



## FOR IMMEDIATE RELEASE

### **Myositis Support and Understanding Joins Rare Disease Day® and the Global Movement to Raise Important Awareness for Rare Diseases**

**Lincoln, DE—February 22, 2016** — For the third year in a row, Myositis Support and Understanding Association (MSU) has joined forces with rare disease patients and health care advocates in the United States and around the world for **Rare Disease Day®** held on February 29, 2016. Rare Disease Day is an annual awareness day dedicated to elevating public understanding of rare diseases and calling attention to the special challenges faced by patients and the community.

This year's Rare Disease Day theme, "Patient Voice," is in line with what MSU does every day to give patients with Myositis a voice by:

- Providing various avenues of support which allow MSU members and Myositis patients to help each other, support each other, brainstorm ideas, ask important questions to hear the experiences of others, find their voice in talking with other patients living with the same disease, and, hopefully, to their family members.
- Supplying patients and caregivers with information to educate themselves and with materials that they can take to doctors who are not familiar with Myositis; helping them to best advocate for themselves to get better care.
- Helping members and patients polish and edit letters and correspondence they are sending to insurance companies, legislators, and policy makers to plead their own case regarding disability, health care matters, etc.
- Inviting patients and caregivers to write their stories to share with the Myositis community, and through the MSU website, because sharing a personal story is cathartic and can help many others facing a similar struggle, and sharing victories can provide hope to others.
- Speaking to policy makers, legislators, insurance companies, and other government agencies about the plight of Myositis patients, their medical and financial needs, and rights.
- Allowing patients with Myositis to ask for help when MSU is able to start its Financial Assistance program, which will pay expenses for patients to travel to see doctors familiar with Myositis, help patients who are struggling with high medical bills pay medical expenses, and help patients pay emergency household expenses when everything seems insurmountable. Patients with financial hardships on top of their health often feel even more stifled, and MSU will help them feel free to live their best life, despite illness.

"We want our members to know they are not alone in their struggle even though it may seem that way at times, especially when they are denied life-improving treatments because Myositis is rare and poorly understood," says Jerry Williams, Founder and President of MSU.

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 two-thirds of these patients are children. There are more than 7,000 rare diseases and only approximately 450 FDA-approved medical treatments.

MSU focuses on the Inflammatory Myopathies, which are commonly termed "Myositis." These include Polymyositis, Dermatomyositis, and Inclusion Body Myositis, each being a rare disease. It is currently estimated that 50-75k people in the United States are living with a form of Myositis, and there is no cure.

Due to the rarity of the Myositis, patients often spend months to years trying to get a correct diagnosis. Part of the issue is diagnosing and treating Myositis, which falls within three specialties: Rheumatology, Neurology, and Dermatology. On top of these specialties, patients may also see other disease-related specialists such as Pulmonologists (for Interstitial lung disease, pulmonary fibrosis), Speech Therapists (for dysphagia), and pain management specialists as Myositis causes pain in approximately 40% of patients. Often, just finding a doctor that has experience with Myositis is a struggle and may require travel.

The difficulties patients living with a rare disease face are complicated and this is part of what makes Rare Disease Day important. These patients must be recognized for the battles they endure, some without support or understanding, and at times with little interest from the medical community in terms of research or treatment, let alone a cure. Rare Disease Day highlights the issues and starts a much-needed conversation about what can be done to better improve the patient's quality of life and to jumpstart the medical community into action.

Jerry Williams adds, "We must rise up and educate, advocate, support, and aid those living with and supporting rare disease patients. If we hope to make any difference, we must all become involved, at some level, to help nonprofits like MSU succeed in their mission. We must be active participants as patients, caregivers, family members, and friends in raising funds, extending outreach and education, and helping others to recognize and better understand our disease."

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)<sup>®</sup>, a leading independent, non-profit 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](http://www.rarediseaseday.us). For information about global activities, go to [www.rarediseaseday.org](http://www.rarediseaseday.org). To search for information about rare diseases, visit NORD's website, [www.rarediseases.org](http://www.rarediseases.org).

For information about MSU's Rare Disease Day plans, and to learn about Myositis, visit [www.UnderstandingMyositis.org/rare](http://www.UnderstandingMyositis.org/rare).

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