

# Brinley's Journey

Brinley's journey with her seizure disorder began a little under a year ago in Houston, Texas when our (then) 3-year-old daughter screamed "Brinny's sick! Brinny's sick!" We looked over and saw our beautiful 17-month-old baby girl laying in a pool of her own vomit on our tile floor not moving. Chris flew over the couch and immediately checked her vitals and picked her up. She was completely limp in his arms, her skin was grey, her lips were blue, our hearts stopped and broke at the same time, and we honestly thought we had lost our precious baby. Her breathing was shallow and obstructed from her inability to completely clear her airway, and it felt like an eternity waiting for the ambulance to arrive at our home. We wish that we could say that this was a one-time event, but unfortunately, this is not the case. Brinley has gone through this experience several more times, and we have had to hold our sweet girl through these terrible events while praying each time for it to stop quickly and for her to come back to us. After months of emergency room scares with seizures limited to fever events (called febrile seizures), our hearts sank when a month ago she had her first unprovoked seizure. We have come to understand the implications of this for our daughter's safety. What her doctors, and our experiences, have taught us is that this means that she is at risk of having a seizure during the night or in one of the brief moments of the day that our eyes are not on her. Those brief windows of time can be enough for her to stop breathing, and for us to lose her.

As a parent you will do anything and everything to keep you children safe, and with our sweet Brinley, the best path forward involves a Furry Hero. To explain further, during one of Brinley's typical seizures, she becomes unresponsive to all stimuli including touch, sound, & vision, and she goes completely limp/ridged. These are a mixture of what is called tonic and tonic clonic seizures. There is also period of time where her breathing either slows or stops, and she usually vomits towards the end of the event. Over the past year as her body has continued to grow, a slight amount of convulsing during the seizures has introduced itself but is not consistent. Our goal during these events is to turn her on her side to ensure that her airway is clear prior to, and once the vomiting phase is over. We also have emergency medication that we can give her to break the seizure, and help her come out of it if it lasts over 5 minutes. Seizures with a duration of around 10 minutes or longer can lead to permanent brain damage. The biggest fear we have developed over the past year is for her to have one of these events while sleeping at night on her back, and us not being there to ensure that her breathing continues. Just two months ago she experienced her first seizure while sleeping. Since Brinley's first seizure, Angela has started sleeping on the floor by her crib on days that she was sick or just seemed a little off. Angela typically wakes up every 30 min. to check on her, and this was one of those nights she was on the floor. Angela rolled over to check on her and saw that he skin was flush of color and her lips were

blue. Our baby girl was in a seizure, and Angela was literally inches away from her and did not know. We are just so grateful that Angela woke up when she did.

Beyond doctors, we have researched for numerous hours on some sort of monitoring technology that could give us some sort of indication that Brinley is seizing. Currently in the United States, there is no system in existence that we, the National Epilepsy Foundation, or several other very reputable foundations are currently aware of that can detect the type of seizures that Brinley has. The monitoring systems that we have come across all work by detecting the repetitive convulsive movements of a grand mal seizure, which is not the type that Brinley currently and consistently experiences.

We have researched and spoken with many organizations recently, trying to find ways to keep our baby girl safe. These foundations have been phenomenal in educating us on all the options available. The heartbreaking part, however, is that many of these organizations are in existence today because they lost a loved one to this condition, and unfortunately there just isn't enough information out there to help people protect themselves and their loved ones. Until this started with Brinley, we had no idea that there were so many variances in epilepsy. We had never heard of SUDEP (Sudden Unexpected Death in Epilepsy). We also had no idea that our baby girl could have a seizure while only inches away from us and make no sounds while being in that kind of danger.

Now, back to Brinley's Furry Hero. When we started this journey, we certainly did not know that a dog could be trained to save our daughter's life. After extensive training, these dogs can detect a seizure sometimes up to twenty minutes prior to the event. They are trained to roll the person onto their side to help clear the airway in case of vomiting, protect them if they start to fall if they're standing, and alert a handler of the ongoing seizure. After several conversations with doctors and multiple epilepsy foundations, they have all unanimously advised us that a seizure response dog is Brinley's best option for safety and security. Unsurprisingly, these amazing Dogs (mostly Golden & Labrador Retrievers) come with a hefty price tag of roughly \$20,000. As a young, single income family, this amount feels unattainable on our own. We have launched a T-Shirt campaign, are in the final planning stages of a TopGolf Fundraising event with a target date range set for late June to early July, have set up a You Caring Fundraising webpage, and have applied for several grants from several epilepsy foundations such as the [Danny Did Foundation](#). Our goal is to raise this money, and begin the dog matching stage by the end of Fall 2018. The response we've received during this time has been very humbling, and I know that Brinley has so many friends and family members in her corner. While we still have a long way to go until we reach our financial goal for Brinley's Furry Hero, we are beyond optimistic for her, and will never stop fighting for her.