



# NIH Pediatric Rheumatology Clinic

## What is the NIH Pediatric Rheumatology Clinic?

The National Institutes of Health (NIH) Pediatric Rheumatology Clinic is a specialty-care medical facility dedicated to evaluating and treating children with pediatric rheumatic diseases who are enrolled in clinical trials. Since the causes of these diseases are unknown, the NIH also seeks to gain a better understanding of why some children develop them. The NIH is a Government agency committed to improving the health of the Nation.

The NIH Pediatric Rheumatology Clinic consists of two major parts: a clinic and a health information resource center. In the clinic, medical staff diagnose and treat children with arthritis, periodic fever syndromes, lupus, and other rheumatic diseases who are enrolled in clinical trials. Clinical trials may be studies of the natural history, signs, and symptoms of disease when usual treatment is given. They may also include experimental treatment or diagnostic tests. Children and their parents will be informed about the details of clinical trials, and enrollment will be offered if the child is eligible. Medical services are provided without charge to the patient.

The health information resource center provides written and oral information on signs and symptoms of arthritis and rheumatic diseases as well as tips for maintaining wellness and managing disease.

## Why has NIH established the clinic?

In children, arthritis, periodic fever syndromes, or other rheumatic diseases can be difficult to diagnose and challenging to treat. Some children experience swollen, painful, or stiff joints. Other common symptoms include skin rashes, weak muscles, fevers, and swollen glands. Children with arthritis and rheumatic diseases may have many disease-related challenges such as pain, disability, growth problems, and difficulty with school and social interactions. Juvenile rheumatic diseases affect each child differently. For many juvenile rheumatic diseases, there is no single diagnostic test; for a number of fever diseases, a genetic test can be used to diagnose the syndrome. Doctors and scientists want to learn more about how to treat and prevent juvenile rheumatic diseases.

The NIH established the NIH Pediatric Rheumatology Clinic to serve as a resource for patients, doctors, and scientists around the country. Arthritis specialists (rheumatologists) will be trained at the NIH Pediatric Rheumatology Clinic to



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diagnose and treat children with arthritis, periodic fever syndromes, and rheumatic diseases. This clinic will also help doctors and scientists understand the causes of juvenile rheumatic diseases. With this information, they can find better ways to diagnose, treat, and ultimately prevent these diseases.

### What conditions are treated at the clinic?

Many people use the word "rheumatism" or "arthritis" to describe a broad range of rheumatic diseases. In reality, there are more than 100 rheumatic diseases, any of which can affect children and can be addressed at the clinic. These diseases may cause pain, stiffness, and swelling in joints as well as in muscles, tendons, ligaments, bones, and skin. Juvenile rheumatic diseases include:

- Juvenile Rheumatoid or Juvenile Idiopathic Arthritis
- Juvenile Spondyloarthropathy Syndromes
- Juvenile Psoriatic Arthritis
- Juvenile Dermatomyositis
- Juvenile Systemic Lupus Erythematosus
- Juvenile Vasculitis
- Juvenile Sclerodermas
- Mixed Connective Tissue Disease
- Periodic Fever Syndromes

### Who can be evaluated in the clinic?

Patients can be referred to the NIH Pediatric Rheumatology Clinic by their pediatrician, pediatric rheumatologist, or other health care provider. We see patients without discrimination on the basis of race, religion, ethnic group, citizenship, or residence. We can provide translation services for patients and families who do not speak English. Each protocol or clinical study has specific rules about who can be enrolled. Any patient meeting the criteria is eligible for enrollment.

### What happens during a typical visit to the clinic?

On their first visit to the clinic, patients are examined by medical staff, which includes pediatric rheumatologists, pediatricians, nurse practitioners, research nurses, and doctors in training to become specialists. Some people will need only one visit to the clinic. They will be diagnosed and have medicine prescribed, if necessary. Others will need follow up care to treat their condition. For instance, they might need physical therapy or x rays. Those people will be referred to the appropriate departments at the NIH, where they will receive services. The NIH medical staff will keep your doctor at home informed about the diagnosis and treatment provided at the NIH.

Patients will have the opportunity to participate in studies to help understand pediatric rheumatic diseases. Natural history studies, for example, are designed to study how diseases develop and progress. In natural history studies, patients receive standard medical care. No experimental medicines or treatments are

given. Other studies test a new treatment or help scientists understand why certain diseases run in a particular family. Participation in all studies is voluntary and patients can withdraw at any time. Some of the diseases currently being studied are juvenile arthritis, lupus, and periodic fevers, including Neonatal Onset Multisystem Inflammatory Disease (NOMID).

Medical staff will monitor patients' disease progress and treatment program in order to learn more about how juvenile rheumatic diseases affect them and what treatments work best. The NIH mission is to improve the country's health by learning about disease and treatment, and NIH doctors are among the best in the country. All patients at the NIH Pediatric Rheumatology Clinic will receive top-quality medical care as part of their participation in a clinical trial or natural history study.

### What is available at the clinic?

- Medical Evaluation and Care: NIH doctors and nurses evaluate children with possible rheumatic diseases and provide the needed treatment. If the problem is not a rheumatic disease, patients will be referred for the appropriate care. Children who participate in clinical studies at the clinic will receive medical evaluation and care, including diagnostic procedures such as laboratory tests and x rays, and access to the latest investigational treatments.
- Health Information: Patients and their family members can obtain health information that describes the signs and symptoms of arthritis, joint protection, exercise, nutrition, and weight control.

### Where is the clinic located?

The NIH Pediatric Rheumatology Clinic is located at:

The National Institutes of Health  
Warren Grant Magnuson Clinical Center  
9000 Rockville Pike  
10 Center Drive  
Building 10, Outpatient 13  
Bethesda, MD 20892

For more information, call the National Institute of Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse: 301-495-4484 (direct) or 877-22-NIAMS (226-4267) (free of charge).

To find out if your child is eligible for a clinical study, call the NIH Patient Recruitment Office at 1-800-411-1222 (TTY 1-866-411-1010).