



QUARTERLY REPORT

APRIL – JUNE 2020

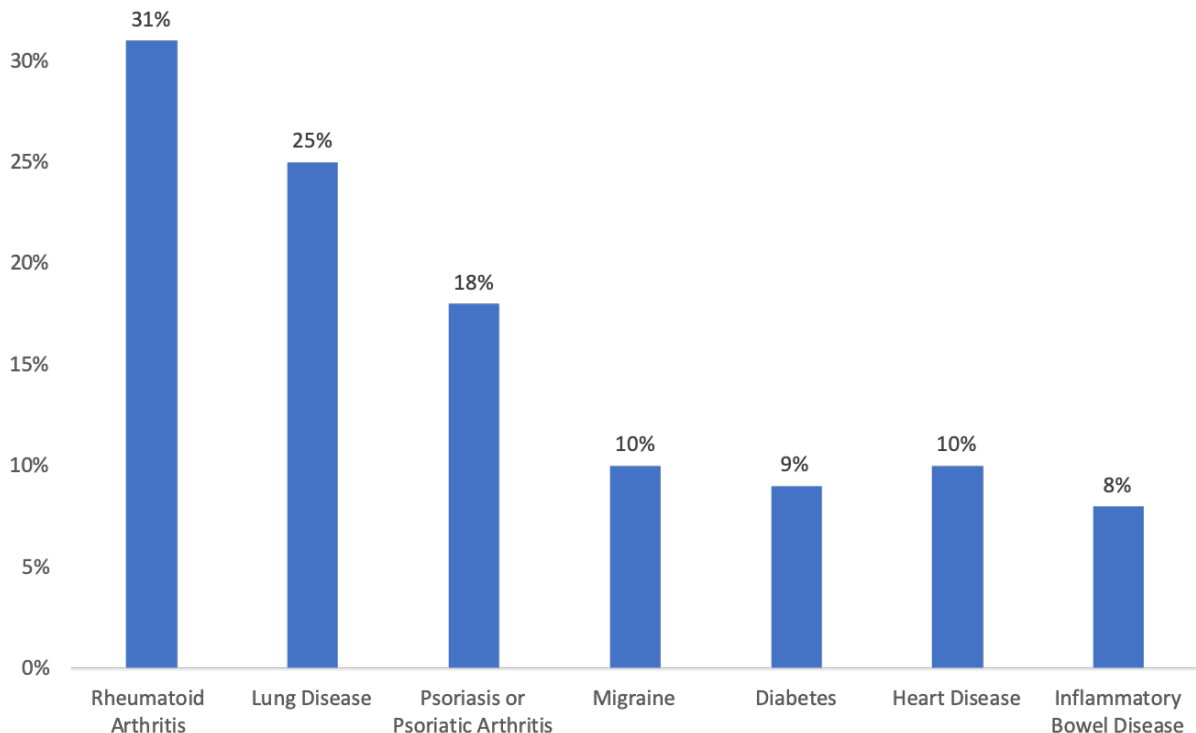


GLOBAL
HEALTHY
LIVING
FOUNDATION

GHLF AND CREAKYJOINTS® CONTINUE TO LEAD THE COVID-19 RESPONSE FOR THE CHRONIC DISEASE COMMUNITY

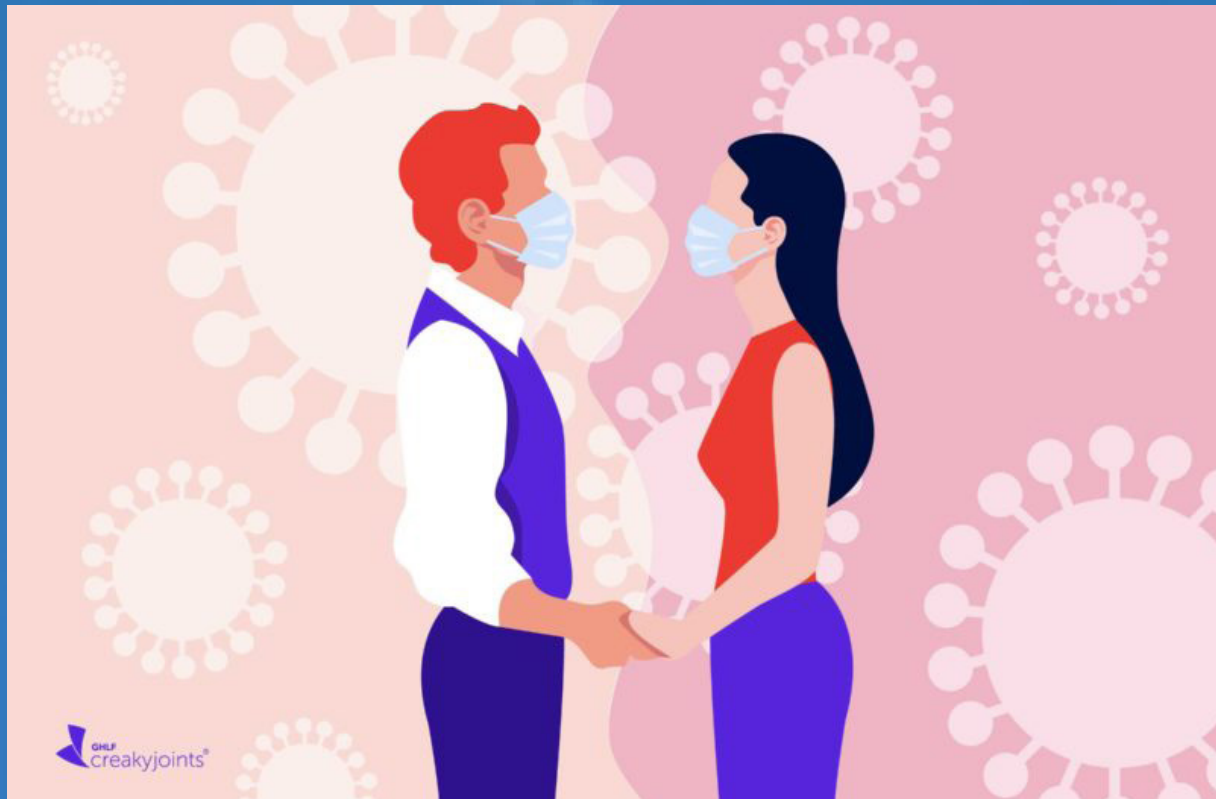
CreakyJoints and the Global Healthy Living Foundation (GHLF) remain committed to being a primary and credible resource to people living with chronic disease during the COVID-19 pandemic. To that end, in mid-March, we launched a patient support program for people living with chronic illness to help them navigate the coronavirus pandemic— **whether they have COVID-19 or not.**

Informed by our COVID-19 Patient Leadership Council, the program has grown rapidly and meets the many underserved needs of high-risk and chronic illness patients. The free program includes more than 15,858 diverse members and more than 26,402 subscribers as of June 30. The disease demographics are:



■ ROBUST CONTENT

We know our arthritis and patient support communities have questions about how to cope during the pandemic. To address these concerns and initiate dialogue, from April through June, GHLF published 10-15 articles per week with original coronavirus-related content, which generated nearly 3.5 million pageviews. Many of these articles were also published in Spanish and made available on the [CreakyJoints Español](#) website and its [Instagram](#) page.



Here are some of our most popular Covid-19 articles from the second quarter, which range from managing mental health, first-person testimonials, and summarizing the latest science:

- [Have Difficulty Breathing in a Face Mask? Advice for People with Asthma and Lung Disease](#)
- [What Is a ‘Cytokine Storm,’ Exactly? What Autoimmune Disease Patients Need to Know](#)
- [Wearing a Face Mask in Public: What Chronic Illness Patients Need to Know](#)
- [You’re High Risk and Your Partner Has to Work Outside the Home: 7 Coronavirus Precautions to Take](#)
- [‘COVID Toes’ and Rashes: 6 Important Things to Know About Coronavirus Skin Symptoms](#)
- [The 5 Main Things We Learned from the Biggest Study on COVID-19 in Rheumatology Patients to Date](#)

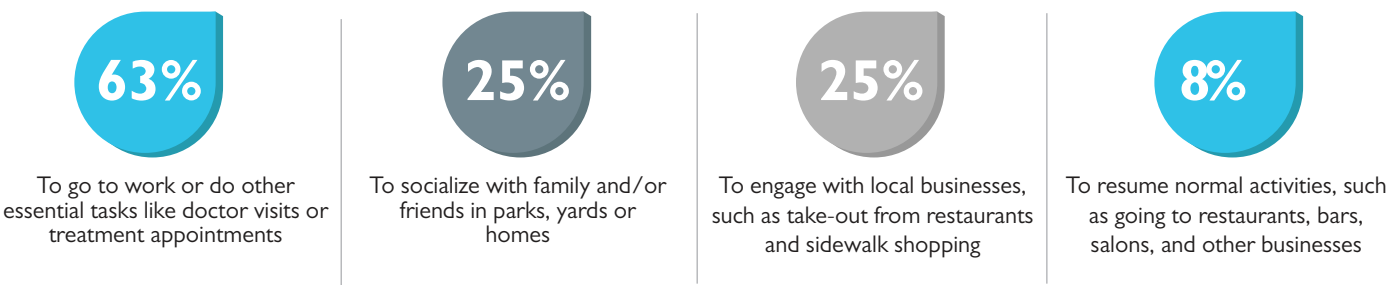
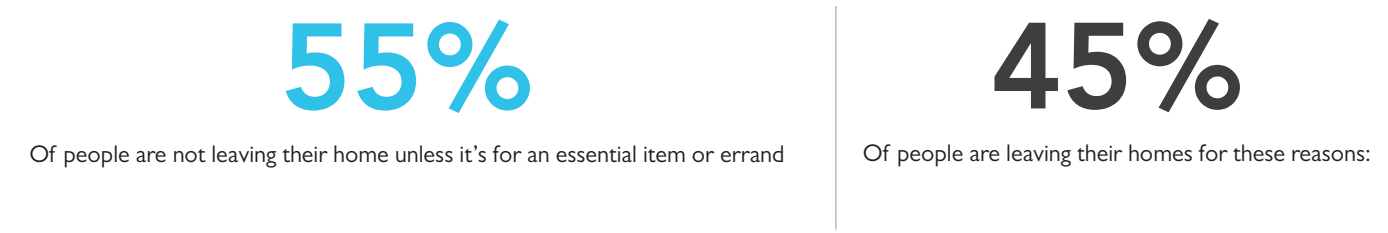
IN TOUCH WITH OUR COMMUNITIES

We've continued to ask questions of the patient support community to better understand the perspective of chronic disease patients. In May, when some states slowly began to re-open for business, our members provided perspective on their willingness to wear masks and their approach to social distancing.

Poll: How often do you wear a mask to protect yourself and others from coronavirus?



Poll: Now that businesses are starting to re-open, what is your approach to social distancing?



The qualitative responses are as informative as the quantitative

“ I try to visit places where masks are required by the business, such as Costco. When walking in my neighborhood, although most people are not wearing masks outside, people watch and step aside when we are going to pass on the sidewalk. We jokingly refer to it as doing the sidewalk dance.

I wear a mask to show that I care about others and their health and mine. Masks are a sign of respect for the whole community. “

“ I am more afraid now than when we were in lockdown. Judging by what I saw when I picked up a curbside order at Target, people are acting like everything is over. The store's parking lot was full and most people were not wearing masks

We've also asked our patient council for their insights on their levels of anxiety, whether they've changed, how and when they see their health care team, and their plans for how they take their medications. In April, our members were most concerned about medication shortages, particularly in light of the U.S. Government suggesting treatments such as hydroxychloroquine which was promoted by President Trump without scientific evidence of efficacy.

#CRAKYCHATS INSPIRE CONVERSATION

April: COVID-19 Hot Topics in the Chronic Disease Community, co-hosted by #SpoonieChat

We were joined by the patient leaders who created the #HighRiskCovid19 movement that was born on Twitter, such as Dawn Gibson, who runs the #SpoonieChat community. Our discussion looked at true costs of re-opening society too early; what life may look like for chronically ill and disabled people in a post-coronavirus world; and ways we can continue to support and build community together during and after this crisis. The conversation generated 5 million impressions and 101 participants.

May: Our May #CreakyChats featured the leading health website Everyday Health as a special guest. With our Arthritis Awareness Month theme “Fine Is Not Fine” powering our discussion, we spoke about various aspects of managing chronic illness during the pandemic. We generated 56 million impressions via 103 participants.



EVERYDAY  HEALTH™

PARTNERING WITH EXPERTS

On May 29, CreakyJoints, the U.S. Centers for Disease Control and Prevention (CDC), and a community-based rheumatologist from United Rheumatology produced a Facebook live for how chronic disease patients can better control their health during COVID19. United Rheumatology is a rheumatology care management organization that serves more than 600 independent rheumatologists across the country.

The invited speakers at this event included:

- Shilpa Venkatachalam, PhD, Associate Director of Patient-Centered Research at the Global Healthy Living Foundation
- Anne Kimball, MD, MPH, CDC National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention; Division of Sexually Transmitted Disease Prevention
- Max Hamburger, MD, Founder, Executive Chairman and Chief Medical Officer of United Rheumatology and Managing Partner of Rheumatology Associated of Long Island (RALI)

Reaching more than 6,000 people, discussion topics included how to manage an underlying chronic illness during the pandemic, how to stay safe when going to the doctor's office, when to take advantage of telehealth appointments, as well as updates on vaccine development and what the latest research says about how people with chronic illness and rheumatic conditions are faring if they get infected.



Additional detail about the event is available on our website at [COVID-19, Chronic Illness, and the CDC: Key Learnings from Our Facebook Live Event](#).

■ DIVING DEEPER TO LEARN MORE ABOUT THE IMPACT OF COVID-19

In the second quarter, our research team launched the Arthritis and Rheumatic Disease COVID-19 Project, part of the Autoimmune COVID-19 Project, a longitudinal study for patients with multiple sclerosis (MS), arthritis, Crohn's and colitis, and vasculitis. It will track the evolving impact of COVID-19 on patients living with these conditions. The Project is being led by CreakyJoints and implemented via its 28,000-member [ArthritisPower® Research Registry](#) in partnership with three other patient research networks, [IBD Partners](#), [iConquerMS™](#), and the [Vasculitis Patient-Powered Research Network](#). All four, including ArthritisPower, are known collectively as the Autoimmune Research Collaborative (ARC), a group initially convened with funding support from the [Patient-Centered Outcomes Research Institute \(PCORI\)](#), a long-term CreakyJoints research funding source.

As reported in [Rheumatology Advisor](#), “What

makes this study unique is that it is more than just a snapshot in time of patient perspectives. By a longitudinal analysis, this study aims to help us understand the experiences, beliefs, and concerns of patients with respiratory illness symptoms, COVID-19 testing, modified doctor visits using telehealth, the choices they make about immunosuppressive treatments, and their preferred sources of information about COVID-19. Through this method, we can advance our understanding on how an infectious disease pandemic affects the quality of life of these patients, and it helps us provide better support for these populations in a way that can also enhance shared decision-making for the management of autoimmune diseases.”

This study is being conducted in both English and Spanish and already has over 20,000 participants. In the second quarter, the study passed the 8-week follow-up for those who completed baseline assessments at launch. Additional follow-up will take place every four weeks moving forward.

- An additional survey has been designed specifically around telehealth and telemedicine to understand patients' perceptions, behaviors and utilization of this healthcare delivery channel.
- Abstracts with preliminary baseline results were submitted for consideration to the American College of Rheumatology (ACR) 2020 Convergence.
- Manuscripts have been submitted to peer-review medical journals to report early results.
- A webinar for sponsors of the study was held on July 29 to offer an initial look at data and discussion with lead investigators.

THE INTERSECTION OF HEALTH DISPARITIES, DISABILITY AND BLACK LIVES MATTER

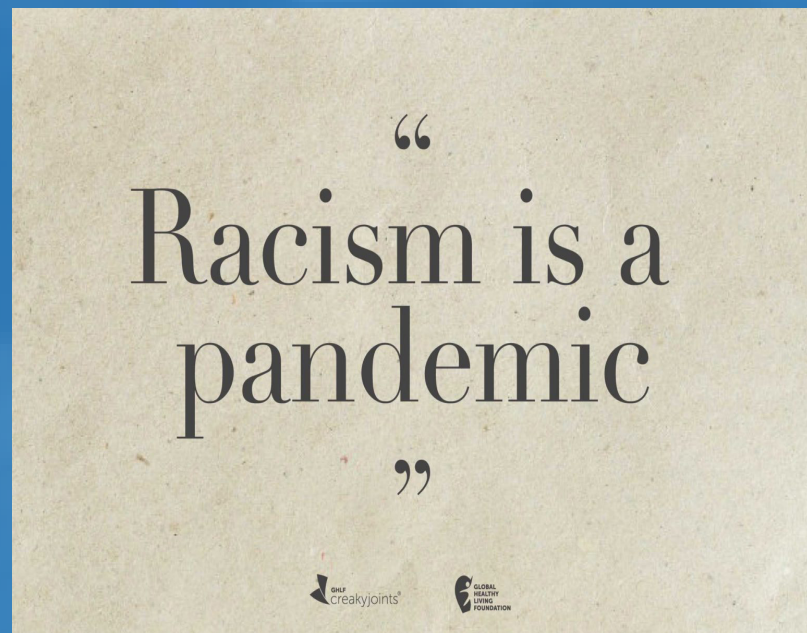
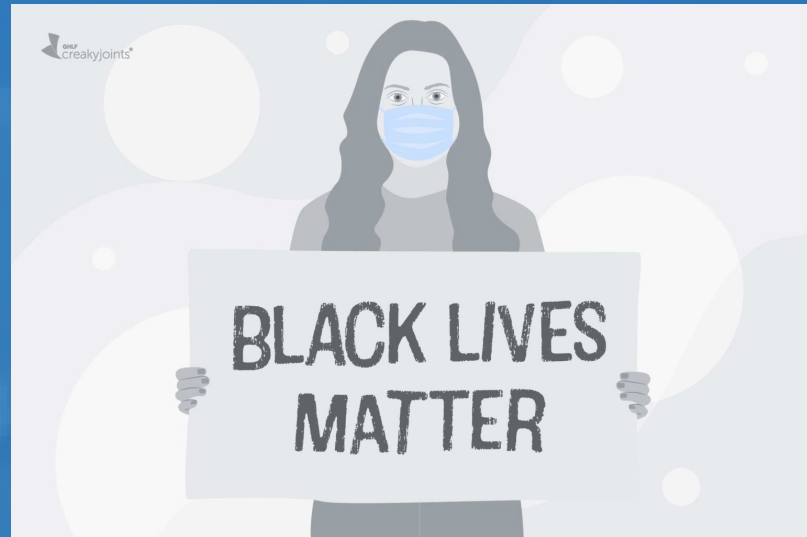
In the United States, on top of the community and individual stress caused by the COVID-19 pandemic, it is also a time of increased social justice activity as the #BlackLivesMatter movement grows following the tragic deaths of George Floyd, Breonna Taylor, Ahmaud Arbery, and many others.

We published these articles and statements to show support:

www.ghlf.org/fight-for-racial-justice-high-risk-for-coronavirus/

www.ghlf.org/racism-is-a-pandemic/

www.ghlf.org/supporting-black-lives-matter/



At CreakyJoints and all of GHLF’s online communities, we focused on how we could help raise the volume of our members’ voices, particularly those people of color who also live with disability. We invited three social influencers to host a #CreakyChats Twitter discussion centered on Black Lives Matter and disability. During that event, there was also a discussion about COVID19 and attending rallies/demonstrations while being high risk for COVID19 complications was raised. Participating hosts included:

- **Tinu Abayomi-Paul (@Tinu)**: Tinu Abayomi-Paul is a disability activist and the founder of [Everywhere Accessible](#). She maintains a master list of Twitter chats and patient-facing hashtags to help the community easily find resources and each other. Her e-book on being a spoonie with cancer comes out later this year.

- **Dawn Gibson (@DawnGibson)**: Dawn Gibson founded the Twitter support group Spoonie Chat in 2013, which has grown into a thriving community of mutual support, friendship, and solidarity for patients living with chronic illness. Health care providers, health care organizations, and non-profit foundations rely on Spoonie Chat to hear directly from the community about patients’ experiences.

- **Imani Barbarin (@Imani_Barbarin)**: A graduate of Eastern University with a degree in Creative Writing and a minor in French from the Sorbonne, Imani Barbarin Twitter-defining sentence is “Crutches&Spice: Rude For A Disabled Person.” She writes from the perspective of a Black woman with Cerebral Palsy. She specializes in blogging, science fiction and memoir.

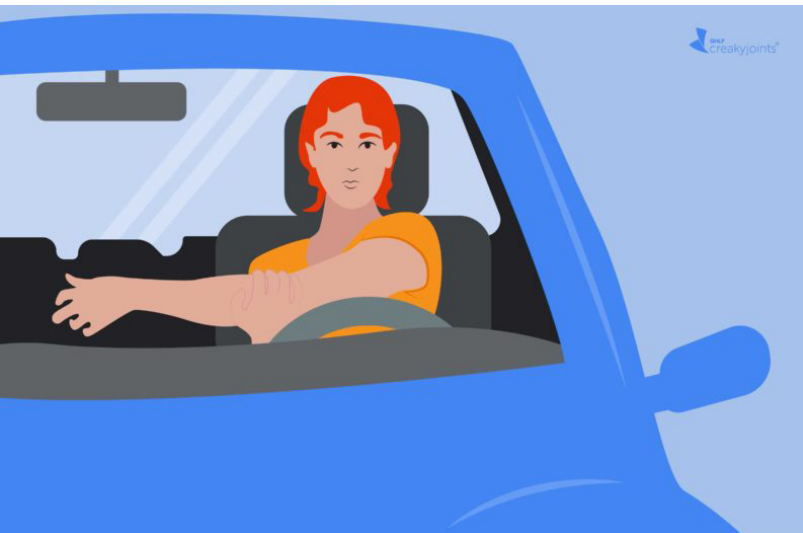
THIS CHAT
GENERATED
24.5 MILLION
IMPRESSIONS,
FROM **920**
PARTICIPANTS
WHO WROTE
3,244 TWEETS

In April, Shilpa Venkatachalam, PhD, Associate Director of Patient-Centered Research at CreakyJoints, raised the voice of patients further when she spoke about how racial health disparities impact people’s ability to access healthcare in a [Public Radio International](#) interview that aired on over 300 stations and posted to 600 websites. She also contributed an opinion piece to [The Future of Personal Health](#) website.

EDUCATIONAL ARTICLES

While we continue to produce engaging and informative content specific to the concerns of many chronic disease communities related to the pandemic, we've also sustained our prolific publishing schedule of general arthritis articles. This included more than 150 original patient-centered articles written in the second quarter that included COVID-19, medical conferences, gout, psoriasis and Arthritis Awareness Month.

- [6 Gentle Stretches to Relieve Stiffness from Driving with Arthritis](#)
- [Summer Shoes and Arthritis: 8 Types That Cause Foot Pain \(and How to Prevent It\)](#)
- [How to Talk to a New Dating Partner About Your Chronic Illness and Disabilities, According to Health Psychologists](#)
- [Working at Home with Arthritis: 5 Important Tips for Less Pain](#)
- [There Are Updated Treatment Guidelines for Gout and Here's What You Should Know About Them](#)
- [Psoriasis Itch: 8 Dermatologist-Approved Home Treatments to Get Some Relief](#)
- [NSAID Timing: Daytime Use Might Be Better than Nighttime Use](#)
- [10 Ways Socks Can Be the Best Arthritis Home Remedy You Never Thought About Using](#)



ARTHRITISPOWER RESEARCH CONTINUES

Current ArthritisPower statistics as of June 30, 2020:

- Total patients: **28,594**
- % increase in membership from 6/30/19: **51%**
- Top 5 Conditions:

| | |
|-----------------------|---------------------|
| Osteoarthritis: | 16,274 (57%) |
| Rheumatoid Arthritis: | 12,700 (44%) |
| Fibromyalgia: | 10,729 (38%) |
| Osteoporosis: | 4,433 (16%) |
| Psoriatic Arthritis: | 3,846 (13%) |
- PROMIS Measures, mean (SD)

| | |
|-------------------|-------------------|
| Pain Interference | 64.2 (7.3) |
| Fatigue | 63.4 (9.1) |
| Physical Function | 37.0 (7.1) |

If you or someone you know would like to participate in an arthritis research study, please sign up at ArthritisPower.org and, after you consent to participate in research, your profile will be matched against open studies. You will receive an invitation to participate when a match is made. If you are an ArthritisPower member and think you may qualify for one of the studies below, please reach out to **Kelly Gavigan, Manager, Research and Data Science** at kgavigan@ghlf.org.

NEWLY PUBLISHED ARTHRITISPOWER RESEARCH

Email vs. Postal Mail For Research Participation

Chen, X., Agiro, A., Nowell, W.B. et al. Harnessing health plan enrollee data to boost membership in patient-powered research networks. *BMC Health Serv Res* 20, 462 (2020).

<https://doi.org/10.1186/s12913-020-05325-z>

The objective of this study was to evaluate the effectiveness of two common insurance company-initiated outreach methods (postal mail versus email) for inviting prospective candidates to participate in their research projects. Invitations were successfully delivered to 13,834 (94.9%) mail group members and to 10,205 (70.0%) of email group members. A small but significantly larger proportion of mail group members, ($n = 78$; 0.54, 95% Confidence Interval [CI] {0.42–0.67%}) registered in patient-powered research networks (PPRNs) relative to the email group ($n = 24$; 0.16, 95% CI {0.11–0.25%}), $p < 0.001$. Dr. Nowell and his research partners concluded that, “A health plan outreach to invite members to participate in PPRNs was modestly effective. Regular mail outperformed less costly email. Providing more value-add to participants may be a possible way to increase recruitment success.”



OTHER STUDIES IN PROGRESS INCLUDE:

- **WEARable Activity Tracker Study Exploring Rheumatoid Arthritis Patients' Disease Activity using ArthritisPower Registry Patient Reported Outcome Measures and Biometric Sensor Data (the WEAR study):** Building on our experience designing and implementing the ArthritisPower Smartwatch study, we are planning a study of people living with rheumatoid arthritis (RA) from several clinical sites across the US to evaluate associations between biometric sensor data, physician-derived data, and electronic patient-reported outcomes (ePROs) over time. In addition to this primary aim, we will explore the accuracy and predictive validity of biometric sensor data, physician-derived data, and ePROs to observe changes in disease activity and symptoms while tracking improvements in patients involved in the study. This study is sponsored by the Health Economics and Outcomes Research (HEOR) group at AbbVie US. The study protocol was recently approved by AbbVie's Protocol Review Committee. Register at [ArthritisPower](#) to be notified when the study opens.
- **Real-World Patient Experience and Preferences in Patients with Psoriatic Arthritis (PsA):** The primary objective of this project is to better understand PsA patients' experience with their disease and its treatment. This study is being designed and conducted in partnership with RTI International and with PsA experts from the rheumatology divisions of the Universities of Pennsylvania and Utah Schools of Medicine. It is sponsored by the Health Economics and Outcomes Research (HEOR) group at AbbVie US. The patient survey was recently pilot tested, and the research team is now reviewing patient feedback. Recruitment will begin in late summer. Register at [ArthritisPower](#) to be notified when the study opens.
- **Patient Outcomes: Real World Evidence in Rheumatoid Arthritis (the POWER study):** The POWER study is being conducted in partnership with the Corrona® RA registry. Approximately 500 RA patient participants will be recruited at Corrona clinical sites and then provide longitudinal ePRO (electronic patient-reported outcomes) data via custom workflow in the ArthritisPower smartphone app. The primary aim of the study is to better understand the experience, disease activity, and symptoms of RA patients treated with janus kinase inhibitors (JAK inhibitors) over time. This study is sponsored by the Health Economics and Outcomes Research (HEOR) group at AbbVie US. The study is expected to launch later this year. Participants can enroll if their doctor is part of the Corrona RA registry.
- **Improving Treat-to-Target by Incorporating the Patient Perspective:** This study aims to understand and assess the psychoeducational needs, barriers and facilitators of ArthritisPower members with rheumatoid arthritis (RA) when they are contemplating a change in treatment regimen. This study will consist of semi-structured interviews with ArthritisPower registry members and CreakyJoints members lasting about one hour to better understand the patient perspective about readiness to make a treatment change ("mental models"). This study is part of a Rheumatology Research Foundation (RRF) award to Liana Fraenkel, MD, MPH, Berkshire Medical Center. Results from the study will help guide development of materials to assist physicians and their patients to work together in treatment decision making. The study team is currently coding transcripts of patient interviews. The team will then use themes identified in interviews to design a survey that will be fielded to hundreds of patients this summer. Register at ArthritisPower to be notified when the study opens.

- **Understanding the Axial Spondyloarthritis (axSpA) Treatment Journey:** This cross-sectional study of ArthritisPower members reporting a physician diagnosis of ankylosing spondylitis (AS) or axial spondyloarthritis (axSpA) examines the experiences of patients, including the journey to getting diagnosed and treated, and managing different treatment options. The study is sponsored by Eli Lilly and Company. The team submitted two abstracts from study data for consideration for the ACR 2020 Convergence. This study is closed to patient enrollment.
- **Understanding Fibromyalgia: The Patient Experience of Symptoms, Diagnosis, and Treatment:** This cross-sectional study aims to understand the patient perspective of disease burden among patients with fibromyalgia, specifically those with lower back pain. It also aims to identify individuals who show signs and symptoms of axial spondyloarthritis (axSpA), regardless of whether the condition has been diagnosed by a rheumatologist, and to characterize patients' information needs. The study is sponsored by UCB and GHLF. An abstract of study findings was accepted for publication as part of the EULAR Congress proceedings this summer. The study team is currently preparing a manuscript to submit for peer-review in a rheumatology journal. This study is closed to patient enrollment.
- **Patient Perspectives on the Benefit and Side Effects of Methotrexate Therapy:** ArthritisPower members living with rheumatoid or psoriatic arthritis are eligible to participate in this study to examine the possible side effects of methotrexate and how taking methotrexate affects people's lives and well-being. The study is sponsored by Amgen Inc. An abstract of study findings was accepted for publication and poster presentation as part of the EULAR Congress proceedings this summer. A manuscript of the study will be submitted for peer review to a rheumatology journal later this year. This study is closed to patient enrollment.
- **Smartwatch Synchronized to Your Health:** The DIGital Tracking of Arthritis Longitudinally (DIGITAL) study is known to participants with rheumatoid arthritis as the ArthritisPower Smartwatch Study, sponsored by Eli Lilly and Company. Data collection for the study is nearly complete and interim data analysis has been conducted. Two abstracts of study findings were accepted for publication and poster presentation as part of the EULAR Congress proceedings this summer. A manuscript of the study engagement methods and participant adherence will be submitted to a peer review medical journal later this year. Preparation of at least two manuscripts is planned. One will feature the primary aim of the study, namely an assessment of the concordance between electronic patient-reported outcomes (ePROs) and passive (smartwatch) data. The other will highlight patient engagement, methods to minimize data missingness and optimize adherence to the study protocol. This study is closed to patient enrollment.
- **CHOICE (Comparative Health Outcomes in Immune-mediated disease Collaborative):** The study will evaluate the comparative clinical effectiveness of various biologic and other medications as assessed through a variety of disease-specific and generic patient-reported outcomes measures. This study is a PCORnet Demonstration Project sponsored by the Patient-Centered Outcomes Research Institute (PCORI). Register at [ArthritisPower](#) to be notified when the study opens.

CREAKYJOINTS PRESENTS ARTHRITISPOWER DATA AT THE EULAR E-CONGRESS

In early June, CreakyJoints presented data that demonstrates how integrating digital tools into patients' arthritis management strategies can improve understanding of arthritis. This data was shared during the European E-Congress of Rheumatology 2020, presented virtually by the European League Against Rheumatism (EULAR). The patient-centered research, conducted prior to the COVID-19 outbreak, illuminates paths forward for patients entering or already in their new digital realities.

In the press release, W. Benjamin Nowell, PhD, study author, Director of Patient-Centered Research at CreakyJoints, and principal investigator of ArthritisPower said, "Smartphones, wearables, and social media are ubiquitous in our daily lives and we are increasingly comfortable using these tools to help us communicate with each other and access information, including about our own health. The data we are presenting at European E-Congress of Rheumatology 2020 examines how digital technology can be integrated into arthritis management and how it can be used to conduct arthritis research. We wanted to learn more about the feasibility of patients using a smartphone app and commercial grade fitness tracker to share daily data over an extended period of time, as well as gain insight into which aspects of their condition patients prefer to track digitally. Our findings help inform future clinical trials and disease management strategies, and they come at the right time as we all adjust to our lives in a COVID-19 world."

The EULAR data was covered by healthcare media, including [DocWire](#), [Rheumatology Network](#) and [Fibromyalgia News Today](#).

In total, CreakyJoints presented four posters, three abstracts and a presentation at EULAR this year:

- [Which Patient-Reported Outcomes Do Rheumatology Patients Find Important to Track Digitally? A Real-World Longitudinal Study in ArthritisPower](#). Poster. PARE0026
- [Participant engagement in an ArthritisPower real-world study to capture smartwatch and patient-reported outcome data among rheumatoid arthritis patients](#). Poster. THU0564
- [Using self-reported outcomes to detect new-onset flare in a real-world study of participants with rheumatoid arthritis - Interim results from the Digital Tracking of Arthritis Longitudinally \(DIGITAL\) study](#). Poster. FRI0018
- [Changes in Patient-Reported Outcome \(PRO\) Scores for Nausea and Fatigue Following Weekly Methotrexate Dose in a Real-World Sample of RA and PsA Patients in the ArthritisPower Registry](#). Poster. Presentation number: SAT0150
- [Patient Perceptions of Fibromyalgia Symptoms and the Overlap with Axial Spondyloarthritis](#). Abstract. AB0710
- [Stepping up for Inflammatory Arthritis: A pilot trial to test behavioral economics strategy to increase physical activity in Inflammatory Arthritis](#). Abstract. AB0354

JOINT EFFORT FILM PREMIERES DURING ARTHRITIS AWARENESS MONTH

During May's Arthritis Awareness Month, CreakyJoints® premiered a new short film titled [“Joint Effort.”](#) produced by filmmaker Zeppelin Zeerip, founder of Field Work Creative, about his younger sister Zoe, 23, a cyclist who was diagnosed with juvenile idiopathic arthritis (JIA) at age 13. Using black and white images to demonstrate the pain and challenges Zoe faced as a child learning to manage JIA, the video dramatically raises awareness of a chronic illness that impacts an estimated 300,000 children in the United States. In addition to sharing this video on our social media platforms, our media outreach offered Zoe an opportunity to share her perspective with the [Outspoken Cyclist](#) podcast and [Bycycling.com](#), one of the largest online destinations for people seeking news about all things cycling, as well as [Juvenile Arthritis News](#).



Also in May, we launched our “Fine is Not Fine” social media campaign, which asked our arthritis community to weigh in on the aspects of the disease that need better awareness. We encouraged our members to not hide their experience of disease just because it was hard to talk about or because they felt their “complaints” might weigh down or burden their loved ones. The “Fine Is Not Fine” campaign reached over half a million people on Facebook, Instagram and Twitter.

Finally, in May, we partnered with [Everyday Health on a Facebook Live](#) event to raise awareness of living well with RA. Shilpa Venkatachalam was a panelist during this event. To date, the video has been viewed over 48,000 times.

HISPANIC PATIENT OUTREACH AND EDUCATION

This quarter, CreakyJoints Español continued its rapid growth among the Hispanic community in the United States, developing and sharing original contextualized Spanish-language content related to the Hispanic experience with arthritis as well as, more broadly, to the COVID-19 pandemic. Some of the most popular articles were:

- [El Metotrexato y el coronavirus: ¿el metotrexato te pone en alto riesgo de contraer el coronavirus \(COVID-19\)?](#) (Methotrexate and coronavirus: Does methotrexate put you at high risk of contracting the coronavirus (COVID-19)?)

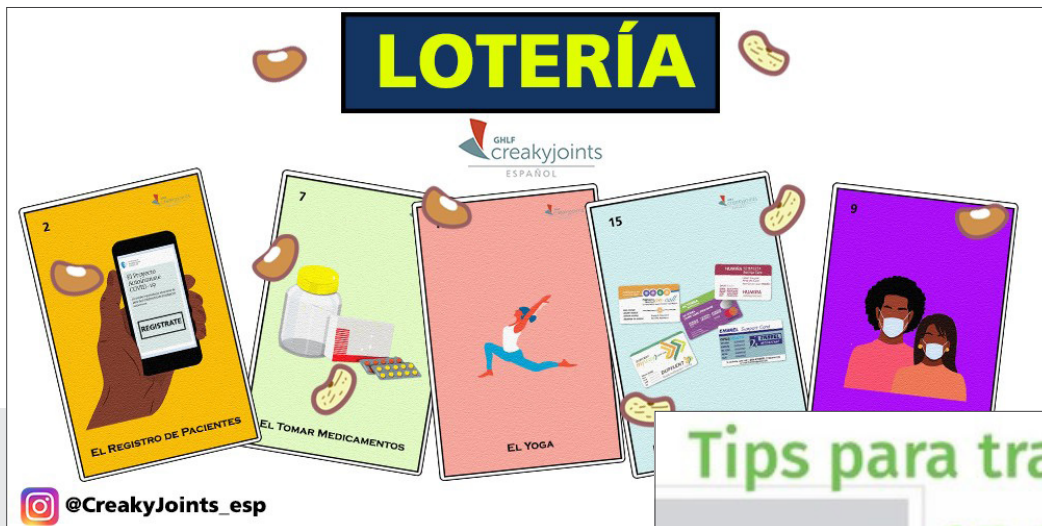
- [Anticoagulantes y el coronavirus: ¿Estos medicamentos te convierten en una persona de alto riesgo para contraer el COVID-19?](#) (Anticoagulants and the coronavirus: Do these medications make you a high-risk person for contracting COVID-19?)
- [Enfermedad inflamatoria intestinal y el coronavirus: lo que las personas con enfermedad de Crohn y colitis ulcerosa necesitan saber](#) (Inflammatory bowel disease and the coronavirus: what people with Crohn’s disease and ulcerative colitis need to know)

In addition, in April, CreakyJoints Español launched a Spanish-language version of the Autoimmune COVID-19 Project research. To encourage participation in the longitudinal research project, our media outreach resulted in Daniel Hernandez, M.D., CreakyJoints Director, Medical Affairs and Hispanic Outreach, being interviewed on television by [UNIVISION NY](#). He was also interviewed by [El Diario NY](#) and the article was picked up by La Opinion Los Angeles and Spanish-language newspapers across the country. He also appeared on the radio program Hablemos de Reumatología to speak about our COVID-19 longitudinal survey and to invite the Hispanic community to participate. It was broadcast through Radio Isla, a Puerto Rican radio station that also broadcasts outside of Puerto Rico through their Radio Isla TV platform and Facebook Live.



Cutline: Univision reporter, Rafael Bello, Presentador del Tiempo en Univision 41 (left), and Daniel Hernandez, GHLF Director, Medical Affairs and Hispanic Outreach.

We also engaged the Hispanic community for Arthritis Awareness Month with wellness programming on [Instagram](#) using daily cards and information inspired by Mexican Bingo or Lotería. This, combined with our Spanish language resources available through CreakyJoints Español and our social media platforms, provided the most complete Hispanic Arthritis Awareness Month activities in the U.S.



We also have produced at-home physiotherapy [videos](#) for our Hispanic rheumatic community during COVID-19.



Fisioterapia en casa

Ejercicios de mano para la artritis

CREAKYJOINTS AUSTRALIA GROWS THEIR FOOTPRINT

In addition to regularly contributing articles to Rheumatology Republic that include patient-centric perspectives on living with arthritis during the pandemic, CreakyJoints Australia continues to communicate with people living with arthritis and related chronic diseases by producing new educational content and updating existing information to include up-to-date and localized information. Recent articles during the second quarter include:

- [Answers To Your Top 5 Questions About Arthritis Medications and COVID-19](#)
- [Chronic Health Conditions and COVID-19 Face Mask Regulations in Australia](#)
- [Important Information From the Australian Rheumatology Association About COVID-19 – Updated 9 April 2020](#)
- [Will The New Opioid Prescribing Rules Affect Your Arthritis Pain Management?](#)



All of the COVID-19 education resources are now collated to this page: https://creakyjoints.org.au/covid_19/

We also collaborated with other health care organizations to produce a [Q&A session](#) with Sydney rheumatologist Professor Paul Bird who answered the most pressing questions from a group of immunocompromised patients, such as:

- Am I at increased risk of COVID-19?
- Should I wear a face mask?
- What precautions should I take if I still need to work?
- Should I continue to take my medications?
- Will my medications be available?
- How do telehealth appointments work?



■ EDUCATING ON ARTHRITIS

CreakyJoints Australia is currently working to develop AxSpA Patient Guidelines in collaboration with Professor Bird. It will include quotes from Australian patients about their experience living with AxSpA. The target date for release is World Arthritis Day, October 12, 2020.

We continue to share our website articles via Facebook (targeted to Australia) and Instagram (@creakyjoints_au) and subscribers are growing steadily on these platforms. Over the past 7 months, the site has recorded 12,371 users with 26,152 page views. Instagram followers are just about to hit 500.

Stakeholder roundtable participation

– Alongside other well-known health organizations and government bodies, CreakyJoints Australia has been invited to join stakeholder roundtables and panels. We're growing our reputation as an important consumer voice alongside other well-known health organizations. Notable recent events include:

- **Medicines Australia** – In May, a roundtable met to discuss the medicine supply chain during COVID-19. We know the difficulties patients were experiencing with accessing some of their medicines like

hydroxychloroquine, so MA responded by holding this collaborative meeting to address the questions they were receiving from organizations like ours. Topics discussed were understanding what was happening with the supply chain, how we can help patients through this situation, and what can be done better in the future. The outcomes from this meeting were sent to the Department of Health for review and from that three top-line recommendations have been highlighted to be worked on through the National Medicines Shortages Working Group.

- **NPS MedicineWise** – As part of their Value in Prescribing bDMARDs program, nine health organizations led by NPS MedicineWise and engaged by the Department of Health, met with the goal to optimize the use of bDMARDs to achieve better health outcomes and support PBS sustainability.

ArthritisPower in Oz. CreakyJoints Australia were recently approached by AIMSS (Australian Institute for Musculoskeletal Science) who have shown interest in the possibility of partnering with CreakyJoints on getting ArthritisPower up and running in Australia. Watch this space.

RAISING THE VOICE OF MIGRAINE PATIENTS

During June’s Migraine Awareness Month, Joseph Coe, MPA, Director, Education and Digital Strategy, encouraged all GHLF staffers, interns, and consultants to participate in the Shades for Migraine social media campaign. As a result, many took fun pictures of themselves (and often their dogs) wearing sunglasses, which posted to our social media channels. GHLF worked with New York State to designate June as Migraine Awareness Month.

Joseph Coe participated in a Facebook Live event sponsored by Everyday Health titled [Developing and Practicing Resilience with Migraine](#), where he had an opportunity to represent the millions in of people in the United States living with debilitating migraine.

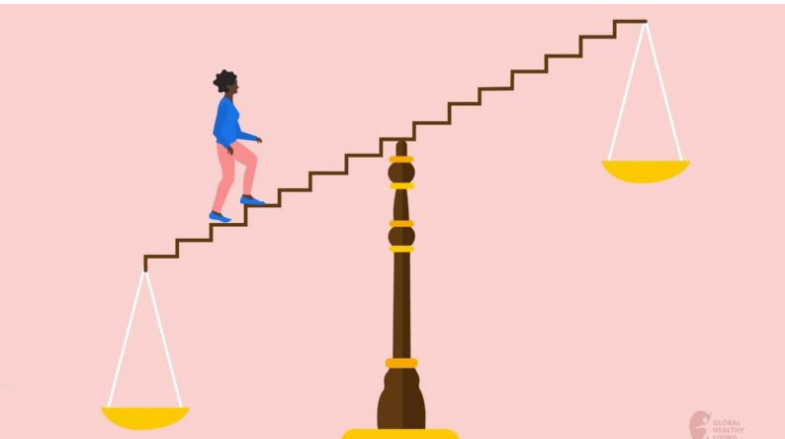


During the second quarter GHLF amped up production of our migraine content to better support migraine patients during the COVID-19 pandemic. The long-term result was increased patient participation in social media linking to original migraine content on our websites. Depending on the topic of the article, we are embedding calls to action to join the 50-State Network to participate in migraine advocacy. Each article includes a uniquely designed graphic to increase social media engagement.



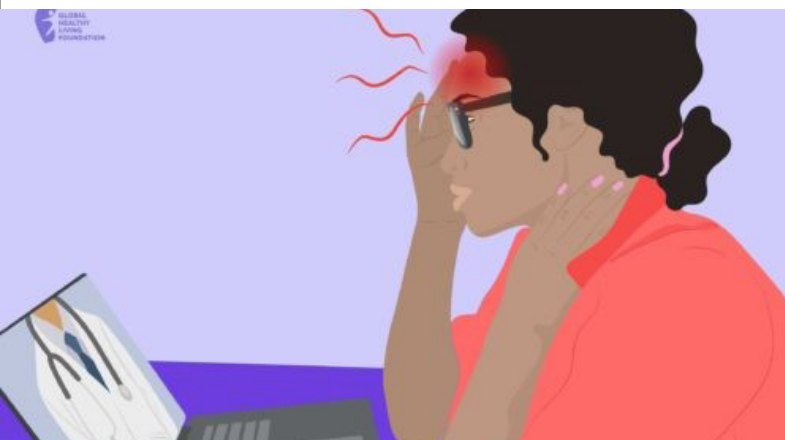
[Managing Migraine During the Summer](#)

This “Listicle” type article with neurologist-approved tips and advice was one of the most popular during Migraine Awareness Month.



[Migraine and Health Disparities](#)

Learning how health care disparities affect migraine treatment and how to recognize discrimination against minorities helped people advocate for change in this article.



[Dos and Don'ts for Telemedicine for Migraine](#)

You could be visiting your doctor on your laptop or smartphone. This must-read article prepared patients for the doctor visit, and explained how insurance pays for it.

SPEAKING WITH AND FOR THE CHRONIC DISEASE COMMUNITY

PARTNERING WITH THE CDC TO ANSWER PATIENT'S QUESTIONS ON THE PANDEMIC

On April 29, the Global Healthy Living Foundation was a main sponsor of a CDC-led webinar for patients titled, “National Briefing with the CDC: COVID-19 and the Chronic Disease Community.” Shilpa Venkatachalam, PhD, MPH, Associate Director, Patient-Centered Research, at the Global Healthy Living Foundation (GHLF), CreakyJoints and Co- Principal Investigator (PI) of ArthritisPower Patient-Powered Research Network was one of the moderators of the program. Questions addressed during the event included:

- What makes an individual high-risk for coronavirus complications ?
- Why are people with certain chronic conditions more severely affected than others?
- What are some of the things people living with chronic conditions can do to protect themselves against this virus?
- What are some of the treatment options for people living with chronic conditions?
- What to do and be aware of if a high-risk individual contract the virus
- What it means to safely resume everyday routines once “stay at home” orders begin to lift
- The status of testing for COVID-19 infection and antibody testing

The event was also presented by the Chronic Care Policy Alliance and Allergy & Asthma Network. In order to achieve maximum reach into the patient community, GHLF recruited 60 other patient-facing organizations were as supporters.

ANTICIPATING PANDEMIC FALLOUT

As the COVID-19 pandemic continued to threaten chronic disease patients’ potential access to their doctors and treatments, the advocacy team tried to anticipate how our existing healthcare system will respond to heightened need for healthcare. Steven Newmark, JD, MPH, GHLF Director of Policy and General Counsel, contributed an opinion piece to The Hill titled, “[Medicaid Enrollment May Hit Like a Tsunami.](#)” In the article, Newmark points out that it’s likely states will be forced to reduce their budgets after collecting less income and sales tax while, simultaneously, many unemployed Americans have lost their health benefits and will be newly eligible for Medicaid, adding to the Medicaid rolls. He says, “State health officials across the country — whether from red or blue states — will be facing tough choices about how to support the health of their residents with significantly fewer resources.”

PROMOTING GHLF RESOURCES

The Advocacy Team continued to connect with legislators around the country to encourage them to share GHLF’s free patient support program resources. For example, Virginia State Senator Scott Surovell promoted the Patient Support program on [his blog](#) on May 8 and also [Tweeted](#) about it to his followers.

During the second quarter our advocacy team’s outreach included federal, state, and city legislators in 43 of the 50 states.

■ NEW POLICY CONCERNS...WHAT OUR MEMBERS ARE SAYING

In June, members of the advocacy team joined a CreakyJoints Patient Council monthly teleconference call to present on policy issues and learn from patients' perspectives. Three key questions were posed to the group and we are using the patient insight to inform our advocacy efforts.

Home Infusions: Would you feel comfortable receiving an infusion in your home?

“

I previously had received some medications through home infusions and found the experience very good. My current meds do not give me a home infusion option but if coverage was expanded to include them, I would gladly do it.”

I am very comfortable receiving treatment in my home vs going to a doctor's office. I would even be ok for routine blood work taken at home so I can avoid going into labs as well.”

“

Medicaid Cuts: Will state budget deficits impact (or potentially impact) your care?

“

“Yes, I receive my health care through Medicare and California's Medicaid plan. On top of that, CA Medicaid pays for my Medicare premiums so any reduction in coverage or eligibility could have major impacts on both of my health plans. I am very scared about the potential for cuts to my benefits and what it would mean for my care.”

Vaccinations: Would you feel comfortable going to your pharmacist to receive a vaccine?

“

Yes! I see no difference in getting a vaccine from one or the other

Additionally, expanding pharmacists' ability to vaccinate would save significant costs on the administrator (employer) side of the plan so many employers would also likely support this as a way save them money without cutting benefits for their employees.”

“

■ GHLF SPEAKS DIRECTLY TO FEDERAL LEGISLATORS TO ADVOCATE FOR PATIENT-PROTECTIVE LEGISLATION

Access to innovative medicines continues to be a challenge for patients and providers, especially as the COVID-19 pandemic has upended many aspects of our nation's health care system. On June 23, Steven Newmark, GHLF Director of Policy and General Counsel, participated in a virtual Congressional Briefing that featured panelists discussing two ways consumers and patients are harmed by drug price manipulation and lack of oversight: step therapy and rebate walls. [“Rebate walls”](#) block access to new, innovator therapies,

depress innovation in key areas such as immunology, and cost the healthcare system more money. Most importantly, these walls block patient access to medications, and therefore blocks patients from having a say in their healthcare. Rebate walls and step therapy arise when insurance companies and their pharmacy benefit manager partners require drug manufacturers to provide rebates for their products based on volume. This disadvantages new, potentially cheaper, medications that do not have the volume necessary to generate substantial rebates for pharmacy benefit managers and insurers.

Panelists



Professor Robin Feldman, Arthur J. Goldberg Distinguished Professor of Law and Director of the Center for Innovation, UC Hastings Law



Dr. Madelaine Feldman, MD, FACR, Practicing Rheumatologist, President, Coalition of State Rheumatology Organizations



Steven Newmark, Director of Policy and General Counsel at Global Healthy Living Foundation



Jennifer Snow, Vice President, Reimbursement & Policy Insights at Xcenda



Holly Vedova, Attorney Advisor, Commissioner Rohit Chopra, Federal Trade Commission



GHLF REPRESENTS PATIENTS AT INDUSTRY, ACADEMIC AND GOVERNMENT MEETINGS

With the Coronavirus continuing to spread across the United States, all previously scheduled meetings and conferences GHLF planned to attend were canceled. However, like most things, there was a gradual shift to a virtual format and GHLF attended or participated in the following virtual meetings:

| | |
|----------------|---|
| <p>May 27</p> | <p>Louis Tharp, GHLF Executive Director and co-founder, attended the Brookings “COVID-19 and The Financial System” conference.</p> |
| <p>June 3</p> | <p>Steven Newmark, Director of Policy and General Counsel and Corey Greenblatt, Manager, Policy and Advocacy, attended the Collaborating for Care Virtual Meeting along with other patient and provider groups.</p> |
| <p>June 23</p> | <p>Louis Tharp attended the Alexandria Summit Covid-19 Policy Forum 2020 organized by the Duke Margolis Center for Health Policy.</p> |
| <p>June 24</p> | <p>Corey Greenblatt and Steven Newmark, along with Zoe Rothblatt, Patient Advocate, Community Outreach Manager, and Daphne DeRose, GHLF Fellow, conducted a virtual meeting with New York State Senator Brad Hoylman and his staff to discuss policies related to COVID and vaccines.</p> |



*New York State Senator
Brad Hoylman*

■ GHLF SUBMITS PATIENT-CENTERED COMMENTS TO U.S. FEDERAL AND STATE GOVERNMENTS

In the second quarter GHLF submitted 19 public comments and sign-on letters:

| FEDERAL | |
|------------------|---|
| 4 APR | <u>Promotional Labeling and Advertising Considerations for Prescriptions Biological Reference and Biosimilar Products</u> |
| 6 APR | <u>2021 and 2022 Policy and Technical Changes to Medicare Advantage Program (ATAP Sign-on)</u> |
| 14 APR | <u>Letter to Leadership of Senate Subcommittee on Defense about Defense Health Research Programs</u> |
| 14 APR | <u>Letter to Leadership of House Subcommittee on Defense about Defense Health Research Programs</u> |
| 22 MAY | <u>Letter to CMS about Part D Modernization “Smoothing” Demonstration (Alliance for Aging Research Sign-On)</u> |
| 15 JUN | <u>CDC Request for Comment about Management of Acute and Chronic Pain</u> |
| 15 JUN | <u>Letter to FDA and NIH about Pain Treatments and the SUPPORT Act (Healthy Women Sign-On Letter)</u> |
| STATE | |
| 7 APR | <u>Executive Order on Ohio House Bill 469, Copay Accumulator Adjustor Ban (Patient Organizations Sign-on)</u> |
| 15 MAY | <u>Letter to Ohio Drug Transparency and Affordability Advisory Council about Patient Burdens (ACS Sign-On)</u> |
| 15 JUN | <u>Utah HB 106, Supporting the Utah Rare Disease Advisory Council</u> |
| COVID-19 RELATED | |
| 1 APR | <u>Letter to Governors asking for more state action with regards to Coronavirus (Aimed Alliance Sign-on)</u> |
| 1 APR | <u>Letter to State Medicaid Directors asking for more state action with regards to Coronavirus (Aimed Alliance Sign-on)</u> |
| 7 APR | <u>Expansion of Paid Family and Medical Leave Act (Cystic Fibrosis Foundation Sign-on)</u> |
| 9 APR | <u>Letter to Congressional Leadership to ask for increased funding and support for CDC and NIH (Crohn’s and Colitis Foundation Sign-on)</u> |
| 15 APR | <u>Letter to state Governors, Insurance Commissioners, Medicaid Directors, and Executive Directors of State Boards of Pharmacy with regards to the Coronavirus Relief Efforts (Every Life Foundation Sign-on)</u> |
| 29 MAY | <u>Comments to CMS about Policy and Regulatory Revisions in Response to the COVID-19 Public Health Emergency</u> |
| 29 MAY | <u>Letter to CMS about Step Therapy concerns during COVID-19</u> |
| 3 JUN | <u>Letter to Congressional Leadership about Prior Authorization and COVID-19</u> |

CREAKYJOINTS AND THE GLOBAL HEALTHY LIVING FOUNDATION IN THE NEWS

During the second quarter, there were 77 earned media placements featuring CreakyJoints members or leadership, generating more than 264 million media impressions. Notably, several high profile placements, including USA Today, Business Insider, and Public Radio International were syndicated across the country and around the world, respectively. During the second quarter, national media continued to cover how our GHLF members with chronic disease are coping with the pandemic. We also saw coverage of our research, particularly when we promoted the data presented at the EULAR E-Congress (as referenced above). Everyday Health partnered with CreakyJoints and Global Healthy Living Foundation multiple times, including in articles about telehealth and affording medications. They also hosted our leadership during two Facebook Live events on RA Self Care and managing migraine (referenced above).

THE CREAKYJOINTS COMMUNITY CONTINUES TO GROW AND EXPAND TO NEW PLATFORMS

In the second quarter, over 2.3 million people visited CreakyJoints.org to consume its information and support content about rheumatic diseases. The metrics below illustrate the quality of traffic coming to CreakyJoints.org, the diversity of visitors, and rheumatic topics they're interested in.

Social Media

In the second quarter, grew to 120,000+ fans on Facebook and 15,000+ followers on Twitter. Our Facebook page generated 1.8 million impressions and our Twitter handle generated over 90 million impressions during the quarter. The influential and engaging monthly Twitter chat, #CreakyChats, is a large driver of impressions. Our recent chat on racial disparities in healthcare, racial justice and equality included 920 participants who contributed 3,244 Tweets, reaching more than 24.5M impressions.

Website visitors are highly diverse in terms of age:

| | |
|--------|-----------------------------|
| 18-24: | 10% of total traffic |
| 25-34: | 23% of total traffic |
| 35-44: | 17% of total traffic |
| 45-54: | 16% of total traffic |
| 55-64: | 18% of total traffic |
| 65+: | 17% of total traffic |

Audience age data is not collected for visitors under age 18.

There were 3,400,000+ total page views in the second quarter:

Average site visit is 4 mins, 39 seconds (far longer than the industry's average of 1 min, 7 seconds).

WHO WE ARE

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 websites www.CreakyJoints.org, <https://creakyjoints.org.es/>, www.creakyjoints.org.au, and the [50-State Network](#), which includes more than 1,500 trained volunteer patient, caregiver and healthcare activists.



As part of the Global Healthy Living Foundation, CreakyJoints also has a patient-reported outcomes registry called ArthritisPower® (ArthritisPower.org) with more than 28,000 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” series, which are downloadable patient-centered educational and navigational tools for managing chronic illness. It also hosts PainSpot (PainSpot.org), a digital risk assessment tool for musculoskeletal conditions and injuries. For more information and to become a member (for free), visit www.CreakyJoints.org.

Find us on social media:

Facebook: <https://www.facebook.com/creakyjoints> and <https://www.facebook.com/GlobalHealthyLivingFoundation/>

Twitter: @GHLForg, @CreakyJoints, #CreakyChats

Instagram: @creaky_joints, @creakyjoints_aus, @creakyjoints_esp

TikTok: globalhealthylivingfnd

About ArthritisPower®

Created by [CreakyJoints®](#), [ArthritisPower®](#) is the first-ever patient-centered research registry for joint, bone, and inflammatory skin conditions. With more than 28,000 consented arthritis patients, 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. Results from ArthritisPower studies are frequently published in peer-reviewed journals and presented at medical meetings in the United States and around the world. ArthritisPower Patient Governors serve as gatekeepers for researchers who seek to access registry data or solicit the community to participate in unique, voluntary studies. ArthritisPower’s past participation in PCORnet®, the National Patient-Centered Clinical Research Network, was supported through multiyear, multimillion-dollar Patient-Centered Outcomes Research Institute funding awards [PPRN-1306-04811]. To learn more and join ArthritisPower, visit www.ArthritisPower.org



WHO WE ARE

About 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 (such as arthritis, osteoporosis, migraine, psoriasis, and cardiovascular disease) by advocating for improved access to health care at the community, state, and federal levels, and amplifying education and awareness efforts within its social media framework. GHLF is also a staunch advocate for vaccines. The Global Healthy Living Foundation is the parent organization of [CreakyJoints®](#), the digital arthritis community for millions of arthritis patients and caregivers worldwide who seek education, support, activism, and patient-centered research through [ArthritisPower®](#) ([ArthritisPower.org](#)), the first-ever patient-centered research registry for joint, bone, and inflammatory skin conditions, and hosts [PainSpot](#) ([PainSpot.org](#)), a digital risk assessment tool for musculoskeletal conditions and injuries. Visit [www.GHLF.org](#) for more information.



About the 50-State Network

The [50-State Network](#) is the grassroots advocacy arm of the [Global Healthy Living Foundation](#). It is comprised of patients with chronic illness who are trained as health care 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](#).



About PainSpot

PainSpot by CreakyJoints® is an innovative algorithmic-based web site for musculoskeletal disease or injured patients that features an interactive, easy-to-use pain assessment tool using the same validated clinical decision-making tools used by healthcare professionals in a clinical setting. PainSpot aims to educate and empower people to better understand their health, so they can get diagnosed and treated faster. After participating in the assessment tool, the user receives a summary of three possible conditions that could be causing the pain and is invited to join, for free, the Global Healthy Living Foundation, CreakyJoints and/or the ArthritisPower Research Registry. They will also receive a follow-up email series designed to drive action toward a diagnosis and chart a pathway for living the best, healthiest life with that condition or post-injury. The first version of PainSpot was created by Doug Roberts, MD, an independent clinical rheumatologist with 30-plus years of experience diagnosing and treating patients with arthritis and musculoskeletal diseases. For more information, visit [www.PainSpot.org](#)

