

Our Research Approach

- Prioritizing research initiatives that will benefit the quality of life of myositis patients here and now.
- Crowdsourcing patient's needs/wants by myositis type to capture the voice of the patient (VOP) and communicate those to the medical community.
- Carrying out burden of care research that addresses gaps in myositis care management and clinical trial participation.
- Partnering with academia, industry, and government agencies to understand disease evolution and biomarkers to improve clinical trial design.
- Providing research grants through MSU or affiliate partners for studies that impact near-term functional diagnostics and treatment improvements.



Are you living with myositis?

You are
not
alone.

We are here for YOU.



+888-MYO-RARE (696-7273)

info@understandingmyositis.org

Register for your FREE MSU Membership to get a full list of current events, updates, support reminders, and ways to get involved!



Visit www.understandingmyositis.org or use this QR code to learn more!

MSU MYOSITIS SUPPORT
& UNDERSTANDING
EMPOWERING THE MYOSITIS COMMUNITY

Research from the HEART

Your data and experiences drive
research



Our Research Philosophy

Patients are the experts in their disease, and we keep the patient front and center in every collaboration with industry, corporate partners, academia, and other organizations. Where appropriate, patients will be fairly compensated for sharing their experiences. We will be intentional in our partnerships and research funding based on the impact on the overall patient population.

Our Engaged Community

Patients and care partners from our diverse, multicultural myositis community serve as experts in clinical trial design activities, councils, focus groups, and surveys. MSU's team of advocates lobby at the federal level, along with other rare disease organizations, to improve the regulatory process and accelerate access to improved therapies.

The MSU Research Team

MSU is collaborating to bring precision medicine solutions to the myositis community. Our research team includes:

- Lynn Wilson - Director
- Manuel Lubinus- Chief Science Officer
- Pai Hu - Data Analysis, Marketing
- Izandra Rudolph-Heard - Community Outreach, Mental Health
- Stephen Moore - CME, DM Projects
- Benita Moyers - Anti-MDA5 DM Study Advisor
- Dr. Salman Bhai - Medical Advisor, UT Southwestern
- Dr. Abhiram Bhashyam - Research Partner, Mass General

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Patient-Led Projects

"Pain profile and opioid medication use in patients with idiopathic inflammatory myopathies" was presented at 2022 GCOM and published in *Rheumatology*.

FDA Listening Session on Adult DM hosted by MSU in April 2022.

Myositis Journey and Burden of Disease Study Insights will be presented at the 2022 Neuromuscular Study Group Annual Scientific Meeting. Findings include: risk factors for falls and fracture in myositis, delayed diagnosis, and financial burden.

Collaborations

Founding partner with AllStripes since 2019 - DM and IBM Programs

- Provides clinical record insights and machine learning.
- Free access to data at research institutions.

Novel Collaboration with UT Southwestern and Mass General on Tendon Transfer Surgery for IBM patients:

- Provides longer hand usage for IBM patients through surgery.
- Non-drug approach for mobility enhancement.



RESEARCH

