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Q3 2023 GLOBAL HEALTHY LIVING FOUNDATION QUARTERLY REPORT: EMPOWERING PATIENTS, SHAPING POLICY, AND EXPANDING REACH

In the last part of 2023, the Global Healthy Living Foundation (GHLF) stayed focused on its goal of supporting those with chronic diseases, making sure their voices are heard, and pushing for positive changes in health care policies and awareness.

Looking back at the highlights from the past few months, we encourage you to take a closer look at the impactful projects, partnerships, and accomplishments that have helped us continue our mission of improving the lives of individuals living with chronic illnesses.



U.S. ADVOCACY: AMPLIFYING THE CHRONIC DISEASE PATIENT VOICE

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

- GHLF Patient Advocate Brandi L. provided testimony to the Colorado Drug Price Review Board about her experience using Enbrel for her treatment. Brandi provided additional testimony to CMS on October 31st while they are evaluating the medications in the price negotiations.
- GHLF Community Outreach Manager and Patient Advocate JP Summers provided testimony to CMS about her experience taking Entresto to help prevent heart failure.
- GHLF Patient Advocate Terri B. provided testimony about her experience using Stelara for treatment of inflammatory bowel disease.
- We joined other patient groups as part of the Safe Step Coalition in a sign-on letter asking for senate leadership to support the Safe Step Act and include it in the final PBM reform package.
- We signed on to a letter with the New England Hemophilia Foundation and other patient groups in Massachusetts in support of an amendment to ban copay accumulator adjustors in the state.

We submitted comments to FDA about Laboratory Developed Tests that labs use for diagnostic purposes but do not currently fall under FDA oversight.

■ WEBINAR: IMPACT OF FORMULARY EXCLUSIONS ON INDIVIDUAL PATIENTS

In this webinar we explained how formulary exclusions impact a patient's care and well-being. We also shared about original research conducted by the GHLF researchers regarding formulary exclusions and our GHLF's plans to raise awareness concerning this important issue with policymakers. Watch the recording



GHLF HEADS TO JAPAN FOR J-FORUM

Japan is on the Eve of an Advocacy "Awakening."

GHLF convened the first-ever J-Forum meeting of 12 different patient advocacy groups across eight chronic diseases in Japan this quarter to better understand the unmet needs, insights, and perspectives of patients in Japan.

A few interesting findings from our trip:

- There is a lack of understanding on how to be an advocate to advance pro-patient laws and policies.
- Advocacy is often translated as "patient rights protection," but patients and doctors feel this
 working is too strong and inappropriate. There is no direct Japanese translation of the word
 advocacy.
- There are too many hurdles for patients to go directly to the government in Japan. Cancer patients are the exception, with funding and outreach efforts funded by the government.
- Chronic disease patients are passive, and we have to awakened empowerment and awareness within people.
- The average patient does not respond to the concept of advocacy.



For more information on how to partner with GHLF on patient-centered health policy, please contact Steven Newmark, JD, MPA, Chief Policy and Legal Officer, at snewmark@ghlf.org.

PATIENT-FOCUSED ECONOMIC AND POLICY RESEARCH: DRUG EXCLUSIONS, VACCCINE ACCESS, AND MORE

During this quarter, we explore the intersection of patient-focused economic and health policies through a variety of mediums, including a groundbreaking report on "The Importance of Intellectual Property Protections for Patients" by William Smith and Robert Popovian, alongside podcasts, webinars, and presentations addressing critical issues such as drug exclusions, shortages, vaccine access, and the economics of drug pricing ecosystems.

Podcasts

- <u>S4</u>, <u>E8</u>, <u>Beyond the Formulary: Uncovering the Hidden Impact of Drug Exclusions.</u> Apple Podcast
- S4, E7, Prescription for Uncertainty: Navigating the Maze of Drug Shortages. Apple Podcast

Webinar

• Drug Store News Webinar, Vaccine Access – Oct 2023

Presentations

- Association for Value-Based Cancer Care (AVBCC) Understanding the Economics of the Oncology Drug Pricing Ecosystem – Oct 2023
- BMS / Pfizer Alliance Anticoagulation Advocacy Summit 2023 Formulary Exclusions Impact on Cardiovascular Patients – Oct 2023

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.

PATIENT-CENTERED RESEARCH: 13 SUBMISSIONS AT THE AMERICAN COLLEGE OF RHEUMATOLOGY CONVERGENCE

This November, GHLF, along with its digital arthritis patient-centered research registry (formerly ArthritisPower), jointly presented eight scientific abstracts and five patient perspective posters at the American College of Rheumatology Convergence 2023.

Collectively, GHLF researchers focused on innovative approaches to remote therapeutic monitoring, patient engagement, and personalized care in rheumatic and musculoskeletal diseases.

These studies contribute valuable insights to the field of rheumatology and patient-centered research.

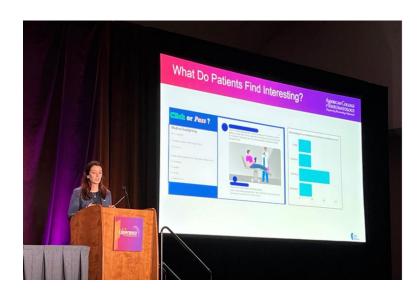
- (0344) Patient Engagement and Adherence to Digital Study Tasks: WEARable Activity Tracker Study Exploring Rheumatoid Arthritis Patients' Disease Activity using Patient-Reported Outcome Measures, Clinical Measures, and Biometric Sensor Data (the WEAR study)
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- (0380) Use of Digital Health Tools to Evaluate Change in Clinical and Patient-Reported Outcomes Among Patients with Rheumatoid Arthritis Initiating Treatment with a JAKi or TNFi
- (0214) COVID-19 Vaccine Uptake, Hesitancy, and Flare in a Large Rheumatology Practice Network (0990) Association of Treatment and Disease Activity with Antibiotic Use and Hospitalized Infection among People Living with Rheumatoid Arthritis: Baseline Data from a Longitudinal Study in the ArthritisPower Registry
- (2092) Feasibility and Efficacy of Culturally Appropriate Spanish Language-First Patient Education for Rheumatoid Arthritis
- (2089) Social Listening Analysis of IgG4-Related Disease Social Media Discussions
- (2026) Developing a Guided Joint Self-Exam for Rheumatoid Arthritis Patients to Use in Telehealth-Delivered Care
- (2025) Osteoporosis Treatment Attributes and Levels for an Online Decision-Making Tool for Patients: Findings from Adaptive Choice-Based Conjoint Analysis

RAISING AWARENESS FOR EARTHQUAKE RELIEF IN MOROCCO

The five patient poster presentations presented by members of the Creakyjoints community highlight how people living with chronic, autoimmune illness take control of their disease management by finding community, identifying health care providers who act as partners, and adding complementary therapies or management strategies to their regimen to improve disease outcomes.

- (PP08) Finding Gratitude in Adversity: The Impact of Finding the Right Rheumatologist
- (PP10) Saved by Plants: How a Necessary Lifestyle Change Led to a Happier Life with Decreased Rheumatoid Arthritis Pain and Fatigue
- (PP01) You Can't Get This From A Doctor: The Role of Support Groups for Adults Aged 22-25 Living With Arthritis
- (PP09) Practicing Mindfulness to Improve Quality of Life
- (PP04) Bouncing Back: How I Found My Running Shoes Using a Rebounder for My Psoriatic Arthritis

In addition, Zoe Rothblatt,
Director of Community Outreach
at GHLF, gave a presentation at
an ACR session on "Strategies
for Health Communication for
Specific Target Audiences." In
her presentation, she shared the
importance of sharing health
information to patients and tips
for defining and disseminating
research to targeted audiences.



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.

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 <u>Facebook</u> and <u>Instagram</u> (in English and <u>Spanish</u>), <u>WhatsApp (in Spanish)</u>, <u>Twitter, YouTube</u>, <u>TikTok</u>, <u>LinkedIn</u>, and <u>Threads!</u> Notable posts from this quarter:

- Instagram: Not a Failure: Changing the Language We Use to Talk About Our Bodies and Illness
- TikTok: Realizing my exes will be forced to think of me whenever they hear the rheumatoid arthritis medication commercials
- Twitter: CreakyChats: Holidays Health & Hurdels

#CreakyChats continued to generate engagement with #CreakyChats: Holidays, Health, & Hurdles, during which our community members generously shared their experiences and strategies for managing the holiday season.



Our YouTube channels views <u>doubled</u> 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 AND CANOPY NEPAL: IMPACTING CHILDHOOD AND EARLY-ADULT EDUCATION AND ADVOCACY

- GHLF continued its third year of support for International Student Learning Inc. (ISLearning) and Canopy Nepal's program, "Beyond Borders," further expanding the program's milestones and programing across Nepal and the U.S.
- With GHLF's support, ISLEarning and Canopy Nepal worked together to reach nearly 850 students across 21 schools over 44 sessions. These sessions included career support, technical and vocational training, overall health and well-being, and psychosocial support.



Photo credit: "Canopy Nepal Newsletters – July & August 2023"

- A major milestone of Q4 2023 was that all of Canopy Nepal's work was recognized on a global stage and was awarded as one of HundrED's 100 most impactful and scalable education innovations globally with the HundrED Innovation Summit and Award.
- Potential new partnerships, such as with elementary schools in Malaysia and enhanced efforts in school in Bangladesh, are being explored through Q1 2024. "Beyond Borders" efforts align directly with the United Nations' Sustainable Development Goals (SDGs), including SDGs 3, 4, 5 11, and 13.

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

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

- In Q4 2023, we conducted all recordings of our Canadian-focused episodes for a new podcast series about alopecia areata, "From Hair to There: Life with Alopecia." Launch of the podcast is planned for Q1 2024. We collaborated closely with the Canadian Alopecia Areata Foundation (CANAAF) alongside Canadian dermatologists and patient advocates across Canada.
- We continued our strong collaboration alongside other patient organizations and contributed
 to patient input submissions to the Canadian Agency for Drugs and Technologies in Health
 (CADTH) that make the case for the need for innovative new treatments, including
 for ankylosing spondylarthritis and psoriatic arthritis.
- Adam Kegley, GHLF Associate Director, Global Partnerships, spoke to <u>Readers Digest Canada</u> & <u>Sélection</u> for a video interview and article about remission and living with rheumatoid arthritis, detailing the myriad ways GHLF supports patients in Canada and around the world and discussed how the definition of remission can vary depending on a patient's goals, provider's goals and more. Kegley also talked about an important GHLF resource, <u>Remission Possible</u>, our podcast series on remission and chronic conditions, featuring a Canadian patient in episode 1.
- GHLF's Canadian Arthritis and Migraine Patient Councils came together for a joint meeting
 in Q4 to discuss patient advocacy in Canada, including how to better advocate at the federal
 and provincial levels and participate in patient input submissions to CADTH, engage provincial
 politicians and more. GHLF has been proud to provide a space and platform for our Patient
 Council Members through 2023 and looks forward to continued collaboration in 2024.



GLOBAL OSTEOPOROSIS INITIATIVE: STRONG BONES & ME

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 had reached tens of thousands of people across 85 countries worldwide by the end of Q4 2023, including the U.S, Canada, Australia, United Kingdom, Mexico, Japan, Germany, France, Spain, Italy,



PHOTO: (credit "StrongBonesAndMe.org")

and many more. Our patient survey reached thousands in over 35 countries.

To further impact Spanish-speaking osteoporosis patients and those at risk around the world, we launched our Spanish-language site, survey, and resources for the program "Mis Huesos Fuertes" in Q4 2023 with planned promotion in Q1 2024 and beyond.

Our social media campaign for World Osteoporosis Day received tens of thousandsd of impressions and many comments from our community. We also distributed the materials to our Global Council Members, who sent many of our materials and posts to their communities as well, further reaching tens of thousands across the globe.

Our next steps include English and Spanish-language interviews with patients and health care professionals from around the world to increase our reach and resources available to patients and also an update to our site with results from the first survey and a planned second survey and additional localized osteoporosis resources for various countries around the world later in 2024.

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.

CREAKYJOINTS AUSTRALIA

- The CreakyJoints Australia team was proud to co-host the Holidays, Health and Hurdles #CreakyChats session alongside our global colleagues in December.
- We were invited to attend a virtual Lupus Advocates Forum run by Astra Zeneca in November. Australia does not have a national lupus organisation so the forum was set up to foster a greater connection between those who support and advocate for the lupus and autoimmune disease community.
- The event provided an opportunity for organizations and individuals to meet and share, ask questions, and hear the latest about lupus from Eric Morand, Professor of Medicine and Head of the School of Clinical Sciences at Monash University and Head of Rheumatology at Monash Health in Melbourne, Australia. Prof Moran's clinical research focusses on systemic lupus erythematosus.
- There was general agreement amongst attendees that it would be beneficial for patient organizations and patient advocates to meet again to further discuss opportunities for collaboration and advancement of lupus advocacy.
- We attended a virtual meeting run by Pfizer and learned about their plans to make RSV vaccines available in Australia for different cohorts. Their first vaccine is for pregnant mothers, but it is intended for the unborn child as newborns are highly susceptible to this virus. Participants were invited to help them advocate for this maternal vaccine to be added to our National Immunisation Program.
- In collaboration with Alopecia Areata Foundation Australia, GHLFA completed recording three episodes for the podcast From Hair to There. These episodes hosted by GHLFA's National Coordinator, Naomi Creek are co-hosted by Jo Burch a psychologist living with alopecia. Together they have in-depth conversations with patients and dermatologist Rodney Sinclair. The episodes will launch in March 2024 and follow on from three recently released Canadian episodes created by GHLF and the Canadian Alopecia Areata Foundation.
- We continued our commitment to sharing relevant research opportunities through our social media channels, including clinical trials and surveys.

OCT-DEC '23

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, CreakyJoints Australia <u>published an
article promoting the release of the Standards</u> and outlining the process involved in developing
them.

- Arthritis Australia invited us to provide feedback on their new <u>Consumer Care Guide for Rheumatoid Arthritis and Consumer Care Guide for Juvenile Idiopathic Arthritis prior to publication of those resources in December. Our feedback was informed by our lived experience of these conditions and our knowledge of the lived experience of members of our community. Many of our suggestions were included in the published version of these resources.
 </u>
- We have been sharing the Australian Rheumatology Associations updates on COVID-19 vaccines since the start or the pandemic. In the <u>November update</u>, we included additional content about the ongoing need to protect ourselves against COVID-19.
- On World Psoriasis Day, we published the <u>video of Eliza Spencer</u> talking about her experience of growing up with psoriasis and eczema on our GHLF Australia website.
- In the lead up to World Arthritis Day, we asked members of our community to share their
 experiences of living with these chronic conditions across different age groups. We used their
 comments in our article World Arthritis Day 2023: Stories of Life with Arthritis.
- We also gathered single words to describe arthritis from our community. These contributed to the CreakyJoints word cloud infographic which was shared across our global platforms.
- Our <u>Government Supports for People with Chronic Conditions</u> page is our most visited page on our website. The Australian Government launched several major health initiatives in this quarter, so we updated our page accordingly.
- We provided an article for every edition of *Rheumatology Republic*, a publication distributed across Australia to rheumatologists, GPs and health professionals interested in this field. <u>In our article for the November edition</u>, we were invited to share our insights on a research project that explored patient experience of outpatient rheumatology care.
- Our <u>CreakyJoints Australia Community</u> closed Facebook group now has 315 members, including 19 who joined since the end of Q3. We now promote it as a call to action at the end of our published content and it is proving a very important source for hearing the voices of our patient community.

TALKING HEAD PAIN COVERS THE AMERICAN HEADACHE SOCIETY AND EUROPEAN HEADACHE CONGRESS

This quarter, GHLF took Talking Head Pain on the road, attending both the American Headache Society and European Headache Congress. Our goal was to delve into the latest advancements in migraine care, exploring emerging trends, innovative treatments, and gaining insights into specialized care for migraine patients.

Episodes included:

- Moving Beyond Pain: Uncovering Migraine Patients' Surprising Activity Trends with Dr. Maoz Halevy
- Shaping the Future of Migraine Care in Puerto Rico: A Brief Discussion with Dr. Franchesca Fiorito
- Following The Pain: Botox's Role in Migraine Treatment with Dr. Jana-Isabel Huhn-Doll
- Medication Overuse Headache and Vestibular Migraine: A Brief Discussion with Dr. Miguel Lainez



GHLF LAUNCHES VACCINE HUB

In Q4 we created a central hub for vaccine advocacy and education, which aggregates all of our related work onto a single landing page. This hub also emphasizes our dedication to vaccine-related scientific research and public health.

- The hub encompasses a range of sections, including our initiatives in vaccine education and research, our efforts to combat vaccine misinformation, our partnerships with health care organizations, and our commitment to policy advocacy. In that regard, all GHLF's vaccine related publications can be found on the landing page.
- The hub also incorporates audiovisual resources such as podcast episodes and webinars dedicated to vaccine education and information.
- This comprehensive resource reflects our continuous efforts to promote health and wellness across communities, ensuring that every individual has access to the critical vaccine information and support they require.



GLOBAL HEALTHY LIFESTYLE EVENTS

At the GHLF, we understand that living with a chronic condition involves more than just doctor visits and medication. Our "Global Healthy Lifestyle Events" are specially crafted to promote healthier living and offer attendees a treasure trove of resources and practical tips for effectively managing everyday decisions that influence our well-being.

GHLF partnered with Walgreens to host virtual health events promoting healthier living and providing resources for managing health conditions. In December of Q4, we hosted "Staying on Track: How Eating, Exercising, and Mindfulness Play a Role in Medication Adherence" which talked about the nuances of medication adherence and the myriad benefits of integrating pharmacists, dietary habits, physical activities, and mindfulness practices into health routines.

Guests included: Pharmacist Dr. Dorothy Loy, Senior Director of Pharmacy Services and Patient Outcomes at Walgreens; Dr. Alejandro Chaoul, Mind-Body Practice Expert; Ginger Hultin, Nutritionist; and our host Dr. Chad Woodard, Physiotherapist.



COMMITTED 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 fourth quarter included:

- COVID Finally Caught Me!
- 75 Percent of People with Chronic Illness Received or Plan to Get Both COVID and Flu Shot This Season
- New Research Shines Light on COVID-19 Vaccine Uptake and Flares in Rheumatology Patients
- #CreakyChats: Fall into Healthiness: Season of Vaccines

We also conducted patient polls with our COVID support group to learn more about how our community feels about the RSV vaccine, which was approved earlier in the year, and recommended for adults ages 60 and older and infants. While the majority of eligible participants were opting for the shot, the GHLF poll found lack of doctor advice, unawareness, and timing issues were key factors in skipping RSV vaccine. You can read the full results <u>here</u>.



CROHN'S AND COLITIS WEEK: GHLF SUPPORTS CROHN'S PATIENTS

GHLF partned with Walgreens to ramp up content during this year's Crohn's and Colitis week to support patients in recognizing symptoms and creating a care plan. Crohn's and Colitis week takes place each year during the first week of December in the U.S. It is a time of year aimed at raising awareness about Crohn's disease and ulcerative colitis, which are both forms of inflammatory bowel disease (IBD).

Notable videos and reels published for Crohn's and Colitis Week:

My Gut Check: When I Took Charge of My IBD - Jaime's Story My Gut Check: When I Took Charge of My IBD - Basmah's Story My Gut Check: When I Took Charge of My IBD - Brad's Story

Health Advocates: Crohn's and Colitis Awareness Week with Pharmacist Mallory Schmoll



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.

HISPANIC OUTREACH AND EDUCATION

As part of GHLF's ongoing efforts in Hispanic outreach and education, we launched several key initiatives aimed at addressing the specific healthcare needs of the Hispanic community. These initiatives include:

- Hispanic Heritage Month GHLF celebrated the rich culture, history, and contributions of
 the Hispanic community. It remained dedicated to addressing the unique challenges faced
 by Spanish-speaking populations in health care, emphasizing the importance of supporting
 individuals navigating health care and insurance systems. As part of its ongoing efforts,
 GHLF highlighted social determinants of health and worked to foster a sense of community
 and empowerment among Hispanic individuals, advocating for positive change and inclusivity
 in health
- 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, the launch of MisHuesosFuertes.org, a comprehensive osteoporosis resource for
 the Hispanic community, with a specific focus on the Latin American (LATAM) and Spanishspeaking audience, highlighting osteoporosis risks and prevention measures.



SIX NEW PODCASTS DRIVE MORE THAN 400,000 LISTENERS IN 2023

Our podcast network broke a new performance record and Q4 confirmed exponential growth for our network with a total of 432,000 listens in 2023! This growth is in large part driven by the release of six new podcast series and the release of two new seasons of existing shows in 2023, building upon our existing audience.

Notable podcast series in Q4 include:

"Informed Immunity" presented by "Wellness Evolution" where we tackle the most pressing topics on vaccines, from debunking myths to advocating for public health. The hosts make it their mission to translate medical jargon into bite-sized, actionable insights to cover the latest vaccine developments and provide health guidance.

The series was released in English and also Spanish under the name "Inmunidad Informada" and totaled eight episodes. It has garnered over 67,000 listens since its release.

Our weekly and biweekly series, "The Health Advocates" and "Talking Head Pain" continued to deliver vital health care news and patient journey insights with listenership spikes due to popular live episodes captured at various congresses and events and other episodes that attracted listeners via YouTube and social media. Episode 28 of the sixth season of "The Health Advocates" on topics related to Crohn's and Colitis Awareness Week enjoyed 1,900 listens alone.













<u>Dungeons & Diagnoses:</u> 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.



<u>Getting Clear on Psoriasis</u>: 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.



<u>Gut Culture:</u> 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.



<u>Healthcare Matters:</u> 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.

















<u>Patient PrepRheum:</u> 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.

<u>Patiently Connecting</u>: 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 hig:hlights 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.

<u>Wellness Evolution</u> 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

1.9 MILLION NEW ARTHRITIS VISITORS AT CREAKYJOINTS.ORG

Our websites saw continued growth, with more than 1.9 million new users on CreakyJoints.org. Our email list grew to more than 250,000 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:

- Tis the Season to Set Boundaries
- You Can't Get This From a Doctor: The Impact of Support Groups for Those Living with Arthritis
- <u>Don't Throw Out Those Running Shoes</u> <u>How You Might Renew a Passion for Exercise</u>
- Your Guide to IgG4-RD
- Linda's Polymyalgia Rheumatica Journey: From Not Being Able to Move to Moving Others Toward Advocacy
- The Right Doctor for You Might Be Just Around the Corner



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.

CGHLF

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 <u>CreakyJoints</u>, 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 <u>50-State Network</u>, which includes more than 1,700 trained volunteer patient, caregiver, and provider health care activists.

CreakyJoints' patient-reported outcomes registry, ArthritisPower (<u>ArthritisPower.org</u>), 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 <u>podcast series</u> that provide both patient and provider perspectives. It also hosts PainSpot (<u>PainSpot.org</u>), a digital risk-assessment tool for musculoskeletal conditions and injuries, and eRheum (<u>eRheum.org</u>), for telehealth and virtual-care support. All programming is free, always. For more information, visit <u>CreakyJoints.org</u> or its parent organization, the <u>Global Healthy Living Foundation</u>, 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 <u>CreakyJoints</u>, <u>ArthritisPower</u> 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 <u>ArthritisPower.org</u> (in English) or <u>ArthritisPower.org</u> (in Spanish).





About the 50-State Network

GHLF's Patient-Centered Policy Research Initiative

ghlf.org/our-work/economic-policy-research.

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.

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



About PainSpot

PainSpot by <u>CreakyJoints</u> 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, Creaky Joints, and/or the Arthritis Power 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 Creaky Joints, eRheum.org is a website designed to help patients get the most from their telehealth appointments. Written in patient-friendly language, eRheum defines telehealth and how rheumatologists utilize it, provides patients with access to different videoconferencing portals to try with their physician, and explains how to make the most of quick-moving appointments. To learn more, visit eRheum.org (in English) or eRheum.org.es (in Spanish).





Find us online

CreakyJoints: CreakyJoints.org

CreakyJoints Español: www.CreakyJoints.org.es

CreakyJoints Canada: CreakyJoints.ca

CreakyJoints Australia: <u>CreakyJoints.org.au</u> Global Healthy Living Foundation: <u>ghlf.org</u>

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

GlobalHealthyLivingFoundation

Twitter: @GHLForg, @CreakyJoints, #CreakyChats

Instagram: @creaky joints, @creakyjoints_aus, @creakyjoints_esp

TikTok: globalhealthylivingfnd

LinkedIn: linkedin.com/company/ghlf











