



# QUARTERLY REPORT

OCTOBER - DECEMBER  
2019



GLOBAL  
HEALTHY  
LIVING  
FOUNDATION

# PAINSPOT RELAUNCHES

In mid-October [CreakyJoints®](#) announced the relaunch of [PainSpot.org](#). PainSpot is an innovative algorithmic-based website featuring an interactive, easy-to-use pain assessment tool. Originally developed by rheumatologist Doug Roberts, MD, to help people living with pain get trusted answers about their symptoms based on the clinical questions doctors ask during patient visits, PainSpot helps provide patients with acute injuries and chronic musculoskeletal disease individualized insight into the potential causes of their pain. CreakyJoints considers

this a vital service to our patient community. According to Google data, every month there are nearly 250,000 searches for lower back pain, 100,000 searches for neck pain, and 135,000 searches for shoulder pain.

PainSpot helps people who are searching for such pain symptoms find personalized, trusted, and medically reviewed information. Importantly, PainSpot patients also receive ongoing support from the Global Healthy Living Foundation and CreakyJoints along their journey to an accurate diagnosis.



ABOUT PAINSPOT

FOR HEALTH CARE PROVIDERS

*Find Your*

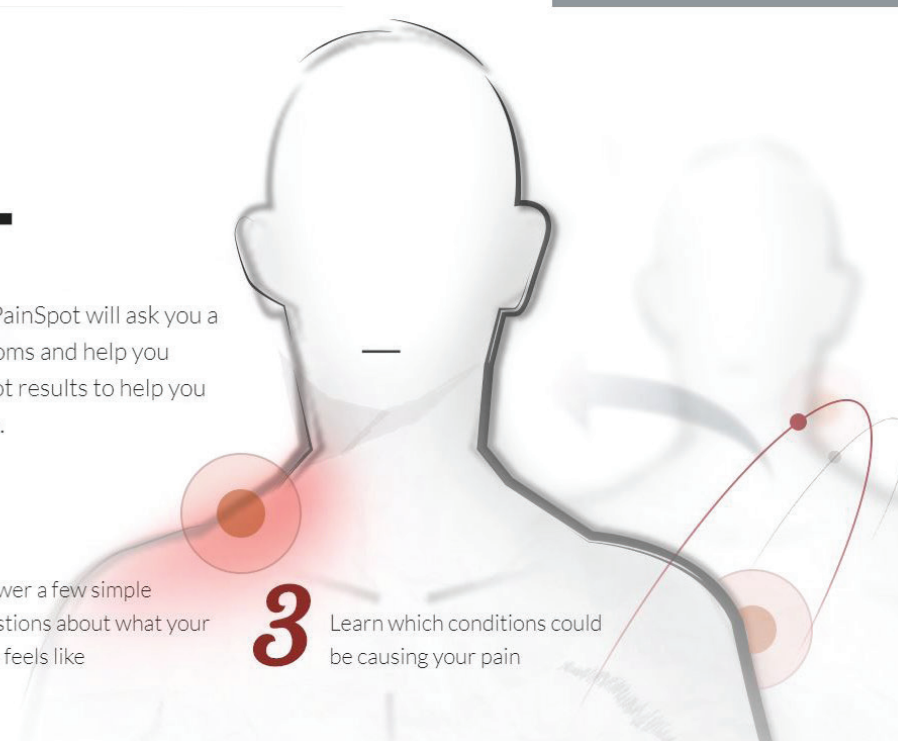
## PAINSPOT

What's causing your joint, back, or neck pain? PainSpot will ask you a simple set of questions about your pain symptoms and help you figure out why you're in pain. Use your PainSpot results to help you and your doctor get to the bottom of your pain.

Find out. Feel better.

START YOUR QUIZ

- 1** Click on the body part where you have pain
- 2** Answer a few simple questions about what your pain feels like
- 3** Learn which conditions could be causing your pain



In addition to a refreshing redesign of the website interface and updating the algorithm to include more conditions, PainSpot now connects site users with actionable results. We provide people with a complete suite of educational resources (including new infographics and visual education tools), link them to digital support services at our websites, and engage in ongoing communication via our customer relationship management tools. Since PainSpot's relaunch, more than 38,000 people have used the assessment tool as of December 31, 2019. Of 237 people who answered our follow-up survey about whether or not they plan to see their doctor about the injuries and diseases in their PainSpot results, 202 said yes.

To use PainSpot, a user clicks on a body part (ex: knee, shoulder, hip, foot) where they are experiencing pain and then answers a series of easy questions about the nature of their pain. These questions come from the same standardized clinical decision-making tools used by health care professionals in a clinical setting. PainSpot patients also receive a follow-up email series designed to drive action toward a diagnosis and chart a pathway for living the best, healthiest life with their conditions injuries.

“PainSpot is not a diagnostic tool — it's not meant to tell you what's wrong. But based on your answers to specific clinical questions about the nature of your pain, it suggests possible conditions that may be responsible for your symptoms and that you should discuss with your doctor. PainSpot will help people in pain have more productive conversations with their health care team.”

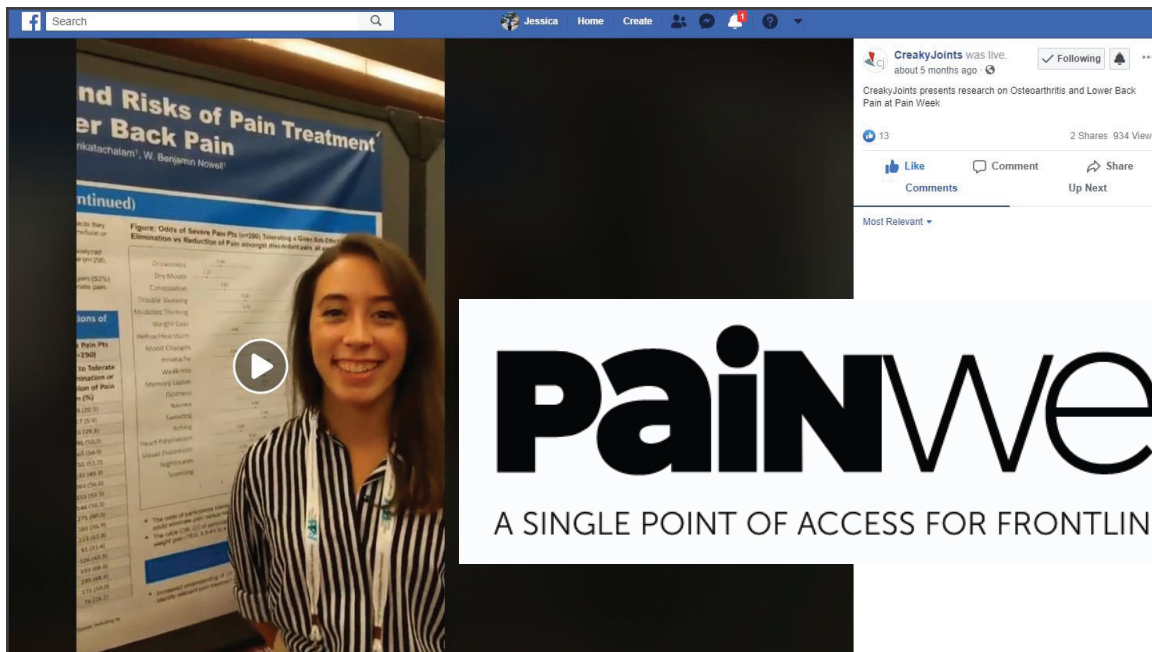
— Seth Ginsberg, CreakyJoints president and co-founder



# CREAKYJOINTS ATTENDS PAIN WEEK

During PAINWeek 2019 in Las Vegas, CreakyJoints presented a poster that showed that people living with osteoarthritis (OA) or chronic lower back pain (CLBP) aren't willing to endure certain bothersome medication side effects even if they might experience relief or elimination of pain. Following the meeting, we also shared our study results with our community in a Facebook Live event.

Results stemmed from a 53-item survey developed in partnership with OA and CLBP patient partners and administered online via the CreakyJoints patient community and [ArthritisPower®](#). Our researchers concluded that most OA and CLBP patients deem side effects such as weight gain and trouble sleeping to be bothersome to the point of intolerability. However, the likelihood of participants tolerating these two symptoms for elimination of pain versus reduction of pain was much higher than the likelihood of their tolerating less bothersome side effects in order to achieve elimination versus reduction of pain.





# GHLF ADVOCATES FOR COMMON SENSE ACCOMMODATIONS

This fall, the [Global Healthy Living Foundation](#) and [CreakyJoints](#) continued to advocate for common sense, quality-of-life accommodations for people living with chronic disease.

One of our most popular articles this fall, [“Plastic Straw Bans Are Not Fair to People with Disabilities, and Here’s What We Can Do About It.”](#) highlighted the hardships that people with chronic diseases may face as plastic straws are banned for environmental reasons. For example, U.S. cities like [Oakland, California](#) and [Seattle, Washington](#) have bans that “prohibit(s) the use of single-use plastic straws in the city’s restaurants, bars, and cafes unless customers ask for them.” Large companies, such as Starbucks, are enacting plastic straw bans too. Given that the plastic bendy straw was actually first used among people with illness and disability before it became a mainstream utensil, we educated our members about how to cope with reduced access to straws while still living a “green” lifestyle, and how they can take action

in the movement to support people with disabilities (such as limited hand, arm or facial muscle movement) who wish to keep plastic straws accessible.



In December, we were alarmed [to read](#) about a British inventor who was advocating for the uptake of his redesigned toilet, which slopes at a 13-degree angle instead of the standard 11 degrees. He suggested that a more sharply angled toilet would be less comfortable during long sitting sessions and hence reduce “wasted” time at work. Immediately, Creaky-Joints took action to share and amplify the concerns of our patient community on social media because we

understand that these toilets can be viewed as ableist, particularly for those living with illnesses that affect gastrointestinal health and the need for restroom access, including Crohn’s disease, ulcerative colitis, and irritable bowel syndrome (IBS). Our Twitter protest was picked up by news outlets including [The Mighty](#) and [Don’t Waste Your Money](#).

# ACR HIGHLIGHTS

This November, CreakyJoints again earned and enjoyed high visibility at the American College of Rheumatology annual meeting, held in Atlanta, Georgia. Notably, on Saturday morning during the session “Doctor, Should I Get This App?” Alexis Ogdie, MD, MSCE, Associate Professor of Medicine and Epidemiology, Perelman School of Medicine, University of Pennsylvania, and W. Benjamin Nowell, MSW, PhD, director, Patient-Centered Research, Global Healthy Living Foundation and Principal Investigator of [ArthritisPower® Patient-Powered Research Network](#), identified features of apps available for rheumatology clinicians and researchers and their patients. They also

explained how apps can be used effectively for patient care and support. The session was covered by the [ACR Daily News](#), which is read by thousands of attendees at the meeting.

During the meeting, CreakyJoints retained its position as the number-one patient group on Twitter (according to Symplur analytics), reaching 5.4 million people through more than 400 patient-friendly [Tweets](#) designed to translate for the lay public the science, education, and advocacy messages from this important medical conference.

During ACR, we also presented seven posters that speak to decisions patients make when treating and tracking their arthritis:

- [Legal Matters: Attitudes Regarding Marijuana for Medical Use Among Patients with Rheumatic and Musculoskeletal Disease](#) (Abstract: 2248)
- [Patient Beliefs and Perceptions of Methotrexate for the Treatment of Rheumatoid Arthritis and Psoriatic Arthritis](#) (Abstract: 2256)
- [Understanding which Patient-Reported Outcomes are Important to Rheumatology Patients: Findings from ArthritisPower](#) (Abstract: 435)
- [Comparison of Medication New User Definitions in Multi-Specialty EMR Data](#) (Abstract: 2067)
- [Art for Arthritis: A New Approach](#) (Abstract: PP06)
- [Patient and Clinical Characteristics Associated with Increased Willingness to Adopt Rheumatoid Arthritis Treatment After an Educational Intervention: An Analysis of the Confident Treatment Decisions for Living with Rheumatoid Arthritis \(CONTROL-RA\) Trial](#) (Abstract: 2257)
- [Patient Factors Associated with Willingness to Change Rheumatoid Arthritis Medications](#) (Abstract: 2247)

## ACR HIGHLIGHTS (CONTINUED)

In the poster, “[Legal Matters: Attitudes Regarding Marijuana for Medical Use Among Patients with Rheumatic and Musculoskeletal Disease \(Abstract 2248\)](#),” we continued to share results from our ArthritisPower® research registry study that reported on how people with arthritis responding to a survey (n=1,059 participants) use marijuana for medical use (MMU, 37%). We found that among those who use MMU, the majority (77%) live in a state where marijuana is legal for medical reasons, though only 40 percent have an actual medical marijuana card for legal purchase. Among the respondents who had never used MMU (63%), illegality (40%), potential impairment (24%), and not knowing where (21%) or how (20%) to obtain MMU (legally or not) were cited as top reasons for not using it. Of respondents who live in states where marijuana is medically legal, most (68%) had informed their health care provider (HCP) about their MMU use, whereas only slightly more than half (54%, p=0.02) informed their HCP in non-legal states. This study was covered by [DocWire](#), [Healio.com](#) and [MedicalResearch.com](#).

We also generated coverage of our posters titled, “Patient Beliefs and Perceptions of Methotrexate for the Treatment of Rheumatoid Arthritis and Psoriatic Arthritis,” and “Understanding which Patient-Reported Outcomes are Important to Rheumatology Patients: Findings from ArthritisPower.” Supported by Amgen, the study of perceptions about methotrexate found that fatigue and gastrointestinal complaints were the most common patient-reported adverse events associated with methotrexate among individuals with rheumatoid arthritis and psoriatic arthritis. This study was reported by [Healio.com/rheumatology](#) and [RheumNow](#), in a video commentary.



The Patient-Reported Outcomes (PRO) study, supported by Eli Lilly, found that the top three PRO measures chosen by participants at baseline tracked fatigue (83%), pain (83%) and mental health (82%). Physical function (72%), social health (69%), sleep (65%), and duration of morning joint stiffness (57%) were also selected by participants in this ArthritisPower. [MedicalResearch.com](#) and [Healio.com/rheumatology](#) covered this story.

As of early 2020, pending articles on our ACR posters are slated with [Consultant360](#), [Pain Medicine News](#), and [Rheumatology Network](#).

# CREAKYJOINTS ESPAÑOL INTRODUCE CULTURALLY SENSITIVE CONTENT

This fall, CreakyJoints Español (CJE) continued developing Spanish-language outreach activities, based on the newly launched [CreakyJoints.org.es](http://CreakyJoints.org.es) (Spanish-language) website content, and updated the published rheumatoid arthritis patient guidelines. CJE will continue to feature culturally sensitive, in-language programming with disease education, treatment landscape information, community support opportunities, advocacy resources, and patient-centered research initiatives targeting the U.S.-based Hispanic inflammatory disease patient community.

During the fourth quarter we introduced CreakyJoints Español Instagram (@creakyjoints\_esp) to enhance reach through social media channels. CreakyJoints Español continues to build grassroots communities and urban advocacy networks focused in the United States including Puerto Rico with the majority of traffic to the site and its social media coming from these areas. The program aims to continue nurturing collaborative efforts with existing Hispanic community, religious, and civic organizations.

In October, [CreakyJoints®](http://CreakyJoints.org) announced its renewed commitment to sponsor “Hablemos de Reumatología con Fundación FER,” a 30-minute, Saturday morning program airing on [Radio Isla 1320](http://RadioIsla1320.com) in Puerto Rico

to provide arthritis and rheumatology education to its listeners. Since launching in 2016, Fundación FER, a Puerto Rico-based organization promoting education, research, support and empowerment for people with rheumatic conditions, has produced more than 70 podcasts airing via AM radio, social media portals, and streaming services. Seth Ginsberg, president and co-founder, said, “We’re no longer limited by antennas and geography because on-demand talk show formats allow anyone to access information conveniently and easily. We are excited and proud to again partner with Fundación FER to increase awareness of all arthritis conditions and bridge the arthritis knowledge gap under the guidance of our Medical Advocacy Liaison, Daniel Hernandez, MD.”



# ARTHRITISPOWER RESEARCH BROADENS ARTHRITIS UNDERSTANDING

## Current ArthritisPower statistics as of December 31, 2019:

- Total patients: **25,741**
- Total number of completed patient reported outcomes (PRO) assessments: **356,698**
- Number of unique participants who have completed PRO assessments: **18,840**
- Number of unique participants who have reported at least one medication (includes combination of medications): **7,103**

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](#), 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, PhD, Associate Director of Patient-Centered Research.



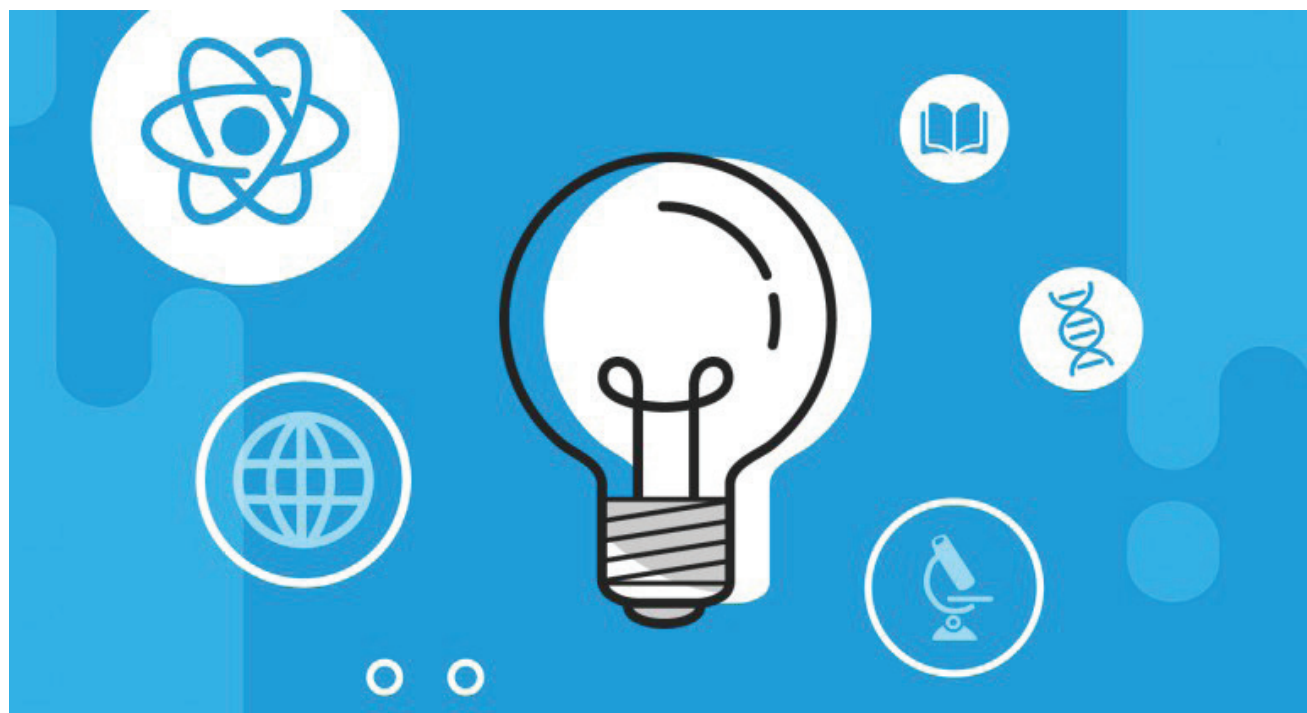
## NEWLY PUBLISHED ARTHRITISPOWER RESEARCH

**Agiro, A., Chen, X., Biruk, E., et al. “Data linkages between patient-powered research networks and health plans: a foundation for collaborative research,” *Journal of the American Medical Informatics Association*, 26(7), 2019, 594–602 doi: 10.1093/jamia/ocz012**

This study demonstrated that data from patient-powered research networks (PPRN) and health plans can be successfully linked using privacy-preserving methodology, and that the linked data can be 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. This descriptive study identified overlapping members from 4 PPRN registries, including ArthritisPower, and 14 health plans.

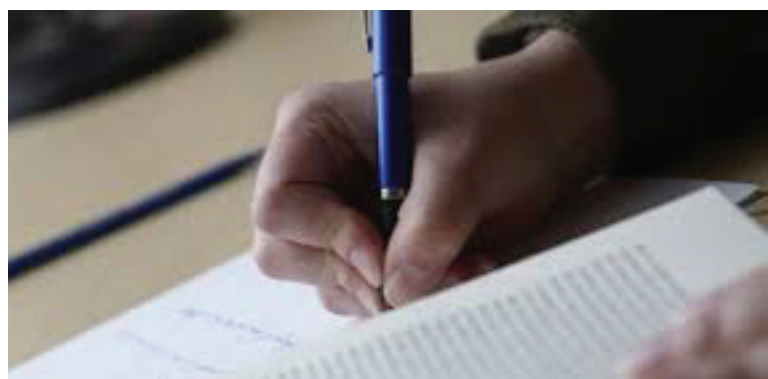
**Leverenz, DL, Eduy, AM, Jayasundara, M., et al. “Contraception methods used by women with rheumatoid arthritis and psoriatic arthritis,” *Clinical Rheumatology* (2019) 38:1207–1212. <https://doi.org/10.1007/s10067-018-04420-1>**

Using survey data taken from clinical surveys as well as a survey administered to CreakyJoints participants, the pooled analysis found that high rates of contraceptive use were reported in both rheumatoid arthritis (RA) and psoriatic arthritis (PsA) populations. The highest rates of effective and highly effective contraception method use in our study were among women on methotrexate, a medication known for increasing risk of birth defects. However, high rates were still seen in women on TNF inhibitors, which are now considered to be relatively safe during pregnancy. This suggests that other factors beyond patients’ knowledge (or lack thereof) regarding medication’s potential for toxicity drive many patients’ decisions to use effective and highly effective methods of contraception.



## OTHER STUDIES IN PROGRESS INCLUDE:

- NEW: Improving Treat-to-Target by Incorporating the Patient Perspective:** This study aims to understand and assess the psychoeducational needs, barriers, and facilitators of ArthritisPower members with rheumatoid arthritis (RA) when they are contemplating a change in treatment regimen. This study will consist of semi-structured interviews with ArthritisPower registry members and CreakyJoints members lasting about one hour to better understand the patient perspective about readiness to make a treatment change (“mental models”). This study is part of a Rheumatology Research Foundation (RRF) award to Liana Fraenkel, MD, MPH of Berkshire Medical Center. The study is open for enrollment.
- 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 experiences of patients, including the journey to getting diagnosed and treated, and managing different treatment options. The study opened for enrollment in October and is sponsored by Eli Lilly and Company.
- Understanding Fibromyalgia: The Patient Experience of Symptoms, Diagnosis, and Treatment:** This cross-sectional study aims to understand the patient perspective of disease burden among patients with fibromyalgia, specifically those with lower back pain. It also aims to identify individuals who show signs and symptoms of axial spondyloarthritis (axSpA), regardless of whether the condition has been diagnosed by a rheumatologist, and to characterize patients’ information needs. The study, sponsored in part by UCB and GHLF research funds, opened 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 possible side effects of methotrexate and how taking methotrexate affects people’s lives and well-being. The study is sponsored by Amgen Inc. 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 by Eli Lilly and Company. 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.



## ■ ENGAGEMENT AWARD ON CHRONIC PAIN MANAGEMENT

Our work continues to support the project, “Encouraging Patients to Manage Chronic Pain Using the Latest Evidence from Research,” funded by the Patient Centered Outcomes Research Institute (PCORI).

This project consists of a dedicated team of patients, patient advocates, researchers, and physicians committed to preparing people with arthritis and chronic pain to become ambassadors in the dissemination and use of science-based information on effective chronic pain management. There is a lot of information available online regarding medication and non-medication approaches for chronic pain management, yet it is not always easy for patients to determine whether the information is science-based. Through this project we will disseminate high-quality, evidence-based research on chronic pain management so that patients can use this information to help themselves and educate others in the management of chronic pain.

In 2020, the project will include a series of 60-minute online sessions about what the latest science tells us about chronic pain.

## ■ ARTHRITISPOWER ENGAGEMENT AWARD UPDATE

Despite having nearly 26,000 consented patients who track their disease while volunteering to participate in longitudinal and observational research, the ArthritisPower® registry lacks an adequately representative population. For example, people living with rheumatoid arthritis (RA) who have joined ArthritisPower are primarily white (88%) women (91%) around age 50; a more representative sample would reflect the fact that the population of RA patients across the country is 68% white, 76% female, and older.

ArthritisPower has begun efforts to ensure that all voices are heard in arthritis research by conducting engagement groups with patients so we can listen and understand how best to meet their needs and interests and, if they choose, engage them in future research.

This fall, the first engagement group was held with participants aged 75 years and older at a retirement community in New York City. About half did not feel represented in current research for their arthritis. The participants shared that they were motivated to participate in research to increase understanding about the disease, but were worried about trusting researchers with their information.

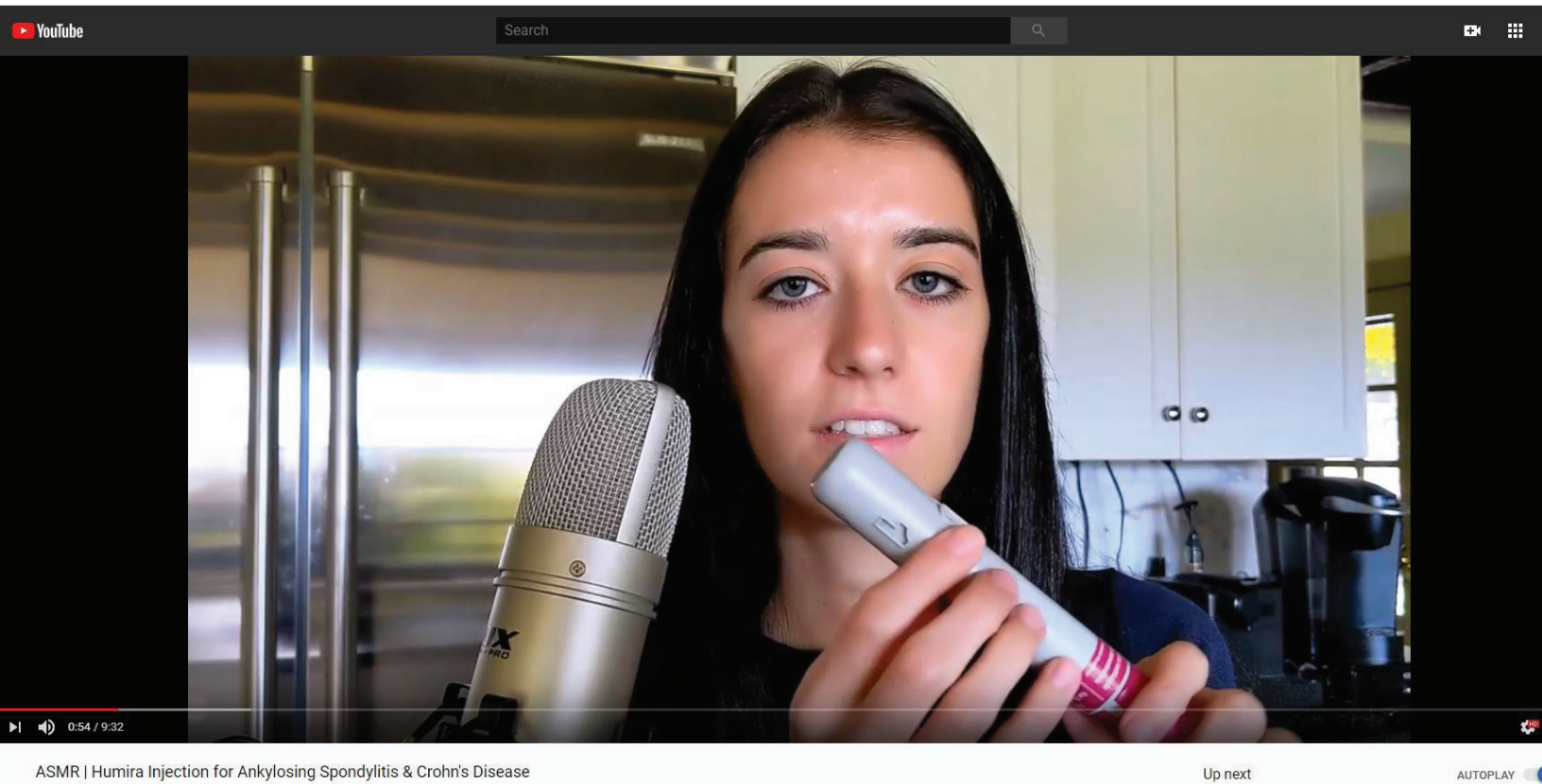


## ■ CREAKYJOINTS ON YOUTUBE

This past quarter, CreakyJoints continued hosting webinars and producing videos that helped people with arthritis and other chronic diseases learn more about how to manage their conditions.

- [The 2 Ps of Arthritis Treatment: Why You Should Care about Precision & Personalized Medicine webinar](#) (Nov. 4, 2019) featured Daniel Hernandez, MD, Medical Advocacy Liaison for the Global Healthy Living Foundation (GHLF) discussing personalized and precision medicine and why it matters to people with chronic disease.
- [ASMR | Humira Injection for Ankylosing Spondylitis & Crohn's Disease](#) (Nov. 5, 2019), In this video, a CreakyJoints member diagnosed with ankylosing spondylitis and Crohn's disease, walked the audience through her usual bi-weekly routine of self-injecting her biologic medication. This video was filmed in the ASMR (autonomous sensory meridian response) style, which means it has a meditative quality with soft voices and hand gestures.

These videos are archived on our CreakyJoints YouTube channel:  
<https://www.youtube.com/user/CreakyJointsInc/videos>



# THE CHRONIC DISEASE COMMUNITY'S VOICE IS BEING HEARD

This quarter, with the majority of state legislatures out of session, our advocacy team was extra active in Washington D.C., helping advocates reach their representatives and commenting on three different federal rules to help people living with chronic disease advocate for patient-protective legislation.



From left to right:  
Patient Advocates JP  
(WI), Mia M. (WI),  
Regan R. (NC) and  
GHLF Manager of Policy  
and Advocacy Corey  
Greenblatt

## ADVOCACY DAY

On November 4, 2019 GHLF held an Advocacy Day on Capitol Hill in Washington, D.C. with patient advocates from the 50-State Network. GHLF patients from across the country met to advocate for step therapy reform and legislation calling for increased transparency for pharmacy benefit managers (PBMs). These patients came from Florida, Massachusetts, North Carolina, and Wisconsin. They represented patients with migraine, rheumatoid arthritis, ankylosing spondylitis, and familial hypercholesterolemia.

Federal step therapy legislation, called the Safe Step Act, would require health insurance providers to implement an exception process for step therapy protocols. The legislation would reach a greater swath of the population than companion state bills as more insurance plans are covered under federal law (ERISA) than under state laws, and it would keep medical decisions between patients and their providers. State

and federal step therapy was the topic of a detailed GHLF white paper, which is currently in peer-review for publication. GHLF patients also advocated for the Lower Health Care Costs Act (specifically Section 306), which addresses the role of PBMs. This legislation would require PBMs to pass-through 100 percent of all drug rebates and increase transparency regarding revenue from drug manufacturers.

GHLF 50-State Network advocates met with 12 Senate and House offices and shared their personal experiences of dealing with step therapy and how it affects their treatment. They explained how changes to federal law would impact their care. These two important pieces of legislation will help deliver patients important therapies to control chronic conditions, shorten the time for patients to get on the right therapy, and keep patients on therapies that are successfully controlling their conditions.





## ■ GHLF REPRESENTS PATIENTS AT INDUSTRY AND GOVERNMENT MEETINGS

GHLF had the opportunity to attend a variety of meetings with health policy stakeholders including legislators, regulators, insurance commissioners, and physicians. Public meetings (attended by invitation) include:

**30-31**  
OCT

Corey Greenblatt, MPH, Manager of Policy and Advocacy, attended the BIO Patient Advocacy Summit in Washington, D.C.

**4**  
NOV

Steven Newmark, JD, MPA, Director of Policy and General Counsel, and Corey Greenblatt attended meetings with legislators in Washington, D.C. along with 50-State Network Advocates to discuss the Safe Step Act and Section 306 of the Lower Health Care Costs Act.

**13**  
NOV

Conner Mertens, Patient Advocate and Community Outreach Manager, and Corey Greenblatt attended the National Day of Advocacy in Washington, D.C. with the Digestive Disease National Coalition (DDNC) to meet with legislators and discuss step therapy.





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

In the fourth quarter GHLF submitted three public comments:

**18**  
NOV

GHLF joined a sign-on letter with 23 other patient groups to support a new tiering proposal for Medicare Part D that would grant immediate access to lower-cost generics and biosimilars upon launch, place generics on the lower-cost sharing tiers, and create a new specialty tier for biosimilars and specialty generics with lower cost-sharing for patients.

**12**  
DEC

GHLF submitted comments to the House of Representatives about provisions in pending legislation relating to biosimilars. We commented on two specific sections of the legislation: (i) the BIOSIM Act, which would increase reimbursement rates to doctors for prescribing biosimilars to patients; we opposed this provision because we feel savings should inure to the benefit of patients first and that doctors should not be financially incentivized to prescribe one therapy over another; and (ii) the Advancing Education on Biosimilars Act of 2019, which would continue to develop education programs on biosimilars and would require the FDA to create a website to educate patients about biologics and biosimilars and interchangeability; we supported this provision because of its focus on increasing education for patients.

**20**  
DEC

GHLF commented on FDA draft guidance regarding the 21st Century Cures Act and specifically on how social media platforms can be better utilized moving forward.

## ■ NEW STRATEGY NEEDED IN NEW YORK STATE

To our disappointment, at the end of 2019 Governor Cuomo of New York vetoed the non-medical switching law that GHLF and many other professional and patient groups supported. In his veto statement, Governor Cuomo suggested the bill would prevent insurance companies from making plan changes mid-year if the bill passed as is, which is false. In 2020, GHLF and partners will determine next steps to protect chronic disease patients in New York State from mid-year formulary changes that reduce access and increase costs.

## ■ PROMOTING OUR PERSPECTIVE

- In November, the [Global Healthy Living Foundation](#) reported that according to a forthcoming report on the impact of state-level, patient-centric step-therapy legislation, too few patients were impacted and too much money was spent trying to stop patients from failing on drugs their doctor did not prescribe. In many states with existing or pending step therapy laws less than half of the population benefits from that legislation. The goal is to publish this data and more in a peer-reviewed journal in 2020 and begin working toward GHLF's seven-step program to strengthen state laws, improve enforcement and education, and support federal legislation.
- In December, the [Global Healthy Living Foundation](#) announced that Louis Tharp, executive director and co-founder, joined the board of trustees of AIDS United. This national organization is devoted to ending

the HIV epidemic in the U.S. through strategic grant-making, policy and advocacy, and capacity building. In the statement Tharp said, "For 20 years, I've dedicated my professional and personal life to raising awareness and improving support for people living with serious and lifelong chronic diseases. It's an honor and privilege to join the board of AIDS United, whose work has meaningfully advanced and improved the availability of community-driven responses to the HIV epidemic." AIDS United has granted over \$120 million to organizations addressing HIV across the U.S. during its history, including \$8 million currently to over 250 grantees in 40 states and territories.

You can read all of our press releases at [www.CreakyJoints.org/press-releases](http://www.CreakyJoints.org/press-releases)



# CREAKYJOINTS PROVIDES EDUCATION TO PEOPLE WITH ALL FORMS OF ARTHRITIS

## CREAKYJOINTS & THE GLOBAL HEALTHY LIVING FOUNDATION IN THE NEWS

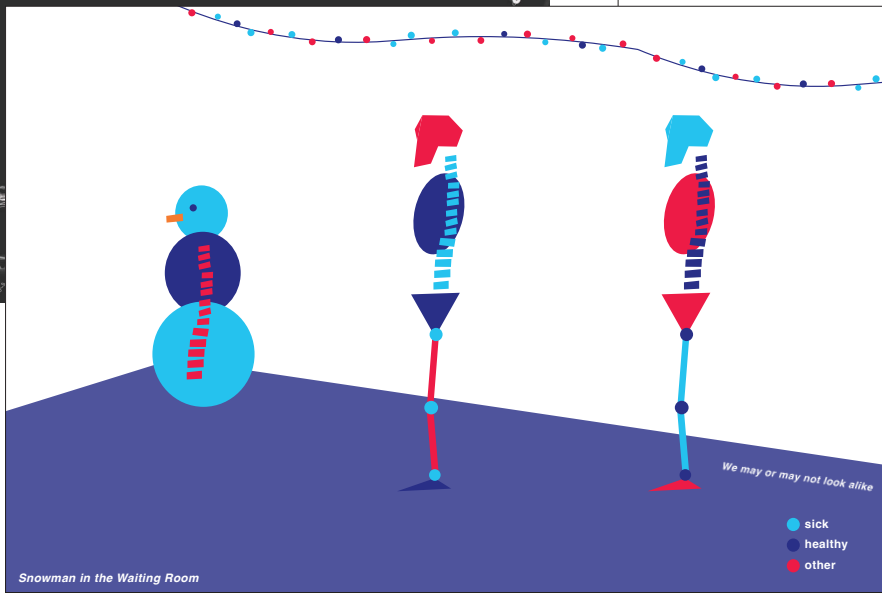
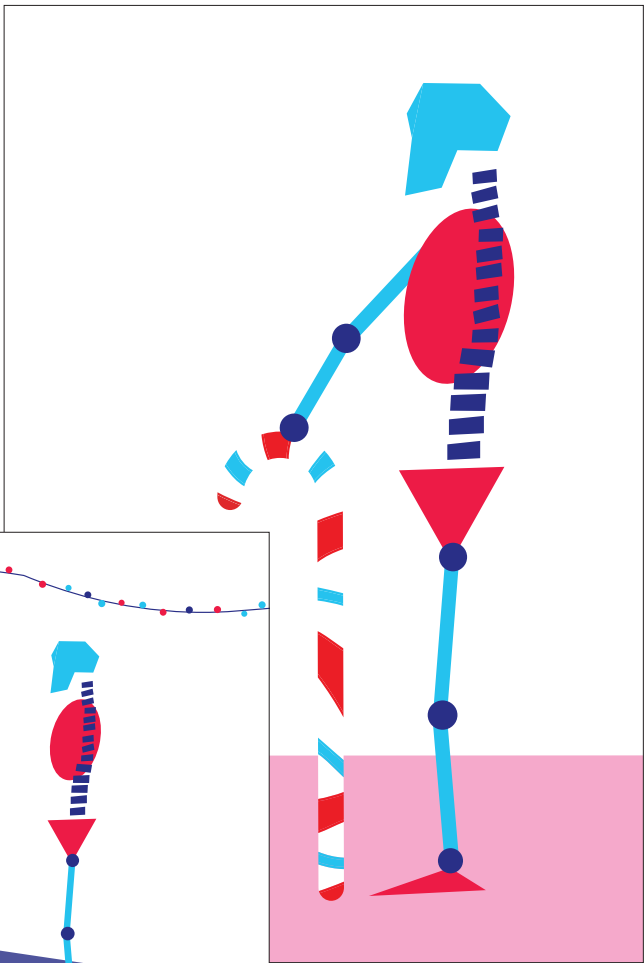
During the fourth quarter, there were 47 earned media placements featuring CreakyJoints members or leadership, generating nearly 65 million media impressions. As reported earlier, a significant amount of coverage stemmed from outreach during the American College of Rheumatology annual meeting. In addition, [Healio.com](#) published a lengthy feature article on pharmaceutical DTC advertising that featured perspective from Louis Tharp, executive director and co-founder. Kelly Boyd, a person with arthritis who rolled down the runway in her wheelchair at the Michael Kuluva fashion show in September was profiled by [Everyday Health](#) and her local paper, [Times of Trenton](#) (NJ). [The Doctor Weighs In](#) published an article by Seth Ginsberg on the impact of marijuana for medical use on the physician-patient relationship.

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In 2019, there were over 200 earned media placements, generating more than half a billion media impressions.

## CUSTOMIZED CREAKYJOINTS GREETING CARDS HELP THE CHRONIC DISEASE COMMUNITY EXPRESS GRATITUDE AND FIGHT LONELINESS DURING THE HOLIDAY SEASON

This holiday season CreakyJoints provided our community a free opportunity to send a physical or digital postcard to a fellow person living with a chronic disease or to a caregiver, friend, family member, health care provider, or other special person in their life who has helped them throughout the year. Four postcards were designed by two CreakyJoints members, New York-based Sal Marx, a multimedia artist with ankylosing spondylitis and Texas-based Jennifer Walker, a patient with rheumatoid arthritis and multiple chronic diseases who creates art to express how she manages life with chronic illness. The campaign reached 80,000 people and postcards were sent to people across 43 states.





## ■ THE CREAKYJOINTS COMMUNITY CONTINUES TO GROW AND EXPAND TO NEW PLATFORMS

From Q3 to Q4 2019, CreakyJoints.org website traffic grew by 11 percent. The referral sources that contributed the most to our Q4 growth was Facebook (18 percent increase) and organic search (7 percent increase). We also experienced an all-time record of visitors to CreakyJoints.org during the month of November 2019, which was supported by our robust coverage of the annual meeting of the American College of Rheumatology.

Historically we have seen remarkable increases in our traffic from organic Google searches, but this quarter we also saw significant gains from Bing, Yahoo, and DuckDuckGo.

This is the result of continuing to regularly produce SEO-optimized, patient-friendly editorial content on topics that our community is actively searching for.

By the end of Q4, the CreakyJoints member community grew by 35 percent. This was a result of encouraging PainSpot visitors to subscribe to CreakyJoints, launching new campaigns to sign up CreakyJoints members, using popular engagement tools on our most visited CreakyJoints articles, and ongoing lead generation efforts with Google Ad Grants.

Popular content published in the fourth quarter includes:

- [What Is Axial Spondyloarthritis? What to Know About This Inflammatory Back Pain](#)
- [The 4 Stages of Gout Progression \(and How to Stop Gout from Getting Worse\)](#)
- [Fibromyalgia vs. Lupus: What's the Difference?](#)
- [14 Things Massage Therapists Wish Arthritis Patients Knew](#)
- [Walking with Arthritis: Benefits, Tips, How to Prevent Pain](#)
- [Cold Weather Joint Pain: 15 Tips for Managing It](#)
- [ACR 2019: 50+ Arthritis Updates That Should Be on Your Radar](#)
- [The Largest Randomized Trial on Methotrexate Revealed a Lot of Info About Its Side Effects](#)
- [What Is Erosive Osteoarthritis? These Are the Signs You Could Have It](#)
- [7 Diseases That Can Mimic Psoriatic Arthritis — and Delay Your Diagnosis](#)

# 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](http://www.CreakyJoints.org), and the [50-State Network](#), which includes more than 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®](#) ([ArthritisPower.org](http://ArthritisPower.org)) with nearly 28,000 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, and hosts [PainSpot](#) ([PainSpot.org](http://PainSpot.org)), a digital risk assessment tool for musculoskeletal conditions and injuries. For more information and to become a member (for free), visit [www.CreakyJoints.org](http://www.CreakyJoints.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. With nearly 28,000 consented arthritis patients, 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](http://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](http://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®](#) ([ArthritisPower.org](http://ArthritisPower.org)), the first-ever patient-centered research registry for joint, bone, and inflammatory skin conditions, and hosts [PainSpot](#) ([PainSpot.org](http://PainSpot.org)), a digital risk assessment tool for musculoskeletal conditions and injuries. Visit [www.GHLF.org](http://www.GHLF.org) for more information.

