



CAUDA EQUINA
FOUNDATION

IN PARTNERSHIP
WITH CoRDS

CAUDA EQUINA SYNDROME

NATURAL HISTORY STUDY

PATIENT REGISTRY

Questions:

cesnathx@ceslife.org

cords@sanfordhealth.org

ceslife.org

CAUDA EQUINA SYNDROME NATURAL HISTORY STUDY PATIENT REGISTRY

IN PARTNERSHIP
WITH
**Coordination of
Rare Diseases at
Sanford (CoRDS)**



What is a Natural History Study?

The natural history of a disease (condition or syndrome) is typically thought of as the course the condition takes in the absence of intervention in people who have the condition, from its onset until its resolution or the patient's death. .

Why is it important to participate in the Natural History Study?

The knowledge obtained from a Natural History Study is essential to help plan drug and device intervention studies. In the case of CES being a syndrome with a large variety of symptoms it is more important than ever to try and describe its natural history based on the empirical data this study will generate.

Who is eligible to participate in the Natural History Study?

Anyone who was diagnosed with cauda equina syndrome by a physician at least six months ago.

Why did the Cauda Equina Foundation partner with CoRDS?

The Cauda Equina Foundation is the ideal organization to lead this project given our vast knowledge and experience with this syndrome, including the medical expertise to design and execute a Natural History Study. We are very fortunate to be partnering with CoRDS who have the rare disease registry infrastructure up and running.



QUESTIONS:

Cauda Equina Foundation:

Email: cesnathx@ceslife.org

Phone: 407-984-6394

CoRDS:

Email: CORDS@sanfordhealth.org

Phone: (877) 658-9192

CAUDA EQUINA SYNDROME **NATURAL HISTORY STUDY** **PATIENT REGISTRY**

In Partnership with CoRDS

WHY SHOULD YOUR PATIENTS PARTICIPATE?

The knowledge obtained from a Natural History Study is essential to help plan drug and device intervention studies. In the case of CES being a syndrome with a large variety of symptoms it is more important than ever to try and describe its natural history based on the empirical data this study will generate.

VISIT CESLIFE.ORG TO LEARN MORE



HOW TO PARTICIPATE IN THE CAUDA EQUINA SYNDROME NATURAL HISTORY STUDY

in partnership between the Cauda Equina Foundation and
CoRDS



CREATE YOUR CoRDS PROFILE

- Visit CoRDS to create your profile and generate your user name and password.
- Add cauda equina syndrome as your rare disease to be able to access the correct questionnaire
- The questionnaire is also available to be completed by phone or paper copy. See the contact information below.
- Your progress will be saved as you complete the questionnaire, allowing for participants to take breaks and complete it in multiple sessions

COMPLETE THE CoRDS QUESTIONNAIRE

Part one of the questionnaire will take approximately 15 minutes and includes demographics questions created by CoRDS.

If your time is limited, please complete only the mandatory questions to leave enough time to complete part two of the questionnaire.

COMPLETE THE CAUDA EQUINA FOUNDATION QUESTIONNAIRE

Part two of the questionnaire will take approximately 30 minutes and includes Cauda Equina Syndrome (CES) questions created by the Cauda Equina Foundation.

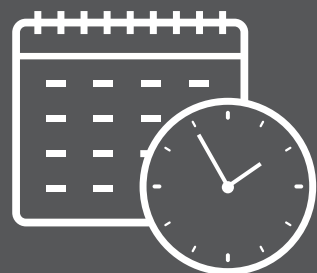


SUBMIT

When part one and part two of the questionnaire are completed click submit!

UPDATES

Visit your CoRDS profile to update your profile once a year or after any major medical changes.



THANK YOU

We want to thank you for taking the time to participate in the Cauda Equina Syndrome (CES) Natural History Study Questionnaire.

Visit ceslife.org to subscribe to our newsletter and keep an eye out in the future for information on Phase Two.

HAVE A QUESTION?

Email: cords@sanfordhealth.org
Phone: 1-877-658-9192



ceslife.org

P.O. Box 381
Howey in the Hills, FL 34737



CAUDA EQUINA SYNDROME NATURAL HISTORY STUDY

PATIENT REGISTRY

In Partnership with CoRDS

What is a Natural History Study?



A Natural History Study is a planned observation of a large number of participants over a sufficient period of time using a registry where each patient's course is tracked.

What is a patient registry?



A collection—for one or more purposes—of standardized information about a group of patients who share a condition or experience.

Who is eligible to participate?



Patients with a confirmed diagnosis of cauda equina syndrome (CES) by a doctor at least six months ago

Questions?



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Cauda Equina Syndrome

NATURAL HISTORY STUDY

Patient Registry



WHAT IS A NATURAL HISTORY STUDY?

The natural history of a disease (condition or syndrome) is typically thought of as the course the condition takes in the absence of intervention in people who have the condition, from its onset until its resolution or the patient's death.

A Natural History Study is a planned observation of a large number of participants over a sufficient period of time using a registry where each patient's course is tracked.

WHAT IS A PATIENT REGISTRY?

"an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves a predetermined scientific, clinical, or policy purpose(s)." - Workman TA

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Why is the Natural History Study and participation in it important?

The knowledge obtained from a Natural History Study is essential to help plan drug and device intervention studies. In the case of CES being a syndrome with a large variety of symptoms it is more important than ever to try and describe its natural history based on the empirical data this study will generate.

WHO IS ELIGIBLE TO ENROLL IN THE STUDY?

This natural history collects participant data on cauda equina syndrome in its chronic stage beginning after six months from diagnosis of the disease over the course of the syndrome to define the syndrome in its chronic stage.

WHO OWNS THE DATA?

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

HOW OFTEN DOES A PARTICIPANT UPDATE THEIR INFORMATION?

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

