



CARRA Registry Newsletter

Welcome to the CARRA Registry Newsletter! This newsletter was created to keep families informed of all the latest happenings in the CARRA Registry, STOP-JIA and FROST studies.

Please contact us at DCRI-CarraRegistry@dm.duke.edu to suggest topics or information you would like to see in future newsletters.



The current CARRA Registry sites in the US and Canada

THE CARRA REGISTRY

WHAT IS THE CARRA REGISTRY?

The CARRA Registry is a database of information collected from children and young adults with pediatric-onset rheumatic diseases such as juvenile idiopathic arthritis (JIA) and lupus. The CARRA Registry allows children from all over North America share their identity protected information including clinical outcomes, patient reported outcomes, and blood sample collection that is then shared with researchers to better understand pediatric rheumatic diseases.

DID YOU KNOW?

The CARRA Registry was created to monitor the long-term safety of the medications used in pediatric rheumatic conditions. Long term safety was voted by JIA and JDM families as their #1 research priority in a recent survey.

WHAT HAVE WE LEARNED?

5,104 patients with JIA have enrolled from **62 different sites across the US and Canada**. Patients will be followed for at least 10 years, even when they become adults. Here are some interesting facts that we have learned about these patients from the Registry so far. This is information that we have never before been able to collect accurately in such a large number of patients!

- 72% are female
- The average age at enrollment is 12 years
- The registry enrolls patients with all different types of JIA, but more than 65% have ever had at least 5 joints involved at the time of enrollment.
- Approximately 45% of patients currently take methotrexate
- Approximately 55% of patients currently take a biologic medication



Patient Drawing by Chris, age 7

In addition to JIA, the Registry is now also enrolling other pediatric rheumatic diseases:

- **227 patients with lupus and related conditions** have been enrolled so far
- **10 juvenile dermatomyositis/polymyositis patients** have been enrolled so far

If you would like more information on the CARRA Registry or updates on Registry progress, please visit: <https://carragroup.org/carra-registry-updates>. *as of June 2018.



555 East Wells Street, Suite 1100
Milwaukee, WI 53202
414-918-9822

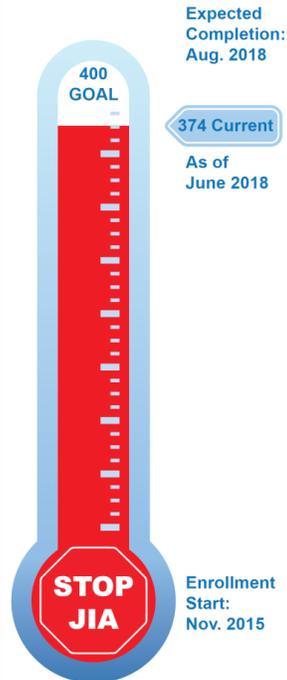
carragroup.org

STOP-JIA

We have almost reached our enrollment goal of 400 Patients! This means by late 2019, we will have the results of the study.

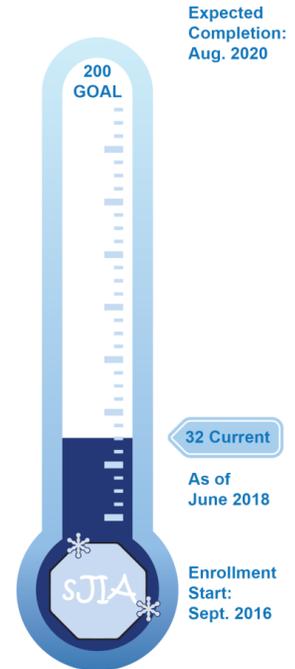
What is STOP-JIA? STOP-JIA (Start Time Optimization of Biologic Therapy in Polyarticular JIA) is a CARRA Registry research project that will answer a critical question: **When is the best time to begin biologic medications to achieve the best possible outcomes?** In this study, patients with polyarticular JIA, their families and doctors will discuss and choose one of 3 treatment plans which differ in the timing of when biologics are started. For more information on STOP-JIA please visit the STOP JIA page on the CARRA Website:

<https://carragroup.org/research/stop-jia>



FROST

What is FROST? FROST (First Line Options for SJIA Treatment) is another CARRA Registry research project that **compares the four most common treatments for new-onset Systemic JIA (sJIA):** Steroid medications, Methotrexate, IL-1 blocker (Kineret® or Ilaris®), and an IL-6 blocker (Actemra®), because we don't know which one(s) will work the best. In FROST, systemic JIA patients, their families and doctors will discuss and select one of these commonly used treatments. They will get regular checkups to see how they are doing, and answer questions about how they are feeling at the doctor's office and at home through an app. For more information on FROST, please visit the FROST page on the CARRA website: <https://carragroup.org/research/frost>



The 2018 CARRA Annual Scientific Meeting in Denver: Reflections from a Parent

By Melanie Kohlheim

Parent of a 7 year old girl with polyarticular JIA and a STOP-JIA Stakeholder Advisor

As the parent, all you feel like you can do at the time when your child is diagnosed is just keep yourself and your child alive and well. Once you get the hang of your "new normal," you start to wonder more about these amazing rheumatology care providers and the work they do each and every day to help kids like your own. If you are lucky enough, you'll develop great relationships with some of these outstanding people. If you jump in head first, you can even work alongside them, making strides towards better treatments and care practices for children across the globe. I'm one of the lucky (and crazy) ones who jumped in head first. I have had the privilege of attending four CARRA meetings now and each and every year the meeting blows me away. It's inspiring to sit with care teams and brainstorm TOGETHER better solutions, better strategies, and better research questions to hopefully someday lead to a cure. As a lead parent now, I have the opportunity to mentor new families attending the meeting and have the experience of seeing the meeting for the first time through their fresh eyes each year. Parents and patients appreciate their invitation to the table so very much and are always energized and empowered by the experience. Last month in Denver, alongside other patients, families, and care team members, I participated in several committees and work groups. We accomplished so much! Once again, I felt appreciated, valued, and blessed to be able to contribute to and even lead discussions. The parent and patient group has tripled in size over the last four years and the workgroup discussions are more rich and diverse because of it. Click to [learn more about the CARRA meeting](#)



Patient Drawing by Megan, age 7

WHY GIVE BLOOD SAMPLES FOR RESEARCH?

In both STOP-JIA and FROST, blood samples are collected from patients before starting treatment, so that scientists can find blood markers that will help predict whether children will respond to these treatments in the future.

FROM A PARENT: WHY DONATING BLOOD FOR RESEARCH IS SO IMPORTANT

When we were asked to donate our son's blood for research, we were initially hesitant. But then we learned that if we agreed along with other patients, the blood samples could be used to help discover new treatments, search for the cause of his disease, or learn if there is a way to use markers in the blood to predict how he and other children will respond to certain medications. Researchers can learn most when blood is drawn before treatment starts. It wasn't easy to say yes, especially when we had just been diagnosed and were so overwhelmed, but we thought that if research done on our son's blood can help make any of these breakthroughs a reality, it would be incredibly worthwhile. Drawing blood on my son was hard for us, especially because he was only 15 months old at the time. But since blood drawing is necessary to help diagnose and monitor his condition, we were comforted by the fact the blood for research would be drawn at the same time as routine blood tests that as much as possible to avoid extra needle sticks. Looking back, we are happy that we decided to support research, and our son – now 17 years old – is also glad that he could make a difference for other kids and their families.



SELF-ADVOCACY AND SELF-MANAGEMENT FOR PATIENTS

By Lauren Revis

Lauren is a 19 year old college student who has had oligoarticular JIA and uveitis since the age of 2. She is on the STOP-JIA Stakeholder Advisory Panel

Self-advocacy and management is a vital tool when dealing with any illness or disease.

Your doctors have vast experience and knowledge concerning your disease, but they do not have experience and knowledge about dealing specifically with *you* and your preferences. Patients are impacted the most by medical decisions, so communication between two equals is vital in patient/doctor relationships. Patients should seek to become informed about their options. They should ask questions, honestly describe symptoms, and not be afraid to ask for clarification on answers if need be. It is the patient's responsibility to take their medication on time and follow doctors' orders, as well as it is their responsibility to report side effects of medications and discuss with their doctor if switching treatment plans is a better course of action for them than dealing with side effects. By doing so, patients can make sure their own values and preferences are being met. In my treatment for Juvenile Idiopathic Arthritis and Uveitis, I have utilized self-advocacy and management. When one of my medications caused side effects that hindered me from playing sports, one of my favorite activities, I talked to my doctor and was able to make an informed decision on new medications that I and my doctors together believe will be effective in controlling my disease while also allowing me to continue to handle a busy lifestyle as a college student and an athlete with fewer side effects. Communication is a two-way street, and patients should never be hesitant or intimidated to ask questions and advocate for themselves.



For more information about Self-Advocacy, visit the *Kids Get Arthritis Too* website: <http://www.kidsgetarthritisoo.org/kids-and-teens/teens/every-day-with-ja/take-charge-of-your-health.php>



CARRA Registry Research Team Member Highlights

Mary Ellen Riordan

Mary Ellen is the project coordinator for STOP-JIA and FROST, sub-studies of the CARRA Registry. She has been a nurse at Hackensack University Medical Center for 30 years and has worked as a Research Nurse Coordinator for pediatric rheumatology for the past 15 years. Mary Ellen lives in New Jersey with her husband. They enjoy traveling and dining out, and are looking forward to becoming grandparents this summer.



Marian Jelinek

Marian was diagnosed with Systemic Juvenile Rheumatoid Arthritis (now called systemic JIA) when she was 10 years old, and is a Patient Partner on the FROST study. She is originally from Portland, Oregon and moved to the San Francisco Bay Area for college. While in school, she majored in civil engineering. After graduation, she started her career designing transportation systems. She now works for a general contractor, and is currently working on constructing a new building for a high school in San Francisco. She loves hiking and exploring on weekends with her husband and three year old labradoodle Artchy.



From Parents and Patients Who Have Been There

The time of diagnosis can be a very overwhelming one, as are the following months and sometimes years. When my daughter was diagnosed four years ago, I wanted nothing more than to talk to a parent who had been through this same journey. I have spent lots of time in the past years mentoring newly diagnosed families and just being a soft place for people to call/email/text to vent knowing that I understand. The registry, STOP-JIA and FROST study team is comprised of many “experienced” parents and young adults diagnosed with JIA when they were children, and we would like to make ourselves available to you. If you are looking for that type of support and someone to talk to, please feel free to reach out to either Melanie Kohlheim, Vincent Del Gaizo or Kate Murphy.

Melanie Kohlheim - melaniejaprojects@gmail.com - (765) 532-6843 (parent)

Vincent Del Gaizo - vdelgaizo@comcast.net - (908)-303-9037 (parent)

Kate Murphy - katherinelinnea@gmail.com - (760) 470-0077 (young adult patient with JIA)



CARRA is grateful for ongoing financial support from the Arthritis Foundation which helps make the CARRA Registry possible.
For a complete listing of all CARRA Registry supporters visit www.carragroup.org