

# REN PROPOSAL FOR DATA USE



Complete this online form to describe your proposed research and request use of existing REN data. The text boxes will expand as you type. A complete application includes:

- This completed form.
- A biosketch or CV for the lead investigator.
- IRB approval letter, if applicable

Once your application is final, it will take approximately 2-3 weeks for it to be reviewed and discussed by the REN Steering Committee.

**Email completed application and associated documents to [ren@rti.org](mailto:ren@rti.org).**

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1. Short Descriptive Title

2. Authors and Affiliations (including lead author and co-investigators)

Author	Affiliation

3. Background and Rationale

4. Aims and Objectives

5. Short statement in lay language of significance of proposed research

6. Characteristics of patient population requested (eligibility criteria)

Diagnosis, age, gender, etc.

7. Type of REN data requested for analysis

- |   |   |
|---|---|
| <input type="checkbox"/> Patient Demographics                 | <input type="checkbox"/> Conditions & Symptoms            |
| <input type="checkbox"/> Caregiver Demographics               | <input type="checkbox"/> Seizure Treatments & Medications |
| <input type="checkbox"/> Seizure Characteristics              | <input type="checkbox"/> Surgery                          |
| <input type="checkbox"/> Epilepsy Syndrome/Disorder Diagnosis | <input type="checkbox"/> Genetic Testing                  |
| <input type="checkbox"/> Seizure History                      | <input type="checkbox"/> Birth & Maternal Symptoms        |
| <input type="checkbox"/> Development                          |   |

7a. More details about specific data requested if not obvious from Q.7.above

8. Other inclusion or exclusion criteria

9. Will REN data be combined with other population or cohort data?  No  Yes

10. Describe analysis plan or type of analyses to be conducted

11. Anticipated deadlines (e.g., abstract due dates)

12. Source of funding for this proposal

13. Status of IRB approval  Attached  Pending

14. Other comment:

**NOTE: Publications and presentations that use REN data must cite the REN using the following acknowledgement:**

*The Rare Epilepsy Network is supported under PCORI contract PPRN-1306-04577 with the Epilepsy Foundation.*

## To Be Completed by REN:

Tracking Number

Date Received

Date Reviewed and Approved by EC

Date Sent to SC for Review

Status of Original  Approved  Needs Revision  Not Approved

Status of Revised  Approved  Not Approved

Date of Final Decision by SC

Date Final Decision Sent to Requestor

Comments