International OCNDS Awareness Day on April 5th Aims to Illuminate Ultra-Rare Genetic Syndrome

CSNK2A1 Foundation shines a light on Okur-Chung Neurodevelopmental Syndrome

April 5 Int'l OCNDS Awareness Day

SAN FRANCISCO, CA, USA, March 19, 2024 /EINPresswire.com/ -- The CSNK2A1 Foundation is gearing up for its annual International OCNDS Awareness Day on April 5th, shining a spotlight on Okur-Chung Neurodevelopmental Syndrome (OCNDS) and its impact on affected families worldwide.

OCNDS, an ultra-rare genetic syndrome stemming from a mutation in the CSNK2A1 gene, presents a host of challenges for those living with it, including severe speech delays, global developmental delay, epilepsy, autism spectrum disorder traits, behavioral difficulties, and feeding issues. These hurdles can significantly impact daily activities such as communication, learning, and social interactions.

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> *Jennifer Sills, President of the CSNK2A1 Foundation*

The significance of April 5th lies in its historical connection to OCNDS. On April 5, 2016, the first paper detailing this syndrome was published, identifying five initial cases. Since then, more than 240 individuals worldwide have been diagnosed with OCNDS, highlighting the urgent need for awareness and support. In tribute to those pioneering patients who received validation for their struggles on April 5th, the Foundation established an annual awareness day.

Jennifer Sills, President of the CSNK2A1 Foundation, emphasized the importance of awareness in fostering societal understanding and compassion for families grappling with OCNDS. "Knowledge and awareness pave the way for social acceptance and kindness, crucial elements for families facing daily challenges," Sills remarked. "Moreover, heightened awareness attracts interest from researchers, biotech, and pharma, offering hope for potential treatments or even a cure."

The CSNK2A1 Foundation envisions International OCNDS Awareness Day as a catalyst for progress, uniting communities, individuals, and researchers worldwide in their quest for solutions. Through collaborative efforts, the Foundation aims to drive advancements in OCNDS research and expand support networks for affected individuals and families.

To mark the occasion, the Foundation encourages participation in various activities, including sharing information about OCNDS on social media and donating to ongoing research initiatives. Additionally, on April 5th, landmarks and bridges worldwide will be illuminated in the Foundation's signature green and blue colors, symbolizing solidarity with the OCNDS community. Families and supporters are encouraged to gather at these sites, demonstrating their solidarity and commitment to raising awareness for OCNDS.

About CSNK2A1 Foundation:
CSNK2A1 Foundation is focused on finding a cure for Okur-Chung Neurodevelopmental Syndrome and ensuring affected individuals have the opportunities and supports necessary for happy and full lives. CSNK2A1 Foundation is a 501(c)(3) non-profit organization operated and funded by a committed team of volunteers, advocates, and researchers. To date, the Foundation has registered over 240 individuals with OCNDS in its patient registry worldwide.
www.csnk2a1foundation.org

Jennifer Sills
CSNK2A1 Foundation
+1 415-483-2488
email us here
Visit us on social media:
Facebook
Twitter
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YouTube

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