



**Position:** The Epilepsy Foundation supports \$175 million in funding for epilepsy research at the National Institutes of Health (NIH) and \$38.4 billion in overall funding for NIH. We urge Congress to continue to invest in research initiatives that have been partially funded at NIH, and to support funding for a cure and better treatments for epilepsy. **We urge Congress to continue to support the following initiatives at National Institute Neurological Disorders and Stroke (NINDS):**

- **NINDS Centers without Walls.** The initiative promotes key opportunities for collaborative research on critical topics, such as Sudden Unexpected Death in Epilepsy (SUDEP).
- **BRAIN (Brain Research through Advancing Innovative Neurotechnologies) Initiative.** The initiative calls upon the private and scientific communities to form partnerships to advance research on human brain networks.
- **ICARE (Interagency Collaborative to Advance Research in Epilepsy).** Led by NINDS, this initiative coordinates the research efforts of federal agencies and voluntary organizations to identify areas for collaboration.

**In addition, we ask that Congress urge the NIH to include epilepsy in the All of Us initiative** as a model for the development of precision medicine in neurological disorders. The epilepsy research community is uniquely positioned to take on this challenge, in large part because of the strong and sustained commitment that the NINDS has made to gene discovery in the epilepsies over the last decade. Now is the time to catalyze the rich knowledge we have gained in understanding the genetic basis of the epilepsies into actionable treatments that target the mechanisms of these often devastating disorders.

**About Epilepsy:** The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of more than 3.4 million Americans with epilepsy and seizures. We foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime.

**Background:** There is no "one size fits all" treatment for epilepsy, and about a third of people living with epilepsy suffer from uncontrolled or intractable seizures, despite available treatments. Many more people live with debilitating side-effects. Uncontrolled seizures can lead to disability, injury, and even death. Despite the advances in medical treatment that have allowed many individuals with epilepsy to control seizures, many individuals, especially children with rare, severe epilepsies that are especially resistant to current treatments are still waiting for new therapies to control their seizures and for a cure. This significant unmet need could be addressed in great part with increased investments in research.

The Epilepsy Foundation has been a long-standing supporter of research, investing more than \$65 million into epilepsy research in the past 40 years. Many of today's educators, senior investigators, and thought leaders in the study of epilepsy were supported in their early careers with financial assistance from the Epilepsy Foundation. Despite private investments in research, federal funding is critical for advancing epilepsy research and building on the considerable progress that has been made in the last decade to identify genes associated with epilepsy and in developing new medications, devices, and surgical treatments.

NIH is the premier federal agency for conducting medical research in the United States, and its institutes are the world's foremost research centers. Each year the government spends tens of billions on medical research at the National Institutes of Health. Yet, less than ½ of 1% is spent on epilepsy. Funding is needed to make progress in epilepsy research and improve health outcomes. As noted in the 2012 Institute of Medicine report, *Epilepsy Across the Spectrum: Promoting Health and Understanding*, epilepsy is the 4th most prevalent neurological disorder, yet “gets less funding than the other neurological disorders when adjusted for prevalence.”

**If you have any questions or concerns, please contact Beatriz Duque Long, Interim Vice President Public Policy and Advocacy at [bduquelong@efa.org](mailto:bduquelong@efa.org) or 301-918-3764.**