

THE OUTLOOK



THE MYOSITIS ASSOCIATION®

WINTER 2025
Quarterly Magazine



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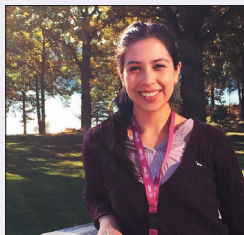
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THE OUTLOOK

A quarterly publication of The Myositis Association



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Inaugural Recipient of
Meredith C. Thomas
Memorial Fellowship**



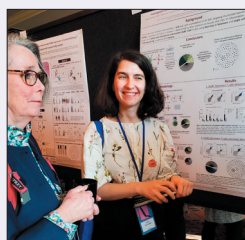
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On the cover: Professional beach volleyball champion Tri Bourne with his wife Gabby. Tri was celebrated as TMA's 2025 Patient Ambassador awardee at our Heroes in the Fight Gala.

TMA's mission is to improve the lives of persons affected by myositis, fund innovative research, and increase myositis awareness and advocacy.

TMA's vision is a world without myositis.

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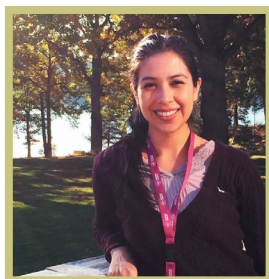
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TMA Announces Inaugural Recipient of Meredith C. Thomas Memorial Fellowship



Since 2002, TMA has awarded a variety of research grants to qualified investigators and clinicians for basic, translational, and clinical research across the spectrum of myositis diseases and specialties.

The goal of these awards

is to advance our understanding of the causes and potential cures for myositis diseases. This year's grant was the Meredith C. Thomas Memorial Fellowship award for a project related to antisynthetase syndrome (ASyS) and interstitial lung disease (ILD).

TMA is pleased announce the recipient of this grant for \$107,500 is **Angeles Galindo Feria, MD, PhD**, for her project titled, "Clinical and Immunological Determinants of Interstitial Lung Disease in Antisynthetase syndrome: Integrating Prognostic Markers with Autoreactive B and T Cell Profiling." Dr. Galindo Feria is a rheumatology specialist at Karolinska Institute in Stockholm, Sweden. She is working together with globally recognized myositis expert Dr. Ingrid Lundberg as mentor.

"This fellowship is a transformative opportunity to change how we understand and manage lung

complications in antisynthetase syndrome," said Dr. Galindo Feria. "By profiling the immune cells that drive lung damage and developing simple saliva- and sputum-based tests, we aim to move beyond the current one-size-fits-all approach toward true precision medicine. Our goal is to predict which patients are at risk of severe, irreversible lung scarring—potentially with a test as simple as a sputum sample—so that earlier and more targeted interventions can be offered to those facing this challenging disease."



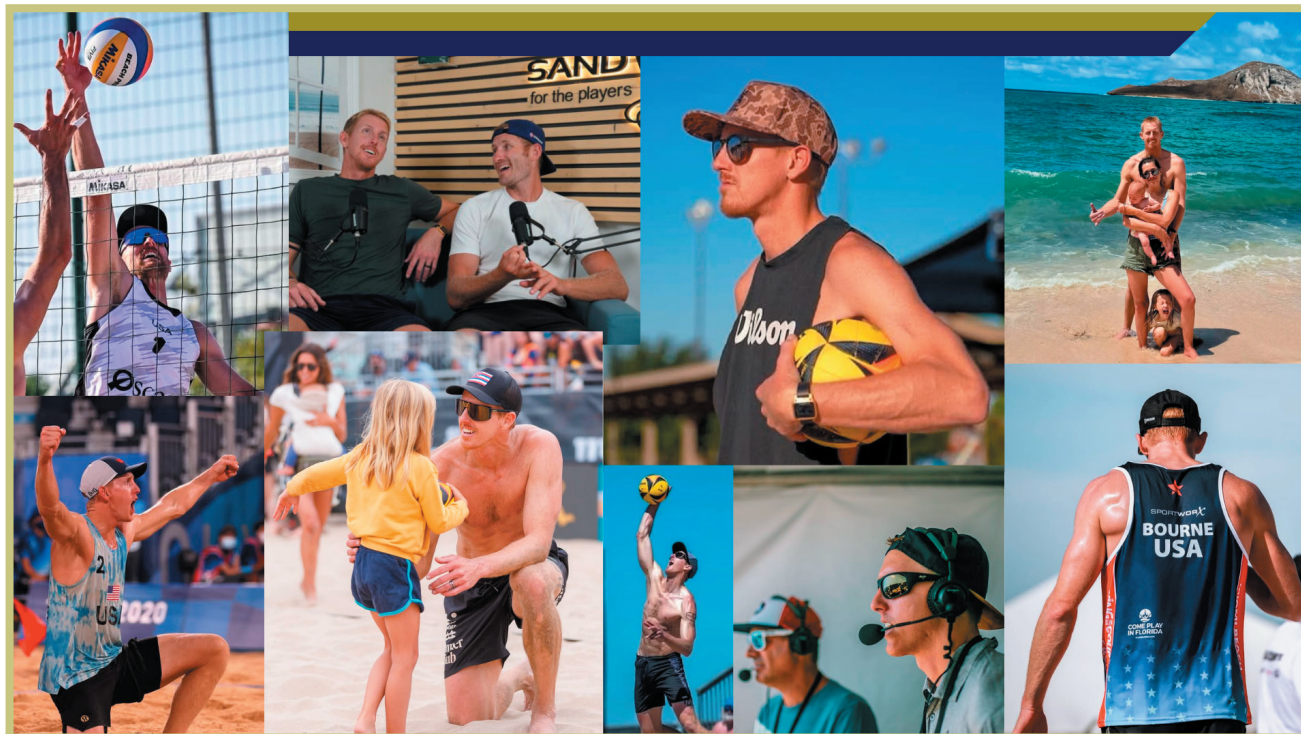
Meredith Thomas was diagnosed with antisynthetase syndrome and interstitial lung disease (ILD) and passed away at age 33 in November 2023. In her honor, her family created the fundraiser "Meredith's

Legacy" to support a Myositis Research Fellowship aimed at providing funding for early-career researchers and clinicians focused on learning more about how best to treat ASyS and ILD.

Dr. Galindo Feria's research focuses on how certain immune cells, called T and B cells, become overly active and contribute to lung injury in those with ASyS. She is also looking for ways to detect these harmful immune responses early, using simple tests on saliva or mucus, instead of more invasive procedures like lung biopsies. By analyzing blood and lung samples, she hopes to identify specific markers that could help doctors predict how the disease will progress and who is at higher risk for severe lung problems. Ultimately, she hopes this research will lead to more effective treatments and improved quality of life for those living with myositis lung disease, including ASyS.



Angeles Galindo Feria (4th from left) with the Thomas family TMA Board Chair Laurie Boyer, and Dr. Iaszmin Bauer Ventura at the 2nd Annual Meredith Thomas Trivia Night Fundraiser, October 17, 2025, Chicago, IL



From Sand to Spotlight: Tri Bourne Honored for Myositis Advocacy

When Olympian and beach volleyball champion Tri Bourne stepped onto the stage at The Myositis Association's Heroes in the Fight Awards Ceremony in Dallas this September, the applause carried more weight than any victory on the sand. Bourne was recognized with TMA's 2025 Patient Ambassador Award, a tribute not only to his athletic achievements but to his resilience and advocacy for those living with rare autoimmune diseases.

Bourne's journey has been anything but straightforward. In 2016, at the height of his career, he was diagnosed with dermatomyositis. The diagnosis forced him into a two-year hiatus from competition, a period marked by uncertainty and physical struggle. Yet Bourne returned to the sport's highest level, finishing in the top ten worldwide at the Tokyo Olympics in 2020. His comeback became a symbol of perseverance, not just for athletes but for anyone facing the invisible challenges that come with myositis.

"Tri Bourne embodies the spirit of this award," says Paula Eichenbrenner, Executive Director of TMA. "By sharing his journey on one of the world's biggest stages, he has turned personal challenge into powerful advocacy by educating the public, inspiring fellow patients, and shining a spotlight on a disease too often ignored."

For Bourne, the honor is deeply personal. "Overcoming dermatomyositis has been one of my greatest challenges, but it's also given me purpose," he reflects. "I want others to know they're not alone. You can find the positives in your own journey, even with an invisible disability."

Raised in Honolulu, Hawaii, Bourne built a career that includes 12 Association of Volleyball Professionals titles, highlighted by two Manhattan Beach Open victories. Though he retired from professional beach volleyball this fall, his voice remains strong in the community. He continues to co-host SANDCAST, the world's most downloaded volleyball podcast, and has coauthored two books, extending his reach far beyond the court.

At MyoCon 2025, Bourne's recognition underscored the power of patient voices in advancing awareness of myositis. His story is a reminder that resilience can redefine purpose, and that advocacy often begins with the courage to share one's own journey.

TMA thanks argenx for their generosity as lead sponsor for the Patient Ambassador Award.

Relive the Magic of MyoCon 2025!

From inspiring keynote speeches and enlightening breakout sessions to joyful reunions and unforgettable moments of connection, MyoCon 2025 was a celebration of strength, community, and hope. Held on September 18-21, this year's Global Myositis Patient Conference brought together patients, care partners, researchers, and advocates from around the world—

all united by a shared mission to advance understanding and support for myositis and those who live with these rare diseases.

Whether you were there in person or cheering from afar, we invite you to take a look at the highlights through this vibrant photo review. Get ready to smile, reflect, and feel the energy of a truly remarkable event!

Photos courtesy of Laurie Boyer, Rich DeAugustinis, Paula Eichenbrenner, Chip Galloway, Susie Helm, Michael Lothrop, and Justin Williams.



Ed and Marilyn McGrath



2025 Heroes in the Fight: Awardees, Family Members, and Presenters



Tri and Naia Bourne



Dr. Adam Schiffenbauer discusses IMNM



TMA Board of Directors



Paula shows off with Women of Color



AT&T Stadium excursion



CSI Pharmacy excursion



Rep. Steve Bartlett introduced by MDA leader and disability advocate Mindy Henderson



MyoCon volunteers



MyoCon crowd



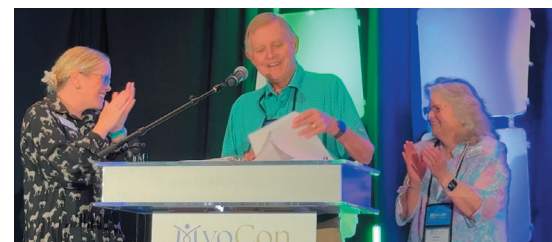
MyoCon Speaker and TMA Minnesota Support group Leader Lindsay Guentzel



Jazz saxophonist Randy Scott entertains at jazz brunch



Chip Galloway with former Rep. Steve Bartlett, principal co-author of the landmark civil rights legislation Americans with Disabilities Act (ADA)



Announcing MyoCon 2026—St. Louis!



TMA recognizes World Myositis Day 2025



Dr. Suur Biliciler discusses lifestyle medicine

49

SPEAKERS

41

BREAKOUT
SESSIONS

5

VIRTUAL
EVENTS

493

ATTENDED
MYOCON



30th

ATTENDED
THE HEROES
IN THE FIGHT
AWARDS DINNER

272

TMA ANNUAL PATIENT CONFERENCE

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MyoCon 2025

BY THE NUMBERS

5,100
miles (Stockholm)

FARTHEST DISTANCE
TRAVELED

13

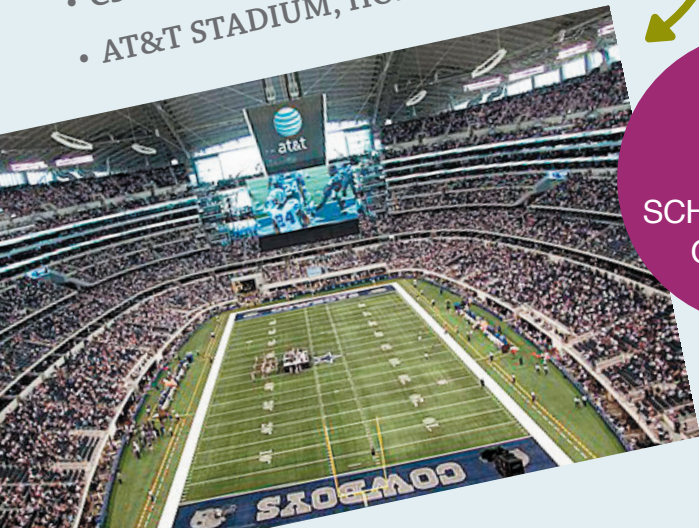
NETWORKING
EVENTS

34

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2 EXCURSIONS:

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- AT&T STADIUM, HOME OF THE DALLAS COWBOYS



29

SCHOLARSHIPS
OFFERED

8

HEROES

Recognized during the Heroes in
the Fight Awards Celebration:

- **Tri Bourne** - Patient Ambassador Award
 - o Professional Beach Volleyball Player
 - o Podcast Host and Broadcaster
 - o Living with dermatomyositis
- **Victoria P. Werth, MD** - Heroes in Research Award
 - o Professor of Dermatology and Medicine, University of Pennsylvania School of Medicine
 - o Chief of the Division of Dermatology, Philadelphia Veterans Administration Hospital
 - o Member of TMA's Medical Advisory Board
- **Mayo Clinic** - Heroes in Healthcare Award
 - o Inflammatory Myositis Clinic, Department of Rheumatology and Neuromuscular Disease Division, Department of Neurology, Rochester, Minnesota
 - o Accepted by **Drs. Floranne C. Ernste, Margherita Milone, and Elie Naddaf** with special recognition to **Dr. Steven R. Ytterberg**
- **Nancy Harber and Rhonda Rogers**
 - o Marianne Moyer Myositis Leader Award
 - o Group leaders in Southern California

Reflections from MyoCon 2025

By Linda Thomas



I just got back from MyoCon25, and honestly? I'm still recovering—in a good way. For those of us living with a rare disease like inclusion body myositis (IBM), this kind of conference is more

than just PowerPoints and name tags. It's a lifeline. A chance to be with people who get it without needing a long explanation, and to hear from experts who actually know what they're talking about.

The first thing that struck me was how valuable the breakout sessions were this year. They weren't just "talk at you" presentations—they were real conversations. Practical tips on adaptive exercise, nutrition tailored to inflammatory myopathies, and how to navigate daily life when your body no longer cooperates like it used to. There was one especially helpful session about assistive devices—not just what to use, but how to mentally and emotionally adjust to needing them. Another session touched on caregiver relationships, which hit close to home for many of us. It wasn't all serious either—there were laughs, some gentle teasing, and even some hallway scooter races (we're not naming names).

The keynote speaker set the tone from the start: former Representative Steve Bartlett who co-sponsored the original ADA legislation. Hearing directly from someone who helped shape the laws that protect our rights reminded us that advocacy isn't optional—it's survival.

And the closing speaker, Dr. Julius Birnbaum, gave us a gift with his talk *Living Well with Autoimmune Diseases*. He brought clarity, empathy, and just the right dose of humor. His message—and his book of the same title—wasn't sugar-coated or unrealistic. Instead, it offered hope that felt grounded. Yes, our diagnosis may rewrite parts of the script, but the story itself is far from over.

And then there were the people. My people. The ones who know what it's like to drop your fork because your grip gave out, or to stare at a staircase like it's Mount Everest. We swapped tips, emails, and stories—some heartbreaking, some hilarious—and formed bonds that go beyond the conference badge. It's a strange kind of comfort, finding yourself in a crowd of people with the same rare thing.

The real cherry on top was hearing from the doctors and researchers leading the charge. These weren't fly-by-night internet experts—they're the ones in the trenches, studying this disease from every angle. They shared updates on ongoing clinical trials, new diagnostic approaches, and the latest thinking on what actually causes IBM. And they did it in plain English, without making us feel like we needed a medical degree to keep up.

So yes, I came home tired. But also encouraged. Seen. Reminded that even though this disease is rare, I am not alone—and neither are you. MyoCon25 gave us knowledge, support, and community. And that's more powerful than anything you'll find in a textbook.

Linda Thomas co-leads TMA's Arizona Support Group. This reflection was written on the way home from MyoCon.

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My First MyoCon

By Dorothy Vetrano



Dorothy Vetrano and Marilyn McGrath

When I joined TMA a few years ago, I had heard about their annual conferences, but I was reluctant to attend. Maybe it was because I thought I could handle my diagnosis on my own. Or maybe I was afraid—

afraid of meeting others with the same disease and hearing about their struggles. I already had the support from family, friends, and great doctors. What more could I possibly gain?

Turns out a lot.

As soon as registration opened for the 2025 MyoCon Conference in Dallas, I signed up. The schedule was packed with breakout sessions and exhibitors over three days. But as a first-time attendee, I started to feel overwhelmed and worried I wouldn't get the most out of the experience if I didn't have a plan.

Then, a few weeks later, I received a welcome email introducing the Conference Buddy Program. This program pairs first time attendees with experienced ones. The buddy's role is to welcome you, answer questions, share tips, and offer support along the way. It was exactly what I needed, and I immediately signed up.

My buddy, Marilyn McGrath, gave me a wonderful experience I'll never forget.

Before the conference, we met virtually to put a name to a face and get to know each other. We discovered we had so much in common: both of us live with dermatomyositis we're originally from New York (she still lives there), we love hosting dinners for our families, and both of us enjoy meeting new people.

Marilyn shared some incredibly helpful tips that made all the difference to my first conference:

- ✉ **Pace yourself** – Participate as much as you can but understand it's impossible to attend everything.
- ✉ **Care partner support** – Have your care partner attend a session that overlaps with one you are interested in.
- ✉ **Conference is recorded** – Missed a session? No problem; it's all recorded. And all attendees automatically receive the recordings package.
- ✉ **Rest** – Listen to your body and take breaks.
- ✉ **Make connections** – Meet people, share contacts, and build your support network.
- ✉ **Bring snacks.**

Marilyn was knowledgeable, encouraging, and down to earth. We shared meals and sessions, and I learned more about her personal journey: the ups and downs, treatments that worked (and didn't), and how she persevered. She never gave up and came out stronger. Her story gave me hope. And there is hope—for all of us.

So whether you're a first-time attendee or a seasoned veteran, I highly recommend signing up for TMA's Conference Buddy Program. It will make your experience so much more meaningful, more personal, and more connected.

And finally, I'd be remiss if I didn't give a huge shoutout to Marilyn's amazing husband, Ed. What a firecracker! His passion for TMA and for the love of his life is absolutely contagious.

I hope to see them both again in St. Louis, if not sooner.

Dorothy Vetrano was diagnosed with DM in 2021. She lives in Houston, TX with her loving and supportive husband and two four-legged babies. She's a teacher of students with visual impairments with more than 32 years of experience working with the blind and visually impaired.



A Story of Discovery and Success...So Far

By Bryan Gilbrech



I was diagnosed at 28 years old in 1996 while I was in the Army. It started with what I call a benign pain in my right buttock that persisted for several months. I did not seek explanation or treatment because it just seemed a part of life as a soldier, and there was no associated injury. This

buttock pain progressed into a loss of appetite, muscle pain throughout the body, and fatigue. At this point, I did seek medical assistance, and I was told that I was

malnourished. Admittedly, I did not have a normal appetite and that would result in malnourishment, but it still seemed an odd diagnosis. I also received two other diagnoses during this time period: I was told that carrying my wallet in the back pocket of my clothing was the result of the buttock pain and that one of my legs was shorter than the other which would cause the pain.

I was not getting better, and one day I woke up with what we know now as the malar rash on my face and the shawl pattern on my upper chest. When I sought medical treatment, I was told you have a bad case of allergies. I was quite frustrated at this point. I do not recall lab tests being conducted during this initial period so there was no record of muscle inflammation, which was surely flaring during this time period. I do not know who on the medical staff recommended I attend Grand Rounds at the local university hospital, but I credit them with starting me and the Army medical system on the path of discovery and treatment. *Continued on page 12.*

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It was during the Grand Rounds that one of the civilian physicians thought I had some type of myositis. At this point the Army medical system had a lead, and real momentum began to occur. I had numerous blood tests and results showed very high CK levels. I had a muscle biopsy in order to make a definitive diagnosis, and it was positive for myositis. I was started on high dose prednisone and methotrexate and received a topical cream for the rash. The good news is my body responded well to the treatment, and after approximately a year I was off the prednisone and tapering the methotrexate to a maintenance dose.

After a couple years I searched for an alternative to the methotrexate, because the side effects of fatigue, suppressed thirst, and GI upset were not much fun. I was switched to azathioprine which I tolerated very well with no side effects, but after approximately three years I relapsed. This manifested itself with mostly skin signs like redness of the face and neck, awful itching, muscle weakness, and elevated CK levels. I started back on prednisone and methotrexate and

soon tapered off the prednisone but remained on methotrexate until 2022.

I had been very reluctant to stop the methotrexate for many years because of the relapse I experienced, however in 2022 I decided to give it a try. I was on a low dose of 5mg of methotrexate at that time, so I took the chance. I have had no issues since then and I'm very grateful for that.

I have often wondered if there was a correlation with an outbreak of shingles that I had a couple months prior to the onset of the buttock muscle pain. It seemed an odd situation for a 28-year-old. I still believe today that stress was either the cause or significant contributor to the onset of my dermatomyositis. I participated in Desert Storm, so there is always the possibility that some environmental toxins could also be a contributor. We'll likely never know for sure.

Bryan Gilbrech is Deputy Chief Information Officer with the US Military Medical Readiness Command in Europe which provides health services support to military personnel and their families.

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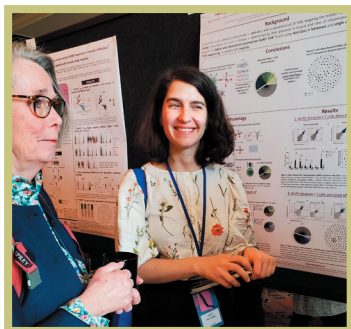
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TMA Funding Supports Early Career Researcher

By Begum Horuluoglu, PhD



Dr. Begum Horuluoglu with mentor Dr. Ingrid Lundberg

Thanks to the generous support of The Myositis Association (TMA), I have been able to pursue groundbreaking research into the immunological mechanisms underlying idiopathic inflammatory

myopathies, particularly focusing on the role of faulty T cells in myositis.

My project, titled “*Characterization of Jo-1 specific T cells in idiopathic inflammatory myopathies and development of MyoT mouse*,” aims to identify and understand a subset of white blood cells—T lymphocytes—that, for reasons still unknown, begin to attack the body’s own tissues. These rogue immune cells are found at sites of inflammation in muscles, lungs, and skin of patients with myositis, but the mechanisms driving their behavior remain elusive.

During the first year of my TMA-funded fellowship, I applied a novel methodology developed and optimized in our research group to detect these faulty T cells in blood samples from patients with anti-Jo1-positive myositis. Our preliminary findings are promising: we successfully identified T cells that mistakenly recognize the body’s own proteins as foreign and initiate an immune attack. This is the first time such cells have been reported in myositis patients.

Even more compelling, we found that these faulty T cells persist in patients even after a year of conventional immunosuppressive treatment. Although disease activity was low, none of the patients were in remission, suggesting that current therapies may suppress symptoms without addressing the underlying disease mechanisms. We are now integrating detailed clinical data with our findings to better understand the role of these persistent T cells and their contribution to disease progression.

The TMA fellowship has been instrumental not only in advancing this research but also in shaping my career. At the time of my application in 2022, I was a postdoctoral fellow in Professor Ingrid Lundberg’s group at the Karolinska Institutet in Stockholm, Sweden. The fellowship allowed me to pay my own salary, which significantly increased my independence and led to my promotion to Assistant Professor in August 2023. In fall 2024, I became a junior team leader at the Center for Molecular Medicine, and in October, I recruited my first PhD student as a main supervisor—milestones that mark my transition to an independent researcher.

In November 2024, I had the privilege of presenting my findings during a TMA-hosted webinar attended by 118 participants. Sharing my work with individuals living with myositis was deeply meaningful and motivating. The supportive feedback I received reaffirmed the importance of bridging molecular research with patient experience.

The fellowship also opened doors to international collaboration. I was invited to speak at the 6th International Molecular Immunology and Immunogenetics Congress in Istanbul, Turkey, and will participate in the Korea-Nordic Next-Generation Leaders Workshop in Research and Innovation this September in Stockholm. These opportunities have expanded my network and helped secure additional funding to support my research.

Looking ahead, I remain committed to unraveling the immunological mechanisms of autoimmune diseases, with a continued focus on myositis. I am deeply grateful to TMA for their support, which has been a cornerstone of my scientific journey. Together, we are moving closer to understanding—and ultimately treating—the root causes of myositis.

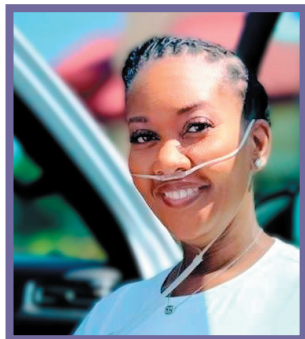
Dr. Horuluoglu was awarded a \$100,000 two-year fellowship grant from TMA in 2022. We are committed to supporting young investigators like Dr. Horuluoglu who want to dedicate their career to the study of myositis diseases. If you would like to provide resources to support the scientists of the future, please consider **making a donation to TMA**.

“This research has the potential to shift the paradigm in myositis treatment, moving from symptom management to targeted therapies that address the root cause of the disease.”

~Begum Horuluoglu

With Gratitude to TMA Donors

By Holly Jones



To members of our community who have donated to The Myositis Association, it is both an honor and a joy to celebrate your generosity and to recognize the profound impact each of you has made in the lives of those we serve.

Because of your commitment, we have expanded programs that provide real-time support, hosted events that inspire connection and education, and invested in research that brings us closer to answers, treatments, and ultimately, to a cure. Your support allows TMA staff, Board of Directors, Medical Advisory Board, Affinity and Support Groups, and Community Volunteers to have hope for a future where patients and families feel seen, supported,

given equitable healthcare, but most importantly, to never feel alone, dismissed, or minimized on their journey with myositis.

But beyond the impact of your giving, it is your spirit that sustains us. You remind us that this work is not only about science and services, but also about the people and their families who share stories and moments of inspiration that carry us forward even on the hardest days.

You give life to programs that ease burdens and inspire resilience that transform our challenges into opportunities for change.

Together, we are building a foundation of care and inspiration, and we thank you for walking alongside us with compassion, hope, and the shared vision of A World Without Myositis!

*Holly Jones serves as Chair of the TMA Board of Directors Development Committee. She offered a version of these remarks during TMA's Donor Dessert event during MyoCon 2025 in Dallas. **Watch a video of her presentation.***

*You can make a difference too! **Please consider donating to TMA.***

Discover why interstitial lung disease can develop during myositis

Interstitial lung disease (ILD) can be a serious condition that may cause scarring of the lungs, often referred to as pulmonary fibrosis. That scarring may worsen over time and can make it difficult to breathe.

In some autoimmune diseases—including myositis—multiple organ systems can be affected, including the respiratory system. Symptoms like a persistent cough, shortness of breath, and fatigue are similar to symptoms of more common conditions but could be ILD.

Talk to your doctor about your risk for ILD

“

The scans had found scarring in my lungs, known as pulmonary fibrosis... I never even knew there was a problem in my lungs.”

Dale is living with myositis-related ILD



Scan for information on your risk for ILD



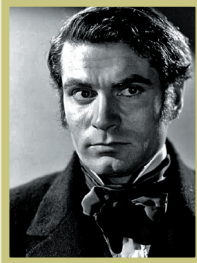
For more information about ILD, visit <https://bit.ly/ild-risk>

**TMA is grateful to our sponsors and exhibitors
who made MyoCon 2025 possible!**



**Special thanks to Texas Bald Eagle sponsors
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Did You Know...



Lawrence Olivier in *Wuthering Heights*

Sir Lawrence Olivier lived with dermatomyositis?

Perhaps the 20th century's best-known stage and film actor, Olivier had a number of health challenges, including cancer and thrombosis in addition to dermatomyositis. His restrained but powerful performances on the British stage set the standard for serious actors for decades. He was knighted by a young King George IV in 1947. When he found himself with flagging energy and a loss of mobility, he turned to acting in films, where he also excelled. Finally, he was diagnosed in the 1970s with dermatomyositis. Olivier suffered from occasional skin rashes, which sometimes made appearances difficult. He died of unrelated causes in 1989.

What Brings You Joy?



For Bob Nudelman, it's fighting back

Inclusion body myositis imposes limits on me, but my goal is to push

back. Whether it's feeling the sand beneath my wheels, engaging in walking, or working out at the gym, I'm fighting the fight and I'm not done fighting. That's what brings me pleasure.



TMA'S GLOBAL MYOSITIS PATIENT CONFERENCE

HYATT REGENCY • ST. LOUIS AT THE ARCH



Save the Date!

SEPTEMBER 24-27, 2026

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**NOW
RECRUITING!**

RAINBOW

Trial in Myositis

Eligibility

You may be eligible to participate in the RAINBOW study if you:

- Are 18–75 years old
- Diagnosed with dermatomyositis (DM) or immune-mediated necrotizing myopathy (IMNM)
- Meet other requirements, which will be discussed with you during screening.

Investigational drug

- Phase 1b trial of RAY121 in immunological diseases
- Investigational drug aims to block a pathway known to be involved in the development of immune system issues

QUICK TRIAL FACTS



This trial will last for about **9 months**.



Participants will receive the investigational drug once every **4 weeks** for **3 months** (4 times overall).



The investigational drug is given as an injection under the skin (subcutaneous) of your stomach.



Trial sponsor Chugai Pharmaceuticals Co., Ltd
Learn more at clinicaltrials.gov/study/NCT06371417

What is a clinical trial?

A clinical trial is a medical trial that helps to answer important questions about an investigational medication or drug, such as:

- Does it work?
- How safe is it?
- What are the side effects?
- Does it affect people differently based on their age, sex, gender, race, and ethnicity?

The results of clinical trials are used as part of an in-depth review process to help decide whether new medications can be approved for widespread use. Clinical trials are an important part of developing new medications. An Institutional Review Board (IRB)/Ethics Committee (EC) protects the rights, safety, and well-being of all trial participants. An IRB/EC has reviewed this trial.

