

THE CARRA REGISTRY

You and your child can improve the health of children with arthritis and rheumatic diseases.



CARRA 
Childhood Arthritis and Rheumatology Research Alliance





Thoughts from a parent of a child with JIA:

"Being told your child has a rheumatic disease can make you relieved and scared at the same time. Relieved because you now know what is wrong with your child, and scared because you don't know what will happen next."

We want a crystal ball to answer all our questions. What should we do? What treatment should we use? What works best? What are the long term risks? What works fastest? What are the possible side effects? Will he be ok? Unfortunately, we have no crystal ball, so we have to make hard choices with little information to guide us. But it comforts me that through the CARRA Registry, we will start to answer these questions. That is why we all need to join and support the CARRA Registry!"

Q: What is the CARRA Registry?

A: The CARRA Registry stores information collected about your child's illness and other pediatric rheumatic diseases. The information is identity protected and securely stored.

Q: Why was the CARRA Registry created?

A: The registry was created to monitor the long term safety of the medications used to treat pediatric rheumatic diseases. A recent survey of parents listed understanding long term safety of medications as their #1 priority. But the registry does so much more: It also collects large amounts of information on thousands of patients, their treatments, side effects and quality of life, so you will be able to make more informed decisions about your/your child's health. The goal is to have all the information you need to choose the safest treatment for your desired outcome.

Q: What information will the CARRA Registry collect?

A: The registry will collect information about you/your child's illness including:

- Medications used
- Blood tests results
- Information your doctor enters about how you are doing
- Information you enter about how you are doing
- Any side effects or illnesses you may have

Most of this identity protected information is already collected during your normal visit. But by being a part of the registry, the information can be shared with other doctors, researchers and families to learn more about these illnesses. The information can eventually be used to understand which treatments will work best for each disease, and even for each individual person. We will also learn more about the long and short term safety of all medications, because each child will be followed for a long time.

Q: Will I receive the same care from my doctor?

A: The care you receive from your doctor will be the same, whether you agree to join the registry or not.

Q: What is the risk of joining the CARRA Registry?

A: CARRA uses the most up to date security to protect and keep your identity and health information separated. However, there is always a chance that your identity could be linked to your data in the event of a security breach.

Q: Can I quit the registry?

A: You can quit the registry at any time, and your information will stop being collected.

Q: What do I have to do to join?

A: To join the registry you have to sign a document to agree to share your identity protected data, and to answer a few additional questions during your clinic visits.

Q: What is CARRA?

A: CARRA stands for Childhood Arthritis and Rheumatology Research Alliance (www.carragroup.org). CARRA is a non-profit group of more than 500 doctors, researchers and other health care professionals throughout the US and Canada. Almost every pediatric rheumatologist in North America is a member. CARRA was formed so that better, more effective research can be performed by many pediatric rheumatologists working together. Through CARRA, a child in Iowa can be part of research being done across North America and beyond, and still see their same doctor. Working together lets CARRA do larger studies, which will lead to faster and more meaningful results and answers.





To learn more about the CARRA Registry, contact:

Clinic Name: _____

Study Coordinator: _____

Phone Number: _____



CARRA 

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For a complete listing of all CARRA Registry supporters visit www.carragroup.org