We Care for Rare Summit

Celebrating Myositis Science and Rare Patient Stories

Friday, February 28, 2025 1 PM - 4 PM ET | 10 AM - 1 PM PT

Community Tips & Trusted Resources

Myositis Resources for Rare Disease Day

Myositis 101 - Videos

The Myositis 101 for patients videos by Dr. Rohit Aggarwal, Co-Director of the Myositis Center of University of Pittsburgh, Chair of Medical Advisory Board of The Myositis Association (TMA) and author of the book “Managing Myositis: A Practical Guide,” explains myositis management and treatment in terms that are accessible to everyone.

https://www.myositis.org/myositis-101-for-patients/

Myositis 101 - Free E-Book

This basic guide to understanding and coping with myositis aims to answer the questions of those who have been recently diagnosed with myositis. With a glossary of medical terms, easy-to-understand descriptions of the disease process, treatment and prognosis, this booklet will inform you from diagnosis through treatment, while supplying resources for support and information.

https://www.myositis.org/myositis-library/tma-publications/

60 Seconds to Impact: Sharing your Myositis Story with Purpose

Do you struggle with explaining your invisible illness to others? Do you wish there was a quick way to get the point across to family, friends, and acquaintances? Or are you ready to become an advocate for myositis and want to enhance your elevator speech?

Award-winning journalist, writer, and advocate Lindsay Guentzel offers a powerful empowerment clinic that will help you harness the transformative power of storytelling.

https://youtu.be/kzJup2VDYeI?feature=shared

Rare Disease Day YouTube Playlist

In honor of Rare Disease Day 2025, The Myositis Association (TMA) presents this playlist featuring expert insights, patient stories, and educational content on living with myositis. Learn about myositis symptoms, treatments, and support resources to help patients and caregivers navigate this journey.

https://youtube.com/playlist?list=PLC7vBNLVigcAe4JA2tuDgBM9eQT28o7zM&feature=shared

Navigating Myositis: Community Tips for Rare Disease Day

During Rare Disease Week, the myositis community shared their best strategies for overcoming isolation, staying connected, and making daily life a little easier. Inside this guide, you'll find practical coping strategies, creative ways to make infusion days more manageable, stress relief tips, and words of encouragement from those who truly understand.

Please share the tip that has helped you the most in navigating your rare medical journey in myositis.

The Myositis 101 [E-Book from TMA] which I have used and shared with any of my new doctors unfamiliar with myositis. When I have been to physical therapy the book goes with me to share with the therapist.

It is most important to find a neurologically based physical therapist and occupational therapist. Joining support groups has also been a big help, talking with others who have the same diagnosis.

Keep a medical binder to include doctor information, all tests, surgeries, current labs, medications, and a summary of visits so you have a record to take with you to each and every doctor appointment.

I advocate for myself. I have great doctors, but the thing about rare disease is that it isn't well documented or understood, so you have to advocate for yourself and be a proactive and thought provoking member of your care team.

Early on, a specialist told me to "use it or use it." This mantra has encouraged me to keep doing things no matter the difficulties I am having. It also encourages me to keep exercising.

Join The Myositis Association is my best tip! Being part of a family that understands how I feel makes me not feel alone in this fight! We share the journey, including our life hacks and treatments.

Seeking help and support from family and friends is my best tip. Find ways to keep your mind busy, keep your body moving, and find others who can help each other out.

What advice or other tips would you like to share about living well with your form of myositis?

I designed my home with spacious, open work areas to facilitate navigation. The kitchen features high-swivel chairs with arms, creating a welcoming space for family and friends. Large drawers replace traditional cabinets, allowing easy access to pots, pans, and bowls, promoting connection and reducing isolation.

Surround yourself with others who have IBM. We have a unique understanding of what it's like to live with IBM.

Keep moving! Exercise when you can, eat well if possible, and get sleep; something I continue to strive for. Read a good book and find things you enjoy. At the end of the day, it can't always be about doctor appointments and medications.

Education and more education on disease treatments and real-life experiences. Try to eat healthy, stay active as much as you can, and exercise.

Get yourself a support network. Physiotherapists, speech pathologists, hand therapists and occupational therapists can help mitigate the day-to-day impacts of the disease. It’s not a cure but helps day to day.

Be kind and patient with yourself. Music – listen to music at least once a day. Keep busy – find anything to keep your mind active. Read books, find a craft or hobby, watch a movie or TV series.

Keep moving and exercising as much as possible. Do what brings you joy every day and love those who are with you.

What advice do you have for myositis care partners?

I tell my care person "Today is a Myositis 8" (on a scale of 1-10), which kind of gives an idea of how I feel.

Search for the right doctor. A doctor who listens. It can save your life.

Our work is to keep our strength as long as we can. Light exercise and daily living take care of this. Don’t overwork your body. Listen carefully to what it needs.

Please be patient, loving, and kind. Don’t always ask questions like why do you feel like that? Why can’t you go today. Why are you so weak? Why, why, why. Try to be empathetic and walk in our shoes. We have good days and not so good days. Allow us our space and to not have to explain ourselves.

Be patient and remember that even if we act fine and push through, we are still dealing with a lot and need to feel that it's ok to do less.

Find a support group for carers. Talk to your partner. Do something for yourself as often as you can, such as getting your hair done, going to lunch with a friend, or eating your favourite chocolate.

Share the TMA website (https://www.myositis.org/), which has great info. Be patient with your partner. Get educated so you understand the condition and know about your loved one’s physical and emotional well-being too.

What advice do you have for myositis clinicians or researchers?

Listen! We are not lying. We are confused too.

You are the best. Use your knowledge and expertise to find everything possible to conquer this disease. We cannot give you enough thanks for what you do!

Please listen to your patients. Keep an open mind and educate yourself in this rare disease. It’s different for everyone. It affects us mind, body, and spirit.

Listen, listen, listen. You might be surprised by how well your patient knows their own body. Don't discourage them from trying complementary alternative medicine, and don’t discount how effective some of these things can be and how badly your patients want to feel they have some control in their treatment.

Don't always adjust our medication too quickly.

Clinicians, please listen and hear your patients. Don't lump us all into one category. We are individually different. Don’t just go by labs but symptoms as well.

Listen to your patients. Respect the decisions of patients. Give them information and honesty and be prepared to answer their questions and concerns. Be empathetic, kind, and caring.

I have three specialists who work together and include my primary doctor. This makes everything so much easier for me when scheduling appointments.

Please don’t disregard how we feel physically and mentally. Keep searching and doing more tests and don’t blow us off.

What is the make and model of any equipment that has really worked well for you?

Cubii leg exerciser. I also use an electronic muscle stimulator (EMS) and am trying Red Light Therapy. Not sure if they work. Too soon to tell.

Eosprim Rolling Shower Chair with Handles Arms-Used for moving stuff like laundry basket, etc.

Baby Pull up Rings to open washing machine lid.

Drive Medical 4-Wheel Rollator Walker with Seat, or Medline Steel Rolling Walker. Use with Sleepavo Office Chair Cushion, the one with the handle.

Hamilton Beach Electric Jar Opener for Arthritis Hands, Automatic Glass Jar Opener for Seniors, battery powered jar opener for weak hands

Crossbody Wallet Case for iPhone 12/12 Pro, RFID Blocking PU Leather Zipper Handbag Purse Flip Cover, Kickstand Folio Case with Card Slots Holder Wrist Strap Lanyard 5G 6.1 Inch LuBanSir Cinch Straps - 2" x 18" (6 Pack)

Elastic Hook and Loop Storage Straps with Buckle – hand support for PT.

byACRE Carbon Ultralight Rollator. It was expensive but we’re worth it!

Recumbent bike. Lift-to-stand chair. Grabber to pick things up. Fitness Apps to do training at home. A bed rail helped getting up and turning in bed – get the one with a pouch for keeping things in.

Love my Stihl power pruners. Helps me keep the garden tidy along with my plastic bed making wedges. Fortunately, I don’t need heavier equipment yet.

I use ankle-foot orthotics (AFOs) for my weak ankles, game changer! At home, I have a lift chair and handrails for the toilet. At work, I have a tall office chair and a toilet seat riser. I also use a walker.

Would you like to share words of encouragement and inspiration?

You are seen. The way you think and feel about yourself makes a difference. Allow the spirit of love to fill your being.

Speaking to others / Keeping in Touch is important. Yes, it is a rare disease, but others have it and they may help you. Your experiences will help them, too.

While we can't control what happens to us physically, we can control how we respond or react to it. Find joy in the smallest daily moments: a sunset, the smell of freshly mowed grass, a baby’s smile or laugh, your dog who runs to greet you at the end of the day, a warm and loving hug. All these things remind us that life can and is good if we allow ourselves to see what's in front of us at that moment. Live in the moment. "Do not look forward in fear to the changes in life. Be at peace and put aside all anxious thoughts and imaginations."

Love and accept yourself. Waking up in a different body and losing the life that you had is extremely difficult. Allow yourself to mourn. Stay in the present moment, the past is gone. Tomorrow is not here. And know that you are beautiful, wonderful, very special and one of a kind. Love yourself even when you don’t like yourself. ROAR!!!

Find one thing each day that makes you smile. Don't give up, keep going!

From the time I was diagnosed, I have learned that it is OK to cry and be sad, but I also have learned that it's OK to ask for help without being ashamed.

Thank you to everyone who submitted responses during Rare Disease Week!