THE OUTLOOK

THE MYOSITIS ASSOCIATION®

WINTER 2023
Quarterly Newsletter

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THE OUTLOOK

A quarterly publication of The Myositis Association

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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Dear Members of The Myositis Association,

As my time at TMA comes to a close, I wanted to take a moment to express my deepest gratitude and admiration for each of you. As your interim executive director, I have had the privilege of being a part of this remarkable community, and I have been continually inspired by your resilience, hopefulness, tenacity, and unwavering courage.

The journey we've shared at TMA has been nothing short of extraordinary. Transitions within organizations can be challenging. I am immensely proud of how The Myositis Association has navigated this time of transition with grace and determination. I am especially grateful for the support and leadership of Board of Directors Chair Dr. David Mochel, and for the efforts of the TMA staff who were able to navigate through many endings in order to create new beginnings. I have no doubt that TMA will continue to thrive and make a meaningful impact for many years to come.

I am delighted to welcome Paula Eichenbrenner as TMA's new executive director. (You can read more about Paula on page 4.) I believe that she is the ideal candidate for this amazing organization. The board, staff, and I have spent the last eleven months preparing TMA for this leadership transition and we will make it as seamless as possible. I wish Paula all the best in this new position.

As I step into new opportunities, please know that I will continue to champion the cause of myositis and support TMA from afar. I have the utmost confidence in the strength of this community, and I look forward to seeing the continued growth and success of The Myositis Association in the future.

Thank you again for your inspiring presence in my life and for the incredible work you do every day. Please stay in touch, and I wish you all the very best in your ongoing individual journey and in your efforts to make a difference in the lives of those affected by myositis.

With heartfelt gratitude and warmest wishes,

Rhonda Buckley-Bishop

Rhonda Buckley-Bishop

On the cover

Laurie Boyer (right) takes over as chair of TMA's Board of Directors in January 2024. Together with our new executive director, Paula Eichenbrenner (left), TMA will be led by these two dynamos. We're excited for the future!

Meet TMA's new executive director!

Paula Eichenbrenner started her position as TMA's new executive director on November 29, and she couldn't wait to get to know the people on whose behalf she would be working in this new role. So, in September, she spent several days at TMA's Annual Patient Conference in San Diego, meeting with attendees and learning firsthand about myositis diseases and the challenges faced by patients and those who care for them.

"Throughout my career I've really focused on community building," Paula says. "I'm a people person, and I like to marshal people together for a cause."

Paula comes to TMA after nearly 20 years leading nonprofit associations related to pharmacy, nutrition, affordable housing, and community development. This professional experience gives Paula a broad view of the healthcare delivery system in this country.

On a personal level, however, she serves as a care partner for her brother who has a complex behavioral health diagnosis. That is, in part, why she felt called to the opportunity with TMA and is thrilled to lead an organization that directly represents the patient experience.

"Serving as TMA's executive director means I can do even more to reduce the fragmentation of our nation's medical, social, and public health systems," Paula says. "I see the importance of doing the work well, so that the myositis community of patients, caregivers, and providers is well represented."

"We couldn't be more delighted to welcome Paula to TMA," says Board of Directors Chair Dave Mochel. "She possesses not just the business skills we need to grow the organization, but also a huge heart and a genuine interest in the well-being of our members. We are so fortunate to have found such an incredible leader!"

"Because myositis is a rare disease, it makes an organization like TMA even more essential to the patients and families we serve," she says. "The need is even more dramatic, and I'm excited to work with the terrific TMA team to enhance the resources available to families navigating myositis, starting from day one of the diagnosis."

One of Paula's goals is to raise TMA's profile in the rare disease world. She wants TMA to be one of the top patient advocacy organizations in the country, one whose name is top-of-mind to decision makers, legislators, regulators, and other advocacy organizations.

It's a lofty goal, and she realizes she doesn't have all the answers. Elevating the voices of those who experience the day-to-day challenges of this disease is important to her, so she invites members to be in touch. You can share your ideas and vision for TMA by emailing Paula at **paula@myositis.org**.

"I have goals, but I'm the least important person in all of this!" she says. "I'm an expert in operations, fundraising, and business management, but moving boldly into TMA's future will require that we all work together. Partnering with the dynamic TMA Board, we will create the organization our members want and need."

In her remarks when she was introduced at the Annual Patient Conference, Paula invited attendees to catch up with her in the hallway and share their stories. She's been learning about myositis, reading about the treatments, diagnosis, and complications. But she knows that the only way to really understand the community of people who live with these diseases is to spend time with them.

She came away from the annual conference with a powerful sense that this community is built on stories. She also recognizes that TMA members are resilient and resourceful and have a well-developed sense of humor, qualities that are essential to navigate the mental health and well-being challenges that come with the diagnosis.

"TMA's track record of creating meaningful connections and funding groundbreaking research is impressive," Paula says. "I look forward to opportunities to enhance health equity as we continue to deliver on the TMA mission: improving the lives of persons affected by myositis."

Paula lives in Alexandria, Virginia where she enjoys museum hopping and hiking trips to Virginia's waterfalls. Her fiancé, Iain, is a native of New Zealand, and they have one dog and two cats. With an undergraduate degree in foreign languages and an MBA specialization in global business, she sees opportunities for collaboration on patient-centric approaches modeled by international myositis organizations.

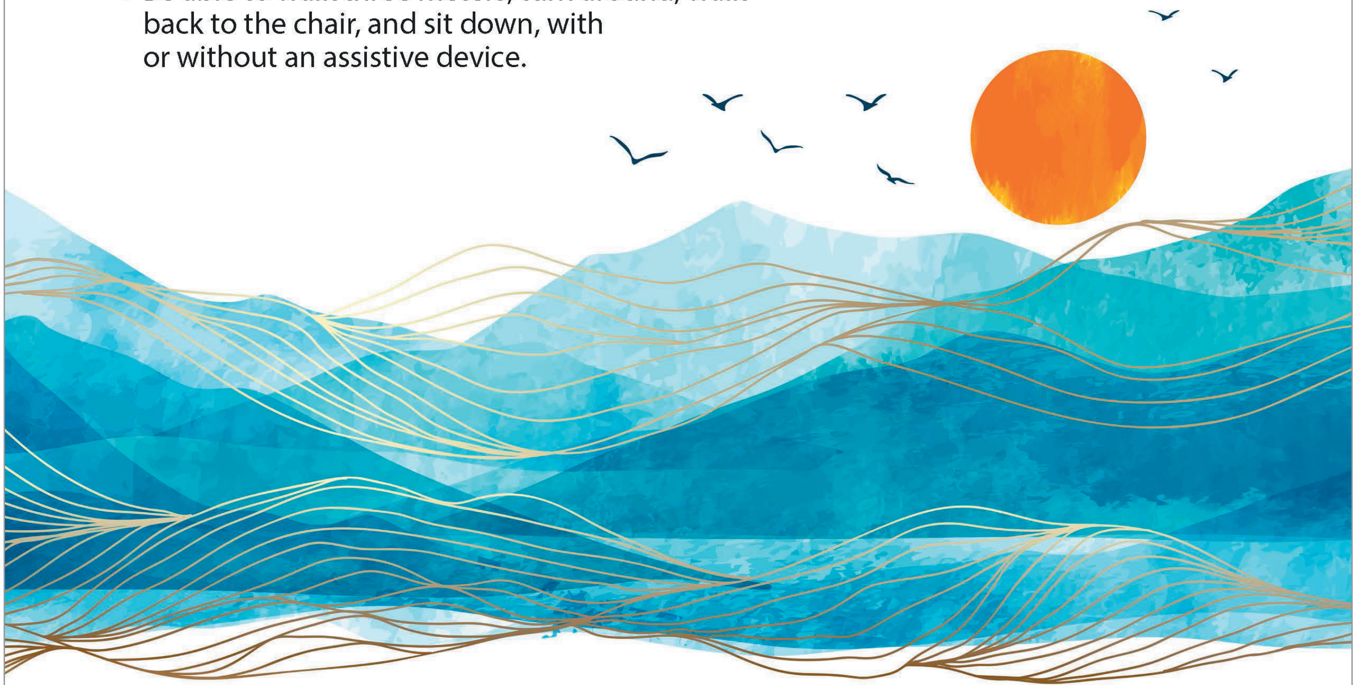
NOW ENROLLING:

A clinical study for adults with inclusion body myositis

A clinical research study is looking for participants **40 years of age or older** with a **confirmed diagnosis** of inclusion body myositis (IBM). Researchers are evaluating a study drug given as injections to learn more about its impact in people with IBM.

To be eligible for this study, participants must:

- Be able to arise from a chair (with armrests), with use of their arms but without support from another person or device.
- Be able to walk three meters, turn around, walk back to the chair, and sit down, with or without an assistive device.



To learn more about this study, please visit clinicaltrials.gov, study ID: NCT05721573.

abcuro

Celebrating our myositis heroes: TMA's Annual Patient Conference

TMA's 2023 Annual Patient Conference was filled with learning, connecting, and so much fun! More than 350 attendees joined us in San Diego for a Celebration of You: Our Myositis Heroes. Here are just some of the highlights.

Dr. Fiorentino answers attendee questions

Rachel with volunteers John and Colleen Layton

Peter Frampton

Celebrating diversity

Myositis warriors

Attendees practice finger exercises

Myositis Warrior Rhonda Rogers with Drs. Goyal and Mozaffar

Frampton fans

Peter Frampton greets board members at Heroes in the Fight Awards Reception

TMA's Heroes in the Fight Awardees

MAB Town Hall Q&A

Veronica Moore

Holly Jones

Health equity for all

Holly Jones grew up in a small town in East Texas, where finding adequate healthcare for her rare disease was a challenge. When she was diagnosed with polymyositis, interstitial lung disease, and pulmonary hypertension in 2003 at the age of 19, she'd never heard of a rheumatologist or pulmonologist. And the primary care physician who treated her had never heard of myositis.

"The health care that I got there was basically trial and error," Holly says. "The doctor told me my prognosis was five years."

It wasn't until she was an adult and moved to Houston that she was able to connect with the specialists who understood her disease and could provide the care she needed. It helped her realize that myositis was not a death sentence and made her determined to take back control of her life. Since then, Holly has become a strong advocate for those who live with myositis.

Public health professionals have long known that factors such as where a person is born, lives, learns, works, plays, worships, and ages can affect our health and quality of life in many ways. In the world of public health, these factors are called social determinants of health (SDOH).

"We know that zip code is a big indicator of healthcare outcomes," says Veronica Moore, a patient advocacy and public health professional. "Our location determines how easy it is to access high-quality resources such as specialized care, for example."

Where you live also determines a multitude of other factors that have an impact on health. Air and water quality, for example, are both tied to geographic location. The quality of schools and other educational resources can be very different depending on the locality. Availability of employment opportunities and childcare, whether your neighborhood is safe and housing is affordable, how accessible the community is for those with disabilities all depend on where you live.

Through her work in industry, Veronica urges her colleagues in biotech to use the SDOH framework to evaluate patient and community needs and create sustainable changes based on those insights.

As a leader in the myositis community and an advocate for health equity, Holly is hoping to move the needle in the same way for those who live with myositis. She stresses that equity is not just an issue for black and brown communities or those who live in poor neighborhoods.

"Health equity has everything to do with social determinants of health," she says. "And everybody is affected by these things."

For example, there are only a handful of major medical centers in the country where you can find expert specialty care for myositis. And it doesn't matter what your income level is or what color your skin is, if you don't live close to one of these centers, it's unlikely that you will be able to access these specialty resources. And no matter where you live, it can take months sometimes to get an appointment to see a rheumatologist or neurologist, simply because there are not enough of these specialists available anywhere.

Similarly, if you're a single woman living alone, you may choose not to have that outpatient surgery, because you don't have someone to drive you home after you've had anesthesia. If finances are tight, you may be faced with the choice of paying the rent or paying for medications. And what do you do when you're living on Social Security or Disability and in the same week that your roof needs to be replaced your doctor also wants you to have an MRI?

Some communities may have resources that can help in such situations, but what do you do if you live in a small town in East Texas where these resources aren't available? And many people who need such resources are just not aware of them or how to access them.

Social determinants of health are a framework that provides an opportunity for the rare disease community to understand what systems and situations are at the root of healthcare challenges and to adapt their programming to the community they serve. As a part of what Veronica calls the healthcare ecosystem, The Myositis Association can be part of creating solutions for this rare disease community.

"This is a way to bring everybody together," says Holly, who serves on TMA's Board of Directors. "We don't have to think of disparities as just within a certain group. This creates a common foundation for everybody."

"Our equity work is about using SDOH to put our brains together to think about systemic solutions to address problems," Veronica says. "This involves action, and TMA is a great example. You're working with the affinity groups and patient advocates in the community. You're reaching out to research institutions and academic centers. You're not leaving anyone behind as you engage in the work of moving the needle of health equity for the myositis community. You're working to change the world!"

For more information about social determinants of health, see the Healthy People 2030 website: **https://health.gov/healthypeople/priority-areas/social-determinants-health**

Veronica Moore is a patient advocacy professional and health equity advocate, currently serving as Associate Director for R&D Global Patient Advocacy at Horizon Therapeutics for myositis and other rare autoimmune diseases.

Holly Jones is the founder of HERstory In Color, a women's health empowerment nonprofit organization. She currently serves on the TMA Board of Directors, TMA Women of Color Affinity Group (co-leader), and committees that aid in the promotion of TMA.

Partners in the fight

By Ed McGrath

At TMA, we know that a diagnosis of myositis also affects those who care for and about the person who has the disease. In this article, Ed McGrath shares his insights into the care partner experience.

My wife Marilyn has dermatomyositis, diagnosed in 2008. Her dermatologist initially thought she had lupus, but two years later she finally saw a rheumatologist who knew exactly what Marilyn was suffering from. “The Man,” as I call him, now manages Marilyn’s myositis treatment, and we often touch base with him about meds prescribed by her other doctors who don’t understand myositis.

Once we recovered from the shock of Marilyn being diagnosed with a rare disease, we learned all we could about DM. That’s when we joined TMA and began attending the TMA conferences. I consider myself a “care partner” as opposed to a “caregiver,” because we’re a team. We fight this disease together.

As her partner in this disease, I watch for telling signs. I notice when Marilyn gets fatigued, for example, or when her right eye starts to droop. When her skin flares, I know to draw a circle around the rash to see if it’s spreading, which means things are getting worse. I know how to lift her out of a chair, and I know when she needs rest.

When Marilyn was first diagnosed, we talked with our children about what it meant and the impact it would have on all of us. The biggest disappointment for Marilyn was having to give up taking care of our young grandchildren. She no longer had the mobility or the energy needed to safely care for them. Instead, we started spending time with the kids through Sunday family dinners and attending their school and sports events, even if we had to watch from the car. Most of our grandchildren are grown now, but they still look forward to those Sunday dinners, as do we.

Myositis has challenged us but also helped us to focus on what’s really important. Before myositis, we enjoyed being active: exercising, traveling, dancing, and entertaining. Myositis took a lot of that away, but we learned to adapt, finding ways to still do things we enjoy.

We started traveling again, calling ahead to check for accommodations with handicap access and no stairs. When we go to the beach, I set up a tent so we can still enjoy the sand and surf. We even dance, albeit from a sitting position.

The decision to sell our two-story home and move into a one-floor townhouse was really difficult. Without the big yard, even the dog felt that one! But one-floor living made life easier for us. We installed a high toilet and walk-in shower and added a large patio with an awning so Marilyn can be outside without risking a flare from the sun.

Before we joined TMA, we’d never met another person with myositis. Thanks to TMA’s Annual Patient Conferences, though, we’ve met so many others who are in our position. We’ve even had conversations with some of the leading myositis experts in the field. Marilyn has become her own advocate, and I’ve met, learned from, and shared with others who care for someone with myositis. We now, and will forever, consider these fellow members of the myositis community our friends.

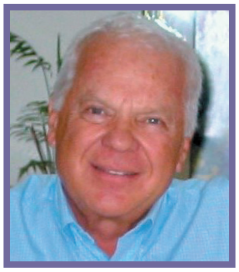
And we’ve learned so much through TMA. When we heard about new treatments like IVIG, we shared that information with “The Man.” We’re fortunate that our medical partner, her doctor, was open to trying new treatments. IVIG has made it possible for Marilyn to wean off prednisone and methotrexate after seven long years.

As a husband, father, and professional, myositis has affected me personally in many ways. I’ve always made decisions based on how it will affect Marilyn and our family, so when she first got sick, I took early retirement. It’s tough sometimes, because I’m a very outgoing person. When I went back to work part-time, I laid down the ground rules: my schedule had to be flexible.

Cont’d on Page 13

10 tips for living with IBM

By Mike Bradbury



I'm not sure what the heck a "hack" is but having lived with sIBM for 20+ years I have a few suggestions for making the journey easier.

1. **Do your chores.** As best you can, continue your normal routine, doing the things you love or need to do as long as possible.

2. **Exercise, exercise, exercise.** Without compromising safety, work out with light weights, ride a stationary bike, take a daily walk, or swim. The important thing is to get into a routine so you don't skip or forget.

3. **Keep your brain engaged!** Read a good book, stay involved in your business or job, take a class

4. **Stay involved socially.** Stay connected with family, friends, and neighbors. Join a club or group or volunteer with your favorite charity.

5. **Keep exploring.** Check off some of those places on your bucket list. Take a cruise. Tour your own town.

6. **Focus on the positive.** The world looks brighter, and you'll feel better. Besides, your friends and family don't need to hear about all your aches and pains.

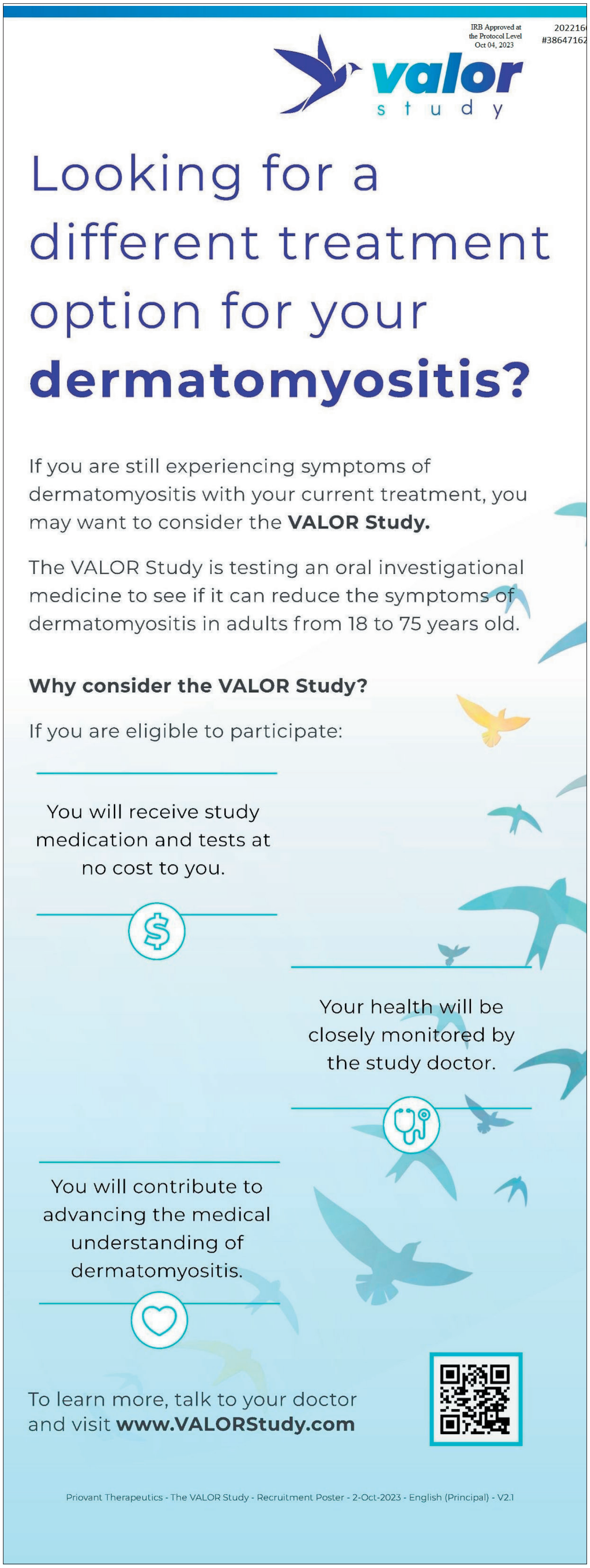
7. **Spread awareness.** Write an occasional article for the local newspaper about your disease. (Most have never heard of it.) Who knows? It may help someone who is suffering.

8. **Keep a journal.** Write about your daily condition, attitude, and mental/emotional status. It's amazing how helpful thinking and writing like this can be. It makes you focus on what needs to be done and where you can make improvements.

9. **Help others understand.** Explain to your family and closest friends how the disease affects you, so they better understand your needs and behavior.

10. **Never, ever, ever, give up!**

Mike Bradbury is a retired attorney living in California.



Important Information about an upcoming Patient Focused Drug Development meeting

TMA is collaborating with Myositis Support and Understanding in an exciting project that will provide valuable insight to researchers who are developing new therapies for those who live with dermatomyositis.

The project is called Patient Focused Drug Development (PFDD). It involves a half-day town hall meeting with members of the Food and Drug Administration (FDA), the government body responsible for assessing the safety and effectiveness of all new medical treatments.

This meeting is an opportunity for the myositis community to participate with leaders in the development of medications to treat DM. It's your chance to have direct influence on drug development and the drug approval process.

TMA encourages all those with DM and their family members to add this meeting on June 7, 2024 to your calendars. We're hoping to have as many members of our community as possible participate. More voices will lead to more impact!

A PFDD website will be launched just after the first of the year to help you keep in touch with the planning. And we'll be reaching out to all of our DM members to provide updates as the planning proceeds, so do be sure that you're signed up as a member of either or both organization and make sure your memberships are updated with your latest contact information.

Attention
Adult Dermatomyositis Patients

MSU and TMA Announce

Externally-Led
Patient-Focused Drug Development
Virtual Town Hall

ENGAGE, EDUCATE, EMPOWER

SAVE THE DATE
Friday, June 7, 2024

What is it? This unique community event is designed for you and your care partner to share your experience with the FDA and other government agencies, doctors, scientists, and medical product developers to help them gain a better understanding of how Adult DM affects lives.

Why participate? This is your opportunity to affect the decisions made in developing and approving drugs for your condition and highlight what is most important to you! The meeting on June 7, 2024 is hosted by MSU in partnership with TMA. We hope to recruit as many participants as possible to maximize our impact.

How do I engage? Look for our new community website launching in January 2024, where you can learn more, provide testimonials, and take surveys. If you are a member, or join TMA or MSU, we will provide notifications to keep you up to date as the process develops.

For information contact Lynn Wilson, lynn@understandingmyositis.org

For email updates https://form.jotform.com/232623765075055

MSU Myositis Support & Understanding
EMPOWERING THE MYOSITIS COMMUNITY

The Myositis Association®

Securing tomorrow's legacy: The power of planned giving

Do you ever look at the calendar and wonder how time passes so quickly? Each year has its seasons, and our lives have seasons as well. Many TMA supporters at one time or another ask themselves what kind of impact they would like to make over the course of their lives. Some of this involves how they invest their time and talents. Some also consider how they can invest their financial resources—both present and future—to reflect their values.

Bob Goldberg, a former TMA Executive Director, has asked himself those questions. When Bob and his wife Karen both lost their fathers, they began thinking more seriously about estate planning.

"You never know when your time will come, and we wanted to be proactive about our financial planning as we got older," Bob says.

As a regular supporter of TMA through annual giving, he began considering the greater impact he could make with a planned gift.

Bob has always been amazed at how strong, resilient, and optimistic people with myositis are, and he was deeply touched by those he met through TMA. He wanted to do more to help them and find a cure.

He knew that bequests and other planned gifts could have a significant impact on TMA programs such as patient education, research, and raising awareness about rare diseases.

Bob is making his planned gift the way many other people make theirs: as a bequest. All it takes is to include a few words in your will. You can designate a fixed amount for TMA, a percentage of your estate, or a percentage of the "remainder" of your estate—the amount left over after specific distributions to other beneficiaries.

"I'm not doing this so people remember me. Rather, I just want to help people with myositis and their families. And I know for sure that TMA could do even more than it is currently if it had more resources."

Bob may also consider making TMA a beneficiary of a life insurance policy or an IRA to increase his impact. He knows he doesn't have to make all these decisions at one time. "As my adult children become even more financially independent, I might adjust the amount I leave to TMA."

He also is quick to remind others that the amount of the gift is less important than the desire to help those living with myositis.

"You don't have to be rich to make a difference, particularly when giving to a rare disease organization. Your donation to TMA, which is a small-budget organization, will have much greater impact than giving to a charity focused on a more common disease such as cancer or diabetes. The key is leaving a gift to an organization that you trust, have respect for, and believe is going to use the money wisely."

TMA has information about planned giving on its website ("**Get Involved**"). There are many planned giving options to give to TMA. It is recommended that you speak to a financial advisor about your personal financial situation and wishes. If you let TMA know that you're leaving a future gift, you have the option to be included in TMA's Legacy Society, a group of TMA supporters who have committed to making a planned gift.

Legacy gifts help those who live with myositis, now and in the future. Bob says, "Do what feels right for you, so you feel good about yourself. These gifts add up and can make a major difference."

Thank you for considering TMA in your future plans.

Partners in the fight - Continuation from Page 10

The toughest thing I struggle with is watching Marilyn's pain and loss and not be able to fix it. I like making people smile or laugh; it's good medicine, and I tend to use humor as a way to cope and communicate.

Marilyn and I are always looking and hoping for a cure. But we will continue to fight, we won't let myositis win. And I will always be Marilyn's care partner.

Ed and Marilyn McGrath have been committed members of TMA for twelve years. They live in Troy, NY and are the proud parents of three children and six grandchildren.

Pfizer is proud to support the Ig community

We're committed to supporting your DM treatment experience by providing patients and caregivers with:

- Support
- Treatment options
- Resources

Scan to learn about Pfizer's treatment option for adults with DM

DM=dermatomyositis; Ig=immunoglobulin.

October 2023

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SEPTEMBER 6-8, 2024
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