

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



» What is the ACD Patient Insights Network (PIN)?

The ACD Patient Insights Network (PIN) is a database created for the purpose of collecting historical information from a patient or caregiver's perspective related to Cerebral Creatine Deficiency Syndromes (CCDS).

» How is my information used?

All information is de-identified. This means your personal information is not shared. Collected disease statistics are shared with interested researchers, physicians, and families. Genetic and health information can also be shared with publicly available databases including ClinVar.

» What is ClinVar?

ClinVar is a free database funded by the NIH that reports genomic variations and their relationships to human health. Submissions will be facilitated by certified genetic counselors who carefully curate the genetic information making it useful as a medical reference.

More information on ClinVar is available at www.ncbi.nlm.nih.gov/clinvar.

ACD PATIENT INSIGHTS NETWORK (PIN)

» Who should register?

This registry is for all CCDS patients worldwide. Patients or caregivers with one of the following CCDS diagnoses can register with the ACD Patient Insights Network (PIN):

- › X-linked Creatine Transporter Deficiency (CTD)
- › Guanidinoacetate Methyltransferase Deficiency (GAMT)
- › Arginine: Glycine Amidinotransferase Deficiency (AGAT)

» Why should I register?

There are many advantages to joining a registry. The ACD Patient Insights Network (PIN) aims to:

- › Help specialists gain more knowledge about the prevalence, the epidemiology and the natural history of CCDS
- › Accelerate research into new therapies for CCDS
- › Facilitate patient recruitment for clinical trials

» How do I register?

Registration is done online. Getting started is as easy as:

1. Visit www.creatineinfo.org/patient-registry and click Register Now.
2. Create an account or sign in with an existing account.
3. Start completing the registry and supplemental questionnaires to help CCDS patients find better treatments and cures!

» How is patient privacy protected?

The ACD has partnered with Invitae to provide our community with a safe and confidential patient registry. Invitae's systems are managed and operated to allow compliance with HIPAA and FISMA. All information is de-identified. For more information, visit: www.invitae.com/en/pin-security/.



Researchers and clinicians worldwide need a centralized database to understand critical data on the CCDS patient population. As a community, this is the way that we can take control of these diseases, provide hope, and help change the future of CCDS.

- **WHITNIE STRAUSS**
ACD President



TAKE ACTION.

Join ACD's Patient Insights Network (PIN) today at:
www.creatineinfo.org/patient-registry

The ACD Patient Insights Network (PIN) was created to develop a comprehensive database of individuals with Cerebral Creatine Deficiency Syndromes (CCDS) making it easier for researchers to study CCDS, for patients and families to learn about CCDS treatments, and for advocates to speak on behalf of those with these conditions.

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