

Celebrating our Connection

INTERNATIONAL

ANNUAL PATIENT CONFERENCE

SEPTEMBER 6-8, 2024 | HILTON BALTIMORE INNER HARBOR



octagam 10%

Immune Globulin Intravenous (Human) 10% Liquid Preparation

The First & Only IVIg Approved for the Treatment of Dermatomyositis (DM) in Adults¹⁻³





In the ProDERM clinical study, the time to TIS response was 35 days with octagam 10% vs 115 days with placebo.^{1-3,a}



Treatment with octagam 10% was generally well tolerated—most adverse events were mild in intensity.^{2,3}

Visit us at booth #1

to learn more about octagam 10% and the entire Octapharma Immunology portfolio

Indications

Octagam® 10% is an immune globulin intravenous (human) liquid preparation indicated for the treatment of dermatomyositis (DM) in adults. Octagam® 10% is also indicated for the treatment of chronic immune thrombocytopenic purpura (ITP) to rapidly raise platelet counts to control or prevent bleeding in adults.

WARNING: THROMBOSIS, RENAL DYSFUNCTION AND ACUTE RENAL FAILURE

Please see octagam 10% full Prescribing Information for complete BOXED WARNING and additional important information.

- Thrombosis may occur with immune globulin intravenous (IGIV) products, including octagam® 10%. Risk factors
 may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial
 thrombosis, use of estrogens, indwelling vascular catheters, hyperviscosity, and cardiovascular risk factors.
- Renal dysfunction, acute renal failure, osmotic nephropathy, and death may occur with the administration of Immune Globulin Intravenous (Human) (IGIV) products in predisposed patients. Renal dysfunction and acute renal failure occur more commonly in patients receiving IGIV products containing sucrose. Octagam® 10% does not contain sucrose.
- For patients at risk of thrombosis, renal dysfunction or renal failure, administer octagam® 10% at the minimum infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk for hyperviscosity.

Please see an Octapharma Representative at booth #1 for Full Prescribing Information.

IVIg=intravenous immune globulin; TIS=Total Improvement Score.

Improvement of ≥20 points on TIS (based on 6 core Set Measures).

References: 1. Octagam 10% Full Prescribing Information. Paramus, NJ: Octapharma; rev March 2022. 2. Octapharma. Data on file. 3. Aggarwal R, Charles-Schoeman C, Schessl J, et al. Trial of intravenous immune globulin in dermatomyositis. N Engl J Med. 2022;387(14):1264-1278. doi:10.1056/NEJMoa2117912

Scan the QR code to visit octagamusa.com/gam10pi for Full Prescribing Information, including BOXED WARNINGS.



ASSISTANCE

Now Available for Eligible Patients With DM Treated With Octagam 10%

The Octapharma Co-Pay Assistance Program Offers Significant Cost Savings

RECEIVE UP TO \$12,500 PER CALENDAR YEAR

on the out-of-pocket costs associated with octagam 10% for adult DM

Eligible patients may receive up to \$12,500 in co-pay assistance for octagam 10% usage in the current calendar year. Patients must currently be using octagam 10%, or have a prescription to begin therapy, for the FDA-approved indication of adult DM.

- Co-pay assistance can be applied to co-payments, deductibles, and co-insurance that may be associated with the cost of Octapharma products
- The program does not cover costs associated with administration of therapy, such as office visits, infusion costs, or other professional services



Enrollment Is Fast And Easy

Call the Octapharma Support Center at 1-800-554-4440



Your healthcare provider (HCP) completes and signs the Co-Pay Assistance Form



Your HCP writes a prescription for octagam 10% for adult DM



Your prescribing HCP faxes the completed forms and octagam 10% prescription to Program Administrator

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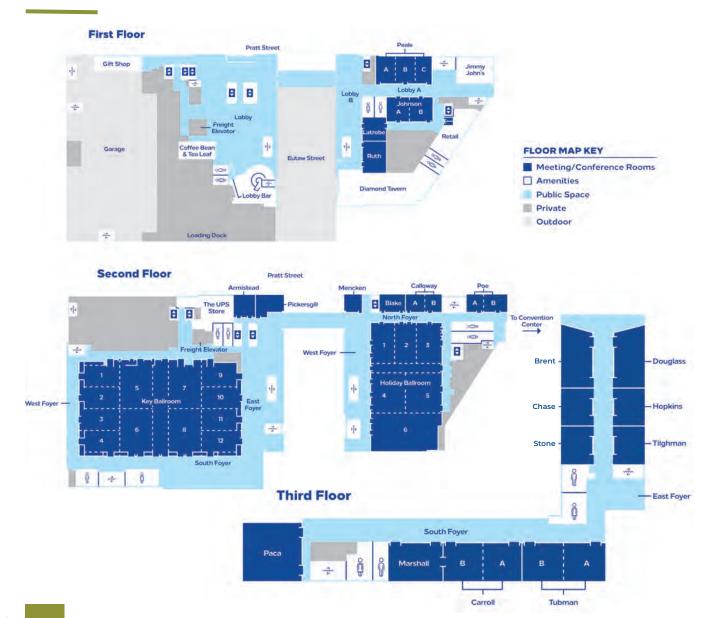
octapharma

TABLE OF CONTENTS

- Conference Floor Plan
- 5 Exhibitor Information
- 6 General Information
- 8 Conference Schedule
- 16 Speakers
- 20 Medical Advisory Board

- 22 Board of Directors
- 23 TMA Staff & TMA Conference Team in Baltimore
- 23 Corporate Advisory Council
- 24 Exhibitors & Sponsors
- 26 Notes

CONFERENCE FLOOR PLAN



EXHIBITOR INFORMATION

Exhibit Hours

Friday, September 6

Exhibits Open 5:00pm - 6:00pm

Saturday, September 7

Exhibits Open 7:30 am - 4:30pm

Breaks

10am, 12-1:30pm, 2:30pm & 4pm

Sunday, September 8

Exhibits Open

7:30 am - 11:00am

Breaks

9am, 10:30am



Download the Official INTERNATIONAL ANNUAL PATIENT CONFERENCE App!

Install on your mobile device

 Scan the QR code or on your smartphone, visit

> https://my.yapp.us/ TMA2024IAPC

2. Follow the instructions on screen. It's a quick, two step process.



Scan here



Already have the Yapp App installed?

- Tap "Add an Existing Yapp" or the green "+" button (top right)
- 2. When asked for the Yapp ID, enter: **TMA2024IAPC**
- 3. Press the device keyboard's enter button, or tap "Next"





GENERAL INFORMATION

Thank you for attending the International Annual Patient Conference, TMA's 29th gathering of the worldwide myositis community. We are thrilled you're here!

Special Needs

The staff of the Hilton Baltimore Inner Harbor Hotel and The Myositis Association are here to help with any special needs. Please ask for assistance at the TMA registration desk in the meeting space foyer or at the hotel front desk.

Name Badges

Name badges are required for entry to **all** conference sessions, events, and meals.

Restrooms

Restrooms are conveniently located on the same floor as the meeting space. Refer to the hotel map on page 4.

Dress

Casual attire is suggested for all conference events and meals. Cocktail attire is appropriate for the Heroes in the Fight Awards Celebration.

Meals

Conference registration includes the Welcome Reception on Friday evening, breakfast Saturday and Sunday, and lunch on Saturday. If you have special dietary needs, place the dietary restriction card included in your registration packet on the table in front of you at each meal. If you did not receive a dietary restriction card, please let the registration staff know.

Courtesies

While attending conference sessions and keynote addresses, please silence cell phones and anything else that could disrupt speakers and fellow attendees.

Creative Connections Corner

This is a space near registration designed to inspire, reflect, create, and connect with one another while together in Baltimore. Be sure to check out the activities available here Friday afternoon through Sunday morning.

Sponsored by CSL Behring

Evaluations

Printed evaluation forms are not available this year. Please scan these QR codes codes or access the online forms through our conference app. We ask that you complete a session evaluation for each session you attend, as well as one overall conference evaluation. We value your input and use it to improve the conference experience.

Session Evaluation



Overall Conference Evaluation





Wheelchair and scooter users: please try to keep aisles and doorways clear in meeting rooms.

Your journey matters. Share your myositis story with us

You are more than your myositis diagnosis. You are a dynamic person who wants the most out of life, but myositis challenges—like muscle pain and increasing muscle weakness—may be a struggle. Spread awareness and understanding of myositis by sharing your story with us.

Let your story be told



Each story counts. Help us amplify your voice.

This storytelling project aims to raise awareness of myositis, through engaging and connecting with those living with this condition and and with those who care for them. Now you can build upon the community's collective voice as you share your myositis story. Please use one of the prompts below to help you get started or choose a topic that speaks to you.

Don't want to share your story but interested in future communications about myositis?





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CONFERENCE SCHEDULE

Thursday • September 5, 2024

1:00pm - 5:00pm Board of Directors Meeting By Invitation Only

5:00pm – 7:00pm Early Registration Open 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 | |
| /00mm F-00mm | Catting A agusintad Breakaut Bases | |

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 MyositisModerators: Howard Gerrin and Ricky MarksDermatomyositisModerators: 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

5:15pm - 6:00pm TMA Women of Color Affinity Group 5th Anniversary Award Ceremony and Toast

Sponsored by argenx

5:00pm - 6:00pm Welcome Reception and Exhibits Open

6:00pm - 7:00pm Welcome | Laurie Boyer, MBA

Opening General Session

IBM Patient Story | Nancy Marx Erickson

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.

Don't Forget.

Your conference registration includes access to conference recordings. Access information will be automatically emailed to you around **October 15.** The complete package includes:

- Video recordings of pre- and post-conference virtual sessions
- Video recordings of the opening and closing keynote addresses
- Thirty+ audio-recorded sessions synced with slides from the presentation
- Video of the Heroes in the Fight Awards Ceremony featuring supermodel and DM patient Karen Alexander and our other myositis heroes

| 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 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. <i>For everyone</i> . | Chip Galloway | |
| 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 I 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.*

NEW! 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, Annlise Calypso, MSN, CRNP; 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, LCPC, CST 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.

NEW! 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*.

Are you making friends with other myositis warriors at the conference?

Plan to stay in touch by attending the postconference virtual reunion on September 27. All registered attendees will receive an email Zoom link to access the session.

Saturday • September 7, 2024 (continued)

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 | Annlise Calypso, MSN, CRNP; Sonye Danoff, MD, PhD; Valerie LeClair, MD, PhD; Erin Wilfong, MD, PhD

Dermatomyositis | Victoria Werth, MD; Eleni Tiniakou, MD; Christopher Mecoli, MD, MHS; lazsmin Bauer Ventura, MD

Sponsored by CSL Behring

Inclusion Body Myositis - Diagnosed More than 5 Years | Tahseen Mozaffar, MD; Anthony Amato, MD; Tom Lloyd, MD, PhD; Tae Chung, MD

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 I 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.*

NEW! 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.*

NEW! Clinical Trial Design: Industry Perspectives | Moderator: Ray Mankoski, MD, PhD, 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

NEW! National Physical Therapy Leadership 'Ask Me Anything' Panel | Moderator: Jim Milani, DPT; 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.*

Saturday • September 7, 2024 (continued)

2:30pm - 3:00pm Break, Networking, Exhibitors

3:00pm - 4:00pm Breakout Sessions

Defining Idiopathic Inflammatory Myopathies and Classification Criteria I Ingrid Lundberg, MD, PhD Learn how researchers from around the world are working together to refine the 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.*

NEW! 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*.

NEW! 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.*

NEW! Sitting in their Seats: Patient and Care Partner Perspectives | Moderators: 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 | Moderator: Meriel Parker, MS; 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*.

NEW! 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, IqCN, CRNI

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

Saturday • September 7, 2024 (continued)

4:30pm -5:30pm

Breakout Sessions

NEW! Highlights from George Washington University Myositis Clinic: Juvenile vs. Adult Myositis, Disease Flares, and More | Rodolfo 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 other than IBM*.

NEW! 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.*

NEW! 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 - 7:15pm Heroes in the Fight Reception Separate Ticket Required 6:30pm-7:15pm VIP Reception

7:00pm -9:00pm

Heroes in the Fight Awards Ceremony & Dinner

Separate Ticket Required

By Invitation Only

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, 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-10:45am Registration & Exhibits Open

8:00am -9:00am

Breakout Sessions

NEW! 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; lago 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 and Gabby Lothrop; 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

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 in the US Armed Forces, Reserves, or National Guard. Care partners, advocates, and interested attendees also welcome.

Sponsored by Mallincrokdt

9:00 am - 9:30am

Break, Networking, Exhibitors

Sunday • September 8, 2024 (continued)

9:30am -10:30am

Breakout Sessions

NEW! 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, children 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 Mallincrokdt

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.**

NEW! Chimeric Antigen Receptor (CAR) T-Cell Therapy: A Promising New Frontier for Myositis Treatment | Tahseen Mozaffar, MD; Maximilian Koniq, MD

CAR T-cell therapy is a revolutionary new treatment, borrowed from oncology, that is being tested for myositis. In this talk, you'll discover bispecific antibodies and how special cells in our body can be trained engineered 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







TMA is tremendously grateful to the many donors to our Conference Scholarship Fund.

These generous individuals, along with matching funds from Augie and Rich DeAugustinis, raised more than \$16,000, making it possible for 21 members and their care partners to attend the conference or receive the recordings.

SPEAKERS

Jemima Albayda, MD | Assistant Professor of Rheumatology Johns Hopkins Myositis Center

Karen Alexander | Supermodel, DM warrior, and Patient Ambassador Awardee

Anthony Amato, MD | Professor of Neurology, Harvard Medical School and Brigham and Women's Hospital

Martha Arnold | Member of the TMA Board of Directors; Martha lives with IBM

Kerry Baker | Accredited Claims Agent for Hill & Ponton, veteran disability attorneys

Noelle Benach | Sex therapist based in Baltimore, MD

Laurie Boyer, MBA | District administrator for St. Lucie Public Schools for instructional technology, marketing outreach, and curriculum coaching. Chair of TMA Board of Directors

Rachel Bromley | Senior Manager of Patient Education, Support, and Advocacy at TMA

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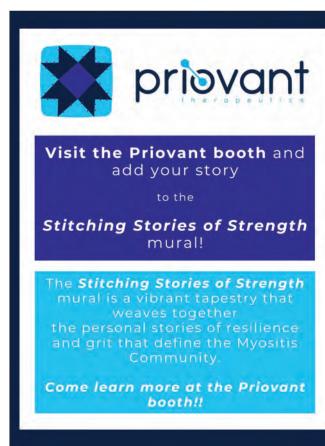
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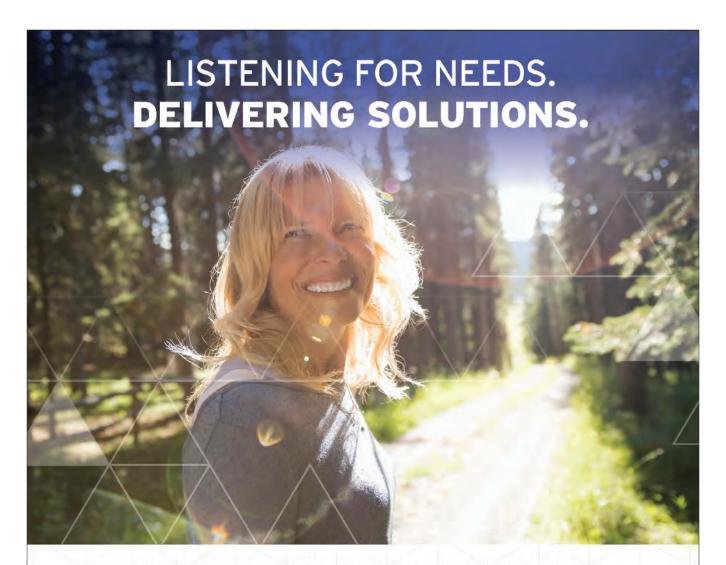
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TMA offers a free, interactive "Ask the Doc" webinar each month? Ask the Doc provides an opportunity for you to meet a member of TMA's expert Medical Advisory Board or another distinguished member of the myositis medical community. This is a session where you can get answers to almost any question about myositis diseases.

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argenx is a global immunology

company committed to improving the lives of people suffering from severe autoimmune diseases. We are sciencebased, data-driven and patientfocused. We are on a bold mission to achieve the unthinkable: to redefine immunology.

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As a leading cell therapy company and pioneer in modulating the body's immune response, Bristol-Myers **Squibb** is uniquely positioned to unlock the potential of CAR T in a new frontier: autoimmune diseases. BMS has a robust development strategy investigating cell therapy for the treatment of people living with diseases across the autoimmune spectrum.

Cabaletta Bio is a clinical-stage biotechnology company focused on developing T cell therapies with potential to provide durable, perhaps curative, treatment for patients with autoimmune diseases. CABA-201, a CD19-CAR T cell therapy, is being evaluated in the RESET Phase 1/2 trials across several autoimmune diseases, including adult and juvenile myositis.

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Founded by pharmacists, CSI Pharmacy is a national infusion pharmacy that specializes in treating patients with autoimmune disorders, including myositis. We employ specially trained pharmacists and nurses to provide treatments to patients nationwide. Experience the difference of CSI Pharmacy! Call us today at (833) 569-1005 or learn more at csipharmacy.com. **CSL Behring** is a global leader in developing and delivering high-quality medicines that treat people with rare and serious diseases. Our treatments offer promise for people in more than 100 countries living with conditions in the immunology, hematology, cardiovascular and metabolic, respiratory, and transplant therapeutic areas.

EMD Serono is the healthcare business of Merck KGaA, Darmstadt, Germany in the US and Canada. They aspire to create, improve, and prolong life for people living with difficult-to-treat conditions. The business is working to translate the discovery of molecules into potentially meaningful outcomes for people with serious unmet medical needs.

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IgNS Immunoglobulin

B00TH #25

IndeeLift*

B00TH #15

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Immunoglobulin National Society (IgNS) is a national professional organization advancing immunoglobulin therapy and biologics. Since 2012, it has led the field through Standards of Practice, specialized education, professional credentialing, and comprehensive resources. IgNS is committed to supporting patients, clinicians, and organizations, enhancing practice, ensuring patient safety, and achieving optimal clinical outcomes.

IndeeLift provides human lifts to help maintain independence and safety of many people with falling and mobility issues. We take pride in the fact that we developed a floor-to-stand lift specifically for those with IBM and others who need help up from the floor or a seated position.

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At Johnson & Johnson, health is everything. Our strength in healthcare innovation empowers us to build a world where complex diseases are prevented, treated, and cured, where treatments are smarter and less invasive, and solutions are personal. Our Innovative Medicine and MedTech enable us to innovate today to deliver the breakthroughs of tomorrow.

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MSU is an all-volunteer, virtual nonprofit organization of myositis patients, care partners, and supporters. Helping others by providing "From the Heart" support on various platforms, educational webinars, and financial assistance to myositis patients is our passion. Our patient-led research focuses on addressing patient's quality of life issues.

Nufactor offers safe, convenient, and reliable infusion solutions for patients receiving immunoglobulin, antihemophilic factor, and infliximab. Count on us for high-quality therapies and individualized care—all in the comfort of your home.

octapharma

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Optum

B00TH #8

Headquartered in Lachen, Switzerland, Octapharma is one of the largest human protein manufacturers in the world, developing and producing human proteins from human plasma and creating products across three therapeutic areas: immunotherapy, hematology, and critical care. Octapharma has five state-of-theart manufacturing facilities and operates more than 190 plasma donation centers across Europe and the US.

Option Care Health is committed to delivering high-quality, cost effective solutions to make a positive difference in people's lives. We are guided by our purpose to provide extraordinary care that changes lives through a comprehensive approach to care along every step of the infusion therapy process including: intake coordination, insurance authorization, resources for financial assistance, education and customized treatments.

With infusion pharmacists and nurses across the country, **Optum Infusion** Pharmacy administers high-quality, cost-effective infusion therapies for acute and chronic conditions in the comfort of a patient's home or a conveniently located infusion suite. We support intravenous immunoglobulin (IVIG) and subcutaneous immunoglobulin (SCIG) treatments.



CAC

B00TH #4

priovant CAC

B00TH #3

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Priovant is a clinical-stage biotechnology company focused on delivering novel therapies for autoimmune diseases with the greatest morbidity and mortality. We are developing oral brepocitinib, a potential first-in-class dual inhibitor of TYK2 and JAK1, across multiple severe autoimmune indications, unlocking new treatment options for patients who are underserved by existing therapies.

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Rare Patient Voice (RPV) empowers patients and family caregivers to share their voices with researchers and companies developing products, devices, and treatments through paid surveys and interviews to improve lives. Payment is based on a \$120 per hour scale.

Soleo Health is a national provider of complex specialty pharmacy services and infusion therapy administered in home or alternate sites of care. Soleo Health's team comprises experienced clinical pharmacists, registered nurses, reimbursement specialists, and patient ambassadors. Soleo has 24 pharmacies with national nursing coverage and pharmacy licensure in 50 states.

Somavive helps individuals improve or maintain vitality with individualized Blood Flow Restriction (BFR) services and ongoing proactive performance.



B00TH #6

The Myositis Association (TMA) is one of the leading patient organizations for those who live with myositis. For more than 30 years we have been providing educational materials for patients and physicians, facilitating support and affinity groups, hosting educational programming, provide resources for living with myositis, and advocating for better treatment and funding for rare disease research.

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To learn more about sponsoring or exhibiting at next year's conference, stop by the registration desk or visit **www.myositis.org.**

Transforming patients' lives through science™

We are in the business of breakthroughs our diverse, promising pipeline is focused on innovative medicines that transform patients' lives. Our scientists are researching ways to address some of the most challenging diseases of our time, myositis among them. We will never give up our search for more hope, for more patients, around the world.

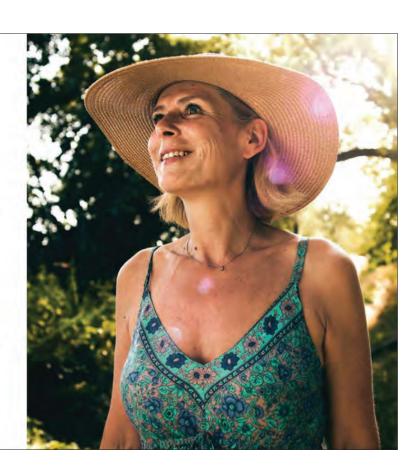


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KEYNOTE SPEAKERS



Jessica Buchanan will deliver the keynote address during the Opening General Session on Friday, September 6. Her talk, "**Impossible Odds: A Story of Strength and Survival**," 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.

Jessica is an expert in impossible circumstances. Her unique journey of enduring kidnapping and captivity at the hands of Somali pirates in 2011 offers insights into resilience. Grit and tenacity are demanded daily when you live with myositis. Ms. Buchanan's inspiring presentation will encourage us all to access our inner resilience by identifying our own autonomy and choice amid life-changing circumstances.

Jessica is a teacher, author, humanitarian, speaker, and survivor. On October 25, 2011, while on a routine field mission in Somalia, working as the Education Advisor for her non-governmental organization, Jessica was abducted at gunpoint and held for ransom by a group of Somali pirates for 93 days. Forced to live outdoors in deplorable conditions, starved, and terrorized by more than two dozen gangsters, Jessica's health steadily deteriorated until, by order of President Obama, she was rescued by the elite SEAL Team VI on January 25, 2012. Jessica's ordeal is detailed in her New York Times bestselling book, Impossible Odds: The Kidnapping of Jessica Buchanan and Her Dramatic Rescue by SEAL Team Six.



Dr. **Victoria Shanmugam**, MBBS, MRCP, FACR, CCD, Director of the NIH Office of Autoimmune Disease Research, will deliver the keynote address during TMA's Closing General Session. Her presentation is titled "Accelerating Autoimmune Disease Research at NIH to Advance Treatment and Therapies for Patients."

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. Dr. Shanmugam will share her perspective on the current state of research in autoimmunity, rheumatology, and rare disease. Her presentation promises valuable insights into research that has an impact on myositis diseases.

In 2022, the National Academies of Sciences, Engineering, and Medicine (NASEM) conducted an analysis examining research efforts of the National Institutes of Health (NIH) related to autoimmune diseases, publishing their findings in a report titled "Enhancing NIH Research on Autoimmune Diseases." Based in part on the findings articulated in this report, Congress, via the Fiscal Year 2023 Consolidated Appropriations Act, subsequently directed the establishment of the Office of Autoimmune Disease Research (OADR) within the Office of Research on Women's Health (ORWH).

Dr. Shanmugam is an experienced physician-scientist, rheumatologist, and academic leader. She completed her medical degree at Imperial College School of Medicine in London and is a member of the Royal College of Physicians. Dr. Shanmugam joined the faculty of Georgetown University School of Medicine in 2007 and was a KL2 scholar at the Georgetown-Howard Universities Center for Clinical and Translational Science. Her research focused on scleroderma and wound healing, as well as the interplay of the host immune system with the microbiome in patients with chronic wounds. A talented academic leader, Dr. Shanmugam subsequently served as chief of rheumatology at the George Washington University School of Medicine and Health Sciences from 2014 to 2021. She was the inaugural chair of the Clara Bliss Hinds Society for Women in Medicine and Health Sciences and is widely respected in the field of autoimmune diseases, having served in multiple leadership roles for the American College of Rheumatology.

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DM=dermatomyositis; Ig=immunoglobulin.



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October 2023



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