



QUARTERLY REPORT

APRIL - JUNE 2022



GLOBAL
HEALTHY
LIVING
FOUNDATION

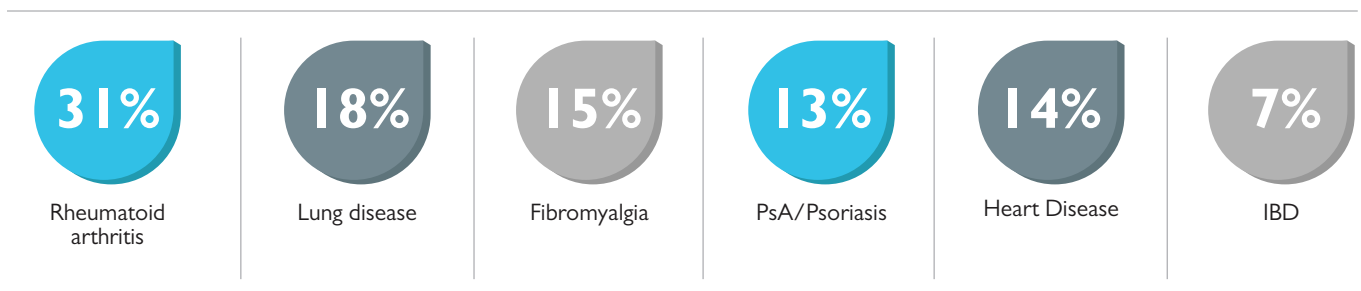
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COVID-19 AND CHRONIC DISEASE — SPRINGING BACK INTO NORMAL, WITH CAUTION FROM THE CHRONIC DISEASE COMMUNITY

This spring, much of the country returned to “business as usual,” with the pandemic seemingly approaching its endemic stage. However, we remain committed to providing education on what COVID-19 means for people living with chronic disease, who are just as eager to spend quality time with family, friends, colleagues, and other members of their communities. Our comprehensive information and support, informed by our scientific experts, helps everyone make individual decisions about engaging in the activities important to them.

Our free COVID-19 Patient Support Program remained robust in the second quarter and now includes 27,972 members and 43,325 subscribers. Self-reported conditions include:



■ ROBUST CONTENT

This spring, we continued to share the stories of our members — those immunocompromised by their diseases or the medications that treat them — highlighting diverse stories to ensure our content is relatable and actionable for our entire patient community. As always, many of these articles were also published in Spanish and made available on the [CreakyJoints Español website](#) and its [Instagram page](#).

“

As many people are becoming more relaxed, obviously immunocompromised patients don't have that luxury," says clinical rheumatologist Magdalena Cadet, MD, Associate Attending Physician at NYU Langone Health in New York City. "It's important that these individuals still reach out to each other to provide that social and emotional support."

Impactful content from the quarter included:

- [Testing COVID-Positive: My Experience as a Black, Disabled, Immunocompromised Woman](#)
- [How the Immunocompromised Community Can Support Each Other During This Stage of the Pandemic](#)
- [Your Thoughts on Lessons Learned from the COVID-19 Pandemic](#)
- [New Research Shows Booster Shots Give Patients on Immunosuppressants More Protection Against COVID-19](#)
- [What Does Wearing a Mask Mean to You?](#)
- [How to Stay Safe From COVID-19 While Traveling — Even When Others Aren't Wearing Masks](#)



■ TAKING THE PULSE OF THE CHRONIC DISEASE COMMUNITY

Our COVID-19 Patient Support Program continued to poll members to ensure we understand the hot topics we need to address to provide valuable support and resources. Highlights from the second quarter include:

April Poll Topic: How many of our community members have experienced breakthrough cases, and what was their experience like?

1,824 (87%)

reported being vaccinated and boosted against COVID-19.

20%

of respondents reported having COVID-19 symptoms or testing positive for COVID-19.

The most common symptoms reported were

77%

new/worsened fatigue

72%

headache

68%

runny nose/sinus congestion

Despite getting sick, many members commented on their relief to be vaccinated:

“ Glad I didn't have to find out what it was like to get this before being vaccinated. It would have been rough.”

Glad I was vaccinated. Could have been much worse if I hadn't been.”

“ I had been very concerned about how my body might respond if I were to contract COVID-19. It turned out to be a surprisingly mild case, and I felt confident that the vaccine regimen is effective even though I take immune-suppressing medications.”

Late-April Poll Topic: What is your experience with Evusheld, a long-acting monoclonal antibodies medication that can be used to prevent COVID-19 before exposure in immunocompromised individuals?

1,024 (64%)

reported they'd heard of Evusheld before and, of those who had heard of it, nearly half (41.46 percent) had at least one dose.

People obtained Evusheld from

36%
rheumatologist

19%
primary care physician

Others got it
from other
specialists

The majority of those who had not taken Evusheld reported that there was a lack of doctor recommendation and access.

The free-response section offered highly variable reasons for not being able to access Evusheld, such as being on a waiting list, uncertainty about insurance coverage, or a doctor wanting to wait until more studies were complete before prescribing.

OUR LEADERSHIP PROVIDES PERSPECTIVE AROUND THE GLOBE

Our leaders are in demand to participate in events that raise the volume on the health and health-policy issues that matter most to the chronic disease community. During the second quarter, select engagements included:



Robert Popovian, PharmD, MS, Chief Science Policy Officer, was a featured panelist at the June 28 National Alliance of Healthcare Purchaser Coalitions Leadership Summits focused on mental health, immunizations, and sleep. The meeting was covered by the [*American Journal of Managed Care*](#) and included remarks from Popovian about income inequality as the greatest barrier in getting populations in the country immunized. Popovian was also invited to share his perspective at nine other meetings, including the Institute for Health and Productivity Management: Workplace Wellness Alliance, the Healthcare Management Academy, and Pharma Pricing, Reimbursement and Market Access 2022.



Daniel Hernandez, MD, Director of Medical Affairs and Hispanic Outreach, moderated a panel discussion at Digital Pharma Innovation Week in June. The conversation focused on developing strategies to improve population health equity.



Corey Greenblatt, Manager of Policy and Advocacy, provided testimony to the Delaware Senate Banking, Business, and Insurance Committee to discuss Senate Bill 267, a copay accumulator adjuster ban.



Sarah Shaw, BIPOC Patient Advocate and Community Outreach Manager, spoke at [Life with Migraine: Stories from BIPOC Communities](#), a Healthline virtual patient roundtable, on May 2.

As always, our advocacy team participated in many virtual meetings, representing the concerns of all patients living with chronic disease and influencing the development of patient-friendly health policy. A full list is available later in the report.

A graphic for a panel discussion. The background is dark blue with a network of white lines. At the top left is the logo for Digital Pharma Innovation Week, consisting of three red slanted bars followed by the text "DIGITAL PHARMA INNOVATION WEEK". Below the logo, the text reads "Panel Discussion Multicultural Marketing: Develop Strategies and Messaging to Improve Population" and "Wednesday June 22, 2022 | 10:40am - 11:25am EDT". At the bottom, there are four portrait photos of the panelists, each with their name and affiliation below it.

DIGITAL PHARMA
INNOVATION WEEK

Panel Discussion
Multicultural Marketing: Develop Strategies and Messaging to Improve Population
Wednesday June 22, 2022 | 10:40am - 11:25am EDT

Daniel I. Hernandez
Global Healthy Living Foundation

Robert Allen
Bristol-Myers Squibb

Pallavi Garg
Takeda Oncology

Cristina Carlis
Gilead Sciences

DATA-INFORMED POLICY RESEARCH DRIVES AWARENESS FOR PATIENT-CENTERED POLICY DISCUSSIONS

In May, GHLF announced the publication of a new peer-reviewed paper in the Journal of the American Pharmacists Association, which found that pharmacists can play a critical role in increasing vaccine access for people who live in low-income communities, particularly seniors, and reduce health disparities. [“Accessibility of Adult Immunizations in Pharmacies Compared to Physician Offices in Low-Income Communities”](#) found that in communities with a poverty rate of at least 30 percent, the number of pharmacies is 15 percent higher than the number of physician offices, and that pharmacies offer significantly more hours for vaccination compared with physician offices. This study was conducted with support from the [American Disease Prevention Coalition](#).

Lead author Robert Popovian, PharmD, MS, Chief Science Policy Officer at the Global Healthy Living Foundation as well as Senior Health Policy Fellow at the Progressive Policy Institute and Senior Visiting Health Policy Fellow at the Pioneer Institute, said in the press release, “We believe that expanding the authority and ability of pharmacists to administer all FDA-approved or -authorized or CDC-recommended vaccinations similar to their physician colleagues should be considered across state and federal programs. . . . As we return to normalcy, pharmacists are well positioned to continue providing immunizations at convenient times and locations in all communities across the country.” Popovian discussed the study in an op-ed published on the website [Governing](#), and it was covered by [Pharmacy Times](#), [Pharmacy Today](#), [Infectious Disease Advisor](#), and [ContagionLive](#).



In June, a peer-reviewed paper published in *Health Science Journal* evaluating the 2022 national formulary of the second-largest pharmacy benefit manager (PBM) in the U.S. found that nearly half (46 percent) of its 563 exclusions had questionable clinical or financial benefits to patients, meaning that prescribers are forced to select treatments that may have adverse financial or medical outcomes for their patients. The study also found that in some cases, the exclusions violate the core principle of a “formulary,” in which lower-priced generics, authorized generics, or biosimilars should be preferred over equivalent brand-name medicines.

Lead author Robert Popovian said in the press release, “The original intent of formularies was to incentivize the use of the least costly medication that was also safe and effective for a particular medical condition. However . . . what we now have is a warped system driven by profits that stem from rebates coordinated in secret negotiations between PBMs, payers, and drug manufacturers. Excluding a drug means that the insurer will not cover any portion of the cost and the patient must cover the full cost, which presents an insurmountable financial barrier for many patients.” An op-ed written by Popovian and Louis Tharp, GHLF’s executive director, was published on [Healthcare Business Today](#), and the study was covered by [STAT](#), [Healio](#), and [InsideHealthPolicy](#).



Popovian was one of the lead authors of a white paper published by the University of Southern California’s Schaeffer Center for Health Policy & Economics titled [“U.S. Consumers Overpay for Generic Drugs.”](#) The paper reports that generic prescription drugs save the U.S. health care system money overall and that there is growing evidence showing that U.S. consumers often overpay for generics as pharmacy benefit managers game opaque and arcane pricing practices to pad profits. The authors write, “Greater transparency across the generic prescription drug supply chain and policies to spur competition and deter anticompetitive practices can reduce generic drug costs for patients.”

RESEARCH AND PATIENT EXPERIENCES HIGHLIGHTED AT EULAR 2022

During the 75th anniversary this year, the European Alliance of Associations for Rheumatology (EULAR) held its 2022 EULAR European Congress of Rheumatology in Copenhagen in June, which included the EULAR PARE (people with arthritis/rheumatism across Europe) track. CreakyJoints® presented or had published four abstracts highlighting the patient experience of living with arthritis.

Kelly Gavigan, MPH, Director, Data Management and Analytics, was the lead author on a study titled [“Changes in Patient-Reported Outcome Scores During the COVID-19 Pandemic: Data from the ArthritisPower Registry.”](#) which was part of the international meeting’s official poster tour. This study included over 2,200 participants, who contributed nearly 50,000 patient-reported outcome (PRO) scores, of which about 8,400 were contributed between May and December 2021. The study reported that participants’ mental and social health-assessment scores improved and worsened over the last eight months of 2021 in a manner that corresponded with major events during the COVID-19 pandemic. After vaccines became widely available throughout the U.S., scores for anger and social isolation declined. However, social isolation scores worsened by one-half of a standard deviation compared with the overall study period mean in July, when the Delta variant emerged in the U.S. Gavigan shared this research in an interview with [MedicalResearch.com](#).

eular

EUROPEAN ALLIANCE
OF ASSOCIATIONS
FOR RHEUMATOLOGY

CreakyJoints also presented data demonstrating that patient-satisfaction scores, using a typical Likert scale, are affected by social and cultural norms in the Spanish-speaking population with rheumatoid arthritis (RA) in the United States and Puerto Rico. The study, titled [“Do Patient and Physician Assessments of a Health Care Visit Match for Hispanic/Latinx Patients with Rheumatoid Arthritis in the United States and Puerto Rico?”](#) aimed to validate a Spanish-language patient-provider questionnaire (PPQ) for Hispanic/Latinx patients with RA that had previously been validated in a study in Sweden. The study also aimed to understand if rheumatologist and patient assessments for Hispanic/Latinx people with RA are concordant when using a Spanish-language digital PPQ. However, the study found that answers between physicians and patients were too highly matched to constitute an adequate assessment of patient-physician discordance. Daniel Hernandez, MD, Director of Medical Affairs and Hispanic Outreach, discussed these surprising results and the need for tailored assessments for the U.S. Hispanic community with [Rheumatology & Arthritis Learning Network](#). The study was also covered by [Rheumatology Network](#) and [Rheumatology Advisor](#).



Privacy policy

Hernandez also provided perspective on other presented EULAR studies in two articles published by Everyday Health.

CreakyJoints presented four studies at EULAR 2022:

- [Do Patient and Physician Assessments of a Health Care Visit Match for Hispanic/Latinx Patients with Rheumatoid Arthritis in the United States and Puerto Rico? \(Abstract: AB1585-PARE\)](#)
- [Education Topics and Smartphone App Functions Prioritized by People with Rheumatic and Musculoskeletal Diseases \(Poster: POS1564-PARE\)](#)
- [Understanding Heterogeneity in Patients' Conceptualization of Treatment for Rheumatoid Arthritis: A Cluster Analysis \(Abstract: AB1584-PARE\)](#)
- [Changes in Patient-Reported Outcome Scores During the COVID-19 Pandemic: Data from the ArthritisPower Registry \(Poster: POS0088-PARE, selected as part of the poster tour\)](#)

As usual, CreakyJoints was a leading voice on social media to share our data as well as important studies presented by other researchers. CreakyJoints tweets reached an estimated 7.3 million impressions.

UNITED RHEUMATOLOGY PARTNERSHIP ADVANCES RA UNDERSTANDING

In May, [United Rheumatology](#), the preeminent rheumatology care-management organization known for empowering rheumatologists to advance the standard of care across the country, announced with [CreakyJoints](#) the launch of the [Rheumatoid Arthritis Wellness Center](#). This resource provides rheumatologists with a trusted place to refer patients for educational information and tools to incorporate into their RA management strategy post appointment. The Rheumatoid Arthritis Wellness Center’s digital resources were developed in consultation with health care professionals and the CreakyJoints patient community and overseen by the medical leadership of United Rheumatology. Key topics include managing fatigue, sleep, exercise, and nutrition as well as recommendations for managing the overall mental and emotional aspects of living with a chronic disease. United Rheumatology and CreakyJoints will expand the center later this year to include related rheumatic conditions. [Healio](#) covered this announcement.

UNITED RHEUMATOLOGY
A Specialty Networks Company

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NATIONAL HEALTHY LIVING FOUNDATION

Rheumatoid Arthritis Wellness Center

Welcome!

Living with rheumatoid arthritis can be hard — and it often takes a village to help you feel better.

You're here because your health care provider wants to give you more information

CREAKYJOINTS ESPAÑOL DRIVES UNDERSTANDING OF RA IN THE NEWLY DIAGNOSED

Coverage continues in support of [CreakyJoints Español](#)'s new digital guide — available at [cjes.org](#) — written specifically for people whose primary language is Spanish to educate them about living with rheumatoid arthritis. Optimized for mobile and desktop use, the digital guide's activity center includes different learning modules, such as videos, quizzes, and infographics, which will help people living with RA understand their treatment and management options and offer tips for working with their health care provider team. The research team is studying how the guide is being used and understood in order to evolve programming, as needed.

In the second quarter, both the [Los Angeles Times en Español](#) and [La Opinión](#) — two of the largest Spanish-language newspapers in the country — covered CreakyJoints Español activities, including interviews with Daniel Hernandez, MD, Director of Medical Affairs and Hispanic Outreach, and CreakyJoints Español member Wigna Cruz. [El Vocero de Puerto Rico](#) published a video story and a [print article](#), and Cruz also appeared on Univision Atlanta and another local TV station in Texas.

As mentioned earlier in the report, CreakyJoints Español research was presented at EULAR 2022, focusing on how a patient-response questionnaire could not be validated, possibly due to Hispanic cultural norms. Further research will be undertaken to learn more.

As always, CreakyJoints Español continued to educate the Spanish-speaking arthritis community and their loved ones about arthritis and the pandemic via educational articles on its website and associated social media platforms, such as:

- [Cómo Mejorar tu Sueño con Gota](#)
- [La FDA Aprueba Upadacitinib para la Espondilitis Anquilosante](#)
- [Video de Ejercicios para la Artritis Inflamatoria \(Artritis Reumatoide\)](#)

Los Angeles Times

EN ESPAÑOL

La Opinión
Desde 1926

El periódico #1 en Puerto Rico en lectoría y circulación.

el Vocero de Puerto Rico

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Concesionario independiente de la compañía matriz

15

GHLF PODCAST NETWORK NEARLY DOUBLES LISTENERSHIP

Our library of podcasts at the GHLF Podcast Network continues to grow. We've generated more than 36,000 downloads to date, an 80 percent increase over last quarter! Visit the GHLF Podcast Network at ghlf.org/patient-education/listen to see the full list of shows and/or download our podcasts from any streaming platform.

NEW SERIES IN THE SECOND QUARTER



Thriving While Aching is a podcast series hosted by CreakyJoints' Laurie Ferguson, PhD, Director of Education, a licensed clinical psychologist and a certified health care coach. She showcases the stories of older adults doing what they love while also living with aches and pains.



Wellness Evolution brings together a diverse community to discuss topics such as mindfulness, chronic illness, and mental health, as well as cultural and spiritual similarities and differences that make each of us unique yet very much alike. It is hosted by GHLF's Angel Tapia, Patient Advocate and Hispanic Community Outreach Manager, and Danielle Ali, Systems Analyst.

ONGOING SERIES



Breaking Down Biosimilars: In this podcast, our goal is to introduce you to biosimilars: what they are, how they get approved, their potential savings, and what promise they hold.



Dungeons & Diagnoses: Delve into the realm of Gaedia: a world where fantasy and reality combine! This podcast, set in the Dungeons and Dragons universe, brings those who have different lifestyles, live with different chronic conditions, and are differently abled to the forefront.



Getting Clear on Psoriasis: Listeners will learn about living better with psoriasis, and each episode includes relatable insights from fellow patients and key information from leading dermatologists and other experts.



Gut Culture: A podcast that gut checks assumptions about inflammatory bowel disease (IBD) through real conversations with two health care leaders.



The Health Advocates: This podcast helps listeners understand what's happening now in the health care world and helps everyone make informed decisions to live their best lives.



Healthcare Matters: This podcast explains complex health-policy topics so everyone can understand what is happening in the world of health care.



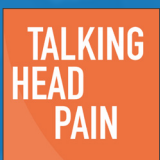
MatterOfVax: MatterOfVax explores the issues surrounding patients, caregivers, and community on the topics of vaccination, COVID-19 risks, and staying safe, with an Australian focus.



Patient PrepRheum: This podcast speaks to Australian patients and renowned doctors to explore important and often-misunderstood aspects of living with autoimmune arthritis and related conditions in Australia.



Patiently Connecting: This series reviews how medicine is evolving in light of technology changes.



Talking Head Pain: This podcast confronts head pain head-on, speaking to people who live with migraine and other disorders, as well as medical professionals.

Notably, James Dybisz, Senior Manager, Web Development, and CreakyJoints member Grayson Shultz, host and contributor respectively for the Dungeons & Diagnoses podcast, were featured on Dragon Talk, an official Dungeons & Dragons podcast and one of the largest-reaching podcasts in the gamer genre. Dybisz and Shultz spoke for over an hour about why the GHLF podcast includes people (and fictional characters) living with challenging conditions that can't be magically transformed, and why it is important to represent all people.

ARTICLE

DRAGON TALK: #378 - GLOBAL HEALTHY LIVING FOUNDATION, HOW TO DM

Dragon Talk

By Shelly Mazzanoble and Greg Tito - 04/13/2022



DRAGON TALK - AN OFFICIAL DUNGEONS & DRAGONS PODCAST • EPISODE 378

Dragon Talk: #378 - Global Healthy Living Foundation, How To DM



1x



00:00 | 01:39:43

SUBSCRIBE SHARE MORE INFO

GETTING REAL - MEMEBBERS SHARE THEIR PSORIASIS STORIES

CreakyJoints published a series of YouTube videos featuring true-life stories of [living with psoriasis](#) and psoriatic arthritis.



Vickie Wilkerson's Psoriasis Story | CreakyJoints



Psoriasis: Why It's So Much More Than Your Skin

ARTHRITISPOWER INCREASES UNDERSTANDING OF ARTHRITIS, PUBLISHING FOUR NEW STUDIES

STUDY 1: CREAKYJOINTS FINDS LACK OF RESEARCH STYMIES UPTAKE OF EVIDENCED-BASED PRESCRIBING OF MEDICAL MARIJUANA FOR PAIN ASSOCIATED WITH RHEUMATIC CONDITIONS

In May, CreakyJoints announced the publication of [“Cannabis for Rheumatic Disease Pain: A Review of Current Literature”](#) in *Current Rheumatology Reports*. The study reports that there has been limited progress in understanding the potential of cannabis-based therapies for the treatment of pain associated with rheumatic conditions in the past five years because of a lack of standardization of clinical research and barriers to conducting research due to existing federal and state regulations.



In the press release, lead author W. Benjamin Nowell, PhD, Director, Patient-Centered Research, says, “In 2019, CreakyJoints presented data from our ArthritisPower Research Registry study showing more than half of arthritis patients reported wanting information on, or actually had tried, marijuana and/or cannabidiol products for a purpose they perceived as medical (most often for pain relief or help sleeping), and yet, three years later, there’s been virtually no advancement in the research necessary to provide clinical evidence that rheumatologists and patients need to make decisions about cannabis use for symptom relief in combination with approved treatments. Without this research, it is impossible to develop clinical guidelines for medicinal cannabis in the U.S.”

Dr. Nowell and study coauthor Dr. Stuart Silverman participated in media interviews with DocWire News, Healio, Physician’s Weekly, Rheumatology Network, and Everyday Health. It was also covered by Cannabis Health (U.K.), Ganjily, Analytical Cannabis, and Global Cannabis Times.

In addition to the above study and the EULAR studies referenced earlier, our research team published three other peer-reviewed articles in top journals during the second quarter:

■ **STUDY 2:** Weiner, J., Lui, G., Brown, M., Páez Y. D., Fritz, S., Sydnor-Campbell, T., Allen, A., Jr., Jabri, A., Venkatachalam, S., Gavigan, K., Nowell, W. B., Curtis, J. R., Fraenkel, L., Safford, M., Navarro-Millán, I. “Protocol for the Pilot Randomized Trial of the CArdiovascular Risk assEssment for Rheumatoid Arthritis (CARE RA) Intervention: a Peer Coach Behavioral Intervention.” *Pilot Feasibility Studies* no. 8 (April 2022): article number 84. doi.org/10.1186/s40814-022-01041-z. PMID: 35428359; PMCID: PMC9011938.

Key finding: This describes the protocol of a pilot study to test the feasibility of a peer-coach intervention using peer coaches to facilitate the implementation of evidence-based treatment guidelines among people with RA.

■ **STUDY 3:** Nowell, W. B., Gavigan, K., Hunter, T., Bolce, R. J., Lisse, J. R., Himelein, C., Dubey, S., Curtis, J. R., Walsh, J. A. “Patient Perspectives on Biologics for Axial Spondyloarthritis in a Cross-sectional Study in a Predominantly Female Population: Treatment Satisfaction, Wear-off Between Doses, and Use of Supplemental Medication.” *Rheumatology and Therapy* no. 9 (April 2022): 509–520. doi.org/10.1007/s40744-021-00417-6. PMID: 34958453; PMCID: PMC8964844.

Key finding: In a predominantly female sample of patients with axial spondyloarthritis/ankylosing spondylitis and high disease activity who were treated with biologic disease-modifying antirheumatic drugs (bDMARDs), the majority of respondents expressed satisfaction with their current bDMARD treatment. However, most experienced wear-off between doses and relied on supplemental medications, including opioids, to manage symptoms.

■ **STUDY 4:** Hsiao, B., Downs, J., Lanyon, M. et al. “Rheumatologist and Patient Mental Models for Treatment of Rheumatoid Arthritis Help Explain Low Treat-to-Target Rates.” *ACR Open Rheumatology* (June 2022). doi.org/10.1002/acr2.11443.

Key finding: Rheumatologist and patient mental models for RA treatment are significantly more complex than the treat-to-target (TTT) model. Information gaps and differences in how patients and physicians value trade-offs were among the discrepancies between patients and physicians found in this study. These discrepancies can serve as specific targets to improve patient-physician communication and ultimately inform interventions to improve uptake of TTT.

ARTHRITISPOWER PATIENT RESEARCH HITS NEW HIGHS

Current ArthritisPower statistics as of June 30, 2022:

- Total patients: **37,945**
- % increase in membership from June 30, 2021: **14%**
- Top Conditions:

Osteoarthritis:	20,021 (53%)
Rheumatoid Arthritis:	16,801 (44%)
Fibromyalgia:	13,113 (35%)
Psoriasis/Psoriatic Arthritis:	7,035 (19%)
Osteoporosis:	5,475 (14%)
IBD:	4,715 (12%)
Lupus:	2,110 (6%)
- PROMIS Measures, mean (SD)

Pain Interference	64.0 (7.4)
Fatigue	63.1 (9.3)
Physical Function	37.3 (7.2)

This means that, on average, participants in ArthritisPower report symptoms that are more than 1 standard deviation worse than the U.S. general population average.

If you or someone you know would like to participate in an arthritis research study, please sign up at [ArthritisPower.org](https://www.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. Individuals interested in proposing new research with ArthritisPower should contact Dr. Ben Nowell, Principal Investigator and Director of Patient-Centered Research, at bnowell@ghlf.org.

ArthritisPower is overseen by Advarra IRB.

ARTHRITISPOWER RESEARCH REGISTRY OVERVIEW OF STUDIES IN PROGRESS

• Patient Perspectives of Rheumatoid

Arthritis Blood Work: Physician-ordered laboratory tests (blood work) are part of the rheumatoid arthritis treatment decision-making process, especially on the part of physicians, to inform patients' personalized treatment plans. No published studies to date have examined RA patients' perspectives on their RA-related blood work. This one-time survey of RA patients within ArthritisPower aims to examine how patients perceive their RA-related blood work and what their preferences are for a blood test that could help them predict whether an RA medication would work well for them. This study is being led by ArthritisPower co-Principal Investigators Ben Nowell, PhD, MSW, and Shilpa Venkatachalam, PhD, MPH, and is sponsored by Scipher Medicine. Recruitment is closed, and data analysis is being conducted.

• Stronger Together PsA Wellness Study:

As patients diagnosed with psoriatic arthritis (PsA) confront decisions about treatment and disease management, they may also seek to change or improve lifestyle behaviors that may improve their treatment outcomes. The goal of the study is to learn about PsA patients' experiences with and motivations for wellness. With sponsorship support from Janssen and in partnership with rheumatologists M. Elaine Husni, MD, and

Leonard Calabrese, DO, from Cleveland Clinic, a brief survey was designed to better examine PsA patients' perspectives of wellness. Participants who complete the survey will be invited to a wellness webinar ("town hall") hosted by GHLF with presenters from Cleveland Clinic, following which participants may consider participating in a multiweek wellness program with e-coaching. Study recruitment is ongoing in 2022.

• Rheumatoid Arthritis (RA)

Treatment Common Infections Study:

Immunosuppression is the mainstay of RA treatment but increases risk of infection. Leveraging the ArthritisPower infrastructure, this study will prospectively assess nonhospitalized infections and their impact on patients to better understand how the medications that people take for RA, such as glucocorticoids, methotrexate, and tumor necrosis factor inhibitors, affect patients' risk of common colds and other infections. Participants recruited through Bendcare/American Arthritis and Rheumatology Associates (AARA) practices and ArthritisPower in this longitudinal study will fill out six monthly surveys in the ArthritisPower app to report on the medications they are taking, their symptoms and RA disease activity, and any colds or other infections they experience.

Recruitment began in July 2022 and will end when approximately 250 participants are enrolled. The Principal Investigator for this study is Michael George, MD, of the University of Pennsylvania; it is funded by a National Institute of Arthritis and Musculoskeletal and Skin Diseases/National Institutes of Health award.

• **Telehealth-delivered Healthcare to Improve Care (THRIVE):** Funded by a two-year, \$400,000 grant from the American College of Rheumatology’s Rheumatology Research Foundation, THRIVE seeks to evaluate the quality of telehealth services when provided to a rheumatology patient in their home and deliver recommendations for physicians about best practices regarding what telehealth-related care delivery should include, how to deliver it, and how to standardize high-quality care. The first aim of the study is to produce a peer-reviewed white paper that describes those best practices. The second aim is to facilitate RA patients performing a joint self-assessment and to compare its accuracy with an in-person clinician joint exam (the gold standard) performed within the following 24 to 48 hours. The GHLF research team is building a patient joint self-assessment instructional tool into the ArthritisPower app for this study and so that it can be a regular feature for other studies going forward. Patient recruitment for this study will begin in 2022.

• **WEARable Activity Tracker Study Exploring Rheumatoid Arthritis Patients’ Disease Activity using ArthritisPower**

Registry Patient Reported Outcome Measures and Biometric Sensor Data (ArthritisPower Wearable Study):

Building on our experience designing and implementing the ArthritisPower smartwatch study, we are conducting a study of people living with rheumatoid arthritis from several clinical sites across the U.S. 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. RA patients on upadacitinib are currently being recruited from participating rheumatology clinic sites across the U.S. Recruitment will continue until August/September 2022.

• **Patient Outcomes: Real-World Evidence in Rheumatoid Arthritis (the POWER study):** The POWER study is being conducted in partnership with the CorEvitas (formerly Corrona) RA registry. Approximately 250 RA patient participants have been recruited at CorEvitas clinical sites and continue to provide longitudinal ePRO data via a 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 over time. This study is sponsored

by the HEOR group at AbbVie US. Study recruitment is closed; findings will soon be presented in abstracts and peer-reviewed manuscript.

• **Improving Treat-to-Target by Incorporating the Patient Perspective:**

Now complete, this study aimed to understand and assess the psychoeducational needs, barriers, and facilitators of ArthritisPower members with rheumatoid arthritis when they are contemplating a change in treatment regimen. This study consisted of semistructured 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”), followed by a quantitative survey with a larger sample of several hundred patients to identify potential patient-level interventions to enhance a treat-to-target approach in RA. Specifically, results from the study will guide development of materials to assist physicians and their RA patients in treatment decision-making. This study is part of a Rheumatology Research Foundation Innovation award received by Liana Fraenkel, MD, MPH, of Yale School of Medicine and Berkshire Medical Center. The study team is preparing two manuscripts to share findings, and has developed patient-facing videos featuring discussions among people living with RA talking about their experiences with treatment decision-making, which can be accessed at creakyjoints.org/rheumatoid-arthritis-treatment-patient-perspective-videos.

Spanish-language RA patient videos are also being developed and will be available on CreakyJoints Español in late 2022.

• **CARE-RA (CARDIOVASCULAR RISK AssEssment for Rheumatoid Arthritis):**

Cardiovascular disease (CVD) is the most common cause of death among patients with RA. To understand and assess the effectiveness of a peer coaching intervention called CARDIOVASCULAR RISK AssEssment for RA (CARE-RA) in helping people with RA receive reliable CVD education and risk assessment and treatment, we partnered with researchers and clinicians to help develop and design the peer coaching program and recruit participants for the study. This study is being led by Dr. Iris Navarro-Millán, a rheumatologist at Weill Cornell Medicine in New York City with current appointments at Hospital for Special Surgery (HSS) and New York-Presbyterian Hospital. The protocol for the study was recently published in the journal *Pilot and Feasibility Studies*, and the study is ongoing.

• **Vaccine Uptake Research in Autoimmune Disease: Multistakeholder Planning:**

GHLF/ArthritisPower was awarded a one-year Patient-Centered Outcomes Research Institute (PCORI) Engagement Award for Stakeholder Convening to help prioritize the study of vaccine uptake among adults with autoimmune conditions. The four patient-powered research networks (PPRNs) that constitute the Autoimmune Research Collaborative (ArthritisPower, IBD Partners, Vasculitis PPRN, and IConquerMS) are part

of this project, and research will examine and optimize uptake of pneumonia, shingles, flu, and COVID-19 vaccination among adults living with autoimmune conditions. Prioritization of research topics has concluded. Work has begun on a manuscript to submit for peer review, which will present the stakeholder-informed agenda for future research that improves our understanding of how best to increase vaccine uptake among adults with autoimmune conditions.

• **Patient and Provider Alignment (PAPA) Initiative to Explore Dual-Target for RA Treatment Outcomes:** The GHLF research team is bringing together clinicians and adults living with rheumatoid arthritis to rethink how patient-specified outcomes and goals compare with clinician-specified goals in the treatment of RA, and how best to align them in the future. Leonard Calabrese, DO, and M. Elaine Husni, MD, MPH, of Cleveland Clinic are advising on this project, which included a series of meetings to review current outcome measurements and explore dual- or multi-target setting with the aim of enhancing the standard of care in RA. This work is supported with a sponsorship from AbbVie. Initial recommendations and next steps were created by the clinicians and patients engaged in this project, and we are currently drafting a proposal to continue this work.

• **Remote Patient Monitoring for Clinical Use of ArthritisPower Infrastructure:** We have taken steps to make the ArthritisPower patient symptom and medication tracking infrastructure available outside of research, specifically for clinical use in remote patient/therapeutic monitoring. To date, we have established pathways to monitor patients for disease worsening/RA flares and for response to treatment following a new medication start. This information will be made available for clinical use directly to patients and their physicians. During summer 2022, patients from Bendcare/AARA practices will be invited to participate in a pilot for remote therapeutic monitoring. It is hoped that 500–1,000 patients will take part in the pilot phase. This work is being sponsored by GHLF.

OSTEOPOROSIS & ME DECISION TOOL ANNOUNCED

■ DELIVERING PATIENT AND PROVIDER-FOCUSED IMPROVEMENTS IN THE MANAGEMENT OF OSTEOPOROSIS IN THE ERA OF TELEHEALTH:

The GHLF research group is developing a website called Osteoporosis&Me with an embedded interactive online decision tool to help patients with osteoporosis decide on the right treatment based on their preferences. The website's main focus will be the decision tool, which utilizes choice-based conjoint (CBC) analysis and is informed by research conducted at Cedars-Sinai as part of this project. It will also include an educational video about how to use the decision tool, educational content about osteoporosis and available treatment options, and a personalized osteoporosis risk assessment. The website's decision tool will generate a personalized report that a patient can share with their doctor and will go live this fall. This project is supported by funding from Amgen.



SPEAKING WITH AND FOR THE CHRONIC DISEASE COMMUNITY IN THE UNITED STATES

As always, it is a priority of the organization to represent members of the chronic disease community by ensuring their voices are heard in policies, protocols, and laws that affect them.

Notable activities included:

- Writing a letter to CDC Director Rochelle Walensky commenting on the draft guidance “Proposed 2022 CDC Clinical Practice Guideline for Prescribing Opioids.” We advocated for the CDC to consider the chronic disease patient perspective for this guidance, saying, “We support the appropriate use of opioids to manage this pain and allow patients to live out their daily lives as close to normal as possible. This guidance will help patients within our community suffering from legitimate pain have access to both safe and effective medications to help them live fuller, more productive lives.”
- Signing on to a letter to the Senate HELP Committee leadership and House E&C Committee urging them to include in the Prescription Drug User Fee Act (PDUFA) reauthorization provisions to strengthen the FDA’s accelerated approval pathway and enable patient access to these critical, often lifesaving therapies.
- Writing a letter and signing on to coalition letters to submit comments to the Federal Trade Commission (FTC) to inform the FTC on the role of pharmacy benefit managers on patient access and affordability. We discussed ways that the FTC can help patient access and affordability.
- In June, the entire organization honored the life of the late [Dr. Arthur Virshup](#), the founder of the John Whelton Arthur Virshup CreakyJoints South Florida Arthritis Clinic. Today, the clinic serves South Florida arthritis patients who cannot afford treatment, providing regular and free rheumatology care to more than 100 area patients. Dr. Virshup was known for spending ample time with every patient, getting to know each one personally – and understanding them, not just their disease.



Dr. Arthur Vishop

In addition to securing publication in peer-reviewed journals (reported earlier in this document), during the second quarter, Robert Popovian, PharmD, MS, Chief Science Policy Officer, published many op-eds, including:

- STAT: [“PBMs Are Inflating the Cost of Generic Drugs. They Must Be Reined In”](#) (June 2022)
- Today90: [“Drug Pricing Bill Would Benefit Out-of-State Pharmacies, Not California Patients”](#) (June 2022)
- La Opinión: [“Propuesta de ley Sobre Precios de Medicamentos Beneficiaría a Farmacias Fuera del Estado, no a Pacientes en California”](#) (June 2022)
- Inside Sources: [“Biopharmaceutical Innovation Should Be Championed”](#) (June 2022)
- Healthcare Business Today: [“Insurers and PBMs Are Undermining Employee Health Benefits”](#) (June 2022, with Louis Tharp)
- RealClear Health: [“The Out-of-Pocket Cost Ponzi Scheme”](#) (May 2022)
- Governing: [“Pharmacist-Administered Vaccinations Should Be Here to Stay”](#) (May 2022)
- The Center for Biosimilars: [“Biosimilar Adoption Will Help Achieve a Bipartisan Goal”](#) (April 2022)

Executive Director Louis Tharp recently began contributing to Newsweek as a Newsweek Expert, discussing public policy and leadership. During the second quarter, he was quoted in one story and published two opinion pieces:

- [14 Essential Qualities of a Good Leader](#) (June 2022)
- [How Medicare Gets It Right and Wrong](#) (May 2022)
- [12 Practical Ways Managers Can Ensure Junior Employees Are Supported](#) (April 2022)

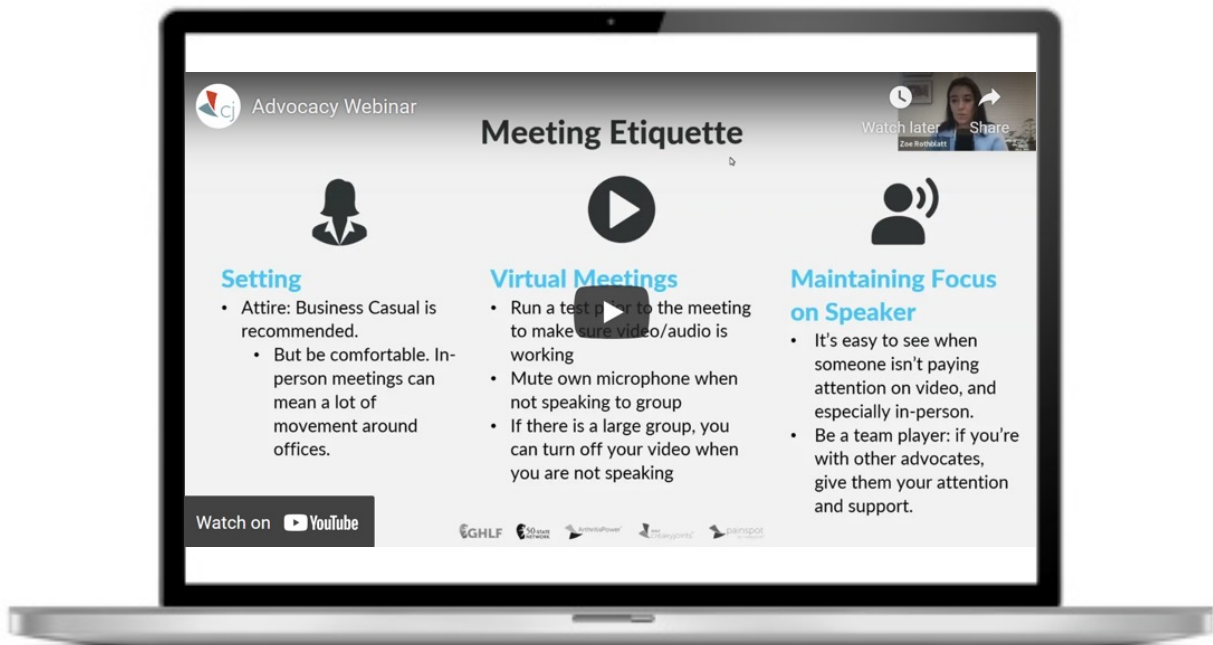


NEW PATIENT ADVOCATES TRAINED

The Global Healthy Living Foundation’s 50-State Network works side by side with hundreds of patients, sharing their stories with key decision makers to inspire change in our health care system. In May, the 50-State Network team hosted a training session (via webinar) on the basics of advocacy to educate patients on how to be effective advocates.

Presenters included:

- Zoe Rothblatt, MPH, Associate Director, Community Outreach
- Corey Greenblatt, MPH, Senior Manager Policy and Advocacy
- Sarah Shaw, BIPOC Patient Advocate, Community Outreach Manager
- Conner Mertens, Patient Advocate, Community Outreach Manager
- JP Summers, Advocacy Fellow



HEADS UP FOR MIGRAINE AWARENESS

Leading up to and during June's Migraine and Headache Awareness Month, several media outlets covered our members and staff living with migraine, including bezzymigraine.com. GoodRx featured both [Joseph Coe](#), Director of Digital Strategy and Education, and [Sarah Shaw](#), Senior Manager, BIPOC Community Outreach, with profiles about living with migraine. [Healthline](#) also included Shaw as a panelist in a roundtable to discuss living with migraine.

We also encouraged our members to share their personal experiences with migraine, which we [highlighted in articles](#) and shared on social media. Notably, advocate [Qasim Amin Nathari](#) shared his experience with GHLF. Stanford Medicine's [Neurology & Neurological Science](#) department also featured the Talking Head Pain podcast on its website, noting that Stanford's Robert Cowan, MD, discussed research on chronic/episodic migraine and how access barriers harm patients.

[Podcast Magazine](#) said of Talking Head Pain:

“

When [host Joe Coe] pointed out that we are the 'experts on our own experiences' and advised us to approach medical care as a partnership, it felt worthy of a standing ovation. If you or anyone you love is dealing with intense pain, Talking Head Pain is a must-listen.”





MIGRAINE AND HEADACHE AWARENESS MONTH

WHAT ARE THREE THINGS YOU WISHED OTHERS KNEW ABOUT MIGRAINE?

"Migraine is not just a garden-variety headache." - Prachi K.

"It affects all walks of life no matter age, gender, race, etc." - Sean M.

"Those with migraine can be significantly impaired making work, school, social obligations extremely difficult to manage." - Susan C.

Migraine & Headache Awareness Month

“

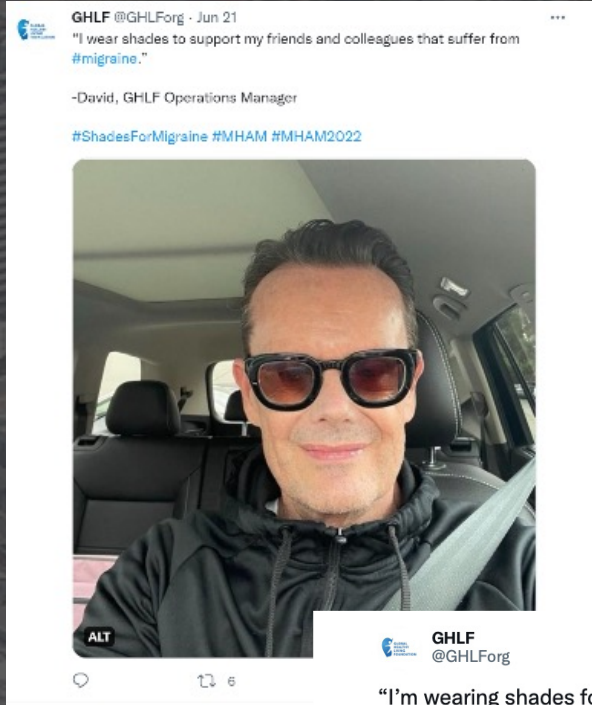
"That migraine it of itself is a chronic disease with a spectrum of intensity, severity and frequency. It's like someone who has asthma or epilepsy. Migraine is always there. Attacks are extremely debilitating and incapacitate us for days, weeks, months, and even years"

- [@migrainediva](#)





In June, the organization also supported #ShadesforMigraine on social media.



■ #CREAKYKITCHEN TURNED UP THE HEAT

The advocacy team hosted #CreakyKitchen twice in the second quarter, once again inviting CreakyJoints member Chantelle Marcial to be the resident chef.



Creaky Kitchen Ep 13

[Episode 12: Arthritis Awareness Month](#)

In this episode, Chef Chantelle taught us a recipe for Mediterranean-style anti-inflammatory salad dressing and hosted Seattle-based registered dietitian nutritionist Ginger Hultin, who shared tips on how to incorporate anti-inflammatory foods into your diet.

[Episode 13: Migraine and Headache Awareness Month](#)

In this episode, Chef Chantelle taught us a recipe for black-eyed pea bruschetta, and we were joined by migraine patient advocate Ellie Donner-Klein, who prepared a ginger-hibiscus mocktail.

GHLF ADVOCACY IN ACTION

Our staff represents the chronic disease community by submitting comments on legislation under consideration and attending meetings at the state and federal level to influence the development of patient-centered health policy. Below is a comprehensive list of activities during the second quarter of 2022. At the end of the year, we'll summarize all our activities in an annual report. To review 2021, [click here](#).

CONTRIBUTED COMMENTS

FEDERAL

- 4**
APR
[Letter to Senate HELP Committee leadership and House E&C Committee about accelerated approval](#)
- 11**
APR
[Comments to CMS about clinical practice guidelines for prescribing opioids](#)
- 5**
MAY
[Comments to FTC about PBM practices and impact on access and affordability \(ATAP sign-on\)](#)
- 23**
MAY
[Comments to FTC about PBM practices and impact on access and affordability \(ACCC sign-on\)](#)
- 24**
MAY
[Comments to FTC about PBM practices and impact on access and affordability](#)
- 24**
MAY
[Comments to FTC about PBM practices and impact on access and affordability \(HIV+Hep Policy Institute sign-on\)](#)
- 6**
JUL
[Letter to Secretary Becerra about clarifications regarding nation's pharmacies \(coalition sign-on\)](#)



GHLF REPRESENTS PATIENTS AT INDUSTRY, ACADEMIC, AND GOVERNMENT MEETINGS

Recently, GHLF attended or participated virtually in the following meetings:

- 10**
MAY | AAM Briefing: How Key PBM Practices Negatively Impact Access to Affordable Medicines
- 21-24**
MAY | Steven Newmark and Joseph Coe attended the 2022 Digestive Disease Week Conference
- 13-16**
JUN | Corey Greenblatt attended the 2022 BIO International Convention
- 17-18**
JUN | Steven Newmark attended the 2022 National Infusion Center Annual Conference

GLOBAL HEALTHY LIVING FOUNDATION CANADA / LA FONDATION MONDIALE POUR VIVRE EN SANTE AU CANADA PARTNERS WITH NON-PROFITS

During the second quarter, GHLF Canada participated in a psoriatic arthritis–related patient input submission process to Canada’s Drug and Health Technology Agency (CADTH), in collaboration with the Canadian Arthritis Patient Alliance (CAPA), the Canadian Psoriasis Network (CPN), the Canadian Association of Psoriasis Patients (CAPP), and the Arthritis Society (TAS). This patient input submission ensured that psoriatic arthritis patients’ voices were heard among the highest level of Canadian federal health authorities to advocate for access to new medication and treatment pathways to better their disease journey. We conducted a survey among our entire Canadian patient community to help inform the submission.



CREAKYJOINTS
CANADA

■ CREAKYJOINTS CANADA – MAKING AN IMPACT THROUGH THE POWER OF PATIENTS

We continued to invite diverse Canadian patient advocates to provide powerful perspectives on a wide array of issues faced by the Canadian chronic disease community, publishing this content and our general educational content in English and French to serve as the trusted digital resource for people living with all forms of arthritis across Canada. We also shared these articles regularly on our social media channels.



Notable new articles include:

- [Facing the World with Rheumatoid Arthritis: When the Masks Come Off](#)
- [Two Years Later: A Frontline Worker with Rheumatoid Arthritis Reflects on COVID, Reopening, and Moving Forward](#)
- [How Art Is My Physiotherapy for Rheumatoid Arthritis](#)
- [What the Canadian Family Physician Shortage Means to Me as Someone With Chronic Illness](#)

■ CANADIAN PATIENT COUNCILS — WORKING FOR AND WITH THE CANADIAN PATIENT COMMUNITY

In the second quarter, our Canadian Arthritis Patient Council met several times to address pressing educational and advocacy-based needs of the Canadian arthritis patient community, which will lead to a social media campaign this September during Canada's Arthritis Awareness Month. Council members' voices continue to play a crucial role in advocating for patient needs and enhanced patient well-being across Canada at the federal, provincial, and local levels.

We also continued our advocacy in the migraine space thanks to the work of our Canadian Migraine Patient Council. Several members participated in successful global social media campaigns for Migraine and Headache Awareness Month in June. Together, we explored the issues of reimbursement for treatments across provinces (e.g., Botox treatments), access to specialists, and shortening time to diagnosis.

■ PARTNERING FOR A STRONGER CANADIAN VOICE

We continue to forge new — and enhance existing — partnerships with several different Canadian patient organizations on a wide array of issues, including the Canadian Arthritis Patient Alliance, the Canadian Psoriasis Network, the Arthritis Society, Migraine Canada, and Migraine Québec.

GHLF Canada formed a new partnership with Cambrian College in Ontario and worked with three graduate-level students on a data-driven research project that looked at the landscape of several chronic illnesses in Canada, including rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, and migraine. Issues explored included access to pharmacies and specialists, wait times for appointments, and rural versus urban comparisons, among other issues. The students used the province of Ontario as their case study. This partnership and the outcomes proved invaluable for GHLF Canada in our work to address the most pressing and very real needs of Canadian chronic disease patients.

CREAKYJOINTS AND GHLF AUSTRALIA REPORT RESEARCH, THERAPY AND BEST PRACTICES

HIGHLIGHTS FROM THE ARA 2022 ANNUAL SCIENTIFIC MEETING

The CreakyJoints Australia team recently attended the Australian Rheumatology Association (ARA) 2022 Annual Scientific Meeting to learn what the latest in research, therapies, and best practices will mean for people with arthritis and related conditions. We then shared that information via a long series of tweets and an in-depth article.

We joined the recent Australian Rheumatology Associations ASM to learn what the latest in research, therapies and best practice will mean for people with arthritis and related conditions.



NEWS AUSSIES CAN USE!

CreakyJoints Australia prioritizes bringing the latest Australian and pan-Pacific stories to our members, in addition to localizing U.S. CreakyJoints articles. Impactful Australian articles from the quarter include:

- [What Is Healthcare Horizon Scanning and What Does It Mean for You?](#)
- [Report Reveals the Impact of Opioid Rules on People with Chronic Pain](#)
- [Support the 1 in 7 Australians with Arthritis](#)
- [Rheumatologists Share Updated COVID-19 Vaccination Advice for Rheumatology Patients](#)
- Published in Rheumatology Republic: [Tips for Helping Patients to Be More Involved](#)

GHLF AUSTRALIA GROWS

In the second quarter, we launched [a new psoriasis page](#) to help patients manage their condition, featuring a psoriasis quick guide, treatment information, patient stories, and other resources. Notably, this new section [includes a perspective](#) from Australian Karen Ridsdale, who shares what it is like to watch her daughter deal with pain and stigma from the disease.



Karen Ridsdale has lived with the skin disease, [psoriasis](#), since childhood. She learned to deal with the social stigma and a limited range of smelly, greasy treatments. Yet, the hardest thing for her was watching her daughter, Sarah, grow up with a more severe form of the disease. Today, Karen is the President of [Psoriasis Australia](#) and a passionate advocate for people with psoriatic disease.

Karen's journey

Karen developed scalp psoriasis when she was seven years old after a strep throat infection. Karen's mother recognised the condition as it ran in their family and took Karen to a dermatologist for diagnosis and treatment.

RESEARCH OPPORTUNITIES CONTINUE FOR THE AUSTRALIAN PATIENT COMMUNITY:

Community and Patient Preference Research (CaPPRe): Two recent research studies for people living with psoriasis and psoriatic arthritis are exploring what is important when it comes to their treatment. Our members were asked: 1) What is important to patients when it comes to diagnosis, treatment, and care? And 2) If their treatment and care needs are being met and, if they aren't, what could be done better? We are awaiting results.

GHLF CONTINUES ITS IMPACT IN CHILDHOOD AND EARLY-ADULT EDUCATION IN NEPAL

GHLF’s support of International Student Learning Inc. (ISLearning) and Canopy Nepal’s program Beyond Borders continues to be successful and advance health and related education efforts in Nepalese schools. In the second quarter, the initiatives reached hundreds of students in over 15 schools across 11 sessions. Students experienced growth in their critical analysis and writing skills and expressed clear growth in not only self-expression and confidence but also leadership skills, critical analysis skills, and more for an overall average 88 percent growth rate in capabilities.

With our in-country partners, we also established a series of GHLF-led virtual educational sessions for students on a variety of topics, from hygiene to living with rheumatoid arthritis. We will kick off sessions with students this fall.



Photos credit: Beyond Borders Report: April 2022 – June 2022)

CREAKYJOINTS AND GHLF EARN 79 ORIGINAL MEDIA PLACEMENTS

During the second quarter, there were 79 original placements, generating an estimated 556 million media impressions. In addition to coverage mentioned earlier in this report, notable outlets covering CreakyJoints leadership or projects included an article from [MedPage Today](#) highlighting the history of the John Whelton Arthur Virshup CreakyJoints South Florida Arthritis Clinic. [Everyday Health](#) continued to include perspectives from our physicians regularly, and we generated an opportunity for Shanthini Kasturi, MD, to speak about her ArthritisPower lupus research with [Rheumatology Network](#).

LONG SESSIONS COMMON WITH OUR EDUCATIONAL CONTENT

In the second quarter, there were nearly 3.3 million combined page views of CreakyJoints.org, ghlf.org, CreakyJoints Español, and CreakyJoints Australia content. The metrics below illustrate the quality of traffic coming to CreakyJoints.org, the diversity of visitors, and the rheumatic topics they're interested in.

The average site visit on CreakyJoints.org is 18 minutes, 58 seconds (far surpassing the industry's average of two to three minutes).

Not only are people engaging with content on the website, but they're also opting to receive more content from CreakyJoints. This quarter, the CreakyJoints' email list grew 33 percent, reaching more than 170,000 people.

Some of our most popular resources this quarter included:

- [Top 10 Frustrations I Regularly Experience Living with Rheumatoid Arthritis](#)
- [The Power of Pets for Patients with Chronic Illness](#)
- [How to Improve Your Sleep with Gout](#)
- [The 5 Rules of Psoriatic Arthritis Skin Care You Should Be Following](#)
- [Patient Perspective: Notable Rheumatic Disease Studies at EULAR](#)
- [Pride and Chronic Disease: Raising Awareness Together](#)
- [When the Elephant in the \(Rheum Exam\) Room Is S-E-X](#)



melanatedmona commented: I was diagnosed with RA today 😞. I just want you to know that a Creaky Joints article I read changed my life. If it wasn't for the article I read (shingles in RA patients) I would've never requested my Dr order the blood work, that ultimately shows I do have RA. 11h



■ GHLF AND CREAKYJOINTS SOCIAL MEDIA TOPS 40 MILLION IMPRESSIONS

Our social media channels are key ways that GHLF and CreakyJoints communicate with our patient community, obtain member insights and perspectives, share new content and resources, and keep members informed about the organizations’ activities, opportunities, and accomplishments. Channels include Facebook and Instagram (in English and Spanish), WhatsApp (in Spanish), Twitter, YouTube, TikTok, and LinkedIn. Notable posts from this quarter:

- Instagram: [Who else is feeling like their arthritis should take a vacation?](#)
- TikTok: [Have you used this hack before?](#)
- Twitter: [Cool street art aimed at raising #gout awareness](#). Take a close look here: goutrevealed.com #ArthritisAwarenessMonth



#CRAKYCHATS

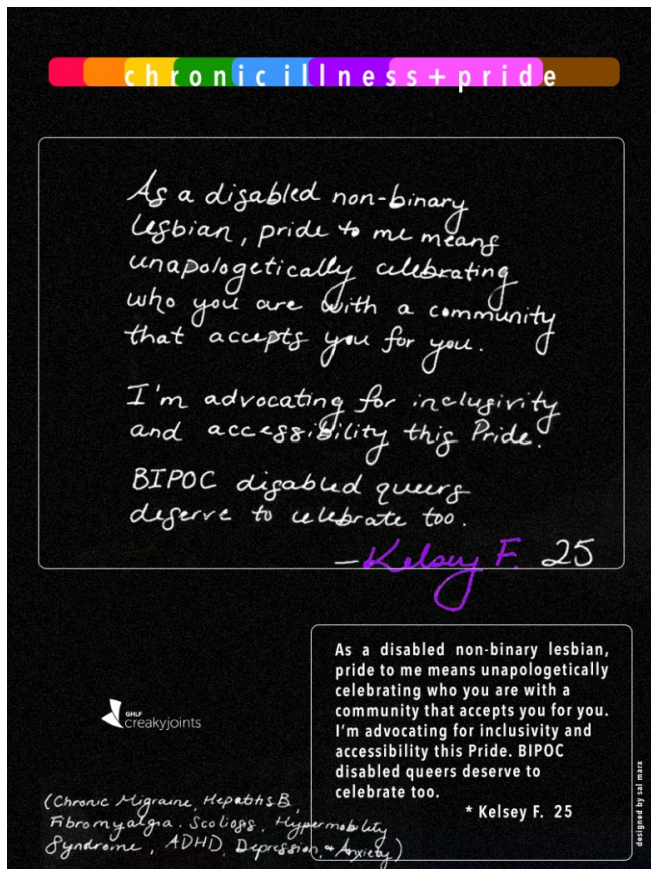
Our #CreakyChats continue to be very popular, generating engagement even after the live event is complete. This quarter's topics included:

April: Mo'Conditions, Mo'Problems

May: Arthritis Awareness Month, cohosted with Everyday Health

June: LGBTQ+ Pride and Chronic Illness

During June's #CreakyChat, we asked our LGBTQ+ community members to discuss what Pride means to each of them and what it's like to navigate the health care system as queer people. For example, we heard from @djali_here on Twitter: "Some are taught to always be humble and that pride should be silent. The truth is, if you don't take pride in yourself and ALL communities you are part of, then your communities will continue to be silenced." Ankylosing spondylitis patient and visual artist [Sal Marx](#) collaborated with several of our patient advocates to create graphics sharing their unique stories.



WHO WE ARE

About CreakyJoints®

CreakyJoints® is an international digital community for millions of arthritis patients and caregivers who seek education, support, advocacy, and patient-centered research. We represent patients in English, Spanish, and French through our popular social media channels, our websites, and the [50-State Network](#), which includes more than 1,700 trained volunteer patient, caregiver, and provider health care activists.



Part of the [Global Healthy Living Foundation](#), CreakyJoints also has a patient-reported outcomes registry called ArthritisPower® ([ArthritisPower.org](#)), which includes tens of thousands of consented arthritis patients who track their disease while volunteering to participate in longitudinal and observational peer-reviewed research. In addition to online and downloadable educational resources, CreakyJoints publishes many arthritis and chronic disease podcast series, available on all major streaming platforms, that provide both patient and provider perspectives. It also hosts PainSpot ([PainSpot.org](#)), a digital risk-assessment tool for musculoskeletal conditions and injuries, and eRheum ([eRheum.org](#)), for telehealth and virtual-care support. All programming is free, always. For more information, visit [CreakyJoints.org](#).

About Global Healthy Living Foundation

The [Global Healthy Living Foundation](#) is a 501(c)(3) nonprofit organization whose mission is to improve the quality of life for people with chronic illnesses (such as arthritis, osteoporosis, migraine, psoriasis, inflammatory bowel disease, 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 international digital community for millions of arthritis patients and caregivers worldwide who seek education, support, activism, and patient-centered research in English and Spanish through our ArthritisPower® ([ArthritisPower.org](#)) Research Registry. In response to the COVID-19 pandemic, GHLF started a Patient Support Program, informed by a patient council made up of people living with a wide range of chronic illnesses, that now serves more than 46,000 subscribers. Via CreakyJoints, GHLF also hosts PainSpot ([PainSpot.org](#)), a digital risk-assessment tool for musculoskeletal conditions and injuries, eRheum ([eRheum.org](#)), for telehealth and virtual-care support, and a constantly refreshed library of podcasts via the [GHLF Podcast Network](#). Visit [ghlf.org](#) for more information.



About ArthritisPower®

Created by [CreakyJoints®](#), [ArthritisPower®](#) is the first-ever patient-centered research registry for joint, bone, and inflammatory skin conditions, as well as arthritis and rheumatologic manifestations of gastrointestinal-tract (GI) and skin conditions. With tens of thousands of consented arthritis patients, the free ArthritisPower mobile and desktop application allows patients to track their disease and participate 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. To learn more and join ArthritisPower, visit [ArthritisPower.org](#) (English) or [ArthritisPower.org.es](#) (Spanish).



About the 50-State Network

The [50-State Network](#) is the grassroots advocacy arm of the [Global Healthy Living Foundation](#). It consists 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 [50StateNetwork.org](#).



GHLF's Patient-Centered Policy Research Initiative

The mission of the Global Healthy Living Foundation's new Patient-Centered Policy Research Initiative is to bring research into health policy considerations to better educate stakeholders, legislators, and other decisionmakers on how proposed and existing policy impacts on patient communities. Through peer-reviewed published research, amicus briefs, op-eds, media interviews, podcasts, and mobilizing patients in our 50-State Network, the GHLF Advocacy team uses research to inform our discussions with policymakers in Washington and around the states about the urgent need for health care reform. For example, in 2021, we published an analysis titled, [Do patients benefit from legislation regulating step therapy? \(April 2021\)](#), in the peer-reviewed journal Health Economics, Policy and Law and also published peer-reviewed commentaries on topics such as the detrimental effect to patients of [rebate walls](#) and [prior authorization](#).



GHLF has participated in multiple legal actions, most recently regarding the regulation of the Pharmacy Benefit Manager Industry. In [PCMA v. Wehbi](#), we argued in the [8th Circuit Court of Appeals](#) that states have a legal right to regulate the PBM industry, and explained the harmful effects of patients as a need for regulation.

About PainSpot

PainSpot by [CreakyJoints®](#) aims to educate and empower people to better understand their health, so they can get diagnosed and treated faster. It is an innovative algorithm-based website for patients with musculoskeletal diseases or injuries that features an interactive, easy-to-use pain-assessment tool, based on the same validated decision-making tools employed by health care professionals in a clinical setting. After participating in the assessment, the patient 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 postinjury. 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 [PainSpot.org](#).



About eRheum

Created by [CreakyJoints®](#), [eRheum.org](#) is a website designed to help patients get the most from their telehealth appointments. Written in patient-friendly language, eRheum defines telehealth and how rheumatologists utilize it, provides patients with access to difference videoconferencing portals to try with their physician, and explains how to make the most of quick-moving appointments. To learn more visit, [eRheum.org](#).



Find us online

CreakyJoints: CreakyJoints.org

CreakyJoints Español: www.CreakyJoints.org.es

CreakyJoints Canada: CreakyJoints.ca

CreakyJoints Australia: CreakyJoints.org.au

Global Healthy Living Foundation: ghlf.org

Facebook: facebook.com/CreakyJoints & facebook.com/GlobalHealthyLivingFoundation

Twitter: [@GHLForg](https://twitter.com/GHLForg), [@CreakyJoints](https://twitter.com/CreakyJoints), [#CreakyChats](https://twitter.com/CreakyChats)

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