



**Tai P. (Massachusetts):**



**What is your connection to rare disease?**

I consider myself a rare disease advocate and researcher. I joined this community before knowing I had a personal connection. However, my grandfather, who I was extremely close to, died from a rare cancer, and we have some rare autoimmune conditions in my family.

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

Connecting with other members of the rare disease community is always so energizing. There is so much we can all learn from each other, both from successes and the challenges we have faced along the way. I am really excited to learn more about these experiences both within our region and across the country. As a member of the MA RDAC, I am also excited to learn about state-based initiatives and opportunities to share that information with other members of the RDAC.

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

I started my career as a member of the NORD team, which is when I found my passion for working with this community. I am particularly proud of helping organize and raise awareness for some of the very early Rare Disease Days. It is incredible to see how far the day's observance has come!

**What inspires you about the rare disease community?**

I am always in awe of the perseverance of rare disease families. There are so many obstacles and challenges that rare disease patients and their families face, but you see so many people who focus on helping others. The generosity of individuals in the rare disease community to share their time, experiences, and expertise to help other patients and organizations thrive is really inspiring.