

# May is Myositis Awareness Month and Myositis Support and Understanding Association's 5-year anniversary

*During May, MSU honors Myositis Awareness Month and celebrates its 5th anniversary with an adapted and timely theme, High Fives from the Heart*

LINCOLN, DE, UNITED STATES, April 30, 2020 /EINPresswire.com/ -- Myositis Support and Understanding (MSU), an all-volunteer, patient-focused 501(c)(3) nonprofit organization, serves as the heart of the myositis community. During May, MSU honors [Myositis Awareness Month](#) and celebrates its 5th anniversary with an adapted and timely theme, High Fives from the Heart: #MyositisLIFE in a Pandemic World.



High Fives from the Heart

While the original theme was being discussed and formulated, the world turned upside down with the appearance and rapid worldwide spread of COVID-19. MSU quickly shifted focus to how to best support the myositis community during the pandemic while still promoting awareness of our rare autoimmune diseases, the idiopathic inflammatory myopathies, collectively called myositis. MSU's entire community looks forward to a more robust celebration of awareness activities in September.

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As a community, we can gather virtually and share High Fives from the Heart to make our #MyositisLIFE better in a Pandemic World.”  
*Jerry Williams, MSU Founder & President and myositis patient*

MSU launches a slightly scaled back Myositis Awareness Month, mindful of the enormous impact the pandemic has and will continue to have on myositis patients and caregivers.

How MSU has adapted to include relevant issues pertaining to COVID-19

To honor MSU's 5th Anniversary they will use Myositis Awareness Month to highlight the five main patient-centered programs that are a part of MSU's mission to improve the lives of and empower those fighting myositis. As a patient-led organization, the programs MSU offers and develops are truly from the heart. The volunteers that run MSU understand what life is like living with myositis since they live it too.

Here are some examples of the adaptations of awareness activities to include relevant issues pertaining to COVID-19.

Education – [Webinars with myositis experts](#) exploring the unique health issues COVID-19 presents to myositis patients, coping strategies from mental health experts and caregivers on how to deal with isolation, anxiety, stress and the new normal; updated information on the pandemic from trusted sources, and other information specific to the autoimmune/myositis community that is unrelated to COVID-19.

Support – MSU’s Myositis Patient Video Support sessions provide a safe and confidential outlet for fellow patients to interact in fun and sometimes serious conversations with others who are similarly situated and possibly staying home more due to COVID-19. This may be because of age, mobility issues, and/or compromised immune systems. MSU hopes this support and face-to-face contact helps patients feel

less alone in this scary time. The organization continues maintaining a safe and compassionate environment for patients and caregivers in the online support groups during the pandemic.

Financial Assistance – Allocating at least \$60,000 for patient financial assistance to help myositis patients during the COVID-19 pandemic, with a higher priority on applications for emergency household expenses and medical bills. Financial assistance in the amount of \$1500 per patient per rolling year is available for medical and non-medical expenses, including but not limited to rent and mortgage assistance, utility bills, mobility and assistive devices, medical bills, and other emergency household expenses.

Advocacy and Outreach – Patient stories and projects on the #MyositisLIFE website to raise awareness of the impact of COVID-19 on myositis patients’ lives. [Myositis Mask Memes](#) – telling the story of how COVID-19 impacts #MyositisLIFE, sponsored by Corbus Pharmaceuticals. Working with researchers and clinicians to help them understand how COVID-19 affects those with autoimmune disease, immune suppression, and specifically myositis. Working together with specialty pharmacies to assist patients in obtaining their infusion medications.

Research – MSU has formed a new partnership with The Global Healthy Living Foundation to promote a deeper understanding of the impact of COVID-19 on the myositis community. The patient research survey is available in the U.S. and Canada. Additional details can be found on the MSU website. MSU is communicating with its partners and sponsors to provide the community with any changes to the status of ongoing and upcoming clinical trials for myositis.

MSU invites the community to join in participating in Myositis Awareness Month events and educating family and friends about myositis.

“We know this awareness month will be different than others, and in many ways we will miss our usual activities, but we do have some great support and educational events planned to bring us together. As a community, we can gather virtually and share High Fives from the Heart to make our #MyositisLIFE better in a Pandemic World.” -Jerry Williams, President and Founder, Myositis Support and Understanding.



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