

YOU HOLD
THE KEY,
**HELP UNLOCK
THE ANSWERS**



» Why is an international Patient Registry for CCDS patients important?

Patient registries are powerful for rare diseases like CCDS. They provide patient information and medical data that allows researchers to more accurately estimate both the prevalence and incidence of a disease, to determine the natural history or typical progression of symptoms, and to focus research on disease-specific questions.

The CreatineInfo Registry gathers patient-reported data from patients worldwide in one secure database powered by NORD (National Organization of Rare Disorders).

Due to the low prevalence of CCDS patients, compiling all patient records into one international patient registry is much more useful for research than having several different national registries.

» How is patient privacy protected?

The CreatineInfo Registry follows strict government guidelines to assure patient information is protected. The registry platform is served over HTTPS, providing secure encryption of traffic. Communication between the registry platform application server and the database is also encrypted.



» What is the CreatineInfo Registry?

The CreatineInfo Registry is a Patient-Reported Registry and Natural History Study created by ACD and hosted by the National Organization of Rare Disorders (NORD) for furthering research and empowering the Cerebral Creatine Deficiency Syndromes (CCDS) community.

» Who can participate?

This registry is for all CCDS patients worldwide. Patients or caregivers with the following CCDS diagnoses can participate in this registry:

1. Creatine Transporter Deficiency (CTD)
2. Guanidinoacetate Methyltransferase Deficiency (GAMT)
3. Arginine: Glycine Amidinotransferase Deficiency (AGAT)

» Why should I join?

There are many advantages to joining the registry. The CreatineInfo Registry aims to:

- » Improve understanding of the natural history and impact of CCDS in patients' lives
- » Provide valuable information to doctors and scientists to help them develop treatments and improve patient outcomes
- » Assist ACD with representing the CCDS community accurately
- » Share community-reported recommendations and standards of care

» How do I register?

Registration is done online at creatineinfo.iamrare.org. Getting started involves a few simple steps:

1. Visit creatineinfo.iamrare.org and click "Register" under "Join the Registry"
2. Create an account. With one account, you can add multiple participants, as needed. Each participant will have their own surveys to take.
3. Provide consent for your participation and begin completing the registry questionnaires.



Researchers and clinicians worldwide need a centralized database to understand critical data on the CCDS patient population. The power of our community relies on our stories. Our data provides hope for the future.

- KIM TUMINELLO
ACD DIRECTOR OF ADVOCACY



JOIN THE CREATINEINFO REGISTRY TODAY. REGISTER AT [CREATINEINFO.IAMRARE.ORG](https://creatineinfo.iamrare.org)

TAKE ACTION.

Join the CreatineInfo Registry for Creatine Deficiencies today at: creatineinfo.iamrare.org

Creatine **INF**  TM

Questions about the registry?
Contact registry@creatineinfo.org

YOU HOLD THE KEY,
HELP UNLOCK THE ANSWERS.



6965 El Camino Real, Suite 105-598 | Carlsbad, CA 92009
info@creatineinfo.org | www.creatineinfo.org