

Isabella Costello  
A Brother and Inspiration to All  
April 7th 2020

### A Brother and Inspiration to All

My name is Isabella Costello and I am a sophomore at the Bay Shore High School. When I was only a newborn, my birth parents made the extremely difficult decision to put me up for adoption. Soon after that I was adopted by an amazing family, The Costellos. They were all so ecstatic to meet me and welcome me into their family. My parents have three biological typical children and have adopted fourteen children with special needs including mental, emotional, and physical disabilities. I was born with bilateral hearing loss which means I am deaf in both ears. I utilize hearing aids to assist in my ability to hear expressive language and noise. I was also born with a very rare heart defect. Transposition of the Great Arteries. I had an open heart surgery at two days old and another at seven days old. I still see a cardiologist for check ups but no longer take cardiac medications at this time. As an infant through the first two years of my life I was tube fed but with feeding therapy I eat all foods now. Although my assorted physical differences are a daily struggle, I continue to strive to be the best person possible! Through my adversities I have learned to overcome anything that may interfere with my success. While learning to be proactive in my own life, I have also learned to push for success in others' lives.

I have a younger brother who is in 8th grade named Matthew. Matthew was born with a rare neurological syndrome called Moebius Syndrome. Moebius Syndrome is a disability that is the absence of the 6<sup>th</sup> and 7<sup>th</sup> cranial nerves which control our facial muscles. Additional symptoms of this syndrome may include clubbed feet, deformed fingers and/or hands, speech impairment, developmental delays, and learning disabilities. Universally people with Moebius Syndrome cannot move their eyes bilaterally. This impacts multiple learning situations. Matthew wears prosthetic feet and also he only has a few partial fingers but with intensive therapy he has learned to do almost anything he desires. Some people with Moebius Syndrome are tube fed and or require a tracheotomy. Matthew is deaf in one ear and has an immense amount of trouble using his expressive language due to the loss of his ability to utilize his facial muscles. He also had brain surgery two years ago to control his seizures. Although he has multiple physical and intellectual disabilities, he tries his best to endure these challenges that inhabit his daily life. These challenges have helped shape him into the sweet and caring young boy he is today.

Moebius Syndrome has a day dedicated to sharing awareness and promoting the ability of those with this syndrome rather than the disability. The color that represents Matthew's syndrome is purple. Each year on January 24<sup>th</sup> people around the world wear purple in order to express their awareness and support of those with Moebius Syndrome. This worldwide day inspired me to raise awareness for my brother in my own school and hometown. In just a couple of weeks, I put together a slideshow with all of the imperative information and facts about his

syndrome. I presented this slideshow to multiple groups I am involved with including: The High School Band, Choir, Wind Ensemble, and Orchestra. I spoke in front of at least four hundred people that day. Throughout the week I gave speeches to the entire faculty, staff, and sophomore class in order to involve each of them in my project. During this speech I asked each of those present to wear purple to support and raise awareness for Moebius Syndrome. Following this meeting, I met with my principal, Mr. Pashkin. I presented the idea of making an announcement over the loudspeaker in order to inform as many of my peers as possible in addition to handing out informational flyers about Moebius Syndrome. Through all of my efforts, the staff and students in the Bay Shore High School wore purple to support my brother and others with Moebius Syndrome. I was thrilled to see that my peers who promised they would help raise awareness followed through and spread the word to as many people as they know. They texted in group chats, told their teammates, posted on social media, and informed others in school about this awareness day. I was truly surprised when my band teacher bought purple awareness bracelets in case my peers did not have any purple to wear. Additionally, I handed out purple pencils that my mom made online. They have Matthew's name on them along with the name of his syndrome. Pictures of the band, choir and faculty members were taken and posted on the Bay Shore High School's Facebook, Instagram, Twitter accounts and the Bay Shore Schools monthly newsletter. My principal went even further to show his support and appreciation by sending a letter home with each student to inform families and members of the Bay Shore community of the awareness day put together by myself.

Producing this awareness day made me feel like an upstander because it allowed me to introduce a plethora of people to Moebius Syndrome. This allowed me to help my little brother and other children and adults who have Moebius Syndrome feel heard and understood. Throughout this process I helped promote awareness and inclusion of those with Moebius Syndrome. To my surprise many people were unaware of what the syndrome is and the effects it has on the people that are born with it. I feel proud that I had the courage to speak in front of my school in order to stand up and promote my little brother and his disability. I continue to live my life and strive to do whatever I can, for anyone who cannot be heard and/or get what they need and/or want. I will continue to strive to be this person throughout my entire life and stand up and make great decisions not only for myself but for others as well. One of the reasons why I wanted to raise awareness was because Matthew will be joining my sister and I at the Bay Shore High School in September 2020. I wanted everyone to know who he is and why he looks differently than others. What Matthew looks like has so little to do with what an awesome person he is! Now that most people in my school know what Moebius Syndrome is and that Matthew suffers from it, I hope he will get the respect and love from the other children and adults in the school that he deserves.

When I graduate High School, I will continue to be an Upstander by becoming a Special Education teacher or a teacher for the Hearing Impaired. My parents and family inspired me to be a teacher and change peoples' lives. Throughout my lifetime I will always try to help others who may have a hard time advocating for themselves, continuing to be an upstander!

Here are some photos of from my awareness day:



This is my brother Matthew!

