

**(Rebecca Alexander) Okay, good morning everyone, thank you so much for having me. So it's so wonderful to hear parents share their experiences and talk about all the work that they have done for Usher syndrome.**

Particularly as a woman living with Usher syndrome, I'm 39 now. I was diagnosed with retinitis pigmentosa at 12, and at 19 I was diagnosed with Usher syndrome. At 19 when I was diagnosed with Usher syndrome they said yes, Rebecca, you have Usher syndrome, but we have never seen it as it presents itself in you. And fortunately, because of the research that is being done and all of us in the community, we were able to connect with researchers in Finland, in Helsinki Finland. And it was with my family's blood work and with these researchers and of the population in Finland that to the identification of Usher syndrome 3A became possible. So we now know of 88 people in the registry who have the type of Usher syndrome that I have.

This is part of what Mark so eloquently spoke about in terms of the importance of having people registered. If you know people, particularly in the community who have not been genotyped just yet, that is probably the biggest

REBECCA ALEXANDER

thing we can do in terms of research. More importantly, living with Usher syndrome requires you to be vulnerable. Being alive requires you to be vulnerable. So I encourage all of you living with Usher syndrome, one of the most difficult things that I found for me in my own experience of progressively losing both my vision and my hearing was asking others for help.

And what I've learned is that the more I've been able to ask people for help, the less isolated I felt, the more included I have become in my community, and the more of a sense of community I have created, not just with people within the Usher syndrome community, but with the sighted and hearing as well.

And lastly I'll say that when you ask someone to help, when you tell them that you need help, when you own what you have, that is vision and hearing loss, you are able to create a sense of empowerment within yourself, and you empower others to want to help you. There is nothing we want more in this world than to know that we matter. And when you ask others for help, you let them know that they matter. Have a wonderful day everyone, and I would love to meet as many of you as I can while I'm here in Germany. (applause)