

Epilepsy Therapy Project & Epilepsy Foundation



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Stronger Together

Mission

The Epilepsy Foundation (EF) is a national nonprofit with more than 47 affiliated organizations throughout the U.S. that has led the fight against seizures since 1968. The mission of the Epilepsy Foundation is to stop seizures and sudden unexpected death in epilepsy (SUDEP), find a cure and overcome challenges created by epilepsy through efforts including education, advocacy, and research to accelerate ideas into therapies.

In December 2012 EF merged with the Epilepsy Therapy Project (ETP), a patient-organized group with the mission of accelerating ideas into therapies for people living with epilepsy and seizures. ETP is now an initiative of the Epilepsy Foundation. In 10 years of existence before the merger, ETP and EF created the New Grants Program, a joint venture to fund new, translational research to speed the search for new therapies and a cure for epilepsy. The newly merged organization allows ETP to continue to work to accelerate new therapies in a timeframe that matters as an initiative of EF.

Strategy/Approach

The Foundation supports research, advocacy, and patient support related to epilepsy. The advocacy work of EF prioritizes securing funding for a cure, better treatments & programs, improving access to medical care and treatment, and ending stigma and discrimination against people with epilepsy. EF seeks to improve incentives and encourage commercial investment in new therapies. It brings together financial resources, scientific insights, and business expertise from leading academic and commercial industry participants. Key ongoing programs include:

- **epilepsy.com** – Created to inform and empower patients and families facing newly diagnosed epilepsy or those struggling with epilepsy that has resisted the usual treatments. It is the most visited Web site in the world on the topic of epilepsy and features a Clinical Trial finding resource.
- [epilepsy.com for Professionals](http://epilepsy.com/professionals) – Designed to inform and empower doctors, nurses, and other healthcare providers with the latest information on epilepsy management.
- **Epilepsy Study Consortium** – Created by ETP, a group of scientific investigators from academic medical research centers who are dedicated to accelerating the development of new therapies in epilepsy. Its goals include building a partnership among academics, industry, and regulatory agencies

and optimizing clinical trial methodology in order to responsibly speed new treatments to patients.

- **Epilepsy Pipeline Update Conference** – This annual conference showcases the most promising epilepsy therapies in development from entrepreneurs, startups, and established companies.

Research Portfolio

EF dedicates research efforts to four areas: bringing new clinicians to the field, funding new therapies, exploration of key issues in epilepsy care, and bringing attention to exciting new ideas.

Through several **Research Training Grants** EF encourages students and clinicians to develop careers in the field of epilepsy research. Varieties of awards are funded each year and are available as posted.

- Behavioral Sciences Student Fellowship
- Health Sciences Student Fellowship
- Behavioral Sciences Post-Doctoral Fellowship
 - Up to \$40,000 for one year
- Predoctoral Research and Training Fellowship
 - Up to \$20,000 for one year
- Postdoctoral Research and Training Fellowship
 - Up to \$45,000 for one year
- Research Grants Program
 - Up to \$50,000 for one year
- Research and Training Fellowship for Clinicians
 - Up to \$50,000 for one year

EF provides financial support and scientific and business direction to promising new therapies and emerging epilepsy-focused companies through **Targeted Research Programs**. Grants focus on the field of translational epilepsy research and provide resources to accelerate the progress of breakthrough research and new therapies from bench to bedside.

- **New Therapy Commercialization Grants Program** – These grants are awarded only to programs that have progressed beyond the basic science discovery stage. Preference is given to proposals that already have a commercial partner engaged to assist with development, and/or have committed or matched funding from a sponsoring institution, commercial partner, or other third-party source. Grant proposals are solicited and multiple grants are awarded semi-annually.
- **Focused Ultrasound Foundation Study**—A two-phase study in collaboration with researchers at the Swedish Neuroscience Institute will investigate the possibility of using focused ultrasound as a non-

invasive and surgery free alternative. This treatment is aimed at patients with mesial temporal lobe epilepsy who do not respond to medication.

- **Targeted Research Initiatives**—Research programs targeted at areas of unmet need in epilepsy research. Support research that generates initial data leading to more extensive projects that will generate knowledge and ultimately improve the healthcare of patients with epilepsy. Current topics include:
 - *Health Outcomes*
 - *Morbidity & Mortality*
 - *Severe Symptomatic Epilepsies*
 - *Women*
 - *Youth*

The **Epilepsy Innovation Seal of Excellence Award** was established in 2013 to recognize groundbreaking product development programs deemed by the foundation as deserving of significant and urgent support.

- **Epilepsy Innovation Seal of Excellence Award** – This award is not primarily a grant program but provides a competitive, in depth review to generate interest in the project and a one-time funding award. The SEAL award is for one year and may be renewed for up to 4 years, but funding is only awarded the first year.
 - *\$25,000 for the first year*

Partnership Practices

EF participates in several types of partnerships with industry members.

- **National Corporate Partners**—financial support and efforts to raise awareness
 - *Eisai Corporation*
 - *GlaxoSmithKline*
 - *Pfizer, Inc.*
 - *UCB Pharma, Inc.*
 - *And many others*
- **Strategic Alliance Partners**—leading the way in supporting research, finding new therapies, and breaking down barriers in the field
 - *Danny Did Foundation*
 - *American Epilepsy Society*
 - *Health Resources and Services Administration (HRSA)*
 - *Centers for Disease Control*
 - *National Association of Epilepsy Centers*
 - *Jacoby Development, Inc*
- **Community Partners**—devoting themselves to diverse spectrum of epilepsies
 - *Giant Foods*
 - *NBC4*
 - *Larabar*
 - *PepsiCo*
 - *And others*

EF partners with biotech and pharmaceutical companies.

EF/ETP has made and continues to make investments in promising start-up companies with an emphasis on finding new treatments for epilepsy through the **New Therapy**

Commercialization Grants Program. In 2012, EF invested in an anti-inflammatory drug clinical trial by Harbor Therapeutics.

Financials

The most recent financial information available for ETP and EF from before 2012. Information presented here details ETP and EF financial statements separately before merger.

ETP is a 501(c)(3) nonprofit health organization. The most recent financial information available is from 2012.¹

Year ending 12/31/12:

- Revenue: \$2,531,249
- Assets: \$732,238 (market value)
- Grants: \$736,867
- Gifts received: \$2,421,721
- Expenditures: \$2,299,129

The Epilepsy Foundation is a 501(c)(3) nonprofit health organization. The most recent financial information available is from 2012.

Year ending 6/30/12:

- Revenue: \$10,053,381
- Assets: \$18,225,598
- Grants: \$2,614,557
- Gifts Received: \$2,614,557
- Expenditures: \$13,034,662

Key Accomplishments

- Hosts the most visited Web site in the world on the topic of epilepsy.
- Supports the three leading worldwide conferences on epilepsy therapy development – Antiepileptic Drug Trials Symposium, Eilat Conferences on Antiepileptic Drugs, and the Epilepsy Pipeline Update Conference.
- Launched **Epilepsy Therapy Pipeline**, identifying an estimated 80 product candidates in early- to late-stage development, as a public resource to foster support for innovative new therapies.
- Provided financial support and expertise to more than 60 of the 123 active new therapy projects in the epilepsy therapy pipeline including therapeutic drugs, biologics, devices, and other treatments over the past decade.
- Three EF/ETP funded projects have reached patients
 - *Visualase MR guided laser system for epilepsy surgert*
 - *SmartWatch seizure detection and caregiver notification device*
 - *Non-invasive NeuroStigma eTns stimulator for control of seizures*

Leadership

Epilepsy Therapy Project is governed by a **Board of Directors** and overseen by a professional leadership **staff**. A **Scientific**

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

Advisory Board assesses grant and investment opportunities, and a **Business Advisory Board** provides advice and direction to support the commercialization of new therapies. A

Professional Advisory Board provides strategic and creative direction across the portfolio of programs.

- **Chair of Board of Directors:** Warren Lammert, warren@granitepoint.com
- **President & CEO:** Phil Gattone, pgattone@efa.org
- **Vice President of Programs & Research:** Janice Buelow jbuelow@efa.org
- **Co-Chair of Business Advisory Board:** Stephen D. Collins, MD, PhD; President & CEO, NeuroTherapeutics Pharma
- **Co-Chair of Business Advisory Board:** Garry E. Menzel, PhD; Executive Vice President Corporate Development and Finance, Regulus Therapeutics
- **Chair of Professional Advisory Board:** Joseph I. Sirven