

THE OUTLOOK



SUMMER 2018
Quarterly Newsletter



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THE OUTLOOK

A quarterly publication of The Myositis Association

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Cover Photo

2002 International Myositis Assessment and Clinical Studies Group (IMACS) meeting in New Orleans

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

Trust

This issue of *The OutLook* has an article from one of TMA's former Medical Advisory Board members, Dr. Fred Miller, who leads the Environmental Autoimmunity Group at the National Institutes of Health. He describes the growth of TMA that he has witnessed during the past 25 years since TMA's founding in 1993. I think you will find the history of interest. As you read through Dr. Miller's piece and other news items in this issue, I hope you will recognize something else that is consistent throughout: the establishment and maintenance of the highest standards of quality, integrity, and trustworthiness.

Nonprofit organizations are dependent on the constituents they serve for financial support and to share with others through word of mouth the value of the organization to the patient community. Maintaining the trust and confidence of those we have served for a quarter century is one of TMA's greatest accomplishments. There are always opportunities to cut corners and do what might be most expedient, but we have never done that at TMA and will not.

Whether it has been the selection of who we invite to serve on TMA's Medical Advisory Board (you will read about five current members in the pages that follow) or which research grants get funded, the standard has always been the same: take the one with the highest integrity and the most to contribute in the search for a cure.

The same standard has been applied to selection of TMA Board members and staff. All are held to this same standard of who can best serve the myositis patient and research community. Each year, TMA invites anyone at its Annual Patient Conference who feels that they would like to serve on TMA's Board of Directors to let me know of their interest. Some years, there have been as many as eight candidates considered to serve on the Board. They are all evaluated through that same prism that applies to the entire organization: who has the experience, skills, and qualities that will best serve the myositis community. Not everyone who applies gets chosen, but each candidate gets careful consideration—just as we do with candidates for the Medical Advisory Board, applicants for research funding from TMA, and individuals looking to serve on the TMA staff. If you have an interest in serving on TMA's Board of Directors, we invite you to email me at [**Goldberg@myositis.org**](mailto:Goldberg@myositis.org).

TMA knows that patients and physicians need to trust the information we provide about the disease, treatments, and future prospects for a cure. We have always made certain that what is communicated is accurate, validated, and trustworthy. Likewise, we have never shared your personal information without your permission with any outside parties and never will.

You can count on TMA!

Former TMA medical advisor reflects on a quarter century of TMA

by Frederick W. Miller, MD, PhD



I have witnessed an amazing transformation over the last 25 years. Who would have guessed that the very successful, international patient support group and medical research funder that is TMA today, along with all the research advances it has

spawned, would have evolved from IBM patient Betty Curry's kitchen table a mere quarter century ago? As I reminisce about the incredible TMA accomplishments and advances in research that so many dedicated individuals have made possible over this time, it is impossible to capture them all in a short summary here. This, then, is my attempt at hitting the milestones and events that seem most substantive.

Perhaps the first important milestone, following the organization's founding in 1993, was the critical fusion, in 1996, of two organizations—the Inclusion Body Myositis Association, which Betty Curry organized, and the National Myositis Association, founded by Tina Kline, which had been focusing on only dermatomyositis (DM) and polymyositis (PM)—to form the Myositis Association of America (MAA). This allowed for the first time the coordination of activities under one umbrella group that would now support all forms of myositis and made it possible to focus these energies with an economy of scale and without unnecessary duplication of efforts.

I was fortunate to be asked, along with Drs. Chet Oddis, Lauren Pachman, and Lisa Rider, to become an official MAA advisor then. This was shortly followed by MAA's expansion to include juvenile myositis (JM). This expansion offered a newsletter, the *JM Messenger*, and support groups for families affected by JM. In 1998, Dr. Lisa Rider served as the first JM representative on the Annual Patient Conference medical panel.

In 2001, many critical events further shaped the organization and laid the foundation to allow for a number of future myositis research advances. Janice Goodell organized the first Myositis Awareness Day on September 21 in Massachusetts. The first annual patient conference to be held outside the Washington, DC area took place in San Diego. And MAA received a \$1.6 million bequest for IBM research from a Canadian member, which established the research funding program that still exists today.

In 2002, further important milestones occurred. First, the Board of Directors, which I had the honor to serve on during this time, changed the organization's name from MAA to The Myositis Association (TMA) to recognize that myositis is a worldwide concern. TMA also opened an office in Washington, DC to increase exposure and advocacy efforts in Congress. The organization awarded the first round of research grants, amounting to nearly \$1 million, to scientists around the world. And, perhaps most importantly, Bob Goldberg began his tenure as Executive Director.

In 2006, after much work by many TMA representatives, Congress officially recognized September 21 as Myositis Awareness Day. Shortly after that, at the request of TMA, I had the great privilege, with Dr. Lisa Rider, Dr. Lauren Pachman, and Harriet Bollar, grandmother of a child with JM, to edit the 2007 TMA-sponsored book *Myositis and You: A Complete Family Guide to Juvenile Dermatomyositis and Other Inflammatory Myopathies*. This book is a comprehensive review of all



TMA Executive Director with Dr. Miller, Dr. Lauren Pachman, and Dr. Lisa Rider present the publication of Myositis and You: A Complete Family Guide to Juvenile Dermatomyositis and Other Inflammatory Myopathies

aspects of myositis and, while focused on JM, it has implications and lessons for all who suffer from myositis, their families, and caregivers.

Over the next decade, the array of impressive TMA accomplishments grew exponentially. These included:

- ✚ The US Congress awarded TMA \$167,000 for the creation of a myositis patient registry.
- ✚ TMA's research funding program was significantly expanded thanks to the many donors who participated in the Matching Research Challenge.
- ✚ TMA funded the first gene therapy research related to myositis.
- ✚ The TMA website was upgraded to enhance user experience and provide more information and educational videos.
- ✚ TMA established online discussions where members could ask their questions directly to myositis experts.
- ✚ The Board of Directors and Medical Advisory Board were expanded to incorporate broader representation for all forms of myositis and added expertise.

- ✚ TMA developed a Visiting Professors Program to educate medical school students from dozens of medical schools about myositis.
- ✚ Myositis Awareness Day (September 21) was changed to Myositis Awareness Month (May) to increase opportunities for raising awareness of the disease.
- ✚ The Department of Defense funded a study into the causes of myositis in the US military.
- ✚ A Myositis Symposium for health care providers was added to the Annual Patient Conference to facilitate collaboration among the many clinical specialties that care for myositis patients.

Because of these specific events and advances, and as a result of many other significant activities, TMA has played a central and global role in helping thousands of people, both myositis patients and those who care about them, to better understand myositis and find the support and care they so greatly need. TMA has also, perhaps more than any other organization, helped researchers in the field collaborate better and make new discoveries, which has had a great impact on those with myositis.

TMA's awarding of 53 research grants and fellowships, totaling nearly \$7 million over the past 15 years, has played a crucial role in advancing many scientific findings. This program has also contributed to growing the number of investigators in the field, which was only a handful of researchers when I began. This cadre of myositis researchers has now evolved into hundreds around the world.

Important research developments in the last several decades that TMA has played a role in include:

- ✚ An increased recognition of myositis by the general public and health care providers
- ✚ Enhanced ways for us to now diagnose myositis with newly-approved classification criteria

- ✚ Identification and definition of the different types of myositis based on clinical features, muscle pathology, and now more than a dozen myositis autoantibodies
- ✚ Understanding how different types of myositis respond to different treatments
- ✚ Increased understanding of infectious and non-infectious environmental risk factors and the many genes that predispose to myositis
- ✚ Added new insights into the molecular mechanisms of how myositis develops and is sustained
- ✚ Creation of natural history studies, biorepositories, and registries that will continue to reap discoveries and research advances long into the future

- ✚ Development of new outcome criteria to better assess patient improvement
- ✚ Conducting more clinical trials assessing novel biologic and other therapies in myositis than ever before

Finally, TMA has been a strong supporter of international collaborations with both myositis support groups and researchers around the world. This is a necessary requirement for a rare orphan disease like myositis. TMA has donated needed funds to host conferences that bring together those with diverse backgrounds interested in myositis. They have helped to host the annual International Myositis Assessment and Clinical Studies Group (IMACS) meetings, several International Consensus Conferences on Myositis Response Criteria, and the biannual Global Conference on Myositis (GCOM), all of which allow for increased collaboration and coordination in myositis research.

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More than 300 myositis researchers, experts, and patient advocates attended the 2017 Global Conference on Myositis.

These are great successes for TMA. The organization's work in patient support, advocacy, and research over the last 25 years was only made possible by the dedicated efforts of many individuals who have sustained TMA's growth and influence and made many research projects possible that would not otherwise have materialized. TMA is a gift to all whose lives are touched by myositis diseases, and I look forward to this organization continuing to play a central role in supporting myositis patients and assisting researchers to make new discoveries that will further improve their lives over the next quarter century.

Frederick Miller, MD, PhD, is head of the Environmental Autoimmunity Group at the National Institute of Environmental Health Sciences at the National Institutes of Health in Bethesda, MD. His work in the field of autoimmune diseases spans three decades, much of it focused on autoimmune muscle diseases. He leads a number of studies to identify environmental and genetic risk factors for autoimmunity and systemic autoimmune diseases. Fred was among the first medical researchers and clinicians to serve as a Medical Advisor for what has since become TMA.

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> To enroll or for more details, contact Lisa Rittwage, BSN, RN at 216-444-4659 or rittwal@ccf.org

World experts serve as TMA medical advisors

For nearly two decades TMA has had a Medical Advisory Board (MAB) made up of the world's foremost myositis researchers, scientists, and clinicians.

These myositis leaders donate their time to TMA to, for example, review research proposals and recommend those worthy of funding and consult with a patient's local physician when they need advice on how to treat myositis. They also help TMA staff write educational materials, like the newly revised *Myositis 101* booklet. This and other publications help patients and physicians better understand myositis.

TMA's MAB members also serve as the foundation of our Annual Patient Conference. At this year's Conference in Louisville, Kentucky, MAB members will offer a wide variety of informative talks, including new presentations on "Autoimmune disease as a complication of cancer treatment," "Getting in sync with your healthcare team," "The gut microbiome and inflammation," and "Myositis and genetics."

These respected professionals—rheumatologists, neurologists, dermatologists, immunologists, and rehabilitation specialists—do this because they are committed to making life better for those who live with myositis diseases, and they are committed to finding better treatments and ultimately a cure for myositis.

In each issue of *The Outlook*, TMA profiles members of our MAB. The MAB currently has 22 members. Here we share some interesting facts about five of them.



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Margherita Milone

Specialty: Neurology, neuromuscular diseases, and muscle pathology. I evaluate patients with neuromuscular diseases and interpret diagnostic muscle biopsies.

Institution: Mayo Clinic, Rochester MN

Research interests: Characterization of muscle diseases, inflammatory and genetic, by correlating clinical features, muscle biopsy findings, serological makers, and genetic data

Personal: Sea water-skiing and swimming



Rohit Aggarwal, MD

Specialty: Rheumatology

Institution: University of Pittsburgh

Research interests: Clinical, translational, and outcomes research in polymyositis, dermatomyositis, antisynthetase syndrome, and necrotizing myopathy, as well as myositis-associated ILD

Personal: I have two children: a daughter (Kavya), 4 years old, and a son (Nivit), 2 years old. My hobbies were (I'm too busy now): painting and traveling



Marianne de Visser, MD

Specialty: Neurology

Institution: Academic Medical Center, Amsterdam, The Netherlands

Research interests: Clinical, imaging, and histological studies for all subtypes of myositis

Personal: My husband is a pediatrician. We have no children. My hobbies: reading books (I am a member of a book club) and playing golf



Sue Maillard, PT

Specialty: Pediatric rheumatology

Institution: Great Ormond Street Hospital, London

Research interests: Pediatric myositis and rehabilitation

Personal: My family, riding my horse, driving our family Morgan (a classic British car), and enjoying my pets



Neil McHugh, MD

Specialty: Rheumatology

Institution: Royal National Hospital for Rheumatic Diseases, Bath, England and the University of Bath

Research interests: Autoimmune mechanisms and the characterization of autoantibodies in myositis

Personal: I grew up in New Zealand, so I'm an avid supporter of the All Blacks rugby team. I have two grandchildren, Caleb (23 months) and Amalia (4 months)

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Traveling adventures for the physically challenged

by Susan Honigstock



Traveling can be arduous for anyone, but going solo and handicapped requires more than just purchasing a ticket and packing a bag.

Airline personnel will help make reservations over the phone without additional charge, so if one is not comfortable with the computer this is

a plus. Remember to mention that you will be needing a wheelchair or riding a scooter. Representatives will try to accommodate your needs regarding seating for you as well as your caregiver, also at no additional charge.

My biggest problem has been going through security. There I sit, in my wheelchair, awaiting a female assistant to make sure I'm not a threat to security. This can take time. Meanwhile, all my carry-on items have rolled through the scanner and been spit out the

other side, and there they sit, unattended, until the wheelchair assistant goes through his/her security process with me. This is my panic time. Everything that I need—my cane, my meds, my money—is left there at the end of the conveyor belt waiting to be picked up by someone else.

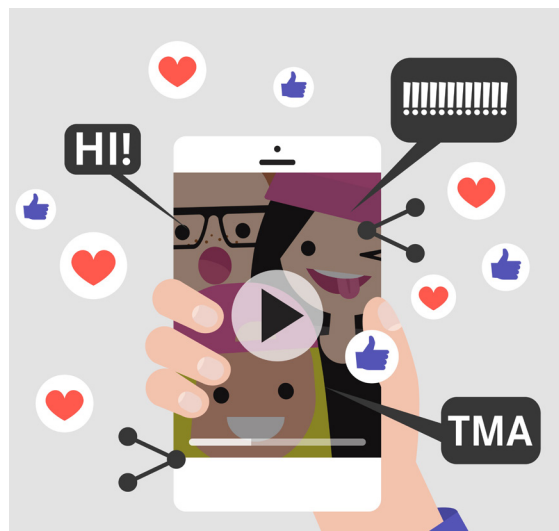
Fortunately, I have become an advocate for myself. I contacted the Transportation Security Administration (TSA), explained my concerns, and have solved this problem. A few days before my flight, I call TSA, and there is always a representative, either when I check in or at security, waiting to attend to my belongings. It's a tremendous relief. I have found that most airline personnel are quite attentive to the needs of those of us who have physical challenges and will try their best to make the journey pleasant.

I have also been able to aid others in my travels. Once while waiting for a delayed flight, I sat next to a young lady in a wheelchair who needed to use the restroom. Her pleas were unnoticed by the personnel behind the counter. Using my "teacher voice," I succeeded in getting her the help she needed and also made a new friend.

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.

We want to hear from you!

Do you have an original workaround for accomplishing something that is difficult for you? Do you have an idea that makes your daily life or your care partner's life a little easier? We welcome selfies, links to videos, and written articles for a new section of TMA's website. Send ideas to linda@myositis.org



Pitching in for Myositis Awareness

"Fans, please turn your attention to the pitcher's mound for today's ceremonial First Pitch. The month of May is Myositis Awareness Month, and Vance Robinson is kicking off his Second Annual First Pitch Awareness Campaign to help spread awareness of the rare disease inclusion body myositis."

Vance Robinson was diagnosed with IBM in 2009. When increasing weakness forced him into retirement and eventually made him move from Seattle closer to where his parents live in Santa Barbara, his friend Joni McCormick told him, "You can't just sit around. You're an outgoing guy. You need to do something positive with this."

It got him thinking. Two weeks before May last year, he had the idea to throw out the first pitch at a college baseball game. And during this pregame ceremony, he'd have the announcer read a script he'd prepared, telling the crowd about this rare disease that has no treatment or cure.

"It's a great way to spread awareness," Vance says. "It's crazy how it's taken off. I have this audience for about 20 minutes, and I get to tell them all about myositis."

Vance started with Stanford, because that's where his rheumatologist practiced. Using his doctor's name, he thought the marketing folks at the university would be more inclined to accept his offer. But other schools heard about his campaign, and by the end of the month, he had appeared at four college games and one little league game.

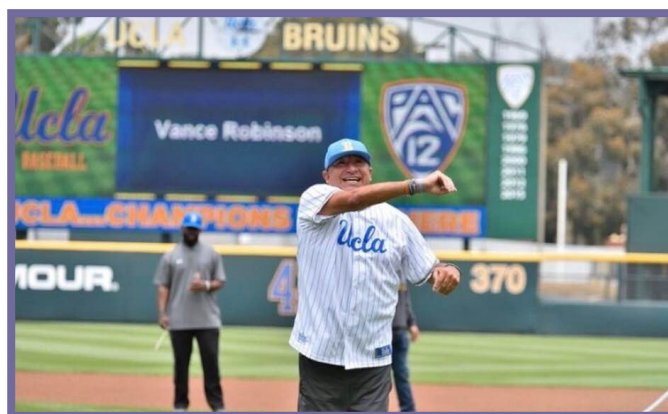
Most exciting of all, during the Stanford game, he met the Grammy Award-winning musician David Longoria who invited Vance to bring his message of myositis awareness to the White House for the 19th annual Day of Prayer for Our Nation.



The stadium was packed this year at the UCLA game against the University of Oregon where 3,000 people heard about myositis. In this his Second Annual Myositis Awareness First Pitch Campaign, Vance also threw the first pitch for games at San Diego State, Pepperdine, and UC Santa Barbara. And he made his way to the pitcher's mound at a game of his childhood team, the Goleta Valley South Little League.

"Sports has been a big part of me," he says. "I always go to college football, basketball, and baseball games. And it just happens that May is in the middle of the college baseball season. So that just clicked."

Not surprisingly it is the little league game that moves him the most.



“When I was 16, my older brother was 19, and he died in a car accident,” Vance explains. “Little league baseball was huge for us growing up, and to be on the mound where my brother played and all our friends...that brought back a lot of memories.”

That was also the game where the coach got all his kids together and gave them a pep talk about never giving up. “Look at Vance,” he told the boys, which made Vance choke up. He’d never been this kind of role model before.

This year Vance had offers to throw the first pitch at ten other colleges that friends and family suggested—schools in North Carolina and Texas and Nevada. And while he has lots of support from these folks, he just doesn’t have the wherewithal—physical or financial—to travel all over the country.

Strength and resources aside, however, Vance has another project to bring the message of Myositis Awareness to all 50 states. He has given away hundreds of TMA Myositis Awareness wristbands, asking family and friends and friends of friends to give them to people—especially celebrities—and have them send him a photo of them wearing it. To date he has managed to plant these seeds in all but two states, and his FaceBook page is plastered with pictures of people sporting blue or orange bands that say Cure Myositis.

This includes a photo of Lavon Coleman, a running back from Lompoc, California, near where Vance grew up. Vance gave the wristband to Coleman’s father last year at the Stanford game and asked that Lavon send him

a photo as a way of showing support. Vance never did hear back from Lavon, but when he saw the college senior signing his NFL contract with the Houston Texans, there was the myositis wristband.

“He’d been wearing it for months,” Vance says.

The best part of this whole experience, however, is when people come up to him at a game to talk about myositis. At the San Diego state game, for example, a woman found him sitting in his scooter in the stands and told him she has dermatomyositis and thanked him for what he is doing to raise awareness for myositis.

And at Pepperdine, one of the players came up to him and said, “I just want you to know you’re doing this for my dad, too. He was walking with a cane, and now he’s in a wheelchair, and we don’t know what’s going on with him.”

“It’s been tiring,” Vance says, “but I think I’m having an impact. Being disabled, you don’t get anything by not asking. You have to step up. You have to ask.”



“Being disabled, you don’t get anything by not asking. You have to step up. You have to ask.”



TMA celebrates 25 years as Your Myositis Association



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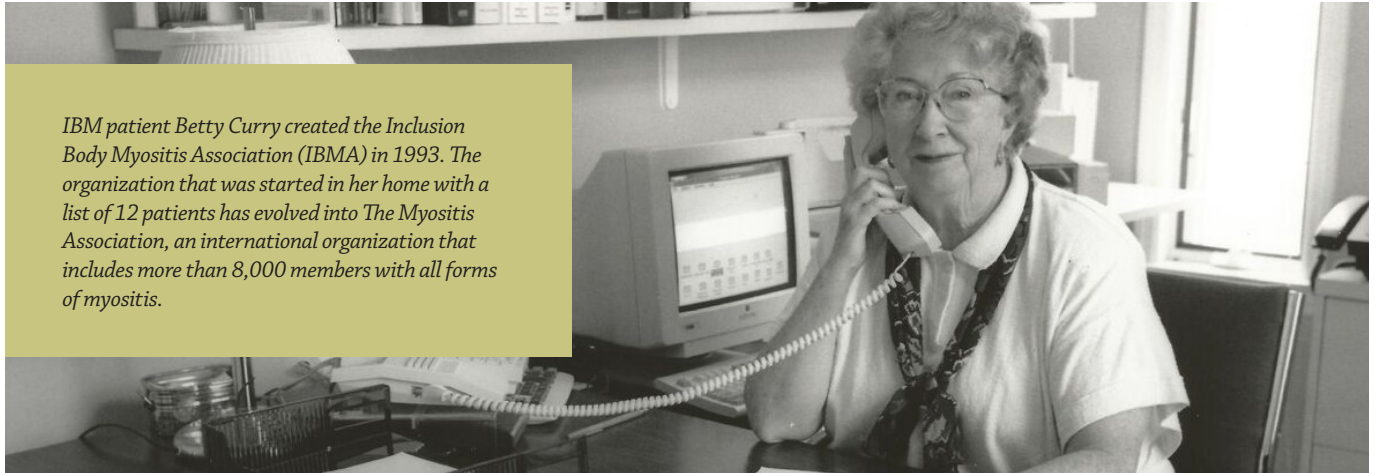


Patients with active DM or PM needed

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.

IBM patient Betty Curry created the Inclusion Body Myositis Association (IBMA) in 1993. The organization that was started in her home with a list of 12 patients has evolved into The Myositis Association, an international organization that includes more than 8,000 members with all forms of myositis.



Participants enjoyed the San Diego weather 2017



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agenda and conference updates.

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