

There was no winter break for the Global Healthy Living Foundation (GHLF) and CreakyJoints. As always, our efforts to raise awareness of the issues important to chronic disease patients and those living with arthritis take our full and undivided attention. Since our last report, we successfully re-launched a bigger and better version of [ArthritisPower](#), our unique mobile application for arthritis disease management and research. On the advocacy side, we continue to push for the passage of patient-friendly legislation that makes a difference in the lives of people living with chronic disease, and our conversations with our members continued in our blogs and industry-leading CreakyChats.

Our latest quarterly report provides 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



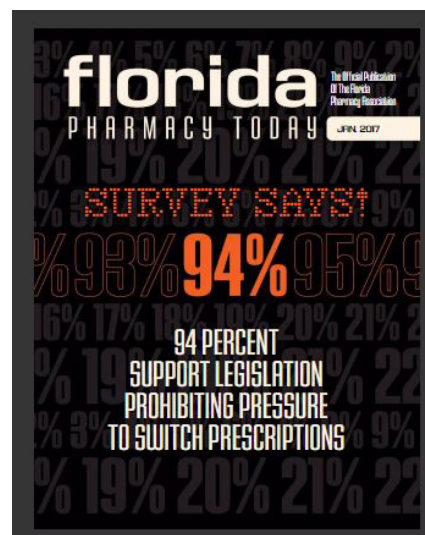
ADVOCACY – PATIENT VOICES AMPLIFIED

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. Most recently, the 50-State Network supported biosimilar substitution legislation NE LB 979 in Nebraska as well as Alaska SB 32, which included volunteer advocate, Ashlyn Antonelli contributing a letter and her testimony on February 10. Similarly, in January, volunteer advocate Elizabeth Chute provided testimony for Montana HB 233, which was later signed into law by Governor Bullock. GHLF also contributed letters and conducted outreach to legislative offices as well as the Governor’s staff in support of to Iowa HF 233, which is a bill to curb step therapy (“fail first”) procedures by insurance companies.



In early January, GHLF announced the results of a survey conducted on behalf of the **Floridians for Reliable Health Coverage** coalition showing that chronic disease patients have been victims of non-medical prescription drug switching implemented by insurance companies. The survey media outreach was timed to roughly coincide with the introduction of Florida HB 95/SB 182, known as the “Bait and Switch” bill and introduced by Florida State Senator Debbie Mayfield and Florida State Representative Ralph Masullo. The bill is meant to curb non-medical switching by commercial health plans. In addition, following up on a similar survey launched with the **Tennessee Patient Stability Coalition** in late 2016, Steve Marmaras, Director of State and National Advocacy, travelled to Nashville in March to represent Tennessee patients with chronic disease, meeting with key members of the House and Senate Insurance Committees.



Chantelle Marcial

In February, CreakyJoints provided a written comment to the Institute for Clinical and Economic Review (ICER) to offer its strong objection to their draft **Rheumatoid Arthritis: Evidence Report**. In a press statement remarking on the written comments, Louis Tharp said, “If this report is used as evidence by payers to erect additional barriers to treatment that favor older, less expensive medications, the health of millions of people living with rheumatoid arthritis (RA) as well as their right to determine their personal treatment plan, is threatened.” CreakyJoints community member and patient advocate Chantelle Marcial provided additional comments on behalf of the organization in person at ICER’s public meeting on arthritis on March 24, 2017 in Boston. Chantelle is also a local advocate for Global Healthy Living Foundation. In March, she participated in a taped TV interview (to air in May) about step therapy practices in Massachusetts.

Efforts continued 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. In addition to speaking with local legislators and local media in their respective states, in March 2017, volunteer patient advocates Cameron Credle (from North Carolina) and Craig Davis (from Florida) travelled to Washington, D.C. to attend the American College of Cardiology (ACC) annual meeting to offer their perspectives on trying to obtain a PCSK9 inhibitor prescription for FH. The advocates shared their personal experiences specifically at meetings of the National Lipid Association and the American Society for Preventive Cardiology (at the ACC meeting). GHLF support of these advocates also resulted in PCSK9 inhibitor access issues (along with the issue of non-medical switching) to be highlighted in high profile news articles in **Forbes** and **Pew/Stateline**.



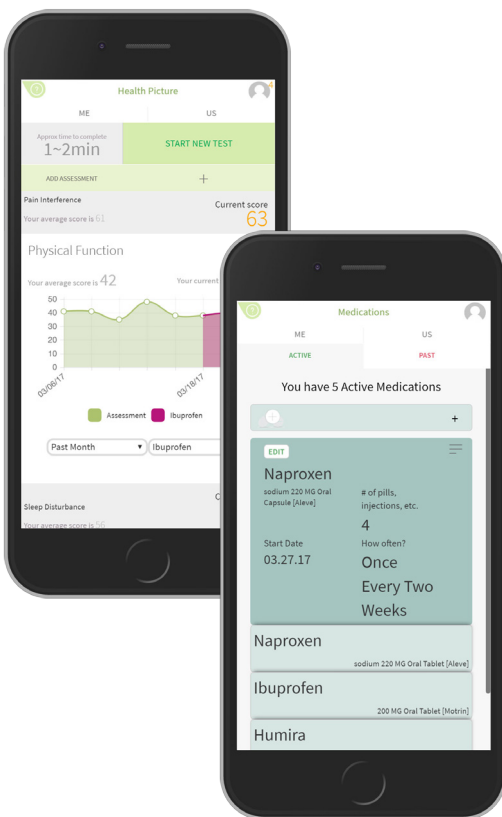
Notably, in March, Steve Marmaras also spoke with Hispanic/Latino physicians at the National Hispanic Medical Association Leadership Summit in Austin, TX, sharing the power and importance of getting minority populations involved in health advocacy.

CreakyJoints also distributed a statement announcing its support of Scott Gottlieb, nominated by President Donald Trump to be the next U.S. Food and Drug Administration (FDA) Commissioner.

ARTHRITISPOWER & PATIENT-CENTERED RESEARCH

ArthritisPower

During the first quarter, CreakyJoints launched ArthritisPower 2.0. Completely refreshed since the launch of the beta version in 2015, the free mobile app allows arthritis patients to track their treatment while participating in research studies. Valuable app features include:



- **Symptoms tracking:** ArthritisPower allows patients to track their symptoms and treatments, and share that information with their health care providers via email. Now, the graphs that demonstrate tracking over time have been redesigned to be easier to understand. In addition, the RxNorm dictionary of possible medications is more comprehensive, listing both generic and brand name medication names. It then auto-fills dosage info so a person can scroll down and select the correct information.
- **Advanced reporting:** Participants can track results over varying durations of time and overlay their usage of medications, so that they can see when a new treatment began impacting their symptoms.
- **Symptoms journal:** Patients can create a symptoms journal to record personal insights, giving context to their flares or improvements.
- **Messaging and social sharing:** Patients can initiate private message circles in order to communicate directly with each other and/or external health care providers and caregivers. Data can be shared via social media and email, as well.

ArthritisPower is supported by a contract from the Patient Centered Outcomes Research Institute, created by the Affordable Care Act, and was developed in partnership with the University of Alabama at Birmingham. CreakyJoints is spreading the word about the availability of ArthritisPower via an integrated marketing campaign that includes digital marketing, social media, public relations and direct-to-member communications. We are also working closely with our members and Patient Governors to encourage them to share news of ArthritisPower with their personal network.

Research Update

Simultaneous to preparing for the launch of ArthritisPower, we continued to implement research studies within the research registry, often in partnership with academic organizations. Studies in progress include:

- Healthy Mind, Healthy You: A Dose Finding Study of Mindfulness. **Harvard University**
- The effectiveness of a specific carbohydrate diet versus a Mediterranean diet among patients with Crohn’s disease. **University of Pennsylvania**
- Comparing Risk Presentation Formats for Total Knee Replacement (TKR). **Yale University**
- Comparative Effectiveness and Safety of Biologic Medications: Three CDRNs (Mid-South, PEDSnet, 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. **University of Alabama at Birmingham**
- Reproductive concerns (pregnancy, breastfeeding, and birth control) of patients with inflammatory arthritis. **Duke University**
- Enhancing patient ability to understand and utilize complex information concerning medication self-management. **University of North Carolina at Chapel Hill**
- Improving patient engagement and data integration with PCORnet PPRNs and payer stakeholders. **HealthCore**



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. Projects that propose integration with one or more EHR systems, linkable to ArthritisPower data, were also prioritized. GHLF convened the External Review Panel to review letters of intent (LOI) that had been submitted in response to the RFP. In total, eight LOIs were presented to the review panel and four were notified of the committee’s decision to request a full proposal. Full proposals were due from applicants on May 1. After reading and scoring proposals, the External Review Panel will convene in person on May 31 to make final decisions about which two projects will receive funding in the amount of \$500,000 each.

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. 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. Recently, CreakyJoints put together a panel that will meet in August in New York to discuss the project. Included on the panel are Mike Siegel, Vice President of Research Programs, National Psoriasis Foundation, Richard Howard, Spondylitis Association of America, and Dr. Elaine Husni, M.D., Rheumatology, Cleveland Clinic. We also have patient partners working with us as patient advisors (Dawn Gibson and Kelli Carlson) and we will be attending the National Psoriatic Foundation’s Research Symposium in August before the one-day workshop.

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. Preliminary research results are scheduled to be announced in the second quarter.

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 first quarter, 70 media stories reported on CreakyJoints projects or spokespeople, including six articles in **Everyday Health**. Fashion designer and CreakyJoints member Michael Kuluva was profiled in a Healthline article and was also the cover story in the winter issue of **Arthritis Health Monitor**. As a result of media efforts to educate stakeholders in North Carolina about access issues related to PCSK9 inhibitors, several radio segments featuring GHLF advocates aired on over 75 stations across the state via the **North Carolina News Network**. **Pew/Stateline**, a news service from the Pew Charitable Trusts, twice worked with GHLF to publish in-depth health policy articles. One article highlighted the issue of non-medical switching and the other reviewed consequences of step therapy and prior authorization. Both articles included interviews with several GHLF advocates and were picked up by **Kaiser Health News** and **Huffington Post**, among others. In total, earned media outreach during the first quarter exceeded 220 million media impressions. A listicle – a short article supported by pictures and captions – distributed in support of ArthritisPower reached nearly 1,100 online news outlets and 60 print newspapers, generating an additional 71 million media impressions.

CreakyJoints on Social Media

#CreakyChats

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

- A discussion with the chronic disease community with Patients Rising (@patientsrising)
- Communicating with your caregiver / support team
- CJ Patient Guidelines, with special guests: Members of the CJ Patient Council

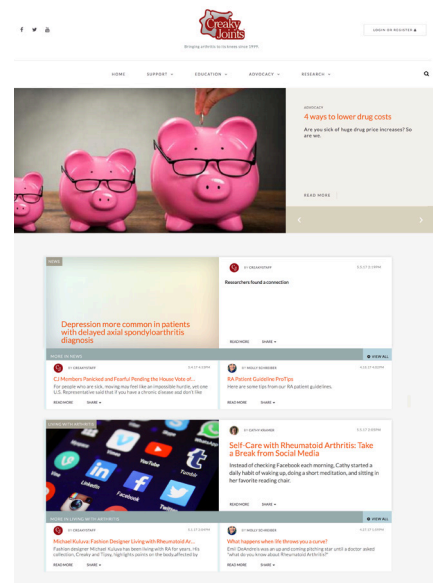
Website Updates

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

Recent additions include:

- A petition that includes [4 ways](#) that we can simply and easily lower drug prices
- Educational resources on arthritis [co-conditions](#), including diabetes, mental health, and heart disease
- Additional educational content on RA, from the Patient Guidelines. Topics include: [symptoms and their causes](#), [strategies for treatment](#), [new treatments](#) on the horizon, and more.

Notably, Molly Schreiber, a patient and new member of the CreakyJoints team, has been engaging with the blogging team to review content and make topic suggestions.



Raising the Voice of Patients

A PATIENT'S GUIDE TO LIVING WITH RHEUMATOID ARTHRITIS

Second Edition

Patient Guidelines

In January, CreakyJoints announced the publication of [“Raising the Voice of the Patient: A Patient’s Guide to Living with Rheumatoid Arthritis.”](#) 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. Already, 2000 complete copies have been downloaded and there have been about 4,000 individual page visits (to specific content). CreakyJoints also has other patient-friendly guidelines in development that will cover 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.