



# The Epilepsy Patient Engagement Continuum: Highlighting Engagement Strategies from National, State and Local Programmatic Efforts

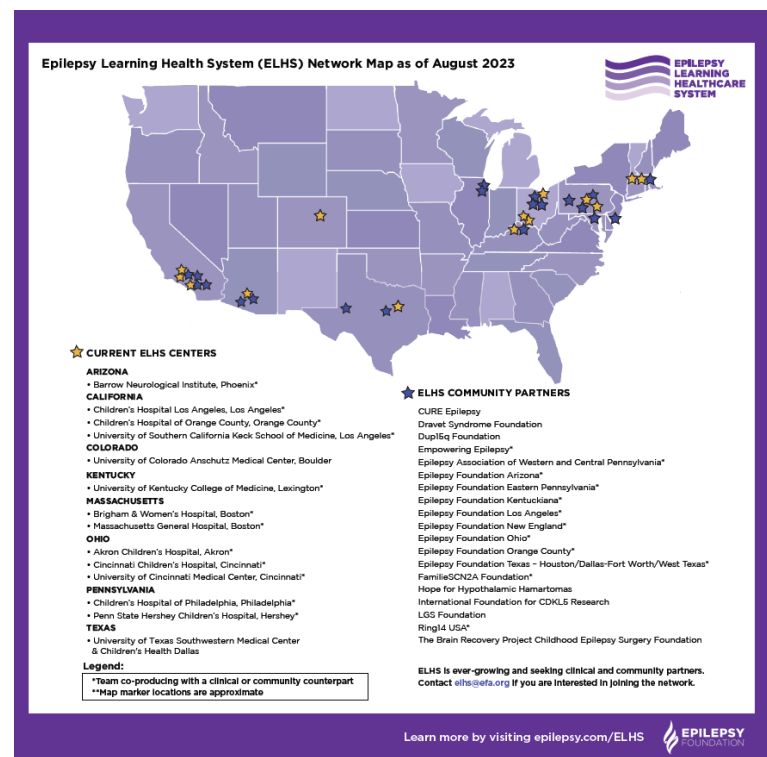
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## Executive Summary

Epilepsy is a chronic disorder of the brain that causes seizures. In 2021, 1.1% of the total US population had active epilepsy. This is about 3.4 million people with epilepsy nationwide: 3 million adults and 470,000 children. Epilepsy is the 4th most common neurological problem, yet diagnosis and treatment are often delayed or inadequate. Fifty-six percent of people reporting seizures continue to have seizures despite treatment. Additionally, only 1 out of 3 are being treated by a neurologist or epileptologist. These simple facts highlight the disparities in care facing people with seizures and epilepsy that leads to poor quality or delays in epilepsy care.

Patient engagement is essential for achieving better health outcomes, enhancing patient experiences and promoting more efficient healthcare delivery. It includes various interactions and behaviors where patients actively participate in managing their health with increased self-efficacy, confidence in decision-making and better adherence to treatment plans. The Epilepsy Foundation of America (EFA) and its Network of affiliates, partners and collaborators have been engaging patients to address epilepsy-related disparities and improve health outcomes.

Source: OSP. Riken Shah. 2024



## Recipients of Engagement Services

This poster offers insights into patient engagement efforts in healthcare settings, community services, and supportive programs. Patients discussed in these projects are adults and youth living with epilepsy who are seeking medical care for seizures and related health issues and/or reached out for additional services, including grief counselling due to losing someone through seizure-related death.

## Patient Engagement Strategies and Campaigns

### NATIONAL:

#### Epilepsy Learning Healthcare System (ELHS)

ELHS was founded on the practice of co-production (where people with epilepsy and their families are equal partners with clinicians) and connecting pediatric and adult epilepsy centers with each other and with community service providers,

#### SUDEP and Bereavement Services

The EFA SUDEP Program offers a variety of bereavement support services for individuals and families who have lost a loved one due to epilepsy. These services include 1:1 bereavement support with certified grief counselors and two online Bereavement Support Groups – one for Adults (27+) and one for Young Adults (18 – 26).

### STATE:

#### Florida Epilepsy Services (FES)

- **FLORIDA EPILEPSY MEDICATION PROGRAM:** FES partners with the Florida Department of Health so clients may access unaffordable epilepsy medications and maintain seizure control.
- **FLORIDA SPANISH SUPPORT GROUPS:** Hybrid monthly groups in Spanish allow underserved Spanish-speakers access to information, education, and advocacy while reducing isolation and unmet social needs.
- **CLINIC DAYS AT NEUROLOGY OFFICES:** Case managers visit local neurology offices to meet with patients and clients to update and follow up on their annual review progress.

### HEALTHCARE / COMMUNITY:

EFA serves on the advisory council of the National Coordinating Center for Epilepsy of the American Academy of Pediatrics. The Center has grantees in 7 states to address epilepsy disparities among children and young adults living with epilepsy and their families. Two of these grantees from healthcare settings have provided examples of their patient engagement efforts.

#### Boston Medical Center (BMC)

**HYPE PEERS** epilepsy awareness and anti-stigma Instagram campaign, included 5 youth with epilepsy as Campaign Ambassadors created content highlighting their personal stories and diverse lived experiences with epilepsy.

**Mighty Networks** platform hosted online, moderated social cohort community for youth with epilepsy. This micro-community is centered around 8-week social-emotional learning curriculum, including topics such as goal-setting and social identity.

#### Children's Hospital of Philadelphia (CHOP)

**Medication Matters** is an interactive, online scenario-based game that walks patients through a series of events to help them manage their medication - from getting a prescription to setting reminders to take their meds. The game was created in collaboration with Youth Advisory Council to make sure it meets the needs of adolescent and young adult population living with epilepsy.



## Outcomes & Conclusion

With currently 14 pediatric and adult clinical centers, various tools have been coproduced between clinicians and Patient Family Partners (PFPs), including a **Telemedicine Visit Checklist**, **Barriers to Medication Adherence Screening Tool** and corresponding tools to address various barriers, publications and more. PFPs bring the important lived experience perspective to identification of outcomes that matter, and Quality of Life is the next up for ELHS.

As a member of ELHS, CHOP is active in Quality Improvement (QI) activities. Alongside the EFA's national 24/7 Helpline and the EF Eastern Pennsylvania, they are piloting a **closed-loop referral system** by which children with epilepsy being seen at CHOP can be referred by their provider to community-based services. This work lends itself to **improved access to resources such as food, housing, transportation and medication supports**, as well as enhanced communication between the clinic and community elements of care and quality of life.

SUDEP and bereavement support groups have helped people to feel less isolated in their grief. The **8-week Grief Recovery Method Program** is an evidence-based and action-oriented program designed to help people acknowledge, process, and move through the pain caused by death. It will be offered annually due to the successful response of the initial cohort.

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### FOR MORE INFORMATION CONTACT:

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