



Global Healthy Living Foundation
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www.ghlf.org

**FOR IMMEDIATE RELEASE
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Global Healthy Living Foundation Urges Insurance Companies to Pass Savings to Patients Following Repatha (evolocumab) Price Reduction

UPPER NYACK, N.Y. October 24, 2018 – Global Healthy Living Foundation asserts that health insurance companies are obligated to pass cost savings to patients resulting from the just-announced price reduction for Repatha (evolocumab, Amgen). Repatha is a treatment in the PCSK9 inhibitor class for familial hypercholesterolemia (FH), an inherited disorder that can lead to aggressive and premature cardiovascular disease, and atherosclerotic cardiovascular disease.

“The retail price of a drug is often irrelevant to the patient because they don’t pay retail. Instead, they pay a copay, a deductible, and the premium itself to their insurer.” said Louis Tharp, co-founder and executive director of the Global Healthy Living Foundation.

“So, before we applaud a retail price reduction this close to an election, we want to hear the insurance companies say they will lower patients’ actual expenses. Nothing else matters. It is reasonable to expect the Medicare Part D copay for this class of drugs to drop to \$25-\$50 a month with this retail price reduction – if insurers pass on the savings. If they don’t, it will remain around \$300, an unconscionable amount to ask anyone to pay, let alone fixed-income seniors with a life-threatening disease.”

About Global Healthy Living Foundation

The [Global Healthy Living Foundation](http://www.ghlf.org) is a 501(c)(3) non-profit organization whose mission is to improve the quality of life for people living with chronic illnesses (such as arthritis, osteoporosis, migraine, IBD, psoriasis, and cardiovascular disease) by advocating for improved access to health care at the community, state, and federal levels, and amplifying education and awareness efforts within its social media framework. GHLF is also a staunch advocate for vaccines. The Global Healthy Living Foundation is the parent organization of [CreakyJoints](http://www.creakyjoints.org), the digital community and advocacy organization for millions of arthritis patients and caregivers worldwide who seek education, support, advocacy, and patient-centered research through [ArthritisPower](http://www.arthritispower.org), the first-ever patient-centered research registry for joint, bone, and inflammatory skin conditions. Visit www.ghlf.org for more information.





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Global Healthy Living Foundation Launches Comprehensive Support Center to Navigate Health Insurance Decision-Making During Open-Enrollment

State-by-State Resources Available to All Chronic Disease Patients

UPPER NYACK, NY (October 31, 2018) – Global Healthy Living Foundation recently published [A Patient's Guide to Insurance Enrollment](#) to help people living with chronic disease understand and make decisions about their health insurance coverage options in time for the 2019 open enrollment season. “Patients shouldn't need specialized education to understand insurance, but unfortunately, they do because of the complex structure of insurance policies,” said Seth Ginsberg, president and co-founder of the Global Healthy Living Foundation.

A Patient's Guide to Insurance Enrollment defines common benefit terminology, explains how to decode a formulary and tiered drug lists to determine available prescription coverage, organizes the paperwork and information a family needs to apply for coverage, and guides people to resources in every state that are set up to facilitate enrollment in private, employer-based, and/or public health insurance options. The program launch anticipates the start of open enrollment to 2019 health insurance contracts, typically in November, to allow people ample time to access this resource. It was designed to be used by patients and their families in need of specialty care for any chronic disease.

“People managing a lifelong, chronic illness rely on stable access to their doctors and medications, but the deliberately complex language used in health insurance policies makes it hard for people to decipher available benefits and their price points,” Mr. Ginsberg said. “Insurers can change programs within the fine print, and these changes can cost patients more money out-of-pocket. Our response was to create an online resource to arm the chronic disease community with what they need to know to identify, apply, and sign-up for the optimal health plan they can afford – while avoiding some new plan design features that hit patients’ wallets hardest.”

A Patient's Guide to Insurance Enrollment expands on the recently published [A Patient's Guide to Healthcare](#), a comprehensive and free, downloadable booklet that explains the different kinds of insurance coverage available while empowering patients to advocate for themselves and the chronic disease community.

Protocols and Policies Impede Patient Care

Every day, Global Healthy Living Foundation hears from people living with chronic diseases, ranging from osteoarthritis, chronic inflammatory diseases such as Rheumatoid Arthritis or Crohn’s Disease, migraine, and cardiovascular disease, regarding the challenges they face accessing the treatments they’ve selected in consultation with their health care provider. Health insurance protocols such as step therapy (“fail



first”), prior authorization, and non-medical switching all delay or sometimes prevent access to prescribed medications, which can lead to serious health consequences. The newest and often unannounced protocol employed by health insurance companies to influence prescription coverage are co-pay accumulator adjustment programs, which shift the cost of prescribed medications to patients because they do not apply the value of their co-pay assistance card to patients’ deductibles.

“For years, my co-pay assistance card covered \$12,000 in annual prescription assistance, which more than covered my deductible and co-pays, thereby allowing me to maintain stable access to my medications to adhere to my treatment plan,” said Kip Burgess, a Chicago-based [CreakyJoints®](#) member who also serves as a patient governor to the [ArthritisPower® Research Registry](#). “This March, I was shocked to be billed for my medication by the specialty pharmacy, and it took more than two weeks of phone calls and emails to find out from my health insurance provider that my co-pay assistance was used up, but not applied to my deductible. Out of the blue, I owed \$4,500 to cover my deductible and my co-pay jumped from \$10 to \$200. Certainly, I didn’t budget for this expense nor did it seem fair given how my plan worked in the past. I received no communication about the change.”

“Kip’s experience is not isolated. Many of our members have found that insurance companies are shifting drug costs to them, despite the availability of co-pay assistance,” stated Mr. Ginsberg. “Given our deep understanding and concern about health insurance protocols and their impact on the patient-provider relationship, *A Patient’s Guide to Insurance Enrollment* prepares the chronic disease community to translate insurance policy language and to discover provisions that might limit their access to medicine.”

A Patient’s Guide to Insurance Enrollment is available for free at <http://www.50statenetwork.org/patient-guide-health-insurance/>

About ArthritisPower®

Created by [CreakyJoints](#) and supported by a multiyear, multimillion dollar investment by the Patient-Centered Outcomes Research Institute (PCORI), [ArthritisPower](#) is the first-ever patient-centered research registry for joint, bone, and inflammatory skin conditions. The free ArthritisPower mobile and desktop application allows patients to track and share their symptoms and treatments while also participating in voluntary research studies in a secure and accessible manner. ArthritisPower Patient Governors serve as gatekeepers for researchers who seek access to registry data or solicit the community to participate in unique, voluntary studies. To learn more and join ArthritisPower, visit www.ArthritisPower.org

About CreakyJoints

CreakyJoints is a digital community and advocacy organization for millions of arthritis patients and caregivers worldwide who seek education, support, advocacy, and patient-centered research. We represent patients through our popular social media channels, our website www.CreakyJoints.org, and the 50-State Network, which includes more than 1,200 trained volunteer patient advocates. As part of the Global Healthy Living Foundation, CreakyJoints also has a patient-reported outcomes registry called ArthritisPower with more than 17,000 consented arthritis patients who participate in longitudinal and observational research. CreakyJoints also publishes the popular series “Raising the Voice of Patients,” which are downloadable patient-centered navigational tools for managing chronic illness. For more information and to become a member (for free), visit www.CreakyJoints.org.



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Visual Aids Help Patients Understand Risk in Knee Replacement Surgery

CreakyJoints Data Published in the Arthritis Care & Research

UPPER NYACK, NY (March 4, 2019) – Today, CreakyJoints, a Global Healthy Living Foundation community, announced the publication of “The Impact of Information Presentation Format on Preference for Total Knee Replacement Surgery,” in *Arthritis Care & Research*, an official journal of the American College of Rheumatology and the Association of Rheumatology Health Professionals. The study found that among patients without an existing strong preference for total knee replacement (TKR) surgery, visual aids to explain procedural risks help patients make a decision about TKR. Of four methods tested, participants exposed to images or a numerical, graphical spinner had stronger preferences for TKR (after controlling for baseline preferences) compared to those viewing the numbers only format (mean differences all $p < 0.05$).

“The vast majority of people who undergo total knee replacement surgery have high satisfaction following the procedure; however, the decision to undergo major surgery is complicated when a patient either underestimates the potential benefits or overestimates their risk for complications,” stated Liana Fraenkel, M.D., MPH, Yale School of Medicine and lead investigator of the study. “This study suggests there is value in developing visual decision-making tools that help patients better understand the benefits and risks of total knee replacement surgery to make choices about their care in consultation with their physician.”

Pictures and Graphics Increase Knowledge and Preference in TKR

Recruited via email from the CreakyJoints member database as well as the CreakyJoints Facebook page, English speaking participants age 50 and older, living in the U.S., with self-reported physician diagnosis of rheumatoid, psoriatic and/or osteoarthritis involving one or both knees, and had not had previous total hip or knee replacement surgery were eligible for the study (n=648). At study initiation, each participant read a brief paragraph with numeric information only, about the possible outcomes of TKR surgery. They were presented with three options regarding their chance of different outcomes including:

- Most patients (about 42 in 50) do great. They have significant pain relief and are very satisfied with the surgery. These patients would have the surgery again without hesitation.
- Some patients (about 7 in 50) don't do as well as they expected. They continue to have a fair amount of pain and are not very satisfied with the surgery. They don't think they would have this surgery again if they had bad arthritis in their other knee.
- A few patients (about 1 in 50) have a serious complication after the surgery (such as an infection in the replaced knee). These patients regret having had the surgery.

Study participants were then randomized into four groups who reviewed outcome risk information by: 1) numeric only, 2) numeric with an icon array (IA), which depicted people who do great in blue, people

who don't do as well as expected in orange, and people who have a serious complication in black; 3) numeric with a set of 50 images depicting happy and unhappy patients (sorted randomly for each person); and, 4) numeric with a functional spinner, programmed to rotate with a limited-range, randomly generated, initial speed after being clicked on by the participant. Preference and knowledge of risk for TKR were then tested in all participants.

After controlling for baseline preference, preferences for TKR were higher in the IA [LS mean (SE) = 7.17 (0.10), $p=0.0002$], images [LS mean (SE) = 7.14 (0.10), $p=0.0005$] and spinner groups [LS mean (SE) = 7.19 (0.10), $p=0.0001$], compared to the numbers only format [LS mean (SE) = 6.66 (0.10)]. Results remained unchanged after also controlling for age, insurance (private vs other), knowing someone who did poorly after TKR, and knee pain. No significant differences in preferences were observed across formats for participants with an uncertain or very strong preference for TKR at baseline (Table 2).

Interestingly, the information format also influenced participants' knowledge ($F=13.62$, $p<0.0001$) of the risk of different outcomes for TKR (remembering the actual risk as presented in numeric form). The mean (SD) knowledge score (possible range 0 to 3) was higher in the IA group [2.0 (1.1)] compared to all other formats [numeric= 1.4 (1.2), images= 1.4 (1.1), spinner= 1.3 (1.1)].

"We recently completed a qualitative study of people with arthritis considering arthroplasty that found patients lacked information about various decisions related to their joint replacement, including timing of surgery, choice of surgeon, surgical site, and implant device," stated W. Benjamin Nowell, Ph.D., Director of Patient-Centered Research at CreakyJoints and study coauthor. "At CreakyJoints, we want patients to understand the decisions that are being made about their care and to play a central role in making those decisions. This study confirms that visual decision aids can help patients to understand their risk of a less than ideal outcome, thereby allowing them to make informed decisions about TKR."

The authors concluded that further research is required to examine whether these tools increase the accuracy of patients' expectations in clinical practice.

About CreakyJoints®

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As part of the [Global Healthy Living Foundation](#), CreakyJoints also has a patient-reported outcomes registry called ArthritisPower® with nearly 18,000 consented arthritis patients who track their disease while volunteering to participate in longitudinal and observational research. CreakyJoints also publishes the popular "[Raising the Voice of Patients](#)" series, which are downloadable patient-centered navigational tools for managing chronic illness. For more information and to become a member (for free), visit www.CreakyJoints.org. To participate in our patient-centered research program, visit www.ArthritisPower.org.



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**GLOBAL HEALTHY LIVING FOUNDATION PRESENTS TUMBLER AND TIPSYPY® BY MICHAEL KULUVA AT
PALM SPRINGS FASHION WEEK**

Collection Designed for People of All Abilities including those with Chronic Disease

UPPER NYACK, NY (April 11, 2019) – The [Global Healthy Living Foundation](#) (GHLF), parent organization to [CreakyJoints®](#), the digital arthritis community for patients and caregivers worldwide, today announces it will present the Tumbler and Tipsy® by Michael Kuluva 10 Year Anniversary Retrospective Runway Show during Palm Springs Fashion Week, April 11-13, 2019. As a person living with an invisible chronic disease (rheumatoid arthritis (RA)) and an active member of CreakyJoints, Michael understands the challenges people living with chronic disease face. His current collection includes magnetic closures, which are designed to be on trend yet accessible, in recognition that getting dressed can be challenging for many people who may experience pain and limitations when it comes to fastening their clothes.

“Fashion should be fun and it should be accessible to everyone,” said Michael Kuluva, designer of Tumbler and Tipsy. “Global Healthy Living Foundation is a fantastic partner because we both open our arms and hearts to diverse communities. As a person living with a chronic disease, I can use my platform to encourage others to learn about their disease, ask questions of their doctors, and seek support when they need it.”

Highlighted by a 100 ft runway suspended over a pool in the Coachella Valley, Tumbler and Tipsy® by Michael Kuluva will present their retrospective runway collection on April 11, 2019 at the Riviera Hotel in Palm Springs.

Chronic Disease Communities Need Visibility

Global Healthy Living Foundation this month published [Migraine Patient Guidelines](#), a free resource for people live with migraine that explains how they can speak to their health care professionals about their treatment plan, how to address migraine stigma, and best practices for leveraging their important story to advocate for change. The guidelines also describe different migraine medication options as well as complimentary therapies.

“Our Migraine Patient Guidelines are the newest in our series of educational resources that help people living with chronic disease understand our diagnosis and feel empowered to make informed decisions about our treatment,” said Joseph Coe, director of education and digital strategy for the Global Healthy Living Foundation and CreakyJoints. “We welcome the opportunity to support Michael’s Tumbler and Tipsy show and announce the availability of this resource to the community because we believe that



education and awareness around invisible and chronic diseases should happen in as many venues as possible.”

Also available from the Global Healthy Living Foundation and CreakyJoints are patient guidelines for people living with rheumatoid arthritis, osteoarthritis, psoriatic arthritis, ankylosing spondylitis, juvenile idiopathic arthritis, and gout, among others. All are available for free download at <https://creakyjoints.org/patientguidelines/>

About Migraine Disease

Affecting about 12 percent of Americans, migraine is a neurobiological disorder in which attacks of pain and other neurological and physical symptoms usually last from four to 72 hours. Anyone can develop migraine disease, but women; those with a family history of migraine; and those with certain other medical conditions (such as sleep disorders, depression and anxiety, and epilepsy) are more prone. The most common description of migraine is unilateral (one-sided) head pain with a pulsating or throbbing quality. But many people have bilateral pain, or pain that does not throb. All patients with migraine have other symptoms, such as nausea or vomiting, sensitivity to lights, sounds, or smells, fatigue, dizziness, blurry vision, brain fog/cognitive difficulties, language disturbance, disability that goes beyond the severity of the pain, scalp sensitivity, on rare occasions diarrhea or other bowel disturbances, and/or the experience of aura. This variety of symptoms makes migraine disease much more complicated than just a bad headache. People with chronic migraine experience 15 or more headache days per month. Read more about managing RA in "Migraine Patient Guidelines," available for free download at <http://creakyjoints.org/patientguidelines>.

About Tumbler and Topsy

Anchored by the creative mind and brilliant talents of professional figure skater turned fashion designer, Michael Kuluva, Tumbler and Topsy is not only reworking, redefining and revamping the world of fashion but is taking it over with his sexy yet stylish brand. Tumbler and Topsy is produced in Los Angeles, CA with colorful collections that are distinctive but never repetitive, chic and classy while being comfortable and versatile. Tumbler and Topsy is not just a line of clothing, it's a collection of art, it's an embodiment of chic fashion in the modern world, and it's a representation of a lifestyle: fun, bold, luxurious and daring. www.tumblerandtipsy.com

The Tumbler and Topsy® by Michael Kuluva 10 Year Anniversary Retrospective Runway Show is proudly presented by Global Healthy Living Foundation.

More information on Tickets and VIP Access can be found at <https://psfashionweek.com>

About Palm Springs Fashion Week:

PSFW brings together the best in Festival, Swimwear, & Resort fashion brands that foster creation and international development. It seeks to promote fashion and music culture, where design and creation have a major market impact by keeping festival fashion at the forefront of the global fashion scene.

About the Global Healthy Living Foundation

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awareness efforts within its social media framework. GHLF is also a staunch advocate for vaccines. The Global Healthy Living Foundation is the parent organization of [CreakyJoints®](#), the digital arthritis community for millions of arthritis patients and caregivers worldwide who seek education, support, activism, and patient-centered research through [ArthritisPower®](#), the first-ever patient-centered research registry for joint, bone, and inflammatory skin conditions. Visit www.GHLF.org for more information.





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CreakyJoints Publishes First Ever Rheumatoid Arthritis Patient Guidelines in Spanish

Education and Support Now Available on CreakyJoints Español

UPPER NYACK, NY (April 23, 2019) –[CreakyJoints®](#) today announced that their flagship publication, “Raising the Voice of the Patients: A Patient’s Guide to Living with Rheumatoid Arthritis,” is now available in Spanish. First published in 2017, these unique patient guidelines are the first ever to be developed by patients and reviewed by rheumatologists, specifically for use by rheumatoid arthritis (RA) patients and their caregivers. The Raising the Voice of Patients series is available for free download on the CreakyJoints website, and other volumes address osteoarthritis, psoriatic arthritis, ankylosing spondylitis, gout, and family planning for people living with arthritis in English. CreakyJoints also launched a dedicated [Spanish-language version](#) of their website to provide additional resources to the arthritis community. The website as well as the patient guidelines were reviewed by patients and physicians to ensure the content was accessible for all.

According to the U.S. Centers for Disease Control, there are 4.4 million Hispanics with doctor-diagnosed arthritis.ⁱ Though prevalence of arthritis among Hispanics is less than non-Hispanic whites, Hispanic people are more than twice as likely to become disabled from arthritis and experience joint damage.ⁱⁱ

“I lived with painful symptoms of RA (and other co-morbid autoimmune diseases) for nine years before getting accurately diagnosed. During that time, I tried a wide array of traditional, homeopathic, and complimentary therapies until I found a treatment plan that helped me achieve remission. There were days when I felt great, and other times I felt overwhelmingly tired or in pain,” says Maraliz Campos, a volunteer patient advocate on the CreakyJoints Latino/Latina Patient Council and a sonic meditation teaching artist and yoga instructor. “When a person with arthritis needs education and support, these patient guidelines will help them understand their disease better, and also explain its progression to family and friends.”

These patient guidelines, written for patients and by patients, help us raise our voices, it gives us a voice by providing us with information step-by-step that is easy to understand, so we can incorporate it into our lives without too much stress and effort. All people experience pain, but that shared experience can connect us to each other.”

Patients at the Center of Treatment

Following a declarative Patient Charter, which details the guiding principles that underscore the CreakyJoints perspective on arthritis education, support, advocacy and research, the patient guidelines explain how people with arthritis can 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. The patient guidelines also describe the different RA medications as well as complimentary therapies with evidence-based citations.

“The diagnosis and day-to-day management of a chronic disease like rheumatoid arthritis can be overwhelming and confusing, particularly because we’re asking patients to make important choices about their disease management strategy, which usually includes a combination of medications, physical activity plans, and other complimentary approaches,” said Dr. Irene Blanco, MD, MS, rheumatologist and Rheumatology program director at Albert Einstein College of Medicine in New York. “These patient guidelines will serve as a resource to people with arthritis who are seeking comprehensive information about RA, including answering questions about insurance coverage. It can also help them to form the questions they have for their health care team in advance of their next appointment.”

“CreakyJoints strives to provide education to our entire community, including those who speak Spanish,” stated Seth Ginsberg, President and Co-Founder of CreakyJoints. “Our goal is to empower patients to ask questions about their disease journey, including treatment options, and inspire them to proactively communicate their preferences to their healthcare team.”

The patient guidelines were written by a dedicated panel that included patients, rheumatologists, and CreakyJoints’ staff writers. “Raising the Voice of the Patients: A Patient’s Guide to Living with Rheumatoid Arthritis” translation into Spanish was reviewed by Dr. Oscar Soto, rheumatologist and president of Fundación FER, a rheumatoid patient organization in Puerto Rico.

“Raising the Voice of the Patients: A Patient’s Guide to Living with Rheumatoid Arthritis” in Spanish is available for free download [here](#).

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ⁱArthritis Related Statistics. U.S. Center for Disease Control and Prevention https://www.cdc.gov/arthritis/data_statistics/arthritis-related-stats.htm Accessed on 5/8/2018.

ⁱⁱ Song, J., Chang, HJ, Tirodkar, M. et. al. “Racial/ethnic differences in activities of daily living disability in older adults with arthritis: A longitudinal study” *Arthritis & Rheumatism*. First published: 30 July 2007 <https://doi.org/10.1002/art.22906> <https://onlinelibrary.wiley.com/doi/10.1002/art.22906> Accessed on 5/8/2018



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New Study: Infertility and Anxiety about Diagnosis Diminish Family Size in Women with Arthritis

CreakyJoints® and ArthritisPower® data published in *ACR Open Rheumatology*

UPPER NYACK, NY (May XX, 2019) – Today, [CreakyJoints®](#), a [Global Healthy Living Foundation](#) patient community, reported study results suggesting that infertility, alongside potentially outsized fear and anxiety related to their diagnoses, may affect the family sizes of women with inflammatory arthritis. “Pregnancy, Periods, and “The Pill”: Exploring the Reproductive Experiences of Women with Inflammatory Arthritis,” was recently published in *ACR Open Rheumatology*, a peer-reviewed publication of the American College of Rheumatology.

The study found that most women with inflammatory arthritis (60 percent) wanted fewer children as a direct result of their diagnosis. Some of the reasons women limited their family size were related to concerns about their ability to care for children (85 percent), fear that antirheumatic drugs might harm a fetus or infant (61 percent), concern that their child might inherit arthritis (52 percent) or that arthritis might cause their premature death so that she might not be able to raise her child (34 percent), among others. Of those who did not have fears that reduced their planned number of children (37 percent), more than half of those women had borne all their children before diagnosis (51 percent). The study also found that 40 percent of the surveyed women reported infertility, which mirrors other studies showing that women with inflammatory arthritis are at increased risk for infertility.

“Despite significant improvements in the identification and treatment of inflammatory arthritis, this study suggests that the diagnosis all by itself makes women rethink how they want to build their families,” said Megan E.B. Clowse, MD, MPH, a rheumatologist at Duke School of Medicine who led the research team. “As physicians, we need to do a better job addressing patients’ concerns about perceived childbearing risks related to disease onset and treatment. Most existing studies show that women with inflammatory arthritis can have healthy pregnancies and children, particularly if their disease is well controlled at the time of conception. We’d also benefit from studying more closely why women with inflammatory arthritis seem to experience increased risk for infertility.”

Women Sensitive to Monthly Flares

Nearly half of women (49 percent) also reported that they experienced arthritis flares over the course of their menstrual cycle and of those nearly all (96 percent) had worse disease activity in the days before or during menstruation. Oral contraceptive pills (OCPs) were the most common birth control method used by women in the survey sample (52 percent). Most (82 percent) did not observe or were unsure whether OCPs had any effect on their disease activity, but nearly 10 percent reported that OCPs improved their arthritis symptoms. In open-ended responses, several survey participants reported a



disease management strategy that included taking OCPs daily (skipping the sugar pills meant to induce menstruation), which had the effect of reducing their experience of flares.

“We surveyed women about menstruation and arthritic disease flares because our research registry community leaders, the ArthritisPower Patient Governors, raised colloquial concerns they had heard – via blogs or other unverified sources – that OCPs could worsen inflammatory arthritis. Yet data from several clinical studies, and now this one, instead suggest that OCPs likely have no ill effect on inflammatory arthritis disease activity and may even improve it for some,” said W. Benjamin Nowell, Ph.D., Director of Patient-Centered Research at CreakyJoints, principal investigator of ArthritisPower and study co-author.

Seth Ginsberg, president and co-founder of CreakyJoints and also a principal investigator of ArthritisPower added, “What makes ArthritisPower Research Registry unique is that it includes patient-leaders who help shape research priorities and even contribute significantly as members of the research team as the patient coauthors in this study did. This study points to a greater need for reproductive health education in women with inflammatory arthritis.”

Study Design

In partnership with researchers from Duke University, CreakyJoints developed an ArthritisPower based cross-sectional online survey consisting of 183 questions primarily formatted as multiple-choice responses, but which also included several optional short-answer responses. The questions assessed patients’ experiences with pregnancy, miscarriage, or infertility; historical medication use before and during pregnancy; contraception; menstruation; engagement with primary care providers and subspecialists; preferred resources for reproductive health information; and myths and perceptions related to inflammatory arthritis and pregnancy, childbearing, and disease-modifying antirheumatic drug (DMARD) use. The survey included female patients ages 18-50 who were registered members of ArthritisPower or CreakyJoints, provided they had a diagnosis of inflammatory arthritis.

Of the 15,332 recruitment emails sent, 416 patients (2.7%) expressed interest in participating in the study, and 267 women met eligibility criteria. Participants were an average of 39.6 years old (SD=7.1 years) at the time of survey completion and had been an average of 27.2 years old (SD=12.3 years) at the time of their arthritis diagnosis. Most women identified as white (84%), and 9% of women reported Hispanic ethnicity in addition to white, black, multiracial, or other race. Over two-thirds of women had attained at least a college degree (69%). Twenty-seven percent of women (n=71) had pregnancies after their disease diagnosis, with a range of 1-5 pregnancies postdiagnosis. The most common of the inflammatory arthritides in the sample included RA (79%), followed by juvenile idiopathic arthritis (JIA) (14%), psoriatic arthritis (11%), ankylosing spondylitis (9%), and inflammatory bowel disease (IBD)-associated arthritis (6.4%). Nearly all women had used at least one conventional or biologic disease-modifying antirheumatic drug (DMARD) prescribed for inflammatory arthritis (93%).

CreakyJoints Patient Guidelines Target Family Planning

“Raising the Voice of Patients: A Patient’s Guide for Pregnancy and Family Planning with Rheumatic Diseases,” is available for free download at CreakyJoints.org. Similar to other editions in the patient guidelines library, it was written by patients and CreakyJoints staff writers and reviewed by rheumatologists to make sure it provides comprehensive, unbiased information about the managements and treatment of arthritis, with emphasis on family planning.

About ArthritisPower

Created by [CreakyJoints®](http://www.CreakyJoints.org) and supported by a multiyear, multimillion dollar investment by the Patient-Centered Outcomes Research Institute (PCORI), [ArthritisPower](http://www.ArthritisPower.org) is the first-ever patient-centered research registry for joint, bone, and inflammatory skin conditions. The free ArthritisPower mobile and desktop application allows patients to track and share their symptoms and treatments while also participating in voluntary research studies in a secure and accessible manner. ArthritisPower Patient Governors serve as gatekeepers for researchers who seek to access registry data or solicit the community to participate in unique, voluntary studies. To learn more and join ArthritisPower, visit www.ArthritisPower.org.

About CreakyJoints®

CreakyJoints is a digital community for millions of arthritis patients and caregivers worldwide who seek education, support, advocacy, and patient-centered research. We represent patients through our popular social media channels, our website www.CreakyJoints.org, and the 50-State Network, which includes more than 1,500 trained volunteer patient activists.

As part of the [Global Healthy Living Foundation](http://www.GlobalHealthyLivingFoundation.org), CreakyJoints also has a patient-reported outcomes registry called ArthritisPower® with more than 18,000 consented arthritis patients who track their disease while volunteering to participate in longitudinal and observational research. CreakyJoints also publishes the popular “[Raising the Voice of Patients](http://www.RaisingTheVoiceOfPatients.org)” series, which are downloadable patient-centered navigational tools for managing chronic illness. For more information and to become a member (for free), visit www.CreakyJoints.org. To participate in our patient-centered research program, visit www.ArthritisPower.org.