

# GET THE FACTS



## Childhood Arthritis & Rheumatology Research Alliance (CARRA)

### MEDICAL REVIEWERS:

**John Hardin, MD**, Vice President for Research, Arthritis Foundation

**Norman T. Ilowite, MD**, Chair, Childhood Arthritis & Rheumatology Research Alliance; Chief, Pediatric Rheumatology, The Children's Hospital at Montefiore; Professor of Pediatrics, Albert Einstein College of Medicine, Bronx, New York

**Yukiko Kimura, MD**, Chair, JIA Research Committee of the Childhood Arthritis & Rheumatology Research Alliance; Chief, Pediatric Rheumatology, the Joseph M. Sanzari Children's Hospital, Hackensack University Medical Center, Hackensack, New Jersey

### What Is the Childhood Arthritis & Rheumatology Research Alliance (CARRA)?

The Childhood Arthritis & Rheumatology Research Alliance (CARRA) is a North American network of pediatric rheumatologists who have joined together to answer critical research questions in childhood rheumatic diseases and arthritis. The mission of the Alliance is to find the causes of these conditions and to develop the most effective therapies to treat children and adolescents and ultimately cure them of their disease.

### What Is CARRAnet?

CARRAnet is the name of a National Institutes of Health (NIH)-funded project of CARRA-affiliated pediatric rheumatology research centers across North America. The research centers are electronically linked so researchers can access data from the large numbers of patients enrolled in the CARRA Registry about their disease, treatment plan, therapy efficacy and toxicities; collaborate on how to design more effective clinical trials; and share information to achieve critical research conclusions faster. Currently, there are 60 CARRAnet sites in the U.S. More centers are being added to the CARRA network in the U.S. and sites are scheduled to open in Canada in 2012. For more information about CARRAnet and to find a CARRAnet center, go to [www.carranetwork.org](http://www.carranetwork.org).

### What Is the CARRA Registry?

The CARRA Registry is an observational study of children and adolescents with rheumatic diseases. The goals of the study are to:

- Determine how the diseases start
- Compare treatments to ascertain efficacy and safety
- Find the most effective treatment for each patient
- Evaluate long-term outcomes

All patients whose disease onset began at 18 years of age or younger

(for juvenile idiopathic arthritis, onset of disease has to be before age 16) and who are cared for at a CARRA-affiliated medical site are eligible for participation in the CARRA Registry. The defined pediatric rheumatic diseases include:

- Juvenile idiopathic arthritis (JIA)
- Systemic lupus erythematosus (SLE)
- Sjögren's Syndrome
- Mixed connective tissue disease (MCTD)
- Juvenile dermatomyositis (JDM)
- Localized scleroderma (LS)
- Idiopathic uveitis
- Autoinflammatory diseases (fever syndromes)
- Vasculitis
- Sarcoid
- Juvenile primary fibromyalgia syndrome (JPFS)

To date, 7,000 children and adolescents are enrolled in the Registry and about 50 new patients are added each week. The goal is to enroll at least 10,000 patients in the registry.

### Why Is Research Needed for Childhood Rheumatic Diseases?

About 300,000 children and adolescents in the U.S. suffer from some form of arthritis or rheumatic disease. The goals of the CARRA Registry are to better understand the causes of rheumatic diseases and improve treatment outcomes through more effective therapies and reduce or eliminate treatment side effects that impact quality of life.

### What Does Participation in the CARRA Registry Involve?

The CARRA Registry is an observational study. Currently, to participate in the CARRA Registry, the medical institution involved in your child's care must be a CARRAnet site.

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At your child's first visit, the study investigator will explain the purpose of the study and answer any questions you may have about the purpose of the study and what your role and your child's role will be. If you decide to enroll your child in the CARRA Registry, you will be asked to review and sign a consent form. You then will be asked a series of questions about your child's medical and family history and how your child's disease affects his or her life and physical function. You will also be asked to give your contact information.

There are two follow-up study visits required per year in which you will be asked to update any changes in your child's medications, condition or contact information. Each visit takes approximately 15 minutes to complete. You may leave the study at any time without penalty and no affect to your child's healthcare in any way. There is no cost to you for enrollment in the CARRA Registry.

### How Is Privacy Protected?

Health information stored in the CARRA Registry is identified by a unique code, which is used in the Registry and is kept separately from the patient's name and contact information. Information included in the Registry is seen only by CARRA investigators and is not sold to or used by any third parties.

### Are There Safety Concerns for the Study Participants?

The CARRA Registry is an observational study and confers no physical risk to your child. The safety of all children enrolled in the study is the top priority of study investigators. The study is approved and periodically reviewed by the Institutional Review Board (IRB) of your medical institution, which includes a committee of doctors, administrators, ethicists and members of the general public designated to approve, monitor and review the study. The Registry also has oversight from the NIH.

### Why Should You Allow Your Child to Participate in the CARRA Registry?

Having large numbers of patients enrolled in observational studies enables researchers to analyze vast amounts of data regarding dis-

ease onset, number of treatments prescribed, treatment effectiveness, treatment side effects, quality of life issues and long-term outcomes. By participating in the CARRA Registry you and your child are making a contribution to furthering a better understanding of the causes of rheumatic diseases, helping to achieve the goal of making personalized medicine a reality for thousands of children and helping researchers get closer to finding cures for these diseases.

### What Has CARRA Accomplished?

Important knowledge gained by CARRA investigators so far include:

- Treating a form of juvenile idiopathic arthritis (JIA) known as polyarticular JIA aggressively at an early stage leads to more favorable outcomes
- Atherosclerosis (hardening of the arteries) can begin in childhood in children with lupus
- Using medications that inhibit the overexpression of interleukin-1 (IL-1), a molecule that fights infection but that can cause tissue inflammation when it is over produced, is effective in children with systemic JIA
- The types of medications currently used in the U.S. to treat patients with specific types of juvenile arthritis
- The vast majority of American children with arthritis today are generally doing well and have little joint damage or disability

### What Is the Arthritis Foundation's Role in CARRAnet?

In 2011, the Arthritis Foundation committed more than \$750,000 over the next three years for the development of the CARRA network administrative and informatics infrastructures and to facilitate the opening of additional CARRAnet sites in the U.S. and throughout Canada.

### How to Make a Donation

For more information about The Childhood Arthritis & Rheumatology Research Alliance or to learn how you can help support CARRAnet, please contact the nearest Arthritis Foundation office near you or visit the Arthritis Foundation's website at [Arthritis.org](http://Arthritis.org).