

# 2019 RNDS

**Thursday - Saturday, September 19 - 21, 2019**

Crowne Plaza, Columbus – Downtown, OH



The Transverse Myelitis  
Association



CONQUER  
Collaboration on Neuroimmunology  
Question, Understand, Educate, Restore



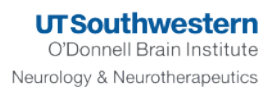
JOHNS HOPKINS  
TRANSVERSE MYELITIS  
CENTER



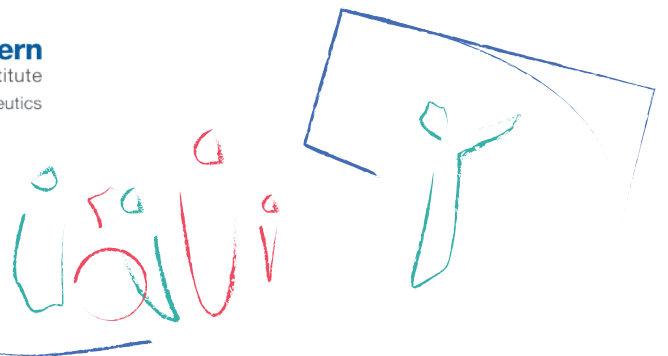
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**Welcome to the 2019 Rare Neuroimmune Disorders Symposium**, a conference dedicated to the exchange of information about diagnosis, research, and treatment strategies of rare neuroimmune disorders. It also provides an opportunity to bring together individuals diagnosed with rare neuroimmune disorders, their families, caregivers, and the medical professionals who are specializing in these disorders.

You will learn about acute disseminated encephalomyelitis (ADEM), acute flaccid myelitis (AFM), MOG antibody-associated disease (MOG-Ab disease), neuromyelitis optica spectrum disorder (NMOSD), optic neuritis (ON), and transverse myelitis (TM), receive updates on the latest clinical and research advances, and learn from each other.

## Objectives

- Gather an understanding of the latest knowledge on the biology and causes of rare neuroimmune disorders (ADEM, AFM, MOG-Ab disease, NMOSD, ON, and TM) and how they relate to each other.
- Learn about the latest medical and surgical strategies to manage the symptoms associated with these chronic disorders.
- Gain knowledge on current and upcoming scientific research and clinical studies that will improve the quality of life of our community.

***All presentations will be video-recorded and made available at [myelitis.org](http://myelitis.org)***

## Agenda

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### Thursday, September 19

- |                |                               |
|----------------|-------------------------------|
| 5:00 - 5:30 pm | Registration Begins           |
| 5:30 - 7:30 pm | Welcome Reception and Connect |

### Friday, September 20

- |                |   |
|----------------|---|
| 7:00 - 8:00 am | Breakfast and registration  |
| 8:00 - 8:15 am | <b>Welcome and Goals of the 2019 RNDS</b><br>Sandy Siegel, PhD   President, the TMA   |
| 8:15 - 9:00 am | <b>Living with a Rare Neuroimmune Disorder: Sharing Stories and Experiences</b><br>Moderated Discussion with Members of our Community |

## Agenda ...CONTINUED

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- 9:00 - 9:30 am**                    **Stronger Together: Why Study These Disorders Collectively?**  
Benjamin Greenberg, MD, MHS | University of Texas Southwestern and Children's Medical Center
- 9:30 - 12:15 pm**                    **Sessions on the Diagnosis and Treatment of Rare Neuroimmune Disorders: Pediatric and Adult**
- 9:30 - 10:00 am**                    **Transverse Myelitis**  
Michael Sweeney, MD | University of Louisville
- 10:00 - 10:30 am**                    **Acute Flaccid Myelitis**  
Sarah Hopkins, MD, MPH | Children's Hospital of Philadelphia
- 10:30 - 10:45 am**                    **Mid-morning Break**
- 10:45 - 11:15 am**                    **MOG Antibody-Associated Disease**  
Kyle Blackburn, MD | University of Texas Southwestern Medical Center
- 11:15 - 11:45 am**                    **Neuromyelitis Optica Spectrum Disorder**  
Michael Levy, MD, PhD | Massachusetts General Hospital and Harvard Medical School
- 11:45 - 12:15 pm**                    **Acute Disseminated Encephalomyelitis**  
Cynthia Wang, MD | University of Texas Southwestern Medical Center
- 12:15 - 1:15 pm**                    **Connect and Lunch**
- 1:15 - 1:45 pm**                    **Recurrent vs Monophasic Disorders**  
Cynthia Wang, MD | University of Texas Southwestern Medical Center
- 1:45 - 2:15 pm**                    **Vascular Myelopathies**  
Carlos Pardo-Villamizar, MD | The Johns Hopkins University School of Medicine
- 2:15 - 2:45 pm**                    **Myelitis in Systemic Rheumatologic Conditions**  
Michael Bradshaw, MD | Billing's Clinic
- 2:45 - 3:00 pm**                    **Updates from the TMA**  
TMA Staff
- 3:00 - 3:15 pm**                    **Afternoon Break**
- 3:15 - 4:15 pm**                    **The Future of NMOSD Therapeutics: What Have We Learned?**  
Michael Levy, MD, PhD | Massachusetts General Hospital and Harvard Medical School  
Benjamin Greenberg, MD, MHS | University of Texas Southwestern and Children's Medical Center  
Ankur Bhambri, DO | Alexion Pharmaceuticals  
Eliezer Katz, MD, FACS | Viela Bio

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## Agenda ...CONTINUED

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4:20 - 4:50 pm

### Small Group Workshop Sessions (select one topic in each session)

#### **SGWS I: Finding Medical Care in Your Area**

Denise Maddox, RN | University of Texas Southwestern and Children's Medical Center  
Katherine Treadaway, LCSW, MSCIR | University of Texas Southwestern Medical Center

#### **SGWS II: IEPs and 504s**

Anjali Forber-Pratt, PhD | Vanderbilt University  
Lana Harder, PhD | University of Texas Southwestern and Children's Medical Center

5:00 - 5:30 pm

### Small Group Workshop Sessions (select one topic in each session)

#### **SGWS III: ADA, Disability, and Benefits**

Anjali Forber-Pratt, PhD | Vanderbilt University  
Sandy Hanebrink, OTR/L, CLP, FAOTA | Touch the Future, Inc.  
Katherine Treadaway, LCSW, MSCIR | University of Texas Southwestern Medical Center

#### **SGWS IV: Sexual Dysfunction: Answers to the Questions You Were Afraid to Ask**

Philippines Cabahug, MD | Kennedy Krieger Institute

## Saturday, September 21

7:30 - 8:30 am

### Breakfast

8:30 - 9:00 am

### Rehabilitation and Rare Neuroimmune Disorders: Current Best Practices and Future Advances

Cristina Sadowsky, MD | Kennedy Krieger Institute

9:00 - 9:20 am

### Study to Investigate the Safety of the Transplantation of Human Glial Restricted Progenitor Cells in Transverse Myelitis

Benjamin Greenberg, MD, MHS | University of Texas Southwestern and Children's Medical Center

9:20 - 9:40 am

### Are Rare Neuroimmune Disorders Genetic?

Michael Levy, MD, PhD | Massachusetts General Hospital and Harvard Medical School

9:40 - 10:45 am

### Collaborative Efforts to Address an Urgent Health Need: AFM Working Group

Carlos Pardo-Villamizar, MD | The Johns Hopkins University School of Medicine  
Benjamin Greenberg, MD, MHS | University of Texas Southwestern and Children's Medical Center  
Sarah Hopkins, MD, MPH | Children's Hospital of Philadelphia  
Janell Routh, MD, MHS | CDC  
Emily Erbelding, MD, MPH | NIAID, NIH  
Cristina Sadowsky, MD | Kennedy Krieger Institute

10:45 - 11:00 am

### Mid-morning Break

## Agenda ...CONTINUED

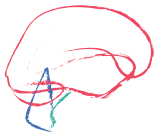
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- 11:00 - 11:30 am**      **What is Spasticity in Rare Neuroimmune Disorders?**  
Philippines Cabahug, MD | Kennedy Krieger Institute
- 11:30 - 12:00 pm**      **All Things Urological: UTIs, Catheters, and Incontinence**  
Cristina Sadowsky, MD | Kennedy Krieger Institute
- 12:00 - 12:30 pm**      **Why Am I So Tired All the Time?**  
Carlos Pardo-Villamizar, MD | The Johns Hopkins University School of Medicine
- 12:30 - 1:30 pm**      **Connect and Lunch**
- 1:30 - 2:00 pm**      **The Central Nervous System (CNS) Connection: Understanding Depression, Cognitive Functioning, and Fatigue in CNS Demyelinating Disorders**  
Lana Harder, PhD | University of Texas Southwestern and Children's Medical Center
- 2:00 - 2:20 pm**      **Updates in Imaging Research**  
Nadia Barakat, PhD | Boston Children's Hospital
- 2:20 - 2:50 pm**      **What is Pain, Numbness, and Tingling?**  
Jacqueline A. Nicholas, MD, MPH | OhioHealth
- 2:50 - 3:10 pm**      **New Trends in Pain Management**  
Maureen A. Mealy, PhD, RN, BSN, MSCN | Viela Bio
- 3:10 - 3:30 pm**      **How is Disability Identity Formed? Findings from a Study with Adolescents**  
Anjali Forber-Pratt, PhD | Vanderbilt University
- 3:30 - 3:45 pm**      **Afternoon Break**
- 3:45 - 4:15 pm**      **Pregnancy and Rare Neuroimmune Diagnoses**  
Moderated Panel Discussion
- 4:15 - 4:45 pm**      **How to Manage Constipation and Prevent Accidents: Bowel Management Strategies**  
Janet Dean, MS, RN, CRRN, CRNP, CRND | Kennedy Krieger Institute
- 4:45 - 5:50 pm**      **The Future of Rare Neuroimmune Disorder Care: Meet the Fellows and Q&A**  
Michael Sweeney, MD | University of Louisville  
Cynthia Wang, MD | University of Texas Southwestern Medical Center  
Kyle Blackburn, MD | University of Texas Southwestern Medical Center  
Jonathan Galli, MD | University of Utah
- 5:50 - 6:00 pm**      **Closing Remarks**  
Carlos Pardo-Villamizar, MD | The Johns Hopkins University School of Medicine

## 2019 SPONSORS

The logo for Alexion, featuring the word "ALEXION" in a bold, blue, sans-serif font. A blue arc curves over the letters "A", "L", and "E", ending with a small red triangle pointing upwards.The logo for Vielabio, consisting of a stylized blue icon of three vertical lines of varying heights on the left, followed by the word "VIELABIO" in a bold, blue, sans-serif font.The logo for Genentech, featuring the word "Genentech" in a large, bold, blue, sans-serif font. Below it, the text "A Member of the Roche Group" is written in a smaller, italicized, grey serif font.

International Center for Spinal Cord Injury  
at Kennedy Krieger Institute  
*Research. Restoration. Recovery.*



**2019 Rare Neuroimmune  
Disorders Symposium**  
**Crowne Plaza, Columbus – Downtown**  
33 East Nationwide Boulevard  
Columbus, OH 43215

**Thursday - Saturday**  
September 19-21, 2019

**More info:**



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