THE OUTLOOK

The Myositis Association

SUMMER 2023
Quarterly Newsletter

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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.

Published by:
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Change is a constant

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

As the Greek philosopher Heraclitus, said, *change is the only constant in life*. And so, as we celebrate our thirtieth year of service to the myositis community, The Myositis Association is changing, growing, and evolving as we move into the future.

As many of you know, TMA's executive director, Chrissy Thornton, left the organization at the end of last year after a successful two years. While the Board of Directors is involved in a search for a new permanent executive director, they have hired me to lead the organization through this transition.

I'm Rhonda Buckley-Bishop, TMA's Interim Executive Director. Since I stepped into this role in January, I along with our dedicated staff have been hard at work carrying out the Boards' robust plan for building capacity and strengthening our organizational structure to keep us strong throughout this transition and beyond. At the same time, we've continued providing you, our members, with the services and support you have come to rely on.

Primary among the Board's list of priorities is organizational leadership. They are devoting themselves to an executive search that will provide strong, stable leadership for years to come. Of course, this process will take several months to be carried out properly.

In the meantime, the Board and staff continue to commit themselves to TMA's other responsibilities to our members, including support for ongoing programs and services and a vigorous plan for resource development.

In outlining these priorities, the Board remains dedicated to and focused on **TMA's mission**, which is "To improve the lives of persons affected by myositis, fund innovative research, and increase myositis awareness and advocacy"—as well as **the vision** of a world without myositis.

I want you, our members, to know that I am committed to providing leadership for TMA until a new executive director is identified and hired, and I will remain in my position throughout the hiring process and early transition into the job.

I know many of you have questions and concerns about what all this might mean for you personally and for the myositis community that has developed around TMA. So I want you to feel free to contact me, if you like. You can email at **TMA@myositis.org**.

Most important of all, I want to thank each and every one of you for the part you play in making TMA such a successful and effective support organization for those who live with myositis. You are the reason we are here, and we want you to know that we will continue to be here for you every step along the way of your myositis journey.

Peter Frampton is TMA's Patient Ambassador Award winner

Attendees at this year's Heroes in the Fight awards event will finally have the chance they've been waiting for. Grammy-winning rockstar **Peter Frampton** will attend the annual ceremony as this year's **Patient Ambassador Award** recipient.

This award is presented to a member of the myositis community who has demonstrated extraordinary effort and success raising awareness of myositis diseases within the larger community; raising funds to support TMA and its educational mission, programs and services, and research initiatives; and/or supporting legislative advocacy initiatives for rare diseases, including myositis.

Since announcing his diagnosis of inclusion body myositis (IBM) in 2019 during a televised interview with journalist Anthony Mason on CBS Saturday Morning, Mr. Frampton has been actively raising awareness of myositis diseases around the world. With his indominable spirit and can-do attitude, he is also inspiring others with myositis to live their best life, regardless of their physical limitations.

Those in the myositis community are grateful that Mr. Frampton is taking advantage of his celebrity to raise much-needed funding for research into the cause and treatment of myositis. He established the Peter Frampton Myositis Research Fund at Johns Hopkins where he is being treated. During his 2019 Peter Frampton Finale: The Farewell Tour, one dollar of every ticket sold, along with proceeds from T-shirt sales, was donated to the fund.

The Myositis Association appreciates Mr. Frampton's honesty in sharing his story with the public to help raise awareness and his message of inspiration and hope in the face of this progressive, disabling disease of the muscles. We also appreciate the several times he has provided this motivational messaging directly to those who live with myositis through video presentations for TMA conferences and fundraising events.

"Peter Frampton's candid sharing about his disease provides inspiration and hope to the thousands of IBM patients across the country," says John McClun, former chair of TMA's Board of Directors and an IBM patient himself. "His message—'It's not life threatening, it's life changing'—is a most powerful antidote for the fear and loss experienced by those of us who live with this disabling condition that has no treatment and no cure."

While there is still no treatment for IBM, this is an exciting time in IBM research. Scientists are currently recruiting patients for at least two clinical trials with the hope of finding an effective therapy.

"Peter Frampton is increasing awareness just at a time when I believe therapies will emerge," says Conrad C. Weihl, MD, PhD, professor of neurology at Washington University School of Medicine in St. Louis in the publication *Brain & Life*. "That's why the awareness that Peter Frampton is bringing right now is so important."

In addition to the Patient Ambassador Award, this year's Heroes in the Fight awards will honor **Dr. Rohit Aggarwal** with our **Heroes in Research Award** and **the University of California at Irvine** with our **Heroes in Healthcare Award**. We are grateful for these dedicated researchers and clinicians working hard to make progress in the care and treatment of myositis diseases.

This year, a special recognition will be bestowed upon **Octapharma**, the company that developed the immune globulin therapy Octagam, which is the only product specifically approved for the treatment of myositis. As they celebrate 40 years, we celebrate with them at TMA's 30th anniversary.

Our annual **Heroes in the Fight Awards Ceremony** takes place September 9 in conjunction with TMA's **Annual Patient Conference** in San Diego, California.

SATURDAY, SEPTEMBER 9TH | 6:15 P.M.
AWARDS CELEBRATION
SHERATON SAN DIEGO HOTEL & MARINA

Thank you to our Myositis Awareness Month sponsors for their support in spreading awareness of myositis diseases and the challenges faced by those who live with them.

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octapharma

New faces at TMA

Over the last few months, TMA has welcomed a number of new staff, board members, and medical advisors. This is an exciting time for us as we evolve into a more dynamic, member-focused organization. We hope you will join us in welcoming these new (and returning) members of our TMA team.

New staff

Rhonda Buckley-Bishop joined TMA in January as our Interim Director. She is a seasoned nonprofit management executive with more than 25 years of experience in leadership roles, both interim and permanent, and is passionate about strengthening nonprofit organizations. Rhonda has worked with organizations in both growth and crisis situations, and her special talent is fortifying teams so they can achieve or expand their organization's missions.

"I've chosen to be an interim director as a profession," she says. "I love what I do, which is to come into impactful organizations like TMA to make sure that the infrastructure remains strong so that the mission stays strong and the members and staff feel supported as the Board of Directors searches for its next leader.

"I know this work can be very stressful and cause uncertainty for staff, volunteers, and members. Please know that serving you, TMA's members, is the first priority for me as well as for the staff and board."

Rhonda has degrees in music education and saxophone performance and a masters in general administration with an emphasis on nonprofit management. She lives in Takoma Park, Maryland with her husband Kelley.

Linda Kobert has rejoined the TMA team after spending three years working for a specialty pharmacy that provides immune globulin therapy to rare disease patients in the home. She returns to again serve as Research and Communications Specialist.

Linda started her career as a registered nurse and nurse educator. After leaving that field, she spent many years as a freelance writer with a specialty in science and medical writing.

"TMA has always challenged me to use all of my knowledge and skills—and my passion for promoting health and wellness—to the very best of my ability," she says. "I am thrilled and grateful to be back and to reconnect with the people and purpose that drive me."

Linda has a bachelor's and master's degree in nursing as well as an MFA degree in creative writing. She lives in Charlottesville, Virginia and has two grown sons and five granddaughters.

New members of the TMA Board of Directors

Howard Gerrin, JD, LLM, began his career as an estate and gift tax attorney for the Internal Revenue Service. This work inspired Howard to pursue a career educating individuals and companies to prepare for all of life's financial possibilities. Howard has a Master of Laws Degree in Taxation from Boston University and a Law Degree from Suffolk University. He lives in Framingham, MA.

Ricky Marks earned a Bachelor of Pharmaceutical Science degree from the University of Toledo, then found his calling working with Bristol Myers Squibb as a sales representative and district manager. During his 36-year career in the pharmaceutical industry, Ricky developed a stronger understanding of drug-based therapeutics.

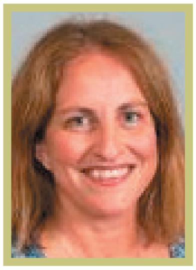
Ricky was diagnosed with IBM in 2016 and looks forward to helping The Myositis Association achieve its mission. He lives in Matteson, Illinois with his wife Cynthia. They have two adult children and are looking forward to relocating to Georgia within the next year to be closer to them.

Nita Sharma has a PhD in Computer Engineering from North Carolina State University and has held leadership positions in engineering and product management across diverse technological domains. She wants to use this knowledge and skill to help TMA. She lives with her husband and two dogs in California. They have two adult children.

New medical advisors

Yves Allenbach, MD, PhD

Associate Professor, Department of Internal Medicine and Clinical Immunology
Sorbonne University
Paris, France



Helene Alexanderson, PhD, PT

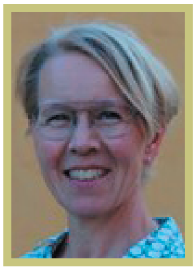
Associate Professor and Physical Therapist
Karolinska University Hospital
and Karolinska Institute
Stockholm, Sweden

Lisa Christopher-Stine, MD, MPH

Professor of Medicine and Neurology
Director of the Johns Hopkins Myositis Center
Johns Hopkins University Hospital
Baltimore, Maryland

Ingrid de Groot, LCSW

Social Worker and Patient Advocate
Chair, Dutch Myositis Working Group of Spierziekten
(Dutch patient association for neuromuscular disease)
Rotterdam, The Netherlands



Louise Diederichsen, MD, PhD

Associate Professor and Rheumatology Consultant
Copenhagen University Hospital
Copenhagen, Denmark

Christopher Graham, DClinPsychol, PhD

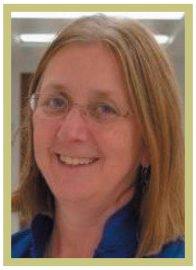
Clinical Psychologist and Professor of Clinical Psychology
University of Strathclyde
Glasgow, Scotland

Valerie LeClair, MD

Rheumatologist
McGill University Medical Center's Jewish General Hospital
Montreal, Canada
and PhD student in epidemiology at the Clinical Epidemiology Unit
Karolinska Institute
Stockholm, Sweden

Elie Naddaf, MD

Assistant Professor of Neurology
Mayo Clinic College of Medicine
Rochester, Minnesota



Clarissa Pilkington, MD

Consultant in Adolescent and Pediatric Rheumatology
University College Hospital
and Great Ormond Street Hospital
London, England

Nicole Voet, MD, PhD

Rehabilitation Physician and Researcher
Radboud University Medical Center
Nijmegen-Arnhem, Gelderland, Netherlands

TMA says goodbye to Aisha Morrow

Aisha Morrow had just married her husband Daryl a few months before she came to TMA in October 2008. Her daughters were ten and two years old at the time, her son was just one. Aisha and Daryl recently celebrated their fifteenth anniversary, her kids are mostly grown now, and she's about to become a grandmother for the first time. Aisha has decided it's time for her to spread her wings and fly into a new adventure.

"Now is the time for me to put more into my professional career," she says. "I am starting my own business, which will support all aspects of nonprofit/association management, while still pursuing new professional growth opportunities with other associations."

Aisha left TMA at the end of May.

During her 15-year tenure as TMA's Operations Manager, Aisha has touched every part of the organization from membership to accounting, from the Board of Directors to corporate sponsors, and most importantly members. She negotiated with vendors, managed TMA events, and even designed the new office in Columbia, Maryland.

Aisha also oversaw several major changes at TMA. She managed a major office relocation and two local moves, implemented two database conversions and the building of two new websites, created two Virtual Patient Conferences and three Virtual Summits, and transitioned TMA through three new executive directors. And for a period of about five months at the end of 2020, Aisha Morrow was TMA's only employee.

"I love TMA," Aisha says. "My job has allowed me to do many functions within organizational management. I can do six jobs as one person. So in 2020, I knew exactly what we needed to do to keep running. It allowed me to fully tap into my nonprofit background with assistance from TMA's Board of Directors."

The thing that made her most visible to members was the Annual Patient Conference. Since 2009, Aisha has masterfully organized, negotiated, planned, and executed many operational aspects of this important four-day service to the myositis community. The APC, as it is known, is a logistical juggling challenge, but it has been one of the most rewarding parts of her job.

"We're engaging with our community, listening and understanding what's happening for them," she says of the APC. "And it's the small things that we have to be conscious of. I try to look at everything from the patient's standpoint to ensure that they're taken care of."

This means, for example, hosting the conference in a city where the altitude won't make it difficult for patients to breathe, making sure meals are suitable for people who have trouble swallowing, ensuring there are enough accessible hotel rooms, leaving room for wheelchairs at the dining tables, removing tripping hazards in conference areas, filling water pitchers only half full so they can be lifted with weak muscles, making sure bathrooms have elevated seats, ensuring meeting space is on one level, and so many other tiny but important details that often go unnoticed.

Aisha is grateful for all the opportunities she's had at TMA, even the times retired Executive Director Bob Goldberg pushed her to do things that she never thought she could do. Working here has stretched her, she admits, in unexpected ways that leave her now more prepared to go out on her own to share her knowledge with other organizations.

She's also grateful for all the connections she's made with members of the myositis community.

"One of the things I will always take with me is the community," Aisha says. "I have met so many wonderful people who have touched my life and brought lasting friendships. And it always encourages me when I know what their struggles really are, yet they keep going. That's one of the reasons why I was willing to be the only employee at TMA, because I knew who it affected, and I knew we were helping."

Aisha and husband Daryl on their wedding day, March 2008

TMA members appreciate all that Aisha does for them as well. Florida support group leader Marianne Moyer, for example, is in awe of the care and attention Aisha gives to every detail of her efforts for patients.

“How does she do it?” Marianne says. “I’ve thought that to myself so many times after a meeting, call, email, or Zoom with Aisha. No matter what I ask, no matter how short the deadline or how late on a Friday it is, she has been the steady, professional, and still amazingly personable face of TMA. I’ve loved knowing and working with her and will miss her very much. I know that whatever endeavors await her, those with whom she works will soon come to know and love her as so many of us at TMA do.”

Aisha has been a vital team member at TMA, and we wish her much success with her new ventures! Still, she promises she won’t stray far from us. She plans to stay on as a member of the organization, and volunteer in ways that will continue to impact TMA.

“I already have a bunch of ideas about new programs we could develop, or new directions TMA can take,” she says. “I would love to help continue building and growing this wonderful international organization.”

TMA was among the crowd of rare disease advocates who showed up on Capitol Hill during Rare Disease Week in February to lobby lawmakers in support of healthcare funding and legislation.

A long COVID story

By Gail Bayliss

It was the end of March 2020 when COVID caught up to me. I had just finished five long 12-hour shifts in the emergency room, and I was looking forward to several days off. It was a Thursday night when I began running a fever. My body ached all over, and I was short of breath. I took some Advil and went to bed with my BiPAP machine on. When I woke up the next morning, the fever was gone and, as the day progressed, I felt better and better. I knew I had the dreaded virus, but I hoped that was the worst of it.

Unfortunately, I have polymyositis (PM), a chronic autoimmune disease in which I suffer from inflamed muscles, weakness, and fatigue. I knew I was at higher risk of complications from COVID.

Sure enough, two days later I became extremely short of breath and developed a cough. That day I was diagnosed with COVID pneumonia and started on Zithromax, an antibiotic often used to treat respiratory infections. I also started myself on hydroxychloroquine, an antirheumatic drug sometimes used for PM, which was also, in those confusing early days of the pandemic, suggested as a treatment for COVID. And I used home remedies for viral infections, such as oregano tea and more onions and garlic in my diet.

Still, I quickly got worse. I spent my days on the sofa resting, pushing liquids, and using my BiPAP 24 hours a day. At that time, we knew almost nothing about COVID and had no specific treatment. After five days, I finally started improving. I was very relieved and considered myself out of the woods.

COVID, however, had different ideas. I had about four days of feeling much improved, although I was still a little short of breath. But on the fifth day, I felt like COVID pneumonia was starting all over again. I found out later this is now understood as a "cytokine storm."

In simple terms, cytokine storm is an uncontrolled overreaction of the immune system to an infection. This excessive response damages cells and tissues, can cause organ damage, and may even lead to death. Those with chronic health conditions seem to be more susceptible, but we still don't know whether people with an immune-mediated inflammatory condition (like myositis) are at increased risk.

I struggled through the next few days, mostly sleeping on the sofa. I used my BiPAP all the time and continued my antiviral home remedies. I slowly began to recover, but it took months before my breathing felt even halfway back to normal. None of my doctors, including my pulmonologist, rheumatologist, and family physician, really knew what to do at that time. In retrospect, what I had was most likely long COVID.

Long COVID is a term used by lay people to explain why their COVID symptoms never seem to go away. The medical term is post-acute sequela of COVID or PASC. It is defined as continued symptoms for more than three months after a COVID infection.

We know that viral infections sometimes leave patients with lingering symptoms, most commonly fatigue (think chronic fatigue syndrome). With long COVID, people can experience problems with nearly every organ system and often report headaches, chest pain, brain fog, and feeling like they "crash" after exercising. Mental health issues, such as anxiety, depression, and sleep disorders, can also be a problem.

For me, long COVID was very challenging. I am used to working hard, putting in long hours as an emergency department physician. Now I could barely walk across the room without becoming very short of breath. My thinking was slow and foggy, I couldn't remember the simplest things, and I became very anxious about trivial concerns. I was unable to work and was so weak and fatigued I could barely get out of bed. My world became very small, revolving around only the activities I needed to do to get through the day. I almost never left the house. Even simple tasks that used to bring pleasure were very difficult.

Looking back, I can say that my long COVID lasted at least two of the last three years. It has been a very long, very slow recovery, but I now have a new normal and am living a good life. I have learned to enjoy the little things and take time to rest when I need it. I have not returned to the emergency department for work and do not expect to return. I now do some telemedicine with patients, but even that is very fatiguing.

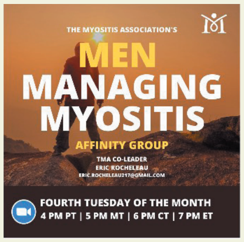
Polymyositis continues to be a challenge, though. And because it's a "hidden" disease, my friends and family don't understand why I sometimes choose not to participate in certain activities. I do what I can, though, and don't dwell on what I can't. And I enjoy each day as a gift from God.

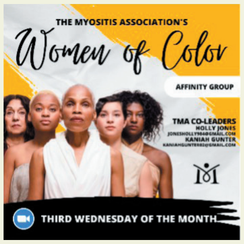
Gail Bayliss is an ER physician living in Houston, Texas. She was diagnosed with polymyositis in 2017 and joined TMA's Board of Directors so she could use her experience to help myositis patients.

Did you know TMA offers eight Affinity Groups?

TMA believes in creating safe spaces for communities that share more in common than their myositis. Our Affinity Groups allow people to feel supported and respected in an environment free from judgment, unsolicited opinions, and the need to explain yourself to those who don't understand. They also play a vital role in ensuring an inclusive environment where all are valued, included, and empowered to succeed.

We invite you to learn more about TMA's Affinity Groups by taking part in one or more of these virtual monthly meetings. You can find out more on our website: ***www.myositis.org****. Registration can be accessed through our calendar page:* ***www.myositis.org/calendar****.*





Finding another way

By Susan Honigstock

Due to a careless misstep, I found myself in the role of patient instead of the get-up-and-go organizer. After a visit to the emergency room, a transition to a hospital, and then to a rehab center, my knee was finally released from the brace.

But my orthopedic doctor insisted on an x-ray with a color dye contrast before he would finally release me from his care. So I dutifully made the appointment at the assigned imaging center and showed up at the appointed time.

I always prepare for any trip—medical or not—like a warrior going into battle. I packed up my four-inch step stool, my travel walker, a bottle of water, and enough reading material to last half the day. I was still unable to drive, so I also had a caregiver in tow.

I checked in at the imaging center, filled out wads of paperwork, and was finally ushered into the procedure room. Once there, the technician placed a twelve-inch step stool next to the massive x-ray table and waved a hand for me to climb aboard.

Well, my step reach at the time was only four inches. Panic set in! I then remembered my mantra and recited: "I have an autoimmune disease that affects the muscles in my legs and arms. I am not able to climb this stepladder to hop on your giant-sized x-ray table. We will have to find another way."

I was led back out of the room and told to wait. Ten minutes later the technicians rolled out a gurney and ushered me back into the x-ray room. They lowered the gurney to a height that I could lay myself down on it and pumped it up to the height of the x-ray table. Using transfer sheets, they easily slid me over to the x-ray table and began the procedure. Upon completion, the process was reversed.

I was delighted that these technicians were able to construct a process to aid this physically challenged patron, and I eagerly expressed my thanks. Of course, my praise was overwhelming to the staff. I wrote a letter of praise to the company, too.

I just love it when an out-of-the-box solution is dreamed up for an out-of-the-normal situation!

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 more than ten years ago.

Avoid the folly of falling

Myositis muscle weakness makes falling a constant concern for those who live with all forms of this disease. Here are some tips from TMA members to help you avoid a possibly serious injury from falling.
** Install grab bars in the shower and bathroom.*
** Don't be too proud to use a cane or other assistive device.*
** Walk backwards down the stairs and hold onto the railing.*
** Plan your moves so you aren't overreaching or stepping in the wrong place.*
** Remove tripping hazards from your home—like those cute area rugs that slide too easily.*

Rare opportunities

When you live with myositis, you already know you are rare, but being rare also makes you valuable.

When researchers conduct clinical trials to test new treatments, they need a certain number of participants for the results to show a significant effect. It's not hard to find enough participants to test a new medication for heart disease or rheumatoid arthritis. There are lots of people who live with those conditions. With only about 75,000 people in the US with myositis, though, it can be hard for studies to enroll enough qualified participants. That's why you are so valuable and why TMA encourages our members to consider becoming a research subject.

The charts on the following two pages outline a number of clinical trials as well as observational and natural history studies. We invite you to take a look at these research projects and consider taking part. Details of each project can be found at ClinicalTrials.gov; use the NCT number in the search feature.

You could be part of making a difference for the whole myositis community!

Dr. Jens Schmidt
TMA Medical Advisor

Currently recruiting myositis clinical trials

Name	Eligible	Study sites	More information
ABC008	Adults with IBM	12 sites in US	**More Details** Abcuro/Syneos 617-865-5079 NCT05721573
Brepocitinib (VALOR)	Adults with DM	22 sites in US 20 sites abroad	**More Details** Priovant 646-402-6892 NCT05437263
Efgartigimod (ALKIVIA)	Adults with IIM	8 sites in US 10 sites abroad	**More Details** argenx 857-350-4834 NCT05523167
Enpatoran (NEPTUNIA)	Adults with DM, PM, ASyS	Orlando, FL Austin, TX	**More details** EMD Serono 888-275-7376 NCT05650567
GLPG3667	Adults with DM	3 sites in US	**More details** Galapagos NV 321-534-2900 NCT05695950
IgPro20 (Hizentra)	Adults with active DM	76 sites worldwide	**More details** CSL Behring 610-878-4000 NCT04044690
Nipocalimab (SPIREA)	Adults with IIM	51 sites worldwide	**More Details** Janssen 844-434-4210 NCT05379634
Ravulizumab	Adults with DM	10 sites in US 29 sites abroad	**More details** Alexion 855-752-2356 NCT04999020
Sirolimus	Adults with IBM	2 sites in US 7 sites in Australia	**More details** 913-945-9926 NCT04789070

Currently recruiting myositis observational and natural history studies

Name	Eligible	More information
Adult and juvenile myositis	Adults and children with DM, PM, sIBM, and related conditions	**More details** NIH - Adam Schiffenbauer 301-451-6270 NCT00017914
Environmental risk factors for antisynthetase syndrome	Adults and children with myositis, with or without ASyS autoantibodies	**More details** NIH - Adam Schiffenbauer 301-451-6270 NCT01276470
Evaluation of clinical responsiveness of DM using cutaneous DM diseases area and severity index (CDASI)	Adults with DM with skin disease	**More details** Victoria Werth 215-615-2940 NCT02945345
IBM disease registry at Yale	Adults with IBM	**More details** Kurt Petschke 203-785-6453
IBM Natural History Study (INSPIRE-IBM)	Adults > 40 y/o with IBM	**More details** NIH - Tahseen Mozaffar 714-456-2525 NCT05046821
Natural history of autoinflammatory diseases and JDM	Children and adults > 2 y/o with autoimmune disease, including JDM	**More details** NIH - Hanna Kim 301-594-6196 NCT00059748
Rheumatology patient registry and biorepository	Adults with rheumatic autoimmune disease	**More details** Nicolas Page 203-737-5571 NCT04402086
Study and treatment of inflammatory muscle diseases	Adults and children > 16 y/o with IIM (suspected or confirmed)	**More details** NIH - Andrew Mammen 301-480-3191 NCT00001265

THE MYOSITIS ASSOCIATION

6950 Columbia Gateway Drive, Suite 370
Columbia, MD 21046



THE INTERNATIONAL ANNUAL PATIENT CONFERENCE

CELEBRATING *you* OUR MYOSITIS HEROES

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THE MYOSITIS ASSOCIATION

September 7-10, 2023
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For more information (including hotel reservations) and to register online:
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