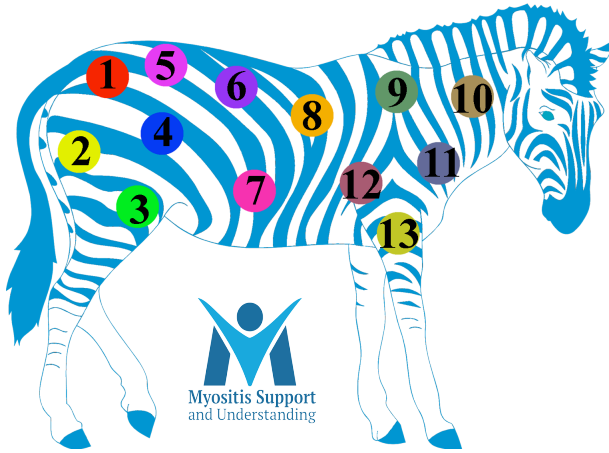


## “With Myositis, Sometimes Zebras Have Spots!” Myositis Awareness Month May 2017 -- “Spots” Talking Points



Myositis Support and Understanding Association aims to help our members spread awareness this month by supplying talking points on our Awareness Month theme: “With Myositis, Sometimes Zebras Have Spots!” You may know that rare diseases are represented by the Zebra. Even though many Myositis patients don’t look sick, MSU is using the irony and ridiculousness of the spotted zebra to show the unique difficulties we face with our specific rare disease, Myositis. This uniqueness makes it especially difficult to tolerate, diagnose, and treat. When MSU members wear the 2017 MSU Myositis Awareness Month “Zebra” T-Shirt and utilize these talking points, you help us *Put a Face* to Myositis and raise awareness. By sharing our name and website, [SupportMyositis.org](http://SupportMyositis.org), you can help us raise money for our support programs, including patient financial assistance. Please share these Myositis Spots with friends and family so they can understand more about your life

- 1. Symptoms vary from patient to patient so diagnosis is difficult and takes time due to varied results from blood tests, EMGs, and biopsies that can change over time. Also, some patients do not display “typical” symptoms and Myositis can mimic other, less rare diseases.
- 2. It sometimes takes multiple treatments before finding one (or a combination) that works and those treatments often come with dangerous and/or uncomfortable side effects, including a compromised immune system. Patients must be careful to prevent infections and illness resulting from certain medications that suppress the immune system.
- 3. Symptoms can change over time, making treatment difficult to maintain. Medications may stop working, requiring patients to go through the process of trial and error once again to find another treatment that will work.
- 4. Medical professionals aren’t always familiar with Myositis so patients often have to educate their medical team or travel to see a doctor with experience.
- 5. Myositis is often accompanied by excruciating pain. This was once not recognized and some patients were misdiagnosed due to having pain. Now, it is widely accepted that pain can be a part of Myositis.
- 6. Myositis is often accompanied by other autoimmune diseases, cancers, and other chronic illnesses so regular checkups and screenings become a way of life. Overlap syndrome makes it even more difficult to treat Myositis, as we sometimes do not know which disease is causing our symptoms.
- 7. Myositis is a systemic disease meaning it can affect other organs in our body, not just our muscles. Some have GI complications, others have lung involvement, and others may no longer be able to eat due to complications and weakening of the swallowing muscles, which requires them to be tube fed.
- 8. Every aspect of a patient’s life is touched by Myositis, including areas like finances, mental health, physical abilities, the ability to care for oneself, and the ability to work, among many others. With IBM particularly, the necessity of adapting to progressive disability due to loss of muscle often results in costly home renovations and creativity in designing unique assistive devices.
- 9. Myositis severely affects the care partners, families, and friends of patients who often try to understand what the patient is going through. This can be a difficult feat without educating themselves. MSU has an all-inclusive website to provide that education.
- 10. Some forms of Myositis include a mandate to be extremely careful about the sun, sometimes due to the medications, and sometimes due to the disease itself.
- 11. Many people with Myositis find it necessary to use assistive devices and are considered to be disabled, although many refer to themselves as ability-challenged or other, more positive phrases.
- 12. Many times, Myositis can be an “invisible disease” meaning that its patients look fine on the outside even as their bodies are fighting a battle to stay healthy on the inside. This often creates a sense of guilt and feelings of “others not understanding.”
- 13. Many patients with Myositis try to maintain a positive attitude and utilize MSU support groups and video chat support sessions to keep from becoming focused on all the negatives of their disease. Living with Myositis can feel lonely so they try to find ways to be passionate about life even with their limitations. MSU is here to help with programs and services designed to bring support directly to patients in ways that are structured to meet different needs as some are unable to drive, walk, or leave the house.

**Make a donation today at [SupportMyositis.org/donate](http://SupportMyositis.org/donate)**