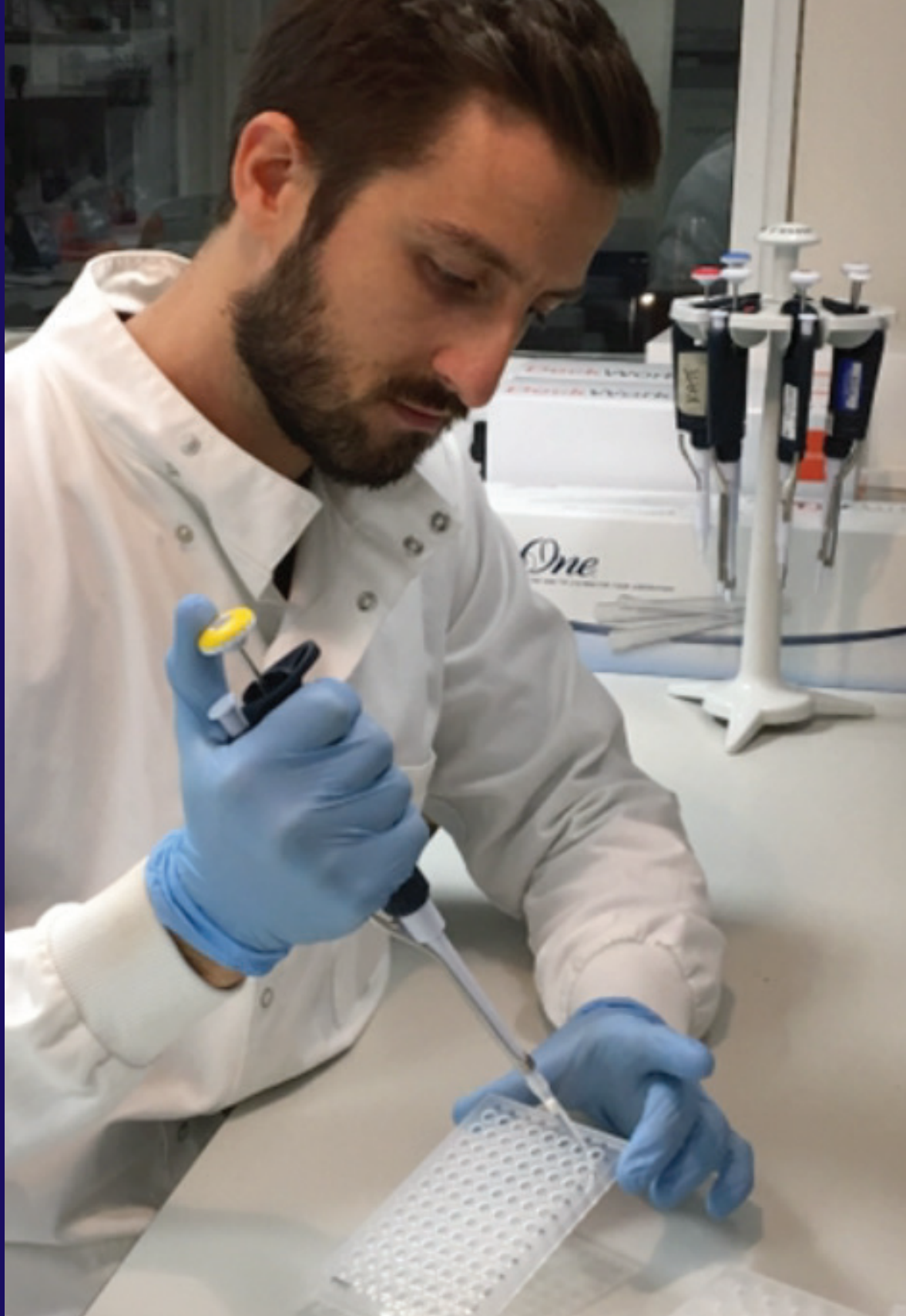


# THE OUTLOOK



**Research Review | Page 4** | *Clinical registries offer a view into myositis diseases*

**News | Page 8** | *Creating awareness of myositis among physicians*

**Meet Our Members | Page 12** | *Show and tell*

**Wellness | Page 14** | *Integrating complementary medicine*

**SPRING 2018**  
Quarterly Newsletter

# THE OUTLOOK

A quarterly publication of The Myositis Association

## 8 Creating awareness of myositis among physicians



## 10 TMA welcomes new members to the Board of Directors



## 12 Show and tell



## 14 Integrating complementary medicine



## 3 Corner Office

## 4 Research Review

Opening a window: Clinical registries offer a view into myositis diseases

Clinical registries and observational studies for myositis

## 9 News

TMA to unveil new website

## 13 Meet Our Members

More show and tell

*Cover Photo*  
TMA research fellow Simon Rothwell

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**The mission of  
The Myositis Association  
is to increase support,  
awareness, and funding  
for the myositis patient,  
caregiving, and research  
community.**

Myositis Awareness Month is here, and this issue of *The Outlook* focuses on TMA's efforts to create greater awareness of myositis in the physician community and the research progress that has been made since TMA was founded 25 years ago.

TMA is expanding its Medical Advisory Board to 24 members later this year to allow an even greater diversity of viewpoints and perspectives on these mysterious myositis diseases.

Four years ago, TMA launched an ambitious initiative, the Visiting Professors Program, to educate young physicians about myositis and to expand TMA's reach deeper into the medical community. As you will read, this program has proven to be remarkably successful, with myositis presentations being made through Grand Rounds at 38 North American medical schools so far. And, we have arranged for real, live myositis patients to give young physicians a firsthand look at what a myositis patient actually looks and feels like.

TMA's Myositis Symposium is now entering its 9th year and remains one of the only opportunities for multiple medical specialists to meet and compare notes about myositis and potential paths to a cure. Plans are now being made for the 3rd Global Conference on Myositis to continue bringing together the best minds in myositis research and to share knowledge.

The amount of information about myositis that has been collected from TMA members has enabled several registries to be formed for sharing data with the research community. Through the collaborative efforts of patients, physicians, and myositis researchers, more is now known and understood about myositis than ever before.

The information and knowledge being assembled from all these activities is being applied and put to use. There are more research trials now underway with multiple therapies being tested. Even major pharmaceutical companies like Bristol-Myers Squibb, Pfizer, and Novartis are testing drugs for myositis.

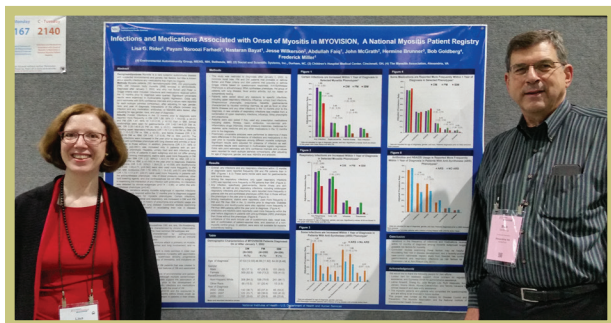
As TMA celebrates its 25th Anniversary this year, we are celebrating the progress being made and the hope that lies ahead. We are optimistic about prospects for treatments for all forms of myositis. We are celebrating success in creating greater awareness of myositis among primary care physicians as well as specialists. We are celebrating the strength and commitment of the 60 health professionals who have now served on TMA's Medical Advisory Board. And, most importantly, we are celebrating you—those who live with myositis and those who care for them. Your strength and determination has been an inspiration to TMA, our Medical Advisory Board, and the Board of Directors.

We all want a cure tomorrow or at least effective treatments until we unlock the key to curing this disease. Through the unified efforts of very many dedicated, knowledgeable people we will get there.

THANK YOU for your support and patience!



## Opening a window: Clinical registries offer a view into myositis diseases



*Dr. Lisa Rider and Bob Goldberg at American College of Rheumatology meeting presenting findings from MYOVISION registry*

When it comes to rare diseases like myositis, clinical registries are an essential tool. Studies involving registries and biorepositories are projects

that collect a wide variety of information—demographic, social, environmental, clinical—from volunteer patients and make it available (through strict protocols that ensure individual anonymity) for clinical research.

TMA members have generously contributed to a number of registries, providing information that has proven extremely useful to researchers as they seek to understand the complexities of idiopathic inflammatory myopathies and associated diseases.

Some registries, such as the TMA-sponsored MYOVISION registry, conducted in conjunction with the NIH and Cincinnati Children's Hospital Medical Center, collect information that can be used to track trends related to myositis diseases. Since its inception in 2011, this registry has collected data from more than 1,800 individuals. This has allowed researchers to more fully understand each of the forms of myositis and to associate these characteristics with genetic and environmental factors.



### **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](http://www.MyositisTrial.com).*

Data from this registry, for example, has shown that patients with myositis have a lower quality of life when compared to either a healthy population or to patients with rheumatoid arthritis. This may be obvious to myositis patients and their families, but researchers must establish this baseline in order to show a particular treatment has a measurable impact, or to demonstrate to a pharmaceutical company that developing a new drug is worthwhile.

MYOVISION data also showed an association between smoking, genetic factors, and a risk for developing antisynthetase syndrome. By combining data from another registry—the European EuroMyositis registry, which includes data from more than 3,000 patients—the impact of smoking on myositis becomes more evident. In addition to its association with interstitial lung disease, smoking was found to be more frequently associated with connective tissue overlap diseases, dysphagia, malignancy, and cardiac involvement in myositis patients.



Worldwide, more than 45 myositis research registries, often with associated biorepositories, have enrolled more than 30,000 myositis patients. This provides extraordinary opportunities for researchers to collaborate. Combining data in this way creates a larger cohort, so results will be more statistically valid. Together these registries have helped the myositis research community to understand, for example, what

## **ProDERM** **A clinical research study**



### ***Are you affected by dermatomyositis?***

*If you are between 18 and 79 years of age and diagnosed with dermatomyositis, you may be interested in the ProDERM clinical research study.*

*ProDERM is a clinical research study that will evaluate the effectiveness of an investigational drug for the treatment of dermatomyositis.*

*To find out more, please contact the study team, or talk to your doctor.*

*Study sponsored by Octapharma Pharmazeutika Produktionsges mbH*

**Contact details:** Cheryl Bell, Clinical Study Manager [\*\*cheryl.bell@octapharma.com\*\*](mailto:cheryl.bell@octapharma.com)

myositis-specific autoantibodies can tell about the different forms of myositis, their prognosis, best treatments, and more.

Genetic information has also been derived from tissue samples in these biorepositories and is being used to explore, for example, the genome of dermatomyositis patients, and to develop additional diagnostic and prognostic biomarkers of myositis.

More than 900 patients with sporadic inclusion body myositis, most of them TMA members, participated in the Inclusion Body Myositis Registry at Yale University. This study collected clinical, demographic, and social information through a national online survey to develop a better understanding of who gets IBM, the trajectory of the disease, its impact on quality of life, and more. One of the outcomes of this project was to develop a calculator to help IBM patients evaluate how their personal experience compared to others who live with the disease. [Find the calculator here: <http://ibm.yale.edu/ibmindex/>]

Over the last two years, TMA has partnered with Mallinckrodt Pharmaceuticals to engage patients in

an online survey of myositis patients about health issues and overall quality of life. Nearly 800 TMA members participated in this study that asked about physical symptoms and challenges, pain and other symptoms, impact on work and leisure activities, treatments and medications, and more. Responses to these questions are still being analyzed, but this data will help physicians better understand the issues patients face when they are diagnosed with a myositis disease. It will also help pharmaceutical companies develop better research protocols that include patient-focused evaluation criteria.

Studies using myositis research registries have greatly enhanced our understanding of so many aspects of the idiopathic inflammatory myopathies. They offer insights into this rare disease that can be discovered in no other way. All of which leads to better treatments and potential cures.

*To participate in one of the ongoing registry studies or another non-drug research project, please see the chart on the following page.*



**Do you or a loved one suffer from myositis and have trouble getting on and off the toilet? LiftSeat can help.**

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# Clinical registries and observational studies for myositis

Name	Purpose	Eligibility	Study Sites	More information
MYORISK Environmental risk factors for the antisynthetase syndrome	To determine whether selected environmental exposures are more common in individuals who have myositis with antisynthetase syndrome, compared with healthy volunteers	Adults and children with myositis, with or without antisynthetase autoantibodies	Miami, FL; Pittsburgh, PA; Boston, MA; Baltimore, MD; Rockville, MD; Research Triangle, NC; Rochester, MN	Meghana Vijaysimha <a href="mailto:meghana.vijaysimha@NIH.gov">meghana.vijaysimha@NIH.gov</a> 301-451-6031 <b><u>NCT01276470</u></b>
Environmental risk factors for myositis in military personnel	To study environmental risk factors for myositis in military personnel	Military personnel who developed myositis during their period of service	National Institutes of Health, Bethesda, MD	Meghana Vijaysimha <a href="mailto:meghana.vijaysimha@NIH.gov">meghana.vijaysimha@NIH.gov</a> 301-451-6031 <b><u>NCT01276470</u></b>
MYOPROSP (Prospective cohort study in myositis)	To develop a registry of myositis patients to better understand myositis diseases and genetic factors associated with them	Adults with PM, DM, ADM, sIBM, AS syndrome, myositis overlap, CAM, NM, JM in adulthood, orbital myositis, suspected myositis, CTD with MSA/MAA	University of Manchester + 7 additional centers throughout the UK	Paul New <a href="mailto:paul.new@liverpool.ac.uk">paul.new@liverpool.ac.uk</a> +442755993 <b><u>NCT02468895</u></b>
Study of families with twins or siblings discordant for rheumatic disorders	To identify risk factors for rheumatic disorders and to better understand associations among genetic relationships	Adults and children, twins or siblings within 5 years, one of whom has the adult or juvenile forms of RA, SLE, SSc, or IIM	National Institutes of Health, Bethesda, MD; University of Wisconsin, Madison, WI	Frederick Miller <a href="mailto:millerf@NIH.gov">millerf@NIH.gov</a> 301-451-6273 <b><u>NCT00055055</u></b>
Studies in the natural history and pathogenesis of childhood-onset and adult-onset idiopathic inflammatory myopathies	To learn more about the causes, immune system changes, and medical problems associated with myositis diseases	Adults and children with DM, PM, sIBM, and related conditions	National Institutes of Health, Bethesda, MD	Lisa Rider <a href="mailto:riderl@NIH.gov">riderl@NIH.gov</a> 301-451-6272 <b><u>NCT00017914</u></b>
Studies on the natural history and pathogenesis of polymyositis, dermatomyositis, and related diseases	To describe this group of diseases, further delineate important groups of patients, and obtain information about immunological abnormalities, pathogenesis, and etiology of IIM	Adults and children, aged 16 or higher, with possible idiopathic muscle disease (suspected or confirmed), DM, PM, sIBM	National Institutes of Health, Bethesda, MD	Eileen Lange <a href="mailto:langeeil@NIH.gov">langeeil@NIH.gov</a> 301-435-8434 <b><u>NCT00001265</u></b>

## Creating awareness of myositis among physicians

Creating awareness of the myositis diseases is one of the primary goals of The Myositis Association. Earlier recognition of myositis by physicians will result in improved patient care and better outcomes. To achieve this, TMA sends to more than 1,000 physician offices brochures about the myositis diseases, our publication *A Physician's Guide to Myositis*, copies of *Myositis 101*, posters about myositis to display in their office, and other materials. We do this each May as a component of our outreach to the physician community during Myositis Awareness Month.

A year-long activity TMA conducts to educate the medical community is our unique Visiting Professors Program. Each school year, TMA invites US and Canadian medical schools to have one of our Medical Advisory Board (MAB) members conduct Grand Rounds at their school to educate residents, interns,

and medical students about myositis. In addition to the Grand Rounds, our MAB member will often meet separately with fellows and others at the school who are interested in learning about myositis. We often hear that, had it not been for the presentation in medical school on myositis, it is unlikely that the physician would have recognized this odd, rare disease.

Over the past four years, TMA has sent MAB members to 38 medical schools to lecture on myositis and answer questions from these young, aspiring physicians. The participating schools range from the more well-known, such as Yale University, Johns Hopkins, and Harvard, to the less well-known, such as Mercer, South Alabama, and University of Toledo. It is a program that we are very proud of and one that not many other rare disease organizations are able to offer to medical students.

On average, it takes a person with myositis at least five physician visits before they are correctly diagnosed. TMA's Visiting Professors Program aims to reduce that number of doctor visits. We are deeply grateful for our 22-member Medical Advisory Board's support of this program.

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# TMA to unveil new website

In celebration of May as Myositis Awareness Month, TMA is excited to announce its new, improved website. The site, which is expected to go live in May, features all-new updated content, including the latest evidence-based information on all forms of myositis, in a user-friendly platform that makes navigation more accessible online as well as on mobile devices.

As TMA celebrates 25 years as Your Myositis Association, the new website is a place where

members can continue to return over and over to read the latest research news, view educational videos from Annual Patient Conferences, share patient stories, find information about upcoming events, exchange support and practical information with other members in the myositis community, and more. Particularly exciting is the new blog feature, which will allow TMA to share ongoing information on a wide variety of topics of interest to patients and care partners who live with myositis.

The website may be new, but the address is still the same: **[www.myositis.org](http://www.myositis.org)**. Keep an eye out for an announcement about when the new site goes live.

## TMA celebrates 25 years as Your Myositis Association



### Experimental treatment study: H.P. Acthar Gel

*Principal investigator Anthony Fernandez, MD, PhD at the Cleveland Clinic is currently enrolling patients with juvenile dermatomyositis who are 18 years of age and older, as well as patients with the adult form of dermatomyositis. Study participants must have refractory cutaneous symptoms, meaning that skin manifestations (calcinosis, rash, etc.) do not respond to treatment with steroids plus one other medication, such as methotrexate or IVIg.*

*For more information on the study, go to: <https://clinicaltrials.gov/ct2/show/NCT02245841> To enroll or for more details, contact Lisa Rittwage, BSN, RN at 216-444-4659 or [rittwal@ccf.org](mailto:rittwal@ccf.org)*

# TMA welcomes new members to the Board of Directors



**Laurie Boyer's** big brother started feeling like he had the flu in April 2012. Tommy Worthington was a police detective for St. Lucie County Sheriff's Office in Florida. He worked out every day, and he was not used to feeling so achy and breathless when he walked or

climbed out of bed. It took nearly two months before Tommy was diagnosed with dermatomyositis and ILD with the MDA5 autoantibody. Six weeks after diagnosis, however, the rapidly progressing disease took his life at the young age of 39.

While Tommy was in the ICU at a Miami hospital, Laurie, Tommy's wife Dana, and Tommy's parents took turns staying with him. They were such a constant that hospital staff started calling them Team Tommy. The team played Scrabble together and talked about Tommy's desire— "When I get out of here," he said—to do something to help others with this rare disease. Two weeks after Tommy died, Laurie and Dana fulfilled that final wish by starting the Team Tommy Foundation.

Since that time, Team Tommy has been a dynamic supporter of TMA, both in the local Florida area and

nationally. Each year, the foundation shares a portion of its fundraising proceeds with TMA. Team Tommy provides financial assistance for myositis patients who can't afford certain expenses related to their disease. It also funds dozens of scholarships to enable myositis patients and their care partners to attend TMA's Annual Patient Conference. And the Foundation supports TMA's research funding, seeking new treatments and an eventual cure for myositis diseases.

Laurie works as an Instructional Specialist in Professional Development for St. Lucie Public Schools and serves as Administrative Director for the Team Tommy Foundation. She is married to her firefighter husband Wayne for 15 years and has two children, an 11-year-old son Derek and a 7-year-old daughter Victoria. She, Dana, and the rest of the Team Tommy board have attended and volunteered at five of the last six TMA Annual Conferences. (They were very disappointed when Hurricane Irma kept them away last year.) Laurie joined TMA's Board of Directors this year and is excited to be able to contribute in this way.

"Being part of the TMA board is such an honor," Boyer says. "From Team Tommy's perspective, it has been extremely fulfilling to be part of the Annual Conferences and to support TMA's efforts to find a cure. Now, on a larger level, it's really powerful, knowing that I can contribute to making other people aware of this disease and helping to fund research. This work is so necessary and I am grateful for the opportunity to support myositis patients and their care partners."



## MYOSITIS AWARENESS MONTH

*For ideas about how you can tell  
your #myositis story, go to*

**[http://www.myositis.org/get-involved/  
myositis-awareness-month](http://www.myositis.org/get-involved/myositis-awareness-month)**



It was a big deal for **Martha Arnold** to attend TMA's Annual Patient Conference in San Diego last year. Like other TMA members who have IBM, she worried that what she would encounter would be too intimidating and sobering. Also like others who take that leap,

she's glad she did. It made her think that she might have something to offer to the myositis community, and she's happy to have been selected to serve on the TMA Board of Directors.

Martha noticed some weakness in her hands as much as five years before she mentioned it to her doctor. After being referred to a neurologist and undergoing many tests—lots of blood work, CT and MRI scans, EMG studies, a bone marrow biopsy, and more—Martha herself diagnosed her condition.

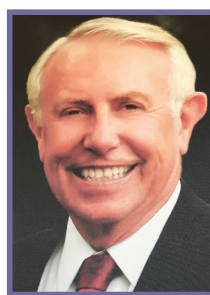
"I finally said, 'I've done some research. I really think this is myositis. Let's do a muscle biopsy,'" she says. "All the signs were there." The diagnosis was confirmed in November 2014.

Among the things Martha hopes to represent as a member of the Board is the perspective of early IBM and the impact exercise can have on the disease. Her weakness is only apparent in her hands. She's fairly sure her legs will become involved at some point, but she also thinks that her milder symptoms are the result of a long history of vigorous exercise. She has been working out aggressively (spinning) four or five times a week for nearly 20 years.

Martha has spent her career working with pharmaceutical companies, both in marketing and in regulatory communications. Currently she serves as a consultant, helping pharma companies prepare for the formal presentation before an FDA advisory committee, which is frequently a required step in the process of getting a drug approved. This experience, which has given her some insight into the drug development and approval process, is another perspective she hopes to bring to the TMA Board.

"Obviously I have a personal interest [in serving on the TMA Board] as someone who has the condition," Martha says. "But with my background in the health sciences and drug development and my interest in exercise, I feel I have a unique perspective that might be useful."

Martha lives near Philadelphia with her husband, Mark. They have a 28-year-old son, Eric, who lives nearby.



### **Owen "Wayne" Mortenson**

spent his early career as a farmer in the American Southwest.

In the mid-1970s, Wayne, his wife, and four young children moved to Kentucky, so he could attend dental school at the University of Louisville. The family

put down roots in the area, and now, more than 40 years later, Wayne serves as CEO of Mortenson Family Dental, a group of more than 140 dental practices in Kentucky and eight other states. Now Wayne's three sons as well as his daughter's husband are all practicing dentists in the group.

Wayne has stopped seeing patients, focusing instead on running the company for the last five years. In retrospect, however, that may be when he first noticed he was having trouble walking up the stairs and standing up from a low seat. After working with a personal trainer and exercising diligently without much improvement, his primary care doctor referred him to a local neurologist. Several lab tests and a muscle biopsy resulted in Wayne being diagnosed in 2015 with sporadic inclusion body myositis.

"I feel wonderful and have good energy, but my quads and triceps are getting weaker," Wayne says. "There is no treatment, so it's just a matter of understanding what I have and trying to manage myself."

Last year, in an effort to strengthen his understanding of his disease, Wayne attended the TMA Annual Patient Conference for the first time. What he learned gave him a lot of insight and hope. And when Wayne was approached about joining the TMA Board of Directors, he couldn't say no.

"I'm always willing to contribute," he says. "I'm on several other boards in addition to my company. And my wife, Sue, and I have quite a bit of experience raising funds for charitable efforts that our company has done. So I'm sure we'll be able to help to some degree."

"It's a bit challenging," Wayne adds. "Few people really know anything about myositis, but we're spreading the word."



## Show and tell



**Renee Lantner**

When Renee Lantner's dermatologist asked her if she might be willing to talk to medical students at Loyola University as a patient with dermatomyositis, Lantner was eager to raise awareness of her disease. As a doctor herself—a specialist in allergy and immunology—she remembers how important this sort of direct contact with a rare disease patient was for her.

“When I was a med student, I specifically remember a man who had a particular condition,” she says. “Twenty or thirty years later, I remembered that man, and that experience helped me diagnose my own patient.”

For four years now, Renee has participated in an annual medical school teaching session as a model patient, telling second-year medical students of her journey with myositis and discussing her physical symptoms. Each time, she was one of several patients who presented her case to a rotating group of 20-25 students at a time for several 15-minute sessions.

“I don't tell them right away what my diagnosis is,” says Renee, who currently serves as Board Secretary for the TMA Board of Directors. “I tell them about all the things that happened to me, my weakness, what I couldn't do, and what medications I've been on. And then I explain about my rash and show them my hands.”

Not many of these students can come up with the correct diagnosis during this session, but that's not the point. What Renee and the dermatology specialists teaching this section of the medical curriculum hope is that, years from now when a myositis patient shows up in their clinic or office, this experience will spark some memory that will help these new doctors make the correct diagnosis more quickly.

Renee suggests that this is one more way that myositis patients can raise awareness for their rare disease.

“I would encourage anybody to do this,” Renee says, “because what we have is so rare that there is a chance that these new doctors might not otherwise see a myositis patient.”

Patients can start with their own physician, asking her or him about how they might find such an opportunity in their community. Patients can also seek out a medical school directly and reach out to the curriculum director. TMA support groups that are located near an academic medical center can also take this on as a project, contacting medical schools and perhaps offering several members of their support group as model patients.

Renee also suggests bringing along TMA brochures. TMA can provide these materials for you; contact TMA at [tma@myositis.org](mailto:tma@myositis.org) or 800-821-7356.

“We are the ambassadors for this disease,” Renee says. “We need to get the word out in whatever way we can.”



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# More show and tell



**Mike Matthews**

Serving as a standardized or simulated patient is another way that myositis patients can spread myositis awareness in the medical community. A great many medical schools across the US and Canada have a standardized patient program that uses trained individuals as teaching tools to help medical students assess and diagnose specific conditions.

TMA member Mike Matthews, who was diagnosed with dermatomyositis in May of 2017, serves as a standardized patient at the University of Louisville Medical School.

"I kept thinking back to the more than two years of suffering and wasted time before my diagnosis and

decided to transform my chagrin into action," Mike says. "I contacted the medical school and proposed that they add myositis diseases to their curriculum, so that future myositis patients may not have to endure the needless suffering that I did."

Standardized patient programs use a practical, hands-on approach to teaching medical students to recognize symptoms, understand diagnostic criteria, and have a working knowledge of treatment guidelines and management for diseases. Individuals pose as patients, and students, with guidance from their instructors, interview and examine them and try to diagnose their condition.

"I saw this as a way of perpetuating the TMA mission of increasing awareness of myositis within the medical community," Mike says. "In fact, I see no better way to fulfill this mission than to make future doctors aware of myositis, and at the same time, educating the teachers and doctors at the medical school about the disease."

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# Integrating complementary medicine



**Lori Love**

Many myositis patients, out of frustration with an inadequate response to conventional therapies or simply to enhance their current treatment regimen, may turn to what is known as integrative medicine. Integrative healthcare is an approach to healing that weaves

together practices arising out of both conventional medicine and complementary methods.

According to Dr. Lori Love, MD, PhD, complementary approaches to health are broad and may include exercise, yoga/tai chi/qi gong, hypnosis, movement therapies, meditation, acupuncture, dietary supplements, other botanical products, homeopathy, special diets, and more.

While many TMA members have noticed some satisfying results with complementary therapies, too often there is little scientific data to demonstrate that many of these products and processes actually have an effect on disease symptoms, particularly in myositis.

“Products identified as complementary are, for the most part, regulated very differently than traditional drugs,” says Dr. Love. “Drugs are reviewed and approved by the FDA based on their safety and efficacy in a particular disease. But there is much we don’t know about the safety profile of complementary products.”

Dr. Love has dermatomyositis and lupus overlap syndrome, so she has firsthand experience with the signs, symptoms, treatments, and frustrations of living with myositis.

“One of the issues we all struggle with is how to personalize our medical and health care so that we are more in control,” she says. “For me, it has been an ongoing learning experience with lots of trials, errors, and subsequent modifications over time.”

Dr. Love cautions that patients should work together with their physician and use their conventional

medications as prescribed. Exercise, under the guidance of a physical therapist, has been shown to have beneficial effects for those with myositis and is now a component of mainstream treatment for myositis, including IBM.

Even those who don’t live with a chronic illness can benefit from following healthy lifestyle recommendations, such as using sunscreen and wearing protective clothing in the sun; getting adequate sleep; managing other conditions such as hypertension, diabetes, heart disease, and depression; and managing stress and expectations.

“Stress is a real issue for me and is associated with flares and increased symptoms,” Dr. Love says. “I find that approaches that help me control my stress level are very beneficial. I use yoga, meditation, and self-hypnosis to help control stress and the pain associated with my disease.”

Dr. Love has also explored many different complementary approaches, including traditional Chinese medicine, acupuncture, and mind-body approaches. In addition to these stress-reducing practices, she also suggests that having something in your life that brings you rewards or pleasure—hobbies, friends, family, a pet—can also be very helpful.

## Diet as therapy

Eating a healthy diet is another important element of a healthy lifestyle. This means eating a variety of primarily plant-based foods, such as vegetables, fruits, whole grains, legumes, nuts, and seeds. Dr. Love also recommends avoiding trans- and saturated fats, too much salt, and too much sugar. All of these practices have good scientific evidence to back them up.

When it comes to specific dietary interventions, however, few well-controlled studies have been done in myositis. Nevertheless, published scientific studies in other chronic disorders and autoimmune diseases indicate that dietary habits can have a crucial effect on human health and disease.

In autoimmunity, these studies have mainly focused on patients with rheumatoid arthritis (RA) and lupus. Diet affects the gut microbiome through a variety of mechanisms we are just starting to understand, but we know there are interactions between the gut and the



immune system. Diets high in saturated fats, salt, meat (particularly red meat), and sugar are now known to be pro-inflammatory. Diets rich in omega 3 fatty acids are anti-inflammatory and have resulted in improved disease activity in lupus and RA.

Because of these results in other autoimmune diseases, it is reasonable to expect that dietary habits would have an effect in myositis, and that controlling certain dietary elements may be beneficial to patients. But studies are needed to address this in myositis, to understand what dietary components may be important, in what patient clinical groups they are effective, and at what dosage and frequency of use specific dietary interventions might result in clinical improvements.

There is also some support from research for going gluten free. A fair amount of genetic overlap has been found between genes associated with gluten-sensitive celiac disease and other autoimmune diseases, including inflammatory myopathies. Furthermore, it has been reported that up to 25% of patients with an autoimmune disorder have or will develop both disorders at some time in their disease course.

In these patients, controlling gluten in the diet is critical, as it can have a marked effect on symptoms and severity of disease. There are anecdotal reports of gluten sensitivity in myositis whereby any contact with gluten causes flares in the patient's muscle disease and increased symptoms, and maintaining a strict gluten-free diet improves this disease activity. Given these findings, it might be reasonable to explore a gluten-free diet to see how your disease responds.

## Dietary supplements

Recommendations for dietary supplements, however, are complex. For some supplements, such as calcium and vitamin D, there is clear scientific evidence of benefits in autoimmune diseases similar to inflammatory myositis, as well as other health conditions.

Good quality scientific data are lacking, however, for the efficacy of other supplements in myositis. Often, it is difficult to identify exactly what's in a particular product or to assess its quality. In addition, the effects of isolated, high potency nutrients and other substances given as dietary supplements have not

been shown to confer the same benefits as eating these nutrients in whole foods, perhaps because of fiber and other constituents in whole food.

Dietary supplements and other natural products may also have adverse effects or interact badly with medications. This is why Dr. Love stresses the importance of keeping your doctors informed and working with them if you want to try these products.

Dr. Love also points out that certain products marketed as dietary supplements should probably be avoided by those with myositis, because they may cause increased muscle symptoms and enhance inflammatory responses. These include red yeast rice given as a cholesterol lowering substance (contains the same chemical as lovastatin and has been associated with myopathy), high dose creatine supplements (may cause myopathy or disease flare), tryptophan (may cause myopathies), echinacea and other immunostimulatory products, such as Spirulina and blue-green algae (associated with myositis flares).

Given that there is so little research related to complementary practices and myositis, it is important for patients to participate in clinical trials of these products, to identify which of these therapies can be used safely and effectively. To find research studies for which you may be eligible, you can call the NIH patient referral number at 1-800-411-1222. Another good place to look is at **ClinicalTrials.gov** where you can do searches by disease or condition and other terms, such as "botanical" or a particular ingredient or therapy.

*Lori A. Love, MD, PhD, worked for many years in the National Institutes of Health (NIH) and the Food and the Drug Administration (FDA) at both the Center for Food Safety and Applied Nutrition and The Center for Drug Evaluation and Research. A special focus during her time at FDA was dietary supplements and other botanical products. Dr. Love is a board-certified pathologist who has a broad research background that for many years has focused on the idiopathic inflammatory myopathies.*

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More information about integrative healthcare can be found here: <https://nccih.nih.gov/health/integrative-health#integrative>

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