

The background features a stylized illustration. On the left, a person with dark skin and a yellow headband is shown in a meditative pose with eyes closed. On the right, several hands in light blue business suits are shown holding and reviewing documents. A large, semi-transparent blue rectangle is centered over the image, containing the report's title and date.

QUARTERLY REPORT

JANUARY - MARCH 2023



GLOBAL
HEALTHY
LIVING
FOUNDATION

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GHLF AND IQVIA INSTITUTE FOR HUMAN DATA SCIENCE PUBLISH IMMUNIZATION ACCESS REPORT



In January 2023, the [Global Healthy Living Foundation \(GHLF\)](#) published a [new report](#) finding an increase nationwide in people receiving vaccines at pharmacies compared with physician practices in 2020 and 2021. Data show that across all vaccines for adults (regardless of location, gender, or income), a large majority were administered at pharmacies (as compared with nonpharmacy medical settings), with most COVID-19, shingles, and flu shots administered by pharmacists. The share of pneumococcal and adult HPV vaccination at pharmacies was up as well.

This report was commissioned by the Global Healthy Living Foundation and the IQVIA Institute for Human Data Science to better understand immunization access improvements following the enactment of the Public Readiness and Emergency Preparedness Act (PREP Act) and subsequent modifications made during the COVID-19 pandemic,

which authorized pharmacists and pharmacy technicians to administer COVID-19 (age 3+), pediatric (3–18), and flu (18+) vaccines without a prescriber order. The PREP Act will lapse in 2024 in 25 states where this authority has not yet been made permanent by new state laws.

Read: [“Trends in Vaccine Administration in the United States”](#)

GHLF promoted the report with a [press release](#) and via our [podcast](#) to raise awareness of the role pharmacists play in providing vital health care services and to aid in advocating for federal and state laws that will protect patients’ access to vaccination in the health setting they most frequently encounter — the pharmacy. Previously shared Global Healthy Living Foundation [studies](#) have shown that pharmacies have more locations and greater operating hours than physician practices in low-income communities, further highlighting the critical function pharmacies play in expanding vaccination services.

■ PRESS COVERAGE



As a result of our media outreach, GHLF generated both online and video interviews about the report, with most featuring Robert Popovian, PharmD, MS, Chief Science Policy Officer at GHLF, who led this project for the organization. Notably, several media outlets included supportive statements by outside experts, adding credibility to the report. For example, Pharmacy Practice News included comments from William Schaffner, MD, a professor in the Division of Infectious Diseases at Vanderbilt University and medical director of the National Foundation for

Infectious Diseases (which [tweeted](#) about the report), and National Journal sourced Representative Brad Schneider (D-IL) and the National Association of Chain Drug Stores. Media coverage also included [Contagion Live](#), [Pharmacy Times](#) (twice), National Journal, MediaPost, [Employee Benefit News](#), [Policy & Medicine](#), [Pharmacy Practice News/Infectious Disease Special Edition](#) (online and in print), [Precisions Vaccinations](#), and [DocWire News](#).

■ COALITION SUPPORT

GHLF previewed the IQVIA/GHLF report with the American Diseases Prevention Coalition, a group working on the federal and state level to advocate for maintaining/broadening vaccination authority. With their support, Robert Popovian and Walgreen's Kevin Ban published an op-ed in The Hill titled "[Getting Vaccinated at Pharmacies Works: It Could Soon Disappear.](#)" which was picked up by several online outlets, including the [American Council on Science and Health](#) and [MSN](#). The team also secured an article in [Pluribus News](#), featuring an interview with Popovian. Their local outreach resulted in coverage in Texas in [D Magazine](#) and [The Eagle](#) as well as in Minnesota in the [Mankato Free Press](#).

As estimated by Similarweb, coverage of the IQVIA/GHLF report has generated nearly 82 million media impressions to date.

This project was supported by Pfizer.

For more information on how to partner with GHLF on similar health policy research projects, please contact Dr. Robert Popovian, PharmD, MS, Chief Science Policy Officer at rpopovian@ghlf.org

GHLF HONORS BLACK HISTORY MONTH

February's Black History Month is a time to celebrate and commemorate important Black heroes, achievements, and events throughout our history. It's also a time to reflect and raise awareness of racial and ethnic disparities across all the health care sectors. While there is always more work to be done, the Global Healthy Living Foundation is committed to continue this work through honoring, amplifying, and uplifting the experiences of those living with chronic illness in the Black community. In a dedicated space, GHLF promoted the personal stories of members of our Black community throughout the month. Notable new stories included:

- [Joshua Denton's Ulcerative Colitis Story: "I Didn't Have a Lot of Exposure to What This Condition Was"](#)
- [Christele Felix's Lupus Story: "This Is the Best I've Ever Been"](#)
- [Raven Miller's Rheumatoid Arthritis Story: "I Found My Motivation"](#)



#GHLFONTHEROAD: WE ADVOCATE ACROSS THE COUNTRY TO PROMOTE PATIENT-CENTERED HEALTH LAWS

During the first quarter, the GHLF advocacy team crisscrossed the United States to raise awareness of proposed patient-centered health bills in different state legislatures and in Washington, D.C., particularly as they relate to copay accumulator programs. Copay accumulator programs are often hidden in health insurance contracts and prevent money paid by charitable patient-assistance programs (provided by drug manufacturers) from counting toward a patient's deductible or out-of-pocket maximum. These programs shift the burden from insurance companies to patients as they are asked to keep paying toward their deductible even after their patient-assistance copay cards are exhausted of funds — the exact opposite of their intent. Referenced last quarter, [research conducted](#) by GHLF's Anne Sydor, PhD, Director, Research Development & Communications, and Robert Popovian, PharmD, MD, Chief Science Policy Officer, with support from Esteban Rivera, MS, Data Scientist, demonstrated that when states prohibit copay accumulator programs, health insurance premiums do not rise, as postulated by insurers.



■ WISCONSIN AND TEXAS

A resident of both states, JP Summers, GHLF Patient Advocate and Community Outreach Manager, twice spoke about how copay accumulator programs built into health insurance contracts negatively affected her ability to afford the migraine medication she needed to function. In Wisconsin, Summers shared her story at a press conference, part of which was picked up by the local [ABC affiliate](#). In Texas, Summers testified to lawmakers about her experience.

■ WEST COAST ROAD SHOW

West Coast Road Show: Conner Mertens, GHLF Patient Advocate and Community Outreach Manager, and Corey Greenblatt, MPH, Associate Director of Policy and Advocacy, hit the road in March, visiting Washington, Oregon, and California. Also inviting local 50-State Network members to participate, GHLF met with dozens of legislators and staffers to advocate for patient-centered health policy.

GHLF @GHLForg · Mar 15

Thank you Salem, OR! The team had many productive talks with lawmakers & aides about issues facing the Oregon patient community. We hope this session sees the passage of [#AllCopaysCount](#) legislation.

We're ready to finish [#GHLFonTheRoad](#) strong in Sacramento, California!



1 6 21 785

GHLF @GHLForg · Mar 17

Thank you for following along on this West Coast Advocacy Roadtrip. Three state capitols, three days. Dozens of productive meetings.

If you're interested in [#GHLFonTheRoad](#) or other advocacy opportunities, click the link below to join our 50-State Network: ghlf.org/become-a-50-st...



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■ DIGESTIVE DISEASE NATIONAL COALITION SPRING PUBLIC POLICY FORUM

On March 6, for the first time in three years, members of the Digestive Disease National Coalition gathered in Washington, D.C., to advocate for increased funding for research into digestive diseases and the passage of the Safe Step Act and the HELP Copays Act. Corey Greenblatt, GHLF's Associate Director of Policy and Advocacy, met with senators and representatives from Colorado, Washington State, and California.

■ WASHINGTON, D.C., BRIEFING

On March 30, GHLF, the Association of Women in Rheumatology, and the AIDS Institute hosted a congressional briefing on copay accumulator programs, the focus of the [HELP Copays Act](#). While sixteen states have passed laws to prevent copay accumulator programs, federal law is needed to ensure all patients are protected. [GHLF research](#) (highlighted in the Q4 2022 report) demonstrates that these laws do not increase health insurance premiums. Corey Greenblatt helped organize this event with our partners, and speaking at the event were:

- Stephanie Ott, MD, Cochair of Advocacy, Association of Women in Rheumatology
- Steven Newmark, JD, MPA, Director of Policy and General Counsel, Global Healthy Living Foundation
- JP Summers, Patient Advocate, Community Outreach Manager, Global Healthy Living Foundation
- Stephanie Hengst, Manager of Policy & Research, the AIDS Institute

More than 75 congressional staffers attended, and the event was covered by [InsideHealthPolicy](#).



For more information on how to partner with GHLF to support our advocacy projects, please contact Steven Newmark, JD, Chief Legal Officer at snewmark@ghlf.org

MAKING MIGRAINE MATTER: EDUCATING DIVERSE STAKEHOLDERS TO MEET THE NEEDS OF DIVERSE PEOPLE



Joseph M. Coe, MPA, Director, Therapeutic Area Growth and Integration, and host of GHLF’s migraine-focused podcast, *Talking Head Pain*, and Sarah Shaw, Senior BIPOC Patient Advocate and Community Outreach Manager, were two of the featured speakers on a February webinar hosted by the American Migraine Foundation called [“Migraine in the LGBTQ+ Community.”](#) The hosts noted that members of the LGBTQ+ community often face additional challenges when managing migraine, including stigma and barriers to accessing care. This educational event offered support to minimize some of these common obstacles.

HEADACHE ON THE HILL

In February, Sarah Shaw and Joe Coe, alongside other 50-State Network advocates, participated in the annual Headache on the Hill advocacy awareness event in Washington, D.C. Notably, this advocacy day brought together the BIPOC community to amplify how its members need access to migraine specialists and therapies.

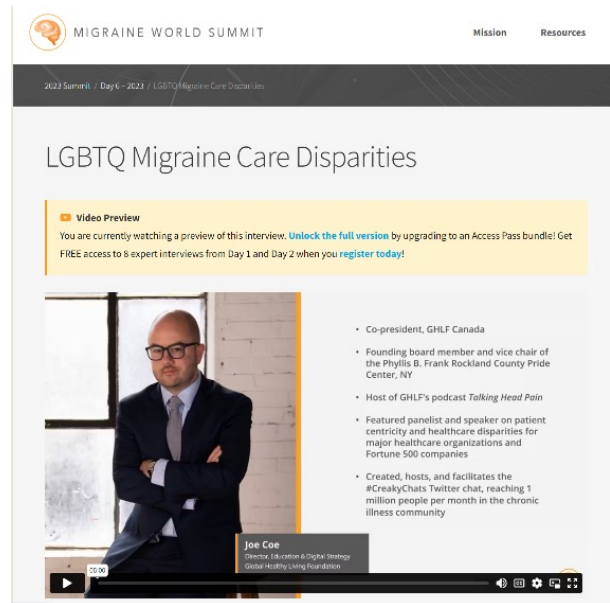
Related, this quarter the [Talking Head Pain podcast](#) featured guest Nina Riggins, MD, Director of the Headache and Traumatic Brain Injury Center at UC San Diego Health. Dr. Riggins is a neurologist and headache specialist who participated in Neurology on the Hill as well as Headache on the Hill. Plus, GHLF 50-State Network advocate Kelsey Feng shared their experience at Headache on the Hill in a [GHLF-published article](#).





During the first quarter, Sarah Shaw was interviewed by the BBC’s international radio program *The Conversation*, discussing her personal experience with migraine as a woman of color. This program was broadcast on BBC radio affiliates across the world.

In March, Joseph Coe gave a talk at the [Migraine World Summit](#) about how health care disparities are affecting the LGBTQ+ community and how stigma and discrimination are preventing people in the LGBTQ+ community with migraine from seeking routine medical care.



For more information on how to partner with GHLF to support our migraine advocacy projects, please contact Joseph Coe, MPA, Director, Therapeutic Area Growth and Integration, at jcoe@ghlf.org

COVID-19 AND CHRONIC DISEASE — TRIPLE WINTER THREAT

We all may have stayed hunkered down and inside more during the colder months, but many of us still ventured out into our community for work, errands, worship, or friendly gatherings. That means we all still needed to understand the latest recommendations for reducing risk of COVID-19. In the first quarter, our COVID-19 Patient Support Program (PSP) continued to provide actionable advice to people living with chronic disease about how to best manage their illness and participate according to their preferences. We also focused on what our community needed to understand related to the federal government announcement that the official COVID-19 public health emergency would end in May.

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 reaches nearly 41,000 subscribers with an email open rate of 28.9 percent (health-industry average = 22 percent) and an email click rate of 5.5 percent (health-industry average = 2.5 percent).

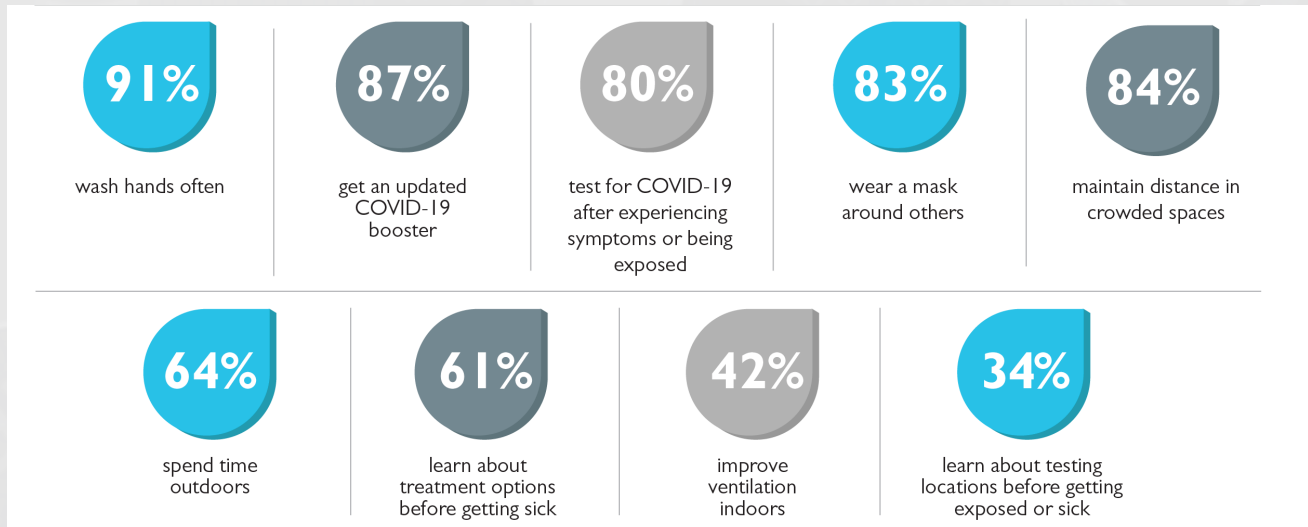
Impactful articles from the first quarter included:

- [The Risk Factors for Long COVID Are Still Ambiguous — But Here’s What You Should Know if You’re Immunocompromised](#)
- [CDC Releases COVID-19 Action Plan for People with Weakened Immune Systems](#)
- [The COVID-19 Emergency Orders Are Ending This May — Here’s What That Means And How Our Community Feels](#)
- [5 Reasons Why Your Doctor May Not Prescribe Paxlovid If You’re High-Risk — and When to Get a Second Opinion](#)



Quick Poll: How do you manage your risk for COVID-19?

The COVID-19 PSP continues to take the pulse of our community. In light of the Centers for Disease Control and Prevention recently issuing a [COVID-19 action plan](#) for people with a weakened immune system, in February, we asked (n = 1,087) about which recommended prevention measures people take:



Caption: What members of our PSP program think about the official public health emergency ending

GHLF LAUNCHES ITS FIRST ASTHMA CAMPAIGN

In February, GHLF launched its first dedicated asthma campaign to reach even more people living with serious chronic disease. Called Love Should Take Your Breath Away, Not Asthma, the campaign targeted the LGBTQ+ community because this community is disproportionately affected by the disease. Through articles and podcasts, the educational module encouraged people living with asthma to educate themselves about living well with asthma and to seek support from their partners to ensure everyone gets the care they deserve.

The Asthma Podcast

In this edition of The Asthma Podcast, we dive into the stories of LGBTQ+ asthma patients within the theme of “Love Should Take Your Breath Away, Not Asthma,” exploring how LGBTQ+ individuals navigate their identities, relationships, and asthma all at the same time.



Episode 1: Carly's Story

In this episode, we hear from Carly, Chief Research and Innovation Officer of #LupusChat, member of the National Institute of Health's COVID-19 treatment guidelines panel as well as a research lead and liaison with the COVID-19 Global Rheumatology Alliance. Carly offers her unique perspective and valuable insight as a person living with lupus and asthma.

[Listen Now](#)

[View Transcript](#)

Episode 2: Frankie's Story

In this episode, we hear from Frankie Lee, a trans asthma patient who works in tech support and enjoys streaming. Frankie talks to us about the importance of support, listening to your body, and the value of self-advocacy when it comes to getting proper asthma care.

[Listen Now](#)

[View Transcript](#)

This campaign was sponsored by Amgen and AstraZeneca.

GHLF REACHES OUT TO THE CROHN'S DISEASE COMMUNITY

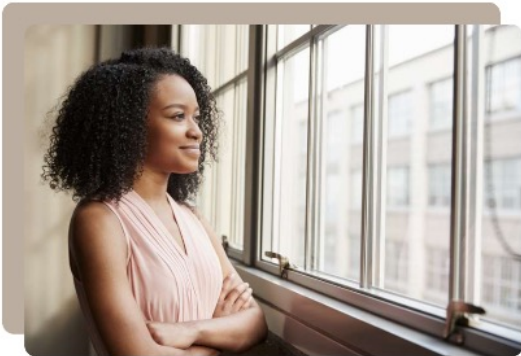
In January, GHLF launched a new educational guide all about the challenges of living with Crohn's disease and complex perianal fistula. Fistulas are common in people with Crohn's and cause painful tunnels between the intestine and other tissue, leading to pain and diarrhea. While a fistula diagnosis may be frightening, it can also provide reassurance and the opportunity to finally start understanding how to manage, treat, and live better with your symptoms. As always, GHLF is dedicated to helping people living with complex chronic disease better understand their management options, which is why the campaign platform includes educational articles and two audio guides, available at ghlf.org/fistula-support.

Working Through Crohn's and Complex Perianal Fistula Stigma

We spoke with patient advocates and a gastropsychologist about some common (and harmful) myths about living with fistulas — and what you can do to overcome them.

"I have a right to be loved and supported and so does everyone else who is struggling with Crohn's disease or fistulas." — Tina Aswani-Omprakash, patient advocate

KEEP READING



Coping with a Fistula Diagnosis

With no quick fix for treating a fistula, it's normal to feel stress and anxiety. The good news: There are steps you can take to support your emotional well-being as you care for your physical health.

"It's important that there is shared decision-making between patient and provider." — Michele Rubin, APRN

GET ADVICE

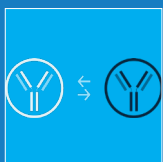
GHLF'S 18-STRONG PODCAST NETWORK OUTPACES 2022 IN JUST THE FIRST QUARTER

The audience for our GHLF Podcast Network is growing at a rapid pace, with Q1 downloads (95,000) nearly exceeding the total number of downloads in 2022 (96,000). In March alone, we reported more than 46,000 listens, a new record. We anticipate reaching our stretch goal of 250,000 listens by year-end. 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. You can now also find our podcast series on YouTube.

ONGOING SERIES



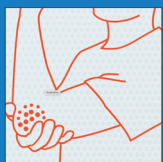
The Asthma Podcast: Listen in as patients share tips for avoiding asthma triggers, seeking out the best treatment, and getting the support you need to live a more full and productive life.



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.



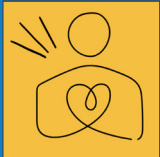
Dungeons & Diagnoses: Delve into the realm of Gaedia: a world where fantasy and reality combine! This podcast, set in the Dungeons and Dragons universe, brings those who have different lifestyles, live with different chronic conditions, and are differently abled to the forefront.



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.



Let’s Get Personal: This podcast features rheumatologists and patients living with rheumatoid arthritis who share about the physical and mental toll of starting and switching therapies and how to make your rheumatologist a trustworthy partner in this often-grueling process.



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.



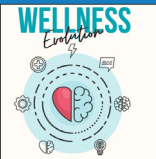
The Psoriatic Arthritis Club: Through personal chats with fellow psoriatic arthritis patients, as well as insights from top PsA experts, our host explores the ups and downs of navigating psoriatic arthritis.

The logo for 'Talking Head Pain' features the words 'TALKING HEAD PAIN' in white, stacked vertically on an orange square background.

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.

For more information on how to partner with GHLF to support our GHLF Podcast Network, please contact Ben Blanc, Manager, Programs and Special Projects, at bblanc@ghlf.org

RESEARCH PUSHES OUR UNDERSTANDING OF CHRONIC DISEASE FORWARD

Stemming from our presented research at the American College of Rheumatology Convergence 2022, Shilpa Venkatachalam, PhD, MPH, Director, Patient-Centered Research Operations and Ethical Oversight, and Shubhasree Banerjee, MD, spoke with [Rheumatology Advisor](#)'s podcast about COVID-19 vaccine hesitancy and what patients need to know about getting vaccinated.

GENERAL RHEUMATOLOGY

COVID-19 Vaccine Hesitancy: What Your Patients Want You to Know

Meghna Rao | February 8, 2023



Rheum Advisor
ON AIR

Shilpa Venkatachalam, PhD, and Shubhasree Banerjee, MD, evaluate the factors associated with COVID-19 vaccine uptake and hesitancy among patients with autoimmune rheumatic diseases, and the importance of tailored messaging and communication between patient and provider.



Latest News

Lower Fracture Rates With Gastro-Resistant Risedronate in Women With Osteoporosis

Overdiagnosis of Behçet Syndrome May Result From Broad Classification Criteria

Increased Analgesic Prescribing Observed in Patients With Knee Osteoarthritis

Current ArthritisPower statistics as of March 31, 2023:

- Total patients: **41,627**
- % increase in membership from March 31, 2022: **14%**
- Top Conditions:

Osteoarthritis:	21,077 (51%)
Rheumatoid Arthritis:	18,786 (45%)
Fibromyalgia:	13,895 (33%)
Psoriasis/Psoriatic Arthritis:	7,742 (19%)
Osteoporosis:	5,768 (14%)
IBD:	4,962 (12%)
Lupus:	2,230 (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.

For more information on how to partner with GHLF to support future research, please contact Dr. Ben Nowell, PhD, Principal Investigator and Director of Patient-Centered Research, at bnowell@ghlf.org

■ ARTHRITISPOWER RESEARCH REGISTRY: OVERVIEW OF STUDIES IN PROGRESS

NEW — Polymyalgia Rheumatica (PMR): PainSpot is a diagnosis-accelerator tool and website used by hundreds of thousands of people to better facilitate conversations with their doctors about their chronic or acute pain. The tool utilizes an algorithm to capture the user’s undiagnosed symptoms and/or pain to estimate the likelihood that the user could have an injury or chronic condition. PainSpot’s algorithm currently includes osteoarthritis; inflammatory conditions like rheumatoid arthritis, psoriatic arthritis, and ankylosing spondylitis; and various injuries. For this project, we are adding polymyalgia rheumatica (PMR), an inflammatory condition affecting people over age 50, to PainSpot’s list of potential diagnoses. In addition, we are developing resources for people living with PMR. This project is sponsored by Sanofi.

NEW — IgG4-Related Disease (IgG4-RD): To understand the needs and challenges of those living with IgG4-RD, we are conducting a social listening analysis across multiple social media platforms. The insights from these conversations will be used to program a needs-assessment survey, which will be fielded to a group of people living with IgG4-RD. Findings from this project will inform the development of new education and other resources for people living with IgG4-RD to help improve their disease journeys. This project is sponsored by Horizon Therapeutics (now part of Amgen).

Building the Capacity of Patient Advocacy Organizations to Disseminate Patient-Centered Outcomes Research to Patient Communities: Patient advocacy organizations are uniquely situated to disseminate evidence-based health information because of their strong established 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, GHLF will develop a resource, or “playbook,” which can be used as an instruction guide and 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. By doing so, we will build the capacity and infrastructure of patient advocacy organizations specifically to disseminate evidence-based information on patient-centered research.

Stronger Together PsA Wellness Study:

As patients diagnosed with psoriatic arthritis confront decisions about treatment and disease management, they may also seek to change or improve lifestyle behaviors that may improve their treatment outcomes. The goal of the study is to learn about PsA patients' 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 Cleveland Clinic's multiweek Immune Strength wellness program with e-coaching. More than 300 participants have completed the survey to date. Study recruitment is ongoing in 2023, with a limited number of spots still available for Immune Strength participation.

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 closing in Q2 2023, as approximately 400 participants are now 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 was 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 New York-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 (ENRGY), 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 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 in 2023. A study to evaluate the osteoporosis conjoint analysis tool in the context of fracture liaison services in the U.S. and Canada is in the planning stages. Both projects are supported by funding from Amgen.

STRONG BONES & ME: A GLOBAL OSTEOPOROSIS INITIATIVE FOR PATIENTS EVERYWHERE

One of our newer areas of focus at GHLF is the Strong Bones & Me program, a global osteoporosis education initiative. This program prioritizes patient-centered education, awareness, and engagement about osteoporosis with a focus on secondary fracture prevention and postfracture care. We collaborate with patients and patient organizations across various disease states, emphasizing the connections between osteoporosis and related conditions that may increase risks to bone health and for osteoporotic fractures.

Our goal is to redefine the way we all think about osteoporosis, its connection to our overall health, and the risks involved to better prioritize bone health.

In the first quarter, we began to collect evidence and share experiences from patients and patient organizations to convey their understanding of osteoporosis and fracture prevention and to better enhance their understanding of — and engagement in — postfracture care and secondary fracture prevention. We also began to work on a survey and a website to house forthcoming educational resources, which is expected to launch in the second quarter.

We also convened a global council, composed of nine patient organizations from around the world. These groups will collaborate with us on materials, identify patient stories, and help to disseminate the forthcoming survey.



For more information on how to partner with GHLF to support our international educational initiatives, please contact Adam Kegley, MA, MS, Manager, Global Partnerships, at akegley@ghlf.org

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

In addition to promoting our recently published IQVIA/GHLF report on vaccination in pharmacies (referenced earlier in this report), during the first quarter, our leadership provided commentary on health policy in the news:



Robert Popovian, PharmD, MS, Chief Science Policy Officer, spoke several times on background and on the record with [Reuters](#) to provide perspective on Humira biosimilars and whether prices would drop; he suggested that several new biosimilars need to enter to market before prices fluctuate. Dr. Popovian also spoke with [Medscape](#) for their lengthy feature on the future of biosimilars. The article reports that patients may push back if they don't save money when switching to a biosimilar, with Dr. Popovian saying, "This dilemma raises the question of who is profiting when a biosimilar is dispensed . . . As a pharmacist, I will choose the medicine that will incur the lowest out-of-pocket cost for the patient."



Louis Tharp, Executive Director and Cofounder, and Dr. Popovian published an op-ed in [Healthcare Business Today](#), which was then excerpted by the American Council on Science and Health, titled "[It Is Time for Policymakers To Protect Patients from Predatory Practices of Insurers and PBMs.](#)" They conclude by saying, "It is about time for state and federal legislators to support such legislations to ensure that ONLY patients benefit from such patient assistance programs and to stop PBMs and insurers from profiteering on the backs of patients."



Steven Newmark, JD, MPA, Chief Legal Officer and Director of Policy, provided perspective to [WebMD](#) regarding what to expect after the federal government ends the COVID-19 emergency order. He said, “People who are immunocompromised by their chronic illness or the medicines they take to treat acute or chronic conditions remain at higher risk for COVID-19 and its serious complications. The administration needs to support continued development of effective treatments and updated vaccines to protect the individual and public health. We’re also concerned that increased health care services — such as vaccination or telehealth — may fall back to pre-pandemic levels while the burden of protection, such as masking, may fall to chronic disease patients alone, which adds to the burden of living with disease.”



Newmark also spoke with [Everyday Health](#) to provide advice on how to read a health insurance contract to determine if it has a copay accumulator clause in the fine print. He said, “As a result, patients are caught by surprise that they haven’t met their deductible and their budget is impacted by unanticipated payments, which could be thousands of dollars depending on the structure of their health plan. Transparency and fairness is needed to protect patients from predatory payer policies.”



Dr. Popovian published an op-ed in National Review with cowriter Catherine Barr Windels titled, [“Transparency Laws Are the First Step Toward Creating a More Sustainable Health-Care System.”](#)

■ PUBLICLY REPRESENTING GHLF TO ADVANCE HEALTH POLICY

During the first quarter, Robert Popovian, PharmD, MS, Chief Science Policy Officer, published several reports, including [an interactive mapping tool](#) identifying the number and location of pharmacies affiliated with 340B-covered entities in partnership with Pioneer Institute and a report on the [biosimilars marketplace](#). He also was also a presenter at “Covid Long-Hauler: The Newest Wave of Chronic Disease Patients” via Chronic University in February and at the Festival of Biologics in March.

■ GHLF 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. As referenced above, we spent much of the winter visiting with policymakers across the country to advocate for patient-centered laws, particularly around the copay accumulator issue.

In addition, on February 23, GHLF joined an [amicus brief](#) to the Supreme Court with the HIV+Hepatitis Policy Institute, Aimed Alliance, and other patient groups to get a ruling on whether copay accumulator adjusters are lawful.

The advocacy team continues to share its perspective on hot topics on [The Health Advocates](#) podcast, hosted by Steven Newmark, Chief Legal Officer and Director of Policy, and Zoe Rothblatt, MPH, Associate Director, Community Outreach, and the [Healthcare Matters](#) podcast, hosted by Dr. Popovian and Conner Mertens, Patient Advocate and Community Outreach Manager.

For more information on how to partner with GHLF to support our advocacy projects, please contact Steven Newmark, JD, Advocacy Director and Chief Legal Officer at snewmark@ghlf.

CREAKYJOINTS ESPAÑOL GROWS ENGAGEMENT

HOPE-CAPE SUCCESS

During the first quarter, CreakyJoints® Español evaluated the success of the ongoing Hispanic Outreach Program Effect–Culturally Appropriate Education (HOPE–CAPE) study, which focuses on education for Spanish-language speakers with rheumatoid arthritis. As mentioned in the Q4 2022 quarterly report, results from this study were also presented at the American College of Rheumatology Convergence 2022.

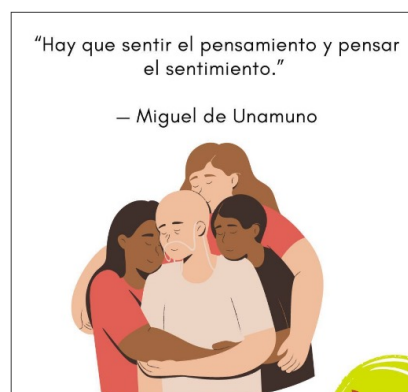
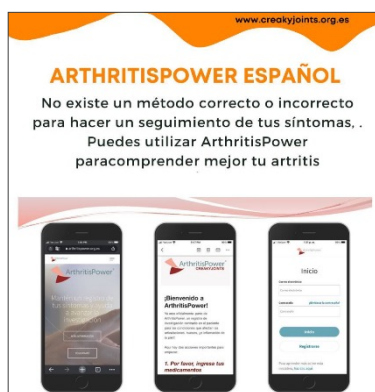
The first phase of the HOPE–CAPE project included an educational module presented in Spanish, which links to expanding educational content through various social media and online channels. The project aimed to recruit 1,400 Hispanic users with RA geotargeted in top-ten metropolitan statistical areas for a WhatsApp messaging pilot. Of those, 70 percent progressed to the second module, far exceeding industry standard of 50 percent progressing to a second question, and 30 percent completed all five modules with statistically significant improvement in education (industry standard: 15 percent completion rate).

CreakyJoints Español’s HOPE–CAPE project was made possible by a grant from the Bristol Myers Squibb Foundation. This finalized project created the framework for a Train the Trainer Promotores digital pilot, which is currently ongoing.

PROVIDING COMMUNITY AND EDUCATION

During the first quarter, we continued to publish educational articles and social media posts in Spanish to build community and increase awareness of management and treatment options for patients. Recent articles and posts include:

- [Consejos para Identificar \(y Superar\) el Síndrome del Impostor](#)
- [Un Estudio Valida la Importancia de los Datos del Paciente en la Atención a la Artritis Reumatoide](#)



For more information on how to partner with GHLF to support our Spanish-language education, research and advocacy projects, please contact Daniel Hernandez, MD, Director of Medical Affairs and Hispanic Outreach, at dhernandez@ghlf.org

CREAKYJOINTS AUSTRALIA AND GHLF AUSTRALIA LAUNCH NEW EDUCATION INITIATIVES



■ NEW FACEBOOK GROUP

In February, we launched a new Facebook group to share our latest news, feature articles, arthritis resources, and other content with our Australian community. We invite members to provide feedback on any of our posts and chat with one another in the comments. Administered and moderated by CreakyJoints Australia (CJA) staff, it already has 229 members who are very active and have provided comments and feedback for various articles.

■ JUVENILE IDIOPATHIC ARTHRITIS

Australian children with severe juvenile idiopathic arthritis (JIA) currently have access to three biologic systemic therapies subsidized by the Pharmaceutical Benefits Scheme (PBS), including adalimumab, etanercept, and tocilizumab. These treatments are available as subcutaneous injections, and tocilizumab can also be administered intravenously. However, a new oral treatment option, tofacitinib, is currently being considered for listing on the PBS, which we supported with a letter.

In addition, we recently highlighted the Juvenile Arthritis Foundation of Australia's (JAFA's) newly launched Juvenile Arthritis Awareness Week in Australia. The aim of this event (held March 18–25, 2023) was to educate the public about juvenile arthritis and the challenges faced by those living with the condition. That week also saw the launch of the Australian Juvenile Arthritis Registry at the Australian Parliament House in Canberra. The registry is the result of a collaboration between JAFA, the Australian Rheumatology Association, and the Australian Arthritis and Autoimmune Biobank Collaborative.

OSTEOPOROSIS

Romozosumab is currently available through the [Pharmaceutical Benefits Scheme](#) only for people with severe osteoporosis as a second-line therapy. However, the Pharmaceutical Benefits Advisory Committee is currently considering making romozosumab available as a first-line therapy for people with a very high, imminent risk of fracture who need immediate treatment, which we supported [with a letter](#). The contents of this letter were informed by a recent [community poll](#) we conducted.

50%

of the respondents were not aware of the connection between arthritis and osteoporosis

50%

of the respondents had not been diagnosed with osteoporosis by a medical professional

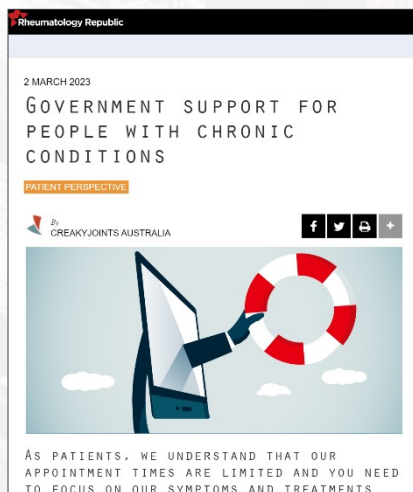
80%

of those did not think they had osteoporosis

20%

suspected they did have osteoporosis

There was much uncertainty, with people not fully understanding how osteoporosis can affect them. Some people were conscious of their vitamin intake and bone strength training but were still unsure if they were doing enough to prevent osteoporosis. Lack of proper communication between patients and medical professionals seemed common. For that reason, GHLF Australia has joined the GHLF's Osteoporosis Global Council and has started organizing interviews with Australian osteoporosis patients.



RHEUMATOLOGY REPUBLIC ARTICLE

In the first quarter, our [contributed article](#) discussed a recent report by Arthritis Australia, “[What Consumers Want: Identifying the Unmet Needs of Australians Living with Arthritis.](#)” including covering some key resources on our CJA website, which doctors can share with their patients.

INTERNATIONAL WOMEN'S DAY

On this year's International Women's Day (March 8), [members of our Australian community](#) joined patient advocates from around the world to share their advice, their challenges, and how they've found support. In addition, we supported the [Advantage Hers](#) campaign (created by UCB and partners), which seeks to show women that living with chronic inflammatory disease does not need to hold them back and that they should continue to reach for their dreams. It encourages women to support one another and share their stories. It empowers women with information and support to seek diagnosis and treatment and helps give them the flexibility to live the lives they want.

For more information on how to partner with GHLF to support our international educational initiatives, please contact Adam Kegley, MA, MS, Manager, Global Partnerships, at akegley@ghlf.org

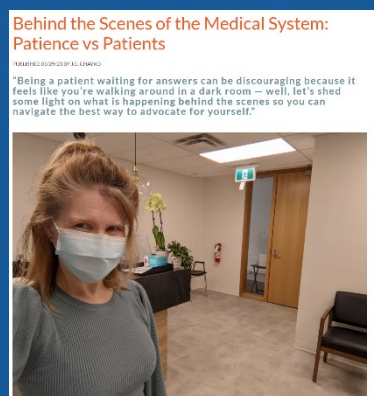
GLOBAL HEALTHY LIVING FOUNDATION CANADA/ LA FONDATION MONDIALE POUR VIVRE EN SANTÉ AU CANADA PUSHES FOR BROAD PATIENT-CENTERED VOICES ACROSS DISEASE STATES

GHLF Canada kicked off 2023 focused on enhancing patient education and beginning the expansion of our work from 2022 in Canadian patient advocacy and programming.

In 2023, we aim to develop new educational and awareness-raising programs with Canadian patients regarding a wide range of disease states, from inflammatory arthritis and migraine to dermatological conditions such as psoriasis and alopecia. We will continue diving further into federal and provincial-level advocacy efforts alongside other Canadian patient organizations and will also strive to continue building partnerships with Canadian universities to establish new, patient-centered research projects.

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

Our content library on CreakyJoints.ca in English and French continues to expand, and we remain 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 new articles published in the first quarter of 2023 include:

- [Living with Arthritis — Behind the Scenes of the Medical System: Patience vs Patients | French version](#)
- [Living with Arthritis — When What We Don't Know Can Hurt Us | French version](#)
- [Downtime: Making Space with Rheumatoid Arthritis | French version](#)

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

GHLF Canada held its first 2023 meetings of our Canadian Arthritis and Migraine Patient Councils this quarter to kick off a new year of patient-centered educational programming, raising awareness, and advocacy.

Our council members provided input for the creation of educational and awareness-raising materials aimed at both patients and health care providers about issues they wish their primary care physician (PCP) would have informed them about when beginning their disease journey. We will be working on turning these thoughts into a helpful infographic to share among patients and providers via social media and other channels.

Some major themes that came up for discussion and programing ideas through the year include:

- General enhancement of PCP education and awareness on migraine and headache disorders
- How to navigate the Canadian health care system as an uninsured person
- Specialists and family doctor shortages across different provinces in Canada
- Treating conditions holistically with a comprehensive care team

Our Canadian patient councils continue to help us ensure that the topics covered and programs developed by GHLF Canada are patient-centered and that they deliver for and with Canadian patients.

For more information on how to partner with GHLF to support our international educational initiatives, please contact Adam Kegley, MA, MS, Manager, Global Partnerships, at akegley@ghlf.org



GHLF SUPPORTS CHILDHOOD AND EARLY-ADULT EDUCATION AND ADVOCACY IN NEPAL AND THE UNITED STATES

GHLF’s second full year of support for International Student Learning Inc. (ISLearning) and Canopy Nepal’s very successful program Beyond Borders came to completion at the end of Q1 of 2023.

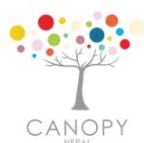
In its second full year of programing, Beyond Borders reached over 60 schools and colleges and over 1,600 students across 65 sessions with targeted programming and educational materials. Students showed clear growth in all growth categories, especially in mental and emotional well-being categories and other skills such as leadership and written abilities, culminating in a cumulative 86 percent growth rate for students overall.

Through ISLearning, similar health-based programming and needs were achieved for differently abled, socioeconomically disadvantaged students in New York and Washington, D.C., across two schools and involving 340 students, including a focus on nutrition and supplying flexible seating and health and hygiene kits for middle school-aged students.

Photo credit: “ISLearning 2022 report” for first photo and “Beyond Borders March 2023 report” for 2nd photo)



In light of this success, GHLF decided in Q1 to issue continued grant funding for another year to enhance the impact of this powerful program, notably its health-education efforts in areas of physical, mental, and emotional health and well-being through ISLearning and Canopy Nepal. Together, we are hard at work on developing educational and cultural exchange sessions, as well as hygiene kits for distribution to middle school-aged students in Nepal. Beyond Borders will continue expanding its reach and deepening its programming as part of its mission to deliver education and empowerment to learners belonging to socially, ethnically, and financially disadvantaged communities in Nepal.



Through ISLearning, we will also continue expanding our work more broadly to support similar health-based programming and needs for differently abled, socioeconomically disadvantaged students in New York and Washington, D.C.

GHLF is very proud to continue supporting ISLearning, Canopy Nepal, and Beyond Borders' aims to contribute directly to the United Nations' 2030 Agenda for Sustainable Development and to the many targets of the United Nations Sustainable Development Goals (SDGs), including SDGs 3 (Good Health and Well-Being), 4 (Quality Education), 5 (Gender Equality), 11 (Sustainable Cities and Communities), and 13 (Climate Action).



For more information on how to partner with GHLF to support our international educational initiatives, please contact Adam Kegley, MA, MS, Manager, Global Partnerships, at akegley@ghlf.org

CREAKYJOINTS AND GHLF IN CONVENTIONAL NEWS AND ONLINE

During the first quarter, GHLF and CreakyJoints spokespeople, members, and data were featured in over 59 original placements, reaching an estimated 112 million media impressions. Several of these earned media articles were syndicated national and internationally, such as coverage in [Reuters](#) and BBC's [The Conversation](#). Also syndicated were two articles from the U.K.'s Daily Express, the first [on signs of osteoporosis](#) and another on [gout](#), featuring an interview with Dr. Theodore Fields that we coordinated. [Everyday Health](#) featured CreakyJoints spokespeople or educational resources in six different articles, and [HealthCentral](#) continued to reach out to us for expert commentary. W. Benjamin Nowell, PhD, Director, Patient-Centered Research, gave an interview with [Healio on telehealth](#), and a future interview with them will focus on how patient advocacy groups can be more involved with clinical research.





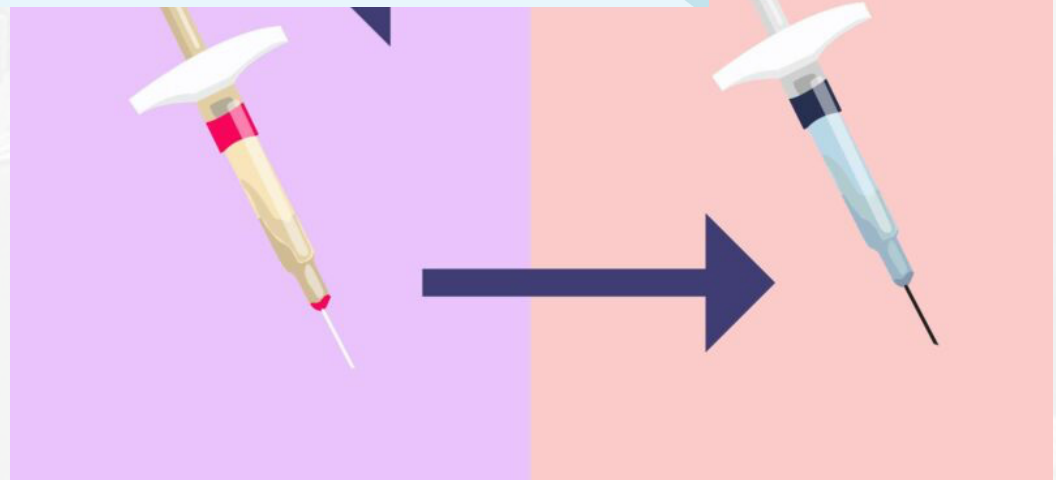
LONG SESSIONS COMMON WITH OUR EDUCATIONAL CONTENT

In the first quarter, there were over 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 19 minutes, 21 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 to 240,000 subscribers.

In addition to publishing content tied to our educational modules and ongoing advocacy and research work (some referenced earlier), we continue to publish stand-alone content to live well with chronic disease. Some popular resources this quarter included:

- [9 Ways to Recover Your Spoons After a Bustling Holiday Season](#)
- [Study Suggests Disconnect Between Doctors and Patients Over Psoriatic Arthritis Fatigue](#)
- [How Will Artificial Intelligence Impact Our Patient Community?](#)
- [More Biosimilars Are Coming, But Don't Expect Instant Savings](#)
- [Yet Another Symptom: Dealing with Long-Haul Covid as a Person with Chronic Illness](#)
- [Celebrating Women with Chronic Illness: Meet 30 Patient Advocates](#)



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



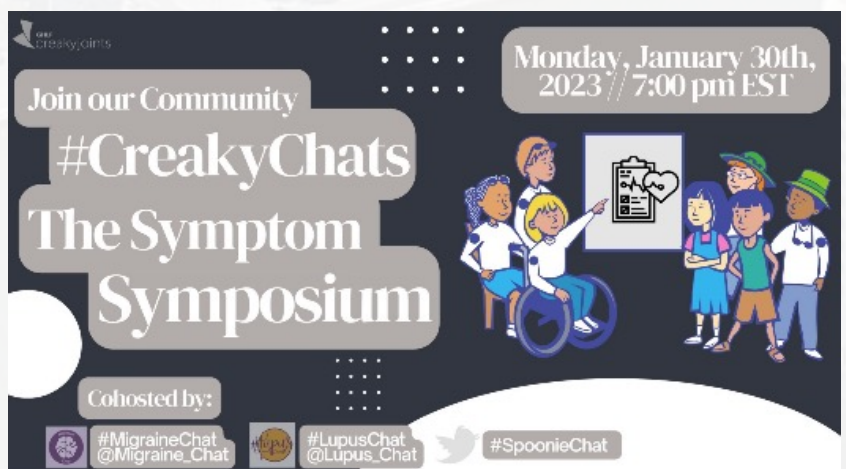
Our social media channels are key ways that GHLF and CreakyJoints directly communicate with our patient community, obtain member insights and perspectives, share new content and resources, and keep members informed about the organizations' activities, opportunities, and accomplishments. Channels include 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: [An #InvisibleIllness refers to a physical, mental, or neurological condition that cannot be seen from the outside. Here are 14 realities a patient advocate says about the challenges of living with an invisible illness.](#)

■ #CREAKYCHATS

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

January: In “The Symptom Symposium,” we asked members of our community to share their chronic health conditions, what surprised them about their symptoms, how they communicated their concerns with their medical provider, and how they felt when they learned that other people were living with similar conditions. This was cohosted by @Migraine_Chat, @Lupus_Chat, and #SpoonieChat. This chat generated nearly nine million media impressions stemming from 871 tweets and 105 participants.





February: This month, our #CreakyChat honored Black History Month, partnering with @Lupus_Chat and #SpoonieChat, both of which have large Black patient followings. This chat generated more than 14 million media impressions stemming from 1,125 tweets and 126 participants.

March: This month, we invited participants to discuss how it felt to be gaslighted or not believed when talking to their health care team. People also shared their best practices for advocating for what they need for their physical and mental health. This chat generated more than 2.4 million media impressions stemming from 225 tweets and 38 participants.



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

Facebook: [facebook.com/CreakyJoints](https://www.facebook.com/CreakyJoints) & [facebook.com/GlobalHealthyLivingFoundation](https://www.facebook.com/GlobalHealthyLivingFoundation)

[GlobalHealthyLivingFoundation](https://www.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)

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