



QUARTERLY REPORT

JANUARY - MARCH 2022

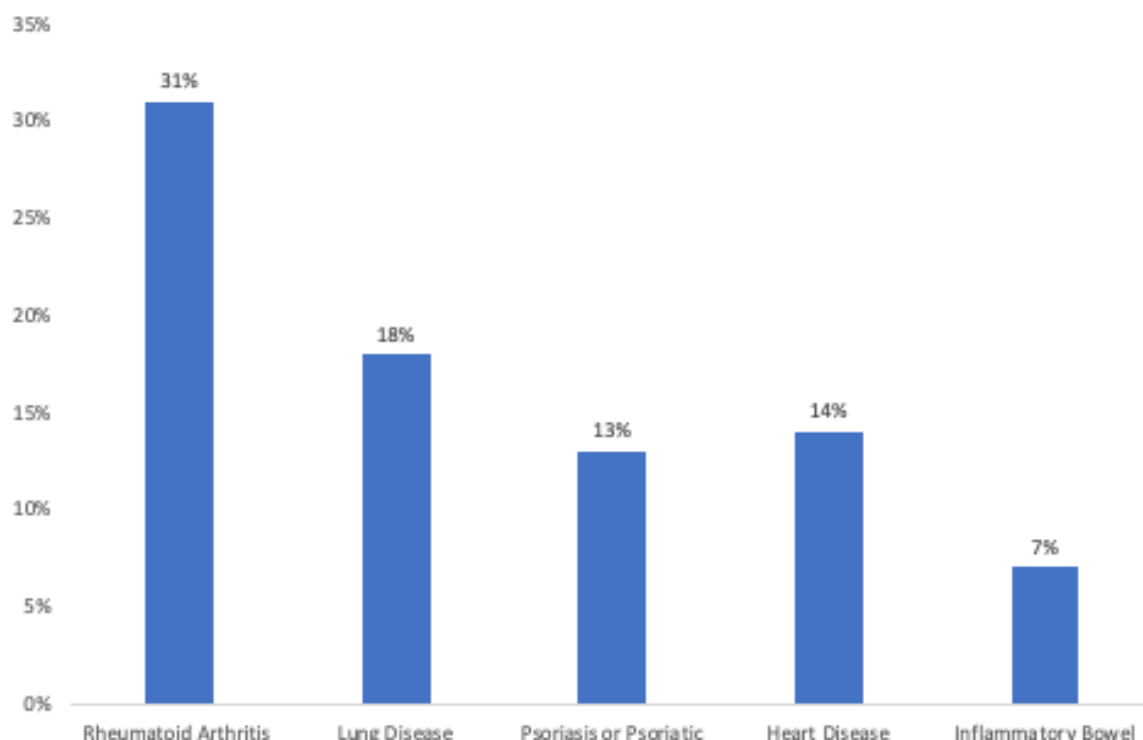


GLOBAL
HEALTHY
LIVING
FOUNDATION

COVID-19 AND CHRONIC DISEASE — WINTER “REOPENINGS” AND ENSURING OUR COMMUNITIES DON’T GET LEFT BEHIND

We were grateful to enter 2022 with many in our patient communities vaxxed and boosted. However, despite seeing a decline in both infections and hospitalizations, we couldn’t help but be worried about what it meant for people living with chronic disease to see family, friends, colleagues, and other members of their communities unmask and restart a “normal” life. For that reason, at the [Global Healthy Living Foundation \(GHLF\)](#) and CreakyJoints®, we continue to provide comprehensive information and support so that everyone can make individual decisions about engaging in the activities important to them. As always, our trusted group of scientific and medical experts contributed perspectives to provide reassurance and guidance, while our members contributed their personal stories and participated in online community events. [CreakyJoints](#) and GHLF remain committed to providing the most up-to-date science-based information, support, and advice about the pandemic for people living with chronic disease.

Our free COVID-19 Patient Support Program remained robust in the first quarter and now includes 28,568 diverse members and 44,387 subscribers (as of April 1, 2022). Website visits continue to exceed one million per month. Common conditions of members in the program include:

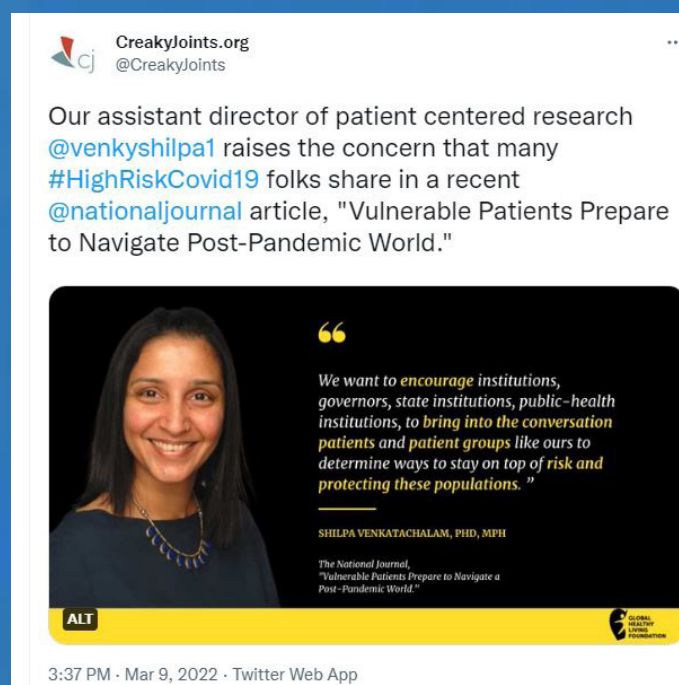


■ COVID ISN'T DONE AND NEITHER ARE WE -- GHLF PUBLISHES SEVEN REPORTS

This winter, we saw the rise of the Omicron variant, prompting us to publish a [comprehensive guide](#) about what chronic disease communities need to know. We also provided advice on extra booster doses and summarized studies that looked at the effectiveness of the vaccines on people immunocompromised by their illness or the medications that treat them. Our content is informed by leading experts in rheumatology, infectious disease, public health, and other specialties to help us explain the most important medical research about COVID-19 for people with chronic medical conditions. From January through March, GHLF continued to publish new COVID-19-related content each week. Many of these articles were also published in Spanish and made available on the [CreakyJoints Español website](#) and its [Instagram](#) page.

Impactful content from the quarter included:

- [Omicron and the Immunocompromised: A Guide for Those at High Risk for COVID-19](#)
- [Getting a 4th “Booster” Dose of the COVID-19 Vaccine for Immunocompromised Patients](#)
- [Large Study Finds Fully Vaccinated Immunocompromised People at Higher Risk for Poor COVID-19 Outcomes](#)
- [Most Immunocompromised People Have Gotten the 4th COVID-19 Vaccine Dose, But Want More Information About Its Effectiveness](#)
- [What’s It Like Having COVID When You’re Immunocompromised — and What I’m Still Worried About](#)
- [Life After Recovering From COVID-19: What Immunocompromised Patients Should Know](#)
- [Omicron Uncertainty Is Depleting Your Mental Health Reserves. Here’s How to Restore It, According to a Health Psychologist](#)



In March, National Journal, a publication covering health policy, interviewed Shilpa Venkatachalam, PhD, Associate Director of Patient-Centered Research, about how vulnerable patients can navigate the “post-pandemic” world. She was quoted saying, “We want to encourage institutions, governors, state institutions, public-health institutions, to bring into the conversation patients and patient groups like ours to determine ways to stay on top of risk and protecting these populations . . . because there are different things that have to go into consideration when we’re thinking about people who have underlying conditions and who are on specific immunosuppressive therapies.”

■ MASKS, BOOSTERS AND MISUNDERSTANDING WORRY OUR CONSTITUENTS

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

January Poll Topic: How has our community been coping and navigating life while the Omicron variant surges?

1,772 (89%)

survey respondents reported that their condition or treatment put them at high risk of severe coronavirus illness.

72%

felt that most people misunderstood
“why the virus is still life-threatening for me.”

“ I look fine and try to act fine, so people cannot imagine that I am in this pool that I’m in. They don’t understand my condition at all, and they can’t understand when I try to explain.

February Poll Topic: Have you gotten the fourth booster shot?

2,384 (93%)

reported they were immunocompromised), the majority (96 percent) had received the two-dose mRNA vaccines as well as a third shot.

96%

reported having received a fourth COVID-19 vaccine dose.

59%

had no difficulties getting the fourth shot;
some had challenges, such as being turned away at the vaccine site - 20%
or not being able to get an appointment at first - 7%.

“

I am a nurse, and it is my 14-year-old daughter who is immunosuppressed. We went to a small clinic run by a doctor I work with to receive the fourth dose. Initially they said, "Oh, she has already had her third dose." I had to explain the newest recommendation. We were promptly cared for then, but I also had to name-drop the doctor who runs the clinic. I don't believe many people would have had the resources and ins that we had.

March Poll Topic: As a person who is immunocompromised, will you continue to wear masks, especially indoors in public spaces, despite mandate lifts?

2,296 (93%)

reported being vaccinated against COVID-19, including having received all additional vaccine doses that are available.

When asked if they would continue to wear masks in indoor public spaces, 91% said yes, 7% said no, and 2% said they didn't currently wear a mask in that situation.

When asked if they would continue to wear masks on public transportation, 96% said yes, 3% said no, and 2% said they didn't currently wear a mask in that situation.

73%

The one indoor situation where people with chronic illness were more willing to go without a mask was socializing indoors. In the free-response section, many said that their openness to reduce mask wearing related to with whom they planned to socialize.

“

I am still really uncertain. I have been evaluating each situation indoors. I look at the size of the group. Do I know the vaccination status of the people? I also check the risk in my county.

Join our community

#CreakyChats

Finding Community in Isolation

Monday, February 28th, 2022, 7:00 pm ET

Hosted by



@CreakyJoints
#CreakyChats

Cohost by



@ACICommunity
Autoimmune
Community Institute

■ #CREAKYCHATS: FINDING COMMUNITY IN ISOLATION (FEBRUARY 28, 2022)

During our monthly #CreakyChat on Twitter, we had an in-depth conversation about how to make connections and feel part of a community. The event was cohosted by the Autoimmune Community Institute (@ACICommunity). During the chat we highlighted the resilience of our community and provided ways to continue supporting one another.

AUTOIMMUNE COMMUNITY INSTITUTE

COMMUNITY-CENTERED
RESEARCH, ADVOCACY
AND SUPPORT

OUR LEADERSHIP PROVIDES PERSPECTIVE AROUND THE GLOBE

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



Robert Popovian, PharmD, MS, Chief Science Policy Officer, presented at eight different conferences during the first quarter, often on drug pricing and access to affordable medications. Popovian presented to the Asian Pacific American Medical Student Association, State of Reform, the National Association of Boards of Pharmacy, the Dean's Lecture Series at the University of Southern California, School of Pharmacy, the World Biosimilars Congress, the Pioneer Institute Policy Briefing, and Vaccine Virtual Days.



Shilpa Venkatachalam, Associate Director of Patient Centered Research, was invited to present an overview of the Global Healthy Living Foundation and ArthritisPower® to the South Asian Health and Research Group (SAHARA) based at the NYU School of Global Health, which was established in 2019.



Corey Greenblatt, Manager of Policy and Advocacy, participated in a virtual advisory-panel discussion by global pharmaceutical company UCB on barriers that patients face to access their care and what GHLF and other leading patient groups are doing to combat these barriers.



Sarah Shaw, BIPOC Patient Advocate and Community Outreach Manager, led the presentations for the New Jersey Headache on the Hill team in February, speaking directly to members of Congress.

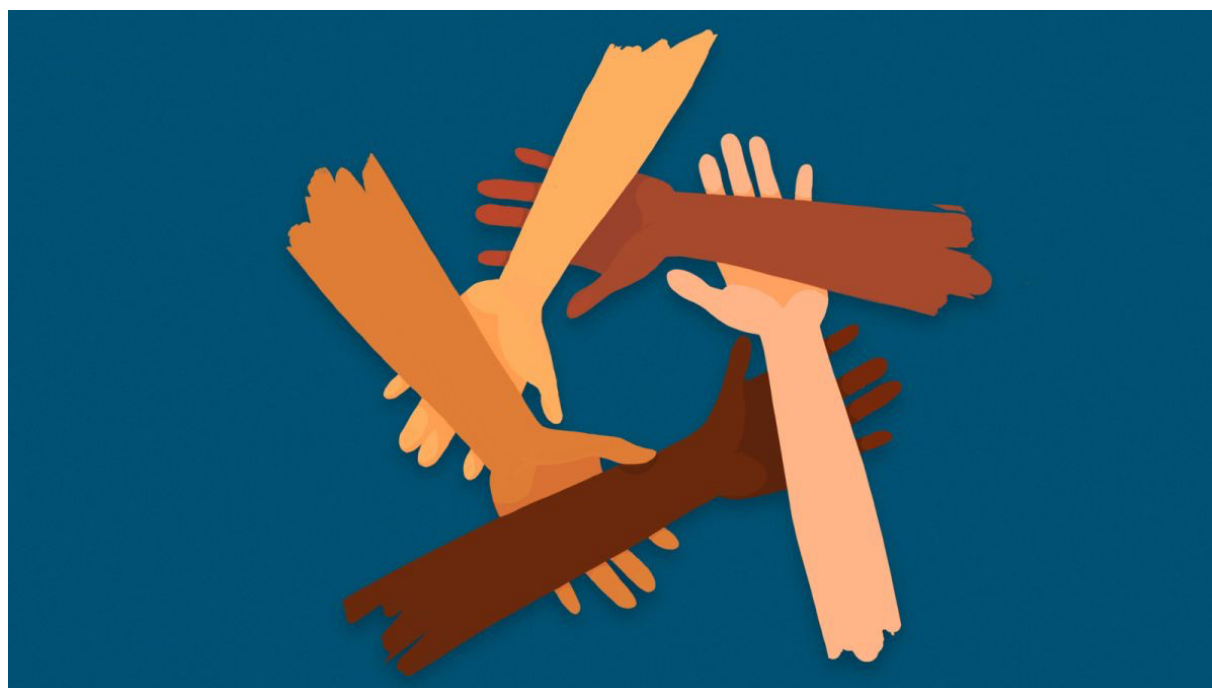
As always, our advocacy team participated in many virtual meetings, representing the concerns of all patients living with chronic disease to influence the development of patient-friendly health policy. Please see “Speaking with and for the Chronic Disease Community” for additional detail.

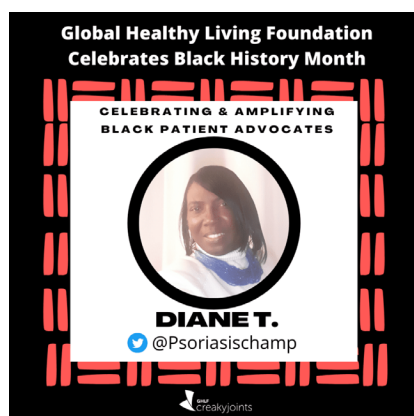


RAISING THE PROFILE OF MARGINALIZED COMMUNITIES

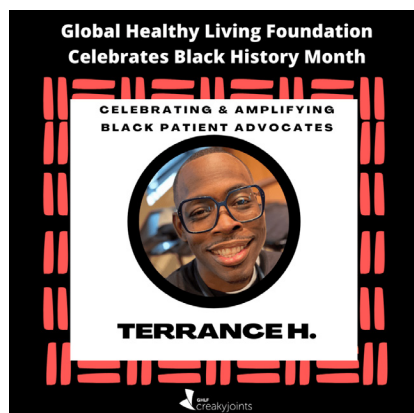
In February, which is Black History Month, GHLF highlighted how many of our members are discussing racial injustice and health disparities among Black patients with chronic illness, from rheumatic conditions to migraine to heart disease and more.

As explained by Sarah Shaw, BIPOC Patient Advocate, Community Outreach Manager at the Global Healthy Living Foundation, in an in-depth article published on our websites and amplified on social media platforms, after enduring painful health journeys — including staggering lags in diagnosis and poor quality of treatment and other aspects of care — these advocates are “amplifying Black patient voices to help spark important conversations and show others within Black patient communities that they’re not alone.” Eighteen Black patient advocates shared their stories throughout the month.

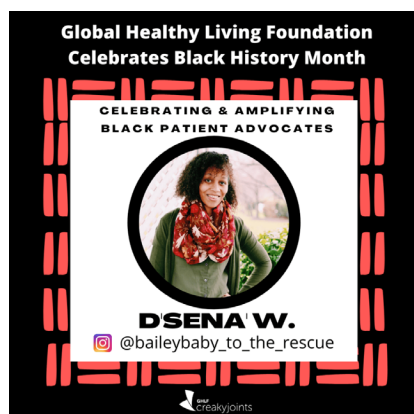




Diane T., who has psoriasis, psoriatic arthritis (PsA), diabetes, and high cholesterol, explains that she's been a prisoner in her own body for 30 years, saying, "I had an invisible illness that no one understood, and my doctors told me it was all in my head. I was young, always smiling, and showed self-confidence on the outside. But on the inside, I was having unbearable pain." Years later, her psychologist helped her realize that she was smiling on the outside and crying on the inside. "One day someone told me I had a voice and I needed to use it."



Terrance H. is a sickle cell warrior and advocate who lives with complications related to sickle cell disease. After battling the condition his whole life, Terrance received a successful stem cell transplant in 2016, which leaves him with just the genetic trait. In speaking about why he pursued a graduate degree even during the pandemic, he said, "I want to be an example to the sickle cell community — to show what you can accomplish while spending time in isolation with a chronic illness. I am determined to succeed. Failure is not an option. By embracing the goals of our lost warriors who strive to advocate for those afflicted with rare diseases, I will continue to spark the flame they have ignited, for they are deeply missed but never forgotten."



D'Sena' W. is a single mom with two young boys. She has been living with migraine since age nine and also has dysautonomia and hypermobile Ehlers-Danlos syndrome (hEDS). After sustaining a traumatic brain injury in a motor vehicle accident in 2010, D'Sena' was diagnosed with chronic migraine and then complex migraine. She says, "Once becoming one with the community, I noticed there weren't many people of color that could quite relate to my treatment as a woman of color. I found my voice as I was trying to navigate through a system that is constantly trying to push me off as someone not worthy of the care I deserve. I ran with it and never looked back."

■ PROSTATE CANCER SCREENING AND TREATMENT OUTREACH BEGINS IN NEW YORK CITY

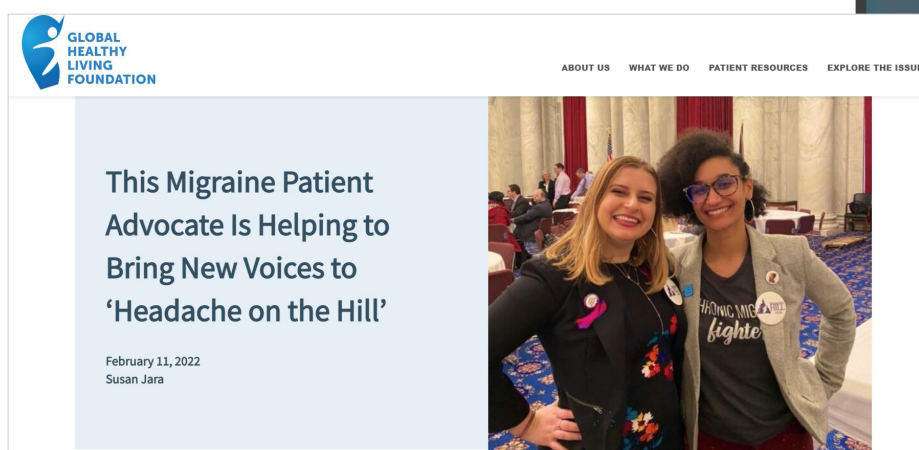
Members of the GHLF team have initiated community outreach with the Department of Urology at Mount Sinai Health System to reach the Black community throughout New York City for prostate cancer screenings. The Department of Urology recently launched the Mount Sinai Robert F. Smith Mobile Prostate Cancer Screening Unit, which is committed to the early detection of prostate cancer in Black men. The screening unit is a state-of-the-art mobile facility, equipped with advanced scanning and staff. Through community outreach, the mobile screening unit will cover the five New York City boroughs to help address the disparity of prostate cancer in Black men.



■ ADVOCATING FOR MIGRAINE AWARENESS

Each year, the Alliance for Headache Disorders Advocacy (AHDA) unites health professionals, migraine and cluster headache advocates, and patients to present requests to Congress during the annual advocacy event Headache on the Hill. These asks are typically focused on improving awareness about the impact of headache disorders and the need for research funding. In March, Sarah Shaw, GHLF's BIPOC Patient Advocate and Community Outreach Manager, joined the NJ Headache on the Hill team. The team met virtually with six different congressional offices to request funding to establish Indian Health Service (IHS) Headache Disorders Centers of Excellence (HCoE). We met with staffers from the offices of:

- Senator Robert Menendez
- Senator Corey Booker
- Representative Bonnie Watson Coleman
- Representative Bill Pascrell
- Representative Chris Smith
- Representative Donald Norcross



GHLF also [profiled several of our migraine advocates on our website](#), such as Fred Flores (they/she). In the profile, Fred says, “My journey began seven years ago, when I was first diagnosed with chronic migraines, after two years of crippling headaches, nausea, photosensitivity, and fatigue that ER doctor after ER doctor couldn’t provide relief from. Like many brown people in my community, the lack of adequate health care is what kept me burdened with the symptoms of chronic and episodic migraines for years. Because of migraine disease, I had to move my energies from completing my degree to having a job that could provide basically subpar health insurance to help me manage my chronic illnesses. Thus, my journey in how to navigate in this new reality began.”

■ ADVOCATING FOR DIGESTIVE DISEASES

We joined the Digestive Disease National Coalition's 32nd Annual Public Policy Forum to advocate for digestive disease research and improved patient care. In virtual meetings with U.S. congressional offices, we shared our support for the Safe Step Act. We met with staffers from the offices of:

- Representative Joe Morelle
- Representative Paul Tonko
- Representative Andrew Garbarino
- Senator Chuck Schumer

After participating in the virtual meetings, we hosted two discussions on [*The Health Advocates*](#) podcast about our advocacy experience and how patients can get involved with our 50-State Network. In one episode we discussed [the power of virtual advocacy](#) with Corey Greenblatt, GHLF's Manager of Policy and Advocacy. In another, we [sat down with Dale Dirks](#) from the Digestive Disease National Coalition to talk about how patient stories can influence legislators to make change.



In addition to being a comprehensive education program, the digital guide is also stand-alone, institutional review board–approved research that will inform understanding of the best practices to educate people about living with RA. CreakyJoints Español tracks engagement and responses to the quizzes and other activities, and analyzes if this educational format improves understanding of RA. In the press release, Daniel Hernandez, MD, Director of Medical Affairs and Hispanic Outreach at the Global Healthy Living Foundation, said,

“ We started CreakyJoints Español nearly five years ago understanding that there is a significant lack of health resources for people whose primary language is something other than English. Our website and social media platforms now include hundreds of articles about living with arthritis, updates on the latest arthritis research, and the stories of our members managing their day-to-day symptoms. With this new digital guide, we’ll be able to both measure the impact of our education and attempt to address the disparity that affects our community, especially those newly diagnosed with RA.”

To generate additional excitement, on March 30, Dr. Hernandez participated in a six-hour radio media event, giving 19 interviews in Spanish, each lasting seven to eight minutes. During each interview, Dr. Hernandez had the opportunity to provide in-depth information about the digital guide and why it is vital to the Hispanic/Latinx community, and encouraged listeners to visit the website to engage with the guide. Our media tour resulted in:

- 19 interviews in Spanish, 11 of which aired live and three that were syndicated across the United States
- 401 airings on 391 radio stations across the United States
- 9.7 million estimated impressions

We also published a sponsored article in [*La Opinión*](#) and sister publications from ImpreMedia, one of the largest Spanish-language online media outlets in the country. The article will reach at least 195,000 impressions.

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. Impactful articles from the first quarter included:

- [Pruebas de COVID en el hogar: lo que las personas inmunocomprometidas necesitan saber](#)
- [Así es como puede apoyar a alguien durante un brote de artritis reumatoide](#)
- [Cómo evitar el “fenómeno del estacionamiento”: cuando olvidas decirle a tu médico información clave durante tu visita](#)



ARTHRITISPOWER VERSION 3 LAUNCHES

In late March, the [Global Healthy Living Foundation](#) relaunched its successful [ArthritisPower Research Registry](#) with version 3 of the free app, redesigned to improve overall usability and increase the volume of educational resources available. In the past five years, ArthritisPower research has been presented annually in more than 70 conference abstracts at major national and international rheumatology scientific congresses and published in more than 45 peer-reviewed papers.

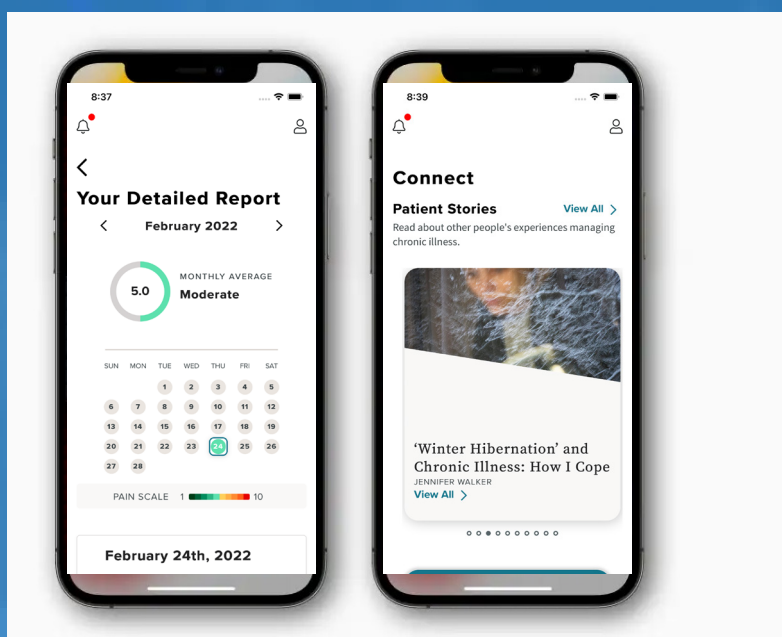
The ArthritisPower Research Registry app was redesigned with the patient experience in mind. CreakyJoints interviewed users and then conducted confirmatory market research to ensure that planned enhancements met the needs of the CreakyJoints community. Following user research, patients were included in every additional step of the process as well — from planning and concepting to post-launch validation testing.

In the press release, W. Benjamin Nowell, PhD, Director, Patient-Centered Research and Principal Investigator of ArthritisPower, said, “This new and improved version of ArthritisPower will help each person self-select and prioritize the domains they most want to track from dozens of options — whether it’s pain, physical function, or fatigue — and connect better to our CreakyJoints

community by accessing educational articles and stories about peer patients in the app.”

David Curtis, Director of Technology and Data Services, said, “Input from our patient community determined how we augmented the app, and we think most users will find that the interface is easier to use and that we’ve increased the volume of supportive, educational information that they can access in between inputting their assessments. We’re really proud to offer ArthritisPower to our community.”

Curtis and Nowell appeared in a [Rheumatology Network](#) podcast about the relaunch this spring.



PODCAST AND PUBLISHED WORK FOCUSES ON PSORIASIS AND PSORIATIC ARTHRITIS

In the first quarter, CreakyJoints spotlighted people living with psoriasis and psoriatic arthritis. In addition to launching a new podcast, [Getting Clear on Psoriasis](#) (see the podcast section of this report), we attended the 2022 American Academy of Dermatology (AAD) annual meeting in Boston. The in-person team was led by Steven Newmark, Chief Legal Officer and Director of Advocacy. Daniel Hernandez, MD, Director of Medical Affairs and Hispanic Outreach, and Shilpa Venkatachalam, PhD, MPH, Associate Director, Patient-Centered Outreach, also attended.

During the meeting, our team interacted with physicians and other stakeholders to discuss how CreakyJoints connects with the psoriasis community and the educational tools and resources people living with chronic conditions need today and in the future.

Throughout the meeting, we also shared information and education about psoriasis on our social media platforms.

Leading up to the AAD meeting, CreakyJoints also published articles covering the latest research on psoriasis and psoriatic arthritis to further educate our patient communities, such as:

- [Depression Impacts Psoriatic Arthritis Patients Even More Than It Does People with Psoriasis](#)
- [How to Cope When People Stare at Your Psoriasis](#)

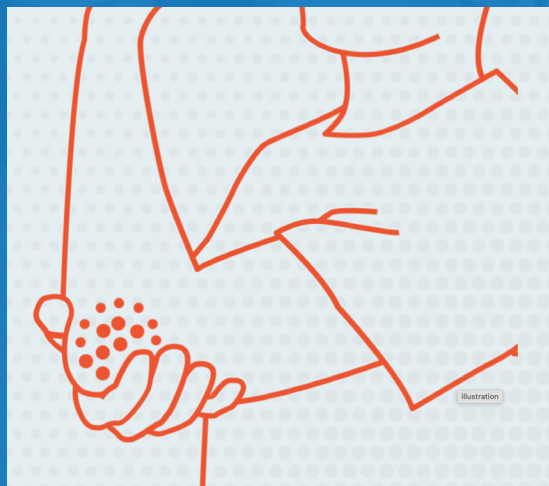


GHLF PODCAST NETWORK NEARLY DOUBLES LISTENERSHIP

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! We're proud of the content that helps inform our patient communities about the latest treatment options and health-policy proposals, and have found that our members positively relate to hearing the true stories of people sharing their disease journey. Visit the GHLF Podcast Network to see the full list of shows at ghlf.org/patient-education/listen and/or download our podcasts from any streaming platform.

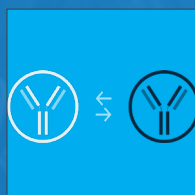
■ NEW SERIES IN THE FIRST QUARTER:

Getting Clear on Psoriasis



Having psoriasis isn't easy. It can be physically and mentally challenging, causing uncomfortable symptoms and making you feel disconnected from loved ones and daily activities. But the right information, treatment plan, and support can make a big difference in your health and happiness. Host and psoriasis patient David Brandt, Operations Manager at the Global Healthy Living Foundation, guides listeners through important topics about living better with psoriasis, and each episode includes relatable insights from fellow patients and key information from leading dermatologists and other experts.

ONGOING SERIES



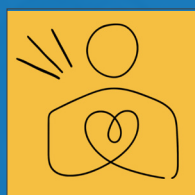
Breaking Down Biosimilars: In this podcast, our goal is to introduce you to biosimilars: what they are, how they get approved, their potential savings, and what promise they hold.



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.



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.



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, Joseph Coe, MPA, host of the Talking Head Pain podcast and Director, Education and Digital Strategy, was featured in a video published by WebMD in late March. In the video, shot in and near his home, Coe describes his personal experience with migraine, talked about his management strategy and exercise, and spoke about the GHLF Podcast Network, which was referenced on-screen multiple times. During the first quarter, a new season of Talking Head Pain was recorded, and it will premiere this spring.



The newly published third season of The Health Advocates generated some great comments from our listeners, such as:

“

“Great and informative material I can relate to as a chronically ill patient.” — writergal5404

“

“Great podcast, engaging hosts, and timely topics. Highly recommend.” — corecore9222

“

“Too often we only think about health care when we urgently need it, when we may lose it, or when our politicians are fighting about it. This podcast is raising important topics in public health and healthy living that don’t get enough airtime elsewhere. More, please!” — tunezoon

“

“This podcast was super interesting and just the right length. I was able to quickly get clear and concise answers to the many questions I had about vaccines, boosters, and antibody tests.” — Lyn1911

ARTHRITISPOWER PATIENT RESEARCH HITS NEW HIGHS

Current ArthritisPower statistics as of March 31, 2022:

- Total patients: **36,423**
- % increase in membership from March 31, 2021: **14%**
- Top Conditions:

Osteoarthritis:	19,409 (53%)
Rheumatoid Arthritis:	16,068 (44%)
Fibromyalgia:	12,710 (35%)
Psoriasis/Psoriatic Arthritis:	6,677 (18%)
Osteoporosis:	5,263 (14%)
IBD:	4,569 (13%)
Lupus:	2,033 (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 STUDY AMONG TOP CITED IN ACR OPEN RHEUMATOLOGY JOURNAL

During the first quarter, GHLF learned that our ArthritisPower study that analyzed the impact of social distancing, telemedicine, and treatment interruptions during the COVID-19 pandemic received enough citations to be a top cited article in the journal ACR Open Rheumatology. This demonstrates the quality of the research as other investigators used the data to support their own studies and analysis.

George, M. D., Baker, J. F., Banerjee, S., Busch, H., Curtis, D., Danila, M. I., Gavigan, K., Kirby, D., Merkel, P. A., Munoz, G., Nowell, W. B., Stewart, P., Sunshine, W., Venkatachalam, S., Xie, F., Curtis, J. R. “Social Distancing, Health Care Disruptions, Telemedicine Use, and Treatment Interruption During the COVID-19 Pandemic in Patients With or Without Autoimmune Rheumatic Disease.” *ACR Open Rheumatology* 3, no. 6 (May 2021): 381–389. doi.org/10.1002/acr2.11239.



■ PROLIFIC DATA PUBLICATION IN THE FIRST QUARTER

Our research team published five studies in the first quarter in top journals:

1. Ledbetter S. S., Xie, F., Stewart, P., Cutter, G., George, M., Saag, K. G., Nowell, W. B., Mikuls, T., Jackson, L., Danila, M. I., Winthrop, K., Curtis, J. R. “COVID-19 Vaccine Uptake and Vaccine Hesitancy in Rheumatic Disease Patients Receiving Immunomodulatory Therapies in Community Practice Settings.” *Arthritis & Rheumatology* (January 2022). doi.org/10.1002/art.42067. Epub ahead of print. PMID: 35235715.

Key Findings: Patients with autoimmune and inflammatory rheumatic diseases were significantly less likely to have been vaccinated (76.9 percent) versus comparator patients (i.e., osteoarthritis or osteoporosis, receiving no disease-modifying antirheumatic drugs). As anticipated by the ACR Task Force, these findings indicate that vaccine hesitancy remains an important and persistent problem despite the wide availability of the COVID-19 vaccine. The authors suggest that providers should make specific efforts for at-risk immunocompromised patients to both ascertain vaccine status and recommend vaccination and supplemental dosing absent contraindications.

2. Dharia, T., Venkatachalam, S., Baker, J. F., Banerjee, S., Curtis, D., Danila, M. I., Gavigan, K., Gordon, J., Merkel, P. A., Shaw, D. G., Young, K., Curtis, J. R., Nowell, W. B., George, M. D. “Medication Interruptions and Subsequent Disease Flares During the COVID-19 Pandemic: A Longitudinal Online Study of Patients With Rheumatic Disease.” *Arthritis Care & Research* 74, no. 5: 733–740. doi.org/10.1002/acr.24837.

Key Findings: During the COVID-19 pandemic, anxiety and interruptions in disease-modifying antirheumatic drug (DMARD) use initially decreased over time, but DMARD interruptions increased during 2021, possibly related to an increase in COVID-19 cases or vaccine availability. Interruptions in DMARD use were associated with increased rates of severe disease flares, highlighting the importance of avoiding unnecessary DMARD interruptions.

3. Ogdie, A., Myers, K., Mansfield, C., Tillett, W., Nash, P., Leach, C., Nowell, W. B., Gavigan, K., Zueger, P., McDearmon-Blondell, E., Walsh, J. “Experiences and Treatment Preferences in Patients With Psoriatic Arthritis: A Cross-Sectional Study in the ArthritisPower Registry.” *Rheumatology and Therapy* 9: 735–751. doi.org/10.1007/s40744-022-00436-x. Epub March 13, 2022. PMID: 35279798.

Key Findings: Patients with psoriatic arthritis from the ArthritisPower Research Registry found musculoskeletal pain symptoms to be the most bothersome and prioritized improvements to functional impacts of their disease. Patients reported that improvements in the ability to perform physical activities were most important, followed by improvements in the ability to function independently, sleep quality, and the ability to perform daily activities. These findings can better inform development of new therapies and guide shared patient-provider treatment decision-making.

These study results were covered by Rheumatology Network.

4. Gavigan, K., Nowell, W. B., Hunter, T. et al. “Employment, Work Productivity, and Biologic Treatments in Self-Reported Axial Spondyloarthritis: a Cross-Sectional Study in a Female Predominant Population from the ArthritisPower Registry.” *Rheumatology and Therapy* 9 (2022): 663–677. doi.org/10.1007/s40744-022-00428-x.

Key Findings: In the axial spondyloarthritis (axSpA) study population, compared with not-employed participants, employed participants had more favorable disease activity and overall health. They were also diagnosed at an earlier age (36.0 versus 42.5 years, respectively) and experienced a shorter time between symptom onset and diagnosis (9.5 versus 13.6 years, respectively). Employed participants reported missing on average 6.5 days of work and experienced a 52.7 percent impairment on work productivity due to axSpA over a three-month period. Absenteeism and presenteeism were statistically similar between participants taking a biologic disease-modifying antirheumatic drug (bDMARD) versus those not taking a bDMARD.

5. Danila, M. I. et. al. “Patient Perceptions and Preferences Regarding Telemedicine for Autoimmune Rheumatic Diseases Care During the COVID-19 Pandemic.” *Arthritis Care & Research* (January 2022). doi.org/10.1002/acr.24860. Online ahead of print.

Key Findings: During the COVID-19 pandemic, patients with autoimmune rheumatic diseases frequently had telemedicine visits, with the majority held via video, and were satisfied with these visits. These results suggest that because patients prefer telemedicine for certain visit reasons, maximizing effective use of telemedicine will require personalized patient scheduling.

■ RESEARCH TEAM WELCOMES NEW RESEARCH FELLOW



GHLF Research Fellow Vandana Dronadula is graduating in spring 2022 from Vassar College with a BA in science, technology, and society (STS), along with a chemistry minor. She is also a part of the Vassar/Columbia University 4+1 MPH program, pursuing a master of public health at the Mailman School under the Department of Health Policy and Management. At GHLF, she has been working part-time as a research fellow during the spring semester, and she will continue full-time in summer 2022. Her duties include assisting in data analysis, literature reviews, proposal writing, and more. Dronadula’s passions lie in global public health and promoting equitable access to health care, especially in regard to rheumatology and chronic diseases, which is what spurred her to pursue an opportunity with GHLF.

■ THE NATIONAL ACADEMIES PRESS INCLUDES ARTHRITISPOWER IN NEW PUBLICATION

A new book from the National Academies Press, *Examining the Impact of Real-World Evidence on Medical Product Development: Proceedings of a Workshop Series*, includes a chapter highlighting the ArthritisPower Research Registry (see page 110). In the chapter, the authors describe ArthritisPower and how it came to be, noting that “patients can input and track their own symptoms and treatments, run analytics on their own data, send reports to providers, connect to other patients, and learn about research opportunities.”

W. Benjamin Nowell, PhD, Director, Patient-Centered Research, says,

“The fundamental assumption that drives ArthritisPower as a platform for patient-centered research is that it enables patients to make a decision about their health care. In order to enable patients to make good decisions, facilitating access to relevant evidence and choosing study designs that are best suited to generating that evidence are needed. Most important is determining which study designs and data sources will permit us to answer the research question and engage our partners. The patient-driven research process is iterative and requires ongoing consideration of patient needs and priorities, the patient experience in the study, transparency, and consent.”

■ ELEVEN ARTHRITISPOWER 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.

• **Stronger Together PsA Wellness Study: As patients diagnosed with psoriatic arthritis 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 will begin in April/May 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 will begin this summer and 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 or adalimumab are currently being recruited from participating rheumatology clinic sites across the U.S. Recruitment is ongoing.

• **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.

• **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 NewYork-Presbyterian Hospital. Recruitment for this 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. The final deliverable of this project will be a research agenda, based on multistakeholder input, to implement future projects that improve the understanding and effectiveness of initiatives that increase vaccine uptake in this population.

• **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 will include a series of meetings to evaluate 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.

• **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. In May, we plan to invite patients from Bendcare/AARA practices to recruit 500–1,000 patients to participate in a pilot for the program. This work is being sponsored by GHLF.

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

We are 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 adaptive conjoint analysis (ACA) 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. 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.

During the first quarter, Robert Popovian, PharmD, MS, Chief Science Policy Officer, published (often with coauthors) several op-eds, including:

- The Center for Biosimilars (video interview): “Robert Popovian, PharmD, MS, Discusses Biosimilar Progress and Education in the United States” (January 12, 2022)
- Pharmacy Today: “Most physicians unable to estimate patients’ out-of-pocket costs: How pharmacists can help” (March 1, 2022)

He also continued to cohost the podcast Healthcare Matters (referenced earlier in the report). The podcast covered a wide range of topics, including drug development, COVID-19-vaccine development, and non-medical switching and how it harms patients. In March, Popovian was awarded the Innovation in Pharmacoeconomics Award at the 2022 University of Southern California School of Pharmacy Alumni Awards.

In addition to appearing in a WebMD video (referenced earlier), Joseph Coe, MPA, Director, Education and Digital Strategy, participated in an in-depth video interview about the impact of migraine, personally and in the patient community, with the nonprofit Chronic Migraine Awareness. He also contributed an op-ed to Medium titled “The Migraine Community Needs to Oust the Word Police” to encourage advocacy groups to focus on the experience of migraine and the needs of patients, particularly in light of health disparities in marginalized communities, versus focusing on nuanced terminology.



RECENT COMMENTS AND LETTERS SUBMITTED TO POLICY MAKERS INCLUDE

FEDERAL

26

JAN

[Comments on Notice of Benefit and Payment Parameters 2023](#)

7

FEB

[Comments on national coverage determination for monoclonal antibodies directed against amyloid for the treatment of Alzheimer's disease](#)

7

MAR

[Comments to the Centers for Medicare & Medicaid Services on negotiated price and price concessions](#)

10

MAR

[Comments on FY22 supplemental funding COVID-19 letter](#)

STATE

26

JAN

[Washington Senate Bill 5532: Regulating upper payment limits](#)

8

FEB

[Washington Senate Bill 5888: Share the savings](#)

8

FEB

[Washington Senate Bill 5610: Banning copay accumulator adjustors](#)



Caption: Joseph Coe, MPA, Director of Education and Digital Strategy, and Esteban Rivera, Data Scientist, represented CreakyJoints and the Global Healthy Living Foundation at the National Kidney Foundation gala in New York City.

■ GHLF REPRESENTS PATIENTS AT INDUSTRY, ACADEMIC, AND GOVERNMENT MEETINGS

Virtual meetings continue to be the norm. Recently, GHLF attended or participated in the following virtual meetings:

18
FEB

Health Affairs Speaker Series, Policy Spotlight: One-on-One with Meena Seshamani

7
MAR

Race in America: Health Disparities

8
MAR

Digestive Disease National Coalition Annual Policy Forum

16-24
MAR

Migraine World Summit

25-29
MAR

American Academy of Dermatology Annual Meeting

28
MAR

PDUFA VII: A Vital Reauthorization

6
APR

Global Advocacy Network Learning Session Hosted by Amgen and the International Federation of Psoriasis Associations (IFPA)



GLOBAL HEALTHY LIVING FOUNDATION CANADA/LA FONDATION MONDIALE POUR VIVRE EN SANTÉ AU CANADA SURPASSES 1 MILLION VISITS

Canada represents one of GHLF's largest audiences outside of the U.S., and GHLF Canada showed steady growth and active engagement as our first full year of active presence in Canada came to a close.

During GHLF Canada's first 12 months, Canadians accounted for more than 1 million combined visits across the U.S. and Canadian CreakyJoints websites, as well as GHLF, PainSpot, and eRheum. We've seen over 15,000 unique visits to CreakyJoints.ca, with hundreds of Canadians subscribing every month to receive our ever-growing content.

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

We expanded our content library at CreakyJoints.ca in English and French to serve as the trusted digital resource for people living with all forms of arthritis across Canada. Many articles featured the voices of Canadian patient advocates, who provided powerful perspectives on issues faced by the Canadian chronic disease community.



Caption: Eileen Davidson at the counterprotest of the Freedom Convoy

Notable new articles include:

- [My Message to the Freedom Convoy as an Immunocompromised Canadian](#)
- [When Rheumatoid Arthritis Fatigue Is Worse Than Pain: How I Cope](#)
- [Menopause Threw My Body for a Loop, But Having Rheumatoid Arthritis Prepared Me Surprisingly Well](#)
- [A Working Life with Rheumatoid Arthritis: The Big Change That Made It Manageable for Me](#)
- [How the Canadian Rheumatologist Shortage Affects Your Care — and What We Can Do to Fix It](#)

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

Our Canadian Arthritis Patient Council addresses the educational and advocacy-based needs of the diverse Canadian arthritis patient community. We held our first meeting of the new year during the first quarter and will host several more throughout the year with the goal of turning voices into action via powerful individual stories. Members' voices will play a major role in advocating for patient needs and enhanced patient well-being across Canada at the federal, provincial, and local levels.

This March, we held the inaugural meeting of our Canadian Migraine Patient Council. The council is already hard at work on sharing best practices for how to engage in advocacy and education and to mobilize personal communities for the betterment of people living with migraine and their caregivers across Canada. Throughout the year, we will be exploring a variety of topics including migraine advocacy, unmet needs, treatment and migraine-management education, and how to turn what we learn together into action.

■ 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 (CAPA) and Migraine Canada.

Through our new and growing partnerships, we are able to reach and empower millions of Canadians living with chronic diseases through education and support to help them put themselves at the center of their own care.



CREAKYJOINTS
CANADA

CREAKYJOINTS AUSTRALIA AND GHLF AUSTRALIA ADVOCATE FOR ALL

RAISING OUR VOICES

CreakyJoints Australia (CJA) and GHLF Australia provided comments or engaged in dialogue on behalf of our patient communities during the first quarter.

- **Regarding the abatacept shortage:** CreakyJoints Australia maintained ongoing communications with Medicines Australia, Arthritis Australia, the Australia Rheumatology Association, and other health care organizations to provide patient input on the impact of the shortage and offer [community updates](#).
- **Pharmaceutical Benefits Advisory Committee:** We submitted comments to the Pharmaceutical Benefits Advisory Committee (PBAC) on behalf of our community for two medicines that were up for listing at the March 2022 meeting: risankizumab (Skyrizi) for psoriatic arthritis and apremilast (Otezla) for severe chronic plaque psoriasis. GHLF Australia also submitted comments on behalf of our community for Vaxelis, a hexavalent (six-in-one) combination vaccine, not currently available in Australia.
- **Parliamentary inquiry into childhood rheumatic diseases:** CJA and GHLF put in a [joint submission](#) to the House of Representatives Standing Committee on Health, Aged Care and Sport, which sought public input to inform the research into the causes of childhood rheumatic diseases.
- **Audit of Australia's COVID-19 vaccination rollout:** CJA and GHLF put in a [joint submission](#) to the Australian Department of Health, which is conducting an audit to assess the effectiveness of the planning and implementation of the COVID-19 vaccine rollout.
- **Consultation Draft, National Medicines Policy:** We submitted comments for the Consultation Draft of the National Medicines Policy in 2021, and the revised draft was published for comments in February 2022. The view of many patient organizations and other stakeholders was that the revised draft was unacceptable and was being pushed through before the federal election in May 2022. GHLF Australia and CJA added our organizations' names to Medicine Australia's call to put the draft on hold, to be revisited after the election. This call was successful.
- **National Patient Organisation Network conference, February 2022:** CreakyJoints Australia attended this two-day online conference, which aimed to increase awareness of the role and services provided by patient organizations as an integral part of the health system.

■ CONTRIBUTING OUR PATIENT PERSPECTIVE VIA RESEARCH

CreakyJoints Australia members were invited to contribute to research during the first quarter:

- [Steroid PRO research study baseline survey](#): A global collaborative project to measure patient perspectives of using steroids for rheumatic diseases. The study is being led by the University of the West of England, Bristol, with support from arthritis researchers and organizations across the U.K., the U.S., and Australia.
- [Creaky knees focus group study](#): Researchers at the University of New South Wales are conducting a project to further understand how people with “creaky” (or grinding, popping, noisy) knees feel about these noises in their knees and how this affects their behaviors.
- [Delays in receiving prescriptions and biologic medication](#): A national survey to discover the impact for patients who have experienced delays in receiving prescriptions and biologic medication.
- [Autoimmunity and Health Quantifying Diagnosis survey](#): Researchers at the Garvan Institute of Medical Research are gathering information about how autoimmune conditions are diagnosed and treated from a patient’s perspective.

■ KEEPING OUR MEMBERS UP TO DATE

As always, CreakyJoints Australia and GHLF Australia published articles and narratives to support people living with chronic disease. Highlights include:

- [New COVID-19 Self-Care Guide — An Essential Pre-Planner for People with Chronic Conditions](#)
- *Rheumatology Republic publication*: [Rheumatology Patients Share Their Experiences of the Covid Pandemic](#)
- [Jess Ragusa: Trikafta Urgently Needed on PBS for Cystic Fibrosis Patients](#)
- [MatterOfVax podcast episode](#): GHLF Australia continued its podcast series with an episode featuring Stephanie O’Connell speaking with Associate Professor Dr. Anthony Byrne, a thoracic physician at St Vincent’s Hospital in Sydney and a researcher at the University of New South Wales.

COVID-19 self-care guide

Essential pre-planning information
for people with chronic conditions



GHLF IMPACTING CHILDHOOD AND EARLY-ADULT EDUCATION AND ADVOCACY IN NEPAL

GHLF's first full year of grant funding in support of International Student Learning Inc. (ISLearning) and Canopy Nepal's program Beyond Borders came to completion in Q1 of 2022 and proved very successful.

The program reached 70 schools and over 1,400 students across nearly 50 sessions. Students expressed clear growth in not only self-expression and confidence but also leadership skills, critical analysis skills, and more for an overall 93 percent growth rate in students.

Thanks to this successful first full year of partnership, GHLF decided this quarter to issue expanded grant funding for another year to enhance the impact of this powerful program, notably its health-education efforts. Therefore, Beyond Borders will be able to expand its reach and deepen its programming as part of its mission to deliver education and empowerment to learners belonging to socially, ethnically, and financially disadvantaged communities in Nepal.

GHLF is very proud to continue supporting Beyond Borders' aim to contribute directly to the United Nations' 2030 Agenda for Sustainable Development and to the many targets of the U.N.'s Sustainable Development Goals (SDGs), including SDGs 3 (good health and well-being), 4 (quality education), 5 (gender equality), 11 (sustainable cities and communities), and 13 (climate action).



Photos credit: Beyond Borders Report: March 2021–February 2022

CREAKYJOINTS AND THE GHLF EARN 66 ORIGINAL MEDIA PLACEMENTS

During the first quarter, there were 66 original placements, with several radio interviews in Spanish syndicating to more than 170 additional stations. In addition to the op-eds, interviews, and videos referenced earlier in the report, [HealthCentral](#) published a six-episode video series in January featuring CreakyJoints member Regan Brown Reynolds sharing her experience living with ankylosing spondylitis. Our members were also featured in articles from [Everyday Health](#) and [Canadian Medical Journal News](#) about the importance of exercise. Our research was featured in [Rheumatology Network](#), [Healio](#), and [DocWire News](#). Shilpa Venkatachalam, PhD, Associate Director, Patient-Centered Research, contributed perspective to the National Journal about what the “post-pandemic” world looked like for people living with chronic disease. For the quarter, we estimate nearly 272 million media impressions.

In the first quarter, there were nearly four 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 five minutes, 34 seconds (far surpassing the industry’s average of two to three minutes).
- As GHLF’s COVID-19 Patient Support Program continued to grow, the CreakyJoints community also continued to expand. This quarter, CreakyJoints’ email list grew 17 percent, reaching more than 129,000 people.
- Visitors to non-COVID-19 resources remain steady — indicating people with arthritis and their loved ones continue to seek information and support at the same level as prior to COVID-19.

Some of our most popular resources this quarter included:

- [How I Cope with the Emotions of Pain-Free Days](#)
- [How to Eat Well with Inflammatory Arthritis During Inflation and Rising Food Prices](#)
- [Facing the World with Confidence and Chronic Illness](#)
- [Chronic Illness Patients Share Their Powerful Acts of Self-Love](#)
- [What Quality of Life Really Means When You Have Chronic Illness](#)



■ 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: [Arthritis Self-Care](#)
- TikTok: [#ehlersdanlosawareness](#)
- Twitter: [Immunocompromised Patients: COVID-19 Public Service Announcement](#)

Arthritis self-care



☐ SLEEP
EARLY



☐ STRETCH
AND REST



☐ HYDRATE



☐ MOVE ANY
WAY YOU CAN



☐ EAT WELL
& BE PRESENT



☐ LEARN ABOUT
YOUR CONDITION



☐ LOVE
YOURSELF



☐ REFLECT ON
YOUR JOURNEY

■ #CreakyChats

Our #CreakyChats continue to be very popular, generating engagement even after the live event is complete.

- **January 19: Wellness, Chronic Illness, and Disability**

Cohosted by media outlet Everyday Health, our January event featured Dr. Leonard Calabrese of Cleveland Clinic, a thought-leading rheumatologist, and Lauren Scholl, a personal trainer and nutrition coach who lives with psoriatic arthritis. During our chat, we discussed how we define wellness, go-to practices of incorporating self-care, and the biggest challenges and frustrations a person might face practicing wellness while living with a chronic illness and/or disability.

- **February 28: Finding Community in Isolation**

As referenced earlier, our chat focused on how to make connections and feel part of a community during the ongoing pandemic. The event was cohosted by the Autoimmune Community Institute (@ACICommunity).

- **March 28: Let's Vent**

During our March event, our members talked about all the big and small things that frustrate us when living with chronic disease. We also discussed how to express those frustrations and how to find joy. Why do we sometimes pretend everything is all right when it really isn't? What are some ways you decompress when you're feeling worked up?

Join our community

#CreakyChats

Let's Vent

Monday, March 28th, 2022, 7:00 pm ET

Hosted by



@CreakyJoints #CreakyChats

ALT

7:49 PM · Mar 27, 2022 · Twitter Web App

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](https://www.CreakyJoints.org)

CreakyJoints Español: www.CreakyJoints.org.es

CreakyJoints Canada: [CreakyJoints.ca](https://www.CreakyJoints.ca)

CreakyJoints Australia: [CreakyJoints.org.au](https://www.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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TikTok: [globalhealthylivingfnd](https://www.tiktok.com/@globalhealthylivingfnd)

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