

QUARTERLY REPORT

APRIL – JUNE 2019



BIENVENIDOS A CREAKY- JOINTS EN ESPAÑOL

In April, CreakyJoints announced that our 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. Simultaneously, this announcement marked the launch of a dedicated Spanish-language version of our website, [CreakyJoints Español](#), 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.

Notably, [EFE América](#), which is a wire service serving Spanish-language newspapers around the world, reported on our launch during May’s Arthritis Awareness Month resulting in coverage in major dailies such as LA Times en Español, [Hoy Newspaper](#), [El Diario NY](#), [La Opinion](#), and dozens of others.

Daniel Hernandez, MD, Medical Advocacy Liaison at CreakyJoints, is leading the

CreakyJoints Español effort. In addition to developing articles and content for the website, this quarter he attended the two-day 10th annual ReumaExpo, hosted in Plaza Las Américas, Hato Rey, San Juan, Puerto Rico, by Fundación Puertorriqueña de Enfermedades Reumáticas. Dr. Hernandez along with two of the members of the GHLF Puerto Rican Patient Council presented a Spanish language patient leadership pilot program co-led by CreakyJoints and Fundación FER.

A GHLF-sponsored weekly radio show hosted by Fundación FER’s executive director, Griselle Lugo, was hosted live during the event and the educational pilot project, CreakyJoints Español, and other educational content for rheumatoid patients were transmitted through Radio Isla, a popular Puerto Rican radio station, and Facebook Live.

MORE THAN HALF OF ARTHRITIS PATIENTS HAVE TRIED CBD OR MEDICAL MARIJUANA

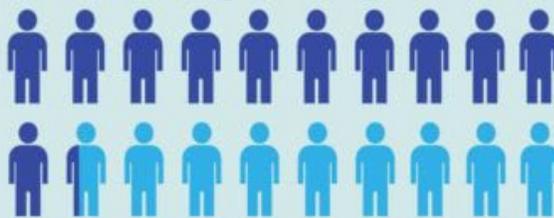
On June 13, CreakyJoints presented a poster at the Annual European Congress of Rheumatology (EULAR 2019) meeting in Madrid, Spain titled, ["Patients' Perceptions and Use of Medical Marijuana."](#) [The ArthritisPower® Research Registry](#) study found that more than half (57.3%) of arthritis patients surveyed (N=1,059) reported trying marijuana for medical use (MMU) and/or cannabidiol (CBD) products for a purpose they perceived as medical. Of those who use MMU regularly, 62 percent reportedly use MMU at least once daily. Most participants who tried MMU or CBD claimed that it improved their condition (MMU= 96.1%, CBD=93.1%) or their symptoms (MMU= 97.1%, CBD=93.7%), particularly pain and sleep disturbance. Our infographic and related [educational article](#) provide highlights of study findings.

Patient Perceptions of Medical Marijuana and CBD



1,059
patients

Average age: 57



57% have used marijuana or CBD for a medical reason

43% have not used marijuana or CBD

In the press release, W. Benjamin Nowell, PhD, Director of Patient-Centered Research at GHLF, ArthritisPower principal investigator, and study lead said, “Despite best efforts by rheumatologists and patients to find an effective arthritis treatment and management strategy, there are still many patients who seek additional relief for chronic symptoms. It’s alarming that so many arthritis patients use medical marijuana and cannabidiol products in the absence of high-quality evidence about their safety, effectiveness, and appropriate dosing. This underscores the urgent need to conduct randomized, controlled trials to study their effectiveness at addressing symptoms common to arthritis as well as their potential to interact with other medications. Moreover, it’s concerning that patients may not be discussing their use of these products to augment or replace other arthritis treatments with their health care team.”

Tapping into growing interest about CBD products and medical marijuana, this study was covered by many MMU-focused

blogs, such as [Times of CBD](#), [Medical Marijuana UK](#), [Pure Dosage](#) and many others. [Leafly](#), one of the larger media outlets in this space, included an interview with CreakyJoints volunteer patient advocate Tien Sydnor-Campbell. The article says, “Overall, [Tien]Sydnor-Campbell, as a member of the patient governor’s board, got involved with the CreakyJoints study because she wanted to help illuminate more about medical cannabis as a treatment option for arthritis sufferers. She’s also passionate about the push towards legalization, which she says would make cannabis more accessible to patients and encourage doctors and patients to be transparent about using it. ‘[The only way] doctors can be armed with information is to have...clinically-sound research...We already know people are using this, so it’s time we start studying it now, now, now.’”

Notably, the national online publication [STAT](#) also referenced our study in their

“ We already know people are using this, so it's time we start studying it now, now, now...

recent coverage of CBD and **USA Today** published an opinion piece [online](#) and in print by Seth Ginsberg.

In addition to the study, GHLF distributed a news release calling on all presidential candidates to de-schedule marijuana. It is currently classed as a Schedule 1 narcotic, prohibiting any research into its safety or effectiveness.

USA TODAY

OPINION

Doctors and patients are flying blind as medical marijuana use rises, research lags

Seth Ginsberg, Opinion contributor Published 5:00 a.m. ET July 23, 2019

Doctors and patients must demand changes to federal restrictions on medical cannabis research to allow for more evidence-based health care.

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Marijuana's role in the health care universe has grown exponentially over the past few years. Currently, 33 U.S. states have legalized the use of medical marijuana, and more and more states are considering making it legal for recreational purposes as well. As cannabis becomes more accessible, many people are turning to tetrahydrocannabinol (THC) and cannabidiol (CBD) products to treat health issues like rheumatic and musculoskeletal disease (the aches and pains of arthritis).

Unfortunately, because cannabis remains illegal and classified as a Schedule 1 drug under federal law (defined as being of no medical use), there has been a troubling lack of scientific and medical research on the effectiveness of cannabis treatments. This dearth of evidence-based data has left many health care providers unable to counsel their patients on everything from whether a cannabis treatment could be effective for their condition, to what dosages are appropriate, to how cannabis might interact with



CREAKYJOINTS DELEGATES ATTEND OARSI (OSTEOARTHRITIS RESEARCH SOCIETY INTERNATIONAL) PUBLIC MEETING

Two passionate patient leaders from our CreakyJoints community did an outstanding job of representing osteoarthritis patients while attending the OARSI (Osteoarthritis Research Society International) Public Meeting to Discuss Unmet Need for New Therapies to Treat OA on May 16th, 2019, in Washington, D.C.

Ranay C., one of the 50-State Network's first Delegate Coordinators, and Denise M., a long-standing CreakyJoints Patient Council member, conveyed the impact of living with OA and the need for therapies that not only help manage symptoms, but potentially modify joint destruction.



Denise and Ranay participated in a panel discussion with multiple clinicians to address the prevalence of OA, the risk factors, and the overall burden, bringing their message to a larger audience. U.S. Food and Drug Administration (FDA) also attended this public to discuss opportunities and regulatory pathways for designing clinical trials of OA structure-modifying drugs.

Ranay and Denise both urged the medical

procedures, drug therapies, and new treatments to give patients the hope that they can continue to be productive members of society and address the social determinants of health that lead to social isolation and depression. A better quality of life, dignity and peace of mind, is all patients like Ranay and Denise ask for, and that begins with better treatment options being explored, implemented and made accessible to patients.

PUTTING PATIENT PERSPECTIVES FRONT AND CENTER

Shilpa Venkatachalam, PHD, MPH, Associate Director, Patient-Centered Research, represented CreakyJoints at several important meetings to convey the importance of a patient-centered treatment approach

- In June, she attended the Patient & Caregiver Connection (P&CC) Town Hall at the U.S. Food and Drug Administration (FDA). The Town Hall highlighted patient organizations for the FDA's CDRH (The Center for Devices and Radiological Health) staff. Exhibition time was included in the program to serve as a meet-and-greet for CDRH staff to become acquainted with the 14 patient organizations that were invited to participate. CreakyJoints shared information about its ArthritisPower Research Registry to pursue collaboration with FDA's ongoing patient science effort to encourage the incorporation of patient organizations in CDRH research efforts. The meeting focused on discussion around the importance and potential to include robust and reliable patient-reported outcome measures and patient preference information in research related to medical devices.
- Also in June, Dr. Venkachalam attended the ARM, or Annual Research Meeting, on behalf of Academy



Health and the Patient-Centered Outcomes Research Institute (PCORI). CreakyJoints was the proud recipient of a patient scholarship to attend this Washington, D.C. event. Various issues concerning health policy and implications of new cutting-edge research findings across disease conditions were discussed. The aim was to encourage discussion on how to use these new findings to better care for individuals and communities. Chronic disease-specific and chronic pain panels shared innovative ways to impact outcome and care for patients living with a range of chronic diseases and managing chronic pain.

I have pain every single day (for 9 years now) but most days it's tolerable enough to function (ie. walk, drive, work, cook, shop, socialize) but **RARELY** do I ever do these things on the same day.

Many don't see the **emotional pain** it takes to cancel important plans.

ARTHRITIS: AS NOT SEEN ON TV

During May's Arthritis Awareness Month, CreakyJoints deployed a multiplatform campaign aimed at sharing the reality of living with chronic disease called "Arthritis: As Not Seen TV." This patient-generated initiative highlighted the invisible nature of arthritis. The campaign reached more than 100,000 people and was liked and shared on social media more than 7,000 times.

Here are 50 invisible truths our community shared with us:

<https://creakyjoints.org/living-with-arthritis/arthritis-invisible-truths/>

When I have a good day I'm not running through daisy fields, **I'm doing laundry.**

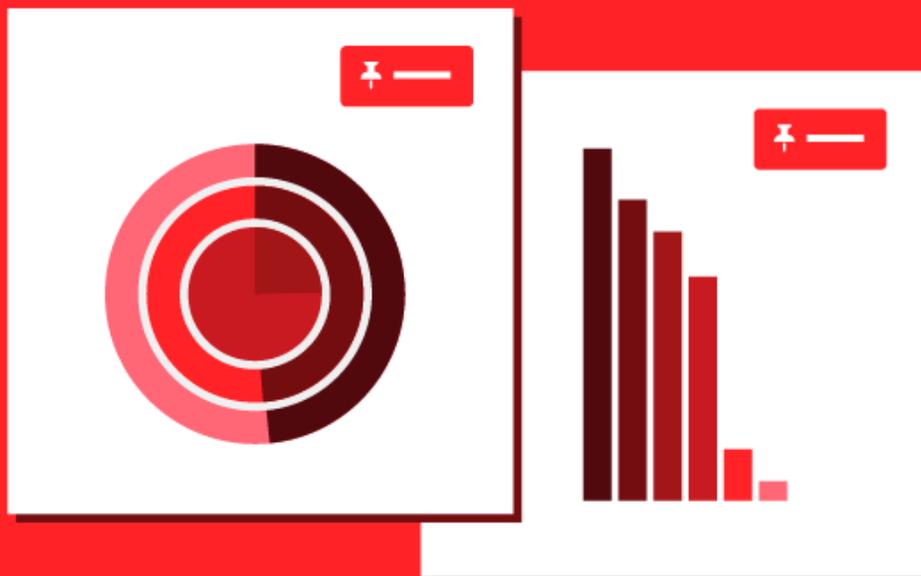
Many don't see the **amount of meds, supplements, and assistive devices** I use to function.



ARTHRITISPOWER RESEARCH BROADENS ARTHRITIS UNDERSTANDING

Current ArthritisPower statistics as of June 30, 2019:

- Total patients: **18,891**
- Total number of completed patient reported outcomes (PRO) assessments: **225,116**
- Number of unique participants who have completed PRO assessments: **14,187**
- Number of unique participants who have reported at least one medication (includes combination of medications): **5,421**



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.

■ ENCOURAGING PATIENTS TO MANAGE CHRONIC PAIN USING THE LATEST EVIDENCE FROM RESEARCH

This dissemination-focused PCORI Eugene Washington Engagement Award will convene and train patients as ambassadors to share and promote evidence-based information on effective chronic pain management, targeting an audience of U.S. adults with chronic pain due to rheumatic and musculoskeletal disease. The primary objective is to disseminate information from PCORI-funded pain studies, supplemented with other chronic pain management strategies that meet pre-specified evidentiary standards.



■ DIVERSIFYING, EXPANDING, AND TRACKING PATIENT ENGAGEMENT IN ARTHRITIS RESEARCH

Patient-Powered Research Network (PPRN) Limited Competition PCORI Engagement Award: During the two-year project, we will work with other PPRNs and the University of Alabama at Birmingham (UAB) Minority Health & Health Disparities Research Center, an NIH Center of Excellence, to attract and engage underrepresented patients in research activities of PPRNs and PCORnet. Specifically, the project aims to recruit and activate a more representative study population in ArthritisPower, pilot and assess a new participant navigation model for hard-to-reach patients who join the registry, and work with PCORnet and other PPRNs to create shared engagement metrics.

Many other studies continue in ArthritisPower, such as:

HEALTHY MIND, HEALTHY YOU: A STUDY OF MINDFULNESS

Most people experience stress at some point in their lives. Stress, especially when severe, can not only make you feel bad, it can also worsen existing health problems like heart disease, type 2 diabetes, obesity, high blood pressure, depression, and even cancer. Healthy Mind, Healthy You is a study about how mindfulness can help people cope with stress. Funded by PCORI, led by Andrew A. Nierenberg, MD, of Massachusetts General Hospital, and involving 19 Patient-Powered Research Networks (PPRNs), including our ArthritisPower PPRN and Dr. Nierenberg’s MoodNetwork PPRN, Healthy Mind Healthy You is examining the effects of mindfulness across a variety of populations and conditions. Study recruitment ended August 1.

Other studies in progress include:

<p>Smartwatch Synchronized to Your Health</p>	<p>The DIGItal Tracking of Arthritis Longitudinally (DIGITAL) study is known to participants as the ArthritisPower Smartwatch Study. The study is open for enrollment.</p>
<p>What Symptoms Matter to You?</p>	<p>The study is seeking to understand the relative importance of disease symptoms across a number of conditions. The study is full, closed to new patients, and is in the analysis phase.</p>
<p>CHOICE (Comparative Health Outcomes in Immune-mediated disease CollaborativE)</p>	<p>The study is open and 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.</p>
<p>Shared Decision Making in Lupus Study</p>	<p>The study is open to participants identified by Tufts and the Hospital for Special Surgery.</p>

■ EXTRA! EXTRA! NUMEROUS CREAKYJOINTS PEER REVIEW STUDIES JUST PUBLISHED

In May, CreakyJoints announced 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,”* published in *ACR Open Rheumatology*, a peer-reviewed publication of the American College of Rheumatology. Key findings from the study are:

- Most women with inflammatory arthritis (60%) 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%), fear that antirheumatic drugs might harm a fetus or infant (61%), concern that their child might inherit arthritis (52%) or that arthritis might cause their premature death so that she might not be able to raise her child (34%), among others.
- Forty percent of the surveyed women reported infertility, which mirrors other studies showing that women with inflammatory arthritis are at increased risk for infertility.



“

As physicians, we need to do a better job addressing patients’ concerns about perceived childbearing risks related to disease onset and treatment,” said study author Megan E.B. Clowse, MD, MPH, a rheumatologist at Duke School of Medicine. “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.”

Notably, the second quarter also saw the publication of five other peer-reviewed ArthritisPower studies including:

- Bingham, CO, Gutierrez, AK, Butanis, A., et. al., “PROMIS Fatigue short forms are reliable and valid in adults with rheumatoid arthritis,” et al. *Journal of Patient-Reported Outcomes* (2019) 3:14, <https://doi.org/10.1186/s41687-019-0105-6>
- Hsiao, B., Binder-Finnema, P., Nowell, WB, “Preference Phenotypes in Support of Shared Decision-Making at Point-of-Care for Patients With Rheumatoid Arthritis: A Proof-of-Concept Study,” *Arthritis Care & Research* Vol. 71, No. 5, May 2019, pp 629–637 DOI 10.1002/acr.23684
- Nowell, WB, “Information Patients Can Provide Will Strengthen the Real-World Evidence That Matters to Them,” *Clinical Pharmacology & Therapeutics*, Volume 0, Number 0, Month 2019; Received January 21, 2019; accepted April 1, 2019. doi:10.1002/cpt.1460
- Nowell, WB, Curtis, D., Thai, M., et. al., “Digital Interventions to Build a Patient Registry for Rheumatology Research,” *Rheum Dis Clin N Am* 45 (2019) 173–186, <https://doi.org/10.1016/j.rdc.2019.01.009>
- Ogdie, A., Nowell, BW, Reynolds, R, et al., “Real-World Patient Experience on the Path to Diagnosis of Ankylosing Spondylitis,” *Rheumatol Ther*. April 30, 2019 <https://doi.org/10.1007/s40744-019-0153-7>

■ DIRECT TO PATIENT ARTHRITIS EDUCATION

Our series of educational webinars continued in the second quarter and recorded versions of each are at our [YouTube](#) channel. Topics presented during the second quarter included:

[Shared Decision Making: What It Is, and How to Benefit From It](#), conducted in partnership with the Autoimmune and Systemic Inflammatory Syndromes Collaborative Research Group (ASIS CRG) of PCORnet. The presenters were Carole Wiedermeyer, MBA, a market researcher and past ArthritisPower Patient Governor, and Liana Fraenkel, MD, MPH, Adjunct Professor of Medicine at Yale University School of Medicine and Director, Patient Centered Population Health Research at Berkshire Health System. She is also an ArthritisPower Research Advisory Board member.

■ THE CHRONIC DISEASE COMMUNITY'S VOICE IS BEING HEARD



Lauren Gelman, Director of Editorial Services; Steven Newmark, Policy Director and General Counsel, and Joseph Coe, Director, Education and Digital Strategy, cheerfully travel on behalf of CreakyJoints and the Global Healthy Living Foundation's 50-State Network to raise awareness of the needs of arthritis patients.

If you can guess which airport this is, we'll send you CreakyJoints and GHLF-branded products! (Send to Ryan Johnson at rjohnson@ghlf.org)

This quarter, our advocacy team has been active in more than 10 states and Washington D.C., commenting on 15 different proposed state laws and federal rules to help members of the Global Healthy Living Foundation's 50-State Network advocate for patient-protective legislation. Comments were related to step therapy, non-medical switching, and copay accumulator programs, which are all protocols implemented unilaterally by insurance companies to reduce costs regardless of individual patient needs.

■ 50-STATE NETWORK ACTIVISTS MAKE A DIFFERENCE

In May, North Carolina volunteer activist and ankylosing spondylitis patient Regan R. met with her state representative, Rep. Grier Martin, in Raleigh during the Fair Health NC Advocacy Day, intended to urge lawmakers at the NC General Assembly to pass legislation to reform the step therapy process to better protect patient health. Regan R. (right) with N.C. State Representative Grier Martin (D)



In April, Tennessee volunteer advocate and rheumatoid arthritis patient Beth M. (center and below) spoke about her experience as a patient at the Amgen Health Equity Summit. (Photo to the left: GHLF Director of Policy Steven Newmark, Beth M., and GHLF Community Outreach Manager and Patient Advocate Regis Wagner)



■ NEW YORK PASSES NON-MEDICAL SWITCH LEGISLATION!

Working on behalf of chronic disease patients in New York State for several years, we were thrilled when this June the NYS legislature passed a bill that would limit non-medical switching, protecting patients against unexpected changes to their formulary coverage mid-plan year. As of mid-July, the bill awaits Governor Cuomo's signature. Notably, [Crain's New York Business](#) included our perspective in their regular coverage of the progressing bill.

■ 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.

11-14
APR

GHLF Medical Advocacy Liaison, Daniel Hernandez, MD, attended the annual meeting of the National Hispanic Medical Association where he gave a talk on the value of working at a non-profit, in Arlington, Virginia.

23
APR

GHLF Director of Policy and General Counsel, Steven Newmark, JD, MPA, and Manager of Policy and Advocacy, Corey Greenblatt, MPH, attended the Collaborating 4 Care meeting sponsored by Takeda Pharmaceuticals to provide the patient perspective.

24
APR

GHLF Community Outreach Manager, Patient Advocate, Regis Wagner, MSW, attended the Health Equity Summit sponsored by Amgen.

Steven Newmark, Corey Greenblatt, and GHLF Executive Director and co-founder Louis Tharp, attended the Transparency & Policy Considerations Summit held by Janssen Pharmaceuticals.

2-4
MAY

Corey Greenblatt and Regis Wagner attended the Congress of Clinical Rheumatology annual meeting in Destin, Florida.

3-6
JUN

Corey Greenblatt attended the BIO annual meeting in Philadelphia, Pennsylvania.

11
JUN

Daniel Hernandez, MD, and GHLF Advocacy and Policy Fellows, Zoe Rothblatt and Hanne Genyn, attended the SOMOS 1st Annual Conference on neighborhood-based primary care at the NY Academy of Medicine in New York, New York.

12
JUN

Corey Greenblatt and Hanne Genyn were in Albany, NY to support a proclamation to proclaim June as Migraine Awareness Month in New York State.

23
JUN

Corey Greenblatt attended the meeting of the National Infusion Center Association in Austin, Texas.

26
JUN

Steven Newmark attended meetings with legislators on Capitol Hill with the Alliance for Transparent and Affordable Prescriptions in Washington, D.C.

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

In the second quarter GHLF submitted two public comments:

1
APR

GHLF submitted comments to the Inter-Agency Task Force within the Department of Health and Human Services studying Pain Management Best Practices.

8
APR

GHLF submitted a comment letter in support of the Administration's "PBM Rebate Rule." We also signed on to a letter with the Alliance for Transparent and Affordable Prescriptions.

The Advocacy Team also worked on behalf of patients in Colorado, North Dakota, Idaho and Utah to oppose changes in state Medicaid programs and reduce the burden of step therapy, mid-year formulary changes and copay accumulator programs, which shift costs to patients and delay care.

■ DELEGATE COORDINATORS

At the 50-State Network, our goal is to create a movement that is nonpartisan and focused on making necessary changes in our nation's health care system for everyone. We selected three patient leaders from our community, J. Nagy, R. Collins, and JP Summers, to be volunteer Delegate Coordinators.

They are instrumental in leading our advocacy efforts as patients in their community who help cast a wide net to mobilize fellow patient advocates.

They are the trailblazers for change as we promote connectivity in communities across our network. Our Delegate Coordinators initiative is co-led by GHLF's Director of Policy, Steven Newmark, and Patient Advocate, Community Outreach Manager, Jessica Boles. If you would like more information about becoming a Delegate Coordinator, contact Steven Newmark at snewmark@ghlf.org

CREAKYJOINTS PROVIDES EDUCATION TO PEOPLE WITH ALL FORMS OF ARTHRITIS

CREAKYJOINTS AND THE GLOBAL HEALTHY LIVING FOUNDATION IN THE NEWS

During the first quarter, there were 77 earned media placements featuring CreakyJoints members or leadership, generating more than 167 million media impressions. While we saw a significant amount of media coverage surrounding the launch of CreakyJoints Español and the CBD/MMU survey presented at EULAR (see above), other coverage focused on arthritis awareness in connection with Arthritis Awareness Month in May. Notably, Seth Ginsberg, president and co-founder of CreakyJoints, appeared on one of the world’s largest podcasts for caregivers called, [Parents are Hard to Raise](#), where he spoke about patient-centered arthritis care and ArthritisPower. Several consumer health outlets, including [Healthline](#), [Everyday Health](#) and [Health Central](#) recommended CreakyJoints as a resource for people seeking education about arthritis and also included our members and leaders in interviews. The June issue of *Prevention* magazine reported on a CreakyJoints (ArthritisPower) quick poll on the value of exercise.

For May’s Arthritis Awareness Month, CreakyJoints partnered with HealthCentral to jointly publish two articles:

- [What Every Person with Arthritis Needs to Know About Cannabis](#)
- [These Hacks Promise a Better Day with Arthritis](#)

In addition to publishing and sharing the articles on social media, HealthCentral was our special guest during a #CreakyChat.



Exercising With Arthritis

About 54 million Americans live with some form of arthritis, but a recent poll found that only about half of patients follow the recommendation to exercise more after diagnosis. Being physically active is important for arthritis patients because it helps strengthen muscles around the joints (which helps support them) and improves overall physical function. Now a small study in *Restorative Neurology and Neuroscience* shows that



a week for two months experienced “significant improvement” in inflammation and disease activity as well as reduced depression, letting them function better in their day-to-day routines. Alexis Ogdie,

with 10 minutes of daily walking, then add more time until you reach 30 minutes five days a week. **Get in the water.** Aquatic exercise takes some of the weight off joints, and a warm-water pool can feel good and

■ NOW STREAMING: 'MY BACK IS KILLING ME'

In conjunction with World Ankylosing Spondylitis Day on May 4, CreakyJoints launched a comprehensive educational campaign focused on raising awareness of inflammatory back pain and ankylosing spondylitis. Anchored by a five-part police-procedural web series titled *My Back is Killing Me*, the campaign targets young adults who may not realize that their back pain isn't mechanical, but rather a form of inflammatory arthritis in need of treatment from a rheumatologist. The educational campaign also includes two additional video series. The series *My Backstory* features several CreakyJoints members sharing their stories about their symptoms and journey to getting diagnosed with AS. The animated series *Backsplaining* includes "explainer" videos that clear up common misconceptions about AS and encourage people to see their health care provider if they have inflammatory back pain symptoms.

Digital marketing and media relations supported the launch to reach new audiences, increase video views, and encourage visits to our campaign landing page, CreakyJoints.org/backpain, for more information. Fardina Malik, MD, a rheumatologist with NYU Langone Health in New York City who is featured in the CreakyJoints campaign, participated in an hour-long live interview on **DOCTOR Radio** (SiriuXM radio). Hannah M., a CreakyJoints member who has AS and is featured in multiple campaign videos, contributed her perspective to an essay published on RadioMD.



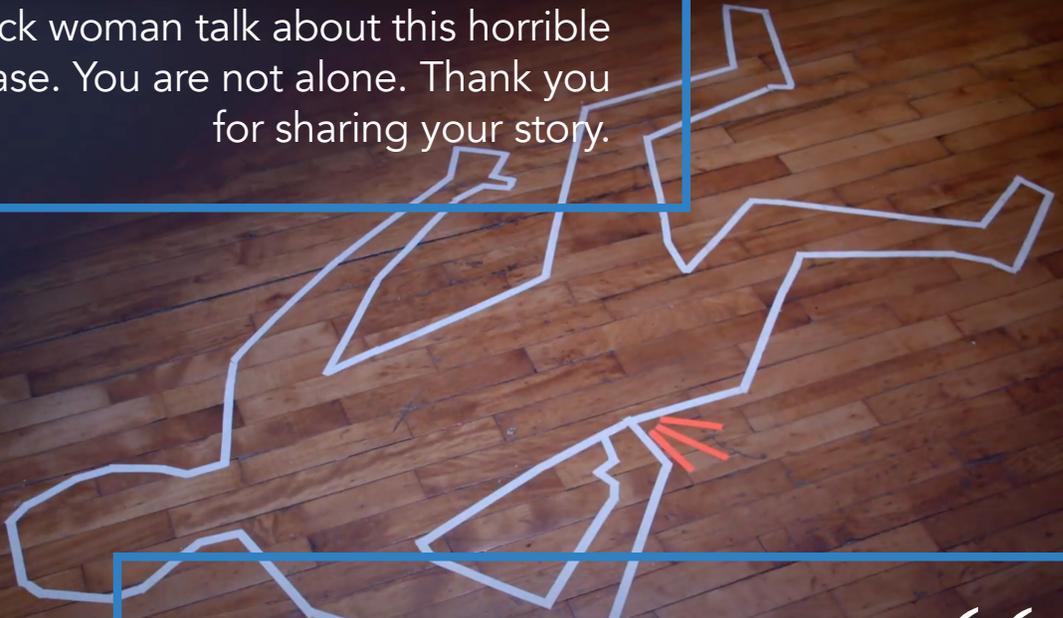
The campaign launched with much initial success in terms of topline video views and watch time and engagement with our landing page's educational resources. Within the first three weeks, the campaign:

- Generated more than 20K views across social media platforms such as YouTube and Facebook
- Prompted 1,800 people to take our inflammatory back pain quiz (80% presented with inflammatory back pain)
- Encouraged 700 people at high risk of inflammatory back pain to opt into our personalized email series

What Patients Are Saying:



It's about time, I'm a black woman too with AS. I don't have the gene either. This is the first time I've EVER seen a black woman talk about this horrible disease. You are not alone. Thank you for sharing your story.



I need to have this [HLA-B27] marker drawn. They say my issues are autoimmune, but it has to be more than fibromyalgia/RA.



I did the survey yesterday. I'll make an appointment with the doctor, as I have those symptoms.



■ FINDING A COMMUNITY OF 5.5 MILION 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. First quarter #CreakyChats generated an average of 5.5 million impressions each. The most recent chat topics were:

- **April:** Lightning Rod Topics That Impact People with Chronic Disease: Marijuana, Vaccines, Opioids, Medicare for All, and Drug Rebates, with special guest Tien Syndor-Campbell, a CreakyJoints member and 50-State Network activist
- **June:** Invisible Truths about Arthritis and Chronic Disease, with special guest @HealthCentral and Lene Anderson (@theseatedview)

■ CREAKYJOINTS ENJOYS HIGH VISIBILITY AT EULAR WITH TOP SOCIAL MEDIA RANK AND MARIJUANA POSTER

In addition to presenting the survey on patients' perceptions on the use of medical marijuana, several members of the CreakyJoints team travelled to the annual European Congress of Rheumatology (EULAR), held this year in Madrid, Spain, to report on research and attend scientific sessions. EULAR provides a forum for rheumatologists and other health care providers and researchers to learn about the latest scientific advances and clinical guidance for treating rheumatic and musculoskeletal disease.

During the meeting, GHLF shared real-time insights and impressions via our CreakyJoints social media channels, resulting in @CreakyJoints being the conference's number-one influencer on Twitter by mentions. Following the meeting, we summarized what we learned at the Congress in a popular article titled [“EULAR 2019: 50+ Arthritis Updates That Could Change Your Health.”](#)

Our Community

#CreakyChats

 Our Conversation

CREAKYJOINTS AND THE GLOBAL HEALTHY LIVING FOUNDATION GROWS ITS AUDIENCE

PEP TALK NOW AVAILABLE NATIONWIDE

CreakyJoints concluded its pilot launch for a new peer education program called Pep Talk following the success of two of Pep Talk’s trial locations, hosted by David Snow, MD, in North Carolina and Vinicius Domingues, MD, a CreakyJoints medical advisor, in Florida, respectively. Pep Talk was created to bridge the gap between what a seasoned patient living with rheumatoid

...patients can become more informed and engaged



arthritis has learned during their patient journey and what a newly diagnosed patient or patient facing barriers to treatment has yet to overcome. Through guidance, support, and non-medical advice from a certified Peer Education Specialist, patients in the Pep Talk program can become more informed, engaged, and satisfied with their care and disease management.

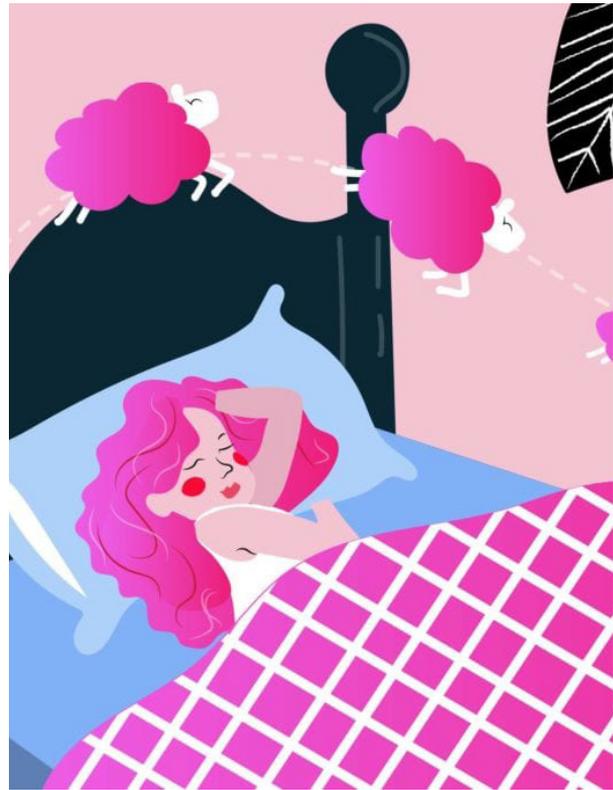
Talk is available via email and phone for patients living with rheumatoid arthritis, however, we are soon looking to expand the services to other disease states. Like all other CreakyJoints programs, participating in Pep Talk is entirely free of charge. The program is being led by Jessica Boles, MSW, LSW, a GHLF patient advocate and community outreach manager.

In our new digital program design, patients who sign up for CreakyJoints are given access to connect with CreakyJoints certified Peer Education Specialists. Currently, Pep

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

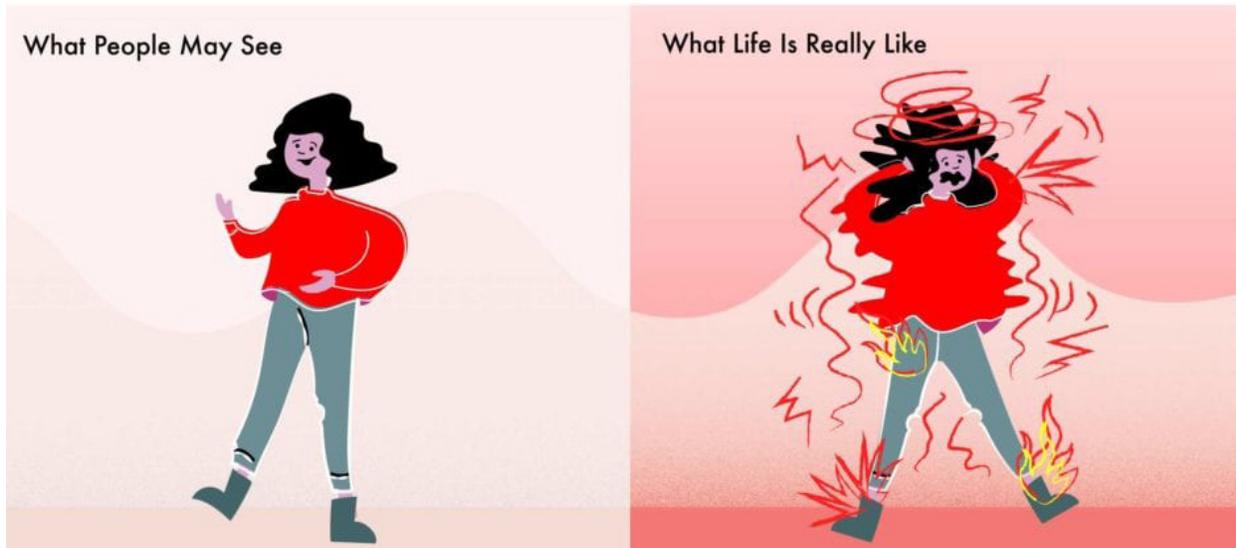
From Q1 to Q2 2019, CreakyJoints.org website traffic grew by almost 90 percent. The referral source that contributed most to our Q2 growth was organic Google search traffic, which increased almost 175 percent from Q1 to Q2 thanks to the regular production of quality, SEO-friendly editorial content for the arthritis community. In addition to the quantity of traffic increasing, quality also increased: The average session duration for CreakyJoints.org increased almost 20 percent to nearly 5 minutes per session.

This June, CreakyJoints also launched an Apple News channel dedicated to news and tips about living well with arthritis. We also reinvigorated our Instagram presence with a new content strategy that includes multiple daily posts, interactive Instagram stories, polls, and more.



Popular content published in the last few months includes:

- [How to Get a Better Night's Sleep with Arthritis: 18 Tips that Patients Swear By](#)
- [What Is Dactylitis? The Sausage Finger Swelling You Should Know About](#)
- [What Is Costochondritis? The Alarming Arthritis Chest Pain You Might Not Know About](#)
- [How I Explain What Rheumatoid Arthritis Actually Is to People Who Don't Have It](#)
- [Giving Yourself Biologic Injections: 21 Practical Tips to Try](#)
- [Diseases That Could Mimic Rheumatoid Arthritis — and Delay Your Diagnosis](#)
- [Using CBD for Arthritis: Tips for How to Get Started](#)
- [Sjögren's Syndrome Symptoms: 11 Clues You Might Be Ignoring](#)
- [Getting a Handicap Parking Permit When You Have Arthritis](#)
- [Can Inflammatory Arthritis Cause Hearing Loss?](#)



■ CREAKYJOINTS AND WALGREENS PARTNER FOR ARTHRITIS AWARENESS MONTH EDUCATION

More than 8,400 Walgreens pharmacists and thousands of Walgreens employees learned more about CreakyJoints and how we can help their patients. Walgreens uses an internal newsletter platform to provide education and resources to its pharmacists, pharmacy managers, pharmacy technicians, and others. For Arthritis Awareness Month, we teamed up to address a crucial unmet need: *How do we help pharmacy employees better understand what it's like to live with arthritis from the patients' perspective?* CreakyJoints produced a custom email newsletter with an accompanying landing page at CreakyJoints.org/walgreens to provide:

- Fast facts about arthritis created specifically for the Alliance Rx Walgreens Prime team
- CreakyJoints membership for Alliance Rx Walgreens Prime employees
- Custom content about disease burden, support, and empathy
- Access to free downloadable Patient Guidelines for managing arthritis

Walgreens

MEET OUR 2019 SUMMER FELLOWS



NAME: Kelly Wang

COLLEGE/PROGRAM: Columbia University: Mailman School of Public Health; on track for a Masters in Public Health; Department: Biostatistics

SUMMER FOCUS AT GHLF/CREAKYJOINTS: Kelly primarily worked on our PCORI Engagement Award, “Diversifying, Expanding and Tracking Patient Engagement in Arthritis Research,” where she contacted different Naturally Occurring Retirement Communities (NORCs) and created materials needed for in-person and webinar engagement groups. In addition, she performed statistical analysis on various surveys and datasets from ArthritisPower.

ONE FUN FACT: Kelly recently learned how to ride a bike, but is still afraid of riding on New York City streets.



NAME: Hillary Caiazzo

COLLEGE/PROGRAM: Associates in Cyber Security at Rockland Community College

SUMMER FOCUS AT GHLF/CREAKYJOINTS: This summer Hillary was primarily responsible for auditing and updating GHLF’s software and hardware security measures on the server and client side. She also supported the help-desk function for laptops, smartphones, desktops, and the cloud. Working with the IT team, she helped organize file access permissions and updated software, hardware, and backup processes.

ONE FUN FACT: Hillary’s all-time favorite food is sliced green apples dipped in Nutella.



NAME: Hanne Genyn

COLLEGE/PROGRAM: Columbia University Mailman School of Public Health, Department of Health Policy and Management, Certificate in Health Policy and Political Analysis. On track for a Masters in Public Health.

SUMMER FOCUS AT GHLF/CREAKYJOINTS: This summer, Hanne has taken the lead in building our Vaccine Advocacy Guide. Additionally, Hanne has provided internal analysis on state and federal policies covering a range of issue areas including: state vaccination exemptions, copay accumulators, pharmacy benefit manager transparency, and rebate pass-throughs or “share the savings” bills.

ONE FUN FACT: Hanne has been skiing since she was 2 years old.



NAME: Zoe Rothblatt

COLLEGE/PROGRAM: Columbia University Mailman School of Public Health, Department of Health Policy and Management, Certificate in Health Policy and Political Analysis. On track for a Masters in Public Health.

SUMMER FOCUS AT GHLF/CREAKYJOINTS: This summer Zoe was the primary researcher and author of a white paper policy brief on the impact of step therapy legislation at the state level and what the potential passage of legislation at the federal level could mean. Zoe has also worked very closely helping GHLF grow our IBD patient community and educational resources.

ONE FUN FACT: Zoe tries to cook a new recipe every week.



NAME: James Patterson

COLLEGE/PROGRAM: University of Pennsylvania, Health and Societies: Healthcare Markets and Finance concentration in the College of Arts and Sciences. On track for a Bachelor of Arts, Healthcare Markets and Finance.

SUMMER FOCUS AT GHLF/CREAKYJOINTS: James worked closely with Seth Ginsberg, president and co-founder, working in health care advocacy and entrepreneurship. During his time here at GHLF, he worked on soon-to-be-announced patient outreach programs, Caribbean CreakyJoints, and CreakyJoints Physical Therapy.

ONE FUN FACT: James performed with his high school's symphony orchestra in London.



NAME: Michael Fields

COLLEGE/PROGRAM: Columbia Mailman School of Public Health. On track for a Masters in Public Health

SUMMER FOCUS AT GHLF/CREAKYJOINTS: Michael worked on various research projects, designing surveys, performing statistical analyses, and conducting literature reviews. His projects included patient tolerability of different side effects, patient experiences with multiple conditions, and patient perspective of medical marijuana.

ONE FUN FACT: On a bike ride in Brooklyn, Michael almost got hit by Whoopi Goldberg opening her car door.



NAME: Matthew Rella

COLLEGE/PROGRAM: Marymount Manhattan College. On track for a BA in Theater Performance with musical theater minor.

SUMMER FOCUS AT GHLF/CREAKYJOINTS: Matthew gathered and managed CreakyJoints promotional materials, organized and filed financial documents, and helped prepare for GHLF's annual audit. He also researched and wrote the upcoming Dupuytren's education and support project, which will live on CreakyJoints.org and GHLF.org.

ONE FUN FACT: Matthew's favorite sport is ice hockey. Go Rangers!

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 healthcare activists.



As part of the [Global Healthy Living Foundation](#), 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”](#) 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.

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 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) nonprofit 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. Visit www.ghlf.org for more information.

