PRESS RELEASE

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The CACNA1A Foundation Appoints its First Development Director to Raise Funds for Finding Treatments and a Cure for a Rare Neurological Disease

Estimated 1 in 11,700 people in the world affected by a CACNA1A gene mutation

Norwalk, CT—April 30, 2024—The CACNA1A Foundation, a parent-led 501(c)(3) non-profit organization dedicated to advancing research, supporting families, and raising awareness for *CACNA1A*-related disorders, today announce the appointment of **Lynn Tusa** as its **first Director of Development.** Lynn brings a wealth of experience and unwavering passion to the foundation's mission of accelerating the development of treatment options and a cure for this rare neurological disease.

Since entering the non-profit world in 2008, Lynn has dedicated her career to making a difference in the lives of children and families. Her commitment to helping others led her to the CACNA1A Foundation, where she will play a pivotal role in raising funds and building awareness for this critical cause. Previously, Lynn was the Chief Development and Communications Officer for the Stamford Public Education Foundation (SPEF), spending a decade focused on elevating the success of all students in Stamford, Connecticut's public schools.

Lynn's appointment underscores the foundation's commitment to building a sustainable organization that will continue to push science forward and improve the lives of families impacted by CACNA1A-related disorders. **"**The appointment of a Development Director is a significant milestone for our young organization. We are committed to creating awareness and finding a cure for CACNA1A-related disorders and have a lot of promising research to support. Lynn's expertise will be instrumental in securing resources, building awareness, and fostering partnerships to drive our mission forward," said Lisa Manaster, President of the CACNA1A Foundation.

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CACNA1A-related disorders are a group of neurological and developmental conditions caused by mutations in the CACNA1A gene. Just four years ago, the CACNA1A Foundation was established by three families who shared a common desire: to fund innovative research and discover treatment options for their children affected by this rare disease. Individuals with this condition experience a range of disabilities, including developmental delays, seizures, movement and coordination disorders, hemiplegic migraines (stroke-like episodes), and speech and language issues. Currently, there are no targeted treatment options or a cure available.

“I am honored and excited to join the CACNA1A Foundation as its first Development Director. I look forward to applying my fundraising and communications skills to support the important work being done by this organization. Working alongside a dedicated team of staff, board members, clinicians, and scientists from around the world, I aim to raise awareness and critical funds to find treatments and ultimately a cure for rare CACNA1A-related disorders,” said Lynn Tusa, Development Director for the CACNA1A Foundation.

About The CACNA1A Foundation: Founded in 2020, the foundation’s mission is to find specific treatment options and a cure for CACNA1A patients by building a collaborative network of patients, families, clinicians and scientists that will work together to raise awareness and accelerate the understanding, diagnosis and treatment of CACNA1A-linked diseases. For further information visit www.cacna1a.org.

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