



QUARTERLY REPORT

JULY – SEPTEMBER 2021

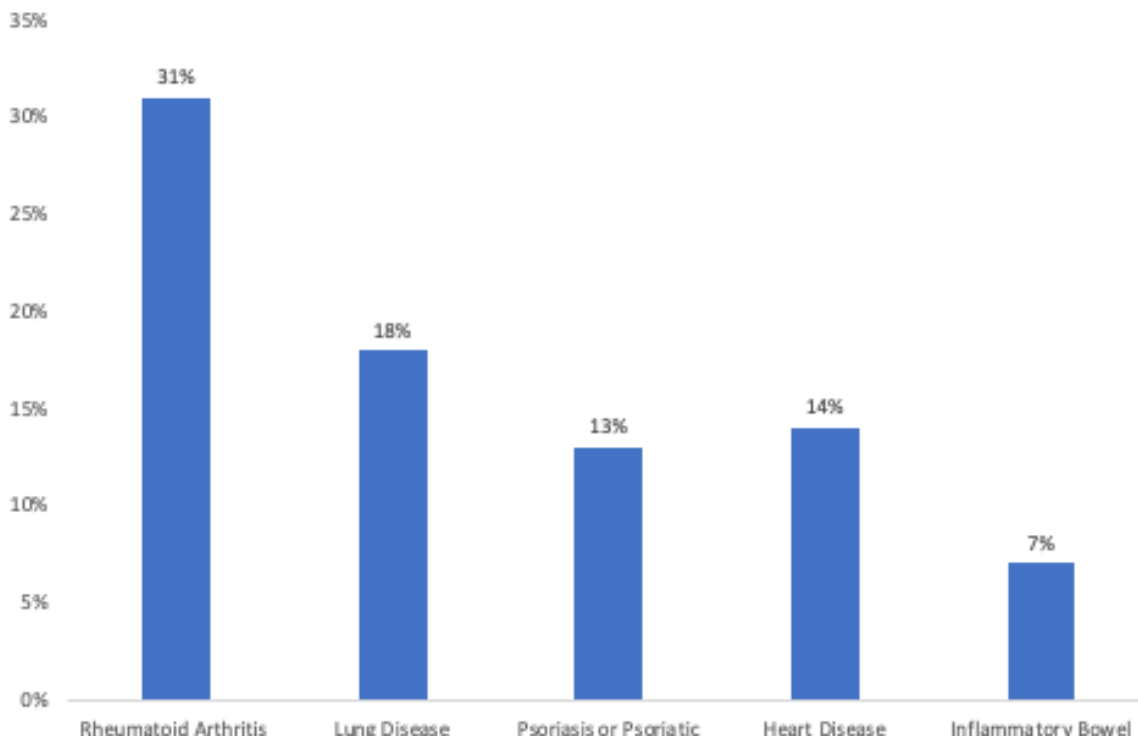


GLOBAL
HEALTHY
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FOUNDATION

PERPETUAL PANDEMIC: HELPING THE CHRONIC DISEASE COMMUNITY COPE WITH DELTA, REOPENING, AND VACCINE HESITANCY

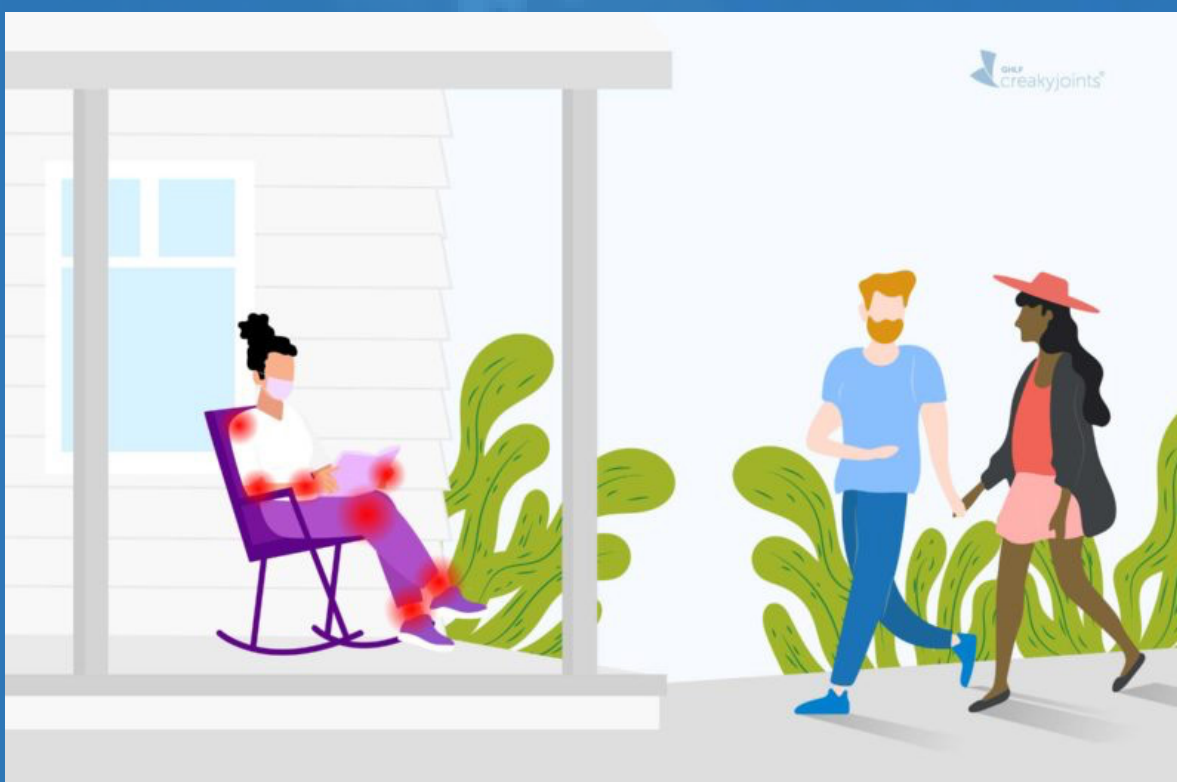
During the summer, we hoped that COVID-19 vaccination rates would continue to rise while infections, hospitalizations, and complications would fall. Unfortunately, the Delta variant required people to stay vigilant and continue to take precautions, particularly in our community of chronic disease patients. They continued to need tailored information and support so that they could make decisions about engaging with family, friends, work, and the activities important to them. As always, we turned to experts and science to provide reassurance and support, with a big focus on breakthrough infections, the third vaccine dose and booster shots, updates on vaccine effectiveness in people taking immunosuppressant medication, and more. CreakyJoints® and the Global Healthy Living Foundation (GHLF) remain committed to providing the most up-to-date science-based information, support, and advice about the pandemic — with a special focus on vaccine education — for people living with chronic disease.

Our free COVID-19 Patient Support Program continued to grow in the third quarter and now includes 29,487 diverse members and 46,447 subscribers (as of September 30, 2021). Website visits continue to exceed one million per month. Common conditions of members in the program include:



■ PATIENTS GET REAL WORLD COVID CONTENT

Despite concerns about the Delta variant, more of our members had the opportunity to travel, spend time outside, and engage in hobbies during the summer. They also got ready for back-to-school season. Our content offered a variety of advice on managing the risks of the pandemic while enjoying the important benefits of community. We also covered the potential need for a third dose of the vaccine among the immunocompromised and what to expect from breakthrough infections. We continue to consult with the leading experts in rheumatology, infectious disease, public health, and other specialties for advice. We also review and explain the most important medical research about COVID-19 for people with chronic medical conditions, while sharing personal perspectives from members of our CreakyJoints and GHLF community. Impactful content from the quarter included:



- I'm Immunocompromised Because of Rheumatoid Arthritis: Here's How I Want Society to Move Forward from the Coronavirus Pandemic
- Study: Autoimmune Disease Patients Have a Slightly Lower Antibody Response to the COVID-19 Vaccine
- What Immunocompromised People Need to Know About the CDC's Updated COVID-19 Masking and Testing Guidance
- Breakthrough COVID-19 Infections: What to Know If You're Immunocompromised
- Immunocompromised and Worried about Back-to-School and COVID-19? Here's How to Stay Safe Now
- Getting the Additional Third COVID-19 Vaccine Dose for Immunocompromised People: What You Need to Know

From July through September, 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.

We also hosted a #CreakyChats in August titled “COVID Vaccine Myth Bustin’” to open dialogue about the importance of COVID-19 vaccination and hear from our community about why they have or have not been vaccinated, while sharing educational resources to bolster confidence in vaccination.

In July, abcnews.com interviewed GHLF member Peter Morley, who lives with lupus, about how mask shaming ignores the fears of people who are immunocompromised. In the article, Peter described how at a New York City parade, a local photojournalist got frustrated when he refused to remove his mask for a picture. After Morley declined, the photographer responded, “COVID is over. Get on with your life.” Psychologist Laurie J. Ferguson, PhD, Director of Educational Development at GHLF, also contributed to the article, explaining why people wearing masks trigger responses in others. “Anybody wearing a mask is kind of symbolizing the fear and the concern,” she said in the article. “It’s like, why can’t we all just be normal? Why can’t we go back to what was?” After reporting that some of her clients have also been harassed or bullied about wearing masks, she said, “It’s not a moral issue; it’s not a political issue. It’s a health issue . . . Unfortunately, it’s going to come down to the situation where, again, it’s on the shoulders of the vulnerable to have to carry this and do a lot of the communication.” This article was picked up by Yahoo! News and syndicated on ABC Audio, which produces online stories for ABC-affiliated news radio stations across the country, resulting in significant additional pickup of the story.

Mask shaming ignores COVID-19 fears of immunocompromised people

The delta variant has many with autoimmune and other diseases on edge.

By **Kiara Alfonseca**

July 14, 2021, 6:09 AM • 8 min read



“This is my new normal,” Morley said. “You don’t know who the person behind the mask really is. You can’t know someone and their story and their struggles.”



Courtesy Peter Morley

Peter Morley and Anjelika are pictured in an undated handout photo.

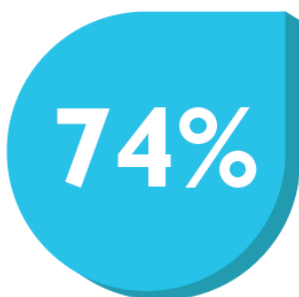


■ TAKING THE PULSE OF THE CHRONIC DISEASE COMMUNITY

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 third quarter include:

Poll Topic: What Are Your Concerns About the Delta Variant?

A total of 2,137 Patient Support Program subscribers responded to our early August quick poll on their concerns about the Delta variant. Nearly all respondents (99.9 percent) said they were aware of the COVID-19 Delta variant.



of respondents said they were moderately or very worried about getting infected with the Delta variant.

Our members said:

““

As someone with an autoimmune disease, I never stopped wearing a mask, and now with Delta, I feel stuck at home again.

””

I was so happy when vaccines came out and cases went way down that I ventured out of my home, and even went to Hawaii. Now I'm scared to leave my house. I feel like I will never have a life again.

““

It feels impossible to do the daily calculations to figure out what is reasonably safe with masks and what is not. It's bad enough being chronically ill without having to constantly assess risk and then justify my conclusions to everyone else I interact with, most of whom are vaccinated people not following Delta as closely or taking it as seriously because they believe they are protected.

Poll Topic: What Do You Know About the Third Dose of the COVID-19 Vaccine?

A total of 2,738 Patient Support Program subscribers responded to our late August quick poll on their thoughts about the CDC’s recommendation of a third COVID-19 vaccine dose for immunocompromised people.

1,412 / 53%

had already received a third dose of the COVID-19 vaccine
(Of the 97 percent of fully vaccinated respondents)

10%

of those who received the third dose had done so
before the CDC’s recommendation

After getting the shot

59%

felt hopeful

52%

felt relieved

28%

felt protected

9%

felt nervous

Our members said:

“ I got a bad rheumatoid arthritis flare-up four days after the second vaccination, and it has gotten worse. I'm afraid the third vaccination would make arthritis even worse.

I plan to wait to learn of positives or negatives of the third shot.

“ While I am hopeful I will finally mount an immune response after the third shot, it won't make any difference in my behavior since the vaccinated people who are getting sick enough to be hospitalized or die are primarily immunocompromised.

”

Although I am hopeful, I am still nervous and will continue to wear a mask inside and sometimes out.”

Poll Topic: Are Your Friends and Family Vaccinated?

A total of 1,454 Patient Support Program subscribers responded to the July poll to weigh in on whether their family members' and friends' vaccination status affected how they would interact with them.

95%

of respondents had already been vaccinated themselves.

81%

of respondents said they avoided eligible but unvaccinated family and friends

66%

of respondents indicated they encouraged vaccination to their family and friends

Our members said:

“

I am still in isolation, regardless of what my friends and family are doing. Being around others is simply too risky at this time, which is depressing and frustrating.

Being immunocompromised has me in a difficult position. Because I wear a mask and am vaccinated, I am seen as a sellout by family members.”

“

I have four adult children, and one doesn't believe in the vaccine. I also have one sister who won't get vaccinated. This situation has caused a divide in my family.

■ OUR RESEARCH EXPLORES HOW THE PANDEMIC AFFECTED THE CHRONIC DISEASE COMMUNITY

During the third quarter, every abstract GHLF submitted to the November American College of Rheumatology (ACR) Convergence 2021 was accepted, including several abstracts related to our Autoimmune Research Collaborative (ARC) COVID-19 research. Specific to COVID-19, accepted abstracts include:

Scientific Program:

- Changes in Patient-Reported Outcome (PRO) Scores During the COVID-19 Pandemic: Data from the ArthritisPower Research Registry (POSTER, Tues., 11/9, 8:30–10:30 a.m.)
- Impact of the COVID-19 Pandemic on the Quality of Life of Patients with Rheumatic Conditions: A Qualitative Analysis of Perceived Risk and Decision Making (POSTER, Tues., 11/9, 8:30–10:30 a.m.)
- Trends in Medication Interruptions and Associations with Disease Flares During a Public Health Crisis: Longitudinal Data from Patients with Autoimmune Rheumatic Diseases During the COVID-19 Pandemic (POSTER, Tues., 11/9, 8:30–10:30 a.m.)
- Perceptions About COVID-19 Vaccination Among Patients with Rheumatic Diseases Enrolled in a National Patient Registry (POSTER, Tues., 11/9, 8:30–10:30 a.m.)
- Changes in Telemedicine for Rheumatologic Care During the COVID-19 Pandemic: Patient Perceptions and Preferences (POSTER, Tues., 11/9, 8:30–10:30 a.m.)

Patient Perspectives Program:

- Should I Get the COVID-19 Vaccine with My RA? Using Evidence-Based Resources for Decision-Making (POSTER, Sun., 11/7, 8:30–10:30 a.m.)
- Fighting for the Care We Deserve: My Experience as a Latina Patient-Researcher During the COVID-19 Pandemic (ORAL PRESENTATION, Sun., 11/7, 4:00–4:15 p.m.)
- How Online Spanish-Language Resources Got Me and My RA Through the COVID-19 Pandemic (POSTER, Sun., 11/7, 8:30–10:30 a.m.)
- CreakyKitchen: How the Online Cooking Show I Started Is Building Community and Encouraging Better Food Choices for Me and Others Living with Rheumatic and Chronic Disease (ORAL PRESENTATION, Sun., 11/7, 4:15–4:30 p.m.)

Note: Additional non-COVID-19-specific abstracts were accepted for the ACR meeting as well. Look for more information in the next quarterly report.

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 third quarter, select engagements included:



Robert Popovian, PharmD, MS, Chief Science Policy Officer, was a panelist at three events: the Houston Business Coalition on Health – Follow the Money of Your PBM, the HIMSS Conference – Pharmaceutical Industry Applications and Consortia, and the Blockchain Summit Global – Use Cases of Blockchain in Healthcare. He also presented at the Congressional Staff Briefing: Bipartisan Solutions to the Rising Cost of Prescription Drugs; the Western School of Pharmacy – Drug Pricing, Spending, Affordability and Access; and the 5th Pharma Pricing, Affordability and Market Access Conference – Drug Pricing.



Shilpa Venkatachalam, PhD, Associate Director of Patient-Centered Research, was a featured panelist at a PCORnet Engagement Coordinating Center–sponsored webinar on the unique tools available to support patient-partner engagement in research and explore the opportunities and challenges for scaling and sustaining these types of tools.



Sarah Shaw, BIPOC Patient Advocate, Community Outreach Manager, was a featured panelist at the Lundbeck-sponsored Lunch Power Hour alongside GHLF President Seth Ginsberg and patient advocate JP Summers, speaking about ongoing GHLF projects, patient engagement and patient-centered research.

TUMBLER AND TIPSY FASHION SHOW GOES GLOBAL

The Global Healthy Living Foundation and CreakyJoints were once again the presenting sponsors of the Tumbler and Topsy by Michael Kuluva collection, timed to New York Fashion Week. Recognizing how our world has grown closer during the pandemic through the accelerated adoption of online video platforms, designer Michael Kuluva offered a virtual presentation including models — many of whom are CreakyJoints and GHLF members — from around the globe. The models created their own runways and showed off clothing and

accessory items selected especially for them. The Tumbler and Topsy by Michael Kuluva 2022 Collection event premiered on YouTube on September 14, 2021, at 8 p.m. (ET). Immediately preceding the premiere, GHLF hosted a live #CreakyChats on Twitter with media partner Everyday Health as well as the Canadian Arthritis Patient Alliance (CAPA) and CreakyJoints Canada and CreakyJoints Australia to reflect on how the chronic disease community can amplify its representation and voices by participating in events like Michael's inspirational collection.

FASHION

What Do Fashion & Rheumatoid Arthritis Have In Common?

SEPTEMBER 27, 2021



SHARE    

This year's event also expanded beyond arthritis, featuring patient advocates who live with migraine as well. As part of Michael's collection, he designed a pair of sunglasses to highlight migraine awareness and featured models who live with migraine, including GHLF's Joseph M. Coe.

Notably, Michael's fashion line was covered by Elle magazine in light of his collaboration with actor Tara Reid to create a sustainable, cactus leather purse. Michael and CreakyJoints member Eileen Davidson were also featured in Canadian media outlets including simcoe.com, the Toronto Star, and VitaDaily.



Despite physical distancing, we've all found ways to stay connected to our family, friends, and the other important people in our lives. For me, staying connected to the CreakyJoints arthritis community and the broader chronic disease community has helped me stay grounded during uncertain times, which is why I invited so many members to model my latest collection.

”

CREAKYJOINTS ESPAÑOL HIGHLIGHTS MISINFORMATION PROLIFERATION ONLINE

In mid-August, CreakyJoints Español shared new research finding that of the three most-viewed factual and three most-viewed inaccurate Spanish-language videos about rheumatoid arthritis (RA) on YouTube, the videos containing misinformation had at least twice the views of factual videos (1.45 million versus 660,000). An analysis of the text suggests Spanish-language RA misinformation videos focus on a simple explanation with a promise for a cure, whereas Spanish-language RA factual videos focus on the technical explanation of the disease, which fosters negativity and fear in the comments section. This analysis was presented virtually at the 23rd Pan-American Conference of Rheumatology (PANLAR) 2021, August 12–15.

71%

According to the Pew Research Center, 71 percent of Hispanic people obtain health information through social networks and 79 percent follow through and act on the information. Unfortunately, health information available to the Hispanic/Latinx community online is oftentimes dangerous misinformation—leading to low levels of diagnosis and a growing knowledge gap.



Pew Research Center

In the press release, coauthor Esteban Rivera, MS, Data Analyst at the Global Healthy Living Foundation, said, “Within Hispanic communities, it is vital to help patients overcome existing barriers and better engage in their health care, especially given that we are disproportionately impacted by many debilitating health conditions, including arthritis. Our study confirms what we knew anecdotally: that misinformation is appealing because it’s packaged as a solution or cure, despite there being no cure for arthritis.”

These results were covered by MM+M (Medical Marketing + Media), PRWeek, Rheumatology Network, and DocWire News. Daniel Hernandez, MD, Director, Medical Affairs and Hispanic Outreach, also contributed a bylined article to Clinical Leader.

TWO EXPERTS DISCUSS HEALTH MISINFORMATION IN THE HISPANIC COMMUNITY

By Robert Dillard - October 5, 2021

Like 3

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Watch on YouTube

CLINICAL LEADER

Trial Design Partnering Clinical Technologies Regulatory Market Research Find A Partner Clinica

Guest Column | August 31, 2021

Tackling Health Misinformation Among Hispanics For Better Clinical Research & Patient Data

By Daniel Hernandez, MD, CreakyJoints and Global Healthy Living Foundation

The global pandemic has shined a much-needed spotlight on the health disparities in Hispanic communities. For years, Hispanic communities have faced inequities in many aspects of healthcare — from finding health education, being health literate, accessing healthcare, and underrepresentation in clinical research.



As patients become increasingly engaged in managing their own healthcare, it is critical to ensure key stakeholders from all areas of healthcare ramp up efforts to close gaps in care. This rings especially true as Hispanics are disproportionately affected by some of the leading causes of death and illness, including heart disease, cancer, diabetes, and more, compared to non-Hispanic whites. Even when disease prevalence is lower

■ CREAKYJOINTS ESPAÑOL RAISES THE VOLUME OF HISPANIC/LATINX PATIENTS

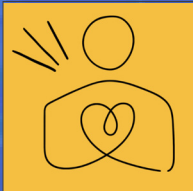
This summer, CreakyJoints Español participated in ReumaExpo's 2021 summit with a group of Hispanic/Latinx rheumatologists and patient advocates to discuss the importance of research within the Hispanic/Latinx rheumatology community.

In addition, leaders presented at the 4th Pan American Congress of Patients with Rheumatic Diseases, a full-day event

that focused on the patient experience of rheumatic disease. CreakyJoints Español covered disease-modifying antirheumatic drugs (DMARDs) for rheumatic conditions. Mindful of the ongoing global impact of the COVID-19 pandemic, CreakyJoints Español also reviewed special risks and considerations for people living with rheumatic conditions as well as how to prepare for telemedicine appointments.

GHLF PODCAST NETWORK UP TO FIVE SHOWS, WITH MORE COMING

At the Global Healthy Living Foundation, we're committed to bringing our community (and beyond) a comprehensive library of podcasts to inform how they understand their experience of disease as well as broaden their perspective related to current issues in health policy. Our podcasts feature GHLF leaders as well as GHLF members sharing the lived experience of their conditions; plus we invite experts to offer advice and guidance. Of course, we also aim to entertain, engage, and provoke action. 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. Recently published shows include:



The Health Advocates: This podcast is hosted by Steven Newmark, JD, MPA, Director of Policy and Chief Legal Officer at GHLF, and Zoe Rothblatt, Patient Advocate and Community Outreach Manager at GHLF. Our goal is to help listeners understand what's happening now in the health care world to help everyone make informed decisions to live your best life.



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 conditions, and are differently abled to the forefront. It is hosted by Dungeon Master James Dybisz, GHLF's Manager, Web Development.



Talking Head Pain: This podcast confronts head pain head-on. It is hosted by Joseph M. Coe, Director, Education and Digital Strategy at GHLF, who speaks to people living with migraine and other disorders as well as medical professionals.



Healthcare Matters: In this podcast, host Conner Mertens, GHLF Patient Advocate, Community Outreach Manager, speaks with GHLF's Chief Science Officer, Robert Popovian, to explain complex health-policy topics so everyone can understand what is happening in the world of health care.



The Psoriatic Arthritis Club: This series is hosted by Deanna Kizis, a journalist and author who was recently diagnosed with psoriatic arthritis (PsA) but has yet to connect with many other PsA patients and is seeking more information and support. In the show's inaugural episodes, she interviews other people with PsA to learn about their journeys as well as top rheumatologists Eric Ruderman, MD; Alexis Ogdie-Beatty, MD; and Grace Wright, MD.

GHLF MAKES A DIFFERENCE IN NEPAL

GHLF's support of International Student Learning Inc. (ISLearning) and Canopy Nepal continues via our grant funding to support their program Beyond Borders, for people belonging to socially, ethnically, and financially disadvantaged communities in Nepal. During the third quarter, Steven Newmark, Director of Policy and Chief Legal Officer, and Kelly Gavigan, MPH, Manager, Research and Data Science, conducted educational sessions on topics related to the history and structure of health policy in the U.S. and the U.K. and an introduction to data and how we use data in our everyday lives in August and October 2021 respectively.



NEW VIDEO HIGHLIGHTS THE JOHN WHELTON ARTHUR VIRSHUP CREAKYJOINTS SOUTH FLORIDA ARTHRITIS CLINIC

This summer, Conner Mertens, GHLF Patient Advocate, Community Outreach Manager, produced a [short video](#) to highlight the services and resources provided to underserved rheumatology patients at the [John Whelton Arthur Virshup CreakyJoints South Florida Arthritis Clinic](#). Since early 2021, CreakyJoints has provided administrative and financial support to the clinic. The video includes interviews with longtime volunteer rheumatologist Michael C. Schweitz, MD, past president of the Coalition of State Rheumatology Organizations (CSRO), and past president of the Florida Society of Rheumatology, and Barbara Boyd-Floering, who is GHLF’s patient care coordinator at the clinic. In this role, Barbara works directly with people living with rheumatic disease to navigate the free rheumatology services we offer. She sets up appointments with the 14 volunteer doctors, coordinates lab work and x-rays, and helps patients get medications. She also introduces people using the clinic to the arthritis education, resources, and tools offered by CreakyJoints, including [ArthritisPower](#), our interactive patient-reported outcomes smartphone and desktop app with more than 34,000 patients.




GHLF MEASURES THE VALUE OF PEOPLE'S TIME WASTED LIAISING WITH INSURANCE COMPANIES

At the Global Healthy Living Foundation, we understand that living with chronic pain and chronic symptoms is already difficult. It's made worse when our members have to battle back and forth via phone with medical insurance companies over denials for medication/treatment that a doctor prescribed according to their specific history and treatment goals. In July, we asked our members to help us calculate the value of that wasted time, so that we can share that data with insurance companies and the public to demonstrate how much time chronic disease patients spend fighting for their care and how much patients should be compensated for that lost time.



*As of the end of September, **154** members reported spending more than **4,700 hours!***



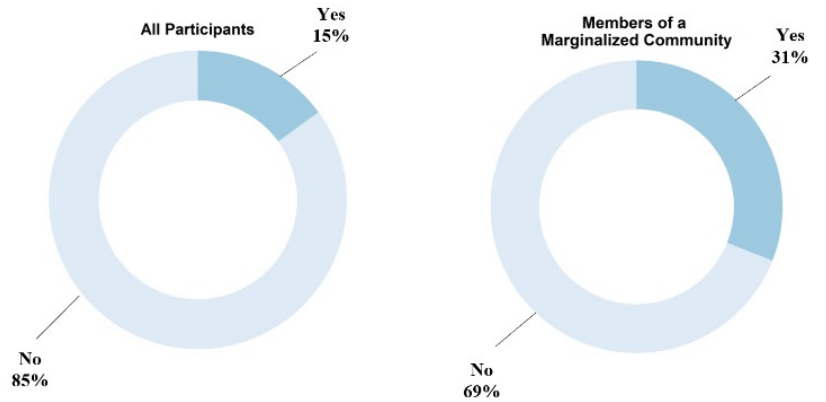
According to our calculations, our members are owed a staggering **\$105,586.40 total, or \$685,64 per person.***

*Portrait F, Hoozemans M, van den Berg B. The total value of time of children undergoing treatment: A contingent valuation from the perspective of parents in the orthopaedic department of a Dutch hospital. *J Paediatr Child Health*. 2019 May;55(5):539-547. doi: 10.1111/jpc.14236. Epub 2018 Oct 11. PMID: 30311326; PMCID: PMC7379632.

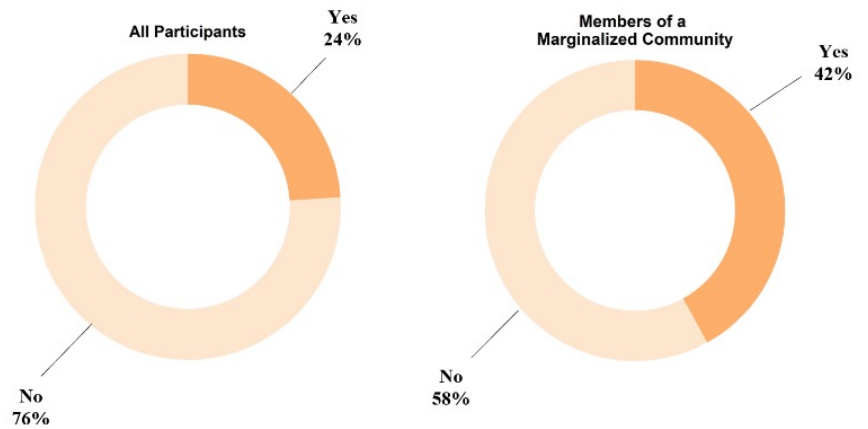
■ MARGINALIZED COMMUNITIES PARTICULARLY AFFECTED BY LACK OF MEDICATION ACCESS

Earlier this month, we asked our community members about the ways they got their prescribed medication when their insurance would not cover the prescription. Many of our participants responded that they have shared prescriptions with others or gotten prescriptions from outside of the U.S. because of issues with their insurance. However, participants who responded that they are members of marginalized communities (including BIPOC, LGBTQ, and disabled patients) reported using these methods to access their prescribed medications at much higher rates than the overall group of participants. More than a quarter of the 942 survey respondents reported being members of marginalized communities.

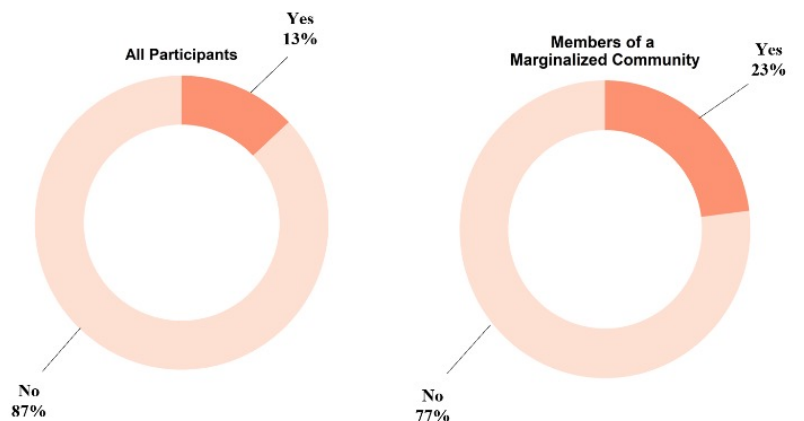
Gotten a medication that was prescribed to them from a friend/family member with the same prescription



Given a friend or family member a medication with the same prescription



Gotten a prescribed medication through a non-US-based pharmacy



ARTHRITISPOWER GROWTH RESEARCH HITS NEW HIGHS

Current ArthritisPower statistics as of September 30, 2021:

- Total patients: **34,276**
- % increase in membership from September 30, 2020: **17%**
- Top Conditions:

Osteoarthritis:	18,500 (54%)
Rheumatoid Arthritis:	15,146 (44%)
Fibromyalgia:	12,219 (36%)
Psoriasis/Psoriatic Arthritis:	6,260 (18%)
Osteoporosis:	5,015 (15%)
IBD:	4,366 (13%)
Lupus:	1,942 (6%)
- PROMIS Measures, mean (SD)

Pain Interference	64.1 (7.3)
Fatigue	63.2 (9.2)
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 STUDIES IN PROGRESS INCLUDE:

- **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. It will produce a peer-reviewed white paper that describes those best practices. Overall, the goal is to expand the impact of rheumatology by increasing patient access to care, especially among those marginalized or most at risk because of the COVID-19 pandemic. The study will facilitate RA patients performing a joint self-assessment and compare its accuracy with an in-person clinician joint exam (the gold standard) performed within the next 24 to 48 hours. The GHLF research team is building a patient joint self-assessment and instructions 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; the protocol was reviewed and approved by AbbVie's Protocol Review Committee and Advarra IRB. RA patients on upadacitinib or adalimumab are currently being recruited from participating rheumatology clinic sites across the U.S. Recruitment is ongoing.
- **Real-World Patient Experience and Preferences in Patients with Psoriatic Arthritis:** The primary objective of this project is to better understand PsA patients' experience with their disease, including which symptoms they consider most bothersome, and preferences about treatment. This study was designed and conducted in partnership with RTI International and with PsA experts from the rheumatology divisions of the Universities of Pennsylvania and Utah Schools of Medicine. It is sponsored by the HEOR group at AbbVie US. Recruitment is now closed, and findings will soon be presented in abstracts and peer-reviewed manuscript.

- **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 500 RA patient participants will be recruited at CorEvitas clinical sites and then 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 (JAK inhibitors) over time. This study is sponsored by the HEOR group at AbbVie US. The study launched in September and already has 205 participants from CorEvitas sites across the country. Participants can enroll if their doctor is part of a CorEvitas site.
- **Improving Treat-to-Target by Incorporating the Patient Perspective:** This study aims to understand and assess the psychoeducational needs, barriers, and facilitators of ArthritisPower members with rheumatoid arthritis when they are contemplating a change in treatment regimen. This study consists 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 (RRF) Innovation award received by Liana Fraenkel, MD, MPH, of Yale School of Medicine and Berkshire Medical Center. Recruitment is closed. 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.
- **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. People living with autoimmune conditions have nearly twice the risk of acquiring severe vaccine-preventable infections and a higher risk of serious complications, making this a high-priority vaccination group. Risk is increased by the underlying immune dysfunction and immunomodulatory therapies used in this population, yet vaccination uptake remains low despite evidence demonstrating safety and efficacy. The objective of this project is to build a multistakeholder alliance with whom the team can create a strategic plan and research agenda to facilitate patient-centered outcomes and comparative-effectiveness research of vaccine uptake among U.S. adults living with autoimmune conditions. The four patient-powered research networks (PPRNs) that constitute the Autoimmune Research Collaborative (ArthritisPower, IBD Partners, Vasculitis PPRN, and IConquerMS) are convening a multistakeholder steering committee and coalition that includes patients, caregivers, researchers, physicians and other clinicians, and health system and health plan leaders, plus representatives from regulatory, industry, and public health entities, to identify and prioritize patient-centered outcomes research in this area. 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.



CREAKYJOINTS AUSTRALIA RAISES THE VOLUME OF PATIENT VOICES

■ AUSTRALIA IN LOCKDOWN

Nearly 60 percent of Australians spent most (or for those in Melbourne, all) of the third quarter of 2021 in lockdown, amid rapidly escalating COVID-19 cases and clusters throughout populations that, at the time, lagged far behind in vaccination rates. Dramatic progress made in September was possible due to the country's rapid turnaround in vaccination uptake — once a supply of vaccines became available to the general population. GHLF Australia took important steps from inside lockdown as the country moved tentatively toward reopening its borders in the fourth quarter. We featured regularly updated information and advice to patients from the Australian Rheumatology Association.

Australia's National Medicines Policy (NMP) is a high-level framework from the Department of Health that aims to deliver positive health outcomes for all Australians through access to, and appropriate use of, medicines. GHLF Australia recently submitted feedback for NMP review on behalf of the patient community after soliciting its feedback.



Australian Government

Department of Health

■ CREAKYJOINTS AUSTRALIA

We actively participated in several online programs and workshops:

- Consumers Health Forum of Australia's webinar "COVID-19 Vaccine Confidence and Community Safety"
- BJC Health's webinar "Should I Be Vaccinated for COVID-19?"
- BJC Health's webinar "Rheumatology and Women's Health"
- Medicines Australia's briefing on their five-year strategic agreement with the Australian Government Department of Health
- Health Technology Assessment Consumer Consultative Committee's "Making Connections" Symposium
- Consumers Health Forum of Australia's webinar on the National Medicines Policy review

The BJC Health Connected Care Rheumatology Centre in Sydney is the largest private rheumatology clinic in Australia and a long-standing partner and friend of CreakyJoints. We featured their extensive online programming in supportive materials in this online post: "How to Access Holistic Allied Health and Rheumatology Support Online."

CreakyJoints Australia also met online with Arthritis Australia to identify consumers' frequently asked questions related to the tocilizumab shortage in Australia. Our input was used to inform the content on their website on this topic.

Following the release of several adalimumab biosimilars on the Pharmaceutical Benefits Scheme (the federal government's medicine-subsidy program) and around the time of the introduction of the new citrate-free formulations of adalimumab, we noticed a lot of confusion about the various products among patients. To help address this, we wrote the article "How to Help Patients Understand Their Biosimilar Options" for Rheumatology Republic to ask rheumatologists to improve their communication with patients.



■ ASIA PACIFIC LEAGUE OF ASSOCIATIONS FOR RHEUMATOLOGY (APLAR)

CreakyJoints Australia editor and features writer Rosemary Ainley was invited to share her personal story about living with autoimmune arthritis and becoming a member of the CreakyJoints Australia team for the online Australian edition of the Voice of APLAR, the magazine of the 2021 APLAR conference held in Kyoto, Japan, August 28–31, 2021.



■ FASHION FROM AUSTRALIA AND NEW ZEALAND

CreakyJoints Australia participated in the Tumbler and Topsy global fashion show, with National Coordinator Naomi Creek from Flinders Island, Tasmania, providing photos and video of her modeling some of the clothing. Alice Jones, a member of the CreakyJoints Australia Patient Council, also participated in the show from her home in New Zealand. Australian patient leaders and members of the patient community cohosted and actively participated in the #CreakyChats session that preceded the event and shared the experience in an article for the CreakyJoints Australia website.



Creating Global
Community
Through Fashion

15 SEPTEMBER
9am AEST
#CreakyChats

10am AEST
2022 Collection
VirtualFashionShow.net

Tumbler & Topsy®
BY MICHAEL KULUVA

GHLF

GHLF
creakyjoints®
AUSTRALIA

SPEAKING WITH AND FOR THE CHRONIC DISEASE COMMUNITY

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

- Morning Consult (September 2021): “We Should Not Lose Sight of the Upcoming Flu Season”
- Progressive Policy Institute (September 2021): “Aiming Drug Price Reform at the Right Target”
- The Hill (September 2021): “Vaccines Are the Future of Health Care”
- Morning Consult (July 2021): “It Is Time for Outcomes-Based Reimbursement for Biopharmaceuticals”
- Journal of Commercial Biotechnology (September 2021): “Waiving COVID-19 Vaccine Patents: A Bad Idea and a Dangerous Precedent”
- BioProcess Online (July 2021): “Why Should We Rescue the Legislative Intent of the BPCIA?”





We also helped our members amplify their voices on the issues that matter to them.

- Daniel Garza, a member of the GHLF Covid-19 Patient Support Program, contributed an op-ed to his local online newspaper, the Stu News Laguna (California), to urge investment in cancer research and better diagnostics. Daniel is a cancer survivor and lives with HIV. In his article he says, “I never considered that I might develop another serious illness on top of coping with an HIV+ status for nearly 20 years. It was overwhelming to be thrust into decision-making about my cancer treatment. Despite enduring months of chemotherapy and radiation, I made the difficult choice to be fitted with a colostomy bag (which I named Tommy) in 2016. That bag and associated treatments saved my life, but sometimes I wonder, what if I had been diagnosed sooner? Would I have a different outcome?”
- Elisa Comer, a 50-State Network Patient Advocate, contributed to an article that dives deep into non-medical switching. The article, “Why Won’t Insurance Cover the Medication Your Doctor Prescribed?” was published by the advocacy group No Patient Left Behind. “It’s really, really hard when you go through these non-medical switches, because then you have to start all over,” says Elisa.

RECENT COMMENTS AND LETTERS SUBMITTED TO POLICY MAKERS INCLUDE

COVID-19-RELATED COMMENTS

8
AUG

[Letter to stop vaccine disinformation](#)

27
JULY

[Comments to Senate HELP Committee about medications in emergencies](#)

FEDERAL

10
SEPT

[Safe Step inclusion in reconciliation \(Federal Step Therapy Coalition sign-on\)](#)

9
SEPT

[132 organizations ask for key Medicare Part D OOP reforms in budget reconciliation package \(Project LOOP sign-on\)](#)

28
JULY

[Improving patient drug affordability through standardized benefit plans \(HIV+Hepatitis Policy Institute sign-on\)](#)



■ 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:

14 JULY	Encuentro Digital: Latino Digital Conference
14 JULY	American Disease Prevention Coalition strategy conference
19 JULY	Health Care Resilience & Sustainability, presented by the Washington Post
20 JULY	Accessing Community Health Needs ACS for Health Care Professionals, presented by the U.S. Census Bureau
22 JULY	A Conversation on Biosimilars and Drug Development, presented by Axios
27 JULY	Vaccines, Trusted Info and Fake News, from the Fellowship of Postgraduate Medicine
27 JULY	Meeting Evolving Needs of your Oncology Customers: A Cross-Stakeholder Panel Discussion, World Congress/Validation Institute
27 JULY	Making Medicare Work Better for Patients, The Hill
12 AUG	Association of Women in Rheumatology Annual Conference
17 AUG	Oncology Endpoints, IQVIA
2 SEPT	The Path Forward: Global Vaccination with Seth Berkley, MD, the Washington Post
8 SEPT	How to Remotely Measure Longitudinal Health Data for Better Outcomes, PharmaVOICE
8 SEPT	Lean Muscle Mass: How to Prevent or Reverse Sarcopenia, Metagenics
9 SEPT	Digital Vaccine Technologies, Galien Foundation

- 14**
SEPT

Combining Patient Data with the Patient Voice, PharmaVOICE
- 15**
SEPT

American Disease Prevention Coalition strategy conference
- 16**
SEPT

Role of Machine Learning and Genomics in Drug Development, IQVIA
- 16**
SEPT

Digital Health and Pharmacovigilance: An Unlikely Partnership? PharmaVOICE
- 17**
SEPT

Health Equity and Access Committee Meeting, hosted by the Texas Society of Clinical Oncology and the Association of Community Cancer Centers
- 21**
SEPT

Evaluating Your Options for Natural History of Disease Studies, IQVIA
- 22**
SEPT

Digital Health Trends 2021, IQVIA
- 23**
SEPT

PBMs and EMR Talk with Elisa Comer, Becker Hospital Review
- 24**
SEPT

Understanding the German Drug Pricing System, Pfizer Germany
- 28**
SEPT

Equity and Outcomes, Ensuring Fair Access to Healthcare, the Fellowship of Postgraduate Medicine
- 30**
SEPT

The Evolving Landscape for Biosimilars, presented by STAT



■ VIRTUAL ADVOCACY

We organized virtual meetings with Massachusetts state legislators about copay accumulator adjuster programs. The proposed legislation, Massachusetts bill H.1053 / S.644, which is currently in committee awaiting a hearing, would require all copay coupons to count toward a patient's deductible and out-of-pocket costs.

We have recently advocated for patient-centered policies through meetings with:

- Representative Patricia Duffy (D-MA)
- Representative Mindy Domb (D-MA)
- Representative Tricia Farley-Bouvier (D-MA)
- Senator Joseph A. Boncore (D-MA)

We have been virtually meeting with Pennsylvania legislators about bill S.196. Like the Massachusetts bill, it would require that any cost-sharing amounts paid by the insured or on behalf of the insured would count toward the insured person's cost-sharing contribution requirements. The bill was referred to the Banking and Insurance Committee in February 2021 and is expected to get a hearing in the fall.

- Jonathan Humma (R-PA), Executive Director of Pennsylvania Senate Banking and Insurance Committee
- Senator Lisa Boscola (D-PA)
- Senator Gene Yaw (R-PA)
- Senator Daniel Laughlin (R-PA)
- Senator Christine Tartaglione (D-PA)
- Senator Elder Vogel, Jr. (R-PA)
- Senator Amanda Cappelletti (D-PA)



CREAKYJOINTS AND THE GLOBAL HEALTHY LIVING FOUNDATION IN THE NEWS

During the third quarter, there were 66 original placements, plus additional pickup from stories about the Tumbler and Topsy fashion show and the abcnews.com article on mask shaming (see earlier in the report). Other notable placements that highlight the perspective of CreakyJoints and GHLF members researchers and leaders include several articles on health.com offering advice on how to live well with psoriatic arthritis and rheumatoid arthritis, and Everyday Health updated its RA resources page to reference CreakyJoints resources. Healthline.com published a video interview with GHLF/CreakyJoints President Seth Ginsberg on the importance of finding community, and elle.com featured one of our CreakyJoints members discussing how she copes with managing her career and her symptoms.

Our efforts to raise awareness of migraine and the Talking Head Pain podcast, which launched this summer, included feature articles in New Jersey's Holmdel Journal (print and online), migraine.com, thedailyheadache.com, and migrainedownunder.com, a blog based in New Zealand.

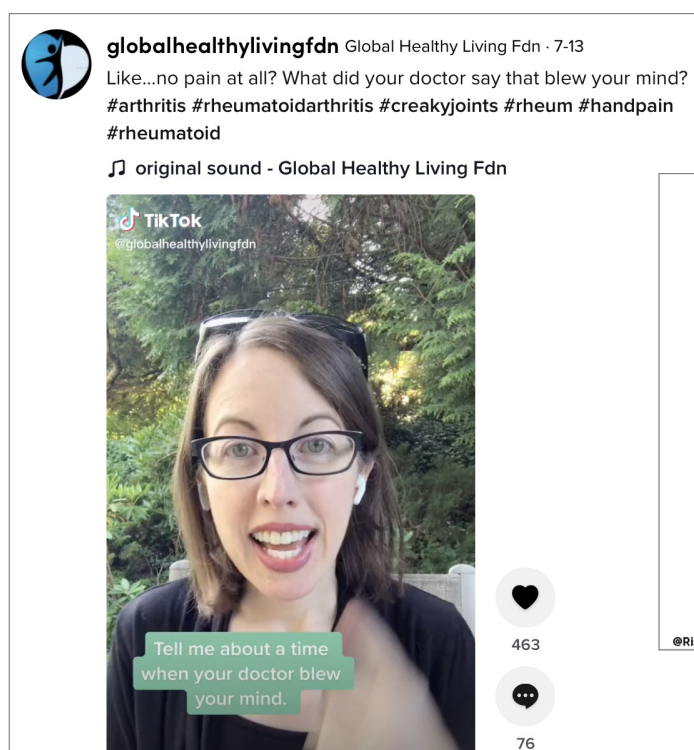
In the third quarter, there were nearly 4 million combined page views of CreakyJoints.org, ghlf.org, CreakyJoints Español, and CreakyJoints Australia content. The metrics below illustrate the quality of traffic coming to CreakyJoints.org, the diversity of visitors, and the rheumatic topics they're interested in.

- The average site visit on CreakyJoints.org is 17 minutes, 31 seconds (far, 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 6.7 percent, reaching more than 110,000 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:
 - o 12 Ways to Make Road Trips and Car Rides Easier When You Have Arthritis
 - o How to Create an Arthritis-Friendly Bathroom That Makes Life Just a Little Easier
 - o What Is an Occupational Therapist, and How Do They Help People with Arthritis?
 - o Dehydration and Arthritis: How Not Drinking Water Affects Your Joints
 - o Sneaky Signs Someone Isn't Supportive of Your Chronic Illness — and What to Do About It

SOCIAL MEDIA

Our social media channels are a key way 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:

- TikTok: Like . . . no pain at all? What did your doctor say that blew your mind?
- Instagram Post: How do you describe your #fatigue?
- Instagram Reel: Migraine: It's Tricky (RunDMC)



#CREAKYCHATS KEEPS THE CONVERSATION GOING

During the months of July, August, and September, #CreakyChats averaged over 17 million impressions.

- “Inaccessibility in Everyday Life”: featuring patient leaders/advocates Tinu Abayomi-Paul and Charis Hill
- “COVID-19 Vaccine Myth Busting”: featuring GHLF patient leaders
- “Creating Global Community Through Fashion”: featuring the Canadian Arthritis Patient Alliance, Everyday Health, CreakyJoints Australia, and CreakyJoints Canada

We continued publishing unique content on TikTok and Instagram highlighting everyday struggles and providing uplifting support for people with chronic disease.

WHO WE ARE

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 digital community for millions of arthritis patients and caregivers worldwide who seek education, support, activism, and patient-centered research through our [ArthritisPower®](#) 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 30,000 people. Via CreakyJoints, GHLF 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. Visit [ghlf.org](#) for more information.



About CreakyJoints®

[CreakyJoints®](#) is a digital community for millions of arthritis patients and caregivers worldwide who seek education, support, advocacy, and patient-centered research. We represent patients in English and Spanish through our popular social media channels, our websites, and the [50-State Network](#), which includes more than 1,600 trained volunteer patient, caregiver, and health care activists.



Part of the [Global Healthy Living Foundation](#), CreakyJoints also has a patient-reported outcomes registry called [ArthritisPower®](#), which includes tens of thousands of consented arthritis patients who track their disease while volunteering to participate in longitudinal and observational research. CreakyJoints publishes the popular “[Raising the Voice of Patients](#)” series, which offers downloadable patient-centered educational and navigational tools for managing chronic illness. It also hosts PainSpot ([PainSpot.org](#)), a digital risk-assessment tool for musculoskeletal conditions and injuries, and eRheum ([eRheum.org](#)), for telehealth and virtual-care support. All programming is free, always. For more information and to become a member, visit [CreakyJoints.org](#).

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 rheumatological manifestations of gastrointestinal-tract (GI) 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](#).



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, @CreakyJoints, #CreakyChats

Instagram: @creaky_joints, @creakyjoints_au, @creakyjoints_esp

TikTok: globalhealthylivingfnd

LinkedIn: linkedin.com/company/ghlf

