

2019 RNDS

Thursday - Saturday, September 19 - 21, 2019

Crowne Plaza, Columbus – Downtown, OH



The Transverse Myelitis
Association



CONQUER

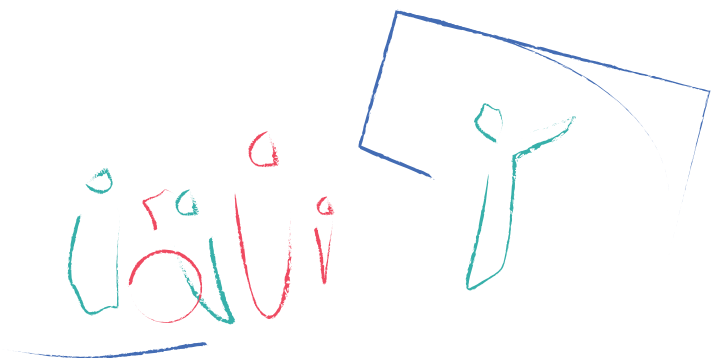
Collaboration on Neuroimmunology
Question, Understand, Educate, Restore



JOHNS HOPKINS
TRANSVERSE MYELITIS
CENTER



JOHNS HOPKINS
NEUROMYELITIS OPTICA CLINIC



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

Agenda

Thursday, September 19

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

Friday, September 20

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

Agenda ...CONTINUED

- 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 | The Johns Hopkins University School of Medicine
- 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**
Sara Qureshi, MD | Billing's Clinic
- 1:45 - 2:15 pm** **Vascular Myelopathies**
Carlos Pardo-Villamizar, MD | The Johns Hopkins University School of Medicine
- 2:15 - 2:45 pm** **Rheumatological Conditions and Rare Neuroimmune Disorders**
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 | The Johns Hopkins University School of Medicine
Benjamin Greenberg, MD, MHS | University of Texas Southwestern and Children's Medical Center
Alexion Pharmaceuticals
Viela Bio
Genentech

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Agenda ...CONTINUED

4:20 - 4:50 pm

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

SGWS I: Finding Medical Care in Your Area

Sara Qureshi, MD | Billing's Clinic

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 | The Johns Hopkins University School of Medicine

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 Erbeling, MD, MPH | NIAID, NIH

Cristina Sadowsky, MD | Kennedy Krieger Institute

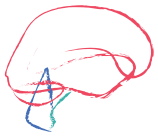
10:45 - 11:00 am

Mid-morning Break

Agenda ...CONTINUED

- 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?**
Allen DeSena, MD, MPH | Carolinas HealthCare System Neurosciences Institute
- 12:30 - 1:30 pm** **Connect and Lunch**
- 1:30 - 2:00 pm** **The Central Nervous System Connection: Depression and Cognitive Dysfunction**
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**
Riley Bove, MD | UCSF Medical Center
- 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**
Allen DeSena, MD, MPH | Carolinas HealthCare System Neurosciences Institute
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



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

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More info:

