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FOR IMMEDIATE RELEASE

Press Release

The Cure Blau Syndrome Foundation launches campaign to fund research into rare auto-inflammatory disease

Campaign will support a Blau Scholar at Oregon Health and Science University

Research will examine the role of T cells in a possible treatment for a progressive inflammatory disorder that affects children's skin, joints, and eyes

YORBA LINDA, CA – OCTOBER 9, 2023 – The Cure Blau Syndrome Foundation today launched a campaign that will fund a dedicated Blau Scholar at Oregon Health and Science University (OHSU). The campaign aims to raise $40,000 by year end and will support important research that could help lead to an effective treatment for Blau.

Blau Syndrome is a progressive auto-inflammatory disease that results from mutations in the NOD2 gene. The disease typically affects the skin, joints, and eyes and usually presents itself in the first 4-12 months of life. Blau creates systemic inflammation, meaning every aspect of the body can be negatively affected. There is currently no cure for Blau syndrome, and no treatment for the disease itself. Instead, the emphasis to date is on treating symptoms, usually with immunosuppressive and anti-inflammatory drugs. The rare disease affects fewer than 200 known people worldwide.

"Blau Syndrome is both rare and mystifying," says Erica Howell, Executive Director of the Cure Blau Syndrome Foundation. "Fortunately we have seen tremendous strides in research over the last few years, and we may be on the brink of a significant breakthrough. For those of us supporting loved ones with Blau, time is of the essence. The Blau Scholar program will help accelerate discovery of a treatment and, eventually, a cure."

Leah Huey has been awarded as the first Blau Scholar. Leah is a doctoral student at OHSU's Napier Lab, the only facility worldwide with a Blau mice model. Her research focuses on the relationship between the NOD2 mutation and the T cells that the body needs to stay healthy.

"Blau is caused by a mutation to the NOD2 gene," says Blau Scholar Leah Huey. "Our hypothesis is that NOD2 is a central regulator of T cell function—and therefore all human health. Instead of fighting infection, we think these Blau T cells go rogue and create unchecked harm throughout the body. We hope that our research will determine the mechanism by which mutations in NOD2 affect T cell function and cause uveitis and arthritis. If we come to understand this mechanism, we begin to have the building blocks needed for future drug development. I'm honored to serve as the first Blau Scholar, and I'm hopeful that the work we do now can eventually lead to the treatment and cure for Blau Syndrome."

To learn more about the Blau Scholar, or to make a donation, go to https://www.curebs.com/fundraiser.

Cure Blau Syndrome Foundation

About the Cure Blau Foundation

The Cure Blau Syndrome Foundation is a network of parents, patients and collaborating scientists and doctors. We aim to fundraise and foster steps toward a cure and effective treatment options, increase awareness among medical professionals and scientists, and provide education and advocacy opportunities for our Blau Syndrome community. More information at https://www.curebs.com/.

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