Nearly half a million dollars in grant funding for rare disease research reaps rewards for myositis patients

Bringing hope to those who live with rare diseases

COLUMBIA, MD, UNITED STATES, January 28, 2025 /EINPresswire.com/ -- The Myositis Association (TMA) recognizes that the best hope for a cure for myositis diseases lies in research. Since 2002, TMA's annual research funding program has approved 68 projects totaling nearly $8.2 million to study the underlying causes and natural progression of myositis, develop better treatments and more effective therapies, and ultimately to create a cure for this collection of rare, disabling conditions.

> "These projects help us under the different forms of myositis, bringing hope to those of us who live with these debilitating conditions for which there are few, if any, effective treatment options."
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> *Martha Arnold, former member of TMA's Board of Directors*

TMA funds projects across the spectrum of myositis diseases for researchers around the globe. We are pleased to announce that in 2024 three of these research projects, totaling nearly half a million dollars, were completed.

• A pilot grant of $200,000 to Cheilonda Johnson, MD, MHS, Assistant Professor of Medicine (Pulmonary, Allergy and Critical Care) at the University of Pennsylvania School of Medicine, Philadelphia, PA. Dr. Johnson's project identified specific genes associated with interstitial lung disease (ILD) that occur in those with myositis and created a database of lung tissue samples from patients with different forms of the disease. This project showed that having myositis genes not only predicts if a person is at risk for developing ILD, but also the type of myositis genes predicts which patients are at higher risk for severe disease.

• A clinical research fellowship grant of $100,000 to Alexander Oldroyd, MD, Academic Clinical Lecturer at the University of Manchester, Manchester, England, UK. Dr. Oldroyd helped to develop a smart phone application to remotely monitor continuous activity levels of patients with myositis with the ability to detect disease symptom-based flares. Not only can this provide a more accurate measure of disease activity, but it can be a more accurate measure of treatment effectiveness that can be valuable for clinical trials.

• A research fellowship grant of $100,000 to Chiseko Ikenaga, MD, PhD, Assistant Professor of Neurology at Kitasato University, Tokyo, Japan. During the fellowship, Dr. Ikenaga worked with neurologist Dr. Thomas Lloyd at the Myositis Center at Johns Hopkins University School of Medicine, Baltimore, MD. Dr. Ikenaga demonstrated that there is a genomic pathway related to stress that may cause critical muscle damage in patients with inclusion body myositis (IBM). This pathway is associated with atrophy of muscle fibers and inflammation and can be a potential target for drug therapy.

“These projects advance our understanding of different forms of myositis, bringing much-needed hope to those of us who live with these rare, debilitating conditions for which there are few, if any, effective treatment options,” says Martha Arnold, former member of TMA’s Board of Directors, who lives with inclusion body myositis.

About Myositis

Myositis is a collection of rare autoimmune diseases of the muscles that cause severe pain and weakness, debilitating skin rashes, scarring of the lungs, and other life-threatening symptoms. These chronic, disabling conditions are a challenge to diagnose, are difficult or impossible to treat, and have no cure.

About The Myositis Association

The Myositis Association is an international nonprofit organization committed to support and education for myositis patients and caregivers, increasing awareness of myositis throughout the community and among physicians, and funding for myositis-related research.

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