May is Myositis Awareness Month

May 1, 2018

Thousands of Americans may suffer from a chronic disease and not even know it. The purpose of Myositis Awareness Month is to create awareness about a little-known disease of the muscles that causes weakness, pain, and disability. Nationwide, myositis patients and their families observe the month of May as a time to educate the community about their rare disease. This month-long observance recognizes the need for more research and understanding of myositis in the hope of faster diagnoses, better treatments, and ultimately a cure. This month is an opportunity for advocates at national and local levels to inform the public about these rare diseases.

On average it takes more than 3 years and 5 doctor visits to receive a correct autoimmune disease diagnosis. Myositis patients—including frantic parents of severely weakened children—find a great deal of damage is done during this wait. Raising awareness of myositis, its symptoms, and treatments will help these patients and families.

“Our biggest challenge is to create awareness for the disease, so patients can seek an accurate diagnosis,” says Dr. Lisa Christopher-Stine, director of the Johns Hopkins Myositis Center. “Because damage caused by myositis can occur in the first few years, early diagnosis means early treatment to improve quality of life.”

While there is no cure yet for myositis, some treatments are available. They include medications, exercise, lifestyle adaptation, and support from patients with the same diagnosis. Starting a treatment plan early is essential to ensure the best possible outcomes and highest quality of life.

“For any rare disease, particularly one as rare as myositis, creating public and physician awareness of the disease ensures quicker diagnosis and a better outcome for the patient,” says Bob Goldberg, Executive Director of The Myositis Association. “By asking our members and friends to spread awareness, we hope to inform the public and improve the outcome for anyone having to live with this debilitating disease.”

About Myositis

Myositis is one of 80 autoimmune diseases affecting nearly 50 million Americans. It is one of the rarest of the autoimmune diseases, and its different forms—dermatomyositis, polymyositis, necrotizing myopathy, and inclusion body myositis—may affect 50,000-75,000 adults and children in the United States, although precise numbers are not known. Each of the four forms causes weakening of skeletal muscle, often beginning with the shoulders and thighs. The average time from onset of symptoms to diagnosis is between three and four years. These critical years are when significant damage can take place.

About The Myositis Association (TMA)
The Myositis Association provides information and support to the myositis community and physicians who treat patients with the disease. TMA also funds research in search of better treatments and a cure. TMA’s member and patient support network spans the globe.

The mission of TMA is to increase support, awareness, and funding for the myositis patient, caregiver, and research community. If you feel you or a loved one are experiencing symptoms of myositis, consult with your physician for diagnosis and visit www.myositis.org for more information to help manage the disease.

Journalists are invited to attend any conference activities. Find more information about myositis at myositis.org. For photos, or to set up an interview with a local patient, myositis medical experts, or TMA’s executive director, call TMA Communications Director Linda Kobert at 434-882-2189 or email linda@myositis.org.