



Kellie H. (Colorado)



What is your connection to rare disease?

My son was born with a disease so rare that it is only called by the gene name impacted, SLC6A1.

What are you hoping to accomplish by advocating and volunteering with NORD?

I hope to be able to improve access to genetic testing and help others in the rare community to find their voice as we all work towards change together.

What has been helpful to you on your rare disease journey?

I appreciate the work being done around various legislation. Specifically, I am hopeful about the work being done around prescription drug step plans.

What inspires you about the rare disease community?

The people. There are so many impacted in profound ways, yet they avail themselves to supporting not only their own cause but the cause of others, too.