

# CSNK2A1 Foundation Announces Collaboration with TREND Community to Gain Insights from Rare Disease Conversations

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/EINPresswire.com/ -- CSNK2A1

Foundation, a leading rare disease organization, is proud to announce its collaboration with TREND Community, a digital health analytics company that specializes in extracting actionable

insights from conversations related to rare, chronic, and emerging diseases.



By leveraging TREND's cutting-edge technology, this groundbreaking collaboration aims to analyze organic social media conversations securely and anonymously within disease

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The information gathered will help identify gaps in current treatments, highlight unmet needs, and provide valuable input for researchers, healthcare practitioners, and policymakers.”

*Dr. Gabrielle Rushing, Science Program Director for the CSNK2A1 Foundation*

communities. These conversations will provide valuable perspectives from patients, caregivers, and care partners, shedding light on underrecognized symptoms, uncovering potential therapies, and understanding the daily challenges faced by individuals living with Okur-Chung Neurodevelopmental Syndrome (OCNDS).

First described in 2016, OCNDS is an ultra-rare genetic syndrome caused by a mutation on chromosome 20 in the CSNK2A1 gene. OCNDS affects every aspect of life, with symptoms ranging from mild to severe and can include the inability to speak or delayed speech, global developmental delay, epilepsy, autism spectrum disorder traits, behavioral challenges, hypotonia, feeding difficulty, and severely

disrupted sleep pattern. To date, there is no treatment for OCNDS.

According to Dr. Gabrielle Rushing, Science Program Director for the CSNK2A1 Foundation, "We are thrilled to partner with TREND Community on this exciting initiative. By examining the conversations taking place within our community, we can gain a deeper understanding of the needs and experiences of those affected. This information will prove invaluable in our efforts to

advance research, education, and drug development with our community as active partners."

TREND's advanced analytics technology can identify emerging patterns and sentiments within these online discussions, enabling the medical community to connect the dots and develop a more holistic understanding of the conditions under study.

By tapping into the rich source of firsthand experiences shared on social media platforms, the collaboration between CSNK2A1 Foundation and TREND Community promises to make significant strides in understanding OCNDS. The information gathered will help identify gaps in current treatments, highlight unmet needs, and provide valuable input for researchers, healthcare practitioners, and policymakers.

"CSNK2A1 Foundation's dedication to supporting individuals living with OCNDS aligns perfectly with TREND's mission to transform healthcare through data-driven insights," said Maria Picone, CEO of TREND Community. "We are excited about the potential impact this collaboration can have in driving better healthcare outcomes for OCNDS patients."

The collaboration between CSNK2A1 Foundation and TREND Community represents a powerful partnership that holds great promise for the OCNDS community. By harnessing the potential of social media conversations, these organizations are working together to create a more comprehensive understanding of OCNDS and ultimately improve the lives of those affected.

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 that is operated and funded by a committed team of volunteers, advocates, and researchers. To date, the Foundation has registered over 210 individuals with OCNDS in its patient registry worldwide.

[www.csnk2a1foundation.org](http://www.csnk2a1foundation.org)

About TREND Community:

Our vision at TREND Community is to revolutionize the world's understanding of diseases. Our work has the power to bridge patient communities, caregivers/care partners, healthcare providers, researchers, pharmaceutical sponsors, and regulatory agencies. Together, we advance our collective mission to accelerate therapeutic development and commercialization, spread awareness, and strengthen advocacy. <https://trend.community/>

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