



**Nick K. (Colorado)**



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

My connection to rare is my 5-year-old daughter, who has a rare disease called cystinosis, which affects 1 in 2,000 worldwide.

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

I'm looking forward to working on policy that can help benefit all of us in the rare disease community.

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

NORD has been a tremendous resource. In 2022 we were able to establish a [Rare Disease Advisory Council](#) here in Colorado. It's a great first step in getting everyone involved with rare diseases to collaborate and push future policy forward.

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

I'm inspired by my daughter each and every day. She has an incredible outlook on life and doesn't let complications from her condition slow her down. She's a ray of sunshine in a 5-year-old body and she motivates me every day with her resilience.