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PARENTS OF CHILDREN WITH NALCN DISORDERS CHANNEL HOPE, RAISING AWARENESS OF RARE DISEASES ON FEBRUARY 29, GLOBAL RARE DISEASE DAY

(Kansas, Texas, New Hampshire, New York, February 26, 2024) - Eight-year-old Lukas U is joining families of Channeling Hope in a global effort to raise awareness about rare diseases, including his own, this Thursday, February 29, on Rare Disease Day <https://www.rarediseaseday.org/>. Rare Disease Day is a globally-coordinated movement raising awareness for rare diseases and working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease. Rare Disease Day is observed every year on February 28 (or 29 in leap years) – the rarest day of the year, in support of 300 million people across the world living with rare diseases.

Lukas joins with his family and the families of Channeling Hope Foundation (CHF) <https://www.channelinghope.org/>, to shine a spotlight on rare diseases, an organization started in 2023 by parents of children with NALCN genetic mutations who connected over a shared hope for a world free of complications from NALCN channel diseases. These sodium leak channel diseases result from mutations in the NALCN gene and associated proteins that play a crucial role in regulating the healthy firing of neurons and other cells involved in the body's rhythmic processes like breathing and sleep.

In a testament to the strength of parental love and the unbreakable bonds of community, five parents of children with NALCN disorders have individuals united in a shared mission through CHF. These devoted parents, brought together by a common purpose, dedicate countless hours each week to propel forward the foundation they started in July. Despite never having met in person, these parents have forged deep connections, finding solace and understanding in each other's shared experiences. As they continue to work towards their goal of building a nurturing

community for those affected by NALCN disorders, they eagerly anticipate the day when they can finally come together, embrace, and celebrate their shared journey in person.

In the short time since its inception, CHF has garnered many collective partnerships, including with Dr. Wendy Chung, chair of the Department of Boston Pediatrics and recipient of Rare Impact Award from the National Organization of Rare Disorders, and a champion for children and doctor for Lukas and other children living with rare diseases, emphasized the significance of Rare Disease Day, "Rare diseases may be individually rare, but they are collectively common. There are millions of people living with rare diseases. Today and every day, doctors like me care for rare, and it's our privilege."

Lukas has reached out to several local businesses in the Rochester area, asking for them to support his cause. Special thanks to Ridge Donuts, Schutt's Apple Mill, and Secret Ingredient Cupcakery who will be selling baked goods on February 29 representing zebras, the symbol of rare diseases. Lukas will also be sharing his personal story with his third grade classmates, by reading a book he wrote about his journey with a rare disease.

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