(Julia Moser) So hi, hello, good afternoon, everyone, thanks very much for the invitation, I am very happy to be here and to meet so many of you.

When I was 4 years old, I got my first diagnosis and at the same time I got my first label. Doctors told my parents that I had a severe hearing impairment, I had not really developed any language by then. They also told them that, and that was the label I would not develop any language, it was too late and I would not go to school. So, life options didn‘t seem all that bright. And at the age of 13, I got my second diagnosis, and again, I also got a label with this. That was the time when I learned that I have Usher syndrome and the doctor who told me this also told me at the same time, that I would go blind I would not really have a career option. I would not have many options, family, kids, if I did decide to have kids, they would probably have Usher syndrome, too.

So, these two experiences really did have a huge impact on my life it really impacted on how I viewed myself as a person. My identity was questioned and I think there were two things that really came with it, one was to try even harder, because I did not want this to come true. And the second was, what I learned, I had to hide. I had to hide that I have Usher syndrome, because only then I would I

be entitled to a happy life and to the life that I wanted to life. I was lucky, because my parents did not believe those doctors when I was 4 years old.

I got my first set of hearing aids I got speech therapy and when I was 6 years old, I went to primary school, local primary school, small village in the countryside. I was the only kid with a disability, it worked fine. I think that was also down to the fact, that I loved books and I loved reading and this really compensated for a lot. When I didn‘t understand what was spoken around me, I could always rely on books. I then later moved on to grammar school again, reading was really, really important to me, so I was actually able to get the education that I wanted, I loved going to school. And when around the time I was 12 years old puberty kicked in, I started feeling very self-conscious about my hearing aid. I hated them, only grandmothers have them, but not 12-year-old girls.

I wanted to be normal, I wanted to be like everyone else. And soon after that, I found out that I was also short sighted, and I got my first set of glasses and I loved them, because glasses, that was something my friends had as well. And I also thought that diverts from the fact that I have hearing aids.

And then about a year later, when I was 13, my mother had noticed I tripped over a lot and at night I didn‘t really see that well. She took me to the eye doctor, I was with her to hospital, tests were taken, and they told me that I had RP and then they referred me to a geneticist and

that was when I first heard the word Usher syndrome. The geneticist told me, he did nice drawings, lines and a little defect gene and not defect gene and how it all worked. And he explained to me why I had Usher syndrome and why no one else in my family had it, that was the time before genetic testing.

But he didn‘t only diagnose me with Usher syndrome, he also labeled me, because he then said, you will go blind, you should really choose a job that is suitable. I asked him what job that could be, I was 13. He didn‘t have an answer and instead he told me, that my kids will have Usher syndrome, too. And he had not got the facts wrong, because he had told me about the inheriting pattern, but what he meant was that if I did find I partner he will certainly have Usher syndrome, because I would meet him in a patient organization. (laughter) I did not join a patient organization for a very long time. (laughter)

Well, I went back home, I was shocked, and I am sure my family was shocked, too. We did not discuss this issue very much, it was there, but it was also a bit of a taboo, it was not something you like talking about I did not have much information. That was the time before the internet.

We had one book at home, a thick book, family health, lots of diseases, there was one tiny paragraph on RP and I kept reading it, reading it, looking for clues about what my life would look like in 10 years, 20 years. I did not have any more information, I did not have any contacts, I didn‘t want them, yeah? And then I thought okay, this disease

progresses very slowly, surely there will be a therapy option by that time, I relied on that. And then I started doubting, what if there was no therapy option in time, what would I do? I do not want to go blind. This was not something I could imagine.

So, I needed an exit strategy and what I decided to do then, was, I was 14, 15 maybe surely it would be better not to life at all than to life with Usher syndrome. This sounds horrible, I know, but, this really helped me, because I did not have to deal what might happen one day, it really enabled me to focus on the present, on the life that I have now. So, it did help.

So clearly I lived in denial and I lived in denial for a very, very long time. And when I thought about my experiences with Usher syndrome and about my life with Usher syndrome, I recognized a model that describes the stages of grief, people go through when they lose a loved person. My eyes were to me like a very dear friend, my most important friend, because my eyes compensated for what I didn‘t understand. So it really did feel like I had a friend who was very sick and who would die. And the five stages, that were described are denial, anger, bargaining, depression, acceptance. So, I did live in denial for a very long time, I don‘t think I ever had a clear stage of anger, I don‘t remember that. what I did certainly have was the stage of bargaining.

I started thinking about whether I could trade in my disease against something else. I grew up in the Austrian

alps, I did not like climbing, as opposed to my parents who did that a lot, I hated it. But there was this very distinct mountain that I saw every day, I thought, maybe if I climb this mountain every day, - an exhausting day trip, 9 hours - if I climbed it every day and didn‘t have Usher syndrome that might be an idea. Then I thought every day, no, maybe once a week. But I never tried. Because I came to the conclusion that maybe a life doing something I don‘t like at all and not having Usher syndrome might actually be worse than having a life with Usher syndrome and doing things I like.

The problem I had then was, how you can still do the things you like, when you go blind. I didn‘t have any role models, I did not know that it would be ok to be visual impaired. I didn‘t know that it was possible to live with an impairment, with a disability, so I went back to denial. I completed grammar school and I then went abroad. I worked a lot because I always felt rushed, I felt like I have to complete my tasks as quickly as possible before it was too late. I completed a university degree, and when I came back to Austria, I considered my options again and said ok, and then decided to go for legal studies, because I thought legal studies could be compatible with Usher syndrome.

And I think looking back, this was one first step of acceptance, because I was looking for alternatives, I was thinking about ok, what can I do to provide for the fact that my vision gets really bad. What I still didn‘t do was get open about Usher syndrome. I didn‘t talk about it, I still denied

it most of the time, I thought, ok, let‘s live in the present, who knows what will be in 10 years‘ time whenever. I then started my career at a lawyer‘s office and I also started a family. Soon after that. I was not in any patient organization which wasn‘t too difficult in Austria, because there was no patient organization on Usher syndrome.

My kids are now 10 and 7 years old. I think, having kids was actually really important to me, because kids accept people as they are, and they ask questions. And I was forced to give answers. And these really did quite a lot. But what also happened around that time, was, that my vision degenerated quite quickly in a short time frame and I realized that there are a lot of things that I couldn‘t do any longer as I used to do, and my answer was to withdraw. To stay at home at night, not go out, find excuses.

I didn‘t tell people why I chose to not participate. I also quit my career at the lawyers‘ office, because there were some instances that made me realize that it is really difficult, I did not talk to my bosses about my disease, they knew about the hearing impairment, that was ok, but they did not know about my visual impairments. I am quite sure, if I had told them, it would have not been a problem. We would have found a solution, but I wasn‘t prepared to come out. I had young children anyway who needed all my attention.

So, there was couple of years where I wasn‘t really that active. I think you could call this my years of depression. But I am also very lucky because I didn‘t develop a full-

blown depression, but it was a time of loneliness, with not knowing how to proceed. And then I decided to get lots of information, it was a lot easier now than it was many, many years ago. There was the internet, I decided to connect to others with Usher syndrome and I met awesome people and I met them and there was this recognition from the beginning, there was this understanding, a level of understanding I haven‘t known before because I hadn‘t known anyone with Usher syndrome before. And this was the best step I could take, yeah.

What I did, as well, was to start asking for help. This was something that was very difficult to me. I started a mobility training, at that time I didn‘t get funding for this, so I only did a very basic training, but it helped me, I started going out more again. I couldn‘t read books any longer, that was something, you know the saying if you have Usher syndrome or RP, you can‘t find the bus stop but can read the time table. When I don‘t find the bus stop, I can‘t read the timetable either. So, I can‘t read books any longer, which is a loss for me, but I turn to electronic books. I got software for my computer, so I can still read what is on the screen, I can find items on the screen, I got good lighting. I got assistive technology.

I got a smartphone which really is extremely helpful, because it has a torch, it has voice over, it has navigation, I can read my e-books on that, I get all my information from my smartphone. And I think smartphones are actually key when considering assistive technology for the future. And what we did as well there was this dedicated

team of people, of individuals affected by Usher syndrome, family members affected by Usher syndrome. We got together and it was our vision to found a patient organization in Austria and that is what we did. I think that that was a very important step, I am very happy about this.

Those were all factors that contributed to me accepting myself as a person with Usher syndrome, accepting my identity, not hiding any longer. Hiding just makes matters worse, because as long as I hide I can‘t get the help I need. And you just really need to get open about it, come out and then this really is the pre-condition for asking for help and help and support really is so important to all of us, so we can lead the life’s that we want to lead. And I am also extremely happy that I was able to travel with a deafblind assistant to come here.

It is the first time I have done this and it is amazing, it just empowers so much, finally I find the people I want to talk to, because I have got eyes with me, I have got ears with me, who tell me what someone says if I didn‘t understand it.

I always considered myself quite independent anyway, but it does really make a very big change. So when, I think we all have our unique stories my story is just one story and I think some of you might recognize some of the stages, some things will be completely different. I do think that patterns of coping with a disease like Usher syndrome are similar but also of course very individual.

JULIA MOSER

And I think what important is to find a way of enabling people with Usher syndrome to live the life they want to live. So they feel confident that they are entitled to the life they want to live. I think that is also important, because when I think back to the time when I was diagnosed, I was denied the right to a happy life, really. I was degraded, my life appeared worthless to me, and I think this shouldn‘t happen.

Of course it is a shock and denial will always be part of the process and it is a difficult process, but I think what it really needs is that we have professionals from different disciplines, who get together in a network to support individuals. So individuals can turn to them when they need to at the time they need to at their own pace. That is how we can support individuals to cope with their disease and to find a good way to live.

And also, when I look back at my life, I think what really helped me, I had a supportive network from the start, which was very important. I chose to get information about Usher syndrome, I chose to connect to others with Usher syndrome, I chose to get help, and I chose to work actively in a patient organization.

And keeping this in mind, then considering how to provide support for individuals, I think, we really know it needs a multi-professional, multi-disciplinary approach. And that is why I do the work that I do, because I feel privileged. I feel lucky, I had a lot of chances in my life that got me to where I am now. And I think everyone

deserves this, that is why I am doing that work. I am extremely happy if we get together to do this, so the vision is that everyone who has Usher syndrome can live an independent life, can become reality for everyone. Thank you. (applause)