

THE OUTLOOK



THE MYOSITIS ASSOCIATION

SPRING 2019
Quarterly Newsletter



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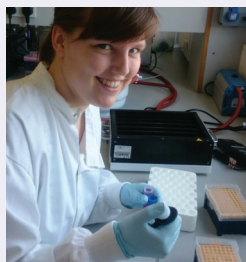
THE OUTLOOK

A quarterly publication of The Myositis Association

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TMA's vision is a world without myositis

TMA's mission is to provide education, research, and support to the myositis community

Who you are matters

Ah, spring! Flowers blooming, birds singing, life bursting forth everywhere with renewed vigor. My favorite part of spring centers around all the wildlife bearing young. I love the chance to encounter baby animals, offering new beginnings and hope, along with a reminder of the vast and unique differences life has to offer.

Spring also brings a sense of renewal and is a great opportunity for some self and professional reflection. It is a time to reflect and celebrate all that has passed and to consider what may be born in the future. It's a time to learn how we can build upon those experiences as we grow stronger for ourselves, our communities, and our workplaces.

As I reflect on 18 years working with the American Academy of Pediatrics (AAP), I am reminded that the AAP was founded because *children are not small adults* when it comes to healthcare. In the 1930's, physicians broke away from the American Medical Association because the science, at the time, was showing that children were emotionally and physically different than adults, and they have very specific needs. Pediatricians have since made a significant difference in addressing these specific pediatric healthcare needs.

Also, as the national spokesperson for eight years for the 48 million American women living with or at risk of heart disease, I am also reminded that *women are not small men*. Heart disease can be, and is, different in women than it is in men, and gender-sensitive care and treatment results in better patient outcomes.

In fact, many diseases and treatments affect women differently, including myositis diseases. As you will see in our feature article this month, dermatomyositis, polymyositis, necrotizing myopathy, and antisynthetase syndrome are more prevalent and are experienced very differently by women versus men. (Interestingly, inclusion body myositis is the exception to this rule: more men are affected by IBM than women.)

As May approaches, TMA is making plans for Myositis Awareness Month. We hope you and your friends and families will join us to raise awareness about this rare and chronic disease.

With thousands of women affected and minority women at even greater risk, TMA will have a special focus during May on raising awareness and educating women, especially women of color, about risk factors and symptoms, and we will offer lifestyle changes that can help everyone live better with myositis. We will also emphasize the need for more participation in clinical trials, especially by women.

TMA and our members are on the front lines in our communities educating, supporting, and advocating for patients with myositis. In our work to achieve better patient outcomes, we must also educate about gender and cultural differences.

The truth is, every month is Myositis Awareness Month at TMA. With the help of our dedicated TMA volunteer network of those who live with myositis, we raise awareness about myositis, provide social and emotional support, raise money for research, and advocate for policies that meet the needs of the 75,000 people living with myositis diseases.

We know just how much patients rely upon TMA's evidenced-based information about myositis diseases and their diagnosis, treatment, complications, and more. With greater investment, gender-specific research, and access to care, we can all help patients receive the individual treatment they deserve, resulting in better patient outcomes.

As we begin to better understand these gender and cultural differences in myositis, this will open the door for further in-depth and insightful investigation and understanding. TMA's goal is to ensure that all patients receive the best and most appropriate research-based treatment.

So, as we encounter baby animals this spring time, let's all be reminded of the vast differences in life and that *who you are matters*.

Mary L. McGowan

Women are not small men



Scientific research indicates that the evolution of male and female bodies developed crucial physiological differences to improve the chances for human survival, countless differences between the sexes that are often overlooked. Yet the medical establishment largely treats male and female patients

as though their needs are identical. Medical research is still done predominantly on men, with the results then applied to the treatment of women.

This is critically important information as, in fact, many diseases and treatments affect women differently:

- ✚ Women are more likely to suffer from autoimmune diseases.
- ✚ Women are more resistant to infectious diseases than men.
- ✚ Lung cancer is 170% higher in women than in men for the same number of cigarettes smoked.
- ✚ Women are 50% more likely to suffer from depression.
- ✚ Alzheimer's disease is expressed differently in men and women.
- ✚ The pain threshold is different for men and women.
- ✚ Women are more sensitive to antihistamines.
- ✚ Aspirin is more effective in stroke prevention for women, but more effective in heart attack prevention for men.

While the law obligates researchers to include women in their studies, in practice many neglect to analyze the results according to the participants' gender. Even in studies of diseases whose incidence is much higher in women, initial experiments primarily use male animal models.

There is insufficient research into the distinct gender differences that exist between men and women with

autoimmune diseases, including myositis. In the absence of gender-specific data, it is difficult to draw accurate conclusions about benefits or risks to women for a particular drug or device.

Myositis clinical trials rarely report gender-specific results, and some new drugs in development still have few female participants in their clinical trials. This has a negative impact on all women, because without female participation in clinical trials, it's impossible to know how treatment strategies work for women. Research needs to reflect the wide range of biological and psychological differences between women and men and how they affect treatment. This is true for women broadly, but it is especially important for African American women, Native American women, Hispanic women, and Asian women, as even amongst women, diseases manifest themselves differently.

For two decades, researchers have been striving to reduce health disparities among specific population groups by including in clinical trials and other studies participants who represent the diversity of the populations to which the study results will be applied. Still, scientists continue to face multiple challenges as they seek to include historically underrepresented populations in their research.

Despite these challenges, the importance of including women from diverse ethnic backgrounds in clinical research studies and analyzing the results by gender cannot be underestimated. Providing women with information on how diseases like myositis uniquely affect them will help them make informed treatment decisions in close collaboration with their health care team. More women in clinical trials could result in more appropriate prevention and early detection, more accurate diagnosis, and more effective treatment for all women with myositis. Research on women with myositis must be adequately funded to generate this critically important data.

Significant developments in research related to gender and gender-specific medicine during the last decade clearly indicate that gender differences can no longer be neglected in the medical community. Women are entitled to the medical treatment befitting their special traits as women—a change toward gender medicine to which medical care should aspire. Gender medicine needs to be at the core of the precision medicine concept that is changing the face of the medical field today.

Myositis: Not an equal-opportunity disease



Myositis experts often say that dermatomyositis is the easiest form of myositis to recognize. In addition to extreme weakness and fatigue, patients often present with an obvious rash that is distinctive for DM. This rash is not so obvious in every patient, however. For those with darker skin, such as African Americans and other people of color, the red or purple blotchiness over the shoulders and chest or around the eyes may not be as easy to identify as it is on lighter skin. A variety of research studies indicate there are other differences in how myositis diseases affect people of color as well:

- ✚ IBM is significantly less frequent in African American patients with myositis than in European American myositis patients.
- ✚ In adults, DM, PM, and NM affect more African Americans than Caucasians.
- ✚ Creatine kinase levels were found to be significantly higher in men compared to women, African Americans compared to Caucasians, and PM compared to DM.
- ✚ African-American myositis patients had higher frequencies of autoantibodies to anti-PL-12 (associated with antisynthetase syndrome) and anti-SRP (associated with necrotizing myopathy) compared with European American myositis patients.
- ✚ African Americans who have myositis-specific autoantibodies are less likely than other groups to have anti-Jo-1 antibodies (associated with antisynthetase syndrome).
- ✚ Independent of antisynthetase antibody status, African American patients experience more severe lung involvement than white patients.
- ✚ When compared with patients of other races, African-Americans with interstitial lung disease (ILD) were younger at diagnosis.
- ✚ Unique genetic factors have been found in both African Americans and Hispanics that appear to either protect individuals from myositis diseases or place them at greater risk.
- ✚ Mortality rates from DM and PM are highest among women of color. Nonwhite women are twice as likely to die than others with the disease, and they are four times more likely to die than white men with the disease.
- ✚ Nonwhite women die at a younger age than others with DM and PM.
- ✚ In the childbearing years (ages 15-34), mortality in nonwhite women is 3.5 times greater than in Caucasian women.
- ✚ Nonwhite women with multiple chronic conditions have the highest rates of hospitalization for dermatomyositis.
- ✚ Nonwhite DM patients have greater lengths of stay and higher costs of care when they are hospitalized.
- ✚ African American children with JDM have an increased risk of developing calcinosis.

TMA research funding made the difference

by Conrad “Chris” Wehl, MD, PhD



TMA funding has come at critical points in my career. Specifically, funding for a fellowship project enabled me to have “protected” time away from the clinic to focus on research, which is very critical early in one’s career when

the demands are on clinical care. The TMA pilot grant I received was an opportunity to perform a research study that would not be funded by any other agency, because it was a “fishing expedition,” trying to identify new therapeutic targets in patients with sporadic inclusion body myositis.

Traditional funding mechanisms, such as NIH grants, fund projects that are believed to have a reasonable chance of success. But often researchers need pilot funding to move a project forward. Our sequencing project directly led to two manuscripts and has identified a therapeutic target that we are now modeling in cells and mice with the hope of bringing a new treatment to the market.

As the research chair, my experience in being awarded both types of funding mechanisms has made me very sensitive to making sure that we identify 1) future leaders and 2) high-risk and high-reward projects that can be leveraged into traditional funding mechanisms that will advance the field.

Dr. Chris Wehl is a member of TMA’s Medical Advisory Board, serving as chair of the Research Committee. He is a neurologist at Washington University in St. Louis, Missouri.

Post-graduate fellows and early-career physicians and scientists committed to a career in myositis are invited to apply for TMA research funding. For application and other information go to: <https://www.myositis.org/research/tma-grants-fellowships/research-funding-opportunities/>



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OFFICIAL NOTICE: *The MYOVISION registry, in which many TMA members participated, is being closed in the spring of 2019 at Cincinnati Children's Hospital. The final dataset will reside with investigators at the National Institutes of Environmental Health Sciences (NIEHS) to complete the study objectives and analyses. By housing the data with NIEHS, future researchers may also be able to apply to use the registry database for additional studies not yet performed. Study subjects can be assured that TMA will be the sole group to re-contact any study subjects in the future, if needed. Anyone who previously participated in the study who would like to be excluded from future analyses of the data should send notification in writing to Linda Kobert, RN, MSN, Research and Communications Director, The Myositis Association, 1940 Duke Street, Suite 200, Alexandria, VA 22314.*

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.

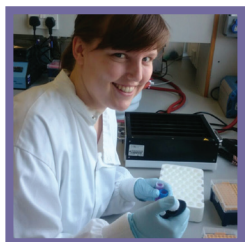
This clinical trial is underway and aims to enroll 150 patients over a three-year period. Multiple study sites are available throughout the US and abroad. Participants will first receive either abatacept, the study drug, or a placebo via a weekly injection under the skin for 24 weeks. Then, all study 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.

New research grants awarded



Since 2002, TMA's research funding program has awarded 37 grants and 19 research fellowships, totaling nearly \$7 million. This year, TMA's Medical

Advisory Board recommended the funding of three new research projects.

Harvard neurologist **Dr. Steven Greenberg** was awarded a grant for a "Pilot study of CD8 T-cell imaging with 89Zr-Df-IAB22m2C in IBM." This is a novel imaging agent that has been shown to be effective in monitoring immune system activity during cancer treatment. Dr. Greenberg hopes this new agent will provide a means for monitoring similar immune activity in patients with IBM.

Rheumatologist and Director of the Johns Hopkins Myositis Center **Dr. Lisa Christopher-Stine** received funding for the project "The gut and skin microbiota in patients with DM." The microbiome is increasingly being recognized as an important influence in a wide range of diseases, especially autoimmune conditions. Dr. Christopher-Stine hopes to begin an exploration of the significance of the microbiome in myositis patients by identifying organisms commonly occurring in dermatomyositis patients.

Geneticist **Dr. Johanna Parkes** received a post-doctoral fellowship grant for the project "Role of innate immune and metabolic pathways in mediating muscle weakness in myositis." Dr. Parkes hopes to identify specific areas of cell metabolism that may be related to chronic muscle weakness in patients with myositis. Dr. Parkes is working with TMA medical advisor Dr. Kanneboyina Nagaraju at SUNY Binghamton.

Funds for TMA's Research Funding Program come primarily from myositis patients, their families, and friends. Each year, proposals are sought for basic and applied research projects as well as applications for fellowships from young scientists who have an interest in a career studying myositis. Based on

recommendations from TMA's Medical Advisory Board of international myositis experts, TMA's Board of Directors chooses the most promising of these proposals to fund.

More information about past TMA-funded projects can be found at www.myositis.org.

TMA appoints myositis experts to MAB

TMA is pleased to announce the addition of three new myositis expert to its Medical Advisory Board. The MAB brings together 23 of the world's most prominent myositis researchers and clinicians in the fields of rheumatology, neurology, pulmonology, dermatology, and rehabilitation to unite their unique research and clinical perspectives in the effort to bring better understanding, new treatments, and eventually a cure for myositis diseases. These specialists also lead TMA's educational efforts and advise the organization's research funding program.

These new appointments expand the range of disciplines represented on the MAB to include, for the first time, a pulmonologist, an occupational therapist, and a physical medicine/rehabilitation specialist.



Tae Chung, MD developed his interest in treating neuromuscular diseases while serving in the military in his home country of South Korea.

"I was exposed to a lot of musculoskeletal injuries that needed rehabilitation when I was in the army," he says. "I was interested in neurology, so I thought combining neurological disorders and rehabilitative interventions made a lot of sense."

Following his two-and-a-half-year service obligation, Dr. Chung started residency at Johns Hopkins University in Baltimore in the physical medicine and rehabilitation program. While there, he cared for a patient with polymyositis.

"I've seen a lot of people with strokes and spinal cord injuries, very severely debilitated patients," Dr. Chung says, "but that man was probably the most disabled patient I'd ever seen. He was literally only able to flick his fingers and roll his eyes. But his entire sensory function was completely intact, so he was in a lot of pain. I wanted to know more about this disease."

Through this patient, Dr. Chung discovered that Johns Hopkins had recently created a Myositis Center, so he called TMA medical advisor and co-director of the Center Dr. Andrew Mammen. Since then, Dr. Chung has devoted much of his career to studying, diagnosing, and prescribing rehabilitation for patients with myositis diseases. He has organized a myositis rehabilitation team at the Center, comprising specialists in physical, occupational, and speech therapy.

Dr. Chung is excited that his discipline of physical medicine and rehabilitation has become an important part of TMA's team of medical advisors.

"A lot of people get confused with the roles of exercise, physical therapy, and physical medicine/rehabilitation doctors," he says. "I explain to patients that I am like a pharmacist for exercise. My role is to understand the biomechanics of the patient and the nature of the disability and to prescribe specific rehabilitation therapies that will improve their condition."

It was an individual patient who led pulmonologist **Sonye Danoff, MD, PhD** toward a career treating and trying to figure out what's behind interstitial lung disease (ILD). Dr. Danoff has served on the faculty at Johns Hopkins University Medical School for more than 18 years. She is Co-Director of the Interstitial Lung Disease Clinic there and serves as Associate Director of the Hopkins Myositis Center.

"During my first year on faculty, I took care of a really wonderful man who had very rapidly progressive ILD," she says. "He was initially told he had idiopathic pulmonary fibrosis, which is a disease of aging. But he was a young man. We realized he had autoimmune lung disease, and when we started to treat him as such, he stabilized and did very well."

As Dr. Danoff worked with this patient, she realized how incredibly interesting and challenging this disease is, a disease that appears as a symptom in a wide range of autoimmune conditions. She is now one of the leading physician scientists dedicated to understanding and treating ILD, which disproportionately affects women and minorities.

Her work focuses on understanding why some people who have myositis also develop ILD. Along with others at the Hopkins Myositis Center, Dr. Danoff has helped to discover and understand what autoantibodies tell us about myositis diseases and how they best respond to a particular treatment.

But it's not just disease that Dr. Danoff learned about from that first ILD patient she treated. She developed a close relationship with this African American man who also helped her understand a great deal about how some minority patients may view the healthcare system.

"He was very honest with me about his distrust of the medical system," she says. "And for both of us, it was an eye-opening experience to have this close relationship."

This honest, sharing relationship is, Dr. Danoff says, important for all doctors and patients. "We need to make this journey of understanding together. Good outcomes really depend on incredibly good communication between the physician and the patient and a willingness to be partners, both in the decision-making process and in the research process."

Dr. Danoff says, "I am very excited to be part of TMA's Medical Advisory Board. ILD is so clinically important in myositis diseases and has such an impact on patient outcomes, that it's so important for the pulmonologist to be at the table with all the other physicians."



When **Malin Regardt, OT, PhD** started graduate school, she never expected to create a career in myositis. She was working as an occupational therapist in the rheumatology clinic at Karolinska University in Sweden where one of the world's most distinguished myositis experts,

Dr. Ingrid Lundberg, has led some of the most important myositis studies for several decades.

"I wanted to do hand exercises for RA [rheumatoid arthritis]," Dr. Regardt says. "But Ingrid said, 'We have some data in which we have recognized that patients seem to have less strength in their hands than the textbooks say they do.' So I thought maybe this could be interesting."

Dr. Regardt went on to complete her PhD work, and in 2015, she received a post-graduate fellowship from TMA to study hand exercise, activities of daily living, and quality of life in people with IBM. Many TMA members served as subjects for this project.

Dr. Regardt now serves as head of research and development at Karolinska University Hospital and continues to study the therapeutic impact of hand exercise on myositis diseases. She is also an investigator with the OMERACT (Outcome Measures in Rheumatology) Myositis Special Interest Group, an international collective working to incorporate the patient perspective into myositis research studies.

This past fall, Dr. Regardt joined the TMA Medical Advisory Board, adding for the first time an occupational therapist to the MAB.

"As occupational therapists, we talk to patients about the kinds of activities they have problems doing, so we can help them develop new strategies to manage their daily activities," she says.

While patients might list many things that they struggle with, Dr. Regardt explains that she tries to emphasize activities that are most meaningful and makes suggestions that will help them balance their energy throughout the day. Focusing on what brings the individual joy is important to maintain a good quality of life. So if a patient thinks that vacuuming the house is too much of a chore, for example and there are other activities that give more meaning and energy, she suggests patients hire someone to clean the house, if possible, so they can spend their energy on a more meaningful activity, such as playing with their grandchildren.

"I do a lot of clinical research," Dr. Regardt says.

"That is what drives me. I want to see what we can do for the patients, because it's the patients who are important to me."

Dr. Regardt is married with two sons ages 9 and 12. And cleaning the house is not one of her priorities either. She'd rather be out in the garden or picking wild mushrooms in the forest.

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Tricha Shiva joins TMA staff



TMA's newest staff member can't remember a time when she wasn't concerned about those who live with chronic diseases. As TMA's new Development Director, Tricha Shivas feels the challenges of chronic illness have an impact

on everyone in our society, and she learned from a young age that it is important to reach out and lend a hand whenever you can.

"My mom thought it was important for us, even as kids, to be helpful to anybody in need," she says. "Everybody has different challenges, so when you can offer assistance to someone, it's your duty to do that."

With an academic background in biomedical ethics, Tricha has spent her career in health care services and administration. She worked with hospital staff in an organ donation program and coordinated a camping program for children with disabilities, but it was in her work with the Muscular Dystrophy Association where she first became acquainted with myositis.

As Director of Health Care Services and Family Support at a Washington, DC area MDA clinic, Tricha saw people with all forms of myositis, and she worked directly with a number of folks with inclusion body myositis. It was an eye-opening experience for her to realize the impact IBM can have on someone's life. Many of her patients were progressing in their illness, needing more help with mobility and adaptive changes in their homes.

"There was one gentleman with IBM who was fantastic," Tricha recalls. "He was really keen on being a mentor to other folks who were newly diagnosed. He would talk to them about his journey and what they could expect. I thought it was incredible that he was willing to offer himself to someone else in that way. He wanted to be able to say don't give up!"

After several years in clinical services, Tricha decided to make a shift into fundraising. As part of this process, her journey took her to WomenHeart: The National Coalition for Women with Heart Disease, where she worked with TMA's new executive director, Mary McGowan as Senior Manager for Partner Relations and Development.

"I'm crazy about fundraising," Tricha says. "Philanthropy is a way for people to demonstrate that they are passionate about something. And fundraising is a way to reach out to people, talk about what you're passionate about, and help them become passionate about it too."

Raising money for WomenHeart was, for Tricha, another opportunity to lend a hand to those in need. "Heart disease in women is a health issue that is largely ignored in this country," she says. "And one of the things I wanted to do was to give a voice to those women whose voices are not being heard."

After working with myositis patients at MDA, coming to TMA as Director of Development and Strategic Partnerships is like coming home, for Tricha.

"It's such an honor to work with people with myositis," she says. "This is a condition I am familiar with, and I am very passionate about making sure that rare diseases get the attention they deserve."

NEEDED: Adults with moderate to severe Dermatomyositis (DM)

Pfizer is currently seeking adults 18 to 80 years of age for a dermatomyositis clinical trial. This clinical trial will assess the effectiveness and safety of an investigational study drug compared to placebo. The study drug is a type of drug called a biologic and is given monthly by infusion.

The clinical trial is currently active and enrollment is open at multiple sites across the United States. Qualified participants will receive all study-related care and study drug (or placebo) at no cost.



Learn more at:
www.pfizer.com/science/find-a-trial/nct03181893

When everything is going wrong

by Mike Matthews



My wife and I were pumped up after the 2018 TMA Annual Patient Conference in Louisville. The conference exceeded our expectations, which were very high to start with. We were dazzled and amazed by how organized the event

was, the quality of the presentations, and the networking opportunities available. After struggling for the past three years with the isolation of such a rare condition as dermatomyositis, we felt the interconnectedness with peers who are striving to live life to the fullest despite the difficulties of a serious chronic condition. It felt like a big family reunion, and we left feeling hopeful and optimistic.

We went from blissed to stressed, however, when we returned home to Indiana to find a flooded basement from a broken sump pump. This was the first of a constellation of problems that happened all within one week of returning from the conference. Hurricane Florence hit North Carolina, and relatives who evacuate needed a place to stay. My 93-year-old aunt in Cincinnati fell and broke her clavicle and needed our help. And for the first time, I experienced a very serious, full-body dermatomyositis rash with swelling so bad I could hardly flex my arms. This happy myositis warrior was very humbled by all this, but I was not defeated.

I've always worked very difficult and challenging jobs (teaching, counseling, social work, law enforcement), which were rewarding but required a strategy to maintain sanity during the tough times. I made a life-long vow decades ago to stay positive no matter what the external circumstance, and this commitment has served me very well. In the crucible of extreme circumstances and the cascade of challenges they can present, however, it is easy to know what to do but to not do what you know. I knew I had to snap myself out of the gauntlet of negativity as soon as possible.

After reaching that challenging threshold, I slowed my breathing and thinking and executed the strategy that has always worked to get me from feeling stressed to feeling blessed: I simply count my blessings. I have a wonderful family, legs I can still walk with, two eyes to see all the circumstances that bring me happiness and fulfillment. Although I had 59 years of becoming bigger, stronger, and faster as a life-long competitive athlete, now that I'm start my seventh decade of life I'm trending toward smaller, weaker, and slower. But I still have a sharp mind that I can use to reinvent myself to become poised for the best and healthiest life possible, even with dermatomyositis. I even found a way to make my horrible rash beneficial by volunteering to be a case study patient for the Kentucky Dermatology meeting, which raised awareness of myositis among the 50 doctors attending the meeting.

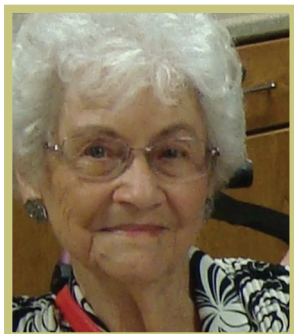
I'm an optimist. I honestly appreciate the lessons I have learned during my painful journey with myositis. I've participated in two fire walks, walking barefoot over burning coals, not to learn new picnic tricks, but as a metaphor for walking confidently through the fires of life. Nothing feels as good as the cold water sprayed on my feet after walking through 2,000-degree coals. But even more significant is the mental euphoria of the accomplishment. Walking through the fire of myositis has made me more focused, compassionate, and grateful for every moment of life. The suffering of DM and the positive coolness of awakening has run together for me.

My message to others is this: develop a vision and set of beliefs that ignite your passion and gratitude for every day of your life. Be realistic and authentic, but stay enthusiastic as you adjust your goals to reinvent yourself based on your circumstances. I strongly believe that I always have more than enough circumstances to be happy. Life happens for me, not to me. Every day is a blessing, and I must find ways to be kind and useful. My experience with dermatomyositis has been brutal at times, but I have always had a profound acceptance of life's ultimate goodness, no matter what happens. We can "do hard," give thanks, and be grateful in all circumstances.

TMA member Mike Matthews was diagnosed with dermatomyositis in May of 2017. Though he is now fully retired, he continues to fulfill his personal mission of creating a healthier and more positive community.

TMA is support for a lifetime

by Ruth Peto Wieclaw



I am a survivor of an autoimmune disease called polymyositis. It is a very rare illness, one that I had never heard of until I was diagnosed. Until I became ill, my doctors had never seen a case.

I became ill at the age of 63 in 1986. First I had a case of the flu. I didn't recover normally. I was working at the time as a nurse in the obstetrical department. My last duty of the day was to discharge a mother with her new baby. There was construction going on in the hospital, and I had to push her wheelchair a long distance to the temporary

discharge area. I was very weak and stumbled on the way, and I thought to myself that I needed the wheelchair more than the patient. Driving home that day was not easy; I couldn't move my leg to step on the brake and had to pick the leg up with my hand.

My condition deteriorated until I lost the use of many muscles and could no longer function. I had to quit working. I had trouble walking, and swallowing was a problem. It took both hands to hold a glass of water, and it was difficult to hold my head up.

My doctor treated me like I just had something minor and told me to come back in ten days for another blood test. But I changed doctors, and the new one recognized the severity of my illness and immediately called in a local neurologist. He tentatively made a diagnosis of polymyositis based on having seen the disease when he was a resident physician. I was admitted to the hospital the same day. After spending two weeks in the local hospital with little improvement, though, I was transferred to Atlanta's Emory University Hospital for another two weeks.

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It took some time to correctly diagnose and treat my illness, because the doctors were considering a number of other similar maladies, including polio and Guillain-Barré syndrome. I was finally diagnosed with polymyositis.

Once finally diagnosed, medications were started, including methotrexate and huge doses of prednisone, along with IVs and daily treatments with plasmapheresis (a process for cleansing the blood). I was also getting tube feedings, because I could no longer swallow.

After returning to my hospital room following one of the plasmapheresis sessions, I put a small piece of ice into my mouth, because my throat was so dry, and immediately felt a sensation of cobwebs being swept from my throat. It was the turning point of recovery; I call it my miracle.

When I was released from the hospital, I thought they were being cruel because I still could hardly move. Every movement was an effort; I just wanted to lie there. After I got home, there were months of physical therapy until I could walk and resume normal activity. It took a whole year to recover.

In 1994, eight years after my initial illness, I started having symptoms of muscle weakness again. My illness was returning. This time my doctors knew what to look for and were able to treat me with medication before it got a good start. I recovered after a few months and have not had a recurrence of that dreaded disease again.

I've gotten on with living my life. There were many good times and a few sad ones. I was happy to still be alive and thanked God daily for surviving. I didn't dwell on the terrible illness I had endured. Every day of my life was, and is, a bonus.

Years went by and I never met anyone who shared my illness. I was a phenomenon, I thought. Then in July of 2014, I happened to read an article in the local newspaper, announcing a meeting of the Myositis Support Group of Southwest Florida. I perked up and decided I would qualify to attend since I had been afflicted with a myositis illness. I called in my reservation.

I met many friendly people with whom I had much in common, although I knew none of them. They had come from all over the west coast of Florida. Some were in wheelchairs or using canes or walkers. Some had caregivers with them. They were in various stages of their illness, all of which I could identify as having shared.

The Southwest Florida Myositis Support Group was founded by The Myositis Association to give support to those with myositis, their families, and caregivers. The primary goal is to raise awareness of the disease and to raise funds for research, along with offering support and friendship to each other. These TMA KIT Groups (which stands for "Keep In Touch") have been founded all over the country.

I've enjoyed meeting many people who are associated with myositis illnesses, and I gain knowledge by attending KIT meetings. I'm fully in remission of that terrible illness, but I attend meetings to learn more about it and to lend support to anyone who is struggling with it now.

Even at the age of 95 and having been in remission for nearly 25 years, Ruth Wieclaw still enjoys attending every meeting of her TMA KIT Support Group. "It's interesting to me," says Ruth Wieclaw. "I've made friends there and I've learned a lot." She has four children, five grandchildren, and three great-grandchildren. She lives in Venice, Florida.

Find out more about the TMA KIT Support Group near you. <https://www.myositis.org/patient-support/support-groups/>

Taking a stand for accessibility

by Susan Honigstock



Exercise is good for all of us, so I am lucky that there is a warm indoor pool not far from my home. I have been taking aerobic classes for many years and, if I choose, I can go into the deep water and exercise as I please. The facility offers two electric chairs to help enter and exit the water, but the changing room is another story.

The changing room is fairly conventional: two rows of whole and half lockers separated by benches one can sit on while changing. The benches are secured to the floor, so if one uses a walker, scooter, or wheelchair one cannot access the lockers in the middle of the rows.

No matter how early I arrive for a class, the corner lockers are usually taken, which is frustrating. So I spoke to the pool supervisor, describing my situation and suggesting a change. "Yes," she agreed, "we should do something."

But the following months brought new supervisors, which forced me to repeatedly express my frustration. I really did not ask for much; I just wanted the corner lockers to be accessible to people with disabilities. Eventually, a supervisor looked up the ADA rules and regulations, agreed that the facility was obligated to fix this problem, and considered when the maintenance man could add this to his schedule.

This week, I had a lovely surprise when I entered the locker room. The corner lockers, four full and four halves, had signs on them noting these lockers are reserved for handicapped individuals and families with small children. Yes!

Making a reasonable request in a persistent and constructive way actually can work. I am mindful of changes I can make in my own environment as well as changes that will take a bit more persistence. I take these changes as a challenge, and I try to stand firm.

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.



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Be sure to check TMA's website
(www.myositis.org) for the most current
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