Reasons to believe

Raising Epilepsy Awareness

This document is designed as a resource for fundraisers to help guide conversations about epilepsy, and the vital difference Young Epilepsy makes. Use these key messages and facts when speaking at events, sharing stories, or engaging your community to raise awareness and support for children and young people living with epilepsy.

Seizures can be frightening for children and young people

Seizures can leave children in pain, feeling confused and alone. Many young people live with the worry of when the next seizure might happen. No child should live in fear of their own body. Epilepsy awareness helps more people understand this hidden reality and the impact it has on everyday life.

Epilepsy awareness helps people understand what epilepsy is really like

Epilepsy is far more than the seizure itself. It touches school, friendships, confidence, sleep, and mental health. Families often carry these worries quietly. Raising awareness creates space for honest conversations so that children and young people feel seen, heard, and supported.

More children need understanding and support

Nearly every hour, another child or young person in the UK is diagnosed with epilepsy. Families face shock, fear, and many unanswered questions. Increasing awareness is urgently needed so that understanding and support can reach those affected.

Epilepsy awareness brings people together

When people share stories, wear symbols, or join in fundraising for epilepsy awareness, they help build a kinder, more informed community. This sense of solidarity helps young people feel less alone in something that can be isolating and frightening.

Your support helps turn fear into hope

While awareness campaigns cannot take away the fear that seizures bring, *you* can help shine a light on it. Your fundraising helps to deliver trusted support, better services, and the guidance families desperately need. You make breakthrough treatments possible—the kind of help that can transform a child's life. Every pound you raise brings us closer to a future where every child with epilepsy can feel safer, stronger, and one day live seizure free. Your support can turn fear into hope.

What does childhood epilepsy look like?

- **Epilepsy is a condition that affects the brain and nervous system, causing repeated seizures.** It can be an overwhelming diagnosis for children and their families, with seizures often starting between ages 4 and 10 and sometimes occurring many times a day. Children's brains are still developing, so seizures and delayed diagnosis can affect learning and participation in daily activities.

- **Childhood absence epilepsy** is a common form, affecting up to 18 in every 100 school-aged children with epilepsy. Seizures are often brief and may look like daydreaming, making them easy to miss or misunderstand. Even brief absence seizures interfere with learning and can leave children feeling frustrated or left behind.

- Seizures can be subtle and misinterpreted as inattention or daydreaming, rather than recognised as a medical condition. Many families wait a long time for answers, making early support crucial.

- Children with absence epilepsy are usually otherwise healthy and developing normally, but the frequency of seizures can disrupt learning at school and daily life. Although children with epilepsy may appear healthy and develop typically, frequent seizures can impact their education, confidence, friendships, and overall well-being.

- **Emotional and social challenges:** Epilepsy affects more than just health—it shapes childhood experiences and confidence.

- 1 in 3 children with epilepsy have seizures that cannot be controlled by medication, putting their safety, education, and mental health at risk. Treatment can be complex, as finding the right therapy for children is challenging and treatments haven't advanced rapidly.

- **Diagnosis delays are common:** Many families wait a long time for answers, making early support crucial.

- **Childhood epilepsies can change over time:** Ongoing support is needed as children grow and their needs evolve.

- About half of all childhood epilepsy cases have **no known cause**, highlighting the urgent need for research and support for children and their families.

Because epilepsy impacts every aspect of a child's life, Young Epilepsy tailors its support to the unique challenges faced by young people - making your support truly life-changing.

Why your support is essential

Your fundraising directly enables Young Epilepsy to:

1. **Drive critical research:** Advance understanding of causes and develop new treatments for childhood epilepsies.
2. **Impact:** Young Epilepsy currently leads **45** active research projects covering diagnosis, treatments, mental health, and education.
3. **Improve treatment journeys:** Reduce waiting times and improve the quality of care for families.
4. **Provide information, guidance and emotional support** to help children and their families navigate life with epilepsy.

The difference your support makes:

276 referrals were made to our Youth Support Service, with 185 children and young people receiving one-to-one specialist support.

250 Youth Voice Network members, amplifying lived experience at a national level.

244 took part in our Virtual Youth Groups – a 70% increase on the previous year.

87% increase in referrals compared to the previous year.

305 schools and **117 higher-education professionals** completed our free epilepsy awareness eLearning – a **20% year-on-year increase**

90% of professionals report increased knowledge and confidence when supporting young people with epilepsy.

16,163 signed #UnderstandMyEpilepsy petitions for safer, more inclusive schools.

46 active research projects covering diagnosis, treatment, mental health and education.

93 patient/carer feedback score (well above the benchmark of 58).

Key partnerships with NHS England, Epilepsy Research Institute UK, and other leading organisations.