

JANUARY – MARCH 2018

# QUARTERLY REPORT



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

### ArthritisPower – The Patient-Powered, Patient-Reported Outcomes Registry Continues to Grow and Engage in Research

The ArthritisPower Research Registry continues to thrive. More than twenty different studies, most in partnership with major academic research institutions, are either underway, in development, or in the process of completing analysis and disseminating findings. Further, we continue to recruit new participants to the ArthritisPower informed consent and registration process through an integrated digital marketing, social media, and public relations campaign. Once signed up, our members are prompted to complete regular assessments, enter past and current medications, and participate in research studies. For more information on ArthritisPower click [here](#) and [here](#).

In January, one of our ArthritisPower Patient Governors shared her positive experience engaging with ArthritisPower research via a TV segment on [FOX Tampa](#). During the segment, Shelley F. demonstrated how she uses the ArthritisPower app. Via Skype, W. Benjamin Nowell, Ph.D., Director of Patient-Centered Research, explained how ArthritisPower helps bring together researchers, patients, and providers.





Trying to reach diverse audiences, the research team worked with Lifestyle List and Daytime, which are syndicated TV programs that produce health segments largely targeting women. Our produced segment highlighted ArthritisPower data presented at the 2017 American College of Rheumatology Annual Meeting regarding women's understanding of treating their RA during pregnancy and lactation. The segments aired in January and were shared on [CreakyJoints](#) and social media platforms. In addition, patient governor Regina G-S. contributed an article about staying active with arthritis to [Heart and Soul](#), a lifestyle magazine for African-

American adults.

Current ArthritisPower statistics as of March 31, 2018:

- Total members: 12,966
- Total patients: 12,642
- Total number of completed patient reported outcomes (PRO) assessments: 114,792
- Number of unique participants who have completed PRO assessments: 9,259
- Number of unique participants who have reported at least one condition (Includes variations of co-morbidities): 12,550
- Number of unique participants who have reported at least one medication (includes combination of medications): 3,268

### **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 over time after patients make a change in 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)

### **ArthritisPower User Experience Updated To Include Easy-To-Read Progress Charts**

We also continue to improve the functionality of ArthritisPower. From a technology perspective, we're working to update the user experience and user flow. As soon as this important update is available, we'll let you know.

### **ArthritisPower and Yale Find Out What Concerns Patients**

In January, GHLF's Dr. Nowell and Dr. Liana Fraenkel of Yale University published a study in *Annals of Rheumatic Disease* titled, "Preference phenotypes to facilitate shared decision-making in rheumatoid arthritis." The peer-reviewed article describes five "patient preference

phenotypes"—groups of patients sharing similar concerns about the attributes of different RA medications. For example, one group was most concerned about troublesome side effects, like whether a medication causes headaches or nausea, while another group was most interested in how quickly the medication would begin to take effect. Cost was extremely important to the largest of the five groups. The study lays the groundwork to develop a decision aid or tool that may be used in clinic to help patients and physicians quickly identify which among an array of treatments might be most appropriate for discussion and prescription. This study was covered by [Everyday Health](#) and [Rheumatology News](#), and will soon be featured in *Value-Based Care in Rheumatology*.



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## ADVOCACY – PATIENT VOICES CONTINUE TO BE AMPLIFIED

### 50-State Network Exceeds 1,000 Advocates

As of the first quarter of 2018, we can boast that over 1,000 people from across the United States have joined the 50-State Network to amplify the voice of the chronic disease community about the need for patient-centric health policies on the local, state and federal level. Our volunteer patient advocates contribute their perspective when they testify to health committees in the state legislatures, participate in surveys, and contribute interviews or opinion pieces to local media. For example, an advocate from Ohio, Jennifer B. contributed an article to the Ashtabula Star Beacon, her local newspaper, about how step therapy harms patients and interrupts the physician-patient relationship. Notably, media are recognizing how ability to mobilize our patient community, too, such as [Everyday Health](#) and [Daily Dot](#).

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Organizations like the Global Healthy Living Foundation also have a strong social media presence and provide advocacy for the chronic illness community, like publishing its own healthcare guide.

– Daily Dot



## Patient Guide To Healthcare Released

In February, GHLF announced the inaugural publication of [“A Patient’s Guide to Healthcare: 2018 Edition.”](#) The new publication defines commonly used terminology, explains how to get the most from insurance coverage (across all types of insurance), and empowers patients to advocate for themselves and the chronic disease community. GHLF president Seth Ginsberg discussed why deft navigation of health insurance is necessary in a contributed article to [The Doctor Weighs In.](#)

## GHLF Co-Founder Seth Ginsberg Pens Op-Ed

Working with the Doctor Patient Rights Project (DPRP), a coalition of patients and providers with GHLF as a founding member, Seth wrote an Op-Ed to the Washington Examiner titled, [“Insurers’ exclusion of disease treatments increases costs.”](#) His article discusses the tough choices patients make when their medications become unaffordable because of insurance company practices.



## [Center For Biosimilars](#) Publishes Seth Ginsberg Interviews

GHLF forged a close relationship with the Center for Biosimilars. This winter, the organization continued to publish video interviews featuring Seth Ginsberg speaking about the impact of biosimilars on the chronic disease community. This spring, the series will continue and feature videos with Louis Tharp, executive director of GHLF, and Stephen Marmaras, Director, State and National Advocacy.



## **GHLF Represents Patients At Industry and Government Meetings**

This past quarter, GHLF had the opportunity to attend a variety of meetings with health policy stakeholders including legislators, regulators, insurance commissioners, and physicians.

- February 6: Stephen Marmaras, director of policy and advocacy, travelled to New Hampshire to testify before the Senate Health and Human Services committee in support of Senate Bill 481, which established a committee to look at the impacts of PBMs on patient access and cost of care. GHLF also supports House Bill 1791 and House Bill 1741 that make the common-sense argument that patients should pay the lowest possible price for their prescribed medications.
- February 7: 50-State Network advocates in Massachusetts sent 56 letters to House Leadership and members of the House Health Committee to support including step therapy reform into the complete House Healthcare Reform bill.
- February 17: As a result of our outreach, [Patriot Ledger](#) published an Op-Ed written by an advocate of the Massachusetts Patient Access and Safety Coalition who described his experience with non-medical switching, referencing Global Healthy Living Foundation Massachusetts-specific survey results
- March 14: Patient advocate Kelli Carlson attended an advocacy day coordinated by the Minnesota Step Therapy Coalition. As a group, they held 80 meetings with legislators and since that day, multiple legislators have signed on as new authors or sponsors.
- March 21: GHLF sent a formal letter to The Honorable Paul Ryan and The Honorable Nancy Pelosi to oppose H.R. 5247, a bill that would impact a patient's ability to work directly with the FDA to secure compassionate use of investigational drugs.
- March 23: GHLF submitted a group sign on letter, which included more than 10 patient groups, in opposition to Rhode Island Senate Bill 2532. SB 2532 would prevent manufacturer copayment assistance from counting toward a patient's out of pocket maximum. This would result in patients suddenly being confronted with significant out of pocket costs midway through the plan year, when manufacturer coupons typically run out. This unexpected burden would decrease medication adherence, increase prescription abandonment rates, and would ultimately result in poor health outcomes.

### **Non-Medical Switching Continues To Be a Top GHLF Priority**

GHLF continues to focus on the impact of non-medical switching. [Non-medical switching](#) is when the copay for a drug dramatically rises, forcing a patient to go to a cheaper drug which, interestingly, the insurance company makes more money on. It's a complicated profit-driven tactic which effectively denies the drug that works by raising its price. In February and March, chronic disease patients in New York were surveyed about their experience with non-medical switching. Results will be announced later this spring in the hopes that data can be shared with NY legislators.

### **GHLF Migraine Efforts Reach New Intensity Level**

GHLF advocates for people living with migraine. In addition to providing advocacy guidance on the 50-State Network [website](#), we work with [The Migraine Diva](#) (Jaime Sanders), who will advocate on behalf of GHLF and the migraine community online. In addition, we are working closely with Dr. Amaal Starling, Assistant Professor of Neurology, Mayo Clinic College of Medicine, who is contributing byline articles to physician and consumer facing media.

## CreakyJoints in the News Nets 148 Million Media Impressions This Quarter

Recently, CreakyJoints was identified as a top source for arthritis blogs by both [Medical News Today](#), [Daily Dot](#) and Feedspot. This recognition demonstrates how well CreakyJoints leadership and members are delivering impactful messages about the ability to live well with arthritis and chronic disease as well as how to advocate for best care. During the third quarter, 30 media stories reported on CreakyJoints projects or spokespeople, including [Everyday Health](#), which called out CreakyJoint’s “[Raising the Voice of Patients: A Patient’s Guide to Living with Rheumatoid Arthritis](#),” as a “Resource We Love,” in their new overview about

rheumatoid arthritis.

During the first quarter, Global Healthy Living Foundation began educating our chronic disease community about the impact and treatment of migraine. Dr. Amaal Starling, Assistant Professor of Neurology, Mayo Clinic College of Medicine, contributed an article to [News-Medical](#), explaining how treatment of migraine ought to mirror the approach taken by those living with asthma. She also contributed a second article to a physician-facing magazine that may publish in early summer. Overall, media outreach efforts generated over 146 million media impressions this quarter.

The screenshot shows a webpage from Medical News Today. At the top, there is a navigation bar with a menu icon, the text 'NEWSLETTER', the 'MEDICALNEWS TODAY' logo, a search icon, and 'LOGIN'. Below the navigation bar is an 'ADVERTISEMENT' placeholder. The main content area features the article title 'The 10 best blogs for osteoarthritis' in a large, bold font. Below the title, it says 'By Hannah Nichols | Published Monday 12 March 2018' and 'Fact checked by Jasmin Collier'. The article text begins with 'Living with a long-term condition such as osteoarthritis can affect many aspects of a person's life. Blogs for individuals who have osteoarthritis and written by those with the disease can go a long way to helping with the day-to-day challenges that are associated with the condition.' There is a sub-section titled 'Osteoarthritis is the commonest type of arthritis, affecting more than 30 million adults in the United States.' followed by another sub-section 'Osteoarthritis is often known as a degenerative joint disease as it leads to the slow breakdown of the bones and cartilage within a joint.' and a final paragraph 'It usually affects the knees, hips, and hands and causes symptoms including pain, stiffness, impaired motion, and swelling.' To the right of the text is an image of an elderly person's hands holding a tablet. Below the image is a caption: 'Blogs designed for people with osteoarthritis can provide tips on how to live well with the condition.' On the right side of the article, there is an 'ADVERTISEMENT' box with a blue and green logo and the text 'Joint Pain Foods To Avoid' and 'Eliminate these 5 foods and greatly decrease joint pain. Free video.' Below this is a 'SPOTLIGHT ON: Osteoarthritis' section with two sub-articles: 'What can cause hip pain at night?' and 'What causes pain behind the knee?'. Each sub-article has a small thumbnail image.



## New Patient Guidelines Published To Positive Media Reviews

In 2018, we continue to develop comprehensive volumes in the Raising the Voices of Patients series of patient guidelines. In January, CreakyJoints launched “[\*Raising the Voice of Patients: A Patient’s Guide to Living with Osteoarthritis\*](#),” which was under the medical direction and review of Dr. David Borenstein, M.D., Clinical Professor of Medicine, Division of Rheumatology at The George Washington University Medical Center in Washington, DC, Dr. Jonathan Krant, M.D., Chairman of Medicine & Section

Chief of Rheumatology, Adirondack Health Systems, Saranac Lake, New York, and Dr. Tuhina Neogi, M.D., Ph. D., Professor of Medicine, Boston University School of Medicine, Professor, Epidemiology, Boston University School of Public Health. The publications was reported on by [Healio.com/Rheumatology](#) and Orthopedics This Week. This year, the organization will also publish patient guidelines on management of gout and juvenile RA.

## 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:

- January: 24hour + discussion: Sharing our #CreakyTruth (invisible realities of living with a chronic disease)
  - o 3.18 million impressions; 360 participants (over two days)
- February: Chronic Disease + Research
  - o 4.25 million impressions; 120 participants
  - o Special Guest: Arthritis National Research Foundation
- March: Advocacy Be the Squeaky Wheel
  - o 3.9 million impressions; 94 participants
  - o Special Guest: US Pain Foundation

Notably, our Facebook page generates lively discussion. For example, one question asked this February, “What concerns you more? The side effects of NOT TREATING your disease?-or- The POTENTIAL SIDE EFFECTS of medications used to treat your disease?,” [generated 268 comments, and 134 shares, potentially reaching 26,500 Facebook users.](#)



## 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 mobile 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 the 50-State Network

The 50-State Network is a grassroots advocacy component of the Global Healthy Living Foundation comprised of chronic disease patients who proactively connect with State and Federal health policy stakeholders to share their perspective and influence change. 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 by providing public and personalized opportunities to advocate for the chronic disease community. 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, 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 and [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.