Juvenile idiopathic arthritis, or JIA, is a disease that causes joint damage, stiffness, and swelling. One of the most common forms of JIA is polyarticular JIA (pJIA), meaning that it involves swelling in five or more joints. Left untreated, pJIA can lead to permanent joint damage, which can cause chronic pain and disability.

There is no cure for pJIA but there are many treatments available that work well. The most commonly used medicines to treat pJIA fall into two major categories. The older, less expensive, and more widely available medicines are called disease-modifying antirheumatic drugs (DMARDs). This includes medicines like methotrexate. The other major category is a newer class of drugs called biologics that target very specific parts of the immune system. Examples include etanercept (Enbrel®), adalimumab (Humira®), and tocilizumab (Actemra®). Despite having all these treatment options, providers do not know whether to start with a DMARD, biologic, or both. The Start Time Optimization of biologics in pJIA (STOP-JIA) study looks to answer that question.

STOP-JIA is a study that compared the effectiveness of three commonly-used treatment strategies developed by CARRA:

- Step Up (start treatment with a DMARD only, then add a biologic if needed)
- Early Combination (start treatment with both a DMARD and a biologic)
- Biologic First (start treatment with a biologic only)

STOP-JIA Patient Partner

Katherine Murphy, MPH

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CARRA Membership Cards—You’re in the Club!

The first time you’ve probably heard of pediatric rheumatic diseases was on diagnosis day. You might feel alone because pediatric rheumatology diseases are rare. However, you are not alone! You are now part of a close-knit community of families battling these conditions. There are approximately 300,000 children in the US just like you who were diagnosed with pediatric rheumatic diseases like JIA, lupus, JDM, scleroderma, and CRMO.

Introducing the new CARRA Registry Membership Card! The card was created for everyone who signed up to be in the CARRA Registry. There are over 11,000 children diagnosed with rheumatic diseases who are in the CARRA Registry. Information collected in the Registry can answer important questions about how safe medicines are, how well medicines work, and how well children do over time. CARRA will collect this information for at least 10 years.

The membership card is a reminder that you are part of a very special community. The cards will be sent to all CARRA Registry sites over the next few months. All people who signed up for the Registry can ask their provider for a card at their next clinic visit. Then you can proudly wear it to all future clinic and telehealth visits!

To keep up to date with CARRA Research results, current activities, and to stay in touch, please ask your doctor about re-consenting in the CARRA Registry today!

Advice for Transitioning from Pediatric to Adult Rheumatology

Authored by: Missy Skolnik, 21-year Linear Scleroderma Veteran Patient

If you are thinking about stopping regular visits with your pediatric rheumatologist because you’re aging out, or because you’re in remission - be aware - it’s tough to urgently establish yourself as a new patient if you “fall out of care” for more than two years! It may take longer than ideal to be seen if you are worried about a potential flare or begin treatment to halt disease progression. My symptoms growing up were contained to my left extremities. I was in remission for more than 10 years, yet at age 22, it took months of denial, ignoring a deep crack on my tongue which compromised its strength and mobility, to connect the dots.

When you’re aging out of treatment with a pediatric rheumatologist, ask for an adult rheumatologist referral and “shop around” to find the right fit before you need it. Find someone you’re comfortable with, who’ll respect you, trust what you’re saying, and treat you with meds you’ve come to rely on (this should be an explicit conversation the first time you meet with your new doc). Find someone with experience treating patients with your exact diagnosis, who’s willing to speak with your pediatric rheumatologist to understand your medical and treatment history, who’ll use a patient portal and be responsive when you send messages, and ideally, who takes your insurance. Have a plan for what to do if you start feeling symptoms, even if they appear to be unrelated.

Finally, if you’re a kid with scleroderma, please get involved in this community. Get to know others like you, join a registry, and follow up with the registry to give updates over time on your rare, and valuable disease. It is up to us. Twenty-one years into having this disease, I can assure you - there won’t be a cure or improved treatment options until we all work together at this. Onward, together.

To read more about Missy’s experience, click here for her story.
CARRA Registry Enrolls over 200 JDM Patients!

Why are children with JDM being enrolled in the CARRA Registry?
JDM Committee Chair Dr. Adam Huber explains the goal for JDM in the Registry is to have a lot of information collected to make it easy to do many different kinds of research, that are not typically possible since JDM is so rare. As of February 5, 2021, there are 230 children with JDM in the CARRA Registry! That is over a 30% increase from 2020 which is amazing considering the pandemic forced many sites to pause enrollment and many clinic visits had to be cancelled. The first child with JDM enrolled in the Registry in February 2018.

What can you learn about JDM?
With the Registry, we can learn more about illness features, how JDM changes over time, and how children do on their treatment. We want to be able to predict which children are at high risk for bad outcomes and which children will have mild JDM, as well as which patients will reach full remission. Being able to predict these things will allow us to better personalize treatment for each child. The goal is to get the right medicine to the right child at the right time and to minimize side effects of therapy.

How can you learn which children will have mild JDM?
One way we hope to learn this through biosamples and lab based research. Thanks to funding by Cure JM, the CARRA Registry is also collecting biosamples from children with JDM. Biosamples are samples such as blood, saliva, and urine that come from the patient. Currently there are 79 samples collected from children with JDM! Having biosamples allows researchers to better understand the cause of JDM, how the immune system interacts with genetics, and how the condition will progress. By linking biosamples to CARRA Registry information we can begin to understand which treatments will work best for each person’s biology.

What is the biggest challenge for JDM in the CARRA Registry?
The biggest challenge is getting patients enrolled as early as possible into the CARRA Registry. There is a lot going on when children are first diagnosed with JDM, and the doctors and families often have a hard time thinking about research when there is so much going on so early in the diagnosis.

In addition, there is the challenge of collecting all the information for the CARRA Registry. We need information about muscle disease (CMAS-Childhood Myositis Assessment Scale and MMT-Manual Muscle Testing) and skin disease (CDASI-Cutaneous Disease Area and Severity Index) which is hard to do when children are very young or very sick. Sometimes it’s because the clinic staff is very busy or the family does not have time. The best way for families to help is to remind the clinic staff to collect this information and be aware that the appointment might take some extra time. CARRA members and families are also working on ways for families to collect some of this information at home before the clinic visit.

Where can I learn more about the CARRA Registry?
Visit https://carragroup.org/patients-families/registry to learn more about the CARRA Registry. You can view past Registry Newsletters and sign up to automatically receive new issues by visiting https://carragroup.org/research-registry/registry-newsletter. You can also ask your doctor about the CARRA Registry.

Spotlight:
Adam Huber, M.D.

Q&A:
Site: IWK Health Centre and Dalhousie University in Halifax, Nova Scotia, Canada
Role: Chair JDM Committee
Research Area of Special Interest: Assessment and Outcomes in JDM
Favorite Movie: Princess Bride (really)
Favorite TV Show: The Mandalorian
Favorite Hobby: Golf
Favorite Food: Spicy Thai Noodles
Favorite Season: Fall
Favorite Animal: my dog (or Red Pandas)
Favorite Color: Red
Book you’re reading: A Hero Born and Indigenous Relations: Insights, Tips and Suggestions to Make Reconciliation a Reality
Favorite Quote: "Do or do not, there is no try"
Logan Lentini, Research Coordinator:

Logan Lentini is a Research Coordinator for the University of Florida College of Medicine, who works on the CARRA Registry with the Division of Pediatric Allergy, Immunology, and Rheumatology. He started his work at the University of Florida CARRA Registry site as an undergraduate research assistant in the Fall of 2016. Logan graduated from the University in 2019 and has continued to play a key role in the success of the Registry. With his help, UF has become the 4th highest enrolling site, and the top site collecting biosamples in the CARRA Registry. To date, Logan has worked on 5 CARRA sub-studies within the Registry and 1 drug study.

Logan also has a personal connection to the CARRA Registry. In 2010, his younger brother, Parker, was diagnosed with polyarticular juvenile idiopathic arthritis. Since then, his diagnosis has evolved to systemic juvenile idiopathic arthritis. Watching Parker live with arthritis for the last decade has inspired Logan to act; he has volunteered extensively with the Arthritis Foundation, fronted sibling support groups at national Juvenile Arthritis Conferences, and, of course, worked on the CARRA Registry. Logan plans to enroll into PA school in the future so that he can continue to help children with chronic illnesses.

STOP-JIA Study Results, Continued

Medicines were changed or added for any patients whose symptoms didn’t get better after three months.

The STOP-JIA research team enrolled patients with pJIA before they started treatment. The choice of treatment was made by the provider, patient, and family based on what they thought was best. Once enrolled, patients and their families were asked to visit the doctor every three months for 1 year at which time they filled out surveys about their disease.

STOP-JIA Results:
• 400 children with pJIA patients enrolled across 56 clinics in the United States
• 291 (72.8%) of the children identified themselves as white, 30 (7.5%) of the children identified as black, and 79 (19.8%) identified as another race.
• The average age of patients in the study was 10 and 292 (73%) were girls.
• 256 (64%) chose Step Up, 100 (25%) Early Combination, and 44 (11%) Biologic First

In all three treatment groups, patients had less pain and greater mobility after one year. However, less than half of the patients in the study had complete disease control. In addition, levels of active inflammation in joints were not very different in each of the treatment groups at 12 months, but the Early Combination group responded faster when compared to those in the Step Up and Biologic First groups.

STOP-JIA is the largest study of its kind in the history of pediatric rheumatology. Becoming symptom free within just 1 year after pJIA starts is hard to achieve. Fortunately, children who enrolled in STOP-JIA also enrolled in the CARRA Registry. They will continue to be followed for 10+ years which will allow us to learn which plan is best over a long period of time. Stay tuned for updates from the STOP-JIA team as they learn more.

CARRA is grateful to the following organizations for their financial support which makes the CARRA Registry possible:

Arthritis Foundation
Lupus Foundation of America
Centers for Disease Control and Prevention
NIH’s National Institute of Arthritis and Musculoskeletal and Skin Diseases Patient-Centered Outcomes Research Institute Rheumatology Research Foundation

We want to hear from you!
Send feedback and make suggestions for future newsletter topics by contacting Vincent Del Gaizo (vdelgaizo@carragroup.org) or Melanie Kohlheim (mkohlheim@carragroup.org).