

Talk and Support

The stories of the
people behind the new
support groups video

Also in this issue

- using art to transform memory damage **left by epilepsy**
- the future of automatic **seizure detection**
- the fears and blessings when your **child has epilepsy**



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editor's letter

Welcome to the March 2023 issue of *Epilepsy Today*.

Happy New Year! It feels like we are already flying through 2023 – but there is a lot to look forward to. At Epilepsy Action, we have lined up some very exciting events at different places around the UK to get involved with. These will offer the opportunity to meet others living with epilepsy, hear the latest from some of the biggest names in epilepsy healthcare and research right now, and maybe even get to pet a support dog or two! There is more information on these on page 9 and online at epilepsy.org.uk/lets-talk.

Another fantastic way to be in the company of incredible people from the epilepsy community is to attend a Talk and Support group. We share some behind the scenes photos and information from the stars of the recent video we put together to raise more awareness about the groups (watch it here: bit.ly/3w17GwR) on page 10. Each person's story and reason for attending speaks volumes about what the group can really bring to someone's life – and it is very much worth having a look.

This issue, we've brought you a bit of a focus on research. We have a summary of one of the sessions from the most recent ILAE British Branch meeting, focusing on the effect of music on the brain (page 10). This incredible piece of research showed how an EEG of healthy brain activity could be translated into a tune which can then be played back to the person during sleep to help reduce seizure activity. On page 20, we have the last part of the Epilepsy Research UK's Shape Network conference, discussing the future of research – using data everyday collected to improve healthcare, and using mathematical modelling to offer seizure risk prediction. Finally, on page 24, we round-up some recent research into wearable technology and how it can change the landscape for people with epilepsy and people with depression.

We also have two very heartwarming stories to thaw a bit of the January frost. The first is from Ruth on page 16. Ruth's epilepsy has meant she has lost a lot of her childhood memories. But she undertook an art project using photography and an old Japanese fabric mending technique to work through her experiences and build new memories. Meanwhile, on page 26, Marc describes his experiences as a dad when his daughter was diagnosed with epilepsy at five months, as well as the challenges the family has faced and the joys they find in the small things.

I hope you enjoy this issue!

Kami Kountcheva
Editor

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

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Marc shares what it's been like for him and his family when his daughter was diagnosed with epilepsy at five months old

NHS launches laser beam brain surgery

A new fibre-optic laser therapy for people with drug-resistant focal epilepsy will be offered on the NHS, with the first of these surgeries taking place in early 2023.

This new technology allows surgeons to target the specific part of the brain causing seizures without the need for the more traditional invasive surgery.

The laser beam brain surgery will initially be available at two specialist service providers in England.

The laser treatment is carried out in an MRI scanner to help the medical team accurately navigate through the brain and avoid important structures. The treatment requires a small probe (1.5mm-wide) to be placed into the skull with the fibre optic laser at the tip of it. It works by removing the part of the brain where seizures start using heat.

People having this treatment are likely to be able to go home the next day and be back to work or usual activities within a week, according to NHS England.

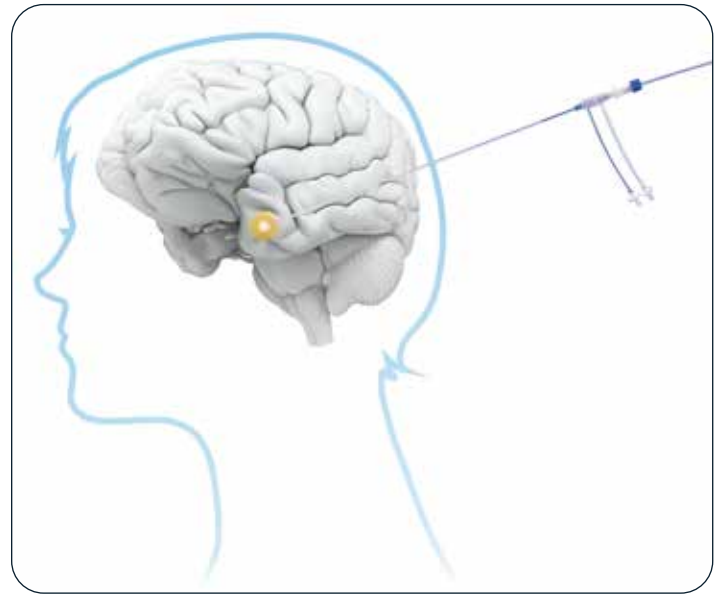
The organisation said the laser beam brain surgery will benefit up to 150 people each year.

NHS national medical director Professor Sir Stephen Powis said: "This pioneering laser beam treatment for epilepsy patients is life-changing and will offer hope to hundreds of people every year who have not had success in preventing seizures with traditional drugs.

"By replacing invasive neurosurgery with a cutting-edge laser therapy, allowing clinicians to better target the parts of the brain causing the epilepsy, we not only dramatically reduce risks to these patients, but drastically reduce their recovery time both in and out of hospital."

Alison Fuller, director of Health Improvement and Influencing at Epilepsy Action, said: "This new therapy is an exciting ray of hope for the many people with epilepsy whose lives are being impacted by the harsh reality of uncontrolled seizures.

"Research shows that around three in 10 people with epilepsy have seizures which do



not respond well to standard treatment with epilepsy medication. This means many continue to face significant challenges in other areas of life, from education to employment.

"Traditional brain surgery can be a really effective treatment, for those eligible, and we hear from many people who say it has had a positive impact on their seizures.

"But, choosing to have invasive surgery can be an incredibly difficult decision to make, given the potential risks and long recovery times involved.

"We hope that making this exciting new treatment available on the NHS gives even more people with epilepsy the chance to achieve better seizure control, which will improve outcomes and ultimately their quality of life."

NHS England says this is the latest example of the NHS delivering on the Long Term Plan commitment to ensure patients across the country have access to the latest and most effective treatments available.

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Some strengths of Teva's zonisamide out of stock



Zonisamide 25mg and 100mg capsules made by Teva are temporarily out of stock, according to Epilepsy Action.

Teva have told the organisation that the 100mg capsules are

expected to be back in stock in February 2023 and the 25mg capsules in April 2023.

If you are worried about taking a different version of your medicine, Epilepsy Action advises to speak

to your pharmacist or GP for advice.

Epilepsy Action also has more advice about switching between different versions of epilepsy medicines at: [bit.ly/3XAByyq1](https://www.epilepsy.org.uk/3XAByyq1).

Sodium prescription rules to tighten for men as well as women



Sodium valproate prescription rules will change in the UK for both women and girls, and men and boys, from spring this year.

This will be the first time valproate prescription rules will apply to men and boys, and comes in light of a recent review of the latest safety data by the Commission on Human Medicines (CHM).

The Medicines and Healthcare products Regulatory Agency (MHRA) has announced changes to the way sodium valproate will be prescribed for anyone under the age of 55. These changes are due to come into effect later this year.

The new rules state that no one under the age of 55 should be prescribed sodium valproate, unless two epilepsy specialists independently agree it's the only suitable epilepsy medicine for them.

Anyone currently taking sodium valproate will need to have a review of their epilepsy treatment and ideally be prescribed a different epilepsy medicine, according to the MHRA.

People currently taking valproate are advised to continue taking their medicines as normal in the meantime. Stopping epilepsy medicines could put people at risk of increased or breakthrough seizures.

The MHRA have advised that patients do not need to take any action at this time. However, Epilepsy Action believes that anyone with urgent concerns about their treatment should speak to their epilepsy specialist.

There are already strict rules in place around the use of valproate for women and girls of childbearing potential because of the significant risks if taken during pregnancy. These include a higher chance of birth defects or learning disabilities in babies exposed to the medicine in the womb.

The MHRA has reminded healthcare professionals about these risks and the need to ensure that the current Pregnancy Prevention Programme measures are followed, as there are concerns that this is not being done consistently.

The MHRA has also highlighted that some research suggests there may be a risk of reduced fertility in men and boys. Animal studies also suggest there may be effects passed from animals taking valproate to their offspring and future generations, but researchers are not sure if this would be the same in humans as it is in animals.

Alison Fuller, director of Health Improvement and Influencing at Epilepsy Action, said: "While we welcome these new guidelines as set out by the MHRA to improve patient safety and reduce risks around prescribing valproate, we urgently need more detail on how they will work in practice and with ongoing monitoring.

"At a time when the NHS is under more pressure than ever, we are concerned about the challenges people with epilepsy will face in getting opinions from two different clinicians, particularly if valproate is the only effective drug in managing their seizures.

"The proposed new measures will also mean men with epilepsy under the age of 55

are required to undergo a full review prior to the prescribing of valproate. However, we are still waiting to understand the full body of evidence behind these restrictions and its potential impact.

"Patient engagement was a key recommendation in the Cumberlege report, yet we are concerned that these new guidelines have come without adequate consultation from people with epilepsy and how they will impact on people's treatment.

"It is, however, vital that anyone taking valproate must continue to do so until they have had a conversation about their medication with their healthcare professional.

"In the meantime, we will be calling on the MHRA and NICE to ensure these new measures are appropriately implemented, managed, and monitored to ensure that people with epilepsy are able to make informed decisions in a timely and safe manner."

The National Institute for Health and Care Excellence (NICE) is expected to review and update its treatment recommendations in February 2023.

There is more information on the gov.uk website: bit.ly/3IUMiLN.

People taking valproate are advised to continue taking their medicines as normal, unless advised otherwise by their specialist. Stopping epilepsy medicines could put people at risk of increased or breakthrough seizures.

Further nurse strikes scheduled for February

UK nurses will strike on the 6 and 7 February in the fight for fair pay. This follows 'record numbers' of nurses who are members of the Royal College of Nurses (RCN) voting at the end of 2022 to take strike action. This was the first time RCN nurses have voted to strike in the 106 years of the RCN.

Strike action already took place in December 2022 and January 2023, with many of the biggest hospitals across the UK affected. This comes at a time when NHS waiting times for routine hospital treatments have reached record highs, according to NHS England.

When the strikes were announced, the RCN said they will be carried out legally and

safely, and emergency services and other urgent care will not be affected. However, they have affected routine services, including planned operations, mental health services and district nursing, which can have an impact on people with epilepsy.

The RCN is asking the government to act to acknowledge the life-saving role nurses play in healthcare and to ensure nursing is an attractive job, to help fill the "tens of thousands of unfilled nursing posts".

Pat Cullen, RCN general secretary and chief executive, said: "Anger has become action – our members are saying enough is enough. Our members will no longer

tolerate a financial knife-edge at home and a raw deal at work.

"Ministers must look in the mirror and ask how long they will put nursing staff through this. Across the country, politicians have the power to stop this now and at any point.

"This action will be as much for patients as it is for nurses. Standards are falling too low [through understaffing] and we have strong public backing for our campaign to raise them."

Alison Fuller, director of Health Improvement & Influencing, Epilepsy Action: "We know the decision by nurses to take strike action has been a difficult one. Nurses are a lifeline for people with epilepsy and their families in delivering safe care and yet for too long, their workload, morale and staffing levels have been stretched to breaking point.

"We are calling on the Health Secretary to recognise the contribution nurses make to ensure they are able to do their essential work safely. In the meantime, we recognise the short-term impact the strike action will have on people with epilepsy who will

be understandably concerned about their continuity of care.

"We are actively seeking the views of people with epilepsy and how this is affecting their access to services and delays in their care and treatment."

The action has followed the NHS Agenda for Change pay announcements earlier in 2022, which left experienced nurses worse off than a decade ago, according to the RCN. The salaries of nurses have been consistently below the rate of inflation. With the strike action, the RCN is campaigning for a pay rise that is 5% above inflation, which would be around 12%.

The RCN represents around two-thirds of nurses in the NHS.

If you are worried about any disruption to services, you can contact the Epilepsy Action Helpline by calling 0808 800 5050 or emailing helpline@epilepsy.org.uk.

You can also share your concerns or experiences with us to help us campaign by emailing health@epilepsy.org.uk.



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Torrent lamotrigine stock problems

Lamotrigine 25mg tablets made by Torrent are temporarily out of stock, the company has told Epilepsy Action. Torrent told the organisation that they expect these to be back in stock in April 2023.

Torrent have confirmed that their lamotrigine 50mg tablets are in stock.

Epilepsy Action said that other manufacturers' version of lamotrigine are also still available.

Epilepsy Action advises that anyone worried about their medicine speak to their GP or pharmacist for advice.



UK epilepsy prevalence and incidence update



A new update on the number of new cases of epilepsy and the number of people with epilepsy in the UK has found differences between the nations.

The new UK study by Wigglesworth and colleagues aimed to provide an update on the incidence of epilepsy (the number of new cases) and the prevalence (the number of people with epilepsy) in the UK between 2013-2018.

The researchers used electronic health records of around 14 million people, representing around one fifth (20%) of the UK population.

The study found that overall in the UK, just over nine people would have epilepsy in every 1,000 people each year. This means that an estimated 633,000 people are living with epilepsy in the UK.

When looking individually at England, Northern Ireland, Scotland and Wales, the team found there were slight differences. In England this drops to just under nine people in every 1,000 having epilepsy a year. In Scotland, this was just over 10 people, in

Wales it was over 11 people and in Northern Ireland it was over 12 people.

The team also looked at the incidence of epilepsy. They found that in the UK there would be around 43 new cases of epilepsy in every 100,000 people in one year.

Reflecting the pattern of prevalence, this was lower in England (37 people), and higher in Northern Ireland (46 people), Scotland (48 people) and Wales (55 people). Overall this means that there are 28,813 new cases of epilepsy each year in the UK, or 79 a day.

The study, published in *Seizure*, found that the prevalence and incidence of epilepsy is similar to that of other high-income countries, with peaks at younger and older age, and a dip in the middle. This is in contrast to the previous research, which didn't show as much of a peak in older age.

The study authors said that while the prevalence of epilepsy has reduced slightly from 2011, there were significant differences between the different nations and between regions.

The researchers also noted that there was a connection between more deprived areas and a higher level of epilepsy, confirming previous findings. People in the most deprived areas of the UK are more than a third more likely to have epilepsy than those in the least deprived areas, which is something the study authors say needs more research.

You can find the full paper online at bit.ly/3iDIPH7.

Better communication needed in adult care

Better communication is needed across UK hospitals treating adult epilepsy patients admitted after having a seizure, a new report said.

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) released its report 'Disordered Activity?' on 8 December 2022. The report is a review of the quality of epilepsy care for adults who went to hospital with a seizure. The review spans between 1 January and 31 December 2020. This included people who already had an epilepsy diagnosis and people who were diagnosed after being admitted to hospital with a seizure.

NCEPOD used data from 610 clinical questionnaires, 264 sets of case notes and 158 questionnaires for its review.

The report concluded that there are areas throughout a patient's journey where improvements could be made.

The review found that for around two in five people (42.2%) the hospital did not let their usual epilepsy care team know that they had been admitted. Around a quarter of people (26.1%) did not have their epilepsy medicines written in their notes.

Over two in five people (43.5%) left the hospital without input from the neurology team. In around two in five hospitals (38.5%), specific epilepsy information was not routinely provided until their first clinic appointment, which could be weeks later. Only around one in 10 people (12.6%) had any information in their notes that the risk of sudden unexpected death in

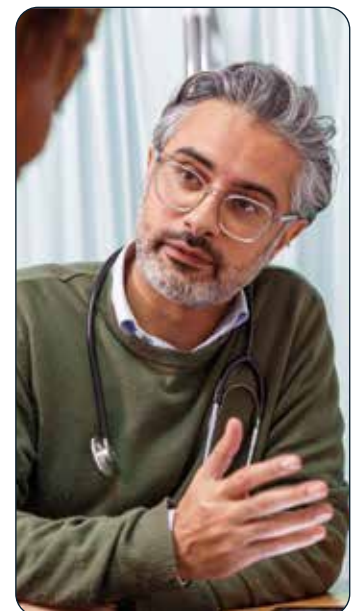
epilepsy had been considered and discussed with them.

NCEPOD said that improved communication is the main theme of the report. It recommended improvements to alerting patients' usual epilepsy teams when they have come to hospital as a result of a seizure. The enquiry also added that hospitals need to document epilepsy medicines and action clear plans for investigations needed.

The enquiry also recommended better communication regarding neurology advice and explaining the risks of seizures to patients and their families and carers. Hospitals are also urged to communicate the discharge and follow-up plans with the patient, their family, carers and healthcare teams.

Epilepsy Action said it fully endorses the findings and that the organisation is eager to see future improvements to patient safety and quality of care.

The full report is available at bit.ly/3QPbBXN.



Let's Talk About Epilepsy

Words by Kami Kountcheva and Josh Booth.

Happy New Year, everyone! We are starting off strong in 2023, with an exciting offering for you – a series of events in various cities around the UK. These promise to bring exciting presentations from some of the biggest epilepsy professionals and researchers doing innovative work, as well as real life experiences from people living with epilepsy. Not just that, but you will have a chance to share your thoughts and views about life with epilepsy, and help shape the future of our work.

Some of the advancements the events will cover include how mathematical models can support diagnosis, treatment and monitoring in epilepsy and the lowdown on a new long-term EEG monitoring device. You'll also have the chance to hear about developments around the ketogenic diet, and maybe even meet some epilepsy support dogs!

These events will also be a great opportunity to meet other people and families with epilepsy and hear their stories of living with the condition. We all know having epilepsy can feel very lonely and isolating, especially when you or your loved ones are first diagnosed. One of the main reasons for these events is to give you the time and space to make connections with others in similar situations and truly feel like a part of the epilepsy community.

You are cordially invited to Epilepsy Action's Let's Talk About Epilepsy events, offering cutting-edge epilepsy information, lived experience from others with epilepsy and a chance to have your say!

The events will take place on weekday evenings for around three hours. They will bring you five or six speakers – both professionals and people with epilepsy experiences – and offer plenty of time at the beginning and the end to catch up with others, meet people and ask questions. You can catch us at:

Manchester, Wed 1 March, 6pm

There'll be opportunities to hear from experts on preconception and family life with epilepsy, as well as some information about Epilepsy Action's new befriending scheme, and maybe even a guest appearance from a support dog!

Bristol, Thu 9 March, 6pm

This event will be focused on 'treatment beyond medication', with expert speakers from Neuronostics and Matthew's Friends among others. You'll also get to hear more about the difference Epilepsy Action's Talk and Support groups make.

London, Wed 15 March

A variety of speakers will talk about their lived experience of epilepsy, and there'll be the opportunity to learn more about exciting developments in the world of wearable EEG devices.

Cardiff, Tue 21 March, 5pm

This event will focus on 'living well with epilepsy'. A group of Welsh ESNs will

be there, and the event will feature talks on NEAD, the impact of sodium valproate, and Epilepsy Action's new counselling service in Wales.

Belfast, Tue 28 March, 6pm

Former neurologist Jim Morrow will be speaking about this own epilepsy journey at this event, along with other talks about the impact of epilepsy on family life, and Epilepsy Action's new counselling service in Northern Ireland.

Leeds, Wed 5 Apr, 5pm

You'll hear from local ESNs, scientists at the cutting edge of epilepsy treatment, and a variety of people from Epilepsy Action. There might be a support dog or two there as well!

Virtual (online) TBC

You can keep an eye on the Epilepsy Action website at epilepsy.org.uk/lets-talk for more details and information and to sign up for the events for free!

If you can't wait for one of the big days, you can have your say right now! We want to hear from everybody in the epilepsy community about their perspective on life with the condition in 2023. Just visit epilepsy.org.uk/lets-talk to get started.



Kerry-Ann

The family you choose

The value of a support group is more than the sum of its parts, and that is made all the clearer by Epilepsy Action's new Talk and Support groups video – and the people behind it.

Words by Kami Kountcheva.

It's hard to convey the value of a support group without actually experiencing it. It might sound nerve wracking, or like you're off to make small talk with strangers for an hour or two. Or some people might think, "what's the point of talking about my epilepsy?"

But the truth of it is that there is nothing like the feeling of hearing someone say something that you've been worrying about or going through on your own. It's a sudden warmth and lightness where you felt heavy in your stomach before. It's the unloading, unburdening feeling of connection and of true understanding from someone of what's going on in your life.

That's what the Epilepsy Action Talk and Support groups can offer. It's not just

a seat and a room and a coffee. It's a community and understanding and a sense of belonging.

And for incredible Epilepsy Action volunteers, who lead groups throughout the country, this is a life-changing gift they can bestow on people at difficult points with their epilepsy.

A wonderful group of new friends

One of these people is Kerry-Ann.

Kerry-Ann was first diagnosed at the age of 13. "All I can really remember from that first day is that I had been speaking to my cousin in Australia online. The next thing I knew, I had come round to see six paramedics and I was taken to hospital to be checked out.

"When I was first diagnosed, it was a total shock and a lot to take in, not just for me, but for my family too. I struggled for a long time to understand what was going on and it was hard for me to accept. I went through depression and anxiety attacks, which still happen now from time to time."

Kerry-Ann's tonic-clonic and absence seizures seemed to cost her many friends a big part of her social life. "I lost friends because they didn't understand what I was going through and what to say to me. I looked okay on the outside, apart from the odd black eye or broken nose as a result of a seizure. I would hide away from everyone when that happened as I was worried about what people would think or say.

“I used to get invited out all the time, but the invites dried up. It hurt a lot. I was also excluded from things because sometimes people think that just because you have epilepsy, you are unable to do something.”

Kerry-Ann and her parents came across a poster for an epilepsy support group in Norwich and, in a bid for advice and support, Kerry-Ann phoned up and went along to a meeting.

“We were made to feel welcome and it was amazing to be able to talk to others who knew what I was going through. It also helped my parents talking to other parents about how they were feeling and to know it was not just them in this situation.

“I made a wonderful group of new friends who I could be open with and talk to about my epilepsy and experiences. They all understand, as they were struggling with the same things, or have been through them.

I knew I wanted to set up my own group in my town

“A few weeks after joining the Norwich group, I knew I wanted to try and set up my own group in my home town. In April 2018, I set up the Lowestoft group with the support of Epilepsy Action.

“It’s amazing leading the group and I always look forward to my Talk and Support meetings each month, seeing my regular members and meeting new people too. It’s a fantastic opportunity to support the community and supporting people with epilepsy and their families.”

I surprised myself

And these are not the only benefits of being a part of the groups. Bec first attended a group after it was suggested to her by her epilepsy specialist nurse (ESN). She initially felt nervous and reluctant to go. “But it turns out it’s one of the best things I’ve ever done,” she said.

Bec has had juvenile myoclonic epilepsy and photosensitive epilepsy since she was nine years old, experiencing a host of different types of seizures. She explains that she has come to terms with her epilepsy, having lived with it most of her life, and has even found many positives in volunteering, raising awareness, and educating and supporting others.

But this isn’t to say that she still hasn’t dealt with many different challenges throughout her life. Bec has experienced everything from exhaustion, memory problems and loss of independence to misconceptions and prejudices about her condition, especially at work.

Initially worried about going along to a group, Bec found it instantly warm. “As soon as I walked in the room, I was made to feel really welcome. Everyone was really friendly and relaxed, and it didn’t take long for me to feel settled in. I wasn’t under any pressure to talk, but the group atmosphere was so easy-going that I didn’t feel too self-conscious for long.

“For the first time in my life, I was surrounded by people with epilepsy! I wasn’t the only person I knew with it anymore. I’m so glad I kept attending, as now some of my best friends are people that I’ve met at the group.

“The group means everything to me, as it has been such a life changer and it’s given

me a lot of much-needed support. It makes me feel happy and confident, and has taught me to be positive and to speak up for myself when I need to. My knowledge and understanding of my own epilepsy, and epilepsy in general, has improved.”

In 2021, one of the volunteers running the group Bec attended moved away. The meetings were being held virtually at the time, because of the pandemic, and someone needed to take over hosting. “I was desperate for the group to keep going, because I needed the support, so I offered.”

Together with another volunteer, Paula, Bec helps to run the Truro group.



The Talk and Support groups are warm and welcoming



Shannen

And at a particularly low ebb, the Talk and Support groups provided her with a lifeline.

“I was going through a period where my seizures were uncontrolled and, because of this, my mental health was deteriorating. This is a pattern that happens often in my life. I went for an assessment with a mental health support team and spoke about how I had felt alone for a very long time, ever since my diagnosis. I felt strongly that I was alone in this struggle and that no one in my close circle could ever understand how I was feeling.

“One of the recommendations the practitioner gave was for me to attend the Talk and Support group. I had known about them for a year or so, but had not felt able to attend. With the deterioration in my mental health and the encouragement from the practitioner, I finally decided to attend.

“It felt like a release. I finally had a space where I could speak about all the things I had been holding in for over 15 years. It was very emotional for me and I remember crying in the first group. Everyone was so welcoming and

I could speak my truth
and be accepted
and supported

I knew straight away that there was no judgement. I felt that I could speak my truth, however dark it was, and be accepted and supported.

“The support and relationships I quickly built with the people in my group felt like connections unlike any others that I had ever made. These people understood me fully and I never felt like I had to explain myself, they just got it! I feel lighter after I have attended a group because I’ve been able to get things off my chest or ask questions that I needed answers to.”

Part of a family

Many of Shannen’s experiences are shared by others too. Sukhdeep has



Sukhdeep

“The best part is seeing what the group means to each person who attends. It’s great to see people open up and feel like they are in a safe place with no judgements. But also, it’s been great to realise that I have the confidence to lead the group. I’ve surprised myself! When I first started attending all those years ago, never in my wildest dreams did I think I would one day be leading the group!

“I definitely recommend volunteering. I’ve learnt a lot about myself, developed some new skills and made some good friends through doing it.”

Feel lighter

The groups play a huge part in helping people break down the loneliness and isolation that epilepsy can bring. For Shannen, this played a huge part in her first attending one of the Talk and Support groups.

Shannen has had juvenile myoclonic epilepsy since she was 13, with periods of uncontrolled tonic-clonic, myoclonic and absence seizures. Living with epilepsy has taken its toll on things like longer-term travel, working full time and dealing with discrimination, Shannen explained. And like others, Shannen struggled to open up about her epilepsy when she was younger, as she wanted to be treated the same as all her peers.

“As it turned out, I love being a group leader. It has its challenges, but there are definitely outweighed by all the positives. Seeing people benefit in the way that I have and knowing that I’m a big part of making that happen is so rewarding.

“It gives me a real sense of self worth, because I know from my own experience how vital these groups are, and volunteering to run a group means I’m doing something I actually believe in 100%. I’m still getting the support myself from attending, but I’m also I’m helping to run it!

epilepsy and has had focal aware and absence seizures, which are now controlled with medicines. He initially struggled with his epilepsy as a child, as he didn't have anyone to relate to. While Sukhdeep explained that he is comfortable being open with people about his epilepsy, there are still aspects people don't understand.

He said: "The challenge is explaining how complex it can be and how it affects me, as people have lack of knowledge about epilepsy."

For Sukhdeep, the value in the group is forging new connections. He said: "I wanted to meet more people with epilepsy. I made friends and met people I would never have met otherwise. The group makes me feel part of a community."

The sense of community and the understanding you get from the groups is one of the key things for many people. Dan's epilepsy has been going since he was seven years old, with focal impaired awareness and tonic-clonic seizures. The unpredictability has been difficult for Dan, and, like Shannen, it affected his mental health, bringing on anxiety.

The group was a chance for Dan to be with people who have had the same experiences as him and share his story too. "Everyone was welcoming and friendly, and I felt like I really fit in. It was amazing, it felt like home, as everyone understood me and we were all able to relate to each other. It's a place I can offload, feel comfortable and not feel judged. It's like being part of a family."

Less alone

And for some, like Hasna, the groups represent a place where she feels comfortable opening up and being vulnerable. Hasna has had seizures for nearly 17 years but only got a diagnosis of epilepsy last year. She has tonic-clonic seizures around every eight weeks.

Hasna has found strength from living with epilepsy for years, but there are still challenges that stop her in her tracks, like not being able to drive and feeling sad and anxious about having seizures in public or alone.

She said: "It is hard for me to speak openly about my seizures to my friends, because I don't want to burden them with the impact it has on my life. I would feel guilty about opening up, as I am so determined to not let the seizures be my identity. Also, there are times when I discuss my seizures with my colleagues, but speak like they are less serious than they actually are. I'd say, 'I just have seizures' or 'I live my life and it doesn't affect me', because I don't want their sympathy."

"I decided to attend the Talk and Support group after coming across the link online and thinking it's worth a try. When I first joined the virtual group, I was very nervous about speaking to new people about my epilepsy, and I felt a bit on edge. This was mainly because I hadn't been part of an epilepsy community my whole life. It was great when I started to engage in conversation and I felt very positive."

"What kept me going was the warm atmosphere and meeting people who have similar experiences was comforting. Stories from people about how epilepsy didn't just affect their physical health but also their mental health really resonated with me. Being a part of the group has provided me with a sense of calm and I feel less alone. I know that if I have a question, there is someone there to offer their support."

Join in

The group decided to take part in the filming of a new Talk and Support

promotional video, put together to raise awareness of the groups and what they can offer. Many members of the group said they wanted to give back and make more people aware of how helpful the Talk and Support groups can be.

You can watch the video and find out more about joining a group on our website at: bit.ly/3Qz9LUF. If you would like to become a volunteer and lead a Talk and Support group, there is more information at epilepsy.org.uk/volunteer, and you can search for the latest vacancies by area.





In tune with epilepsy

We summarise research around finding and using your brain's own healing music to suppress seizures, presented at the ILAE British Branch conference last year.

Words by Kami Kountcheva.

I don't know anyone who doesn't like music. It's true that we all like different things – some enjoy the relaxing tones of classical music and others crave the exhilarating sounds of electric guitar and grungy, raspy vocals.

The beauty of all of us is in the differences between us, but the connecting factor we have is that we all love music. Something primal in our brains responds to music. It can be exciting, it can be relaxing, it can help jog memories or help children learn. It's a very powerful tool for influencing our brains. And, as such, it can even have an effect on seizures.

This isn't always positive. In a rare form of epilepsy, called musicogenic epilepsy, seizures are triggered by music. This has been described as early as 1841 in scientific literature, and is a form of reflex epilepsy, one that has its own very specific trigger, like photosensitive epilepsy.

But in many cases, music can very much have a positive effect on seizures. This is something shown more and more often in research now.

You might have heard of the Mozart effect before. This is basically the idea that listening to Mozart's Piano Sonata in C Major (K545) or Sonata for Two Pianos in D Major (K448) can reduce epileptic activity in the brain. This was found to be the case especially with K448, particularly in areas of the frontal lobe of the brain, which is linked to emotion.

The reason why this piece of music has this calming effect on epileptic activity is still not well understood. A recent study from the US found that changes between longer segments in the piece were linked to this therapeutic effect. The researchers' theory as to why this happens was that maybe it has a subconscious emotional effect.

The Mozart effect is probably the most famous and widely studied example of music therapy for seizures that we have. But other research is looking into music's vast potential for seizure suppression too, with a really interesting process and a very hopeful outcome.

Your brain's electronic score

At the International League Against Epilepsy (ILAE) British Branch Meeting in October 2022, composer and professor of music at the University of Edinburgh Nigel Osborne spoke about music and the brain.

Prof Osborne said we have a lot of evidence to show that music can affect the brain in many ways – particularly its electrical activity. It can be changed or regulated with music. But also, he added, we can influence the systems in the brain that give rise to electrical activity.

Music is "in very close dialogue" with the autonomic nervous system – the one responsible for controlling subconscious bodily functions like heart rate, he explained. This includes things

like the systems controlling hormones and the transfer of information between brain cells.

Prof Osborne and his team have been studying this effect of music and its potential in improving the natural brain activity of children with epilepsy in Croatia during sleep – although, he said it could apply to everyone.

The process begins with looking at EEG recordings of the children throughout their night's sleep. The team, which includes neurologists and epileptologists, then try to find a section of EEG data that reflects non-epileptic activity. "We try to identify the passages that are most 'healthy', most beneficial, where the child is most at peace and the brain is behaving in the most regulated way," Prof Osborne explained.

The next step is to identify the most important frequencies using a process called 'ridge extraction'. The team uses a special program to do this, called MODA (multiscale oscillatory dynamics analysis). This allows them to create a simpler wave to represent the brain activity.

The team then turn this signal from MODA into sound – a process called audification. The team move the waves up in octaves to reach the wavelengths that are within hearing range and there is your "electronic score", as Prof Osborne calls it.

Did you ever think you could hear your brain's own musical score? And all from scribbled brainwaves on a piece of paper? Prof Osborne's team is doing all of that and taking it further.

The team puts this electronic score through another program – X-system – to identify the piece of music most closely matching the brain's own 'healthy activity' song. This includes music from all over the world.

The X-system has been developed for both medical and musical purposes, and it models the areas and networks of the brain that are involved in processing

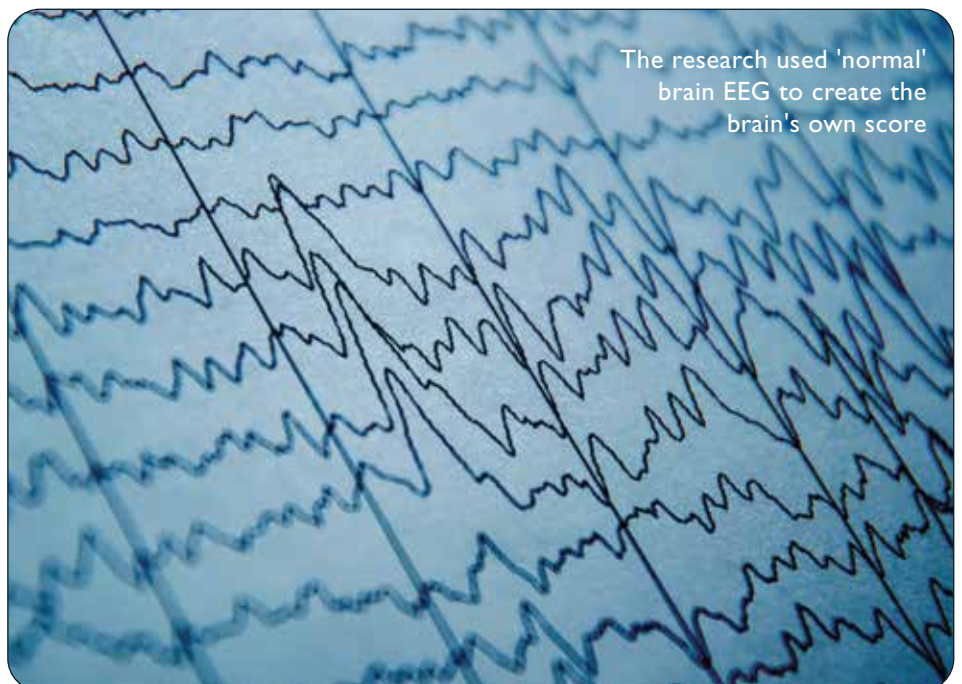
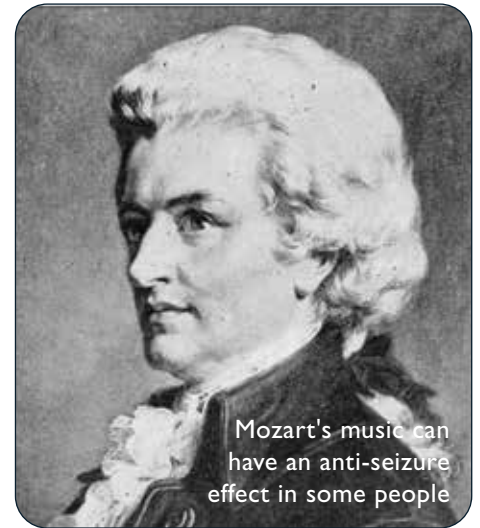
music. The system can very accurately predict if a piece of music will create excitement or alertness in a person's brain, or provoke an emotional response, for example.

Prof Osborne said that once the system has selected the music that reflects the brain activity for the child, a night-time playlist is produced. In their research, the team then analysed the musical and brainwave activity.

They saw that the brainwaves were "catching up" to the music in order to form the same pattern at the same time. This shows that the music was helping to regulate the brainwaves into their own healthy activity patterns.

Prof Osborne's team is continuing to focus on this fascinating research area, which is offering a lot of hope and promise for what music really has to offer.

Our understanding of the effects of music on the brain – and specifically on epilepsy – is still limited. It's a slow and steady progress to our understanding, but studies like these are really exciting. With all of this in mind, the future is sounding better and better.





Transforming the damage

Ruth's epilepsy has wiped many childhood memories, but through her photography and a Japanese fabric repair technique, she is determined to make new ones

Words by Ruth Cleverdon.



I was diagnosed with epilepsy between 2010-11, when I was around 10 years old. I had irregular generalised tonic-clonic seizures. When I had my first ever seizure, I was at a sleepover. We were watching TV and at first my friend thought I was joking, but eventually she went to get her mum because I wouldn't get off the floor. Luckily, her mum was a care assistant at a school and knew

exactly what was happening, so she helped me straight away.

When I was diagnosed, my dad knew a fair amount about the condition from his job at the time, but it was definitely a learning curve for the rest of my family. I think that's one of the reasons why I wasn't too upset when I got the diagnosis – I didn't really know how



Part of my project was using old photographs from my family album, like this image which features a very young me (left). To represent the memory loss, I partially submerged the images in water mixed with milk. This created an emotive visual effect, which I was quite happy with. It showed how I feel when I try to remember childhood memories – they're shrouded in fog.

Once I had the images I wanted to use, I printed the photo onto fabric. I then patched over my face with colourful fabric and embroidered my complete image. The embroidery represented me reconstructing my lost memories.



big a deal it could be. My dad always tells me that I seemed to take it in my stride and never really stopped me from doing things.

The main thing I remember about that time is the kindness of the people around me that helped when I was having seizures, and the health professionals who cared for me afterwards. I'm aware that without the NHS, there is a chance I might not be here now, so I am so very thankful to them.

Epilepsy was completely out of my control, and, at times, it was terrifying. I started getting warning signs that I was going to have a seizure about 10-15 minutes before I fell unconscious. This would start with lines going across my vision. These lines would grow thicker





As well as my embroidery work, I also took a number of digital photos set in and around the area where I grew up, in Leicestershire. This image, for example (4), taken in 2020, features a bedsheet from when I was a small child, strewn across a public footpath post. This speaks to the feeling of loss and confusion I felt daily at this age.

until I couldn't actually see anything and all I could see was white. All my limbs would go heavy until it felt like I couldn't move anymore, and I would have about five minutes of being conscious but being effectively blind and not able to move. Those five minutes are the most scared I have ever felt in my life. In those moments, I felt completely helpless and I was just waiting for the inevitable.

I am extremely lucky that I have seemed to grow out of my epilepsy and I haven't had any seizures since I was around 16. I was weaned off my medicines twice. The first time was unsuccessful, and I had another seizure about a year after, so I had to go back onto another medicine. A few years later, my doctors tried again, and I haven't had a seizure since! But I still live with the after-effects of epilepsy. The seizures I had as a young teenager left me with extensive memory loss. I sadly can't remember much of my childhood and as I reached young adulthood I really had to come to terms with the extent of the memory loss.



As well as digital photographs, I also used traditional 35mm film. During my third year at university, I shot a roll of film around my family home. The film was exposed to light whilst being developed, which unfortunately fogged most of the images. I was upset about this at first, but a classmate pointed out the similarity of this to the concept behind my project.

I ran with this idea and used embroidery to fill in the obscured areas of the images. The images – the memories – were damaged by factors outside of my control, but I could use my own creativity to rebuild those. This project has been extremely empowering. I felt that I could take charge of the cards I had been dealt.



Trying to figure out who you are as a person moving into adulthood is difficult for everyone but I really struggled with not knowing who I was previously. It felt, at times, that I had been dropped on Earth without knowing how I actually got there. But I found my own creativity could be a way of coming to terms with my experiences and reclaiming my childhood memories.

In my second year of university, I started my 'Fabrication' project, which is still ongoing.

I see photography as a tool with which a person can capture an exact moment

in time and keep it there forever. I used photographs to keep my memories alive and I love looking through my own family albums. Although I can never reach those memories myself, I can create my own new ones from what my friends and family tell me.

One of the inspirations of my project was the Japanese fabric repair technique, called Sashiko. This practice focuses not only on mending an item, but also transforming the damage into something more beautiful and stronger moving forward.

The project was supported by my dissertation, in which I looked into the

links between photography, nostalgia and memory. At the beginning of the dissertation process I had a theory that photography was a tool with which to capture memories and keep them alive. But in actual fact, photography acted more as a way of illustrating the version of events you had in your mind. The images that are selected to go into the family album are chosen to support a narrative.

Since starting my 'Fabrication' project, I have come to realise how powerful creativity can be. I know I can't regain those memories exactly as they were, but I can begin to heal my inner child and help find her again.

The future of research

In the last of this three-part feature, we look at new ways of using data for research and how mathematical modelling can improve diagnosis.

Words by Kami Kountcheva.

Talking about personal data can make anyone feel a little bit on edge. And it's good to be cautious. But when it comes to medical research, our data is very safe and can be just the thing to transform our healthcare and bring important answers where there are currently only questions.

Talking about maths can also make some people feel on edge. But, fortunately, some bright minds have done all the hard work. They have created amazing mathematical models which can be a huge help in many aspects of epilepsy care, one of which is early diagnosis.

Intrigued? Keep reading for all the highlights from the final session in the Epilepsy Research UK Shape Network conference, looking at the future of research.

The answers in the data

Dr Kathryn Bush from Newcastle University started off the final session of the conference explaining what data research is. She said this is research performed using any information that is collected as part of routine care or specifically for research. This could be from medical records, prescription data, A&E data, blood tests, HPs, death certificates, genetic tests, MRI or CT scans, and lots of other places.

Dr Bush explained that data research can take the form of clinical trials, surveys, questionnaires and data from registries, for example.

This data is a "precious resource", Dr Bush said. She said it's really important

in helping to understand patients and improve care and services for people. She explained that while data from clinical trials is also incredibly valuable, it's also small. Clinical trials also involve a different group of people to the general population, as it doesn't include people who can't or choose not to take part. Routinely collected data represents everyone and can be lifelong, so it can give a bigger picture, she explained.

Addressing one obvious concern many people have, Dr Bush said that data for research isn't what people should worry about. She said this kind of data is kept safe, secure and confidential. It's anonymous, and there are legal protection contracts in place in the UK to ensure it is safe. IT systems are secure and controls are strict. She added that there are strict penalties for data misuse and people can also opt out if they want.

One big recent example of the use of routine data in real time was around COVID-19, Dr Bush said. Aspects could be monitored and shared with the public, such as the number of COVID cases, the number of daily deaths from it, vaccine uptake, vaccine safety and effectiveness, and groups that were more at risk. This showed the power of using routine data, and the opportunities it offers.

Dr Bush said she and her team are working on using routine data on work around health inequality. She said previous big data has found that in the least deprived areas, epilepsy affects around one in 200 people (0.5%), while in very

deprived areas, this is over one in 100 people (more than 1%). This means that more than twice as many people living in deprived areas have epilepsy than people living in wealthier areas. The team wants to find out more about why epilepsy is more common in more deprived parts of the UK and why people with epilepsy in these areas are more likely to die early. The team is working to find out whether they can use routine data to model what changes might have the biggest impact in preventing epilepsy and epilepsy-related deaths.

A model brain

Prof John Terry from the University of Birmingham closed the conference, speaking about the role of mathematical models in improving diagnosis of epilepsy.

A mathematical model is a model built using equations, approximations and assumptions. Prof Terry said there are billions of neurons and thousands of connections for each neuron. But despite these complexities, there are equations that can help to create a model of some epilepsies, which could try to predict the likelihood of seizures.

Prof Terry explained that brain network ‘ictogenicity’ (BNI) is the ability of a given brain network – a group of connected neurons – to generate seizure-like activity. The BNI calculated by the model could be low, medium or high, indicating no risk, a small risk or a large risk of seizures.

Seizures could be the result of regions of the brain being changed or the cells, networks or connections being disrupted to cause epilepsy.

Usually, an EEG is done when a patient first comes to the doctor having had a seizure, to help diagnose epilepsy. However, Prof Terry said that about seven in 10 (70%) first seizure clinic EEGs are inconclusive, so the doctor can’t say for sure from it whether the person has epilepsy or not.

Prof Terry said, however, that with mathematical models, a short segment of a ‘normal’ EEG can be used to inform a model, which can then produce more data on a computer over time. He said that rather than having to collect all this data – for example, a year’s worth – we can simulate it in a matter of minutes.

The model can then be used to calculate the risk of seizures occurring. Researchers can change different properties through the model and see how easy it is for seizure-like activity to happen. The easier it is, the higher the risk of epilepsy.

The team is continuing to work on optimising these mathematical models and checking how effective they are through research.

Answering your questions

How will the genetic element of many epilepsies affect data and conclusions when studying health inequalities in deprived areas?

Kathryn Bush (KB): I think there are two different aspects to it. Certainly in the adult onset (late onset) epilepsies, we know that they are linked to underlying socioeconomic factors. We know that it’s more common in the most deprived communities, and we can make a really good guess about the reasons for that, because we’ve got data on this. What we’ve never actually done is looked at it in the UK.

In terms of the genetic epilepsy, I think it’s a really interesting question. There are some data out there which show that in children who get epilepsy before the age of three, there is, again, a social element.

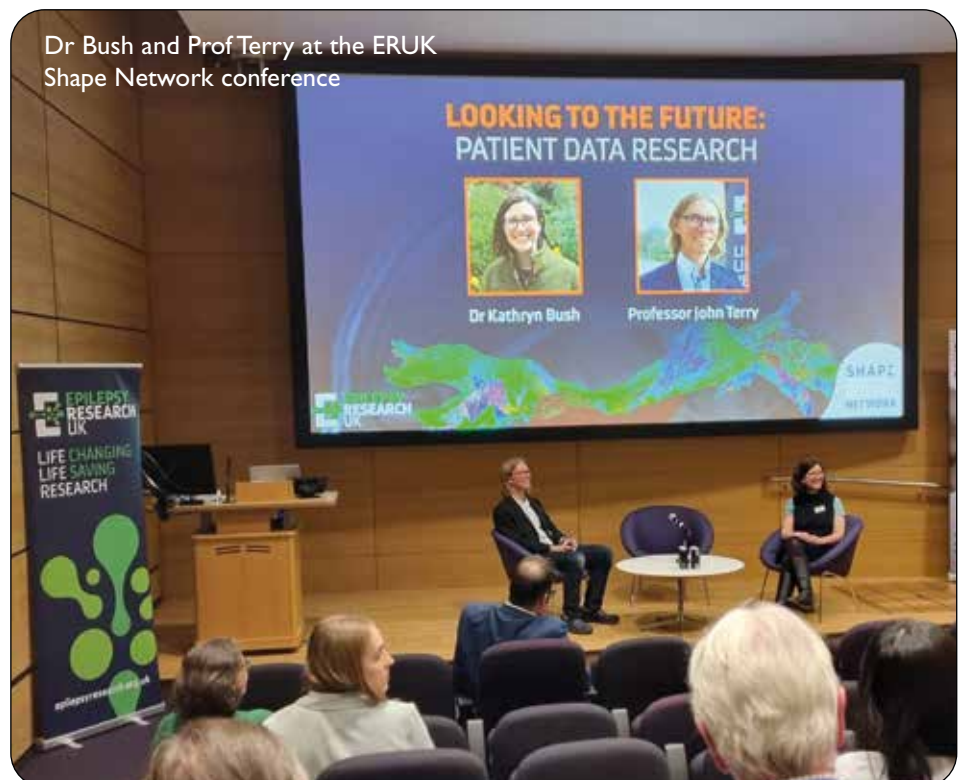
We don’t understand why that is, and there are a lot of different theories about genetics and things which pass on through generations. I think it’s a really exciting area but it’s an area that needs a lot more research – I don’t have an answer.

In what other areas could you apply similar mathematical models?

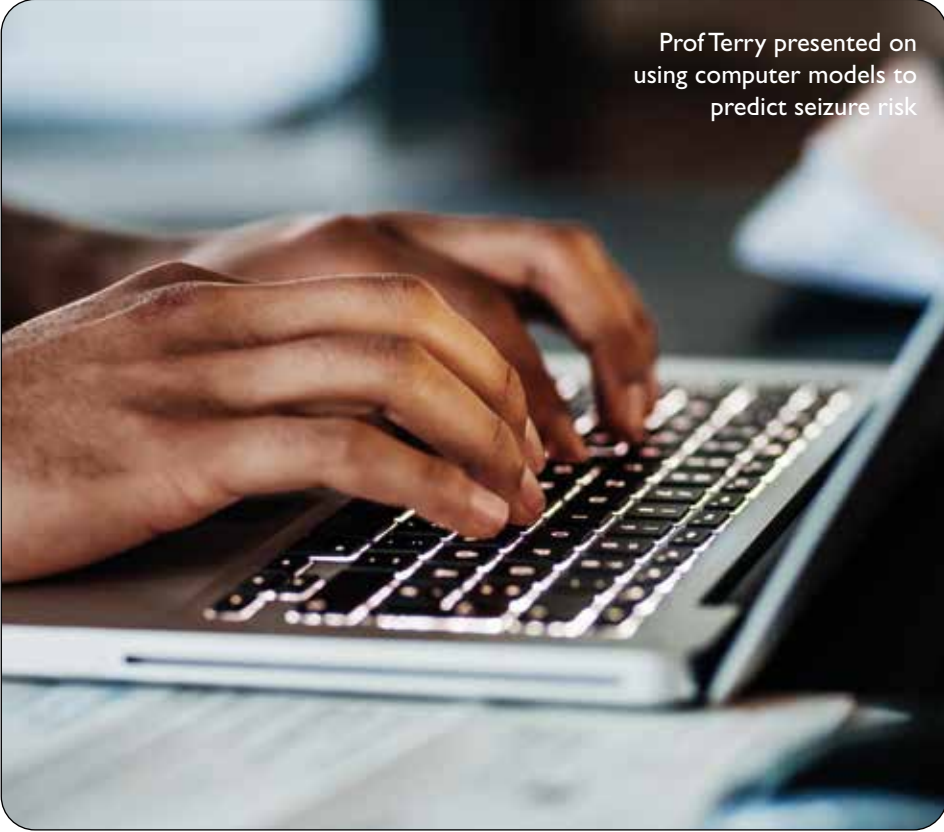
John Terry (JT): I think there’s a lot of potential, at least from network-based approaches, to understand other neurological conditions.

So, from a research perspective, there have been several research studies into pretty much every neurological condition. They have shown that if you take groups of people with a neurological condition, you will find differences between them and people without the condition. But, what we don’t know is how that maps onto groups of people with a neurological condition versus groups of people who are suspected of having that neurological condition.

We also want to know, can we go that step further and understand how that maps onto each individual rather than at group level. So, I could get a population average and that gives me confidence that there’s a link to the condition in that group. But, that’s absolutely no use



Dr Bush and Prof Terry at the ERUK Shape Network conference



Prof Terry presented on using computer models to predict seizure risk

to you, as an individual, if I can't say with any confidence whether you have the condition or not. So this is one of the important steps that you have to take to go beyond populations to individuals when it comes to diagnosis.

We're also interested in prognosis. We have some interesting pilot data from these sorts of measures, where we can measure the risk of seizures from segments of apparently normal data. These data show that the risk of seizures can change in response to medication, in particular after a few months of taking a medication. If the medicine is working well for you, the BNI risk score appears to drop compared to the original score you had. In cases where the treatment isn't working so well, that doesn't appear to happen. That's something we're really excited about and are looking into at the moment, but it is only very early data.

Will research be looking at epilepsy as a single condition or as a collection of diseases, and will the NHS coding systems create problems?

KB: I wish that the NHS coding system was better. The data are not going to be

as good as I would like them to be. But there are different things that we can do to make sure that we're accurately identifying people with epilepsy. We can use different combinations of hospital codes, GP codes and medication codes. People have done a lot of validation studies in the past, to look at how accurate they are at identifying epilepsy and things like epilepsy turning into a stroke.

I think we will need to do a little bit of validation work ourselves. I want to make sure that we are identifying the right people and that we get as close as we can to identifying what the causes of epilepsy are in those people.

JT: It's interesting to think how some of the mathematical modelling approaches could add value. Traditionally, epilepsy has been defined based on clinical characteristics. But what we are trying to do is attempt to give a diagnosis and risk prediction before clinical presentations.

And, actually, developing that understanding – moving from just epilepsy as a single condition, to understanding all of the mechanistic basis – is going to

be increasingly important in developing more appropriate treatments and using existing ones better. We could identify, for example, who are the right people to give the right treatments to and at what time, as there's increasing evidence that time of day or month can have an impact on the treatment as well.

'Data save lives' – what do you think of that statement?

JT: I think it's quite challenging. I think with a lot of data approaches and modelling approaches, for me it, it depends on the context.

I think back to the definition of mathematical models having equations and assumptions and simplifications. There are a lot of approaches where you take an existing model 'off the shelf', with some algorithm which we may or may not understand. When we repurpose it in the context of epilepsy without a real understanding of how it works or the assumptions that have gone into it, it's very difficult to know whether the outcome of it is appropriate or not. That's why, at the moment, there is a lot of interest in how we regulate artificial intelligence technologies.

So, I think the inappropriate use of data can definitely cost lives, and the opposite, I think, ultimately, will prove to be true, but I think that is a work in progress.

KB: I think, from my perspective, data absolutely do save lives. But, Prof Terry is absolutely right – they have to be the right data, at the right time, and used by the right people, and they do have to be interpreted correctly.

It's not enough to just have the data there. They have to be looked at, and have clinicians and statisticians involved.

I think I can say that during the COVID-19 pandemic, data have absolutely saved lives, and I think the safest approaches can be applied to other condition like epilepsy. It won't be as fast, and not with all the resources we had during the pandemic, but I really do think that data have the potential to change how healthcare is delivered in this country.



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Seizure detection innovations

The RADAR-CNS project has been looking at the effectiveness of using a wearable device to monitor and detect seizures, and gathering opinions from people on whether they want a device like this. The results are definitely something to feel hopeful about

Words by Kami Kountcheva.

Having to keep a health diary of any description, like a food diary or a seizure diary, can be tedious at the best of times. We know it's important, but, even with the best of intentions, it's just hard to remember and keep up with sometimes.

With seizures, which can often affect consciousness and memory, it can be nigh on impossible to keep a truly accurate diary. Some seizures pass in seconds, others happen during sleep – and you may not even know about them. Even the most diligent among us would find it tricky to keep a completely precise diary.

This is one of the aspects of epilepsy where technology has been making really significant progress recently. Seizure tracking devices of all different kinds are being developed, researched and improved to bridge this gap in epilepsy care.

Knowing the exact number of seizures may not sound like much, but it's the foundation on which many other aspects of care can be built. It can mean better seizure control, because doctors will be able to know very quickly if a medicine or device is working or not. It can mean family or carers are alerted and help can

be sent right away if you have a seizure. It can help predict patterns of seizures, and offer a bit of a forecast of when they might occur, which could reduce injuries for many people.

Detecting motor and non-motor seizures

A recent project, called RADAR-CNS, has looked at how effective wearable technology and smartphone devices are in measuring and monitoring depression, multiple sclerosis and epilepsy. While there are wearable devices on the market, many have struggled to detect seizures accurately and have not been able to detect non-motor seizures. This project used the RADAR-Base, which includes two apps and supports seven different wearable devices. The team looked at what kinds of wearable devices people with epilepsy were comfortable with, and how the data collected by these devices could be used to detect seizures.

Dr Elisa Bruno is a member of the research team working on the epilepsy arm of the project. For this research, the team included 243 participants and analysed seven wearable devices. The wearables allowed the researchers to collect data on more than 350 seizures. The team had 160 questionnaire responses on the technology assessment and conducted 21 face-to-face interviews on whether people accepted the technology.

Dr Bruno explained that the project has let the researchers gain an understanding of the usefulness of wearable devices for people with epilepsy. They developed an algorithm with machine learning that could detect the presence of seizures involving a lot of movement, and could also be promising for seizures that don't involve movement.

Importantly, Dr Bruno explained that one of the things the project is working on is developing a device that can monitor some signs of a seizure that might lead to sudden unexpected death in epilepsy (SUDEP). The team developed an algorithm that can detect some of these signs, particularly lack of movement after a seizure. This means the device can pinpoint states after a seizure linked with a higher risk of SUDEP and this can be used in future studies to try to reduce the incidence of SUDEP.

The RADAR-CNS project also looked at whether people would be welcoming of technology like this and found that the epilepsy community – patients and healthcare professionals alike – are keen for technology like this to be developed.

The team has collected a large amount of data and is now looking at analysing this and answering the most important questions with their results.

Wireless, removable and comfortable

Tom Shillito, health improvement and research manager at Epilepsy Action, said the organisation worked alongside the researchers to make sure the research put people with epilepsy at its heart. He said: "The researchers first consulted with people with epilepsy, their loved ones and their healthcare professionals to discover how they felt about wearing devices that could track seizures. This included two Epilepsy Action research volunteers, who were on the patient and public involvement panel and helped to steer the project.

"The researchers found that people with epilepsy would want to wear something that wouldn't stand out as a medical device and could blend in to their normal clothes and daily activity. People with epilepsy thought it was most important to track their heart rate and brain activity, as well as sleep, diet and anxiety levels.

They also wanted specific members of their epilepsy health care team to be responsible for managing the technology.

"The most popular types of technology for recording and detecting seizures were smartphones, and this was agreed by both people with epilepsy, their carers and healthcare professionals. They also found that wearable devices were best if they were wireless, removable and comfortable. The researchers decided to test out a Fitbit-style device, which is worn like a bracelet on the wrist and can send information to a smartphone. The devices tracked lots of different factors, including heart rate and movement. They found that this device could detect 10 out of 11 seizures on average, and very rarely detected a seizure when one wasn't happening."

Game-changing

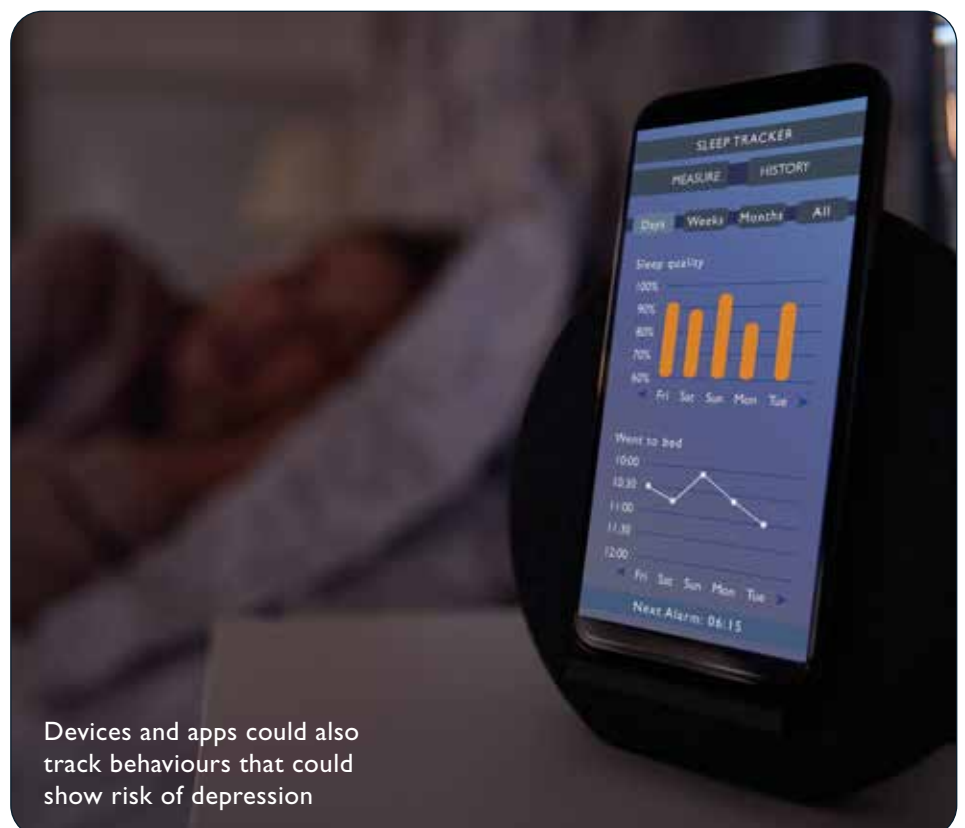
It's worth noting that the RADAR-CNS project also focused on depression, which is one of the mental health conditions that can often affect people with epilepsy, whether or not their seizures are controlled.

The research on depression showed that devices and apps could track behaviours

and behavioural changes in people at risk of having a major depressive episode. These included things like movement, sleep and contacting friends, among other behaviours. The device allows these to be tracked in real time, giving doctors a greater understanding of a person's wellbeing over the time between clinics. With this, people and their doctors can detect changes that indicate a risk of a major depressive episode and they could intervene earlier. The research also found that even people with severe depression were willing to partake in these kinds of studies.

The RADAR-CNS project offers a lot of promise for the future. A device that can detect seizures well would be game-changing for many people who experience seizures and everything that goes along with them. For people also at risk of depression, there is potential to manage this a lot better as well, as a result of this research.

There is more information on the project at radar-cns.org and there is more about seizures (epilepsy.org.uk/info/seizures), mental health (epilepsy.org.uk/living/health) and alarms and monitors (bit.ly/3Hc3J89) on the Epilepsy Action website.



Devices and apps could also track behaviours that could show risk of depression

My journal



Author Marc Palmieri talks candidly about being a parent to a daughter with epilepsy, championing the magnitude of a parent's love and the incredible might of a child's will



Anna

I am 52 years old (yikes!) and I live in Queens, New York City, with my wife Kristen and two daughters, Anna and Nora. These days I'm working with many epilepsy advocacy events, conferences and reader groups since the release of my book, *She Danced With Lightning*, about life with my daughter's epilepsy. I have always liked to do many things. One of my favourite Shakespeare quotes is, "Thus play I in one person, many people." I am a playwright, I love to read, and I have four pet birds, three of which I rescued after they were either lost or injured (rescuing birds is another thing I do). I coach high school-level baseball in summer and I am also an assistant professor at a lovely college called Mercy College here in New York, on the Hudson River. I get to advise the theatre club and teach classes in film, theatre and communications studies. I have done a lot of acting too – about a dozen national television commercials, some soap operas, film, and lots of stage plays. I love scrambling each week from my work to rushing my daughters to their dance classes, sports and schools.

My daughter Anna has been through a lot, but meeting her, you may not know it. She is a varsity soccer player (football to you in the UK, of course!) and runs track for her high school. She dances competitively with a local studio, and is an actress – (she just shot a scene in a horror movie due out in the fall!) She is very social. She loves being with friends, loves to laugh, doesn't love homework, and is very good with little children. They seem to gravitate toward her.

But Anna has been living with epilepsy almost all her life. She was diagnosed with intractable (medicine-resistant) epilepsy, caused by cortical dysplasia (problem with the top layer of the brain) in the left side of her frontal lobe. She mostly had complex partial seizures, now known as focal onset impaired awareness seizures.

The first time Anna had a seizure, she was a tiny baby, and we had no idea what this was. She would be herself – present, aware, happy, alert – and then, suddenly, it would be as if something

snapped inside her. Her eyes would avert, her right arm would stiffen, her breathing would become laboured, and she would sort of start rolling onto her side. Then, after about 30-60 seconds, she'd snap out of it, look at us like we had just appeared out of nowhere, smile, then go back into another seizure.

We rushed her to the hospital as per our doctor's advice, and she had gone into status epilepticus. She had some 40 of these seizures before a large loading dose of phenobarbital stopped the cluster.

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Confusion and terror

When she was diagnosed, it was painful and frightening. For her, life had been little else but comfort, feeding, laughter, discovery and rest. Suddenly, it was wires, noise, the physical brutality of each seizure, separation from her mother as they rolled her away to MRIs, spinal taps, blood tests... When the initial smoke cleared and we restarted life at home, she had to endure medicine delivery, orally, twice a day, which caused her to kick, scream and punch in defiance. So, all I saw was suffering she had not known before that fifth month.



Anna loves dancing, acting, playing football and running



Marc and Anna as a toddler in the hospital

For us, it was a sudden world of confusion and terror. We thought we were living in one kind of story – two people having their first baby, figuring it out, making plans, sharing our new love with our friends and family – but found we were in another, where the unthinkable was looming. After epilepsy revealed itself in Anna, not an hour passed without us worrying, fighting off panic that we would lose her. We were forever changed.

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Beforehand, I had seen one seizure in my life when I was in middle school in the early 80s. I only remembered a girl beside me in class falling, shaking, seeming as if she was being punched by an invisible enemy, unable to fight back. The teacher ran her out of the room. It had been decades, and I hardly ever thought of epilepsy, or had any interest in it at all, until it came into our lives.

Anna's story is unique in some ways. Her epilepsy was bad, then not as bad, then bad again, then almost deadly bad, and then, for now, after an emergency surgery, better than ever. It had always affected her daily life in different ways at different times. For most of her childhood, her seizures happened during sleep, so

epilepsy experience



Anna's epilepsy worsened around her 12th birthday

her waking life could mostly 'look normal'. She went to school, danced, made friends, played sports... The most noticeable difference from the outside from everyone else being that a teaching assistant followed her around school all day, that she couldn't go to sleepovers, and that a parent slept on her floor at home. However, the nightly seizures and her medicines made her very tired. She fought fatigue every day.

Things worsened as her 12th birthday approached. The patterns changed, and the seizures not only came by day as well as night, they came closer and closer together. Within a matter of weeks, she was nearly in a state of permanent seizure, on six medicines, unable to walk straight, see clearly or speak with much sense. Medication had finally entirely failed, and we were left with no choice but a major surgery.

Over the years, we tried as many as seven or eight different medicines, none of which achieved full seizure control. At three years old, one combination of medicines caused a terrible reaction. She was hospitalised for weeks and lost a year of her cognitive development. But in 2018, Anna had brain surgery. This radically changed things and she is now taking a low dose of Trileptal (oxcarbazepine). We don't see much in terms of side effects from this medicine, which does have a good reputation for them being mild. She has been on the same dose since May 2019 and has not had a seizure in as long.

A privilege and a blessing

For me the experience has been, in some ways, like any parent's life who has a child with a particular vulnerability. Any parent worries – any parent at all – but when your child is headed out into the world with a kind of target on her back, with

a condition that can be ruinous and deadly, there is only a relentless fear. So, you respond to that with a commitment to finding answers, and it becomes a second, third or fourth fulltime job. You constantly hope to hear about, read about, stumble into the newest promising treatment, technology, miracle vitamin, diet – whatever. You feel alienated, like only other parents of children with seizure disorders could possibly understand what the lifestyle is. And you're often frustrated. It can feel like nobody talks about epilepsy, or knows much about it (as I hadn't), or wants to. That's one of the reasons I wanted to write about it.

I have certainly become far more aware of the magnitude of a parent's love. I have become more aware of how much good is out there in people, who want to help when they learn of a child's suffering. I have seen how epilepsy can stress and damage a marriage. Anna is sixteen now, and within those years I've changed in different ways at different times. In some ways, the intensity of vigilance has made us all closer as a family. In some ways, not. In other ways, we have come to appreciate the 'smaller' things life offers, realising they aren't small at all, because they are a privilege and a blessing to have.

We can never know that we've seen the last of Anna's epilepsy. She's only 16, has growth spurts ahead, and who knows what's coming. But when we were in the worst points, like all the warrior parents I've been meeting lately, there's a kind of natural, emergency mode that can push just about everything else in life out of the way, until the crisis passes. Over and over again, the A&E visits, the tests, the seizures... a kind of overdrive of stony courage has to come. You just try to remember there will be a tomorrow when the emergency is over, and that life will resume.



Anna and Nora supporting Purple Day

We worried about Nora through this too, and tried to stay conscious of her needs through the best and worst of times. Now that Anna has done so much better for these three plus years, Nora and Anna seem to be getting along like typical teen sisters two years apart: loving and rooting for one another one minute, and then in pitched battle over the bathroom counter space the next. When Anna was young, and Nora old enough to observe, we could see how troubled Nora could become.

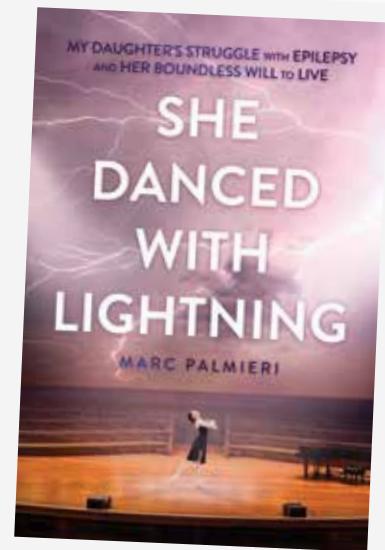
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One time, Nora was with me when I brought Anna to one of her many blood tests, which were sometimes painful to watch, because Anna was frightened of the needle, no matter how many times she'd had it. Nora's stomach began to hurt. Nora had had stomach complaints for a few years – and we had her checked by specialists to no conclusion. At that blood test, we had our conclusion. All of this was hurting Nora, not only emotionally, but physically. Every seizure is an event, as anyone who lives with this knows, and it can hardly be hidden from an alert child. She is a thriving, social, talented kid – but I try to make sure that our necessary focus on Anna, her story and future, does not compromise our engagement with Nora.

Incredible might

I've been a writer for a long time. Primarily, a playwright and screenwriter, but I hadn't yet written about epilepsy until now. For me, there is a story to write about when a change happens to someone. This is a memoir, and the change that came was upon me. What changed me was Anna's courage and her commitment to living a full life in spite of the near-crippling, horrific health condition she was in at that moment, just weeks away from the surgery. Her zest for life even included what I thought was an absolute irresponsible, irrational insistence on performing in her annual dance recital in the worst state she had ever been in, an insistence which I tried to stop.

As I write in the book, I realised that I was a person with the unearned privilege of perfect health, and that I could not possibly ever know, or think to know, what should be enough of a life for a person like Anna, facing such a challenge. I realised I could never truly know what any hour of life is for someone with this in their lives. And that is an important realisation, because it made me commit to encouraging her to do everything and anything she dreamed of with her life, rather than merely survive.



Marc's memoir She Danced With Lightning

So, I thought this was worth writing. It is not a victory lap about a successful surgery. It is most definitely about life with epilepsy, the common mysteries and torments around life with epilepsy, and the incredible might of a child's will.

In doing so many of these wonderful events lately, not only literary events in the book world but events with the many heroic epilepsy advocacy groups that see the book as a chance to spread this awareness, I realise what the awareness we ask for means to me. To me, awareness leads to an interest, which can lead to demystification, a normalising familiarity. That can lead to people more willing to connect with people with epilepsy, and vice versa. Those connections lead to meaningful relationships (so incredibly important to anyone's mental health). They also help spread the word about essential information – someone tells someone else about a new medicine, a team of doctors doing something effective, a new detection device, a support group. Awareness can lead to all of this. When Anna went into her worst spiral in the spring of 2018, we were given the name of a neurosurgeon whose team would ultimately save Anna's life. If we hadn't made our own community aware of Anna's situation, we may never have gotten that name.

For the future, I hope I never see another seizure again. I hope that we all prove as successful as the many cause-related campaigns for awareness (look at the amazing progress made bringing autism, addiction, and mental health challenges into the mainstream conversation, for example). I hope the meds get more effective while getting lighter on side effects. I hope doctors and patients communicate better. I hope people never stop looking for a better answer, and I hope, as we wait for all these things, people with epilepsy live their lives to the fullest, in spite of it.

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 vigabatrin and tiagabine.

Vigabatrin

Vigabatrin was first approved in the UK in 1989 as an add-on treatment of focal seizures whether or not they progress into tonic-clonic seizures. Any side effects were initially well tolerated by people, and effectiveness was impressive. However, around eight years after vigabatrin's introduction, visual field problems started to be noted in around two-fifths (40%) of patients taking the medicine. This was about the same time that its effectiveness was demonstrated in more than half (50%) of children with infantile spasms, many of whom were reported as becoming seizure free after just a few weeks of treatment. This



Professor
Martin
Brodie

was particularly the case in those with underlying tuberous sclerosis, a rare genetic condition that causes mainly non-cancerous (benign) tumours to develop in different parts of the body. Other side effects with vigabatrin, outside of the visual field problems, include tiredness, dizziness, headache and weight gain.

The short-term use of vigabatrin in children with infantile spasms (West syndrome) is still recommended. However, its long-term use in focal seizures for children, young people and adults is now greatly limited to situations where there are no other effective options. This must be an unusual scenario these days, given the wide range of well tolerated epilepsy medicines that are now available. No important medicine interactions have been noted with vigabatrin. Formal visual field monitoring in people taking vigabatrin, however, is recommended and should be performed every 6-12 months.

Tiagabine

Tiagabine works by affecting brain cells' ability to communicate. Tiagabine was licensed in the UK in 1995 as an add-

on treatment for focal seizures. It is available as 5mg, 10mg and 15mg tablets in the UK, with studies suggesting a minimal effective dose of 20-30mg a day. Treatment usually begins in adults with 4-5mg once or twice daily, followed by weekly increases of 4-5mg, as necessary. According to the British National Formulary (BNF), the usual dose range is 15-30mg. In people taking a certain group of epilepsy medicines called enzyme inducers, this can go up to 30-45mg daily in two or three divided doses, although, in my experience, some people have benefited from (and tolerated) amounts of up to 80mg daily. Tiagabine should be taken with food to avoid quick rises in the medicine in the blood.

Side effects with tiagabine include dizziness, agitation, nervousness, tremor, poor concentration and depression. Muscle weakness can occur at high doses. The safety of tiagabine for newborn babies and infants is unknown. Blood levels of tiagabine can fall quickly when the medicine is used in combination with enzyme inducing epilepsy medicines, including carbamazepine, phenobarbital and phenytoin. Tiagabine is a safe treatment for use in older people.

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.

Council of Management 6 December

At a meeting of the Council of Management held at New Anstey House on 6 December, the following decisions were made.

- A revenue budget and business plan for the charity were approved for 2023.
- Council reviewed and renewed the charity's National Advisory Councils for Wales and Northern Ireland.
- It reviewed, updated and renewed its scheme of delegation. This is the record of how the Council delegates authority on some matters to the Chief Executive to make decisions and manage day to day operational issues.
- It reviewed and updated the role description for Council's EDI champion. EDI stands for Equality, Diversity and Inclusion.
- It appointed six people to a new panel set up to advise the charity on matters relating to young people and epilepsy.
- It reviewed the charity's corporate risk register and ensured adequate measures are in place to manage those risks.
- It reappointed Karen Armstrong, Paul Maynard MP and Professor Ray Tallis as Vice Presidents of the Association when their current term of office expires at the date of the AGM in June 2023.

The next meeting of the Council of Management will be on 7 February 2023.



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 iso@epilepsy.org.uk or calling **0113 210 8899**.

Online resources

There are many ways to be part of Epilepsy Action's online epilepsy community. You can find us on HealthUnlocked (healthunlocked.com/epilepsyaction), Discord, (bit.ly/3vHLOkT), Facebook (facebook.com/epilepsyaction), Twitter ([@epilepsyaction](https://twitter.com/epilepsyaction)) 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.

Do you need to talk?



Our FREE UK helpline offers confidential advice to anyone affected by epilepsy.



Call: **0808 800 5050** (Monday-Friday 8:30am to 5pm, Saturday 10am to 4pm)



Email: **helpline@epilepsy.org.uk**



Live chat: **epilepsy.org.uk** (Monday-Friday 10am to 4pm)