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FOR IMMEDIATE RELEASE

ASSOCIATION FOR CREATINE DEFICIENCIES EXPANDS BOARD OF TRUSTEES

Carlsbad, CA (June 10, 2026)— The [Association for Creatine Deficiencies](#) (ACD) announced the expansion of its [board of trustees](#) with the addition of Seung Chun, Carole Chehowah, and Matt Henley. Additionally, Kristofer DeVault and Kelly Johnston join as board advisors.

Seung Chun, Board Member - Chun has nearly 15 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 of Science 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 Creatine Transporter Deficiency (CTD) at age two in 2022.

Carole Chehowah, Board Member - In addition to spending almost 25 years working in finance, Chehowah, the mother of a child with CTD, has been committed for nearly 20 years to supporting families impacted by this syndrome. Her primary focus has been on promoting awareness and funding research in France. She also contributes to improving visibility of the syndrome by organizing symposiums and events across France and Europe.

Matt Henley, Board Member - Henley has nearly 20 years of business experience, including over a decade in the engineering and construction industry. He currently oversees corporate development at Verdantas, a 2,000+ 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. Henley holds a Bachelor of Arts from Washington University in St. Louis and an MBA from [The Wharton School of Business at the University of Pennsylvania](#). Henley is a native of Philadelphia, and currently lives in Rhode Island with his wife Jill, daughter Drew, and son Lucas, who was diagnosed with CTD in 2024 at four years old.

Kristofer DeVault, Board Advisor - DeVault is an active-duty U.S. Marine Corps major currently serving with [Marine Corps Special Operations Command](#) (MARSOC), where he programs and resources future capabilities to support special operations forces. He holds an MBA from [UCLA](#)



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[Anderson School of Management](#) and a Master of Science in finance from the [Naval Postgraduate School](#), with a focus on defense innovation and resource strategy. DeVault brings experience in financial management, acquisition, and strategic partnerships. In his role with ACD, he is actively involved in advancing fundraising, awareness, and strategic initiatives to accelerate treatment development. DeVault's work is deeply personal, driven by his son's diagnosis of CTD, and he is committed to helping bring meaningful therapies to families affected by rare diseases.

Kelly Johnston, Board Advisor - Johnston is a husband, dad, and someone who's had his perspective on life completely reshaped over the past year. He and his wife, Margy, are raising their six-year-old daughter Elmslie and son Kelly ("3sey"), who was diagnosed with CTD in December 2025 at age 4. 3sey is a happy kid who loves big hugs, fire trucks, and all things construction-related. Their children are at the center of everything they do. What started as a family challenge has turned into a passion for raising awareness, connecting with other families, and pushing for progress in the rare disease community. Professionally, Kelly has spent over 20 years in the beverage industry building relationships and growing businesses, and he has found that same mindset now carries over into advocacy—bringing people together and finding ways to make a real impact.

"This expansion reflects how far the creatine deficiency community has come. Since its inception in 2012, ACD is no longer a small group of families searching for answers in isolation – we have built a global network of advocates, researchers, clinicians, and business leaders united around one mission," said ACD Board Chair Dan Coller. "The addition of these board members and advisors strengthens our ability to think bigger, move faster, and increase the partnerships necessary to change the future for individuals living with CCDS."

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, cerebral palsy, 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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