

Myositis India



August 2025

Patient–General Body Meet: “Myositis: Conversations that Matter” (10 August 2025)

This meet brought together patients and caregivers from across India and we warmly welcomed several new participants. We began with a brief overview of Myositis India’s work—webinars, “Ask the Doctor,” and regional outreach—setting the context for a conversation shaped by patient voices.

In the “Myositis Puzzle” segment, participants spoke candidly about their journeys, everyday challenges, and what helps overcome these challenges. Members of the Medical Advisory Board listened closely and offered clear, practical answers, effectively addressing doubts as they arose. To ensure comfort and inclusion, questions could be submitted anonymously in advance and during the session, and were taken up in real time.

An open forum then gathered constructive feedback, identified priority support needs, and surfaced ideas for future programmes. The meet strengthened community bonds, engaged new patients, and reaffirmed our commitment to patient-centred advocacy—grounded in clear information, timely guidance, and pathways to care. Insights from this session will directly inform upcoming webinars, regional outreach, and the “Ask the Doctor” series.

Our Social Media Reach

2,475 FOLLOWERS
ON INSTAGRAM

4 MILLION PLUS
VIEWS ON A
SINGLE POST IN
THREE MONTHS

WE
COLLABORATE
WITH MYOSITIS
SUPPORT GROUPS
ALL OVER THE
WORLD

ACTIVE AND
ENGAGING
WHATSAPP
GROUP OF
DOCTORS AND
PATIENTS.



We would like to thank Mr. Kaushik Dasgupta and Brinton Pharmaceuticals Ltd. for their support.

Myositis India x

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Hear from our Patient - Dr. Harshagopal Deshpande

Living with Myositis: A Journey of Strength and Awareness

My journey with myositis began with excessive fatigueness a symptom which I ignored as I am Cardiothoracic Surgeon who general stands in the operation room for prolonged time.. A visit to neurologist ended up visiting a rheumatologist, and after multiple tests, I was diagnosed with Ro 52KD positive myositis and lumbar disc bulge.. Emotional struggles made the journey harder, but with the support of my loved ones, I pushed through. Early diagnosis is crucial, and raising awareness can change lives. I now contribute to Myositis India, sharing my story to help others seek timely medical advice. My message is simple: Adapt, persevere, and never give up. You are not alone in this fight.

Let's continue to stand strong and support one another.



Frequently Asked Questions

CAN INFECTIONS MAKE MYOSITIS WORSE?

Yes, infections like the flu or a cold can trigger myositis flare-ups and worsen symptoms. Because the immune system is already overactive — or suppressed by medication — patients are often more vulnerable to infections. Practicing good hygiene, staying up to date on vaccines (if approved by your doctor), and avoiding sick contacts when possible can help.

ARE THERE LIFESTYLE CHANGES THAT CAN HELP MANAGE MYOSITIS BETTER?

Yes, small changes like pacing activities, doing gentle stretches or low-impact exercises, and eating nutritious foods can make a big difference. Stress management techniques such as yoga, meditation, or deep breathing may also help reduce flare-ups. Staying connected with a support network helps patients cope emotionally. For more information on diet, refer to - <https://youtu.be/Wr2HBhMALZI?si=FSBvg8ZGxdvmcvBe>

Frequently Asked Questions

CAN WOMEN WITH MYOSITIS HAVE A HEALTHY PREGNANCY?

Many women with myositis do have successful pregnancies, but it's important to plan ahead. Pregnancy can sometimes cause symptoms to worsen, so working closely with your rheumatologist and obstetrician helps manage medications and monitor disease activity. Good pre-pregnancy planning and regular check-ups are key.

HOW OFTEN SHOULD I SEE MY DOCTOR FOR MYOSITIS?

This depends on how active your disease is. In the early stages or during a flare, visits may be more frequent — every few weeks or months. Once stable, check-ups every 3–6 months are common to monitor blood tests, medication side effects, and any new symptoms.

Our Volunteers

Shreya Sridhar

Hello everyone! I'm Dr. Shreya Sridhar, a recent medical graduate from SIMSRC, Bangalore. I currently serve as the Senior Manager at Myositis India, after previously leading the Patient Services team. Working closely with patients and caregivers has taught me the importance of building a compassionate community through education, outreach, and support. Overseeing various initiatives has been both a responsibility and a rewarding journey. Outside of medicine, I've trained in Bharatanatyam for several years, which has helped me stay grounded and focused. My work with Myositis India continues to be one of the most meaningful parts of my journey and gives me a sense of purpose.



Rishi Nalkande

Hello everyone, I'm Dr. Rishi Nalkande, an MBBS graduate from BJ Govt Medical College and Sassoon General Hospital, Pune. I have been a volunteer at Myositis India for 2 years now. Initially I was a part of the social media and content creation team and now I am the Head of the Patient Services team. Leading this team has given me a unique perspective into the lives of patients living with Myositis and reaffirmed my belief that what we do here makes a big difference in their lives. I believe the doctor-patient sessions help the patients in making their appointments with their treating rheumatologists more productive by enabling them to ask the right questions and gain another valuable perspective into their condition. I feel incredibly grateful to be contributing to their healing journey in a meaningful way and look forward to keep doing the same for as long as I can.

Suhani Jain

Hello everyone,
I'm Dr. Suhani Jain, an MBBS graduate from Grant Medical College and Sir JJ Group of Hospitals, Mumbai.
I joined Myositis India just a few months ago with the hope of giving back to the community through volunteering. Honestly, it was my friends who encouraged me to be a part of this wonderful initiative—and I'm so glad they did! It's been a truly rewarding and fun experience so far.
Recently, I've had the pleasure of organizing yoga webinars and coordinating sessions with both national and international speakers, bringing valuable content to the myositis community.
I've always been deeply interested in research, and the opportunity to support clinical trials or help people feel more comfortable participating in them is something that genuinely excites me.
Above all, I believe in the power of doctor-patient interaction and strive to promote it wherever I can. I'm happy to contribute in any way possible. Looking forward to learning and growing together!





Our Medical Advisory Board Member - Dr. Parthajit Das

Dr Parthajit Das is presently working as a consultant rheumatologist at the Manipal hospitals, Kolkata and Asst Professor at the Ramakrishna Mission Sevapratisthan. He is also working as the Director of the Asian Institute of Immunology and rheumatology in Kolkata with an extensive experience in the management of all aspects of rheumatic & musculoskeletal conditions. In United Kingdom, he worked as a consultant rheumatologist in Kings College Hospital London and Kettering General Hospital. During that time, he was nominated as the Clinical lead for the management of the osteoporosis and metabolic bone service in Northamptonshire.

He has published my work widely in several peer-reviewed and international journals and is a peer reviewer for well-recognized international journals. He was also nominated as the “Teaching lead” for the medical students in Kettering general Hospital and was awarded an “Honorary lecturer” in the University Hospitals of Leicester. He was also awarded Fellowship from the Royal College of Physicians (Edinburgh in 2017) and (London in 2019) and enjoyed his role as a MRCP examiner since 2018.

Recently he has taken up the role of WHO Peer Review Group for Musculoskeletal Conditions working on the development of the WHO's Package of Interventions for Rehabilitation and Convenor for the Osteoporosis Special Interest Group in Indian Rheumatology Association.

Thank you for reading!

OUR TEAM

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