentina.

The study, carried out by Dr Roberto Caraballo and colleagues, was published in the journal *Epilepsy & Behavior*. The researchers wanted to find out if sulthiame was effective and well tolerated in children.

The research included 35 children with myoclonic atonic epilepsy, also sometimes known as Doose syndrome, who had all tried at least four other epilepsy medicines, but they had not worked. The participants were examined and had EEGs, video-EEGs and MRI scans done. The effectiveness of sulthiame was assessed by comparing the number of seizures before and after using the medicine.

Seizures reduced by more than half in three-fifths of the children (60%) who took sulthiame as an add-on medicine. Two of the children became seizure free. In the remaining children (40%), seizures reduced by between a quarter and a half (25-50%).

The researchers noted that around a third of the children (31.4%) had side effects. These included shortness of breath or unusually fast breathing, a loss of appetite, headaches, or feeling sick, drowsy or irritable. However, the authors said these were mild and passed in all cases, and did not cause anyone to come off the medicine.

The study concluded that sulthiame was effective and was well tolerated. It was especially effective for myoclonic-atonic and myoclonic seizures, but also helped with atypical absences and tonic-clonic seizures, the researchers said. However, they added that further long-term studies are needed.

This medicine is available in Australia, the US, Europe and Israel, but not yet in the UK.

For the full study, visit ***bit.ly/3S4bUZ5***.

Changes in epilepsy guidelines

People with well-controlled epilepsy may not be offered an annual review, according to the updated guidelines for epilepsy healthcare professionals from The National Institute for Health and Care Excellence (NICE).

NICE now recommends that regular reviews (at least once a year) should be offered to certain groups of people with epilepsy, according to the new guidelines published on 27 April. These include, children and young people, those with hard-to-treat epilepsy and those at a high risk of sudden unexpected death in epilepsy (SUDEP).

People with a learning disability or other health conditions, such as complex mental health problems, will also be offered annual reviews. Those taking medicines with long-term side effects, such as bone health problems, and women of childbearing potential taking medicines which carry a risk in pregnancy, will also be offered reviews.

If you are outside these groups, NICE says you should still get a review if you have concerns with your epilepsy, but you would need to ask for one.

The guidelines say people who continue to have seizures should be offered appointments with an epilepsy specialist nurse (ESN) at least twice a year and after any A&E visits.

Another change is that the ketogenic diet can be considered as a treatment option in adults as well as children, according to the updated guidelines. This is in people with certain epilepsy syndromes or in people with hard-to-treat epilepsy where other treatments haven't worked or are not suitable. In the previous guideline, the ketogenic diet was only recommended for children and young people.

Grace Haydon, senior advice and information officer at Epilepsy Action, said: "The newly-updated NICE guidelines for epilepsy is important, because it tells healthcare professionals what treatments, tests and information they should offer to people with epilepsy.

"NICE makes recommendations to the NHS in England and Wales about the treatment and care it should provide for different health conditions. Its guidelines are also taken into account in Northern Ireland.

"It's also important for people with epilepsy to know about the NICE guideline, because it sets out the standards of treatment and care you should be able to expect for your epilepsy.

"We know that in reality, many people with epilepsy aren't getting access to the full range of services in the timescales that NICE recommends.

"Epilepsy Action will continue to campaign for people to get the care these guidelines recommend, so that everyone with epilepsy gets the care and support they need."

The guidelines also state that a doctor should urgently refer someone who has had a breakthrough seizure after a period of being seizure free. Urgent assessments should happen within two weeks.

Those who might be suitable for epilepsy surgery and have an epilepsy likely to be resistant to epilepsy medicines should also have an early referral for surgery assessment, according to NICE.

The full guidelines are available on the NICE website at ***bit.ly/3Jdgosb***.

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Predicting risk of returning seizures

Adolescent age at diagnosis and unusual EEG findings are among factors that predict breakthrough seizures risk after withdrawal of epilepsy medicines in children, says a new *Epilepsy & Behavior* study.

The research, by Yıldırım and colleagues, included 269 seizure free children able to come off their epilepsy medicines. They were followed up for at least 18 months.

The researchers found that around a third of the children (33.5%) ended up having breakthrough seizures. Of them, just under half (45.6%) had had their seizures return at six months, three quarters (74.4%) at two years and almost all (94.4%) at five years.

Three characteristics were found to predict a higher chance of having returning seizures. These were adolescent age at diagnosis, unusual EEG findings after the epilepsy medicines were stopped, and having a high number of seizures while taking epilepsy medicines. The vast majority (93.3%) of the children who had returning seizures got seizure control again with just one epilepsy medicine. For the full study, visit ***bit.ly/3J5zBfc.***

Early surgery may help prevent medicine-resistance

Epilepsy surgery is a successful treatment, especially in people with focal epilepsy which is not medicine-resistant, according to a recent study from Italy published in *Epilepsy & Behavior Reports*.

Researchers Veronica Pelliccia and colleagues explained that epilepsy surgery is typically offered to people with epilepsy where medicines have not worked (medicine-resistant epilepsy).

But the authors suggested that this treatment can also benefit people with epilepsy that is not medicine-resistant. They said that if offered earlier, especially in children, surgery can be more successful and could prevent some people's epilepsies from becoming medicine-resistant.

The researchers wanted to find out whether the outcomes of surgery are different depending on whether people with epilepsy have become resistant to medicines or not.

They studied 250 people with focal epilepsy who had at least 3 months of seizure freedom after starting treatment with medicine. The participants were split into two groups. One group comprised those who had epilepsy surgery during the period of seizure freedom (74 people). The other included those who had surgery later, when their seizures had returned and their epilepsy had become resistant to medicines (176 people).

Almost everyone (95.9%) in the group who had surgery during the period of seizure freedom stayed seizure free, and the rest had only focal aware seizures for at least two years after surgery. In the group who had become medicine-resistant, this was the case in just over three-quarters of people (77.3%). Also more than four in five people (83.8%) in the group who had early surgery were able to come off their epilepsy medicines after surgery. In the group with medicine-resistant epilepsy, this was around half (49.4%).

The researchers concluded that epilepsy surgery should be considered earlier and may help prevent epilepsy becoming medicine-resistant in some people. This echoes the updated guidelines on epilepsy by the National Institute for Health and Care Excellence (NICE). The guidelines say people with epilepsy that is not medicine-resistant should be referred for surgery assessment if an MRI shows a high risk of their epilepsy becoming medicine-resistant. The full study is available at ***bit.ly/3vfOsyi***.

Valproate prescriptions fall between 2018-2021

New figures show that the number of women prescribed sodium valproate in a month fell by over 7,000 between April 2018 and September 2021. This is according to findings published by NHS Digital in March 2022.

Valproate (brand name Epilim) is a medicine used to treat epilepsy. In some cases it may be the only medicine that is effective in stopping seizures. But valproate is associated with increased risks of physical and developmental problems to unborn babies if taken during pregnancy.

The published figures showed that the number of women prescribed valproate fell from 27,448 in April 2018 to 20,192 in September 2021.

However, they also showed that 247 women were prescribed valproate while they were pregnant between April 2018 and September 2021 and 25 of the these were in the six months from April 2021 to September 2021.

Daniel Jennings, senior policy and campaigns officer at Epilepsy Action said: "We are pleased to see that the number of prescriptions for valproate have decreased, however it remains the case that for many people with epilepsy it is the only medication that controls their seizures. It is vitally important that women are made aware of the risks of taking this medication, and other AEDs, during pregnancy so they can make an informed decision about their treatment."

In 2018, the guidelines for prescribers changed to say that no one of childbearing potential should be taking valproate without being made aware of the risks in pregnancy and without having adequate birth control in place.

This still may not be happening in some cases, as a survey done by Epilepsy Action, Epilepsy Society and Young Epilepsy in 2020 found that two-fifths (44%) of women hadn't discussed the risks of valproate with their consultants in the last 12 months. This is despite the guidance also stating that women should have a yearly review of their medicine.

Mr Jennings added: "We have seen the catastrophic impact that valproate has had on many children and families, and it is essential that all women are aware of these risks. Much more still needs to be done to ensure that all women are aware of the risks, as well as further research into the risks of taking other AEDs during pregnancy."

It's important not to stop taking your medicines without the advice of your doctor, as this could cause harm to you or your unborn baby. If you are worried about your medicine and pregnancy, you should speak to your doctor.

"Government inaction" called out two years after safety review

Epilepsy Action has said it is "alarmed at the worrying lack of progress" the government has made in the last two years, following the safety review published two years ago by Baroness Cumberlege in July 2020.

The Independent Medicines and Medical Devices Safety Review acknowledged major failings in the health system around three separate healthcare scandals, dating back decades, including around the medicine sodium valproate.

Over many years, women took sodium valproate for conditions including epilepsy, without being made aware of the risks to unborn babies if taken during pregnancy. The organisation said this has led to years of "avoidable suffering" for families affected.

Sodium valproate can be a very effective medicine for epilepsy, and may be the only one that works for some women. However, women need to be made aware of the risks so they can make an informed choice.

The report made a series of recommendations, some of which the government is still considering, two years on, and others which have been rejected. This includes a redress scheme to "meet the costs of providing additional care and support to those who have experienced avoidable harm". Other recommendations that have been rejected include creating specialist centres for people affected by sodium valproate.

The government has made recent progress on one of the nine recommendations, appointing a Patient Safety Commissioner. However, the charity says this new role "will do nothing to help families that have already been harmed by valproate".

Alison Fuller, director of heath improvement and influencing at Epilepsy Action, said: "Families who live with the impact of taking sodium valproate in

pregnancy often have to meet the costs of the additional care and support their children need. Some of these children are now adults with even more complex needs.

"As the cost-of-living crisis deepens, it is more vital than ever they receive the financial redress they deserve. We urge the government to reconsider its position on this.

"Much more needs to be done to ensure women with epilepsy are aware of the risks of the medication they are taking. Every woman must have access to specialist preconception counselling. It is also unclear whether the risks posed by other medicines are being properly communicated to health professionals and women with epilepsy.

"It is crucial that women do not stop taking their epilepsy medicines without talking to a healthcare professional first. Any woman who is concerned about any of the issues discussed should make an appointment with their doctor.

"We cannot be having these same conversations another two years down the line."

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Brand-name epilepsy medicine prices skyrocket

The cost of brand-name epilepsy medicines has increased more than two-and-a-half times between 2010 and 2018, according to a new US study from the journal *Neurology*.

Researchers Samuel Terman and colleagues set out to better understand the trends in epilepsy medicine prescriptions and costs from 2008-2018 in the US.

There were between 77,000 and 133,000 people with epilepsy included a year. In 2008, phenytoin was the most common epilepsy medicine prescribed. This changed to levetiracetam in 2018. Brand name medicines, older medicines, and those that stimulate the production of proteins called enzymes, all reduced over the time period. The researchers found that in 2018, brand name epilepsy medicines accounted for nearly four fifths (79%) of the cost of epilepsy medicines, but less than one fifth (14%) of prescriptions.

The cost of brand-name epilepsy medicines increased more than two-and-a-half times (277%) from 2010 to 2018, while generic epilepsy medicine reduced in price by two-fifths (42%) in that time.

The study authors found that many common brand-name epilepsy medicines cost 10 times more than the generic versions. The study authors said previous studies have shown that medicines are the most expensive part of neurology care. They added that epilepsy medicines were the second most expensive medicines prescribed by neurologists. The full study is available at: ***bit.ly/3PSakHG***

Strokes, seizures and swimming in the cold

When Paul got Covid-19, his health started to deteriorate fast. He describes how one of his favourite hobbies may have helped save his life – and how he's now encouraging better safety measures for people with invisible disabilities taking part in that very hobby

Words by Kami Kountcheva and Paul Mylrea.

If anyone has recently watched Freeze the Fear with Wim Hof on BBC iPlayer, the benefits of the cold might have crossed your mind. In the programme, celebrities joined the proclaimed Ice Man, Wim Hof, in the north Italian mountains. They took on a series of challenges, from jumping into an ice-cold lake, to swimming under the ice, to learn to become the masters of their own fear.

In the process, the programme discussed the benefits of experiencing cold conditions, of which, reportedly, there are many. They include better sleep quality, boosted appetite, changes in body fat, reducing inflammation and more. Researchers are still looking into this to fully understand the potential effects of the cold.

One person sold on the experience, though, is Paul Mylrea. Paul, 66, lives in London with his wife, Frances, and they have three children and three grandchildren. Paul has been wild swimming (swimming outdoors in natural spaces) year-round in Hampstead ponds for more than a decade. And last year, his beloved pastime may well have helped save his life.

Paul tells his story below.

Touch and go

"It was right at the start of the Covid epidemic. I had gone to hospital with a toothbrush, thinking I would be out in a day or maybe two. I ended up staying six weeks. And I have no memory of four of them.

"I was tough and fit. I cycled every day. I did at least two gym classes a week. I swam all year round outdoors in cold water. So how could Covid affect me?

"I was wrong.

"It started like a bad cold. I stayed in bed. Almost two weeks later, my daughter – a doctor – told me to go to hospital. I did not think I needed to go, but I rang the NHS. They agreed with my daughter.

"My wife, Frances, drove me to University College Hospital. I jumped out of the car. I was going to be home in a day, maybe two, wasn't I? How wrong could I be.

> It may seem strange, but the doctors believe that my love of **swimming in cold water may have helped save my life**

"At the hospital, I tested positive for Covid and I was quickly taken to a ward.

"Things started moving fast. Doctors seemed concerned. Apparently, my oxygen levels were low. They moved me to intensive care where they had special breathing apparatus. I was put in a full-face mask. It sliced through my nose. They put another one on me and I relaxed a bit, although I felt boxed in and claustrophobic.

"That's the last I remember.

"The next few weeks have disappeared. I have no memory, no dreams, nothing.

"Apparently, I was awake and even talking to my family by phone. I wasn't calling them – I had forgotten how to use the phone. But they managed to keep in touch. Sometimes I made sense, sometimes not.

"Although I have no memory of that time, I now know I nearly died. It was only thanks to the brilliant doctors and nurses that I survived.

"One of those brilliant doctors was Dr Arvind Chandratheva. He was on his way home when a colleague called him. The colleague said there was a new patient coming in, and he thought the case didn't feel right. Dr Chandratheva rushed back – and saved my life.

"I was having a stroke that blocked an artery in my brain. A few days later, I had another one, blocking another key artery.

"My survival was touch and go.

"At one point Dr Chandratheva, who called my wife and daughter every day to update them, warned things were bad. He warned that I might not make it.

"Frances wanted to see me. The last time she had seen me was when I walked into hospital. But, because of Covid, she couldn't. She had to wait and hope to see me again."

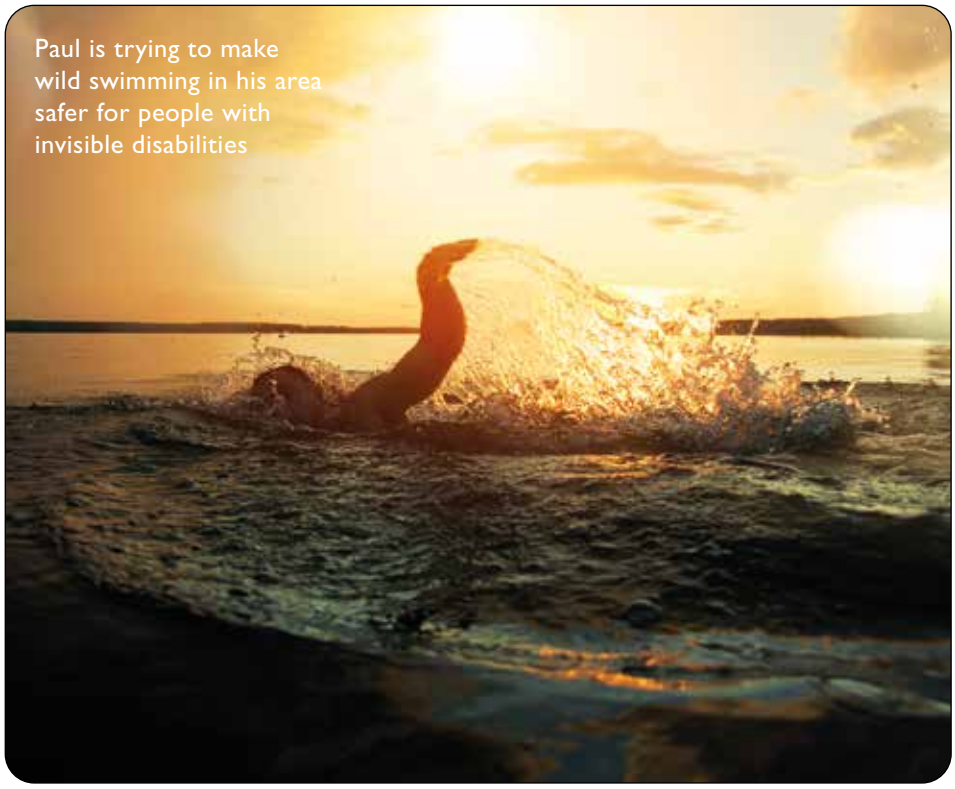
It wasn't over

"I did come through, thanks to his care and that of the rest of the NHS team – and probably also to my swimming!

"It may seem strange, but the doctors believe that my love of swimming in cold water may have helped save my life. I'll explain later.

"When I finally became aware, I was in a recovery ward. I had to be told that I had suffered strokes and had nearly died. It was like hearing a story about someone else. I had survived thanks to the care I had received. I was so lucky.

Paul got Covid, had two strokes and developed epilepsy



Paul is trying to make wild swimming in his area safer for people with invisible disabilities

"But it wasn't over.

"I went home. I was applauded into my house by neighbours who were on the street paying tribute to the NHS. I wept and hugged my wife and daughter, who had come back from her job abroad to support Frances.

"My recovery began. I had lost some strength on my right side. My memory was damaged. My mood was up and down. But it was basically fine, I thought.

"Doctors were fascinated by my case. Why had I had such a bad time when I was so fit? What was the reason for the strokes? And why was my blood so 'sticky'? Why had I had clots?

"They diagnosed Antiphospholipid syndrome – a condition where the immune system creates antibodies that mistakenly attack tissues in the body and can create blood clots. I was put on blood thinners. It was a blow.

"Still, I thought the worst was over. And again, I was wrong.

"A couple of months later I was cycling for my morning swim when I felt strange. My eyesight was weird. I could see a couple of coloured dots.

"I made it home. Frances found me sitting on the stairs. She managed to get me upstairs and into bed – a decision I later found out was not ideal.

"I started to thrash about. I fell out of bed and hit my head on the bedside table. I had bitten my tongue. There was blood everywhere.

"Frances was amazing. She got me safe and called an ambulance. When I was told what had happened after that, I had to laugh – even though it was serious.

"An ambulance had arrived quickly and the paramedics had tried to get me downstairs so they could rush me to hospital. I am not small – over six foot and 80 kilos. They had trouble lifting me and had to call another ambulance to help. They were struggling to get me down the stairs when I woke up and asked what all the fuss was about! You have to keep your sense of humour, even in these kinds of situations.

"As you might have guessed, an epilepsy diagnosis followed. Coming on top of the other problems, it felt like a heavy blow.

"But again, I was looked after. The doctors and nurses were caring as well as expert. Dr Chandratheva, no longer in charge of my care, even came to see how I was doing.

"The drugs seemed to stabilise things. Then I had another seizure, this time less dramatic but equally life changing.

"I was at my daughter's house to help look after her one-year old boy, my grandson. I had been watching an online presentation about strokes and their effects. I went into the kitchen and realised things were not right.

I started to thrash about. I fell out of bed and hit my head on the bedside table. **I had bitten my tongue. There was blood everywhere**

"I didn't pass out this time, but I was confused. I wasn't making sense.

"Both my daughters were there. They told me I had to go to hospital. I became difficult. By now I could stand, so I started climbing the stairs saying I wanted to lie down. But my daughters convinced me to go with them.

"Hospital tests didn't point to anything new, but my doctors decided to look at my epilepsy medicine. They increased the dose.

"That was over six months ago. Since then, I have been well. I'm swimming again.

I am so happy to be able to have time with my family."

Grateful to be alive

"I'm still puzzled. My epilepsy was caused by the strokes. But did I have Antiphospholipid or clot tendencies before Covid? Did I just not know about it?

"My doctors believe my swimming played a big role in my survival. Cold water swimming has been shown to have big health benefits.

"Cold water swimming for me has been life changing as well as life saving. There is the exhilaration of swimming outdoors in all weathers, the buzz you get from the cold, and the knowledge that it's doing you good.

"But there is also the company of other swimmers, all of whom understand the addiction to the cold. And there is the way a swim in cold water in the morning creates a feeling of happiness and wellbeing that lasts for the rest of the day.

"Getting back to the ponds lifted my spirits in recovery. I was forced to give up scuba diving – my other passion – but the doctors were happy for me to continue with my swims.

"It can also be dangerous. It isn't something to try without medical approval and in a place where you can be monitored and helped if you have a seizure.

"The pond management are planning a separate changing area and a hoist for swimmers who need it to enjoy the ponds. I welcome this. But I have also urged them to think more broadly and consider ways to make the ponds accessible and safe for people with less visible disabilities.

"I have been swimming outdoors for more than a decade. But even I needed to be careful after my ill health. It was approved for me to go back to wild swimming by my medical team.

"I always swim with lifeguards present and have informed them of what happened to me and the diagnosis. They keep a close watch on me. I never swim alone.

"I am so grateful to be alive. It's thanks to doctors – and institutions like the epilepsy charities – that I can now manage my condition and, I hope, keep it under control.

"Most importantly, I can see and be with my children and grandchildren. I make up stories for the young ones. I play games. I read to them. And they have given me such joy and the determination to stay fit and well.

"When my youngest granddaughter had a difficult day at nursery a few months ago, my son and daughter-in-law found her packing a bag. 'What are you doing', they asked. 'I'm going to stay with Grandpa Paul. He's very silly, but I love him,' she replied.

"What more can you want? I may have epilepsy, but I am still silly Grandpa Paul."


Grandpa Paul

Staying safe

Does anyone else feel tempted? The possible benefits of wild swimming are very alluring, but it would be hard not to immediately forget them and turn and run as a toe first dips into the cold water.

As Paul mentions, swimming in cold, deep, or moving water should be done with caution in itself, let alone factoring in epilepsy and seizures. He takes important safety precautions, such as sticking to places where lifeguards are present and never swimming alone. It's a good idea to speak to your doctor or epilepsy nurse before deciding whether to take part in any activities in open water, especially if your seizures are not fully controlled. We have information on epilepsy and swimming on the Epilepsy Action website – ***bit.ly/3OfiI3a***. Take a look at ways to keep yourself as safe as possible. And there is general advice about wild swimming safety online, such as ***bit.ly/3xzCgsi***.

Sacked for a seizure

Many people with epilepsy tell us they've faced discrimination at work. But when Avril was fired following a seizure at work, she decided to fight back

Words by Kami Kountcheva and Avril Coelho.

What is a job to you? To me, a job is independence. A job is a meaningful contribution to a common goal. A job is purpose. It's security and opportunity and social connection.

While I know not everyone is able to work due to their health or circumstances, for people who can, but are being denied opportunities, this is incredibly frustrating. Of course, we all look forward to a day off or a break from work, but not having a job is not the long holiday it may look like to some. It's stressful and isolating.

Notoriously, people with epilepsy are some of the most disadvantaged in the work arena. According to the Office of National Statistics, just over one third of people who considered their epilepsy their 'main' health condition (34%) are in employment. In the UK as a whole, more than three-quarters of people are in employment. The difference is drastic! Adding insult to injury, research by the Trade Union Congress (TUC) found that people with epilepsy who are employed earn on average around one-tenth (11.8%) less than non-disabled counterparts.

You may well have seen these statistics before and they were probably as frustrating then as they are now. Epilepsy affects everyone differently, and seizures come in all shapes and sizes, so many people with epilepsy can do a huge number of jobs safely and effectively. There is no good reason for this very extreme gap in employment between people with epilepsy and non-disabled people.

At Epilepsy Action, we have been campaigning for change from both the government and employers. One of the biggest problems is how poorly epilepsy is understood by people, which is why we have put together our employer toolkit. Our campaigning is urging employers to use

this toolkit and take on epilepsy-specific training to better understand the condition.

We are also calling on the government to make employers more accountable and their employment and pay gaps more transparent. We want to see the government offer more support with employment for disabled people, too, and for this to be better communicated.

Avril knows, first hand, how unfair the workplace can be for someone with epilepsy. In fact, she knows exactly what it's like to be fired for having a seizure. But with a little encouragement from her friends, she decided to take on her employer and fight for fairness. She tells her story below.

Avril

"At university I had a bar job right next to my halls. The landlord of this pub chain knew about my epilepsy and what to do and not do if I had a seizure. I disclosed it on my application form.

"One day, he and his family went on holiday and got a couple to cover. I had two seizures the week they were on holiday. I'd told the couple temporarily covering the bar management about my epilepsy, and how to manage a seizure. I carried on working post seizure, no problem. I had done bar work in my home town in a far busier Free House biker's pub, where I'd often been responsible for opening the function room and running the bar solo.

"On return from my employer's holiday, I had another seizure at work, and the landlord insisted his 16-year-old son, who he employed behind the bar unlawfully, walked me home immediately. I had only one narrow side road to cross and didn't want or need to go home.

"At my next shift, some of my friends from one of my university course buildings were in the pub. They were on the fruit machines, just next to where the landlady, employed as bar staff, sacked me on arrival, saying it's because I had a seizure at work. I was given no notice and no pay in lieu of notice. I told my friends what had happened.

"I wasn't all that politically aware then, and I didn't watch the news properly as we just had a communal TV lounge in halls. My friend Chrissy, a mature student from my course pathway, had seen in the news about the Disability Discrimination Act of 1995. She said I should see Citizens Advice so I did. There, a trainee lawyer took on my case.

"He said she was right to recommend their help. He said that it may not apply, as I was sacked the day before it came into force, but as they gave me no notice or pay in lieu, technically I'd have been employed when the Disability Discrimination Act 1995 began. He told me to request pay in lieu of notice in writing.

"I did as he advised and the landlord refused both pay in lieu of notice and refused me notice. The friends who were there that night, and heard everything that happened, wrote statements. They were prepared to go to court too, if it came to it.

"It was a week from trial. The Citizens Advice trainee lawyer representative suggested a settlement and the landlord's representatives suggested a low figure. He went back to them and they offered more. It was only enough to cover what I lost that year, but to a poor student only seeking justice, it was adequate and I accepted it.

"My Citizens Advice representative and I made the front page of the local newspaper. The headline was a quote from him saying: "The new Act has teeth!" in reference to the Disability Discrimination Act 1995.

"Two years later, an ex-manager of that pub chain was at another bar I was working in, and told me his experience of them. We exchanged stories in confidence, and he told me I'd have got at least 11 times that if I'd gone to trial. But I was just happy I'd got justice thanks to support from my friends.

"Tell your friends if you're able to open up about your epilepsy, as they really can make a difference, like mine have. It's unlawful to discriminate against someone who has epilepsy. If you're in England, like me, you're protected under the Equality Act 2010, which the Disability Discrimination Act 1995 was incorporated into."

Help and support

If you want to fight against discrimination at work, as Avril says, in England, Scotland and Wales, you are covered by the Equality Act 2010 and in Northern Ireland, by the Disability Discrimination Act 1995. It can sometimes feel like an uphill battle, but Avril's approach certainly says something for looking for help and support, and for standing up for ourselves and regaining some of the self-confidence a situation like that can rob us of.

We have more information on employment at ***epilepsy.org.uk/info/employment*** and the equality laws on ***epilepsy.org.uk/daily-life/your-rights***. You can also access the employers toolkit at: ***bit.ly/3HTgW5W***.

Do you have an employment story – positive or negative? You can share it with us – just email ***press@epilepsy.org.uk***.

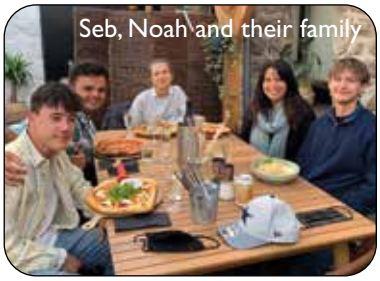
Avril arrived for her shift at the pub to be fired by the landlady

National Epilepsy Week roundup

As Dinah Washington sang in 1959, what a difference a day makes! And not to mention seven of them! The seven days in question came in May in the form of National Epilepsy Week, and the difference made? Epilepsy awareness. This is always an enormous part of the fundamental foundation on which positive change is built.

This year's National Epilepsy Week was themed around 'Epilepsy Together'. At Epilepsy Action, along with other epilepsy charities, we worked to spread the message far and wide. We wanted to show the impact of epilepsy on our families and loved ones, and equally the impact that the support from others can have in improving the lives of people with epilepsy.


Dai Greene


Seb, Noah and their family

In the week, we helped get epilepsy in the news, on the radio and on TV, most notably our media volunteer Murray Goulder (more on page 26) and Grace Upcraft appearing on BBC1's Morning Live alongside Martin Kemp. We put the spotlight on our Talk and Support groups and running events, helping to support everyone affected by epilepsy, and we shared our 'What is epilepsy?' video. (Have you seen it? Check it out at ***epilepsy.org.uk/WhatIsEpilepsy***)

We also shared more of your stories. Dan Bedeau talks on his blog about the wider impact epilepsy has on his family. Noah also shared what it's like caring for his brother Seb, who has epilepsy and cerebral palsy. Noah spoke about the challenges of lacking support to be able to help Seb. Noah and two of his friends did a bike-ride from Canterbury to Rome, raising epilepsy awareness and £3,800. Dai Greene, 400 metre hurdles world champion also shared his experiences with epilepsy in a video on Instagram.

Every story helps to bring epilepsy further into the public eye. After these seven days, we're in a better place than we were before.

Cost-of-living crisis and epilepsy

The cost-of-living crisis has been in the news a lot recently. We've all seen energy bills skyrocket, petrol prices climbing and the photos of nearly £10 blocks of butter with security tags on them. It's genuinely a worrying time for so many of us and it can be especially difficult when you're living with epilepsy.

Employment

Only 42% of working-age people with epilepsy are currently in employment. 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. This means that not only are people with epilepsy less likely to have a paid job, but when they do, they earn less than their non-disabled peers.

Welfare

Many people with epilepsy have struggled to successfully apply for Personal Independence Payments (PIP). The current PIP assessment process is not working for people with epilepsy.

And while people on Universal Credit received an extra £20 per week during the pandemic, people on disability benefits such as PIP received no such help. This is despite research showing that extra costs faced by disabled people add up to £583 a month on average.

Cost-of-living

The combination of people with epilepsy struggling to find employment, and the problems they face trying to get sufficient support through the welfare system, means that they are particularly vulnerable to the impact of the cost-of-living crisis.

Inflation is now at 9% and is predicted to hit 10% later in the year, as energy bills rocket and food prices shoot up. This is on top of the extra costs that many disabled people already faced. However, despite this, benefit payments have only increased by 3.1%. Many people were already struggling but these factors will make their situations much worse.

Eight million people on low-income benefits are to get £650 in two instalments, with the first due between 14 and 31 July. Six million people receiving disability benefits, will get a £150 payment from September, a difference of £500 between groups.

At Epilepsy Action, we're calling on the government to make employment more transparent and better supported, improve the PIP assessment process and offer more financial help with the cost of living. But we know as autumn and winter set in, the impact of the situation will really become clear.

Have you been affected by the rising cost of living? Have you had to make adjustments in your daily life to accommodate the rising prices? We want to hear from you. Email your experiences to ***press@epilepsy.org.uk*** or fill our online survey at: ***bit.ly/3A8vAUq***.

Words by Kami Kountcheva and Daniel Jennings.

Baton-bearing for epilepsy!

Birmingham man Glyn Marston has been through a transformative journey in his life. He was diagnosed with epilepsy in 1977 at the age of 14. Encouraged to "keep things in the family circle" and not speak about his condition, he feared his seizures.

He said: "When I started having seizures, I was certain that my next seizure would be my last. Fear of going to sleep at night was part of my routine and, for a while, I would try to stay awake for as long as I could."

Eventually the fear went away and Glyn's epilepsy became controlled with medicines. In adulthood, Glyn turned his life around in a number of ways. He stopped smoking and took up running, breaking world records for running on treadmills, running marathons around the world and even running across the Grand Canyon.

"I also felt the need to break my silence about my medical condition in the hope of inspiring others in a similar situation. This has made me turn all the negatives in my life into positives."

Glyn was chosen to carry the Queen's Baton through the city ahead of the Commonwealth Games in Birmingham in July this year. He and the other baton-bearers carried the baton across the country, each person incredible and inspirational in their own right. Glyn's son Liam was there to see Glyn carry the baton, arriving in a limo after rail strikes disrupted his journey.

Glyn has done brilliant work in his community, including setting up a range of inclusive and supportive sports clubs for people of all abilities, including dodgeball and walking football. He has also fundraised for people with epilepsy by running the London Marathon in a gorilla suit and doing the Ride London cycling challenge.

Glyn said he was overwhelmed to get the news that he has been chosen to carry the baton. He said: "This is for everyone in the same position, dealing with epilepsy. It's proof that there really is light at the end of the tunnel."

Brilliant achievement, Glyn, congratulations!

Bob's paintings

Birthday Honours for Bob!

Teacher and painter Robert (Bob) Sutcliffe is a man whose paintings tell a thousand words. And they also raise thousands of pounds for charity!

Since 2018, Cumbria-based Bob has been painting images for Christmas cards to be sold by Epilepsy Action to raise funds for epilepsy. He has donated three Christmas card images and four paintings for auction, and a fifth to be auctioned at this year's Doodle Day (2 September). All of these have raised around £24,000 to date. One year, he even painted the image for the Christmas card while recovering from two broken wrists caused by a seizure!

This year, Bob has been awarded a British Empire Medal in the Queen's Birthday Honours for all his volunteer work. In 2019, he also scooped the Epilepsy Action Fundraiser of the Year Award. Bob was also chosen to take part in the baton relay through Cumbria for the Commonwealth Games.

Epilepsy Action corporate and fundraising officer, Harvinder Chaggar, said: "Robert's determination and drive to deliver is so strong. Every time I have asked Robert to paint something for us, the request is always received with such warmth, enthusiasm and gratitude for the opportunity and encouragement. He is a role model to everyone as he will not let epilepsy get in the way of him achieving his goals."

Congratulations, Bob!

Bob's cards

Words by Kami Kountcheva and Claudia Christie.

Lab research lowdown

We find out more about how lab research works and what new techniques are being developed in the lab for treating epilepsy from the Epilepsy Research UK's Shape Network Conference.

Words by Kami Kountcheva.

I really love research. It's so exciting to get evidence of something working, or to help confirm something we've been thinking but not been sure about. Research is the driver behind safe and effective new medicines and provides evidence for things that need to change or need attention. Information backed by research just always feels more reliable.

Having said that, research can sometimes feel a bit far in the distance. It feels like those trials will need repeating and lots of time before they turn into a new medicine or updated guidelines or more understanding. Or it can feel like scientists are studying the smallest molecules in the smallest cells in one small part of the brain, and it's hard to link that to a practical change in our lives.

I went to Epilepsy Research UK's Shape Network Conference in May, where speakers discussed different types of research and the new topics being looked at. The organisation is also working to establish research priorities for the future, making sure that future research focuses on what's important to people with epilepsy.

In the first of a three-part feature, we bring you the lowdown from the first session of the conference on lab-based research.

Animal models

First up, Prof Stephanie Schorge from University College London (UCL) talked about animal models in research. To describe the importance of animal models, she first gave an example of a condition that can't be easily modelled in animals – Alzheimer's disease. She said cells and mice don't model memory loss, and this can hold back research on these key aspects of the disease.

Prof Schorge said we are lucky in epilepsy that we have a lot of animal models – allowing us to study different forms of epilepsy, both short- and long-term, and monitor things like EEG. Animal models can also help with the other aspects of epilepsy, which can be worse than seizures for some of us, such as learning and memory, anxiety and side effects of treatments. Work at the moment is looking at treatments that stop epilepsy itself, rather than treating seizures.

Addressing the elephant in the room, Prof Schorge also mentioned the moral question of ethics around animal models, in her capacity as the Head of the Ethics Committee at UCL. She said that there have been enormous changes in the last 30 years, and today researchers make sure their animals are safe, comfortable and happy. This is partly because healthy animals make better models, but also because researchers feel empathy for their animals. She added that someone is in charge of ensuring the animals are being properly looked after, and groups of people are invited to visit the research facility and see the animals.

From cell research to answers

Prof Mike Cousin from the University of Edinburgh presented next on the role of cell biology in epilepsy research. He called cells in the human body the basic unit of bodily processes and explain how cells communicate within themselves and with other cells in the body. Cells in the brain communicate with each other by releasing and receiving chemicals known as neurotransmitters.

Prof Cousin said that 10-15 years ago, anyone would have been surprised by the idea that problems with neurotransmission may be part of the reason for certain forms of epilepsy. However, he gave an example of a problem with a gene called Dnm1 which affects proteins involved in neurotransmission.

Looking at this gene defect in a mouse models, the team saw that it meant cells couldn't receive the neurotransmitter. This disrupted the brain circuits and caused seizures. The team knew the gene and the change in it that was responsible, and the exact problem it caused. This meant they could try different treatments on the cells in a dish until they found one that corrected the problem but didn't affect other brain circuits.

Prof Cousin concluded saying this all highlights that cell biology can answer a lot of questions we couldn't do with animal models alone.

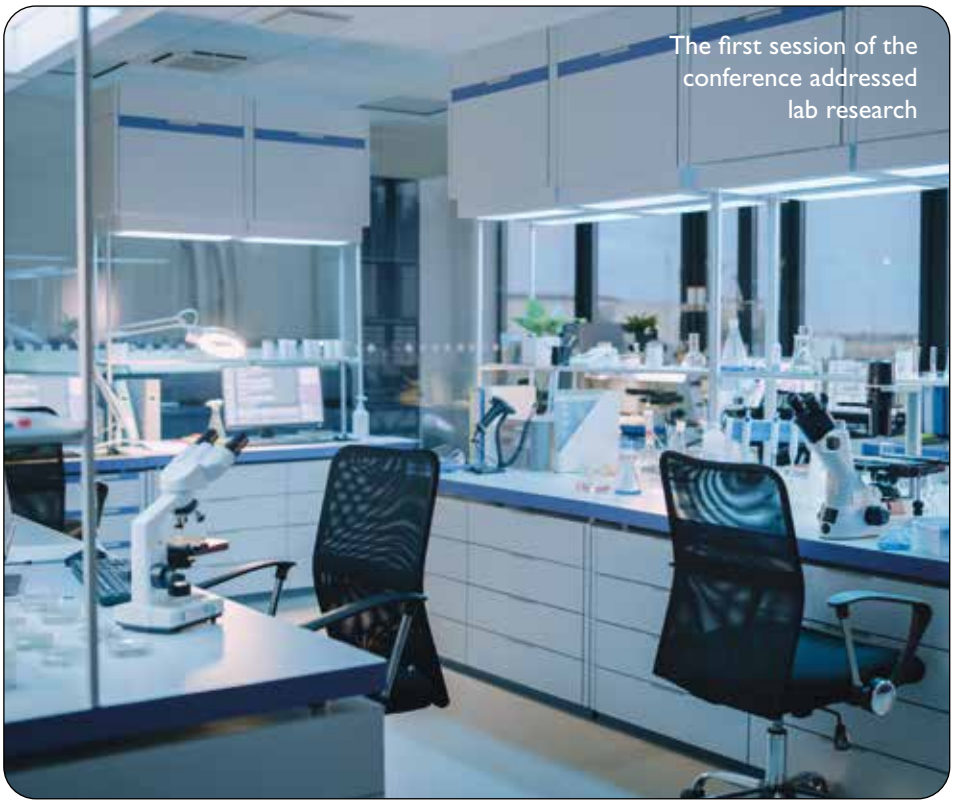
10-15 years ago, anyone would have been surprised by the idea that **problems with neurotransmission may be part of the reason for certain forms of epilepsy**

Gene therapy and how it could be like Batman

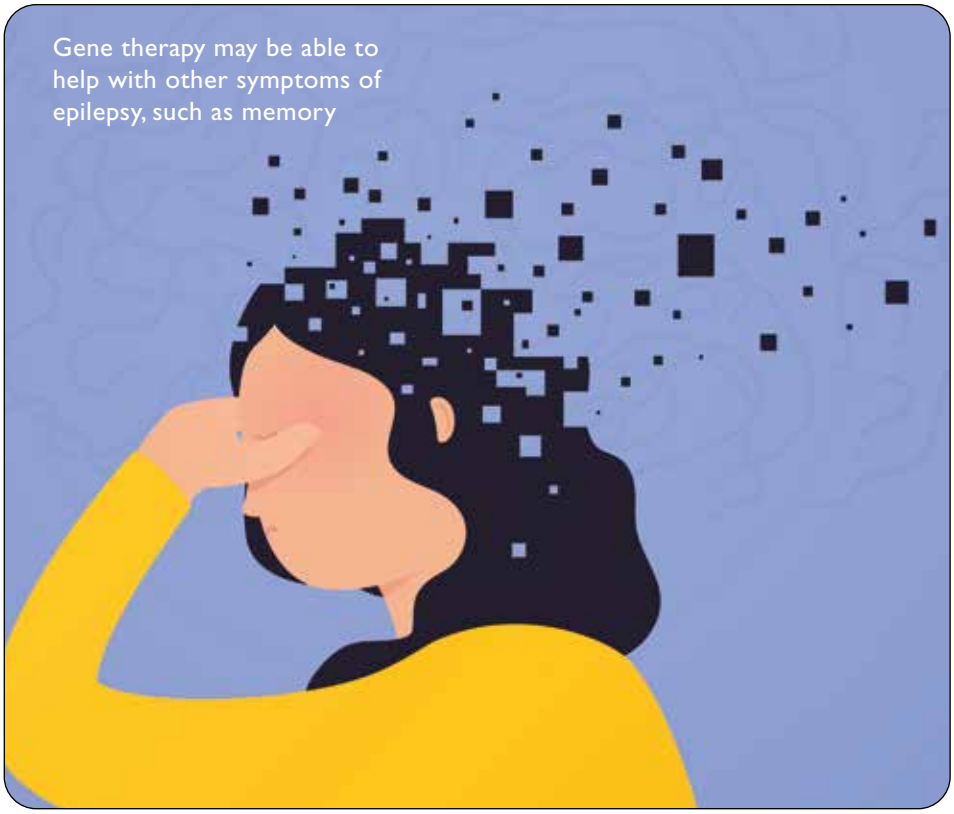
Finally, Dr Gareth Morris, also from UCL, presented on gene therapy and relating the ideal gene therapy to Batman (hear him out). He started off describing the current challenges with treatments and said better treatment would:

- Be long-lasting or permanent
- Stay at or around the area where the seizure starts
- Only affect the particular cells driving the seizures
- Be active only when seizures are likely to happen, and be inactive the rest of the time

He explained that gene therapy work is looking at adding a helpful gene into cells to try to stop seizures from happening. This can be done using a virus which has been changed in the lab to remove its ability to cause diseases. Gene therapy uses a virus' natural ability to deliver



The first session of the conference addressed lab research



Gene therapy may be able to help with other symptoms of epilepsy, such as memory

Dr Morris, Prof Schorge and Prof Cousin during the Q&A

genetic material into cells to help put the treatment where it's needed. The researchers find a molecule specific to the target cells to make sure the treatment is delivered only there. This means that the therapy is targeted and long-lasting.

The team is currently working on ways to make treatments only active when they're needed, and inactive the rest of the time. Dr Morris is working on gene therapy that is activated by a natural marker of seizures, which is called microRNA. Essentially, he is hoping that these markers would act as the bat signal, calling for help. When the signal goes off, the therapy would become activated, and once the seizure is stopped, it would become inactive again. So a bit like how Batman swoops out of the shadows when the bat signal appears in the sky, and once the villain is defeated, he retreats back to the shadows until he is next needed.

Answering your questions

How would gene therapy help with symptoms of epilepsy other than seizures, such as learning and mood?

Dr Morris said: "We don't necessarily understand these aspects of epilepsy that well yet. A lot of these problems occur because the circuits causing epilepsy also have another job. Memory is a good example. Seizures often occur in the part of the brain that controls memory and that's why people have challenges with memory. So the hope is that by restoring normal function to these circuits we would not only stop seizures but also restore the ability of that circuit to work as normal.

> Dr Morris said gene therapy work is looking at adding **a helpful gene into cells to try to stop seizures from happening**

"It's something that we test in our animal models. It's equally important for us to address things like memory as well as seizures. Also, the whole idea of creating specific treatments is that the treatment itself doesn't have any further impact on other aspects, like memory."

Can gene therapy treat the masses rather than the few? What hope is there for people with chromosomal disorders where the faulty genes aren't always known?

Dr Morris said: "One of the really promising things with this kind of gene therapy is that we don't necessarily need to know the exact underlying genetic mechanism – we are sometimes still able to treat the condition."

Prof Schorge said: "Looking back even just a few years, we'd have this feeling of: 'Are we just treating the very few? How much are these treatments going to get out to the world?' During the pandemic, there was advancement in the supply chain and in developing these viruses used in the vaccines, which are a form of gene therapy. They are using many of the same tools and pathways that we hope one day to capture to deliver gene therapy [for epilepsy] throughout the world.

"Also, most of the animal models I talked about did not have a genetic cause. In

those animals, we're treating the epilepsy [regardless of] what has caused it. That won't happen in all genetic epilepsies, but it does give hope that this treatment may help independent of whether the cause is a gene or an injury."

Prof Cousin said: "One strand of hope is that when more people look at these genetic epilepsies, you do tend to see overlap points, even at a cellular level. It might be that there will be maybe 10 different points where we could potentially intervene to help a far broader spectrum of people than just the 10 people in the world who have this particular faulty gene."

Would you be able to treat different types of seizures with gene therapy?
Prof Schorge said: "It will be a challenge, but it is something we are looking at now. One of the big projects that we and different groups around the world are looking at, is how networks and circuits come together in focal epilepsy. With gene therapy you do want to be cautious, you don't want to treat the bit that isn't causing [the problems]. The 'Batman' approach gives us much more hope about treating larger parts of the brain."

Dr Morris said: "[There is an idea about using] tiny molecules which can spread quite far around the brain. In some situations that's not great, [if your seizures always start in one small area]. But in the case where [seizures can start from multiple places], that might actually be an advantage. So there are other [treatments] being developed which might have different characteristics and may be suitable to different types of epilepsy."

Is gene therapy cheap and would it end up hindered by pharmaceutical drugs that are cheaper even if they are less effective?
Prof Schorge said: "We are advancing slowly towards trial and gene therapy is notoriously expensive. One of the reasons is that it's stupidly hard to make, so that translates to stupidly expensive. The other is that most gene therapies are focused on treating rare genetic diseases. So, if you have a treatment that is targeted to a small number of people in the world, that cost of development is spread over a very small number of patients. In the sort of epilepsy that we, and other groups, are starting to treat, we estimate there's a prevalent population of people who could benefit of about 25,000 in the UK alone. So instead of dividing your £2m development fee across 10 patients, you are now dividing across thousands. If you extend that globally, it's a much bigger pool. We are hoping that the cost of gene therapy will be less than the cost of resective surgery. We can't promise, but that is our goal, to make this a practical thing.

Prof Cousin said: "Additionally, at the cell level, another way to try to reduce cost is to repurpose drugs that are already approved for use in people. There is screening going on currently, at a cellular level, of medicines that are perfectly safe to use in people, and we are looking for potential in treating epilepsy."

> There are other treatments being developed which might have different characteristics **and may be suitable to different types of epilepsy**


Gene therapy may also work if we don't know the exact affected gene

The researchers are hoping that gene therapy will be cheaper than resective surgery

Look-a-like seizures

Doppelgangers, twins, look-a-likes – whatever we call them, some seizures really resemble other situations, behaviours or conditions. You shared five ways your seizures can be misread

Words by Kami Kountcheva.

Having seizures mistaken for something else is almost like a rite of passage. We hear about it all the time from people with epilepsy. If it's not children at school whose absence seizures have been mistaken for not paying attention, it's adults being accused of being drunk while in the throes of a seizure.

Sometimes, it can be down to a lack of awareness causing people to mistake some seizures for something else. I think we're all done with hearing that it can't be a seizure because we didn't fall to the ground or because there weren't any flashing lights, aren't we?

But sometimes, it's because seizures are just really good at looking like other behaviours. It's part of their nature – they are a burst of electrical activity in some or all parts of the brain. If a seizure happens in a part that controls a specific behaviour, that's what the seizure may well look like.

Even so, it can still be frustrating or upsetting to have your seizures mistaken or not recognised as seizures. If it's happened to you, you're definitely not alone. In fact, we asked you over on Facebook to share your experiences, and we had more than 100 comments with stories and anecdotes.

We share five situations or behaviours that you told us your seizures can look like or be mistaken for.

Laughter

Laughter is one of the happiest, jolliest sounds and it's hard to believe it might be something more ominous. But, in fact, some seizures, called gelastic seizures, can look just like laughter. Laura said she's had these in the past. "I've had 'laughing fits' in my sleep – hysterical laughing."

And she wasn't the only one. Nicki said: "I laugh during my bad seizures. They usually last around eight minutes. I have Alice in Wonderland syndrome (where sizes of body parts or other objects appear different) as an aura, and overwhelming fear washes over me. My eyes roll and rapidly blink. My arms will jerk and I laugh very loud. I've actually turned blue from it. Sometimes I can't speak for hours afterwards – my speech gets muddled up and I can't make actual words. It can take me a few days to recover. It's scary because it doesn't look like a seizure when you're laughing and it's a worry how people will react. It's definitely not funny!"

Kelly also shared that her daughter used to have seizures that looked like laughter, but they changed. She said: "My daughter has what we call 'scream fits'. She jerks backwards and forwards and screams very loudly for between 1-4 minutes. She has them most mornings when she wakes. I do wonder what someone walking by the house must think is going on. She's almost 17 now and has had this type of seizure for around 5-6 years. They used to present as laughter, but it changed when

she started using vigabatrin (Sabril). But their frequency did reduce."

Drunk

A pretty unfavourable comparison is one heard time and again by people with epilepsy – the one with being drunk. You came out in droves to say this has happened to you on Facebook too. Cara said: "I can collapse or blackout at any time, zone out or have memory loss, also at any time. I've been told I looked drunk when I zone out or when I lose my balance walking."

Bethany added simply: "'What has she taken?' or 'How much has she had to drink?' are my pet peeves."

This neatly encapsulates how many people feel about this particular mistake. Completely relatable. Whatever the seizure may look like, it's not too much to ask for the benefit of the doubt.

Heart attack

Some people said their seizures have been mistaken for health emergencies. This is understandable, but still not ideal. It could mean you don't receive the right kind of first aid, or that ambulances are called out unnecessarily, for example.

Murray said: "People have mistaken my seizures for heart attacks in the past. I have had this happen a couple of times at least. Once I walked autonomously and sat down in mud in a car park. When I came out of the seizure, the family that found me were ready to call an ambulance. I explained my condition and, ever since, have worn a printed lanyard explaining that I have these types of seizures."

Daydreaming

This is another one we hear about often from you, and another one that can be really frustrating. We know this seemingly small mistake can have quite a big impact. We've heard from people who didn't know they were having seizures. Meanwhile, friends, teachers or colleagues were making assumptions about why they appeared to be 'zoning out'.


Drunk

Many people have absence seizures, and these can sometimes get lost among everyday mannerisms. Natalia said: "I've been told my absence seizures look like I'm daydreaming or ignoring. My eyelids tend to flutter when I have an absence so I have been laughed at or shouted at when people don't know what is going on."

Kelsie echoed Natalia's experiences, saying: "People always say that my absence seizures look like I'm daydreaming, I'm in my own little world or that it looks like I'm not listening to them."

One responder said their seizures look like they were "sleepy", and Charlotte said people described hers as her being "in a trance". Meanwhile, Lauren recalled a time when these misunderstandings led to an unpleasant situation. She said: "I remember going shopping and I had a seizure at the till. The woman was screaming in my face, saying there's a queue and she hasn't got time for me to think what I want."

Crying

Last but not least, a more unusual behaviour a seizure could look like – crying. Kathryn said: "I look like I'm crying sometimes because my eyes involuntarily stream with tears."

This is all a reminder that we are all unique. So are our brains, and so are seizures. It's understandable that people might make honest mistakes about what they're seeing, especially when seizures can really resemble other conditions and behaviours. But this isn't an excuse


Heart attack


Daydreaming


Crying

for anyone to be rude to you. It shows that we have more work to do to make seizures and epilepsy better understood.

Most of all, this all highlights that we are all in this together. If you ever feel like it's only you going through challenging times, remember there are thousands of us who are right there with you and understand what you're going through.

Do you want to share what your seizures have been mistaken for? Email ***editor@epilepsy.org.uk***.

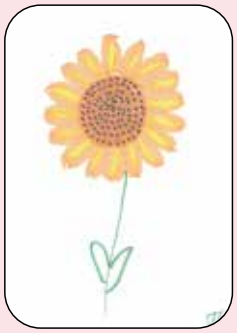
Pencil in Doodle Day – 2 September

Famous names from the world of art and entertainment have put pen to paper and created unique works of art for Epilepsy Action. These original pieces will be available to bid on through eBay from National Doodle Day, which takes place on Friday 2 September. The event celebrates its 18th anniversary this year.

This year's auction includes works from acting legends Sir Ian McKellen (Lord of the Rings, X-Men) and Joanna Lumley (Absolutely Fabulous, The Wolf of Wall Street), and TV favourites Aisling Bea (This Way Up) and Joe Lycett (Travel Man, The Great British Sewing Bee). Many artists and illustrators have also created artworks for the auction, including Axel Scheffler (The Gruffalo, Stick Man) and Martin Brown (Horrible Histories). The proceeds from every artwork sold will go to supporting the 600,000 people living with epilepsy in the UK.

Michael King, fundraising events officer at Epilepsy Action, said: "National Doodle Day is a fantastic event that gives people the opportunity to own a unique piece of art created by their favourite celebrities, artists and illustrators. Every doodle sold raises vital funds to support people affected by epilepsy.

"The selection of doodles up for auction this year is wonderfully varied – there is something for everyone to buy and love. Since launching National Doodle Day 18 years ago, we've had over 1,500 celebrities and artists support us. We can't wait to unveil this year's creations, so take this opportunity to snap up a unique doodle and help to make a difference!"




The presents and the future

Off the back of the heatwave this summer, reaching record-breaking temperatures for the UK, we've all been trying to cool off any way we can. We tried it all, I'm pretty sure – sitting firmly in the shade, dipping our feet in paddling pools, pointing every fan in the house at our faces. But now, as an additional little mental cooldown, we've brought you the Epilepsy Action Christmas Collection 2022.

There are new products this year, on the cover sheet of your September *Epilepsy Today* magazine, and many more online. By choosing the cards and gifts we offer, you are helping to improve the lives of people living with epilepsy and raise awareness of the condition. A very cool thing to do.

To ensure you receive all your items in time for Christmas, please place your order by Friday 16 December.

You can order online (***epilepsy.org.uk/christmas***), by phone (by calling 0113 2108851 or 0113 210 8832) or by post, by completing your order form on the cover sheet.




Words by Rebecca Lock and Kami Kountcheva.

Medical files

Every issue, Professor Martin Brodie looks briefly at the various anti-seizure medicines for people with epilepsy. This time round, he talks about phenobarbital.

Phenobarbital

Phenobarbital was created in 1911 and came into everyday clinical use a year later. After more than 100 years, phenobarbital is still one of the most widely prescribed epilepsy medicines in developing countries. It also remains a cost-effective choice for people with epilepsy in many industrialised countries, including the UK. Phenobarbital is effective for focal and generalised tonic-clonic seizures, as well as for all forms of myoclonic and other seizure types with the exception of typical absences. It is still an option for the treatment of status epilepticus, especially in babies and young children. The typical dose of phenobarbital in adults ranges from 60-240mg/daily, while in children 2-5mg/kg daily is the usual dose. It will take 2-4 weeks for steady blood levels to be achieved with phenobarbital. Most people take it once or twice daily without too much trouble.

Professor Martin Brodie

Side effects with phenobarbital are frequent, particularly at higher doses. Common problems include sleepiness and drowsiness, anxiety and nervousness, irritability, dizziness and depression. Hyperactivity in children and older people can also be bothersome. Allergic rashes can occur when starting phenobarbital. Long-term problems include causing a shortage of the vitamin folic acid, which can lead to anaemia and osteoporosis, which can, in turn, lead to thinning of the bones. Phenobarbital can also cause problems with the joints, resulting in conditions like Dupuytren's contracture (thickened tissue in the palms) and frozen shoulder (where shoulder ligaments become inflamed and thick). More unusual side effects include damage to the liver and bone marrow.

When withdrawing phenobarbital, doing so slowly is essential, often over 12 months or more. Withdrawing the medicine more quickly can result in worsening seizures or even status epilepticus, as well as other symptoms, such as a change in mood and behaviour and sleep disturbances including insomnia. For this and the other reasons discussed below, phenobarbital is not now regarded as an epilepsy medicine of first choice. However, many people, who have been taking it for many years, can continue on a modest dose without any problem. If a person has been taking phenobarbital for many years and is seizure free without side effects, it is sensible to stay on the treatment lifelong.

Phenobarbital increases the breaking down in the body of many other medicines, including most epilepsy medicines, by half (50%) or more. It substantially reduces their levels in the blood. This is a major drawback to its everyday use. Another potential problem is the increased risk of causing birth problems in babies exposed to the medicine in the womb. In view of phenobarbital's affordable cost, reliable supply, ease of use with once daily dosing, broad spectrum of activity and efficacy similar to that of other epilepsy medicines, it is not surprising that it is still widely used around the world. However, its side effects have limited its everyday use, and has raised general ethical concerns, which has made it less likely for it to be prescribed for newly diagnosed people. The use of phenobarbital in the UK is now largely restricted to people with epilepsy who have been taking it for many years.

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

Jog 30 miles in June

A huge number of you took part in our latest running challenge in June to raise vital funds to help people with epilepsy. Hayley and Alex share their motivations and experiences

Words by Rebecca Lock, Hayley Excell and Alex Noble.

Inspiring attitude to life

Hayley Excell took on Epilepsy Action's Jog 30 Miles in June challenge with her best friend Lucie for her six-year-old son Bleu, who has been living with epilepsy since May 2021.

Bleu was born with a brain tumour and associated hydrocephalus, a build-up of fluid on his brain. He's had eight brain surgeries, the first being when he was less than a day old, and countless other medical interventions. After his sixth operation, Bleu woke up and couldn't move his right side and his mouth had dropped on that side. This caused him to have right-sided hemiplegic cerebral palsy and following this, years of rehabilitation with physio, occupational therapy, speech-language and visual therapy. Two years ago, Bleu was diagnosed with autism spectrum disorder, meaning that he can find certain sounds, foods and environments overwhelming and upsetting.

Last year in May, Bleu started having seizures, and a week before Bleu was started on epilepsy medicine, he had a two-hour long seizure. Since then, Bleu has been on a mixture of different medicines, but unfortunately the seizures haven't completely stopped. He still has around sixteen seizures a month and has to sleep with a seizure alarm.

"Despite everything that life has thrown at him, Bleu is a bubbly, cheeky six-year-old, and I'm so proud of how he has overcome so many difficulties," said Hayley. "He fights on and finds happiness in the smallest of things, taking it all in his stride. He's learnt to speak, has started reading and has now also made the transition to mainstream school."

Together, Hayley and Lucie are hoping to raise £200 for Epilepsy Action to help the charity support people affected by epilepsy.

"We've enjoyed the challenge and have found that jogging is a great way to boost your mood and clear your mind when going through stressful situations. This is especially important when caring for someone with a disability and additional needs.

"Although we live with a constant anxiety about Bleu's seizures, it doesn't

stop us from trying new things and finding something to laugh about every day. Bleu is our absolute world, and we pull strength from his bright smile and inspiring attitude to life."


Hayley, Lucie and Bleu


Bleu

Something bigger than myself

Alex Noble took on the Jog 30 Miles in June challenge for his friend Luke who was a media volunteer for Epilepsy Action.

He said: "I had known Luke O'Donnell (or Luke-O as I liked to call him) as a work colleague for four years at BT. He had joined not long after I did, and we struck up a good bond through our similar senses of humour. We also met socially on numerous occasions, including a fellow colleague's stag do.

"I had an inkling about what Luke had done on behalf of the epilepsy community. The odd Facebook post here and there, with a photo of some sensor cables attached to his head. But at his funeral, I learned what an impact he'd made. In 2018, his benefits were unfairly sanctioned after he missed an interview. At the time, Luke was in fact recovering in hospital after multiple seizures. His story made a national newspaper and he talked to BBC Look North about what had happened. He called out the 'cold hearted' system and even gave evidence to the House of Commons select committee. A few weeks later, because of Luke's campaigning, the DWP decided to reverse their decision.

"Luke felt very strongly about his epilepsy. He'd been diagnosed when he was 21, and I could only imagine the struggle both physically and mentally of living with it. He would often highlight the impact a seizure had on his work. His job could only allow him so much time off, so he dealt with both the physical and mental stress of trying to live his life within the 'acceptable amount' of seizures. Listening to him, I considered myself lucky that my body hasn't failed me, and I've been able to attend every single one of my shifts. While he was sometimes at odds with managers about his punctuality, they respected Luke for standing up and getting his point of view across, opening up that dialogue.


Luke

"I normally don't take part in charity fundraisers. But when Luke passed away in April, I was in shock. One day he was with us, 'putting the world to rights' as he would often say, the next day he wasn't. He was only a young man with his whole life ahead of him. Luke has inspired me to be more physically active and take part in something bigger than myself. I felt compelled to take on this challenge as a continuation of his life and legacy.

"His memorial webpage has already raised over £700 for Epilepsy Action. I left a comment on there and at his funeral, I was honoured that the priest read it out. It says: 'I wonder sometimes how many more accomplishments you've achieved in your young life. But the one accomplishment that matters most was that you were loved dearly by your family, friends, and colleagues. Rest in Paradise, my dude.'"

Alex

My journal

Hi, it's Murray here. I was recently asked to take part in a trial of a device called the SubQ EEG and I decided to record my experiences in a diary. Find out how I got on below.

Wednesday, 24 November 2021

I've had epilepsy for the past 25 years – it started when I was 16. I have about five or six seizures a month but the most I ever had were 90 in one weekend.

I've tried many medications over the years and have recently started some new ones, which are proving challenging as I'm having lots of migraines. I've also explored surgery but it's very risky and it's not something I want to delve into right now.

I was lucky enough recently to be asked by my neurologist if I wanted to take part in a trial to have a new device that will help predict when my seizures will happen. It's a small device that will go under my skin near the part of my brain where my seizures happen.

If I can be the one person who helps change things for others then that's great – I wish I'd had something like this when I was a kid. There have been so many times when I've been injured as a result of my seizures and anything that could have prevented that would have made such a difference. I'm also hoping it will help teach me more about my own epilepsy. For example, I might think I've only had a few seizures, whereas more could have been happening.

Interesting times ahead!

Monday, 29 November 2021

Currently waiting at King's College Hospital to have some tests done before the surgery to fit the device. It's been a tough week. It's been a mixture of settling in on my new medicines, feeling both anxious and excited about having the device fitted and also having to fill out a big document applying for a Blue Badge.

Tuesday, 7 December 2021

It's been a busy weekend! We went out to see a few musicals to celebrate my wife's birthday. I've also had a few seizures over the weekend – one this morning.

I also started my self-isolation ahead of my surgery. My Covid-19 test has come back negative thankfully. I'm going to be picked up to be taken to the hospital in London – apparently I'm a 'green pathway patient'. That means I can't travel to the hospital by public transport because of the Covid risk and they want to make sure I'm safe before the surgery.

I might also have a little bald patch to show you next time as they're going to shave a patch of hair by my right ear!

Monday, 13 December 2021

It's Monday and it's all done! I don't look much different.

So, last Thursday I spent about six hours in King's College Hospital where surgery was carried out under local anaesthetic.

There's about a 10-15cm wire running down my temporal lobe on the right-hand side of my head – that's where my seizures happen

I can feel the patch where it was done – I have a nice bald patch now, but they promised me my hair is going to grow back. There's about a 10-15cm wire running down my temporal lobe on the right-hand side of my head – that's where my seizures

Murray has had epilepsy since the age of 16

Murray before his operation

happen. Once everything is healed up and I have the device hooked up to me, it's going to be drawing information from my temporal lobe.

There will be a small disc that is fixed on the outside of my head that feeds into a small recording device sort of the size of the old mp3-style players. The waves that go down the wire in my head will be converted to data that once a month will be downloaded on a computer. The researchers will then use that

The researchers are aiming to make a device that will be able to tell people when they're likely to have a seizure to help keep people safe

data to try to create a wrist-worn device. In the future, they're aiming to make a device that will be able to tell people when they're likely to have a seizure to help keep people safe. I think that's incredible.

The surgery was a strange experience – quite painful at times and I could feel certain things that were being done to me throughout. I was told that I was one of a small number of people who were chosen for this trial, so I am feeling humbled, honoured and just a little bit sore. I also feel incredibly fortunate to have had this opportunity and to meet some of the people – some who came from Europe to watch the surgery – involved in the project.

The device was implanted behind Murray's ear

In a few days I will take the bandage off and my neurologist will have a look at the scar and see if we can move on to the next step. It's getting exciting now!

Monday, 20 December 2021

I can't believe there are just a few days to Christmas! My neurologist said my scar is healing well – it's really itchy but I'm just trying to ignore it. I think there's going to be a delay to them fitting the exterior part of the device because of Covid but hopefully it'll only be a matter of a few weeks.

Tuesday, 17 May 2022

I was recently asked if I would like to be interviewed by the BBC's Morning Live programme about my epilepsy and the SubQ implant that records and measures the data on my seizures. I was happy to help.

At first I was told I was going to be interviewed at King's College where the surgery took place, by none other than Martin Kemp, 80s pop legend! This was a dream for me! I am a massive fan of music of that era – I still remember sitting on the floor as a boy, watching Martin striding across Wembley Stadium playing bass at Live Aid '85 with his band Spandau Ballet.

Things got a bit madder when the producer phoned me back and told me that Martin said that he wanted to interview me at my house.

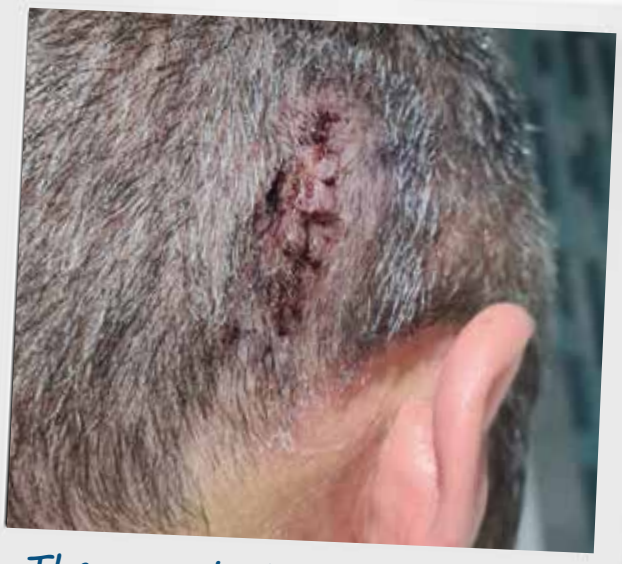
Martin was completely down to earth, incredibly humble and took his time to talk about our experiences of epilepsy, the side effects and medications. He wasn't a celebrity that day – we were two guys sharing our epilepsy stories and he knew his stuff. I really admired his attitude and positivity.

We did later go to King's College to do some more filming. It was amazing seeing the first 100 days' worth of data on screen for the first time with Martin and Professor Mark Richardson, who headed up the SubQ project. It showed the seizures, which lasted longer than I thought, but also other seizures I hadn't seen, and even muscle movements. The science behind this is incredible and I'm confident it will change – and save – lives.

The SubQ itself has become part of me now. It doesn't feel like it's there anymore. I can't believe it's been just over six months since I had it fitted. To think there's a 10cm wire running the length of my temporal lobe, yet it's invisible and taking in all that information, 24 hours a day. To anyone else, the wire looks like it could be connected to my headphones when I'm listening to my music. It really isn't noticeable and looks like I'm wearing some futuristic MP3 player.

I think the device itself will make a change to my life because, after 26 years of living with epilepsy, it will finally tell me the story of my condition over longer periods

Sure, it took a little while getting used to locating the sweet spot when connecting the outer pad to the embedded disc, but it's second nature to me now. I've caught it a couple of times in my sleep, but it doesn't hurt. I just reconnect and I'm ready to go again. I can't really break it. There's only one simple rule I need



The neurologist said Murray's scar is healing well

to follow – don't get it wet. For anyone living with epilepsy, you download the data like you take your medication each day. It's part of the plan of looking after your health. It's a digital diary of sorts and it's a million times more accurate because your brain is doing all the work.

On the day of the operation, I was both nervous and excited, but probably more of the latter. I had so many questions. Would it hurt? Why was I doing this? Would it help me? Would it help others? Will it tell me anything about myself?

After my first review recently, I got the answer to my final question. This device really works. Going forward, algorithms will be able to predict what seizures may come before they even happen to me. Incredible. I think the device itself will make a change to my life because, after 26 years of living with epilepsy, it will finally tell me the story of my condition over longer periods. It is constantly being monitored. I recently had a fall and hurt my back during a seizure. It has only happened three times in my life, but this time I was wearing the SubQ, so I feel like I have captured it and I will find out what was happening in my brain at that moment and why it happened.

If I were to give any words of wisdom, it would be to make sure that you live with and own your condition as much as you can. Don't let it be the other way around. Talk to people about it. It really helps. I have come to accept that epilepsy is part of who I am. It always will be. I don't fear it, I embrace it. I used to be scared but I can't live like that anymore because it will make me ill in other ways. I cannot be cured, but I hope that what I have to share will, someday, save someone else. That is my only wish.

Watch Murray's story on BBC iPlayer - Morning Live - Series 4: 17/05/2022 at ***bbc.in/3Bf8Brl***.

Martin Kemp, Murray and Prof Mark Richardson

Q&A on the SubQ EEG device with Professor Mark Richardson , King's College London

What is the SubQ device?

It's a miniaturised EEG recording system, placed under the scalp on the head, which can record EEG continuously for up to 15 months.

How does it work?

The miniature device under the scalp is essentially the same as an EEG recording system in a hospital except that it's hundreds of times smaller. It detects the electrical signals from the brain.

How is it implanted?

The implantation takes about 15 minutes. It involves local anaesthetic injected into the skin behind the ear, and then a small cut is made in the skin. The recording device is then placed under the skin on the head, and the small cut closed with stitches.

What are you aiming to do with the data you're getting from it?

There could be several ways this device might be useful. Firstly, we would like to use it to accurately and automatically count the number of seizures the person is experiencing – we know that it's often very difficult to keep an accurate diary of seizures. This would help us to be more certain about whether a change to treatment is being effective. We hope this would enable us to find an effective treatment more quickly.

Secondly, we are trying to develop a method to forecast or predict when the person will experience their next seizure – in principle, we have already shown this is possible, but we are still working to improve the accuracy of the forecast. This would reduce the uncertainty that many people with epilepsy feel about when their next seizure will occur.

What are the plans for this device in the future?

As with any new innovation in monitoring or treating a health condition, we need well-conducted clinical trials to provide evidence about whether the innovation is helpful. There are several clinical trials going on at the moment studying the SubQ EEG device, and we can expect these trials to report results over the next few years. If trials show the device brings benefits to people with epilepsy, I would expect it to become widely available.

Annual General Meeting

14 June 2022 ballot results

1. Summary of Response

	Number	Percentage
Electorate	8,060	100
Valid proxies returned	286	3.55
Invalid proxies returned	9	0.11
Total proxies returned	295	3.66
Members voting at AGM	1	0.01
Total response	296	3.67

2. Election of Members of the Council of Management

Candidate	Votes received	Percentage share	Outcome
Jane Riley	**255**	**15.92**	**Elected**
Peter Clough	**217**	**13.55**	**Elected**
Diane Hockley	**206**	**12.86**	**Elected**
Stephen Timewell	**179**	**11.17**	**Elected**
Katie Stevens	**177**	**11.05**	**Elected**
Tom McLaughlan	**169**	**10.55**	**Elected**
Steve Moran	146	9.11	Not elected
Jim Berrington	119	7.43	Not elected
Alice Wisden	93	5.81	Not elected
Linda Sutch	41	2.56	Not elected

3. Confirmation of re-appointment of a Vice President

	Votes yes to confirm	Percentage yes	Votes no	Percentage no
Prof. Gus Baker	272	97.49	7	2.51
William Fiennes	235	86.72	36	13.28
Dr Adam Noble	244	90.71	25	9.29
Beryl Sharlot	242	89.63	28	10.37

4. Result of resolution 1

Resolution 1	Number for	Percentage for	Number against	Percentage against
To re-appoint RSM UK Audit LLP as auditors	264	97.78%	6	2.22

Council of Management 10 May 2022

The last time the Council of Management met together in the same room was in December 2019. After a break of nearly two and a half years of entirely remote meetings, the Council met together again at the charity's offices at New Anstey House on 10 May. Five members of Council attended by remote video connection.

This was the last Council meeting before the Council elections take place at the Annual General Meeting on 14 June. Members used this opportunity to express thanks to the three Officers – Richard Chapman, Chair; Jane Riley, Vice Chair and June Massey, Honorary Treasurer – who will all complete their three year terms of office in July. They were applauded for their outstanding leadership and support of Council and the charity during the unprecedented turbulent times of the Covid pandemic.

Members also noted that this was Beryl Sharlot's last Council meeting. Beryl has decided to retire and is not seeking re-election at the AGM in June. Members noted that she has served continuously on Council for more than 30 years and at various times has held every Council Office. Her experience and wisdom as well as her friendly support and deep commitment will be greatly missed.

Council made the following decisions.

- The approval of a series of recommendations to enhance the effectiveness of Council's working practices including wider use of technology to facilitate meetings and decision making.
- Council received and approved the annual reports of each of its Committees.
- The terms of reference of every Committee was reviewed, amended and approved. All Committees were confirmed to continue for a further 12 months.
- The following people were reappointed for a 12 month term as members of the Scientific Awards Panel:
  - Linda Mayhew
  - Leone Ridsdale
  - Emily Holmes
  - Andrew Trevelyan
  - Melissa Maguire
  - Fiona McKinnon
  - Prof. Michael Johnson
  - Stephanie Kilinc
  - Dr Khalid Hamandi
  - Rajiv Mohanraj
- The following people were all re-appointed as members of Epilepsy Action's National Advisory Council for Wales.
  - Louise Capeling
  - Michael Dix-Williams
  - Dr Frances Gibbon
  - Malissa Pierri
  - Craig Williams
- Council approved a process and timetable for the review of the charity's current strategic plan.
- The next meeting of the Council of Management will be on 12 July 2022. It was agreed that this will again be held in person with the option of remote attendance for those who cannot attend at New Anstey House.

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. The traditional face-to-face group meetings just aren't possible right now, so the local services team have set up online meetings using video calls instead (technical support is available). If this is of interest, you can find out more at ***epilepsy.org.uk/virtual-groups*** or by calling **0113 210 8800**.

If you previously went to a local support group, they may also be offering a chance to get together online. You can find out if this applies to the group you attended by emailing ***lso@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***) and Instagram (***bit.ly/3zSKMVM***).

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

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Visit www.vnstherapy.com to learn more and view important safety information.

1. Brodie MJ. Epilepsia 2013; 54 (Suppl. S2):5-8.