



Barbie Ann S. (Maryland):



What is your connection to rare disease?

I was recently diagnosed with a rare disease. I am also a caregiver to my son who has a rare disease.

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

Through advocacy and volunteering, I hope to identify and connect with other people who share my experience with rare diseases. I also hope to make a difference by helping to increase public knowledge and awareness of the reasons and problems that limit people's access to high-quality, affordable healthcare and by having a significant effect on legislative choices at the highest levels. I am thrilled to be a member of a group where I can share my knowledge and expertise while also gaining new ones to aid in achieving NORD's aims and objectives. I hope to participate in raising funds for NORD's activities, particularly its research and knowledge-sharing campaigns.

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

I first heard of NORD in 2022, when a friend of mine invited me to one of NORD's conferences in DC. She was presenting at this conference and had suggested that I attend since I had also just recently been diagnosed with a rare disease and was struggling to find evidence-based information about my condition. On NORD's website, there were resources available not only for me to understand more about my condition, but I was also able to identify that there was a specialized clinic at Johns Hopkins. I was able to get a referral from my PCM to this specialized clinic and I am now receiving a better quality of care from providers who are knowledgeable and have experience in this area.

What inspires you about the rare disease community?

After my attendance at the NORD's conferences in DC, I learnt that there was a community full of people with so many different types of rare diseases. On listening to some of the testimonies, I felt inspired to be a part of this community, not only because I also have a rare disease but also because I feel that I can truly lend my skills towards supporting NORD's objectives and goals.