A Voice in the Room -
A Caregiver Perspective on CARRA's Strategic Planning Process

CARRA is currently going through a forward thinking, strategic planning process to re-examine priorities and chart a course for the organization for the next few years. Throughout this process, CARRA has provided a seat at the table to parents, patients and caregivers. Our voices were first heard in small focus groups during which we answered various questions and had the opportunity to provide ideas for change throughout January 2022.

After the focus groups, outside strategic planning consultants combined the feedback from all interested groups (clinicians, external partners, patients, caregivers, investigators, etc.). The summarized information was shared out to a small group of individuals who would represent these stakeholders at a strategic planning conference held over 3 days in February 2022.

Due to COVID concerns, the Strategic Planning Conference was held virtually in early February. The virtual conference was led by an expert moderator who took the participants through a series of exercises and discussions to help provide guidance for the CARRA leadership to consider.

I am thankful to CARRA for allowing parents and patients to have a voice at the table. I am honored to have had the opportunity to represent the wonderful families that are affected by rheumatic conditions. From my caregiver perspective, it was important to thank all of the professionals who have dedicated their careers to helping provide hope to our families and patients. At the end of the day, the children fighting the rheumatic diseases are the reason behind CARRA and the dedication from members. We are thankful for the hope that CARRA and the critical research it encourages provides. I am excited to see the plans that emerge from the hard work the Strategic Planning Committee is completing. Here is to the bright future of CARRA!

We learn so much from our patients, parents and other caregivers. They provide a unique and meaningful perspective that is essential to steer our work and our organization in the right direction. - Bob Colbert

Including patients and caregivers in our work helps us to ensure that we are addressing the research questions and needs of the people who are living with rheumatic disease, every day. - Emily von Scheven

CARRA Registry Update
Total Patients Enrolled in CARRA Registry - 12,251

<table>
<thead>
<tr>
<th>Condition</th>
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<td>Scleroderma</td>
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Emily Neu, MBA
Parent Caregiver
CARRA RPAC Co-Chair

CARRA
Childhood Arthritis and Rheumatology Research Alliance
555 East Wells Street, Suite 1100
Milwaukee, WI 53202
414-918-9822
carragroup.org
Lupus Biosamples Stored Since 2009 Released for Two Research Studies

Drs. Laura Schanberg and Christy Sandborg led a large study in children with lupus in 2003-2009 called APPLE (Atherosclerosis Prevention in Pediatric Lupus Erythematosus). Patients enrolled in this study gave biosamples, provided information at their clinic visits, and had ultrasounds of their hearts to support the work of this study. The study team looked at whether a medication used for high cholesterol could be used to prevent hardening of arteries (atherosclerosis) in children and young adults with lupus. This hardening can lead to heart attacks and strokes, which tends to happen at a higher rate among people with lupus. This study was the first and largest trial ever done in childhood-onset lupus, and researchers are still learning from these patients to this day. Biosamples collected during the APPLE study were transferred to the CARRA Biobank, which is like a library for samples. CARRA members can apply to use the samples for new studies, just as someone would check out a book from the library. Two studies were recently approved.

Dr. Laura Lewandowski from the National Institutes of Health is using the samples to study genetics in lupus patients. She is also one of the lead researchers of the CLUE (Child/Adolescent Lupus Study: Understanding Etiology) study and will use these APPLE samples along with new lupus samples being collected. She plans to study rare and common changes in the genes of lupus patients to better understand how those changes help doctors identify who will get lupus and how serious lupus is in each person who has it.

Dr. George Robinson from the University College of London is also using the APPLE samples to study early biomarkers and fat levels in the blood that could be a warning sign for patients who might be at a higher risk of heart disease at an early age. This would allow doctors to identify these patients sooner and help avoid more serious heart disease.

Both Dr. Lewandowski and Dr. Robinson are CARRA members who will learn from these APPLE participants, many of whom are grown adults now. Patients enrolled in the CARRA Registry are continuing to help investigators learn more about lupus over a decade later! It makes you realize just how much difference today’s patient contributions can make for years to come. We are excited to learn more and eager to share progress with patients and families who made all of this possible.

Researcher Spotlight

Laura Schanberg is a Professor at Duke. She has held many positions at CARRA over the years! Founding member of steering committee, Chair of SLE group, 8 years on Exec Committee, President, DCRI PI of CARRA Registry, Co-Chair RROC

Hobbies: Knitting & Pickleball
Currently Reading: The Yellow House by Sarah Broom
Movie: Anything with Cary Grant
TV Show: The Marvelous Mrs. Maisel
Food: Chocolate
Season: Summer
Animal: Dog
Color: Duke Blue
Limit-JIA Study Makes Big Changes Thanks to CARRA Registry Data

Limit-JIA is a study looking to learn if we can prevent arthritis in children from spreading or getting worse by using a biologic medication called abatacept (Orencia). Limited JIA refers to JIA patients who have 4 or fewer joints affected by their arthritis. Sometimes, children with limited JIA have their arthritis spread to more joints or develop inflammation in the eyes called uveitis. Children newly diagnosed with limited JIA had the opportunity to join the study. Those who joined were assigned at random (like flipping a coin) to one of 2 groups:

- Abatacept Group - children would receive abatacept for 6 months.
- Usual Care Group - children would receive the care normally given to limited JIA-anti-inflammatory medicine like naproxen or ibuprofen and joint injections when needed.

Unfortunately, the COVID-19 pandemic greatly affected Limit-JIA. Clinics were overwhelmed caring for people with the virus and families were unable to go to the clinic and join the study. In order to answer the question “can abatacept prevent limited JIA from getting worse?” the study needed to enroll a total of 306 children within 4 years. Because of COVID, there was a risk we wouldn’t be able to meet that goal.

Fortunately, the CARRA Registry has grown since the start of Limit JIA. There are more than enough children in the Registry who received usual care. These children had their rheumatology visits tracked in the Registry, the medications they had been taking, and disease activity documented. Because of the rich and complete data in the Registry, the Limit JIA study no longer had to enroll children to the usual care group. Now all children who chose to join Limit will receive abatacept and the total number of children needed has been greatly reduced from 306 to 89! We also learned from the Registry that the study which originally lasted 18 months can be shortened to 12. These patients would then continue to be tracked in the CARRA Registry all together for up to 10 years!

The use of the CARRA Registry data to fulfill study requirements is very exciting for Registry leaders. This is also wonderful news for patients and their families who join the Registry as their participation is helping to make this study successful!

“This is such an exciting time to be part of the CARRA Registry. Not only is the Registry helping us understand the outcomes of children with rheumatic diseases, but to see the data from the Registry used to make research in children better, more efficient and meaningful is simply awesome. I must thank our patients and colleagues for continuing to enroll and participate in the Registry. You are ALL making a difference!” (Mara Becker, MD MSCE)

CARRA RPAC Member & Patient Spotlight

Christina Loccke is a writing teacher and mother of four children, including 15-year-old Claudette, who has localized scleroderma. She serves on the Board of Directors for the National Scleroderma Foundation, the CRMO Foundation, and on the Registry Committee (RPAC) for CARRA. She lives with her family in Montclair, New Jersey.

Christina continues to advocate specifically for juveniles with scleroderma. During her efforts, the National Scleroderma Foundation has earmarked $500,000 in awards to specifically fund Juvenile Scleroderma Research.

Claudette Johnson was diagnosed with localized scleroderma six years ago. She is a competitive diver and plays classical piano despite having scleroderma in her hands. Claudette takes after her mother and is eager to advocate for juveniles and pediatric patients. Her dream is to have an organized youth council so patients can speak first-hand about their experiences and guide physicians and researchers when prioritizing research and important patient reported outcomes.

For more information on Scleroderma, please visit the Scleroderma website: https://scleroderma.org/
Introducing REDCap Cloud: A better way for families to participate in the Registry

What is REDCap Cloud (RCC)?
REDCap Cloud (RCC) is software that provides an easy way to collect data for research studies – REDCap stands for Research Electronic Data Capture. CARRA will begin using RCC to collect Patient Reported Outcomes (PROs) such as pain and physical function surveys. RCC will also be used to simplify the consent process when children join the Registry and other research studies.

Why do we need RCC?
Currently, PRO surveys and data are collected on paper or an iPad in clinic and over the phone for patients followed by the call center. The data must be collected at the time of the visit or during the phone call. With RCC, patient reported outcome surveys can be completed online within a specified time window. This can be done from the comfort of your home with an internet connection.

Consent and assent documents required to join the CARRA Registry and associated studies are also completed on paper. With RCC, these documents can be completed electronically and securely stored in your account. In addition, CARRA will be able to easily keep in touch with Registry families through RCC. We hope that using RCC will allow families to remain engaged with the Registry between visits and over time.

How will participants interact with the RCC system moving forward?
CARRA is working with families to test RCC to make sure it is easy to use and a pleasant experience. Once ready, Registry families will be contacted and given instructions to register for an account. People will use RCC whether they participate in the Registry at a clinic site or with the call center. RCC can be accessed on whatever type of device users prefer – a computer, tablet, or smart phone. All you need is an internet connection.

Once the account is set up participants will use RCC to complete patient reported outcome surveys within a certain time window based on their visit schedule. Reminders will be sent when it is time for them to be completed. If updates to consent are needed or participants choose to enroll in a study associated with the CARRA Registry the consent and assent forms will be completed in RCC.

Participants may receive occasional reminders or messages via RCC. RCC will be used to continue collecting data from participants long term when they leave their CARRA Registry site.

Young Patient Spotlight: Antoinette Neu
Antoinette is a 13 year old fighting Ankylosing Spondylitis. Antoinette was diagnosed at 3 years old and has volunteered to participate in many studies over the years at her local hospital and at NIH.
She is a feisty, sassy, hard-working, nurturing teenager who loves to play basketball and sing. Unfortunately, her disease has proven hard to control and manage. She has tried over fifteen different combinations of medicines.

What I Wish My Doctor Knew...
Antoinette said if she could tell her doctor anything, it would be -
“Don’t give up on me and I won’t give up on you!”

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

Arthritis Foundation
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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