

Havyn's Hope Fundraiser



Havyn's Story:

Havyn had her first seizure the day before she turned 3 months old. We had no indication she could even possibly start having seizures before her first one. This led to 3 rounds of genetic testing to try to find the cause of her epilepsy. On June 19, Havyn was admitted to the hospital. We thought this would be her typical admission, a week in the hospital to adjust her meds. Havyn ended up having a UTI and was septic. She was put in the PICU just after 8 hours of being admitted to the regular floor. The first week was one of the scariest weeks we have ever experienced. Havyn accumulated multiple infections in her abdomen, causing severe ascites. All the fluid build up put pressure on her lungs which led to her being placed on a ventilator. With two failed extubations, we had to make a decision. We chose to place a trach. Havyn showed us she can thrive with support. She has been able to keep her eyes open most of the day, hold toys, move around, and so many other amazing improvements. During this admission, we also learned her true diagnosis.

ALG1-CDG is a rare neurological disorder. Havyn is 1 of 40 recorded cases in the world. This flipped our world upside down. The doctors have no idea what's in store for Havyn, but we do know we have to get the awareness out. There are only a small number of children diagnosed with any form of CDG. We can work together as a community to raise awareness. Not only for Havyn, but for all the other children and families dealing with this rare disorder. Through clinical trails and research, new medicines and therapies may be discovered to help them all live a better life.

Please keep sweet Havyn and all others with CDG in your prayers. All funds raised will go to Havyn's medical expenses and the equipment she will need when she gets home with a portion being donated to further CDG research.

For more information on CDG, visit <https://cdgcare.org/what-is-cdg/>

For more information on ALG1-CDG, visit <https://medlineplus.gov/genetics/condition/alg1-congenital-disorder-of-glycosylation/>

How to Donate:

Paypal - havynshope@gmail.com

CashApp - \$havynshope

Venmo - @Havyns-Hope

Check payable to Havyn's Hope
PO Box 229, Cornelia, GA 30531



@HavynsHope