



CARRA Registry Newsletter

VOLUME 2, ISSUE 1 • WINTER 2019

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Here are the currently active CARRA Registry sites in the US and Canada

What is the CARRA Registry?

The CARRA Registry is a database of information about children and young adults with pediatric-onset rheumatic diseases

such as juvenile idiopathic arthritis (JIA), pediatric lupus and juvenile dermatomyositis (JDM). The CARRA Registry allows children from all across North America and beyond to share their identity protected information, including disease status, patient reported outcomes, and blood samples. This information is then shared with researchers to better understand pediatric rheumatic diseases.

Why is the CARRA Registry important?

Researchers can use the information collected to answer important questions about how safe medications are, how well medications work, and how well patients do over time. Combining Registry information with biological samples such as blood and/or genetic tests can be a very powerful tool for researchers, with which we might be able to predict which patients will respond to a particular medication, have side effects, or even find a cure for the disease.

Did you know?

As of March 1, 2019:

- Over 23,000 registry visits have occurred
- 7,902 patients have been enrolled from 65 different sites across the US and Canada
- 7,122 JIA patients have been enrolled since July, 2015
- 449 lupus patients have been enrolled since March, 2017
- 75 JDM patients have been enrolled since February, 2018

JIA:

- Among JIA patients, the start of a new medicine has been reported for thousands of participants so far. This is very important because the best opportunity to study the safety and effectiveness of medications is when they are started!

Pediatric lupus:

- A very diverse cohort of pediatric SLE patients with moderate disease activity and varying treatment regimens have been enrolled.
- Continued enrollment and follow-up will allow us the very rare opportunity to study disease course and outcomes of pediatric SLE patients!

JDM:

- 68 new onset JDM patients have been enrolled over the past 15 months which is great for such a rare condition!
- Almost 25% of these patients were considered to be in the amyopathic JDM category, meaning they have no significant weakness.
- Biosample collection for our JDM patients started in February 2019. Together with the registry data, we have a better chance of understanding JDM and treat it better in the future.



Childhood Arthritis and Rheumatology Research Alliance

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For CARRA Registry Participants: What is Long-Term Follow Up?

When you/your child transitions from pediatric to adult providers, or move away from a CARRA Registry site, we still want to follow you if you are participating in the Registry because it's critically important to continue to know how you are doing in the long-term. That is one of the main purposes of the CARRA Registry. We plan to follow every participant for at least 10 years. This is why we collect contact information from you which we need to keep current.

Getting A Call From The CARRA Registry's Long Term Follow Up Program

I remember a while ago our house phone rang. My daughter looked at the caller ID and said "I don't know who this is." My response? "That's why you answer the phone." What do you do when your phone rings and it's an unfamiliar number? **The CARRA Registry's goal is to collect information about every patient for 10 years.** But sometimes children transition to adult doctors or move to a site that isn't in the Registry. When this happens, someone from the Registry will call you to complete a brief phone survey so you can continue your participation in the registry. These calls will last 10-15 minutes and are twice a year. It's a small inconvenience for the huge reward of learning the answers to our/your many questions. Thank you and please answer the phone, especially if it comes from a **919 area code!**



*When your child grows up:
the Long Term Follow-Up Program*

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



**Thank you to Cure JM!
Biosample collection for JDM has
now started!**

STOP-JIA Update

- Enrollment is complete! 401 Polyarticular JIA patients have been enrolled
- More than half of the STOP patients have completed their follow up visits
- All visits will be completed by September 2019
- You can expect results by the end of the year
- **If you are in STOP-JIA, don't miss your clinic visits! If you don't know if you are participating, ask your provider or nurse**
- **If you are in STOP-JIA and had blood samples collected at enrollment, additional samples must be collected at your visit 6 months from when you were diagnosed/enrolled.**
- Visit the STOP page on the CARRA website: <https://carragroup.org/research/stop-jia>



FROST

- 49 Systemic JIA patients have been enrolled
- We need to enroll 51 more patients with newly diagnosed systemic JIA
- If you are in FROST and had blood samples collected at enrollment, additional samples must be collected at your visit 6 months from when you were diagnosed/enrolled.
- Don't forget to complete your Home questionnaires when you get alerts on your smart phone or tablet. This is how we can better track how you are responding to your treatments!
- Visit the FROST page on the CARRA website:
<https://carragroup.org/research/frost>

PROMOTE

Predicting Response of Methotrexate Treatment

A National Institute of Health (NIH) funded study using the CARRA Registry

JIA patient families have a love/hate relationship with methotrexate (MTX). On the one hand, methotrexate works well, has been used for many years and is safe. On the other hand, MTX can make children nauseous and can take 3 months to start working. Currently we can't predict who will be a good responder to MTX without trying it, but we want to change this and you can help. The PROMOTE study looks to find a genetic marker that will predict whether or not methotrexate will work.

How does PROMOTE work?

Children with JIA who are in the CARRA Registry and start MTX can be in PROMOTE. A single sample of blood will be collected 6 months later. This sample will be used to search for genetic markers and MTX concentrations in the blood to learn if there are differences between patients who don't respond to MTX and those who do well. The goal of PROMOTE is to know if MTX is the right drug for the patient before they start it.

Where do I learn more about PROMOTE?

Visit the PROMOTE page on the CARRA Website. You can also ask your care team for more information about PROMOTE.
<https://carragroup.org/research/promote>

Transitioning to College for Kids with Pediatric Rheumatic Diseases

If you are anything like me, talking about an invisible illness is not information you volunteer when meeting new people. Yes, I have had Rheumatoid Arthritis for as long as I remember. I take copious amounts of medications (including weekly injections), frequent doctor's offices, and cannot participate fully in high-impact sports. However, I am also a strong, sympathetic, and funny student. I have a personality and talents that speak for themselves. My illness does not, and has never, defined me.

Your first year in college is an exciting and busy time. The last thing you want to think about is managing your chronic illness. Feeling tired, sick, and overwhelmed with medications and doctor's visits can seem like an intrusion. That being said, the best advice I have for this transition is accept you are different, plan ahead, and prioritize taking care of yourself.

It took me three years of college, a flare, and a stint in the ICU to finally realize how essential taking care of myself is to my success. In life, and especially in a busy environment such as college, learning to say "no" in favor of self-care is critical. Ignoring when you are feeling drained, sick, or just in need of a good sleep will not do any good. Understand and respect your limits. Staying up late to study, going out and socializing, and participating in extracurriculars are all important parts of the college experience, but maintaining your own well-being is even more so. If you are struggling to remember to refill your prescriptions, set up automatic refills with your pharmacy to lessen the mental burden. Set reminders on your phone to make your next doctor appointment or take your medications each day. If you are feeling overwhelmed or having a rough day, visit your campus mental health clinic, or lean on family, friends, classmates and other trusted members of your support system. Listen to your body, lean on others, and know that it is okay to not do it all!

A major component of maintaining a healthy and successful college career is utilizing resources. It was not until my junior year at college that I discovered the benefits of being involved with my

campus' Disabled Students Program (DSP), an organization on most college campuses specifically focused on making accommodations for students that may need them to ensure their success at school. For me, the DSP was especially useful in helping me start conversations about my illness with professors, allotting me extra time for exams, navigating extension requests because of missed classes, and even connecting me with other seasoned students in situations similar to mine. As much as it may feel like it, you are not alone. Every college will have resources, so utilize the existing systems designed to support you.

Take care of yourself, and be excited for your next chapter. Going to college with a chronic illness is what you make of it, so choose to make that a positive experience and it will be!



Lauren Revis

Save the date! The first international **World Young Rheumatic Diseases Day (WORD Day)** is coming on **March 18, 2019!** CARRA and the Arthritis Foundation are partnering with patient families, doctors and researchers from all over the world **to raise awareness that children and young people get rheumatic diseases too.** Be on the lookout for more information about WORD Day coming soon.





CARRA Registry Research Team Member highlights:

Suz Schrandt, JD

Suz Schrandt, JD, is the Director of Patient Engagement at the Arthritis Foundation. In this role, she is working to infuse the wisdom and lived experience of patients into clinical research, drug and device development, and many other healthcare activities.

Suz's passion for patient engagement comes in large part from her own diagnosis with Polyarticular JIA 28 years ago. Before joining the Foundation, she served as the Deputy Director of Patient Engagement for PCORI where she helped to develop PCORI's engagement infrastructure. In that role, she co-created the PCORI Engagement Rubric, the Engagement Officers program, and the Pipeline to Proposal awards program. Suz is a lawyer by training and has held prior roles in health and disability law and policy. She lives in Arlington, Virginia with her husband Jay and their many four-legged "children".



Marcela Riano

Marcela Riano is originally from Bogota, Columbia. She has a daughter with polyarticular JIA diagnosed at age 11, who is now 17. Marcela is currently a patient (caregiver) investigator on the LIMIT JIA study team and is also a member of PARTNERS. Being involved in research has given her the opportunity to better understand her daughter's disease, and has allowed her to contribute to answers and improved care for pediatric rheumatology patients. She majored in Communications at Universidad Javeriana, worked as a journalist and TV host for many years. Marcela lives in El Paso, Texas with her husband who is a radiologist, and her teenaged daughter. Her eldest daughter is a student at St. Edward's University. Marcela is the owner of Young Rembrandts in the El Paso and Las Cruces area, where she dedicates her time to sharing the power of drawing and the importance of art education.



Notes From a Parent Who Has 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 myself, 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)



<http://arthritis.org/>

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