



FOR IMMEDIATE RELEASE

Channeling Hope Foundation Receives \$800,000 Grant from the Chan Zuckerberg Initiative for Rare As One Network Cycle 3

San Antonio, TX – October 16, 2024 Channeling Hope Foundation is proud to announce that it has been selected as one of 30 family-driven rare disease organizations to receive funding as part of the third cohort for the Chan Zuckerberg Initiative Rare As One Project. Following a competitive application process, Channeling Hope Foundation has been awarded a five-year \$800,000 grant to accelerate organizational growth.

This significant grant will support Channeling Hope Foundation's mission to advance research and improve outcomes for patients living with rare diseases, specifically focusing on those impacted by a mutation in the Sodium Leakage Channel, which is critically comprised of the NALCN gene and UNC79, UNC80 & FAM155A proteins. The foundation, which plays a critical role in raising awareness, funding research, and providing resources for families affected by NALCN-related diseases, is honored to be recognized for its commitment to patient-led initiatives.

"We are truly grateful to the Chan Zuckerberg Initiative for this remarkable opportunity to be a part of the Cycle 3 Cohort for Rare As One," said Shyanne Martin, Executive Director of Channeling Hope Foundation. "This funding will allow us to exponentially ramp up our work to support groundbreaking research and foster a strong community for families affected by rare

NALCN diseases. Working together as an entire network, we push the boundaries of rare disease research."

Over the next five years, Channeling Hope Foundation will work towards the grant objectives, which include strengthening its organizational and scientific capacities, enhancing a collaborative research network, convening the disease community globally, and developing a patient-prioritized research agenda for NALCN-related conditions. With training support and mentorship from Rare as One, Channeling Hope is excited to drive meaningful progress in the rare disease space and bring much-needed hope to families affected by CLIFAHDD, IHPRF 1 & 2, and UNC 79-related syndromes

The Chan Zuckerberg Initiative Rare As One Project is designed to support patient-driven groups advancing rare disease. With this grant, Channeling Hope will join a prestigious global network of organizations working collectively to find cures and treatments for rare diseases that impact millions of individuals and families worldwide. Grant funding is specifically for building organizational and research capacity, so fundraising for research is as important as ever to directly fund research and therapy development.

Supplemental Information:

About Channeling Hope Foundation:

Channeling Hope Foundation is a nonprofit organization dedicated to supporting families affected by NALCN channel-related diseases and providing financial support for innovative research to discover treatments. Through advocacy, education, and collaboration, Channeling Hope Foundation is making a difference in the lives of those facing the challenges of rare diseases. For more information on Channeling Hope Foundation and its mission, visit www.channelinghope.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, its mission is to help build a more inclusive, just and healthy future for everyone. For more information, please visit www.chanzuckerberg.com.

About the Rare as One Project

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.

Media Images:

Pictures shown below can be provided through press contact below with consent agreements.



Fundraising:

A fundraising graphic with a white background on a green and blue background. It features the 'CZI' logo (a red circle with 'CZI' inside), the 'Rare As One' logo (a red square with 'Rare As One' text), and the 'Channeling Hope Foundation' logo (a green and blue DNA helix with 'CHANNELING HOPE FOUNDATION' text). To the right of the logos are three icons: a puzzle piece, a wrench and screwdriver, and a handshake. The text reads: 'The **Chan Zuckerberg Initiative** has named **Channeling Hope Foundation** as a **Rare As One** grantee, cycle 3. CZI grant money will be used to build our organization! **HELP us match this grant with dollars to be prioritized for RESEARCH!**'

The **Chan Zuckerberg Initiative** has named **Channeling Hope Foundation** as a **Rare As One** grantee, cycle 3.

CZI grant money will be used to build our organization!

HELP us match this grant with dollars to be prioritized for RESEARCH!

<https://secure.givelively.org/donate/channeling-hope-foundation/rare-as-one-help-us-match-czi-grant-funds-for-research>

Contact:

Jill Wahl

Marketing & Public Relations

Channeling Hope Foundation

620-937-1825

channelinghopefoundation.jwahl@gmail.com

www.channelinghope.org/press

END