



Lily

Motto: “Never give up”

Age: 8

Champion Teammate: Cassie Ford

HS Team: Bowie Silver Stars

As a small child, Lily was developmentally delayed and had a difficult time eating. She learned to roll over at 11 months and was delayed with crawling and walking. At age two, she ended up in the ICU in metabolic acidosis. Doctors have been searching for answers to Lily’s metabolic issues for over five years now, yet her condition remains undiagnosed. Lily is often hospitalized when she becomes ill because she can become acidotic. If left untreated, this could cause a coma or death. A few years ago, doctors diagnosed Lily with scapular winging, a symptom of a neuromuscular disorder. Lily had whole exome sequencing done, which uncovered a mutation on her RYR1 gene. Doctors suspect she has an RYR1 myopathy. The screening also showed

that both Lily, and her twin brother, have ADNP syndrome. ADNP is extremely rare, with only 120 children diagnosed worldwide. Additionally, Lily was diagnosed with malignant hypothermia (MH). Doctors will have to take special precautions during any surgical procedures and she also shows symptoms of awake MH. MH can be deadly. Lily was most recently diagnosed with Epilepsy that was uncovered during a sleep study. Lily’s conditions cause her to overheat quickly, fatigue easily, and she has to have a cool place to go when it’s hot outside. Lily has cognitive impairment and receives special education services at school. Weekly Lily attends PT, OT, and speech therapy. Despite her struggles, she is a happy brave girl and rarely complains.



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