

Raising Awareness of Moebius Syndrome: My Story

By: Will Harrison, MORC Support Coordinator

In 1981, I was born with Moebius Syndrome. Only 1 out of 500,000 people are born with Moebius Syndrome. This means spreading awareness for this rare condition is critical for people like me all around the world. On January 24th, you can join me in raising awareness on Moebius Syndrome Awareness Day.

To tell you a little about this condition, Moebius Syndrome does not allow people to make facial expressions because the 6th and 7th cranial nerves become paralyzed and do not develop. Vision difficulties arise as well because eye movement from side to side is restricted. The effects of Moebius Syndrome differ from person to person. For me, I have hearing loss and speech difficulties saying certain letters. I have had over 20 corrective surgeries on my eyes, ears, legs, and jaw throughout my life. Being different is not easy. I was often bullied throughout my school years feeling like there was no one like me! It was not until I was 29 years old that I finally met someone else with Moebius for the first time and began to connect with even more people within my new Moebius family.

At the age of 35, I started graduate school for Social Work. It is an honor to now be working for MORC, an organization that clearly values people with disabilities and advocates for their needs. I never imagined I would become a social worker until my wife and I almost lost our daughter after cleft palate surgery complications six years ago. She spent a week on a ventilator, and during this time I realized I wanted to advocate for other people with disabilities.

Today, I serve as a board member for the Many Faces of Moebius Syndrome where we advocate for and support individuals with Moebius Syndrome. I am also the Vice Chair on the Michigan Statewide Independent Living Council. Although having Moebius has been challenging, I have not allowed this to stop me from advocating for others with disabilities.

What can you do to raise awareness for Moebius Syndrome? On January 24th, Moebius Syndrome Awareness Day, please join me in wearing something purple and post a picture to Facebook or Instagram using the hashtag [#msad2021](#). To find out more about Moebius please visit mfoms.org. Feel free to share this website on social media to continue to help spread awareness of Moebius Syndrome worldwide!

