You hold a piece of the puzzle

If you or a family member have been diagnosed with a rare genetic disease, you can help researchers see the whole picture. You are important to finding cures and improving treatments.

Registration is simple and won't take up a lot of your time. If you are interested, a CoRDS staff member will connect with you to briefly discuss the registry, answer questions and send you a consent form and a short questionnaire. You will be asked to sign a consent form and complete the questionnaire, returning it to CoRDS personnel in a pre-paid envelope we will send you.

Your information will then be entered into the CoRDS database at Sanford Research. We will follow up with you every year to update your information. Your privacy is our priority. Our database is secure and your information is protected under HIPPA.

For more information on the CoRDS registry, existing partners, on-going rare disease research and how you can help, please visit sanfordresearch.org/cords.

To register

Please call (605) 312-6413 or email us at cords@sanfordhealth.org.

You will be asked to provide:

- Name
- Contact information
- Preferred method of contact
- Best time to contact

Questions?

Please contact us.

Liz Donohue, CoRDS administrator
2301 E. 60th St. N.
Sioux Falls, SD 57104-0589
(605) 312-6413
cords@sanfordhealth.org

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SANFORD RESEARCH

800-11000-0019 rev. 11/11

CoRDS Registry

Coordination of Rare Diseases at Sanford

SANFORD RESEARCH

At Sanford Research we are committed to finding cures and advancing therapies for rare diseases. Through the CoRDS program you can help us advance this mission.

Right now there are approximately 25–30 million people in the United States affected by more than 6,800 rare diseases.

Finding cures and improving treatments can't be done without important pieces of the puzzle. Each piece plays a role in bringing us a step closer to a cure, helping us better understand what causes these diseases and how we can best treat them.

CoRDS participants are helping researchers at Sanford and around the nation find the answers we're searching for.

What is the CoRDS Registry?

The Coordination of Rare Diseases at Sanford registry is a national and central registry of people with a confirmed diagnosis of any rare disease. In the United States, a disease is considered rare if it affects fewer than 200,000 people. A central registry helps researchers who are looking to find a cure and improve treatments for these rare diseases.

The registry holds basic contact and diagnostic information on those who agree to enroll. Any researcher with the appropriate approval can then request information from the registry that might be helpful to the research they are conducting.

By enrolling in CoRDS, patients who qualify will be notified of any opportunities to participate in clinical trials and other research opportunities.

CoRDS is headquartered in the Sanford Children's Health Research Center at Sanford Research in Sioux Falls, SD and supervised by David Pearce, PhD and Chun-Hung Chan, PhD.