



Aaron B. (Mississippi):



What is your connection to rare disease?

I have an ultra-rare genetic bone disease called Hypophosphatasia.

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

I hope to help more people get involved in rare disease policy. Policy is an amazing way to enact change for patients and to help bridge those gaps we face in our own care and in our own states.

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

I've used NORD for information on my disease, policy updates and even help navigating some of the financial aspects related to living with a rare disease.

What inspires you about the rare disease community?

The resiliency of rare disease patients. We face some pretty big obstacles and most rare diseases don't have a treatment and getting a diagnosis is very hard and then finding people with your disease is hard because of how rare it is. To face all of that and still be such a strong community and band together across disease states is truly inspiring.