CreatineINFO™

The CreatineInfo Registry for Creatine Deficiencies is now live!

Register at creatineinfo.iamrare.org

What is the CreatineInfo Registry?

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

Why is this Patient Registry important?

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

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)

To 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.

Questions about the registry? Contact registry@creatineinfo.org

ACD
ASSOCIATION FOR CREATINE DEFICIENCIES