

THE OUTLOOK



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Quarterly Newsletter

THE OUTLOOK

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Cover photo by Brian Bohannon

Other photos in this issue by Brian Bohannon, LaShan Davis-Lanier, and Linda Kobert

Published by: TMA, Inc
THE MYOSITIS ASSOCIATION
 1940 Duke Street
 Suite 200
 Alexandria, VA 22314
P: 800-821-7356
F: 703-535-6752
E: tma@myositis.org
W: www.myositis.org
 Mary McGowan, *Executive Director*
 Linda Kobert, *Editor*

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Mary McGowan, Executive Director

**The mission of
The Myositis Association
is to increase support,
awareness, and funding
for the myositis patient,
caregiving, and research
community.**

Change is in the air: Happy autumn

I love autumn! Autumn is exciting. There is a harmony in autumn and a luster in its sky. It's the season for enjoying the fullness of life: partaking of the harvest, sharing the harvest with others, and reinvesting and saving portions of the harvest for yet another season of growth. This brings excitement, physical exhilaration, mental stimulation, and a heightened sense of purpose.

This autumn brings change to TMA.

It starts with a change in leadership. I am honored to be taking the helm as Executive Director, following Bob Goldberg's outstanding work, honored to be working for this extraordinary organization that makes a difference in the lives of those living with myositis, and honored to be providing education, research, and support to the myositis community.

Many of us also experienced change and transformation at TMA's Annual Patient Conference in Louisville, Kentucky. What an extraordinary conference! This event was most inspiring for me, having had the opportunity to meet many of you in the myositis community and hear and learn from patients, care partners, corporate partners, TMA's Medical Advisory Board, and our Board of Directors. The harvesting of personal stories, ideas, and passion throughout the conference helps us all reap and build upon the benefits of this investment.

Your ongoing commitment to each other and to the fight against myositis is exhilarating. In harmony, we all experienced change by becoming more empowered, inspired, motivated, and enriched with greater understanding and a clearer vision. We are thrilled to be hosting next year's Annual Patient Conference in Minneapolis.

Change is also in the air as TMA moves into our next quarter century. The 25th Anniversary provides us the opportunity to renew and deepen our commitment to move forward in the fight for everyone affected by myositis. TMA has been and will continue to be at the forefront, leading the charge for the kind of quality healthcare, better treatment options, ongoing support, and research that myositis patients and their families deserve.

Autumn is also a reminder that although we may have traveled tough roads on our journey through life, beauty and change is in the air. We carry on knowing there is always a place that supports us as we dream about what lies ahead and take comfort in the light that guides our way.

As we enjoy this season of change with a cascade of tangerine and russet leaves, the harvesting of the season's last crops, skies that are a deeper blue, and nights that become suddenly clear and crisp, let's all dwell in the future possibilities resulting from the harmony of our unified power in the fight against myositis. Together, we will continue to make changes and accomplish great things on this important journey.

Mary E. McGowan

What causes myositis?



TMA's Medical Advisory Board of distinguished myositis researchers respond to members' questions at the Annual Patient Conference

No doubt everyone who lives with this disease wants to know why they have it. But figuring out what causes myositis is a bit like trying to tease out the end of a string in a very tangled knot of many different strings. What we are learning more and more is that myositis is not one disease. It is many different diseases, and each person's experience of the disease is unique. And for each person with myositis, the cause may be related to a complex mix of several different factors.

Scientists also don't use the term "cause" very readily. Studies can show a relationship or association, but in order to say this relationship is causal, many, many studies must be done and repeated with the same outcome every time. In a complex disease like myositis, this almost never happens.

Having said this, however, it is fairly clear that recently developed cancer treatments using immune checkpoint inhibitors actually are related to the development of autoimmune diseases, including myositis. Again, it is not a specific autoimmune disease. This happens

because checkpoint inhibitors "release the brakes" on the immune system so the cancer can be destroyed. But this also allows the immune system to turn against the body's own tissues, which is what happens in autoimmune diseases.

With more typical cases of myositis, however, some of the things we do know are these:

- ✦ People who get an autoimmune disease seem to have a genetic predisposition to getting some kind of autoimmune disease. When several other people in a family have diseases like rheumatoid arthritis or lupus or myositis, scientists think there must be something in this family's genes that increases the risk of developing some form of autoimmune disease.
- ✦ There is probably some event that triggers the development of the autoimmune disease, especially in genetically predisposed people. This could be related to things like drugs (necrotizing myopathy has been shown to be triggered by statin medications in some people), something in the environment (first responders at the World Trade Center site after 9/11 were found to have an increased incidence of autoimmune diseases, including myositis), sun exposure (DM occurs more in populations that live closer to the equator), viral infection, or some other exposure.



Dr. Lisa Rider from the NIH researches triggers to autoimmune disease

✚ Most researchers believe that the autoimmune response (that is, the targeting of the body's own tissues as a foreign substance that needs to be destroyed) to skeletal muscle tissue is responsible for the muscle fiber damage and muscle weakness in myositis diseases.

✚ Studies have found associations between various forms of myositis and specific autoantibodies. Anti-Jo-1 antibody, for example, is associated with myositis with antisynthetase syndrome. These autoantibodies are created as part of the body's autoimmune mechanism. They do not cause the disease, but they do give doctors some idea about how the disease might progress, what complications to look for, and what treatments might work better than others.



Dr. Ingrid Lundberg's research has helped identify molecular pathways that lead to muscle damage and can be targeted by medications.

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- ✚ While not causes, researchers are identifying more and more “targets” within the complexity of various myositis diseases to which they can direct treatments. For example, certain immune cells (T and B lymphocytes) have been identified in muscle and lung tissue of myositis patients. Certain medications, including rituximab, are used to inhibit these cells.
- ✚ Other research focuses on understanding the role of immune system factors, like Janus kinases (JAK); cytokines such as interferons, interleukins, tumor necrosing factor, and others; and the role of certain gene mutations, especially in IBM.
- ✚ Because IBM usually occurs in older age, suspected causes include immune system changes, degenerative changes, abnormalities in mitochondria (a component of muscle and other cells), and the changes in the muscle fibers related to aging, all of which involve a complex interaction between environmental triggers (possibly viral) and genetic susceptibility.

If you'd like to help researchers learn more about what causes myositis, consider participating in one of the following NIH research studies:

- The **Study of Families with Twins or Siblings Discordant for Rheumatic Disorders**, also known as the Twin-Sib Study is looking for families with siblings or twins in which one sibling has developed an autoimmune disease and the other has not. Find out more here: https://clinicalcenter.nih.gov/recruit/protocols/12_autoimmune-disease.html
- If you served in the military, you can participate in the **Environmental Risk Factors for Myositis in Military Personnel**. Find out more here: <https://www.niehs.nih.gov/research/clinical/studies/myositis/index.cfm>
- The **Environmental Risk Factors for the Anti-synthetase Syndrome** (also known as the MYORISK Study) is recruiting individuals who have been diagnosed with myositis within the last two years, whether or not you have antisynthetase syndrome or interstitial lung disease. Find out more here: <https://www.niehs.nih.gov/research/clinical/studies/myorisk/index.cfm>



Leaving a Legacy

When one's days are over, they are remembered and not forgotten by family and those who knew them. You can be remembered by those close to you and an even larger “family”—those who follow you in having to live with myositis. Please consider including TMA as a beneficiary of your estate, a life insurance policy, or an IRA.

Your “myositis family” will appreciate you thinking of them, and they, too, will not forget you.

You can make a difference!

Thank you!

Support for care partners



Taking care of yourself is one of the most important things you can do as a care partner. Selfcare not only helps you feel better, but it gives you more energy and a more positive attitude

that will help you cope better with the challenges of taking care of your loved one. And one way to take care of yourself is to have a circle of friends who know what you're going through and with whom you feel comfortable sharing your fears, frustrations, and joys.

TMA recently introduced a new program for care partners called Talking Circles. This program offers a network of myositis care partners who connect by phone or email as a way to give and receive emotional support. Like TMA Support Groups, Talking Circles

are a safe place where care partners can feel free to share their feelings without being judged.

At many group gatherings, care partners talk shop, offering useful information and opinions about hospitals and physicians, medications and treatments, home health agencies, and equipment manufacturers. You can also pass along your own tips and strategies that make life easier, and other resources that have come in handy when caring for your loved one. And you can ask for specific advice from other group members and share some of the details about your own journey through the challenges of caring for someone with myositis.

Care partners often become absorbed in daily routines and forget that others face similar struggles. It can be a relief to hear your fellow caregivers' experiences and learn that you are not alone.

Everyone copes better when they feel supported, heard, and understood.

To sign up or for additional information, please contact TMA's Member Services Manager LaDonna Johnson at ladonna@myositis.org.

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TMA recognizes outstanding myositis researchers



Dr. Kanneboyina Nagaraju, Dr. Lisa Rider, Dr. Ingrid Lundberg

In celebration of TMA's 25th Anniversary at this year's Annual Patient Conference, TMA recognized three outstanding myositis researchers whose significant contributions have helped increase understanding of myositis diseases and treatments and are moving closer to finding a cure.

The award for the researcher who has had a significant impact on the myositis research community over the past five years was presented to **Dr. Kanneboyina Nagaraju** in recognition of his work in immunology and inflammatory muscle disease. In particular, Dr. Nagaraju has developed a first-in-class dissociated glucocorticoid, Vamorolone, a drug that has far fewer severe side effects than traditional glucocorticoids such as prednisone. This drug is now in phase 2b clinical trials, and we look forward to FDA approval in the not-too-distant future.

The award for the researcher who has had a significant impact on the myositis research community over the past 15 years was presented to **Dr. Lisa Rider**. As Deputy Chief of the Environmental Autoimmunity Group at the National Institute of Environmental Health Sciences, her research focuses on understanding the genetic and environmental risk factors, pathogenesis, outcome assessment, and therapy of systemic autoimmune diseases, particularly myositis. She has led or contributed to several national registries, including the MYOVISION

registry, for which TMA was instrumental in acquiring funding, and which has led to significant insights into myositis diseases.

Dr. Rider is a tireless promoter of research collaborations, having led international projects to establish response criteria for juvenile and adult myositis and contributed to the development of new myositis classification criteria. She continues to play a leading role in the International Myositis Assessment and Clinical Studies (IMACS) Group, a 350-member consortium of myositis clinical researchers working together to advance the science of myositis. And she has received many awards, including Physician Researcher of the Year awarded by the US Public Health Service.

The award for the researcher who has had a significant impact on the myositis research community over the past 25 years was presented to **Dr. Ingrid Lundberg**, who, in 1993 at Karolinska University in Sweden, started one of the first multidisciplinary research and clinical centers in the world to focus on myositis.



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Aware of the importance of collaboration in understanding this rare disease, Dr. Lundberg has been a leader in establishing multidisciplinary networks, in Sweden with SweMyoNet and internationally with the MyoNet network. She has also led the development of a web-based myositis register in Europe that now has more than 4,500 patients from 23 centers world-wide enrolled.

She served as the lead investigator of the large interdisciplinary, international collaborative team that developed the 2017 EULAR/ACR Classification Criteria for Adult and Juvenile Idiopathic Inflammatory Myopathies and their Major Subgroups.

And in 2014 she initiated the Global Conference on Myositis (GCOM) where myositis researchers from

around the world and from every discipline gathered to share their research findings and their ideas about myositis diseases, treatments, and the quest for a cure. The GCOM has become a biannual event, with the third meeting scheduled to take place in Germany next year.

Her research focuses on understanding the molecular mechanisms that lead to muscle weakness in patients with myositis. This work has helped identify molecular pathways that lead to impaired muscle performance and can be targeted by medications. Her research group also recently discovered a new myositis specific autoantibody, anti-FHL1, the first myositis-specific autoantibody that targets a muscle-specific autoantigen.

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TMA's new Executive Director: Mary McGowan



Mary McGowan wasn't looking for a new job. She was thriving, serving as Chief Executive Officer at WomenHeart: The National Coalition for Women with Heart Disease. It was a cause she was passionate about: working to educate, support, and advocate for the 48

million American women living with or at risk of heart disease, the leading cause of death of women, and working with hospitals across the nation to offer gender-specific care and treatment.

But the search firm hired by TMA's Board of Directors found her profile on LinkedIn and thought she might be a good candidate for TMA's Executive Director position. When they contacted her, she decided to consider the idea.

"One of the things that intrigued me about this organization was the opportunity to work with individuals living with a rare disease," Mary says. "This is a community with its own unique set of challenges, and I knew that this was an organization I wanted to lead."

Mary comes to TMA with more than 35 years of nonprofit healthcare management experience. In addition to WomenHeart, she has held leadership positions with the American Academy of Pediatrics and the Allergy and Asthma Network, where among other things she advocated for national legislation in support of children's health issues.

Immediately following the events of 9/11, Mary worked with the nation's leading pediatricians to develop pediatric terrorism disaster preparedness resources and tools. And when children with allergies were dying because they were not allowed to have

needed medication with them at school, she worked to change state laws so kids could carry EpiPens with them, even during the school day.

"My entire professional career has been dedicated to supporting patients, working with physicians, and advocating for health care," Mary says.

This passion and dedication developed out of her own personal experiences with the health care system.

Mary grew up in Greenwich, Connecticut, the youngest of four children. At the age of five, she was admitted to Memorial Sloan Kettering Hospital in New York with what doctors thought was cancer. As it turned out, Mary did not have cancer, but with the experience of spending close to a month in the hospital, undergoing surgeries and treatment, she witnessed first-hand the challenges of severe illness, deformity, and human suffering, which had a profound impact on her.

"I learned from a very early age the importance of access to quality health care and empathy for people struggling with illness," Mary says. "And I learned the importance of advocating for, taking care of, and speaking up for patients."

Mary's compassion for those who care for people living with chronic diseases has also been shaped by her own experience with caregiving. In her 20s, her father developed diabetes and underwent amputations on both of his legs, leaving him a double amputee. He was confined to a wheelchair for two decades, and as his primary caregiver for some of that time, Mary lived the challenges of this often-unrewarded role. It's why she's also passionate about TMA's support for both patients and those who care for them.

As she takes the lead at TMA, Mary is excited to be part of this organization that has been at the forefront of myositis research, as well as education and empowerment for those who must cope on a daily basis with the challenges of this chronic, often debilitating disease. She looks forward to collaborating with other patient advocates, the scientific community, and industry in an effort to eliminate disparities in care, improve understanding of myositis, and spread awareness of this rare disease.

World experts serve as TMA medical advisors

TMA's Medical Advisory Board (MAB) draws from the world's foremost myositis researchers, scientists, and clinicians. These respected medical professionals are nominated and elected to serve on this distinguished board by their medical colleagues, because they are committed to making life better for those who live with myositis diseases.

Members of the MAB donate their time to TMA and serve by, for example, reviewing research funding proposals and drafts of the newly revised *Myositis 101: Your Guide to Understanding Myositis*. MAB members agree to consult with a patient's local physician when

they need advice on how to treat myositis. They also help raise awareness of this rare disease among their medical colleagues by presenting lectures to medical students and grand rounds talks with medical trainees such as residents and research fellows.

These committed professionals also serve as the foundation of TMA's Annual Patient Conference. At this year's Conference in Louisville, Kentucky, MAB members offered a wide variety of informative talks and answered countless questions from attendees about myositis diseases. Videos of many of these talks will be available on the TMA YouTube channel starting in November.

In each issue of *The OutLook*, TMA profiles several members of our MAB. The MAB currently has 23 members. Here we share some interesting facts about four of them.



Olivier Benveniste, MD

Specialty: Internal Medicine and Clinical Immunology

Institution: Assistance Publique Hôpitaux de Paris

Research interests: Immunology of

inflammatory myopathies

Personal: Blues music and skiing!



Floranne C. Ernste, MD

Specialty: Rheumatology

Institution: Mayo Clinic

Research interests: Dermatomyositis, polymyositis, calcinosis

Personal: Two children; enjoys running, cooking, home improvement, bluegrass and country music



Mazen M. Dimachkie, MD

Specialty: Neurology

Institution: The University of Kansas Medical Center

Research interests: Myositis and other neuromuscular disorders

Personal: Two children, cycling classes, KC Chiefs fan!



Wael Najib Jarjour, MD

Specialty: Rheumatology

Institution: The Ohio State University Wexner Medical Center

Research interests: My laboratory investigates

the female sex-bias in autoimmunity, the role of regulatory T cells (Tregs) in myositis and uveitis Sjögren's syndrome, and the role of membrane defects in predisposing patients to myositis.

Personal: Two grown children; enjoys hiking, fishing, and cooking

TMA's 2018 Annual Patient Conference and 25th Anniversary Celebration

TMA returned to Louisville, Kentucky for this year's Annual Patient Conference and

25th Anniversary Celebration. More than 500 participants gathered for the four-day event that offered the chance to learn the latest about myositis diseases, treatments and therapies, and tips for living well despite the challenges. Perhaps the best part of the Conference, though, was the chance for patients and care partners to meet and share experiences with others who also know what it's like to live with myositis. Here are some of the highlights.



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Myositis Warriors



KIT Groups display their strengths



Team Tommy volunteers with Bob Goldberg



Sponsors celebrate TMA's 25th Anniversary



Medical advisors respond to participants' questions



ProDERM A clinical research study

Are you affected by dermatomyositis?

If you are between 18 and 79 years of age and diagnosed with dermatomyositis, you may be interested in the ProDERM clinical research study.

ProDERM is a clinical research study that will evaluate the effectiveness of an investigational drug for the treatment of dermatomyositis.

To find out more, please contact the study team, or talk to your doctor.

Study sponsored by Octapharma Pharmazeutika Produktionsges mbH.

Contact details: Cheryl Bell, Clinical Study Manager [**cheryl.bell@octapharma.com**](mailto:cheryl.bell@octapharma.com)

Patients with active DM or PM needed

Bristol-Myers Squibb is currently recruiting adults with active dermatomyositis or polymyositis for a clinical trial. The goal is to evaluate the effectiveness and safety of a study drug, called abatacept, in combination with standard medicines in improving symptoms of active myositis. The effectiveness of this combination therapy will be compared to standard therapy for myositis.

*This clinical trial is underway and aims to enroll 150 patients over a three-year period. Multiple study sites are available throughout the US and abroad. Participants will first receive either abatacept, the study drug, or a placebo via a weekly injection under the skin for 24 weeks. Then, all study participants will receive abatacept for 28 weeks. More information on this clinical trial can be found at [**www.MyositisTrial.com**](http://www.MyositisTrial.com).*

Experimental treatment study: H.P. Acthar Gel

Principal investigator Anthony Fernandez, MD, PhD at the Cleveland Clinic is currently enrolling patients with juvenile dermatomyositis who are 18 years of age and older, as well as patients with the adult form of dermatomyositis. Study participants must have refractory cutaneous symptoms, meaning that skin manifestations (calcinosis, rash, etc.) do not respond to treatment with steroids plus one other medication, such as methotrexate or IVIG.

*For more information on the study, go to: [**https://clinicaltrials.gov/ct2/show/NCT02245841**](https://clinicaltrials.gov/ct2/show/NCT02245841) To enroll or for more details, contact Lisa Rittwage, BSN, RN at 216-444-4659 or [**rittwal@ccf.org**](mailto:rittwal@ccf.org).*

Opting for the positive

by Gail Woods



I've been saying that I was diagnosed about ten years ago, until my husband reminded me that it's closer to fifteen. He's right. Sometime between 2002 and 2004, I developed a rash on the back of my neck. My hair-dresser pointed it out to me. But I felt fine, so I ignored it. When the rash spread to my face, I went to the doctor. Like so many others, that's when my journey began. But, I was blessed. Very blessed.

A visit to a local dermatologist and a positive biopsy pointed to either lupus or dermatomyositis. I opted for lupus. I had heard of it. I knew people who had it. Dermatomyositis? I couldn't even say it. My disease progressed rapidly: fatigue, incredibly dry skin, strange things happening to my hands...all the familiar signs that retrospectively seem so clear. After waiting three months to see a rheumatologist, I started taking Plaquenil. I still had no definitive diagnosis, but I started to feel better. Except for the sun.

Purple. Yes. My arms, legs, knees, elbows, back, and chest were all purple. Was I the starting point of a new race? Seems that the Plaquenil exacerbated my photosensitivity, so long pants and long sleeves were the order of the day. No big deal.

My daughter, home for a visit dragged me into the city to see a rheumatologist she knew. I wanted to go shopping. I wasn't even in the door before she told me I had dermatomyositis.

"No, I don't," I said. Like everyone else, I had searched the internet to learn more. I thought I could deal with lupus, but I wasn't so sure about dermato. But it wasn't up to me.

Soon I found myself in the office of myositis dermatologist Victoria Werth, MD. To me she is the epitome of knowledge and treatment options for dermato. With her help, I got through the initial onset, including mechanics hands that bled constantly; an allergic reaction to Imuran that put me in the hospital; and a broken foot, three broken ribs, and two hip surgeries as a result of prednisone. I continue to hang in.

The issue I still wrestle with is disclosure. Initially, I looked different. When co-workers asked if I had been on an island vacation, I laughed. But when I couldn't open a can of soda or a bottle of water at lunch, I knew it was time to tell. My boss, a wonderful woman who let me have all the time I needed to have the countless tests prescribed, gave me time at a staff meeting.

As hard as this was, for me it was the right thing to do. I stepped down from a position as a director and worked from home when I needed to. I continued to work for another ten years and eventually was able to regain a position as a marketing director. Now retired from a corporate position, but still in my early-seventies I continue to work part time as a writer and consultant.

The message I want to share is this: have hope. Sure, I dragged my body around and dealt with all the issues, but I improved. Yes, I still have flares, but they are minor compared to my initial symptoms. I must go back on prednisone from time to time, and I hate it, but it sure makes me feel better. I get down when I don't feel well and have no energy. I know how hard it is to see the light at the end of the tunnel when you're in it, to wonder if you'll ever feel like your "old self again." Maybe you won't, but life does change.

I refuse to feel sorry for myself. I focus on all the things I can do, not the things I can't. I have a rich full life with dermato, I also have a wonderful supportive husband and family who keep an eye on me. "Gail, don't forget your hat." Yes, they are my greatest blessing.

Gail Woods lives in eastern Pennsylvania and is a member of TMA's Philadelphia Support Group.

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

An Evening to Remember, Celebrating the 25th Anniversary of The Myositis Association
Thursday, September 6, 2018 at the Muhammad Ali Center in Louisville, KY

