



THE MYOSITIS ASSOCIATION®

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THE MYOSITIS ASSOCIATION®

THE INTERNATIONAL ANNUAL PATIENT CONFERENCE

SEPTEMBER 6-8, 2024  
HILTON BALTIMORE INNER HARBOR



*Celebrating our Connection*

## Exciting New Opportunity for Conference Attendees: Field Trips!

This year for the first time ever, TMA adds three unique excursions to the 2024 International Annual Conference experience. These special offerings will give you even more to look forward to when you come to Baltimore on September 6-9!

Trips take place on Friday, September 6. Options include:

- National Institutes of Health (NIH) Clinical Center in Bethesda, MD
- Johns Hopkins Myositis Center at the Bayview campus in Baltimore
- Sightseeing in Baltimore

Sign up now for one of these exclusive activities provided only to TMA conference participants. Space is limited, so don't delay!

[LEARN MORE](#)

## SESSION INTRODUCTION

- ▶ As individuals living with a **physical disability**, we encounter a variety of issues with **airline travel**.
- ▶ We are consistently required to make **accessibility adaptations** for **safe air travel**.
- ▶ Some **regulations** are **mandated**; however, there are **differences** in how these **regulations** are interpreted.
- ▶ It's **crucial** for us to be aware of **current regulations** and **learn to effectively advocate** for ourselves.



## Let's Fly: Making Disability Air Travel More Accessible

Mindy Henderson, Vice President, Disability Outreach, & Empowerment for the Muscular Dystrophy Association joined TMA's Women with IBM Affinity Group meeting in February.

Henderson, a disability advocate, shared the challenges she encountered when she took her first journey after 14 years. She discussed the latest FAA legislation and offered accessibility travel tips and tricks for those with a disability.

[WATCH NOW](#)

## TMA's Top 10 travel Tips

Everyone needs a bucket list. It gives you something to look forward to. TMA's top 10 travel tips help you achieve those bucket-list wishes, including making the most of our International Annual Patient Conference.

[LEARN MORE](#)



## You Can Help Someone Attend TMA's Conference!

Scholarships for TMA's International Annual Patient Conference are available thanks to our generous donors. And right now, you can double your donation!

Two generous TMA leaders, Augie and Rich DeAugustinis, have offered to match every gift to the scholarship fund, dollar for dollar, up to \$10,000. Your generosity will help people who may feel very alone connect with others and learn more about how they can live their best lives by attending this amazing conference.

## Congratulations to our 2024 Myositis Awareness Month MyoMutt Pet Photo Contest Winners!

- The Cutest Puppy award goes to Skip (Theresa Gregorcy, Rockford, Illinois).
- 🐱 The Cutest Cat award goes to Charlotte (Michelle Charvet, Seattle, Washington).
- The Cutest Dog goes to Gwap (Angela Petersen, Henderson, Nevada). Each winner receives a \$20 PetSmart gift card.

Thanks to everyone who spread awareness with their pets!



### What People Told the FDA About Dermatomyositis

The first-ever Externally Led Patient-Focused Drug Development (EL-PFDD) meeting for dermatomyositis on June 7 offered a critical way for patients and their family members to highlight what life with DM is like.

TMA Board member highlighted how those who live with dermatomyositis described this many-headed monster for members of the FDA who make drug approval decisions.

[READ MORE](#)

### Speaking Up

TMA medical advisor and patient advocate Ingrid de Groot insists that patients be involved in myositis research. She represented more than a dozen international myositis patient organizations when she presented to scientists and clinicians at the Global Conference on Myositis (GCOM) in March.





A promotional graphic for a webinar. It features two circular headshots of speakers: Alexander Oldroyd, PhD, and David Mochel, MD, FACS. The text "MYOSITIS RESEARCH INSIGHTS WEBINAR" is prominently displayed in large, bold, yellow letters. Below this, a blue button says "REGISTER TODAY!". The date and time "TUESDAY JULY 9, 2024 12 PM ET | 9 AM PT" are listed in blue. At the bottom, a yellow banner contains the text "LEARN ABOUT DR. OLDROYD'S MYOSITIS RESEARCH AND ITS POTENTIAL IMPACT" and a small icon of a person with arms raised. The background has a yellow and white circuit-like pattern.

## TMA Myositis Research Insights Webinar

### Featuring Dr. Alexander Oldroyd

July 9, 2024, 12 PM ET | 9 AM PT

TMA's Myositis Research Insights webinar series features a member of TMA's Medical Advisory Board or another distinguished member of the myositis research community about their research and its impact on the myositis community.

Dr. Alexander Oldroyd, MD, PhD is a rheumatologist and serves as an Academic Clinical Lecturer at the University of Manchester in the UK where he is completing work on a TMA-funded fellowship. This research involves developing a remote continuous gait monitoring system that can be used to evaluate myositis treatment outcomes. He will discuss this project in which he is developing an app that can potentially provide direct evidence for clinical and research evaluation.

This webinar will be moderated by TMA's immediate past chair David Mochel, MD,

[REGISTER TODAY](#)

**EMPOWERMENT CLINIC**

**HELPING VETERANS WITH IBM**

**THURSDAY, JULY 11, 2024**  
**4 PM ET | 1 PM PT**

**FIND OUT WHAT YOU CAN DO FOR THOSE WHO SERVED!**

## Empowerment Clinic: Helping Veterans with IBM

July 11, 2024, 4 PM ET | 1 PM PT

Find out what simple steps you can take to help veterans with IBM get the care they need from the Veterans Administration. Advocates from TMA Military Veterans with Myositis Affinity Group have been hard at work making progress toward this goal and now turn to you for support! In this empowerment clinic, we will discuss their efforts and have a special screening of the recently released documentary *Not the Life We Wanted: An Inclusion Body Myositis Documentary*.

[REGISTER TODAY](#)



**ROBERT HALLOWELL, MD**

**PULMONOLOGIST**

**THURSDAY, JULY 18**

**12 PM ET | 9 AM PT**



HAVE MYOSITIS WITH INTERSTITIAL LUNG DISEASE?

## Ask the Doc Pulmonology with Dr. Robert Hallowell

July 18, 2024, 12 PM ET | 9 AM PT

Do you have burning questions about your lung condition that can't wait for your next visit with a doctor? Would you like to know what a leading global expert on myositis and interstitial lung disease has to say about the subject?

Bring your questions to this live Q & A with TMA medical advisor Robert Hallowell, MD. Dr. Hallowell is a pulmonary and critical care specialist at the Massachusetts General Hospital. His research focuses on factors that influence outcomes in patients with ILD, particularly those associated with autoimmune and rheumatologic disorders.

**REGISTER TODAY**

# MEET AND GREET



*Paula Eichenbrenner  
& Laurie Boyer*

**July 25, 2024  
4 PM ET**

## Meet and Greet with TMA Leadership

July 25, 2024, 4 PM ET | 1 PM PT

Join us for an engaging episode of TMA's Meet & Greet Leadership Series! Executive Director Paula Eichenbrenner and Board Chair Laurie Boyer will provide unique insights into the upcoming International Annual Patient Conference, exploring it from the perspectives of patients, care partners, physicians, and both first-time and repeat attendees. Don't miss the live Q&A session at the end!

**REGISTER TODAY**

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## Mind Your Mental Health

Human beings are social creatures. We *need* to spend time with friends and engage with others to literally survive. Research supports this: feeling connected helps us maintain a healthy weight, control blood sugar, improve cancer survival, decrease heart disease, overcome depression and PTSD, and improve overall mental health.

So what can you do to boost your social connections? Here are just a few ideas:

- ☐ Text a friend you haven't seen for a while. Go ahead, do it now. Don't think about it too much. See what happens.
- ☐ Email an old friend out of the blue and invite them for dinner, a glass of wine, or to take a walk. You've been meaning to catch up, right?
- ☐ Call a friend just to check in and say hi.
- ☐ Ask someone—your brother-in-law, stepdaughter, neighbor, cousin's best friend—for help. (Human beings also need to feel useful.)
- ☐ Get out some old photos and reminisce with your family.
- ☐ Walk up to someone and ask, "What's wonderful with you today?"



□ Join one of the many TMA support or affinity group meetings that happen [every month](#).

Now [send us an email](#) and tell us what other ideas you have.

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Finding a healthcare practitioner who knows how to care for someone with myositis is often a challenge.

While we can't guarantee you'll find an elite physician, [TMA's Find a Doctor](#) tool can at least provide options.

We've worked with our partners at MediFind to update providers and make finding the best care more accessible. Check out our [suggestions for using the tool here](#).

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## Community Tips

Sometimes it's the little everyday annoyances that make life so frustrating. TMA members share their tips for making the day go smoother.

- I have a complete set of cleaning supplies in the kitchen and another in the bathroom, so I don't have to carry them from floor to floor.
- Use the claw end of a hammer to open the refrigerator, washer and dryer, drawers, and lots of other things.
- Lower closet rods to make it easier to reach things.
- Change to lever door handles rather than doorknobs.
- I can't reach the hook on the door to hang up my housecoat, so I bought an over-the-door Christmas wreath hanger that is 14 inches long, providing a much lower hook.
- Get gadgets like a button hook tool (also works for zippers), an electric can opener, and a strap wrench for opening jar lids.





## The Impact of Falling on Quality of Life in Patients with Myositis: Patient Survey

The clinical research team at Washington University in St. Louis is conducting an anonymous survey to better understand the impact of falling and fear of falling on quality of life in patients with myositis.

You may open the survey in your web browser by clicking the link below:  
[https://redcap.link/os2ur\\_uws](https://redcap.link/os2ur_uws)

Thank you for your time and participation!

[TMA's YouTube channel](#) has been updated with links to all the most recent myositis webinars. Check out one of our playlists to learn more about myositis and available resources. Each month's webinars are published on the first of the following month.

TMA is able to support people with myositis and their families because of the generosity of individuals who support our work financially.

Please [make a gift](#) to TMA to support our impact today!

[DONATE TODAY](#)



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