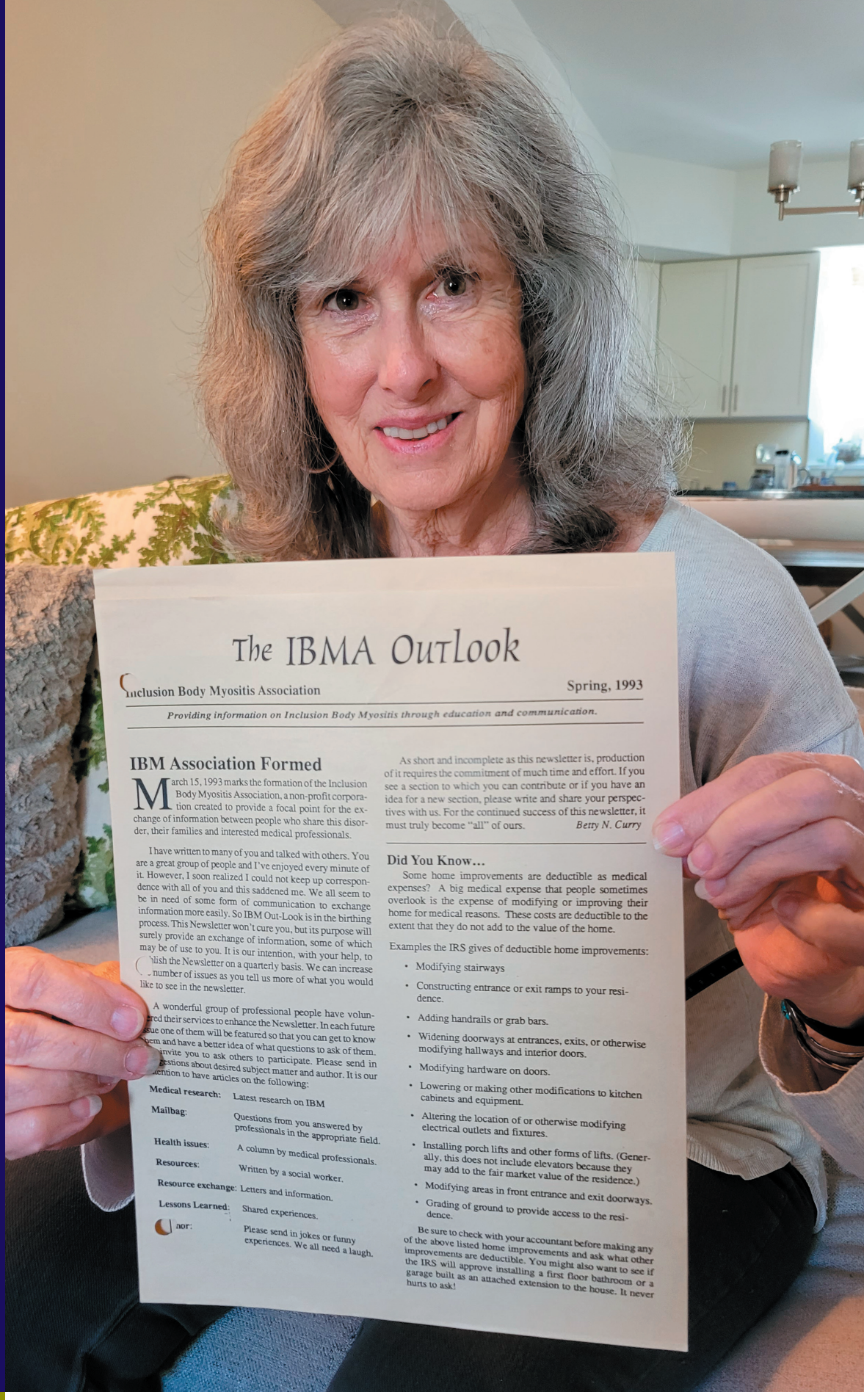
THE OUTLOOK

THE MYOSITIS ASSOCIATION®



FALL 2025
Quarterly Magazine

NOW RECRUITING!

RAINBOW
Trial in Myositis

Eligibility

You may be eligible to participate in the RAINBOW study if you:

- Are 18–75 years old
- Diagnosed with dermatomyositis (DM) or immune-mediated necrotizing myopathy (IMNM)
- Meet other requirements, which will be discussed with you during screening.

Investigational drug

- Phase 1b trial of RAY121 in immunological diseases
- Investigational drug aims to block a pathway known to be involved in the development of immune system issues

QUICK TRIAL FACTS

This trial will last for about **9 months**.

Participants will receive the investigational drug once every **4 weeks** for **3 months** (4 times overall).

The investigational drug is given as an injection under the skin (subcutaneous) of your stomach.

Trial sponsor Chugai Pharmaceuticals Co., Ltd
Learn more at clinicaltrials.gov/study/NCT06371417

What is a clinical trial?

A clinical trial is a medical trial that helps to answer important questions about an investigational medication or drug, such as:

- Does it work?
- How safe is it?
- What are the side effects?
- Does it affect people differently based on their age, sex, gender, race, and ethnicity?

The results of clinical trials are used as part of an in-depth review process to help decide whether new medications can be approved for widespread use. Clinical trials are an important part of developing new medications. An Institutional Review Board (IRB)/Ethics Committee (EC) protects the rights, safety, and well-being of all trial participants. An IRB/EC has reviewed this trial.

CHUGAI

A RAY121 CLINICAL TRIAL
RAINBOW

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THE OUTLOOK

A quarterly publication of The Myositis Association

On the cover: Former TMA Communications Director Theresa Curry displays the first issue of The OutLook, published in Spring 1993.

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.

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TMA welcomes new medical advisors

TMA is excited to announce the addition of two new members to our Medical Advisory Board (MAB). This year, in order to round out the specialists most needed by those who live with myositis, the MAB Nominating Committee, along with the full MAB and Board of Directors, sought to elect one neurologist and, for the first time ever on TMA's MAB, a speech and language pathologist. We look forward to working with these outstanding myositis experts.

Christiaan Saris, MD, PhD

Personal statement: Kintsugi is the Japanese art of repairing fractured pottery and means "golden joinery." Instead of repairing as close to its original as possible, cracks are repaired with a golden resin to attach broken pieces. Breakage and repair are a unique part of the history of an object. As we go through life, we will acquire physical, emotional, and mental scars. It is a normal and inevitable part of the human experience. Illness, trauma, and loss change us. Kintsugi teaches us we cannot go back to the way we were before, but we can move forward with this new precious way of being, if we work the meaning of it.

Although treatments for myositis have evolved quickly in the last several years, with exciting new methods on the horizon, in many cases the disease is still chronic, leaving many physical, emotional, and mental scars behind. As a myositis specialist, I not only advise people with myositis on the best possible treatments, I also advise on how to deal and cope with all the symptoms that result from muscle inflammation and fibrous tissue replacement. It is one of the reasons I'm also interested in the non-pharmacological interventions in treating myopathies.

Since 2014, I have worked as a consultant neurologist and clinical neurophysiologist at the department of Neurology, Radboud University Medical Center Nijmegen, the Netherlands. At the outpatient clinic I mainly see patients with myositis or mitochondrial diseases. During consultation, I combine technological possibilities in our center ("high tech") with a personal approach and advice ("high touch").

My research focuses on the improvement of diagnostics, understanding the pathophysiology, and treatment of inflammatory myopathies, including inclusion body myositis (IBM) and mitochondrial diseases. Areas we focus on at the Radboud Medical Center are the use of ultrasound in myositis, and lifestyle interventions, like nutrition and exercise. For all types of myositis, exercise is an important part of rehabilitation.

Future treatments can hopefully be able to really cure myositis. A timely diagnosis and a doctor who helps to heal the impact of myositis will, however, always be necessary. It is an honor to serve the Medical Advisory Board of The Myositis Association.

Georgia A. Malandraki, PhD, CCC-SLP, BCS-S

Personal statement: I am a medical speech and language pathologist and a board-certified specialist in swallowing and swallowing disorders (dysphagia) with more than 20 years of experience in treating individuals with dysphagia caused by neurological conditions. I am also a research scholar and tenured full Professor in the Department of Speech, Language, and Hearing Sciences and the Weldon School of Biomedical Engineering at Purdue University.

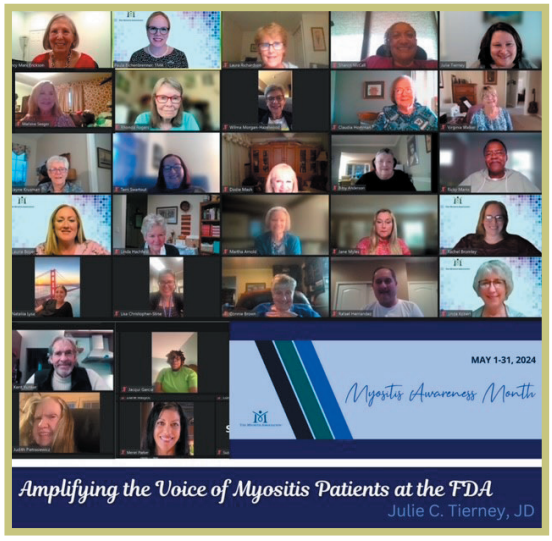
My research expertise is in investigating the neurophysiology of swallowing function in aging and neurogenic dysphagia, developing and testing neurophysiology-based rehabilitative swallowing treatments, and improving access to swallowing management through telehealth and wearable technologies. I direct a nationally known research laboratory (Purdue I-EaT Research Lab), and our work has been extensively published and funded by the National Institutes of Health, private foundations, and other agencies. I also had the honor

to serve as the 2022-2023 President of the Dysphagia Research Society (DRS), which is the leading international multidisciplinary research society focused on the study of swallowing disorders.

I started treating patients with different types of myositis during my clinical fellowship year at the Swallowing Clinic of the University of Wisconsin (UW) Hospital in Madison, WI. As you know, dysphagia is a significantly under-studied but devastating symptom for those who live with myositis. Because of this, these individuals are often treated for their dysphagia symptomatically or through compensatory strategies (for example, with thickened liquids or postural adaptations while eating). Although these strategies may provide temporary relief, they do not address the underlying cause of the swallowing difficulty and therefore lack the ability to prevent or slow the progression of swallowing decline associated with the disease.

Our multidisciplinary group at UW was among the first to initiate and pilot an exercise-based approach for patients with inclusion body myositis (IBM) with the first longitudinal 5-year case study published in 2012 in the Archives of Physical Medicine and Rehabilitation journal. This was the first study that showed that low dose oropharyngeal strengthening exercise holds promise for maintaining swallowing function and even delaying dysphagia progression. This study has also inspired more efforts for rehabilitative swallowing programs in the field. Since then, I have continued to use a multidisciplinary, multi-pronged, personalized treatment approach for those with myositis as I am committed to improving the lives of those who live with myositis.

Celebrating TMA Support and Affinity Groups



A Tribute to Our Tenacity: Women Honoring our IBM Journey

By Nancy Marx Erickson, TMA Affinity Group Leader

Five years ago in 2020, a small group of women—**Nancy Marx Erickson**, **Lisa Motley**, **Martha Arnold**, **Laura Richardson**, and **Patty Meyer**—began discussions about women's issues involving how to live with inclusion body myositis. Women, we realized, have different challenges and concerns than men with IBM, or even women with other forms of myositis.

This monthly discussion evolved into a new TMA affinity group with a mission: **To improve the lives of women affected with inclusion body myositis (IBM) through virtual connections and support that transcend geography.** The mission statement proved to be prophetic. Not only has the monthly zoom gathering WomenWithIBM expanded to more than 400 women, with 60 to 100 showing up each month, but meetings include women from the United States, Canada, Europe, and Australia. Speakers on the monthly programs have included distinguished, brilliant clinical and medical experts, both women and men, from the United States and internationally.

Initially, the meetings dealt with issues on the day-to-day problems women face in their IBM journey. But as the group attracted more and more participants, discussions have involved research and clinical trials in myositis, physical therapy, coping with travel domestically and international, and advocacy for local and national funding for rare diseases.

We are grateful for the women who show up each month to share their stories and insights of how they cope every day with IBM. We learn and support one another. We also encourage other women with IMB to join and enjoy the sisterhood.

TMA's WomenWithIBM Affinity Group's five-year anniversary was recognized during the **opening festivities at MyoCon 2025**, and the group hosted a **special evening celebration**.

A huge shoutout to the WomenWithIBM leader and co-leaders: Nancy Marx Erickson, Sharon Kern McCall, and Laura Richardson.

TMA's Women of Color Affinity Group

Looking for information, connection, inspiration, and support? TMA's Support and Affinity Groups are your lifeline! Meet others who get it, share your journey, and grow stronger together. Whether newly diagnosed or a seasoned advocate, there's a place for you to belong, learn, and lead. **Join any online meeting** and find out more about **all the options available**.

TMA's Southern California Support Group Celebrates 30 Years

Nancy and Charlie Harber in 2004

This year marks the 30th anniversary of TMA's Southern California Support Group—a milestone that reflects three decades of resilience, leadership, and community care.

The group's roots trace back to 1995, when **Charlie Harber**, a college history professor newly diagnosed with inclusion body myositis (IBM), was referred by his UCLA neurologist to a local support group in San Diego. At the time, San Diego County was so large that two separate groups were meeting. When the original leader discovered he had a different illness, Charlie stepped up to consolidate the groups and lead them forward.

Charlie's personal experience with myositis and his thoughtful leadership helped shape a welcoming and informed space for others navigating the same journey. After his passing in 2006, his wife **Nancy Harber**, a nurse and devoted care partner, continued his legacy by keeping the group active.

Rhonda Rogers AKA The Myositis Warrior

Rhonda Rogers joined the San Diego Keep in Touch (KIT) Group in 2015, shortly before receiving her correct diagnosis of IBM—after twelve years of being misdiagnosed with polymyositis and unaware of TMA or any support group. "The San Diego KIT group became my lifeline," Rhonda recalls. "The members were kind and informative, and they helped me navigate the shock of my new diagnosis."

In 2018, Rhonda became co-leader of the group along with Nancy Harber, after then-leader **TeriAnn Moser** moved to Hawaii. The group met monthly in person at local restaurants, sharing stories, advice, and occasional guest speakers. When COVID-19 disrupted in-person gatherings in 2020, Rhonda helped transition the group to Zoom—a format that continues today with quarterly virtual meetings.

This year, Rhonda and Nancy were honored with the **Marianne Moyer Myositis Leader Award** at TMA's Heroes in the Fight Ceremony during MyoCon 2025 in Dallas, Texas. The award recognizes their leadership and enduring commitment to the myositis community.

As we celebrate this 30-year milestone, we honor TMA's Southern California Support Group not only for its longevity but for its profound impact on the lives of countless individuals and families affected by myositis.

What Brings You Joy?

For Alicia Lowther, it's the word "Joy" that brings her JOY!

"Joy is my word. If I see anything with the word 'Joy' on it, the item is purchased without hesitation. There is a special story regarding this special word. Five years ago, Dan (my husband who has IBM) was surprised to find out through 23 and Me that he was the biological father of a daughter he did not know existed. The 'event' occurred shortly after he was discharged from the Navy (so well before we were married), and his name is not on the birth certificate. Her finding us has been a huge blessing. We are now grandparents, and I tease his daughter that her name should be Joy because she has brought us so much JOY. I find Joy in family – both old and newly discovered."

From a Basement Office to a Global Voice: TMA's Origin Story

By Theresa Curry

In 1997, I was typing furiously in a Virginia newsroom when a woman wheeled past the counter, sped by the receptionist, and abruptly braked to a stop next to my cluttered desk. The counter and receptionist were meant to shield reporters from interruptions on deadline—but they were no match for this visitor. She had the advantage of a contraption none of us had ever seen: a shiny red electric scooter, which she drove too fast but skillfully through the narrow rows between desks.

Betty Curry (no relation) had never met me, hadn't made an appointment, and was seriously interfering with my work. But she refused to be put off. A month later, I found myself in an unfamiliar city, writing about a disease I'd never heard of, as the communications director for a new rare disease organization.

That organization was the **Inclusion Body Myositis Association (IBMA), officially launched in 1993**. At the time, the internet was just beginning to emerge, and most scientific knowledge was still shared through printed journals and conferences. For patients, information about rare diseases like myositis was hard to find, but Betty was determined to change that.

A Force of Nature

Betty Curry was a successful artist, entrepreneur, and real estate developer. But her biggest challenge came at age 64, when she was diagnosed with inclusion body myositis (IBM). She refused to accept the idea that information about her disease was "too difficult" for patients to understand. Betty believed that knowledge was power—and she was determined to share it.

She recruited others, like Madeline Sabia, whom she met when they were both participants in a research study at the NIH. Together, they formed the IBMA to educate and support IBM patients. Betty and her volunteers attended neurology conferences, gathered research papers, and introduced themselves to doctors, urging them to refer patients to the new nonprofit.

Betty's basement apartment in Harrisonburg, Virginia became IBMA's headquarters. She launched a newsletter called *The IBMA OutLook*, writing in the first issue: **"This organization won't cure you, but its purpose will surely provide an exchange of information, some of which may be of use to you."** She described herself as "editor, reporter, errand girl, research person, data programmer, organizer, beggar of funds, and cleaning lady."

She convinced a local attorney to help with nonprofit paperwork, scientists to send research articles, and doctors to answer patient questions.

In 1993, IBMA had just 33 members—16 names from the National Organization for Rare Diseases (NORD) and a handful of patients Betty had met during her NIH study. She wrote to every one of them. Their replies saddened her but strengthened her resolve. Some had been diagnosed for more than ten years and still knew nothing about their disease or future. "I found this intolerable," Betty said in an interview. "They were simply not getting the information they needed."

By 1994, the organization was growing. Betty and her team returned from the American Academy of Neurology meeting with nearly 200 new names. The fall issue of The OutLook expanded to 10 pages and listed a "who's who" of IBM researchers as medical advisors. Their support lent credibility to the fledgling organization and helped attract both patients and professionals.

A Parallel Path: The National Myositis Association

Meanwhile, in Cooperstown, New York, **Tina Kline** was building a similar community for patients with dermatomyositis (DM) and polymyositis (PM). She founded the **National Myositis Association (NMA) in 1986**, using patient lists also from NORD to connect with others. Tina had no office experience, but she had a gift for writing and a deep compassion for others.

She mailed handwritten letters, treatment updates, and research notices to members. In 1992, Vickie Jahaske, a Tucson support group leader living with DM, joined NMA and became Tina's assistant. Together, they created the first newsletter in 1993.

National Myositis Association Newsletter
National Support Group for Myositis
Newsletter No. 18 Fall Edition 1996

Tina wrote by hand, Vickie typed and designed, and a small press printed the newsletters for free.

"We were very low-tech," Vickie recalls. But the newsletters were powerful. They connected patients across the country, shared frustrations and triumphs, and offered hope.

Tina believed that handwritten mail was more personal than digital communication and resisted switching to the internet. But she also recognized the need to grow. She wanted to ensure that the organization retained its warm, personal touch even as it expanded.

Coming Together

By 1996, both Tina and Betty saw the value in merging their organizations. In the Fall 1996 newsletter, Tina announced with grace the merger and the organization's new name:

"We've decided to throw our support to the IBMA and blend the groups together as one. The Myositis Association of America (MAA) is a fine organization and has quite an impressive medical advisory board."

The merger allowed for better coordination, reduced duplication, and opened doors to joint research. Medical advisors like Drs. Fred Miller, Chet Oddis, Lauren Pachman, and Lisa Rider joined the new organization, helping shape research priorities and guide patients.

Dr. Miller wrote: "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."

Tina reassured members with heartfelt words: "As one strong, united group we shall be a voice to be heard and reckoned with."

Going Global

As the internet gained traction, MAA's reach expanded. Patients in Europe began translating MAA materials and sharing them with local networks. Research collaborations emerged in France, Sweden, and Mexico. In The Netherlands, an IBM patient relayed information from MAA to a network of patients and notified staff about European IBM research.

It became clear that MAA was no longer just a national organization—it was international.

Under the leadership of the Board of Directors and Executive Director Bob Goldberg, the organization officially became **The Myositis Association (TMA) on January 1, 2003**. The new name reflected its broader mission and global reach.

A Lasting Legacy

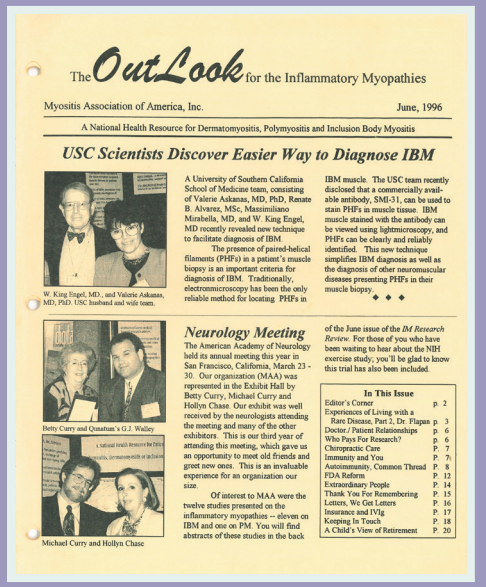
From just 27 names shared by NORD—11 PM/DM patients and 16 IBM patients—TMA has grown to serve more than 13,000 members worldwide. It has awarded nearly $9 million in research funding, hosted international conferences, and continues to be a lifeline for patients and families affected by myositis around the globe.

Betty Curry passed away in 2014, and Tina Kline died in 2021 from COVID-19. Their legacy lives on, however, in every newly diagnosed patient who finds answers, every researcher who receives a grant, and every care partner who feels less alone.

World Myositis Day 21 Sept

What began as two small, self-published newsletters has become a global voice for hope, education, and progress in the fight against myositis. TMA is proud to stand together with the international myositis advocacy community working to drive awareness on World Myositis Day and every day.

Over the decades, TMA and its predecessor organizations have communicated with members and stakeholders through a quarterly magazine. Enjoy this retrospective of our publication covers!



The OutLook for the Inflammatory Myopathies

Myositis Association of America, Inc. June, 1996

A National Health Resource for Dermatomyositis, Polymyositis and Inclusion Body Myositis

USC Scientists Discover Easier Way to Diagnose IBM

A University of Southern California School of Medicine team, consisting of Valerie Askanas, MD, PhD, Renate B. Alvarez, MSc, Massimiliano Mirabella, MD, and W. King Engel, MD recently revealed new technique to facilitate diagnosis of IBM.

The presence of paired-helical filaments (PHFs) in a patient's muscle biopsy is an important criteria for diagnosis of IBM. Traditionally, electronmicroscopy has been the only reliable method for locating PHFs in IBM muscle. The USC team recently disclosed that a commercially available antibody, SMI-31, can be used to stain PHFs in muscle tissue. IBM muscle stained with the antibody can be viewed using lightmicroscopy, and PHFs can be clearly and reliably identified. This new technique simplifies IBM diagnosis as well as the diagnosis of other neuromuscular diseases presenting PHFs in their muscle biopsy.

W. King Engel, MD., and Valerie Askanas, MD, PhD. USC husband and wife team.

Neurology Meeting

The American Academy of Neurology held its annual meeting this year in San Francisco, California, March 23 - 30. Our organization (MAA) was represented in the Exhibit Hall by Betty Curry, Michael Curry and Hollyn Chase. Our exhibit was well received by the neurologists attending the meeting and many of the other exhibitors. This is our third year of attending this meeting, which gave us an opportunity to meet old friends and greet new ones. This is an invaluable experience for an organization our size.

Of interest to MAA were the twelve studies presented on the inflammatory myopathies -- eleven on IBM and one on PM. You will find abstracts of these studies in the back of the June issue of the *IM Research Review*. For those of you who have been waiting to hear about the NIH exercise study; you'll be glad to know this trial has also been included.

Betty Curry and Qunatum's G.J. Walley

Michael Curry and Hollyn Chase

In This Issue

The OutLook for the Inflammatory Myopathies

Myositis Association of America, Inc. March, 1997

A National Health Resource for Dermatomyositis, Polymyositis and Inclusion Body Myositis

From left to right: Donna Sundre Ed.D., statistician from JMU, Michael Curry, MAA Project Manager, and Christina Pierce, MAA Survey Assistant, listen to Sundre explain details of analysing statistics drawn from the questionnaire.

Welcome Jeffrey Callen, MD

Dr. Jeffrey P. Callen, Professor and Chief of the Department of Medicine, Division of Dermatology at the University of Louisville, Kentucky has graciously accepted a place on MAA's Board of Medical Advisors. We have been told by his peers that Dr. Callen is one of the top three dermatologists in the United States. We are honored that he accepted our invitation.

We are especially pleased that MAA dermatomyositis members will have their skin-problem questions answered by the best.

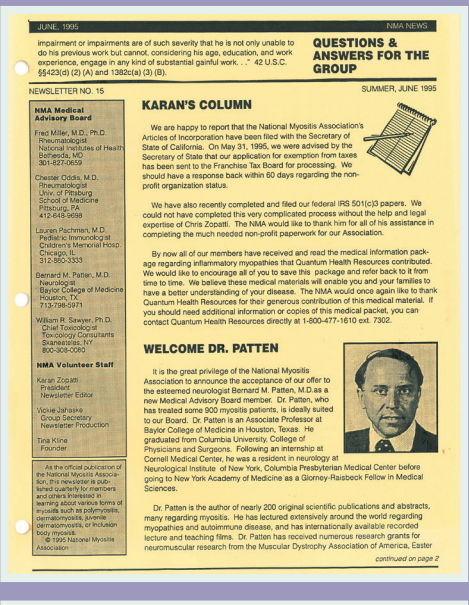
Quantum / Olsten funds balance of 1st Year Inflammatory Myopathy Patient Survey

Quantum Health Resources, now known as Olsten Kimberly QualityCare, deserves a big round of applause for its generosity in support of the survey we've been working on this past year. The check we received in December will take us through May of this year.

After MAA members returned sufficient questionnaires to have an idea of how best to construct the data base, Curry and Pierce spent four weeks in its development—no easy task. It is a monstrous data base, with seven tables linked together using referential integrity. After the tables were in place, forms were designed to look similar to the questionnaire so the data processor can page through the (electronic) survey while the data is automatically stored in the tables and forwarded to the newly opened forms.

The past few weeks have been spent entering about 40 surveys to test and debug the database. Minor adjustments have been made, now the work begins of data entry from the balance of questionnaires. Our goal is to have 500 questionnaires entered by March 15, with a preliminary analysis available by the end of May.

In This Issue



JUNE, 1995 NMA NEWS

QUESTIONS & ANSWERS FOR THE GROUP

impairment or impairments are of such severity that he is not only unable to do his previous work but cannot, considering his age, education, and work experience, engage in any kind of substantial gainful work. . .." 42 U.S.C. §§423(d) (2) (A) and 1382c(a) (3) (B).

NEWSLETTER NO. 15 SUMMER, JUNE 1995

NMA Medical Advisory Board

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William R. Sawyer, Ph.D. Chief Toxicologist Toxicology Consultants Skaneateles, NY 800-308-0260

NMA Volunteer Staff

Karan Zoatti President Newsletter Editor

Vicki Jahaske Group Secretary Newsletter Production

Tina Kline Founder

As the official publication of the National Myositis Association, this newsletter is published quarterly for members and others interested in learning about various forms of myositis such as polymyositis, dermatomyositis, juvenile dermatomyositis, or inclusion body myositis.

© 1995 National Myositis Association

KARAN'S COLUMN

We are happy to report that the National Myositis Association's Articles of Incorporation have been filed with the Secretary of State of California. On May 31, 1995, we were advised by the Secretary of State that our application for exemption from taxes has been sent to the Franchise Tax Board for processing. We should have a response back within 60 days regarding the non-profit organization status.

We have also recently completed and filled our federal IRS 501(c)3 papers. We could not have completed this very complicated process without the help and legal expertise of Chris Zopatti. The NMA would like to thank him for all of his assistance in completing the much needed non-profit paperwork for our Association.

By now all of our members have received and read the medical information package regarding inflammatory myopathies that Quantum Health Resources contributed. We would like to encourage all of you to save this package and refer back to it from time to time. We believe these medical materials will enable you and your families to have a better understanding of your disease. The NMA would once again like to thank Quantum Health Resources for their generous contribution of this medical material. If you should need additional information or copies of this medical packet, you can contact Quantum Health Resources directly at 1-800-477-1610 ext. 7302.

WELCOME DR. PATTEN

It is the great privilege of the National Myositis Association to announce the acceptance of our offer to the esteemed neurologist Bernard M. Patten, M.D.as a new Medical Advisory Board member. Dr. Patten, who has treated some 900 myositis patients, is ideally suited to our Board. Dr. Patten is an Associate Professor at Baylor College of Medicine in Houston, Texas. He graduated from Columbia University, College of Physicians and Surgeons. Following an internship at Cornell Medical Center, he was a resident in neurology at Neurological Institute of New York, Columbia Presbyterian Medical Center before going to New York Academy of Medicine as a Glomey-Raisbeck Fellow in Medical Sciences.

Dr. Patten is the author of nearly 200 original scientific publications and abstracts, many regarding myositis. He has lectured extensively around the world regarding myopathies and autoimmune disease, and has internationally available recorded lecture and teaching films. Dr. Patten has received numerous research grants for neuromuscular research from the Muscular Dystrophy Association of America, Easter

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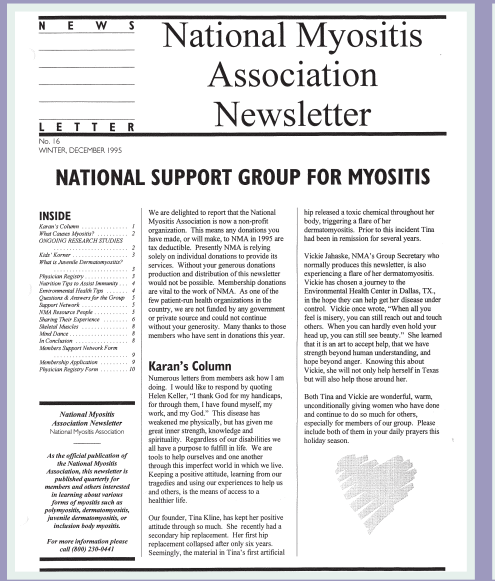


NEWS LETTER

National Myositis Association Newsletter

No. 16 WINTER, DECEMBER 1995

NATIONAL SUPPORT GROUP FOR MYOSITIS

INSIDE

National Myositis Association Newsletter National Myositis Association

As the official publication of the National Myositis Association, this newsletter is published quarterly for members and others interested in learning about various forms of myositis such as polymyositis, dermatomyositis, juvenile dermatomyositis, or inclusion body myositis.

For more information please call (800) 230-0441

We are delighted to report that the National Myositis Association is now a non-profit organization. This means any donations you have made, or will make, to NMA in 1995 are tax deductible. Presently NMA is relying solely on individual donations to provide its services. Without your generous donations production and distribution of this newsletter would not be possible. Membership donations are vital to the work of NMA. As one of the few patient-run health organizations in the country, we are not funded by any government or private source and could not continue without your generosity. Many thanks to those members who have sent in donations this year.

Karan's Column

Numerous letters from members ask how I am doing. I would like to respond by quoting Helen Keller, "I thank God for my handicaps, for through them, I have found myself, my work, and my God." This disease has weakened me physically, but has given me great inner strength, knowledge and spirituality. Regardless of our disabilities we all have a purpose to fulfill in life. We are tools to help ourselves and one another through this imperfect world in which we live. Keeping a positive attitude, learning from our tragedies and using our experiences to help us and others, is the means of access to a healthier life.

Our founder, Tina Kline, has kept her positive attitude through so much. She recently had a secondary hip replacement. Her first hip replacement collapsed after only six years. Seemingly, the material in Tina's first artificial hip released a toxic chemical throughout her body, triggering a flare of her dermatomyositis. Prior to this incident Tina had been in remission for several years.

Vickie Jahaske, NMA's Group Secretary who normally produces this newsletter, is also experiencing a flare of her dermatomyositis. Vickie has chosen a journey to the Environmental Health Center in Dallas, TX., in the hope they can help get her disease under control. Vickie once wrote, "When all you feel is misery, you can still reach out and touch others. When you can hardly even hold your head up, you can still see beauty." She learned that it is an art to accept help, that we have strength beyond human understanding, and hope beyond anger. Knowing this about Vickie, she will not only help herself in Texas but will also help those around her.

Both Tina and Vickie are wonderful, warm, unconditionally giving women who have done and continue to do so much for others, especially for members of our group. Please include both of them in your daily prayers this holiday season.

THE MYOSITIS ASSOCIATION

JM COMPANION

FALL 2005 For patients, families and friends affected by juvenile myositis

Changed forever: Senior talks about college years with myositis

It's been a long journey and a hard one for Lynne Messinger, a college senior who's spent her college years battling polymyositis. But she's learned some things, too - lessons that have nothing to do with arts and sciences. Lynne is beginning her supervised teaching at the middle school level, and she knows a thing or two about pain, courage and compassion. When her struggles began, she was not much older than the students she faces in her practice teaching. "I can't help but think how awful it would be to be 12 or 13 and have to go through this," she said.

It was hard enough for her. One day she was a beautiful, normal teenager at her senior prom; months later, she was weak, in pain and worried about what was wrong. "It was almost a relief when I was diagnosed," Lynne said. "I thought I was going insane, that it was all in my mind. I was confused, exhausted, completely terrified." All this happened in her first and second years of college. Along with the tests came the needles: "I'd always been afraid of them," Lynne said. "In fact, I still am - but it was something I just had to live through." Lynne had her EMG and biopsy while she was on winter break during her sophomore year.

Once diagnosed, Lynne was treated with prednisone, starting at 60 mgs. "Boy, was I not prepared for that," she said. Lynne, who'd always been slim without watching what she ate, gained 40 pounds in two weeks. "I ate all the time," she said. "I was so hungry, it hurt. I couldn't imagine not eating; I was that hungry." After two weeks, she looked in the mirror and saw someone she didn't recognize. "My face changed completely. I was covered with zits and I had facial hair. I looked like a fat 13-year-old boy."

Lynne and Scott

Lynne used what energy she had to study: "That was one good thing - since I couldn't go out, I had more time to read. And I quickly learned who my real friends were." The real friends were those who went out of their way to check on her, to let her talk about her illness, to learn how to help her. "Even today, when someone opens a bottle or a can for me without me asking, I just appreciate it so much." Lynne recently wrote a term paper about the kinds of community support she found when struggling with polymyositis.

Her boyfriend amazed her: "There I was, fat and miserable, hairy and with zits and he continued to tell me I was beautiful," she said. "Of course, I didn't believe him, but it was great for him to try." He told her later that he was confused about how to help her. Other people came out of nowhere when she was sick, then disappeared when she felt better. "What's up with that?" Lynne asked. "It's like they only liked me when I was in rough shape." The response of family members was mixed: "My parents felt guilty, like it was their fault," she said. "But they came through for me again and again." Her little sisters didn't know how to react. One minute they accused her of dodging household chores; the next minute they'd catch a glimpse of her stretch marks (from prednisone) and feel sorry for what she'd been through.

Lynne's much better now, although there are remnants of the disease. She's lost most of the weight and regained some of her strength. She's recently had a flare and is starting on methotrexate (more needles!). Her skin dries out, especially when she takes hot showers, and her hands are often the rough "mechanic's hands" that are typical of polymyositis. And, she says, she's forever changed inside. "I have more compassion, more understanding,"

Lynne and Donald Duck

Lynne with friends Scott and Katie

Continued on page 2

THE MYOSITIS ASSOCIATION

OUTLOOK EXTRA

WINTER 2006 2006 Conference Report

In this issue:

Looking ahead:

Coming in Spring *OutLook*

- Myositis Center opens at Johns Hopkins
- TMA award's new round of research grants
- Research: seeking understanding and a cure

Also, coming soon!

- Chats are back! Watch for news at www.myositis.org.

Myositis research gaining momentum, attracting international attention

This is a new era of myositis research, with multi-center studies and international collaboration. That was the message delivered by The Myositis Association medical panel at the Annual Conference. Medical Advisory Board Chair Richard Barohn, MD, University of Kansas, said TMA made the right decision when TMA-funded research money was opened up to the international myositis community. "We've funded investigators from Germany, Japan and Sweden," Dr. Barohn said, and by the same token people come from all over the world to donate their time for the important work of evaluating myositis research proposals.

Dr. Barohn reviewed the two ways TMA funds research: The cash grants he defines as "seed money" are $50,000 one-year grants to get a project off the ground. "With the kind of research we need, it's amazing how quickly you can go through this much money," he told myositis patients and families. Most investigators use the grants from TMA to get started, with the ultimate goal of interesting a larger agency to help them continue the research.

Also very important are the fellowships designed to train the next wave of investigators. "There's nothing else out there for a young investigator who may be interested in myositis but has finished his or her residency," Dr. Barohn said. He praised the diversity of the myositis scientific community: "There are some PhDs, some MDs, some running clinical trials and some concentrating on basic science," he said. "More than $2 million in research funds have been raised through your blood, sweat and tears, and TMA has been an important funding source since the beginning of its research program four years ago. As someone who works in this field, I thank you."

Dr. Barohn noted that TMA does not presently suggest specific topics for research (called "directed research") but some larger agencies set aside a certain portion of resources to make sure promising avenues are pursued. "We're probably

See Research, page 2

THE MYOSITIS ASSOCIATION

THE OUTLOOK

SPRING 2008 For the inflammatory myopathies

Matching Research Challenge Nets $400, 000

The 2007 Matching Research Challenge proved very successful. The Challenge, offered by an anonymous TMA member, inspired more than 350 people to contribute last year as well as several new campaigns to raise funds.

The member who offered to match $500,000 in research donations in 2007 hoped this would provide TMA with an additional $1 million for research. He would still like to see TMA reach that goal and has generously agreed to extend the Challenge into 2008.

He is offering to match up to $300,000 this year and hopes that at the end of 2008 TMA will have another $600,000 to fund promising myositis research. Because of the expense of research and his desire to raise money quickly, he will only match donations of $150 or more but will match 2:1 any donation of $15,000 or more – your gift of $15,000 will yield a total of $45,000 more for myositis research!

Also, since there have been exciting developments in the applicability of gene therapy to myositis, the donor has requested that $200,000 of his money contributed in 2008 be directed toward gene therapy research which has promise to benefit all forms of myositis.

Help TMA meet the goal of raising $1 million by contributing to the Matching Research Challenge. To do so, mail in a check along with a note that the donation is for the Matching Research Challenge. Or, you can use a credit card to contribute by calling TMA at 1-800-821-7356 or going online to www.myositis.org.

TMA: 15 years later

Break out the fancy glasses and propose a toast. TMA is celebrating its 15th (crystal) Anniversary, marking a decade and a half of tremendous significance and progress for people with myositis. Those who have received our mailings already know that TMA is doing a lot with the number "15" during its international celebration, which will go on through the year and culminate with the Annual Conference in Denver on September 18-21.

Some of the Anniversary events have been revealed; others will unfold throughout the spring and summer, finishing with some additional surprises at the Conference, which is expected to be the biggest in TMA's history. Some key Anniversary events so far:

$1.5 of all TMA full membership - both renewals and new members - will go towards myositis research. Renew today, and help TMA in its mission to find better treatments and a cure for myositis. This Anniversary research initiative is expected to raise more than $25,000 for the grants and fellowships TMA's board of directors awards to promising veteran and new scientists each year. For more news on TMA's current research program, see pages 4 and 5.

To make the Annual Conference - and the spectacular 15th Anniversary-Myositis Day celebration -- affordable for all, TMA has set a special Anniversary rate during 2008 only. If you have always wanted to attend but couldn't quite afford it, TMA offers a $15 registration fee. That's four days of information, celebration and support, and includes Conference breakfasts, lunch and the 15th Anniversary reception.

Many of you can afford the standard Conference fee, and regularly attend. For you, TMA offers a registration fee of $150 - lower than last year's and available anytime until June 15. By now you should have received a Conference brochure, register now to make this deadline.

When you register you'll be automatically entered into our Anniversary lottery. The 15th, 150th, 200th, 250th, and 300th person to register will have their registration refunded. They will be our guests and attend for free.

Keep-in-Touch (KIT) support group members will have a chance for more TMA "lucky 15" surprises. Groups who have more 15 or more members attending the Conference will get a $15 gift card for each member in their KIT that are TMA members. See more details on this incentive, page 8.

15th Anniversary

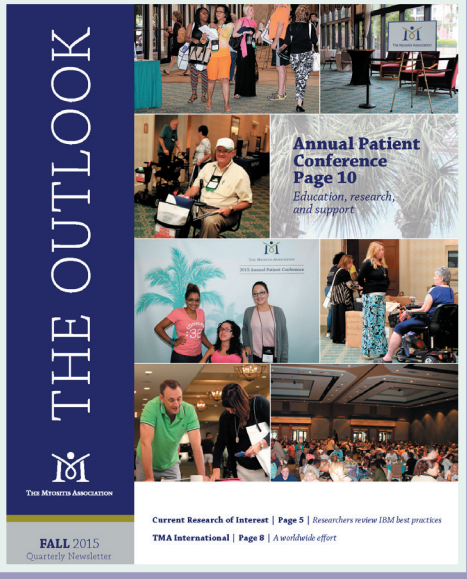
Research, Education, Advocacy, Support

The OutLook

WINTER 2014 Quarterly Newsletter

Dog: Myositis' Best Friend? | pg 8

In the Spotlight: **Research in progress**
Patients and researchers report | pg 3



THE OUTLOOK

THE MYOSITIS ASSOCIATION

FALL 2015 Quarterly Newsletter

Annual Patient Conference Page 10

Education, research, and support

Current Research of Interest | Page 5 | *Researchers review IBM best practices*

TMA International | Page 8 | *A worldwide effort*

Fueling Discovery: The Myositis Association's Research Grants Program

Ten years ago, the treatment landscape for myositis diseases was, let's be honest, bleak. We had no FDA-approved treatments for myositis, other than Acthar® Gel (repository corticotropin injection) for PM and DM. Few clinical trials were available to test new treatments for this community, and those trials failed. Today, all of that has changed thanks in part to TMA's Research Grants Program.

Our support of myositis basic research, early pilot projects, and research fellowships has laid the groundwork for larger projects that are now bearing fruit. In 2021, a new treatment was approved: intravenous immune globulin (IVIG) for dermatomyositis. And hope is on the way for other forms of myositis, with more than a dozen therapies currently in clinical trials and more in the pipeline.

Since 2002, The Myositis Association (TMA) has been a driving force behind groundbreaking research in the fight against myositis. TMA has made scientific research a cornerstone of our mission. Thanks to our donors and partners, we have invested in innovative studies that aim to uncover the causes, improve diagnosis, and develop effective treatments for this complex group of rare muscle diseases.

One of the most significant components of TMA's research program is our fellowship program, which supports early-career investigators as they begin their journey into myositis research. The results speak for themselves:

- 87% of TMA-funded fellows are still actively working in the field of myositis.
- 26% have become leaders in the myositis research community, contributing to major discoveries, clinical advancements, and international collaborations.

These fellowships not only fuel individual careers but also help build a robust pipeline of dedicated researchers committed to improving the lives of people living with myositis.

Just turn the page and take a look at our successes.

By the way, if you'd like to contribute to TMA's research success, **you can do so here**.

THE MYOSITIS ASSOCIATION®

TMA's Research Grants Program:
Investing in Research Since 2002

At The Myositis Association, our vision is a world without myositis. We know the only way to achieve this lofty goal is through scientific research. That's why investing in innovative research is at the heart of our mission.

Overview

Every year since 2002, TMA's research grants have provided financial support to qualified investigators and clinicians for basic, translational, and clinical research. Our goal is to advance our understanding of the underlying causes and pathophysiology, means of prevention, early detection, accurate diagnosis, effective treatments, ways to improve quality of life, and methods for curing myositis and related diseases and complications.

Over the last twenty-plus years, **TMA has invested nearly $10 million in 68 projects** that span the spectrum of myositis diseases and specialties.

32% of TMA grants have supported early career training

43% of TMA grants have supported non-US investigators

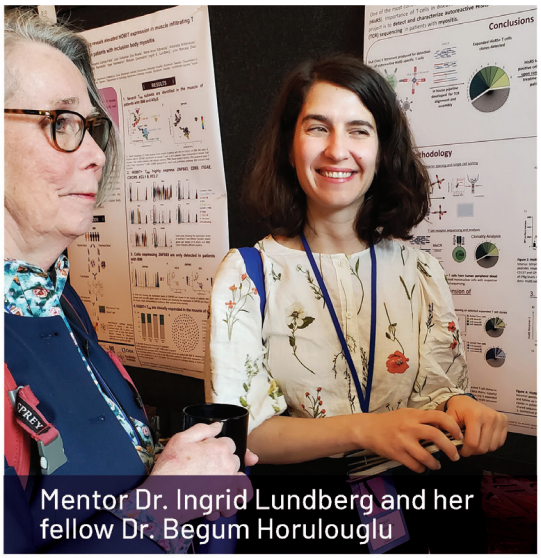
$120k average dollar amount of a TMA grant award

22 number of Fellowship Grants TMA has provided over the years

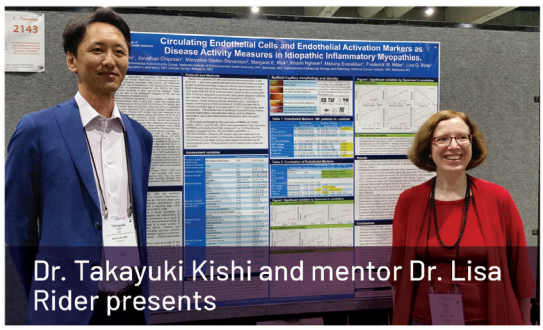
Career Achievements by TMA Grantees

Recipients of TMA's fellowships and grants are now distinguished myositis experts serving as:

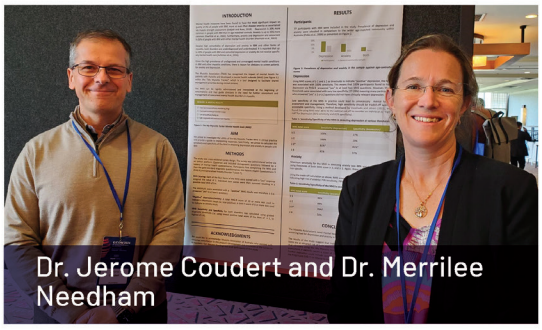
- TMA Medical Advisory Board members
- Founder and head of the International Myositis Society (iMyoS)
- University professors
- Medical center department heads
- Research scientists at research institutes
- Members of myositis consortia and study groups



Mentor Dr. Ingrid Lundberg and her fellow Dr. Begum Horulouglu



Dr. Takayuki Kishi and mentor Dr. Lisa Rider presents



Dr. Jerome Coudert and Dr. Merrilee Needham

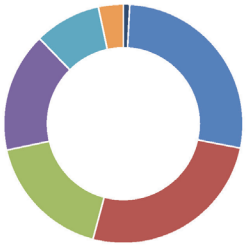
The Myositis Association®

"TMA's award allowed me to continue to focus on research in myositis-ILD. Had it not been for this award, I would no longer be conducting research in patients with myositis. I am proud of what I built here at Penn, and I am excited to continue to work with patients with myositis with the goal of better understanding this disease to improve and save lives."

– Cheilonda Johnson, MD, MHS, pulmonologist and TMA pilot grant recipient

2002 – 2025

Number of Projects by Disease Type*



- IBM: 26
- DM: 24
- JM: 16
- PM: 15
- IIM: 08
- ILD: 04
- NM: 01

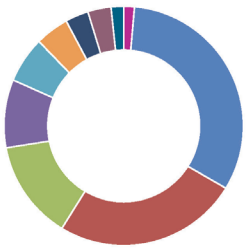
Projects by disease type

Dr. Thomas Lloyd's project "Human skeletal muscle xenografts to model inclusion body myositis (IBM)" successfully developed a mouse model to test therapeutic pathways in IBM. This project has had a significant impact on understanding disease mechanisms and identifying potential therapeutic targets for this complex disease.

* Some projects included more than one form of myositis.

2002 – 2025

Number of Projects by Investigator Specialty



- Neurology: 21
- Rheumatology: 17
- Pediatric: 09
- Immunology: 06
- Neuroscience: 04
- Genetics: 03
- Pulmonology: 03
- PT/OT/Rehab: 02
- Biostatistics: 01
- Dermatology: 01

Investigator specialty

As a pediatrician, Dr. Takayuki Kishi's fellowship project "Responses to treatment in the juvenile idiopathic inflammatory myopathies" revealed significant correlations between endothelial markers and clinical assessments of disease activity in juvenile myositis (JM), including muscle and cutaneous involvement. These findings provide valuable insights into the pathogenesis of JM, improving management and treatment.

2002 – 2025

Non-US Investigators

- Sweden: 07
- UK: 06
- Germany: 03
- Italy: 03
- Australia: 02
- Canada: 02
- Spain:02
- Japan: 02
- Korea: 01
- Peru: 01

Non-US investigators

In the UK, Dr. Sarah Tansley's project "Inter-center variation in myositis specific autoantibody (MSA) testing" aims to improve reliability of MSA testing. This will close an important gap in the myositis diagnostic journey, reducing or eliminating erroneous results due to poor testing procedures.

Support TMA research at myositis.org/donate

Living in the Present

By Kristin Hicks

Kristin and Troy Hicks

Kristin Hicks's husband, Troy, lives with inclusion body myositis. Thank you to Kristin for sharing this snippet of life with myositis.

What was you or your loved one's first myositis symptom?

My husband, Troy, noticed something was not right when he started having trouble getting up off of the floor and climbing stairs. There was also a physical difference in the appearance of his thighs.

How long did it take to receive an accurate diagnosis?

He was first diagnosed with polymyositis in October of 2017. This diagnosis came pretty quickly after seeking medical help for his symptoms. After several unsuccessful attempts to treat symptoms of polymyositis, we decided to try to get an appointment at the Mayo Clinic. Within minutes of seeing a doctor there, he was given the news that he probably had IBM. With confirmation through a muscle biopsy, he was diagnosed with IBM in June of 2022.

How has myositis affected your life?

Troy's IBM has affected his life in so many ways! While we are lucky that he can still walk and do things independently, it has definitely taken a toll. He is sore every day. He has always been very athletic and cannot be physically active like he used to be. We find ourselves having to take note when we go places: Are there stairs? Is there an elevator? How much walking is involved? Do we need to get tickets in the handicapped section? Basically, we can't do some things that we used to do together, and we always have to be aware of limitations when we make plans.

One thing that Troy hates most of all is that he has missed out on being able to do things with our youngest son. This disease not only affects physical health, but it also affects mental and emotional health as well.

What is one thing you wish every medical student knew about myositis, before they entered practice as a physician?

I wish that every medical student was informed about all the different types of myositis and at least had some kind of training in diagnosing them. I have heard about some cases where the patient didn't get a proper diagnosis for months or years! One of Troy's doctors stated that he remembers hearing about myositis during medical school, but the time spent on it was very brief.

I also think it is important for doctors to realize when something is beyond their field of understanding so they can send patients along to someone else who can help them when needed.

How has TMA been helpful to you and your family?

My husband and I have attended the past three TMA conferences, including this year's MyoCon in Dallas. These conferences are so helpful! We learn, get new ideas, and see that we are not alone in facing this disease.

Troy also attends TMA's Men Managing Myositis and Military Veterans with Myositis virtual affinity group meetings. Those calls provide a platform to be able to communicate and share experiences with people who have the same disease.

Describe how you have advocated for the myositis community, and for all those on a rare medical journey.

I've hosted a fundraiser for TMA for the past two summers. I am a Pampered Chef consultant, and every year the company offers double funds on fundraising parties during the summer. I decided to run a fundraising party for TMA, and 30% of all sales (along with my commission) were donated to TMA. This was such a success! I'm glad I am able to help out like this.

I think it's important to raise awareness about this disease and the people living with it. And I think it's important to support research to help find ways to treat and eventually cure it!

What is your most useful hint, hack, or tip for navigating daily life with myositis? Do you have a specific self-care practice or resource that you recommend to others?

Troy's advice is to slow down and listen to your body. It will let you know what you can and cannot do. He believes that working out on a daily basis with light to moderate weight is so important in maintaining good muscle. He recently has incorporated water aerobics and swimming, which have allowed him to exercise at a higher intensity due to minimizing impact and muscle soreness.

Troy has also recently found an ankle-foot orthosis (a brace that supports the ankle and foot for people with mobility issues) that works really well for him. It is lightweight, less "clunky," and a lot more comfortable than his previous one. I am glad that he is finally wearing one consistently.

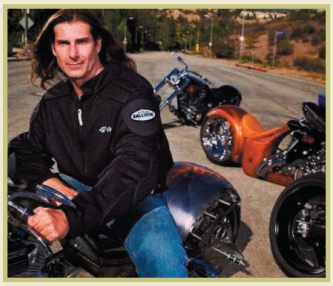
What words of encouragement do you want to share with others on a journey with myositis?

For my own mental and emotional health, I want to live in the present, tackle the problems we are faced with right now, and not worry about what the future might hold. I've always been an optimist, so maybe there will be treatment or a cure before Troy's symptoms get really bad!

You can help TMA raise funds too through our third-party campaigns. ***See samples of campaigns.*** ***Start your own campaign.***

Donate directly to TMA

Did You Know…



Model, actor, and author Fabio is a myositis advocate?

Born in 1959 in Italy and discovered as a teenager by a photographer while he was lifting weights in a Milan gym, Fabio Lanzoni became a men's fashion model for luxury fashion brands like Versace and Armani at the age of 14. When he moved to America in his 20s, a job as the cover model for a romance novel established him as the face of choice for hundreds of romantic sagas that followed. At the height of his popularity—he was so famous he went by his first name only—he also made films and was featured in ad campaigns. Fabio often poked fun at himself as a romantic icon and played a long-running part in a **series of ads for a butter substitute** where he parodied his image with irony and good humor.

Fabio sought out TMA because a family friend had inclusion body myositis. As he observed his friend's challenges, especially with swallowing and mobility, Fabio volunteered to bring public attention to the disease in interviews and public appearances. One fundraiser in Florida highlighted his love of motorcycles, and some lucky TMA members won a dinner with him in 2011. He also recorded a **short video used to promote TMA's case** to legislators and the public.

Keep in touch with TMA!

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A Healthy Gut is a Happy Gut

By Dorothy Vetrano

Your gut doesn't just affect digestion. It plays a major role in immunity, mood regulation, and even skin health! Before being diagnosed with an autoimmune disease, I never gave much thought to gut health. But everything changed when I started paying attention.

As challenging as it can be to shift habits, I discovered that taking care of your gut isn't as hard as it seems. With a little self-discipline—and invaluable guidance from my doctors and nutritionist—I've been able to eliminate two medications and gain a real sense of control over my health.

Here are some tips that have helped me keep my gut happy:

1. Stay hydrated – Drinking plenty of water helps support digestion and nutrient absorption and promotes regular bowel movements. I like to add fresh lemon or mint to my water. Not only does it make it more enjoyable to drink, but both ingredients can help soothe and support digestion.

2. Eat a range of healthier foods – A mixture of fruits, vegetables, whole grains, and lean proteins helps feed good bacteria in your gut. Some of my favorite foods are:

- Overnight Oats – They're quick, nutritious, and incredibly versatile. You can find endless variations online, but I like to keep mine simple and packed with gut-friendly ingredients. I typically include plain Greek yogurt or powdered peanut butter, ground flaxseed, and fresh blueberries or raspberries. Since I'm already adding fruit, I skip the honey or added sugar. The natural sweetness from the berries is more than enough!

- Mixed Green Salads – Salads are one of my favorite ways to pack in fiber, antioxidants, and lean protein. I love mixing it up with colorful, flavorful ingredients that fuel my body. Some of my go-to combo's are red onions, cherry tomatoes, red/yellow peppers, olives, and lean protein (salmon, lean ground turkey, or shredded white chicken). My low-fat dressing mixes olive oil and balsamic vinegar with spices like minced garlic, pepper, or turmeric.

3. Include probiotic foods – Yogurt, cottage cheese, and sourdough bread are great sources.

4. Listen to your gut's signals – Be mindful of how your body responds to different foods that may upset your stomach, cause bloating, or trigger inflammation and adjust as needed. Keeping a log or diary of foods that work and foods to avoid can help you stay on track.

5. Cut back on processed sweets – I'll be honest, this one has been the hardest for me. I love chocolate, cookies, desserts, and fresh bread. But over time, I learned that highly processed foods, refined sugar, and artificial sweeteners can disrupt the gut and lead to inflammation or digestive issues. So, little by little, I began phasing these treats out of my daily routine. The biggest change? I stopped keeping them in the house. Now, I only indulge occasionally when dining out or celebrating something special.

That said, I do keep a bar of dark chocolate (78% cocoa or higher) at home for an occasional afternoon treat. It satisfies my sweet tooth without wrecking my gut health. Plus, dark chocolate in moderation may even support a healthy gut.

6. Avoid caffeine and alcohol whenever possible.

7. Get physical activity daily – Staying active for 30 minutes a day, whether it's walking, running, cycling, yoga, swimming, or light exercise can support digestion and reduce stress.

8. Pay attention to posture – Good posture is a key player in your digestive health and something I struggle with daily. When we slouch or hunch over, we compress the organs in our abdomen which can slow down digestion, cause bloating, and even contribute to acid reflux. Over time, poor posture can interfere with the gut's ability to move food through efficiently. Sitting or standing upright helps with better gut life ensuring proper blood flow to your digestive organs.

9. Manage stress – Stress can negatively affect your gut health so it's important to practice stress-reducing techniques daily. Breathing exercises, reading scripture, journaling, yoga, and walking my dogs have been helpful to me.

10. Get enough sleep – Rest is key to gut repair and immune balance. Aim for 7-9 hours of sleep each night. Preparing for a good night's sleep is just as important. About 30 minutes before bed, turn off digital devices. Try reading a light book, gentle stretching, or calming yoga to prepare your body for rest.

True wellness doesn't come from perfection or quick fixes, but from consistency, intention, and grace with ourselves. The idea that gut health is a journey, not a destination, is such an empowering reminder because it allows space for growth, setbacks, and self-compassion. Be consistent, stay kind to yourself, and trust the process. Healing happens over time, so embrace the journey.

Note: Before making changes to your diet, starting new supplements, or even drinking certain herbal teas, it's important to consult your medical team. Even natural remedies can interact with medications or underlying conditions. Partnering with your healthcare provider ensures your gut health journey is safe, personalized, and effective.

Dorothy Vetrano considers herself to be a DM newbie and grateful that she's doing pretty well overall. She lives in Houston, TX with her loving and supportive husband and two four-legged babies. She's a teacher of students with visual impairments who has worked with the visually impaired for the past 32 years.

Check out our Nutrition, Diet, and Alternative Therapies playlist on YouTube. Additional playlists include Autoimmune Disease and Myositis, Interstitial Lung Disease, and Physical Therapy.

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