SOUTH GRAY COMMUNITY'S CELEBRATION OF INCLUSION AND SUPPORT

Montezuma, KS – February 29, 2024 – Rare Disease Day unites patients across thousands of rare conditions, where each condition has a very small number of patients. Rare Disease Day was celebrated this year on February 29, the rarest day of the year!

John and Jill Wahl, the parents of Rory, invited their community to celebrate Rare Disease Day with them this year. Rory and her first grade classmates hosted a party for her elementary school to celebrate. The Wahl family wanted to treat the students and staff to thank them for their inclusion, extra support, patience, and love. Rory loves school and it is the wonderful people in her school that help her thrive.

The Sister's Boutique and Coffee Connection both shared information about Rare Disease Day with their patrons on February 28 & 29 and helped raise donations to advance research. Through donations received from the community, family, and friends, over $12,000 has been raised on Rory's behalf to be sent to Channeling Hope Foundation. The Foundation raises money and awareness for CLIFAHDD, a rare genetic condition that affects development of young children. Rory was diagnosed with this rare genetic condition and Jill joined the Board of Directors of Channeling Hope Foundation to help raise awareness and advocate for research. More information on the foundation can be found at www.channelinghope.org

About Channeling Hope Foundation:

The Channeling Hope Foundation is dedicated to accelerating research for families impacted by NALCN-related diseases. Founded by parents of children with NALCN including Shayanne Martin, Dr. Jeremy Tanner, and Suzanne Engel.

NALCN (Sodium Leak Channel) diseases are a group of rare genetic disorders that result from mutations in the NALCN gene and associated proteins (UNC79, UNC80, FAM155A). NALCN plays a crucial role in regulating the electrical activity of neurons and other cells.

Supported by a global network of NALCN scientists and a small but mighty community of affected families, the Channeling Hope Foundation was established in 2023 to work together to advance care and develop treatments for children affected by NALCN genetic disorders.

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FOUNDATION


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