



National Center
for Advancing
Translational Sciences

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

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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

Burden Disclosure: Public reporting burden for this collection information is estimated to average 2 minutes response, including the time reviewing instructions, searching existing data source, gathering and marinating the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it display a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA#0925-XXXX. Do not return the completed form to this address.

Although Open data access does not requires prior permission, authorization or review by a committee, persons seeking Open Access are required to register on the GRDR program portal and provide the minimal information as requested in the form below.

**GRDRSM Repository
Request for Open Access**

*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: _____