



### **For Immediate Release**

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## **Enrollment Completed for Largest New Onset Cohort Study in Juvenile Idiopathic Arthritis (JIA) History**

The Childhood Arthritis and Rheumatology Research Alliance (CARRA) is pleased to announce completed enrollment of 403 newly diagnosed children with polyarticular JIA children in STOP-JIA (Start Time Optimization of Biologic Therapy in Polyarticular JIA). “We are excited that we were able to complete enrollment in the largest prospective research study of newly diagnosed JIA patients. CARRA was formed a little over 15 years ago to make it possible to do large-scale studies like this in rare rheumatic diseases like JIA,” said Dr. Yukiko Kimura, the lead investigator of the STOP-JIA study and immediate Past President of CARRA.

### **What is STOP-JIA about?**

JIA is one of the leading causes of acquired disability in children and has no cure. The most common form is polyarticular (poly-JIA), meaning 5 or more joints are involved. Symptoms include pain, fatigue, and stiffness, and it can lead to permanent joint damage and disability.

Over the past 10-20 years, treatment has changed as new medications have become available to treat poly-JIA. The medications have drastically improved outcomes for children. However, little evidence exists to know when to start the new medications. STOP-JIA compares patient outcomes depending on when the new medicines are started. Once the study ends in 2019, the results will indicate which strategy works best.

### **Teamwork = Success**

The STOP-JIA study is a massive team effort that includes patients and families, pediatric rheumatology researchers at 57 sites in the US and Canada, CARRA, the Arthritis Foundation and the Duke Clinical Research Institute (DCRI).

### **Patient families as partners**

Kate Murphy, a young adult diagnosed with poly-JIA as a small child, actively partnered in the research process. Along with a father of a child with JIA (Vincent Del Gaizo), Kate is part of the STOP study team and created a [PREZI](#) for newly diagnosed families. “Patient families are so overwhelmed and feel isolated when they are told they have this condition. We created the PREZI to provide basic information about JIA and explain the STOP-JIA study to new families,” said Kate. In addition, a Stakeholder Advisory Panel provides patient oversight of the study and creates materials such as newsletters to keep study participants informed. “Involving and engaging patients is key because they are the reason we are doing the research. Patients and families give us new and eye-opening perspectives that make our research more relevant,” said Dr. Sarah Ringold, the co-lead investigator for the study.

## **About CARRA**

The [Childhood Arthritis and Rheumatology Research Alliance \(CARRA\)](#) is a North American research network whose mission is to conduct collaborative research to find treatments and a cure for pediatric rheumatic diseases. Founded in 2002 and headquartered in Milwaukee, Wisconsin, CARRA is a 501c3 recognized nonprofit organization of pediatric rheumatology health and research professionals. CARRA has more than 500 members and over 120 sites across the US and Canada. The [CARRA Registry](#) of pediatric rheumatic diseases, which seeks to enroll more than 10,000 patients and follow them for at least 10 years, is a cornerstone of CARRA's research. The [Arthritis Foundation](#) has been a supporter of CARRA since its inception, and has been a major partner since 2015. Learn more about CARRA at <https://carragroup.org>.

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