

Cyclist with Blinding Eye Disease Biking 3,000 Miles to Increase Choroideremia Awareness and Research Funding

Fight to End CHM - Jason's Journey Begins January 7, 2020 in San Diego, CA

WASECA, MN, UNITED STATES, December 9, 2019 /EINPresswire.com/ -- Jason Folie, a 35-year-old man from Waseca, MN, is going blind, but his vision is saving sight.

Folie was diagnosed with Choroideremia (CHM), an X-linked recessive retinal degenerative disease that affects roughly 1 in 50,000 males in the United States. CHM begins with night blindness at a young age, followed by loss of peripheral vision, and eventually leads to total blindness. There is currently no treatment or cure for CHM.

"I'm not someone who would typically want my story heard. I have been an independent person and hard worker all my life: a business owner, workout fanatic, wrestler, investor and all over "go-getter," said Folie. "When I officially got the news two years ago, it was the first time in my life that I realized that this isn't something I could fix. It's the first time in my life I've EVER let fear win. I knew I needed to start believing there was a bigger purpose."



Jason Folie and Krista Kramer - their vision is saving sight!

“

This is not for myself, but for the research that is needed to find a cure. For the boys, and men who are in my shoes and don't want to admit it but are terrified of that dark day in their future.”

Jason Folie

Folie connected with the Choroideremia Research Foundation (CRF) and decided to help fight for a cure. He created a plan to ride his bike across the country to raise \$100,000, and he is already halfway to his goal. Jason's Journey will begin January 7 in San Diego, CA and Folie will travel the Southern Tier Trail over 3,000 miles to St. Augustine, FL, making stops throughout California, Arizona, New Mexico, Texas, Louisiana, Mississippi, Alabama and Florida.

Krista Kramer, Folie's fiancée, said "My heart sinks a little every time he says he doesn't want kids if he can't see

them. I have such a love for children and building a family someday! The CRF has been extremely supportive-they are a family and a community that understands what you're going through. CRF makes me HOPEFUL!"

Following the conclusion of Jason's Journey, a welcome home "Dining in the Dark" dinner is planned for Saturday, March 28 in Waseca, MN at The Mill Event Center. Attendees will be invited to wear sleep masks during dinner to simulate eating while blind. Additional information regarding the event can be found at www.curechm.org.

Folie emphasized, "This is not for myself, but for the research that is needed to find a cure. For the boys, and men who are in my shoes and don't want to admit it but are terrified of that dark day in their future."

To support Jason's Journey, please visit: <https://donate.curechm.org/fighttoendCHM>

About the Choroideremia Research Foundation Inc.

The Choroideremia Research Foundation was founded in 2000 as an international fundraising and patient advocacy organization to stimulate research on CHM. Since its inception, the CRF has provided over \$3 million in research awards and is the largest financial supporter of CHM research worldwide. Research funded by the CRF has led to the development of a CHM animal model, the pre-clinical production of gene therapy vectors currently in clinical trials, and the CRF Biobank which stores tissue and stem cell samples donated by CHM patients. For more information, visit www.curechm.org

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