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First Ever Rheumatoid Arthritis Patient Guidelines Announced by CreakyJoints

_CreakyJoints Presents Five Posters at 2016 ACR/AHRP Annual Meeting_

UPER NYACK, NY (Nov. 14, 2016) – CreakyJoints®, the go-to source for more than 100,000 arthritis patients and their families world-wide who are seeking education, support, advocacy, and patient-centered research, today announced the forthcoming publication of “A Patient’s Guide to Living with Rheumatoid Arthritis.” During the 2016 ACR/AHRP Annual Meeting, taking place in Washington, D.C., November 11-16, 2016, CreakyJoints will preview the guidelines’ Patient Charter, which was developed and endorsed by CreakyJoints’ national Patient Council as well as select rheumatologists, who informed the full-length patient guidelines to be published during the first quarter of 2017. “A Patient’s Guide to Living with Rheumatoid Arthritis” is the first in a planned series of patient-friendly guidelines that will cover additional related conditions such as psoriatic arthritis, ankylosing spondylitis, and others.

“The diagnosis of a lifelong chronic disease like RA can be overwhelming, but it is vital that patients be at the center of decisions about their treatment and management strategy,” stated Seth Ginsberg, President and Co-Founder of CreakyJoints. “The Patient Charter spells out the eight tenets that the arthritis community should expect and demand from the healthcare they receive to better ensure that we patients are at the center of decision-making. Coming soon, for the first time, patients have a detailed, straight-forward guide to help them navigate and understand their options, including tips about applying health knowledge so that they can feel more in control of their journey with RA.”

Similar in spirit to the current RA Guidelines developed by the American College of Rheumatology for medical professionals, the new patient guidelines are being written by a dedicated panel that included patients, rheumatologists, and CreakyJoints’ staff writers. As demonstrated by a CreakyJoints study published in November 2015 in _Arthritis Care & Research_, patients are ready and able to evaluate existing scientific evidence and this capability informed these new guidelines. The patient guidelines are being written to be understood and referred to by patients seeking guidance for how to speak to their rheumatologist or other health professionals about their treatment plan, how to ask questions of their insurance company regarding coverage, and best practices for meeting or communicating with local legislators to advocate for patient-friendly health care laws.

“More than ever before, patients across all disease categories can access a mountain of information simply by asking ‘Dr. Google,’ but the risk is that it can be challenging to identify credible sources and to assess what constitutes good medical advice,” stated Dr. Jonathan Krant,
MD, Medical Director of CreakyJoints and Section Chief of Rheumatology at Adirondack Health Systems in Saranac, N.Y. “These guidelines will help patients decode their treatment options and provide tools to help them ask the questions that are important to them as they decide their management strategy.”

“A Patient’s Guide to Living with Rheumatoid Arthritis” is under review by Dr. Krant; Dr. Madelaine Feldman, MD, Rheumatology Alliance of Louisiana and Coalition of State Rheumatology Organization executive committee member; and Dr. Sarah Doaty, MD, Rheumatologist with the Alaska Native Tribal Health Consortium. A national Patient Council convened by CreakyJoints in early October provided additional input and direction for the Patient Charter and patient guidelines. The Patient Charter is available on the CreakyJoints website, https://creakyjoints.org/patientcharter/

CreakyJoints Presents Data at ACR/AHRP Annual Meeting
Sunday, November 13, CreakyJoints presented five posters at the 2016 ACR/AHRP Annual Meeting in Washington, D.C. Dr. W. Benjamin Nowell, Ph.D., Director of Patient-Centered Research for CreakyJoints presented a poster in partnership with Dr. Liana Fraenkel, MD, MPH, Yale University School of Medicine, titled “Development of RA Patient Preference Phenotypes.”

When RA treatment escalation is being considered because methotrexate or other monotherapy has proved inadequate, it can be challenging for a patient to understand and evaluate the pros and cons of different medication options presented by a physician. In such cases, patients are often curious about the choices that other patients like them have made. This study surveyed 1,100 RA patients to categorize how they weigh differences among medications’ various features (effectiveness, mode of administration, risk factors, cost, and other factors) to make treatment decisions. Five major patient preference phenotypes were identified that may support the decision-making process for physicians and patients. Survey respondents were identified via CreakyJoints.

“During a short office visit, physicians and patients may benefit from a common tool to facilitate better communication. Patient preference phenotypes may help rheumatologists understand their patients’ values better, thereby making conversations about treatments more meaningful,” stated Dr. Nowell. “We strive to keep patients at the center of all research conducted by CreakyJoints. This study and others we presented at the ACR meeting, along with the new RA patient guidelines, align with our mission to improve patients’ health outcomes, overall health care experience through shared decision-making, and by listening to what patients have to say.”

Data for two other posters were collected via ArthritisPower™, the first patient-centered, patient-directed arthritis research registry developed by CreakyJoints in partnership with the University of Alabama at Birmingham and part of the PCORnet network of research registries. One final poster highlighted the decisions that patients think are most important when considering hip or knee joint replacement. These findings emerged from a CreakyJoints pre-research engagement project titled “BeTTER SAID,” funded by the Patient Centered Outcomes Research Institute (PCORI). BeTTER SAID (Bringing Stakeholders Together for Engagement in Research for the Selection of Arthroplasty Implant Devices) aims to develop a cohort of patients, patient
advocates, researchers, physicians/surgeons, and health system leaders examining strategies to improve joint replacement device safety and effectiveness.

Posters presented at the 2016 ACR/AHRP Annual Meeting included:

- Development of RA Patient Preference Phenotypes (Abstract #516)
- Patient Decisions Related to Hip and Knee Arthroplasty and the Factors Influencing Them (Abstract #110)
- What Factors Relate to Patients Contributing Longitudinal Data Using Smartphone Technology? Findings from RA Patients Participating in ArthritisPower Registry (Abstract #8)
- Optimizing the Efficiency of Patient Data Capture Using Smartphone Technology: Evaluation of the Correlation Between PROMIS Instruments for PRO Data Capture (Abstract #86)
- People with Rheumatoid Arthritis Recruited from an Online Patient Community May Differ from Clinical Populations in Symptoms and Impacts (Abstract #103)

About ArthritisPower
ArthritisPower is the first ever patient-led, patient-centered research registry for arthritis, bone, and inflammatory skin conditions. The ArthritisPower mobile and desktop application allows patients to track, measure, and share their symptoms and treatments outcomes while simultaneously participating in arthritis research via informed consent. ArthritisPower Patient Governors serve as gatekeepers for researchers seeking to access registry data or solicit the community to participate in unique, voluntary studies and arthritis research. To learn more and join ArthritisPower, visit www.ArthritisPower.org

About CreakyJoints
CreakyJoints®, now in its 17th year, has evolved into the go-to source for more than 100,000 arthritis patients and their families world-wide who are seeking education, support, advocacy, and patient-centered research. Co-founded in 1999 by arthritis patient Seth Ginsberg and social entrepreneur Louis Tharp, CreakyJoints is part of the Global Healthy Living Foundation, whose mission is to improve the quality of life for people with chronic illness. For more information and to become a member (for free), visit www.CreakyJoints.org.