



2024 RNDS

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

October 18 - 20, 2024

Hosted by



SRNA
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Siegel
Rare Neuroimmune
Association



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 **Inspired by patients.
Driven by science.**

Welcome to the 2024 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)

Friday October 18

8:00 - 9:00 am **Breakfast, 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.

9:00 - 9:20 am **Welcome remarks**
Sandy Siegel, PhD | Siegel Rare Neuroimmune Association
Benjamin Greenberg, MD, MHS | University of Texas Southwestern

Diagnosis and Acute Treatment of Rare Neuroimmune Disorders

The morning session presented by medical experts and community members will focus on the diagnostic journey, diagnostic criteria, acute treatments and understanding relapses.

9:20 - 10:20 am **“What’s my diagnosis?” Community members share their diagnostic journey**
Angela Jackson, Andrew Jopson, Ashley Harrington, Lyd Lacey and Andreas Melitsanopoulos

Program Agenda ...CONTINUED

10:20 - 10:45 am **“What’s my diagnosis?” Physician Panel Discussion based on the community panel presentations**

Carlos A. Pardo, MD | Johns Hopkins University
Benjamin Greenberg, MD, MHS | University of Texas Southwestern
Michael Levy, MD, PhD | Massachusetts General Hospital
Tammy Smith, MD, PhD | University of Utah
Leslie Benson, MD | Boston Children’s Hospital

10:45 - 11:00 am **NETWORKING AND COFFEE BREAK**

11:00 - 11:30 am **Rare neuroimmune disorders: Diagnostic criteria**

Kyle Blackburn, MD | UTSW Medical Center
Shruti Mahale | UTSW Medical Center

11:30 - 11:55 am **Plasma exchange for acute inflammatory demyelination: How we got here and where to next?**

Brian Weinshenker, MD | UVA Health - recorded

11:55 - 12:20 pm **A conversation: How do I identify a relapse?**

Cynthia Wang, MD | UTSW Medical Center
Rebecca Salky, RN | Massachusetts General Hospital | Community member

12:20 - 1:15 pm **LUNCH | MEET AND GREET**

Breakout Sessions

The disorder specific breakout sessions will offer an opportunity for attendees to engage with experts and participate in an informal learning environment.

1:30- 3:00 pm **In-Person Breakout Session I: NMOSD**

Dean Wingerchuk, MD | Mayo Clinic
Tammy Smith, MD, PhD | University of Utah
Peter Sguigna, MD | UTSW Medical Center

1:30- 3:00 pm **In-Person Breakout Session II: MOGAD and ADEM**

Michael Levy, MD, PhD | Massachusetts General Hospital
Grace Gombolay, MD | Emory University SOM/Children’s Healthcare of Atlanta
Teri Schreiner, MD,MPH | University of Colorado

1:30 - 3:00 pm **In-Person Breakout Session III: TM and AFM**

Leslie Benson, MD | Boston Children’s Hospital
Carlos A. Pardo, MD | Johns Hopkins University
Benjamin Greenberg, MD, MHS | University of Texas Southwestern

1:30 - 3:00 pm **Hybrid Session: Care for the Caregiver**

Paula Hardeman, MPAS, PA-C | University of Texas Southwestern
Jeff Harrington | Community member

Program Agenda ...CONTINUED

3:00 - 3:15 pm **NETWORKING AND COFFEE BREAK**

Long-term Therapy and Management of Symptoms Part I

This session will focus on long term therapies for NMOSD, MOGAD, and conversations with community members and experts on symptom management.

3:15 - 3:45 pm **Management of neuropathic pain: medical and surgical options**

Paula Barreras Cortes, MD | Cedars Sinai

Michael Levy, MD, PhD | Massachusetts General Hospital

Jacqueline Nicholas, MD | Ohio Health

3:45 - 4:15 pm **Management of spasticity**

Cristina Sadowsky, MD | Kennedy Krieger Institute

4:15 - 4:45 pm **Management of sexual dysfunction**

TBD

4:45 - 5:15 pm **Management of bladder and bowel dysfunction**

Janet M. Dean, MS, RN, CRRN, CRNP | Kennedy Krieger Institute

Philippines Cabahug, MD | Kennedy Krieger Institute

5:30 - 7:30 pm **EVENING RECEPTION**

The reception offers an opportunity to mingle and get to know each other. We will also reflect on 30 years of SRNA, and our community since SRNA's founding in 1994.

Keybote by Doug Kerr, MD, PhD | Atlas Venture

**Saturday
October 19**

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

Research on Rare Neuroimmune Disorders Part I

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

9:00 - 9:20 am **TBD**

Haiwen Chen, MD, PhD | Johns Hopkins University

9:20 - 9:40 am **Advancements in ADEM & optic neuritis treatment with TRE-515: A clinical stage, dual orphan drug designated, first-in-class, deoxycytidine kinase inhibitor**

Kenneth A. Schultz, MD | Trethera

9:40 - 10:00 am **Cannabis use in rare neuroimmune disorders**

Melanie Delgado | Massachusetts General Hospital

10:00 - 10:20 am **Social determinants of health in TM**

Ka-Ho Wong, MBA | University of Utah

Program Agenda ...CONTINUED

10:20 - 10:35 am **NETWORKING AND COFFEE BREAK**

10:35 - 10:55 am **TBD**
Linda Nguyen, MD | University of Texas Southwestern

10:55 - 11:15 am **Muscle evoked potential operant conditioning (EPOC) to improve sensorimotor functions in people with spinal cord lesions**
Aiko Thompson, PhD | Medical University of South Carolina

Long-Term Therapy and Management of Symptoms Part II

These sessions will focus on long term therapies for NMOSD, MOGAD, and conversations with community members and experts on symptom management.

11:15 - 11:45 am **The mind-body connection in rare neuroimmune conditions: Exploring the relationship between mental health, fatigue, and cognition**
Lana Harder, PhD, ABPP | UTSW | Children's Medical Center Dallas
Natalie Escalante, PsyD | Children's Medical Center Dallas

11:45 - 12:30 pm **Rehabilitation strategies**
Janet M. Dean, MS, RN, CRRN, CRNP | Kennedy Krieger Institute
Cristina Sadowsky, MD | Kennedy Krieger Institute
Rajashree Srinivasan, MD | University of Texas Southwestern
Heakyung Kim, MD | University of Texas Southwestern
Clarice Sinn, DO | University of Kentucky
Paul Garrett | Community member

12:30 - 1:30 pm **LUNCH | MEET AND GREET**

1:30 - 2:00 pm **Management of visual symptoms**
Robert Shin, MD | University of Virginia

2:00 - 2:30 pm **Fatigue and rare neuroimmune disorders**
Bardia Nourbakhsh, MD | Johns Hopkins University
Julia Lefelar | The MOG Project | Community member

2:30 - 2:50 pm **How do advocacy and awareness organizations support our community?**
Julia Lefelar | The MOG Project
Leah Campbell | SRNA Peer Connect Leader
Jacinta Behne | Guthy-Jackson Charitable Foundation
Jasmine Patel, MPH | The Sumaira Foundation Patient Ambassador

2:50 - 3:15 pm **Aging: What to expect?**
Carlos A. Pardo, MD | Johns Hopkins University
Michael Levy, MD, PhD | Massachusetts General Hospital

3:15 - 3:30 pm **NETWORKING AND COFFEE BREAK**

Program Agenda ...CONTINUED

Living with a rare neuroimmune disorder

These sessions will focus on adaptive tools and resources in conversations with experts and community members.

3:30 - 4:00 pm

Disability: Adapting to and embracing disability

Cyrena Gawuga PhD, MSW | Community member

4:00 - 4:30 pm

Adaptive Tools and resources

Sandy Hanebrink, OTR/L, CLP, FAOTA | Touch the Future, Inc. | Community member

4:30 - 5:00 pm

Community perspectives panel: Navigating work, travel, setting boundaries, and more

Moderator: Benjamin Greenberg, MD, MHS | University of Texas Southwestern

Philip Rive | Community member

Rebecca Salky | Massachusetts General Hospital | Community member

Leah Campbell | Community member

Dinner and TAKE CHARGE® Program

(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. This is the first part of the education program with dinner.

5:00 - 5:30 pm

CHECK-IN | NETWORKING | BREAK

5:30 - 5:45 pm

Welcome and goal setting

Dinner Served

5:45 - 6:15 pm

Building your healthcare team

TBD

6:15 - 6:45 pm

Your questions answered: Open Q&A with healthcare providers

Sunday

October 20

8:00 - 9:00 am

Breakfast and check-in

TAKE CHARGE® Program **(IN-PERSON ONLY)**

This program is designed as smaller group workshops for those diagnosed and their support partners to learn about SMART goals, conversation starters and make lasting connections. Topics covered will include coping and adapting to change, managing movement and daily activity and achieving restorative sleep.

Program Agenda ...CONTINUED

	Welcome
9:00 - 9:15 am	
	Panel discussion: Managing your whole health
9:15 - 10:15 am	Coping and adapting Restorative sleep Nutrition Fatigue <i>TBD</i>
	NETWORKING COFFEE BREAK
10:15 - 10:45 am	
	Collaborate
10:45 - 11:45 am	1) <i>Getting through your day: Fatigue management</i> 2) <i>How to thrive and survive as a care partner</i>
	Reflect
11:45 - 12:00 pm	<i>Key take-aways</i>
	LUNCH MEET AND GREET
12:00 - 1:00 pm	
	Research on Rare Neuroimmune Disorders Part II
	This session will continue to focus on the latest basic science, clinical, medical and surgical advances in the field of rare neuroimmune disorders.
	Understanding genetics of rare neuroimmune disorders
1:00 - 1:20 pm	<i>Monique Anderson MD, PhD Massachusetts General</i>
	Updates on the Q- cells study
1:20 - 1:40 pm	<i>Benjamin Greenberg, MD, MHS University of Texas Southwestern</i>
	NMOSD and MOGAD clinical trials
1:40 - 2:00 pm	<i>Michael Levy, MD, PhD Massachusetts General Hospital</i>
	Advances in immunotherapies and tolerance
2:00 - 2:30 pm	<i>TBD</i>
	Open Q&A
2:30 - 3:00 pm	This session will be an open forum to engage with speakers and other attendees. <i>Darina Dinov, DO University of Texas Southwestern</i> <i>Denise Maddox, RN University of Texas Southwestern</i>

2024 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.



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Friday - Sunday

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Hyatt Regency DFW Airport

2334 N International Pkwy

Dallas, TX 75261

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srna.ngo/2024-rnds



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