When a patient family is asked to join the CARRA Registry, the doctor and research coordinator explain what participation in the Registry will mean to the family. This process is called informed consent. A form is given to the family to sign and explain what they will need to do, how their information will be securely stored, and that participation is voluntary and can be stopped at any time. CARRA is excited to announce that we have updated the CARRA Registry consent form to allow new ways to communicate with patients and families. Families are asked to sign a new consent form even if they are already part of the CARRA Registry.

One goal of the CARRA Registry is to follow patients for at least ten years after enrolling. A lot can happen in ten years! A patient may transition to adult care, move to another rheumatology clinic for care, or improve enough to not follow their pediatric rheumatology doctors anymore. When this happens, the Registry call center contacts the patient to collect information over the phone. However, these days patients often do not answer phone calls. Because of this, we are unable to get the valuable information we need to support the Registry. The new Registry consent provides approval for us to contact patients in multiple ways and offer different opportunities for participating in the Registry (rather than just during a clinic visit or over the phone).

The new consent makes it possible for participants to interact with the Registry via email and text.

"Long-term follow-up information about Registry participants is a critically important part of the Registry," said Dr. Tim Beukelman, Scientific Director for the CARRA Registry. "It is how we will learn more about the long-term safety of medications and long-term outcomes for kids with rheumatic diseases. Currently, participants and their families only grant consent to be contacted by telephone for long-term follow-up interviews. With the new Registry consent, participants will be able to receive emails and texts to schedule the telephone interviews or be directed to the new internet-based survey. A CARRA Registry app is also in development to provide another way to collect long-term follow-up data,” added Dr. Beukelman.

In addition to improving long-term data collection, the new consents allow us to share back research and Registry information with participants and their families, but only to those families who re-consent! We are excited about the future of the Registry and the important updates coming our way.

Thank you to all of our Registry participants for sharing valuable information about their condition and care. We learn more and more every day about pediatric rheumatic diseases and how they affect children, even into adulthood.

Ask your doctor about consenting or re-consenting today!

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**CARRA Registry Updated Consent**

**Registy & Biosample Updates**

As of September 18, 2020 10,693 patients are enrolled in the CARRA Registry. Additionally, 483 biosamples have been collected and we surpassed 200 JDM/JPM in the Registry!

**Patients Enrolled**

<table>
<thead>
<tr>
<th>Year</th>
<th>Patients Enrolled</th>
</tr>
</thead>
<tbody>
<tr>
<td>2020</td>
<td>10,693</td>
</tr>
<tr>
<td>2019</td>
<td>8,558</td>
</tr>
</tbody>
</table>

**JIA: 9,278 JDM/JPM: 205**

*Scleroderma: 53*  
*new this year*

Thank you for joining the CARRA Registry!
Restarting Research: A Limit-JIA Update

Limit-JIA is a randomized clinical trial study testing whether a short course of abatacept (Orencia®) at the time of diagnosis can prevent limited JIA (arthritis in 4 or less joints) from extending to additional joints and/or the eyes (uveitis). Newly diagnosed JIA patients with four or fewer joints affected are eligible to participate. This study began enrolling patients in late 2019 and paused enrollment due to the COVID-19 pandemic.

Recently, the study team has reopened enrollment but made changes to the study to ensure that participants remain safe. The team has worked with its safety board to develop procedures to safely reopen the study. Before participants receive their weekly injection they must take their temperature and answer COVID-19 related screening questions in a survey. This survey will ask if the patients have any COVID-like symptoms, exposure risks, or have tested positive for COVID-19.

The study team uses a mobile phone app to track eye disease and medication use for all Limit-JIA patients enrolled in the study. Moving forward, the app will also send this weekly COVID-19 survey to participants. If patients have a fever or any signs/symptoms of COVID-19, the app will recommend that they contact their doctor before taking their medication. The team hopes that use of this app, will help patients stay safe during the pandemic.

If your child is newly diagnosed with JIA affecting four or less joints and you’d like to learn more about the Limit-JIA study, ask your pediatric rheumatologist today!

Meet your RPAC Member: Kendal Tiffany

My name is Kendal Tiffany and I am a Juvenile Dermatomyositis (JDM) patient. I was diagnosed in December of 2006 at the age of 10. I went from being one of the fastest soccer players on the field and the quickest liberos on the volleyball court to being unable to dress myself. As devastating as it was for me as a child, my parents were the ones who suffered the most.

At the time of my diagnosis, we had no idea what to expect. JDM is rare and we had no connections to other patient families. Throughout middle school, my parents tried to make my life as “normal” as possible. There were days when I was too tired and weak for school, but my parents made sure that I was able to keep up with my work and friends.

A few years after my diagnosis, we took a trip to the National Institutes of Health (NIH) where we met Dr. Lisa Rider and Dr. Susan Kim, who were researching calcinosis (calcium deposits that form around muscles in the body). We were also introduced to the Cure JM advocacy organization and began meeting families all over the country. CureJM is a wonderful organization that provides resources, programs, and support to families with juvenile dermatomyositis and similar diseases. Although my own disorder was in remission, we wanted to share information and hope with newly diagnosed families.

Cure JM connected us with CARRA, and their wonderful research related to rare rheumatic disorders. My family and I were lucky enough to be adopted by the CARRA family and truly appreciate everything they are doing. We learned how important long term follow up is for the Registry. This is where CARRA collects information from patients even as they move to adult care. Learning what happens to patients many years after they are diagnosed is very important to CARRA and will help future families make decisions about their care. When a patient moves out of their pediatric rheumatology clinic, they will be called twice a year from Duke University phone numbers to answer questions about their disease and medicines.

I am very thankful and happy to say that my JDM has remained in remission for the last 11 years. I have been able to lead a “normal” life with the help of some amazing physicians and researchers. I will be graduating from the accelerated nursing program at the University of Florida in August and can only hope to have as positive an impact on my future patients as the nurses and medical staff did in my life. After my family’s struggles and hardships from rheumatic disease, we feel truly blessed by our Cure JM and CARRA family!
iPERSONAL: New In-Home Study for Children and Teens with Lupus

For families with children or teens with lupus, remembering to take medicines can be a challenge. iPERSONAL is a CARRA-endorsed study conducted by the Duke Clinical Research Institute to:
- Find out if an electronic pill bottle cap can help patients better remember to take their medicine; and
- Find the best dose of hydroxychloroquine (Plaquenil®) for younger patients.

iPERSONAL, which is funded by the Food and Drug Administration (FDA) and guided by a Stakeholder & Patient Advisory Group, comprised of caregivers, patients with lupus, and stakeholders from the CARRA Registry and the Lupus Foundation of America will begin enrollment in the fall of 2020. To participate, patients must:
- have pediatric lupus and are enrolled in the CARRA Registry,
- be between the ages of 5 and 17.5 years old,
- have been taking hydroxychloroquine for at least three months,
- have access to the internet and are eager to learn how new technologies can help improve medication use.

Conducting research at home
Families enrolled in iPERSONAL will be able to participate fully from the comfort of their own homes. Participants will be given an electronic pill bottle cap and a smartphone to track when they take hydroxychloroquine. They will also receive a Fitbit®, which will track their physical activity and vital signs (temperature, heart rate, blood pressure, etc.). A nurse will visit their home 4 times over 6 months to collect blood and urine samples and ask questions about symptoms. Researchers will share important findings with participants’ primary pediatric rheumatologist/rheumatology team. At the end of the study, researchers will share findings with all participants.

Researching important questions in light of COVID-19
As many families and healthcare providers are aware, hydroxychloroquine (HCQ) is being studied as a potential drug of interest for treating COVID-19. However, little data exists for dosing in children, and the iPERSONAL study team hopes to provide this information.

iPERSONAL will allow researchers to study ways of conducting research outside of a site or clinic visit, which could be helpful if stay at home orders continue or have to restart.

Where do I learn more about iPERSONAL?
If you are interested in learning more, please contact the study’s principal investigator, Dr. Stephen J. Balevic, MD, MHS, Assistant Professor of Pediatric Rheumatology at Duke University at Stephen.balevic@duke.edu.
Arthritis Foundation’s Live Yes! Arthritis Network has so much to offer to keep you connected even while patients are more socially distant than ever before. You can connect with people like you, virtually in our Connect Groups, and online in the online community forums. Find people who understand your challenges and triumphs, share information, and support one another. Get the information and resources you need. And give the Live Yes with Arthritis podcast a listen for conversations with experts about hot topics in the arthritis community. https://www.arthritis.org/liveyes

Tamar Rubinstein, MD, MS, Assistant Professor of Pediatric Rheumatology, Children’s Hospital at Montefiore and Lupus Foundation of America Medical-Scientific Advisory Council member, answers some common questions about children living with lupus amid the coronavirus - including considerations for returning to school, when socializing with friends, and easing stress. lupus.org/coronavirus

The CRMO Foundation was recently awarded a $450,000 grant from the Chan Zuckerberg Initiative and invited to be part of their inaugural Rare As One Network, a group of 30 nonprofits working together to build collaborative research networks. We are also excited to be working with CARRA to add CRMO to the CARRA Patient Registry! October is also CRMO Awareness Month. Check out our Facebook page for more information.

International Autoinflammatory Awareness Month in August had a lot of outreach and global engagement to 89 countries (https://autoinflammatorymonth.org) with engagement from many patients, patient organizations, and research centers. The 2020 Boston Children’s Autoinflammatory Disease Family Workshop led by Dr. Dedeoglu and Dr Hausmann from the CARRA PFAPA and Autoinflammatory Workgroups was a great success, and patients and families got a lot out of the program. It will be online for viewing at a later date at autoinflammatorydiseases.org (Dr. Hausmann’s blog).

Visit spondylitis.org for information about their fall Virtual Seminars tentatively scheduled for October 3rd and December 5th.

Scleroderma: Scleroderma Foundation: Scleroderma: Beginning Summer 2020, the Scleroderma Foundation will host a “Virtual University” patient education series. There will be a new webinar every Wednesday from 3-4 pm EST through November. https://www.scleroderma.org/site/SPageServer/#.XwXnQy2z0Wo

Send feedback and make suggestions for future newsletter topics by contacting Vincent Del Gaizo (vdelgaizo@carragroup.org) or Melanie Kohlheim (mkohlheim@carragroup.org).