



Pam J. (Ohio)



What is your connection to rare disease?

Eight years ago, my healthy, athletic, attractive 22-year-old son, Connor, was stricken with neuromyelitis optica (NMO), a rare disease that predominantly affects middle aged women. His humor and grace have carried him through paralysis and blindness and severe nerve damage - all the bumps of handling an unwanted adventure in this space.

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

By volunteering with NORD, I am hoping to accomplish being a helping hand through unknown territory. I am most inspired by the rare disease community and how invisible they are until you are one of them.

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

Charlene Y., a wonderful patient advocate we met at our foundation event inspired us to work with NORD and bring Rare Disease Day to Cleveland to raise awareness. CLE is now in our 4th year and we have a commitment from a host for next year!

What inspires you about the rare disease community?

I am most inspired by the rare disease community and how invisible they are until you are one of them. Each rare disease community is small until patients, families and caregivers get together under NORD to tell their stories, advance legislation and work with clinicians and pharma to move things forward. This rare space has some of the most precious people in it!