



“The step therapy process is scary and concerns all parents of children like Braden. We have trouble getting a number of medicines, and literally had to jump through hoops, and it took us days, if not weeks, to get the antibiotic we needed for Braden. It shouldn’t be such a process just to get what your doctor prescribes.”

## Meet Crystal and Braden Brown | Austin, TX

Crystal works hard to advocate for her son and all children like him. Together the family makes an extremely forceful and loving team, and they depend on medicines every single day to survive.

“This whole insurance situation has the potential to end someone's life if it isn't handled correctly and with care. I don't think they realize how much power they have and how quickly they can ruin our lives, quite possibly unintentionally, by causing unnecessary hassle.”

Handsome Braden Brown is now 10 years old and goes to school five days a week for half days. The love shared among Braden, his parents and sisters is deep. In fact, Braden’s sisters, Rylee and Macee, know exactly what to do when he needs medical help. They know to grab oxygen tanks and can assist in bagging Braden and obtaining other necessary medical supplies for their mom Crystal while she calls 9-1-1 for help. Braden’s Dad, Brien, is often away at work as an Austin firefighter.

## Their Story

Although taking care of Braden and her family is a full-time job, Crystal has become a tireless advocate not only for him, but for all medically-fragile children who are struggling to get the medicines and healthcare they need.

“Braden doesn’t always have ‘typical’ or ‘normal’ reactions to certain medications prescribed to him. When doctors and I discuss possible side effects, we take into extreme caution all the unknowns of Braden’s metabolic processing. Having someone who doesn’t know Braden taking over medical decisions, like step therapy, isn’t a safe option and could potentially be life threatening to all he has overcome.”

**“The stakes are high here. Let’s say the opinion made by the health insurer in the step therapy process is one that we, as parents, were not only forced into, but one that doesn’t work. Not only did that decision delay the access to the drug the doctor and the authorized legal representative/parent made, it also just imposed a hospitalization because of an adverse reaction simply because the health insurer did not know first-hand information about the patient.”**

Crystal says she is not speaking from fear, but from invaluable, crucial, vital experience as a parent of a special needs child. What Braden has taught her cannot be taught in class or written in a book.

**“I plan to fight for Braden as long as he needs me to. My goal is to fight for the future and rights of all children who can't do so for themselves. Braden has taught me the importance, and the gift, of the simple ability to breathe - and how easily and quickly it can all end. Not having what you need when you need it is extremely critical.”**

Braden Brown’s medical history is extremely complex. He was born at 34 weeks and five days by emergency C-section with central hypotonia (low muscle tone, extreme head lag); no suck, swallow, gag or cough reflex (dysphagia); neonatal encephalopathy; severe developmental delay; hypermetropia; astigmatism; staring spells; head "spinning"; cortical visual impairment; intermittent ex tropia; 50% bilateral conductive hearing loss before PE tubes (20%-30% loss after PE tubes, with chronic purulent otitis media, acute otitis media); tracheitis; gastroesophageal reflux disease; micrognathia (small, set back jaw); a strong, left cavovarus foot deformity (helped by Botox and serial casting); generalized convulsive epilepsy; epilepsy characterized by intractable complex partial seizures; and a type of neuro-metabolic disorder/infantile cerebral palsy. His medical procedures include: g-tube placement; muscle biopsy; nissen fundoplication for GERD (reflux); a swallow study; sleep studies; spinal tap; multiple EEGs; MRIs and CT scans; tracheostomy; skin biopsy; frequent blood and urine analyses; visual evoked response tests; EKGs; echocardiograms; blood transfusions; Vagus Nerve Stimulator (VNS); and many others.

When Braden was born, he didn't move, cry, or respond to anything done to try to stimulate him. He was a month old before he cried for the first time. According to Crystal, the doctors never wanted her and her husband to take him home. Instead, they felt institutionalizing Braden was a better option because of his perceived "failure to thrive." But after 67 days in the NICU, Crystal and Brien took Braden home knowing it was his best option. They accepted the risks and challenges, and learned all they could, every single day.

Braden has been living at home now for more than 10 years. He is occasionally admitted to the hospital for things like pneumonia that require IV antibiotics; pneumatosis (air in the lining of his intestinal wall because of the use of steroids); severe constipation; or for seizures that have lasted hours and that require recovery time on a ventilator. Braden has an implanted VNS pacemaker (for his brain) in his chest, which doctors considered his best option for trying to control the length of his seizures, along with the anti-epileptic medications he takes daily. Braden's longest seizure to date has been over three hours; his shortest has been 20 minutes. Braden started walking a couple of years ago and enjoys going to the beach so that he can, as he says, feel the waves “crash up against my belly.” His favorite movie is *Cars*.



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