

Kevin's Story

Video description: Kevin (a male with short brown hair and dark grey shirt) sits in front of a dark blue background, looks into the camera and signs.

TRANSCRIPT: Hi! Today I'm going to share my personal experience. I'm opening myself up to you! I was born deaf. I'm the only Deaf person in my family. At about the age of 15, the school for the deaf that I attended started to suspect that something was going on with me. After some testing, and more questions, they sent me to a specialist who discovered that I had Usher syndrome! I...was...stunned. My family, friends and I were just devastated, of course. I went to UCLA in California for further testing. Then over to Penn State University where they determined that I had Usher type 1B. Despite this news, I decided to get on with my life. Now - I hadn't yet accepted this new identity, but on I went. Fast forward a few years...I got my master's degree in Deaf Education from Rochester Institute of Technology. I graduated in 2012, and, that same year, moved to Burlington, VT. I was hired by the University of VT to teach ASL. I was eventually hired full time and this is my 3rd year teaching full time. I teach ASL, plus "Understanding Deaf Culture." And this semester, I'm excited to also be teaching "Introduction to the Deafblind Community!" I also work for Starbucks as a barrista. I've been there for almost 5 years in various locations. I've also worked with Starbucks headquarters creating videos in ASL teaching the signs related to Starbucks products and how Starbucks welcomes, values and includes the Deaf community. If you look at Starbucks' ASL videos from last year, you'll see Yours Truly in them! I'd like to go back a bit, if you will to the "identity" discussion. I have always identified myself as "Deaf" and I hid the fact that I had Usher syndrome for a long time. It wasn't until grad school that I was finally ready to let people know that I had Usher syndrome. But it was still difficult for me to accept. Sometime after I moved to VT, I had the opportunity to fly out to Seattle, WA. I met some fantastic - amazing - DeafBlind people there. I met two leaders in particular who were incredible inspirations to me. They taught me that We. Are. Fine! And really - we just needed to shift our communication to "Pro Tactile" or PT for short. That experience had a profound impact on me. It went straight to my heart. You know, I looked around at all of these independent, persistent, busy and capable people who had adjusted to their vision loss, and then just kept on going as they had before. My goodness - what an inspiration! It was then that I decided to publicly identify myself as DeafBlind and to accept that I was part of the DeafBlind culture. That experience had such a tremendous impact on me. Their positive spirit has energized me, and I'm passing it to all of you. Usher syndrome is just a diagnosis. A label. And I don't really share that label. I prefer to just say, "I'm DeafBlind." Of course if you ask me, I'm happy to share that I have Usher syndrome type 1B. But it's kind of like when you tell someone that you're deaf and they ask, "Oh, what's the specific dB loss in each ear??" My response to that is, "I'm Deaf." And that's it. It's the same concept with my identity as "DeafBlind" rather than "Usher syndrome." So, who am I? What is my true identity? I'm DeafBlind. I'm gay. I'm an adoptive father to my Deaf son. That's had a big impact on my life. I'm truly blessed. I'm thankful for my life, for the opportunity to travel and learn as a person who is DeafBlind. I hope that by sharing my experiences, it will help you to see things from a different perspective. Oh, one more thing I want to add. I did go for genetic testing. I worked with the specialists at Massachusetts Eye and Ear. They took a blood sample and I'm waiting for the results. But you know - it's important to stay in the present, and live each day, doing what we can do to move forward. I don't sit back, anxiously waiting for treatments or a cure.

Instead, I focus on my culture, having access, using technology and taking advantage of the many opportunities we have right now. The point is to enjoy life while we can. Thank you.