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Cauda Equina Syndrome

Natural History Study

Patient Registry

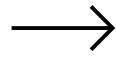
In Partnership
with CoRDS

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Natural History Study

Who can participate?



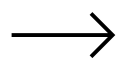
Participation is open to anyone who has been officially diagnosed by a physician and has been living with chronic cauda equina syndrome (CES) for a minimum of six months.

If you were diagnosed less than six months ago we encourage you to come back and participate when you are able to.



Data Identification

How am I identified?



Each participant is assigned a Global Unique Identifier that enables de-identification of the data when shared with approved researchers to protect the patient's privacy. This means that your name and other identifying information will not be passed on.

The de-identified data will be shared only with researchers approved by Sanford's Scientific Advisory Board (SAB).

The registry is compliant with the European Union General Data Protection Regulation (GDPR).

Can data be collected worldwide? →



Yes, the registry can be accessed all over the world.
International participation is highly encouraged.

CoRDS

How often do I update my information? →  

Please update your information once a year or if there are any major changes to your health.

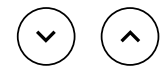
CoRDS

How is my personal information used and protected?

The information you provide will be provided to researchers studying cauda equina syndrome. CoRDS has put many safeguards into place to ensure that this information will be kept safe and confidential. The registry is compliant with the European Union General Data Protection Regulation (GDPR).

CoRDS

Data Access →



Providing your consent to Cauda Equina Foundation to have access to the data you provide will allow us to better understand cauda equina syndrome, help us understand where to drive our research initiatives, and let us know how patients need more support.

CoRDS

Who owns my data? →



Importantly, the participant owns their personal data and can withdraw the data from the registry at any time.

CoRDS

What is CoRDS?

The Coordination of Rare Diseases at Sanford (CoRDS) is a registry that stores information on individuals affected by a rare disease – and others who have not yet been diagnosed with a rare disease – to help accelerate research into rare diseases. It was developed because access to information about rare diseases presents a challenge to researchers, physicians, patients and their families.

CoRDS provides a better way for researchers conducting studies or clinical trials to search for individuals who are interested and may be able to participate. The CoRDS registry also keeps individuals and families aware of any opportunities to participate in research studies or clinical trials.

Rare disease registries help researchers:

- Learn how certain treatments of rare diseases may or may not be effective
- Accelerate their research efforts by storing individual information that is accessible for the recruitment and contact of potential participants for clinical research studies
- Help medical professionals improve treatment of patients with rare diseases
- Notify individuals of opportunities for clinical research studies or clinical trials



CoRDS
Coordination
of Rare
Diseases at
Sanford

Who can access my data?

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RESEARCHERS



The de-identified information in CoRDS will be made available to researchers studying rare, uncommon or undiagnosed disorders if they have obtained approval for their research project from (1) the Institutional Review Board (IRB) at the researcher's institution and (2) the CoRDS Scientific Advisory Board (SAB). The SAB is a group of scientists and laypersons (e.g., lawyers, clergy and professors) who review proposed research using human subjects. The SAB will review the research to ensure that the rights of CoRDS participants are upheld.

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OTHER PATIENT REGISTRIES



A subset of de-identified information collected from each profile can be shared with some other databases. CoRDS shares data with other databases to help improve researchers' understanding of rare diseases, to avoid duplication of efforts, and to collaborate with existing research efforts and organizations dedicated to rare diseases.

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PATIENT ADVOCACY GROUPS



Patient advocacy groups (PAGs) representing individuals with rare or uncommon diseases who have partnered with CoRDS may also request access to information in CoRDS that may or may not include participants' names. The PAG will sign an agreement stating they will not use the information for research purposes. If a participant indicates that they would like their information shared in this way, CoRDS personnel will not be held responsible for the use of information by the PAG.

YOU WILL BE ABLE TO CHOOSE HOW YOU WOULD LIKE YOUR DATA SHARED.





CoRDS Contact Information

For questions, comments and inquiries

PHONE NUMBER

(877) 658-9192

EMAIL ADDRESS

cords@sanfordhealth.org

WEBSITE

<https://research.sanfordhealth.org/rare-disease-registry>



Cauda Equina Foundation Contact Information

For questions, comments and
inquiries

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