

Rare Disease Organization Offers Unique Educational Event

The Myositis Association teaches patients and families how to live well with the rare disease myositis

ALEXANDRIA, VA, USA, September 3, 2019 /EINPresswire.com/ -- The premiere [myositis](#) patient education event of the year, hosted by the world's leading myositis patient organization, [The Myositis Association](#) (TMA), takes place in Minneapolis on September 5-8.

TMA's [Annual Patient Conference](#) brings together nearly 500 myositis patients and family members to learn how to live more fully with one of these rare, debilitating diseases of the muscles. This year's theme, "Who you are matters," highlights the diversity of experiences these diseases can cause for those diagnosed with myositis. More than 90 sessions during the four-day event offer information and resources focusing on these individual differences.

Featured among the weekend's speakers will be members of TMA's Medical Advisory Board, global leaders in myositis research and clinical care, reporting on the latest findings from myositis studies, exciting new therapies, and reflections on cutting-edge treatments. TMA's Medical Advisory Board is comprised of 23 of the world's foremost myositis experts from such distinguished institutions as Mayo Clinic, Johns Hopkins University, the NIH, and UCLA. These experts will be joined by their international colleagues from France, Sweden, Germany, and the Netherlands.

This conference offers more than 60 additional speakers leading sessions on exercise, nutrition, adaptive technologies, coping with a chronic disease, and more. Sessions focused on the needs of care partners are also a priority, including sessions on mental health and finding helpful resources. Equally as important, this gathering gives individuals, who often struggle alone with a largely unknown condition, the chance to meet and share experiences with others who also live with similar challenges.

"Because myositis diseases are rare, many physicians have never seen a patient with myositis," says TMA Executive Director Mary McGowan. "It can take years for patients to receive an accurate diagnosis. This conference is the best place for those who live with these chronic, often disabling conditions to learn about their own disease, so they can work better with their healthcare team."

Psychologist Mary E. Siegel, PhD, coauthor of *Sick and Tired of Feeling Sick and Tired: Living with*

Invisible Chronic Illness kicks off the event with a keynote address focused on a topic that attendees know intimately: how to manage in the world when you have a chronic, debilitating disease that is often invisible.

Also offering words of support will be Sarah Franz, Outreach Director from the Office of Senator Amy Klobuchar (MN) who serves as co-chair of the US Congressional Rare Disease Caucus.

Myositis is a diagnosis that includes dermatomyositis, polymyositis, necrotizing myopathy, and inclusion body myositis. Patients cope daily with many challenges ranging from extreme muscle weakness and painful rashes to complete disability. They also face a number of other life-threatening disorders, including interstitial lung disease, antisynthetase syndrome, and a higher risk of cancer and other diseases. These are diseases that are difficult to diagnose and difficult or impossible to treat. There is no cure.

As a way of helping participants share their journey through the challenges of their disease, advocacy coach, John Capecci, PhD, leads workshops designed to help participants craft their personal story. Being able to speak more effectively about their experiences will help patients bring essential awareness that will improve patient outcomes for those who live with myositis.

In an effort to increase awareness among health care professionals, the weekend also features a Myositis Medical Symposium. In this day-long session, designed for medical professionals, members of TMA's Medical Advisory Board share the results of their latest research.

Myositis patients, their care partners, and families can register in person at the DoubleTree by Hilton Bloomington – Minneapolis South on Thursday, September 5, after 10am. TMA is grateful to platinum sponsor Mallinckrodt Pharmaceuticals for supporting the 2019 Annual Patient Conference.

About The Myositis Association

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

Contact:

Journalists are invited to attend any conference activities. More information about myositis and the conference at www.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 434-882-2189, email linda@myositis.org.

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