

Back-to-School Kit

Guide for Interested Parents

Dear parent,

One of your child's classmates has a rare neuroimmune disorder, so we here at the Siegel Rare Neuroimmune Association have developed this Back-to-School kit to keep you informed.

As an organization, we represent and support thousands of people who are impacted by rare neuroimmune disorders. Rare neuroimmune disorders can have a variety of impacts on a person's health, potentially causing blindness, paralysis, fatigue, brain fog, and many other symptoms.

While those with these conditions may experience life-altering damage to the brain, optic nerves, and/or spinal cord, aspects of social development may also be slightly delayed or even completely stagnated after the onset of these disorders.

We have developed a **comprehensive kit with information and resources on how to support a student with a rare neuroimmune disorder**, such as one of your child's classmates.

- Kids are often curious, and they can ask rather pointed questions. If a child with a rare neuroimmune disorder acts or appears different than their peers, your child may ask questions about the child's condition (i.e. *Why is Sarah sitting down and not running around playing with me?* or *Why does Sarah always get to leave class to use the bathroom whenever she likes, while I'm told to wait?*). It is important to stay informed of this child's condition so you can answer these questions correctly, and in whatever age-appropriate way you deem fit.
- Unfortunately, children can also bully or mistreat those they see as different. It is important to keep an eye out for such behaviors and intervene as needed.
- Children with rare neuroimmune disorders may react in different ways to their condition, particularly if they were recently diagnosed. Some may look to their peers for support, while others may isolate themselves. This can be prevented. Sometimes just a smile can keep a child going—and a friend, or many friends, can greatly help a child with a rare neuroimmune disorder. Encouraging your kids to be friends with everyone, including the child with the rare neuroimmune disorder, can assist in alleviating the depression and anxiety the child with an rare neuroimmune disorder may face.
- Consider talking with your child in an age-appropriate way about sickness. Many children don't fully grasp the idea of a lifelong illness, asking things like *When will Sarah get better?* or *Am I going to catch what Sarah has?* which can impact the child with an rare neuroimmune disorder, even if



it was an innocent question. There is not usually a full recovery from an rare neuroimmune disorder—it instead tends to consist of lifelong chronic symptoms, such as paralysis, blindness, or pain. There is no way to “catch” these illnesses, as they are not transmitted. Instead, they are inherent to the body of the child and are often triggered by their environment. Keeping your kids somewhat in the know can greatly assist those with rare neuroimmune disorders.

Thank you for taking the time to read this information. Disorder-specific back-to-school kits that detail the rare neuroimmune disorder the student has been diagnosed with can be found on the right side of this page. Please reach out to us if you have any questions about accessibility and inclusion in classrooms, questions about the disorders themselves, or if you have any suggestions on how we can better help students with rare neuroimmune disorders.

Ireland Thomas

Program Associate, Communications and Community Programs

ithomas@wearesrna.org



SRNA

PO Box 826962

Philadelphia, PA 19182-6962

phone: +1 (855) 380-3330

email: info@wearesrna.org

website: wearesrna.org

facebook.com/wearesrna

twitter.com/wearesrna

instagram.com/wearesrna