Learning from every patient with Epilepsy

By connecting epilepsy centers with each other and with community service providers, and including people with epilepsy and their families, the ELHS will empower all people with epilepsy to live their highest quality of life, striving for freedom from seizures and side effects.

ELHS centers learn from every patient at every visit. Data is gathered from ELHS clinics across the country into a registry. The data is analyzed centrally to find best practices that will lead to better outcomes for patients and their families.

At each center, site improvement teams will facilitate learning sessions. Monthly webinars will be held in which providers can share improvement on practices with the entire network. New ideas are generated and tested in ELHS centers using iterative Plan-Do-Study-Act (PDSA) cycles. Patients and families are integrated at every step to drive priorities, design new initiatives, and provide insight.

ELHS strives to improve quality of life and to reduce or eliminate seizures for all people with epilepsy.

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

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 THAT.

With the support of the Epilepsy Foundation, the National Association of Epilepsy Centers, the Patient Centered Outcomes Research Institute, the James M. Anderson Center for Health Systems Excellence, the Center for Disease Control and Prevention (CDC), and other sustaining partners, the ELHS is building a quality improvement and research network dedicated to improving outcomes for children and adults with epilepsy.
The ELHS plans to offer the following tools to its members:

**PRE-VISIT PLANNING:**
PVP reports summarize key patient information and ensure prerequisites for patient visits (lab tests, screenings, and others) are met before the encounter so clinicians can provide optimum care by proactively planning for and addressing patients’ clinical status.

**POPULATION MANAGEMENT:**
ELHS members will have access to PM reports in the registry. The PM Tool enables centers to better stratify their patient population and immediately identify and care for patients at risk.

**COMMUNITY ENGAGEMENT:**
People with epilepsy and caregivers will receive coaching to participate in local QI activities so they can use their personal situation to help others and support centers efforts.

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**THE LEARNING NETWORKS MOVEMENT**

“When medical evidence is imperfect, and its application must account for preferences, a collaborative approach by providers and patients is essential. The nation needs a healthcare system that learns.”

Institute of Medicine Roundtable on Evidence-Based Medicine

**MAKE A DIFFERENCE IN THE FUTURE OF A PERSON**
Join the ELHS and help us transform healthcare all over the country as we seek out ways to improve health and outcomes for patients with epilepsy.

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**CONTACT ELHS:**
CONTACT US AT ELHS@EFA.ORG

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

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**Areas of Focus**
The ELHS has identified high impact outcomes to focus on and improve:

**SEIZURE CONTROL:**
We plan to increase the percentage of epilepsy visits in which seizure frequency and severity is documented, as well as the percentage of patients who have met their goal for seizure reduction and seizure freedom.

**QUALITY OF LIFE:**
ELHS will work together with centers and communities to support people with epilepsy and their families with seizure documentation, self-management and quality of life. Together we will identify aspects of care and outcomes that most influence patient and caregiver sense of well-being and integrate these ideas seamlessly in all our work.

**TREATMENT ADHERENCE:**
ELHS will pursue identification and overcoming of barriers to treatment adherence, recognizing it as one of the critical factors in seizure control and quality of life.

**SCREENING AND TREATMENT OF DEPRESSION AND ANXIETY:**
Reported prevalence of depression in patients with epilepsy ranges from 13 to 35%, higher among patients with uncontrolled epilepsy. The ELHS centers are dedicated to developing systems to identify and treat depression and anxiety for all patients seen in the network.

**STATUS EPILEPTICUS:**
We will work together to prevent and terminate status epilepticus by deploying interventions that reduce the time from recognition of seizure to management.

**PATIENT TRANSITION FROM PEDIATRIC TO ADULT CARE:**
We believe that it is essential to provide adequate care to every person living with epilepsy at all stages of life. We plan to increase the number of people who have received evidence-based management of transition of care.

**COUNSELING ON CONTRACEPTION AND PREGNANCY:**
Other ELHS goals include decreasing the percentage of unplanned pregnancies in women with epilepsy, establishing proper pregnancy planning, and ensuring appropriate care in all pregnant women with epilepsy.

**Benefits of Joining ELHS**
ELHS provides to participating teams:

- Monthly data reports for both team-specific and network aggregate outcomes.
- Ongoing training in Improvement Science methodology and tools.
- A diverse forum with which to collaborate alongside a growing family and patient engagement initiative.
- Access to population management and pre-visit planning tools.
- Closer connections to the patient support programs offered by community service providers.
- Shared clinical tools, documents, processes and best practices on network-wide action-oriented calls, over a secure platform, and in person at face-to-face learning sessions with nurses, physicians, other clinical staff, researchers, community service providers, and families.

ELHS is one of four PCORI Learning Networks, which receive coaching support from the James M. Anderson Center for Health Systems Excellence at Cincinnati Children’s Hospital Medical Center. www.cincinnatichildrens.org/andersoncenter

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