

# THE OUTLOOK



THE MYOSITIS ASSOCIATION

**SPRING** 2020  
Quarterly Newsletter



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# THE OUTLOOK

A quarterly publication of The Myositis Association

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Home Modification

**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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**THE MYOSITIS ASSOCIATION**  
2000 Duke Street, Suite 300  
Alexandria, VA 22314  
**P:** 800-821-7356  
**F:** 703-548-9446  
**E:** tma@myositis.org  
**W:** www.myositis.org  
Mary McGowan, *Executive Director*  
Tricha Shivas, *Editor*

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## Leadership



*Mary McGowan, Executive Director*

The Myositis Association is fortunate to have extraordinary leaders at our helm. TMA's leadership consists of our Governing Board of Directors, our global Medical Advisory Board Members and our Support Group Leaders. These volunteer leaders work tirelessly to ensure that TMA is at the forefront of rare disease research, patient and care partner advocacy and support, and disease awareness.

The Board of Directors provides strategic direction and guidance on TMA goals and plans in providing support for those living with and caring for those living with myositis, in structuring outreach and awareness activities, in advocating for patients and care partners, and in providing financial support for innovative research and young researchers in the myositis field.

TMA's Medical Advisory Board (MAB), the world's most respected myositis researchers, scientists and clinicians, provides TMA with guidance on how to most successfully advance the science toward better treatments and potential cures for myositis. Additionally, the MAB serves as faculty for TMA programmatic activities, provides essential feedback and guidance for TMA's educational materials for physicians and patients, and even approves our corporate partnerships to ensure TMA is aligning ourselves with those that are in line with the science of the disease, or at least that there is no conflict thereof. These efforts ensure that patients, care partners and the medical community remain informed and engaged with the most up-to-date accurate information on myositis and myositis research.

TMA's Support Group Leaders are the boots-on-the-ground providing leadership and support for those living with or caring for someone living with myositis in communities all around the world. We are pleased to announce that two new support groups recently launched in Spain and Africa. TMA's Support Group Leaders are the cornerstone of TMA's support and outreach services. TMA's Support Group Leaders share their dedication, compassion, and knowledge with community members in order to help them feel welcomed and to help ease the burdens that come with a diagnosis of a rare disease.

In this Outlook, you will learn about the work of our current leaders as well as our most recent past leaders of our Governing Board of Directors and our Medical Advisory Board who have left an indelible mark on the myositis community through their hard work and dedication. And, you will learn how new leadership on these boards will guide TMA into a new decade of extraordinary growth and progress. You will also learn about TMA's new leadership training to provide our Support Group Leaders more advanced resources and tools to enhance their efforts as community leaders.

We are very excited to share this issue with you as a thank you to all those leaders who have dedicated their time and expertise to the myositis community and as a welcome to the 2020 leaders. Our new leaders will guide TMA in this new decade, filled with the opportunity of revolutionary collaborations in the pursuit of groundbreaking research, unprecedented hope for awareness, compassion, and support, and the promise of a bright future through the development of novel treatments and therapies. I hope you are as excited as I am about what the future holds for our leading international organization committed to the global community of people living with myositis, their care partners, family members, and the medical community who are dedicated to serve them.



*TMA's Board of Directors presenting at the Meet the Board session at TMA's Annual Patient Conference (Missing Jeff Autrey)*

## TMA's New Governing Board and Medical Advisory Board Leadership

As we welcome this new decade – TMA is proud to introduce you to our new leadership team who is prepared to take the helm and guide TMA on an exciting path into the new decade.

However, before we introduce our new leadership, we would like to express our sincerest gratitude for the extraordinary leaders who have shepherded us through the last 2 years—John McClun and Dr. Andy Mammen in their roles as Chair of the Governing Board of Directors and Chair of TMA's Medical Advisory Board, respectively. Under John's leadership, TMA created a new and updated website and community user forum, celebrated its 25th anniversary, and made a seamless transition from its long-time Executive Director, Bob Goldberg, to our new Executive Director, Mary McGowan. Under, Dr. Mammen's leadership, TMA strengthened and grew its long-time relationship with the NIH, increased the number of *Visiting Professor Presentations* while educating clinicians about myositis

diseases at universities across America and granted almost one million dollars in research funding in the quest for treatments and cures for myositis. We are incredibly grateful to John and Dr. Mammen for their years of dedication and volunteer service to The Myositis Association and to those living with and caring for those living with myositis.



Please meet **Jim Matthews**, TMA's new Chair of the Governing Board of Directors. Jim was first diagnosed with inclusion body myositis in 2015. At that time, he could no longer make a good fist with his left hand. Jim believes he can trace the disease back to as early as 2005 when he had slightly elevated liver

enzymes that the doctors were unable to attribute to any particular disease or condition.

Jim is a retired pharmacist with executive and management level experience. Although Jim had never served on a national Board of Directors prior to joining TMA's Board of Directors in 2017, he has served on a number of advisory boards which provided him extensive experience to draw from as an organizational leader for TMA.

Jim is excited to be in his new role as Chair of the Governing Board of Directors. He is eager to build on the outstanding work of his predecessors and to expand TMA's outreach and engagement with our Medical Advisory Board members, industry partners, government regulators, and researchers, and other organizational partners in the myositis, autoimmune, and rare disease space.

For Jim, outreach and increased awareness of myositis are top priorities as these are the most impactful tools for influencing research funding, drug development and approval, and support resource funding for patients and care partners.

TMA's Governing Board of Director's Leadership team is rounded out by David Mochel, MD, as Vice Chair, Wayne Mortensen, DMD, as Treasurer, and Martha Arnold as Secretary. To learn more about these leadership team members and the rest of our prestigious and dedicated Board, please visit <https://www.myositis.org/about-tma/board-directors/>



Please meet **Dr. Rohit Aggarwal**, the new chair to TMA's Medical Advisory Board. Dr. Aggarwal first heard about myositis during his residency when he was rotating in rheumatology at the University of Pittsburgh. It was very rewarding to be able to make an accurate diagnosis of a rather complex disease and see his patient improving on therapy.

In 1995, TMA provided Dr. Aggarwal with a fellowship grant to help him conduct research with Dr. Chester Oddis who had a wealth of research, to begin to unravel mysteries of myositis. This grant from The Myositis Association set Dr. Aggarwal on the path that has determined his trajectory for current and future research and his clinical practice at the University of Pittsburgh.

Dr. Aggarwal was recently awarded another TMA grant for his work to study patient reported outcome

measures as well as a physical activity monitor as a tool to better understand and evaluate improvement based on treatment regimes applied. If these measures are proven, then they could be used in clinical trials as well as clinical care to evaluate objective functional improvement in myositis patients.

Dr. Aggarwal is very dedicated to the myositis community. He says, "My patients have been many things to me - from friends or colleagues to inspiration. My patients have given me many reasons to keep going after the disease using research as a vehicle until we find a cure. Most importantly, I have learned from my patients that a combination of hope, perseverance, and positive attitude can achieve unbelievable results."

Dr. Aggarwal sees the TMA Medical Advisory Board as an excellent platform to interact with interdisciplinary teams of scientists working in the myositis field and an opportunity to increase our understanding and learning of different aspects of myositis as seen by different subspecialties. Moreover, he believes the Medical Advisory Board offers unique opportunities for researchers to collaborate with each other and work collectively to find solutions to this enigmatic disease.

Dr. Aggarwal hopes to be able to help expand the awareness and understanding of the extraordinary work of TMA and of myositis diseases among researchers, medical schools, fellowships, residency programs and physicians. He says, "I have a lot of hope for the myositis community as there are 2 major phase 3 clinical trials completing in 2020 and another 2 finishing up in 2021. I strongly believe 1 or more of those trials will be positive and will lead to an FDA-approved therapy in myositis."

Dr. Aggarwal is excited to be working with the new MAB Vice-Chair, Dr. Conrad "Chris" Weihl, neurologist, from Washington University. Dr. Weihl recently transitioned from his very successful role as Chair of the MAB Research Committee, where he helped significantly improve the quantity and quality of myositis grants by developing a webinar entitled, **Position Your Myositis Grants for Success**, to instruct potential grantees on what a successful grant proposal looks like. We are also very grateful for Dr. Weihl for updating assessment and review criteria for TMA.





## Thank You, Terry

The Myositis Association would like to thank, Terry Anderson, former Chair of the Board of Directors and care partner to Bitsy, his wife, for his years of

dedication to TMA, and people living with myositis and their care partners. Terry first answered the call to serve on TMA's Board of Directors in 2012. Terry officially transitioned off of the Board in December 2019. In addition to Terry's service on the Board, he has worked tirelessly alongside Bitsy, to raise funding for myositis research through their 5k Walk, Run, N' Roll for Myositis, which takes place annually in Severna Park, MD each year.

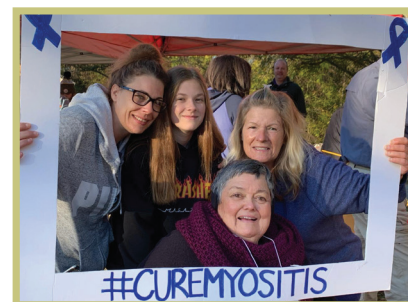
"Terry has a wonderful sense of humor, warmth, passion and extraordinary dedication that has helped TMA to build a strong rapport with patients, care partners, researchers, and industry partners," says Mary McGowan, TMA's Executive Director. "We have been truly fortunate to have such an incredible leader on our team. Thank you for your years of dedication, hard work, and drive to improve the lives of those living with myositis, Terry."

## Raising Awareness and Funds through Local Fundraisers

As a mother of a child living with juvenile dermatomyositis, Monica Pedano, always makes sure that people leave her events with a deeper understanding of myositis and the support that The Myositis Association brings to those living with this condition, and she also makes sure that everyone is entertained and engaged by the event itself. Each year, Monica hosts a spectacular bowling event to "Strike out Myositis." The event includes goofy trophies, a

silent auction, and friendly competitions. A more recent addition to Monica's event list is her Pickleball Event. Pickleball, a fun mix between tennis and whiffle ball, has been sweeping the nation in the last few years. Monica quickly picked up on this trend and hosted a fun pickleball event at a local bar with a space large enough to house a pickleball court. It is attention to small details that makes Monica's events so successful and draws people to return year after year – even her cookies were shaped like pickleball paddles and she wore pickleball socks to keep everyone in the mood. When planning an event, creating a fun and themed atmosphere is essential to the outcome of the event. Monica's most successful annual event is her golf tournament, which will be celebrating its 18th Anniversary this year. Monica gives each golf foursome the VIP treatment on the course and then creates a five-star feel to the evening dinner and silent auction. Each event raises thousands of dollars resulting in almost \$1M raised for myositis research.

Like Monica, the support group in the DC, MD, VA area has been organizing an incredible Annual Walk, Run, N' Roll raising awareness of myositis and lots of funding for myositis research during the past 10 years. The 2019 Walk, Run, N'



Roll, coordinated by TMA's Support Group Leader, Bitsy Anderson, had representatives from over 24 states, 353 registered walkers or runners and raised over \$50,000 for TMA research. This event was also attended by representatives from the Johns Hopkins Myositis Clinic and TMA leadership to help share messages on the importance of research.

If you would like to learn about how to start your own fun and educational fundraising programs in your local community, please reach out to us at [tma@myositis.org](mailto:tma@myositis.org)

# TMA's New Governing Board of Director Members



TMA is pleased to welcome **Chai Hoang** to our Governing Board of Directors. Chai has an undergraduate degree in accounting and finance from Northwestern University and an MBA and JD from Hofstra University. Chai is currently working for a tech start up.

The initial symptoms of Chai's myositis journey appeared in 2010 with her Graves' Disease. Her initial symptoms included rashing and muscle fatigue; however, in 2011 Chai had a thyroidectomy and this seemed to successfully address the rashing and muscle weakness symptoms as well. It wasn't until 2017, when Chai went on a long cycling ride, her skin broke out in a severe rash that seemed to get worse with sun exposure, that she was officially diagnosed with dermatomyositis by Dr. Adam Schiffenbauer at the NIH.

Chai attended her first TMA Annual Patient Conference in September 2018. She was thoroughly impressed with the programming, the generosity of the global myositis experts with their time and knowledge, and the support provided to patients and care partners and to the myositis community. As a young Asian woman, she identified the need for more engagement with younger individuals and individuals of various ethnic backgrounds living with myositis. Both during and after the conference, Chai began conversations with TMA's Executive Director, Mary McGowan, to discuss her ideas about how TMA might begin outreach and engage with younger and more ethnically diverse communities. As a result of these conversations, Chai learned about the opportunity to apply for TMA's Board of Directors.

Chai intends to call on her experience in law, finance and accounting and to build upon her knowledge of social media to help TMA accomplish its goals and to develop strong outreach programs for young and diverse populations.

Chai lives in Stamford, CT and despite her dermatomyositis, remains a serious athlete.



TMA is excited to welcome **Lisa Motley** to the Governing Board of Directors. Lisa recently retired from her position as Executive Director for the University of Louisville and University of Louisville Physicians and brings extensive experience in management,

patient advocacy, and provider relations to the TMA Board.

Lisa's myositis journey began when she was in her mid-40's. Her initial symptoms were sporadic --- she found she began to trip, falling on stairs and even on flat surfaces. But it wasn't until she started to have difficulty with tasks that used to be simple like spraying her hairspray or pumping sunscreen that she began working with a neurologist. Initially, Lisa was told that she may have ALS until her muscle biopsy resulted in her diagnosis of inclusion body myositis in January 2016.

As a former member of her local Board of the American Heart Association and Juvenile Diabetes Research Foundation, Lisa knows the importance of community outreach, awareness, and support to the success of a patient advocacy organization.

Lisa is excited to work with the leading international organization committed to advancing awareness of myositis. She is especially interested in developing a program for newly diagnosed patients designed to help mitigate the isolation and uncertainty that comes with a myositis diagnosis. Lisa is also interested in strengthening TMA's mentoring and outreach to younger patients and care partners.

Lisa lives in Louisville, Kentucky with her husband, Joe. She has twin daughters, Savannah and McKenna, and her son, Mitch.

## NEEDED: Adults with moderate to severe Dermatomyositis (DM)

Pfizer is currently seeking adults 18 to 80 years of age for a dermatomyositis clinical trial. This clinical trial will assess the effectiveness and safety of an investigational study drug compared to placebo. The study drug is a type of drug called a biologic and is given monthly by infusion.

The clinical trial is currently active and enrollment is open at multiple sites across the United States. Qualified participants will receive all study-related care and study drug (or placebo) at no cost.



Learn more at:  
[www.pfizer.com/science/find-a-trial/nct03181893](http://www.pfizer.com/science/find-a-trial/nct03181893)



# TMA's New Medical Advisory Board

TMA would like to extend our sincerest gratitude to the following members for their time, expertise, and dedication as they rotate off our Medical Advisory Board: Helene Alexanderson, PhD, RPT, Mazen M. Dimachkie, MD, Andrew Mammen, MD, PhD, Margherita Milone, MD, PhD, Paul Plotz, MD, and Ann M. Reed, MD. These individuals have dedicated countless hours to improving myositis research and increasing awareness and understanding of myositis among patients and care partners through presentations at our International Annual Patient Conferences, regional conferences, and webinar presentations. We are grateful for their commitment and sharing their expertise as we make strides towards our vision of a world without myositis.

TMA is pleased to announce the appointment of the following international experts as the newest members of TMA's distinguished Medical Advisory Board:



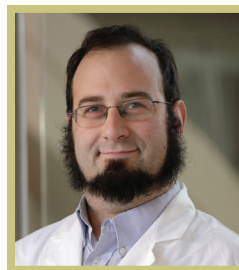
**Erik Ensrud, MD** has a joint appointment as associate professor in the department of neurology and the department of orthopedics and rehabilitation at the Oregon Health and Sciences University School of Medicine.

His clinical practice focuses on rehabilitation and exercise-based treatment of neuromuscular disorders, physical medicine and rehabilitation, and electrodiagnostic medicine. Dr. Ensrud's research interests include exercise in neuromuscular diseases such as myositis, efficient and accurate physical examination of the neuromuscular system, use of orthotics for nerve and muscle disease, clinical trials for neuromuscular diseases, electromyography education, and neuromuscular disorders unique to service veterans.



**Janine Lamb, PhD** is a reader in complex human genetics/genomics in the Center for Epidemiology and Faculty of Biology, Medicine, and Health at the University of Manchester in the UK. Her research focuses on human genetics

research, including research on idiopathic inflammatory myopathies, autism, myasthenia gravis, inherited retinal diseases, and interstitial lung disease. Dr. Lamb is internationally recognized for her myositis research, making significant contributions to a number of scientific organizations, including the Global Conference on Myositis (GCOM), the EU Myositis Network (EUMYONET), the UK Myositis Network (UKMyoNet), and the International Myositis Genetics Consortium (MYOGEN).



**Adam Schiffenbauer, MD** is a rheumatologist and clinical researcher at the NIH's National Institute of Environmental Health Sciences (NIEHS). He also serves as a member of the faculty of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

Dr. Schiffenbauer's research focuses primarily on myositis diseases, including as principal investigator for the NIH study of sodium thiosulfate as a treatment for calcinosis in dermatomyositis. As a member of the International Myositis Assessment and Clinical Studies Group (IMACS), Dr. Schiffenbauer serves on the Scientific Committee and chairs the Billing and Coding subcommittee.



**Lesley Ann Saketkoo, MD, MPH** is a rheumatologist trained in internal medicine and pediatrics. She is an associate professor of medicine at Tulane and Louisiana State Schools of Medicine and professor of undergraduate honors studies at Tulane University School

of Medicine, co-director of University Medical Center – Comprehensive Pulmonary Hypertension Center & Interstitial Lung Disease Clinic Programs, and director of the New Orleans Scleroderma and Sarcoidosis Patient Care and Research Center. Her research and clinical interests are wide ranging and include myositis, scleroderma, autoimmune lung disease, patient reported outcome measures, end-of-life preparedness, and mind/body care for chronic disease. Along with Dr. Maryam Dastmalchi from Karolinska Institutet, produced an instructional film on minimally invasive, or 'suture-less', muscle biopsy which is housed on the NIH website. With a dedicated interest in rehabilitation in myositis and cardiopulmonary diseases, Dr. Saketkoo is a multi-certified yoga instructor and develops



mindfulness and expressive arts programs for healing for patients, students and health providers. She has served in leadership positions in the International Myositis Assessment in Clinical Trials (IMACS) and the Outcome Measures in Rheumatology for Clinical Trials (OMERACT) initiative.



**Victoria Werth, MD** is professor of dermatology and medicine at the University of Pennsylvania School of Medicine and chief of dermatology at the Philadelphia Veterans Administration Medical Center. She specializes in clinical and translational

research in autoimmune skin diseases, including dermatomyositis. Among her many accomplishments, Dr. Werth has guided the development and validation of a disease severity tool known as the Cutaneous Dermatomyositis Disease Area and Severity Index (CDASI), which is currently being used in clinical research for dermatomyositis. And she is a principal investigator in Corbus Pharmaceutical's phase 3 multicenter clinical trial assessing the efficacy and safety of Lenabasum for the treatment of dermatomyositis.

## 2020 Annual Patient Conference

Be sure to mark your calendar for this year's Annual Patient Conference taking place September 10-13th in Bellevue, Washington. TMA's Annual Patient Conference provides patients and care partners the opportunity to attend over 90 sessions facilitated by the world's leading global myositis experts in myositis research, therapeutics, rehabilitation, and mental health. This unique in-person conference provides patients and care partners networking opportunities and opportunities to build connections with special interest groups such as women living with myositis, younger patients living with myositis, care partners, and newly diagnosed individuals.

This year's theme is New Decade...Imagine the Future. Throughout this year's conference TMA will be looking ahead at what the next decade will bring with regard to new research, new therapies, and new technologies to support those living with myositis.

This year's conference is in a beautiful location. Bellevue is just outside of Seattle in Washington state. If you love beautiful scenery then you will love Bellevue.

- ✚ Bellevue Botanical Gardens (<https://bellevuebotanical.org>) is 53 acres of nurtured gardens, woodlands, and curated wetlands. Bellevue Botanical Gardens has accessible parking and restrooms. They have a map to guide accessible travels on the most accessible trails.
- ✚ Lake Washington is the second largest lake in Washington State and provides you a beautiful view of Seattle and Mount Rainier. Lake Hills Greenbelt is an accessible part of the Lake Trail taking you through the blueberry farm and the wetlands.
- ✚ You can find a full list of Accessible Trails at <https://www.alltrails.com/us/washington/seattle/ada>

If you enjoy museums, Bellevue has a lot to offer:

- ✚ Bellevue Arts Museum is one of few museums in the nation with a focus on art, craft, and design. This museum originally evolved from a street art and craft fair and has evolved to a space dedicated to highlighting the work of artisans and featuring the power of design.
- ✚ South of Bellevue in the city of Tukwila, you will find the Museum of Flight. The Museum of Flight is the largest independent Flight museum, with over 175 aircrafts and spacecrafts on display. It is a must see for any airplane fanatic.



**LiftSeat®**  
Powered toilet lifts™

**Do you or a loved one suffer from myositis and have trouble getting on and off the toilet? LiftSeat can help.**

LiftSeat reduces the risk of falls during toileting and can increase a person's independence by safely and securely lowering and lifting a person on and off the toilet.

Request a free info-kit at [liftseat4home.com](http://liftseat4home.com) or call (877) 665-4381

The advertisement features a woman sitting on a white LiftSeat toilet lift in a bathroom. A smaller inset image shows a person being lowered into a toilet. The background is a clean, modern bathroom with white tiles and a mirror.

# TMA's 2020 Funded Research

The Myositis Association, under the advisement of The Medical Advisory Board, has selected three outstanding research projects for support this year. TMA is proud to report that this year was a particularly outstanding year with regard to both the number and quality of research proposals that we received through our annual application process.

At the beginning of 2019, TMA implemented a number of strategies in order to work to increase interest, engagement, and the quality of the TMA research grants.

TMA directly contacted medical societies, fellowship programs, and hospitals with a focus in myositis programs to inform them of the availability of research grants. TMA's research chair, Dr. Chris Weihl, conducted an informational webinar for interested researchers to inform them of what a successful research proposal for TMA looks like. TMA recorded this webinar and made it available on our website to interested parties throughout the grant application process.

As a result of these increased efforts, TMA received 33 letters of intent, a 40% increase over last year. Of the 33 initial letters of intent, the quality of the projects were so high that 29 were invited to submit full applications. Of the 29 that were invited to submit full applications, 26 completed the full application process, which was a 25 % increase of grant applications received by TMA over last year.



33 LETTERS OF INTENT WHICH IS A 40% INCREASE OVER LAST YEAR



29 APPLICATIONS APPROVED TO SUBMIT FULL APPLICATION



26 APPLICATIONS SUBMITTED FOR REVIEW WHICH IS A 25% INCREASE OVER LAST YEAR

Not only was the quality of these projects higher than they have been in previous years, but the Medical Advisory Board was impressed by the variety of institutions that submitted, the diversity of disciplines that submitted, and the innovation in their project approaches.

TMA provided \$350,000 in research funding this year to three very promising international research projects. Dr. Yves Allenbach from Sorbonne University in Paris, France, received \$50,000 for one year for his project “MyotoxICI: A study of pathomechanism of in immune checkpoint inhibitor-induced myositis.” This project will analyze the way in which these new cancer treatments cause myositis. It has recently been discovered that new treatments that dramatically improve cancer outcomes may cause autoimmune diseases, including myositis, in some patients. This project will examine this correlation more closely.



Dr. Cheilonda Johnson (pictured left) from The University of Pennsylvania, received \$200,000 for two years for her project, “Autoimmune myositis-associated interstitial lung disease gene expression profiles.” This research project aims to try to identify genetic

markers for ILD in order to try to identify the cause of this complicated condition. By developing a better understanding of the molecular basis of myositis-ILD, the hope is that we will be able identify potential targets for future drug development.

Dr. Erin Wilfong from Vanderbilt University received funding for \$100,000 for two years for her project, “Pathological role of B cells in idiopathic inflammatory myopathies.” The purpose of this project is to better understand the immune mechanisms of idiopathic inflammatory myopathies by studying how B cells those with idiopathic inflammatory myopathies function differently from healthy B cells. These studies will give critical insights into how the immune system works and to increase opportunities for drug development.



# Clinical Drug Trials

Name	Eligible	Study sites	More information
Abatacept (Orencia)	Active DM/PM/NM/JDM (over 18), overlap	78 sites in US, Australia, S. America, Asia, Europe	<b>More details:</b> BMS StudyConnect; NCT02971683
Abatacept for treatment of myositis-associated interstitial lung disease (Attack My-ILD)	ILD + antisynthetase antibody (Jo-1, PL-7, PL-12, EJ, OJ, KS)	Los Angeles, CA, Denver, CO, Baltimore, MD, Boston, MA, Pittsburgh, PA	<b>More details:</b> Courtney Ward 412-648-9989; NCT03215927
KZR-616	Active DM, PM	10 sites in US	<b>More details:</b> 650-822-5600; NCT04033926
Lenabasum	Adults with DM	12 sites in US, more expected	<b>More details:</b> Lindsey Smith 1-617-963-0707; NCT03813160
PF-06823859	DM	12 sites in US	<b>More details:</b> 1-800-718-1021; NCT03181893
Rituximab vs Cyclophosphamide in Connective Tissue Disease-ILD (RECITAL)	DM, PM, MCTD + ILD	London, UK	<b>More details:</b> Toby M Maher 02073518018; NCT01862926
Sodium thiosulfate for treatment of calcinosis associated with juvenile and adult dermatomyositis	DM and JDM with calcinosis	National Institutes of Health, Bethesda, MD	More details; Adam Schiffenbauer 301-451-6270; NCT03267277
IgPro20 (Hizentra)	Active DM, ADM (over 18)	94 sites in US, Australia, Japan, Argentina, Mexico, Europe, Ukraine, Russia	<b>More details:</b> Trial Registration Coordinator 610-878-4000; NCT04044690

# Travel Tips

by Susan Honigstock



Our family gets together as a large group about every two years – our last gathering was in Minneapolis. I had wonderful handicapped accommodations, but between the planning, food shopping, and the other responsibilities, hosting all 12 of us put quite a burden on my son and daughter-in-law. And that got me wondering how we could get together in ways everyone could enjoy without one family being responsible for all the planning and preparations. Then and there, I suggested a cruise that would be a vacation for everyone. We all agreed that Alaska would be a great place for all generations of our family.

Of course, I was nominated to get things started. I am the retired one, which gives me plenty of time to do the planning. After much deliberation and discussion, we finally agreed on a week that would be good for everyone. That in itself was a job! Then I got on the phone to get things started and quickly discovered that most of the handicapped rooms were already booked. And this was a year before the trip!

My detective work was eye opening, but Royal Caribbean was most helpful in giving me a sense of handicapped availability. Here is a rundown on some of their ships:

- ✦ Ovation of the Seas: 2090 rooms total.  
Handicapped rooms: 2 suites, 12 balconies, 8 outside rooms, 9 inside rooms
- ✦ Enchantment of the Seas: 1142 rooms total.  
Handicapped rooms: 4 balconies, 7 ocean view, 2 suites, 6 inside rooms.

- ✦ Grandeur of the Seas: 997 rooms total.  
Handicapped rooms: 2 suites, 4 balconies, 4 ocean view, 4 inside cabins.

With so few handicapped cabins available, I settled for an ADA-compliant inside cabin and booked the rest of the family into other cabins near me.

Our cruise starts and ends in Seattle, so we needed hotel rooms near Seattle airport before and after the cruise.

Hotels and cruise lines are always parroting family and or friend's vacations. If one of the members need a handicapped room, one can usually predict a major problem.

One of my biggest traveling solo problems has been getting to the gathering place, i.e. a hotel. Many larger hotels offer free bus service from the airport. Upon further questioning beforehand the busses all have stairs. This is not an option for me.

Again, I set to work on ideas. According to the ADA regulations if a hotel offers free bus service to and from the airport, it must offer an equal plan for people with disabilities. Planning ahead is always prudent. If the hotel employees are not familiar with this knowledge, I speak to the managers who are usually familiar and offer suggestions usually paying for my cab fare both coming and going.

This knowledge has eased my concern and made my travel adventures run more smoothly.

*Susan Honigstock is a transplanted New Yorker living in Oregon. She retired from teaching young children to teach adults the wonderful game of Mah Jongg. Three sons, two daughters-in-law, and four grandchildren now make up her family, which is scattered across the country. Susan was diagnosed with sIBM about seven years ago*

**If you are interested in booking a cruise prior to this year's Annual Patient Conference, Kristy Lacroix from WheelChair Escapes can help you find the right accessible package. Kristy has over 26 years of experience assisting those who need assistance with accessible travel and is a certified Accessible Travel Specialist. You can contact Kristy at [klacroix@cruiseplanners.com](mailto:klacroix@cruiseplanners.com) and find her website at [www.wheelchairescapes.com](http://www.wheelchairescapes.com)**





## TMA's Support Group Leadership Training

In December of 2019, **Global Genes** awarded The Myositis Association with a RARE Patient Impact Grant for our Peer Led Support Certified Training Program in the Rare Innovation Category. With the support from this grant, TMA will design a peer support certification training program so that all TMA support leaders feel confident as they take on the important task of helping others cope with a rare chronic and debilitating disease. TMA believes that a formal certification process serves several purposes, including legitimizing leaders among peers and invoking confidence in those seeking out educational resources and psychosocial support.

There are good data to show that peer-led support programs with trained volunteer leaders can have significant impacts on the health outcomes of individuals living with severe chronic diseases. Peer support groups with trained leaders have been shown to create improved self-management in chronic diabetes care,<sup>1</sup> improve lipoprotein levels, improved blood pressure,<sup>2</sup> increased medication compliance,<sup>3</sup> and even lower rates of hospitalization.<sup>4</sup> Furthermore, individuals who attend a support group with a trained peer Support Group Leader report lower levels of stress, anxiety, and depression.<sup>5</sup>

Armed with this knowledge, TMA conducted a survey of our peer Support Group Leaders to assess their needs through a peer-led training program. The result of this survey helped TMA to identify the key areas that will formulate the foundation of our certified peer support training program. These four training areas are 1) how to organize and grow a support group; 2) how to cope with emotionally challenging circumstances, including the loss of a community member; 3) how to deal with group conflict and; 4) how to be the voice of myositis in their community.

During the 2019 Annual Patient Conference TMA held a first-of-its-kind training workshop for TMA Support Group Leaders. During this workshop, TMA provided the Support Group Leaders with a formal orientation training, accompanied with TMA's new support group training manual, meant to provide the Support Group Leaders with resources, processes, and structural guidance for how to successfully engage the local community through the myositis support group.

During this training, TMA also provided Support Group Leaders with a safe space to explore challenges they faced in managing and running a support group in their local communities. Through an open forum discussion, TMA provided Support Group Leaders the opportunity to provide learnings from successful and failed attempts to address similar issues in their own group, resources and tools they have used to assist them, and insights into strategies they believe could assist their fellow support leaders in dealing with the specific challenges they are facing in their community.

With the support of this grant, TMA will take our formalized training process to the next level by creating educational webinars with subject matter experts to provide official training and tools in the four areas as identified by those in our TMA support community. Those who complete this formalized training will be given the title, "Myositis Maven". TMA would like to thank Global Genes for making the development of this certified peer-to-peer-training possible.

- 1 Tang TS, Funnell MM, Sinco B, et al. Comparative effectiveness of peer leaders and community health workers in diabetes self-management support: results of a randomized controlled trial. *Diabetes Care*. 2014; 37 (6): 1525-1534
- 2 Tang TS, Funnell MM, Sinco B, et al. Peer-Led Empowerment-Based Approach to Self-management efforts in Diabetes (PLEASED): A randomized control trial in an African American Community. *Ann Fam Med*. 2013; 13 (Suppl 1) S27—S35
- 3 Witt D, Benson G, Campbell S, Sillah A, Berra K. Measures of Patient Activation and Social Support in a Peer-Led Support Network for women with Cardiovascular Disease. *J Cardiopulm Rehabil Prev*. 2016 Nov/Dec; 36 (6): 430-437.
- 4 Chan JC, Sui Y, Oldenburg B, et al; JADE and PEARL Project Team. Effects of telephone-based peer support in patients with type2 diabetes mellitus receiving integrated care: a randomized trial. *JAMA Intern Med*. 2014; 174 (6) 972-981.
- 5 Witt D et al (n 4)

# Myositis Awareness Month

May is Myositis Awareness Month. Last year TMA conducted an incredibly successful Myositis Awareness month with 16 articles published in the traditional media, a live television interview, a live radio interview, a podcast, a declaration of myositis awareness month by the Mayor of Nashville, and a live awareness event at a national major league ball game and educational webinar. TMA reached over 5 million individuals through our awareness activities in that one month last year and with your help we can reach even more in 2020.

How can you help?

**Campaign Goals** **May is Myositis Awareness Month**

**Promote disease awareness:**

- Among physicians and the general public to increase the average time to diagnosis, which is currently too slow (takes over three-and-a-half years).
- Among family members and friends to foster a deeper understanding of the impact of myositis on patients' lives and how best to support patients in every day ways.

**Engage "Myositis Messengers":**

- With the TMA membership and broader myositis community to lead a grassroots awareness campaign.
- Provide easy-to-use resources and tools that can be adapted and applied by anyone, anywhere.

**Why do we need awareness? On average it takes more than three and a half years and five doctors to receive a correct autoimmune disease diagnosis. Myositis patients – including family members of chronically weakened children – that find a great doctor of change is done during this wait. Raising awareness of myositis, its symptoms, and treatments will help these patients and families. Can you help us to help them? Please join TMA in raising awareness of myositis in the month of May. Here are some of the fun and easy ways that you can help:**

**Tell your story** You, the patients, and families affected by myositis are the most powerful voices we have to raise awareness about this disease by sharing your personal stories with friends, colleagues and neighbors, you can help others. Post your TMA short-essay photo, video or your TMA short-essay photo, video or other personal story that has touched someone else, including by answer.

**Post, tweet, & share** With 17% of adults in the US on Facebook and other social media platforms, you probably have a larger audience than you think! The virtual mix of online, meeting, and promoting myositis awareness, connect with your own, something from TMA, or other personal story that has touched someone else, including by answer.

**Phone physicians** In campaign events and phonebanking is taking place across the country. So, we're taking a step from the political playbook and pushing myositis awareness. The purpose is to meet general practitioners and other healthcare providers with information about myositis. So, we "know the signs" and can diagnose and treat patients more quickly than if they had never heard of the disease. We will provide you with scripts and an answer to help you raise awareness from your kitchen table (or Support Group meeting).

The Myositis Association | www.myositis.org | @TheMyositisDoc

Download TMA's **Myositis Awareness Month Guide**. It is full of tips and tricks for how to spread the word about about myositis in your community, over social media, and to among medical professionals.

### Start a Campaign

Thank you for supporting The Myositis Association through Fundraising Campaigns. Donations from personal fundraising campaigns allow us to continue expanding and improving the programs and services we offer those battling myositis.

**Contact Information**

Your Name \*  
 First  Last

Your Email Address \*

Your Phone Number

Your Address \*  
 Street Address  
 Address Line 2  
 City  State / Province / Region  
 ZIP / Postal Code  Country

**Campaign Information**

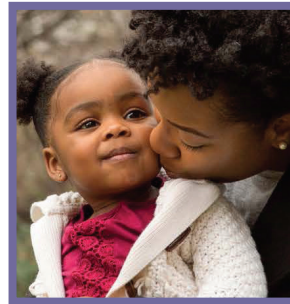
What do you want to call your fundraising campaign? \*

What name would you like to show as the creator of the campaign? \*

Tell us your story. Why are you creating this campaign? \*

Upload a photo for your campaign

Start an educational **fund-raising campaign** throughout the month of May to educate those in your community about myositis, the **need for research and research funding**, the **unique resource and support challenges** faced by our community, and the **tools and services that TMA provides** to help those living with myositis.



Participate in TMA's Women of Color and Myositis Awareness initiatives. During Myositis Awareness Month, TMA will be running Phase 2 of our Women of Color and Myositis Campaign to help increase awareness of the increased prevalence of dermatomyositis, polymyositis, and necrotizing myopathy among women of color. During this year's campaign, TMA will be conducting a Facebook Live educational series, a twitter chat and sharing educational tools to help improve time to diagnosis. Please attend and share these events widely on social media. Please share information with your doctors, family, friends, and community members, and help TMA as we work to improve the lives of women of color living with and at risks of myositis.

Keep an eye on your email and visit our website **www.myositis.org** for frequent updates on additional events and ways that you can assist in raising awareness about myositis.



# Home Modification

According to the US Department of Health and Human Services Administration on Aging, 83% of older Americans want to stay in their current homes for the rest of their lives.<sup>6</sup> However, according to Rodney Harrell, the AARP's housing expert, of the "100 million homes in the United States, only one percent are conducive to aging in place."<sup>7</sup>

If you plan to stay in your home and make modifications to upgrade it to make it more accessible, keep in mind that modifying an existing home to meet your accessibility needs is typically more expensive than incorporating accessible features into new construction. For example, the cost of a stair lift can range anywhere from \$3,000-\$12,000.<sup>8</sup> In new construction, people have the option to potentially choose a ranch style home or build a home that has accessible features built in from the start, such as a first floor bedroom or a step in/roll-in shower.

Here is a list of a few resources that you might find helpful in planning and financing and your home modification:

## Resources to Learn More

- ✚ **Independent Living Center** Directory of Independent Living Centers Across the US.

- ✚ **Area Agency on Aging** Area on aging's home modification resources. [www.eldercare.gov](http://www.eldercare.gov)
- ✚ **AginginPlace.Org** Tips and tricks on how to modify home for safety.
- ✚ **Consumer Reports** provides has an excellent guide for determining which stairlift is right for you, if this is the path you would like to choose.

## Funding

- ✚ Home modification repair funds from title II of the older Americans Act distributed through local area **Agency on Aging**. 1-800-677-1116
- ✚ **Rebuilding Together** National volunteer organization that can help low income seniors with home modifications. [www.rebuildingtogether.org](http://www.rebuildingtogether.org)
- ✚ **State specific Tax Credits** Search here to see if your state is offering tax credits for any home modifications.

6 US Department of Health and Human Services Administration on Aging Home Modification Fact Sheet

7 [www.aginginplace.org](http://www.aginginplace.org)

8 [www.mhealthtalk.com/get-a-home-ready/](http://www.mhealthtalk.com/get-a-home-ready/)

## TMA'S INAUGURAL MYOSITIS VIRTUAL SUMMIT

MAY 8TH

8AM-6PM ET

### Registration Fee

(includes 30-day access to all content)

Patient/Care Partner \$35

Non Profit Partner \$40

Medical Provider \$50

Industry Partner \$100

### Description

This virtual summit will allow participants to attend from their computers and view and engage in 8 educational presentations with Q&A, virtual exhibit booths, a virtual networking room, and educational resources.

For more information please visit:

[www.myositis.org](http://www.myositis.org)



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