



Nicole I. (Illinois)



What is your connection to rare disease?

My son Noah was diagnosed with Malan Syndrome in November of 2021 at the age of two.

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

I am hoping to gain the knowledge and platform to advocate on the state level, and help others do the same for themselves, or a loved one living with a rare disease. I want to push for change, as I too had to fight for answers and testing to receive my son's diagnosis.

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

The Malan Syndrome community has been so helpful along our journey and I am so glad we have them.

What inspires you about the rare disease community?

HOPE. With Noah's diagnosis, and at such a young age; it was easy to lose hope of what his future would look like. I have learned through my son to live in the NOW, and enjoy all the Noah milestones that he accomplishes on his own timeline. People living with a rare disease are fighting their own battles daily, but the strength they have to enjoy life as it comes, is incredible. I have also found that the caregivers supporting their rare disease loved ones is a whole new family you never knew you needed. The support, love, and advocacy that you can have through this new community is beyond words. What felt like such a lonely journey, became more of an incredible community!