

May is Myositis Awareness Month. Myositis Support and Understanding commemorates the month with patient-centered events

Our theme, "With Myositis, Sometimes Zebras Have Spots" refers to the multitude of ways patients lives are affected in every aspect by Inflammatory Myopathies

LINCOLN, DELAWARE, USA, April 28, 2017 /EINPresswire.com/ -- [Myositis Support and Understanding Association](http://MyositisSupportandUnderstanding.org), a 501(c)3 nonprofit organization, commemorates [Myositis Awareness](http://MyositisAwarenessMonth.org) month with our 2017 Theme, "With Myositis, Sometimes Zebras have Spots."



MYOSITIS AWARENESS MONTH

"Sometimes Zebras have spots"

Myositis is a rare, complicated, systemic autoimmune disease without a cure. There are 4 main types of inflammatory myopathies that we focus on: Polymyositis, Dermatomyositis, Inclusion Body Myositis, and Juvenile Myositis.

Even though patients may have the same form, they never experience the same symptoms and these diseases often mimic less rare illnesses making diagnosis very difficult and time consuming.

Help us move forward with a donation!

SUPPORTMYOSITIS.ORG/DONATE

The MSU Myositis Awareness Theme

The zebra is the well-recognized symbol of rare diseases. Myositis, a rare disease without a cure, is often hard to diagnose, taking years for a proper diagnosis, and even more difficult to treat, due to differences in disease markers, overlap symptoms, side effects from medications, etc. MSU has decided to use 2017's May month of

awareness to teach about how the experiences and symptoms of this rare disease are different, even among the patients with the same disease. Doctors are now starting to be trained when you hear hoof beats, look for zebras (rarities), instead of horses (common ailments), when in the past, they only looked for horses (the most common ailments). Through our public education and support of our members, plus our financial assistance program, MSU helps patients deal with the spots of the zebra called Myositis.

“

Myositis is such a difficult and complicated disease that goes beyond just muscle and skin. Living with this disease is difficult and affects every aspect of the patient's life. We are here to help.”

Jerry Williams, President

Myopathies of which there are several types, and are all classified as rare diseases. Myositis does not only affect the muscles and skin. It is a systemic disease and can affect many different organ systems.

Polymyositis causes muscle weakness around the middle of the body and affects both sides of the body. Dermatomyositis can cause the same muscle weakness, while for some the muscle weakness never presents. This is referred to as Amyopathic Dermatomyositis. DM also causes skin rashes, however, for darker skinned people, especially of African descent, these rashes can be difficult to see thus leading to a longer period of getting a proper diagnosis. Juvenile Dermatomyositis differs from the adult form because of the coexistence of Vasculitis (inflammation of blood vessels). Inclusion body myositis mainly affects older individuals and as muscle weakness becomes severe, it is accompanied

by muscle wasting and diminished deep-tendon reflexes. Unlike Polymyositis and Dermatomyositis, the muscle weakness is often asymmetric and may be prominent in the smaller muscles of the forearms and calves.

No matter which form of Myositis patients may have, getting a proper diagnosis is often years in the making. And, there are multiple potential complications and many patients become disabled due to the weakness and other factors. Education of patients so they can advocate for themselves is key. MSU is here to help.

To raise awareness of this complicated, rare disease, MSU has scheduled many activities to promote awareness and to educate.

Talking points to use with the MSU Zebra
T-shirt/Hoodie or even without



Myositis Awareness Month

'Spots' Talking Points'

Download and share the Zebra "spots" talking points for Myositis

These help to provide you with wording when asked questions

FB.me/UnderstandingMyositis
UnderstandingMyositis.org/awareness

MSU Talking points for our Zebra Spots campaign



Myositis Support and Understanding

Myositis Support and Understanding Association, Inc.

- “Sometimes Zebras have Spots” T-shirt Campaign and Talking sheet. We have had our best T-Shirt campaign yet, selling shirts with our awareness theme, a spotted zebra, which will be accompanied by an information sheet giving members talking points about the “spots” of myositis.
- #PutFacetoMyositis – We’ve invited members to share their own “Spot” stories of a difficult diagnosis, rarity, adaptation, they have made, or side effect of medication to be placed on an interactive Zebra graphic on our website.
- Strategic Plan Survey – MSU is committed to making its actions be a better and better reflection of its members. As such, we are asking our members to speak up and share their voice by participating in our strategic planning by filling out an important survey about our services and platforms, as well as where they would like to see us go in the future. This will further help us #PutFacetoMyositis and make sure we have accounted for all the “Spots” of myositis.
- Video Chats – We have scheduled interactive video chats to entertain, build community, educate, and advocate for ourselves. And, we are in the final stages of planning an “Exercise and Myositis” video chat session with one of our medical committee advisors, Dr. Tao Chung.
- Social Media Outreach – As always we want to increase awareness of myositis so we have again enlisted the Thunderclap tool. This helps us to multiply our reach exponentially. We ask that our members, and their friends and family members, add their social strength by joining the campaign. The campaign link will be available on our Facebook page and website.
- Educational Outreach – The President of MSU, Jerry Williams, has been invited to speak about MSU and Myositis at Idera Pharmaceuticals Pennsylvania location on May 25th. Jerry will speak about his experience in living with Polymyositis, discuss the other forms of idiopathic inflammatory myopathies (myositis) such as Dermatomyositis, Inclusion Body Myositis, and the Juvenile forms of Myositis, in an effort to educate and promote awareness to the employees of Idera. Heather Spadaccini, a friend and often care partner for Jerry, will speak about how frightening this disease can be and some of the complications she has witnessed along the way. As this disease affects everyone around us, hearing

from a friend and care partner helps others to better understand this disease. MSU collaborated with Idera on their clinical trial that is still recruiting for the experimental drug IMO-8400 for adults with Dermatomyositis.

- Fundraising – MSU operates an all-volunteer board and staff, but our programs cost money. We run three major Facebook support groups boasting over 2000 members, we have an interactive membership website full of resources and ways to connect, we offer regular video chats, we have a financial assistance program that provides funds to myositis patients in need of financial help for medical expenses, medical travel, and household expenses, and we continue to listen to our constituents to build new programs where needed. To ensure we continue to have available funds to continue our important work we ask that you consider donating at least \$25 during the month of May or even setting up a recurring donation on a monthly or yearly basis. Support our mission and our work by making your [contribution](https://www.understandingmyositis.org/donate) at [UnderstandingMyositis.org/donate](https://www.understandingmyositis.org/donate)

For announcements during Myositis Awareness Month and all year long, please visit our Facebook page at [FB.me/UnderstandingMyositis](https://www.facebook.com/UnderstandingMyositis) and our website, [UnderstandingMyositis.org](https://www.understandingmyositis.org), where you will find an abundance of information.

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