

APRIL-JUNE 2017

# QUARTERLY REPORT



*Our work in 2017 continues to advance conversations between patients, doctors, and policy makers about what it means to live with a chronic condition. Since our last report, we launched the second volume in our series of patient guidelines, this time focusing on people living with ankylosing spondylitis. In addition to presenting ArthritisPower research at the Annual European Congress of Rheumatology (EULAR) meeting, we also launched a major educational campaign about gout to encourage people to monitor their levels and talk to their physician about treatment options. On the advocacy side, we helped members react to the Senate and House revised healthcare plans while continuing to push for the passage of patient-friendly legislation that makes a difference in the lives of people living with chronic disease. As always, our conversations with our members continued in 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 members and our coalition partners to raise awareness on access issues at the state and federal levels that face the chronic disease community.



## Prescription Pricing

This spring, GHLF contributed its perspective on the New York Patient Notification bill regarding interchangeable biologics via a letter and call campaign. This bill (NY AB 7509) passed through the legislature on June 20, 2017 and is awaiting signature from Governor Cuomo. In addition, GHLF joined the ATAP Coalition (Alliance for Transparent & Affordable Prescriptions) to present a united and vocal front to raise awareness of how pharmacy benefit managers (PBMs) impact drug pricing, a practice that is largely misunderstood by patients. On a related issue, CreakyJoints reached out to members with an educational campaign regarding drug pricing. The initiative describes four ways that people with arthritis (or chronic disease) can better understand what their medicines cost and how to negotiate for better pricing. Extending beyond CreakyJoints' website and social media platforms, *RadioMD*, *Healio.com/rheumatology* and also reported on the campaign.

## Cholesterol

As a result of our work to improve access to PCSK9 inhibitors, which are an important new treatment option for people living with atherosclerotic cardiovascular disease (ASCVD) and familial hypercholesterolemia, Blue Cross, Blue Shield Alabama moved to cover the ASCVD indication. This is a major breakthrough for patients in need because Alabama has had some of the worst prescription rejection rates in the country at 53 percent, generally, and 60 percent for Blue Cross Blue Shield. Global Healthy Living Foundation repeatedly connected with lawmakers, regulators, media, and co-hosted an educational briefing in Birmingham to bring about this change. Beyond Alabama, both Stephen Marmaras, Director of State and National Advocacy, and Sarah Aoanan, Community Outreach Manager, State & National Advocacy, shared best practices for mobilizing advocates to engage key stakeholders at the National Hispanic Medical Association in Austin and New York, respectively.

The 50-State Network continues to project patient voices and attract diverse members to our cause, recruiting 68 new members in the second quarter. It also continues to track monitor and update members on House and Senate efforts to repeal and replace the Affordable Care Act. In June, North Carolinian Regan Reynolds successfully placed an opinion-editorial piece in the *Raleigh News and Observer* protesting Congressional efforts to overhaul healthcare, pointing out how their plan will hurt people with chronic disease.

GHLF continues to encourage its members to attend local professional society meetings to ensure the patient perspective is provided. Florida CreakyJoints member Kristen Towery attended the Mayo Conference Rheumatology CME meeting on Amelia Island, FL, and Georgia CreakyJoints member Cynthia Arnsdorff attended the Georgia State Rheumatology annual meeting.



*Kristen Towery*

After several years' hiatus, CreakyJoints turned its attention back to osteoporosis and has begun to reinvigorate our CreakyBones community. Californian Lisa Tent represented patients with osteoporosis at the Institute for Clinical and Economic (ICER) review meeting in Los Angeles, offering her perspective on medication access. Louis Tharp, Executive Director and Co-founder of GHLF, also spoke at a Patients Rising Event: *Voices of Value Speak Up: Spotlight Osteoporosis*, a patient education event for people living with osteoporosis and their caregivers.



*Lisa Tent and Louis Tharp*

## ARTHRITISPOWER & PATIENT-CENTERED RESEARCH

### ArthritisPower

During the second quarter, CreakyJoints continued to support the launch of ArthritisPower 2.0. As a result of our integrated marketing campaign that includes digital marketing, social media, public relations, and direct-to-member communications, we can report the following impressive statistics (current as of end of June 2017).

- Total members: 8,307
- Total patients: 8,080
- Total number of PRO results: 59,544
- Total number of reported medications: 9,108
- Total number of reported conditions: 17,915
- Total unique participants who have completed 1 or more PRO assessments: 5,961
- Total unique participants who have reported 1 or more conditions: 7,985
- Total unique participants who have reported 1 or more medications: 1,856



In the second quarter, we also recruited and selected a new group of ArthritisPower Patient Governors to monitor the continued development and maintenance of ArthritisPower, providing a vital patient-user perspective. The new Patient Governors represent a variety of demographic, diagnosis, and treatment characteristics. We plan to work with our new leaders to encourage them to share news of ArthritisPower within their personal network and via media pitches nationally and in their local communities.

### Research Update

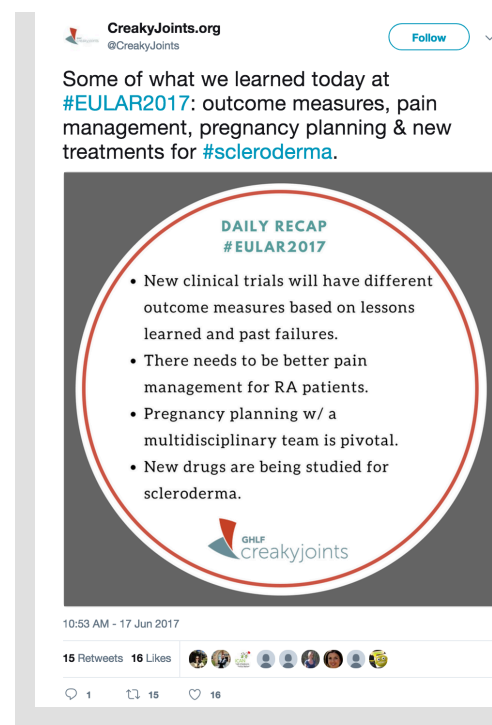
ArthritisPower research continues. Studies in progress include:

- Research Networks and Payer Stakeholders Comparative Effectiveness and Safety of Biologic Medications: Three CDRNs (Mid-South, PEDSnet, and pSCANNER) and five PPRNs (ARPoWER “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)
- Patient Perspectives on Living with Both Rheumatoid Arthritis and Inflammatory Bowel Disease (PI: W. Benjamin Nowell, PhD)
- 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)

- Reproductive concerns (pregnancy, breast-feeding, and birth control) of patients with inflammatory arthritis (PI: Megan E.B. Clowse, MD, MPH)
- Enhancing patient ability to understand and utilize complex information concerning medication self-management (PI: Susan Blalock, PhD)
- Comparing Risk Presentation Formats for Total Knee Replacement (PI: Liana Fraenkel, MD, MPH)
- 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-PI: W. Benjamin Nowell, PhD)
- PCORnet Bariatric Study Secondary Aim— Rheumatoid Arthritis Patient Experiences (PI: Beatriz Hanaoka, PhD)
- Linguistic Differences in Gout-Related Online Content: A Comparison of Professional Health Literature for Consumers Vs Patients’ Online Discussions of Gout (Co-PI: W. Benjamin Nowell, PhD)
- Global Patient-Reported Outcome Measure for RA (G-PROM) (PI: Liana Fraenkel, MD, MPH)

## EULAR

CreakyJoints participated in sessions, meetings, and poster presentations at the 2017 Annual European Congress of Rheumatology meeting, held in Madrid, Spain. W. Benjamin Nowell, Ph.D., Director of Patient-Centered Research, was the lead or supporting author of five abstracts (four of which were poster presentations). Two of the posters updated findings from the ArthritisPower research registry and a third presented results from the CreakyJoints research engagement project, BeTTER SAID (*Bringing Stakeholders Together for Engagement in Research for the Selection of Arthroplasty Implant Devices*), being conducted in partnership with RAND Corporation, and funded by the Patient Centered Outcomes Research Institute (PCORI). A fourth abstract reported on findings from a qualitative study of RA patients’ perspectives about treat-to-target and was submitted by GHLF partners at the University of Massachusetts. EULAR data was covered by arthritis trade publications and shared via original content disseminated on CreakyJoints digital and social media platforms. Throughout the busy week, CreakyJoints leaders in Madrid, Seth Ginsberg, Louis Tharp and W. Benjamin Nowell, also met with international and US-based rheumatologists and stakeholders.



## Shared Decision Making RFP

In November 2016, Global Healthy Living Foundation announced a Request for Proposals (RFP) titled, *Rheumatoid Arthritis Shared Decision Making*. Supported 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 implementing data linkages between patients' clinical electronic health records (EHR) and their ArthritisPower outcomes data were prioritized. After requesting four full proposals from eight submitted letters of intent, an External Review Panel selected two proposals to fund, each being awarded \$500,000. The projects will be announced in Summer 2017.

\$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 the use of social media for all phases of patient centered outcomes research (PCOR) and comparative effectiveness research (CER). 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. CreakyJoints will convene a panel of patients and technical experts in New York during August to pilot the project. Included on the panel are 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, both have a significant social media presence and patient experience, and are advising on the project. Prior to the one-day workshop, GHLF research staff will attend the National Psoriasis Foundation (NPF) August Research Symposium in Chicago.

# CREAKYJOINTS – SUPPORT AND EDUCATION INITIATIVES

RA EMPOWERMENT



## Yes, you can thrive —even with RA!

"I may have been confused by my rheumatoid arthritis diagnosis and how to manage it—but you don't have to be!" says Kelli Carlson, who's been living with RA for more than a decade. Here, she passes down a few tips she wishes she'd known way back when. —BY KELLI CARLSON

### If a pain doesn't feel right, don't accept it—dig deeper!

Looking back, I realized I'd had the symptoms of RA long before I was diagnosed. But I chalked up my pains to my active lifestyle, and when my knees swelled every time I got my period, I figured that was "just the way it is." When I finally decided to see an orthopedist, he couldn't find anything wrong.

It wasn't until I woke up one morning and I literally couldn't move one entire side of my body that I got my answer. My regular doctor was away, so I saw another orthopedist instead, who immediately recognized my symptoms were caused by RA and referred me to a rheumatologist.

**Takeaway tip:** If you have a hunch something's wrong, despite an all-clear from your doctor,

follow it. Drive home the point you're not well by logging your symptoms and how they're affecting your ability to do everyday activities—then show it to them. Ask more questions, and don't be shy about getting a second opinion.

### Get support by setting people straight!

Having RA isn't like being pregnant—there's no "pregnancy bump" for people to try on to get an idea of what it feels like. It may be hard for others to understand what you are going through, let alone empathize. When I was in college and needed to see my doctor, it meant I'd have to skip classes from time to time. One of my professors said to me, "You can be a student or a patient, but you can't be both." Even today, I feel some people confuse my lack of energy or my need to pace my activities as laziness.

**Takeaway tip:** Talk about your RA to friends and family, and let them know how it makes you feel. Try: "I may look healthy and normal to you, so it may be hard for you to understand why I have to go at my own pace or occasionally back out of activities. The fact is, RA is an inflammatory disease that sometimes makes it hard for me to do things like dress myself or lift a heavy pot." You can also invite loved ones to join you at appointments, so they can hear first-hand about your RA and even ask their own questions.



*"Tell others, I may look healthy, so it may be hard for you to understand that I have to go at my own pace,"*  
says author  
**Kelli Carlson.**

### Turn to people who are really in the know—others with RA!

It's great to have a whole healthcare team who can treat our individual cases, pros who understand the condition from a medical perspective and can help us understand how the latest

medical guidelines apply to us. But there's something we can't get from them—and that's the unique perspective that comes from having RA. Only another patient with RA can tell you what it's like to go through the trial and error of finding the treatment that put them into remission...share the decision-making tools that helped them figure out how to manage their RA...reveal how they got their friends and family to empathize and provide the support they need.

**Takeaway tip:** Join a support group like CreakyJoints, which counts 100,000 arthritis patients among its members. Check out ArthritisPower, the first-ever patient-led, patient-centered research registry for arthritis, bone and inflammatory skin conditions. And consult the first-ever Rheumatoid Arthritis Patient Guidelines (find at [CreakyJoints.org/education/rheumatoid-arthritis-patient-guidelines](http://CreakyJoints.org/education/rheumatoid-arthritis-patient-guidelines)), which were developed by a group of patients (including me), a panel of rheumatologists and CreakyJoints to help people with RA make informed decisions about their healthcare and prepare them for meaningful conversations with their doctors and loved ones. 🗨️

### Just learned you have RA?

Try asking your doctor two or three questions at each visit so you don't get overwhelmed. You might start with "What is RA?" "How is it affecting my body?" and "What is your plan to control my RA?" In time, and with the right support, you will learn everything you need to know.

12 Arthritis | HEALTH MONITOR

HealthMonitor.com 13

## 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 second quarter, 53 media stories reported on CreakyJoints projects or spokespeople, including eight articles in **Everyday Health**, which reaches over 10.8 million unique viewers per month. Fashion designer and CreakyJoints member Michael Kuluva continued to support the launch of ArthritisPower by participating in interviews with **MyND Radio** (syndicated), **RadioMD**, and the **Jiggy Jaguar Show** (syndicated). CreakyJoints Medical Director Dr. Jonathan Krant appeared live on **Sirius/XM's DOCTOR Radio** for 30 minutes, discussing ArthritisPower and why it helps patients be proactive about their care. Seth Ginsberg promoted organizational key messages via contributed byline articles. In **U.S. News & World Report** he delineated the difference between real and fake medical news; in **Rheumatology Network** he discussed the importance of clear physician-patient communications. The latter was picked up by **MedPage Today**. CreakyJoints member Kelli Carlson was featured in the summer issue of **Arthritis Health Monitor** talking about how the [RA patient guidelines](#) help her manage her condition. **FOXNews.com** referenced GHLF support of Scott Gottlieb for FDA director and both **Health News Florida** and **Florida Medical Business** reported on GHLF support of PCKS9 inhibitor access. Overall, media outreach efforts generated **185 million media impressions** this quarter.



During May’s Arthritis Awareness month, the CreakyJoints team worked around-the-clock to raise awareness of the many forms of arthritis and the people and families impacted by it. Highlights included: daily postings featuring CreakyJoints members sharing what they wish the world knew about arthritis, a highly engaging Facebook Live event with rheumatologists from the Hospital for Special Surgery, a #CreakyChats about arthritis awareness with

the Arthritis National Research Foundation as well as landing placements in **The Mighty**, **Everyday Health** and **PCORNET**. There were more than 3 million social media impressions across our social media channels, including over 24,000 likes, shares and retweets of our content, over 65,000 page views on CreakyJoints.org and 2,145 new patients recruited into ArthritisPower.

## Gout: Survey Says it is Out of Control

On May 22, Gout Awareness Day, CreakyJoints launched an awareness campaign announcing results from a comprehensive survey of 1,000 gout patients and 500 caregivers of gout patients, which painted a portrait of a disease that is out of control. Patients surveyed experienced an average of eight painful gout attacks per year and more than half these patients reported attacks that lasted three or more days. Moreover, 76 percent of patients indicated gout hinders their ability to walk, climb stairs, or sleep, causing a rippling effect not only on patients’ lives, but also on the lives of their caregivers and families. To educate people with gout about how they can get better control of their disease, the announcement was supported by a social media and public relations outreach effort. A satellite TV and Radio tour yielded 23 live and live-to-tape interviews featuring CreakyJoints advisor Theodore Fields, M.D., Hospital for Special Surgery, New York and CreakyJoints Advisor. Additional media reporting on the campaign included **U.S. News & World Report**, **Senior.com**, **Everyday Health**, several arthritis trade publications and a forthcoming article in **Arthritis Health Monitor**. On Gout Awareness Day, CreakyJoints Tweeted 10 times, resulting in 42 retweets and 6,107 impressions. On Facebook, 2 posts generated 5 shares, 135 likes and 9,747 impressions.

**GOUT: IT TAKES 2**  
Have gout? You don't have to go it alone:

- You and your loved ones**  
are in this together. Talking about your condition can be hard, but staying silent or hiding gout attacks won't solve the problem.
- You and your doctor**  
can find the best treatment approaches. Tell your doctor about every single gout attack, and ask your doctor to test your blood regularly to measure your serum uric acid (sUA) level. Your goal is to get your sUA level under 6 mg/dL and keep it there!
- You and your community**  
have each other. There are 8 million people in the U.S. with this disease, and patient advocacy and support groups, like CreakyJoints, are here to help you!

**And Remember, There are 2 Causes of Gout:**  
Gout is caused by your body producing too much uric acid, and your body getting rid of (excreting) too little uric acid. Over time, the uric acid builds up in your body. Talk to your doctor for more information.

**The 2 Causes of Gout**  
↑ overproduction of uric acid  
↓ underexcretion of uric acid

For more info and resources, visit [www.CreakyJoints.org/goutsurvey](http://www.CreakyJoints.org/goutsurvey) NP-UNB-US-00176 5/2017

## 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. Q2 chat topics were:

#### April 2017

A Discussion on Healthcare with the Chronic Disease Community

Special Guest: Patients Rising

#### May 2017

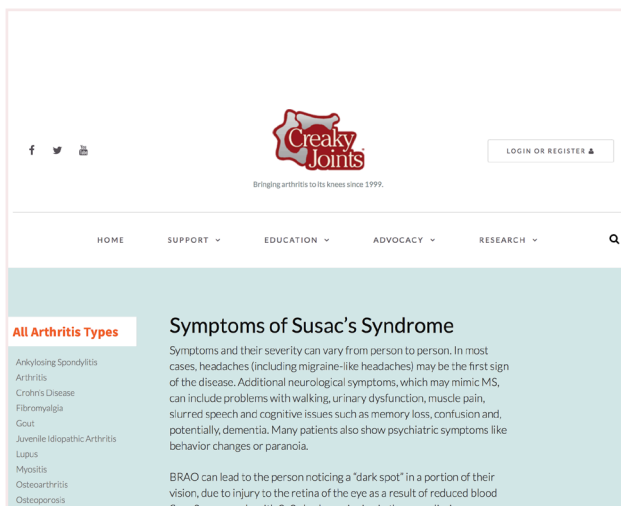
Kicking off Arthritis Awareness Month

Special Guest: Arthritis National Research Foundation

#### June 2017

Advocating For Your Care: Navigating Health Insurance Obstacles

Special Guest: Stephen Marmaras, GHLF Director of State and National Advocacy



## Website Updates

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

- New educational resources on arthritis diseases, including the symptoms and treatment of Susac's Syndrome
- A community-driven list of ways to describe the brain fog that often accompanies chronic disease
- A summary of the current state of gout in the United States to support the gout survey campaign
- A list of lessons our community has learned from living with chronic disease

This spring, the organization also worked on revamping GHLF.org and it will relaunch with a new interface in summer 2017.



## Patient Guidelines

In late June, CreakyJoints announced the publication of the second volume in the “Raising the Voice of the Patient” series, called [“A Patient’s Guide to Living with Ankylosing Spondylitis.”](#) the first ever AS 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 AS treatment and management strategies. This quarter CreakyJoints also developed a volume on psoriatic arthritis, to be published in Summer 2017.

## 2017 Summer Interns

This May, CreakyJoints and Global Healthy Living Foundation welcomed five interns. All summer, these ambitious and bright post and undergraduates positively contributed to the work of our organization. We thank them for their efforts and wish them well in the next school year. Meet our interns:



**Susanna Buff:** Susanna graduated from the University of Pennsylvania’s School of Nursing in May 2017 and hopes to work as a Registered Nurse to provide direct patient care and ground her future in policy development.



**Corey Greenblatt:** Corey graduated from the University of Miami in 2014 with a BA in International Studies and Public Health and is currently studying Health Policy Analysis at Columbia’s Mailman School of Public Health in pursuit of a Masters of Public Health degree. Corey has had Type 1 Diabetes since he was 13 and is very passionate about healthcare reform and chronic disease treatment education. Fun fact: after college he spent two years in Colorado as a Snowboard Instructor before returning to school.



**Kenzie Libbesmeier:** Kenzie is a social work student, rheumatoid arthritis patient-advocate, and writer of the blog Life According to Kenz. She lives in Minneapolis with her service dog in training, Ophelia.



**Kelsey Trumbach:** Kelsey graduated in 2016 from New York University with a BA in history and public health and is attending Columbia University Mailman School of Public Health for her masters of public health in public health policy and management with certificate in health policy analysis. She hopes one day to get her PhD with a focus in public policy and health economics.



**Marguerite Lally:** Marguerite earned her BA in History from Boston College and is currently studying to get her masters of public health at the Columbia University Mailman School of Public Health in the Sociomedical Sciences Department, concentrating on Climate and Health.

## 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](http://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](http://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](http://www.ArthritisPower.org).