

APRIL-JUNE 2018

# QUARTERLY REPORT



## ARTHRITISPOWER & PATIENT-CENTERED RESEARCH

### **ArthritisPower®, the First Patient-Reported Outcomes Registry, Continues to Grow and Engage in Research**

The ArthritisPower team is currently juggling more than 20 different studies, with regular platform updates and educational opportunities for nearly 17,000 consented ArthritisPower participants.

#### **Current ArthritisPower statistics as of June 30, 2018:**

- Total members: **16,930**
- Total patients: **16,535**
- Total number of completed patient-reported outcomes (PRO) assessments: **147,873**
- Number of unique participants who have completed PRO assessments: **12,054**
- Number of unique participants who have reported at least one condition (includes variations of comorbidities): **16,442**
- Number of unique participants who have reported at least one medication (includes combinations of medications): **4,352**





## Learn at Home via Educational Webinars

CreakyJoints® continues to offer members access to renowned rheumatology clinicians and researchers. In April, we hosted an educational webinar featuring Megan E.B. Clowse, MD, MPH, assistant professor of medicine, Duke University, and director, Duke Autoimmunity in Pregnancy Clinic, who discussed family planning with arthritis. Her talk focused on ArthritisPower data presented during the 2017 American College of Rheumatology annual meeting on the reproductive and breastfeeding concerns of women making decision about childbearing and child-rearing. Dr. Clowse also spoke about this topic in late June on **Doctor Radio**, a nationally available station on Sirius/XM satellite radio.

In May, Hye-Chung Kum, PhD, associate professor at Texas A&M University, was joined by the CreakyJoints community for a webinar to discuss patient health data and record linkage.

In June, one of our most popular webinars to date featured Jeff Curtis, MD, MS, MPH, an ArthritisPower principal investigator and the William J. Koopman Endowed Professor in Rheumatology and Immunology at the University of Alabama at Birmingham (UAB) and codirector of the UAB Center for Education and Research on Therapeutics (CERTs) of Musculoskeletal Disorders. He spoke about the comparative effectiveness of treatments that work on the immune system response. Because these medications take time to begin working, it is important for patients to keep track of how their symptoms may change when they initiate or continue a new therapy, Dr. Curtis explained. He highlighted research that he is leading in this area with a \$2.5 million award from [PCORI](#).

Please note, past webinars are available to view at <https://creakyjoints.org/education/webinars/>

## Making Headlines at EULAR

During the Annual European Congress of Rheumatology (EULAR 2018) meeting in Amsterdam, Netherlands, CreakyJoints had three abstracts accepted for publication and poster presentations. One was titled “Barriers to Rheumatoid Arthritis Treatment Optimisation: Real-World Data from the ArthritisPower Registry.” Utilizing the ArthritisPower research registry, the poster reported data from a sub-study of 257 rheumatoid arthritis (RA) patients who experienced high disease activity despite 70 percent being treated with DMARDs (non-biologic or biologic). Of those, only 37 percent were offered a treatment change at their last physician visit, with 72 percent of those patients agreeing to a switch. Most

patients intensified their treatment because their symptoms remained bad or worsened, whereas only 36 percent of patients elected to change therapies because they did not reach predetermined treat-to-target goals. As reported by both [RheumNow](#) and [Healio.com/Rheumatology](#), the findings indicate that patients are highly deferential to their physician’s recommendations for treatment escalation. In an interview, W. Benjamin Nowell, PhD, director of Patient-Centered Research and ArthritisPower co-principal investigator, said that it’s concerning that rheumatologists and patients may not be effectively engaging around treat-to-target goals even when symptoms, lab results, or patient-reported outcomes data reported via ArthritisPower warrant such discussion.



**EULAR Annual Congress**

### VIDEO: Patients with RA ‘highly deferential’ to rheumatologists for treatment escalation

June 19, 2018

[+ ADD TOPIC TO EMAIL ALERTS](#)

**eular2018**  
Annual European Congress of Rheumatology  
**Amsterdam**  
13-16 June 2018

*Dr. W. Benjamin Nowell speaks at EULAR*

## Multiple Arthritis Research Projects Underway

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 after patients change their treatment regimen for adult and pediatric arthritis, adult and pediatric inflammatory bowel disease, and vasculitis (PI: Jeffrey R. Curtis, MD, MS, MPH)
- RA Patient Perspectives on Treatment Optimization and Switching (PI: W. Benjamin Nowell, PhD)
- 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)
- Stepping Up for Inflammatory Arthritis (SUFIA) (PI: Alexis Ogdie, MD)
- Different Stories, Same Diseases: Patients’ vs. Health Professionals’ Understanding of Gout, Rheumatoid Arthritis, and Gastroesophageal Reflux Disease (GERD) (Co-PI: W. Benjamin Nowell, PhD)
- Global Patient-Reported Outcome Measure for Rheumatoid Arthritis (G-PROM) (PI: Liana Fraenkel, MD, MPH)
- Workplace Perspectives and Productivity Among People Living With RA (Co-PIs: W. Benjamin Nowell, PhD; Leticia Ferri, MD; Jeffrey Curtis, MD, MS, MPH)
- Analysis of the Top Patient Reported Outcomes (PROs) Within ArthritisPower (Co-PIs: Carol Gaich, PhD; W. Benjamin Nowell, PhD; Jeffrey Curtis, MD, MS, MPH)
- Digital PRO and Wearable Data Collection From Rheumatoid Arthritis Patients in a Real-World Setting (Co-PIs: Ginger Haynes, PhD; W. Benjamin Nowell, PhD; Jeffrey Curtis, MD, MS, MPH)

## CreakyJoints Offers Two \$500,000 Research Awards to Study Shared Decision Making

In April, CreakyJoints announced that they have selected the Mayo Clinic and the University of Alabama at Birmingham (UAB) to each receive a \$500K research award funded by Pfizer Independent Grants for Learning & Change (IGLC). Both studies will focus on improving shared decision making among adults with rheumatoid arthritis and their health care providers. The announcement was covered by [Orthopedics This Week](#), which reported “the objective is to improve shared decision making about treatment options and thereby enhance disease outcomes and health-related quality of life for patients with rheumatoid arthritis (RA) by testing the value of engaging patients in use of ArthritisPower mobile application for collection of patient-reported symptoms data on a weekly basis during the period between clinic appointments.”

### **Patient Voices Amplified at the First VA Medical Device Registry Summit**

Dr. Nowell and Shilpa Venkatachalam, PhD, associate director, Patient-Centered Research, were on the organizing committee for June's VA Medical Device Registry Summit, hosted by the Department of Veteran Affairs (VA) in partnership with other federal agencies. Christine Stake, PhD, MA, a volunteer patient advocate for GHLF and a patient governor of the ArthritisPower research registry, was the only patient participant. She spoke about the vital role medical device registries can play in alerting patient communities about safety recalls, identifying the brand and serial number of individual patients' medical devices, tracking and comparing device outcomes, and linking to other relevant data such as patient-reported outcomes.



*Christine Stake, PhD, gives her presentation*

### **Autoimmune Patients Need Vaccines, Too**

The [PCORnet Autoimmune and Systemic Inflammatory Syndromes Collaborative Research Group \(ASIS CRG\)](#), coled by ArthritisPower, has established a new Research Interest Group (RIG) focusing on vaccination among patients with autoimmune conditions. This research group will be led by Justin Owensby, PharmD, PhD (AR-PoWER, UAB). People living with autoimmune and systemic inflammatory syndromes are at increased risk of vaccine-preventable infections yet many patients are not getting vaccinated. The vaccination among patients with autoimmune conditions RIG aims

to examine factors that may contribute to vaccination hesitancy and low vaccination rates in people affected by ASIS conditions.

Currently there are four Research Interest Groups (RIGs) within the [Autoimmune and Systemic Inflammatory Syndromes Collaborative Research Group \(ASIS CRG\)](#). The Autoimmune and Systemic Inflammatory Syndromes Collaborative Research Group (ASIS CRG) brings together patients, clinicians, investigators, and other stakeholders within PCORnet to focus on research areas with crosscutting relevance for people living with ASIS conditions.

### **GHLF Patient Councils Promote Health Care Education and Gout Advocacy**

GHLF's national patient council of specially trained and enthusiastic volunteer patient advocates (who reside in each of the 12 Medicare Administrative Carrier regions) continue to drive new programs and patient-centered perspectives. Following the wintertime publication of [\*A Patient's Guide to Health Care: 2018 Edition\*](#), a free tool that defines commonly used insurance terminology and explains how to get the most from insurance coverage across all types of insurance, the patient council has now turned its attention to promoting the resource

within local or regional communities. For example, council members are encouraged to share the publication on social media, which has increased visibility and recruited new members to the 50-State Network.

GHLF has also launched a second patient council of advocates living with gout. The gout patient council is dedicated to exploring the disease journey, identifying common barriers, and raising awareness of gout's impact and severity. Although gout affects millions of Americans, it is misunderstood and stigmatized. The gout patient council aims to address these issues and increase quality of life for all people living with gout.

### **New Yorkers Advocate Against Non-Medical Switching**

On May 1, 50-State Network volunteer advocate Lisa M. and former GHLF Director of State and National Advocacy Stephen Marmaras participated in a press conference in Albany with other patient and provider groups to announce GHLF survey findings finding that many New York chronic disease patients are subjected to harmful formulary changes in their contracted coverage year. This results in increased out-of-pocket costs and potential delays in treatment. Advocates continued to call for the passage of S5022-C/A2317-C, sponsored by Senator Sue Serino and Assemblywoman Crystal D. Peoples-Stokes since 2015. The bill would establish consumer safeguards to ensure that New Yorkers have access to lifesaving and life-enhancing therapies through consistent coverage, stable formularies, and fair out-of-pocket costs. The press conference was widely covered by local and statewide media, including [Capital Tonight](#) (Spectrum Cable News), which featured Lisa and Stephen in a 10-minute segment. [Capital Press Room](#), [Newsday](#), [State of Politics](#), [WTEN-TV](#) (ABC), [Talk 1300AM](#), [Rheum Now](#), and [Crain's New York Business](#) also covered the conference.



## Mission Migraine Takes Off

In May, the U.S. Food and Drug Administration approved the first medication, a CGRP inhibitor, specifically designed for the prevention of migraine. Renewed hope and excitement for people living with migraine helped GHLF grow our group of activated migraine advocates by 140 percent during the first half of 2018. The migraine initiative is led by Joseph Coe, MPA, director of digital content and patient advocacy, and GHLF migraine patient advocate Jaime Sanders, author of the blog The Migraine Diva, who continues to engage in peer-to-peer outreach among the migraine patient community. On June 13, we collaborated with The Headache and Migraine Policy Forum and CHAMP

(Coalition for Headache and Migraine Patients) to [host a meeting](#) of migraine advocates in Los Angeles prior to the Institute for Clinical and Economic Review's (ICER) June 14 meeting to discuss their cost-benefit analysis of available treatments for migraine. The coalition was aware in advance that very few migraine patients (four) were invited to provide their perspective during the six-hour ICER meeting. To raise awareness of how ICER policies have the potential to undermine access to the new medication class, GHLF worked with volunteer advocates to craft and submit opinion pieces and letters to their local papers. This resulted in print and online coverage in the [Matthews-Mint Hill Weekly](#) (Matthews, North Carolina) and [Buffalo News](#) (Buffalo, New York). In addition, Coe had the opportunity to contribute a story about his personal experience with migraine to Health Monitor, which will publish this fall.



*For the second straight year, the 2018 Medical Economics Payer Scorecard shows that physicians are greatly dissatisfied with the policies payers implement, many of which cost them both time and money. The healthcare system is too focused on reducing costs and improving payer bottom lines, says Stephen Marmaras, [former] director of state and national advocacy for the Global Healthy Living Foundation, which aims to improve the quality of life for people with chronic illness. “Physician autonomy and patient choice and overall patient outcomes fall victim to that prioritization in the system,” he says, adding that prior authorizations and fail first medication policies are the results of a bottom-line focus by payers.*

*– Medical Economics, June 14, 2018 cover story*

### Copay Accumulator Watchdog

GHLF is closely monitoring and prioritizing awareness of copay accumulator adjustment programs, which are relatively new policies that some pharmacy benefit managers and insurers are using to prohibit manufacturer copay cards or other forms of manufacturer assistance from being used to pay down a patient's deductible or out-of-pocket maximum. Several GHLF members who have been victims of this new protocol have spoken with reporters at national newspapers about their experience.



### 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.

- **April 3:** GHLF data scientist Kelly Gavigan, MPH, presented the results of a survey about non-medical switching to a gathering of advocates in Hartford, Connecticut, to educate and inform legislators about the importance of the non-medical switching bill HB 379. Results of this study demonstrated the medical, psychological, and financial impact of this policy on patients.
- **May 5:** GHLF attended the ReumaExpo 2018 event in San Juan, Puerto Rico. After Hurricane Maria devastated so many in Puerto Rico, GHLF spearheaded an awareness and support campaign that raised more than \$50,000 earmarked entirely for recovery efforts for the rheumatology patient community.
- **May 15:** GHLF attended the Institute for Patient Access and the Partnership to Advance Cardiovascular Health Summit, highlighting the importance of stroke prevention and PCSK9i access.
- **June 4 to June 7:** GHLF attended the 25th annual BIO International Convention in Boston.
- **June 12:** GHLF participated in the Collaborating 4 Care working group meeting held by Takeda Pharmaceuticals. This year the focus was on IBD patient care and ways to support shared decision making between patients and their providers.
- **June 19:** GHLF attended a Forum on Medicare held by Bristol-Myers Squibb in Washington, DC. The Forum brought together more than 20 patient advocacy groups to discuss the impact of the Trump administration's drug pricing plan and coordinate responses to the administration's request for information.
- **June 21:** GHLF participated in the National Organization of Rheumatology Managers regional board meeting in Raleigh, North Carolina, to discuss a new pilot program to increase access to care for people newly diagnosed with rheumatoid arthritis.

MY STORY

BY J. G. CHAYKO

THE NEXT DANCE



YKO  
 e first time I slipped on a pair of ballet  
 y the soft leather hugged my foot, the way  
 nder the glow of the studio lights. I loved  
 e polished floor, feeling the grainy texture  
 arre beneath my hands and looking at the  
 hat showed us how well we were doing, and  
 to go. Those shoes were my first step into a  
 movement and story. Dance was the origin  
 fe. It stimulated me, led me to the theater  
 the power of my own body.

H DANCE began  
 arts class when I  
 r my sixth grade  
 e school play, a  
 Sawyer, I fell in  
 let was my first  
 ed to appreciate  
 s of dance. I stud-  
 and afterwards  
 to support my

to face with a beast that threatened to  
 steal my agility. The vigorous life I knew  
 began to change. I was working full-time,  
 attending rehearsals and dance classes.  
 The fatigue made it difficult to manage  
 an eight-hour day, so I switched to part-  
 time work. My swollen joints could no  
 longer absorb the impact of the dance  
 floor. I took a break from theater while  
 I tried to adjust to new limitations and  
 find ways to manage my symptoms.

growing artistic life. I was a cashier, a



J.G. Chayko has found new ways to express herself and her creativity

and people. I discovered another path  
 into the artistic world and new oppor-  
 tunities began to present themselves.

had left behind.

Last fall, my partner took on the task  
 of directing a holiday pantomime. I

CreakyJoints in the News

During the second quarter, CreakyJoints and Global Healthy Living Foundation members and leadership had many opportunities to contribute to the national conversation on living well with chronic disease and arthritis. CreakyJoints Medical Advisor Vinicius Domingues, MD, appeared live on **Doctor Radio** (Sirius/XM) during Arthritis Awareness Month to answer questions about management and treatment. During Arthritis Awareness Month, Seth Ginsberg, president and cofounder of CreakyJoints, appeared on the New York City cable show *In Conversation with Michael Stoler* to offer his advice on finding community and support. In April, **Everyday Health** included CreakyJoints as one of [“5 Inspiring Rheumatoid Arthritis Social Media Accounts to Follow.”](#) In addition, **Health Central** and **Pain Free Living** (a national print publication) both featured the story of CreakyJoints blogger J.G. Chayko resuming dancing and choreography despite living with arthritis. During the second quarter GHLF had 48 earned media placements, generating more than 74 million media impressions\*.

\* Note, during this quarter the reach of many TV and radio placement were not available.

## Got Gout? New Patient Guidelines Published

On Gout Awareness Day, [CreakyJoints](#) announced the publication of [Raising the Voice of Patients: The Patient's Guide to Treating and Managing Gout](#). Reflective of the CreakyJoints 2017 survey finding that half of all patients surveyed said they failed to tell their health care providers about all their gout attacks, and almost one-third hid attacks from loved ones, the new gout patient guidelines explain how people with gout can speak to their rheumatologist or other health professionals about their treatment plan, how to ask questions of their insurance company regarding coverage, and share best

practices for meeting or communicating with local legislators to advocate for patient-friendly health care laws. Theodore Fields, MD, professor of clinical medicine at Weill Cornell Medical College and an attending physician at the Hospital for Special Surgery, who medically reviewed the guidelines, offered his perspective on managing gout during a CreakyJoints educational webinar on Gout Awareness Day. He contributed an article about gout to [The Doctor Weighs In](#) and also wrote a piece on gout management for *Today's Geriatric Medicine*, which will publish in November.

## CreakyJoints on Social Media Continues Its Leadership Position

### #CreakyChats

Our popular #CreakyChats Twitter chats are well attended, particularly when we partner with special guests. The most recent chat topics were:

- **April:** What Would You Do If You Had Three Days Disease Free?
  - o 1.8 million impressions; 120 participants
- **May 31:** Arthritis Awareness Month Recap
  - o 10.1 million impressions; 79 participants
  - o Special Guest: Everyday Health

Notably, each day during Arthritis Awareness Month we celebrated a person or organization who is “doing good” for and in the arthritis community on our social media platforms.

## Hablas Español?

According to the U.S. Centers for Disease Control, there are 4.4 million Hispanics with doctor-diagnosed arthritis. Though the prevalence of arthritis among Hispanics is less than that of non-Hispanic whites, Hispanic people are more than twice as likely to become disabled from arthritis and experience joint damage. Given that many Hispanic and Latino/a Americans speak Spanish as their first language, during the second quarter CreakyJoints began translating important content to launch a Spanish language section on CreakyJoints.org in the third quarter. We will also publish *Raising the Voice of the Patients: A Patient's Guide to Living with Rheumatoid Arthritis* in Spanish and support it with media outreach in Spanish-language communities. Daniel Hernandez, GHLF medical advocacy liaison, is leading this effort for the organization.



## Meet Our 2018 Summer Interns



### **Francois Ban – Research Intern**

- Enrolled in the Columbia University Mailman School of Public Health, Department of Epidemiology
- “I am interested in improving the daily lives of patients with chronic illness, whether through examining their everyday behaviors and their impact on their physical/mental well-being or through examining the different types of health insurance and their impact on patients’ work productivity.”



### **Jennie Chavis – Advocacy Intern**

- Enrolled in the Master of Public Health/Master of Social Work dual degree program at Columbia University
- “Through helping to create the individual health insurance marketplace/open enrollment website for GHLF, I’ve had the opportunity to learn about and help reduce the complexities of the marketplace insurance process and the state variability of resources.”



### **Jennifer Teets – Advocacy Intern**

- Enrolled at Columbia University and an MPH candidate in sociomedical sciences with a certificate in chronic disease
- “I hope to gain a better understanding of how social and economic factors affect access to care and to effectively work toward better and more equitable health outcomes for chronic disease sufferers in the United States and, ideally, to reduce the burden of chronic disease.”



### **Amin Yakubu – Research Intern**

- Enrolled in the Columbia University Mailman School of Public Health, Department of Epidemiology
- “I’m interested in assessing the relationship between health insurance coverage and economic productivity to better understand the economic impact of providing health insurance.”

## WHO WE ARE



### About CreakyJoints

[CreakyJoints®](#), founded in 1999, is a digital community and advocacy organization for millions of arthritis patients and caregivers worldwide who seek 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 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 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 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 advocates to proactively connect with 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, diabetes, 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 community and advocacy organization for millions of arthritis patients and caregivers worldwide who seek education, support, advocacy, 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.