**CARRA Registry Growth Creates New Scientific Director Roles**

The CARRA Registry continues to grow! As of October 25, 2021, there are 11,854 children who joined the Registry. The Registry has collected information from almost 57,000 clinic visits, thanks to families and clinics that participate! The goal of the Registry is to increase understanding of long-term outcomes and the long-and short-term safety and effectiveness of the medications used to treat children with rheumatic diseases.

Because of this growth, the CARRA Registry has greatly increased its capabilities, the number of ongoing projects, and potential Registry partners. The Scientific Director role has been held by Dr. Tim Beukelman, and the duties of this position have grown to be more than one person can perform.

CARRA is pleased to announce the addition of two Assistant Scientific Directors (ASD) to assist Dr. Beukelman.

Congratulations to both Drs. Stephen Balevic and Colleen Correll on being selected as CARRA Registry Assistant Scientific Directors.

"Both Stephen and Colleen have extensive experience with the inner workings of the Registry in their prior roles as Registry Associates, so they are in a great position to start contributing from day one. They will bring a fresh perspective and new ideas to some of our current and future challenges. As they become more familiar with the role and act more independently, it will free up time for all of us to spend more energy thinking and planning for the future." -Dr. Tim Beukelman, CARRA Scientific Director

Dr. Beukelman, Balevic and Correll will work to ensure that the Registry continues to operate smoothly while they help increase the scientific output in the form of published studies and will also help bring about new technologies for the Registry such as app and cloud-based data collection for families.

**CURRENT REGISTRY ENROLLMENT**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Patients Enrolled</th>
</tr>
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<tbody>
<tr>
<td>JIA</td>
<td>10,339</td>
</tr>
<tr>
<td>SLE</td>
<td>1,015</td>
</tr>
<tr>
<td>JDM/PM</td>
<td>269</td>
</tr>
<tr>
<td>SCLERODERMA</td>
<td>96</td>
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</tbody>
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**CARRA Registry Newsletter**

**FALL 2021**

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Caregivers and Patients Help to Guide Future CARRA Research

Historically, research has been driven by drug companies and researchers at academic institutions and NIH. They were the ones who decided what, how and when research should be done. Caregivers and patients were left out of the discussion and had no voice in the process. Today, caregivers and patients are an integral partner in guiding CARRA’s research.

The CARRA/Arthritis Foundation Intramural Grant Program was created in 2016. Over the past 5 years, it has funded 89 research projects in many pediatric rheumatology diseases. This past Spring, 5 new projects were funded. Caregivers and patients played an important role in deciding which projects were funded.

How does the process work? CARRA members submit their research ideas to a Scientific Review Committee (SRC). The SRC includes researchers, clinicians, caregivers and young adult patients. The committee members review the projects to decide if they should be funded. Patients and caregivers score projects based on 3 things:

- Impact (Is the project important to the patient community?)
- Feasibility (Would families want and be able to participate in the study?)
- Patient Engagement (Are patients and caregivers on the study team? Is there a plan to share project results back to the patient community?)

Why do parents and caregivers review research proposals? “As a parent, it is important for us to contribute to and enhance the review process. We are the most qualified people to decide if the projects are important to us and if we can participate. Access to research results for the patients/public are also important factors for families to consider when reviewing projects” - Jamie Dianni

How are patients and caregivers selected to review projects? Vincent Del Gaizo, CARRA’s Director of Strategic Partnerships and Patient Engagement, assigns patient and caregiver reviewers to a project that might be interesting to them, or to a project that is about an area where they have personal experience. Vincent conducts a short training and then the reviewer will be given the chance to review projects in the future.

How can I become a CARRA/Arthritis Foundation Grant Reviewer? Contact Vincent through email at vdelgaizo@carrgroup.org or call him at 908-303-9037 to let him know you would like to help guide future CARRA research.

“...an important role in the pediatric rheumatology community by providing research support to CARRA members. The grants fund pilot and small-scale studies which will ensure a pipeline of important pediatric rheumatology research.” - Dr. Emily von Scheven, CARRA President

Predicting Eye Disease in Juvenile Idiopathic Arthritis-Uveitis

PEDIA-U is a new CARRA Registry study looking at eye disease in children with juvenile idiopathic arthritis.

Why is the PEDIA-U study important? The main reason for this study is to help us learn more about children with juvenile idiopathic arthritis (JIA) and/or uveitis (inflammation of the eye), and to help us identify who is at the greatest risk of developing uveitis. Uveitis is one of the most common and devastating issues in children with JIA. 10-20% of children with JIA develop uveitis. Currently, there is no way to predict which children with JIA will develop uveitis. When uveitis does occur, there are often no symptoms in the beginning. Untreated, it can progress to vision loss and blindness. Therefore, regular eye screening is crucial to detect disease early when it can be treated more easily.

What is PEDIA-U? PEDIA-U is a study that will look at DNA samples and information from clinic visits in the hopes of predicting a patient’s risk for developing uveitis. This will allow doctors to target high-risk children for more regular and aggressive screening.

"I am so grateful to the researchers who are studying this disease and I hope they can shed light on why some children with JIA get uveitis, and stop the next generation of children with JIA from experiencing eye damage." - Catherine Lavallee, JIA-Uveitis patient

How do you get involved? Please ask your CARRA coordinator or contact Dr. Sheila Angeles-Han (Sheila.Angeles-Han@cchmc.org).
What is Systemic JIA Lung Disease?
Over the past decade, children with Systemic JIA have increasingly been found to have a life-threatening lung disease, but the causes and best treatments for this deadly complication are unknown. This lung disease is known as SJIA-LD. In general, children suffering from SJIA-LD have uncontrolled inflammation in their lungs making it harder to move air in and out of their lungs to provide enough oxygen in their bloodstream. The severity of SJIA-LD can range from very little impact on their day-to-day lives to those who require oxygen, daily breathing treatments, and lung specific medications. Some children require a ventilator to help them breathe. Sadly, there are also children who lose their lives due to SJIA-LD.

What is CARE-NETS?
Researchers at Cincinnati Children’s Hospital, with help from CARRA, are working on a project called the “CARRA Registry Research Network for SJIA-LD” (CARE-NETS) that will allow SJIA-LD data to be collected at several hospitals in the US and Canada in order to better understand this disease. Currently, there are 40 SJIA-LD patients scheduled to participate in this project, but more will be added as the study grows. The research team, led by Dr. Grant Schulert, will analyze clinical information along with blood samples that have been collected over several months by the SJIA-LD’s local rheumatologist and shipped to Cincinnati Children’s Hospital. The research team will use the blood samples to look for biomarkers which will be critical in identifying patterns among the SJIA-LD kids.

Why is the CARE-NETS Project Important?
Even though the number of SJIA-LD children are increasing, it is still a rare complication and researchers/doctors need to rely on information from the entire patient-group to identify trends and to help determine which medications are most appropriate for their individual patients. This project will launch the first research network that will collect clinical data and blood samples from children with SJIA-LD through the CARRA Registry. CARE-NETS is an essential first step to find the cause of SJIA-LD, which will be done using the CARRA network.

My 6-year-old daughter, Sophia, has been battling SJIA-LD for 5 years and is one of the more extreme cases. We are very lucky she is still alive. As a result of her SJIA-LD she has a trach and is oxygen and ventilator-dependent. Her lungs are badly damaged. Providing clinical details and blood samples a few times a year is a simple way to try and help my daughter, but more importantly, to make sure other SJIA kids don’t suffer the damage and limitations my daughter now deals with every day. We are excited to participate in the CARE-NETS trial to help doctors learn more about this condition!

Grant Schulert, MD PhD
SITE: DIVISION OF RHEUMATOLOGY, CINCINNATI CHILDREN’S HOSPITAL AND DEPARTMENT OF PEDIATRICS, UNIVERSITY OF CINCINNATI COLLEGE OF MEDICINE
ROLE: VICE-CHAIR OF THE TRANSLATIONAL RESEARCH AND TECHNOLOGY COMMITTEE (TRTC), CO-PI OF THE CARRA REGISTRY SJIA-LD COHORT STUDY
SPECIAL INTEREST: REFRACTORY SYSTEMIC JUVENILE IDIOPATHIC ARTHRITIS AND ITS COMPLICATIONS

Grant's Favorites
HOBBIES: PM HALO
MOVIES: STAR WARS
FOOD: BBQ
TV: "LIVING IN THE NOW"
SEASON: SPRING
COLOR: BLUE
ANIMAL: BEAR
QUOTE: "Luck is the residue of design" – Branch Rickey
**Patient-Facing Tools**  
By Emily Neu

Patient biosamples play a very important role in CARRA’s work. By pairing biosamples (normally blood samples) with the data collected in clinic by pediatric rheumatologists, researchers can learn tremendous amounts about patients and the conditions they live with. As parents and patients, we need to better understand why we are being asked to participate in research and why biosamples might be needed. The request for extra blood samples can feel very overwhelming and intimidating, especially at initial diagnosis. As parent and patient representatives, we wanted to create easy to understand tools to help explain why research is so important and how we can make a difference by contributing biosamples to the CARRA Registry.

CARRA is excited to share that we have a new tool for patients and their families to learn more about research and biosamples. Families may see this flyer at their rheumatology clinic in the near future!

**Patient Spotlight: Catherine Lavallee**

Catherine Lavallee was diagnosed with JIA and uveitis at age five. While that has certainly posed some challenges over the last twenty years, instead of letting it stop her dreams, it inspired them. Now, she’s a second-year medical student at Virginia Tech Carilion School of Medicine (VTCSOM).

Prior to starting medical school, Catherine worked at Boston Children’s Hospital doing food allergy research in the Immunology Division. It was there that she met Dr. Lauren Henderson, who got her involved with CARRA. Since 2018, Catherine has participated as a patient stakeholder on LIMIT-JIA (a clinical trial) and patient engagement projects to get children involved with the CARRA Registry. Now, Catherine is the chair of the TRTC genomic data sharing workgroup, is involved with the Reproductive Health Workgroup and the Cross-Cutting Committee, and she participates as a researcher while still providing patient input.

At VTCSOM she is getting ready to take STEP 1 in March, the first major medical school exam. Catherine loves the problem-based curriculum that involves learning from patient cases. She is also very involved in the Ultrasound Interest Group, where students can learn and practice ultrasound in a clinical setting. Catherine’s life experience continues to influence her professional interests and she is using her CARRA connections to establish shadowing opportunities in pediatric rheumatology.

Catherine hopes to become a pediatric rheumatologist and researcher.