

Myositis Studies in the Environmental Autoimmunity Group (EAG) at the National Institute of Environmental Health Sciences (NIEHS)

What is the NIH?

The National Institutes of Health (NIH) is recognized as the nation's medical research center. The goal of NIH research is to gain new knowledge to help prevent, detect, diagnose, and treat disease and disability. This includes understanding the rarest genetic disorder to developing state of the art treatments for cancer and many different conditions.

Over 10,000 patients are seen at the NIH Clinical Center annually, and they come from all over the country and the world. The NIH is primarily located in Bethesda, MD, approximately 30 minutes north of Washington, DC. The NIH consists of 27 institutes, one of which is the National Institute of Environmental Health Sciences (NIEHS).

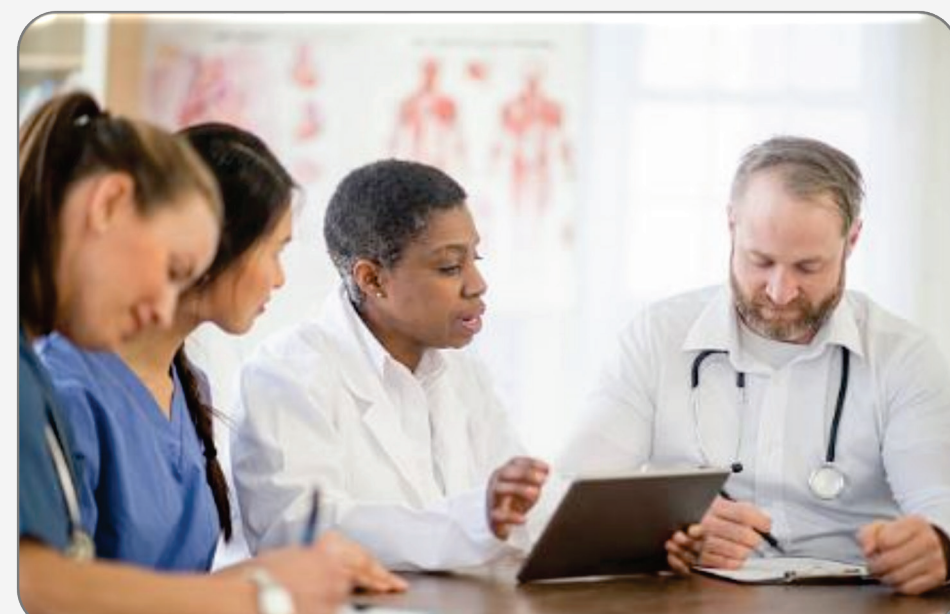


What is research?

One of the goals of health research is to learn more about a disease, attempt to understand how and why a disease happens, which helps to identify better treatments, and ultimately cure people of their disease.

Physicians who are part of NIEHS are conducting clinical research studies on myositis and other systemic autoimmune diseases in children and adults, and we are looking for your help! You can make a difference by joining a research study.

What are the benefits of joining a research study?



- Taking a more active role within your own health care and having the opportunity for improved health
- Receiving detailed medical evaluations and testing from experts at the NIH.
- Minimal costs, including meals and travel (travel programs available by patient application). Lodging is generally covered, and there is no charge for the medical testing in the study.
- In a treatment study, you may have access to medication not available to the general public
- You will be helping to move research forward!

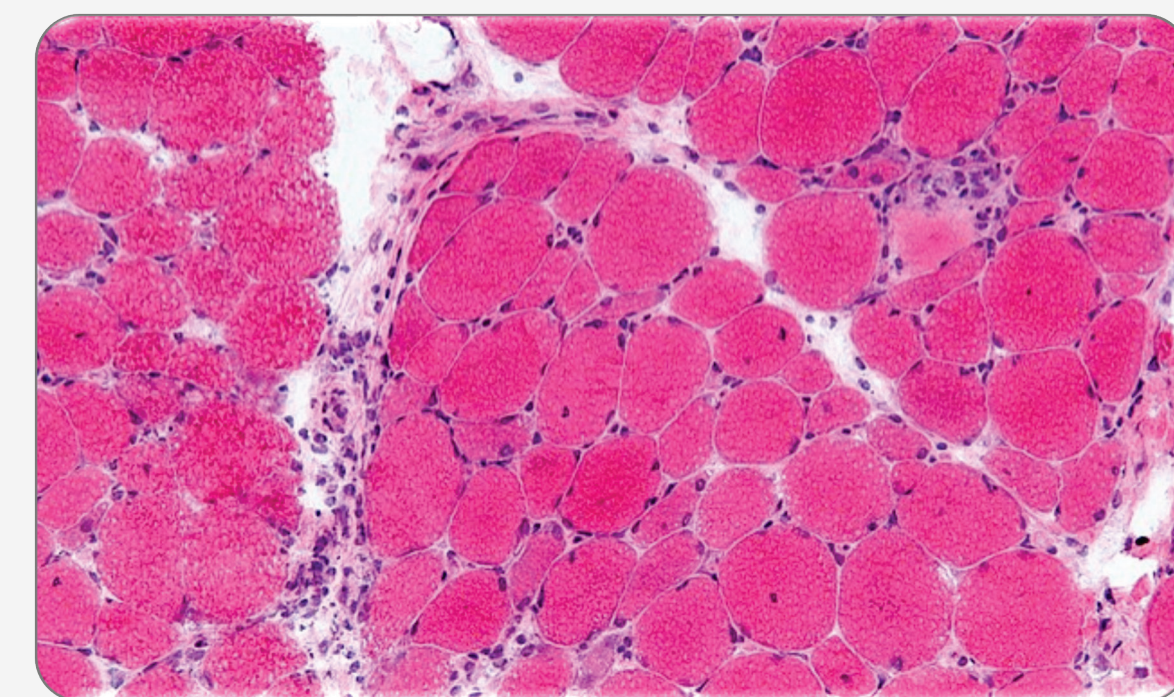
What are the actively enrolling studies in the EAG at the NIEHS?

Myositis Natural History Study

The Myositis Natural History Study enrolls patients with a diagnosis of myositis, unaffected family members, and healthy control subjects. The study provides a thorough evaluation of each patient's myositis and enables NIEHS physicians to make treatment recommendations. Current enrollment priorities include patients with potential to enroll in other EAG studies, as well as patients in which two or more relatives have myositis, those with certain environmental exposures, and selected others. Most patients will enroll at the NIH Clinical Center in Bethesda, MD and some patients may enroll at home through a telehealth visit.

FAST for DM Clinical Trial

The FAST for DM clinical trial will examine the effects of Omega-3 fatty acid (O3FA) supplementation, along with a study diet based on a healthy diet pattern, on dermatomyositis disease activity in a randomized controlled clinical trial at the NIH Clinical Center. As part of this study, patients will receive dietary coaching and take 4 fish oil or placebo softgel capsules twice a day. Adults ages 18-60 years with mild to moderately active dermatomyositis (DM)/juvenile dermatomyositis (JDM) meeting study criteria will be seen over 9 months with 5 in-person visits in addition to telehealth visits. Patients will undergo thorough evaluations, complete online questionnaires, provide blood, urine, and stool samples, and complete MRIs and other testing. Some study activities will be completed at home including dietary coaching and watching videos about the study diet online.



You may qualify to enroll in more than one study, and there is no charge for evaluations and medical tests in these studies. However, we do not provide compensation for transportation to the NIH Clinical Center. The only study that offers a study treatment is **FAST for DM**.

What are some qualifications you need to enroll?

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

- Have been diagnosed with juvenile or adult myositis, be a close relative to such patients, or a healthy individuals matching to myositis patients in these studies
- Send us your past medical records to confirm eligibility
- Be willing and able to signed informed consent and complete testing for the study

How can you learn more about our studies?

NIEHS physicians include:

Lisa G. Rider, MD
Lead Investigator and Pediatric Rheumatologist

Adam Schiffenbauer, MD
Associate Lead Investigator and Adult Rheumatologist

Visit our webpages to learn more:

<https://joinastudy.niehs.nih.gov/>

Call: 1-800-411-1222, TTY: 1-866-411-1010

Email: ccopr@nih.gov

Se habla español



Where can you enroll?

You can enroll at the NIH Clinical Center in Bethesda, MD, at the NIEHS Clinical Research Unit in Research Triangle Park, NC or through your local healthcare provider! For some studies, however, enrollment is only at the NIH Clinical Center in Bethesda, MD. We will share more details about your enrollment options once you give us a call.

You may apply for assistance to support your travel to the NIH; we can provide you with information about charity airline programs. Many patients are admitted to the NIH Clinical Center hospital for their visit. Some patients are seen in the clinic and stay overnight, at the Edmond J. Safra Family Lodge (adult patients), at local area hotels, or at the NIH Children's Inn (pediatric patients/families). Your visit would last between 1 to 6 days.



What are general enrollment steps?

After completing eligibility phone calls and your participation is confirmed, we will set up your schedule and stay. Your visit may range from 1 - 6 days.



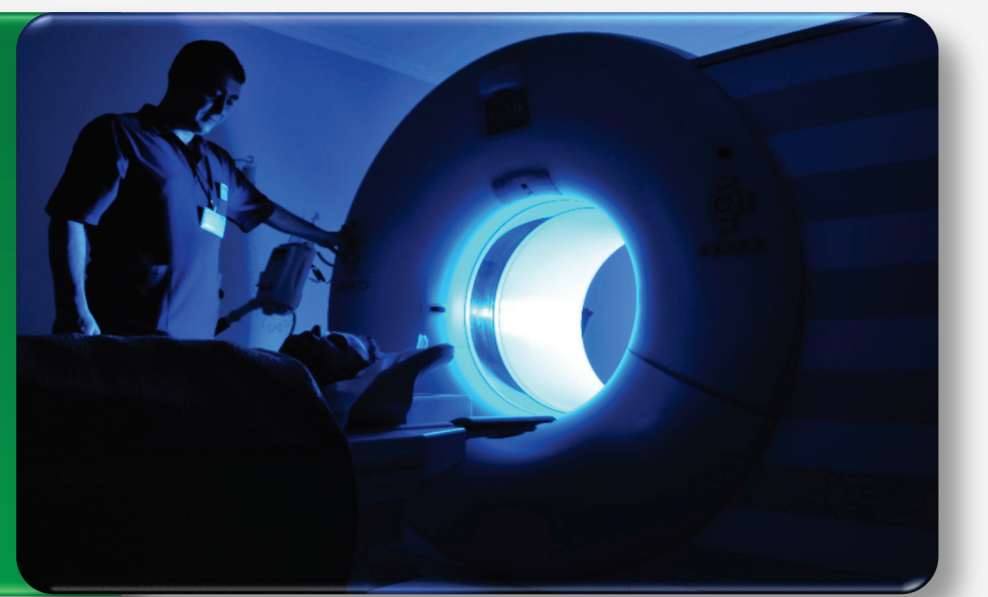
Upon your arrival, complete the NIH admissions process and then move to your home clinical area - pediatric or adult clinic, day hospital, or hospital ward.



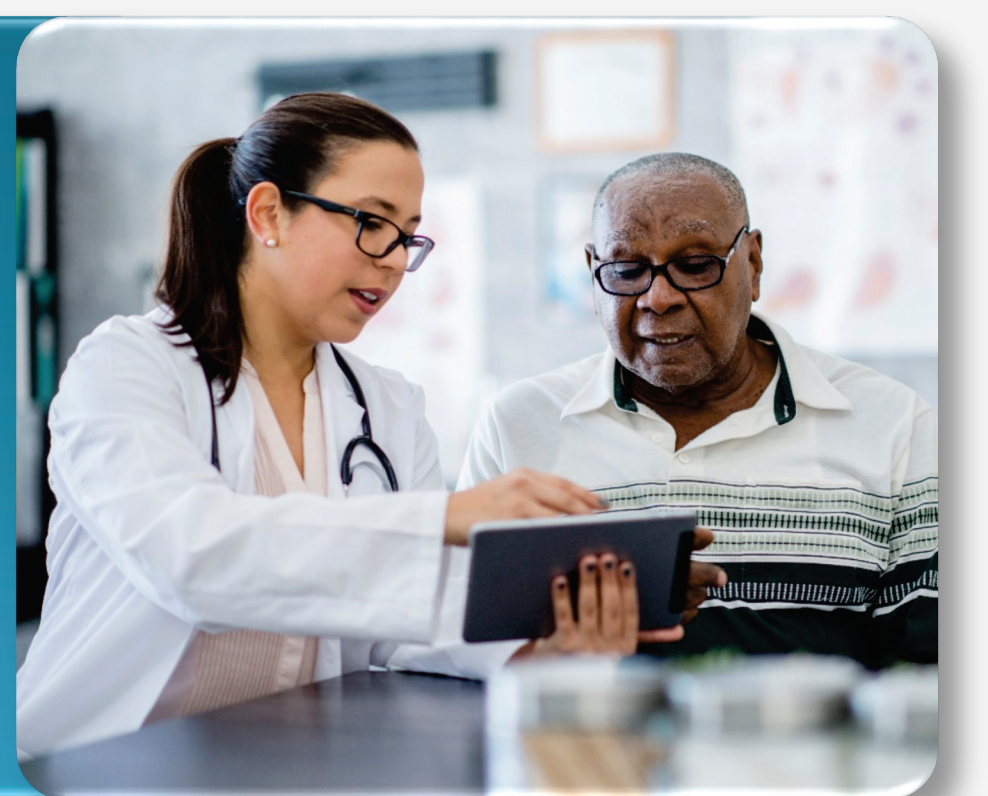
Meet your research team and study doctor, complete the consent process, discuss your study visit plan, and receive questionnaires.



Complete a physical exam, blood draws, and urine testing. Some patients may also complete imaging, muscle strength tests, and other tests and consults as needed.



Review completed questionnaires and results with your study doctor/research team. Your study doctor will also share results and speak with your referring physician, if you have authorized this.



Complete any follow-up phone calls or in-person visits that may be needed for some studies.



Done, thank you! Compensation is provided upon completion of a study.

