

Launch of NAEC Surgical Data Collection Program

May 6, 2026

Dr. Stephan Schuele, NAEC President
Dr. Adam Ostendorf, NAEC Secretary/Treasurer
Johanna Gray, NAEC Deputy Director



Agenda

- Overview and FAQ about Launch of Surgical Data Collection Program
- Logistics
- Walk through Website and Enter Cases
- Q+A



Surgical Data Collection Program: How Did We Get Here?

- 2022-2025: 15 centers participated in pilot program to test feasibility of submitting procedure/patient-level data and refine data fields
- 2024: NAEC announces that Surgical Data Collection Program will be broadened to all level 4 centers in 2026
- 2025: NAEC prepares for program expansion by:
 - Updating website capacity to collect data
 - Worked with lawyer and statistician with HIPAA and data privacy expertise to set program guardrails



Goals for Program

- Gather and aggregate de-identified data on methods and outcomes of surgical epilepsy treatment to extend and enhance NAEC's accreditation program:
 - To go beyond currently-collected aggregate data by collecting procedure-level data
 - To use data to improve and increase the evidence base for NAEC's accreditation process
- **Ultimate goal of NAEC's accreditation program: to improve processes and patient outcomes**



Tie to Accreditation

- All level 4 centers must submit data on all surgeries performed in 2026, except VNS battery replacements, to maintain accreditation in 2027.
 - We hope centers will submit all data via the new Surgical Program
 - Centers may also just submit 1 case via the new Program and complete the Center Annual Report chart
- Level 4 centers that do not upload any cases to the Program will be conditionally accredited.



Uses of Data

- NAEC may use and/or share the de-identified dataset for the following purposes:
 - To evaluate, support, and improve NAEC’s accreditation process
 - For providing confidential feedback to participating centers for benchmarking and comparison with the broader group
 - For research and data analytics on surgical outcomes, epilepsy care and treatment to benefit epilepsy centers
- NAEC’s existing Data and Survey Policy will apply to this data.



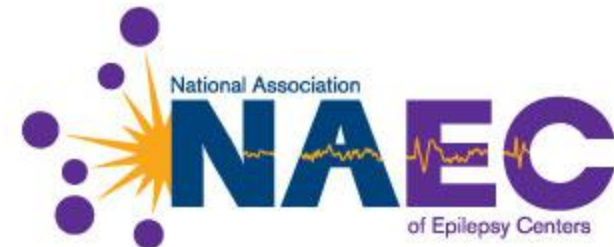
Legal agreements

- Centers have asked whether they need to have legal agreements with NAEC:
 - Business Associate Agreements (BAAs) and Data Use Agreements (DUAs) under HIPAA
 - Institutional Review Board (IRB) review
 - Non-Disclosure Agreements (NDAs)
- NAEC hired a lawyer who is an expert in data privacy rules and HIPAA to analyze program and help develop policies



HIPAA

- Business Associate Agreements (BAAs) are only required if protected health information (PHI) is submitted
- NAEC intends for all new data submitted to be de-identified
- HIPAA regulations allow for expert certification to confirm de-identification and compliance with relevant rules



HIPAA Certification of Dataset

Expert analysis and certification that the data provided by centers is de-identified:

“It is my determination that the data sent by covered entities to the National Association of Epilepsy Centers, as described in this document, meets the de-identification requirements set forth in the HIPAA Privacy Rule and other related laws and regulations. This determination is based on the representation of the NAEC data management practices as of October 30, 2025.” –
Brad Malin, Ph.D., Vanderbilt University



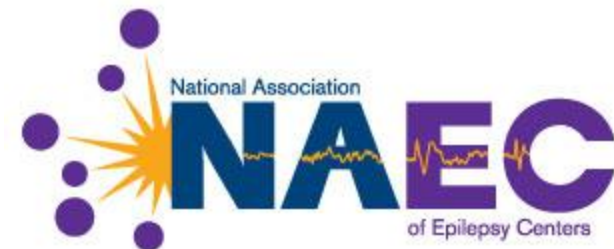
HIPAA

- NAEC will follow rules to ensure that data remains de-identified and the certification is not inadvertently invalidated, including:
 - Not re-identifying patients
 - Not identifying centers submitting the data
- **Since only de-identified data will be submitted, Business Associate Agreements (BAAs) and Data Use Agreements (DUAs) are not necessary or appropriate**



Institutional Review Boards (IRBs)

- **IRB review for participation in the Surgical Program is not necessary or relevant.**
 - IRB review is required for human subjects research, which involves interaction or intervention with individuals or collection of individually identifiable information.
 - These elements are not present with the Surgical Program.



Non-Disclosure Agreements

- **Non-disclosure agreements (NDAs) are not necessary or appropriate.**
- NAEC will use data collected from centers to support accreditation – including use of de-identified benchmarking data and identifying accredited centers.
- An NDA or similar agreement would unduly restrict or inhibit NAEC's accreditation program. It also is not necessary or typical with accrediting bodies.



NAEC Letter on legal agreements



NAEC Board Policy Related to the Release of NAEC Data and Surveying NAEC Members for Research and/or Publications – Adopted December 7, 2025

Background: NAEC periodically gets requests for data on epilepsy centers as well as requests to survey member centers for research purposes. These requests come from NAEC members, academics involved in research, sister non-profit organizations interested in information on epilepsy care and from epilepsy device and drug manufacturers. NAEC evaluates requests for data and to survey its member center directors on a case-by-case basis, evaluating if the topic is complementary to NAEC's mission to improve and promote the quality of specialized epilepsy care.

Annually, NAEC holds a webinar and distributes a slide set to NAEC Members of the annual presentation of the data NAEC collects through its accreditation process. In addition, NAEC has conducted surveys of its members with the goal of furthering the program. NAEC has worked in various circumstances, NAEC creates policies to protect the use and confidentiality of the data.

NAEC Policy: The policies regarding the use and publication of NAEC data apply to requests from member centers (average length of stay). NAEC encourages member centers to take advantage of the opportunity to request data.



May 6, 2026

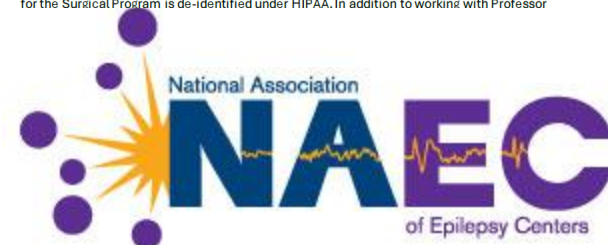
Dear NAEC Accredited Level 4 Center Medical Directors:

In March 2026, NAEC provided accredited level 4 centers with an overview/timeline and data dictionary of its Surgical Data Collection Program (the "Surgical Program"). The Surgical Program will expand the data NAEC will collect and analyze as part of its accreditation of all Level 4 centers. I am writing to provide some clarification around the Surgical Program and to respond to questions we received from some centers.

As an accrediting entity, the privacy and protection of patient data is vitally important to NAEC. This is why we designed the Surgical Program to avoid collecting any identifiable patient information. Centers will share with NAEC, as has always been the case, only patient data that is fully de-identified in accordance with HIPAA.

For many years, centers have shared de-identified patient data with NAEC for accreditation purposes. The Surgical Program does not change that. The data shared with NAEC still will be limited to information that is fully de-identified under HIPAA. As explained in the overview document, Brad Malin, a respected HIPAA statistician, has certified that the data requested for the Surgical Program is de-identified under HIPAA. In addition to working with Professor

- NAEC will share resources with centers re: legal agreements being unnecessary
 - Letter on legal agreements
 - Accreditation Policies and Procedures Manual
 - Data and Survey Policy
- Centers are encouraged to share with their legal/compliance departments if they have questions

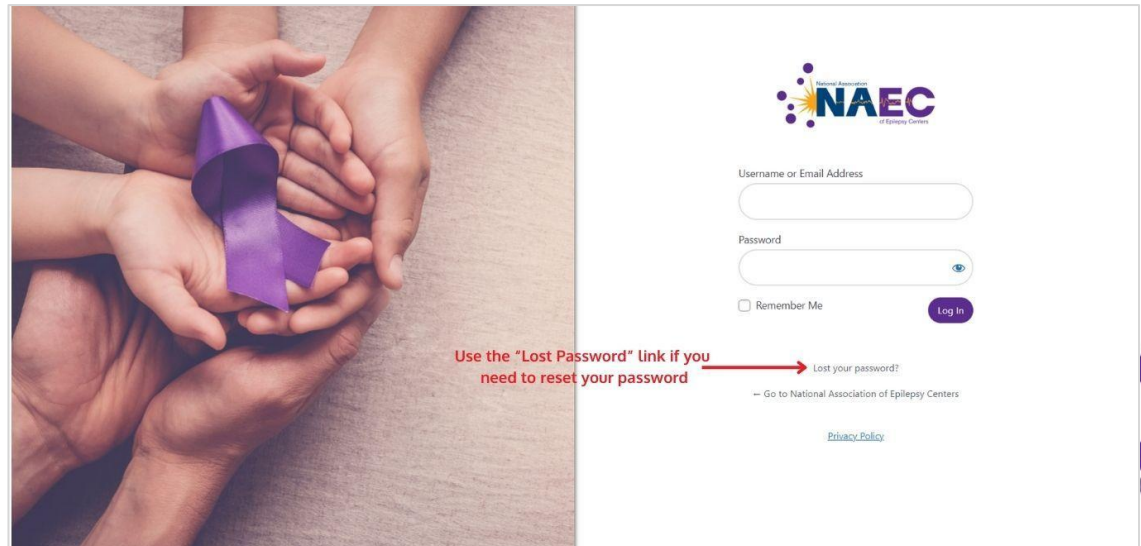
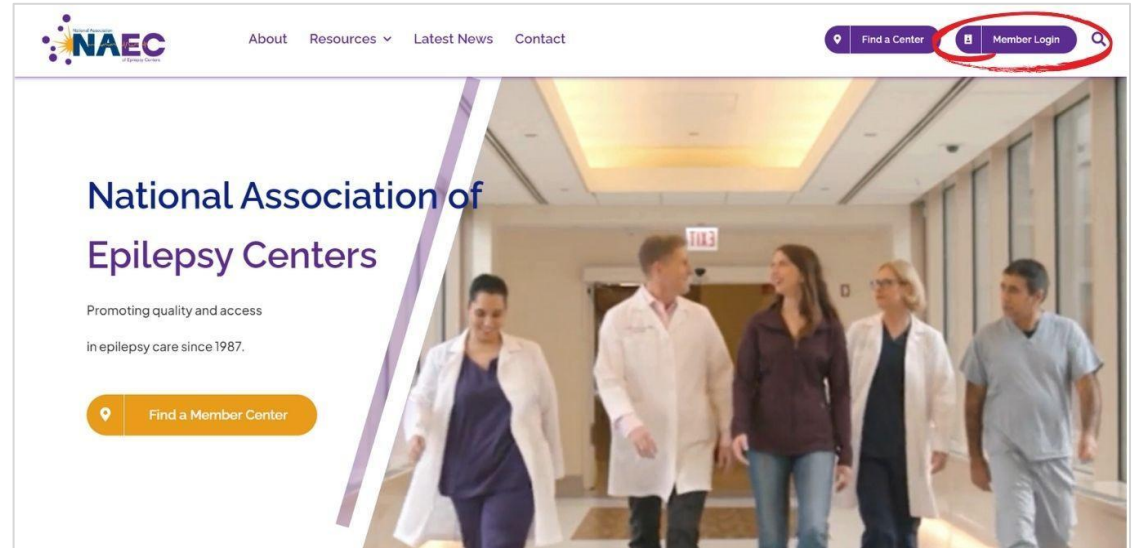


FAQ – 2026 Timeline for Implementation

Month	Step
March	NAEC shares overview and timeline for the program, HIPAA certification report, and data dictionary.
May	NAEC launches program and opens data portal for level 4 members to participate. NAEC will hold a webinar and “Office Hours” to teach centers how to upload data.
May - July	NAEC members should start submitting data. NAEC will work with centers and continue “Office Hours” to answer center questions.
September	Staff will assess participation and check in with centers that have not uploaded any data to learn about challenges and barriers to participation.
January 31, 2027	Deadline for level 4 centers to submit data on all surgeries performed in 2026 except VNS battery replacements.

Logistics – Accessing the Data Portal

- Log into members section of the NAEC website



Logistics – Accessing Data Portal

NAEC

About Resources Latest News Contact

Find a Center Log Out

Member Resources

My Centers

Select a Center to View

[NAEC Test Center2](#)

Accreditation Tools

NAEC has provided centers with many tools to assist them in completing the annual accreditation process.

[View Accreditation Tools](#)

Center Operations Tools

Epilepsy center personnel training manuals and communications tools produced by NAEC Member Centers.

[View Center Operations Tools](#)

Meetings & Webinars

Each year at the NAEC Annual Meeting, NAEC Board Members present summary data from the Center Annual Reports submitted that year.

[View Meetings & Webinars](#)

Publications

Policy Analysis, Coding

Marketing Tools

Access your center profile to enter data



Who has access? What if you want to change?

- Center Medical Director, Co-Medical Director, Administrator and people with access to Center Annual Report have access.
- Pilot sites also have anyone else who participated in the pilot
- Submit brief form on page to add or remove anyone

The image displays two screenshots of the NAEC Surgical Reporting Program interface. The top navigation bar includes the NAEC logo, links for About, Resources, Latest News, and Contact, and buttons for Find a Center, Log Out, and a search icon.

Left Screenshot: Shows the "Surgical Reporting Program" header with a "Submit a New Surgery report" button. A red arrow points to the "+ Add/Remove Surgical Reports Users" link. Below this is the "Existing Surgery reports" section, which includes a "Please select a reporting year to display surgeries" instruction, a "Year of Surgery" dropdown menu, a "Type(s) of Surgery" dropdown menu, a "Search" button, and a table of reports. The table has columns for "Delete Entry", "Patient ID", and "Year of Surgery".

	Delete Entry	Patient ID	Year of Surgery
View/Add Outcomes Open Report Delete Entry		9,876	2026

Right Screenshot: Shows the "Surgical Reporting Program" header with a "Submit a New Surgery report" button. A red arrow points to the "- Add/Remove Surgical Reports Users" link. Below this is the "Center Name" field with "NAEC Test Center2" entered. A section titled "Current Users with Surgical Reports Access for this Center. To REMOVE access for a current user, please check the box next to their name." contains a list of users with checkboxes: bsmall@artemispolicygroup.com, eriker@artemispolicygroup.com, jgray@artemispolicygroup.com, and sean@sunrisedigital.co. Below this is a section titled "Please add Surgical Reports access for these users:" with a note to click the + icon to add a new line. The form includes fields for Name, Title, and Email Address, and a "Submit" button. A yellow arrow points to the "+" icon next to the Email Address field.

Logistics – Submitting Cases

Surgery Reports are listed in an editable table. Search and filter functionality is included above the Surgery Report table. New reports are submitted via the Submit a New Surgery Report button.

NAEC

About Resources ▾ Latest News Contact

Find a Center Log Out

Surgical Reporting Program

[Submit a New Surgery report](#)

+ Add/Remove Surgical Reports Users

Existing Surgery reports

[Toggle Inline Edit](#)

Please select a reporting year to display surgeries

Year of Surgery Type(s) of Surgery Patient ID

Show entries

		Delete Entry	Patient ID	Year of Surgery	Surgery Details	Age at Diagnosis (years)	Sex	Rate
View/Add Outcomes	Open Report	Delete Entry	9,876	2026	Laser ablation	12	Male	

Logistics – Submitting Cases

- Now let's walk through submitting a few cases...



Materials on Website

- Overview and Timeline for 2026
- Data Dictionary
- Letter from NAEC on BAAs, DUAs, IRBs, NDAs
- HIPAA Certification Report of Surgical Dataset
- User Instructions
- FAQ
- Webinar Recording and Slides on Surgical Data Reporting Program

Member Resources



My Centers

Select a Center to View

 NAEC Test Center2



Surgical Data Reporting

Participation in the surgical data collection program is a requirement for Level 4 centers to maintain their accreditation.

[View Surgical Reporting Resources](#)



Questions?



NAEC email:
info@naec-epilepsy.org

