



**GIVE TODAY TO CHANGE
THE FUTURE OF CCDS.**

The ACD

The Association for Creatine Deficiencies (ACD) is the only patient advocacy group devoted to the three known Cerebral Creatine Deficiency Syndromes (CCDS), individually referred to as: GAMT, AGAT and CTD.

We are committed to meet the goals set forth by our mission statement, which are 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 these three rare diseases.

Understanding the Challenges

Creatine is essential to sustain the high energy levels needed for muscle and brain development. As a result, CCDS are devastating diseases. With a diagnosis of CCDS, many children struggle with Global Developmental Delay, intellectual disabilities, speech and language impairments, movement disorders, and seizures.

While symptoms impact the child directly, they are difficult for the entire family. Parents face the daily challenges of how to best integrate and care for their special needs child(ren). Without proper treatment or cure, these children will grow into adults that require lifelong care.

SHOCKING RARE DISEASE STATISTICS

8 is the average number of physician visits it takes to reach a diagnosis.

3 is the average number of misdiagnoses

95% of rare disorders have no FDA approved drug treatment.

7+ years is the average length of time it takes for rare disease patients to receive a proper diagnosis.

YOUR DONATION AT WORK

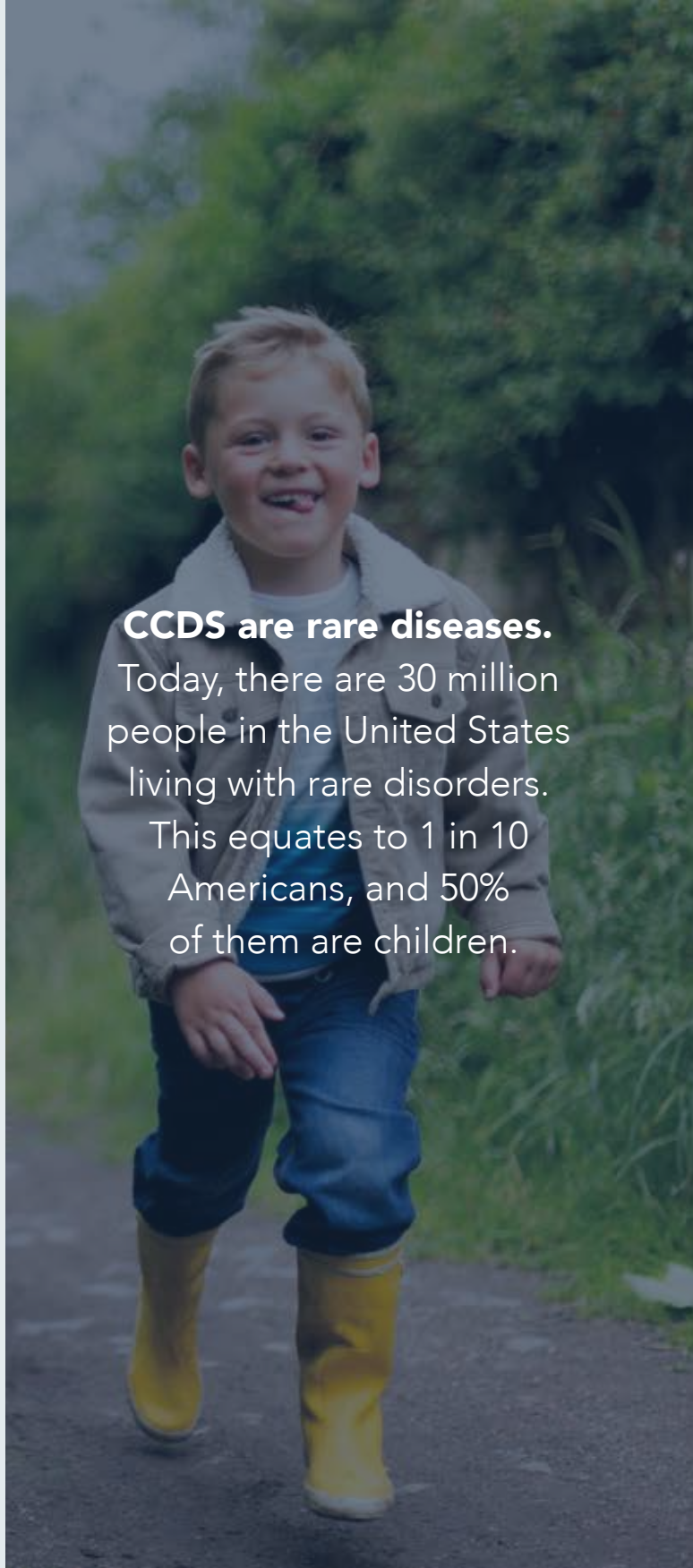
Money raised goes towards:

Education and Advocacy

- » Attending medical symposiums, conferences, and rare disease seminars
- » Speaking at FDA public forums
- » Providing up-to-date online CCDS resources
- » Producing educational videos and materials for the public and allied healthcare professionals
- » Partnering with other rare disease advocacy groups like the National Organization for Rare Disorders (NORD) and Global Genes to increase CCDS visibility
- » Advocating for newborn screening at the state and national level

Medical Research

- » Building a secure and comprehensive international patient registry
- » Supporting non-drug clinical research
- » Collaborating with medical professionals, drug developers, the Advisory Committee for Heritable Disorders in Newborns and Children, the National Institutes of Health (NIH), the Centers for Disease Control (CDC), and several others on research efforts related to early detection and potential therapeutics



CCDS are rare diseases.
Today, there are 30 million people in the United States living with rare disorders. This equates to 1 in 10 Americans, and 50% of them are children.

Dear Friends,

The Association for Creatine Deficiencies (ACD) was started in 2012 by three moms who wanted to make a difference for children with Cerebral Creatine Deficiency Syndromes (CCDS). Each mom had individually navigated the same rare disease odyssey and struggled to find answers and a diagnosis for their children. Today, the ACD is much more than parental support. It has become a passion and it is with a strong purpose that these mothers, turned patient advocates, have built a thriving organization that is determined to eliminate the challenges of CCDS.

As we have seen first hand, these diseases impact both patients and caregivers who will spend a lifetime fighting the long-lasting mental and physical effects. While these diseases are relentless, equally tragic is the knowledge that two of the three represented deficiencies are treatable. Today, GAMT and AGAT patients needlessly suffer with life-long impairments due to the lack of awareness and screening for these rare disorders. Parents search years for answers and by then, it's too late due to irreversible brain damage. For CTD patients, there is no treatment. These families cling to hope that one day a treatment will be available for their children.

The ACD is committed to building strength and changing lives, but we can't do it alone. Your support is crucial to funding CCDS education, advocacy efforts, and medical research.

Please give today to help change their tomorrow.

With sincere gratitude,



Whitnie Strauss
ACD President

GIVING IS EASY

Our combined efforts CAN change lives.
Your support matters.

Give online

For secure credit card and/or PayPal processing, go to: creativecommonsinfo.org/make-a-donation

To learn about more ways to lend support, visit: creativecommonsinfo.org/ways-to-give or contact info@creativecommonsinfo.org to find out how you can get involved.

Give by mail

Mailed check, cash or credit card donations may be sent directly to the address below. Please make checks payable to: The Association for Creatine Deficiencies or ACD.

Mailing Address

Association for Creatine Deficiencies
6965 El Camino Real, Suite 105-598
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The Association for Creatine Deficiencies is a 501(c)(3) tax exempt, non-profit public charity. Association for Creatine Deficiencies Tax Exempt Status DLN 17053130313013, EIN 462133007



WE DON'T DREAM
ABOUT CHANGE;
WE MAKE IT

“ ”

Approximately 50% of rare diseases do not have a disease specific foundation supporting or researching their rare disease.

- GLOBAL GENES

