

## **Skin to Stem: One family's odyssey to the space city to support CLIFAHDD research**

*San Antonio, TX – June 21, 2024* – The Channeling Hope Foundation is on a mission to accelerate research for families impacted by NALCN Channel-related disorders. These are rare neurodevelopmental diseases affecting children from birth – and currently, there are no treatments. After fifteen years of breakthrough research, developing a treatment appears closer than ever.

To take the next step forward, the scientific community has been seeking patient-derived stem cells to be able to develop and test gene therapies and other treatments. The Foundation was supporting the collection of a skin biopsy from a 12-year-old Ohio volunteer with a common NALCN mutation. However, regulatory barriers for care and research provide too much of a barrier for rare disease collaborations between medical systems.

Despite concerted efforts by the patient's mother, securing a doctor willing to perform the biopsy proved futile due to hospital regulations required for research procedures. Repeated rejections, including from internationally renowned institutions, have left the family with no choice but to take matters into their own hands.

This summer, the family will travel from Ohio to Houston in an RV to for the skin biopsy to develop patient-derived stem cells at Baylor College of Medicine. This arduous journey is necessitated by the patient's special care requirements that make air travel impractical.

The Foundation is launching a special fundraising campaign to support the family's travel expenses and raise awareness of the challenges rare disease families encounter. They aim to shed light on [Baylor College of Medicine Pediatric Neurology and and Developmental Neuroscience](#) for their unwavering support in this research endeavor.

For more information on how to support the Channeling Hope Foundation and their mission, please contact Shayanne Martin at 919-262-4267 or via email at [channelinghopefoundation@gmail.com](mailto:channelinghopefoundation@gmail.com).

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