



C.A.R.E.

Corporate Alliance
for Research & Education

JOINING FORCES **TO MAKE A DIFFERENCE**

The Association for Creatine Deficiencies Corporate Alliance for Research and Education Committee was established to bring together corporate industry experts to support the Cerebral Creatine Deficiency Syndrome (CCDS) patient community.

Together, we can change the lives of CCDS patients.

C.A.R.E Program Overview

The mission of the Advisory Committee is to bring together corporate industry resources to support the Cerebral Creatine Deficiency Syndrome (CCDS) patient community. Our committee members consist of Key Opinion Leaders in the pharmaceutical, biotech companies, and other relative industries.

Advisory Committee participants are CCDS stakeholders committed to collaborative efforts and the exchange of relevant information among the ACD Board, the Scientific Medical Advisory Board (SMAB), the CCDS patient community, and CCDS or rare disease health-related organizations.

Our key collaborators work together to:

- Guide ACD in efforts to improve patient engagement to support the advancement of prospective therapeutics; Through effective patient education, we can increase present and future participation in natural history studies and clinical trials;
- Guide ACD to identify new patients, nationally and internationally; so we can increase participation in ACD's Patient Insights Network (PIN);
- Help strategize for newborn screening, at the state and national levels;
- Provide up-to-date related resources and patient-related education to keep ACD informed on all current information;
- Help in the development of patient resource(s) for CCDS testing labs and specialty physician directory to help screen effectively;
- Examine our patient challenges to help understand the disease process and bring forth possible biomarkers of the disorder;
- Discuss CCDS developing topics to help ACD with current affairs;
- Partner with other rare disease groups, like the National Organization for Rare Disorders and Global Genes, so we may increase CCDS visibility;
- Give expert viewpoint and help guide basic research programs, and these opinions will help guide ACD's research initiatives.

Advisory Committee monetary support will be restricted to the initiatives below:

- PatientStrong™ Patient Travel Grants, given during conference year
- CCDS patient family workshops
- Patient family educational webinars and/or videos
- De-identified patient surveys for basic research for measurable results on ACD basic research projects, such as educational posters, analysis charts and for aggregated examination(s)
- Other outlined projects that support and build CCDS patient family relations and patient family involvement

2019 C.A.R.E Commitment

Advisory Committee Participation is **\$10,000** annually and includes:

- Invitation for three (3) representatives to participate in ACD Board hosted quarterly CARE Advisory Board conference calls
- Recognition as an Advisory Board member on ACD website, social media, newsletters and signature fundraising events
- One featured editorial and/or industry ad in ACD's E-Newsletter per year
- Invitation to participate in patient family educational webinars/videos
- Receive de-identified patient survey information from ACD basic research project(s), within the current year
- Opportunity to strategize with third-party clinical and patient experts
- Recognition for the year(s) served as Advisory Committee member at ACD hosted CCDS Scientific and Patient Symposium in scheduled biennial *(The next CCDS Scientific and Patient conference is scheduled for year 2020. Opportunity for Advisory Committee sponsorship and/or underwriting will be requested and available third quarter 2019.)*

CARE Call Schedule

CARE calls* will be hosted and facilitated by an ACD representative and will also include participation from third-party clinical and patient experts to help provide valuable insight.

CARE committee calls will be up to an hour and will take place at:
12:00pm EST | 11:00am CST | 9:00am PST

2019 CARE Call Dates:

- January 30th
- April 24th
- July 31st
- October 30th

**Disclaimer: This committee is specific to patient engagement. No discussions about intellectual property, therapeutics or treatment protocols should be discussed.*

Together, we are Building Strength, Changing Lives

Our CCDS patient community is uniting to fight these rare diseases with debilitating effects. Our continued strength and determination powers our efforts, but collaboration is the key to success. The ACD believes when courage and generosity hold hands, all things are possible.

The ACD values every CARE Advisory Committee Member. We look for support and guidance to aid our direction with patient engagement, and efforts towards effective therapeutics. But most important, we look forward to a shared understanding and partnership towards eliminating the challenges associated with CCDS.