

# ICARE Member Report: Vision 20-20

- Collaboration of voluntary epilepsy organizations (501c3), associations, and governmental organizations to promote epilepsy information, support, research, and cure.
- Founded in 2004 by 6 groups; grown to include 27 groups in 2012.
- Regular meetings to collaborate on common objectives, i.e., IOM Report, conferences, clinical studies etc.

# ICARE Member Report: Vision 20-20

## Non-Profit

**Anita Kaufman Foundation**

**Brain Recovery Project**

**Charlie Foundation**

**Child Neurology Foundation (CNF)**

Citizens United for Research in Epilepsy (CURE)

**Danny Did Foundation**

**Dravet.org**

**Dup 15q Alliance**

Epilepsy Foundation (EF)

**Epilepsy Therapy Project (ETP)/Epilepsy.com**

**Finding A Cure Against Epilepsy and Seizures (FACES)**

**Hemispherectomy Foundation**

**HHV-6 Foundation**

**Hope for Hypothalamic Hamartomas (HH)**

**International League Against Epilepsy (ILAE)**

**Intractable Childhood Epilepsy (ICE) Alliance**

**Lennox-Gastaut Syndrome (LGS) Foundation**

**My Epilepsy Story**

**Preventing Teen Tragedy (PTT)**

**RE Children's Project**

Tuberous Sclerosis Alliance

## Association

American Epilepsy Society (AES)

**National Association of Epilepsy Centers (NAEC)**

## Governmental

Center for Disease Control & Prevention (CDC)

Health Resources & Services Administration (HRSA)

National Institute of Neurological Disorders & Stroke (NINDS)

## For Profit

**Seizure Tracker**

**\*\*\* Slide deck representing organizations in bold; remaining organizations participating individually in ICare meeting**

# ICARE Member Report: Vision 20-20

- Major topics of interest in epilepsy research
  - Many individual organizations support mission focused research
- Types of research support or other activities
  - Institute of Medicine Report – collaboration
  - Topic Specific Conference Collaboration – PAME, ILAE, AES etc.
- Resources available for shared use or other opportunities for collaboration
  - AES supported online database inventory research initiatives
  - Regular, coordinated meetings
- Priorities and/or plans for future activities
  - IOM Report Implementation –surveillance, healthcare providers, caregiver education task forces
  - Increase epilepsy research and funding – governmental, private, public
  - Increase patient participation in clinical research studies

# ICARE Member Report: ADVOCACY & RESEARCH



**The Anita Kaufmann Foundation**  
*Educating the public not to fear epilepsy*  
*Global Sponsor of Purple Day®*  
[www.akfus.org](http://www.akfus.org)



**The Brain Recovery Project**  
Rebuilding the Developing Brain



## **Anita Kaufman Foundation**

**Educating the public not to fear people with epilepsy and seizures**

Purple Day is March 26th -  
Wear your purple to support epilepsy awareness globally.  
Visit [www.purpleday.org](http://www.purpleday.org).

## **Brain Recovery Project**

Funded gait study of three children several years post-hemispherectomy

Funded language comprehension and reading study of children post-hemispherectomy

Funded detailed physical therapy assessment of infant post-hemispherectomy

## **Charlie Foundation**

Seek more comparative effectiveness research of ketogenic diet therapy with medication therapy for infantile spasms (IS).

# ICARE Member Report: ADVOCACY & RESEARCH



## **Child Neurology Foundation**

Funded 30 research grants (most on epilepsy) and building an inclusive collaboration for the 18 million children with neurologic disorders.



## **Danny Did Foundation**

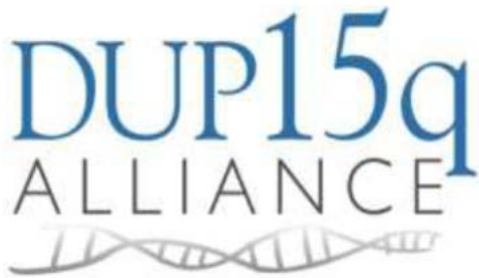
Raising awareness about technology and devices that can help to treat seizures and improving communication between doctors and patients about SUDEP



## **Dravet.org**

Funds research projects and supports others' research to find effective treatments and cures for Dravet syndrome and Dravet Spectrum Disorders.

# ICARE Member Report: ADVOCACY & RESEARCH



## **Dup 15q Alliance**

Collaborate with researchers interested in research on chromosome 15q duplications by disseminating research information and promoting opportunities for Dup15q Alliance families to participate in research studies



## **Epilepsy Therapy Project/ Epilepsy.com**

**Acceleration is our mission.**

Supports the commercialization of new therapies through direct grants and investments in promising academic and commercial projects.

We work to turn ideas into new therapies in a timeframe that matters to people living with epilepsy and seizures today.



## **Finding A Cure Against Epilepsy Seizures**

Improve the quality of life for all people affected by epilepsy through research clinical programs, education, raising awareness and community-building events

Supports translational research and helps establish research networks focused on improving the lives of people with epilepsy

# ICARE Member Report: ADVOCACY & RESEARCH



## **Hemispherectomy Foundation**

Funding research with Yale and the RE Children's project examining genetic components of Rasmussen's Encephalitis

Exploring a similar study focusing on Hemimegalencephaly

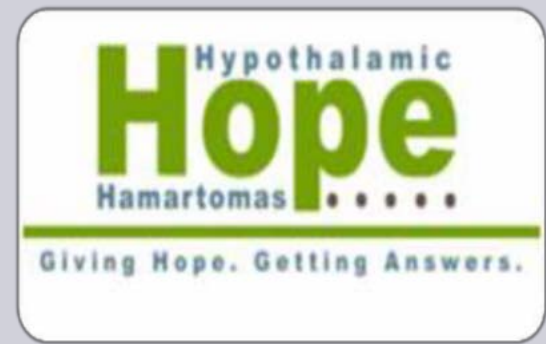


## **HHV-6 Foundation**

Promoting research into viral etiology and treatment

Strong evidence that persistent virus triggers at least 1/3 of MTLE and that HHV-6 & 7 cause 40% of status epilepticus

Funding studies of HHV-6B & HHV-7 in MTLE resections in China



## **Hope for Hypothalamic Hamartomas (HH)**

Seek research into cause, progression and efficacy of available treatments

Registry/Natural History Studies are key!

Provide information and support



# ICARE Member Report: ADVOCACY & RESEARCH



## **International League Against Epilepsy**

Umbrella organization of over 100 national chapters of epilepsy care professionals who are dedicated to the goal that no one's life is limited by epilepsy

Supports education and advocacy to ensure that people whose lives are affected by epilepsy have access to effective care



## **Intractable Childhood Epilepsy Alliance**

Funds research in discovery and understanding of the ion channelopathies

Understanding the CAUSE of the intractable epilepsies will lead to a CURE

**LGS FOUNDATION**  
LENNOX-GASTAUT SYNDROME

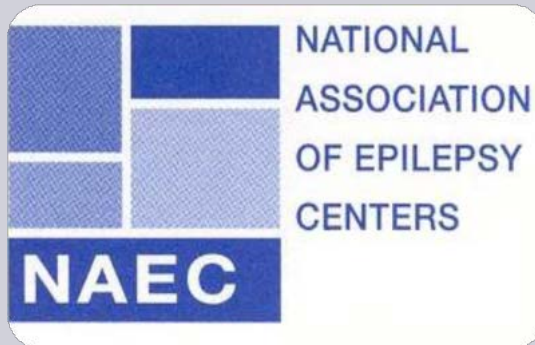


## **Lennox-Gastaut Syndrome (LGS) Foundation**

Funding research in Lennox-Gastaut Syndrome while providing services and programs to the LGS community.



# ICARE Member Report: ADVOCACY & RESEARCH



## **National Association of Epilepsy Centers (NAEC)**

170 centers that diagnose  
and treat individuals with  
intractable epilepsy

NAEC's mission is to  
improve the quality of  
epilepsy care in the US

## **My Epilepsy Story**

Dedicated to sharing the  
stories of women and  
girls who have epilepsy  
and to raising funds for  
research for this  
devastating neurological  
disorder

## **Preventing Teen Tragedy**

Assist individuals and  
families affected by  
mental illness and  
epilepsy

# ICARE Member Report: ADVOCACY & RESEARCH



## **RE Children's Project**

Sponsored cross-disciplinary research conferences

Funded leading edge research around the globe focused on finding the cause and an eventual cure for RE

Multi-center collaboration to inventory/transfer RE tissue



## **Seizure Tracker.Com**

Provides free comprehensive tools to help understand relationships between seizure activity and anti-epileptic treatments

The Seizure Tracker Clinical Trial Monitoring Tool is a FDA compliant web based clinical management system designed to enhance epilepsy related data collection