Lucas Foundation is Actively Working to Save Children with Rare Diseases

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 the lower rate of occurrence. Lucas experiences daily seizures that require 24-hour care, and he 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.

The Culp family is 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.

Since January 2019, the Lucas John Foundation has been Raising Awareness for Rare Disease and Gene Therapy – and the foundation is in continual fundraising mode for the cure.

At the core of the foundation are these essentials

- Fundraising for rare disease research.
- Fundraising for gene replacement therapy.
- Offer scholarships for families
- Care kits for NICU, Neonatal, Intensive Care Unit families.
- Offer financial support to families with children diagnosed with rare diseases.
- And, a variety of 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:

"We are protecting his brain until we have gene therapy for Lucas."

– Dr. Neuro (replace with name)

Cause of rare diseases
With a variety of causes, rare diseases can stem from a genetic origin and can be a direct cause of changes in genes or chromosomes. Some believe these diseases can be passed from one generation to the next. In other cases, they occur randomly in a person who is the first in a family to be diagnosed.

The Cure: Gene Replacement Therapy is the answer and the cure for many children living with an orphan disease in the United States.

Now What: It is essential to bring awareness to rare diseases.
Gene Replacement Therapy is the cure and requires $3 million in funding for children nationwide. Contact the Lucas John Foundation for more information and to donate to the cause, contact the Lucas John Foundation at 888-464-5344.

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