

The Rare Epilepsy Network (REN) survey launched in 2014 and enrolled over 1,450 participants. Patient data across 40 rare epilepsy diagnoses is now available for research request via [proposalCENTRAL](#).

### **Starting an Epilepsy Foundation Electronic REN Application**

Applicants applying for any Epilepsy Foundation award must begin their application by registering as a proposalCENTRAL user.

If you already have a proposalCENTRAL account, please use the same login information to apply for an Epilepsy Foundation grant.

For help with electronic application process or technical issues, please contact the help desk for proposalCentral: [pcsupport@altum.com](mailto:pcsupport@altum.com) or 1-800-875-2562.

For REN research-specific questions, please contact [ren@efa.org](mailto:ren@efa.org)

The Data Transfer Request (DTR) for access to REN registry data is submitted via proposalCENTRAL as a pdf. The pdf that is uploaded must have the following eight sections completed:

1. Information about the Researcher who is requesting the Data (Recipient Researcher).
2. Information about the research project from which the Data are requested.
3. Types of Data being requested and the study population from which the Data were collected.
4. Are any direct identifiers (*e.g.*, name, address, telephone numbers, Social Security numbers, medical record numbers, date of birth, zip code, State, etc.) included in the Data being requested?
5. Current proposed use and analysis plans for the Data.
6. Safeguards (administrative, technical, physical) that will be used by the Recipient to protect the confidentiality of the Data.
7. List of Individuals, Groups, or Classes of Persons who will have access to or use the requested Data *at the Recipient Institution*, including the principal Researcher (named in Item 1). ***NOTE: Data may not be shared with researchers outside the Recipient Institution without written agreement of Provider Institution.***
8. Requested data transfer date.

### **DTR Submission**

Submit the completed DTR through proposalCENTRAL: <https://proposalcentral.altum.com>. Once there, click 'Applicants: Click Here to Login, Register to Apply', and setup an account or use your existing account. Complete sections, upload required documents and click on 'Validate' to make sure all required fields have been filled in Click on the 'Submit' link to submit DTR in proposalCENTRAL.

### **DTR Applicant Notification**

The DTR will be reviewed within approximately two weeks of submission, at which time Principal Investigators / Contacts will be notified of acceptance or rejection. If application is accepted Principal Investigators / Contacts will be invited to submit a Data Use Agreement (DUA) for a full review.

The individual proposal IRB status – “approved”, “pending”, “exempt” or “not applicable”. If approved, please provide the corresponding date of approval on the electronic application. If “exempt” from IRB approval within your institution, place “exempt” and the date the exemption was approved.”

**NOTE: Requestor will need to provide IRB approved document indicating that their research project has been reviewed and approved.**

### **Completing an Electronic Application - DUA**

Once you have been notified that your DTR has been approved, log into your proposalCENTRAL account and begin your DUA application/proposal. Follow the directions in each section and submit when completed.