

2026 RNDs

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A three-day hybrid educational
conference for those affected by
rare neuroimmune disorders

October 15 - 17, 2026

Hosted by



Siegel
Rare Neuroimmune
Association



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Welcome to the 2026 RNDS, the three-day educational conference for those affected by rare neuroimmune disorders – acute disseminated encephalomyelitis (ADEM), acute flaccid myelitis (AFM), MOG antibody disease (MOGAD), neuromyelitis optica spectrum disorder (NMOSD), optic neuritis (ON), and transverse myelitis (TM). This conference is dedicated to the exchange of information regarding diagnosis, research, and treatment strategies. It is also an opportunity to bring together the community of individuals diagnosed with rare neuroimmune disorders, families, caregivers, and the medical professionals who specialize in these disorders. **This hybrid event will take place both online and in person at the Hyatt Regency DFW Airport, 2334 N. International Pkwy, Dallas, TX 75261.**

Objectives

- Gather an understanding of the knowledge to date on the biology, causes and diagnosis of rare neuroimmune disorders and how they relate to each other,
- Understand controversies and challenges with rare neuroimmune disorders, and
- Learn about the latest research advances, and strategies for management and treatment.

Audience

This conference is open to all individuals diagnosed with rare neuroimmune disorders, their families, and caregivers. Medical professionals interested in these disorders are also welcome to attend.

Program Agenda (TIMES LISTED IN CT)

Thursday October 15

1:00 - 2:00 pm **Registration and meet and greet**
Let us know you have arrived, collect your badge and network with attendees and speakers, and meet our sponsors and exhibitors.

2:00 - 2:15 pm **Welcome remarks and conference orientation**
Sandy Siegel, PhD | Siegel Rare Neuroimmune Association
Benjamin Greenberg, MD, MHS | University of Texas Southwestern
Carlos A. Pardo, MD | Johns Hopkins University

Diagnosis and Acute Treatment of Rare Neuroimmune Disorders

This session presented by medical experts and community members will focus on the diagnostic journey and new diagnostic criteria.

2:15 - 3:15 pm **“What’s my diagnosis?” Community members share their diagnostic journey**
Moderated by Benjamin Greenberg, MD, MHS | University of Texas Southwestern

Program Agenda ...CONTINUED

- 3:15 - 3:45 pm** **Diagnostic workup masterclass: medical professionals share insight on diagnostic tests and criteria**
Carlos A. Pardo, MD | Johns Hopkins University
Benjamin Greenberg, MD, MHS | University of Texas Southwestern
- 3:45 - 4:20 pm** **New diagnostic criteria update: transverse myelitis**
Kyle Blackburn, MD | University of Texas Southwestern
- 4:20 - 4:55 pm** **New diagnostic criteria update: neuromyelitis optica spectrum disorder**
TBD
- 4:55 - 5:00 pm** **DAY ONE WRAP UP**

Friday
October 16

- 8:30 - 9:00 am** **Breakfast, networking, and exhibitor time**
- 9:00 - 9:10 am** **Day two kickoff: “Quality of life as a clinical outcome”**
Carlos A. Pardo, MD | Johns Hopkins University

Long-Term Therapy and Management of Symptoms

These sessions will focus on symptom management following a rare neuroimmune diagnosis.

- 9:10 - 9:30 am** **Pain and sensory symptoms toolkit**
Shuvro Roy, MD | University of Washington
- 9:30 - 9:50 am** **Spasticity management and mobility**
TBD
- 9:50 - 10:10 am** **Bladder and bowel management strategies**
Janet Dean, MS, RN, CRRN, CRNP | Kennedy Krieger Institute
- 10:10 - 10:30 am** **Fatigue, sleep, and cognition**
Bardia Nourbakhsh, MD, MAS | Johns Hopkins University
- 10:30 - 10:45 am** **COFFEE BREAK**
- 10:45 - 12:00 pm** **Breakout Sessions (to run concurrently)**
These breakout sessions provide an opportunity for attendees to engage in smaller, more focused discussions tailored to pediatric or adult experiences with rare neuroimmune disorders.
- Pediatric Sessions**
- 10:45 - 11:10 am** **Pediatric symptom toolkit: fatigue, pain, mobility, and bladder/bowel routines**
TBD

Program Agenda ...CONTINUED

11:10 - 11:35 am **School supports 101: IEP/504, accommodations, and advocacy**
Yuri Shishido, PhD, ABPP | Children's Healthcare of Atlanta

11:35 - 12:00 pm **Family resilience: siblings, mental health, and building independence**
Camille S. Wilson, PhD | Nationwide Children's Hospital

Adult Sessions

10:45 - 11:10 am **Sexual dysfunction and intimacy**
TBD

11:10 - 11:35 am **Getting back to work**
Janelle Hewitt | U.S. Department of Veterans Affairs

11:35 - 12:00 pm **Funding and equipment navigation**
Sandy Hanebrink | Touch the Future, Inc

12:00 - 1:00 pm **LUNCH, MEET AND GREET, AND CAMP INFO SESSION**
Janet Dean, MS, RN, CRRN, CRNP | Kennedy Krieger Institute

Can Do Multiple Sclerosis (CDMS) Sessions

(IN-PERSON ONLY AND ONLY FOR THOSE DIAGNOSED AND THEIR CARE PARTNERS)

SRNA is proud to partner with Can Do Multiple Sclerosis (CDMS) to offer the TAKE CHARGE® Program for those diagnosed with rare neuroimmune disorders. This is a one-of-a-kind program to learn how you can take charge of your disease, your healthcare and your life. The goal of this program is to find support from who people who really get it, find solutions to manage your disease and find guidance for navigating the healthcare system.

1:00 - 1:10 pm **Can Do MS welcome**

1:10 - 1:30 pm **Living with a rare condition: the emotional reality**

1:30 - 2:15 pm **Building strategies and tools to manage fatigue and pain**

2:15 - 3:00 pm **Can Do MS breakouts (choose one):**

1) What does it mean to maintain independence and live fully?

2) What does it mean to thrive and survive as a care partner (session exclusively for care partners)

3:00 - 3:30 pm **Communications skills and what you CAN DO going forward**

Program Agenda ...CONTINUED

3:30 - 3:45 pm **COFFEE AND NETWORKING BREAK**

Collaborative Workshop and Symptom Management Q&A

These sessions feature an interactive collaborative workshop focused on practical day-to-day strategies, accessibility, and funding resources, followed by an open Q&A where attendees can ask experts questions about symptom management and living with rare neuroimmune disorders.

3:45 - 4:25 pm **Community Solutions Lab: “What works for me” + funding pathways**

*Sandy Hanebrink | Touch the Future, Inc
SRNA Staff*

4:25 - 4:55 pm **Ask the experts: symptom management open Q&A**

*Shuvro Roy, MD | University of Washington
Janet Dean, MS, RN, CRRN, CRNP | Kennedy Krieger Institute
Bardia Nourbakhsh, MD, MAS | Johns Hopkins University*

4:55 - 5:00 pm **DAY TWO WRAP UP**

5:00 - 7:00 pm **EVENING RECEPTION (IN-PERSON ONLY)**

The reception offers an opportunity for community members to mingle and meet others with similar experiences. Enjoy dinner and a chance to converse with other attendees.

Saturday October 17

8:30 - 9:00 am **Breakfast**

9:00 - 9:10 am **Day three kickoff: “Research that changes lives”**

Michael Levy, MD, PhD | Massachusetts General Hospital

Research on Rare Neuroimmune Disorders

Learn about the latest basic science, clinical, medical and surgical advances in the field of rare neuroimmune disorders.

9:10 - 9:50 am **State of the science across rare neuroimmune disorders and clinical trials panel**

*Carlos A. Pardo, MD | Johns Hopkins University
Benjamin Greenberg, MD, MHS | University of Texas Southwestern*

9:50 - 10:10 am **How to get involved in research**

TBD

10:10 - 10:30 am **Research talk - TBD**

10:30 - 10:50 am **COFFEE BREAK**

10:50 - 11:10 am **Q Study updates**

Benjamin Greenberg, MD, MHS | University of Texas Southwestern

Program Agenda ...CONTINUED

- 11:10 - 11:30 am** **Research on NMOSD preventive treatments and quality of life**
Sydney Lee, MD | University of Utah
- 11:30 - 11:50 am** **Research Talk - TBD**
- 11:50 - 12:50 pm** **LUNCH**
- 12:50 - 1:10 pm** **Research Talk - TBD**
- 1:10 - 1:30 pm** **Research Talk - TBD**
- 1:30 - 1:50 pm** **Research Talk - TBD**
- 1:50 - 2:10 pm** **BREAK**
- 2:10 - 2:30 pm** **Research Talk - TBD**
- 2:30 - 2:50 pm** **Research on predicting MOGAD patients at risk for relapse**
Linda Nguyen, MD | University of Texas Southwestern
- 2:50 - 3:10 pm** **Research Talk - TBD**
- 3:10 - 3:30 pm** **Research Talk - TBD**
- 3:30 - 3:50 pm** **Research Talk - TBD**
- 3:50 - 4:50 pm** **Open Q&A: research and clinical care**
Sydney Lee, MD | University of Utah
- 4:50 - 5:00 pm** **Closing remarks**
Benjamin Greenberg, MD, MHS | University of Texas Southwestern

2026 SPONSORS

All educational content and programs are solely developed by SRNA staff, members of the SRNA scientific board and approved by SRNA Board of Directors.



2026RNDS

Friday - Sunday

October 15 - 17 2026

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