NAEC Annual Meeting

December 4, 2023

Agenda

1. Welcome and 2023 Update – Dr. Fred Lado

   a. NAEC Operations Update

   b. 2023 Activities and Accomplishments

2. Accreditation Changes for 2024 – Dr. Stephan Schuele

3. NAEC Pilot Program – Dr. Kate Davis and Dr. Adam Ostendorf

2023 NAEC Update

Dr. Fred Lado
NAEC President

2023 NAEC Epilepsy Center Accreditation

Center Demographic			
	Adult	Adult/Pediatric	Pediatric	Total
Level 4	79	71	46	196
Level 3	43	11	4	58
Total	122	82	50	254

NAEC Centers Accredited by Year							
	2023	2022	2021	2020	2019	2018	2017	2016
Level 4	196	198	197	199	192	188	181	184
Level 3	58	61	62	57	54	52	52	41
Total	254	259	259	256	246	240	233	225

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2023 Activities and Accomplishments

Standard Setting

Advocacy

Member Center Support

Community

Assuring quality epilepsy care by supporting strong specialized epilepsy centers

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2023 Activities: Standard Setting

- Completed the 2023 Accreditation Process

- Updated Accreditation Criteria and Process for 2024

- Epilepsy Center Guidelines completed and submitted for publication

2023 Activities: Advocacy

- Worked with AES and ACNS to advocate with CMS re: Epileptologist Subspeciality Designation

- Analysis and comments on Medicare regulations

- Analysis of the end of the COVID PHE on telehealth and Medicaid Enrollment

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2023 Activities: Member Center Support

- Work Group Activities
  - Epilepsy Center Tools and Resources
  - Marketing and Improving Access to Underserved
  - Surgical Data Pilot Program
- Webinars
  - NAEC 2023 Accreditation and Trends Data
  - Business Planning for NAEC Centers
  - Roles of Technologists and Neuroanalysts in Epilepsy Centers – Collaboration with ASET and ABRET
- Responded to questions from members on accreditation, coding, reimbursement, insurance coverage policies

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2023 Activities: Community

- Work with AES, ACNS, AAN, CNF, CNS on advocacy and other issues

- Leadership roles in Epilepsy Leadership Council – serving on Steering Committee and as Co-Chair of Advocacy Work Group

- Joining AES/ILAE Joint Taskforce on Epilepsy Healthcare Disparities

Thank You to 2023 NAEC Volunteers!

Accreditation Committee
Dr. Meriem Bensalem-Owen – Chair
Dr. Christi Heck
Dr. Ammar Kheder
Dr. P. Jay Foreman
Dr. John Stern

Finance Committee
Dr. Mohamad Koubeissi – Chair
Dr. Ahmed Abdelmoity
Dr. Madeline Fields

Guidelines Panel
Dr. Susan Arnold – Co-Chair
Dr. Fred Lado – Co-Chair

Guidelines Oversight Committee
Dr. Christi Heck – Co-Chair
Dr. David Labiner – Co-Chair
Dr. Stephan Schuele
Dr. Kevin Chapman
Dr. Lara Jehi

Data and Survey Work Group
Dr. Adam Ostendorf – Chair
Dr. Stephanie Ahrens
Dr. Anto Bagic
Dr. Kevin Chapman
Dr. Nathan Fountain
Dr. Jay Gavvala
Dr. Kyle Rossi

Thank you to 2023 NAEC Volunteers!

Tools and Resources Work Group
Dr. Ahmed Abdelmoity, Chair
Dr. Meriem Bensalem-Owen
Dr. Liu Thio
Dr. Sima Patel
Dr. Stephan Schuele
Dr. Dan Weber

Surgical Pilot Work Group
Dr. Kate Davis, Co-Chair
Dr. Adam Ostendorf, Co-Chair
Dr. Leo Bonilha
Dr. Sue Herman
Dr. Lawrence Hirsch
Dr. John Pollard
Dr. John Rolston
Dr. Stephan Schuele

Marketing and Access Work Group
Dr. Dave Clarke – Chair
Gabrielle Conecker
Dr. Fred Lado
Dr. Suchetta Joshi
Dr. Emily Klatte
Dr. Sandi Lam

NAEC Coding Session
Dr. Greg Barkley
Dr. Jonathan Edwards
Dr. Sue Herman
Dr. Marc Nuwer

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Thank You to NAEC Staff!

- Ellen Riker, Executive Director
- Johanna Gray, Deputy Director
- Barbara Small, Programs Manager

NAEC Board for 2024

President	**Fred Lado, MD, PhD** Hofstra Northwell Comprehensive Epilepsy Center
Vice President	**Stephan Schuele, MD, MPH** Northwestern Medicine Comprehensive Epilepsy Center
Secretary/ Treasurer	**Dave Clarke, MD** Dell Children's Medical Center
At-large	**Ahmed Abdelmoity, MD** Children's Mercy Epilepsy Center
At-large	**Kathryn Davis, MD** University of Pennsylvania
At-large	**Jennifer Hopp, MD** University of Maryland
At-large	**Mohamad Koubeissi, MD** George Washington University
Past President	**Susan Herman, MD** Barrow Neurological Institute

2024 Activities and Accomplishments

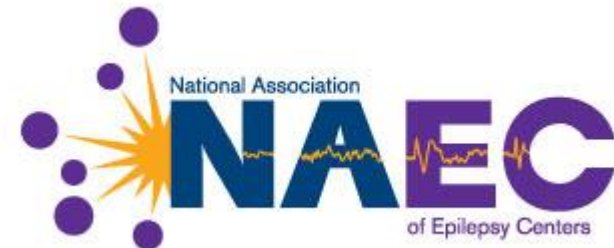**Standard Setting**

Advocacy

Member Center Support

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Assuring quality epilepsy care by supporting strong specialized epilepsy centers

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2024 Activities

- Publication of Epilepsy Center Guidelines
  - Dissemination and promotion of guidelines
  - Initiating process to incorporate guideline recommendations into NAEC center accreditation
  - Evaluation of living guideline model for updating guidelines.

2024 Activities

- Improving Access to Accredited Epilepsy Centers
  - Exploring expanding access to epilepsy centers for underserved communities
  - Furthering relationships with American Academy of Pediatrics and National Association of Pediatric Nurse Practitioners
  - Promoting an epilepsy screening tool for primary care providers to improve referrals to epilepsy centers

2024 Activities

- Final year of NAEC 3-Year Surgical Data Pilot
- Website Rebuild
- Developing Resources and Tools for Epilepsy Centers
  - Webinars on center management – staffing models and job descriptions
  - Toolkit

Call for Nominations

- Accreditation Committee – one slot
- Work Groups
  - Data and Survey Work Group
  - Tools and Resources
 - Marketing and Access

Questions?

NAEC Accreditation Updates

Dr. Stephan Schuele

NAEC Vice President

2024 Accreditation Timeline

- **November 7, 2023:** NAEC 2024 accreditation process began; Instructions distributed.
- **January 31, 2024:** Deadline to pay dues, complete the Center Annual Report, upload required documents to Box.com, and complete the supplemental survey.
- **February 1-15, 2024:** Review and Revise Period: NAEC staff will review your center's submission for completion and let you know if anything is missing.
- **March 1, 2024:** Final deadline for any revisions or additions. **We cannot accept dues or materials after this date.**
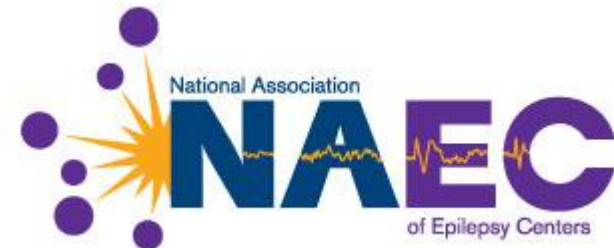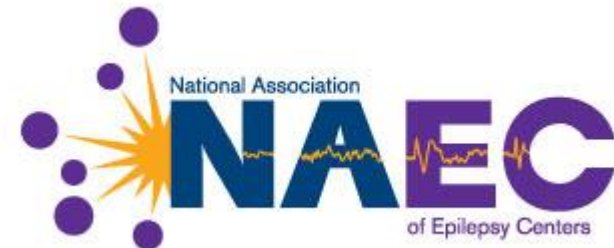
Overview of 2024 Changes

- New core criterion for pediatric centers
- Epileptologist and neurosurgeon requirements for level 3 centers
- Intracranial monitoring for level 4 centers
- Neuromodulatory devices
- Ongoing staff training
- Curing deficiencies
- "Access to" vs. on-site standards for all centers
- Split for adult/ped centers

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New Core Criterion for Ped Centers

- As announced last year, starting in 2024, pediatric centers will be required to submit a VEEG EMU report for a patient under age 2.

- This will be a core criterion, meaning that pediatric centers that cannot meet this criterion will lose their accreditation (the center cannot receive conditional accreditation).

Epileptologist and Neurosurgeon Requirements for Level 3 Centers

- Level 3 centers will no longer be required to have two board-certified epileptologists on staff; level 3 centers can be accredited with only 1 board-certified epileptologist.

- If a level 3 center only implants VNS devices (rather than performs other neurosurgical procedures), it can list an ENT rather than a neurosurgeon.

Intracranial Monitoring

- Level 4 centers and level 3 centers that perform surgery completing the full process in 2024 must report – and provide de-identified patient reports for – six intracranial cases from 2021 to 2023 with at least one 2023 intracranial case.
- Centers completing the full process in 2025 will have to comply at that time.

Neuromodulatory Devices

- The prior requirement for centers to "implant and manage VNS and other neuromodulatory devices" was separated into distinct criteria to be clearer.

- There will be separate requirements for implantation of VNS, management of VNS, implantation of RNS or DBS, and management of RNS or DBS. See below:

New Neuromodulatory Criteria			
Criterion	**Level 3 Nonsurgical**	**Level 3 Surgical**	**Level 4**
Implantation of VNS	Not required	Required if perform	Required
Management of VNS	Required	Required	Required
Implantation of RNS or DBS	Access to (adult only)	Access to (adult only)	Access to (adult only)
Management of RNS or DBS	Access to (adult only)	Access to (adult only)	Access to (adult only)

Ongoing Training

- Centers will be required to list an additional nurse who has completed the AANN/NAEC training module each year, until they reach 51% of their nurses.

- In a center's full accreditation year, they will have to submit proof of training for the nurse they list this year and last year, if appropriate.

Curing Deficiencies

- NAEC centers can address or "cure" deficiencies after the accreditation process concludes only for missing personnel or documents (if the service was performed in the relevant year, but the report hadn't been submitted).

- Centers cannot cure an inadequate number of admissions or lack of a service (i.e., centers can't count a January 2024 surgery for the 2023 thresholds). For those services, it is only what the center performed in the given calendar year that can be counted.

Access to Vs. On-Site Criteria

- Clarified that certain criteria now only "access-to" (does not need to be within 4 walls of center):
  - Wada testing or functional neuroimaging
  - Cerebral angiography
  - Interictal PET or ictal/interictal SPECT
  - Implantation and management of RNS and DBS
  - Neuropsychologist
  - Neuroradiologist

Adult/Pediatric Center Split

- All adult/ped centers completing the 2024 full accreditation process will be accredited as an adult **OR** pediatric center or as **separate** adult and pediatric centers.

- Adult/ped centers completing the full process in 2025 will meet requirements then.

- Centers that split may have different accreditation levels for the adult and pediatric programs

Adult/Ped Split –
Centers that Choose One Demographic

- Centers that choose to not split – but to be only an adult center or a ped center – must meet all relevant criteria for their chosen demographic.

- As is currently true, adult centers can include EMU admissions and procedures for patients under age 18, and pediatric centers can include EMU admissions and procedures for patients over age 18.

Adult/Ped Split – Shared vs. Separate Resources

- It is preferable for an adult and a pediatric center at the same institution to have separate EMUs.

- If there are two EMUs, centers can count all relevant admissions to each EMU, regardless of the patient age (i.e., a ped center with a separate ped EMU can count admissions for patients aged 18+).

- If there is one EMU shared between the centers, only the adult (age 18+) patients will count towards the adult center and only admissions age <18 will count for the pediatric center.

Adult/Ped Split –
Shared vs. Separate Resources

- Centers may share staff but they must be listed in both Center Annual Reports

- Centers must have sufficient surgical and intracranial monitoring cases for patients with the ages for their desired demographic

- A level 3 center may refer to a level 4 partner at the same institution, but it must certify that it has the resources to serve the patients

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2024 Accreditation Webinars

- Introduction to Accreditation Process Webinar: December 14, 2023 3-4pm Eastern
  - Geared towards new center directors and staff who have not done an NAEC accreditation process

- General Accreditation Webinar: January 11, 2024 2-3pm Eastern
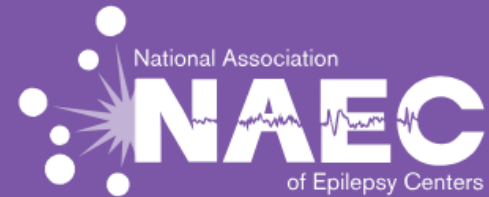 - For all center directors and staff completing the 2024 process

Questions?

Surgery Data Pilot Program

December 2023 Update

NAEC Data Collection Work Group

- Kate Davis (Chair)
- Adam Ostendorf (Co-Chair)
- Leo Bonilha
- Larry Hirsch
- Sue Herman
- Stephan Schuele
- John Rolston
- John Pollard (Level III Center)

Overview

The purpose of this data collection pilot program is to gather and aggregate information about methods and outcomes of surgical epilepsy treatment from participating centers. De-identified patient data is collected, summarized into annual reports, and shared with member centers with the aim of improving processes and patient outcomes.

Over the past several months, data collection has been transitioned from a simple upload of Excel spreadsheets to a web-based reporting form and relational database. This process has improved the consistency of collected data and simplified analysis and reporting.

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Involved Centers

Centers with Access to the Platform
Barrow Neurological
Children's National
Dell Childrens
Henry Ford
Mayo Clinic Arizona
University of Colorado
UFHealth Shands
University of Michigan
Washington University Pediatrics
Yale
University of Pennsylvania

Interested Centers
Children's Hospital of Michigan
F.E. Dreifuss Comprehensive Epilepsy Program
Inova
Le Bonheur Children's Hospital
Mott Children's Hospital at University of Michigan
Seattle Children's Hospital
Texas Children's Hospital
The International Center of Epilepsy at Ochsner
U of MN MINCEP Epilepsy Care
U W Medicine Valley Medical Center
UNC
University of Cincinnati
University of Kentucky
University of Maryland
University of New Mexico
University of South Alabama
University of Virginia
Vanderbilt University Medical Center
Virginia Commonwealth University Health System
Washington University Pediatric Epilepsy Center
Wayne State University/Detroit Medical Center
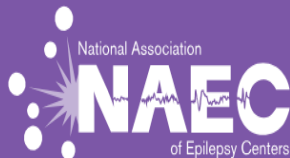
Demographics From 10 Pilot Centers
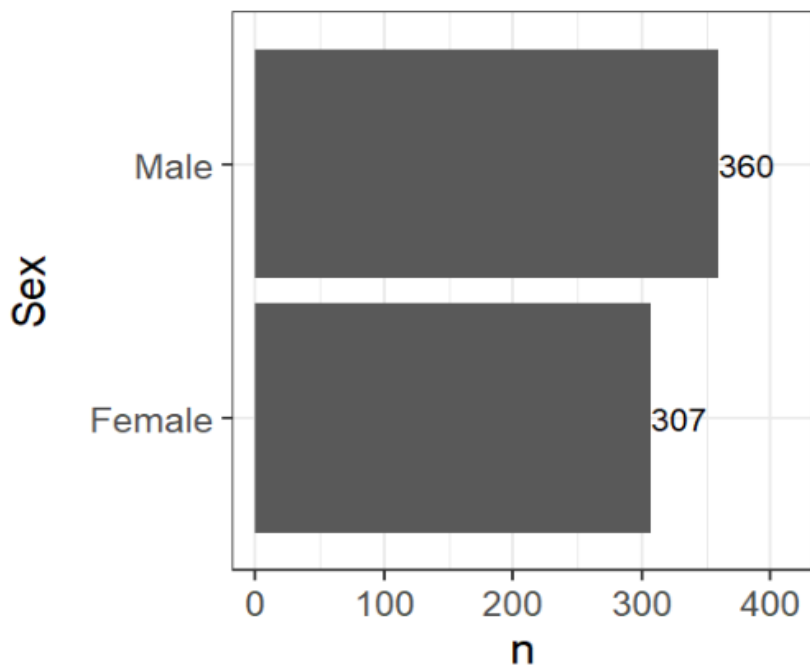
Characteristic	N	N = 575[1]
Race	575	
American Indian or Alaska Native		2 (0.3%)
Asian		6 (1.0%)
Black or African American		41 (7.1%)
White		487 (85%)
Multiracial		14 (2.4%)
Unknown		25 (4.3%)

Etiology: genetic	79 (14%)
Etiology: immune	12 (2.1%)
Etiology: infectious	18 (3.2%)
Etiology: metabolic	3 (0.5%)
Etiology: structural	246 (43%)
Etiology: unknown	248 (44%)

Complication: operative site infection	621	3 (0.5%)
Complication: symptomatic intracranial hemorrhage	621	6 (1.0%)
Complication: readmission or reoperation or prolonged length of stay	621	21 (3.4%)
Complication: unexpected temporary 6 month neurological deficit	621	17 (2.7%)
Complication: unexpected permanent 6 month neurological deficit	621	6 (1.0%)
Complication: death	621	1 (0.2%)
Complication: other	621	40 (6.4%)
Complication: none	621	574 (92%)

	n	%
Resection, disconnection or ablation		
Laser ablation	49	7.3%
Anterior temporal lobectomy	25	3.7%
Lesionectomy	20	3.0%
Neocortical resection	14	2.1%
Open Corpus callosotomy	12	1.8%
Lesionectomy plus	10	1.5%
Hemispherectomy/otomy	5	0.7%
Selective Amygdalohippocampectomy	5	0.7%
Anterior temporal lobectomy plus	3	0.4%
Multi-lobar resection	3	0.4%
Laser Corpus callosotomy	2	0.3%
Deferred Treatment		
Treatment surgery later same year	65	9.7%
Treatment surgery planned but not performed this year	34	5.1%
No treatment surgery planned	26	3.9%
Device only	395	59.1%
Total	668	
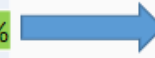
Locations

Frontal	5
Insula	1
Medial temporal	28
Occipital	1
Other	12
Parietal	1
Temporal neocortical; Parietal; Occipital; Insula	1
Grand Total	49

Complications

None	41
Other	3
Readmission or reoperation or prolonged length of stay	1
Unexpected temporary (< 6 month) neurological deficit	4
Total	49

PATIENT YEAR OF BIRTH

2019

AGE AT DIAGNOSIS (YEARS)

2

PLEASE ENTER A NUMBER FROM 0 TO 120.

AGE AT TIME OF SURGERY (YEARS)

2

SEX

Male

RACE

Black or African American

ETHNICITY

Not Hispanic or Latino

ETIOLOGY (SELECT ALL THAT APPLY)

☐ STRUCTURAL
☐ GENETIC OR PRESUMED GENETIC
☐ INFECTIOUS
☐ METABOLIC

Type(s) of Surgery (select all that apply)

☐ Intracranial EEG
☐ Neurostimulation
☑ Resection, Disconnection, Ablation

Resection, Disconnection, Ablation Details (select all that apply)

☐ Lesionectomy
☑ Lesionectomy plus
☐ Anterior temporal lobectomy
☐ Anterior temporal lobectomy plus
☐ Selective amygdalohippocampectomy
☐ Neocortical resection
☐ Multi-lobar resection
☐ Hemispherectomy/otomy
☐ Open corpus callosotomy
☐ Laser corpus callosotomy
☐ Laser ablation
☐ Radiofrequency ablation
☐ Multiple subpial transections

Intent of surgery (select all that apply)

☑ Curative
☐ Palliative

Data Filtering & Export

FILTER BY YEAR OF SURGERY

[2020] [2021] [2022] [2023] [2024]

| 🔍 Type here to search | Intent of Surgery ⌄ | Complications ⌄ | **Export Table** |

Actions	Center - Patient ID - Year	Year of Surgery	Outcomes	Age at Surgery	Intent of Surgery
Add Outcome	Nationwide-19-2021	2021	NationwideChildrens - 19 - 12	15	

Outcomes are tracked as related records, allowing multiple outcome reports to be submitted for each patient over time.

| Type here to search | Engel Outcome ⌄ | ILAE Score ⌄ | **Export Table** |

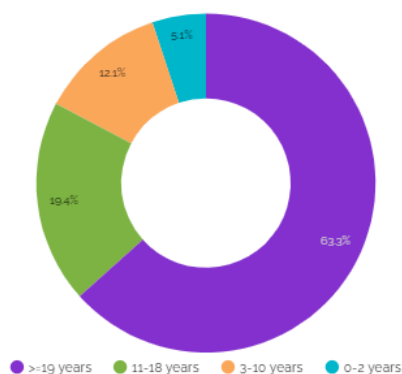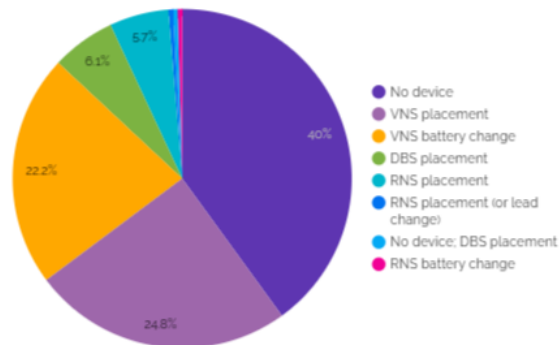| Surgery	Time Post-Surgery (months)	Engel Outcome	ILAE Score	Cause of Death (if applicable)
NationwideChildrens-1-2022-Palliative	12	III	4	

2023 Annual Totals

Age Range	Total	Temporal Resection	Temporal Resection with IC	Extratemporal Resection	Extratemporal Resection with IC	IC Without Treatment	Corpus Callosotomy	Laser Ablation	Radiofrequency Surgery	VNS Implanation	VNS Battery Replacement	RNS Implantation	RNS Battery Replacement	DBS Implantation	DBS Battery Replacement	Hemispherectomies
>=19 years	214	6	4	0	0	10	3	19	0	28	41	13	1	13	0	2
11-18 years	63	1	0	1	1	8	4	5	0	12	8	1	0	2	0	1
3-10 years	35	2	2	0	0	2	6	1	0	14	1	0	0	0	0	1
0-2 years	26	0	0	0	0	0	0	0	0	3	1	0	0	0	0	3
Grand total	338	9	6	1	1	20	13	25	0	57	51	14	1	15	0	7

Patient Age Range

- >=19 years — 63.3%
- 11-18 years — 19.4%
- 3-10 years — 12.1%
- 0-2 years — 5.1%

Neurostimulation Details

- No device — 40%
- VNS placement — 24.8%
- VNS battery change — 22.2%
- DBS placement — 6.1%
- RNS placement — 5.7%
- RNS placement (or lead change)
- No device: DBS placement
- RNS battery change

Intent of Surgery

- Palliative — 50.3%
- Curative — 26%
- Diagnostic — 23.6%
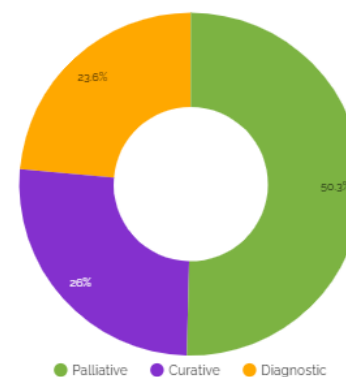
Data Visualizations
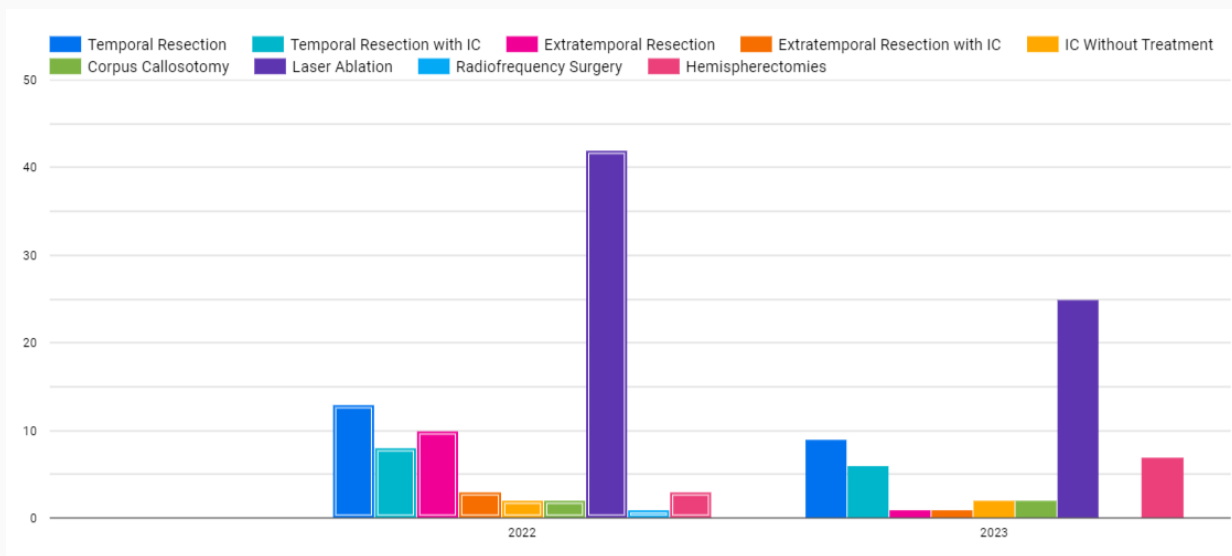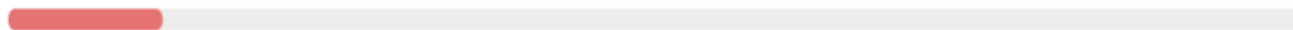
Year 3 - Goals

- Benchmarking for individual Centers
- More reporting Centers
- Improved standardization of data
- All functionality within NAEC website Members area

Questions?