



TMA MYOSITIS SUPPORT GROUP

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

Support Group News

Dear friends,

We look forward to seeing you at our next meeting on **Saturday, Oct. 18, at 1p.m. Eastern.**

Please make sure to register for the meeting! This is a step that we 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:

<https://us02web.zoom.us/join/zoom-join?secret=72929292&pwd=72929292>

Below are some articles that might interest you.

Warm regards,

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RESEARCH NEWS

Sounds of discovery ring at the Undiagnosed Hackathon

At the first U.S. Undiagnosed Hackathon at Mayo Clinic, researchers solved six rare disease cases and advanced eight more toward answers. Over three days, 130 experts from 28 countries reviewed 29 complex cases using large-scale genomic data. The event, organized with Wilhelm Foundation, reflects a shift toward collaborative, data-driven rare disease diagnosis. The organizers said multi-team efforts like this one can speed identification and potential treatment. Rare diseases affect an estimated 350 million people globally, but most remain undiagnosed. Ongoing meetings will continue work on unsolved cases.

Article by Mayo Clinic: <https://newsnetwork.mayoclinic.org/discussion/sounds-of-discovery-ring-at-the-undiagnosed-hackathon/>

Nobel Prize awarded for immune system research

Three scientists received the 2025 Nobel Prize in Physiology or Medicine for discovering how the immune system prevents attacks on the body's own tissues. Their work identified regulatory T cells and the key gene FOXP3, which keeps immune responses in check. The discoveries explain autoimmune disease mechanisms and are driving more than 200 clinical trials targeting cancer, autoimmunity and transplant tolerance. The Nobel committee called the research "fundamental" to understanding immunity and disease, opening new directions for therapies that could one day help patients.

Article by New York Times: <https://www.nytimes.com/2025/10/06/health/nobel-prize-medicine-physiology.html>

Brepocitinib shows promise for dermatomyositis

The oral therapy brepocitinib improved muscle strength, skin health and overall function in adults with dermatomyositis. Benefits appeared as early as four weeks, and nearly half of patients with moderate-to-severe skin disease achieved remission by 52 weeks. Importantly, many patients were able to reduce or stop steroids. Brepocitinib was well tolerated in the Phase III VALOR trial of 241 adults. Roivant and Pfizer plan to file a new drug application, the official request to get the drug approved for dermatomyositis, with the FDA in early 2026, with potential availability in 2027.

Article in Medscape: <https://www.medscape.com/viewarticle/brepocitinib-shows-positive-results-phase-3-dermatomyositis-2025a1000p1n?form=fpf>

New guidelines for interstitial lung disease

The European Alliance of Associations for Rheumatology and the European Respiratory Society have released joint guidelines for interstitial lung disease linked to connective tissue diseases, including myositis. The recommendations call for early lung screening — using high-resolution CT scans — for patients with systemic sclerosis, mixed connective tissue disease, and inflammatory myopathies. They also outline monitoring schedules and treatment strategies based on disease severity and progression risk. Experts say these standardized, evidence-based guidelines will help doctors better identify and manage high-risk patients, improving outcomes and quality of life.

Guidelines: <https://publications.ersnet.org/content/erj/early/2025/09/04/1399300302533-2024>

Why women are more prone to autoimmune diseases

Women's higher rates of autoimmune disease may be linked to X-chromosome inactivation. Normally, one of a woman's two X-chromosomes is silenced by the Xist molecule to balance gene expression with men. Studies at Stanford University and France's CNRS show that when X-chromosome inactivation is imperfect, certain genes remain active and can trigger autoimmune responses, including lupus and Sjögren's syndrome. Environmental triggers or genetic susceptibility may be needed for disease onset. Researchers hope understanding Xist-related mechanisms could eventually improve prediction, diagnosis and treatment for female-biased autoimmune disorders.

Article in National Geographic: <https://www.nationalgeographic.com/premium/article/autoimmune-disease-common-women?loggedin=true&md=1758140991521>

Episode by Radiolab: https://radiolab.org/podcast/unsilencing_

FDA approves nerve stimulator for rheumatoid arthritis

The FDA approved a new vagus nerve stimulator for patients with rheumatoid arthritis whose symptoms are not controlled by medication. The small, implantable device delivers daily electrical pulses to the vagus nerve, reducing inflammation by signaling the brain and spleen to regulate cytokine production. Clinical trials showed that about 35% of patients with difficult-to-treat rheumatoid arthritis experienced meaningful improvement, including reduced joint pain and swelling. The outpatient procedure is similar to surgeries used for epilepsy stimulators.

Article by NPR: <https://www.npr.org/sections/shots-health-news/2025/09/22/nx-s1-5544463/rheumatoid-arthritis-new-device-nerve-stimulator>

DISABILITY NEWS

Trump plans to limit disability benefits for older Americans

The Trump administration is preparing a rule that would make it harder for older adults to qualify for Social Security disability benefits by eliminating or raising the age factor used to assess whether applicants can adjust to other work. Analysts estimate this could reduce eligibility by up to 10%, cutting benefits for about 750,000 people over the next decade. Disability advocates warn it could push older disabled workers into early retirement and permanent income loss.

Article in Washington Post: <https://wapo.st/473h6om>

U.S. will not enforce wheelchair passenger protections

The U.S. Department of Transportation said it will not enforce key parts of a Biden-era rule requiring airlines to reimburse passengers for damaged wheelchairs or fare differences when aircraft cannot accommodate mobility devices. The decision weakens essential protections for wheelchair users.

Article by Reuters: <https://www.reuters.com/world/usdot-will-not-enforce-biden-wheelchair-passenger-protection-rule-2025-09-29/>

Trump vows election changes that will affect disabled voters

President Trump announced plans to eliminate mail-in voting and restrict voting machines, citing false claims of widespread fraud. Experts stress he has little constitutional authority over elections, which are run by states and local jurisdictions. Advocates warn that ending mail-in voting would disproportionately harm disabled, elderly and homebound voters.

Article by Associated Press: <https://apnews.com/article/trump-elections-mail-voting-midterms-2026-8be6dba80091fd7e6d8570814b34a7fe>

Article in Mother Jones: <https://www.motherjones.com/politics/2025/08/trump-vote-mail-disabled-ballot-order/>

More physicians move to private equity-owned practices

Physicians are increasingly leaving private practices for practices owned by hospitals or private equity firms. In 2024, only 42.2% of doctors worked in physician-owned practices, down from 60.1% in 2012, while hospital-owned practices employed 34.5% of physicians. Private equity-owned practices accounted for 6.5%, up from around 4.5% in 2020 and 2022.

Article by American Medical Association: <https://www.ama-assn.org/press-center/ama-press-releases/more-physicians-move-practices-owned-hospitals-private-equity>

Patient deaths rise after private equity hospital acquisitions

A study found that emergency department mortality increased in U.S. hospitals after acquisition by private equity firms. Medicare patients experienced seven additional deaths per 10,000 visits

Article by Harvard: <https://hms.harvard.edu/news/deaths-rose-emergency-rooms-after-hospitals-were-acquired-private-equity-firms>

See if your hospital is owned by private equity

The Private Equity Hospital Tracker lists 488 U.S. hospitals owned by private equity firms and provides an interactive map to improve transparency in hospital ownership.

Tracker: <https://pestakeholder.org/private-equity-hospital-tracker/>

Number of family caregivers surges to more than 63 million

Over 63 million Americans — nearly one in four — served as family caregivers in the past year. Many perform complex medical tasks at home with little training, and one-third care for children and adults simultaneously. A new report calls for federal policies including paid leave, caregiver tax credits and greater access to training and respite

Article in The 19th: <https://19thnews.org/2025/07/family-caregivers-surging-aarp/>

TMA NEWS

MyoCon 2025 session recordings available for pre-order

TMA is offering pre-orders for recordings of the 2025 MyoCon conference. The \$149 package includes video of pre-conference virtual sessions, opening and closing keynotes, the Heroes in the Fight Awards Ceremony, and audio-recorded breakout sessions synced with slides.

Order: <https://fs17.formsite.com/myositis/2025Recordings/index>