

Good (morning/afternoon, depending on the time of day). My name is Alma Burt, and I appreciate the opportunity to get to share my family's story with you and hopefully shed some light for you on the challenges that many families around the state of Ohio face every day.

Normally, I get nervous speaking in public, but today is an exception. Today, I have the opportunity to represent my daughter Abby and be her voice along with the hundreds other individuals like her who don't have that ability or have this chance.

My daughter Abigail Burt was born on March 17<sup>th</sup> 1997 with multiple facial abnormalities. She was like a mixed up puzzle, all her pieces out of place. She had no eyelids and had a bilateral cleft lip and palate. Of course, I hadn't even heard of this, so I was clueless on what it meant. All I know that is I got the chance to spend about ten minutes with her before they took her away from me and send her to Cincinnati Children's Hospital for intensive tests. My husband Michael went with her. I was left alone with my thoughts of why this happened and the devastation I knew was ahead of Abby and our new family.

Our world was turned upside down when the doctors gave us “No Hope” in regard to Abby’s condition. I suspect that this is normal with cases like ours with so many unknowns. They told us Abby would be blind, deaf, mute, nonverbal and also would never walk. The genetics specialists told us that there was only four other cases in the world like her. They diagnosed her with the condition: Frontofacialnasodysplasia. Basically that term means the front of the face was displaced. (I could have told them that). Knowing the name of her condition was all well and good, but we had many questions that were much larger and more important to us. What would her future be? What was ahead of her?

They also told us she had a marker on a chromosome that affected one third of her cells and that our chances of having other children without a condition like this would be 1 out of 4. It was pretty overwhelming, because really that told us nothing. Only time would tell Abby’s future.

Abby endured several surgeries in her very early life to create functional eyelids. We felt that saving her vision was top priority to give her a chance since her hearing tests showed her as a moderate to severe hearing deficit in both ears. She also ended up having reflux due to her stomach not emptying fast enough and

even discovered she had many food allergies including milk, eggs, malt, barley, peanut, meat, and wheat. Due to food limitations and her cleft palate and other GI problems, Abby became “failure to thrive”. This resulted in a g-tube being placed. Of course with any procedures, Abby always is the 1% chance it will never happen...it always happens to her. (True Story).

As time went on Abby started to amaze us with her abilities even though her odds were against her. She began to crawl, walk, run and climb. She is considered legally blind and had hearing loss but could still hear to understand. She followed two directional commands and responded correctly. She is a smart but still struggles to communicate. She did, however, know some sign language I had taught her. She was potty trained with some accidents and at that point, was doing pretty well for the most part.

The doctors diagnosed her severely mentally disabled which I completely refused to believe. She had autistic tendencies but because of her hearing and visual loss, they couldn't test her, but it was obvious that all the characteristics were there. With all this one would think life would get easier. One thing I have learned about children with multiple handicaps is that the obstacles are real and that NOTHING is ever easy. School was another challenge

for Abby and our family. Working under the umbrella of her IEP, it was a serious and constant struggle to make sure that Abby got her needs met in terms of her education. We had to constantly push back and advocate for what we thought our daughter needed in school. She really didn't fit anywhere. She didn't belong in a deaf school or a blind school. She related mostly with autistic children with the exception of medical issues and the safety issue with her vision. We achieved her education needs with hard work and persistence but not without a fight.

We grew to cope with our situation at this point and thought things were doing well. We decided to have other children. Life was beginning to get some sense of normal. We had nurses coming to our home for couple hours a day to help give us a needed break. I started nursing school. Things were normal for our semi-normal life. Then things changed again. Just like a tornado sneaks in surprise so does complications with Abby. Abigail's personality changed. She started to pull her hair out, tear off her fingernails, hit her head on walls and floor. Before this she had never attempted to touch her g-tube, but now she wanted to pull it out.

After calling the doctors, they said it was probably puberty. We would take her to the hospital. She would be put in restraints and

even put in the psychiatric unit. After five years of struggling with her behaviors and knowing something was seriously wrong, a new doctor saw Abby and took started treating her. We were sent to the colon rectal team, which we never knew existed. We discovered that Abigail's behavior was all linked to her inability to communicate that she was in tremendous abdominal pain.

Through this treatment, we learned that her bowel was extremely enlarged. It soon perforated almost killing her with infection in her blood. Many surgeries later Abigail endured a colostomy to an ileostomy bag. Over time her entire colon was removed and even had a number of surgeries into her small intestine. Like I said earlier, Abigail is that 1% it will never happen.

With all her surgeries and intense medical needs, we now needed intensive care around the clock and could not get approved or have the guarantee nurses could be staffed in our home. So, after years of debate, my husband and I decided that the best course of action for Abby and our entire family was to place Abby into a facility where her needs could be met. We were convinced, with heavy hearts, that this decision would be the best thing for our daughter. But, we've learned the hard way, anything related to multiple handicap becomes a fight to get what you need. To be placed, her being non-mobile would be required. The problem is that she

walks. The facility would take individuals who could walk but not ones with behavior issues. The facility would take individuals with behavior issues but not ones with medical issues. In other words, no facility would take Abigail due to her extreme case.

Abby lived in the hospital for over a year due to these issues. She was turned down by sixty eight different facilities. Even the home she lives in today turned her down initially until they met her in the hospital and realized she was a wonderful person with great personality. So, today she resides in Brookside facility with staff that loves her and a family that visits her often. Brookside helped us connect with a company that helped us secure funding to buy her a \$4,000 bike that she loves to ride. She loves walking down the long hallways at Brookside which she couldn't do at home. She helps with laundry and assists putting her clothes away. She even watches and listens to TV now which she never did at home. This is her home. It took us over a year to give Abby a chance. This was the best thing for her and for us.

Please don't take her home and family that she lives with away. She does better at Brookside that she ever did at home. She is grown up now he and even though she enjoys visiting us at home, she is always ready by 8pm to go back to Brookside with a smile

on her face. DO NOT TAKE THIS AWAY from her. Hasn't she been through enough? Abby, as it is with so many others like her around the state of Ohio, are thriving in these facilities and have gotten the chance to make a home in places where their needs are met and where they are treated with love and respect. Isn't that what life is all about?

Again, thank you for the opportunity to share Abby's story with you. She is a special young woman, and I am happy to have had to chance to speak on her behalf today.