

MSU, Rare Disease Day Press Release



FOR IMMEDIATE RELEASE

Myositis Support and Understanding Association Supports Rare Disease Day® and Joins Global Movement to Raise Important Awareness for Rare Diseases

Lincoln, DE—February 20, 2018—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. 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.

As part of the MSU patient-centered focus and commitment to educating and supporting those with myositis, a rare disease, MSU is hosting two live online video education sessions on Rare Disease Day, February 28, 2018, as well as a month-long celebration with patient support and activity sessions. The focus for MSU is the idiopathic inflammatory myopathies, which includes dermatomyositis, polymyositis, juvenile dermato- and poly- myositis, inclusion body myositis, and necrotizing autoimmune myopathy.

Dr. Victoria Werth, MD, will join MSU for a live, online video education session titled “Overview and new developments in dermatomyositis” at 2PM EST on Rare Disease Day.

Also, Nurse Vicky Starr, RN, IgCN, will join MSU for a live, online video education session at 6PM EST on Rare Disease Day, titled “IV and SubQ IG Therapy for Myositis.”

Register for these online video education sessions by visiting the MSU Events page at UnderstandingMyositis.org/events. Both Rare Disease Day events are open to the public and are free of charge. For assistance with these sessions, please contact Jerry Williams at info@understandingmyositis.org.

Jerry Williams, Founder and President of MSU, will also be attending Rare Disease Week on Capital Hill this year to learn more about advocacy efforts for Rare Disease patients and to discuss several topics of interest for the myositis community with lawmakers and other Rare Disease advocates.

MSU works each and every day to give Myositis patients a brighter future. Aside from the important support, advocacy, and education programs, MSU also offers a need-based financial assistance program for myositis patients for medical-related expenses and travel, as well as some household expenses.

MSU helps to match patients with clinical trials to help researchers find the often-difficult number of patients required for a rare disease clinical trial, and to help patients access these important myositis research studies.

“Rare Disease patients, in our case those living with one of the idiopathic inflammatory myopathies (myositis), are often well-educated patients because they are willing to research and reach out to others for shared experiences in order to learn more about their disease so they can effectively advocate for themselves and make informed medical decisions,” says Jerry Williams.

MSU, Rare Disease Day Press Release



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. With Myositis, the estimates are approximately 50-75K patients are living with a type of myositis in the U.S.

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.

For more information about idiopathic inflammatory myopathies (myositis) visit UnderstandingMyositis.org.

###

Media contacts:

Jerry Williams, MSU, info@UnderstandingMyositis.org

Laura Mullen, NORD, 203-744-0100, media@rarediseases.org

rarediseaseday.us