



A WORLD

WITHOUT LIMITS



2024-2030 STRATEGY EPILEPSY ACTION

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WELCOME TO OUR NEW STRATEGY

Epilepsy Action has been fighting to improve the lives of people with epilepsy for over 70 years, and we've delivered some life changing support in that time.

But post-pandemic, and with growing challenges in both healthcare and society more generally, we know that we need to be more ambitious, and bolder, in what we do.

Our goals as a charity are not significantly changing, but the scale needed to achieve them is, and this is at the heart of our 2024-2030 strategy.

We need to extend our reach, support new communities and become a more inclusive organisation. We know that epilepsy has no boundaries in the people it affects, so we need to be more effective in reaching into new communities and empowering people with epilepsy to live their best lives.

This will mean thinking big and ensuring epilepsy is as much in the public consciousness as other major health conditions. It will also mean that we as a charity need to think about new ways to deliver our ambitions, which includes working with others for maximum impact.

Creating this strategy was a team effort and we are so grateful to the 5,000+ people who contributed their thoughts to developing it. We cannot deliver this without your help, so please join us in building a world without limits for people with epilepsy.

With best wishes for the future from the trustees, staff, volunteers and supporters at Epilepsy Action

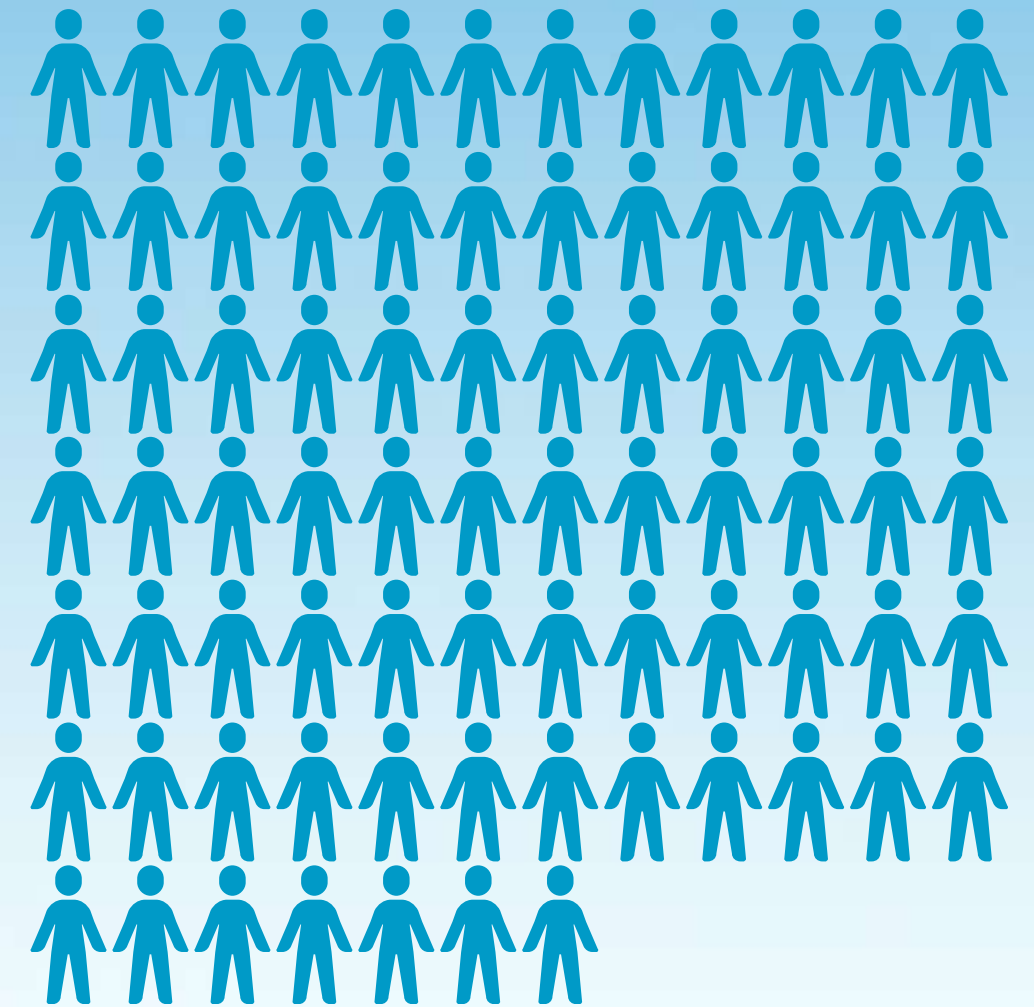
WE ARE **EVERYONE** AFFECTED BY EPILEPSY



5,000 of you told us what you really think about epilepsy, through our [Let's Talk About Epilepsy](#) campaign. Your answers were frank, honest and not always easy to read, but every single one of them was so important. This is the biggest and most open response we've ever had to questions about life with epilepsy and that is what this strategy is built on.

5,000
survey
respondents

600,000+
people in
the UK



79
new diagnoses
every day

(That's one person diagnosed every 18 minutes)

OUR VISION:

A WORLD **WITHOUT LIMITS** FOR PEOPLE WITH EPILEPSY

OUR BIG 3 AMBITIONS

1

By 2030 everyone in the UK who has epilepsy will be able to say that life has improved because of the things we are achieving together.

2

By 2030 everyone in the UK will understand what epilepsy is and how they can support people who live with epilepsy.

3

By 2030 we will be fully inclusive in who we are and who we support.



AMBITION 1



By 2030 everyone in the UK who has epilepsy will be able to say that life has improved because of the things we are achieving together.

People with epilepsy tell us they feel isolated, stigmatized, and discriminated against. They tell us there is a lack of understanding about the wider effects of the condition beyond seizures, such as the life-changing restrictions on driving, employment and education.

But lots of people tell us that life with epilepsy can be a positive one. People with epilepsy have so much to contribute, in so many ways. We promise that we will help you by understanding the individual journey you are on, supporting and empowering you every step of the way.

HOW

- ★ Provide personalised support journeys and impactful services for everyone who needs us, empowering people to live their best life with epilepsy.
- ★ Support all healthcare professionals to understand the wide-ranging impact of epilepsy on people's lives and how to engage in social prescribing as part of a treatment programme.
- ★ Continue to be the number one provider of up to date, evidence based and accredited information on epilepsy, equipping people with the knowledge to understand how to live their best life.
- ★ Collaborate with organisations where epilepsy can exist with another condition, and partner with epilepsy charities to lobby for increased resources and recognition of epilepsy as a major health condition. Work with Epilepsy Research Institute UK to represent the voice of the lived experience and translate research into quality improvement services.
- ★ Create a digital space for people to share their experiences of companies, public services, technologies and medical experiences to enable us to understand where we need to change attitudes and reduce stigma.



MARTHA

WITHOUT LIMITS

In 2023, we directly helped over 20,000 people through our services. But we know that there are so many more people out there who are facing the challenges of epilepsy without our help. By 2030, every single one of them will know that Epilepsy Action is here and ready, whenever they need us.

I'M NOT ALONE



Epilepsy took me to a very dark place. I lost friends, my job, my independence and nobody could really understand.

I spoke to Epilepsy Action and they put me in touch with people just like me. At first, I just listened but over time I got the confidence to share my story. The epilepsy community around me gave incredible advice including how to talk about it to my kids.

Now I have clarity. I know what I need to do to live the best life I can with epilepsy. Most importantly, I know I am not alone.

Martha



AMBITION 2

By 2030 everyone in the UK will understand what epilepsy is and how they can support people who live with epilepsy.

People affected by epilepsy tell us that this is the number one thing we can deliver: ensuring that people who have no contact with epilepsy in their lives understand what the condition is. This can have so many positive impacts on their wellbeing, sense of belonging, and opportunities in life.

We will do everything we can to create a positive attitude to epilepsy so that people are proud, not afraid, to talk about the condition they live with.



HOW

- ★ Deliver a high profile national campaign every year that encourages the wider public to develop positive attitudes towards epilepsy.
- ★ Find new ways to embed epilepsy into our national media and culture, so that through regular exposure to the condition people understand more about it and feel comfortable talking about it.
- ★ Use a growing public consciousness about epilepsy to encourage high profile individuals to share their experiences and influence attitudes to epilepsy.
- ★ Invest new resources in the development of learning and training programmes that enable companies and public services to become “epilepsy friendly” resulting in a reduction in discrimination in the workplace.
- ★ Target online community networks to spread the word about epilepsy and reach new and diverse communities.



ANDY

WITHOUT LIMITS

In 2023, our CARE campaign helped millions of people to understand how to help someone having a tonic-clonic seizure. But that was only the start. By 2030, everyone will know how to help someone having any kind of seizure.

I KNEW WHAT TO DO



We've had the same season tickets for 20 years. You sort of know people around you but not many of them by name.

Last season a guy in front of me had a seizure. He fell to the ground between the rows of seats and started shaking. Everyone around him moved away.

Earlier that week, I had seen the Epilepsy Action campaign on TV. Their CARE acronym was easy to remember so I cushioned his head, asked someone to shout for a steward, held his hand and timed his seizure. Jimmy came round a few minutes later and apart from a nasty cut on his tongue he was completely fine. I was so glad I knew what to do.

Andy



AMBITION 3

By 2030 we will be fully inclusive in who we are and who we support.

There is no point delivering our first two aims if we are only reaching certain communities. We understand that communities come in many shapes and sizes and that some are more definable than others. But we also know that there are some communities that we are not currently reaching, and they are often the most at risk in terms of isolation, discrimination and social barriers.

We need to demonstrate that everything about our organisation, culture and ways of working defines us as an inclusive charity: if we are unable to do that, we will never achieve inclusivity in our strategy.



HOW

- ★ Develop our services with our volunteers and supporters at the heart of everything we do to ensure that all our work has the maximum positive impact.
- ★ Use our data and the latest technological advances to identify the groups that we are not reaching and set specific plans to reach them.
- ★ Be transparent in our successes and failures, and explain the impact we are having as a charity by sharing real time results and regular updates for everyone to see.
- ★ Review the way we are governed to ensure it is fit for purpose for the ambitions we have, and representative of everyone who engages with us.
- ★ Recognise the wider social responsibilities we have as a charity in the way we support our staff and volunteers, develop our culture and reduce the impact we have on the environment.



ALEX

WITHOUT LIMITS

Epilepsy affects people from all walks of life. Yet we know that there are so many communities where support is difficult to come by. We need to reach those communities, making sure that everyone, wherever they are and wherever they're from, is getting the help they need.

FIRST EVER ASTRONAUT WITH EPILEPSY



When Alex first went to school she struggled. The teachers constantly told her off for looking out of the window even though I'd told them about her epilepsy and absence seizures in particular.

Now we have the support we need she's doing great. I'm determined that she can be whatever she wants to be. This week, she's told me she wants to be an astronaut. Good luck to anyone who gets in our way.

Tom (Alex's Dad)

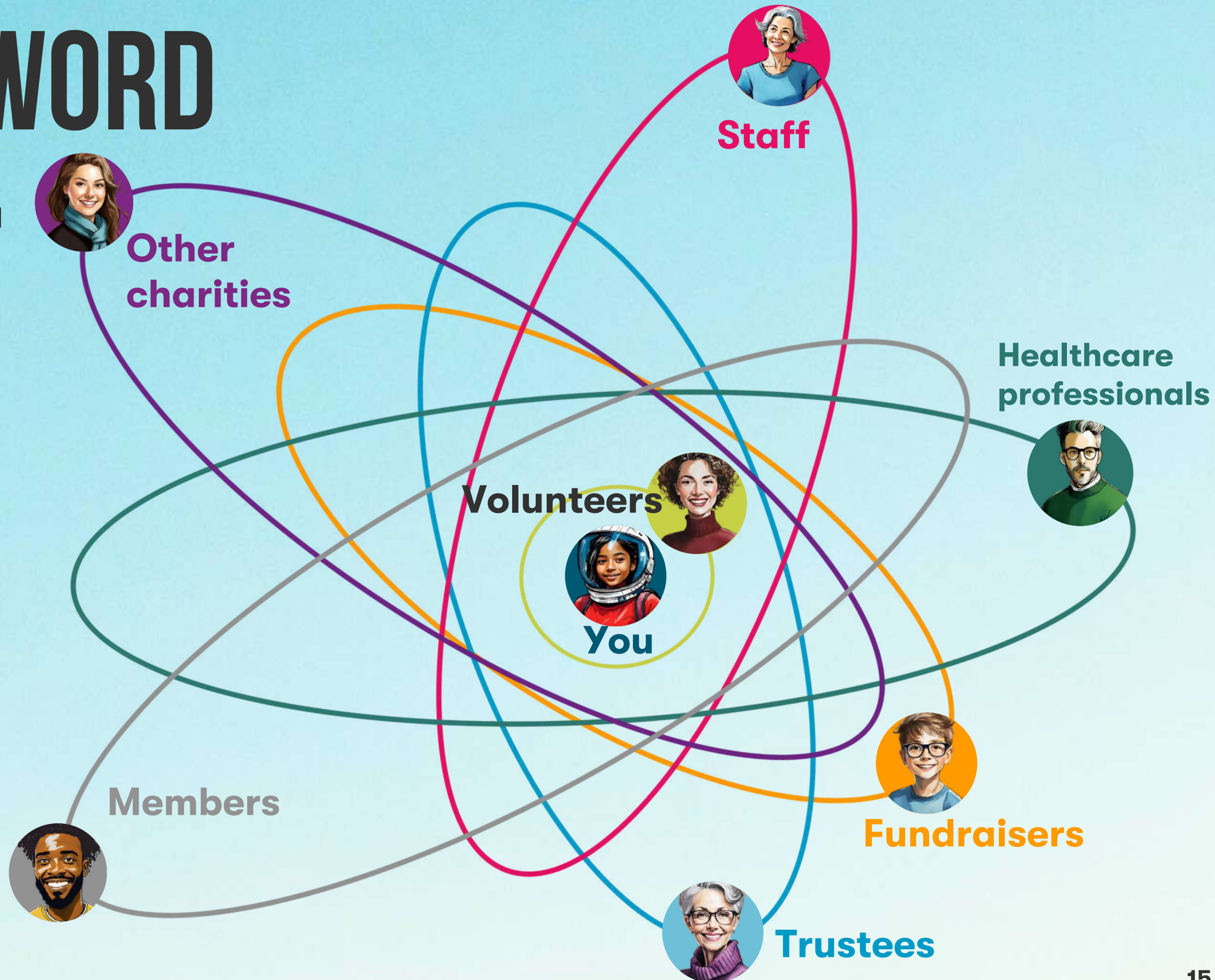


SPREAD THE WORD

We cannot deliver any of this without the support of our volunteers, as they are crucial in our ambition to reach more people. We understand the commitment involved in volunteering and will look at more informal delivery models so more people are able to get involved.

We know meeting our ambitions is a team effort and we will develop tools that enable anyone connected with epilepsy to get actively involved in raising public support.

None of our ambitions will be achievable without a significant growth in income. We want to be a charity with an £8-10 million turnover by 2030. We have a new income strategy, but we know it can only be achieved by increasing awareness of epilepsy, and through that, the number of people who support us.



VALUES WE WILL MAKE A DIFFERENCE BY BEING:

AMBITIOUS

We will do whatever is needed to create a world without limits for people with epilepsy.



INCLUSIVE

We will be here for everyone affected by epilepsy.



EMPOWERING

We will put people with epilepsy in control of creating the world, community and life they want.



SUPPORTIVE

We will be by your side every step of the way.

OUR STRATEGY

Our strategy for 2024-2030 can be split into two parts. We want to spend the next few years growing a community of support around the condition, increasing public consciousness and making sure as many people as possible care about epilepsy.

Then, as we get closer to 2030, this expanded community will ensure we are reaching all communities to deliver the change people with epilepsy are in desperate need of.



How will we measure success?

There are four key things we will measure:

1

That we are increasing public understanding of epilepsy.

2

That we are improving the lives of people with epilepsy.

3

That we are reaching more diverse and underrepresented communities.

4

That people want to engage with Epilepsy Action and help deliver these ambitions.

WE WILL DO THIS BY:

You can check on
our progress at
[epilepsy.org.uk/
withoutlimits](https://epilepsy.org.uk/withoutlimits)



Continuing to talk to the 5,000 people who completed our Let's Talk About Epilepsy survey to keep track of their experiences and whether they improve.

Talk to new people on an ongoing basis to find out how they feel about living with epilepsy and the impact we are having to see if we are making progress.

Use the contacts we make to monitor who is connecting with our services and who is committed to supporting us through fundraising and volunteering.

SO HOW CAN YOU HELP?

If you agree with what we are trying to do, we are going to need help from people like you to help us achieve our vision.

VOLUNTEER

We're going to need people who are able to give up a little bit of time to make a massive difference.

epilepsy.org.uk/volunteer



FUNDRAISING

We're going to need people who can take on big challenges to help raise big funds.

epilepsy.org.uk/fundraising



SPREAD THE WORD

We're going to need people who can speak openly and honestly about epilepsy, to help spread the word.

epilepsy.org.uk/spreadtheword



DONATE

And we're going to need people who believe in our vision to contribute to making it happen.

epilepsy.org.uk/donate

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A WORLD WITHOUT LIMITS

FOR PEOPLE WITH EPILEPSY

We hope you like the AI-generated images we've used, based on our real volunteers and supporters. Both these amazing people and these developing technologies will be at the heart of us achieving everything set out in this strategy.

Be sure to keep an eye on [epilepsy.org.uk/withoutlimits](https://www.epilepsy.org.uk/withoutlimits) to see how we're getting on. You can also go there to access this document in various formats.

A WORLD WITHOUT LIMITS



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