

FOR IMMEDIATE RELEASE

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Myositis, a rare muscular inflammatory disease that often goes undiagnosed or misdiagnosed, disproportionately impacts women of color

Awareness campaign kicking off Myositis Awareness Month aims to ensure the over 75,000 people with the disease are diagnosed and get treated

(NOTE: A webinar with doctors who specialize in myositis and a patient who suffers from the disease will be held on May 8 at 12:00PM eastern. More information below.)

Arlington, VA (May 1, 2019) – Dale Scott was in her 50s when she started having trouble falling, because her legs were too weak for her to keep her balance. She also started noticing unusual rashes on her hand, and she was having trouble breathing. It took more than a year and seven different doctors to figure out that she had myositis, a rare inflammatory disease of the muscles.

An estimated 75,000 Americans suffer from myositis, a chronic, debilitating disease, yet many do not know it or are misdiagnosed with other, more common, autoimmune diseases. Often even doctors are not aware that muscle weakness, pain, extreme fatigue, and a characteristic rash may be signs of myositis. Delays in diagnosis, however, can be catastrophic in terms of disability, long-term physical damage, and even death. This is especially significant for African Americans and women of color.

“Many patients think symptoms like falling or feeling fatigued are just part of getting older,” says Mary McGowan, Executive Director of The Myositis Association. “Patients – especially African American women who are more likely to suffer from the disease – need to know that these warning signs should not be ignored. Early diagnosis and prompt treatment results in better patient outcomes. It is imperative that they seek a diagnosis and care as soon as they experience symptoms and that they’re educated enough about this rare disease to raise it with their doctors.”

[A new analysis released today by The Myositis Association \(TMA\)](#) shows that nonwhite women are twice as likely to die than others with the disease, and they are four times more likely to die than white men with the disease. In childbearing years (ages 15-34), mortality in nonwhite women is 3.5 times higher than in Caucasian women.

“We are on a mission to raise awareness about myositis, and in particular among the communities it affects most – women of color,” added McGowan. “Patients need to be educated, as do doctors who are on the front lines of making an accurate medical diagnosis, including dermatologists, rheumatologists, and pulmonologists.”

SIGNS of MYOSITIS

Myositis is a rare autoimmune disease involving chronic inflammation of the muscles, often occurring together with other symptoms. Symptoms of weakness, swelling, and muscle damage often appear gradually. Early, often missed, signs of myositis include:

- Trouble getting up from a chair, climbing stairs, or grasping objects with their hands.
- Unexpected falls
- Difficulty reaching arms up
- Difficulty swallowing

Myositis is not an equal opportunity disease. Myositis experts often say that dermatomyositis (DM) is the easiest form of myositis to recognize. In addition to extreme weakness and fatigue, patients often present with an obvious rash that is distinctive for DM. For those with darker skin such as African Americans and other people of color, however, the red or purple blotchiness over the shoulders and chest or around the eyes may not be as easy to identify as it is on lighter skin.

"Since women of color with dermatomyositis are at increased risk for mortality, early access to diagnosis and treatment is particularly important," says Michael Walsh, Executive Director of the Derma Care Access Network.

BACKGROUND on MYOSITIS

On average it takes more than three-and-a-half years and five doctors to receive a correct autoimmune disease diagnosis. Myositis patients—including frantic parents of drastically weakened children—find that a great deal of damage is done during this wait.

The disease is highly variable and has been classified into a number of forms, including [dermatomyositis](#) (DM), [polymyositis](#) (PM), [necrotizing myopathy](#) (NM), [sporadic inclusion body myositis](#) (sIBM), and [juvenile forms of myositis](#) (JM). Myositis is often accompanied by antisynthetase syndrome, a condition that makes it difficult to breathe because of scarring of the lungs due to interstitial lung disease (ILD).

The Myositis Association's [analysis](#) how there are other differences in how the diseases affect people of color as well:

- Women with DM, PM, and NM outnumber men by 2:1.
- African American myositis patients are at greater risk for developing antisynthetase syndrome than Caucasians.
- African American patients with antisynthetase syndrome experience more severe lung involvement than white patients.
- African Americans with ILD are usually younger at diagnosis.
- Nonwhite women die at a younger age than others with DM and PM.
- Nonwhite women with multiple chronic conditions have the highest rates of hospitalization for dermatomyositis.

- Nonwhite DM patients have greater lengths of stay and higher costs of care when they are hospitalized.
- African American children with JDM have an increased risk of developing calcinosis, a condition in which hard lumps of calcium form under the skin.

WEBINAR DETAILS

WHAT: Women of color and myositis: signs of the disease, misdiagnoses, treatment, and what women of color and their doctors should know

WHEN: Wednesday, May 8 at 12:00 PM eastern time

WHO:

- Mary McGowan, Executive Director, The Myositis Association
- Sonye Danoff, MD, PhD, Co-Director, Interstitial Lung Disease Clinic at Johns Hopkins University Medical Center and Associate Director of the Hopkins Myositis Center
- Cheilonda Johnson, MD, MHS, Assistant Professor of Medicine, Hospital of the University of Pennsylvania
- Myositis patient

Please RSVP in advance, [here](#).

To set up an interview with a local patient, myositis medical experts, or TMA's executive director, contact Linda Kobert at 434-882-2189 or linda@myositis.org.

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The Myositis Association is the leading international organization committed to the global community of people living with myositis, their care partners, and family members. The nonprofit provides patient education and support, advocacy, physician education, and research funding for myositis diseases. Learn more at myositis.org.