

# 2022 RNDs

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A three-day hybrid educational conference for those affected by rare neuroimmune disorders

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**October 7 - 9, 2022**

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Siegel  
Rare Neuroimmune  
Association



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**CONQUER**  
Collaboration on Neuroimmunology  
Question, Understand, Educate, Restore

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**ALEXION**  
AstraZeneca Rare Disease

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**HORIZON**

**Welcome to the 2022 RNDS** – The three-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 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 hybrid event will take place both online and in person at the Hilton Los Angeles Airport, 5711 West Century Boulevard, Los Angeles, California, 90045.

This year, three different tracks will be available during part of the second 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. Most sessions will be recorded and made available on our website.

## Agenda (TIMES LISTED IN PT)

### Friday October 7

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- 11:00 - 1:00 pm**     **Check in/Registration/Meet and Greet** IN-PERSON  
Let us know you have arrived, collect your badge and network with attendees and speakers, and meet our sponsors and exhibitors.
- 12:45 - 1:00 pm**     **Hopin Tour** VIRTUAL  
*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.
- 1:00 - 1:15 pm**     **Welcome**

## Agenda ...CONTINUED

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- 1:15 - 3:15 pm**      **Panel presentations on diagnosis and treatment of ADEM, AFM, MOGAD, NMOSD, and TM**  
*Benjamin Greenberg, University of Texas Southwestern (moderator)*  
*Carlos A. Pardo, Johns Hopkins University*  
*Michael Levy, Massachusetts General Hospital*  
*Eoin P. Flanagan, Mayo Clinic*  
*Grace Gombolay, Emory University SOM/Children's Healthcare of Atlanta*
- Community Presenters: Jodi Arminio, Chantal Banks, Emily Martin, Sarah Mendenhall, and Hannah Stadler*
- 3:15 - 3:30 pm**      **CONNECT AND NETWORK**  
Visit the Expo Area or use the Networking feature on Hopin **VIRTUAL**  
Visit our partners, sponsors, and exhibitors (Carmel Room) **IN-PERSON**  
Share your story at the This is Me campaign booth (Catalina B) **IN-PERSON**  
Learn more about ongoing research (Catalina C) **IN-PERSON**
- 3:30 - 5:00 pm**      **...continued Panel presentations**
- 5:00 - 6:30 pm**      **Reception** **IN-PERSON**

## Saturday October 8

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- 8:00 - 9:00 am**      **Breakfast and check in** **IN-PERSON**
- 9:00 - 9:30 am**      **Management of neuropathic pain**  
*Ram Narayan, Barrow Neurological Institute*
- 9:30 - 10:00 am**      **What are the long-term treatments for NMOSD and MOGAD?**  
*Anastasia Vishnevetsky, Massachusetts General Hospital*
- 10:00 - 10:30 am**      **Learn about new clinical trials in MOGAD and NMOSD**  
*Michael Levy, Massachusetts General Hospital*
- 10:30 - 11:00 am**      **CONNECT AND NETWORK**  
Visit the Expo Area or use the Networking feature on Hopin **VIRTUAL**  
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Share your story at the This is Me campaign booth (Catalina B) **IN-PERSON**  
Learn more about ongoing research (Catalina C) **IN-PERSON**
- 11:00 - 11:30 am**      **Management of spasticity**  
*Daniel Becker, International Neurorehabilitation Institute*

## Agenda ...CONTINUED

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- 11:30 - 12:00 pm**    **Research updates on management of neuropathic pain and spasticity**  
*Michael Levy, Massachusetts General Hospital*
- 12:00 - 12:30 pm**    **Respiratory complications of Acute Flaccid Myelitis**  
*Keith Van Haren, Stanford University*
- 12:30 - 1:30 pm**    **LUNCH** IN-PERSON
- 12:30 - 1:30 pm**    **CONNECT AND LEARN** VIRTUAL
- 1:30 - 2:35 pm**    **The next two sessions are offered concurrently in breakout rooms. For those attending in person, please select the talks that are most relevant and of interest to you. For those attending virtually, we will only be able to stream Track 1. There will also be a special Q&A session available for the online track during this time.**
- 1:30 - 2:35 pm**    **Open Session for Q&A** VIRTUAL  
*Cynthia Wang, University of Texas Southwestern*  
*Kyle Blackburn, University of Texas Southwestern*
- 1:30 - 1:50 pm**    **TRACK 1: Transitioning from hospital to home**  
*Janet Dean, Kennedy Krieger Institute*
- 1:30 - 1:50 pm**    **TRACK 2: Building a health care team** IN-PERSON  
*Grace Gombolay, Emory University SOM/Children's Healthcare of Atlanta*
- 1:30 - 1:50 pm**    **TRACK 3: Pediatric mental health** IN-PERSON  
*Camille Wilson, Nationwide Children's Hospital*
- 1:50 - 2:10 pm**    **TRACK 1: Early rehabilitation strategies**  
*Rajashree Srinivasan, UT Southwestern Medical Center*
- 1:50 - 2:10 pm**    **TRACK 2: Therapy for retaining function** IN-PERSON  
*Dennis Tom-Wigfield, Kennedy Krieger Institute*
- 1:50 - 2:10 pm**    **TRACK 3: Transitioning from childhood to adolescence to adulthood** IN-PERSON  
*Melissa Hutchinson, Nationwide Children's Hospital*
- 2:10 - 2:35 pm**    **TRACK 1: Open Session for Q&A**
- 2:10 - 2:35 pm**    **TRACK 2: Open Session for Q&A**
- 2:10 - 2:35 pm**    **TRACK 3: Open Session for Q&A**
- 2:35 - 2:40 pm**    **Reconvene in the main meeting space.**

## Agenda ...CONTINUED

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**2:40 - 3:00 pm**      **How do I know if I am having a relapse?**  
*Benjamin Greenberg, UT Southwestern Medical Center*

**3:00 - 3:30 pm**      **CONNECT AND NETWORK**  
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Learn more about ongoing research (Catalina C) **IN-PERSON**

**3:30 - 4:30 pm**      **An open moderated panel session to discuss trending topics in rare neuroimmune disorders**  
*Benjamin Greenberg, University of Texas Southwestern (moderator)*  
*Carlos A. Pardo, Johns Hopkins University*  
*Michael Levy, Massachusetts General Hospital*  
*Eoin P. Flanagan, Mayo Clinic*  
*Grace Gombolay, Emory University SOM/Children's Healthcare of Atlanta*

This session will address your questions on vaccinations and rare neuroimmune disorders, when to start treatment for monophasic MOG, whether infections trigger attacks, and rare neuroimmune disorders and COVID-19.

**4:30 - 5:00 pm**      **Open Session for Q & A**

## Sunday October 9

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**8:00 - 9:00 am**      **Breakfast and check in**

**9:00 - 9:30 am**      **Impact of rare neuroimmune disorders on cognition, depression, and quality of life**  
*Lana Harder, UT Southwestern Medical Center & Children's Medical Center Dallas*

**9:30 - 10:00 am**      **How to cope with grief, anxiety, and loss? How to talk to others about my diagnosis?**  
*Christa Hutaff-Lee, Children's Colorado*

**10:00 - 10:30 am**      **Research Updates: Tele-neuropsychology and Neuropsychological Outcomes Associated with MOGAD**  
*Lana Harder, UT Southwestern Medical Center & Children's Medical Center Dallas*

**10:30 - 11:00 am**      **CONNECT AND NETWORK**  
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Share your story at the This is Me campaign booth (Catalina B) **IN-PERSON**  
Learn more about ongoing research (Catalina C) **IN-PERSON**

## Agenda ...CONTINUED

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- 11:00 - 11:45 am**    **Bladder, bowel, and sexual dysfunction**  
*Philippines Cabahug, Kennedy Krieger Institute*
- 11:45 - 12:30 pm**    **Adaptive tools and technology for improved quality of life**  
*Sandy Hanebrink, Touch the Future/ReBoot, Inc.*
- 12:30 - 1:30 pm**    **LUNCH** IN-PERSON
- 12:30 - 1:30 pm**    **CONNECT AND LEARN** VIRTUAL
- 1:30 - 2:00 pm**    **Disability: Adapting to and embracing disability**  
*Panel discussion moderated by GG deFiebre, with Paul Garrett, Cyrena Gawuga, and Janelle Hewelt*
- 2:00 - 2:20 pm**    **Navigating the insurance landscape**  
*Stephanie Gaines, Genentech*
- 2:20 - 2:40 pm**    **Know RND and the CORE™ Registry**  
*Kyle Blackburn, UT Southwestern Medical Center*
- 2:40 - 3:00 pm**    **Association of rare variants in genes of immune regulation with pediatric autoimmune CNS disease**  
*Saba Jafarpour, Children's Hospital Los Angeles*
- 3:00 - 3:20 pm**    **CONNECT AND NETWORK**  
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Share your story at the This is Me campaign booth (Catalina B) IN-PERSON  
Learn more about ongoing research (Catalina C) IN-PERSON
- 3:20 - 3:40 pm**    **APERTURE: New Insights on ADEM**  
*Cynthia Wang, UT Southwestern Medical Center*
- 3:40 - 4:30 pm**    **Q&A and Closing Remarks**

# 2022 SPONSORS



## 2022RNDS

Friday - Sunday

October 7 - 9, 2022

### More info:

[srna.ngo/2022-rnds](https://srna.ngo/2022-rnds)



International Center for Spinal Cord Injury  
at Kennedy Krieger Institute

*Research. Restoration. Recovery.*



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