



# QUARTERLY REPORT

APRIL – JUNE 2021

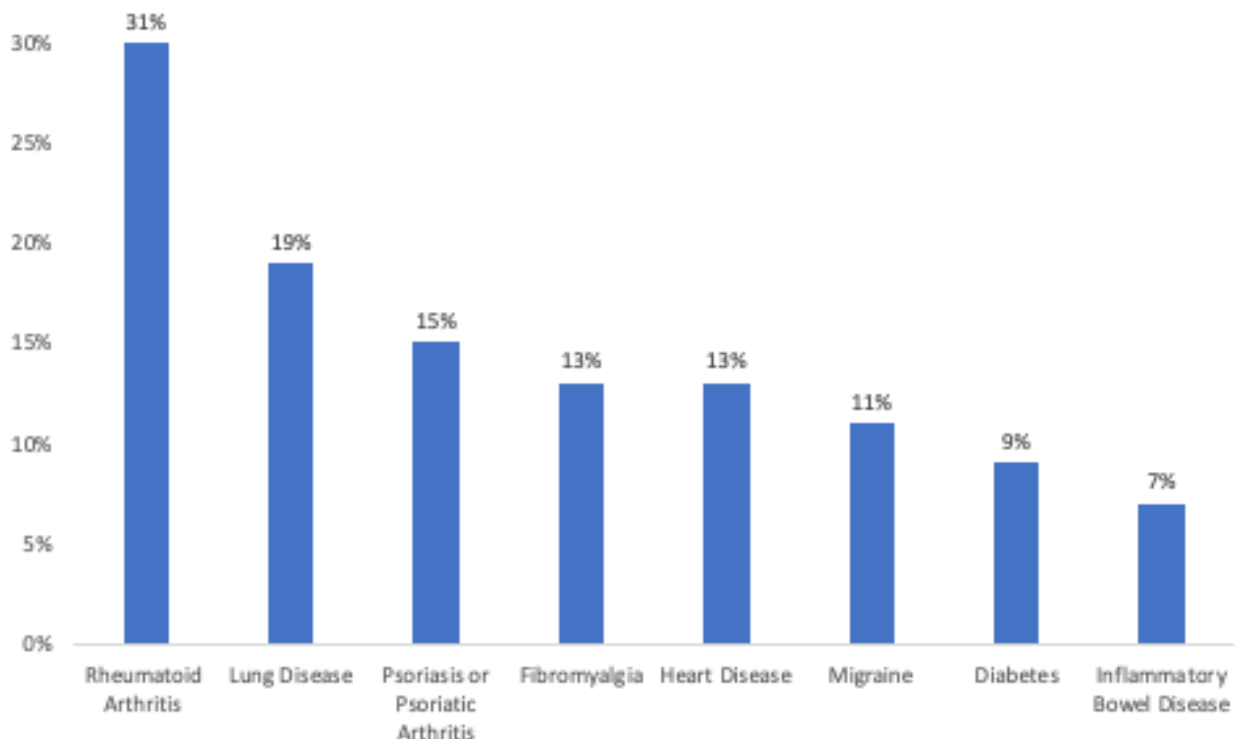


GLOBAL  
HEALTHY  
LIVING  
FOUNDATION

# TURNING THE CORNER: INCREASING VACCINATION BRINGS NEW OPTIMISM TO THE CHRONIC DISEASE COMMUNITY

During the spring, we looked ahead to what our post-vaccine community might expect in the United States and abroad. We provided reassurance and support to those living with chronic disease, encouraging vaccination but recognizing their concerns and providing a platform for an exchange of ideas. As always, [CreakyJoints®](#) and the [Global Healthy Living Foundation \(GHLF\)](#) provides the most up-to-date science-based information, support, and advice about the pandemic — with a special focus on vaccine education — for people living with chronic disease.

Our free COVID-19 Patient Support Program continued to grow in the second quarter and now includes 27,936 diverse members and 45,344 subscribers (as of June 30, 2021), an increase attributed to new members joining after reading our COVID-19 vaccine content. Website visits continue to exceed one million per month. Common conditions of members in the program include:



## ■ ROBUST CONTENT

Even as the country (and the world) reopens for travel, working in an office environment, or sending kids back to school or camp, our members have unique questions and concerns about the COVID-19 pandemic and vaccines, given their underlying health issues and medications, which may make them immunocompromised. Over the past few months, top content has shifted to help our immunocompromised community adapt to the ever-changing pandemic landscape, specifically changes in mask-wearing and reopening guidance. We're committed to addressing concerns by consulting leading experts in rheumatology, infectious disease, public health, and other specialties for advice. We also review and explain the most important medical research about COVID-19 for people with chronic medical conditions, while sharing personal perspectives from members of our CreakyJoints and GHLF community. Impactful content from the quarter included:



- [Should You Attend Weddings if You're Fully Vaccinated and Immunocompromised?](#)
- [What to Know About Going Back to the Office if You're Fully Vaccinated and Immunocompromised](#)
- [What Immunocompromised People Should Know About the CDC Recommendations for Outdoor Mask Use](#)
- [New Research Shows that Rituximab and JAK inhibitors Are Linked with Worse COVID-19 Outcomes in Rheumatoid Arthritis](#)

From April through June, GHLF continued to publish new COVID-19-related content each week, which has generated nearly 1.7 million page views. Many of these articles were also published in Spanish and made available on the [CreakyJoints Español website](#) and its [Instagram page](#).

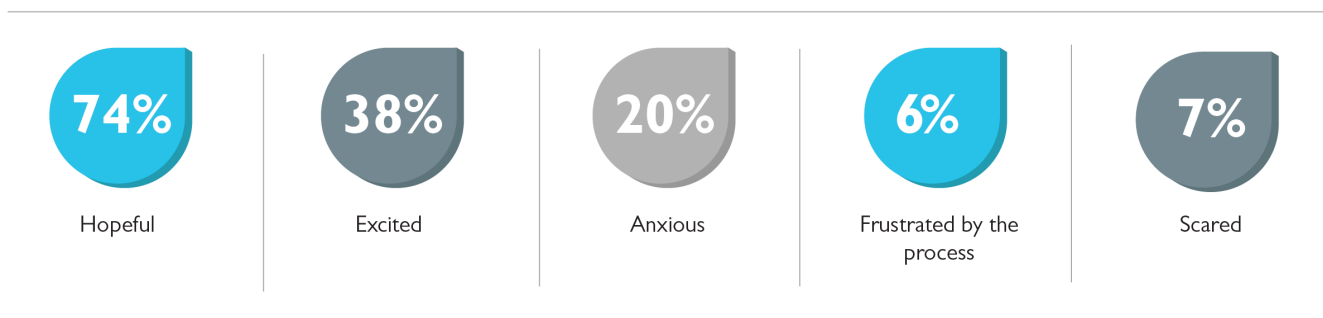


## ■ TAKING THE PULSE OF THE CHRONIC DISEASE COMMUNITY

We regularly connect directly with our COVID-19 Patient Support Program members to understand their concerns and needs, which informs the education and support resources we develop. Poll questions during the second quarter asked about the community’s understanding of Centers for Disease Control and Prevention (CDC) guidance, their plans for summer, and what they want next from our patient support program. Below are results from select recent polls:

### **Poll Topic: What Are Your Emotions Given the Availability of the COVID-19 Vaccine?**

By the start of the second quarter, many in our community had the opportunity to get vaccinated against COVID-19. In our April 1 poll (N = 2,379), nearly 84 percent had already received at least one dose of the vaccine. Our community reported feeling a variety of emotions after getting vaccinated, such as:



**Our members said:**

“ I felt that this was exciting and hopeful because it was the first step in getting protection from the virus and suggested that a life of more freedom was going to come back again.

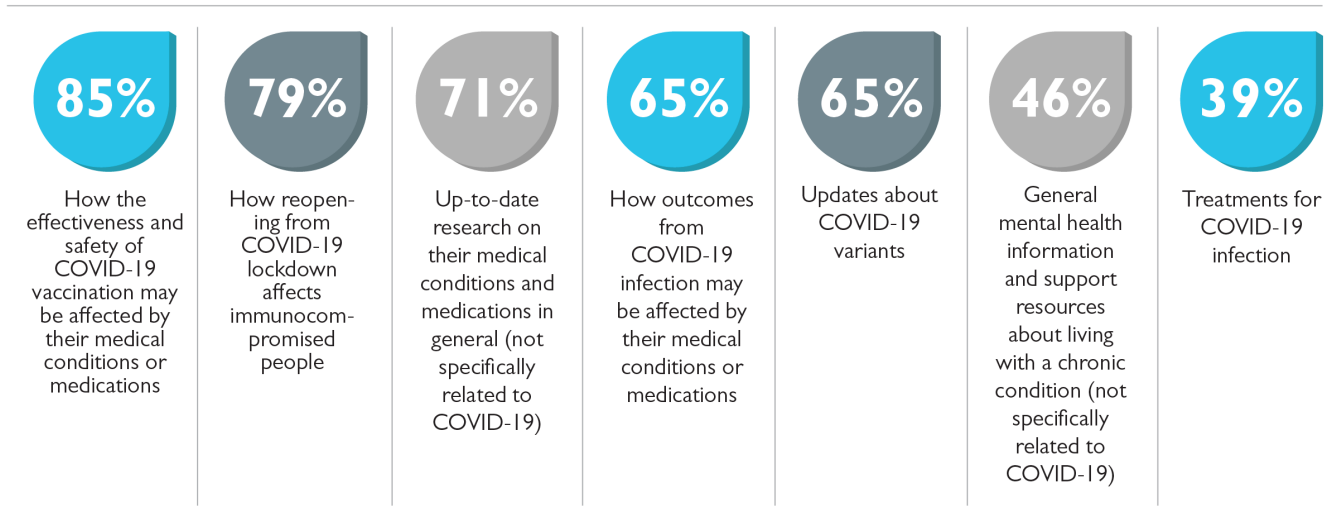
” The process is going painfully slow as there are not enough vaccines where I live. I am also anxious about others getting the vaccine and not taking precautions anymore.

” I've been homebound since March 2020 and have low mobility. It's frustrating that the program for home vax is still not finished in our area, but my feelings about the vaccine itself: I can't wait. Nothing but positives about the vaccine at our house!

“ I'm a week into my second shot and feel like the whole world has opened back up to me, after being isolated for a year. I haven't even dined outside, do grocery curbside pickup, don't see friends... at least my husband isolated with me. We're both so excited for the world to become seminormal!

**Poll Topic: Where Should We Take the Patient Support Program Next?**

We want to provide relevant and timely information to our community, which is why this June we asked for feedback on our Patient Support Program. We were thrilled that 94 percent of respondents (n = 1,606) still find the program and news updates from GHLF helpful. The topics that our members indicated were of interest moving forward include:



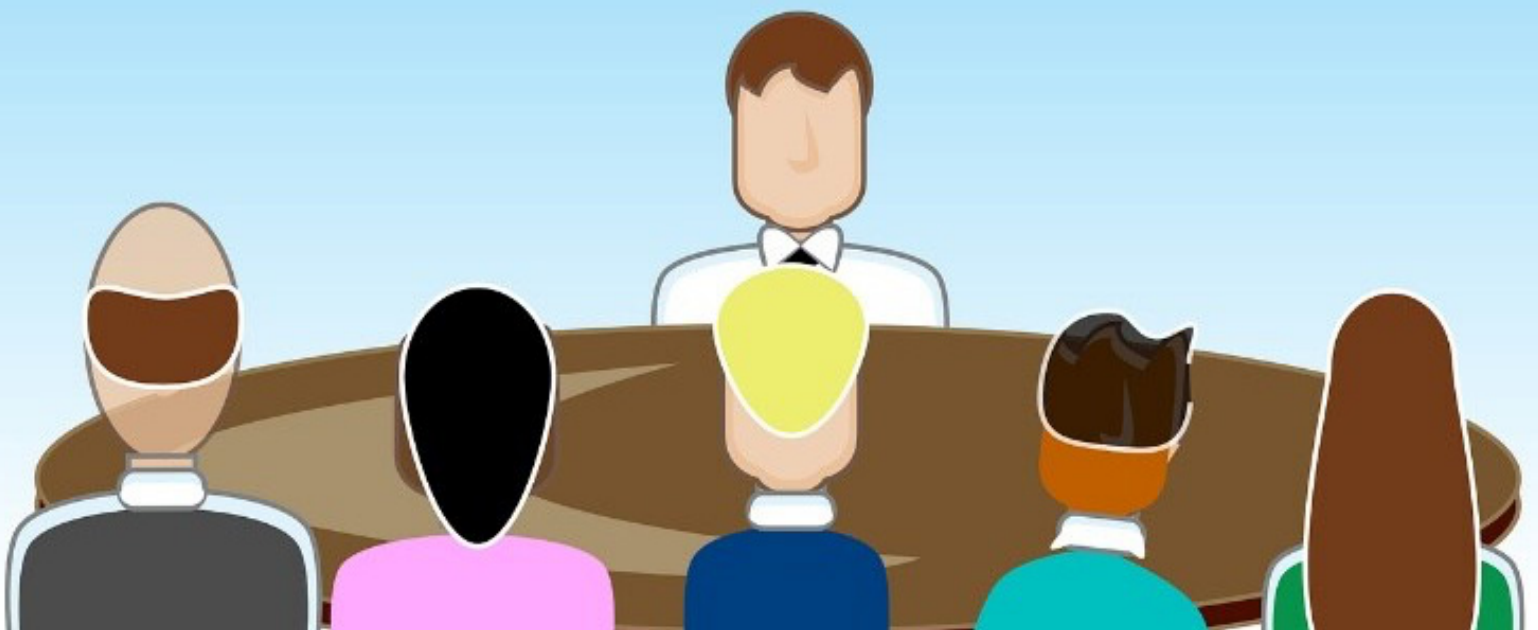
**75%**

of respondents also said that the patient support program helped them decide what precautions to take to protect from COVID-19, and a similar amount said it helped them to understand how their conditions and medications are affected by COVID-19. These results confirm that our hard work is appreciated and valued by our community.

## ■ OUR RESEARCH IS GROUNDBREAKING

During the second quarter, GHLF was honored with a new Patient-Centered Outcomes Research Institute (PCORI) Stakeholder Convening Engagement Award for our proposed Vaccine Uptake Research in Autoimmune Disease: Multistakeholder Planning project. This is a one-year award to bring together a diverse group of stakeholders in this area (patients, physicians, pharmacists, the CDC, the FDA, researchers, vaccine manufacturers, etc.) to build partnerships to plan future research.

We will leverage the Autoimmune Research Collaborative (ARC), which we lead, to convene and facilitate a multistakeholder group to identify and prioritize patient-centered research topics to build a research agenda on autoimmune patients' vaccine uptake. This award complements GHLF's vaccine-related work in advocacy, education, and research and strengthens our efforts to address misinformation and distrust of vaccines, including the COVID-19 vaccine, among patients with autoimmune conditions. Based on stakeholder input, the final goal of this project will be generating a research agenda on patient-centered topics around vaccine uptake so we can implement patient-centered research in the future with the aim of improving vaccine uptake for adult autoimmune populations.



## ■ CREATING VIRTUAL COMMUNITY: CREAKYKITCHEN CONTINUES

CreakyKitchen, our series of virtual cooking classes that brings our community together, continued in the second quarter.

In April, “Episode Six: CreakyKitchen’s Celebration of Spring Vegetables” planned for sunny days ahead. Guest chef and CreakyJoints member Chantelle M. shared her recipe for a colorful and veggie-packed pasta primavera, and CreakyJoints member Charis H. walked us through their garden and shared tips for maintaining a garden when you have arthritis. Cohosts Zoe Rothblatt and Corey Greenblatt answered the most common questions the CreakyJoints community has about gardening.

In May, “Episode Seven: CreakyKitchen Celebrates Arthritis Awareness Month” featured Chantelle teaching us her recipe for fish en papillote, an easy oven-ready and tasty entrée. In the spirit of Arthritis Awareness Month, several other members discussed how they use social media to share posts about food and cooking while managing chronic illness.

In June, “Episode Eight: CreakyKitchen Swap Meat” focused on food swaps to make favorite dishes healthier or to help them fit into specific diets. Chantelle taught us a recipe for chicken meatballs in a curry sauce. During the event, we also provided our audience with a preview of our new podcast Talking Head Pain, which focuses on managing migraine and headache disorders.



Do you have an idea for a virtual event? Email us at [zrothblatt@ghlf.org](mailto:zrothblatt@ghlf.org).



# OUR LEADERSHIP PROVIDES PERSPECTIVE AROUND THE GLOBE

Global Healthy Living Foundation staff are regularly invited to participate in events that elevate the health and health-policy issues that matter most to our community. During the second quarter, some engagements included:



**Seth Ginsberg**, President and Cofounder, was a panelist at an event titled You Say It All Looks Good, but I’m Still Not Feeling Well, hosted by Sydney-based BJC Health. Seth contributed the patient perspective on behalf of CreakyJoints Australia on the importance of patient-centered outcomes at this symposium held during the Australian Rheumatology Association’s annual scientific meeting in May. The event was sponsored by Eli Lilly.



**W. Benjamin Nowell**, PhD, Director, [Patient-Centered Research, presented at Patient-Generated Health Data Throughout the Total Product Life Cycle of Medical Devices](#), a virtual summit hosted by the U.S. Food and Drug Administration (FDA) in early May. During the session on patient-driven registries, Dr. Nowell highlighted ArthritisPower® infrastructure and described our research and digital community engagement successes.



**Shilpa Venkatachalam**, PhD, MPH, Associate Director of Patient-Centered Research, presented in May at “Digital Tools for Facilitating Patient Partner Engagement: Town Hall Webinar,” organized by the National Patient-Centered Clinical Research Network (PCORnet) Engagement Coordinating Center (ECC) and led by AcademyHealth in collaboration with the Patient Advocate Foundation. During this webinar, Dr. Venkatachalam shared examples of digital tools and platforms used by GHLF and ArthritisPower to facilitate patient engagement and patient-centered research. She also participated in [Neural Interfaces 2021](#), hosted by the National Institutes of Health (NIH) and the North American Neuromodulation Society (NANS). The discussion focused on the topic of patient engagement and patient-centered research.



**Joseph M. Coe**, MPA, Director, Education & Digital Strategy, spoke at [Amgen's 2021 Health Equity Summit](#) in April in a session titled "Disrupt Health Disparities Through Partnerships," which focused on the opportunities to create meaningful change.



**Daniel Hernandez**, MD, Director of Medical Affairs and Hispanic Outreach, spoke at FER's ReumaExpo patient conference in June and at the ORENCIA Patients Pre- and Post-Pandemic: Understanding Pathology and Care Virtual Meeting in May. Along with Angel Tapia, Patient Advocate, Hispanic Community Outreach Manager, Dr. Hernandez also spoke at an event sponsored by Bristol Myers Squibb for their Hispanic group, Organization for Latino Achievement (OLA).



**Robert Popovian**, PharmD, MS, Chief Science Policy Officer, spoke at several engagements, including the 4th Pharma Pricing, Reimbursement & Market Access 2021 on regulatory updates and development and the IEEE Healthcare: Blockchain & AI Virtual Series on decentralized clinical trials. He also spoke at the Annual Meeting of Advanced Topics for Oncology Pharmacy Professionals in a discussion titled "Let's Get in Gear: Shifting from Low-Value to High-Value Care" and at PhRMA's We Work for Health – Summit.

As always, our advocacy team participated in many virtual meetings, representing the concerns of all patients living with chronic disease to influence the development of patient-friendly health policy. Please see "Speaking with and for the Chronic Disease Community" for additional detail.

# CREAKYJOINTS ESPAÑOL LAUNCHES NEW SOCIAL MEDIA CHANNELS AND ARTHRITISPOWER ESPAÑOL

The COVID-19 pandemic shined a much-needed spotlight on health disparities in Hispanic communities (among others), but multiple inequities and inequalities facing Spanish-speaking communities predate the pandemic, including the lack of adequate access to health care and information. Hispanic patients are also [underrepresented](#) in medical research.

In May 2021, CreakyJoints Español launched new social media platforms (on Facebook and WhatsApp) and [ArthritisPower Español](#), continuing its mission to improve access to credible health information for Spanish-speaking people living with all forms of arthritis and their families. Outreach to reporters, combined with controlled media vehicles, delivered key campaign messages in print, online, and via broadcast to Hispanic communities across the U.S. in English and Spanish.

CreakyJoints Español also launched a [Spanish-language COVID-19 podcast](#) focused on explaining the various COVID-19 vaccines available in the United States and addressing the most common concerns. This podcast series also included an episode specifically targeting rheumatoid arthritis patients and pertinent information about the COVID-19 vaccines.

In the press release, Dr. Daniel Hernandez, Director of Medical Affairs and Hispanic Outreach, CreakyJoints Español, said, “It’s incredibly exciting to offer ArthritisPower Español to our Spanish-speaking community. We know that engaged patients — those who are educated about their disease and participate in shared decision-making with their providers — have improved health outcomes. ArthritisPower Español is an easy-to-use tool that will help patients monitor the aspects of their disease most important to them and discuss their data with their doctors.”



Outlets across the country (and Latin America) covered the launch, including:

- [EFE America](#), the fourth-largest news agency wire service in the world and the largest providing Spanish-language content to media outlets around the globe. Featuring interviews with Dr. Hernandez and CreakyJoints member Yaideliz A., EFE America's story ran in the [top Hispanic outlets](#) in the United States, including in print in La Opinion (Los Angeles), the largest U.S. daily paper in Spanish.
- On May 12, we coordinated a [satellite media tour](#) (SMT), booking 20 back-to-back TV and radio interviews with Dr. Hernandez and Yaideliz A. in English and Spanish across a five-hour window, resulting in
  - more than 1,400 airings (related to four nationally syndicated placements)
  - an estimated 11.8 million media impressions
- A “mat feature” article published in English and Spanish on more than 1,800 websites and 12 print placements, with 75 percent of placements in top-100 media markets and 47 percent in top-50 media markets
- In addition, Dr. Hernandez appeared on [A Su Salud](#), an English-language PBS health program targeting the Latino community of Pennsylvania's Lehigh Valley, and he gave a live interview to a major Miami-area Spanish-language radio news program.
- [Rheumatology Advisor](#), [Rheumatology Network](#), and [DocWire News](#) also covered our story, coordinating video interviews.

CreakyJoints Español continues to provide up-to-date information during the COVID-19 pandemic, focused on addressing health equity, doctor-patient relationships, vaccine information, and wellness through our CreakyJoints Español properties and partnerships. This quarter, we invited our community to participate in a webinar about COVID vaccination.

The collage consists of three distinct visual elements:

- Top Left:** A screenshot of a news article from 'La Opinión' dated May 17, 2021. The headline reads 'Millones de latinos padecen artritis' (Millions of Latinos suffer from arthritis). The article text mentions that arthritis is a common condition among Hispanics in the US, with over 4.4 million diagnosed. It notes that access to information in Spanish for education is limited.
- Top Right:** The front page of the newspaper 'La Opinión' from May 17, 2021. The main headline is 'Solo 7% de los alumnos de secundaria han regresado a las clases presenciales en LA por miedo al covid' (Only 7% of high school students have returned to in-person classes in LA due to fear of COVID). The page also features a large photo of a beauty pageant winner, Andrea Meza, with the text 'BELLEZA MEXICANA' and 'Andrea Meza gana la corona de Miss... en un concurso marcado por la prof... nuevos valores y liderazgo fem...'.
- Bottom Right:** A graphic for the program 'A SU SALUD' with the tagline 'Cheers to Good Health'. The graphic has a blue background with white and yellow text and a circular logo element.

At the bottom of the collage, there is a small disclaimer: 'navegar por diferentes páginas en internet. \*Lo primero que uno hace es meterse a Google a buscar información. Mi mamá es'.

# OUR WEBINARS DIVE DEEP TO DEFINE AND EXPLAIN

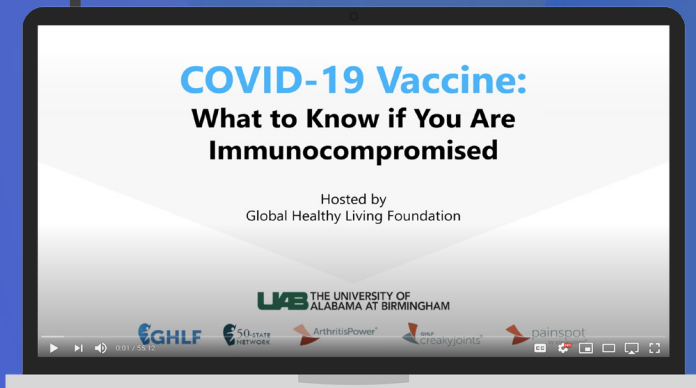
During the second quarter, we presented three webinars targeted primarily for patient audiences.

In April, we organized “[COVID-19 Vaccine: What to Know if You Are Immunocompromised](#)” to help people living with autoimmune and inflammatory conditions make better-informed medical decisions with their health care providers during the COVID-19 pandemic. The featured expert was Jeffrey Curtis, MD, MS, MPH, Professor of Medicine at the University of Alabama at Birmingham, who explained why the CDC and a task force convened by the American College of Rheumatology (ACR) called the ACR COVID-19 Vaccine Clinical Guidance Task Force, which was chaired by Dr. Curtis himself, recommend that people with autoimmune conditions and those who are immunocompromised get the COVID-19 vaccine. In short, the benefits of getting the vaccine outweigh the risks of not getting it.

In May, we hosted “[Telehealth vs. In-Person Doctor Visits: Optimizing Your Rheumatology Care](#)” to provide insights on understanding telehealth and when to utilize it and related services. Featured presenter Grace Wright, MD, PhD, FACR, a consultant rheumatologist in New York City, described the differences between telehealth, telemedicine, and in-person visits, providing advice on how to navigate and prepare for each kind of appointment. This webinar was supported by AbbVie.

In June, we invited our members to watch “[Let’s Get Physical: Chronic Pain and Physical Therapy](#).” The speaker was Susan Nowell, a physical therapist with a doctorate in physical therapy (DPT) from the University of Utah who practices in San Francisco and specializes in outpatient orthopedic physical therapy. She provided advice on the benefits of physical therapy for managing chronic pain and what physical therapy is really like.

To watch this webinar (or past webinars), visit [creakyjoints.org/category/webinar](https://creakyjoints.org/category/webinar).

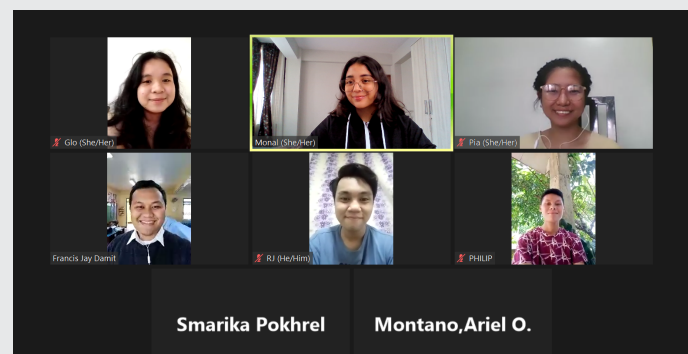


# GHLF GOES BEYOND BORDERS

GHLF's support of International Student Learning Inc. (ISLearning) and Canopy Nepal continues via our grant funding to support their program Beyond Borders, for people belonging to socially, ethnically, and financially disadvantaged communities in Nepal. The program aims to empower learners to become independent, well-informed, and proactive individuals.


- In May, Beyond Borders reached 86 participants in 13 schools. The team worked with youths in Nepal as well as the Philippines, conducting sessions on gender identity in education, child-protection policy, and the effects of digital learning.
- In June, students from Canopy Nepal and The Churchill School (based in NYC) met each other via video conferencing. The Churchill School is a K-12 coeducational college preparatory day school dedicated to working with educators and families to help students with language-based learning disabilities realize their full potential.
- On June 9, Dr. Chad Woodard, a physiotherapist and a board member of ISLearning, conducted a session with students on body posture and physical warm-ups to help maintain their posture. There was also a program for high school students with the Maths Initiative in Nepal to discuss the representation of women in the education sector.
- In addition to the above, the Beyond Borders team conducted sessions on other topics including women empowerment, pride month, and inclusivity in education.

We're also seeing the global reach of our education, such as when the Arthritis and Rheumatism Association Malta shared one of our articles.



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← **People Who Shared This**



**Arthritis & Rheumatism Association  
Malta - ARAM VO 0425**

5h · 🌐

More on Fibromyalgia symptoms, thank you  
[CreakyJoints](#)

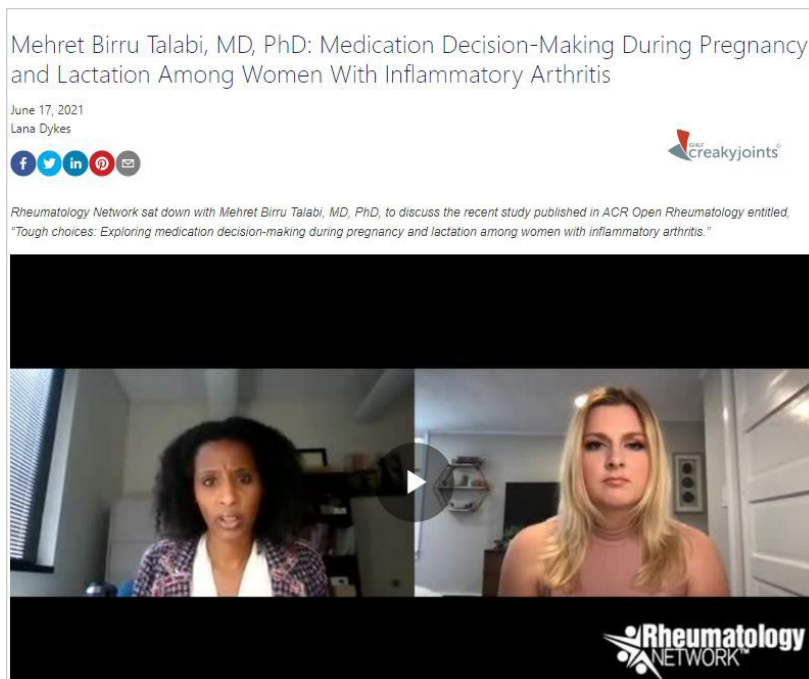


CREAKYJOINTS.ORG  
**People with Fibromyalgia May Be More Sensitive to Heat and Sound**

# OUR DATA DEMONSTRATE THAT EDUCATION IS VITAL WHEN MANAGING ARTHRITIS OVER A LIFETIME

In mid-June, [CreakyJoints](#) announced a new peer-reviewed article showing that women will often choose to endure active, inflammatory arthritis symptoms, rather than using disease-modifying antirheumatic drugs (DMARDs) because of their concerns about medication safety during pregnancy and breastfeeding, despite many drugs for arthritis being approved as safe for pregnant and lactating mothers. Published in ACR Open Rheumatology, the article, [“Tough Choices: Exploring Medication Decision-Making During Pregnancy and Lactation Among Women with Inflammatory Arthritis.”](#) also highlights that childbearing women receive conflicting medical advice from their health providers when asked to make decisions about their arthritis treatment.

- In the press release, lead author Mehret Birru Talabi, MD, PhD, of the Division of Rheumatology and Clinical Immunology, Department of Medicine, University of Pittsburgh, said, “We know that some women who discontinue inflammatory arthritis treatment during and after pregnancy may experience health consequences beyond impairments to their own physical functioning and quality of life, ones that may lead to worse fetal outcomes, such as prematurity or low birth weight. This study highlights clinicians need to make sure that we explain the potential risks and benefits of maintaining arthritis treatment during pregnancy and breastfeeding, and to address patients’ questions and concerns. We also need to make sure that we convey this same information to high-risk OB/Gyns, primary care physicians and other clinicians on the health team, to ensure that our messages are consistent and accurate.”



This study was covered by [DocWire News](#), [Healio](#), [BabyGaga](#), [Rheumatology Network](#), and [HCPLive](#).

Earlier in June, CreakyJoints presented data at the [EULAR European Congress of Rheumatology 2021](#) as part of the EULAR PARE (people with arthritis/rheumatism across Europe) track presented by the European Alliance of Associations for Rheumatology, including:

- **Perceptions of Biologic Dose Wear-Off Among People Living with Axial Spondyloarthritis: Using CreakyJoints' [ArthritisPower research registry](#)**, our first poster showed that most patients on a biologic disease-modifying medication (bDMARD) (n = 128) reported being somewhat satisfied (58 percent) or very satisfied (27 percent) with their current axial spondyloarthritis (axSpA) treatment, and more than half (53 percent) were satisfied with how well their bDMARD controls axSpA-related pain. On the other hand, nearly two-thirds (61 percent, n = 78) of participants reported that their current bDMARD typically wears off before the next dose and, among those reporting medication wear-off, 82 percent (n = 64) reported using additional medications or supplements to help with symptoms, mainly NSAIDs (69 percent), muscle relaxers (42 percent), and/or opioids (38 percent). Treatment satisfaction was lower for participants experiencing wear-off compared with those without wear-off. This study was supported by Eli Lilly and Company, Global Patient Outcomes and Real World Evidence, Lilly Bio-Medicines.
  - Senior author and rheumatologist Jessica Walsh, MD, of the University of Utah School of Medicine and the George E. Wahlen Department of Veterans Affairs Medical Center, explains, “Patients expect more from their axSpA treatment. Future research needs to address how patients manage breakthrough symptoms in axSpA and what prompts them to seek a new treatment strategy.”
- **PsA Patient Treatment Preferences: A second poster** showed that patients reported joint pain-related symptoms (e.g., joint, lower back or spine, and enthesitis-related pain) as the most bothersome, while the least bothersome were psoriasis-related. In thinking about the impact of their treatment, patients most wanted to improve the ability to perform physical activities, followed by the ability to live/function independently, quality of sleep, and the ability to do daily activities. Nearly two-thirds of respondents preferred a treatment regimen for psoriatic arthritis (PsA) that does not include methotrexate, with the most common reasons for methotrexate dissatisfaction being its known bothersome side effects and a lack of effectiveness. When asked to choose among four modes of treatment administration (an oral tablet once daily or twice daily, or subcutaneous injection once monthly or twice monthly) that were assumed to be equally safe and efficacious, the method preferred by the most patients was a once-daily tablet (38 percent) followed by a once-monthly injection (25 percent) or no preference (26 percent). This study was supported by AbbVie, Global Health Economics and Outcomes Research, Rheumatology.
  - “It’s important to understand how people living with PsA experience common symptoms, such as pain, stiffness, and fatigue, as well as their goals for treatment so that we can develop new management strategies that reflect their preferences,” said lead author Alexis Ogdie-Beatty, MD, Associate Professor of Medicine and Epidemiology and rheumatologist at the University of Pennsylvania.



- A Mindfulness Program Dosing Study to Evaluate Improvement in Emotional Distress Among People with Rheumatic Disease: This ArthritisPower study was done as part of a larger PCORI-funded study called Healthy Mind Healthy You, involving 19 patient-powered research networks and coordinated by Massachusetts General Hospital and MoodNetwork, a patient research network based there. Participants who enrolled were randomized to one of two mindfulness training programs delivered online. One was the full eight-week program, and the other was a brief three-week program. To be included in our final sample for ArthritisPower, participants had to complete the sessions as well as the follow-up surveys for at least eight weeks. We looked at the following outcome measures: WHO-5 to measure well-being, PSS for stress, PROMIS Anxiety, and PROMIS Depression. Among all assessments, there was no difference in scores based on the duration of the mindfulness program a participant was in. This may indicate that even brief mindfulness meditation training can benefit people living with rheumatic and musculoskeletal disease, especially in reducing feelings of anxiety. The Healthy Mind Healthy You study (PI: Nierenberg) was funded by PCORI (XPPRN-1512-33786).

CreakyJoints' EULAR data was covered by [Rheumatology Network](#) in two different [video interviews](#) and by [Rheumatology Advisor](#). Our team also produced a [comprehensive guide](#) to all EULAR data, which was shared with members via our social media channels.



# STEP THERAPY LAWS PROTECT VERY FEW PEOPLE ACROSS THE COUNTRY

In April, GHLF [announced](#) the highly anticipated publication of a study reporting that despite a well-intentioned investment of time and money to advocate, state by state, for protective, patient-centered step therapy laws, the resulting legislation generally protects less than 10 percent of state populations. Further dampening the impact of these laws is a lack of codified penalties, meaning that most of these laws cannot be enforced. The Health Economics, Policy and Law peer-reviewed study titled [Do Patients Benefit From Legislation Regulating Step Therapy?](#) is the result of a Global Healthy Living Foundation analysis of the structure and language of step therapy laws in 29 states.

Understanding the countrywide impact of our analysis, Stateline, a nonprofit news initiative of the Pew Charitable Trusts that syndicates content nationally, interviewed Executive Director and Cofounder Louis Tharp and Zoe Rothblatt, MPH, Patient Advocate, Community Outreach Manager, about the paper and what needs to happen next to improve patients’ access to medication. In addition, we coordinated interviews with two GHLF members, who spoke about their step therapy experience. The resulting article, titled [“Laws to Help Patients Get Pricy Drugs Fall Short, Advocates Say”](#) was published in English and Spanish and picked up by [Kaiser Health News](#), the [Chicago Tribune](#), the [New York Daily News](#), many other local papers, and select legislative news websites.

In addition, the story was covered in depth by Healio, which also featured interviews with Louis and Zoe. The story was titled [“Step Therapy Legislation ‘Lacks Teeth’ to Defend Patient Access to Doctor-Prescribed Drugs.”](#)



# GHLF SHOWS ITS PRIDE

During June, GHLF and CreakyJoints invested positive energy to support our LGBTQ community. Throughout the month, our social media channels highlighted art created by member Sal Marx and featuring other select members.

## YOU CAN'T SEPARATE MY GENDER AND CHRONIC DISEASE REALITY

*I'm professionally disabled, autistic, queer, trans/non-binary, & POC but white-passing.*

*I live in forced poverty with four cats and I grow my own fruits & vegetables.*

**I'd love to talk about how I am a drag queen & how my being autistic & trans is so validating and whole... without it being boiled down to a clinical note I'll never see.**

*It seems so simple, & I hope it is someday:*

*Being correctly gendered;*

*Asked for my pronouns;*

*Not facing assumptions about my gender every time I interact with someone from the medical field.*

**EACH PAIN HAS ITS OWN DISTINCT COLOR & PATTERN**

ghlf.org

## MY GENDER IS LIQUID

*My chronic illness has been with me for 10 years now. It all started with rheumatoid arthritis. So it is a part of me. There is no part of my life that isn't affected.*

*I would like folks to realize there are more of us pansexual folks than they realize. And more genderfluid people than they might think. We are just normal people.*

*I'm scared to tell my other doctors. It's part of the reason it has taken me so long to discuss being genderfluid.*

*It's a struggle to get good care. And I'm afraid I will lose what I already found.*

*It doesn't define all my boundaries, but it does give me new paths to walk on.*

*New ways of thinking. New ways of connecting. New ways to love and be loved.*

*Ask what our pronouns are; Speak to us correctly; Don't make assumptions based on gender and sexuality.*

*I live with guilt because I feel unseen.*

*That will go a long way towards helping us feel safe and free.*

ghlf.org

*I am a Queer, Disabled, African American Woman living with chronic illnesses.*

*My art empowers me to better understand myself.*

*My chronic illnesses make me feel like I'm an astronaut in a spaceship, exploring new and different planets. My experience of the atmosphere, gravity and landscape is challenging.*

*I had multi-layered internalized oppression because of discriminatory social assumptions that all people are or should be heterosexual, persuasive anti-Blackness in American culture and because of ableism.*

**QUANA** DENVER, CO  
ARTIST @quana.madison

ghlf.org **LGBTQIA+ CHRONIC PATIENT STORIES** @salmarx11

## MIGRAINE IS EXHAUSTING

*Migraines to me are paralyzing.*

*They're exhausting, mentally draining, so physically painful, they completely disrupt my life.*

*They alter my moods and affect my mental health. Because of the need to be in a dark room in silence.*

*I want others to know that you aren't alone and that you're seen.*

*There's a lot of people who don't always believe you because it's something they can't physically see. It can feel invalidating at times.*

*I try to be a little more conservative when I see doctors because I don't want to be treated differently in the medical field.*

*There's an entire community of people.*

**MELISSA** LOS ANGELES, CA

**LGBTQIA+ CHRONIC PATIENT STORIES**

ghlf.org

# JUNE IS NATIONAL MIGRAINE AND HEADACHE AWARENESS MONTH

The Global Healthy Living Foundation is becoming a leader in the migraine space, advocating for patients seeking access to treatments and support for the challenges they face coping with symptoms.

In June, during Migraine and Headache Awareness Month, we launched *Talking Head Pain*, a new podcast whose first season features six people from different walks of life describing their daily and long-term challenges living with migraine and other headaches. Additional education audio guides also were produced that explore topics such as migraine at work, understanding migraine treatments, and lifestyle modifications. The podcast is hosted by Joseph Coe, MPA, Director, Education and Digital Strategy, who lives with migraine himself. Peter McAllister, MD, a board-certified neurologist and Director of the New England Center for Neurology and Headache, provided expert perspective across all episodes.

The podcast was well received:

- Since launch, the podcast has reached over 60,000 people.
- *Practical Neurology* covered Talking Head Pain in an article also shared on its social media channels.
- Podcast sponsor Amgen featured the podcast on its [web site](#) to highlight the episode featuring Lori Johnston, Executive Vice President, Human Resources, who lives with migraine.
- Sarah Shaw, BIPOC Patient Advocate, Community Outreach Manager, hosted two virtual listening and discussion events for BIPOC and LGBTQ patient leaders to hear their thoughts on the “Black, Queer, and in Pain” episode and allow them to share their own lived experiences and challenges within health care.



Via our advocacy team, GHLF member Morgan F. contributed an op-ed to the Coast News (San Diego) about the challenges she’s faced dealing with step therapy to secure her migraine medications. In her piece, [“Commentary: California Is Last When It Comes to Protecting Patients’ Rights.”](#) Morgan says, “I’m one of those people caught in the step therapy loop, having lived more than half my life with debilitating migraine. Migraine is a complex neurological disease affecting more than 12% of the U.S. population. Symptoms commonly interfere with daily activities and can be so severe as to be disabling.” Her piece also spoke about our recently published peer-reviewed study on U.S. step therapy laws (see above). Notably, Morgan’s story also was featured in the Stateline story on step therapy.

In addition to launching Talking Head Pain, during Migraine and Headache Awareness Month GHLF participated in #ShadesofMigraine with several other migraine organizations. Many of our staffers provided a photo of themselves (and their dogs, kids, and partners) wearing cool sunglasses. We also secured a resolution from the [New York General Assembly](#) about Migraine and Headache Awareness Month. Joseph Coe also [testified](#) during a recent meeting of the New York State Drug Utilization Review Board. He hopes to help other New Yorkers with migraines get access to better treatments.

For the entire month, GHLF was the leading social media influencer using the hashtag #MHAM (Migraine Health Awareness Month).



# ARTHRITISPOWER RESEARCH CONTINUES

## Current ArthritisPower statistics as of June 30, 2021:

- Total patients: **33,179**
- % increase in membership from June 30, 2020: **16%**
- Top Conditions:
 

Osteoarthritis:	<b>18,049 (54%)</b>
Rheumatoid Arthritis:	<b>14,692 (44%)</b>
Fibromyalgia:	<b>11,911 (36%)</b>
Psoriasis/Psoriatic Arthritis:	<b>5,972 (18%)</b>
Osteoporosis:	<b>4,910 (15%)</b>
IBD:	<b>4,247 (13%)</b>
Lupus:	<b>1,888 (6%)</b>
- PROMIS Measures, mean (SD)
 

Pain Interference	<b>64.2 (7.3)</b>
Fatigue	<b>63.4 (9.2)</b>
Physical Function	<b>37.1 (7.1)</b>

This means that, on average, participants in ArthritisPower report symptoms that are more than 1 standard deviation worse than the U.S. general population average.

If you or someone you know would like to participate in an arthritis research study, please sign up at [ArthritisPower.org](https://ArthritisPower.org) and, 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 Kelly Gavigan, Manager, Research and Data Science, at [kgavigan@ghlf.org](mailto:kgavigan@ghlf.org). Individuals interested in proposing new research with ArthritisPower should contact Dr. Ben Nowell, Principal Investigator and Director of Patient-Centered Research, at [bnowell@ghlf.org](mailto:bnowell@ghlf.org).

ArthritisPower is overseen by Advarra IRB.

## ■ PUBLISHED RESEARCH IN THE SECOND QUARTER

It was a highly productive second quarter, with four studies published by the ArthritisPower research team.

- Birru Talabi, M., Eudy, A. M., Jayasundara, M., Haroun, T., Nowell, W. B., Curtis, J. R., Crow-Hercher, R., White, W., Ginsberg, S., and Clowse, M. E. B. “Tough Choices: Exploring Medication Decision-Making During Pregnancy and Lactation Among Women With Inflammatory Arthritis.” *ACR Open Rheumatology* 3 (2021): 475–483. [doi.org/10.1002/acr2.11240](https://doi.org/10.1002/acr2.11240).

Key findings: Women often chose to endure active inflammatory arthritis rather than to use disease-modifying antirheumatic drugs because of concerns about medication safety during pregnancy and lactation. Conflicting medical advice from health care providers undermined patients’ trust in their providers and in the safety of their medications. (See higher in this report for additional detail.)

- George, M. D., Baker, J. F., Banerjee, S., Busch, H., Curtis, D., Danila, M. I., Gavigan, K., Kirby, D., Merkel, P. A., Munoz, G., Nowell, W. B., Stewart, P., Sunshine, W., Venkatachalam, S., Xie, F., and Curtis, J. R. “Social Distancing, Health Care Disruptions, Telemedicine Use, and Treatment Interruption During the COVID-19 Pandemic in Patients With or Without Autoimmune Rheumatic Disease.” *ACR Open Rheumatology* 3 (2021): 381–389. [doi.org/10.1002/acr2.11239](https://doi.org/10.1002/acr2.11239).

Key findings: Patients with autoimmune rheumatic disease (ARD) and non-ARD reported similar concerns about COVID-19 and social distancing behaviors. Missed office visits were strongly associated with interruptions in immunomodulatory medication.

- Nowell, W. B., Merkel, P. A., McBurney, R. N. et al. “Patient-Powered Research Networks of the Autoimmune Research Collaborative: Rationale, Capacity, and Future Directions.” *Patient* (2021). [doi.org/10.1007/s40271-021-00515-1](https://doi.org/10.1007/s40271-021-00515-1).

Key findings: Research conducted by, or in collaboration with, patient organizations can return value to patients in a variety of ways for participation in the Patient Powered Research Networks (PPRNs) or in specific studies. Ideally, when PPRNs are aligned with principles of patient-centered outcomes research, they engage with patients repeatedly over time to identify patient concerns and turn them into patient-centric research questions and study designs, recruit patients to participate in studies, enlist patients in registry governance and in the analysis and interpretation of findings, provide educational content to patient communities using the most up-to-date evidence, and advocate for health policy to patients’ benefit.

- George, M. D., Venkatachalam, S., Banerjee, S. et al. “Concerns, Healthcare Use, and Treatment Interruptions in Patients With Common Autoimmune Rheumatic Diseases During the COVID-19 Pandemic.” *The Journal of Rheumatology* 48, no. 4 (April 2021): 603–607. doi.org/10.3899/jrheum.201017.

Key findings: In the early months of the COVID-19 pandemic, patients with rheumatoid arthritis (RA), PsA, ankylosing spondylitis (AS), and systemic lupus erythematosus (SLE) frequently avoided office visits and laboratory testing. DMARD interruptions commonly occurred without the advice of a physician and were associated with lower socioeconomic status, avoidance of office visits, and lack of telehealth availability, highlighting the need for adequate health care access and attention to vulnerable populations during the pandemic.

## ■ ARTHRITISPOWER STUDIES IN PROGRESS INCLUDE

- **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. It will produce a peer-reviewed white paper that describes those best practices. Overall, the goal is to expand the impact of rheumatology by increasing patient access to care, especially among those marginalized or most at risk because of the COVID-19 pandemic. The study will facilitate RA patients performing a joint self-assessment and compare its accuracy with an in-person clinician joint exam (the gold standard) performed within the next 24 to 48 hours. The GHLF research team is building a patient joint self-assessment and instructions into the ArthritisPower app so that it can be a regular feature for other studies going forward. Patient recruitment for this study will begin in late 2021.
- **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, we are planning a study of people living with rheumatoid arthritis from several clinical sites across the U.S. to evaluate associations between biometric sensor data, physician-derived data, and electronic patient-reported outcomes (ePROs) over time. In addition to this primary aim, we will explore the accuracy and predictive validity of biometric sensor data, physician-derived data, and ePROs to observe changes in disease activity and symptoms while tracking improvements in patients involved in the study. This study is sponsored by the Health Economics and Outcomes Research (HEOR) group at AbbVie US; the protocol was reviewed and approved by AbbVie’s Protocol Review Committee and Advarra IRB. RA patients on upadacitinib or adalimumab are currently being recruited from participating rheumatology clinic



sites across the U.S. At the end of the second quarter, there were 22 enrolled study participants.

- Real-World Patient Experience and Preferences in Patients with Psoriatic Arthritis (PsA):** The primary objective of this project is to better understand PsA patients' experience with their disease, including which symptoms they consider most bothersome, and preferences about treatment. This study was designed and conducted in partnership with RTI International and with PsA experts from the rheumatology divisions of the Universities of Pennsylvania and Utah Schools of Medicine. It is sponsored by the HEOR group at AbbVie US. Recruitment is now closed, and data are being analyzed to present findings in abstracts and a manuscript.
- Patient Outcomes: Real-World Evidence in Rheumatoid Arthritis (the POWER study):** The POWER study is being conducted in partnership with the CorEvitas (formerly Corrona) RA Registry. Approximately 500 RA patient participants will be recruited at CorEvitas clinical sites and then provide longitudinal ePRO data via a custom workflow in the ArthritisPower smartphone app. The primary aim of the study is to better understand the experience, disease activity, and symptoms of RA patients treated with Janus kinase inhibitors (JAK inhibitors) over time. This study is sponsored by the HEOR group at AbbVie US. The study launched in September and already has 205 participants from CorEvitas sites across the country. Participants can enroll if their doctor is part of a CorEvitas site.
- Improving Treat-to-Target by Incorporating the Patient Perspective:** This study aims to understand and assess the psychoeducational needs, barriers, and facilitators of ArthritisPower members with rheumatoid arthritis when they are contemplating a change in treatment regimen. This study consists of semistructured interviews with ArthritisPower registry members and CreakyJoints members lasting about one hour to better understand the patient perspective about readiness to make a treatment change (“mental models”), followed by a quantitative survey with a larger sample of several hundred patients to identify potential patient-level interventions to enhance a treat-to-target approach in RA. Specifically, results from the study will guide development of materials to assist physicians and their RA patients in treatment decision-making. This study is part of a Rheumatology Research Foundation (RRF) Innovation award received by Liana Fraenkel, MD, MPH, of Yale School of Medicine and Berkshire Medical Center. Recruitment is closed. The study team is preparing two manuscripts to share findings, and also developing patient-facing videos featuring discussions among people living with RA talking about their experiences with coping and treatment decision-making.
- The COVID-19 Pandemic: Perspectives from People Living with Rheumatic Diseases:** This study aims to understand the risk, incidence, and prevalence, along with the frequency, of COVID-19 infection in patients with a variety of autoimmune and inflammatory conditions. In addition, researchers aim to understand what the knowledge, concerns, and behaviors of patients are regarding the novel coronavirus and evaluate the impact of these infections

on quality-of-life-related aspects and medication discontinuation. This study will consist of semistructured interviews with people especially from underrepresented communities (including racial/ethnic minorities) and those who are not active advocates but living with autoimmune conditions and use a narrative interview approach so that the interviewer can follow the lead of the participant to expound on what the patient deems to be most important about the COVID-19 experience. Information from these interviews might help researchers and clinicians better understand how patients with autoimmune conditions feel about COVID-19. This study is being conducted in collaboration with researchers at the University of California, San Diego, and the University of Wisconsin–River Falls. Recruitment is now closed and findings are being written up for publication.

- **Survey Study on Patient Perceptions and Preferences Regarding Telemedicine for Rheumatologic Care During the COVID-19 Pandemic:**

To better understand the perceptions and preferences about telemedicine among patients with autoimmune rheumatic diseases during the COVID-19 pandemic, an online survey study was launched in June 2020 among participants in the Autoimmune COVID-19 Project. Attitudes about telemedicine were evaluated using the validated telemedicine perception questionnaire (TMPQ score). The study aimed to understand patient satisfaction with different types of telemedicine visits, and to understand patient experiences and perceptions of access to care and telemedicine, and patients' preferences for next visit type. Manuscripts are being submitted to peer-reviewed medical journals to report research results.

- **Survey Study on Understanding Patient Thoughts and Concerns Around Getting the COVID-19 Vaccine:**

Infections are a major contributor to morbidity and mortality in patients with autoimmune diseases. To understand what the knowledge, attitudes, and behaviors of patients are regarding the COVID-19 vaccinations with the goal of addressing and filling these knowledge gaps with evidence-based information, an online survey study was launched in March 2021 in English and Spanish. The main objective of the study is to identify potential determinants of vaccine uptake and barriers to vaccine acceptance in people living with arthritis and inflammatory arthritis-related conditions. This study is being conducted in collaboration with Dr. Maria I. Danila, Associate Professor of Medicine in the Division of Clinical Immunology and Rheumatology at the University of Alabama at Birmingham. The study is now closed and the data are being analyzed.

- **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. Recruitment for this study is ongoing.

## ■ OUR RESEARCH TEAM ADVOCATES FOR PATIENTS

Shared last quarter, in March, the National Pain Advocacy Center (NPAC) announced its formation and includes a group of scientists, clinicians, civil rights advocates, and people with pain who will advocate to remove systemic barriers that block pain patients' access to medication and health care. Shilpa Venkatachalam, Associate Director, Patient-Centered Research at CreakyJoints, continues to serve on their Science and Policy Advisory Council, which has convened twice since forming.

Separately, Dr. Venkatachalam will be serving on a new committee called Determi-Nation, a first-of-its-kind collective movement to address racial and social inequities in the diagnosis and treatment of psoriasis and psoriatic arthritis. It is sponsored by Janssen.



# CREAKYJOINTS AUSTRALIA GROWS ITS FOOTPRINT

You may not have heard of GHLF Australia before now, but get used to seeing the name. In the second quarter of 2021, work began to launch the Australian affiliate of GHLF in July.

GHLF Australia is proud to step in and be a part of the health care landscape in complex and challenging times for Australian patients and their communities. Our contributions aim to support the patient community through education and empowerment during the COVID-19 pandemic and well beyond, with a continued focus on chronic disease patient communities and their families.

## ■ HEALTH CARE OUTREACH

We undertook an intensive schedule of engagements to meet health care–industry representatives and peak consumer health groups to introduce GHLF Australia and discuss current patient support challenges. Following the consultation, a strategy for development of a vaccination education program and patient support program tailored for Australian patients, carers, and community was presented to the Consumer Health Forum, the Australian Patients Association, the Continuity of Care Collaboration, and other groups representing more than 300 health care organizations in Australia. Comments will continue to be canvassed as GHLF Australia develops its first two programs. A Patient Community Council will help guide the programs, while development of the GHLF Australian Scientific Advisory group will provide evidence-based scientific and medical insights and review for accuracy.

## ■ ADVOCACY IN AUSTRALIA

GHLF Australia met with pharmaceutical-industry representatives and patient-advocate members to better understand current challenges facing health care in Australia and to discuss the year ahead at the 2021 Post Budget Health Briefing with the Australian Minister for Health and Aged Care, Greg Hunt, MP, hosted by the Australian Institute of Policy and Science at the Australian Parliament House in Canberra. The budget in the coming financial year will focus again on health, economic recovery, and ongoing support of the Australian public as they negotiate a changing social and economic environment in 2022.

In Sydney, GHLF Australia met the Shadow Minister for Health and Ageing, Mark Butler, MP, at the Post Budget Opposition Health Briefing, to hear the opposition's response to the budget. The Shadow Minister voiced concern for growing vaccine hesitancy rates and vaccination supplies and called for greater investment in research and development and preventive health in Australia.



*From left to right:  
Stephanie O'Connell,  
GHLF Australia  
Public Affairs Lead;  
Mark Butler, MP,  
Shadow Minister for  
Health; Seth Ginsberg,  
GHLF Cofounder and  
President*

## ■ #MEDICINESMATTER

The patient voice has never been so important for future development of fit-for-purpose health system delivery in Australia. GHLF Australia was invited by Medicines Australia to attend #PharmAUS21 to hear from health-industry representatives about this year's #MedicinesMatter. The evening brought together patient-advocacy groups, industry leaders, and both the Minister for Health and Shadow Minister, who weighed in on next steps for health. GHLF Australia welcomed Hunt's announcement of the National Medicines Policy review, scheduled to commence on August 1, 2021.

## ■ CREAKYJOINTS AUSTRALIA

CreakyJoints Australia launched the [Patient PrepRheum](#) podcast and audio guide series, initially focused on biosimilars, doctor-patient communication, and the regulatory and drug coverage schemes, to a very receptive audience of listeners.

In May, GHLF President Seth Ginsberg presented on a panel at the Australian Rheumatology Association's annual scientific meeting about the importance of good doctor-patient communication.



# SPEAKING WITH AND FOR THE CHRONIC DISEASE COMMUNITY

We continue to represent the chronic disease community by ensuring their voices are heard in policies, protocols, and laws that affect our patient communities.

During the second quarter, Robert Popovian, PharmD, MS, Chief Science Policy Officer, published (with his writing partner, Wayne Winegarden), a peer-reviewed paper analyzing the economic impact of prior authorization policy as well as several op-ed pieces.

## PEER REVIEW

- Popovian R., Winegarden W. “An Estimate of the Net Benefits from Prior Authorization Policies in the U.S.” Health Science Journal 15, no. 4 (2021): 833. [hsj.gr/medicine/an-estimate-of-the-net-benefits-from-prior-authorization-policies-in-the-us.pdf](https://hsj.gr/medicine/an-estimate-of-the-net-benefits-from-prior-authorization-policies-in-the-us.pdf).

Key findings: Based on our analysis, health care costs associated with prior authorizations exceed the benefits of reduced drug spending, increasing total health care spending by \$1.9 billion per year. While additional research evaluating the net benefit from prior-authorization policies is necessary, our analysis indicates that prior-authorization policies as an administrative tool cannot be justified based on their net financial impact on the health care sector.

## OP-EDS

- **Morning Consult:** [Innovation in Cancer Diagnostics Is the First Step in Ensuring Equity for All Patients](#), June 2021
- **Outsourced Pharma:** [The US Drug Pricing System Needs to Be Fixed](#), June 2021
- **Townhall.com:** [Waiving Covid-19 Vaccine Patents Is a Bad Idea and Sets a Dangerous Precedent](#), June 2021
- **Morning Consult:** [Stop Failing Patients](#), May 2021
- **Morning Consult:** [We Can Address Vaccine Equity](#), April 2021
- **Healthcare Business Today:** [Blurring the Lines between Medical Practice and Insurance Coverage](#), April 2021
- **Bioprocess Online:** [No, Biologics Are Not Natural Monopolies](#), April 2021

We also helped our members amplify their voices.

- GHLF 50-State Network member Morgan F. secured an op-ed in the Coast News (California) titled [“Commentary: California Is Last When It Comes to Protecting Patients’ Rights”](#) on how step therapy affected her ability to access migraine treatments. (Mentioned in the migraine section above.)
- GHLF 50-State Network member Elisa C. secured an opinion piece in The Tennessean, the largest daily paper in the state. Her piece about patient assistance programs is titled [“When Health Care Costs More than Your House, You Have to Make Hard Choices.”](#) She says,

“

“I choose to believe that American health care exists for the patients it’s supposed to serve. So I advocate and tell my story in support of House Bill 0619 and Senate Bill 1397, which will protect thousands of Tennessee patients by ensuring they can use valuable patient assist programs, regardless of whether they are in their deductible corridor with their insurance. It is absolutely unconscionable that insurance companies would take funds intended for patients and then not apply that money to the patients’ accounts. This would not stand in any other industry. If this bill becomes law, patients just like me will not have to experience interruptions to their treatment, and compromises to their health could be prevented.”

- Migraine advocate, nurse, and 50-State Network member Elizabeth A. shared her story in hopes of helping others with migraines get access to better treatments regardless of their health care coverage plan on our website.

[Managed Healthcare Executive](#) featured an interview with Steven Newmark, JD, Chief Legal Officer and Director of Policy, discussing the rise in formulary exclusions. This article published online and in print. He says in the article, “Typically, formulary inclusions are based on complex negotiations among drug manufacturers, insurance companies and the PBMs. A pharmaceutical company may bundle its medications and offer price concessions on some to get better placement on the formulary for others. One of the complaints about exclusions — PBMs more generally — is that those negotiations and their outcomes are secret. PBMs and insurers do not publicly share this information.”

RECENT COMMENTS AND LETTERS SUBMITTED TO POLICY MAKERS INCLUDE

FEDERAL

22  
JUN

[Coalition statement in support of research using human fetal tissue](#)

21  
JUN

[FTC Pharmaceutical Task Force comments](#)

12  
MAY

[Rheumatic community comments on HR3 \(American College of Rheumatology sign-on\)](#)

22  
APR

[Letter to CMS about step therapy and Part B \(American Academy of Ophthalmology sign-on\)](#)

STATE

13  
MAY

[Rhode Island Senate Bill 859, copay accumulator adjuster ban](#)

5  
MAY

[North Carolina gout medication coverage policies \(Alliance for Gout Awareness sign-on\)](#)

5  
MAY

[South Carolina gout medication coverage policies \(Alliance for Gout Awareness sign-on\)](#)

16  
APR

[Florida House Bill 1373; Rare Disease Advisory Council \(NORD sign-on\)](#)





## ■ GHLF REPRESENTS PATIENTS AT INDUSTRY, ACADEMIC, AND GOVERNMENT MEETINGS

Virtual meetings continue to be the norm. Recently, GHLF attended or participated in the following virtual meetings:

<b>14</b> APR	United Healthcare COVID-19 Update
<b>16</b> APR	United Rheumatology's 2021 Virtual Spring Conference
<b>26</b> MAY	Galien Foundation – Restructuring Health System Financing & Delivery in a Post-COVID World
<b>27</b> MAY	IQVIA – Use AI/ML to Identify Patient Sub-Population
<b>3</b> JUN	MIT – Racism and Inequity Cost in the U.S.
<b>1</b> JUN	OutSummit – Proudly Resilient, LGBT Overview
<b>6</b> JUN	HHS Office of Infectious Disease and HIV/AIDS Policy (OIDP) – Live with Leadership conversation about Long-Term Survivors
<b>10</b> JUN	Westchester Medical Center – Post COVID-19 Recovery Program
<b>10</b> JUN	The Economist – Achieving the promise: Analytics and Machine Learning in Healthcare
<b>17</b> JUN	<a href="#">A Discussion on Innovation Policy and Patents</a> hosted by the Hudson Institute Forum for Intellectual Property
<b>23</b> JUN	Data insight and mobility solutions for health care with IBM & Moonwalk

## ■ FOCUS ON MASSACHUSETTS

During the second quarter, we organized virtual meetings with Massachusetts state legislators about copay accumulator adjuster programs. The proposed legislation, Massachusetts Bill H.1053 / S.644, which is currently in committee awaiting a hearing, would require that all coupons used count toward a patient's deductible. We advocated for patient-centered policies through meetings with:

- Representative Marcos Devers
- Representative Daniel Carey
- Representative Steven Owens
- Representative Brian Ashe
- Representative David LeBoeuf
- Representative Daniel Carey
- Representative Claire Cronin
- Senator Ryan Fattman

# CREAKYJOINTS AND THE GLOBAL HEALTHY LIVING FOUNDATION IN THE NEWS

During the second quarter, there were 114 original placements and over 3,000 placements overall, including pickup from the CreakyJoints Español satellite media tour and mat feature article. Combined, there were an estimated 636 million media impressions. Notable placements (not referenced earlier) included an article from [Healio](#) that focused on the “infodemic” created by the pandemic, which featured an interview with Joseph Coe, MPA, Director of Education and Digital Strategy for GHLF. Several [Everyday Health](#), [Self](#), [Express UK](#), and [Prevention](#) articles included expert commentary from our partner medical advisers and our members, who spoke about the challenges of living with arthritis. Impressed by our COVID-19 coverage, [The Doctor Weighs In](#) invited Daniel Hernandez, MD, Director of Medical Affairs and Hispanic Outreach, CreakyJoints Español, to contribute an article on what people living with chronic disease need to know about COVID-19 vaccination, published in May. In addition, Lauren Gelman, Director of Editorial, gave a video interview to [Rheumatology Network](#) that comprehensively defined all that CreakyJoints has to offer patients and referring rheumatologists.

The screenshot shows the Rheumatology Network website. At the top is the logo for Rheumatology NETWORK. Below the logo is a navigation bar with links for NEWS, MEDIA, CONFERENCES, COLUMNS, CME/CE, RESOURCES, and SUBSCRIBE. A search icon is on the right. The main content area features a 'Spotlight' section with links to Psoriatic Arthritis, RA Quiz, and Rheumatoid Arthritis. Below that is a 'Clinical' section with links to Arthritis, Cancer, Cardiovascular Disease, Chronic Kidney Disease, Cognitive Disorders, COVID-19, Gastrointestinal Disorders, Gout, and Imaging in Rheumatology. The featured article is titled 'Lauren Gelman: What is CreakyJoints?' by Lana Dykes, dated April 16, 2021. Below this are two smaller article teasers: 'Guselkumab Effective in Treating Enthesitis in Psoriatic Arthritis' by Lana Dykes (April 15, 2021) and 'Brad Marder, MD: Pegloticase Therapy in Gout Patients Undergoing Dialysis' by Lana Dykes (April 14, 2021).

Said Dr. Alexis Ogdie-Beatty of the University of Pennsylvania and CreakyJoints in an interview she gave to Rheumatology Network on one of her ArthritisPower studies,



CreakyJoints is a great reference for your patients. I give that to my patients all the time. It's nice because it's reviewed by physicians. So there's some good content there. There are also patient guideline booklets that have a lot of detailed information for the patient who wants a lot of detailed information. And then ArthritisPower is great because there's an app and they can track their outcome measures. So, if you have that patient that's really interested in improving their fatigue, or you want to do an intervention or something, they can track their own symptoms on that app and then show you their symptoms. I find it not only a good way to contribute to the research community, but actually it's a very practical way of tracking outcome measures. That's something that I recommended to my patients."

In the second quarter, there were nearly 6.2 million combined page views of CreakyJoints.org, GHLF.org, CreakyJoints Español, and CreakyJoints Australia content. The metrics below illustrate the quality of traffic coming to CreakyJoints.org, the diversity of visitors, and the rheumatic topics they're interested in.

- The average site visit on CreakyJoints.org is 15 minutes, 28 seconds (far, far surpassing the industry's average of one minute, seven seconds).
- As GHLF's COVID-19 Patient Support Program continued to grow, the CreakyJoints community also continued to expand. This quarter, CreakyJoints' email list grew 6 percent, reaching more than 106,000 people.
- Visitors to non-COVID-19 resources remain steady — indicating people with arthritis and their loved ones continue to seek information and support at the same level as prior to COVID-19. Some of our most popular resources this quarter included:
  - o [What Chronic Disease Patients Should Know About ICD Medical Coding](#)
  - o [Sulfasalazine Shortage: What to Do if You Have Issues Accessing This Disease-Modifying Antirheumatic Drug \(DMARD\)](#)
  - o [Training Resources for Rheumatologists Include Few Images of Skin of Color, Study Finds](#)
  - o [How Helping to Create the Latest American College of Rheumatology Rheumatoid Arthritis Treatment Guidelines Gave One Patient 'Faith in the Process'](#)
  - o [I Just Found Out That President Biden's Son Beau Had Ankylosing Spondylitis and It's Giving Me Major Hope for the Future](#)
  - o ['But You Don't Look Sick' Is Not a Compliment to People with Chronic Illnesses](#)

## ■ CREAKYJOINTS CANADA

We continued to expand our content library at CreakyJoints Canada to feature the voices of Canadian advocates with arthritis. We then share these articles on our social media channels and with other patient-advocacy partners. Notable new articles include:

- [What I Learned About My Rheumatoid Arthritis by Using a Health Tracker to Participate in Research \(and How You Can Too\)](#)
- [I Have Rheumatoid Arthritis and Am Immunocompromised: Here’s Why I Decided to Get the COVID-19 Vaccine](#)
- [Rheumatoid Arthritis Has Helped Me Experience the Worst and Best of Life](#)

## ■ ARTHRITIS AWARENESS MONTH: MAKING THE INVISIBLE VISIBLE

For Arthritis Awareness Month in May, our theme focused on the idea that even with the increase in awareness that COVID-19 has brought to high-risk illnesses, many members of the CreakyJoints community still feel invisible when it comes to people understanding their experience with chronic disease. As society continues to emerge from this traumatic year and figure out a “new normal,” we want to continue to emphasize the message of not leaving our community behind. During this monthlong campaign, we asked our community members various questions about living with an invisible illness and shared their stories on social media. The campaign generated more than 600 comments across Instagram, Facebook, Twitter, and TikTok. <https://www.instagram.com/p/CPOEgRNsRY-/> <https://www.instagram.com/p/COIDO82rp-Z/> [https://www.instagram.com/p/CO9EXufj\\_Xn/](https://www.instagram.com/p/CO9EXufj_Xn/)



**creaky\_joints** Do you worry about sounding like a complainer?

#ArthritisAwarenessMonth  
#WereStillInvisible

Image Description: On a purple background, text at the top reads “Arthritis Awareness Month,” to the left of the text is a drawing of one hand gripping the other. Larger text in center reads “(The most challenging part of having an invisible illness) is feeling I should cover up how bad my pain is because I’ll sound like a complainer if I talk about it too much.”

## SOCIAL MEDIA



During the second quarter we celebrated securing our [10,000th Instagram follower!](#) In addition, we grew Facebook to more than 121,000 fans and grew to more than 16,400 followers on Twitter. This quarter, our Facebook pages generated 150,000 impressions, and our Twitter handles generated over 54 million impressions.

## #CREAKYCHATS KEEPS THE CONVERSATION GOING

In April, we coordinated a chat with partner Everyday Health titled “Tell Me You Have a Chronic Illness Without Telling Me You Have a Chronic Illness.” It featured special guest artist and CreakyJoints member Sal Marx (who created artwork for our LGBTQ outreach). During the chat, our members shared the everyday occurrences that shape their experience with chronic disease. This chat generated more than 731 tweets from 100 participants to reach an estimated 41 million impressions.



In June, we partnered with #SpoonieChat to host a conversation called “Is the Pandemic Over? A #CreakyChats Discussion on What It Means to Reopen.” Members of our COVID-19 Patient Council offered their perspective as well.

# WHO WE ARE

## About Global Healthy Living Foundation

The [Global Healthy Living Foundation](#) is a 501(c)(3) nonprofit 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 at the community, state, and federal levels, 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 digital community for millions of arthritis patients and caregivers worldwide who seek education, support, activism, and patient-centered research through our [ArthritisPower®](#) Research Registry. 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 30,000 people. Via CreakyJoints, GHLF 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. Visit [ghlf.org](#) for more information.



## About CreakyJoints®

[CreakyJoints®](#) is a digital community for millions of arthritis patients and caregivers worldwide who seek education, support, advocacy, and patient-centered research. We represent patients in English and Spanish through our popular social media channels, our websites, and the [50-State Network](#), which includes more than 1,600 trained volunteer patient, caregiver, and health care activists.



Part of the [Global Healthy Living Foundation](#), CreakyJoints also has a patient-reported outcomes registry called [ArthritisPower®](#), which includes tens of thousands of consented arthritis patients who track their disease while volunteering to participate in longitudinal and observational research. CreakyJoints publishes the popular “[Raising the Voice of Patients](#)” series, which offers downloadable patient-centered educational and navigational tools for managing chronic illness. 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 and to become a member, visit [CreakyJoints.org](#).

## 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 rheumatological manifestations of gastrointestinal-tract (GI) 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](#).



### About the 50-State Network

The [50-State Network](#) is the grassroots advocacy arm of the [Global Healthy Living Foundation](#). It consists of patients 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](#).



### About PainSpot

PainSpot by [CreakyJoints®](#) aims to educate and empower 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 difference videoconferencing portals to try with their physician, and explains how to make the most of quick-moving appointments. To learn more visit, [eRheum.org](#).



### Find us online

CreakyJoints: [CreakyJoints.org](#)

CreakyJoints Español: [CJES.org](#)

CreakyJoints Canada: [CreakyJoints.ca](#)

CreakyJoints Australia: [CreakyJoints.org.au](#)

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

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

Twitter: @GHLForg, @CreakyJoints, #CreakyChats

Instagram: @creaky\_joints, @creakyjoints\_au, @creakyjoints\_esp

TikTok: globalhealthylivingfnd

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

