

THE OUTLOOK



THE MYOSITIS ASSOCIATION

WINTER 2022
Newsletter



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A publication of The Myositis Association

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TMA's vision is a world
 without myositis

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

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From The Desk Of Chrissy M. Thornton

WINTER 2022 OUTLOOK



Dr. Iazsmin Bauer Ventura, Holly Jones, and TMA Staff

I am humbled to be celebrating a very successful year at The Myositis Association.

It was our goal in 2021 to listen to our community and position the organization for rebuilding and growth. In doing so we learned just how much "The Power Of US!" was needed to make a difference. Every gain we celebrate today is because of our community - our patients, care partners, caregivers, loved ones, friends, healthcare partners, and corporate partners who all have a commitment to supporting the mission of The Myositis Association.

In 2021, we awarded both a research grant and a fellowship, because of the generosity of our donors! We also awarded 69 full registration scholarships to our virtual International Annual Patient Conference. We connected with patients, heard their unique stories, and encouraged many to step up and become volunteer leaders in the organization!

As we travel through 2022, you can expect to see fully developed educational programming, with monthly webinars around psychosocial topics and a monthly "Ask The Doc" series featuring our world renowned Medical Advisory Board members. You can look forward to increased connectivity through our Remo platform "Community Convos" and a new nationwide virtual support group. Joining our Women With IBM and Women Of Color Affinity groups are a Caregivers group and a Military Veterans with Myositis group. And, we will launch Adelante, our first Spanish speaking virtual support group.

The outstanding success of our new National Signature Fundraising and Awareness event, FUN FIT FLEX will bring forward new event locations in 2022. This branded TMA fitness and wellness festival serves as a platform for us to educate, inform, and build our community, while raising much needed funds to sustain our work. FUN FIT FLEX has also opened the door to non-industry corporate partnerships, for which we are extremely grateful.

We will kick off May 2022 with a TMA Myositis Family Day, giving us all the opportunity to celebrate the village born from our connection to this disease community. Our Myositis Awareness Month Virtual Summit will return this year, reminding us to be Encouraged, Engaged, and Empowered - together! And, after what seems like a very long time not being able to gather in person, we will be traveling to Orlando, Florida for our 4 day in person International Annual Patient Conference: A Focus On The Future!

Our Patient and Family Advisory Council (PFAC) is in full swing and will be producing some new patient-focused tools and initiatives for the community's needs. The team at TMA is committed to serving our myositis community with education, resources, support, and advocacy - and most of all with LOVE.

Thank you to each of you for your willingness to come along on a journey where we've done things differently, with intention. Thank you for embracing our desire to grow and strengthen the organization. There is so much more work to do.

Let's GO!

Chrissy M. Thornton
Executive Director

2021 International Annual Patient Conference: The Power of US!

The Virtual Annual Patient Conference made myositis experts available to those not able to travel to in-person conferences, and was our biggest conference to date! In this issue of the Outlook, we hope to give you key points from some of the sessions.

Pre-Event Activities

Cookies, Cocktails & Convo - A Reception for Support Group Leaders

To kick off the 2021 Annual Patient Conference, TMA hosted a virtual reception for Support Group Leaders called Cookies, Cocktails and Convo on September 8th. Each guest received a curated kit with goodies for the event – mix to bake cookies, drink mixes for their choice of cocktail, a wine glass and silicone straw. Everyone gathered together to play games, win prizes, enjoy their treats and just get to know one another better! Overall, the event was a great success and we hope the support group leaders went away knowing how appreciated they are for their service to TMA. Our support groups are the bedrock of the organization and we couldn't do it without the hard work of our volunteer leaders!

Annual Patient Conference Kickoff - TMA Virtual Reunion Conference attendees experienced a new virtual environment as we utilized technology through a platform called Remo. This TMA Reunion allowed attendees to catch up with old friends and meet new ones while enjoying some much-needed facetime.

Conference Highlights

This year's conference hosted several Town Hall meetings and informative medical sessions and workshops.

•**Inclusion Body Myositis** MAB members: Tom Lloyd, MD, PhD; Namita Goyal, MD; Chris Weihl, MD, PhD; Tahseen Mozaffar, MD; Tae Hwan Chung, MD and

Lindsay Alfano, PT, DPT, PCS, held a Q&A session with attendees.

•**DM/ILD/Antisynthesis Syndrome** MAB members Rohit Aggarwal, MD, MS; Sonye Danoff, MD, PhD; Victoria Werth, MD; Marianne de Visser, MD and Cheilonda Johnson, MD, MHS, held a Q&A session with attendees.

•**PM/Necrotizing Myopathy** MAB members Jens Schmidt, MD; Wael Najib Jarjour, MD; Erik Ensrud, MD; Olivier Benveniste, MD and Adam Schiftenbauer, MD, held a Q&A session with attendees.

T-Cell Infiltration & Inclusion Body Myositis Dr. Anthony Amato from Brigham and Women's Hospital provided attendees an overview of the latest research involved with T-Cell Infiltration.

Creating Collaboration: Managing your Healthcare Team Dr. Namita Goyal, TMA Medical Advisory Board member, helped attendees figure out how to balance and encourage synergy with their doctors.

Staying Connected to the Myositis Community Jim Mathews, TMA's Board of Directors, spoke on the importance of patient involvement and being prepared to spread the word about what's happening in the community. Staying connected and engaged can help maintain momentum and should be a part of your personal plan.

Myositis 101 - Julie Paik, MD, MHS from Johns Hopkins Myositis Center, provided the basics of myositis diseases. If you were newly diagnosed, needing a refresher, or the family member of someone with myositis, she gave a full overview of the disease to increase understanding.

Living Your Best Life - Refocusing Your Energy TMA Member Elisa Glass shared her myositis journey. Many times hearing someone else share their experience of living with myositis can help you understand and better navigate your own myositis path.

Congratulations to Monika Davis! She was the grand prize winner of our 2021 APC attendee prize drawing. She will receive conference registration and hotel accommodations for two for our 2022 International Annual Patient Conference in Orlando, Florida!

May is Myositis Awareness Month

The purpose of Myositis Awareness Month is to create awareness about this group of rare conditions. Nationwide and even internationally, myositis patients and their families observe the month of May as a time to educate the community about their rare diseases. TMA will lead the way again in 2022 as we join together to recognize the need for more research and understanding of myositis in hopes of faster diagnoses, better treatments, and eventually – a cure!

“Our biggest challenge is to create awareness for the disease, so patients can seek an accurate diagnosis,” says Dr. Lisa Christopher-Stine, director of the Johns Hopkins Myositis Center. “Because damage caused by myositis can occur in the first few years, early diagnosis means early treatment to improve quality of life.”

We are planning plenty of activities for our community, including the Myositis Awareness Month Virtual Summit. In 2022, The Myositis Association continues our quest to support our patients and care partners in being “Encouraged, Engaged, & Empowered” as we work all month long to create broader community awareness, direct our members to TMA offerings and resources, educate around patient and disease advocacy, share clinical insights, and build a stronger and more connected myositis community.

REGISTRATION IS OPEN!

Early Bird: \$45 before March 31, 2022

Registration: \$55 after April 1, 2022



THE MYOSITIS ASSOCIATION PRESENTS

MYOSITIS AWARENESS MONTH

Encouraged. Engaged. Empowered

 **MAY 2022**

VIRTUAL SUMMIT - SATURDAY MAY 21, 2022

WWW.MYOSITIS.ORG

The banner features a central graphic of stylized human figures in various colors (yellow, orange, red, blue, green) holding hands in a circle, set against a blue and yellow background with a light flare effect.

Your advocacy and commitment to building awareness improves the lives of myositis patients everywhere.



Take The Journey With Us!



SHARING YOUR PATIENT STORY

Patient stories offer valuable insights that go way beyond the statistics and the outcomes: they have the power to inspire, humanize, compel action, and challenge assumptions. Your experience deserves a seat at the table.



FUNDRAISING

Raising money builds support and momentum for our cause in the myositis community. Our organization depends on generous support to continue toward our mission of finding a cure – and to fund much needed myositis research.

Every dollar matters!



ADVOCATING FOR YOUR HEALTHCARE JOURNEY

Be your own advocate. Never be afraid to ask questions! It is your right to know about the benefits, side effects, and any disadvantages of recommended procedures and treatments. Understand how insurance works. Participate in trials. Maintain your own records. Know that you are entitled to other opinions.



CREATING COMMUNITY AWARENESS

It's time to activate! Host a community event, wear branded items and share marketing materials about myositis. Reach out to your networks, contact the media to share your story, use your social media to educate.

Be a billboard for myositis!



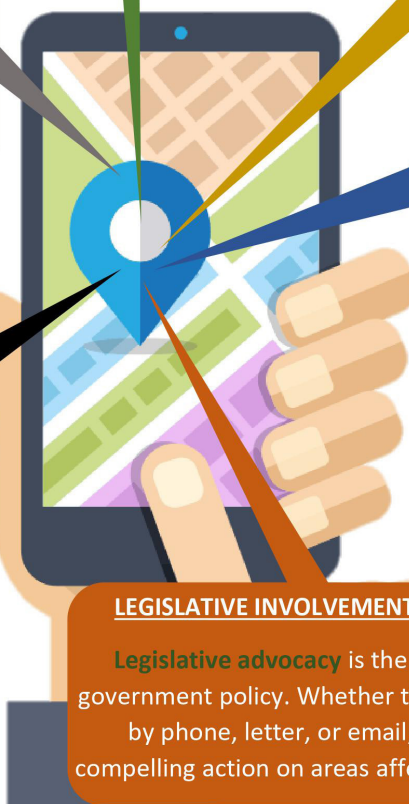
VOLUNTEERISM

Volunteering can provide a healthy boost to your self-confidence, self-esteem, and life satisfaction. You are doing good for others and the community, which provides a natural sense of accomplishment. Your role as a **volunteer** can also give you a sense of pride and identity.



LEGISLATIVE INVOLVEMENT

Legislative advocacy is the most direct way to cause change in government policy. Whether through lobbying, contacting legislators by phone, letter, or email, sharing your views on issues, and compelling action on areas affecting our patients, your voice matters.



Myositis Association Australia



Christine Lowe, President, Myositis Association - Australia Inc.

The Myositis Association Australia was formed in 2003 at the suggestion of long-time TMA Executive Director Bob Goldberg who brought the idea to Anita Chalmers, one of Myositis Australia's longstanding members. Today, the organization is still pushing forward with a goal to build awareness for their over 370 members. The organization is patient and volunteer run and they pride themselves on taking advantage of the smaller membership numbers by speaking with members individually and visiting with them during hospital stays.

Of their 370 members, about 40% are based outside of the major cities in the rural or regional areas, so the Association appoints state coordinators to facilitate connectivity. They participate in awareness raising activities, including meeting within their Health Minister's electorate, where they have addressed the impact of myositis and the unmet needs of the community to have better treatments. They've pursued and gotten media coverage and space in local publications and national Australian magazines where they've included patient stories. They additionally work closely with Professor Merrilee Needham, who combines the challenging

roles of leader of the Myositis Research group and consultant neurologist at the Perron Institute, Director of Research, South Metropolitan Health Service, and Consultant Neurologist and Foundation Professor of Neurology at Fiona Stanley Hospital, Murdoch University and Notre Dame University. Dr. Needham is also a member of The Myositis Association's Medical Advisory Board.

Myositis Association Australia considers themselves very fortunate to have a good team of neurologists and rheumatologists around the country who have made myositis one of their specialties. As an organization, they've gathered together a referral list to help guide patients when they find themselves seeking a diagnosis or even seeking a second opinion from a doctor with the right expertise.

Like TMA, Myositis Association Australia maintains a network of State Support Groups which meet together to share experiences and information.

They offer two types of memberships: Member (any person diagnosed with Myositis or parent of child with JM) and Associate Member (family member, relative or friend) for \$10. Membership benefits include: National Newsletter, National and State events, advocacy for myositis patients, updates on research and educational sessions, attendance and voting rights at AGM and general meetings and much more.

Myositis Association Australia is a valued partner of The Myositis Association and a member of the World Myositis Coalition, organized by TMA in 2021.

For more information on Myositis Association Australia please visit their website at <https://myositis.org.au/>



New Ideas for Everyday Living

by Susan Honigstock



I did not realize how many helpful items I have accrued since I last wrote.

Most came out of sheer frustration in chores I have been doing for years.

1. Problem: Unable to re-close bread bags once opened.
Solution: Amazon sells bag or food clips in varied sizes. They are easy to use and go into the freezer as well. Some brand names are Anphsin, Linden, or Bakhuk. I use them for many items for pantry or refrigerator.

2. Problem: Safety pins are too much of a challenge. The only ones that work for me are old diaper pins from forty years ago that have a top that can be pushed up when opening and pushed down for closing. I only found a very few about the house.
Solution: Amazon and knitting stores carry knitting pins made of plastic and thus easy to open and close. They come in a variety of sizes.

3. Problem: I am unable to put a half gallon of juice, even in a plastic container, above my height into the refrigerator.
Solution: I pour the half gallon liquid into 2 quart plastic containers and do fine!

4. Problem: I have found I am having trouble grasping larger items from the floor, especially grocery items like orange juice or milk.
Solution: I use a broom or stick to move the item into a cloth bag with handles. I then can use my wrist to elbows to carry it into the appropriate room.

5. Problem: I have been unable to arise, even from

a handicapped toilet due to either water on the floor making it dangerously slippery, or the material of the flooring itself dry but slippery. Trust me, twice was a nightmare. Even though I carry my phone 24/7 I did not have the presence of mind to use it.

Solution: I now carry in my purse a 12 by 12 piece of webbing, the kind you can use in dish closets or under rugs. It works like a charm and can be washed. No feet can slip!

6. Problem: Hair spray and other aerosols. I am not able strength-wise to use.

Solution: An old standby recommended by fellow Myositis patients is Rust-oleum Spray Grip which fits any spray can. #243546.

7. Problem: Arising from a bed from a sitting position. It is getting harder and harder, especially when my legs are tired at the end of the day.

Solution: Purchasing a Yoga Strap in the desired length making sure it has many handles and does not stretch. Buying a threaded eye hook which is made in varied sizes. Make sure the Yoga strap will fit through the eye. The hook is then set into a stud. I bought an 8 foot Strap which is doubled and I use both handles to assist me. This idea is also one that I heard from another Myositis patient and then modified for my needs.

I would love to hear ideas from my Myositis family that we can share with others.

Please write to me at msdurite@comcast.net



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Support Group Standards of Excellence

by Rachel Bromley

Part of my new role as Senior Manager, Patient Education, Support and Advocacy has been to create Standards of Excellence for TMA's support group model. With consistency of service delivery in mind, the goal is to create the same branded experience nationwide. That means someone attending a support group on the West Coast would have the same, or similar, experience as someone attending a group on the East Coast and anywhere in between. To provide this standardization, we had to ask ourselves, "What does excellence look like?"

At The Myositis Association, excellence looks like support group leaders and co-leaders who are trained, skilled and certified from the same curriculum. In addition, an excellent support group is:

Branded • Marketed • Structured • Delivered • Communicated • Activated

Branded – All support groups should be using the same approved logo and logo colors. Emails should be branded from the organization with limited use of personal email accounts. Group names should follow the TMA branding formula to ensure consistency.

Marketed – Groups need to be marketed via TMA's calendar and website, with a personalized landing page for each group that is updated regularly. Group meetings should also be marketed via social media and in their own support group newsletter. Groups will be highlighted at both the Annual Patient Conference and the TMA Virtual Summit. In particular, group meetings benefit most from healthcare engagement, so marketing should occur in doctor's offices, other healthcare settings, and visibility anywhere patients are is a priority.



Structured – Successful support groups will have a structured format with an agenda. The format might be curriculum-based, topic-focused, open forum, or a combination of all of these methodologies. Social get-togethers, whether virtually or in-person, do not require an agenda, and are encouraged for relationship building!

Delivered – TMA encourages support groups to meet at least 3 to 4 times a year for at least 90 minutes each time.

Communicated – TMA asks support groups to submit a meeting report following each meeting. It is also effective to talk about your most recent meeting in your support group newsletter to encourage increased attendance and participation. Let them know what they missed out on!

Activated – This is the pinnacle of excellence – when a group goes beyond meetings, and organizes get-togethers, participates in fundraising collaboratively, and/or engages in legislative advocacy. Coming together to leverage our collective voice makes a difference!



Standards of Excellence

(Continued)

In August, TMA hosted a two-day certification process for our new model. Support Group Leaders were trained on the Standards of Excellence, got highlights from the new support group manual, and attended sessions on Managing and Growing a Support Group, Managing Group Dynamics, Being a Voice, and Emotional Wellness.

Congratulations to our current Support Group or Affinity Group Leaders who are now officially TMA certified:

Barbara Kluding ~ Barbara Shaw ~ Bill Simeral ~ Bob Nudelman ~ Dale Scott ~ Darlene Eschete ~ Darlene Carruthers-Shelton ~ Dianne Browne ~ Donna DeFant ~ Elisa Glass ~ Gail Woods ~ Holly Jones ~ Jodie Garcia ~ Kaniah Gunter ~ Karen Paddock ~ Katheryn Goode ~ Katie Weyhrauch ~ Linda Sabatino ~ Madge Chambers ~ Marianne Moyer ~ Martha Arnold ~ Meriel Parker ~ Nancy Marx Erickson ~ Pixie Allison ~ Randy Heinig ~ Renee Gori-Carroll ~ Rhonda Rogers ~ Shawna Nielson ~ Sheila Prather ~ Stacey Erekson ~ Stanley Prather ~ Susan McLoughlin ~ Vickie Jahaske

TMA is here to support all our support groups, from the long-standing and well-established groups to those still in foundational stages!

If you would like more information or need to get connected to a support group (either in person or virtually), please reach out to me at rachel@myositis.org

Veterans Affinity Group

Are you a veteran with a myositis diagnosis?



If so, you are eligible to join TMA's Military Veterans with Myositis Affinity Group. If you are involved with a TMA support group already, you are more than welcome to participate in both groups. TMA launched Affinity Groups as a way for patients with more than the diagnosis in common to come together for support. The affinity brings them even closer together as

participants navigate the myositis journey through the lens of commonality. Currently led by TMA's Senior Manager, Patient Education, Support and Advocacy Rachel Bromley, a veteran herself, this affinity group is in the foundational stages.

Joining this peer affinity group can help you to feel better in any number of ways, such as:

- Knowing that others are going through something similar
- Learning tips on how to handle day-to-day challenges
- Meeting new friends or connecting to others who understand you
- Learning how to talk about things that bother you or how to ask for help
- Learning to trust other people
- Hearing about helpful new perspectives from others

If interested in joining, please email rachel@myositis.org



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Holly Jones

Holly Jones is passionate about Teens/Young Adults with myositis and Pregnancy/Parenting with myositis. Being diagnosed at 19 yrs old, she had to learn

how to navigate her adult life with Polymyositis and Interstitial Lung Disease. As a member of TMA, Holly has served as a Maven Ambassador, Conference Panelist, KIT Leader, and Co-Leader for the Women of Color Affinity Group. She lives in Houston, TX with her husband, Kameron and two daughters, Kynadee and Kynsley.

Rich DeAugustinis



Rich DeAugustinis is the CEO of DeAugustinis Associates, LLC. He recently retired from The Coca-Cola Company after a 30+ year career and is presently on sabbatical as he explores new opportunities in

nonprofit leadership.

Rich is a seasoned executive and leader with broad international management experience. Rich's career at Coca-Cola spanned customer leadership, strategy and planning, new business development, marketing and more. Most notably, he served in a variety of leadership roles on the global team responsible for Coca-Cola's business with McDonald's (Coke's largest and most strategic foodservice customer). Rich's international experience is built from traveling to and working in over 70 countries around the world.

Rich resides in Chamblee, Georgia and he and wife Nina are blessed with 3 young adult children – Megan, Christian and Aubrey. On a lighter note, Rich is a kid at heart. He is a Disney fanatic, an aspiring Lego master builder, and loves to travel.



Iazsmin Bauer Ventura

Dr. Bauer Ventura is a rheumatologist specializing in inflammatory myopathies and

interstitial lung diseases. She is part of the University of Chicago multidisciplinary interstitial lung disease team and is the director of the University of Chicago Myositis Center. She is passionate about developing trusting and compassionate relationships with her patients diagnosed with all types of myositis and working to improve equity in health care. She is also a clinical educator and is involved in the teaching of medical students, internal medicine residents and rheumatology fellows.

Frank Lipiecki



Frank Lipiecki has a background in chemical engineering, and has held leadership positions in research, engineering, manufacturing, supply chain and project management during his 40 plus year career. He has worked for leading

international companies as well as small emerging bio-economy firms. He is interested in supporting efforts to find therapies and cures for myositis. Frank lives with his wife, Laurie, in Cherry Hill, NJ.

Campaign Highlights

The Myositis Association depends on the generous support of our community to continue our mission - to improve the lives of persons affected by myositis, fund innovative research and increase myositis awareness and advocacy.

A great way to support The Myositis Association is to create a Fundraising Campaign. In 2021, our member-led Fundraising Campaigns brought in over \$36,000. These donations continue to allow us the opportunity to expand and improve the programs and services we offer to those living with myositis.

Below we are highlighting a few of the Fundraising Campaigns that were created this past year:

◆ **The Myositis Association Annual Scholarship Fund** – Thanks to the generosity and support of the myositis community, we were able to raise over \$5,400 and sponsor over 30 people for our 2021 International Annual Patient Conference. This campaign was created to help provide a complimentary registration for those who could not otherwise afford to attend.

◆ **The Tony Nestico Memorial 5k Campaign** was created to celebrate the life of Tony Nestico, who lost a 3-year battle with polymyositis on November 22, 2018. This year, The Anthony J Nestico Foundation surpassed their \$6,000 fundraising goal and brought in over \$7,500.

No campaign goal is too small or big. The funds raised and the awareness created help our work towards our mission. Feel compelled to get in on the action? **Visit our website at <https://www.myositis.org/get-involved/fundraise/start-campaign/> to start your campaign today!**

◆ **Run for the Cure** was established by Lang Ngov to honor his brother who passed away suddenly from Dermatomyositis. The campaign's goal is to raise money for research in the treatment of Dermatomyositis. So far, Run for the Cure has raised over \$350.

◆ **Helen's Hope** was created by Denita Jones in May 2021 to honor her mom, Helen Jones. Helen was diagnosed with Dermatomyositis in 2006 but her positive outlook & determination saw her survive well beyond medical expectation. May will forever be special to Denita and she raised \$620 to help make an impact in the myositis community.

◆ **Amma's Legacy** honors Selina Alam Yazdan who battled from anti-MDA5 Amyopathic Dermatomyositis. To honor her life and the love that she spread, her family raised over \$10,000 for The Myositis Association to help support research efforts to address this rare disease, those affected by it, and their families.

◆ **Father's Day Fundraiser** - was created for Vazir Karsan, who was a kind, loving, and compassionate person. His focus was simple, making sure everyone was happy and always smiling. In honor of him, his family raised \$12,710 for The Myositis Association surpassing their goal of \$5,000.

Also in 2021, our Fundraising Hero, Monica Pedano reached the \$1 million fundraising mark for TMA (over 10 years) at the **18th Annual Myositis Awareness, Dr. & Mrs. Pedano Memorial Golf Event!**



Monica Pedano and family at the 18th Annual Myositis Awareness, Dr. & Mrs. Pedano Memorial Golf Event



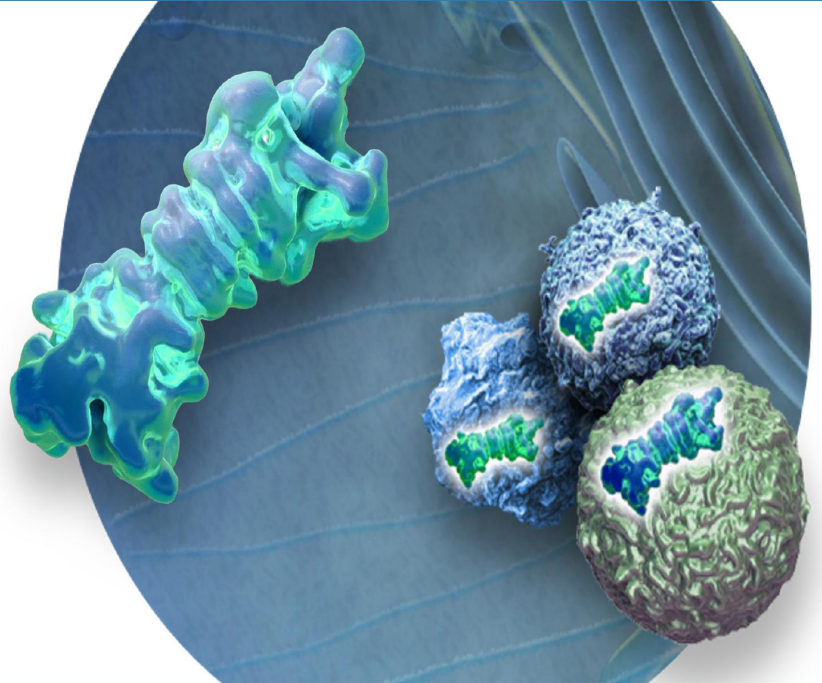
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Gail Woods



“Do you know that you have a patch on the back of your scalp?” Gail met her hairdresser’s eyes in the mirror. Her hand drifted up to the back of her head. She ignored the question and ignored the patch. “I’m in my late fifties, surely it is just me getting older,” she thought to herself.

Later, the acute onset was impossible to ignore. Her skin, now purple, was beginning to raise questions

from those she knew. Her daughter, a physician, came home for a visit. Seeing the breakthrough bleeding of her mom’s hands spurred her to call one of her former professors to squeeze Gail in for an appointment. Miraculously, she was able to see her that same day.

The doctor took one look at her and said “You have Dermatomyositis. Let me refer you to a friend of mine who specializes in this.” That is how Gail met Dr. Victoria Werth.

Over the 17 years since, Dr. Werth and Gail have managed the disease. “I am one of the lucky ones. My case is mild with just occasional flares. I live a fairly normal life with just a few limitations. I live close to quality care. I exercise – I do yoga, tai chi and go to the gym. I am blessed with a supportive family and of course I have my support group!”

Gail is the leader of the Philadelphia area support group. “Having the opportunity to connect is the reason I stepped in to lead and the reason I continue. It doesn’t take much time out of my schedule to be a support group leader, and it is a constant reminder that I am not the only one. There is such comfort in that.”



Howard Gerrin

Before IBM, Howard Gerrin was an athlete. As a track star teenager, he had been half a second off from the world record for the 100-yard dash. “Speed was always my thing. In tennis, what I didn’t have in expertise, I made up for with speed. I just could get to the ball faster than the other person!”, he jokes. Howard enjoyed playing tennis all the way up to his diagnosis at the age of 71. “I feel fortunate to have not gotten IBM

until later in life but losing my ability to play tennis did depress me. I went through the Five Stages of Grief until finally I decided to let IBM motivate me instead. I even had shirts made that say IBM – I have Been Motivated!”

One of Howard’s motivations is his wife, Florence. They have been married 40 years. They met on an airplane when she was coming to Boston to research dental schools. “My wife is my angel. She helps me so much. I don’t know what I would do without her!” Howard and his wife had the unexpected honor of meeting Peter Frampton, a fellow IBM patient, at his Boston concert in 2019. “I paid for the VIP package to get backstage. Once one of his people saw my IBM shirt, they told Mr. Frampton. His manager came up to us and said that Peter would like to meet us. While talking to him, he gave us two signed guitars – one of which I donated to TMA to use as an auction item!”

What advice does Howard have for other patients? “Never be afraid to ask for help but try to do as much as you can without hurting yourself. It’s normal to be depressed but try to move past that if you can.”

The Patient Voice

by Rachel Bromley

“Over the past 25 years, the patient voice has become stronger and louder and it has had an incredible



impact on the health and medical fields”, says Bob Capecci of Capecci Communications. In his advocacy course, “Being a Voice”, he explains, “Now of course there is a lot of work that still needs to be done and sometimes it feels as if the rate of change

moves at a glacial pace, but really so much has happened BECAUSE patients have been at the table to talk about what a lived experience of living with a disease or caring for someone who has a disease is and how the medical system can respond more sympathetically and more accurately to patients - even how drugs are researched and gone through the pipeline has all been influenced by the patient’s voice.”

One of TMA’s strong patient voices is that of Elisa Glass. Elisa never saw herself getting into any sort of politics, much less full-blown advocacy. A four-month stint in the hospital with myositis changed her mind. “I saw the need for it. I saw some things missing. Instead of saying to someone else to go do it, I decided to become an advocate myself.”

Elisa made that decision from her hospital bed, paralyzed, unable to write. Her sister wrote the first letter to legislative representatives for her. From that hospital bed, she begged others for their letters as well. She says, “I had to get a new identity as a disabled person and legislative advocacy is a huge part of that new identity for me.”

However, she first had to relearn – relearn how to swallow, how to sit up, stand, walk again. Her mantra was “I Got This!” And she did. She even recovered from losing her voice, although she still has days she must forego speaking to keep her voice rested. “I remind

myself to nap, to take my meds, to be mindful of the mental health component of my recovery”. She also stays very active with TMA, serving on the Patient and Family Advisory Council (PFAC), as a MAVENS Ambassador, with TMA’s Women of Color Affinity Group, and hosting the new Caregivers Affinity Group (Elisa is a patient with DM but also a caregiver for her veteran spouse). Along with fellow PFAC member Barbara Shaw, she will additionally be co-leading the new support group for Spanish speakers, Adelante! She also makes sure to attend the TMA Virtual Summit and Annual Patient Conference each year. At the 2021 APC, she led a break-out session on Living Your Best Life that was extremely well-received by the community.

While attending a past TMA conference, Elisa met a pharmaceutical representative in the Exhibit Hall. They struck up a conversation and Elisa got invited to be part of a patient focus group. Word got out about her involvement and a similar company approached her for their focus group. Elisa sees a need for communication between pharma and patients and that drives her volunteerism. Lindsey Smith, former Head, Corporate Communications and Patient Advocacy for Corbus Pharmaceuticals stated that Elisa’s contribution had greatly impacted their work at Corbus. “The Corbus team is a collection of passionate and devoted people on the mission to develop a medicine to treat Dermatomyositis. Elisa’s message of hope and positivity inspire and urge us to stay focused on our mission. We keep Elisa and her story front and center when making decisions. She energizes us to drive research forward.”

If you are interested in joining Elisa in advocacy efforts as a representative for TMA, please contact me at rachel@myositis.org to get connected.



FUN FIT FLEX

In 2021, The Myositis Association launched its very own national signature awareness and fundraising campaign – FUN FIT FLEX. Through FUN FIT FLEX, we are dedicated to raising awareness and funds for the 75,000+ people living with myositis. Funds raised through FUN FIT FLEX help support patient programs, enhance professional education efforts, and propel critical research for cures.

Our events took place in four markets that each had their own individual flair – DMV, SW Florida, Chicago, and Nashville. Each event site hosted a non-competitive fun walk, a festival of fitness demonstrations and activities, nutrition and wellness components, and family fun! We were excited to have Peter Frampton serve as our National Ambassador.



The first event took place in Centennial Park in the DMV (DC, Maryland, Virginia) area on October 17th, the second on October 23rd in SW Florida at Tom Bennett Park, the third on October 30th at Cantigny Park in Chicago, and the final event on November 20th at Hadley Park in Nashville.

Our 2021 FUN FIT FLEX events were proudly sponsored by Octapharma USA Inc., NuFactor Inc., CSI Pharmacy, Corbus Pharmaceuticals Inc., Pfizer, Northwestern Medicine, Optum RX, Activ Financial, Forum Financial Management, BioTek ReMEDys, EZ-Step, Free2Go Mobility Products Inc., Western DuPage Landscaping, Giant Food, and Wegmans.

With the support of our sponsors and community supporters we were able to raise over \$160,000 on an initial fundraising goal of \$100,000 for our pilot program. This is a testament to all that we can accomplish when we work together towards a common goal!

FUN FIT FLEX is an amazing opportunity to come together as a community (both in-person and virtually) while raising awareness about myositis through wellness. Exercise and healthy living are critical for myositis disease management. Through FUN FIT FLEX, we will continue to raise awareness, fundraise, and promote health/wellness. We will celebrate, honor, and remember those touched by myositis.

We are so excited for our 2022 events. We hope you will continue to FLEX with us!

The logo for FUN FIT FLEX features the words "FUN FIT FLEX" in a bold, blue, sans-serif font. The word "FIT" is replaced by a stylized human figure icon in green and yellow, with arms raised in a 'Y' shape.

TMA Highlights

• In May of 2021, TMA relocated from Alexandria, VA to Columbia, MD into permanent office space effecting a more than 60% monthly cost savings. Our new home allows for more community engagement, collaboration, and for TMA staff to better serve persons affected by myositis.



- TMA increases corporate engagement with formal partnership package and adds six new members to its Corporate Advisory Committee for 2021.
- For the first time TMA hosted a month-long effort for 2021 Myositis Awareness Month quadrupling virtual engagement. MAM videos and presentations consisted of: 2 Physicians Perspectives, 4 Empowerment Clinics, 3 Patient Stories, 4 Community Awareness presentations and the 2nd Annual Virtual Summit: A Call To Action! Visit our website for a full recap <https://www.myositis.org/myositis-library/myositis-awareness-month/>.
- TMA hosted its 2nd Virtual - International Annual Patient Conference: The Power Of US! There were over 40 educational workshops, clinical presentations, breakout sessions, networking opportunities, a multi-generational focus, patient and provider recognition, and virtual social activities.
- TMA creates its Patient and Family Advisory Council. The objectives include ensuring patients and their families are at the center of everything we do at TMA and providing patients and family members with a platform to share their stories and to help improve care for all patients.
- In 2021, TMA awards a research fellowship to Chiseko Ikenaga, MD, PhD, Postdoctoral Research Fellow, Johns Hopkins University School of Medicine and a research grant to Kanneboyina Nagaraju, DVM, PhD, Binghamton University.

How can www.myositis.org help you?

Please **visit our website www.myositis.org** to find information on topics of interest to myositis patients and caregivers. Some quick links:

We have dozens of pages of **basic information about myositis: www.myositis.org/about-myositis/**



We can help you find a support group, either virtual or in your area: www.myositis.org/patient-support/support-groups/find-support-group/. If there's no support group near you, we'll help you form one. (tma@myositis.org)



We have hundreds of videos, newsletters, presentations, podcasts, webinars, live discussions, published research, patient stories, and tools for disease management in the Myositis Library. (www.myositis.org/myositis-library/)

We can help you find a doctor: On



our website (www.myositis.org/patient-support/find-doctor/); By emailing TMA (tma@myositis.org); By asking on TMA's Facebook page (<https://www.facebook.com/Myositis>); Or by finding the support group in your area www.myositis.org/patient-support/support-groups/find-support-group/ and asking the members.





SAVE THE DATE: 2022 International Annual Patient Conference:

TMA invites you to our 4-day in person International Annual Patient Conference experience featuring myositis specialists and expert presenters on everything related to myositis and its treatment. There will be educational workshops, clinical presentations, breakout sessions, networking opportunities, a multi-generational focus, patient and provider recognition, social activities, exhibitors, new conference components, and much, much more!

Visit TMA's Website for additional information:

<https://www.myositis.org/myositis-library/annual-patient-conference/>