On January 26, 2021, our world was turned upside down when our son, Bennett had a long focal seizure. A few days later after numerous tests and several specialist appointments, he was diagnosed with both focal and generalized epilepsy. Despite being on anti-epileptic drugs, Bennett continued to have seizures of varying types and lengths. After undergoing more EEGs, it was discovered that when sleeping, Bennett was having seizures. We were immediately referred to the Blue Bird Neurology Clinic for Epilepsy at Texas Children’s Hospital. Thankfully, under the care of his medical team, Bennett received specialized care and was given a medication combination that was able to stop a lot of the seizures or shorten them, but the damage was done. After suffering through multiple seizures, Bennett struggled with both gross and fine motor skills as well as convergence insufficiency with his eyes. As his doctor said, Bennett’s neuropathways became overgrown and were not as accessible, so the brain was having a hard time finding and using these pathways which impacted his coordination. Once this was discovered, Bennett started physical therapy, occupational therapy, and vision therapy to reconnect these pathways. The summer of 2022 was completely packed with numerous appointments, so Bennett could work to regain control of his body. He continues to see his therapists inside and outside of school as his handwriting was severely impacted.

After discussions with his teachers and researching, we realized that epilepsy often goes hand in hand with other neurodevelopmental disorders. Bennett preferred to play alone, did not like to get his hands messy, and did not like changes in routine. We had Bennett assessed and he was diagnosed with autism. This answered so many questions for us, and now we know how to parent him better and help him overcome obstacles pertaining to autism. He regularly sees a psychologist to help him talk through his feelings and behaviors, and we have implemented a calm down bag and a sensory swing in his room to help him cope.

One thing that helped us as a family come to navigate his diagnoses and meet other families like ours, was A Kid Again. A Kid Again is an organization that offers free local events and activities for families who have a child facing a life-threatening condition. They handle all expenses and details so we could take a break from the doctors and therapists

and enjoy quality time with our family while also meeting other families facing similar situations. Knowing we weren’t alone gave us newfound hope and encouragement.

Bennett will be a first grader at Sampson Elementary this year where he will continue receiving occupational therapy and speech therapy. Bennett is aware that he has epilepsy and understands that his brain works differently than others, but that it makes him unique. He loves to read and is currently reading the Harry Potter series and Redwall series in addition to any Star Wars books he can find. He absolutely loves to play strategy games such as Chess, Star Wars Villainous, and Star Wars Risk. He has an amazing sense of humor, and a wonderful imagination. He has convinced his little sister to also love all things Star Wars as it is his favorite interest. Bennett participates in Cub Scouts and Coles Crossing Youth Soccer where he is making friends and building relationships. We truly are so grateful to be his parents. We sincerely appreciate your thoughts and prayers as we go through the next battery of tests and continue to work with Bennett’s medical team to keep his seizures under control as he grows, all while giving him the least amount of medication as these can cause numerous side effects such as fatigue, anger, depression, weight loss, and vomiting.