

## New CCDS Family Guide

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### Join the Creatine Deficiency Facebook Support Group:

If you have a child diagnosed with a Cerebral Creatine Deficiency Syndrome (CCDS: CTD, GAMT, AGAT), join other parents on the [Creatine Deficiency Facebook Support Group](#) (search "Creatine Deficiency Support Group" on Facebook). The group is private and made strictly for CCDS families to connect in a safe and confidential setting. You can connect to CCDS families worldwide and gain insight from other families with similar experiences and challenges. The group provides many of us, parents, with support, advice, and encouragement.

### Join the CreatineInfo Registry:

The CreatineInfo Registry ([creatineinfo.iamrare.org](http://creatineinfo.iamrare.org)) is a tool developed by ACD for furthering research and empowering the CCDS community. This registry is patient-reported and all information is de-identified (anonymized) before it is shared for research purposes. *Patients have the power to drive CCDS Research forward!* For more information, contact [registry@creatineinfo.org](mailto:registry@creatineinfo.org)

### What Are Cerebral Creatine Deficiency Syndromes (CCDS)?

CCDS are inborn errors of metabolism, which interrupt the formation or transportation of creatine. Creatine helps supply energy to all cells in the body. There are three CCDS: AGAT, CTD, and GAMT. Symptoms may include intellectual delays, expressive speech and language delay, autistic-like behavior, hyperactivity, seizures, projectile vomiting in infancy, failure to thrive, and movement disorders.

### About the Association for Creatine Deficiencies (ACD):

The ACD is a parent and volunteer-led nonprofit organization dedicated to the three CCDS. The ACD's mission is to provide patient, family, and public education, to advocate for early intervention through [newborn screening](#), and to promote and fund medical research for treatments and cures for Cerebral Creatine Deficiency Syndromes (CCDS). For more information, visit: [creatineinfo.org](http://creatineinfo.org).

### Other ACD resources:

- [CCDS Overview](#): Learn in-depth information about each CCDS including symptoms, prevalence, treatment options, and medical references.
- [2018 Creatine Deficiency Educational Video](#): featuring CCDS families, board members, and experts the video is meant to be shared to educate the public on CCDS.
- [The Insider eNews](#): Subscribe to future issues of ACD's quarterly eNewsletter to be informed on important news, event and conference recaps, and other announcements.
- [Creatine Community Blog](#): The community blog is made up of posts written by CCDS community members touching on their experiences, challenges, successes, and more.
- **Social Media**: Follow the ACD (@creatineinfo) on Facebook, Instagram, Twitter, and LinkedIn, for daily announcements, events, advocacy opportunities, and more!