



## NAEC BOARD POLICY Adopted April 16, 2014

### **Board Policy Related to Surveying NAEC Members and Release of NAEC Data to Individuals and Outside Organizations for Research and/or Publication**

Background: NAEC periodically gets requests for data on epilepsy centers as well as requests to survey member centers for information. These requests come from NAEC members, academics involved in research, sister non-profit organizations interested in information on epilepsy care and from device and drug manufacturers. Our current practice is to only release the data presented at the annual meeting by request and we have provided NAEC members with email addresses for conducting new surveys if the topic is complementary to NAEC's mission to improve and promote the quality of specialized epilepsy care.

In 2013, NAEC developed a memorandum of understanding with one of its member centers to convert NAEC's historic data into a searchable database with the thought that interested individuals could access the data for studies that further the advancement of epilepsy care. It is expected that requests for data will increase. The policies below will guide NAEC staff and leadership in determining access to, the release and publication of NAEC data and requests to survey NAEC centers.

Section 1 – Access to NAEC data: Access to NAEC data will be determined on a case-by-case basis outlined in Sections 2 - 5. All members of the NAEC are eligible to apply for access to NAEC data. Members of academic organizations (such as universities, foundations, and think tanks), advocacy groups (such as the Epilepsy Foundation and other Vision 20/20 groups) and other not-for-profit/non-governmental organizations are eligible to apply. Applications from for-profit companies will require a two-thirds positive majority vote of the full NAEC Board prior to release of NAEC data.

#### Section 2 – Procedure for applying to access NAEC data

- The application for access to NAEC data must include:
  - Cover letter describing specific NAEC data being requested and purpose of request
  - Written proposal to include Research Question, Introduction of Problem, Proposed Methodology and Data Analysis. No more than 5 pages, double-spaced, 11-size font.
  - 1-page NIH-style biosketch of the applicant

Section 3 – NAEC data to be released: Only aggregate data from NAEC members can be released. All data will be de-identified in terms of site of origination. No center-specific data will be released. Applications may conceivably request information from specific regions or states. In those circumstances, in order to maintain the goal of de-identification, those regional data released must include, in aggregate form, data from at least four (4) centers.

#### Section 4 – Procedure for publication of NAEC data

- The applicant will allow NAEC access to all analyses and findings which used NAEC data
- Manuscripts containing NAEC data or analyses derived from NAEC data must be reviewed and approved by the NAEC prior to submission for peer review?
- Manuscripts containing NAEC data or analyses of NAEC data must specifically attribute NAEC.

#### Section 5 – NAEC Publications Review

- The NAEC President will designate a Board Member in addition to himself/herself to review all applications requesting access to NAEC data.
- Unanimous decisions are final. In the event of opposing opinions, a third Board Member will review the application, and the majority opinion should be adopted. If the dissenting member feels strongly about the significance and impact of the proposal, he/she may request a discussion by the full Board. The majority opinion of the full Board will be final.
- The designated Board Member will serve as a liaison with the applicant in obtaining the appropriate data and in working through all phases of manuscript preparation and review.

Section 6 – Requests to Survey NAEC Centers: NAEC will consider requests to survey member centers on a case-by-case basis following the parameters outlined in sections 1 - 5 related to accessing NAEC data.