Issue 27, Winter 2022

Epilepsy Review

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epilepsysociety.org.uk

epilepsy society

Over the last few weeks we have been reflecting on what Her Majesty The Queen meant to us as Patron of the Epilepsy Society. Her sad loss at the end of an amazing life leaves a real hole in the charity. But it also shines an important light on what many believe may have underpinned her loyalty to people with epilepsy – her uncle, Prince John, is thought to have died of a seizure at just 13.

The young prince died in 1919, before the Queen was born, but we know how the loss of a loved one, particularly one so young, can be felt in a family many generations later. Time and again we see how the death of a family member can inspire parents, siblings, cousins, friends and neighbours to devote time and energy to raising money for epilepsy research; running, cycling, climbing, baking to combat the pain and bring hope of a cure for others in the future.

It is over 100 years since Prince John died yet still today, in spite of ground-breaking research into epilepsy, 1,200 people in the UK die of epilepsy-related causes every year. And too often they're young people, in the prime of their lives.

On page 5 you will see a beautiful painting 'Hope shines eternal' which was completed by 18-year-old Alisha, the night before she died. Alisha had epilepsy. She left the painting outside her mum's bedroom door as a gift for her to discover when she woke up. There are no words that do justice to the tragedy of Alisha's loss for her family. Yet in spite of their heartbreak, they are already fundraising in Alisha's memory, turning their grief into money that will make a difference to the lives of others with epilepsy.

Here at the Epilepsy Society we are also determined to turn epilepsy on its head and to stop people dying from seizures. And we are taking a new and radical approach to this.

The charity was still in its early days when Prince John was born. Throughout his short life, our founding fathers were busy acquiring 300 acres of land to be used for the benefit of people with epilepsy.

One hundred years ago, the land provided gainful employment for those the charity supported. But not today. Today much of the land is costing us money when it could be funding research to transform your lives.

We want to dig up the wealth in our land and turn it into research. So we have applied to develop part of our land for housing. And it could be a game-changer. It could revolutionise the diagnosis and treatment of epilepsy and spell real hope for the future.

Tragically, it's too late for Alisha. But the poignant message that she wrote on the painting for her mum, is an inspiration for us all – 'hope shines eternal'. And it is for us to make it happen. In memory of Alisha and all those affected by epilepsy, we are determined to revolutionise epilepsy. You can read more about our plans on page 11.

Nicola Swanborough
Editor

Front cover
We pay tribute to Her Majesty The Queen who was Patron of the Epilepsy Society from 1952 – 2022. Photograph by kind permission of Press Association *(page 8)*.

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CAMPAIGNS

Get jabbed, stay safe this winter

The Epilepsy Society is encouraging everyone who is eligible, to have vaccinations for both Covid-19 and flu as we head for the winter. Everyone with epilepsy, aged five and over, is eligible for the Covid-19 booster, but they will not be automatically eligible for the flu jab. This is at the discretion of your doctor (see below).

Experts have warned of lower levels of natural immunity to the flu and an increase in the circulation of Covid-19. Data shows that H3N2 is currently the most-commonly detected flu virus worldwide and has recently caused waves of infection in southern hemisphere countries such as Australia.

The H3N2 strain circulated in the UK last winter but was largely held in check by COVID-19 restrictions when people mixed a lot less and worked from home. This helped to protect people from catching flu but has also led to lower levels of natural immunity to this strain within the population.

The UK Health Security Agency say that there are also early indications that Covid-19 rates are beginning to rise ahead of winter.

Study results from early in the pandemic show individuals who catch both flu and Covid-19 at the same time, known as co-infection, are around twice as likely to die compared to those who only have Covid-19.

Ley Sander, Medical Director at the charity and Professor of Neurology at UCL said: “Vaccines for Covid-19 are the best way to protect yourself from this virus. Some people worry that the vaccine may cause a seizure, but the benefits of the vaccine far outweigh the risks. If you are unvaccinated and contract Covid-19, your symptoms are likely to be far worse including a high fever which may trigger a seizure. If you have been vaccinated, you may still contract Covid, but the symptoms should be less severe.

“People with epilepsy are not automatically eligible for the flu jab. This is at the discretion of your GP. I always recommend that people I look after have the jab. Flu can cause a high temperature which again can trigger a seizure. I have written a letter of support (see below) which you can give to your GP, explaining why the flu jab is important.”

Find out if you are eligible for the flu jab and download the letter of support at epilepsysociety.org.uk/jab

INFORMATION

Cost of living crisis – find help

As we go into the winter, we know that many people will be struggling as a result of the cost-of-living crisis. So it is important to make sure that you are taking advantage of all the benefits, grants and discounts that you are eligible for.

To help you navigate your way through the options that are out there, the Epilepsy Society has a list of resources and information that may be useful. You can access the information at **epilepsysociety.org.uk/cost-of-living-crisis**

Our information page includes the following areas:

Transport Including Access to Work grant, disabled person’s rail card or bus pass or a refund on travel costs for medical treatment.

Benefits There is a whole range of benefits available depending on your individual circumstances, but make sure you are receiving the benefits that you are entitled to.

Healthcare Everyone with epilepsy is entitled to epilepsy medication for free, but find out whether you might also qualify for free dental services or sight tests.

For Carers If you care for someone with epilepsy, find out whether you are entitled to a carer’s allowance. Unpaid carers, such as friends and family members, are entitled to a free carer’s assessment.

Van Gogh: hidden portrait, hidden disability

This summer, much of the world was shocked to learn that a previously hidden self-portrait by the artist Van Gogh had been found on the reverse of one of his paintings at the Scottish National Gallery.

For the Epilepsy Society, it held a special kind of interest. Van Gogh was diagnosed with epilepsy and wrote frequently about the condition. And there is a certain symmetry to an artist with a hidden disability “hiding” a self-portrait behind another piece of work.

Van Gogh died in 1890, at a time when understanding of epilepsy was very different. Just two years later, the Epilepsy Society was founded. In the lifetime of the Society we have seen many changes. While, sadly, the stigma affecting people with epilepsy remains, there is much greater awareness than in Van Gogh’s day. You can read more at epilepsysociety.org.uk/van-gogh

MEDICATION

Risks linked to medication in pregnancy

Concerns have been raised about risks linked to two anti-seizure medications during pregnancy.

A new safety review has been launched into the epilepsy medication topiramate. And new advice has been published about pregabalin.

Topiramate (brand name Topamax) is already associated with an increased risk of congenital malformations and effects on fetal growth during pregnancy.

But a new study has pointed to an increased risk of neurodevelopmental disabilities including autism spectrum disorder and effects on learning and development in children exposed to the drug in the womb.

The study has been launched by the regulatory agency responsible for the safety of medicines – the MHRA – which will assess all relevant data.

The MHRA has also reviewed results from a new study from four European countries into pregabalin (brand names Lyrica, Alzain, Axalid and Lecaent).

Studies have shown that taking pregabalin during pregnancy is associated with an increased risk of the baby being born with physical birth abnormalities, although it could not be proved that pregabalin was the cause of the physical disabilities.

Any woman of childbearing age who is taking topiramate or pregabalin, should seek the advice of her doctor. They will be able to discuss different treatment options and the use of effective contraceptives while taking these medications. If you are planning to have a baby, you should discuss your treatment options urgently with your doctor before stopping contraception.

You should never stop taking your epilepsy medication without medical advice.

CAMPAIGNS

Beyoncé stands up for epilepsy while R&B's Chris Brown laughs at mock seizures

Singer songwriter Beyoncé proved to be more than just a musical star when she added a seven-second warning to her video containing flashing images. Meanwhile R&B's Chris Brown was condemned for sharing a post that mocked seizures.

They were just a few short weeks apart, but separate, high-profile incidents which involved two of the music world's biggest names, showed why some people deserve to be called legendary while others don't.

In June, Beyoncé launched the first single, Break My Soul, from her new album *Renaissance*. However, the video contained flashing images which could be potentially dangerous for anyone who is photosensitive. And it came with no warning.

The Epilepsy Society, along with other epilepsy charities and many of our supporters, contacted Beyoncé via Twitter. And within 48 hours her team had added a seven-second warning to the start of the video, alerting fans that it contained flashing images.

Seven seconds that could stop a seizure. Thank you, Beyoncé.

In another quarter of the music world, all did not end so happily.

The controversial R&B artist, Chris Brown, shared a Tik Tok post with his 119m followers on Instagram of a freelancer dancer pretending to have a seizure. The post was widely criticised with followers calling the dance 'offensive' and asking him to remove it.

When one woman who regularly posts about her epilepsy messaged Brown direct, she said the singer threatened to visit her house with a strobe light. In a further message, he wrote: "Alexa – play flashing lights by Kanye."

The Epilepsy Society condemned the R&B artist for using his platform to laugh at people with a disability and for threatening to use strobe lighting to try to trigger a seizure.

The Epilepsy Society was unsuccessful in persuading Brown to take down the post, but Tik Tok acted swiftly to remove the original post from their platform, saying it violated their rules.

Nicola Swanborough, Head of External Affairs at the charity said: "We are really grateful to Beyoncé and her team for acting so quickly. This shows what empathy and consideration for others can achieve.

"Chris Brown, by comparison,

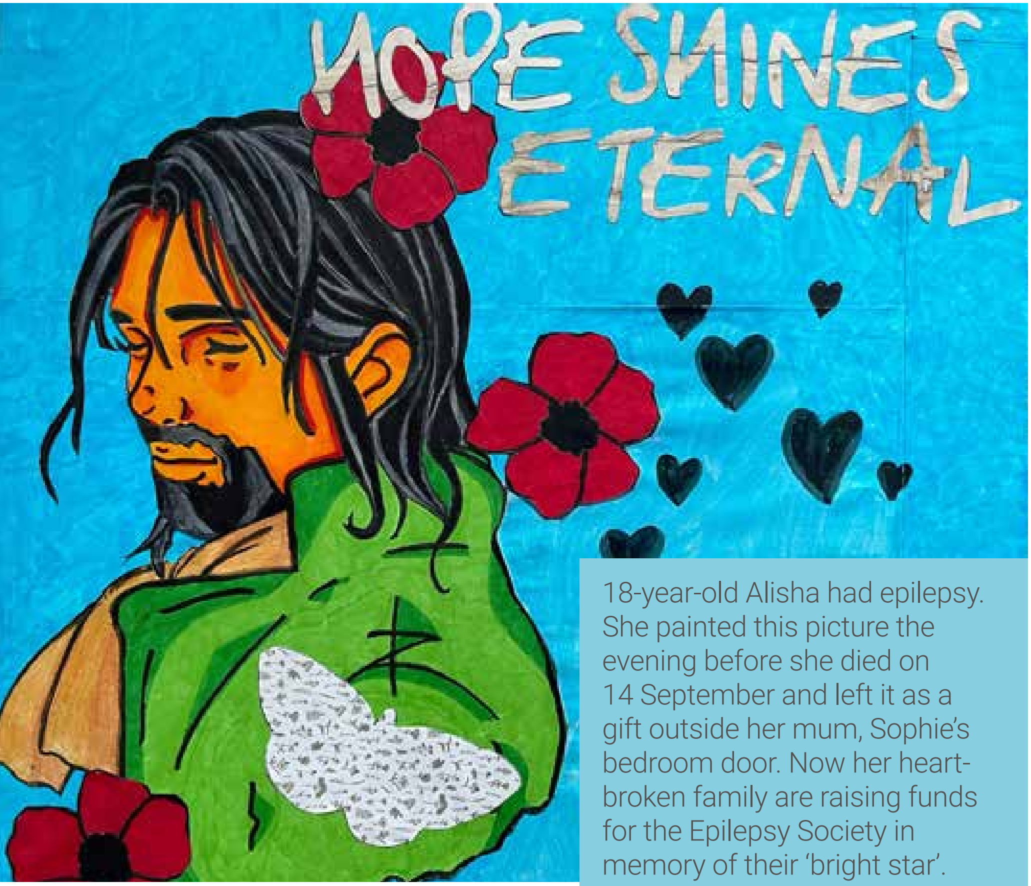
SAFE MUM, SAFE BABY

New Patient Safety Commissioner receives our petition

In one of her first official meetings, the newly appointed Patient Safety Commissioner was presented with our Safe Mum, Safe Baby petition by a young woman with epilepsy.

The petition – signed by 1,647 people – calls on the Government to invest in vital research into safer epilepsy medicines for pregnant women. It was presented to Dr Henrietta Hughes, right, by Yasmin Golding. Yasmin, who hopes one day to have a child, spoke passionately on behalf of the many women who have to make difficult decisions about starting a family when taking epilepsy medication. You can read more about our Safe Mum, Safe Baby campaign on page 17.

In memory of our ‘bright star’



18-year-old Alisha had epilepsy. She painted this picture the evening before she died on 14 September and left it as a gift outside her mum, Sophie’s bedroom door. Now her heart-broken family are raising funds for the Epilepsy Society in memory of their ‘bright star’.

If you would like to donate, please go to **www.justgiving.com/fundraising/sophie-edwards63**

showed no sensitivity to thousands of his followers who are likely to have epilepsy and possibly also be photosensitive. One in 100 people have epilepsy, so with a following of 119m, it is likely that 1.19m of them will have epilepsy and thousands of them may be photosensitive.”

Clare Pelham, Chief Executive of the charity added: “Mocking a group of people with a hidden disability that is often stigmatised and overlooked, is unforgivable. Chris Brown could be using his platform to raise awareness of the condition and increase understanding of epilepsy among his millions of followers.

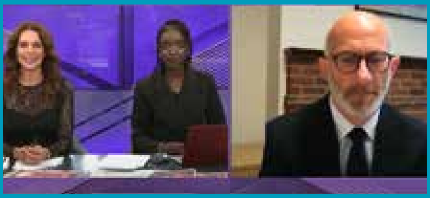
“We hope that, in the future, other artists will show the same degree of sensitivity that Beyoncé did when producing videos.”

Royal coverage

Watch or listen to our team paying tribute to the late Queen and our Patron at **epilepsysociety.org.uk/HM-Queen**

Our Chief Executive, Clare Pelham, talks to BBC Radio 5 Live about her experience of attending the State Funeral of Her Majesty The Queen.

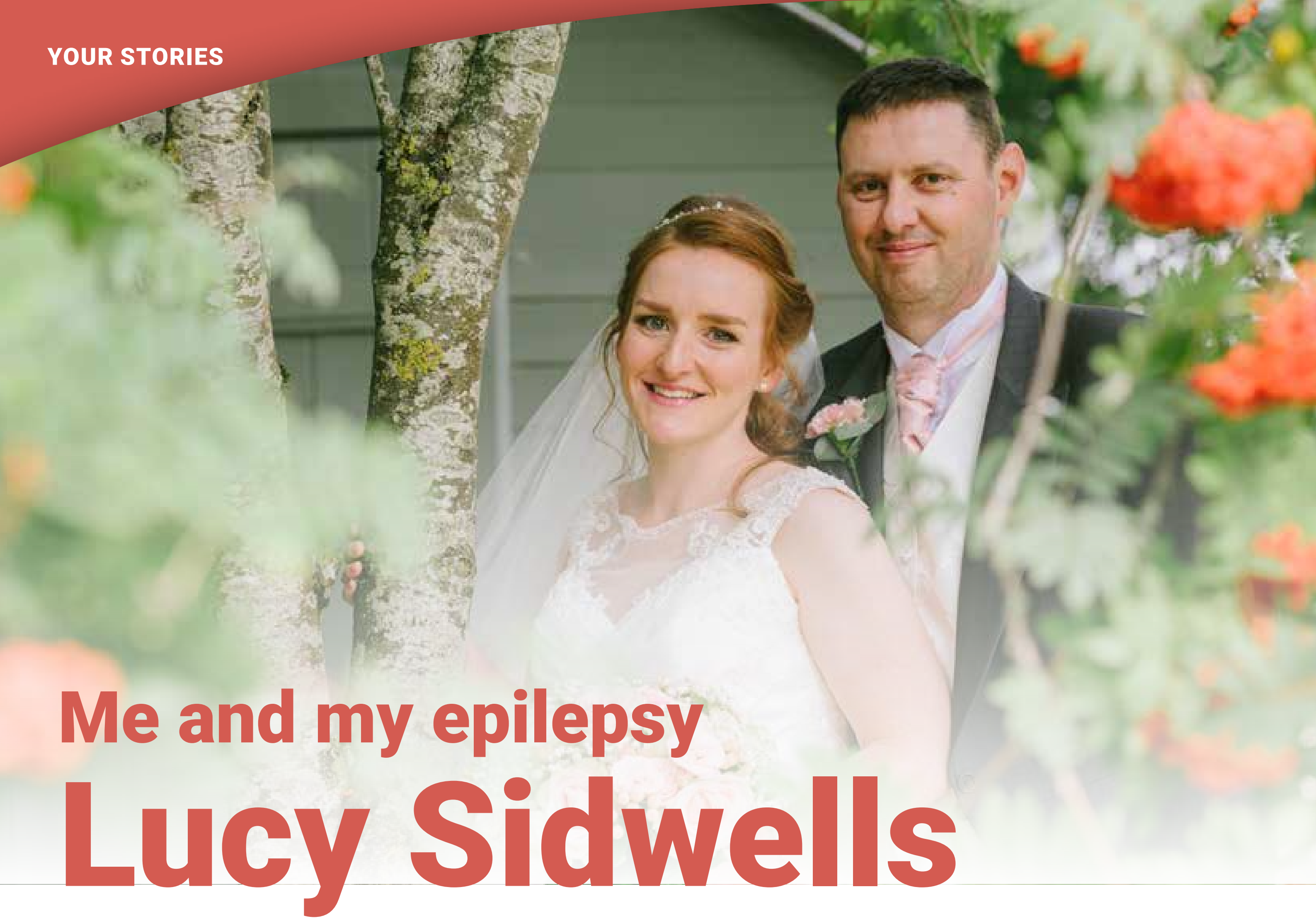
Our Head of External Affairs, Nicola Swanborough, talks to Anne Diamond and Stephen Dixon on GB News about how important the Queen was as Patron of the charity.



Our Chief Financial Officer, Andy James talks to GB News about a letter from the Queen that helped raise £40,000 for people with epilepsy.

And here, Andy James talks to LBC News about the legacy of the late Queen Elizabeth II.

You can find archive footage of the Queen's visit to the Epilepsy Society in 1985 at youtube.com/epilepsysociety



Me and my epilepsy

Lucy Sidwells

Midwife, Lucy Sidwells, 30, explains how she had her first tonic clonic seizure after finishing a shift in the hospital where she works. And how the challenges she now faces with her epilepsy medication mean having a baby will be a difficult decision for her.

Epilepsy diagnosis

I was diagnosed with epilepsy in 2019, just three weeks before getting married.

I had just finished a long shift at the hospital. I was driving home and had a headache and started to feel sick. Luckily my husband was at home. I went and laid down as I needed to be in the dark. The next thing I knew there were two paramedics in the bedroom. I had had my first tonic clonic seizure. I was rushed to hospital where I had another two seizures. After the third one, I was unconscious for several hours.

Partial seizures

Over the years I had been to see my GP many times because of funny episodes that I experienced where I felt confused. Looking back, I had been having partial seizures since I was four or five. I did tell people at the time but trying to explain at that age how your body is feeling inside, is very difficult. People thought I was day-dreaming or just not paying attention. Epilepsy can be very difficult to spot. In the end, I just got on with things and accepted the seizures and rarely talked about them.

It was one of the midwives who I work with who noticed what was happening. I had a partial seizure in front of my colleagues after a long shift at work. She has a son with epilepsy and recognised the symptoms. She said I should check it out and she was right. I insisted on seeing a neurologist but I ended up in hospital with a diagnosis before that could happen.

I started on epilepsy medication a few years ago and initially things improved, then during 2020-2021, they got worse again. I started on a low dose of levetiracetam and once we reached the maximum, added in lamotrigine. My seizures are now a bit better controlled, probably about half the number they were before, but I've had about 16-18 seizures since 2021.

Mental well-being

At the end of last year I had to have time off work to get to grips with the impact that epilepsy has on my mental health. I have had some CBT (cognitive behavioural therapy) which has helped me to deal with things, and I'm back at work now.

My colleagues have all been very supportive and reasonable adjustments have been made by my manager to keep me in work. My neurologist didn't want me to work night shifts anymore as tiredness triggers my seizures, so this was changed immediately. I am a core member of staff on the ante-natal and post-natal wards so I don't deliver babies, just in case I have a seizure.

When we have young mums in with epilepsy, they are often reassured that I understand their worries and am able to share my own experience with them. I always have to minimise any risks. If I am carrying out an assessment of a baby, with top to toe checks and heart rate, I will always do it while the baby is in its cot.

Challenges of pregnancy

My husband, Martin, and I aren't planning for children at the moment and potentially not at all. I am very aware of the risks around epilepsy medications during pregnancy. My neurologist always checks that I am on contraception. On my current medication, the risks for a baby would be lower during pregnancy, but if I have to introduce new medications to control my seizures, I would need to make some difficult decisions. I would either have to wean myself off the dangerous medications and risk having seizures, or I would have to stay on the drugs that control my seizures and then risk the health of my baby. It is an impossible choice. Either you put yourself first or the baby.

London Marathon

After my first tonic clonic seizure, I became quite nervous about going out for a walk by myself. But I pushed myself to return to work before getting married which I'm glad I did. I felt quite confident on my wedding day as there were several doctors and midwives present, so I felt very safe.

> **“To my fellow epilepsy sufferers, I say hold your head high and reach for the stars – you can achieve anything you set your mind to despite the challenges we face daily**

I receive a lot of support from my younger sister Rachel who is my friend and my therapist. She keeps me sane. During lockdown I started running and on 2 October we ran in the London Marathon – it was an amazing experience, one I will remember forever and will always be proud of myself for completing.

I always wear a wristband that says I have epilepsy, so if I am training and have a seizure, people would know why I seem confused. I make sure I run on public footpaths where there are other people. I have had seizures while out running but I just wait and re-orientate myself or turn round and run home.

To my fellow epilepsy sufferers, I say hold your head up high and reach for the stars – you can achieve anything you set your mind to despite the challenges we face daily.

Clockwise from left: Lucy and Martin on their wedding day; Lucy training with Frank; Lucy and sister, Rachel; with Martin and Frank; and fundraising for the Epilepsy Society

Thank you to Lucy and Rachel for supporting Epilepsy Society. You can sponsor them at **https://justgiving.com/fundraising/rach-evans95**

Thank you, Your Majesty

Queen Elizabeth II – our Patron

1952–2022

Throughout a 70-year reign, Her Majesty The Queen gave her unwavering support to people with epilepsy, as our Patron. Here, we look back at what her patronage has meant for us while over the page, we describe how our Chief Executive, Clare Pelham joined the nation in a poignant farewell to the Queen.

Since the sad loss of Her Majesty The Queen on 8 September 2022, every newspaper, website, news programme, shop window and billboard has been covered with photos of our much-loved monarch. People up and down the country have displayed hand-drawn pictures of Her Majesty alongside poems and memories of a woman who we all thought immortal.

But few have seen some of the wonderful archive photos and artefacts that bear testimony to her Majesty as Patron of the Epilepsy Society. And we are proud to share those with you here, in this issue of *Epilepsy Review*.

> **“They all had a simple message for the Queen, which I believe says it all, from all of us at the Epilepsy Society: ‘Thank you.’**

For almost seven decades, we were privileged to have the Queen as Patron of the Epilepsy Society.

We know that epilepsy was a cause that was very close to her heart. The Queen's uncle, Prince John lived with seizures during his short life and is believed to have died of his epilepsy at the age of 13. As anyone who has lost a loved one to epilepsy knows, the impact on a family can live on for generations to come. The loss, the heartache and the need to stop others living through the same grief are unending.

During her lifetime the Queen supported over 600 charities and organisations in the UK, recognising the invaluable role they play in making a difference to the lives of people both at home and abroad. Following her 90th birthday, Her Majesty began to relinquish some of her patronages. We are proud that she remained, until her death, our much loved Patron

Clare Pelham, Chief Executive of the Epilepsy Society said: “Her Majesty The Queen was an inspiration to people around the world. Everyone, in nations far and wide, will have cherished memories of what she meant to them. That is what makes it so special for us at the Epilepsy Society that, in spite of all the demands on her time as monarch, the Queen remained a loyal and constant supporter of our charity and of the 600,000 people in the UK with epilepsy.

“Epilepsy is often considered a Cinderella condition. But the Queen’s stalwart position as our Patron meant royal recognition for the condition. It meant solidarity, empathy and understanding.

“We often say that epilepsy has no respect for kings and castles. It can affect anyone of any race, faith, age or gender. The Queen’s patronage of the Epilepsy Society was a great testimony to this.”

During Christmas 2020, with the nation in lockdown, we sent a special festive message to Her Majesty at Windsor Castle via Zoom. Many people whose lives have been changed by the Epilepsy Society joined us on the call to tell the Queen just what a gamechanger her charity has been.

Well-wishers included a young mum who had undergone brain surgery to stop her seizures and who is now a nurse in the NHS with two young boys; there was a GB judo fighter whose dreams of representing Great Britain in the next Paralympics have been made possible by treatment at the Chalfont Centre; and a couple whose family have been helped through genomic sequencing.

Clare Pelham continued: “They all had a simple message for the Queen, which I believe says it all, from all of us at the Epilepsy Society: ‘Thank you.’ ▶

Ellie and the Queen

Dear the Queen,
I am Eleanor
I am 10 years
old. a person that
I know has just
died of an epaleptic
stroke at the age
of 10 please do
Samthing about
it and try to
get someone to
make a cure for
other people who
are suffering from the
same, please help
from Eleanor

Sheffield

please make a
difference

In 2017, 10-year-old Ellie wrote to the Queen after losing her young friend, Patrick to epilepsy. Ellie had one request, that the Queen should ask someone to find a cure for epilepsy. The Queen put Ellie in touch with the Epilepsy Society and we were able to work with Ellie and her family to raise just under £40,000 for research into epilepsy. The Queen asked not to be named. It is only now that we can reveal the important part she played in our Christmas Appeal.

Left: During her visit to the Epilepsy Society in 1985, the Queen was able to find out about many of the activities that residents enjoyed, including knitting. **Right:** meeting some of the residents who lived at the Epilepsy Society. **Page 8:** We're not sure if the Queen was putting in an order for her Christmas turkey from one of the residents, 'Tiny' Morrison.

A royal visitor at the Epilepsy Society

In 1985, the Queen paid a visit to the Epilepsy Society's Chalfont Centre in Buckinghamshire. She spent time meeting residents at the centre and heard, first-hand, about the challenges of living with uncontrolled seizures. But she was also keen to learn about the latest diagnostic tests for epilepsy and how new medications and treatments were bringing greater hope to people with epilepsy.

Over the years, with the Queen as our Patron, we have also been privileged to enjoy visits from other members of the Royal Family, including The Queen Mother, Princess Anne, Princess Diana and the Countess of Wessex.

In 2016, five Epilepsy Society 'heroes' and their guests joined the Queen for the Patron's Lunch – a street party stretching the length of the Mall, to celebrate her 90th birthday. The Queen invited representatives from all of her 600 plus charities, to help celebrate the support and service she has provided over 70 years.

Reflections from inside the Abbey

Clare Pelham, Chief Executive at the Epilepsy Society was among the guests honoured to be invited to Westminster Abbey for the funeral of Her Majesty, our late Queen.

Clare shared her reflections with BBC Radio 5 Live immediately after the service, and you can hear these in full (see page 5 *Royal coverage*).

Clare was seated in the nave near the West Door of the Abbey, alongside members of the armed forces and leaders of public organisations and some of the other charities for whom the Queen had also been a patron. Also in attendance were members of the public who had been appointed MBE in the recent honours list. It was a wonderful blend of diverse individuals. Clare said the service had the form and structure of a ceremonial occasion but the spirit of a family occasion.

She paid tribute to the commitment of the late Queen as our Patron in her private and public support of the Epilepsy Society. Her Majesty had written movingly to us during the pandemic saying that she had been continually impressed by the excellent work of our staff. Her resolute championship of our cause was always so helpful to us in tackling the stigma that is often attached to epilepsy and we will always honour her invaluable contribution to our work.

Clare described how she maintained her composure until almost the end of the service when the Archbishop of Canterbury gave the commendation with the words, 'Go forth, O Christian soul'. She was particularly moved by that phrase as it called to mind how much Her late Majesty's faith was central to her life. And how much it informed her desire to do her best for all her subjects, whatever their challenges. This was apparent in her wonderful support for the Epilepsy Society. We shall miss her hugely.

Her Majesty The Queen by kind permission of Mirrorpix.

The legacy in our land that could revolutionise epilepsy

Clare Pelham, Chief Executive at the Epilepsy Society, explains how the charity's 130-year old legacy could spell hope for the future for people with epilepsy.

Last year we shared with you our exciting new vision for the future at the Epilepsy Society.

We talked about how we want to accelerate the pace of research into epilepsy, ensure a fully integrated model of health and social care for those with complex epilepsy, and amplify the voices of people with epilepsy in the political arena to bring about radical changes in their lives.

In short, we want to make epilepsy irrelevant in people's daily lives. Now we want to share with you some of our plans to make this happen.

We have a wonderful legacy at our headquarters in Buckinghamshire – 300 acres of land which was originally bought by our founding fathers – a group of doctors – at the end of the 19th century. They wanted to enable people with epilepsy to enjoy fresh air, good food and meaningful employment, farming the land to produce crops and dairy produce. It was a triumph in Victorian times. Those doctors were brave and pioneering. But times have changed. Now, of course, it is ground-breaking research that is needed to revolutionise the diagnosis and treatment of people with epilepsy.

So, we must be equally brave and pioneering in ensuring that we push forward the boundaries of research. And to do that we must access the wealth that is buried in our land and use it to expand, develop and deploy all the available resources at epilepsy – innovative diagnostic techniques, big data and scientists.

We want to ensure that the brightest minds from around the world can join us at our Chalfont Centre and be part of the solution not just to tackling seizures, but to tackling epilepsy itself.

Today our research centre sits alongside our medical centre, ensuring that patients are at the heart of all our research. And I am proud to say, our research is world-leading.

But across the site we have dilapidated buildings which are no longer fit for purpose, either for residential accommodation or science. We have land which is neither beautiful nor bountiful. Both are a financial strain on our resources and it is important that we ensure the charity is sustainable for the future. We must allow it to grow and develop better outcomes for people with epilepsy.

It is our charitable duty, as guardians of an enviable legacy, to consider turning all our assets, which no longer benefit people with epilepsy, into funds that could transform their lives. ▶

> **“It is our charitable duty, as guardians of an enviable legacy, to consider turning all our assets, which no longer benefit people with epilepsy, into funds that could transform their lives.**

So we are applying for planning permission to develop part of our land for housing. It is a once-in-a-lifetime opportunity that could generate sufficient income to revolutionise the treatment of epilepsy.

It could mean that a young mum with epilepsy who cannot hold her baby without fear of dropping him during a seizure, will be able to relax and enjoy parenthood. It could mean that a young man with epilepsy would be able to make himself a cup of tea without fear of scalding himself should a seizure happen.

Epilepsy has baffled science for almost two and a half millennia, but today our researchers have the expertise and the knowledge to understand at a molecular level, the underlying architecture of epilepsy and move the story on.

We have a breath-taking range of diagnostic tools. Sophisticated neuroimaging can enable us to see deeper into the brain than ever before. Where human vision reaches its limitations, we are using artificial intelligence to teach computers to read brain scans at yet another level. Genomics is enabling us to read the small print of our DNA, unravelling the genetic changes that contribute to epilepsy, with real hope of better diagnosis and better treatments.

And now we are on the cusp of using medical avatars to diagnose epilepsy remotely. This could mean using digital versions of each individual to diagnose epilepsy and work out the best treatment course. It is mind blowing.

People ask us at the Epilepsy Society “Where is the hope?”. Well, I feel privileged to be able to tell you that the hope lies in our land. It has yielded fruit and vegetables, as required. It has yielded dairy produce. And now we are infinitely grateful that it has the potential to yield the funding that will turn epilepsy on its head.

We asked over 1,000 of our supporters what concerns you most about epilepsy and what changes would you like to see.

What you told us:

92%

want to see more funding into research

93%

want research to understand the causes of epilepsy and eliminate seizures

90%

want to see a greater understanding of Sudden Unexpected Death in Epilepsy

57%

don't have access to a neurologist with a special interest in epilepsy

76%

think people with uncontrolled seizures should have access to specialised expertise in epilepsy with advanced diagnostic equipment

Naturally, there are hurdles ahead of us. Much of our land lies within the green belt and although it is not all typical of the verdant, rolling countryside one associates with this designation, we must persuade the authorities and ultimately, the Government, that it is in the interest of people with epilepsy to release its wealth and save lives.

We are in no doubt that it is. There are 600,000 people with epilepsy in the UK. One third of them have uncontrolled seizures. There are as many as 1,200 epilepsy-related deaths every year. The suicide rate among people with the condition is higher than in the general population, particularly among men. People with uncontrolled seizures cannot drive or live their lives to the full without anxiety and this impacts education, employment and their ability to support a family. And epilepsy is often accompanied by mental health issues including depression.

It costs billions to send a rocket or satellite into space. It will cost billions to get a high-speed train to Birmingham, Manchester and beyond. But we are not asking for public money. We are asking only for permission to develop our own land, offering homes and job opportunities for young and old. This permission would turbo-charge our research and transform the lives of people with epilepsy. Making epilepsy irrelevant.

What would our founding fathers say if they were here now? I am guessing they would say 'Just do it!'

Find out how you can help. ▶

What is a medical avatar?

Medical avatars are virtual humans that use powerful computing to simulate the precise working of an individual's biology, from the functionality of the brain, right down to each of the three billion letters of our DNA. Using an individual's own unique avatar, clinicians and researchers may be able test the effects of different treatments to assess which one works for them.


Artists illustration of the site plan

What our plans will include

We want to develop 115 acres of our land to provide:

- 975 house (including affordable housing)
- accommodation for 75 people of retirement age
- a new primary school
- local shops and post office
- enhanced sports facilities
- a green bus service (initially)

What this will mean for people with epilepsy

We will be able to expand our research centre, with 10 more professors and over 100 new researchers; treat an additional 11,650 people with epilepsy every year, using the most advanced techniques; safeguard the future of the residents who live on site; and build a new therapy centre with hydrotherapy pool, gym and treatment rooms for people we support at our Buckinghamshire site.

How you can support our plans?

Please help us to turn epilepsy on its head by telling Buckinghamshire Council just why our plans are critical for the 600,000 people with epilepsy across the country. Why they are critical for you.

We need you to tell them how epilepsy affects your life and why revolutionary new treatments are an absolute must. 1,200 people die from epilepsy in the UK every year. The wealth in our land could literally save lives.

It only takes three simple steps:

1 Go to https://pa.chilternandsouthbucks.gov.uk/online-applications or scan the QR code below.

2 Search PL/22/2898/OA

3 Click on the 'comments' button and register to post your comment.

This is the most important opportunity the charity has ever had to revolutionise epilepsy at such a scale. Please help us to make this happen. Please help us change epilepsy today and for generations to come.

Celebrating family and friends

This year, during National Epilepsy Week, we ran a regional radio campaign, raising awareness of what it is like to live with epilepsy and the important role that family, friends and carers play. **Angshupriya Danda** looks back at the campaign.

Every day the Epilepsy Society witnesses the important role that families, friends, colleagues, and healthcare professionals play in supporting people with epilepsy. We also see the impact that epilepsy can have on those people themselves, as they strive to support loved ones.

While 600,000 people in the UK have epilepsy, we know there are millions more who are there to help when a seizure happens, or to help manage the anxiety and depression that can accompany epilepsy.

We know that epilepsy is about more than having seizures. It is about dealing with the unpredictability of never knowing when a seizure is going to happen. Worrying about disclosing epilepsy to employers and friends. Depending on public transport or lifts from others. Trying to stay awake and concentrate when your body is just saying ‘sleep’. And so much more.

Our Epilepsy Helpline takes over 3,000 calls a year. And almost half of those calls – 1,290 of them – are from people who support someone with epilepsy, including 810 from family members.

That is why we felt it was important to focus on family, friends and carers, as well as people with epilepsy during National Epilepsy Week. We wanted to recognise the vital role that they play in ensuring that their loved ones are supported to lead a full life.

Andrée Mayne, Helpline Manager at the charity said: “We always say that epilepsy doesn’t just affect the person with the condition but also the whole family and those around them. Doctors’ appointments tend to focus on making sure a person is on the right medication to optimise their seizure control, but in between appointments it is those around them who have to support the person when they have a seizure. They play a vital role in helping them to cope with their epilepsy and the side effects of medication, and often need support themselves.”

Nicola Swanborough is Head of External Affairs at the Epilepsy Society. She said: “It is really important to recognise the role that family and the community play in supporting people with epilepsy to cope. A good employer who has empathy and who understands epilepsy can be the difference between someone being in employment or on benefits.

“We took part in 17 interviews reaching an audience of 2.5 million listeners

“A school which has a good support system in place for a child with epilepsy can make sure that pupil has every opportunity to achieve alongside their peers. A parent who supports their child to live their life without allowing epilepsy to define them, will help that child to reach their full potential."

During National Epilepsy Week we were lucky to work with a Broadcast PR agency, Shout Communications. Every year the agency supports a different charity to help raise awareness of a particular condition and this year they chose the Epilepsy Society.

The team at Shout worked with us to secure some high profile interviews on radio and TV, including GB News. And we were grateful to all the amazing people who agreed to join us on the radio and share their stories.

We took part in 17 interviews, reaching an audience of 2.5 million listeners. We broadcast on BBC Radio and independent stations from Lancashire and Merseyside, through to Somerset.

You can read the stories of some of our spokespeople on the following pages. ▶

Dilan

Dilan had his first seizure in July 2021 at the age of 14. It was the last day of term before the summer holidays. He collapsed in his sister's room with a tonic clonic seizure. Since then he has had multiple tonic clonic seizures and has been hospitalised three times with several trips to A&E.

Dilan, pictured here with his seven-year-old sister, Shivani, said: "My parents have had to call an ambulance to our house five times in the last nine months. Epilepsy has changed my life. It's meant I can't do certain things I want to and that I can't be left alone. It's changed my independence and my life at school."

Dilan describes how his epilepsy affects his parents, sister, and his grandparents. "It's horrible for them to see, especially if I injure myself. I also feel bad when they're upset and worried. After a seizure, my parents and sister sit with me and look after me even if I want to sleep for hours."

Anky

Growing up in the traditional culture of India, Anky, a 26-year-old clinical neuropsychologist in the NHS, was hidden away during childhood on account of her epilepsy. The condition was highly stigmatised in India, and her parents felt a sense of shame and fear that the condition would limit Anky for the rest of her life, leaving her isolated. In 2010, she underwent brain surgery which stopped her seizures and changed her life, though she still experiences a lot of anxiety.

Anky said: "My uncontrolled seizures had negatively impacted different parts of my life. I barely had any friends at school who made sure I was safe when I had seizures. Most of the time I did not receive disability accommodation as my school did not understand my condition, which is typical because epilepsy is an invisible disability."

"There was a time I remember where my family were hesitant to speak about my epilepsy even though my seizures had gone. When I left India after my treatment and started to travel around the world to learn about epilepsy diagnosis and stigma, this gave them confidence and they felt proud of me. On the positive side, my journey of overcoming epilepsy gave me direction in life to pursue a career as a clinical neuropsychologist."

Lisa

Lisa is 50 and mum to 13-year-old Sophia. In spite of being diagnosed with epilepsy at secondary school, Lisa was determined to fulfil her ambition to become a solicitor. In 2001, she set up her legal practice, and last year celebrated 20 years in business.

In January 2021, Lisa had seven consecutive seizures which were diagnosed as being Covid induced. Her daughter Sophia was with her at that time and was the one who decided to call an ambulance. Lisa said: "Sophia was extremely frightened and anxious about the whole experience though she kept calm and was very mature. Without her I may not be here now. I owe her so much.

"My parents both coped extremely well when my seizures were first diagnosed, and with every seizure, they kept calm and helped me come round. My mum went to every appointment, of which there were many. She still attends all appointments now. My dad was always there to ensure I was kept away from anything dangerous. In 2017 my dad died – due to the stress, I had a seizure by his bedside. Because of his condition, he was unaware but would have been so upset he could not be there for me."

For almost every call that the charity's Helpline takes, there is another that we are unable to answer. So we are hoping to extend our Helpline to more evenings and weekends and to introduce web chat to reach a younger audience.

Kyle

Kyle was 21 and enjoying life to the full when he had his first tonic clonic seizure. His life changed overnight. His seizure was so serious that he had post-ictal psychosis for almost half an hour and ended up in hospital.

Kyle said: "My mother saw me in the post-ictal state and thought I had a stroke as I was unable to walk or talk and was groaning and rolling around on the floor. I had to leave my job as it wasn't safe for me as my seizures were nocturnal or upon waking. I am constantly in pain and exhausted. I feel I am not worthy of anything as my life has changed completely, I live in fear.

"My mum has been a huge support. She deals with everything to do with my epilepsy. She collects my prescriptions and reminds me to take my tablets and refills my dosette box every week. I have a monitor for when I am asleep. My partner and I both have anti-suffocation pillows to help prevent SUDEP (Sudden Unexpected Death in Epilepsy). I have a very supportive family and partner. We have been housed locally to my mum who comes over every day to help us with our new baby girl who is a blessing."

Rebekah

At 23 a diagnosis of epilepsy shattered Rebekah's independence and confidence as an actor. Anxiety around having a seizure whilst performing and filming became a constant worry for her. She is now a drama teacher.

Rebekah said: "I'm terrified of having a seizure on stage or in front of a camera surrounded by crew I don't know well. I struggle with trusting new people in my life because I never know how they would respond should I have a seizure. I constantly worry that people will walk past me, record me, think I'm a drunk or taking drugs.

"I'm lucky to have a good support network. I do trust my friendship group, so I am comforted. My family are probably most affected.

"My dad has simple partial epilepsy and has different seizures to mine. His aren't controlled. We are in a constant state of worrying about each other. It almost gives me a sense of guilt, because I wish he would save that worry for himself. My family worry when I go to auditions or to new places, in case I have a seizure far from home.

My mom gets upset when talking to me about my seizures. She has seen most of them. She tells me that it's horrible being unable to help your child at a time like that. I can absolutely imagine how traumatic it is to watch your own child having a seizure, knowing that you can only wait for it to finish."

Stuart

Self-employed graphic designer Stuart, 51, can take several weeks to recover from a seizure. This is a challenge when he has several projects on the go. He also has to avoid spending too much time on the computer screen. Stuart once had a seizure while driving his car on the M25 and crashed into the central reservation.

Stuart said: "Recovering from a seizure can take up to a few weeks. This means I must pace myself with returning to work. This is a challenge when I have lots of projects on. I struggle to focus on some conversations and take in lots of information."

"I don't drive now and I had to give up motorsport as I couldn't get a licence. My wife has been with me for most of my seizures. She has vivid pictures in her mind that won't go away and has hurt her back rolling me into a safe position. My son has also helped with many of them. The feeling I have knowing they have had to see me like that is distressing. I feel guilty that they have to go through this to help me."

Campaigning the highs and lows

Our Policy and Public Affairs Manager, Nathan Draper, explains how Zach's Law is so close to crossing the finishing line, while our Safe Mum, Safe Baby campaign was temporarily thwarted by political unrest.

Editor of the Daily Express, Gary Jones, chaired our Zach's Law panel event at last year's Conservative Party Conference where Zach was able to tell MPs about the impact of epilepsy trolling.

There have been few more momentous days in the Society's history than 21st June 2022, when the Government gave their full backing to Zach's Law.

This announcement, made in a televised parliamentary committee hearing, came after many months of intense campaigning by a cross-party coalition of MPs. As ever with a political campaign, things had not always gone smoothly.

We were disappointed in March when the initial draft of the Online Safety Bill did not include Zach's Law, which seeks to outlaw the sending of online flashing images to a person with epilepsy. Despite assurances that the Ministry of Justice were "road-testing" the proposed offence, we faced an uphill struggle to convince the Government of its importance.

Of particular concern was the Government's claim that Zach's Law was unnecessary and would be covered by existing provisions addressing psychological harm. The suggestion that seizures do not also result in physical harm was simply unbelievable.

But we had our secret weapon: 11-year-old Zach Eagling and his loyal gang of MP supporters.

After lobbying from SNP, Labour and Conservative backbenchers, the Government finally saw sense when Chris Philp, then minister for the digital economy, announced that Zach's Law would be included as part of the Online Safety Bill.

One of the driving forces behind this success was Zach's local MP, Kim Leadbeater, who spoke publicly on the need to protect people with epilepsy. And the campaign received a huge boost when Paul Maynard, a Lancashire MP who has epilepsy and cerebral palsy, gave Zach his full backing.

We were hopeful, following the Government's announcement, that the Bill would progress quickly. Instead, political upheaval took hold. As the race to find a new Prime Minister began, the Online Safety Bill was postponed. We have, however, received assurances that Zach's Law will be included in the Bill this autumn. We are now working with Government departments to ensure the wording of Zach's Law is watertight.

Winning all the way

Changing the law to ensure online trolls can no longer attack people with epilepsy is the biggest prize of all. But it is always nice for our work to be recognised by others. In September we won Campaigning Team of the Year in the Charity Times Awards for our Zach's Law campaign. This followed two national awards in June. We won Best Advocacy Campaign at the Purpose Awards, run by magazine *PR Week*, and received a Mark of Excellence for Best Public Affairs Campaign at the CIPR Excellence Awards. We were delighted that Zach's mum – and champion campaigner – Claire Keer was able to join us to receive the Mark of Excellence. Pictured: campaigners Nicola Swanborough and Nathan Draper.

All about advocacy

Advocacy, Research and Care. These three words often crop up when discussing the work of the Epilepsy Society. While Research and Care speak for themselves, people often ask us what exactly is advocacy? And what does it mean for people with epilepsy?

The Oxford English Dictionary says that advocacy is "the support or recommendation of a particular cause or policy." In practical terms this means speaking to politicians at all levels – from local councillors, to MPs, to Government Ministers – and making sure the voices of people with epilepsy are heard. And it is not only politicians. We also speak with representatives from organisations such as the DVLA, NHS England and the national medicines regulator, the MHRA.

You will have read about our Zach's Law campaign (see opposite), but we have also run campaigns around medicines shortages and transport. And we advocate for greater awareness of epilepsy among policymakers, the media and the general public.

In recent months we have focused on our Safe Mum, Safe Baby campaign. This campaign calls for investment in genomic research so that safer, more personalised, treatments can be developed for pregnant women with epilepsy. Too many anti-seizure medications pose risks of physical or neurodevelopmental harm to an unborn baby when taken by their pregnant mother. We are determined to ensure that women no longer have to choose between taking their life-saving drugs and protecting their unborn child. We believe that genomic research is the answer.

To further this campaign, we had hoped to host panel discussions at the Labour and Conservative party conferences. These conferences are attended by MPs, journalists and political campaigners and are an opportunity to meet with senior politicians in order to raise the profile of policy campaigns. Last year's Conservative Party conference event was pivotal in achieving the goals of our Zach's Law campaign.

This year we wanted to speak up for women of childbearing age who want to start a family but are worried about the risks for their unborn child. Unfortunately, events conspired against us. The conferences were in Liverpool (Labour) and Birmingham (Conservative), but planned disruptions to public transport through rail strikes plus the Conservative party leadership debate made it impossible to finalise our plans.

Ministers and MPs were unable to guarantee us their time, mainly due to political uncertainties. And we couldn't allow our dedicated supporters who so willingly share their experiences about the impact of epilepsy, to travel so far when transport was widely disrupted.

However, many MPs have expressed their support for our Safe Mum, Safe Baby campaign and we will be meeting them outside of the conferences instead.

Contact our campaigns team at campaigns@epilepsysociety.org.uk.

> **"Last year's conference was pivotal in achieving the goals of our Zach's Law campaign**

Food for thought

When we arrange an event at party conference, we are always obliged to book refreshments for delegates. This is mandatory. It is a cost we have to bear, and we always opt for the minimum amount of food and drink. At last year's conferences, we were dismayed to see that virtually no-one ate any of rolls and sandwiches laid out for delegates. The food went to waste. It felt morally wrong.

This year, when booking the Labour Party Conference, we asked the caterers if they could instead donate our food to a local food bank in Merseyside. They didn't hesitate in saying 'yes' and went one step further in promising to substitute non-perishable items for the buffet that we had paid for. Merseyside has some of the areas hardest hit by the cost-of-living crisis. We will be asking all the major parties to consider this as an option at their conferences, going forward.

Good doing business

The workplace can be like an extended community, especially when it comes to charity. Here, our new Partnerships Manager, Martin Thornton, explains how businesses, big and small, can help to support people with epilepsy.

Hi, I'm Martin and, after many years in fundraising for academia, I'm delighted to be a new addition to the Epilepsy Society team. As Partnerships Manager, it's my privilege to support our corporate supporters' and our individual supporters' on their giving journey.

The Epilepsy Society couldn't do any of the world-leading research, advocacy and care that you are reading about in this *Epilepsy Review* without the generosity of the individuals, trusts and businesses who share our vision. And today I'd like to talk about the businesses and their amazing contribution to our charity.

Corporate Partnerships

Corporate partnerships are the less visible, but no less important, arm of our fundraising and aim to foster a mutually beneficial relationship between the Epilepsy Society and a business/organisation whose purpose or ethos is aligned with ours.

Our corporate partnerships range from 'charity-of-the-year' awards with companies such as Easy-Jet, Live Innovative Solutions and Bahlsen Biscuits to pharmaceutical companies who generously sponsor our world class research each year. We have everything from our popular volunteering days where corporate teams rejuvenate a garden or refresh a wall with a lick of paint, to the internal lottery run by Convey Law which raised a thousand pounds for the Epilepsy Society.

If you have visited one of the Oakman Inns' restaurants you may have noticed that, if you order the Porchetta (a delicious pork dish with fennel and rosemary), a small donation is made to the Epilepsy Society. We are delighted to announce that these small donations have amassed to £25,000 over the last three years and we will be welcoming, Oakman Inns Chairman, Peter Borg-Neal to the Epilepsy Society later this month to say thank you for this fantastic donation.

In the meantime, we asked Kelly Beard, Head of Marketing at Oakman Group, what it means to partner with the Epilepsy Society. Kelly said: "Our company ethos is to run a business that we're proud of; leaving things a little better than we found them, for our community, the environment and our guests, and we look to support a charity that shares these ideals.

"Just one of the stats the Epilepsy Society mentions: 'Therapeutic drug monitoring of anti-seizure medication, conducted in the unique specialist laboratory in Chalfont, can reduce epilepsy related healthcare costs by 46.9 per cent'. This certainly syncs with 'leaving things better than we found them' so we're delighted to be changing the world for the better together".

Becoming a partner of the Epilepsy Society will help us to support the 600,000 people living with epilepsy in the UK but can also help you and your colleagues better understand epilepsy, provide opportunities for training/team building exercises, show the world that your business is socially responsible and, most importantly, be part of realising the Epilepsy Society's vision of a world where epilepsy is irrelevant.

How can you help?

Give As You Earn (GAYE) enables you to give to the Epilepsy Society directly from your pre-tax salary. Because donations are taken before tax is applied, our charity will get more of your donation and it costs you less. Ask your employer if they support this scheme.

Maybe your workplace will match the funds you raise for a works team running a marathon, cycling to Brighton or running a golf day. Or perhaps the Epilepsy Society can be your charity of the year. Can your product be sold with a donation like Oakman Inns or do your staff have an expertise they could share?

No matter how big or small, if you think your organisation can partner with the Epilepsy Society, please get in touch by emailing me: martin.thornton@epilepsysociety.org.uk.

Go Amanda! One of our amazing 60-strong Team Purple.

Record breaking runners raise over £100k

On Sunday 2 October, 60 runners took part in the 2022 TCS London Marathon as part of Epilepsy Society's Team Purple. Our incredible team of runners have dedicated hours, days and weeks to fundraising and training for this event. It was an honour and privilege to support each and every one of them on their London Marathon journey. Our runners all have a personal connection to our cause, whether they have epilepsy themselves, know someone living with epilepsy or have sadly lost someone close to them.

As a group, the team have raised over £100,000 for the Epilepsy Society – our highest ever fundraising total for the London Marathon. Which is just incredible! We are so grateful to everyone who has donated and supported their fundraising efforts. The funds raised by the team will help us to transform the lives of people living with epilepsy and will support our vital work in research, advocacy and care.

If you would like to apply to join Team Purple for the 2023 TC London Marathon in April 2023, we'd love to hear from you. You can complete our application form at: epilepsysociety.org.uk/apply-2023-london-marathon

Fancy a different challenge?

If running a marathon isn't your thing you can take on another running event (from 5Ks to half marathons) or a UK walk as part of Team Purple in 2023. To browse the full list of 2023 events visit: **epilepsysociety.org.uk/fundraising-events** Some of our most popular events in 2022 were the Thames Bridges Trek, Great North Run, RideLondon and the South Coast Challenge!

More than just a Christmas card

Our 2022 Christmas card and merchandise range is now available. With contemporary and traditional designs, we have something for everyone.

By purchasing Epilepsy Society cards and gifts this festive season you will help us to transform the lives of people living with epilepsy through world-leading research, advocacy, and care.

Visit **epilepsysociety.org.uk/christmascards** to view our full Christmas range. You can place an order on our website or by calling **01227 811664.**

Thank you so much for all your support in 2022

Tonic comic

All-round funny girl Juliet Stephens has the last laugh when it comes to her epilepsy

Though she was nearly a hundred years old and just four years away from sending herself a telegram, the death of Her Majesty The Queen came as a shock to us all. Her life force and established place in our lives seemed so unwavering; news of her death seemed almost impossible.

Grief often echoes grief, so it is not only the Queen and the end of this era which we mourn, but often the memory of others we have lost. In the UK, 1,200 families each year mourn the loss of a loved one due to epilepsy.

The Queen herself lost an uncle, Prince John, who is believed to have died from a serious seizure when he was just 13 years old. One can only imagine this was a factor in her patronage of the Epilepsy Society. Epilepsy was so little understood, and people with epilepsy were frequently locked away in institutions. Her Majesty had a personal connection to the helplessness around epilepsy. It is no wonder that she supported research into the causes and treatment of epilepsy through her 70-year-long reign.

When the time came, Operation London Bridge, the famously named procedural response to the death of the monarch, kicked into gear with military precision.

The public response to the news was similarly immediate. We saw an outpouring of admiration, respect, sorrow and gratitude for the woman we carried in our wallets and pockets every day though few of us ever met in person.

The Queen's life was one of commitment to service. She demonstrated great fortitude and resilience; values that people with epilepsy develop just by living with such an unpredictable and often frightening condition.

She also exhibited that most treasured of British values: a good sense of humour. The delightful skit for her Platinum Jubilee earlier this year, of taking tea with Paddington Bear showed her to be not just a fine actor with pots of charm but connected her in a very real way with some of Paddington's youngest fans. She became a sort of Regal Grandma.

> **"We all hit a sort of: 'In Case of Emergency, Activate Britishness' button**

Historic events like this can remind us of who we are as a nation. I feel that we all hit a sort of: 'In Case of Emergency, Activate Britishness' button. Some ICE moments must be learnt – Calm, Cushion, Call for example when dealing with a seizure. But response to the loss of our Queen, seemed embedded in our DNA. Kettles were put on across the land as we absorbed Huw Edwards' soft, calm tones as he delivered the news, talked us through the process and reassured us that everything was going to be ok. And we queued. With magnificent Britishness.

I visited Buckingham Palace (well, the driveway), and looked at the floral tributes in Green Park. It really was tremendously moving, to see this collective expression of loss and celebration. The phrase I heard time and again in the days and weeks after Her Majesty's death was announced was: "I don't really consider myself a Royalist, but..." The continuity of the Queen's reign reflected the story of our own lives and connects us to those we love and perhaps also have lost.

Grief needs to have a personal and private side, but often we are moved to some sort of action – for the Queen's death we saw public displays of mourning. For us commoners we might set up a Just Giving page to raise funds in memory of loved ones or for organisations that have supported us, as a way to remember the journey we took and the stories we told along the way.

We often hear runners say that they run at their grief. And the same can be said of the many activities we undertake to help process loss and turn it into something positive. No-one is ever totally gone if their legacy is hope for the future for someone else.

We must hold close the things and people we love and that make us smile. In her 96 years, the Queen developed a wisdom which we can continue to benefit from. In 2008 she encouraged us that "When life seems hard, the courageous do not lie down and accept defeat; instead, they are all the more determined to struggle for a better future." How true of the people that Her Majesty supported through her patronage of the Epilepsy Society.

Juliet Stephens
Laughing allowed

Society matters

John from Texas wins Peter Hook Signature BB Bass Guitar

A big thank you to our friend and music legend, Peter Hook who raised £4,000 for the Epilepsy Society by auctioning a Peter Hook Signature BB Bass Guitar.

The winning bidder at the online auction was lifelong fan John Walker from Dallas, Texas whose brother was diagnosed with epilepsy in his early '20s.

John said: "My oldest brother has fought epilepsy his entire life and I have watched that struggle. So whenever possible I do what I can to support him and the fight to find a cure. To watch him deal with that has always been hard. Any little way I can help find a solution to epilepsy is something I will always be part of."

The limited-edition guitar donated by Yamaha Guitars was signed by Peter. John also received a complete set of Joy Division and New Order vinyl LPs, courtesy of Warner Music UK, signed by 'Hooky'. The signed bass and the LPs were handed over to John Walker personally by Hooky during a concert at Austin in Texas.

Peter Hook was a founding member of seventies band Joy Division. The band's lead singer and lyricist, Ian Curtis had epilepsy and tragically died at the age of 23. Peter Hook has been a loyal supporter of the charity ever since.

Commenting on his support for the charity, the singer said: "Without Ian Curtis and his help in the group I would never have achieved half of what I have done. To lose him as we did to a terrible disease was heart-breaking and my hope and ambition is that nobody will suffer in the same way ever again."

The £4,000 raised by John's winning bid will help to support the charity's dedicated epilepsy Helpline which provides emotional support and information to people affected by epilepsy.

Nicola Swanborough, Head of External Affairs at the Epilepsy Society said: "True friendship lasts a lifetime, but Hooky's friendship with Ian Curtis, has lasted much longer. The money raised through the auction of this guitar will help to ensure that our Helpline is there for anyone to call in their darkest moment. Music can be healing in so many ways and this generous gift is truly one of them."

Winning bidder, John continued: "Given the charity and my connections with epilepsy, this was an opportunity I could not pass up. I am not a guitarist; I am just a fan."

And so to the last dance

A double celebration in the summer turned out to be a bitter sweet moment for the Epilepsy Society. In June we celebrated both 130 years of the charity and the Queen's Platinum Jubilee. As we waved our flags, we didn't realise that it was to be Her Majesty's last.

It was our final event with the Queen as our Patron and we hope that we marked her 70 years on the throne in style, with staff and some 93 residents turning out for an epic street party that ran through the site, to the sound of the amazing band 'Two Metres Apart'.

The music played. We danced. And when the sun went down, residents from our Thursday Activities Group sent a hand-made card to the Queen thanking her for her support over the years. The Queen graciously sent a letter of thanks in response. Possibly one of the last letters to be sent by Queen Elizabeth II. Rest in peace, Your Majesty.

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
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SL9 0RJ
Enquiries 01494 601 300
Fundraising 01494 601 414

epilepsysociety.org.uk

/epilepsysociety

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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

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