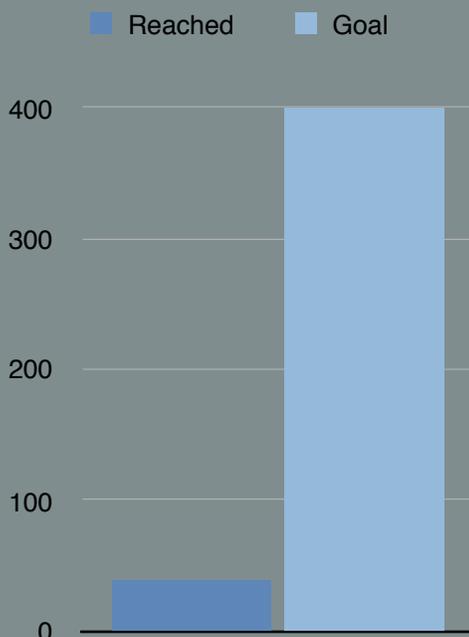


STOP-JIA TIMES

Start Time Optimization of Biologics in Polyarticular JIA

Study Update

STOP-JIA enrolled the first patients on 1/20/2016. As of June 24, there are 42 active sites across North America, and 43 patients enrolled in STOP-JIA. Our target is 400 newly-diagnosed patients with Poly JIA. We really appreciate all the patients and families who have enrolled so far, because it is so challenging to enroll in the registry and complete all the questionnaires for STOP-JIA when you're feeling overwhelmed with a new diagnosis of JIA.



2016 CARRA Annual Scientific Meeting

CARRA, Parents and JIA Patients-Partners in Research:

This year's CARRA Annual Scientific meeting was held in Toronto on April 14-17 and attended by over 400 doctors, nurses, study coordinators, care-givers and young adults diagnosed as children with JIA and other rheumatic diseases. At the meeting, attendees discussed and worked together on ongoing and future research in pediatric rheumatology. The STOP-JIA study team and Stakeholder



Advisory Panel also met at the meeting to discuss the study. One session titled "Engaging Patients: What Matters?" was presented by STOP-JIA patient

partners Vincent Del Gaizo, Kate Murphy, Jen Horonjeff and Colleen Ryan. This session received the highest rating of the entire meeting! This is a shining example of how JIA families, researchers and healthcare providers are partnering to improve care for our children!

“ It’s been a real challenge adjusting to life with my son’s JIA diagnosis. My wife and I both work and have other children. We live 50 miles from our pediatric rheumatologist. A clinic visit means a day away from work and from school. As hard as it can be sometimes, we accept it as part of our new life because we know how important the clinic visit is. My son needs to be watched closely by our healthcare team so we can see how he is doing with his arthritis and his medicines. ”

- Vincent Del Gaizo
Parent of child with
JIA

Seeing your doctor as scheduled can prevent a small problem from becoming a big one, so please don’t miss your clinic visits! Information on your child’s health status and their care needs to be updated in the CARRA registry so we can continue to learn as much as we can about how to treat this disease.

Spelling It Out--Defining the Acronyms You Might Come Across

- **EHR (Electronic Health Record)** - an electronic version of a patient’s medical history that is maintained by the provider over time, such as past medical history and medications.
- **PHI (Protected Health Information)** - defined by the Health Insurance Portability and Accountability Act of 1996 as individually identifiable health information.
- **IRB (Institutional Review Board)** - is a group that reviews and approves research on people. The purpose of the **IRB** is to make sure that all human research is conducted in accordance with all federal, **institutional**, and ethical rules.
- **HIPAA (Health Insurance Portability and Accountability Act)** - passed in 2003, HIPAA is a law that protects privacy and patient medical records. HIPAA allows patients to control how their health facts are used and shared.
- **ICF (Informed Consent Form)** - a form that is signed before joining a research study. The form has details about the study and its risks.

STOP-JIA Prezi Video is online!

If you haven’t seen the STOP-JIA video, please check it out or send it to someone you know at

https://youtu.be/oI2_j3ZDDDE

The STOP-JIA Prezi was created by JIA patients and caregivers and reviewed by the STOP-JIA study team. We hope you find it helpful! Feel free to contact us if you have any questions about STOP-JIA, poly JIA or have suggestions for newsletters. Our email address is: STOP-JIA@carragroup.org

A Parent's Perspective

By: Melanie Kohlheim

The winding road of life with JIA brings many struggles and challenges, especially at the very beginning. My family struggled with our diagnosis like most families do, and my daughter's young age seemed to amplify feelings of stress, despair, and heartache.

Within a week of Megan's diagnosis, we were prescribed oral medication, injectable medication, and sent for (more) lab work. The oral medications were a struggle, and once I decided to try a drop of the medicine myself, I completely understood why! Even when flavored by the pharmacy, the liquid tasted gross! On top of daily and weekly meds, we had to go to the lab for blood draws to be sure the medications we were giving to Megan were not doing harm to her body.

As is said often in life, "I wish I knew then what I know now." Here are some tips and tricks for getting your children to take oral medications (that often have a not-so-pleasant taste) as well as managing blood draws for safety labs.

Getting your child to take medications:

- Hide in orange soda or something strong tasting (I've heard of chocolate syrup, too!)
- Have the meds made at a special compounding pharmacy that can reduce the quantity of liquid and add strong flavoring (although this costs more, it can be worth it!)
- Bribe with chocolate or other small treat
- To teach kids to swallow pills, practice starting with mini M&M's, then regular M&M's

What to do when getting blood drawn:

- Hydrate, hydrate, hydrate! Try to get your child to drink 16oz of fluid an hour before their visit to the lab
- Ask for numbing cream to put at least 30 minutes before on the area where the needle will go
- Sing a song while blood is being drawn
- Ask the child to identify animals/foods/etc. that start with a given letter as a distraction

I hope these suggestions will help make your medication doses and blood draws go more smoothly. We have all been there in those first months after diagnosis and understand the stress it can bring. There are always parents out there willing to share their story and lend support, and young adults with JIA who understand what your child is going through!

Do you have any tips or other thoughts you'd like to share with us or other parents and patients? If so, please email them to STOP-JIA@carragroup.org

Getting to know our STOP-JIA team:



Melanie Kohlheim is a wife, mom, and JIA patient engagement specialist living in Ohio with her husband and two daughters. Katelyn is 8 and Megan is 5. Megan was diagnosed with Poly-JIA when she was just 20 months old. Her diagnosis was a shock to her family, and Melanie jumped in head first to research, patient engagement, and co-production activities at their local hospital. Currently, Melanie works on several JIA research projects including STOP-JIA as well as working closely with a JIA learning health system network. In her free time, Melanie loves to travel (especially to the beach), read, and ride horses with her daughters.



Sarah Ringold MD, MS, (co-PI) is a pediatric rheumatologist at Seattle Children's in Seattle, WA. She is originally from northern California and moved to Seattle for residency training after college on the East Coast. Her primary interests are understanding how to measure disease activity in patients with Juvenile Idiopathic Arthritis and optimizing treatment approaches. In her spare time, she and her husband spend their time chasing after their busy 2-year-old toddler.



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