



# MYOSITIS INDIA

Dear readers,

We are pleased to share our first quarterly newsletter with you, providing you insights into Myositis India – a compassionate initiative under the umbrella of the Madalasa Foundation. This non-profit organisation is dedicated to enhancing the lives of individuals grappling with myositis in India.

Our organisation endeavours to raise awareness, extend support, and drive research for myositis—a complicated autoimmune disease causing inflammation and muscular weakness. We serve as a collaborative platform, nurturing connections among patients, caregivers, and healthcare professionals, enabling mutual learning as well as delivering evidence based medicine to our patients in order to achieve better patient care and prognoses.

We acknowledge the significant impact of the challenging journey of Myositis which affected individuals undergo, from the delays in diagnoses extensive tests and delayed treatments to securing a timely and accurate diagnosis, resulting in a diminished quality of life. Through heightened awareness and understanding, we aspire to enhance outcomes for patients and attenuate the burdens associated with this complex disease. Our commitment extends beyond awareness as we take an active initiative to promote research opportunities in India and strive to advance Myositis research, seeking a deeper understanding and more effective patient centric care

Whether you find yourself in the role of a patient, caregiver, or healthcare professional, we extend a warm invitation to join us in our mission. Together, we can make a huge impact and instill hope in the lives of those bravely facing the challenges posed by Myositis.

## HIGHLIGHTS

1. Brand Ambassador – Samantha Ruth Prabhu. She herself has been a Myositis warrior and joined us in our mission.
2. Patient Welfare activities conducted which include 14 Ask the Doctor sessions, Patient Volunteer panels, Patient Support and QnA groups on Whatsapp, plethora of content on social media and website for patient education, webinars for patients.
3. Academic activities include webinars for Doctors, case presentation competitions, research projects, updates on Myositis and treatments on social media.
4. Social media highlights: More than 10k people reached through our content and outreach programmes.
5. Total patients = 368, Total Doctors = 151, Total volunteers = 51.  
80 – 100 visitors per day, for our website.



**Samantha Ruth Prabhu**

## OUR VOLUNTEERS

Greetings,

My name is Parth Ladha, an intern doctor at BJ Government Medical College and Sassoon General Hospital, Pune. Since the beginning of my medical career, I have been deeply interested in activities that involve patient care. Engaging in conversations with patients and their families, alleviating their anxiety, and providing a sense of support during their time of need have always been important to me.

I was among the first volunteers to help build this organisation from the ground up. Our initiatives have included a wide range of activities, such as support groups, doctor-patient one-on-one sessions, webinars, and WhatsApp Q&A groups. During the initial months, we started outreach programs for patients throughout India.

Our first patient ambassador was Mr. Prashant Verma, with an incredible story of his battle against Myositis. His story was eye-opening for me as a medical professional, helping me understand the challenges endured by our patients while undergoing a barrage of tests, imaging, scans, procedures, their after-effects, and taking multiple medications. Interviewing him gave me a new perspective on the field, and made me a better doctor who approaches work holistically.

As we grew, we expanded into social media. I led the content creation team and started coordinating various related activities. We began making informative reels where doctors made short videos answering questions about Myositis. Leading these activities taught me valuable lessons in teamwork and effective communication.

As we continued to grow, we ventured into the academic realm with research projects focused on Myositis. These academic pursuits have broadened my horizons and helped me grow professionally.

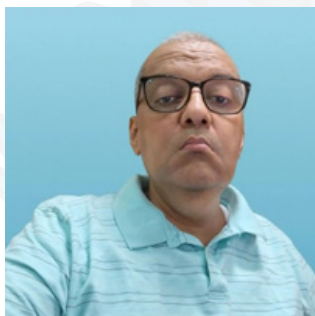
Reflecting on this journey, the change in perspective and personal growth I've experienced through this work has been incredible. The tangible difference our efforts have made in the lives of patients and their families has been a driving force and motivation for me personally. I extend my heartfelt gratitude to the dedicated volunteers and Dr. Aggarwal for providing a platform to share my journey in this newsletter.

Warm regards,  
Parth Ladha



## PATIENT STORIES

A tale of resilience and triumph. We interviewed our patient, Mr. Prashant Verma, with an inspiring story towards recovery. Prashant's ordeal began in August 2020 when he started experiencing weakness and pain in his limbs. At first, he brushed it off as fatigue, but the symptoms persisted and worsened with time. Swelling in his face, difficulty eating and swallowing soon followed. Concerned, he sought medical help, visiting several doctors, but none could pinpoint the issue. The timing of his symptoms coincided with the COVID-19 pandemic, leading to evaluations for the virus and its potential complications. When all COVID related tests came back negative, he faced a frustrating period of uncertainty. The medical professionals initially believed it might be a psychological problem, leaving Prashant in a state of distress.



After months of uncertainty, he was eventually referred to a Rheumatologist who, after extensive testing and evaluation, diagnosed him with Myositis. By the time the diagnosis was made, almost 3-4 months had elapsed since the onset of his symptoms. Treatment commenced promptly thereafter, and initially, Prashant experienced relief. But fate had different plans. While taking medications for another illness, he suffered a severe relapse. He found himself almost immobile, relying on a caretaker for basic tasks. He struggled both physically and emotionally during this time. Despite the challenges, Prashant continued with the treatment under the guidance of his doctors. He decided to fight back with everything he had. He began incorporating physiotherapy and exercises into his treatment routine.

With each passing day, Prashant made steady progress. Slowly, he started to move his limbs, swallow, and work. The spark of life returned, and he was on the path to recovery. Supported by his family, friends, and medical team, he found renewed hope in life. Today, we are overjoyed to report that Prashant has made an incredible recovery. His determination knows no bounds, and he is even planning to scale Mt. Kalsubai, the highest peak in Maharashtra. His story is a testament to the power of perseverance and the support of loved ones. Looking back at his journey, Prashant credits his recovery to the unwavering support of his family, friends, and the skilled medical professionals who guided him throughout. Now, he has made it his mission to help other patients going through similar experiences, offering guidance and support during this challenging phase of their lives. We are honoured to be associated with Prashant and commend his indomitable spirit in the face of Myositis. His remarkable fight against the odds serves as an inspiration to us all.



## MAB



Dr. Neeraj Jain, DNB, FACR, FRCP (Edin), a distinguished Professor at GRIPMER and Vice

Chairman at Sir Ganga Ram Hospital, New Delhi, is a distinguished expert in Rheumatology. With a Fellowship from prestigious institutions like Royal National Hospital for Rheumatic Disease, UK and King Edward Memorial Hospital, Mumbai, he also holds memberships in the Indian Rheumatology Association and Delhi Rheumatology Association. Dr. Neeraj Jain's commitment to patient care is reflected in his extensive contributions to the field of Rheumatology. As a Senior Consultant at the Department of Rheumatology & Clinical Immunology, Sir Ganga Ram Hospital, he has played a critical role in advancing the diagnosis and treatment of rheumatic disorders.

Dr. Jain's benevolent approach to patient care is complimented by his active involvement in clinical trials, ensuring that patients have access to the most present day evidence based medicine. His dedication to improving patient outcomes is further highlighted by his leadership and editorial role in the development of the first book on Biologics in Rheumatological disorders published on established platforms like Springer, Nature. He also has 45 national and international publications. Dr. Neeraj Jain's holistic contributions extend beyond research, emphasising a comprehensive and patient-centric approach in managing Rheumatologic diseases.

## OUR TEAM



### Content Creation and Editing:

- Dr. Namratha - Mamata Medical College, Khammam
- Dr. Simran - BJ Government Medical College, Pune
- Dr. Rutvij - BJ Government Medical College, Pune
- Dr. Prithvi - Smt. Kashibai Navale Medical College and General Hospital, Pune
- Dr. Parth Ladha - BJ Government Medical College, Pune

### Content Designing and Editing:

- Dr. Ujjwal Madan - University of Missouri Kansas City, MO, USA

### Support Staff:

- Rimzim Mathur - Manager, Partnerships and Res Mobilization
- Sartaj Akhtar - Web Developer