

Back-to-School Kit

Letter | Pre-K/Elementary

Dear child with a rare neuroimmune disorder,

Hi there! I wanted to write you this letter—my name is Ireland and I also have a rare neuroimmune disorder called neuromyelitis optica spectrum disorder, or for short, NMOSD. I got sick with it when I was six years old, and I am now 22. I have a job at the Siegel Rare Neuroimmune Association where I help kids and adults with these conditions.

Growing up with this disorder meant that other kids my age didn't really understand me. I could not walk for very long, and I had a lot of pain in my legs that made it hard to stand up. Even standing up for the pledge of allegiance in school made me tired, and recess was not as much of a good time for me as it was for others my age.

The other kids often would make fun of me for not being able to play tag or other games where I would need to run around. The way my body looked after steroids also confused them—and me! My body didn't look like me, and couldn't run like I could. With time, I became used to the way my body now worked and looked, and I learned to love myself once again.

When a problem happens like people not understanding you and your disorder, you should always talk to your parents and teachers. They are the people in your life who care about you the most, and they will try to help you sort things out.

Don't forget—you are not alone! The things you are facing have been faced by others, too. It was really hard some days, but not every day was bad. I could have let these things stop me, but I made good choices and made friends even though I have this disorder. The friends I made don't care whether I have this disorder or not—they like me for me, and I'm so grateful to have them in my life.

For now, take care of yourself and your body as best you can. Spend time with the people who love you, and love them back. If you have any struggles you're facing that you need advice on, talk to your parents or legal guardians. I've given them my email, so they can reach out at any time. I'd be more than happy to help in any way I can!

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