



# QUARTERLY REPORT

JANUARY – MARCH 2024

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# Q1 2024 GLOBAL HEALTHY LIVING FOUNDATION QUARTERLY REPORT: EMPOWERING PATIENTS, SHAPING POLICY, AND EXPANDING GLOBAL REACH

Welcome to the first quarterly report of 2024 from the Global Healthy Living Foundation (GHLF).

This report showcases our ongoing efforts to empower patients, shape health care policy, and expand our reach globally. In this edition, you'll discover impactful projects, strategic partnerships, and significant accomplishments that have furthered our mission to improve the lives of individuals living with chronic illnesses worldwide.



# U.S. ADVOCACY: COLORADO & OREGON DRUG PRICING, NEW HAMPSHIRE REBATES, AND CMS SUBSTITUTION

Our advocacy efforts in the United States centered on amplifying the chronic disease patient voice and promoting patient-centered health policy.

- We wrote a letter to the Centers for Medicaid and Medicare Services (CMS) about changes regarding biologic substitution. We shared support for the access and growth of the biosimilar market, while expressing concern for maintaining the physician patient relationship and decisions around treatment.
- We were active in Colorado's Prescription Drug Affordability Board (PDAB) hearings, sharing comments and patient stories about the importance of access to medications.
- We testified on behalf of patients in Maryland for two bills, HB876 (anti-steering legislation) and HB1270 (share the savings legislation).
- We submitted comments in New Hampshire in support of Senate Bill 555. This legislation would ensure that patients are able to realize the full benefit of the deals and rebates that insurers and pharmacy benefit managers (PBMs) negotiate with drug manufacturers.
- We were the only patient group to provide comments in Oregon's most recent PDAB meeting and following our statement, members of the board used our logic as reasons for why they excluded one of the medications from further review.
- Our 50-State Network also joined the Digestive Disease National Coalition and Obesity Action Coalition (OAC) in D.C. to meet with policymakers and share patient stories.

*For more information on how to partner with GHLF to support patient-centered health policy, please contact Steven Newmark, JD, MPA, Chief Legal Officer and Director of Policy, at [snewmark@ghlf.org](mailto:snewmark@ghlf.org).*



# GHLF GOES TO HEADACHE ON THE HILL

Team GHLF packed up and headed to Washington, DC, along with a few other 50-State Network migraine advocates, for the annual advocacy event Headache on the Hill. Advocates from all 50 states came together this week to advocate for crucial legislative support for folks living with migraine and headache disorders. This year the asks that were presented to our members of Congress were:

1. Safe Step Act
2. NIH Clinical Trial Diversity Act
3. Increased funding for the VA Headache Disorders Centers of Excellence

Don't miss out on our special episode of Talking Head Pain, where Associate Director, Diversity, Equity, Inclusion & Community Outreach, Sarah Shaw was reporting live during Headache on the Hill and connecting with enthusiastic migraine advocates.

<https://omny.fm/shows/talking-head-pain/championing-change-a-conversation-with-migraine-ad>



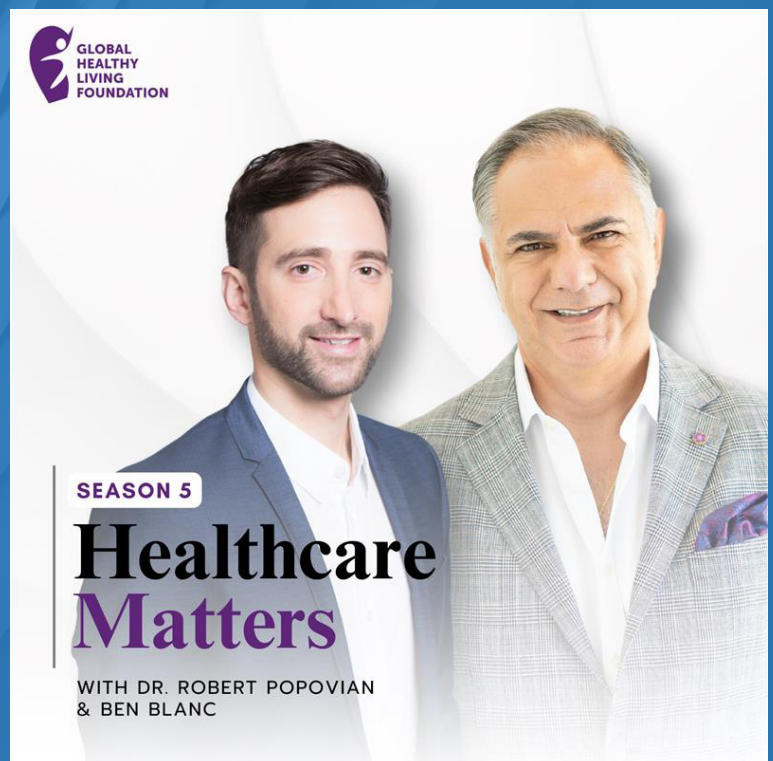


# PATIENT-CENTERED ECONOMIC AND POLICY PODCASTS, REPORTS, OPEDS & PEER-REVIEWED PAPERS

In Q1 2024, GHLF continued its dedication to patient-focused economic and policy research, providing critical insights and advocating for policies that support chronic disease patients. Our work in this area has been prolific, with a range of publications, presentations, podcasts, and media engagements aimed at influencing policy and improving patient outcomes.

## Publications:

- [Report: Value and Pricing Models for Gene Therapy Replacements: The Current State of Affairs. Pioneer Institute Report](#), March 2024, Anne Sydor, William Smith and Robert Popovian.
- Sydor AM, Bergin E, Kay J, Stone E, Popovian R. [Modeling the Effects of Formulary Exclusions: How Many Patients Could Be Affected by a Specific Exclusion?](#) JHEOR. 2024;11(1):86-93. doi:10.36469/001c.94544
- [Opinion Editorial: Arizona must prioritize reform of federal safety net program.](#) Arizona Capital Times and Arizona Daily Star, March 2024.





- [Report: IQVIA Human Data Sciences and Global Healthy Living Foundation Trends in Adult Vaccination in the U.S., This report examines the impact of reimbursement to healthcare providers on influenza vaccination for the Medicaid fee-for-service population.](#) IQVIA Report, February 2024.
- [Opinion Editorial: Pharmacy Benefit Managers Are Not Conservative.](#) National Review, February 2024, William Smith and Robert Popovian.
- [Opinion Editorial: Bipartisan Reform Required to Turn Back the Clock on Outcomes of Federal Drug Discount Program.](#) Real Clear Health, January 2024, William Smith and Robert Popovian.
- Chea S, Sydor AM and Popovian R. [Analysis of Drug Formulary Exclusions from the Patient's Perspective: 2023 Update.](#) Health Science Journal, 2023. Vol. 17 No. S8:002.
- [Paper: Quantifying The Economic and Health Benefits From Rapid-Development COVID-19 Vaccines and Boosters.](#) Progressive Policy Institute Report, January 2024, Michael Mandell, Robert Popovian and Wayne Winegarden.

#### Podcasts:

- Healthcare Matters:

[S5, E1, New Findings Unveiled: The Economic Path to Increased Vaccination](#)

[S4, E10, PBM Practices Uncovered: A Closer Look at Drug Pricing.](#) Apple Podcast

[S4, E9, Pandemic Economics: How Vaccines Changed the Game.](#) Apple Podcast

- [Drug Discount Distortions: How Middlemen Increase Costs and Reduce Access](#)

#### Media:

- [The Vicki McKenna Show, 2/7/2024, Accumulators, Maximizers and Patient Assistance Programs](#)

*For more information on how to partner with GHLF to support Patient-Focused Economic and Policy Research, please contact Robert Popovian, PharmD, MS, Chief Science Policy Officer, at [rpopovian@ghlf.org](mailto:rpopovian@ghlf.org).*

# GHLF ANNOUNCES IRAE CONSORTIUM TO ADDRESS IMMUNE-RELATED ADVERSE EVENTS IN CANCER IMMUNOTHERAPY PATIENTS

## PATIENT-CENTERED RESEARCH

In Q1 2024, the nonprofit Global Healthy Living Foundation (GHLF) co-founded the irAE Consortium, a collaborative effort uniting clinicians, researchers, and patients to address adverse reactions in cancer patients undergoing immunotherapy. Other co-founders included experts from Cleveland Clinic, Massachusetts General Hospital, Ohio State University, Duke University, MD Anderson Cancer Center, and Stanford Cancer Center. The inaugural meeting took place on March 7-8, 2024, at the Cleveland Clinic in Ohio.

“

As a leading advocate for patient empowerment, patient-centered research, and access to quality health care, GHLF is honored to be part of the irAE Consortium, a coalition that shares our commitment to improving the lives of individuals affected by serious health conditions,” remarked Seth Ginsberg, Co-Founder of GHLF.

This initiative aimed to meet the needs of cancer patients experiencing adverse reactions to immunotherapy by prioritizing cutting-edge research, shared expertise, and patient-centered approaches to elevate the quality of care and support.



New studies published by GHLF's research team this quarter included:

- [Wearable activity tracker study exploring rheumatoid arthritis patients' disease activity using patient-reported outcome measures, clinical measures, and biometric sensor data \(the WEAR study\)](#). This study used digital health tools, including electronic patient-reported outcomes (ePROs), wearables, and clinical data to provide a comprehensive picture of patient health. Newly initiated RA patients on upadacitinib or adalimumab are recruited, with data collected over three to six months to evaluate correlations among physician data, ePROs, and wearable sensor data. The study aimed to demonstrate the feasibility of digital data capture for remote patient monitoring in rheumatic diseases.
- [A Real-World Effectiveness Study Using a Mobile Application to Evaluate Early Outcomes with Upadacitinib in Rheumatoid Arthritis](#). This study evaluated the impact of upadacitinib on RA symptoms during the first 12 weeks of treatment using patient-reported outcomes (PROs) collected via a mobile health application. Results showed early and significant improvements in disease activity, pain, morning stiffness, and fatigue, with clinically meaningful improvements observed as early as week 1 and maintained or further improved through week 12.

*For more information on how to partner with GHLF to support patient-centered research, contact Shilpa Venkatachalam, PhD, Chief Patient Centered Research and Ethical Oversight Officer, at [svenky@ghlf.org](mailto:svenky@ghlf.org).*

# SOCIAL MEDIA ENGAGEMENT: STAYING CONNECTED

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](#), [LinkedIn](#), and [Threads!](#) Notable posts from this quarter:

- Instagram: [Exploring the Connection Between Arthritis and Disabilities](#)
- CreakyJoints X: [What are your go-to products to make cleaning and organizing easier?](#)
- GHLF X: [Itching About Psoriasis? A HEROES webinar about Hair, Scalp, and Skin Health](#)

#CreakyChats continued to generate engagement with #CreakyChats: Honoring Black History Month, cohosted by our special guest Tinu Abayomi-Paul, a writer, motivational speaker, and disability advocate who lives with multiple chronic conditions and cancer.



**Our YouTube channels views doubled between 2022 vs 2023, with almost 1M views total (994,147 views). The watch time increased by 225% for a total of 63,752 hours watched on our channels in 2023.**

# GHLF'S PARTNERSHIP WITH ISLEARNING INC AND CANOPY NEPAL: "BEYOND BORDERS" CONTINUES SUCCESS — IMPACTING STUDENTS AND TEACHERS

- In Q1 2024, with GHLF's support, ISLearning and Canopy Nepal worked together on the "Beyond Borders" program to reach hundreds of students in dozens of classrooms on topics like general health and well-being. Together, we also reached teachers via Canopy Nepal's teacher trainings on classroom safety, work-life balance, and the impact teachers' roles can have on the mental health and well-being of students.
- We would also like to recognize that late last year Ms. Monal Bhattarai, Head of Canopy Nepal and Nepal Country Coordinator for ISLearning, became part of Healio 2023 Honors as an official Honoree for her steadfast, innovative work on education and support for young people in Nepal and beyond. We congratulate Monal, and by extension Canopy Nepal and ISLearning, on this incredible honor.
- "Beyond Borders" efforts align directly with the United Nations' Sustainable Development Goals (SDGs), including SDGs 3, 4, 5 11, and 13.



*If you would like to get involved in our work in Nepal and elsewhere around the world, please contact Adam Kegley, Associate Director of Global Partnerships, [akegley@ghlf.org](mailto:akegley@ghlf.org)*



GLOBAL HEALTHY LIVING FOUNDATION CANADA /  
LA FONDATION MONDIALE POUR VIVRE EN SANTÉ AU CANADA

# COLLABORATION, NEW PROGRAMS, PATIENT ADVOCACY — GHLF CANADA'S IMPACT CONTINUES

## NEW ALOPECIA AREATA PODCAST

- In Q1 2024, we officially launched our new podcast “[From Hair to There: Life with Alopecia](#),” a podcast series dedicated to uniting voices and providing resources to support individuals living with alopecia areata. The first three episodes of this series focus on the lived experiences of patients and providers in Canada. For this podcast, we collaborated closely with the Canadian Alopecia Areata Foundation (CANAAF) and with leading Canadian dermatologists in hair loss and alopecia areata, a mental health professional, and patient advocates across Canada and the United States. Our next set of three episodes debuting in Q2 will be focused the lived experiences of those in Australia. We plan to continue featuring experiences with alopecia areata and the similarities and differences between those experiences from around the world.
- GHLF plans to continue expanding our work in alopecia areata in Canada specifically by producing provider-focused content through “From Hair to There” along with accompanying helpful resources providers can distribute to alopecia patients.
- We continue, as always, our very strong collaboration alongside other patient organizations and contributed to patient input submissions to the Canadian Agency for Drugs and Technologies in Health (CADTH) that raise the voices and concerns of patients to make the case for the need for innovative new treatments, including for conditions like ankylosing spondylitis and psoriatic arthritis in Q1 2024.
- We partnered with the Canadian Arthritis Patient Alliance and began planning a series of three webinars for Q2 2024 that will focus on patient advocacy at the federal level for chronic disease patients, how new treatments get approved at the federal level, and the subject of getting involved in clinical trials in Canada.
- In Q1 2024, we also commenced planning for a new episode of [Remission Possible](#) focused on a Canadian patient and provider discussion on remission. We plan to record this new episode later in Q2/Q3 2024.

*If you would like to get involved in our alopecia areata work and programing, please reach out to Adam Kegley, Associate Director of Global Partnerships, [akegley@ghlf.org](mailto:akegley@ghlf.org)*

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

The [Strong Bones & Me](#) program is GHLF's global osteoporosis education and engagement-based initiative. The program's mission is to redefine the way we all think about osteoporosis across the globe and in our respective localities, its connection to our overall health, and the risks involved including connection conditions, secondary fracture prevention and post-fracture care to better prioritize our bone health.

- Our program's educational and engagement-based resources (available in English and Spanish) have reached over 183,000 people in over 180 countries as of end Q1. Our patient survey reached over 7,000 people now dozens of countries.



PHOTO: (credit "StrongBonesAndMe.org")

- As a highlight to our newly launched Spanish version of Strong Bones & Me. [Mis Huesos Fuertes](#), we are planning a social media campaign in Spanish during US Osteoporosis Awareness and Prevention Month (May). We have also recently interviewed two health professionals in Spanish and will be launching these videos as part of our Patient & Provider Story Series, which will both be available Q2 2024 on the website and YouTube.
- We held our first Global Council meeting of the year in which we discussed strategy and the way forward for the program this year, including a further emphasis on treatments available depending on where patients live around the world as well as options for patients after experiencing a fracture (e.g. Fracture Liaison Services, fall prevention, and more).
- Next steps include continuing our English and Spanish-language interviews with patients and health care professionals from around the world to increase our reach and resources available to patients. We will soon close our survey in English and Spanish to update our site with results and plan a second survey and additional localized resources later this year in the US, EU, Australia, and beyond.

*For more information on how to partner with GHLF to support Strong Bones & Me, please contact Adam Kegley, MA, MS, Associate Director of Global Partnerships, at [akegley@ghlf.org](mailto:akegley@ghlf.org).*



# CREAKYJOINTS AUSTRALIA: ADVANCING ADVOCACY AND EDUCATION

After many years, in late March, GHLF Co-Founder Seth Ginsberg met up with colleagues Naomi Creek and Rosemary Ainley in Melbourne, Australia. This was a great opportunity to plan upcoming projects in Australia and meet with local sponsors.

On International Women's Day, we published the article [Parenting with Arthritis: Tamara's Story and Practical Tips](#). Tamara shared the ups and downs of her journey as a parent with arthritis and provided tips for others in similar situations.



We also published our revised [Family Planning, Pregnancy and Parenting with Rheumatic Diseases](#) hub on our website. This now includes a page on each stage of becoming a parent with arthritis.

We wrote several submissions for the Pharmaceutical Benefits Advisory Committee (PBAC) March 2024 meeting and included comments from our community whenever possible. The PBAC makes decisions on which medicines to subsidize, or expand access to, through the Australian Government's Pharmaceutical Benefits Scheme (PBS). Subsidized products cost the consumer no more than \$40 per script. Our submissions were for:

- **Bimekizumab** (Bimzelx®) for the treatment of severe psoriatic arthritis, ankylosing spondylitis, and non-radiographic axial spondyloarthritis.
- **Anifrolumab** (Saphnelo®) for the treatment of severe systemic lupus erythematosus.
- **Tofacitinib** (Xeljanz®) 11mg extended-release tablet (Xeljanz® XR) for the treatment of severe active rheumatoid arthritis and severe psoriatic arthritis.
- **Respiratory Syncytial Virus Bivalent Vaccine** (Abrysvo®) on the National Immunisation Program for infants from birth through to 6 months of age, by active immunisation of pregnant individuals.



CreakyJoints Australia Editor Rosemary Ainley has continued to be a consumer representative in the Australian Rheumatology Association/Arthritis Australia Rheumatoid Arthritis Clinical Care Standards Working Group. During this quarter, the working group collaborated on two abstract posters to be featured at the Australian Rheumatology Association/New Zealand Rheumatology Association ASM in May 2024.

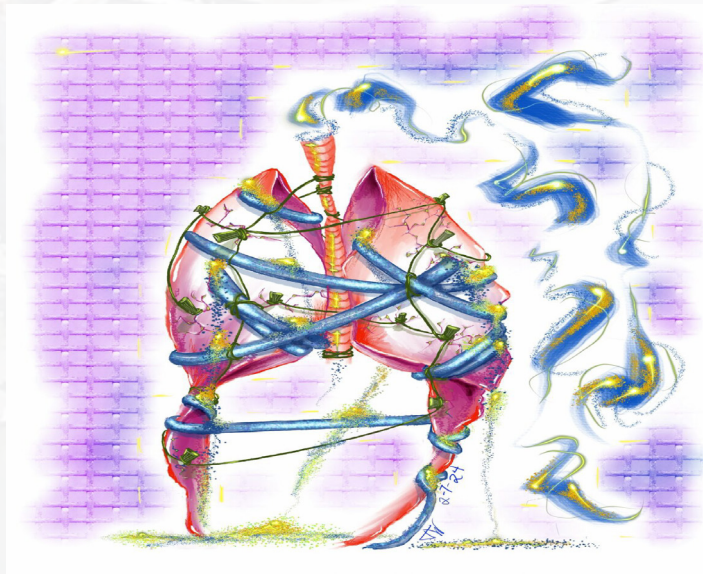
Rosemary also co-authored the research study Patients' Attitudes and Experiences in the Primary Care Management of Rheumatoid Arthritis: A Qualitative Synthesis with other members of the Consumer Patient-Centred Care working group. This group forms part of the Maridulu Budyari Gumal (Sydney Partnership of Health, Education, Research, and Enterprise) Musculoskeletal Clinical Academic Group. An abstract of this research study will also be presented at the ARA/NZARA ASM in May.

## GHLF REMAINS DEDICATED TO COVID-19 EDUCATION

At GHLF, we remain committed to providing comprehensive and updated information about the status of the COVID-19 pandemic. We want people living with chronic disease or who are immunocompromised to feel knowledgeable and confident so they can ask questions of their health care providers and their community to create a safe and healthy environment.

Notable articles published in the first quarter included:

- [New CDC Guidelines May Lower COVID-19 Isolation Period to Just One Day](#)
- [Unveiling the Impact of COVID-19 Vaccines](#)
- [When I Had COVID](#)
- [Still Wearing a Mask](#)



*For more information on how to partner with GHLF to support our education modules, please contact Susan Jara, Director, Patient Education, at [sjara@ghlf.org](mailto:sjara@ghlf.org).*



# GHLF CELEBRATES BLACK HISTORY MONTH

For Black History month, we added to our Black History Month curated landing page with important content, including:

- [Black History, Patient Voices: Advocating for Equity Beyond February](#)
- [Wash Day and Chronic Illness](#)
- [Navigating IBD and LGBTQ+ identity](#)



This month’s Melanin Health Table Talk focused on “Mental Health and Natural Hair” and “Representation in Healthcare Settings.” Additionally, we continued our ChronicHue monthly group meetings that we launched in September 2023. ChronicHue is a global online community empowering melanated people living with chronic illnesses and disabilities.

Run by Sarah Shaw, Associate Director of Diversity, Equity, and Inclusion at GHLF, ChronicHue provides a forum for discussions on topics that combine chronic illness, culture, and navigating the world as BIPOC patients. Spaces like these are crucial to our DEI efforts at GHLF, as we need to reach our marginalized communities where they are and listen to what support they need. This initiative will continue to grow and build more trust within BIPOC patient communities.

# ENHANCING HEALTH CARE FOR THE HISPANIC COMMUNITY

As part of the Global Healthy Living Foundation's (GHLF) commitment to Hispanic outreach and education, we launched a key initiatives to address the specific health care needs of osteoporosis in the Hispanic community.

**Strong Bones and Me/Mis Huesos Fuertes** — Spanish Engagement initiative aims to raise awareness about secondary fractures, underscore the significance of the Fracture Liaison Service, and promote osteoporosis prevention. This effort includes a social media campaign and precedes the launch of [MisHuesosFuertes.org](https://www.MisHuesosFuertes.org), a comprehensive osteoporosis resource for the Hispanic community, with a specific focus on the Latin American (LATAM) and Spanish-speaking audience, highlighting osteoporosis risks and prevention measures.





# GHLF PODCAST/YOUTUBE NETWORK REACHES 3.5 MILLION

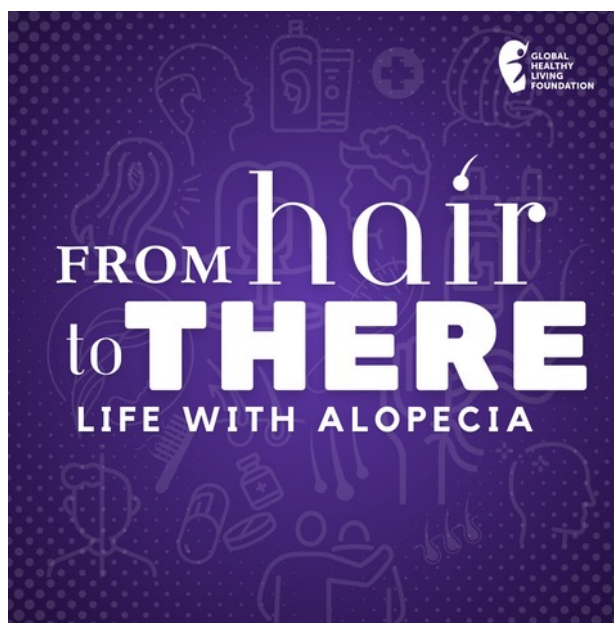
Our YouTube channels have now reached 3.5 million views total representing over 176,000 hours watched for our programs. During Q1 we acquired an additional 1,600 subscribers on YouTube bringing our total of subscribers to 28,000 people.

Our podcast network is off to a great start this year and brought in 92,000 listens in Q1 alone, which is in line with last year's performance for Q1. This good performance in Q1 is due to the release of a new podcast series and several audio guides across multiple conditions.

Notable podcast series in Q1 include:

The second season of "Thriving While Aching," which shed light on caregivers and care partners who play a crucial role in supporting their loved ones as they age. This new season garnered 17,600+ listens for a total of 37,700+ listens over its two seasons.

We also released our global-facing podcast series called "From Hair to There: Life with Alopecia," a podcast series dedicated to uniting voices and providing resources to support individuals living with alopecia areata. The series explores the multifaceted world of alopecia areata with patients and health care professionals from around the world. The first set of episodes features alopecia areata patients and professionals based in Canada and garnered over 30,000 total listens in Q1.



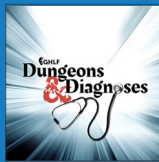
ONGOING SERIES



**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.



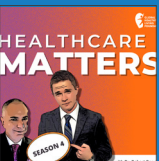
**Getting Clear on Psoriasis:** Listeners will learn about living better with psoriasis, and each episode includes relatable insights from fellow patients and key information from leading dermatologists and other experts.



**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.



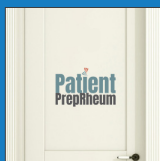
**Healthcare Matters:** This podcast explains complex health-policy topics so everyone can understand what is happening in the world of health care.



**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.



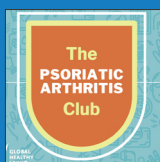
**MatterOfVax:** MatterOfVax explores the issues surrounding patients, caregivers, and community on the topics of vaccination, COVID-19 risks, and staying safe, with an Australian focus.



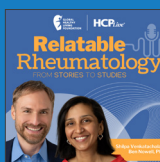
**Patient PrepRheum:** This podcast speaks to Australian patients and renowned doctors to explore important and often-misunderstood aspects of living with autoimmune arthritis and related conditions in Australia.



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



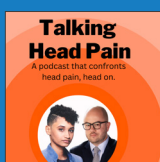
**The Psoriatic Arthritis Club:** Through personal chats with fellow psoriatic arthritis patients, as well as insights from top PsA experts, our host explores the ups and downs of navigating psoriatic arthritis.



**Relatable Rheumatology:** From Stories to Studies: In partnership with HCPLive, this podcast highlights personal experiences with rheumatic disease and how that translates into ongoing or future research and management strategies.



**Remission Possible:** Patients share their experience and strategies to target remission from symptoms.



**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 podcast network, please contact Ben Blanc, Associate Director, Digital Production and Engagement, at [bblanc@ghlf.org](mailto:bblanc@ghlf.org)*



# 1.1 MILLION NEW USERS ON CREAKYJOINTS; EMAIL LIST GROWS TO 300,000

Our websites saw continued growth, with more than 1.1 million new users on CreakyJoints. Our email list grew to more than 300,000 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:

- [New Year's Resolutions: Chronic Illness Edition](#)
- [What You Need to Know About Clinical Trials](#)
- [The Impact of Inflammation and How to Talk to Your Doctor](#)
- [7 Common Myths About Precision Medicine](#)
- [Reevaluating Your Goals with Your Doctor](#)

*For more information on how to partner with GHLF to support our education modules, please contact Susan Jara, Director, Patient Education at [sjara@ghlf.org](mailto:sjara@ghlf.org).*

# WHO WE ARE

## 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 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 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](https://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)

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

LinkedIn: [linkedin.com/company/ghlf](https://www.linkedin.com/company/ghlf)

