Research Priorities among Parents & Families of Children with Rheumatic Disease

The Colleen Correll Research Prioritization Study

“Life as I once knew it seemed to be fading off in a distant shore. I was a strong, vibrant woman and I found myself in the most challenging position you can imagine. Getting a diagnosis of Lupus SLE, Rheumatoid Arthritis, and having a stroke to the left side of the brain was overwhelming. This was the moment of limitations, restrictions, and pain.” Sylvia Faircloth shares her experience living with these diseases. Many others share Sylvia’s concerns, and more patient centered search is needed.

The goal of this project was to improve the relevance of research to patients and families. Click here to view more

Engaging Patients & Parents to Improve the Emotional Health of Youth with Rheumatologic Disease

The Andrea Knight Mental Health Study

Young patients with rheumatologic conditions require complex and ongoing treatment to manage their diseases. In addition to physical health challenges, issues related to emotional health such as anxiety, depression, and adjustment disorder are common. Emotional health can impact a patient’s pain, fatigue, willingness to take medication, and overall quality of life. However, providers lack knowledge about how best to address emotional health problems for pediatric rheumatology patients. Research can positively impact overall care and outcomes for these young patients as well as identify emotional health needs and intervention strategies. Click here to view more

What is PARTNERS?

PARTNERS formally links childhood arthritis and lupus patients, family members, the CARRA network, the Lupus Foundation of America, Cure JM, the Arthritis Foundation and a quality improvement network called PR-COIN. Our vision is to improve the lives of children with rheumatic diseases through research that matters to YOU. PARTNERS is a patient-powered research network funded by PCORI.

Lupus Foundation of America Recognizes National Advocates

The Lupus Foundation of America presented its first Sandra C. Raymond Advocate of the Year Award last week during the nation’s largest-ever gathering of lupus advocates in Washington, DC. The award is named in honor of the Foundation’s immediate past President & CEO for advocacy achievements during her 17 year tenure at the helm of the Lupus Foundation of America. Click here to view more

Would you like to join the PARTNERS Network?
Click on one of these links to an advocacy organization to learn more:
⇒ Arthritis Foundation
⇒ Cure JM Foundation
⇒ Lupus Foundation of America