PARTNERING TO IMPROVE OUTCOMES

ELHS CEC MEMBER OPPORTUNITIES
- Participate in surveys describing your priorities.
- Be part of a local site improvement team.
- Provide feedback on draft documents and materials.
- Educate others about what the ELHS has learned.
- Create new tools, interventions, or contribute to make current tools better.
- Help providers understand the views and needs of people with epilepsy, families, and caregivers.
- Help people with epilepsy, families and caregivers learn how to navigate health care systems.

ELHS CEC MEMBER BENEFITS
- Develop new leadership skills.
- Make a difference for people living with epilepsy in your community.
- Engage with your local epilepsy program.
- Enhance connections with your medical providers and their peers.
- Meet other people living with epilepsy and their families and caregivers.
- Participate in and lead sessions designed specifically for people living with epilepsy.

THE ELHS COMMUNITY ENGAGEMENT CORE (CEC)
The CEC, made up of people living with epilepsy and their families, is a critical part of the ELHS. The group engages people with epilepsy and others from across the epilepsy community by giving them the opportunity to share their experiences, needs, hopes, successes, and challenges with the ELHS Team. CEC members help define the priorities of the Learning Network. Current areas of focus are listed on the back of the flyer.

CONSIDER JOINING THE CEC!
At individual epilepsy centers, there will be more volunteer opportunities for CEC members to get involved at their local sites and within the larger group. By participating in the ELHS with your local health care team, you will help them learn from you and your experience with epilepsy.

To join the CEC, contact ELHS@efa.org

30% of people living with epilepsy do not have seizure control.

Epilepsy often goes undiagnosed or is misdiagnosed.
Epilepsy affects people of all ages and is the 4th most common neurological disease. 30% of people living with epilepsy do not have seizure control. Epilepsy often goes undiagnosed or is misdiagnosed. For people with epilepsy, there is often:

- A lack of access to specialized care
- Under-usage of effective treatments
- Health issues in addition to seizures that go unaddressed
- Higher rates of death and disability than in the general population

The Epilepsy learning Health System (ELHS) is looking to change these issues. The ELHS is building a quality improvement and research network to improve outcomes for children and adults with epilepsy.

“The improvement of healthcare related to epilepsy is a major priority for the Dup15q Alliance. While the ELHS has so much potential to change the quality of care, the need for community engagement is paramount. The Dup15q Alliance is dedicated to using our voice to ensure that improvements of epilepsy care address the needs of as many patients as possible.”

VANESSA VOGEL-FARLEY
REN PARTNER

“I will never forget hearing the words ‘You have epilepsy.’ I felt so confused and alone. It’s helpful being able to share experiences, struggles, and successes with others in our community.”

JESSICA VEECH, EF NORTHWEST

Epilepsy is the 4th most common neurological disease and affects people of all ages.

CONTACT ELHS:
ELHS@EFA.ORG

To learn more visit us at: Epilepsy.com/ELHS