The Family Voice

Making Deacon Visible

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ABSTRACT

Children with complex medical conditions often have developmental challenges. It is easy for the medical gaze to overlook a child as a child, versus a child as object of medical assessment. This narrative describes a family's experience trying to make their child, Deacon, visible.

As a parent, I have always believed the hospital was a place that would value my child, where clinicians would fight for my child's life as much as I would. I understood that clinicians took an oath to do no harm, but that they also wanted to do good. I have always believed that every life is valuable and worth fighting for. Then I had a child, Deacon, who didn't fit into the normal. I soon learned that doctors will not struggle to fight for your child when they don't "see" your child.

Deacon James was born via c-section at term, and we immediately knew something was not quite right. He was our fifth and last baby; we were seasoned parents and knew what was expected, and what was not. We spent three weeks finding a clinician who would listen to us and not blow us off by saying Deacon had a virus and asking if we were new parents. To fight for our son, we assembled a team of people we called "Team Deacon." Sadly, not all his careproviders were on Team Deacon, and we found that out the hard way.

We found our first Team Deacon physician, an otolaryngologist, that listened, sat, and listened some more. He "saw" Deacon James and, at three weeks, diagnosed him with an airway disorder. In another three weeks, Deacon had his first surgery to open his airway. He spent the first six months of his life in and out of the hospital while we fought to find another diagnosis. We repeatedly heard that he was too cute and must only have a virus. Each test came back just slightly off, or normal. He was clearly suffering, and most could see that it was something, just not what clinicians saw as "their something." Gastroenterology would refer to pulmonology, pulmonology to otolaryngology, otolaryngology to genetics, and around and around we went.

At six months old, Deacon had spent almost six weeks in the hospital. He developed a terrible lung infection complicated by his underly-

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ing airway disorder. He had aspirated too much milk and was very sick. During this stay, he was diagnosed with a rare genetic condition and we finally felt some validation. It was not the end of our fight for our son, though.

After his diagnosis, we were referred to more specialists to help evaluate the potential symptoms from his condition. We were also referred to pain and palliative care consultants, the first specialty to "see" our son and to "see" us. These clinicians saw that when one person in a family suffers, the whole family suffers. They believed that it was not okay to allow a child to be in pain just because they didn't have a test to prove that a diagnosis was causing pain. They saw a behavior, saw that it may be caused by pain, treated the pain, and watched a baby become a baby, smiling and laughing instead of crying in pain. Our pain and palliative physician was the second member of Team Deacon. During that stay, Deacon started pain medication and learned to sit up. He began to babble and smile.

Deacon would continue to be in and out of the hospital for the following year. I felt like just as we would get him feeling better, he would be sick again. Each body system was so intertwined with the next that we always needed multiple clinicians to help each time. That was no easy task, and they rarely agreed on the best approach; what was suitable for gastroenterology wasn't always what pulmonology thought was best. We continued to be thankful for pain and palliative as they always looked at Deacon's comfort first and everything else second.

That year Deacon received a heartbreaking diagnosis, visceral hyperalgesia, meaning high pain in the visceral muscles. For Deacon, this meant food caused him pain. We would try to increase the amount he could get via his feeding tube and he would soon be screaming in pain. This is not a diagnosis that could be tested for, rather it is a diagnosis of exclusion after many other diagnoses are ruled out. It is a diagnosis with no cure. There are treatment options, but they do not always work. This pain led to other behaviors: head banging started at about nine months, throwing, hitting, and intense episodes of anger, screaming, and being inconsolable. Being nonverbal at the time, it was impossible to know what behaviors were from pain, developmental delay, or otherwise motivated. Each clinician we sought help from had a different answer. However, we knew Deacon was much calmer when we treated for pain or turned off his feeding tube.

We found two new clinicians that joined Team Deacon. A neurologist who focused on thinking outside the box and maximizing quality of life, and a physical medicine and rehabilitation physician with much the same goals. They were both recommended because they did well with kids who didn't fit into the box; kids like Deacon James whose symptoms presented differently than expected. These clinicians, along with our pain and palliative care physician, helped keep him comfortable and thriving when he was well throughout the year.

We took every moment that we could and enjoyed it. This meant that even though it is a great amount of work and planning we didn't just stay home. We went to plays, museums, the library, parks, and traveled. We brought Deacon James to the ocean! Each and every outing out of the house requires careful planning with medications, feeding pumps and formula, oxygen tanks, and so much more. We found so much joy in experiencing the world with him; we never said that we couldn't do something; we figured out how to do something but most of all we held on to hope.

We saw how happy our son could be when he was comfortable. He was still developing and working on meeting goals. Feeding was still a challenge, we learned that we had to go at Deacon's pace, and sometimes that is hardly any food at all. We still keep trying and helping him by decreasing the feeding rate, tweaking medications, and other things to help keep him comfortable. Through this he learned to crawl at 10 months and was walking at 15 months. He couldn't talk yet, but he made sounds and had a few signs to communicate. He developed a personality; he was (and still is!) a momma's boy. Deacon still loves to be held close and to be near mom.

Throughout that year we would battle periods of intense rage and behaviors. We were referred to therapists, psychiatrists, and play specialists. The Team Deacon clinicians thought this was all pain, but his other careproviders were not convinced. They wanted to make sure it wasn't something else. They worried we were treating mental health or behavioral issue with pain medications.

At 18 months we faced our largest battle. Deacon James developed pancreatitis. He was in so much pain and misery. He would scream for hours, lay on the floor listless, and was not tolerating any amount of formula through his feeding tube. He was admitted to the hospital and stayed for just over a week. They gave pain medication and intravenous fluids, allowing his body to rest and heal. He wasn't entirely better when we were discharged home. Less than a week later, we were back. Deacon James had not made any further improvement. He was still in pain; he would bang his head, pull his hair out, pull mom's hair, and grab her face. He would cry and cry. No playing or smiling, just miserable. He was admitted again, and this time the clinicians were much different. These were doctors we had seen before and it was clear they were not on Team Deacon.

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There was not a clear plan of care. There were discussions of discharge almost immediately at a time when he could not get any nutrition and was miserable. The clinicians saw a child needing too much pain medication and felt this was unethical as we were told, "you cannot give so much medication that he is sedated to give nutrition." We were also told we were "between a rock and a hard place." We disagreed with the new plan of care, which was no care. We often had to beg for pain medication and struggled to keep our son comfortable.

The clinical team's recommendation was for him to go home and only feed him as he tolerated it. We felt that this would quickly lead to death, as he wasn't even tolerating any formula or fluids at that time. They denied that this would be killing our son. They denied they were placing him on hospice. No one would admit they were giving up on our son. It felt like they were giving up because there was not a clear way to help him feel better.

We asked for an ethics consult and were dismissed; the doctor told us that ethics was inappropriate in this situation. We have since learned this is precisely the type of situation ethics is suitable for. We were denied our Team Deacon clinicians to be called in to consult. We were told we were out of options and that it was best just to let him be comfortable. We knew that wasn't true. There had to be a way to keep him comfortable while he healed from this infection. He needed time. We begged for more time. We pushed for a more extended recovery period, asked for total parenteral nutrition (TPN—feeding that bypasses the gastrointestinal tract), and just kept getting denied. Gastroenterology agreed to try a new formula, but were clear that this was not a great option, and they did not think it would make a difference. The clinicians told us that they wanted a care conference after the weekend and that they would make a plan for our son's future. It was not said but implied that we would be discharged whether we liked it or not and that our son would not be with us much longer.

We then reached out to social media to ask for support and prayers. We shared that we felt our son was dying and we desperately needed help. We received a miracle, and we know that many people worldwide prayed for our son. Over that weekend, we had different clinicians who hadn't seen our son's behaviors. They could read the notes, but at this point our son was starting to calm down and had more periods of comfort. He stopped crying on Saturday, and on Sunday he played for the first time in weeks. Each day we added slightly more formula and he could tolerate it at a very slow rate.

On Monday, a new team arrived, and they didn't understand the need for the care conference. Then, a member of our team who had been with us the whole stay came in. She was shocked at his improvement and agreed to move the care conference, stating that she thought it would go much differently now. The next day we had his care conference, and most members were new to his team that week. They were hopeful and helped to make a recovery plan. One team member there said she was glad he turned a corner, and that they could give us hope. This stay left us so raw as parents; we had to fight for the clinicians to see value in our son's life, which hurt. We felt like he wasn't valued as much because he was disabled, with difficult behaviors and delayed communication skills that made it difficult to understand what was wrong.

Deacon recovered from his pancreatitis, but it took close to another year before he would gain the weight he had lost during that month. He is now six and still medically complex. He continues to have pain with eating, and we still work to find ways to provide him comfort. He remains on oxygen and has a feeding tube. He can eat orally, not enough to sustain growth, but enough to enjoy food. He loves mud and water fights, camping, and playing Paw Patrol. He can memorize a book after hearing it read once and then play out the stories repeatedly. He is bright, and despite his obstacles, he continues to grow, learn, and love life to the fullest.

I wish that was the last time we would experience differences in care for our son because of his disabilities, but we see it often from lab techs to physicians. Clinicians who do not talk to our son do not look at him and just talk to us. When my other kids have had medical procedures, we have had child life specialists, and so much care taken so that they experienced as little trauma as possible. These comforts, dignity, and respect are just given. For Deacon, we have to ask to make sure that clinicians ask him, "see" him. We model this by repeating what the careprovider said to us back to our son—we want to take every chance to give him chances to speak and participate in his treatment.

Sadly, our most vulnerable kids often experience medical trauma after medical trauma, and do not get the same dignity, compassion, and care as their noncomplex peers; and as a result they receive a worse quality of care. All kids deserve comfort, dignity, and hope. Deacon's life matters, even though it may look different from that of his peers. I can understand how the clinicians would just see Deacon's suffering at that moment and focus only on his comfort. I hope that one day, clinicians can see beyond immediate suffering into the future and find hope. This experience has led us to hesitate to seek help, fearful that our son will not be seen or valued by his care team, and I do not wish that fear on any parent.