

# NAEC Pediatric Centers Meeting

Moderator: Dave Clarke

1. Overview of NAEC Pediatric Center Data – Adam Ostendorf, MD
2. A Neurosurgeon's Quest for Better Data – Sandi Lam, MD
  - 5 questions that Neurosurgeon's need to know.
  - 2 Questions that would be helpful, but not necessary.
3. Epilepsy data collection and existing hospital databases with seizure/epilepsy content, used by other subspecialities – Dave Clarke, MD

Reactions to presentations:

- How do AAN Quality of Life Metrics fit in – Anup Patel, MD
- Convincing administration of the need for support – Zach Grinspan, MD



# NAEC Pediatric Center Data

Adam Ostendorf, MD

# Background

- NAEC has 50 pediatric level 4 centers and 90 adult/peds combined centers
- Annual accreditation data includes:
  - Staffing
  - Services offered
  - Volume of admissions, EEG, surgeries, etc.
- Changed over time (2003-current)

# Accreditation Data

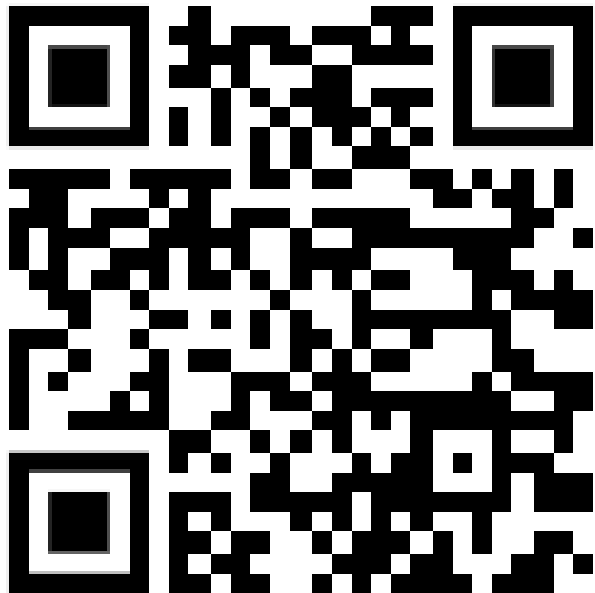
- Several publications with details, trends over time, and impact from COVID pandemic
- 2003-2012 reviewed by Kaiboriboon et al.
- Pre-accreditation changes



Kaiboriboon et al.,  
Epilepsy Res. 2015

# Accreditation Data

- Data from 2012-2019 were reported this year
- Reported changes in staffing and volumes across center types



Ostendorf et al.,  
Neurology 2022

# Accreditation Data

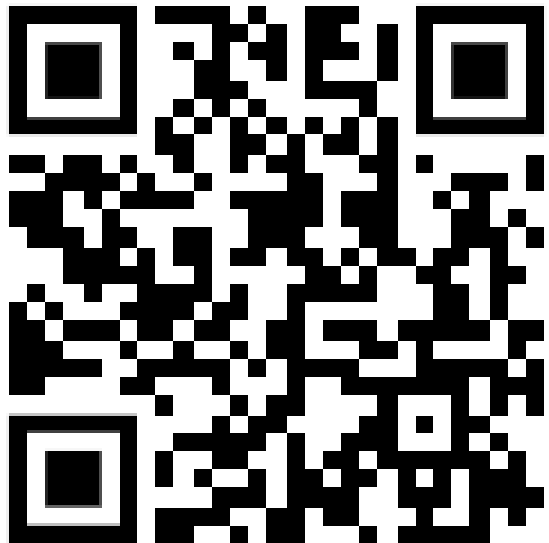
- Data from 2019-2020 were reported this year
- Reported COVID-related impacts



Ahrens et al.,  
Neurology 2022

# NAEC Center Director Study Group

- Surveys meant to better understand center needs and practices
- Inform centers and upcoming guidelines
- Testing patterns published this year



Ahrens et al.,  
Epilepsia 2022

# NAEC Center Director Study Group

- Treatment patterns were also reported this year
- Several others submitted or in publication



Arredondo et al.,  
Neurology 2022



# Gaps

- NAEC mission includes standard setting
- ILAE and others have volume-based recommendations for surgery centers
- Based on volume-complication associations (Kwon 2020; Englot 2013)
- Current NAEC data include volumes but not outcomes
- Centers have little/no feedback

# Future State

- NAEC goal is to use outcomes data to develop outcome measures and better incentivize care
- NAEC data pilot for new accreditation data
  - 3 years, iterative and voluntary
  - Changes in data collection (patient-level)
  - Focus on outcomes

# More to come...

- More info tomorrow at the NAEC Annual Meeting
- 7:00 to 8:30 in Legends Ballroom G (Omni)

# Quest for Better Data Neurosurgery perspective

Sandi Lam MD MBA

Division Chief, Pediatric Neurosurgery, Lurie Children's Hospital

Professor & Vice Chair, Neurosurgery, Northwestern University Feinberg School of Medicine

David McLone endowed professorship in Pediatric Neurosurgery



Establish shared values

## **Take care of patients well**

- Right care
- Right place
- Right time

## **Continually pursue “better”**

- Outcomes
- Quality & safety
- Efficiency

# Answers to

## 5 questions that neurosurgeons need to know

Is this SAFE?

Are we HURTING people?

How are we HELPING people?

Can we do it BETTER?

Are we helping in a TIMELY manner?

## 2 questions that would be helpful

How to improve ACCESS?

How to improve INTEGRATION of health systems needs?

## ...but may not ask

How do we fit in patients' lives?

social

financial

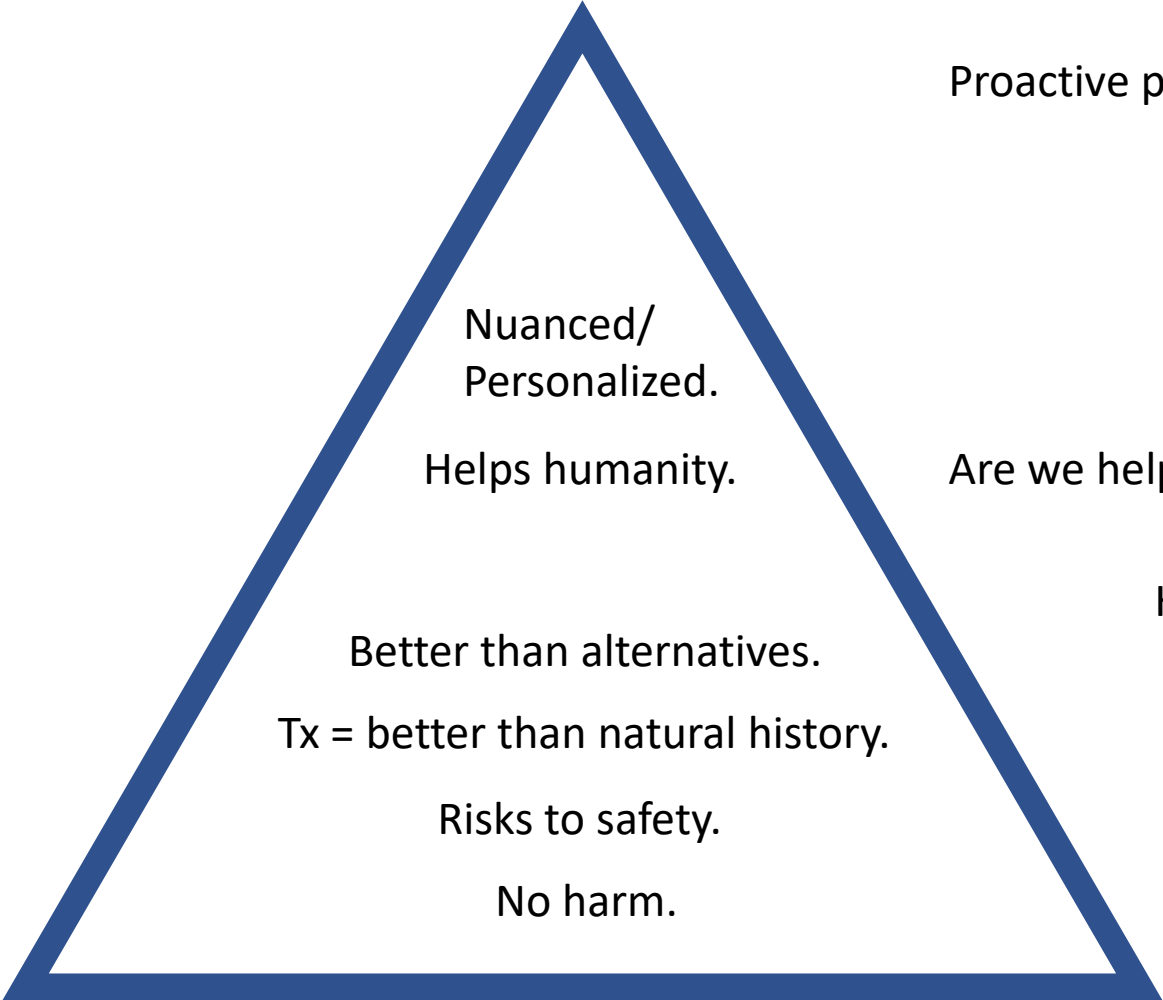
direct & indirect costs

How can we make it easier/better?

Demonstrate in order to do surgery ethically.

Helpful to know

Need to know



Proactive prediction & risk modification

Are we helpful everyone who can benefit?

How are we doing it?

Should this be done?

Is this safe?



# More than just neurosurgery

In order to have good surgical outcomes:  
timely referral, workup & good patient selection are key

What happens before getting to surgical evaluation?

How do we identify & lower barriers?







Right  
care



Right  
setting



Right  
time



Putting it into practice

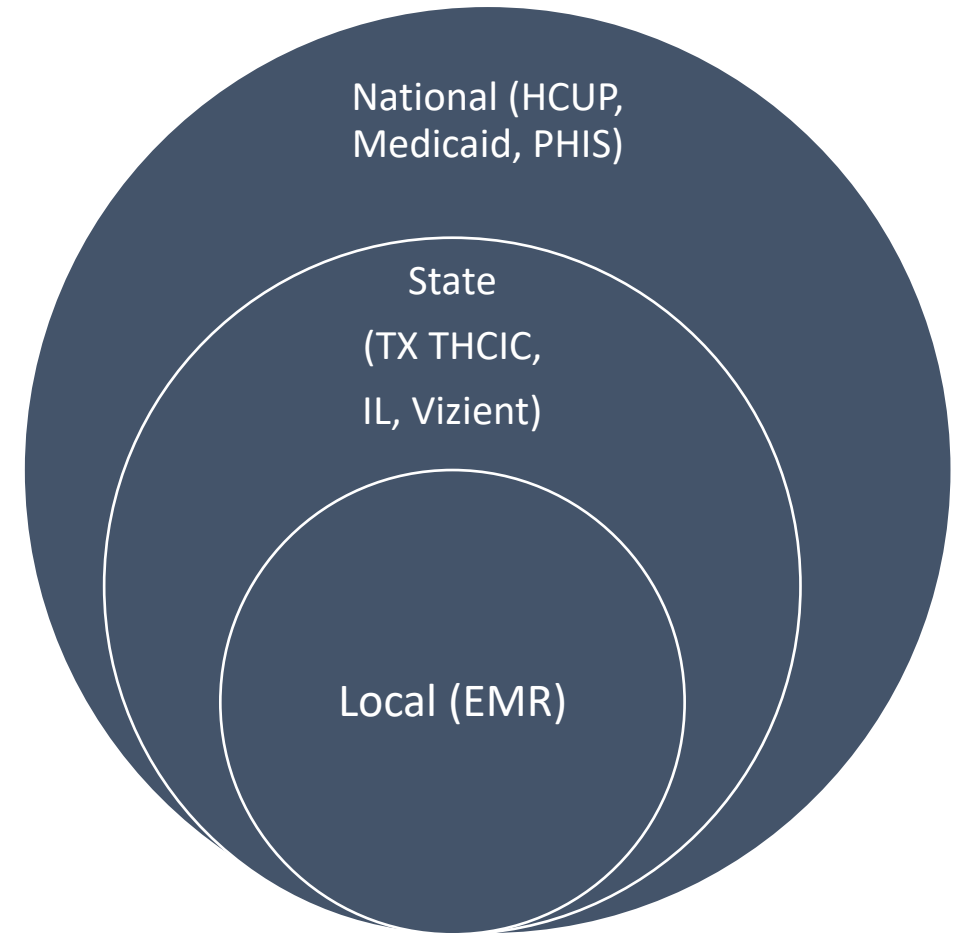
Pediatric hospital data and resources that already exist in most settings

Name	# Hospitals	Representative + example ques.	Function
Childrens Hospital Association	220	A: # ASM's floor pixel	Safety; collaborative projects together
Solutions for Patient Safety	>145	B: Epi related injuries	QI –Learn from other hospitals (which has the least).
Pediatric Health Information System	44	C: Fairly detailed: codes	Most detailed and data driven
Vermont Oxford Network	1400 Neonatal Hosp.	D: ASM's Neonates	Neonatal data
Trauma Registry	31 level 1 and 32 level 2 PTC	E: When stop AED's	Trauma related
Virtual Pediatric System Registry	>200 ICU settings	F: Post op stay	PICU
Congenital Heart Surgery - STS	>120	G: Stroke vs Sz	Cardiac Surgery related
PC4 – Pediatric Cardiac Critical Care Consortium	>70 Hosp	H: Most 3 common ASMs	Cardiology related conditions and pathology

# Other data sources



MARKETSCAN® RESEARCH



# The Effectiveness of Medical and Surgical Treatment for Children with Refractory Epilepsy

## Retrospective Study

Children's Hospital  
Association PHIS Database



Pediatric, Refractory  
Epilepsy, 2008-2014  
(n = 78 839)



Treated Medically or  
Surgically  
(n = 12 292)



Matched Cases  
(2025 pairs, n = 4050)

## Outcomes

Survival at 2-and 5- years:

- Medical: 98.07% and 96.66%
- Surgical: **99.58% and 98.99%**

There were significantly fewer:



ER, Ambulatory, and Inpatient  
Visits.



Significantly fewer AEDs used

## Key Findings

Surgically compared to medically  
treated group had significantly:

- ↓ Inpatient visits
- ↓ Ambulatory visits
- ↓ ED visits
- ↓ AEDs used
- ↑ Survival rates

## Conclusions

Pediatric epilepsy surgery  
provides favorable outcomes,  
long-term effectiveness, and  
decreased healthcare use  
compared to medical  
management over time.

Need to lower barriers in  
access to care  
to help more children

Pan et al. *Neurosurgery*. July 2020

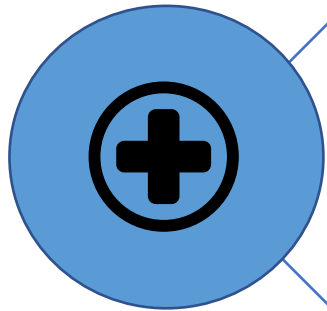
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NEURO SURGERY  
THE REGISTER OF THE NEUROSURGICAL MEME

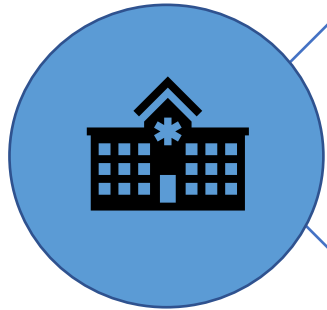


# Healthcare utilization was reduced in the surgical group

at 5 years after the index/treatment date:



↓ 37% of all-cause inpatient visits, 50% of ED visits

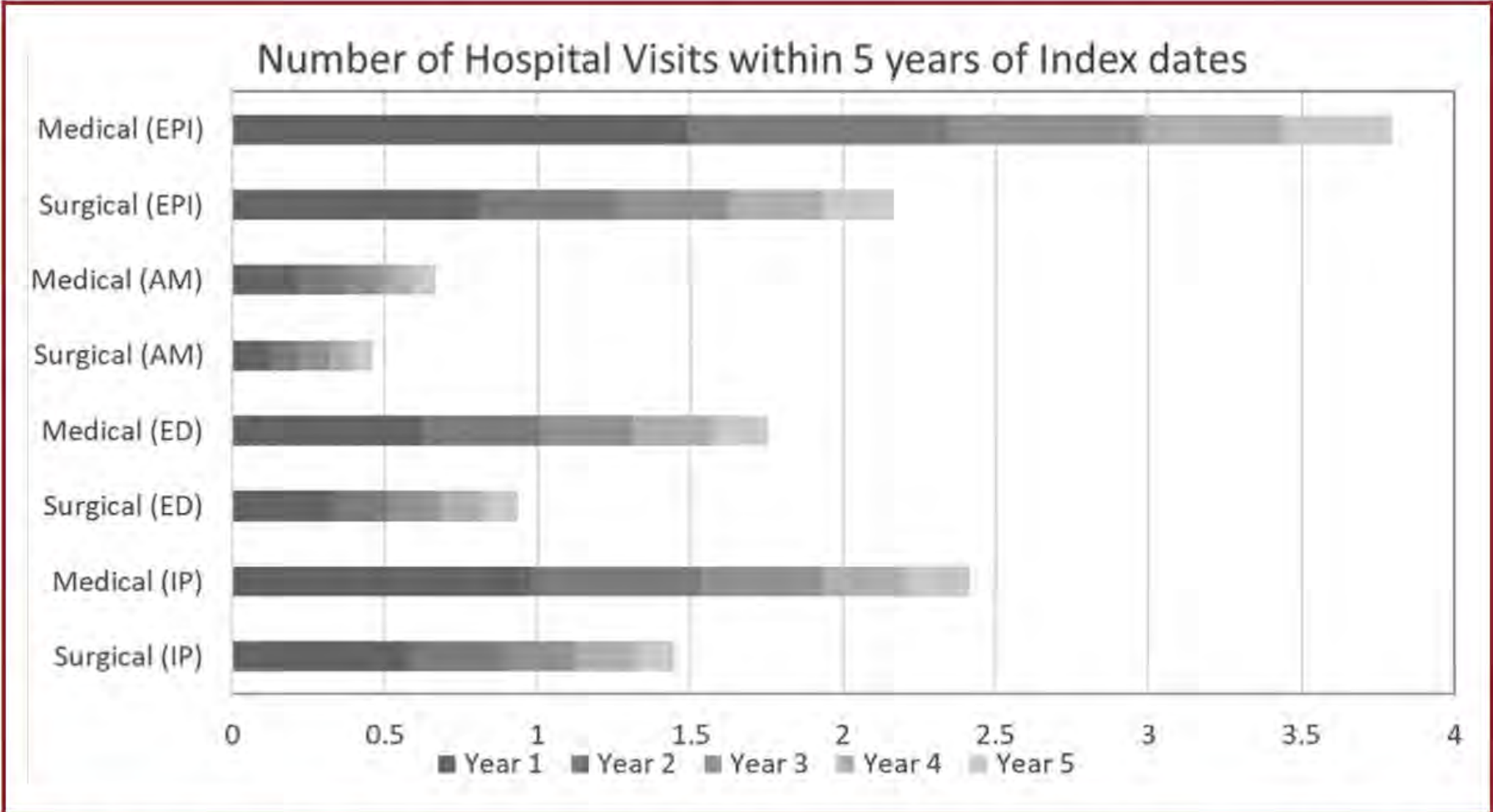


↓ epilepsy-associated visits by 43% in the surgical group compared to the medical group



↓ AEDs by 16% more in surgical group  
↑ survival rates in surgical group





**FIGURE 2.** *Number of hospital visits, for epilepsy related, ambulatory, ED, and IP visits, trended over 5 yr postindex, demonstrate reduction in visits in the surgical group compared to the medical group.*



Individual site



# Single institution retrospective chart review

98 patients, same diagnosis:  
cortical dysplasia  
Retrospective chart review

Time between diagnosis & surgery  
Disparities found by  
distance to hospital  
insurance  
race

Pediatric Neurology 107 (2020) 71–76



ELSEVIER

Contents lists available at [ScienceDirect](#)

**Pediatric Neurology**

journal homepage: [www.elsevier.com/locate/pnu](http://www.elsevier.com/locate/pnu)

Original Article

## Sociodemographic Factors in Pediatric Epilepsy Surgery

Hudin N. Jackson, MD<sup>a</sup>, Nisha Gadgil, MD<sup>a</sup>, I-Wen Pan, PhD<sup>b</sup>, Dave F. Clarke, MD<sup>c</sup>,  
Kathryn M. Wagner, MD<sup>a</sup>, Christopher A. Cronkite, BS<sup>a</sup>, Sandi Lam, MD, MBA<sup>d, e, \*</sup>

**TABLE 3.**  
Comparison of Seizure and Demographic Characteristics by Race

Patient Characteristics	White		Non-White	P Value
	Non-Hispanic n = 48 n (%)	Hispanic n = 32 n (%)	n = 14 n (%)	
Sex				
Male	26 (54)	19 (59)	9 (64)	0.77
Female	22 (46)	13 (41)	5 (36)	
Distance traveled				
In-state (median = 30.7 miles)				0.0003
Below median distance	9 (19)	20 (63)	8 (57)	
Above median distance	23 (48)	11 (34)	3 (21)	
Out-of-state (median = 619 miles)	16 (33)	1 (3)	3 (21)	
Health insurance				
Private	44 (92)	16 (50)	9 (64)	0.001
Government funded	2 (4)	13 (41)	5 (36)	
Uninsured	2 (4)	3 (9)	0 (0)	
Seizure type				
FGTC	16 (33)	20 (63)	9 (64)	0.02
Focal	32 (67)	12 (38)	5 (36)	
Previous surgery				
Yes	17 (35)	10 (31)	6 (43)	0.75
No	31 (65)	22 (69)	8 (57)	
Anatomical location				
Temporal	21 (44)	21 (66)	5 (36)	0.08
Extratemporal	27 (56)	11 (34)	9 (64)	
Seizure onset				
Median, S.D. (yr)	4.00, 4.30	3.00, 3.28	3.00, 3.28	0.37
Age at surgery				
Median, S.D. (yr)	12.0, 6.00	11.0, 5.60	12.0, 6.60	0.64
Epilepsy duration				
Median, S.D. (yr)	4.00, 4.22	6.58, 4.70	9.50, 6.50	0.03
Preoperative medications				
Median, S.D.	2.00, 1.00	2.00, 0.80	2.00, 1.15	0.05
Failed antiseizure medications				
Median ± S.D.	2.00, 1.82	2.00, 2.00	2.00, 2.85	0.83
Postoperative medications				
Median ± S.D.	2.00, 0.99	2.00, 0.95	2.00, 1.29	0.10

Abbreviation:

FGTC = Predominantly focal to generalized tonic-clonic seizures

Patients of nonwhite race:

had longer duration of epilepsy before receiving epilepsy surgery

>3 years

more likely on Medicaid

traveled a shorter distance to the hospital



# How do we interpret & learn from these findings?

- Appropriate and timely referral?
- Barriers in access to care
- Socioeconomic
- Ethnocultural
- Health literacy
- Education of primary care MDs
- Managing expectations

**TABLE 4.**

Comparison of Seizure and Demographic Characteristics by Distance Traveled

Patient Characteristics	In State		Out-of-State	P Value
	Below Median n = 37 n (%)	Above Median n = 37 n (%)	n = 20 n (%)	
Gender				
Male	24 (65)	21 (57)	9 (45)	0.22
Female	13 (35)	16 (43)	11 (55)	
Seizure type				
FGTC	22 (59)	17 (46)	5 (25)	0.04
Focal	15 (40)	20 (54)	15 (75)	
Previous surgery				
Yes	13 (35)	12 (32)	8 (40)	0.61
No	24 (65)	25 (68)	12 (60)	
Seizure onset (yr)				
Median, S.D.	2.25, 4.05	4.00, 4.76	2.00, 3.27	0.16
Age at surgery (yr)				
Median, S.D.	15.0, 5.62	12.0, 6.20	6.00, 4.78	0.005
Epilepsy duration (yr)				
Median, S.D.	9.00, 5.31	5.00, 4.42	3.00, 4.12	0.01
Preoperative medications				
Median, S.D.	2.00, 0.89	2.00, 0.75	3.00, 1.32	0.01
Failed antiseizure medications				
Median, S.D.	2.00, 2.14	2.00, 1.61	3.00, 2.37	0.06
Postoperative medications				
Median, S.D.	2.00, 1.72	2.00, 1.37	3.00, 1.69	0.46

Abbreviation:

FGTC = Predominantly focal to generalized tonic-clonic seizures

# Healthcare encounters as opportunities for HEALTH

not just for sickness

# Define at-risk times

## Offer appropriate intervention & support

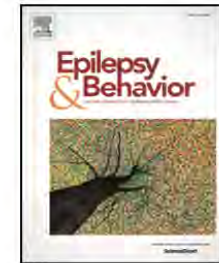
Epilepsy & Behavior 89 (2018) 48–54



Contents lists available at ScienceDirect

### Epilepsy & Behavior

journal homepage: [www.elsevier.com/locate/yebeh](http://www.elsevier.com/locate/yebeh)



## Insurance transitions and healthcare utilization for children with refractory epilepsy☆☆☆



I-Wen Pan <sup>a,b,\*</sup>, Sandi Lam <sup>a,b</sup>, Dave Fitzgerald Clarke <sup>c,d</sup>, Ya-Chen Tina Shih <sup>e</sup>

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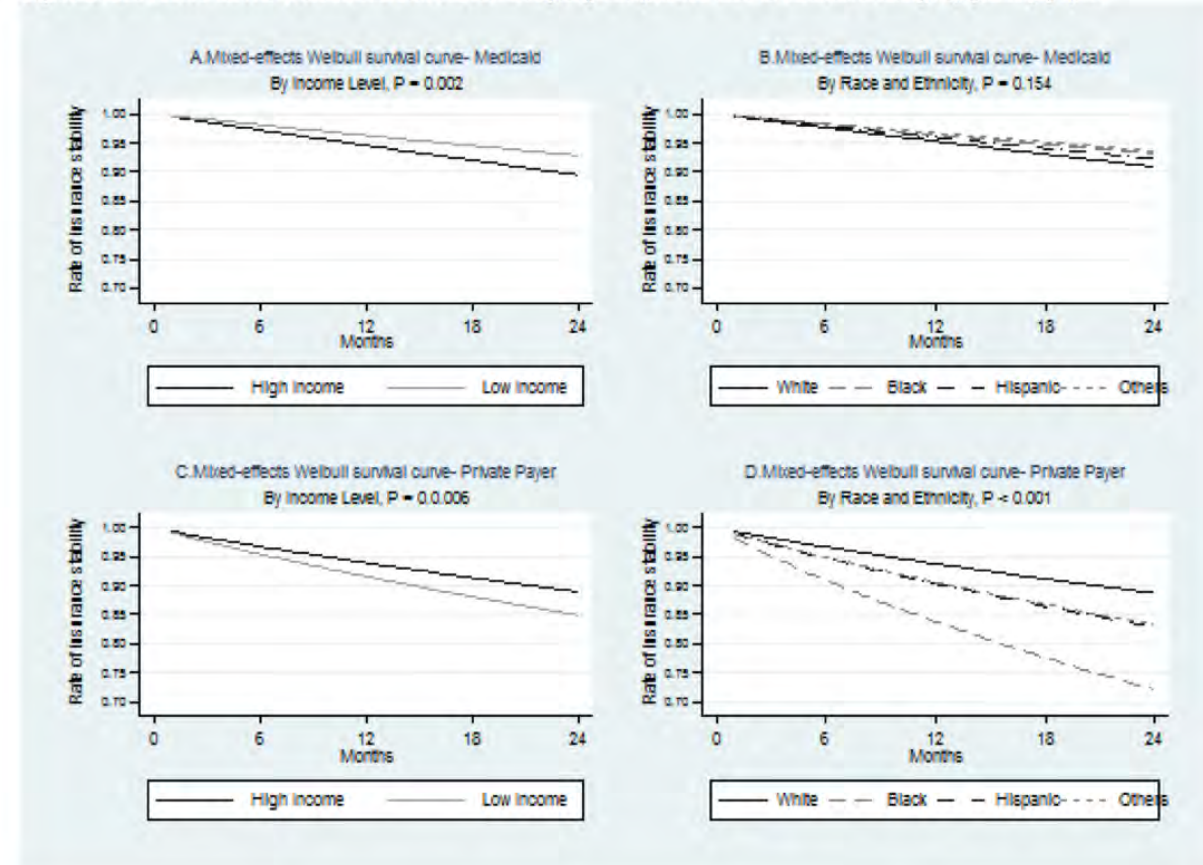
# Medicaid has an important role: stable insurance coverage

3488 pediatric epilepsy patients  
with drug-resistant epilepsy:

Changes in insurance associated with higher risk  
of epilepsy-related ER utilization

**Stable healthcare coverage is essential** for  
children with epilepsy

Figure 2: The Mixed-effects Weibull survival curves - subgroup analysis for time to insurance change by primary payer



# So much more to do

Who What When Where Why How?

Thank you

[slam@luriechildrens.org](mailto:slam@luriechildrens.org)



[@lurieneurosurg](https://www.instagram.com/lurieneurosurg)

**M Northwestern Medicine®**  
Feinberg School of Medicine





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



## 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:  
Sandi Lam MD MBA *Neurosurgeon/Health Services*  
Marc Rosenman MD *Pediatrician/Informatics*  
Anup Patel MD *Epileptologist/Quality*  
Tracy Dixon-Salazar PhD *Neuroscientist/Advocacy*

## 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>



1) PEDSnet sites  
2) other PCORnet sites

Aims 1a, 1b, 2  
Mixed Methods  
& EHR data  
Kickoff 2022

### 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>

Aim 2  
EHR data  
Kickoff 2023



# NAEC Pediatric Center Overview

Dave Clarke, MD

- *Introduction to public health surveillance, CDC: **Pediatric Epilepsy** surveillance is “the ongoing, systematic collection, analysis, and interpretation of health-related data essential to planning, implementation, and evaluation of public health practice.” — Field Epidemiology*

- Institute of Medicine (US) Committee on the Public Health

### **Dimensions of the Epilepsies.**

England MJ, Liverman CT, Schultz AM, et al., editors. Epilepsy Across the Spectrum: Promoting Health and Understanding. Washington (DC): National Academies Press (US); 2012. 2, Surveillance, Measurement, and Data Collection. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK100594>

- *“Data collection is the first step toward better classification and understanding of the problems individuals with epilepsy and their families face. These data are critical to position us to make informed decisions on deploying limited resources ... [to] improve the life of individuals and their families .... We are dealing with a poorly addressed public health problem, and we urge you to help us better define its many dimensions and magnitude in order to begin to offer desperately needed solutions.”*

• –Michelle Marciniak

- The committee's vision for effective epilepsy surveillance involves:
- active and passive data collection systems that follow standardized methodologies to obtain valid measurement.
- Systems need to be coordinated, comprehensive, accurate, and timely.
  - In times of economic constraint, collaborative efforts may facilitate this surveillance.
- Surveillance data can be used to achieve a range of goals, including:
  - guiding programs and policies aimed at prevention, treatment, and rehabilitation;
  - detecting barriers in health care access and quality,
    - such as delayed diagnosis, treatment gaps, and disparities
  - determining optimal service delivery models that are cost-effective; and
  - providing a basis for further epidemiologic and health services research.

# EPILEPSY DATA ELEMENTS, IOM report 2012

Age (including birth date when possible)  
Sex  
Geographic location  
Race/ethnicity  
Personal and family demographics  
    Relationship status  
    Household composition  
    Educational attainment  
    Employment status  
Occupation  
    Income  
Personal  
Household  
Current health status  
    General health status  
    Epilepsy-specific status  
    Current medical treatment status  
Surgical status  
    Disability status  
    Mortality

Epilepsy-related  
    Age at onset  
    Seizure type and frequency  
    Epilepsy syndrome  
    Etiology  
Stability of underlying condition  
    Severity  
Comorbidities  
    Somatic disorders  
    Neurological disorders  
    Mental health conditions  
    Cognitive disorders  
    Infectious diseases  
    Infestations  
    Physical disabilities  
    Injuries  
    Nutritional problems  
Health insurance status  
Health care  
    Source of care  
    Type and frequency of use  
    Quality of care  
    Patient's perceptions of care quality  
    Direct costs  
Use of informal and community services  
    Type of caregiver  
    Type of community service

Quality of life  
    Overall quality of life  
    Seizure worry  
    Emotional well-being  
    Energy-fatigue  
    Cognitive functioning  
        Attention or concentration  
Memory  
    Medication effects  
    Social functioning  
    Role limitations  
Emotional  
Physical  
    Stigma  
Enacted  
Felt  
    Indirect costs

Thurman DJ, Beghi E, Begley CE, Berg AT, Buchhalter JR, Ding D, Hesdorffer DC, Hauser WA, Kazis L, Kobau R, Kroner B, Labiner D, Liow K, Logroscino G, Medina MT, Newton CR, Parko K, Paschal A, Preux PM, Sander JW, Selassie A, Theodore W, Tomson T, Wiebe S. Standards for epidemiologic studies and surveillance of epilepsy. *Epilepsia*. 2011;52(Suppl. 7):2–26.

# Few extremely important questions from Colleagues!?!

## 1. Is the data available?

Do we have to create another database? Is IRB necessary? Is it complicated? Will it be difficult for the families?

## 2. What is the cost?

Will it be supported by Admin.? Where do I find the resources?

## 3. Who is going to collect it?

We don't have the time! We don't have personnel!

## 4. Who is going to analyze it?

Not everyone has a grant, statistician, writer etc.

## How does it benefit my patient/ me/ hospital/ colleagues/ program?

Will this help in QI? Not everyone is a part of National research groups - ELHS, PELHS, PERC, MRLitt etc.

Are we collecting data for others to benefit from? Will the same few centers/persons benefit from publications? How does this help promote junior faculty?

# Practical examples

## Basic (Chart)

### *Demographic*

Age/Sex/handedness,  
Insurance, Zip code, Language,  
Ethnicity/Race.

Family history of epilepsy or  
epilepsy related factors  
Health/systemic factors related  
to epilepsy

## Epi related (NAEC+ Chart)

Age at onset, type(s), frequency,  
syndrome/ etiology,  
comorbidity(s).

### *Invest./Management*

Present ASM(s), Past ASM(s),  
Device, Prior surgery/ablation,  
Investigative studies (MRI,  
VEEG, PET, SISCOM, PET...).

# QOL

Last Neuropsy. eval, Function  
(stable/improve/decline), Sz.  
Related morbidity, Med related  
morbidity, Sleep


Emotions (depression,  
anxiety...), School, Extra  
curricular, Stigma (felt – teased),  
Does Epi affect Family?

**Reach across the aisle!!**  
 Pediatric hospital data and resources that already  
 exist in most 3<sup>rd</sup> and 4<sup>th</sup> level Centers.

Name	# Hospitals	Representative + example ques.	Function
Childrens Hospital Association	220	A: # ASM's floor pixel	Safety; collaborative projects together
Solutions for Patient Safety	>145	B: Epi related injuries	QI –Learn from other hospitals (which has the least).
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Trauma Registry	31 level 1 and 32 level 2 PTC	E: When different centers start and stop AED's	Trauma related
Virtual Pediatric System Registry	>200 ICU settings	F: Post op stay post procedure	PICU
Congenital Heart Surgery - STS	>120	G: Stroke vs Sz	Cardiac Surgery related
PC4 – Pediatric Cardiac Critical Care Consortium	>70 Hosp	H: Most 3 common ASMs used	Cardiology related conditions and pathology




“It is a capital mistake to theorize before one has data.” — Sherlock Holmes.



Never forget that intelligence rules the world and ignorance carries the burden. Therefore, remove yourself as far as possible from ignorance and seek as far as possible to be intelligent.

— Marcus Garvey —

AZ QUOTES



“  
Everybody gets so much information all day long that they lose their common sense.


Gertrude Stein  
(REFLECTIONS ON THE ATOM BOMB 1946)

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“With data collection, ‘the sooner the better’ is always the best answer.”

Marissa Mayer  
IT executive and co-founder of Lumi Labs, former Yahoo! president and CEO




If we have data, let's look at data. If all we have are opinions, let's go with mine.

- Jim Barksdale  
Former Netscape CEO



**Torture the data, and it will confess to anything.**

- Ronald Coase  
British Economist and Author



It's easy to lie with statistics. It's hard to tell the truth without statistics.

- Andrejs Dunkels

Ask big of Admin!! Start basic!! Start Now!!  
Don't run into the “academic-equity paradox”!!

# NAEC Accreditation – Changes in Pediatric Criteria for 2023 and 2024

## For 2023

- **One Pediatric Epilepsy Specialist for Pediatric and Adult/Pediatric Centers:** Pediatric and adult/pediatric centers must have a board-certified pediatric epileptologist, who has ABPN Child Neurology board certification in addition to at least one of the following board certifications: ABPN epilepsy, ABPN clinical neurophysiology, ABCN clinical neurophysiology, or ABCN epilepsy monitoring.
- **Referral Relationships Between Level 3 and 4 Centers:** Level 3 Centers going through the full accreditation process will be required to upload proof of adult and pediatric patient referrals depending on the demographic served by the center.

## For 2024

- **Separate Accreditation for Adult and Pediatric Centers Requiring Adult/Pediatric Centers to Seek Separate Accreditation:** All adult/pediatric centers will be required to separate or to choose to be either an adult or pediatric center. If the center chooses to separate into adult and pediatric centers, then each center will need to meet all criteria for its desired level independently – each will complete the full accreditation process, pay separate dues, and would be listed separately in NAEC’s member directory. Centers could apply for different levels of accreditation for its pediatric and adult centers.
- **New Core Criterion:** Pediatric centers will be required to submit a VEEG EMU report for a patient under age 2. Pediatric centers that cannot provide this could be accredited as adult centers if they can meet all other criteria for adult centers.