

CSNK2A1 Foundation Announces Annual International OCNDS Awareness Day for April 5th

On April 5th, the CSNK2A1 Foundation will raise awareness about Okur-Chung Neurodevelopmental Syndrome and the families affected by it.

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[/EINPresswire.com/](https://EINPresswire.com/) -- The CSNK2A1

Foundation is proud to announce its annual International OCNDS Awareness Day on April 5th in honor of Okur-Chung Neurodevelopmental Syndrome (OCNDS), an ultra-rare genetic syndrome caused by a mutation in the CSNK2A1 gene. This day aims to raise awareness about OCNDS and help families worldwide affected by the syndrome.



OCNDS is an acronym for an ultra-rare genetic syndrome that is characterized by the following symptoms: severe speech delay or inability to speak, global developmental delay, epilepsy, autism spectrum disorder traits, behavioral challenges, and feeding difficulty. Those living with OCNDS have many daily challenges such as swallowing, toileting, dressing, learning, and making friends.

Why April 5th? On April 5, 2016, the first paper was published describing a brand new syndrome called OCNDS. Initially, there were 5 children identified in the paper. Soon these 5 children would be joined by others around the world. In honor of the first 5 patients who on April 5th finally received a diagnosis for the symptoms that affected their ability to talk, walk, eat, and live normal lives, the Foundation created an annual awareness day.

The CSNK2A1 Foundation hopes that the continued observance of International OCNDS Awareness Day will help further advance their efforts in discovering a cure for the syndrome. By bringing together communities, individuals, and researchers around the world, the Foundation aims to create a powerful movement that will drive progress and increase support for those living with OCNDS.

“Never underestimate the power of knowledge and awareness. With awareness comes social

acceptance and kindness, which can mean all the difference for a family struggling with basic daily activities,” said Jennifer Sills, President of the CSNK2A1 Foundation. “With awareness also comes the interest from researchers, biotech, and pharma, which can lead to a treatment or a cure.” she added.

The CSNK2A1 Foundation encourages everyone to participate in International OCNDS Awareness Day by sharing information about the syndrome on social media and donating to OCNDS research. In addition, this year, on April 5th, over 18 bridges and landmarks are lighting up in foundation colors green and blue in recognition of OCNDS Awareness Day. The Foundation encourages families and friends to gather at these sites in support of OCNDS Awareness Day.

More information about the event is available at: <https://www.csnk2a1foundation.org/events>

For updates, follow CSNK2A1 Foundation on Social Media:

Facebook: <https://www.facebook.com/csnk2a1>

Instagram: https://www.instagram.com/csnk2a1_foundation/

Twitter: <https://twitter.com/csnk2a1org>

LinkedIn : <https://www.linkedin.com/company/csnk2a1-foundation/>

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