

2017 Year in Review



2017 YEAR IN REVIEW



Education

Increased our collaborative rare disease partnerships to help strengthen our visibility and capacity to serve our patient population, and to increase CCDS knowledge within the medical community and the public, at large.

Continued attendance at national symposiums, conferences and rare disease seminars.

Sponsored the Child Neurology Foundation's Respite Care Notebook, nominated for the Eyeforpharma National Award in Most Valuable Pharma category.



Advocacy

CCDS should be placed on newborn blood screens nationwide for the best outcomes for children. We worked toward the addition of GAMT at the state level in Georgia, Michigan, and New York.

Advocated on the national level by appealing to the Secretary of Health's advisory committee on newborn screening.



Research

Supported approved non-drug research studies for CCDS by promoting volunteer participation in observational studies.

Initiated patient surveys to gather data for global research efforts.

Collaborated with medical professionals, drug developers, local, state and national committees and organizations.



2017 was another fantastic year for Creatine Deficiencies! Visible progress is being made as we continue to see more CCDS patients being diagnosed, more states showing interest in newborn screening programs for GAMT, and more interest in learning about signs and symptoms and natural histories of these disorders.

The Association for Creatine Deficiency Syndromes is committed to building strength and changing lives for those living with CCDS. We would like to thank the CCDS community for the continued support we receive as we carry on with this important mission.

With sincere gratitude,

Whitnie Strauss
ACD President



FINANCIALS

OVER **\$95,000**
RAISED FOR CCDS

Fundraising Initiatives

Rockin' for a Cause

Benefit Concert, Raffle & Auction | Austin, Texas

\$50,523 Gross | \$45,531 Net

2017 Walk for Strength

ACD Signature Walk Event

\$7,988. Gross | \$7,276 Net

Suffering for a Cause | Iron-man, Louisville

Independent Fundraiser by: Jerry Robinson

\$5,475 Net

General Income

Independent Donations \$21,510

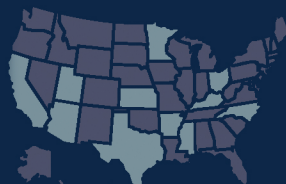
Fundraising Initiatives \$63,986

Newborn Screening \$10,000

PatientStrong \$455



COMMUNITY ENGAGEMENT



WALK FOR STRENGTH 2017



WALK FOR STRENGTH 2016

100% National Increase for CCDS Community
Walk to Raise Awareness

MEASURABLE GROWTH

73% CTD
PATIENT
INCREASE



182,000

Social media impressions

46% CCDS
PATIENT
GROWTH



four

Legislative initiatives proposed



three

Average patients identified monthly

OUR VISION

To help eliminate the challenges for those living with Cerebral Creatine Deficiency Syndromes.

OUR MISSION

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.

OUR BOARD

The ACD was founded in 2012 by parents with children diagnosed with a CCDS. The ACD was established to raise awareness and education of CCDS among the medical community, and the general public, and to advocate on the behalf of patients and families living with CCDS.

2017 Executive Directors

Whitnie Strauss

President

Heidi Wallis

Vice President

Kim Tuminello

Director of Advocacy, Co-Founder

Linda Cooper

Director of Special Initiatives, Co-Founder

Melissa Parker

Director of Finance

2017 Scientific Medical Advisory Board (SMAB)

Dr. Nicola Longo, M.D., Ph.D.

Chief Division of Medical Genetics
University of Utah Health Care
Pediatrics, Medical Genetics

Dr. Bruce Barshop, M.D., Ph.D.

Metabolic and Mitochondrial Medicine
Pediatrics, Rady Children's Specialty
University of California San Diego.

Dr. Denise Morita, M.D.

Pediatric Neurologist Granger
Medical Clinic Riverton, Utah

Dr. Sarah Young, Ph.D.

Assistant Professor Department
of Pediatrics - Medical Genetics
Duke University School of Medicine
North Carolina

Dr. Matthew Skelton, Ph.D.

Assistant Professor, Department of Pediatrics,
University of Cincinnati Division of Neurology
Cincinnati Children's Hospital

Dr. Andreas Schulze, M.D., Ph.D.

Assistant Professor Department
of Pediatrics - Medical Genetics
Duke University School of Medicine

Dr. Yiumo Chan, Ph.D.

Preclinical Drug Discovery Consultant

Dr. Sylvia Stockler

Professor of Pediatrics at University of British
Columbia Vancouver, British Columbia, Canada

2017

Ambassadors:

Laura Martin
Kelly Shedd
Tina Strauss

2017 Volunteer

Representatives:

Beth Robinson
Jerry Robinson
Jolene Negre
Amy Perry
Nathan Vandenberg
Celine Wheaton

2017 Blog

Contributors:

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