

Back-to-School Kit

Letter | Middle/High School

Dear young person living with a rare neuroimmune disorder,

Hello! I wanted to reach out to you through this letter. My name is Ireland, and I also have a rare neuroimmune disorder called neuromyelitis optica spectrum disorder (NMOSD). The initial onset of my illness was when I was six years old, and I finally got my diagnosis when I was eight years old. I'm now 22, and I just got my bachelor's degree in college. I work for the Siegel Rare Neuroimmune Association to help others with these conditions.

Growing up with this condition meant that other kids my age often didn't understand what I was going through. I couldn't walk for long periods, and I had a lot of neuropathy and muscle spasms in my legs that made standing up difficult. Even simple activities like standing for the pledge of allegiance in school made me tired, and recess wasn't ever enjoyable because I couldn't participate fully.

Sometimes, other kids would bully me because I couldn't stand for long periods of time and I couldn't run. The changes in my body's appearance from taking steroids also confused them—and it always tended to confuse me. I felt disjointed from my body—it didn't look like I used to look, and it couldn't move like I used to. With time, I became used to the way my body now worked and looked, and I learned to love myself once again.

Although my parents were heartbroken on my behalf that school was not the most welcoming environment to return to after my NMOSD impacted my health to such an extent, there wasn't much to be done—it seemed as though the other kids chose to be ignorant, and although I so badly wanted everyone to accept me, what really mattered were the friends who loved me regardless of whether I had an illness or not.

When you face challenges like this, it's important to talk to your parents and teachers. They care about you and can help you navigate difficult situations.

Remember, you're not alone in this. Many others have faced similar challenges. Although there were days at school that made me cry, moments with friends made it worth it. I'm grateful to have them in my life.

For now, take care of yourself as best as you can. Spend time with people who love you. If you need advice or someone to talk to about your struggles, don't hesitate to reach out! Your parents or legal guardians have my email and can contact me on your behalf anytime. I'm here to help however I can. We also often have teen support groups available. [Click here for our events page](#) to check if one is coming soon.

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