

# Empowering the Myositis Community

UNDERSTANDINGMYOSITIS.ORG

## MYOSITIS QUICK TIPS

- 01** Idiopathic Inflammatory Myopathies (myositis) are rare diseases with an estimated 50-75k patients in the U.S. There is no cure for any form of myositis.
- 02** It is estimated that 5 people per million are diagnosed each year with a form of Myositis.
- 03** Polymyositis (PM) and Dermatomyositis (DM) are found more often in women, and even more in women of color, while Inclusion Body Myositis is found often more in men.
- 04** Myositis can be an “Invisible Illness.” Patients may look healthy on the outside, but inside they are suffering.
- 05** There is a higher incidence of cancer with Dermatomyositis and Polymyositis. Be sure to get appropriate cancer screenings.
- 06** Inclusion Body Myositis (IBM) is different from other forms of myositis in that it causes muscle wasting and there are no available treatments.
- 07** Immune-Mediated Necrotizing Myopathy may be associated with autoantibodies and presents with severe muscle weakness, high CK levels, pain, and findings of muscle cell death (necrosis) on a muscle biopsy.
- 08** Self-advocacy is important, especially when visiting many specialists that manage myositis. Speak up, loudly, for your health.
- 09** Learn more about the various types of myositis on our comprehensive myositis website, [UnderstandingMyositis.org](http://UnderstandingMyositis.org).



### Share your #MyositisLIFE

Join our new #MyositisLIFE program & website. Become an author and share your patient and caregiver experiences. Visit [MyositisLife.org](http://MyositisLife.org) to get started and to read stories from others.

## MSU PROGRAMS AND SERVICES

Learn more about our patient-centered programs



### ONLINE & VIDEO SUPPORT

We offer Myositis patients and caregivers the best in support, including 24/7 online support and live video support. Support is available worldwide. Get the educational support you deserve! Join at [Myositis.Inspire.com](http://Myositis.Inspire.com)



### EDUCATION

“Knowledge is Power.” We provide education for patients, caregivers, family members, friends, and healthcare providers about Myositis in order for the disease to be better recognized and understood. This is Knowledge in Action!



### PATIENT FINANCIAL ASSISTANCE

We offer need-based Financial Assistance for Myositis patients including medical bills, assistive and mobility devices, travel to see a myositis specialist, and for household expenses.



### CLINICAL TRIAL MATCHING

We have partnered with Antidote Technologies to help you find your clinical trial match. We also partner with pharmaceutical companies in clinical trial stages and assist with patient recruitment efforts.



### ADVOCACY

Myositis patients and caregivers need a voice with all levels of public-policy makers, insurance companies, and other healthcare decision-makers. We will be that voice!



### MYOSITIS EMPOWER WALK

Created in loving memory of Robert “Bob” Landman by his family, the Myositis Empower Walk is held annually in-person and virtually, and is our largest fundraising and community gathering event. You can be a part of this no matter where you are.

## WHAT IS MYOSITIS?

The Idiopathic Inflammatory Myopathies (IIM), generally referred to as Myositis (my-oh-sy-tis), is a group of rare, often-debilitating autoimmune diseases that involve chronic muscle inflammation, muscle weakness, and, in some cases, muscle pain. Myositis may affect other organs such as the skin, heart, and lungs, may be associated with cancer and other autoimmune diseases, and may cause complications such as trouble swallowing. Muscle weakness may necessitate the need for assistive devices for mobility.

## TYPES OF MYOSITIS

There are several types of Myositis, each with unique and variable symptoms and manifestations, including Polymyositis (PM), Dermatomyositis (DM), Clinically Amyopathic Dermatomyositis (CADM), Inclusion Body Myositis (IBM), Antisynthetase syndrome (AS), Immune-Mediated Necrotizing Myopathy (IMNM), and Juvenile Myositis (JM).

## DIAGNOSING MYOSITIS

Myositis is often difficult to diagnose. It is rare, symptoms may develop slowly, and it can be mistaken for other more common diseases. Many patients are misdiagnosed, or go undiagnosed for many years. We recommend patients see doctors with experience diagnosing and treating Myositis. To assist with a diagnosis, a complete medical and family history and clinical exam are important. Diagnostic tests may include a muscle and/or skin biopsy, MRI, EMG and Nerve Conduction study, swallowing studies, CT scan of the lungs, and pulmonary function tests. Blood work may include various autoimmune and cancer markers, creatine kinase (CK), liver enzymes (AST, ALT), aldolase, and others. Myositis-Specific (MSA) and Myositis-Associated antibodies (MAA) can be helpful for diagnosis and disease classification.

## TREATING MYOSITIS

Myositis can be as difficult to treat as it is to diagnose, often requiring a combination of medications and therapies. The goal of treatment is to reduce inflammation, prevent muscle loss, and improve quality of life. Typically corticosteroids such as prednisone are the first line treatment followed with immunosuppressive agents such as CellCept, Methotrexate, or Imuran. Antimalarial agents may be used for skin involvement. Immunoglobulin (Ig), Rituxan, and Solumedrol are intravenous treatments that may also be used. There are currently no available treatment options for Inclusion Body Myositis (IBM). Exercise is important for all Myositis patients and should be coordinated with a physician and physical therapist.

## MYOSITIS: PAIN AND FATIGUE

It is estimated that 40% of Myositis patients experience pain. Fatigue, widely recognized in all autoimmune diseases, can be life-altering and disturb sleep patterns. Fatigue is one of the common symptoms patients discuss in our support groups.



### **EMPOWERING THE MYOSITIS COMMUNITY**

*Learn more about Myositis Support and Understanding*

Myositis Support and Understanding Association (MSU) is an all-volunteer, patient-centered 501(c)(3) nonprofit organization founded by myositis patients, for myositis patients and caregivers. MSU is instrumental in empowering the myositis community and helping to improve the lives of patients and caregivers fighting this rare, complicated immune-mediated muscle, skin, and often multi-organ disease. MSU is the first patient-centered myositis organization to offer live online video support, education, and activity sessions that enable patients with limited mobility and their caregivers to interact with each other and with myositis experts. MSU also provides a "Simply Put" and "Exercise in Place" series, clinical trial matching, access to research, advocacy, online and video support, awareness building programs, partnerships and sponsorships with industry, academia, and other organizations, and need-based financial assistance for patients. At the end of each day in our support groups, we count ourselves a success if even one new member can say, "I'm relieved to know that I'm not alone and that my experiences are real!"

Details provided are for informational purposes only and are not meant to be used as medical advice. This information should not be used for diagnosing or treating a health problem or disease. Always seek the advice of a qualified healthcare professional regarding any medical condition.

#### **MSU MISSION**

Our mission is to improve the lives of and empower those fighting myositis through education, support, awareness, advocacy, and access to research.

#### **OUR VISION**

Our vision is to create a world where patients, caregivers, and providers have better knowledge, support, and understanding of myositis.

#### **VOLUNTEER WITH US**

We are an all-volunteer managed nonprofit and we could use your help! Various remote volunteer opportunities are available.

#### **FREE MEMBERSHIP**

Register and join us as a member on our website. Membership is free and open to anyone with an interest in myositis.

#### **TAKE ACTION. GET INVOLVED.**

There are many ways to get involved with MSU to help the Myositis Community. Whether you volunteer, create a fundraiser, share your story, join a support group or a video support session, or make a donation of any amount, we hope you will get involved.

#### **MAKE A DONATION**

Donations are tax-deductible in the U.S. Your donation ensures we have the funding for vital support and financial assistance programs and to support patient-centered research. There are many ways to give, and we appreciate your support and generosity. See giving options at [UnderstandingMyositis.org/giving](http://UnderstandingMyositis.org/giving)

#### **CONNECT WITH US ON SOCIAL MEDIA**



#### **CONTACT US**

Email: [Info@UnderstandingMyositis.org](mailto:Info@UnderstandingMyositis.org)  
Website: [www.UnderstandingMyositis.org](http://www.UnderstandingMyositis.org)  
Toll Free: 888-MYO-RARE (696-7273)

#### **Mailing Address:**

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Lincoln, DE 19960 USA



**A nonprofit supporting, educating, empowering, and advocating together with fellow myositis patients, caregivers, researchers, and partners.**

**Visit us online**

**[UnderstandingMyositis.org](http://UnderstandingMyositis.org)  
[MyositisLife.org](http://MyositisLife.org)**

**Improving the lives of myositis patients and caregivers**

**Education, Support, Awareness, Advocacy, Access to Research, and need-based Financial Assistance.**

**#MyositisLIFE #Myositis #RareDisease**