



epilepsy  
leadership council

Amy Brin, MSN, MA, PCNS-BC  
Chair, Epilepsy Leadership Council

2021 ICARE Update

# ELC History

- October 2004 AES convened a meeting of epilepsy groups on state of epilepsy research - referred to as Vision 2020
- Vision 2020 was part of the commissioning of the 2012 IOM Report on Epilepsy
  - **Strengthening Stakeholder Collaboration**  
**Recommendation:** *Create a framework and mechanism for continued cross-organizational collaboration by establishing a set of working groups in key areas.*

# ELC Membership in 2021

## **Nonprofit Organizations**

- Aicardi Syndrome Foundation
- The Anita Kaufmann Foundation
- Batten Disease Support and Research Association
- The Bow Foundation
- The Brain Recovery Project: Childhood Epilepsy Surgery Foundation
- Bridge the Gap SYNGAP Education and Research Foundation
- Charlie Foundation for Ketogenic Therapies
- Chelsea's Hope Lafora Children Research Fund
- Child Neurology Foundation
- Citizens United for Research in Epilepsy (CURE)
- CSWS Epilepsy & Landau Kleffner Syndrome (ESES) Foundation
- The CUTE Syndrome Foundation
- Danny Did Foundation
- Dravet Syndrome Foundation
- Dup 15q Alliance
- Epilepsy Foundation
- Families SCN2a Foundation
- HHV-6 Foundation
- Hemispherectomy Foundation
- Hope4Harper
- Hope for Hypothalamic Hamartomas
- Hope for ULD
- International Foundation for CDKL5 Research
- Jack Pribaz Foundation (KCNq2)

- KCNQ2 Cure Alliance
- LGS Foundation
- Mickie's Miracles
- My Epilepsy Story
- The NORSE Institute
- PCDH19 Alliance
- Phalen-McDermid Syndrome Foundation
- Project 8P
- Ring14 USA Outreach, Inc.
- SLC6A1 Connect
- Seizure Tracker
- Syngap Research Fund
- TESS Research Foundation
- Tuberous Sclerosis Complex Alliance
- Wishes for Elliott

## **Professional Societies**

- American Clinical Neurophysiology Society
- American Epilepsy Society
- International League Against Epilepsy
- National Association of Epilepsy Centers

## **Federal Agencies**

- Centers for Disease Control and Prevention
- National Institute of Neurological Disorders and Stroke
- Veterans' Health Administration Epilepsy Centers of Excellence

# Research & Advocacy

Historically, ELC areas of work.



# Epilepsy Research Connection

Developed by the ELC, the Epilepsy Research Connection is a growing group of non-profit and government organizations focused on providing funding for epilepsy related research.

The ERC website provides a single place for researchers to search for funding.

<https://epilepsyresearchconnection.org/>

# Research Grant Partnerships

- Several ELC organizations fund or co-fund AES early career and established investigator awards related to their specific research interest



Phelan-McDermid Syndrome Foundation



Treatments for Epilepsy & Symptoms of SLC13A5



2020 - The Year of the “Pivot”

# 1. New Governance Structure Established: Steering Committee

- Chair: Amy Brin, MSN, MA, PCNS-BC from the Child Neurology Foundation
- Vice-chair: Gabi Conecker, MPH from Wishes for Elliott
- Immediate Past Chair (ex-officio): Christi Heck, MD, MMM, FAES from the National Association of Epilepsy Centers
- Members:
  - Dave Clarke, MD from National Association of Epilepsy Centers
  - Beth Dean, MBA, MPA from CURE Epilepsy
  - Brandy Fureman, PhD from the Epilepsy Foundation
  - Jennifer Burke from the FamilieSCN2A Foundation
  - Gabrielle Rushing, PhD from the TSC Alliance
- Federal Liaison: Vicky Whittemore, PhD from NINDS



## 2. Advocacy Sustained: Bringing patient voice to Research Benchmarks Workgroup for CTE


- Co-Chairs:
  - Laura Lubbers, PhD, CURE Epilepsy
  - Ilene Penn Miller, JD, LLM, Rare Epilepsy Network (REN)
- Members:
  - Mary Anne Meskis, Dravet Syndrome Foundation
  - JayEtta Hecker, Wishes for Elliott
  - Monika Jones, JD, The Brain Recovery Project: Childhood Epilepsy Surgery Foundation
  - Heidi Grabenstatter, PhD, International Foundation for CDKL5 Research
  - Brandy Fureman, PhD, Epilepsy Foundation
  - Steve Roberds, PhD, Tuberous Sclerosis Complex Alliance
  - Vanessa Vogel-Farley, Dup15q Alliance

# Advocate Commentary

- AES Epilepsy Research Benchmarks Stewards Committee Co-chairs wrote commentary on CTE and invited advocates to draft a companion commentary to submit to Epilepsy Currents
- *Epilepsy Community at an Inflection Point: Translating Research Toward Curing the Epilepsies and Improving Patient Outcomes*
  - Translating research gains into improved patient outcomes
  - Opportunities to accelerate research and patient-centered outcomes for the epilepsy community

### 3. Leveling Up: As an Advocacy Coalition

- Consensus -building process reflecting the “We”, and not a “Me”
- Prioritization conversations to define who we are AND who we are not to the larger community
- Professional development opportunities for members
- Establishment of essential membership processes and procedures to ensure efficient and productive functionality

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The more complex the world becomes,  
the more difficult it is to accomplish  
something without the cooperation with  
others.

- Alexander Fleming, MD