



# Myositis Support and Understanding

## About Myositis Support and Understanding (MSU):

Myositis Support and Understanding is a growing nonprofit organization founded on the idea that even though people, with this rare disease Myositis, are diverse and far-stretched across the globe, they can come together to share information on the effects, commonalities, and complexities of Myositis to make each other's lives better. Through individual trial and error, similar experiences, and empathy for each other, we are building a supportive and informational network of camaraderie in which people can better understand their disease, effectively advocate for themselves, and realize they do not have to be alone in their struggles. We hope that our members will feel informed and empowered. At the end of each day, if even one new member can say, "I'm relieved to know that I'm not the only one and that my experiences are real," we will count ourselves a success!

Our ultimate goals include providing financial assistance to our members on an as-needed basis to help cover the following extraordinary circumstances: expensive treatments that are not covered by insurance, travel expenses to see one of few doctors who specialize in Myositis, and help with emergency household expenses. We will advocate for our members and all Myositis patients with all levels of policy-makers, insurance companies, and other medical service decision-makers. We will also contribute any excess funds, if any, to Myositis cure- and treatment-centered research organizations to help further our shared goals.

## Why should you care about Myositis?

Myositis is one of over 80 autoimmune conditions of which there is no cure. Myositis is known to strike at any time of life. Polymyositis and Dermatomyositis can both manifest during childhood and adulthood. Inclusion Body Myositis most commonly occurs in later adulthood. While there are presently only an estimated 50,000-75,000 Myositis patients in the United States, as diagnostic criteria and testing become more sophisticated, more people with undifferentiated autoimmune symptoms will likely be identified as having a form of Myositis. As this happens it is more and more possible that you will know someone affected by Myositis.

## Why should you contribute to Myositis Support and Understanding?

No one wants to be alone when facing medical issues. MSU exists solely to help Myositis patients and caregivers through education, advocacy, financial assistance, and emotional support. Making a financial contribution and volunteering your time with MSU ensures that we can achieve the following goals:

- MSU provides materials for patients to take to doctors who may have never encountered Myositis before in their careers, other than in a medical school textbook.
- MSU provides online Myositis support groups, led by patients, in which patients and caregivers are free to share their fears, symptoms, and experiences honestly and openly – with the opportunity to get feedback, advice, and encouragement – knowing that they are not alone in their struggles.
- MSU provides financial assistance to Myositis patients for emergency medical and household expenses related to the costs of living with a rare disease and the financial devastation caused by interruption of the ability to work.
- MSU assists patients in advocating for themselves to insurance companies and legislators; as well as providing educational materials to policy makers about the importance of access to appropriate medications.

MSU is a volunteer-managed nonprofit organization, so there are very few operational costs. This ensures that a large portion of all donations goes toward our mission and goals.