

ISMRD 2019 Family conference summary report

ISMRD's 6th annual conference was held in Atlanta, GA at the Marriott Alpharetta hotel. It was attended by both the scientific community and by families that are affected by glycoprotein storage diseases. Many of our scientific community and families flew in from long distances, such as Europe, Australia and New Zealand to take part in this conference.

The focus of our meetings was primarily scientific this time, but a part of the conference was given to some of our families to share their experiences with the attendees. Families were able to listen in to the scientific presentations and even with much of it being difficult to understand they came away with a broader knowledge of what it is they are dealing with, along with answers to questions they had in understanding more about their rare disease.

I believe the meetings were also beneficial in growing relationship between the researchers and the families, as researchers were able to identify more with the families. I think it gave them even more reason to pursue their avenues of research and encourage them in their work.

We didn't have specific breakout sessions for the families this time around, but it was encouraging to see families group together and discuss the issues that they deal with on a daily basis. Families that have been living with these disorders for some time were able to encourage and help families that were newly diagnosed and didn't have as much experience with these diseases. It was wonderful seeing the children greet friends from past conferences, make new friends and create a lasting bond with one another. I know many of these children – and adults too for that matter will keep in touch with each other over the years to come.

As a board, we were able to communicate where we have come from, where we are now and where ISMRD is going. Among several topics, we discussed how we have updated our website (which now has the ability to translate into several languages), and the future of ISMRD conferences in both the USA and Europe – with the hope of eventually reaching the Asia Pacific basin. We knew we wanted to grow our board, so we were able to approach several families about becoming board members - and at the time I write this we have at least three additional individuals added to our board!

We ended our conference with an awards dinner for those that have contributed greatly to the rare disease world over time. Two scientific awards were given out, one to Thomas Braulke and the other to Steve Walkley and two family advocate awards to Dag Malm and Denise Crompton. Their passion and dedication to the rare disease world goes above and beyond and for that we are so very grateful.

To summarize, this conference was a time of education, sharing, connecting, and making a lifetime impact on both our families and those in the scientific community that strive to make a difference. I'm very much looking forward to our next conference!