

OCTOBER-DECEMBER 2016

QUARTERLY REPORT



ADVOCACY + EDUCATION



SUPPORT + RESEARCH



**GLOBAL HEALTHY LIVING
FOUNDATION**



As always, the Global Healthy Living Foundation (GHLF) and CreakyJoints are committed to raising awareness of the issues important to chronic disease patients and those living with arthritis. This Fall was no exception. Our organization presented data, influenced the passage of patient-friendly legislation and promoted conversation in our community via our blogs and CreakyChats.

Our latest quarterly report will provide a brief overview of our advocacy, research 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 coalition partners to raise awareness of issues facing the chronic disease community to influence health policy on the state and federal level.

Specifically, the **50-State Network** continues to project patient voices. In New York, we furthered our work with the **New York Step Therapy Coalition** to urge Governor Cuomo to sign legislation that would create a transparent process for appealing step therapy protocols. We celebrated with champagne on New Year's Eve when the Governor signed the unanimously passed bill into law. The 50-State Network also supported biosimilar substitution legislation in Ohio, Montana and Alaska. In Ohio, a volunteer advocate submitted an Op-Ed to her local paper in favor of the bill, which ultimately was signed into law. In Alaska, Steve Marmaras, GHLF's Director of State and National Advocacy, appeared live in studio on the **Mark Colavecchio Show on KFQD (AM 750)** to promote the introduction of a new bill outlining appropriate circumstances for biosimilar substitution.



In late November, GHLF announced the results of a survey conducted on behalf of the **Tennessee Patient Stability Coalition** showing that chronic disease patients have been victims of non-medical prescription drug switching implemented by insurance companies. Local and national reporters expressed concern that patients in the state have experienced worse health as a result of non-medical switching as well as higher costs. **Tennessee Citizen Action** covered the news and we will continue to communicate with local and national media when the bill to close this business practice loophole is introduced in 2017. In particular, GHLF connected with a reporter who writes for The Guardian U.S. and Mosaic Science who expressed interest in non-medical switching as a concern facing patients across the country. We provided in-depth background information on the issue to the reporter and will continue to work with her in 2017 in the hopes of generating a long-form journalism piece.



This Fall, GHLF also fielded and completed a survey of Florida chronic disease patients on behalf of the **Floridians for Reliable Health Coverage** coalition, and prepared for a media outreach effort in 2017.

Right after the presidential election, GHLF provided public comment at a meeting of the **U.S. Food and Drug Administration (FDA)** regarding how unapproved uses of approved or cleared medical products (“off-label” uses) are communicated to patient communities. GHLF supports responsible off-label communications because it could more uniformly educate patients about possible treatment options. However, that support is framed by the need to continue to incentivize pharmaceutical companies to engage in appropriate research across multiple indications to improve understanding of safety and efficacy.

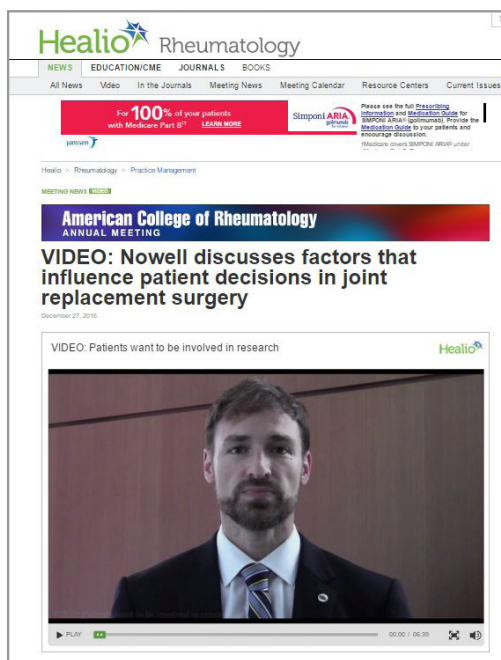


This Fall, the 50-State Network continued its efforts to raise awareness of access issues related to the new drug class, PCSK9 inhibitors for the treatment of familial hypercholesterolemia and for those who do not respond to or cannot tolerate statins. Since their 2015 FDA approval, payers have set up significant barriers preventing patients from easily accessing these medications, which are more expensive than statins. The 50-State Network identified patients with PCSK9 inhibitor access issues and these advocates travelled to the 2016 American Heart Association meeting in New Orleans to participate in an event hosted by the advocacy group, Patients Rising. They also shared their story in a video vignette.

ARTHRITISPOWER & PATIENT-CENTERED RESEARCH

During the fourth quarter, CreakyJoints shared findings from its patient-centered research projects during the **2016 ACR/AHRP Annual Meeting** in Washington, D.C., November 11-16, 2016.

On Sunday, November 13, CreakyJoints presented five posters. Of note, Dr. W. Benjamin Nowell, Ph.D., Director of Patient-Centered Research for CreakyJoints, presented a poster in partnership with Dr. Liana Fraenkel, MD, MPH, Yale University School of Medicine, titled “Development of RA Patient Preference Phenotypes.” The study surveyed more than 1,000 people living with rheumatoid arthritis (RA) to categorize how they weigh differences among medications’ various features (effectiveness, mode of administration, risk factors, cost, and other factors) to make treatment decisions. Five major patient preference phenotypes were identified that may support the decision-making process for physicians and patients. All survey respondents were identified via CreakyJoints.



Another poster highlighted the decisions that patients think are most important when considering hip or knee joint replacement. These findings emerged from a CreakyJoints and RAND Corporation pre-research engagement project titled “**BeTTER SAID,**” funded by the Patient Centered Outcomes Research Institute (PCORI). BeTTER SAID (Bringing Stakeholders Together for Engagement in Research for the Selection of Arthroplasty Implant Devices) aims to develop a cohort of patients, patient advocates, researchers, physicians/surgeons, and health system leaders examining strategies to improve joint replacement device safety and effectiveness.



Posters presented at the 2016 ACR/AHRP Annual Meeting included:

- Development of RA Patient Preference Phenotypes (Abstract #516)
- Patient Decisions Related to Hip and Knee Arthroplasty and the Factors Influencing Them (Abstract #110)
- What Factors Relate to Patients Contributing Longitudinal Data Using Smartphone Technology? Findings from RA Patients Participating in ArthritisPower Registry (Abstract #8)
- Optimizing the Efficiency of Patient Data Capture Using Smartphone Technology: Evaluation of the Correlation Between PROMIS Instruments for PRO Data Capture (Abstract #86)
- People with Rheumatoid Arthritis Recruited from an Online Patient Community May Differ from Clinical Populations in Symptoms and Impacts (Abstract #103)

CreakyJoints received attention from rheumatology medical and trade press for its ACR presentations and RA Patient Guidelines. Articles appeared in **Healio.com/Rheumatology**, **Rheumatology Advisor**, **RheumNow**, and **Orthopedics This Week**. Seth Ginsberg, GHLF co-founder, also participated in a panel discussion on how technology influences patient care, which was highlighted by the **ACR Daily Live**.



ArthritisPower, CreakyJoints' flagship research registry in partnership with the University of Alabama at Birmingham, continued working with partners to advance a range of studies. These include:

- Comparative Effectiveness and Safety of Biologic Medications: Three CDRNs (Mid-South, PED Snet, and pSCANNER) and five PPRNs (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.
- Healthy Mind, Healthy You: A Dose Finding Study of Mindfulness
- The effectiveness of a specific carbohydrate diet versus a Mediterranean diet among patients with Crohn's disease
- Enhancing patient ability to understand and utilize complex information concerning medication self-management
- Improving patient engagement and data integration with PCORnet PPRNs and payer stakeholders

Other ArthritisPower research in partnership with independent institutions includes:

- Shared Decision Making for RA Treatment in partnership with Yale University and funded by the Rheumatology Research Foundation: Additional targeted recruitment of Spanish-speaking patients will be conducted during early 2017.
- Reproductive concerns (pregnancy, breastfeeding, and birth control) of patients with inflammatory arthritis in partnership with Duke University: The completed survey will be launched soon.



Shared Decision Making RFP

In November, Global Healthy Living Foundation announced a Request for Proposals (RFP) titled, Rheumatoid Arthritis Shared Decision Making. Funded by Pfizer Independent Grants for Learning & Change (IGLC), the RFP requested studies focusing on shared decision making for RA treatment with an emphasis on quality improvement, and projects that propose integration with one or more EHR systems, linkable to ArthritisPower data, were also prioritized. GHLF will lead the grant application evaluation process and oversee a proposal review committee that will make funding decisions. A total of \$1 million is available, with the largest single amount available set at \$500,000.

Social Media and Research Toolkit (SMART) and Conference

The **Social Media and Research Toolkit (SMART) and Conference** is a PCORI engagement award proposal (EAIN) for the development of a best practices toolkit and one-time workshop on social media tools for Patient Centered Outcomes Research or PCOR. SMART aims to develop best practices for using social media and networking sites to raise research questions, engage open dialogue between patients and clinicians, disseminate evidence based information, and match patients with research opportunities. CreakyJoints will focus 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. Specifically, we'd like to consolidate the expertise and build the capacity of SpA patients, clinicians and other stakeholders (e.g. NPF and SAA) to propose topics and disseminate research findings via social media. The model and toolkit along with the in-person workshop that we develop, would be replicable for other chronic conditions, but our focus for this pilot would be SpA.

ArthritisPower

ArthritisPower recruited four new Patient Governors to take on a leadership role in the network. They participated at the Patient Governors' Summit October 7-10, 2016 at the Hilton O'Hare in Chicago.

Operation: Biosimilar Confidence

Leveraging its nearly five-year commitment to biosimilar awareness, education and advocacy, GHLF announced Operation: Biosimilar Confidence, an ambitious, multi-year program including research and education. Phase 1 will focus on comprehensive market research among eight different stakeholders.

CREAKYJOINTS – SUPPORT AND EDUCATION INITIATIVES



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 fourth quarter there were 22 media stories, including four stories in **Everyday Health**. CreakyJoints' medical director, Dr. Jonathan Krant, related his own personal experience with joint replacement in **Arthritis Health Monitor** and CreakyJoints member Christina Fairbrother appeared in **Yoga Digest** to offer her expert tips about practicing yoga with autoimmune arthritis, as she is a Yoga for Arthritis instructor. Ben Nowell contributed an article to **News-Medical** about managing RA during the winter weather and it appeared on the home page of the news outlet for over a month.

CreakyJoints on Social Media

Our popular #CreakyChats on Twitter continue, reaching, on average, 50 to 100 participants per chat and over 1.6 million impressions. This fall the chat topics were:

- Surviving the Holidays, featuring guest Lene Anderson (@TheSeatedView)
- What You Wish The World Knew About Your Chronic Disease, featuring guest Kirstin Schutlz (@Kirstie_Schultz)
- Your Future, Your Health: A pre-election #CreakyChats

Twitter at ACR:

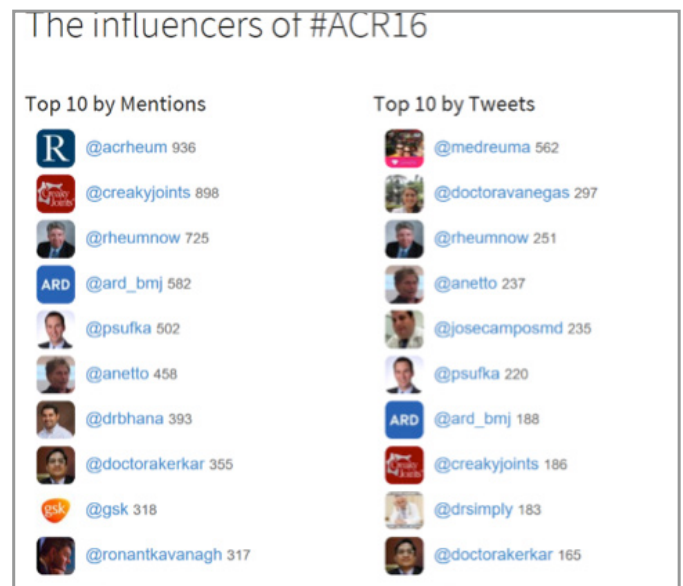
Pulsing our news of our data, meetings and social activities at the 2016 American College of Rheumatology annual meeting, resulted in the organization being the 2nd top influencer (#ACR16).

Website Updates

CreakyJoints continued to generate content that resonates with the patient community by highlighting patient voices.

Recent additions include:

- [“You Know Your Body Best”](#)
- [“Chronic Christmas: How to survive the holidays”](#)
- [“Parenting without Pain”](#)
- Updated and optimized [“chronic pain and sleep”](#) and [“weather and arthritis pages”](#) these continue to generate positive social media engagement



Patient Guidelines

“Raising the Voice of the Patient: A Patient’s Guide to Living with Rheumatoid Arthritis” is the first ever RA guidelines to be developed by patients for patients. Written by a national Patient Counsel assembled by CreakyJoints in collaboration with rheumatologists and CreakyJoints staff writers, the guidelines use lay language to explain RA treatment and management strategies. The guidelines also provide tools to help patients navigate the health care system and advocate for their preferred treatment plan. The goal is to make these guidelines

the “go-to” guide for patients to empower each person with RA to put themselves at the center of treatment decision making. On October 8, the Patient Council, representing the Medicare Administrative Carrier (MAC) regions, met to oversee the development of these guidelines for people with RA. These guidelines were medically reviewed by reviewed by Dr. Jonathan Krant, Medical Director of CreakyJoints®, rheumatologist and Chairman of Medicine at the Adirondack Medical Center in Saranac Lakes, NY; Dr. Madelaine Feldman, MD, Rheumatology Alliance of Louisiana and Coalition of State Rheumatology Organization executive committee member; and Dr. Sarah Doaty, MD, Rheumatologist with the Alaska Native Tribal Health Consortium. The guidelines were distributed in early January and are the first in a planned series of patient-friendly guidelines that will cover additional related conditions such as psoriatic arthritis, ankylosing spondylitis, and others.

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.