



SRNA

connect. care. cure.

Siegel
Rare Neuroimmune
Association



**Founded in
1994**



**We are a team of
11 people**



**Supporting
15,351 people**



**From
121 countries**



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The Siegel Rare Neuroimmune Association (SRNA) **advocates** for, **supports** and **educates** individuals and their families diagnosed with acute disseminated encephalomyelitis, acute flaccid myelitis, MOG antibody disease, neuromyelitis optica spectrum disorder, optic neuritis, and transverse myelitis, and **accelerates** and **invests** in scientific research, therapy development and training of clinician-scientists dedicated to these disorders. Our end goal is to **improve the quality of life of individuals with rare neuroimmune disorders** and redouble our commitment to finding a cure. Together.

Connect

- **Walk-Run-N-Rolls**
 - Organized by community members
 - Raise awareness, fund education and research opportunities
 - Inform local community



Connect

- Support Group Network and Peer to Peer program
- Personalized support via phone calls and emails



Connect

- **Blogs and Magazines**

- Weekly blog posts and biannual magazine
- Stories from members, research summaries, announcements, event recaps, and urgent information
- Subscribe via email in addition to our magazine

SRNA Magazine

2020 | ISSUE 2

President's Column

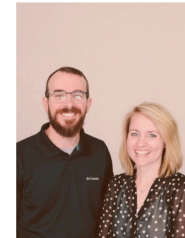
Can you imagine what changes are coming our way from the experiences we are currently having with The COVID? Some of these changes are going to be unimaginably profound.



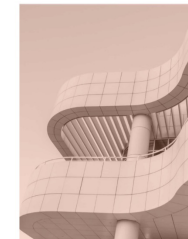
Magazine Archive



2020 | Issue 1



2019 | Fall



2019 | Summer



2019 | Winter



Connect

- **Family Camp**

- Unique opportunity
- Brings families affected by rare neuroimmune disorders together
- Connect with medical professionals
- Children, siblings included, connect with peers with similar situations



Connect

- Hope Ambassadors
- Collaboration/Partnership with other organizations
 - Increases awareness and support opportunities

Meet our Hope Ambassadors

A community of heroes for a common cause.

[BECOME A HOPE AMBASSADOR](#)



You have reached the Myelitis Helpline, an online tool that was developed by The Siegel Rare Neuroimmune Association to answer your questions about our organization and rare neuroimmune disorders, such as acute disseminated encephalomyelitis, acute flaccid myelitis, MOG antibody disease, neuromyelitis optica spectrum disorder, optic neuritis, and transverse myelitis.

The information on this site is provided for general information purposes and should not be relied on as a substitute for professional medical advice, care, treatment or for diagnosis. Do not change your medication or regime without talking to your doctor first.

If you are not a member of SRNA, we encourage you to become a member by visiting this [link](#). Membership is completely free and will allow you to stay up to date with our programs, events, and research.

1. What is the diagnosis you or your family member has been given?

- Acute Disseminated Encephalomyelitis or ADEM
- Neuromyelitis Optica Spectrum Disorder (NMOSD) or Devic's Disease
- Optic Neuritis
- Transverse Myelitis
- Acute Flaccid Myelitis
- MOG Antibody Disease
- Clinically Isolated Syndrome or suspected Multiple Sclerosis
- Multiple Sclerosis
- Spinal Stroke or AVM/Vascular Myelopathy
- Radiation Myelopathy
- No diagnosis has yet been given
- I do not have a rare neuroimmune disorder
- Other (please specify)

Resource Library

FILTER RESOURCES

To search for articles, newsletters, videos, and podcasts in the library, please use the categories on the left to access relevant information. For specific topics not listed below, please [contact us](#).

Search by keyword

Topic

Type of resource

Disorder

Date



Child Neurology Foundation: TM Information

Authoring Date: 2021-09-21

Disorders: Transverse Myelitis

Type of Resource: External Resource



Child Neurology Foundation: NMOSD Information

Authoring Date: 2021-08-26

Disorders: Neuromyelitis Optica Spectrum Disorder

Type of Resource: External Resource



COVID-19 Vaccines with Dr. Greenberg | Part VI

Authoring Date: 2021-08-19

Disorders: Applies to all

Type of Resource: Q&A



ABCs of NMOSD – Navigating Treatment Options

Authoring Date: 2021-08-19



RNDS OBJECTIVES



BIOLOGY AND CAUSES

Acquire an understanding of the biology and causes of rare neuroimmune disorders (TM, NMOSD, MOGAD, AFM, ADEM, and ON) and how they relate to each other



MANAGING SYMPTOMS

Learn about the latest medical and surgical strategies to manage the symptoms associated with these chronic rare neuroimmune disorders



RESEARCH AND STUDIES

Gain knowledge on current and future basic science research and clinical studies that will improve the quality of life of our community

Care

- Disorder Information Sheets
 - Available for all disorders
 - All website and printable publications from SRNA are reviewed by members of medical and scientific council

Fact Sheet

Acute Disseminated Encephalomyelitis

ADEM



Revised 5/27/2021 | This information sheet has been reviewed and approved by members of SRNA's Medical and Scientific Council.

ABCs OF NMOSD

Hosted by



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In collaboration with







AFM Physician Consult and Support Portal

The goal of the AFM Physician Support Portal is to **connect medical professionals and offer 24/7 consultation**. If you suspect a case of Acute Flaccid Myelitis (AFM) and would like to **schedule a consult with neurologists specializing in AFM** and other rare neuroimmune disorders, please complete the form below. We will help set up a **peer to peer consult** for clinical support from physicians at the University of Texas Southwestern's Transverse Myelitis Center or Johns Hopkins Myelopathy and Myelitis Center.

[+ For Medical Professionals](#)

[+ For Families & Caregivers](#)

Feedback

27
Shares




Cure

- We accelerate research to advance our understanding of
 - the causes and the natural history of these disorders
 - to develop new acute and restorative therapies
 - to improve the quality of life of those affected by these disorders
- Research to date has included:
 - CAPTURE study
 - The SRNA Registry
 - Study on experiences with vaccinations
 - COVID-19 survey




The James T. Lubin Clinician Scientist Fellowship Award


Objectives



PROVIDE HIGH QUALITY,
STATE-OF-THE-ART,
COMPREHENSIVE
CLINICAL CARE TO
PATIENTS WITH ADEM,
AFM, MOG-Ab DISEASE,
NMOSD, ON, AND TM



ADVANCE THE RESEARCH
AND UNDERSTANDING
OF THESE DISORDERS
THROUGH CLINICAL
RESEARCH AND/OR BASIC
SCIENCE RESEARCH



BECOME AN ACTIVE
PARTICIPANT AND
FUTURE LEADER IN THE
RARE NEUROIMMUNE
DISORDERS CLINICAL
COMMUNITY