

Our annual SLOS family meeting 2021

5th November - 7th November, 2021

The report about our annual meeting is always written by one of our youngest families.

This year a young family with a young boy wrote our report, which can be found on our homepage in German <https://slodeu.wixsite.com/home/2021>.

For several months now the date of the annual SLO meeting has been marked as a special date in our calendar. After our son was born and diagnosed with Smith-Lemli-Optiz syndrome after one week, the website of the SLO Deutschland association was an initial guide for us. Since our first contact with the association, we were excited to meet other families and get more information about the syndrome.

On our journey I started being nervous... what if the impressions would be too much for us? But there was no time to worry, as we were welcomed very openly and warmly. Our son was the youngest child and most of the other members had known each other for a long time, so it was obvious that we were new. During the first evening, many children and adults arrived and joined our meeting first for dinner, later in the bar, where everybody was in a good mood.

On Saturday our chairwoman Petra welcomed us after breakfast and introduced Dr Dorothea Haas from the University of Heidelberg. Most families already knew her or even met her in Heidelberg to have their child examined. We also knew her already as we had travelled to Heidelberg before to get more information about SLOS. It was a great opportunity to meet her outside the clinical setting and spend some more time together and have informal conversations.

In the afternoon we met for coffee and homemade muffins. While we were eating there was a magic show for the children. In the evening we had our party dinner. Our chairwoman presented us with photos, videos and a speech why she had initiated the Association SLO Deutschland 20 years ago and how these 20 years have passed, it was a very touching story. The bar was full of people, everybody was in an excellent mood and the food was delicious.

On Sunday morning one of our members presented the European reference network MetabERN and her work as a patient representative. We felt very hopeful about the European commitment and the engagement of institutions like MetabERN for rare diseases like Smith-Lemli-Opitz-syndrome to improve our lives and the lives of our children. The next item on the agenda was our annual meeting for the members of the association. After lunch everybody said goodbye and started their journey home.

Although the schedule was full, we found enough time for relaxing, taking a walk and of course having conversations with different families. On our way back home, we noticed that we were inspired, gained more knowledge and felt more empowered. Our impression was that the parents were happy, patient and strong. We are already looking forward to the next meeting in November 2022.