



Andrew L. (South Dakota)



What is your connection to rare disease?

My connection to rare began two years ago when I was diagnosed with a rare disorder, stiff person syndrome, and learned about my new condition.

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

I am hoping to help the rare disease community by spreading awareness and knowledge about rare disorders and how they affect people. I also want to help advocate for laws that will further the care, research, and protection for the rare disease community.

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

NORD and the resources you have provided have been helpful to me in gaining an understanding into my rare disease and providing me with tools to assist in my own advocacy and that of others.

What inspires you about the rare disease community?

What inspires me about the rare disease community is the resiliency and the willingness to provide information and support to others within and outside of the community.