



QUARTERLY REPORT

OCTOBER - DECEMBER 2022



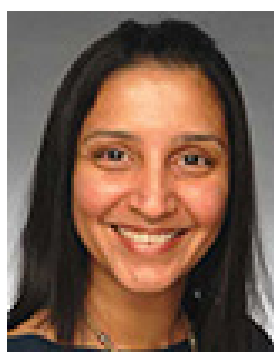
GLOBAL
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CREAKYJOINTS SECURES LEADERSHIP IN RESEARCH AT ACR CONVERGENCE 2022

At the American College of Rheumatology Convergence 2022, CreakyJoints® shared more findings and patient experiences than in any previous year, presenting 12 scientific posters (some in collaboration with research partners) and eight patient-perspectives posters. In addition, and for the first time, we secured a prestigious oral presentation slot to describe key findings from our multidisciplinary steering committee that identified critical research topics to decrease vaccine hesitancy and improve vaccine uptake in adults living with autoimmune disease, a project led by Shilpa Venkatachalam, PhD, MPH, Director, Patient-Centered Research Operations and Ethical Oversight, Global Healthy Living Foundation.



In the [press release](#), Dr. Venkatachalam said, “There is an urgent need to improve uptake of vaccines and reduce the risk of vaccine-preventable diseases such as pneumococcal pneumonia, influenza, zoster, human papillomavirus, and SARS-CoV-2 among adults living with autoimmune conditions — who are at nearly twice the risk of acquiring vaccine-preventable infections and complications from these infections. The first step is to identify priority topics for future patient-centered outcomes research. If we can better understand the safety and efficacy of vaccines for people living with autoimmune conditions, along with the concerns patients with these underlying conditions have, we may be able to optimize vaccine uptake in this vulnerable population.”



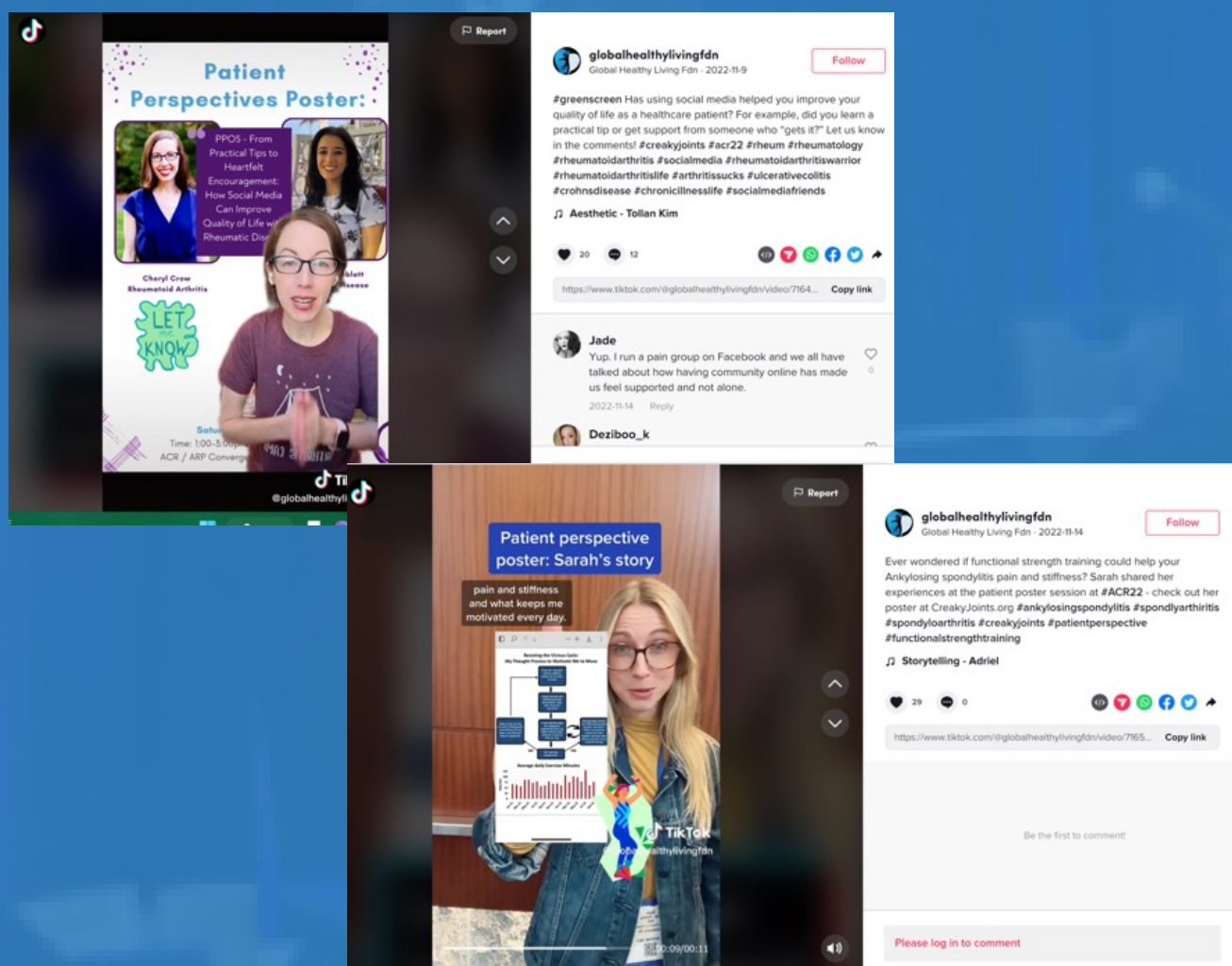
In addition to the patient-perspectives posters, CreakyJoints promoted inclusion of the [patient perspective in research](#) when W. Benjamin Nowell, PhD, MSW, Director, Patient-Centered Research, Global Healthy Living Foundation, presented the talk “Patient Perspectives on Telemedicine” as part of the session “Advancing Telemedicine in Rheumatology.” He said, “Patients have long demanded more flexible health care options, but the pandemic really expanded the opportunity for telemedicine in rheumatology as well as remote therapeutic monitoring, where patient-generated data can be tracked in real time for clinical care, like at the start of a new treatment. The good news is that, as of this year, physicians can be reimbursed for remote therapeutic monitoring.”

CreakyJoints and ArthritisPower® data was highlighted by trade media including [Rheumatology Network](#), which [covered](#) seven different posters; [Rheumatology & Arthritis Learning Network](#); [Healio](#); and [RheumNow](#).

■ SOCIAL MEDIA DRIVES ACR AWARENESS

Notably, CreakyJoints was the top patient advocacy organization social media influencer during the meeting, which Healio will highlight in a 2023 feature article.

In addition to publishing educational articles and tweets that described our research and highlighted other research findings from the meeting, we invited our researchers and patient-perspective-track presenters to share their research via videos on [Instagram](#) and TikTok. As always, our goal is to disseminate research findings to professional health providers and our patient community.



■ SCIENTIFIC POSTERS BY CREAKYJOINTS AT THE ACR CONVERGENCE 2022

- [Priority Research Topics for Vaccine Uptake Among Adults with Autoimmune Conditions](#)
- [Exploring Patient Journeys and Education Needs of Hispanic Individuals with Rheumatoid Arthritis](#)
- [Patient Perspective of Unique Support and Education Needs of Latinx/Latino\(a\)/Hispanic Rheumatoid Arthritis Patients: Implications for a Culturally Tailored and Disease Specific Intervention](#)
- [What Education Topics and Smartphone App Functions Do Rheumatology Patients Consider Important? Survey of Patients in a Community-Based Practice Network](#)
- [Patient Perceptions of Rheumatoid Arthritis Blood Work: A Cross-Sectional Survey in the ArthritisPower Registry](#)
- [Managing Psoriatic Arthritis: Patients' Views and Attitudes to Using an Online Wellness Program](#)
- [Early Real-World Effectiveness of Upadacitinib in Rheumatoid Arthritis Using Patient-Reported Outcomes Collected via Mobile Application](#)
- [Acceptance of Virtual Reality for Managing Their Disease Among People with Rheumatologic Conditions with and Without Prior Experience Using Virtual Reality](#)
- [Fertility and the Use of Assisted Reproductive Technologies: Perceptions, Thoughts and Experiences of Men and Women with Rheumatic Disease](#)
- [Home-Based Telehealth in Rheumatology: A Systematic Review & Narrative Synthesis](#)
- [COVID-19 Vaccine Uptake and Reasons for Hesitancy in a Large Rheumatology Practice Network](#)
- [Peer Coach Intervention to Improve Primary Cardiovascular Disease Screening for Patients with Rheumatoid Arthritis](#)
- [Real-World Evidence from Social Media Provides Insights into Patient Mental Health Outcomes in the Management of Gout](#)



■ CREAKYJOINTS POSTERS INVITED TO THE PATIENT PERSPECTIVES TRACK

- [Living with Rheumatoid Arthritis in a Rural Farming Community: How I Found a Rheumatologist and Got Targeted Treatment](#)
- [Please Hear Me: How Effective Provider-Patient Communication Improved My Psoriatic Arthritis](#)
- [From Practical Tips to Heartfelt Encouragement: How Social Media Can Improve Quality of Life with Rheumatic Disease](#)
- [What Lies Beneath: Making Rheumatoid Arthritis Visible for the Seronegative Patient Through Blood Work](#)
- [From Devastated to Empowered: How Patient Engagement in Research Changes Lives](#)
- [We Became Advocates, Educators, and a Support System for Hispanic/Latino Patients with Rheumatoid Arthritis and Their Caregivers Through Involvement in a Virtual Patient Advisory Board](#)
- [Exercise as a Supportive Treatment for My Ankylosing Spondylitis](#)
- [Engaging with the Spoon Theory: How I Make Decisions Using a Cost-Benefit Analysis That Works to Improve My Mental Health While Living with RA](#)

■ INTRODUCING DETERMI-NATION

GHLF has been a participating member of the Janssen initiative [Determi-Nation](#), which brings together stakeholders in health care and is led by health care providers (HCPs), patients, and advocates from different backgrounds to identify ways to diagnose psoriatic disease in people of color earlier and more accurately. This year at the ACR meeting, Determi-Nation showcased [“Beyond the Textbook,”](#) a resource for HCPs about culturally inclusive care. Determi-Nation members, including GHLF, contributed to the development of this tool, which provides insights to HCPs on how to establish trust with patients, address inequities in care for communities of color, and listen to patients with empathy to deliver optimal care. Determi-Nation also announced a pilot program in partnership with SUNY Downstate Health Sciences University, which enlists medical students as patient navigators, connecting people of color with psoriatic disease to important resources to help navigate the complexities of their health care journey. The *Essence* Facebook page hosted a recent [discussion](#).

TAILORED EDUCATIONAL MATERIALS BOOST UNDERSTANDING AND OUTCOMES FOR SPANISH-SPEAKING RA PATIENTS

During the ACR Convergence 2022, CreakyJoints presented two posters summarizing findings from the ongoing Hispanic Outreach Program Effect–Culturally Appropriate Education (HOPE–CAPE) study, which focuses on education for Spanish-language speakers with rheumatoid arthritis (RA). In [“Exploring Patient Journeys and Education Needs of Hispanic Individuals with Rheumatoid Arthritis.”](#) researchers reported that many Spanish speakers turned only to family and/or friends for information about RA and were encouraged to consider home remedies and putative “cures” alone rather than to use those options to complement specialty care. With increased participation in HOPE–CAPE, which was conducted in Spanish, participants stressed the importance of finding physicians with Spanish-speaking support, navigating insurance reimbursement for disease-modifying antirheumatic drugs (DMARDs), and having trustworthy information regarding DMARDs, diet, exercise, and home remedies for RA.

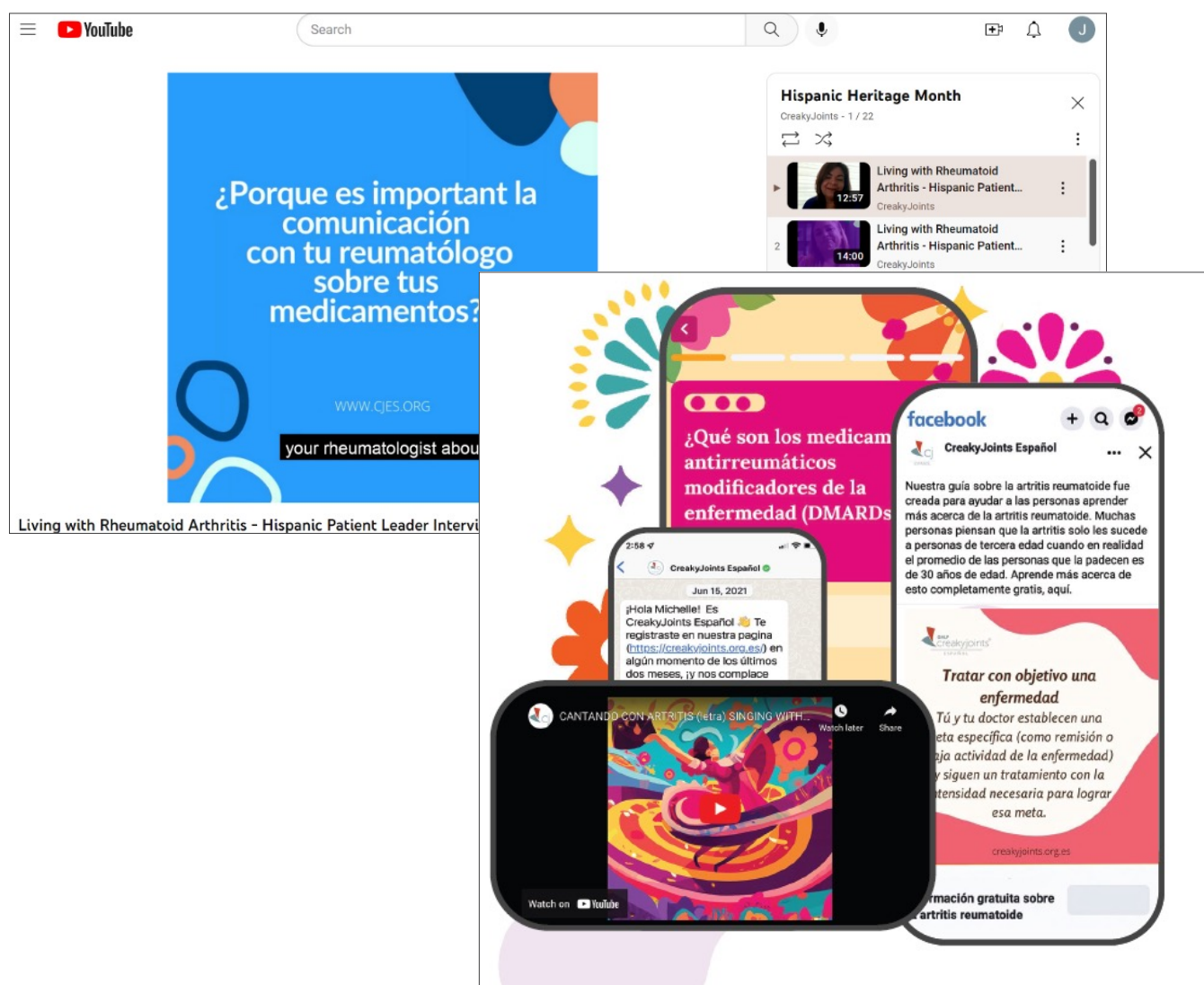
“

We found that even when patients identified trustworthy information in Spanish, it was more effective overall to present the same material in various ways such as articles, videos, podcasts, graphics, and more,” says Daniel Hernandez, MD, Director of Medical Affairs and Hispanic Outreach, Global Healthy Living Foundation, and lead study author. “In addition, our program materials were written using conversational, idiomatic Spanish, which patients found more useful and trustworthy than materials simply translated from their original English. This proves what we already do is working and provides important insights regarding how to improve on our delivery of education to this community in the future.”



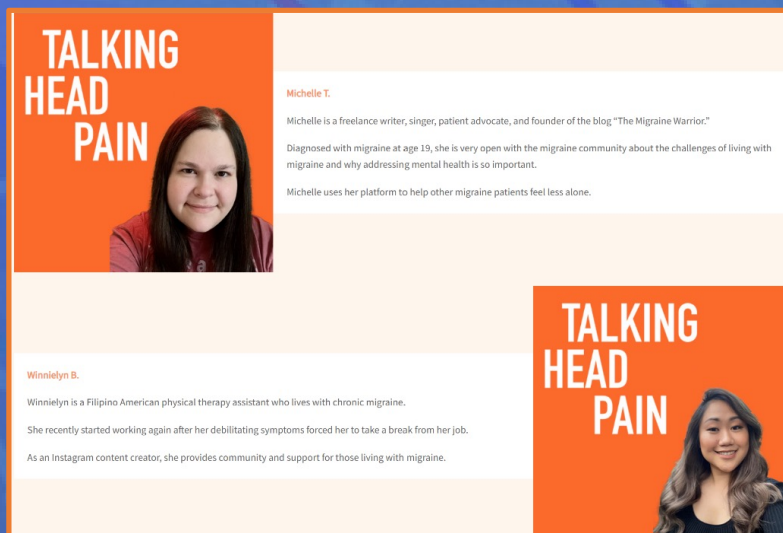
In [“Patient Perspective of Unique Support and Education Needs of Latinx/Latino\(a\)/Hispanic Rheumatoid Arthritis Patients: Implications for a Culturally Tailored and Disease Specific Intervention.”](#) GHLF collaborated with researchers at Hospital for Special Surgery in New York City on a mixed-methods qualitative study, using a licensed bilingual social work researcher to conduct semistructured interviews with doctor-diagnosed members of the Hispanic/Latinx RA community (ages 18+) to identify unique education and support needs. Preliminary findings highlight the unique emotional and mental health needs in the Hispanic/Latinx community, related to participants’ willingness to share with family and friends their experience with symptoms, seek out mental health and community support, and develop good patient-provider relationships. This study was reported on twice by [Rheumatology Network](#).

Hispanic Heritage Month: During Hispanic Heritage Month (September 15 to October 15) CreakyJoints Español produced and published educational multimedia content in Spanish.



MASTERS OF MIGRAINE: EXPERTS AND PATIENTS SHARE BEST PRACTICES

Hosted by Joseph M. Coe, MPA, Director, Education & Digital Strategy, Global Healthy Living Foundation, who lives with migraine, GHLF launched season three of *Talking Head Pain*, the innovative podcast that features the voices of migraine experts and people living with this chronic neurological condition. In 2022, this series produced more than 50 episodes!



In November, Mr. Coe attended the Scottsdale Headache Symposium, a program hosted by the American Headache Society. At this event, he connected with migraine experts, taping ad hoc episodes of *Talking Head Pain* on-site. Some of the experts he spoke with included:

- Dr. Liza Smirnoff, a headache specialist at the University of Miami, who discussed the importance of migraine care in pregnancy and for those receiving gender-affirming care, as well as the work she and her peers are doing to reduce the number of monthly migraine days in adults.
- Dr. Sarah Bobker, a headache medicine specialist at the University of California, San Francisco, and the Associate Editor for the American Headache Society's journal, *Headache*, to discuss the growth of headache medicine fellowships and why this matters for patients.
- Dr. Adelene Jann, a headache specialist and licensed acupuncturist, to discuss how acupuncture can be used for migraine patients.
- Dr. Lauren Natbony, a headache specialist who told Coe about the connection between autonomic disorders, such as postural orthostatic tachycardia syndrome (POTS) and Ehlers-Danlos syndrome, and migraine.

■ RAISING THE VOICES OF BIPOC PATIENTS LIVING WITH PSORIASIS AND PSORIATIC ARTHRITIS

Mr. Coe also taped episodes from the European Headache Congress in Vienna in December. Some of the experts he connected with there included:

- Dr. Messoud Ashina, Professor of Neurology at the University of Copenhagen and the Director of the Human Migraine Research Unit at the Danish Headache Center and Department of Neurology, Rigshospitalet Glostrup, about the interictal burden of migraine and the need for continued research that gives patients hope.
- Elena Ruiz de la Torre, Executive Director for the European Migraine and Headache Alliance (EMHA), about her career in migraine advocacy, what the EMHA does, and how she is working with European advocates to reduce migraine stigma.
- Dr. Brad Torphy, Managing Director of the Chicago Headache Center and Research Institute, about global access challenges and the need for more research on combination therapy.

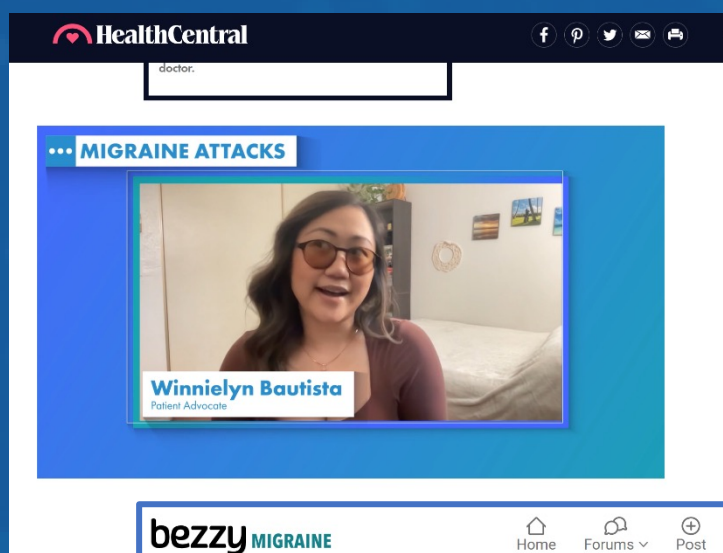


You can find the complete Talking Head Pain library at ghlf.org/talkingheadpain.

■ HOW TO TALK TO YOUR DOCTOR ABOUT MIGRAINE

In partnership with HealthCentral, GHLF member and Talking Head Pain guest Winnielyn Bautista was featured in a 10-video series about her experience living with migraine. The series offers Bautista's advice on how to talk to your doctor about migraine triggers, treatments, and self-care, among other topics.

Mr. Coe and GHLF member [Carmen Rose Fiallo](#) also contributed first-person accounts about living with migraine to the website [Bezzy Migraine](#). Meanwhile, Sarah Shaw, Senior Manager, BIPOC Community Outreach, Global Healthy Living Foundation, was interviewed about her experience with migraine on [WHYY-FM](#) (on air and online).

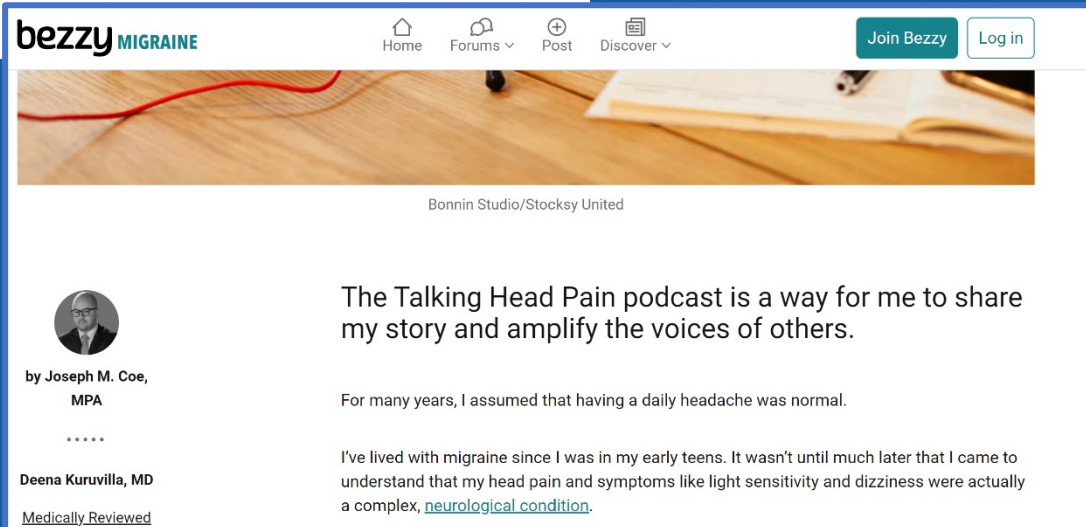


HealthCentral

doctor.

... MIGRAINE ATTACKS

Winnielyn Bautista
Patient Advocate




bezzy MIGRAINE

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Bonnin Studio/Stocksy United


by Joseph M. Coe,
MPA

Deena Kuruvilla, MD
[Medically Reviewed](#)

The Talking Head Pain podcast is a way for me to share my story and amplify the voices of others.

For many years, I assumed that having a daily headache was normal.

I've lived with migraine since I was in my early teens. It wasn't until much later that I came to understand that my head pain and symptoms like light sensitivity and dizziness were actually a complex, [neurological condition](#).

COVID-19 AND CHRONIC DISEASE — TRIPLE WINTER THREAT

With Halloween, Thanksgiving, and the winter holiday season adding activities to many people's busy calendars during the fourth quarter, our COVID-19 Patient Support Program (PSP) continued full speed ahead to provide actionable advice to people living with chronic disease about how to best manage their illness and participate in the season according to their preferences. This fall, we also proactively encouraged our patient communities to get their COVID-19 boosters and flu shots because people living with chronic disease are at higher risk for infection with and complications from COVID-19, flu, and respiratory syncytial virus (RSV). As always, our COVID-19 Patient Support Program provides comprehensive education to ensure that our communities can make educated decisions about how to protect their health and spend time with family, friends, colleagues, and neighbors. The program includes:

26,594

Number of members

40,994

Number of subscribers

28.9%

Email open rate
(health-industry average= 22%)

5.5%

Email click rate
(health-industry average = 2.5%)

32%

Rheumatoid arthritis

19%

Lung disease

16%

Fibromyalgia

13%

PsA/Psoriasis

15%

Heart Disease

12%

Migraine

9%

Diabetes

7%

AxSpA

7%

Inflammatory bowel disease

■ IMPACTFUL ARTICLES (MANY OF WHICH ALSO PUBLISHED IN SPANISH) FROM THE FOURTH QUARTER INCLUDED:

- [How to Time Your Latest COVID-19 Booster and Annual Flu Shot](#)
- [The Current State of Long COVID Research — and What It Means for You](#)
- [How to Protect Yourself Against COVID-19 During the 2022 Holiday Season](#)
- [How Your Mental Health Can Affect Your Risk of Long COVID — and How to Maintain a Healthy Baseline](#)

Notably, Oregon.gov included our patient support program in its list of resources about COVID-19: covidblog.oregon.gov/do-you-need-to-talk-explore-what-resources-are-right-for-you



Oregon Health News

News & Stories for Oregonians

■ TAKING THE PULSE OF THE CHRONIC DISEASE COMMUNITY

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

In October, ahead of the holiday season, GHLF [polled PSP](#) members to understand how the evolving COVID-19 pandemic will affect plans among the chronic disease community to celebrate the holidays with family and friends. Even though 93 percent of respondents (n = 802) are up to date on all COVID-19 vaccines they're eligible for and/or have taken preexposure preventive medicine (e.g., Evusheld), many patients were opting to isolate or plan smaller gatherings.

Key findings included:

25%

planned to celebrate in person with their usual family and/or friends but take COVID-19 precautions

19%

planned to celebrate with their household (no outside family or friends)

15%

planned to celebrate in person with a smaller group than usual

5%

planned to cancel usual holiday plans and celebrate alone

5%

planned to celebrate virtually with family and/or friends

In a news alert we shared with media (covered by [Verywell Health](#) and [Health Digest](#)), Susan Jara, Associate Director, Patient Education, GHLF, said, “Although the availability of [the bivalent COVID-19 boosters](#) should make holiday planning a little easier this year than the last two, people are still struggling to decide what is and isn't okay to do. Adding to the confusion is that the U.S. Centers for Disease Control and Prevention (CDC) has not released suggestions for safely celebrating the holidays yet . . . Our poll highlights that many people in the chronic disease community remain fearful about their risk for infection and, also, frustrated that attitudes about preventative measures are changing. In the free-response sections of the poll, many reported feeling left behind as the general public resumes activities similar to pre-pandemic times.”



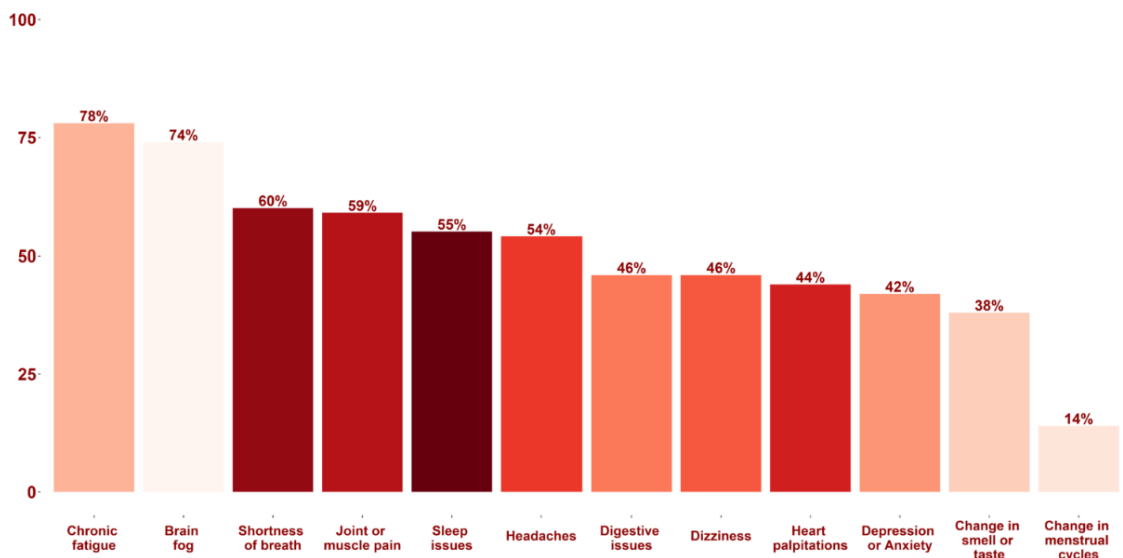
A [December poll](#) evaluated the chronic disease community's experience with long COVID. Of the 438 respondents, 89 percent are up to date on all COVID-19 vaccines they're eligible for and/or have taken preexposure preventive medicine. Of the 65 percent who have been diagnosed with COVID-19, 44 percent have been diagnosed with long COVID. In the free-response section, many members further detailed how COVID-19 affected their chronic disease, with one person reporting,

“COVID caused a flare of my arthritis. My medications were adjusted accordingly, and now I'm okay.”

Another said,

“Conditions I suffered prior to contracting COVID have exacerbated after having COVID (i.e., fibromyalgia, hypertension, high cholesterol, eczema, seasonal allergies, etc.).”

What Symptoms Did You Have While Living With Long Covid/Post-Covid Condition



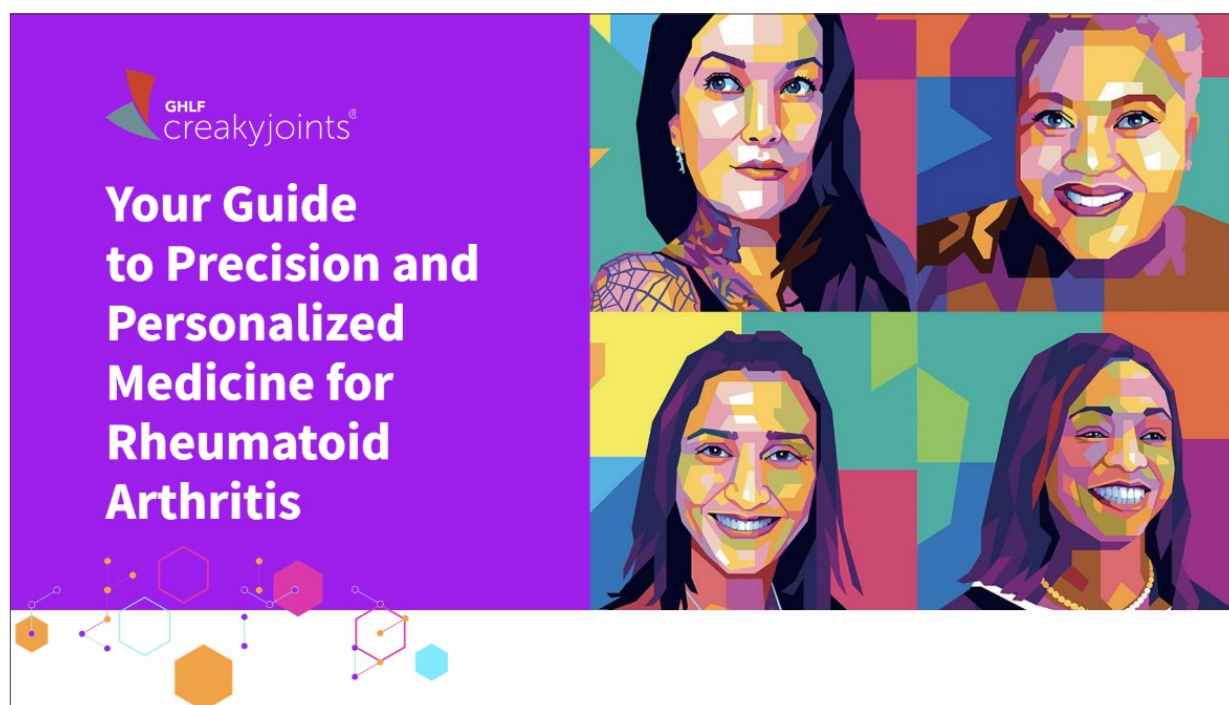
GHLF COVID-19 Patient Support Program Poll (12/1/2022)(n = 125)

PRIORITIZING PRECISION MEDICINE IN RHEUMATOID ARTHRITIS

This fall, CreakyJoints introduced [a new online hub](#) and podcast focused on precision medicine for people living with rheumatoid arthritis. Precision medicine uses objective data gathered by the health care professional from the patient to determine the best treatment plan. Hosted by Daniel Hernandez, MD, Director, Medical Affairs and Hispanic Outreach, GHLF, the podcast Let's Get Personal features several CreakyJoints members discussing how they evolved their RA treatment based on their personal experience with certain medications, goals for treatment, and experience with side effects.

In addition to a free [downloadable guide](#) that patients can bring to their doctors to help guide the treatment conversation and [an infographic](#), this module also includes two audio guides:

- [Understanding Precision & Personalized Medicine for RA](#)
- [Understanding Trial and Error in RA](#)



FIRST CLASS OF GUIDING LIGHTS RECOGNIZED BY GHLF

On October 12, a.k.a. World Arthritis Day, GHLF launched the [Guiding Lights: Beacons for Better Health](#) program, announcing the first class of health care providers and patient advocates who, through their daily activities and efforts, are helping define a way forward for members of the global chronic disease community, while showing them they are not alone.



In the press release, Seth Ginsberg, GHLF President and Co-founder, said, “We’ve defined Beacons as patients, caregivers, doctors, or providers who are shining lights to lead other chronic disease patients toward a better trajectory for their own overall wellness while helping steer them clear of possible obstacles. All around the world, we find Beacons who are setting a positive example for the chronic disease community.

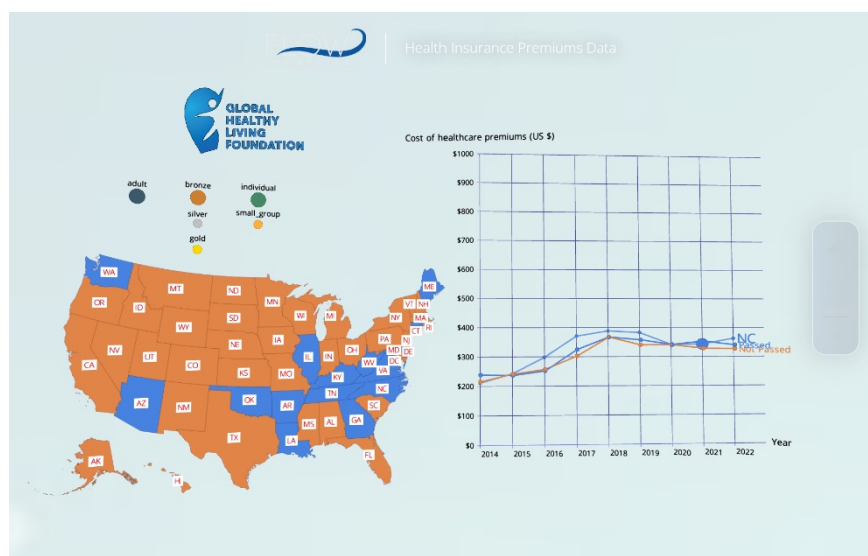
We thank these individuals for guiding us through the darkness — those times when we face the ‘unknowns’ about what to expect from our condition — and encouraging us through education, research, support, and story sharing towards a better-lit path.”

You can learn more about this first class of professional and patient influencers at ghlf.org/beacons-for-better-health, where there are profiles and a mini podcast series. Those recognized included:

- Carlo V Caballero-Urbe, MD, PhD, past President of the Pan-American League of Associations of Rheumatology (PANLAR), Barranquilla, Colombia
- Sarah Doaty, MD, FACP, a rheumatologist at Virginia Mason Franciscan Health, Washington
- Michael C. Schweitz, MD, a volunteer rheumatologist with the John Whelton Arthur Virshup CreakyJoints South Florida Arthritis Clinics, past President of the Coalition of State Rheumatology Organizations, and past President of the Florida Society of Rheumatology, Florida
- Grace Wright, MD, PhD, FACR, President and Founder, Association of Women in Rheumatology, New York
- Rosemary Ainley, a patient advocate living with rheumatoid arthritis, ankylosing spondylitis (AS), and fibromyalgia, Victoria, Australia
- Michael Kuluva, a patient advocate living with rheumatoid arthritis, Ontario, Canada
- Cristina Montoya, RD, a patient-advocate living with Sjögren’s syndrome and arthritis, Ontario, Canada
- Judy Nagy, a patient advocate living with rheumatoid arthritis, Ohio
- Ana Vieira, a patient advocate living with Sjögren’s syndrome, Marinha Grande, Portugal

GHLF CALLS FOR LEGISLATION TO PROTECT PATIENT ASSISTANCE

In November, GHLF launched a free interactive tool that will provide legislators, policy makers, and interested parties with objective data demonstrating how U.S. health-insurance premiums have fluctuated since 2014. GHLF analysis shows no statistically significant change in the rates of health-insurance premium increases after the passage of state laws requiring that patient-assistance funds count toward policyholders' deductibles or out-of-pocket (OOP) maximum payments. As explained in the press release, legislation is needed across the country because accumulator and maximizer programs instituted by insurance companies and pharmacy benefit managements (PBMs) have shifted the burden of paying for expensive, brand-name drugs — often used by the chronic disease community — to individual patients.



Robert Popovian, PharmD, MS, Chief Science Officer, Global Healthy Living Foundation, said, “Copay accumulator programs lengthen the amount of time it takes for a patient or family to reach their deductible and OOP limit, and an individual may only learn of their enrollment in such a program when they try to fill a medication and are told that they still owe

the full price for that prescription in the middle of a plan year. Our analysis shows that the assertion made by insurance companies and PBMs that restricting accumulator and maximizer programs will cause higher health insurance premiums simply isn’t true.” Dr. Popovian discussed this research with InsideHealthPolicy.

■ ROUNDTABLE DISCUSSION

On December 6, GHLF hosted a roundtable discussion on state and federal legislative priorities patients should be aware of in 2023. The panel consisted of Louis Tharp, GHLF's Executive Director and Cofounder (lower right); Dr. Popovian (lower left); and Terry Wilcox (upper left) of Patients Rising. GHLF's Erik Stone (upper right) moderated. Topics included PBMs, step therapy, the 340B program, and how these programs affect patients.



GHLF ADVOCACY AND EDUCATION LAUNCH IN JAPAN



In 2021, GHLF began research into the Japanese health system. Then, in December 2022, GHLF visited with doctors, public-health officials, and patients in Japan.

GHLF's Seth Ginsberg, President and Co-founder; Steven Newmark, Chief Legal Officer and Policy Director; and Aya Fujiwara, Japan Health Care Lead, had an opportunity to tour several hospital and clinic sites around Japan for chronically ill patients. The GHLF team focused on patients with inflammatory bowel disease (IBD), psoriasis, and rheumatoid arthritis. The team learned a lot about the Japanese health system and plans to continue engaging with Japanese thought leaders to help Japanese patients live their best lives.

CAPTION: Dr. Keisuke Nagamatsu, MD (left) - general practitioner from Ashiya, a city of about 100,000 people in Hyōgo Prefecture (between Osaka and Kobe), discusses digitizing the patient experience in the healthcare system in Japan. Also pictured from GHLF: Ayo Fujiwara, Japan lead, Steven Newmark, policy director and General Counsel, and Seth Ginsberg, co-founder.



WE CELEBRATED THE SEASON WITH OUR MEMBERS

As the holidays approached, we celebrated Thanksgiving and the New Year with our members.

■ CREAKYKITCHEN

October 2022: Fall Squash Recipe and Caring for Chronic Illness During the Holidays

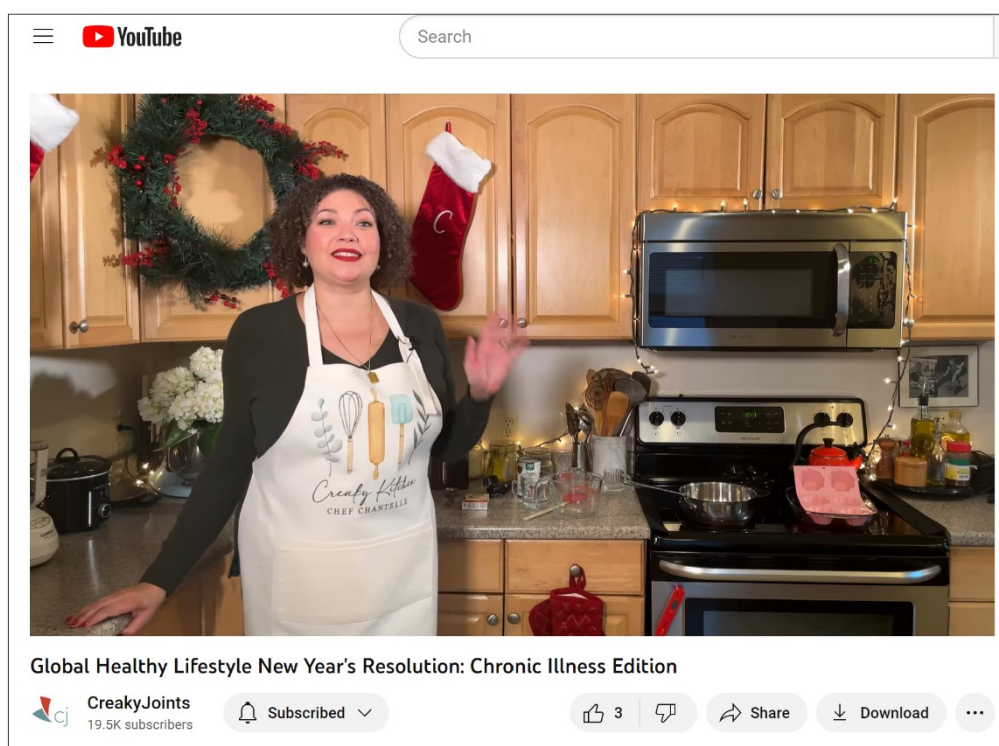
In this episode, [CreakyKitchen](#) chef Chantelle Marcial shared a delicious fall recipe for black beans with squash and rice. Saint Louis–based rheumatologist Donica Liu Baker, MD, FACR, appeared to discuss the importance of self-care during the holiday season and shared tips on how to avoid triggers that might cause flares.

November 2022: Happy Friendsgiving

In this episode, we celebrated our third annual virtual Friendsgiving with food and community! CreakyKitchen chef Chantelle Marcial shared a delicious fall recipe for roasted brussels sprouts and carrots. We also heard members' favorite stories and recipes from Thanksgivings past as well as their best tips for managing chronic disease during the holidays.

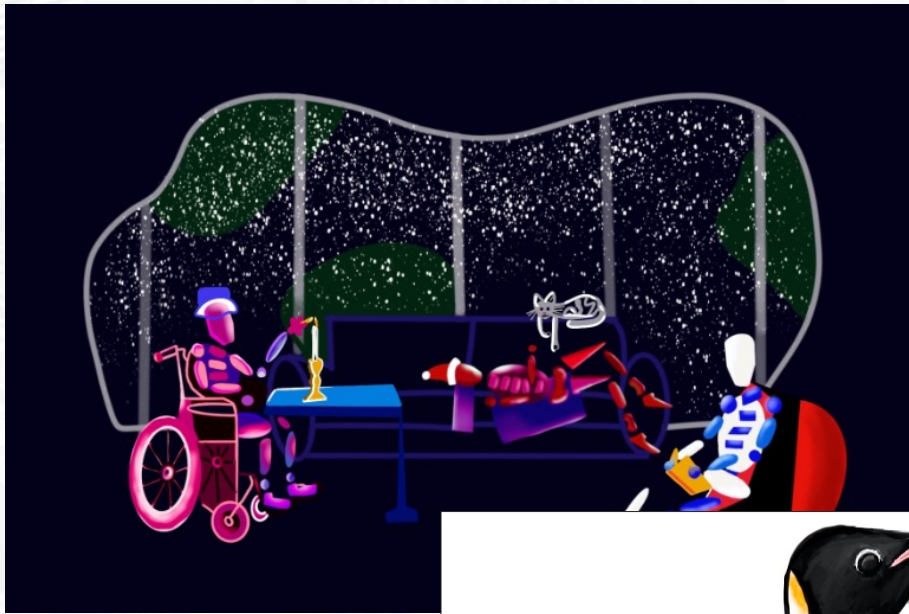
December 2022: New Year's Resolutions — Chronic Illness Edition

Resolutions are hard when you live with a chronic illness that's unpredictable. That's why in this episode, we came together as a community to create resolutions in our own chronic-illness-friendly way. We learned simple stretches from physical therapist Chad Woodard, PhD, DPT, to help build a foundation for movement, and CreakyKitchen chef Chantelle Marcial taught us a holiday dessert recipe for dairy-free panna cotta.

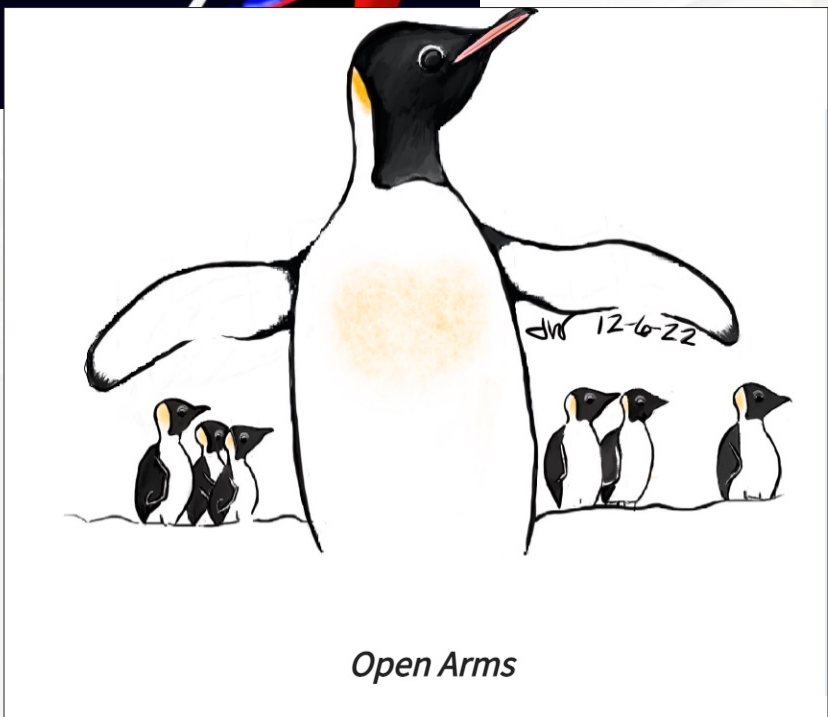


■ SEASON'S GREETINGS!

For the past three years, we've provided to our community a special and free opportunity to send a message of thanks, appreciation, or inspiration to a fellow person living with a chronic disease, a caregiver, a friend, a family member, a health care provider, or another special person who has helped them throughout the last year. This year, we had four cards created by two CreakyJoints artists, Sal Marx and Jennifer Walker, with nearly 100 people sharing their art with their loved ones. Here are examples of two of them:



*Rest Your Aching Bones by
Sal Marx*



Open Arms

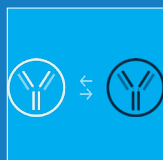
Open Arms by Jennifer Walker

GHLF PODCAST NETWORK REACHES RECORD-HIGH DOWNLOADS

Our library of podcasts at the GHLF Podcast Network continues to grow, and, this fall, we started bringing our podcasts on the road. We taped episodes of The Health Advocates live at the ACR Convergence 2022 and recorded many episodes of Talking Head Pain at the Scottsdale Headache Symposium and the European Headache Congress (see earlier section for more information).

Visit the GHLF Podcast Network at ghlf.org/patient-education/listen to see the full list of shows, and/or download our podcasts from any streaming platform.

ONGOING SERIES



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



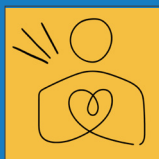
Dungeons & Diagnoses: Delve into the realm of Gaedia: a world where fantasy and reality combine! This podcast, set in the Dungeons and Dragons universe, brings those who have different lifestyles, live with different chronic conditions, and are differently abled to the forefront.



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



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



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



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



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



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



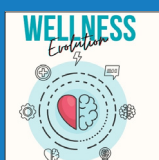
Patiently Connecting: This series reviews how medicine is evolving in light of technology changes.



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



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



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

RESEARCH PUSHES OUR UNDERSTANDING OF CHRONIC DISEASE FORWARD

ArthritisPower Wins New Research Grant

At the end of the year, GHLF was awarded a Eugene Washington Engagement Award: Dissemination Initiative under the Building [Capacity for Dissemination funding track](#) titled [Building the Capacity of Patient Advocacy Organizations to Disseminate PCOR to Patient Communities](#) (EADI 26826). This two-year project, which started January 2, 2023, aims to build the capacity and infrastructure of patient advocacy organizations specifically to disseminate evidence-based information on patient-centered research through the development of a resource called the playbook.

Patient advocacy organizations are uniquely situated to disseminate evidence-based health information because of their strong connection with health care stakeholder groups, notably patient populations. The translation gap between research publication and uptake of recommended new health information by patient populations occurs in part due to ineffective dissemination. Moreover, resources for dissemination fail to offer a step-by-step guide that patient advocacy organizations can follow to optimally disseminate research findings to their patient communities using social media and novel technologies. Through this project, we will design and develop an instruction guide that contains real-life examples of dissemination planning, implementation, and feedback to suit the unique requirements of patient advocacy organizations as they apply promising or successful practices in their own dissemination activities. Advisers on this project include patients, clinicians, and allied health experts.

Current ArthritisPower statistics as of December 31, 2022:

- Total patients: **40,370**
- % increase in membership from June 30, 2021: **14%**
- Top Conditions:

Osteoarthritis:	20,750 (51%)
Rheumatoid Arthritis:	18,096 (45%)
Fibromyalgia:	13,651 (34%)
Psoriasis/Psoriatic Arthritis:	7,567 (19%)
Osteoporosis:	5,669 (14%)
IBD:	4,883 (12%)
Lupus:	2,184 (5%)

If you or someone you know would like to participate in an arthritis research study, please sign up at ArthritisPower.org. 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 Angela Degrassi, Research Manager for Patient-Centered Research, at adegrassi@ghlf.org. Individuals interested in proposing new research with ArthritisPower should contact Dr. Ben Nowell, Principal Investigator and Director of Patient-Centered Research, at bnowell@ghlf.org. ArthritisPower is overseen by Advarra IRB.

■ ARTHRITISPOWER RESEARCH REGISTRY: OVERVIEW OF STUDIES IN PROGRESS

Stronger Together PsA Wellness Study:

As patients diagnosed with psoriatic arthritis (PsA) confront decisions about treatment and disease management, they may also seek to change or improve lifestyle behaviors that may improve their treatment outcomes. The goal of the study is to learn about PsA patients' motivations to participate in wellness programs and interest in programs delivered online with e-coaching support. With sponsorship support from Janssen and in partnership with rheumatologists M. Elaine Husni, MD, and Leonard Calabrese, DO, from Cleveland Clinic, a brief survey was designed to examine PsA patients' perspectives on wellness and wellness programs. Participants who complete the survey may consider participating in a multiweek Cleveland Clinic wellness program with e-coaching. More than 300 participants have completed the survey to date. Study recruitment is ongoing in 2023.

Rheumatoid Arthritis (RA)

Treatment Common Infections Study:

Immunosuppression is the mainstay of RA treatment but increases risk of infection. Leveraging the ArthritisPower infrastructure, this study will prospectively assess nonhospitalized infections and their impact on patients to better understand how the medications that people take for RA, such as glucocorticoids, methotrexate, and tumor necrosis factor inhibitors, affect patients' risk of common colds and other infections. Participants recruited

through Illumination Health community rheumatology practices and ArthritisPower in this longitudinal study will fill out six monthly surveys in the ArthritisPower app to report on the medications they are taking, their symptoms and RA disease activity, and any colds or other infections they experience. Recruitment is ongoing and will end when approximately 400 participants are enrolled. The Principal Investigator for this study is Michael George, MD, of the University of Pennsylvania Perelman School of Medicine; the project is funded by a National Institute of Arthritis and Musculoskeletal and Skin Diseases/National Institutes of Health award.

Telehealth-delivered Healthcare to Improve Care (THRIVE):

Funded by a two-year, \$400,000 grant from the American College of Rheumatology's Rheumatology Research Foundation, THRIVE seeks to evaluate the quality of telehealth services when provided to a rheumatology patient in their home and deliver recommendations for physicians about best practices regarding what telehealth-related care delivery should include, how to deliver it, and how to standardize high-quality care. The first aim of the study is to produce a peer-reviewed white paper that describes those best practices. The second aim is to facilitate RA patients performing a joint self-assessment and to compare its accuracy with an in-person clinician joint exam (the gold standard) performed within the following

few days. The GHLF research team has built a patient joint self-assessment and instructional tool into the ArthritisPower app for this study and so that it can be a regular feature for other studies going forward. The team utilized a patient-centered design process from concept to implementation, resulting in a novel tool that both instructs the patient and captures the joint count information. Patient recruitment for this study began in late 2022 and is ongoing. THRIVE coinvestigators highlighted elements of this important project during a Business of Rheumatology panel at the [ACR Convergence 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 ([DIGITAL](#)), we are conducting a study of people living with rheumatoid arthritis from over 30 clinical sites across the U.S. to evaluate associations between biometric sensor data, physician-derived data, and electronic patient-reported outcomes (ePROs) over time. In addition to this primary aim, we will explore the accuracy and predictive validity of biometric sensor data, physician-derived data, and ePROs to observe changes in disease activity and symptoms while tracking improvements in patients involved in the study. This study is sponsored by the Health Economics and Outcomes Research (HEOR)

group at AbbVie US. RA patients on upadacitinib and adalimumab were recruited from participating rheumatology clinics across the U.S. Recruitment is now closed, but follow-up data will be collected through April 2023 with plans to present initial findings at the ACR Convergence 2023.

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. The protocol for the study was recently published in the journal [Pilot and Feasibility Studies](#), and the study is ongoing.

Remote Therapeutic Monitoring for Clinical Use of ArthritisPower

Infrastructure: In a number of rheumatology clinics across the U.S., we are piloting ArthritisPower patient symptom and medication tracking infrastructure for clinical use, specifically for remote therapeutic monitoring (RTM). To date, we have created pathways to monitor

inflammatory arthritis patients for disease worsening/RA flares and for response to treatment following a new medication start. Data gathered via app workflows based on these RTM pathways will be made available for clinical use directly to patients and their physicians. Patients treated by community rheumatology providers who are members of the Excellence NEtwork in RheumatoloGY (ENERGY), [a practice-based research network](#) started in 2022 by Illumination Health, are being invited to participate in an ongoing pilot for RTM. This work is partially sponsored by Amgen Digital Health & Innovation and by GHLF.

Delivering Patient and Provider-Focused Improvements in the Management of Osteoporosis in the Era of Telehealth:

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

U.S. ADVOCACY ACTIVITIES AMPLIFY THE CHRONIC DISEASE PATIENT VOICE

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.

National Media Trust GHLF as an Expert Source: During the fourth quarter, our leadership provided commentary on health policy in the news:

- Seth Ginsberg, President and Cofounder, spoke with [ABC News](#) about this fall's Pennsylvania Senate race between John Fetterman (D) and Dr. Mehmet Oz (R) and how it highlighted ableism in politics. He said, "We hear daily from people with chronic diseases that they've experienced social prejudice and diminished opportunities based on people's assumptions about how or what they can or cannot do with their conditions . . . Roughly a third of [Global Healthy Living Foundation] staff has a chronic disease that might otherwise prevent them from holding a job. And, frankly, these people absolutely excel at their jobs."



- Robert Popovian, PharmD, MS, Chief Science Policy Officer, spoke with USA Today for two articles. The [first](#) explained how patient assistance programs work, and the second discussed whether patient assistance programs contribute to rising drug costs. His comments supported the idea that patient assistance programs can be hard to identify without some detective work, but that the "need for drug copay assistance among the insured has grown as health plans have shifted more and more of the cost burden onto patients via high-deductible health plans."



- Zoe Rothblatt, Associate Director, Community Outreach, spoke with [USA Today](#) about how the U.S. Supreme Court's Dobbs decision on abortion access affected patients, particularly women, seeking methotrexate for the treatment of chronic disease. She says, "After the overturning of Roe, we started getting emails, tweets, calls from patients saying, number one, 'I'm hearing about this; is this going to happen to me? I'm really, really concerned.'" She said the second-most-common thing the organization heard was patients having to give extra verification for their diagnosis. "So they would show up to their pharmacy and the pharmacist would say, 'We can't prescribe this, we can't dispense this drug to you, because it can be used for an abortion.'"



■ PUBLICLY REPRESENTING GHLF TO ADVANCE HEALTH POLICY

- During the fourth quarter, Robert Popovian, PharmD, MS, Chief Science Officer, had several opportunities to advocate for fairer drug pricing at the Association of Value-Based Cancer Care (October), Health Management Academy (October), Rutgers University School of Pharmacy Lecture (November), Houston Business Coalition on Health Conference at Rice University – Navigating the Value (December), Richmond Coalition for Healthcare Equity – 340B (December), and NW Rare Disease Coalition: Community Briefing – Drug Pricing and Spending (December). He advocated for broader vaccination access via pharmacists at the Association of University Centers on Disabilities (November) and the Ohio Chamber of Commerce (November). Dr. Popovian and writing partners Wayne Winegarden and Peter Pitts also published [“What Is the Value of the Interchangeability Designation for a Biosimilar?”](#) via the Center for Biosimilars (November).
- Steve Newmark, JD, MPA, Chief Legal Officer and Director of Policy, contributed to the December 2022 [Healio Rheumatology cover story](#) (print and online) about the future of biosimilars. The article says, “In a perfect world, multiple new drugs would lead to competition that would lower the burden of copays, deductibles and premiums for patients. However, Newmark fears that pharmaceutical companies, insurance carriers and pharmacy benefit managers (PBMs) are more likely than patients to benefit from the expanded number of treatment options.”



Robert Popovian, PharmD, MS, Chief Science Officer



Steve Newmark, Chief Legal Officer and Director of Policy

■ FEDERAL COMMENTS IN THE FOURTH QUARTER INCLUDE

- 10/11/22 – [Comments to Palmetto GBA regarding coverage for biomarker testing](#)
- 10/3/22 – [Comments to HHS regarding copay assistance and ACA Section 1557 \(HIV+HEP Policy Institute sign-on\)](#)

GHLEF ADVOCATES FOR PATIENT-CENTERED BILLS

Our staff represents the chronic disease community by submitting comments on legislation under consideration and attending meetings at the state and federal level to influence the development of patient-centered health policy. Below is a comprehensive list of activities during the fourth quarter of 2022. An annual report for 2022 is forthcoming.

October

This month we participated in the All Copays Count Coalition Hill Day, which brought together 80 national nonprofit, nonpartisan patient advocacy and provider organizations representing millions of people living with chronic illness. During the virtual meetings, we raised awareness of copay accumulator policies in insurance plans and explained how they hurt patients. We asked senators to champion the HELP Copays Act ([HR5801](#)) by introducing a companion bill.

We met with:

- Senator Marsha Blackburn (R-TN)
- Senator Mike Braun (R-IN)
- Senator Bob Casey (D-PA)
- Senator Tammy Duckworth (D-IL)
- Senator John Hickenlooper (D-CO)
- Senator Mark Kelly (D-AZ)
- Senator Patty Murray (D-WA)
- Senator Tim Scott (R-SC)
- Senator Kyrsten Sinema (I-AZ)



“GHLEF’s Patient Advocate and Community Outreach Manager, JP Summers, says, “As someone who experienced issues due to a copay accumulator adjuster program during the early stages of my chronic illness diagnosis, and then again a few months later when my son became chronically ill, it was important to share how our household went through the financial, medical, and emotional burden of these unnecessary practices.”

Other legislation we advocated for in October included:

- Texas pharmacy benefit reform and copay accumulator adjuster ban
- Utah copay accumulator adjuster ban ([SB139](#))
- Ohio copay accumulator adjuster ban ([HB135](#))
- Massachusetts step therapy ([H4929](#))
- Massachusetts copay accumulator adjuster ban ([S644](#))

The remainder of the quarter was a bit quieter from a direct advocacy perspective. During November and the election season, all state legislatures were closed, and December sessions focused on budgeting in the state houses that were open.

2022 LEGISLATIVE RECAP

It was gratifying to see legislation pass that we advocate for with our 50-State Network. These laws protect patients from [copay accumulator adjusters](#), [non-medical switching](#), and [step therapy](#).

Copay Accumulator Adjusters Laws:

- [Delaware SB267](#)
- [Maine SP621](#)
- [New York S5299A](#)
- [Washington SB5610](#)

Non-Medical Switching Laws:

- [New York S4111](#)

Step Therapy Laws:

- [California AB1880](#)
- [Massachusetts H4929](#)

The advocacy team continues to share its perspective on hot topics on [The Health Advocates](#) podcast, hosted by Steven Newmark, JD, MPA, Chief Legal Officer and Director of Policy, and Zoe Rothblatt, Associate Director, Community Outreach. In the fourth quarter, The Health Advocates produced a two-part special on non-radiographic axial spondyloarthritis (nr-axSpA). The hosts were joined by guests including rheumatologist [Dr. Jeff Stark](#), patient advocate [Ricky White](#), and policy expert Amanda Ledford. They highlighted advocacy to improve diagnosis for nr-axSpA and the challenges that remain in accessing affordable treatment.



EIGHT WARRIORS INSPIRE: CROHN'S AND COLITIS AWARENESS WEEK

During Crohn's and Colitis Awareness Week, we spoke with eight inspiring warriors who are living their best lives despite the challenges of inflammatory bowel disease. These advocates shared their daily struggles with IBD — and why advocacy and community have become crucial to their health journey. We also invited them to [share their stories](#) on social media.



CREAKYJOINTS AUSTRALIA AND GHLF AUSTRALIA LEAD ADVOCACY FOR PEOPLE WITH CHRONIC DISEASE

■ AMPLIFYING OUR PERSPECTIVE: PARACETAMOL ACCESS

Having sought feedback from the CreakyJoints Australia patient community on the proposed changes to how paracetamol (acetaminophen) is supplied in Australia, we provided our recommendations to the Therapeutic Goods Administration (TGA) following an [independent expert report](#) on the risks of self-harm from intentional paracetamol misuse. In general, GHLF Australia supports greater availability of paracetamol, but only via blister packs for general sale preparations, provided that people who need larger quantities for chronic pain can access bottles via prescription or over the counter at pharmacies.

Here is our submission to the TGA: ghlf.org.au/wp-content/uploads/2023/01/CJA-GHLFA_Submission_to_TGA_on_proposed_paracetamol_access_changes_-_Submitted_version.pdf

■ PSORIASIS PATIENT PANEL

As we continue to build our psoriasis patient resources, CreakyJoints Australia held an online focus group in December for patients living with psoriasis.

Our objectives for the session were:

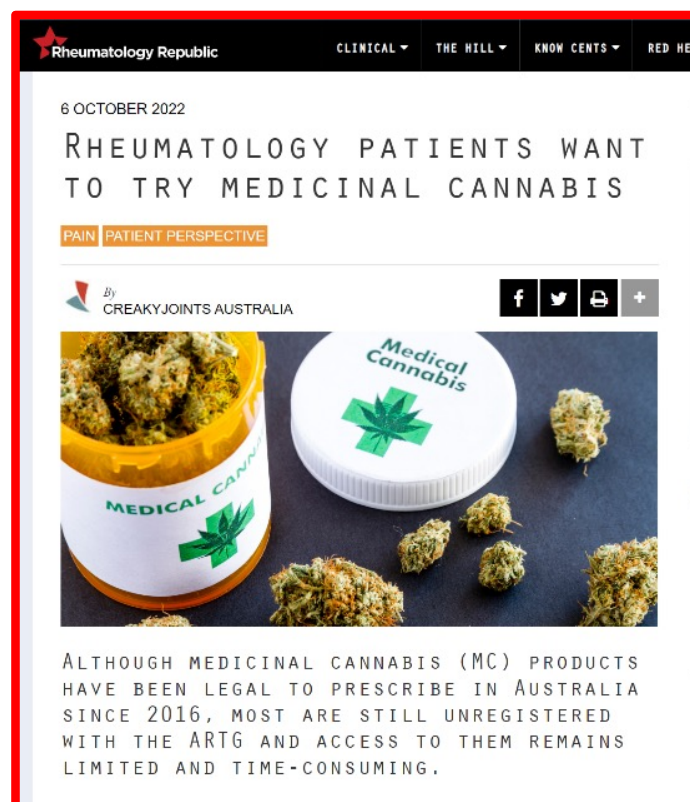
- to understand the journey for patients with psoriasis from topical treatment to first or subsequent oral medicines, and to find out when they seek new information
- to identify what information, resources, or additional support patients currently receive
- to find out what additional information, resources, or support people with psoriasis would like — whether from their doctor, a patient support program, or elsewhere
- to identify ways to reach a broader group of people with psoriasis

The information shared in the group was extremely helpful in gaining a better understanding of patient needs. We will be running a second focus group in early 2023.

RHEUMATOLOGY REPUBLIC

Our partnership with this media outlet continues with two new articles:

- [“Rheumatology Patients Want to Try Medicinal Cannabis”](#): We share some of the challenges patients with arthritis face in accessing medicinal cannabis for treating pain and some responses to our medicinal cannabis poll.
- [“Overcoming Barriers to Consumer Participation at Medical Conferences”](#): We address some of the barriers that consumers face in attending conferences. We believe it is essential for health consumers to participate in all conversations that relate to access to treatment, safety, and the quality of their care. This includes participating in medical conferences at all levels.



Additional editorial content published in the fourth quarter by CreakyJoints Australia includes:

- [Rheumatologists Share Updated COVID-19 Vaccination Advice for Rheumatology Patients](#)
- [Australians with Arthritis Can Access Tocilizumab \(Actemra\) Again](#)



GLOBAL HEALTHY LIVING FOUNDATION CANADA/LA FONDATION MONDIALE POUR VIVRE EN SANTÉ AU CANADA ACCEPTS BROAD PATIENT- CENTERED ROLE ACROSS DISEASE STATES

In the fourth quarter, GHLF Canada joined forces with the Canadian Arthritis Patient Alliance, the Canadian Spondylitis Association, and Arthritis Society Canada on a patient-input submission to Canada's Drug and Health Technology Agency (CADTH) about ankylosing spondylitis. As part of this submission, we conducted a bilingual (English and French) survey of our Canadian community members to gather testimonials. Together with our partner patient organizations, we helped ensure a positive recommendation from CADTH regarding a new treatment option for Canadian AS patients and provided patients a voice in the process.

As we look toward 2023, we will continue growing our strong collaboration with Canadian patient organizations to ensure the voices, needs, and desires of Canadian patients are heard and represented on the national stage.

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

Our content library on CreakyJoints.ca in English and French continues to grow. CreakyJoints Canada remains dedicated to providing a platform for diverse voices of Canadian patient advocates who contribute their perspectives on a whole host of pressing matters the Canadian chronic disease community faces. We share these articles regularly on our social media channels along with other nonprofit partners.

Notable articles published in the fourth quarter include:

- [Behind the Reflection: How I Look Is Not Always How I Feel](#)
- [Medication Is Important to Treat Rheumatoid Arthritis, but How Do You Afford It?](#)
- [And Then There's Mexico: Travelling with Friends When You Have Rheumatoid Arthritis](#)

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

Our Canadian Arthritis and Migraine Patient Councils finished 2022 with meetings that reflected on all we accomplished during our first full year of both councils, including full advocacy and educational campaigns for arthritis and migraine awareness months, numerous CreakyJoints articles written by various council members, and deep dives into Canadian health care structures at the federal and provincial level and how decisions affect people living with chronic conditions.



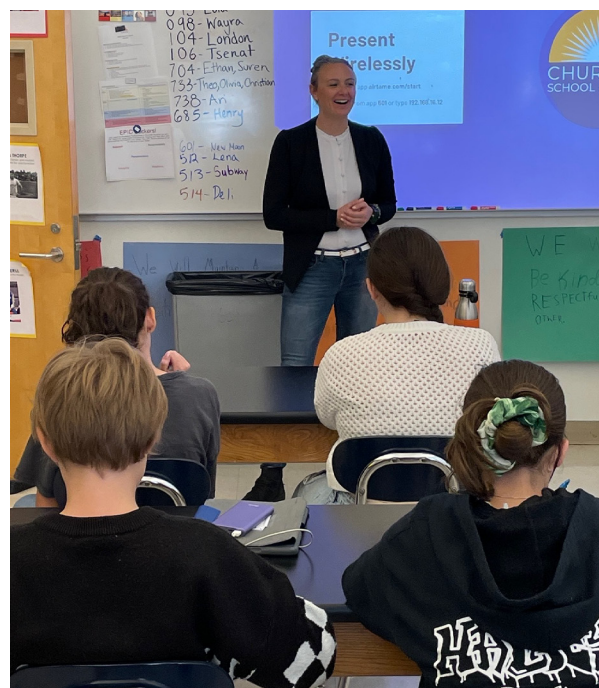
GHLF SUPPORTS CHILDHOOD AND EARLY-ADULT EDUCATION

In the fourth quarter, our GHLF-sponsored program continued its unique efforts to reach underprivileged students from diverse backgrounds in Nepal and the United States.

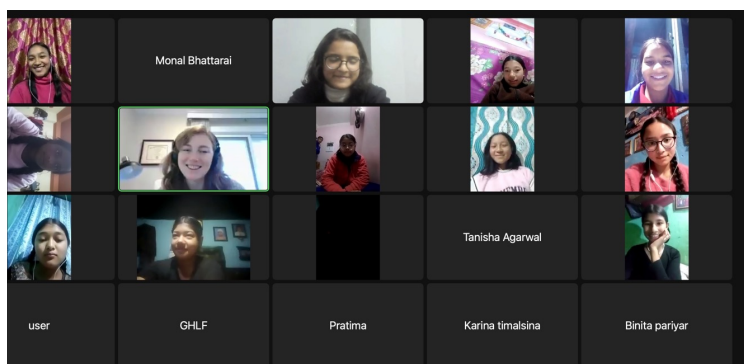
GHLF and Canopy Nepal held an educational virtual session with high school-aged students in Nepal titled “Social Media and Mental and Physical Well-Being.” We talked about how social media works, its impact on mental and physical health, and cyberbullying, and we heard testimony from students on social media’s impact on their lives.

In Nepal, our partnership facilitated educational efforts related to health and holistic well-being for hundreds of students in 14 schools across 20 sessions. Students

Angela Degrassi, GHLF Research Manager, talks about “Infectious Diseases: Contact Tracing and Disease Spread” at a joint GHLF/ISLearning session.



Photos & Logos: (Photos credit: Beyond Borders report: October 2022 – December 2022)



** GHLF and Canopy Nepal’s session “Social Media and Mental and Physical Well-Being”*

experienced growth in many areas via these sessions, including in their critical-thinking skills and self-expression as well as their writing capabilities and initiative, for an overall average 87 percent growth rate in capabilities.

GHLF also held its first in-person session with International Student Learning Inc. (ISLearning) at the Churchill School and Center in New York City. Middle school students attended an interactive session, “Infectious Diseases: Contact Tracing and Disease Spread.”

GHLF looks forward to continuing this unique, meaningful work with ISLearning and Canopy Nepal in 2023 to continue making a difference in students’ lives.



CREAKYJOINTS AND GHLF IN CONVENTIONAL NEWS AND ONLINE

In 2022, GHLF and CreakyJoints spokespeople, members, and data were featured in over 220 original placements, reaching an estimated 2.4 billion media impressions (as of December 19 and as determined by Cision and Similarweb metrics). Our spokespeople were featured in national and international media (several syndicated) in outlets such as ABC News, USA Today, HealthCentral, Everyday Health, La Opinión, Podcast Magazine, Bezzy Migraine, and nearly all of the rheumatology trade publications (repeatedly). Notably, our efforts to raise awareness of how people with uterus were affected by the Supreme Court's Dobbs decision resulted in national and international media from outlets such as the Washington Post, Los Angeles Times, MSNBC, BBC Radio, the Independent (U.K.), and CBS Atlanta, to name just a few. This spring, we also conducted a successful radio media tour in Spanish, educating listeners about the HOPE—CAPE project.

Notable in the fourth quarter, [HealthCentral](#) published 10 videos featuring GHLF migraine advocate WinnieLyn Bautista discussing how she works with her doctor to make decisions about her care. [Everyday Health](#) published actionable advice from CreakyJoints medical adviser Vinicius Domingues, MD, and both [GoodRX](#) and [WebMD](#) published feature articles about Nicole Cech, a person of color living with psoriatic arthritis. As highlighted earlier in the report, our outreach efforts also generated many opportunities to share data presented at the ACR Convergence 2022 with rheumatology trade publications.

GoodRx Health

[Health Conditions](#)
[Medications & Treatments](#)
[Healthcare](#)
[Well-being](#)

medical providers may not have as much exposure to what these problems look like on Black skin.

"I think it's just a testament to why having representation in the medical field is really important," Nicole says.



1

Having representation
in the medical field is
really important.

Nicole Cech

LONG SESSIONS COMMON WITH OUR EDUCATIONAL CONTENT

In the fourth quarter, there were nearly three 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 20 minutes, three seconds (far surpassing the industry's average of two to three minutes).
- Not only are people engaging with content on the website, but they're also opting to receive more content from CreakyJoints. This quarter, the CreakyJoints' email list grew 32 percent, reaching more than 230,000 people.

Some popular resources this quarter included:

- [Holiday Dos and Don'ts](#)
- [How to Simplify Holiday Meals When You Have Inflammatory Arthritis](#)
- [Overcoming "Med Dread"](#)
- [How COVID Changed My Life as Someone Who Is Immunocompromised](#)
- [13 Tips to Make It Easier to Dress for Colder Weather with Arthritis](#)
- [8 Inflammatory Bowel Diseases Patient Advocates Share Their Stories to Raise Awareness](#)
- [Osteoporosis and Osteoarthritis: What You Need to Know](#)



■ GHLF AND CREAKYJOINTS SOCIAL MEDIA STAYS IN TOUCH WITH THE COMMUNITY

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

- Instagram: ["My body is confused. My joints are confused. Everything is confused."](#)
- TikTok: [What are you adding to @mindful_joey's list of things to leave in 2022?](#)
- Twitter: ["Our time at #ACR22 is winding down. We are exhausted yet exhilarated from all of the new findings in #rheumatology research. We are still processing information so keep visiting #ACR22 and our page for updates for the patient community."](#)

■ #CREAKYCHATS

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

October: A Truly Creaky Chat: Celebrating World Arthritis Day, cohosted by the Canadian Arthritis Patient Alliance, Take a Pain Check Foundation, CreakyJoints Australia, and special guest Michael Kuluva, who discussed the impact arthritis has on our daily lives, including what a wish list for workplace accommodations looks like. (Metrics are not available for this chat due to the metrics site being temporarily down on that date.)

November: FlareCare: Dealing with the Triggers, to discuss how holiday triggers (changing weather, the varying of schedules, traveling, delicious food) can affect chronic diseases and set us up for a disease flare. This chat generated nearly six million impressions from 676 tweets.

December: Holiday Meet n' Greet, which invited members to get to know one another better. This chat generated over three million impressions from 413 tweets.

Join our community
#CreakyChats

A Truly Creaky Chat: Celebrating World Arthritis Day
Monday, October 10, 2022 – 7:00 pm ET

Cohosted by

- CreakyJoints Australia @CreakyJointsAus
- CreakyJoints Canada @CreakyJointsCan
- Take a Pain Check @takeapaincheck
- CAPA @CAPA_Arthritis

Special guest

Michael Kuluva
Fashion Designer and Patient Advocate
@MichaelKuluva

Join our community
#CreakyChats

FlareCare: Dealing with the Triggers
Tuesday November 29, 2022 // 7:00 PM EST

Hosted by: @CreakyJoints

GHFLF creakyjoints®

■ TWITTER SPACES

CreakyJoints Canada and GHLF participated in two Twitter Spaces events this quarter.

The first one was on October 10 with the Canadian Arthritis Patient Alliance and Take a Pain Check Foundation. The panel discussed navigating the workplace with arthritis. CreakyJoints Canada patient council member Michael Kuluva participated in the panel, and GHLF's Sarah Shaw moderated the conversation. Over 80 people attended/viewed the event.

In addition, GHLF participated in a Twitter Spaces event hosted by Project N95 on December 14. The topic was chronic illness, COVID-19, and the holidays. GHLF patient council member Tinu Abayomi-Paul was on the panel, and over 600 people attended.



Twitter Spaces

WED, OCTOBER 12 | 7PM EDT | TWITTER

NAVIGATING THE WORKPLACE WITH ARTHRITIS



Natasha Trehan
Founder and Host of
Take a Pain Check



Michael Kuluva
CreakyJoints
Canada Patient
Council Member



Annette McKinnon
Board member
Canadian Arthritis
Patient Alliance



Sarah Shaw
Moderator &
special guest,
CreakyJoints

**Featuring perspectives across the lifespan and
career stage**




with special guest



WHO WE ARE

About CreakyJoints®

CreakyJoints is an international digital community for millions of people living with arthritis and their supporters 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.

CreakyJoints' patient-reported outcomes registry, ArthritisPower ([ArthritisPower.org](#)), includes tens of thousands of consented arthritis patients who track their disease while volunteering to participate in longitudinal and observational peer-reviewed research. Always free, CreakyJoints publishes many educational articles and downloadable health education guides, and produces arthritis and chronic disease [podcast series](#) 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](#) or its parent organization, the [Global Healthy Living Foundation](#), an international, patient-centered nonprofit organization whose mission is to improve the quality of life for people with chronic illness. CreakyJoints never asks patients for donations.

About Global Healthy Living Foundation

The [Global Healthy Living Foundation](#) is a U.S.-based 501(c)(3) nonprofit, international 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 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 people living with arthritis and their supporters worldwide who seek education, support, activism, and patient-centered research in English, Spanish, and French. Our ArthritisPower ([ArthritisPower.org](#)) patient registry has more than 40,000 consented patients who participate in best-in-class patient-reported outcomes research. 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. GHLF never asks the public for donations.

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](#) (in English) or [ArthritisPower.org.es](#) (in 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 living 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

At the Global Healthy Living Foundation, the Patient-Focused Economic and Policy Research Division conducts original research on health-policy economics and outcomes research to better understand how current and proposed health policies, regulations, and legislation affect patients' financial, health care, quality-of-life, and other outcomes. We aim to increase transparency and understanding of the public-health policies, regulations, and legislation affecting chronic disease patient communities by sharing our research via publication, our website, social media platforms, and conventional media. Our researchers also address these important topics through editorials, speaking engagements, and our world-class podcast series Healthcare Matters. Our experts have published extensively on the impact of biopharmaceutical and health policies on costs and clinical outcomes in the most prominent medical sources and media publications. They are sought-after speakers, providing briefings and expert reviews for the U.S. Congress, for dozens of state legislatures, and at conferences and medical symposiums around the world. Learn more at [ghlf.org/our-work/economic-policy-research](#).



About PainSpot

PainSpot by [CreakyJoints](#) educates and empowers 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 different videoconferencing portals to try with their physician, and explains how to make the most of quick-moving appointments. To learn more, visit [eRheum.org](#) (in English) or [eRheum.org.es](#) (in Spanish).



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

