



Melanie F. (California)



What is your connection to rare disease?

I have experienced rare disease symptoms since I was a child. My first notable attack was a hospitalization when I was 23 years old. It took 22 years and an attack of optic neuritis, which caused me to lose my vision in my left eye, for doctors to finally put the puzzle pieces together about what I was going through. I was subsequently diagnosed with seronegative NMOSD with Sjogren's syndrome.

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

Being diagnosed with a rare disease and the adversity I have faced since my diagnosis, has ignited a commitment in me to help other patients with rare diseases. In the short term, I'd like to ensure that a Rare Disease Advisory Council is established in California (where I live) and the many other states throughout the US where there is not one. I would also like to get the Interstate Medical Licensure Compact passed in all 50 states throughout the US, ensuring that all rare disease patients can access the specialist care they need.

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

NORD has helped me immensely. I looked to NORD for resources for my disease when I was first diagnosed, and they have also been instrumental in supplying a road map and information during the exploratory phase of setting up my own foundation in California to support rare disease patient advocacy.

What inspires you about the rare disease community?

I'm inspired by the resilience, positivity, and hope of each and every single fellow patient, caregiver, and community member I meet. We didn't choose this life, but I have met some of the most fierce people I have ever known.