

# 2015

## RARE NEURO-IMMUNE DISORDERS SYMPOSIUM

### *Emerging Science and Treatments*

An education and advocacy conference for families, caregivers and individuals diagnosed with Transverse Myelitis (including the subtype Acute Flaccid Myelitis), Neuromyelitis Optica, Optic Neuritis, and Acute Disseminated Encephalomyelitis




*Friday & Saturday | October 23-24, 2015 | Dallas, Texas*  
*UT Southwestern | T. Boone Pickens Biomedical Building*








Welcome to the 2015 Rare Neuro-Immune Disorders Symposium on Emerging Science and Treatments for Transverse Myelitis (TM) (including the subtype Acute Flaccid Myelitis), Neuromyelitis Optica (NMO), Optic Neuritis (ON), and Acute Disseminated Encephalomyelitis (ADEM). This conference, hosted by The Transverse Myelitis Association (TMA), The University of Texas Southwestern Medical Center (UTSW), Children's Health – Dallas and The Johns Hopkins Transverse Myelitis Center (JHTMC), is dedicated to the exchange of information regarding diagnosis, research, and treatment strategies, and to providing an opportunity to bring together the community of individuals diagnosed with these rare neuro-immune diseases, families, caregivers, and the medical professionals who have interest and are specializing in these diseases.

In addition to the education program, the TMA will be hosting pre-conference workshops and courses to build an enhanced support network system and advance the clinical training and science to achieve better quality of life for individuals diagnosed with rare neuro-immune disorders and their families.

-  The International Myelitis Working Group Meeting will be held on October 23<sup>rd</sup> with invited scientists and clinicians to update diagnostic criteria and recommended diagnostic evaluation for non-traumatic myelopathy, with special emphasis on Myelitis.
-  An advocacy workshop will be held on October 23<sup>rd</sup> with TMA support group leaders to expand the support group network and infrastructure globally.
-  A neuro-rehabilitation pre-course will be held on October 23<sup>rd</sup> in partnership with The International Center for Spinal Cord Injury at The Kennedy Krieger Institute and The University of Texas Southwestern Medical Center to offer physical therapists and occupational therapists an opportunity to learn about neuro-rehabilitation in AFM, TM, NMO and ADEM.

## OBJECTIVES

-  Acquire an understanding of the biology and causes of rare neuro-immune disorders (TM, NMO, AFM, ADEM, and ON) and how they relate to each other
-  Learn about the latest medical and surgical strategies to manage the symptoms associated with these chronic rare neuro-immune disorders
-  Gather information and knowledge on the latest acute and long-term immunotherapies, clinical studies, and future treatment strategies



## AUDIENCE

This conference is open to all individuals diagnosed with AFM, TM, NMO, ON, or ADEM, their families and caregivers. Medical professionals interested in these diseases are also welcome to attend.

## REGISTRATION FEES

### TMA MEMBERS

#### REGISTRATION DEADLINES

	Early Bird - By July 31	Aug 1 - Sept 15	Sept 16 - Oct 15
Conference Participant	\$ 40	\$ 50	\$ 60
Additional Participant	\$ 30	\$ 40	\$ 50
Children (12 - 18 years)	\$ 10	\$ 15	\$ 20

### NON-MEMBERS

#### REGISTRATION DEADLINES

	Early Bird - By July 31	Aug 1 - Sept 15	Sept 16 - Oct 15
Conference Participant	\$ 65	\$ 75	\$ 85
Additional Participant	\$ 50	\$ 60	\$ 70
Children (12 - 18 years)	\$ 15	\$ 20	\$ 25

\* Children under 12 years of age can attend the symposium at no cost

\*\* TMA Membership is free. To join The TMA go to <https://myelitis.org/join>

## REGISTRATION

To register for the symposium, please go to <http://myelitis.org/2015-rnds>

All presentations will be video-recorded and made available at <http://myelitis.org>

# AGENDA



## FRIDAY OCTOBER 23, 2015

**5:30-8:00 pm**

**WELCOME RECEPTION AND DINNER**

### **Keynote Panel**

State of The Union of Rare Neuro-Immune Disorders  
Benjamin Greenberg, MD, MHS | University of Texas Southwestern  
Medical Center and Children's Medical Center Dallas

Fight SMA: The Journey to a New Therapy  
Douglas Kerr, MD, PhD, MBA | Biogen

Living with a Rare Disease: Hardships and Hopes  
Barbara Nichols | TMA Texas Support Group Leader

## SATURDAY OCTOBER 24, 2015

**8:00-8:30 am**

Myelitis and Subtypes: Report from the International Myelitis Working Group  
Benjamin Greenberg, MD, MHS | University of Texas Southwestern  
Medical Center and Children's Medical Center Dallas

**8:30-9:00 am**

Management of Acute Flaccid Myelitis  
Teri Schreiner, MD | University of Colorado School of Medicine and Children's  
Hospital Colorado

**9:00-9:30 am**

Neuromyelitis Optica Spectrum Disorder - Is it always a Recurring Disease?  
Michael Levy, MD, PhD | Johns Hopkins University School of Medicine



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**... CONTINUED SATURDAY OCTOBER 24, 2015**

<b>9:30-10:00 am</b>	<b>Advances in Neuro-Rehabilitation</b> Daniel Becker, MD   International Neurorehabilitation Institute and Johns Hopkins University School of Medicine
<b>10:00-10:15 am</b>	<b>BREAK</b>
<b>10:15-11:15 am</b>	<b>PANEL DISCUSSION: Novel Therapies for Rare Neuro-Immune Diseases</b> Michael Levy, MD, PhD   Johns Hopkins University School of Medicine (moderator)
<b>11:15-12:00 pm</b>	<b>Question and Answer Session</b> Allen DeSena, MD   Cincinnati Children's Hospital Medical Center (moderator)
<b>12:00-1:00 pm</b>	<b>LUNCH</b>
<b>1:00-1:30 pm</b>	<b>The Multiple Faces of TM, NMO and ADEM</b> Carlos Pardo, MD   Johns Hopkins University School of Medicine
<b>1:30-2:00 pm</b>	<b>New Approaches to Neuropathic Pain</b> Scott Newsome, MD   Johns Hopkins University School of Medicine
<b>2:00-2:30 pm</b>	<b>Autonomic Loss of Function (Bowel, Bladder, and Sexual Dysfunction)</b> Janet Dean, MS, RN, CRRN, CRNP   Kennedy Krieger Institute
<b>2:30-3:00 pm</b>	<b>BREAK</b>



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... CONTINUED SATURDAY OCTOBER 24, 2015

**3:00-4:00 pm**

**BREAKOUT GROUP SESSION 1**

**Depression and Cognitive Dysfunction**

Lana Harder, PhD | University of Texas Southwestern Medical Center and  
Children's Medical Center Dallas

**Bowel, Bladder, and Sexual Dysfunction**

Janet Dean, MS, RN, CRRN, CRNP | Kennedy Krieger Institute  
Paula Hardeman, MPAS, PA-C | University of Texas Southwestern Medical Center

**Rehabilitation**

Karen McCain , PT, DPT, NCS | University of Texas Southwestern Medical Center  
Melanie Farrar, PT, DPT | University of Texas Southwestern Medical Center

**Support for Caregivers**

Audrey Ayres, RN, BSN | University of Texas Southwestern Medical Center  
Katherine Treadaway LCSW, MSCIR | University of Texas Southwestern Medical Center

**4:00-5:00 pm**

**BREAKOUT GROUP SESSION 2**

**Depression and Cognitive Dysfunction**

Lana Harder, PhD | University of Texas Southwestern Medical Center and  
Children's Medical Center Dallas

**Bowel, Bladder and Sexual Dysfunction**

Janet Dean, MS, RN, CRRN, CRNP | Kennedy Krieger Institute  
Paula Hardeman, MPAS, PA-C | University of Texas Southwestern Medical Center

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The Transverse Myelitis  
Association

[www.myelitis.org](http://www.myelitis.org)