

Jessica's Statement

I was fully prepared to quit my job when William was born if Mariel wasn't everything we needed in a childcare provider. She was the perfect caregiver for our precious boy. We trusted her. We were friends. And what she did to Will has caused our lives to be irreparably changed. It is impossible to convey the tragedy and depth of devastation and sorrow as we watched our son fight for his life for days and weeks. No one could even tell us with confidence that he would even wake up. Then wondering if he would breathe on his own, open his eyes, eat and drink on his own, if he would ever stop seizing, twitching, shaking, and crying. We learned that he had lost the vast majority of the left side of his brain, with some damage to the right side, as well. Even if he did wake up, they said, he would be severely impacted for life, and the extent was impossible to know. It all seemed like too much as we forced him through grueling therapy session after session, and attempted to comfort him when he was screaming and screaming for what seemed like hours on end because everything hurt and everything was too much work for his extremely weak, confused body and brain. It is impossible to adequately describe the stress, grief, and hell of our lives in the hospital as we spent almost five months frozen in time caring for our sweet, broken boy whose skills and abilities were not even as developed as a premature baby. There were many moments of triumph as Will beat the odds over and over again, but even with the support of the incredible nursing and therapy staff, there was never enough time in the day to do everything that needed to be done to help him heal. His therapists worked tirelessly, and so did we, but despite everyone's best efforts, his goals were rewritten over and over again to be easier to meet and give more time to meet them. Even when we were discharged, he hadn't met most of them. I read them now and he still can't do most of them. We continue to learn in waves just how terrible his brain injury was. It seems like every time we think we understand the gravity of what he was going through, we hear doctors or nurses or therapists or researchers suggest that he shouldn't've woken up. He shouldn't be able to sit. It's a true miracle, meant in the most literal sense of the word, that he is even alive and progressing.

And now, even as we have transitioned home, it still feels as though our lives have been put on hold while we figure out how to raise a disabled child and help him to progress as much as is humanly possible. I quit my job to manage his therapies and appointments and care full time, because there is no one else we trust who is available to provide the kind of care he needs all day, every day. There aren't enough hours in the day to do every recommended activity, so I have to prioritize, knowing that taking away one thing will likely lead to more deficits in other areas. And if we decide to do something "normal," like go to the zoo or have a play date with other children, then I know that we won't get all his basic therapy needs met that day. But we have to: he needs a childhood and a mom. So we chalk it up to a vision therapy day and try to get in some tummy time on the side.

It is impossible for anyone who hasn't spent a day with us to realize the extent of Will's injuries. Since we were finally discharged from the hospital in February, we've had three visits to the emergency room and two overnight stays, one for a really bad seizure, which caused him to stop breathing, and one for intractable pain that had him screaming in pain and terror at the top of his lungs for literally hours on end, and off and on for days after that while his doctors tried fruitlessly to find a cause. These hard days

are sometimes impossibly hard. My perfect boy has a broken brain, and despite any outward improvements, there are countless non-improvements. The screaming is gut-wrenching. The lengths we have to go to keep him from overreacting to everyday sounds and experiences make me feel (necessarily) like a crazy neurotic helicopter baby-er of a mom. Watching therapists hook him up to electrodes is much worse than I thought it would be-he hates it. And all to try anything that might make the muscles on his right arm and leg fire. The daily grind of uncomfortable, and downright painful, work he has to endure breaks my heart into tiny pieces. The "normal" days without doctors appointments or therapy are almost worse, though, because the "normalcy" (and really, lack thereof) always triggers intense and gut-wrenching sadness. The crushing kind that physically hurts in your heart because Will used to do all the toddler things. He would drive his cars all over the house. He used to love Thomas the Train. He used to have favorite toys and books. He used to wrap his arms around my neck and collapse in my lap and belly laugh. Now I put his arms there and help him stand up, and his legs buckle beneath him and he collapses in my lap and is scared because he doesn't realize how he got there, and the startle it elicits causes him a visceral kind of pain and fear that makes him a scared, crying, hyperventilating mess. He doesn't have many favorites-every toy goes equally in the mouth. It's been a fight to get him to actually play with toys using his one good hand. Going out and doing "normal" things is also sad. At Target, someone's two year old says, "look mama, a baby," and the mom agrees, even though they are obviously the same age. It's worse when a parent casually asks how old he is while we're pushing our children side by side at the park, and the answer triggers a long, awkward pause because I don't know how to tell them he has a traumatic brain injury, and they don't know how to say, "yeah, he definitely doesn't look or act like he's two...". Or when they don't say anything at all until their child asks why he's flexing his arms and legs hard as the swing makes him startle, and he starts to cry, and then they just shush him and walk away. Or when people openly stop and stare when they see his feeding tube.

One year ago last week, I put my perfect boy to bed without realizing that the next morning would be the last time I ever say him play with two hands. The last time he would point to something he wanted. The last time he would have a coordinated suck that didn't cause him to choke, aspirate, cry, or just dribble it everywhere. The last time he would nurse. The last time I would hear only his perfect voice and babble, without any of the brain injury sounds. The last time he would cry out for us normally when he woke up. The last time I would find him sitting or standing up in his crib waiting to be picked up. The last time he would stand on his own with a look of toddler triumph, and then "tackle" me. The last time I would see him walk or crawl. The last time I would see the light of his soul in his eyes until Christmas. The last time he would look and act "typical."

For reference, 90% of people with brain injuries as bad as his don't even wake up from their comas. And of the ones that do, most don't keep making progress the way Will has. We are so very thankful for the miracle that Will's life continues to be, but we have to realistically acknowledge that eventually he will "plateau." His motor abilities will never be the same. He can't consistently roll over, doesn't really use his right arm or hand, and can't scoot or push himself into sitting position, much less walk. If he does "walk," doctors have a huge range of what that term means to them. One of our doctors prefers to say, "ambulate in some fashion," because to them, Will "walking" could mean someday learning to take just

a few steps with a walker, and never doing more than that. Or maybe he'll only need a walker or a cane. Like just about everything with his recovery, we have no idea where he'll end up. It will hopefully be years before we even have an idea, because that would mean his recovery is progressing longer and better than anyone thought it would. But one thing is certain: none of it will be easy, and it will have cost our family far more emotionally than the multiple millions of dollars in charges Will has racked up just this last year. Hours and hours of therapy and doctor's appointments, home exercises, trouble with attention and schoolwork and motor skills, not to mention the devastation at having lost Will's childhood. No child deserves this. At his young age, Will already has all the hallmarks of the kid who gets stared at and teased mercilessly by uncaring and unknowing peers and adults who don't know better: crossed eyes, huge scars all over his head, back, and stomach, a feeding tube, seizures, a short attention span, muscle tightness and spasticity, very limited language abilities, and can't walk. Our new normal is "routine" surgeries, orthotics, feeding tubes, medications, therapies, services, specialists, doctors in four different medical facilities.

The trajectory of his young life has been forever altered, and there should be real consequences for this. Will is never going to have the life every child deserves to have: instead of wondering where he'll go to college, or if he'll be an engineer like his daddy, or a teacher like his mama, or an astronaut or a writer or an athlete, we have to wonder if he'll even be able to have a job. To participate in school. To play a sport. To drive a car. To go to college. To live on his own. We do not take anything for granted anymore.

Trying to do normal life is crushing, despite the astonishing progress he has made. Even though he is the sweetest, most smiliest, joyful, belly-laughing giggle-box I have ever met. I too often have to wonder and ask, as no mother should, "where did you go, Will?" and wonder if I should administer a rescue med to stop the seizure as the light goes out of his eyes and he just stares. I don't know where he is, or what he's thinking, or if it is even a seizure at all. And I just can't bear it-the pain of our new normal is too real, and it will never, ever go away, even on the "good" days.

John's Statement

August 12, 2015 was the best day of my life. William was born healthy and bonded with us immediately. The love I felt for him was different than anything I'd experienced before. I was ready to pour my life into Will. From the beginning, I looked forward to teaching him and watching him learn.

Laughter, snuggles, tickles, and smiles. That's what motivated William. With these tools, I helped him learn how to use his arms to play peek-a-boo. I laid on the floor next to him and taught him to roll over for the first time. He wasn't interested in chasing after toys, but copying daddy and hearing my cheers he worked so hard and finally rolled over. Likewise, I taught him to crawl, play with balls, stand, cruise along the coach, walk and climb stairs. He was just starting to take steps independently, but mostly he loved to walk around the house holding my hand.

I also tried to teach him words. He learned "ma-ma" long before he could make a "d" sound, but I worked on that for months and he learned to call me "dad" shortly before the injury.

September 22 was the worst day of my life. Seeing him unconscious in the emergency room, learning he had a brain injury, being told he'd probably die. We made the decision to save him with the second surgery knowing that he would be affected forever - he will never fully recover.

My commitment to Will hasn't changed. I will teach him and help him reach his potential. But William has permanent brain damage; his potential is lower now because of the injury. The right half of his body is weak and he has almost no control of his right arm. His vision and oral coordination have been impacted as well. He lost most of his muscle mass from laying in a bed for months. He has seizures that are expected to affect him for his entire life.

We've had to re-teach him from a starting point even less functional than a newborn. Before the injury, he could crawl over to his water bottle and take a drink on his own; now we have to pour the water into his feeding tube because he can't drink liquids. Before the injury, he could crawl and walk; now he can't move himself.

I often catch myself getting excited about things I'm going to teach Will when he gets older only to remember that we'll probably never get to have those discussions. I probably won't get to teach him how to play chess or to play the piano. How to form a logically sound argument or critically evaluate marketing claims. I won't get to spend nights helping him with his calculus or working on a physics project. I probably won't be able to teach him how to use power tools or change the oil. We won't go on runs together or workout at the gym. I might not get to help him choose a college and a major or proudly tell my friends about his new job. I probably won't be able to give him relationship advice, see him get married, or hold his children.

It's devastating to me to watch his peers grow. They're running, jumping, talking, eating. So many things I was planning to teach Will. So many things I won't get the opportunity to teach him now. We were going to start a college saving fund, now we're going to start a special needs fund. It has made it difficult

for me to interact with some of my friends who have kids. I've cut myself off from social media because of the sadness it brings.

I need to mention his pain. William has been through an extreme amount of pain due to issues caused by the injury. With everything that has happened to him, there are many sources of the pain which ranges from mild to excruciating. In the worst cases, the pain was so severe that William would scream until he stopped breathing and turned purple. The first emotion I saw from William after the injury was fear - his eyes wildly trying to escape the burning pain inside him saying help me, make it stop. He still occasionally has unexplained pain that is almost as bad.

The devastation that she caused will be with us for our entire lives. William's pain and his deficits will be with him for his entire life. I ask for the maximum sentence for her. Prison is far less harsh than what she did to Will, and even the maximum sentence is far, far less than the sentence she inflicted on William.

