



## **Neuro Event Labs: Nelli** **An AI-enabled diagnostic tool for epilepsy**

Sara Oliveira

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Ambassador Paula McGowan OBE – Grace Wood

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The PIF TICK – Emily Mossman

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100 years since the first EEG – Grace Wood

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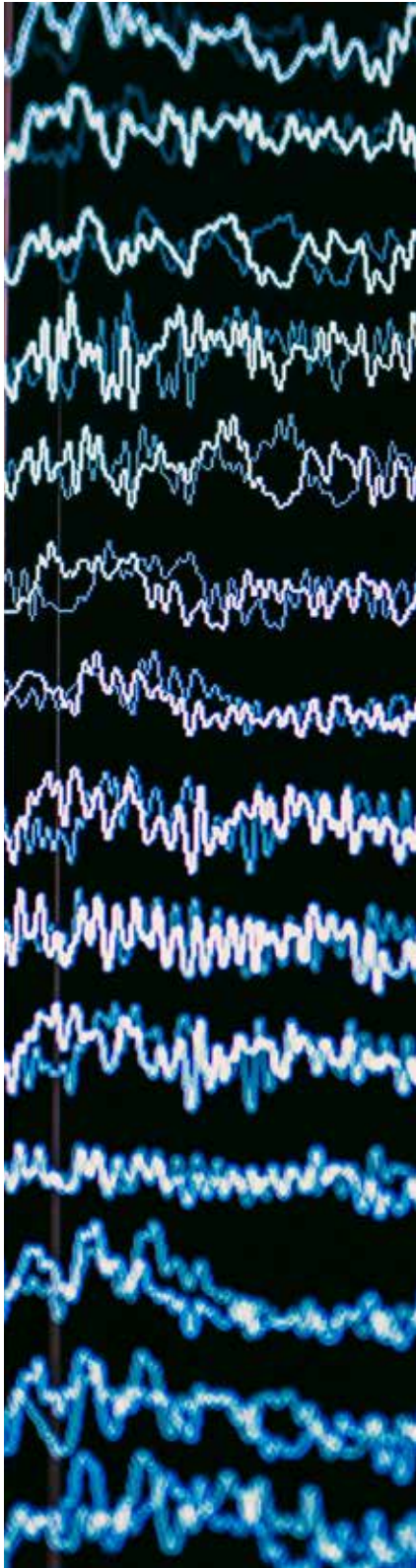
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**W**elcome to the summer 2024 edition of *Epilepsy Professional*. We have some compelling articles for you to help in your clinic day to day.

We all know the challenges of diagnosis in epilepsy and the short comings of the current investigations we have to help come to the correct diagnosis and classification of seizures. This is compounded by the inaccuracy of recording seizures in patients whom we are sure we have the right diagnosis. Sara Oliveira from Neuro Events Labs, describes the development, evaluation and clinical use of Nelli as a diagnostic and monitoring tool in epilepsy. The artificial intelligence system helps to filter and classify events captured with audio and video recordings to improve diagnostic accuracy and help monitor treatment changes.

The consequences of an incorrect diagnosis when it comes to seizures can be catastrophic. The difficulties in diagnosing seizures correctly contributed to the death of Oliver McGowan, a young man with autism and epilepsy. Grace Wood writes about how this led Oliver's mother Paula McGowan OBE to campaign for changes to training and education for healthcare professionals to improve the understanding of autism and epilepsy, leading to the Oliver McGowan Mandatory Training. This aims to help prevent future deaths by



education and training. An inspirational example of forging change out of tragedy.

Even as trained healthcare professionals, it is very hard to be sure the information we find online about healthcare conditions is correct. It is even more difficult for our patients. Having trusted organisations certify sources of online information is one way to help signpost us all to information that can be trusted. Emily Mossman from EP describes the Patient Information Forum (PIF) TICK certification and how it is obtained. This has been achieved by Epilepsy Action since 2021 and gives independent assurance that the information on our website can be trusted by patients and healthcare professionals alike.

Finally, Ann Johnston gives an opinion on balancing the harms when prescribing valproate and the importance of working with patients to help them make the right treatment choices.

I hope you enjoy this edition of *Epilepsy Professional*.

Dr Seán J Slaght  
Consultant neurologist  
Executive medical adviser  
*Epilepsy Professional*



## 6 News

### The latest in epilepsy care

This issue: neurological conditions found to be leading cause of illness worldwide; Welsh study shows impact of Covid and epilepsy; levetiracetam linked to mental health and behavioural issues, and more

## 14 Nelli

### Sara Oliveira

Sara Oliveira, from Nuero Event Labs, explains how Nelli, the digital epilepsy diagnosis tool, which optimises the review time of healthcare professionals, reduces diagnosis-related costs and supports diagnosis in the natural home environment



## 20 Paula McGowan

### Grace Wood

Epilepsy Action's latest ambassador Paula McGowan OBE talks about The Oliver McGowan Mandatory Training and the importance of educating all healthcare professionals about autism, learning disabilities and seizure types

## 30 Highlights

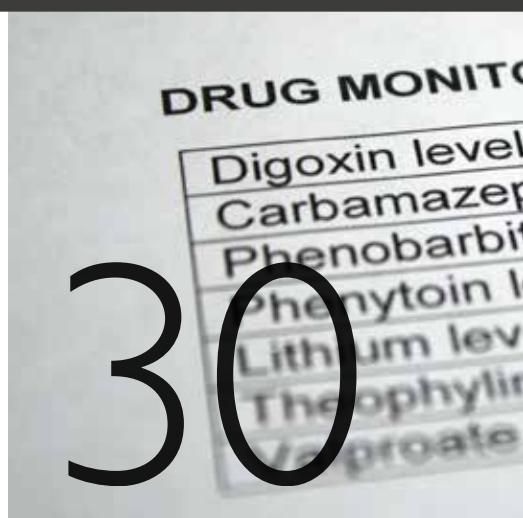
### Markus Reuber

Professor Reuber highlights the key papers from the latest edition of *Seizure*. This issue: a special issue of *Seizure* on the genetics of epilepsy

## 30 Prescribing valproate

### Dr Ann Johnston

Dr Johnston talks about balancing the risks of harm when prescribing sodium valproate, both to the potential child and the person with epilepsy





## 24 The PIFTICK

Emily Mossman

Epilepsy Action's health information and research officer Emily Mossman explains what the PIFTICK is and why it means you can safely guide patients to the information on our website



The two smiling faces on our front page this issue are mother and daughter Taina and Martta. They used the Nelli diagnosis tool (on page 14) to help Martta, who was discovered to be having nocturnal seizures. Taina said using Nelli was “much more comfortable” than an EEG in hospital. Martta was able to go about her normal life at home while a clinician and an AI-algorithm diagnosed her.

Of course, for many clinicians and people with epilepsy, EEG remains a core diagnosis tool. On page 12 we mark the technology's 100th anniversary by looking back at the story of its first use on a human patient and the clinician behind that discovery: Hans Berger.

As Paula McGowan OBE points out on page 20, tools don't have to be technological. Reflecting on the death of her son Oliver, she discusses the importance of training. The Oliver McGowan Mandatory Training on Learning Disability and Autism educates healthcare professionals in the behavioural symptoms of many of the comorbidities associated with epilepsy.

We hope that Epilepsy Action's website can be another invaluable tool in your kit. This issue we are celebrating our PIFTICK accreditation, which means the information on our site has been independently recognised as trustworthy and evidence-based. We explain what this means for you and your patients on page 24.

So, whatever tool you need for your clinic this summer, we hope this issue of EP can be of assistance.

Grace Wood

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## Half of neurology patients waiting more than 18 weeks

More than half of neurology and neurosurgery patients are waiting longer than 18 weeks to start treatment, according to the latest waiting time figures from the NHS.

Data from NHS England showed 54% of patients were waiting more than 18 weeks for neurology treatment. While there are fewer patients waiting for neurosurgical services, 55% had been waiting for more than 18 weeks.

Across the NHS, around 6.3 million patients are waiting to start treatments. In total, 58% of patients are waiting longer than 18 weeks.

The referral to treatment data is reported on a monthly basis. The latest data comes from February 2024.



The NHS Constitution says “patients have the right to start non-emergency consultant-led treatment within 18 weeks of referral”, with a target to complete 92% of pathways within that period.

Meanwhile, a recent paper published in *Seizure* found that access to neurosurgical procedures was

delayed, particularly if a person’s initial visit was not at a tertiary epilepsy centre.

It added that “despite NICE guidance, visits to neurosurgery clinics remain uncommon and are seldom followed by surgical interventions”.

The paper studied 84,093 people with epilepsy from the period between January 2013 and December 2015. It concluded that “although clinically recommended for suitable individuals, neurosurgical procedures remain uncommon even after consultation at a tertiary epilepsy centre”.

The research, which was supported by LivaNova, also found significant geographical variation in access to neurosurgery.

## Neurological conditions leading cause of illness – study

The number of people living with, and dying from, neurological conditions has increased globally by 18% in the last 30 years, according to research published in *The Lancet Neurology*.

The research included conditions such as epilepsy, stroke, dementia, migraines and nervous system cancers.

According to the study, in 2021 3.4 billion people had a neurological condition – the leading cause of illness worldwide.

The paper, titled: Global, regional, and national burden of disorders affecting the nervous system, 1990 –2021: a systematic analysis for the Global Burden of Disease Study 2021, was published on March 14, 2024.

The authors concluded that

effective prevention, treatment and rehabilitation strategies for neurological disorders were needed.

The study’s lead author, Dr Jaimie Steinmetz, from the Institute for Health Metrics and Evaluation (a global health research organisation based at the University of Washington in Seattle), told PA News: “We hope that our findings can help policymakers more comprehensively understand the impact of neurological conditions on both adults and children to inform more targeted interventions in individual countries, as well as guide ongoing awareness and advocacy efforts around the world.”

According to The Neurological Alliance, one in six people in the UK

lives with a neurological condition.

Epilepsy Action’s deputy chief executive Rebekah Smith said: “These findings highlight the urgent need for epilepsy and other neurological conditions to be prioritised by government and the department of health and social care.

“All too often we have seen that epilepsy has been left behind, as seen when neither epilepsy, nor other neurological conditions, were included in the government’s Major Conditions Strategy.

“With an election due to be called this year we will be urging all parties to ensure that epilepsy health services, and the impact the condition has, are given the urgent attention they need.”

# Neurology crisis costing UK £96bn – Economist report

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

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

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

The study considered 10 neurological conditions: Alzheimer's disease, brain cancer, epilepsy, migraines, MS, Parkinson's disease, spinal cord injury, type 1 SMA, stroke and traumatic brain injury.

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

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

Epilepsy affects 937 per 100,000 people in the UK. The report focused on idiopathic generalised epilepsy – which has a prevalence of 358 per 100,000. It said this cost the economy 0.07% of GDP in 2019 or £1.7 billion, more than half of which is due to lost productivity.

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

"Delays and gaps in diagnosis and treatment can have huge repercussions on patient safety, from unplanned hospital admissions to



**Epilepsy Action's Alison Fuller and Rebekah Smith speak with Lord Markham at the House of Commons**

breakthrough seizures, and even an increased risk of sudden unexpected death."

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

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

The study said neurology and neurosurgery services were performing worse than other health services – even amid a struggling NHS.

The report's authors said there were three challenges that stop the UK healthcare system from improving neurology services. These were a lack

of overarching strategy, a lack of human resources and a lack of access.

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

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

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

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

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

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



## Welsh study shows impact of Covid and epilepsy

People with epilepsy had a higher risk of being hospitalised with Covid and of dying from Covid, according to new research from Swansea University and the University of Edinburgh.

The study found that people with epilepsy had a 60% higher rate of hospital admission with Covid and 33% higher rate of death.

The research was supported by Epilepsy Action and funded by Health and Care Research Wales.

It focused on the first 15 months of the pandemic, from 1 March 2020 to 30 June 2021.

It followed 27,000 people with epilepsy in Wales. There were 933 admissions to hospital for Covid and 158 deaths. Epilepsy affects around 30,000 people in Wales.

The study had a control group of 135,000 people who matched on

other key criteria – sex, age, other health conditions and socioeconomic status – but who did not have epilepsy.

Researchers said this allowed them to isolate epilepsy as a factor and see some of the effects of Covid on people living with epilepsy in Wales in the early stages of the pandemic.

The research was based on anonymised health data for the Welsh population, which is collected and stored at Swansea University.

The researchers found there were fewer emergency department attendances, hospital admissions and outpatient appointments for people with epilepsy. It also said there did not seem to be an increase in status epilepticus during the pandemic.

Wales manager at Epilepsy Action Cymru, Jan Paterson, was one of the authors of the study. She said: “We were very pleased to work with the

researchers from Swansea University on this important report.

“With the increasing pressure on post-pandemic health services and workforce, it is important to ensure that sufficient resources are in place to deal with the effects and implications of these findings.”

The research was led by consultant neurologist and honorary clinical associate professor at Swansea University Medical School, Dr Owen Pickrell. He said: “The Covid-19 pandemic had significant effects on healthcare and it is important to try to understand its full implications for people living with long-term conditions such as epilepsy.

“People with epilepsy were at higher risk of Covid hospitalisations and deaths, but it is not clear exactly why. Further research is needed in this area.”

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## Covid no more likely than flu to lead to epilepsy

Covid-19 patients are no more likely to need epilepsy care in future than those who have flu, according to a study from Yale University.

The study compared patients who were hospitalised with Covid-19 to patients who were admitted with influenza, focusing on six neurological diagnoses: epilepsy, migraine, stroke, neuropathy, movement disorders and dementia.

It was published in the March 20, 2024, online issue of *Neurology*, the medical journal of the American Academy of Neurology.

It found Covid-19 patients was less

likely to need care for all the listed neurological conditions in future when compared to flu patients.

It added that Covid-19 infection was also associated with a lower risk of a neurological diagnosis in the year after infection.

The results showed a diagnosis rate of 2.79% in the Covid-19 group and 4.91% in the flu group.

The study looked at 77,272 people with Covid-19 and 77,272 people with flu. The data came from TriNetX, a global health research network.

The data from the Covid group followed the period from April 1, 2020,

until November 15, 2021, and in the flu group the period from 2016 to 2019.

About 57% of the patients were female and about 42% were white.

Brian C. Callaghan, chair of the American Academy of Neurology's Health Services Research Subcommittee, said: “While the results were not what we expected to find, they are reassuring in that we found being hospitalised with Covid did not lead to more care for common neurological conditions when compared to being hospitalised with influenza.”



## Fix medicine supply chain or risk lives, warn charities

Charities and pharmacists are calling for a review of the medicine supply chain as shortages continue to put people's health at risk.

Epilepsy Action, Epilepsy Society, SUDEP Action and Parkinson's UK joined with the Association of Independent Multiple Pharmacies to warn the government that unless there is greater openness with drug manufacturers, medicine shortages will continue to cause harm to patients.

A survey from the charities found 70% of respondents had difficulties getting hold of medication in the past year. It also found 22% had experienced problems in the last month.

More than half (55%) visited multiple pharmacies before getting their medication, and two-thirds were given a fraction of their prescription.

The Association of Independent Multiple Pharmacies added that community pharmacists were spending two hours every day trying to track down medications for patients.

The charities and pharmacists are calling for an urgent meeting with the UK health secretary, Victoria Atkins.

A Department of Health and Social Care spokesperson said: "We have taken swift action with NHS England and other stakeholders to improve the supply of epilepsy medications and access to some has already improved while we expect supplies of others to improve in the coming months. We have issued guidance to health professionals on how to support patients while supply is disrupted."

## Levetiracetam linked to mental health and behavioural issues

A study of patients taking levetiracetam for epilepsy found that almost 8% experienced mental health or behavioural issues connected to the anti-seizure medication (ASM).

The research, from Chongqing Medical University in China and published in *Seizure*, found the most common psychiatric symptoms were irritability (21 manifestations), hallucinations (19) and aggressive behaviour (14).

One patient attempted suicide three times during the two years that she was taking levetiracetam. These attempts ceased after switching to a different drug.

Levetiracetam is often sold in the UK under the brand name Keppra.

The study took place over five years, from 2017 to 2021, and followed 1,412 patients with epilepsy who were taking levetiracetam for more than one month.

Most patients said their psychiatric symptoms began between one to three months after starting to take levetiracetam. Most were on a dosage of 1-2g a day.

The researchers recommended that "clinicians monitor patient psychiatric symptoms in the four weeks after levetiracetam treatment initiation".

Suicide and self-injury were the most serious of the observed psychiatric symptoms. Nine patients recorded these symptoms and three attempted suicide.

The paper added that clinicians should also "be alert for symptoms of suicidal behaviour" and that "if these symptoms are observed, levetiracetam



should be discontinued".

It concluded that the severe psychiatric symptoms caused by levetiracetam require special attention.

The research was carried out at the Department of Neurology, the First Affiliated Hospital of Chongqing Medical University, Chongqing Key Laboratory of Neurology in China.

The paper, titled 'Levetiracetam induces severe psychiatric symptoms in people with epilepsy', was authored by Kaiyan Tao, Hongnian Chen, Yuanyuan Chen, Yixue Gu and Xuefeng Wang.

Patients were excluded from the study if they had comorbidities with other diseases that could cause mental or behavioural abnormalities; psychiatric symptoms before taking levetiracetam; psychiatric symptoms after epilepsy surgery or from nondrug causes; did not experience relief of symptoms after medicine reduction or withdrawal, or who irregularly took their medicine.

The British National Formulary – the UK's pharmaceutical reference guide – lists anxiety, altered mood, abnormal behaviour and depression among the common side effects of levetiracetam. It stated that psychotic disorders and suicidal behaviours are uncommon.

# UCL team develop mental health treatment for children with epilepsy

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

The study was published in *The Lancet* on March 7.

The Mental Health Intervention for Children with Epilepsy (MICE) is based on recommended treatments for common mental health difficulties such as anxiety and depression, but was modified to help children who have more than one problem.

The study found that children who went through the MICE treatment had fewer mental health difficulties than those who had the usual treatment.

It was delivered over the phone or via video call so that people did not have to travel to hospital and miss time from school or work. It was also integrated into epilepsy services – meaning it could be delivered by non-mental-health specialists.

Patients were given an initial assessment followed by weekly calls with a clinician.

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

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

"The treatment can be delivered



from within epilepsy services to join up care. It doesn't need to be delivered by specialist mental health clinicians such as psychologists.

"Integrating the care can help children with epilepsy and their families more effectively and efficiently. We were particularly pleased that benefits were sustained when treatment ended."

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

Co-chief investigator, professor Roz Shafran, said: "These groundbreaking findings not only promise brighter futures for children with epilepsy but also pave the way for a revolutionary shift in mental healthcare practices.

"The collaborative efforts of scientists, patients and healthcare professionals have brought forth a new era of treatment of mental health challenges associated with epilepsy, offering a beacon of hope for families in the face of mental health challenges associated with epilepsy."

Concluding the report the authors suggested that the treatment should be rolled out across epilepsy centres.

It said: "The strong evidence from this trial suggests that such a model should be fully embedded in epilepsy services and serves as a model for other chronic health conditions in young people.

"The model is highly consistent with global priorities and action plans. Future research should consider the most effective methods of implementation of this integrated model of care, in both high-resource and low-resource settings."

## People with epilepsy more likely to develop Parkinson's

People with epilepsy are twice as likely to develop Parkinson's disease than others, according to a study from South Korea.

According to the research, 21 in 10,000 people with epilepsy will develop Parkinson's. This figure was 11 in 10,000 for people without epilepsy.

The researchers from Jeonbuk National University Medical School and Hospital studied 10,510 patients from across South Korea.

There were 5,255 patients with epilepsy. According to the study, the

epilepsy group had a 2.19 times higher risk of developing Parkinson's disease than the control group.

The research was published in *Journal of the Neurological Sciences* on the 24 January, 2024.

In the paper, the researchers said: "This study indicates an increased risk of Parkinson's disease in patients with epilepsy. However, further research is needed to prove an exact causal relationship between these two brain disorders."

The study followed up with

patients later on and found that 85 of the 5,255 with epilepsy went on to develop Parkinson's. Meanwhile, 57 of the patients without epilepsy were diagnosed with Parkinson's.

In March 2022, a study of GP practices in East London found epilepsy was a risk factor for developing Parkinson's disease. That study found people with epilepsy were 2.5 times more likely to be diagnosed with Parkinson's than the general population. It was published in *JAMA Neurology*.

## Spring Budget: epilepsy research funding announced

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

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

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

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

Epilepsy Action deputy chief executive Rebekah Smith said: "It's really encouraging to see additional funding for epilepsy research being included in this week's budget announcement by the chancellor of the exchequer."

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

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

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

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

He added that the UK's ability to manufacture new medicines would be boosted by plans for a £650 million AstraZeneca investment to build a



vaccine manufacturing hub in Liverpool and expand the company's footprint in Cambridge.

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

A government announcement on March 7 said the £45 million would be used to "launch the careers of the next generation of medical researchers".

It added the grants would be delivered through the Medical Research Charities Early-Career



## A hundred years after the first human EEG: who was Hans Berger?

The first use of electroencephalography (EEG) on a human patient was recorded 100 years ago this year by German psychiatrist Hans Berger.

Nearly 50 years earlier, in 1875, Richard Caton had undertaken neurophysiologic recordings of animals, but it wasn't until 1924 that Berger pioneered the use of EEG in humans [Louis et al, 2016].

The first patient to have an EEG was undergoing surgery for a brain tumour. Berger placed electrodes under the patients' periosteums – only later developing a non-invasive method. The research was reported five years later in a paper titled 'Über das Elektrenkephalogramm des Menschen' in 1929 [Fine, 2014].

But Berger's journey to EEG was inspired by something altogether less scientific. While serving a year in the German military, Berger was thrown off his horse. Later that day he received a telegram from his father stating that his sister had a feeling Berger had been in danger. Believing that they had telepathically shared some information, Berger devoted himself to the study of human brain waves [Millett, 2001].

It was Berger who named the EEG and invented the electroencephalograph [Millet, 2001].

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**In 1938, Berger was forced to retire by the Nazi part**

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He stated that EEG waves compromised alpha and beta waves, with alpha waves slowing in the presence of "tumours, encephalitis, intracranial hemorrhages, brain tumours, abscesses, and cerebral contusions". Berger also reported spike and slow complex waves during epileptic seizures [Fine, 2014].

Just 14 years after that first human EEG, in 1938, Berger was forced to retire by the Nazi party. His laboratory was taken apart and three years later he died by suicide [Fine, 2014].

An obituary in *The Lancet* in 1941 stated: "Hans Berger was not an extraordinary man, nor was he an outstanding intellectual, but using all his talents fully in the course he had set for himself he made rare advances in knowledge and gained an honoured place in medicine."

### Further reading

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## Drugwatch updates

### Tegretol

27 March: Epilepsy Action has heard of further reports of people struggling to get supply of Tegretol. We asked Novartis, the manufacturer, to provide a further update.

Novartis told us that all strengths of Tegretol standard and prolonged release is in stock and wholesalers are receiving regular weekly supplies.

### Zonegran in Northern Ireland

21 March: Advanz Pharma, the manufacturers of Zonegran, has told



us about further supply problems affecting all forms of Zonegran in Northern Ireland. Supplies are being sent to wholesalers next week and should be available for pharmacies to order soon after.

### Epistatus

4 March: Epilepsy Action is aware that Epistatus (Midazolam) 2.5mg/0.25ml and 5mg/0.5ml oromucosal solution

pre-filled oral syringes made by Veriton Pharma are currently out of stock with no confirmed return date.

The pharmacist may offer a different manufacturer's version until the Epistatus version is back in stock.

### Epilim sodium valproate syrup

1 March: The Department of Health and Social Care has advised that Epilim 200mg/5ml syrup is out of stock from mid-March until w/c April 22, 2024.

Epilim 200mg/5ml sugar free remains available and can support increased demand.

Drugwatch is updated regularly at: [epilepsy.org.uk/drugwatch](https://epilepsy.org.uk/drugwatch)

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



# Nelli

An artificial intelligence-enabled diagnostic tool for epilepsy

Sara Oliveira, from Neuro Event Labs, explains how Nelli: the digital epilepsy diagnosis tool that optimises the review time of healthcare professionals, reduces diagnosis-related costs and supports diagnosis in the natural home environment





According to a report published by the World Economic Forum in 2023, AI is poised to make healthcare more accurate, accessible and sustainable. The NHS Digital Transformation and Long Term Workforce plans highlight that digital solutions are at the forefront of ways to address the challenges that centre around shortages of healthcare professionals, capacity constraints and rising healthcare costs [NHS Long Term Plan].

Epilepsy diagnosis and treatment is often overlooked, under-resourced and a challenging area of healthcare. More than 60% of patients are unable to accurately record their seizures, leading to more than 85% of undocumented seizures at night time [Oto, 2017]. Limited availability of VEEG (video-electroencephalogram) is another challenge faced by healthcare systems [Oto, 2017].

Epilepsy, when chronic and uncontrolled, affects the daily quality of life for both patients and their families [National Clinical Guideline Centre, 2012; Kwan et al, 2011]. The uncertainty of seizure reporting leads to delays finding the appropriate treatment options. Around 30% of epilepsy patients have reoccurring seizures and become resistant to anti-seizure medications, which can increase the prevalence of SUDEP (Sudden Unexpected Death in Epilepsy). Therefore, an early diagnosis

followed by identifying an effective treatment is of critical importance [National Clinical Guideline Centre, 2012; Kwan et al, 2011].

Electroencephalography (EEG) is the current standard of care for diagnosis. VEEG is widely used to record seizures and quantify these events [Shih et al, 2018]. However, the variability of seizures and their sometimes sporadic frequency makes it hard to predict how likely they are to be recorded during a fixed, limited-time period. VEEG has been shown to be inconclusive in more than 23% cases, even with a recording longer than seven days [Adenan et al, 2022].

For the last decade, tools have been developed that aim to improve epilepsy care [Hixson et al, 2020]. The emergence of AI brings with it the possibility to combine digital tools with trained professionals' experience to enhance care for a range of chronic diseases [Singareddy et al, 2023].

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### **The uncertainty of seizure reporting leads to delays finding the appropriate treatment option**

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A team of experts specialising in software engineering and experienced HCP's in Tampere, Finland, have combined their skill sets to attempt to reduce the main challenges faced when diagnosing people with epilepsy. In 2015, they formed Neuro Event Labs. The technology they developed, known as Nelli, is an AI-enabled seizure monitoring system.

Jukka Peltola, professor of neurology, Tampere University Hospital, Finland, and medical director at Neuro Event Labs says: "Providing quality care for people with epilepsy is my passion. Despite treatment options improving, the tools used for diagnosing epilepsy have not kept pace with the needs of patients. Despite their best efforts, people with epilepsy and their carers are often unable to describe seizures accurately, diaries are inconclusive and patient videos are just a snapshot that often don't capture critical moments, such as the start of the seizure. VEEG can be a useful tool but it is time-limited, resource heavy and often poorly tolerated by patients who are subjected to artificial environments.

"Over the last few years I have been privileged to work alongside a dedicated team of software engineers, most of whom trained and worked for some of the world's leading tech companies, such as Nokia and Microsoft, they have truly understood the challenges clinicians face and been

focussed on developing a solution to the diagnostic challenges.

“Working with Nelli has been a journey of discovery for me, despite many years of clinical practice. Nelli has meant I have had to relearn what’s really happening to my patients. Nelli is an important tool that has the potential to provide objective, quality data that is accessible to a wider range of people who can be monitored at night and during the daytime with minimal change to their normal daily routines. Nelli has become an integral part of mine and my colleagues practice when seeking an initial diagnosis, as well as optimising existing treatments. I am thrilled to see this technology adopted across Europe and globally, as more and more patients have access to this much-needed innovation.”

Nelli is designed to minimise the impact on the lives of people with epilepsy by performing the diagnosis

in the comfort of the patient’s home environment, while significantly improving the efficiency of HCP when compared to the standard of care [NHS Long Term Plan; Peltola et al, 2023].

## Overview of the Nelli service

The process is simple, following patient enrolment using an online browser portal, the camera system is sent and the recording starts. Videos of patient movements are analysed in the cloud by the algorithm. Following an agreed period of recording, a group of specialised physiologists analyse the data and provide a classification of seizures according to the International League Against Epilepsy (ILAE) 2017 classification [Fisher et al, 2017]. The clinician then accesses a dashboard and a report, including videos and sound of the events to determine the most suitable treatment regime.

Nelli has supported the diagnosis

of more than 5,000 people with epilepsy globally and has been used in more than 60 hospitals across 10 different countries [Basnyat et al, 2022]. Martta is one of those patients. She received her epilepsy diagnosis at the age of 4 and by the age of 21 she’s had multiple VEEG. In order to have a longer overview of her condition, her clinician requested a Nelli evaluation at home.

## Martta and Taina

Martta’s mother, Taina, considers Nelli “a much more versatile method”. Martta says: “Compared to a hospital, [Nelli] is a much more comfortable way.”

Martta believes Nelli changed her life. She says: “With the help of Nelli, we discovered a new drug that has decreased my nocturnal seizures.”

This is also highlighted by her mother: “Without Nelli, we might not know about it [nocturnal seizures]”.



Taina and Martta



Nelli is a clinically valid alternative to VEEG for detecting convulsive and other seizures with a motor component, which means even seizures that have a minimal movement, from a simple eye opening to a major seizure are captured [Basnyat et al, 2022]. There have been a total of 12 published clinical studies that included more than 850 patients.

The technology allows HCPs to develop a better understanding of the disease and therefore choose the most effective treatment approach, but also gives a better perspective to the patient and caregivers [Ojanen et al, 2022] .

Nelli enables fast and safe clinical decision making. Being a clinically valid alternative tool for recording of events, it allows for differential diagnosis, quantification of events and changes in diagnosis. Furthermore, with its recording length, it allows

HCP to access, change and restart treatment following accurate objective data [Basnyat et al, 2022].

Some of the main use cases for Nelli are to screen and prioritise patients for in-patient video-EEG, help with differential diagnosis, classification, quantification of seizure types, complex case analysis and assess treatment effect. It is an addition to the seizure diaries presented by the patients, which are very inaccurate most of the time [Basnyat et al, 2022] .

Due to the challenges faced by the NHS, and the potential positive impact for people with epilepsy, HCP and providers, the technology was selected by the NHS Transformation Directive, part of NHS England, to receive funding for a real-world evaluation.

The evaluation was run by Health Innovation Oxford and Thames Valley, York Health Economic Consortium (YHEC) provided a health economic

model that can be tailored to each ICS (Integrated Care System) in England. Leading HCPs from the University of Oxford NHS Trust and Royal Wolverhampton NHS Trust offered the technology to people who potentially had epilepsy. A focus group was also carried out for people with epilepsy and carers by Epilepsy Action [NHS Long Term Plan; Hayden et al, 2023]. As an overview, the evaluation results showed cost savings and a reduction in HCP time, while keeping patients out of hospital and reducing the need for VEEG [Hayden et al, 2023].

Ashley Aitken, senior programme manager at Health Innovation Oxford and Thames Valley, says: "As an NHS professional who is focussed on identifying appropriate innovative technology that will positively impact the healthcare system, I have been thrilled to be part of Nelli's journey





and I am very excited about the impact Nelli can have on some of the biggest challenges faced by the NHS. This is an exciting and much-needed game-changing development that has the potential to positively impact the whole healthcare system, healthcare professionals and, critically, people with epilepsy.”

The focus group organised by Tom Shillito, health improvement and research manager for Epilepsy Action, included people with epilepsy and their carers. Tom shared his insights into the findings:

“There is a neurology workforce crisis. The number of epilepsy specialists is low across the country, and especially low in the areas with the highest need – those areas with the most people with epilepsy. This has serious implications for waiting times for appointments and investigations, and the length of time it takes to receive a diagnosis and begin treatment. This was reflected in the experiences shared in the focus groups, with both people with epilepsy and carers highlighting the very long waits they faced for investigations and diagnosis. Focus group attendees felt at-home options for investigations would reduce the wait for an appointment, allow for faster diagnosis and for patients to receive treatment more quickly. This could lead to a patient becoming seizure free months or years earlier than they otherwise would have.

“Focus group attendees also reported unhappiness with typical video telemetry experiences. Video telemetry in hospital requires the person to be an inpatient for many days, removing them from their normal lives, necessitating time off work and putting strain on their personal relationships. Video monitoring at home would allow them to stay in their own environment

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## **The number of epilepsy specialists is low across the country, and especially low in the areas with the highest need**

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where they are most comfortable, and live their normal life while the investigation is happening. Additionally, many people with epilepsy have to do many rounds of video monitoring in hospital as it is only effective if a seizure happens to occur while they are an inpatient. Video monitoring at home can take place over a much longer period so it is more likely to capture a seizure. Focus group attendees felt this would be an improvement both in the likely success of the investigation and also the quality of life of the patient.”

Rohit Shankar, professor of neuropsychiatry at University of Plymouth Medical School and director of Cornwall Intellectual Disability Equitable Research unit, has published work he and his team produced following a clinical study designed to assess the impact of Nelli on the intellectually disabled patient population. In this study, Nelli recorded 707 seizures, 247 of which were not recognised by carers and 165 carer-reported events, which carers deemed to be seizures but were shown not to be epileptic in nature [Lennard et al, 2023].

Professor Shankar says: “Mitigating SUDEP and epilepsy-related harm in people with intellectual disabilities is a priority. However, this could be challenging given the nebulous and ambivalent nature of information and descriptions provided of possible

seizures. Nelli adds an extra tool in the epilepsy clinician's toolkit by improving the quality of evidence and helping make clinical decisions on epilepsy better with patient stakeholders."

Additionally, Phil Tittensor, a consultant nurse for the epilepsies at Royal Wolverhampton NHS Trust, chairperson for the Epilepsy Nurses Association (ESNA), also shares his view of the technology, based on using it to support the diagnosis of the patients under his care over the last couple of years.

"Seizures from sleep can be particularly dangerous, especially if the patient has no bed partner, where the risk of SUDEP is greatly increased. Often patients find it difficult to

tolerate an ambulatory EEG, which leaves clinicians needing to use seizure diaries to base their next treatment decision on. These can be notoriously inaccurate, and Nelli is a huge advance in terms of providing certainty about the frequency of the episodes and clarity around the diagnosis."

Globally, and in the UK, there are ongoing clinical publications being worked on, concurrently HCPs are also working to implement Nelli into their care pathways as part of standard clinical use across the NHS.

Nelli has been proven to save costs (£432 per patient based on YHEC data), improve HCP efficiency and is positively received by people with epilepsy [Hayden et al, 2023].

Nelli meets the UK regulatory

requirements for a Class I medical device and is DTAC (Digital Technology Assessment Criteria) compliant and so can now be offered to people with epilepsy in the UK. To date, five leading NHS university trusts have used Nelli, with more planning to start throughout 2024.

To learn more email: [contact@neuroeventlabs.com](mailto:contact@neuroeventlabs.com) or go to: [www.neuroeventlabs.com](http://www.neuroeventlabs.com)

### Sara Oliveira

**Clinical education specialist at Neuro Event Labs, formerly senior clinical physiologist in neurophysiology at King's College London NHS Trust and Karolinska University Hospital, Sweden**

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# Paula McGowan

The campaigner joins Epilepsy Action as ambassador

The Oliver McGowan Mandatory Training was introduced in 2022 to educate healthcare professionals about learning disabilities and autism. Oliver's mother Paula McGowan OBE became an ambassador for Epilepsy Action earlier this year – she explains why the training matters





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

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

According to a 2022 metanalysis, about 10% of autistic people have epilepsy worldwide [Liu et al, 2022]. It can be difficult to diagnose autism in PWE as it can present differently and change based on reactions to seizures [Holmes et al, 2021]. This is why training is key.

In April 2022, Oliver's Campaign led to learning disability and autism training becoming law. The Health and Care Act 2022 introduced a statutory requirement that regulated service providers must ensure their staff receive learning disability and autism training appropriate to their role [Health Education England, 2023]. The Oliver McGowan Mandatory Training has been designed, evaluated and is delivered alongside learning disabled and autistic people to meet this law.

The standardised training is the government's preferred and recommended training for health and social care staff. It is recognised by national advisory bodies.

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**That's how Oliver died – as a result of what was done to him, which was giving him anti-psychotics, when in actual fact he was just having a seizure**

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

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

just having a seizure. For him, that had devastating consequences."

Over the course of a year Oliver was administered antidepressants and anti-psychotics because of a misunderstanding of his seizures and behaviours. The drugs caused changes to Oliver's mood and increased his seizures. Paula said he would hallucinate, have up to 30 seizures a day, had problems urinating, extreme high blood pressure and sweating, all of which may have been linked to the medication. During this time, Oliver was moved to various hospitals. He was very frightened and told Paula





he was scared of how staff were making him feel. In October 2016, Oliver was diagnosed with Neuroleptic Malignant Syndrome, a serious side effect of antipsychotic medications. He died a month later on November 11.

“Oliver’s epilepsy was his biggest condition,” says Paula. “He had meningitis as a newborn baby, which caused an infarction, which in turn led to focal seizures. So, as a newborn he

had seizures during meningitis and then we were told it was febrile convulsions, but I think he must have been about 13 when I realized febrile convulsions don’t last more than three hours like his did.

“His EEGs showed issues, but they never showed the seizure itself – even when he was dying. When he was dying it was obvious he was having tonic-clonic seizures, which he rarely had. He was jerking off the bed and

they were treating him for them and it never showed on the EEG.”

Oliver normally remained fully conscious throughout his seizures. He could also pre-empt when something was happening, which caused him anxiety.

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

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

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

Paula and the family believe that, rather than assigning blame for

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**One of Oliver’s doctors said he had never come across any patient who had so much insight into his own epilepsy and autism**

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## There are lots of clinicians who are passionate about their patients

Oliver's death to clinicians or organisations, the answer is training and communication.

Paula adds: "I have a lot of my family members who are clinicians – one of whom is an epilepsy specialist, actually he became an epilepsy nurse as a consequence of Oliver. I know there are loads of clinicians who are passionate about their patients and want to get things right.

"It's about working together collaboratively and listening. If we are in battles we will never ever get anything done."

The Oliver McGowan Mandatory Training has been backed by leaders across the UK, and now also in Ireland, Jersey and Australia. Amanda Pritchard, the CEO of the NHS, is a supporter.

Paula is also an academic fellow with Plymouth University, and a fellow of Cornwall Intellectual Disability Equitable Research (CIDER), headed by Professor Rohit Shankar.

In the future, Paula would like to see more health and care staff educated better about epilepsy, and the different types of seizures.

She says: "I would like to see staff, especially those who don't specialise in epilepsy, to really understand that not all seizures are tonic-clonic. There's so little understanding around seizures, which is actually a patient safety issue. There's a lot to be done."

**If you would like to undertake The Oliver McGowan Mandatory Training, or find out more about Oliver's Campaign go to: [www.olivermcgowan.org](http://www.olivermcgowan.org)**



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Trusted  
Information  
Creator

# The PIFTICK

Why you can trust Epilepsy Action's online resources

Epilepsy Action's health information and research officer Emily Mossman explains what the PIFTICK is and why it means you can safely guide patients to the information on our website





In a world where the internet is overcrowded and littered with misinformation, how do you know where to go for reliable and up-to-date health information? The answer comes in the form of a simple green tick that represents reassurance and trust: the PIF TICK.

Epilepsy Action achieved this certification from the Patient Information Forum (PIF) in 2021, just one year after the scheme was established. And, in April 2024, our information was accredited for another year. This means our information is evidence-based, understandable, jargon-free and up-to-date. By undergoing PIF's annual review process, we know we are providing high-quality information to people with epilepsy.

A PIF report found 58% of healthcare professionals had difficulty sourcing reliable information to share with patients. But you can be confident when signposting patients to Epilepsy Action.

To achieve the PIF TICK mark, we have to show we are meeting 10 key steps every year:

1. We create our information using a defined and thorough process
2. We undergo training to ensure we have the skills to produce high-quality content

3. Our resources fulfil a genuine need, addressing areas identified by people affected by epilepsy
4. Our information is based on reliable, up-to-date evidence that is communicated accessibly to a wide range of audiences
5. We involve users throughout the process. We ask experts to review and advise on content and ask people affected by epilepsy to give feedback based on experience
6. Information is accessible and written in plain English to help people overcome health inequalities
7. Content is easy to access and legally sound
8. Feedback is critical throughout and there are systems to make sure opinions are heard and acted on
9. Information is shared through multiple channels, including social media, publications, our helpline and volunteer networks
10. We measure the impact of our information: how many people we are able to help, are people able to find our information, do they have questions we're not addressing?

The health information team is working towards achieving the PIF TICK for all its information webpages. However, this is a collaborative effort. Without the help and feedback from people with lived experience and

experts, we would not be able to reach the standards outlined by PIF.

Our network of experts includes professionals such as epilepsy specialist nurses, neurologists, GPs and researchers. When updating or creating a resource, we ask an expert to review a draft and check whether the information is accurate and relevant. This process has been invaluable in making Epilepsy Action what it is: a trusted source of information covering all aspects of someone's life that epilepsy can affect.

## Can you help?

We are looking for more experts and would greatly appreciate it if you had the time to help with the occasional review of our information. This could be as little as 2-3 hours per year. It's an excellent opportunity for you to share your expertise, help create trusted information for people affected by epilepsy and add to your CPD portfolio.

**If you are interested in being involved or to find out more information, please email [health@epilepsy.org.uk](mailto:health@epilepsy.org.uk).**



## Excellence Collective update

**Epilepsy Action health improvement and research manager Tom Shillito shares updates from Epilepsy Action's Excellence Collective**

It's been a busy few months since the Excellence Collective launched in February. We have two new projects underway and two more in development. We're really pleased to share our updates on these projects, and please do get in touch if you're interested in hearing more.

But the Collective isn't just about the projects we run – its aim is to bring together the whole epilepsy community to share information, shape ideas and drive forward improvements for everyone affected by epilepsy. We will be organising our

first group discussion sessions very soon. These will bridge the distance between people living with epilepsy, health and social care professionals, researchers, policy-makers and everyone else in our community.

Everyone is welcome to join the Excellence Collective. Membership is free and will give you access to the discussion sessions, the ever-growing Excellence Collective information repository and all of our other resources.

**To join us and have your voice heard in the epilepsy community, please visit [epilepsy.org.uk/ExCo](http://epilepsy.org.uk/ExCo)**

### Current projects

#### **Preconception, pregnancy and perinatal care**

Pregnancy and birth can be difficult experiences for someone with epilepsy, with the risks higher when compared to the general population. The latest MBRACE report states that 40% of maternal deaths related to neurological conditions were due to epilepsy and, in a two-year period, 17 pregnant people died due to their epilepsy in the UK. Anti-seizure medications can also increase the risk of birth defects, and those risks are often not adequately explained to people with epilepsy before they become pregnant.

#### **What are we doing?**

Our preconception and pregnancy project, which launched in January, is looking to tackle these problems.

- Catherine Owens, our midwifery epilepsy coordinator, has designed a gap analysis tool and, in partnership with Dr Janine Winterbottom, will be evaluating service provision for people with epilepsy from preconception through to the perinatal stage. This has full support

### **The Excellence Collective isn't just about the projects we run – its aim is to bring together the whole epilepsy community**

from the North West Regional Midwifery lead Claire Mathews. It will be made available to the 18 NHS trusts that provide maternity care within the NHSE's North West region. Using this approach will provide us with a clear picture of the pathway, identifying strengths and what areas need to be developed.

- A series of listening events are currently being organised to capture experiences from service users and maternity providers to understand what they believe is needed to provide a safe, holistic and welcoming pathway for someone with epilepsy.
- We will then develop a service specification and associated benchmarking toolkit, based on these sources of information. The responses to the toolkit will support service pathway redesign.

**To find out more please contact [researchadmin@epilepsy.org.uk](mailto:researchadmin@epilepsy.org.uk)**

#### **Be epilepsy aware**

Almost a quarter of people with learning disabilities will have epilepsy, and they are much more likely to have treatment-resistant seizures and other comorbidities that impact on their quality of life. They are also at a higher risk of SUDEP, and their risk of mortality increases with the severity of their learning disabilities.

We have heard from people with epilepsy and learning disabilities, their families and carers, and healthcare professionals, who have shared just

how challenging living with epilepsy and learning disabilities can be. People with epilepsy and learning disabilities often don't feel as though they have control over their health, and this can lead to a lower quality of life and a lack of self-management.

### **What are we doing?**

We are working in partnership with North East and North Cumbria ICB to develop self-management training for people with epilepsy and a learning disability. This training will empower individuals to take an active role in their epilepsy management by giving them a better understanding of their condition, and provide easy tips to help monitor and assess their seizures.

The training will be delivered by people with a learning disability and epilepsy using both online and in-person training models, and will be available to their peers and the wider community.

To develop this approach we have sought the views and experience of people with epilepsy and learning disabilities through a scoping survey. We are now contacting respondents, as well as other learning disability organisations in the area, to invite them to the North East and North Cumbria co-production workshops. The workshop participants will help us to create the training as well as to deliver it.

## **Upcoming projects**

### **GP toolkit**

We have heard, both from people affected by epilepsy and from healthcare professionals, that epilepsy management is often something that GPs find challenging. GPs themselves report a high level of uncertainty when it comes to epilepsy care, whether that's medication changes, seizure management or understanding

## **People with epilepsy and learning disabilities often don't feel as though they have control over their health**

the referral pathways available to them. We want to make this easier for GPs and to improve the experience they provide to their patients.

### **What next?**

We have started discussions with a number of GPs, but we need more information, especially from GPs with a special interest in epilepsy.

Are you, or any GP colleagues, able to give us information on the following?

- How do you currently manage your patients with epilepsy? What services do you provide and when?
- What barriers do you face in providing an efficient and effective service?
- How could you be supported to provide a more holistic or streamlined service?

**If you are a GP and would like to be part of this, please contact us.**

### **Transition**

Young people with epilepsy have highlighted to us how difficult transition into adult services can be for them. Adult epilepsy services are organised differently and offer very different experiences to paediatrics, with more onus on the patient to coordinate their own care. Healthcare professionals have also raised concerns with transition arrangements, with some patients falling through the gaps and being lost to adult services, and others not



receiving the full range of support available to them.

We would like to help healthcare professionals overcome these issues and support young people who are making the move to adult services. We are in discussion with healthcare providers already working on quality improvement projects in this area, to find out what is currently being done and what problems are being faced. We are also in conversation with an ICB that would like to improve its transition care for people with epilepsy.

### **What next?**

We would like to hear from as many people as possible. If you have experience of transition, whether that is from seeing your patients transition or from going through the process yourself, we would like to hear from you. The information you share with us will be used to inform a tool that will improve information sharing and patient experience.

**For more information about any of the projects mentioned, please get in touch with us at [researchadmin@epilepsy.org.uk](mailto:researchadmin@epilepsy.org.uk).**



# Highlights

## Top picks from *Seizure*

Editor of the journal *Seizure*, Professor Markus Reuber highlights his key papers from the latest edition

**I**mpressive scientific progress has been made in many fields of medicine, but arguably the most amazing growth in understanding over the last century has been in genetics. The discovery that genes are made of DNA was made in 1952 and the molecular structure of DNA described one year later. Since then, there has been a dramatic acceleration in this field. While it took a few years to establish that Down Syndrome is caused by the presence of an extra copy of chromosome 21 (1959) the growth rate of scientific developments in clinical genetics has been on an exponential trajectory, especially since the discovery of DNA sequencing in 1975. [DNA Worldwide, 2014; Claussnitzer et al, 2020].

The pace of innovation in clinical genetics is reflected in epilepsy

research. By 2017, the team that produced my editor's choice from the current Special Issue of *Seizure* on the Genetics of Epilepsy was able to compile a list of 977 genes associated with epilepsy [Wang et al, 2017]. However, many genetic discoveries since have called for an update of this list. The new list by Zhang et al. is an impressive piece of work. The updated search identified nearly 3,000 genes potentially associated with epilepsy. About half of these (1,506) were found in the Online Mendelian Inheritance in Man (OMIM) database. These included 168 epilepsy genes (86 of which were newly added), 364 genes linked to neurodevelopment-associated epilepsies (including 291 new ones) and 974 epilepsy-related genes (438 more than that in the first version) [Zhang et al, 2023].

The identification and categorisation of genes was based on a rigorous procedure involving a search of epilepsy-associated genes in the OMIM database, followed by the exclusion of items for which there was no definite molecular genetic confirmation or for which information about clear links between specific genes and epilepsy in humans was lacking. After additional HGMD and PubMed searches, the likely relevance of the identified genes was confirmed by cross-referencing the list with the Seizure-Associated Genes Across Species database (comprising 2,876 genes potentially associated with seizures or epilepsies in multiple species), and the Gene4epilepsy database (containing 926 genes included in the epilepsy panels of major clinical diagnostic providers and research resources).

Of course, the increased number of genes potentially linked to epilepsy only hints at the complex interactions between different genes or genes and environmental and developmental factors that determine whether a

particular genetic abnormality contributes to the causation of epileptic seizures. As highlighted in Wei-Ping Liao's editorial comment in the Special Issue (*Seizure* volume 116) [Liao et al, 2024], the pathogenicity of a particular genetic abnormality also depends on factors such as the Genetic Dependent Quantity, i.e. the lowest limit of the required genetic function to maintain the biophysiological function, the Genetic Dependent Nature (whether a gene is vital to survival, obligatory for development of disease-phenotypes, capable of causing mild biological alterations but not apparent disorders, or dispensable) or the Genetic Dependent Stage (the stage at which a gene is expressed).

These complexities – and the fact that, from where we are standing, we can only see the outline of the start of genetic therapies for the epilepsies – mean that, despite the impressive progress, there is much more to learn.

## Further reading

Claussnitzer M, Cho JH, Collins R, Cox NJ, Dermitzakis ET, Hurler ME, Kathiresan S, Kenny EE, Lindgren CM, MacArthur DG, North KN, Plon SE, Rehm HL, Risch N, Rotimi CN, Shendure J, Soranzo N, McCarthy MI. A brief history of human disease genetics. *Nature* 2020;577:179-189.

Liao WP. Epilepsy-associated genes: discovery, clinical significance, and underlying principles of genetic medicine. *Seizure*. 2024 Jan 3;S1059-1311(24)00002-5. The History of DNA Timeline, DNA Worldwide (2014). <https://www.dna-worldwide.com/resource/160/history-dna-timeline%20> (Accessed: April 2024). Wang J, Lin ZJ, Liu L, Xu HQ, Shi YW, Yi YH, He N, Liao WP. Epilepsy-associated genes. *Seizure* 2017 Jan;44:11-20. Zhang MW, Liang XY, Wang J, Gao LD, Liao HJ, He YH, Yi YH, He N, Liao WP; China Epilepsy Gene 1.0 Project. Epilepsy-associated genes: an update. *Seizure* 2023 Sep 23;S1059-1311(23)00254-6.



# Epilepsy Action is here for you



helpline

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



counselling

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



talk and support

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



family support

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



befriending

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



[epilepsy.org.uk/support](https://epilepsy.org.uk/support)

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

**Epilepsy Action Helpline: freephone 0808 800 5050**  
**email [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk) [epilepsy.org.uk](https://epilepsy.org.uk)**

Registered charity in England and Wales (No. 234343)



## Tough decisions: prescribing valproate

**T**he harm and cost of epilepsy, and especially its treatment, has recently made headlines with the new MRHA regulations on sodium valproate. A report from the Office of Health Economics, titled *Individual, Health System and Societal Impacts of Anti-seizure Medicine Use During Pregnancy* in 2024 puts the lifetime cost of harm caused by epilepsy medications as high as £2.5 million [Henderson et al, 2023].

It reports this sum as the cost for one child exposed to high-risk drugs during pregnancy and includes costs to the NHS, education, welfare system, the affected individual, their family and society. The cost to the NHS alone is more than half a million.

There is no doubt that practice, surrounding the licensing, responsibility, information-giving and

prescriptions of sodium valproate had to change, and has. However, most of us as epilepsy professionals probably ask the question: who are we protecting and who are we harming. A life lost due to ongoing uncontrolled generalised tonic-clonic seizures – which may have been potentially treatable with valproate – can't be replaced or reimbursed. For affected families, this cost is immeasurable, life changing and lifelong.

The new regulations on valproate serve to protect the unborn child – the life yet to be lived and the associated individual and family harm, comorbidity, suffering and survivor guilt that women and now, in theory, men may experience from valproate exposure in childbearing years. However, we also know there is a large hidden harm at play for those who stop taking valproate, as we encounter not only increasing cases of SUDEP and maternal death, but also the harm associated with uncontrolled epilepsy.

The new regulations actually force us towards using potentially less-effective anti-seizure medications to protect unborn lives, but for some we may be placing individuals with epilepsy on a journey of harm, of ongoing seizures and the consequences of that.

The change in licensing of valproate has acutely brought home the message of harm, not just from some anti-seizure medications in pregnancy and development, but the harm from epilepsy as a whole. It has caused me to reframe many of my clinical encounters, to reinforce safety, to push for seizure freedom and to have more open discussions.

Interestingly, recent data from Michigan found a 2.5-fold higher rate of death in patients with functional, non-epileptic, dissociative seizures compared to those without such

seizures. Again, those who died had significant medical comorbidities [Kerr et al, 2024]. So, contrary to some of the discussions around dissociative seizures, harm can occur, and not just as a consequence of iatrogenic medical interventions, but perhaps because other comorbid factors are overlooked or do not take precedent to the seizures themselves.

I acknowledge that we shouldn't construct all consultations around harm, death and risk. At the risk of gaining a reputation, we want to develop working relationships with our patients; to encourage engagement and attendance, to promote responsibility and self-management, and to enable informed discussions around care. But maybe, in light of these new drug regulations, the hidden risk they might pose and the ongoing risk of seizures – whether epileptic or dissociative – is another reminder that we need to strive to treat people early, to acknowledge that seizures and comorbidities do matter, and to channel patients into appropriate services for their epilepsy and other associated conditions.

### Further reading

Henderson N, Bray G, Skedgel C. 2023. Individual, Health System, and Societal Impacts of Anti-seizure Medicine Use During Pregnancy. OHE Grant-Funded Research Report. London: Office of Health Economics. Available at: <http://www.ohe.org/publications/impacts-anti-seizure-medicine-use-during-pregnancy/> Kerr WT, Patterson EH, O'Sullivan IM, Horbatch FJ, Darpel KA, Patel PS, Robinson-Mayer N, Winder GS, Beimer NJ. Elevated Mortality Rate in Patients With Functional Seizures After Diagnosis and Referral. *Neurol Clin Pract*. 2024 Apr;14(2):e200227. doi: 10.1212/CPJ.0000000000200227. Epub 2024 Jan 10.

## Dates for the diary

Dates and events may be subject to change – please check on the relevant websites.

5-8 May

Seventeenth Eilat Conference on new Antiepileptic Drugs and Devices (EILAT XVII)  
Madrid, Spain  
[bit.ly/3u7Mzm6](https://bit.ly/3u7Mzm6)

11-12 May 2024

ILAE British Branch 19th Epilepsy SPR Teaching Weekend.  
Birmingham University, UK  
[bit.ly/47ysQy4](https://bit.ly/47ysQy4)

15-18 May

ILAE School on Neuroimaging  
Potsdam, Berlin and online  
[bit.ly/3Hrzkn3](https://bit.ly/3Hrzkn3)

29 June-2 July

10th Congress of the European Academy of Neurology  
Helsinki, Finland  
[bit.ly/47LSi3L](https://bit.ly/47LSi3L)

20-27 July

6th ILAE School on Advanced EEG and Epilepsy  
Dianalund, Denmark  
[bit.ly/3xqeGSp](https://bit.ly/3xqeGSp)

7-11 September

15th European Epilepsy Congress  
Rome, Italy  
[bit.ly/45p17Pg](https://bit.ly/45p17Pg)

19-22 September

14th International Summer School for Neuropathology and Epilepsy Surgery  
Erlangen, Germany  
[bit.ly/3UCYOWp](https://bit.ly/3UCYOWp)

23 September

ILAE British Branch Annual Scientific Meeting, Liverpool, UK  
[bit.ly/3Gjx8gO](https://bit.ly/3Gjx8gO)

2025

30 August-3 September

36th International Epilepsy Congress  
Lisbon, Portugal  
[bit.ly/3uz1ARq](https://bit.ly/3uz1ARq)

## Next issue:

### Dr Owen Pickrell

Dr Pickrell discusses Swansea University's study into epilepsy and the risk of Covid-19 in the Welsh population

### Castañeda and Ultanir

Marisol Castaneda and Dr Sila Ultanir describe new therapeutic targets for CDKL5 deficiency disorder

If you are interested in submitting a research paper for inclusion in *Epilepsy Professional*, please contact the editor:

[gwood@epilepsy.org.uk](mailto:gwood@epilepsy.org.uk)

## Epilepsy Professional's advisory panel

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Claire Isaac

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Howard Ring

Ivana Rosenzweig

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Martin Brodie

Matthias Koepp

Mike Kerr

Philip Patsalos

Richard Appleton

Richard Chin

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Susan Duncan



## We need more experts to join our forces!

Our health information needs professional feedback to continue to be PIF-TICK accredited.

If you can lend your professional skills to review information on an occasional basis, send an email to [health@epilepsy.org.uk](mailto:health@epilepsy.org.uk) with the area you specialise in.

This is a great opportunity for your CPD portfolio as well as making a huge difference to people affected by epilepsy.



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