

# Vision 20-20 ICARE Report

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# Mission

- Improve lives of people with epilepsy and their families
- Provide a forum for epilepsy voluntary, professional, and governmental organizations to identify and pursue common goals.
- Currently 35 organizations are participating

# Organizations



# Topics of Interest

- Many organizations support research programs reflecting their missions and goals
- Common topics include: SUDEP, genetics, TBI, stroke, infantile spasms, therapeutic development, and comorbidities

# Types of Research Support

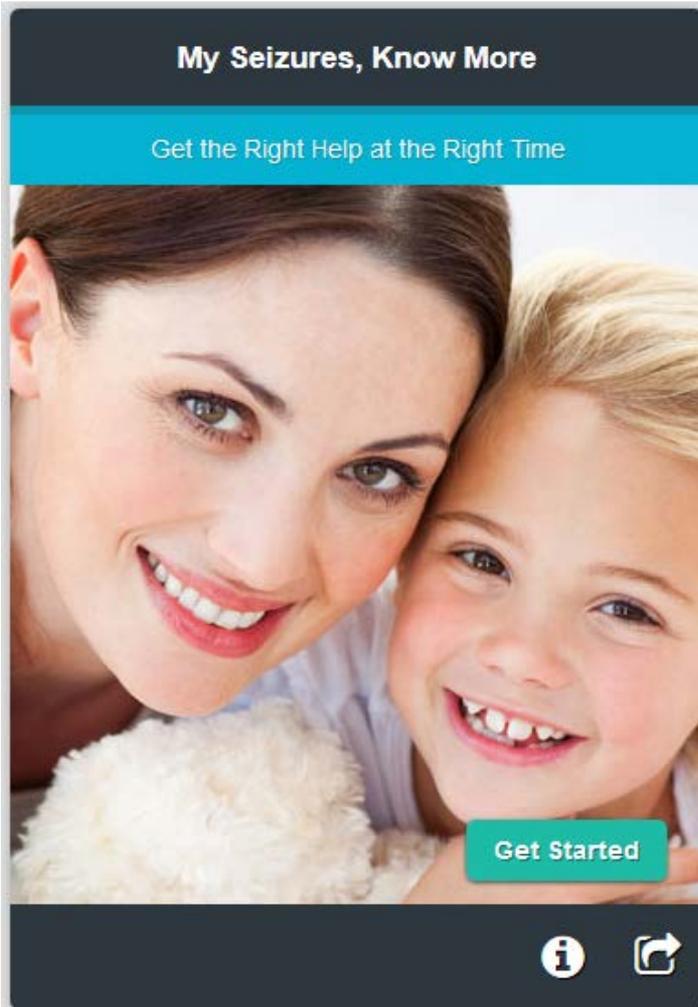
- Basic, clinical, and translational studies
- Incidence & prevalence studies; registries
- Pre-doc, Post-doc, and clinical fellowships
- Seed grants/pilot studies
- Infrastructure awards
- Workshops
- Travel awards
- Targeted and investigator-initiated research

# Current Activities

- IOM Report Implementation
- Rare Epilepsy Network (REN) of PCORI
- Vision 20-20 Special Interest Group
- Resources in Epilepsy Research  
website- [epilepsyresearchresource.org](http://epilepsyresearchresource.org)
- PAME Conference, June 19-22, 2014



Collaborative efforts of multiple epilepsy organizations made possible through Vision 20-20.



- Empowers patients to communicate their concerns with their care providers.
- Guides patients to seek more specialized epilepsy care if they are having seizures, side-effects from drugs, other health problems, or social or educational issues.
- It can be placed on any website or blog.



**HERO** Human Epilepsy Research Opportunities

Home Find an Epilepsy Study Vision 20/20 Partners FAQs

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**Tracy Dixon-Salazar, PhD**  
CURE (Citizens United for Research in Epilepsy)

**Clinical Trials for Epilepsy**

**PE: Clinical Trials**

**I'm Not Just a Pill**

**Get the HERO Badge!**  
Place a badge on your website to help people with epilepsy find appropriate clinical studies and become a part of life-changing research. [More >](#)

**Heroes and Clinical Research**  
The heroes who participate in clinical research studies are everyday people who want to make the world a little better.

**Who are the heroes that become involved in clinical research?**

The heroes who participate in clinical research studies are everyday people who want to make the world a little better. A hero could be anyone you encounter throughout your day, like your letter carrier, the convenience store clerk, or your child's kindergarten teacher. If you take medicine for your epilepsy or know someone who does, that medicine exists because someone else (a hero) participated in the research necessary to get that drug to the market.

Heroes can be people who have epilepsy, or they can be family members who may be healthy. They are people who have learned that clinical trials are

**GREETINGS TO RESEARCHERS AND CLINICIANS**  
We are delighted to have investigators and clinicians reviewing the HERO website. All research studies that are available through the National Institutes of Health website are accessible through the HERO trial finder. We invite you to send potential participants to the HERO website to read FAQs and learn more about epilepsy research in general. We deeply appreciate your commitment to helping to work toward cures for this

## EpilepsyHERO.org :

- provides a clear explanation of clinical research
- answers many frequently asked questions
- includes informational videos featuring patients and researchers in the epilepsy community
- makes it easier for individuals to **find and enroll in clinical studies** and advance epilepsy research.
- can be leveraged on any website or blog