Impact report
2017/18
What we did
The Challenge

1 in 3 people can’t gain seizure control through medication

87 people are diagnosed everyday

1,000 epilepsy related deaths each year
1 in 3 people can’t gain seizure control through medication. People diagnosed everyday. People have epilepsy. Live with epilepsy in the UK. Epilepsy-related deaths each year.

1 in 100 people have epilepsy.

500,000 live with epilepsy in the UK.

40+ types of seizure.
Why Epilepsy Society?

**Research**
Because we want to understand more about the causes of epilepsy and deliver better, more personalised treatments

**Fundraising**
Because we want to work with you to fund our ambitious research programmes and provide support which can make a difference to people’s lives

**Advocacy**
Because we want to make sure every one of the 500,000 people with epilepsy in the UK has a voice

**Care**
Because we believe all those with severe epilepsy and other disabilities should also lead the life they want to lead

**Information**
Because we want to support everyone with a diagnosis of epilepsy, their families and friends

**Medical**
Because we believe everyone with hard-to-treat epilepsy deserves the very best, most advanced care
Vision

Our vision is a full life for everyone affected by epilepsy. We want everyone affected by epilepsy to have the best opportunity for a full life as free from seizures as possible.

We set out to make a difference to every person affected by epilepsy whatever their background, however seriously it affects them, and whether they have the condition themselves or are close to someone with epilepsy.

Mission

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.
Message from our Chief Executive and Chairman

In the past year the Society’s focus has been on intensifying its genetics related research, providing high quality care for our 100 residents, as well as advocating for people with epilepsy whilst ensuring the long term sustainability of the Society’s endowment and finances.

We know that anyone with epilepsy can feel lonely, isolated or suffer from discrimination. And we are here to support them. Last year we trained 2,000 people in dealing with epilepsy in the workplace as part of our national programme, and 4,562 people contacted our helpline service, and we provided 76,964 items of support information.

We are finding our voice

We campaigned this year for change in the prescribing regulations around the epilepsy drug sodium valproate. We were proud to work alongside the tireless and heroic women who campaigned for change and better communication for future generations. Thanks to the collaborative efforts of families affected by sodium valproate, charities, politicians and the media, no child should be born with an avoidable disability in the future because their mother was not told about the wide effects of this drug. In a small but significant way, together we changed the world.
Our priorities as we go forward together

Our research has the potential to achieve breakthroughs in personalised assessment, treatment and outcomes for people with epilepsy. The Society’s care remains a priority and we are looking at how we might best utilise our limited charitable funds, such as provision of specialist nursing capability to a wider community. Our advocacy is directed at reducing the stigma around epilepsy and related neurological conditions.

We are preparing for the future

We will continue to refine our vision, strategy and plans to define and secure a better future for our beneficiaries. There is a genuine sense of optimism within the Society that life enhancing change for our beneficiaries is potentially within sight.
Thank you

We are so grateful to those who helped to raise over £2 million this year so that this amazing work can take place.

However, we cannot be satisfied until every call to the helpline is answered, every request for support is met in full and discrimination against people with epilepsy is a distant memory.

We could do much more with more funds. And that is why we’re doubling our fundraising efforts.

Clare Pelham
Chief Executive

Peter Worthington
Chairman
Our year in numbers

808 genomes sequenced
1,000
Thank you letters or emails sent every month

1,111
Associate Members

1,331
patients to our Gowers diagnostic centre

1,7 million
1.7 million unique visits to epilepsysociety.org.uk

4,562
people contacted our helpline service

400 people took part in a sporting or challenge event

76,934
Information resources sent out

1,075
MRI scans through our dedicated scanner

1,000

Changing lives every day

Melanie Allen had her first seizure at 23 while sitting at her office desk. After multiple EEG tests and MRI scans, Mel suddenly found herself unable to drive and with a life-changing diagnosis.

After Mel’s second seizure almost three years later, her mum started to do some research and found Epilepsy Society.
Mel was referred to the Chalfont Centre and into the expert care of our team. She was seen regularly and her drug levels monitored, particularly as Mel had discovered she was also pregnant.

Mel now has a beautiful two year-old son, Luca, and managed to stay seizure-free throughout the birth and his early months, despite tiredness being one of her seizure triggers.

Mel's advice to others: "If you yourself have epilepsy or someone you know has it, get in touch with Epilepsy Society. I have a much more positive outlook now on dealing with my epilepsy and I do believe this is because of their team!"
Discovery through research

Our world-leading research programme is aiming to create a future where a diagnosis of epilepsy becomes a minor inconvenience rather than a life-changing event.

Only through research can we uncover the answers to the mystery of why epilepsy occurs in each individual, and how best to treat that individual from day one.

Over the last year, one of our major projects has given us an insight into the brain. In a study led by our Director of Genomics, Professor Sanjay Sisodiya, we have seen how epilepsy affects the volume and thickness of certain regions of the brain.

Professor Sisodiya said: “While we haven’t yet assessed the impact of these differences, our findings suggest there’s more to epilepsy than we realise, and now we need to do further research to understand the causes of these differences.”
It’s all in the DNA

Neurologist Dr Simona Balestrini is using a pioneering technique to understand how variations in the DNA of someone with epilepsy can affect their brain activity.

By combining two different tools Transcranial Magnetic Stimulation and Electroencephalogram, we can look at the pattern of electrical currents in the brain and how brain activity impacts on motor and sensory functions, while also investigating whether the cause of epilepsy is in a person’s DNA.

Over time we can look at the path of epilepsy and its impact on the person, to see whether particular medications are helping and if any brain functions are affected by the epilepsy or the treatment.

Simona says “I am really excited about this project. I feel it will help us to gain a greater understanding of the causes of epilepsy and translate clinical research into clinical care. I really hope to make a difference to the lives of the people I see in clinic every day.”
Raising awareness of epilepsy and making a difference

Chelsea Flower Show

This year, for the first time, we had a garden at RHS Chelsea Flower Show.

The Embroidered Minds Epilepsy Garden was the smallest garden at the show but its impact was huge.
157,000 visitors to the show

220 million viewers and listeners on TV and radio

24 million reach for one article in Sunday Telegraph
Hidden Disabilities campaign

We were part of Transport for London's Hidden Disabilities campaign encouraging passengers to offer their seat to someone with a hidden disability, including epilepsy.

Our poster-boy Tom was seen on potentially 360 million passenger journeys in one month across London.
Sodium valproate campaign

We were part of a successful campaign to bring about fundamental changes in the way sodium valproate is prescribed to girls and women under the age of 50.

2,350 women and girls with epilepsy took part in our survey which highlighted that 1 in 5 of those taking sodium valproate were not aware of the risks around the medication during pregnancy.

Thanks to the campaign, no woman can now be prescribed the medication without being warned that the drug can cause physical or neurodevelopmental disabilities for babies exposed to it during pregnancy. Every woman should now be able to make an informed choice around her treatment.
The precious gift of time

We have been fortunate in that we’ve welcomed 50 new volunteers over the past year who selflessly give up their time to help others.

Volunteers have a very positive impact on the lives of our residential care clients and we are so grateful to each and every one from our regular warm and friendly faces in the coffee shop to the groups of corporate volunteers who roll up their sleeves and keep our extensive gardens neat and tidy.

We aim to launch a brand new volunteering scheme in early 2019 with a plan to expand into regional fundraising volunteers in the very near future.

“I feel like I’m doing a good job helping here and that feels nice. There’s a good bit of banter with the regulars, especially as I’m the only male in the coffee shop!”

Stanley, Coffee shop volunteer
Changing lives every day

Our seven on-site residential care and supported living services provide far more than day to day care for our residents.

Our dedicated team of support workers, nurses and activities coordinators strive daily to empower residents to make their own choices and experience their full potential from making a meal to skiing, or going on holiday.

Although our residents all have epilepsy and often other additional needs, at Epilepsy Society we recognise them as individuals. Everyone deserves to live the life they want a core value at the heart of our person-centred care services.

This year our neurologist, Professor Matthias Koepp, who has been training to be an adaptive snowsport instructor, took residents skiing on the real snow ski slopes at Hemel Hempstead.
What we raised

Together we brought in £17.2 million this year through a combination of fundraising, trading and care income and charges to the NHS for our medical services.

- **71%** Residential and care services
- **14%** Medical services
- **13%** Donations and legacies
- **2%** Other

- Donations and legacies: Fundraising events, sponsorship and lotteries; legacies; donations and grants
- Other: Information, education and support, training services, trading and investments.
Where your money went

We spent £17.0 million on our core charitable activities: residential care services, medical services in partnership with the NHS, undertaking innovative scientific research, influencing to tackle the remaining stigma around epilepsy and providing support and information for everyone affected by epilepsy.

- **77% Charitable Activities**
- **53% Residential and care services**
- **23% Charity Costs**
- **23% Other**
- **7% Fundraising costs**

**Fundraising costs**
Fundraising events, sponsorship and lotteries; activities to generate funds

**Other**
Information, education and support, costs of running the charity, training services, trading and investments.
Helpline
01494 601 400
Monday and Tuesday 9am to 4pm,
Wednesday 9am to 7.30pm.
Confidential, national call rate.
Information and emotional support.

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