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GENOMICS

*Whole genome sequencing –
how it will make a difference
to people with seizures*

Changing people's lives, page 8

SEIZURE CONFUSION

*People with seizures say they
are often wrongly accused
of being drunk*

It's epilepsy, actually, page 15

CULTURE

*Read about BBC Radio 4's
new play looking at a young
mum with epilepsy*

Slipping through time, page 18



REVIEW

**epilepsy
society**
125 years

epilepsysociety.org.uk

There's no escaping the fact that the world has gone digital. The potential for disseminating information by 'liking', 're-tweeting' or 'sharing' is huge. With the tap of your finger on a tablet or phone, you can instantly let friends and acquaintances the world over know what interests you, makes you laugh, or what you value and think they might value too. On page 15, you can read how a single post on our Facebook page was shared 2,209 times. Powerful stuff!



But there is still something special about personally and physically sharing an item of your own that you value in the real world. Taking the trouble to seek out a friend or neighbour and give them something you feel may be of use or interest to them, is equally important and touching.

That is why we have printed extra copies of this issue of *Epilepsy Review* to share at our annual conference in London. We know this might mean some of you may receive two copies of the magazine – one at the conference and one in the post – but we hope this will give you the opportunity to pass one of them on to someone who you feel might benefit from reading it.

Whether you have passed on the magazine by calling round to a friend to hand deliver it, or have walked to the post office to buy a stamp and send it via traditional methods, the effort will endorse your consideration and care and could make a difference to someone's life.

We rely heavily on people sharing at Epilepsy Society and we are always grateful

for people's generosity in sharing their stories to raise issues around epilepsy. Again you can read the impact of this on page 15.

But perhaps more unusually, this spring we are very grateful to the neighbours of one of our supporters who, without hesitation, have lent us one of their newly born lambs to help us raise money for epilepsy around Purple Day on 26 March.

It's a good example of the bon homie of old-fashioned neighbourliness meeting the viral velocity of Facebook and Twitter. It's a synergy that will hopefully bring in vital funds to support research into the causes of epilepsy, and improve diagnosis and treatment of the condition.

You can see our purple lamb on page 5 or follow us at [Facebook.com/epilepsysociety](https://www.facebook.com/epilepsysociety) or [Twitter.com/epilepsysociety](https://twitter.com/epilepsysociety) so you can share the springtime joy with your friends and family.

Nicola Swanborough
Editor



FRONT COVER

Gus the gnome

Adopt your very own gnome for just £5 (+ p&p) and help to fund vital epilepsy research. See the back cover for more details or call 01494 601414 or order online at [epilepsysociety.org.uk/shop](https://www.epilepsysociety.org.uk/shop)

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APPOINTMENT

Epilepsy Society's new CEO, Clare Pelham says we can now 'glimpse a different future'



Epilepsy Society has appointed a new chief executive, Clare Pelham. Her appointment comes as the charity marks the 125th anniversary of its foundation in 1892.

Clare joins the charity from Leonard Cheshire Disability where she was chief executive for five years.

Clare said: 'I am delighted to join Epilepsy Society as it marks its big birthday. This 125th year will be a defining moment in our history. These are hopeful times for all those affected by epilepsy. Thanks to amazing advances by our pioneering scientists, we can now glimpse a different future on the horizon.'

Before joining Leonard Cheshire Disability in 2010, Clare was the first chief executive of the Judicial Appointments Commission and held senior positions in the Cabinet Office, Home Office and Department for Constitutional Affairs.

She has also worked in the private sector at IBM and was a member of the executive committee of Coca Cola GB and Ireland where, as director of active lifestyles, she was responsible for the company's partnerships with the voluntary sector.

Vice chairman at Epilepsy Society,

Adrian Waddingham, said: 'We are delighted to welcome Clare to the Society. We are looking forward to working together to deliver expert care at the Chalfont Centre, continuing our cutting edge research and providing support to the half a million people living with epilepsy in the UK.'

Clare's appointment times with a landmark year at Epilepsy Society as the charity enters a new and exciting era of genetic research which it hopes will lead to improved diagnosis and personalised treatment of epilepsy.

Through an ambitious genomics project, it is hoping to unravel the underlying genetic architecture of epilepsy, to help understand the causes of the condition and how it might be better diagnosed and treated.

Alongside genetic research, the charity is also continuing its innovative neuro-imaging programme, looking deeper into the brain than ever before and teaching computers to read information on brain scans that the human eye might be missing.

You can read about the history of Epilepsy Society on page 11 and find out more about its genomics project on page 8.

PHARMACEUTICALS

Tribunal puts health ahead of business

Epilepsy Society's chief executive Clare Pelham is encouraged that the health of patients is being put ahead of business after the Competition Appeal Tribunal refused to suspend a ruling that drug companies Flynn Pharma and Pfizer had to reduce the price of phenytoin sodium capsules.

In December 2016, The Competition and Markets Authority (CMA) fined distributor Flynn Pharma £5.2 million and Pfizer a record £84.2 million after it accused the pair of "excessive and unfair" pricing for the epilepsy medicine, pricing that saw the price of the drug increase by up to 2,600 per cent over night.

Flynn Pharma asked the Competition Appeal Tribunal (CAT) for the CMA's decision to be suspended while they appealed against the watchdog's decision. The UK-based drug company said that if it were forced to reduce its prices it would not be "commercially feasible" to restore them at a later date should their appeal against the CMA's decision be successful. However, the tribunal concluded that the harm to the public from allowing the continuation of higher prices for the product outweighed the harm to Flynn that this may cause.

Chief executive of Epilepsy Society Clare Pelham said: 'I am encouraged that the Competition Appeal Tribunal is putting the health of patients and the sustainability of our hardworking NHS ahead of business.'

Sad farewell to loyal supporters

Epilepsy Society has said a sad farewell to three loyal supporters who gave time and effort to help raise awareness of epilepsy and funds for research into the condition.

The legendary jockey Walter Swinburn, right, who was diagnosed with epilepsy following a riding accident in 1996, has died at the age of 55 after falling from a

window at his London flat. The nation's much-loved Rabbi, Lionel Blue passed away after a lifetime where he insisted at laughing at his own epilepsy. And BBC weatherman Ian McCaskill, a long-standing friend and vice president of the Society, has died at the age of 78.

We are very grateful for the support they gave people with epilepsy.



BENEFITS

Changes to PIP



Epilepsy Society has contacted the Department of Work and Pensions following news that it is amending the assessment criteria for PIP – personal independence payments.

PIP is a points-based benefit designed to contribute to the extra cost of living with a disability. It is divided into two categories – daily allowance and mobility allowance.

Two Upper Tribunal rulings recently challenged and broadened the criteria under which PIP should be interpreted.

The first ruling said someone who needed support in managing medication and a health condition at home should be scored equally to a person who needed support with therapy such as home dialysis.

The second ruling said claimants who experience 'overwhelming psychological stress' when travelling alone, should receive similar points to someone who has trouble navigating. Someone with anxiety issues would receive similar points to a person who is blind.

Penny Mordaunt, minister of state for disabled people, health and work, told parliament in a written statement that the rulings broadened PIP beyond its original remit to recognise people with non-physical conditions in the same way as those with physical ones. She said the amendments would not result in any claimants seeing a reduction in the amount originally awarded by DWP.

Epilepsy Society has asked that the DWP engages with patient groups before future amendments so that changes can be accurately communicated to ensure people get the right information.

TECHNOLOGY

Watch finds seizure links

New research using an Apple Watch app to track epileptic seizures, has found that the most common triggers are often stress and missed sleep.

The 10-month study looking at 177 people with focal seizures and auras, found that 37 per cent of seizures were linked to stress, 18 per cent to lack of sleep, 12 per cent to menstruation and 11 per cent to over exertion.

The study found that stress was more commonly reported as a trigger for participants who worked full-time, at 35 per cent, compared to those who worked part-time, 21 per cent; were unemployed, 27 per cent; or were disabled, 29 per cent.

The study was supported by John Hopkins University, Baltimore. Researchers hope wearable technology will one day be able to predict seizures.

Epilepsy Society's medical director Professor Ley Sander commented: 'This is certainly the way forward in terms of data collection and hopefully in the future it may help us to predict seizures and give people better control over their lives. However at the moment it is only relevant to those with focal seizures.' epilepsysociety.org.uk/apple-watch

MEDICATION

Risk of falls

People with drug resistant partial seizures who are prescribed the epilepsy drug perampanel, should be counselled and monitored about the risk of falls.

Recent clinical studies, published in the journal, *Epilepsia*, showed that in this group, 5.1 per cent of people experienced falls in comparison with 3.4 per cent of those who were treated with a placebo.

The studies showed that the risk of falls, particularly in the elderly, was related to dose, but that higher doses also helped to control seizures and reduce their frequency. Treatment should be appropriate to each individual's profile.

In people with primary generalised tonic clonic seizures, the rate of non-seizure related falls was low.

TRANSPORT

Please offer me a seat

Transport for London (TfL) has announced it is to roll out its badges for people with hidden disabilities this spring.

The 'Please offer me a seat' badge and card were trialed last year by 1,200 people in London. During the trial, people said 72 per cent of journeys were easier as a result of the badge.

It is thought that TfL will become the first European transport provider to officially recognise hidden impairments in such a way.

There is no set definition of conditions that qualify for the badge and card, but TfL says the system will be based on trust – as with its 'Baby on board' badge scheme.

Epilepsy Society commented: 'This is great news. People with uncontrolled seizures are unable to drive and often rely on public transport. Unless someone has a convulsive seizure in public, their epilepsy is often invisible and it may not be obvious that they would benefit from being able to sit down.'

'Hopefully other transport companies will follow TfL's example and adopt similar practices.' Visit tfl.gov.uk/accessibility

RESEARCH

New molecule holds hope

A new small molecule called ADX71149 could have anti-seizure properties when taken on its own or in combination with the epilepsy drug, levetiracetam.

Studies carried out in epilepsy models by Janssen Pharmaceuticals in collaboration with Addex Therapeutics, showed that while seizures are reduced when the molecule is administered on its own, a fixed dose of the molecule could increase the potency of levetiracetam by 35-fold.

Tim Dyer, chief executive officer of Addex said: 'Treatment-resistant epilepsy remains a high unmet medical need, with new avenues of treatment urgently needed. We are continuing to explore with Janssen how best to move ADX71149 into a Phase 2a proof of concept study.'

Thank ewe!



This little lamb is in a field of her own as she helps us raise money for Purple Day, the international day for epilepsy on 26 March. Text PDAY26 £4 to 70070 or follow the link below to find out how you can donate.

epilepsysociety.org.uk/purpleday

PEOPLE

Philip wins award

Epilepsy Society's Professor Philip Patsalos has been awarded the 2016 Excellence in Epilepsy Award by the British Chapter of the International League Against Epilepsy. The accolade is for lifetime achievement in the field of epilepsy.

Professor Patsalos is head of the charity's Therapeutic Drug Monitoring (TDM) Unit at the Chalfont Centre in Buckinghamshire, where he has worked for 34 years. He is also professor of clinical pharmacology at the Institute of Neurology-University College London.

John Paul Leach, president of the ILAE British Chapter said: 'Philip's landmark studies have been absolutely pivotal in allowing the adoption of the newer anti-epileptic drugs introduced since the 1990s. He is held in such warm and high regard and is a particularly fitting recipient of this year's award.'

PEOPLE

Top in neurology

Epilepsy Society's medical director Professor Ley Sander has been presented with the Professor Baldev Singh Oration Award in recognition of his outstanding work in neurology.

The award was presented at the 24th Annual Conference of the Indian Academy of Neurology in Kolkata, where Professor Sander was talking about epilepsy and women and how technology can help to reduce the impact of seizures.

Watch it on video

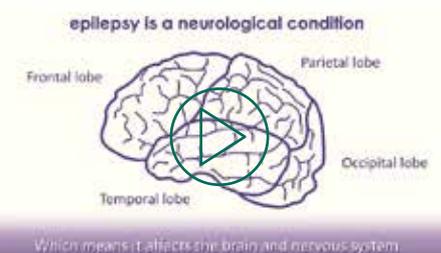
You can find these videos at youtube.com/epilepsysociety



Stuck for ideas for fundraising on Purple Day, 26 March 2017? Check Hayley's 'how to' video.



Listen to our chief executive Clare Pelham, talking on Sky News about the overpricing of epilepsy drugs.



Take a look at our epilepsy awareness raising video.



Find out how to put someone in the recovery position.

Me and my epilepsy

Deborah Mann

Deborah Mann and her two daughters all live with disabilities and all care for each other. Here Deborah describes how they push forward together, never allowing epilepsy to beat them.

Hanging on to life

During my first few days of life, I died three times due to a lack of oxygen. The priest was called and I was given the name 'Nicola'. I was expected to die. Obviously I didn't, so to celebrate my living, I was re-christened 'Deborah'.

Early diagnosis

I was diagnosed with epilepsy at the age of 12. An aunt found me unconscious and blue at the end of a seizure. They think the epilepsy was caused by lack of oxygen at birth.

My mum says I was never quite right but she could not put her finger on it. There were things in my personality that bothered her. I was very emotional and would go from one extreme to the other. I was always clumsy. Mum thinks I have always had epilepsy, but undiagnosed. She thinks I was having absence seizures before I had my first tonic clonic seizure.

Failing at school

I wasn't good at anything at school whereas my brother and sisters were. I always wanted to be more like them. I wanted to achieve more but was put in a class for children with learning difficulties.

I came out of school with no qualifications. I couldn't be bothered. Even when I left school and took a one-year secretarial course at college, I did really badly.

Living with fog

Initially I was prescribed phenytoin, then at the age of 14, I was put on sodium valproate. That made everything foggy for me. I couldn't think straight but that just became the norm.

I assumed everyone else was the same. Memories of that period are very unclear. I reacted to life rather than experienced it.

Pregnancy and loss

At 24 I became pregnant but lost my first daughter, Trelissa. I then lost a son, Keverne, and a second daughter, Jasmine.

When I was expecting my fourth baby, I was taking a high dose of sodium valproate. Rhonnie was born with two holes in her heart and was diagnosed with fetal valproate syndrome. My fifth child, Branwen was also born with fetal valproate syndrome.





Living with disabilities

Both my daughters have congenital malformations, dysmorphic features, learning difficulties, Asperger's, odd feet and are short sighted. Branwen, 21, has hypotonia which means her nerves are not stimulating her muscles properly. Rhonnie, 23, has hyperextendable joints that pop out all the time. She has asthma and some of her organs don't function properly.

Sign language and seizures

Rhonnie is also deaf. I have learnt sign language so that I can communicate with her. Sadly she can't sign back to me as looking at the signs triggers my seizures. This is because of damage in my brain behind each of my eyes.

Cognitive difficulties

Rhonnie experiences a lot of pain and dizziness. She is taking part in a Prince's Trust back-to-work course

which involves team building and boosting qualifications. It really helps if she is happy and busy.

Branwen looks after children with learning difficulties. She is now finding it difficult to write and her memory is appalling. She is losing her cognitive abilities and has chronic migraine. An MRI has shown that she has a malformation in her brain and a pituitary cyst. She is very frightened.

Frightening as a mum

It is frightening on a daily basis for me as a mum. Over the years my health has deteriorated too and my marriage broke down. We are all disabled and all carers. We have to push forward together. We are going to be assessed as carers but not as disabled people, but at least we will have some support.

The fog lifts

Nine years ago, under my consultant at the National Hospital for Neurology and Neurosurgery, I came off sodium valproate. I am now on lamotrigine and lacosamide. It has made an enormous difference to my life. I have found that I am actually quite intelligent. The fog has lifted and I am able to think differently. I now teach adults human biology. I used to have seizures a few times a week, now I only have two or three a month.

Making life better

Best of all, I have been able to be pro-active for my daughters. I don't drive so we have to take public transport, but I have been able to work out better, more logical routes. I have also been able to look at what

is available for them and what they can achieve. Rhonnie finds my seizures very stressful but a counsellor has taught her how to deal with stressful situations.

Both girls have done a first aid course. This empowers them to feel in control and takes away a lot of fear.

Support through OACS

I am now secretary of OACS, the Organisation for Anti-Convulsant Syndrome. We support families affected by this syndrome. I talk to many mums and can't believe the stress that many people with epilepsy live under, without any support. When you are caring for a family, it is very important not to feel alone. Mums with children with fetal anti-convulsant syndromes are some of life's heroes. No-one wants to believe this can happen today.

Feeling lucky

I think I have been a very lucky person. I would not be me today without my experiences of frequent prejudice. The challenges that come with my epilepsy have moulded me. Things may not always be great, but I am not unhappy with me today.
oacscharity.org

Tell us your story

Would you like to share your story about how epilepsy impacts on your life. You might also like to talk about the effect it has on those around you. Or you might like to talk about how you get on with your life in spite of your epilepsy.

To share your story in *Epilepsy Review*, please:

- Fill in our online form at epilepsysociety.org.uk/become-media-contact
- Download the form at epilepsysociety.org.uk/yourstoryresearch and send to: Press Office, Epilepsy Society, Chesham Lane, Chalfont St Peter, Buckinghamshire SL9 0RJ.
- email pressoffice@epilepsysociety.org.uk for a copy of the form to send to us at the above address.

Genomics

Changing people's lives



Professor Sanjay Sisodiya, our director of genomics, explains how the new era of whole genome sequencing will make a difference to those whose lives are dominated by seizures



Before his diagnosis Aidan was languishing on the sofa and had little interest in life. Today he is back in supported living. He is responsive to friends and family and has even been to see Take That. This photo was taken when he came home for Sunday lunch."

ANN-MARIE MCKENDRICK, AIDAN'S MUM, TALKING ABOUT THE GENETIC DIAGNOSIS THAT CHANGED HIS LIFE (FULL STORY, PAGE 10)

The happy, smiling photo of Aidan below, is what genomics is all about. It is about the Sunday lunches: it is about giving people quality of life and the ability to enjoy the simple pleasures that we take for granted – roast potatoes at home with the family, a trip to see a favourite band with friends.

Genomic medicine is the diagnosis and treatment of people based on their DNA or genome and it has the potential to transform the way we care for people with epilepsy.

Too often as neurologists, we have the frustration of not being able to provide any true explanation as to why a person has debilitating seizures and associated difficulties. Medical notes often record 'refractory epilepsy with learning disabilities.' Medication can be trial and error and investigative tests, laborious and inconclusive.

But today we are cautiously optimistic that there is real hope. At Epilepsy Society we are on the cusp of an exciting new era in the diagnosis and treatment of the condition. We are on the cusp of a genomic era which could revolutionise the way we diagnose and treat epilepsy.

In recent years we have already been able to show how genetic testing can transform lives just by looking at a very small but significant portion of a person's DNA called the exome.

This has helped us to identify more effective treatments for people with serious forms of epilepsy. In Aidan's case, new treatment has already been life changing and you can read his full story on page 10.

Now we are starting whole genome sequencing. While the exome is made up of 10 million letters, the whole genome comprises three billion letters. We believe that whole genome sequencing will help us to unravel the genetic architecture underlying the epilepsy of more people like Aidan.

We hope it will help us determine a person's risk of seizures, their response to anti-epileptic medication and their susceptibility to Sudden Unexpected Death in Epilepsy (SUDEP). We hope it will enable us to prescribe more personalised, targeted treatments and reduce the burden that epilepsy places on many people's lives.

Genetics can tell us more about epilepsy in a single test than any other source. In the last few years the number of genes that we have been able to identify as being responsible for different forms of epilepsy, has gone from a handful to hundreds.

We are recognising epilepsy syndromes, defining them genetically and we are beginning to understand them biologically. We are moving from discovering genes that are responsible for epilepsy, to applying that knowledge in clinical practice.

Our plan is to sequence a significant number of people with epilepsy although in the long-term we hope to make whole genome sequencing a routine diagnostic tool for people with epilepsy.

It will be the largest scale epilepsy genomics research programme in the

It is my greatest wish that by mining the DNA of people with epilepsy, we will be able to give our patients answers and ultimately solutions to their epilepsy."

world and is central to tackling the problems of uncontrolled seizures and side effects of epilepsy medication.

Through our genomic programme, our intention is to look at three different areas of epilepsy:

- firstly we will be looking at what is sometimes referred to as 'epilepsy plus' – this means we will be focusing on people with complex epilepsy and associated conditions
- the second area will focus on people with Dravet syndrome, a particularly severe form of childhood epilepsy
- the third area will examine the underlying causes of Sudden Unexpected Death in Epilepsy (SUDEP).

Initially our focus will be the extreme forms of epilepsy characterised by uncontrolled seizures and difficulties such as learning disabilities. The reason

for this is simple. In severe forms of epilepsy which give rise to similar characteristics, it can be easier to pinpoint the part of the genome which is causing mal-functioning genes.

In less severe epilepsies where there are no similar characteristics, it can be more challenging to pick out the genetic variants causing the seizures.

This is exactly the same approach that we adopted when we first used MRI as a diagnostic tool 21 years ago. We began by scanning those with the most severe epilepsy, those who had most to gain from a better diagnosis. But just as MRI scans are now a routine form of investigation for everyone with epilepsy, we anticipate that within the not-too-distant future, DNA sequencing will become a routine part of diagnosis, too.

By genetically defining the epilepsy syndromes, we will establish a model for progressing our understanding of the more common epilepsies.

We know that by recognising a recurrent clinical picture occurring in several people, we can start to explore what is happening genetically and biologically. Once we have established a faulty gene, we can create a model of that gene in a dish and try to get a better understanding of how it functions and how it responds to different medications.

My hope is that whole genome sequencing will eventually be life changing for all people with epilepsy. We are at the start of a new genomics era. We don't yet have solutions but we believe they lie deep within the three billion letters that make up our DNA.

I call the genomics research programme 'the big project'. It is my greatest wish that by mining the DNA of people with epilepsy, we will be able to give our patients answers and ultimately solutions to their epilepsy.

Just as MRI scans are now a routine form of investigation ... we anticipate that DNA sequencing will become a routine part of diagnosis, too."



Aidan's story

How a genetic diagnosis changed Aidan's life

Aidan McKendrick came into the world on Sunday 17 January 1982, a happy, healthy baby boy.

But at the age of 10 months, he had the first of what was to be a lifetime of seizures. Over the years his parents watched as their beautiful son struggled with as many as 36 seizures a month.

In spite of a cocktail of drugs, his seizures remained uncontrolled and his awareness of the world around him and his cognitive abilities gradually declined.

At the age of 27 Aidan moved into supported living, but, as his mum explains, he spent much of his time in and out of hospital.

'By the age of 30 Aidan was no longer responding to emergency medication to bring him out of his seizures,' says Ann-Marie 'He would be admitted to hospital for intravenous medication but this didn't always work either.

'He was in a critical state. On four occasions they had to put Aidan into an induced coma in order to stop the seizures.

'I was twice asked if I would sign a "do not resuscitate" consent form for him, but I refused point blank.

'Then on a hunch, Aidan's consultant neurologist in Leeds, decided to seek the advice of Professor Sanjay Sisodiya, director of genomics at Epilepsy Society's Chalfont Centre in Buckinghamshire. He had heard about Professor Sisodiya's work looking

at genetics as part of the diagnosis process in severe forms of epilepsy and he thought it might help to understand Aidan's condition.

'After talking through Aidan's epilepsy with our neurology team, Professor Sisodiya suspected that Aidan may have Dravet syndrome, a severe form of childhood epilepsy that usually begins in the first year of infancy. He recommended that our neurologist should arrange for Aidan's DNA to be tested for specific mutations in the gene SCN1A which are known to cause this syndrome.

'We had spent a lifetime clutching at straws with Aidan and were willing to give it a try.'

Genetic tests showed that there was a mutation on the gene SCN1A underlying Aidan's seizures.

Although there was no cure for the condition, the diagnosis was life changing for Aidan. The drugs that Aidan was taking were making his seizures worse, and Professor Sisodiya recommended a change to a more suitable combination.

Ann-Marie continues: 'When we first got the diagnosis, I had very mixed emotions. I wanted a diagnosis for Aidan but I did not want him to have Dravet syndrome. I had read a lot of negative things about the condition and it all felt a bit bleak. Now, however, I feel very differently.

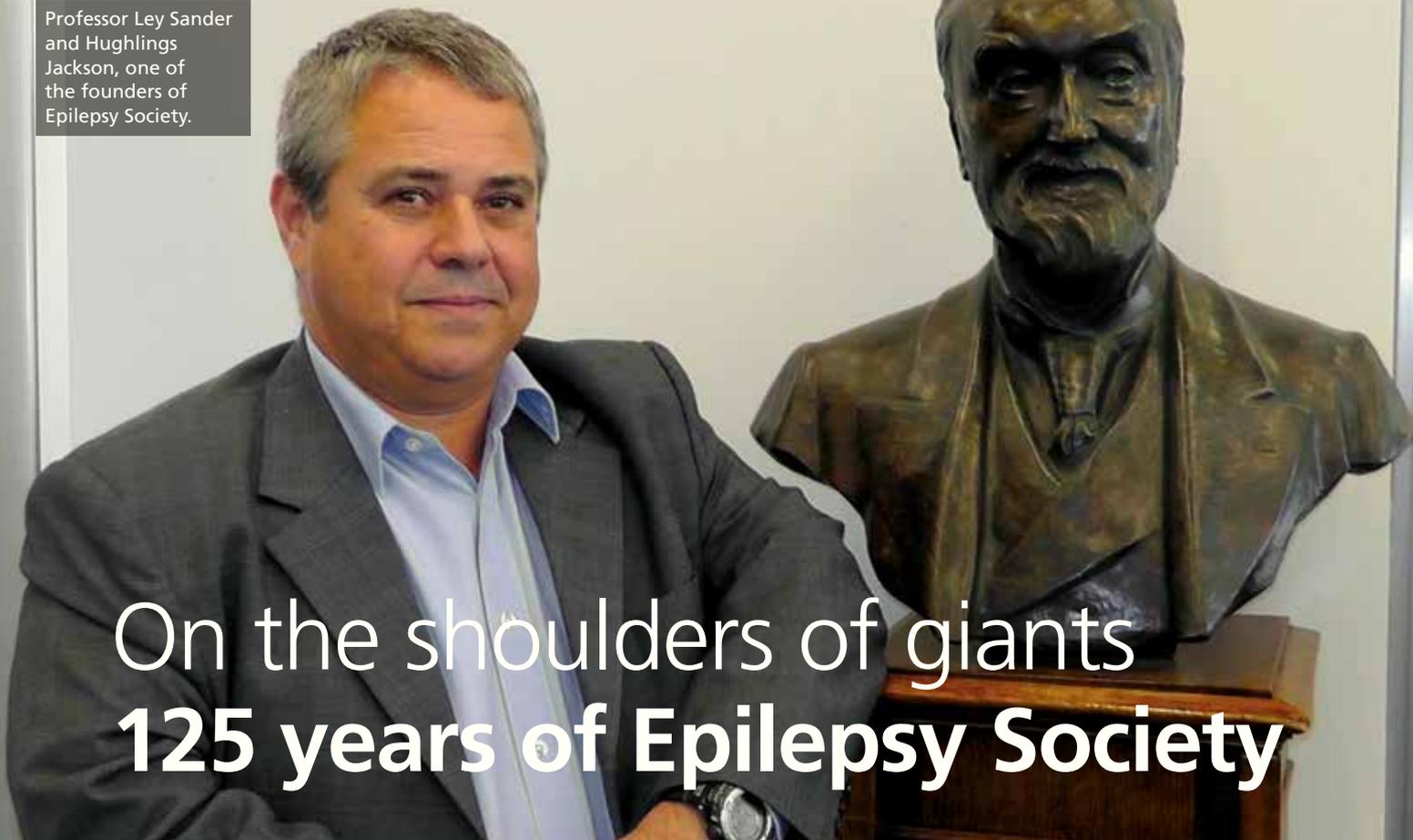
'Aidan is looking better than we have seen him in a long time. Before the diagnosis he was languishing on the sofa and had little interest in life. He wasn't engaging with the world or the people around him.

'Today he is back in supported living. He is responsive to friends and family and is generally much more alert. He has been to a Take That concert, Blackpool and Disneyland Paris. He is even learning to swim.

'His seizures haven't stopped but they are far less frequent and we are still looking at different combinations of medication for him. The great thing is that he is responding once again to emergency medication. This is all thanks to the amazing progress that has been made in being able to diagnose epilepsy, helped by looking at a person's DNA.

'I know that Aidan's epilepsy is genetic and there is no cure for it, but now we can concentrate on his quality of life. I am very aware of the high risk of Sudden Unexpected Death in Epilepsy for those with Dravet syndrome and a nugget in the back of my mind says we are living on borrowed time. Aidan is 35 and now I just want him to do all the things he wants to do. I don't want epilepsy to stand in his way. I just want him to make the most of every minute of his life and to be happy.'

Professor Ley Sander and Hughlings Jackson, one of the founders of Epilepsy Society.



On the shoulders of giants 125 years of Epilepsy Society

As we mark our 125th anniversary, we look back over the history of the Society from the early days of Hughlings Jackson, father of English neurology, to today's cutting edge science and technology led by our medical director and the world's leading epilepsy expert, Professor Ley Sander

On 11 April 1892, a group of doctors, all with a special interest in epilepsy, gathered in the home of neurologist Thomas Buzzard at 74 Grovesnor Square London.

Queen Victoria was on the throne. The North and South Poles were still uncharted territory. The Wright brothers were in development stage with their first powered plane and Einstein had yet to publish his theory of relativity.

It was an age of brave, new

ideas, pioneering expeditions, and scientific exploration. People were taking risks with a can-do attitude that was to shape the fast approaching 20th century. And Buzzard and his colleagues were part of that excitement.

With an ambitious dream, they were ready to turn the tide of medicine and society in a way that would change the lives of people with epilepsy forever.

Victorian England was a hostile environment for anyone with seizures. Epilepsy was largely misunderstood and stigmatised and employment prospects were virtually non-existent. Those with seizures were hidden away or ended up in institutions for the incurably sick, gaols or the workhouse.

Addressing colleagues in Grovesnor Square, Hughlings Jackson, widely regarded as the father of English neurology, proposed creating '*a home for such epileptic persons as are capable of work but unable to obtain regular employment on account of their liability to fits.*'

Buzzard and his fellow doctors,

all from what is now the National Hospital for Neurology and Neurosurgery, passed the resolution and Epilepsy Society was born under its inaugural name – the National Society for the Employment of Epileptics (NSEE).

Recognising that in between seizures, people with epilepsy could lead fulfilling and purposeful lives, Jackson, Buzzard and their peers set out to create an alternative way of life for people with epilepsy, one that would offer employment, fresh air, good nutrition and medication.

With the generosity of philanthropists such as John Passmore Edwards, the founding fathers established the Chalfont Centre for Epilepsy in Buckinghamshire, heralding a new era of research, social care and hope.

One hundred and twenty-five years later, Epilepsy Society is no longer a retreat for people with epilepsy. We still provide state-of-the-art residential homes for those with complex epilepsy and associated conditions but our mission has expanded to support

the half a million people with epilepsy living in the UK.

On the following pages you can read how the services we provide have grown and developed with medical advances and scientific discovery. We have transformed from being a small, isolated centre, to being part of a collaborative international community of researchers and doctors, at the very cutting edge of scientific discovery.

But we know that many of the challenges still faced by people with epilepsy today are similar to those faced by Buzzard and Jackson's patients: isolation, stigma, seizures, employment issues. Many people with epilepsy are in full-time, rewarding work and leading full lives. But not all.

Ironically, one of the most liberating innovations in modern times – the motor car – has proved one of the greatest challenges for people with seizures. The car has afforded people untold freedom. But it has also created a spatially stretched and fragmented society, with a diminished public transport system. Employment opportunities, entertainment, out-of-town shopping are all just a car's drive away. But not if you have seizures.

The diagnosis, treatment and management of epilepsy has improved dramatically in the last 125 years, but 30 per cent of those with the condition still live with uncontrolled seizures and that drives our urgency at Epilepsy Society to better understand the underlying causes of the condition.



The opening of the first house at the Chalfont Centre for women.

Then and now

Research

In 1907, Dr William Aldren Turner was responsible for the first clinical research carried out at the Chalfont Centre and published *Epilepsy – a study of the idiopathic disease* based on his research.

Today research is a key focus at Epilepsy Society. We use both neuro-imaging and genomics to try to understand the underlying causes of epilepsy. We use 3T magnetic resonance imaging (MRI) to look deep into the brain to try to establish any structural abnormalities that may be causing epilepsy. We also use functional MRI to map language, memory, vision and movement within the brain.

By looking at a person's DNA we are beginning to understand the genetic contribution to epilepsy. Our researchers have been able to pinpoint several genetic changes which may be significant in the risk for sudden unexpected death in epilepsy (SUDEP); we have established changes in a specific gene which could contribute to photosensitive epilepsy; we have shown that it may not only be those with a Glut-1 deficiency who will respond well to the ketogenic diet; and we can show those who are at greatest risk of memory impairment following epilepsy surgery.

Our research tools also include 3D imaging to map the face and optical coherence tomography which maps the retinal fibres at the back of the eye.

Epilepsy Society timeline

1892

National Society for the Employment of Epileptics – the 'Colony' as it was known – was formed

1894

Skippings Farm, Chalfont St. Peter was purchased and the first 'Colonists' – all men – were admitted.

1897

The first women joined the Colony

1909

Children were admitted after two homes and a school had been built for them

1957

Children were transferred to Lingfield – now Young Epilepsy

1965

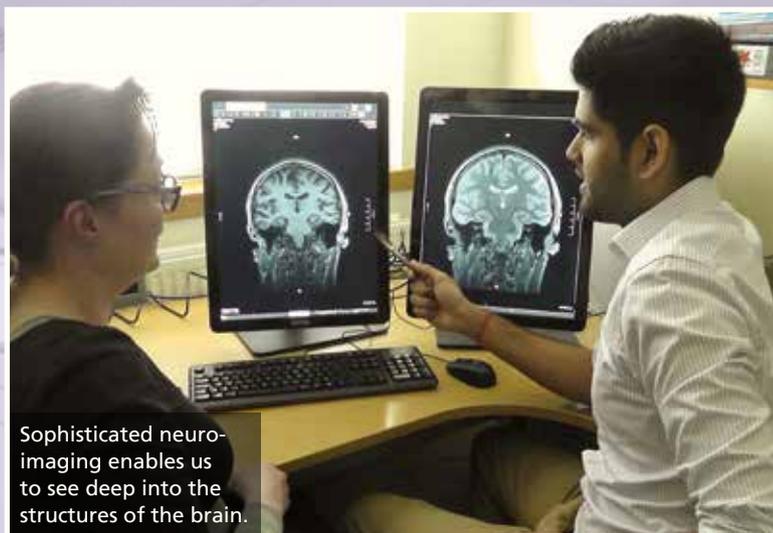
The first resident doctors with responsibility for assessment, treatment and rehabilitation were appointed

Diagnosis

Our tertiary care assessment unit is named after Sir William Gowers, one of the founding members of Epilepsy Society. During Sir William's time, people were prescribed bromide salts until 1922 when the first anti-epileptic drug, phenobarbital – known as luminal – was introduced.

Today our medical unit leads the way in the most advanced techniques for the diagnosis and treatment of epilepsy. Diagnostic equipment includes electroencephalogram (EEG), video-telemetry EEG, ambulatory EEG and MRI.

Over 1,000 patients are assessed at the Gowers Centre every year and our doctors see over 2,000 outpatients. We also have the UK's only therapeutic drug monitoring unit that specialises in epilepsy drugs.

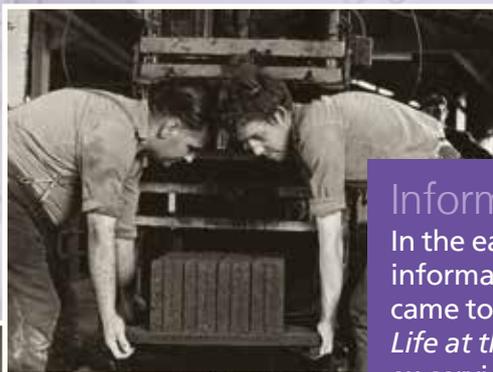


Sophisticated neuro-imaging enables us to see deep into the structures of the brain.

Campaigns

The establishment of NSEE was a campaign in its own right to provide a better life for people with epilepsy.

Today we campaign on national issues that affect people with epilepsy. We have campaigned at government level to reduce the number of premature deaths in epilepsy; we are campaigning to ensure that every woman of childbearing age with epilepsy is aware of the risks associated with sodium valproate during pregnancy; and we have campaigned to raise public awareness of misunderstandings around seizure types, most recently those that are sometimes mistaken for drunkenness.



Tailor made: residents made their own clothes, and bricks to build the centre.

Information

In the early days of Epilepsy Society, information was based on those who came to live at the Chalfont Centre. *Life at the Colony* was given to all ex-servicemen admitted with epilepsy after the First World War.

Today our information leaflets range from seizure control, employment issues and driving, with information available via our website, YouTube, social media and our leaflets. Some 150,000 people visit our website every month.

1966

The first EEG (electroencephalogram) was used at Epilepsy Society

1972

Chalfont Special Centre, a national hospital was established providing hospital and residential components

1977

Queen Elizabeth medical centre was officially opened. This houses the therapeutic drug monitoring unit which tests blood from people with epilepsy from across the UK and overseas

The '80s

The Society's medical and scientific staff gained an international reputation as leading in the field of epilepsy

1990

Epilepsy Society opened its national Helpline. EEG-video telemetry became available at the centre

1995

Epilepsy Society installed the first and only epilepsy 1.5 Tesla MRI scanner in the UK used for both clinical and research purposes

Residential care

In 1909 a group of 'colonists' as residents were then known, asked if they could travel to Lords to see England play Australia at cricket. Their request was turned down.

Today residents sail, horse ride and swim; visit Buckingham Palace, Harry Potter World, the Victoria and Albert Museum, Bournemouth and the list goes on.



Connects

For many of the residents who came to live at NSEE in the early days, it was the first time they had met anyone else with epilepsy. A review from 1895 noted; *'The improvement in the expression on the faces is most marked... there is always the utmost readiness and even anxiety to assist each other when a fit occurs.'*

Today we have a vibrant online community via our social media platforms with 48,000 followers on Facebook and 18,000 on Twitter. People with epilepsy, their families, friends and carers share their experiences and offer each other support.

Helpline

In the early days of Epilepsy Society, the need for emotional support was barely recognised. Our Helpline was first set up in 1990 but even then, its aim was to provide information for professionals.

Today our Helpline provides confidential support and information for people with epilepsy, their friends, families and carers, employers and healthcare professionals.



Ironing al fresco before the introduction of electricity.

Research is one of our key focuses at Epilepsy Society. We use neuro-imaging and genomics to try to understand the underlying causes of epilepsy.

Fundraising

In 1905 our records show how the philanthropist Passmore Edwards turned the dreams of neurologists into bricks and mortar. £18,230 bought a farm and paid for the erection of six houses at the Chalfont Centre.

Today we rely on trusts, grants, donations and the never-ending fundraising efforts of our supporters across the UK. Money goes to fund vital research into better diagnosis and treatment of epilepsy, and information and support for people with epilepsy through our Helpline and information services.

The New Millennium

At the beginning of the millennium more people were empowered to live independently. Our information services grew to meet this need

2002

The Sir William Gowers Centre opened, a National Health Service unit offering specialised assessment and treatment for people with seizures

2004

Our MRI scanner magnet was upgraded to 3 Tesla

2013

Our MRI scanner was updated to generate the most advanced images of the brain

The Epilepsy Society Research Centre opened

2014

Epilepsy Society Brain and Tissue Bank was the first of its kind dedicated to epilepsy

Exome DNA sequencing began

2017

Epilepsy Society marks 125 years and expands its genetic research programme to include whole genome sequencing

It's epilepsy, actually



People with epilepsy say they are often wrongly accused of being drunk when they are at their most vulnerable, either during a seizure or as they recover. We set out to address this misunderstanding.

Epilepsy can be a hard call. People with uncontrolled seizures often tell how they lose the confidence to go out by themselves, for fear of having a seizure in public and of how others may react. But a recent campaign via our social media platforms, Facebook and Twitter, has revealed just how devastating that public reaction can sometimes be.

Clare Pelham, chief executive at Epilepsy Society, said: 'People with epilepsy tell us they are often unfairly accused of being drunk as they recover from a seizure. And young people with the condition feel they are at increased risk of being wrongly accused, as slurred speech, confusion and the inability to walk properly after a seizure, lead people to think they have been binge drinking or taking drugs.'

Mental healthcare assistant Laura, 26, told us she has been accused of being drunk many times when she has ended up in A&E following a seizure. ►

'It is really infuriating,' she says. 'I have had epilepsy for over a year and wear a MedicAlert bracelet, but on numerous occasions, doctors and nurses in A&E assume I am drunk and call the alcohol liaison officer to talk to me.'

Deminique

'Younger healthcare professionals tend to have a better understanding of mental health issues, but all of them should know about the post-ictal stage after a seizure.'

'All I ask is to be treated with compassion and given reassurance after a seizure, not accused of being drunk. It is horrible when someone is being judgemental when you are feeling confused and exhausted.'

Diane Malyon from Peterborough worries about her 19-year-old daughter, Deminique, going out by herself. 'It's fine when she is in the middle of a seizure because she shakes and her limbs go stiff and it's obvious what is happening,' she says.

'It is in the period after the seizure when her eyes aren't focusing properly and she can't walk straight or communicate, that I fear people will walk on by and leave her, thinking she is drunk.'

'The first time she had a seizure, even my husband thought her drinks had been spiked. He said she had all the symptoms of someone who had taken drugs. It is very scary. So many people don't understand about epilepsy.'

Mother of two Sarah Reid from Bristol describes how she was shouted at by a passerby when she was staggering around outside Sainsbury's following a seizure. 'The man said I was drunk and wasn't fit to be a

mother,' she says. 'In fact I don't drink alcohol because of my medication. Luckily my partner was with me and was able to explain.'

These experiences are not unusual and you can read other comments on this page. But what can be done to change public perceptions and how does someone with uncontrolled seizures ensure that their seizures are not misinterpreted?

Information officer at Epilepsy Society, Andrée Mayne, said: 'The problem is that when someone is having a seizure, or is recovering from a seizure, they are in a very vulnerable state and are unlikely to be able to explain what is happening. This is where they need the compassion and understanding of the public and those in public service such as the police and medical staff. This is very much a matter of raising epilepsy awareness and educating people in all walks of life.'

One of the goals of our campaign around the confusion between

Mirror

NEWS ▾ POLITICS SPORT ▾ FOOTBALL CELEBRITIES

Teen with epilepsy accused of DRUGS while recovering from

Deminique Malyon can't communicate, walk straight or focus on her of being drunk

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LIFESTYLE

Epilepsy Charity Urges Public Not To Ignore Seizure Symptoms With Drunkenness

Seizures can lead to slurred speech, confusion and difficulty walking.

© 31/01/2017 09:22

epilepsy and being drunk, has been to raise awareness of the issue, and Facebook and Twitter are powerful tools in sharing this message.

Our Facebook posts were shared over 2,200 times, and generated 1,722 reactions and 146 comments. This means that the message about seizures being confused with the after effects of alcohol or drugs, potentially reached over 200,000 people.

The story was picked up by the Huffington Post, an online newspaper with a UK readership of 10.7 million unique monthly viewers. The Mirror Online, with almost five million daily unique viewers, ran a feature around the issue.

We also created a new graphic, below, to enable people to share

don't assume I'm drunk
because I'm staggering around
and my speech is slurred

I may have had a seizure

people often appear confused
during or after a seizure

please reassure them and stay
with them while they recover

#epilepsyawareness epilepsysociety.org.uk

When I have a seizure it's as though I'm drunk afterwards and it's not nice at all. Fortunately all my mates know what to do should I have a seizure" LIZ



My son just been in trouble at college. They told him never come in drunk or rough again. He never drinks :-(So annoying, people need be made aware and educated about epilepsy. It's not fair" EMMA

a positive message about epilepsy. We hope that this will help to raise awareness that if someone is staggering around with slurred speech, it does not necessarily mean they are drunk: they may have had a seizure.

Epilepsy Society's medical director Professor Ley Sander said: 'Epilepsy is a really difficult condition.

During a complex focal seizure or during the post-ictal period following a seizure, a person may be confused and unaware of where they are. They can have trouble walking properly and may stagger around.

'It is understandable how this could be confused with alcohol abuse, but anyone who is in difficulty should be treated with dignity and respect. All healthcare professionals should be aware of the post-ictal stage following a seizure and should treat the person

with compassion and care.

'It is important to talk to the person calmly, find them somewhere safe to recover and ensure that a friend or family member is called.

'If medical attention is required then of course call 999.'

Epilepsy is a very individual condition, affecting different people in different ways. And people's own ways of coping with the condition are equally diverse. Not everyone chooses to disclose their epilepsy to those around them and that is all about choice, but this is one instance where telling others about your epilepsy may help:

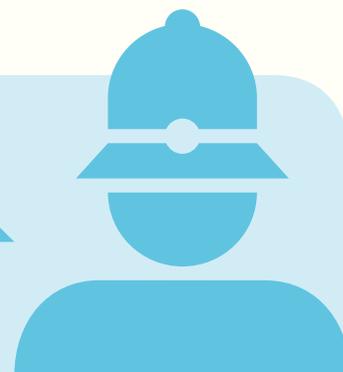
- if friends, colleagues, neighbours and those in your daily life know about your epilepsy, they will be more able to support you if you have a seizure. This might include reassuring members of the public, if necessary, that you are having a seizure, rather than having anyone jump to the wrong conclusion
- many people with epilepsy choose to carry a medical ID card with them or to wear some form of medical jewellery that will quickly let others know that they have a medical condition. You can find information about cards and jewellery at epilepsysociety.org.uk/medical-id-cards-and-jewellery, including Epilepsy Society's free ID card

- visit [Facebook.com/epilepsysociety](https://www.facebook.com/epilepsysociety) or [Twitter.com/epilepsysociety](https://twitter.com/epilepsysociety) and share our awareness raising graphic, shown on the opposite page
- if you are wrongly accused of being drunk during a seizure in a public place, you might like to consider arranging to speak to those people when you have recovered. It might help to explain about the different types of epileptic seizures and how a person might behave following a seizure. Awareness raising can be very powerful and help to change public perceptions
- Epilepsy Society provides epilepsy training for people in commercial organisations, the public sector, health bodies and for schools and those working with the public. You can find more information at epilepsysociety.org.uk/training

My husband has had seizures outside and people have walked by staring, telling us to help him with his drug and alcohol addiction."



Epilepsy Society is working with Thames Valley Police to help new cadets understand more about epilepsy. Throughout the year cadets spend the day at Epilepsy Society's Chalfont Centre learning about different seizure types and the impact of epilepsy.





Slipping through time



On 1 June 2017 at 2.15pm, just after *The Archers*, BBC Radio 4 will be broadcasting a new play, *Slipping through time*. Written by Louise Monaghan, the play follows the story of a young mum with epilepsy. Louise talks to Nicola Swanborough about her research and inspiration for the play

Without giving too much of the story away, can you tell us a little about *Slipping through time*?

The play follows the story of a young mum, Izzy, 25, played by Ellie Kendrick. Izzy had experienced seizures as a teenager but they had stopped in adult life. However, after having her first baby, her epilepsy comes back.

Initially Izzy is in denial and her family struggle with the diagnosis. Her mother-in-law has concerns about Izzy

breastfeeding the baby and initially Izzy refuses to take her medication.

Then she finds her teenage diaries. It is by reading these that she reconnects with her own story, slipping through time from present to past, and eventually starts to come to terms with her epilepsy.

It is interesting to hear how she deals with her epilepsy both as a teenager and as a young woman and first-time mum.

What inspired you to write the play?

I was partly inspired by my own epilepsy. When I was about two, I had a febrile convulsion in the garden at home. Then during puberty I would have petit mals, although not that often. I would also fall to the floor shaking with my eyes in the back of my head.

It would happen if I was upset about something. For example one day I was watching a programme about babies being circumcised. I went into the

▲▲ ... my mother was running the tap. I told her the water had a kink in it and was running at a funny angle. The next thing I was having a seizure and was taken to hospital.

kitchen where my mother was running the tap. I told her that the water had a kink in it and was running at a funny angle. The next thing I was having a seizure and was taken to hospital.

I never liked the fact that there was a part of me that I had no control over. It is a bit like giving birth or vomiting; you cannot stop your body from going through the process.

I remember being 15 in a biology class at school and wetting myself during a seizure. It felt degrading. You feel very vulnerable.

As an adult I cannot say that epilepsy has had a big impact on my life. My husband, Mike, knew about my fits but it was not something we were majorly worried about. For 30 years I didn't have any fits, then suddenly I had a one five years ago. I was in hospital for a minor operation. When I came round from the anaesthetic, I felt sick and could feel my leg banging against the bed. The consultant said I had fainted but Mike said it was a seizure.

It was only then that we decided to tell our two sons, Will, 25 and James, 27, about my epilepsy. They were quite shocked that we hadn't told them before. It wasn't that I didn't want them to know, I just hadn't seen it as hugely significant.

As I have been writing the play it has made me think deeply about my epilepsy and I have discussed it more with my sons. They have been very positive about it and it is good that they would now know what to do if they saw someone having a seizure. They would also know more about how to support a friend with epilepsy.

How much research is involved in writing a play about epilepsy?

When you are writing a play, it is very important to both engage and entertain your audience so that they have a greater sense of the subject you are dealing with. This is the first time

I have written about epilepsy. When I pitched the idea of the play to my producer, she was very keen. Like me, she felt that there wasn't enough awareness of the condition. But she was also keen for me to explore other people's experiences of epilepsy, beyond my own.

I had already seen the moving photo journal of a girl called Helen who wrote beautifully about her epilepsy. Her friend Matt took a series of photos of her and together they were featured in a national paper. But I felt that there was a lot of space to explore between the words and the pictures.

Then Epilepsy Society put me in touch with a young mum, Sarah, who talked to me about her epilepsy, pregnancy, birth, labour and new babies. She said she was told not to breastfeed after having her first child. By the time she was told she could, it was too late. I was very shocked by this but I found Sarah very inspirational.

I also have a friend who developed epilepsy following encephalitis, so I was able to speak to her and her husband about their experiences.

You say this is the first time you have written about epilepsy? What other subjects have you written about?

My last radio drama was about the prison service and Story Book Dads. It can be difficult for dads to maintain a relationship with their children from prison, and good family relationships are significant in not re-offending.

The play was about a little girl whose dad is in prison and she thinks he has died. He sends her recordings of him reading her stories and she thinks he is on the radio and is so proud of him.

Another of my plays was about someone who wanted a home burial so they could be buried in their back garden. But not all the relatives were happy about it. I like to write about families and relations and how they work through different issues.

How did you come to be a playwright?

In 1992 I lost my only sister to skin cancer. When she was in hospital I started to write letters to her with anecdotes about the boys growing up. She shared these with other patients and they seemed to like them.

This led me to do a writing certificate as a foot in the door to writing more. I hadn't been to university but I went on to complete a diploma in drama writing and an MA. I then started sending work to theatres and the BBC and have gone on from there. I have been lucky enough to write plays for the theatre as well as the radio. I am also developing a piece of work with another writer for television.

Do you prefer working in radio or the theatre?

I like both but they can be very different. Theatre work is far more collaborative and takes longer. There will be a month of rehearsals. You get more involved in the creative process and the play continues to develop during rehearsals. On the radio, the play will obviously go through several drafts and re-drafts but the rehearsal time is very short. The actors will be given their script then will only be in the studio for two days. They will have a read through and then it will be recorded. They don't have to learn their lines.

By writing *Slipping through time*, what did you learn about epilepsy that you didn't know before?

I hadn't realized quite how varied the condition was and how severe it could be for some people. Sarah's experience of epilepsy shocked me. She explained that she could have up to five seizures a day and that she'd undergone surgery for this.

I'm also much more aware of how absences affect people's lives and how often they are misunderstood. Sarah talked about teachers at school who told her off for daydreaming. My own friend experiences absences. I think I'd now be better able to support her.

'Unseen' disability has its own challenges and I think we need to be more aware of this. Hopefully, the play will highlight this.

Help with health costs

Many people with seizures find they repeatedly break their glasses or damage their teeth, resulting in expensive trips to the dentist or optician. However, although dental and eye care is not automatically free on the NHS, you may be entitled to help with healthcare costs. We look at the help that is available.

Dental care

You are entitled to free NHS dental care if you are:

- aged under 18, or under 19 and in qualifying full-time education
- pregnant or have had a baby in the previous 12 months
- staying in an NHS hospital and your treatment is carried out by the hospital dentist
- an outpatient at an NHS hospital dental service – however, you may have to pay for dentures or bridges

Eye care

You are entitled to free a sight test if you are:

- aged 60 or over
- registered blind or partially sighted
- diagnosed with diabetes or glaucoma
- aged 40 or over and have a close relative (parent, sibling or child) with a history of glaucoma
- you have been advised by an ophthalmologist that you are at risk of glaucoma

You will also qualify for a free NHS sight test and be eligible for an optical voucher if you are:

- aged under 16, or under 19 and in qualifying full-time education
- eligible for an NHS complex lens voucher – see below
- a prisoner on leave from prison

Further help with healthcare costs

Help with healthcare costs such as dental treatment, sight tests and optical vouchers, is also available if you or your partner – including civil partner – are on one of the following means-tested benefits. This also applies if you are under 20 and are the

dependent of someone on these benefits:

- Income Support
- Income-related Employment and Support Allowance
- Income-based Jobseeker's Allowance
- Pension Credit Guarantee Credit
- Universal Credit and qualify (see nhs.uk/NHSEngland/Healthcosts/Pages/universal-credit.aspx)

You may also be able to get help with NHS costs through the NHS Low Income Scheme (LIS).

You can apply for the scheme as long as your savings, investments or property (not counting the place where you live) don't exceed the capital limit. In England, the limit is:

- £23,250 for people who live permanently in a care home
- £16,000 for everyone else

Any help you're entitled to is also available to your partner and any dependent young people.

If you get Working Tax Credits, then you may be eligible for an NHS tax credit exemption certificate, entitling you to full help with NHS health costs.

Getting help with dental costs

When you book an appointment at your dentists, tell them you want NHS treatment. When you arrive for your appointment, you will be asked to fill out a form and should put an 'x' in the appropriate box.

If you have a valid HC2 certificate or tax credit exemption certificate, write the number on the form. If you have an HC3, write in the maximum your certificate says you can pay.

You must show proof of your

entitlement to help with dental costs. If you are claiming a refund, ask your dentist for the NHS receipt form FP64, or a receipt that shows the total NHS charge, and the date you paid. You'll also need the HC5 (D) claim dental charges form.

To apply for an HC2 or HC3 certificate, you will need to fill in an HC1 form, available from JobCentre Plus offices and most NHS hospitals, doctors, dentists and opticians. For an HC5 (D) form go to nhsbsa.nhs.uk/HealthCosts/1129.aspx or call 0300 3301343.

Getting help with eye care costs

If you have paid for an eye test, glasses or lenses but think you are entitled to a refund, ask your optometrist for a HC5 (D) optical charges form. You will need to include your optical prescription and receipts when applying for a refund.

This information applies in England. For help with healthcare costs in Wales and Scotland, see below.

Further help

Dental services helpline – 0300 330 1348

NHS Low Income Scheme helpline – 0300 330 1343

Queries about medical exemption certificates – 0300 330 1341

Queries about tax credit certificates – 0300 330 1347

To find out more go to www.nhs.uk/NHSEngland/Healthcosts/Pages/help-with-health-costs.aspx or

For help with healthcare in Scotland see gov.scot

For help with healthcare in Wales see healthcosts.wales.nhs.uk

I have recently been diagnosed with epilepsy. I have had three tonic clonic seizures in all, mainly after being out late with friends.

I work in a department store and have a lot of interaction with customers. I have been in my job for just under two years and have always had great support from managers and staff.

However, I am worried about telling my boss about my epilepsy. I am on medication and am hoping that it will fully control my seizures. I don't want people to treat me differently or for epilepsy to affect my chances of promotion.
Josh, Southampton

Epilepsy Society, to let my new boss know what to do, and it's kept in my HR folder! You might never have a seizure again, but you may feel more embarrassed if you do and haven't warned people.

Francesca, facebook.com/epilepsysociety

■ If your employer has an occupational health team, get them involved. They can advise you on 'reasonable adjustments'. Under the Equality Act 2010 employers have to consider making reasonable adjustments. They also have to maintain confidentiality. I would also advise the first aider.

Sharon, facebook.com/epilepsysociety

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

Your replies

■ Don't be afraid to tell your boss, it's the best thing to do. I worked in a super market for 36 years, now retired. I think it's always best to let people know about your epilepsy as some people don't know how to handle it. Good luck.

Rita, facebook.com/epilepsysociety

■ My partner also suffers from tonic-clonic seizures. His first thoughts were not to tell his employers. He was nervous about explaining it, but much to his surprise they were understanding and were able to put things in place for his safety.

They held training for the other staff so they would know what to do just in case, which made my partner feel safe and secure at work.

If you are worried about it affecting your ability to be promoted please don't be. It is against the law to withhold a promotion from an employee due to a medical problem or disability. You'll be surprised how understanding people will be.

Emma, facebook.com/epilepsysociety

■ You need your employer to be aware of your epilepsy because of

health and safety. As long as you are able to continue to do your job they can't discriminate against you, and need to make sure you are safe.

Try to get plenty of sleep before nights out with your mates and keep an eye on how much you're drinking, they're both known triggers.

Sandra, facebook.com/epilepsysociety

■ I was diagnosed a few years ago after several tonic-clinic seizures.

I was working front-of-house in a theatre. I told my boss and colleagues, because I was in charge of health and safety. I knew that someone needed to know how to look after me, and explain to the public that I was alright if a seizure did happen.

I understand the desire to keep it hidden, it can feel personal and you feel vulnerable opening up to people.

Since I was diagnosed, my medication has let me carry on. I've never had a seizure in public, I have travelled by myself across the country and the world, and I've learnt that the only way I can be this independent is to tell everyone about my epilepsy, because then I'm not surprising anyone. I've just used the cards from

Next issue

My partner suffers from uncontrolled epilepsy, and has also been told he may be having non-epileptic attacks as well. Last year he had 32 fits.

His application for PIP was refused because he was still able to get out of bed by himself, speak to other people and manage to wash and dress by himself.

They did not take into account that after a fit he needs looking after 24/7 until he feels better, which can be up to four days. He lost his job because of the time he took off and the stress of having another fit makes things worse.

The assessors did not seem interested in his condition at all. We don't know what to do next.
Karen, Guildford.

WOULD YOU LIKE TO SHARE YOUR THOUGHTS WITH KAREN?

Or do you have a question to ask our readers? 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

Tonic comic



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

Sitting in the waiting room before my latest appointment with my neurologist, I was startled by the reminder of how epilepsy does not discriminate. It affects anyone, at any age and any walk of life. Also waiting with me in the hospital were scores of people, some with parents, some with children, some with partners, some alone. There were patients of every age, skin colour, height, build and, if I could have dug a little deeper, no doubt every religious persuasion, political ideology and sexual orientation too. Epilepsy does not divide along lines of gender, ethnicity, social status and academic nous: we are everywhere!

We are already several months into a new year, and these seem to be divisive times. There are some topics of conversation that we all squirm at the thought of being caught in (talking about sex, most commonly), but it just seems that these days there is so much controversy in the air, and hackles can rise at the slightest provocation. Perhaps like me you have even had to impose conversational sanctions at Christmas to avoid 'hot' topics. We all have thoughts on the Brexit vote to leave the EU and The Great British Bake Off leaving BBC for Channel 4, and we all feel strongly about the pronouncements, policies and personages of Theresa May, Jeremy Corbyn and Donald Trump. We are encouraged, in this divided world, to find the common ground with our neighbours and even our enemies to 'heal the wounds' that have separated us.

If you're reading this then in all likelihood you, or someone you love, has epilepsy. We are all united by that. I don't know the exact readership of *Epilepsy Review* but I'm guessing that it reflects every age group, ethnic group, sexual orientation and socio-economic group. In the UK one in every 100 people (600,000 roughly) has epilepsy and perhaps among this issue's readers are some of the 87 people who were diagnosed with epilepsy yesterday. *hello new readers, if this is your first issue!*

Epilepsy is something which brings people of different backgrounds together. It removes people from their micro-communities of like-minded people, out of their Facebook echo chambers where you only see and hear people who agree with you. Epilepsy draws people out of betting shops and polo stables, out of Top Shop and Tiffany's, out of nurse assisted housing, urban tower blocks and thatched cottages, even palaces and prisons. Though

some aspects of our lives are very different, we all share the experience of having epilepsy.

My neurologist appointments are in London, and being such an enormous city there is just more of everything in London, both the good and the bad – more diversity, more choice, more jobs and more crime. It doesn't necessarily make it better, but everything is more visible. I can see firsthand, on the tube or in the hospital waiting room, reminders of the things that bring us together.

It isn't just the people who have epilepsy, but around us, the whole community of medical practitioners, nurses, ambulance drivers and A&E staff. During my last session in hospital the neurologist I saw was German, the phlebotomist who took my blood was Greek there was an American researcher; the whole team was a *melée* of international expertise.

Have you ever heard the expression 'to find your tribe'? It means to find the people who you can identify with, who are like you. The instinct to find others to relate to is very strong, and I think we each have various 'tribes' – our families, our geographical community perhaps, or sports community, fellow hobbyists, and those we share life experience with.

After I 'came out' to my family as bisexual – which was about as welcome to my parents as breaking wind loudly in front of the Queen – I found great curiosity and comfort in knowing which other famous people were 'in the gay way'. Turns out: millions of us! I would Google search people I had my suspicions about; the internet is an incredible resource (though not always reliable) for such musings.

Perhaps you too have searched the internet as I have for famous people who have epilepsy? It is a rag tag alumnus of the University of Seizure that's for sure, with the great, the good, the benevolent and notorious all represented.

If music is your thing, then you might be interested to know that artists as diverse as Neil Young to Lil Wayne have epilepsy. If you're a literary buff then perhaps you already know Edward Lear and Laurie Lee had epilepsy.

It's not just about listing people who might share a diagnosis, it's about the shared experience of vulnerability, fear, anger and injustice. The thing with healing in a divided world is that it is a real challenge to listen to people you disagree with, and be open to those you'd rather not engage with. The surprising thing is that we don't have to travel far to find things that unite us.

JULIET STEPHENS
LAUGHING ALLOWED

United
we fall

Made by Chelsea



New York actress, model and DJ Chelsea Leyland is once again using her creative talents to help raise awareness of epilepsy and at the same time vital funds for Epilepsy Society.

Chelsea and her sister, Tamsin both have epilepsy and last year Chelsea designed a unitard to raise £10,000 for the charity. Now she is designing a pair of limited edition handbags to raise even greater awareness and money.

Chelsea is working in collaboration with Mark Cross whose handbags

are a must-have for devotees of his trademark structured leather bags.

Chelsea's two designs are a set of day and night bags in alternating navy and blush pink, inspired by a vintage '80s swimsuit. Twenty per cent of proceeds from the sale of the bags will be donated to Epilepsy Society.

The handbags were launched at a special celebration in New York where Chelsea told *Vogue*: 'If someone opens up a magazine and sees the bag connected to the charity and says, "Oh, what's that charity?" Then I feel I've done my job.'

Royal gift

Epilepsy Society is one of almost 300 organisations to receive a charitable gift from The Patron's Fund following Her Majesty the Queen's 90th birthday celebrations in the Mall last year.

The gift recognises Epilepsy Society's work in making a real difference to the lives of people with epilepsy. The Fund was made available from generous donations and the proceeds from The Patron's Lunch.

Clare Pelham, Epilepsy Society's new chief executive said: 'We are thrilled to receive this very generous donation from The Patron's Fund. It will really help us to support people with epilepsy, both through information from our helpline and research that will transform the management and treatment of epilepsy in the future.'

SOS button saves life

Lucky passenger John Cook is keen to let others know how an in-built SOS button in his car helped save his life when he needed emergency treatment and medication for his epilepsy. John and his wife Paula were on their way back from a family visit to Cornwall when John was taken ill.

Neither of the couple had reception on their phones but fortunately Paula was able to call for help using their Vauxhall car's OnStar SOS button. Staff at the OnStar Call Centre established their locality and notified the emergency services. An ambulance arrived and took John to hospital for emergency care.

John said: 'Vauxhall OnStar saved my life. I want to raise awareness of the service and also of epilepsy.'



Vikings warrior

Actress Jennie Jacques who plays Judith in the series *Vikings* (Amazon Prime), took on Tough Guy the Original to raise money for Epilepsy Society.

Go to epilepsysociety.org.uk/ fundraise and find out how you can fundraise for us by taking on a challenge, holding a bake sale or cycling or walking.

Champion runners

Good luck and thank you to everyone who will be running for Epilepsy Society in the 2017 Virgin Money London Marathon.

Among the runners will be Chrissie Wellington who is a former professional triathlete, and has won 13 ironman competitions and four world championships.

We will be cheering on Chrissie and all our runners on 23 April. Everyone of them is a champion. epilepsysociety.org.uk/running-events



Give a gnome a home

Don't miss the chance to adopt your very own Gus the Gnome for just £5 and help fund research into better diagnosis and treatments for people with epilepsy. Go to epilepsysociety.org.uk/shop and click on Gus or see back cover for details.

Gnome is where the heart is!

Introducing Gus the Gnome, the latest addition to our Epilepsy Society research team!

Adopt your very own Gus and help us in our quest to bring effective treatment to everyone with epilepsy. Gus comes complete with an Epilepsy Society lab coat and an adoption certificate.

Buy now for just £5.00 (+ P&P) and contribute to our world class research programme. For your own limited edition Gus, please call 01494 601414 or order online at epilepsysociety.org.uk/shop



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for just £5
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