

New CCDS Family Guide

For Parents: Join the Creatine Deficiency Facebook Support Group

If you have a child diagnosed with a Cerebral Creatine Deficiency Syndromes (CCDS -GAMT deficiency, AGAT deficiency, or Creatine Transporter Deficiency) join other parents on the [Creatine Deficiency Facebook Support Group](#). 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 similar experiences and challenges. The group provides many of us, parents, with support, advice, and encouragement. You can find the group by searching for the Creatine Deficiency Support group on Facebook.

What Are Cerebral Creatine Deficiency Syndromes (CCDS)?

Cerebral Creatine Deficiency Syndromes (CCDS) are inborn errors of metabolism, which interrupt the formation or transportation of creatine. Creatine is essential to sustain the high energy levels needed for muscle and brain development. There are three Cerebral Creatine Deficiency Syndromes: Creatine Transporter Deficiency (CTD), Guanidinoacetate Methyltransferase Deficiency (GAMT), and Arginine:Glycine Aminotransferase Deficiency (AGAT). Symptoms may include developmental delay, intellectual disability, speech/language delays, seizures, failure to thrive, hypotonia (low muscle tone), movement disorders, hyperactivity, autistic-like behavior and/or other behavioral problems. Projectile vomiting in infancy and other gastrointestinal problems are also common in individuals with CTD.

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 diagnosis, and to promote and fund medical research for treatments and cures for CCDS. For more information, visit: creatineinfo.org

Other ACD resources:

We offer various materials and communication methods to ensure consistent and timely updates with our community.

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.

Take Action: Learn about ways to get involved. Awareness and advocacy tips and suggestions on how you can help CCDS community.

Social Media: Follow the ACD (@creatineinfo) on key social media platforms such as Facebook, Instagram, Twitter, and LinkedIn, for daily announcements, community events, advocacy opportunities, scholarship opportunities, new blog posts, and more!