DATA TRANSFER REQUEST (Step 1)

Complete and return to ren@efa.org

EPILEPSY FOUNDATION ON BEHALF OF THE RARE EPILEPSY NETWORK (REN)

Permanent Release/Transfer of Data by REN

Information that is obtained or used for research is confidential and must be used only for statistical reporting or research purposes. Therefore, it is necessary to ensure, to the extent possible, that any use of such data be limited to research by legitimate researchers, and in accordance with applicable laws and this Data Transfer Request (Request).

This Request to transfer data is made from the following Recipient Institution to the following Provider Institution:

Provider of the Data (Provider Institution): __REN__________________

And

Recipient of the Transferred Data (Recipient Institution): _____________________

A. RECIPIENT, PROVIDER AND DATA INFORMATION

1. Information about the Researcher who is requesting the Data (Recipient Researcher):

   Signature: ____________________  
   Date: ___________________  
   Email: ______________________

2. Information about the research project from which the Data are requested:
   Project Title from which Data will be transferred: REN  
   IRB Code: ____________________

   REN Contact Person: ____________________
   Contact Person’s e-mail address: ____________________
   Contact Person's telephone no. ____________________

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?

Direct Identifiers _____ Yes/No____
Indirect Identifiers _____ Yes/No____

If Yes to Direct Identifiers, list the direct identifiers that are included in the Data:

If Yes to Indirect Identifiers, list the indirect identifiers that are included in the Data:

5. Current proposed use and analysis plans for the Data.

Data Requested:

Proposed Uses and Analysis:

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.

Identity of person(s) with responsibility at the Recipient Institution for monitoring access to data (To include name, position, phone number, and e-mail):

Name: __________________
Position: ________________
Phone Number: __________________
Email: ____________________

8. Requested data transfer date

Requested date for Data transfer to you: ________________
B. TERMS AND CONDITIONS
Terms and Conditions for any approved data transfer are specified in the Data Use Agreement (Step 2). Recipient should be familiar with all Terms and Conditions prior to submission of this Data Transfer Request.

C. Signatures and Clearance for PROVIDER Institution (REN):

Recipient certifies that the statements made in the Applicable Data Use Agreement and as above regarding the planned use of the Data are complete and accurate. The signatures below indicate that REN and Recipient agree to consider the request for transfer of and receipt of, respectively, the Data under the above stated provisions and pursuant to an Data Use Agreement (Step 2).

1. Signature of REN representative Responsible for this Data Transfer

Signature: ____________________________
Date: ________________________________
Telephone No.: ____________________________
E-mail Address: ____________________________

2. Signature of RECIPIENT

Signature: ____________________________
Date: ________________________________
Telephone No.: ____________________________
E-mail Address: ____________________________

3. IRB Approval for Use of Data from RECIPIENT Institution, if applicable

Recipient Researcher must provide documentation of Recipient Institution’s IRB approval for the proposed use of the data. Attach a copy of the Recipient IRB
approval notice/letter and complete the section below related to the Recipient Institution IRB:

Recipient Institution IRB Federal Wide Assurance (FWA) Number or relevant identifier: 
____________

Check here indicating that a copy of the IRB Approval is attached: _________