The Smile That Changed My Life

by Kara “Sunshine” James

My name is Kara DeLynn “Sunshine” James, and I was born in 1982 with Moebius Syndrome and Poland Syndrome. I would like to share my story with you.

At 2 years old, I was soon to be adopted by Buck and Norma James. Prior to my adoption, they were told that I would be intellectually and developmentally disabled. Despite the news of my impairments, Buck and Norma still adopted me and raised me with love and kindness; this is where my journey begins. I was born the youngest of four children, I have an older brother, John, and two older sisters, Tiffany and Cerina. Our birth parents were unable to take care of us and so we were eventually put up for adoption. While we waited to be adopted, we spent time in numerous foster homes--some of which were not so kind to us. We were finally placed into a home that was willing to adopt my three siblings, but not me, for fear I would require too much care. John, the oldest of my siblings, told the caseworker that he didn't want any of us to be separated, especially the two of us, because we share the same birthday, and I was his birthday present. Everyone honored John’s request and we went back into foster homes. God finally blessed us with a loving home; the James family. Cerina and I were adopted by the James family, and John and my sister, Tiffany, were adopted by the Bates family. While we never wanted to be split up, we were all satisfied with the new families. The James’ and the Bates’ are cousins, so even though we were not going to be living in the same house, we would still be in the same family. This new family arrangement made us not only siblings, but cousins as well. Tiffany and John were adopted into a family without other children. When the James family adopted us, they were already a family of 6, and all children had been adopted. God had already blessed me with siblings that loved me and, I loved them. When the James’ adopted Cerina and I, we were blessed with an entirely new family. While the James’ knew that I was going to have challenges in life, they willingly took me into their home and made me a part of their family. I am so blessed to call them my parents. Mom and Dad spent many hours making long trips to Dallas and other cities in Texas to get the medical attention I needed. There were surgeries, and time spent in hospitals and hotels as I went through various treatments and recoveries, along with hotel stays in order to visit doctors in the hopes they would be able to help as well. Mom and Dad spent countless hours working with me, and helped me to learn to do everyday things like tying my shoes and buttoning by clothes. My parents are the backbone of our family and I am where I am today because of the love, support, and encouragement they have continually given me. I cannot stress how much children need their parents--someone to stand up and fight for them, disabled or not. If it was not for my parents I would not be the person I am today. I would not be a strong-willed, God-fearing person - knowing that I was put on this earth for a reason. They taught me how to believe in myself, to love myself how God made me, to stand strong in any battle life brings my way. God gifted me with parents that could and would love me unconditionally.

Living with Mobius Syndrome was very difficult. I was ridiculed and had hardly any friends. Because I had no facial expressions, everyone thought I was mad all the time. My family members were the only people that could identify my emotions. At times I just wanted to hide from everyone because no one ever understood me. I felt like I was all alone in this world. None of my biological family have any kind of birth defect. As a child, it was very difficult for me to understand why I was so different from everyone else. All I wanted was for someone outside of my family to notice me for who I was and not for how I looked. I used to be made fun of all the time. I have been told that I was a curse. Students and teachers told me that I would never be like the normal kids. The thing that I hated the most in school was picture day. Every year from pre-K through 8th grade all students would stand in a line and wait for the picture guy to say, “next”. When it was my turn, I would go up to sit on a stool and we had the following conversation.
Photographer - “Smile”.
Me - “I can’t smile”
Photographer - “Oh, come on. You can smile.”
Me - “I can't smile”. He would continue to pressure me to smile until I finished the conversation by saying very firmly, “I can't smile.” Every year the students standing behind me would laugh at me. On those day I would go home upset and angry, because I could not smile, I was so different from everyone else, and my whole class laughed at me. I remember I use to dream of smiling. Everyday I would put my fingers at the corner of my mouth and push up just to see what I would look like with a smile. My family, church family, friends and I prayed everyday for years that God would give me a smile. When I entered school at the age of 4, I was automatically placed in the self-contained unit for students with multiple disabilities. Yes, I have a disability but I was not disabled or slow. I felt so out of place. I was not learning anything and I fell further and further behind in the education I was suppose to be getting. I began to tell my parents that I was not happy in those classes. My parents talked to teachers, school board members, anyone who knew anything about education trying to get me out of the self-contained unit. The teacher explained that I simply have to stay in those classes because there was no place for someone with my disabilities in a regular classroom. Despite our efforts, I was kept in a self-contained

room without being tested for ability or I.Q. Because of the way I looked and talked, the education system just assumed that I would never be able to learn anything and I would be best served in a self-contained unit. They took one look at me and decided that my brain would not work. After ARD meeting upon ARD meeting, no one would listen to my parents. After a family meeting, my oldest brother Kyle and his wife, Kathy (a 6th grade teacher at the time), went to the school with my parents and demanded that I be tested. They had to threaten the school to get results that would ensure that I would get the education I deserved. At that time in my life when I could not stand up for myself, my family took a stand for me. Well, as you can guess, I got to take the test, and I tested out of the self-contained unit. I was in the fifth grade before I was allowed to attend a general population classroom.

One day when I was 13 years old, my mother and I were watching the Oprah show when a young girl named Chelsea Thomas, came on talking about the miraculous surgery she had. This surgery gave her the smile that she was not born with. She had Möbius syndrome like me. Until that day, I had never seen anyone with Mobius syndrome. The idea that this type of surgery could take place was like God handing a miracle to me on a golden platter. A new journey began -- a journey and miracle that would change my life forever. I will never forget that day, 20 years ago, when I found out about the surgery. Within 20 minutes after the show aired, my dad called the contact number to a large baptist church, who gave him Chelsea's parents number. Her parents shared Dr. Zuker's contact information. Dad called Dr. Zuker and had a lengthy conversation about this miracle surgery for me. Before we could schedule the surgery, Dr. Zuker and his team had to decide if I was a good candidate for it. We had to make a video of me talking and reading. Pictures were taken of me from all angles and sent to Dr. Zuker. Now all that was left was the praying and waiting. I was so excited when Dr. Zuker said I was a perfect candidate. I can not express the emotions that I felt. God answered my prayers in his time. Fourteen years of my life, I waited, hoped, and prayed... I could not believe it! But there was another obstacle in achieving my life's dream -- the cost of the surgery. I was on Medicaid at the time. When my parents presented the surgery to Medicaid, we were denied approval because it was not life threatening. But in a way, for me, it was. How could they deny me my miracle? I could not believe that they would not pay. As usual, my dad and mom were going to make a way, find a way, do anything possible to help me. They took me off Medicaid and put me on my dad's insurance, which was Goodyear's insurance. My dad, as a supervisor of the tire proving grounds, was well respected. When my dad asked for approval from his insurance to cover the surgery, the company picked me up and offered to pay for the whole surgery, almost 48,000 thousand dollars, when it was all said and done. Our church family and my parents split the cost of airfare, hotels, meals and other travel expenses, for us to be able to make the trip to Canada twice. After finances were arranged and it was a go for the the surgery, all I had to do was wait for a year. That year I was told not to drink or eat anything with caffeine. Let me tell you, that was so difficult because I love cokes and chocolate.

The day we left for Canada for the first surgery, the feeling was so surreal. It's finally happening! I'd been waiting for this my whole life. The first trip to Canada it was snowing a lot. For this Texas girl that was an adventure. I had never seen that much snow on the ground, blankets of pure white snow. As we landed, I remember thinking to myself, this is totally God with us in everything. If it was not for me being adopted into my family, I probably would never be standing in this beautiful country, waiting to undergo the biggest surgery of my life. We went to the Hospital for Sick Children in Toronto, Ontario, Canada, where we met with Doctor Zuker. He explained that the surgery would take 12 hours or more and they would be taking the inner thigh muscle and placing it in my face. He also explained how they were going to hook the nerves in my brain up to the muscle that would cause my smile to happen. Dr. Zuker went step by step with me and my parents through the whole process of the surgery and what to expect after surgery. When surgery day came I remember walking into the hospital and being so cold. I always get very cold when I know I am going into surgery. As we were in the waiting room, all emotions were going through me, joy, thankfulness, anxiety, and fear. But I kept it inside, I did not want my parents to see me cry, I did not want them to worry, I wanted them to see that I was strong. When it came time to go into surgery, a pregnant nurse walked me down this long hallway. As we got away from my parents, I remember crying. I started telling the nurse I wanted to go back to my parents, I was so scared. The nurse looked at me and said, "Kara, you came all the way up here to have this surgery, something that you have wanted for a long time. You have to face your fears." I remember thinking, "Man, she is hormonal." Instead of babying me, she basically told me, "suck it up". I don't think I ever told anyone that but it really made a lasting impression on me, she was right. I had taken a long journey to get to this point and needed to move forward.

After surgery, I woke up in the recovery room, I saw my parents and Dr. Zuker standing over me. The next few days, I had to lay flat on my back; then I slowly began to get up and walk. The day came when we got to go home. I was so excited to go home and show everyone my new smile. Before I could do that though, I had to wait for 6 weeks. After the 6 weeks I would see the first twitch, and then my full smile would slowly appear was told to do exercises to work the muscles in my face to get the muscle working and stronger. We flew in to my hometown, my parents and I were greeted by my family and friends at the airport. That meant so much to me. My new smile was a half smile.

When the time came for the second surgery, it was summertime and my sister, Cerina go to go with us to Canada. I cannot express how thankful I was that she got to go. I really needed her there with me. This time the plains of Canada were clean, crisp and green -- something this West Texas girl had not seen in her lifetime. We went a week early so we could tour the city of Toronto. We went to see our first Major League baseball game. We tried to get a ball signed by the Blue Jays, but they lost the game so did not feel like signing autographs. We also went to see the CN tower, at the time it was the tallest tower in the world. Then we went to my favorite place of the whole tour, the Casa Loma castle. I fell in love with that castle and the history that went with it. From the grand ballroom to the hidden tunnels, it was just amazing. We also went to see Niagara Falls which is such a breathtaking sight. Then the day came for surgery, but this time I was not as scared because my sister was there.

I have been through so much in my lifetime including 18 eye surgeries, 5 hand surgeries, 2 Smile surgeries and various other surgeries to correct issues caused by Mobius Syndrome and Poland Syndrome. For a short time, I did think I was a curse. But why else would God make me like this, when my siblings are perfect. There would be days that I just stared at my family's facial expressions and wondered what mine would be like. Would I have the dimply smile like my sister Cerina? Would I have a big grin like my sister Tiffany with teeth showing? What would my facial expression be like if I was scared or grossed out? Then I realized that I would never know. I remember the day that my mom saw the first twitch on my left side, it was a small twitch but I knew it would only get bigger. My brother Butch saw the twitch on the right side. After the twitching started and with the help of the exercises for my muscles, my smile began to grow. I was so excited and felt so blessed when I looked in the mirror for the first time and saw my smile. I was overcome with joy, no more pushing the corners of my mouth up, it was actually a smile, a real smile, a gift from God that I'd been waiting for my whole life. I called my whole family into the bathroom, and as everyone was standing around me I smiled for the first time for my family. I was so happy now, when the picture guy said smile I could actually smile.The day I realized I had a full smile was the day my story came out in our local newspaper, which happened to be the first day after spring break during my 8th grade year. I will never forget the feeling I felt walking into my first period, it was Mr. Costello's class. I walked in late, of course, because to this day I'm not a punctual person. As I walked in I received a standing ovation from the entire class. They were cheering for me, and everyone was yelling “Smile Kara, Smile!” I will never forget that day. The day I showed the world, my friends, family and classmates my BEAUTIFUL, unique smile (with one dimple that my sister requested the day i went in to my second surgery) I could smile and i wanted the whole world to see it it was a true miracle. BSomeone asked me a long time ago, what would I say to God if He came down and asked me if I wanted a right hand. What would I say? My first thought would be, “No, I like my nub. I am unique with it.” But then I got to thinking what would it be like to have two hands? It sure would make putting my hair up a lot easier or tying my shoe a whole lot faster. I would be able to paint my nails -- both hands instead of one hand. I would be able to give two thumbs up instead of one thumb up and a nub. I would be able to do a lot with two hands. I don’t really know my answer. If I had to answer right now, I would say, “no thanks. I have lived with my nub for 33 years. I have learned to cope and adapt to doing things a certain way. I go through struggles everyday. I always prove I can do anything I set my mind to.

Philippians 4:13, I can do all things through Christ who strengths me, I live by that daily. I live my life as normal as possible, I have challenges but there is always a way, if you put your mind to it. I love the life that God has blessed me with. I feel like God has used me everyday to show people that nothing is impossible. I have always felt like I have to prove myself to everyone, especially if they said I can't do something then I’m bound and determined to show them I can. I love new challenges and enjoy conquering each one that comes my way. I work in an Emergency Room, as an ER Tech, one of the most stressful, fast paced, challenging jobs I could ever hope to have, a job many people thought I could not do. My boss Ann believes in me and gave me this opportunity. Many of my coworkers have helped me overcome some of the challenges I face during day to day operations in the ER, such as a way to do an in and out catheter while maintaining a sterile field, and doing it with a nub. Drawing blood is another challenge for me, after many attempts to use a clip on tourniquet, my coworker Becky suggested a different way using a banded tourniquet, and worked with me for a while until I was able to do it properly. I was honored that my coworkers put their minds together to help me figure out a way to do my job and overcome some of the challenges I would face. I enjoy working in the ER, even though it's not easy at all, but I'm proud of myself. I know I’m not perfect, or a curse, but I do know that there is a reason why I’m made different and unique. I believe that God put me on this earth to make a difference in people's lives and show the world that there are miracles and they can happen.

Dr. Zuker and his team changed my life. God used his brain and his hands to create my miracle smile. I can not think of a better Doctor to perform the surgery, he will probably never know how much he help changed my life for the better. I can not imagine what my adult life would be like if I didn't have a smile, and i don’t want to know. God has a purpose and a plan for everyone, I believe we have one life to live and we need to live it to the fullest and with a smile from the inside out.