



TMA MYOSITIS SUPPORT GROUP

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

Support Group News

Dear friends,

Our next meeting will be from 1 p.m. to 2:30 p.m. Eastern on April 19 on Zoom. We'll host guest speakers from CSI Pharmacy (more info on the following page).

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/ztYqdeiqqTIsGdz4dsX2WHPMKJ3-dNr-G4BA#/registration>

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 April 19 support group meeting

Our next meeting will have guest speakers from CSI Pharmacy, which administers in-home infusions. (Group co-leader Jenna uses CSI.) This discussion will cover the insurance process for infusions, tips for making the infusion more comfortable, and other insights to make the infusion process easier. Please email us if you have questions that we can share with CSI in advance. You can learn about the company at [csipharma.com](https://www.csipharma.com).

NEWS FROM TMA

TMA reports results from research grants issued in 2024

The Myositis Association in late January reported the following findings:

- A study by Cheilonda Johnson's team at University of Pennsylvania School of Medicine identified **genes associated with interstitial lung disease**.
- Alexander Oldroyd at the University of Manchester helped to develop **a smart phone app** to monitor patient activity levels and detect flares.
- Chiseko Ikenaga at Kitasato University demonstrated that there is **a genomic pathway** related to stress that may cause critical muscle damage in patients with inclusion body myositis.

Read the press release: myositis.org/blog/funding-for-myositis-research

TMA names 2025 research grant winners

TMA announced in late January the following awardees of research grants:

- Thomas Lloyd of Baylor College of Medicine will **study existing drugs** to see if they can be repurposed to treat IBM.
- Christian Lood at the University of Washington School of Medicine will study **the role of mitochondria** (often called the "powerhouse of the cell") in juvenile myositis.

Read the press release: myositis.org/blog/myositis-research-awards-bring-hope-to-those-with-rare-diseases.

STUDY

Natural history study at NIH in Bethesda, Maryland

The National Institute of Environmental Health Sciences has an ongoing natural history study for patients with myositis and for their first-degree relatives. You can learn more about the study here: joinastudy.niehs.nih.gov/studies/myopathies.

Parent of juvenile myositis patient may/may not lead DOGE

Under pressure to significantly reduce spending, federal agencies that fund medical and scientific research have been canceling research grants for universities and academic medical centers and firing researchers. President Donald Trump has said the new Department of Government Efficiency is led by Elon Musk. On paper, it's led by a woman whose (now adult) child has juvenile myositis. Amy Gleason in February was named acting director, but she has since stated that she doesn't work with, report to or oversee Musk. Below are two links to coverage of this mystery.

<https://www.nbcnews.com/news/us-news/doges-amy-gleason-ex-nurse-data-cruncher-straight-shooter-rcna195114>

<https://www.businessinsider.com/doge-office-amy-gleason-affadavit-elon-musk-chain-command-2025-3>

Measles wreaks havoc on the immune system

Excerpt: "Essentially, when you're infected with measles, your immune system abruptly forgets every pathogen it's ever encountered before — every cold, every bout of flu, every exposure to bacteria or viruses in the environment, every vaccination. The loss is near-total and permanent. Once the measles infection is over, current evidence suggests that your body has to re-learn what's good and what's bad almost from scratch."

Read the article: [bbc.com/future/article/20211112-the-people-with-immune-amnesia](https://www.bbc.com/future/article/20211112-the-people-with-immune-amnesia).

More info on measles

- People born before 1957 are presumed to have naturally induced immunity, because they were likely exposed to the disease itself.
- People vaccinated between 1963 and 1968 should find out which vaccine they received because one version used then (an inactivated one) was to be less effective and was ultimately withdrawn from the market.
- Today, two shots of the vaccine are recommended. But the second shot wasn't introduced until 1989. Check your vaccination records to see how many you got.
- If you're immunocompromised or can't get the vaccine for another reason, there is an antibody test to check for immunity, but it's not definitive.

If you're concerned about your vulnerability to measles, please talk to your physician.