Vic Hamilton, carer and supporter.
Message from our Chief Executive

Every day we are asked to give to a good cause. Sometimes, it's on the radio or on the television, sometimes it's online and, perhaps less often than ever before, it's in person.

Personally, I like to ask face-to-face because I love to talk about our charity. But most people don't have time for a long conversation. And there's certainly not much you can say in 280 characters on social media anyway!

So, many of us give on trust. We do not always stop to consider how our money will be spent. We just have complete faith that it will make a difference to someone's life. That it will bring about change.

As a charity supporting people with epilepsy, we are at the other end of that chain of trust, hope, belief and kindness. Not a day goes by at Epilepsy Society when every single donation is not appreciated and valued for its generosity and faith.

It is your money that enables us to be a voice for people with epilepsy. It is your money that enables us to push forward the boundaries of research, working towards our goal of one day making epilepsy irrelevant to all those with a diagnosis.

This year we have extended the different ways that you can support us, through digital channels and through your own innovative fundraising ideas. This has seen our voluntary and trust income grow by an incredible 20 per cent to £2.4 million.

This total increases still further to £2.9million, when we include funding for a research collaboration.

In this Impact Report, I hope you will enjoy reading about the many ways your money is making a difference to the lives of people with epilepsy. I would like to highlight two key areas which I know are of huge importance to many of you and to us.

First, with your support, we have been calling on the Department of Health and Social Care to commission a complete review of the medicines supply chain so that continuing problems can be resolved on a long-term basis. We know how stressful it is when you are anxious about whether you will be able to get the drugs you need.

Second, we are working with the Government and social media companies to enable people with photosensitive epilepsy to be safeguarded against online harms through new legislation. We couldn't do it without you.

Your donation could mean the difference between someone being able to get their prescription when they need it or having to trawl around other pharmacies hoping to find it in stock. It could mean a young teenager with epilepsy being able to chat safely to her friends on social media, without fear of online content triggering a seizure.

It could mean our researchers gaining a better understanding of the underlying causes of epilepsy and how to control it. It could mean fewer people dying from Sudden Unexpected Death in Epilepsy.

A heartfelt thank you to each and every one of you who makes our work possible.

Clare Pelham
Chief Executive
About the Epilepsy Society

The Epilepsy Society was established in 1892 by neurologists from the Hospital at Queen Square, the forerunner for the National Hospital for Neurology and Neurosurgery and the UCL Institute of Neurology. The charity’s primary purpose then was to provide a safe working environment for an incurable and stigmatised condition. The Founding Fathers also envisaged a future research powerhouse which would help understand epilepsy and to discover appropriate treatments.

Today the charity exists to work for everyone affected by epilepsy across the UK and beyond through cutting edge research, specialist medical services and expert care. Its site in Buckinghamshire is well known in medical and academic research circles as ‘The Chalfont Centre’.

The Epilepsy Society is part of a unique tripartite partnership with the NHS (UCLH National Hospital for Neurology and Neurosurgery) and academia (UCL Institute of Neurology). This partnership gives access to established research infrastructure and collaborations, attracting top researchers and clinicians. It has been recognised by the World Health Organisation with the research group designated as a Centre of Excellence.

The world-renowned Sir William Gowers Assessment and Treatment Centre at Epilepsy Society’s site is run by UCLH in conjunction with the Epilepsy Society and is the last port of call in the UK for people with refractory epilepsy (ie people whose seizures are not controllable by medicine).

The research facilities at the Chalfont Centre integrate research with the medical assessment facilities, our dedicated MRI suite and a therapeutic drug monitoring unit.

The Epilepsy Society is also a primary provider of residential care for people with complex epilepsy, with on-site therapy provision and an outreach programme.

More than 600,000 people have epilepsy in the UK. The charity has a extensive reach with 2.5 million visits to our website every year, 100,000 social media followers and an active database of 10,000 supporters. Information and Support Services receive 3,000 calls to the helpline annually, send out 75,000 information resources to individuals and hospitals, and provide corporate training to 2,000 people annually.

Influencing and tackling the stigma that still exists around epilepsy are core objectives of the charity. We do this through active campaigns on issues relevant to people with epilepsy and collaborative projects with other charities, organisations and stakeholders.
How we help

Emma was first diagnosed with epilepsy in her late teens.

“It felt pretty impossible to see anything positive at the time,” she says. She found it tough coping on a day to day basis and feeling the impact of medication side effects was exhausting on every level for her.

Emma was referred to the Epilepsy Society’s Chalfont Centre under the care of one of our consultants. Emma says:

“He has been phenomenal and helped support me in finding a better quality of life and encouraged me to accept the negative thoughts that came when an epilepsy diagnosis was put in place.”

Emma is now helping the Epilepsy Society to support others with epilepsy through raising awareness and becoming one of our community ambassadors to represent the charity around the country.

Amanda’s story

“The psychological impact of epilepsy and trying so many drugs is huge. You lose sense of who you are. You don’t know your place in the world. You become isolated and live a life of ‘what if?’ What if I step outside my front door and have a seizure? Many times I have wished to give up the fight and admit defeat. I have had anxiety and depression and suicidal thoughts. The one thing that has kept me alive is art therapy. I first started painting when I was in the Sir William Gowers Assessment Centre at the Epilepsy Society. Now art is a lifeline for me. If it wasn’t for my art therapy at the Epilepsy Society, I don’t know that I’d still be here today.”

Amanda Smith (pictured above)
Our year in numbers...

175,000 ENGAGEMENTS
You’ve liked, tweeted, shared and commented on our social media posts, helping us to raise awareness of epilepsy.

2.5 MILLION VISITORS
These visits to our website include 1.7 million to our online support pages.

1,000 VOLUNTEER HOURS
Our amazing volunteers have helped at the Chalfont Centre site and we now have volunteers working around the country helping to raise awareness of epilepsy.

64 PERSONALISED PATIENT PLANS
Our personalised patient plans, delivered by our expert clinical team, make a huge difference to people’s lives.

41 ACADEMIC PAPERS
These papers acknowledge our powerhouse multidisciplinary team who contribute to a wide ranging spectrum of epilepsy research.

4 NEW RESEARCH POSITIONS
We’ve recruited 1 Bioinformatician, 2 post docs and one Clinical Researcher to our team to increase the pace of our research.

41,765 RESOURCES SENT OUT
We’ve sent out information around seizure first aid, benefits, driving and work.

2,981 HELPLINE CALLS
Our helpline operators have an in-depth knowledge of the many issues faced by people with epilepsy. You can call our helpline on 01494 601 400.

6 INFLUENCING CAMPAIGNS
Our campaigning is tackling the stigma around epilepsy through raising awareness of the condition and its impact on people’s lives.

829 PEOPLE
Our Team Purple who fundraise for us continue to be inspiring.

£1 MILLION INVESTED INTO RESEARCH
We continue to invest in groundbreaking research to find a functional cure for epilepsy.

970 WHOLE GENOME SEQUENCED DATA
We’re working to understand the genetic architecture of each individual person’s epilepsy through our world leading research projects.
This year we have seen some incredible highs in research at the Epilepsy Society that spell real hope for the future.

In February we were proud to announce a unique collaboration with the pharmaceutical industry. Together we are working on a pioneering 2.5 million Euro genomics research programme which could bring life-changing treatments to people with epilepsy whose seizures do not respond to current treatment options. It is a five year project and our researchers will be working to develop an improved understanding of the complex nature of epilepsy through genomic sequencing and the analysis of genetic biomarkers.

For anyone whose seizures are drug resistant, the greatest hope of becoming seizure free is brain surgery. But this is only possible if we can identify the focal point of their seizures though an MRI scan.

And in about one third of cases, brain scans appear normal. So we are now using AI algorithms to teach computers to differentiate between areas of the brain that do, or do not, generate seizures. It is early days but the feeling of hope is inspiring.

For up to date information on all of our research projects and published academic papers, go to our online research hub - launched this year - www.epilepsysociety.org.uk/research
Care at the centre

People are at the centre of all we do at Epilepsy Society, be that in the clinical support offered, research for people affected by epilepsy or in the houses we have that enable people to lead as full a life as possible.

We support approximately 95 people at Chalfont, some of whom have complex needs and a further 25 people in community based supported living arrangements. Our commitment is to support what is important for the person in terms of heath, well being and their aspirations in life.

This is often referred to as person centred working and over the last year we have been striving to ensure that each individual has a personalised package of support that is tailored to their support needs.

We wouldn't be able to do any of this without the help of our wonderful volunteers.

Thank you.

Changing lives every day

Across the UK, and locally, our volunteers bring their enthusiasm, skills, experience and time to make a difference to people affected by epilepsy.

In the last year our onsite volunteers have dedicated 984.5 hours to the Epilepsy Society. Whether it be craft sessions, corporate groups building liveable garden spaces or helping to send out fundraising items to our supporters. Since launching our regional volunteer roles we now have volunteers from all around the country helping to deliver our vision.

“The Epilepsy Society is delighted that all our houses and domiciliary support services have an overall rating of ‘good’ from CQC, as well as ‘good’ in every area. We are determined to make sure that we provide outstanding care to all those living at the Epilepsy Society.”
Support and information for everyone affected by epilepsy

“I felt listened to. I can’t recall ever feeling listened to properly in the past by other people or services.”

This year we answered just short of 3,000 telephone calls but we know we missed 2,000 people who couldn’t get through.

We’re currently raising funds to extend the opening hours of the helpline and 2020 will see that project realised to help even more people affected by epilepsy.

While our digital platforms provide a solid network of some 100,000 supporters across the UK, and we know that there are 1.7 million visits to our online support pages every year, our helpline remains a flagship communication channel that influences and underpins all that we do.

Our callers raised the issues around medication shortages and also the issues they were having with the pregnancy prevention programme that informed our sodium valproate campaign the previous year.

“Thank you so much for listening. I can’t talk to anyone else because I don’t want to worry them. It really helps just to say it out loud.”
In the last year we have seen an unprecedented rise in the number of epilepsy medication shortages. This is a long-standing issue and we know that worries about shortages have caused anxiety, which can trigger seizures for some people with epilepsy.

We have worked with the Department of Health and Social Care and the pharmaceutical companies to ensure our beneficiaries have the most up-to-date information. And we are calling on the Government to commission a review of the medicines supply chain in order to better understand and prevent shortages.

**Medication shortages and Sodium Valproate**

Earlier this year, our Chief Executive, Clare Pelham, gave evidence to an independent review into valproate, chaired by Baroness Cumberlege. This review is examining the way that the health system has responded to concerns raised by women whose families have been severely affected by the drug. Clare Pelham told Baroness Cumberlege:

“Yes it is hard to campaign as a woman with a young family. But it is a million times harder to campaign when you have a hidden disability and children with multiple disabilities.”

**Sodium Valproate**

The Epilepsy Society has been at the forefront of a campaign to make sure that any woman who is prescribed the epilepsy medication, sodium valproate, is fully aware of the risks that the drug could have for an unborn child if taken during pregnancy.

This year we called on the Government to safeguard people with photosensitive epilepsy from online harm by regulating flashing images online, that could induce a seizure.

In a letter to the then Secretary of State for Digital, Culture and Media, Jeremy Wright, our Chief Executive, Clare Pelham said:

“It would be widely welcomed if you could make it clear that online posts will be required to carry comparable warnings to those in traditional media, if they contain flashing lights or imagery.”

We have asked the Government for consistency. This includes regulatory measures in its Online Harms White Paper and we are waiting to hear the outcome.
Calm, Cushion, Call

We know that two out of every three people who do not have a family member with epilepsy, would not know how to help someone during a seizure. That is why we launched our new three ‘C’s campaign to make sure everyone is #seizuresavvy.

We have continued to work with Transport for London throughout the year to make sure that all their staff know what to do if someone has a seizure.

Our Medical Director, Professor Ley Sander, also spent time at Baker Street, making sure that new blue under-platform lighting would not cause a problem for anyone who is photosensitive.

Calm, Cushion, Call

1. Stay calm and take control of the situation

2. Cushion their head with something soft

3. Call an ambulance if it lasts longer than five minutes

Remember the three ‘C’s and make sure you’re #seizuresavvy

Right: Our Chair, Peter Worthington, and Trustee, Mike Stone, at Waterloo during National Epilepsy Awareness Week
**Our income**

Together we raised £17.2 million this year through a combination of fundraising, trading and care income and charges to the NHS for our medical services. Our total income for the year, however, increased to £26.4 million as a result of the sale of a small part of our estate, the profit from which is being used to reduce our pension deficit, subsidise our research and help maintain our estate.

The £17.9 million is broken down as set out below:

- Donations and fundraising, fundraising events, sponsorship and donations
- Grants - grants from trusts to support our work
- Commercial grants - Income from industry collaborations, which will help fund our research
- Legacies - amounts receivable from gifts in supporters’ wills
- Care - fees received for providing residential care to people with epilepsy.
- Medical - services provided to UCLH and other health bodies
- Trading - merchandise sales, lotteries and commercial operations
- Other - information, education and support, training services, trading and rental income.

**Where the money went**

Voluntary income after fundraising costs is spent primarily to support our strategic charitable activities: undertaking innovative research, influencing to tackle the stigma around epilepsy; and providing support and information for everyone affected by epilepsy. Our other income represents fees which cover the costs of our care and medical services. Our costs totalled £18.0 million in 2018/19, which are divided as follows:

- Charitable Activities: 52% Care, 17% Running costs, 6% Research
- Cost of running the Charity: 5% Additional Estate costs, 3% Other Corporate costs
- Cost of raising funds: 3% Raising funds, 12% Medical Services, 6% Research
- Costs of raising funds: Fundraising - costs of putting on events, encouraging donations and applying for grants.
- Costs of running the charity comprise: Running costs - the cost of providing management and support for the charity, including normal day to day costs of running our estate and our buildings; Additional estate costs - these represent additional costs incurred as a result of having to maintain our large and ageing estate; Other corporate costs - these primarily relate to running our old pension scheme.
Our mission is to enhance the quality of life of people affected by epilepsy by promoting public awareness and education, by undertaking research and by delivering specialist medical care and support services.

To fundraise, volunteer or campaign for the Epilepsy Society, please call:

01494 601 300

or visit epilepsysociety.org.uk

**Helpline**

01494 601 400

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

**Epilepsy Society**

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SL9 0RJ

Enquiries 01494 601 300
Fundraising 01494 601 414

epilepsysociety.org.uk

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