

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







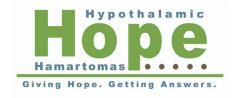
















2020 - The Year of the "Pivot"

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

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

- Alexander Fleming, MD