



QUARTERLY REPORT

JULY-SEPTEMBER 2019



GLOBAL
HEALTHY
LIVING
FOUNDATION

ARTIST PRESENTS HER UNIQUE PERSPECTIVE ON ARTHRITIS

A computer software engineer by day, Jennifer Walker is a CreakyJoints member, ArthritisPower Patient Governor, and artist who lives with rheumatoid arthritis, osteoarthritis, fibromyalgia, and axial spondyloarthritis. For the past six months, CreakyJoints has been sharing Jennifer's artwork online, where her pieces — which convey the diverse experiences of people living with arthritis and chronic pain — resonate powerfully with our chronic illness community.

Jennifer had two recent opportunities to share her artwork with the greater arthritis community. In September, she attended the National Organization of Rheumatology Managers annual meeting in Grand Rapids,

Michigan, where she gave a keynote address during the Friday night reception. Her artwork was on display for all attendees. Earlier in the month, Jennifer also attended the Spring/Summer 2020 Tumbler and Topsy® by Michael Kuluva collection during New York Fashion Week in New York City. Her artwork was featured prominently during the show and was on display during the after party. Notably, CreakyJoints helped submit Jennifer's work to the American College of Rheumatology, and she was chosen to present it as an abstract in the Patient Perspectives Poster Session during the 2019 American College of Rheumatology/Association of Rheumatology Health Professionals Annual Meeting this November.



MEDICAL MARIJUANA REMAINS BIG NEWS

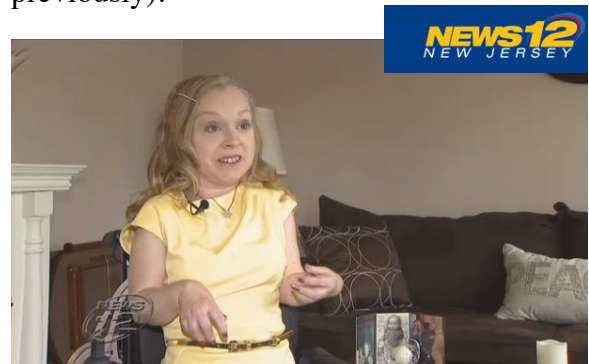
Coverage of our recently presented poster titled, "Patients' Perceptions and Use of Medical Marijuana," at the June Annual European Congress of Rheumatology (EULAR 2019) meeting in Madrid continued to generate interest across major media and specialty publications in the third quarter. In discussing our survey results finding that more than half of people with arthritis have tried marijuana for medical use, *U.S. News & World Report* included a comment from W. Benjamin Nowell, PhD, director of Patient-Centered Research at CreakyJoints who said, "We weren't entirely surprised that so many people living with chronic rheumatic and musculoskeletal conditions have tried such products for what they considered medical reasons...With the proliferation of unregulated CBD products in the U.S., people have greater access. However, there is currently no definitive way to compare different brands or types of CBD products, due to the dearth of high-quality clinical studies evaluating their safety, effectiveness and appropriate dosing." This article was picked up by [Yahoo! News](#).

Seth Ginsberg, president and co-founder of CreakyJoints, appeared on several podcasts to discuss the survey results, including CBD Source and Weedsday Wednesday, among others. As reported in our previous quarterly report, *USA Today* also published an op-ed written by Seth on this topic.

MICHAEL KULUVA'S LATEST FASHION SHOW INCLUDES 3 CREAKYJOINTS MEMBERS

For the fourth year, CreakyJoints presented the Spring/Summer 2020 Tumbler and Tippy® by Michael Kuluva collection during New York Fashion Week in September. As a designer with rheumatoid arthritis (RA) and CreakyJoints member, Michael brings color, energy, and a unique perspective to his work in fashion while embracing and commenting on the experience of living with chronic disease. His collections are innovative and deliberately sassy yet include easy-to-wear fabrics and fasteners, allowing them to be very wearable for people with arthritis who may experience pain and limitations when it comes to putting on their clothes. The spring/summer collection is inspired by Michael's love of the water and featured clothes perfect for a sunny day on a boat or a glamorous evening at sea. This year's show demonstrated Michael's and CreakyJoints' dedication to inclusivity as three CreakyJoints members participated in the show. Model Charis Hill, an ankylosing spondylitis patient and advocate, took the

runway along with Kelly Rouba-Boyd, who lives with RA and is also 2nd Vice President of the Arthritis National Research Foundation Board of Directors. Kelly rolled down the runway in her powered wheelchair. Artist and arthritis patient Jennifer Walker displayed her artwork (as described previously).



Inspired by Kelly's participation in the fashion show, [News 12 New Jersey](#) aired a feature and Kelly was profiled by the [Times of Trenton](#) and Everyday Health (forthcoming). Kelly also contributed an opinion piece to the [New York Daily News](#) and Michael did a Facebook Live event with Health Central.

DAILY NEWS

“ And while some of the most famous models in the world will be featured at many of the New York Fashion Week shows again this year, the Tumbler and Tippy show is bound to make one of the strongest impacts as Kuluva has chosen a more unique approach with his decision to foster inclusion by having three of us who have various forms of arthritis grace his show.



WEBINARS: DEEP DIVES INTO TOPICS PEOPLE WITH ARTHRITIS CARE ABOUT

This past quarter, CreakyJoints hosted three webinars that helped people with arthritis and other chronic diseases learn more about how to manage their conditions. These webinars are archived on our CreakyJoints YouTube channel, <https://www.youtube.com/creakyjoints>.

- [More Than Just a Headache: Understanding Migraine](#), July 3, 2019: This webinar featured expert commentary from Dawn C. Buse, PhD, a clinical professor of neurology at the Albert Einstein College of Medicine, a licensed psychologist, and a member of the American Headache Society Board of Directors, and Jelena Pavlovic, MD, PhD, a neurologist and headache specialist at the Montefiore Headache Center and assistant professor at the Albert Einstein College of Medicine. Both are members of the Society for Women's Health Research Interdisciplinary Network on Migraine
- [What Do These Numbers Mean? Decoding Your Labs](#), August 1, 2019: This webinar featured special guest Robin K. Dore, MD, clinical professor of medicine, UCLA and a rheumatologist in private practice.
- [Understanding Psoriatic Arthritis: Signs, Symptoms and Treatment](#), August 23, 2019: We hosted Jessica Walsh, MD, MBA, MSCI, rheumatologist and instructor at the University of Utah School of Medicine and George E. Wahlen Veteran Affairs Medical Center and Alexis Ogdie, MD, MSCE, associate professor of medicine at the Hospital of the University of Pennsylvania, Rheumatology, and assistant professor of epidemiology in biostatistics and epidemiology.

What Is Migraine?

Migraine (the disease)	Migraine Attack
A common, disabling neurological disease	Moderate to severe head pain that, if untreated, can last 4-72 hours
Characterized by painful, debilitating migraine attacks	Pain often accompanied by nausea, sensitivity to light/sound and other symptoms

Source: American Headache Society, GHFL

What is psoriatic arthritis (PsA) and who gets it?

- An inflammatory arthritis that affects up to 20-30% of patients with psoriasis rash.
- It's possible to have PsA without psoriasis but rare (and usually in the setting of a family member with psoriasis).
- To have PsA, you have to have had (or currently have) inflammation in the joints, tendons, or spine

ARTHRITISPOWER STUDY REPORTS ARTHRITIS PATIENTS ARE DISSATISFIED WITH TREATMENT

During the third quarter, data from the ArthritisPower Research Registry published in the peer reviewed journal *Rheumatology and Therapy*. The study found that nearly three-fourths of people with rheumatoid arthritis (RA) responding to a survey expressed dissatisfaction with their treatments, despite the wide variety of available medications including biologic disease-modifying antirheumatic drugs (bDMARDs). Even on treatment, respondents experienced bothersome symptoms, such as fatigue (82%), pain (76%) and physical limitations (75%), which negatively impacted their quality of life.

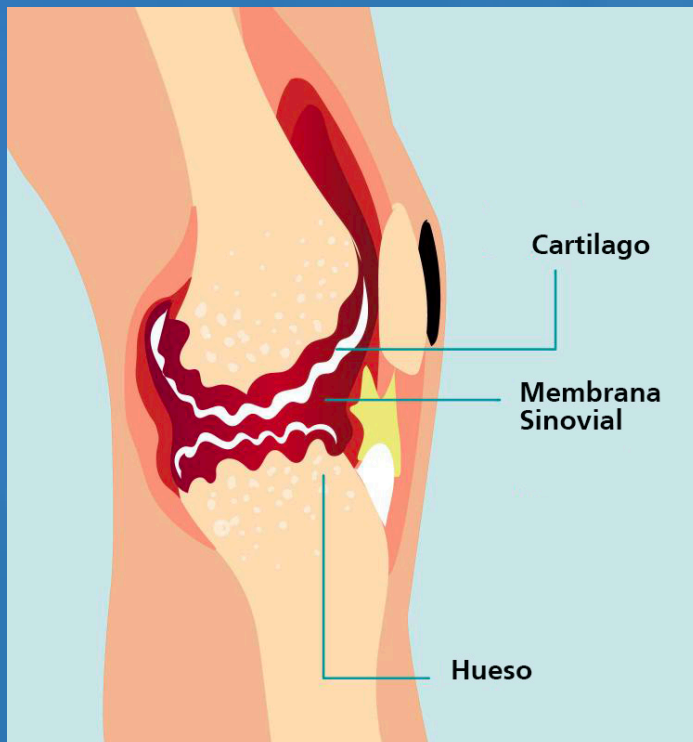
This study was covered by [Everyday Health](#), [RheumNow](#), [DocWire](#), [MedicalResearch.com](#) and [Rheumatology Advisor](#).



In the press release, Dr. W. Benjamin Nowell, PhD, CreakyJoints' director of Patient-Centered Research, said, "The results from this study suggest that there are unmet treatment needs in the RA patient community even among those currently using bDMARD medications, which are known to greatly improve outcomes including relief from pain and other RA symptoms... The findings raise questions about why patients do not change their medications when they experience persistent moderate-to-high disease activity on their current treatment, as recommended by a treat-to-target approach. Perhaps there is a disconnect between the patient's and physician's perceptions of acceptable disease activity and appraisal of their current experience of the disease, or a lack of frank discussion about available options for adjusting treatment to improve control of the disease."

CREAKYJOINTS ESPAÑOL SPEAKS TO PATIENTS IN THE UNITED STATES AND PUERTO RICO

During the third quarter, CreakyJoints Español presented its first Spanish-language webinar on how disease modifying anti-rheumatic drugs (DMARDs) work. The educational session (and archived video) defined the different types of DMARDs and the value of implementing a shared decision-making process based on individual patient preferences between patients and doctors to choose which medication is best.



In addition, this July, CreakyJoints Español patient council members participated in a Puerto Rico event to speak about their disease journey. Along with Medical Advocacy Liaison Daniel Hernandez, MD, they participated in a Puerto Rico Radio program speaking on the value of patients learning about their condition.

ARTHRITISPOWER RESEARCH BROADENS ARTHRITIS UNDERSTANDING

Current ArthritisPower statistics as of September 30, 2019:

- Total patients: **21,888**
- Total number of completed patient reported outcomes (PRO) assessments: **267,160**
- Number of unique participants who have completed PRO assessments: **16,402**
- Number of unique participants who have reported at least one medication (includes combination of medications): **6,214**



ArthritisPower offers researchers access to a unique, dynamic, and robust patient community. There are many opportunities for registry participants to opt into research that will inform our future understanding of arthritis and potentially lead to new management and treatment strategies. If you would like to participate in a study, go to ArthritisPower.org, sign up and, after you consent to participate in research, your profile will be matched against open studies. You will receive an invitation to participate when a match is made. If you are an ArthritisPower member and think you may qualify for one of the studies below, please reach out to Shilpa Venkatachalam, our associate director of Patient-Centered Research at svenky@ghlf.org.

■ NEWLY PUBLISHED ARTHRITISPOWER RESEARCH

- This September saw the publication of “Digital Tracking of Rheumatoid Arthritis Longitudinally (DIGITAL) Using Biosensor and Patient-Reported Outcome Data: Protocol for a Real-World Study,” in the *Journal of Medical Internet Research - Research Protocols* ([JMIR Res Protoc 2019;8\(9\):e14665](https://doi.org/10.19187/jmir.resprotoc.2019.8(9):e14665)). The study detailed the protocol for a forthcoming study on the relationship between passively collected digital measures related to activity, heart rate, and sleep collected from a smartwatch with ePROs related to pain, fatigue, physical function, and RA flare entered via smartphone app. The study will also determine predictors of adherence with smartwatch and smartphone app technology and assess the effect of study-specific reminders on adherence with the smartwatch.
- A study published in the *Journal of the American Medical Informatics Association* titled, “Data Linkages Between Patient-Powered Research Networks and Health Plans: A Foundation for Collaborative Research,” used ArthritisPower and other research registries to determine that patient-powered research network (PPRN) membership and health plan data can be linked using privacy-preserving record linkage methodology, and used to confirm self-reported diagnosis. Identifying and confirming self-reported diagnosis of members can expedite patient selection for research opportunities, shorten study recruitment timelines, and optimize costs. (*Journal of the American Medical Informatics Association*, Volume 26, Issue 7, July 2019, Pages 594–602, <https://doi.org/10.1093/jamia/ocz012>)
- In *Clinical Rheumatology*, researchers assessed contraceptive methods in young women with rheumatoid arthritis (RA) or psoriatic arthritis (PsA) and correlated contraceptive method efficacy with use of concomitant rheumatic medications. The study, “Contraception Methods Used by Women with Rheumatoid Arthritis and Psoriatic Arthritis,” found that approximately two-thirds of women with RA and PsA reported using effective or highly effective methods of contraception, though women with PsA were more likely to report no methods of contraception. Overall, high rates of contraceptive use were reported in both the RA and PsA populations with the highest rates of effective and highly effective contraception methods used by women on methotrexate, which is known to cause birth defects. However, high rates were still seen in women on TNF inhibitors, which are now considered to be relatively safe during pregnancy. (*Clinical Rheumatology*, April 2019, Volume 38, [Issue 4](#), pp 1207–1212).

OTHER STUDIES IN PROGRESS INCLUDE:

- Understanding the Axial Spondyloarthritis (axSpA) Treatment Journey:** This cross-sectional study of ArthritisPower members reporting a physician diagnosis of ankylosing spondylitis (AS) or axial spondyloarthritis (axSpA) examines the experiences patients, including the diverse range of symptoms, the journey to getting diagnosed and treated, and managing different treatment options. The study will open for enrollment in October and is sponsored in part by Eli Lilly and Company and GHLF research funds.
- Understanding Fibromyalgia: The Patient Experience of Symptoms, Diagnosis, and Treatment:** This cross-sectional study aims to learn the patient perspective of disease burden among patients with fibromyalgia, specifically those with lower back pain, and to identify individuals who also show the signs and symptoms of axial spondyloarthritis (axSpA), regardless of whether the condition has been diagnosed, and to characterize their information needs. The study, sponsored in part by UCB and GHLF research funds, will open for enrollment in October.
- Patient Perspectives on the Benefit and Side Effects of Methotrexate Therapy:** ArthritisPower members living with rheumatoid or psoriatic arthritis are eligible to participate in this study to examine the possible side effects of methotrexate and how taking methotrexate affects people's lives and well-being. The study is being conducted with support from Amgen Inc and GHLF research funds. This study is open for enrollment.
- Smartwatch Synchronized to Your Health: The DIGital Tracking of Arthritis Longitudinally (DIGITAL)** study is known to participants with rheumatoid arthritis as the ArthritisPower Smartwatch Study. The study, which began recruiting widely in September, is sponsored in part by Eli Lilly and Company and GHLF research funds. The study is open for enrollment.
- CHOICE (Comparative Health Outcomes in Immune-mediated disease CollaborativE):** The study will evaluate the comparative clinical effectiveness of various biologic and other medications as assessed through a variety of disease-specific and generic patient-reported outcomes measures. This study is a PCORnet Demonstration Projects sponsored by the Patient-Centered Outcomes Research Institute (PCORI). The study is open for enrollment.

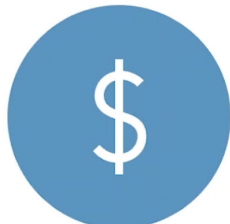
ASSESSING EFFECTIVE TREATMENT OF RHEUMATOID ARTHRITIS

In August, we announced our contribution to the National Committee for Quality Assurance's (NCQA) Value-Based Care Model Amplifying Patients' Voices in Treatment Decisions. In this ongoing project, CreakyJoints (led by Shilpa Venkatachalam, PhD, our associate director of Patient-Centered Research) represents the patient perspective among distinguished health provider professional organizations, health networks, payers, and other experts who convened at the guidance of the National Committee for Quality Assurance (NCQA) to assess existing rheumatoid arthritis (RA) disease activity assessment tools. The organizations first met for three days in late 2018 and then again at the National Committee for Quality Assurance (NCQA) and Health Level 7 International (HL7) Digital Quality Summit in mid-July this year to identify and address challenges with data capture, performance measurement and rational incentivization of evidence-based, patient-centric care. These meetings resulted in the recently published white paper titled, "Rheumatoid Arthritis: Transforming Care Delivery to a Value-Based Model."


WHAT'S IN YOUR FORMULARY?

This summer, CreakyJoints launched a [video series](#) that defined insurance formularies, decoded how to read them, and explained what to do if a person's drug is not listed. These short videos are an excellent companion piece to last year's online publication of [A Patient's Guide to Insurance Enrollment](#).


WHAT IS IN A FORMULARY?



TIERS (\$,\$\$,,\$\$\$,\$\$\$\$\$)



ABBREVIATIONS



DRUGS COVERED

THE CHRONIC DISEASE COMMUNITY'S VOICE IS BEING HEARD

This quarter, our advocacy team has been active in seven states and Washington, D.C., commenting on eight different proposed state laws and federal rules to help people living with chronic disease advocate for patient-protective legislation. Comments were related to state Medicaid waivers, proposed changes to the ACA, and changes to NIH requirements, which are all policy changes that have a direct impact on patient access to necessary medications.

■ GHLF SPEAKS DIRECTLY TO INDUSTRY INFLUENCERS VIA MEDIA

Executive director and co-founder of CreakyJoints and the Global Healthy Living Foundation, Louis Tharp, recently contributed an interview to [Drug Topics](#), a publication read by stakeholders in the pharmaceutical and pharmacy industry, regarding the slow uptake of biosimilars. In the article, he comments on challenges related to pricing, access, and cost savings to patients, saying “We have to sit down and seriously change the structure, and in the process, we cannot kill insurance companies, drug companies, PBMs, hospitals, (or) doctors.” The article goes on to report that “Tharp says he remains optimistic that if the country as a whole slows down and reconsiders its current healthcare philosophy, it may be possible to reverse current trends and once again appreciate the value that generics can play in the marketplace.”

Seth Ginsberg, president and co-founder, spoke with *BioCentury*, another publication read by pharmaceutical executives and other stakeholders, about the value technology brings to patients and why they should feel in control of how their personal health data is used. He specifically referenced ArthritisPower, noting it, “allows patients to report day-to-day symptoms related to their arthritis, and stores medication information and dosage.” He went on to say, “The patients get feedback for themselves and their outcomes as they were recorded...They get the results of the study and interpretation of the results so that they understand what they contributed to.”

Shilpa Venkatachalam PhD, associate director of Patient-Centered Research, successfully posted a comment to [STAT News](#), in response to an article on how ICER makes its recommendations related to drug pricing, stating that “instead, attention should be shifted to how, and why, treatments and care can be made more cost-effective so patients can benefit from them, and live better-quality lives.”



Drug Topics
Voice of the Pharmacist

■ GHLF REPRESENTS PATIENTS AT INDUSTRY AND GOVERNMENT MEETINGS

In addition to the activities already noted, GHLF had the opportunity to attend a variety of meetings with health policy stakeholders including legislators, regulators, insurance commissioners, and physicians. Some of the meetings were private. Public meetings (attended by invitation) are listed below.

2
JUL

Steven Newmark, JD, MPA, director of policy, Corey Greenblatt MPH, manager of policy and advocacy, and Hanne Genyn, policy and advocacy Fellow, attended a meeting with Amy Bassano at the Center for Medicare and Medicaid Innovation (CMMI) to discuss possible further collaborations between GHLF and CMMI.

5
JUL

Daniel Hernandez, MD, medical advocacy liaison, and Steven Newmark attended the NYC Department of Health and Mental Hygiene Blood Pressure Coalition Meeting.

12
SEP

17
JUL

Steven Newmark attended the annual meeting of the Alliance for Transparent and Affordable Prescriptions in Washington, D.C.

5-8
AUG

Steven Newmark and Corey Greenblatt attended the annual meeting of the National Conference of State Legislators in Nashville, Tennessee.

7-10
AUG

Jessica Boles MSW, community outreach manager and patient advocate, and Zoe Rothblatt, policy and advocacy fellow, attended the annual meeting of the Rheumatology Nurses Society in Orlando, Florida.

15-18
AUG

Jessica Boles and Kelly Gavigan, MPH, manager, research and data science, attended the Association of Women in Rheumatology (AWIR) Annual Conference.

14
SEP

Jessica Boles and Zoe Rothblatt attended the annual meeting of the National Organization of Rheumatology Managers in Grand Rapids, Michigan.



■ GHLF SUBMITS PATIENT-CENTERED COMMENTS TO FEDERAL AND STATE GOVERNMENTS

In the second quarter GHLF submitted 8 public comments:

1
JUL

GHLF submitted comments in opposition of Idaho's Coverage Choice Waiver for their state Medicaid program.

2
JUL

GHLF submitted comments in support of North Dakota's 1332 Medicaid Waiver

10
JUL

GHLF submitted comments in support of Colorado's 1332 Medicaid Waiver.

10
JUL

GHLF submitted comments in opposition of Utah's Medicaid Enrollment Per Capita Cap.

13
AUG

GHLF submitted comments in opposition of proposed changes to Section 1557 of the Affordable Care Act.

15
AUG

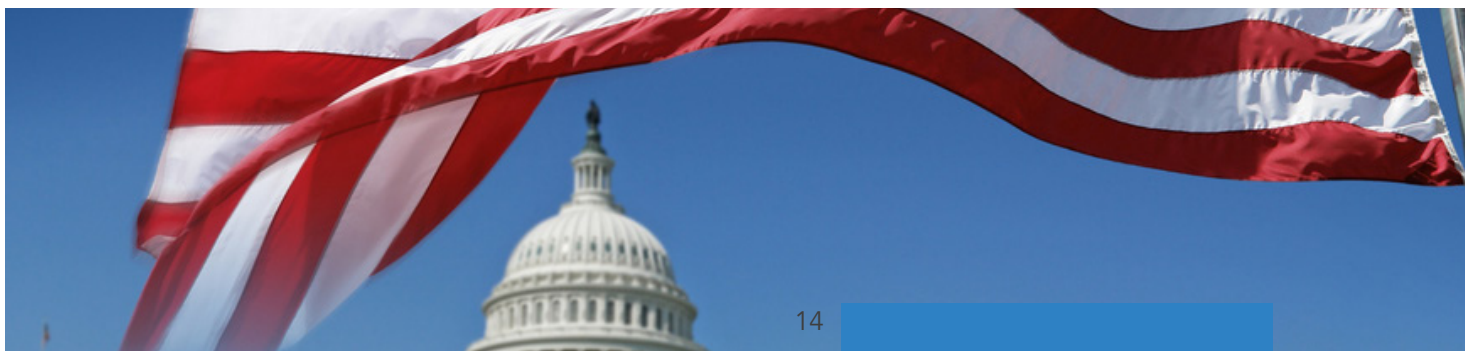
GHLF submitted comments to the FDA in support of finalizing proposed DA draft guidance intended to help industry understand the FDA's thinking on benefit-risk assessment for opioid analgesic drugs.

9
SEP

GHLF joined a sign on letter to support H.R 3107, Improving Seniors Timely Access to Care.

11
SEP

GHLF submitted comments to share out concern on changes to the National Institute of Health requirements regarding proposed human fetal tissue research.



■ PROMOTING OUR PERSPECTIVE

During the third quarter, GHLF issued a [press release](#) calling for presidential candidates and the current administration to reschedule marijuana for medical use so that it can be studied in high quality clinical trials.

In addition, in August, GHLF and the George Washington University's Institute for Corporate Responsibility announced via [press release](#) a partnership to expand the role of impact investing to improve health. Impact investing refers to investments made by companies, organizations, and funds with the intention to generate a measurable, beneficial social or environmental impact alongside a financial return. The full role that impact investing could play in improving global health is vast and has yet to be discovered. This project is ongoing.

In September, Global Healthy Living Foundation [expressed its support](#) of North Carolina Attorney General Josh Stein who in August filed lawsuits against eight e-cigarette companies alleging that these companies aggressively target children and do not require appropriate age verification when selling these dangerous and addictive products. According to the CDC, e-cigarettes use is on the rise among youth, with “the number of middle and high school students using e-cigarettes [increasing] from 2.1 million in 2017 to 3.6 million in 2018.”

You can read all of our press releases at www.CreakyJoints.org/press-releases.

CREAKYJOINTS PROVIDES EDUCATION TO PEOPLE WITH ALL FORMS OF ARTHRITIS

■ CREAKYJOINTS AND THE GLOBAL HEALTHY LIVING FOUNDATION IN THE NEWS

During the third quarter, there were 50 earned media placements featuring CreakyJoints members or leadership, generating nearly 175 million media impressions. There was a significant amount of coverage related to the CBD/marijuana for medical use survey presented at EULAR as well as coverage of the Michael Kuluva fashion show. Notably, the [USA Today op-ed](#) on marijuana for medical use published in July was picked up online by many local papers in the *USA Today* family such as [The Tennessean](#), [Milwaukee Journal Sentinel](#), and [Delaware Online](#). Everyday Health published several stories featuring our members or leadership, including on how people with RA [build resilience](#) during treatment and referring readers to CreakyJoints in their coverage of September's [Rheumatic Disease](#) Awareness Month.

■ FINDING A COMMUNITY OF 5.5 MILLION DURING #CREAKYCHATS

Our popular #CreakyChats Twitter chats are well attended and generate impactful conversations about living with chronic illness, particularly when we partner with special guests. Third quarter #CreakyChats generated an average of 5.5 million impressions each. The most recent chat topics were:

September	Understanding the Differences between Chronic and Acute Pain: A Pain Month Wrap-up Discussion, with special guest @US_Pain
August	The Personal is Political: How Politics and Health Care Policy Impact the U.S.
July	Chronic Voices: Sharing Our Strength and Experience, with special guests @Tinu, @ADVofSpoonieMom, @chroniceileen, and @Doitwell01

Our Community

#CreakyChats

 Our Conversation

■ THE CREAKYJOINTS AUDIENCE CONTINUES TO GROW AND EXPAND TO NEW PLATFORMS

From Q2 to Q3 2019, CreakyJoints.org website traffic grew by almost 50 percent. The referral source that contributed most to our Q3 growth was organic Google search traffic, which increased 60 percent from Q2 to Q3 thanks to the regular production of quality, SEO-friendly editorial content for the arthritis community. Additionally, a more robust automated email strategy helped increase traffic from email by 36 percent, and a revamped presence on Instagram led to a 4,200 percent increase in Instagram-referred traffic.

In addition to the quantity of traffic increasing, our quality of traffic also increased. Our average session duration increased from 4 minutes, 50 seconds in Q2 to 5 minutes and 10 seconds in Q3. We also saw a 162 percent increase in the number of visitors who are subscribing to CreakyJoints. If you are not yet a CreakyJoints member, register on our homepage at www.creakyjoints.org.



On Instagram, we saw a 110 percent increase in followers, with the most engagement on posts when we polled the community.

Popular content published in the third quarter includes:

- [Napping and Arthritis: What Sleep Experts Wish You Knew](#)
- [The FDA Just Approved Generics for Lyrica, the Fibromyalgia Medication](#)
- [What's a Real Day in the Life with Rheumatoid Arthritis? Here's a Look at Mine](#)
- [Is It a Bunion or Something Else? 6 Health Problems You Might Mistake for Bunions](#)
- [Here Are the Embarrassing Moments of Arthritis No One Wants to Talk About](#)
- [Showering and Bathing with Arthritis: 18 Tips to Make It Easier](#)
- [Bras for Arthritis: How to Pick the Right Bra to Avoid Pain and Be More Comfortable](#)
- [Can Inflammatory Arthritis Cause Hearing Loss? What You Must Know](#)
- [8 Reasons CBD Might Not Be Working for Your Arthritis \(and What to Do About It\)](#)
- [Cycling and Arthritis: Why Cycling Is Good for Your Joints, and How to Get Started](#)

WHO WE ARE

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 nearly 1,500 trained volunteer patient, caregiver, and health care activists. As part of the [Global Healthy Living Foundation](#), CreakyJoints also has a patient-reported outcomes registry called ArthritisPower® with more than 22,000 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 educational and navigational tools for managing chronic illness. GHLF recently acquired [PainSpot](#), a digital risk assessment tool for musculoskeletal conditions and injuries. 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 and to evaluate symptoms for a risk assessment, visit www.PainSpot.org.



About ArthritisPower®

Created by [CreakyJoints®](#) and supported by a multiyear, multimillion dollar investment by the Patient-Centered Outcomes Research Institute (PCORI), ArthritisPower, with more than 22,000 consented arthritis patients, 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 the 50-State Network

The [50-State Network](#) is the grassroots advocacy arm of the [Global Healthy Living Foundation](#). It is comprised of patients with chronic illness who are trained as health care activists to proactively connect with local, state and federal health policy stakeholders to share their perspective and influence change. Through public and personalized opportunities to advocate for the chronic disease community, the 50-State Network mobilizes patients to voice their concerns about access to treatment, quality of care, and the need to prioritize the physician-patient relationship. For more information, visit www.50StateNetwork.org.



About Global Healthy Living Foundation

The [Global Healthy Living Foundation](#) 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, 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®](#), 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. GHLF recently launched www.PainSpot.org, a digital risk assessment tool for musculoskeletal conditions and injuries. Visit www.ghlf.org for more information.



The information in About Us is current. It does not reflect the past quarter.