Advancing Understanding and Treatment of Okur-Chung Neurodevelopmental Syndrome Through Groundbreaking Research

Grant funds research on cilia's role in OCNDS, aiming to uncover key molecular changes and accelerate future treatment breakthroughs.

SAN FRANCISCO, CA, UNITED STATES, February 5, 2025 /EINPresswire.com/ -- The CSNK2A1 Foundation, a patient-centered 501(c)(3) nonprofit organization dedicated to advancing the understanding and treatment of Okur-Chung Neurodevelopmental Syndrome (OCNDS), is thrilled to announce the recipient of the CSNK2A1 2024 Million Dollar Bike Ride pilot grant.

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> *Dr. Gabrielle Rushing, Chief Scientific Officer of the CSNK2A1 Foundation*

After a rigorous review process, the Orphan Disease Center Million Dollar Bike Ride has awarded a pilot grant of $60,013 to Dr. Abdelhalim Loukil to support his research aimed at identifying the specific molecular changes in cilia caused by the gene mutation and their effects on brain development. This critical work has the potential to unlock new insights and pave the way for more effective treatments for individuals living with OCNDS.

"This project represents an exciting leap forward in OCNDS research by building on prior findings that identify cilia as a critical focal point in understanding the biology of OCNDS," said Dr. Gabrielle Rushing, Chief Scientific Officer of the CSNK2A1 Foundation. "Through our recent participation in the Rare As One Cycle 3 cohort, funded by the Chan Zuckerberg Initiative, we've joined forces with other ciliopathy groups to advance collaborative research. Dr. Loukil's work holds immense promise—not only to uncover the mechanisms behind specific CSNK2A1 gene mutations but also for providing insights that could benefit the broader rare disease community."

OCNDS is a neurodevelopmental syndrome caused by a mutation in the CSNK2A1 gene, which

plays a critical role in brain development and function. Individuals with OCNDS often experience a range of symptoms, including intellectual disability, developmental delays, autism, seizures, and various physical and behavioral challenges. By funding research that delves into the specific molecular changes caused by the gene mutation, the CSNK2A1 Foundation aims to drive progress in the understanding and treatment of this syndrome.

"I am deeply honored to receive the CSNK2A1 Million Dollar Bike Ride pilot grant," said Dr. Loukil. "This support empowers us to investigate the fundamental role of primary cilia in OCNDS and how their disruption contributes to the condition's underlying biology. We are excited to embark on this research, which brings us closer to unraveling the complexities of OCNDS and paving the way for future therapeutic advances. My heartfelt thanks to the Orphan Disease Center and the OCNDS community for their trust and dedication to this important work."

The CSNK2A1 Foundation's mission is to serve as a catalyst for scientific advancement, foster collaborative research efforts, and provide support and resources to the OCNDS community. Through initiatives like the Million Dollar Bike Ride grant, the foundation is dedicated to accelerating the development of new treatments and improving the overall quality of life for those living with this rare and challenging condition.
For more information about the CSNK2A1 Foundation and its ongoing efforts, please visit www.csnk2a1foundation.org

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