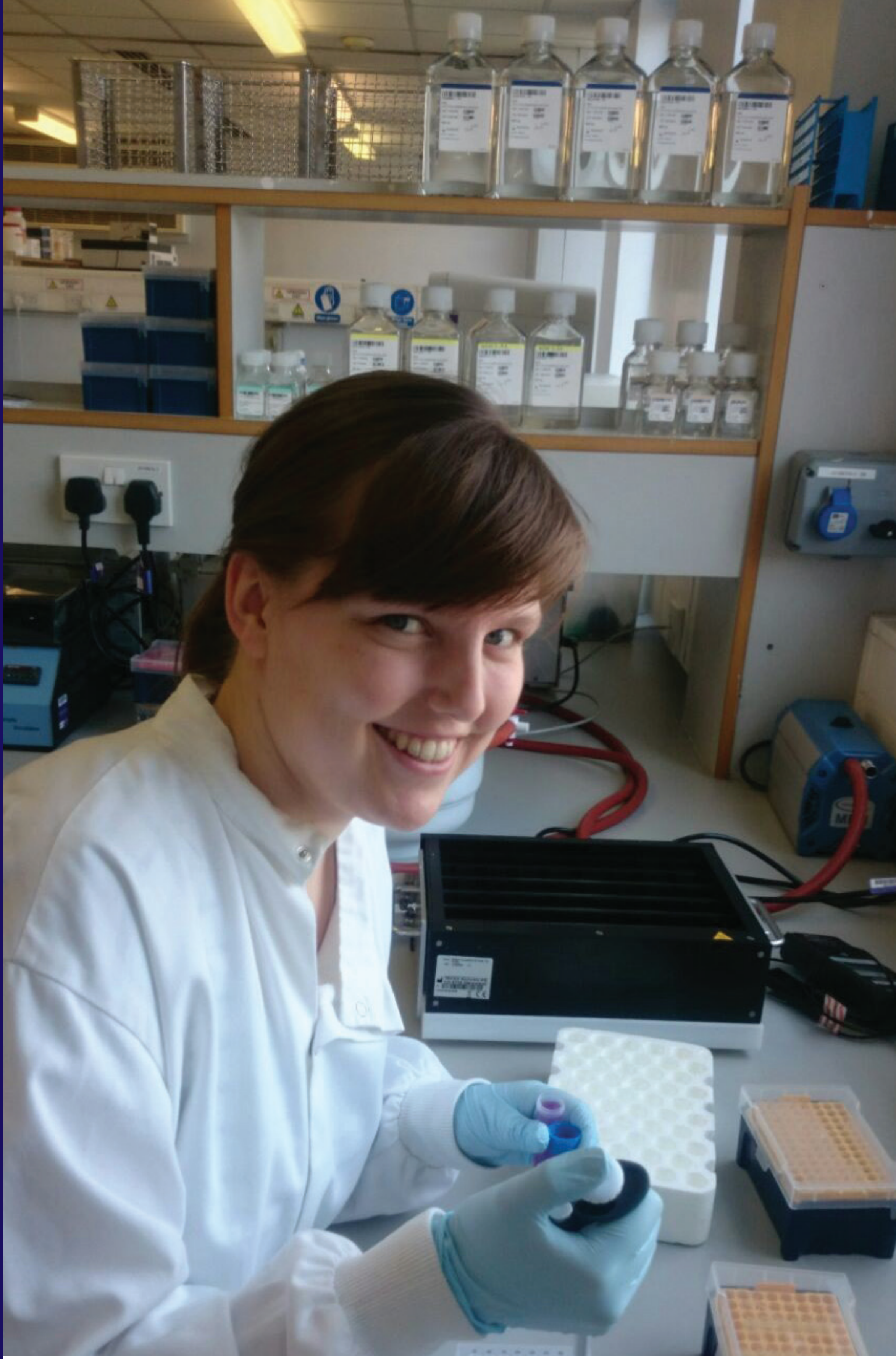
THE OUTLOOK

THE MYOSITIS ASSOCIATION

SUMMER 2019
Quarterly Newsletter



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THE OUTLOOK

A quarterly publication of The Myositis Association

Cover photo courtesy of Joanna Parkes

Published by: TMA, Inc
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Changing the world of myositis

TMA continues to hold research efforts at the forefront of our work and to expand its reach in the international myositis research community. TMA was a proud sponsor this year of the Global Conference on Myositis held in Berlin. I was honored to have the opportunity to provide a presentation on TMA's efforts and to learn about the most recent myositis research. It was thrilling to hear presentations by scientists from around the world, including those who had received grant funding from TMA and to learn about the progress and extraordinary outcomes of their work.

In 2002, TMA began funding research to find better treatments and ultimately a cure for all forms of myositis, and we have been making tremendous strides ever since. Each year, TMA's Board of Directors designates the level of research funding and, based on recommendations from TMA's Medical Advisory Board of global myositis experts, chooses the most promising of these proposals to fund.

TMA awards research grants to top international investigators and fellowships for scientists who have an interest in pursuing a career in the field of myositis. It's an extraordinary initiative, with an annual cycle that begins on May 15 when investigators who expect to apply for a TMA grant will submit their letters of intent. The formal proposals are due in June, and awards are announced in October.

Funds for TMA research grants come from myositis patients, care partners, family members, physicians, and others. This is why it is critically important to donate to TMA, as the more money that is raised, the more funding we can provide to myositis research.

In an effort to increase the number and quality of research applications we receive, for the first time TMA hosted a *Position Your Myositis Grant for Success* webinar for investigators as well as institutional leaders who advise trainees and early career faculty. Our sincere thanks to TMA's Research Chair, Dr. Chris Weihl, who presented his personal story about receiving TMA grants early in his career and outlined the TMA grant process as well as what makes a grant application most likely to be awarded. This and other TMA webinars are archived on our website.

We are very excited about the upcoming TMA Myositis Medical Symposium taking place in Minneapolis on September 6. This day-long symposium is for health care professionals and medical trainees. Attendees learn about the latest research from the world's leading experts on TMA's Medical Advisory Board. Please be sure to inform your clinicians about this exciting opportunity to learn about myositis. Additional information can be found at **www.myositis.org**.

We hope to see you as well in Minneapolis in September at TMA's Annual Patient Conference. The theme this year is *Who YOU Are Matters*, focusing on the diversity of needs and challenges among patients, care partners, and within the entire myositis community. You will have the opportunity to hear talks by leading global experts in the field of myositis research, therapeutics, rehabilitation, mental health, and other important fields. Armed with more knowledge about your disease and how it relates specifically to you, and coupled with the new relationships you will form or rekindle from past conferences, the Annual Conference will inspire you to find new ways to live with myositis and perhaps become a part of research.

We thank the many TMA members who have participated in medical research and clinical drug trials. We hope you enjoy this *Outlook* and learn more about the clinical trial process, currently recruiting clinical trials, and why it is so critically important for those with a rare disease like myositis to participate in research. It's your chance to change the world!

TMA's vision is a world without myositis

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

Clinical trials: Your chance to change the world

When Vera Cardinale found out about a phase 2 clinical trial for the skin disease of dermatomyositis, she had very little hesitation about becoming a research subject. Vera has hypomyopathic dermatomyositis, a form of DM where muscle symptoms are minimal, but the skin symptoms can be very severe. She had read up on this new medication, lenabasum—a drug that had shown good results in clearing skin symptoms in DM and other diseases in earlier studies—and she thought it was worth a try.

“I felt like there weren’t any serious risks to trying it, and I liked that it was not an immunosuppressive,” Vera says. “I also believe in research and wanted to contribute, because there aren’t any other good options for myositis skin disease. All the other medications are used off label.”

For Vera, who lives in the Washington, DC area, the only downside to participating in this 12-week trial and its extension study was the time it would take to travel to Pennsylvania every few weeks. But the folks running the study made this inconvenience as easy as possible. They paid for her travel to Philadelphia, and the research team was always available by email and phone to answer any questions. They even handle most of her routine care and other prescriptions while she is in the study, so she doesn’t need to see other doctors.

Clinical trials are a critical part of medical research. Testing a new treatment or procedure on human subjects is the only way to see if new drugs or medical devices are safe for people to use and if they actually have the effect on the human body that scientists think they have. Clinical trials are also an essential step in the Food and Drug Administration (FDA) approval process for new treatments.

Many TMA members have participated in a variety of clinical drug trials. It’s especially important for those with a rare disease like myositis to volunteer as research subjects. That’s because, in order for the trial to be scientifically valid, trials require a significant number of participants. The exact number required will vary depending upon what type of data researchers are seeking. The fewer people who have the disease, the harder it is to get enough qualified participants to be able to achieve these clear results.

Choosing to participate in medical research is a big decision, however, one that should not be made lightly. While TMA encourages members to participate in clinical trials, we also encourage you to gather as much information as you need from the trial coordinator about the risks and benefits of participating in a particular study, so you can make an informed decision about enrolling. You should also discuss your participation with your family and your doctor to be sure they are comfortable with your participation and the role they may need to play in the process.

You should also learn all you can about the treatment being tested and the protocol’s requirements. When Vera was considering the lenabasum trial, for example, she also looked into the doctor who was running the study.

“I researched Dr. [Victoria] Werth and realized she’s *the* number one skin doctor in dermatomyositis,” Vera says. “I had nothing but roadblocks with my local doctors who don’t understand my disease and couldn’t help me. So, this was my opportunity to be evaluated by this myositis expert.”

Vera also suggests that research subjects need to have a sense of altruism about their participation.

“I think you have to be motivated in part by a willingness to help others,” she says. “Your mindset can’t be ‘What’s in it for me?’ There are going to be some inconveniences along the way.”

You may experience uncomfortable side effects. If you are randomly assigned to the control group, you will receive a placebo instead of the study drug. The study may even fail to show good results.

Still, Vera, who has also participated in two non-drug trials at the National Institutes of Health (NIH), has no hesitation about recommending clinical trials to others.

“I’m very, very happy I did it,” she says.

About Clinical Trials

What is a clinical trial? A clinical trial is a research study that tests a new medical treatment to see how well it works and if it can safely be used by people. It's an essential step in the Food and Drug Administration's (FDA) process for approving new treatments.

How does a clinical trial work? Clinical trials follow a strict protocol designed to arrive at clear answers to research questions about the treatment. Protocols usually compare two or more groups of subjects, and they have strict rules about who can participate in the study. Often the protocol involves comparing outcomes of patients who receive the new treatment with those who are given a placebo (a non-active substitute).

What are "phases" of clinical trials? Developing new drugs and other treatments happens in a step-by-step process both before it is tested in humans (preclinical phases) and including human testing. Each phase of a clinical trial tries to answer different questions. The phases of clinical testing involve the following:

Phase 1	Multiple doses of the drug are tested for the first time in a small group of healthy people—usually less than 100. • What are the side effects? • Is this drug safe to continue testing?
Phase 2	The drug is tested in a larger group of people —ideally a few hundred—who have the disease. • What are the side effects in this population? • Does the drug work as treatment for this specific disease?
Phase 3	The drug is tested in a much larger group of people —ideally several hundred to several thousand—who have the disease. • What are the side effects? • How well does the drug work to treat the disease? • How much of the drug should people take? • How does the drug compare to currently available treatments?
Phase 4	This phase happens after the drug is approved by the FDA and is available for use by patients. • What are the long-term effects of the drug? • What is the best way to use this drug as treatment? • Are there other risks to using this drug? • Are there other benefits not previously identified?

How safe are these experiments? While all medical interventions carry some amount of risk, researchers are required to build into the protocol certain measures to make sure the study is ethical, that the rights and welfare of participants are protected, and ensure that the risks are reasonable when compared to the potential benefits. And any time human subjects are involved, an independent Institutional Review Board (IRB) of scientists and ethicists must review, monitor, and approve the protocol.

Lisa Rider, MD, Deputy Chief and Senior Research Physician, Environmental Autoimmunity Group, on why patients participate in myositis clinical research at the NIH

Most people participate in NIH studies because they want to contribute to the greater good. They want to help us learn more about their disease.

Many come to the NIH for a second opinion about their myositis. Our studies are very in-depth, often involving several days of evaluation. And all care under the research study is free.

Patients learn a lot from the experience, and they return home with a whole different perspective on their disease.

Currently recruiting clinical drug trials

Name of Drug Investigators	Eligible	Protocol	Study Sites	Recruitment Status	More information ClinicalTrials.gov ID #
Abatacept (Orencia) Bristol-Myers Squibb	Active DM/PM/NM/JDM (over 18), overlap	SubQ inj wkly + current treatment x 24 wks + 28 wks ext	94 sites in US, Australia, Asia, S. America, Europe	RECRUITING 150 patients needed	**BMSStudyConnect.com** NCT02971683
Abatacept for ILD Univ of Pittsburgh + Bristol-Myers Squibb	ILD + antisynthetase antibody	SubQ inj wkly x 24 wks	6 sites in US	RECRUITING 20 patients needed	Nicole Neiman 412-648-9989 **nmn19@pitt.edu** NCT03215927
Arimoclomol Orphazyme	IBM	2 pills x 3/day, 8 visits over 2 yrs	Kansas City + 10 other sites in the US; and London	No longer recruiting 150 patients	Laura Herbelin **lherbelin@kumc.edu** NCT02753530
Lenabasum Corbus	Adults w active DM	1 capsule x 2/day	60 sites in US, Europe, Japan	RECRUITING 150 patients needed	617-963-0707 **DMpatients@corbuspharma.com** NCT03813160
PF-06823859 Pfizer	Adults w active DM	Infusion monthly 12 wks	18 sites in US	RECRUITING 30 patients needed	800-718-1021 **Inquiries@pfizer.com** NCT03181893
Sodium thiosulfate for calcinosis NIEH/NIH	DM and JDM with calcinosis	IV infusion x 3/wk over 10 wks; multiple pre- and post-treatment visits	Bethesda, MD	RECRUITING 250 patients needed	Adam Schiffenbauer 301-451-6270 NCT03267277
Janus kinase (JAK) inhibitor Johns Hopkins + Pfizer	Adults w DM w active, treatment-resistant disease	1 pill daily x 12 wks + 4 wk extension	Baltimore, MD	RECRUITING 10 patients needed	Julie Paik, MD 410-550-1741 NCT03002649
Pioglitazone Johns Hopkins	Adult over 50 with IBM	2 pills daily x 2 wks then 3 pills daily x 32 wks	Baltimore, MD	RECRUITING 15 patients needed	Jemima Albayda, MD 410-550-6962 NCT03440034

TMA welcomes new members to the Board of Directors

Jeff Autrey has a unique perspective on the behind-the-scenes workings of health care providers and insurers. He's a retired attorney who specialized in regulation of the insurance industry, including health insurance. He also advised the medical and dental professions concerning their insurance benefits and related issues. But when his wife, Pam, was diagnosed with IBM a few years ago, he had the same concerns as any partner.

"I wanted to help her in any way I could," he says about his decision to apply for TMA Board membership. "Thankfully, due I believe to her lifetime of exercise, prudent diet, and strong positive attitude, she has been able to continue most of the activities she enjoys without much help from me."

Living in Austin, Texas, since their college days at the University of Texas, he and Pam took up ranching as a hobby and raised cattle on their place in the nearby Hill Country for several years. These days the Autrey's have turned instead to managing wildlife and habitat, watching birds, and fishing on their property on the Pedernales River. They also enjoy hiking, swimming, and kayaking with their two daughters and six grandchildren, who also live in Austin.

Jeff has an insider's view of non-profits as one of the directors of a family charity. After attending two TMA Annual Patient Conferences, he figured that the best thing he could do in his role as a care partner was to use his talents to support TMA.

"I was especially impressed by the quality of the conferences," he says. "TMA is dealing with such a rare disease and a small patient base, yet has managed to pull together and coordinate an impressive support base from myositis patients, care partners, and the medical community."

Partly because of his wife's experience, Jeff would like to see more investigation into nutrition and physical activity as important parts of myositis treatment. As a board member, he's also interested in expanding myositis research into treatments for all kinds of myositis.

Once new drugs are developed, Jeff hopes to use his experience with insurers, health care providers, and regulatory authorities to help make sure innovative myositis drugs and treatments are included in insurance coverage.

"This is an issue that affects all myositis patients," he says.

Gail Bayliss happened to be working in Cincinnati when she found out that TMA's 2018 Annual Patient Conference was right down the road in Louisville. She'd been having symptoms since 2012, was diagnosed in 2017 and, as an emergency medicine physician, she was searching for a way to use her profession and her experience with polymyositis to help patients who had questions. She also wanted to contribute to research and realized she could do both as a member of TMA's board of directors.

Gail originally chose this medical specialty as a way to be available to her family. Although their work is often high stress, ER doctors are able to work a regular shift and don't have to be on call.

After raising her family, however, she decided to take her job on the road. She became a traveling physician who moves from one job to another, temporarily staffing the emergency room for a new hospital, or filling in when a physician is needed. She's found that both the work and the travel suit her.

Gail understands a great deal more than most physicians about the confusion patients feel when an illness has alarming symptoms and is not immediately recognized. Her diagnosis was complicated by cancer. But she was also unable to get up from a chair and was tripping frequently. During one dramatic month, she lost 20 pounds of muscle. A muscle biopsy was finally done. The verdict: "I was told to get to a rheumatologist *now*," Gail remembers.

When her disease was diagnosed and treated, her recovery was equally dramatic: "Within a week, I was a new person," she says.

Her treatment has continued to be successful enough for her to keep up with her strenuous routine. Still, she realizes that not all myositis responds to treatment, and that many current treatments have side effects.

"We need to stay in the forefront when research is being done into new uses for stem cells, hormones, all kinds of gene therapy," she says. "And we need to make sure doctors get the education they need about myositis."

Rex Bickers is still sketching out the plans for his retirement, which began less than three years ago. As he winds down from a 34-year career as a neonatologist, part of his transition includes being back home in Floyds Knobs, Indiana.

Rex found satisfaction in a rather unconventional career, traveling widely to areas where his specialty was needed. He and his wife, Marcia, also ran a medical database management company.

Rex had the same long journey to diagnosis as most IBM patients. He initially recognized trouble with swallowing and went to Wake Forest, where a classmate from medical school was part of the team that treated him.

"While I was there, I asked my neurologist friend for a private consultation to address what seemed to be problems with my feet and legs," he says.

He was assured that his walking difficulty was a side effect from treatment for a long-ago lymphoma. Finally, when his hands became involved, Rex was correctly diagnosed. His doctor told him about TMA and pointed him towards the Annual Patient Conference.

As a doctor whose first interaction with his tiny patients is to pick them up and hold them, Rex felt he could not continue in his work. "It was just inconceivable that I could ever drop a baby," he says.

He knew that he needed to change gears. Rather than belaboring his slowly weakening muscles, Rex is turning his attention to pursuits that do not require a lot of muscle.

He'll bring his formidable energy and medical knowledge to TMA's Professional Relations Committee. The collaborative spirit he experienced in the NICU inspires him to reach across all specialties to educate physicians and other health professionals, both to improve diagnosis and to promote myositis research.

James McTevia thrives on confronting the challenges that most of us try to avoid. As a financial advisor and consultant for nearly 60 years, he has worked with seriously financially distressed corporations, including Saab Automotive, Multivest Options, and DeLorean. He has an international reputation as a serious business problem solver, and he prides himself on being able to confront any challenge.

Around 2012, however, Jim started noticing he didn't have his usual strength. It was harder to ski, and he was worn out more than usual when clearing brush at his Michigan farm. Then he started having trouble holding a pen; his right index finger wasn't cooperating. Arthritis he thought. Old age creeping up.

In 2013, during his routine annual physical, Jim was advised that this weakness was not in fact arthritis, but was most likely an incurable, untreatable, rare disease. He would need a muscle biopsy to confirm the diagnosis. Jim's response, however, was exactly like those failing companies he works with: he ignored the advice of his doctor.

It took another nine months—nine months in which his growing weakness increasingly confused and frightened him—for him to accept the recommended muscle biopsy. Even then, he didn't ask about the results until his annual physical three months later. As it turns out, the biopsy confirmed the diagnosis: inclusion body myositis.

"I was blindsided," Jim says. "I just couldn't handle it emotionally. What do you mean I have a problem I can't solve? I've solved some of the hardest problems in the world. I can solve anything!"

Jim documents his journey into acceptance of his condition in his book, coauthored with Tom W. Ferguson, *One-Eyed Kings: Lessons I Learned from an Incurable Disease* (Highlandview Farms, 2018). As he spins out the details of his story, this serious problem solver realizes that the challenge of IBM has forced him to follow that checklist of advice that he has used to counsel clients for decades.

"We all have things we would rather not deal with," Jim says. "But in facing your problems and solving them, you become a full human being. Most of us have many, many more blessings than problems, and we are all going to be okay."

Jim and his wife Joan split their time between homes in Florida and Michigan. He's looking forward to sharing his business expertise as a member of TMA's Board of Directors. He is also sharing the profits of his book *One-Eyed Kings* with TMA; it is available here: **https://www.myositis.org/about-tma/store/**

Unlike most people, **David Mochel** actually had met someone with inclusion body myositis before he was diagnosed himself. David met the patient, not in a support group, but when she needed hip surgery. He's been an orthopedic surgeon for 25 years. Lately, he's been trying to remember her name.

"She did fine," he says, "but I remembered her because the disease is so rare. I would love to get in touch with her."

Fast forward a decade or two and David began to show some disturbing signs. "I guess doctors are like anyone else, maybe worse," he says. "We want to explain away our symptoms. But leave it to a nurse to recognize that something is wrong."

That nurse would be David's wife, Peg, who insisted he go to a doctor. So began the search—familiar to almost anyone with myositis—for a diagnosis. Eventually, he was diagnosed with IBM, and his disease appeared to have a particularly inflammatory component.

For an orthopedic surgeon, joint replacement requires a significant amount of physical coordination, a strain that David was beginning to sense. "I was doing fine," he says, "but I didn't think it would be ethical to continue."

Luckily, his experience and medical knowledge were not lost to the Chicago area. Northwestern Medicine health system made him an administrator, the medical director for its western region. David and Peg live in Wheaton, Illinois, about 30 miles west of Chicago, and spend time in Naples, Florida in the winter.

David also uses his knowledge of the musculoskeletal system as a volunteer, answering questions from members of TMA's Chicago support group where he is a member. He was drawn to a leadership role in TMA after attending an Annual Patient Conference.

A fan of exercise, David plays golf regularly, even if he does occasionally use his clubs for a little extra support. He would like to see more attention paid to the effects of systematic, personally-designed exercise programs that an individual patient can manage.

"We need to look at all kinds of lifestyle interventions, while still going forward with our drug investigations," he says.

> *Find the latest news, events, clinical trials, and more on the TMA blog:*
> **https://www.myositis.org/blog/**

Strength in numbers: Advocating for rare diseases

Rare diseases are not rare

TMA members Martha Arnold and Dale Scott and other rare disease advocates meet with staffers for Senator Robert Casey

TMA has teamed up with The EveryLife Foundation, a rare disease advocacy organization, to empower our members to advocate on legislative matters. During Rare Disease Month in February, TMA participated in the Foundation's Rare Disease Legislative Advocates program, where TMA members and staff learned the process of pressing lawmakers on issues important to the rare disease community.

- Myositis patients are part of the RARE army.
- 7,000 rare diseases affect 30 million people in the US.
- 95% of rare diseases do not have an FDA-approved therapy.

TMA board member Martha Arnold and former board member Dale Scott were among the TMA participants in this program. They met with staffers for five members of Congress from their home state of Pennsylvania, asking them to support increased funding for the NIH and FDA and to build the membership of the Congressional Rare Disease Caucus. They also left legislators with printed information about myositis diseases.

As TMA builds its advocacy program, members don't need to wait for Rare Disease Month or a special advocacy event to initiate a conversation with their own lawmakers. Members are encouraged to speak out and tell their stories to legislators on the federal and state level as well as locally. Here is some advice for myositis advocates:

- Make an appointment with your legislators while they are at home in their local offices on break (during Memorial Day or July 4 holidays, for example). This will increase the probability that you can meet with more senior members of the staff or even the lawmaker him- or herself.
- Consider inviting legislators to attend your support group meeting, so they can hear the stories of several patients. Be sure to get the local press to cover the event.
- Make your own media with these meetings by taking pictures or video and posting to Twitter (@TheMyositisAssc), Facebook (@Myositis), and other social media. Be sure to use hashtags, such as #MyositisAwareness, and include the TMA website: **www.myositis.org**.
- Always leave behind printed material about myositis, such as TMA brochures and flyers that have our contact and website information. Please let us know if you leave behind information.

Martha admits that approaching lawmakers can be intimidating. "While we had every right to be in that office, it's always a bit challenging to put yourself out there," she says. "As we proceeded, however, we got better at honing our stories and getting our key points out. This was excellent training and practice that will come in useful in other activities as we move forward."

TMA can provide support for advocacy efforts. Email us at ***TMA@myositis.org****.*

Speaking out about myositis

Lynn Lizarraga and her husband John

A former junior high school algebra teacher for many years, Lynn Lizarraga is not afraid to speak in front of an audience. So, when TMA was looking for a member in Arizona to share their myositis story with a group of healthcare professionals, she was eager to volunteer.

Lynn took the stage during a breakout session in a national strategy meeting for TMA Corporate Advisory Committee member BriovaRx, a national specialty infusion company that provides home IVIg and other infusion medications. She spoke to about 50 of the company's infusion care specialists and sales representatives who specialize in treating myositis and other autoimmune diseases.

Lynn was diagnosed with IBM in 2003. For a decade before that, however, she was diagnosed with Sjogren's syndrome and mixed connective tissue disease. And despite having IBM, which usually doesn't respond to IVIg, Lynn's doctor wanted to give it a try.

"When they invited me to speak, they just wanted someone to talk about myositis," Lynn says. "It was a happy coincidence that I had used IVIg. I was able to talk about how much benefit it was for me, the way it helped with the dysphagia and made me feel like I had more energy."

For the infusion specialists at BriovaRx, Lynn's story was an important touchpoint, a way for them to put a face to the diagnosis when a myositis patient comes to them for treatment. It helps them provide better support while they are caring for patients with these diseases.

This is one example of the way TMA is working to spread awareness of myositis and the impact these diseases have on patients and care partners. Many of the healthcare professionals in the audience had never seen a patient with myositis. Some may not have even known what myositis is. Hearing the stories of individual patients like Lynn can have a great impact on the quality of care they are now able to provide.

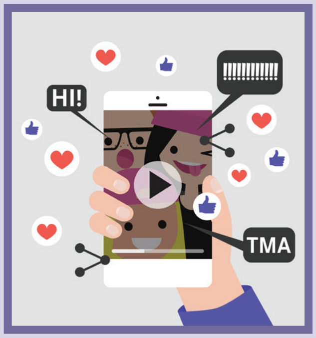
Presenting in this way before an audience of professionals is also a rich experience for TMA members. Talking about their symptoms, the journey to diagnosis, the changes they've needed to make because of their disease, and the ways TMA has helped them thrive is empowering.

"It was a wonderful experience," Lynn says. "TMA made everything so easy for me. It was my honor to help raise awareness of myositis as a representative of TMA."

Hints & Hacks

by Susan Mines

My "helper" is a simple wooden back scratcher. I have two around the house and now keep one in the basket of my walker in the bedroom and the other in a basket by my lift chair. I couldn't manage as easily without them. I can scoop up dropped items such as clothing, pull clothes up or down while dressing or undressing, and lift or lower shoes while sitting on my raised bed without danger of slipping off. Long barbecue tongs with rubber ends also help immensely in the kitchen, because my grip is weak and I often drop things. I live alone and was finally diagnosed with IBM five years ago. Any device to counteract frustration and promote safety is welcome.



We want to hear from you!

Do you have an original workaround for accomplishing something that is difficult for you? Do you have an idea that makes your daily life or your care partner's life a little easier? We welcome selfies, links to videos, and written articles describing how you have overcome some challenge with myositis. Send ideas to ***linda@myositis.org***

A splendid transportation find

by *Susan Honigstock*

In May I fell in my home, and our wonderful fire department came and picked me up from the floor. I soon discovered a large bump on the back of my head. My neck had begun hurting before the fall, and a friend took me to the doctor who checked me out and told me not to drive for at least ten days. I knew I had to heed his warning, since I couldn't possibly be a safe driver if I couldn't easily turn my neck.

I quickly realized that I had scheduled doctor and dentist appointments for the following week, so I decided to call my city's para transit office. They were most helpful and told me that I needed to register in order to qualify for this service. They drove me into the city, interviewed me, and watched as I negotiated some indoor sidewalks, then they drove me home.

A few days later, I received notification of my acceptance along with other information. I called para transit a week in advance and scheduled rides to my appointments. They gave me a time frame for pick up on both ends. Each ride costs only $2.50, and the drivers were friendly, helpful, and professional. I was delighted to learn that this service is also available for errands, social events, and going to meetings or the pool.

My pleasure turned to delight when I learned that the para transit service would also take me to the airport for a flight to Florida for a wedding. I will be traveling alone, but this service also lets a companion accompany you. In addition, they told me that once I reserve my hotel room and decide how many days I will be there, my local para transit will fax my paperwork to the county in which I will be staying. If that county has a para transit system and will provide me with visitor status, the same services will be available to me there. This opens up so many new traveling possibilities.

Does your community offer special services for the elderly or otherly abled? Try making a few phone calls to the social services department of your local government. You may be surprised what you learn.

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.

Kansas City Regional Conference

On April 6th, more than 60 patients and care partners traveled to Kansas City to participate in a day-long regional conference on myositis hosted by the Kansas University Medical Center and The Myositis Association. Attendees heard from experts in dermatomyositis, polymyositis, necrotizing myopathy, and inclusion body myositis. The Myositis Association's Executive Director, Mary McGowan, also presented on TMA programs and services. Attendees learned about the role that physical therapy, respiratory therapy, and nutrition can play in improving and maintaining their health.

The key note speaker, Dr. Olivier Benveniste, a member of TMA's Medical Advisory Board and Bohan Prominent Speaker, provided attendees an overview on "Recent Advances in Myositis Classification and Treatments." Since Dr. Benveniste lives and works in France, this conference provided the attendees the unique opportunity to learn about his leading research in this field.

The KU Medical Center and The Myosotis Association would like to extend our gratitude to the corporate host, Corbus Pharmaceuticals, and our exhibiting sponsor, ARJ Infusion Services, for making this unique event possible.

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****.*

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.***

THE MYOSITIS ASSOCIATION

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