

Epilepsy Review

Back driving after 40 years of seizures. Maggie Izzard tells her story

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A couple's heart wrenching decision over whether to have a second baby

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Looking inside the brain without electrodes

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2018 has been a remarkable year. People with epilepsy have been responsible for two key dates – 24 April and 1 November. The first marks the introduction of new regulations around sodium valproate. The second is the day, specialist doctors in the UK were allowed to start prescribing medicinal cannabis for epilepsy. But neither story has yet found its happy ending.



Both milestones were made possible largely thanks to the determination of women whose children have been affected either by side effects from epilepsy medication or by lack of access to treatments they felt would help alleviate seizures.

The valproate women, along with charities and patient organisations, campaigned to raise awareness of side effects associated with the epilepsy drug, sodium valproate. Up to 40 per cent of babies exposed to the medication during pregnancy are born with a physical or neuro-developmental disability.

On 24 April the Medicines and Healthcare products Regulatory Agency announced new regulations around sodium valproate, meaning every woman prescribed the drug would have a discussion with her doctor to help her make an informed decision about pregnancy and future medical treatments.

But the campaign is not yet over. Early pointers suggest there are still obstacles in making sure the information reaches the right people. The women, and we as a charity, will not rest until every woman on valproate is aware of the risks. And next year, we will be repeating our survey to find out how effective communications have been around the risks.

Changes in the law around medicinal cannabis were also led by a similarly determined group of women who were

accessing cannabis-based medicinal products for their children from abroad.

People often accuse the wheels of the government of grinding laboriously slowly. But not this time. Responding to the stories of families travelling to Canada to access medicinal cannabis, and after a review by the Government's chief medical officer, cannabis-based products for medicinal use were rescheduled. This means that specialist doctors can prescribe them where there is un-met clinical need. And, importantly, research can begin to gather a robust evidence base for these products.

But that is where the story has yet to find its happy ending. Interim guidance around the products is tight and only a small number are likely to benefit from the relaxed laws. The real hope is for more research, but this is likely to take a minimum of three years to yield results. And when you have a child with ongoing seizures, three years is a long time to wait.

It feels like a battle half won and half lost. Yet doctors cannot prescribe on anecdotal evidence and robust evidence takes time.

So 2018 has been ground breaking, but there is still much tilling of soil to be done before both issues are resolved. We will keep you updated in 2019. Happy Christmas.

Nicola Swanborough



Front cover

Transcranial magnetic stimulation is a non-invasive way to look inside the brain. This is helping researchers at Epilepsy Society to interpret information generated through reading a person's DNA. You can find out more on page 9.

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SUDEP

New partnership could lead to greater understanding of SUDEP



We are excited to announce a new partnership with Congenica, a global diagnostic decision support platform provider based in Cambridge, to study the genomics of SUDEP. The new collaboration aims to improve the clinical understanding, prediction and treatment of the condition.

Sudden unexpected death in epilepsy (SUDEP) occurs in roughly 1/1000 people with epilepsy and is often misunderstood. By using genomic studies, we will seek to identify underlying genetic causes and improve clinical understanding.

SUDEP often occurs during sleep and is thought to be caused by a complex interaction of genetic factors. The initial joint study looked at a group of 100 SUDEP clinical cases to better understand epilepsy's underlying genetic causes.

Using Congenica's gold-standard Sapienta diagnostic decision support platform, whole genome and exome sequencing and analysis will be carried out to determine possible genetic causes of SUDEP. Sapienta is being used as part of the recently-launched NHS Genomic Medicine Service.

The multi-disciplinary research

team will include scientists from the Epilepsy Society and members of Professor Sanjay Sisodiya's clinical research team at UCL (University College London), alongside Congenica's clinical scientists.

Professor Sisodiya (UCL Queen Square Institute of Neurology) who is also Director of Genomics at the Epilepsy Society, said: "This important study may help us find and understand some possible risk factors for SUDEP. Collaborating with Congenica will ensure analyses of the data are robust and comprehensive, optimising the chances of discovery."

Nick Lench, Chief Scientific Officer at Congenica, said: "We are excited to form a partnership with the Epilepsy Society and collaborate with Professor Sisodiya, whose pioneering use of genetic medicine is beginning to enable the use of precision medicine for patients.

"The genomic knowledge generated in this project has great potential to positively impact the way we manage epilepsy patients by better understanding of any underlying genetic factors that might contribute to SUDEP."

There are three epilepsy-related deaths a day in the UK alone.

MEDICATION

Review into sodium valproate

An independent safety review into the epilepsy medication sodium valproate was launched in October with a 'call for evidence' put out for those affected by the medication.

The review, chaired by Baroness Julia Cumberlege, is examining the way the health system responded to concerns raised about the harmful side effects of the anti-epilepsy medication.

Up to 40 per cent of babies exposed to sodium valproate in pregnancy are born with physical or neuro-developmental issues.

The call for evidence is being carried out by the Independent Medicines and Medical Devices Safety Review. Regional meetings have been held across the country to hear the views of those affected. These are an opportunity to share your experiences but are not evidence-gathering meetings. Go to immdsreview.org.uk/visits.html for further updates.

Regulations have changed around the way in which sodium valproate is prescribed to girls and women of childbearing age with epilepsy. If your doctor has not called you in for a review, make an appointment with them to discuss. You can read more about the changes at epilepsysociety.org.uk/sodium-valproate-guidelines.

You should never stop taking sodium valproate without consulting your doctor.

Medical Director at Epilepsy Society honoured with new post

The Epilepsy Society is pleased to announce that our medical director, Professor Ley Sander, has been appointed as the Head of the Department of Clinical and Experimental Epilepsy at UCL Queen Square Institute of Neurology.

Professor Sander has just been ranked as the world's leading epilepsy expert for the sixth year running by Expertscape. He took up

the position on 1 December 2018, leading the highly successful epilepsy department, spanning basic science through to clinical trials.

Professor Sander said: "This is a wonderful opportunity to really push forward our epilepsy research programmes and bring exciting developments to the people we see in clinics. I am thrilled to be heading up the department."



SEIZURES

It's seizures, not fits

Doctors have been told to use plain simple English rather than medical jargon when writing to their patients.

The Academy of Medical Royal Colleges launched a 'Please write to me!' initiative that is designed to improve communications between doctors and patients to make hospital letters easier to understand.

The word 'seizure' to describe a person's epileptic seizures is among the terminology which the Academy is asking doctors to avoid. The Academy has said that doctors should replace this with the word 'fit'.

While welcoming the initiative, Epilepsy Society's medical director Professor Ley Sander has said that the new guidelines on medical terminology contradict preferences expressed by people with epilepsy.

"Writing to people in plain English is fundamental to good communication and effective health treatment," he said. "This helps to empower people and enable them to take an active role in the management of their health condition and we fully welcome the Academy initiative.

"However, the term 'seizure' rather than 'fit' does not class as medical jargon in describing epileptic seizures. Some years ago people with epilepsy were asked in a survey what their preferred terminology was for describing their epilepsy. People were adamant that 'seizure' was more preferable to the word 'fit' which carried much stigma with it and in some contexts was used as a derogatory term," he said.

"We still hear some people in clinic talking about their 'fits', and that is certainly their prerogative. We would not question this. But as medics at a centre of excellence for epilepsy and as a national charity, which supports more than half a million people with epilepsy, we will still continue to respect the wishes of people with epilepsy and refer to seizures as seizures."

Find out more at epilepsysociety.org.uk/epilepsy-terminology.

SCIENCE

Protein found in worms helps to stop seizure activity

New research that involves using protein in worms to suppress seizures could spell hope in the future for thousands of people with epilepsy.

Scientists at University College London (UCL) have used a chemical found in worms to reduce seizure activity in the brains of epileptic rats. The chemical produces a protein that reduces brain activity when glutamate levels build up, causing neuronal excitement in the brain.

The chemical is delivered into the brain by injecting it through the skull inside a harmless virus. Using gene therapy, this enables the worm DNA to spread throughout the brain.

Epilepsy Society works as part of a unique arrangement with UCL and the National Hospital for Neurology and Neurosurgery. The charity's medical director Professor Ley Sander is hopeful the new gene therapy could benefit discoveries being made through its own genomic sequencing programme.

He warned there was a long way to go before it could be used in humans, but said: "This is a very exciting piece of work offering great hope in the future for people with focal epilepsy that does not respond to conventional treatment.

"Focal epilepsy starts in a specific area of the brain and where that area can be pinpointed, it is sometimes possible to remove the focal point through brain surgery. But this is only possible if it is in an area of the brain that will not compromise essential functions such as language and movement.

"Modifying the excitability of nerve cells by introducing a targeted 'virus' that will not infect a nerve cell but instead deactivate the seizure, may offer a real alternative to surgery. It also has the advantage of preserving the functional areas of the brain."

"At the moment results have only been shown in animal models and it is important that this is now translated into humans."

If the chemical induces the same response in humans, the UCL research team hopes a new treatment could be available on the NHS within 10 years.

The research is published in the journal Nature Medicine.

TREATMENT

Laws relaxed for medicinal cannabis

As of 1 November, specialist doctors in the UK can now prescribe cannabis-based medicines following a change in law by parliament.

The following conditions can be considered for treatment with medicinal cannabis:

- Children and adults with rare, severe forms of epilepsy
- Adults with nausea caused by vomiting caused by chemotherapy
- Adults with MS-related muscle spasticity.

It will be the specialist doctor's responsibility to prescribe the products where they feel it is needed.

The change in law came after Home Secretary Sajid Javid responded to concerns from the parents of children with severe epilepsy, who were campaigning to make medicinal cannabis legalised.

Previously, doctors were required to seek approval from experts before patients could access these medications.

The decisions on prescriptions for cannabis-based products for medicinal use must be made on a case-by-case basis, so the drug is prescribed to those who need it.

The Home Office advises all those seeing a specialist to discuss their treatment plan with them. It stresses the new laws do not pave the way for legalising recreational cannabis. Please see page 18 for more information.

Voice of the future



BREXIT
Brexit and AEDS

Epilepsy Society has welcomed Government plans to ensure that people with epilepsy in the UK will be able to access their medications in the event of a no-deal Brexit in March 2019.

The Health Minister has written to pharmaceutical companies asking them to ensure that they have a minimum six week stockpile of prescription-only medicines in case of potential delays at UK borders.

Many anti-epileptic medications are imported from Croatia, Hungary, Germany and Switzerland.

The Minister wrote: "We are confident that, with adequate preparation... we can safeguard patient care in the event of no deal."

Chief Executive at Epilepsy Society, Clare Pelham, said she felt

Kadijah Mkwella bravely stood up at Epilepsy Society's annual conference to ask for more epilepsy awareness raising in schools. We will be giving a talk to pupils at Kadijah's school early in 2019, and they have named us their charity of the year. Well done Kadijah!

Annual conference page 11

reassured that the Government was making plans in a timely manner.

"It is absolutely vital that people with epilepsy are able to access a consistent supply of medication without having to worry," she said.

"Any interruption to medication, can result in a breakthrough seizure and this can have a high impact on a person's life.

The Government is asking pharmaceutical companies to arrange for medicines with a short -shelf life to be air-freighted in, rather than risking border delays.

Watch it on video

You can find these videos at youtube.com/epilepsysociety



Professor Sanjay Sisodiya talks about his half marathon to fundraise for a special chair for his epilepsy clinic. Page 8.



Sarah explains why she is leaving a gift for Epilepsy Society in her will and what she hopes it could mean for the future.



Team Purple abseils down Broadgate Tower in London to raise money for Epilepsy Society.



Rev Bob Mayo shares his poem describing his experience of a seizure.

Me and my epilepsy

Maggie Izzard

Maggie Izzard's father taught her to drive when she was a teenager, but shortly after leaving home for university she was diagnosed with epilepsy and had to give up her driving licence. After 40 years of struggling to get her epilepsy under control, Maggie is finally seizure free and back behind the wheel of her car. Here she describes how perseverance, patience and a positive attitude have helped get her back out on the open road

Learning to drive

I had a great childhood, learning how to cope with life and enjoy it. My best friend and I learnt to drive at 17. My father taught me. He was in the RAF and instructed officers how to drive all the military vehicles. I passed my driving test first time. My friend and I took turns driving each other out for a night once a week to the nearest disco seven miles away.

Leaving home and epilepsy

Then came the stress of college exams, the challenge of leaving home and going to university.

All went well at first then about

two months after the start of term I noticed that I occasionally felt as if I had a kind of short absent mindedness or interruption in concentration and awareness during the day. I went to see my new GP and told her that I thought I might have epilepsy.

She was most surprised but I was eventually given a diagnosis of epilepsy and was put on the first of a long trial of medication. And, I had to hand in my driving licence.

Living with seizures

My seizures were not tonic clonic but partial and happened approximately once every three

to four weeks. Part of the problem was that I never knew when they were going to happen, what was going to happen or what the outcome was going to be. Things got worse when I graduated and moved to work in London.

Disclosing my epilepsy

I loved the city, the excitement of feeling part of a trendy environment and starting a graphic design business, working mainly with the art and antique world. Clients seemed to understand when I mentioned about my epilepsy just in case I had a seizure. I would not refer to it as a

disability because I felt people with disabilities were misunderstood.

A positive outlook

But in my late 30s I started to realise that one should try to feel positive, happy and reassured and look on the bright side. I realised that I could get a bus pass and help with fares on trains, all of which was great.

Not responding to medication

My medication was still not working. My drugs and dosage were regularly changed which was very tiring. It was at the hospital in Queens Square in London that I had a scan with the newly installed MRI, confirming that the only way to proceed was with medicine.

Accidents during seizures

I had several accidents as a result of my seizures, almost falling through a glass window, walking into a side of a building in Regent Street, leaving a lot of blood on the pavement then being taken away in an ambulance.

I closed my business and tried to get employment in print management which was very

difficult because of having to declare that I had a disability or medical condition. The bias against a disability or being of an older age was a constant barrier, especially being over 40 in London.

Marriage break down

I moved away from London in 2000 when my marriage broke down, seeking refuge with my parents and trying to rebuild my self-esteem.

I started doing oil painting and found that painting portraits was very inspiring.

I was now under the care of Walton Centre in Liverpool and was on levetiracetam but it was still not working. We tried various doses and kept persevering.

Improvement in well being

As time went by my life started to feel more positive. I felt far more at ease and less anxious, getting

Clockwise from far left: Queen of the road, Maggie, back behind the wheel; wedding day bliss with husband, Trevor; RAF years for proud Dad and driving instructor, Tom Izzard; Maggie with her Dad in later years.

Below: a portrait of Trevor by artist, Maggie.

advice on things like breathing exercises and balanced diets. I always had a note book to hand so that it was never a problem trying to remember everything. I got remarried two years ago, developing my hobby in painting portraits and when I saw my specialist I mentioned that life was far less stressful and that I felt more reassured.

Seizure free at last

Then in June this year – for the first time in four decades – I realised I had been one whole year without a seizure. I could not believe it. After 40 years of feeling doubtful and unsure of when my epilepsy might occur, I was finally seizure free. I put this down to both perseverance and self assurance. I think that not feeling anxious has certainly helped to keep my epilepsy under control and feeling sure about my medicine.

Back behind the wheel

Recently I received my full driving licence back from the DVLA. I felt so delighted and could not stop telling everyone. I am now out on the road having 'reminder'

lessons. I was quite surprised that this was my full driving licence with no word of advice from the DVLA recommending that I have a number of reminder lessons. Forty years not

driving is quite a long time but I am starting to feel more confident and will soon love it as much as I did when I was a teenager. I think my father would be thrilled to see me back out on the road after all these years.



Professor in the park

Epilepsy expert **Professor Sanjay Sisodiya** explains why he and colleagues ran through London's rain-soaked royal parks to raise money for a chair they hope will make a difference to the people who they see in clinic. Nicola Swanborough writes

Sanjay Sisodiya is director of genomics at Epilepsy Society and professor of neurology at UCL. When he is not seeing patients, his work is focused on pioneering research to understand the complexities of epilepsy, unravel its many causes and discover new treatments.

Every day he looks at the small print of what makes us who we are. Doctor, scientist and some might say detective, his work involves mining the three billion letters that make up our DNA, searching for duplications, deletions or recurring patterns that might suggest a genetic contribution to a specific type of epilepsy.

Sanjay calls genomics his 'big project'. 'It is something I want to do for people with epilepsy, for the families who I have been seeing over many years and for whom, quite often, we have no answers to explain their epilepsy and no treatment options that will control their seizures,' he says.

Based at Epilepsy Society's Chalfont Centre in Buckinghamshire and at UCL, Sanjay is leading one of the largest epilepsy genetic sequencing projects in the world, looking at the DNA of 5,000 people with epilepsy. Already results are bringing hope of a future based on more precise personalised medicine with individuals being prescribed the right medication, at the right dose, from the point of diagnosis.

But today Sanjay is not talking about his work as a scientist or a doctor. He is here to talk about his most recent personal project and one that had him feeling ever so slightly nervous.

On Sunday 14 October, he swapped his more familiar suit and lab coat for running vest and trainers to take part in the London Royal Parks Half Marathon. His aim was to help raise £10,000 for a much needed dedicated chair that is integral to a new diagnostic test – transcranial magnetic stimulation with electroencephalography (TMS-EEG). The chair will make diagnostic tests more comfortable for people undergoing the test and will also enable him to produce more accurate diagnostic results.

TMS is a non-invasive tool that helps to interpret information gained through new genetic tests and build up a clearer picture of how those changes impact on the function of the brain. This can then help to guide and monitor treatment options. (See right.)

However, tests can take up to two hours and require the patient to lie as still as possible in a reclined position. Many of those who currently undergo TMS-EEG often have mobility issues.

Sanjay was joined on the run by two of his colleagues: Katri Silvennoinen, research associate at Epilepsy Society and neurologist Meneka Sidhu. Together they formed the Epilepsy Society



What is TMS-EEG?

Dr Simona Balestrini is using Transcranial Magnetic Stimulation (TMS) with electroencephalography (EEG) to look at brain activity in people with epilepsy. Here she explains what she hopes to achieve.

'TMS is a sophisticated tool that is part of our genomics toolkit. It is a means of looking inside a person's brain without using needles or electrodes. It is a non-invasive test that can be used to interpret information gained through genetic sequencing. TMS uses a strong magnet, similar to the one used in the MRI scanner, to induce very brief electric currents in the brain. We can measure the response of cortical circuits in the brain to TMS and generate a direct profile of brain activity and function. Put simply, TMS can establish a link between brain activity and different types of sensory, motor and cognitive functions. We can then establish whether a specific genetic change is impacting on the function of the brain.

For some time we have been looking at the brain using TMS together with electromyogram (EMG). This allows us to measure electrical activity of muscles. But this technique has only allowed us to look at the motor cortex in the brain.

Now with TMS-EEG we are able to look at brain activity across the whole of the cortical part of the brain, guiding and monitoring potential treatment options.

By repeating the test over a period of time, TMS can be used to show the course of epilepsy in the brain and whether different medications lead to an improvement or a decline in the condition.

It is hoped that in the future TMS will be used to predict individual response to anti-epileptic medications. We also hope that it may help us to predict outcome in epilepsy, including the risk of SUDEP (Sudden Unexpected Death in Epilepsy).



“The money they raise really helps to push forward our research. And alongside my patients, they have been one of the inspirations for my taking part in the Royal Parks Half Marathon.”

about it,’ he said.

‘I have never been much of a sportsman. At school I was always picked last for every team but I have always liked running and recently have been doing a bit more. So I thought why not combine being a doctor, a scientist and a runner and see if I can literally go that extra mile.

‘Research costs money and I am always very aware of the tremendous support we receive from people with epilepsy, their family and friends who jump out of planes, bake cakes, undertake amazing physical challenges or simply make a donation because they want to help make a difference for people with epilepsy in the future.

‘The money they raise really helps to push forward our research. And alongside my patients, they have been one of the inspirations for my taking part in the Royal Parks Half Marathon.’

Katri said she was proud to wear her Epilepsy Society vest. ‘I’m really grateful to everyone who supported us throughout this journey. On race day, a number of people braved the rain to cheer us on, and this definitely helped me reach my target time, which I’m thrilled about.’

Meneka said she was pleased that all their training and preparation would help to make life more comfortable

for those people who undergo transcranial magnetic stimulation in clinic. ‘It is really good to feel that by doing something we enjoy, we will have made a difference to the people we see in clinic,’ she said.

Sanjay was pleased with his run, in spite of injuries in the build up to the day: ‘I like to think that by pushing ourselves in training and on the day, we have helped to improve the experience for patients when they come for a TMS test. The more accurate the results we obtain, the more precise the treatment will be. And that is certainly worth enduring a few aches and pains along the way.’

You can still support Sanjay, Katri and Meneka by making a donation, at www.justgiving.com/fundraising/epilepsy-society-research-team

Thank you.



Sponsor Sanjay!
Visit Sanjay’s Just Giving page to show your support

Our annual conference

This autumn we held our annual conference in London, with some 200 delegates joining us at the Holiday Inn to hear from leading experts in the field of epilepsy. As well as medics we were joined by the Rev Bob Mayo, vicar of a London parish and chaplain at Queens Park Rangers Football Club. Bob was talking about his own experience of living with epilepsy. Here we provide a taste of some of the talks from the day. Watch out in *Epilepsy Review* for details of our conference in 2019.

Peter Worthington, our Chair of Trustees, reflects on the difference a year makes at Epilepsy Society

“A year has become even more significant as a milestone in the last year as I have come to understand just what impact epilepsy, and in particular uncontrolled seizures, can have for someone with the condition.

Time and again I see that

celebration of, or longing for, a year of seizure freedom – that glorious goalpost that means you can either start learning to drive or reapply for your licence.

The car is a passport to freedom; a passport to wider job opportunities; wider choice of shopping venues; better education choices; a wider social life. Driving is the holy grail. And somehow, for me, that really makes sense of all

the effort, the thought, the collaboration and the pure dedication that goes into research at Epilepsy Society.

In the last year, it has been awe inspiring to meet with our researchers and scientists; with our professors Ley Sander and Sanjay Sisodiya and their wonderful teams who come to us from all over the world.

I don’t think I’ve ever met such a focused, determined group of people – a group so committed to understanding the causes of epilepsy and finding better, more effective treatments for the condition. Initially I assumed this was the drive and ambition of the ‘scientist’. The need to discover and know and make better. But in the last year, I have realised that the real drive behind our scientists and their research programme is people with epilepsy, the people our neurologists know, the people they see and talk to in their clinics. It is your stories and the impact that epilepsy has on your lives, that motivates and inspires our research team.

And indeed the same is true across the organisation, whether we are talking about advocacy, influencing, awareness raising or fundraising. The driving force is the people affected by epilepsy.’

Seven top tips for better sleep

Dr Hugh Selsick is a consultant psychiatrist working in sleep medicine, based at the Royal London Hospital for Integrated Medicine. He shared his top tips for dealing with sleep problems.

Changing how we think about sleep

For people with insomnia, there is often anxiety around how insomnia may impact their long-term health. There is very little evidence to suggest that insomnia will shorten a person's life span, and for some people knowing that insomnia is not going to kill them can often reduce this anxiety considerably. Then there is the myth of the eight hour sleep. But the truth is that the amount of sleep that is right for us varies. We each need the amount of sleep that will allow us to feel alert most of the time, most days of the week.

Sleep, sex and getting dressed

To help break the feeling of being awake while lying in bed, we have to separate our "awake" activities from our place of sleep. This means limiting time in the bedroom to only three things – sleep, sex and getting dressed. Keep any other activity outside of the bedroom.

Tea and temperature

Two golden rules:

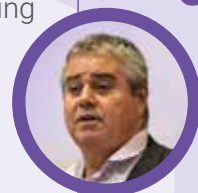
- Have a cut-off point for caffeine intake, ideally 1 or 2pm
- Keep your bedroom cool (ideal temperature 18 degrees centigrade).

Setting your alarm

People often think that a good night's sleep is dependent on keeping a constant bedtime but it is the time that you get up that is the regulator. It is the one thing you can absolutely control. So, get an alarm clock and set it for the same time every day, seven days a week, regardless of what time you go to bed.



Dr Fergus Rugg-Gunn discusses advanced neuro-imaging



"Our DNA is like our fingerprint. Every single one of us has a different genetic make up. It is our blue print. You would never build a house without having a blueprint in place first. This is where the genomic revolution will make a huge difference. Once we can understand our genetic make-up, we will be able to deliver personalised medicine from the point of diagnosis. But person-centred treatment is not just about controlling seizures. It is about tackling the stigma that is attached to epilepsy. One of my patients has not left the house for nine years because of the stigma associated with the condition. The only time that person sees the sunlight is in the garden. Person-centred treatment must take this into account."

PROFESSOR LEY SANDER, MEDICAL DIRECTOR, EPILEPSY SOCIETY

Dr Hugh Selsick talks sleep



Our sleep fuel tank

Fatigue makes you sleepy. From the moment you wake up you start to accumulate sleepiness. You are filling up your sleep fuel tank. When it is full, you fall asleep. It is important to guard your sleep fuel by not sleeping during the day. This will only steal from your night sleep.

Quality before quantity

We try to improve quality of sleep before we look at quantity. But this comes with a warning for people with epilepsy. If sleep deprivation triggers your seizures, it is important that this is managed by an expert and is taken in easy steps.

We ask patients at the sleep clinic to work out the average amount of time they are asleep. This is then subtracted from their wake up time. We then say don't go to bed until that time. For example, if you sleep for six hours



Dr Simona Balestrini talking about TMS (see page 9)



on average and your wake up time is 7am, you shouldn't go to bed before 1am. This greatly improves sleep quality. For people with epilepsy, it is important to achieve this by moving the bedtime later in very small steps, 15 minutes a week, rather than in one go. This takes longer but it is worth taking things slowly. As sleep improves, we gradually make the bedtime earlier to increase sleep quantity.

Relaxation before bedtime

Progressive muscle relaxation is helpful for everyone. This is a matter of working through the body, tensing muscles in turn for five seconds and then relaxing them. This can help to get the body and mind into a relaxed state and ready for sleep.

You can read more about epilepsy and sleep in *Epilepsy Review* Issue 16.



"We've all got our own experience of epilepsy but in my experience I've had some seriously cool and funny seizures, coming back to some lovely, caring people."

I fall over every four to five weeks. But I don't need to be defined by what happens when I fall over.

You've got to think your way around things. With epilepsy, you may lose your mind but you don't lose your intelligence.

I run a paper diary, an electronic diary and I tell my wife what I'm doing. If I have a seizure, I have three ways back to working out what I'm doing."

REV BOB MAYO, VICAR OF ST STEPHEN AND ST THOMAS, LONDON AND CHAPLAIN AT QUEENS PARK RANGERS FOOTBALL CLUB. YOU CAN READ MORE ABOUT BOB IN EPILEPSY REVIEW ISSUE 19.

LOOK OUT IN EPILEPSY REVIEW FOR DETAILS OF OUR 2019 CONFERENCE

Why fundraising is in my DNA

In the first of a new series, **Debbie Bromley-Derry, 53**, tells *Epilepsy Review* why she ran the Great North Run for Epilepsy Society

I was privileged to have race number 0001 for the Great North Run on 9 September. This accolade should have gone to the Olympian and marathon runner Mo Farah, as he won the race last year. However, the race organiser, former Olympic athlete and BBC commentator, the amazing Brendan Foster gave me the accolade as he felt inspired by my journey with epilepsy.

Brendan has been a friend for a long time. I was also lucky enough to be supported through my training and through the run by another dear friend, Eugene Gilkes, who is a Commonwealth Games medal winning decathlete. Everybody at the Great North Run has been so supportive and encouraging and I cannot thank them enough. It is truly a great event.

My journey with epilepsy started when I was three years old and a high temperature triggered a seizure. For many years I did not realise the full extent of my epilepsy. I was a social worker for over 20 years. But my seizures became progressively worse.

At one point, around 2010, I used to experience up to ten seizures a day. My life was made up of "sleeping and seizing!"

I was fortunate that the brilliant staff at the National Hospital for Neurology and Neurosurgery (NHNN) and at Epilepsy Society's Chalfont Centre in Buckinghamshire were able to pinpoint the source of my seizures. On one occasion I was able to watch my seizures on a video. This helped me understand what my family experienced.

As a result of this assessment work, I had the opportunity to be one of the first people in the Rose Trial epilepsy surgery programme at the NHNN in 2012. This used radiosurgery, or gamma knife, as opposed to a temporal lobectomy, to treat my temporal lobe epilepsy. Throughout my journey I have been lucky to have the fantastic support of my husband, Kim and my two lovely daughters, Rebekah and Chloe-Lou.

The surgery changed my life and put me back on the planet. My word in life is positivity. Myself and my two daughters all had the word 'positivity' tattooed on us after my operation was a success.

I ran the Great North Run this year in order to raise money and awareness for the Epilepsy Society



and for the Epilepsy Surgery Friends Group, a Facebook group offering a network of support for people undergoing surgery, or who have undergone surgery in the past. I am a great believer in raising awareness and supporting others and I wanted to inspire hope in other people with epilepsy and give something back.

I hope that the money I have raised will push forward research into epilepsy surgery.

www.justgiving.com/Debs-Bromley-Derry

Will power

As a young man, the support that Andrew Redhead received from Epilepsy Society, helped change his life. Now a generous gift in Andrew's will could change the lives of many in the future.

Luke Edwards writes

Andrew Redhead was born in 1943 but in spite of having epilepsy as a child, he wasn't properly diagnosed until the age of 17. As a result he was often punished at school for his poor attention span, when he was actually experiencing seizures alongside his dyslexia.

Seizures meant that Andrew regularly found himself at home, confined to bed, but it was while convalescing that he developed a skill that he would carry with him throughout his life. Andrew had a natural instinct for fixing things, including everything from plumbing and electric circuits to heating.

"He just seemed to know innately how things worked," said his step-brother David Read.

"Friends, neighbours and relatives all turned to Andrew for advice or assistance. I think Andrew left a little of himself in every house he ever lived in."

Andrew experienced much stigma due to his epilepsy. And side effects from his medication often impacted on his social life and development throughout his teenage years and early 20s.

Andrew's brother, Paul, continued: "It was very difficult for Andrew to find employment, and we know of at least one instance where a promising interview was terminated when his epilepsy arose."

As a young man Andrew worked as a backstage technician at the local amateur dramatics society. However his family always described him as somehow "fading into the background."

That was until neurologist Professor Ley Sander, now medical director at Epilepsy Society, helped to turn his life around. Professor Sander discovered that Andrew was being prescribed the wrong medication for his epilepsy. Andrew was being prescribed sedatives rather than anti-epilepsy medication.

After a change of medication Andrew's health and seizure control improved dramatically and he was able to hold down a full time job, working as a technician at London Southbank University from 1969 right up to his reluctant

retirement many years later.

Andrew and his family also began to receive vital support and information from Epilepsy Society. This helped Andrew manage his epilepsy, but it also helped him deal with the associated stigma.

His brother continued: "The reference Andrew received after leaving the South Bank University shows that the early prejudice he encountered when looking for work, was entirely unjustified."

After his retirement Andrew dedicated his time to looking after his elderly parents, returning the care and tenderness they had shown him throughout his life.

Andrew passed away last year after a battle with prostate cancer. His epilepsy was well controlled and he had not experienced any seizures for a long time. But his brother Paul said Andrew's gift of a legacy to the Society was his thank you for the medical treatment and support he had received.

"He really appreciated being looked after by people who recognised that his epilepsy was as important and significant in his life as he felt it was."

Andrew restricted his legacy to research. His hope was that it would help drive forward Epilepsy Society's genomics research.

If you are considering leaving a gift in your will, please do call us to discuss. 01494 601300.

Cannabis and epilepsy: A story still searching for its happy ending

On 1 November 2018 the Government's landmark decision to reschedule some cannabis based products for medicinal use, came into force. The change in law means that specialist doctors in the UK can now prescribe medicinal cannabis to people with a limited number of conditions, including epilepsy. But what does the change in the law really mean for people and who is likely to benefit?

Nicola Swanborough and Luke Edwards provide an update

The context around cannabis has always been complex. Cannabis has been a legal issue in the UK since 1971 when its medical use was banned under the Misuse of Drugs Act. While many other countries began legalising cannabis for medicinal use long ago, until recently the UK has remained relatively hard-line.

To understand why the Government didn't immediately

back cannabis-based drugs we must understand how they work. The marijuana plant contains the active ingredients cannabinoids. These break down into cannabidiol (CBD) and tetrahydrocannabinol (THC). While the THC part is associated with the "high" of the cannabis drug and is illegal, CBD has been shown to relieve symptoms of epilepsy for some and, in its purest form, is legal.

A high profile campaign was

launched by the families of children with severe epilepsy who had benefitted from medicinal cannabis accessed abroad. Some products contained a higher proportion of THC than is legal in the UK. But the families wanted their children, and others like them, to have the same access to these medications in their own country.

In June of this year, the Home Office launched a review into the scheduling of cannabis and

cannabis-based products for medicinal purposes. Professor Dame Sally Davies, Chief Medical Officer for England assessed their therapeutic and medicinal benefits and found there was conclusive evidence of therapeutic benefit for certain medical conditions. As a result, these products were moved out of Schedule 1 into Schedule 2.

This means that the drugs can now be prescribed where there is an un-met clinical need. It also means that clinical trials can be carried out to investigate products which currently lack evidence to support their use.

However, as cannabis-based medicinal products are currently unlicensed and because there is still a limited evidence base for their use, only a specialist doctor can prescribe them and this will be on an individual basis.

The reality is that currently medicinal cannabis can only be prescribed in three specific conditions meaning very few people in England are likely to be eligible and the tight guidelines around prescribing indicate many who campaigned for a change in the law are likely to be disappointed. Only products containing CBD can be prescribed. Those with greater than 0.2 per cent THC – as with many products accessed outside the UK – remain illegal.

Cannabis-based medicinal products can only be considered for the following three conditions:

- Children and adults with rare, severe forms of epilepsy

“The reality is that currently medicinal cannabis can only be prescribed in three specific conditions, meaning very few people in England are likely to be eligible

Getting a prescription for medicinal cannabis



Cannabis-based medicinal products can only be prescribed by a specialist. A GP cannot prescribe the medication but could refer you to a specialist. The specialist will discuss

all other treatment options with you first before considering a cannabis-based product.

A prescription for medicinal cannabis would only be given when all other treatment options have been tried or are considered unsuitable, and would only be given if the doctor considers it to be in your best interests.

People always have the option of seeking a second opinion.

- Adults with nausea caused by chemotherapy
- Adults with MS-related muscle spasticity.

NICE – the National Institute of Health and Clinical Excellence – is drawing up formal guidance on the prescribing of medicinal cannabis. This is expected to be published in October 2019. In the meantime, the British Paediatric Neurology Association (BPNA) has drawn up interim guidance around epilepsy on behalf of NHS England. The Association of British Neurologists is currently drawing up guidance for adults.

What does the guidance say?

The BPNA guidance states that non-licensed medicinal cannabis should only be considered for children who:

- have an epilepsy that does not respond to conventional licensed anti-epileptic medications
- have not responded to the ketogenic diet or who are not suitable for the ketogenic diet
- who are not candidates for epilepsy surgery.

The BPNA states that the current best evidence for medicinal cannabis is CBD, a highly purified liquid, which has been licensed in the US by the Food and Drug Administration and is currently going through the application process for a licence from the

European Medicines Agency. CBD does not contain any significant amount of THC.

The BPNA is only recommending CBD because there is evidence to show that this newly developed drug can be effective in reducing some type of seizures in Dravet and Lennox Gastaut syndromes.

While some studies have also suggested that THC may have an anti-epileptic effect, animal studies suggest it can also trigger seizures. There is no evidence from randomised controlled clinical trials for products with higher proportions of THC (more than 0.2 per cent).

Concerns have also been raised about the effect of THC on the developing brain in children and young people. Evidence suggests that chronic exposure to THC can affect brain development, structure and mental health.

There is also no good scientific evidence to support suggestions that the addition of THC in combination with CBD increases the efficacy of cannabis-based medicinal products for children.

The BPNA also recommends that where children are already taking other cannabis-based products that contain higher proportions of THC, they should be transitioned on to CBD until strong evidence for these products can be produced through clinical trials.

The Government has no plans to legalise the use of cannabis for recreational purposes.

For the love of Noah

Faye Waddams and her husband **Chris** have a beautiful son, three-year-old Noah. But Faye describes her first pregnancy as hell. Her seizures put her life and her baby's life at risk several times. So choosing whether to go through it all again so that Noah could have a little brother or sister was a heart wrenching decision. Here Faye explains the anguish of weighing up all they had against all they could lose in order to make their family complete



I always imagined that I would have two children. I am very close to my sister and I always thought that I would give my children the chance to have that same relationship. The idea of growing up without a sibling felt alien to me.

In October 2014 I was seizure free and was thinking about driving again. Then I found I was pregnant with our much wanted baby and everything changed.

I suffered with hyperemesis gravidarum and almost instantly began experiencing complex partial seizures. The sickness made it impossible to keep my medication down and my drug levels were plummeting (a common problem with lamotrigine in pregnancy).

I suffered my first tonic clonic seizure in pregnancy at five months and as a result I fell down a flight of tube station stairs. It was the worst moment of my life.

The doctors thought I had broken my neck. They were unsure if my baby was ok and then if the stress of the fall would make him come early. I was hospitalised and then either housebound or constantly with someone.

But a month later on a trip to the seaside I went to get a parking ticket. With no warning I suffered my second tonic clonic seizure during pregnancy, waking up face down, with nobody around to help.

For a second time I was hospitalised and this time I was experiencing Braxton Hicks contractions. Once again there was a fear my precious baby would come too early.

I was eventually induced three weeks early and Noah arrived safely on 13 June 2015. My pregnancy was hell. It scared my family and it scared me. Sudden Unexpected Death in Epilepsy (SUDEP) was frequently mentioned and finding the balance between what was best for me and best for my baby meant I was often making heart wrenching choices. Having said that, I would do it all again to have Noah.

After going through all of that,

it was no longer a given that we would have another child. It was obviously something myself and my husband needed to talk about. Initially, we brushed it under the carpet, getting on with parenthood and gaining control of my epilepsy again. But as Noah turned two it became the elephant in the room.

This was the year we were supposed to start trying for another child, but neither of us mentioned it. It weighed heavily on us.

Chris was first to broach the subject. I remember my heart breaking as he told me he didn't know if he could put me through it all again. He said to me "Why should I gamble with my luck? It feels like we dodged some huge bullets during pregnancy with Noah."

It broke my heart that I knew he wanted a second child and I felt it was my fault that he wouldn't have one. We looked into other options such as surrogacy and adoption, deciding they weren't for us.

For the next year we were like a yo-yo. One minute I was all for a second baby while Chris would be dead against it. Then the tide would change and I'd be against it while Chris was all for it.

During this time my medication was also changed and a secondary drug was introduced. I had been advised not to fall pregnant while on this drug but the choice was still ours. I did my research, I knew the risks of the medication and have seen the devastation some epilepsy drugs can cause for families.

Chris explains his concerns to Faye about the risk of her going through a second pregnancy

"You've got several sheets of bullet proof glass lined up spinning on an axle, some clockwise and some anti clockwise and all at different speeds. Each sheet of glass has holes in it big enough for a bullet to be fired through. Then you've got a gun being fired at the bullet proof glass."

"Nine times out of 10 the bullet hits the glass and nothing happens. Then that one time it gets through a hole, but you're lucky again and it just hits the next sheet of bulletproof glass. This could keep happening over and over again and the

"I remember my heart breaking as he told me he didn't know if he could put me through it again... we dodged some huge bullets during pregnancy with Noah"

Noah's third birthday came and went. We had a perfect son and it was time for us to make a decision. We sat down one evening and finally both agreed. If I couldn't carry another baby then we were more than ok with only having Noah.

It turned out we were both scared of upsetting the other by saying we didn't want to take the risk.

It's a big decision to make and I struggled to find any support which is why I now run a support group.


It still hurts and breaks our hearts to have had to make that decision. But I am forever grateful that our story continues. We may only have one child but our hearts are full and our life complete.

Find out more at:

fairyfaye1986.weebly.com
epilepsysociety.org.uk/pregnancy-and-parenting

worst case scenario never happens. But eventually that gun is going to be fired just as those holes all line up and that bullet is going to travel through and destroy everything you hold dear.

"This is how I feel about you falling pregnant again. We might have a smoother journey the next time you are pregnant, but we might not. It could mirror your pregnancy with Noah blow for blow. But it could also result in my wife and unborn child dying."



Make sure you have a review of your epilepsy

Did you know that you should have a review of your epilepsy every year? This is your chance to make sure that your medication is giving you the best possible seizure control, with minimum side effects. If you haven't been called in for a review by your GP, make sure you call them and arrange a date.

Luke Edwards writes

Your epilepsy review is exactly that – yours. The NICE guidelines state that all adults with epilepsy should have a review once a year with their GP or specialist. A review is your opportunity to discuss with a healthcare professional how epilepsy impacts on your life.

Your review gives you a chance to talk to someone about anything that's worrying you and to try and find a solution together.

The following are just a few examples of issues you might like to discuss at your review:

- **Seizures** From variations in timings to length of seizure, any

change could denote a need to amend your medication. If you have a seizure diary, take that along with you. If anyone has captured your seizures on a mobile phone, with your permission, that would also be useful to share with your GP or specialist

- **Medication** If you are experiencing any side effects such as dizziness, tiredness, weight change, memory loss or cognitive impairment discuss these with your doctor. It could be that your dosage needs changing.

- **Reminders** Taking your medicine on time is important. Alarms and timed text messages are available

to remind when to take your medication.

- **Stopping your medication**

Sometimes, depending on the cause of your epilepsy and how easily it was controlled with medication, your doctor might suggest you gradually stop taking your medication. However, this should only ever be done under the supervision of a doctor. For many people, it is important to take medication for life.

- **Other medication** Any other medication you take, including the Pill, could affect your epilepsy medications so this is your chance to check there are no interactions.

- **Women** You may have noticed that you are experiencing more seizures around the time of your period or you are thinking of starting a family. These are issues that should be discussed.

- **Sodium valproate** If you are a woman of childbearing age and are taking sodium valproate you should be called in for an annual review to discuss the risks around sodium valproate during pregnancy; to discuss the need for effective contraceptives; and to consider whether you should change to a different medication. You should never stop taking your medication without the supervision of your doctor. You can read the guidelines around sodium valproate at epilepsysociety.org.uk/sodium-valproate-guidelines

- **Anxiety and depression**

Many people with epilepsy experience these. It is important to tell your doctor how you feel and discuss any coping mechanisms.

- **Stress, lack of sleep, alcohol and recreational drugs** All these can affect seizures so are worth talking about at your review.

- **Sudden Unexpected Death in Epilepsy (SUDEP)** This only happens to a very small number of people with epilepsy – about 1 in 1,000. By talking about your epilepsy at your review you can work out how it can be best managed to help keep you as safe as possible. Find out more at epilepsysociety.org.uk/sudep

"I have been suffering from seizures during the day for about three years now and although I am not aware of what is happening during the seizure, I definitely know when one has happened and of course people are able to tell me.

However, I wonder whether I might also be having seizures in my sleep. I live on my own so there is no-one for me to ask. I often wake up feeling exhausted and a bit sore although I've never woken up on the floor or with blood on my pillow from biting my tongue. How could I find out if I am also having night time seizures?"

MARK, HARLOW

Your replies

I would recommend investing in a watch that detects convulsive seizures and alerts your chosen caregiver through the alert app. Although I live with my partner, there are some days where I am alone early in the morning and if it wasn't for the watch then I wouldn't have known I have had some seizures whilst asleep. *Hannah, facebook.com/epilepsysociety*

I make sure there are no sharp corners around my bed, just in case I have a seizure in the night and hurt myself falling out of bed. *Michelle, Monmouthshire*

Speak to your epilepsy nurse. My mum had a bad spell with epilepsy and they gave her a camera to take home. She also had to wear an EEG glued to her head for two days. The EEG noted changes in her brain, then the specialists would look at the camera to see what she was doing. *Becky, facebook.com/epilepsysociety*

I have an alarm on my bed which detects my seizures and calls a company who checks that I'm safe. Maybe make a journal of how you feel the day after you think you've had a seizure to compare with how you feel normally. Or maybe if you can feel a seizure coming on set up a camera.

I would say if you think you're having nocturnal seizures I would get a cheap removable barrier to put on your bed. Mine just slips under the mattress but you don't want to risk injuring yourself as I have in the past. *Brenna, facebook.com/epilepsysociety*

It might be worthwhile to buy an anti-suffocation pillow just in case you have night seizures. Talk about it with your epilepsy nurse or specialist, they'll be able to help you. *Daniel, Cardiff*

You can also buy alarms and bed monitors for movement and sound. Google them and it brings

Next issue

My 22-year-old son has had uncontrolled seizures for eight years. He has tried 12 medications and the ketogenic diet. He is not suitable for surgery and our consultant will not consider medicinal cannabis because the trials have only been done on children. Has anyone else gone through the same experience and how did they overcome it?
DARREN, MANCHESTER

Would you like to share your thoughts with Darren?

Email nicola.swanborough@epilepsysociety.org.uk, write to Editor, Epilepsy Review, Epilepsy Society, Chalfont St Peter, Bucks, SL9 0RJ, or reply at: facebook.com/epilepsysociety

up lots of companies Our son Richard, aged 24 years, died from SUDEP in 2004. I would hope this technology would help prevent deaths like Richard's. *Isabelle, facebook.com/epilepsysociety*

If I have a night-time seizure, I wake up with a general feeling of haziness and a weakness that isn't associated with sleep. I'd also wake up with a few bruises from my convulsions. If you're unsure about if you've had a seizure in your sleep, you could ask a friend to stay a few nights at your house to keep an eye on you. *Joshua, Liverpool*

I would have a chat with your GP and if necessary ask if you can be referred to a specialist for 24 hour tests with videotelemetry. *Eamonn, Reading*

You can read more replies to Mark's letter at facebook.com/epilepsysociety

Tonic comic

Stand-up comic and all-round funny girl Juliet Stephens has the last laugh when it comes to her epilepsy

I am really pleased to hear that Prof Sanjay Sisodiya, the Epilepsy Society's Director of Genomics, ran the Royal Parks Half Marathon to raise money for a TMS-EEG machine (see page 8). I applaud Professor Sisodiya's commitment to take on a challenge, relying on the generosity of friends, family and perhaps readers (and columnists) of *Epilepsy Review* to help him reach his fundraising goal.

I am sure Professor Sisodiya is a healthy sort of chap, and hopefully someone who already chooses to run for "fun". Personally I do not run for fun, I run for cake. Running is awful, as far as I'm concerned – hence my admiration, and if I'm really honest, resentment for those who sincerely enjoy it.

I did join a running group as a way to meet people when I moved to Kent. It wasn't a great success, because I couldn't manage much in the way of conversation. I was limited to "hello I'm not looking forward to this..." before we set off and the "well that was awful, thank god it's over," at the end.

You'll understand then, that in spite of my cynicism for running, my sense of achievement when I do it is wildly disproportionate to what I have actually achieved. For example, I took part in a 10k run in May 2014 to raise money for Epilepsy Society, and I'm still wearing the medal now. I won't lie, wearing a medal feels pretty heroic. I really would love to be the kind of person who sincerely loves to run;

someone who after a busy and stressful day at work, slips into their running shoes and goes out for a quick 5k as a way to 'relax'.

I'm not a total slob though, I do exercise, but walking is more my pace. A healthy lifestyle does involve exercise, and what better way to discover new parts of the world than a nice long walk.

My Dad has also become fonder than ever of walking. He had a

“ Personally, I do not run for fun, I run for cake. Running is awful as far as I'm concerned, hence my admiration for those who enjoy it

heart attack and bypass and valve replacement surgery in 2016. As part of his recovery he bought an activity tracker – a wristwatch which calculates how many steps you walk in a day. As he got healthier he became slave to his activity tracker, through which he could set himself daily targets to increase his distances and challenge himself.

It was only a matter of time before he found a charity challenge and over a family Sunday lunch he declared: "I've found a walk." Well it would have been churlish to have

asked the 70-something-year-old heart attack survivor about the details of the walk before instantly jumping in with enthusiastic support, encouragement and "Well of course we'll all join you – it'll be a family fundraising challenge".

It was only later we learned that the walk, whilst delightfully scenic, was 30 miles/47 kilometres long. That's nearly four miles/eight kilometres more than a marathon! I did several training walks but none of them ever more than about 15 miles/24 kilometres and at the end of them, the prospect of walking that same distance all over again was dreadful. I began to worry for all of us. What we had signed up to was not a pleasant country walk, but an endurance event.

We started at 8am on a very hot day in June, my siblings, husband, Dad and I. We knew we had to keep drinking water and only stopped twice along the way.

I didn't imagine it would be as tough as it was, but it was tough. Whatever you are doing, even if it's your absolute favourite thing in the world, after doing it for eight or nine hours, you tire of it. We made it though. The whole walk took us over 12 hours. It was in equal measure brilliant and awful. We got blisters and tired muscles, but we made memories and raised money.

As with Professor Sisodiya, I wish any readers who have similar challenges in the pipeline all the very best with all your fundraising endeavours. I hope you all get a medal at the end. Wear that with pride, fellow heroes!

Juliet Stephens
Laughing allowed

Society matters



Going the extra mile

This autumn, 14 employees from across the Epilepsy Society at Chalfont St. Peter went the extra mile for the charity. 'Team Purple' ran, swam and abseiled to raise vital funds to support people with epilepsy.

Epilepsy Society's director of genomics, Professor Sanjay Sisodiya and two of his colleagues donned their running shoes and took on the Royal Parks Half Marathon. Read more about their run on page 8.

Lorenzo Caciagli, a research fellow in the MRI unit and a keen open-water swimmer, swam two miles in London's Swim Serpentine in September.

Also in September, 40 fearless supporters, including eight employees, abseiled 540 feet down Broadgate Tower in London to raise funds for the charity.



Our own superheroes

An amazing team from the Epilepsy Society went above and beyond the call of duty by channelling their super powers for the Superhero Tri 2018.

Seventeen caped crusaders from Micholls House, one of our residential care homes in Chalfont St Peter, were joined by staff, friends and families. They were all on a mission to pull on their masks and capes, and have the best time ever.

The Superhero Tri Challenge at Dorney Lake near Windsor included a swim, cycle and push/run, or participants could run, walk, push or cycle around the picturesque lake.

As well as having fun, the Epilepsy Society team was raising money for special projects at Micholls House.

Manager Tracy Cousins said residents, staff and their families had been looking forward to the event for weeks. "This was a brilliant opportunity for us all to get together and have fun and at the same time raise money for something that everyone in the house could enjoy".

Purple Day planning

Purple Day, the international day for epilepsy, is on 26 March, and although it's still several months away, it's never too soon to start planning how you might like to raise funds and awareness to support people with epilepsy.

With your help in the past, the Epilepsy Society has turned workplaces, schools and even Trafalgar Square purple.

Whether it's a bake sale, a fun run or a parachute jump, all proceeds raised go towards helping people with epilepsy. Just £17 means that someone can speak to our confidential helpline for as long as they need to.

Head to epilepsysociety.org.uk to find out more or email fundraising@epilepsysociety.org.uk.

And another date for next year's diary – National Epilepsy Week will be from 20-26 May 2019. Look out at epilepsysociety.org.uk for more details.

Get into the festive spirit

Don't miss out on Epilepsy Society's range of Christmas cards available through our online shop. This year, there are 16 different cards to choose from with designs to suit all tastes.

Prices start from £3. Go to epilepsysociety.org.uk/christmas-cards to view the range.

All dogs and Christmas cheer

Dogs were the centre of attention when we held an afternoon of fun on Bank Holiday in August at our Chalfont Centre in Buckinghamshire.

Dogs of all shapes and sizes took part in the dog show hosted by Doberdayz, with prizes in multiple categories including: best puppy and most handsome dog. We also had a visit from 'Chase' from children's favourite Paw Patrol (right).

Visitors had the opportunity to take a peek inside the charity's research laboratories and understand more about the causes and treatment of epilepsy.

Visitor John Lisle from Chalfont St Peter, said: "We found the tour of the research centre absolutely fascinating. The range of projects being undertaken was amazing and the genomics

research was particularly impressive and exciting."

As we went to press, we were preparing for a second event at our head office our Christmas 'Chalfont Cheer' afternoon.





Helpline

01494 601 400

Monday and Tuesday 9am to 4pm,
Wednesday 9am to 7.30pm.
Confidential, national call rate.
Information and emotional support.

Epilepsy Society

Chesham Lane
Chalfont St Peter
Buckinghamshire
SL9 0RJ

Enquiries 01494 601 300
Fundraising 01494 601 414

epilepsysociety.org.uk



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**"Thank you for helping to
keep the helpline open for
people throughout the year."**

Rev Bob Mayo

A lifeline for people with epilepsy

The Epilepsy Society helpline is a vital resource for many people with epilepsy when they need a listening ear or expert knowledge. Reverend Bob Mayo has used the helpline on many occasions and has written to our supporters this Christmas to ask for their help to maintain and expand the helpline so others may benefit.

Read Bob's letter and make a donation at
epilepsysociety.org.uk/christmaslifeline