THE OUTLOOK

THE MYOSITIS ASSOCIATION®

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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.

On the cover: Jeff and Pam Autrey, dedicated supporters of TMA's Research Grants Program

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Jeff Autrey

Martha Arnold

Dr. Iazsmin Ventura

With gratitude to retiring board members

TMA wants to celebrate and express our deepest appreciation for three incredible individuals who have concluded their terms on the Board of Directors as of the end of 2024: Martha Arnold, Jeff Autrey, and Dr. Iazsmin Ventura.

Throughout their time with us, they have shown remarkable dedication and passion, and have shared their pharma, research, legal, and medical expertise with us. Their contributions have not only propelled our mission forward but have also touched our hearts.

Their legacy of service will undoubtedly continue to inspire us all. While we will miss their invaluable presence, we expect their support and involvement in our myositis community will continue. They were amazing board members but even more importantly they are phenomenal people that we are proud to call our friends.

Nearly half a million dollars in grant funding for rare disease research reaps rewards for myositis patients

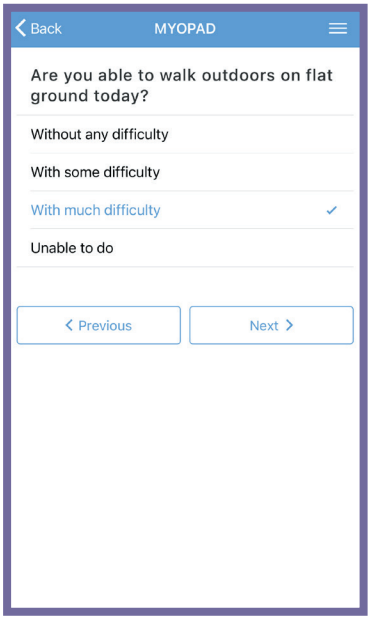
We are pleased to announce that three projects within TMA's Research Grants Program were completed in 2024. These projects, totaling nearly half a million dollars, bring those who live with myositis just a little closer to a cure. We're grateful to the following researchers for their efforts on behalf of the myositis community.

Alexander Oldroyd, MD, PhD, Academic Clinical Lecturer at the University of Manchester, UK, completed a two-year research fellowship working with Dr. Hector Chinoy. Dr. Oldroyd received a TMA fellowship award of $100,000, which helped him develop a smart phone application to remotely monitor continuous activity levels of patients with myositis.

Currently clinicians measure how "active" a person's myositis is through a series of tests, such as manual muscle strength testing and blood tests. In reality, however, disease activity can only be measured at infrequent clinic appointments that may happen only every three months to a year.

As most patients know, however, that their myositis symptoms can vary on a day-to-day basis. These daily symptom variations and flares may be missed if clinicians rely only on disease activity measurements at clinic appointments alone.

In a pilot project for his PhD dissertation, Dr. Oldroyd demonstrated that symptom data can effectively be collected using a smartphone app. This project expanded on that work to include a larger group of participants over a longer period.



Using the app, he assessed muscle pain through the question, "On a scale of 0-10, what level of muscle pain are you having today?" Abnormal walking patterns, which are affected by muscle weakness due to myositis, were identified using small adhesive sensors attached to the side of a person's leg.

Dr. Oldroyd's findings indicate that myositis flares occur at a higher frequency than we've previously thought—every three weeks on average. Patient-reported flares are also associated with increased symptom levels (global activity, fatigue, weakness, myalgia, overall pain). And—no surprise—flares are also associated with reduced work productivity and detrimental impact on function.

"The hope is that this monitoring will allow patients and providers to detect symptom-based flares earlier," Dr. Oldroyd says. "Not only can this provide a more accurate measure of disease activity, but it can be a more effective measure of treatment effectiveness that can be valuable for clinical trials."

This grant and the work carried out during his fellowship allowed Dr. Oldroyd to dedicate his time to conducting this important clinical research in myositis. It also allowed him to secure a competitive Academic Clinical Lectureship at the University of Manchester (UK).

Cheilonda Johnson, MD, MHS, Assistant Professor of Medicine (Pulmonary, Allergy and Critical Care) at the University of Pennsylvania School of Medicine completed a pilot project for which she received a grant of $200,000. Dr. Johnson's project identified specific genes associated with interstitial lung disease (ILD) that occur in patients with myositis and created a database of lung tissue samples from patients with different forms of myositis. This project showed that having myositis genes not only predicts if a person is at risk for developing ILD, but also the type of myositis genes predicts which patients are at higher risk for severe disease.

Based on data from this project, Dr. Johnson received a prestigious R01 grant from the National Institute of Health (NIH). With this NIH funding, she will expand on her work by developing and validating a tool that will help clinicians better predict disease progression. Her work will also test for unknown influences in myositis-ILD patients using clinical, genomic, and proteomic data.

After completing a fellowship at the Myositis Center at Johns Hopkins University School of Medicine, working with former TMA medical advisor Dr. Sonye Danoff, Dr. Johnson moved to the University of Pennsylvania. Unlike the robust myositis resources available to her at Johns Hopkins, there was no research database of myositis patients at Penn. Without TMA's support, Dr. Johnson would no longer have been able to continue her research on myositis lung disease.

"I am excited to continue working with myositis patients," Dr. Johnson says. "We know that the genes of a person with myositis can identify to different major groups with different risks for ILD development and progression. We plan to study these two groups to understand if these differences explain different disease mechanisms. Our goal is to better understand this disease to improve and save lives."

Chiseko Ikenaga (l) with Lloyd Lab colleagues

Chiseko Ikenaga, MD, PhD, Assistant Professor of Neurology at Kitasato University, Tokyo, Japan, also completed a two-year research fellowship working with neurologist Dr. Thomas Lloyd at the Myositis Center at Johns Hopkins University School of Medicine. During her fellowship, for which she received a grant of $100,000, Dr. Ikenaga worked on several projects related to inclusion body myositis (IBM) and collaborated with colleagues from across the globe.

In one of these projects, Dr. Ikenaga was able to show that there is a genomic stress pathway that may cause critical muscle damage in patients with IBM. This pathway is associated with atrophy of muscle fibers and inflammation and can be a potential target for drug therapy.

In another project, she sequenced RNA in cells that form muscle fibers called myoblasts to identify autoimmune triggers that may cause changes in those cells and may explain why patients with IBM don't respond to immunosuppressive therapy.

A third project was done in support of the IBM rapamycin clinical trial currently being conducted at several sites around the world. Dr. Ikenaga tested the effect of this drug on muscle biopsy samples in the laboratory to see if there really is an effect. Her findings show that three months of rapamycin treatment reduced rimmed vacuoles (one of the main causes of muscle dysfunction) in the muscle cells without causing muscle atrophy. This suggests that rapamycin may be effective for those with IBM.

"I am honored to be awarded this grant by The Myositis Association," Dr. Ikenaga says. "Dr. Tom Lloyd has been a great mentor, and I have been happy to be guided by him. During this fellowship, there were many opportunities to collaborate with other researchers. These experiences are invaluable to me. I will go back to Japan and continue both clinical and research work. I deeply appreciate all the support from TMA."

Myositis research awards bring hope to those with rare diseases

Every year, TMA provides research funding to scientists working to understand, treat, and ulitmately cure myositis diseases. Over the last 22 years, we have approved 68 projects totaling nearly $8.2 million.

TMA invites and funds projects from across the spectrum of myositis diseases. In 2024, for example, we had ten active grants from researchers in six different countries and five different states working on projects as diverse as reviving lost technology to identify biomarkers for ILD, a clinical trial for IBM, an investigation of the microbiome in DM patients, and a deep dive into anti-Jo1 antisynthetase autoantibodies.

In our most recent quest for new projects to fund, our process was a little different. While continuing the effort to advance research into the cause, prevention, detection, treatment, and cure of myositis and related diseases, last year's grant cycle targeted projects specifically related to two forms of myositis: inclusion body myositis (IBM) and juvenile myositis (JM).

With this evolution toward more targeted research grants, for the first time we invited members of the patient community to participate in the evaluation process as stakeholder reviewers. Along with scientific reviews completed by TMA medical advisors, all applications were critiqued by a lay member of the myositis community. These stakeholders also had a voice in the final decision on which applications would be awarded funding.

The 2024 call for applications brought 19 letters of intent, 11 of which submitted full applications. We are grateful to Pam Autrey, who lives with IBM, for reviewing all seven IBM applications. Jonathan Weisman, whose now-22-year-old daughter has juvenile dermatomyositis, reviewed the five JM applications.

"The importance of this kind of independent grant funding for rare diseases like myositis cannot be overstated," says TMA's Research Grants Committee Chair Lindsay Alfano, PT, DPT, PCS, research assistant professor of pediatrics at The Ohio State University School of Medicine, Columbus, OH. "These grants not only increase our understanding of these devastating conditions but also allow investigators to gather preliminary data to support applications for larger grants such as those from the NIH."

And the recipients are…

A grant of $80,000 for an IBM project was awarded to **Thomas Lloyd, MD, PhD**, Chief of Neurology at Baylor College of Medicine, Houston, TX, for his project "Senolytic therapies in a novel patient-derived myoblast model of inclusion body myositis (IBM)."

This study proposes the innovative hypothesis that the chronic inflammatory condition in IBM causes new muscle cells to become aged and deteriorated. With new drugs in development for various age-related diseases (senolytic therapies), this project will test these drugs with an in vitro model of IBM to quickly identify drugs already approved by the FDA that may be effective for treating this rare disease. The hope is to identify treatments that can enter clinical trials in patients with IBM within the next 3-5 years. As the American population ages, conditions like IBM, Alzheimer's disease, and ALS are a significant cause of disability and diminished quality of life. This new approach to drug development offers hope for such conditions that have few treatment options.

Our second grant of $45,000 for a JM project was awarded to **Christian Lood, PhD**, Associate Professor of Medicine at the University of Washington School of Medicine, Seattle, WA, for his efforts to identify "Mitochondrial contribution to juvenile dermatomyositis (JDM)."

Mitochondria are special structures within human cells that provide energy to the cell. It has recently been discovered that mitochondria can leave cells and transfer elsewhere. How this may affect other cells is not fully understood. Mitochondria have been found in the bloodstream of those who have juvenile dermatomyositis (JDM), but it's unclear what effect this may have on disease progression. This study will investigate the role of mitochondria in JDM, with the long-term goal to improve patient care and quality of life.

Funds for TMA's Research Funding Program come primarily from myositis patients, their families, and friends. If you would like to contribute to TMA's mission to fund research into myositis conditions, please consider making a ***donation today***.

TMA announces 2025 Research Grant Request for Proposals

TMA's Meredith C. Thomas Memorial Fellowship is an award of $107,500 that will be granted to a fellow pursuing a disease-specific, targeted project that advances the understanding of the cause, prevention, detection, treatment, or cure of antisynthetase syndrome and/or myositis interstitial lung disease. Specific criteria can be found on our **website**.

Timeline for the 2025 Grant Program

- Letter of intent due **April 14, 2025**
- Invitation for full application by **April 21, 2025**
- Full application due **May 19, 2025**
- Notification of awards **September 2025**
- Funding to begin after **November 2025**

WHAT BRINGS YOU JOY?

Rachel Bromley, TMA Senior Manager for Patient Education, Support, and Advocacy

Making friends with people in the myositis community—from all over the world—brings me immense joy! Whether it's in person at TMA's International Annual Patient Conference or over Zoom in meetings and webinars, these friendships have sustained me during my own personal struggles.

This past year I was diagnosed with breast cancer—small and detected very early, thank goodness—but still scary. Not only did the TMA team support me, but many of my friends with myositis attended my personal Facebook live event when I finally got to ring that bell signaling the end of my cancer treatment! TMA's Women of Color Affinity Group even sent me a bouquet of flowers for encouragement.

Knowing that the myositis community is not only there for each other but for me personally too meant the world to me, and it continues to bring me joy! Thank you to each of you!

Pam Autrey: Being an IBM expert

Jeff and Pam Autrey

Pam Autrey was diagnosed with inclusion body myositis in August of 2017. She'd been having symptoms for about eight years by that time, but it took her and her husband Jeff no time at all to seek out TMA and find their way to our Annual Patient Conference in San Diego that September. They've been passionate supporters of TMA's efforts ever since. Jeff has even served on the Board of Directors, rotating off this January after six years.

One of the Autreys' biggest concerns is that there is still no effective treatment that will limit or reverse the progressive muscle degeneration that causes so much disability in those who live with IBM. It's why they have focused their efforts on generating funds for IBM research.

"We are fortunate in having a family foundation," Pam says. "So we thought, wouldn't it be nice to create a matching grant to raise funds for IBM research. It's hard for one or two people to do it alone, but if it's all of us together, we could possibly make a difference."

Indeed, their matching grant campaign was a great success. They were able to raise $80,000, enough for a TMA research grant for a disease-specific project dedicated to IBM. Applications were solicited and the grant was awarded in TMA's 2024 grant cycle. As a stakeholder in this process, the Autreys were also able to help decide on criteria for the type of projects the grant would fund.

It was important to them, for example, that the outcomes of the project would be likely to lead to new or improved treatment options for IBM within three to five years. And they wanted to include projects to address quality of life or therapies for IBM-related conditions such as dysphagia, hand function, mobility challenges, preservation of muscle function, and/or other impairments.

As part of our effort to incorporate the voice of patients in myositis research, this year TMA also included those who live with myositis as stakeholder reviewers for all our research grant applications. Pam was eager to serve as a stakeholder reviewer for the IBM disease-specific grant that was awarded last year. [see story p. 3]

While she doesn't have the scientific background as that of other reviewers from TMA's Medical Advisory Board of international myositis experts (she has a doctorate in management and taught in the business school at the University of Texas for several years, specializing in entrepreneurship and corporate strategy), Pam is an expert on what it's like to live with IBM. And while the grant applications went into medical and technical detail that was beyond her, the process of what they were trying to accomplish was easily apparent to her.

In the end, the review committee chose a project from former TMA MAB member, Dr. Tom Lloyd. Pam was pleased with the decision and with the process.

"Being part of this process made me so grateful that we have a medical advisory board that is willing to put in this time and effort and to share information with each other in these discussions about the proposals," Pam says. "I certainly learned a lot. It was fascinating to see what they felt were priorities in terms of research that needs to be done. And they had some perspectives on the science that was really useful."

As a donor and as a stakeholder reviewer of this IBM-specific research grant, Pam has only one regret: "My biggest disappointment was we didn't have more funding to be able to award more than one grant."

What is a stakeholder reviewer?

Stakeholder reviewers join scientific reviewers from our Medical Advisory Board in evaluating TMA research grant applications and choosing which to fund. These reviewers were adopted by TMA in 2024 and are common at many other research-oriented organizations, including the Department of Defense and the Patient-Centered Outcomes Research Institute (PCORI).

TMA invites stakeholder reviewers who are affected by conditions associated with the disease specific target(s) of our call for proposals to review those applications. Stakeholder reviewers are typically an individual, patient, family member, or other unpaid caregiver. We ask that each stakeholder reviewer represent his or her personal experience with condition as well as that of the broader myositis community.

Including stakeholder reviewers allows TMA to more directly incorporate the views of those affected by myositis into the grant review process. As disease experts, stakeholders read and evaluate grant applications for particular relevance to the needs and concerns of those who live with the disease. Then, stakeholder reviewers participate in a virtual meeting with scientific reviewers, discussing the applications and deciding on which one(s) to fund.

The primary and distinct role of a stakeholder reviewer is to help ensure that funded investigators are addressing a problem that is meaningful from the perspective of patients, care partners, and families. This is one of the key ways that TMA has made our research initiatives more patient-centric.

You too can join forces with others in the myositis community to support TMA's research initiatives. ***Create a fundraiser*** *and share the link with your friends and family. You can also* ***donate here*** *or share the QR codes below with everyone you know and invite them to support this research that means so much to you. We will happily apply your donation to a specific area of myositis research.* ***Let us know*** *if you'd like to support research into IBM, DM, ASyS, NM, or PM specifically.*

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Disc golf and pickleball slow my IBM progression

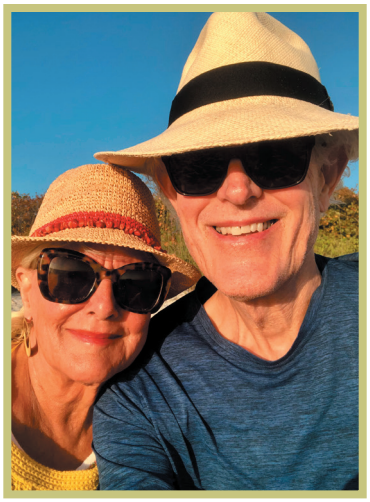
by Joe Feidt

Joe Feidt (l) with his disc golfing buddies

I was having trouble swallowing. That's how it started. It's now been 11 years since I heard my neurologist say, "Joe, I've got good news and bad news. The good news is you don't have ALS; the bad news is you have IBM." I said, "I have WHAT?!"

My reality today is it takes me about five minutes to pull on my socks and 10 minutes to get dressed. I have to use all of my leg strength to simply stand up. Low chairs and benches? I'm not sitting there! And it takes me, oh, about a half hour to eat a hamburger. And yet …

Despite the IBM, I've been able to lead a relatively normal life and maybe you can too. This is due to good fortune and staying active. I play disc golf and pickleball, lift weights, take short hikes, and work. And I eat well. So far so good; knock on wood.



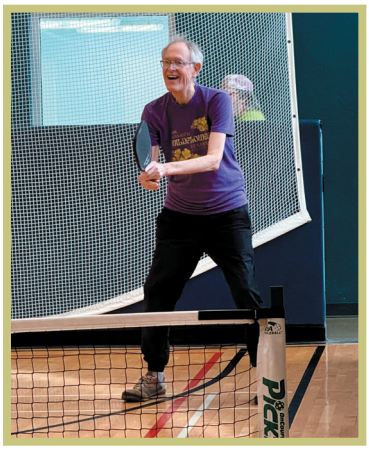
Joe and his partner Susanna

I admit I'm a slacker occasionally, but I try to do something active every day: Sometimes I play disc golf on a pitch-and-putt course overlooking the Mississippi River. It's getting harder to throw but I can still do it. I enjoy getting outside and walking through a beautiful course, breathing fresh air, and most importantly (for me) having fun with my longtime golfing buddies. I feel a sense of accomplishment just playing nine short holes. (FYI, disc golf is like traditional golf, but instead of using a ball and clubs, you throw a disc (aka Frisbee) into a disc-catching contraption. You can read more about it **here**.

My life's passion: disc golf

My father told me: "Life passes quickly. Find something you really like to do and stay with it." I followed his advice. When I was 26, I discovered disc golf and have been playing and promoting it for about 50 years. Today, disc golf is one of the fastest-growing sports in the world. This year's world championships will take place in Finland, and the sport will be an event in the 2025 World Games — a stepping stone to the Olympics. Thousands of disc golf courses are located in some 90 countries and most are free to play. No matter where you live, there's probably a course not too far away.

During the winter I go to the Midway YMCA in St. Paul and play a couple of games of pickleball. It's getting harder to "pickle," but I can still grip the paddle and hit a ball. Like disc golf, I'm mindful of my footing; I'm in full Fall Avoidance Mode (FAM) every step I take. After pickleball I do strength training which is so important. On nice days, I and my partner, Susanna, go for nature walks using hiking poles for stability.



Joe on the pickleball court

To keep my mind sharp, I edit *DiscGolfer* magazine, a 64-page, full color quarterly published by the Professional Disc Golf Association, the governing body of the sport. I collaborate with eight writers and one very talented art director. I'm also writing my memoir *DiscGolfer* is available in paper and digital formats.

Hope: A drug called ABC008

We IBMers need hope. Here is some: a drug called Ulviprubart (aka ABC008). I'm honored (and fortunate) to be taking part in a clinical trial to try to find the miracle drug that we long for. I'm one of just a few hundred people in the whole world taking part in this trial. It started over a year ago and is happening now in the US, UK, Europe, and Australia.

Every two months I drive 75 miles south to the Mayo Clinic and receive two injections in my abdomen. Is Ulviprubart our IBM silver bullet? Fingers and toes crossed. You can find info on this trial **here**. (They are not recruiting anymore patients because the trial is getting close to the end.)

Thanks to good fortune and staying active, life is good 11 years after hearing: "You have IBM." I'm so fortunate this disorder has been progressing slowly and that I have a loving, supportive partner who is totally with me on our IBM journey.

*Joe Feidt lives in Saint Paul, MN and can be reached at **jfeidt1@gmail.com**. He is known as the Father of Disc Golf in Minnesota and was inducted into the World Disc Golf Hall of Fame in 2011.*

Reboot your wellbeing

By Dorothy Vetrano

It happens to all of us now and then. Your computer freezes in the middle of working on a document or searching the internet. You've tried the "escape" button and "control, alt, delete" but nothing works. The last resort is to shut down and reboot. That usually is the fix and once again you are back up and running.

Recently, I discovered we sometimes need to reboot our bodies. In the Fall 2024 issue of *The Outlook,* I wrote about how I think about coping strategies: Accept, Seek, and Knowledge (ASK). Since then, my journey has had me on a "Seek mission." In addition to my dermatomyositis, I have autoimmune hepatitis of the liver. Loss of weight, changes in medication, blood work, scans, and physical therapy were just a few of the things that hit me all at once towards end of 2024, and I didn't know what to do. How was I going to get through the holidays? Thankfully I did. My health had to start with me first, and I needed to be more proactive than ever.

So, my "seek" mission began: finding ways that will help my overall attitude and wellbeing. With a great team of doctors behind me, I was referred to a nutritionist. Overall, my eating habits and calorie intake were good, but I was taking in too much fat and not enough protein. The nutritionist made some changes and "rebooted" my diet to include the nutrients my body needed. She taught me the right foods to eat, how often to eat, and even gave me a wonderful array of menu choices.

I was thrilled to discover I can eat some of my favorite foods, in moderation, while adding more healthy protein to each meal. I also found I really don't miss the foods I used to eat, even the occasional glass of wine. I now enjoy nonfat plain yogurt with fruit, salads with chicken or salmon, vegetables, hummus, and even chickpea pasta. Occasionally I even enjoy dark chocolate and pretzels, all in moderation of course. And if I want bread, I make homemade whole wheat or rye. The journey isn't easy but when you only have one liver, you'll do anything to protect it.

Even though the holidays were a little hard, I was able to enjoy some of our traditional family meals, albeit with adjustments. A favorite Italian dish my family enjoys is pasta e fagioli. A hearty soup made with meat, beans, tomatoes, and pasta. Unfortunately, meat, tomatoes, and white pasta don't always agree when you have autoimmune and liver issues. With a little tweaking, I made a baked pasta e fagioli, and to my surprise my family loved it. There were no leftovers. So, from my kitchen to yours…*mangia!*

As always please check with your doctor or a nutritionist to make sure you are on the right eating habits. I highly recommend it.

Baked Pasta e Fagioli

(Prep – 20 min)

(Bake – 15 min)

(Makes – 6 main dishes)

Ingredients:

- 8oz. mini penne or elbow whole wheat pasta
- 1 can (28 oz) can of diced/chopped tomatoes in sauce
- 1 tablespoon olive oil
- 1 medium onion, chopped
- 1 stalk celery, chopped
- 2 cloves garlic, crushed with press
- 2 cans (15 – 19 oz each) navy or other small white beans (northern beans are fine), rinsed and drained
- 1 cup reduced-sodium chicken broth
- Ground black pepper
- 1 pkg. (10oz) frozen chopped kale, thawed and squeezed dry
- ½ cup freshly grated Romano cheese

Preparation:

- Preheat oven 400. Heat large, covered saucepot of water to boiling over high heat. Add pasta and cook 2 minutes less than label directions. Drain pasta, reserving ¼ cup cooking water. Return pasta to saucepot.
- In 4-quart saucepan, heat oil over medium heat until hot. Add onion and celery and cook 9–10 minutes or until tender, stirring occasionally. Add garlic; cook 1 minute.
- Stir in tomatoes and sauce, beans, broth, and ¼ tsp. pepper; heat to boiling over high heat. Reduce heat to medium; stir in kale.
- Add bean mixture, reserved pasta cooking water, and ¼ cup Romano to pasta in saucepot and toss until well mixed. Transfer pasta mixture to 3-quart glass or ceramic baking dish. Sprinkle with remaining Romano cheese. Bake 15 minutes or until center is hot and top is golden.

May is the time for the myositis community to raise our collective voices and let the world know what this rare disease is all about! TMA has a whole month's worth of learning and connecting, including diagnosis-focused days where you can tune in to learn from the world's leading myositis experts. Plus, we have a toolkit of powerful resources to help you tell your story, support each other, expand the world's understanding of myositis, and, in doing so, shorten the wait between symptoms and diagnosis.

TMA has a whole lineup of fun events and fundraisers to help spread the word about myositis to those who might never hear the term otherwise. Just click the button to find out more.

LEARN MORE

Tee off at TMA's virtual or in-person golf tournament on May 2!

LEARN MORE

Get in the mood with Melodies for Myositis: A Smooth Jazz Concert, featuring platinum recording artist Randy Scott. Also virtual or in-person.

LEARN MORE

Get your national, state, or local government to proclaim May as Myositis Awareness Month! We're working to secure a declaration in all 50 states, and we're almost there!!

LEARN MORE

Pitch in as we hit it out of the park with 31 First Pitch events during the month of May. TMA volunteer and First Pitch originator Vance Robinson says you can deliver the first pitch at any baseball game in town, even your little one's T-ball game!

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Keep in touch with TMA!

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