

2024 CURE Epilepsy Program Service Accomplishments:

Our Mission

CURE Epilepsy's mission is to fund breakthrough research that will transform the lives of people with epilepsy as we lead the search for a cure.

CURE Epilepsy Background:

Founded in 1998, CURE Epilepsy is the only nonprofit organization committed to the [singular goal of finding a cure for epilepsy](#). We accelerate cures by filling gaps that exist across the research landscape. Our efforts fund groundbreaking research focused on understanding epilepsy's underlying causes and mechanisms to get to the root of the problem.

CURE Epilepsy was founded by Susan Axelrod and a small group of parents of children with epilepsy who were frustrated with their inability to protect their children from seizures and the side effects of medications. Unwilling to sit back, they joined forces to spearhead the search for a cure. Since its inception in 1998, CURE Epilepsy has raised more than \$100 million to fund epilepsy research and other initiatives that will lead the way to cures for the epilepsies.

2024 Financial Metrics:

Total Revenue	\$6,220,909
Total Expenses	\$6,184,753
Awareness	\$1,089,563
Research	<u>\$4,103,408</u>
Program Expenses	\$5,192,971
Fundraising	\$679,998
Administration	\$311,784
12/31 Net Assets	\$6,996.108

CURE Officers:

Beth Dean - Chief Executive Officer

Laura Lubbers – Chief Science Officer

John Anderluh – Chief Financial Officer

CURE Board of Directors:

Lisa Cotton – Chair

Justin Gover – Chair Elect

Kathy McKenna – Treasurer

Shalee Cunneen – Secretary

Other Board Members – Steve Austin, Irina Colon, Kim Borden, Carrie Garman, Maureen Flood Rabus, David Reifman, Walter Kelly, Matt Schneider, Hannah Whitten, Kelly Cervantes, Michael Axelrod

Research Strategy and Focus Areas

Epilepsy is complex. That's why our research strategy needs to be multifaceted and bold. Since our inception, we have funded the most innovative, promising science that might otherwise go unfunded.

CURE Epilepsy both solicits broad ideas and drives deep engagement into critical areas ripe for impact. We are focused on high-risk high-reward science that will move the needle and bring breakthroughs that will make an impact across the epilepsies. We also prioritize the patient voice with the inclusion of lived-experience reviewers.

With our unique, cross-sector relationships and influence, CURE Epilepsy sits at the intersection of public, private and industry investment in epilepsy and is poised to lead the way to a cure.

Post-Traumatic Epilepsy:

From our original \$10M grant from the U.S. Department of Defense to current work on common data elements, CURE Epilepsy has been focused on team science and collaboration to solve the biggest challenges in this acquired epilepsy.

See “Our Research/Areas of Focus” on our website for further details & findings

Sudden Unexpected Death in Epilepsy:

Sudden Unexpected Death in Epilepsy (SUDEP), which occurs when a seemingly healthy person with epilepsy dies for no known obvious reason, is perhaps the most devastating possible consequence of epilepsy. For 20 years, CURE Epilepsy has been a leader in SUDEP research, pushing the field to better understand risk factors that can lead to prevention.

See “Our Research/Areas of Focus” on our website for further details & findings

Genetic and Rare Epilepsy's:

Genes implicated in epilepsy continue to be discovered, and rare epilepsies can struggle to get the research attention they need. With its broad mandate to search for cures for all the epilepsies, CURE Epilepsy's work in specific diagnoses has the potential for impact across the field. From a potential treatment for infantile spasms to proving the value of reanalyzing genetic data, CURE Epilepsy is focused on leveraging discoveries for the benefit of all.

See “Our Research /Areas of Focus” on our website for further details & findings

2024 Research Grant Awards

In 2024, CURE Epilepsy awarded \$2.2 million in 13 research grants across our portfolio of investigator led research opportunities. Each year, grants are funded based on promising trends in the field and the potential for breakthroughs in a specified area.

- 1) CURE Epilepsy Awards:** Two-year, \$250,000 awards focusing on scientific advances that have the potential to truly transform the lives of those affected by epilepsy, with prevention and disease modification as critical goals. Priority areas include: 1) Basic mechanisms of epilepsy, 2) Acquired epilepsies, 3) Pediatric epilepsies, 4) SUDEP, 5) Treatment-resistant epilepsies and 6) Sleep and Epilepsy
- 2) Taking Flight Awards:** 1.5 year, \$125,000 awards that promote the careers of young epilepsy investigators, allowing development of a research focus independent of their mentor(s).
- 3) Catalyst Awards:** The CURE Epilepsy Catalyst Award (2 years / \$250,000) supports nimble development of data necessary to attract larger commercialization funding opportunities and is not intended to replace those opportunities.
- 4) Rare Epilepsy Partnership Award:** The Rare Epilepsy Partnership Award (1 year/\$100,000) will support the development of necessary research tools, techniques, model systems, and data collection platforms to stimulate and accelerate research on rare epilepsies. Each award will be co-funded by CURE Epilepsy and one or more of the rare epilepsy advocacy groups (partners)

See “Our Research/Grants Awarded” on our website for the specific grants we awarded

Federal Grant Research: Investment continued with our U.S. Department of Defense research program focusing on post-traumatic epilepsy. In total, we invested an additional \$0.5 million in post-traumatic epilepsy because of traumatic brain injury.

CURE Sponsored Research Conferences: CURE Epilepsy sponsors conferences focused on communicating and advancing epilepsy research. We are dedicated to engaging the research community, promoting collaboration, and increasing epilepsy’s visibility with the goal of finding a cure. These conferences bring together epilepsy researchers and enable learning opportunities and sharing. During 2024, CURE Epilepsy provided sponsorship to 5 individual epilepsy focused conferences with an investment of \$44,000.

Epilepsy Educational Resources & Epilepsy Awareness:

Treatment Talks

Learn more about specific epilepsy syndromes or seizure types, including cutting-edge therapies, treatment options, and holistic approaches for those living with epilepsy. Our speakers will provide valuable insights and practical strategies, from both the clinical and patient perspectives, to support the epilepsy community. See “Understanding Epilepsy/Treatment Talks” on our website.

Seizing Life

Seizing Life® is a CURE Epilepsy podcast and videocast aiming to inspire empathy, offer helpful stories, and give hope as we search for a cure for epilepsy. Listen as guests share stories and insights on living with epilepsy in conversation with our host, Kelly Cervantes. In total 12 Seizing Life episodes were generated in 2024. See “Understanding Epilepsy/Seizing Life” on our website for further details.

Webinars

Discover comprehensive insights into epilepsy and seizures from industry-leading experts. Explore the latest advancements in the cure for epilepsy, innovative treatment options, seizure management strategies, and effective ways to support individuals living with epilepsy. In total 7 webinars were generated in 2024. See “Understanding Epilepsy/Webinars” on our website for further details.

Epilepsy Explained Videos

CURE Epilepsy’s video series Epilepsy Explained provides basic information on epilepsy in easy-to-understand language. Each month a featured epilepsy expert will answer questions about a specific area of epilepsy. See “Understanding Epilepsy/Epilepsy Explained Videos” on our website for further details.

Awareness:

CURE Epilepsy invested ~\$1.1 million in 2024 on Epilepsy Awareness. CURE Epilepsy believes Epilepsy Awareness is a critical vehicle to increase the amount of funding available for Epilepsy research and to share key learnings and opportunities for those impacted by Epilepsy. CURE Epilepsy creates, sponsors and levers our website, webinars, seminars, podcasts, educational events and other digital communication to drive this critical awareness.

In 2024, CURE Epilepsy launched a more user-friendly new website. A continued specific focus was investing in the information insights available on our website for epilepsy patients. The new site includes Educational Resources, Epilepsy Basics, Diagnosing Epilepsy and information on Treatments and Therapies for those impacted by Epilepsy.