CoRDS Researcher Access Request (RAR) Form

If you are the principal investigator for a rare disease research study or clinical trial and would like to use CoRDS Registry to identify potential study participants, please provide the following information to begin the CoRDS access approval process. CoRDS personnel will be in touch shortly to discuss your application. Please contact CoRDS with any questions.

All researchers are required to complete this application in order to access data from the CoRDS registry. The data is not transferable to any non-approved investigator, institution or commercial enterprise. These established procedures, policies, guidelines and other supplements are the only method to gain access to this material.

PRINCIPAL INVESTIGATOR	
Name	
Degree(s)	◯ PhD ◯ MD ◯ Other _____
Title	
SPONSORING INSTITUTION	
Institution Name	
City, Town or Village	
State or Province	
Country	
PREFERRED CONTACT INFORMATION	
Email Address	
Primary Telephone Number	
Mailing Address - Street	
City, Town, or Village	
State or Province	

Zip / Postal Code	
Country	
FedEx Account Information	
RESEARCH STUDY OR CLINICAL TRIAL	
Study Name	
Rare Disease(s) of Interest	
Please briefly describe your research study or clinical trial, and explain how CoRDS will be used to support your research. Please attach an abstract and specific aims.	Add attachments
Please indicate the type of resources that your project will require from the CoRDS Registry. ☐ Data from the [illegible] ☐ [illegible] ☐ [illegible] ☐ [illegible] ☐ [illegible]	
Please attach documentation of your study's Institutional Review Board (or comparable international entity) approval.	Add attachments
Please attach your CV	Add attachments

Additional information:

- Please note the information in the CoRDS registry is all patient-reported data. CoRDS cannot confirm the accuracy of the information at this time.
- Researchers who receive access to CoRDS will need to re-apply annually.
- If you identify an individual that you would like to contact regarding a research study or clinical trial, you must complete a Research Contact Request Form.
- Researchers who publish articles must report this information back to CoRDS.
- CoRDS must be recognized in presentations, papers, articles, etc. as the source of the data you use.
- CoRDS may request additional information from Researcher at any point. Refusal to provide information may terminate Researcher's access to CoRDS data.
- Researcher may be required to sign a data transfer agreement with Sanford Research to access data.