



## Finding a Cure & Better Treatments: Federal Funding for Epilepsy Research

**Position:** We support \$160 million in overall funding for epilepsy research at the National Institutes of Health (NIH). The Epilepsy Foundation urges Congress to not abandon research initiatives that have been partially funded at the NIH, and to support funding for a cure and better treatments for epilepsy. Each year the government spends \$30 billion on medical research at the National Institutes of Health. Yet just ½ of 1% is spent on epilepsy. Funding is needed to make progress against epilepsy and improve health outcomes. As the 2012 Institute of Medicine report *Epilepsy Across the Spectrum* noted epilepsy is the 3<sup>rd</sup> most prevalent neurological disorder, yet “gets less funding than the other neurological disorders when adjusted for prevalence.”

**Background:** Since 1968, the Epilepsy Foundation has served as the only national voluntary health organization wholly dedicated to the welfare of people with epilepsy. The mission of the Epilepsy Foundation is to ensure that people with seizures are able to participate in all life experiences; and to prevent, control and cure epilepsy through research, education, advocacy and services. During more than 40 years of service, the Epilepsy Foundation and its generous supporters have channeled more than \$35,000,000 into epilepsy research.

Many of today’s educators, senior investigators, and thought leaders in the study of epilepsy were supported in their early careers with thanks to financial assistance from the Epilepsy Foundation. While advances in medical treatment have allowed some individuals with epilepsy to control their condition, at least 45 percent of people with epilepsy have uncontrolled seizures and yet a third of those people are not receiving the appropriate level of care to manage their condition. Some forms of childhood epilepsy are especially resistant to current treatments.

The Epilepsy Foundation has been a long-standing supporter of the NIH and views the Institutes as one of the world’s foremost research centers and the premier federal agency for conducting medical research in the United States. The majority of federally directed epilepsy research takes place at the National Institute of Neurological Disorders and Stroke (NINDS), one of the 27 Institutes at NIH. In the last decade, considerable progress has been made in identifying genes associated with epilepsy and in developing medications, devices and surgical treatments. Further, as the IOM report noted, we concur and hope that future “research will result in curative treatment and prevention strategies.” The Foundation commends the commitments that NIH and NINDS have made to epilepsy research. **We are encouraged by the following initiatives at NINDS, and would urge Congress not to back track on these epilepsy investments:**

- NINDS Centers without Walls program: based on a successful model used in other NIH Institutes, these new Centers will promote a virtual opportunity for collaborative research to solve specific challenges identified as priorities.
- Translational Research Program for the Epilepsies: program with focused grant opportunities in critical areas such as anti-epileptogenesis and treatment resistant epilepsy. Many of the grant topics are based out of the benchmarks established in the 2000 and 2007 NINDS conferences on curing epilepsy – these are important investments that should not be abandoned.
- EUREKA grants – The Epilepsies Exceptional, Unconventional Research Enabling Knowledge Acceleration program, a set of special grants to support highly innovative and novel approaches in epilepsy research.

**We urge Congress to allow NINDS to carry out its epilepsy research priorities and to support \$160 million in overall funding for epilepsy research at NIH.**