

# Raising Hope Campaign

## \$2.8 Million by 2028

### Why we raise hope

There are currently no treatments for people living with NALCN channel-related diseases (CLIFAHDD, IHPRF1, IHPRF2, and UNC-79 Disorder). Yet 25 years of NALCN research shows that effective therapies are possible. Unfortunately, progress toward discovering treatments remains slow because funding is limited. The Channeling Hope Foundation exists to change that by accelerating research, building collaborative networks, and ensuring that families are partners in the research process. We're raising \$2.8 million to get an effective treatment through clinical trials and safely to our community.

### The Raising Hope Goal

\$2.8 million to support critical studies and research infrastructure that move discoveries from bench to bedside.

### How You Can Help

**Give Today:** One-time or monthly gifts to Channeling Hope make an immediate difference.

**Become a Champion:** Start a peer-to-peer fundraiser or corporate match.

**Share Hope:** Spread the word and amplify Channeling Hope's mission.

**Donate:** [www.channelinghope.org/donate](http://www.channelinghope.org/donate)

### What your gift makes possible

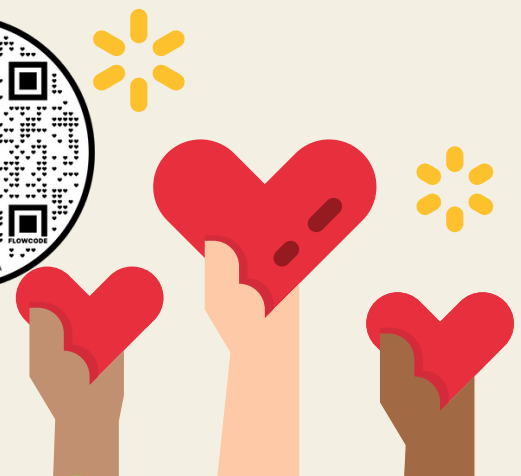
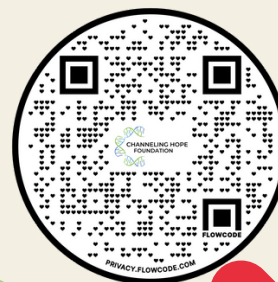
- **Accelerated Research:** Fuel patient-oriented and investigator-driven studies, including natural history studies necessary for clinical trials and translational research.
- **Data to Therapies:** Support shared data resources that transform insights into therapeutic targets and targets into treatments.
- **Family-Centered Impact:** Empower families through engagement, education, and access to research opportunities, including clinical trials.

### The Channeling Hope Foundation

is a 501(c)(3) non-profit organization registered in the United States (EIN: 93-2536735). All donations are tax-deductible. Every dollar is stewarded with transparency and directed to high-impact research and programs that matter most to families.

### Interested in learning or doing more?

Contact Diana Duggan:  
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### Clinical Trial Readiness

We have developed cell models and a drug discovery pipeline to advance us toward clinical trials, but first **we have to know how to measure success**. “Clinical trial readiness” means having validated biomarkers, clinical outcomes, and knowledge of NALCN-related disease across our whole community and over time. Without these benchmarks, we cannot measure if potential treatments are effective.

Thanks to the support of our community and donors, we are already on the right track. In 2025, patients and caregivers from around the world contributed data on symptoms and experiences for a Natural History Study to begin documenting the progression of NALCN-related disease over time without intervention.

This information is enabling us to begin verifying potential candidates for **drug repurposing** and for **drug development** while we remain on the lookout for successful gene editing techniques that could work for NALCN-related conditions. The Raising Hope Campaign will allow us to build a repository of data, knowledge, and samples related to NALCN disease, test treatments, and measure their impact for individuals with NALCN-related diseases.

### NALCN Disease Symptoms

The Channeling Hope community includes individuals with variants in the NALCN gene and NALCN Channel-related proteins (UNC79, UNC80, and FAM155). Symptoms affect many body systems because NALCN is important for functioning throughout the body. Every individual’s experience is different, but these symptoms are common throughout the community:

