

**MEDIA ADVISORY**

***LOCAL FAMILIES “WALK FOR STRENGTH” TO CURE RARE GENETIC DISORDERS***

WHAT: On Saturday, June 15, 2024, local (COMMUNITY/REGION) families will come together to participate in the international annual Walk for Strength event to raise funds, advocate, and support research for a cure for Cerebral Creatine Deficiency Syndromes (CCDS). <INSERT PERSONAL STORY/NAMES FOR LOCAL COMMUNITY MEDIA – ie: Due to his \_\_\_\_ diagnosis, \_\_\_\_\_\_\_, a sweet and happy boy/girl, is affected by symptoms including seizures, developmental delays, speech delays, and more. Until a treatment or cure is found to get creatine into his brain, \_\_\_\_\_ will continue to need countless hours of therapy to learn to do things like talk, eat with a fork and learn basic self-care skills. >

CCDS is a group of three rare inborn errors of metabolism which interrupt the formation or transportation of creatine--Creatine Transporter Deficiency (CTD), [Guanidinoacetate Methyltransferase](https://creatineinfo.org/overview-of-creatine-deficiency-syndromes/) Deficiency (GAMT)*,* and L-Arginine: Glycine Amidinotransferase Deficiency (AGAT). Creatine is essential for healthy muscle and brain development --- without it, children's brains don't get the creatine they need to develop and function normally. Children and adults with CCDS are affected by speech/language impairments, intellectual disability, behavioral challenges, and seizures.

WHEN: Saturday, June 15

 (TIME OF LOCAL WALK)

WHERE: (LOCAL WALK LOCATION)

WHY: The quality of life and future for everyone affected by CCDS is dependent upon finding treatments or cures that will work to get creatine into the cells and brains that need it to function properly.

The exact prevalence of CCDS is unknown. Yet, sources estimate that approximately 1% of individuals with intellectual disabilities of unknown origin may have a CCDS. It is estimated that CTD represents the second largest cause of x-linked intellectual disability, behind Fragile X syndrome.

WHO: (NAMES OF ACD REPRESENTATIVES OR WALK ORGANIZERS/FAMILY

MEMBERS AVAILABLE FOR INTERVIEWS)

PHOTOS: (LIST HIGHLIGHTS OF LOCATION, NUMBER OF PEOPLE, SPECIAL

EVENTS AT WALK)

HOW: To find out more information on the (CITY) Walk for Strength or to register, please visit [creatineinfo.org/wal](http://www.creatineinfo.org/walk)[k](http://www.creatineinfo.org/walkforstrength)

CONTACT: NAME
 PHONE NUMBER

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