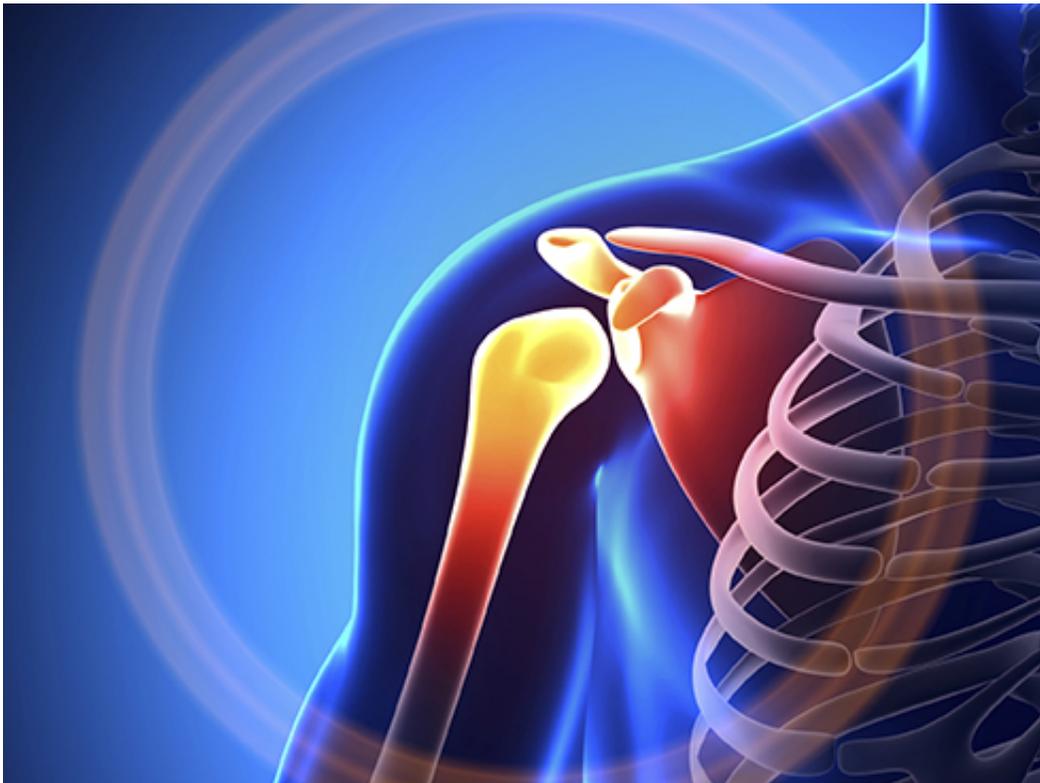


First patient-led research registry for arthritis patients launched

May 19 2015, by Linda Gunter



CreakyJoints, an online, nonprofit, patient support community with more than 80,000 members, has launched [Arthritis Power](#), the first patient-led, patient-generated, patient-centered research registry for arthritis, bone, and inflammatory skin conditions. Focusing on rheumatoid arthritis, psoriasis, psoriatic arthritis as well as numerous other musculoskeletal

conditions, the goal of Arthritis Power is to securely collect health data from tens of thousands of arthritis patients to support future research.

Arthritis Power includes a steering committee of [patients](#) called the Patient Governor Group that identifies research needs for study development and prioritizes research requests from the CreakyJoints patient community around the world. The new initiative is launched in partnership with the University of Alabama at Birmingham. Arthritis Power is supported in part by the Patient Centered Outcomes Research Institute (PCORI), a nonprofit, nongovernmental organization created by Congress as part of the Patient Protection and Affordable Care Act of 2010. Its overall goal is to enhance informed health-care decision-making and to improve health-care delivery.

Usually patients with rheumatoid, [psoriatic arthritis](#) or other chronic conditions learn about opportunities to participate in research from their health-care providers. Arthritis Power will offer a variety of clinical trial and other research opportunities, allowing patients to proactively decide when and how to participate. Securely donated data will be used by patients, universities, research facilities, and physicians to better understand how to fight these diseases and perhaps, contribute to finding elusive cures. Arthritis Power data will be collected using a smart phone, laptop, desktop or tablet where there is an Internet connection.

"Patient-centered research means that we can more effectively use big data to answer questions that are important to those living with these illnesses. This opportunity will produce results that help patients weigh the value of health-care options according to their personal circumstances, conditions, and preferences," says Jeffrey Curtis, M.D., M.S., MPH, William J. Koopman Endowed Professor in Rheumatology and Immunology in the UAB Division of Clinical Immunology and Rheumatology.

"The more people who join and share information about their symptoms and treatments, the more quickly we are able to find answers," he said.

Arthritis Power empowers patients to take control of their disease. First, patients positively support and advance the understanding of [arthritis](#) by participating in studies shaped by their peers. Second, patients can conveniently and easily track changes in their symptoms over time with their health-care team via the "My Reports" function of the application. This close-up view of a patient's day-to-day experience will help doctors work with their patients to adjust medications and promote healthy behaviors.

"With the launch of Arthritis Power, we now have the ability to prioritize our community's most urgent treatment and disease management questions," said Seth Ginsberg, president and co-founder of CreakyJoints and the Global Healthy Living Foundation. "It will be easy to track, share, and send [health data](#), enabling patients and physicians to have more productive and meaningful dialogue about ongoing treatments."

More information: To learn more about CreakyJoints, see www.creakyjoints.org/

Provided by University of Alabama at Birmingham

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