

JULY-SEPTEMBER 2017

QUARTERLY REPORT



Though we enjoyed long summer days with family and friends, our ongoing commitment to our members persisted as we continued to communicate about the needs of the arthritis and chronic disease community. Since our last report, we launched the third volume in our series of patient guidelines, this time focusing on people living with psoriatic arthritis. We also achieved a major ArthritisPower milestone by recruiting over 11,000 consented participants, thereby creating an invaluable resource for researchers to tap into to learn more about the arthritis experience. On the advocacy side, we continued to educate our members about drug pricing and possible ways individuals might lower their costs now and in the future. As always, our conversations with our members continued in our blogs and CreakyChats and we even celebrated New York Fashion Week by once again supporting designer Michael Kuluva's Tumbler & Topsy Spring/Summer 2018 collection.

Our latest quarterly report will provide a brief overview of our advocacy, research, support, and educational initiatives. As always, we invite our members and supporters to reach out to us with any questions or additional detail. Thank you for supporting GHLF and CreakyJoints.

Louis Tharp



Seth Ginsberg



ADVOCACY – PATIENT VOICES AMPLIFIED

Global Healthy Living Foundation continues to work closely with our members and our coalition partners to raise awareness on access issues at the state and federal levels that face the chronic disease community.



This summer, GHLF became a founding member of a new coalition called the Doctor Patient Rights Project, which conducted a nationwide survey with alarming findings related to insurance access and claim denials. The survey reported:

- 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.
 - 70 percent of the denied treatments for chronic or persistent illnesses were for conditions described as “serious,” and 43 percent were for treatment of patients described as “in poor health.”
 - Nearly a third (29 percent) of patients initially denied coverage reported that their condition worsened, even if they eventually convinced their insurer to cover their treatments.
- CreakyJoints shared this information with members and the media to raise awareness of barriers to treatment faced by chronic disease patients. Seth Ginsberg, president and co-founder of Global Healthy Living Foundation, also participated in live interviews with **Nurse Talk Radio** and the Sirius/XM radio show “**Business Talk from Wharton,**” to describe the results. Further, a series of opinion pieces will be published in newspapers across the country beginning in October.

Additional Important Advocacy

Work continues to express our organizational perspective on biologics and biosimilars. CreakyJoints’ Medical Director, Dr. Jonathan Krant, MD contributed an interview to **Rheumatology Advisor** supporting biosimilars and discussing the fears rheumatologists have about extrapolation of indications when biosimilars are approved.

From an advocacy perspective, GHLF also attended several meetings with the Senate Committee on Health, Education, Labor and Pensions staff as part of the Alliance for Transparent and Affordable Prescriptions activities. The goal of these meetings was to call

for more transparency in the activities of medical and pharmacy benefit managers and their role in rising out of pocket costs for the consumer.

GHLF additionally met with key House offices representing North Carolina, Alabama, Mississippi, and Florida about severe access issues facing patients with cardiovascular disease in those specific states.

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

- August 2-3: GHLF provided comments to the FDA Arthritis Advisory Committee Meeting regarding a new treatment option for rheumatoid arthritis and expanded indications for a treatment for psoriatic arthritis.
- August 4: GHLF attended the Florida Medical Association conference to coordinate and support inclusion of a 50-State Network patient advocate on a panel discussing cardiovascular therapy access barriers in that state.
- August 5-6: GHLF attended the National Association of Insurance Commissioners conference in Philadelphia where we had a booth engaging insurance commissioners and their staff. We also disseminated a white paper that we published in collaboration with the University of Michigan Value Based Insurance Design Center on patient assistance programs.
- August 7-8: GHLF attended the National Coalition of State Legislators conference in



From left, the foursome of Brian Nyquist, executive director, National Infusion Center Association., Ryan Johnson, GHLF administrative coordinator, Stephen Marmaras, GHLF Director, Policy and Advocacy, and Zach Manfredi, emergency room trauma nurse at Danbury Hospital, Danbury CT, supported the 17th annual Lupus Charity Golf Classic at Turning Stone Resort & Casino, Verona,

Boston, MA.

- August 9-10: GHLF attended the Rheumatology Nurses Society annual conference where we learned about new opportunities to partner with critical members of the treatment team.
- August 24: GHLF both attended and sponsored the 17th annual Lupus Charity Golf Classic of the Lupus and Allied Diseases Association.
- On September 8, GHLF attended the Coalition of State Rheumatology Organizations annual advocacy meeting where Stephen Marmaras, Director, Policy and Advocacy, participated on the panel dealing with advocacy in the trenches, learnings and opportunities for the future.
- As the month advanced, GHLF submitted comments advocating for unique reimbursement codes for each biosimilar to the Centers for Medicare and Medicaid Services regarding ‘Revisions to Payment Policies under the Physician Fee Schedule and Other Revisions to Part B for CY 2018’.
- The month also included meetings with the Alliance for Transparent and Affordable Prescriptions and officials at the federal Office for Management and Budget to discuss the role that pharmacy benefit managers are playing in the rising out-of-pocket costs for patients in our community, as well as a meeting with the Arkansas Board of Pharmacy to discuss adoption of a rule addressing biosimilar substitution.

Importantly, on September 28, GHLF met with Food and Drug Administration (FDA) officials interested in the use of real world evidence in device regulatory decisions. GHLF shared information about its patient-reported outcomes work, newly built research infrastructure, and future capabilities. We look forward to continuing to explore a formal partnership with FDA where our patient-reported outcomes can be incorporated into FDA’s initiatives.



The 50-State Network continues to project patient voices and recruit diverse members to our cause, recruiting **66 new members** in the third quarter. Given the high-profile efforts to repeal the Affordable Care Act, GHLF conducted analysis to understand how each of the different proposed replacements would impact patients. To disseminate this research and education, a teleconference was held for the 50-State Network community on July 11th where GHLF leadership reviewed the proposals and team members provided an in-depth look at the various proposals and what they would mean for people battling chronic disease.

66 new members

ARTHRITISPOWER & PATIENT-CENTERED RESEARCH

ArthritisPower™

During the third quarter, CreakyJoints' multi-pronged approach to recruit members into ArthritisPower 2.0 included digital marketing, social media, public relations and direct-to-member communications. In September, the organization successfully completed enrolling and consenting 11,000 patients into ArthritisPower, fulfilling one of its primary contract requirements with the Patient-Centered Outcomes Research Institute (PCORI) more than 12 months ahead of schedule. Since launching a completely refreshed and advanced version of the patient registry smartphone app in March 2017, more than 8,500 new patients were recruited. ArthritisPower is part of PCORnet, the National Patient-Centered Clinical Research Network, developed with support from the Patient-Centered Outcomes Research Institute (PCORI), a nonprofit, nongovernmental organization authorized by Congress in 2010. Its overall goal is to support clinical research that will enhance informed health care decision making and improve health care delivery.

Current ArthritisPower statistics as of September 30, 2017:

- Total members: **11,747**
- Total patients: **11,465**
- Total number of completed patient reported outcomes (PRO) assessments: **88,787**
- Number of unique participants who have completed PRO assessments: **8,295**
- Number of unique participants who have reported at least one condition (Includes variations of co-morbidities): **11,371**
- Number of unique participants who have reported at least one medication (includes combination of medications): **2,775**

CreakyJoints May 2 · 🌐

It can be challenging to communicate symptoms like pain, fatigue, and anxiety with doctors and loved ones. ArthritisPower helps you do that.

PAIN

DOESN'T HAVE TO BE INVISIBLE

Make Invisible Symptoms Visible with ArthritisPower
ArthritisPower™ is a research registry and app that is designed to help patients track and communicate their symptoms while advancing arthritis research.

ARTHRTISPOWER.CREAKYJOINTS.ORG [Learn More](#)

Research Update

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 (Co-PIs: W. Benjamin Nowell, PhD; Jeffrey R. Curtis, MD, MS, MPH; Jeffrey Starck, MD)
- 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; MPH, Peter Hur, PharmD, MBA)
- 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 W. Pennebaker, PhD)
- Global Patient-Reported Outcome Measure for Rheumatoid Arthritis (G-PROM) (PI: Liana Fraenkel, MD, MPH)



Upcoming: 2017 American College of Rheumatology Annual Meeting

During the summer, the American College of Rheumatology confirmed to CreakyJoints that eight abstracts featuring either ArthritisPower data or data culled from surveys of the CreakyJoints membership would be featured in posters or oral presentations at the 2017 American College of Rheumatology Annual meeting in November in San Diego. Preparation for social and traditional media announcements to explain and highlight the data began in September. Accepted studies include:

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)



**AMERICAN COLLEGE
OF RHEUMATOLOGY**
EDUCATION • TREATMENT • RESEARCH

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)



Back Row: Seth Ginsberg (GHLF), Charis Hill (Patient Partner), Michael Siegel (National Psoriasis Foundation), Eddie Applegate (Patient Partner), Lilly Stairs (Patient Partner), Ben Nowell (GHLF)

Front Row: Rachel Mosbacher (PCORI), Dawn Gibson (Patient Leader), Regan Reynolds (Patient Partner), Kelli Carlson (Patient Leader), Joe Coe (GHLF), Shilpa Venkatachalam (GHLF), Layne Martin (Patient Partner), Elaine Husni (Cleveland Clinic)

Missing: Laurie Savage (Spondylitis Association of America)

Social Media and Research Toolkit (SMART) and Conference

Thanks to earning an award from the Patient-Centered Outcomes Research Institute (PCORI), in August, CreakyJoints hosted the Social Media and Research Toolkit (SMART) and Conference to develop a best practices toolkit on the use of social media for all phases of patient-centered outcomes research (PCOR) and comparative effectiveness research. The workshop focused on spondyloarthritis as a pilot for this new engagement approach with the aim of developing a framework that can be employed for other chronic disease conditions. The panel included Dr. Elaine Husni, M.D., Rheumatology, Cleveland Clinic, Mike Siegel, Vice President of Research Programs, National Psoriasis Foundation, and Richard Howard, Spondylitis Association of America. Also, CreakyJoints members Dawn Gibson and Kelli Carlson, whom both have a significant social media presence and patient experience, advised on the project. During the workshop, the group developed a three-part training for patients interested in partnering in research activities online. The training will be finalized by the end of the year.

New Publications

Director of Patient-Centered Research and ArthritisPower Principal Investigator W. Benjamin Nowell, Ph.D. and ArthritisPower principal investigator Dr. Jeffrey R. Curtis, M.D., MS, MPH, Professor of Medicine and William J. Koopman Endowed Professor in Rheumatology and Immunology, University of Alabama at Birmingham, Division of Clinical Immunology and Rheumatology had an article accepted for publication in the prestigious peer-reviewed journal **Medical Care**. Speaking to ArthritisPower governance, the article will appear in a special Patient-Centered Outcomes Research Institute (PCORI) supplement of the journal. The article will be titled, “Patient Governance in a Patient-Powered Research Network for Adult Rheumatologic Conditions.”

In addition, Dr. Nowell is a co-author of the recently published article, “Stakeholders’ Views on Data Sharing in Multi-Centered Studies,” published in the Journal of Comparative Effectiveness Research. CreakyJoints participated in this study in partnership with the Harvard School of Public Health, the University of Alabama at Birmingham and several other organizations. (Reference: Mazor KM, Richards A, Gallagher M, Arterburn DE, Raebel MA, Nowell WB, Curtis JR, Paolino AR, Toh S. (2017) Stakeholders’ Views on Data Sharing in Multi-Center Studies. Journal of Comparative Effectiveness Research. Published Online: 14 Aug 2017



CreakyJoints in the News

CreakyJoints leadership and CreakyJoints members continue to have opportunities to share their perspective and stories with both physician-facing and consumer-facing media. During the third quarter, 39 media stories reported on CreakyJoints projects or spokespeople, including **NBC-Philadelphia**, which aired a news segment featuring ArthritisPower Patient Governor Tien describing why she advocates for arthritis and uses the app to manage her condition. In addition, several bylines written by CreakyJoints leadership were published in **U.S. News & World Report** (on insurance coverage), **The Doctor Weighs In** (on drug pricing), **Managed Care Magazine** (in support of Merck’s Ken Frazier), **Rheumatology Advisor** (on biosimilars) and **MedPage Today** (on caregiving). In support of the research project **BeTTER SAID** (Bringing STakeholders Together for Engagement in Research for the Selection of Arthroplasty Implant Devices) and ArthritisPower, CreakyJoints distributed a “listicle,” which is a photo-heavy article that included tips on how to make decisions about joint replacement and use ArthritisPower. As of the end of September, the article was published on more than 1,000 websites. During the fall, it will also appear in print in smaller newspapers across the country. Overall, media outreach efforts generated over **168 million media impressions** this quarter. (This number does not include the reach of the listicle, whose distribution is not complete as of this writing.)

Michael Kuluva Tumbler and Topsy Spring/Summer 2018

On September 13, 2017, CreakyJoints presented fashion designer Michael Kuluva’s Tumbler and Topsy Spring/Summer 2018 runway show at KIA 360 New York Fashion Week. A member of CreakyJoints, last year the Los Angeles-based designer revealed for the first time that he had been living with rheumatoid arthritis for the past seven years). Despite managing an often painful and tiring chronic condition, Michael continues to pursue his dreams and career by designing youthful, colorful, and arthritis-friendly clothes. This year’s show was attended by many CreakyJoints staffers as well as supporters, such as reporters from **Everyday Health** and **Arthritis Health Monitor**. Michael and Seth also contributed Skype interviews to **Health Central** and Michael will be the cover story in a forthcoming **Arthritis Digest UK** magazine.



CreakyJoints on Social Media

#CreakyChats

Our popular #CreakyChats Twitter chats continue, reaching, on average, 50 to 100 participants per chat and over 2 million impressions. Q3 chat topics were:

July 2017

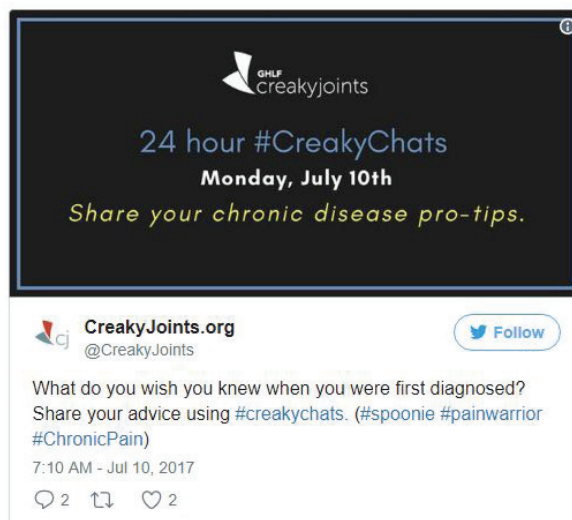
24 Hour #Creaky Chat: Share your chronic disease pro tips

August 2017

Chronic Disease: A discussion of emotional impact

September 2017

Empowering Patients Through Action
Special Guest: WEGO Health



Website Updates

CreakyJoints continued to generate content that resonates with the patient community by highlighting patient voices. Recent additions include:

- Expanded educational content around ankylosing spondylitis, including its symptoms, treatments and management
- A primer on health insurance
- A directory with current and future patient guidelines
- Educational content on medical foods that can be used to supplement treatments for OA, RA and Osteoporosis

This summer, the organization re-launched its website, GHLF.org, with a completely refreshed look and feel. We're excited that this website contains a wealth of education and information for people not only living with arthritis, but also to those living with other chronic diseases. Later in the Fall, the 50-State Network website will also relaunch with a new format.

Patient Guidelines

Over the summer, CreakyJoints continued to develop and publish new volumes in the “[Raising the Voice of Patients](#)” series of patient guidelines. As always, the patient guidelines are written by patients and CreakyJoints writers and reviewed by rheumatologists to provide comprehensive and unbiased information about what to expect from a specific diagnosis and the wide variety of traditional, complementary and alternative treatment and management strategies. Over the summer, the third volume, specific to Psoriatic Arthritis was published. In addition, patient guidelines are in development to address conditions such as osteoarthritis, arthroplasty (joint replacement), as well as a family planning supplement for autoimmune diseases.

WHO WE ARE



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 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. In addition to specific initiatives focused on arthritis, osteoporosis, diabetes, psoriasis, cardiovascular disease, and chronic pain, GHLF advocates for important state and national healthcare policies, such as transparent biosimilar substitution and patient-centric insurer utilization management, by activating patients locally via the 50-State Network. GHLF is also a staunch advocate for vaccines. Co-founded by arthritis patient Seth Ginsberg and healthcare reform activist Louis Tharp, the Global Healthy Living Foundation is the parent organization of CreakyJoints, the go-to source for more than 100,000 arthritis patients and their families world-wide who are seeking education, support, advocacy and patient-centered research, and the recently launched ArthritisPower, the first ever patient-led, patient-centered research registry for arthritis, bone and inflammatory skin conditions. To learn more and join ArthritisPower, visit www.ArthritisPower.org. GHLF does not ask patients or the public for donations.



CreakyJoints

CreakyJoints®, now in its 18th year, is the go-to source for more than 100,000 arthritis patients and their families world-wide who are seeking education, support, advocacy and patient-centered research. Co-founded in 1999 by arthritis patient Seth Ginsberg and healthcare reform activist Louis Tharp, 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.



ArthritisPower

Created by CreakyJoints in collaboration with the University of Alabama at Birmingham, 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, measure and share their symptoms and treatments while simultaneously participating in research via informed consent. 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 about the ArthritisPower Research Network, visit www.ArthritisPower.org.