



# QUARTERLY REPORT

APRIL - JUNE 2023



GLOBAL  
HEALTHY  
LIVING  
FOUNDATION

# Contents

GHLF Launches Salon HEROES .....	3
ArthritisPower Research Presented at the 2023 EULAR Congress in Milan .....	7
June: We Show our Pride .....	10
Strong Bones & Me: A Global Osteoporosis Initiative for Patients Everywhere .....	13
Published Research Propels Arthritis Knowledge Forward.....	15
Committed to COVID-19 Education .....	18
GHLF’s Introduces Two New Podcasts to Its Extensive Library .....	20
ArthritisPower Research Reaches Thousands of Patients .....	23
U.S. Advocacy Activities Amplify the Chronic Disease Patient Voice .....	29
CreakyJoints Español Grows Engagement .....	32
CreakyJoints Australia and GHLF Australia Launch New Education Initiatives.....	33
Global Healthy Living Foundation Canada/La Fondation Mondiale pour Vivre en Santé au Canada Pushes for Broad Patient-Centered Voices Across Disease States ....	36
GHLF Enters Third Year Supporting Childhood and Early-Adult Advocacy in Nepal and the United States .....	38
CreakyJoints and GHLF in Conventional News and Online .....	39
Who We Are .....	42

# GHLF LAUNCHES SALON HEROES

According to a new Global Healthy Living Foundation (GHLF) survey, 96 percent of stylists surveyed (n=118) know what psoriasis is, but only 27 percent often or always talk to their clients with psoriasis about the condition. Similarly, 99 percent of surveyed stylists know what eczema is, but only 35 percent of them often or always talk to their clients with eczema about the condition.

96%

stylists know what psoriasis is

27%

stylists often or always talk to their clients with psoriasis about the condition

99%

stylists know what eczema is

20%

stylists often or always talk to their clients with eczema about the condition

To bridge the gap between knowledge and action, in June, GHLF launched the [HEROES \(Health Education + Reliable Outreach + Empathetic Support\)](#) program. Created by, with, and for stylists, salons, and barbershops, with input from patients and health care professionals, GHLF's HEROES program is a free platform to equip salon professionals to better support their clients with skin and scalp conditions. Upon signing up, hair professionals receive evidence-based information about psoriasis, as well as atopic dermatitis (eczema) and alopecia, in accessible, easy-to-understand formats for both HEROES and their clients. In our survey, we found that 98 percent of stylists interested in the HEROES program reported that, after receiving information about skin conditions from GHLF, they would suggest a client gets medical care if they have signs of a skin condition.

“

Over time, our stylists, barbers, and related beauty professionals become close confidants, someone we share personal stories with while sitting in the chair. Building on those trusting relationships, we created the HEROES program to spark positive health conversations, reduce stigma, and accelerate diagnosis to improve health outcomes for patients with chronic skin conditions. Addressing the fact that skin diseases might present differently in Black, Indigenous, and People of Color (BIPOC) is one way we are working to reduce health disparities. One of the most important ways to improve health outcomes is helping to facilitate early and fast diagnosis in marginalized communities.”

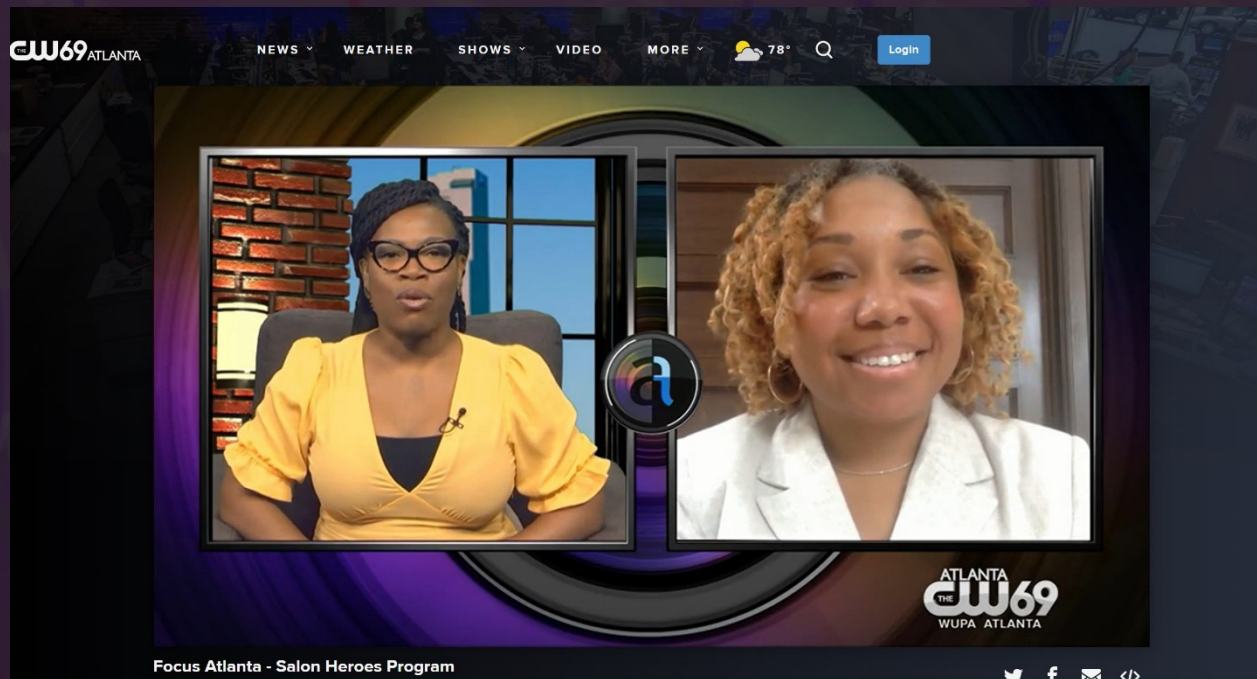
In addition to the press release, our Instagram page [@GHLF Heroes](#) launched with regular content to encourage HEROES conversations at the salon, which we also promoted via our editorial and podcast platforms.



In advance of our launch, we onboarded professional and patient spokespeople to deliver key messages about the Salon HEROES campaign, clinical perspectives about skin diseases of the scalp, and living with chronic skin diseases of the scalp. We are presently working with:

- Dr. Loyd Godwin, MD, Founder of Dermatology Physicians of Connecticut, Norwalk and Shelton, CT, serving as a primary medical advisor to the HEROES program and appearing in the press release
- Dr. Elle de Moll, also a dermatologist with Dermatology Physicians of Connecticut
- Dr. Andrew Alexis, Dermatologist and Vice-Chair for the Diversity and Inclusion for the Department of Dermatology at Weill Cornell Medicine and President of the Skin of Color Society
- Brittane Thames, an Atlanta-based social media manager for a major public health organization and mobile barber who lives with psoriasis since she was 8 years old
- Alisha Bridges, an Atlanta-based member of the Salon HEROES patient advisory board who lives with psoriasis
- Beth Morton, a member of the of the Salon HEROES patient advisory board who lives with psoriasis and migraine

Media outreach to reach hair professionals, dermatologists and people living with these conditions generated many interview opportunities, some of which will occur in the third quarter. Notable secured coverage in the second quarter included [Urban Health Today](#), [Practical Dermatology](#), [American Salon](#), [Focus Atlanta](#) (a local CW-TV segment featuring Brittane Thames), [Dermatology Times](#), and the [Westchester & Fairfield County Business Journals](#).

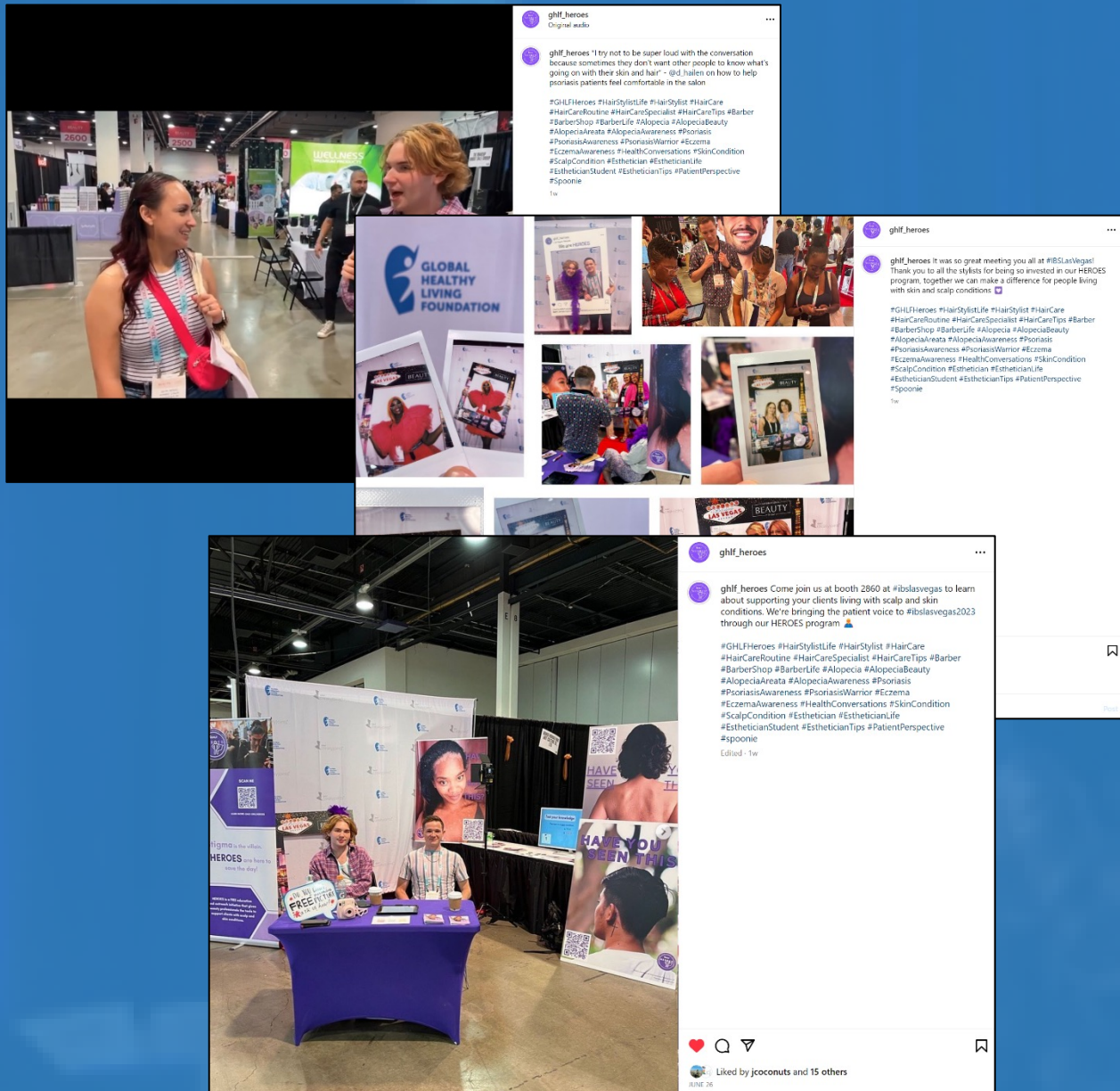


Pending third quarter media includes a short article in the *Atlanta Journal Constitution*, a 30-minute radio interview with **WICH-AM** (Norwich, CT), an online article in **Psoriasis Advance**, a 45-minute interview on the **Alopecian Queen** podcast, a 60-minute segment on the **Hair Therapy** podcast, **PBS South Florida's All Health Go Instagram Live** event, and two online articles with **GoodRx**. Media outreach continues.



## INTERNATIONAL BEAUTY SHOW LAS VEGAS

To increase visibility and directly recruit HEROES, the GHLF team attended the International Beauty Show in Las Vegas, June 22-24. At our interactive booth, we spoke with hair professionals from across the country, many of whom appeared on camera to talk about best practices for empathetic conversations about skin diseases for social media segments that aired during and after the show.

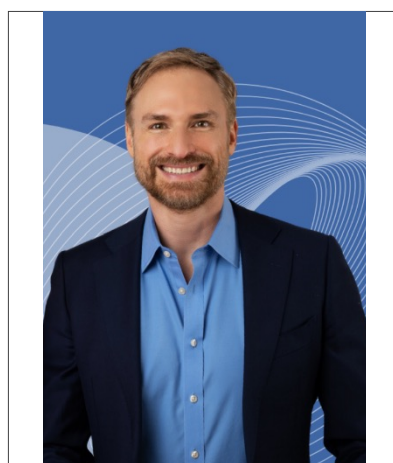


*For more information on how to partner with GHLF on the HEROES program, please contact Sarah Shaw, Senior Manager of BIPOC Community Outreach, at [sshaw@ghlf.org](mailto:sshaw@ghlf.org)*

# ARTHRITISPOWER RESEARCH PRESENTED AT THE 2023 EULAR CONGRESS IN MILAN

At the 76th EULAR European Congress of Rheumatology presented by the European Alliance of Associations for Rheumatology, May 31-June 3, 2023 in Milan, Italy [CreakyJoints](#) gave an oral presentation of the first ever assessment of the perspectives of people with RA on disease-related lab testing and its role in treatment decision-making alongside presenting two additional posters.

The presentation titled, [“Patient Perceptions of Rheumatoid Arthritis Blood Work and Utility of a Test Predicting Response to New Medication: A Cross-sectional Survey in the ArthritisPower.”](#) included results from a recent survey (n=405) that asked patients to share their perceptions about RA bloodwork, reasons their doctor orders these tests, and how results are used. Most patients understood that their doctor ordered laboratory tests to check for active inflammation (85.9%) or assess side effects of medications (81.2%). Most feared (91.4%) that their current RA medication would stop working and that they would waste time trying to find (81.7%) an alternative, effective therapy. These findings also published in [Arthritis Care & Research](#) in late June.



In the press release, lead author W. Benjamin Nowell, PhD, Director, Patient-Centered Research and principal investigator of the ArthritisPower Research Registry said, “To feel engaged in treatment decision making, people living with RA need to understand why their rheumatologist orders tests and how the results are used to guide choices about care.” A [podcast](#) on the study produced by Rheumatology & Arthritis Learning Network (which published in the third quarter) was the most popular article on the entire network even a week after it published, according to the editor.

## ■ PSORIATIC ARTHRITIS (PSA) PATIENTS SEEK WELLNESS PROGRAMS, BUT FACE BARRIERS

A poster titled, “[Managing Psoriatic Arthritis: Patients’ Views and Attitudes to Using an Online Wellness Program.](#)” reported results from a recent ArthritisPower survey finding that nearly all (90%) of patients were ‘somewhat likely’ or ‘very likely’ to interact with an online coach at least twice (90.4% and 92.6%, respectively) if they had the opportunity to take part in a wellness program. However, only 8.7 percent were currently participating in a wellness program. Barriers to participating to learn more about nutrition, exercise, sleep, and stress management were cost and not having the energy to make changes.



**Rheumatology & Arthritis Learning Network**

HOME EDUCATION RESOURCES TOPICS EXCELLENCE FORUMS CLINICAL UPDATES CONFERENCE COVERAGE ABOUT JOB BOARD

**PODCAST**

**Shilpa Venkatachalam, PhD, on Patient Attitudes to Online Wellness Programs for Psoriatic Arthritis**

06/15/2023

Are your patients meeting their therapy goals?  
**HEAR FROM YOUR PEERS**

**Full Prescribing Information >**  
**IMPORTANT SAFETY INFORMATION!**  
**INDICATION!**  
RINVOQ is indicated for the treatment of adults with active psoriatic arthritis who have had an inadequate response or intolerance to one or more TNF blockers.

**Shilpa Venkatachalam, PhD, on Online Wellness Pr...**

Dr Shilpa Venkatachalam reviews the results of a survey among patients with psoriatic arthritis regarding interest in and barriers to participation in an online wellness program.





















**Shilpa Venkatachalam, PhD, is director of Patient-Centered Research Operations and Ethical Oversight at the Global Healthy Living Foundation.**

Shilpa Venkatachalam, PhD, MPH, Director, Patient-Centered Research Operations and Ethical Oversight and co-principal investigator of ArthritisPower said, “Successful treatment of any chronic disease, including psoriatic arthritis, requires a holistic approach that goes beyond diagnosis and taking medication. This study tells us that while PsA patients are willing to add wellness education and lifestyle adaptations to their disease management strategy, those programs need to be both accessible and affordable to optimize participation.” Dr. Venkatachalam spoke about her research on a podcast published by [Rheumatology & Arthritis Learning Network](#) and was also interviewed by Health Central (pending). [HCPLive/Rheumatology](#) (formerly Rheumatology Network) also covered the data.



## ■ MINING SOCIAL MEDIA CONVERSATIONS INFORMS UNDERSTANDING OF GOUT

A poster titled [“Using Social Media Conversations to Understand Patient Care: Factors Driving Proactive vs. Reactive Management of Gout.”](#) reported on an artificial intelligence analysis of social media conversations among gout patients and a public subreddit to evaluate how they discuss onset of symptoms (reactively) and disease management (proactively). Reactive care gout conversations were associated with a significantly higher probability of mentioning ‘pain’ and ‘swelling’ and a significantly lower probability of mentioning ‘uric acid’ than were proactive care conversations, meaning that discussions about reactive care experiences tended to be more negative than those about proactive care.

Highest Impressions	Prolific Tweeters
 <a href="#">@RheumNow</a> 2.9M	 <a href="#">@RheumNow</a> 233
 <a href="#">@CreakyJoints</a> 2.9M	 <a href="#">@omaremm28</a> 161
 <a href="#">@LouisTharp</a> 1.3M	 <a href="#">@CreakyJoints</a> 157
 <a href="#">@ARD_BMJ</a> 1.2M	 <a href="#">@GHLF_Kelly</a> 156
 <a href="#">@Janetbirdope</a> 1.0M	 <a href="#">@authorjpsummers</a> 147
 <a href="#">@eular_org</a> 934.6K	 <a href="#">@LouisTharp</a> 139
 <a href="#">@abbvie</a> 630.4K	 <a href="#">@NoufAhmedAlham2</a> 131
 <a href="#">@EMEUNET</a> 576.4K	 <a href="#">@ARD_BMJ</a> 127
 <a href="#">@authorjpsummers</a> 529.8K	 <a href="#">@StevenNewmark</a> 115
 <a href="#">@Noboru_Hagino</a> 492.9K	 <a href="#">@LupusEurope</a> 114

Daniel Hernandez, MD, Director, Medical Affairs and Hispanic Outreach, Global Healthy Living Foundation discussed this study with **DocWire News** (pending).

As always, CreakyJoints prioritizes the dissemination of research results (ours and external studies) via our social media platforms. During EULAR the @CreakyJoints handle tied for the most impressions at the conference and GHLF-affiliated accounts occupied three of the top 10 spots for that metric. Additionally, we were responsible for 5 of the top 10 tweeters of the conference, establishing ourselves as the most present and impactful patient group covering EULAR 2023. We earned over 1,500 likes

and over 1,400 retweets throughout the course of our coverage and our engagement rate peaked on Thursday, June 1, at a whopping 6.4%, (For context: average engagement rates on twitter are between 0.02%-0.09%, with anything over 1% being considered very successful.) We averaged a 4.5% engagement rate throughout the conference, as well.

*For more information on how to partner with GHLF on future research, please contact Dr. Ben Nowell, Principal Investigator and Director of Patient-Centered Research, at [bnowell@ghlf.org](mailto:bnowell@ghlf.org) and Dr. Shilpa Venkatachalam, Director of Patient-Centered Research Operations and Ethical Oversight and Co-Principal Investigator, at [svenky@ghlf.org](mailto:svenky@ghlf.org)*

# JUNE: WE SHOW OUR PRIDE

At the Global Healthy Living Foundation (GHLF) and CreakyJoints, we recognize the significance of raising awareness about migraine and headaches, while also celebrating and advocating for LGBTQ+ individuals' rights and well-being, which is why we celebrated both National Migraine and Headache Awareness Month and Lesbian, Gay, Bisexual, Transgender and Queer+ (LGBTQ+) Pride Month in June.

Specific to National Migraine and Headache Awareness Month, GHLF released special episodes of the Talking Head Pain podcast that featured people from Canada who live with migraine disease. We also attended the American Headache Society 2023 annual meeting in June, where we recorded conversations with Dr. Barbara Nye, a Neurologist, Headache Specialist, and the Program Director for the Headache Fellowship at Atrium Health Wake Forest Baptist to discuss the latest trends and developments in headache research, including a focus on diversifying patient representation and understanding the unique experiences of different ethnicities and genders. Dr. Hida Nierenburg, a double-board certified in neurology and headache medicine from New York discussed the transformative potential of recent therapies in managing head pain and migraine, along with her anticipation for future breakthroughs in treatment.



During June, Joseph Coe, MPA, Director, Therapeutic Area Growth and Integration, also saw the publication of his first in a series of articles for [WebMD](#) about living with migraine.



At GHLF, we strive to amplify diverse voices, advocate for comprehensive care, and ensure that every individual feels supported on their healthcare journey, regardless of their intersecting identities. For LGBTQ+ Pride Month, we invited all to hear firsthand from members of our chronic illness community about the vital importance of representation for the LGBTQ+ community in achieving health equity. Several of our members contributed comments and photos to our Pride Month [landing page](#). Some examples are:



*Follow Yuri on Instagram @migrainetalk*

Yuri C. (they/them), who resides in California, lives with chronic migraine: “I’m othered by society all the time”

#### **Why Representation Matters to Me:**

“

“I’m othered by society all the time, being Queer, mixed, and Disabled; it’s everything to see people like me. We need to improve social safety so people don’t have to constantly monitor how they look or speak to avoid being harmed. Especially in migraine groups where we’re looking for education and support. I’m already exhausted by chronic migraine. Being constantly vigilant is another level of exhaustion. We need a community that reflects us.”





### Why Representation Matters to Me:

“

As a bisexual person with multiple chronic illnesses/disabilities, I feel representation is essential. Studies show members of the LGBTQ+ community are more likely to have a disability. As marginalized communities, we need to be inclusive and respectful of all sexualities. We face enough exclusion and abuse from others.”

Follow Karen on Instagram @chronic.kp

We also published new articles, such as, [Health Care Disparities in the LGBTQIA+ Arthritis Community: Breaking Barriers and Promoting Equality](#) and [Proud to Be](#).

*For more information on how to partner with GHLF on programs that target the migraine or LGBTQ+ community, please contact Sarah Shaw, Senior Manager of BIPOC Community Outreach, at [sshaw@ghlf.org](mailto:sshaw@ghlf.org)*

### Health Care Disparities in the LGBTQIA+ Arthritis Community: Breaking Barriers and Promoting Equality

PUBLISHED 06/23/23 BY KELSEY KLOSS

Here we look at several of the challenges faced by the LGBTQIA+ community — and how you can take steps to advocate for yourself or a loved one in the doctor's office.



Credit: Tatiana Ayazo



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

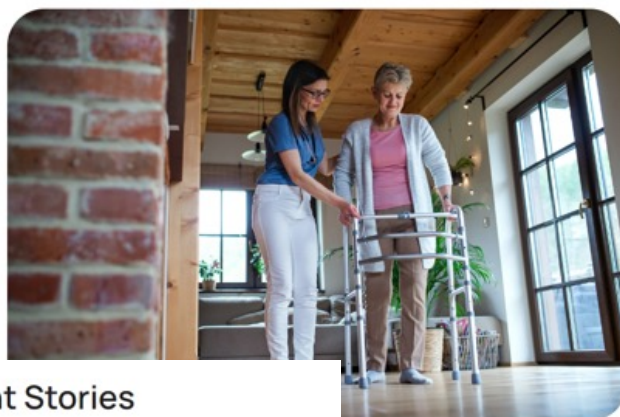
Launching this year, GHLF's [Strong Bones & Me](#) built on its momentum in the second quarter, continuing to focus on patient-centered education to increase awareness and engagement on osteoporosis with a focus on secondary fracture prevention and post-fracture care across the globe.

In May, we released our new [Strong Bones & Me](#) website, which is a hub of osteoporosis-centered engaging articles, patient and provider story videos, our patient survey and much more. To coincide with the release of the site, GHLF held a special bone health and osteoporosis-based #CreakyChats on Twitter, which reached over a million people around the world and included participation from some of our Strong Bones & Me Global Council members (partner organizations), who help guide and disseminate the program's resources.

### Fracture Prevention



### Care After a Fracture




### Patient Stories



We also launched a comprehensive osteoporosis-centered social media campaign during the month of May during Osteoporosis Awareness and Prevention Month. The campaign reached tens of thousands of people around the world with impactful resources on everything from risks of osteoporosis, connected conditions (pre/co-conditions), secondary fracture prevention, post-fracture care options and much more.

Our osteoporosis [patient survey](#) continues to collect experiences from people living with – or at high risk for – osteoporosis around the world and has already seen thousands of people from over 37 countries participate. We will be keeping our survey open through the third quarter and use the findings to develop further program resources later this year and early 2024.



***What do you know  
and what do you need  
to learn?***

Take our short bone health survey and share your insights. What you share is valuable to us.

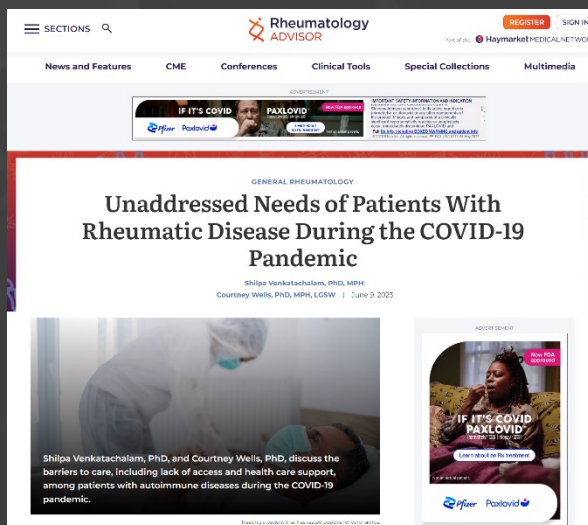
Take The Survey

Next, the program will translate the website and all our resources into Spanish to make our material more accessible to those around the world as well as continuing to create tailored resources for those living in North America, Latin America, Europe, and Australia. As an example of a global resource, Fiona Naughton, an Australian lady with years of lived experience of osteoporosis [shared her story in a video](#) for the Strong Bones & Me website.



# PUBLISHED RESEARCH PROPELS ARTHRITIS KNOWLEDGE FORWARD

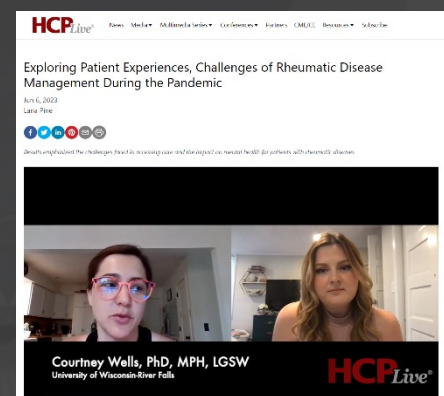
In addition to EULAR, during the second quarter, the GHLF Research team saw three additional ArthritisPower studies publish:



A study published in ACR Open Rheumatology found that during the COVID-19 pandemic, patients with autoimmune rheumatic diseases (ARDs) experienced multiple care disruptions and barriers to care related to issues with navigating information and lacking health care support that persisted past the date when vaccines became available, particularly among the 32 percent of Hispanic study participants looking to access information in Spanish. This was the first study to employ rigorous qualitative methods to document diverse patient perspectives particularly those from

underrepresented communities regarding the first year of the COVID-19 pandemic. A key theme that researchers reported was that the challenges posed by information processing, health care restrictions and disruptions, and balancing risks took a toll on participants' mental health. Participants frequently reported feelings of anxiety or sadness that were associated with the compounded burdens of COVID-19-related risk and managing ARD-related health.

Lead authors Courtney Wells, PhD, MPH, LGSW, Assistant Professor & Field Director, University of Wisconsin-River Falls and Shilpa Venkatachalam, PhD, MPH, Director, Patient-Centered Research Operations and Ethical Oversight discussed this study in a byline article published by Rheumatology Advisor. Dr. Wells also appeared in a video interview (in two parts) with HCP Live/rheumatology.





Other studies published in the second quarter included:

- Beukelman T, Long MD, Rhee RL, Kappelman MD, Merkel PA, Nowell WB, Clinton C, Ringold S, Del Gaizo V, Price B, Shaw DG, Venkatachalam S, Cuthbertson D, Xie F, Zhang X, Curtis JR. **Assessment of Real-World Patient-Reported Outcomes in Patients Initiating Biologic Agents for the Treatment of Autoimmune Diseases: An Observational Study in Four Patient-Powered Research Networks.** *Patient Relat Outcome Meas.* 2023;14:171-180 <https://doi.org/10.2147/PROM.S392174>

**Conclusion:** “As expected, many patients experienced improvement in PROs following initiation of treatment with biologics for autoimmune diseases. Nevertheless, a substantial proportion of participants did not exhibit abnormalities in all PROs domains at baseline, and these participants appear less likely to experience improvement. For PROs to be reliably and meaningfully included in the evaluation of real-world medication effectiveness, more knowledge and careful consideration are needed to select the most appropriate patient populations and subgroups for inclusion and evaluation in studies measuring change in PROs.”

- Rao K, Speier W, Meng Y, Wang J, Ramesh N, Xie F, Su Y, Nowell W, Curtis J, Arnold C., **Machine Learning Approaches to Classify Self-Reported Rheumatoid Arthritis Health Scores Using Activity Tracker Data: Longitudinal Observational Study,** *JMIR Form Res* 2023;7:e43107, <https://formative.jmir.org/2023/1/e43107>, DOI: 10.2196/43107

**Conclusion:** “While further validation of our results and evaluation in a real-world setting remains, this study demonstrates the ability of physical activity tracker data to classify health status over time in patients with rheumatoid arthritis and enables the possibility of scheduling preventive clinical interventions as needed. If patient outcomes can be monitored in real time, there is potential to improve clinical care for patients with other chronic conditions.”

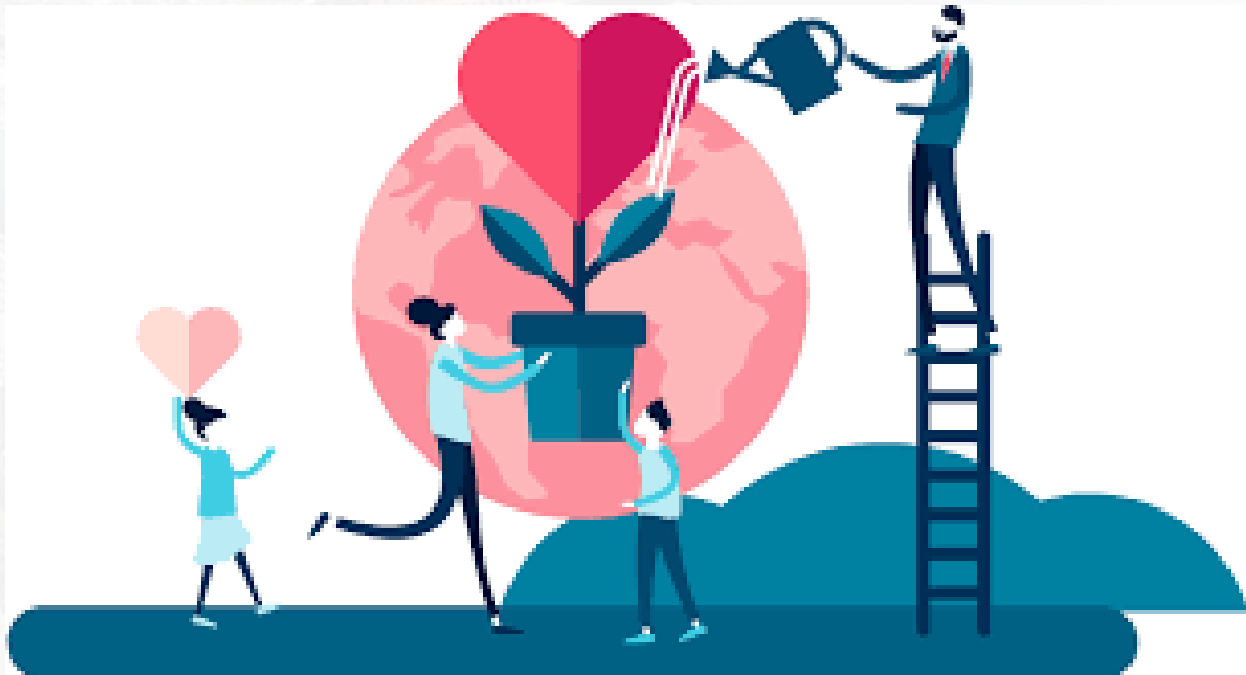




The below citation included ArthritisPower in its analysis:

- Webber, C.M., Riberdy Hammer, A., Saha, A. et al. **Integrating Patient-Generated Health Data Throughout the Total Product Life Cycle of Medical Devices.** *Ther Innov Regul Sci* (2023). <https://doi.org/10.1007/s43441-023-00505-5>

**Study overview:** “Nearly ubiquitous use of personal electronics, wearable sensors, and other types of digital health technologies, along with wireless connectivity, makes the capture of health data directly from an individual easier, enabling the use of patient-generated health data (PGHD) as a potential bridge between a patient’s home and the healthcare system. This type of real-world data may be a completely new type of information, or it may be a more frequent collection of traditional information over longer time periods to form a longitudinal view of a patient’s health status that can inform decision-making in clinical, medical product regulatory, and coverage and reimbursement settings...This manuscript presents highlights from various discussions at this meeting including those on the importance of stakeholder engagement, characteristics of high data quality, and PGHD in practice in patient-driven registries, as well as a look forward to some of the opportunities in the field.”



*For more information on how to partner with GHLF on future research, please contact Dr. Ben Nowell, Principal Investigator and Director of Patient-Centered Research, at [bnowell@ghlf.org](mailto:bnowell@ghlf.org) and Dr. Shilpa Venkatachalam, Director of Patient-Centered Research Operations and Ethical Oversight and Co-Principal Investigator, at [svenky@ghlf.org](mailto:svenky@ghlf.org)*

# COMMITTED TO COVID-19 EDUCATION

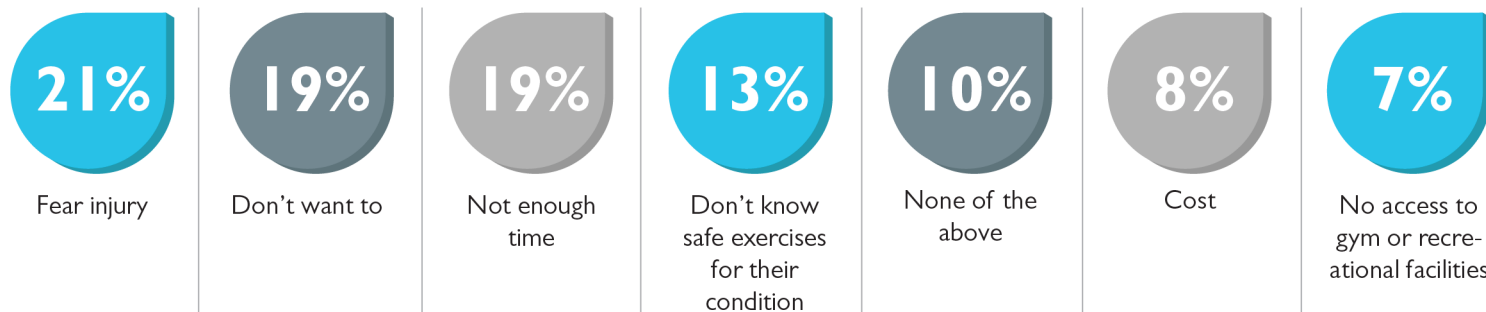
At GHLF, we remain committed to providing comprehensive and updated information about the status of the COVID-19 pandemic. We want people living with chronic disease or whom are immunocompromised to feel empowered to ask questions of their health care providers and their community to create a safe and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

Notable articles published in the second quarter included:

- [Covid Vaccination Linked to Increased Risk of Flares — But So Is Covid Infection](#)
- [Managing Unsolicited Advice When Living with Arthritis](#)
- [5 Questions to Ask Your Doctor for a COVID-19 Treatment Strategy \(Before Infection\)](#)

We also continued to poll our Patient Support Program community.

**April:** The COVID-19 Patient Support Program poll (n=3,303) reveals chronic pain (57%) and fatigue (48%) get in the way of forming exercise habits. These symptoms can make it feel nearly impossible to stay active. Participants were able to select all that apply, and other barriers included:



**May:** The poll revealed (1,460) that most have gotten or planned to get the second COVID-19 Bivalent Booster Vaccine – only 12% did not plan to get it. However, while many expressed concerns about possible side effects (like triggering a flare), most were also confident in the protection the vaccines provide.

Patient Perspectives During COVID-19

### New Poll Reveals Most Have Gotten or Plan to Get Second COVID-19 Bivalent Booster Vaccine

PUBLISHED 05/22/22 BY GHLF STAFF

In the Global Healthy Living Foundation's latest COVID-19 Patient Support Program poll, only 12 percent of respondents said they do not plan on getting the latest COVID-19 booster shot.

Learn more about our FREE COVID-19 Patient Support Program for chronic illness patients and their loved ones.

**June:** As COVID-19 mandates and restrictions end in countries throughout the world, we wanted to learn more about what precautions people who live with chronic illness are taking and what their COVID action plan and experience looks like. In the Poll (n=2,722) free response section, one common theme that emerged was around “common sense” or recognizing that people with chronic conditions may be more vulnerable to COVID. Some said:

“Support and a voice for the immunocompromised in terms of advocacy and representation among health care sectors and political leadership so we are not left to our devices and left to live out high-risk or isolated lives just to maintain health.”

“I think public service messages need to say: ‘If you are coughing or sneezing or feel unwell, please stay home. If you can’t, then wear a mask, so you don’t spread your sickness around! If people did this, we could reduce lots of illness.’”

“Awareness for people who still need to be careful. For example, theater companies that have one show a week where people need to wear masks if they want to come. Businesses maintaining outdoor spaces for eating. Recreation classes held outside for seniors.”

In this same poll, 52 percent said they have had and/or tested positive for COVID-19 and of that group only 38 percent said their symptoms lasted longer than four weeks. While 97 percent of those surveyed have access to COVID-19 boosters where they live, there was an overwhelming amount of people want masks in public spaces, especially in health care facilities.

# GHLF'S INTRODUCES TWO NEW PODCASTS TO ITS EXTENSIVE LIBRARY

The audience for our GHLF Podcast Network is growing at a rapid pace. We revised our original 2023 listen goal from 200,000 to 300,000 because engagement is already so high in the first half of the year. In the second quarter, we had more than 120K listens. Our newest series *Remission Possible* and *Relatable Rheumatology* performed very well, with nearly 8,600 listens across only three episodes of *Remission Possible* and more than 2,000 for *Relatable Rheumatology*. Our popular *Mental Health Awareness Month* series in May generated nearly 70,000 listens.

Visit the GHLF Podcast Network at [ghlf.org/patient-education/listen](https://ghlf.org/patient-education/listen) to see the full list of shows, and/or download our podcasts from any streaming platform. You can now also find our podcast series on YouTube.

**Introducing *Remission Possible*:** *Remission Possible* is the podcast dedicated to guiding and supporting members of our community who are on a mission to take back their lives and control symptoms. Each episode features patients talking about how they support their mission to remission and discusses how patients and doctors can work together to better understand the optimal course of treatment for different chronic conditions while keeping personal goals and lifestyle choices in mind.

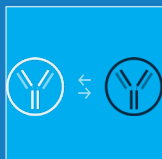




## ONGOING SERIES



**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.



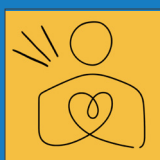
**Dungeons & Diagnoses:** Delve into the realm of Gaedia: a world where fantasy and reality combine! This podcast, set in the Dungeons and Dragons universe, brings those who have different lifestyles, live with different chronic conditions, and are differently abled to the forefront.



**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.



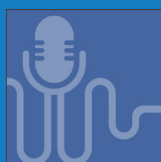
**Patient PrepRheum:** This podcast speaks to Australian patients and renowned doctors to explore important and often-misunderstood aspects of living with autoimmune arthritis and related conditions in Australia.



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



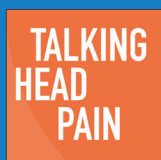
**The Psoriatic Arthritis Club:** Through personal chats with fellow psoriatic arthritis patients, as well as insights from top PsA experts, our host explores the ups and downs of navigating psoriatic arthritis.



**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.



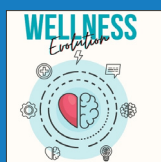
**Remission Possible:** Patients share their experience and strategies to target remission from symptoms.



**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 GHLEF's Angel Tapia, Patient Advocate and Hispanic Community Outreach Manager, and Danielle Ali, Systems Analyst.

*For more information on how to partner with GHLEF to support our GHLEF Podcast Network, please contact Ben Blanc, Manager, Programs and Special Projects, at [bblanc@ghlf.org](mailto:bblanc@ghlf.org)*

# ARTHRITISPOWER RESEARCH REACHES THOUSANDS OF PATIENTS

Introducing **Relatable Rheumatology – From Stories to Studies**: Created and co-published in partnership with the physician-facing media outlet [HCP/Live](#), Relatable Rheumatology is a podcast where we explore the personal experiences of people living with rheumatic diseases in the context of the latest research evidence. Each episode is hosted by either W. Benjamin Nowell, PhD, principal investigator and director of patient-centered research or Shilpa Venkatachalam, PhD, MPH, Director, Patient-Centered Research Operations and Ethical Oversight and co-principal investigator of ArthritisPower. Each episode features at least one patient guest and their story, along with one clinical or research expert highlighting relevant research studies.



## Current ArthritisPower statistics as of June 30, 2023:

- Total patients: **42,929**
- % increase in membership from June 30, 2022: **13%**
- Top Conditions:

Osteoarthritis:	<b>21,495 (51%)</b>
Rheumatoid Arthritis:	<b>19,408 (45%)</b>
Fibromyalgia:	<b>14,214 (33%)</b>
Psoriasis/Psoriatic Arthritis:	<b>7,789 (18%)</b>
Osteoporosis:	<b>5,903 (14%)</b>
IBD:	<b>5,061 (12%)</b>
Lupus:	<b>2,310 (5%)</b>

If you or someone you know would like to participate in an arthritis research study, please sign up at [ArthritisPower.org](https://ArthritisPower.org). After you consent to participate in research, your profile will be matched against open studies. You will receive an invitation to participate when a match is made. If you are an ArthritisPower® member and think you may qualify for one of the studies below, please reach out to Angela Degrassi, Research Manager for Patient-Centered Research, at [adegrassi@ghlf.org](mailto:adegrassi@ghlf.org). ArthritisPower is overseen by Advarra IRB.

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



## ■ ARTHRITISPOWER RESEARCH REGISTRY: OVERVIEW OF STUDIES IN PROGRESS

### **Polymyalgia Rheumatica (PMR):**

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

**IgG4-Related Disease (IgG4-RD):** To understand the needs and challenges of those living with IgG4-RD, we conducted a social listening analysis across social media platforms Reddit and YouTube. IgG4-Related Disease (IgG4-RD) is an immune mediated fibro-inflammatory disease that can affect multiple organs. The insights from these conversations will be used to program a needs-assessment survey, which will be fielded to a group of people living with IgG4-RD. Findings from this project will inform the development of new education and other resources for people living with IgG4-RD to help improve their disease

journeys. This project is sponsored by Horizon Therapeutics (now part of Amgen).

### **Building the Capacity of Patient Advocacy Organizations to Disseminate Patient-Centered Outcomes Research to Patient Communities:**

Patient advocacy organizations are uniquely situated to disseminate evidence-based health information because of their strong established connection with health care stakeholder groups, notably patient populations. The translation gap between research publication and uptake of recommended new health information by patient populations occurs in part due to ineffective dissemination. Moreover, resources for dissemination fail to offer a step-by-step guide that patient advocacy organizations can follow to optimally disseminate research findings to their patient communities using social media and novel technologies. Through this project, GHLF will develop a resource, or "playbook," which can be used as an instruction guide by Patient Advocacy Organizations (PAOs) and contains real-life examples of dissemination planning, implementation, and feedback to suit the unique requirements of patient advocacy organizations as they apply promising or successful practices in their own dissemination activities. By doing so, we will build the capacity and infrastructure of patient advocacy organizations specifically to disseminate evidence-based information on patient-centered research. This project is supported by the Patient

Centered Outcomes Research Institute (PCORI)

### **Stronger Together PsA Wellness Study:**

As patients diagnosed with psoriatic arthritis confront decisions about treatment and disease management, they may also seek to change or improve lifestyle behaviors that may improve their treatment outcomes. The goal of the study is to learn about PsA patients' motivations to participate in wellness programs and interest in programs delivered online with e-coaching support. With sponsorship support from Janssen and in partnership with rheumatologists M. Elaine Husni, MD, and Leonard Calabrese, DO, from Cleveland Clinic, a brief survey was designed to examine PsA patients' perspectives on wellness and wellness programs. Participants who complete the survey may consider participating in Cleveland Clinic's multiweek Immune Strength wellness program with e-coaching. More than 300 participants have completed the survey to date. Study recruitment is ongoing in 2023, with a limited number of spots still available for Immune Strength participation.

### **Rheumatoid Arthritis (RA)**

#### **Treatment Common Infections Study:**

Immunosuppression is the mainstay of RA treatment but increases risk of infection. Leveraging the ArthritisPower infrastructure, this study is prospectively assessing non-hospitalized infections and their impact on patients to better understand how the medications that people take for RA, such as glucocorticoids, methotrexate,

and tumor necrosis factor inhibitors, affect patients' risk of common colds and other infections. Participants recruited through Illumination Health community rheumatology practices and ArthritisPower in this longitudinal study are completing six monthly surveys in the ArthritisPower app to report on the medications they are taking, their symptoms and RA disease activity, and any colds or other infections they experience. Recruitment closed this quarter with more than 350 participants enrolled. The Principal Investigator for this study is Michael George, MD, of the University of Pennsylvania Perelman School of Medicine; the project is funded by a National Institute of Arthritis and Musculoskeletal and Skin Diseases/National Institutes of Health award.

#### **Telehealth-delivered Healthcare to Improve Care (THRIVE):**

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

following few days. The GHLF research team built a patient joint self-assessment and instructional tool into the ArthritisPower app to facilitate this and future studies with RA patients. The team utilized a patient-centered design process from concept to implementation, resulting in a novel tool that both instructs the patient and captures the joint count information. Patient recruitment for this study began in late 2022 and is ongoing. THRIVE coinvestigators highlighted elements of this important project during a Business of Rheumatology panel at the ACR Convergence 2022.

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

Building on our experience designing and implementing the ArthritisPower Smartwatch study (DIGITAL), we conducted a study of people living with RA initiating upadacitinib or adalimumab treatment from over 30 clinical sites across the U.S. to evaluate associations between biometric sensor data, physician-derived data, and electronic patient-reported outcomes (ePROs) over time. In addition to this primary aim, we are exploring the accuracy and predictive validity of biometric sensor data, physician-derived data, and ePROs to observe changes in disease activity and symptoms while tracking improvements in patients involved in the study. This study is sponsored by the Health Economics and Outcomes Research (HEOR) group at

AbbVie US. Recruitment is now closed, but follow-up data was collected through April 2023 and analysis is being finalized, with plans to present initial findings at the ACR Convergence 2023.

**CARE-RA (CARDiovascular Risk AssEssment for Rheumatoid Arthritis):**

Cardiovascular disease (CVD) is the most common cause of death among patients with RA. To understand and assess the effectiveness of a peer coaching intervention called CARDiovascular Risk AssEssment for RA (CARE-RA) in helping people with RA receive reliable CVD education and risk assessment and treatment, we partnered with researchers and clinicians to help develop and design the peer coaching program and recruit participants for the study. This study is being led by Dr. Iris Navarro-Millán, a rheumatologist at Weill Cornell Medicine in New York City with current appointments at Hospital for Special Surgery (HSS) and New York-Presbyterian Hospital. The protocol for the study was recently published in the journal *Pilot and Feasibility Studies*, and the study is ongoing.

**Remote Therapeutic Monitoring for Clinical Use of ArthritisPower**

**Infrastructure:** In a number of rheumatology clinics across the U.S., we are piloting ArthritisPower patient symptom and medication tracking infrastructure for clinical use, specifically for remote therapeutic monitoring (RTM). To date, we have created pathways to monitor inflammatory arthritis patients for disease worsening/RA flares and for response to

treatment following a new medication start. Data gathered via app workflows based on these RTM pathways will be made available for clinical use directly to patients and their physicians. Patients treated by community rheumatology providers who are members of the Excellence Network in Rheumatology (ENRGY), a practice-based research network started in 2022 by Illumination Health, are being invited to participate in an ongoing pilot for RTM. This work is partially sponsored by Amgen Digital Health & Innovation and by GHLF.

**Delivering Patient and Provider-Focused Improvements in the Management of Osteoporosis in the Era of Telehealth:** The GHLF research group continues to develop a website called Osteoporosis&Me with an embedded interactive online decision tool to help patients with osteoporosis decide on the right treatment based on their preferences. The website with embedded tool will also include an educational video about how to use the decision tool, educational content about osteoporosis and available treatment options. Expected to go live in Q3 of 2023, the website's decision tool will generate a personalized report that a patient can share with their doctor. This project is supported by Amgen.



# U.S. ADVOCACY ACTIVITIES AMPLIFY THE CHRONIC DISEASE PATIENT VOICE

As always, it is a priority of the organization to represent members of the chronic disease community by ensuring their voices are heard in policies, protocols, and laws that affect them.

## NATIONAL MEDIA TRUST GHLF AS AN EXPERT SOURCE

During the second quarter, several of our leaders provided health policy perspective to media, including:



Robert Popovian, PharmD, MS, Chief Science Policy Officer spoke with [Health Central](#) about non-medical switching, or when insurers force beneficiaries (read: patients) to switch to another medication for non-medical reasons. He also spoke with [The Rheumatologist](#) about Mark Cuban's Cost Plus Drug Co. that, as of 2022, distributes and home delivers prescribed generic medications to consumers. Then, Robert offered insight to [Clinical Leader](#) about takeaways from the 2023 BIO meeting and spoke with [Reuters](#) several times about forthcoming Humira biosimilars and their impact on access and pricing.





Louis Tharp, Executive Director and Co-founder, and Dr. Popovian, spoke with [Employee Benefit News](#) about innovations in capping the cost of insulin, offering advice for how employers can ensure that the cost of this medicine is reasonable for both their employees and their health plans.



J.P. Summers, Patient Advocate, Community Outreach Manager, continued to see pick-up of her Op-Ed advocating for a law that protects Patient Assistance Programs in Texas newspapers across the state such as [Kernville Daily Times](#) and [Comanche Chief](#), among others. She also discussed this issue alongside Corey Greenblatt, MPH, Associate Director of Policy and Advocacy, with [Chronic Migraine Awareness](#), which covered their in-person advocacy engagement in Ohio.



W. Benjamin Nowell, PhD, Director, Patient-Centered Research, worked with [Everyday Health](#) to update an article on medical cannabis, explaining why access and more research investment matters to people living with chronic disease.

## ■ ADDRESSING DRUG PRICING, SPENDING, AFFORDABILITY AND ACCESS

Robert Popovian, PharmD, MS, Chief Science Policy Officer, who is also a Senior Fellow of Health Policy, Progressive Policy Institute and a Visiting Health Policy Fellow at the Pioneer Institute for Public Policy Research had several speaking engagements spanning topics from drug pricing to access to medication. In addition to participating in the Congressional briefing described below, during the second quarter, he spoke at:

- Life Science Strategic Patient Advocacy Conference on Drug Pricing, Spending, Affordability and Access – April 2023
- Partnership to Advance Cardiovascular Health on 101: Prescription Drug Supply Chain & Policy – May 2023
- Industry Studies Association Conference on PBMs – May 2023
- BIO conference panelist speaking about New Tools in the Infectious Disease Toolbox: Combatting Future Biological Threats – June 2023

He also contributed articles to:

- Opinion Editorial: [Pharmacists are the solution for the lagging vaccination rates of seniors in the U.S.](#) **The Medium**, June 2023.
- Paper with Progressive Policy Institute: [Are we on the cusp of a new drug pricing program? Co-written with Erin Delaney and Michael Mandel of the Progressive Policy Institute.](#) **The Medium**, May 2023.
- Opinion Editorial: [The Federal Government Fails on Hospital Charity Care](#), co-written with William Smith of the Progressive Policy Institute and Robert Popovian, **National Review**. May 2023
- Report with Pioneer Institute: [Out-of-Pocket Pirates: Spotlight on Accumulator & Maximizer.](#) **Pioneer Institute Report**, April 2023, by William Smith, Robert Popovian and Wayne Winegarden.
- [The ICER Effect: Industry Perspectives](#), **MarketingResearch.com**, June 2023
- [Drugs left off PBM lists can lead to worse patient outcomes, higher costs](#), **Morning Brew**, 4/4/2023



## VIRTUAL AND IN-PERSON ADVOCACY ENGAGEMENTS PROMOTE PATIENT-CENTERED HEALTH POLICY

**Hill Day on PBMs:** On April 17, the [Alliance for Transparent and Affordable Prescriptions](#) hosted a hill day and congressional briefing to focus on pharmacy benefit manager (PBM) reforms and accountability. Corey Greenblatt, MPH, Associate Director of Policy and Advocacy, met with senators and representatives from New York and Connecticut to support the Safe Step Act, the HELP Copays Act, and the Prescription Pricing for the People Act. Dr. Robert Popovian, PharmD, MS, Chief Science Policy Officer, spoke at the briefing to highlight recent actions made by manufacturers to lower drug prices and actions taken by PBMs that harm patients.



**Skin Diseases:** On April 25th, GHLF joined the [Coalition of Skin Diseases](#) for a Congressional Briefing and a Day of Action. Patients and other advocates spoke with lawmakers and their staffs about living with a chronic skin condition and how pending legislation could make a difference in the lives of these patients.



**Advocating Against Accumulators:** In May, we invited members of the 50-State Network in Wisconsin and Ohio to join us for a day of advocacy in support of proposed legislation that prohibits co-pay accumulator programs from diverting funds provided by patient assistance programs away from patient's co-pay and deductibles as they are intended. Notably, our advocacy around this issue in Texas led to the passage of a patient-centered bill in April!

**Safe Step Act Advances:** On the federal side, the 50-State Network, along with other members of the Safe Step Act Coalition were major factors in garnering enough support on the U.S. Senate HELP Committee for the Safe Step Act that it was successfully included in the bipartisan Pharmacy Benefit Manager (PBM) Accountability Act. The PBM Accountability Act would bring much needed reforms to the PBM industry, and we will be actively supporting its passage over the coming months. GHLF recently met with Senator Richard Blumenthal (D-CT) and Senator Chuck Schumer (D-NY). Patient Advocate and Community Outreach Manager, JP Summers shares “there was also positive feedback from Senator Tammy Baldwin’s office and the support we need for passage is to continue sharing patient stories.”

*For more information on how to partner with GHLF to support our advocacy projects, please contact Steven Newmark, JD, Advocacy Director and Chief Legal Officer at [snewmark@ghlf.org](mailto:snewmark@ghlf.org).*

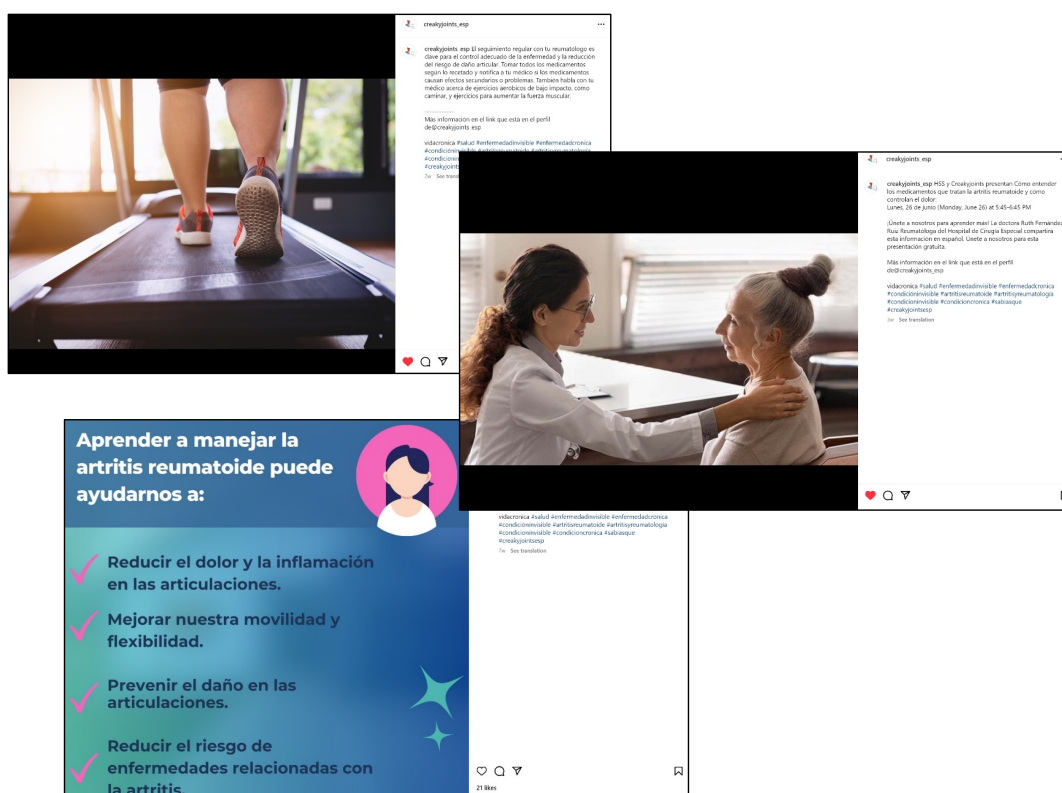
# CREAKYJOINTS ESPAÑOL GROWS ENGAGEMENT

## PROVIDING COMMUNITY AND EDUCATION

During the second quarter, we published educational articles and social media posts in Spanish to build community and increase awareness of management and treatment options for patients. Notably, we also recruited 2,000 new participants into our WhatsApp through our engagement with members who visit CreakyJoints.org.es. WhatsApp is a popular social media platform for the Hispanic community.

Recent articles and posts include:

- [Evaluación de la respuesta al tratamiento de la artritis reumatoide: ¿Qué tiene que ver la percepción de tu médico sobre tu salud?](#)
- [12 Errores que Cometí al Comienzo de mi Diagnóstico de Artritis Reumatoide](#)
- [Las visitas frecuentes al inodoro podría ser un nuevo factor de riesgo de artritis reumatoide](#)



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



# CREAKYJOINTS AUSTRALIA AND GHLF AUSTRALIA LAUNCH NEW EDUCATION INITIATIVES

## ■ FOCUS ON PSORIASIS

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

## ■ JUVENILE IDIOPATHIC ARTHRITIS

**May Focus Group:** In May, we coordinated our second online focus group (following one in late 2022) to gain a deeper understanding of the participants' experience of living with the condition, their treatment preferences, and the resources they would like to have to help them better manage their psoriasis.

**GHF Australia Psoriasis Education Hub:** As part of our commitment to developing resources for psoriasis patients, we expanded [the psoriasis education hub on our GHF Australia website](#). This included adding the page [How to build your psoriasis healthcare team](#) to the site. We also published [the video of Jo Mohan's psoriasis journey](#), who has lived with psoriasis since childhood.

We were especially proud to launch our [Psoriasis Wellness email series](#), a free resource for psoriasis patients. Each week, over four weeks, subscribers received an email that includes helpful daily living tips and links to articles related to managing the following aspects of psoriasis:

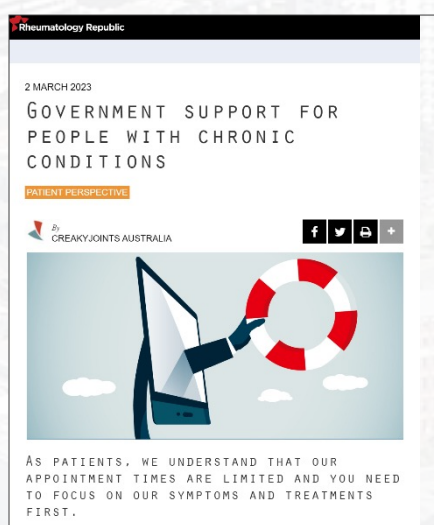
- Fatigue
- Mental health, stress and stigma
- Appropriate diet and exercise
- Accessing support

Each article also includes suggestions for communicating better with their healthcare team about that topic. Notably, we'll share news of this program in upcoming issues of Rheumatology Republic and Dermatology Republic.

## OUR LATEST RHEUMATOLOGY REPUBLIC ARTICLES

CreakyJoints Australia published two articles with our media partner Rheumatology Republic this quarter.

[Patient Perspectives on Achieving Remission](#) was inspired by a session on the topic of remission presented by rheumatologist Professor Janet Pope at the 2023 Australian Rheumatology Association Annual Scientific Meeting in May. Prof. Pope looked at the challenges associated with defining remission. We looked at potential reasons for this confusion and also asked members of our community how they viewed remission. We shared some of their quotes in the article.



[I Wish I Had Known...](#) For this article we asked members of the CreakyJoints Australia social media community what they wished they'd known earlier about their condition, symptoms, treatments and more. The most common responses we received were:

- I wish I had known my diagnosis earlier.
- I wish I had known what to expect along my journey.
- I wish I had received more holistic advice about managing my condition.
- I wish I had received more information on medications, side effects and co-occurring conditions.

From the editor of Rheumatology Republic:

“This article was the top rating article in the Rheumatology Republic newsletter that week. It also did really well in the Medical Republic newsletter (second-top rating article). Clearly, doctors want to know about it.”



## ■ ATTENDING THE AUSTRALIAN RHEUMATOLOGY ASSOCIATION ANNUAL SCIENTIFIC MEETING



The CreakyJoints Australia team attended the Australian Rheumatology Association (ARA) 2023 Annual Scientific Meeting in May in Hobart, Tasmania. This was the first time the event was held in person since 2019. Highlights included sessions on pregnancy and arthritis, remission, pediatric osteoporosis, telehealth exercise programs, and pain management options. We took this opportunity to speak with sponsors and patient organization representatives along with many rheumatologists and others working in this field. We were active on social media at this ASM and shared 16 Tweets of our own and retweeted others.

## ■ ADVOCATING FOR ACCESS

Late last year and earlier this year we sent submissions to Australia's Pharmaceutical Benefits Advisory Committee calling for the following medicines to be subsidized through the Pharmaceutical Benefits Scheme. During the second quarter, we received the good news that these medicines (along with other rheumatology medicines) have been approved.

- Deucravacitinib (Sotyktu®) for the treatment of patients with severe chronic plaque psoriasis.
- Romosozumab (Evenity®) for the treatment of severe established osteoporosis in the first-line setting.
- Tofacitinib (Xeljanz®) for juvenile idiopathic arthritis.

We also regularly promote research and advocacy opportunities from other organizations with our online community.

## ■ OUR LEADERSHIP IS SELECTED FOR PERSPECTIVE

CreakyJoints Australia editor Rosemary Ainley, a person living with RA, was invited to participate as a consumer representative in the Australian Rheumatology Association/Arthritis Australia Rheumatoid Arthritis Clinical Care Standards Working Group.

Quality standards comprise a small number of quality statements based around measurable processes and outcomes, designed to drive and measure quality improvements in priority areas. The working group was asked to select these priority areas for RA treatment in Australia and to create a short list of draft statements and rationales. These statements will be presented via a public survey distributed in part by arthritis patient organizations (including CreakyJoints Australia) with the final document to be published by the end of 2023.

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

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

## ■ EXPANDING OUR REACH

During the second quarter, GHLF Canada began the early stages of planning and developing a new educational and awareness-raising program for patients with alopecia which will include a podcast mini-series and landing page with educational resources on living with alopecia for patients.

We also continued our collaboration with Cambrian College, a prestigious academic research institution in Canada, where students began research to explore the relationship between chronic respiratory conditions (e.g. asthma) and climate change. We anticipate publishing their findings in 2023.

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

CreakyJoints Canada remains dedicated to providing a platform for diverse voices of Canadian patient advocates. We share these articles regularly on our social media channels along with other nonprofit partners. Notable new articles published in the second quarter of 2023 include:

- [Life Transitions and Rheumatoid Arthritis](#)
- [Chronic Illness Care Is Not the Same as Self-Care](#)
- [When Rheumatoid Arthritis Means You Can No Longer Travel](#)



## ■ CANADIAN PATIENT COUNCILS – WORKING FOR AND WITH THE CANADIAN PATIENT COMMUNITY

At GHLF's Arthritis and Migraine Patient Councils this quarter we planned for ways to continue our patient-centered educational programming, awareness-raising and advocacy in Canada.

Our Arthritis Patient Council brainstormed on a variety of topics, some of which included life changes as well as travel while living with arthritis which became articles that some of our Canadian Patient Council members wrote for CreakyJoints.ca. Another Canadian Arthritis Patient Council member worked with GHLF Canada team to submit a patient perspective poster abstract for the American College of Rheumatology (ACR) conference later this year.

Our Migraine Patient Council members asked for content surrounding best practices for travelling (abroad) with migraine. With their words and guidance, GHLF Canada created a helpful social media post for the entire migraine community about ways to prepare and navigate traveling abroad. We interviewed Council members and in the larger migraine community to come up with these helpful tips, making sure it was easily shareable on social media. One member's experience as a university student living with migraine with a lack of resources for students like them. GHLF Canada did a special episode of Talking Head Pain with a fellow migraine patient, who is also university student, about navigating life as a chronic condition patient at a university. We will soon be polling the larger migraine community with request for ideas for resources and tips for students living with migraine.

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



# GHLF ENTERS THIRD YEAR SUPPORTING CHILDHOOD AND EARLY-ADULT ADVOCACY IN NEPAL AND THE UNITED STATES

GHLF's third year of support for International Student Learning Inc. (ISLearning) and Canopy Nepal's very successful program, Beyond Borders, began in Q2 2023.

In April 2023, we kicked off planning for our new programming year with all three organizations coming together to discuss experiences with social media as it pertains to physical and mental well-being and the cultural differences on social media in different parts of the world. We then started planning for its health education efforts in areas of physical, mental, and emotional health and well-being for the coming school year. This includes developing educational and cultural exchange sessions as well as hygiene kits for distribution to middle school-aged students in Nepal.



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

GHLF continued support of ISLearning and Canopy Nepal's 'Beyond Borders' aims to contribute directly to the 2030 Agenda for Sustainable Development and to the many targets of the United Nations Sustainable Development Goals

(SDGs), including SDGs 3 (Good Health and Well-Being) 4 (Quality Education), 5 (Gender Equality), 11 (Sustainable Cities and Communities) and 13 (Climate Action).

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

# CREAKYJOINTS AND GHLF IN CONVENTIONAL NEWS AND ONLINE

During the first quarter, GHLF and CreakyJoints spokespeople, members, and data were featured in 51 original placements, reaching an estimated nearly 220 million media impressions. Notably, [Healio.com/rheumatology](https://www.healio.com/rheumatology) published a long feature article highlighting how CreakyJoints uses social media to disseminate research to patient communities, featuring interviews with J.P. Summers, Patient Advocate, Community Outreach Manager and Joseph Coe, Director, Therapeutic Area Growth and Integration. During the second quarter, Ms. Summers and GHLF member Qasim Amin Nathari spoke with Everyday Health about the challenges of access disability benefits, one of several Everyday Health and Health Central articles that included GHLF or CreakyJoints perspective. Conner Mertens, Community Outreach Manager, appeared on an episode of The Waiting Room podcast to describe CreakyJoints online resources.

“JP Summers, patient advocate and community outreach manager at CreakyJoints, found the community and the solace it provided shortly after receiving a diagnosis of fibromyalgia. “I am so thankful for social media because it has been a lifeline for me through some of my hardest days,” Summers told Healio. “Even before COVID, we had this community, so it was nothing new for us. We embraced it and each other more after COVID.” Aside from the community aspects of social media, CreakyJoints and other advocacy groups also work to make patient resources widely available.

“CreakyJoints furthers this mission by sponsoring patient research for presentation at major rheumatology meetings, such as the annual American College of Rheumatology Convergence. Following the 2022 meeting, staff and presenters broke new ground by posting patient presentations of new research on TikTok, Coe said. In addition, CreakyJoints trains volunteers to get involved by becoming patient-reporters. ...“We view our role as being patient translators — being able to take this complex information and distill it into a tweet to help empower patients to make better decisions and help them become better informed about their disease and care,” Coe said.



## ■ LONG SESSIONS COMMON WITH OUR EDUCATIONAL CONTENT

In the second quarter, there were nearly three million combined page views of CreakyJoints.org, ghlf.org, CreakyJoints Español, and CreakyJoints Australia content. The metrics below illustrate the quality of traffic coming to CreakyJoints.org, the diversity of visitors, and the rheumatic topics they're interested in.

- The average page view on CreakyJoints.org is 19 minutes, 42 seconds (far surpassing the industry's average of two to three minutes).
- Not only are people engaging with content on the website, but they're also opting to receive more content from CreakyJoints. This quarter, the CreakyJoints' email list grew to 244,000 subscribers.

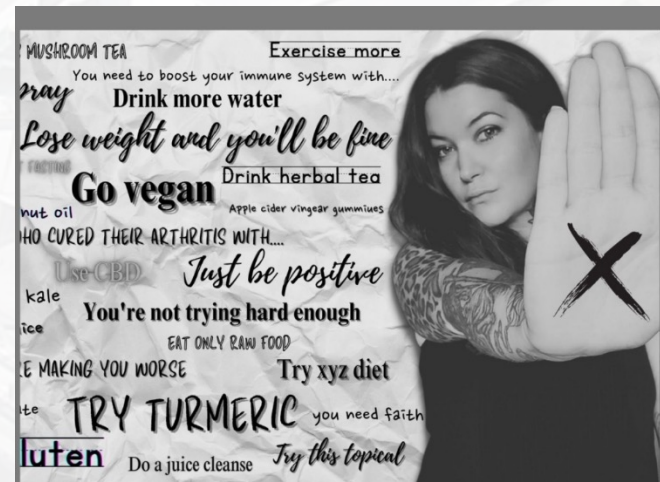
In addition to publishing content tied to our educational modules and ongoing advocacy and research work (some referenced earlier), we continue to publish stand-alone content to live well with chronic disease. Some popular resources this quarter included:

- [Eve Stern: From Migraine Warrior to Psoriasis Advocate](#)
- [Dropping the Ball: The Art of Juggling Life with Chronic Illness](#)
- [How My Dog Helps Me Thrive with Rheumatoid Arthritis](#)
- [Jumpstart Your Mental Well-Being: 10 Days of May Motivation](#)

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

Our social media channels are key ways that GHLF and CreakyJoints directly communicate with our patient community, obtain member insights and perspectives, share new content and resources, and keep members informed about the organizations' activities, opportunities, and accomplishments. Channels include Facebook and Instagram (in English and Spanish), WhatsApp (in Spanish), Twitter, YouTube, TikTok, and LinkedIn. We also launched our Threads channel! Notable posts from this quarter:

- Instagram: [“It seems that if you just whisper ‘arthritis,’ someone inevitably emerges from the woodworks to shower you with unsolicited advice.” - @chroniceileen](#)
- TikTok: [If using scissors hurts your thumbs, these 3 alternate designs may help!](#)
- Twitter: [Every #ArthritisAwarenessMonth, we raise awareness about the nuances of living with arthritis.](#)
- Threads: [Don’t let chronic pain apologies weigh on your mental health. Manage cancellations without placing blame on yourself. Here’s 5 things to say instead of ‘I’m Sorry’](#)



## Managing Unsolicited Advice When Living with Arthritis

- Eileen Davidson



## #CRAKYCHATS

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



**June:** [Pride & \(Not\) Prejudiced](#) explored the intersections of identity and chronic illness.

**May:** [Strong Bones & Me](#), co-hosted by members of the GHLF- assembled global council, composed of nine patient organizations from around the world who are collaborating with us on materials, identifying patient stories, and disseminating surveys all on the prevention of fractures.



Some of the partner organizations include:

- Bone Health & Osteoporosis Foundation (USA)
- Chronic Disease Coalition (USA)
- Prostate Cancer Foundation of Australia
- Musculoskeletal Australia
- International Federation on Aging (headquartered in Canada)

o An organization representing 80 countries with general consultative status at the United Nations and is a non-State actor in official relations with the WHO.

- Healthy Women (USA)
- Agora (Platform of Organizations of people with Rheumatic Disease in Southern Europe)
- Association of Migraine Disorders (USA)
- CreakyJoints, part of the Global Healthy Living Foundation (USA, Canada, Australia, and in Spanish)



**April:** Mission: Remission – What Does Remission Mean to You? Co-hosted by the Canadian Arthritis Patient Alliance (CAPA) and featuring GHLF member living with migraine and psoriasis, Beth Morton.

# WHO WE ARE

## About CreakyJoints®

CreakyJoints is an international digital community for millions of people living with arthritis and their supporters who seek education, support, advocacy, and patient-centered research. We represent patients in English, Spanish, and French through our popular social media channels, our websites, and the [50-State Network](#), which includes more than 1,700 trained volunteer patient, caregiver, and provider health care activists.

CreakyJoints' patient-reported outcomes registry, ArthritisPower ([ArthritisPower.org](#)), includes tens of thousands of consented arthritis patients who track their disease while volunteering to participate in longitudinal and observational peer-reviewed research. Always free, CreakyJoints publishes many educational articles and downloadable health education guides, and produces arthritis and chronic disease [podcast series](#) that provide both patient and provider perspectives. It also hosts PainSpot ([PainSpot.org](#)), a digital risk-assessment tool for musculoskeletal conditions and injuries, and eRheum ([eRheum.org](#)), for telehealth and virtual-care support. All programming is free, always. For more information, visit [CreakyJoints.org](#) or its parent organization, the [Global Healthy Living Foundation](#), an international, patient-centered nonprofit organization whose mission is to improve the quality of life for people with chronic illness. CreakyJoints never asks patients for donations.

## About Global Healthy Living Foundation

The [Global Healthy Living Foundation](#) is a U.S.-based 501(c)(3) nonprofit, international organization whose mission is to improve the quality of life for people with chronic illnesses (such as arthritis, osteoporosis, migraine, psoriasis, inflammatory bowel disease, and cardiovascular disease) by advocating for improved access to health care and amplifying education and awareness efforts within its social media framework. GHLF is also a staunch advocate for vaccines. The Global Healthy Living Foundation is the parent organization of [CreakyJoints](#), the international digital community for millions of people living with arthritis and their supporters worldwide who seek education, support, activism, and patient-centered research in English, Spanish, and French. Our ArthritisPower ([ArthritisPower.org](#)) patient registry has more than 40,000 consented patients who participate in best-in-class patient-reported outcomes research. In response to the COVID-19 pandemic, GHLF started a patient support program, informed by a patient council made up of people living with a wide range of chronic illnesses, that now serves more than 46,000 subscribers. Via CreakyJoints, GHLF also hosts PainSpot ([PainSpot.org](#)), a digital risk-assessment tool for musculoskeletal conditions and injuries; eRheum ([eRheum.org](#)), for telehealth and virtual-care support; and a constantly refreshed library of podcasts via the GHLF Podcast Network. Visit [ghlf.org](#) for more information. GHLF never asks the public for donations.

## About ArthritisPower®

Created by [CreakyJoints](#), [ArthritisPower](#) is the first-ever patient-centered research registry for joint, bone, and inflammatory skin conditions, as well as arthritis and rheumatologic manifestations of gastrointestinal-tract (GI) and skin conditions. With tens of thousands of consented arthritis patients, the free ArthritisPower mobile and desktop application allows patients to track their disease and participate in voluntary research studies in a secure and accessible manner. Results from ArthritisPower studies are frequently published in peer-reviewed journals and presented at medical meetings in the United States and around the world. ArthritisPower Patient Governors serve as gatekeepers for researchers who seek to access registry data or solicit the community to participate in unique, voluntary studies. To learn more and join ArthritisPower, visit [ArthritisPower.org](#) (in English) or [ArthritisPower.org.es](#) (in Spanish).



### About the 50-State Network

The 50-State Network is the grassroots advocacy arm of the [Global Healthy Living Foundation](#). It consists of patients living with chronic illness who are trained as health care activists to proactively connect with local, state, and federal health-policy stakeholders to share their perspective and influence change. Through public and personalized opportunities to advocate for the chronic disease community, the 50-State Network mobilizes patients to voice their concerns about access to treatment, quality of care, and the need to prioritize the physician-patient relationship. For more information, visit [50StateNetwork.org](#).



### GHLF's Patient-Centered Policy Research Initiative

At the Global Healthy Living Foundation, the Patient-Focused Economic and Policy Research Division conducts original research on health-policy economics and outcomes research to better understand how current and proposed health policies, regulations, and legislation affect patients' financial, health care, quality-of-life, and other outcomes. We aim to increase transparency and understanding of the public-health policies, regulations, and legislation affecting chronic disease patient communities by sharing our research via publication, our website, social media platforms, and conventional media. Our researchers also address these important topics through editorials, speaking engagements, and our world-class podcast series Healthcare Matters. Our experts have published extensively on the impact of biopharmaceutical and health policies on costs and clinical outcomes in the most prominent medical sources and media publications. They are sought-after speakers, providing briefings and expert reviews for the U.S. Congress, for dozens of state legislatures, and at conferences and medical symposiums around the world. Learn more at [ghlf.org/our-work/economic-policy-research](#).



### About PainSpot

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



### About eRheum

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





**Find us online**

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

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

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

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

Global Healthy Living Foundation: [ghlf.org](https://ghlf.org)

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

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

