The Silvia Mitova Invitational "Flipping to Find Cures"

Dravet Syndrome

Kye is Taylor Goering's (Level 3) twin sister. She was born just the same as her twin until she had her first seizure at 5 months old. They thought it was a one-time occurrence. Then another one occurred, accompanied by a fever, so they thought it was a febrile seizure. A few weeks later, Kye was back in the hospital with more seizures that could only be controlled by medicine. At that point, she was tested for Dravet Syndrome and it returned positive. Kye also has a service dog, "London," that helps her with the following:

- Security – We can tether Kye to her dog, so she can't run away.
- Tracking – If Kye ever wandered or ran away, her dog would be able to track her scent and find her quickly.
- Seizure alert
- Mobility- The dog has a harness to help steady Kye while walking on uneven ground.
- Behavior disruption – The dog is trained to nuzzle, lick, etc. to help calm Kye.
- Companionship/Socialization

The smiles Kye (and London) get from all the girls at the gym make her feel part of the "team". She loves being their cheerleader and getting to do open gym with them! :)

The **Dravet Syndrome** Foundation www.dravetfoundation.org fights for these kids everyday and is making a huge difference in their lives. We would be honored if you would be able to make a donation to them.

Dravet Syndrome is a rare, catastrophic, lifelong form of epilepsy that begins in the first year of life with frequent and/or prolonged seizures. Previously known as Severe Myoclonic Epilepsy of Infancy (SMEI), it affects 1:15,700 individuals, 80% of whom have a mutation in their SCN1A gene [1]. While seizures persist, other comorbidities such as developmental delay and abnormal EEGs are often not evident until the second or third year of life. Common issues associated with Dravet Syndrome include:

- Prolonged seizures
- Frequent seizures
- Behavioral and developmental delays
- Movement and balance issues
- Orthopedic conditions
- Delayed language and speech issues
- Growth and nutrition issues
- Sleeping difficulties
- Chronic infections
- Sensory integration disorders
- Disruptions of the autonomic nervous system (which regulates things such as body temperature and sweating)

Current treatment options are limited, and the constant care required for someone suffering from Dravet Syndrome can severely impact the patient's and the family's quality of life. Patients with Dravet Syndrome face a 15-20% mortality rate due to SUDEP (Sudden Unexpected Death in Epilepsy), prolonged seizures, seizure-related accidents such as drowning, and infections [2,3]. Research for a cure offers patients and families hope for a better quality of life for their loved ones.