January 2025

Issue 14

TMA MYOSITIS SUPPORT GROUP

Maryland, Delaware, Washington DC, and Northern Virginia Connected by Myositis and the Chesapeake Bay!

Support Group News

HAPPY NEW YEAR!

Sending Hope and Best Wishes

Dear friends,

Our next meeting will be from 1 p.m. to 2:30 p.m. Eastern on Feb. 15 on Zoom.

Please make sure to register for the meeting! This is a step that we will continue to need you to take so that we can accurately report attendance to TMA. Please click on the registration link below and enter your name and email address. Thank you for your cooperation!

Here is the Zoom link: <u>https://us02web.zoom.us/meeting/register/tZYqdeiqqTIsGdz4dsX2WHPMKJ3-dNr-</u> <u>G4BA#/registration</u>

We are planning our regional meetings for 2025 and reaching out to presenters. If you want to learn more about a topic, please email us (contact info below) and we'll do our best to get a speaker and/or more information.

The following pages include some updates and info we hope you'll find interesting.

If you have any questions or suggestions, please email one or both of us.

Warm regards, Angela Hopp (ahopp@yahoo.com) Jenna Radke (jenna.radke@gmail.com)

NEWS FROM OUR GROUP

Topic for Feb. 15th meeting

Join us as we welcome speaker Marissa Locke Rottinghaus, Ph.D.

Marissa is the science writer for the American Society for Biochemistry and Molecular Biology. She was born and raised in Kansas and developed her love of science and writing at a young age. Marissa earned her B.S. in biological sciences and a minor in Spanish from DePaul University in Chicago, Illinois. She then went on to pursue a Ph.D. in immunology at Washington University School of Medicine in St. Louis, where she studied the role of type I interferons in viral pathogenesis. Before joining the ASBMB in 2023, Marissa worked as a managing editor at The American Association of Immunologists as well as a freelance writer and editor. Her hobbies include reading, baking, crafting, exercising and spending time with family and friends.

Marissa will prepare a short talk covering basic immunology: parts of the immune system, how it works in good times, and how things can go wrong. By learning more about how our immune system works, we can better understand what's happening in our bodies, ask more informed questions during medical appointments, and feel more empowered in our health journeys. Whether you're newly diagnosed or have been managing myositis for years, this discussion is sure to be enlightening. Join us as we deepen our understanding of the science behind our experiences and connect as a community.

NEWS FROM TMA

Empowerment session — Finding Peace: Easing Anxiety in the Face of Myositis (12 p.m. Eastern on Jan. 22)

Do you struggle with anxiety like so many do? Anxiety can feel incredibly scary because it triggers both physical and emotional responses, leaving us feeling out of control or unable to cope with everyday situations.

Join The Myositis Association on Wednesday, Jan.. 22, for a special webinar, "Finding Peace: Easing Anxiety in the Face of Myositis," featuring **Sanchita Sharma, Psy.D.,** from the Maryland CBT Center.

In this empowering session, the speaker will guide you through proven cognitive behavioral therapy (CBT) techniques that help reduce anxiety, stress and emotional distress — tools you can start using right away. This webinar will equip you with practical strategies to find emotional balance, improve resilience, and cultivate peace of mind.

Register at https://www.myositis.org/calendar/events/finding-peace-easing-anxiety-in-the-face-of-myositis-webinar/

Unlocking the potential of CAR T therapy in myositis (5:30 p.m. Eastern on Jan. 28)

Join TMA for an exciting and informative webinar exploring the groundbreaking role of CART (chimeric antigen receptor T cell) therapy in the treatment of myositis.

As autoimmune diseases like myositis continue to challenge traditional treatment approaches, CAR T cell therapy offers new hope by harnessing the power of the immune system to target and destroy disease-causing cells. This session will dive deep into the latest advancements, clinical trial results, and the potential impact of CAR T on myositis care.

Speaker **Iazsmin Bauer Ventura**, M.D., is leading Cabaletta Bio's CART clinical trial at the University of Chicago. She is an expert in inflammatory myopathies and directs the Myositis Program at the University of Chicago. She is also an immediate past member of TMA's board of directors.

Register at <u>https://www.myositis.org/calendar/events/unlocking-the-potential-of-car-t-in-myositis-advances-insights-</u> with-iazsmin-bauer-ventura-md-msc/

OTHER NEWS

New protections enhance air travel for people with disabilities

The U.S. Department of Transportation introduced a landmark rule to improve air travel for passengers with disabilities, particularly those using wheelchairs. The rule mandates rigorous standards for assistance, hands-on training for airline staff, and specific protocols for handling wheelchairs to prevent damage or delays. This initiative aims to ensure safe and dignified travel for all passengers. Notably, DOT data indicates that for every 100 wheelchairs or scooters transported on domestic flights, at least one is damaged, delayed or lost.

Learn more at https://www.transportation.gov/briefing-room/secretary-buttigieg-announces-sweeping-protectionsairline-passengers-disabilities

Advancements in dysphagia treatment offer hope

Speech-language pathologist Catriona Steele has developed an objective grading system for assessing swallowing disorders, enhancing diagnosis and treatment. Her research focuses on personalized interventions, such as specific swallowing maneuvers and tailored food textures, to improve patients' swallowing functions. These advancements offer promising avenues for myositis patients experiencing dysphagia, aiming to restore the pleasure of eating and improve quality of life.

Novel drug eases disease activity in dermatomyositis

A new paper in The Lancet reports that an investigational monoclonal antibody targeting interferon beta (IFN β) led to rapid and pronounced reductions in disease activity in adults with dermatomyositis. Patients with skin-predominant involvement showed a significant 12-week benefit with both tested doses compared with patients who took a placebo.

Read the story at https://www.medpagetoday.com/dermatology/generaldermatology/113791

Read the paper's abstract at https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(24)02071-3/abstract

When art imitates life

In a fascinating intersection of art and medicine, doctors have identified signs of dermatomyositis in figures from two renowned paintings: Joseph Wright of Derby's "An Experiment on a Bird in the Air Pump" and Andrew Wyeth's "Christina's World." This practice, known as "diagnosing the canvas," not only offers insights into historical medical conditions but also underscores the enduring presence of autoimmune diseases throughout history.

Learn more at <u>www.smithsonianmag.com/smart-news/doctor-will-frame-you-now-mds-diagnose-diseases-two-famous-paintings-180959227</u>