CARRA Annual Scientific Meeting

CARRA embraces the voice and participation of parents and patients throughout the entire research process. One way CARRA does this is at their Annual Scientific Meeting. Each year, CARRA hosts a working meeting for its members and collaborators to plan and discuss research. The meeting is the largest annual pediatric rheumatology meeting in North America. The 2019 meeting was held in Louisville, KY from April 11-13. Over 480 attendees, including a record number of 65 invited parents and patients, came to the meeting to work side by side on research in many pediatric rheumatic diseases.

The CARRA Annual Scientific Meeting is a unique opportunity for parents and patients to collaborate on research. Autoinflammatory mother and first-time attendee Alyse Tankanow said “The CARRA meeting was a perfect way for me to get my feet wet with partnering in research. There was so much to learn and I’m beyond grateful for the opportunity.” Lupus mother Shannon Oscar added “I appreciate CARRA makes such an effort to include the patient voice. My thoughts were valued and I was able to change the doctors’ opinion on a controversial topic.”

The meeting is organized into workgroups that address specific diseases, but there are also workgroups that include more than one disease, such as Mental Health and Transition. Meetings are also held for specific research studies like the CARRA Registry. This year, the CARRA Registry meeting included a panel discussion addressing challenges of long term follow up of Registry participants. One of the major goals of the Registry is to follow patients for at least 10 years to learn about long term safety of medications and how patients do in the long-term. JIA mother Charla Cary represented the parent voice on the panel and discussed strategies to contact patients after they are no longer being seen by a CARRA Registry site or move to adult doctors. Be on the lookout for CARRA Registry Membership cards and information about receiving texts from the long-term follow-up center at Duke coming very soon!

CARRA would like to thank the Arthritis Foundation for their support and partnership. Their generous funding makes it possible to bring so many parents and patients to the meeting.

“Patient and parent participation in the CARRA meeting is critically important to making sure the patient’s voice is involved in advancing pediatric rheumatology research. Patients and parents will be nominated to be invited by the disease committee chairs, workgroup leaders and the newly formed CARRA Patient Advisory Committee. It is an exciting experience for researchers and patients/parents alike to be able to work together.” said Yukiko Kimura, MD, CARRA Registry Co-PI and Past President of CARRA.
Biosamples: Giving Blood and other Samples for Research

A goal shared by families and CARRA doctors is giving the right medication to the right child at the right time. How do we move toward realizing this goal? One way is to follow symptoms, like pain, rash, fatigue or swelling. However, it may be better to try and understand what is actually happening in the body. One way to do this is through giving biosamples. Biosamples are any substances taken from the body, and include blood, urine, saliva, or biopsies of skin, muscle or other tissues. These samples are sent to the CARRA Biobanks located in Cincinnati and Toronto. Biobanks are laboratories where samples are sent, processed and then stored for future use in research. These biosamples may help doctors to learn about the causes of conditions, understand what is happening with the immune system at different stages of disease and hopefully help to tailor treatment for each child’s unique circumstances.

Juvenile Dermatomyositis (JDM) Biosample Collection in the CARRA Registry

Newly diagnosed children and adolescents with juvenile dermatomyositis (JDM) who enroll in the CARRA Registry can donate their biosamples for research. Currently, blood is taken at diagnosis and after 6 months of treatment for newly diagnosed JDM children who elect to contribute. Other biosamples will eventually be added. Projects in the future will study the genetics of JDM, how different parts of the immune system contribute to the illness, how to tell if children are in remission or having a flare, and which treatments are most likely to work in which children. The JDM biosamples are an incredibly important and valuable resource. A very big thanks to the Cure JM Foundation (www.curejm.org) for providing the funding for this very important project.

LIMIT-JIA: A Patient-Centered Outcomes Research Institute (PCORI) funded study using the CARRA Registry

How can we prevent oligoarticular (oligo) JIA (arthritis that affects 4 or fewer joints) from getting worse? That is the question the LIMIT-JIA study looks to answer. The usual care for oligo-JIA often starts with an NSAID like ibuprofen and can include joint injections. About half of these children will have their arthritis spread to more joints or the eyes (uveitis). Once the arthritis gets worse, treatment is often intensified to methotrexate and/or a biologic medication. In the LIMIT-JIA study, children will receive the biologic abatacept (Orencia) when the disease starts to see if doing so prevents the arthritis from spreading to more joints or the eyes.

How does LIMIT-JIA work?
The LIMIT-JIA study will enroll 306 newly diagnosed children with oligo-JIA. Some children will receive usual care and some will receive usual care in addition to 6 months of abatacept (Orencia). Abatacept (Orencia) is an FDA-approved medicine that is commonly used in patients with other types of JIA. Data from LIMIT-JIA will be entered in the CARRA Registry. About 30 CARRA sites will participate in the study.

In addition to the clinical side of the project, LIMIT-JIA will also collect biological samples. A little extra blood will be drawn when usual lab work is done to search for clues that will predict how well children respond to medications. CARRA shares with patients and families the goal of being able to give the right medication to the right child at the right time. The bio-sample collection in LIMIT-JIA will help us move toward this goal.

Where do I learn more about LIMIT-JIA?
Visit the LIMIT-JIA page on the CARRA website. You can also ask your care team for more information about LIMIT-JIA. https://carragroup.org/research-registry/projects/limit-jia

CARRA Registry Tops 9,000 Patients!

As of September 20th, 9,332 patients have enrolled in the CARRA Registry! Highlights include:

- 8,281 patients with JIA, 606 patients with SLE and related conditions, 135 patients with JDM or JPM, and 11 scleroderma patients have been enrolled!
- 285 biosamples have been collected!

Thank you for joining the CARRA Registry! Your participation helps us learn the best and safest ways to treat pediatric rheumatic diseases. Look for future newsletters when we share what we are learning.

Biosamples: Giving Blood and other Samples for Research

Many CARRA studies in other conditions besides JDM also give patients the opportunity to contribute to the CARRA Biobank, so be sure to ask your doctor about whether this is possible at your next clinic visit!
Predicting Response of Methotrexate Treatment
A National Institute of Health (NIH) funded study using the CARRA Registry

Here is an update including a Q&A from Dr Mara Becker. Dr Becker is a pediatric rheumatologist from Duke University, a Principal Investigator for PROMOTE and Chair of CARRA's JIA Committee.

In case you missed it:
PROMOTE is still recruiting! You can access the first PROMOTE newsletter article for more information about the study here: https://carragroup.org/UserFiles/file/carra-RegistryV1-Iss4_v8.pdf

Wouldn't it be great to have an idea of how well methotrexate (MTX) will work BEFORE you start taking it? The PROMOTE study looks to find a genetic marker that predicts whether or not MTX will work. All children diagnosed with JIA in the CARRA Registry (except systemic JIA) who start methotrexate can enroll in PROMOTE.

A single sample of blood will be collected 6 months after starting MTX. 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. https://carragroup.org/research-registry/projects/promote. You can also ask your care team for more information about PROMOTE.

Q&A with Dr. Mara Becker:
Q: How many children are you looking to join PROMOTE?
Dr. Becker: We are looking to enroll 400 children that are in the CARRA Registry.

Q: How many have joined so far?
Dr. Becker: On June 1, 2019 we had 74 children in the study.

Q: Where can someone join the study?
Dr. Becker: All CARRA Registry sites allowed to collect biospecimens for the CARRA Biobank can enroll you in PROMOTE. We are also working with doctors in Italy that are contributing samples.

Q: Any challenges so far?
Dr. Becker: One of the biggest challenges we see is the timing of sample collection. We look to collect at the same time as routine clinic labs so there is not an extra visit or an extra poke. In PROMOTE we need to collect the sample at about 6 months but sometimes children need more medication before that time. New medications could mean new labs making everything a little confusing. And sometimes patients obtain their clinical labs at outside locations, which makes obtaining the PROMOTE sample a little harder as well.

Q: Anything families can do to help?
Dr. Becker: Yes! All patients can help by asking their doctor about PROMOTE labs at every clinical visit. “When do we need to go for our PROMOTE labs?” Or if the doctor says it’s time to collect routine labs you can ask “Do we need to collect PROMOTE labs now too?” Families reminding the clinic staff and working with the coordinators on a little pre-planning will be a huge help!
CARRA Receives over $2 Million to Support Lupus Research

CARRA was awarded a 3-year, $2.4 million grant from the Centers of Disease Control and Prevention (CDC) for lupus research. The award will support natural history studies using the CARRA Registry to learn the lifetime impact of lupus on children. Natural history studies are the necessary first steps toward new drug development. Currently there are over 600 children diagnosed with lupus in the Registry. The award will support CARRA’s goal of enrolling over 1,000 patients and follow them for over 10 years. Aimee Hersch, MD pediatric rheumatologist at the University of Utah and Chair of CARRA’s Lupus Committee said, “We are thrilled to receive this funding from the CDC that will further our mission of advancing meaningful research in pediatric rheumatic diseases.” Thank you to the Lupus Foundation of America and lupus parents and patients for your important advocacy efforts that made this award possible.

CARRA Registry Research Team Member Highlights:

Bhupinder Nahal, CCRP, MS
CARRA Registry Research Coordinator
The University of California San Francisco (UCSF)

Bhupinder Nahal has been the Clinical Research Coordinator for the CARRA Registry at UCSF for the last 3 years. She has a background in healthcare administration and leadership and has over 7 years of experience coordinating multiple research studies. Her Pediatric Rheumatology research team aims to advance our understanding of complex rheumatic diseases and to improve outcomes for affected children. Bhupinder is obsessed with organizing and enjoys traveling with her husband and her daughter Zara.

Valarie Morrow, MD
Project Leader at the Duke Clinical Research Institute (DCRI)
LIMIT-JIA Study

Valarie Morrow is the project leader for the LIMIT-JIA study. She is a Graduate of Duke University and UNC School of Medicine. She has also done coursework at Duke Divinity School. Val has over 20 years of clinical trials research experience. She has experience in all Clinical Trial Phases. She has worked in the following therapeutic areas: CV, Device, ID, Endocrinology, Pulmonology and Pediatric Trials. She has experience in Project Management, Safety, Site Management and Medical Writing.

Val resides in North Carolina with her husband and has 6 children. She is a motivational speaker and speaks at Women’s Conferences frequently. She and her husband run a Transition Home for Ex-Offenders and during her down time she also loves watching DUKE Basketball! Go Blue Devils!

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