



**SRNA**

connect. care. cure.

Siegel

Rare Neuroimmune

Association

# Education

- Disorder Information Sheets
  - specific for AFM - currently undergoing review & revision
  - 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
  - 270+ specifically for and related to AFM

# Education, cont...

- Rare Neuro-Immune Disorders Symposia (RNDS)
  - Open to all, attend lectures from experts in AFM and various workshops
  - Since 2015, lectures specific to AFM and included in every RNDS since
  - 2019 RNDS, most recent
  - 2020 Regional RNDS planned; will include AFM specific lectures
- 'Ask the Expert' Podcast series
  - Community driven; topic specific
  - Many relevant to more than AFM or all disorders however we include disorder specific topics as well
  - 1<sup>st</sup> AFM podcast was in 2014 with Dr. Greenberg & Dr. Schreiner
  - AFM specific podcasts w/ family members as well as public health officials
  - AFM community members as volunteer moderators; e.g. nerve transfers, a very specific and unique treatment for AFM
  - Special AFM Podcast series beginning in July through the summer & fall; will be in collaboration with AFM WG members, AFMA, and public health

# 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 AFM together
  - Connect with medical professionals
  - Children, siblings included, connect with peers with similar situations



# Support

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

## 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
- AFM-specific research to date has included:
  - CAPTURE study
  - The SRNA Registry
  - Study on experiences with vaccinations

# 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
- 22 participants with an AFM diagnosis

# 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
- 5 AFM diagnoses
- Data analysis underway

# 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.

# Coping and adjustment: Keeping kids motivated



Margaret Tunney, PsyD

*Licensed Psychologist*

*Pediatric Psychology Inpatient Consultation & Liaison Coordinator*

*Kennedy Krieger Institute*

*Instructor, Department of Psychiatry & Behavioral Sciences*

*Johns Hopkins University School of Medicine*