

OCTOBER -DECEMBER 2018

# QUARTERLY REPORT

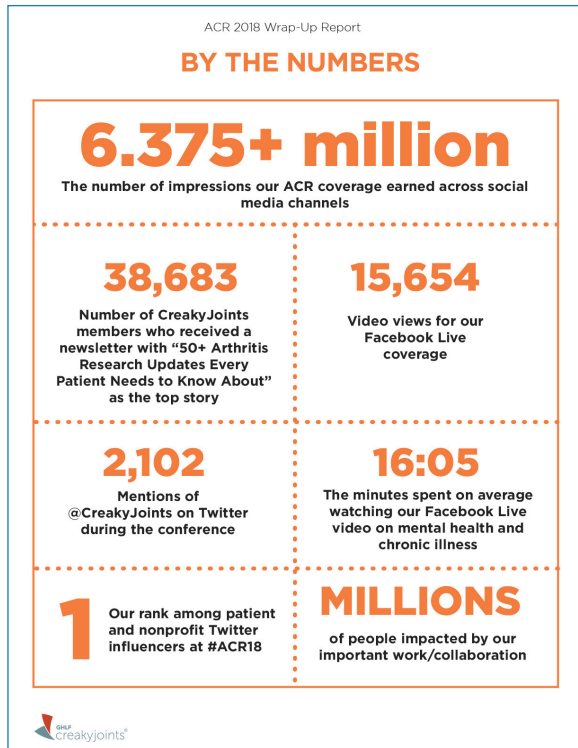


# CREAKYJOINTS DOMINATES SOCIAL CONVERSATION AT ACR ANNUAL MEETING

CreakyJoints continued to establish a leading presence during this year’s American College of Rheumatology (ACR) annual meeting in Chicago (October 19-24, 2018) by connecting directly with scientists, doctors, and patients to disseminate new research findings to our community.

## Live From the ACR Annual Meeting — It’s CreakyJoints!

Under the leadership of Joseph Coe, Director, Education and Digital Strategy, CreakyJoints was the conference’s number-one Twitter influencer among nonprofit and patient groups — and the second-highest overall influencer, according to Symplur.com. We used our voice to give patients a front-row seat to #ACR18. Our team regularly shared key takeaways from posters, abstracts, sessions, and more. There were more than 2,000 mentions of @CreakyJoints on Twitter during the conference.





*From left to right, CreakyJoints staffers W. Benjamin Nowell, PhD; Ryan Johnson; Joseph Coe, MPA (front); and David Curtis during the ACR annual meeting*

For the second year in a row, CreakyJoints was given “Special Reporter” status by ACR, allowing us to provide patient-centered reporting live from the conference floor. Lauren Gelman, CreakyJoints Director, Editorial Services, conducted twice-daily Facebook Live videos with rheumatology experts, covering such topics as managing painsomnia, addressing mental health with chronic illness, and managing osteoarthritis, psoriatic arthritis, rheumatoid arthritis, and ankylosing spondylitis. In a combination of live and taped segments, CreakyJoints interviewed more than 20 doctors, patients, and health care thought leaders. We discussed research, advocacy, and how advances from the conference could impact patient care back home. Our Facebook Live coverage generated more than 15,000 video views during the conference and according to our follow-up polls, 75 percent of people planned to discuss what they learned from the videos with their health care team. In addition, CreakyJoints published more than 25 online news stories disseminating research from the conference in patient-centered language. Our most popular articles included:

- [The 50+ Arthritis Research Updates Every Patient Needs to Know About](#)
- [Fatigue Is a Problem for More Than 80 Percent of People with Arthritis, Says a New Study](#)
- [A New Genetic Test Can Predict Who’s Likely to Get Ankylosing Spondylitis \(and Make It Much Easier to Get Diagnosed Quickly\)](#)
- [These 4 Factors Will Affect Whether or Not You Hit Remission with Rheumatoid Arthritis](#)
- [A New \(Non-Opioid\) Kind of Drug for Knee and Hip Pain May Be a Gamechanger](#)

In addition, our external media outreach to promote our presented research data in conference posters and a podium presentation resulted in trade and consumer coverage in such publications as [MedicalResearch.com](#), [Healio.com/Rheumatology](#), [Health Central](#), and [RadioMD](#).

*Angus Worthing, MD, chair of the American College of Rheumatology (ACR) Government Affairs Committee is interviewed by Lauren Gelman, CreakyJoints Director, Editorial Services during the ACR meeting*



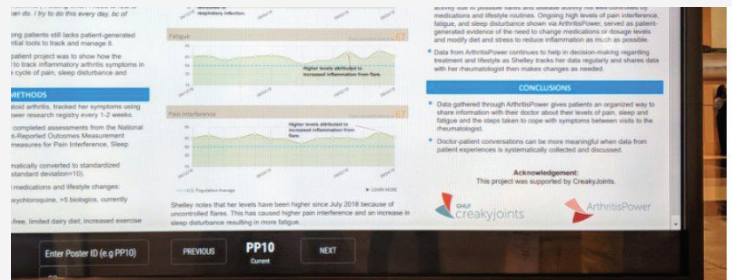
## CreakyJoints Data May Change How Arthritis Is Treated

During the ACR meeting, CreakyJoints data was featured in one oral presentation and seven presented posters. The oral presentation summarized the development of a new tool called the Global Patient-Reported Outcomes Measure (G-PROM). G-PROM combines the range of possible benefits and the full spectrum of potential side effects of medications for rheumatoid arthritis at the individual patient level, thereby helping patients better understand the pros and cons of their treatment options. The study was led by Liana Fraenkel, MD, of Yale School of Medicine. W. Benjamin Nowell, PhD, Director of Patient-Centered Research at the Global Healthy Living Foundation and co-principal investigator of ArthritisPower, was a coauthor.

As part of the first ever [Patient Perspectives Poster Program](#) at the 2018 ACR/ARHP Annual Meeting, patient advocates sponsored by CreakyJoints presented a poster discussing patients' adaptations to better manage painsomnia, or pain-related insomnia. The poster titled "[Using a Mobile App to Facilitate Patient-Doctor Discussions to Make Informed Decisions Regarding 'Painsomnia'](#)" evaluated self-reported ArthritisPower data from a patient who was able to track how her painsomnia was triggered by different medications or disease progressions.

Our studies presented at ACR this year included:

- [Development of a Rheumatoid Arthritis Global Outcome Measure to Enable Comparisons of Patient Experiences Across Treatment Arms in Randomized Clinical Trials](#)
- [Examining Workplace Supports in the Context of RA Disease Activity](#)
- [Health-Related Quality of Life in Patients with Ankylosing Spondylitis in the United States](#)
- [Understanding Patients' Perceptions of Gout](#)
- [Enhancing Patient Ability to Process and Use Information about Medication Risks and Benefits](#)
- [Privacy-Preserving Linkage Between the ArthritisPower Registry and Commercial Payer Claims Data to Support Comparative Effectiveness and Outcomes Research](#)
- ["Doctor, a Storm Is Coming and My Joints Hurt": Evaluating Associations between Weather Changes and Arthritis Symptoms](#)
- [Using a Mobile App to Facilitate Patient-Doctor Discussions to Make Informed Decisions Regarding 'Painsomnia'](#)



*CreakyJoints community member and poster coauthor Dawn M. Gibson presents her poster on painsomnia during the ACR annual meeting.*

## MAKING PHARMACISTS A BIGGER PART OF THE HEALTH CARE TEAM

### CreakyJoints Announces New Partnership with Walgreens

During the ACR annual meeting, Walgreens and AllianceRx Walgreens Prime, a specialty and home delivery pharmacy formed in 2017 by Walgreens and Prime Therapeutics, kicked off a new collaboration with the [Global Healthy Living Foundation](#). The collaboration is focused on helping people living with inflammatory conditions, such as rheumatoid arthritis, Crohn's disease, and psoriasis, better manage their conditions. Walgreens, AllianceRx Walgreens Prime, and GHLF will provide patients with educational resources, including unique digital and print content and products.

Walgreens and AllianceRx Walgreens Prime will work with [CreakyJoints](#) to educate patients about how they can best benefit from working with their pharmacists, who

help them access prescribed medications and manage insurance roadblocks, get symptom relief sooner, and achieve long-term remission of their conditions.

Together, the companies will provide enhanced training for pharmacists at 31 Walgreens community-based specialty pharmacies, as well as AllianceRx Walgreens Prime central specialty locations, to help patients navigate their inflammatory conditions. Walgreens specialty pharmacies and AllianceRx Walgreens Prime's specialty and home delivery pharmacies help patients access, afford, and adhere to their treatments while also helping them to successfully manage their conditions. Designated as specialized locations for inflammatory conditions, all of these locations will offer unique personalized care and resources for patients.

## What's a Specialty Pharmacy?



Walgreens



**A specialty pharmacy is much more than just a medication dispenser. Patients with complex, chronic diseases may need extra help with:**

- ★ Answering questions about how to administer injectable drugs and monitoring side effects
- ★ Managing multiple medications and possible drug interactions
- ★ Dealing with insurance roadblocks to access the medications your doctor prescribes
- ★ Helping find ways to make your medications more affordable

## NEWLY PUBLISHED: PATIENT GUIDELINES EDUCATE AND SPARK ACTION

Biosimilars represent medication choices for chronic disease patients and their physicians. However, despite biosimilars being available for years in Europe and the U.S. Food and Drug Administration (FDA) approving several drugs for a range of diagnoses, very few biosimilars are actually available to patients by prescription due to legal challenges raised by innovator manufacturers, physician prescribing inertia, and barriers to access created by insurance providers and pharmacy benefit managers. To help people with chronic disease better understand the potential of biosimilars, this fall the Global Healthy Living Foundation published [\*A Patient's Guide to Understanding Biosimilars\*](#), which is available as a free downloadable PDF. [The Center for Biosimilars](#) reported on the publication and [Managed Healthcare Executive](#) solicited GHLF Executive Director and cofounder Louis Tharp's perspective on what to expect from the biosimilar marketplace in 2019.

This fall, we also published [\*Caring for Children with Juvenile Idiopathic Arthritis \(JIA\), A Parent's Guide\*](#). JIA affects as many as 294,000 children and adolescents in the U.S. today. The caregiver guide helps people better understand:

- Current treatment options
- How medications work
- How your child will take their medications
- Possible side effects and disease management tips



## ACTIVISTS MAKE HEALTH CARE CHANGE ACROSS THE COUNTRY

### Success in Massachusetts and Ohio

Activists in our 50-State Network alongside our professional team celebrated two key legislative wins toward the end of 2018.

In Ohio, Governor John Kasich signed into law SB265, which adopted patient-friendly requirements related to step therapy protocols implemented by health plan issuers and the Department of Medicaid. Leading up this, in November, our activist Judy Nagy (accompanied by GHLF's Jessica Boles, MSW, LSW, Patient Advocate, Community Outreach Manager) participated in an advocacy day at the state capital to promote passage of this legislation. Judy spoke at the press conference, participated in interviews, and met with her local representatives.

In Massachusetts, several of our 50-State Network activists mailed letters to State Senator Karen E. Spilka urging her to introduce an amendment already passed by the Massachusetts House (and supported by the governor) that would extend the availability of copay assistance programs in the commonwealth through the end of 2019. Without action, the law would have expired (sunset) in the middle of the year. The Massachusetts Senate acted in time to save copay assistance through 2019 right before year end. This year, we will continue to educate legislators about why copay assistance should be an ongoing benefit to people living with chronic disease in Massachusetts — and across America.



*From left to right: Gregory Kapcar, Public Affairs Manager, Global Center for Health Innovation; a patient advocate from another organization; Jessica Boles, GHLF Patient Advocate, Community Outreach Manager; Ohio State Senator Michael Skindell; and 50-State Network volunteer patient advocate Judy Nagy attend a step therapy advocacy day in Ohio.*

## 50-State Network Amplifies Access Issues Related to Migraine Treatment

Helping patients access a full range of novel medications for the treatment of chronic disease remains a core goal for the Global Healthy Living Foundation. People living with chronic migraine can spend years trialing preventive and acute medications for migraine attacks. Despite the availability of a new class of preventive medications, few can access it due to insurance company barriers such as step therapy and prior authorization. At our request, Amaal Starling, MD, a Mayo Clinic neurologist, raised awareness of this issue in a contributed article to [Today's Geriatric Medicine](#) titled, "Crack the Migraine Mystery: It's Not Just a Headache."

Patient activist and chronic migraine patient Peggy S. is an example of how access issues can drive life decisions. In an Op-Ed published

in the [Sandy Springs \(GA\) Neighbor](#), Peggy shared that her preferred physician, in-hospital treatment, and medications were not covered by any of the available health plans on the Georgia healthcare exchange. Therefore, she had a dilemma for 2019. She and her husband could 1) move to a state with more health insurance options or 2) her husband could close his small business and try to find a job that provided better and affordable health insurance. Peggy soon learned she wasn't alone. She posted her published editorial to the Facebook group [Pantsuit Nation](#), which includes more than 3.3 million followers. Within hours, her post generated 300 comments and was "liked" by more than 1,000 people. (As of this writing, Peggy was trying to negotiate with her 2019 HMO plan to cover her prescribed treatment from her out-of-state doctor, a type of specialist not available in Georgia.)

The screenshot shows a Facebook post within the 'Pantsuit Nation' group. The post is by Peggy McGovern Stumhofer, dated December 10, 2018, and is categorized as 'Healthcare, Call to Action'. The text of the post reads: 'To get decent healthcare coverage & the treatments I need for my chronic illness in 2019, my husband & I either have to leave GA or he has to close his small business. Here's our story. "We shouldn't have to move, leave family and friends and drastically change our lifestyle in order to access my doctor and treatments." #ProtectTheACA'. Below the text is a link to an article on MDJONLINE.COM titled 'Do I need to leave Georgia to get decent healthcare?' with a sub-headline 'Washington lawmakers' efforts to chip away at the Affordable Care Act have reduced the variety and affordability of health plans in Georgia so drastically that my husband and I may'. There is a photo of Peggy McGovern Stumhofer. The post has 311 comments and 1K likes. The right sidebar shows the group's profile with 147,312 likes and a 'Sign Up' button. Below that are 'POPULAR TOPICS IN POSTS' including Call to Action (383), Candidates (273), Elections (227), Women Who Lead..., Womens March (124), LGBTQIA (95), Immigration (86), Events (78), and Me Too (73). The 'INVITE MEMBERS' section has a search bar. The 'DESCRIPTION' section says 'We're building the foundation for a more equitable and engaged d... See More'. The 'MEMBERS' section shows 3,351,356 members with a row of profile pictures. The bottom section says 'A SPACE FOR JUST THE PEOPLE YOU WANT' and 'Groups are great for getting things done and staying in touch with just the people you want.'



### **For High Cholesterol Patients, PCSK9 Inhibitors Could Be Their Lifeline**

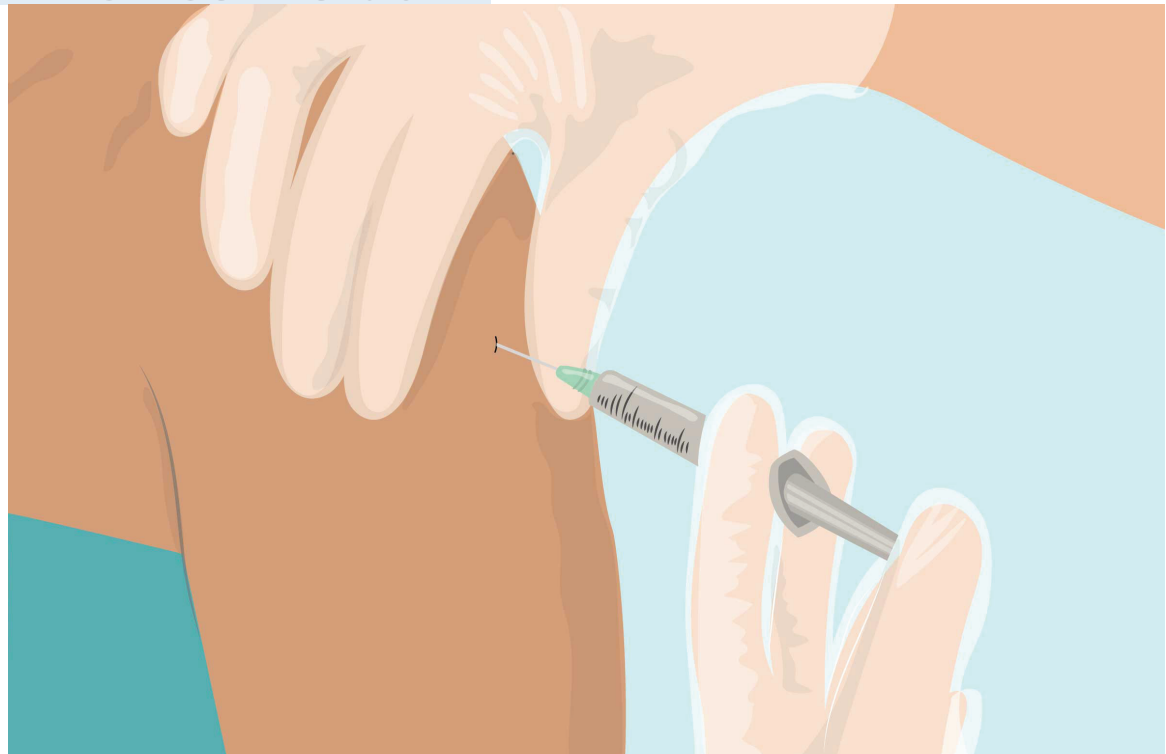
The Global Healthy Living Foundation remains committed to helping people with high cholesterol, such as those with familial hypercholesterolemia (FH) — a genetic disorder that leads to tough-to-treat high LDL cholesterol — or atherosclerotic cardiovascular disease (ASCVD), access prescribed treatments. Despite being FDA-approved more than two years ago, PCSK9 inhibitor medications to treat FH and ASCVD are difficult to access due to insurance protocols demanding step therapy and prior authorization.



In 2018, Sanofi-Regeneron (makers of PCSK9 inhibitor Praluent) and Amgen (makers of PCSK9 inhibitor Repatha) both lowered the cost of their medication, but by different mechanisms. Amgen reduced the list price of their medicine by 60 percent; Sanofi-Regeneron reduced the cost to insurance companies by offering rebates on volume sales.

GHLF is monitoring the situation and providing a phone script that members can use to call their insurance providers to learn what may or may not have changed with their ability to access and pay for these prescriptions. We're asking insurance companies to pass the savings to patients and not keep it for themselves.

This fall we attended and spoke on behalf of patients regarding the importance of medication access at the Association for Black Cardiologists Spirit of the Heart Health and Education Fair and Forum Dinner (October 5-6, 2018 in Charlotte, North Carolina) and during the 2018 American Heart Association Scientific Sessions (November 10-12, 2018, in Chicago, Illinois). The GHLF advocacy team and the FH Foundation also met with the Florida delegation in the U.S. House of Representatives to discuss patient access to high cholesterol drugs. We are hopeful that the reduction in price will be passed on to patients and are keeping the Congressional delegation informed of whether this is happening or not.



**Vaccines Save Lives, But Hesitancy Could Reverse Progress**

GHLF is a staunch supporter of vaccination. We’re particularly invested in ensuring that high school and college students are protected against deadly meningitis. In the fourth quarter, we updated our map tracking meningitis cases across the country. In September, we also worked with the Idaho Immunization Coalition to [promote meningitis vaccination](#).

Despite efforts to raise awareness of vaccination, it’s dismaying that vaccine-preventable disease incidence is on the rise. According to the [World Health Organization](#), “vaccine hesitancy — the reluctance or refusal to vaccinate despite the availability of vaccines — threatens to reverse progress made in tackling vaccine-preventable diseases.” Vaccine hesitancy is listed as one of the top 10 health threats in 2019.

In Rockland County, New York, home of the GHLF and CreakyJoints headquarters, 124 cases of measles (as of January 30, 2019) have been reported and have been traced back to parents not vaccinating their children.

Washington Gov. Jay Inslee recently declared a public health emergency when Washington’s measles outbreak reached 30 cases. Meningitis is a quick and silent killer, but measles is not just a harmless childhood disease, as many people think. The Centers for Disease Control [says](#), “Some people may suffer from severe complications, such as pneumonia (infection of the lungs) and encephalitis (swelling of the brain). They may need to be hospitalized and could die. As many as one out of every 20 children with measles gets pneumonia, the most common cause of death from measles in young children.”

# CREAKYJOINTS GROWS COMMUNITY WITH NEW PROGRAMS, CONTENT

## CreakyJoints and Global Healthy Living Foundation in the News

During the fourth quarter, there were 38 earned media placements featuring CreakyJoints members or leadership, generating more than 46 million media impressions. Coverage of the Spring/Summer 2019 Tumbler and Topsy® by Michael Kuluva collection at New York Fashion Week sponsored by CreakyJoints included high-profile placements in [LA Fashion Magazine](#), two [Healthline videos](#) (featuring Michael and CreakyJoints member Charis Hill, who walked as a model in the show), and [Health Central](#). Our leadership also had the opportunity to comment on breaking news in interviews with [Everyday Health](#) on their coverage of newly approved Humira biosimilar and [STAT's](#) coverage of Amgen reducing its pricing on its PCSK9 inhibitor. As a result of our outreach, [Today's Geriatric Medicine](#) published online and in print an expert perspective on the challenges of living with gout, which highlighted CreakyJoints' 2017 State of Gout survey results.

## Finding Community During #CreakyChats

Our popular #CreakyChats Twitter chats continue to be well attended and generate impactful conversations about living with chronic illness, particularly when we partner with special guests. Recent chat topics include:

- **November:** Having a Seat at the Table: What “Patient-Centered” Means to Us, featuring @DawnMGibson and @SynceNerd\_Carli
- **December:** Make Sure You Don't Lose Your Sparkle: Taking Care of Yourself in the New Year, featuring @hannahmosk



Join #CreakyChats

Make Sure You Don't Lose Your Sparkle:  
Taking Care of Yourself in the New Year

Monday, December 17th, at 6:00 PM EST

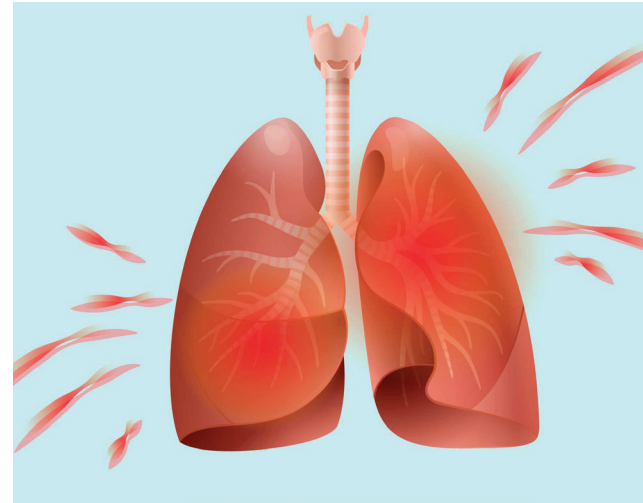
Hosted by  Special Guest:  
@hannahmosk 



## What the CreakyJoints Community Is Reading

Our editorial department continues to develop a robust library of educational content about arthritis and rheumatic conditions. Our reporters and writers cover arthritis news, CreakyJoints research, stories of our members, and advice for living well with arthritis and related diseases. Here's a sample of popular content produced in the fourth quarter:

- [The 4 Stages of Rheumatoid Arthritis Progression](#)
- [A New Report Says These Are the 15 Best States to Live In If You Have Arthritis \(and Here Are the 2 Worst\)](#)
- [The Signs Arthritis Is Affecting Your Lungs, and the 3 Things You Must Do to Protect Them](#)
- [11 Common Questions About Taking Methotrexate for Rheumatoid Arthritis](#)
- [12 Ankylosing Spondylitis Symptoms You Can't Afford to Ignore](#)
- [Arthritis Fatigue: 7 Science-Backed Tips to Help You Cope](#)
- [CBD Oil for Arthritis Pain: Does It Relieve Symptoms?](#)
- [Gout Home Remedies: Here's What You Can \(and Can't\) Do to Relieve Gout Pain Fast](#)
- [10 Tricks to Cut Out Sugar and Improve Arthritis Symptoms \(and Not Even Miss It\)](#)



### **[PainSpot](#) by CreakyJoints: A Destination for Enhanced Educational Content**

In the fourth quarter, CreakyJoints merged with PainSpot, a digital risk assessment tool, to form PainSpot by CreakyJoints. Created in 2015 by Sacramento rheumatologist Doug Roberts, MD, PainSpot contains information about more than 50 different musculoskeletal conditions. Users take a short 15- to 20-question assessment about their pain symptoms and are then provided with a risk assessment sheet for conditions they are most likely to have. Patients can use this report to have informed, proactive conversations with their health care providers.

In 2019, PainSpot by CreakyJoints will improve its functionality and user interface, enhance educational content and calls to action, and connect users with physicians for further evaluation. Dr. Roberts now chairs GHLF's international diagnosis accelerator medical advisory board, which will meet throughout 2019 in person and by teleconference.

### **Be Empowered via the Pep Talk Program**

Our Pep Talk pilot program is a peer-to-peer educational resource that offers guidance, support, mentorship, and non-medical advice to newly diagnosed patients living with rheumatoid arthritis and patients facing barriers to treatment from seasoned patient peers that are trained and certified to provide peer education.

In October, GHLF's Jessica Boles met with various stakeholders at the National Organization for Rheumatology Mangers conference in Tampa, Florida, to introduce Pep Talk to our community partners. We have developed a robust curriculum and various training tools to educate our peer education specialists for our new peer-to-peer pilot program. In December, we began recruitment through a few select rheumatology practices to begin offering our peer education specialist training to seasoned patients and volunteer participants.

## **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. Some of the meetings were private. Public meetings are listed below.

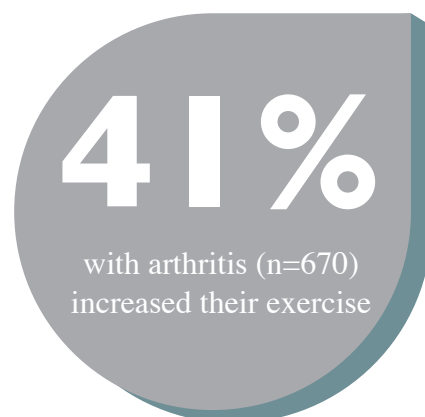
- October 4-6: Jessica Boles and Corey Greenblatt, MPH, Manager of Policy and Advocacy, attended the annual conference of the National Organization of Rheumatology Managers to discuss advocacy and peer education opportunities.
- October 9: Corey Greenblatt provided public comment to New Hampshire legislators in support of reforms to pharmacy benefit manager practices and drug pricing transparency.
- October 13: Regis Wagner, MSW, Patient Advocate, Community Outreach Manager, attended the Miles for Migraine Race in Washington, D.C. to support migraine awareness.
- October 30: Corey Greenblatt and Steven Newmark, MPP, JD, Director of Policy and General Counsel attended the annual board meeting for the Digestive Disease National Coalition to present on common patient access issues at the state and federal policy level.
- November 9: Jessica Boles attended the Rheumatology Nurses Society Advocacy Experience Day.
- December 13-15: Steven Newmark attended the annual Advances in IBD conference to learn about the latest innovations in IBD treatment and meet with key opinion leaders.

## **ARTHRITISPOWER® & PATIENT-CENTERED RESEARCH**

### **ArthritisPower Brings Research to Real People**

Each month, we send one-item “quick polls” to more than 17,500 consented ArthritisPower participants. This allows us to regularly engage with all our users and remind them to use ArthritisPower, which is vital to inform the many different studies in progress.

Through our community polls, in December, we learned that only 41 percent of people with arthritis (n=670) increased their exercise following diagnosis, despite regular exercise being recommended for everyone (osteoarthritis and inflammatory arthritis). In addition to sharing poll results and associated educational content with our members, we also used the poll to generate a live interview on DOCTOR Radio (Sirius XM) for Dr. Alexis Ogdie, Assistant Professor of Medicine at the Hospital of the University of Pennsylvania, Assistant Professor of Epidemiology in Biostatistics and Epidemiology and Medical Advisor to CreakyJoints. The interview aired in early January.



## Current ArthritisPower statistics as of December 31, 2018:

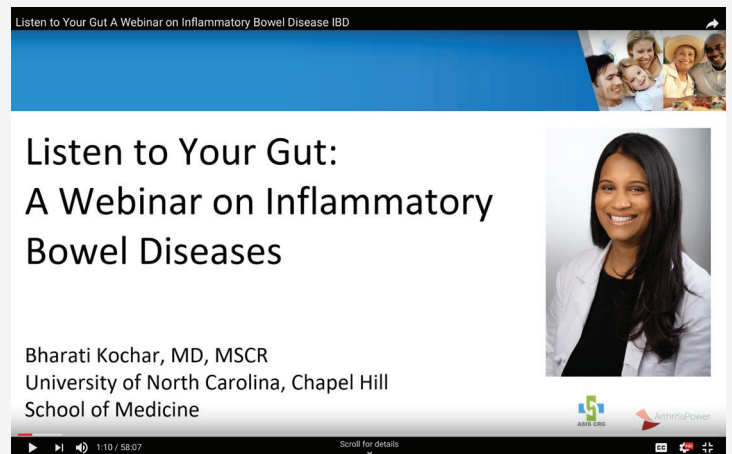
- Total members: **17,940**
- Total patients: **17,505**
- Total number of completed patient reported outcomes (PRO) assessments: **177,336**
- Number of unique participants who have completed PRO assessments: **12,912**
- Number of unique participants who have reported at least one condition (includes variations of comorbidities): **17,415**
- Number of unique participants who have reported at least one medication (includes combination of medications): **4,776**

17,940

## Our Educational Webinars Tie Back to Research

Many of our members are looking for a deep dive into specific health topics, some of which are under investigation in ArthritisPower. Recorded versions of each webinar are available at [CreakyJoints.org](http://CreakyJoints.org) and on our YouTube channel. Topics presented during the fourth quarter included:

- [Listen to Your Gut, A Webinar on Inflammatory Bowel Disease IBD](#), featuring guest speaker Bharati Kochar, MD, MSCR, University of North Carolina, Chapel Hill, School of Medicine (December 13, 2018)
- [Vaccination Concerns Among Patients with Autoimmune Diseases](#), featuring guest speaker Justin K. Owensby, PharmD, PhD, Department of Clinical Immunology and Rheumatology, University of Alabama at Birmingham (UAB) (December 5, 2018)
- [Know Your Medical Device Why the Unique Device Identification UDI System Should Matter to You](#), featuring guest speaker Terri L. Reed from the U.S. Food and Drug Administration Center for Devices and Radiological Health (October 12, 2018)



Listen to Your Gut: A Webinar on Inflammatory Bowel Diseases

Bharati Kochar, MD, MSCR  
University of North Carolina, Chapel Hill  
School of Medicine

1:10 / 58:07

ArthritisPower

### Multiple Arthritis Research Projects Underway

ArthritisPower research continues. Select studies in progress include:

- The Smartwatch Study: Digital Patient-Reported Outcomes and Wearable Data Collection from Rheumatoid Arthritis (RA) Patients in a Real-World Setting (Co-PIs: W. Benjamin Nowell, PhD; Jeffrey Curtis, MD, MS, MPH; Ginger Haynes, PhD)
- Examining the Experience of Rheumatoid Arthritis (RA) and Psoriatic Arthritis (PsA) Patients on Methotrexate Therapy (Co-PIs: W. Benjamin Nowell, PhD; Shilpa Venkatachalam, PhD; Jeffrey Curtis, MD, MS, MPH; Elaine Karis, MD)
- Analysis of the Top Patient-Reported Outcomes (PROs) by Disease within ArthritisPower (Co-PIs: W. Benjamin Nowell, PhD; Jeffrey Curtis, MD, MS, MPH; Carol Gaich, PhD)
- Healthy Mind, Healthy You: A Dose Finding Study of Mindfulness (PI: Andrew A. Nierenburg, MD)
- 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; Timothy Beukelman, MD)
- Arthritis Patient Attitudes and Behaviors Relating to Medical Marijuana (Co-PIs: W. Benjamin Nowell, PhD; Kelly Gavigan, MPH)

### ArthritisPower Patient Governors Annual Summit

The ArthritisPower Patient Governor Group (PGG) is a group of arthritis patients dedicated to patient-centered research who serve as advisors, advocates, ambassadors, and research collaborators for ArthritisPower, the first ever patient-led, patient-centered research registry for joint, bone, and inflammatory skin conditions. The Patient Governors’ Summit is an annual in-person meeting where we invite the members our Patient Governor Group (PGG) to discuss current trends in research and the specific research projects we are currently working on related to ArthritisPower.

During our 2018 summit in Phoenix, Arizona held October 5-7, we covered topics such as cardiovascular risk among patients with rheumatoid arthritis; management and treatment of osteoarthritis; biosimilars; vaccination concerns among patients with autoimmune diseases; common commodities in arthritis; and coping with a chronic disease. Joining us to present these topics were experts in rheumatic and musculoskeletal diseases from across the country: Nancy Lane, MD (Director, Center for Musculoskeletal Health at University of California at Davis School of Medicine); Madelaine Feldman, MD

(President, The Coalition of State Rheumatology Organizations); Justin Owensby, PharmD, PhD (University of Alabama at Birmingham, Rheumatology); Joan Bathon, MD (Columbia University School of Medicine, Rheumatology) and Laurie Ferguson, PhD, a New York-based psychotherapist, and Director, Education Development at the Global Healthy Living Foundation.



## WHO WE ARE



### **About the Global Healthy Living Foundation**

The [Global Healthy Living Foundation](http://www.GHLF.org) is a 501(c)(3) non-profit 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®](http://www.CreakyJoints.org), the digital arthritis community for millions of arthritis patients and caregivers worldwide who seek education, support, activism, and patient-centered research through [ArthritisPower®](http://www.ArthritisPower.org), the first-ever patient-centered research registry for joint, bone, and inflammatory skin conditions. Visit [www.GHLF.org](http://www.GHLF.org) for more information.



### **About the 50-State Network**

The [50-State Network](http://www.50StateNetwork.org) is the grassroots advocacy arm of the [Global Healthy Living Foundation](http://www.GHLF.org). It is comprised of patients with chronic illness who are trained as health-care activists to proactively connect with local, 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](http://www.50StateNetwork.org).



### **About CreakyJoints®**

CreakyJoints is a digital community 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](http://www.CreakyJoints.org), and the 50-State Network, which includes more than 1,200 trained volunteer patient activists.

As part of the [Global Healthy Living Foundation](http://www.GHLF.org), CreakyJoints also has a patient-reported outcomes registry called [ArthritisPower®](http://www.ArthritisPower.org) with nearly 18,000 consented arthritis patients who track their disease while volunteering to participate in longitudinal and observational research. CreakyJoints also publishes the popular “[Raising the Voice of Patients](http://www.RaisingtheVoiceofPatients.org)” series, 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](http://www.CreakyJoints.org). To participate in our patient-centered research program, visit [www.ArthritisPower.org](http://www.ArthritisPower.org).



### **About ArthritisPower®**

Created by [CreakyJoints®](http://www.CreakyJoints.org) 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 to access registry data or solicit the community to participate in unique, voluntary studies. To learn more and join [ArthritisPower](http://www.ArthritisPower.org), visit [www.ArthritisPower.org](http://www.ArthritisPower.org).