

House on Bear Paw Lane

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As I am writing, I have realized that the turmoil of emotions that I have described coming about from anticipating an upcoming celebration is a constant in my day to day life. Somehow, I have learned to live with it and push it aside in order to get through the day. Special occasions, holidays and milestones tend to amplify the feelings that are always present to the point that it is hard not to be overcome by them. Each day with William is an absolute blessing. At the same time, each moment tears at my heart because I know I will never have enough time with him on earth with me. A Mom “fixes” things, and this is something that I cannot “fix.” It is heartbreaking.
-Oralea M.

As I drove up to the gate to punch in the entrance code, I thought about the nice neighborhood with beautiful houses. The gate opened, and I drove around trying to find the address on Bear Paw Lane. I also thought the streets had cute names. I turned into the driveway and scoped out the house for a few seconds. It was very well landscaped with a three car garage and beautiful flowers everywhere. Any unknowing stranger would think that the family who lives in this house must really put a lot of work into it and be well off. Little would they know that the family living in this house has suffered for so many years with a heavy heart that no regular person could ever fathom.

On my first visit to William’s house, I was greeted at the door by a friendly woman with a warm smile on her face. She introduced herself to me as William’s mother, Oralea. She was so glad to have another medical student caring for her son. I immediately noticed her accent and asked her where she was from. She stated that she and her husband were both from Quebec, Canada, but had been living in the states for 13 years. As I walked through their house, just taking it all in, my senses were working overtime. I could hear an unfamiliar loud noise coming from the back. I could smell bleach throughout the house like someone had just finished cleaning. I could see a little munchkin crawling on the ground. He was William’s 11-month-old brother. I continued on to the family room in the back of the house where I saw something unlike anything I had ever seen before. There was

a hospital bed in the middle of the family room and in it lay a small boy in the post-ictal state. Before I realized I was staring at him, William’s mom said, “Let me tell you about my angel.”

I soon learned that William had a rare lysosomal storage disease that was diagnosed when he was 13-months-old. Oralea first began to notice that something just wasn’t right when he was 9-months-old and began losing some of his previously achieved developmental milestones. He was taken to the pediatrician who initially thought that maybe he was just developmentally delayed, but when things got worse he was sent to many specialists. Finally, right after his first birthday, his parents got the dreaded call from a geneticist at Miami

Children’s Hospital who stated, “We found out what is wrong with your son; how soon can you come in?”

William was put into hospice care at the tender age of two; when I met him he had recently celebrated his fifth birthday. As we sat down and went through the entire history and circumstances around his diagnosis, William’s mom constantly had to run by his bedside or tend to his 11-month-old brother. Observing her suctioning, repositioning, or running behind an 11-month-old, I immediately thought to myself, “How does she do it all by herself every day?” When we

finished the discussion, I was hesitant to do a physical exam. I was used to 5-year-olds asking me if they could hold my stethoscope or if they were going to get any shots today. Some of those kids were even excited to tell me about their best friends in kindergarten. I was not used to a 5-year-old that would never be able to do any of those things.

As I began my physical with the help of my attending guiding me through it, I saw before me a young boy who barely had his eyes open. I thought to myself, “Can he hear me? Can he see me? Does he feel me touching him?” All these thoughts bombarded my head, and I spaced out for a few seconds. However, I was immediately brought back to reality as William began to make a loud moan, shake for a brief moment, and then pass out. I jumped back and immediately looked to his mother for any reaction. There was none. His

mother nonchalantly stated that it was one of his seizures, one of 10 to 15 that he had per day. She was not worried; however, witnessing my first seizure was terrifying—that it was in a 5-year-old made it even worse.

I followed William throughout the year with weekly updates on a blog that his mother had created for parents of children with similar diseases. I felt her pain and could feel her tears of sadness when she blogged about the first day back to school from summer break. That day would have been the start of kindergarten for William, so his mother blogged, “How I wish I could see William with his little uniform and Spongebob backpack on, walking in and meeting his teacher for the first time.” She was saddened that he could not attend but rejoiced in the fact that he was still here with her fighting his disease. Throughout the year, we had a few scares from serious upper respiratory infections to aspiration pneumonia. Some of these scares were intense to the point where we thought William probably would not make it through. William amazed us each time and had continued to fight.

On my last visit with William, I again pulled up to his house and embraced the beautiful landscaping I saw before me. Oralea greeted me at the door, and we sat at the kitchen table to go over everything that had happened this year. My attending and I had discussed a new program in the area known as the Prescribed Pediatric Extended Care (PPEC) program. PPEC was a non-residential health care center designed for children with terminal or medically-complex illnesses that require continuous therapeutic or skilled nursing supervision. We were going to talk with Oralea about the program as a means for her to have some form of respite care for William during the day. Oralea to me was a machine that never needed a tune up. She was with William throughout the entire day and only received help at night when a hospice nurse would give her time off during the night to sleep. She had learned to live with William’s illness and saw him as a blessing that has only made her into a stronger person.

As we began the discussion about the PPEC program, Oralea immediately began to cry. I sat and waited for a moment, and I could feel the tears welling up in my own eyes. I was sort of shocked that this discussion made her so emotional since I had never seen her cry before. After we comforted her, we discussed why this made her so emotional. Oralea explained that she knew William did not have much time left; she could feel it. She wanted to be with her angel all the time because if the moment ever came when he would take his last breath on earth, she would never be able to forgive herself

if she were not there. At that point I knew Oralea understood the extent of William’s disease and she was preparing herself for “the moment.”

Oralea stated that she spent all of her life looking for meaning and purpose, and she finally found it when she had her first child, William’s older sister. She knew that life at that point would be all about her family. When William was diagnosed with GM1, her meaning and purpose in life made even more sense to her. I was taken aback by William and Oralea. They have touched me in ways that no other patient has thus far.

Last Friday, Oralea made an update on William’s blog: “Tomorrow, William will be 5 years, 10-months-old! I can’t believe it! It is also hard to believe that his 6th birthday is approaching. I am starting to think about how to celebrate his big day with cautious hope that he will be here to celebrate it with us. William has been doing really good lately, but from past experiences, we know all too well that things can turn on a dime and change so very quickly. It is hard for me to plan 24 hours ahead let alone 2 months. Yet here I am thinking of the best way to honor my beautiful son and the milestone he is about to reach—one that we never thought we would be able to see...”



Yaowaree Leavell