

**ZoomWalkathon.com Video Conferencing Platform
Lucas John Foundation is Actively Working to Save
Children with Orphaned Rare Diseases using
FOR IMMEDIATE RELEASE**

May 2020 (Mesa, Arizona) – The family of Brandon and Chancee Culp in Mesa, Arizona, is fighting for the life of their two-year-old son, Lucas John Culp. He was born in 2018 with a rare disease, Non-ketotic hyperglycinemia (NKH). It is an inborn metabolic disorder caused by a defect in the enzyme system that breaks down the amino acid glycine, resulting in an accumulation of glycine in the body's tissues and fluids. This creates neurological conditions, including seizures, vision damage, and lack of muscle control.

A rare disease is also known as an orphan disease because drug companies have not taken an interest in developing treatments for them, due to it not affecting enough of the population to make a profit. Children with NKH can experience daily seizures up to 100s per day and require 24-hour care. Lucas is fortunate to have six family members assisting around the clock to keep him safe and comfortable. In the search for a cure, the Culp family took the matter into their own hands and started a foundation to help Lucas and many other families across the nation. With Covid-19 fundraising has been impacted deeply. Determined to keep research alive for the cure the Culp family created a virtual website platform to host walkathons for nonprofits to use, Zoomwalkathon.com hosting Zoom the Room for NKH campaigns we are able to host distance fundraisers. Using Zoom technology, it allows for a virtual fundraiser while honoring social distancing requirements in every state. There are currently three NKH families actively running Zoom Walkathons across the country and more will be signing up. The first walkathon is schedule for Lucas John Foundation this Saturday May 16th at 9 am Arizona time. This fundraiser is global with people signed up all over the United States and the United Kingdom with 100+ in attendance.

Since January 2019, the [Lucas John Foundation](#) has been Raising Awareness for Rare Disease and Gene Therapy research– and the foundation is in continual fundraising mode for the cure. Due to the rarity of the condition all the funding for research falls into the laps of the families of these babies.

At the core of the foundation are these essential

- Fundraising for rare disease research.
- Fundraising for gene replacement therapy.
- Offer scholarships for families
- Care kits for NICU at Phoenix Children's Hospital.
- Offer financial support to families with children diagnosed with rare diseases.
- And, a variety of alternative therapy support on the [Lucas John Foundation](#) website.

When Rare isn't so Rare

There are approximately 7,000 known rare diseases in the United States, with an estimated 25-30 million total Americans living with rare genetic diseases. While specific conditions can be isolated, the total number of people with an orphan disease is overwhelming.

Rare diseases/Orphan disease

Brandon and Chancee Culp, the parents of Lucas John, are actively making a difference in the lives of many who struggle with life-threatening diseases. Through the [Lucas John Foundation](#), there is support, community, and hope.

Quote from the Physician:

"The goal is to protect Lucas's brain until the cure is available. Gene therapy is close and could be the cure for Lucas."

– Lucas's Neurologist, Phoenix, AZ

The Cure: Gene Replacement Therapy is the answer and the cure for many children and adults living with an orphan disease in the United States. Each advancement in gene therapy for any disease widens the field for all the other rare diseases.

Now What: It is essential to bring awareness to rare diseases.

Gene Replacement Therapy for the cure and requires \$3 million in funding for children nationwide. [University of Notre The Boler-Parseghain Center for Rare & Neglected Diseases](#) is promoting the Zoom the Room for NKH campaign for the cure. They are actively in mice research studies currently with the NKH Gene in partnership with the [Orphaned Gene Center at Pennsylvania University](#). Contact the [Lucas John Foundation](#) for more information and to donate to the cause.

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