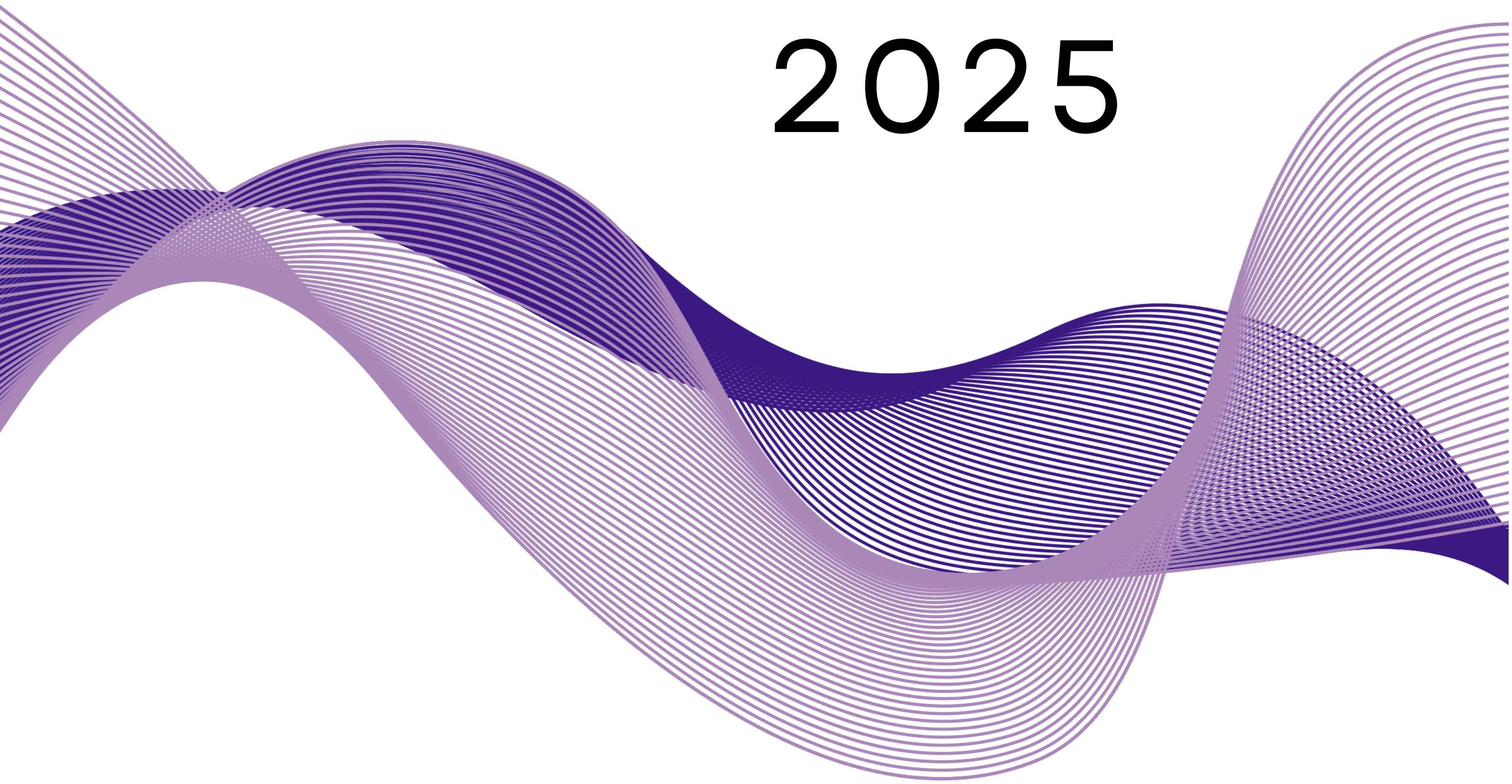
EPILEPSY
LEARNING
HEALTHCARE
SYSTEM

STATE OF ELHS REPORT

2025



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ELHS: TURNING ASPIRATIONS INTO STANDARD PRACTICE

MESSAGE FROM THE COORDINATING CENTER

Pushing forward, Powering growth, Pursuing improvement

2025 has been a year of several firsts and a great deal of fortitude for the Epilepsy Learning Healthcare System (ELHS). The dedicated providers and Patient Family Partners (PFPs) in ELHS remain focused on a mission to improve seizure control and quality of life for all people with epilepsy.

The ELHS network has been administratively housed at the Epilepsy Foundation since its launch in 2019. This year, facing EF budget constraints and the current climate of federal funding uncertainty, ELHS Operations made a difficult decision to stop individual-level PHI data collection and sunset the central ELHS Registry. The Registry has been housed at the MGH Data Coordinating Center (DCC) since late 2021. The DCC team led by Lidia Moura worked closely with sites to create avenues for data submission and aggregated the data to optimize real-time learning from population health reports. The 2019-2025 Registry Population Health Dashboard is available here. **Julianne Brooks, Aya El Hassan, Andrea Donahue, Anjana Rayapureddy** and several past team members have been central to building ELHS recognition, powering publications and personifying the network core value of achieving more together than alone. As of December, they are finalizing delivery of site-level datasets back to originating sites and working with the Epilepsy Foundation on the final Registry closure processes. The DCC team will continue working on the **Health Equity Research in Neuroscience (HERN)** grant analyses of Registry data over the next 18 months and planning additional epilepsy health equity grant applications. Please join us in expressing our gratitude to the DCC for their tremendous work! A de-identified dataset of the Registry data remains available for secondary research analyses by ELHS participants – please contact elhs@efa.org if interested.

Accomplishments this year include completion of ELHS' first industry-sponsored research collaboration with **Jazz Pharmaceutical**s, creation of a **Community Engagement Specialist EMU Toolki**t, two in-person **Learning Session**s in Dallas and Philadelphia, four abstracts at the American Epilepsy Society annual meeting in Atlanta, renewed momentum in the **Tonic, Clonic Seizures Reduction Projec**t, and new champions joining the network.

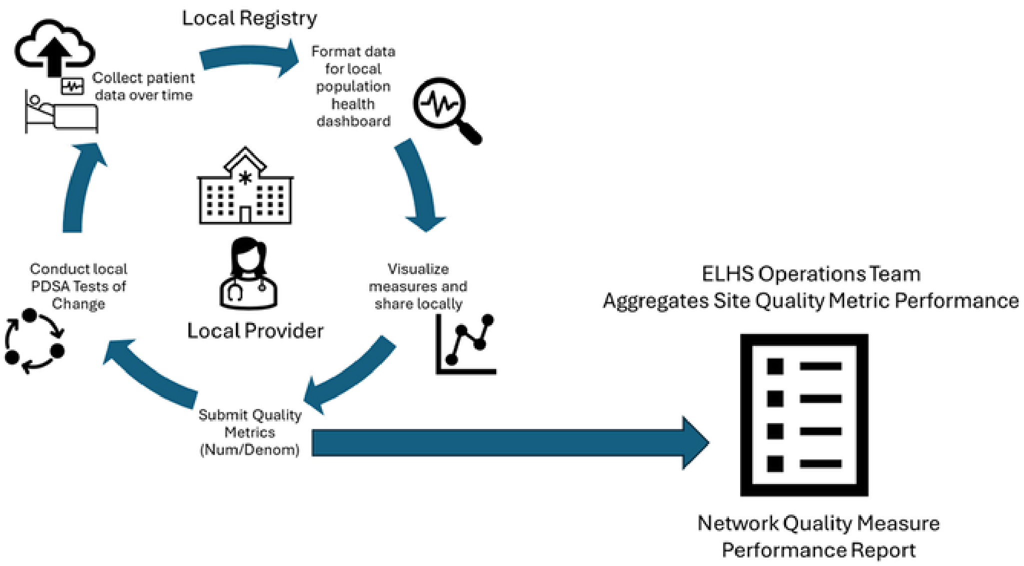
Shared solutions for faster progress

Moving forward, ELHS has reframed membership from site-level to provider-level to harness the energy of motivated improvers and provide them a platform to share learnings among others in the epilepsy and neurology field. Simplified data submission of numerators and denominators-only and the elimination of an annual membership fee address identified barriers to membership. The Operations Team will create network charts, and provide site-level support for providers, to continue the identification of improvements and opportunities.

Brandy Fureman, PhD
ELHS Principal Investigator

Kathleen Farrell, MB BCh BAO
ELHS Executive Director

Jeffrey Buchhalter, MD, PhD
ELHS Quality Improvement Lead



Elevating the standard of healthcare

We are proud to convene this network of improvers, whose dedication has shone through peaks and valleys on the journey together that began in 2018, whose focus has remained on the network North Star: that all people with epilepsy can live their highest quality of life, striving for freedom from seizures and side effects – and we won't stop until we get there.

We have much to continue share and learn together, and we sincerely thank you for your partnership. If you're interested in joining the ELHS movement for improvement, we can't wait to connect with you.

Onward!

ON BEHALF OF THE ELHS OPERATIONS TEAM

Brandy

Brandy Fureman, PhD
ELHS Principal Investigator
Chief Outcomes Officer
Epilepsy Foundation

Kathleen

Kathleen Farrell, MB BCh BAO
ELHS Executive Director
Vice President, Public Health Outcomes
Epilepsy Foundation

Lidia Moura, MD, PhD, MPH
ELHS Data Coordinating Center Lead

Scott Badzik
ELHS Community Council Co-Chair

Adriana Sartorio, MS
ELHS Community Council Co-Chair

Registry Population Health Report

Insights from the over 43,000 individuals in the ELHS registry are available in this Registry Population Health Report.

Measures including Seizure Frequency Documentation, Barriers to Medication Adherence, Anxiety and Depression Screening, Quality of Life, Demographics, Social Determinants of Health and more are available.

HERN Update

HERN COMMUNITY-ENGAGED HEALTH EQUITY RESEARCH IN NEUROSCIENCE

The Epilepsy Foundation of America (EFA), together with Massachusetts General Hospital and additional collaborators, has launched a planning grant aimed at developing a heath disparity research agenda for epilepsy. Under the direction of Dr. **Brandy Fureman**, PhD (Chief Outcomes Officer, Epilepsy Foundation) and Dr. **Lidia Moura**, MD, PhD, MPH (Associate Professor of Neurology, Harvard Medical School, Associate Professor of Epidemiology, Harvard T.H. Chan School of Public Health, Director of Population Health, Neurology Department, Mass General Brigham, and Co-Director, Center for Value-based Healthcare and Sciences, Massachusetts General Brigham) the Foundation was awarded planning grant funding from the National Institute of Neurological Disorders and Stroke (NINDS) to address disparities in epilepsy outcomes, with an initial focus on understanding the local drivers of epilepsy disparities for Black and African American people with epilepsy, as part of the Community-Engaged HERN Initiative to address neurological health disparities awarded by NIH/NINDS. While the NINDS program funds studies across multiple neurological conditions, including multiple sclerosis and stroke, this is the only grant focused specifically on addressing disparities in epilepsy.

Although epilepsy affects people across all demographic groups, decades of research have shown that the burden is not equally shared. Differences in outcomes, which are shaped by socioeconomic status, geography, race and ethnicity, and access to adequate health insurance, contribute to higher rates of mental health challenges, emergency department use, hospitalization, and early mortality. These disparities also reflect deeper systemic barriers that reduce access to high-quality, coordinated care.

This grant seeks to understand what drives these differences within local communities and to map out pathways for meaningful intervention. The central focus of the project is the development of new community-focused survey tools designed to identify the barriers that prevent people with epilepsy from receiving timely and effective care. These tools will help measure the impact of socioeconomic factors, health system navigation challenges, neighborhood environments, and other structural barriers. Once developed, they will be tested locally and refined into toolkits that can be used in other communities across the Epilepsy Learning Healthcare System (ELHS) network and beyond.

"This planning grant represents a critical step in addressing the disparities that have persisted for far too long in epilepsy care," said **Thometta Cozart**, MPH, MS, CPH, CHES, Senior Director of Multicultural Outreach and Health Equity at the Epilepsy Foundation. "Communities most affected by disparities have repeatedly told us that solutions must be shaped with them, not simply delivered to them. This includes ensuring that the experiences of Black and African American patients, who face some of the greatest barriers to care, are centered in our work. We are eager to begin our work with this grant to ensure that equitable, high-quality support reaches every person with epilepsy, no matter their background or circumstances."

HERN Update

The project strengthens collaborative capacity within ELHS, a national network advancing epilepsy care through quality improvement and co-production with patients, families, clinicians, and researchers, directed by Dr. Fureman. With data analytics expertise from Mass General's team directed by Dr. Moura, the grant brings together expertise in implementation science, epidemiology, neurology, community engagement, and patient advocacy. This multidisciplinary approach supports the development of rigorous methods to engage local community partners and patient/family advisors, identify and monitor disparities in real time, and prepare for future large-scale interventions.

A key contributor to the community engagement work is **Tonya Nash**, MPH, CHES, Chair of the Advisory Committee. The Advisory Committee consists of people living with epilepsy, caregivers, epilepsy providers, and community engagement researchers. Tonya's lived experience as a caregiver for her son with Lennox-Gastaut Syndrome, a rare form of epilepsy, informs her approach to supporting the grant's mission. "As both a parent of a child with Lennox-Gastaut Syndrome and Chair of the Advisory Committee, I've seen firsthand how deeply disparities impact families," said Tonya. "We're not just being consulted. We are co-producing this work from the ground up. Our perspectives are shaping the questions being asked, the tools being created, and the solutions that will emerge. Communities are not an afterthought; we are essential partners in transforming epilepsy care."

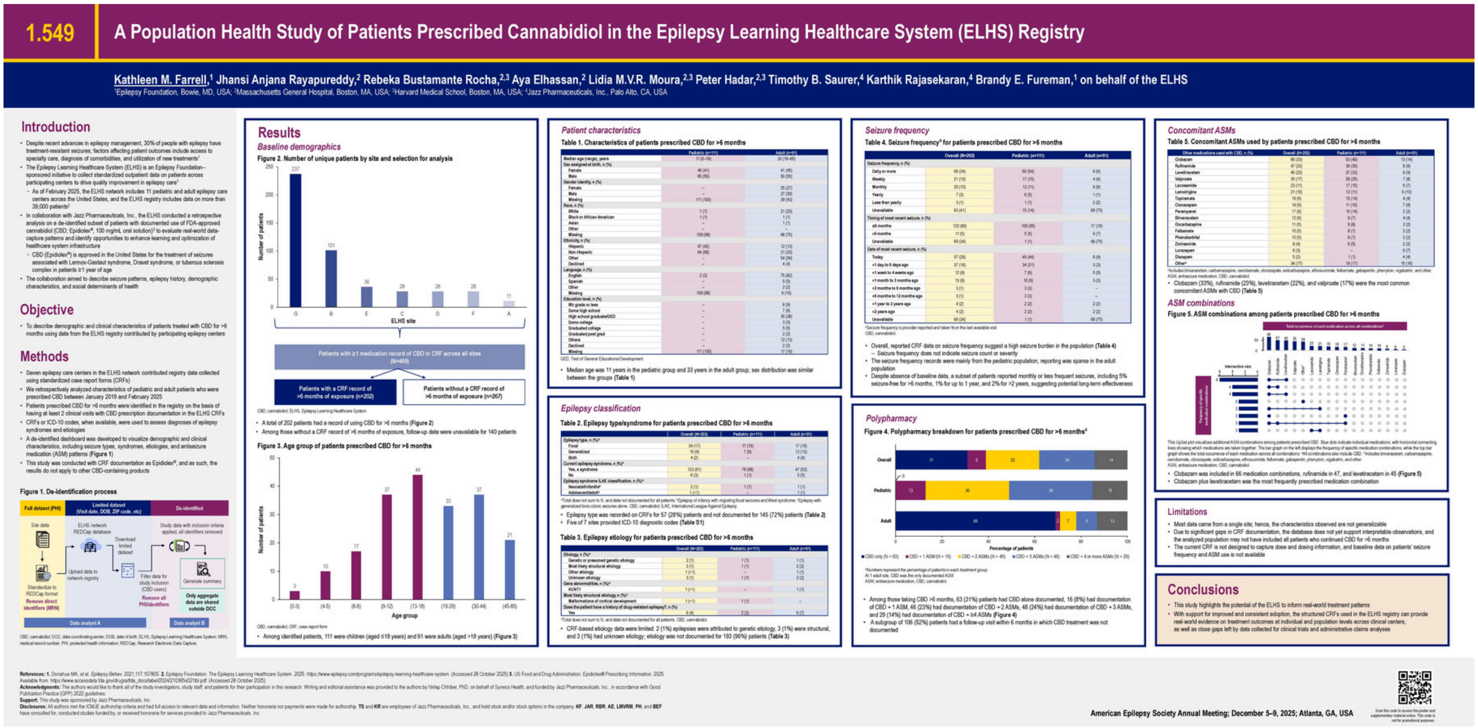
Through this grant, the team will build the infrastructure needed to conduct longitudinal studies on epilepsy outcomes with ELHS centers and their community partners. By piloting interventions locally and creating scalable toolkits, the project aims to extend successful approaches to reduce disparities across the national ELHS network and into new settings.

This initiative aligns with and will feed directly into the quality-improvement framework of ELHS, ensuring that the findings and toolkits developed through this effort contribute to continuous improvement in epilepsy care.

HERN Working Breakfast at AES: (L to R): Porsha Hall (Morehouse School of Medicine), Kathleen Farrell, Shelkecia Lessington, Brandy Fureman, Tonya Nash, Thometta Cozart, Rakale Quarells (Morehouse School of Medicine), Brian Gilchrist

Power in Partnerships

In collaboration with **Jazz Pharmaceuticals** this year, ELHS conducted a retrospective analysis of patients with epilepsy treated with Epidiolex for at least 6 months, with an aim to describe demographic and clinical characteristics and concomitant use of other antiseizure medications (ASMs). Thank you to **Karthik Rajasekaran**, PhD of the Medical Affairs team for partnering on this secondary analysis. Check out learnings from this project in this poster presented at AES:



1.549 A Population Health Study of Patients Prescribed Cannabidiol in the Epilepsy Learning Healthcare System (ELHS) Registry

Kathleen M. Farrell,[1] Jhansi Anjana Rayapureddy,[2] Rebeka Bustamante Rocha,[2,3] Aya Elhassan,[2] Lidia M.V.R. Moura,[2,3] Peter Hadar,[2,3] Timothy B. Saurer,[4] Karthik Rajasekaran,[4] Brandy E. Fureman,[1] on behalf of the ELHS
[1]Epilepsy Foundation, Bowie, MD, USA; [2]Massachusetts General Hospital, Boston, MA, USA; [3]Harvard Medical School, Boston, MA, USA; [4]Jazz Pharmaceuticals, Inc., Palo Alto, CA, USA

Introduction

- Despite recent advances in epilepsy management, 30% of people with epilepsy have treatment-resistant seizures; factors affecting patient outcomes include access to specialty care, diagnosis of comorbidities, and utilization of new treatments[1]
- The Epilepsy Learning Healthcare System (ELHS) is an Epilepsy Foundation–sponsored initiative to collect standardized outpatient data on patients across participating centers to drive quality improvement in epilepsy care[1]
  - As of February 2025, the ELHS network includes 11 pediatric and adult epilepsy care centers across the United States, and the ELHS registry includes data on more than 39,000 patients[2]
- In collaboration with Jazz Pharmaceuticals, Inc., the ELHS conducted a retrospective analysis on a de-identified subset of patients with documented use of FDA-approved cannabidiol (CBD; Epidiolex®, 100 mg/mL oral solution)[3] to evaluate real-world data-capture patterns and identify opportunities to enhance learning and optimization of healthcare system infrastructure
  - CBD (Epidiolex®) is approved in the United States for the treatment of seizures associated with Lennox-Gastaut syndrome, Dravet syndrome, or tuberous sclerosis complex in patients ≥1 year of age
- The collaboration aimed to describe seizure patterns, epilepsy history, demographic characteristics, and social determinants of health

Objective

- To describe demographic and clinical characteristics of patients treated with CBD for >6 months using data from the ELHS registry contributed by participating epilepsy centers

Methods

- Seven epilepsy care centers in the ELHS network contributed registry data collected using standardized case report forms (CRFs)
- We retrospectively analyzed characteristics of pediatric and adult patients who were prescribed CBD between January 2019 and February 2025
- Patients prescribed CBD for >6 months were identified in the registry on the basis of having at least 2 clinical visits with CBD prescription documentation in the ELHS CRFs
- CRFs or ICD-10 codes, when available, were used to assess diagnoses of epilepsy syndromes and etiologies
- A de-identified dashboard was developed to visualize demographic and clinical characteristics, including seizure types, syndromes, etiologies, and antiseizure medication (ASM) patterns (**Figure 1**)
- This study was conducted with CRF documentation as Epidiolex®, and as such, the results do not apply to other CBD-containing products

Figure 1. De-identification process

CBD, cannabidiol; DCC, data coordinating center; DOB, date of birth; ELHS, Epilepsy Learning Healthcare System; MRN, medical record number; PHI, protected health information; REDCap, Research Electronic Data Capture.

Results

Baseline demographics

Figure 2. Number of unique patients by site and selection for analysis

CBD, cannabidiol; ELHS, Epilepsy Learning Healthcare System.

- A total of 202 patients had a record of using CBD for >6 months (**Figure 2**)
- Among those without a CRF record of >6 months of exposure, follow-up data were unavailable for 140 patients

Figure 3. Age group of patients prescribed CBD for >6 months

CBD, cannabidiol; CRF, case report form.

- Among identified patients, 111 were children (aged ≤18 years) and 91 were adults (aged >18 years) (**Figure 3**)

Patient characteristics

Table 1. Characteristics of patients prescribed CBD for >6 months

	Pediatric (n=111)	Adult (n=91)
Median age (range), years	11 (0–18)	33 (19–65)
Sex assigned at birth, n (%)		
Female	46 (41)	41 (45)
Male	65 (59)	50 (55)
Gender identity, n (%)		
Female	–	25 (27)
Male	–	27 (30)
Missing	111 (100)	39 (43)
Race, n (%)		
White	1 (1)	21 (23)
Black or African American	1 (1)	1 (1)
Asian	–	1 (1)
Other	–	–
Missing	109 (98)	68 (75)
Ethnicity, n (%)		
Hispanic	47 (42)	12 (13)
Non-Hispanic	64 (58)	21 (23)
Other	–	54 (59)
Declined	–	4 (4)
Language, n (%)		
English	2 (2)	75 (82)
Spanish	–	5 (5)
Other	–	2 (2)
Missing	109 (98)	9 (10)
Education level, n (%)		
8th grade or less	–	8 (9)
Some high school	–	7 (8)
High school graduate/GED	–	35 (38)
Some college	–	3 (3)
Graduated college	–	5 (5)
Graduated post grad	–	2 (2)
Others	–	12 (13)
Declined	–	2 (2)
Missing	111 (100)	17 (19)

GED, Test of General Educational Development.

- Median age was 11 years in the pediatric group and 33 years in the adult group; sex distribution was similar between the groups (**Table 1**)

Epilepsy classification

Table 2. Epilepsy type/syndrome for patients prescribed CBD for >6 months

	Overall (N=202)	Pediatric (n=111)	Adult (n=91)
Epilepsy type, n (%)[a]			
Focal	34 (17)	17 (15)	17 (19)
Generalized	19 (9)	7 (6)	12 (13)
Both	4 (2)	–	4 (4)
Current epilepsy syndrome, n (%)[a]			
Yes, a syndrome	123 (61)	76 (68)	47 (52)
No	6 (3)	1 (1)	5 (5)
Epilepsy syndrome ILAE classification, n (%)[a]			
Neonatal/infantile[b]	2 (1)	1 (1)	1 (1)
Adolescent/adult[c]	1 (<1)	–	1 (1)

[a]Total does not sum to N, and data not documented for all patients; [b]Epilepsy of infancy with migrating focal seizures and West syndrome; [c]Epilepsy with generalized tonic-clonic seizures alone. CBD, cannabidiol; ILAE, International League Against Epilepsy.

- Epilepsy type was recorded on CRFs for 57 (28%) patients and not documented for 145 (72%) patients (**Table 2**)
- Five of 7 sites provided ICD-10 diagnostic codes (**Table S1**)

Table 3. Epilepsy etiology for patients prescribed CBD for >6 months

	Overall (N=202)	Pediatric (n=111)	Adult (n=91)
Etiology, n (%)[a]			
Genetic or presumed genetic etiology	2 (1)	1 (1)	1 (1)
Most likely structural etiology	3 (1)	1 (1)	2 (2)
Other etiology	1 (<1)	–	1 (1)
Unknown etiology	3 (1)	1 (1)	2 (2)
Gene abnormalities, n (%)[a]			
KCNT1	1 (<1)	–	1 (1)
Most likely structural etiology, n (%)[a]			
Malformations of cortical development	1 (<1)	1 (1)	–
Does the patient have a history of drug-resistant epilepsy?, n (%)			
Yes	8 (4)	2 (2)	6 (7)

[a]Total does not sum to N, and data not documented for all patients. CBD, cannabidiol.

- CRF-based etiology data were limited: 2 (1%) epilepsies were attributed to genetic etiology, 3 (1%) were structural, and 3 (1%) had unknown etiology; etiology was not documented for 193 (96%) patients (**Table 3**)

Seizure frequency

Table 4. Seizure frequency[a] for patients prescribed CBD for >6 months

	Overall (N=202)	Pediatric (n=111)	Adult (n=91)
Seizure frequency, n (%)			
Daily or more	68 (34)	60 (54)	8 (9)
Weekly	21 (10)	17 (15)	4 (4)
Monthly	20 (10)	12 (11)	8 (9)
Yearly	7 (3)	6 (5)	1 (1)
Less than yearly	3 (1)	1 (1)	2 (2)
Unavailable	83 (41)	15 (14)	68 (75)
Timing of most recent seizure, n (%)			
≤6 months	122 (60)	105 (95)	17 (19)
>6 months	11 (5)	5 (5)	6 (7)
Unavailable	69 (34)	1 (1)	68 (75)
Date of most recent seizure, n (%)			
Today	57 (28)	49 (44)	8 (9)
>1 day to 6 days ago	37 (18)	34 (31)	3 (3)
>1 week to 4 weeks ago	12 (6)	7 (6)	5 (5)
>1 month to 3 months ago	13 (6)	10 (9)	3 (3)
>3 months to 6 months ago	3 (1)	3 (3)	–
>6 months to 12 months ago	3 (1)	3 (3)	–
>1 year to 2 years ago	4 (2)	2 (2)	2 (2)
>2 years ago	4 (2)	2 (2)	2 (2)
Unavailable	69 (34)	1 (1)	68 (75)

[a]Seizure frequency is provider-reported and taken from the last available visit.
CBD, cannabidiol.

- Overall, reported CRF data on seizure frequency suggest a high seizure burden in the population (**Table 4**)
  - Seizure frequency does not indicate seizure count or severity
- The seizure frequency records were mainly from the pediatric population; reporting was sparse in the adult population
- Despite absence of baseline data, a subset of patients reported monthly or less frequent seizures, including 5% seizure-free for >6 months, 1% for up to 1 year, and 2% for >2 years, suggesting potential long-term effectiveness

Polypharmacy

Figure 4. Polypharmacy breakdown for patients prescribed CBD for >6 months[a]

[a]Numbers represent the percentage of patients in each treatment group.
At 1 adult site, CBD was the only documented ASM.
ASM, antiseizure medication; CBD, cannabidiol.

- Among those taking CBD >6 months, 63 (31%) patients had CBD alone documented, 16 (8%) had documentation of CBD + 1 ASM, 46 (23%) had documentation of CBD + 2 ASMs, 48 (24%) had documentation of CBD + 3 ASMs, and 29 (14%) had documentation of CBD + ≥4 ASMs (**Figure 4**)
- A subgroup of 106 (52%) patients had a follow-up visit within 6 months in which CBD treatment was not documented

Concomitant ASMs

Table 5. Concomitant ASMs used by patients prescribed CBD for >6 months

Other medications used with CBD, n (%)	Overall (N=202)	Pediatric (n=111)	Adult (n=91)
Clobazam	66 (33)	53 (48)	13 (14)
Rufinamide	47 (23)	39 (35)	8 (9)
Levetiracetam	45 (22)	37 (33)	8 (9)
Valproate	35 (17)	28 (25)	7 (8)
Lacosamide	23 (11)	17 (15)	6 (7)
Lamotrigine	21 (10)	12 (11)	9 (10)
Topiramate	19 (9)	15 (14)	4 (4)
Clonazepam	18 (9)	11 (10)	7 (8)
Perampanel	17 (8)	15 (14)	2 (2)
Brivaracetam	12 (6)	8 (7)	4 (4)
Oxcarbazepine	11 (5)	9 (8)	2 (2)
Felbamate	10 (5)	8 (7)	2 (2)
Phenobarbital	10 (5)	8 (7)	2 (2)
Zonisamide	8 (4)	6 (5)	2 (2)
Lorazepam	6 (3)	–	6 (7)
Diazepam	5 (2)	1 (1)	4 (4)
Other[a]	34 (17)	19 (17)	15 (16)

[a]Includes brivaracetam, carbamazepine, cenobamate, clorazepate, eslicarbazepine, ethosuximide, felbamate, gabapentin, phenytoin, vigabatrin, and other. ASM, antiseizure medication; CBD, cannabidiol.

- Clobazam (33%), rufinamide (23%), levetiracetam (22%), and valproate (17%) were the most common concomitant ASMs with CBD (**Table 5**)

ASM combinations

Figure 5. ASM combinations among patients prescribed CBD for >6 months

This UpSet plot visualizes additional ASM combinations among patients prescribed CBD. Blue dots indicate individual medications, with horizontal connecting lines showing which medications are taken together. The bar graph on the left displays the frequency of specific medication combinations, while the top bar graph shows the total occurrence of each medication across all combinations. [a]All combinations also include CBD. [b]Includes brivaracetam, carbamazepine, cenobamate, clorazepate, eslicarbazepine, ethosuximide, felbamate, gabapentin, phenytoin, vigabatrin, and other.
ASM, antiseizure medication; CBD, cannabidiol.

- Clobazam was included in 66 medication combinations, rufinamide in 47, and levetiracetam in 45 (**Figure 5**)
- Clobazam plus levetiracetam was the most frequently prescribed medication combination

Limitations

- Most data came from a single site; hence, the characteristics observed are not generalizable
- Due to significant gaps in CRF documentation, the database does not yet support interpretable observations, and the analyzed population may not have included all patients who continued CBD for >6 months
- The current CRF is not designed to capture dose and dosing information, and baseline data on patients' seizure frequency and ASM use is not available

Conclusions

- This study highlights the potential of the ELHS to inform real-world treatment patterns
- With support for improved and consistent adoption, the structured CRFs used in the ELHS registry can provide real-world evidence on treatment outcomes at individual and population levels across clinical centers, as well as close gaps left by data collected for clinical trials and administrative claims analyses

References: **1.** Donahue MA, et al. *Epilepsy Behav.* 2021;117:107805. **2.** Epilepsy Foundation. The Epilepsy Learning Healthcare System. 2025. https://www.epilepsy.com/programs/epilepsy-learning-healthcare-system. (Accessed 28 October 2025) **3.** US Food and Drug Administration. Epidiolex® Prescribing Information. 2025. Available from: https://www.accessdata.fda.gov/drugsatfda_docs/label/2024/210365s021lbl.pdf. (Accessed 28 October 2025)

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Disclosures: All authors met the ICMJE authorship criteria and had full access to relevant data and information. Neither honoraria nor payments were made for authorship. **TS** and **KR** are employees of Jazz Pharmaceuticals, Inc., and hold stock and/or stock options in the company. **KF**, **JAR**, **RBR**, **AE**, **LMVRM**, **PH**, and **BEF** have consulted for, conducted studies funded by, or received honoraria for services provided to Jazz Pharmaceuticals, Inc.

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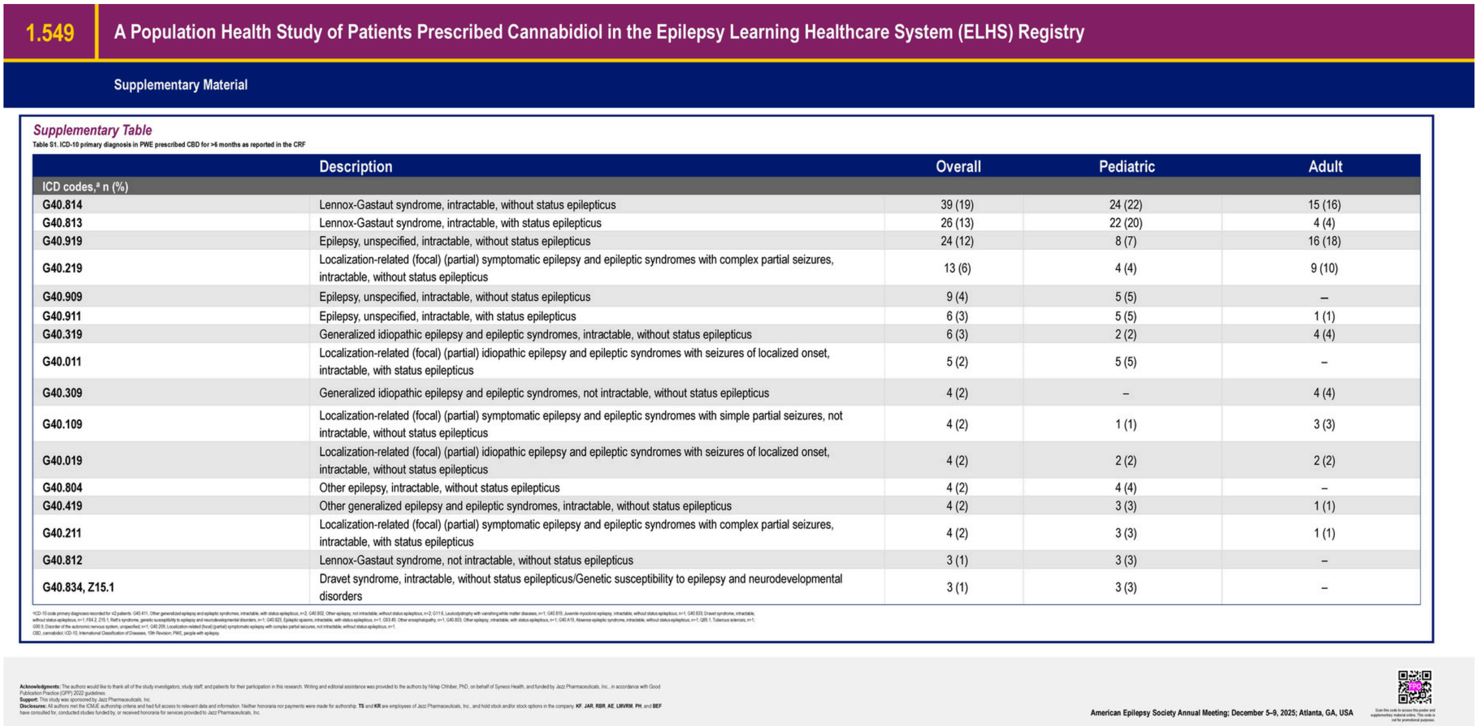

1.549 A Population Health Study of Patients Prescribed Cannabidiol in the Epilepsy Learning Healthcare System (ELHS) Registry

Supplementary Material

Supplementary Table

Table S1. ICD-10 primary diagnosis in PWE prescribed CBD for >6 months as reported in the CRF

	Description	Overall	Pediatric	Adult
ICD codes,[a] n (%)				
G40.814	Lennox-Gastaut syndrome, intractable, without status epilepticus	39 (19)	24 (22)	15 (16)
G40.813	Lennox-Gastaut syndrome, intractable, with status epilepticus	26 (13)	22 (20)	4 (4)
G40.919	Epilepsy, unspecified, intractable, without status epilepticus	24 (12)	8 (7)	16 (18)
G40.219	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, intractable, without status epilepticus	13 (6)	4 (4)	9 (10)
G40.909	Epilepsy, unspecified, intractable, without status epilepticus	9 (4)	5 (5)	–
G40.911	Epilepsy, unspecified, intractable, with status epilepticus	6 (3)	5 (5)	1 (1)
G40.319	Generalized idiopathic epilepsy and epileptic syndromes, intractable, without status epilepticus	6 (3)	2 (2)	4 (4)
G40.011	Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, intractable, with status epilepticus	5 (2)	5 (5)	–
G40.309	Generalized idiopathic epilepsy and epileptic syndromes, not intractable, without status epilepticus	4 (2)	–	4 (4)
G40.109	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with simple partial seizures, not intractable, without status epilepticus	4 (2)	1 (1)	3 (3)
G40.019	Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, intractable, without status epilepticus	4 (2)	2 (2)	2 (2)
G40.804	Other epilepsy, intractable, without status epilepticus	4 (2)	4 (4)	–
G40.419	Other generalized epilepsy and epileptic syndromes, intractable, without status epilepticus	4 (2)	3 (3)	1 (1)
G40.211	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, intractable, with status epilepticus	4 (2)	3 (3)	1 (1)
G40.812	Lennox-Gastaut syndrome, not intractable, without status epilepticus	3 (1)	3 (3)	–
G40.834, Z15.1	Dravet syndrome, intractable, without status epilepticus/Genetic susceptibility to epilepsy and neurodevelopmental disorders	3 (1)	3 (3)	–

[a]ICD-10 code primary diagnoses recorded for ≤2 patients: G40.411, Other generalized epilepsy and epileptic syndromes, intractable, with status epilepticus, n=2; G40.802, Other epilepsy, not intractable, without status epilepticus, n=2; G11.6, Leukodystrophy with vanishing white matter diseases, n=1; G40.819, Juvenile myoclonic epilepsy, intractable, without status epilepticus, n=1; G40.833, Dravet syndrome, intractable, without status epilepticus, n=1; F84.2, Z15.1, Rett's syndrome, genetic susceptibility to epilepsy and neurodevelopmental disorders, n=1; G40.823, Epileptic spasms, intractable, with status epilepticus, n=1; G93.49, Other encephalopathy, n=1; G40.803, Other epilepsy, intractable, with status epilepticus, n=1; G40.A19, Absence epileptic syndrome, intractable, without status epilepticus, n=1; Q85.1, Tuberous sclerosis, n=1; G90.9, Disorder of the autonomic nervous system, unspecified, n=1; G40.209, Localization-related (focal) (partial) symptomatic epilepsy with complex partial seizures, not intractable, without status epilepticus, n=1.
CBD, cannabidiol; ICD-10, International Classification of Diseases, 10th Revision; PWE, people with epilepsy.

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American Epilepsy Society Annual Meeting; December 5–9, 2025; Atlanta, GA, USA

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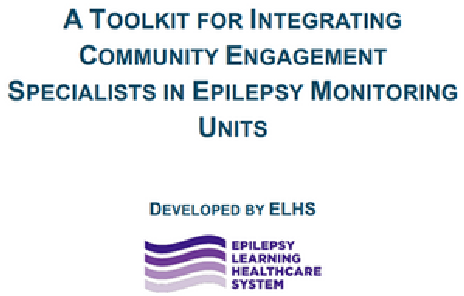
New ELHS Tool: EMU Toolkit

Born from pilot programs led by **ELHS Community Council leader and Patient Family Partner** Scott Badzik at the **University of Cincinnati (leaders Dave Ficker and Anne Paul)** and **Cincinnati Children's Hospital Medical Center (leader Nan Lin)**, the Community Engagement Specialist EMU Toolkit shares insights on how a clinical center can integrate peer education programming to benefit patients admitted to their Epilepsy Monitoring Unit (EMU). If you're interested in learning more, let us connect you with Scott!



A TOOLKIT FOR INTEGRATING COMMUNITY ENGAGEMENT SPECIALISTS IN EPILEPSY MONITORING UNITS

DEVELOPED BY ELHS

EPILEPSY LEARNING HEALTHCARE SYSTEM

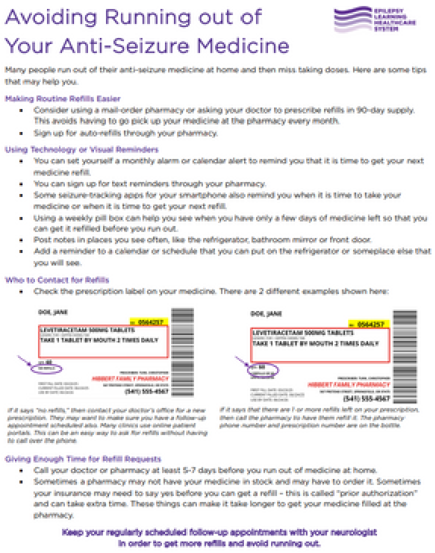
New ELHS Tool: Barriers addition

A new addition to the ELHS Barriers to Medication Adherence Toolkit is now available:

Avoiding Running out of your Anti-Seizure Medications (ASMs). Available in Spanish here.

This resource was adapted from one created by the **UTSW Children's Health Dallas (leaders Deepa Sirsi and Sam Arroyo Solis)**.

Specials thanks goes to the Tonic, Clonic Seizures Reduction Project co-leads **Kelsey Merison (Akron Children's)** and **Sara Molisani (CHOP)**, QI advisor **Jeff Buchhalter** and members of that workgroup who co-produced this tool (co-production = community and clinician partnership) and continue to develop interventions for people with uncontrolled tonic and/or clonic seizures.



Avoiding Running out of Your Anti-Seizure Medicine

EPILEPSY LEARNING HEALTHCARE SYSTEM

Many people run out of their anti-seizure medicine at home and then miss taking doses. Here are some tips that may help you.

Making Routine Refills Easier

- Consider using a mail-order pharmacy or asking your doctor to prescribe refills in 90-day supply. This avoids having to go pick up your medicine at the pharmacy every month.
- Sign up for auto-refills through your pharmacy.

Using Technology or Visual Reminders

- You can set yourself a monthly alarm or calendar alert to remind you that it is time to get your next medicine refill.
- You can sign up for text reminders through your pharmacy.
- Some seizure-tracking apps for your smartphone also remind you when it is time to take your medicine or when it is time to get your next refill.
- Using a weekly pill box can help you see when you have only a few days of medicine left so that you can get it refilled before you run out.
- Post notes in places you see often, like the refrigerator, bathroom mirror or front door.
- Add a reminder to a calendar or schedule that you can put on the refrigerator or someplace else that you will see.

Who to Contact for Refills

- Check the prescription label on your medicine. There are 2 different examples shown here:

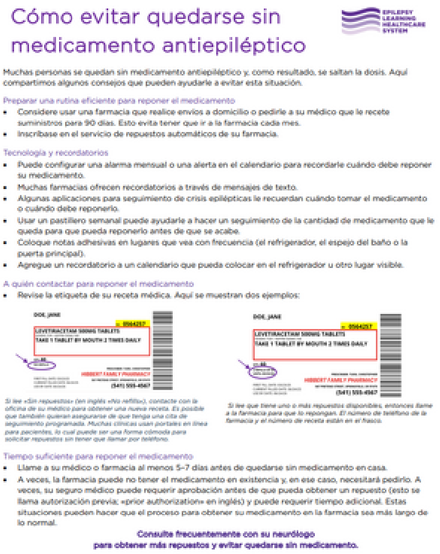
If it says "no refills," then contact your doctor's office for a new prescription. They may want to make sure you have a follow-up appointment scheduled also. Many clinics use online patient portals. This can be an easy way to ask for refills without having to call over the phone.

If it says that there are 1 or more refills left on your prescription, then call the pharmacy to have them refill it. The pharmacy phone number and prescription number are on the bottle.

Giving Enough Time for Refill Requests

- Call your doctor or pharmacy at least 5-7 days before you run out of medicine at home.
- Sometimes a pharmacy may not have your medicine in stock and may have to order it. Sometimes your insurance may need to say yes before you can get a refill - this is called "prior authorization" and can take extra time. These things can make it take longer to get your medicine filled at the pharmacy.

Keep your regularly scheduled follow-up appointments with your neurologist in order to get more refills and avoid running out.



Cómo evitar quedarse sin medicamento antiepiléptico

EPILEPSY LEARNING HEALTHCARE SYSTEM

Muchas personas se quedan sin medicamento antiepiléptico y, como resultado, se saltan la dosis. Aquí compartimos algunos consejos que pueden ayudarle a evitar esta situación.

Preparar una rutina eficiente para reponer el medicamento

- Considere usar una farmacia que realice envíos a domicilio o pedirle a su médico que le recete suministros para 90 días. Esto evita tener que ir a la farmacia cada mes.
- Inscríbase en el servicio de repuestos automáticos de su farmacia.

Tecnología y recordatorios

- Puede configurar una alarma mensual o una alerta en el calendario para recordarle cuándo debe reponer su medicamento.
- Muchas farmacias ofrecen recordatorios a través de mensajes de texto.
- Algunas aplicaciones para seguimiento de crisis epilépticas le recuerdan cuándo tomar el medicamento o cuándo debe reponerlo.
- Usar un pastillero semanal puede ayudarle a hacer un seguimiento de la cantidad de medicamento que le queda para que pueda reponerlo antes de que se acabe.
- Coloque notas adhesivas en lugares que vea con frecuencia (el refrigerador, el espejo del baño o la puerta principal).
- Agregue un recordatorio a un calendario que pueda colocar en el refrigerador u otro lugar visible.

A quién contactar para reponer el medicamento

- Revise la etiqueta de su receta médica. Aquí se muestran dos ejemplos:

Si lee «Sin repuestos» (en inglés «No refills»), contacte con la oficina de su médico para obtener una nueva receta. Es posible que también quieran asegurarse de que tenga una cita de seguimiento programada. Muchas clínicas usan portales en línea para pacientes, lo cual puede ser una forma cómoda para solicitar repuestos sin tener que llamar por teléfono.

Si lee que tiene uno o más repuestos disponibles, entonces llame a la farmacia para que lo repongan. El número de teléfono de la farmacia y el número de receta están en el frasco.

Tiempo suficiente para reponer el medicamento

- Llame a su médico o farmacia al menos 5–7 días antes de quedarse sin medicamento en casa.
- A veces, la farmacia puede no tener el medicamento en existencia y, en ese caso, necesitará pedirlo. A veces, su seguro médico puede requerir aprobación antes de que pueda obtener un repuesto (esto se llama autorización previa; «prior authorization» en inglés) y puede requerir tiempo adicional. Estas situaciones pueden hacer que el proceso para obtener su medicamento en la farmacia sea más largo de lo normal.

Consulte frecuentemente con su neurólogo para obtener más repuestos y evitar quedarse sin medicamento.

ELHS on the Road

2025 Institute for Healthcare Improvement (IHI) Annual Forum

Akron Children's site Champion **Kelsey Merison** and ELHS Ops Team member **Brandy Fureman** attended the **IHI Forum** in December 2025. We also found our beloved Jeff Buchhalter gracing the conference program brochure! In addition to excellent keynote speakers Will and Kristin Flanary (of "Dr. Glaucomflecken" fame), Dr. Eric Topol, Candy Chang and Dr. Don Berwick, our team joined valuable workshops and sessions. Meeting others in the QI community from across the world is another benefit of attending IHI; Brandy's workshop in the Return On Investment (ROI) Measures for QI was taught by Amar Shah, National Clinical Director for Improvement, NHS, England and Chelsey Leruth, Director Measurement, Evaluation, and Learning, IHI. It offered a practical framework for evaluating the return on investment (ROI) of improvement initiatives, using real-world examples to build fluency in key financial concepts such as productivity, efficiency, cost avoidance, cost improvement, revenue, and income.

We hope you consider representing ELHS at the [2026 IHI Forum]() which will be held December 6-9, 2026 in Phoenix, Arizona. A limited number of travel scholarships may be available to ELHS participants to attend – more information coming soon!

Above: Kelsey & Brandy representing ELHS at the IHI Forum

Above: Brandy in an IHI Forum breakout

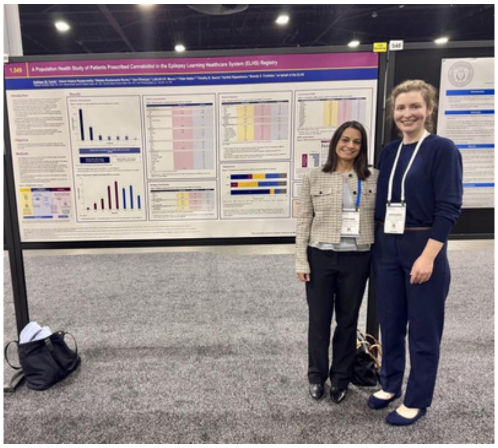
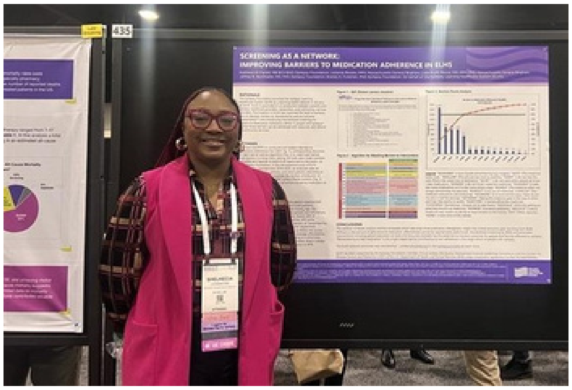
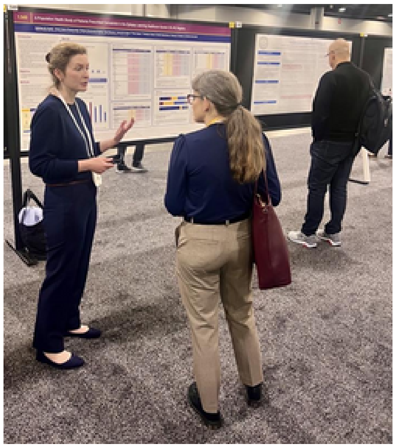
Above: ELHS QI Champion Jeff Buchhalter in this years' IHI program!

ELHS on the Road

2025 American Epilepsy Society Annual Meeting

ELHS was well represented at the 2025 American Epilepsy Society (AES) annual meeting, with **three abstracts** accepted and presented as posters:

- Screening as a Network: Improving Barriers to Medication Adherence in ELHS
- A Population Health Study of Patients Prescribed Cannabidiol in the ELHS Registry
- Social Vulnerability Index is Associated with Poor Epilepsy Care Delivery and Seizure Outcomes

Current champions showcased their team storyboards at the **ELHS Open House**, where prospective new network members visited to learn more. Great conversations were had by the mix of adult and pediatric epilepsy providers, Patient Family Partners and advocacy organizations, with continued discussions coming in the new year.

Special congratulations to **Peter Hadar**, ELHS champion from the MGB team, who was awarded the prestigious Susan S. Spencer Clinical Research Training Scholarship 2025-2027!



ELHS on the Road

Learning Sessions

Our Network convened twice for in-person/hybrid Learning Sessions this year, and once virtually in May. These meetings are opportunities for teams to share their improvement work (all teach, all learn), collaboratively troubleshoot barriers and hone Quality Improvement practical skills.

The January Learning Session was co-hosted by the **UTSW Children's Health Dallas** team led by **Deepa Sirsi** and **Sam Arroyo Solis**, and the **Epilepsy Foundation Texas** team led by **Rebecca Moreau** and **Suzanne Thomas**.

In October, the Learning Session was co-hosted by the **Children's Hospital of Philadelphia** team, led by **Nick Abend** and **Sara Molisani**, and the **Epilepsy Foundation of Eastern Pennsylvania** team led by **Rena Loughlin**.

Stay tuned for the "when and where" for our next Learning Session – tentatively planned for May 2026.

Community travel scholarships and support for improvers will be available, more details to come in Q1 2026!

We'd love to visit your city sometime soon - reach out to elhs@efa.org if you're interested in hosting a meeting.

Getting Involved

Why Join ELHS?

WHAT'S NEW

- No annual site fee
- Individual-level membership
- Numerators/Denominators
- No legal/IRB agreements
- Quarterly AP webinars
- Run & SPC chart tools
- Self-organized QI projects

WHAT'S CONTINUING

- Free IHI Open School
- In-person Learning Sessions
- Standardized measures
- QI Journal Club
- MOC Part IV credit
- Grant collab opportunities
- Spirit of improvement

If you're doing improvement work in the epilepsy space, you're welcome to join ELHS!

Reach out to set up a 1:1 to learn what each member brings to the community of learners and how the network and Operations Team supports you. A letter of commitment formalizes membership, and while divisional/institutional buy-in is nice to have, it's not required to get started.

Contact elhs@efa.org to connect with us.

Looking Ahead

In the true spirit of Quality Improvement, 2026 will be a year focused on testing, adapting and communicating! The following are strategic priorities:

Reach – by engaging more directly with individual providers, we hope to expand epilepsy QI to more parts of the country, thus improving outcomes for more people affected by epilepsy

Sustainability – pursuit of additional support for network QI activities, enhancing the ways the Operations Team can assist improvement teams

Outcomes – demonstrable impacts in seizure control, barriers to medication adherence and quality of life