



Rare Disease Patients in Austin Find HOPE



Imagine being told after your child's birth that something is wrong, and while doctors are unable to identify the issue, they also do not think your child will live for more than a few weeks. That is the story for Vanessa Vaughan, Director of Communications for U.R. Our Hope. It would be nearly 2 years before her family received a rare diagnosis for her son, Braxton. Thankfully, the diagnosis, while lifelong, is not terminal. Braxton is now a happy, thriving, 5-year-old boy who faces a number of developmental challenges daily.

The Walter family has twins, Lily and Kyle, affected by multiple medical issues. A partial diagnosis has been found, but Lily still has significant medical ailments that currently elude diagnosis by her medical team. Due to errors made by CPS during their adoption, the Walter family has been unable to get supplemental insurance coverage through the Texas Medicaid program or the state's adoption subsidies. As a result, the Walter family has medical debt up to \$14,000 and when their Air Conditioning system broke last summer, they were unable to find a company willing to work with them due to those outstanding bills. Nearly a year later, the system is still not fixed and the twins spent the summer sleeping downstairs to try and keep cool due to the metabolic issues they both face. The family is hoping the winter is not too harsh and they will be able to keep the house warm enough for their children. Tarah Walter is the Director of Development for U.R. Our Hope.

These stories are just two of many. U.R. Our Hope has about 25 active families in the Austin area who have come to us in search of a diagnosis for their child. Currently, 30-40% of children with special needs do not have a definitive diagnosis. With over 7,000 identified rare diseases, for many of them, it can take up to 7 years and dozens of specialists to find the rare diagnosis causing their symptoms. U.R. Our Hope seeks to help these families shorten the time spent Undiagnosed by helping families navigate the healthcare system; making referrals to specialized physicians and research programs; and providing financial assistance in the form of gas and meal cards to these families who travel out of town or out of state for adequate medical care. Once diagnosed, many of these families do not have the backing of a national support group for their diagnosis to assist with research, continuity of care, or emotional support. U.R. Our Hope continues to be a beacon of hope for these families throughout the journey and beyond.

This week, U.R. Our Hope celebrates their 4th Annual Evening of Hope Gala on Saturday, December 3rd at the Doubletree Northwest Arboretum. The gala seeks to raise funds to help families like the Vaughan's and Walter's who have children with undiagnosed and rare medical conditions. This year we are honored to have Noah Coughlan, a rare disease advocate and one of 3 people to have crossed the US by foot THREE times! Noah is the founder of Run for Rare and has completed three runs across the United States raising awareness for the 350 million people worldwide affected by a Rare Disease. Noah will be speaking at the gala about his upcoming documentary and book to be released in 2017 chronicling his cross-country treks and advocacy efforts. He has also worked closely with various legislators to discuss the needs of the Rare Disease community.

We are reaching out to local media in hopes of featuring the stories of these families to raise awareness of a largely unknown issue facing many Americans daily and hope you will consider featuring our cause in your broadcasts this week.

Prior Media

Prior Media coverage for Noah Coughlan and Run For Rare: <https://www.run4rare.org/press-coverage/kcra-3-sacramento-ca-run-for-rare/>

Press videos and promotional documentary footage: <https://www.run4rare.org/video/>

U.R. Our Hope families in the news: <http://urourhope.org/media/>

Promotional video for U.R. Our Hope: <https://www.youtube.com/watch?v=6BOGwPHpGCA&feature=youtu.be>

Contacts

Dr. Mary Elizabeth Parker, PhD, PCS, NCS, founder U.R. Our Hope

She can be contacted for interview by phone at (512) 484-6227 or by email at mary@urourhope.org

Local families are also available for interview and can be reached via Dr. Parker.

Vanessa Vaughan, Director of Communications for U.R. Our Hope
Phone (512) 709-9420 or by email vanessa@urourhope.org

U.R. Our Hope is a registered 501(c)(3) non-profit based in Austin, TX assisting families on the journey to diagnosis and helping them navigate the healthcare system with a rare diagnosis. Learn more at www.urourhope.org -- See more on our families by clicking the "Our Families" tab

Noah Coughlan

Noah Coughlan, 32, of Vacaville, California is an extreme athlete and ultra-distance runner. He is the Founder of Run for Rare, a movement created to bring awareness and rally support for the global rare disease community.

Noah became just the 3rd person ever to cross the United States of America on foot a total of 3 times after completing 3 separate transcontinental treks in 2011, 2013, and 2015. The journey is not over. A feature length documentary and book are currently in development, as well as plans to run internationally for Rare and Undiagnosed diseases.