

CSNK2A1 Foundation Organizes FORWARD TOGETHER, a Global Fun Run Event, to Raise Awareness and Find a Cure for OCNDS

Register Today for the Virtual Run, Walk & Roll to Support Okur-Chung Neurodevelopmental Syndrome Research and Help Change Lives



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In an effort to make a difference, the CSNK2A1 Foundation (Foundation) is organizing the FOWARD TOGETHER Virtual Run, Walk & Roll for Okur-Chung Neurodevelopmental Syndrome (OCNDS) on October 14th and 15th. This global event aims to raise awareness and fund research for OCNDS, with the ultimate goal of finding treatments and a cure for OCNDS.

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Elisabeth Mellinger, Parent Advisory Board Member

Around the world, families and friends are encouraged to come together on October 14th and 15th to raise awareness about OCNDS. When asked about the significance of this event, Elisabeth Mellinger, Foundation Parent Advisory Board member, stated, "We believe that by coming together as a community and supporting one another, we can make a real impact in the lives of those affected by OCNDS. Life with a rare disease can be lonely and isolating, and awareness can make a difference in a

family's daily struggle."

First described in 2016, OCNDS is an ultra-rare genetic syndrome caused by a mutation on chromosome 20 in the CSNK2A1 gene. OCNDS is a life-long condition that profoundly affects the lives of individuals and their families. Symptoms range from mild to severe and can include the inability to speak or delayed speech, global developmental delay, epilepsy, autism, behavioral challenges, low muscle tone, feeding difficulty, and sleep disorders. There are less than 250 individuals diagnosed with OCNDS worldwide. Currently, there are no specific treatments or cures for OCNDS; however, the Foundation aims to change this reality through events like the FORWARD TOGETHER Run, Walk & Roll.

"We are living in a time where medical advancements are continuously being made, giving hope to individuals with previously untreatable genetic conditions. By participating in this event, you are joining us in our mission to fund life-changing research that will bring us one step closer to finding effective treatments and, ultimately, a cure for OCNDS," emphasized Jennifer Sills, Foundation President and Founder.

Funds raised through the event will be dedicated to supporting crucial research initiatives to develop treatments and find a cure for OCNDS. Additionally, a portion of the funds will be allocated to translation services to allow families, regardless of their native language, to access vital information, as well as promote global awareness and advocate for necessary changes within the medical community to increase families' ability to receive a diagnosis.

The Foundation encourages individuals and families impacted by OCNDS and community members and supporters to participate in the FORWARD TOGETHER Run, Walk & Roll. Whether you choose to run, walk, or roll, every step taken and every dollar raised will contribute to the collective effort to make a difference.

To register for the event, donate, or learn more about the Foundation and OCNDS, please visit their website at www.csnk2a1foundation.org.

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 190 individuals with OCNDS in its patient registry worldwide.

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