

THE OUTLOOK



THE MYOSITIS ASSOCIATION®



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Quarterly Magazine

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THE OUTLOOK

A quarterly publication of The Myositis Association



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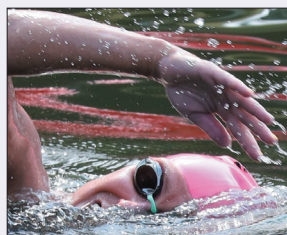
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TMA's mission is to improve the lives of persons affected by myositis, fund innovative research, and increase myositis awareness and advocacy.

TMA's vision is a world without myositis.

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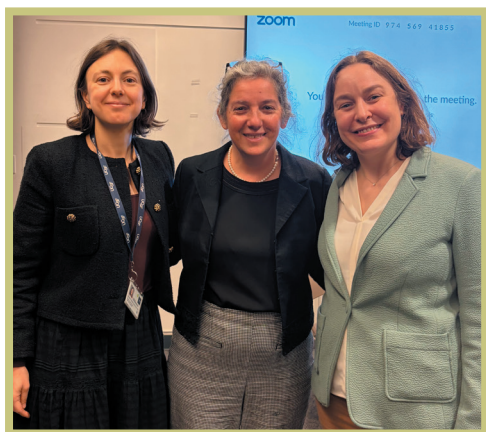
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Inaugural Visiting Professor Program Sparks Collaboration at UCSF



Drs. Dr Charlotte Hurabielle, Sonye Danoff, and Anna Haemel

The Visiting Professor Program event at the University of California, San Francisco (UCSF) was a resounding success, bringing together specialists from pulmonology, rheumatology, and dermatology to advance education and collaboration around myositis and rapidly progressive interstitial lung disease (RP-ILD).

The event also marked the highly anticipated return of TMA's Visiting Professor Program, launching a renewed series of grand rounds lectures led by TMA medical advisors for the first time since the COVID-19 pandemic.

A key feature of the program was the participation of Sonye Danoff, MD, PhD, pulmonologist and interstitial lung disease specialist at Johns Hopkins University, who delivered two educational

presentations focused on the recognition and management of MDA-5-related disease. By intentionally bringing multiple specialties together, the program created valuable opportunities for physicians to learn from one another and discuss strategies for earlier diagnosis, timely referrals, and coordinated patient care.

Approximately 15 to 20 physicians attended each session in person, with additional participants joining virtually. The discussions were marked by a high level of engagement, with clinicians exploring both clinical challenges and opportunities for stronger interdisciplinary partnerships. The event also provided an opportunity for healthcare professionals who frequently collaborate through referrals and consultations to connect face-to-face, helping to strengthen professional relationships across departments and specialties.

The day's impact extended beyond the formal presentations. Conversations continued during a Women in Pulmonary luncheon and through one-on-one meetings with faculty members specializing in interstitial lung disease and lung transplantation. These discussions helped identify shared interests in improving care for patients with MDA-5 disease and highlighted opportunities for future research and multi-institutional collaboration.

Supported by The Myositis Association (TMA) and **Nori's Fight**, the Visiting Professor Program successfully advanced awareness of these rare and often difficult-to-diagnose conditions while fostering meaningful dialogue among clinicians. The event demonstrated the power of bringing experts together around a common goal and laid the groundwork for ongoing partnerships that could improve outcomes for patients and families affected by myositis and associated lung disease.

A second multidisciplinary Visiting Professor event is planned for ILD Awareness Day, September 16, in Pittsburgh.

"We started Nori's Fight because we watched someone we loved face a disease almost no one around us understood. That's the reality for so many families with Anti-MDA5 dermatomyositis and interstitial lung disease. Only a few centers of excellence in the country specialize in it, and most doctors outside these centers have never seen a case. That gap in knowledge costs patients precious time. The Visiting Professor Program closes that gap, bringing leading experts directly to the physicians and communities who need them, so expertise no longer stays in a few centers. What has moved me most is watching the energy and engagement in the room: doctors leaning in, asking questions, and hungry to learn more so they can help their patients. It's how we turn what we learned the hard way into something that protects the next family."

~Julia Nickerson, President, Co-Founder of Nori's Fight

Two TMA Research Grants Completed

Earlier this year, two TMA-funded research projects were finalized. These studies, funded by TMA donors, provide important insights into the role of mitochondria in juvenile myositis and cell aging in inclusion body myositis. We are grateful to Dr. Lloyd and Dr. Lood who are making progress toward a better understanding of these diseases and the possibilities of new, effective treatments.



New Model for Understanding IBM

Dr. Thomas Lloyd and a team of scientists at Baylor College of Medicine are advancing understanding of inclusion body myositis (IBM) by developing a novel

model using muscle cells derived directly from patients. Their research shows that IBM muscle cells have intrinsic abnormalities—even outside the body—including increased inflammation, degeneration, and signs of cellular stress.

A key finding is that these cells exhibit persistent DNA damage and impaired repair mechanisms, which appear to drive cellular senescence—a form of aging that may contribute to muscle weakness and disease progression. The team also identified increased production of inflammatory molecules associated with senescence, suggesting a cycle of damage and inflammation within muscle tissue.

To explore potential treatments, the researchers tested senolytic drugs (dasatinib and quercetin) designed to target and eliminate aging cells. While these therapies did not improve senescence markers in this model, the findings provide important direction for future studies, including testing in more complex systems.

Importantly, this project establishes a reliable patient-derived model that closely reflects IBM

biology, offering a valuable platform for studying disease mechanisms and testing new therapies. Overall, the work highlights cellular aging and impaired DNA repair as central drivers of IBM and points toward new therapeutic targets for this challenging disease.

Read more about Dr. Lloyd's TMA-funded project.



Exploring the "Power Plants" in JDM

Dr. Christian Lood and his team at the University of Washington are working to uncover the role of mitochondria—the tiny "power plants"

inside our cells—in juvenile dermatomyositis (JDM).

The team has identified unique changes in mitochondrial DNA in children with JDM, findings that may help predict disease progression and guide future treatments. The team also discovered that mitochondria released into the bloodstream—normally contained within cells—may serve as powerful new markers of disease activity, even outperforming commonly used tests.

Importantly, these circulating mitochondria may also contribute to inflammation, as the immune system can mistake them for harmful invaders. Within muscle tissue, the researchers found that inflammation can reduce the number of mitochondria, potentially contributing to muscle weakness. Encouragingly, they also observed that platelets may help restore energy by delivering healthy mitochondria to damaged muscle.

This emerging research points to new possibilities for both monitoring and treating JDM, including strategies to protect or replace mitochondria. With further study, these insights could lead to innovative therapies to improve strength and quality of life for those affected.

Read more about Dr. Lood's TMA-funded project.



FAST for DM: A Unique Nutrition-based Clinical Trial

The Fatty Acid Supplementation Trial (FAST) for Dermatomyositis is an ambitious, patient centered clinical research study led by physician scientists at the National Institute of Environmental Health Sciences (NIEHS), part of the National Institutes of Health. This project explores a deceptively simple but scientifically compelling question: can omega 3 fatty acids—commonly found in fish oil—meaningfully reduce disease activity and improve quality of life for people living with dermatomyositis (DM) or juvenile dermatomyositis (JDM)?

Current treatments for DM and JDM often rely on immunosuppressive medications, which can be effective but carry substantial side effects.

FAST takes a different approach by investigating whether targeted nutritional supplementation, combined with a healthy diet pattern, can modulate inflammation in a safer, more sustainable way. Participants take omega 3 fatty acid soft gel capsules—or placebo capsules—twice daily while following a guided healthy eating plan. Researchers believe omega 3s may help decrease muscle inflammation, improve strength, and support overall well being.

Led by myositis experts Dr. Lisa Rider and Dr. Adam Schiffenbauer, the study is designed with both scientific rigor and participant experience in mind. Adults aged 18–60 with mild to moderately active DM or JDM complete five in person visits at the NIH Clinical Center over nine months, along with two telehealth check ins. These visits include advanced imaging such as MRI, blood and urine testing, stool sample collection, and detailed clinical evaluations. Participants also receive dietary coaching, wear an activity tracking device to monitor movement and sleep, and periodically report their food intake. All medical evaluations, imaging, coaching, and study medications are provided at no cost, and participants may receive up to \$800 in compensation.

Ultimately, FAST aims to generate high quality evidence on whether omega 3 supplementation can serve as a meaningful adjunct therapy for dermatomyositis. For patients seeking gentler, nutrition based strategies to complement traditional treatments, this study represents an important step toward expanding therapeutic options and improving long term outcomes.

You can find this clinical trial and other research opportunities on TMA's website using these links:

Clinical drug trials provides a list of clinical studies that are currently seeking research subjects to test medications for myositis diseases and their complications.

Registries and natural history studies provides a list of research projects seeking patients who are willing to serve as subjects by providing information and submitting to examinations so scientists can better understand myositis diseases and their impact on patients and families.



Dr. Wehl (c) and his research team

The Small Things: Rethinking How We Measure Hand Function in IBM

For many people living with inclusion body myositis (IBM), the first changes are easy to overlook. A shirt button takes a little longer to fasten. A key doesn't turn as easily in the lock. Picking up coins from a table becomes frustrating. These are small moments—until they aren't. Over time, these everyday difficulties add up, quietly reshaping daily life.

Researchers have long known that hand weakness is a hallmark of IBM. But a growing body of research suggests something equally important: We may not have been measuring that weakness in the most meaningful way.

Not just strength alone

Traditionally, doctors and researchers have relied on a standard questionnaire called the IBM Functional Rating Scale (IBM FRS) to track disease progression. It asks patients to rate their ability to perform certain activities, including those involving the hands.

But IBM progresses slowly, and the changes can be subtle. For patients, there's often a wide gap between “no problem” and “serious difficulty”—a gray area

where real-life challenges exist but may not be captured by standard scoring. That raised an important question: Are we missing important changes because we're not asking the right questions?

To explore this, researchers at Washington University in St. Louis took a closer look at how hand function is measured.



Testing grip strength

In one study, more than 80 people with IBM participated in a detailed evaluation of hand strength and function. Researchers measured how strongly participants could grip and pinch, while also asking them to complete different questionnaires. One was the familiar IBM FRS. The other

was a newer set of questions focused on very specific tasks—things like buttoning a shirt, opening a jar, or turning a key. The difference turned out to be striking.

While the traditional scale often showed little change until weakness became severe, the task-based questions revealed much more subtle shifts in ability—changes that patients were already experiencing in their daily lives. In other words, patients themselves were providing one of the most sensitive measures of disease progression.

Not all strength is the same

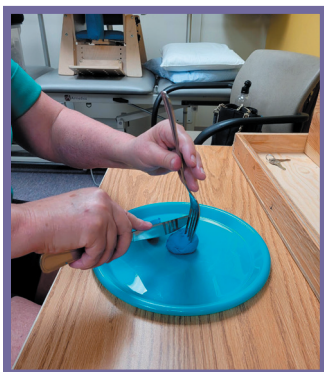
The study also highlighted something else important: Hand strength isn't just one thing.

Grip strength—the ability to squeeze—is different from pinch strength, which relies on the thumb and fingers working together. In IBM, these functions can decline differently because they involve different muscles.

“We measured pinch with the thumb and index finger using a paper-thin force transducer, so people were actually using a pinching motion,” says Dr. Chris Wehl, who served as principal investigator for these studies.

Dr. Wehl's team found that measuring both grip strength and pinch strength gives a clearer, more complete picture. Relying on just one risks missing important changes.

They also observed that declines in hand strength tend to be greatest in the earlier years of the disease, before leveling off later on. This makes early, sensitive measurement even more critical, especially for clinical trials.



Testing real-world tasks

Participants were asked to perform real-world tasks like handling small objects, completing timed dexterity tests, and using their hands in ways that mirror daily life. These performance-based tests offered a window into the practical impact of IBM.

Not surprisingly, they showed that many individuals struggle with fine motor skills, often losing independence in small but meaningful ways. But these tests also revealed something encouraging: they provided a clear, measurable link between strength and real-life function. Grip strength, questionnaire responses, and performance tests were all related, but each captured a slightly different aspect of the experience of living with IBM.

Watching function in action

A second study approached the question from a different angle. Instead of relying mainly on strength measurements or questionnaires, researchers focused on what people could actually do with their

Taken together, these studies point toward a simple but powerful idea: No single measurement can fully capture hand function in IBM. Strength tests, patient-reported experiences, and real-life performance assessments each tell part of the story. When used together, they create a fuller, more accurate picture of how the disease affects daily life.

Why this matters

This matters far beyond the research setting. In clinical trials, the ability to detect small changes can make all the difference. If a measurement tool isn't sensitive enough, a treatment that is actually helping might appear ineffective.

“These studies are also important for current clinical trials, many of which focus on ambulatory patients,” says Dr. Wehl. “Sensitive hand-function measures may help capture meaningful outcomes for non-ambulatory patients as well.”

By improving how hand function is measured, researchers can better track disease progression, more accurately evaluate potential therapies, and design trials that reflect what truly matters to patients. And what matters most is not just muscle strength—it's function. It's the ability to hold a fork, button a shirt, write a note, or open a door. It's independence in the smallest, most personal parts of life.

As research continues, one message is clear: To understand IBM, we need to listen to patients, measure carefully, and look closely at how people live, not just how strong they are. And in doing so, we move closer to treatments that don't just change numbers—but make a real difference in everyday life.

Conrad (Chris) Wehl, MD, PhD, is Professor of Neurology and Head of the Neuromuscular Section at Washington University School of Medicine in St. Louis. Dr. Wehl and his team from Washington University in St. Louis recruited TMA members at several Annual Patient Conferences to serve as research subjects for these studies.

Dr. Wehl will receive TMA's Heroes in Research Award at MyoCon 2026.

Read reports of these studies here:

<https://pmc.ncbi.nlm.nih.gov/articles/PMC9756909/>
<https://pmc.ncbi.nlm.nih.gov/articles/PMC9724478/>
[https://www.nmd-journal.com/article/S0960-8966\(23\)00166-9/fulltext](https://www.nmd-journal.com/article/S0960-8966(23)00166-9/fulltext)

Choosing Joy

By Theresa Curry



Chip Galloway with Columbia Fireflies minor league baseball team mascot

"I almost didn't go to my first TMA conference in San Diego," says Chip Galloway. He'd been diagnosed with IBM and was afraid attending a conference for others who were living with this rare, debilitating disease would plunge him into a crowd of sad and fearful people.

Chip changed his mind, though, when TMA staff member Rachel Bromley invited him to present the popular "Finding Strength through Faith" session at the 2023 Annual Patient Conference. The experience was a big surprise for Chip. Instead of finding a hotel filled with depressed people, "I felt like I had come to a family reunion," Chip says. "We all had something in common, and we were all there to help each other."

For Chip, joy is in him. He feels it as a spiritual state that's there even in the middle of difficult circumstances. When he discovered he had a debilitating degenerative disease, his familiarity with this spiritual state helped him turn his attention to bringing joy and meaning to this difficult circumstance. His deep faith—the reason Rachel thought of him for that conference session—continues to give Chip a sense of purpose in his IBM diagnosis and inspires him to share that delight with others. Indeed, his infectious happiness has made him an unofficial ambassador for joy within the myositis community.

"I'm an encourager," he says. "It doesn't matter if I'm talking to people who aren't believers. I'll find a way to encourage them. I hope they will notice something different in me, my ability to remain positive even as my disease progresses, and that will be a start."

Chip now serves on TMA's Board of Directors as Treasurer and is a tireless, always-upbeat champion for people with myositis. Besides helping others, he manages to combine his work for the myositis community with activities he has always enjoyed. For example, he took a cue from "Myositis Joe" Sanchez and has participated in charity walks to raise awareness about myositis. He also supports the "First Pitch" campaign developed by Vance Robinson.

Those like Chip who live with myositis and learn to embrace the helpful and hopeful parts of their lives despite the struggles, may be on to something. Thanks in part to the innovative and influential research of Anthony D. Ong, PhD, a professor of psychology at Cornell University, we now understand that joy is an important part of dealing with the challenges of everyday life and is especially helpful for those who must navigate the demands of chronic disease.

Studies have shown that focusing on the positive is not just valuable as a distraction from illness and disability. In a body of research spanning more than 30 years, Dr. Ong has shown that a consistent focus on joyful moments can have meaningful effects on pain management and may even influence how disease affects daily life.

A systematic review and meta-analysis Ong and colleagues conducted of studies involving patients with noncancer chronic pain found that greater "positive affect"—that is, the experience of positive emotions and moods, such as joy and happiness—was associated with lower pain severity. This suggests that interventions that foster positive emotions—like noticing positive events, identifying your strengths, feeling gratitude, and doing and receiving acts of kindness—may improve both pain-related and emotional outcomes.

But choosing joy is not about ignoring the hard stuff. Dr. Ong noticed that some studies of people living with chronic pain that focused on reducing negative thoughts produced only modest results. He wondered what would happen if he focused on the other side of the coin. Rather than asking people to minimize these sad and depressing ideas, he designed a study

to test the effect of encouraging them to increase positive thoughts.

In 2024, Ong and his colleagues published a study involving people with fibromyalgia that focused on increasing daily positive experiences. The study found that intentionally choosing positive emotions was associated with improvements in emotional well-being and pain management.

Dutch psychology professor Marjolein M. Hanssen, PhD and her colleagues have also explored whether a cheerful outlook and optimism can help people living with chronic pain. Their findings suggest that cultivating positive emotions can improve pain perception and may contribute to better long-term health outcomes.

The benefits may even extend beyond perception. Other studies have measured the impact of lifestyle interventions on stress and inflammatory markers in the blood such as CRP and IL-6. These studies have found that people with higher levels of positive affect tend to have lower stress hormone levels and, in some studies, lower levels of inflammatory markers.

But how does this work in real life? In another experiment, Dr. Hanssen and her team identified

consistently lower pain perception among people who were guided to imagine their “best possible self.” They theorized that part of the improvement came from reducing pain-related fear. Fear can prevent people from following medical advice, and reducing it may encourage greater physical activity and healthier choices.

Besides imagining future happiness, Dr. Hanssen’s work suggests promising interventions may include such activities as maintaining social connections, listening to music, spending time in nature, embracing spirituality, and valuing friendships.

We will never find these activities on a prescription pad, but fortunately you don’t need one. As Chip Galloway and many others in the myositis community have found, choosing joy can make all the difference in your quality of life and in how your disease responds.

“You have to make that conscious decision to choose joy. It’s not just given to you.”

~Holly Jones, member, TMA Board of Directors

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More Than 40 Years
of Experience

Finding Joy in the New Normal

By Karen Perkul



"I'm getting older." "I've always been rather clumsy." "I need to pay better attention to where I'm walking." Sound familiar?

I was walking three miles a day with my dog, working out

with a personal trainer twice a week. So why was I struggling to get up off the floor? Why were stairs becoming so difficult? Why was I falling so frequently and not able to figure out what had caused it?

Thinking back to 2018 when I was diagnosed with inclusion body myositis, I recall first thinking that it was really hard to pronounce, followed quickly by a feeling of relief that I could make some sense of the physical struggles that I had recently begun to notice. Now that I had a diagnosis—an explanation—somehow everything would be easier. That's what I thought.

A short time later I attended my first TMA conference where I was inspired by the many people who seemed to be doing so well. Yes, they may have been using canes, walkers, and wheelchairs, but they were cheerful and optimistic, eager to learn about clinical trials, the latest research, adaptive techniques and equipment. I promised myself that I would be like them: upbeat, intellectually curious, a myositis advocate, and as independent as possible.

I didn't allow myself to experience self-pity. After all, so many people had it worse than me. The glass was always half full, never half empty. I take care of others; I don't need help. I don't want anyone to feel sorry for me. I don't want to be a downer. I was going to be the perfect myositis patient. I participated in a clinical trial. I attended a myositis support group. I traveled to all the TMA annual conferences. I read the current research. I was always optimistic, never complaining, a true Pollyanna.

This attitude worked really well—until it didn't. It didn't allow me to pay attention to all the losses I had experienced: I used to love hiking, kayaking on the lake, getting down in the dirt to garden. This outlook didn't make room for me to mourn the activities I had previously taken for granted or to truly acknowledge what additional losses are likely in my future.

This denial, what I now think of as my personal blindfold, was painfully removed when my husband and I started to plan a vacation. In the past, national parks had been our favorite. Anywhere we could hike, explore the countryside, be out in nature. Or maybe travel to a quaint location where we could walk cobblestone streets, climb winding steps, investigate old buildings. Each vacation discussion resulted in me feeling sad, frustrated, and confused. If couldn't do these things any longer, what could I do and actually enjoy? My very perception of myself, my identity, seemed no longer to fit.

With the help of a great therapist—I didn't want to unload on family or friends—I gave myself permission to feel sad, to feel angry, to begin mourning for what I could no longer do. Although I struggled with asking for help—I was always the helper, not the helpee—I learned to accept that I could be both. I could be sad about the loss of what I can no longer do AND enjoy to the maximum what I currently am able to do.

As I grieved the past and gradually accepted my current new normal, I was better able to move forward to explore new ways of satisfying my needs. Now I spend more time painting with pastels, recognizing that at some not-too-distant date I may no longer be able to do so. I garden using elevated planters. I take long "walks" in a wheelchair with help from others. I work hard to focus on the present, absorbing all the pleasure in each of these activities. I have found that my relationships with friends and family have become stronger. I continue to volunteer: driving friends to doctors' appointments, serving on committees, making phone calls.

Today, I believe that the most important truth I have learned in my IBM journey is that life is not so much about either—or, but rather and. I can be sad about past, current, and future losses AND be grateful for all that I currently can do. I can feel frustrated when

struggling to do today what I could do much more easily yesterday AND investigate ways to adapt to get these things done. I can help others AND ask for help when I need it. I'm not suggesting that this is easy or that I'm always able to keep these thoughts front and center. I can only do my best AND give myself permission to throw up my hands in despair.

Any time we do something new, there's a learning curve. So let's give ourselves permission to struggle,

learn, and grow as we deal with this disease. After all, we've never had IBM before!

Karen Perkul is a wife, mother, and grandmother. Now retired, she worked as a first-grade teacher, clinical social worker, and bookkeeper. She has always embraced learning and change, tendencies that IBM is providing plenty of opportunities to practice.

Fighting the Fight... and I'm Not Done Fighting!

By Bob Nudelman



Diane, Bob, and Buddy Nudelman

I believe strongly in personal choice. With myositis each of us has to decide what balance of independence, risk, and safety is right for them.

On my personal journey, I went through a stage of denial in dealing with inclusion body

myositis. I was falling and suffering injuries that set me back physically and mentally. It was strongly suggested to me by my medical team that it was time to start using a wheelchair for mobility that would also keep me safe.

Did I want to embrace this new chapter of my journey? No.

Did I want to use a wheelchair? No.

But was it the right thing for me to do? Yes.

One question still challenged me: How could I stay strong while being in a wheelchair?

I was surprised to find that being in a wheelchair opened up my world and allowed me to have more energy to do more things in my day. More time for fun, volunteering, and for exercising.

With the help of my physical therapist and occupational therapist, we came up with a whole set of exercises and routines that were a safer and strong substitute for unassisted walking.

For me, these four areas became my new goals:

1. Committing to regular daily exercise: Dedicating over 50 minutes every day to a disciplined routine of aerobic workouts, resistance training, pool walking/exercises, and stretching.
2. Using accessible equipment that supports my needs and keeps me safe.
3. Choosing exercises that both strengthen unaffected muscles and maintain IBM-affected muscles.
4. Prioritizing safety to reduce the risk of falls (now celebrating four years of being fall free).

I believe these choices have helped me stay stronger, more confident, and more capable of maintaining my independence.

I encourage you to keep your lives open and enjoyable while also keeping yourself safe and strong.

Bob Nudelman lives in Wake Forest, North Carolina. He co-leads TMA's Central North Carolina Support Group, which he started eight years ago.

What Brings You Joy?



Debbie with granddaughter Alice



Debbie's children John, Erin, and Sara



Debbie and friend Michelle

Debbie Armstrong lives with IMNM and is a member of TMA's Board of Directors.

My family and friends bring me the greatest joy. I'm fortunate my 3 children, their partners and my granddaughter either live with me or nearby so they are part of my daily life. And I have a number of very good friends who are very supportive and make me laugh!



Bitsy Anderson and Maya with Dr. Lisa

Dr. Lisa Christopher-Stine is a member of TMA's Medical Advisory Board.

I have been a clinician and researcher in the myositis field for more than 20 years.

Joy for me comes in the form of connections: with my family, with my patients, and with other investigators and clinicians who share my passion and whom I meet presenting research data at meetings around the world.



Ingrid and her electric tricycle



Ingrid speaks up for those who live with myositis

Ingrid de Groot lives with PM and is a member of TMA's Medical Advisory Board.

When myositis took away my job and ability to practice sports like running, I found so much joy in riding my electric tricycle! I go out every day to clear my head, feel the healing power of nature, and improve my fitness. I feel so alive and not hindered by myositis when riding! Another thing I found joy and meaning in is being a member of TMA's MAB, a patient advocate, and a patient research partner. I'm making sure the patient voice is heard and acknowledged in research and care! And I'm raising awareness on topics like mental health and exercise. I am grateful for all these things!

Jane Myles was diagnosed with dermatomyositis in 1997 and serves on the TMA Board of Directors.

I love nature, especially the beach.

Music is a big source of joy—and the fuel for my daily workouts!

And knitting, which turned out to be a way to maintain my fine motor function, brings me joy!



Here I am, hiking on the San Andreas. The lake you see is only visible from that trail!



A recent knitting project

Triumphant Comeback for a DM Champion

By Theresa Curry



Anne McLindon swims the Three Rivers Marathon Swim

This November, Anne Whalen McLindon will travel to Cozumel and subject herself to the most grueling possible test of strength and will. At the 2026 IRONMAN competition, she'll begin in the clear waters of the Cozumel Channel with a 2.4-mile swim. Most triathletes feel comfortable with the 112-mile bike ride and 26.2-mile run in this world-class race, but they dread the swimming. For Anne, however, swimming is her passion, and open water is her happy place.

But Anne has spent a significant portion of the last few years struggling with dermatomyositis, the amyopathic kind that affects only the skin. In her case, it had catastrophic effects, causing tremendous pain whenever even a tiny ray of sun or artificial light hit her body. Even being able to train in the open air has been a victory for Anne.

In early 2020, she was preparing for the biggest swim of her life: the Three Rivers Marathon Swim, an 18-mile ultramarathon contest in the rivers of Pittsburgh. For those of us accustomed to laps in a pool, Anne's sport is quite different. Swimming in open water means everything from weather to wildlife is unpredictable. To stay in condition, she continued training even after the pandemic closed the world down. As she approached the October event, she felt fit and confident.

Then, in July, after a long training swim, she noticed small, red patches on her arms and hips, a sign she chalked up to some kind of minor irritation. Within a month, though, the rash spread across her body from her scalp to her knees. The pain was excruciating, becoming worse with any exposure to natural or even artificial light.

Frustrated, and worried that she would never swim again, she went to see her PCP. After referrals to multiple doctors with no definite diagnosis, her doctor sent Anne to his dermatologist. Thankfully, it was this dermatologist who recognized the pattern immediately.

"I was lucky," Anne said. "He had another patient with the same disease." She was grateful for his skill and kindness, and also grateful for the friendship she quickly formed with that other patient, a woman named Lisa, who was also an athlete.

Anne wasn't so lucky in her treatment journey, however. The diagnosis helped but did not bring relief. Any kind of light became unbearable. She bought blackout curtains, SPF-50 clothing, gloves for driving, and spent much of her time in darkened rooms while her daughters attended pandemic school online. She had no muscle weakness, but the skin pain was overwhelming. At the recommendation and support of her friend Lisa and her doctors, she was able to get an appointment at the Johns Hopkins Myositis Center.

Anne tried every possible treatment. Prednisone provided a little comfort but had harsh side effects. Hydroxychloroquine brought a severe secondary rash. Cellcept caused intolerable heartburn. And methotrexate required constant bloodwork. She pursued acupuncture, multiple three-day fasts, prayer, and sheer endurance. Nothing worked. Her doctors believed IVIG would help Anne, but her insurance denied it.

Anne said she was sinking into despair. She remembers sobbing quietly in the bathroom so her daughters wouldn't hear her.

"I don't like to show pain," she said, no surprise from the woman who pushes herself to superhuman lengths, "but my daughter came in and said, 'Oh, mom, you need a hug.'"

She also had a tight group of friends who checked on her regularly, refusing to let her disappear into her world of pain. To avoid losing all conditioning, she ran when it was raining or at night, taking care to avoid streetlights.



Anne's now husband Tim Trant in support boat at Three Rivers Marathon Swim in Pittsburgh.

Finally, after an appeal to her insurance company by Johns Hopkins, she began IVIG infusions, almost one year after her symptoms began. Within a week, the rash and pain disappeared. It was, in her words, “as if the past year had been a bad dream.”

Her body healed, and her determination returned. She rebuilt her life, regained her strength, and resumed training. Although cautious, her doctors said they could live with her returning to her original goal. So in September 2022—two years after DM entered her life—Anne completed the full 18-mile swim in Pittsburgh.

Covered with zinc oxide cream to limit sun exposure to her skin and enduring eleven hours and three minutes in the water, Anne said her feelings of gratitude were overwhelming: for her doctors, her daughters, her friends, her treatment, and the healing power of her own strong body.



Tim and Anne

The experience deepened her commitment to helping others. People had helped her find specialty care, so now she offers support to anyone she can. She slowly tapered off IVIG with no ill effects, moved to Ohio, and in May will marry a man who supports her athletic goals: “He’s the guy in the boat,

beside me through it all,” she said.

Although her good health now makes it seem as if those years never happened, there were some internal changes that will last forever. Anne’s struggle taught her ways to deal with stress, protect her health, and appreciate the friends and family who checked on her daily during her darkest hours. She counsels other people with chronic disease to be fierce advocates for themselves and to surround themselves with doctors and friends who offer support.

Anne, who was a litigation attorney, became an open water swim coach who trains athletes in more than 60 countries, working with newly-established open water swimming programs and Special Olympics athletes, as she keeps up her own training.



**World
Myositis
Day** 21 Sept

World Myositis Day is September 21!

The commemoration was initiated by TMA in 2001 as National Myositis Awareness Day in the US and adopted in 2023 by the international myositis advocacy community. TMA proudly partners with many global organizations to drive myositis awareness on World Myositis Day.

This is a great opportunity to share your myositis journey with others: friends, neighbors, healthcare professionals, legislators, even your barista, and especially on social media. **TMA’s Awareness Tools and Tips** offers great ideas for spreading awareness.

Rx for Care Partners: Sunshine, Forests, and Fresh Air

By Theresa Curry



John La Puma, MD, a physician, chef, and farmer, tells the story of Sarah, a woman who came to him feeling trapped and exhausted by her role as her mother's care partner. La Puma,

author of *The Indoor Epidemic*, shared the story during an interview with Joe and Terry Graedon, authors and longtime hosts of the nationally syndicated radio program *The People's Pharmacy*.

Sarah had little time and few resources, but she followed La Puma's advice and began sitting outside, starting with as little as five minutes each day. The small investment in time in the outdoors had surprising results. Her blood pressure dropped, her heart rate slowed, she was better able to focus, and she simply began to feel better. Eventually, as she felt more control over her own life, she even managed to find another caregiver to provide occasional respite for her.

The results were not surprising to La Puma, a leading advocate of prescribing time outdoors as a response to the indoor epidemic. He notes that the world we live in now has drastically changed our connection with nature. Americans now spend an estimated 93% of their lives indoors. This shift has changed our circadian rhythms and exposure to natural light, narrowed our focus to progressively smaller screens, and caused problems with sleep, mood, metabolic health, and immune function. He argues that clinicians should suggest time outdoors as a legitimate prescription.

La Puma's advice helped Sarah, but it also touches on truths many care partners learn the hard way.

Popular culture often promotes self-care as spa visits, massages, manicures, and shopping. Those experiences can certainly be enjoyable, but research suggests that advice to simply "take a break" is not enough. Care partners need rituals and habits that help them recover from stress every day.

In addition to restorative time in nature, care partners benefit from simple everyday habits like coffee with a friend, gardening, reading, meditation, artwork, writing, or any activity that previously brought meaning and perspective. The dilemma, of course, is finding time for this when you are responsible for someone who requires constant care.

One approach is to build protected time for care partners into the initial care plan, giving it the same priority as physician appointments, therapy, and medication. Researchers describe one helpful framework as "dyadic coping," a concept from health psychology.

Dyadic coping views illness as a challenge the relationship faces together. Partners continually adapt, communicate, divide responsibilities, and support one another emotionally while planning for both the patient's and the care partner's needs.

A small qualitative study of people living with IBM supports this notion, noting that couples who adapt together appear to maintain better quality of life and stronger relationships despite progressive disability.

Besides the important boost that making time for nature provides, there are less tangible spiritual and philosophical benefits, writes Barry J. Jacobs, PsyD. He's a clinical psychologist who has written extensively about family caregiving. In an article for AARP, he describes how nature can not only affect a care partner's mood but also be a reminder of the part we all play in the vastness of the universe.

When things are especially difficult, he says, "For some family caregivers, greater awareness of nature leads to a deeper personal connection with the larger living world that surrounds us."

In his experience, that connection with the rhythm of life outside the day-to-day restrictions of providing care can be profound: "Caregiving, too, doesn't seem so overwhelming when caregivers see their challenging work as a vital piece of the living and striving and even beauty of this natural world."

DID YOU KNOW?



Tampa Bay Bucs Running Back Ricky Bell



Archie Bell (center) and the Drells

Football Star Ricky Lynn Bell

1955 – 1984

Ricky Bell was the first pick in the 1977 NFL draft, after an outstanding college career as a running back for the University of Southern California. He went on to play for the Tampa Bay Buccaneers. He was inducted into the College Football Hall of Fame in 2004, 30 years after his death of complications from dermatomyositis. Beginning in the early 80's Bell rapidly lost weight—the L.A. Times reported he went from 225 to 180 pounds in a matter of months—and became too weak to accomplish daily tasks, let alone play football. Ricky died long before TMA was formed, but his older brother, Archie Bell, was himself a celebrity as the lead singer of Archie Bell & the Drells. Their hit, “Tighten Up,” was a chart-topping single in 1968. Archie supported TMA whenever he could, including at the TMA Conference in Las Vegas in 2011.

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