

Conference Schedule

Thursday | September 5, 2024

1:00pm – 5:00pm	Board of Directors Meeting	TMA Board of Directors, By Invitation Only
5:00pm – 7:00pm	Early Registration	Registered Attendees

Friday | September 6, 2024

8:00am – 3:00pm	Excursion to National Institutes of Health	NIH Excursion Registrants
9:00am – 1:00pm	Excursion to Johns Hopkins Myositis Center	JHMC Excursion Registrants
10:00am – 12:30pm	Excursion to Baltimore Sightseeing	Baltimore Exc. Registrants
2:30pm – 3:30pm	First-time Attendee Welcome	Moderator: Rachel Bromley
3:00pm – 5:00pm	Community Health Fair	
3:00pm - 7:00pm	Registration Open	

4:00pm – 5:00pm **Getting Acquainted Breakout Rooms**
*Please join this networking session where you can meet fellow conference attendees with the same diagnosis! **For everyone.***

Inclusion Body Myositis	Moderators: Howard Gerrin and Ricky Marks
Dermatomyositis	Moderators: Linda Sabatino and Jane Myles
Polymyositis	Moderator: Dale Scott
Necrotizing Myopathy/Antisynthetase	Moderator: Colleen Layton
Care Partners/Caregivers	Moderators: Dr. Cynthia Marks and Frank Lipiecki

5:00pm – 6:00pm **Welcome Reception and Exhibits Open**

5:15pm – 6:00pm **TMA Women of Color Affinity Group 5th Anniversary Award Ceremony and Toast**
Sponsored by argenx

6:00pm – 7:00pm **Welcome | Laurie Boyer, MBA**
Opening General Session
IBM Patient Story
Keynote Address – *Impossible Odds: A Story of Strength and Survival* | Jessica Buchanan
This session will inspire the entire myositis community. Together, we will face the everyday and extraordinary challenges of our lives with grace and the ability to move forward.

Saturday | September 7, 2024

7:00am-9:00am Myositis Research Symposium **By Invitation Only**

7:00am-8:00am **Early Bird Session: Finding Strength through Faith** | Chip Galloway
*It's no secret that those with a strong faith find support and inspiration in their spiritual practice. Find out how one myositis patient experiences this and share your own experience with others. **For everyone.***

7:30am – 9:00am **Breakfast**

7:30am – 5:00pm **Registration and Exhibits Open**

9:00am –10:00am **Breakout Sessions**

Back to Basics: Dermatomyositis and Antisynthetase Syndrome | Christopher Mecoli, MD, MHS
*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. **For those with DM and ASyS.***

Back to Basics: Inclusion Body Myositis | Tahseen Mozaffar, MD; Colin Quinn, MD
*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. **For those with IBM.***

Back to Basics: Necrotizing Myopathy and Polymyositis | Lisa Christopher-Stine, MD, MPH
*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. **For those with NM or PM.***

Health Equity: Bridging the Gap between Experts and Patients, in Partnership with TMA Women of Color Affinity Group | Moderator: Holly Jones; Yashira Cruz; Jaylah Dorman; Sonye Danoff, MD, PhD; Iazsmin Ventura, MD; Jemima Albayda, MD

*Our panel of experts and patients will discuss how effective communication, accountability, and education between physicians and patients can enhance health equity and outcomes for women of color. **For everyone.***

Sponsored by Bristol Myers Squibb

Intimacy and Relationships: How Chronic Illness Can Bring You Closer | Noelle Benach
*Human beings need to share a close emotional, spiritual, intellectual, and physical connection with a special someone. Far more than just sex, intimacy involves a dynamic communication process that can be shared regardless of one's physical situation. Join us in this safe space for a private, unrecorded conversation about cultivating the kind of relationship with a partner that allows for a multidimensional sense of intimacy. All ages are welcome, as well as those who do not currently have a partner. **For everyone.***

Mental Health: How our Mindset Affects our Myositis Journey, in Partnership with TMA Women with IBM Affinity Group | Moderator: Nancy Marx Erickson; Lisa Motley; Megan McGowan, OTR/L; Allison Fisher, MS, OTR/L, CDP; Eleni Tiniakou, MD

Two Johns Hopkins Myositis Center occupational and behavioral health therapists and a rheumatologist with broad experience in treating all forms of myositis, discuss practical physical and psychological ways of dealing with the daily

challenges of myositis, whether you are the person living with this incurable disease or their care partner or family members. **For everyone.**

10:00am – 10:30am Break, Networking, Exhibitors

10:30am – 12:00pm Breakout Sessions - Ask the Doc In-Person

*These informal Q&A sessions offer the chance to discuss your symptoms, treatments, disease course, and more with a panel of myositis experts. Choose the session with which you most closely identify. **According to disease type.***

Antisynthetase Syndrome and/or Interstitial Lung Disease | Sonye Danoff, MD, PhD; Valerie LeClair, MD, PhD; Erin Wilfong, MD, PhD

Dermatomyositis | Victoria Werth, MD; Eleni Tiniakou, MD; Christopher Mecoli, MD, MHS
Sponsored by CSL Behring

Inclusion Body Myositis – Diagnosed More than 5 Years | Tahseen Mozaffar, MD; Anthony Amato, MD; Thomas Lloyd, MD, PhD

Inclusion Body Myositis – Diagnosed within the Last 5 Years | Namita Goyal, MD; Colin Quinn, MD; Payam Mohassel, MD; Stephanie Hunn, PhD, PT

Necrotizing Myopathy and/or Polymyositis | Jemima Albayda, MD; Adam Schiffenbauer, MD; Lisa Christopher-Stine, MD, MPH

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

1:30pm –2:30pm Breakout Sessions

Latest Research and Clinical Trials Insights for Inclusion Body Myositis | Namita Goyal, MD

*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 | Julie Paik, MD; Eleni Tiniakou, MD

*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.***

Determining Benefits Eligibility: Social Security Disability Insurance, Medicare, and Medicaid | Michelle Vogel, MPA
*This session dives into the ins and outs of Social Security Disability, Medicare, and Medicaid benefits. Discover eligibility criteria and how to navigate the process. Join us to understand how these programs can provide crucial support and peace of mind during challenging times. **For everyone.***

Applying Cognitive Behavioral Therapy and Mindfulness Fundamentals in Your Day-to-Day | Mustafa Shameem; Sanchita Sharma, PsyD
*Living with a chronic disease can make it hard to manage emotional ups and downs, find joy, and cope with setbacks. This session offers two techniques for maintaining daily balance in your mental health and improving quality of life. **For everyone.***

Clinical Trial Design: Industry Perspectives | Moderator: Ray Mankoski, MD, PhD, The NemetzGroup LLC, Abcuro; Panelists: Jeff Wilkins, MD, Abcuro; Pamela Kivitz, J&J; Brad Nohe, AstraZeneca; Brian Lee, PharmD, Bristol Meyers Squibb

*How do pharmaceutical companies decide how to structure clinical trials? Are patients typically involved in this process? What role does the FDA play? In this session, industry representatives from a cross-section of companies discuss the ins and outs of clinical trial development. **For everyone.***

Sponsored by Abcuro and AstraZeneca

National Physical Therapy Leadership ‘Ask Me Anything’ Panel | Justin Moore, DPT; Roy Film, DPT; Clarisse Labor, PT
*This is an amazing opportunity to ask the CEO of the American Physical Therapy Association and the President of the Maryland Physical Therapy Association your burning questions about physical therapy (PT). Learn how to maximize your relationship with your own physical therapist, plus ask questions on any topic including insurance, advocacy, diversity in the PT profession, and how TMA can help more PTs learn about rare diseases like myositis. **For everyone.***

2:30pm – 3:00pm **Break, Networking, Exhibitors**

3:00pm – 4:00pm **Breakout Sessions**

Defining Idiopathic Inflammatory Myopathies and Classification Criteria | Ingrid Lundberg, MD, PhD
*Learn how researchers from around the world are working together to refine how myositis is classified. How do physicians and scientists develop and maintain guidelines for diagnosis? What is the current state of the EULAR/ACR classification system? **For everyone.***

Scanning the Horizon at the Food & Drug Administration | Moderator: Martha Arnold; David Zook, JD; Charles Raver, JD
*The development of treatments for rare diseases like myositis is challenging. Come and learn about trends and initiatives that promise to improve successful drug development for these diseases. FDA’s recent announcement of the Rare Disease Innovation Hub will be discussed. **For everyone.***

Patient Registries and Biorepositories in Myositis: MYOVISION and MYSTIC Outcomes | Moderator: Jane Myles; Lisa Rider, MD; Erin Wilfong, MD, PhD
*Collected data from hundreds of patients is a goldmine for researchers. This session provides an overview of two myositis registries—MYOVISION and MYSTIC—and introduces some of the insights gleaned from these projects, both of which involved TMA members and were conducted in partnership with TMA. **For everyone.***

Sitting in their Seats: Patient and Care Partner Perspectives | Facilitators: Ed and Marilyn McGrath; Ricky and Dr. Cynthia Marks
*As patients and care partners, it can be hard to see through each other's eyes and really empathize with the other's role. In this session, patients will hear candid confessions from a Care Partner Table Captain, and care partners will hear candid confessions from a Patient Table Captain: the joys and the sorrows. Active participation encouraged! **For patients and their care partners, and anyone who would like to learn about these perspectives.***

Financial Self-Care: Easy Estate Planning for All Budgets | Megan Campbell, JD
*Join us for an empowering session that explores the essentials of estate planning for individuals and families on any budget. It’s led by an experienced attorney who will demystify the process of creating a comprehensive estate plan that protects your assets and ensures your wishes are honored. Whether you’re just starting to think about estate planning or looking to refine your existing plans, you’ll gain valuable insights on how to secure your financial future with confidence and peace of mind. Learn practical tips, discover affordable options, and take control of your financial self-care today! **For everyone.***

Pulmonary Rehabilitation | Sonye Danoff, MD, PhD
*Discover the benefits of pulmonary rehabilitation for those who live with myositis. This talk explores how tailored exercises and therapies can improve lung function and overall well-being. Learn practical strategies to manage symptoms and enhance quality of life. **For those with ILD.***

Successfully Adapting to Intravenous Immune Globulin Therapy for Myositis | Rachel Colletta, RN, IgCN

*Intravenous immune globulin (IVIG) therapy is the first FDA-approved treatment for any myositis disease. While it is highly effective therapy for patients, it may also present challenging side effects that can affect quality of life. Proper administration of IVIG, including the care provided before, during, and after the infusion, can significantly improve the patient infusion experience. This session, led by an IG-certified nurse, will discuss IVIG administration and provide valuable resources and guidance in optimizing this important treatment. **For those on IVIG therapy or considering it.***

Sponsored by Option Care Health

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

4:30pm –5:30pm **Breakout Sessions**

Highlights from George Washington University Myositis Clinic: Juvenile vs. Adult Myositis, Disease Flares, and More |

Rudolfo Curiel, MD; Hanna Kim, MS, MD; Lisa Rider, MD

*Three distinguished panelists from the GWU Myositis Clinic will present an overview of this multidisciplinary center, which is focused on the evaluation and treatment of patients with inflammatory muscle diseases. The panel will outline the clinic's notable achievements and studies, describe juvenile vs. adult myositis, and discuss contributions to disease flares for juvenile and adult myositis. **For those with DM and JM.***

Myositis Medications and Management | Valerie LeClair, MD, PhD

*While there is only one FDA approved treatment for myositis diseases (in addition to prednisone), 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.***

Severe Forms of Myositis and Complications: Antisynthetase Syndrome, MDA5 Dermatomyositis, Interstitial Lung Disease, and Other | Julie Paik, MD

*Several forms of myositis can be especially severe, associated with complications like ASyS, MDA 5, and ILD. This talk explores how these conditions can affect muscles and organs, leading to challenges in diagnosis and treatment. Join us to unravel the mysteries surrounding these conditions and learn about the latest advancements in management strategies. **For those with ASyS, MDA 5, or ILD.***

Hazards of Immune Boosting Supplements | Victoria Werth, MD

*Herbal supplements are very popular as individuals seek alternative remedies for a variety of health conditions. As companies promote "immune boosting" properties of their products, it's natural for those who have an autoimmune disease to think they should boost their immune system. But these supplements can be problematic if you have myositis. This session highlights the research and clarifies which supplements a myositis patient should avoid. **For everyone.***

Physical Therapy for Inclusion Body Myositis | Albert "Fin" Mears, DPT

*Physical therapy (PT) is just as important as medications in treating myositis. This session, led by a physical therapist experienced with myositis, will help you understand the principles that guide a therapeutic program specifically for IBM. **For those with IBM.***

Physical Therapy for Myositis | Ruben Pagkatipunan Jr, DPT

*Physical therapy (PT) is just as important as medications in treating myositis. This session, led by a physical therapist experienced with myositis, will help you understand the principles that guide a therapeutic program that can enhance your treatment journey. **For those with forms of myositis other than IBM.***

6:30pm – 7:15 **Heroes in the Fight Reception** **Separate Ticket Required**

6:30pm-7:15pm **VIP Reception** **By Invitation Only**

7:00pm –9:00pm **Heroes in the Fight Awards Ceremony & Dinner** **Separate Ticket Required**

Honorees are supermodel and DM warrior Karen Alexander; researcher Dr. Thomas Lloyd; Karolinska University Hospital Myositis Clinic, accepted by Dr. Ingrid Lundberg; and Donna DeFant, the recipient of TMA's first Marianne Moyer Myositis Leader Award, accepted by Linda Sabatino.

Sunday | September 8, 2024

7:00am – 8:30am **Breakfast**

7:30am-10:30am **Registration & Exhibits Open**

8:00am –9:00am **Breakout Sessions**

Empowering Patients: Navigating Assistive Technologies to Stay Connected, in partnership with TMA Board of Directors' Chair | Laurie Boyer, MBA

*Join us for an inspiring session that celebrates the power of assistive technology in everyday life. Whether you're a patient or care partner, discover how cutting-edge tools enhance communication, independence, and social connections. From smart devices to customized apps, we'll explore practical solutions that empower patients to thrive in our digital world. Let's bridge the gap and stay connected! **For everyone.***

Sponsored by CSL Behring

Autoantibodies: From Bench to Bedside and Back Again | Moderator: Anthony Amato, MD; Iago Pinal Fernandes, MD, PhD

*Learn about the latest advancements in myositis autoantibodies, which can define specific diseases within myositis. A new study about how autoantibodies disrupt biological function in the muscles will be discussed along with how this knowledge applies to myositis. This session will help you understand what these autoimmune factors in your blood can tell your doctor about your disease, how it progresses, and what treatment options may work best. **For everyone.***

Skin and Hair Issues in Dermatomyositis | Victoria Werth, MD

*The skin symptoms of dermatomyositis (DM) can be especially distressing. In addition to dealing with pain, fatigue, and muscle weakness, those with DM may also have to cope with itchy rashes, hair loss, and other distressing symptoms. This session discusses these challenges and offers some helpful treatments. **For those with DM.***

Management of Dysphagia in Myositis | Genevieve McKeon, CCC-SLP; Theresa Walker, MS, CCC-SLP

*Dysphagia (swallowing difficulties) can be a difficult challenge for those who live with any form of myositis. This talk explores how myositis can affect the muscles used for swallowing, leading to challenges with eating and drinking. Discover strategies and therapies to manage dysphagia and improve quality of life for individuals living with dysphagia. **For everyone.***

Hints and Hacks: Making Your Life Work for You | Moderator: Nita Sharma; Allison Fisher, MS, OTR/L, CDP

*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.***

Veteran Open Forum: Navigating Veterans Affairs Claims and Appeals, in Partnership with TMA Military Veterans with Myositis Affinity Group | Moderator: Rachel Bromley; Kerry Baker; Ursula Mecabe, JD

*In this informal session, you will learn from legal and claims experts as well as your fellow veterans. Come with questions and success stories from your experience navigating the VA and the Veterans Benefits Administration. **For those who have served on active duty in the U.S. Armed Forces, military Reserves, or National Guard. Care partners, advocates, and interested attendees also welcome.***

Sponsored by Mallinckrodt

9:00 am – 9:30am **Break, Networking, Exhibitors**

9:30am –10:30am Breakout Sessions

What about the Kids? Helping Children of Any Age—Even Grown Ones—Understand and Adapt to your Diagnosis |

Moderator: Rich DeAugustinis; Stanley Nwogwugwu, PhD, LCPS-S, LCADC, NCC

*When adults in their lives are sick, kids can be confused and scared. This session is aimed at helping children of any age--even adult children--understand your myositis diagnosis. Discover gentle and age-appropriate ways to explain the condition, fostering understanding and support within your family. Gain valuable insights and strategies to navigate this journey together with love and resilience. **For those with kids, grandkids, nieces, nephews, or any special person in their lives.***

Treatment of Myositis Interstitial Lung Disease: Immunosuppression and Beyond | Sonye Danoff, MD, PhD

*Immune suppression is the usual approach to treating myositis with interstitial lung disease (ILD). This session explores this and other emerging approaches to managing ILD effectively. Discover how advancements in treatment options offer hope and improved outcomes for individuals living with myositis-related lung complications. **For those with ILD.***

Understanding and Overcoming Insurance Challenges | Michelle Vogel, MPA

*Understanding the ins and outs of insurance can be overwhelming, from copays and deductibles to pre-authorization, denials, and appeals, and finding health insurance coverage when you need it most. This empowering session will help you learn how to manage the world of insurance for yourself or your loved one. **For everyone.***

Sponsored by Mallinckrodt

Civilian and Military Environmental Risk Factors in Myositis | Adam Schiffenbauer, MD

*Myositis researchers at the NIH have explored for years how everyday things around us affect myositis. Presented by one of the NIH's top myositis scientists, this session explores how everything from sunlight to military service can play a role in myositis diseases. **For everyone.***

Chimeric Antigen Receptor (CAR) T-Cell Therapy: A Promising New Frontier for Myositis Treatment | Tahseen

Mozaffar, MD; Maxamilian Konig, MD

*CAR T-cell therapy is a revolutionary new treatment that is being tested for myositis. In this talk, you'll discover how special cells in our body can be trained to fight autoimmunity. It's like sending superheroes into battle against bad guys! Learn how this therapy can help defeat myositis symptoms, possibly for good. **For everyone.***

Sponsored by Cabaletta Bio and Bristol Myers Squibb

Occupational Therapy for Myositis | Allison Fisher, MS, OTR/L, CDP

*Occupational therapy (OT) can be especially helpful for those living with myositis. This session, led by an occupational therapist experienced in working with those with myositis, will help you deal more effectively and efficiently with these daily challenges. **For everyone.***

10:30am – 10:45am Break, Networking

10:45am – 11:45am Closing General Session

DM Patient Story – Lindsay Guentzel

Keynote Address – Accelerating Autoimmune Disease Research at NIH to Advance Treatment and Therapies for Patients | Victoria Shanmugam, MBBS, MRCP, FACR, CCD

Dr. Shanmugam will share her exciting vision as the leader of the new, NIH-wide, cross-cutting autoimmune research strategy. Her office's mission is to support high priority autoimmune disease research, identify emerging areas of innovation, and foster collaboration.

Closing Remarks | Paula Eichenbrenner, MBA, CAE; Laurie Boyer, MBA