



Alström Syndrome UK

Strength for today, hope for the future

CoRDS Registry

Coordination of Rare Diseases
at Sanford



What is CoRDS?

CoRDS stands for the **Coordination of Rare Diseases at Sanford University**. It is an American based registry which holds patient records for 7000 rare diseases.

Its aim is to connect patients and researchers to advance treatments and cures for rare diseases.

The registry is free for participants and researchers to enrol. As part of this participants are required to provide information on their condition for researchers to access.

The database is secure and all information is protected, the information researchers receive does not identify the participant it only shares the information they have provided about their condition.

How does it work?



Following enrolment **researchers & clinicians** will contact **CoRDS** about opportunities for participants to get involved in clinical trials & research projects



CoRDS provides you with this information



You decide if you want to have contact with the researcher or clinician



CoRDS raises awareness and educates

Your information will help improve awareness and understanding of AS and enable researchers to develop new and improved treatments.



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How is your information used?



The CoRDS registry is **SECURE** and participant information is **PROTECTED**

Participants decide how their information is shared

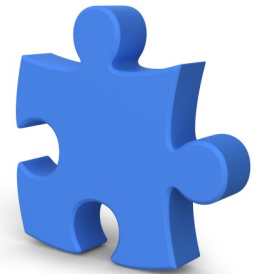


Information sent to researchers and clinicians is anonymised

CoRDS never sells, rents or leases personal information, information in CoRDS remains there unless consent to share is provided by the participant.

ASUK can provide more information about how participant data is protected as well as a copy of the registry consent form.

Join the CoRDS Patient Registry



You hold a piece to the puzzle!

You can help researchers see the whole picture. Play a vital role in finding and improving treatments by joining the CoRDS patient registry.

Contact us to find out more about how you can enrol:

Phone: 01803 368871

Email: info@alstrom.org.uk



www.alstrom.org.uk

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Charity no: 1071196

Company no: 3557191

CoRDS Patient Registry
Information