



SRNA

connect. care. cure.

Siegel

Rare Neuroimmune

Association



**Founded in
1994**



**We are a team of
10 people**



**Supporting
15,351 people**



**From
121 countries**



Jeremy Bennett
Community Partnerships Manager



Jim Lubin
Executive Committee Member



Deborah Capen
Secretary



Linda Malecky
Vice President & Treasurer



GG deFiebre
Associate Director, Research & Education



Roberta Pesce
Creative Director | Strategy Design Lead



Krissy Dilger
Program Associate



Sandy Siegel
President



Chitra Krishnan
Executive Director



Rebecca Whitney
Pediatric Program Manager

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.

Education

- Disorder Information Sheets
 - Available for all disorders
 - All website and printable publications from SRNA are reviewed by members of medical and scientific council
- Peer reviewed scientific research summaries
 - Published in Newsletter, Blog, on our website
 - Summaries to allow accessibility to our community
- Resource Library
 - Over 460 publications, podcasts, symposia videos, newsletters, and more
- Rare Neuro-Immune Disorders Symposia (RNDS)
 - Large symposia every other year
 - Regional symposia
- 'Ask the Expert' Podcast series and ABCs of NMOSD

Education cont...

- SRNA Magazine
 - Subscribe via Email
 - Latest information re programs, community member stories, events, news, and research opportunities and summaries
- Blog
 - Weekly posts
 - Stories from members, research summaries, announcements, event recaps, and urgent information
 - Subscribe via email in addition to our newsletter
- 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

Support

- Walk-Run-N-Rolls
 - Organized by community members
 - Raise awareness, fund education and research opportunities
 - Inform local community
- Collaboration/Partnership with other organizations
 - Increases awareness and support opportunities
- Myelitis Helpline
 - Online resource-can answer individual questions
- Support Group Network
- Personalized support via phone calls and emails
- AFM Physician Support Portal

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](#)

Research and Training

- 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

CAPTURE: 2014 to 2026

- CAPTURE: Collaborative Assessment of Pediatric Transverse Myelitis: Understand, Reveal, Educate
 - Multi-center pediatric transverse myelitis/acute flaccid myelitis study led by Dr. Benjamin Greenberg
 - The study was the first to combine assessments from health care providers and patients relative to pediatric outcomes
 - The collaboration involved multiple health care centers across North America, SRNA, and patients
 - Study included a survey at 3 (if able), 6, and 12 months after diagnosis and a review of treatment records and imaging.
 - Follow-up now will occur every 4 months until 2026 (26 patients so far have agreed to continue in follow-up)

SRNA Registry

- In early 2017, after months of planning, designing, and reviewing, we launched The SRNA Registry
- Ongoing registry to accelerate research across rare neuroimmune disorders
- Self-reported, with outcome measures
- Ability to participate in CORE™ study at UTSW

Experiences with vaccinations study

- In 2018, The SRNA also launched a study on experiences with vaccination before and after diagnosis with a rare neuroimmune disorder.
- The goal of the study is to understand and learn from our member community about their experiences with receiving vaccinations before and after a rare neuroimmune disorder diagnosis, with a focus on their experiences *after* diagnosis.
- Randomly selected 600 participants from our membership database
- Data analysis underway

COVID-19 Survey

- The intention of this research project is to describe the experiences of individuals with rare neuroimmune disorders during the COVID-19 pandemic.
- You can participate in this study if you are an individual with a rare neuroimmune disorder (acute disseminated encephalomyelitis, acute flaccid myelitis, MOG antibody disease, neuromyelitis optica spectrum disorder, optic neuritis, or transverse myelitis), or the parent or legal guardian of a child with one of these disorders.

The James T. Lubin Clinician Scientist Fellowship Award

- The James T. Lubin Clinician Scientist Fellowship Award, established in 2008, supports the post-residency training of clinicians committed to careers in academic medicine specializing in rare neuro-immune disorders of the CNS (ADEM, AFM, MOGAD, NMOSD, ON, and TM) clinical care and research.

2020 RNDS

Connection time!

Head to the Networking Area!

