

Back-to-School Kit

Tips and Tricks on Social Reintegration

Dear Parent,

My name is Ireland Thomas, and I have neuromyelitis optica spectrum disorder (NMOSD). My age of onset was six years old, so I grew up with NMOSD and had to navigate the school system despite it. I work for the Siegel Rare Neuroimmune Association to help others with these conditions.

This guide is meant to share my experiences, insights, and offer some guidance as you embark on this journey with your child.

Understanding the Journey

Living with a rare neuroimmune disorder brings unique challenges, both physical and emotional. I have experienced the weight of these challenges firsthand. From hospitalizations to difficult days at school, these experiences can shape how we perceive the world around us. However, it's important to remember that your child's life, though different from what you might have imagined, can still be full of joy, achievements, and love.

Navigating Memories

Memory can be both a friend and a foe. I have a sharp memory, which means I can recall every detail of my experiences, both good and bad. This can be overwhelming, but I've learned to focus on positive memories, such as the joy of returning home after a long hospital stay or the beautiful experiences my parents made sure I had.

As a parent, it's essential to help your child create and cherish positive memories, even amidst the challenges. These moments will provide comfort and strength during tougher times.

The Power of Resilience

Your child is capable of leading a fulfilling life. Yes, it will be different, and yes, it will be hard at times, but it's not the end. I've learned to adapt to my condition by using tools like a wheelchair when needed and finding ways to manage pain through creative outlets like art and writing. Resilience doesn't always look perfect. There will be setbacks, but each one is an opportunity to overcome and grow stronger. Encourage your child to embrace their journey, and together, you will find ways to navigate the challenges.

The Importance of Advocacy

There may be times when you'll need to advocate fiercely for your child, especially in medical and educational settings. I have faced situations where doctors doubted my ability to improve, but with the support of my family, I pushed for the care I needed. Never hesitate to seek second opinions or pursue the best possible care for your child. Your advocacy can make a significant difference in their quality of life.



Looking Forward

Today, there are better treatment options and more knowledgeable doctors than when I was first diagnosed. The outlook for children with rare neuroimmune disorders is brighter than ever. Hold onto hope for your child's future—life expectancy and quality of life have improved dramatically. I have built a happy life, complete with friends, a relationship, and a pursuit of higher education. These are things I once thought were out of reach, but persistence and support have brought me here. Believe in your child's potential, and help them build a future filled with possibilities.

Education and Social Challenges

School can be a difficult environment for children with rare conditions. Accommodations are key, but social challenges may also arise. I faced bullying when I returned to school, and I want to help your child navigate similar situations. I've included some resources in this guide to assist you in advocating for your child's educational needs. If you need more personalized advice or support, please feel free to reach out to me directly. I am here to help in any way I can, whether that's through direct communication or by connecting you with SRNA's support groups.

Support and Resources

The Siegel Rare Neuroimmune Association offers a variety of support groups for families, children, and siblings. These groups can provide much-needed connection and understanding during challenging times.

Your child's diagnosis is not the end of their story. With resilience, support, and advocacy, they can lead a fulfilling and joyful life. This guide is just a starting point—for further support or to discuss your child's specific needs, please contact me at the email below. I am here to support you and your family every step of the way.

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Learn More

SRNA

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Back-to-School Kit Teacher's Guide

srna.ngo/bts-tg

Back-to-School Kit Parent's Guide

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