



EAN Stakeholder Meeting

September 2025

EAN Stakeholder Mtg\_PERC

A short horizontal bar with a blue-to-teal gradient, positioned above the word "Our".

# **Our Inspiration**

## **COG served as the inspiration!**

**COG demonstrated that a collaborative infrastructure yields faster, better results, and PERC's founders believed that's exactly what was needed in the pediatric epilepsy space.**

The "About Us" section header. It includes a small horizontal bar with a rainbow gradient above the text. The text "About Us" is in a large, bold, white sans-serif font. Below the text is a large, stylized graphic of a waveform, also with a rainbow gradient, that spans across the bottom of the slide.

# About Us

The Pediatric Epilepsy Research Consortium (PERC) is a national collaboration of more than 100 level 3 and 4 pediatric epilepsy centers and over 400 pediatric epileptologists, pediatric neurosurgeons, pediatric neuropsychologists, and other pediatric epilepsy researchers.

PERC has grown to become the leader in pediatric epilepsy research by providing a network and infrastructure to facilitate collegial, collaborative, practice-changing research.

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# Our Founders

**Founded in 2010 when pediatric epileptologists, Drs. Elaine Wirrell and Kelly Knupp, invited 13 centers to have a discussion about collaborating on research.**

From this discussion, two research studies were started: one on early life epilepsy, and the other on infantile spasms. Later, these research groups started to mobilize and organize the United States's pediatric epilepsy centers into a network built around collaborative research, their purpose to define and deliver the best possible care to children with early life epilepsies and then to improve that care through practice-changing research.





## Pediatric Epilepsy Research Consortium (PERC) & EAN Go to Capitol Hill



From Left to Right, PERC Leaders & Advocates: Ellie McCabe, Aaron Warren, Sonal Bhatia, John Schreiber, Jane McCabe, Mark Slater, Scott Perry, Nassim Zecavati and Alyssa Ailion go to Capitol Hill!



# PERC Programs

1. SIGS
2. AIR Accelerator Grants
3. Mentorship Program
4. Publications
5. Retreats & Member Interactions



**SIGs:**

**We now have 17  
SIGs and 10  
Subgroups!**

DEE-SWAS

EMAtS

Early Life Epilepsy

Epilepsy Behavioral Health

Epilepsy Surgery

Epilepsy Surgery Neuromodulation

Genetics

Health Equity

Infantile Spasms

Lennox-Gastaut Syndrome

Neuropsychology

Psychogenic Nonepileptic Seizures

Status Epilepticus

SUDEP

Sunflower Syndrome

Telehealth

Value-Based

**SIGs represent  
PERC's mission  
in action and  
need all the  
support we can  
provide them**

**PERF donated \$50,000 “to support PERC’s  
new ED,” so we’re putting half that toward  
the role of:**

## **SIG COORDINATOR**

**If we like where this goes, we’ll add a  
Project Management System**

**MONDAY.COM**



# AIR Accelerator Grants - Year 1

1. An Innovative Collaboration to Enhance Status Epilepticus Identification and Research
2. A Delphi Consensus on best practices for identifying and treating Early Life Epilepsies
3. Feasibility and Acceptability Qualitative insights (FAQS): Implementing Common Data Elements in Pediatric Health Equity
4. From Assessment to action: Optimizing Neuropsychological and Neurosurgical Communication in Epilepsy Surgical Planning
5. PERC Epilepsy Surgery Database Updating Seizure Outcomes Following Pediatric Epilepsy Surgery
6. Child Opportunity in Pediatric Epilepsy Surgery
7. Cognitive Phenotyping in Presurgical Pediatric Epilepsy
8. Process Mapping of Presurgical Epilepsy Evaluations Across Pediatric Epilepsy Centers in the United States
9. Assessment of Surgical Readiness in Caregivers of Patients During Phase I Evaluations
10. PERC Post-operative Risk Calculator Development: Predicting Language and Memory Outcomes After Pediatric Frontal and Temporal Lobe Epilepsy Surgery
11. Perspectives and experiences regarding pediatric epilepsy surgery among rural families

# Mentorship Program: Trainings, Talks, Webinars

Mentor	Mentee	Area of Focus
Madison Berl, PhD	Aimee Smith, PhD	Psychology
	Puck Reeders, PhD	
Adam Ostendorf, MD	Babitha Haridas, MD	Surgery
	Ruba Al-Ramadhani, MD	
Dennis Lal, PhD	Susan Fong, MD, PhD	Genetics
	Mahjabeen Ahmed Khan, MD	
Kristen Park, MD	Shital Patel, MD	Rare Disease Research
	Afsaneh Talai, MD	
Amanda Pong, MD, MSc	Aaron Warren, PhD	LGS, Clinical Trials Research
	Gozde Erdemir, MD	

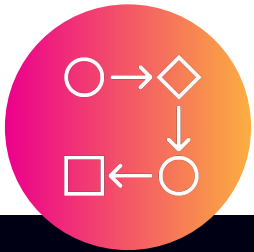
# **Growth & Impact**

**PERC's Exploratory Committee is pursuing two goals, which will propel PERC to COG status:**

- 1. Involvement in Clinical Trials**
- 2. Creation of a Central Database**

# Advocacy

**As PERC grows, so too do our advocacy efforts.**



## Advocacy Committee

PERC has a committee dedicated solely to advocacy..



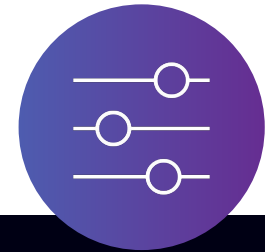
## Hill Visits

PERC participated in a Hill visit last year, and is grateful to EAN and its partners for arranging a second Hill visit this year.



## Virtual Campaigns

The Advocacy Committee is working with EAN and team toward aligning on talking points.



## National Plan

PERC as an organization does not have a formal role, but many of its members are actively involved. Most importantly, the plan relies on a reliable, collaborative infrastructure, and PERC brings that to the table.



THANK YOU