30TH ANNIVERSARY
THE MYOSITIS ASSOCIATION®

MYONews

November 2023 | Issue Eleven

Have you heard?

TMA has a new executive director! Paula Eichenbrenner will begin her position at TMA on November 29.

READ MORE ABOUT PAULA

When you join TMA as a member, you become part of the world's largest myositis patient community.

Members can join one or more of our Support or Affinity Groups, receive early notice of events such as our Annual Patient Conference, get updates on myositis treatments and research, be in the know about upcoming clinical trials that they may be eligible for, and so much more.

TMA strives to provide quality programs and services to improve the lives of those who live with myositis. We also fund research to help find better treatments and, ultimately, a cure for these devastating diseases.

By joining TMA, you can make a difference! Your membership adds to the growing number of patients, family members, and friends who help fight for more awareness and more funding for research.

Become a partner in this important work.

BECOME A MEMBER

It’s not too late to order recordings of TMA’s 2023 Annual Patient Conference!

Each year, TMA’s Annual Patient Conference offers so many amazing opportunities to learn about myositis and how you can live your best life. These sessions, presented by the world’s leading researchers and other experts, offer valuable information that can help you understand your disease and can be shared with your physician. Other sessions provide inspiration, ideas for making life easier, and so much more.

The complete set of recordings includes:
- Eight video-recorded sessions, including opening and closing keynote addresses
- Thirty additional audio-recorded sessions synced with slides from the presentation
- Video of the Heroes in the Fight Awards Ceremony including Peter Frampton and other myositis heroes

All this will be delivered to you through a link where you can view the recordings at your leisure.

If you attended the conference but want another chance to review, you can order the recordings at a reduced price!

Registration Fees:

Regular purchase after October 24: $197
2023 Annual Conference attendees: $99

ORDER NOW

THE MYOSITIS ASSOCIATION

THE INTERNATIONAL ANNUAL PATIENT CONFERENCE

SEPTEMBER 6-8, 2024

HILTON BALTIMORE INNER HARBOR

Save the Date

This year’s Annual Patient Conference brought together the myositis community for an amazing four days of learning and sharing! If you missed this year’s conference or you just can’t wait to do it again, here’s the scoop you’ve been waiting for:

TMA’s 2024 Annual Patient Conference will take place on September 6-8, 2024 at the Hilton Baltimore Inner Harbor!

THE MYOSITIS ASSOCIATION'S

ASK THE DOC SERIES

DR. JULIE PAIK

RHEUMATOLOGY

THURSDAY, NOVEMBER 16, 2023

6 PM ET | 5 PM CT | 4 PM MT | 3 PM PT

EMAIL YOUR QUESTIONS TO RACHEL@MYOSITIS.ORG

Ask the Doc - Rheumatology with Dr. Julie Paik

Thursday, November 16, 2023, 6 PM ET / 3 PM PT

Julie Paik, MD is an assistant professor of medicine in rheumatology and director of clinical trials at the Johns Hopkins Myositis Center. Her research focuses on overlap myositis, scleroderma muscle disease, and novel therapeutics in refractory dermatomyositis. Dr. Paik serves on TMA’s Medical Advisory Board.

REGISTER TODAY

Research Insights Webinar featuring Dr. Nicole Voet

Friday, December 1, 2023 at 12 PM ET / 9 AM PT

Nicole Voet, MD, PhD is a rehabilitation physician and postdoctoral researcher at Radboud University in the Netherlands. Her research focuses on implementing evidence-based rehabilitation interventions and measuring and treating muscle fatigue in neuromuscular diseases. She is a member of the TMA Medical Advisory Board.

REGISTER TODAY

2023 UPCOMING EVENTS

Find YOUR Community

TMA has support groups around the country and many affinity groups for those with shared interests beyond myositis. Most meet virtually, so you can attend from wherever you are. You might want to check out TMA's Nationwide Myositis Support Group Meeting on Saturday, November 4, 2023 | 1:00 pm – 2:30 pm ET.

Visit the TMA Events Calendar to see and register for upcoming support and affinity group meetings, webinars, and more.

Copay Accumulator Programs Struck Down

In a victory for patients, a federal judge recently struck down a policy that allowed health insurance plans to use copay accumulator and maximizer programs, thereby charging patients more for essential prescription medications.

READ THE STORY

Attention Adult Dermatomyositis Patients

MSU and TMA Announce

Externally-Led Patient-Focused Drug Development Virtual Town Hall

SAVE THE DATE

Friday, June 7, 2024

What is it? This unique community event is designed for you and your care partner to share your experience with the FDA and other government agencies, doctors, scientists, and medical product developers to help them gain a better understanding of how Adult DM affects lives.

Why participate? This is your opportunity to affect the decisions made in developing and approving drugs for your condition and highlight what is most important to you! The meeting on June 7, 2024 is hosted by MSU in partnership with TMA. We hope to recruit as many participants as possible to maximize our impact.

How do I engage? Look for our new community website launching in January 2024, where you can learn more, provide testimonials, and take surveys. If you are a member, or join TMA or MSU, we will provide notifications to keep you up to date as the process develops.

For information contact Lynn Wilson, lynn@understandingmyositis.org

For email updates https://form.jotform.com/232623765075055

ENGAGE, EDUCATE, EMPOWER

MSU Myositis Support & Understanding
EMPOWERING THE MYOSITIS COMMUNITY

The Myositis Association

For information contact Lynn Wilson: lynn@understandingmyositis.org

TMA is grateful to our Corporate Advisory Council members for supporting all the great programs and services we offer to the myositis community!

priovant therapeutics · argenx · EMD SERONO · ALEXION AstraZeneca Rare Disease · HORIZON. · Mallinckrodt Pharmaceuticals · octapharma · Pfizer · Janssen Pharmaceutical Companies of Johnson & Johnson · abcuro

Please check out TMA's Find A Doctor tool (through a new partnership with MediFind)! If you are looking for a clinician or specialist with documented experience treating the different types of myositis (or to add to your current care team), this could be a great place to start!

We are working out some things in the partnership to better feature some of the docs known to TMA, but we are so excited about the availability of this new feature for our patients! If you have any trouble navigating, please reach out to us at **tma@myositis.org**.

FIND A DOCTOR

Many members of the TMA community participated in the clinical trial testing a treatment for IBM called arimoclomol. Dr. Mazen Dimachki, who was the principal investigator on this trial, spoke about the publication of the results of this study during TMA’s October Research webinar. You can read that report at the link below.

READ MORE

New Ways November 2023

MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
		1 Make a list of new things you want to do this month	2 Respond to a difficult situation in a different way	3 Get outside and observe the changes in nature around you	4 Sign up to join a new course, activity or online community	5 Change your normal routine today and notice how you feel
6 Try out a new way of being physically active	7 Be creative. Cook, draw, write, paint, make or inspire	8 Plan a new activity or idea you want to try out this week	9 When you feel you can't do something, add the word "yet"	10 Be curious. Learn about a new topic or an inspiring idea	11 Choose a different route and see what you notice on the way	12 Find out something new about someone you care about
13 Do something playful outdoors - walk, run, explore, relax	14 Find a new way to help or support a cause you care about	15 Build on new ideas by thinking “Yes, and what if… ”	16 Look at life through someone else’s eyes and see their perspective	17 Try a new way to practice self-care and be kind to yourself	18 Connect with someone from a different generation	19 Broaden your perspective: read a different paper, magazine or site
20 Make a meal using a recipe or ingredient you've not tried before	21 Learn a new skill from a friend or share one of yours with them	22 Find a new way to tell someone you appreciate them	23 Set aside a regular time to pursue an activity you love	24 Share with a friend something helpful you learned recently	25 Use one of your strengths in a new or creative way	26 Try out a different radio station or new TV show
27 Join a friend doing their hobby and find out why they love it	28 Discover your artistic side. Design a friendly greeting card	29 Enjoy new music today. Play, sing, dance or listen	30 Look for new reasons to be hopeful, even in tough times			

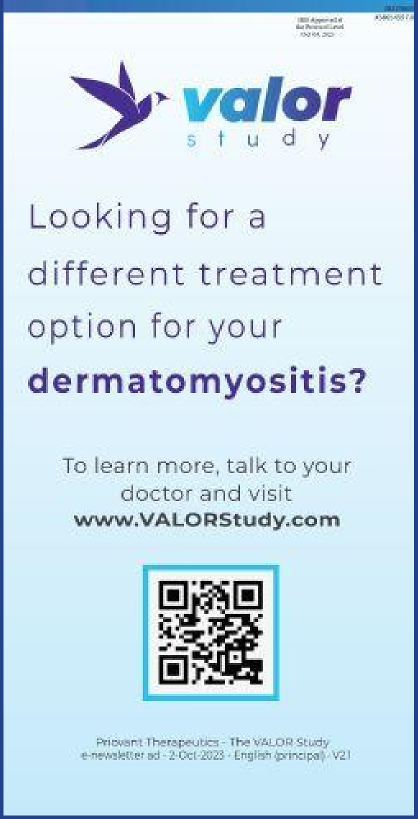
ACTION FOR HAPPINESS

Happier · Kinder · Together

Community Tips

November is the time when we remind ourselves about all the things we’re grateful for. We are also reminded that gratitude is self-care. The Action for Happiness app has daily reminders as well as monthly action calendars to help you focus on what really matters.

DOWNLOAD TODAY



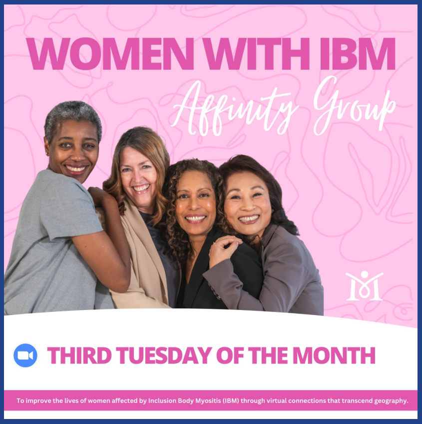
November is National Family Caregivers Month

TMA recognizes that caring for a loved one with myositis can be challenging. That's why we're giving a shoutout to myositis care partners this month and offering some resources from our website.

READ MORE

TMA's YouTube channel has been updated with links to all the most recent myositis webinars. If you missed one of these informative sessions, you can see it now.

AFFINITY GROUP MEETINGS


WOMEN WITH IBM
Affinity Group
THIRD TUESDAY OF THE MONTH
To improve the lives of women affected by Inclusion Body Myositis (IBM) through virtual connections that transcend geography.


The Myositis Association
MILITARY VETERANS WITH MYOSITIS
AFFINITY GROUP
SECOND SATURDAY OF THE MONTH
9 AM PT | 10 AM MT | 11 AM CT | 12 PM ET


FOR THOSE WHO LIVE ALONE
THE MYOSITIS ASSOCIATION'S
FLYING SOLO
AFFINITY GROUP
First Wednesday of Each Month
5 PM PT | 6 PM MT | 7 PM CT | 8 PM ET

REGISTER TODAY

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THE MYOSITIS ASSOCIATION

Connect with us!

The Myositis Association | 6950 Columbia Gateway Drive, Suite 370, Columbia, MD 21046

Unsubscribe tma@myositis.org