Cure Creatine Deficiencies

CONTACT:
Erin Coller, ACD Board of Trustees
erin@creatineinfo.org

ACD NEWS RELEASE

ASSOCIATION FOR CREATINE DEFICIENCIES ANNOUNCES NEW LEADERSHIP FOR BOARD OF TRUSTEES

Carlsbad, CA (October 12, 2027)— The Association for Creatine Deficiencies (ACD) announced updates to its board of trustees with new leadership including Matt Henley as Board Chair and Seung Chun as Vice Chair.

Matt Henley, Board Chair - Mr. Henley has nearly 20 years of corporate experience, including over a decade in the engineering and construction industry. He currently oversees corporate development at Verdantas, a 2,500+ person environmental science and engineering services firm. He has worked in public, employee-owned and private-equity backed businesses, which provides him deep experience in governance and financial oversight. Mr. Henley holds a bachelor's degree from Washington University in St. Louis and an MBA from The Wharton School of Business at the University of Pennsylvania. He is a native of Philadelphia, and lives in Rhode Island with his wife Jill, daughter Drew, and son Lucas, who was diagnosed with Creatine Transporter Deficiency (CTD) in 2024 at four years old.

About his appointment to the role of board chair, Matt said, "I am so excited to step into this role as ACD's board chair. As a parent and advocate, I look forward to working with the ACD community, our partners and collaborators to continue to push the research forward and get treatment for these kids who deserve it."

Seung Chun, Vice Chair - Chun has nearly 17 years of experience in pharmaceutical drug development, specializing in rare diseases. Her work focuses on initiating clinical trials and engaging regulators to advance drug development plans. She earned her bachelor's degree in biology from the University of California, San Diego, where she conducted research in a neurodegenerative diseases lab. Chun lives in Los Angeles with her husband, Chris, and their son, Asher, who was diagnosed with CTD at age two in 2022.

Celeste Graham will continue to serve as ACD board of trustees secretary. Celeste has a background in special education with an undergraduate degree from the University of North Carolina at Charlotte in Child and Family Development and a master's degree from Western Carolina University in Special Education. Celeste is passionate about education and empowering parents. Celeste, her husband, Phil, and their four children, Gabriel, Blaine, Paisley, and Levi, live in North Carolina. Levi was diagnosed with CTD at 5 years old.

Mikelle Law will continue to serve as ACD board of trustees treasurer. Mikelle has over 20 years of experience in technology sales and currently leads a sales organization for a software company. She received her BA in European Studies with a minor in French from Brigham Young University. She and her husband Leif reside in Idaho with their three children–Max, Mason, and Sadie. Her son Max was diagnosed with GAMT in 2010, and she is passionate about helping patients and families affected by creatine disorders.

ACD would also like to extend profound gratitude to Dan Coller for his 3.5 years of service in the role of Board Chair and Jeff Allen for his 5 years of service in the role of Vice Chair. Both Dan and Jeff will continue to serve ACD as valued members of the board of trustees, as well as Carole Chehowah, Erin Coller and Kim Tuminello. Kristofer DeVault and Kelly Johnston also serve as board advisors.

About ACD: The Association for Creatine Deficiencies' mission is to eliminate the challenges of Cerebral Creatine Deficiency Syndromes (CCDS). ACD is committed to providing 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 CCDS. Because CCDS mimic symptoms of other medical conditions, patients are often first diagnosed with autism, global developmental delay, epilepsy, and other disorders. Proper diagnosis and early intervention are critical to establishing screening and treatments needed to improve life quality and longevity for the CCDS patient. For more information regarding ACD, please visit creatineinfo.org.

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