



THE MYOSITIS ASSOCIATION®

MYONews November 2024 | Volume 4, Issue 11



TMA in the News

As part of TMA's International Annual Patient Conference, TMA partnered with the National Institute of Environmental Health Sciences (NIEHS) and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) to bring 35 conference attendees to the NIH Clinical Center for tours and talks about the myositis research being done there.

Thanks to TMA medical advisor Dr. Adam Schiffenbauer and Dr. Lisa Rider, Head of the Environmental Autoimmunity Group for facilitating this excursion.

Read about this event in the NIEHS Newsletter.

[NIEHS Newsletter](#)



THE INTERNATIONAL ANNUAL PATIENT CONFERENCE

SEPTEMBER 6-8, 2024
HILTON BALTIMORE INNER HARBOR



CONFERENCE RECORDINGS AVAILABLE

Order the 2024 International Annual Patient Conference Recordings

The 2024 International Annual Patient Conference recordings are now available! Don't miss your chance—order now for only \$149 and enjoy access to 30 sessions, including keynote presentations, virtual talks, and the Heroes in the Fight Awards Ceremony. Secure your access today to watch these impactful sessions!

Conference attendees have been sent a link to access the recordings free of charge. Email IAPC@myositis.org if you did not receive a message describing how to access the virtual content.

ORDER RECORDINGS TODAY

TMA at ACR

TMA will be attending and exhibiting at the American College of Rheumatology (ACR) annual meeting in Washington, DC on November 14-19. We will be learning a lot about new developments in myositis and autoimmune diseases, networking with representatives of other patient organizations, and meeting with industry representatives offering promising new therapies for myositis diseases. If you happen to be at the meeting, we'd love to see you at booth # 2206 in the exhibit hall.



GIVING TUESDAY

GivingTuesday is Right Around the Corner

TMA is able to support people with myositis and their families only because we receive financial support from generous individuals like you. Please consider giving to TMA on GivingTuesday, December 3! Every contribution helps us provide patient support and fund myositis research. Thank you for your generosity.

Send a Gift

The **Autoimmune Association**, in concert with a **group of concerned rheumatologists** including TMA Board of Directors member Dr. Iazmin Ventura, is seeking to understand the impact of how extreme weather events (e.g., wildfire, heatwaves, hurricanes, etc.) affect people with autoimmune and other rheumatic diseases in the United States with a national signal-seeking survey, found [here](#).

Please consider adding your voice to this important research.

Do you have an autoimmune or rheumatic disease?

Complete our online survey on the impact of the weather on these diseases!

Scan the QR code to take our survey now!



Or use this link:

https://uchicago.co1.qualtrics.com/jfe/form/SV_6D82lNPNtohWG34

If questions/concerns, please email the PI, Iazmin Bauer Ventura MD, MSc, at iventura@uchicago.edu.

For more information, visit <https://reactrheum.org/>

[Take the Survey](#)

Spotlight on Giving

Meredith Thomas was 33 years old when passed away in November 2023 from antisynthetase syndrome and interstitial lung disease. In her honor, her family created a Myositis Research Fellowship to fund research grants for early-career clinicians focused on learning more about how best to treat antisynthetase syndrome and ILD.

TMA is raising funds to support this fellowship within our long-running research grants program. It's a perfect tribute to Meredith's passion for learning and community spirit.

Please join TMA in supporting this important work by donating to the Meredith C. Thomas Research Fellowship Fund.



Mind Your Mental Health: Gratitude

When was the last time you took a deep breath and looked around with gratitude at all the amazing people and experiences in your life? Science has shown that taking just a few minutes a day to reflect in this way can significantly improve social, physical, and mental well-being.

Here are a few ways to add gratitude to your self-care toolbox and increase your feelings of hope, happiness, and peace:

- Say three things you're grateful for out loud every morning when you wake up.
- Keep a gratitude journal and jot down five things you're grateful for just before you fall asleep at night.
- Tell your friends and family how grateful you are to have them in your life.
- Try a gratitude meditation to reflect on things you are thankful for.
- Find inspirational quotes online and hang them on your refrigerator where they can remind you of the good things in life.
- Make a gratitude jar, write down something you're grateful for on a small slip of paper, and tuck it into the jar. Then watch it fill up with all the amazing things in your life!
- Write a letter—by hand, if you can—to someone special in your life that you are thankful for. For extra good feelings, hand deliver the letter to the person.

And remember - TMA is grateful for you! Thanks for being with us!



BEGUM HORULUOGLU, PHD



JANE MYLES
TMA BOARD OF DIRECTORS

SPONSORED BY BRISTOL MYERS SQUIBB

MYOSITIS RESEARCH INSIGHTS WEBINAR

TUESDAY
NOVEMBER 12, 2024
12 PM ET | 9 AM PT



**LEARN ABOUT CELL THERAPY AND
THE ANTI-JO-1 ANTIBODY**



Myositis Research Insights Webinar featuring

Dr. Begum Horuluoglu

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

Are you curious about cell therapy or Anti-Jo-1 antibodies? Join TMA Board Director Jane Myles as she interviews current TMA grant recipient Dr. Begum Horuluoglu from Sweden's Karolinska Institute.

Dr. Horuluoglu's research aims to understand the immunological mechanisms that lead to autoimmunity. Since August 2023, she has held the position of Assistant Professor, Division of Rheumatology at the Center for Molecular Medicine at Karolinska Institute. Her focus has been on integrating molecular techniques with bioinformatic approaches to gain deeper insights into disease pathogenesis in autoimmunity with a focus on myositis.

A special thank you to our webinar sponsor, Bristol Myers Squibb.

[Register Today](#)



DERMATOMYOSITIS EDITION

DR. ELENI TINIAKOU & DR. JUN KANG

WEDNESDAY, NOVEMBER 20, 2024

6 PM ET | 3 PM PT

EXPERTS FROM JOHNS HOPKINS

Ask The Doc: Dermatomyositis Edition


November 20, 2024, 6 PM ET | 3 PM PT

Do you have burning questions that can't wait until your next appointment? Are you newly diagnosed and learning all you can? Please join this Ask the Doc webinar to find out what myositis experts have to say about dermatomyositis.

Eleni Tiniakou, MD is an Assistant Professor of Medicine in Rheumatology at the Johns Hopkins Myositis Center. Her research focuses on identifying and describing specific T cells in myositis and scleroderma, and how these relate to cancer. This program focuses on dermatomyositis and is sponsored by Novartis.

Jun Kang, MD is an Assistant Professor of Dermatology for the Johns Hopkins Outpatient Center as well as the director of Cutaneous Autoimmune Connective Tissue Disease program where he specializes in treating patients with dermatomyositis, cutaneous lupus, and other dermatologic manifestations of rheumatologic disease. Additionally, he has a database and tissue bank and conducts research on dermatologic manifestations of DM and lupus.

[Register Today](#)



THE MYOSITIS ASSOCIATION'S
ASK THE DOC
SERIES

ADAM SCHIFFENBAUER, MD
RHEUMATOLOGIST
TUESDAY, DECEMBER 3, 2024
3:30 PM ET | 12:30 PM PT

GLOBAL MYOSITIS EXPERT

Ask the Doc featuring Dr. Adam Schiffenbauer

December 3, 2024, 3:30 PM ET | 12:30 PM PT

Please join December's Ask the Doc webinar to ask any question you have about any type of myositis.

Adam Schiffenbauer, M.D., is Deputy Head of the Environmental Autoimmunity Group at the National Institutes of Health and serves as an Associate Research Physician. He currently serves as the principal investigator on studies looking at risk factors for myositis in the military, evaluating environmental risk factors in new onset myositis, and an interventional drug study treating calcinosis with sodium thiosulfate. Dr. Schiffenbauer is a current member of TMA's Medical Advisory Board.

Please note that this webinar will not be recorded.

[Register Today](#)



MAXIMILLIAN KONIG, MD



JANE MYLES
TMA BOARD OF DIRECTORS

CAR T-CELL THERAPY AND BISPECIFIC ANTIBODIES: NEW FRONTIERS FOR MYOSITIS TREATMENT



THURSDAY
DECEMBER 5, 2024
6 PM ET | 3 PM PT



CAR T-cell Therapy and Bispecific Antibodies

December 5, 2024, 6 PM ET | 3 PM PT

CAR T-cell therapy is a revolutionary new treatment that is being tested for myositis. In this webinar, moderated by TMA board member Jane Myles, Dr. Max Konig of Johns Hopkins University will share how special cells in our body can be retrained 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.

[Register Today](#)



MALIN REGARDT, PHD, OT



DAVID MOCHEL, MD, FACS
TMA BOARD OF DIRECTORS

REGISTER TODAY!

MYOSITIS RESEARCH INSIGHTS WEBINAR: CARBONHAND TECHNOLOGY



TUESDAY
DECEMBER 10, 2024
12 PM ET | 9 AM PT



Myositis Research Insights webinar featuring Dr. Malin Regardt

December 10, 2024, 12 PM ET | 9 AM PT

Carbonhand is a revolutionary device that assists people with impaired hand function. Pressure sensors and advanced technology ensure the glove adds power in cases where the user's own muscles are inadequate.

In this webinar, moderated by TMA Past Board Chair Dave Mochel, TMA's Medical Advisory Board Member Dr. Malin Regardt discusses this exciting technology and its many uses. Additional topics covered will be hand exercise and function. Dr. Regardt is a researcher at Karolinska University Hospital and at the Department of Neurobiology, Care Sciences and Society, Karolinska Institutet in Sweden.

[Register Today](#)

2 important changes to Medicare Part D

in 2025 may help make the cost of your prescription drugs more affordable and more manageable^{1,2}

Starting in 2025, no matter how many Medicare Part D prescriptions you fill, you won't pay more than \$2000 for prescription drugs that are covered by your Part D plan.^{1,3}

\$2000 maximum out of pocket¹

- There is **no longer** a coverage gap (donut hole)²
- There is **no more** cost sharing in the catastrophic phase²
- Applies to **all** drugs covered by a patient's Medicare Part D plan^{1,4}

¹Includes all drugs covered under the Part D benefit, not those administered in the physician's office.⁴



...and the cost of your copays or coinsurance can be spread more evenly over the entire year²

Patients on Medicare Part D can opt in to the Medicare Prescription Payment Plan⁵

- You still pay the same amount, but spread costs over the year⁶
- Instead of paying when you get your prescription, you will receive a bill each month from your Part D plan with the monthly amount you owe⁵

Will the new payment plan help me?

- The new payment plan may be helpful if you have high cost sharing earlier in the year. By spreading the cost over the remaining months of the year, the payment plan may help you manage your costs⁵

How do I opt in?

- You can opt in at any time, but it's best to do it early. Call your Part D plan after October 15, 2024, or go to its website^{1,7}



Medicare Prescription Payment Plan & You



For enrollees in Medicare Part D, the Medicare Prescription Payment Plan can help make out-of-pocket costs for prescription drugs easier to manage⁵

Medicare Prescription Payment Plan: Key dates

- October 15, 2024: You can opt in during Medicare Open Enrollment and throughout the year.^{1,7} Opting in early may prevent delays at the pharmacy.⁸
- January 1, 2025: Starting January 1, you can spread your out-of-pocket costs more evenly over the entire year.²

How does it work?²

- "Spreading" applies to all of your out-of-pocket expenses for all generic and brand-name prescription drugs that are covered under your Medicare Part D benefit
- When you opt in, you will pay \$0 at the pharmacy and then will receive a monthly invoice from your Part D plan
- There are no fees or interest costs
- The Medicare Prescription Payment Plan may be especially helpful to patients who have high cost sharing early in the year

Who is likely to benefit?

- If you spent more than \$2000 in out-of-pocket costs between January 1 and September 30, 2024, your Part D plan will notify you that you are likely to benefit⁸
- Your pharmacy may also tell you when you fill a prescription, but you will not be able to opt in at the pharmacy, so it's best to sign up early⁸

How can I learn more?⁸

- Before the start of the plan year, you will receive educational materials about the Medicare Prescription Payment Plan from your Part D plan and from Medicare
- Information will also be included on your Part D plan's website

Call your Part D plan and opt in to the Medicare Prescription Payment Plan during open enrollment, starting October 15, or visit your plan's website.

For more information, visit [Medicare.gov/prescription-payment-plan](https://www.medicare.gov/prescription-payment-plan)



References: 1. Lower out of pocket drug costs in 2024 and 2025. Centers for Medicare & Medicaid Services (CMS). Accessed July 18, 2024. <https://www.cms.gov/files/document/low-out-pocket-drug-costs-2024-and-2025-article.pdf> 2. Medicare Prescription Payment Plan. CMS. Accessed July 18, 2024. <https://www.medicare.gov/medicare-prescription-payment-plan> 3. Medicare Prescription Payment Plan. CMS. Accessed July 18, 2024. <https://www.medicare.gov/medicare-prescription-payment-plan> 4. Medicare Prescription Payment Plan. CMS. Accessed July 18, 2024. <https://www.medicare.gov/medicare-prescription-payment-plan> 5. Medicare Prescription Payment Plan. CMS. Accessed July 18, 2024. <https://www.medicare.gov/medicare-prescription-payment-plan> 6. Medicare Prescription Payment Plan. CMS. Accessed July 18, 2024. <https://www.medicare.gov/medicare-prescription-payment-plan> 7. Medicare Prescription Payment Plan. CMS. Accessed July 18, 2024. <https://www.medicare.gov/medicare-prescription-payment-plan> 8. Medicare Prescription Payment Plan. CMS. Accessed July 18, 2024. <https://www.medicare.gov/medicare-prescription-payment-plan>



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Medicare Part D 2025

Two important changes have been made to Medicare Part D in 2025 that may help make the cost of your prescription drugs more affordable and more manageable.

Thank you to TMA Corporate Advisory Council Member Boehringer Ingelheim for creating this helpful infographic.

[Learn More](#)

TMA is grateful to our Corporate Advisory Council member organizations for their ongoing support of our programs and services.



FIND THE CARE YOU NEED

MediFind



THE MYOSITIS ASSOCIATION

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.](#)



CLINICAL
TRIALS
CORNER



Community Tips

November is National Family Caregivers Month. We gratefully acknowledge the extraordinary gifts our myositis care partners provide in improving the quality of life for those who live with these devastating diseases.

Here are some messages for care partners from those who live with myositis:

- Don't forget that your health matters. We love you deeply and want the best for you just as you want the best for us.
- Caregivers need support and self-care and healthy boundaries to stay well. If you don't take care of yourself, you won't be able to care for your loved one. It's not selfish.
- Find a good counselor/therapist so that you can have a safe outlet to discuss fears, frustrations, and be cared for in ways that your loved one may not be able to provide.
- Look into resources for respite or temporary breaks from caregiving.
- Practice self-compassion just as you have compassion for your loved one.
- Take time to breathe and relax throughout the day.
- You are angels. THANK YOU!!

[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.



Pfizer is proud to support the Ig community



We're committed to supporting your DM treatment experience by providing patients and caregivers with:

-  Support
-  Treatment options
-  Resources

Scan to learn about Pfizer's treatment option for adults with DM



DM=dermatomyositis; Ig=immunoglobulin.
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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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