

JULY – SEPTEMBER 2018

QUARTERLY REPORT



ARTHRITISPOWER & PATIENT-CENTERED RESEARCH

ArthritisPower® Community Reaches Nearly 18,000 in This Patient-Reported Outcomes Registry Dedicated to Research and Quality-of-Life Improvements

The ArthritisPower team never has a restful moment as they juggle more than 20 different studies with regular platform updates and educational opportunities for the nearly 18,000 consented ArthritisPower participants.

Current ArthritisPower statistics as of September 30, 2018:

- Total members: **17,723**
- Total patients: **17,306**
- Total number of completed patient reported outcomes (PRO) assessments: **165,248**
- Number of unique participants who have completed PRO assessments: **12,689**
- Number of unique participants who have reported at least one condition (includes variations of comorbidities): **17,215**
- Number of unique participants who have reported at least one medication (includes combination of medications): **4,670**





Multiple Arthritis Research Projects Underway

ArthritisPower research continues to grow. 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)
- Patients’ Perceptions of Gout (Co-PIs: Kelly Gavigan, MPH; Alexa Mear, MD; and 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)
- The Smartwatch Study: Digital Patient-Reported Outcomes 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)
- Examining the Experience of RA and PsA Patients on Methotrexate Therapy (Co-PIs: W. Benjamin Nowell, PhD; Shilpa Venkatachalam, PhD; Jeffrey Curtis, MD, MS, MPH; Elaine Karis, MD)

ArthritisPower Community Questions

With nearly 18,000 consented ArthritisPower users, we have the opportunity to survey members each month about their attitudes, beliefs, and lifestyle. These community questions provide us with guidance for future research and give us the opportunity to share relevant resources to the ArthritisPower community. Recent polls have revealed:

A red circular graphic with a white percentage '88%' inside.

of respondents said they endure pain in public because they worry about complaining too much.

A red circular graphic with a white percentage '45%' inside.

of respondents said they downplay their arthritis symptoms to their doctor because they're worried about changing medication.

A grey circular graphic with a white percentage '59%' inside.

of respondents said that the 0-10 pain scale was not the best way to measure their pain.

ADVOCACY: PATIENT VOICES AMPLIFIED

A Patient's Guide to Insurance Enrollment

Patients shouldn't need specialized education to understand insurance, but unfortunately they do because of the complex structure of policies and related drug tiers called formularies. In response, this August the Global Healthy Living Foundation published [*A Patient's Guide to Insurance Enrollment*](#), a resource to help people living with chronic disease understand and make decisions about their health insurance coverage options.

A Patient's Guide to Insurance Enrollment defines common benefit terminology and explains how to decode a formulary and its tiered drug lists to determine available prescription coverage. It also organizes the paperwork and information a family needs to apply for coverage and guides people to resources in every state that are set up to facilitate enrollment in private, employer-based, and/or public health insurance options. It was designed to be used by patients and their families in need of specialty care for any chronic disease.

Sharing Patient Concerns

In August, a byline penned by Corey Greenblatt, GHLF manager, policy and advocacy, and published on [The Doctor Weighs In](#) website discussed flaws in the new Medicare Part B policy that allows step therapy protocols to be used in Medicare Advantage plans.

The piece also made actionable suggestions regarding how the policy could be improved to protect chronic disease patients and keep them stable on effective medications. Similarly, Corey contributed a byline on the same subject to the [Centers for Biosimilars](#), which published in September.

Joe Coe, director of education and digital strategy, contributed an article to [Research America](#) discussing the power of patient communities with emphasis on people with migraine. He made the important point that every contribution is important and valuable, whether its sharing a story publicly or signing a petition. Notably, Joe's personal experience with migraine and his work with GHLF's 50-State Network of patient advocates was highlighted in the September issue of *Health Monitor*, a patient print publication available in doctor office waiting rooms.

**THE
DOCTOR
WEIGHS IN**

THE CENTER FOR
BIOSIMILARS

**RESEARCH
AMERICA**

Sarah Aoanan, former GHLF patient advocate and community outreach manager, spoke at a September FDA public hearing that included pharmaceutical industry and other stakeholder comments regarding the FDA's Biosimilar Action Plan. Later in the month, Louis Tharp, GHLF executive director and cofounder, spoke at the Association for Accessible Medicines trade conference regarding the uptake of biosimilars in the United States and what it means for chronic disease patients, particularly those with arthritis. This advocacy resulted in his comments being covered by the pharmaceutical industry trade publication, **Pink Sheet**. The Global Healthy Living Foundation's work in the area of biosimilars was also referenced by the [Centers for Biosimilars](#) and **CQ Healthbeat**.

GHLF Represents Patients at Industry and Government Meetings

In addition to the activities already noted, GHLF had the opportunity to attend a variety of meetings with health policy stakeholders including legislators, regulators, insurance commissioners, and physicians. The list below is limited to public meetings.

- August 11: Attended the Rheumatology Nurses Society annual conference to speak about patient access issues and ways nurses can get involved with advocacy.
- August 20: Met with the Florida Congressional delegation to discuss insurance denial rates for PCSK9 inhibitors.
- August 25: Attended the Ohio State Rheumatology conference to speak about GHLF and connect with patient advocates.
- September 4: Presented at the FDA's Facilitating Competition and Innovation in the Biological Products Marketplace Part 15 Public Hearing
- September 4: Met with members of the Florida delegation in the U.S. House to discuss commercial insurance denial rates for PCSK9 inhibitor claims.
- September 15: Attended the State Society Advocacy Conference held by the Coalition of State Rheumatology Organizations.
- September 26: Presented the findings from the Texas Non-Medical Switching survey, which was conducted in partnership with the National Infusion Center Association and with the support of the Coalition for Stable Patients. These results were presented to legislators and other patient advocacy groups in the Texas State Capitol in Austin.
- September 28: Attended a meeting as a member of the Kansas Coalition for Treatment Access with insurance companies active in the state to discuss legislation regarding step therapy.



Do you want to meet with state and federal legislators and their staff to talk about health care? You'll be representing millions of patients in the U.S. who aren't able to participate in these meetings, and feel good about the contributions you can make to improving access to care.

Join the 50-State Network and put your knowledge and experience to work for patients.

CKEAKYJOINTS: INNOVATIVE SUPPORT AND EDUCATION INITIATIVES

HEALTH SMARTS

Loving Care

CAREGIVERS ARE AN ESSENTIAL SUPPORT SYSTEM FOR PEOPLE WITH RHEUMATOID ARTHRITIS

By Stephanie Watson

When Andre Marcial married Chantelle, his childhood sweetheart, four years ago,

WebMD STRONGER THAN RHEUMATOID ARTHRITIS

years ago, her day-to-day life has been marked by pain, fatigue, and other disabling symptoms that often pop up unexpectedly.

"One thing about rheumatoid arthritis is that it's unpredictable," says Chantelle. "Some days my hands hurt. Some days my



person deal with a painful and debilitating disease can also be frustrating. "I wish I could help ease the pain more," Andre says.

One way he tries to help is by making sure Chantelle gets to all of her appointments so her doctor can address any issues she's having. Because she stays on top of her treatment, "my rheumatoid arthritis is pretty well controlled. I work with an amazing team of doctors, and my rheumatologist is wonderful," she says.

Andre's support is

CreakyJoints in the News

During the third quarter, there were 31 earned media placements featuring CreakyJoints members or leadership, generating more than 38 million media impressions. [WebMD the Magazine](#) featured volunteer patient advocate Chantal Marcial and her husband, Andre, talking about the importance of care partner support in managing RA. [Everyday Health](#) invited CreakyJoints to contribute an article about how to manage stress at the beginning of the school year. Their editors also attended fashion designer Michael Kuluva's 2019 Spring/Summer Tumbler and Topsy Show, airing coverage of this New York Fashion Week event via Facebook Live. (See photo and story on the next page.) An inspiring ambassador for CreakyJoints, Michael and his story of living well with rheumatoid arthritis was also covered by [HealthCentral](#) and several fashion blogs in the third quarter. He also contributed an article to the print magazine *Pain Free Living*, which will publish in a 2019 issue. Our good relationship with *Arthritis Health Monitor* continues following their publication of living with osteoarthritis, which featured the personal perspective of Louis Tharp, GHLF executive director.

Arthritis Is Art

For the third year, CreakyJoints presented Spring/Summer 2019 Tumbler and Topsy® by Michael Kuluva collection at New York Fashion Week. As a person living with rheumatoid arthritis (RA) and an active member of CreakyJoints, Michael inspires the arthritis community when he translates his experiences into innovative, bright, and arthritis-friendly clothing. This year's fashion-forward, street-inspired collection kept accessibility in mind as Michael incorporated magnetic closures into his garments. Getting dressed can be challenging for many arthritis patients, who may experience pain and limitations when it comes to buttoning or hooking their clothes.

Of the collection, Michael said, “My collection takes fun seriously. This year's show was the best yet because we featured Olympic athletes and rising stars from reality TV alongside top models, including

a member of the CreakyJoints community, Charis Hill. CreakyJoints is a fantastic partner because we both believe in the power of being positive. The organization has an open door to accessing community and educational resources, as well as the opportunity for everyday people like myself to participate in research with its free ArthritisPower® mobile app, which I use regularly to track how I'm feeling and responding to my treatment.”

Charis Hill, a member of CreakyJoints who lives with ankylosing spondylitis, was cast in Michael's show this year. In addition to walking the runway, Charis participated in earned and social media opportunities to promote the show and CreakyJoints' sponsorship. She did a Facebook Live with [HealthCentral](#) and participated in a [video interview](#) for Healthline with Michael, which published in October. CreakyJoints also aired Michael's show on Facebook Live and published several stories on our website.



Charis Hill, CJ member, patient and model at the Spring/Summer 2019 Tumbler and Topsy® by Michael Kuluva collection at New York Fashion Week

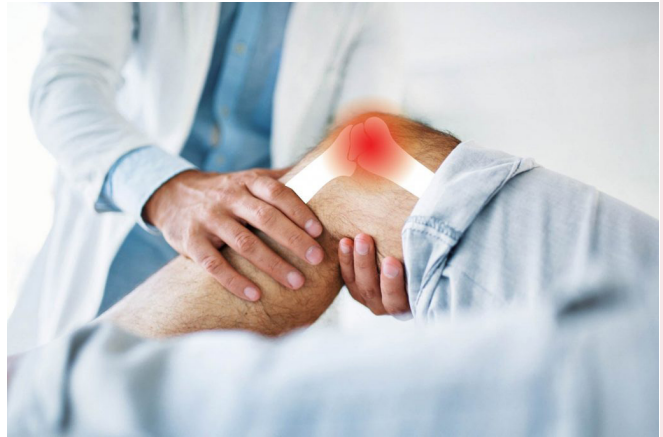


CreakyJoints on Social Media Continues Its Leadership Position

#CreakyChats

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

- July: “If I Knew Then...” What I Wish I Knew About My Chronic Disease
- August: “What’s in Your Chronic Disease Survival Kit?”
- September “Looking and Feeling Your Best with Chronic Disease,” with special guest Fashion Designer Michael Kuluva



What CreakyJoints Patients Are Reading

This summer, our editorial education and support content ramped up, publishing about 10 new articles every week. Article topics include reporting on arthritis research, disseminating our own research projects and advocacy initiatives, stories of inspirational GHLF members, and advice and tips for living well with arthritis. Here’s a sample of some of the content produced in the third quarter:

- [These 12 Healthy Habits for Inflammatory Arthritis Are Worth Adding to Your Daily Routine](#)
- [Got Knee Joint Pain? Learn the Difference Between Osteoarthritis and Inflammatory Arthritis in Your Knees](#)
- [A New Report Says These Are the 15 Best States to Live In If You Have Arthritis \(and Here Are the 2 Worst\)](#)
- [Lupus or Rheumatoid Arthritis? Here’s How It Took This Woman 20 Years to Get to the Bottom of Her Symptoms](#)
- [Here’s What Happens to Your Psoriatic Arthritis During and After Pregnancy. Per a New Study](#)
- [Good News for Nursing Moms with IBD: Biologic Drugs Are Safe During Breastfeeding](#)
- [If You Feel Frustrated With Your Healthy Living Goals, This Fibromyalgia Patient’s Mantra Is the Inspirational Message You Need Right Now](#)
- [‘Have You Tried?’ Some of the Worst Things You Can Say to a Migraine Patient](#)

As a result of increased quality and quantity of content as well as optimizing content to perform well in SEO (search engine optimization), on social platforms such as Facebook and Twitter, and in our CreakyJoints email newsletters, traffic to CreakyJoints.org has more than doubled over the past three months.



Learn at Home via Educational Webinars

In August, guest speaker Ashley Newton, BS, MPS, PMP, vice president, Center for Clinical Excellence Centerstone Research Institute, spoke on the topic “Putting Patients at the Center of Care: Integrated Care.” The speaker defined integrated care as an approach to caring for people with complex health care needs to achieve optimal outcomes. It may involve coordination of mental health, substance abuse, primary care services, and other specialized services. Patients who participated in the webinar said they found it informative and shared that integrated care only happens when they do the coordinating across more than one specialist.

In September, CreakyJoints hosted a webinar titled “Know Your Medical Device: Why the Unique Device Identification (UDI) System Should Matter to You.” Moderated by Terrie Reed, MS, FDA senior advisor for UDI adoption, the one-hour educational session described the unique device identification system and its adoption by health care providers. The unique device identification system established by the FDA is important to patients because it improves the ability to track the safety and effectiveness of different devices and facilitates efficient recall in the rare instance of device defect or adverse event. The unique device identifiers help standardize and document device use, such as in electronic health records, clinical information systems, claims data sources, and research registries like ArthritisPower.

These and other past webinars are available to view at creakyjoints.org/education/webinars/

Six People Join Global Healthy Living Foundation in New York

Recently, the Global Healthy Living Foundation has added five new staff members and transferred one from Houston to the New York City office.



Daniel Hernandez, MD, Medical Advocacy Liaison, transferred from Houston to GHLF's New York City office. In addition to his medical responsibilities, he leads Hispanic outreach across all disease states. He co-founded and is the current advisor to the chair of the International Medical Graduate section, which is part of the National Hispanic Medical Association. Daniel was born in El Paso, Texas. He graduated with a Biology degree from University of Texas at San Antonio and later graduated medical school from the Universidad Autonoma de Guadalajara and recently completed his medical rotations in Houston.



Steven Newmark, JD, MPA, joined as Director of Policy and General Counsel. He was most recently Special Counsel to the President of NYC Health + Hospitals in New York City. Before that he served as the Senior Health Policy Adviser to New York City Mayor Bill de Blasio. He also served as General Counsel in Mayor de Blasio's Public Advocate office, and as a Health Sciences Litigation Associate at Orrick, Herrington & Sutcliffe, LLP in New York City, where he was part of the team that successfully defended the Vaccine Act in *Bruesewitz v. Wyeth* before the Supreme Court. Additionally, he has taught Public Policy at Columbia University and is an Adjunct Professor in U.S. Health Policy at the City University of New York, Baruch College. He received his Juris Doctor from Fordham University School of Law and his Master of Public Policy and Administration, Advanced Policy and Management from Columbia University School of International and Public Affairs. He received his Bachelor of Arts, Philosophy, Politics and Law from the State University of New York at Binghamton. In addition to his General Counsel responsibilities, Steven will lead global advocacy and policy initiatives.



Lauren Gelman, MS, joined as Director, Editorial Services. She was previously Editor-in-Chief at Heathination, Executive Digital Director at Reader's Digest, Executive Editor at Everyday Health and Senior Health Editor at Prevention Magazine. She has extensive experience in print, digital, and video health care journalism as well as a recognized expertise in audience development, content strategy, search engine optimization, and digital analytics. She graduated summa cum laude from Northwestern University's Medill School of Journalism, where she also received her Master's degree in journalism. Lauren is responsible for editorial strategic direction and quality control, including the development and management of print, digital, and video products.



Jessica Boles, MSW, LSW, and Regis Wagner, MSW, joined as Patient Advocate, Community Outreach Manager. They will engage in direct patient communications, supporting GHLF’s 50-State Network of advocates, Patient Governor and Patient Council boards, and patient editorial and publicity activities. They will also be the touch-point with many of GHLF’s partner societies and coalitions.

- Jessica is a licensed social worker with more than 10 years’ experience. She received her Master of Social Work from Rutgers University with a concentration in Nonprofit Management and Public Policy and an emphasis in Advocacy, Aging and Health Policy, and her BA in Psychology from East Carolina University.



- Regis graduated from McGill University’s Intensive French Language program earlier this year, where he received a certificate of proficiency in the French language and culture in Montréal, Québec. He received his Master of Social Work from Temple University in Philadelphia and his BA in Sociology at Thiel College, Greenville, Pennsylvania.



Danielle Ali joined as Manager, Information Technology. Before receiving her BS in Technological System Management with a specialization in Information Systems at Stony Brook University, Stony Brook, New York, she served as Communications Coordinator for the Dean of Students; Data Coordinator, Student Engagement & Activities; Project Coordinator, American Arbitration Association, and Vice President of Academic Affairs-Executive Council of Stony Brook’s Undergraduate Student Government.

WHO WE ARE



CreakyJoints is a digital community and advocacy organization for millions of arthritis patients and caregivers worldwide who seek education, support, advocacy, and patient-centered research. We represent patients through our popular social media channels, our website www.CreakyJoints.org, and the [50-State Network](#), which includes more than 1,200 trained volunteer patient advocates.

As part of the [Global Healthy Living Foundation](#), CreakyJoints also has a patient-reported outcomes registry called ArthritisPower® with nearly 18,000 consented arthritis patients who participate in longitudinal and observational research. CreakyJoints also publishes the popular series “Raising the Voice of Patients,” which are downloadable patient-centered navigational tools for managing chronic illness. For more information and to become a member (for free), visit www.CreakyJoints.org.



About ArthritisPower

Created by [CreakyJoints](#) and supported by a multiyear, multimillion dollar investment by the Patient-Centered Outcomes Research Institute (PCORI), [ArthritisPower](#) is the first-ever patient-centered research registry for joint, bone, and inflammatory skin conditions. The free ArthritisPower mobile and desktop application allows patients to track and share their symptoms and treatments while also participating in voluntary research studies in a secure and accessible manner. ArthritisPower Patient Governors serve as gatekeepers for researchers who seek access to registry data or solicit the community to participate in unique, voluntary studies. To learn more and join ArthritisPower, visit 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.



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 for more information.