National Center for Advancing Translational Sciences

The NIH/NCATS GRDR℠ Program
Global Rare Diseases Patient Registry
Data Repository

Data Submission and Access Request

GRDR Data Submission Request

Organizations wishing to participate in the NIH/NCATS GRDRSM Program and share the de-identified data of their registry first need to provide the information requested in the GRDR Data Submission Request Form.

GRDR Data Access Request

Investigators wishing to access the data in the GRDR Data Repository need first to provide the information requested.There are two levels of access to Data:

Open Access allows broad release of non-sensitive data, including general information, trends, and charts of aggregated data or any information that are available to the public without restrictions and can be browsed online. For Open Access, minimal information is requested.

Controlled Access allows download of GRDR Data, including individual de-identified Data within a disease and across diseases. Any request for Controlled access requires completing the Data Use Certification (DUC) form. Both forms can be accessed by clicking on the GRDR Data Access Request Form.

OMB No 0925 XXXX

Exp. Date XX/XX/20XX

GRDR[SM] Repository
Request for Controlled Access
Recipient Information and Certifications

*Date: _____ *Type of Application: _____ New _____ Renewal

*First Name: _____ *Last Name: _____

*Degree: _____ *Academic Position (or Title):_____

*Institution: _____ *Disease Interest _____

*Street Address_____

*City: _____ *State/Province: _____

*Zip/Postal Code: _____ *Country: _____

*Telephone: _____ *Fax: _____

*E-mail Address:

_____

Research Project
(Title):_____

By signing and dating this DUC as part of requesting access to Data in GRDR, my Institutional Officials and I certify that we will abide by the DUC and the NIH principles, policies and procedures for the use of GRDR Data.

I further acknowledge that I have shared this document and the NIH policies and procedures with any research staff who will participate in the use of GRDR Data.

My Institutional Business Official(s) also acknowledges that they have shared this document and the relevant NIH policies and procedures with appropriate institutional organizations.
Authorized Institutional Business Official

*Name: _____ *Title:[1] _____

*Signature: _____ *Date: _____

*IRB#: _____ *FWA#: _____

[1] Signatory should specify whether he/she is (1) Principal Investigator or; (2) Institutional Official; or (3) Research Collaborator.

Project Director/Principal Investigator Contact Information (if different from above):

*First Name: _____ *Last Name: _____

*Degree: _____ *Academic Position (or Title): _____

*Institution: _____ *Department: _____

*Street Address: _____

*City: _____ *State/Province: _____

*Zip/Postal Code: _____ *Country: _____

*Telephone: _____ *Fax: _____

*E-mail Address: _____

Institutional Official(s)

*First Name: _____*Last Name: _____

*Degree: _____*Academic Position (or Title): _____

*Institution: _____*Department: _____

*Street Address: _____

*City: _____*State/Province: _____

*Zip/Postal Code: _____*Country: _____

*Telephone: _____*Fax: _____

*E-mail Address: _____

Other Project Information:

1. Are human subjects involved? _____ Yes _____ No

   If YES to human subjects:

   Is the project exempt from federal regulations? _____ Yes _____ No

   If yes, check appropriate exemption number: _____ 1 _____ 2 _____ 3 _____ 4 _____ 5

   If no, is the IRB review pending? _____ Yes _____ No

   IRB approval date: _____

2. Research Use Statement/Project Summary:

Senior/Key Profile (Collaborating Investigator)

*First Name: _____*Last Name: _____

*Degree: _____*Academic Position (or Title): _____

*Institution: _____*Department: _____

*Street Address: _____

*City: _____*State/Province: _____

*Zip/Postal Code: _____*Country: _____

*Telephone: _____*Fax: _____

*E-mail Address: _____

*Project Role: _____*Other Project Role Category: _____

Senior/Key Person Profile (Collaborating Investigator)

*First Name: _____*Last Name: _____

*Degree: _____*Academic Position (or Title): _____

*Institution: _____*Department: _____

*Street Address:

_____

*City: _____*State/Province: _____

*Zip/Postal Code: _____*Country: _____

*Telephone: _____*Fax: _____

*E-mail Address: _____

*Project Role: _____*Other Project Role Category: _____

Use additional sheets for additional profiles as needed.

For GRDR administrator only:

Access Approved_____

Access Denied: _____