

**(Dominique Sturz) Thank you Mark, thank you for the kind introducing words. So welcome to you all, and a warm welcome from my side. Today one of my most important dreams of my life has come true.**

We all have many dreams in our lives, but this is really one of my most important ones today. So this is a unique event which I have been working for to have this connection of Europe and the US international Usher syndrome community today here. It means a lot to me personally as a mother of a young adult daughter with Usher syndrome subtype 1B, and also as a patient advocate for Usher syndrome and rare diseases coming from a small country, where there has been no expertise for a long time on Usher syndrome at all.

So next to my dreams. Dream number one, and maybe many of you share this dream with me - dream number one as a mother of a young adult woman born deaf in 1996 and implanted bilaterally very early with cochlear implants. One of my most important dreams and also a dream of my husband has always been that one day she might be able to be as everybody is, to be not as everybody is, but to be able to lead a happy and fulfilling life

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like everybody else. So I'm sure many of you share this dream, all the parents who are here in the room. And now I can say, today I can say that this dream - despite the additional diagnosis of RP she is a happy young woman with friends, who completed her school career, she is a law student, has a boyfriend, and she has turned out to be a genuinely good young woman.

So dream number one in my life has come true. But there is also another dream that has come true today. Dream number two. Dream number two in my life has been that one day we would have some Usher expertise in our country, in Austria, which is a small country, and it is difficult to have expertise on rare diseases there. So and I've learned, my family has learned so much from organizations abroad, when my daughter got diagnosed with RP in 2005. And first of all we didn't know where to turn. So we have learned so much, first of all through Pro Retina Germany, through Retina international. Then I met Stefan Suchert who connected me to the Usher Syndrome Coalition and to Mark Dunning.

Then I met Sebastian Klaes and the team of „Leben mit Usher-Syndrom“ in Germany. And what I wanted was to give some of the knowledge and the expertise back to people in my country, in Austria.

And today we have some Usher expertise and some medical university centers in Austria, so that patients who get diagnosed and their families get a more adequate and professional consultancy and management of the disea-

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se. Much better than it was in 2005 when our daughter was diagnosed. And we also have an organization for families and for individuals diagnosed with Usher syndrome, where they get support and where they can give each other mutual support and exchange their experiences. So this was dream number two.

There is also dream number three. And this is the most important one for today. Having connected Europe and the US, and having here patients, families, experts, scientists, researchers from all over the world in one room - and I'm really impressed to see the room full of people, I mean it's a huge room and it's really full - has been also one of my most important dreams. So why is it so important to have the international community connected? The part of that has already been said by Mark and by Christina. I know exactly, my family, my husband, I know we feel, we know how you feel when you have a diagnosis. It's so important to have the feeling not to be alone, to know where to turn, to know to which organization to go, where you get your support, and also to know where the experts are.

And it is also very important, gives you hope and much motivation and strength to be there for your children if you know that there are hundreds of researchers, scientists, clinicians, patients and patient organizations, all fighting for the same cause, and fighting to find solutions, to find treatment, maybe not cure, but at least the treatment and maybe a cure one day.

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So to have the feeling you are not the only one, and also to have the feeling that you get support, and also to have the feeling that you don't miss anything. Because you are connected to the community, you know what's going on on national and international level, and you know what to do if maybe a therapy comes up, you exactly know where to turn, if you want to get it. So this is a really very important day to me today to see you here.

And I hope you all have inspiring talks, you get interesting insights in scientific, medical, psychosocial and other aspects. I'm very happy to see many familiar and also new faces here, and I'm really looking forward to catching up with you also during the breaks. So I wish you an inspiring conference. (applause)