

# STAR Foundation to Receive Prestigious Rare As One Grant from Chan Zuckerberg Initiative (CZI)

*Accelerates STAR's research & development agenda through supporting and expanding the foundation's infrastructure and capabilities.*

GOLDENS BRIDGE, NY, UNITED STATES, October 2, 2024 /EINPresswire.com/ -- The Salla Treatment and Research Foundation ("STAR"), a non-profit organization dedicated to the development of new therapies for Salla



**STAR**  
Foundation

Salla Treatment and Research Foundation logo

disease, a devastating neurodegenerative disease affecting children, today announced that it has been selected by the Chan Zuckerberg Initiative (CZI) to receive a Rare As One Project grant. CZI was founded by Dr. Priscilla Chan and Mark Zuckerberg in 2015. CZI's Rare As One Project supports patient-led organizations across the globe by strengthening communities, building capacity, and promoting collaboration to find treatments and cures for rare diseases. With this grant award, STAR joins Rare As One's global network and will receive funding, support, and mentorship over a five-year period.

"We are honored to be recognized by CZI's Rare As One Project," said Jessica Foglio, President and Co-Founder of the STAR Foundation. "STAR is driven by the passion of our parents and families. With CZI's support we can now achieve momentum around our research priorities and programs to support the Salla patient community. I am equally looking forward to working with other CZI awardees as we address common challenges."

Through the grant, STAR will implement a series of initiatives aimed at accelerating initiation of clinical trials for patients, driving earlier diagnosis of the disease, and enhancing resources available to families.

Salla disease is the most common free sialic acid storage disorder (FSASD), a class of lysosomal storage diseases caused by genetic mutations. "STAR has successfully galvanized a global community of over 40 world-class researchers – the FSASD Consortium – to work together to uncover the fundamental science behind Salla disease," said Steven Walkley, DVM, PhD, Chair of

the STAR Scientific Advisory Board and Professor Emeritus at the Albert Einstein College of Medicine. “The Rare As One grant provides a springboard for STAR to build on these scientific breakthroughs and now support the clinical development of potential therapeutics.”

The STAR Foundation brings together families of children and adults living with Salla disease, with a community spanning seventeen countries. STAR is proud of its highly patient-focused agenda that enables a tight linkage between resource allocation and the needs of its patient and research community. To learn more, visit <https://sallaresearch.org>.

Supplemental information:

#### About the STAR Foundation

The Salla Treatment and Research Foundation (STAR) is a 501(c)3 tax-exempt charitable organization dedicated to advancing the treatment, research, education, awareness, and patient engagement for Salla disease and related free sialic acid storage disorders (FSASD). STAR was established in 2018 by Jessica and Michael Foglio following the diagnosis of their son, Ben Foglio. Since its founding, STAR has raised over \$800,000 to support Salla research and inspired the creation of the FSASD Consortium, a network of over forty world-class researchers that have delivered key breakthroughs in the understanding of the disease. STAR is driven by an unwavering belief that no disease is too rare to fight, and that with sufficient support, hope, and faith, a committed team of researchers, families, supporters, and advocates can create meaningful solutions for those impacted by this disease. To learn more, visit <https://sallaresearch.org>

#### About the Chan Zuckerberg Initiative

The Chan Zuckerberg Initiative was founded in 2015 to help solve some of society’s toughest challenges — from eradicating disease and improving education, to addressing the needs of our communities. Through collaboration, providing resources and building technology, our mission is to help build a more inclusive, just and healthy future for everyone. For more information, please visit [www.chanzuckerberg.com](http://www.chanzuckerberg.com)

#### About the Rare as One Network

Rare disease is anything but rare. As many as 10,000 rare diseases affect over 300 million people globally. The vast majority are not well understood, and approved treatments have been developed for less than 5% of them. Yet worldwide, patients are meeting these challenges head on. The Rare As One Project is committed to uniting these communities in their quest for cures. For more information, please visit [www.chanzuckerberg.com](http://www.chanzuckerberg.com)

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