



# QUARTERLY REPORT

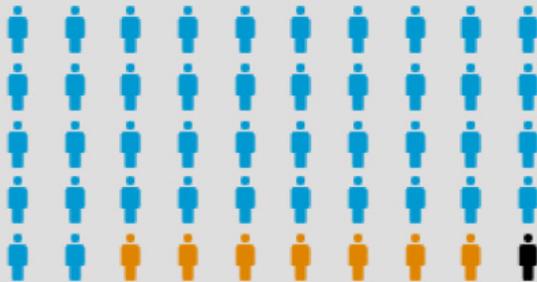
JANUARY – MARCH 2019



GLOBAL  
HEALTHY  
LIVING  
FOUNDATION

## PRESENTING INFORMATION EFFECTIVELY

This picture represents what happens to 50 people after total knee replacement surgery. People who do great are in **BLUE**. People who don't do as well as expected are in **ORANGE**. People who have a serious complication are in **BLACK**.



## THE 'EYES' HAVE IT

This March, the Global Healthy Living Foundation announced the publication of “The Impact of Information Presentation Format on Preference for Total Knee Replacement Surgery,” in *Arthritis Care & Research*, an official journal of the American College of Rheumatology and the Association of Rheumatology Health Professionals. The study, which was led by Liana Fraenkel, MD, MPH, Yale School of Medicine and W. Benjamin Nowell, PhD, Director of Patient-Centered Research at GHLF, found that among patients without an existing strong preference for total knee replacement (TKR) surgery, visual aids to explain procedural risks help patients make a decision about surgery. Of four methods tested, participants who reviewed images or a numerical, graphical spinner had stronger

preferences for TKR (after controlling for baseline preferences) compared to those viewing the risk information in words and numbers only.

“At CreakyJoints, we want patients to understand the decisions that are being made about their care and to play a central role in making those decisions,” says Dr. Nowell, commenting on the importance of the research. “This study confirms that visual decision aids can help patients to understand their risk of a less-than-ideal outcome, thereby allowing them to make more informed decisions about TKR.”

This study was covered in media by [Rheumatology Network](#), [Healio.com/rheumatology](#) and [Orthopedics This Week](#).

# CREAKYJOINTS MEMBER DEFIES GRAVITY

CreakyJoints member Cheryl Ackerman learned how to fly despite having arthritis, but it didn't happen overnight. By 18 years old, she was a professional dancer who traveled around the world as a back-up dancer. But her career was cut short when she experienced a neck injury at age 30 and later went on to be diagnosed with rheumatoid arthritis. It was a massive change of pace to go from being incredibly active to much more still, but Cheryl understood the importance of letting her body heal and seeking treatment for her RA. Yet, she missed the joys of movement.

Almost on a whim, she joined a yoga class and from there gained new perspective. Her body relearned to stretch and move, but she found true joy when she climbed into the hammock style silks for the first time. When she soared and felt the sensation of floating, arthritis was far from her mind because as she hung, her joints and spine loosened and she felt more limber. Today, Cheryl is a certified aerialist and yoga instructor. She shared her inspiring story on the [nationally syndicated TV program Daytime](#), which aired on over 130 stations across the country in early March.



## ARTHRITIS THROUGH ART

On CreakyJoints.org and via our social media channels, we recently began to feature artwork from CreakyJoints member and ArthritisPower Patient Governor Jennifer Walker, in which she illustrates aspects of living with [pain](#), [fatigue](#), [flares](#), and other arthritis symptoms using various artistic media.



# CREAKYJOINTS LAUNCHES NOVEL PEER-TO-PEER SUPPORT

After months of hard work, CreakyJoints launched a new peer education program called [Pep Talk](#). Pep Talk was created to bridge the gap between what a seasoned patient living with rheumatoid 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 will become more informed, engaged, and satisfied with their care and disease management.



To date, there are two Pep Talk trial sites, hosted by David Snow, MD, in Leland, North Carolina and Vinicius Domingues, MD, in Daytona Beach, Florida. Both are highly respected rheumatologists in their communities and avid supporters of the peer-to-peer support model. In the current program design, when a physician signs up their practice for Pep Talk, GHLF provides comprehensive training and certification for their nominated Peer Education Specialists (which lasts four to six weeks). Once training is complete, the doctor can refer newly diagnosed patients, patients facing access issues, and patients seeking general support to receive Pep Talks from a certified Peer Education Specialist within the same practice. As with all other CreakyJoints programs, participating in Pep Talk is entirely free of charge for physician practices and patients.



Due to the success of our pilot program, the GHLF team is now developing a new digital model, which will span nationwide and become available to other disease states. The intent is to begin offering services to all patients who may benefit from peer support. The program is being led internally by Jessica Boles, MSW, LSW, GHLF Patient Advocate, Community Outreach Manager.

# 50-STATE MEMBERS RAISE THE VOLUME OF PATIENT VOICES

This quarter, our advocacy team has been active in more than 23 states and commented on 16 federal laws to help members of the Global Healthy Living Foundation’s 50-State Network advocate for patient-protective legislation related to step therapy, non-medical switching, and copay accumulator programs. (These are protocols implemented across therapeutic areas by insurance companies to reduce costs.) In addition, during the last three months, our Patient Advocates, Community Outreach Managers Jessica Boles, MSW, LSW, and Regis Wagner, MSW, have spoken with more than 300 patients regarding their interest in participating in 50-State Network activities, legislative or community events, or other engagement opportunities.



In Kansas, Jonathon Aumann, a volunteer patient activist with the Global Healthy Living Foundation’s 50-State Network, contributed an opinion piece to the [Topeka Capitol Journal](#) describing his experience as a person with RA trying to navigate step therapy. In the piece, he invited “everyone in Kansas to join me in supporting HB 2120, which implements common sense, patient-focused reforms to ‘step therapy’ and ensures that patients and their physicians will have much greater say in the treatment plan.”

In February, Daniel Hernandez, MD, GHLF’s Medical Advocacy Liaison traveled to Puerto Rico to speak with local rheumatologists about the needs of their local arthritis community. While there, Dr. Hernandez gave interviews to raise awareness of arthritis and available patient resources to the radio program, [Fundacion Puertorriquena de Efermedades Reumaticas](#) and also appeared on [WAPA-TV](#). CreakyJoints will continue to expand the availability of Spanish-language educational and support resources in 2019.

## ■ 50-STATE NETWORK CONTINUES TO HELP PEOPLE WITH MIGRAINE DISEASE

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



## ■ CSRO HOLDS FELLOWS CONFERENCE WITH RECORD ATTENDANCE

On February 9, the Coalition of State Rheumatology Organizations (CSRO) held its annual Fellows Conference in San Francisco to offer enlightening perspectives and valuable insight on how to navigate the next phase of their professional careers. The day-long conference started with a talk on the state of rheumatology by Paul H. Caldron, MD, of Phoenix, Arizona and ended with an informative session on “What Arthritis Patients Want the Next Generation of Rheumatologists to Know,” by Seth Ginsberg, President and Co-founder of the Global Healthy Living Foundation and its arthritis community CreakyJoints. Seth’s speech was informed by CreakyJoints members who contributed to an article published on CreakyJoints.org titled, [“20 Things Patients Wish Rheumatologists Knew.”](#)

## ■ 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 are listed below.

<p>January 16th</p>	<p>Daniel Hernandez, MD, Medical Advocacy Liaison, traveled with patient advocate Judy M. to testify before the FDA on the importance of osteoporosis drug development and gave insight to the patient experience.</p>
<p>February 4th</p>	<p>Corey Greenblatt, MPH, Manager of Policy and Advocacy, met with state legislators in Topeka, Kansas along with other members of the Kansas Fair Treatment Coalition to discuss necessary step therapy reform legislation.</p>
<p>February 7th</p>	<p>Louis Tharp, GHLF Executive Director, met with staff members of Indiana state legislators to discuss a recent survey by GHLF and CSRO about the impact of non-medical switching on patients and potential legislation to protect against it.</p>
<p>February 7th</p>	<p>Steven Newmark, JD, MPA, GHLF General Counsel and Policy Director, attended a Crohn's &amp; Colitis Foundation annual gathering to learn about advances in policy specific to the IBD community.</p>
<p>March 3rd</p>	<p>Corey and Steven attended the Spring Policy Forum of the Digestive Disease National Coalition. Steven and Corey then led a group of patient advocates on visits with legislators on Capitol Hill.</p>
<p>March 4th</p>	<p>Corey and Steven attended the Digestive Disease National Coalition Hill Day and met with staffers for senators and congresspeople who represent New York and Kentucky.</p>

March  
5th

Regis Wagner, MSW, Patient Advocate, Community Outreach Manager, traveled to Albany, New York to attend a roundtable discussion to discuss the Institute for Clinical and Economic Review (ICER) and the negative impact that their evaluations can have on patients, including access to beneficial medications and treatments.

March  
6th

Corey met with state legislators in Madison, Wisconsin along with the Wisconsin Step Therapy Coalition to discuss necessary step therapy reform legislation.

March  
11th

Corey attended the Atlanta Advocacy Day for the Rx in Reach Georgia Coalition at the Georgia State Capitol in Atlanta to support step therapy reform.

March  
21st

Daniel conducted a patient education webinar called "How DMARDs for Arthritis Actually Work in Your Body," which focused on the mechanisms of action of disease modifying anti-rheumatic drugs.

March  
22-23

Steven gave the keynote lunch speech at the Digestive Disease National Coalition Spring Conference and highlighted the development of GHLF and CreakyJoints as the premier patient organization for people living with chronic conditions.

March  
30th

Corey attended the first annual Non-Profit Advocacy Summit hosted by the National Organization of Rheumatology Managers (NORM) in Washington, D.C.

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

GHLE continues to speak on behalf of patients to various state and government legislative bodies and agencies. In the first quarter, GHLE submitted or signed on to 25 public comments – one for nearly every two working days.

FEDERAL AGENCY PUBLIC COMMENTS

- 11**  
JAN

Food & Drug Administration Public Comment to the Arthritis Advisory Committee – Patient Perspectives on Febuxostat, re: support of Febuxostat and the importance of patient education
- 16**  
JAN

Food & Drug Administration Public Comment to the Bone, Reproductive, and Urologic Drugs Advisory Committee, re: support of Romosozumab for patients with osteoarthritis
- 17**  
JAN

Health and Human Services Healthy People 2030 Comments, re: support of HHS’ focus on research and patient access goals for patients with arthritis
- 18**  
JAN

Health and Human Services Market Exchange Program Integrity Comments, re: opposition to the proposal along with 17 other patient groups as part of the Burrito Coalition
- 25**  
JAN

Centers for Medicare & Medicaid Services Proposed Change to Medicare Advantage Program and Prescription Drug Benefit Program regulations, re: opposition of the agency proposal to allow Medicare Advantage plans to use step therapy protocols
- 5**  
FEB

U.S. Food & Drug Administration Comments on their Real-World Evidence framework, re: support of FDA’s effort to recognize the importance of real-world evidence
- 19**  
FEB

Health and Human Services Comments on the Notice of Benefit and Payment Parameters 2020 (submitted two comments; one sign-on with the Burrito Coalition and another sign-on with the I Am Essential coalition), re: opposition to the proposal to ban copay assistance if a generic exists among other patient rulings
- 28**  
FEB

United States Senate Committee on Health, Education, Labor and Pensions comments to inform Committee’s Efforts to Reduce Healthcare Costs, re: ways in which the committee may address raising health care costs for patients
- 18**  
MAR

U.S. Food & Drug Administration workshop on Incorporating Patient Perspective in Clinical Trials; attended an FDA workshop to provide comment on the need to better involve patient perspectives in clinical trials
- 27**  
MAR

Departments of Treasury, Labor, and Health and Human Services Request for Information regarding Grandfathered Group Health Plans and Grandfathered Group Health Insurance Coverage, re: opposition to expanding the provisions regulating grandfathered health plans. Signed as part of the Burrito Coalition

In the first quarter, GHLF also worked on behalf of patients 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.

**COMMENTED IN OPPOSITION OF CHANGES TO STATE MEDICAID PROGRAMS**

- Virginia 115 MEDICAID WAIVER
- Oklahoma 115 MEDICAID WAIVER
- South Carolina 115 MEDICAID WAIVER
- Wyoming MEDICAID WORK

**COMMENTED IN FAVOR OF STEP THERAPY REFORM**

- WISCONSIN ASSEMBLY BILL 24 / SENATE BILL 26
- KANSAS SENATE BILL 93
- VIRGINIA HOUSE BILL 2126
- WASHINGTON

**COMMENTED IN FAVOR OF BANNING MID-YEAR FORMULARY CHANGES**

- INDIANA SENATE BILL 585
- NEW YORK

**COMMENTED IN FAVOR OF BANNING COPAY ACCUMULATOR ADJUSTOR PROGRAMS**

- VIRGINIA HOUSE BILL 2515
- ARIZONA HOUSE BILL 2166
- ILLINOIS SENATE BILL

# ARTHRITISPOWER® & PATIENT-CENTERED RESEARCH

“

45

The number of ArthritisPower studies published in peer-reviewed journals or presented at major medical meetings since ArthritisPower launched in 2015

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

- Total patients: **18,028**
- Total number of completed patient reported outcomes (PRO) assessments: **199,333**
- Number of unique participants who have completed PRO assessments: **13,424**
- Number of unique participants who have reported at least one medication (includes combination of medications): **5,049**

# ARTHRITISPOWER OFFERS UNIQUE ENGAGEMENT OPPORTUNITIES

ArthritisPower offers researchers access to a unique, dynamic, and robust patient community. There are many opportunities for users 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 qualify for one of the studies below but were not invited, please reach out to Shilpa Venkatachalam, PhD, Associate Director of Patient-Centered Research ([svenky@ghlf.org](mailto:svenky@ghlf.org)). Below are summaries of ongoing studies:

## SMARTWATCH SYNCHRONIZED TO YOUR HEALTH

The DIGital Tracking of Arthritis Longitudinally (DIGITAL) study, known to participants as the ArthritisPower Smartwatch Study, is a unique opportunity for 250 ArthritisPower users with RA to track their experience of arthritis in both the ArthritisPower app as well as via a smartwatch that they receive and are asked to wear 24 hours a day for a minimum of 12 weeks. In addition to wearing a smartwatch to track activity, heart rate, and sleep quality, study participants answer brief daily questions on pain and fatigue in the ArthritisPower app as well as longer questionnaires weekly about their experience of RA symptoms. Researchers are exploring the feasibility of remote patient-reported outcomes (PRO) data reporting and biosensor data collection and the association between these two types of patient-generated data. This study, sponsored by Eli Lilly and Company, is still open for enrollment.



**Thank you for being part of the ArthritisPower Smartwatch Study**

# START HERE

This "Start Here" card will guide you through downloading the Fitbit app, setting up your new Fitbit Versa™ smartwatch, and linking smartwatch data to ArthritisPower.

Stuck? Call us at 1-800-601-9857 or send us an email at [SmartwatchStudy@ArthritisPower.org](mailto:SmartwatchStudy@ArthritisPower.org)

<b>Step 1:</b>	<p><b>Prepare for set-up</b></p> <ul style="list-style-type: none"> <li>• Unbox all materials</li> <li>• Charge your new smartwatch to at least 50% before starting</li> <li>• Allow at least 45 minutes to complete the entire set-up</li> <li>• (Optional) Have the Reference Guide available for extra assistance</li> </ul>
<b>Step 2:</b>	<p><b>Open the ArthritisPower app on your smartphone</b></p> <ul style="list-style-type: none"> <li>• You will be prompted to confirm you have received this shipment box</li> <li>• You will then be automatically re-directed to download the Fitbit app onto your smartphone. You may need your personal login for Apple Store or Google Play.</li> <li>• If you already have a Fitbit account and the Fitbit app on your smartphone:               <ul style="list-style-type: none"> <li>▶ Open the Fitbit app</li> <li>▶ Log out of your previous or existing Fitbit account (very important)</li> <li>▶ Continue to Step 3 to log in with your new Fitbit account for this study</li> </ul> </li> </ul>
<b>Step 3:</b>	<p><b>Use the following to log in to your Fitbit account</b></p> <ul style="list-style-type: none"> <li>• Username/Email: _____</li> <li>• Password: _____</li> </ul>
<b>Step 4:</b>	<p><b>Follow instructions in the Fitbit app</b> to set up your smartwatch (this will take most of the 45 minutes) Please turn over card to continue...</p> 

## ■ PERSPECTIVES ON MEDICAL MARIJUANA AND CBD

This cross-sectional study, developed in part by the ArthritisPower Patient Governor Group and sponsored by GHLF, aims to understand the perspectives and behaviors of patients with rheumatic and musculoskeletal disease regarding marijuana and/or cannabidiol (CBD) use for medical reasons. Patients with various conditions were eligible to take the survey in the ArthritisPower app. Preliminary results will be shared this June at the Annual European Congress of Rheumatology in Madrid (EULAR 2019). This study is closed.



## ■ WHAT SYMPTOMS MATTER TO YOU?

In this study, we seek to understand the relative importance of disease symptoms across a number of conditions: rheumatoid arthritis (RA), osteoarthritis (OA), psoriatic arthritis (PsA), osteoporosis (OP), ankylosing spondylitis (AS), and fibromyalgia. Participants must select which PRO measures they would like to track in ArthritisPower to monitor their symptoms and then complete their selected PRO measures at least once per month for three months. This study is sponsored by Eli Lilly and Company from their Health Economics and Outcomes Research division. This study is closed.

## ■ THE TREATMENT EFFECTIVENESS STUDY

The purpose of this study, referred to by investigators as CHOICE (Comparative Health Outcomes in Immune-mediated disease Collaborative), is to 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. Data are being collected and analyzed with patients in ArthritisPower as well as other patient-powered research networks for other conditions such as inflammatory bowel disease (IBD), vasculitis, and pediatric arthritis. The goal is to understand the relative effectiveness of medications across the health domains that matter to patients. The Patient-Centered Outcomes Research Institute (PCORI) provided funds to support this research through an award to the University of Alabama at Birmingham (UAB). The project is being led by UAB's Jeff Curtis, MD, MS, MPH and ArthritisPower co-principal investigator. This study is open.

## ■ SHARED DECISION MAKING IN LUPUS STUDY

Shanthini Kasturi, MD, Tufts School of Medicine, is leading a project on shared decision making in systemic lupus erythematosus (SLE) using the NIH Patient-Reported Outcomes Measurement Information System (PROMIS). Lupus patients are being enrolled at two academic medicine sites, Tufts and the Hospital for Special Surgery (HSS), to track patient-reported outcomes measures in ArthritisPower during the weeks prior to rheumatology clinic visits. The rheumatologist will review and discuss these results with the patient during the visit and their implications for treatment. The researchers are then measuring the impact of a shared decision making approach on patient self-efficacy, adherence to medications, and quality of life. This study is funded by an NIH K Award to Dr. Kasturi. This study is open only to participants identified by Tufts and HSS.

## ■ DIVE DEEP INTO ARTHRITIS

Our series of educational webinars continued in the first quarter. Recorded versions of each webinar are available at [CreakyJoints.org](http://CreakyJoints.org) and on our YouTube channel. Topics

- [Think You Know Your Arthritis Drugs: A Fascinating Look at How they Actually Work](#), presented by Daniel Hernandez, MD, Medical Advocacy Liaison for the Global Healthy Living Foundation. Dr. Hernandez graduated medical school from the Universidad Autonoma de Guadalajara and is now based in New York City, where he leads medical education and Hispanic outreach across all disease states for GHLF.
- [Diet as Therapy for Inflammatory and Autoimmune Disease: Lessons from the Study of Irritable Bowel Syndrome](#), presented by James Lewis, MD, MSCE, Professor of Medicine and Epidemiology at the Perelman School of Medicine at the University of Pennsylvania.

# CREAKYJOINTS GROWS ITS AUDIENCE BY BEING CREATIVE AND NIMBLE

## CREAKYJOINTS AND GLOBAL HEALTHY LIVING FOUNDATION IN THE NEWS

During the first quarter, there were 159 earned media placements featuring CreakyJoints members or leadership, generating more than 149 million media impressions. Notably, a syndicated [DAYTIME TV](#) segment, featuring CreakyJoints member Cheryl Ackerman, aired on 135 stations across the country, but the reach of these is largely unavailable. In addition, [U.S. News & World Report](#) featured an interview with Seth Ginsberg in their article titled, “15 Things Not to Say to People with Chronic Pain.” [Everyday Health](#) included expert advice from CreakyJoints medical advisor Vinicius Domingues, MD, in an article about menopause and RA, and [News-Medical](#) published a byline written by Ben Nowell, PhD, and CreakyJoints member Dawn Gibson on the experience of painsomnia, stemming from our media outreach during the 2018 American College of Rheumatology meeting. CreakyJoints member and fashion designer Michael Kuluva was featured in a two-page spread in the print magazine *Pain-Free Living* (below).



# Arthritis Is On Trend

When my first collection walked the runway, I was secretly coping with chronic pain. But now, my hiding days are over.

By Michael Kuluva

I spent 20 years balanced on ice skates, first competing and then performing professionally with Disney On Ice. After accomplishing so much in my career, I set my sights on a new challenge and enrolled at the Fashion Institute of Design and Marketing in Los Angeles with the dream of becoming a fashion designer. Hard work, supportive teachers and family, and a bit of luck helped me to translate a school project into an actual brand called Tumbler and Tipsy. My first collection walked the runway in 2012 and featured a young but promising new model—Kendall Jenner. It was all so exciting, glamorous and magical! From the outside, it seemed like all my aspirations were becoming reality, but I was hiding and secretly coping with pain and fatigue following a diagnosis of rheumatoid arthritis (RA).

When I first developed symptoms, I kept my situation private. During my first fashion week show, I kept it secret that my manager was helping me inject my medication. I was afraid of being stigmatized, losing sponsors or being taken less seriously as an artist. I didn't want to be the “fashion designer with arthritis.” I just wanted to be Michael Kuluva, the artist. But as time went on, I got over it. As I learned more about my disease, I realized millions of young people like me have arthritis. I decided I couldn't and shouldn't hide a major part of my life. As my brand and team grew, I asked



for more help. If I couldn't cut a pattern that day, someone else could. In the meantime, I could sort through fabric and find inspiration for my next design. Teamwork makes the dream work, right?

## ■ FINDING COMMUNITY 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:

- January: United Together in 2019, featuring special guests are [@mollyschreiber](#), [@roxannewatson74](#) and [@migrainediva](#)
- February: Loving Yourself While Living with Chronic Disease: A Discussion on Self Care, Emotional Well-being, and Defining Ourselves, which proved so popular that the hashtag #CreakyChats was “trending” on Twitter for much of the chat
- March: Chronic Disease Through the Years: Progress and Promise, featuring Paul Sufka, MD, [@psufka](#)

## ■ WHAT THE CREAKYJOINTS COMMUNITY IS READING

During the first quarter, our editorial department developed more than 120 articles that provide education and support across various arthritis and rheumatic conditions. Of note, our audience has grown eight-fold in the past year, due to an emphasis on optimizing our content for search engines and using analytics to understand our community’s needs, wants, and knowledge gaps. We’ve launched engaging new franchises that are resonating with our patient community, including:

## WHAT EXPERTS WISH PATIENTS KNEW:

Patients in the CreakyJoints community rely on health advice and treatment from many different kinds of care providers. In this series, we focus on tips and insights from different specialists, such as [nurses](#), [mental health experts](#), [occupational therapists](#), [physical therapists](#), and more.

## UNDERSTANDING COMORBIDITIES:

Our patients are craving information about how arthritis and chronic disease affects them systemically and how to better manage their conditions to reduce the risk of comorbid health problems. To that end, we regularly cover news and education about these topics, including [Raynaud’s disease](#), [costochondritis](#), [heart disease risk](#), [gastrointestinal issues](#), and more.

## ■ COMING SOON: MY BACK IS KILLING ME

CreakyJoints spent the first quarter producing content related to a forthcoming educational campaign focused on raising awareness of ankylosing spondylitis. Anchored by a five-part police-procedural style web series series titled *My Back is Killing Me*, the campaign is targeting young adults who may not realize that their back pain could actually be a form of inflammatory arthritis in need of treatment from a rheumatologist. *My Back is Killing Me*, along with other videos in the awareness campaign, features several CreakyJoints members sharing their stories. It will launch this May.

# THINKING OUTSIDE THE BOX WITH FRESH TECHNOLOGY AND PARTNERSHIPS

## ■ PAINSPOT AND CREAKYJOINTS: ONGOING INTEGRATION AND MAJOR ENHANCEMENTS UNDERWAY

At the end of 2018, CreakyJoints acquired PainSpot, a digital risk assessment tool for helping patients understand possible causes of their musculoskeletal pain. Integration between the tool and the CreakyJoints community continues. Although not formally introduced, CreakyJoints now provides educational material to people who use the PainSpot tool and PainSpot users are encouraged to become members of CreakyJoints for ongoing support and information. We've retained a world-class user experience and site design firm to manage a PainSpot redesign that will enhance the existing functionality with increased engagement, calls to action, and search engine optimization. The redesign of PainSpot, which will include new educational products for different arthritis conditions, will launch later this year.

## ■ WALGREENS: LISTENING, LEARNING, AND DEEPENING PATIENT ENGAGEMENT

With a shared goal of enhancing patient education and removing barriers to accessing treatment, the partnership between the Global Healthy Living Foundation and Walgreens continues to deepen as we plan new patient-centered initiatives. The relationship includes Walgreens' AllianceRx Walgreens Prime specialty and home delivery pharmacy formed in 2017 by Walgreens and Prime Therapeutics. Earlier this year, GHLF had the opportunity to tour a Walgreens facility in Puerto Rico to learn about unmet patient needs. GHLF is advising Walgreens and AllianceRx Walgreens Prime on multi-channel patient communication and developing different opportunities to integrate their inflammatory disease patients into the CreakyJoints support community.

# 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 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](http://www.CreakyJoints.org). To participate in our patient-centered research program, visit [www.ArthritisPower.org](http://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](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) 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](http://www.ghlf.org) for more information.

