

THE OUTLOOK



THE MYOSITIS ASSOCIATION®



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SPRING 2024
Quarterly Newsletter

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.

Published by:
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Together at TMA: Advancing The Myositis Agenda

When I first sat down with the board committee that was searching for a new executive director to lead TMA for the long term, I realized that this was my dream job. When I heard their stories, I was impressed by the committee members' dedication to TMA's mission. I desperately wanted to be part of making that mission a reality... and here I am!

Now, after my first hundred days on the job, I am more excited and more committed than ever. Much of what makes TMA great is YOU, our members! You offer one another support and help TMA disseminate evidence-based information about your disease and treatments. It's your voice that we amplify through our advocacy with

government officials and agencies like NIH, FDA, and the Veterans Administration. You volunteer at our International Annual Patient Conferences and serve as speakers for webinars and presentations. You rush to sign up when we put out a call for participants in clinical trials and other research projects. And you support us financially so we can provide all these services to the global myositis community.

But there is so much more we can do to improve the lives of those who live with myositis, fund innovative research, and increase myositis awareness and advocacy. How can we make TMA one of the most robust and achievement-driven patient organizations in the country? I've been thinking deeply about **The Myositis Agenda**.

Shout out to TMA member **Keith Shaftel** for the clever play on our acronym! Keith suggested this as the name for our podcast, relaunching this spring. Though we've chosen a different name for the podcast, I've seized upon Keith's wordplay as I work with the talented TMA team to prioritize 2024 and future initiatives.

What do you think about The Myositis Association and The Myositis Agenda? Your ideas help us do more and do better. Send me a note at paula@myositis.org and TMA@myositis.org.

We have a long way to go to grow into the organization we want this to be, but **Together at TMA** we can—and will—get there!

Paula

P.S. Donate this spring and help TMA increase our impact! In April, there's a Giving Challenge with TMA Southwest Florida KIT support group and at any time, you can give online at www.myositis.org/donate to support Myositis Awareness Month in May. Thank you!



On the cover

*Theresia Danielsson and Annika Rydgård from Bioservo demonstrate the **Carbonhand Glove** technology at TMA's 2023 Annual Patient Conference. See the story on page 11.*



TMA welcomes new leader to Board of Directors

In January, **Laurie Boyer, MBA** took on the role of Chair of TMA's Board of Directors.

Laurie came to TMA after the tragic death of her brother, Tommy Worthington, who passed away only six weeks after being diagnosed with rapidly progressing dermatomyositis and interstitial lung disease at the age of 39. Soon after his passing, she and other members of her family created a foundation to provide financial assistance to others who live with myositis as a way to fulfill her brother's wish to help others with this rare disease.

Team Tommy was for many years a dynamic supporter of TMA, both in the local Florida area where Laurie and Tommy lived and nationally. And while the Foundation has since closed, Laurie has continued her own passionate support of TMA, joining the Board of Directors in 2018.

"When I first came to TMA's board, I was impressed by how focused the organization was on the mission of improving the lives of those who live with myositis," Laurie says. "It's such an honor now to be able to serve this community I love. Raising awareness of myositis and helping to fund research that may someday lead to a cure is a very powerful goal. It's work that is so necessary, and I am grateful for the opportunity to support myositis patients and their care partners in this way."

Laurie works as a district administrator for St. Lucie Public Schools in Florida, focusing on instructional technology, marketing outreach, and STEM initiatives. She brings many of these skills to bear in her work with the TMA board as well.

"I'm thrilled to partner with Laurie. She's a longtime and loyal champion for TMA, who deeply understands the toll myositis can take on a family," says TMA Executive Director Paula Eichenbrenner. "As chair, Laurie is thoughtful and inclusive, and her enthusiasm makes meetings fun. TMA is really going to thrive under her leadership."

Laurie lives in Port St. Lucie with her firefighter husband Wayne to whom she has been happily married for over 20 years. They have two teenage children, Derek and Pippi. In her free time, she enjoys cheering on her children in their music and sport competitions.

Heartfelt thanks to Dave Mochel!

By Laurie Boyer



This year, the Chair of TMA's Board of Directors, Dr. David Mochel, completed his term of office and transitioned to the role of Past Chair. As he passes the proverbial gavel to Laurie Boyer, TMA's new board chair, she was moved to reflect upon Dave's leadership over the last three years.

As Dave Mochel's term as TMA's board chair ends, it gives me great pleasure to reflect on all he has given to The Myositis Association Board of Directors during his tenure.

Many members may not be aware of the hard work and dedication that board members contribute behind the scenes to steering the organization and ensuring it has the resources to carry out its mission. Those of us who have witnessed Dave's undying commitment and steadfast leadership sit in awe and extreme gratitude for the opportunity to work with him in this way.

During Dave's tenure as Chair, TMA faced many challenges, not the least of which was the COVID-19 pandemic. Despite these challenges, he remained committed to ensuring that TMA was able to provide the best possible support to those who live with myositis

and their loved ones. His contributions have been significant and his leadership exemplary.

Despite living himself with the challenges of inclusion body myositis and also trying to navigate the pandemic as a hospital administrator, Dave was the first to roll up his sleeves and dive in on any project or problem that needed solving for TMA. His calm demeanor was essential during the pandemic as we quickly pivoted the Annual Patient Conference to a virtual platform, which was uncharted territory for all of us. He knew the importance of the education provided and the connections made among members of the myositis community during the conference, and he wasn't going to let COVID take that away.

When TMA launched a national fundraising event, Dave and his wife led by example, co-organizing and bringing the event to the Chicago area. Their hard work helped to raise awareness and funds for TMA's mission-driven work. He showed us that volunteering your time towards a great cause can help ignite a spark within a local community and affect TMA's efforts on an international stage.

Throughout his time on TMA's Board of Directors, Dave has demonstrated exceptional dedication, strategic vision, and a commitment to excellence. Whether devoting countless hours to board meetings and committees or guiding the board with wisdom and foresight, he's been instrumental in steering TMA toward success.

During his tenure, for example, **TMA's Affinity Groups** were created and are now flourishing thanks to Dave's vision and encouragement. This innovative program brings further support for myositis patients who also want to connect with people who share an interest beyond their disease. This has led to very meaningful connections on a global scale.

Dave's passion for TMA's mission has been evident in every decision he's made and every action he's taken. His leadership has not only strengthened our foundation but also inspired others to contribute their best.

Thank you, Dave, for your unwavering commitment, vision, and the positive influence you've had on all of us. We are grateful for the opportunity to have volunteered alongside you and look forward to building upon the strong foundation you've laid.

Meet the new Board of Directors



For many years, **Meriel Parker** and her mother served as caregivers for her father who lived with inclusion body myositis. She has a broad leadership background in healthcare and science organizations and has been a committed

volunteer for TMA, serving on committees and as a panelist for the Annual Patient Conference. Recently, she established and serves as executive director for the nonprofit P.E.N. Foundation, which assists the IBM community by connecting patients with mobility equipment that needs a new home.



Chip Galloway was diagnosed in 2020 with inclusion body myositis. Since then, he has been tireless in his efforts to raise awareness of this rare disease in everything he does and every place he goes. Through his experience serving and leading nonprofit boards

and the energy and passion he brings to serving his fellow myositis warriors, he's on a mission to make a difference for those who live with myositis.



With a background in pharmacology and toxicology, **Jane Myles** has spent her career in drug development at pharma/biotech companies and startups promoting patient-centric approaches, raising awareness, and supporting

the adoption of patient-focused clinical research. For more than 25 years, she has also lived with dermatomyositis, an experience that has anchored her passion and brought true meaning to her work. She comes to TMA with a mission to amplify the patient's voice and support the development of groundbreaking diagnostics and treatments.



After a two-year diagnostic journey with enormous challenges, **Mustafa Shameem** was diagnosed with dermatomyositis and antisynthetase syndrome followed by another year of difficult recovery. He wants

to make sure all others who follow have an easier journey. He comes to TMA with more than fifteen years of experience in management consulting and digital product development from the healthcare and financial industries, along with developing healthcare public policy at a life science think tank. His vision is to transform TMA into the gold standard for rare disease organizations.



*Monika Davis, TMA volunteer and member of TMA Women of Color Affinity Group, and Rachel Bromley, TMA's Senior Manager for Patient Education, Support, and Advocacy, traveled to Washington, DC during Rare Disease Week, organized by **EveryLife Foundation**. During the four-day event, they learned about public policy and how to advocate with congressional representatives. Then they met with their state legislators to put that knowledge to work asking for their support on legislation that will help improve the lives of those with myositis.*

*You too can get out there and beat the drum for improved access to healthcare and treatments for myositis during **Rare Across America in August**. This is a time when you can learn how to advocate with legislators and take action locally. If you would like to participate in this virtual learning event, please reach out to **Rachel Bromley**.*

Gratitude to past board members

This year, four devoted members of TMA's Board of Directors stepped down from this leadership role. Ronné Adkins, Gail Bayliss, Rex Bickers, and Marianne Moyer have, for years, helped guide and

sustain the organization through the challenges of transition and beyond. We are grateful for their service and look forward to their wisdom and support in other volunteer roles.



Research grants announced

Since 2002, TMA's annual research funding program has awarded nearly \$8 million in research support for projects intended to expand our knowledge about myositis diseases. This year, TMA received 16 applications for pilot project grants and eight applications for fellowship support. The TMA Board of Directors approved one new award in each of these categories.



Julio Huapaya, a pulmonary and critical care fellow at the National Institutes of Health and a postdoctoral researcher at Johns Hopkins Interstitial Lung Disease and Idiopathic Pulmonary Fibrosis Program was awarded a two-year,

\$100,000 fellowship grant. His project will measure autoantibody levels in the blood of patients with interstitial lung disease (ILD) using a new testing method. He's hoping this will help improve care by identifying those at high risk for ILD complications and how well they respond to treatment.



Neurologist **Merrilee Needham** leads the Myositis Research Group at the Perron Institute and serves in a number of consulting and teaching positions in the Perth area of Western Australia. She was awarded a

two-year pilot grant of \$200,000. Her project aims to use deep learning predictive modeling to analyze muscle biopsy samples donated by individuals who have been diagnosed with inclusion body myositis to try to identify what specific proteins in the muscles trigger the autoimmune attack against muscle cells. Ultimately, she hopes to increase our understanding of the processes underlying IBM so new approaches

can be developed that will reduce the damage and inflammation, promote healing, and potentially find new treatments.

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.

The GALARISSO study is looking at an experimental drug for people with dermatomyositis (DM)

Talk to your doctor to learn more

Who can qualify?

You may qualify if you:

- Are 18 to 75 years of age
- Have been diagnosed with DM for at least 3 months

If you join the study,

- You will receive study-related drug at no cost
- Your health will be monitored closely during the study



GLPG3667-CL-214 GALARISSO STUDY
PATIENT POSTER, V1, 0_22-SEP-22 [V1.0 USA(EN)]

<https://www.glp.com/innovation/disease-areas/immunology/dermatomyositis-dm/>

Traveling to India in Atlanta

By Dave Volk



Dave Volk, his wife Donna, and friends

In 2016, I received a diagnosis of inclusion body myositis (IBM). Despite this challenge, I am grateful that I can still enjoy traveling and attending social events. One of the most memorable ones was our first Indian wedding in Atlanta, GA, where we were invited by our neighbors, the Patels. The wedding was a splendid affair, full of vibrant colors, lively dances, melodious music, delicious Indian food, and warm-hearted people who came to celebrate the happy couple. Our friends were very hospitable, and the hotel was superb. We felt honored to be part of the three-day festivities and to learn more about the rich Indian culture.

Traveling with IBM, however, requires some extra accessories. Among these are the Free2Go Mobility rollator (for a mobile, higher toilet seat), a Carex Uplift Premium Seat Assist with Memory Foam (that I use to get up off the seat on a plane), and a Nitro Rollator with the Uplift seat to give me a 25-26" high seat.



IRB Approved at the Protocol Level Oct 04, 2023 202216 #38647162

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.

Why consider the VALOR Study?

If you are eligible to participate:

You will receive study medication and tests at no cost to you.



Your health will be closely monitored by the study doctor.



You will contribute to advancing the medical understanding of dermatomyositis.



To learn more, talk to your doctor and visit www.VALORStudy.com



Immune boosting supplements can make autoimmunity worse



Herbal supplements have become very popular in recent years as individuals seek alternative remedies for a variety of health conditions. Products advertised as “immune boosting” are especially promoted to prevent or treat viral and other infections such as colds, flu, and of course COVID. And it’s natural to think that when you have an autoimmune disease that you may want to boost your immune system.

While it’s true that remedies such as blue-green algae, echinacea, ashwagandha, elderberry, and chlorella can stimulate the immune system, this may prove problematic for individuals with dermatomyositis.

“Some patients experience flares or even new onset of disease when they use these herbs,” says Dr. Victoria Werth in a publication of the [American Academy of Dermatology](#).

Dr. Werth, who is a member of TMA’s Medical Advisory Board, urges those with autoimmune skin diseases like DM and lupus to avoid immune boosting supplements. And she warns that they may hide in some unsuspecting places.

That green smoothie drink you find in the refrigerator section of the grocery store, for example, probably contains spirulina, a type of blue-green algae that may cause an increase in symptoms. Similarly, you may not expect the elderberry syrup in your nighttime cold medicine to be problematic. Even certain weight-loss products may contain aspergillus, a type of fungi that can affect the immune system. That’s why it’s important to read labels, not just on the foods you eat but also the over-the-counter medications you choose.

Generally speaking, if you stop using the product the symptoms should stop too. If your flare continues or worsens, however, even after you discontinue the supplement, do not hesitate to call your doctor. And always be sure to let them know about all the medications you’re taking, even over-the-counter meds and supplements.

“We don’t have enough data about the safety of many over-the-counter supplements,” Dr. Werth says. “But if a supplement is thought to protect against viruses and other infections, there is a chance it may aggravate autoimmunity.”

Getting a grip: Carbonhand may help



Theresia Danielsson and Annika Rydgård from Bioservo

TMA's International Annual Patient Conference is the best place for those who live with myositis to connect with others who share their experiences. For myositis researchers, however, it's also the perfect place to engage with potential research subjects.

With 300-400 conference attendees each year representing all aspects of the myositis journey, TMA's conference makes it easy for researchers to enroll enough patients in their small, investigator-led, IRB-approved projects to be able to develop reliable conclusions.

TMA has facilitated a number of these projects in the past. In 2022, for example, TMA medical advisors Dr. Chris Weihl and Dr. Lindsay Alfano collected data for a **study on grip strength in IBM patients**.

Last year, another group of physical and occupational therapists led by former TMA medical advisor Malin Regardt wanted to get input from the myositis

community on an electronic assistive device called Carbonhand. This innovative new technology, marketed by the Swedish company Bioservo, fits over the hand like a glove, providing added gripping power for those with impaired hand function.

Regardt and her colleagues wanted to see if this power-enhancing glove, which has been tested on people who have hand weakness related to conditions like stroke, trauma, and multiple sclerosis, would work as well for those with myositis.

The study they did at TMA's conference assessed the individual's grip strength, physical function, and pain and asked questions about quality of life. Participants were then asked to choose activities involving their hands that they had difficulty doing, such as holding a glass or picking up a small object. Researchers then had them perform these actions both with and without the glove and rate the degree of difficulty of their performance.

The potential impact of the Carbonhand on quality of life was immediately apparent. A caregiver watched her mother cry as she was able to pick up a cup for the first time in years thanks to the glove.

While results of this study are still pending, Regardt says, "Based on our preliminary analysis, the glove appears to increase hand function and might improve physical function in those with myositis who experience impaired hand-function."

Regardt and her colleagues plan additional studies to test usefulness of the Carbonhand device in those with myositis.

Recently, we learned that IBM patients who receive care through the US Veterans Administration Medical System can access this assistive device. "Carbonhand is fully covered by Veteran Affairs," says Bioservo's US Commercial Manager Loren Wass in a **press release** announcing its introduction to the US market.

"We would like to thank everyone at TMA who made this trial possible," says study coordinator Annika Rydgård. "We really appreciate everyone's enthusiasm and participation in the trial. The study will play a role in making the glove accessible for people with reduced grip strength and/or impaired hand function in the US."

Making the most of your tax-deductible gift to TMA

By John Suttle



TMA is able to make its impact because generous donors support our work. Thank you! As a nonprofit organization, our donors are eligible to take a tax deduction for their contributions to TMA, but what does that mean exactly? Read on

to learn more about the tax laws, as well as limitations and opportunities of different options for giving.

In general

The US Internal Revenue Code allows an individual taxpayer to claim a deduction on his or her tax return for contributions to a nonprofit organization. However, there are limits that apply to the deduction.

For example, the deduction allowed in the year of the contribution (including the contribution made during the year and any contributions carried over from earlier years) cannot exceed 50% of the taxpayer's *adjusted gross income* (AGI) in that year. (The charitable deduction is limited to 60% of AGI under recent legislation, which will continue to be in effect through 2025. The limitation reverts to 50% of AGI after 2025.)

Any excess over the limitation would carry over to the following year. If the deduction has not been fully utilized by the end of the five-year period following the year of the gift, the amount not utilized will expire.

There are additional limitations that apply when the gift is property, such as securities, rather than cash.

Charitable giving direct from an IRA

Congress recently enacted legislation that allows a taxpayer who has attained the age of 70 1/2 to make a charitable gift directly from an IRA. (The gift may not be made directly from an employer-sponsored retirement plan.) The gift is called a "qualified charitable donation" or QCD. This is beneficial for many taxpayers, because many taxpayers are required to withdraw a certain amount from their IRAs every year (the required minimum distribution). If the taxpayer contributes their distribution directly to charity, they may be able to write off a greater proportion of the gift than if they gave the donation using a different method.

Amounts that are transferred to charity using a QCD count toward the required minimum distribution from the IRA for the taxpayer for that year. Up to \$100,000 may be given in this fashion. In order to qualify for QCD treatment, it is necessary that funds go directly from the taxpayer's IRA to the charity. QCD treatment would not be available if the distribution were made to the taxpayer and then transferred to charity.

This new rule effectively makes 100% of the gift deductible in one year (if the QCD is \$100,000 or less), as compared with a maximum of 50% (or 60% through 2025). Example: Taxpayer has income of \$50,000 and wants to make a \$50,000 contribution to charity. The deduction allowed to the taxpayer for a traditional gift to charity would be at most \$30,000 (60% of adjusted gross income). Disallowed deductions may be carried over, but under rules much less favorable to taxpayers.

If the taxpayer made a QCD from their IRA directly to the charity, the entire \$50,000 would be 100% deductible in one year.

The \$100,000 QCD maximum is indexed for inflation in years beginning in 2024.

Always consult your tax specialist to be sure you are taking full advantage of the tax benefits for charitable giving.

John C. Suttle is a retired tax attorney and a former member of TMA's Board of Directors. He was diagnosed with inclusion body myositis many years ago and lives in California.

Power wheelchair 101

By Susan Honigstock



Finding the best wheelchair for you is not like buying a sweater. You can't just pick it out, take it home, try it on, and decide if it is a good fit. A wheelchair is a friend you will have for years. Like a friend, it must be compatible and comfortable. It's also nice if it can anticipate your needs.

When your doctor suggests a wheelchair, do not run out to your nearest store and order one. Contact Medicare or your insurance provider first to find out what they will cover. As of now, Medicare will cover power seat elevation equipment on Medicare-covered power wheelchairs (typically for those with IBM). This allows the chair to fully extend to an upright position for transferring, a \$2400 bargain.

In the Medicare handbook, wheelchairs are identified as durable medical equipment, and the Medicare Part B deductible will apply. Keep in mind, however, that the price Medicare will pay is not necessarily the price of the wheelchair you need. This is where your Medicare supplement insurance will come in handy.

Armed with the above information and a notebook, it's time to proceed. Your physical therapist or neurologist can probably suggest some companies. The important thing is to have a complete evaluation of your needs now and into the future to evaluate how their equipment can be modified as your condition progresses. For example, at some point you may need to modify the steering mechanism if you are unable to grasp the steering lever.

It's a good practice to consider quotes from at least two or three companies before ordering. Each company will be eager to get your order and just might enhance their service, house calls, and technical help with basic questions. I strongly suggest going online to read up on those companies and their customer service and see how others have reviewed them.

Unfortunately, I was pushed into a company by a "hospital wheelchair expert" and found out too late that service is nonexistent for the company I chose. When I ran into trouble, my phone calls were never returned. The regional salesperson was not helpful until I contacted the president of the company. It wasn't until it was too late that I read the poor reviews from former customers about the company's shabby customer service.

My physical therapist was an asset when my power wheelchair was delivered. She slowly went over the main parts of the chair and how each worked. It took a few mini lessons until I was comfortable. She also encouraged me to take it for a spin outside, down the driveway, and over the nearest sidewalk ramp. Now I feel like a wheelchair expert, zipping around my neighborhood.



TMA improves the quality of life for people with myositis because individuals like you support us through tax-deductible, charitable donations. Please consider making a gift to help us serve even more people affected by myositis. For details, visit www.myositis.org/donate.

Thank you!



Myositis Awareness Month

MAY 1-31, 2024



THE MYOSITIS ASSOCIATION®

THE INTERNATIONAL ANNUAL PATIENT CONFERENCE

SEPTEMBER 6-8, 2024

HILTON BALTIMORE INNER HARBOR

Celebrating our Connection

