



2024 RNDs

connect. care. cure.™

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

October 18 - 20, 2024

Hosted by



Siegel
Rare Neuroimmune
Association



UT SOUTHWESTERN
Medical Center



Presenting Education Sponsors



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**
Moderated by GG deFiebre, PhD | Siegel Rare Neuroimmune Association
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
Dean Wingerchuk, MD | Mayo Clinic

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

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

Kyle Blackburn, MD | University of Texas Southwestern
Shruti Mahale | University of Texas Southwestern

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 | University of Texas Southwestern
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 | University of Texas Southwestern

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

Michael Levy, MD, PhD | Massachusetts General Hospital
Grace Gombola, 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**

Frederick W. Foley, PhD | Yeshiva University

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

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.

Keynote by Doug Kerr, MD, PhD | Atlas Advisor; Chief Medical Officer, Dyme Therapeutics

**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 **Synaptic dysfunction in rare neuroimmune disorders**

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 **Clinical analysis of children presenting with ADEM with or without MOG-IgG**
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 | University of Texas Southwestern | Children's Medical Center Dallas
Natalie Escalante, PsyD | Children's Medical Center Dallas

11:45 - 12:30 pm **Rehabilitation strategies**
Moderated by Rebecca Whitney, RN | Siegel Rare Neuroimmune Association
Cristina Sadowsky, MD | Kennedy Krieger Institute
Heakyung Kim, MD | University of Texas Southwestern
Clarice Sinn, DO | University of Kentucky

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

1:30 - 2:00 pm **Management of visual symptoms**
Peter Sguigna, MD | University of Texas Southwestern
Kory S. Cummings, OD

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?**
Moderated by Leah Campbell | SRNA Peer Connect Leader
Julia Lefelar | The MOG Project
Jacinta Behne | Guthy-Jackson Charitable Foundation
Jasmine Patel, MPH | The Sumaira Foundation

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**
Moderated by 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, goal setting and dinner served**
Roz Kalb, PhD | Can Do MS
- 5:45 - 6:15 pm** **Building your healthcare team**
Roz Kalb, PhD | Can Do MS
Lauren Tardo, MD | University of Texas Southwestern
- 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

9:00 - 9:15 am

Welcome

Roz Kalb, PhD | Can Do MS

9:15 - 10:15 am

Panel discussion: Managing your whole health

Coping and adapting | Restorative sleep | Nutrition | Fatigue

Roz Kalb, PhD | Can Do MS

Katherine Chapman, LCSW, CRND | University of Texas Southwestern

Paula Hardeman, MPAS, PA-C | University of Texas Southwestern

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

10:15 - 10:45 am

NETWORKING | COFFEE BREAK

10:45 - 11:45 am

Collaborate

Getting through your day: Fatigue management

Paula Hardeman, MPAS, PA-C | University of Texas Southwestern

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

How to thrive and survive as a care partner

Roz Kalb, PhD | Can Do MS

Katherine Chapman, LCSW, CRND | University of Texas Southwestern

11:45 - 12:00 pm

Reflect: Key take-aways

Roz Kalb, PhD | Can Do MS

12:00 - 1:00 pm

LUNCH | MEET AND GREET

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.

1:00 - 1:20 pm

Understanding genetics of rare neuroimmune disorders

Monique Anderson MD, PhD | Massachusetts General Hospital

1:20 - 1:40 pm

Update on the Q-cells study

Benjamin Greenberg, MD, MHS | University of Texas Southwestern

1:40 - 2:00 pm

NMOSD and MOGAD clinical trials

Michael Levy, MD, PhD | Massachusetts General Hospital

2:00 - 2:30 pm

Advances in immunotherapies and tolerance

Michael Yeaman, PhD | UCLA

2:30 - 3:00 pm

Open Q&A

Darina Dinov, DO | University of Texas Southwestern

Denise Maddox, RN | University of Texas Southwestern

Cynthia Wang, MD | University of Texas Southwestern

Sydney Lee, MD, FRCPC | University of Utah

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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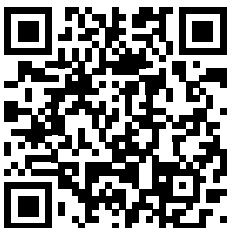
Hyatt Regency DFW Airport

2334 N International Pkwy

Dallas, TX 75261

More info:

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SRNA
PO Box 826962
Philadelphia, PA 19182-6962

phone: +1 (855) 380-3330
email: info@wearesrna.org
website: wearesrna.org

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