THE OUTLOOK

THE MYOSITIS ASSOCIATION

SPRING 2021
Quarterly Newsletter

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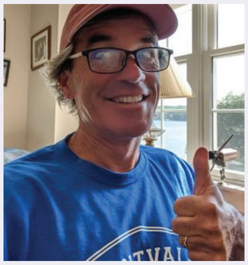
THE OUTLOOK

A quarterly publication of The Myositis Association



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

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What an excellent time it is to be a part of The Myositis Association! My name is Chrissy M. Thornton, and I am the new Executive Director for TMA! I come to The Myositis Association from the Crohn's & Colitis Foundation where I served as Executive Director for Maryland and Southern Delaware for the past 4 years. Prior to that, I worked at the Leukemia & Lymphoma Society (LLS) as their Senior Director of Light The Night and Chapter Corporate Development and the National Alliance on Mental Illness (NAMI) for over 8 years as a Senior National Walk Manager and Director of Development.

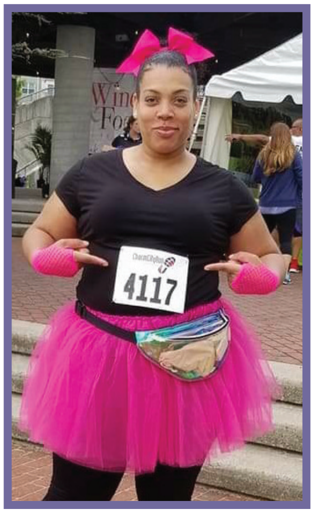
I consider myself a strategic thought leader with experience in developing meaningful relationships, fundraising, developing metrics for measuring progress, diversity and inclusion initiatives, entrepreneurship, and identifying new organizational opportunities. I have a passion for empowerment, supporting patients, and significant experience in program development, execution, and oversight.

Most people would tell you that I am a relationship builder! I have never met a stranger and very much look forward to meeting our patients, care partners, and becoming a part of the overall Myositis Community.

While transition can be hard, I want you to know how excited I am to work in partnership with you to realize our mission. Whether you are a member, care partner, donor, event participant, patient, healthcare professional, or friend; and whether you are currently active or haven't been connected recently, I want you to know that you can rely on me for a few things.

I want to hear your feedback and ideas and am committed to being responsive and timely. Our TMA events and activities will be professionally produced. It will be my priority to partner with you. I will value your participation, your awareness building, your fundraising, your volunteerism, your donations, and your passion.

Many have inquired as to whether I live with myositis. While I do not, for the past ten years, I have lived as a caregiver to my oldest son (now 21) who was diagnosed with aggressive Crohn's Disease at age 11 and is treated at Johns Hopkins Hospital. I share both compassion and empathy for all of those who live with chronic illness.



I have been dedicated to many causes and to my community for many years. Whether it's been through fundraising, hosting creative and engaging community events, participating in 5k races to build cause awareness, or training people in fundraising techniques, I've tried to have a lot of fun while supporting the efforts of the many non-profit organizations I either have worked for, consulted for, or have been personally committed to.

As we look to the future of TMA, I ask for your patience. While the leadership is new, the mission of our organization remains the same. We plan to strengthen the many things we do well, and to embark on some new areas to increase patient engagement and connectivity. You will see our events, albeit virtual this year, executed with an approach to reaching our patient base – multi-generational, across many demographics and disease types. Our goal is to not leave anyone behind.

For those who live with myositis, I know that life can be a roller coaster of active and remitting disease. However, the opportunity for us to collectively make life more manageable for patients who live with uncertainty has never been greater. As you know, the funds we raise and have contributed to research have brought us closer to a cure and enabled us to provide services that support increased quality of life for our patients. I am committed to a culture where every dollar counts. Because it does.

Thank you for all that you have done, and all that we will do together, to continue moving our mission forward. Please do not hesitate to reach out to me at 800-821-7356 or **chrissy@myositis.org**

Sincerely,

Chrissy M. Thornton

TMA adds new staff

Shevelle Montgomery
Manager, development and fundraising events

The Myositis Association is pleased to welcome Shevelle Montgomery as the manager of development and fundraising events. Shevelle's background includes experience in fundraising, event planning, and volunteer management. Her most recent role was as manager of fundraising events and volunteer engagement at the Crohn's and Colitis Foundation in Maryland and Southern Delaware.

Before taking this role, Shevelle worked in annual giving at the University of Maryland School of Medicine.

Shevelle lives in Baltimore City with her husband and newborn baby girl. Shevelle loves to travel and experience new things. In the next five years, her goal is to visit a total of at least 20 countries.

Shevelle is excited to be a part of The Myositis Association and looks forward to connecting with the community. You can reach her at **shevelle@myositis.org**.

Cathy Guenterberg
Coordinator, development and operations

Cathy Guenterberg has joined TMA as the coordinator of development and operations. Cathy has nearly 25 years experience as a social services program coordinator in programs serving the elderly, children, and families in need in a variety of settings, including long-term care, rehabilitation facilities, hospitals and non-profits.

Cathy lives near Baltimore, and has two young adult children who are both students at the University of Maryland. She loves her job teaching swimming to babies and children at a local pool.

Cathy is thrilled to be the most recent addition to The Myositis Association - and cannot wait to begin making connections within the community! You can reach her at **cathy@myositis.org**.

Join us

One important way you can improve the lives of myositis patients everywhere is to encourage them to join TMA. Joining gives them access to local and affinity support groups, virtual and in-person conferences, important treatment and research news, and the continuing support of our staff and medical advisory board.

Although membership is free, growth enables TMA to help researchers enroll patients in new drug trials, improve the quality of member benefits, and serve as the patient representative at national and international conferences that determine the direction of future research.

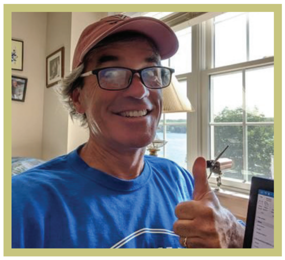
A call to action

Your advocacy improves the lives of myositis patients everywhere

*Myositis Awareness Month is coming up in May, and we've planned plenty of activities, including the Myositis Summit, May 22. Our theme for the summit is "A Call to Action," and we'll have educational programs as well as leadership, advocacy and fundraising training. We've collected many ideas for you on our website, **www.myositis.org**, under "Get Involved."*

This special section of the Outlook has real-life examples of what individual TMA members can do to help people with myositis everywhere.

Tweets record progress, inspire others



At first, it was a little bit of muscle tightness, then a lot of pain after strenuous sports. Finally, Michael Kerin couldn't finish his regular three-mile walk. That's what brought him to his doctor and ultimately to the Mayo Clinic and NIH for a diagnosis of necrotizing myopathy.

Michael, an IT professional, found The Myositis Association and spent enough time researching online to realize there was hope for someone with his condition. "I wondered what I could do to help me stay hopeful, stay focused, and maybe help someone else," he said.

In November, he became "@MyositisMikeMan" on Twitter and tweeted regularly about his progress. This was a good choice, he said, and it filled several purposes. "For one thing, the regular tweets documented my symptoms as well as my progress." This gave him a reliable record of setbacks and improvements as he embarked on his modified exercise program and followed his medication plan.

Many people in Mike's life were worried about his dramatic symptoms and unfamiliar disease. "This gave them a way to see how I was," he said. "All they had to do was follow me." Over time, he realized that the tweets were also keeping his spirits up. "I realized that my small victories might also help someone else newly diagnosed," he said. "If I can provide hope and guidance for even one person, it will be worth it."

Thinking about sharing your myositis experience in short bursts? Some tips to get you started:

- **Begin by briefly telling your story** and letting people know you'll be updating regularly.
- **Use Twitter to learn**. Follow reliable sources such as respected medical centers, researchers and, of course, TMA. Health professionals often use twitter accounts to promote their research and reach their patients, and you may find professionals following you as well.
- **Be specific**. This will help you measure your progress. Mike documents symptoms, uploads copies of test results, and records recent treatments and resulting changes in his status.
- **Use video**. When it's important to show something, or just easier to talk than to write, Mike makes sure there's a visual component to his ongoing story.
- **Have a vision**. Mike reminds himself of where he hopes to be with frequent tweets about future goals. He does this in both written and in visual form, by posting a photo of a lake he plans to swim across in 2021.
- **Advocate**. Speak up for worthwhile projects and share those you support. For instance, Mike made an appeal for plasma donations for IVIG and a donation to TMA based on the weight he hopes to gain back.
- **Have some fun**. Mike films lighthearted moments such as his nightly trips to the hidden stash of ice cream in his garage.
- **Help the next one**. Mike shares the strategies he's devised. With videos on everyday problems such as getting up from a chair or working all day with greater comfort.

A tool for local advocacy and fundraising

It's not just national politicians and celebrities who use Twitter to spread their news. There's a way to use this short-form media to publicize local groups and events. In fact, many people now get most of their local news via Twitter. You may find this platform helpful for promoting your support group meetings, increasing local understanding of myositis, and raising funds.

How to start:

- Visit **https://twitter.com/search-advanced**.
- Enter the name of your town, city or state, and your local news sources in the filter.
- Find the people tweeting from your area and follow them.
- Over time, also follow their followers, especially those in the media and those who have similar interests.

Learn the lingo:

You'll save some time and space by learning the language that Twitter members use. These terms keep your tweets within word limits.

- RT—Retweet: you're reposting someone's exact tweet
- MT—Modified tweet: you're paraphrasing a tweet written by someone else
- DM—Direct message: you're using a direct, private message thread
- DYK—Did you know: where you present a fact (make sure it's correct)
- ICYMI—In case you missed it: you're referring to something you've publicized before, or is currently in the news

Learn the etiquette:

You'll become a good Twitter neighbor if you retweet the messages of followers who add to the conversation, who have their own message, or who cooperate with your message by retweeting your tweets. Always give credit to sources for articles you post, or link to the article if it's available. Be sure to thank people when they begin to follow you.

Follow journalists. Local journalists––print, broadcast and web-based––love Twitter because it's often the fastest way to learn what's happening on their beat. Once you follow them, chances are they'll follow you. And once you begin tweeting about your disease, you'll be seen as an expert, the local go-to person when someone wants to learn about myositis.

Look for requests. Local, national and international journalists on deadline put out requests for people to interview using the hashtag #journorequests. But don't wait around for a journalist to ask about myositis. Answer requests that fall into your other interests or your profession. For instance, one Arizona journalist on deadline was looking for someone who had an example of a random act of kindness, a subject where it might be appropriate to educate people about myositis. You can tell your story in a number of different ways.

Pay attention to hashtags. They can be used to identify your tweets and keep you organized. You can search by a particular hashtag to see what information you've already shared on that subject, or find other people tweeting about the same topic. For instance, at #myositis, you'll find patients, health professionals and volunteers, all with an interest in myositis. Many in the myositis community also include myositis.org so that those interested can find more information on our website.

When it's time to promote your fundraising or publicity event, create a memorable hashtag for your campaign so your followers will find it easy to spread the word. Encourage all those involved to use the same hashtag, so anyone interested can find you.

Fundraisers sometimes use trending local hashtags as well as their own. For instance @msmuscle used #millvillesnowfall to tie her fundraising campaign to the total snowfall in her Ohio town, promising to donate $10 for every inch of snowfall, and asking others to join her.

If you're raising funds, register your event at TMA's website under "Fundraise" in the "Get involved" section and provide a link so people can donate there. If your campaign is designed for educating your friends and neighbors rather than fundraising, direct them to **TMA@myositis.org**.

Ready to start tweeting? Make sure to follow us @themyositisassc.

No matter your situation, you can be an advocate

Maybe you can't join a walk or organize a golf tournament, but there's always something you can do to support other myositis patients. In the nearly 25 years of TMA's existence, members have come up with dozens of creative ways to move our cause forward.

Be a friend. Reach out to the newly-diagnosed when they post on social media or join your support group meeting. Remember how you felt at the beginning, and share your hard-earned experience. Nothing can replace the words of comfort and guidance from someone a few steps ahead on a challenging journey.

TMA can help. We've compiled a guide for Myositis Awareness Month, with all kinds of advice for telling your story in whatever way you choose to do it. Our guide also includes some ways to enlist local physicians. Find information on raising awareness, advocacy and fundraising at "Get Involved" on our website, **www.myositis.org**.

Attend TMA's summit. TMA has planned a whole day of sessions on May 22. The theme this year, "A Call to Action," will have information on telling your story, legislative advocacy, fundraising and volunteerism, as well as research and treatment. Don't worry, we'll have some fun, too! Look for more details about the summit as May approaches. Make sure to email **TMA@myositis.org** to see if you qualify for a free summit pass.

Look for colleagues. As a person with myositis, you may have a few things in common with all those with autoimmune diseases, rare diseases, lung diseases, muscle weakness or difficulty swallowing. Your connection to people within these larger groups sharing your common issues will help you identify joint unmet needs in your community, help people learn about myositis, and work for changes that will benefit all of you. See how support group leader Marianne Moyer did this, page 8.

Think locally. Although TMA and its members have had some success in drawing national attention to myositis, your best bet for coverage might be right in your own hometown. Editors and news directors like sources they can reach immediately as deadlines loom. In fact, many editors of even big-city newspapers and regional broadcast news shows pride themselves on their good local stories. Most media outlets today have a way to submit a story idea online. And it's still possible in many towns and small cities to pick up the phone or drop into the newspaper office. (See "Advice from and editor," page 9).

Try the alternatives. Find the neighborhood or alternative newspapers and television shows that cover stories like yours. Find news shows that target a certain audience. For instance, a farmer with inclusion-body myositis was featured in a "Down on the Farm" episode on his local public television station, an episode that was picked up and broadcast to a national audience. Hospitals today often have their own publications designed to draw support from local officials and patrons. Find out who produces publications for your local hospital and pitch your story. If you have an active support group, make sure the hospital includes it in its online or print listing of patient resources.

Don't overlook the obvious. Radio and television stations need public service announcements to keep their licenses. They'll be able to turn your news release about a fundraiser, support group meeting, or special event into a short announcement. Ask them to interview you or other support group members on the air for a longer story or provide live coverage for your event.

Cultivate a relationship. Often your best chance at publicity is through a reporter rather than the editor or the online submission form. Take a look at who does human interest and health stories. You may have noticed that in some small cities it's the weatherman on television, or a specially designated feature writer on the newspaper staff. Approach that reporter as well as the editor.

Prepare for coverage. If you're expecting a reporter at your event, try to present an overall statement or photo opportunity early in the event, as that's when the journalist or cameraman is most likely to show up. Keep it brief and provide a written copy. Even if you are speaking spontaneously, have a fact sheet available so the reporter doesn't miss anything.

Don't bore everyone. Remember that both print and broadcast media increasingly rely on visual appeal. If your idea of a photo opportunity is two people with a check, you may be disappointed at the photographer's lack of interest. Work hard to make sure there is something appealing, even if it's a member of your group with an especially gripping personal story that has little to do with the main event.

Do all the work for them. Myositis Maven, TMA board member and support group leader Marianne Moyer submitted an account of her experience to the Sarasota Herald Tribune, with good results. See Marianne's advice, page 8.

Promote your support group

One of the most meaningful ways you can improve life for myositis patients and their families is to let them know there is support, encouragement and education in their own community. Over her many years with TMA, Marianne Moyer has been an effective support group leader, board member, fundraiser and mentor to countless other support group members and leaders. When she recently signed up as a "Myositis Maven," she tackled another project. Here's her account.

Do you know how powerful you are?

By Marianne Moyer

If you asked many myositis patients that, they'd probably say something like "Not!" After all, having a myositis disease is an almost instant education in loss of power. Walking, picking up our children or groceries, swallowing, and a myriad of other tasks that take power or strength, seem to have eroded from our lives. Yet many of the myositis patients and their caregivers that I meet have moved past missing what they can't do into rejoicing in what they can do.

Here's something I recently discovered that demonstrated one power I still have and was able to employ. That's the power of a message! I'm a member of the newly formed group of Myositis Mavens whose goal is to take on at least two projects to raise awareness or funds, not just for TMA, but for all our myositis community. I've been involved in a number of fundraisers, so I thought I'd make my first Mavens foray into awareness raising.

And all it took was looking for a space where my message might be well-received. I'm still old-fashioned enough to read a daily newspaper that features a weekly health section. On the front of a recent issue, I found the editor's email address, so I gathered up my courage and sent a message asking if she'd consider printing an article from me. I explained a bit about me, myositis and TMA. Two weeks went by with no response. Time for a bit more courage. The editor of the whole paper also lists his email, so I politely asked if I'd sent my request to the wrong person and could he suggest to whom I should resend.

The next day I received an email saying to go ahead and write and submit the article and she'd see about getting it printed. I asked her for a maximum word count and deadline (showing I was serious).

Note: I have never before written an article to be published in a big city newspaper!

Time to get courageous again. How to write an article that people will actually read and not see a myositis headline and skip over it? So, I wrote about an area of myositis life that is near and dear to me. And that area is the outstanding value of support groups. And for those who know me, you're saying, yeah, it's that KIT (Keep in Touch) lady in Florida. I told about our 13-year-old KIT whose members continue to call each other family. How in 2017 we started using Zoom so our meetings were available to homebound members. I referenced that, at a recent multi-group fundraising event, our KIT was able to link with another rare disease group, Charcot-Marie-Tooth, so our support groups could share best practices.

And more importantly, I tried to stress the powerful message we'd all hear when a new KIT member who may have had the disease for years, comes to a meeting and says, "I've never met another person with my disease! Thank you for inviting me!"

Needless to say, my word count was going way over what I'd been told to use. When I asked if there was any wiggle room, the editor encouraged me and said she'd find space for whatever I sent. Which she did! Word for Word! Imagine how I felt that morning it printed. P-o-w-e-r-f-u-l.

Right after it was published, I got a card in the mail, enclosing the clipping, from the Executive Director of another local health-related nonprofit and a note saying how she learned so much about myositis and our support groups.

Mission Accomplished!

For a copy of the article Marianne sent to the Sarasota Herald-Tribune, email TMA at **TMA@myositis.org**.

Advice from an editor

CURRENT CARMEL

Tuesday, February 2, 2021

FINDING STRENGTH

Former pro hockey player turns to faith, family while battling degenerative muscle disease / P12

Councilors prioritize Home Place projects in $60M bonds / P2

CCPR could add 63-acre park in northeast Carmel / P3

Hydrotherapy helps strength IU Health NICU patients / P17

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Patrick Murray was featured in the cover story of an issue of his hometown newspaper.

Ann Marie Shambaugh edits "Current in Carmel," a local news magazine, one of several sister publications that serve the Indianapolis suburbs. She wrote an article about Patrick Murray, a "Myositis Maven" and former professional hockey player who now has IBM. Shambaugh, who writes and photographs many of the stories as well as editing the publication, gives TMA members some advice about attracting local coverage.

You have a story. "Everyone has a story," Shambaugh said, "especially if you've struggled and had some victories, no matter how small." She suggests you look at your story from all kinds of angles. For instance, for Patrick's story, she was struck by how much his life has changed, and by his steadfast faith.

Introduce yourself. But be brief. "We have piles and piles of emails," Shambaugh said. "If you send several pages of your life story to convince us to write about you, chances are I won't have time to read them all before scheduling a story." The details can come as the story develops.

Give it time. "There may be breaking news that has to be covered while your story waits," Shambaugh said. "Don't be worried if you don't hear back immediately. If your idea is turned down, consider a letter to the editor or a guest column. (See "Promote your support group, page 7)

Don't ask to control the narrative. "I'm surprised how many people think they should approve the story before it's printed," Shambaugh said. Most media outlets consider this an ethics violation. But do ask them to mention TMA and your support group.

Be creative. If you're asking for coverage for an event, try to provide something visual for the photographer. "The more unique and visual your event is, the more likely it is to be covered," Shambaugh said.

*Shambaugh's article on Patrick Murray appears in the Feb. 2 edition of "**Current in Carmel.**"*

Advance planning: consolidate, simplify, budget

Martin Shenkman

We put it off because we don't like to think of our own aging, disability and death, but financial and legal planning is important in the present. "It will make your life safer, easier and more enjoyable," said Martin Shenkman.

Shenkman, an attorney specializing in estate and tax planning in New Jersey and New York, spoke at TMA's 2020 Virtual Annual Patient Conference, giving a unique overview of the steps myositis patients can take to care for themselves and their families as their disease progresses. Shenkman has plenty of personal experience as well as professional knowledge on this topic. His wife was diagnosed with multiple sclerosis years ago and left her job as an anesthesiologist about ten years earlier than the couple had anticipated.

Shenkman said his firsthand experience informs his practice, and also has inspired him to donate a great deal of time to educating other legal and financial professionals on matters that go far beyond wills, estates and taxes.

"You can hire an attorney, you can hire an accountant, and you can hire a financial advisor," Shenkman said, "but they have their own areas of specialization and may not tell you about some of the important organizational jobs you can accomplish on your own." While acknowledging the importance of professional help, and detailing some of important legal and financial issues in his presentation, Shenkman also detailed some practical steps that everyone with myositis can take right now.

Keep an emergency envelope

Compile the documents you might need for a sudden hospital admission in one envelope, and let your family know where it is. Keep in mind that those who treat you may not be familiar with your case or even with myositis. "Write a summary of your current health status," Shenkman said. "Explain the nature of your myositis, with all of your symptoms and your prognosis." Shenkman recommends that the envelope also include a detailed list of all your medications and vitamins.

Also in the envelope: a copy of your HIPAA release (a document allowing someone else to be informed of your medical status); a living will specifying what degree of medical intervention you desire; and the name of your health care proxy (the person who will make decisions regarding your health if you are incapacitated).

Dump your wallet

Shenkman's not advocating sending your wallet and its contents to the landfill. What he means by a "wallet dump" is a secure record of any small document such as a social security card, insurance card, credit card and driver's license. Save the copies into an encrypted file and back it up on your laptop. "Just do it," Shenkman said. "Save them as PDFs and label intelligently."

Gather your documents

You may have created a document for every possible legal and financial development, but that doesn't mean they'll be helpful. "If you have legal documents in a drawer and nobody knows about them, it's kind of pointless," he said. Take your important papers and assemble them in one spot, making sure any paper documents have electronic copies, saved together and backed up in the cloud.

Have a realistic financial plan

A professional can help with this, and may be more affordable than you think, Shenkman said. "But again, there's a lot you can do on your own." Take a look at your savings and your spending and project out to the age of 90 or 95. "This should be a real budget, not a fantasy budget. It should be built on what might happen, including medical costs." He advises people to figure in whatever might be in their future, including home modifications and downsizing. "Model out all kinds of scenarios."

Shenkman noted that many wealthy people think of "budget" as a four-letter word and may be living an extravagant lifestyle. But a budget is absolutely critical no matter what your wealth level. Even if you do not live extravagantly, you'd be surprised at what you can accomplish for your future security. Compounding over the decades is surprisingly effective: "Ten or 20 years of cutting back modestly can have a huge impact. Build savings even if it requires sacrifice," he said.

Know the facts about long-term care

Shenkman challenged a couple of the myths that people tell themselves about long-term care:

- "I'm never going to need long-term care." Fact: Many people do.
- "Medicare will pay." Fact: Medicare does not include long-term care. Those who see themselves needing Medicaid for future long-term care should make themselves aware of all the issues involved.

He advises clients to acquaint themselves with the difference between skilled nursing care and custodial care. "It's like the difference between a heart attack and Alzheimer's Disease," he said.

For those who plan to "age in place," Shenkman believes people should take steps sooner rather than later to improve their living situation. You may be in a better position to accomplish a major change now than years from now. For instance, the Shenkmans moved to a small apartment long before their home became unmanageable for someone with MS.

Automate your bills

You may be fine with paying your monthly bills now, but automating everything possible will help you with peace of mind now, even if you're disabled only temporarily for a hospital visit. "Any bills you can pay automatically, do it," he said. "This also comes in handy if you're traveling." Have bills automatically paid from a credit card or checking account, and deposits automatically paid into your checking account.

Write a letter

Tie together your legal and financial planning with a letter of instruction that explains what you've provided in your will or revocable trust, and why. Stipulate what medical care you want, whether it be no heroic measures or a willingness to try experimental treatments. Those with children should provide guidance on how they should be raised. Include everything that's important to you. "Write down any guidance on personal wishes and matters that don't belong in a formal legal document," Shenkman said.

There are other, more complicated tasks that are best discussed with professionals, or that benefit from a great deal of research. In Shenkman's video, he also discusses practical ways to go about the more complicated aspects of advanced planning, with an eye towards limiting expense. His presentation for TMA includes plenty of advice on legal and health care documents not discussed here, and why you may or may not need them, but the above ideas are those you can put into practice right now. He cautions TMA members to break these tasks into pieces, for example:

- This month - make a financial plan and budget.
- Next month - make sure everything is on your laptop, secured and backed up to the cloud.
- Third month - designate someone to have power of attorney and execute it.
- Fourth month - draw up health care documents.
- Fifth month - complete a will and revocable trust.

One of the worst approaches is to try to do it all at once. "Don't think to yourself 'Marty says I should do this, so I'll spend the whole weekend on this, and get it over with,'" he said. "That's the way to make sure it will never happen.

Find Martin Shenkman's conference presentation on TMA's YouTube channel.

Martin Shenkman, CPA, MBA, PFS, AEP (distinguished), JD, is an attorney in private practice in Fort Lee, New Jersey, and New York City. He's the author of 42 books and more than 1,000 articles, many of them on planning for those with chronic disease and disability. He has served on many editorial boards of legal and business publications and has won dozens of awards. Find him at ***shenkmanlaw.com***.

Save the dates:
"A Call to Action," TMA's Leadership Summit, May 22

"The Power of Us," TMA's Virtual International Patient Conference, Sept. 10 to 12

Save the month:
May is Myositis Awareness Month. Watch for details, coming soon!

Healthy meals can be easy and delicious

Small changes, tangible results

Lindsay Gaucher is a busy dietician with a full-time practice and two preschool children, so she knows a thing or two about being too tired or too rushed to want to spend a lot of time in the kitchen.

Lindsay has a couple of clients with myositis, and more with other inflammatory issues, so she's seen firsthand the fatigue and weakness that make it difficult to complete daily tasks and still have enough energy to put a healthy meal on the table night after night. Based on her experience and that of her clients, she has a realistic perspective when she promotes the benefits of a healthy diet every day in her work. Despite her low-key approach, it's a worthwhile, sometimes life-changing practice, she said. "I've had clients, even those with serious diseases, who find simple changes in how they eat have tangible results, and they end up feeling more energetic and sleeping better."

Lindsay answered questions about nutrition and myositis at the New England Myositis Support Group last January, and later shared some of her tips for healthy eating with the Outlook.

She said it can be hard in today's world to eat healthy, but the main obstacles are not willpower and lack of determination, but the overwhelming availability of processed food and wide-spread lack of knowledge.

Replacing processed food with real food is the single most important thing anyone seeking reduced inflammation and better health can do, she said. "At the same time, I'm a believer that 'all foods fit,'" she said. "If you love potato chips, you don't have to swear you'll never have one again." She believes that the "all or nothing" approach doesn't work for food.

In fact, this approach does harm. Sometimes people come to her in a panic: "They've been told by their doctors they have to lose 50 pounds, and they're overwhelmed," she said. "This is not helpful." Often, clients expect her to be the food police, she said, but her strategy is to arm them with the information they need to plan a way of eating that fits their taste, budget and schedule, using realistic goals they set for themselves with her help.

Also harmful to real success: "Fad diets on social media," she said. "Once people hear they need to lose 50 pounds, they turn to restrictive diets that promise them weight loss in a hurry." They decide to eliminate all carbs, or all fat, when their goal should be healthy carbs and healthy fats."

Lindsay addressed some of the other challenges faced every day by myositis patients.

On corticosteroids: It's no secret that drugs like prednisone can have spectacular effects on appetite, mood and weight gain. "Always take corticosteroids on a full stomach," she said,"And limit salt, which adds to fluid retention and weight gain." Most people don't know that the salt we add to food is only a small part of our daily consumption." The real culprit? Processed food. Limiting processed food, and measuring table salt in your hands before adding it helps keep daily intake less than the 2.000 mg she recommends. She's found that more frequent, smaller meals can help, too.

On sugar: There's a number of ways to reduce sugar, Lindsay said. She said those wanting to limit sugar should not focus on limiting fruit, but focus on added sugars in sodas and desserts and the hidden sugars in breads, dressings and sauces.

On probiotics: Lindsay said that probiotics can cause digestion-related issues in some people, and also might mask other issues. She's found that certain probiotics seem to help people with GI symptoms: Bio K+, Culturelle and Goodbelly were three she mentioned.

On quick, healthy meals: Lindsay keeps plenty of frozen vegetables on hand for when she's pressed for time. "I also like meals that don't mess up the whole kitchen," she said. She likes "sheet pan meals" for easy cleanup, like frozen shrimp and vegetables roasted in the oven. This is a cooking method that works for chicken and pork as well as fish. Also a trick most mothers have learned: "I like having breakfast for dinner," she said. "It's easy to add some vegetables to the eggs, whether they're scrambled or in an omelette, and children love it."

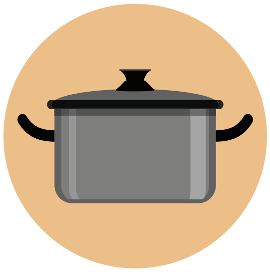
Other tips, tricks, hacks and hints for the hungry

Chef Greg Minkovitz demonstrated an easy, healthy meal at TMA's Annual Patient Conference, and dozens of TMA members cooked along with him. Chef Greg has developed some recipes with his father, who has IBM. He demonstrated a healthy, easy meal with chicken and vegetables. For his dad who has trouble swallowing, he made sure to cut the chicken into small pieces, a strategy that also speeds up the cooking time. He also includes an easy sauce to moisten the food. He likes to serve his father meals that can be eaten with a spoon so the sauce can be swallowed along with the meat and vegetables.

Chef Greg has dermatomyositis, and he finds cleaning up as he goes along makes everything less tiring. He always places a bag nearby while he cooks, to collect scraps and packaging. **Find Chef Greg's Conference presentation**.

Kate Warfel said she consults with a nutritionist regularly to keep her on track. Kate also makes big batches of homemade applesauce and soup, freezing them in large silicone baking cups. When frozen, they're popped into bags so the baking cups can be reused. Kate has had dermatomyositis for 15 years and, like some others with myositis, she also has Celiac disease. She's found that gluten can hide everywhere, including in some kinds of frozen vegetables, in vinegars, and in salad dressings. She finds standing for a long time is hard, and so is reaching up to get food from the microwave and ingredients from overhead cupboards. She recommends consulting an occupational therapist: "That helped me learn ways to navigate and cook, and use certain tools in the kitchen to help me," she said.

Kimberly Jones and many others use their instant pots to reduce time standing and stirring. Kimberly uses it to cook rice, **Shawna Nielsen** uses hers daily for beans. stews and greens. Shawna also has a tip for easy mashed potatoes: use Yukon gold, which don't require peeling, as the thin skin almost disappears in the mashing.



Catherine Hutto breaks out her slow cooker for fuss-free cooking and uses liners to minimize clean up.

Lori Fuller, along with other TMA members, finds that a meal delivery service eliminates a great deal of shopping and cleanup. She's found "Every Plate" is always fresh and more economical than some other services.

Rebecca Russell buys meat when it's on sale at Whole Foods, because the butcher there will cut it into whatever size pieces she needs, eliminating one step in meal preparation.

New members added to TMA's board of directors, medical advisory board

Besides a new executive director and staff members (see pages 3 and 4) TMA has added new members to its board of directors and medical advisory board.

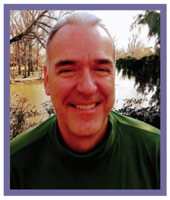
New directors for TMA

Tahseen Mozaffar, MD, is now on both the medical advisory board and the board of directors. Dr. Mozaffar is a long-time friend of TMA. He's a professor and chair of neurology, professor of orthopedic surgery and laboratory medicine, and director of the neuromuscular program and the ALS and neuromuscular center at the University of California at Irvine.

Marianne Moyer, also a long-time friend of TMA and a myositis patient, has led TMA's Southwest Florida support group for 13 years. She previously served as the chair of TMA's board of directors for two years.

Ronné Adkins, PhD, a Tennessee environmental professional, graduated from Dartmouth, received a Master's from Johns Hopkins University's Environmetal Science and Policy Department, and a PhD in Earth Science from the University of Memphis.

Dianne Browne was diagnosed with dermatomyositis in 2000. She's a retired educator with more than 25 years of teaching experience, having taught in every level of primary, secondary and college education. Dianne lives in West Bloomfield, Michigan.

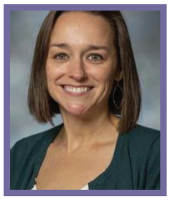


Rodger Oren, PhD, PMP, has devoted his career to Information Technology and Program Management across many sectors, including healthcare. He lives in Nashville, Tennessee.

*Please find photos, special interests and contact information for all board members at **myositis.org**.*

New medical advisors join TMA's medical advisory board

Cheilonda Johnson, MD, MHS, a pulmonary medicine specialist, is an assistant professor of medicine at the Hospital of the University of Pennsylvania in Philadelphia.



Lindsay N. Alfano, PT, DPT, PCS is a physical therapist specializing in progressive neuromuscular disease. She's at Nationwide Children's Hospital in Columbus, Ohio.

Merrilee Needham, MBBS, PhD, FRACP is the head of the Department of Neurology at Fiona Stanley Hospital in Perth, Western Australia.

*Please find names and photos of all TMA board members at **myositis.org**.*

TMA schedules signature events

TMA has exciting events planned for May, the month designated for drawing public attention to the need for more research into better treatments and a cure for myositis, as well as for advancing public understanding of myositis and its related conditions. We invite you to plan events, tell your stories, and reach out to those newly diagnosed. We'll have plenty of our own ideas and fun events to offer you as well.

On May 22, we've scheduled a day for giving you the tools you'll need to become an effective advocate for TMA's work to improve the lives of those living with myositis. Find out more about leadership, advocacy, fund-raising and social media from the experts. We'll also have sessions to fill you in on the latest in research and treatment. We'll make sure to have some fun, too! Register for the summit, "A Call to Action," by emailing TMA.

Our Annual Patient Conference will be virtual this year, following the overwhelming success of our first Virtual Annual Patient Conference in 2020. While we'll miss seeing you in person, we also know that many of you who are unable to travel will be able to join us, Sept. 10 to 12. This year, we've incorporated more ways to interact, and are providing easier access and better tech support. We work hard to make the Conference meaningful to everyone affected by myositis, whether they're people with myositis, care partners, or friends and family.

Registration will begin shortly, and we'll let you know when it's open. Please save the dates!

Looking for a match?

No, TMA is not in the dating business, but we like the idea of affinity groups. The success of the virtual support group meetings during the pandemic reminds us that geography and our diseases are not the only things we have in common. Do you play chess, care for someone with dysphasia, skydive, speak French, paint, or cook gourmet meals? We welcome the chance to put you in touch with other members who have the same interests. A handful of affinity groups already exist, serving veterans, women of color, and women with IBM. Email TMA if you have an interest you'd like to explore with others with myositis. Joining an affinity group will not interfere with participation in your current support group.

TMA supports innovative research projects

The TMA board of directors awarded $200,000 to Mazen Dimachkie MD, professor of Neurology at the University of Kansas. Dr. Dimachkie will work with international IBM investigators on a randomized, doubleblind, controlled Phase III trial of Sirolimus in sporadic IBM. The funding will be used over the course of two years, collaborates with research in France and Australia, and supports U.S. study sites in Kansas and Baltimore.

A fellowship of $100,000 over two years was awarded to Dr. Alexander Oldroyd for a project at the University of Manchester. Dr. Oldroyd's project is at the Center for Epidemiology Versus Arthritis. TMA funds will support remote continuous disease activity monitoring in DM and PM by monitoring gait and daily symptoms.

TMA has awarded more than $7 Million in research and fellowship funds for all forms of myositis. The fellowship program has resulted in young clinicians and researchers developing a lifelong interest in studying and treating myositis.

TMA launches the Pantone Project

With the help of the Malinkrodt Corporation; Iazmin Bauer Ventura, MD; and Oluwakemi Onajin, MD; TMA is working for for quicker diagnosis and treatment of dermatomyositis in people of color. Dermatologists and other doctors are trained to recognize the skin signs of DM and other forms of myositis using mostly slides of how they appear on fair skin. The signs in people of color can look quite different. "Pantone" means "all colors," and TMA is committed to offering resources that help doctors become familiar with disease signs in skin of all colors. The Pantone project is a start: Please find the flier on the TMA website and share with your dermatologist and other health professionals who may find it helpful.

TMA is updating the Outlook and all publications. Please contact us with suggestions: TMA@myositis.org.

Please let TMA know if you prefer to receive all publications electronically: TMA@myositis.org.

THE MYOSITIS ASSOCIATION

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THE MYOSITIS ASSOCIATION

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STARTING FRIDAY JANUARY 15th

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- DEALING WITH THE VA MAZE
- THE PRESIDIO STUDY
- DISEASE SPECIFIC UPDATES
- PT/OT PRACTICAL EXERCISE
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- INTIMACY & MYOSITIS
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- OXYGEN THERAPY FOR LUNG DISEASE
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