

Epilepsy Review

How science could
safeguard tomorrow's
children

PAGE 8

Our vision:
to make epilepsy
irrelevant

PAGE 14

**Thomas and William
and a love that lives on**

PAGE 20

Over the last 18 months, I think my most frequent sign off for emails, messages, texts and even phone calls, has been 'fingers-crossed'. The emoji has rarely, if ever, dropped out of my frequently used emojis on social media. We have lived our lives in hope for a medical breakthrough in the face of Covid, the chance to be reunited with loved ones and a return to normality.



Of course, living in hope is something that people with epilepsy do on a daily basis. Hope that the seizure won't happen. Hope that, if it does, there will be someone there to help. Hope that the new medication will work. Hope that there will be a breakthrough in the treatment of epilepsy.

It is hope that drives us forward at the Epilepsy Society, knowing that vital funds raised by our wonderful supporters will help turn those hopes into reality.

In this issue of *Epilepsy Review*, you will find hope in abundance. We have been campaigning hard to make social media a safer place for people with photosensitive epilepsy, following attacks by internet trolls who try to trigger seizures by posting malicious tweets.

We are thrilled that the Law Commission has recommended that the government introduces a new and specific offence to deal with this type of abuse (page 4). We now have to hope that this will be enacted in legislation and become law. We are cautiously hopeful but the campaign continues.

Ten-year-old Zach Eagling has become the figurehead for this campaign (page 5). He was one of the first targets of the internet trolls and has fought back with interviews on television and in national papers.

We are thrilled that Zach has been short-listed for an Unsung Hero Award in the Third Sector Excellence Awards. It is a much deserved recognition of his commitment to using his voice to fight for all people with epilepsy. He is up against equally worthy nominees from other charities, but we think he deserves to win.

Finally, you will be able to read about our Safe Mum, Safe Baby campaign (page 8) to stop babies from being born with preventable disabilities caused by their mothers' epilepsy medication. Some commonly prescribed drugs have been highlighted as increasing risk of disability for babies during pregnancy. We believe that with the right investment, our scientists could sort this by identifying at a genetic level which pregnancies are likely to be vulnerable to which medications. We hope that the government will step up to the mark and enable science to safeguard the future for tomorrow's generations.

So there is hope. Hope for new legislation. Hope for investment in women and babies. And hope that our hero, Zach, will be named Unsung Hero.

Dare I say it – fingers crossed.

Nicola Swanborough
Editor



Front cover

After three years of growing his hair, Thomas Machell finally had it cut to raise money for the Epilepsy Society, in memory of his friend William who died at the age of four from Sudden Unexpected Death in Epilepsy (page 20).

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Epilepsy Society
Chalfont St Peter, Bucks SL9 0RJ
epilepsysociety.org.uk
Registered charity no 206186
A company limited by guarantee
Registered number 492761 England

Designed by Edge Medical Communications Ltd
madebyedge.co.uk

Produced by Echo Direct Marketing Services
www.echo-dms.co.uk

Printed on chlorine free paper
from sustainable forests

MEDICATION

A change of name for anti-epileptic drugs



You may have noticed a change in the way people are starting to talk about your epilepsy medication.

Historically, medicines used to treat seizures have been called anti-epileptic drugs – or AEDs for short. But all that is changing. In recent months there has been a shift towards the use of the term 'anti-seizure medicine' rather than 'anti-epileptic medicine', with epilepsy experts around the world agreeing that this better describes what the medicines do.

The term 'anti-epileptic' suggests that the medication treats epilepsy as the underlying disease. The truth, however, is that anti-epileptic drugs only treat seizures which are a symptom of the disease. They have no impact on the disease itself. They are, more truthfully, anti-seizure medication.

Equally, huge efforts are being made to develop innovative treatments that stop the development and progression of epilepsy and associated conditions. And these will be truly anti-epileptic or disease modifying.

Emilio Perucca, former President of the International League Against Epilepsy (ILAE), has co-authored a paper about the change, *Time to Start Calling Things by Their Own Names? The Case for Anti-seizure Medicines*.

He said: "ASM (anti-seizure medication) is increasingly preferred to AED. This is a worldwide trend. The ILAE has set up a task force which will produce a position paper endorsing this terminology – preparation of the paper is currently in progress."

In his paper, co-written with Jacqueline A French from the New York University School of Medicine, Perucca explains that anti-seizure medication (ASM) is preferable to anti-seizure drugs (ASD), because the abbreviation, ASD is already established to indicate autistic spectrum disorder.

Professor Ley Sander, Medical Director at the Epilepsy Society, welcomed the change: "I think anti-seizure medication better describes the function of the drugs we prescribe and will help people with epilepsy understand that though their seizures may be controlled, their underlying epilepsy remains the same."

He pointed out that according to the dictionary of standardised medical terminology, MeDDRA, AED indicates an Automated External Defibrillator, as used for cardiac arrest. Anti-seizure medication – or ASM – would also prevent further confusion here.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7160876/>

PRESCRIPTIONS

Digital health info

Epilepsy Society is now working in partnership with Healthinote – a digital platform for doctors, nurses and pharmacists, to share personalised, trusted health information with patients through 'health information prescriptions'.

The digital transformation of the NHS post-Covid-19 has meant that many consultations are now being delivered remotely. The Healthinote platform, used by over 8,500 clinicians across 1,300 GP practices, enables doctors to provide new health information prescriptions to patients in the UK via email, SMS or QR code.

Following a consultation with their doctor a person will be given instructions on how to access their 'health information prescription' via the Healthinote app.

When searching for 'epilepsy' in Healthinote, patients can read reliable information about their condition from the Epilepsy Society.

Andrée Mayne, Education, Information and Support Services Manager at the Epilepsy Society, said: "Healthinote offers a valuable opportunity for doctors and nurses to share our epilepsy information through digital information prescriptions, by linking directly to our website.

"This will really help to support the 600,000 people with epilepsy in the UK."

Absolute Majek

It's the song we can't stop singing at the Epilepsy Society – Calm, Cushion, Call. Twenty-nine-year-old Teni Majek has put our seizure first aid campaign to music to help members of the public remember what to do if they see someone having a seizure.

Teni has tonic clonic and absence seizures and has always worried whether someone would

know how to support her if she collapsed in the street. So she has written a song to spread awareness and make people more seizure savvy.

The song has already been played on BBC radio and showcased at our supporters' conference. You can listen to Teni singing 'Calm, Cushion, Call' by searching 'Teni Majek' on YouTube.

Thank you Teni!



Law Commission stands up for people with epilepsy



Campaigning for people affected by epilepsy is a key area of our advocacy work at the Epilepsy Society. We have been working closely with the Law Commission to tackle internet trolls who send flashing images to people with epilepsy online, in order to trigger a seizure. We believe social media should be safe for everyone. So we were thrilled to hear the Law Commission back our Zach's Law campaign and call on the government to tackle this abuse with a new and specific offence.

The Law Commission is calling on the government to introduce a specific offence to tackle flashing images posted on social media to trigger seizures in people with epilepsy.

The Epilepsy Society has been campaigning to have this type of abuse recognised as an online harm in the government's new Online Safety Bill, following a sustained and co-ordinated attack by internet trolls on our Twitter account and the accounts of many of our followers.

One of the victims of the attacks was 10-year-old Zach Eagling – eight years old at the time of the attack – who has become the figurehead of our campaign 'Zach's Law'.

The government commissioned the Law Commission to look at reform of the criminal law in the Malicious Communications Act 1988 and the Communications Act 2003. The recommendation comes in its newly published report 'Modernising Communication

Offences' and is a huge step towards achieving our goal.

Nicola Swanborough, Head of External Affairs at the Epilepsy Society said: "This is brilliant news and a real recognition of the severity of the attacks sustained online by people with epilepsy. We have always said that the law has not kept pace with modern communication channels and this is a major step towards ensuring that people with epilepsy are protected from online harm."

"The Law Commission has been very keen to work with us on this issue and to understand the vulnerability of people with photosensitive epilepsy on social media. We are thrilled that they have made this recommendation and trust that the government will listen and act upon it."

"The battle is not yet won, but the finishing line is in sight. If this recommendation becomes

legislation alongside tough penalties imposed by regulators, Ofcom, social media could be a much safer place for people with epilepsy."

Over the last year Epilepsy Society has met on several occasions with the Law Commission to explain the severity of the attacks and the potential harm for people with photosensitive epilepsy.

In October we held an Online Harm Roundtable with MPs and the Law Commission's Criminal Law Commissioner, Professor Penney Lewis, to drive home the message that social media was a 'wild west' and operating outside of the law.

The Law Commission's recommendation comes as part of its review of the criminal law governing harmful, threatening and false communications. In its report 'Modernising Communications Offences' it states:

"The last two decades have seen a revolution in communications technology. The rise of smart phones, the internet and social media has offered extraordinary new opportunities to engage with one another – to share ideas, to learn, and to debate – and on an unprecedented scale. However, there is also increased scope for harm. The criminal law has not kept pace with these changes."

"The report sets out the ways

Our unsung hero



Photo: Julian Hamilton, Daily Express

As we went to press, 10-year-old Zach Eagling, figurehead of our Zach's Law campaign, had been shortlisted as an Unsung Hero in the prestigious Third Sector Excellence Awards. We are so proud. We will be sharing the results on social media and at [epilepsysociety.org.uk/unsung-hero](https://www.epilepsysociety.org.uk/unsung-hero)

in which the law could be modernised to address online and offline communications in a proportionate and efficient way."

The report lists four new or reformed criminal offences but also stresses that communications that are genuinely harmful should not escape criminal sanction because they do not fit with one of the proscribed categories.

The Law Commission writes: "We also discuss the issue of flashing images being sent maliciously to known sufferers of epilepsy. We did not consult on

a specific form of criminal offence for this behaviour, and therefore do not make recommendations as to the precise form of the offence, but we do recommend the government introduce a specific offence to address this behaviour."

<https://www.lawcom.gov.uk/project/reform-of-the-communications-offences/>



COMMENT

John Nicolson MP responds

A new super committee of MPs and peers has been appointed to scrutinise the Online Safety Bill line by line, to make sure it is fit for purpose. John Nicolson MP is a member of the Joint Committee and is shadow SNP spokesperson for Digital, Culture, Media and Sport. He writes:

"The online abuse of people with epilepsy is abhorrent. The idea that trolls have been sending flashing GIFs and images to people with epilepsy, with the intention of

triggering seizures, is beyond belief. And yet it continues to happen each and every day.

This is why I am delighted to see that the Law Commission have recommended naming this activity as a specific offence in forthcoming legislation.

In their report, Modernising Communications Offences, the Commission calls for the specific criminalisation of the 'phenomenon of sending flashing images to people with epilepsy with the intention of inducing seizures.'

This is a hugely welcome recommendation from the Law Commission. In the coming months, I will be sitting on the Joint Committee to consider the Online Safety Bill. There is a long way to go, but I am determined to ensure change is enacted.

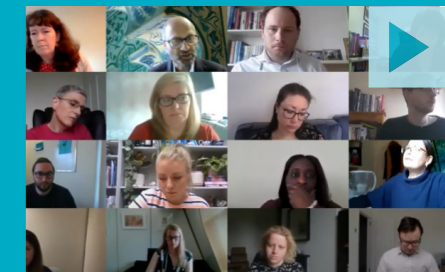
In an article for the Daily Express earlier this year I said: 'Any right-thinking person knows that deliberately sending flashing images to a person with epilepsy is malicious and criminal. It ought to be named as such.'

I stand by these words today. People with epilepsy deserve to feel safe online, free from the fear of targeted and malicious abuse. This is the first step in making that a reality."

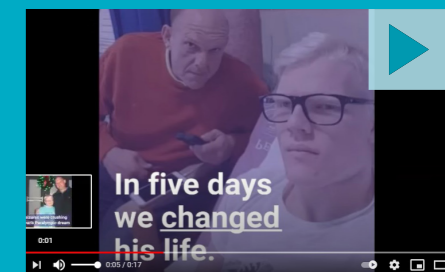
The Joint Committee on the Online Safety Bill will be seeking the views of the public and will report by 10 December 2021. You can find out more details at [epilepsysociety.org.uk/online-safety-bill-your-views](https://www.epilepsysociety.org.uk/online-safety-bill-your-views)

Watch it on video

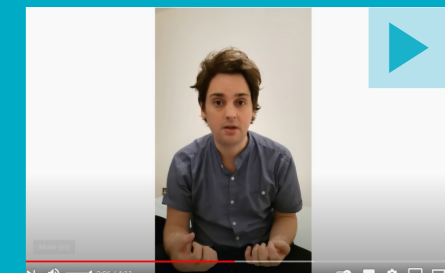
You can view these videos at youtube.com/epilepsysociety



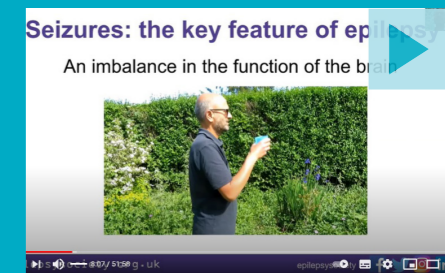
Our Safe Mum, Safe Baby Round Table highlights how research could stop babies being born with preventable disabilities caused by their mothers' epilepsy drugs.



GB judo fighter, Evan Molloy, explains how treatment at the Epilepsy Society has put him back on track for the 2024 Paralympics.



Chris Sharp talks about how his seizures are triggered by reading.



Science made simple. Our Director of Genomics, Professor Sanjay Sisodiya, explains the important role that genes play in epilepsy.

Me and my epilepsy

Sophie Corcoran

Sophie Corcoran is 19 years old. She works the night shift in a burger bar, stood as a candidate to become a local councillor while sitting her A levels and playing for Leyton Orient Women's Football Club. And she has epilepsy. As she prepares to go to university, she tells **William Mayne** how she fits it all in

Finding my voice

My life is very busy, with football training three times a week and, until recently, revising and studying for my A levels. And I've been working shifts at my local burger bar. I recently did an interview with BBC Radio 5 from the staff room at 9pm, in the middle of my shift.

I have been in the media quite a bit, with interviews on GB News, an article in The Telegraph and I appeared in the Express as part

of Epilepsy Society's Zach's Law campaign. As well as talking about my epilepsy, I am also asked to comment on other issues including education and the vaccines.

I'm not afraid to express my opinions and I think that all comes from having epilepsy and wanting to raise awareness of what it's like living with seizures. It is one of the reasons I stood for election as a local councillor in Thurrock, Essex. I didn't get in but I did get 838 votes. And I was one of the

youngest candidates to stand in a local election in the UK. I think that is a pretty astounding achievement considering I was told by my teachers that I would never succeed.

Diagnosis of epilepsy

I was diagnosed with epilepsy at the age of four, after falling off a climbing frame in Colchester Zoo. My identical twin sister, Becca, also has epilepsy. I've always taken the attitude, it is what it is. What more can you do? But it did affect my school life.

The diagnosis of epilepsy left me behind in the fundamentals at primary school. I missed a fair amount of school because of my epilepsy, as I was having maybe 50 to 80 seizures a day.

With all that unpredictability and disruption in my life, I was then put in the bottom set in secondary school as well, even though I felt I was so far ahead of the rest of the

class. Nowadays my epilepsy isn't so much of a problem. I sometimes have an occasional "jolt" or "twitch" but apart from that, my epilepsy doesn't trouble me. It is well controlled with epilepsy medication.

From epilepsy to football

I think it was probably my experience with epilepsy in primary school that led me into football. I wasn't really allowed to go on the gymnastics equipment as it wasn't safe for me with my seizures, so I had the option to sit out or play

People with epilepsy can conquer any task, no matter how hard. You have just got to get comfortable with being uncomfortable

football with the boys. That was when I really learnt to love the sport.

Although football is a passion for me, it is still a hobby and I wouldn't want to take it up as a profession. I am off to Durham University now to study business and management. But in the long term, I see myself more in the classroom as a principal of a school, or as a politician in the House of Commons. I want to help people with epilepsy and other disabilities to realise their dreams, and to make sure that they don't have the same experience as I did with my epilepsy.

I am very interested in politics and would have liked the opportunity to change some of the ways that the government have dealt with issues such as the pandemic.

Flashing images

It was good to use my passion for football to support Epilepsy

Society's Zach's Law campaign*. Although I don't have photosensitive epilepsy myself, I have received some of the flashing images sent on Twitter to trigger a seizure, so I know what it's like for other people with epilepsy.

I think some people with epilepsy might think they are less fortunate than others, but my view is that we just have much more to deal with. People with epilepsy can conquer any task, no matter how hard. In the words of Nike 'just do it'. You have just got to get comfortable with being uncomfortable.

* You can read more about the campaign on pages 4-5.

Epilepsy affects 600,000 people in the UK who hold a wide range of personal views. Epilepsy Society interviews many people with epilepsy, but this does not mean that the charity endorses their views.

Clockwise from left: local council candidate; footballer; university student; twin sister

How science could safeguard tomorrow's children

A new review has shown that some epilepsy drugs pose a risk for babies during pregnancy. Which is why we have launched our Safe Mum, Safe Baby campaign. Nicola Swanborough writes

Earlier this year a new review was published looking at risks associated with some of the most commonly prescribed anti-seizure medications during pregnancy. The review did not make for comfortable reading.

We have known for some time of the risks posed by valproate for any baby exposed to the medication in the womb.

Up to 40 per cent of babies exposed to valproate during pregnancy are born with a physical birth abnormality or neurodevelopmental disability. For this reason, no woman should be prescribed valproate without being part of the pregnancy prevention programme, PREVENT.

But the review has shown that other commonly prescribed epilepsy drugs can also increase risk during pregnancy, while for others, there is insufficient evidence to say whether they are safe.

Just two medications – levetiracetam and lamotrigine – are thought to be safer during pregnancy, while carbamazepine, topiramate, phenytoin and phenobarbital increase risk of birth abnormalities compared with the general population (see table on page 10).

The risks are not as high as for valproate, but the statistics still create a dilemma both for women and their doctors as choices must be made between medications that will give optimum seizure control for each individual, and medications that will present least risk for any developing baby.

Swapping to either of the two safer drugs – levetiracetam and lamotrigine – may not be an option as not all women respond well to these drugs.

Remaining on a high-risk medication will cause untold anxiety during pregnancy which, in itself, can lead to seizures. Equally, swapping to a medication that is safe for the baby but does not give the same level of seizure control, puts the mother at risk of a seizure. And seizures can be dangerous during pregnancy.

The review was carried out by the Commission on Human Medicines and has been published alongside a concerted effort to ensure that all women and girls with epilepsy who are of child bearing age, are called in for a discussion with their doctor about how best to optimise their treatment for both themselves and any future babies.

We are pleased to see that women are being warned of the risks associated with their medications – a luxury few women prescribed valproate were afforded – but we do not believe this is enough. Which is why we have launched our Safe Mum, Safe Baby campaign.

We believe that science could enable us to understand which medications are likely to pose a problem during which pregnancies, according to the genetic make-up of the woman and her baby.

Science, or more precisely genomics, can enable us to understand why some epilepsy drugs cause disabilities in babies, while others don't. It can help us understand why some women are vulnerable during pregnancy while other women aren't.

Science could enable us to tailor drugs according to each individual woman's genetic make-up, giving women the reassurance that the drug they are taking will be the best option for both themselves and their baby.

Our campaign is calling on the government to provide funding for research that could stop babies from being born with preventable disabilities caused by epilepsy drugs.



Professor Sanjay Sisodiya, Director of Genomics at the Epilepsy Society is leading the call to enable scientists to carry out this work.

Speaking at the Epilepsy Society's Safe Mum, Safe Baby Round Table, attended by clinicians, academics, politicians and women with epilepsy, he said: "Every year around 2,500 women with epilepsy go through pregnancy

scale studies that have looked at this in recent years, but we need to address this on a large scale with big data in order to get the sort of learnings that may enable us to predict which medications will be most suitable for which women, long before they start a family.

"This will lead to truly personalised medicine that is safer for women and safer for their babies. By looking at an individual's

PETITION



Please sign our petition calling on the government to fund vital research that could stop babies being born with preventable disabilities caused by their mothers' epilepsy medications.

"We need to look at the genetic make-up of the three people in each pregnancy – the parents and the baby – and find out what might be causing the problem.

"There have been small

The MHRA has already set up a valproate registry to collect data from all women who are prescribed valproate. And they plan to extend this across all epilepsy medications. With the right consents from the women involved, this would give us a unique opportunity to work within the NHS to analyse the genetic make-up of all those registered and begin to understand which pregnancies are vulnerable to which medications.

The government has promised to invest £14.9bn in research and development in this financial year. This will increase to £22bn by 2027.

The government has brought forward its Women's Health Strategy with a particular emphasis on women of childbearing age and pregnancy. It has promised to place women's voices at the centre of the healthcare system.

But words are meaningless

It is important to remember that no woman should stop taking her medication without first consulting her doctor. Seizures can also be dangerous, particularly during pregnancy."

in the UK. We don't have a perfect drug that is safe and effective in all circumstances. We don't have a perfect set of drugs.

"We don't know what the fundamental problems are that are causing the major congenital malformations and neurodevelopmental disorders, but we do have the knowledge and expertise to try to find out why problems occur in some pregnancies but not others. Some part of the problem is likely to lie in genetics.

genes, we may be able to say with greater confidence which drug is likely to cause an adverse reaction leading to malformations during pregnancy. It will be important to use any genetic information in the broader context of all the available information, and recognise that we may not find all the answers we need. But the research could enable those women not at risk potentially to continue to take what is generally a higher-risk medication which could be life saving."

unless money follows the strategy. We are not asking for more money but for a fair share for women and babies that will ensure that women with epilepsy will be able to decide with their doctors on a right course of treatment, based on their own genetic make-up.

Money will lead to research which could end the risk of preventable disability in tomorrow's babies. There isn't time for debate. It is vital that research begins now. ▶

Yasmin's story

Yasmin, 26, is a molecular scientist. She has had epilepsy since the age of 11 and is taking a combination of eslicarbazepine, brivaracetam and phenytoin. Although she still has complex partial seizures, she is managing to get on with her life. Her worry is that the drugs, and particularly phenytoin, would pose a potential risk during pregnancy.



"I would not risk having a baby while taking phenytoin. But it is not easy to just switch to a safer medicine. Most women dream of having a baby but when you have epilepsy it is that much more of a challenge.

"You need to take time out to try different medications and put up with seizures getting worse while you find a drug that suits you. Most of my 20s I have been studying and needed to be ok at lectures and in the labs. I could not have put up with increased levels of seizures.

"Ideally I would like to be on safer medicines but I think as I am not planning a child right now, do I want to risk the seizures? I would like to come off the phenytoin but it does seem to do a bit more than some of the other drugs in controlling my seizures."

Jade's story

Jade has two children – Lily, nine, and Louie, five. Lily arrived before Jade's diagnosis of epilepsy and was born without any health problems. Louie was born after Jade's diagnosis when she was prescribed a variety of medications to control her simple focal seizures. Initially she tried carbamazepine but 'felt like a zombie' and was switched to lamotrigine. A year later she changed to levetiracetam. Louie has hyper-mobility, didn't walk unaided until he was two and has a speech disorder which he is being treated for. Although lamotrigine and levetiracetam are both considered to have the safest profile during pregnancy, Jade worries that the medication may have caused Louie's problems.



"The worries over medication during pregnancy were daunting. The burden that the medication could be the reason for Louie's health problems is heart breaking. So many children have speech and language difficulties but why would I have one child who is fine when I am not taking medication, and another with so many problems when I am?"

"I feel very passionately that there should be more research to find out which medicines are safest."

Laura's story

Laura, 22, has been taking sodium valproate since the age of 15. She was initially prescribed lamotrigine but the medication made her seizures worse. Levetiracetam left her feeling severely depressed. Valproate has meant she has been able to learn to drive and she is now studying for a degree in the decommissioning and management of nuclear waste. But she knows that if she wants to start a family the drug will pose a serious risk to any baby during pregnancy.



"When I was 18, my doctors started talking more seriously about the risks involved with valproate and the chances that if I were to become pregnant, my baby could be born with spina bifida. But at the same time they did not want to mess with my medication. They said they would talk about changing it when I was thinking of starting a family.

"To be honest, I don't want to come off valproate because it makes me feel safe with my epilepsy. If I have a fit it will affect my whole life.

"I know I want to have a family one day and don't want to put my future children at risk. Pregnancy is a big stress for any woman, but when you have to worry about your meds as well, it makes it worse.

"When I was first prescribed valproate, I was told it was my last resort. Now I feel me and my unborn child or children are sentenced to a challenge and an even more stressful situation than epilepsy already is. I just wish that there was a medication that worked as well as valproate for me without the risks during pregnancy.

"Because I wasn't given many options with my treatment, I will have to go back to square one when I try for a baby. I will do it for the safety of my child, but it is such a scary process. I want to make a difference for other women to ensure they avoid issues like this."

Risk of having a baby born with a physical birth abnormality

General population	2 to 3 out of 100 babies
Carbamazepine	4 to 5 out of 100 babies
Phenobarbital	6 to 7 out of 100 babies
Phenytoin	about 6 out of 100 babies
Topiramate	4 to 5 out of 100 babies
Valproate	about 10 out of 100 babies

To read more details of the risks around epilepsy medications during pregnancy go to epilepsysociety.org.uk/medication-risk-pregnancy

2020-2021 IMPACT REPORT

Photo by Matilda Kirby

Our Chief Executive, Clare Pelham, looks back over 2020-2021 and explains how it has been business as usual. And sometimes better.

It could be on your left arm. Or it could be on your right. Whichever it is, most of us now are lucky enough to bear a small mark – a pinprick even – that is a testament to the wonderful power of science that is helping to guide us out of the pandemic and make the world a safer place.

We know we are not yet out of the woods. We know there is still a long way to go before all ages, in all places around the world, are fully vaccinated. But as the ledger closed on the last financial year (April 2020-March 2021), all of us in the world of epilepsy were able to breathe a small sigh of relief.

The 113 people who live at the Chalfont Centre in

Buckinghamshire, whose complex epilepsy and disabilities make them among the most vulnerable in society, had been vaccinated, along with an offer of vaccination to all our staff. And the 600,000 people with epilepsy across the UK were also promised their first vaccine as a part of a government priority group.

For me, an abiding memory of early 2021 will be the socially distanced queues of staff and residents, waiting in masks to be vaccinated at our medical centre by our wonderful team of neurologists. Everyone rolled their sleeves up. And, of course, the relief of our followers on social media, as they awaited a call up by their own GPs for their jabs. There was anxiety, but there was also joy.

The real joy for me is that the power of the scientific response to the pandemic has been mirrored throughout the charity. We have not allowed ourselves to be beaten by the virus. Words could never do justice to our gratitude for the selfless way in which our care staff put residents' safety and happiness ahead of their own. Or the way our medics led from the front in a truly integrated model of care, injecting

confidence in an uncertain world with rigorous testing and tracing.

And the rest of the team, too, has worked tirelessly from their bedrooms, their sofas, their lofts and their spare rooms, to meet the new challenges of a world paused by a pandemic. The fact that most of us had not seen each other for the best part of a year, did not stop us working creatively and collaboratively to ensure that our services continued.

Throughout *Epilepsy Review*, you can read about some of our many achievements, while our statistics over the page demonstrate that it has been business as usual.

I think it was Charles Dickens who said "It was the best of times, it was the worst of times". I would like to re-word that sentiment with the injection of hope that we all feel for the future. It has been the worst of times, and it will soon be the best of times. The best really is yet to come.

We are so grateful for all your support in fundraising, campaigning and volunteering, keeping us strong and bringing hope for the future to everyone with epilepsy.

Our year in numbers



3,223
helpline calls

we also received 1, 999 helpline emails and sent out 5,506 information resources. You can call our helpline on 01494 601 400



647,162
engagements

spread across our Twitter, Facebook, Instagram and LinkedIn platforms



3.9 million
website views

Living with epilepsy was our most visited website section with 418,381 views; *People with epilepsy included in Covid Group 6* was our most visited news item with 38,499 views



“ The five days I spent at the Epilepsy Society’s Chalfont Centre have totally changed my life. I haven’t had a seizure for more than 18 months. Thanks to the Epilepsy Society, I’ll be at the 2024 Paralympic Games.

Evan Molloy, GB judo fighter



806
MRI scans

no patients were seen for MRI scans during April and May 2020, due to the Covid-19 lockdown



11,010
blood and saliva samples

analysed through our Therapeutic Drug Monitoring service, to assess medication levels



622
whole genome sequenced data

helping us understand the genetic architecture of each patient’s epilepsy



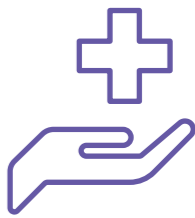
8
new members of our research team

including team members working on PhDs, as clinical research fellows and on data management



26
genomic clinics held

a total of 140 people attended these clinics



263
patients admitted to Gowers

receiving world-class epilepsy treatment from our team of experts



76
research papers published

covering a range of disciplines including genomics, effects of specific medicines, and the use of robotics in surgery



17
parliamentary questions

asked in Parliament by MPs from multiple parties in support of our policy campaigns



724
people

supported us via fundraising events, including our hugely successful Challenge 100 programme

Our income

Together we raised £16m this year through a combination of fundraising, trading and care income and charges to the NHS for our medical services. A full breakdown of our income will be available in our published accounts later this year at epilepsysociety.org.uk/accounts



Where the money went

Voluntary income, after fundraising costs, is spent primarily to support our strategic charitable activities: advocacy, research and care. Our other income represents fees which cover the costs of our residential care and medical services. Our costs totalled £17.1m in 2019/20. A full breakdown of our costs will be available in our published accounts later this year at epilepsysociety.org.uk/accounts

Our vision: to make epilepsy irrelevant

At the Epilepsy Society, our vision is for a world where epilepsy is irrelevant. And people with epilepsy lead the lives they want to lead. This year, following a major survey of people affected by epilepsy, we are looking at new ways to make this happen

It's all about you

Earlier in 2021, we carried out a detailed survey to find out what concerns you most around epilepsy and what are the changes that you would like to see. More than 1,000 of you responded and this gave us a unique insight into the landscape of epilepsy and a solid base on which to build an exciting new agenda for the future across our three core pillars at the Epilepsy Society: advocacy, research and care.

What you told us

Unsurprisingly, three quarters of survey respondents felt that epilepsy care was falling behind that of people with Alzheimer's, dementia, cancer and heart disease. A similar number wanted to see better access to epilepsy specialist centres such as ours. And 43% were unaware that they could be referred for specialist diagnosis.

Over half of respondents have not discussed a different treatment option with their doctor. Just one in five have discussed brain surgery and only 4% have talked about genomic sequencing.

The survey showed a tangible desire for a greater understanding of the causes of epilepsy and of SUDEP – Sudden Unexpected Death in Epilepsy.

An overwhelming 92% felt more money should be channelled into research to push forward the boundaries of discovery. It was interesting to note that on average, people believed that 24% of government funding into medical research went to epilepsy. The actual figure is 0.3%.

Alongside this, there is still an urgent desire to tackle ongoing stigma in the field of epilepsy at every level – public, government, healthcare and the workplace. It is sobering to read that, in spite of our Calm, Cushion, Call campaign, 83%

of people still felt there was a lack of awareness around seizure first aid training.

What we are doing

Across our advocacy, research and care teams, we have been working hard to look at how we, as a charity, should evolve and respond to what people are telling us.

Our research team have exciting plans which, in time, could transform the lives of people with epilepsy across the UK, employing the most advanced diagnostic techniques and treatment options available.

Today, our research focusses on important but specific areas: genomics, neuroimaging, neuropathology, pharmacology and health service research. We have a rich source of invaluable data across all these areas but historically our work has tended to be siloed.

We want to move to a big data-driven intelligent approach that combines information from each strand of our work. We want to amplify the use of existing data through novel approaches to re-evaluation and analysis.

We believe that by weaving ideas and diverse research strands together, we will be able to generate a more complete and better understanding of each individual's needs. We want to develop a unique personalised platform that gives each person a 360 degree assessment using every piece of innovative diagnostic equipment at our disposal. It will be a first in the world for epilepsy.

We want this to become routine practice so that people no longer feel left behind by the healthcare system. The right to choice and options and specialist diagnosis will be there for everyone when they need it.

As we stand, an evaluation

at the Chalfont Centre is widely regarded to be the best there is. But we can be better still. By creating synergies across all our areas of research, we hope to bring about radical transformational step changes in the way we treat people. And that is something that really excites us.

We will be better placed to challenge healthcare, linking genes with epilepsy and other accompanying disease; addressing treatment resistant epilepsy; prescribing individualised therapies based on our better understanding of the disease, reproductive health, the impact of climate change and unpredictable external drivers such as the Covid-19 pandemic.

At the Epilepsy Society we stand on the shoulders of giants but science must never stand still. We are on the cusp of a big data revolution that has the potential to put us on a par with the care of Alzheimer's, dementia, cancer and heart disease. It offers the scope for knowledge and understanding, risk mitigation and a greater capacity to meet the needs of more people.

There is no doubt this vision will require historic levels of research funding. But we must find a way. The lives of millions of people with epilepsy across the world could be transformed, if we do.

Enabling and rehabilitation

The pandemic held a mirror to both our weaknesses and our strengths. It accelerated the speed of change at a pace few of us were probably prepared for. One of the major learnings has been the breaking down of barriers between health and social care. We have seen how care systems can learn and evolve through stress, creating a more robust integrated model of care.

Building on this, our ambition is for the Epilepsy Society to grow as a nationally renowned centre of excellence for care, supporting people with refractory epilepsy and complex care needs. We aim to improve the overall health and well-being of people with complex epilepsy through a fully integrated model that blends

We want to develop a personalised platform that gives each person a 360 degree assessment using every piece of diagnostic equipment

* All photos here are from a collection shared on social media under the hashtag #DoILookEpileptic and are not necessarily respondents to our survey

medical expertise and social care knowledge.

Moving forward, we recognise that specialist epilepsy expertise is our USP and therefore we want new social care placements at the charity to be for those who can benefit most from the specialist services that we have to offer.

In particular, we want to provide support that will enable people with complex needs to progress to living in a less intensive environment including the possibility of a family home.

Subject as always to there being sufficient social care funding to make this possible, we will continue to support the people now living at the charity as well as we always have done. It is envisaged that this new approach will apply only, where appropriate, to new referrals.

Speaking up for epilepsy

Underpinning research and care, will be our advocacy work which continues to be a voice for people affected by epilepsy.

As a respected authority in the field of epilepsy, we know that when our campaigning voice is heard at government level, politicians will listen and act. We must make sure that our plans are relevant to the local and national agenda including the National Life Sciences Strategy and the Buckinghamshire Industrial Strategy, where we are based.

Our campaigns are driven by the needs of people with epilepsy: the need to feel safe and protected by the law when online; the need for safer medicines that will control a woman’s seizures without harming her baby during pregnancy.

And we must make sure our

Helpline is there for people at a time that is right for them.

Making it happen

We must now begin to consider how we can make best use of the resources of the charity to ensure that we can realise the hopes and dreams of the people we support.

Later this year, we hope to share with you further details of our long-term plans and how we are going to make our dreams a reality. And how we can work together to make this happen.

We have the science, the expertise and the commitment. Now we are working on a plan that will ultimately enable us to tell our beneficiaries – epilepsy care no longer lags behind other major diseases. In fact, epilepsy is irrelevant.



76%
feel epilepsy care is falling behind that of Alzheimer’s, dementia, cancer and heart disease

38%
do not have access to a neurologist

72%
would like their GP to have better training in epilepsy

43%
were unaware that they could be referred to a specialist centre if their seizures were uncontrolled

46%
do not have access to an epilepsy specialist nurse

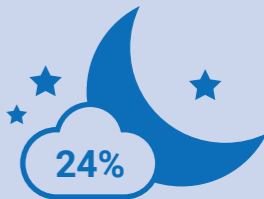
88%
would like to see more epilepsy specialist nurses

76%
feel people should have better access to specialist epilepsy centres with more advanced diagnostic equipment

53%
haven’t discussed different medication options with their doctor



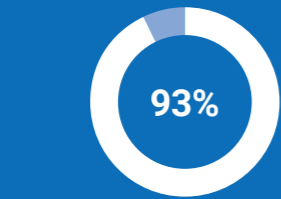
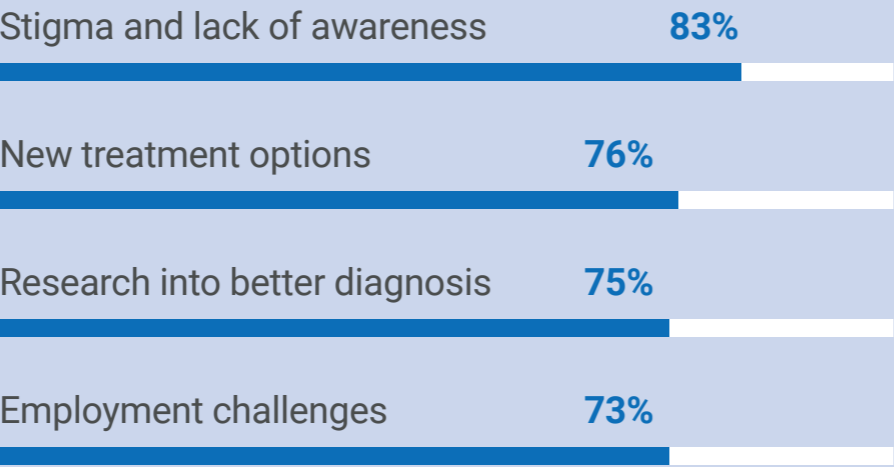
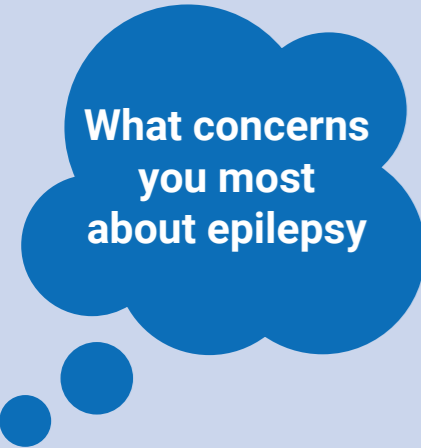
45% prefer to contact our Helpline via email, 39% by phone



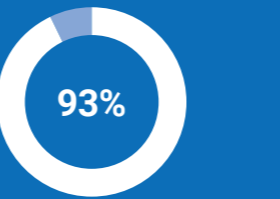
24% would like to see our Helpline open in the evenings – a popular choice for 25-34 year olds (42%)



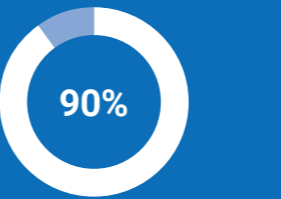
20% would like the Helpline to be open at weekends



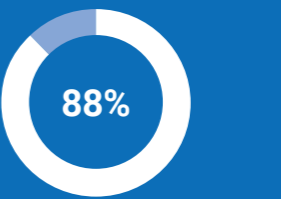
Understanding the causes of epilepsy and stopping seizures



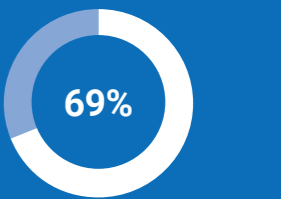
Improved quality of life through treatment options, even if it did not lead to seizure freedom



Understanding the causes of Sudden Unexpected Death in Epilepsy in order to mitigate risk



Personalised treatment



Research into risks around epilepsy medication in pregnancy

'Ain't no stopping us!'

A new era of fundraising events

In 2020, fundraising events faced their biggest challenge to date. No longer could people sign up for a local 10K, organise a quiz night in the local pub or meet with friends for a coffee morning. At first it seemed that fundraising through events and challenges would stop altogether but instead we saw an army of epilepsy heroes come together and raise thousands of pounds to help transform the lives of people living with epilepsy.

Challenge 100, a new virtual challenge launched by us at the Epilepsy Society, asked participants to complete 100 miles in 100 days. Our Challenge 100 fundraisers raised a phenomenal **£93,000** by running, walking and cycling 100 miles between January and April 2021. Despite tackling their miles



Wheels of fortune

Bridgid Duffy chose to double the challenge and completed 200 miles in 100 days raising over £500.



Little helpers

Our fundraisers, wearing their Epilepsy Society tops with pride to support Challenge 100.



To register your interest in Challenge 100 or Purple day 2022 please email fundraising@epilepsysociety.org.uk

from locations all over the world, the collective team spirit and desire to help others was unstoppable.

We always knew that Purple day (26 March) might look a little different this year. Instead of holding the traditional cake sales and coffee mornings, we encouraged supporters to take on a personal challenge or hold a virtual event. From walking 10,000 steps a day in March to holding virtual quiz nights, our ever-creative fundraisers rose to the challenge and raised over **£58,000!**

From all the team at the Epilepsy Society, thank you so much to everyone who has supported us over the past year. Your passion and determination to make a difference, during the hardest of times, has been inspirational.



The greatest gift

Hi there, my name is Yvonne and I'm in the Fundraising Team at the Epilepsy Society. The best thing about my job is that I get to speak to our wonderful supporters every day. An important part of my role is helping people who want to support our work through a gift in their will. Last year more than one third of our voluntary income came through gifts in wills and our work is reliant on these generous gifts. People often have questions about how to make a gift through their will, so I wanted to share some information you might need to support our work in this way.

How would leaving a gift in my will help the Epilepsy Society? We rely on gifts in wills to continue our essential work, transforming the lives of people with epilepsy for generations to come. Our work is only possible through the generosity of people like yourself.

Do I have to leave a large gift in my will? No, it is a common myth that you have to leave a large amount to charity in your will. Any gift you are able to make will help us to continue our vital work in advocacy, research and care. All gifts in wills will make a huge difference.

What about leaving gifts to my family and friends? We understand your family and friends always come first. But if, after taking care of their future, you are able to support our work, a gift in your will could make all the difference to people affected by epilepsy.

If you would like more information about this, please visit epilepsysociety.org.uk/gifts-wills, email donor.support@epilepsysociety.org.uk or call 01494 601300.

Spread a little festive cheer

Epilepsy Society's 2021 Christmas card and merchandise range is now available to buy online, by post or over the phone. We have carefully chosen nine new card designs for this year along with a small number of merchandise items – ideal for stocking fillers!

By purchasing Epilepsy Society's Christmas cards and gifts you are supporting the UK's only charity transforming the lives of people with epilepsy through advocacy, research and care.



Visit epilepsysociety.org.uk/christmascards to view our full range and to place your order or email fundraising@epilepsysociety.org.uk to request a Christmas brochure and details of how to order by post or over the phone.



Left to right: locks down for Thomas; Kaylea makes the first cut; the handsome prince; proud Thomas with William's mum and dad, Kaylea and Jamie Pharoah. Below: brave William

Thomas and William and a love that lives on

We have all been touched by seven-year-old Thomas's commitment to growing his hair in memory of little William, who died of epilepsy. Read the inspiring tale of how Thomas finally had his long hair cut to raise money for the Epilepsy Society through the fundraising group, William's Warriors

It was a very special moment for Kaylea Pharoah when she made the first cut of seven-year-old Thomas Machell's long, blonde hair.

For the last three years Thomas has been growing his beautiful locks in memory of Kaylea's own little boy, William, who died of Sudden Unexpected Death in Epilepsy (SUDEP) at the age of four.

Thomas has put up with three years of being mistaken for a girl,

but the confusion and comments never bothered him as he grabbed the opportunity to explain that he had been growing his hair in memory of his good friend William.

He had hoped to have his hair cut in December to raise money for the Epilepsy Society which carries out research into SUDEP. But lockdown meant that he had to wait until the summer when the hairdressers were finally re-opened and Thomas's mum, Salli Kidson

was able to book an appointment.

William's mum, Kaylea, was at the salon in Barrow-in-Furness to make the first cut before handing over to the professionals. The hairdressers plaited Thomas's hair which has now been donated to the Little Princess Trust to make wigs for children and young people who have lost their own hair due to cancer treatment.

Kaylea said: "We were unbelievably touched when Salli

reached out to us about Thomas's wishes to raise money for William's Warriors – a fundraising group in aid of the Epilepsy Society. He epitomises the resilience, courage and heart that all of our Warriors have shown and at such a tender age. Thomas is the most loving and kind young man around, I distinctly remember him coming to give me a big hug at William's wake; he is so emotionally mature and intelligent, far beyond his years.

"Since losing William, the Warriors have become a huge part of our life. We want to build a legacy to show the world who our boy was. We want to prevent this from happening to other families and ensure that though short, his life was full of love and meaning."

Thomas's mum, Salli said: "We are super proud of Thomas. It was a very emotional moment for all of us, though to be honest, Thomas wasn't emotional. He just wanted to get his hair cut and raise money in memory of William. That is why he was doing it."

"I have been very touched by the remarkable generosity of people

who have donated, and to all the people who came and stood outside the hairdressers with us while either Kaylea or I went in with Thomas. The Epilepsy Society is a cause really close to our hearts because of William."

Thomas and William were born just one day apart and their mums are second cousins. The boys had a special bond from the beginning and their families hoped that the boys would grow up together and become lifelong friends. But at 10 months, William was diagnosed with a rare genetic disorder and epilepsy which meant that he often had to cope with 35-40 seizures a day.

In spite of a brave battle to lead a full life and attend mainstream school, William died of a seizure on 19 December 2018, after doctors fought for 19 hours to save his life.

Clare Pelham, Chief Executive at the Epilepsy Society, said: "We are immensely proud of

Thomas. He has chosen a really special and brave way to remember his friend, William. Every day that he was growing his hair and putting up with being mistaken for a girl will bring hope for children with epilepsy in the future. He has astonishing courage and wisdom for a seven year old.

"SUDEP is one of the key areas of research for our scientists at the Epilepsy Society. We want to be able to identify biomarkers in the brain that may suggest a person is at risk of sudden death in epilepsy. That will enable us to put in place strategies to reduce that risk and hopefully save lives.

"That special bond which Thomas and William had from the beginning will live on through the research which Thomas is helping to fund, and the children whose lives will be changed. And we are very grateful for that."



You can still donate to Thomas's fundraising page at <https://uk.gofundme.com/f/thomass-haircut-for-william>

Read more about William's Warriors at epilepsysociety.org.uk/williams-warriors

Tonic comic



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

Covid is a lot like the Star Wars movie franchise. Come with me on this: in the beginning there was just the one film, and everyone was on the same page about it – it was an exciting tale of plucky everyday heroes joining forces to defeat a shared enemy. In Covid terms, we had a simple message (Hands – Face – Space) and we all joined forces to lock down, show how much we supported the NHS and how much we wanted to defeat the Empire, I mean Covid.

This early victory of collective action was quite quickly followed by a second lockdown, I mean film, but this time the enemy – or 'Empire' – struck back and things were less happy in the Galaxy. There were lots of casualties in this film – Han Solo gets frozen in Carbonite and Luke Skywalker loses a hand in a light sabre battle. The Covid equivalent was emerging news about government blunders and delays in being able to contain the virus and Christmas was cancelled. Winter was long and things felt bleak and exhausting; it felt like the enemy was winning.

The third film in the trilogy (at that time it seemed it was just going to be a trilogy), saw that despite recent defeats, the Rebel Alliance still manages one last desperate attempt to overthrow the Empire. This film had lots of action and derring-do, plus there is the Han Solo/Princess Leia love story, though unlike Matt Hancock, this affair did not lead to him losing his job.

As Star Wars was not just something that happened in the

1970s and 80s, it is a current and continuing saga. I haven't seen all dozen or so Star Wars films so I'm a bit lost as to which characters appear when in the timeline. Similarly, after so many twists and turns in government policy and new strains of the virus, I'm still unclear on the latest guidelines around how we should all co-exist in our new Covid world. I don't know what normal is anymore. At the start of Covid we were all getting used to a New Normal, but are we now back

I'm still unclear how we should all co-exist in our new Covid world

to an Old Normal now, or are we looking for a new New Normal? To be honest, it seems to me that there are multiple 'normals' depending on how much your life is still affected by Covid restrictions.

For my nearly 80-year-old Dad, 'normal' is pretty isolated and cautious, always mindful of how many people might be at a particular event. My 'normal' is considerably more social. I'm still masked in shops and on trains, though I do meet up with friends and family in small groups and work life is pretty much back to, er, 'normal'.

It is also apparently normal now for me to meet my neurologist over the phone rather than in person at the hospital. Whilst this does save me a train journey into town, in all

honesty I miss the ritual of these appointments. There is something reassuring about the experience of the neurology outpatients department, and I'll miss the clinical lighting, clinical smell, and the receptionist almost permanently on the phone.

Neurology appointments are just one aspect of life for people with epilepsy that has adjusted during these Covid times. For some the restrictions have been quite welcome – supermarkets have been quieter and some have been able to adjust working life to be at home more. There has also been a lot of extra anxiety during this time: how might Covid affect me? Am I more vulnerable because of my epilepsy and if I get Covid might my epilepsy get worse? Also, for people with epilepsy who live alone, lockdown increased the risks of having a seizure on your own. Sometimes I think it's only afterwards that we realise how much we have been holding emotionally.

One crucial thing that we do have now, like our Jedi friends, is a kind of 'Force'. We have a vaccine! I got the Pfizer Force and it really has helped me feel better protected against (serious) illness from Covid.

In the end of the Star Wars trilogy it is the Force that saves the day and Luke acknowledges that "The Force Is Strong in my family". It is the dawn of a new, hopeful era at the end of Return of the Jedi; the Dark Side has been beaten and balance has been restored. In our world, though new variants of Covid seem inevitable, and we all need to take some time adjusting to new realities, at least we have an important weapon to protect us. May the Force Be With You.

Juliet Stephens
Laughing allowed

Society matters

Our first ever virtual Supporter Conference

On 16 July we held our first ever virtual Supporter Conference, sharing our achievements of the past 12 months and thanking our incredible supporters for all their fundraising and donations.

We also gave delegates the opportunity to listen to GB judo fighter, Evan Molloy, talking about how five days at the Epilepsy Society turned his life around.

No sooner had Evan finished speaking than he was off to prepare for Tokyo where he was a training partner at the Paralympics 2020.

Over 250 people registered for the conference. Speakers included Clare Pelham, Chief Executive; Dr Lisa Clayton from our research team; Nicola Swanborough, Head of External Affairs; Jonny Anders-Cannon, Director of Care Services; Professor Ley Sander, Medical Director; and Gordon Craig, Director of Fundraising.

Gordon said: "The pandemic gave us an opportunity to trial a virtual supporter conference and we are absolutely delighted with its success. We were so pleased we had such an opportunity to thank so many people and to show them the difference their support makes."



Sad farewell to Cheryl

It was with great sadness that we said farewell to Dame Cheryl Gillan DBE MP and Vice President of the Epilepsy Society, who died earlier this year.

Cheryl had been MP for Chesham and Amersham for almost 30 years and was the longest serving Conservative female MP in parliament.

She championed the cause of people with epilepsy in parliament and for many years served as Vice Chair of the All Party Parliamentary Group on Epilepsy.

Cheryl took every opportunity to draw parliament's attention, with pride, to Epilepsy Society as a centre of excellence which sat within her constituency but which transforms lives throughout the UK and around the world.

Clare Pelham, Chief Executive at the Epilepsy Society said: "Cheryl had an incredible understanding of what it is like to live with epilepsy. She really got people and we have been fortunate to have always been able to call upon her support. Cheryl will be greatly missed by all of us."

Welcoming visitors at the Epilepsy Society



Andrea Baughan and her daughter Emily (centre) on a tour of our laboratories.



Joy Morrissey, MP, meets members of our research team.

After more than a year of closing our headquarters in Buckinghamshire to visitors, in order to protect residents during the pandemic, we have been pleased to gradually start opening our doors again.

Families and friends have been able to visit their loved ones. And we have been able to welcome visitors on site and share some

of our amazing research into the causes and treatment of epilepsy.

Visitors have included Joy Morrissey, MP for a neighbouring constituency, and Andrea Baughan, the new Mayor of High Wycombe who has nominated the Epilepsy Society as one of her two charities during her tenure as Mayor.

For richer, for poorer

As the nation marked the death of His Royal Highness, Prince Philip, our Chief Executive, Clare Pelham was invited to join the BBC Radio 5 Live commentary box on the morning of the Duke's funeral.

Prince Philip had been a constant support at the side of our Patron, Her Majesty the Queen, for almost seven decades, and his funeral was a time to reflect on

how epilepsy had touched the lives of the Royal Family. Prince John, uncle to the Queen, died at the age of 13 from what is believed to have been Sudden Unexpected Death in Epilepsy.

Clare told the nation: "Epilepsy has no respect for castles and palaces. The sad tale of Prince John underlines the fact that epilepsy can affect anyone of any creed, race, gender or age. Rich or poor.

"Prince Philip lived to a wonderful age, and through his hugely successful Duke of Edinburgh's Award, he inspired young people all over the world to think big, dream big and grab hold of life with both hands.

"But young people today are still dying of SUDEP – teenagers with epilepsy who should be off orienteering, sailing and discovering the joy of a life without limits. That is why our research is so vital."

epilepsy society

Helpline

01494 601 400

Monday to Friday 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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**FUNDRAISING
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Give a little love Leave a lasting legacy

By leaving just 1% of your total worth to the Epilepsy Society in your will, you can help fund valuable scientific research to help us treat and beat epilepsy.

To receive your legacy pack call us on 01494 601414 or email donor.support@epilepsysociety.org.uk

To find out more about leaving a lasting legacy visit epilepsysociety.org.uk/loveliveson