We Care for Rare Summit

Celebrating Myositis Science and Rare Patient Stories

Friday, February 28, 2025 1 PM - 4 PM ET | 10 AM - 1 PM PT

RARE DISEASE DAY

The Myositis Association

NORI'S FIGHT

MIHRA Myositis International Health & Research Collaborative Alliance

AGENDA

Virtual (Zoom) | Summit: 1:00-3:00 PM ET | Happy Hour: 3:00-4:00 PM ET

- **Welcome and Group Photo**
  - Laurie Boyer, TMA Board of Directors Chair

- **Pride in Rare Disease and Standing Together for Science**
  Presentation and reactions illuminating the context of rare disease; how common rare diseases are, collectively; and how much rare research affects all of health care.
  - Lesley Saketkoo, MIHRA Chair and TMA Medical Advisory Board
  - Pedro Machado, MIHRA Co-Vice Chair
  - Namita Goyal, TMA Medical Advisory Board Chair
  - Laurie Boyer, TMA Board of Directors Chair

- **Flash Talks in Myositis Science**
  A series of short, exciting presentations highlighting patient-driven research in myositis. Topics include:
  - Muscle Outcome Measures and Heavy Lifters: Does the Reliance on MMT8 Negate Patient Voice and Lead to Delays in Treatment, Resulting in Long-Term Disability?
    - Helene Alexanderson, Karolinska Intsitutet; Marie-Christine Breeveld, Karen Cheng, Ingrid de Groot (TMA MAB), Lia Kolsters, Karen Norris
  - Unintended Consequences of Clinical Trials in Rare Diseases: A Descriptive Experience of Myositis Diseases
    - Victoria Werth, University of Pennsylvania
  - Impact of Exercise, Movement, and Putting One's Self First – A Priority for Rare Disease Patients Worldwide
    - Helene Alexanderson, Karolinska Intsitutet
  - Link between Mitochondrial Dysfunction, Aging, Inclusion Body Myositis and Other Forms of Myositis
    - Elie Naddaf, Mayo Clinic
  - fMET-FPR1 Signaling: A Potential Pathway for a Novel Therapeutic Approach in Myositis
    - Christian Lood, University of Washington

- **Flash Talk in Myositis Science and Myositis ILD Patient Story**
  - Noriel Cunanan's Patient Story
    - Julia Nickerson, Nori's Fight President and Co-Founder
  - Lung Disease in Rare Autoimmune Conditions
    - Julie Paik, MIHRA Co-Vice Chair

- **Keynote Speaker and Dermatomyositis Patient Story**
  - Lindsay Guentzel, Multimedia Journalist, Storyteller, Myositis Advocate, and TMA Leader
  - "The Full-Time Job of Living Rare"
  - Moderator: Paula Eichenbrenner, TMA Executive Director

- **Closing Remarks**
  - Alli Ward, Director of Membership, National Organization of Rare Diseases (NORD)

- **We Share Our Rare Virtual Happy Hour: Let's Show Our Myositis Stripes!**
  - *Join our dazzle of myositis zebras for conversation, fellowship, and fun to celebrate Rare Disease Day.*
  - Facilitator: Linda Zuchegna, TMA Nationwide Support Group Co-Leader

Acknowledgments:

Rachel Bromley, Linda Kobert, Tiffany McCoy, MIHRA leadership, TMA Board of Directors, Sasse Agency

Agenda details are tentative as topics and speakers are confirmed. Please visit our website to view the latest version.