

OCTOBER-DECEMBER 2017

# QUARTERLY REPORT



## ADVOCACY – PATIENT VOICES CONTINUE TO BE AMPLIFIED

Efforts to engage with our members and coalition partners to influence state and federal health policy to benefit the chronic disease community advanced at a steady pace.

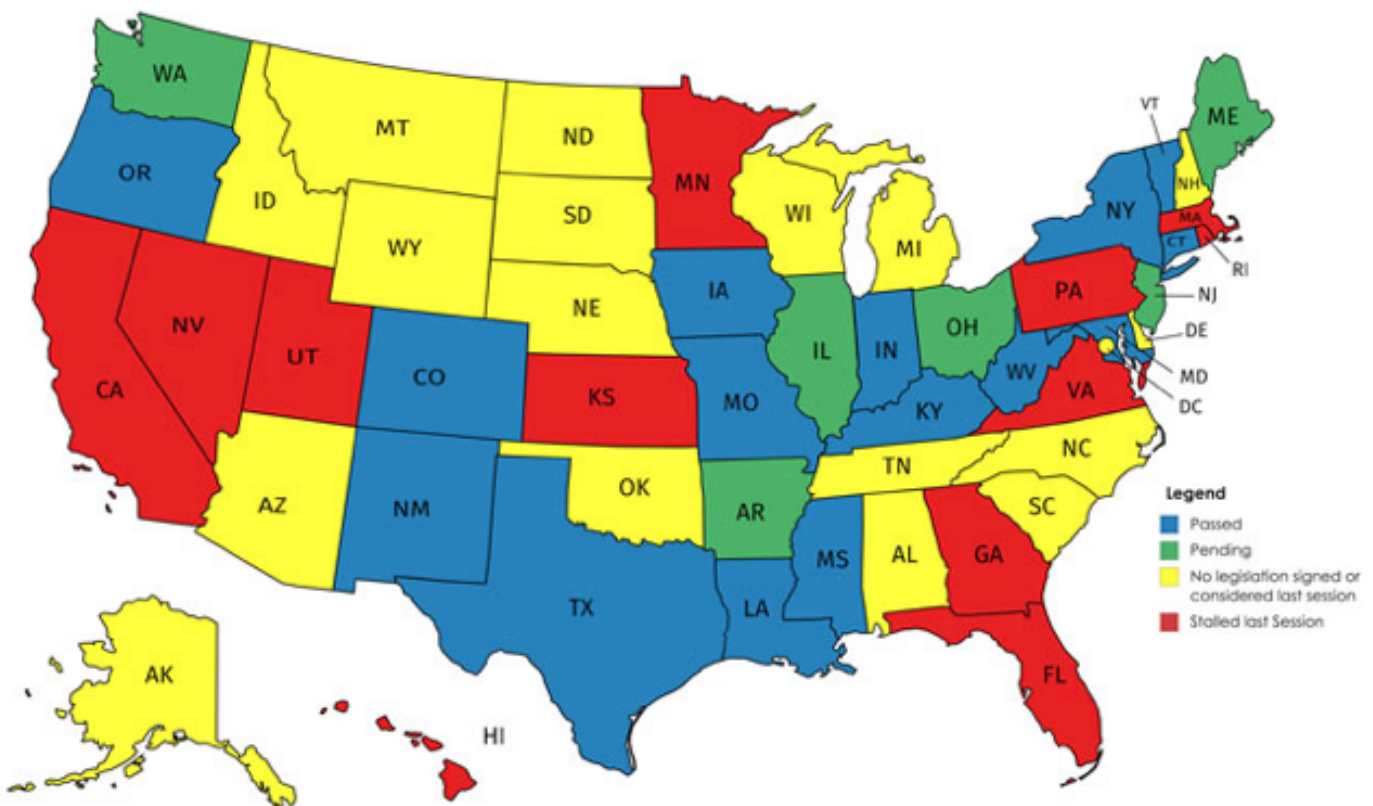
GHLF continued to partner with the Doctor Patient Rights Project (DPRP), which is a coalition of patient and provider organizations of which GHLF is a founding member. In late summer, DPRP announced survey results finding that almost two out of every three patients denied coverage were denied multiple times and most had to wait more than a month before their insurance provider responded to their request for a prescribed treatment. In an effort to raise awareness of how insurance companies interfere with the patient-physician relationship, GHLF president and co-founder, Seth Ginsberg, contributed opinion pieces to local newspapers across the country, such as **Duluth News Tribune** (MN), [The State Journal](#) (Frankfort, KY), [Connecticut Post](#) and several others.



This fall, GHLF had the opportunity to participate in a variety of meetings with health policy stakeholders including legislators, regulators, insurance commissioners, and physicians.

- October 1: Attended the North Carolina Chapter meeting of the American College of Cardiology in Asheville, NC.
- October 2-3: Participated in the BIO Patient and Health Advocacy Summit in Washington, D.C.
- October 4: Participated in the inaugural Biosimilars Forum workshop in Washington, D.C. where leading patient advocacy organizations, manufacturers, pharmacy benefit managers, and FDA engaged on pressing policy questions.
- October 11: Attended the Lupus Foundation of America gala in New York City as guests and in support of the Lupus and Allied Diseases Association.
- October 13: Coordinated the participation of a 50-State Network physician advocate in the Association of Black Cardiologists: Spirit of the Heart Community Education & Health Fair in Jackson, MS
- October 31: Teamed with the Partnership to Improve Patient Care and went to Capitol Hill for an advocacy day to promote the sustained support of the Patient Centered Outcomes Research Institute to members of Congress.
- November 3-8: Attended the American College of Rheumatology conference in San Diego, CA
- November 11-13: Attended the American Heart Association conference in Anaheim, CA
- November 20: Submitted comments to CMS CMMI offering proposals for improving in 2018 and avoiding damaging initiatives like the Part B demo project which would have reduced access for individuals relying on infusions.
- November 20: Hosted a call with executives from Florida Blue insurance company to discuss restricted access issues for patients in the state and modifications to the prior authorization process.
- December 8-9: Presented at the inaugural CreakyJoints Australia Patient Council meeting about recruitment, education, and mobilization of advocacy communities.
- December 14: Coordinated the attendance and participation of a 50-State Network Advocate's involvement in a Massachusetts Senate Financial Services committee hearing considering step therapy reform.
- December 22: Coordinated the submission of 50-State Network Advocate comments on an Institute for Clinical and Economic Review (ICER) draft scoping document on Migraine in America.

In an analysis of step therapy regulations, GHLF reviewed every state bill currently related to step therapy and scored them on a scale of 1-10 on how strongly they protected patients. We then invited members to see if their state has passed or has pending legislation relating to step therapy protocols at <https://failfirsthurts.org/ffh/regulations/analysis-of-current-regulations/>. One result of this analysis was that 50-State Network advocate Jaime communicated her experience with step therapy on her blog, [The Migraine Diva](#).



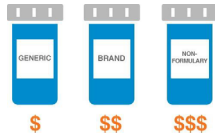
The 50-State Network continues to project patient voices and recruit diverse members to our cause, recruiting 34 new members in the fourth quarter. In total, there are 803 advocates across the United States.



## Insurers Hurting Massachusetts by Non-Medically Switching



Nearly all respondents (94%) support legislation that would prohibit insurance companies from financially pressuring them to switch their prescribed medication for non-medical reasons



Reduction in coverage was so dramatic that the primary therapy used to control their disease became suddenly and significantly more expensive



Two out of every three respondents (68%) were unable to afford the increase in out-of-pocket costs and were forced to switch to an entirely different medication



As a direct consequence of delayed access to their medication: 33% reported having to miss work, 46% reported seeing their healthcare provider or going to the ER



Nearly two-thirds of respondents reported that their insurance company made changes to their health plan's formulary that reduced coverage of the prescribed medication



Working with the Massachusetts Patient Access and Safety Coalition, a coalition of 19 patient and provider organizations, GHLF fielded and shared results from a survey demonstrating that a majority of those in Massachusetts living with chronic health conditions have experienced “non-medical switching”—insurance coverage reductions which pressure patients to switch their prescription medications. Reductions in coverage include increased out-of-pocket costs, eliminating a drug from the those offered or other restrictions around access. In Massachusetts, the survey found

that nearly two-thirds (64%) of residents with chronic illness had to switch to a different medication than was prescribed due to a change in coverage. Further, nearly three out of four patients (73%) experienced changes in coverage that caused their primary therapy to become suddenly and significantly more expensive. The majority of respondents (66%) reported now paying more out-of-pocket for their prescribed medication, with 53 percent reporting they paid a lot more. In 2018, this data will be used to educate legislators about this insurance company practice.



CreakyJoints patient-members and staff served as “[special reporters](#)” on site at the ACR meeting. On set at the San Diego Convention Center, our reporters interviewed researchers about study findings and what they mean for people living with arthritis. Ten live streaming interviews were shared on social media, posted to our [YouTube channel](#), and viewed 820 times. We shared a steady stream of headlines, pictures and insights during the meeting from our Twitter and Facebook pages, which generated 1 million impressions/views on social media (Facebook/Twitter) and 4,500 page views of CreakyJoints ACR produced content.

#### ACR Posters:

- [Answering Reproductive Health Questions That Your Patients Want to Know: Impediments to Family Building and Risks of Contraception \(Abstract #1308\)](#)
- [Tough Choices: Understanding the medication decision-making process for women with inflammatory arthritis during pregnancy and lactation \(Abstract #1298\)](#)
- [Methotrexate Use and Fatigue in Rheumatoid Arthritis Patients: Results from a National Patient Registry \(Abstract #446\)](#)
- [Patients’ Experiences and Attitudes about Non-Medical Switching of Biologics: Results from an Online Patient Survey \(Abstract #362\)](#)
- [Linguistic Differences in Gout-Related Online Content: A Comparison of Professional Health Literature for Consumers Vs Patients’ Online Discussions of Gout \(Abstract #2250\)](#)

#### ACR Oral Presentations:

- [A Trial Testing Strategies to Enhance Patient Understanding of Drug Information: Experience Recruiting Subjects through an Online Patient Community \(Abstract #1860\)](#)
- [Assessing RA Disease Activity with PROMIS Measures Using Smartphone Technology \(Abstract #2781\)](#)
- [Preference Phenotypes Can be Used to Support Shared Decision Making at the Point-of-Care \(Abstract #2780\)](#)

## ARTHRITISPOWER GROWS AND PATIENT-CENTERED RESEARCH USES DATA TO MAKE HEALTHCARE BETTER

### 2017 American College of Rheumatology Is the Platform for CreakyJoints' Research Findings and the Site of Live Broadcasts

During the fourth quarter, CreakyJoints presented five posters and three oral presentations at the 2017 American College of Rheumatology Annual Meeting. Generating particular attention was ArthritisPower data co-presented by CreakyJoints and Duke University that found that 59 percent of women with inflammatory arthritis surveyed (n=250) had fewer children than they desired while only a third had the full number they wanted. The most common fears limiting family size for women with inflammatory arthritis were being unable to care for a child (85%), the possibility of arthritis medications potentially harming a child (61%), and the possibility of a child developing arthritis (52%). Concerningly, 28 percent of women taking methotrexate, which carries risk for miscarriage and birth defects, were using ineffective contraception. In addition to being covered by trade publications, such as **Rheumatology Advisor** and [PatientDaily](#), the study was extensively covered by the consumer-facing [Everyday Health](#), which ran three articles featuring interviews with either W. Benjamin Nowell, PhD, Director of Patient-Centered Research at CreakyJoints or Megan E.B. Clowse, MD, MPH, a rheumatologist at Duke School of Medicine who led the research team. The study was also covered by Healthline and RadioMD. See the next page for more information about each poster and presentation.

**Rheumatology Advisor**



## **ArthritisPower Statistics – Unique In the Arthritis Community, Continues Steady Growth**

Through an integrated digital marketing, social media, and public relations campaign, we continue to invite people with all forms of arthritis to become active ArthritisPower users. Once enrolled in the research network, participants are urged to complete assessments, enter past and current medications, and participate in research studies.

Current ArthritisPower statistics as of December 31, 2017:

- Total members: 12,013
- Total patients: 11,717
- Total number of completed patient reported outcomes (PRO) assessments: 100,119
- Number of unique participants who have completed PRO assessments: 8,580
- Number of unique participants who have reported at least one condition (Includes variations of co-morbidities): 11,624
- Number of unique participants who have reported at least one medication (includes combination of medications): 2,943

## **ArthritisPower Patient Governors Meet To Direct 2018 Growth**

In October, ArthritisPower Patient Governors and staff met in Indianapolis to review ongoing studies, review researchers' proposals soliciting access to the ArthritisPower research registry, and discuss outreach initiatives and plans for future studies. During the meeting, the 10 Patient Governors for the 2017-2018 term also participated in interactive learning sessions with researchers and clinicians to gain insight into current evidence about treat-to-target in rheumatoid arthritis, glucocorticoids, the microbiome and autoimmunity, and pain management.

## **ArthritisPower Research Continues With 11 Studies**

ArthritisPower research continues. Studies in progress include:

- Research Networks and Payer Stakeholders Comparative Effectiveness and Safety of Biologic Medications: Three clinical data research networks (Mid-South, PEDSnet, and pSCANNER) and five patient powered research registries (AR-PoWER “ArthritisPower”, PARTNERS, ImproveCareNow, CCFA, and Vasculitis) are examining outcomes over time after patients make a change in their treatment regimen for adult and pediatric arthritis, adult and pediatric inflammatory bowel disease, and vasculitis (Co-PIs: Jeffrey R. Curtis, MD, MS, MPH; Timothy Beukelman, MD)
- RA Patient Perspectives on Treatment Optimization and Switching (Co-PIs: W. Benjamin Nowell, PhD; Kelly Gavigan, MPH; Jeffrey R. Curtis, MD, MS, MPH)
- Model for Improving Patient Engagement and Data Integration with PCORnet Patient-Powered Research Networks and Payer Stakeholders (PI: Kevin Haynes, PharmD)
- Enhancing patient ability to understand and utilize complex information concerning medication self-management (PI: Susan Blalock, PhD)





- Healthy Mind, Healthy You: A Dose Finding Study of Mindfulness (PI: Andrew A. Nierenburg, MD)
- The effectiveness of a specific carbohydrate diet versus a Mediterranean diet among patients with Crohn’s disease (PI: James D. Lewis, MD)
- Stepping Up for Inflammatory Arthritis (SUFIA) (PI: Alexis Ogdie, MD)
- Assessing Disease Burden and Access to Care and Treatment in Psoriatic Arthritis (PsA) and Ankylosing Spondylitis (AS) (Co-PIs: W. Benjamin Nowell, PhD; Alexis Ogdie, MD; Peter Hur, PharmD, MBA; Jina Park, PharmD)
- PCORnet Bariatric Study Secondary Aim—Rheumatoid Arthritis Patient Experiences (PI: Beatriz Hanaoka, PhD)
- Different Stories, Same Diseases: Patients’ vs. Health Professionals’ Understanding of Gout, Rheumatoid Arthritis and Gastroesophageal Reflux Disease (GERD) (Co-PIs: W. Benjamin Nowell, PhD; James Pennebaker, PhD)
- Global Patient-Reported Outcome Measure for Rheumatoid Arthritis (G-PROM) (PI: Liana Fraenkel, MD, MPH)

### **PCORI Joint Replacement Funding Concludes; GHLF Opts To Fund Continuing Research**

We concluded our Eugene Washington PCORI Engagement Award, Bringing Stakeholders Together for Engagement in Research on the Selection of Arthroplasty Implant Devices (BeTTER SAID) at the end of October. Although the funded project is drawing to a close, our efforts to engage patients as research partners for hip and knee joint replacement will continue. We set out to prepare patients and other stakeholders to engage in research that can improve the safety and effectiveness of hip and knee joint replacement. More than 165 patients signed up from ArthritisPower Patient-Powered Research Network (AR-PoWER PPRN) and the CreakyJoints patient community to participate.

### **FDA/GHLF Meet To Work Together To Include Patient-Reported Outcomes In FDA Decisions**

In September, we met with Food and Drug Administration (FDA) officials interested in the use of real world evidence in (RWE) in device regulatory decisions. During the meeting, we shared information about BeTTER SAID and its focus on mobilizing arthroplasty patients for research and advocacy. FDA staff shared with us the process of getting pre-approval to use patient-reported outcome (PRO) measures for regulatory purposes and RWE generation. We continue to seek ways to work together to ensure the engagement of patients alongside other stakeholders in arthroplasty research.

### Joint Replacement Patient Guidelines Available Soon

We developed two new patient guidelines in the fourth quarter, one on hip replacement and one on knee replacement, called *Raising the Voice of Patients: A Patient Guide to Total Hip / Total Knee Replacement* with input from patients and healthcare professionals. The guides will soon be available for [download](#) at the patient guidelines section of the CreakyJoints website. You can view a brief video, learn more about this project, and stay up-to-date with joint replacement news and resources

here: <https://creakyjoints.org/research/about-better-said/>.

### Spondyloarthritis Social Media Toolkit Available

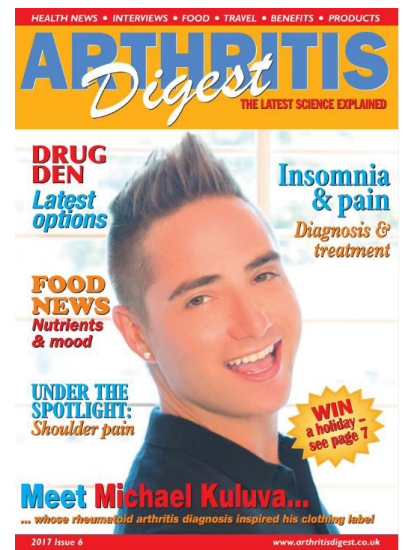
This year-long project culminated with an August committee meeting that led to the development of a best practices toolkit on ways to use specific social media platforms for all phases of patient centered outcomes research (PCOR) and comparative effectiveness research. Focusing on spondyloarthritis, the toolkit will be employed and then used as a model for other chronic disease conditions.

## CREAKYJOINTS – SUPPORT AND EDUCATION INITIATIVES

### GHLF Media Outreach Results in Nearly 1 Billion Impressions in 2017

Media outreach efforts generated more than 142 million media impressions in the 2017 fourth quarter, bringing the total 2017, media outreach efforts to more than 890 million impressions in conventional and social media

CreakyJoints leadership and members shared their perspective and stories with both physician-facing and consumer-facing media. During the fourth quarter, 37 media stories reported on CreakyJoints projects or spokespeople, including a cover story on fashion designer Michael Kuluva in **ArthritisDigest UK**. In addition, CreakyJoints had the opportunity to author two articles for Everyday Health, one on making [smart New Year's Resolutions](#) and the other on [managing fatigue](#) with arthritis, which featured CreakyJoints' medical advisor, Dr. Vinicius Domingues, a rheumatologist in Daytona Beach, Fla. The managing fatigue article was particularly well received, with nearly 200 shares on Facebook. Earlier in the Fall, CreakyJoints distributed a "listicle," which is a photo-heavy article that included tips on how to make decisions about joint replacement and how to use ArthritisPower. As of the end of December, the article was published on more than 1,000 websites and in 67 community newspapers across the country.



## **Pregnancy and Family Planning Patient Guidelines Published; RheumNow Calls It “Invaluable”**

Just before the 2017 American College of Rheumatology meeting in November, CreakyJoints published the fourth volume in the *Raising the Voices of Patients* series of patient guidelines. Titled, “A Patient’s Guide to Pregnancy and Family Planning with Rheumatic Diseases,” the patient guidelines were written by CreakyJoints members and staff, and reviewed by Megan E.B. Clowse, MD, MPH, a rheumatologist at Duke School of Medicine. In an article titled, “CreakyJoints Nails New Patient Pregnancy and Family Planning Guidelines,” [RheumNow](#), a leading arthritis trade publication, said,

*“The guidelines are well-written and an invaluable patient resource that incorporates major rheumatic disease societies (ACR, EULAR, etc) recommendations and views from multidisciplinary experts.”*

### **GHLF Begins Medical Foods Education Effort**

Global Healthy Living Foundation began to educate its members about medical foods on its website. Medical foods are prescription medicines created from food-based, natural molecules. They deliver highly purified, pharmaceutical-grade ingredients to the body to help restore its own balance and normal metabolic processes. Already available to members is a [library](#) that provides background on the conditions that might benefit from medical foods.

### **Advertising-Free Waiting Room WiFi Moves Forward After Successful Pilot**

An 18-month pilot which provides free, secure WiFi in 14 physician offices and waiting rooms, is moving forward with a broad United States and Australia roll-out in 2018. Patients can log into the free, safe network and access email, cloud-services and the internet as well as the more than 10,000 CreakyJoints and GHLF education, support, advocacy and research pages – advertising-free. Patients and physicians can contact CreakyJoints’ Director of Data and Technology Services, David Curtis at [dcurtis@ghlf.org](mailto:dcurtis@ghlf.org) to schedule installation or get more information. Future versions of Waiting Room WiFi will allow patients to update information and communicate with their physician and staff.



## CreakyJoints Sustains Its Social Media Leadership Position With #CreakyChats

Our popular #CreakyChats Twitter chats continue, reaching an average 50 to 100 participants per chat and more than 2 million impressions. The most recent chat topics were:

- What I wish the world knew about chronic disease: Tips for educating and advocating (Special guests: @theseatedview; @DawnMGibson; @JediMaster941)
- A Discussion on Mental Health and Chronic Disease (Special guest: Everyday Health)



When we asked patients how our social media affected them, these were the words they most often used.

## GHLF 50-State Network Gets New Website with Industry-Interactive Features

This fall, GHLF re-launched its [50StateNetwork.org](http://50StateNetwork.org) site with a completely modernized look, and new interactive features that immerse patients in their state healthcare issues. The website highlights advocacy, explaining what people need to know and say to influence health policy. The 50-State Network is a community of patients living with diverse chronic illnesses, including rheumatoid arthritis,

lupus, and psoriasis, cardiovascular disease, migraine and osteoporosis, and the people who care about them. The network is about transforming pain into purpose and empowering those who may feel victimized by disease. It repurposes frustration, despair and helplessness into positive mobilization, action, and fair representation to benefit all patients, caregivers and healthcare professionals.



## WHO WE ARE



### About CreakyJoints

[CreakyJoints®](#), founded in 1999, is the go-to source for millions of arthritis patients and their families world-wide who are seeking education, support, advocacy, and patient-centered research. CreakyJoints is part of the [Global Healthy Living Foundation](#), whose mission is to improve the quality of life for people with chronic illness. For more information and to become a member (for free), visit [www.CreakyJoints.org](http://www.CreakyJoints.org). To participate in research go to [www.ArthritisPower.org](http://www.ArthritisPower.org)



### About ArthritisPower

Created by [CreakyJoints](#) and supported by a multi-year, multi-million dollar investment by the Patient-Centered Outcomes Research Institute (PCORI), [ArthritisPower](#) is the first ever patient-led, patient-centered research registry for joint, bone, and inflammatory skin conditions. The free ArthritisPower smartphone and desktop application allows patients to track and share their symptoms and treatments while simultaneously participating in research in a secure and easy manner. ArthritisPower Patient Governors serve as gatekeepers for researchers seeking 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 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, diabetes, psoriasis, cardiovascular disease, and chronic pain, by advocating for improved access to 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 go-to source for arthritis patients and their families world-wide who are seeking education, support, advocacy and patient-centered research through [ArthritisPower](#), the first ever patient-led, patient-centered research registry for joint, bone, and inflammatory skin conditions. Visit [www.ghlf.org](http://www.ghlf.org) for more information.