

# QUARTERLY REPORT

APRIL – JUNE 2024



GLOBAL  
HEALTHY  
LIVING  
FOUNDATION

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## Q2 2024 SUMMARY

# EMPOWERING PATIENTS, SHAPING POLICY, AND EXPANDING GLOBAL REACH

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

This report highlights our continued 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.



# ADVOCACY IN ACTION: AMPLIFYING PATIENT VOICES IN WASHINGTON, D.C.

In the second quarter, GHLF packed our bags and headed to Washington, D.C. to amplify the chronic disease patient voice and promote patient-centered health policy.

- We joined our coalition partners with the Alliance for Transparent and Affordable Prescriptions' (ATAP) annual hill day as we try to push legislators to support regulating Pharmacy Benefit Managers (PBM) by delinking the price of medications with PBM compensation and passing rebates received through medications onto patients. We met with over 20 offices, including the Speaker of the House and the House Minority Leader, and were encouraged by the agreement that PBMs are bad actors that need regulation.
- We also joined the World Vaccine Congress where Dr. Robert Popovian, PharmD, MS, Chief Science Policy Officer at GHLF, shared the patient perspective as presenter and moderator during panels on health care and vaccine topics.
- During Digestive Disease Week, we engaged with patient groups and gastroenterologists from across the nation. Through these conversations, we shared strategies and learnings for working together to improve access to care for patients living with digestive diseases.
- We also joined with other patient groups to focus on the Inflation Reduction Act's critical impact on access to care.



# AROUND THE STATES

Our 50-State Network has been busy advocating for improved access to care at the state level.

## NEW YORK

- On May 1, we helped organize a Lupus Day of Action along with other patient groups and city hospitals. This day was organized to bring greater awareness to lupus and try to address some of the issues that cause major delays in lupus patients receiving an accurate diagnosis. In partnership with GHLF, NYC Councilmember Shahana Hanif gave remarks on her own patient journey as a lupus patient growing up in NYC to become a city councilmember.
- On May 8, Corey Greenblatt, Director of State Policy and Advocacy, participated in a panel discussion in Albany for the NY Share the Savings (S.2393/A.1962A) bill with State Senator Robert Jackson and Assemblymember Latrice Walker, along with the Diabetes PAC and NAMI. We discussed the benefits of Share the Savings legislation and the impact it would have on directly lowering prescription drug costs for patients.
- We also submitted comments to the New York State Medicaid Drug Utilization Review (DUR) Board to advocate for the coverage of respiratory biologics.

Other comment letters submitted to New York this quarter:

- New York Senate Bill 8992 – 340b Expansion
- New York Senate Bill 2393A – Share the Savings

## VERMONT

- We're excited to announce a big success in Vermont for patient protections. Governor Phil Scott signed into law a step therapy bill (H.766), which reduces the barriers that patients may have to go through to receive their medication.
- We also submitted comments to Vermont Governor Scott to sign the Copay Accumulator Adjustor Ban.

## NEW HAMPSHIRE

- We submitted comments to a hearing in New Hampshire for Senate Bill 555, which would pass 50 percent of rebates received by pharmacy benefit managers onto patients in order to lower the cost of medications for patients at the pharmacy counter.

## TEXAS

- Our 50-State Network patient advocates spoke in front of the Texas Drug Utilization Review Board to support easier access to new asthma treatments for Texas Medicaid patients.

*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).*

# ADVANCING PATIENT-CENTERED ECONOMIC AND POLICY RESEARCH

In Q2 2024, GHLF continued its dedication to patient-focused economic and policy research, providing critical insights and advocating for policies that improve health care access and affordability for people living with chronic illness. 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: Challenges To Vaccine Access for High-Risk Chronic Disease Adults: Real-World Experience Study and Policy Recommendations](#). Global Healthy Living Foundation, June 2024, Robert Popovian.
- [Opinion Editorial: Misguided Proposals Threaten Innovation, Access to Diabetes Medicines](#). *Insidesources*, July 2024, Robert Popovian and William Smith.
- [Report: Challenges in Adult Vaccination: Policy Strategies for Sustaining Access and Supply](#). Global Healthy Living Foundation, May 2024, Robert Popovian.
- [Report: Impact of Inflation Reduction Act \(IRA\) on Pain Treatment Research](#). *Pioneer Institute Paper*, April 2024, William Smith and Robert Popovian.
- [Opinion Editorial: Pharmacists' Crucial Role in Getting Vaccines into Arms](#). *Governing*, April 2024, Anita Patel, Robert Popovian and Vibhu Tewary.
- [Opinion Editorial: Pharmacy benefit managers, not Big Pharma, responsible for high drug prices](#). *Boston Business Journal*, April 2024, William Smith and Robert Popovian.
- [Report: Removing Barriers to Pharmacy Vaccination: A Path to Better Health and Lower Health Care Costs](#). Global Healthy Living Foundation Report, April 2024, Popovian, Robert, Rivera, Esteban and Winegarden, Wayne.

## PRESENTATIONS

- Three presentations at the World Vaccine Congress - April 2024 - Pharmacist Immunization Policies and Vaccine HCP Reimbursement Analysis
- American Osteopathic Association annual conference - April 2024 - Drug Pricing, Spending, Affordability and Access
- National Taxpayers Union Webinar - April 2024 - Public Health = Fiscal Health Webinar
- Pioneer event with Congressman Jake Auchincloss - April 2024
- U.S. Senate policy briefing - May 2024 - 340B program
- Northwest Rare Disease Coalition Payer Forum - May 2024 - Gene Therapy Innovation
- AIR 340B Radio Tour - June 2024 - 340B program

## STATE TESTIMONY

- Missouri - May 2024 - 340B Legislation

## STATE DISCUSSION WITH LEGISLATIVE STAFF OR GOVERNOR STAFF

- Missouri - May 2024 - 340B
- New York - May 2024 - 340B
- Minnesota - June 2024 - 340B

## PODCASTS

- [S5, Ep 6, The Gene Therapy Equation: Costs, Value, and Future Directions](#)
- [S5, Ep 5, Frontiers in Immunization: Learnings from the World Vaccine Congress](#)
- [S5, Ep4, Balancing Act: March-In Rights and Medical Innovation](#)
- [S5, Ep3, Advancing Vaccine Policy: Live from the World Vaccine Congress](#)
- [S5, Ep2, Pharmacies and Public Health: Breaking Down Barriers to Pharmacy Vaccination](#)
- [S5, E1, New Findings Unveiled: The Economic Path to Increased Vaccination](#)

## MEDIA ENGAGEMENT

- [AJMC, 6/19/2024, Part 2: Unlocking the Potential of Biosimilars to Improve Health Equity](#)
- [AJMC, 5/7/2024, Part 1: Unlocking the Potential of Biosimilars to Improve Health Equity](#)
- [WSJ, 4/29/2024, Coming to a CVS Near You: A Store Brand Monoclonal Antibody](#)

*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).*

# POPULAR ARTHRITISPOWER® PATIENT REGISTRY EXPANDS CONDITIONS AND BECOMES PATIENTSPOT™

ArthritisPower, a trusted disease tracking platform and research registry since 2014, has transformed into PatientSpot — an expansive platform dedicated to providing support through education, conducting patient-centered research, and amplifying the voice of people living with chronic disease to raise awareness about chronic conditions. The PatientSpot platform is now a Food and Drug Administration (FDA) approved Class 1 medical device.

PatientSpot embodies GHLF's broader mission to serve the entire chronic disease community by expanding its appeal beyond its digital arthritis community, CreakyJoints®. Patients can now join the registry and its community with any chronic condition they wish to share, establishing it as a truly disease-agnostic platform.

“PatientSpot is a pathway to the future of health care because it is designed to emphasize patient-centered power and decision-making,” said Louis Tharp, Co-Founder and Executive Director at GHLF.

GHLF encourages users to enhance their PatientSpot journey by ensuring they have the latest version of the PatientSpot app (Version 4.0.0) and staying tuned for upcoming enhancements. Feedback is also highly encouraged by e-mailing Mr. Tharp directly, who is directing the artificial intelligence migration at [LouTharp@patientspot.org](mailto:LouTharp@patientspot.org).





# PAINSPOT FINDINGS PRESENTED AT EULAR 2024

The Global Healthy Living Foundation (GHLF) showcased significant research at the EULAR (European League Against Rheumatism) 2024 conference, focusing on improving diagnosis and support for patients with challenging conditions like polymyalgia rheumatica (PMR) and IgG4-related disease (IgG4-RD).

Here are the key findings:

## INNOVATIVE DIAGNOSTIC TOOL FOR POLYMYALGIA RHEUMATICA

- A [new study](#) using GHLF's PainSpot, in collaboration with researchers from Northwestern University and the University of Pennsylvania, was presented at EULAR 2024.
- Researchers highlighted how PMR is often difficult to diagnose due to symptom overlap with other diseases.
- PainSpot, an online tool developed by GHLF, helps identify PMR symptoms by asking specific questions about neck, shoulder, and hip pain.
- This free tool provides possible diagnoses, guiding users to seek proper medical care faster. Initial tests showed high accuracy in identifying PMR, and its use is expanding.

## SURVEY ON IGG4-RD 4 PATIENT NEEDS AND CHALLENGES

- A [new study](#) conducted by GHLF and TREND Community surveyed patients to understand the challenges they face and the support they need.
- Findings revealed that many patients see multiple doctors before receiving a diagnosis, often experiencing organ damage before being diagnosed.
- Patients expressed a strong need for more information about treatment options, side effects, long-term effects, and dietary advice to manage their symptoms.

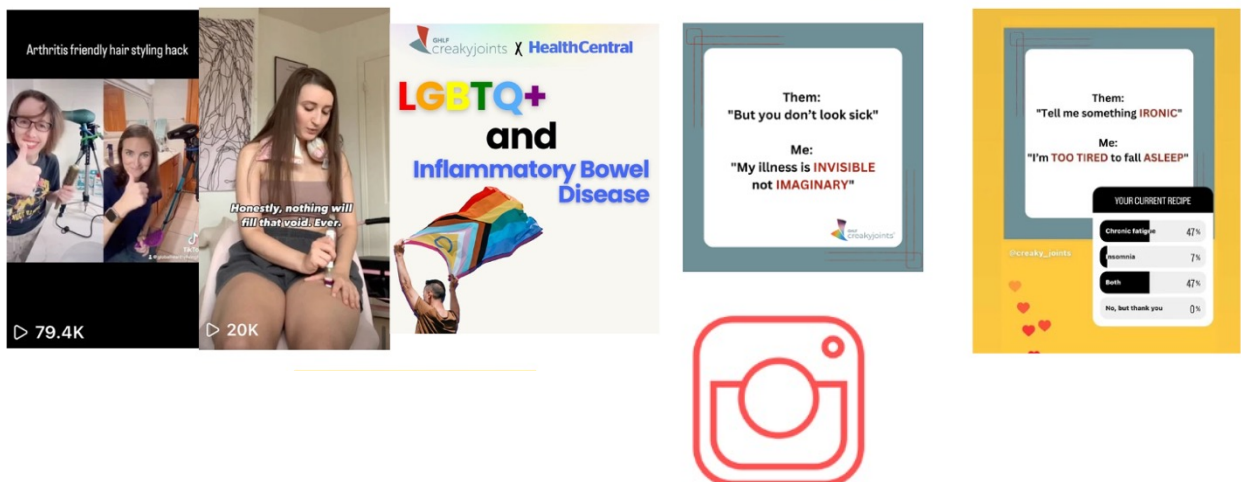
*For more information on how to partner with GHLF to support patient-centered research, contact Shilpa Venkatachalam, PhD, Chief Patient Centered Research and Ethical Oversight Officer, at [svenky@ghlf.org](mailto:svenky@ghlf.org).*

# SOCIAL MEDIA: BOOSTING ENGAGEMENT AND EXPANDING REACH

Our social media presence continues to grow and engage our community effectively. Here are the highlights from our key platforms

## INSTAGRAM

- Followers increase: Up 3.6 percent overall, and up 6.2 percent on our Spanish channel.
- Profile visits: Increased by 39 percent.
- Impressions: Exceeded 600,000.
- Content performance: Achieved more than 150,000 views on original content posted in June alone. We've maintained a balance of informational, educational, and entertaining content, equipping the community with GHLF tools.
- Stories engagement: Increased engagement by mixing relatable and entertaining content with links and teasers to our newest published articles, resulting in an influx of new website visitors.
- Reels performance: Surpassed 350,000 organic views.
- Collaborations: Solidified relationships with creators, organizations, and reputable voices, resulting in successful collaborations that merged their following with ours. Our partnership network is expanding and now includes collaborators in markets like Argentina.
- Engagement: Up 225 percent in reaching non-follower accounts due to relatable, comedic, and influencer reels, along with volunteer collaborations, enhancing algorithmic reach beyond our existing community.



## TWITTER (X)

- Followers increase: 0.5 percent for Creaky Joints and 0.6 percent for GHLF, surpassing expectations amidst internal changes at Twitter.
- Verification: The Creaky Joints X page is now verified, allowing access to longer tweets and bringing priority visibility in the algorithm.



## TIKTOK

- Followers increase: 1.85% growth.
- Milestone achieved: Surpassed the 275,000 likes mark.
- Amplification reach: Our podcast amplification reach efforts are growing as we post teasers and snippets across all social media platforms with direct calls to action to tune in to full episodes.



*For more information about how to partner with GHLF on global multi-language social media, contact David Granados, Social Media Manager at [dgranados@ghlf.org](mailto:dgranados@ghlf.org)*

# JUNE: WE SHOW OUR PRIDE

## ADDRESSING UNIQUE HEALTH CHALLENGES

At GHLF, we recognize the unique health challenges faced by the LGBTQ+ community, including those living with IBD. That's why we launched our "LGBTQ+ IBD Experiences" survey to capture and understand these experiences.

## SURVEY INSIGHTS

- **Gender Diversity:** Over 43% of respondents identified as non-cisgender, highlighting significant gender diversity within the LGBTQ+ IBD community.
- **Diagnosis Awareness:** 35% were unsure of their specific IBD diagnosis, with those on government insurance being 6.4 times more likely to be unaware compared to those with private insurance.
- **Treatment Gaps:** LGBTQ+ IBD patients seeing a primary care provider were 10.4 times more likely not to be on medication compared to those seeing a gastroenterologist. Those seeing another type of doctor were 31.6 times more likely not to be on medication.
- **Mental Health:** High levels of anxiety (75%) and depression (65%) were reported, underscoring the mental health burden on LGBTQ+ individuals with IBD.
- **Sexual Health:** Sexual relationships were among the top three most affected areas of life, with many participants expressing a lack of support from healthcare professionals.
- **Resource Accessibility:** 67% stated there are either not enough or no resources specifically tailored for LGBTQ+ individuals living with IBD, emphasizing the need for more targeted support and information.

“

Our goal is to bridge these gaps by providing much-needed resources and fostering more inclusive healthcare environments.”

— Louis Tharp, a gay man and Executive Director/Co-Founder at GHLF

*For more information about how to partner with GHLF on global multi-language LGBTQ+ projects, contact Sarah Shaw, Associate Director Diversity, Equity, Inclusion and Community Outreach at [sshaw@ghlf.org](mailto:sshaw@ghlf.org) or Adam Kegley, Associate Director Global Partnerships at [akegley@ghlf.org](mailto:akegley@ghlf.org).*

## NOTABLE PRIDE MONTH CONTENT

- [Chronic Pain and Gender Identity: Finding My True Self](#)
- [How Gender-Affirming Hormone Therapy Affects Chronic Disease](#)
- [How to Talk with Your Doctor About Your LGBTQ+ Identity](#)
- [LGBTQ+ Magic in the Mundane: Community Care for Migraine](#)

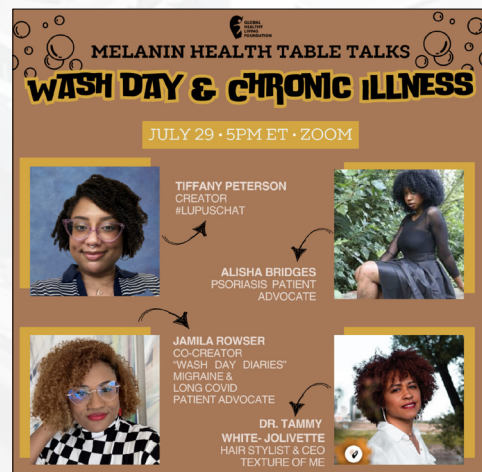
## GHLF SHOWS COMMITMENT TO HEALTH EQUITY AND DE&I

With our commitment to health equity and DE&I we have continued our programming that centers Black, Indigenous and People of Color living with chronic illnesses throughout our projects.

## CHRONICHUE

ChronicHue is a global online community empowering melanated people living with chronic illness and disability. Meeting monthly, it provides a forum for discussing topics that combine chronic illness, culture, and navigating the world as BIPOC patients.

- ChronicHue provides a supportive space for BIPOC folks to connect with others who can share and understand their racial or cultural experiences.
- ChronicHue meets virtually twice a month and is headed by our Associate Director of Diversity, Equity and Inclusion, Sarah Shaw.
- Click [here](#) to see how ChronicHue directly impacts our BIPOC patient community.



## MELANIN HEALTH TABLE TALKS

- June 17: In honor of Juneteenth, LGBTQ+ Pride Month and Migraine and Headache Awareness Month, we held a special Melanin Health Table Talk conversation on Instagram Live. This session, titled “Migraine, LGBTQ+ Pride & Juneteenth,” amplified the voices of the LGBTQ+ Black community living with migraine and delved into the intersections of health, identity, and history.
- July 29: This special panel covered Wash Day & Chronic Illness. This session featured Black women living with chronic illnesses and shared the impact that the wash day ritual has on them and how they’ve had to pivot to make it work alongside their chronic illnesses.

# MIGRAINE AND HEADACHE AWARENESS MONTH

This year for Migraine and Headache Awareness Month, we featured BIPOC and LGBTQ+ patients living with migraine in a quote campaign that centered around dispelling myths about migraine, reducing stigma and sharing advice about living with migraine that were shared widely across social media and encouraged others living with migraine to speak up.



That it is not a one-size-fits-all, invisible disease. For BIPOC individuals, listen to us before judging us. We have real pain and should be heard. Do not brush off our feelings.

**Ronetta**

on “Misconception about migraine attacks you’d like to dispel”



Migraine and Headache Awareness Month



# GHLF PARTNERS WITH ISLEARNING INC AND CANOPY NEPAL TO IMPACT STUDENTS AND TEACHERS BEYOND BORDERS

- In Q2 2024, GHLF is proud to have seen the work of ISLearning and Canopy Nepal on “Beyond Borders” program continue to impact students in Nepal on leadership skills, self-expression, health and well-being.
- We began initial planning for Q3 2023 to include new additional expert-led sessions by members of the GHLF team on health and well-being topics for students of various age groups in Nepal as part of the “Beyond Borders” program. These sessions range of topics like “General Hygiene,” “What is Rheumatoid Arthritis?,” and “Online Mental Health and Well-being: Tackling Bullying and Sexism.” These sessions provide students with additional insight they may not gain in the classroom or at home about chronic disease and mental and physical well-being.
- “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, Director of Global Partnerships at [akegley@ghlf.org](mailto:akegley@ghlf.org).*

# BUILDING MOMENTUM IN CANADIAN PATIENT ADVOCACY: WEBINARS AND NEW PROJECTS

- In Q2 2024, and in collaboration with Canadian Arthritis Patient Alliance (CAPA), we executed a series of three webinars that were focused on patient advocacy at the federal level for chronic disease patients, as well as the process for new medication approval for reimbursement at the federal level, and the ‘ABCs’ of clinical trial involvement for chronic disease in Canada. These webinars benefitted from health care and governmental experts as well as patient advocate testimonies and had a positive impact on audience learning on these subjects. The webinars will soon be published on our YouTube page.
- In Q2 2024, we continued promotion of our new Canadian alopecia areata podcast episodes of “From Hair to There: Life with Alopecia” and began initial planning for further resource development. We also aim to continue expanding our work in dermatology to include educational and engagement-based resources for atopic dermatitis patients in Q3/Q4 2024.
- We also worked with our Migraine Patient Council members to include their perspectives and advocacy messages in our Migraine and Headache Awareness Month programming in June. Their guidance and support continues to be paramount in the direction of our migraine advocacy and educational work in Canada.
- We enhanced our collaboration with patient organizations and contributed to patient input submissions to the Canadian Agency for Drugs and Technologies in Health (CADTH) that raise the voices of patients to make the case for the need for innovative new treatments, including having helped improve access to innovative treatments for conditions like psoriatic arthritis.
- In Q2 2024, we also commenced pre-production for a new episode of Remission Possible focused on a Canadian patient advocate and her journey toward starting her own patient-centered organization. We plan to record and release this new episode later in Q3 2024.

CREAKYJOINTS  
CANADA





## 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:

- [Beyond Burnout: A New Chapter in Disability Advocacy](#)
- [Is Your COVID Vaccination Still Effective?](#)
- [Seeing Myself as a Whole](#)
- [Breathing Again: My Journey Through Pain Management and Insurance Battles](#)

*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).*

## COMMUNITY EFFORTS MADE FOR DISEASE EDUCATION

GHLF is taking direct action to educate and support communities through targeted outreach initiatives. **Strong Bones and Me/Mis Huesos Fuertes** is actively raising awareness about secondary fractures, highlighting the importance of the Fracture Liaison Service, and promoting osteoporosis prevention within the Hispanic community. This effort precedes the launch of [MisHuesosFuertes.org](http://MisHuesosFuertes.org), a comprehensive osteoporosis resource for the Hispanic community.

In Australia, GHLF started its community outreach for HEROES, an educational program for hair stylists, barbers, and beauty service providers to provide practical information on skin conditions such as alopecia, psoriasis, and eczema (atopic dermatitis).

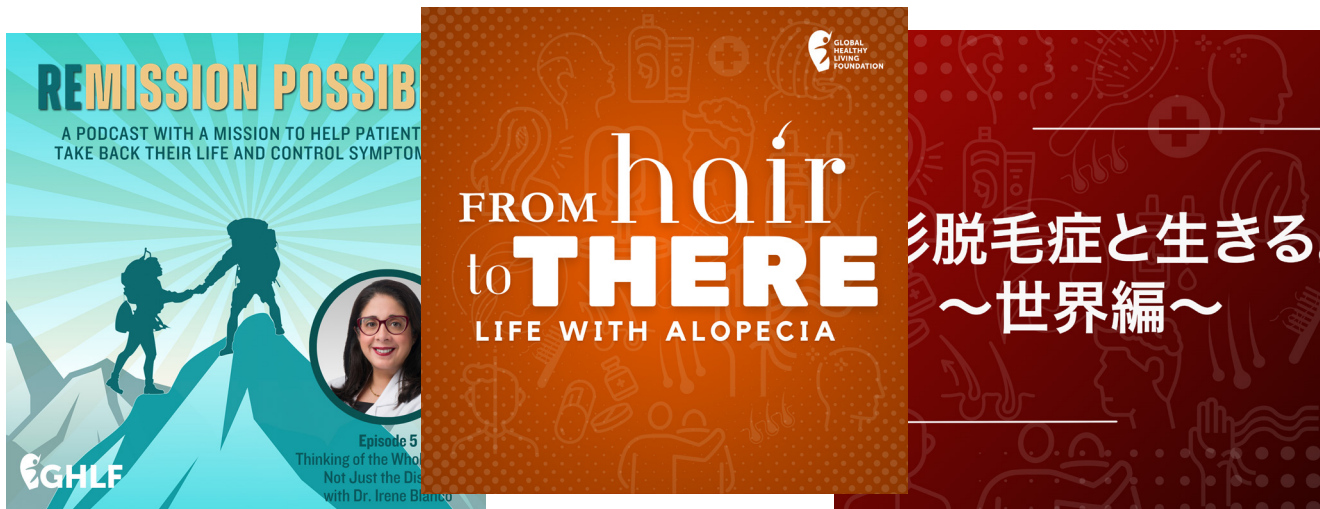
# YOUTUBE HITS 3.7 MILLION; PODCASTS ARE 140,000 IN Q2

During Q2 our YouTube channels generated over 374k views bringing the total views to 3.7 million representing over 185,000 hours watched for our programs. During Q2 we acquired an additional 1,200 subscribers on YouTube.

Our podcast network brought over 140,000 listens in Q2 alone! This great performance in Q2 is due to the release of a few new seasons of sponsored series.

## NOTABLE PODCAST SERIES IN Q2 INCLUDE

- The release of 4 new episodes of Remission Possible. 2 episodes dedicated to understanding remission and systemic lupus erythematosus (SLE) where we shared the perspectives from Racquel, who lives with lupus, and Dr. Blanco, who treats it, as well as 2 episodes in which we explored how patients can work with their doctor to better manage psoriatic arthritis (PsA) and axial spondyloarthritis (axSpA). Together the episodes generated a total of over 46,700 listens.
- We also released 3 new episodes of From Hair to There: Life with Alopecia. The series explores patient journeys from diagnosis to treatment, emphasizing comprehensive care and community support for alopecia areata in various parts of the world. The 3 new episodes focused on Australian patients and experts brought in an additional 22,600 listens to the series, which now totals 53,000 listens. We also released a version of the program in Japanese with an episode that generated over 4,000 listens.



- We also produced 2 new episodes of The Gout Show to dive deeper into the world of gout, debunking common myths and discussing the systemic nature of gout as well as the importance of working with your doctor to find the right treatment. The episodes feature gout patient Gary Ho and his own rheumatologist, Dr. Chris Parker, as well as gout expert and nephrologist Dr. Nissreen Elfadawy. These episodes generated a total of 19,300 listens.
- Another highlight for the network was the release of a special video episode of The Health Advocates featuring singer, songwriter, actress, and activist Cyndi Lauper and chef and restaurateur Michelle Bernstein to talk about their journey with psoriasis and psoriatic arthritis. This special episode garnered over 8,200 listens/views.
- Over its recent episodes, the “Talking Head Pain” podcast has notably covered late-breaking news, highlighted medical conference learnings, and shared diverse stories, particularly during Pride Month.



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.



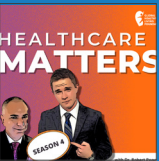
**Getting Clear on Psoriasis:** Listeners will learn about living better with psoriasis, and each episode includes relatable insights from fellow patients and key information from leading dermatologists and other experts.



**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.



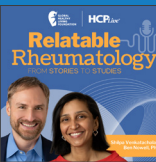
**Patient PrepRheum:** This podcast speaks to Australian patients and renowned doctors to explore important and often-misunderstood aspects of living with autoimmune arthritis and related conditions in Australia.



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



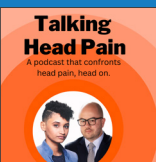
**The Psoriatic Arthritis Club:** Through personal chats with fellow psoriatic arthritis patients, as well as insights from top PsA experts, our host explores the ups and downs of navigating psoriatic arthritis.



**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 WEBSITE USERS; 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:

- Rheumatoid Arthritis Treatment Not Working? Here's What You Need to Know
- Are You Honest with Your Doctor?
- The Other Symptoms of Axial Spondyloarthritis
- Breaking the Silence: How We Talk About Arthritis Symptoms
- My Personal Experience with Biosimilars

*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 by advocating for improved access to health care through education, patient-centered clinical research, support, advocacy, and economic and policy research. 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. In addition to arthritis and autoimmune disorders, GHLF supports dermatology, gastroenterology, neurology, cardiology, oncology, infectious disease, rare disease, and pulmonary patients through a host of different programs and activities which draw more than 700,000 patients a month to GHLF websites and create more than 10 million impressions a month on seven social media platforms. GHLF totals more than 3.7 million views with its patient-centered audio-visual content, found on YouTube and totals more than 840,000 listens on podcast platforms. GHLF never asks the public for donations, receiving funding instead through governments, non-governmental organizations, foundations, industry, family foundations and co-founder Louis Tharp. Visit [ghlf.org](#) for more information.

## 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, PatinetSport ([PatientSport.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 PatientSpot™

Created by [CreakyJoints](#), [PatientSpot](#) is an expansive platform dedicated to providing support through education, conducting patient-centered research, and amplifying the voice of people living with chronic disease to raise awareness about chronic conditions. The PatientSpot platform is now a Food and Drug Administration (FDA) approved Class 1 medical device. To learn more and join PatientSpot, visit [PatientSpot.org](#).



### 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)

