

NAEC Surgical Data Collection Program Office Hours

July 30, 2026

Dr. Adam Ostendorf, NAEC Secretary/Treasurer
Johanna Gray, Ellen Riker, Barbara Small, NAEC Staff



Agenda

- Quick reminders about Surgical Data Collection Program
- Q+A



Goals for Program

- Gather and aggregate de-identified data on methods and outcomes of surgical epilepsy treatment to extend and enhance NAEAC'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 NAEAC's accreditation process
- **Ultimate goal of NAEAC'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 that submit all surgical cases will not need to complete the surgical chart in the Center Annual Report
 - 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.



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.

How to get started

- Log into website → log into your center profile
- Update who from your center has access to the Surgical Program data portal
- Enter cases

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.

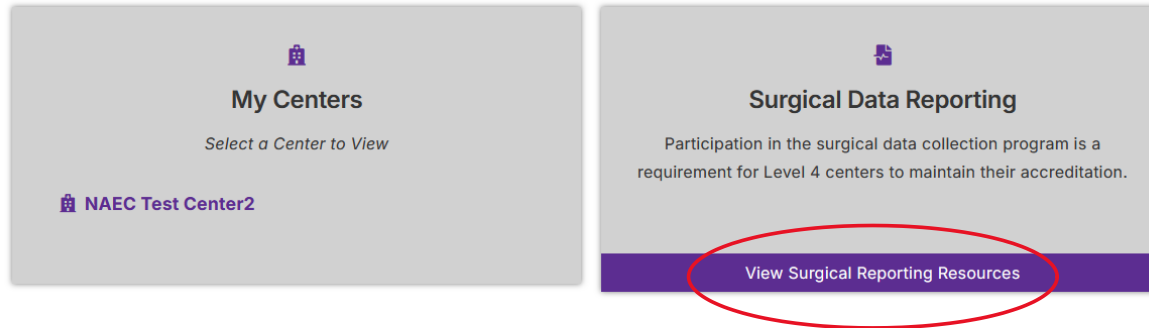
[View Surgical Reporting Resources](#)



Website Resources

<https://naec-epilepsy.org/surgical-data-collection-program>

Member Resources



Important Documents on Surgical Data Collection Program

[Overview and Timeline for 2026](#)

[User Instructions](#)

[Data Dictionary](#)

[Data Sharing Governance Policy](#)

NEW !

[Certification Report of Surgical Dataset](#)

[Letter on Surgical Program Legal Issues](#)

[Surgical Data Collection FAQs \(Updated July 2026\)](#)

NEW!

[Webinar Recording on Surgical Data Collection Program](#)



Questions?



NAEC email:
info@naec-epilepsy.org



Back Up Slides



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 NAEAC:
 - Business Associate Agreements (BAAs) and Data Use Agreements (DUAs) under HIPAA
 - Institutional Review Board (IRB) review
 - Non-Disclosure Agreements (NDAs)
- NAEAC 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
- NAEAC 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

- NAEAC 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 program. NAEC has worked circumstances, NAEC creates use and confidentiality of the

NAEC Policy: The policies by and publication of NAEC data apply to requests from member centers (average length of stay). NAEC provides the opportunity to request



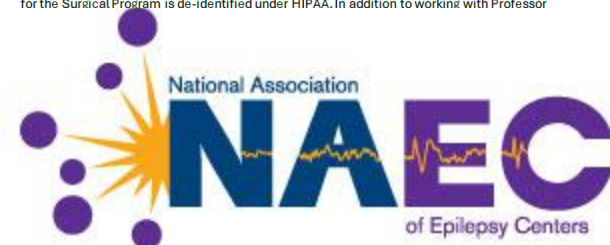
May 6, 2026

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.

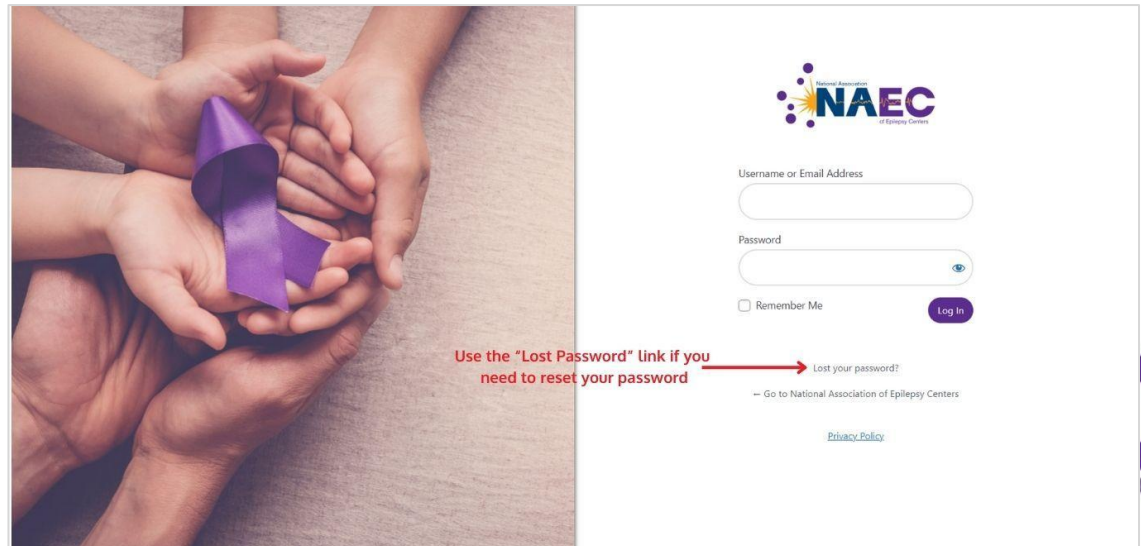
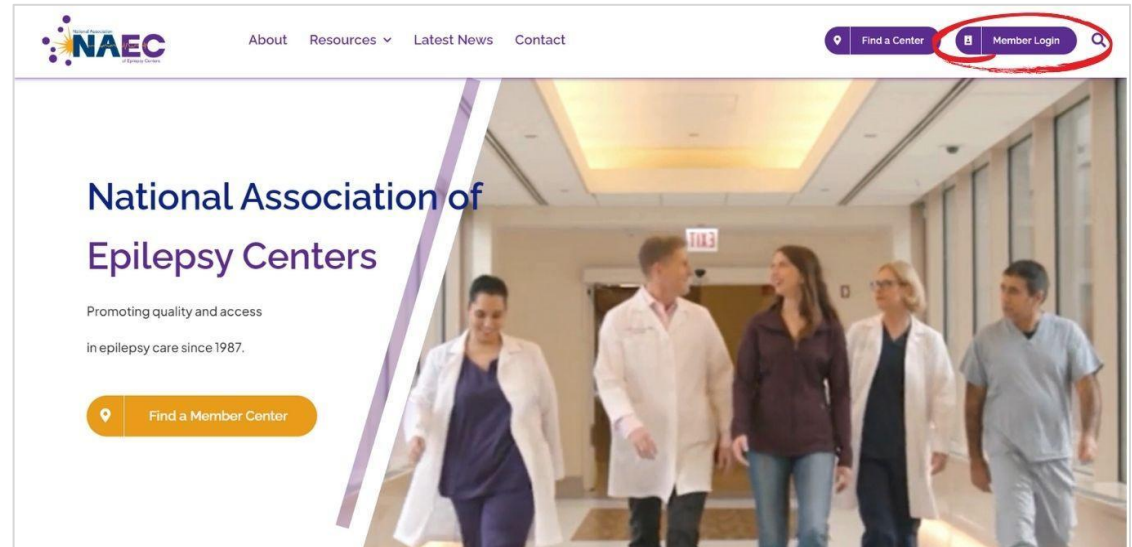
For many years, centers have shared de-identified patient data with NAEC for accreditation purposes. The Surgical Program does not change that. The data shared with NAEC still will be limited to information that is fully de-identified under HIPAA. As explained in the overview document, Brad Malin, a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



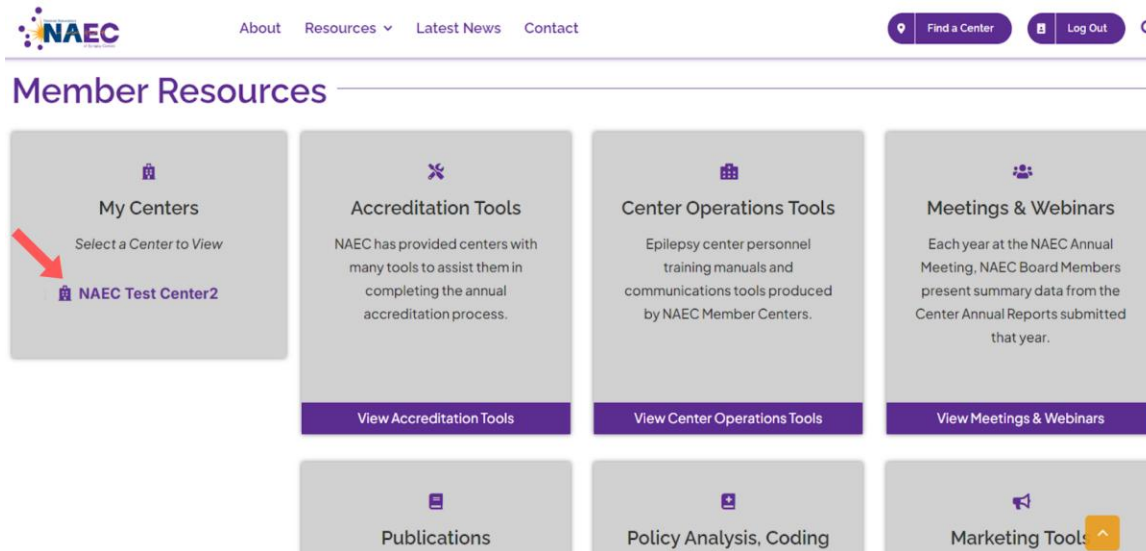
- NAEC will share resources with centers re: legal agreements being unnecessary
 - Letter on legal agreements
 - Accreditation Policies and Procedures Manual
 - Data and Survey Policy
- Centers are encouraged to share with their legal/compliance departments if they have questions

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

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

Please select a reporting year to display surgeries

Year of Surgery: Type(s) of Surgery:

Show 25 entries

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

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Surgical Reporting Program

[Submit a New Surgery report](#)

[- Add/Remove Surgical Reports Users](#)

Center Name:

Current Users with Surgical Reports Access for this Center. To REMOVE access for a current user, please check the box next to their name.

- ☐ bsmall@artemispolicygroup.com
- ☐ eriker@artemispolicygroup.com
- ☐ jgray@artemispolicygroup.com
- ☐ sean@sunrisedigital.co

To REMOVE access for a current user, please check the box next to their name.

Please add Surgical Reports access for these users:
*Click the + icon on the right to add a new line

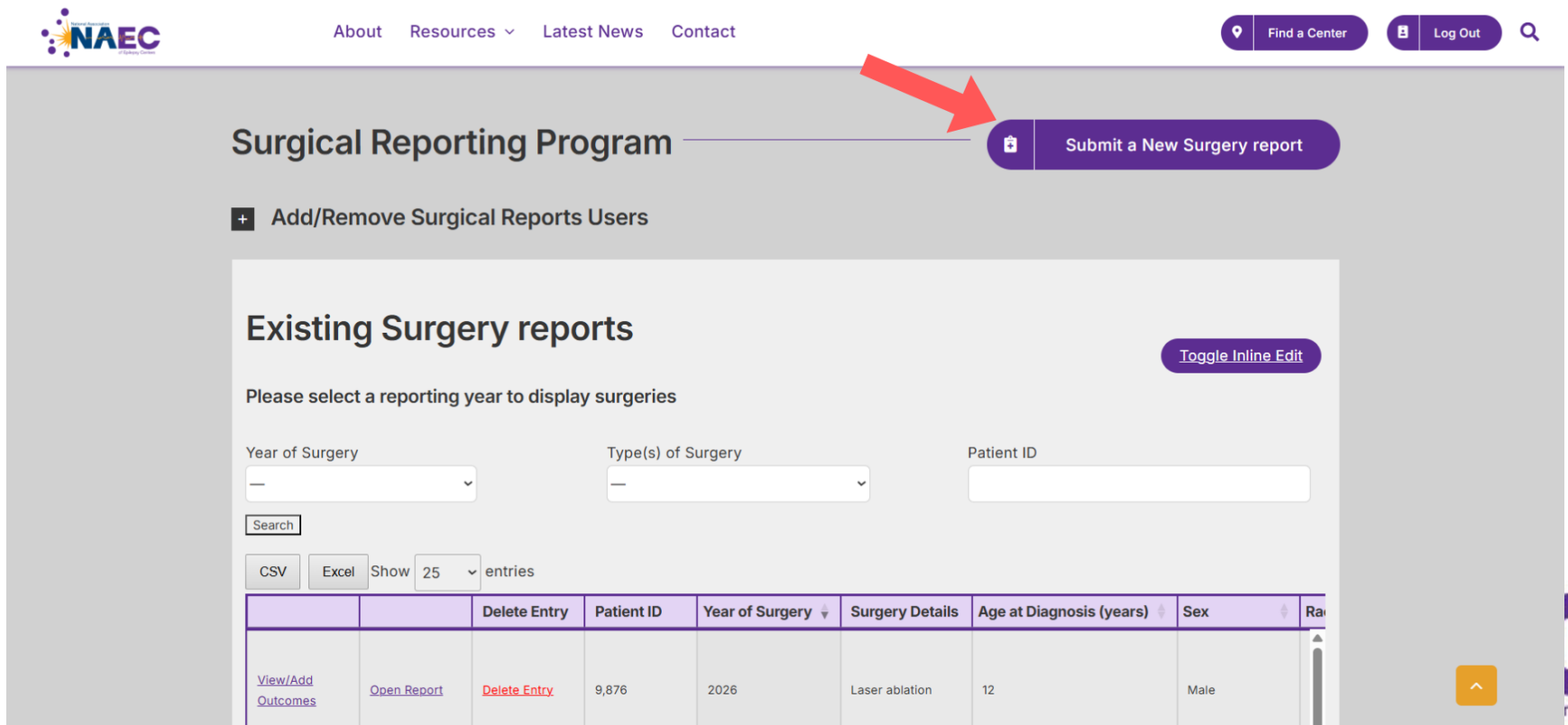
Name	Title	Email Address

[Submit](#)

[+](#)

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.



The screenshot shows the NAEC Surgical Reporting Program interface. At the top, there is a navigation bar with links for About, Resources, Latest News, and Contact. On the right, there are buttons for Find a Center, Log Out, and a search icon. Below the navigation bar, the main heading is "Surgical Reporting Program". To the right of this heading is a button labeled "Submit a New Surgery report", which is highlighted by a red arrow. Below the heading, there is a link to "Add/Remove Surgical Reports Users". The main content area is titled "Existing Surgery reports" and includes a "Toggle Inline Edit" button. Below this, there is a section for selecting a reporting year to display surgeries. This section contains three input fields: "Year of Surgery" (a dropdown menu), "Type(s) of Surgery" (a dropdown menu), and "Patient ID" (a text input field). Below these fields is a "Search" button. Further down, there are buttons for "CSV" and "Excel", and a "Show 25 entries" dropdown. At the bottom, there is a table with columns for "Delete Entry", "Patient ID", "Year of Surgery", "Surgery Details", "Age at Diagnosis (years)", "Sex", and "Race". The table contains one row of data for a patient with ID 9,876, surgery type Laser ablation, age 12, and sex Male. The "Delete Entry" link is highlighted in red.

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Please select a reporting year to display surgeries

Year of Surgery

Type(s) of Surgery

Patient ID

Search

CSV Excel Show 25 entries

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