



**Help Hope Live**

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## **SUPPORT POURS IN FOR SIOUX FALLS 9-YEAR-OLD FIGHTING ULTRARARE DISEASE Ongoing Fundraisers Will Help with Cost of Care for Dezzirae Woods**

**SIOUX FALLS, S.D.**— The community is pledging help and hope to support 9-year-old Dezzirae Woods as she fights the rare and life-threatening disease Giant Axonal Neuropathy (GAN), which has a devastating and progressive impact on mobility, respiratory function, vision, hearing, and cognitive ability. The Woods family is working with the national nonprofit Help Hope Live to [collect donations in Dezzirae's honor](#) to improve Dezzirae's comfort and medical care.

Born in April 2011, Dezzirae spent the start of her life in the neo-natal intensive care unit. She finally got to meet siblings Damien and Destiny on Easter Sunday of 2011. Just before she turned four months old, Dezzirae was diagnosed with congenital heart defects during a routine check-up. She was immediately transferred to a Minneapolis children's hospital for open-heart surgery.

The surgery was a success, but the following year, she experienced seizure-like episodes and was rushed to the emergency room again. The occurrence kicked off the Woods family's quest to find answers about what was happening to their little girl.

The process took more than six years. In 2018, Dezzirae was finally diagnosed with giant axonal neuropathy or GAN. The illness is ultra-rare and life-threatening. While GAN is genetic, Dezzirae's mother had no way of knowing that she was a carrier.

GAN is a progressive illness that will impact Dezzirae's ability to walk and potentially lead to loss of sensation, strength, reflexes, and independent function; difficulty with breathing, sleeping, eating on her own; and vision and hearing impairment.

"GAN is a cruel disease that robs children of their livelihood," explains mom Rachel Woods. "It breaks our hearts to know that most succumb to it in their late teens or early twenties. We



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are raising funds to help our precious little sweetheart live a better quality of life during the time that she has left with us.”

Parents Rachel and David Woods have had roots in Sioux Falls since 1994. Dezzirae attended Rosa Parks Elementary until respiratory infections forced her to begin homeschooling. David works at Sioux Steel and previously worked for Dakota Contracting.

The Woods family is fundraising for Dezzirae’s medical needs at <https://helpholive.org/campaign/17557/>. Donations can be made online or by calling 800-642-8399. Dezzirae has already garnered support from across the region and even around the world, including a video shout-out from her favorite musician Ed Sheeran:

<https://youtu.be/mlhZUTMtgC8>

During the month of August, OverTime Sports Grill & Bar (4529 East 26<sup>th</sup> Street) will also donate 10% of all purchases when customers mention Dezzirae.

Donations are tax deductible to the extent allowed by law, and all funds raised will be managed by the nonprofit to cover verified medical and related expenses. Help Hope Live verifies medical and financial need for every patient.

Help Hope Live is a national nonprofit that specializes in engaging communities in secure, tax-deductible fundraising campaigns for people who need a transplant or are affected by a catastrophic injury or illness. Since 1983, campaigns organized by Help Hope Live have raised over \$145 million to pay patient expenses.

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