

**(Irmgard Reichstein) Dear ladies and gentlemen, I'm very proud to welcome you here to a very challenging event. Goal of our patient day is a transfer from actual scientific research results from scientists to patients.**

We all know how difficult science can be, and we appreciate very much that we can welcome scientists here who will transfer their knowledge using a clear and understandable wording. Conference language is English. And we kindly ask the speakers for today to speak very loud and also slowly.

This is to achieve a good accessibility for all participants. And we offer a lot of interpretation for this. So we offer you simultaneous interpretation into German via headset and conference receiver. And if I look around, everybody is following my words. So is there anybody who cannot follow the conference? Are you all fine? Please give me a short sign, are you all fine and can you hear me? Would you please give me a sign that you can all listen to this conference? You can, you can, you can also?

That's very important for us to lose nobody. And so we also offer American sign language and speech-to-text

*IRMGARD REICHSTEIN*

interpretation in English on the left screen in front of you, and we offer German sign language and German speech-to-text interpretation on this side of the conference room. All people with these needs have been placed before the conference started, so hopefully the communication situation is clear for everybody. You will also see Lorm interpreters for deaf blind people, and you will see tactile sign language for persons, and also a lot of persons with personal assistants for orientation, but also for communication.

We offer a lot of induction loops, and they have been used by much more people than we knew before hand, but we could cover that. So we are very happy that everybody who needs an induction loop really got one. For the blind people: we missed the guidance lines in this very big hotel. But we have assistants. So if every blind person needs an assistant to go to the toilet or for every need they have, please give us a simple sign with your hand and assistants will come to you and help you in that situation.

Also we will offer a livestream for those of you who want to follow the event on their mobile device. After the conference we will post all talks with subscription in German and English language, and we will provide you and everybody who cannot attend today and is interested in the new scientific results with a protocol of this conference to read this slowly at home. Please forward this information to all of your friends who cannot be here today. We kindly asked the speakers to help us with the protocols. All

*IRMGARD REICHSTEIN*

speakers will receive the protocol to make comments or corrections. If you have problems during the conference, please use our accessibility desk in the back of this room. We will do our very best to help you and to answer your questions.

Please also make use of the free assistants we have here. We have five free assistants. May I ask them to stand up? Where are my assistants? They are all in the back of the room. Okay. I guess more than 30 % need these kind of accessibility offers we made here. In total this day will cost us about €150,000. And €120,000 of this large amount are needed for accessibility.

I would like to note that here, because I need to thank all the sponsors who made this possible for us and for you and all of us. So you see in the back all the sponsors we have, we needed a lot. And I really want to mention the most important sponsors for accessibility. This has been Aktion Mensch from Germany, the Usher Syndrome Coalition, the AOK Rheinland-Pfalz-Saarland - a health insurance - and the National Institute of Health, NIH. Without that support we would not have been able to offer this kind of accessibility.

I also thank the organization team, I'm part of it, but I really want to thank the University of Mainz which did the complete organization work, which was really a lot. You see we are more than 200 attendees here today, and that's a very big success for this conference. I guess it's the first time that the patient day has been so full. So

*IRMGARD REICHSTEIN*

thank you very much for coming to this event. And now I wish you a very interesting and pleasant day with hopefully helpful information for you, and I kindly ask you also, you will have the possibility to give us your feedback. We have a film team going around taking pictures, and just if you leave this room on the right side you can give us a feedback. If you would like to do that, we would be very happy, beginning with the lunch break. Okay, so now I will give the word for the scientific part to Mark Dunning, who will introduce the program for you. Have a good day, thank you very much. <sup>(applause)</sup>