

# STOP-JIA TIMES

Start Time Optimization of Biologics in Polyarticular JIA

## What is STOP-JIA?

STOP-JIA is a project of CARRA (Childhood Arthritis Rheumatology Research Alliance), whose Registry will help answer a critical question for patients, their families, and healthcare providers:

**When is the best time to begin biologic medications to achieve the best possible outcomes?**



## Why STOP-JIA?

The STOP-JIA project is important because right now we still don't know whether it is best to start a biologic early in a patient's treatment, either by itself or in combination with other medications, such as methotrexate, or wait until we see if methotrexate has not worked well enough on its own.

## How Does STOP-JIA Work?

STOP-JIA will compare the 3 ways we currently treat Poly-JIA which we call Consensus Treatment Plans (CTPs):

1. **Step Up Plan**: you will start treatment with a disease modifying anti-rheumatic drug (DMARD) and your provider will see how you do. In 3-6 months, a biologic is added if needed. Examples of DMARDS are methotrexate and sulfasalazine.
2. **Biologic First Plan**: you will start treatment with a biologic and your provider will see how you do. In 3-6 months, a DMARD can be added if needed. Some examples of biologics are abatacept (Orencia), adalimumab (Humira), etanercept (Enbrel), infliximab (Remicade), rituximab (Rituxan) and tocilizumab (Actemra).
3. **Early Combination Plan**: you will start treatment with a DMARD and biologic at the same time (or within 1 month of each other) and your provider will see how you do and change medications if needed.

Our goal is to enroll 400 children who have been newly diagnosed with poly-JIA in the STOP-JIA project and follow them for at least one year to see which treatment works best for achieving disease control.

# What is involved in STOP-JIA for me?

Your appointments will run normally, but you will be given an iPad to use when you visit the doctor in order to answer questions about how you are feeling. This information will be collected and stored securely in the CARRA Registry. Your data is private, meaning no one will know it is you who answered those questions. Patients and families, like you, helped to select the questions asked based on their many years of experience living with poly-JIA. They felt knowing the answers to these questions will help new patients with poly-JIA and their families decide which medications to use. Doctors will also be entering information into the CARRA Registry about how you and your arthritis are doing. Your treatment will be up to you and your doctor and will not change because of STOP-JIA.

## Important Tips

- ✓ **Please don't miss your clinic visits!** It's important for you that your healthcare team can check how you're doing every 3 months. This information will also be entered into the CARRA Registry so it can be compared to other patients at each visit.
- ✓ **Answer the questionnaires, either on paper or the iPad,** as completely and honestly as possible. These are called Patient Reported Outcomes (PROs). PROs help us learn as much as we can about how your treatment plan is working for you.
- ✓ For more information on STOP-JIA, **please check out the STOP-JIA info video** at <https://prezi.com/aifg1hc1lrnh/copy-of-stop-jia-patient-recruitment-video/>
- ✓ We will be sending updates on STOP-JIA through newsletters like this one. **Feel free to contact us** if you would like more information or have suggestions for the newsletter. Our email address is: [STOP-JIA@carragroup.org](mailto:STOP-JIA@carragroup.org)

## Stakeholder Advisory Panel

Patients and their caregivers are the focus of STOP-JIA. They make up a majority of the Stakeholder Advisory Panel, which oversees and gives feedback about the project and its materials. Members of the Stakeholder Advisory Panel also include a nurse, research coordinator, patient advocacy organization member and insurance payer. Together they help make STOP-JIA better and more relevant to the patients and their families. Please feel free to reach out and give them feedback about STOP-JIA, this newsletter, or any other non-medical reason at: [STOP-JIA@carragroup.org](mailto:STOP-JIA@carragroup.org). Medical questions and emergencies should always be directed to your providers.



60 of more than 120 CARRA sites participate in the CARRA Registry



## Important Definitions

**Polyarticular JIA (Poly-JIA):** JIA or chronic childhood arthritis that affects at least 5 joints.

**Disease modifying anti-rheumatic drug (DMARD):** DMARDs is the term for a group of medications used to treat arthritis by reducing inflammation. Common DMARDs include methotrexate and sulfasalazine.

**Biologic:** Biologics are proteins that are engineered to target specific parts of the immune system and inflammation. Some biologics used in poly-JIA include abatacept (Orencia), adalimumab (Humira), etanercept (Enbrel), infliximab (Remicade), rituximab (Rituxan), and tocilizumab (Actemra), among others.

**Consensus Treatment Plan (CTP):** CTPs are treatment plans developed through agreement among CARRA members. The CTPs are the most common ways CARRA doctors currently treat their patients.

**Patient-Reported Outcome (PRO):** Any report about how a patient is doing that comes directly from a patient or their care-giver.

# CARRA & The CARRA Registry

**CARRA** is the Childhood Arthritis and Rheumatology Research Alliance. CARRA is an organization of pediatric rheumatology health and research professionals. The mission of CARRA is to work together to prevent, treat and cure pediatric rheumatic diseases. Currently, CARRA has over 400 members throughout the US and Canada, which means almost all pediatric rheumatologists in North America are members.

**The CARRA Registry** is a database of children with JIA and other rheumatic diseases. The Registry will continue to follow children over many years. The purpose of the CARRA Registry is to learn more about the effectiveness and safety of the medications used to treat children with rheumatic diseases, as well as how these children do over a long period of time. But don't worry, all of the information collected for the CARRA Registry is stored securely and identity protected.

# Getting to know your STOP-JIA Team:

Each newsletter will highlight different members of our STOP-JIA Team. This issue features our Patient Partners. They have been members of our team since the beginning of the project, and their role is to represent the patient viewpoint.



Vincent Del Gaizo is a small business owner and lives in NJ with his wife Kelly. They have 2 sons and 1 daughter who are 15 years old. Yes, they are triplets!! One of their sons was diagnosed with JIA when he was a baby. In his spare time, Vincent enjoys watching his boys play ice hockey, his daughter play field hockey, and doing whatever he can to help children diagnosed with pediatric rheumatic diseases. He is a co-leader of the STOP-JIA Stakeholder Advisory Panel (SAP) and provides a patient voice on the STOP-JIA team.



Kate Murphy is a recent graduate of University of California, Berkeley who is currently living and working in San Francisco. After two years of puzzled doctors and very worried parents, Kate was diagnosed with JIA at the age of 6. From serving as a counselor for San Diego's Joint Adventure Camp to speaking at fundraising events for the Arthritis Foundation, Kate has acted as a patient advocate for many years now and loves supporting the pediatric rheumatology community that has helped her continually throughout her childhood and into young adulthood. She is also a co-leader of the STOP-JIA SAP and is another patient voice on the STOP-JIA team.

For more STOP-JIA and other important information, go to: [www.carragroup.org](http://www.carragroup.org)

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**STOP-JIA** is made possible by the following organizations:

