

Treatments, Cures and Your Identity

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 - Today I'm going to talk about "identity." What is your identity? Do you see yourself as a person with Usher syndrome? Deafblind? or something else. As treatments and cures are developed, are you open to these opportunities or have you already decided that they're not for you? Which path would you choose and why? If a cure becomes available for RP that restores your visual fields, would you still identify yourself as someone with Usher syndrome or Deafblind or would that change? If it changed, what would your new identity be, and why? I'd like to share my personal thoughts with you. Obviously, my primary identity is that I am Deaf, and now Deafblind. I believe I will always see myself as "Deafblind." I'm proud of my Deafblind identity. But I am hoping for a cure or treatment. If one becomes available, I would take advantage of it, as long as it was safe with proven successful outcomes. I absolutely would! If there was a cure that increased my visual fields, improved my night vision, and balance, that would be great. But I would still call myself "Deafblind." If there was a single treatment that could improve my visual fields and restore my hearing, I would not go for it. I'd probably ask them to disconnect my ears. I'm Deaf. I was born and raised Deaf. Can you imagine if I could suddenly hear? That would be traumatic... ...so incredibly stressful. I wouldn't want that change. As far as my vision - I was born sighted, and have adapted to my vision loss. Of course I would have to adapt to being able to see again. But I'm proud to be Deafblind. I know that everyone had different experiences, different perspectives and different opinions. There is no right or wrong. But the important things is to respect each other. Thanks for listening!