



epilepsy  
leadership council

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iCARE

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# Epilepsy Leadership Council (ELC)

- ▶ Formerly Vision 20-20: Grew out of collaborative efforts related to IOM report on epilepsy 2012

**Recommendation 12:** *“The member organizations of Vision 20-20 should continue their collaborative endeavors and further these efforts by expanding ongoing working groups that aim to advance the field, support people with epilepsy and their families, and educate the public.”*

## Recommended Areas of Focus:

- *health policy, health reform, and advocacy;*
  - *surveillance and epidemiologic and health services research;*
  - *health care and community resources and services;*
  - *education of health professionals;*
  - *education of people with epilepsy and their families; and public education and awareness.*
- ▶ **Now Composed of 30+ organizations, including:** Patient Advocacy Groups, Professional Societies, Government Agencies
- ▶ **Continues to support IOM recommendations & primary areas of focus are:**
    - Research
    - Advocacy
    - Capacity-building

# Research Highlights

- ▶ **Providing input to the Benchmarks Stewards Committee in preparation for the NINDS Curing the Epilepsies Conference in 2020**
  - **Workgroup chairs:** Ilene Miller (Hope for Hypothalamic Hamartomas) & Laura Lubbers, PhD (CURE)
  - ELC member organizations established this as a major priority. After an open call, the ELC workgroup was formed with representatives from several member organizations
  - This is the first time ELC is providing feedback as a coalition
  - Working with leadership of Benchmarks Stewards Committee and NINDS & AES staff to provide meaningful input including
    - Feedback on the agenda for Curing Epilepsies 2020
    - Feedback on future research priorities within each area
    - A patient advocate vignette within each benchmark area review
    - An option of an ELC patient advocate editorial to go alongside the review articles
  - Important opportunity to incorporate the voice of patients and advocacy community

# Advocacy Highlights

- ▶ ELC had not previously had any formal unified policy positions or advocacy priorities
- ▶ **Advocacy workgroup led an effort to draft a policy agenda that contained an overview of ELC's policy priorities**
  - Involved review of advocacy efforts and policy positions of individual ELC member groups & assessment of policy issues with widespread support within the coalition
- ▶ Draft was formally approved by ELC's membership & will now serve as the foundation for future advocacy efforts

# Community, Collaboration & Capacity-building

- ▶ Idea-sharing allows groups to learn from each other, avoid ‘recreating the wheel,’ and maximize the use of limited resources
- ▶ Coalition members provide support for each other and have been willing to share lessons learned from their organization’s success & failures
- ▶ Exciting new resources in development to help facilitate communication among the ELC members, for example:
  - Coalition newsletter - will include meeting information from individual groups, examples of new programs, initiatives, and collaboration between organizations
  - New listserv tool - will enable easier communication between member representatives

# Community, Collaboration & Capacity-building

- ▶ **Reactivation of collaborative ELC project - Epilepsy Research Connection (ERC)**
- ▶ ERC intended to be “one-stop shopping” site for epilepsy researchers
- ▶ ELC members ranging from NINDS to small, rare disease advocacy organizations can post epilepsy-related research grants
- ▶ **Relaunch of site**
  - Same look and “feel” of original site
  - Streamlined login process for organizations and researchers (SSO with myAESnet.org)
  - Increased data security measures
- ▶ **Next steps - final testing, updating grant information, directing researchers to site**

# Community, Collaboration & Capacity-building

- ▶ Exciting examples of independent collaboration between member organizations:
  - **Sodium Channel Coalition** - includes Dravet Syndrome Foundation, Families SCN2A Foundation & Wishes for Elliott - hosted workshop for top researchers
  - **Collaborative Multi-institutional Research** - FamiliesSCN2A Foundation, Jack Pribaz Foundation, & KCNQ2 Alliance - better diagnosis of babies with early seizures
  - **Research co-funding** - Joint funding of research by the American Epilepsy Society with the Epilepsy Foundation and with other funding partners focused on rare diseases



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