

Honoring and remembering those lost due to myositis on May 20, 2018, during Myositis Awareness Month

May is Myositis Awareness Month and MSU will host an event to honor and remember those lost due to myositis

LINCOLN, DE, UNITED STATES, May 8, 2018 /EINPresswire.com/ -- MSU, in participation with Corbus Pharmaceuticals, Idera Pharmaceuticals, and Diplomat Specialty Infusion Group, as a part of [Myositis Awareness Month](#) will host a live streaming YouTube video event, "[Myositis in Focus: A Day of Remembrance](#)," on Sunday, May 20, 2018, starting at 2 PM EDT.

MSU's honor and remembrance of those who have lost their lives fighting myositis is also a call to action: to iterate the urgent need for safe, effective, and accessible therapies, the importance of patients getting involved in clinical trials and research projects, the opportunities for sharing data with industry and research collaborations, and to increase education, outreach, awareness, and funding.

Myositis refers to a group of rare autoimmune diseases called Idiopathic Inflammatory Myopathies.

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If you have lost a loved one due to myositis, or associated complications of myositis, I hope you will share their name and photo with us so that we may remember them publicly on May 20, 2018.”

Jerry Williams

Each form of myositis is different, as is each patient and how they present with symptoms, respond to therapies, and with which complications they may experience. Myositis is an often-disabling disease and one that may be invisible to the eye. For some patients the disease is fatal.

Jerry Williams, Founder and President of MSU, observes, "We often build close, personal relationships with our members as a part of our patient-centered support programs and through our direct patient and caregiver communications. The sadness of these losses drive us to continue working hard to provide for patients, caregivers, family members, and friends

and to coordinate efforts with outside organizations to fulfill our mission and bring 'Myositis in Focus.'"



**"MYOSITIS IN FOCUS:
A DAY OF REMEMBRANCE"**
SUNDAY, MAY 20, 2018, 2 PM EDT

Join us for a live streaming YouTube video event to honor and remember those we have lost due to myositis.

IN PARTICIPATION WITH THE FOLLOWING SPONSORS

CORBUS PHARMACEUTICALS | **DIPLOMAT** Specialty Infusion Group | **idera**

Myositis In Focus: A Day of Remembrance

 **Myositis Support and Understanding**

Myositis Support and Understanding Association logo

Myositis is understood to be potentially life-threatening due to the complications of the disease itself, or due to secondary factors like infections, associated malignancies, and other concomitant or related conditions. These diseases have no cure; however, in recent years, the life-expectancy of patients with the disease has improved greatly. Many people live long, happy, "productive" lives, some even thrive with few health complications, as the medical knowledge around the diseases has expanded.

Lauren Landman answers why she feels it is important to better awareness saying, "The answer to that is quite simple, it's because my family and I lost our dad to Dermatomyositis. The severe physical pain and emotional stress he had to live with while struggling to find answers was unimaginable. Watching your parent go from being completely able-bodied to sick and unable to care for himself in just six months is something I cannot put into words. Perhaps, the most frightening part of this whole experience was that he was misdiagnosed multiple times thus delaying potential treatments that could have saved his life. The lack of knowledge and understanding of Myositis in the medical community is detrimental and quite frankly, unacceptable. I wish simply to shed light on what needs to be changed in order to prevent others from experiencing the pain my dad endured. I do not say this with anger nor resentment but rather, passion and love in honor of my dad, Robert Landman. Although it saddens my family and I deeply to know he had so much more of his life to live, it gives us happiness to know his story can help others."

In MSU's support groups, there are patients at all levels of the disease process from full un-medicated remission, to medicated remission, to refractory illness (medication resistant), to very ill. For patients with inclusion body myositis, remission is not yet a possibility since there are no available treatment options and patients slowly progress towards full disability. Many patients spend the rest of their lives battling the effects of the disease and the harsh medication side effects. Sadly, MSU, as a community, has seen the loss of many of its members and friends as well.

When asked about why she thinks the day of remembrance is an important aspect of [Myositis Awareness Month](#), Emily Filmore, co-founding director and current board advisor explains, "It touches my heart because dealing with the daily effects of a potentially fatal illness is a continual reminder of our mortality. At the same time that I am grateful for every day I have, I am mindful of my lost friends and the loved ones they left behind. I believe that in living my best life I honor their memory, in taking care of and providing support to each other I believe we, at MSU, celebrate their lives, and in pushing for more awareness and research we all pay our respects to the profound sadness we feel whenever we lose another myositis patient to the disease."

If you have lost a loved one due to myositis, or associated complications of myositis, MSU is asking you to consider sharing their name and some brief information to be included publicly during this event. Names can be shared using the online form at UnderstandingMyositis.org/in-memory through May 13, 2018.

Join us in remembering those who lost their lives fighting inclusion body myositis, dermatomyositis, polymyositis, antisynthetase syndrome, necrotizing autoimmune myopathy, juvenile dermatomyositis, and other forms of the inflammatory myopathies.

Jerry Williams
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This press release can be viewed online at: <http://www.einpresswire.com>

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