

Myositis India



November 2024

Here's what has happened in the last three months and what's to come!

PAST WEBINARS

For Patients

Yoga webinar
Sleep Webinar

For Doctors

Mixed Connective Tissue
Disorder Webinar

UPCOMING WEBINARS

For Patients

Diet Webinar on 24th
November 2024

Yoga Webinar on 7th
December 2024

For Doctors

Calcinosis in Juvenile
Dermatomyositis webinar on
11th December 2024

WORLD MYOSITIS DAY

We are also excited to announce that on the occasion of World Myositis Day (September 21st), we conducted an interview with one of our enthusiastic patient volunteers, detailing his journey from being diagnosed with myositis, to receiving multiple treatments, to finally accepting the reality and willingness to fight the disease.

We shared a post on Instagram in collaboration with Samantha Ruth Prabhu, our brand ambassador and a patient of myositis, to raise awareness about this disease.



Our Social Media Reach

2,249 followers
on Instagram

4,276,396
accounts
reached in one
post

Clinicoinfographic pearls posted
regularly on X.

Active and
engaging
Whatsapp
group of doctors
and patients.

Myositis India x

myositisindia.org

india.myositis@gmail.com

PUBLICATION ALERT!



We're excited to share our recent publication in the **International Journal of Rheumatic Diseases**. This highlights our organization's work over the past year, emphasizing the role of social media in raising awareness, educating on proper treatment, and debunking common myths. We hope you enjoy the read!

Aggarwal A, Bagri NK, Kavadiachanda C, Upadhyaya S, Haldule S, Ladha P, Jain N, Pathak H, Das P, Mittal S, Tope RA, Nikale AA, Nimal S, Mehta P, Chandwar K, Dudam R, Malviya S, Rao VKR, Singh S, Sharma V, Edpuganti N, Nalkande R, Salunke S, Madan U, Batra V, Aggarwal R. Myositis India: Early lessons from a patient support group in a resource-limited setting. *Int J Rheum Dis*. 2024 Sep;27(9):e15351. doi: [10.1111/1756-185X.15351](https://doi.org/10.1111/1756-185X.15351). PMID: 39304342.

Aggarwal A, Chandra T, Ladha P, Mittal S, Haldule S, Nirmal S, Edpuganti N, Jain N, Cavagna L, Zanframundo G, Faghihi-Kashani S, Aggarwal R. Heterogeneity in nomenclature and abbreviation usage for anti-synthetase syndrome: a scoping review. *Rheumatol Int*. 2024 Nov;44(11):2293-2299. doi: [10.1007/s00296-024-05670-w](https://doi.org/10.1007/s00296-024-05670-w). Epub 2024 Aug 30. PMID: 39212691

Frequently Asked Questions

1. WHAT IS INTERSTITIAL LUNG DISEASE IN MYOSITIS AND HOW IS IT TREATED?

INTERSTITIAL LUNG DISEASE (ILD) IS A CONDITION WHERE INFLAMMATION CAUSES SCARRING IN THE LUNGS, LEADING TO BREATHING DIFFICULTIES AND REDUCED OXYGEN LEVELS. TREATMENT TYPICALLY INVOLVES IMMUNOSUPPRESSIVE MEDICATIONS SUCH AS CORTICOSTEROIDS, METHOTREXATE, OR CYCLOPHOSPHAMIDE TO REDUCE LUNG INFLAMMATION. IN SOME CASES, ADDITIONAL THERAPIES LIKE OXYGEN SUPPLEMENTATION OR PULMONARY REHABILITATION MAY BE NEEDED TO IMPROVE LUNG FUNCTION AND QUALITY OF LIFE. FOR FURTHER INFORMATION, PLEASE REFER TO OUR INSTAGRAM REEL [HTTPS://WWW.INSTAGRAM.COM/REEL/C_0BN1DNPIH/?igsh=DTd4ZM0ZAWXLDH4](https://www.instagram.com/reel/C_0BN1DNPIH/?igsh=DTd4ZM0ZAWXLDH4)

2. WILL I EVER BE ABLE TO STOP MEDICATIONS FOR MYOSITIS?

COMPLETELY STOPPING MEDICATIONS FOR MYOSITIS IS RARE, AS IT IS USUALLY A CHRONIC CONDITION REQUIRING ONGOING MANAGEMENT.

Frequently Asked Questions

HOWEVER, SOME PATIENTS MAY ACHIEVE REMISSION OR SIGNIFICANT IMPROVEMENT. ALLOWING FOR REDUCED MEDICATION OR LOWER DOSES. IT'S IMPORTANT TO WORK CLOSELY WITH YOUR HEALTHCARE PROVIDER TO DETERMINE THE BEST LONG-TERM TREATMENT PLAN AND AVOID STOPPING MEDICATIONS WITHOUT MEDICAL GUIDANCE.

3. ARE THERE ANY DIETARY RECOMMENDATIONS FOR MYOSITIS PATIENTS?

AN ANTI-INFLAMMATORY DIET RICH IN FRUITS, VEGETABLES, WHOLE GRAINS, AND OMEGA-3 FATTY ACIDS FOR MYOSITIS PATIENTS CAN HELP REDUCE INFLAMMATION. IT'S ALSO IMPORTANT TO LIMIT PROCESSED FOODS, REFINED SUGARS, AND UNHEALTHY FATS WHILE ENSURING ENOUGH PROTEIN FOR MUSCLE SUPPORT. CONSULTING WITH A NUTRITIONIST IS RECOMMENDED FOR PERSONALISED GUIDANCE. FOR FURTHER INFORMATION, REFER TO THE WRITE-UP ON OUR WEBSITE.

Our Volunteers



Simran Nimal

Hello everyone, I am Dr. Simran Nimal a medical graduate from B.J.G.M.C Pune, who is currently working as a researcher at Mayo Clinic. I started working for Myositis India almost a year back and it has been an incredibly rewarding experience to be a part of an organisation that recognises patient needs and helps them attain the standard of care medicine timely. I have worked on multiple segments of the organisation including research, spreading awareness about Myositis through our social media as well as helped promote academic development in the field of Myositis. The organisation has helped and promoted my ambitions in providing patient centric care as well as work towards expanding my knowledge on this rare disease. I urge other students to join our cause and help build an intricate network that works towards the betterment of quality of life of patients suffering from this diagnosis.

Swaraj Salunke

As a medical intern deeply passionate about volunteering and research, I'm committed to advancing healthcare with a keen interest in global health and medical technology. Myositis India has provided me with the platform to contribute. I balance my professional pursuits with a love for hiking.



Aniket Nikale

I'm Aniket Nikale, an intern at BVDU Sangli. My journey in healthcare is fueled by compassion for my patients. I strive to positively impact their lives daily. In addition to my work at BVDU, I joined Myositis India to support patients facing this challenging condition. This role has been an invaluable learning experience, allowing me to interact directly with patients and address their concerns. Helping them is not just my duty but my passion. I believe each interaction is an opportunity to learn and understand their needs. I'm excited to continue this journey, making a meaningful difference in the lives of those I serve.

Hear from our patient - Mr. Saurabh Sarin

Mr. Saurabh's journey is one of resilience. In October 2022, he began experiencing severe muscle pain and fatigue. After being misdiagnosed with a viral infection by a general physician, his condition worsened, leading him to seek a neurologist. Facing long wait times in Germany, he returned to India for medical help. There, tests ruled out spinal issues, and doctors suspected myositis. A rheumatologist diagnosed him with a specific form involving Anti-Jo 1 antibodies. He started treatment with steroids and immunosuppressants, later connecting with Myositis India for support.

Upon returning to Germany, he had to repeat the diagnostic process but found quicker resolution in India. While his symptoms initially improved, they worsened when medication was reduced. Doctors in Germany recommended stronger medication, but he chose to continue his treatment in India, where he had the support of family and friends.

Today, Mr. Saurabh remains hopeful, crediting his recovery to his supportive network, especially his wife and sister. He is committed to raising awareness about myositis and supporting others facing similar challenges. His story embodies resilience and the strength of community.





Our Medical Advisory Board Member - Dr. Anushka Aggarwal

Dr Anushka Aggarwal is a DrNB Rheumatology resident at Indraprastha Apollo Hospital, New Delhi. After completing her MBBS from Maulana Azad Medical College and MD Medicine from Lady Hardinge Medical College she started working in Rheumatology because of interest in autoimmune disease and immunology. She also has interest in advancing research in India and bringing clinical trials of new-age medicines to India for better access to patients.

Dr Aggarwal is an active researcher working on multiple projects on clinical presentation, patient performance and quality of life in Myositis and Systemic Lupus Erythematosus. She is also a IMACS member i.e. International Myositis Assessment and Clinical Studies Group; and involved in its active projects. She is an avid reader and great orator with multiple presentations at the Delhi Rheumatology Association meetings, the APLAR congress and iMYOS Myositis Meetings.

As an early-career rheumatologist, she is dedicated to advancing the understanding and treatment of myositis. Her passion lies in uplifting and empowering those living with this challenging condition. Through compassionate care and a commitment to research, she strives to make a meaningful difference in the lives of the patients and their families.

With this mission she has been a core member of the Myositis India Team working towards creating awareness about this rare disease. She is the manager of the Medical Advisory Board and participates in weekly patient meetings to provide free medical advice along with Dr Rohit Aggarwal. She is also involved in extending international relations with other myositis groups and collaborating with Industry partners to make myositis care more accessible. With Myositis India, she hopes to achieve her goal of providing state-of-the-art medical facilities to Indian patients.

Thank you for reading!

OUR TEAM

Content Creation: Rutvij Tope, Parth Ladha, Gokulkrishna Nambiar

Content Design: Rutvij Tope, Ujjwal Madan
