



THE MYOSITIS ASSOCIATION®

MYONews August 2024 | Volume 4, Issue 8

Meet the 2024 International Annual Patient Conference Keynote Speakers

We are thrilled to announce the keynote speakers for our 2024 International Annual Patient Conference:

Jessica Buchanan will deliver our opening keynote address on Friday, September 6. Her talk, “Impossible Odds: A Story of Strength and Survival,” will inspire the entire myositis community.

Jessica is an expert in impossible circumstances. Her unique journey of enduring kidnapping and captivity at the hands of Somali pirates in 2011, offers insights into the kind of transcendence and resilience those who live with myositis need on a daily basis. Her inspiring talk encourages everyone to access their inner resilience by identifying their own autonomy and choice in the midst of life-changing circumstances.



Dr. Victoria Shanmugam, MBBS, MRCP, FACR, CCD, Director of the NIH Office of Autoimmune Disease Research, will deliver the closing keynote address at TMA’s International Annual Patient Conference on Sunday, September 8.

Dr. Shanmugam oversees the new NIH-wide, cross-cutting autoimmune research strategy mandated by Congress. Her presentation, titled “Accelerating Autoimmune Disease Research at NIH to Advance Treatment and Therapies for Patients,” promises valuable insights into research that has an impact on myositis diseases.

Dr. Shanmugam’s presence at our conference also underscores the strong TMA/NIH partnership, and the importance of myositis awareness and advocacy.



Heroes in the Fight Awards

Join us for this year's Heroes in the Fight Awards Ceremony and Dinner on September 7th in Baltimore, Maryland. Held in conjunction with our International Annual Patient Conference, this special event honors the dedicated researchers and clinicians in myositis care and celebrates the resilience of our patient community.

These are this year's heroes:

- ▣ Karen Alexander, Patient Ambassador Award
Fashion supermodel, mother, hospice volunteer, and dermatomyositis warrior
- ▣ Karolinska University Hospital Myositis Clinic, Heroes in Healthcare Award
Stockholm, Sweden. Accepted by Clinic Founder Dr. Ingrid Lundberg, Professor, Department of Medicine, Karolinska Institutet.
- ▣ Thomas E. Lloyd, MD, PhD, Heroes in Research Award
Chair of Neurology at Baylor College of Medicine, Houston, Texas

And stay tuned for another special announcement about Heroes In The Fight coming soon!

[LEARN MORE](#)

Tickets are \$75 per person and can be added to your conference registration or purchased separately.

[REGISTER NOW](#)



THE INTERNATIONAL ANNUAL PATIENT CONFERENCE

CONFERENCE RECORDINGS INCLUDED IN REGISTRATION



Conference Recordings

Once again this year, TMA is offering recordings of most sessions at our International Annual Patient Conference.

The complete package includes:

- Video recordings of pre- and post-conference virtual sessions
- Video recordings of the opening and closing keynote addresses
- Thirty+ audio-recorded sessions synced with slides from the presentation
- Video of the Heroes in the Fight Awards Ceremony featuring supermodel and DM patient Karen Alexander and our other myositis heroes

Cost for the complete package is \$149 for non-attendees.

Conference attendees will receive the recordings automatically free of charge.

ORDER NOW



It's not too late to register for TMA's International Annual Patient Conference

TMA's International Annual Patient Conference is the most celebrated event of the year for the myositis community! We'd love to see you in Baltimore, Maryland on September 6-8 at the Hilton Baltimore Inner Harbor Hotel!

Gain insights on myositis science and living your life well in breakouts like "Treatment of Myositis Interstitial Lung Disease: Immunosuppression and Beyond" and "Financial Self-Care: Easy Estate Planning for All Budgets."

[REGISTER TODAY](#)

You Can Help Someone Attend TMA's Conference!

You can still make it possible for those with limited means to be part of this life-changing experience. And if you act now, your donation will be doubled thanks to Augie and Rich DeAugustinis who will match every gift to the scholarship fund, dollar for dollar, up to \$10,000.

Your generosity will help people who may feel very alone connect with others and learn more about how they can live their best lives by attending this amazing conference.

[DONATE TODAY](#)

New Board Officers Elected

Rich DeAugustinis was elected Vice Chair of TMA's Board of Directors, effective July 1, 2024 through December 31, 2025. Rich owns a consulting company and is retired from the Coca-Cola Company. He is also a board member for the Inspire Aviation Foundation and is a past chair, vice chair, and member of the board for Atlanta Ronald McDonald House Charities.

Also at the Board's June meeting, Howard Gerrin was elected Treasurer. He brings expertise in finance and investments to his role overseeing TMA's finances as he holds the designation of Chartered Financial Consultant. An IBM patient, Howard is well known for inventing the "I've Been Motivated" T-shirts. Learn more about TMA's Board [on our website](#).



RARE ACROSS AMERICA

EVERY VOICE, IN EVERY DISTRICT, MATTERS

TMA supports Rare Across America

EveryLife Foundation hosts Rare Across America each August. This is your chance to let your legislators know what it's like living with a rare disease like myositis and to advocate for legislative change right from where you live!

Meetings with senators will be held virtually and meetings with house reps will be in their state offices or virtual.

If you've registered to participate on August 5-16, check your email for a message from EveryLife with your schedule and guidelines for how to participate.

Also, email rachel@myositis.org and let us know what state you are working from.

[LEARN MORE](#)



JANINE LAMB, PHD

TUESDAY, AUGUST 13, 2024

12 PM ET | 9AM PT



Ask the Doc: Geneticist Edition

August 13, 2024, 12 PM ET | 9 AM PT

Janine Lamb, PhD is a reader (professor) in complex human genetics/genomics at the University of Manchester, UK. Her research aims to improve understanding of the causes and pathogenesis of myositis, so that we can better classify individuals and improve the basis for individualized treatment that will improve health outcomes. Dr. Lamb is a member of TMA's Medical Advisory Board.

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The graphic features a green background with a white logo in the top left corner. The text "EMPOWERMENT CLINIC" is in the top right. Below it, "PATIENT INVOLVEMENT IN RESEARCH" is centered. A circular photo of Ingrid De Groot is on the left. To its right, her name and title are listed. At the bottom, the date and time are given, and a video icon is in the bottom left corner.

EMPOWERMENT CLINIC

PATIENT INVOLVEMENT IN RESEARCH

INGRID DE GROOT, LCSW
MYOSITIS RESEARCHER
AND PATIENT

THURSDAY, AUGUST 15, 2024
12 PM ET | 9 AM PT

Empowerment Clinic: Patient Involvement in Research with Ingrid De Groot

August 15, 2024, 12 PM ET | 9 AM PT

Ingrid de Groot, LCSW holds degrees in child life therapy (the study of psychological well-being in chronically/terminally ill or hospitalized children), social work, and counseling. Her research and educational interest in myositis sprung from her own diagnosis of DM in 2006. Her research targets outcomes/outcome measures, quality of life, targeted rehabilitation and exercise in myositis, patient empowerment, and driving a global program on the development and implementation of physical and psychological resilience strategies in neuromuscular diseases, including myositis.

[REGISTER TODAY](#)



TMA Care Partner Affinity Group Leader Needed

Are you a care partner for someone living with myositis and motivated to engage on a deeper level with our community? *We need you!* TMA is currently recruiting a leader for this very important group. The time commitment is a total of four hours a month, and that includes the monthly 90-minute meeting on the third Saturday of each month at 10:30 AM ET. If you want to volunteer, but need a different time, we can accommodate that as well!

TMA provides training and support, and there is no need to be an expert on myositis. If you are a good listener who feels comfortable steering a conversation, then this would be a rewarding volunteer experience for you! If interested, please email Rachel@myositis.org.

“Leading a TMA group always means I get back from the group more than I put in. It is an additional means of support for me in my own myositis journey, as it feels so good to bond with such a great group of people!” - Kent Yunker, TMA Wisconsin Co-leader and Breakout Room Facilitator for TMA Nationwide and TMA Men Managing Myositis

To see what this group is all about, learn more and register for the August 17 meeting!

REGISTER TODAY

WomenWithIBM

Tuesday, August 20, 2024
12:00 - 1:30 PM (EDT)



Dr. Charles-Schoeman
Professor of Medicine
Chief of the Division of Rheumatology
UCLA

MYOSITIS AND HEART DISEASE

Attend this session for a presentation of
features of cardiac disease and the
relationship to Inclusion Body Myositis.

COPY AND PASTE THIS REGISTRATION LINK
<https://us02web.zoom.us/join/register/tZwuduyvqz4pEtlqlmIBaRa8ourzlqJaFOA2>

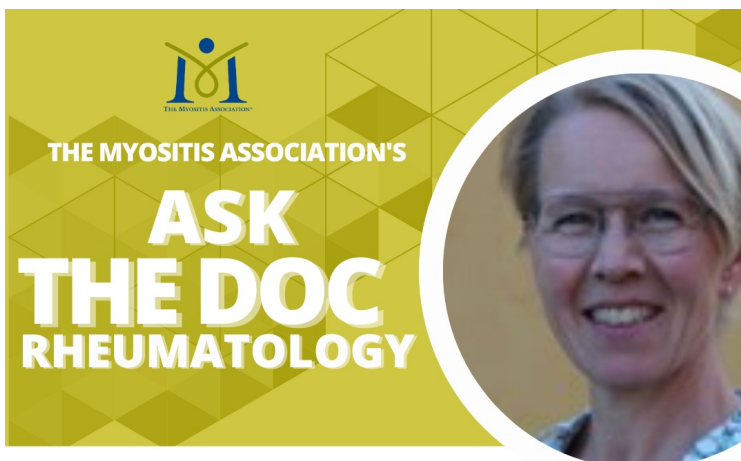


Women with IBM Speaker Presentation: Myositis and Heart Disease with Dr. Christina Charles-Schoeman

August 20, 2024, 12 PM ET | 9 AM PT

Join TMA Women with IBM Affinity Group for a special presentation that covers features of cardiac disease and the relationship to inclusion body myositis.

REGISTER TODAY



LOUISE DIEDERICHSEN, MD, PHD

TUESDAY, SEPTEMBER 24, 2024
12 PM ET | 9 AM PT



Ask the Doc Rheumatology with Dr. Lousie Diederichsen

September 24, 2024, 12 PM ET | 9 AM PT

Louise Pyndt Diederichsen, PhD, MD is associate professor at Copenhagen University

in Denmark. She focuses on imaging modalities as research techniques in myositis. Her research also focuses on the under-recognized area of cardiac involvement, as well as immunologic and genotyping research for IBM and other forms of myositis.

[REGISTER TODAY](#)



New Member Orientation

October 4, 2024, 12 PM ET | 9 AM PT

Living with myositis can be challenging, but you are not alone. Please join us virtually to learn more about TMA's educational programs and resources that can help you on your myositis journey and make new friends who know, understand, and share your new normal. Connect with people like you, connect with resources you need, connect with global myositis experts - connect with TMA!

[REGISTER TODAY](#)



TMA Colorado Myositis Support Group is reactivating!

Meet Jim Milani, a TMA member who was moved by the efforts of the late Marianne Moyer and the TMA Southwest Florida's success in organizing a Myositis Symposium for Physical and Occupational Therapists during our recent Myositis Awareness Month. He called Rachel Bromley, TMA's Senior Manager of Patient Education, Support and Advocacy to offer to organize one in his home state of Colorado. Rachel was ecstatic, as Marianne's vision had always been for this event to branch out to other TMA groups!

One catch though: TMA's Colorado Support Group had been dormant for quite some time. So she swung for the fences and said "How about reactivating the Colorado group at the same time? You can connect more PTs and OTs that way, find a few volunteers to possibly help your efforts, and provide and receive support for myositis along the way!"

Jim replied with one word "Sure!" And so this journey began.

For the past 20 years, Jim has been a Physical Therapist and is Board Certified as a Geriatric Specialist. After several years of misdiagnoses, he was correctly diagnosed with IBM in late 2023. Despite this, Jim continues to pursue his love for activity and sports. He is passionate about sharing his personal and professional "fitness forward" philosophy, helping people understand how to modify and adapt exercises to their functional level. Jim lives in Colorado with his wife, Laura, and is a proud father of six adult children and two grandchildren. Jim says his family and faith help him get through each day. While there is much about IBM that he cannot control, he focuses on what he can: his attitude and effort. #justkeepschwimming

Anyone can join his next meeting, Colorado resident or not. The first meeting is October 12 at noon MT.

[REGISTER TODAY](#)

Mind Your Mental Health

Getting regular exercise can make a world of difference for your mental health. Just 30 minutes of walking every day can boost your mood and improve your health. Small

amounts of exercise add up, so don't be discouraged if you can't do 30 minutes at one time. Do what you can when you can.

As a bonus, do your walking out of doors. Just being outside surrounded by trees, sunshine, and nature can make you feel better.



THE MYOSITIS ASSOCIATION

Conference Volunteer Roles

[Volunteer Sign-Up](#)

Want to Volunteer at the Conference?



THE MYOSITIS ASSOCIATION



Show Your Spirit

Friday
Sept. 6th



Wear your favorite baseball jersey or team shirt

Show Your Team Spirit on September 6th!

Whether you are able to attend this year's conference or not, we'd love the whole

community to come together in solidarity and show our collective team spirit on Friday, September 6! Please wear your favorite sports jersey or shirt and post a selfie on social media!

Here are the IAPC Hashtags: #TMA2024IAPC #TheMyositisAgenda #Myositis #MyositisHeroes #MyositisWarrior #MyoMovement #MyositisLife #MyTMA #TheMyositisAssociation

TMA supports ILD Day, September 18

Hosted annually during Pulmonary Fibrosis Awareness Month in September, ILD Day raises awareness about this devastating condition that affects many in the myositis community.

The Pulmonary Fibrosis Foundation will host an ILD Day webinar at 12 noon CT on September 18 titled The Journey to Diagnosis: Process, Evaluation and Your Care Team.



[LEARN MORE](#)

Are you ready for World Myositis Day?



TMA proudly partners with worldwide patient advocacy organizations to drive myositis awareness on World Myositis Day. This year World Myositis Day will be recognized on Saturday, September 21, 2024.

Stay tuned for updates on special programming for World Myositis Day!

[LEARN MORE](#)



TOMMY'S ANGELVERSARY

Spotlight on Giving

Laurie Boyer's older brother, Tommy Worthington, passed away from dermatomyositis with ILD on July 23, 2012. Since then, Laurie has been a fierce supporter of TMA, currently serving as chair of our Board of Directors.

This year for Tommy's angelversary, she is honoring his memory by raising funds for the important work being done each and every day by The Myositis Association.

[DONATE TO LAURIE'S CAUSE](#)

You Can Start Your Own Fundraising Campaign in 3 Easy Steps!

Step 1. Visit TMA's Start a Campaign page and complete the easy form.

Step 2. Review your personalized web page. TMA team will email you a proof within 2 business days!

Step 3. Send the link to everyone you know and post it on social media, then watch as the contributions add up!

[START YOUR FUNDRAISER](#)

FIND THE CARE YOU NEED

MediFind



THE MYOSITIS ASSOCIATION

Finding a healthcare practitioner who knows how to care for someone with myositis is often a challenge.

While we can't guarantee you'll find an elite physician, [TMA's Find a Doctor](#) tool can at least provide options.

We've worked with our partners at MediFind to update providers and make finding the best care more accessible. Check out our [suggestions for using the tool here.](#)



Community Tips: Exercise, exercise, exercise

For those who live with myositis, exercise is medicine. Our community is determined to remain active, whatever it takes. Here are some of the ways people do this:

- [Fartlek](#) style of training, going with what my body is feeling; some days I go easy, other days I go hard.
- Swimming and stretching everyday
- Bed exercises after awakening, walking with whatever aid is needed, hand PT items that you buy for home use, putty activities for hand
- Recumbent stationary exercise bike
- [Silver Sneaker](#) and yoga exercise classes
- Rowing, treadmill, recumbent bike

And a final word or advice: Find something active that you love doing, whether that's gardening, writing, art, yoga, walking, hiking, or something else and do a small amount of it when you can. Don't abandon what gives you joy, find new ways to adapt to keep the things that bring you delight.

[TMA's YouTube channel](#) has been updated with links to all the most recent myositis webinars. Check out one of our playlists to learn more about myositis and available resources. Each month's

octapharma

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Octapharma is excited to partner with The Myositis Association on their mission to educate and serve dermatomyositis patients at the 2024 International Annual Patient Conference.

**More Than 40 Years
of Experience**
octapharmausa.com

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webinars are published on the first of the following month.



From the Blog

Many people have had questions about a revolutionary new form of treatment for cancer that is now being tested in people with autoimmune diseases. While CAR T-cell therapy is not close to being approved for myositis, this introduction will give you some idea about what may be on the horizon.

[LEARN MORE](#)

TMA is able to support people with myositis and their families because of the generosity of individuals who support our work financially. Please [make a gift](#) to TMA to support our impact today!

[DONATE TODAY](#)



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