



FOR IMMEDIATE RELEASE

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Hike for Team Nolan



January 19, 2018 - The ***“Hike for Team Nolan”*** will take place on July 28, 2018 at the Manitou Incline in Manitou Springs, Colorado. Lindsey Traub, the organizer of Team Nolan, will be participating in the hike in honor of her nephew, Nolan Traub who is affected by RYR-1 myopathy, a form of congenital muscle weakness. This hike is an uphill stair climb with over 2,700 railroad tie stairs in less than 0.8 miles. All proceeds raised by Team Nolan will benefit the RYR-1 Foundation in honor of Nolan Traub. To donate, please visit:

<https://www.crowdrise.com/dashboard/lindseytraub/hike-for-team-nolan1>.

“Nolan has worked so hard to achieve so much in his tiny, little life. He started out as a newborn who was too weak to open his eyes, much less breathe or eat,” said Mandy Traub, Nolan’s mother. “Today he is a charming one and a half year old who can roll over and even hold his

own head up for a short time. Right now he is in a special therapy, trying to learn to swallow his own saliva. Nolan works so hard to accomplish things most of us never think twice about.”

“When we got Nolan’s diagnosis, we never dreamed that a cure was even possible,” said Mandy. “Recent developments in gene therapy make us believe that it is more than possible, and we are hopeful that through your donations, Nolan will someday be able to complete this hike alongside his Aunt Lindsey.”

“The dedication, love, and support shown by Mandy, Lindsey, and the rest of Nolan’s family is incredible. They are an inspiration to myself and the entire RYR-1 community,” said Michael F. Goldberg, MD, MPH, President of the RYR-1 Foundation. “As Mandy said, your support in honor of Nolan will fund world class research projects (<http://www.ryr1.org/research-grants-2017-2018>) and transform our mission of finding a cure into a reality.”

About the RYR-1 Foundation

The Pittsburgh, Pennsylvania-based public charity was launched in October 2014 by members of the Goldberg family, who have been affected by RYR-1 muscle disease. It is currently the only organization that exists solely to advocate for and serve the needs of patients with RYR-1 myopathy, the most common cause of congenital myopathy. The mission of the RYR-1 Foundation is to support research leading to effective treatment or a cure for RYR-1 related diseases, to educate physicians about these diseases, and to provide patient/family support and advocacy. The RYR-1 Foundation is a public charity, designated as a 501(c)(3) by the IRS. To learn more about the RYR-1 Foundation, please go to: www.RYR1.org.