

# THE OUTLOOK



THE MYOSITIS ASSOCIATION

**FALL** 2023

Quarterly Newsletter



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# THE OUTLOOK

A quarterly publication of The Myositis Association

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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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**THE MYOSITIS ASSOCIATION**

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# Making a difference



## A message from Rhonda Buckley-Bishop, TMA Interim Executive Director

We've heard over and over that TMA has made a difference in the lives of those who live with myositis. Time and time again, people tell us they regained some measure of hope when they discovered they were not the only person in the world with this disease. Even care partners, who often feel burdened and overlooked (and guilty because they feel burdened and overlooked), have been able, through support from other TMA members, to reclaim some part of themselves that they thought had been banished by their partner's diagnosis.

Providing a path to hope and optimism for our members is among our most important roles, one that we take very seriously. As our Board of Directors engages in the

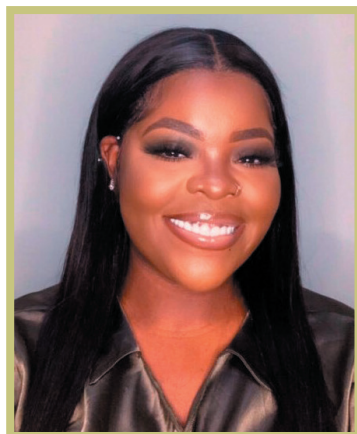
process of selecting a permanent executive director—which we expect to wrap up before the end of the year—TMA continues to move forward with our members at the top of mind.

Our amazing and dedicated staff continue to provide programs, services, information, and individual assistance that can help you live your best life. The distinguished members of our Medical Advisory Board have made themselves available as consultants and presenters for all our programs, providing the most reliable and current medical information out there. It is humbling for me, as interim executive director, to play a part in supporting this effort by ensuring that the organizational structures are in place to sustain it long into the future, because making a difference for you is why we are here.

*Poet Muriel Rukeyser has said, "The universe is made of stories, not atoms." At TMA, the stories of those who live with myositis, their families, and care partners truly are the basis for why we are here. As we celebrate our 30th Anniversary, we remember the story of TMA's evolution from that first conversation around the kitchen table of Harrisonburg, Virginia entrepreneur and IBM patient Betty Curry that aimed to bring together a rare disease support group to today's robust, international, nonprofit organization providing support, education, advocacy, and research funding for all forms of this rare muscle disease.*



## New staff



In May, TMA welcomed **Dawnetta Howard** to our staff as Operations Coordinator. Dawnetta comes to us with extensive experience in direct patient care in a variety of home health and hospital settings. After working for five

years for The Arc Baltimore, caring for individuals with intellectual and developmental challenges, she decided it was time for a change.

"I feel like healthcare is a calling, something I'm supposed to be doing," Dawnetta says.

When she heard about the job at TMA, she was excited by the idea of working for an organization that supports and cares for individuals with rare diseases. It was different but something she has a lot of experience in. She joined TMA wanting to switch from hands-on care to an administrative position to further her personal growth and career.

"I like everything that TMA stands for and what we do for our members," she says. "I'm ready for a little more challenge in the way I can express my creativity, and it's time for me to shine my light in different spaces for other people. Everything that I've done in my career has led me up to this point. It's a perfect fit and I'm excited to be here."

Dawnetta is not the only one who is excited. The entire TMA team is ecstatic to have her on board. "Dawnetta has already made a wonderful impact even in the short time she has been here," says colleague Rachel Bromley. "She often contributes great ideas for furthering TMA's mission, and her calming and compassionate personality makes her perfect for providing the best customer experience for our members. I'm sure the myositis community will love her as much as we do!"

## New group leaders certified



Each January, TMA trains and certifies a new cohort of regional support and affinity group leaders to help improve the quality of life for TMA patients and their families across the nation, and in some instances, the world! The training and certifying process includes five hours of virtual classroom instruction where participants learn:

- ✦ TMA's Standards of Excellence for groups
- ✦ How to start and manage a group
- ✦ How to navigate group dynamics
- ✦ How to be an advocate for TMA and rare diseases
- ✦ How to ensure their own mental, emotional, social, and physical wellbeing so they can pour into the lives of others through their volunteer work

TMA celebrates this year's class of support and affinity group leaders who recently achieved their certification.

**Jim Anderson**, TMA Michigan IBM Regional Support Group Co-leader

**Denise Antonucci**, TMA Illinois (Chicago area) Regional Support Group Co-Leader

**Ed Arnold**, TMA Illinois (Chicago area) Regional Support Group Co-Leader



**Karen Benson**, TMA Utah, Idaho, Wyoming, Washington, and Oregon Regional Support Group Co-Leader

**Christie Chapin**, TMA Michigan IBM Regional Support Group Co-Leader

**Jim Cressman**, TMA Military Veterans with Myositis Affinity Group Co-Leader

**Veronica Fatura**, TMA Adelante! Affinity Group Co-Leader and TMA Michigan Regional Support Group Co-Leader

**Deb Grutter**, TMA Michigan IBM Regional Support Group Co-Leader

**Nancy Harber**, TMA Southern California (San Diego area) Regional Support Group Co-Leader

**Colleen Layton**, TMA New Jersey Regional Support Group Leader

**Cynthia Marks, EdD**, TMA Arkansas, Arizona, Georgia, and Louisiana Regional Subgroup Co-Leader

**Jim Mathews, BS Pharm, MSA**, TMA Michigan IBM Regional Support Group Co-Leader

**Jenna Radke**, TMA MD, DC, DE, and Northern Virginia Regional Support Group Co-Leader

**Joe Sanchez**, TMA North Texas (Dallas-Fort Worth area) Regional Support Group Leader

**Comilla Wimberly**, TMA North Carolina (Charlotte area) Regional Support Group Co-Leader

*We recruit for new leaders throughout the year, so if you are interested in becoming involved, please email TMA's Senior Manager of Patient Education, Support, and Advocacy, Rachel Bromley, at [rachel@myositis.org](mailto:rachel@myositis.org).*

*Nancy Harber has been a support group leader for TMA since it was called the Myositis Association of America, yet even with all that experience she was happy to participate in our new training and certification program. "I am a retired nurse and love helping others, and there are always new things to learn. I lost my husband to IBM and TMA supported us so well before and since. I am so endeared to the myositis community that I never left it, and I still find strength and camaraderie in being a part of such an important organization."*



# Research grants announced

Since 2002, TMA's annual research funding program has awarded nearly \$8.2 million in research support for projects intended to expand our knowledge about myositis diseases. The TMA Board of Directors has approved two new grant awards to the following projects:



A Pilot Grant to **Dr. Sarah Tansley**, senior clinical lecturer in rheumatology at the University of Bath in the UK, to study variability among laboratories for myositis autoantibody testing and to develop a protocol for more reliable identification of these important biomarkers found in the blood of patients with myositis.



A Fellowship Award to **Dr. Begum Horuluoglu**, a postdoctoral fellow in the Division of Rheumatology at Karolinska Institute in Stockholm, Sweden. Her project explores the mechanisms behind why the human immune system mistakenly attacks muscle cells in the autoimmune disease of myositis.

Funds for TMA's Research Grant Program come primarily from myositis patients, their families, and friends. We are grateful for these donations that allow us to support important, promising research projects that likely would not otherwise find funding. If you'd like to be part of making a difference in research or support for myositis, please consider donating to TMA at <https://www.myositis.org/donate>

octapharma

## Proud to support The Myositis Association

Octapharma joins the myositis community in celebrating the 30th anniversary of TMA, and their continuing mission to improve the lives of those affected by myositis, fund innovative research, and increase myositis awareness and advocacy.

[www.octapharmaUSA.com](http://www.octapharmaUSA.com)





Dr. Julie Paik



Veronica Fatura



Dr. Rohit Aggarwal



Holly Jones

## Diversity in clinical trials requires trust

Participating as a research subject is an important gift to the myositis community. Because myositis diseases are rare, more people with rare diseases are needed to participate in clinical trials in order to show significant results. That's why TMA encourages our members to serve in this way.

Now, a new federal law requires drug companies to include a diversity action plan for recruiting patients for clinical trials. The aim is to be intentional about testing new medications on a broad population of subjects, so it will be clear that the drug is safe and effective for all patients, not just Caucasians, as has historically been the case.

This legislation raises important considerations for members of the myositis community. We know that myositis diseases, especially dermatomyositis, necrotizing myopathy, antisynthetase syndrome, and polymyositis, disproportionately affect women, specifically women of color. We are fortunate that several clinical trials are currently recruiting people with DM and PM, but if these trials include few or no Black or Latina women, the results may miss important reactions or effects in these populations.

"If we conduct a clinical trial on a certain population, it does not mean that it will work for everybody," said former TMA medical advisor Dr. Rohit Aggarwal. "That's why including a diverse patient population in clinical trials is so important."

Dr. Aggarwal, who codirects the Myositis Center at the University of Pittsburgh, explored this topic during TMA's Virtual Summit in May. During the discussion, he along with TMA medical advisor Dr. Julie Paik, TMA Board member Holly Jones, and TMA member Veronica Fatura discussed some of the challenges and opportunities for creating clinical trial cohorts that are more representative of the general population. One of the biggest conclusions of the panel was that patients need to have trust in the people and institutions asking them to place themselves in this vulnerable position.

Dr. Aggarwal pointed out that genetics plays a huge role in how people respond to treatments, and one group may have much different outcomes than others. That was the case when a new medication was tested on people with lupus; the drug worked much better in African Americans than other populations.

Sometimes, however, it's a challenge for researchers to convince Black patients to participate in these studies, because so many in the Black community don't trust medical research.

“We’re very clear that some of the patients who have lived in Baltimore City for a long time may not trust us to even broach the topic of participating in research because of the kind of mistakes made in the past,” said Dr. Paik, a rheumatologist at the Myositis Center at Johns Hopkins. “It is very difficult to shake off the past, even if you’ve changed your processes and everything is now safe for patients.”

Holly agreed. “There is always that mistrust from people of color, because it wasn’t that long ago that we were the experiment without our permission or consent.”

Still, Holly, who leads TMA’s Women of Color Affinity Group, is unhappy about this lingering mistrust and urges her peers to join clinical trials.

“Now there are laws and policies in place to protect our bodies and protect our voices, to make sure that we are heard and that we are validated. Now we have that power, we need to use it. We need to step up and be in these clinical trials. In my mind, every clinical trial is a step toward a cure or prevention, and don’t you want to be a part of that?”

Veronica, too, encourages members of her TMA support group in Michigan to participate in clinical trials. “I tell them I’ve been doing a clinical trial, and yes, there may be risks, but there is a benefit that you’re giving to others. I believe that when you do something for others, it’s an investment. There’s always a payback when you do something that can help others.”

All the panelists agreed that, to overcome this suspicion around medical research and allow people to feel confident in their decision to join a clinical trial, trust is essential. From the local doctors at

the clinical site to the principal investigator who is leading the trial to the pharmaceutical company that sponsors it, patients—and their families—need to feel that they are being treated honestly.

Before Veronica enrolled in a DM clinical trial in Chicago, her daughter was uncomfortable with the idea. She knew it was possible that her mother would receive a placebo rather than the drug, and she didn’t want her mom to experience a flare in her symptoms. But when Veronica talked about how much she trusts not only her doctor but the whole team at the study site and how her doctor would be watching her carefully and would pull her out of the study if anything looked like it was going wrong, the daughter agreed to her mother’s decision.

“The first step to joining a clinical trial is that trust you have with your doctor,” Veronica said. “For me and my family, the trust that we have in my doctor is everything. She explains everything and makes sure I understand it.”

“As a patient, we have to have a conversation,” Holly said. “It needs to be real, it needs to be open and effective, and it needs to give us a good understanding of everything. Everybody must do their part and be held accountable for what they’re doing.”

Holly even went so far as to invoke the Golden Rule. “I always say, if everybody treats each other the way that they want to be treated, we will have better outcomes, we will have better everything in life, not just with clinical trials but with health equity across the board.”

To see more about the new law go to <https://news.bloomberglaw.com/pharma-and-life-sciences/diversity-in-clinical-trials-at-fda-gets-a-boost-from-new-law>

***“Now that we have that power, we need to use it. We need to step up and be in these clinical trials. In my mind, every clinical trial is a step toward a cure or prevention, and don’t you want to be a part of that?”***

***- Holly Jones***



# MINT makes it easy to participate in clinical trials



Anxiety about subjecting oneself to an untested treatment and historical mistrust of medical experimentation are only a few of the many reasons why clinical trials often lack a diverse range of participants. Another may be that individuals who don't live close to a medical center where clinical trials are being conducted can't participate because they simply can't get there.

This may not be a problem for long. Former TMA medical advisor Dr. Rohit Aggarwal is currently recruiting patients for a study using an innovative approach that may offer an alternative to the traditional clinical trial protocol.

"It's called a decentralized trial model," he says. "In this model, the research team can do everything for the trial remotely using digital health technologies and telemedicine."

The medication will be delivered to the participants location of choice, they will be monitored using digital equipment that will send results directly to the research physicians electronically, and doctors will assess their health through a secure, private, virtual connection on the participant's computer or mobile device. Research participants can do this anywhere in the country. They won't have to travel to a specific location, and they won't have to lose time at work or disrupt their schedule.

Dr. Aggarwal's study is called the Myositis Lung Disease Nintedanib Trial (MINT). It is testing an already FDA-approved medication, nintedanib, to see how well it works to improve symptoms in participants with myositis-associated interstitial lung disease (MA-ILD).

Interstitial lung disease (ILD, or pulmonary fibrosis) is a condition that affects many who live with certain forms of myositis, and it can be especially distressing. ILD causes abnormal thickening, stiffness, and scarring of the tissues of the lung and can severely limit a person's quality of life.

The study needs adults with a confirmed diagnosis or autoantibody (blood tests) of myositis along with ILD. Participants will still be able to continue their current treatment.

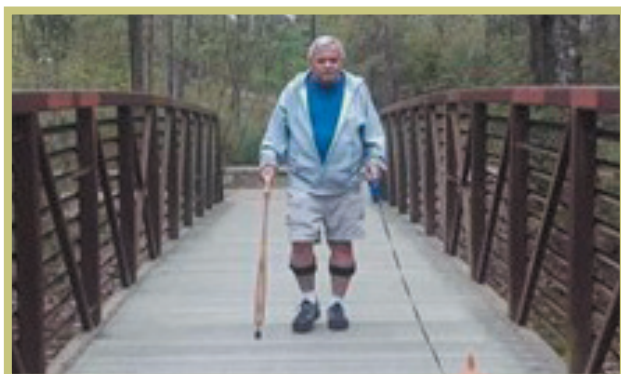
By conducting this trial through this new decentralized model, Dr. Aggarwal hopes to be able to show that this is a viable option for other myositis or rare disease clinical trials as well. It's one way of overcoming the challenge of getting enough patients to participate in rare disease clinical trials.

"This approach can also greatly improve the diversity of participants in clinical trials," Dr. Aggarwal says. "It's one way we can make sure that people from all backgrounds can contribute to important medical research."

*More information about the MINT trial, including eligibility criteria, is available at <https://www.clinicaltrials.gov/study/NCT05799755> or contact Dr. Aggarwal at 412-648-4814; Email: [MINTcc@Pitt.edu](mailto:MINTcc@Pitt.edu).*



*Vance "Vee Rob" Robinson celebrates with the San Luis Obispo Mustangs and his niece Evie*



*Joe Sanchez on his daily walk, supported by his Louisville Slugger cane.*



*Chip Galloway at the finish line after the Community Medical Clinic Classic 5K in Camden, SC, April 29, 2023.*

## Pitching in to raise awareness

When Richard "Chip" Galloway was diagnosed with inclusion body myositis (IBM) in January 2020, it wasn't something he wanted to think about. After his wife survived two major health scares, however, Chip decided he had to face his own progressive, disabling disease.

"I figured it was time for me to do something that would bring awareness to myositis," Chip says. "So I was at church one Sunday morning and went down front to the altar and bowed my head and thanked the Lord for giving me this disease. I asked Him to use me and let me know what I needed to do."

Since that time, Chip has been seeking out opportunities to tell his story and spread the word about myositis. Along the way, he has scrolled social

media and met up with other myositis warriors who are also raising awareness.

One of these is Joe Sanchez, an IBM patient from Tyler, Texas who has been active on Facebook, spreading the word about the benefits of physical therapy and exercise. Joe walks several miles a day and credits this with a return of much of his muscle strength and balance. This spring he walked in a 5K race in his community.

When Chip saw that, he decided to sign up for his first 5K walk sponsored by a community medical clinic in Camden, South Carolina where he lives. Once he accomplished that, he looked around and said, "What's next?"

"I'll never forget it," he says. "I was sitting there on a Saturday, drinking my coffee and watching Vance Robinson and his First Pitch videos on YouTube, and I said, 'Why don't I just reach out to Vance and ask him what he did?' So I did and he called me, and if I could hug his neck over the line I would have done it! He just lit me up that day!"



Vance, who goes by the name Vee Rob on social media, also has IBM and has been sending out first pitches at college baseball games up and down the California coast since 2017. As he does so, announcers read a script describing the challenges of myositis diseases. It's Vance's way of raising awareness of and funds for myositis every May. Though he is now only able to pitch one game each season closer to home in Paso Robles, this year's campaign raised more than \$2,700 for TMA.

After Chip and Vance shared their stories, Chip decided to take a chapter from Vance's playbook and start his own First Pitch Myositis Awareness Campaign. Chip contacted a former college classmate who is now the head baseball coach at The Citadel, The Military College of South Carolina, and arranged to throw the first pitch during the team's May 6th game. Like Vance, Chip provided a script for the announcer that told a bit about his experience with myositis to gathered fans at the stadium that day.

Since that time, Chip has managed to get the Kershaw County South Carolina Council to pass a resolution proclaiming May as Myositis Awareness Month. He's also been the subject of a story in his local newspaper describing his myositis journey with the headline "From Victim to Warrior" and a picture of his victorious finish at the 5K.

Chip is now looking around for his next big myositis awareness gig. With Vance as inspiration and his faith as motivator, he may be looking at a First Pitch Campaign for Major League Baseball.

"Let me tell you what," Chip says, "if you ever ask the Lord to use you, He will wear you out if you're not paying attention!"

*We are grateful to Vance Robinson for his steadfast support of TMA. If you'd like to help raise funds as you raise myositis awareness—during May or any time of the year—we can help you start your own fundraising campaign here: <https://www.myositis.org/get-involved/fundraise/fundraising-campaigns/>*

## Looking for a different treatment option for your dermatomyositis?

If you are still experiencing symptoms of dermatomyositis with your current treatment, you may want to consider the **VALOR Study**.

The **VALOR Study** is testing an oral investigational medicine to see if it can reduce the symptoms of dermatomyositis in adults from 18 to 75 years old.

To learn more, talk to your doctor and visit:  
<https://valorstudy.com/>



## Sharing the voice of myositis



*Not long ago, TMA's Rachel Bromley sat down on Zoom with community member and volunteer Kim Gray to talk about how she came to TMA and the inspiration behind the first TMA Myositis Family Podcast. The show started in February 2022 to give those who live with myositis the opportunity to share more widely their myositis stories as well as tips for living their best lives.*

**RACHEL** How did your diagnosis come about?

**KIM** I was diagnosed with dermatomyositis (DM) in March of 2021, but I've been dealing with it since January of 2021. It came on me all of a sudden. I was having problems getting out of the chair, getting out of the bed. My knees were stiff, my joints would lock up on me, and simple things like opening a bottle or peeling an orange, I couldn't do it.

I thought, okay, this will pass, but it didn't. So after maybe a week of dealing with this, I had to drive to urgent care. I live alone and I'm pulling myself out of the house, I'm using a cane, I can barely walk. And when I got to the urgent care, the doctor says,

'What's wrong with your face?' And I'm like, 'Don't you see me hobbling in here with a cane, and the thing you say is what's wrong with my face?' And he says, 'But your face tells the story about what's going on with you.' I had this pink rash on my eyes. I thought it was an allergic reaction to my soap or something, but that hadn't gone away either. So that set things in motion.

They had me do a follow up with my primary care provider, and she was like, 'Oh my goodness! We're going to get you to a rheumatologist.' But they didn't have any in the VA [Veterans Health Administration], and community care takes at least six weeks before you can get in. So by March, I'm all bent over with the cane again, but the rheumatologist goes, 'I know exactly what's wrong. It's dermatomyositis.' Oh that was such a happy day, to know what it was!

**RACHEL** I bet! Tell us how you found TMA.

**KIM** Well, that was how I could tell when God stepped in. I was so anxious and crying all the time, because I didn't know what was going on, and one day I'm reading an AARP article called "When your body attacks itself." At the very end, it says to find help, do a Google search with the name of your disease plus the word 'association.' So I tried it and TMA popped up. So then I was taking in all this information, signing up for everything, and joining the support groups. That's what gave me hope!

**RACHEL** Can you talk about your idea for the podcast, where that came from?

**KIM** I have a business and I work with introverts, helping them with their marketing strategy. A lot of my clients have embraced podcasting. It's a great way for introverts to share who they are without having the camera on. They can just tell their stories and share their gifts. So when I joined TMA, I'm in these support groups and I'm hearing these amazing stories of how people were diagnosed or how they're living now, and they're giving these great suggestions. And I'm like, 'Why don't you put that stuff on a podcast so other people, who may not be in these support groups, can at least hear the stories and know they're not by themselves?'



So I pitched it to you, Rachel. And you were like, 'Thank goodness! We need this!'

I just feel like this is one of my gifts, and I wanted to help bring those voices, to share our stories. And if we do it right, others are going to say thank goodness, I thought I was losing my mind! Because to hear other people tell their story and their journey and how hard it is sometimes to get the right diagnosis but how important it is that we don't give up, that's an important message.

The thing I love about the podcast is people can choose to be completely anonymous, or they can share just their first name. We don't share anybody's full name [on the TMA podcast]. It's not about who you are or what you do, it's about what you've been through and how you cope and how to move forward in trying to have the best life you can despite the diagnosis. It was amazing for me to hear these stories and then to experience the differences. Everybody's journey is so different, but you can also see the similarities that really connect everyone.



## Cara Zanella

Kim recently turned over the microphone to a new host, Cara Zanella. Cara is an experienced communications professional who also lives with myositis. The podcast airs monthly on Spotify. You can find archives of past podcasts here: <https://bit.ly/3qYQrr9>



# Unshakable optimism

By Mike Matthews



At the end of 2021, Cambridge Dictionary announced their Word of the Year was “perseverance.” On top of all the profound collective challenges that everyone is currently experiencing, the myositis community has the added

personal crucible of managing a chronic disease for which there is no cure.

Despite the best efforts of myositis researchers and clinicians, a large portion of myositis patients still do not achieve sustainable clinical remission. The lack of personal control can lead to learned helplessness, a victim mentality, and a myriad of other mental health challenges that I strongly advise seeking professional help for as needed.

Even as a career counselor with a preternatural optimism, it has been the challenge of my lifetime to persevere with a positive outlook over the past six years with dermatomyositis (DM), which has been refractory to a gauntlet of medications and treatments. Myositis forced my full retirement sooner than planned, and my habit of dispensing advice as a counselor has been replaced with humbly comparing helpful notes with others in the wonderful myositis community, many of whom have struggled longer and more mightily than I.

The Myositis Association (TMA) offers support groups, educational webinars, an amazing Annual Patient Conference—which is more impressive than you can imagine—a massive amount of educational material on their website, and other resources that I have benefitted from greatly. I honestly do not know where I would be without the support of my wife and TMA.

Through physical and other diminishment created by DM, I have had to accept a new personal normal and have embraced an unshakable, often tragic optimism, as I search for meaning and purpose during times of inevitable challenges. Fully accepting our myositis diagnosis can motivate us to find resources within ourselves that enable us to avoid falling into what the father of positive psychology, Martin Seligman, termed “learned helplessness.” This acceptance can help us move instead into learned optimism, despite our greatest challenges.

A “problem” is a situation that has a solution, whereas a “predicament” (which is the current state of myositis) has no solution. It is a situation that must be managed the best we can. We must stay realistic and authentic but maintain enthusiasm for the miracle of life and flourish the best we can alongside our myositis.

As a counselor, my career mission and purpose were to give support to my clients and empower them to overcome their obstacles, but it has always been difficult for me to accept offers of help when I need it. Maybe you have found yourself in the same dilemma. I’ve found that the staff and members of TMA, myositis researchers, medical personnel, and other resources are sincerely interested in helping those of us who live with myositis and our families manage our chronic conditions. I appreciate all their efforts and have unshakable optimism that their efforts will expand and reap tangible rewards in the future.

Through the diversity of our experiences, our myositis community shares triumphs and setbacks, joys and sorrows, and innovative ideas as we unite with common goals of effective treatments and the hope for an eventual cure for myositis. Every time we volunteer, attend a conference or support group, or participate in a webinar, it strengthens our bonds with our myositis family and weaves unbreakable threads that create a resilient fabric for our lives that supports us like a parachute, even in times when it feels like we are in a free fall.

*Mike Matthews is a retired teacher, counselor, and mental health administrator with a mission to create a cohesive and peaceful world. He was diagnosed with dermatomyositis in 2017.*

# Shifting the focus to life after IBM

By Meriel Parker



As the daughter and caregiver for my father who lived with inclusion body myositis for a decade, I can say it is critical to actively protect the mental health of both the IBM patient and the caregiver.

In retrospect, the strain that we both experienced was multifaceted. My

father, a revered litigator, businessman, and Marine Corps Veteran, was accustomed to leading, fixing, lifting, and providing for his family and community. IBM slowly forced him to change his focus to that of safely living each day for himself and his family; and it required total commitment.

When he first realized what an IBM diagnosis entailed, he questioned his purpose and contribution to his family. He clung to my plea that he was so desperately needed for who he was intellectually and emotionally at this phase, and less for his former physical strength. Some days we grieved the visible loss of physical strength and the fear of the unknown ahead. Most days, however, we were grateful for the realization of how blessed we were to have the present moments.

We both had to accept the shifting of roles, with me becoming the protector, leader, lifter, and fixer. We were blessed because we'd worked together for years in business, and this was a platform to pour our energy into something we both enjoyed, truly working as a team. This inspired and motivated him to stay positive and productive.

As my dad's illness progressed, his joy came primarily from the experiences within our home, and it was imperative to him that he had joy-filled moments with my daughter and me throughout each and every day to inspire him to move forward. This was not always easy, as a working mother and a middle-school teen. Nevertheless, our small family was interconnected and fervently committed to uplifting one another as a blessed responsibility of being a loving member of this family unit.

We created adventure and fun in the smallest of activities: a trip to the store, watching the birds in the backyard, a school assignment, or game. But truthfully, this is what he'd always established for us as a norm for our family. IBM reminded us of what truly makes a man the epitome of a grandfather, a father, a husband. It is in his words, his actions, his presence, and his love. In our household, we gave all we could to keep him with us, and he gave all he could to stay with us.

A mental health practitioner was part of his home health care team, weekly providing support and a listening ear. This therapist became a kind support to our household, in fact, as each of us needed to accept the world IBM was forcing us to navigate. I was proud of my father for his willingness to consider care from a mental health clinician just as he did the physical therapist, occupational therapist, speech therapist, and nurse. My dad was a pragmatist, and he sought every resource that could potentially restore him to the man he strove to return to.

At his core, my father exemplified honor, courage, and commitment, standards of the United States Marine Corps in which he served. He upheld these traits throughout his service to his country, career, life for his family, his IBM diagnosis, and to his last breath. "Standing" alongside others with myositis in TMA's Military Veterans with Myositis Affinity Group and the TMA North Carolina IBM Support Group gave him a sense of solidarity and support. He was proud to once again, "stand among his band of brothers," participating in the Zoom meetings, striving to fight (IBM) together with honor, courage, and commitment, as they'd vowed to do many years prior.

Strength, focus, and a desire to fight to live. These were tied to his purpose as father and grandfather, he told us regularly. Moreover, he conceptualized, invested in, and committed to creating a hub for veterans' care in North Carolina, all the while battling late-stage IBM. I strongly believe that adaptation of purpose is necessary to navigate life with joy, despite chronic illness. Giving to others, uplifting others despite your circumstances (or perhaps because of your circumstances) is a gift and makes it possible to find joy in even the smallest ways.

*Along with her mother, Meriel spent many years caring for her late father, the noted civil rights and defense attorney H. Wallace Parker. Meriel serves on TMA's Patient and Family Advisory Council and is developing a regional equipment library to help other veterans with autoimmune disease.*





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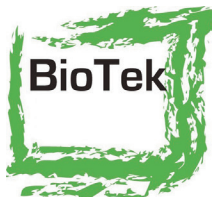
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