2021
RNDS

Friday - Sunday, October 8 - 10, 2021

SRNA connect. care. cure.
Siegel Rare Neuroimmune Association

MGH 1811 MASSACHUSETTS GENERAL HOSPITAL

UT SOUTHWESTERN Medical Center

JOHNS HOPKINS MEDICINE

HARVARD MEDICAL SCHOOL

children's health℠ Children's Medical Center

JOHNS HOPKINS Myelitis & Myelopathy Center

MGH 1811 NMO Clinic and Research Laboratory

CONQUER Collaboration on Neuroimmunology
Question, Understand, Educate, Restore

Welcome to the 2021 RNDS — The three-day online 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 are specializing in these disorders.

This year, three different tracks will be available during the first day of the symposium:

- ☐ Track 1: The educational content in this track is intended to be most helpful to members of our community who have been recently diagnosed (within the last two years) with a rare neuroimmune disorder- ADEM, AFM, MOGAD, NMOSD, ON, and TM.
- ☐ Track 2: The educational content in this track is intended to be most helpful to members of our community who were diagnosed more than two years ago with a rare neuroimmune disorder — ADEM, AFM, MOGAD, NMOSD, ON, and TM.
- ☐ Track 3: The educational content in this track is intended to be most helpful to parents and pediatric members of our community who were diagnosed with a rare neuroimmune disorder- ADEM, AFM, MOGAD, NMOSD, ON, and TM.

Please note that we welcome attendance at any of the talks that are interesting to our audience, even if not in a specific track. You are not restricted to talks in only one track unless they overlap times. All sessions will be recorded and made available on our website.

Agenda

Friday
October 8

10:50 - 11:00 am	**Hopin Tour** *Roberta Pesce, SRNA* A quick tour of the Hopin platform. Learn how to navigate between areas of the event, chat with attendees, join break-out sessions, and visit the exhibitors.	
11:00 - 11:15 am	**Welcome** *Sandy Siegel, SRNA* We will begin our first day of the RNDS with stories from our community members.	
11:15 - 12:00 pm	**How do you get a diagnosis of ADEM, AFM, MOGAD, NMOSD, ON, and TM?** *Kyle Blackburn & Benjamin Greenberg, UT Southwestern Medical Center* The rare neuroimmune disorders all share similarities that can make it difficult to differentiate between them. Learn from Dr. Kyle Blackburn and Dr. Benjamin Greenberg from UT Southwestern Medical Center which diagnostic tests and tools are used to distinguish these disorders from one another and determine the correct diagnosis.	TRACK 1

Agenda ...CONTINUED

11:15 - 12:00 pm **Living with ADEM, AFM, MOGAD, NMOSD, ON and TM** TRACK 2

Michael Levy, Massachusetts General Hospital and Harvard Medical School

It can be frightening and stressful to deal with the unknown after being diagnosed with one of these disorders, including how these diagnoses impact life years after diagnosis. During this presentation, Dr. Michael Levy from Massachusetts General Hospital and Harvard Medical School will address the long-term aspects of living with a rare neuroimmune disorder.

11:15 - 12:00 pm **Understanding pediatric ADEM, AFM, MOGAD, NMOSD, ON and TM** TRACK 3

Sarah Hopkins, Children's Hospital of Philadelphia

If you are a parent or caregiver of a child who was diagnosed with a rare neuroimmune disorder, you may have concerns about your child's care that are unique to pediatric patients. In this talk, Dr. Sarah Hopkins from Children's Hospital of Philadelphia will address issues that are specific to pediatric patients who have these disorders.

12:00 - 12:10 pm **Meet SRNA**

GG deFiebre

What's new at SRNA? Members of the SRNA staff will give an overview on the work we do year-round and updates from the past year.

12:00 - 2:00 pm **Connect and learn**

SRNA is fortunate to have partnerships with other organizations who share a common goal: to help people with rare neuroimmune disorders. Hear from some of these organizations about their work.

12:10 - 12:30 pm **Connect and network**

Do you ever wish you could meet someone who has your same rare diagnosis? Or with an expert? Now is the time to connect with others with rare neuroimmune disorders and share experiences.

12:30 - 1:00 pm **Acute Disseminated Encephalomyelitis (ADEM)**

Cynthia Wang, UT Southwestern Medical Center

Join us for a disorder-specific talk on ADEM with Dr. Cynthia Wang from UT Southwestern Medical Center, including diagnostic criteria, acute treatments, and long-term effects.

12:30 - 1:00 pm **Acute Flaccid Myelitis (AFM)**

Leslie Benson, Boston Children's Hospital

Join us for a disorder-specific talk on AFM with Dr. Leslie Benson from Boston Children's Hospital, including diagnostic criteria, acute treatments, and long-term effects.

12:30 - 1:00 pm **MOG Antibody Disease (MOGAD)**

Michael Levy, Massachusetts General Hospital and Harvard Medical School

Join us for a disorder-specific talk on MOGAD with Dr. Michael Levy from Massachusetts General Hospital and Harvard Medical School, including diagnostic criteria, acute treatments, and long-term effects.

12:30 - 1:00 pm **Neuromyelitis Optica Spectrum Disorder (NMOSD)**

Stacey Clardy, University of Utah

Join us for a disorder-specific talk on NMOSD with Dr. Stacey Clardy from University of Utah, including diagnostic criteria, acute treatments, and long-term effects.

Agenda ...CONTINUED

12:30 - 1:00 pm **Transverse Myelitis (TM)**

Carlos Pardo, Johns Hopkins Medicine

Join us for a disorder-specific talk on TM with Dr. Carlos Pardo from Johns Hopkins Medicine, including diagnostic criteria, acute treatments, and long-term effects.

1:00 - 1:20 pm **Acute treatments at onset and relapse**

Eoin Flanagan, Mayo Clinic

It is extremely important to begin treatments as soon as possible after a rare neuroimmune diagnosis and following a relapse. Learn about the acute treatments that are used to quiet down the immune system after an attack with Dr. Eoin Flanagan from Mayo Clinic.

1:20 - 1:40 pm **Identifying relapses vs. temporary worsening of symptoms**

Paula Barreras, Johns Hopkins Medicine

Have you experienced a worsening of symptoms following a rare neuroimmune diagnosis and wondered if you were having a relapse? Our speaker will discuss what to do if you are experiencing a worsening of symptoms and how to determine whether you are having a relapse.

1:40 - 2:00 pm **A Treatment Option for NMOSD**

2:00 - 2:20 pm **Transitioning from hospital to home** **TRACK 1**

L.A. Campbell, Barrow Neurological Institute

After being diagnosed with a rare neuroimmune disorder, many people are sent home with little idea of what to do next. This talk will include some tips and information on what to expect while transitioning from the hospital to home.

2:00 - 2:20 pm **Understanding MOG and AQP-4 antibody testing** **TRACK 2**

Elias Sotirchos, Johns Hopkins Medicine

There are blood tests that can detect antibodies in some people with MOG antibody disease and neuromyelitis optica spectrum disorder. Learn about this testing and its importance in determining a correct diagnosis with Dr. Elias Sotirchos from Johns Hopkins Medicine.

2:00 - 2:20 pm **Learning to understand your child's symptoms** **TRACK 3**

Janet Dean, Kennedy Krieger Institute

For parents of children who are diagnosed with ADEM, AFM, MOGAD, NMOSD, ON, or TM, their child's symptoms may be difficult to manage and understand. Join this talk to learn about the symptoms these disorders can cause in children and how to recognize them with Janet Dean from Kennedy Krieger Institute.

2:20 - 2:40 pm **Early rehabilitation strategies** **TRACK 1**

Cristina Sadowsky, Kennedy Krieger Institute

Rehabilitation should be started as soon as someone with a rare neuroimmune disorder is medically cleared for activity. Learn about the importance rehabilitation plays in the acute setting following an inflammatory attack with Dr. Cristina Sadowsky from Kennedy Krieger Institute.

Agenda ...CONTINUED

2:20 - 2:40 pm

Ongoing rehabilitation strategies

TRACK 2

Philippines Cabahug, Kennedy Krieger Institute

Rehabilitation is an essential part of the recovery process following a rare neuroimmune diagnosis. Learn about the importance of rehabilitation and what it means for the long-term management of living with one these disorders with Dr. Philippines Cabahug from Kennedy Krieger Institute.

2:20 - 2:40 pm

Pediatric rehabilitation strategies and surgical interventions

TRACK 3

Kim Bjorklund, Melissa Hutchinson & Nathan Rosenberg, Nationwide Children's Hospital

One of the major concerns for children following a rare neuroimmune diagnosis is recovery. During this presentation, you will learn about pediatric rehabilitation and potential surgical interventions.

2:40 - 3:00 pm

Meet an occupational therapist and physical therapist: A conversation

TRACK 1

Kaitlin Hagen & Dennis Tom-Wigfield, Kennedy Krieger Institute

Do you have questions about physical and occupational therapy? Join this discussion between two rehabilitation specialists and learn about the best strategies for rehabilitation following a rare neuroimmune diagnosis.

2:40 - 3:00 pm

Disability benefits and vocational rehabilitation

TRACK 2

Janelle Hewelt, MEd

It can be stressful and confusing to understand how to apply for disability benefits and return to work following a rare neuroimmune diagnosis. During this talk, learn about your options and what resources are available to help you with Janelle Hewelt, who is also a support group leader at SRNA.

2:40 - 3:00 pm

Transitioning from pediatric to adult care: a conversation

TRACK 3

Cristina Sadowsky, Kennedy Krieger Institute & Cody Unser, Cody Unser First Step Foundation

When a child who was diagnosed with a rare neuroimmune disorder nears the age of adulthood, they must begin learning how to handle their care. Join this talk to learn tips and information on how to transition smoothly from pediatric to adult care with Cody Unser and Dr. Cristina Sadowsky from Kennedy Krieger Institute.

3:00 - 3:10 pm

Connect and learn

SRNA is fortunate to have partnerships with other organizations who share a common goal: to help people with rare neuroimmune disorders. Hear from some of these organizations about their work.

3:10 - 3:30 pm

Adaptations: Mobility devices, driving, and home modifications

Sandy Hanebrink, Touch the Future

Rare neuroimmune disorders can cause mobility issues, including gait changes, drop foot, paralysis, and more. Learn about the different devices and modifications you can use to improve your mobility while in your community, at home, or while driving.

Agenda ...CONTINUED

3:30 - 3:40 pm	**Connect and learn** SRNA is fortunate to have partnerships with other organizations who share a common goal: to help people with rare neuroimmune disorders. Hear from some of these organizations about their work.
3:40 - 4:00 pm	**Building your health care team** *Benjamin Greenberg, UT Southwestern Medical Center & GG deFiebre, SRNA* Which health care professionals do you need to see long-term following a rare neuroimmune diagnosis? During this presentation, GG deFiebre from SRNA and Dr. Benjamin Greenberg from UT Southwestern Medical Center will discuss how to build your health care team and strategies for managing your care.
4:00 - 5:00 pm	**Connect and network** The last "Connect and Network" of the day! Make sure to head to the Networking area to meet someone new and share experiences!

Saturday
October 9

10:50 - 11:00 am	**Connect and learn** SRNA is fortunate to have partnerships with other organizations who share a common goal: to help people with rare neuroimmune disorders. Hear from some of these organizations about their work.
11:00 - 11:10 am	**Welcome to Day 2** *Roberta Pesce, SRNA* We will begin our second day of the RNDS with stories from our community members.
11:10 - 11:40 am	**The CNS connection and psychosocial aspects of being diagnosed with ADEM, AFM, MOGAD, NMOSD, ON, or TM** *Lana Harder, Children's Health & UT Southwestern Medical Center* Rare neuroimmune disorders affect the central nervous system, which in turn can cause psychological and behavioral changes in people who are diagnosed. Dr. Lana Harder from Children's Health & UT Southwestern Medical Center will discuss these potential changes and strategies for how to cope.
11:40 - 12:00 pm	**What is neuropathic pain, numbness, and tingling?** *Ram Narayan, Barrow Neurological Institute* Neuropathic pain, numbness, and tingling can be devastating symptoms following a rare neuroimmune diagnosis. Learn about what causes these symptoms and the current medications and other therapies for treating them with Dr. Ram Narayan from Barrow Neurological Institute.

Agenda ...CONTINUED

12:00 - 12:30 pm **Meet our non-profit partners- moderated panel**
Julia Lefelar, The MOG Project, Jacinta Behne, Guthy Jackson Foundation, Cody Unser, Cody Unser First Step Foundation, Sumaira Ahmed, The Sumaira Foundation for NMO

12:00 - 2:00 pm **Connect and learn**
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12:30 - 12:50 pm **UTIs, catheters, and incontinence**
Philippines Cabahug, Kennedy Krieger Institute
Many individuals with rare neuroimmune disorders experience bladder dysfunction as one of their symptoms. Learn about catheters, neurogenic bladder, UTIs, and management.

12:50 - 1:10 pm **Identifying and managing fatigue**
Sara Qureshi, Billings Clinic
Do you ever wonder why you feel tired all the time? Do you experience brain fog and drowsiness? Learn about what causes fatigue in rare neuroimmune disorders and treatment strategies for combatting it with Dr. Sara Qureshi from Billings Clinic.

1:10 - 1:30 pm **Solutions to managing spasticity in kids and adults**
Jacqueline Nicholas, Ohio Health
Spasticity is a common symptom following a rare neuroimmune diagnosis. Learn about spasticity and how it relates to tone, along with management strategies with Dr. Jacqueline Nicholas from Ohio Health.

1:30 - 1:40 pm **Featured Exhibitors**

1:40 - 2:00 pm **How to manage constipation and prevent accidents: Bowel management strategies**
Margaret Jones, Vanderbilt University Medical Center
Bowel dysfunction is a common symptom experienced by people with rare neuroimmune disorders. Learn about different bowel management strategies with Dr. Margaret Jones from Vanderbilt University Medical Center.

2:00 - 2:20 pm **Pregnancy and a rare neuroimmune diagnosis**
Tanuja Chitnis, Brigham and Women's Hospital
Learn what you should know about family planning following a rare neuroimmune diagnosis. What medications are safe or unsafe during pregnancy? How can pregnancy affect the symptoms from my disorder? Dr. Tanuja Chitnis from Brigham and Women's Hospital will address these questions and more.

Agenda ...CONTINUED

2:20 - 2:40 pm **Management of vision after optic neuritis**

John Chen, Mayo Clinic

Optic neuritis can cause visual issues such as blurry vision and eye pain. During this talk, learn management strategies for visual symptoms with Dr. John Chen from Mayo Clinic.

2:40 - 3:00 pm **Connect and learn**

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3:00 - 3:20 pm **Connect and network**

Do you ever wish you could meet someone who has your same rare diagnosis? Or with an expert? Now is the time to connect with others with rare neuroimmune disorders and share experiences.

3:20 - 3:40 pm **Aging with a rare neuroimmune disorder**

Daniel Becker, Johns Hopkins Medicine

If you were diagnosed with ADEM, AFM, MOGAD, NMOSD, ON, or TM, you may wonder what your future will be like. During this talk, a speaker will discuss the effect of aging on people with rare neuroimmune disorders.

3:40 - 4:00 pm **Vaccinations after a diagnosis of a rare neuroimmune disorder**

Benjamin Greenberg, UT Southwestern Medical Center, Michael Levy, Massachusetts General Hospital and Harvard Medical School & Carlos Pardo, Johns Hopkins Medicine

Have you wondered whether you are at risk of experiencing a relapse following a vaccination? Do you have questions about the safety of receiving the COVID-19 vaccine? Join this talk to learn from Dr. Carlos Pardo (Johns Hopkins Medicine), Dr. Michael Levy (Massachusetts General Hospital and Harvard Medical School), and Dr. Benjamin Greenberg (UT Southwestern Medical Center) about vaccines and rare neuroimmune disorders.

4:00 - 5:00 pm **Connect and network**

The last "Connect and Network" of the day! Make sure to head to the Networking area to meet someone new and share experiences!

Sunday
October 10

10:50 - 11:00 am **Connect and learn**

SRNA is fortunate to have partnerships with other organizations who share a common goal: to help people with rare neuroimmune disorders. Hear from some of these organizations about their work.

11:00 - 11:10 am **Welcome to Day 3**

Roberta Pesce, SRNA

We will begin our second day of the RNDS with stories from our community members.

Agenda ...CONTINUED

11:10 - 11:50 am **CDC AFM Biorepository and Moderated Roundtable on AFM Research With Q and A session**
Carlos Pardo, Johns Hopkins Medicine
Learn about the AFM Biorepository study and other AFM research from experts from Centers from Disease Control and Prevention (CDC) and Dr. Carlos Pardo from Johns Hopkins Medicine. Ask questions and learn the importance of participating in these research studies.

11:50 - 12:10 pm **Research 101 – learn about the process of basic science and clinical research**
Benjamin Greenberg, UT Southwestern Medical Center
Do you want to learn about how research is conducted and how it is used in the treatment and understanding of rare neuroimmune disorders? Join this talk with Dr. Benjamin Greenberg from UT Southwestern Medical Center to understand the basic principles of clinical research and scientific studies.

12:00 - 2:00 pm **Connect and learn**
SRNA is fortunate to have partnerships with other organizations who share a common goal: to help people with rare neuroimmune disorders. Hear from some of these organizations about their work.

12:10 - 12:30 pm **TBD**
Benjamin Greenberg, UT Southwestern Medical Center

12:30 - 1:00 pm **Connect and network**
Do you ever wish you could meet someone who has your same rare diagnosis? Or with an expert? Now is the time to connect with others with rare neuroimmune disorders and share experiences.

1:00 - 1:25 pm **Nutrition, Genetics, and stem cells in rare neuroimmune disorders**
Michael Levy, Massachusetts General Hospital and Harvard Medical School
Dr. Michael Levy from Massachusetts General Hospital and Harvard Medical School has been conducting research on nutrition, genetics, and stem cells in rare neuroimmune disorders. Get the latest updates on his research during this talk.

1:25 - 1:40 pm **SRNA research updates: Registry, vaccination study, and COVID-19 study**
GG deFiebre, SRNA
Did you know that SRNA conducts research? Hear about our ongoing and recently completed research studies, along with some of our findings.

1:40 - 2:00 pm **Research on rare neuroimmune disorders and rheumatologic diseases**
Rohini Samudralwar, University of Texas Health Science Center at Houston
Some of cases of rare neuroimmune disorders have been connected to rheumatologic diseases. Learn about the research Dr. Rohini Samudralwar from University of Texas Health Science Center at Houston is conducting on this topic.

2:00 - 2:20 pm **CIRCLES and SPHERES NMOSD Studies**
Jacinta Behne, Guthy Jackson Foundation
Learn more about the CIRCLES and SPHERES studies that are being conducted on NMOSD from Jacinta Behne from the Guthy-Jackson Charitable Foundation.

Agenda ...CONTINUED

2:20 - 2:40 pm **Connect and learn**

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2:40 - 3:00 pm **APERTURE: What have we learned about ADEM?**

Cynthia Wang, UT Southwestern Medical Center

An update on the APERTURE study on ADEM. What are the latest findings and how do they inform our understanding of ADEM going forward?

3:00 - 3:20 pm **Connect and network**

Do you ever wish you could meet someone who has your same rare diagnosis? Or with an expert? Now is the time to connect with others with rare neuroimmune disorders and share experiences.

3:00 - 3:20 pm **Family Connect**

Are you a parent/caregiver of or a child or teen diagnosed with a rare neuroimmune disorder? Join us to connect with other SRNA families and kids for a quick chat and refresh! Say hello to old camp friends or meet new families and friends you haven't had a chance to connect with yet!

3:20 - 3:40 pm **CORE TM and AFM**

Kyle Blackburn, UT Southwestern Medical Center

Dr. Kyle Blackburn from UTSW Medical Center, a former James T. Lubin Fellow, will explain the research he is conducting on TM and AFM through the CORE TM study at UT Southwestern Medical Center.

3:40 - 4:00 pm **COVID-19 and rare neuroimmune disorders**

Benjamin Greenberg, UT Southwestern Medical Center, Michael Levy, Massachusetts General Hospital and Harvard Medical School & Carlos Pardo, Johns Hopkins Medicine

Over a year and a half has passed since the beginning of the COVID-19 pandemic, and many people with rare neuroimmune disorders are still uncertain about how this disease could potentially affect them. Attend this talk to learn the most up-to-date information about COVID-19 and rare neuroimmune disorders from Dr. Carlos Pardo (Johns Hopkins Medicine), Dr. Michael Levy (Massachusetts General Hospital and Harvard Medical School), and Dr. Benjamin Greenberg (UT Southwestern Medical Center).

4:00 - 4:05 pm **Closing Remarks**

Roberta Pesce, SRNA

We will close out the first Virtual Rare Neuroimmune Disorders Symposium with parting thoughts and how to apply what you've learned in the future.

4:05 - 5:00 pm **Connect and network**

The last "Connect and Network"! Make sure to head to the Networking area to meet someone new and share experiences!

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HORIZON

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