



QUARTERLY REPORT

JULY - SEPTEMBER 2022



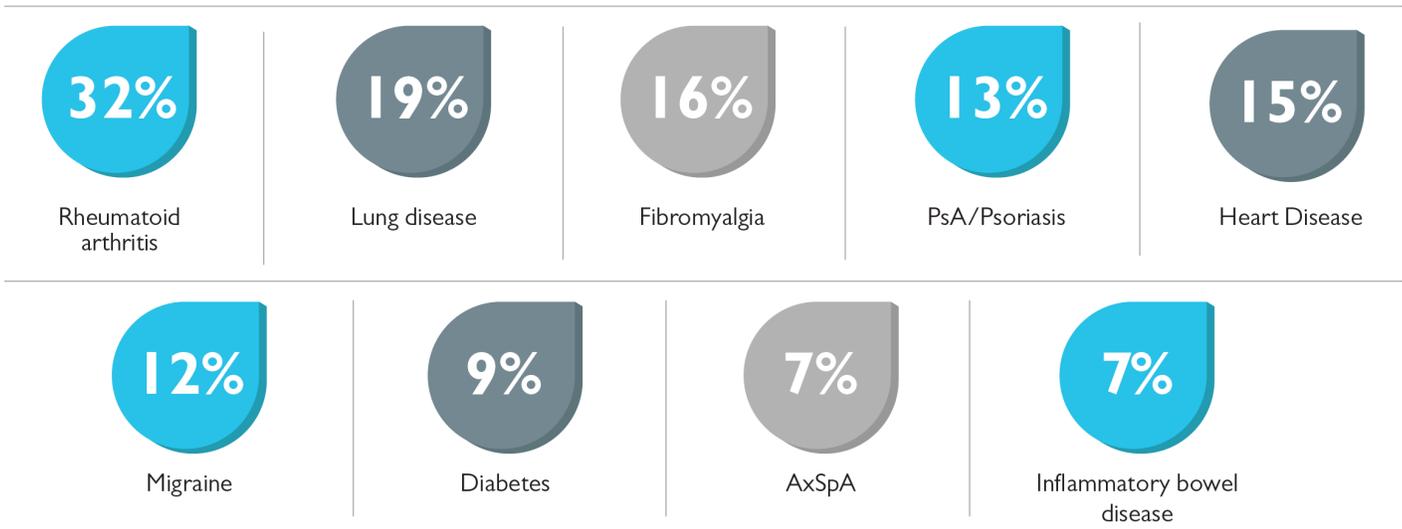
GLOBAL
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Contents

COVID-19 and Chronic Disease — Springing Back into Normal, with Caution from the Chronic Disease Community	3
Dobbs Decision Affects Chronic Disease Patients – Particularly Women and Those with Uteruses	7
Psoriasis: An Inside-Out Disease	9
GHLF Leads Conversation on Overcoming Medical Gaslighting	10
GHLF Podcast Network Reaches Record-High Downloads	11
Research Pushes Our Understanding of Chronic Disease Forward	13
U.S. Advocacy Activities Amplify the Chronic Disease Patient Voice	18
CreakyJoints Español Celebrates National Hispanic Heritage Month	22
CreakyJoints Australia and GHLF Australia Lead Advocacy for People with Chronic Disease	23
Global Healthy Living Foundation Canada/La Fondation Mondiale pour Vivre en Santé au Canada Accepts Broad Patient-Centered Role Across Disease States	26
GHLF Reaches Hundreds of Students in Nepal	29
CreakyJoints and GHLF Spokespeople Sought by National Media	30
Who We Are	33

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

This summer, we remained committed to providing comprehensive education on what COVID-19 means for people living with chronic disease to ensure that they can make educated decisions about how to spend time with family, friends, colleagues, and other members of their communities. Our COVID-19 Patient Support Program includes:

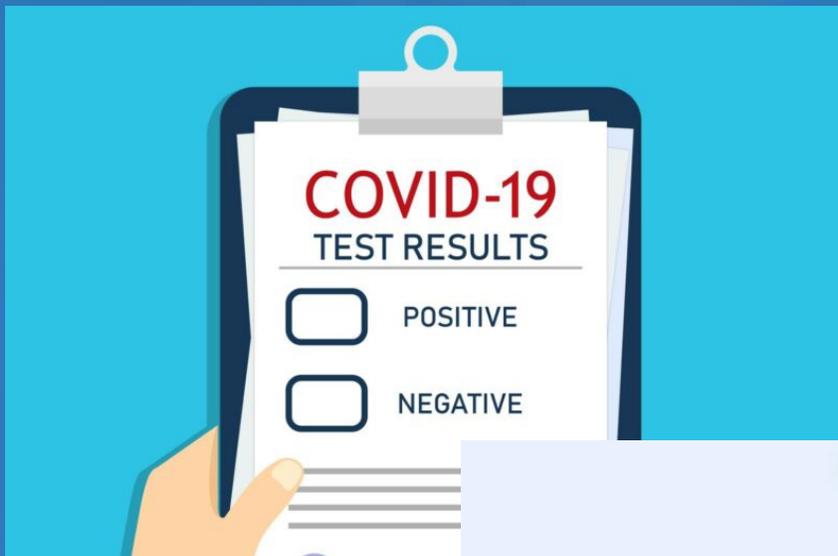


■ ROBUST CONTENT CONTINUES

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

Impactful content from the quarter included:

- [International Travel with RA During COVID: Part One](#)
- [COVID Cases Surging Again: 5 Reminders for Our Patient Community](#)
- [CDC Releases New COVID-19 Guidelines, More Lax Restrictions](#)
- [Tuberculosis Vaccine Might Offer Some Protection Against COVID](#)
- [Everything You Need to Know About the New Omicron Booster](#)

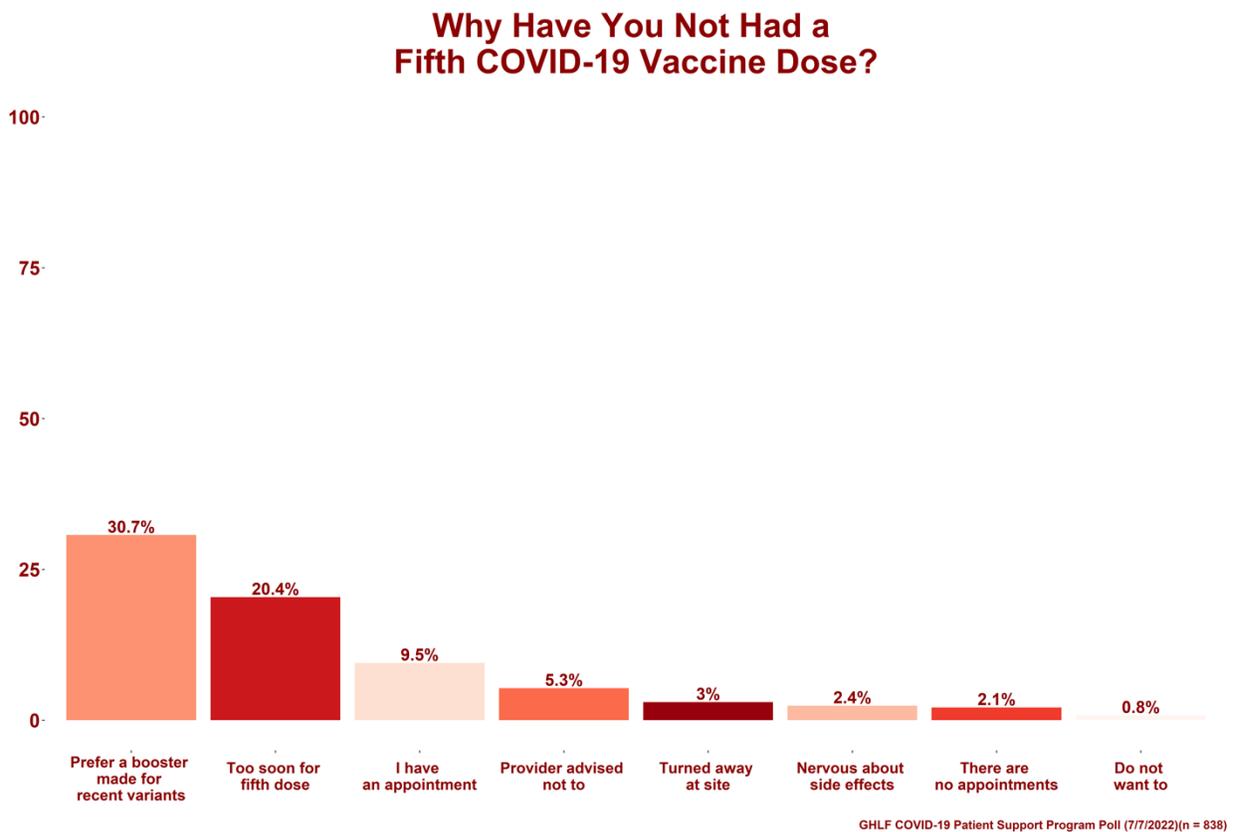


■ TAKING THE PULSE OF THE CHRONIC DISEASE COMMUNITY

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

July Poll: Have you had a fifth vaccine dose?

A total of 1,492 Patient Support Program subscribers responded to our July quick poll on the fifth COVID-19 vaccine dose. Of the 1,125 respondents who had already received a fourth dose, 25 percent had also already received a fifth dose. This survey was covered in the news by [Healio](#).



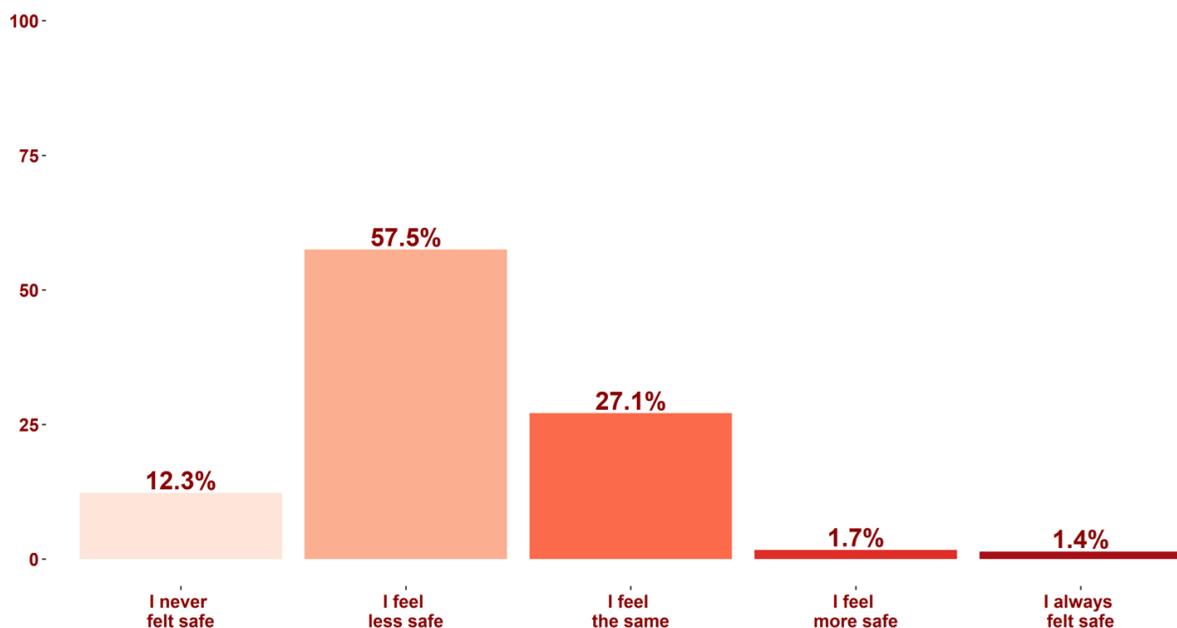
Open-ended responses also revealed that many people were unaware of the CDC’s recommendations about the fifth dose, with some saying:

- “The pharmacists had no idea of the CDC’s recommendation.”
- “Although the CDC approved the shot, no one in my area was aware.”
- “I sense few people are aware that a fifth dose has been recommended. I watch the news pretty closely, and this email is the first I’ve heard of it.”

August Poll: Thoughts on less restrictive COVID-19 guidelines

A total of 1,197 Patient Support Program subscribers responded to our August quick poll with their thoughts about the latest CDC guidelines. Ninety-five percent were already aware of the guidelines. We asked respondents how the guidelines changed how safe they felt when interacting with people outside their household. Here is how they responded:

Do the New, Less Restrictive COVID-19 Guidelines Change the Way You Feel About Your Safety When Interacting With People Outside of Your Household?



GHLF COVID-19 Patient Support Program Poll (8/18/2022)(n = 1187)

In open-ended responses, we heard:

- “A coworker announced that the new guidelines mean COVID is ‘over.’ I’m sure many people have this interpretation.”
- “Each time the guidelines are loosened, I feel more and more unsafe. The immunocompromised are once again left behind, I feel.”
- “I feel frustrated, annoyed, and forgotten. Each time these guidelines lessen, my own life becomes more restricted. It is hard to explain to those not immunocompromised — and even then, some immunocompromised people I know have given up and are facing the risks.”

DOBBS DECISION AFFECTS CHRONIC DISEASE PATIENTS – PARTICULARLY WOMEN AND THOSE WITH UTERUSES

Following the U.S. Supreme Court overturning *Roe v. Wade*, state-level trigger abortion laws have directly affected women and people with uteruses, forcing many of them to jump through extra hoops to “prove” that they need essential medicines like methotrexate or misoprostol. This disrupts and delays care, possibly leading to serious health consequences. It interferes with the patient-provider relationship while simultaneously violating patient treatment preferences.

At the Global Healthy Living Foundation, we believe that all people are entitled to make choices about their care and to access the treatments prescribed to them in consultation with their health care providers. Even though the U.S. Department of Health and Human Services issued a statement following the Dobbs decision that reminded pharmacists and other health care providers of their obligation to dispense medications as written, we’re still hearing that patients are forced to answer invasive and intrusive questions at the pharmacy to verify that they will use their medication as prescribed and not to end a pregnancy. Based on reports from members, these questions are asked only of women, regardless of age, experience with the medication, or dosage.

That’s why GHLF became the loudest voice to protest this discriminatory and dangerous new barrier to medication access. In addition to identifying and supporting patients who told their stories to national media, since early July, the advocacy team has spoken with dozens of reporters at national and international media outlets, including: [the Washington Post](#), [Reuters](#), [Time](#), [BBC Newshour](#), [the Independent \(U.K.\)](#), [the Guardian](#), [Politico](#), [Everyday Health](#), [the Los Angeles Times](#), and [ABC News](#), to name a few. Many other articles, TV reports, and radio segments were published and/or syndicated across the country and around the world. GHLF also [submitted a letter](#) to the governor of Texas protesting a law restricting methotrexate by name, but received no response.

““ We were surprised at the sheer number of complaints from people with arthritis and autoimmune conditions who were having problems filling prescriptions for methotrexate after the Dobbs decision,” said Steven Newmark, director of policy and chief legal officer for the Global Healthy Living Foundation, a nonprofit that advocates on behalf of people with chronic diseases. The group is now attempting to check those accounts, submitted through CreakyJoints, its digital forum for people with arthritis and their caregivers.”

The Washington Post

We have heard of a handful of cases of patients being completely denied [prescriptions] simply because they’re of childbearing age,” says Steven Newmark, director of policy at the Global Healthy Living Foundation, a nonprofit that supports people with chronic illnesses. Other patients have been told they “need to go back to their doctor, or the pharmacist has to check with the doctor, or the doctor is being wary and more reluctant” to prescribe drugs like methotrexate, Newmark says.

””

TIME

““ Patients are saying, ‘I’ve been on this medication for years, I’m finally feeling like myself again, I don’t want to have to switch,’” said Zoe Rothblatt, a community outreach manager at the Global Healthy Living Foundation, a patient advocacy organization. “It’s the gold standard, and we need to get the word out so people aren’t scared and they’re able to get their medication.”

Los Angeles Times

PSORIASIS: AN INSIDE-OUT DISEASE

GHLF launched a new education module and campaign titled [Psoriasis: An Inside-Out Disease](#), in August, which is Psoriasis Awareness Month, to reach the more than [7.5 million people](#) who live with psoriasis in the United States.

[Psoriasis: An Inside-Out Disease](#) educates the newly diagnosed and experienced person with psoriasis about what to expect from the disease and provides tools they can bring to the doctor’s office to ensure they get their questions answered. Importantly, the education module also walks people through the process of working with a specialty pharmacy, which is how many people access their prescribed medications in the event that treatment escalates from a topical cream to an oral medication or injectable/infused medication.

In the press release, Seth Ginsberg, President and Cofounder of GHLF, said, “We spoke with dedicated dermatologists, rheumatologists, primary care doctors, specialty pharmacists, and many psoriasis patients to develop content and tools to help guide our members during crucial parts of their psoriasis journey. With decades of experience supporting people living with chronic disease, we leaned in on why starting (and staying on) treatment matters for a person’s physical, mental, emotional, and social health — and how to make your specialty pharmacists reliable partners in your care team. We want every person with psoriasis to manage it from the inside out.”

On the [Psoriasis: An Inside-Out Disease](#) website, people can download question guides, read articles, and watch videos featuring psoriasis patients and medical experts. [Psoriasis: An Inside-Out Disease](#) was created with support from Amgen.



GHLF LEADS CONVERSATION ON OVERCOMING MEDICAL GASLIGHTING



The September cover story of *Healio Rheumatology* (print and online at healio.com/rheumatology), titled [“Paradigms of Distrust’: Medical Gaslighting Leaves Patients Dismissed and Disrespected.”](#) comprehensively discusses the phenomena of discounting patient concerns or underplaying worries and the impact on patient care. Through her work as Director of Patient-Centered Research Operations and Ethical Oversight at the Global Healthy Living Foundation, Shilpa Venkatachalam, PhD, MPH, provided valuable context to the article, noting she has extensively discussed such topics with patients. She said, “We have a lot of anecdotal conversations with patients on various topics related to their experience with diagnosis, decision-making around management, and treatment of their disease, and several have shared instances about their experiences when either their symptoms were inappropriately addressed, or they have not been believed.” She went on to explain that sometimes the “explanation” given to patients was that the symptoms were simply unexplainable. “In other cases,” she said, “we have heard that they were told that their condition or symptoms were primarily psychological, and that there was no medical diagnosis to be given.”

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

As part of the UPLIFT Innovation Challenge, we launched a program dedicated to uniting people living with psoriatic disease and their health care providers, with the goal of achieving optimal health outcomes. Our project, titled [“BIPOC Patient Voices: Living with Psoriasis and Psoriatic Arthritis.”](#)

features a three-part video series with BIPOC patient advocates who share their experience living with psoriatic disease and how it affects their daily life, including going to the doctor and engaging with their community.

BIPOC Patient Voices: Living with Psoriasis and Psoriatic Arthritis

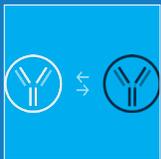
Managing a condition like psoriasis (PsO) or psoriatic arthritis (PsA) can be challenging — and perhaps even more challenging for Black, Indigenous, People of Color (BIPOC). The truth is that psoriasis and psoriatic arthritis do not discriminate — people of all races and ethnicities can experience these diseases — however everyone’s patient journey will not be the same.



GHLF PODCAST NETWORK REACHES RECORD-HIGH DOWNLOADS

Our library of podcasts at the GHLF Podcast Network continues to grow, with September seeing record-high downloads – nearly 11,000! 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.



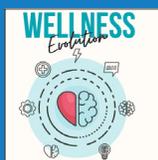
Patiently Connecting: This series reviews how medicine is evolving in light of technology changes.



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

Record Number of 21 GHLF Abstracts to Be Presented at the American College of Rheumatology Convergence 2022

During the third quarter, CreakyJoints® learned that 21 abstracts stemming from our ongoing research (detailed in previous quarterly reports) were accepted to the American College of Rheumatology (ACR) Convergence 2022 (Philadelphia, November 10–14). Of those, one is a prestigious oral presentation stemming from research by lead author Shilpa Venkatachalam, PhD, MPH, Director, Patient-Centered Research Operations and Ethical Oversight, titled “Priority Research Topics for Vaccine Uptake Among Adults with Autoimmune Conditions.”

CreakyJoints researchers and our partners at universities across the country will present 12 additional scientific posters, plus eight posters submitted by CreakyJoints patients in the Patient Perspectives track. Notably, during the ACR Convergence, GHLF’s W. Benjamin Nowell, PhD, MSW, Director, Patient-Centered Research, will be a featured presenter and panelist at the “Advancing Telemedicine in Rheumatology” session. Stay tuned for additional information in our next report.



Current ArthritisPower statistics as of September 30, 2022:

- Total patients: **39,188**
- % increase in membership from June 30, 2021: **14%**
- Top Conditions:

Osteoarthritis:	20,377 (52%)
Rheumatoid Arthritis:	17,389 (44%)
Fibromyalgia:	13,363 (34%)
Psoriasis/Psoriatic Arthritis:	7,345 (19%)
Osteoporosis:	5,570 (14%)
IBD:	4,788 (12%)
Lupus:	2,151 (6%)

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' experiences with and motivations for wellness. With sponsorship support from Janssen and in partnership with rheumatologists M. Elaine Husni, MD, and Leonard Calabrese, DO, from Cleveland Clinic, a brief survey was designed to better examine PsA patients' perspectives of wellness. Participants who complete the survey may consider participating in a multiweek Cleveland Clinic wellness program with e-coaching. Study recruitment is ongoing in 2022.

Rheumatoid Arthritis (RA)

Treatment Common Infections Study:

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

longitudinal study will fill out six monthly surveys in the ArthritisPower app to report on the medications they are taking, their symptoms and RA disease activity, and any colds or other infections they experience. Recruitment is ongoing and will end when approximately 250 participants are enrolled. The Principal Investigator for this study is Michael George, MD, of the University of Pennsylvania; it is funded by a National Institute of Arthritis and Musculoskeletal and Skin Diseases/National Institutes of Health award.

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

WEARable Activity Tracker Study Exploring Rheumatoid Arthritis Patients' Disease Activity using ArthritisPower Registry Patient Reported Outcome Measures and Biometric Sensor Data (ArthritisPower Wearable Study):

Building on our experience designing and implementing the ArthritisPower smartwatch study, we are conducting a study of people living with rheumatoid arthritis from several clinical sites across the U.S. to evaluate associations between biometric sensor data, physician-derived data, and electronic patient-reported outcomes (ePROs) over time. In addition to this primary aim, we will explore the accuracy and predictive validity of biometric sensor data, physician-derived data, and ePROs to observe changes in disease activity and symptoms while tracking improvements in patients involved in the study. This study is sponsored by the Health Economics and Outcomes Research (HEOR) group at AbbVie US. RA patients on upadacitinib were recruited from participating rheumatology clinic sites across the U.S. Recruitment is now closed, but follow-up data will be collected through April 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 New York-Presbyterian Hospital. The protocol for the study was recently published in the journal [*Pilot and Feasibility Studies*](#), and the study is ongoing.

Patient and Provider Alignment (PAPA) Initiative to Explore Dual-Target for RA Treatment Outcomes:

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

Remote Patient Monitoring for Clinical Use of ArthritisPower Infrastructure: We have taken steps to make the ArthritisPower patient symptom and medication tracking infrastructure available outside of research, specifically for clinical use in remote patient/therapeutic monitoring. To date, we have established pathways to monitor inflammatory arthritis patients for disease worsening/RA flares and for response to treatment following a new medication start. This information will be made available for clinical use directly to patients and their physicians. Patients from AARA physician practices are being invited to participate in an ongoing pilot for remote therapeutic monitoring. This work is being sponsored 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 fall. 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.

PUBLICLY REPRESENTING GHLF TO ADVANCE HEALTH POLICY



During the third quarter, **Robert Popovian, PharmD, MS, Chief Science Officer**, had several opportunities to advocate for expanded vaccination through pharmacy access at the Think Tank Roundtable (August 2022), the Employee Wellness Summit (September 2022), the Health Value Institute (September 2022), the Progressive Policy Institute webinar “Antimicrobial Resistance Policy and Economic Discussion” (September 2022), and the IBI/Conference Board Health & Productivity Forum (September 2022).

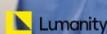
Sarah Shaw, the Senior Manager of BIPOC Community Outreach at GHLF, a migraine patient advocate, and a Lumanity Patient Council member, [provided perspective to Lumanity](#) about her experience as a patient advocate and the stigma she and others face living with chronic pain. Lumanity is a company that partners with life-science companies around the world to transform data into real-world insights and evidence that power successful commercialization and empower patients, providers, payers, and regulators to take timely and decisive action.



“

As a person living with migraine, I have observed that when somebody sees or perceives you have a disability, they expect you may be asking for special accommodations. There is a level of discrimination that takes place with respect to chronic pain. This is really important to us as an advocacy group and there is a lot we have to work on together as a society to help break these stigmas. Migraine is not 'just a headache'.

Sarah Reneé Shaw
Senior Manager of BIPOC Community Outreach
Migraine Patient Advocate
Lumanity Expert Patient Council



■ ADDITIONAL PAPERS AND LETTERS FROM THE THIRD QUARTER INCLUDE

- Robert Popovian, PharmD, MS, Chief Science Officer, and coauthors published a peer-reviewed paper highlighting how private-sector funding helps new medications through the FDA approval process. Citation: Schulthess, D., Bowen, H. P., Popovian, R. et al. [“The Relative Contributions of NIH and Private Sector Funding to the Approval of New Biopharmaceuticals.”](#) Therapeutic Innovation & Regulatory Science (2022).
- Dr. Popovian and coauthors published a white paper that first describes the federal 340B Drug Pricing Program, which entitles eligible hospitals to manufacture discounts on purchases of drugs administered or prescribed in an outpatient setting and provide them to patients regardless of their ability to pay or their insurance-coverage status, but then discusses how corruption has devalued the program for patients. The authors conclude,

“

340B has not fulfilled its promise to help low income and uninsured patients access outpatient medicines. It’s time for lawmakers to put an end to this corruption of legislative intent and enact meaningful reforms that ensure the program offers a genuine lifeline for patients who need it most.”

Citation: Pitts, P., and Popovian, R. “[340B and the Warped Rhetoric of Healthcare Compassion.](#)” Food and Drug Law Institute (September 2022).

- GHLF signed [a letter](#) in support of S.4293, the Pharmacy Benefit Manager Transparency Act of 2022, which would require greater transparency when pharmacy benefit managers (PBMs) contract with plan sponsors/employers and provide the Federal Trade Commission with greater enforcement authority to prohibit unfair or deceptive business practices by PBMs and insurers in the commercial health insurance market. GHLF also signed a letter in opposition to Senator Maria Cantwell’s (D-WA) support of the Prescription Drug Pricing Reform proposal, which could increase barriers people living with rare disease face to access potential treatments.
- Continuing to advocate for the chronic disease community as it relates to the COVID-19 pandemic, GHLF [signed a letter](#) directed at the [CEOs of social media platforms](#) urging them to completely remove the accounts of prominent anti-vaxxers and their organizing pages from their platforms and to immediately begin issuing corrective posts to counter the misinformation and disinformation in platform feeds. GHLF also sent a letter to the Senate [HELP Committee](#) providing input on the building of provisions made for the COVID-19 public health emergency that address medication access in future emergencies.

GHF ADVOCATES FOR 14 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 third quarter of 2022. At the end of the year, we'll summarize all our activities in an annual report. To review 2021, click [here](#).

Bills and causes we advocated for this quarter:

JULY

California Step Therapy (AB347)
 Massachusetts Step Therapy (HB1311)
 Massachusetts Copay Assistance/Anti-Kickback Sunset Provision (passed)
 Pennsylvania Step Therapy (SB225)
 Texas methotrexate access

AUGUST

Utah Copay Accumulator Adjuster Ban (SB139)
 Michigan Copay Accumulator Adjuster Ban (HB4353)
 Ohio Copay Accumulator Adjuster Ban (HB 135)
 Federal telehealth advocacy

SEPTEMBER

Pennsylvania Copay Accumulator Adjuster Ban (SB196/HB1664)
 Ohio Copay Accumulator Adjuster Ban (HB 135)
 Federal HELP Copays Act
 California Step Therapy (AB347)
 Utah Copay Accumulator Adjuster Ban (SB139)



ADVOCACY PODCASTS AMPLIFY PATIENT VOICES

The advocacy team is also sharing its perspective on hot topics on the Health Advocates podcast, hosted by Steven Newmark, JD, Chief Legal Officer and Director of Policy, and Zoe Rothblatt, Associate Director, Community Outreach. Plus, season three of Healthcare Matters with Dr. Popovian and Conner Mertens, Manager, Community Outreach, launched.



CREAKYJOINTS ESPAÑOL CELEBRATES NATIONAL HISPANIC HERITAGE MONTH



Celebrated September 15 through October 15, National Hispanic Heritage Month is a time to come together to recognize the shared culture of many communities and to remember the contributions of Americans with Spanish-speaking roots. GHLF called on individuals and other organizations to work together to overcome the dangers of misinformation and build a stronger community for all. □ The campaign also included educational articles and social media.

During the third quarter, CreakyJoints Español also continued the Hispanic Outreach Program Effect–Culturally Appropriate Education (HOPE–CAPE)

study, which focuses on cultural training for rheumatologists and education for people with rheumatoid arthritis who identify as Hispanic/Latinx. The project will present preliminary findings in two posters during the American College of Rheumatology 2022 Convergence meeting in November.

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

- [8 Estudios Notables del COVID-19 de la EULAR del 2022](#)
- [Alimentación Intuitiva Con Enfermedades Crónicas: Qué Es y Por Qué Funciona Para Mí](#)
- [Un Nuevo Estudio Revela que la Falta de Toma de Decisiones Compartida es la Razón Principal por la que los Pacientes con Artritis Reumatoide no Tomen sus Medicamentos](#)

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

■ FOCUS ON: PLAQUE PSORIASIS

In the third quarter, GHLF Australia and CreakyJoints Australia (CJA) focused on plaque psoriasis, educating their audience about symptoms, diagnosis, and possible treatments through a series of new articles, including a patient perspective. We also engaged our patient community living with chronic plaque psoriasis to share comments about what a new treatment option — deucravacitinib — would mean for them. We then included these comments in our submission to the Pharmaceutical Benefits Advisory Committee (PBAC).

- [Australians with Plaque Psoriasis Can Now Access Apremilast Through a GP](#)
- [My Journey with Psoriasis, Psoriatic Arthritis and Peer Support](#)
- [Help Us Get a New Treatment for Chronic Plaque Psoriasis Listed on the PBS](#)
- [Full-length GHLF Australia PBAC letter](#)



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Global Healthy Living Foundation Australia and CreakyJoints Australia

Submission to support the listing of Deucravacitinib (Sotyktu®) on the PBS for
the treatment of severe chronic plaque psoriasis

For consideration at the November 2022 PBAC Meeting

These comments are submitted by [CreakyJoints Australia](#) and [Global Healthy Living Foundation Australia](#) (GHLF Australia) on behalf of our patient community. We appreciate the opportunity to provide this submission.

Our community members are mostly people with chronic health conditions, including patients suffering from chronic plaque psoriasis. Our comments include insights from an organisational perspective as well as detailed responses from Uli Eichhorn (a patient living with chronic plaque psoriasis) which encapsulates the lived experience of patients living with this condition.

■ THE TRUTH ABOUT MEDICINAL CANNABIS ACCESS IN AUSTRALIA

Medicinal cannabis has been legal in Australia since 2016. However, access is still limited and more data is needed to determine its benefits for many conditions. That's why we [surveyed](#) our Australian members to understand their experience with medical cannabis, sharing the results in an [educational article](#) as well as with *Rheumatology Republic* magazine.

What CreakyJoints Australia Members Said:

“ I had a prescription for medicinal cannabis. It initially worked well and improved my joints, pain, and function by about 80 percent. It also cleared my irritable bowel syndrome, but the efficacy waned after some time.”

“ THC medicinal cannabis was prescribed by my rheumatologist. It has proved as effective as tramadol for pain relief at night, and I also feel more comfortable using it at other times, meaning that my pain is now better managed during the day. I have not experienced any side effects, so the only real downside is the current high cost.”

“ I have wanted to try CBD oil for my fibromyalgia associated with rheumatoid arthritis, but when I asked my GP to fill out the form for a cannabis GP clinic, she said she couldn't do it without my rheumatologist's approval (which was fair enough). My rheumatologist wanted me to go to a pain clinic instead, so I am stuck. I have heard great things about it, but I can't access it.”

■ ACTIONABLE ADVICE: LIVING WELL WITH ARTHRITIS

Notable new articles that include advice from leading physicians and professional bodies like the Australian Rheumatology Association continue to educate our members.

- [Rheumatologists Share Updated COVID-19 Vaccination Advice for Rheumatology Patients](#)
- [5 Things We Still Don't Know About COVID-19 in the Immunocompromised](#)
- [By Learning to Accept When My Body Says No, I Am Able to Say Yes](#)

We also published the fourth episode in the [Patient PrepRheum](#) podcast series, hosted by Naomi Creek, CJA's National Coordinator, who has lived with rheumatoid arthritis for nearly 40 years. Titled "[Methotrexate: Management, Myths and Milestones](#)," the episode discusses methotrexate and clarifies how it is used in rheumatology settings. Creek speaks with Janine Fisher, a patient who has lived with rheumatoid arthritis for 31 years. Fisher shares her journey with methotrexate, starting with her initial concerns about taking it. Rheumatologist Dr Irwin Lim explains why methotrexate is widely used as a frontline treatment for many forms of autoimmune arthritis.

■ GHLF AUSTRALIA WEIGHS IN ON NATIONAL MEDICINES POLICY

Published in 2000, Australia's National Medicines Policy (NMP) aims to deliver positive health outcomes for all Australians through their access to and appropriate use of medicines. In 2021, the Federal Department of Health (DoH) called for feedback on how this policy should be updated. GHLF Australia [submitted our comments](#) on the original policy in late 2021.

In February 2022, the DoH published a consultation draft of the 2022 National Medicines Policy; however, they allowed only a short window for feedback on this draft, wanting to finalize the policy before the federal election in May. There was strong and vocal feedback from an alliance of consumer organizations (including GHLF) calling for the department to spend more time reviewing and incorporating all the original submissions into an updated version of the 2022 policy and to delay the finalization of the policy until after the election. This call was successful, and the DoH released a [revised and more fit-for-purpose consultation draft](#) in August 2022. GHLF Australia [submitted feedback for the NMP review](#) on behalf of our community in September 2022.

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

GHLF Canada continued to be active in myriad spaces to grow its voice in Canada in support of patients and positive outcomes for them.

■ ADVOCATING FOR CANADIAN PATIENTS

GHLF Canada deepened its engagement in patient input submission processes to Canada's Drug and Health Technology Agency (CADTH) by contributing to a lupus nephritis-related submission in collaboration with Arthritis Society Canada (ASC), the Canadian Arthritis Patient Alliance (CAPA), the Canadian Skin Patient Alliance (CSPA), and Lupus Ontario. This patient input submission helped ensure patients have a mechanism to advocate for access to new medication and treatment pathways to better manage their disease across Canada, including patient testimonials in the text. In the fourth quarter, we will continue these efforts by working on an ankylosing spondylitis-related patient input submission.

In the third quarter, our Canadian Migraine Patient Council met, this time to discuss advocacy and how we might best enhance our engagement at the provincial and local levels, for example. The work of our Canadian Migraine Patient Council is crucial to GHLF Canada's better understanding of the disease landscape and how best to enact change for patients in Canada.

CREAKYJOINTS CELEBRATES CANADIAN ARTHRITIS AWARENESS MONTH

During September’s Canadian Arthritis Awareness Month, members of the Global Healthy Living Foundation’s Canadian Arthritis Patient Council weighed in on what they wish others knew about this chronic illness. In [a comprehensive article](#), members reflected on what it is really like to live with this chronic condition and why speaking up is so important for spreading awareness, stopping stigma, and gaining support. We also shared the article on our social media channels.

GHLF Retweeted

 **J.G. Chayko**
@jgchayko

A little bit about my #advocacy journey with #RA with the wonderful folks at CreakyJoints Canada, alongside other patient advocates sharing their stories.
[@CreakyJoints @GHLForg](#)

I've found that there are many gaps in our health care system and that there are large groups of people who aren't getting the care and treatment they need and deserve for many reasons, including poverty, stigmatization, etc, and I wanted to raise awareness of that, work towards a solution and be a voice for someone that didn't have the means to use theirs.

THERESE LANE
GHLF Canadian Arthritis Patient Council Member



creakyjoints.ca
10 Ways I'm Shining a Light on Arthritis Awareness Month and How You Can Too
Learn more about why arthritis advocate Eileen Davidson says it's important for patients to take part in Arthritis Awareness Month in Canada.

“

I've found that there are many gaps in our health care system and that there are large groups of people who aren't getting the care and treatment they need and deserve for many reasons, including poverty, stigmatization, etc, and I wanted to raise awareness of that, work towards a solution and be a voice for someone that didn't have the means to use theirs.

THERESE LANE
GHLF Canadian Arthritis Patient Council Member




Meet Therese Lane

“

People living with arthritis can experience severe fatigue and chronic pain. They need your empathy and support as much as someone living with cancer. If you know someone living with arthritis, don't dismiss it or provide unsolicited advice. Listen and offer genuine help, for example, "I can watch your kid for two hours while you rest." It takes a village to survive and thrive with arthritis.

CRISTINA MONTOYA
GHLF Canadian Arthritis Patient Council Member




Meet Cristina Montoya

“

Arthritis is a serious disease that is the number one cause of long-term disability in Canada. Advocacy is important to me because arthritis has a devastating impact on the Canadian population; however, with advocacy, there is a way to reduce that burden. Advocacy promotes quicker diagnosis, better effective treatments, understanding and support from others, and life changing research.

EILEEN DAVIDSON
GHLF Canadian Arthritis Patient Council Member




Meet Eileen Davidson

We continue adding to our content library at CreakyJoints.ca in English and French to expand our digital resources for people living with all forms of arthritis across Canada. We also provide a platform for diverse voices of Canadian patient advocates.

Notable new articles published in the third quarter include:

- [Returning to Play Has Kept Me Moving with Rheumatoid Arthritis](#)
- [How to Handle the Waiting Period to See a Rheumatologist If You Think You Have Rheumatoid Arthritis](#)
- [How the Vancouver Weather Eases — and Amplifies — My Rheumatoid Arthritis Symptoms](#)

CreakyJoints Canada also participated in an August #CreakyChats during Psoriasis Awareness Month. Over three million impressions were generated from the discussion.



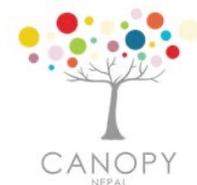
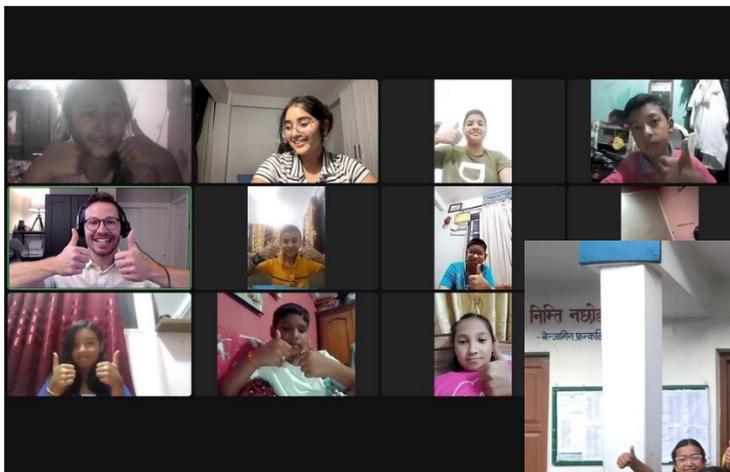
GHLF REACHES HUNDREDS OF STUDENTS IN NEPAL

GHLF and Canopy Nepal held its first in a series of lively educational discussions with young students in Nepal this quarter on the topic of general hygiene for young people. We discussed with students the importance of washing hands, soap and alternatives to hand and body soap, brushing teeth, household hygiene such as taking off one's shoes in a house, the cultural differences related to hygiene between the United States and Nepal, and much more.

GHLF will continue to work with International Student Learning Inc. (ISLearning) and Canopy Nepal to hold virtual educational sessions for students on fitness and physical health, infectious

diseases, living with rheumatoid arthritis, and more, with sessions scheduled in November 2022. GHLF will lead a virtual session for Nepalese high school students on social media and bullying and an in-person session on infectious diseases for middle school students at the Churchill School and Center in New York City.

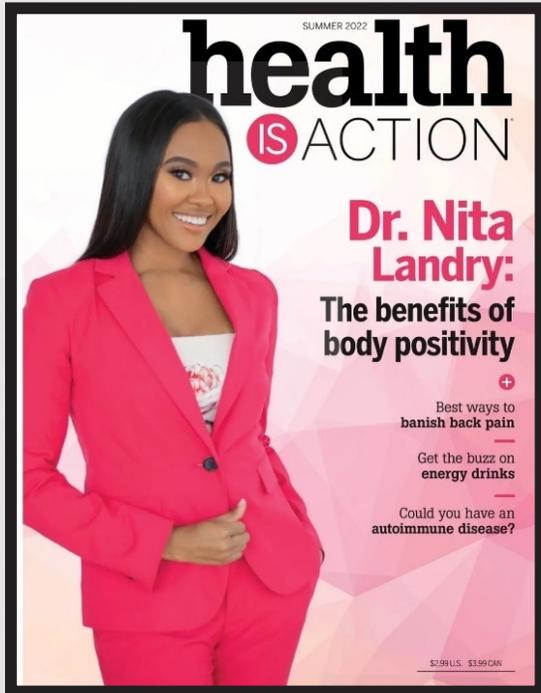
In the third quarter, our GHLF-sponsored program reached hundreds more students in over 13 schools and colleges across 12 sessions. Students experienced growth in leadership and self-expression, with local organizers reporting an overall average 85 percent growth rate in capabilities.



Photos & Logos: (Photos credit: Beyond Borders report: July 2022 – September 2022)

**GHLF and Canopy Nepal's General Hygiene for Young People session*

CREAKY JOINTS AND GHLF SPOKESPEOPLE SOUGHT BY NATIONAL MEDIA



During the third quarter, there were 47 original placements, many of which reported on how women living with chronic disease were affected by the Supreme Court’s Dobbs decision regarding accessing medications. As detailed earlier in this report, U.S. and U.K. coverage syndicated nationally and internationally, resulting in hundreds of placements featuring GHLF spokespeople or members, and an estimated 900 million media impressions.

In addition, this quarter Daniel Hernandez, MD, Director of Medical Affairs and Hispanic Outreach, and Dr. Michael Schweitz, a volunteer rheumatologist with the John Whelton Arthur Virshup CreakyJoints South Florida Arthritis Clinic, were featured in the print magazine Health Is Action. Received by more than 100 hospitals across the country, the article discussed possible signs of autoimmune illness.

GHLF research continued to be featured by trade publications. For example, GHLF’s Dr. Popovian spoke to Heallo Rheumatology about formulary exclusions, and Tufts University’s Dr. Shanthini Kasturi shared her ArthritisPower research on lupus with DocWire News.

■ 20 MINUTES ON CREAKYJOINTS WEBSITE VS. 2-3 MINUTE INDUSTRY AVERAGE; EMAIL LIST GROWS TO 175,000

In the third 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 33 percent, reaching more than 175,000 people.

Some of our most popular resources this quarter included:

- [Dear Diary: It's Infusion Day](#)
- [On a Scale of One to 10: Trying to Measure the Unmeasurable](#)
- [12 Tips for Beating Afternoon Fatigue](#)
- [Fibromyalgia Tender Points: What and Where Are They?](#)
- [How Arthritis Strikes Your Feet, and 11 Ways to Heal Your Arthritis Foot Pain](#)

■ GHLF AND CREAKYJOINTS SOCIAL MEDIA TOPS 40 MILLION IMPRESSIONS

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: [Thanks to arthritis, I'm a walking accuweather report.](#)
- TikTok: [Changing My Insulin Infusion](#)
- Twitter: [“Journalists who are motivated by clicks, at the expense of marginalized/sick people, aren't serving their readers. It's not lost on me that the critique of 'attention seeking' is the embodiment of attention seeking.” @JosephCoe #spoonie #DisabilityTwitter](#)

#CreakyChats

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

July: Accessibility Anxieties — particularly timely in light of the Supreme Court's Dobbs decision, which created new barriers for women and people with uteruses accessing certain medications, like methotrexate

August: Psoriasis: More Than Skin Deep — discussing psoriasis, psoriatic arthritis, and what the community needs to know

September: Inflamed by Irresponsible Reporting — featuring many GHLF members talking about how “clickbait” headlines diminish the chronic disease experience

Join our community

#CreakyChats

Accessibility Anxieties
Thursday, July 28th, 2022, 7:00 pm ET

Hosted by  @CreakyJoints #CreakyChats

ALT

Join our community

#CreakyChats

Psoriasis: More Than Skin Deep
Monday, August 15th 2022 7 P.M. ET

Cohosted by    

Partner 
Patron Advocate: James Lyle May @JamesLyleMay

ALT

Join our community

#CreakyChats

Inflamed by Irresponsible Reporting
Wednesday, September 28th // 7:00 pm ET

Cohosted by #SpoonieChat

Special guests      

ALT

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 decision makers on how proposed and existing policy impacts 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, DC, and across the country 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?" in the peer-reviewed journal Health Economics, Policy and Law and also published peer-reviewed commentaries on topics such as the detrimental effects of rebate walls and prior authorization on patients.



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 Eighth Circuit Court of Appeals that states have a legal right to regulate the PBM industry, and explained that the harmful effects on patients show a need for regulation.

About PainSpot

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



About eRheum

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



Find us online

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

CreakyJoints Español: www.CreakyJoints.org.es

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

CreakyJoints Australia: [CreakyJoints.org.au](https://www.CreakyJoints.org.au)

Global Healthy Living Foundation: ghlf.org

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

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

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

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

LinkedIn: linkedin.com/company/ghlf

