



The Coordination of Rare Diseases at Sanford (CoRDS) registry will provide researchers with access to an existing database of pre-screened individuals who are willing to participate in rare disease research. This will accelerate future research of rare diseases by providing a readily available registry of patients who may be eligible for participation in future research or clinical trials.

For more information on the CoRDS registry, existing partners, ongoing rare disease research, and ways to collaborate, please visit our website at www.sanfordresearch.org/cords

About Sanford Children's Health Research Center

Sanford Children's Health Research Center is a two-site campus researching a childhood diseases at locations in Sioux Falls, SD, and La Jolla, CA. The La Jolla site is located within the Sanford-Burnham Medical Research Institute. A unique partnership is in place with the Sanford-Burnham Medical Research Institute (La Jolla, CA), as well as national

and international research relationships through Sanford Children's Hospital. We're actively using interdisciplinary approaches and establishing collaborations on a national level to understand the underlying basis of a number of childhood diseases and maladies.

About Sanford Research

Sanford Research is a non-profit research organization formed between Sanford Health and the University of South Dakota. In 2007, a transformational gift of \$400 million by Denny Sanford has allowed for an expansion of current goals and will enable Sanford Research to become one of the premiere research institutions in the United States and the world. Sanford Research is composed of several research centers, including Cancer Biology, Cardiovascular Health, Health Disparities, Methodology and Data Analysis, Sanford Children's Health, and the Sanford Project.

About Sanford Health

Sanford Health is an integrated health system headquartered in Fargo, ND and Sioux Falls, SD and consists of two long-standing organizations that merged in 2009. Sanford is now the largest, rural, not-for-profit healthcare system in the nation with a presence in 110 communities in eight states. In addition, Sanford Health is in the process of developing international clinics in Belize and Ireland. Sanford Health includes 30 hospitals, 111 clinic locations and more than 800 physicians in 70 specialty areas of medicine. For more information, visit www.sanfordhealth.org.



Coordination of Rare Diseases at Sanford (CoRDS) Registry

The Power of Hope

An innovative approach to accelerate rare disease research

SANFORD
RESEARCH

Working Together to Fight Rare Diseases

Sanford Children's Health Research Center has made a commitment to finding cures for rare diseases. Our mission is to drive the development of new therapies from discoveries made in research labs by integrating basic science with clinical practice. Establishing the Coordination of Rare Diseases at Sanford (CoRDS) registry is yet another way to implement this "Bench to Bedside" approach.

What is the CoRDS Registry?

The Coordination of Rare Diseases at Sanford (CoRDS) registry is, to our knowledge, the first national registry to incorporate multiple and ultimately all rare genetic diseases. By establishing a central registry of persons with a confirmed diagnosis of any rare disease, we can help accelerate research efforts for effective treatments.

CoRDS is headquartered at Sanford Research in Sioux Falls, South Dakota, and is supervised by David Pearce, PhD, and Chun-Hung Chan, Ph.D. The CoRDS Registry holds basic contact and diagnostic information on patients who have been diagnosed with a rare disease. Any researcher who has Institutional Review Board (IRB) approval can request access to information in the CoRDS registry that is relevant to their area of research.



Why was CoRDS established?

Access to information is a central issue for families, physicians and researchers alike. Since there are fewer numbers of patients with rare diseases, identifying and recruiting participants for clinical trials can be challenging. CoRDS will provide a database of pre-screened study participants to researchers and will also notify patients of opportunities for clinical trials should they be eligible.

How can I Enroll?

If you or a family member have been diagnosed with a rare genetic disease, you are invited to submit information to the registry.

Patients or their Parent/Legally Authorized Representative should contact CoRDS personnel via email at CoRDS@sanfordhealth.org or by phone (605) 312-6413 and provide:

- Name
- Contact information (Mailing and Email Address, Phone Number)
- Preferred method of contact and Best Time to contact

CoRDS personnel will contact the individual to briefly discuss the CoRDS registry, answer questions and send patients a consent form and a short questionnaire. The participant will sign the CoRDS consent form and complete the questionnaire and return to CoRDS personnel using the prepaid envelope.

What Will Happen to My Information?

CoRDS personnel will enter their information into the CoRDS database housed at Sanford Research and will follow up annually to update any changes in information. Any information you provide will be stored in a secured database and protected under the Human Insurance Portability and Accountability Act (HIPAA)

For more information or to ask questions about the CoRDS registry, please contact:
Liz Donohue
CoRDS administrator
2301 East 60th Street North
Sioux Falls, SD 57104-0589
phone: (605) 312-6413
e-mail: Cords@sanfordhealth.org
Web: www.sanfordresearch.org/Cords

About CoRDS

Access to accurate, relevant and updated information is a central issue for families, physicians and researchers alike. Since there are fewer numbers of patients with rare diseases, identifying and recruiting participants for clinical trials can be difficult.