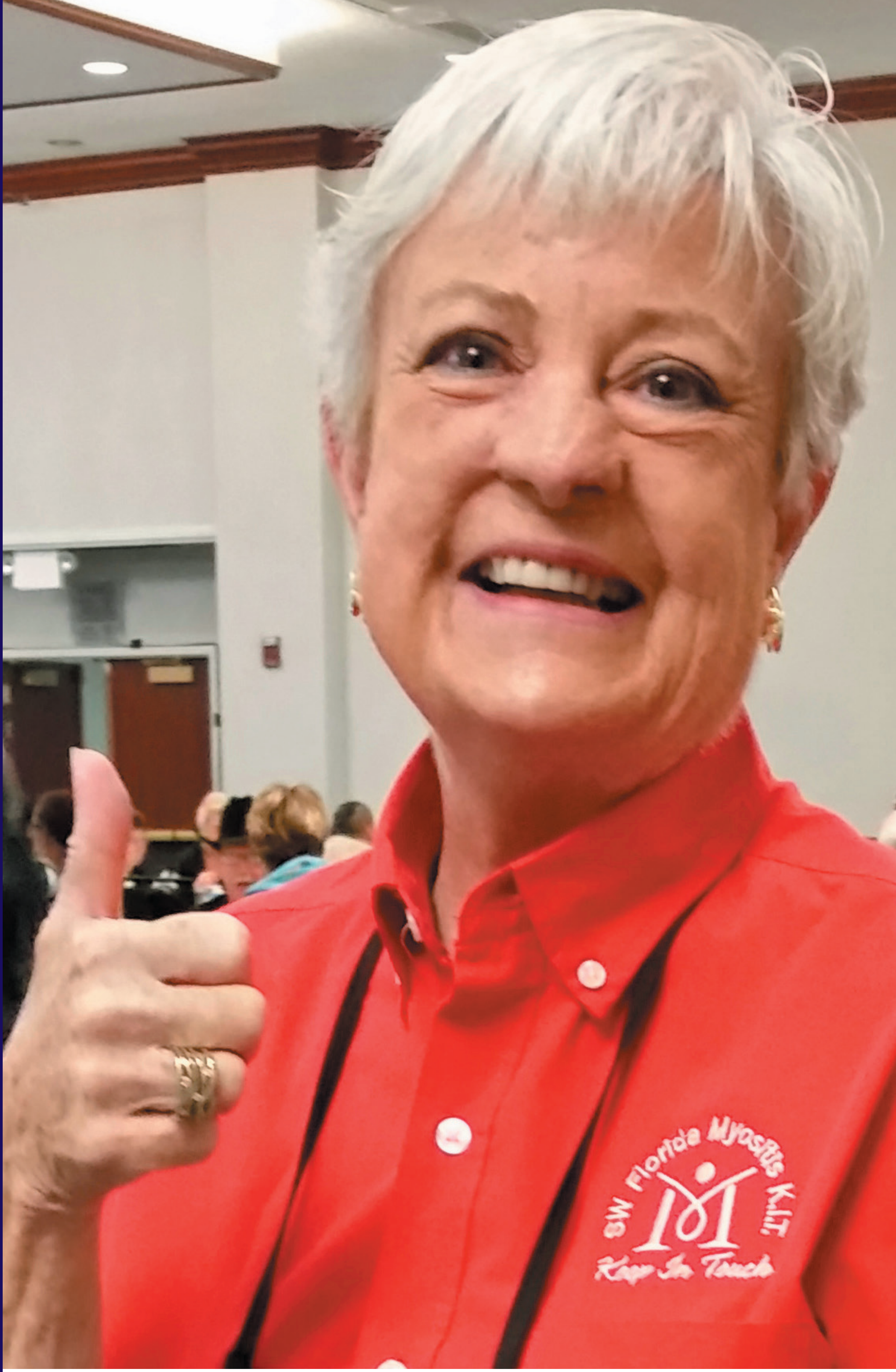
THE OUTLOOK

THE MYOSITIS ASSOCIATION®

FALL 2024
Quarterly Magazine



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THE OUTLOOK

A quarterly publication of The Myositis Association

TMA's mission is to improve the lives of persons affected by myositis, fund innovative research, and increase myositis awareness and advocacy.

TMA's vision is a world without myositis.

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A tribute to Marianne Moyer

It's not often that one meets a person who truly transcends the ordinary, someone whose compassion, wit, and grace leave an indelible mark on the lives of so many whom they meet. Marianne Moyer was such a rare individual, both for those of us who knew her through The Myositis Association and others in the world beyond.

It is with great sorrow that we relate the news of Marianne's passing on May 2, 2024.

A familiar story

In 1999, Marianne was 50 years old and newly retired from her 30-year career at Bell Atlantic. She had a great new consulting job and was looking forward to spending her retirement giving back, investing her time and talents in a variety of volunteer projects.

But one day, while blow drying her hair, the dryer felt too heavy. Soon she couldn't even lift the hairbrush, steer the car, ride her bike, or step up on a curb. She had trouble swallowing food and developed a dry cough that wouldn't go away.

At the time, she was diagnosed with polymyositis, a diagnosis that was later changed to necrotizing myopathy. She spent the better part of a year unable to stand, walk, or care for herself. But she was always grateful for the constant support of John, her husband of 50 years who, like so many care partners, carried her, dressed her, fed her, and pushed her to overcome the challenges of muscles that simply would not work.

Time to give

Once the medications started to work and her symptoms were somewhat controlled, she returned to the work of giving back. She attended her first TMA Annual Patient Conference in 2005 where she met another patient from Bradenton, Florida where she lived. Together Marianne and Barbara Kluding (now also deceased) mapped out a plan to create TMA's Southwest Florida Keep in Touch (KIT) Support Group. In the 18 years since its founding, this group has become one of the largest, most successful of TMA's regional support groups. Marianne continued to actively co-lead that group until her death.

When Marianne met or learned of someone who was living with myositis, she went out of her way to call or write or be in touch with them. She would share tips and resources and contact information for those who lived too far away or couldn't travel to support group meetings. And long before the pandemic made Zoom a part of everyone's daily life, the SW FL KIT Support Group started using it regularly to connect with those distant or less able group members.

On a regular basis, she asked TMA staff to send her copies of our educational booklets—*Myositis 101* for patients and *The Physician's Guide to Myositis* for medical professionals—and handed them out wherever she went.

"I work hard to help our group's members know they are not alone in this myositis journey," she said in a TMA patient story for Myositis Awareness Month in 2019. "I want them to know that they too can overcome the obstacles that loom large at the early stages of this disease."

Marianne's efforts

Over the years, Marianne has been a nearly unstoppable force in support of TMA's mission.

- She has twice served on TMA's Board of Directors, including a two-year term as Chair.
- She was instrumental in making Myositis Awareness Month a reality, providing a full month of time for community awareness programming and projects.

Linda Sabatino, Marianne Moyer, and Donna DeFant

- She twice orchestrated a myositis symposium for physical and occupational therapists in which the experts from the Johns Hopkins Myositis Center in Baltimore came to Sarasota, Florida to teach PTs and OTs about the rehabilitation needs of myositis patients. Those recorded sessions are now available for other PT/OT departments to learn how to care for those with myositis.
- She frequently presented at TMA's International Annual Patient Conferences on topics such as how to successfully lead a TMA support group and how patients can keep track of and organize their medical records.
- She traveled the country to coach other support groups and leaders, strengthening TMA's support network across the globe.
- She co-founded TMA's Legacy Society, a special giving opportunity in which individuals can express their commitment to the organization by naming TMA as a beneficiary in their will.
- On a biannual basis, she orchestrated a 24-hour Giving Challenge hosted by the Community Foundation of Sarasota County, with matching funds from The Patterson Foundation in support of TMA.

Honoring Marianne

In recognition of all Marianne has contributed to The Myositis Association, a new Marianne Moyer Myositis Leadership Award has been created to recognize TMA volunteers who, like Marianne, lead the way in our myositis community by helping others live their best lives with myositis.

The inaugural award was presented during this year's Heroes in the Fight Awards Celebration on September 6 during TMA's International Annual Patient Conference in Baltimore. It was presented to one of Marianne's steadfast coleaders of the SW Florida KIT Support Group, Donna DeFant, and accepted by another of her coleaders, Linda Sabatino. Her husband John was also present to speak on Marianne's behalf.

We are grateful not only for Marianne's efforts on behalf of those who live with these devastating rare diseases, but also for the joy and grace she brought to everything she did. We are thrilled that her legacy lives on in Marianne Moyer Myositis Leader Award.

Donna DeFant

"My friend Marianne Moyer was a force to be reckoned with! Marianne had very big shoes to fill; a hard act to follow. But our SW FL Myositis KIT will carry on her caring work. Marianne was smart, compassionate, organized, and loving. I was so honored to receive the very first Marianne Moyer Myositis Leader Award and will share it with our group."

-- Donna DeFant

Do twice the good

Do you want a great way to double your donations to support TMA's mission? More than 23,000 companies of all sizes now offer matching gifts for their employees when they make donations to their favorite charities. Many will also match your volunteer hours, and some companies even match gifts from retirees and spouses.

Employer-funded matching gifts are often dollar-for-dollar up to a certain maximum level. However, some companies will double or even triple the original donation. Some companies also encourage involvement in nonprofit organizations by providing monetary grants to organizations where employees volunteer regularly.

We encourage you to check with your company's Human Resources department to see if this is an option at your workplace. To activate the matching gift, you will likely need to supply the legal/financial information regarding TMA found in the ***About*** *section of our website. Email* ***tma@myositis.org*** *for assistance in completing a matching gift request.*

Don't miss this opportunity to increase your impact!

Patients make a difference in myositis research

Acacia May and her parents visit the NIH

Patients and patient organizations play a pivotal role in myositis research. Those who live with the disease are, in fact, the experts on myositis, and increasingly they are actively involved in academic research, national and international myositis research organizations, industry-sponsored patient advisory councils, and government supported research initiatives. The value of this expert insight is gaining greater recognition, allowing for more patient-centric projects, focusing on more relevant outcomes, and improving the quality of life for those who live with myositis worldwide.

TMA is proud to be working together with international patient advocacy organizations (PAOs) to amplify the voice of patients in myositis research around the globe. Here are some examples of the high-value efforts member groups are working on:

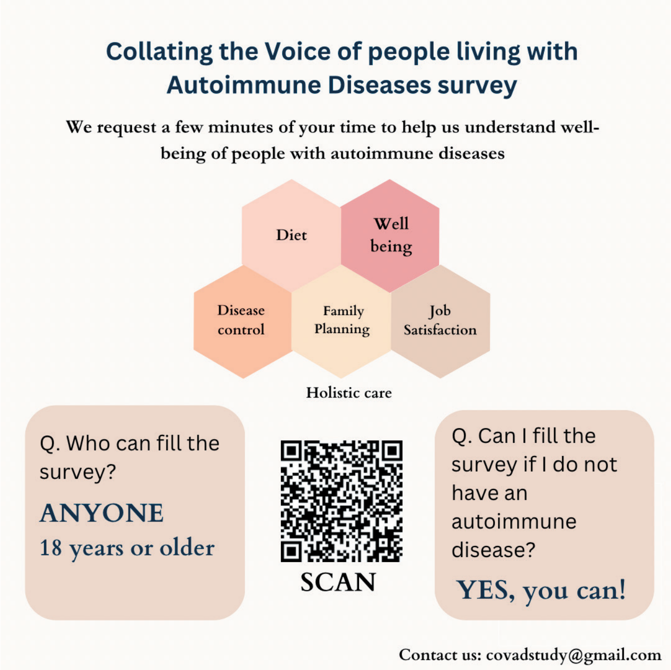
- Cure JM was recently awarded a prestigious Chan-Zuckerberg rare disease research grant to identify new biomarkers and improve precise, personalized care by identifying specific biological interactions that drive inflammation in juvenile myositis.
- Myositis Support and Understanding in partnership with TMA conducted an Externally Led Patient Focused Drug Development (EL-PFDD) meeting on dermatomyositis with the US Food and Drug Administration this past June, bringing the patient's voice to decision-making about the drug development process.
- Myositis Association Australia together with the Myositis Discovery Programme, a research group led by TMA medical advisory Dr. Merrilee Needham, has established a Myositis Consumer Research Panel to provide a community perspective on a variety of research activities across the country.
- Patients, including TMA members, are part of myositis research working groups, including those in the US and abroad, helping to guide clinicians' and researchers' understanding of the experience, impact, and challenges of living with myositis.
- Patients have coauthored and contributed to the design, data analysis, publication, and dissemination of results of international collaborations such as the COVAD study, OMERACT myositis working group, and IMACS Exercise and Rehabilitation study.
- TMA and other PAOs work in partnership with pharmaceutical companies to educate members about new drugs being developed and facilitate clinical trial enrollment.
- Patient coalitions are taking a more active role in advocating for policy changes to help advance research and promote drug development for myositis.
- This year, for the first time, TMA's Research Grant Program will include stakeholder reviewers—patients and/or care partners—who will evaluate grant applications and help to decide which ones will receive funding.

Adapted from the joint Patient Advocacy Organization poster at GCOM 2024

You be the expert!

Here is one way that members of our community can share their expert insights with researchers. The COVAD group, a collection of dozens of the world's leading researchers in autoimmune diseases, began during the COVID-19 pandemic to survey patients about their experiences of vaccines and disease flare. They've moved on to document the voice of the patient for other issues that affect quality of life.

Now they are conducting a survey to explore holistic care for autoimmune conditions. The survey is open to anyone over 18, whether healthy or living with an autoimmune disease. Please take a moment to complete this survey today! Survey Link: **https://www.surveymonkey.com/r/TV6JF75**



Collating the Voice of people living with Autoimmune Diseases survey

We request a few minutes of your time to help us understand well-being of people with autoimmune diseases

Q. Who can fill the survey?

ANYONE
18 years or older

SCAN

Q. Can I fill the survey if I do not have an autoimmune disease?

YES, you can!

Contact us: covadstudy@gmail.com

WHAT BRINGS YOU JOY?

Jack Reider has inclusion body myositis. For him, square dancing is a joy.

"I go square dancing five times a week," he says. "This does three things:

1. Gives me great social contacts with people I'd otherwise never meet.
2. Keeps my brain engaged as you have to learn maneuvers and pay attention to the caller when dancing.
3. And most importantly it's exercise without being exercise. My walking ability has greatly improved. Keeps me off a cane."

World Myositis Day 21 Sept

Did you observe World Myositis Day on September 21 this year? We'd love to hear how you joined with the global myositis community in raising awareness of these rare diseases. Send your stories and photos to **TMA@myositis.org**, and we'll use them to spread awareness throughout the year!

30TH ANNIVERSARY
The Myositis Association

2023 IMPACT REPORT

2023 In Review

2023 was a truly notable year for The Myositis Association (TMA). We celebrated our **30th year of service** to the worldwide myositis community.

Our Mission

To improve the lives of persons affected by myositis, fund innovative research, and increase myositis awareness and advocacy.

Patient Education Impact

383 attendees, including 37 scholarship recipients, gathered in San Diego, Calif., for TMA's 28th **International Annual Patient Conference**, Sept. 7-10, 2023. Brig. Gen. (Ret.) Bob Gaylord delivered the inspiring keynote, "Myositis is Your 100-Miler." Conference content also included 34 breakout sessions and medical advisor panels. 864 attendees participated in TMA's virtual programs in 2023, including more than 30 **Ask the Doc, Empowerment Clinic, and Research Insights webinars.** We hosted the "Beyond Limits" virtual summit during **Myositis Awareness Month**. On Feb. 11, 2023, TMA and the Kansas Univ. Medical Center partnered on a **virtual Regional Conference** for Myositis Patients.

Patient Support Impact

TMA's 36 regional Support Groups and 8 virtual Affinity Groups welcomed 3,118 patients and care partners to group meetings in 2023. **Plus!**

- TMA Illinois marked an amazing **25 years** in 2023! Now known as TMA Missouri & Illinois, the group combined with TMA Missouri and Southern Illinois, which Jean Nolan started in 2016. Key volunteers are Dave Volk, Bill Simeral, Denise Antonucci, Ed Arnold, and Barbara Shaw.
- **TMA Myositis Africa** was established in 2023, with support from the TMA Women of Color Affinity Group. Group leaders are Cynthia Ikediashi and Eniyome Onoviran.
- TMA **Michigan** IBM launched in 2023, as TMA Michigan East & West evolved. Michigan leaders include Jim Mathews, Jim Anderson, Deb Grutter, Christie Chapin, Deborah Keller, Veronica Fatura, and Louise Hartung.

Research Impact: Grants

Since 2002, TMA has awarded **66** research grants totaling nearly **$8 million**. Funding has been in all forms of myositis to advance research, clinical trials, pilot projects, fellowship grants, and myositis registries. Together, we will find better treatments – and one day, a cure.

Twelve grants were active in 2023. Two new grants were approved:

- **Julio Huapaya, MD, Myositis Fellowship:** Application of Quantitative Autoantibody Levels and Proteomic Endotypes in Myositis-associated Interstitial Lung Disease
- **Merrilee Needham, MBBS, PhD, Pilot Project:** Identifying Muscle Antigens Recognized by Autoreactive T Cells in IBM Patients using Deep-learning Based Predictive Modelling.

Two investigators with funded projects concluded their studies last year:

- **Yves Allenbach, MD, PhD, Pilot Project:** MYOTOXICI - Study of the Pathomechanisms in Immune Checkpoint Inhibitor-induced Myositis
- **Erin Wilfong, MD, PhD, Pilot Project:** Pathological Role of B cells in the Idiopathic Inflammatory Myopathies

Research Impact: Career Outcomes

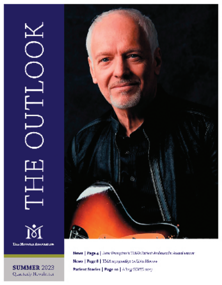
Investigators who receive TMA grants report that our support is instrumental to their ongoing successes. Congratulations to these former grantees for their career accomplishments in 2023!

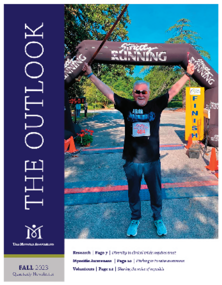
- **Begum Horuluoglu, PhD,** promoted to Assistant Professor, Karolinska Institutet
- **Tom Lloyd, MD, PhD**, appointed Chair of Neurology and Professor of Neurology,Neuroscience, and Human and Molecular Genetics at Baylor College of Medicine

Awareness Impact

In 2023, TMA presented **Three Heroes In The Fight awards.**

- Peter Frampton, legendary musician and Grammy winner living with IBM, received TMA's Patient Ambassador Award.
- Rohit Aggarwal, MD, received TMA's Heroes in Research Award.
- The Neuromuscular Center at University of California, Irvine received TMA's Heroes in Healthcare Award.





Member Impact

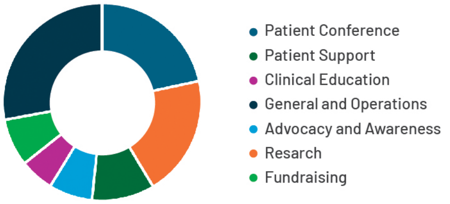
In 2023, TMA's members numbered more than 13,000. More than 5,000 members resided outside the U.S., living in **108 other countries.**

Learn More

Follow us on social media and visit our website at www.myositis.org. You can donate securely online, and view our audited financial statements and federal tax disclosures.

2023 Expenses by Program

Total Expenses $1,909,206



Our 2023 Impact Report is dedicated to the 1,631 donors, families, and Legacy Society members who supported TMA's mission last year. Thank you!

Our Team

Thank you to all who worked **toward a world without myositis** in 2023, including Marek Blaszkiewicz, Webmaster; Rachel Bromley, Patient Education, Support, and Advocacy Senior Manager; Rhonda Buckley-Bishop, Interim Executive Director; Dogwood Event Strategies; Linda Kobert, Research & Communications Specialist; Aisha Morrow, Operations Senior Manager; One Degree Financial; Sapphire Consulting; Sasse Agency; Quist & Associates; and many others whose efforts are sincerely appreciated.

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TMA's Women of Color Affinity Group raises the bar for advocacy and support

It was 2018 when TMA staff looked around at our Annual Patient Conference, realized that the great majority of participants were White, and knew a lot of people were missing. We knew that women outnumber men with all forms of myositis except IBM by two or three to one. But we were also aware of data that told us Black and Hispanic Americans, especially women, were disproportionally affected by these diseases.

So where were they, we wondered? And how could we connect them with our support and educational programming that would help them better navigate the challenges of these diseases?

Working with members of our Medical Advisory Board, TMA gathered data documenting how the burden of myositis was greater for women of color. The rash of dermatomyositis for example, is often more difficult to see on darker skin, making diagnosis more of a challenge. And Black patients with antisynthetase syndrome have more severe lung disease than White patients, which leads to higher mortality.

We developed educational materials based on these data and mapped out a plan for sharing TMA's resources with communities of color. Still, we knew an effective outreach effort would require the input of women who live with these challenges.

Call to Action

TMA approached several members, including Holly Jones and Kaniah Gunter, and invited them to brainstorm with and advise us on raising awareness of myositis among communities of color, especially women. Holly was living with polymyositis, interstitial lung disease, and pulmonary hypertension. Kaniah had dermatomyositis, calcinosis, and scleroderma.

This advisory committee soon morphed into our first affinity group, TMA's Women of Color Affinity Group. Holly and Kaniah continued their leadership of the group, recruiting other women through social media, personal contacts, and word of mouth. Today, the group has nearly 50 women participating in virtual meetings monthly, with a membership of over 250 individuals and 730 social media followers.

This year, we're excited to celebrate five years of TMA's Women of Color Affinity Group advocating for all women of color living with or caring for someone with myositis.

The three Es

In line with the group's mission to Encourage, Educate, and Empower individuals who live with myositis, each year TMA's Women of Color Affinity Group hosts a range of interactive opportunities that are open to everyone in the community.

For the fifth year running, for example, the group hosted a panel discussion at TMA's 2024 International Annual Patient Conference. By assembling a diverse set of speakers for these events, they focus attention on reducing the disparity gap in myositis outcomes for people of color, while also fostering an inclusive community of strength, resilience, and inspiration.

Women of Color actively support TMA's monthly webinar series as well, offering presentations to the community on topics their members want to hear about. Their sessions on the **Impact of Social Connections on Patient Health and Resilience** and **Maternity in Myositis** are among the most-watched videos on TMA's YouTube channel.

Building the sisterhood

Their efforts don't stop when the Zoom meeting ends. Members provide support and comfort, often in person, both individually and as a group, any time they find out someone needs a little love. Their program "I got you," for example, means members never need to go solo to a difficult doctor's visit or medical procedure.

Kaniah Gunter and Holly Jones

"Being able to physically connect with someone who understands your journey is incredibly empowering," Holly says. "I often say that myositis brings us together, but life experiences bond us forever."

Members support each other through tough and joyful times, providing understanding and care during cancer diagnoses, divorce, engagements, and motherhood. These calls have been dubbed "Encouragement Calls" after their 3E's. It's the kind of support you'd get from a beloved aunt or a close friend, if only they knew what it's like to live with a devastating chronic disease.

"We're committed to being accessible leaders and creating a comfortable and trusting environment," Kaniah says. "These calls provide valuable insight into the well-being of our members while providing them with the extra support they need."

You don't have to be a woman or Black to be part of TMA's Women of Color Affinity Group. People of all races and genders and from every part of the world are welcome to participate in the monthly virtual meetings. In fact, this affinity group attracts people who also participate in every other TMA **support and affinity group**.

"We would never turn anyone away," says Holly, who is serving her third year on TMA's Board of Directors. "Our mission focuses on promoting inclusivity and providing support for everyone."

"We help people connect the dots," Kaniah says. "That's what gets us excited, for them to find a home, to find their safe space. We're here for people of all ages, all genders, and all forms of myositis."

Read more about the history of TMA's Women of Color Affinity Group here: ***https://www.myositis.org/blog/tmas-women-of-color/***

Congratulations! The following TMA Support Groups have recently marked milestones:

Celebrating 5 years!

- TMA Alabama, Mississippi, Northwest FL: Madge Chambers
- TMA Central North Carolina: Bob Nudelman, Renee Gori, Marcella Sarzotti Kelsoe

Celebrating 10 years!

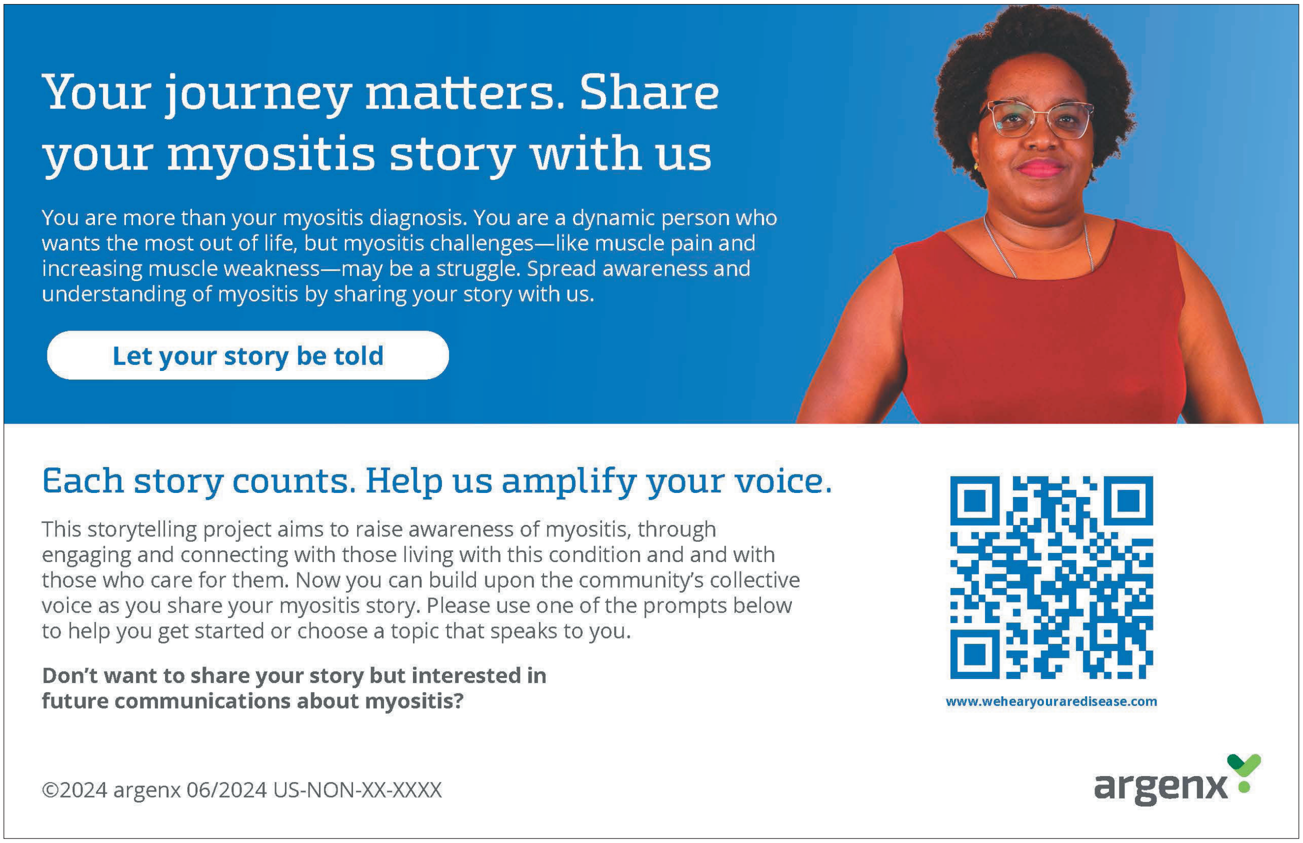
- TMA Michigan: Veronica Fatura, Louise Hartung
- TMA Northern California: Shawna Nielsen, Karen Paddock
- TMA New Mexico, NW Texas: Stanley and Sheila Prather

Celebrating 15 years!

- TMA Eastern Pennsylvania: Yashira Tirado, Martha Arnold
- TMA Nebraska: Laura Deardoff
- TMA Northern California IBM: Katie Weyrauch, Malati Shinazy
- TMA Georgia: Pixie Allison
- TMA Southwest Florida: Donna Defant, Linda Sabatino
- TMA Maryland, Delaware, DC, N Virginia: Bitsy Anderson, Jenna Radke

Celebrating 25 years!

- TMA Hospital of Special Surgery: Suzanne Fischbein
- TMA Missouri & Illinois: Dave Volk, Ed Arnold, Denise Antonucci
- TMA Southern California: Rhonda Rogers, Nancy Harber



Just A.S.K.

By Dorothy Vetrano

I was diagnosed with dermatomyositis (DM) almost four years ago. Since my journey began, I've learned a few coping strategies but it all boils down to one word…

A.S.K. – Accept, Seek, and Knowledge

Accept – You may not want to, but it's so important to accept this new normal so you can learn to live a productive and good life.

Be in the moment and feel whatever emotion that happens to you that day. Don't avoid the emotion. It's okay to cry, get angry, become upset. But don't stay in the negative emotion for too long. Find the strength to move on.

Which leads to…

Seek – Look for ways that will help your overall attitude and wellbeing of living with myositis.

For me, I seek prayer every morning and every evening, thankful for another day. I seek daily exercise (cardio, weight bearing activities, and more importantly yoga). I seek better eating habits by shopping the perimeter of the grocery store and avoiding the middle aisles where less healthy foods tend to be found. I seek a restful sleep; doing a ten-minute yoga practice at night helps. Finally, I seek volunteering; helping others takes my mind off my current health situation by turning it into something positive and productive.

Knowledge – Understanding is powerful! We need to arm ourselves with enough knowledge about myositis so we can become active participants in our medical care. Make yourself a myositis toolbox! Mine is a binder with tabs for each healthcare practitioner I see; I have one for my PCP, rheumatologist, gastroenterologist, endocrinologist, dermatologist, and OBGYN. Within each section are my notes for each visit and copies of any recent lab work so I can share with all my doctors so no one orders same tests. My doctors love and even laugh a little when I show up to my appointment with my big purple binder! They love how it's organized and efficient it is for our visits. Get to know your doctors and question them if you don't understand or agree. This is your health, and everyone needs to be on your team.

Dorothy Vetrano considers herself to be a DM newbie and grateful that she's doing pretty well overall. She lives in Houston, TX with her loving and supportive husband and two four-legged babies. She's a teacher of students with visual impairments who has worked with the visually impaired for the past 32 years.

TMA's Myositis Tracker is a tool to help you track your symptoms and changes in your condition in preparation for discussion with your doctor. Download it at our website: **https://www.myositis.org/wp-content/uploads/2020/05/MyMyositisTracker_FINAL.pdf**

Thank you to our sponsors and exhibitors who made our 2024 International Annual Patient Conference possible!

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ILD Day

Interstitial Lung Disease Awareness and Education

On September 18, TMA recognized Interstitial Lung Disease (ILD) Day in a very special way by announcing **The Meredith C. Thomas Myositis Research Fellowship**. This new research fund is dedicated to the memory of the magical, authentic, pure spirit of Meredith Claire Thomas. It was created to fund research grants for early-career clinicians focused on Antisynthetase Syndrome and ILD.

It's not too late to observe ILD Day in a very special way by donating to the fellowship fund: **https://donorbox.org/meredith-c-thomas-myositis-fellowship**

The Myositis Association

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