

Back-to-School Kit

Teacher's Guide

Dear teacher of a student with a rare neuroimmune disorder,

The Siegel Rare Neuroimmune Association has developed this Back-to-School Kit to help you best support your student with a rare neuroimmune disorder.

As an organization, we represent and support thousands of people who are impacted by rare neuroimmune disorders, which include conditions such as acute disseminated encephalomyelitis (ADEM), acute flaccid myelitis (AFM), MOG antibody disease (MOGAD), neuromyelitis optica spectrum disorder (NMOSD), optic neuritis (ON), and transverse myelitis (TM). These disorders can have a variety of impacts on a person's health, potentially causing blindness, paralysis, fatigue, brain fog, and many other symptoms.

We have developed a comprehensive kit with information and resources on how to support a student with a rare neuroimmune disorder. No one knows better than teachers how to best teach kids, and we hope providing this information will make your job easier.

The Importance of Accommodations in Education

The parent of a child with a rare neuroimmune disorder may request accommodations if needed. These accommodations help make learning—and life—easier for your student. Some common accommodations students with rare neuroimmune disorders may need include the ability to leave class to use the restroom whenever it is needed, longer exam periods, audible rather than visual media formats, and alternatives for some or all aspects of physical education.

Addressing Classroom Dynamics

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, you or the child may be asked 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?*). We ask that you keep yourself informed of this child's condition so you can answer these questions correctly, and in whatever age-appropriate way you deem fit.

It is important to stay informed of this child's condition so you can answer these questions correctly. 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.

Encouraging Social Development

Children with rare neuroimmune disorders may react in different ways to their condition, particularly if they were diagnosed recently. Some may look to their peers for support, while others may isolate themselves. We ask that you consider ways to keep your students with rare neuroimmune disorders engaged and help them find the friends they need to support them throughout their medical journey. Making sure to have group activities that fully allow their participation and engaging with them one-on-one can help bridge the gap and better unite them with their peers.



Inclusive Activities and Participation

Lastly, having activities that allow full participation is very important. It is important to reflect on the ways in which a child with a rare neuroimmune disorder may need different ways of accessing material.

Imagine an elementary school performance where all the students but one are standing in a circle, holding hands and singing. A little girl in a wheelchair with pink wheels is positioned away from the group, holding a bluebird stuffed animal. Although her teacher smiles at her, thinking this gesture and prop are enough to include her, the girl feels left out and is visibly upset. Her parents later expressed that the exclusion was not malicious but a thoughtless oversight. This scenario highlights the importance of genuine inclusion in all activities, ensuring that every child feels a part of the group. Activities like school performances can always be adapted so that anyone regardless of mobility can participate.

Thank you for taking the time to read this information. Disorder-specific back-to-school kits that detail the rare neuroimmune disorder your student has been diagnosed with can be found on the right side of this page, which we believe will help you better understand the condition. We at SRNA would like to thank you for your dedication. 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.

Additional Resources

SRNA

wearesrna.org

ADEM Back-to-School Kit

srna.ngo/bts-adem

AFM Back-to-School Kit

srna.ngo/bts-afm

MOGAD Back-to-School Kit

srna.ngo/bts-mogad

NMOSD Back-to-School Kit

srna.ngo/bts-nmosd

ON Back-to-School Kit

srna.ngo/bts-on

TM Back-to-School Kit

srna.ngo/bts-tm

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