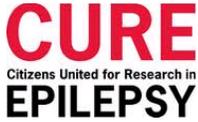


Citizens United for Research in Epilepsy



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Mission

Citizens United for Research in Epilepsy (CURE) is a nonprofit organization dedicated to finding a cure for epilepsy by raising funds for research and increasing awareness of the prevalence and devastation of this disease. CURE was founded by parents of children with epilepsy who were frustrated with the medical options available.

Strategy/Approach

CURE works to increase the amount of innovative and breakthrough research funded, with an emphasis on projects that translate the basic scientific understanding of epilepsy to the treatment, prevention, and eventual cure of all forms of the disease. It awards seed grants for novel research projects that address the goals of “no seizures, no side effects,” and specifically those that address:

- Prevention of epilepsy, including post-traumatic epilepsy
- Advancement of the search for a cure
- Elimination of treatment side effects
- Reversal of deficits caused by frequent seizures

In 2013, CURE produced the second **State of Epilepsy Research Report**, which serves as the basis of an aggressive three-year plan to accelerate progress in research aimed at discovery of a cure. Key elements of the plan include cure focused research, increases in per patient funding, and bolstering translational and clinical research infrastructure.

CURE also engages in aggressive public awareness efforts, which have helped to increase the number of private dollars dedicated to epilepsy research and influenced the epilepsy research agenda at the National Institutes of Health (NIH).

Research Portfolio

Grant recipients are selected with the assistance of the CURE Scientific Advisory Board and the CURE Research Review Board. Awards, which vary from year to year, include:

- **Innovator Award** – supports the exploration of a highly innovative new concept or untested theory that addresses an important problem relevant to epilepsy
 - *Up to \$50,000 for one year*
- **Taking Flight Award** – supports young investigators
 - *Up to \$100,000 for one year*
- **Challenge Award** – supports established investigators
 - *Up to \$250,000 over two to three years*
- **Prevention of Acquired Epilepsy Award** – focuses on prevention and treatment of acquired (post-injury) epilepsy
 - *Up to \$250,000 over two to three years*

- **Sudden Unexplained Death in Epilepsy (SUDEP) Award** – supports SUDEP research
 - *Up to \$100,000 for one year*
- **Advancing Understanding of Infantile Spasms Award** – advances the understanding of the underlying pathology of infantile spasms
 - *Two to three years*
- **Pediatric Epilepsies Award**—supporting research in the areas of systems-level understanding of pathogenic mechanisms, investigations of impact, natural history, and epidemiology, and/or novel treatments which impact disease progression.
 - *Up to \$250,000 for two years*

CURE has also partnered with the U.S. Army Medical Research and Materiel Command to further traumatic brain injury research and prevention.

Partnership Practices

In addition to working closely with many other epilepsy organizations – most recently on the Institute of Medicine's report, "Public Health Dimensions of the Epilepsies" – CURE also sees great value in collaborating with organizations and experts focused on other disciplines and disease states, especially those within other neurological areas, in order to foster innovative solutions. Additionally, CURE continues to seek opportunities for partnership with organizations related to the co-morbidities associated with epilepsy. An example of this is the most recent co-sponsorship of a scientific conference with Autism Speaks.

CURE does not partner with biotech and pharmaceutical companies.

Financials

CURE is a 501(c)(3) tax-exempt nonprofit organization. The most recent financial information available is from 2012.¹

Year ending 12/31/11:

- Revenue: \$5,587,966
- Assets: \$11,308,591
- Grants paid: \$3,405,292
- Gifts received: \$5,517,115
- Expenditures: \$2,730,127

¹ Information obtained from GuideStar, <http://www.guidestar.org>, February 2014

Key Accomplishments

- Raised more than \$26 million to fund research and other initiatives that will lead the way to a cure.
- CURE has quickly become a global influence, and has awarded 134 cutting-edge scientific projects **at** esteemed medical institutions throughout the world. This has spilled over into doctors' offices as well, where patients are no longer accepting that they must live with seizures and side effects as an inevitable and inescapable part of their lives.
- In just 10 years, CURE-funded research has resulted **in** 123 articles in leading scientific journals, indicating that CURE is at the forefront of epilepsy research and scientific advances.
- Many CURE-funded researchers have secured additional, follow-on grants from other sources, and successfully published their findings in more than 100 scientific journals.
- Co-sponsored a first-of-its-kind conference with NIH, initiated by the White House, to focus on epilepsy
- Key sponsor involved in helping shape the direction and outcome of a newly commissioned Institute of Medicine report, "The Public Health Dimensions of the Epilepsies."

Leadership

CURE is governed by a **Board of Directors** and counseled by a **Scientific Advisory Board** and a **Research Review Board**.

- **Founding Chair, Board of Directors:** Susan Axelrod, saxelrod@cureepilepsy.org
- **Chair, Board of Directors:** Gardiner Lapham
- **Interim Executive Director:** Robin Harding
- **Director of Communications:** Samantha Kreindel
- **Research Director:** H. Steve White, PhD
- **Development Coordinator:** Kacie Cysewski