

Kevin's First USH Connections Conference

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

TRANSCRIPT: Hi. I'm going to share my experience at the recent Usher Syndrome Coalition conference in Chicago last July. This was my first time attending a USC conference and I have to tell you it had a tremendous impact on me. Quite a positive impact. When I arrived at the conference, I saw a room filled with people with Usher syndrome. all milling around...it was awesome. You don't find that very often! It was great to meet so many new people. I remember thinking what a diverse group this was. There were individuals with various levels of vision, so many methods of communication being used, every ethnicity and skin color. Remember the video on diversity? That's exactly what I saw in that room. I conversed (in ASL) with new people, but even when I met people who didn't sign, there was an immediate connection. When the conference began, I took my seat and began watching the interpreters. The interpreters were AWESOME and I'd like to give a big Thank You! to the Chicago interpreters. Great job!! There were several presenters. First was Mark (Dunning) who founded the Usher Syndrome Coalition. It was my first time meeting him and I was curious to hear his story. He is an impressive speaker. I found him to be very honest and open. He described the history of the Coalition and his hopes for the future. Following Mark's presentation were a few medical researchers, and then a deafblind (oral) presenter with Usher syndrome. So, there were several different presenters. The researchers talked about genetic testing, treatment options - topics I had heard before but never in a way that was easy to understand. I was ready for more of the same. Well, these presenters were incredible. They explained everything in such beautiful detail, along with PowerPoint slides, it was like a lightbulb went on. I got it!! In fact, I understood it so well that that I became confident enough to share this information with others - - topics like options for treatments, or the research process. This information helped me tremendously. The next presenter was the one I mentioned - with Usher syndrome - He described how he brought together a group of youth with Usher syndrome who shared an amazing expedition...such a touching story. The video clip he showed was terrific. This same gentleman also talked about his travels to another country with a small group. This trip was videotaped as the group hiked for days along a trail. That was such an impressive story and again shows that people with Usher syndrome can do it! We just do it differently.

Anyway, his story was very touching. Later, there was a Q&A; where the audience could ask the speakers questions. The questions AND answers were great. Kudos to everyone who participated! Next, I was on a panel of people with Usher syndrome. I was the only one on the panel who signed. All of the other panelists were oral. One was from Mexico. One from Australia. There was a young person starting college And a superintendent of a hearing school district in Chicago. The panel followed a Q&A; format. It was incredible...so impressive! Everyone on the panel was on the same wavelength. We had similar experiences. Our responses to the audience's questions were on target. And we all shared the same positive spirit regardless of our method of communication. Interestingly, at the end of the panel presentation a few people commented that they want to learn American Sign Language. That made me feel great. Later, a mom of a young daughter who has Usher syndrome came up to me and said, "Thank you!! Your story was incredible. I've been trying to say the same thing to my family but they never got it. After they heard you speak, they said, 'Oh, NOW we understand.'" That just touched me to the core. I made so many new friends with Usher syndrome, met parents and professionals. That conference was truly an eye opener. I look forward to attending them every year from now on. Next year's conference will be in Germany! That one will have 3 days of meetings. People from around the world will be there. C'mon! Join us! You will learn so much from the many professionals there, share new experiences. And

finally, I'd really like to thank the Usher Syndrome Coalition for helping me to become so much more knowledgeable about Usher syndrome. And that was my experience at the USH Connections Conference.