THE OUTLOOK

THE MYOSITIS ASSOCIATION

WINTER 2019
Quarterly Newsletter

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THE OUTLOOK

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A most important gathering

Mary McGowan, Executive Director

Thank you to all who attended the 2019 Annual Patient Conference in Minneapolis! It was wonderful to have the opportunity to reconnect with so many of you and to focus on *Who You Are Matters!* As we all know, myositis diseases affect everyone differently, and the focus of this year's conference was on addressing the diversity of needs and challenges within our myositis community.

This was the second largest Annual Patient Conference in the history of TMA! Our Annual Patient Conference is the most important gathering of the myositis patient community globally. World-renowned myositis experts and researchers travelled to Minnesota to meet with attendees, and attendees had the opportunity to learn about the latest clinical evidence and myositis research and therapies. We extend our sincere thanks to our international leaders for freely giving their valuable time and expertise.

We were thrilled to have a representative from Senator Amy Klobuchar's (S-MN) office welcome attendees and report on the important work the Senator is doing as cochair of the Congressional Rare Disease Caucus. This welcome was followed by 96 sessions conducted by 75 speakers.

One of the most popular sessions was a workshop in which members learned how to craft their myositis advocacy story, empowering them to raise awareness while advocating for change throughout the world.

Attendees also had the opportunity to engage with and hear from TMA's corporate partners and conference sponsors. Our sincere gratitude extends to Mallinckrodt Pharmaceuticals, our Platinum Sponsor, for their very generous support as well as all of our other sponsors for making this year's conference possible.

Thank you to TMA's support group leaders for displaying the great work you do nationwide at the *Show Your Stripes* reception and to all of the volunteers who assisted throughout the conference. A special thank you to the TMA staff, a small but mighty team of only five people. Thank you for all of your work and dedication.

While the Annual Patient Conference was underway, TMA's Myositis Medical Symposium for health care professionals and medical trainees also took place. Attendees learned about the latest progress in research, diagnosis, and clinical care of myositis from the world's leading experts on TMA's Medical Advisory Board.

In addition, our Medical Advisory Board's Research Committee met to review 26 research grant applications received this year. We had a 40% increase in the number of *Letters of Intent* we received and a 25% increase in *Full Grant Applications* submitted. TMA will announce the grants approved for funding in the near future.

A final thank you goes to those who donated silent auction items, helping to raise money for myositis research. Clearly the favorite was the guitar autographed by legendary rock star Peter Frampton who revealed earlier this year that he has been diagnosed with IBM.

TMA's vision is a world without myositis

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

For those who missed the conference, numerous sessions were video recorded and can be viewed on TMA's website. Slides from a number of other sessions are also available, so please be sure to check out all of the educational presentations from this year's as well as past conferences in the Myositis Library.

Armed with more knowledge about your disease and how it relates specifically to you, coupled with practical advice for coping with the challenges, we hope this conference and the relationships you developed inspire you to find new ways to move beyond the barriers this disease creates so you can bring more joy into your life. Because *who you are matters!*

Please mark your calendars for next year's conference September 10-13.
We look forward to seeing you in Seattle!

TMA attends RARE Patient Advocacy Summit

Mary McGowan and Tricha Shivas met with Corbus representative Lindsey Smith at Global Genes Summit

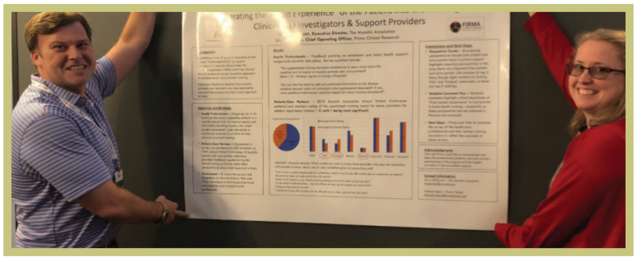
According to the National Institutes of Health (NIH), more than 30 million people in the United States are living with rare diseases. This means one in ten Americans are affected by the more than 7,000 rare diseases. This year, Global Genes hosted its 8th Annual RARE Patient Advocacy Summit on September 18-20 in San Diego. More than 1,000 patients, care partners, organizational leaders, industry experts, and thought leaders—including two TMA staff members—came together to hear more than 80 speakers discuss issues along four educational tracks:

- Caring for yourself and others while rare (for patients and care partners)
- Building and activating your community
- Patients as drivers in drug development
- What's now: Drug development in rare disease

The meeting was very productive for TMA. Staff met with numerous corporate and organizational partners, participated in the Global Genes Alliance Meeting, and learned a lot about the needs of rare disease patients and how TMA can actively work to support those who live with myositis.

TMA partners present research results

Part of TMA's presence at the Global Genes Summit included partnering with Firma Clinical Research to present a poster session based on results of a survey conducted at TMA's 2019 Annual Patient Conference.



Firma representative Mike Keens and TMA's Tricha Shivas display poster presentation at Global Genes Summit

Firma Clinical Research, a contract research organization (CRO) that provides research support services to the biopharma industry, plans to conduct similar enhanced training programs in other disease conditions with which they work.

The poster, "Integrating the Lived Experience of the Patient into the Training of Clinical Investigators and Support Providers," detailed the feedback Firma received from patients and care partners about their experiences living with these rare diseases.

The project was launched when Firma invited TMA to provide training materials for nurses who would implement a clinical trial the company was supporting. These materials pointed out how little information is available to healthcare providers about the challenges myositis patients and those who care for them deal with every day.

At the TMA Annual Patient Conference, TMA asked patients and care partners to complete a short survey. TMA is proud to have one of the most engaged communities of patients and care partners who are always willing to participate in projects like this. We are extremely grateful to all of the attendees at this year's Annual Patient Conference who completed the survey, providing information they felt it was important for homecare staff to know when caring for myositis patients or loved ones.

The patient/care partner survey and its results are one part of an ongoing project to create and evaluate training materials used by home health providers who will attend to myositis patients during the clinical trial. These providers will also be surveyed to identify what materials they found most helpful and what additional information was still needed.

Both surveys sharpen the focus on the needs of patients and their care partners. The information gathered will be used to improve the clinical trial training protocol that will result in increased provider understanding and, hopefully, a more positive home health experience for clinical trial patients.

Myositis research collaborative wins award

IMACS representatives Dr. Frederick Miller and Dr. Lisa Rider accepted Rare Champions of Hope Award

The International Myositis Assessment and Clinical Studies Group (IMACS), is a coalition of more than 450 healthcare providers and researchers with experience and interest in all forms of myositis. This group of diverse researchers from six continents and 42 countries represent multiple medical disciplines, patient support groups, pharmaceutical and biotech companies, and others working together for the benefit of myositis patients.

TMA has been an integral part of this important organization from its inception 19 years ago, and we are proud to have nominated IMACS for the Global Genes Rare Champion of Hope Award.

IMACS seeks to improve the lives of children and adults who suffer from myositis by discovering better therapies through understanding the causes of these diseases. The coalition works to achieve this goal by developing standards that guide how myositis research is conducted and reported; by planning, facilitating, and conducting international collaborative myositis research; and by performing collaborative trials.

As proud collaborators with IMACS on their annual meeting and numerous research projects, TMA is thrilled that Global Genes elected to award IMACS this prestigious award. When TMA received notification that nominations were open for the RARE Champions of Hope Awards, we immediately saw a fit for IMACS for its trailblazing collaborations in the category of science, technology, and research. Specifically, the award seeks to highlight those researchers who have an innovative approach to collaboration. The partnerships IMACS creates among researchers and patient organizations like TMA make it truly unique and noteworthy.

In today's climate where medical institutions are competing for every research dollar, it is admirable and impressive that IMACS researchers have been able to carve out this special space to collaborate with each other and with patient advocacy organizations for the benefit of the patient. Measurable outcomes are critical to clinical reimbursement and in attracting industry interest in funding clinical trials. The IMACS team has come together to create tools, measures, and consensus studies to guide clinical practice that incorporates patient reported outcomes.

TMA has been proud to help support IMACS in the planning and execution of their annual meeting. TMA's members have been eager participants in many of the of the clinical studies conducted by the IMACS team in developing tools and outcome measures. TMA members are also currently helping to furnish data for one of the most comprehensive registries in myositis to date in order to better understand these diseases and seek more effective treatments and a cure.

IMACS was just one of nine recipients of the Rare Champions of Hope Award and was selected from a very competitive pool of over 100 nominees. We are very proud that this collaborative work has been recognized by our peers in the rare disease community. It is a distinct honor to hold up this model of collaboration between TMA, IMACS, and myositis researchers as we continue to strive for treatments and cures.

To view the acceptance speech given by Dr. Lisa Rider, NIH Deputy Chief of the Environmental Autoimmunity Group, and Dr. Frederick Miller, NIH Deputy Chief of the Clinical Research Branch and head of the Environmental Autoimmunity Group, please see the link on TMA's website homepage.

TMA addresses pharma professionals

Mary McGowan addresses pharma executives at EyeforPharma Summit

EyeforPharma is an information exchange platform providing an opportunity for pharma professionals to come together with patient advocacy groups and other health experts to exchange ideas and move the industry forward. Focused on patient support and engagement, their business model is based on an understanding that meeting patient's needs is their ultimate goal.

TMA is proud to have been invited as one of 20 patient advocacy group speakers to participate in the EyeforPharma Patient Summit on October 2-3, 2019. The meeting involved more than 250 attendees, made up of mostly industry professionals. The meeting's focus was on helping pharmaceutical companies to design products, trials, and strategies that better incorporate the voice of the patient as a means for improving patient outcomes.

In her presentation, TMA Executive Director Mary McGowan shared TMA's unique approach to storytelling training for patient and care partner advocates. TMA has successfully used this technique to help advocates more effectively engage with industry partners to learn from their experiences as patients and care partners, increase engagement with the media, and grow awareness of myositis throughout the community. Engaging with a trained advocate can improve clinical trial engagement and interest, deepen industry understanding of complex issues that patients and care partners face, and increase community awareness to drive better therapy and care.

TMA partners with NeedyMeds

NeedyMeds is a national non-profit dedicated to helping people locate assistance programs to help them afford medications and other healthcare costs. They have a wide variety of services, including information on healthcare programs, direct financial assistance, and, perhaps most significantly, prescription drug discounts.

TMA recently formed a partnership with NeedyMeds to improve the support services available to those living with myositis. We hosted a webinar with the organization on October 29 to help spread the word about their cost saving resources and to highlight this new service for TMA members. You can find the recording of this webinar in the library section of TMA's website.

TMA members, friends, and family can download or request the TMA-branded Drug Discount Card provided through NeedyMeds. With this card, you can save up to 80% off the cash price of prescriptions, over the counter medications that are written as prescriptions, and even pet prescriptions. You can also save up to 40% off durable medical equipment, including canes, crutches, splints, incontinence supplies, and more. Diabetic supplies, such as glucose meters, test strips, lancets, and diabetic shoes, are also covered. Visit **www.needymeds.org/dme** to learn more. This discount card cannot be used with your commercial or government insurance.

From their homepage, NeedyMeds also offers a drug pricing calculator that provides price estimates at pharmacies near so you can compare prices.

A downloadable version of the TMA-branded Drug Discount Card is available on the TMA website. To obtain a plastic drug discount card, send a self-addressed, stamped envelope to: NeedyMeds Drug Discount Card PO Box 219 Gloucester, MA 01931. Let them know you would like the TMA-branded Drug Discount Card.

See the NeedyMeds website for other resources, including:

- Database of tools to navigate government insurance and support programs
- Safe needle disposal assistance
- NeedyMeds educational webinars

My first TMA Annual Patient Conference

By Susan Honigstock

As I mailed my check to TMA back in the winter, I was very excited to anticipate summer's end and a visit to Minnesota for TMA's 2019 Annual Patient Conference.

Being a pretty organized person, I tried to anticipate items I would need for a trip by air for a gathering of folks I knew I would want to connect with. So, in addition to all the accessibility aids I must take with me now, I gathered my fun business cards to share with new friends and found a nametag of sorts that would serve as identification.

When I arrived at the hotel in Minneapolis and checked in at the Conference registration desk, though, I received a whole packet of stuff, including a printed program with the schedule of sessions offered, a name badge in a spiffy holder, and a sheet of easy-to-pull off name cards to share with new friends all in a convenient tote bag that made everything easy to carry. So much for my planning ahead; seems TMA had already anticipated so many of my needs.

More than five hundred people attended this Conference. Many of the patients came with care partners too. Our days were filled with choices: there were more than 90 educational and support sessions offered during this four-day event, making it hard to decide which ones to attend. For those who came with a care partner, they could attend one session while the care partner sat in on another during the same time slot. There were early bird sessions, and a number of the more popular topics were repeated more than once.

Breakfast and lunch provided the opportunity to get together with others who have the same disease or folks who live in the same geographic area. Panel discussions offered a presentation on traveling with a wheelchair, updates on clinical trials from pharmaceutical companies, adaptive clothing innovations, and nearly two hours when a panel of myositis experts from the TMA Medical Advisory Board answered pressing questions from the audience.

The Conference theme was "Who You Are Matters," and breakout sessions included a whole range of topics aimed at individual needs: aquatic exercise, nutrition, how to stay resilient as a care partner, insurance denials, and sessions on all the different forms of myositis. There were also focused support sessions geared to who you are: woman only, men only, women of color, care partners, and 20-to-40-year-olds dealing with this disease. Each hour there were at least seven classes to choose from.

I met people from many parts of the country. Many were newly diagnosed, and many, like me, were attending the TMA Conference for the first time.

During one session a fellow member shared the "Spoon Theory" to help explain about living with a chronic illness and how to convey this idea to others. A spoon is a measure of your energy, this person explained. You only have so many spoons in a day, so you have to be careful how fast you give them away.

I learned so many things at this conference. I learned that I was already a mindful walker who watches where I place my foot and negotiates safety with my surroundings. I learned about dealing with stress and how it affects our bodies. And fellow members were delighted to share information regarding the various attributes of different kinds of walkers, scooters, and wheelchairs.

I came home with many notes and many ideas for making this myositis journey a bit smoother. The Conference was a very positive experience for me. It made me feel I was not alone in my journey and there are resources and people I can turn to for help all over the country.

I look forward to attending the Conference next year and would recommend that all myositis patients at least give it a try. Your myositis world will expand and the resources available at the Conference will surpass any information you can find out on your own.

Susan Honigstock is a transplanted New Yorker living in Oregon. She retired from teaching young children to teach adults the wonderful game of Mah Jongg. Three sons, two daughters-in-law, and four grandchildren now make up her family, which is scattered across the country. Susan was diagnosed with sIBM about seven years ago.

TMA in Minneapolis

On September 5-8, over 500 members of the myositis community came together in Minneapolis, Minnesota for four days of inspiration and fellowship at TMA's 2019 Annual Patient Conference.

During the four-day event, attendees participated in talks given by the distinguished international experts from TMA's Medical Advisory Board as well as experts in other fields. This offered the opportunity to learn the latest about myositis diseases, treatments and therapies, and tips for living well despite the challenges. Perhaps the best part of the Conference, though, was the chance for patients and care partners to meet and share experiences with others who also know what it's like to live with myositis.

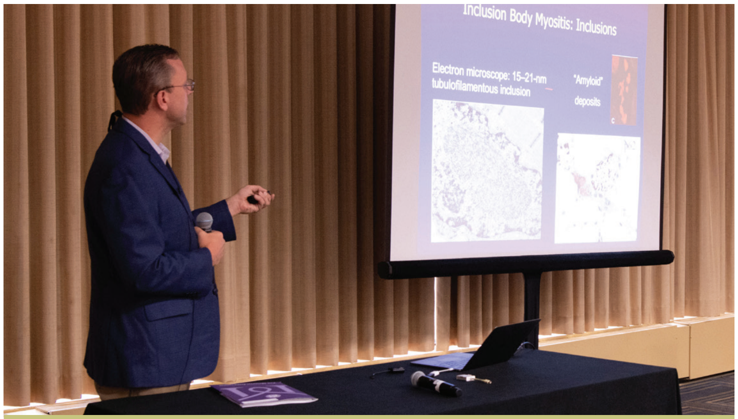
Here are some highlights.

TMA board member Chris Dotur is Unstoppable

TMA's executive director Mary McGowan and Mallinckrodt representative Cathy Jackson

TMA member consults with MAB members Dr. Steven Ytterberg and Dr. Floranne Ernste

TMA's Medical Advisory Board responds to members' questions about myositis diseases



MAB member Dr. Thomas Lloyd talks about IBM

TMA's Patient Advisory Committee for the Myositis Awareness Month Women of Color campaign featured at the Conference

Attendees "Show their Stripes" at Thursday night reception

TMA Annual Conference team

TMA member shows her strength

If you weren't able to attend this year's Annual Patient Conference—or even if you were and would like to hear some of the talks again—you can find presentation material and videos of many sessions on the TMA website: **www.myositis.org**

TMA Board of Directors (missing, Jeff Autrey)

Make your life work for you

By Megan McGowan

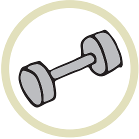
At this year's TMA Annual Patient Conference in Minneapolis, I facilitated a session entitled, "Making your life work for you: Sharing your favorite strategies and devices." The purpose of this group was to share "life hacks," adaptive strategies, and adaptive equipment that can be used to compensate for symptoms related to myositis. Here is a list of recommendations from the discussion that raised the most enthusiasm from attendees. Remember, everyone is different and not all suggestions may work for all individuals. TMA and I do not endorse any specific brand, and most items can be found online or in local stores.

Bathroom aides: These included items such as Pee Pocket, Wee Pee, and Go Girl for women who want to avoid sitting when using public restrooms due to leg weakness. Someone also mentioned the product Free2go, which doubles as a rollator and a toilet seat riser. This device provides assistance with balance, then when nature calls, can be rolled over any public toilet to serve as a raised toilet seat.

Meal preparation and dining: Cutting food is an activity that can be difficult for many due to a weak grip. Buying pre-cut food was one solution suggested. Other workarounds included using a rocker knife or an electric carving knife. Water bottles seem to unanimously cause grief for people. We talked about using a filtered water system and an easy-to-open reusable water bottle rather than a plastic water bottle. For difficulty opening tight lids, you can use a device to improve the friction, such as Dycem non-slip openers, rubberized shelf liner, or rubber bands.

Household chores: Cleaning and laundry were two areas of discussion. Some suggestions included purchasing a front loader washer and dryer and setting them up side-by-side on risers, being mindful that the doors should swing away from each other so transferring the wet laundry requires less effort. Of course, when it comes to chores, delegating tasks is always a viable option to conserve energy as well.

Grocery shopping: This can suck the energy out of anyone, but when you have fatigue from myositis, it can be a daunting task. The topic of the new and growing business of grocery delivery services was discussed. Although most were in favor, others see the experience of grocery shopping as an important way to maintain independence and socialization. Each person has to consider which of their daily tasks provide the most meaning and quality and decide where they want to spend their limited energy.



Exercise: One tool that most people thought was helpful was a finger support brace. This brace has a feature to assist with gripping weights when attempting to exercise as it straps the fingers around the weight to compensate for weak grip.

Planning: One of the major themes that emerged during this session was the importance and emphasis on planning. Although the amount of extra planning that goes into the most mundane of daily activities can seem frustrating at first, the right type of planning can promote independence and improve quality of life. Attendees recommended that you never completely rule out an activity, invitation to an event, or travel experience!

If you want more information on how to adapt your daily life to work for you, reach out to local and online support groups or reach out to a local occupational therapist.

Megan McGowan OTR/L is an occupational therapist working with the rehab team at the Johns Hopkins Myositis Center.

What's the evidence?

Dr. Andrew Mammen

Medications known as statins—such as Lipitor, Crestor, Zocor, and others—are commonly prescribed for older adults to reduce the risk of developing a life-threatening heart attack or stroke. In recent years, research has shown that these medications, used to lower cholesterol, can cause one form of myositis. TMA has heard from a number of members recently who wonder if their myositis was caused by taking statins. We spoke with former TMA medical advisory Dr. Andrew Mammen to get the latest on what we know about statins and myositis.

"The story about statins as we currently understand it is that they can occasionally cause muscular side effects in patients who are prescribed them," says Dr. Mammen.

Although thought to be an uncommon occurrence, these symptoms can include minor muscle cramping, pain, and weakness. An even smaller portion of patients, however—probably about 1:10,000-20,000—develop more severe muscle weakness and/or muscle enzyme elevation similar to that which happens with autoimmune muscle disease. Unlike autoimmune myositis, however, these symptoms go away when the person stops taking the medication.

"But then there are about 1:50,000 people who get put on a statin that do develop autoimmune muscle disease," Dr. Mammen says. "These are people who have autoantibodies against hydroxymethylglutaryl–coenzyme A reductase (HMGCR), which is about 5-10% of all myositis patients."

For these people, the statin triggers a type of myositis called necrotizing myopathy (NM), and stopping the statin does not usually make the myositis go away. For those with other forms of myositis, however, including dermatomyositis (DM), inclusion body myositis (IBM), antisynthetase syndrome (ASyS), and another form of NM called anti-SRP NM, there is no evidence so far that taking statin medications caused their disease.

"It doesn't mean statins absolutely couldn't cause them, but as far as we know right now, they don't," Dr. Mammen says.

Dr. Mammen's studies with IBM and DM patients over the age of 50 show about the same prevalence of statin exposure as the general population. For those with anti-SRP NM, there was almost no statin exposure. "But of our patients over the age of 60 who have anti-HMGCR, about 90% were on a statin when they developed the disease.

People who are HMGCR positive are the only myositis patients who should not take statins. If these patients need to take a cholesterol lowering medication, Dr. Mammen recommends a new class of drugs called PCSK9 inhibitors.

"We think in general that the only myositis patients who shouldn't get statins are people who have the HMGCR antibody. Everybody else should probably be

safe on statins. But because they have an underlying muscle problem, we watch the muscle enzymes, like creatine kinase (CK), a bit more carefully during the time when they first go on the statin just to be sure that the statins aren't making it worse.

"The number of people with necrotizing myopathy is increasing, and one possible reason for that is statins, but it's still very rare. Even at a huge hospital like Johns Hopkins, doctors might see a couple people develop NM per year out of the hundreds of thousands of patients they put on statins every year. And since one heart attack is thought to be prevented for every 100 people on a statin, the small risk of myositis is not a reason to avoid statins."

In addition, not all patients who develop HMGCR-associated myopathy have taken statins. In fact, this form of NM has been found in children who have never been exposed to statins.

Necrotizing myopathy may also appear to be increasing because pathologists may be changing the way they interpret muscle biopsies. Twenty years ago, NM was not recognized as a diagnosis. Back then myositis patients who did not have a rash would most likely have been called polymyositis (PM). Even some people with IBM were misdiagnosed as having PM. Now muscle biopsies can identify necrotic (dying) muscle cells, which more clearly points to NM.

"DM patients do not need to worry," Dr. Mammen says. "If you know you have anti-SRP NM, ASyS, or IBM, then there's also no need to check for HMGCR. But if you don't have a known antibody already, it would be reasonable to check to be sure you don't have HMGCR. And if you have PM and no known myositis autoantibody, it's also worth checking for all the myositis antibodies, because it would help to understand your diagnosis better.

"I would emphasize that statins are really good drugs for preventing strokes and heart attacks. It's very rare, but it can happen that they trigger this one form of NM, and those patients should not take statins again. But nobody else should avoid a statin because of their muscle disease. If your cardiologist thinks you ought to take a statin, it's reasonable to do it."

How often should a TMA Support Group meet?

By Marianne Moyer

The answer to this question, of course, is “it depends.” There is at least one TMA Support Group that meets monthly. They are blessed to have a leader who, in addition to caring about the members, is charged with running the group as part of her job as a social worker. Other groups have a set schedule of quarterly meetings, others meet randomly, and still others meet somewhere between these extremes. What is important is figuring out what helps your members feel connected without burning out the group’s leaders.

Our group, which had been meeting quarterly with a formal agenda, felt the need to get together more often but without an agenda. Our solution was a potluck lunch held half-way between the regular meetings. While these lunches aren’t billed as meetings, with just a tiny bit of extra effort, they *could* morph into a group meeting. No need to go to the effort of providing a speaker; just pick a topic for the day and, as people enjoy their sandwiches and iced tea, encourage them to share their thoughts on that topic.

Where to hold this informal gathering? Well, if the group has a member who has an accessible home (ramps to enter and elevated toilets with grab bars) and is willing, you can hold it there. Everyone pitches in, not only with the food, but also with setup and cleanup.

If someone’s home is not an option, pick a friendly restaurant. It might be a bit noisy or it may be difficult to find one that fits everyone’s budget and taste. So move around: try Italian one time, seafood another, burgers or sushi the next. Turnout will tell you whether it is a successful venue. One group even met for a catered lunch at a hospital cafeteria on a Saturday when they were less busy. That could easily be a potluck, with members pitching in.

TMA recommends that each group meet at least three times each year. That’s a perfect starting point. From there, do what works for your group!

Marianne Moyer was diagnosed with PM in 1999 and re-diagnosed with necrotizing myopathy in 2015. She has co-led TMA’s Southwest Florida Support Group for the past 12 years and served on TMA’s Board of Directors (including two years as chair).

You can leave a legacy too!

Are you looking for a significant way to help TMA grow and flourish? Providing a bequest or legacy gift is a promise to provide support to TMA as we work toward our vision of a world without myositis.

Join the prestigious TMA Legacy Society, a special group of supporters who recognize the importance of keeping TMA's programs and services available for future generations. For more than 25 years, TMA has worked to enhance the lives of those living with myositis through the vital support of the Legacy Society and other individuals who have made special commitments to TMA through their wills and estate planning. Everything we have accomplished we have accomplished with the support of you, our donors.

We hope you will consider joining the Legacy Society and help TMA ensure we can continue to provide and expand much needed services to those challenged with myositis and continue to fund research in our search for a cure. Through your estate plan, you can pass on your cherished values to generations to come.

Become a member of the Legacy Society by doing any of the following:

- Name TMA as a beneficiary in your will or trust
- Name TMA as a beneficiary of your retirement plan, IRA or life insurance policy
- Make a gift to TMA through a charitable gift annuity or charitable remainder trust

In gratitude for your generous lasting gift to TMA and in support of our efforts, you will receive special recognition and benefits.

You can make a difference!

Thank you!

For more information about the legacy society, contact Tricha Shivas, Director of Development and Strategic Partnerships at ***tricha@myositis.org*** *or 703-553-2633.*

Thank you to our Legacy Society members

Members of our Legacy Society have expressed their commitment to The Myositis Association by naming TMA as the beneficiary of a planned gift. We are grateful to these individuals for their enduring commitment and support.

Bitsy Anderson
Severna Park, MD

Terry Anderson
Severna Park, MD

Robert Blair*
Forest, ON

Debbie Brown
Villa Rica, GA

Doreen Cahoon
Cleveland Heights, OH

Angela Conwell
Mesa, AZ

Dave Conwell
Mesa, AZ

LaShan Davis-Lanier*
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Catherine Trejo
Mountain View, CA

Marti Wright
Mountain View, CA

Patrick Zenner
Naples, FL

*Deceased

Patients with active DM or PM needed

Bristol-Myers Squibb is currently recruiting adults with active dermatomyositis or polymyositis for a clinical trial. The goal is to evaluate the effectiveness and safety of a study drug, called abatacept, in combination with standard medicines in improving symptoms of active myositis. The effectiveness of this combination therapy will be compared to standard therapy for myositis.

This clinical trial is underway and aims to enroll 150 patients over a three-year period. Multiple study sites are available throughout the US and abroad. Participants will first receive either abatacept, the study drug, or a placebo via a weekly injection under the skin for 24 weeks. Then, all study participants will receive abatacept for 28 weeks. More information on this clinical trial can be found at ***www.MyositisTrial.com****.*

The Myositis Association

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The Myositis Association wishes to thank all those who donated to TMA during the past year. Your generous support makes it possible for TMA to provide services and programs, such as the Annual Patient Conference, a nationwide network of virtual and in-person Support Groups, educational resources, advocacy efforts, myositis research funding, and so much more.

We also wish to thank all our corporate sponsors, including our Corporate Advisory Committee:

- Mallinckrodt Pharmaceuticals
- Corbus Pharmaceuticals
- BriovaRx Infusion Services