A letter from Mom, GiGi & PaPa

Darby, Tammy & Mark



We noticed very early on that something was not quite right with Isla. The most obvious noticeable issue was her eyes. She has a condition called Nystagmus, where one's eyes make rapid, repetitive, uncontrolled movements. Just before Isla's first birthday, Darby convinced her primary physician to refer us for genetic testing. The results were shocking, to say the least. Isla has two rare genetic duplications, 14q11.2 and 22q11.2. To be born with one of these duplications is incredibly rare, but to be born with both, the odds are somewhere between 1 in 400 million and 1 in 600 million. The features of these conditions can vary widely so it is difficult to know what the future holds. With 22q11.2 duplication, affected individuals may have developmental delay, intellectual disability, slow growth leading to short stature, weak muscle tone, congenital heart disease, recurrent infections, kidney abnormalities, breathing problems, feeding difficulties, gastrointestinal problems, hearing loss and psychiatric disorders. 14q11.2 is characterized by developmental delay, mild to severe intellectual disability with speech impairment and epilepsy.

We have already experienced some of these issues with Isla. Isla struggled with eating and would wake up gasping for air in her early years which ultimately led to her needing surgery to repair the issue. We know that Isla will have to have a second surgery to correct her head turn associated with the Nystagmus. Isla receives speech and developmental therapy services weekly for developmental delays, and she is currently going through testing for autism. Recently, she has been struggling with sleep and is displaying some behaviors. Sometimes Isla will only sleep for a few hours each night and she will wake up crying inconsolably. It was during one of these episodes that Darby just happened to be dog sitting for a friend. Isla's mom was trying to comfort Isla, but she was not settling. The dog went over to Isla and laid his head on her back. When she continued to push back and resist, the dog placed his paw on her bottom and just laid with his head on her back and his paw on her bottom. She began to settle and drifted back off to sleep. Once she was sound asleep the dog moved to the end of the bed. That incident prompted us to start pursuing a dog.

A service dog will be able to help Isla in a few areas. Specifically, her dog will be trained to do behavior intervention (both passive and active). The dog will provide comfort. The dog will be tether trained so if we are in a busy place, Isla can be tethered to her dog to help ensure she does not bolt off. Finally, the dog will be trained in search and rescue specifically for Isla.

We are still learning a lot about what Isla may experience because of her diagnosis and just since being approved for a service dog, we have observed Isla having absence seizures and have learned she may need further cardiac evaluation due to some concerning medical data we have collected. A service dog could even help in these areas, once confirmed, by alerting us.

Training a service dog to meet a child's requirements can be very costly. On average it costs between $40,000-60,000 to raise, train, and place a service dog at 4 Paws for Ability. While 4 Paws for Ability fundraises to help cover a significant portion of this cost, families are tasked with raising $20,000 of that amount or $23,000 if receiving a poodle, doodle or papillon. We hope that we can receive assistance from our beloved family and friends to help make our service dog dream a reality. We need a hypoallergenic breed so we are required to raise $23,000. We are required to fundraise our portion before we are put in a class placement to be trained and receive our dog. Those classes are about a year and a half out once we have our fundraising goal met so trying to accomplish this part of the goal as quickly as possible is important.

Raising 23,000 is no joke and it is going to take a lot of effort, but we know we have the best community to do this with. None of the money comes directly to us. It should all be paid directly to 4Paws. They have a page that allows us to track our progress.
Scan this QR code for more info and to follow our progress. ➔

ALL checks for Isla's fundraiser need to be made out to 4 Paws for Ability.

Your help is more than our family could ask for. We are so grateful for a loving and giving community around our Isla.