



INSIGHTS

Family reflections: benefits for children with service dogs

Melissa O'Bryan¹*Pediatric Research* (2021) 89:1032–1033; <https://doi.org/10.1038/s41390-020-01289-2>

Our son first began having seizures as an infant. As a parent, I suspected his diagnosis before it was officially confirmed. We received a genetic diagnosis thanks to research. A partnership study between our hospital and another hospital was able to do what our insurance was bogging us down with. We finally received our genetic diagnosis that confirmed what we had suspected all along. Dravet Syndrome. A rare and catastrophic epilepsy, it is often uncontrolled by medication and comes with a host of other comorbidities that, as a parent, are terrifying to consider. When you have a child with uncontrolled epilepsy, the world becomes a frightening place. For our son, the first five years of his life brought uncontrolled seizures. These would occur no less than one time a week and would range anywhere from 2 to 34 min. They would happen without warning, indication and often for no reason. Commonly identified “triggers” would sometimes cause them, but often they just happened.

Our family learned so much during this time but also lived a lot in fear. Our son co-sleeps. For us, not knowing if he were going to have a seizure in the middle of the night that a seizure monitor would capture was a risk we didn't feel safe taking. For many families with Dravet Syndrome, this is a common conversation. We became helicopter parents overnight, fearful of not being able to seek emergency services if we were too far out of cell range, no longer doing things we enjoyed as a family, such as boating, hiking and camping because we just couldn't guarantee his safety. As our son aged, and started school he went from having an adult with him at all times at home to an adult paraprofessional with him at school. His independence was so limited, because safety is always our primary concern and with an uncontrolled seizure disorder, keeping him safe is a lot more restrictive than with most typically developing children.

We were recommended a service dog when our son, Owen, was 3 years old by his epileptologist. It took me about a year before I made the decision to do so. I had to grieve his diagnosis first. For me, getting a seizure alert dog felt like we were conceding defeat. We were saying we didn't think he would ever get seizure control and I wasn't ready to face that.

When Owen was four, we applied for a service dog for medical alert, balance and basic overall safety and independence. It was becoming apparent that his life would be a lot more enriched if he had a tool of sorts, a dog to help him stay safe, to alert us if he were in danger, to be his companion and friend as he navigated the world of school with limited social skills.

We were placed on a lengthy wait list and told it would be approximately 2 years and they would reach out when they had a suitable placement. Two years passed. We started to wonder if we were going to be getting a dog at all. During this time, our son continued to try medication after medication with no success. In the medical world, they are called failed medications. But he did not fail anything, they failed him. With Dravet Syndrome, the options for medications are limited. It is a sodium channel epilepsy and many antiepileptic drugs are actually called sodium channel blockers and can make their syndrome worse. So not only were his options more limited but none currently available on the market were working for him. We even tried a medically prescribed ketogenic diet. We started to consider clinical trials but for our family the hardship of this would have meant disrupting our family dynamic for the better part of a year. We live on an island in Southeast Alaska and we receive all our specialty care by flying to Seattle. A clinical trial would have required either a significant amount of time and travel or a move altogether and we weren't sure if we could commit to that.

After 3 years on the wait list, we were notified that a dog was waiting for Owen this summer if we could come to the training. During a pandemic. For our family, the question was not whether

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we were going to get the dog but how? We began the process of fundraising and researching travel mandates in our state and Kansas where we would have to travel to train and planning for this new addition coming to us. At the beginning of August, we flew to Kansas to train with the facility and we received our son's dog, Juno. Training consisted of the two of them bonding, working on commands, understanding the Americans with Disabilities Act and how it applies to service animals and grooming of this trained assistant. The training culminated in several public access tests and one final public access test. Finally, we were ready to head home with our new family member. But she is so much more than that, she is the perfect partner for him. She is sweet when he is salty and a strong, stout black lab for our gangly 7-year-old with balance and gait issues. The training doesn't stop once you get your dog. We continue to work on bonding and practice commands; it is important to be consistent and for some this is difficult. Our son struggled initially with this new accessory. We were adamant that she begin to go everywhere with him and have her tethered to him. This was new for him but he quickly learned how to loop her leash safely around him and continue on his way. We practice daily with our son and his dog the commands. He is the primary handler for her and is responsible for her feeding and watering as possible. If he is having a day where that is difficult for whatever reason, we encourage handover hand tasks and make that a possibility. Our dog struggled with knowing who her boss was for a bit. It is clear to her that our son is her "person" and she will go to him and listen to him but she has also identified my husband and I as HIS boss, so she often looks to us for permission almost before completely listening to him. We are working with our son on cleaning up after her and have also tried to incorporate this into his day when he is bringing her to school. We have a significant process to go through to be able to bring her to school. We also want to make sure that all of those around her know the expectations and it is difficult to train students and staff when the building is locked down to visitors due to COVID. We are working with the district on a plan for our son to begin introducing his service dog to school. Before she is able to go with him, we need to be able to show that he can independently handle her.

We wondered if getting a service dog was the right thing to do, if we weren't exposing our son's disability in a way he wouldn't be comfortable with, or making a decision that would be costly and difficult to follow through on. The constant thought that goes through our minds is the doors that getting this dog have opened for our son. A service dog means that he will continue to learn his strengths instead of being defined by his disability. He will learn tools for independence, and she will help us as a family to know that he is safe. He was so excited to learn that he may get to share a room with his brother

and pick out his own bedding! For a child with previously uncontrolled seizures that has had to sleep with mom for a long time, this is huge! Nothing about our son's disability or our son is a burden but it is a heavy load to bear to know that your number one job is to keep your child safe and that sometimes it may be out of your control. The specialized training this dog has received has helped us to ensure that his safety needs will be met.

Safety and peace of mind are immeasurable for families of children with Dravet Syndrome. When our son would have a seizure, the world would stop turning for us but it would continue all around us. Time stood still and we never knew when the seizure would end. As we watched our child slowly become lost to side effects of medications that were not even working for their intended purpose, we wondered why we were giving them at all. Without targeted research and awareness for specific rare epilepsies we would not be seeing the success we are seeing with our son. If research had not been done on CBD oil, and Epidiolex had not been FDA approved, I have no doubt we would still be watching our son seize every week without fail. Research is so important because we need new medications for our children. Many of our children with Dravet Syndrome are seeing incredible success because we are able to get a genetic diagnosis sooner. Our children are safer because of the adults with Dravet Syndrome who paved the way. But we need to consider them as well. We need continued research into the comorbidities associated with Dravet Syndrome. The behaviors associated with Dravet Syndrome are similar to those on the Autism Spectrum. We need continued targeted research on the behaviors associated with Dravet Syndrome. And with the new promise of a possible research study being done on gene replacement therapy for Dravet, we need that to continue as it could be our children's only hope for a cure.

It is because of research and increased awareness around Dravet Syndrome and CBD oil that the first pharmaceutical grade CBD passed clinical trials, was FDA approved and became available by prescription. For our son, this was a life changer. He went from having uncontrolled tonic clonic seizures weekly to month long stretches of seizure freedom. Then 2 months, and then 3 months, and so on. He is coming up on 1 year of seizure freedom that we did not ever think was possible. Our son will always have a rare seizure disorder but his quality of life will always be our first concern. With his increased independence and his potential for seizure freedom we are hopeful that he will live his best life.

ADDITIONAL INFORMATION

Consent for publication: As the parent of Owen O'Bryan, I provide consent for pictures and narrative to be used and published for my son.