



WELCOME TO OUR Quarterly Newsletter

Hey guys, we are back with the latest issue of our quarterly newsletter! Lots of exciting new activities and developments to share!

✦ Major highlights:

1. Partnership with IPCA

- Exciting News: Funding Support from Ipca Laboratories Ltd!
- We are thrilled to announce that Myositis India has received generous funding support from Ipca Laboratories Ltd. This contribution will significantly enhance our efforts in raising awareness, and supporting patients group.
- This partnership marks a pivotal step in our mission to improve the lives of those affected by myositis. The funds will be allocated towards:
 - Educational Initiatives: Conducting webinars, workshops, and creating informative content for patients and healthcare professionals.
 - Patient Support: Expanding our patient sessions and offering more comprehensive support services.
 - Awareness Campaigns: Enhancing our social media presence and launching new campaigns to educate the public about myositis.
- We extend our heartfelt gratitude to Ipca Laboratories Ltd for their commitment to our cause. Together, we are making strides towards a brighter future for the myositis community.
- Stay tuned for more updates on how this funding will make a difference.

2. World Myositis Day:

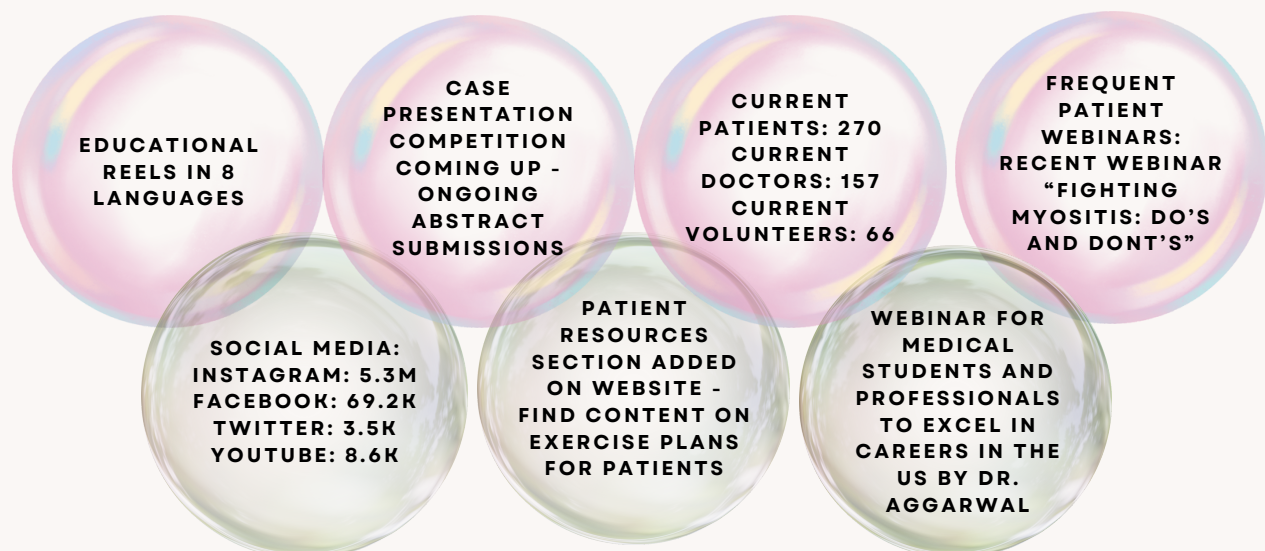
- Representatives of various international myositis groups and organizations have jointly decided to establish the World Myositis Day.
- This special day will be celebrated every year on September 21 from now on. The public should be made aware of myositis and the disease should be brought into the focus of research and medicine. Share this info and join us in celebrating World Myositis Day every September 21!



3. International Collaborations:

- Myositis India is proud to have been invited to enter into a collaboration with other Patient Advocacy Organizations working towards improving the lives of people with Myositis! This joint effort is along with The Myositis Association (USA), Myositis Australia, Myositis Canada, Myositis Support and Understanding, The Dutch Myositis Society, Myositis UK and many others.
- Each organization has common goals of spreading awareness, providing support to patients, creating a community and making their needs heard.
- We are thrilled to be a part of such a wonderful initiative and hope to be able to help and support each other achieve these goals!

UPDATES



FAQs

1. WHAT IS MYOSITIS?

Myositis refers to a group of inflammatory muscle diseases that cause muscle weakness and inflammation. This condition can affect various muscles throughout the body, leading to symptoms such as muscle pain, fatigue, and difficulty with everyday activities. Myositis can be caused by autoimmune reactions, infections, or medications. For further information, please view <https://www.instagram.com/reel/CuRoE4Qoxl5/?igsh=dGsybzl4d2g1OW1x>

2. WHAT ARE THE COMMON SYMPTOMS OF MYOSITIS?

Common symptoms of myositis include muscle weakness, often affecting the hips, thighs, shoulders, and upper arms; muscle pain and tenderness, particularly during movement; fatigue that can be debilitating; and in some cases, difficulty swallowing due to muscle involvement. Additionally, in dermatomyositis, a characteristic rash may appear on the face, eyelids, knuckles, elbows, knees, or back.

3. WHAT IS THE PROGNOSIS FOR MYOSITIS PATIENTS?

The prognosis for myositis patients varies significantly by subtype and individual response to treatment. Generally, early diagnosis and prompt initiation of therapy can significantly improve outcomes, particularly in polymyositis and dermatomyositis. However, inclusion body myositis typically progresses slowly and is less responsive to treatment.

PATIENT STORIES



I am Chintan Shinde from Ahmedabad. I am currently 39 and was diagnosed with polymyositis at the age of 7. My parents realized that I was not able to walk even short distances without getting muscle cramps in my legs. While I don't remember the exact sequence of events, I believe it was a paediatrician who first suggested to see a rheumatologist after correctly suspecting that this could be myositis or some other form of myopathy. We took out an EMG and conducted a muscle biopsy. Based on the results, the rheumatologist confirmed that it was indeed polymyositis.

From my vague memory, I recall that we started a short regimen with some steroids. In about 3-4 months, the condition went into remission. We then focussed on physiotherapy. My parents then got me enrolled in Tae Kwon Do which I managed to keep doing for another two years. It was too painful and tiring for me to continue Tae Kwon Do while balancing schooling, study and other everyday routine. We decided to move to cycling which was a less painful form of exercise. I continued cycling till I was 15. We moved towns and then I never got back to cycling.

Around the age of 24, I realised that my ability to climb stairs had reduced significantly. However, I thought this was just the normal prognosis of the condition. Only around the age of 35, I regularly started doing yoga leading to an improvement in the condition. I still find it quite difficult to climb stairs. But gradually over the last 5 years, the muscle strength is getting better. I wish I had started this earlier and continued cycling. I have found that patience, discipline, and ability to find workarounds are essential parts of living with myositis.

HEARING FROM OUR DOCTORS



Dr. Chengappa Kavadichanda (KG) is a Senior Consultant at RheumaCARE Mysuru, specializing in Rheumatology and Clinical Immunology. With a solid foundation in medicine, he completed his MD in Internal Medicine from the University College of Medical Sciences and GTB, New Delhi, followed by a DM in Clinical Immunology and Rheumatology from JIPMER, Puducherry. He further honed his skills through an observership in Allergy and Immunology at the Royal Adelaide Hospital, Australia.

Dr. Kavadichanda has contributed to the medical field with over 50 research publications in international journals, focusing on conditions like systemic lupus erythematosus, inflammatory myopathies, and rheumatoid arthritis. Notably, his high-impact publications on myositis have significantly advanced the understanding of outcome measures and prognostication for this complex condition, earning recognition within the medical community.

In addition to his clinical and research work, Dr. Kavadichanda has been involved in developing clinical guidelines as a member of the Indian Rheumatology Association's task force for vaccination guidelines.

He is also part of the OMERACT group, which is actively working to understand the impact of steroids on patients with various autoimmune rheumatic diseases. His extensive clinical experience during his tenure as an Associate Professor at JIPMER has allowed him to make significant contributions to both clinical practice and academic mentorship.

Dr. Kavadichanda is a life member of the Indian Rheumatology Association and the APLAR Young Rheumatologists group. He also serves on the editorial boards of The Indian Journal of Rheumatology, PLOS One, and BMC Rheumatology.

As a core team member of Myositis India, Dr. Kavadichanda is committed to supporting patients with myositis by providing up-to-date information and resources. His approach combines research and clinical practice, aiming to create a supportive environment for patients and their families.

OUR VOLUNTEER STORIES

Saloni Haldule

Hello everyone! I'm Saloni Haldule, a medical graduate from BJ Government Medical College, Pune, and Senior Manager at Myositis India. I've been with the organization since its inception and am proud of our work. I'm dedicated to health equity and ensuring all patients receive the best care available. We use social media to educate and connect with our diverse population and host webinars with renowned healthcare professionals. We strive to provide the latest testing and treatments for myositis patients in India and work towards a future where this condition doesn't hinder a full, healthy life. Thank you for supporting our mission!



Srijan Mittal

I am a Second year student at Maulana Azad Medical College, New Delhi. I have a strong interest in translational research, aimed at alleviating patient outcomes. My interest in rare muscle diseases extends to my lab-work, where I have been working in building peptide-based nanoparticles for the treatment of GNE myopathy. I have been a part of MyositisIndia since its inception, and have been fortunate to experience and participate in activities aiding patients and spreading awareness about Myositis.



Rutvij Tope

I am an intern from BJGMC Pune. I am strongly driven towards pursuing a career in internal medicine. As head of the social media and content creation team, I can proudly say that I have been a part of Myositis India for more than a year now. I am actively involved in shooting educational videos, editing and distributing them on our several social media platforms. I have a strong interest in Cardiovascular and Pulmonary Medicine. I have been fortunate enough to be connected to several patients, doctors and fellow medical students through this incredible platform. Thank you!



Vanshaj Sharma



My name is Vanshaj Sharma, and I am currently an intern at Byramjee Jeejeebhoy Government Medical College and Sassoon Government Hospital Pune. I have a profound interest in the cardiovascular field, with a special focus on the innovative application of monoclonal antibodies in treating cardiovascular diseases. I am also actively involved with MyositisIndia, an organization dedicated to supporting patients and raising awareness about Myositis. My involvement with MyositisIndia has provided me with invaluable insights into patient care and the importance of community support in managing rare muscle diseases.

Our team:

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