

My Conference Experience

By: Amanda Gertner

ISMRD's 4th Conference on Glycoprotienoses was sponsored by Washington University and several others. The international conference was held on July 23 – 26, 2015, at Hilton St. Louis at the Ballpark in St. Louis, U.S.A. Doctors and researchers from all over the globe came to talk to families about advances in their understanding of the various Glycoprotein Storage Diseases and developing treatments.

I was one of two afflicted with the Glycoprotien Storage Disease known as Sialidosis at the conference. Meeting the other “patient” afflicted with Sialidosis and spending time with him and his family was fun and enlightening, since I had not met someone with type two, as opposed to my type one Sialidosis. The experience definitely put things in perspective; making me appreciate what health I have and doctors and researchers who are constantly searching for a cure for Sialidosis and other Glycoprotein Storage Diseases.

We spent most of our time together at the conference, listening to several speakers. My brain definitely got a workout between attempting to decipher the multitude of scientific “jargin” and trying to understand the various heavy accents! Hence, I greatly appreciated speaking one – on- one with Dr. D’Azzo, a researcher from St. Jude. I learned the most from her, including that she is working on something that she is hoping to get approved for clinical trials soon!

I had a blast exploring the swanky hotel, meeting people from all around the world, and spending an afternoon in Ballpark Village. The entire experience was well orchestrated and made for a wonderful mini-vacation for my mom and I, who live in St. Louis.

