# Regional 2023 RNDS connect. care. cure. The connect is care.

A one-day education and advocacy conference for those affected by rare neuroimmune disorders

# Saturday, October 7, 2023

T. Boone Pickens AuditoriumUniversity of Texas Southwestern6001 Forest Park Rd, Dallas, TX 75235

Hosted by



Siegel Rare Neuroimmune Association



Sponsors









**Welcome to the 2023 RNDS** — The one-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, hosted by the Siegel Rare Neuroimmune Association (SRNA) and University of Texas Southwestern (UTSW), 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 are specializing in these disorders.

# **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.

## Agenda (TIMES LISTED IN CT)

#### **Saturday** October 7

#### 8:30 - 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 - 9:15 am Welcome

Sandy Siegel, PhD | Siegel Rare Neuroimmune Association Benjamin Greenberg, MD, MHS | University of Texas Southwestern Medical Center

#### Unlocking Controversies in Rare Neuroimmune Disorders

The following topics will be conducted as panel discussions to understand, clarify, debate and learn about the challenges in rare neuroimmune disorders, and answer questions from the audience.

# 9:15 - 10:00 am Unlocking the diagnostic odyssey: Understanding a diagnosis of ADEM, AFM, MOGAD, NMOSD, ON, and TM

Kyle Blackburn, MD | University of Texas Southwestern Medical Center

#### 10:00 - 10:45 am

# Unlocking controversies around causation: The role vaccinations, infections, environmental triggers, and genetics play in ADEM, AFM, MOGAD, NMOSD and TM

In this panel discussion, the speakers will review current understanding and knowledge, and answer questions from the community

Michael Levy, MD, PhD | Massachusetts General Hospital Benjamin Greenberg, MD, MHS | University of Texas Southwestern Medical Center

#### 10:45 - 11:00 am

BREAK

#### 11:00 - 11:30 am

#### Is it a relapse or recurrence?

What are relapses and how do I recognize them to seek medical care?

Lauren Tardo, MD | University of Texas Southwestern Medical Center

#### 11:30 - 12:15 pm

#### Deliberations on acute and long-term treatment guidance

Are all acute treatments the same? What are approved and off-label therapies? Can steroids worsen acute flaccid myelitis? When do we treat for MOGAD? When should we change treatments?

Benjamin Greenberg, MD, MHS | University of Texas Southwestern Medical Center Michael Levy, MD, PhD | Massachusetts General Hospital

#### 12:15 - 1:15 pm

**LUNCH AND MEET & GREET** 

## **Living with Rare Neuroimmune Disorders**

The following sessions will focus on management of symptoms in main and breakout sessions to help improve quality of life after a diagnosis with a rare neuroimmune disorder. All sessions will include a Q&A for attendees to ask their questions and foster interaction.

#### 1:15 - 2:00 pm

#### **Breakout Sessions**

#### Rehabilitation and recovery

Rajashree Srinivasan, MD | University of Texas Southwestern Medical Center

#### Care for the caregivers

Paula Hardeman, MPAS, PA-C | University of Texas Southwestern Medical Center Katherine Chapman, LCSW | University of Texas Southwestern Medical Center

#### Cognition, depression and rare neuroimmune disorders

Lana Harder, PhD, ABPP | University of Texas Southwestern Medical Center

2:00 - 2:45 pm Symptom management panel

Lindsay Horton, MD | University of Texas Southwestern Medical Center

Crystal Wright, MSN, APRN, AGPCNP-BC | University of Texas Southwestern Medical Center

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

Heakyung Kim, MD | University of Texas Southwestern Medical Center

2:45 - 3:15 pm Urological management in rare neuroimmune disorders

Micah Jacobs, MD | University of Texas Southwestern Medical Center

3:15 - 3:30 pm BREAK

#### Research Advances and the Future of Rare Neuroimmune Disorders

These sessions will provide updates on new therapeutics, research studies and provide an opportunity for dialogue and discussion. All sessions will include a Q&A for attendees to ask their questions and foster interaction.

3:30 - 4:00 pm Neuropathic pain research

Diana Tavares Ferreira, PhD | Center for Advanced pain studies | University of Texas Dallas

4:00 - 4:30 pm Clinical trials in MOGAD, NMOSD and more

Cynthia Wang, MD | University of Texas Southwestern Medical Center

**4:30 - 5:00 pm** AQP4/MOG tolerization research

Peter Sguigna, MD | University of Texas Southwestern Medical Center

5:00 - 5:30 pm An update on study to investigate the safety of the transplantation of human glial

restricted progenitor cells into patients with transverse myelitis

Benjamin Greenberg, MD, MHS | University of Texas Southwestern Medical Center

**5:30 - 5:35 pm** Closing

5:35 - 7:00 pm **RECEPTION** 

# **2023 SPONSORS**

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









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#### More info:

srna.ngo/2023-rnds

