Patient Partners in Research (PPR)
A Patient Research Initiative by CreakyJoints,
a part of the Global Healthy Living Foundation

Overview and Background: CreakyJoints is part of the Global Healthy Living Foundation (GHLF), a 501(c)(3) non-profit advocacy organization, based in New York, with the mission to improve the quality of life for people with chronic illness. CreakyJoints is an organization focused on using technology and creative innovation to help people and their families who live with arthritis. Its mission aligns with GHLF’s mission by advocating for improved access to care and by educating the community about the importance of diagnosis, early and innovative medical intervention, long-term lifestyle improvement, and therapeutic adherence. ArthritisPower is the patient-powered research initiative of CreakyJoints.

CreakyJoints is inviting a group of a 50-80 community members who are living with arthritis to serve as Patient Partners in Research (PPRs) to provide input and advice about study design and implementation for a variety of research topics related to diseases of the bones, joints or skin. PPRs will advise on the feasibility of research relevant to their own conditions.

Position Title: Patient Partners in Research (PPRs)

Position Purpose: Patient Partners in Research (PPRs) play an important role in arthritis patient-centered research by interacting with research scientists (rheumatologists, dermatologists, epidemiologists, etc.) and research coordinators who are studying conditions affecting the bones, joints, and skin. It includes such activities as being a “pilot tester” to give feedback on surveys or about the feasibility of a study. Will patients sign up for the study? Will patients be able to answer survey questions? Will patients want to participate in the trial that a researcher is proposing? These are the kinds of questions that pilot testers can help answer. PPRs who have an interest or expertise in research may be called on to act as advisors to researchers. PPRs provide their perspective as a patient about how best to design and/or implement a study and/or to disseminate findings. In some cases, rheumatology researchers may seek co-investigators who also have experience as rheumatology patients.

Expectations: Terms are open-ended, but can be terminated at any time by the PPR or by GHLF/CreakyJoints. PPRs may be contacted to offer advice by participating in brief online surveys or in longer phone interviews or focus groups. Monthly or quarterly conference calls or webinars will be held to provide updates—it is strongly recommended that PPRs attend these. Total yearly time commitment varies and is up to the individual, but will likely require a minimum of 4-6 hours per year. This is a volunteer position, but PPRs may occasionally receive compensation for their input. This is an opportunity to become more involved in research that may help the next generation.

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