

Myositis Studies at the National Institute of Environmental Health Sciences (NIEHS), National Institutes of Health

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What is myositis?

Myositis is a related group of autoimmune diseases that results in muscle inflammation and muscle destruction.

What are the types of myositis?

Dermatomyositis – Myositis with characteristic skin rashes.

Polymyositis – Myositis with no characteristic skin rashes in which the immune system directly attacks the muscles.

Inclusion-body Myositis – Myositis mainly characterized by progressive weakness and wasting of muscles.

Juvenile Myositis – Myositis that begins during the childhood years.

What are the symptoms of myositis?

Each patient has a different combination and severity of symptoms. Symptoms may include the following:

- Muscle weakness, resulting in trouble performing everyday tasks, such as climbing stairs or lifting objects
- General tiredness
- Difficulty swallowing
- Rashes on the knuckles, face, and chest
- Chronic dry cough or difficulty breathing
- Arthritis
- Calcinosis

What causes myositis?

The causes of myositis are currently unknown. NIEHS conducts studies to determine what environmental exposures and genetic factors may be contributing to the onset of these diseases.

What studies are being led by NIEHS?

Twin Sibling Study

The Twin Sibling Study looks at people with myositis who have been diagnosed within the past five years, and their close-in-age, same sex healthy sibling or twin. The goal is to identify the genetic and environmental factors that may result in autoimmune disease in one sibling and not the other. Parents may also enroll in this study.

MYORISK Study

The MYORISK Study is investigating if certain infectious or noninfectious factors are associated with myositis, especially in people with lung disease and arthritis who have a particular myositis autoantibody. People diagnosed with myositis in the past two years and healthy volunteers are eligible to participate.

Military Myositis Study

The Military Myositis Study looks at risk factors for the development of myositis that are unique to military personnel. People who developed myositis while under active duty military service are eligible to participate. Healthy individuals can also enroll.

Myositis Natural History Study

Many patients enrolling in NIEHS myositis studies at the NIH Clinical Center in Bethesda, Maryland, also may enroll in this study, which provides a thorough evaluation of each patient's myositis and enables NIEHS physicians to make treatment recommendations. On occasion, myositis patients may enroll only in this study. Currently this includes patients in which two or more relatives have myositis and certain patients with calcinosis.



What do the studies involve?

- The studies will involve physical examinations, blood draws, completing questionnaires, and meeting with nationally recognized myositis physicians and researchers.
- A thorough clinical evaluation is provided for patients enrolling through the NIH Clinical Center in Bethesda, Maryland. These medical reports can also be shared with your physicians.
- Myositis patients may be eligible for multiple studies.
- There is no charge for evaluations and medical tests.
- Compensation for each study will be provided.
- No medications or therapies are provided.
- Housing or hotel accommodations may be provided for study volunteers at the NIH Clinical Center in Bethesda, Maryland.
- The Twin Sibling Study is also investigating other autoimmune diseases, such as rheumatoid arthritis, juvenile rheumatoid arthritis, lupus, and scleroderma.
- Healthy individuals may also enroll in each of these studies as control subjects for the research.

Why should I participate in a research study?

Your participation may provide new information about your illness to you and your doctors. This information may also help to treat, prevent, and diagnose others with myositis.

Do I qualify for a myositis study?

To be included in one of the studies, you must meet the following criteria:

- Have been diagnosed with adult or juvenile myositis.
- Be able and willing to provide consent and undergo study procedures.

Where will the studies be conducted?

- National Institutes of Health Hatfield Clinical Research Center, Bethesda, Maryland.
- NIEHS Clinical Research Unit, Research Triangle Park, North Carolina.
- At one of several medical centers across the country.
- At your local physician's office.

Where can I get more information about eligibility for a study?

www.niehs.nih.gov/research/clinical/bethesda/participants/index.cfm.

Tel: 800-411-1222

Who do I contact to participate in the study or if I have more questions?

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