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CONTACT:
Erin Collier, Director of Communications
erin@creatineinfo.org

FOR IMMEDIATE RELEASE

**ASSOCIATION FOR CREATINE DEFICIENCIES EXPANDS WITH ADDITION OF
EXECUTIVE DIRECTOR, BOARD CHAIR & DIRECTOR OF COMPLIANCE**

Carlsbad, CA (January 10, 2022)— The [Association for Creatine Deficiencies](https://www.creatineinfo.org/) (ACD) is expanding with the addition of Heidi Wallis as Executive Director, and new roles on the board of directors with Laura Trutoiu as the new Board Chair and Mikelle Law as Director of Compliance.

The ACD organization has seen tremendous growth in the past few years, from the number of patients diagnosed with Cerebral Creatine Deficiency Syndromes (CCDS) to increased efforts in fundraising and in securing grants. In 2021, the ACD Family Network grew from 232 to 272 families from more than 30 countries. Also in 2021, ACD awarded three fellowships, funded gene therapy projects, and produced four educational webinars. In order to continue the organization's growth, ACD has expanded its board of directors and added the position of executive director. The executive director will focus on the day-to-day management of the organization, partnerships, and acquiring the funding needed to maintain our progress.

In late 2021, ACD conducted a thorough executive search and interview process. Wallis, who served ACD in the volunteer board president role for the past two years, will step into the position of executive director. The leadership of the board of directors will transition to Trutoiu, ACD's director of research since July 2018, a position she continues in along with her new role of board chair. The role of director of compliance is a new position being filled by Law.

"Our ACD community is at an exciting stage and we have driven significant progress into creatine deficiencies research since our first symposium in 2018," said ACD Board Chair Trutoiu. "To accelerate the road toward treatments, our board of directors decided to hire a full-time executive director. We are excited that Heidi Wallis, who has served the ACD community for the past seven years, is switching to this new role to lead our daily operations with tremendous expertise, commitment, and passion. As board chair, my goal is to ensure we pursue the bold vision of getting to treatments and early diagnosis for all creatine deficiencies."

Wallis comes to ACD from her previous position managing the newborn screening informatics team at the Utah Department of Health. She serves as Utah team co-lead for the Mountain States Regional Genetics Network and patient advocate representative for Utah's Newborn Screening Advisory Committee. She lives in Salt Lake City, Utah with her husband, Trey and their four children. Samantha, now 18 years old, was diagnosed with GAMT deficiency at age five. Louis, who is 10 years old, was diagnosed with GAMT deficiency and began treatment at birth.

"I am honored to be able to serve in this position. ACD is in its 10th year and many volunteers have worked hard to advance the organization to this point," said Wallis. "I am excited to focus my energy



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full-time on advancing ACD's mission—specifically towards increasing funding to advance research, advocating for adoption of GAMT newborn screening universally and the development of CTD and AGAT newborn screening technologies, and supporting our community through education and networking opportunities.”

The position of ACD board chair is focused on working with the ACD board of directors, as well as the executive director, to develop long term strategy and vision for the organization. The implementation of these strategies is carried out by the executive director and staff.

Trutoiu, a full-time professional researcher, has initiated and led several accomplishments on behalf of ACD. Trutoiu is the patient leader for the Chan Zuckerberg Initiative \$450,000 grant the ACD received in 2019 as well as the principal investigator for the recently awarded [\\$238,000 PCORI grant](#). The [CreatineInfo Patient Registry](#) and the [Scientific Medical Advisory Board](#) efforts are also under the purview of the research committee led by Trutoiu. Trutoiu lives in Seattle with her husband and seven-year old son, Rohan, who was diagnosed with Creatine Transporter Deficiency in 2017.

As director of compliance and ACD's newest board member, Law will focus on ensuring the ACD's compliance with nonprofit regulatory and partner requirements as well as building internal processes to ensure the organization maintains an inclusive and diverse environment.

“I'm incredibly grateful to have an opportunity to give back to an organization that has given so much support, education, and awareness for our children's very rare disorders,” said Law. “The Association for Creatine Deficiencies represents children who need our help and support, and I am hopeful that we can reach more families throughout the world, create awareness, and find better treatments for our children.”

Law works as an area sales director in the technology industry, an industry where she has built her career over the past 20 years. She received her BA in European Studies with a minor in French from Brigham Young University. Law is the mother of three children and enjoys spending time with her family, traveling, cooking, hiking, learning, and watching basketball. Her oldest son, Max, was diagnosed with GAMT Deficiency when he was 11 months old, and she lives each day trying to create the best life possible for Max and his siblings.

About ACD: The Association for Creatine Deficiencies' mission is to eliminate the challenges of 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 Cerebral Creatine Deficiency Syndromes. 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 <http://www.creatineinfo.org>.

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