

# Comparative Effectiveness of Palliative Surgery versus Additional Anti-Seizure Medications for Lennox-Gastaut Syndrome



**SOM-L**  
SURGERY OR MEDS FOR LGS

## Aim 1: Comparative Effectiveness: Surgery versus more anti-seizure medication

### A. Impact on seizure-related emergency department visits & intensive care unit admissions

Chart validation for LGS coding  
Develop computable phenotype for LGS in databases



### B. Impact on

- Expressive communication
- Behavior & Quality of Life



Appropriate survey instruments for measuring outcomes that matter to families  
Qualitative study with families of patients with LGS

This multicenter study is sponsored by PCORI for 2022-2025. It is a mixed methods study: quantitative retrospective health services research (HSR) strategies (Aim 1a/Aim 2) and qualitative methods (Aim 1b). There is no clinical trial component.

This project will study the comparative effectiveness of palliative surgery versus additional anti-seizure medications for LGS. The common palliative surgeries are vagus nerve stimulation and corpus callosotomy; while the study is not powered for analysis of RNS, DBS, and other surgeries, data will be collected and descriptives provided.

This study will explore, validate and leverage national PCORnet data for the study of LGS. In doing so, we work toward building on knowledge to study rare diseases and epilepsies with this data infrastructure and other administrative datasets.

Strong partnership with the LGS Foundation guides research questions and outcomes that matter to patients and families.

Please visit [LGSresearch.org](http://LGSresearch.org) for updates or contact [slam@luriechildrens.org](mailto:slam@luriechildrens.org) for more information. We look forward to hearing from you!

#### Core Team:

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## Aim 2: Utilization of therapies for LGS

Real-world utilization of these treatments in the United States



Identify variability and disparities in use that may pose challenges to optimum access to and use of appropriate therapies



## Sites

### High intensity (Aims 1 and 2)

- Lurie Children's<sup>1</sup>
- Nationwide Children's<sup>1</sup>
- Colorado<sup>1</sup>
- Seattle<sup>1</sup>
- St. Louis Children's<sup>2</sup>
- U. of Michigan<sup>2</sup>
- U. of Pittsburgh<sup>2</sup>



### Light touch (Aim 2)

- CHOP<sup>1</sup>
- Cincinnati<sup>1</sup>
- Nemours<sup>1</sup>
- Stanford U.<sup>1</sup>
- Indiana U.<sup>1</sup>
- Vanderbilt U.<sup>2</sup>
- UNC<sup>2</sup>
- Duke U.<sup>2</sup>
- Johns Hopkins U.<sup>2</sup>
- Nicklaus Children's<sup>2</sup>

- 1) PEDSnet sites
- 2) other PCORnet sites

Aims 1a, 1b, 2  
Mixed Methods  
& EHR data

Aim 2  
EHR data

**LGS FOUNDATION**  
LENNOX-GASTAUT SYNDROME

**pcori** PATIENT-CENTERED OUTCOMES  
RESEARCH INSTITUTE

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