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 (specify): _____
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	
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.**	
Please indicate the type of resources that your project will require from the CoRDS Registry. ☐ Data from the Registry ☐ Participant Referrals (request CoRDS to contact participants on your behalf) **If you are requesting CoRDS to contact participants on your behalf, please complete minimal inclusion criteria:** Age Range: Location (this can be at a state level, country, international) Language: Sex: Other:	
Please attach documentation of your study's Institutional Review Board (or comparable international entity) approval.	
Please attach your CV	

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.
- By submitting this form and receiving CoRDS data, researchers agree to the terms of use defined below.

1. THE DATA

1.1. Sanford will provide access to the data (the "Data") described in the Researcher Access Request Form (the "RARF"). The "Recipient" shall be the Principal Investigator listed in the RARF.

1.2. Sanford is the owner of the Data provided to Recipient hereunder, and except as specifically stated Sanford does not grant Recipient any right, title or interest in or to the Data.

1.3. Sanford retains unrestricted right to disclose or distribute the Data to any other party.

2. PERMITTED USE OF THE DATA

2.1. Recipient shall use the Data solely for the Research Study or Clinical Trial described in the RARAF (the "Purpose"). Subject to these terms and conditions, Sanford hereby grants to Recipient a non-exclusive, royalty-free, non-transferable, non-sublicensable license, under all of its intellectual property rights in and to the Data, to use the Data for one (1) year solely for the Purpose.

2.2. For the avoidance of doubt, Recipient shall not commercialize the Data or use the Data for any purpose intended to derive a profit. If Recipient desires to use Data for any purpose other than the Purpose, then Recipient shall obtain prior written consent from Sanford.

2.3. Recipient shall not disclose the Data to any third party without Sanford's prior written consent, and shall not license, transfer, sell or lease the Data to any third party.

3. ADDITIONAL RECIPIENT OBLIGATIONS

3.1. Recipient shall use appropriate safeguards to prevent use or disclosure of the Data other than as expressly permitted under these Terms of Use. Recipient agrees to report to

Sanford, in writing, any use and/or disclosure of the Data that is not permitted or required by these Terms of Use immediately after becoming aware of such use and/or disclosure.

3.2. Recipient shall comply with all applicable laws and regulations relating to the use, storage and disclosure of the Data.

3.3. Recipient shall not use the Data in any manner that confers on any third party any proprietary rights in or to the Data.

4. PUBLICATION AND PUBLICITY

4.1. Recipient shall be free to publish and present the Data in a publication subject to acknowledgement that the Data was derived and compiled by Sanford.

4.2. In all publications and presentations of Results, Recipient agrees to acknowledge Sanford's contribution to Recipient's research.

4.3. Except as expressly provided in these Terms of Use, nothing herein shall be construed to grant to Recipient the right to use the name, logo or trademark of Sanford or any of its employees in any press release, publicity or advertising without the prior written approval of Sanford, except as required by applicable law or regulation.

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5.2. NOTWITHSTANDING ANYTHING IN THIS TERMS OF USE TO THE CONTRARY, IN NO EVENT SHALL SANFORD BE LIABLE TO RECIPIENT FOR THE USE OF THE DATA PROVIDED HEREUNDER.

5.3. THE DATA IS PROVIDED "AS IS" WITHOUT ANY WARRANTIES OF ANY KIND, EITHER EXPRESS OR IMPLIED, AS TO ANY MATTER INCLUDING, BUT NOT LIMITED TO, ACCURACY, RELIABILITY, COMPLETENESS, FITNESS FOR PARTICULAR PURPOSE, MERCHANTABILITY, EXCLUSIVITY, RESULTS OBTAINED FROM USE, OR FREEDOM FROM PATENT, TRADEMARK, COPYRIGHT OR OTHER INTELLECTUAL PROPERTY INFRINGEMENT.

5.4. These Terms of Use shall be construed according to the laws of the State of South Dakota, without regard to its conflicts of laws provisions.