

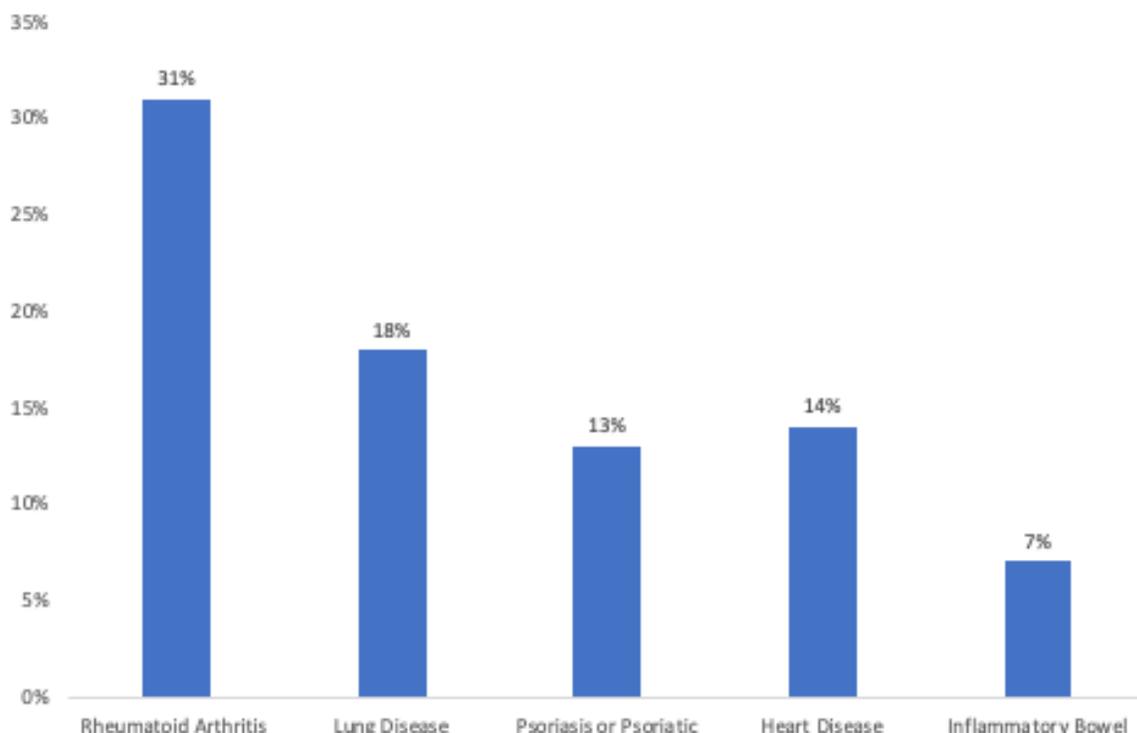
QUARTERLY REPORT

OCTOBER - DECEMBER 2021

DELTA, OMICRON, AND THE HOLIDAYS: OFFERING COMFORT AND RESOURCES TO GUIDE THE CHRONIC DISEASE COMMUNITY

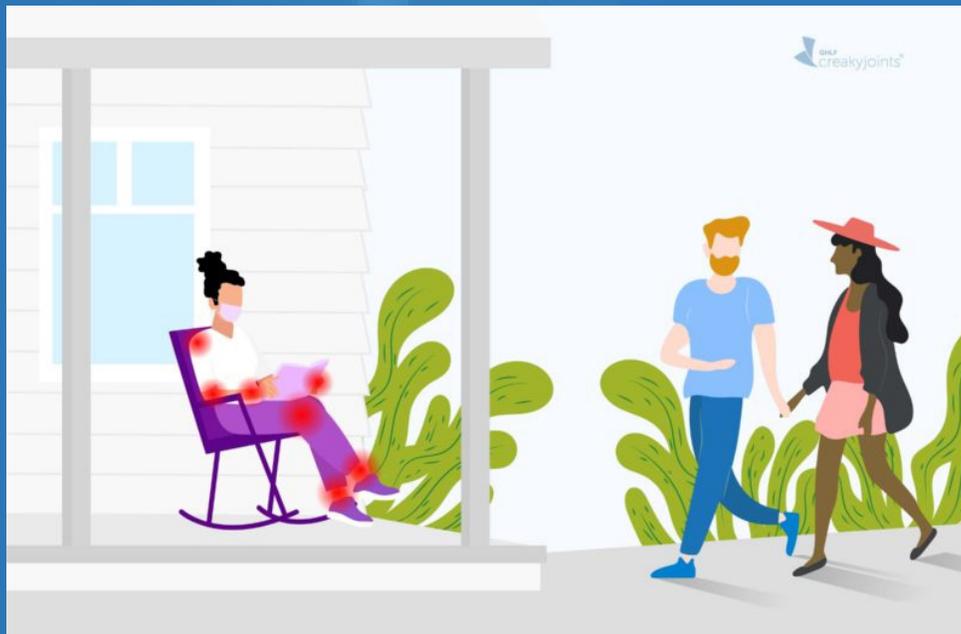
With vaccines and boosters readily available, pockets of the United States (and abroad) are better armed to deal with rising infections. Unfortunately, the fast-moving Omicron variant put a wrench in many people’s plans to spend time with family and friends during the holiday season. At the [Global Healthy Living Foundation \(GHLF\)](#) and [CreakyJoints®](#), we recognized the ongoing need to provide comprehensive information and support so that our patient communities can make decisions about engaging with family, friends, work, and the activities important to them. Our stable 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 continued to grow in the fourth quarter and now includes 29,026 diverse members and 45,365 subscribers (as of December 31, 2021). Website visits continue to exceed one million per month. Common conditions of members in the program include:



■ ROBUST CONTENT

Every year, the fall and winter holidays approach whether we are ready or not: Halloween, Thanksgiving, Diwali, Hanukkah, Christmas, and the New Year. Last year, amid concerns about variants, our members were busy working, visiting with friends and family, and participating in the activities that mean the most to them. Many had the opportunity to get their younger children vaccinated. Our content offered a variety of advice on managing the risks of the pandemic while enjoying the important benefits of community. As always, our content featured 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 October through December, 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:

- [Immunocompromised People Are Relieved More Children Will Be Able to Get a COVID-19 Vaccine, But Still Have Concerns](#)
- [I'm an Actress with Rheumatoid Arthritis, and Returning to the Theatre During COVID-19 Terrifies Me](#)
- [How to Time the Flu Shot, COVID-19 Vaccine, and Immunosuppressive Medications If You're Immunocompromised](#)
- [Immunocompromised? A Guide for Staying Safe from COVID-19 During the 2021 Holiday Season](#)

In November, Slate spoke to CreakyJoints member Chantelle Marcial to understand how people living with autoimmune conditions might feel about the country opening up again and [people getting together for the holidays](#). The article linked to CreakyKitchen, the GHLF program that began last year to inform and entertain our community during the pandemic, which Marcial hosts.

Join our community

#CreakyChats

Vaccines Save Lives: A #CreakyChats with Health Care Leaders

Thursday, November 11th 7 P.M. ET

Hosted by

@CreakyJoints
#CreakyChats

@AIDS_United
AIDS United

@SusanGKomen
Susan G Komen

@LLSusa
The Leukemia & Lymphoma Society

@COTA_ORG
Children's Organ Transplant Association

■ #CREAKYCHATS GETS TO THE HEART OF VACCINATION

In November, we hosted a #CreakyChat titled “Creating Positive Spaces on Social Media: A Special #CreakyChats with Walgreens, AIDS United, Susan Komen, the Leukemia & Lymphoma Society, and the Children’s Organ Transplant Association.” The chat included major health care leaders to discuss the importance of vaccines for chronic disease/immunocompromised patients. During this chat we highlighted the unique challenges chronic disease/immunocompromised patients face when accessing vaccines and how we can build a society that supports science and keeps all safe.



■ 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 fourth quarter include:

October Poll Topic: Have You Gotten Your Flu Shot?

1,667

Patient Support Program subscribers responded to our October poll asking about their flu vaccination status.

92%

reported they were already vaccinated!

“

Flu season last year was mild because of masking. This year we are seeing less masking, which to me means a worse flu season, so having any protection will be extremely helpful.

October Poll Topic: What Are Your Holiday Travel Plans?

1,277

Patient Support Program subscribers responded to our late October quick poll on their travel plans during the holiday season.

15%

reporting that they planned to be away from home.

Many had plans in place to cope with the pandemic, including:



planned to celebrate only with fully vaccinated people.



planned to take COVID-19 precautions.



planned to celebrate only with their household, and less than 9 percent canceled in favor of celebrating alone or virtually.



planned to keep their traditional celebration, with no changes to their usual way of celebrating.

““

My small family will be coming off an airplane the day before Thanksgiving, and we will celebrate on Sunday after everyone has taken a COVID test and is negative. I'm too old to miss a possible last holiday with my family.

November Poll Topic: Are You Satisfied with Your Ability to Socialize?

1,249

Patient Support Program subscribers responded to the November poll to provide perspective on their satisfaction with their ability to get together with family and friends.

92%

said they were immunocompromised because of their condition or the medications they take.

Regarding their satisfaction with their ability to get together with family and friends:



of respondents were very much satisfied.



of respondents were quite a bit satisfied.



of respondents were somewhat satisfied.



of respondents were a little bit satisfied.



of respondents were not at all satisfied.

In thinking about what they needed to feel more satisfied with socialization options, **more than 70 percent** of respondents hoped that more people would get vaccinated, wear masks more often, and get their booster shots. Many people also hoped for more opportunities for outdoor and/or virtual gatherings.

“

This year is almost harder than last: A year ago, everyone who took COVID seriously was masked and adhered to guidelines for gathering. Now, most healthy vaccinated people have moved on, leaving someone like myself, who is immunocompromised, to be left out of gatherings. So I actually feel more isolated than a year ago.”

■ #CREAKYKITCHEN TURNS UP THE HEAT

Our monthly #CreakyKitchen events resumed in the fall, with CreakyJoints member Chantelle Marcial leading a virtual audience in a cooking demonstration.



In episode nine, Chef Chantelle taught a seasonal recipe for butternut squash soup with a spooky balsamic web topping. We were also joined by fitness and nutrition coach Lauren Scholl, a member who lives with psoriatic arthritis (PsA). Scholl shared tips for how to stay on track with healthy eating during the holidays, along with suggestions on how to avoid trigger foods in some of our favorite holiday meals.

In episode 10, Chef Chantelle taught several recipes for delicious Thanksgiving side dishes, like her famous mac and cheese and sweet potatoes. Just like in last year's Friendsgiving episode, members of our community shared favorite holiday memories and recipes.

In episode 11, Chef Chantelle taught us a raisin bar recipe from her mom, a little sweet treat for the holiday season. We were also joined by writer and patient advocate Lene Andersen, who shared tips on managing the holidays with chronic illness.

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

During the fourth quarter, we presented a significant amount of data on the impact of the COVID-19 pandemic on people living with rheumatic disease at the 2021 American College of Rheumatology (ACR) Convergence. These published posters and conference presentations stemmed from our leadership of the Autoimmune Research Collaborative (ARC). Specific to COVID-19, presentations included:

Scientific Program:

- [Changes in Patient-Reported Outcome \(PRO\) Scores During the COVID-19 Pandemic: Data from the ArthritisPower Research Registry \(POSTER, Tues., 11/9/2021, 8:30–10:30 a.m.\)](#)
- [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 \(POSTER, Tues., 11/9/2021, 8:30–10:30 a.m.\)](#)
- [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 \(POSTER, Tues., 11/9/2021, 8:30–10:30 a.m.\)](#)
- [Perceptions About COVID-19 Vaccination Among Patients with Rheumatic Diseases Enrolled in a National Patient Registry \(POSTER, Tues., 11/9/2021, 8:30–10:30 a.m.\)](#)
- [Telemedicine for Rheumatologic Care During the COVID-19 Pandemic: Patient Perceptions and Preferences \(POSTER, Tues., 11/9/2021, 8:30–10:30 a.m.\)](#)



The poster titled [“Changes in Patient-Reported Outcome \(PRO\) Scores During the COVID-19 Pandemic: Data from the ArthritisPower Research Registry”](#) evaluated whether mean Patient-Reported Outcomes Measurement Information System (PROMIS) scores for mental, social, and physical health among people with rheumatic conditions fluctuated during 15 months of the COVID-19 pandemic. Developed by the National Institutes of Health (NIH), PROMIS is a publicly available system of highly reliable, standardized, and precise measures of patient-reported health outcomes. It is used to measure health symptoms and health-related quality of life domains such as pain, fatigue, depression, and physical function, which are relevant to a variety of chronic diseases. These measures of health are scored 0–100, with the U.S. general population mean at 50 and 10 as the standard deviation (SD) of the reference population.

- The study found that mental health scores varied significantly, particularly during the first U.S. wave of the COVID-19 pandemic, whereas scores for physical health remained relatively stable. In January and February 2020, anger and anxiety had significantly lower scores compared with the overall assessment mean for the study period.
- However, during the months of May and June 2020, mean scores were elevated by a standard deviation for anger (May: 74.2 [14.1], $p < 0.001$; June: 76.4 [12.1], $p < 0.001$; overall mean 61.6 [13.0]) and for anxiety (May: 72.0 [11.1], $p < 0.001$; June: 73.3 [12.3], $p < 0.001$; overall mean 63.1 [10.7]).
- Depression scores, while at their lowest in January 2020, increased by half of one standard deviation in May (66.6 [13.0], $p < 0.001$) and June 2020 (67.4 [11.1], $p < 0.001$, overall mean 61.2 [9.5]). In addition, social isolation was at its worst in June 2020 (66.0 [7.1], overall mean 61.7 [9.9]) and emotional support dipped in December 2020 (36.7 [9.6], overall mean 41.4 [9.7]).

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MEETING ABSTRACTS

In the press release that supported the ACR data, Courtney Wells, PhD, MPH, LGSW, an Assistant Professor at the University of Wisconsin–River Falls and a member of CreakyJoints who lives with rheumatoid arthritis (RA), summarized the impact of the data as well as her own ArthritisPower® ACR-presented study, [“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.”](#) Wells said, “The pandemic brought significant uncertainty and fear to the community of people who are immunocompromised due to their illness(es) or the medications used to treat them . . . Given our study and others, it’s important to consider how we address the mental health of affected patients to ensure we are treating each person holistically.”

Notably, four CreakyJoints members earned an opportunity to describe their COVID-19 risk as immunocompromised people, and how they cope with its mental health effects, at the American College of Rheumatology’s Patient Perspectives Program, held at the 2021 American College of Rheumatology Convergence.

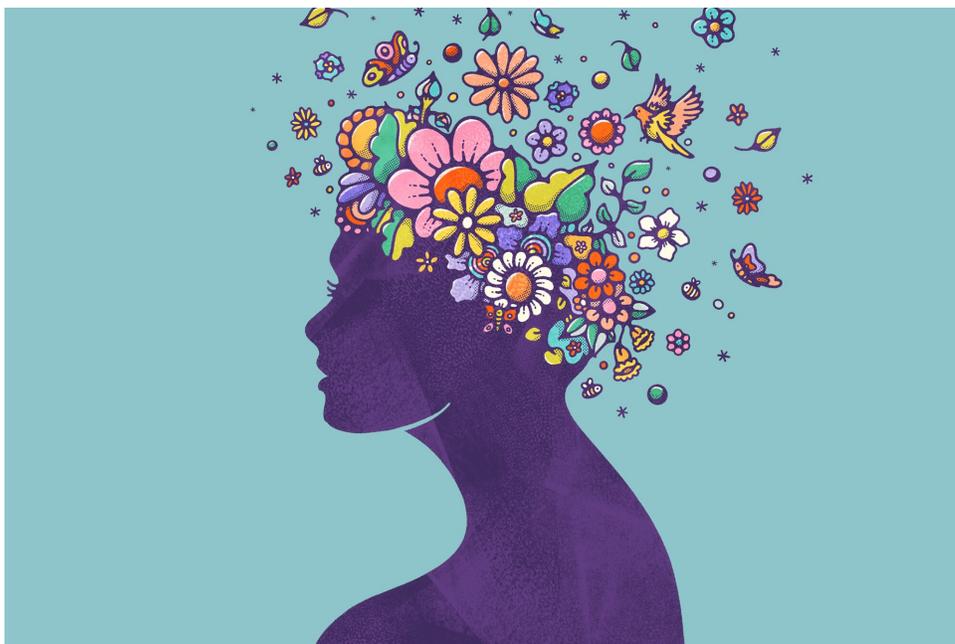


One participating member was Chantelle Marcial, who presented [“CreakyKitchen: How the Online Cooking Show I Started Is Building Community and Encouraging Better Food Choices for Me and Others Living with Rheumatic and Chronic Disease.”](#) Diagnosed at 19, Marcial has lived with rheumatoid arthritis for decades. Noting that “people with chronic disease often go through a trial-and-error process to figure out what foods help them feel good,” Marcial suggested to CreakyJoints that the organization start a program during the pandemic called [CreakyKitchen](#) as a fun way to build a sense of community, share cooking tips and tricks with other patients, and introduce people to new recipes that are easy, healthy, and delicious. Marcial has hosted 11 monthly episodes to date, with attendance growing each time.

In the press release, she said, “Being able to connect with members of my CreakyKitchen community has been a huge boost for my mental health. Also, I spend time each month researching healthier recipes to share, which has made an impact on my own meals at home. I have started rethinking and changing my own go-to recipes and finding ways to alter them to keep the flavors as good as they were, but with a healthier twist. In doing so, I have already shed a few pounds, which is a great relief for my back, knees, and ankles . . . CreakyKitchen gives me a fun, interactive monthly event to look forward to, which has been especially important during the COVID-19 pandemic.”

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 \(ORAL PRESENTATION, Sun., 11/7, 4:15–4:30 p.m.\)](#)



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:



Seth Ginsberg, GHLF President and Cofounder, participated as a special guest representing the patient view during OPAL Rheumatology’s annual debrief to stakeholders in late November. He joined a panel consisting of esteemed rheumatologists from throughout Australia to provide comments about patient perceptions around recent Janus kinase inhibitor (JAK inhibitor) safety signals, medication shortages due to supply-chain issues, and biosimilars.



Shilpa Venkatachalam, PhD, MPH, GHLF Associate Director of Patient-Centered Research, spoke on a patient-advocacy panel for [Black In Immuno Week](#). Black In Immuno is a platform created by a collective of Black immunologists and allies aimed at amplifying, celebrating, and supporting Black people in immunology. In November, she also presented to the Empowering a Nationwide Adolescent & Young Adult Leadership Research Council and at the 2021 PCORI Virtual Annual Meeting.



Robert Popovian, PharmD, MS, GHLF Chief Science Policy Officer, attended and presented at numerous conferences this past fall. Highlights included the Cancercare Circle of Hope Conference, the Texas Health and Bioscience Institute, and the World Vaccine Congress



Corey Greenblatt, GHLF Manager of Policy and Advocacy, presented at the annual conference of the National Organization of Rheumatology Managers (NORM) on October 8 and 9. The presentation, titled “Involving Patients as Advocates,” discussed the various ways that GHLF works with patients around the country to advocate for different causes.



Conner Mertens, GHLF Patient Advocate, Community Outreach Manager, presented an advocacy information and training session to the University of Washington QMed group of medical students in October. This group of future doctors partners with community members and organizations to promote advocacy, education, and wellness for LGBTQ patients and providers, as well as the community at large. In December, he presented similarly to University of St. Augustine for Health Sciences candidates for doctorates in physical therapy.

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.

GHLF **50 STATE NETWORK** **ArthritisPower** **one creakyjoints** **painspot**

Involving Patients as Advocates

NORM Annual Conference, Phoenix
AZ October 2021

- Why We Do What We Do
- Who We Are
- What We Do
- How We Do It
- How We Make An Impact

ART INSPIRES AWARENESS

During the fourth quarter, CreakyJoints highlighted artists to raise awareness of living with chronic diseases such as arthritis.

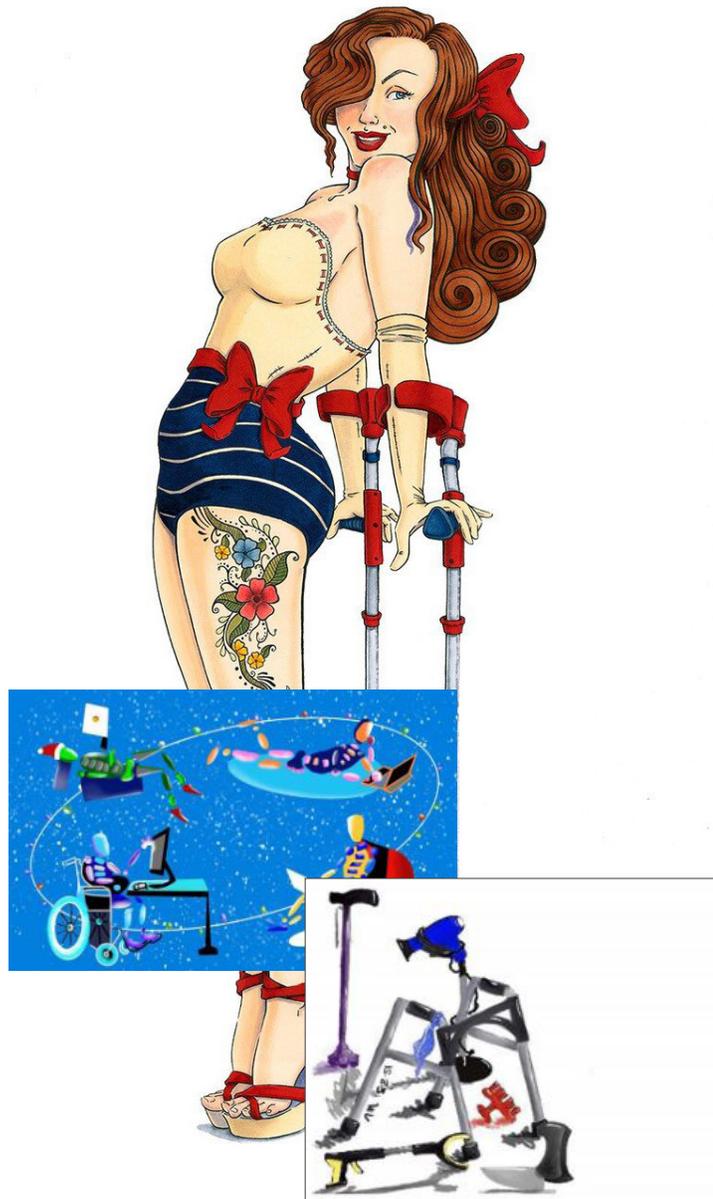
On Pins and Needles

From December 2021 to February 2022, [CreakyJoints](#) presented [“On Pins and Needles: Accessible Burlesque & the Art of Adornment.”](#) an exhibition of works by illustrator Delilah Blue Flynn and graphic designer and knitter Magdalena Truchan. The free exhibition at the Garner Arts Center in Rockland County, New York, spotlighted and redefined the beauty standard with an exploration of disability, seen through the lens of the aesthetic of mid-20th-century pinup illustration and the capabilities of those we categorize as disabled. As the artists explained, the exaggerated sexuality of pinup illustration makes it an ideal medium to explore society’s discomfort with merging stereotypical images of beauty with disability.

Twenty illustrations (13 by 19 inches, ink and marker on paper) highlighted women with a broad-spectrum of disabilities, including autism, blindness, and depression. Describing the initial idea behind this exhibition, Delilah Blue Flynn says, “Magdalena wondered why there are not any interesting and modern representations of disabled people in art. She wanted to see women portrayed as people who are not only sexually desirable, but stylish, much like the mid-20th-century pinups she collects. So I chose to depict her as a modern-day pinup on wheels.”

Holiday Greeting Cards

Two CreakyJoints members, Sal Marx and Jennifer Walker, contributed designs to create four digital holiday greeting cards, which CreakyJoints members could send to family and friends online.



DIVING DEEP INTO ARTHRITIS — CONDITION BY CONDITION

Our CreakyJoints editorial team presented three unique educational programs in the fourth quarter:

■ “GETTING REAL ABOUT RHEUMATOID ARTHRITIS TREATMENT”: AN INNOVATIVE VIDEO SERIES

Research shows that people with RA seek information from their peers to make decisions about medication and disease management — not just their health care providers. Working with a team of researchers and experts from Yale, Carnegie Mellon, ArthritisPower, and Hospital for Special Surgery and led by rheumatologist Liana Fraenkel, MD, MPH, CreakyJoints and the Global Healthy Living Foundation produced a thoughtful video series of diverse patient perspectives on these issues. The videos featured RA patients from across the U.S. discussing their own experiences with starting and changing medication, working with their rheumatologist, caring for their mental health, and more. The videos are available on YouTube and on CreakyJoints.org. The project was funded by the Rheumatology Research Foundation (RRF).



Taking a 'Drug Holiday' from Rheumatoid Arthritis Medications
RA patients discuss the desire to take a break from their treatment — as well as the consequences on their health.

Watch Now



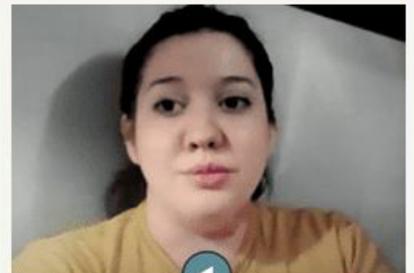
Changing Rheumatoid Arthritis Medications
RA patients reveal how it feels to acknowledge when treatment isn't working — and how to move forward to find a plan that helps.

Watch Now



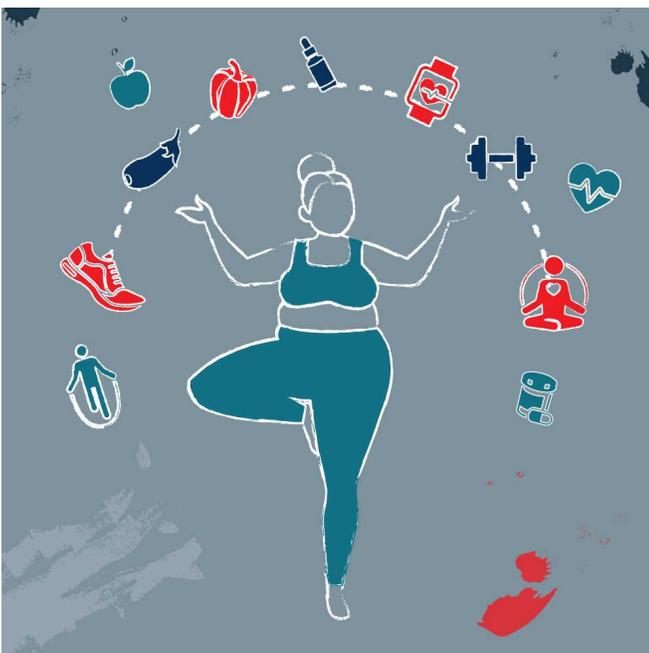
Getting Started on Rheumatoid Arthritis Medications
RA patients weigh in on their hesitations and fears about starting medication — and what they've learned since.

Watch Now



■ EXAMINING “LOSS TO FOLLOW-UP” IN ANKYLOSING SPONDYLITIS THROUGH A NEW PATIENT-EDUCATION CAMPAIGN

It’s not uncommon for people to get a rheumatic disease diagnosis and then stop pursuing care for their condition — an issue known as “loss to follow-up.” CreakyJoints wanted to better understand how this was specifically affecting people with ankylosing spondylitis (AS) and raise awareness of the consequences of avoiding care. In December 2021, we launched a comprehensive campaign called [Ghosting the Doctor with Ankylosing Spondylitis](#), which included a video, an educational article, and a downloadable PDF to facilitate better doctor-patient communication and prevent loss to follow-up. The project was informed by an original survey of 342 CreakyJoints members, which found that 24 percent had reported “ghosting” their doctor at some point.



■ A SURVEY OF CREAKYJOINTS MEMBERS FOUND 24 PERCENT REPORTED GHOSTING THEIR DOCTOR

Managing psoriatic arthritis is challenging — and it goes beyond just treating skin plaques and joint pain. That’s because psoriatic arthritis, and the fatigue that accompanies it, can take a huge toll on a patient’s physical and mental health as well their daily living.

To support patients seeking science-backed information for a more holistic approach to their health, CreakyJoints launched a [comprehensive e-newsletter series](#) on this topic in December 2021. It provides patient-approved and doctor-recommended tips and inspiration to navigate issues like fatigue, diet, exercise, mental health, sleep, and support. The series also guides patients to have more informed and honest conversations with their doctors to ensure better symptom control and quality of life.

CREAKYJOINTS ESPAÑOL HIGHLIGHTS MISINFORMATION PROLIFERATION ONLINE

Each year, from September 15 to October 15, America celebrates the histories, cultures, and contributions of American citizens whose ancestors came from Spain, Mexico, the Caribbean, and Central and South America. During last year’s Hispanic Heritage Month, CreakyJoints addressed the rampant misinformation around rheumatic conditions, which has increased during COVID-19, especially within this community. Our educational articles and outreach dispelled myths about alternative therapies by highlighting some valid, scientifically backed data about alternative therapies and the importance of speaking to a rheumatologist and continuing conventional treatment.



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MEETING ABSTRACTS

■ TWO CREAKYJOINTS ESPAÑOL PATIENTS PRESENT AT ACR

Two members of CreakyJoints Español presented at the American College of Rheumatology's Patient Perspectives Program:

In her poster presentation, "[How Online Spanish-Language Resources Got Me and My RA Through the COVID-19 Pandemic.](#)" Wigna Cruz regularly referenced how she used [CreakyJoints Español](#) articles and social media channels (in Spanish) to access up-to-date information on the pandemic as well as on how to maintain her rheumatoid arthritis. She said, "Interacting with online articles from CreakyJoints Español, and the support I received from other CreakyJoints Español members, made me feel less anxious and more comfortable using the internet. This was especially true in the beginning of the COVID-19 pandemic, when I was getting contradictory information from news outlets and on social media. Luckily, the information I received through CreakyJoints Español was factual and helped me make decisions about my health care, including RA treatment decisions, with my doctor. It made me feel less anxious and gave me confidence to get outside and walk regularly."

Diagnosed with rheumatoid arthritis as a teenager, CreakyJoints member Guadalupe Torres discussed how her work and disease journey converged in her oral presentation "[Fighting for the Care We Deserve: My Experience as a Latina Patient-Researcher During the COVID-19 Pandemic.](#)" Torres describes how she started her disease journey feeling ill-informed about what to expect, compounded by barriers to care related to the difficulties communicating with her physician about her thoughts on her treatment versus the treatment plan being set up for her. As she completed her college education and transitioned to adult rheumatologic care, she felt ready to better engage in understanding and managing her RA. She was recently invited to work as a patient-researcher on a GHLF qualitative research project about people's experiences living with rheumatic conditions during the COVID-19 pandemic; the project was specifically seeking patients from underrepresented communities to participate. She reports that collaborating in this research increased her health knowledge and helped her to build connections with other rheumatology patients, and better manage her mental health during the pandemic.

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 fourth quarter included:

- [Artritis reumatoide y moretones: ¿La artritis reumatoide causa moretones en la piel?](#)
- [Una guía para mantenerte a salvo del COVID-19 durante la temporada navideña del 2021 si tienes artritis reumatoide u otra enfermedad reumática](#)
- [Cómo manejar un brote de artritis, según pacientes y reumatólogos](#)

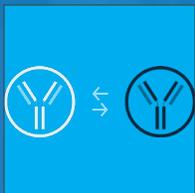
GHLF PODCAST NETWORK DOUBLES TO EIGHT PRODUCTIONS

Our library of podcasts at the GHLF Podcast Network continues to grow, and we've earned more than 20,000 downloads to date! We're proud of the content that helps inform our patient communities about the latest treatment options and health-policy proposals. We've 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. Recently published shows include:

NEW IN THE FOURTH QUARTER



Gut Culture: A podcast that gut checks assumptions about inflammatory bowel disease (IBD) through real conversations with two health care leaders, hosted by Melodie Narain-Blackwell, a passionate health advocate, educator, and mobilizer, and the founder of Color of Crohn's & Chronic Illness, and Steven Newmark, Director of Policy and Chief Legal Officer for the Global Healthy Living Foundation.



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. It is hosted by Zoe Rothblatt, Patient Advocate and Community Outreach Manager at GHLF, and Conner Mertens, Patient Advocate and Community Outreach Manager at GHLF, and features commentary from arthritis patient advocates and perspectives from health-policy experts.

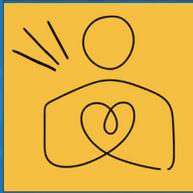


Patient PrepRheum: Host Naomi Creek, CreakyJoints Australia's National Coordinator, who has lived with rheumatoid arthritis for nearly 40 years, speaks with fellow patients and renowned doctors to explore important and often-misunderstood aspects of living with autoimmune arthritis and related conditions in Australia. Listen to interesting, relevant discussions with people who live with arthritis to help you feel more empowered.



MatterOfVax: MatterOfVax explores the issues surrounding patients, caregivers, and community on the topics of vaccination, COVID-19 risks, and staying safe. It is hosted by GHLF Australia's Stephanie O'Connell, MHC, ADip, MAICD.

ONGOING SERIES



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 and to help everyone make informed decisions to live their best lives.



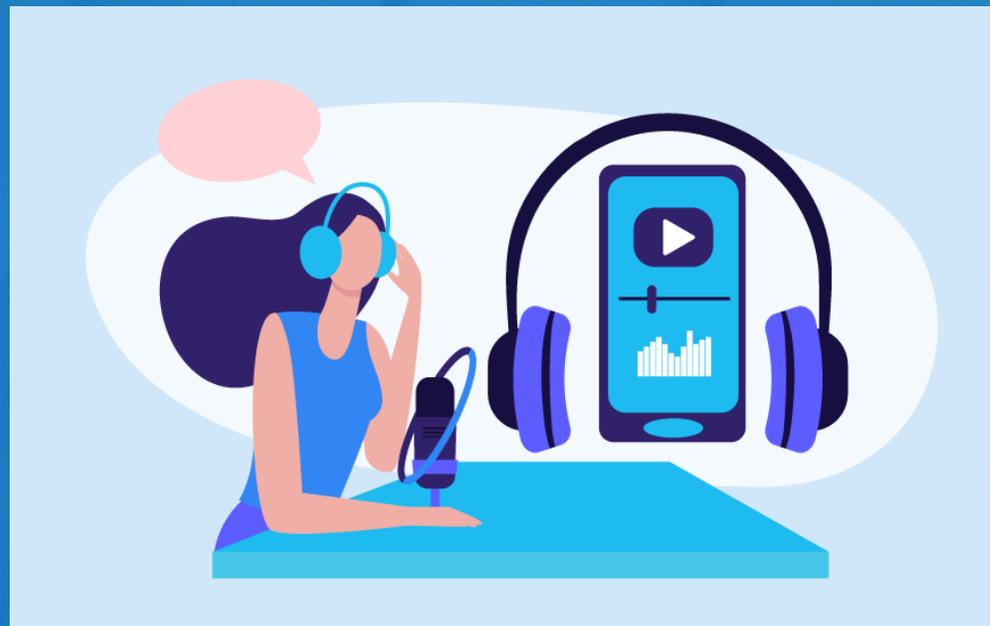
Dungeons & Diagnoses: Delve into the realm of Gaedia: a world where fantasy and reality combine! This podcast, set in the Dungeons and Dragons universe, brings those who have different lifestyles, live with conditions, and are differently abled to the forefront. It is hosted by Dungeon Master James Dybisz,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



ARTHRITISPOWER PATIENT RESEARCH HITS NEW HIGHS

Current ArthritisPower statistics as of December 31, 2021:

- Total patients: **35,269**
- % increase in membership from September 30, 2020: **17%**
- Top Conditions:

Osteoarthritis:	18,943 (54%)
Rheumatoid Arthritis:	15,561 (44%)
Fibromyalgia:	12,430 (35%)
Psoriasis/Psoriatic Arthritis:	6,432 (18%)
Osteoporosis:	5,121 (15%)
IBD:	4,449 (13%)
Lupus:	1,984 (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.

■ PROLIFIC DATA PUBLICATION IN THE FOURTH QUARTER

Our research team published five studies in the fourth quarter, including several that we further shared via press release and that were subsequently reported on by trade media.

- Published in ACR Open Rheumatology, [“Treatment Satisfaction and Decision-making from the Patient Perspective in Axial Spondyloarthritis: Real-World Data from a Descriptive Cross-sectional Survey Study from the ArthritisPower Registry”](#) is among the first studies to quantify the perspectives of people living with axial spondyloarthritis (axSpA) regarding their treatment journey.

The study reported that at their most recent physician visit, more than half of all respondents (56.9 percent, n = 159) discussed a treatment change, with most (79.5 percent) having researched a change on their own and nearly half (46.2 percent) reporting that they needed to proactively raise the issue to their clinician. The most common discussion point focused on escalating treatment (69.2 percent, changing medicines or increasing dose) versus de-escalating (27.6 percent, reducing dosage) or switching (39.1 percent) treatments. Notably, the majority of participants (85.3 percent, n = 133) who discussed a treatment change agreed to it, with most (73.1 percent) reporting that they agreed because their disease was not controlled by their previous treatment or because they thought it could be better controlled by a change in treatment. The primary reasons for declining a change in treatment related to not believing there were more effective treatment options or worries about potential side effects of the new treatment. The top symptoms driving treatment changes overall were pain in the back or buttock, pain in other joints, and fatigue. This study was covered by [MDEdge/Rheumatology](#), [Healio](#), and [Rheumatology Network](#).

- The study [“Patient-Reported Nausea and Fatigue Related to Methotrexate: A Prospective, Self-Controlled Study in the ArthritisPower Registry”](#) was published in Rheumatology and Therapy.

The article describes how our ArthritisPower mobile app may be used to capture patient-reported experiences on a rheumatic disease medication such as methotrexate (MTX), specifically for short-term symptoms that are temporally related to dose administration. Researchers found that nearly two-thirds of rheumatoid arthritis and psoriatic arthritis patients experience methotrexate side effects (including fatigue and nausea) and that for many, the experience of such symptoms is much more intense in the one to two days after each weekly dose is taken. This study’s unique design compares patients’ symptoms measured in the one to two days after taking MTX with their symptoms measured several days later, which demonstrates the high value of a smartphone-based strategy for remote therapeutic monitoring. It also demonstrates that the use of digital technology to assess medication-related symptoms is both feasible and acceptable to patients. This study will be covered by [Rheumatology Network](#) and [Healio](#).

Other published studies included:

- Salt, E., Wiggins, A., Lohr, K., Crofford, L., Studts, J., Nowell, W. B., Cappelleri, J. C., Rayens, M. K. “The Development and Validation of a Patient-Perceived Methotrexate Intolerance Scale for Use in Adult Rheumatoid Arthritis Patients.” *Musculoskeletal Care* (December 2021). doi.org/10.1002/msc.1606.
Key finding: “The newly developed, weighted scale (Patient-Perceived Methotrexate Intolerance Scale [PPMIS]) includes four subscales: Methotrexate Benefits, Methotrexate Risks-Side Effect Considerations, RA Risks, and Methotrexate Risks-Willingness to Take Methotrexate Despite Risks. This is the first known scale with favorable measurement properties to evaluate methotrexate intolerance using a patient-centered perspective.”
- Nowell, W. B., Gavigan, K., Hunter, T. et al. “Patient Perspectives on Biologics for Axial Spondyloarthritis in a Cross-sectional Study in a Predominantly Female Population: Treatment Satisfaction, Wear-off Between Doses, and Use of Supplemental Medication.” *Rheumatology and Therapy* (2021). doi.org/10.1007/s40744-021-00417-6.
Key finding: “In a predominantly female sample of bDMARD-treated patients with axSpA/AS and high disease activity, the majority expressed treatment satisfaction. However, most experienced wear-off between doses and relied on supplemental medications, including opioids, to manage symptoms.”
- 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* (December 2021). [doi: 10.1002/acr.24837](https://doi.org/10.1002/acr.24837). Epub ahead of print. PMID: 34890121.
Key Finding: “Anxiety and interruptions in 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.”

■ ACR PROVIDES OPPORTUNITY TO SHARE PRO DATA

In addition to presenting data from the Autoimmune Research Collaborative, led by ArthritisPower, that spoke to how the COVID-19 pandemic affected patient communities (see higher in the report), CreakyJoints also presented data at the 2021 American College of Rheumatology Convergence that was not related to the pandemic.

For example: Despite treat-to-target (TTT) being the gold standard for the management of rheumatoid arthritis, the study titled “Rheumatologists’ and Patients’ Mental Models for Treatment of RA Explain Low Rates of TTT” describes the disconnect between how physicians and patients value the criteria used to make decisions about treatment goals. The qualitative study interviews 14 rheumatologists and 30 people living with RA. Both physicians and patients valued PROs (86 percent physicians; 97 percent patients), disease activity relative to the set target (86 percent physicians; 83 percent patients), and the need for education before making treatment decisions (100 percent for both). However, the physicians were more focused on the overall trajectory of the disease, adherence, and response to DMARDs, while the patients were less focused on disease-activity measurements using validated instruments and had more uncertainty related to how they might feel on a new medication, particularly related to side effects.

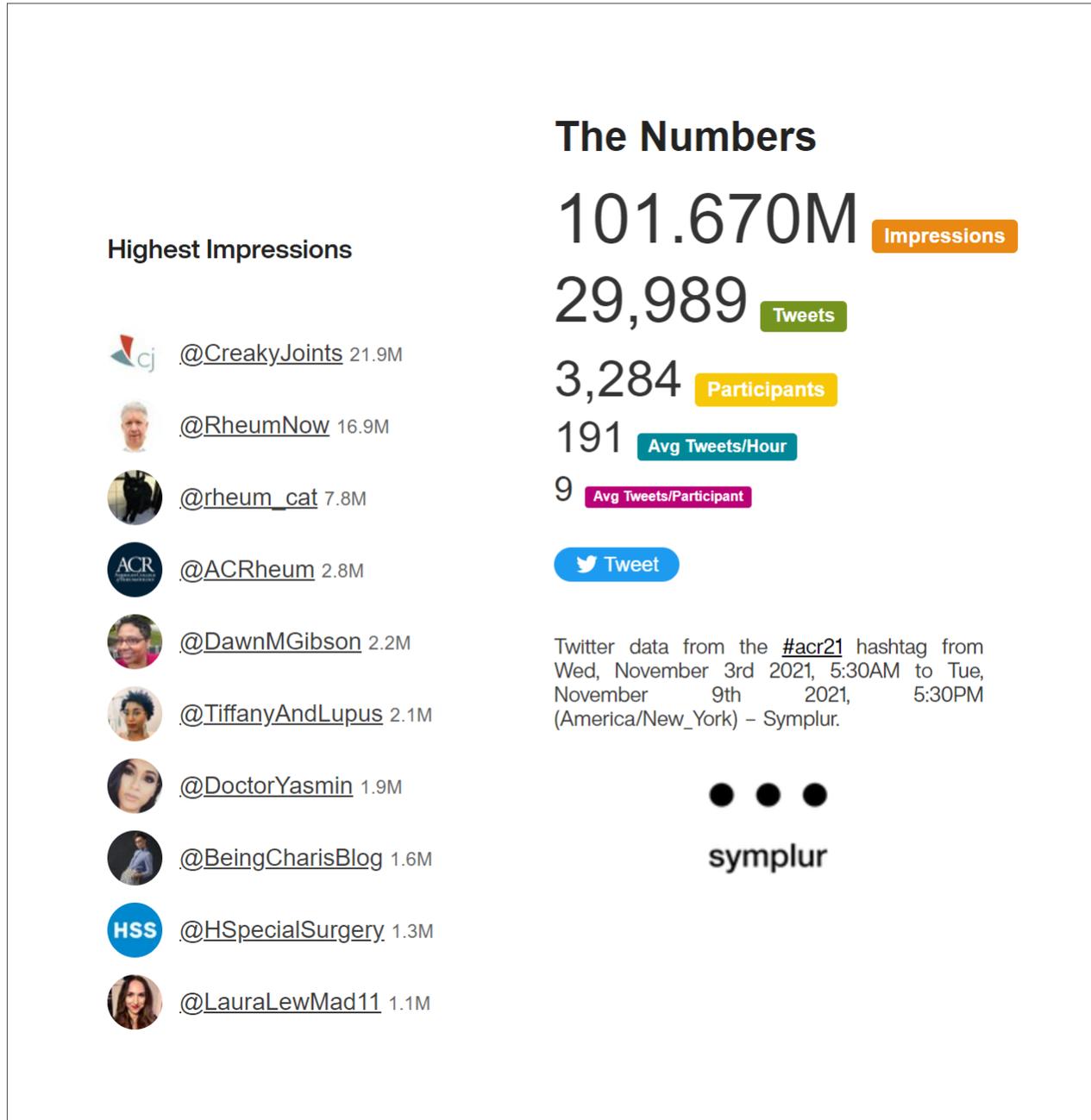
In the press release, the lead author of this study, Betty Hsiao, MD, Assistant Professor, Associate Program Director, Rheumatology, Yale School of Medicine, said, “Shared decision-making should drive TTT conversations in the clinic. However, this study demonstrates that physicians and patients may not be communicating effectively given their differing priorities. Future research should explore how we can improve communication platforms between physicians and patients.” The [study](#) was featured in a 2022 podcast hosted by Rheumatology Network, and Dr. Hsiao will be joined during the podcast by Shilpa Venkatachalam, PhD, Associate Director of Patient-Centered Research at CreakyJoints.

Other non-COVID-19 studies presented at the 2021 ACR Convergence included:

- [Impact of Treatment Experience on Patient Preferences and Disease Burden in Psoriatic Arthritis: Results from a Rheumatology Patient Research Registry](#)
- [Understanding Heterogeneity in Patients’ Conceptualization of Treatment for Rheumatoid Arthritis: A Cluster Analysis](#)
- [Racial and Ethnic Distribution of Rheumatic Diseases in Health Systems of the National Patient-Centered Clinical Research Network](#)

During the ACR meeting, CreakyJoints combed through abstracts to identify the most important studies that our community needed to understand. With the support of CreakyJoints members Dawn Gibson and Charis Hill, who assisted with reporting, CreakyJoints was a leader in publishing articles and summaries about the conference. In addition, we were the leading voice on social media. On Twitter, we generated more than 101 million media impressions.

CREAKYJOINTS TAKES TOP SOCIAL MEDIA SPOT AT ACR



■ SIX ARTHRITISPOWER PATIENT-CENTERED STUDIES IN PROGRESS AMPLIFY THE VOICE OF PATIENTS

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 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 JAK inhibitors over time. This study is sponsored by the HEOR group at AbbVie US. The study recruitment closed at the end of October

2021.

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 awareness.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. In the fourth quarter, the Steering Committee members met regularly to highlight and generate topics and questions for research prioritization based on the determinants mapped out in the area of vaccine uptake in autoimmune populations. Topics will be presented to the Multistakeholder Alliance, which will help to rank and rate these agreed-upon topics based on their stakeholder perspective to create a strategic plan for future PCOR research. The Multistakeholder Alliance comprises patients, patient advocates, payers, vaccine manufacturers, pharmacists, physicians, researchers, policy makers, and regulatory representatives. This project will use the Delphi approach, and we have acquired licensure from the University of Liverpool to use the DelphiManager software for this project. 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.

CREAKYJOINTS AUSTRALIA AND GHLF AUSTRALIA DIVE DEEP TO RAISE AWARENESS OF ARTHRITIS AND THE IMPORTANCE OF VACCINATION

During the last quarter of 2021, **GHLF Australia** launched a [vaccination support program](#). The program focuses on patient support and education and targets patient communities and health care organizations to build vaccine confidence and knowledge for a lifetime of vaccination.

MatterofVax podcast series launch: The podcast explores the issues surrounding patients, caregivers, and community on the topic of vaccination, COVID-19 risks, and staying safe. The series features many Australian physicians in specialties ranging from pediatrics to diabetes to infectious disease, all speaking to the importance of vaccination.

MatterofVax History of Vaccination education series: This first series focuses on preventable diseases and vaccine development. Each video and short story highlights a disease and the fascinating history that led to the development of a vaccine and population immunity. The next series will explore more on COVID-19, flu, hepatitis, childhood vaccination, adult vaccination, and more.

There are seven available on [YouTube](#) in the current series: smallpox, polio, typhoid, national immunization programs, global immunization, and coronaviruses (parts 1 and 2).

Vaccination stories from patients with chronic conditions: Rounding out the vaccination support program is the “[Your Stories](#)” series, in which patients talk about their vaccine and vaccination journeys, including people with diabetes, cardiovascular disease, cancer, organ transplants, diabetes, and multiple sclerosis.



■ CREAKYJOINTS AUSTRALIA PATIENT COUNCIL AND GHLF AUSTRALIA PATIENT COMMUNITY COUNCIL

With the establishment of GHLF Australia (see [this article](#) in *Rheumatology Republic*), we have elected to evolve the CreakyJoints Australia Patient Council (established in 2017) into a new GHLF Australia Patient Community Council, which will include members of the Australian patient community across the chronic disease spectrum.

■ SIX NEW AUSTRALIA PARTNERSHIPS SIGNAL CONTINUED GROWTH

- Australian Patients Association: This partnership's goal is to reach more patients through health care organizations and allied industry groups with our vaccination support program in 2022. The collaboration will broaden the reach of the program and help meet the needs of specific patient groups.
- Australian Rheumatology Association (ARA): As COVID-19 vaccinations rolled out across the country, the ARA regularly updated its advice for rheumatology patients. CreakyJoints Australia [republished and updated this advice on its website](#).
- Biointelect, with the Lung Foundation Australia and the Australian Patients Association: This collaboration will consult on a white paper that addresses community engagement, education, and vaccination and seek to change things for the better through community pharmacies.
- Pfizer: 2D animation video series and digital Vaccine 101 booklet suitable for low literacy school-aged children, and the media.
- Centre for Community Driven Research: GHLF Australia will help promote the "Universal Health Coverage National Study." The study aims to understand how citizens experience universal health coverage in their everyday lives. We will promote this study via our networks and social platforms in early 2022.
- Garvan Institute of Medical Research: The "Autoimmunity and Health: Quantifying Diagnosis" project aims to quantify the diagnosis, self-medication, and treatments of both common and rare autoimmune and chronic diseases. GHLF Australia will promote this study via our networks and social platforms in early 2022.



■ GHLF PATIENT ADVOCACY BRINGS NEW VOICES TO AUSTRALIA HEALTH

- As part of our advocacy, GHLF is reviewing the Consultation Draft of the Primary Health Care 10 Year Plan. This consultation draft focuses on Australia’s primary health care services provided through general practitioners, pharmacies, Aboriginal Community Controlled Health Services (ACCHS), community pharmacies, allied health services, mental health services, community health and community nursing services, and oral-health services. The plan also focuses on the integration of primary health care with hospitals and other parts of the health system, aged care, disability care, and social care systems.
- GHLF is helping to update the “Guiding Principles to Achieve Continuity in Medication Management,” one of the central objectives of Australia’s National Medicines Policy. The publication focuses on selecting management options wisely, choosing suitable medicines if a medication is considered necessary, and using medicines safely and effectively.

We attended the following events as representatives of both GHLF Australia and CreakyJoints Australia:

- [National Vaccine Forum’s](#) “Vaccine Confidence: COVID-19 and Beyond”
- [BMS’s](#) Shaping Healthcare Together roundtable on the future of horizon scanning in Australia
- [Consumers Health Forum of Australia’s](#) webinar on the Consultation Draft of the Primary Health Care 10 Year Plan
- [The Medical Republic’s](#) Writing Workshop for Doctors
- [APPRISE’s](#) Beat COVID: COVID Conundrums Community Forum
- [ARCS Australia’s](#) “Compensating Consumer Partners” webinar
- [Consumers Health Forum of Australia’s](#) #CHFTalks webinar “Reimagining Healthcare: Where to next for digital health?”



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.

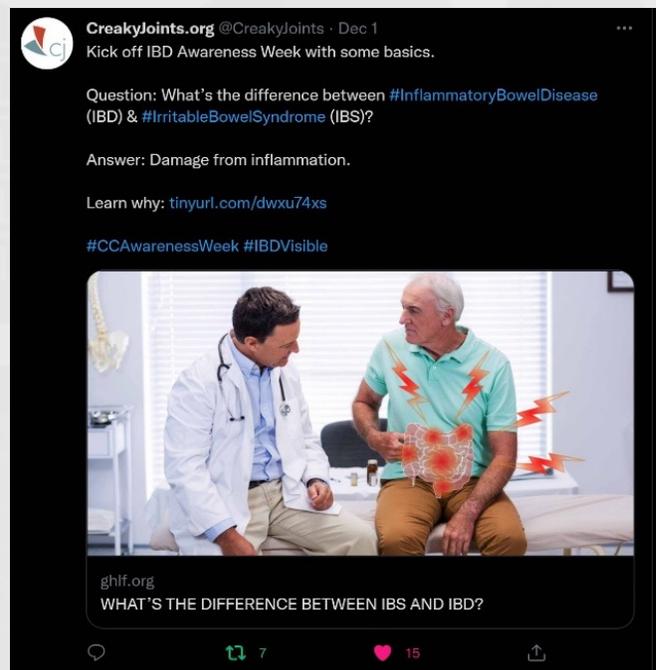
During the third quarter, Robert Popovian, PharmD, MS, Chief Science Policy Officer, published (often with coauthors) several op-eds, including:

- Outsourced Pharma (October 2021): [Benefit Design in Medicare Exacerbates Vaccine Access Inequity](#)
- Morning Consult (November 2021): [When Making Policy Decisions, Quality and Context of Data Should Be Scrutinized](#)

In December, Joseph Coe, MPA, Director of Education and Digital Strategy, was named to the board of directors of the Helen Hayes Hospital Foundation, which advances the mission and strategic objectives of Helen Hayes Hospital through the development of resources and community awareness. In this role, Coe will continue his mission to advocate for and support patient centered health care.

IBD AWARENESS

- In the first week of December, GHLF participated in Crohn's and Colitis Awareness Week through social media by sharing our top resources for living with inflammatory bowel disease.



RECENT COMMENTS AND LETTERS SUBMITTED TO POLICY MAKERS INCLUDE

FEDERAL

6
OCT

[Patient community concerns with drug pricing \(HIV+Hepatitis Institute sign-on\)](#)

21
OCT

[Letter to congressional leadership in support of step therapy reform \(Federal Step Therapy Coalition sign-on\)](#)

2
NOV

[GHLF comments to FDA Acting Commissioner Janet Woodcock regarding JAK inhibitor warnings](#)

23
NOV

[GHLF comments to HHS about accumulator adjustor policies](#)

13
DEC

[Letter to Senator Chuck Schumer about the vaccine provisions in the Build Back Better Act \(AVAC sign-on\)](#)

14
DEC

[Letter to Senate leadership and the Senate Committees on the Budget and Finance](#)

20
DEC

[Letter to Senator Chuck Schumer about Build Back Better Act](#)

STATE

6
OCT

[Written testimony to Ohio House Commerce and Labor Committee on HB 435, Oppose](#)

13
OCT

[Letter in support of New York non-medical switching reform](#)

18
OCT

[Letter on New York S.4111/A.4668, relating to non-medical switching](#)

18
OCT

[Letter on Michigan HB 4353, relating to copay accumulator adjustors](#)



■ 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:

- | | |
|------------------|---|
| 1
OCT | Healthcare Equity Summit, American College of Medical Quality |
| 5
OCT | STAT+ Conversation: Making health care accountable |
| 5
OCT | The New Role of Telehealth, The Hill |
| 6
OCT | The Future of Everything, sponsored by the Wall Street Journal |
| 7
OCT | Technology Innovation, Misinformation and Public Health, the Wall Street Journal |
| 7
OCT | Health Equity: Affordability with Richard E. Besser, MD & Rep. Lauren Underwood, the Washington Post |
| 14
OCT | International Health Technology Assessments and Their Impact on Access and Patient Preferences, hosted by the Advocacy Exchange |
| 14
OCT | State of Reform (Atlantic region) |
| 21
OCT | Cancercare Circle of Hope Conference |
| 22
OCT | Confronting Ageism in Health Care: A Conversation for Patients, Caregivers and Clinicians, Kaiser Health News |
| 25
OCT | Hicks Harris Ferguson Multiple Myeloma + Health Equity Virtual Symposium, Ohio Federation for Health Equity (cosponsored by GHLF) |
| 28
OCT | PharmaVoice: Vaccinating Remaining Populations |
| 28
OCT | American Cancer Society Cancer Action Network Regional Conference |
| 29
OCT | Pharmacists as a Trusted Voice: Transforming Community Engagement in Vaccination Engagement and Beyond, the National Minority Quality Forum |

- 2**
NOV

State of Reform (Northeast region)
- 3**
NOV

Promoting Health Equity in Communities of Color, Ohio Federation for Health Equity (cosponsored by GHLF)
- 4**
NOV

Global Healthcare Collaborations: Maximizing Opportunities in a Changing Landscape, McDermott Will & Emery
- 4**
NOV

PharmaVoice: Can Technology Really Simplify HCP Engagement? A Playbook for Implementing More Efficient and Effective Speaker Bureau and Advisory Programs
- 4**
NOV

American College of Rheumatology Convergence
- 4**
NOV

American Cancer Society Cancer Action Network Tri-State Forum
- 4**
NOV

National Racial Equity Initiative Summit for Social Justice, Congressional Black Caucus Foundation
- 4**
NOV

Health Benefits Nation, hosted by Validation Institute
- 9**
NOV

Women’s Congressional Policy Institute’s Congressional Briefing: Women Veterans and Migraine
- 9**
NOV

Texas Health and Bioscience Institute
- 15**
NOV

DEI Initiatives in Immunology, Black In Immuno Week
- 17**
NOV

American Disease Prevention Coalition
- 17**
NOV

Children and COVID-19 Strategies and Partnerships for Vaccination, Duke-Margolis Center for Health Policy



- 17**
NOV
Future of Healthcare Summit: Tackling Costs & Pathways to Care, The Hill
- 19**
NOV
Digestive Disease National Coalition Fall Forum
- 2**
DEC
PharmaVoice: The new vaccine race: Why a decentralized approach will win
- 2**
DEC
World Vaccine Congress
- 3**
DEC
Next Steps in #CancerHealthEquity: Are You Ready to Engage the Medicaid Population?
National Minority Quality Forum
- 7**
DEC
Health Equity Symposium: Racism and Its Impact on Health in Communities of Color, Ohio
Federation for Health Equity (cosponsored by GHLF)
- 8**
DEC
Driving Positive Patient Outcomes through Services and Enhanced Data, World Congress
- 8**
DEC
McDermott Will & Emery Digital Health Venture Series: What to Look for When Investing in
Digital Health
- 8**
DEC
CMS Innovation Center: Health Equity Strategy
- 8**
DEC
Unpacking the Prescription Drug Provisions of the Build Back Better Act, hosted by the Kaiser
Family Foundation
- 9**
DEC
NEJM Catalyst Innovations in Care Delivery: Clinicians in 2030
- 9**
DEC
Northeast Business Group on Health
- 9**
DEC
Towards a Biosimilar Future: Safety, Savings, Solutions
- 9**
DEC
Patient Advocacy Summit, BioNJ
- 14**
DEC
Health Equity Symposium: Health Equity in the African American Community: The Path
Forward, Ohio Federation for Health Equity (cosponsored by GHLF)
- 16**
DEC
PharmaVoice: Aligning Net Pricing with Patient Outcomes – Removing Barriers to Value-Based
Contracting
- 17**
DEC
Understanding Bias and Fairness in AI-enabled Healthcare Software, Duke-Margolis Center for
Health Policy

CREAKYJOINTS AND THE GLOBAL HEALTHY LIVING FOUNDATION IN THE NEWS

During the fourth quarter, there were 30 original placements, with several articles featuring the experiences of CreakyJoints members, including on [Self](#) and [Slate](#). *Real Health*, a magazine written for the African American community, featured Sarah Shaw, GHLF’s BIPOC Patient Advocate, Community Outreach Manager, sharing her migraine journey and the barriers she faced finding supportive care. For the entire year, there were more than 300 earned media placements (not including syndication) reaching an estimated 1.7 billion media impressions. Coverage of CreakyJoints and GHLF ranged from offering perspective on the pandemic to sharing ArthritisPower data to content about living with arthritis and migraine. Several members and CreakyJoints staff also contributed bylined articles throughout the year.

Robert Popovian, Chief Science Policy Officer, was featured in two stories:

- [Pharmacy Today](#), October, [Walmart–Novo Nordisk Insulin Offers Deep Discounts to Select Few](#)
- [accessWDUN](#), December 31, [LISTEN: Clinical pharmacist discusses between approved COVID-19 vaccines and Novovax](#)



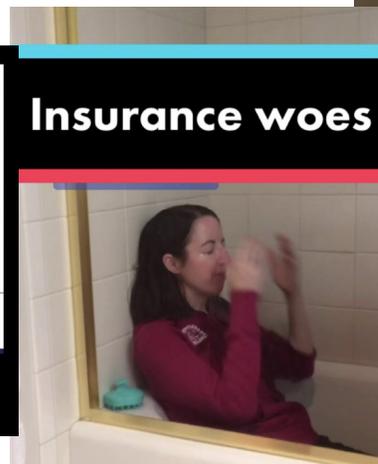
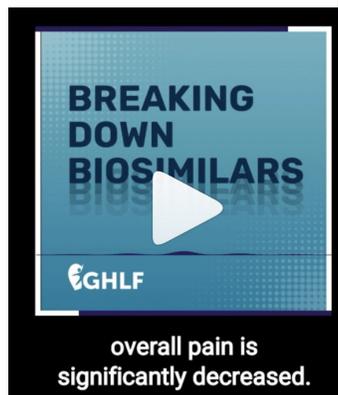
In the fourth quarter, there were nearly four million combined page views of CreakyJoints.org, ghlf.org, CreakyJoints Español, and CreakyJoints Australia content. The metrics below illustrate the quality of traffic coming to CreakyJoints.org, the diversity of visitors, and the rheumatic topics they’re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

- The average site visit on CreakyJoints.org is 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:
 - [JAK Inhibitors and FDA Safety Warnings: What Inflammatory Arthritis Patients Need to Know](#)
 - [22 Things to Try When You Feel Overwhelmed by Chronic Illness](#)
 - [11 Signs You’re Dealing with Fatigue from Inflammatory Arthritis \(and Are Not Just Super Tired\)](#)
 - [Please Stop Saying That My Arthritis Diagnosis ‘Could Be Worse’](#)
 - [Exercising with Psoriatic Arthritis: How to Get Started and Work Out Safely](#)

■ SOCIAL MEDIA

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:

- TikTok: [Insurance Barriers](#)
- Instagram Reel: [Breaking Down Biosimilars](#)
- Twitter: [World Arthritis Day](#)



■ 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. In the fourth quarter, the program expanded support and the broadening of relationships between the students at all worldwide partner schools, despite difficulties posed by the pandemic.

■ #CREAKYCHATS

As mentioned in our COVID-19 section, in November we hosted a #CreakyChat titled "Creating Positive Spaces on Social Media: A Special #CreakyChats with Walgreens, AIDS United, Susan Komen, the Leukemia & Lymphoma Society, and the Children's Organ Transplant Association." In the fourth quarter, we also hosted:

- **October:** "What's Your Chronic Disease Horror Story?" Chronic disease doesn't have to be scary, a special Halloween #CreakyChats
 - **December:** "New Year, Same Chronic Disease" Let's talk about New Year's resolutions (Special guests, members of the CreakyJoints patient councils)
- expanded support and the broadening of relationships between the students at all worldwide partner schools, despite difficulties posed by the pandemic.

WHO WE ARE

About CreakyJoints®

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



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

About Global Healthy Living Foundation

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



About ArthritisPower®

Created by [CreakyJoints®](#), [ArthritisPower®](#) is the first-ever patient-centered research registry for joint, bone, and inflammatory skin conditions, as well as arthritis and rheumatologic manifestations of gastrointestinal-tract (GI) and skin conditions. With tens of thousands of consented arthritis patients, the free ArthritisPower mobile and desktop application allows patients to track their disease and participate in voluntary research studies in a secure and accessible manner. Results from ArthritisPower studies are frequently published in peer-reviewed journals and presented at medical meetings in the United States and around the world. ArthritisPower Patient Governors serve as gatekeepers for researchers who seek to access registry data or solicit the community to participate in unique, voluntary studies. To learn more and join ArthritisPower, visit [ArthritisPower.org](#) (English) or [ArthritisPower.org.es](#) (Spanish).



About the 50-State Network

The [50-State Network](#) is the grassroots advocacy arm of the [Global Healthy Living Foundation](#). It consists of patients with chronic illness who are trained as health care activists to proactively connect with local, state, and federal health-policy stakeholders to share their perspective and influence change. Through public and personalized opportunities to advocate for the chronic disease community, the 50-State Network mobilizes patients to voice their concerns about access to treatment, quality of care, and the need to prioritize the physician-patient relationship. For more information, visit [50StateNetwork.org](#).



GHLF's Patient-Centered Policy Research Initiative

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



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

About PainSpot

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



About eRheum

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



Find us online

CreakyJoints: CreakyJoints.org

CreakyJoints Español: www.CreakyJoints.org.es

CreakyJoints Canada: CreakyJoints.ca

CreakyJoints Australia: CreakyJoints.org.au

Global Healthy Living Foundation: ghlf.org

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

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

Instagram: [@creaky_joints](https://www.instagram.com/creaky_joints), [@creakyjoints_au](https://www.instagram.com/creakyjoints_au), [@creakyjoints_esp](https://www.instagram.com/creakyjoints_esp)

TikTok: [globalhealthylivingfnd](https://www.tiktok.com/globalhealthylivingfnd)

LinkedIn: linkedin.com/company/ghlf

