



TMA'S GLOBAL MYOSITIS PATIENT CONFERENCE

SEPTEMBER 18-21, 2025

Learning
Together

Education Schedule

*This preliminary agenda lists confirmed breakout sessions that await MyoCon 2025 attendees in Dallas.
View the Exercise Schedule and the Conference Schedule on [our website](#).*

Friday | September 19, 2025

9:00am – 10:00am Networking Breakouts: Getting Acquainted Sessions

*Please join a networking session and meet fellow conference attendees! **For everyone.***

Getting Acquainted: 40 and Under | Moderator: Lindsay Guentzel

Getting Acquainted: Care Partners | Moderator: Cynthia Marks

Getting Acquainted: Inclusion Body Myositis | Moderators: Marcella Kelsoe, Rhonda Rogers, David Volk

Getting Acquainted: Myositis Other than IBM | Moderators: Veronica Fatura, Kaniah Gunter

Getting Acquainted: Veterans | Moderator: Joseph Urban

10:00am – 10:30am Break

10:30am – 11:30am Breakout Sessions: Back to Basics

*Whether you're newly diagnosed, need a refresher, or are a family member trying to understand what's happening to your loved one, this session covers the basics of myositis diseases, diagnosis, and management. Choose the session with which you most closely identify. **According to disease type.***

Back to Basics: Antisynthetase Syndrome | Lesley Saketkoo

Back to Basics: Dermatomyositis | David Fiorentino

Back to Basics: Immune-Mediated Necrotizing Myopathy (IMNM, NAM, NM) | Adam Schiffenbauer

Back to Basics: Inclusion Body Myositis | Salman Bhai, Namita Goyal, Armando Villalta

Back to Basics: Polymyositis | Julie Paik

11:30am Lunch on Your Own

12:30pm **Exhibits Open**

1:30pm – 2:30 pm **First-Time Attendee Welcome**

2:30pm – 4:00pm **Breakout Sessions: Ask the Experts Panels**

These informal Q&A sessions offer the chance to discuss your symptoms, treatments, disease course, and more with mini town halls featuring TMA Medical Advisors and invited experts. Choose the session with which you most closely identify. According to disease type.

Ask the Experts: Antisynthetase Syndrome and/or Myositis-associated Interstitial Lung Disease | Cheilonda Johnson, Sandeep Sahay, Lesley Saketkoo

Ask the Experts: Dermatomyositis | David Fiorentino, Julie Paik, Elizabeth Sloan

Ask the Experts: Immune-Mediated Necrotizing Myopathy and/or Polymyositis | Suur Bilicier, Floranne Ernste, Adam Schiffenbauer

Ask the Experts: Inclusion Body Myositis – Room 1 | Salman Bhai, Tahseen Mozaffar

Ask the Experts: Inclusion Body Myositis – Room 2 | Helene Alexanderson, Namita Goyal, Tom Lloyd

4:00pm – 4:30pm **Break, Networking, Exhibitors**

4:30pm – 5:45pm **Opening General Session**

Saturday | September 20, 2025

9:00am – 10:15am **Breakout Sessions**

CAR-T Myositis Trials: First-Person Patient and Physician Perspectives | Lindsay Guentzel, Tahseen Mozaffar
*Chimeric antigen receptor T-cell (CAR-T) therapy is one of the most cutting-edge approaches being explored for autoimmune diseases, including myositis. Join a global myositis expert who is leading CAR-T trials and a patient who participated in a CAR-T trial. Together, they'll offer a powerful look at both the clinical and human sides of this groundbreaking therapy. With 30 to 45 minutes of presentation and 15 to 30 minutes for audience Q&A, attendees will gain insight into how CAR-T therapy works, who it may help, and what it's like to go through the process firsthand. **For those interested in clinical trials.***

Myositis Medications and Management | Floranne Ernste

*While FDA approved treatments for myositis diseases are limited, there are a variety of drugs that are often used off-label for these conditions. As the patient, you can be part of the decision on which of these products to include in your treatment regimen. This session reviews the available medications, their side effects, and some questions to ask your doctor when determining which treatment might be right for you. **For those with forms of myositis other than IBM.***

Pulmonary Hypertension | Sandeep Sahay

*Pulmonary hypertension (PH) is a serious complication that can affect people living with myositis, especially those with interstitial lung disease (ILD). Learn more about PH, improving patient outcomes through research in PH treatment, risk stratification, and ILD-associated PH. **For those interested in lung health.***

Skin Health and Dermatomyositis Symptoms | Omni McCluney

The skin symptoms of dermatomyositis (DM) can be especially distressing. In addition to managing pain, fatigue, and muscle weakness, those with DM may also struggle with itchy rashes, hair loss, and other visible or uncomfortable

symptoms. This session will explore these challenges and discuss evidence-based treatments and skin care approaches to improve quality of life. **For those with DM.**

Travel Accessibility and Current US Policy Environment | Mindy Henderson

*Unpack the current accessibility landscape in U.S. travel and policies for people with disabilities, including the Air Carrier Access Act. Despite the challenges posed to recent progress in Federal Aviation Administration (FAA) regulations, your rights as a passenger remain centered on an equitable, safe, and dignified travel experience. **For all.***

10:15am – 10:45am Break, Networking, Exhibitors

10:45am – 12:00pm Breakout Sessions

Inequities in the Rare Disease Community: Myositis Voices | Jocelyn Cooper, Holly Jones, Sandeep Sahay, Juan and Judith Torres

*Findings from "Inequities in the Rare Disease Community: The Voices of Diverse Patients and Caregivers," a report from the Rare Disease Diversity Coalition (RDDC) and the National Organization for Rare Diseases (NORD), will be illuminated in this session. RDDC will summarize report data and share self-advocacy strategies. TMA's Women of Color Affinity Group will share stories behind the statistics, and lead a discussion about how the report themes resonate within the myositis community. **For all.***

Lifestyle Medicine and Myositis: A Whole Body Approach | Suur Bilicier

*Attendees will learn the principles and pillars of lifestyle medicine, identify how lifestyle medicine can specifically impact myositis management, and understand its broader implications. They will learn practical applications of lifestyle medicine interventions tailored for myositis patients, and recognize how lifestyle modifications can complement traditional treatments to improve patient outcomes and quality of life. **For all.***

Mental Health Matters: Resource and Support

Understanding Dysphagia | Meaghan Arnold

*Dysphagia (swallowing difficulties) can be a difficult challenge for those who live with any form of myositis. This talk will review how the swallow works, what happens when swallow safety and efficiency decline, and what can be done to improve dysfunction. Discover what treatments exist to address dysphagia, the language to use when looking for the right therapy, and what to avoid. Let's bring the joy back into mealtime! **For all.***

12:00pm – 1:15pm Networking Lunch by Location

1:15pm – 2:15pm Breakout Sessions

Before You Dial 911: The 411 on Myositis in the ER | Jennifer Swisher

*The emergency department can be overwhelming—especially when you're living with a rare disease like myositis. From missed infusions and infections to disease flares and unrelated emergencies, patients often face unique challenges that aren't always well understood by ER staff. In this session, an Emergency Medicine PA living with dermatomyositis shares both clinical expertise and personal experience to help you take control before and during an emergency. You'll learn how to recognize red flags, prepare for common ER scenarios, communicate effectively with triage teams, and advocate for timely, appropriate care—even when myositis isn't the focus of your visit. **For all.***

Decoding Insurance Coverage and Health Plans | Annesha White

*High treatment costs, denials, and limited access to specialists are known challenges in living with rare diseases like myositis. This session explains insurance basics from drug pricing, deductibles, treatment coverage, and other managed care pharmacy concepts that are relevant whether your health insurance plan is a public program like Medicaid and Medicare, a private insurance plan, employer-sponsored coverage, or a military benefit such as TRICARE. **For all.***

Extra-muscular Manifestations in Myositis and Associated Risk | Cheilonda Johnson

*Myositis is more than muscle weakness. In this session, we'll explore the often-overlooked extra-muscular manifestations of myositis—including lung involvement, skin symptoms, cardiac risk, and gastrointestinal challenges. Whether you're newly diagnosed or have been living with myositis for years, this session will expand your understanding of how myositis can affect the whole body—not just the muscles. **For all, especially those interested in lung health.***

Mitochondrial Dysfunction and Inclusion Body Myositis | Margherita Milone

*Mitochondrial disorders—conditions caused by dysfunction in the body's energy-producing organelles—can lead to muscle weakness, fatigue, and even multi-organ involvement. But how does this energy failure relate to inclusion body myositis (IBM) and other forms of myositis? The session will reveal similar mechanisms, diagnostic clues, and therapeutic potential. **For those with IBM.***

2:15pm – 2:45pm Break, Networking, Exhibitors

2:45pm – 3:45pm Breakout Sessions

Aging Research, Senolytic Drugs, and Relevance to IBM | Tom Lloyd

*Explore how cutting-edge research on aging and cellular senescence is opening new possibilities for treating inclusion body myositis (IBM). This session will introduce the science behind senolytic drugs—therapies designed to target and remove aging or dysfunctional cells—and examine their potential to slow disease progression and improve muscle health in IBM. **For those with IBM.***

Cancer and Its Implications for Myositis | Lisa Christopher-Stine

*Research has shown an association between myositis and malignancy, which is often referred to as cancer-associated myositis (CAM). This session would discuss this association and the precautions that should be taken for the best outcomes. **For all.***

Challenging Side Effects of Steroids: Learning from Synthetic Corticosteroids like Vamorolone | Melissa Morales

*Long-term steroid use is common in treating myositis, but it often comes with difficult side effects like weight gain, mood changes, bone loss, and more. This session will explore the challenges patients face with traditional corticosteroids and introduce new insights from synthetic alternatives like vamorolone. Learn how vamorolone is designed to reduce harmful side effects while maintaining anti-inflammatory benefits. **For all.***

Life & Legacy Planning: Communicating without Conflict | Amy Jenkins

*Effective communication between partners will keep your family “out of court and out of conflict.” Learn about the evolving legal landscape with special considerations that apply to LGBTQIA+ families, Medicaid Asset Protection Trusts, and more. **For all.***

Journeys: Living with Myositis | Richard Juknavorian, Scott Milligan

*Sharing firsthand accounts curated by TMA and Rare Awareness Radio in a highly engaging and insightful session! Patients and care partners will share their trials, tribulations, but also their successes and sources of hope. Providers will share insights into current processes and procedures, alongside opportunities for improvement in diagnosis, care, and patient engagement. Researchers will explore promising avenues for new treatments. Advocates will look at successes gained, challenges yet to come, and both short-term and long-term goals within the advocacy landscape. **For all.***

3:45pm – 4:00pm Break, Networking, Exhibitors

Sunday | September 21, 2025 | World Myositis Day

8:00am – 9:00am Breakout Sessions

Finding Strength through Faith | Chip Galloway

Schedule as of August 13, 2025

*Living with a chronic illness like myositis can test emotional, physical, and spiritual resilience. This session offers a supportive space to explore how faith, spirituality, and personal beliefs can provide comfort, hope, and strength through difficult times. Hear from members of the myositis community as they share how their faith journeys have helped them cope, find meaning, and stay grounded amid uncertainty. **For all.***

Genetics, Autoimmune Disease, and Myositis | Janine Lamb

*This presentation will highlight research by The Myositis Genetics Consortium (MYOGEN) and our Manchester Myositis Research Group, to increase understanding of myositis. There will be a focus on genetic and environmental risk factors, myositis autoantibodies, and the relationship to comorbid conditions such as cancer. **For all.***

Latest Research and Clinical Trials Insights for Inclusion Body Myositis | Elie Naddaf

*Clinical trials are the gold standard for testing new medications for safety and effectiveness. This presentation highlights some recent clinical trials in IBM with potential treatments that may gain FDA approval if proven beneficial. **For those with IBM.***

Latest Research and Clinical Trials Insights for Dermatomyositis and Other Forms of Myositis | Lisa Christopher-Stine

*Clinical trials are the gold standard for testing new medications for safety and effectiveness. This presentation highlights some recent clinical trials in DM and other non-IBM forms of myositis, with potential treatments that may gain FDA approval if proven beneficial. **For those with DM, NM, PM, and ASyS.***

9:00 am – 9:15am Break, Networking, Exhibitors

9:15am – 10:45am Brunch & Closing General Session

10:45am – 11:45am Breakout Sessions

Effects of Exercise on Physiological, Physical, and Psychological Aspects of Health | Helene Alexanderson

*Regular, appropriate exercise can support muscle function, reduce inflammation, boost mood, and improve energy levels in people living with myositis. Learn the latest about exercise effects on health aspects like aerobic capacity, osteoporosis and fractures, fatigue, and holistic well-being. **For all.***

Flares, Sun Safety, and Preventive Measures | Victoria Werth

*The sun can trigger skin and muscle flares of dermatomyositis (DM). The session will review dermatomyositis-related information on flares, sun safety, and preventive measures. **For those with DM.***

Hints and Hacks: Making Your Life Work for You | Gabriela Lothrop, Rhonda Rogers

*Independence is the goal of this session. Those who live with myositis are invited to share their insights on daily living aides and equipment that make their life easier. Participants are also invited to bring or share strategies and devices they use to help them maintain their independence during their daily living. **For everyone.***