



STATE OF ELHS REPORT

2024

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ELHS: TREATING EPILEPSY WITH COMMUNITY

MESSAGE FROM THE COORDINATING CENTER

We've come a long way since 2018!

2024 marks six years since a group of dedicated epilepsy providers and Patient Family Partners (PFPs) came together to design and plan the launch of the first-ever Epilepsy Learning Healthcare System (ELHS) for all people living with epilepsy. Our network of thirteen pediatric and adult epilepsy centers alongside community-based organizations like the Epilepsy Foundation national and local teams, partners in the Rare Epilepsy Network (REN) and individuals affected by epilepsy are on a mission. We are leading a movement to stop seizures and make life better for all people with epilepsy – and we won't stop until we get there.

Accomplishments this year include the initiation of a Site Champion-led improvement project on reduction of tonic, clonic seizures for people with weekly seizures, a growing monthly Quality Improvement (QI) Journal Club, PFP-led patient education in two Epilepsy Monitoring Units (EMUs) of University of Cincinnati and Cincinnati Children's Hospital, a closed-loop Referral pilot between Epilepsy Foundation's 24/7 Helpline, the Children's Hospital of Philadelphia and the Epilepsy Foundation of Eastern Pennsylvania, and continued Network focus on the areas of Seizure Documentation and Screening for Barriers to Medication Adherence. ELHS has been well represented at various academic conferences again this year, with work featured in abstracts presented at the American Academy of Neurology and American Epilepsy Society annual meetings. The Spring '24 Learning Session was held in Denver, hosted by the University of Colorado site team and local office Epilepsy Foundation of Colorado/Wyoming, and our Network will come together in January for our next Learning Session in Dallas, hosted by the University of Texas Southwestern – Children's Health and local office Epilepsy Foundation of Texas.

In November 2024, Dr. Kathleen Farrell assumed a new role as Executive Director of the Epilepsy Learning Healthcare System (ELHS). As a founding leader of ELHS, Kathleen has shaped its mission and operations since inception of the network. Kathleen is a physician with advanced training in QI methodology through the Institute for Healthcare Improvement (IHI). She has led multiple improvement projects to enhance clinical-community connections. As Vice President for Public Health Outcomes at the Epilepsy Foundation, she has also been a champion of the Extension for Community Health Outcomes (ECHO) program among other work. Kathleen's added role as ELHS Executive Director will allow her to focus most of her time on the needs of the ELHS network participants and transitioning its structure to accommodate community-based neurology practices in addition to specialized epilepsy centers.

An exciting future is ahead for ELHS!

The next year will feature new investment into ELHS Network sustainability and site expansion. We recognize the importance of providing adequate support to participating centers to enable consistent contribution to the Registry -which is what enables Population Health Management and active Quality Improvement projects. The Registry now includes over 28,000 individuals with epilepsy of all types. We are exploring novel partnerships that can create a secure, triple-aim data ecosystem that benefits all stakeholders in the epilepsy space. The data triple-aim concept means that the same data – with appropriate safeguards - can be used for patient care, for quality improvement of outcomes, and for research to generate new knowledge. Orchestrated correctly, this approach can deliver higher quality care and faster research progress for all.



Brandy Fureman, PhD
ELHS Principal Investigator

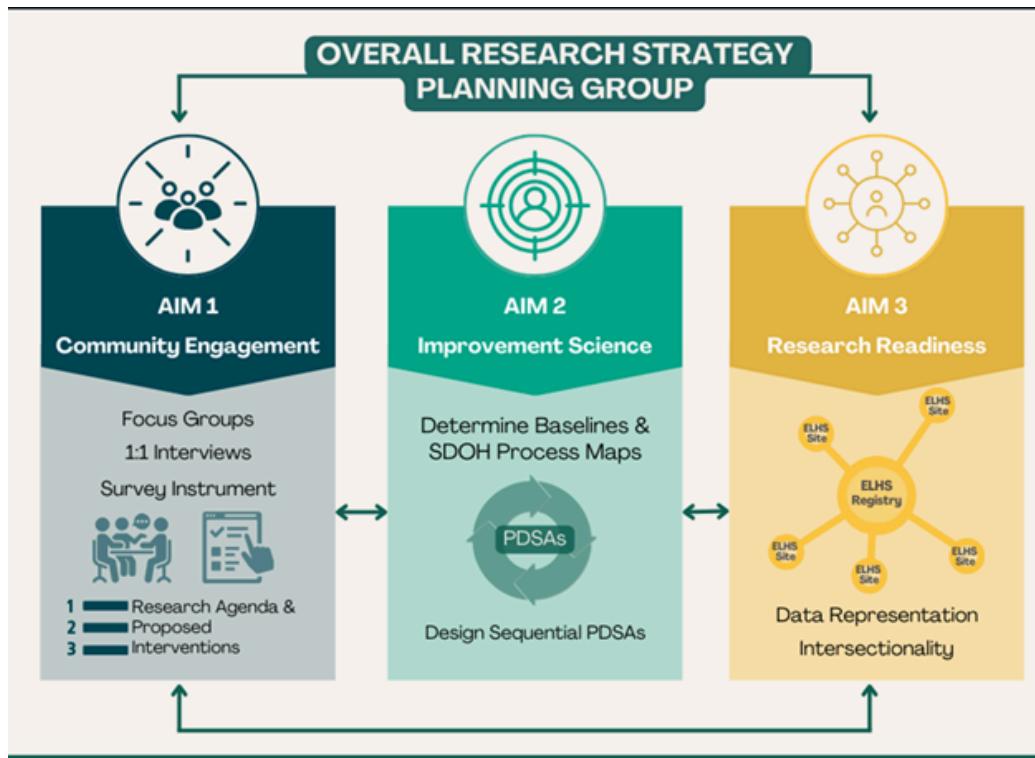


Kathleen Farrell, MB BCh BAO
ELHS Executive Director



Jeffrey Buchhalter, MD, PhD
ELHS Quality Improvement
Lead

Over the next year, we begin an NIH grant-funded planning project to build the tools and relationships to do Health Equity Research in Neuroscience (HERN) in our learning health system. The HERN planning grant will allow us to bring a diverse community together to understand local issues driving health inequity, allow ELHS teams to begin to systematically evaluate health equity and drivers of inequity at two of our care centers, and to establish best practices in collecting information about patients' social determinants of health (SDOH). These best practices will be shared with all ELHS centers to help support their improvement work in this priority area. The ELHS Registry database will be assessed for representativeness and intersectionality. The planning work will result in ELHS-affiliated research teams submitting grant applications to test interventions that will help reduce -and eventually erase - disparities in epilepsy outcomes.



We sincerely thank all of our member sites, motivated site Champions and Patient Family Partners, and supporters for your partnership this year, and we hope to amplify our impact in the year ahead, welcoming more Improvers into the Network.

ON BEHALF OF THE ELHS OPERATIONS TEAM

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

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

SUCCESS AT A GLANCE

Unique Registry Growth

28k+ Number of individual patients in the registry. Patient enrollment has increased by 600-700 patients monthly over the past year.

70k+ Number of new registered visits in the registry, averaging 2,300 new visits per month.



Network Action Period Calls

300+ calls

collaborative calls to action brought together members of the epilepsy learning healthcare network. These monthly meetings include 13 sites, members of the Coordinating, QI, and Data cores, Epilepsy Foundation Chapters, and others to share knowledge and experiences.

Scientific contributions

6

research focused on quality improvement and co-production within the Epilepsy Learning Healthcare System.
AAN posters 2024: 1
AES posters 2024: 4
Publications: 2



13

6 Adult + 7
Pediatric Locations
Across the U.S.

ELHS Clinical Sites

SUCCESS AT A GLANCE

ELHS Publications

2024

Barros L, Donahue MA, Fureman B, Moura LMVR. Healthcare Disparities Among Sexual and Gender Minority People Living with Epilepsy: A Cross-Sectional Analysis. *Neurology*. August 1, 2024; doi: CPJ-2023-000695.

Donahue, M.A.; Akram, H.; Brooks, J.D.; Modi, A.C.; Veach, J.; Kukla, A.; Benard, S.W.; Herman, S.T.; Farrell, K.; Ficker, D.M.; Zafar, S.F.; Trescher, W.H.; Sirsi, D.; Phillips, D.J.; Pellinen, J.; Buchhalter, J.; Moura, L.; Fureman, B.E.; as the Epilepsy Learning Healthcare System. Barriers to Medication Adherence in People Living With Epilepsy. *Neurol Clin Pract*. 2025;15(1):e200403. doi:10.1212/CPJ.000000000000200403.

2023

Nuthalapati P; Thomas L; Donahue M; Moura L.M.V.R.; DeStefano S; Simpson R; Buchhalter J; Fureman B; Pellinen J. Improving Seizure Frequency Documentation and Classification. *Neurol Clin Pract*. 2023 Dec;13(6):e200212. doi: 10.1212/CPJ.000000000000200212. Epub 2023 Oct 19. PMID: 37873534; PMCID: PMC10586801.

2022

Clary H, Josephson A, Franklin G, Herman S, Hopp JL, Hughes I, Meunier L, Moura L, Parker-McFadden B, Pugh MJ, Schultz R, Spanaki MV, Bennett A, Baca C. Seizure Frequency Process and Outcome Quality Measures, Quality Improvement in Neurology. *Neurology*. 2022 Apr; DOI:10.1212/WNL.000000000000200239.

DeStefano S, Pellinen J, Sillau S, Buchhalter J. Standardization of seizure response times and data collection in an epilepsy monitoring unit. *Epilepsy Res*. 2022 Apr; DOI: 10.1016/j.eplepsyres.2022.107013.

Fernandes M, Donahue MA, Hoch D, Cash S, Zafar S, Jacobs C, Hosford M, Voinescu PE, Fureman B, Buchhalter J, McGraw CM, Westover MB, Moura LMVR. A replicable, open-source, data integration method to support National Practice-based Research & Quality Improvement Systems. *Epilepsy Res*. 2022 Oct; doi: 10.1016/j.eplepsyres.2022.107013.

Vinson AH, Seid M, Gamel B, Saeed S, Fureman B, Cronin SC, Bates K, Hartley D. Toward an ontology of Collaborative Learning Healthcare Systems. *Learning Health Systems*. 2022 Feb; <https://doi.org/10.1002/lrh2.10306>.

2021

Fernandes M, Donahue MA, Hoch D, Cash S, Zafar S, Jacobs C, Hosford M, Voinescu PE, Fureman B, Buchhalter J, McGraw CM, Westover MB, Moura LMVR. Establishing a Learning Healthcare System to Improve Health Outcomes for People with Epilepsy. *Epilepsy & Behavior*. 2021 Jan; <https://www.sciencedirect.com/science/authShare/S1525505021000391>.

Goldstein J, Kwon C-S, Harmon M, Buchhalter J, Kukla A, McCallum S, Raman L, Herman ST, Fureman B, Jette N. Seizure documentation in people living with epilepsy. *Epilepsy & Behavior*. 2021 Oct; doi: 10.1016/j.yebeh.2021.108383.

2020

Vjones FJS, Ezzeddine FL, Herman ST, Buchhalter J, Fureman BE, Moura LMVR. A Feasibility Assessment of Functioning and Quality-of-Life Patient-Reported Outcome Measures in Adult Epilepsy Clinics: A Systematic Review. *Epilepsy & Behavior*. January 1, 2020; [https://www.epilepsybehavior.com/article/S1525-5050\(19\)30901-1/fulltext](https://www.epilepsybehavior.com/article/S1525-5050(19)30901-1/fulltext).

Moura LMVR, Donahue MA, Dass D, Sanches PR, Ayub N, McGraw C, Zafar SF, Cash SS, Hoch D. Telemedicine can support measurable and high-quality epilepsy care during the COVID-19 pandemic. *Am J Med Qual*. 2020 Jan; doi: 10.1097/01.JMQ.0000733444.

Smith JR, Jones FJS, Ayub N, Herman ST, Buchhalter J, Fureman BE, Cash SS, Hoch DB, Moura LMVR. Implementing standardized provider documentation in a tertiary epilepsy clinic. *Neurology*. 2020 Jul; <https://n.neurology.org/content/95/2/e213>.

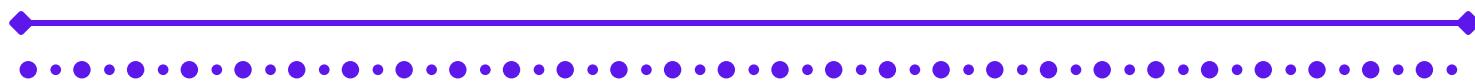
Vinson AH. Putting the network to work: Learning networks in rapid response situations. *Learning Health Systems*. 2020 Oct; <https://onlinelibrary.wiley.com/doi/full/10.1002/lrh2.10251>.

2019

Moura LMVR, Magliocco B, Ney JP, Cheng EM, Esper GJ, Hoch DB. Implementation of quality measures and patient-reported outcomes in an epilepsy clinic. *Neurology*. 2019 Jan; <https://n.neurology.org/content/93/22/e2032>.

2018

Patel AD, Baca C, Franklin G, Herman ST, Hughes I, Meunier L, Moura LMVR, Munger Clary H, Parker-McFadden B, Pugh MJ, Schultz RJ, Spanaki MV, Bennett A, Josephson SA. Quality improvement in neurology: Epilepsy Quality Measurement Set 2017 update. *Neurology*. 2018 Oct; <https://pubmed.ncbi.nlm.nih.gov/30282773/>.



“Epilepsy Learning Healthcare System’s vision is for all people living with epilepsy to live their highest quality of life, striving for freedom from seizures and side effects. . . and we won’t stop until we get there”.

KEY MEASURES - PATIENT POPULATION



On average, in the past year we have added 2,300 visits per month to the ELHS Network registry

Sites submitting Data in the past year

6

>75k

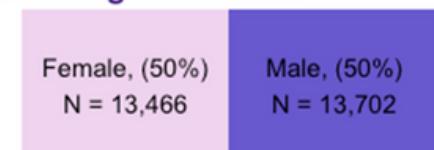
Visits in the ELHS Registry

>28k

Individuals in the ELHS Registry

KEY MEASURES - PATIENT POPULATION

Sex Assigned at Birth



0% 25% 50% 75% 100%
Percent

Note: 1,069 patients not included in chart
due to missingness

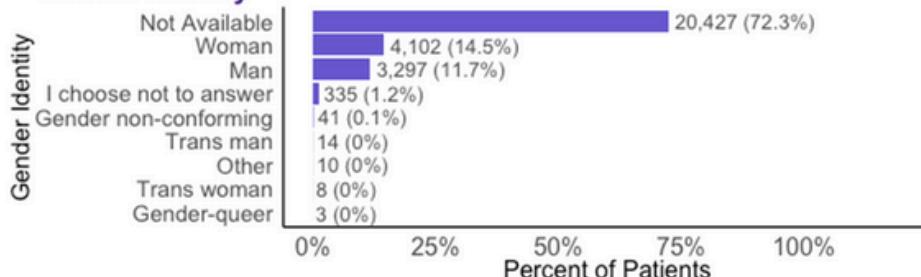
Ethnicity



0% 25% 50% 75% 100%
Percent

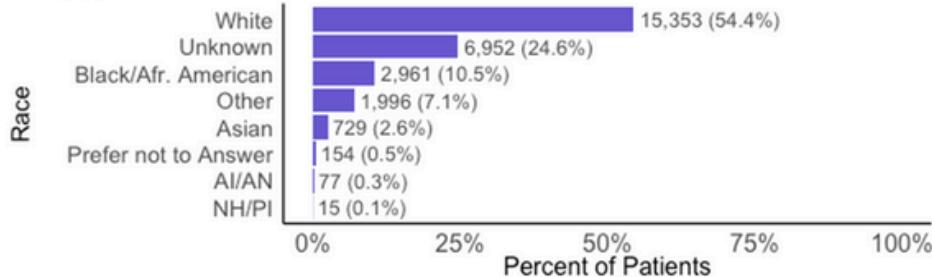
Hispanic or Latino
Not Hispanic or Latino
Refuse Answer/Not Available

Gender Identity



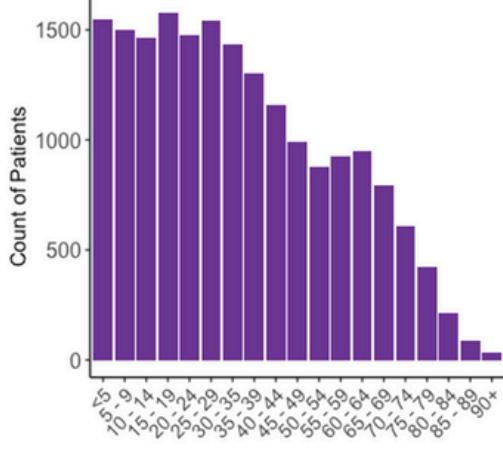
0% 25% 50% 75% 100%
Percent of Patients

Race

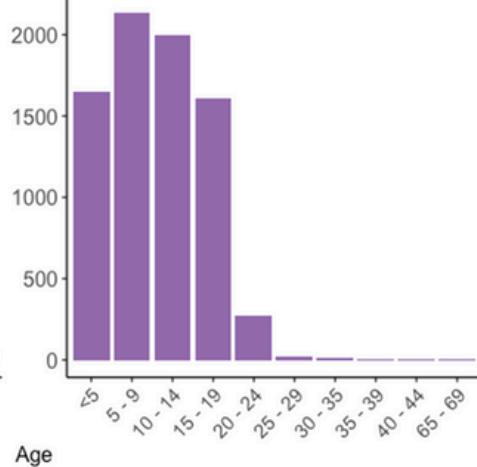


0% 25% 50% 75% 100%
Percent of Patients

Adult Sites



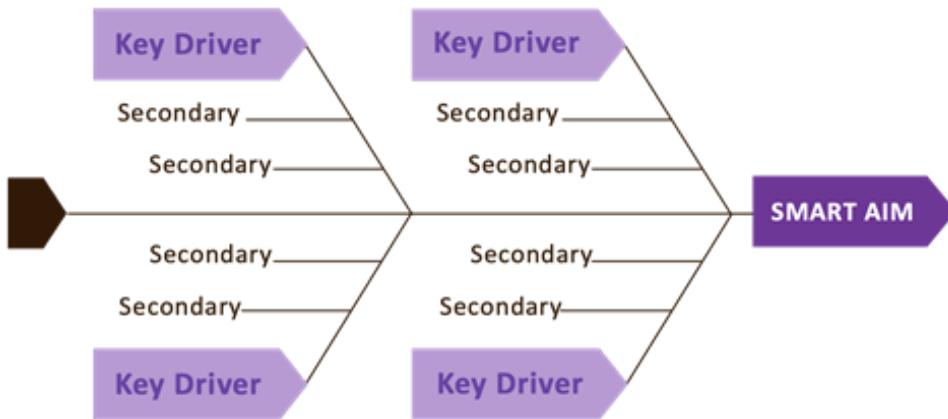
Pediatric Sites



KEY MEASURES - SEIZURE DOCUMENTATION

Epilepsy management aims to reduce or eliminate seizures. ELHS has developed case report forms for providers and patients to standardize seizure documentation. This process focused measure for seizure documentation tracks how often providers and patients document current seizure frequency and date of last seizure.

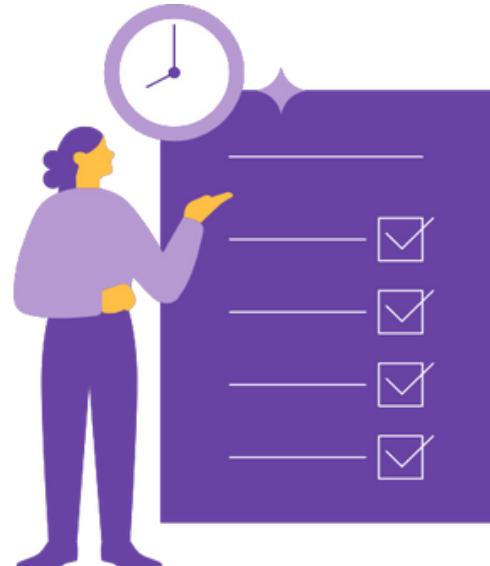
Seizure Documentation
implemented in workflow at
11 Clinical Sites



Standardized seizure documentation is gathered from ELHS clinical sites. Data is received, processed and analyzed by a central Data Coordinating Center. Data reports are generated to track progress of patient and provider seizure documentation. Clinical sites use Plan Do Study Act (PDSA) cycles to improve seizure documentation.



Quality Improvement
Framework



KEY MEASURES - MEDICATION ADHERENCE

Medication adherence is important for the treatment and management of seizures. This process measure tracks how often providers assess barriers to medication adherence.

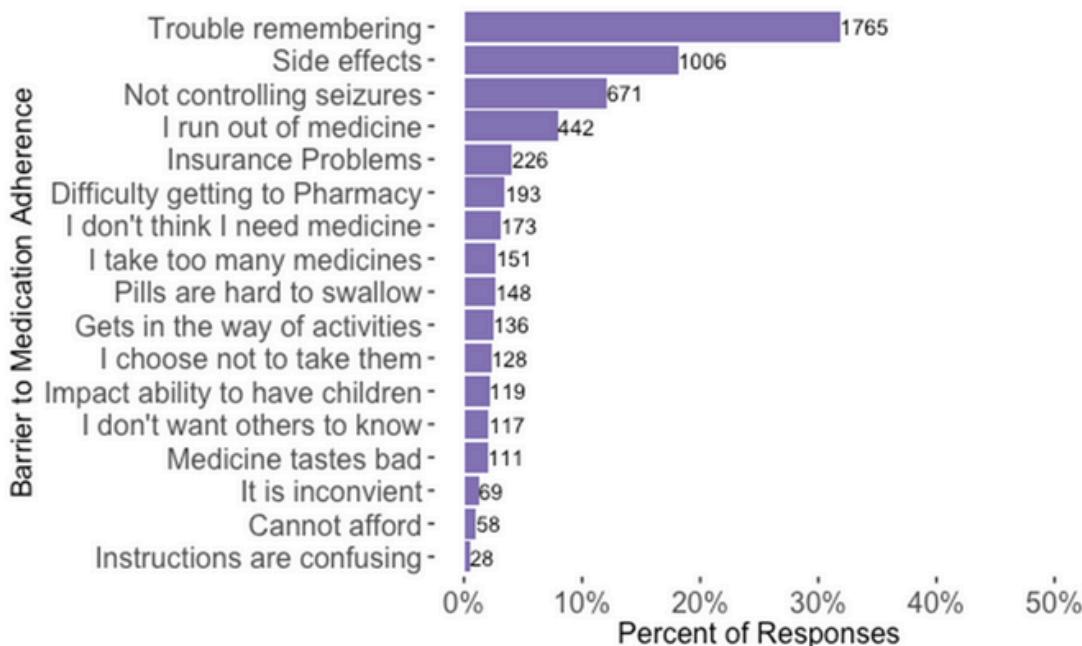


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Clinical Sites

Screening for Barriers to Medication Adherence

ELHS collects information on missed medication doses and things that get in the way of taking medication. The most common reported barriers to medication adherence is trouble remembering, followed by medication side effects. 22% of patients in ELHS report at least one barrier to medication adherence.



COMMUNITY ENGAGEMENT

ELHS is centered on co-production, where patients are equal contributors alongside providers, researchers and other stakeholders, and their journeys and perspectives inform Network direction and pursuits at every stage. Therefore, we seek to increase the lived-experience voice in all activities alongside scaling the clinical membership moving forward.

Providing Support from a Peer Educator

At the **University of Cincinnati Gardner Neuroscience Institute (UCGNI)** and the **Cincinnati Children's Hospital (CCHMC)**, **Scott Badzik (ELHS Community Council co-chair)** has piloted peer-education strategies in the Epilepsy Monitoring Unit (EMU). During their admission, patients can receive personalized time to learn more about the importance of documenting their seizures (why does it matter? What does this information tell your provider? What does your provider do with this information?) and learn strategies to address Barriers to Medication Adherence – or how to troubleshoot issues that get in the way of taking anti-seizure medications as prescribed. While this pilot is ongoing, other ELHS teams can adapt or adopt the approaches tested thus far if they would like to implement at their center. This is one of the most valuable elements of belonging to a Learning Health System: the ability to share seamlessly and learn from others. The **Epilepsy Foundation of Ohio** is another coproduction partner of both UCGNI and CCHMC, and two years ago served as point in a Community Health Worker (CHW) intervention pilot on telephone-based self-management coaching for people with uncontrolled seizures identified in clinic. While this project is not ready to scale, CHWs remain a group of interest to ELHS to amplify support for the epilepsy community.

Connecting families to Community Services

The **Epilepsy Foundation of Eastern Pennsylvania** and **Children's Hospital of Philadelphia (CHOP)** have been engaged in a closed-loop referral pilot with the **Epilepsy Foundation's National 24/7 Helpline**, whereby children seen at the epilepsy clinic at CHOP who would benefit from a referral to a service not provided by the hospital can be seamlessly connected with the national EF team as well as their local EF office. Critically, the referral flow is tracked throughout the families' experiences with outcomes captured, all then being shared back to CHOP to be integrated into the patient record. Opportunities for scaling and spreading this model are being explored.

Lifting up Patient and Family Partner Voices in the Network

Two **ELHS Community scholarships** enabled additional Patient Family Partners to travel to Denver for the Spring '24 Learning Session, both bringing valuable perspectives from the lived- and parent-experience with epilepsy diagnoses, including that of the rare epilepsies and Developmental Epileptic Encephalopathies (DEEs). Three such scholarships are being offered for January '25, in addition to support for ELHS member site-affiliated PFPs via their centers.

VALUE OF ELHS

ELHS provides a forum to “treat epilepsy with community”: clinicians, researchers, patients and families, community leaders and innovators all learn from peers and other stakeholders. The bidirectional learning, ability to test theories of change and opportunity to implement new methods of practice change are what set the learning health system model apart from traditional research and standard of care approaches.

All teach, All learn community

- Monthly Action Period (AP) calls
- Biannual in-person and hybrid Learning Sessions
- Shared “Commons” to house tools and resources

Quality Improvement education

- Cross-site QI projects
- Monthly QI Journal Club
- Free, self-paced modules through the Institute for Healthcare Improvement
- 1:1 QI mentoring

Data support and insights

- Individualized strategies for data submission
- Population health insights for your own site and the broader network

Education opportunities

- Maintenance of Certification IV accreditation
- Early access to telementoring offerings via the new Epilepsies ECHO Hub
- Seizure First Aid and other EF-offered trainings and support

SPRING '24 LEARNING SESSION HIGHLIGHTS



Denver, Colorado

Hosted by: University of Colorado Health & Epilepsy Foundation of Colorado/Wyoming

Key Metrics & Achievements

60

attendees in-person &
via Zoom
Representing

20

sites and organizations

Celebrations and Milestones since the previous (2023) Learning Session

Individual patients in registry doubled in size

95% year over year increase in Seizure Frequency reporting

268% year over year increase in Patient Reported Outcomes (PRO) completion

Expansion to new sites contributing to data and Quality Improvement (QI) initiatives.

- Enhanced reporting tools introduced, such as Tableau dashboards for visualization.

Feedback from Participants



What Went Well

"Learning more about how doctors make decisions treating epilepsy and hearing from others who are affected by it."

"Exceptional material and presentations."

"Very informative to hear different perspectives on this complex condition."



Goals For Next Time

Continued objective-driven, interactive and collaborative breakout sessions.

Additional support to facilitate Patient Family Partners in-person attendance.



Overall Experience

We achieved an 100% satisfaction rating in participant feedback surveys.

Many appreciated the opportunity to connect with a broader community of health improvers.

SPRING '24 LEARNING SESSION HIGHLIGHTS

Discussion Themes

Strengthened Understanding of Quality Improvement (QI)

- Focus on small, incremental changes through Plan-Do-Study-Act (PDSA) cycles.
- Enhanced collaboration between clinical teams and patient-family partners.

Interactive Sessions

- Storyboards highlighted successes in **seizure documentation** and **medication adherence initiatives**.
- Breakout groups explored leveraging **community resources** to improve patient support.

Addressing Challenges

- Identified barriers such as limited time and resources for QI work.
- Explored potential funding opportunities, including grants and data-sharing partnerships.

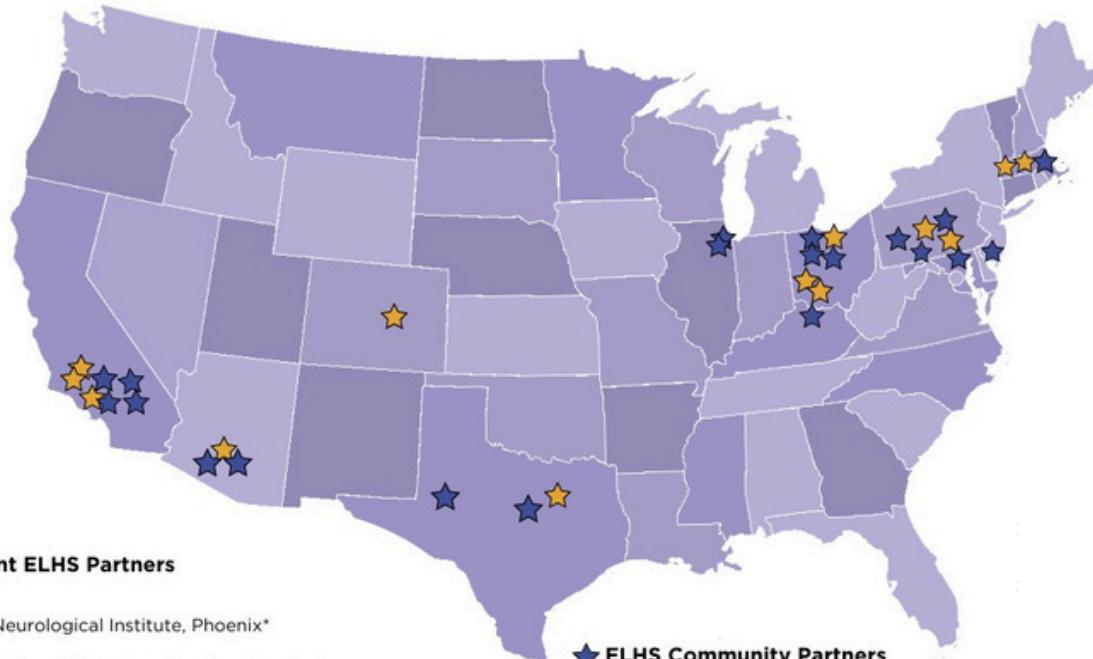
Thank you to all participants for making the Spring 2024 Learning Session a success!

ELHS NATION



Epilepsy Learning Health System (ELHS Network Map)

as of September 2024



★ Current ELHS Partners

Arizona

- Barrow Neurological Institute, Phoenix*

California

- Children's Hospital Los Angeles, Los Angeles*
- Children's Hospital of Orange County, Orange County*
- University of Southern California Keck School of Medicine, Los Angeles*

Colorado

- University of Colorado Anschutz Medical Center, Boulder

Massachusetts

- Brigham & Women's Hospital, Boston*
- Massachusetts General Hospital, Boston*

Ohio

- Akron Children's Hospital, Akron*
- Cincinnati Children's Hospital, Cincinnati*
- University of Cincinnati Medical Center, Cincinnati*

Pennsylvania

- Children's Hospital of Philadelphia, Philadelphia*
- Penn State Hershey Children's Hospital, Hershey*

Texas

- University of Texas Southwestern Medical Center
- Children's Health Dallas

Legend:

*Team co-producing with a clinical or community counterpart
**Map marker locations are approximate

★ ELHS Community Partners

- CURE Epilepsy
- Dravet Syndrome Foundation
- Dup15q Foundation
- Empowering Epilepsy*
- Epilepsy Association of Western and Central Pennsylvania*
- Epilepsy Foundation Arizona*
- Epilepsy Foundation Eastern Pennsylvania*
- Epilepsy Foundation Kentuckiana*
- Epilepsy Foundation Los Angeles*
- Epilepsy Foundation New England*
- Epilepsy Foundation Ohio*
- Epilepsy Foundation Orange County*
- Epilepsy Foundation Texas - Houston/Dallas-Fort Worth/West Texas*
- FamiliesSCN2A Foundation*
- Hope for Hypothalamic Hamartomas
- International Foundation for CDKL5 Research
- LGS Foundation
- Ring14 USA*
- The Brain Recovery Project Childhood Epilepsy Surgery Foundation

ELHS is ever-growing and seeking clinical and community partners.
Contact elhs@efa.org if you are interested in joining the network.

Learn more by visiting epilepsy.com/ELHS



FUTURE STRATEGIC PRIORITIES

Building on the success of last year, the Epilepsy Learning Healthcare System has identified the following strategic priorities for 2025:

Scale

- Increase the number of participating sites, including non-academic centers, in order to reach a more representative population of the epilepsy community. We will prioritize recruitment of additional sites that are geographically diverse and/or provide care to underserved populations.
- Grow the registry with an emphasis on capturing more complete data about epilepsy diagnosis and care for each patient and following their outcomes over time.

Sustainability

- Identify and test methods to provide participating site teams with more resources, such as grant support for improvement teams.
- Create new avenues for engagement with supporting stakeholders, including research collaborations utilizing ELHS data insights.

Quality Improvement

- Build upon current learnings from the Tonic, Clonic Seizures Project, the Closed-Loop Referrals pilot and other site-level QI approaches to further embed the culture of improvement throughout the Network. We are a Community of Improvers!

Equity

- Establish best practices to collect information about social determinants of health (SDOH) and other demographic data, in order to monitor and reduce disparities in care.

We want all people with epilepsy to live their highest quality of life, striving for freedom from seizures and side effects: We won't stop until we get there, and we hope that you find tremendous value in ELHS, whether you are a participating center or a prospective partner. Let's work together to improve outcomes for all!

