

May is Myositis Awareness Month

In observance of Myositis Awareness Month during the month of May, MSU has launched a new patient and caregiver experience website, www.MyositisLife.org

LINCOLN, DE, UNITED STATES, May 9, 2019 /EINPresswire.com/ -- In observance of [Myositis](#) Awareness Month during the month of May, Myositis Support and Understanding Association (MSU) has announced its 2019 theme, “#MyositisLIFE as a #MyositisWarrior,” and the launch of a new patient and caregiver experience website, www.MyositisLife.org.

Myositis (Idiopathic Inflammatory Myopathy) is estimated to affect 50-75K people in the U.S. and is one of the rarest of the 80 autoimmune diseases. On average, it takes 3.5 years to accurately diagnose. Factors creating this delay include a lack of typical diagnostic tools and findings, access to care, as well as the rarity and variability of the disease.

In the four years since MSU officially became a nonprofit organization, the dedicated volunteers of MSU have seen time and time again that patients find it increasingly important to maintain a sense of who they were before illness, as they fight their Myositis. Through these interactions, MSU continues to see the two important, empowering themes emerge: #MyositisLIFE and #MyositisWarrior!

The myositis patient and caregiver experiences encompass not only interactions with the healthcare side of living with this rare disease, but also incorporate everyday living: disease flares, adapting to muscle weakness, trial-and-error treatment approach, dealing with chronic pain and life-altering fatigue, and learning ways to manage swallowing difficulties, lung disease, and itchy-to-painful skin rashes.

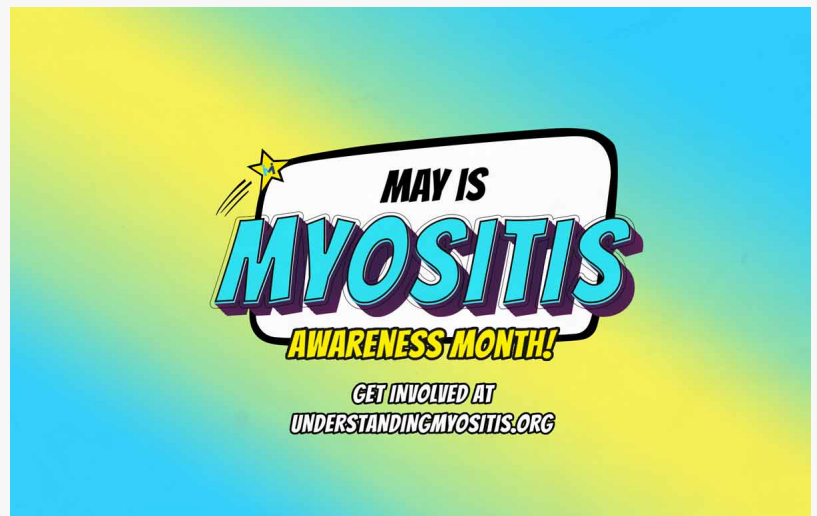
Aside from the physical challenges, living with myositis affects the financial, emotional, and



Myositis Support and Understanding logo



2019 A Day of Remembrance



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spiritual lives of patients. It also affects relationships and sexuality.

One challenge in myositis research is getting people interested. Awareness is a path to potential research and by providing a platform for patients and caregivers to share what their #MyositisLIFE is like is a powerful way MSU can help.

These experiences with myositis may be able to influence medical students to specialize in myositis, or researchers and pharmaceutical companies to learn more about initiating myositis research and clinical trials. #MyositisLIFE also helps patients convey to people around them the day to day hurdles they cross to maintain their relative health and why it is often important to them to keep a positive attitude; as well as why community and family support is crucial to their treatment plan and success. Finally, MSU encourages patients to be their own best advocates at every level of healthcare from ER visits, to dealing with insurance company appeals. Being a #MyositisWarrior is not just about taking care of their health; it's about never giving up.

As a part of its commitment to patients, and in partnership with several caring sponsors committed to the myositis community, MSU will be hosting its Second Annual "[A Day of Remembrance](#)" on Sunday, May 26, 2019, beginning at 2 PM EDT. Join MSU live for this streaming YouTube video event to honor and remember those we have lost. If you or someone you know has lost a loved one to myositis, MSU is asking you to please consider sharing their name and some brief information to be included in this event. Information can be shared online at UnderstandingMyositis.org/in-memory and can include photos and short videos.

MSU has made it easy for anyone interested to get involved in Awareness Month. To view all materials, events, and suggested ways to make an impact, visit the Awareness page of the MSU website (UnderstandingMyositis.org/awareness/).

MSU is proud to be a frontline advocate talking to pharmaceutical companies, doctors, researchers, and other healthcare community members about issues facing myositis patients. Stakeholders who know and understand more about the lives myositis patients live, will be better able to treat them effectively, with compassion, and with shorter time to diagnosis and hopefully, eventually, remission... and one day, a cure.

Jerry Williams
Myositis Support and Understanding Association, Inc.
+1 3023393241

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