

Myositis Support and Understanding Association (MSU) Supports and Partners with Rare Disease Day® 2017

MSU Supports Rare Disease Day® 2017 and Joins Global Movement to Raise Important Awareness for Rare Diseases while hosting an event

LINCOLN, DE, UNITED STATES, February 21, 2017 /EINPresswire.com/ -- [Myositis](#) Support and Understanding Association (MSU) has joined forces with 30 million Americans and health care advocates around the world for [Rare Disease](#) Day® on February 28, 2017. Rare Disease Day is an annual awareness day dedicated to elevating public understanding of rare diseases and calling attention to the special challenges people face.



Myositis Support and Understanding

Myositis Support and Understanding Association, Inc.



PIONEER

A NEW CLINICAL TRIAL IN DERMATOMYOSITIS IS **NOW SEEKING PATIENTS**

FIND OUT MORE AT IDERA.CLINICALTRIALS.COM

Pioneer Clinical Trial

Myositis Support and Understanding Association (MSU) is an all volunteer-managed 501(c)(3) non-profit organization that was founded by myositis patients for myositis patients. We work year-round to provide awareness, advocacy, education, support, and programs and services, such as our financial assistance program, to those affected by this rare disease only affecting an estimated 50,000-75,000 people in the United States.



Having a rare disease is often isolating. What I love about being involved with MSU is how often I hear that the relationships people are making have changed their perspectives on their lives.”

*Emily A. Filmore, MSU
Founding Board Member*

Leading up to Rare Disease Day we have amped up our web and social media postings to provide more information about the symptoms, diagnosis, treatments, and coping of and with Myositis, Inflammatory Myopathies. We encourage our members and followers to share their stories and share our information to increase awareness. We continue to host live video chats sessions to help people build community and learn together; and of course, we welcome tax-deductible donations to help us continue funding our financial assistance program and other upcoming programs and services we are

developing.

On Rare Disease Day, we are hosting a live video chat session with Idera Pharmaceuticals regarding their Pioneer Phase II clinical trial for dermatomyositis. This provides the rare disease patients living with dermatomyositis a chance to learn more about this currently recruiting clinical trial, in 17 sites across the U.S. and the U.K., and the ability to ask questions. Registration for the RDD event is

required, however, the event is free. Registration is available on our website's [Events](#) page.

“Having a rare disease is often isolating. What I love about being involved with MSU is how often I hear that the relationships people are making have changed their perspectives on their lives. They no longer feel alone, saddled with this rare disease, in which they will likely never randomly meet another person with the same disease in the “real world.” Through our support groups, they have made lasting friendships with people who not only understand what they are going through but can help them navigate some of the harder aspects of the disease. This is truly a beautiful gift we are giving our community of patients.” ---Emily A. Filmore, MSU Founding Board Member and Author of “The Marvelous Transformation: Living Well with Autoimmune Disease.”



Lee W. gets involved with MSU and RDD

Patients, family members, friends, and those interested in myositis can participate in our rare disease activities and programs by visiting our website <https://understandingmyositis.org>, or find us on our various social media platforms such as our Facebook page, <https://Facebook.comunderstandingmyositis>, Twitter at <https://Twitter.com/myositissupport>, Instagram, <https://instagram.com/myositis>, and our other social networking profiles as listed on our website.

According to the National Institutes of Health (NIH), a disease is rare if it affects fewer than 200,000 people. Nearly 1 in 10 Americans live with a rare disease—affecting 30 million people—and nearly half of these patients are children. There are more than 7,000 rare diseases and only approximately 450 FDA-approved medical treatments.

Rare Disease Day takes place every year on the last day of February (February 28 or February 29 in a leap year)—the rarest date on the calendar—to underscore the nature of rare diseases and what patients face. It was established in Europe in 2008 by EURORDIS, the organization representing rare disease patients in Europe, and is now observed in more than 80 nations. Rare Disease Day is sponsored in the U.S. by the National Organization for Rare Disorders (NORD)®, the largest and leading independent, nonprofit organization committed to the identification, treatment, and cure of rare diseases. For more information about Rare Disease Day in the U.S., go to www.rarediseaseday.us. For information about global activities, go to www.rarediseaseday.org. To search for information about rare diseases, visit NORD’s website, www.rarediseases.org.

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