

Until You Walk in My Shoes – The Story: My Child with Prader-Willi Syndrome **by Julie Sutton**

Jasmine Andre' Sutton (Jazzy) was born on January 17, 1990, at Miami Valley Hospital in Dayton, Ohio to proud parents, Darrell and Julie. Jazzy was a beautiful baby. But, right after birth, she started having complications and had to be rushed to the Intensive Care Unit. She was there for one week. She weighed, about 5lbs, was pale, had very low muscle tone and did not cry much. Because she had no sucking reflex, she was fed with a tube and had to be taught how to use a bottle.

Jazzy was my second child, so I could tell there was something seriously wrong. The doctors ran many tests. We waited patiently for a diagnosis, but none came. I was really concerned and worried about my baby girl....will she be okay, will she live, and will she be disabled? I had all sorts of thoughts. When I finally was allowed to hold her, I cried. I had prayed for that moment to comfort her and let her know that Mommy was there and that everything was going to be alright. But that wasn't the case. The doctors still didn't have an answer for us, only that she had a floppy/froggy baby like syndrome with very weak muscle tone, a weak cry and no sucking reflex. When she finally was released from the hospital, she still wouldn't eat much, or hold up her head. I had to constantly check on her because she hardly ever cried, and when she did I could barely hear her. We saw many specialists looking for an answer.

I have a lot of cousins with children, so they knew something was terribly wrong. My strong faith-based family was deeply concerned and immediately started praying for our little Jazzy.

Jazzy was small for her age, and due to her low muscle tone she didn't crawl and even had difficulty sitting in a highchair, so I held her constantly. Then at 3 or 4 years of age she started progressing, walking, and trying to communicate with us. It was hard to understand her, so we took some sign language classes to help her communicate. Since she was delayed for her age, she attended special needs classes. But she was always a happy child. She loved animals and baby dolls. She was too weak and uncoordinated to pedal a big wheel or bike. She worked puzzles, colored and played with her baby dolls, dressing them and doing their hair. She loved playing tea and looking at books with her older sister.

In elementary school she loved pushing her classmates that were in wheelchairs and helping the teachers feed them. The teachers always praised Jazzy as being the helper of the class. Then she started asking for more food, getting up in the middle of the night to eat and hiding food in her book bag, dresser drawers under her bed and even in her toy box and under the sink.

Her condition and constant craving for food took a toll on our marriage. My husband couldn't handle Jazzy's condition, so he worked all the time. This left me alone to take care of the girls. Then he started saying that the doctors didn't know what they were talking about. I believe this was caused by the feeling that he didn't have a perfect child. In 1996 we separated and divorced. So I then became working mom raising my girls alone. But I didn't stop researching and working with the doctors to find out what was wrong with my child.

By Junior High Jazzy weighed about 200lbs. She was 4'9", so you can imagine how she felt being so overweight. I met with her teachers to make sure they worked with me for a special diet and that they would not give her extra food. She knew how to convince the other kids to trade candy or chips for her fruit items. Although Jazzy was in special needs classes, she still had to walk to different classrooms for some of her classes. It was difficult for her to walk and to keep up with her classmates. She would be out of breath. So they often made fun of her.

Then one evening she passed out in my bathroom. I was so scared. The doctors said it was her heart. It couldn't handle the excess weight and we had to get her some help immediately. We had an appointment to see Dr. Zipf and he struggled with the insurance company. But, due to her condition and her heart, she was approved for specialized short-term treatment for Prader-Willi Syndrome at the Children's Institute in Pittsburgh PA.

I had to sneak and to pack her a bag. But I had to do this to save her life. I took her to the Children's Institute in May of 2004. She was there for 2 months. She lost 60lbs. Upon her release and return home, we

registered with the Children's Medical Center Body Shop Program in Dayton Ohio to help her lose more weight and to work on a weight maintenance program . We did that for several months. However, once she started back to school and was around some of her friends and family, she slowly started regaining her weight. Then the nightmare started again: she was hiding, stealing, and begging for food. But she couldn't help herself. We were back on the roller coaster ride with her weight.

In March of 2007, Jazzy received an Intermediate Care Facility MR Waiver and was admitted to the Trinity Mission Residential Group Home, now called Foundations. At 335 pounds she was morbidly obese. And she was borderline diabetic and had other complications. This was the hardest decision I ever had to make, to place my beautiful child in a group home. I cried and felt so guilty. I thought I had let her down. However, I knew this was needed to save her life again. It has now been 2 years. I am so proud of her because she has lost 125 pounds and continues to lose 1-2 pounds per week. She loves the new Jazzy. Now, when she comes home on weekend visits, we're given her menu plan, and she knows the rules. She's only allowed to have what's on the list for her meals and snacks, no exceptions! She knows not to ask neighbors for food and not to ask at the store. She knows we must pay close attention to the calories and portion control.

It is April of 2009. I give praises and thanks to God because He answered our prayers. I prayed and asked for help and He brought me the help I needed to save my beautiful daughter's life. He brought me the right people: MRDD, the doctors, nursing staff, and most importantly wonderful support groups, PWSA(USA) and PWSA of Ohio. I personally want to give a special thank you to Dr. Zipf and his nursing staff and to Sandy Giusti for the knowledge about PWS and the love and support they gave me during those trying times. I could not have made it without the love and prayers of my family, my church family, and my close friends. So I thank them from the bottom of my heart.

After going through this experience my advice to parents with children with PWS or other disabilities: No one can understand what you go through with a child with a disability until he walks in your shoes. Remember, "You'll Never Walk Alone". Take time to pray and ask for help. He will provide. And there are support groups to help and to provide the services needed. Just ask and you will receive.

Jazzy and I love all of you. I will keep PWSA of Ohio and PWSA(USA) informed of Jazzy's progress.

God loves you!

Julie Sutton