

Hoe Tom Bo's Story

"Our house is located in a small village in Vietnam, where the climate is tropical and the locals are friendly. On a rainy day in August 2019 at a small hospital, our family welcomed a little angel. She was pretty, small and adorable little girl. The arrival of a new member of our family filled us with excitement.

At first, she was thrilled, but within two weeks, she was wheezing more, having breathing problems, and making a sound that resembled a meowing cat when she breathed. Her baby's feeding became difficult as well, as she was unable to breastfeed and had to feed from a bottle, and she vomited milk continuously after each feeding. On September 5, she was hospitalized with severe pneumonia and a few days later was transferred to the intensive care unit, where she had to breathe oxygen and had a nasogastric tube to pump milk. But the worst was still to come: she was diagnosed with Pierre Robin syndrome, something I had never heard of before. After three months of hospital treatment, the doctors were very inquisitive and asked a lot of questions about her condition. They said she had too many problems: her eyes did not reflect light, she did not blink or move her pupils; her chin was small, her tongue was short and rough, with the right side thicker than usual. Her throat was ultrasounded and found to have a narrowing, which caused difficulty eating. Her chest was concave, and the doctor suspected she might have a congenital heart disease, but fortunately she was not. Those days were extremely difficult for us. Every day we were to see her suffer from disease, and we could only pray to God to heal and strengthen her. After a long-term period of treatment and numerous tests and CT scans, the doctors ultimately determined that she had Pierre Robin syndrome. I still remember very clearly the doctor's instructions to take care of her, especially when she was asleep, because she could stop breathing at any moment. That is why she has always been placed on her left side to facilitate her breathing.

On November 20, we were released from the hospital and the next morning we were home to our eldest son, who was six years old. Joy and happiness broke out in tears because now our entire family was back together. As she continued to wheeze and spit up milk, the days that followed were not easy either. However, little by little her condition improved greatly, but what disturbed me the most was why she still had not smiled. Many times I searched for information on people with Pierre Robin syndrome and I found them still smiling, again showing emotions on their faces. I comforted myself that maybe it was because she hadn't fully developed yet, and maybe when she got older, her emotions would adjust and stabilize, and then she would smile like any other child. She had her first birthday, but she couldn't sit up on her own until two months later. She always put in a lot of effort to train, and once she was able to sit, she switched to crawling. After a long time, she finally crawled, and she met expectations and efforts every day until she was 20 months old and took her first steps at the age of 2. I felt so happy that I couldn't speak. When she was two and a half years old, she first began practicing speaking and calling Mum and Dad. As time passes, she can speak words and short sentences, and start to practice asking questions and finding answers. But I found out that she couldn't say words that started with the sounds 'm', 'b', 'r', and 'l', and words that ended in 'p' also made it difficult for her to speak. I reassured myself that maybe she would improve as she grew up, but it has remained the same. While we understand her words, it can be challenging for others to understand her

meaning, and it's frequently difficult for me to articulate her point. Despite being nearly four years old, she still experiences pain from eating and drinking due to her weak jaw muscles, which also hinder her ability to chew and swallow. Using a straw and blowing out a candle was too difficult for her, which she couldn't do, despite being able to do so.

But what I want most of all is to see the bright smile on my child's face. I often tell my child that she will be able to smile when she grows up. I am always curious about if there are any others like her and what exactly is her illness and how she is different from others? I searched, but I couldn't find anything. However, one day I searched on Google with the keyword "Who can't smile in the world" and I was completely amazed to find the life story of a New Zealand girl with the name "the girl who can't smile in the world." Reading through all the lines of her life, I learned she had Moebius syndrome. I cried because I couldn't keep a negative thought from happening because she had surgery to recover her smile, but couldn't. I read through every article on Moebius syndrome, without missing a word. When I looked at my baby daughter, that was exactly who she was. Her eyes were unable to blink, her pupils were unable to move from left to right, and her facial muscles were not showing any emotion. The face was always the same, regardless of her emotions, whether happy, sad, or angry. The truth is, she won't be able to smile like I'd expected for the sake of her own well-being. I had been convinced that my child had Pierre Robin for almost four years, but it was not the case. Only today had I found out that my daughter's real illness was "Moebius Syndrome," a rare syndrome, and the patient would live with that expressionless face for the rest of her life. From that moment on, I knew my child was not alone or lost, because there are a lot of people like her who understand and empathize. Then I tried to find a community of people with Moebius and, thankfully, three days later, I found and joined the Moebius community. The feeling I felt that moment was so overwhelming, bursting with happiness, as I had found a second home. The stories and lives of people with Moebius all over the world gave me a sense of peace and inspiration, and I felt comforted and encouraged by them. I showed her the friends in that group and told her she wasn't alone; look at this world, there are still many people like her who are inspiring and positive, and who spread love to everyone. Maybe the people who met her for the first time only considered her small, naive and weak. On the other hand, she had an inner girl who was active, happy, loved, and adventurous. She had a passion for dancing to the music, humming to the songs, painting, enjoying outdoor activities, and going out and playing with her friends.

From now on, I will try to make her realize and accept her own differences; that she was made special, that she doesn't have to be like everyone else but just be herself. Each person has their own unique special something. Although I know that the road ahead will not be easy, I believe that with the love and companionship of our family, as well as the advice and sharing of the Moebius community, she will confidently be herself to confront and overcome challenges in life. Because I believe in 'real smiles and joy from the heart.'"