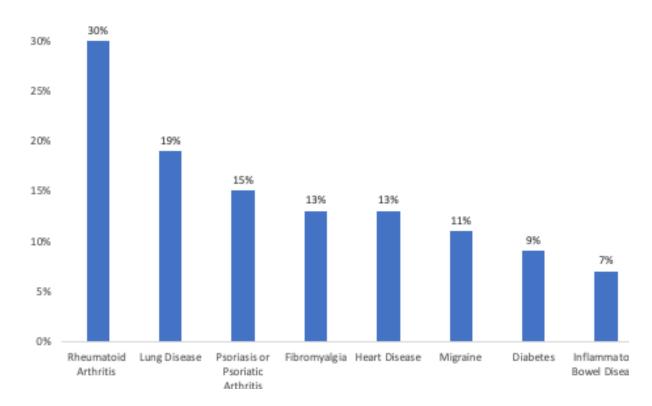
# QUARTERLY REPORT JANUARY-MARCH 2021 GLOBAL HEALTHY **FOUNDATION**

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

The pandemic may not be over, but during the first quarter, we all felt encouraged by the increasing availability of the COVID-19 vaccine. CreakyJoints® and the Global Healthy Living Foundation (GHLF) continued to provide 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.

As always, the goal of our COVID-19 Patient Support Program is to tailor COVID-19 information to people with arthritis and other chronic diseases, who have unique concerns about navigating their health and lives during the pandemic.

The free program continued to grow in the first quarter and now includes 25,896 diverse members and 42,729 subscribers (as of March 31, 2021). This was a 29 percent increase from December 2020, driven largely by 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:



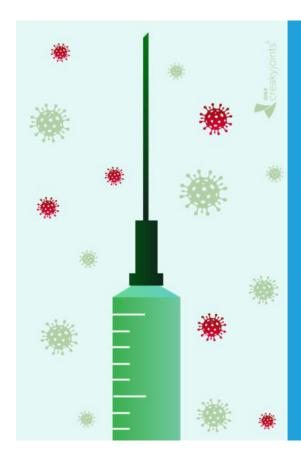
#### ■ ROBUST CONTENT

Many of our members have unique questions and concerns about the COVID-19 vaccine and navigating the pandemic because of their underlying health issues and medications, which make them immunocompromised. Will the vaccine be less effective because of immunosuppressant medication? Could those with autoimmune or inflammatory disease experience disease flares after getting the vaccine? Do recommendations for being "fully vaccinated" need to be different for those with underlying health issues? To address these concerns, we seek out 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:



- What Immunocompromised People Should Know About the CDC Recommendations for Fully Vaccinated People
- Getting a COVID-19 Vaccine with Autoimmune or Inflammatory Rheumatic Disease: New Guidance from the American College of Rheumatology
- Rituximab and the COVID-19 Vaccine: Should You Get Vaccinated if You Take Rituxan?
- Methotrexate and the COVID-19 Vaccine: Should You Stop Taking Methotrexate Temporarily After Getting the Shot?
- How 'Double Masking' with a Medical and Cloth Mask Could Better Protect You from COVID-19
- Reopening Texas Is Another Big Reminder that My Immunocompromised Life Has No Value
- How the COVID-19 Pandemic Is Increasing Anxiety in Rheumatoid Arthritis Patients

From January through March, GHLF continued to publish new COVID-19-related content each week, which has generated more than 895,000 page views. Many of these articles were also published in Spanish and made available on the <u>CreakyJoints Español</u> website and its <u>Instagram</u> page.



## ■ A FOCUS ON VACCINE HESITANCY, HEALTH DISPARITIES, AND UNDERSERVED PATIENTS OF COLOR

As part of our work to fight for racial justice and address health disparities, GHLF has been giving a platform to advocates to address issues of vaccine hesitancy and inequities in underserved communities, especially communities of color. This quarter, we shared the perspective of patient advocate Tinu Abayomi-Paul in a powerful essay on GHLF's site called "We're Not Anti-Vaxxers, We're Traumatized: Here's How to Build COVID-19 Vaccine Trust with People of Color."

### A PULSE ON THE COMMUNITY

We continue to directly communicate with our COVID-19 Patient Support Program members through our twice-a-month polls, which help us understand the concerns and needs of our community and help inform the education and support resources we develop. Poll questions are informed by social listening and insights from our COVID-19 Patient Leadership Council. Below are results from select recent polls:



## Poll Topic: Have Your Views About Getting a COVID-19 Vaccine Changed Since the Emergency-Use Authorization? (January 2021)

Many of our members have wanted more information on how the COVID-19 vaccine relates to those with autoimmune conditions or those who are immunocompromised, which is why we consulted with experts to provide content that empowers patients to make decisions. We wanted to know how this content has affected patients' decisions to get the vaccine and if their views changed after the FDA's authorization of multiple vaccines. Respondents plan on getting the vaccine at the following rates:





are interested but want to wait for more information before getting it.



were already partially vaccinated.



were not interested in getting vaccinated when available.

The poll results showed that our educational resources did impact patients' decision-making: 46 percent of respondents said that our content made them more likely to get the vaccine.

Our members said:

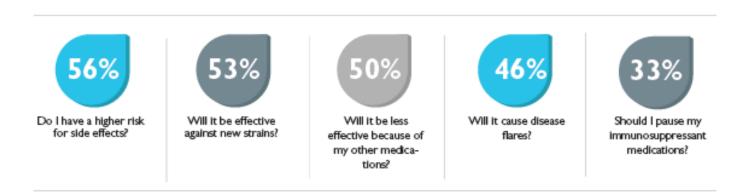
I have already received the first Moderna shot [in late December]. I have four different autoimmune diseases and experienced some side effects, [but] they were tolerable. There should be a test for antibodies for immunocompromised people like myself after the second shot. (I am currently on Remicade and would like to know if I mount antibodies.)

As a high-risk individual, I am more than willing to sacrifice one holiday season with family and friends in exchange for being able to enjoy many more.

I am not concerned about getting the vaccine. I am concerned about efficacy — that vaccine effectiveness could be compromised/ minimized for people with autoimmune disorders.

### **Poll Topic: Talking to a Provider About Vaccination (February 2021)**

We asked if our community members had spoken with their health care providers about getting vaccinated against COVID-19. Nearly three-fourths had spoken to their doctor, but 26 percent had not. (Of those, 31 percent felt they had enough information to make a decision, and another 31 percent had an upcoming appointment soon where it would be discussed.) The questions that respondents (N = 665) identified as the most important to ask a doctor were:



## ■ WEBINAR: COVID-19 VACCINE: WHAT TO KNOW IF YOU ARE IMMUNOCOMPROMISED

Given concerns identified via our polls and questions from the GHLF chronic disease community, GHLF hosted a webinar titled "COVID-19 Vaccine: What to Know if You Are Immunocompromised" on March 23, 2021, featuring Dr. Jeffrey Curtis, Professor of Medicine in the Division of Clinical Immunology and Rheumatology at the University of Alabama at Birmingham and coprincipal investigator of ArthritisPower®. With over 500 people in attendance for the live webinar and over 1,000 registrations in advance of the event, Dr. Curtis, who also served as Chair of the American College of Rheumatology (ACR) COVID-19 Vaccine Clinical Guidance Task Force, provided an overview of the ACR's guidance and debunked myths about the COVID-19 vaccine. More than 100 questions were received in advance of the webinar and during the event, and Dr. Curtis provided answers about getting vaccinated, risks for side effects, concerns around disease flares and pausing of immunomodulating therapies, and what vaccination means for resuming (or not) more normal social engagements.

## **■ CREATING VIRTUAL COMMUNITY: CREAKYKITCHEN CONTINUES**

CreakyKitchen, a series of virtual cooking classes that brings our community together during the ongoing pandemic, continues to be very popular with our members! In January, "Episode Three: A Healthy Start to the New Year" featured CreakyJoints member and guest chef Chantelle Marcial sharing a salad recipe made from pantry staples. Brooke Levine, RD, CDN, in private practice at Brooke's Mission, also shared her expert advice for incorporating foods with anti-inflammatory properties into our routine.

In February, "Episode 4: A Jam-Packed Night with CreakyKitchen" featured CreakyJoints member Cristina Montoya, RD, sharing cooking tips and an easy-to-make berry chia jam. We also heard from patients in our community who shared their

own tips for cooking while coping with a disease-related flare, their favorite recipes that make them feel good, and how their health condition impacts how they prepare foods.

In March, "Episode 5: A SOUPerb Night with CreakyKitchen" featured CreakyJoints member and guest chef Chantelle Marcial sharing her recipe for a veggie-packed soup that provides an easy-to-reheat option to get patients through those days when cooking feels downright impossible. We were also joined by Tien Sydnor-Campbell, MS, CMT, a writer and body-centered psychotherapist, who led a discussion on the intersection of body positivity and chronic illness.

Do you have an idea for a virtual event? Email us at zrothblatt@ghlf.org.



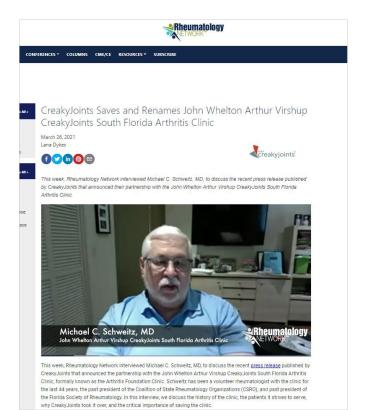
# INTRODUCING THE JOHN WHELTON ARTHUR VIRSHUP CREAKYJOINTS SOUTH FLORIDA ARTHRITIS CLINIC

<u>CreakyJoints</u> announced in late March that starting in 2021 it had begun providing administration, education, support, advocacy, and research to the newly named John Whelton Arthur Virshup CreakyJoints South Florida Arthritis Clinic. GHLF will also guarantee the clinic's future financial viability. Established in 1975 by rheumatologists Dr. John Whelton and Dr. Arthur Virshup, for whom the clinic is now named, the clinic serves South Florida arthritis patients who cannot afford treatment, providing regular and free rheumatology care to more than 100 area patients. CreakyJoints is replacing the Arthritis Foundation, which recently ended its commitment to fund clinic operations.

In the press release, Michael C. Schweitz, MD, a longtime volunteer rheumatologist with the clinic, past president of the Coalition of State Rheumatology Organizations (CSRO), and past president of the Florida Society of Rheumatology, said, "When we learned that our physical clinic home in West Palm Beach, plus our administrative and financial support, were going away, we were concerned about the risk of our patients falling through the cracks. We're thrilled to work directly with CreakyJoints and look forward to welcoming new community supporters. Now more than ever, it's important to work together to prioritize the needs of our patients."

As a result of sharing this news with media, Dr. Schweitz participated in a video interview with <u>Rheumatology Network</u> and contributed a personal perspective on his work with the clinic to <u>Rheumatology Advisor</u>. It was also covered by <u>South Florida Hospital News</u>.

Understanding the importance of reaching Spanish-speaking patients, Dr. Juan Maya, another volunteer rheumatologist for the clinic, gave a live radio interview (in Spanish) on South Florida's Radio Caracol 1260 AM. During the 12-minute interview, Dr. Maya spoke about inflammatory arthritis and the work of the clinic, and drove people to the CreakyJoints Español site for more information.



## INTRODUCING CREAKYJOINTS CANADA

This March, we initiated a soft launch of the Global Healthy Living Foundation Canada and La Fondation Mondiale pour Vivre en Santé au Canada. This includes Creakyjoints.ca in English and French. It is a new digital home for people living with all forms of arthritis across Canada and was created with our Canadian partner, the Canadian Arthritis Patient Alliance (CAPA). We formalized our presence in Canada because we already had a robust audience of Canadian patients coming to our U.S.-based properties and relationships with Canadian arthritis organizations — and felt we could do more to address their rich histories, traditions, and spirits by creating an in-country community with CAPA. CreakyJoints Canada and CAPA will empower Canadians living with arthritis through education and support to put themselves at the center of their own care by talking about their treatment preferences and working in partnership with their health care providers. All content is provided in English and French to improve the accessibility of our education and support activities.

The new organization includes a CreakyJoints Canada Patient Council that already meets to ensure that the topics covered and programs developed by CreakyJoints Canada are patient-centered and reflect the needs of the diverse Canadian patient community. Please visit <u>CreakyJoints.ca</u> to learn more. Recent coverage includes:

- How the Canadian Winter Affects My Rheumatoid Arthritis (and How I Deal with It)
- Meet Arthritis Patient Advocate Linda Wilhelm, President of the Canadian Arthritis Patient Alliance (CAPA)
- <u>Using Twitter for Good: How Twitter Chats Help Unite and Advance the Arthritis Patient Community</u>



## RACISM IN HEALTH CARE WEBINAR

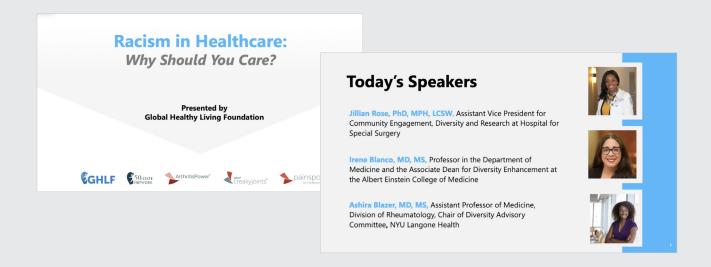
More than 100 people attended our webinar titled "Racism in Health Care: Why Should You Care?"

Racism has profound effects on the health of people of color. The COVID-19 pandemic has further exposed the realities of racism and the impact of systemic racism on people of color. During this webinar, experts discussed how racism affects the health care and health outcomes of communities of color. Presenters included:

- Jillian Rose, PhD, MPH, LCSW, Assistant Vice President for Community Engagement, Diversity, and Research at Hospital for Special Surgery
- Irene Blanco, MD, MS, Professor in the Department of Medicine and Associate Dean for the Office of Diversity Enhancement at Albert Einstein College of Medicine
- Ashira Blazer, MD, MS, Assistant Professor of Medicine, Division of Rheumatology, and Chair of the Diversity Advisory Committee at NYU Langone Health

One of the main topics addressed during the webinar was that conditions in the society or setting in which you live, learn, work, and age affect your health. In a racialized society like that of the U.S., this means that perceptions, systems, and structures tend to favor white people and hurt Black people and other people of color, as well as indigenous people.

To watch this webinar (or past webinars), visit <u>creakyjoints.org/category/webinar</u>.



## CONGRESSIONAL BRIEFING ON NON-OPIOID PAIN MANAGEMENT FOR CHRONICALLY ILL PATIENTS

As reported by the CDC, "Chronic pain [is] one of the most common reasons adults seek medical care, [and] has been linked to restrictions in mobility and daily activities, dependence on opioids, anxiety and depression, and poor perceived health or reduced quality of life." Patients living with chronic pain often face barriers to accessing affordable and quality treatment alternatives that go beyond opioids for pain management. Many will have to navigate prior authorization and/or step therapy ("fail first") management strategies before moving on to other approaches recommended by their doctors.

For this reason, on January 26, the Global Healthy Living Foundation hosted a virtual congressional briefing where issue-areas experts and directly impacted patients discussed how the health care system can better address and make more accessible innovative (non-opioid) solutions for pain management. The event featured Representative Brad Wenstrup (R-Ohio), and the audience included key health staff from multiple congressional offices.





Congressional Briefing on Non-Opioid Pain Management for Chronically III Patients

January 26, 2021, 10:30am-11:30am ET

ecial Remarks: Congressman Brad Wenstrup (OH-2nd)

## GHLF GOES BEYOND BORDERS BY SUPPORTING EDUCATION IN NEPAL

GHLF recently collaborated with International Student Learning Inc. (ISLearning) and Canopy Nepal to provide grant funding to support their program Beyond Borders, tailored to individuals belonging to socially, ethnically, and financially disadvantaged communities in Nepal. The program aims to empower learners to become independent, well-informed, and proactive individuals.

ISLearning unites students worldwide, enabling them to learn about one another's cultures, beliefs, arts, music, environments, strengths, and struggles. Canopy Nepal comprises a team of visionary youths working in the fields of education, skill

and leadership development, diversity, and inclusion. The Beyond Borders program was developed at the beginning of 2020 to implement educational and awareness programs in Nepal. Beyond Borders aims to directly contribute to the targets of the U.N. #Envision2030 Sustainable Development Goals, and in particular the goals related to good health and well-being, quality education, and gender equality, as well as indirectly fulfill the targets of other goals related to sustainable cities and communities and climate action.

Click here to learn more: <u>canopynepal.com/</u> <u>beyond-borders</u>.



## PATIENTS RANK PATIENT-REPORTED OUTCOMES — NEW STUDY

As patient-reported outcomes (PROs) are increasingly integrated with clinical measures to enhance the management and treatment of rheumatic disease, it's important to understand which outcomes are most meaningful and relevant to patients for their health decision-making. Further, as telemedicine and virtual health care become more common (stemming from the COVID-19 pandemic), it's even more important to understand what patients themselves find most important to track their disease over time.

One of several <u>ArthritisPower</u> studies published this quarter (see Research section for more), a new study published in February in Arthritis Research & Therapy titled "Which Patient-Reported Outcomes Do Rheumatology Patients Find Important to Track Digitally?

A Real-World Longitudinal Study in ArthritisPower" found that patients living with inflammatory forms of arthritis prefer to longitudinally track symptoms related to functionality — specifically fatigue, physical function, pain, and morning joint stiffness — versus other PROs.

Lead author Dr. Benjamin Nowell, PhD, Director of Patient-Centered Research at CreakyJoints and principal investigator of ArthritisPower, participated in several multimedia interviews to talk in-depth about the results, including a video interview with <a href="DocWire News">DocWire News</a> and a 35-minute podcast with the <a href="Cytokine-Signaling Forum">Cytokine-Signaling Forum</a>, an internationally read website. It was also covered by other trade publications including <a href="Healio, Rheumatology Network">Healio, Rheumatology Network</a>, and <a href="Rheumatology Consultant">Rheumatology Consultant</a>.



## EDUCATIONAL CAMPAIGNS DIVE DEEPLY INTO THE EXPERIENCE OF ARTHRITIS

In February — timed with American Heart Month — CreakyJoints launched an educational campaign focusing on why people with rheumatoid arthritis are at increased risk for cardiovascular disease. In <u>A Patient's Guide to Understanding Rheumatoid Arthritis and Heart Disease</u>, we produced a comprehensive package of resources to address how patients can measure, monitor, and manage their heart disease risk. We encouraged people living with RA to talk to their rheumatologist, as well as their primary care physician, to learn about managing their heart health.

A Patient's Guide to Understanding Rheumatoid Arthritis and Heart Disease was made possible with a grant from Myriad Genetics Inc.

In March, we launched Fight Back Against Fatigue: A Psoriatic Arthritis Patient's Guide.

As most arthritis patients can attest, fatigue is not just being tired or sleepy. It is a medical symptom that impacts a person's physical and mental state and their ability to think clearly, stay motivated, and do the things they need or want to do. For roughly 30 percent to 40 percent of people with psoriatic arthritis (PsA), debilitating fatigue is one of the most difficult symptoms to live with.

CreakyJoints launched <u>Fight Back Against Fatigue</u>: A <u>Psoriatic Arthritis Patient</u>'s <u>Guide</u> to help people living with PsA understand how fatigue is different from being tired, what causes it, how to treat fatigue, and how to talk to your doctor so you can start feeling better. The educational content includes an impactful video series describing how fatigue affects patients.

Fight Back Against Fatigue was made possible with support from Janssen Pharmaceuticals Inc.



"Fatigue is like getting a blood draw, but instead of taking blood, the energy slowly gets pulled from my body."

— Diane T., CreakyJoints Psoriatic Arthritis Patient Council



## ARTHRITISPOWER RESEARCH CONTINUES

## Current ArthritisPower statistics as of March 31, 2021:

Total patients: 32,029

• % increase in membership from 03/31/20: 14%

• Top Conditions:

Osteoarthritis: 17,156 (56%)

Rheumatoid Arthritis: 14,157 (44%)

Fibromyalgia: 11,645 (36%)

Psoriasis/Psoriatic Arthritis: 5,822 (18%)

Osteoporosis: 4,799 (15%)

IBD: 4,151 (13%)

Lupus: 1,833 (6%)

PROMIS Measures, mean (SD)

Pain Interference 64.2 (7.3)

Fatigue 63.4 (9.2)

Physical Function 37.1 (7.1)

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 <u>ArthritisPower.org</u> 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. 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.

#### PUBLISHED RESEARCH IN THE FIRST QUARTER

• Nowell, W. B., Gavigan, K., and Kannowski, C. L. et al. "Which Patient-Reported Outcomes Do Rheumatology Patients Find Important to Track Digitally? A Real-World Longitudinal Study in ArthritisPower," Arthritis Research & Therapy 23, 53 (2021), doi.org/10.1186/s13075-021-02430-0.

Key findings: As noted earlier in the report, the symptoms that rheumatology patients prioritized for longitudinal tracking using a smartphone app were fatigue, physical function, pain, and morning joint stiffness.

• Fraenkel, L., Wei., Z., and Ramsey, C. et al. "OPEX: Development of a Novel Overall Patient Experience Measure to Facilitate Interpretation of Comparison Effectiveness Studies," PLOS ONE 16(3): e0248598, <a href="https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0245598">https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0245598</a> Published January 29, 2021.

Key findings: In this Rheumatology Research Foundation–funded study, researchers developed a patient-reported measure that will help patients and their physicians compare the desirability of one RA treatment with another using a metric that describes the percentage of patients experiencing the range of desirable and least desirable outcomes across treatments. Patients can better understand the experience of a treatment to inform their decisions before initiation using the Overall Patient EXperience measure (OPEX).



### ■ 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. CreakyJoints will produce a patient-facing training video that will show RA patients how to perform a joint self-assessment and compare its accuracy with an in-person clinician joint exam (the gold standard). The research team is also building the 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 summer 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, physicianderived 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.

 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 JAK inhibitors over time. This study is sponsored by the HEOR group at AbbVie US. The study launched in September and already has more than 130 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 writing up results and developing patient-facing videos featuring discussions among people living with rheumatoid arthritis 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.

- 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 peerreviewed 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.

 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.

## **Introducing the National Pain Advocacy Center**

In March, the National Pain Advocacy
Center (NPAC) announced its formation.
NPAC consists of 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,
is a member of their Science and Policy
Advisory Council.

## CREAKYJOINTS ESPAÑOL EXPANDS ITS RESEARCH, SUPORT AND TELEHEALTH

In January, CreakyJoints Español announced that eRheum, a telemedicine support tool, is now available to our Hispanic/Latinx community in Spanish at <u>erheum.org.es</u>. Through a culturally appropriate translation, this tool offers telemedicine information in patient-friendly language. eRheum defines telehealth and how rheumatologists utilize it, provides patients with access to different videoconferencing portals to try with their physicians, and explains how to make the most of your limited face-to-face time with your physician during the appointment itself.

## ■ INNOVATIVE SPANISH-LANGUAGE SOCIAL MEDIA SUPPORT

During the first quarter, CreakyJoints Español continued efforts to bring tools, education, and support to the Spanish-speaking arthritis community. We successfully launched our Spanish-language Facebook page (@CreakyJointsESP) and soon will launch our WhatsApp handle, which is particularly exciting because this social media portal is very popular among Hispanic/Latinx users. Notably, very few organizations communicate directly to patients via WhatsApp, which is evidence of how our innovative thinking helps to reach patients where they are.



## ■ LAUNCHING SOON: PATIENT-CENTERED RESEARCH FOR SPANISH-SPEAKING PATIENTS

Coming soon is also the launch of ArthritisPower Español, a Spanish-language version of our ArthritisPower Research Registry. More than a simple translation, the app's smart functionality can identify patients who switch between English and Spanish and adapt to how the user wants to engage with the app. Final programming and testing were completed in the first quarter. In an effort to drive Hispanic/Latinx patients to use ArthritisPower Español, we will support the launch with a dedicated media outreach campaign in English and Spanish this spring and summer.among Hispanic/Latinx users. Notably, very few organizations communicate directly to patients via WhatsApp, which is evidence of how our innovative thinking helps to reach patients where they are.

## **■ FACTS FIRST — CREAKYJOINTS ESPAÑOL DISPELS MYTHS AND PROVIDES EDUCATION**

As always, CreakyJoints Español is dedicated to developing and sharing original, contextualized Spanish-language content related to the Hispanic/Latinx experience with arthritis, as well as, more broadly, to the COVID-19 pandemic. Sample articles include:

- 10 artículos para el hogar que puedes convertir en bolsas de hielo para el dolor de la artritis
- Artritis reumatoide y la vacuna contra el COVID-19: lo que necesitas saber
- La artritis reumatoide causa anemia? Lo qué debes saber sobre la relación entre las dos



10 artículos para el hogar que puedes convertir en bolsas de hielo para el dolor de la artritis



Artritis reumatoide y la vacuna contra el COVID-19: lo que necesitas saber

## CREAKYJOINTS AUSTRALIA HAS THE PULSE ON COVID-19 AND ARTHRITIS

#### ■ COVID-19 EDUCATION

Our <u>COVID-19</u> resource page continues to see steady traffic as more and more Australians look for information about the virus and what it means for them and their conditions. With the Australian vaccine rollout there has been a lot of information to share with the patient community, which we update regularly on our website. Recent articles include:

- Rheumatologists Share COVID

  Vaccination Advice for Rheumatology
  Patients
- How Does the COVID Vaccine Approval and Monitoring Process Work in Australia?

As part of our regular contribution to Rheumatology Republic magazine, our focus for the latest issue was "How Patients Want Doctors to Discuss COVID-19 Vaccines." In the article, CreakyJoints Australia Patient Council members share the questions they and other patients with autoimmune conditions would want their rheumatologists to answer about vaccines.

## ■ COMING IN MAY — PATIENT PREPRHEUM

CreakyJoints Australia (CJA) has jumped into the podcast arena with a brand-new series called Patient PrepRheum. Host Naomi Creek, National Coordinator for CJA , who has lived with rheumatoid arthritis for nearly 40 years, speaks with fellow patients and renowned doctors to explore important and often misunderstood aspects of living with autoimmune arthritis and related conditions in Australia. Patient PrepRheum will launch in the second quarter with three episodes: "The Next Step with Biosimilars," "Accessible Medicine Through the TGA & PBS," and "Improving Patient/Doctor Communication." You can access the podcast at creakyjoints.org.au/education/ patientpreprheum.



#### ■ VISIT CREAKYJOINTS AUSTRALIA ON SOCIAL MEDIA

We continue to share our website articles via Facebook (targeted to Australia) and Instagram (@ creakyjoints\_aus), and subscribers are growing steadily on these platforms. In the first quarter, the site has recorded more than 21,000 visitors and nearly 36,000 page views. Instagram followers are just about to hit 800.

#### Recent articles:

- How Do ePrescriptions Work for Australians With Chronic Health Issues?
- Caroline Wozniacki Shares Her RA Game Plan for Advantage Hers Campaign
- Have Your Say on the Upcoming NDIS Reforms
- New App Helps People with Musculoskeletal Conditions Achieve Life Goals

In March, CreakyJoints Australia started its own Twitter account (@CreakyJointsAus) to be able to share more localized content and network more effectively with the Australian health care and patient community.

#### ■ HAVE YOUR SAY! MINI SURVEYS

A new addition to the CJA website is the <u>Have</u> <u>Your Say! Mini Surveys page</u>. These short surveys will gather insights from patients and the wider community on issues that may impact their lives with arthritis, which will then assist our advocacy efforts in specific areas.



#### **■ ADVANTAGE HERS CAMPAIGN**

CreakyJoints Australia is proud to support the <u>Advantage Hers</u> campaign — a global initiative that recently launched in Australia, designed to highlight the unmet needs and unique challenges of women living with a particular subset of chronic inflammatory diseases. These include the various forms of autoimmune arthritis. The campaign also provides resources (including those on CJA's site) to help women with these conditions take more active roles in their care.

World-renowned tennis champion <u>Caroline Wozniacki</u> has partnered with the biopharmaceutical company UCB to share her story. She is the highest-ranking female athlete known to have been diagnosed with rheumatoid arthritis (at age 28) while still playing professional tennis.

Wozniacki is now taking on the title of patient advocate — sharing her personal RA journey with the world.

### **SHIFTING GEARS SUMMIT**

CJA recently attended the 2021 Consumer Health Forum's Shifting Gears Summit. This virtual inaugural Australasian health summit brought together consumers and other leaders from the health sector to explore the latest research and developments that drive health toward a consumer-centered culture.

## SPEAKING WITH AND FOR THE CHRONIC DISEASE COMMUNITY

As always, GHLF is representing the chronic disease community by ensuring their voices are heard in policies, protocols, and laws that impact our patient communities. In addition to the congressional briefing on improving access to pain-management strategies, organized in January (see earlier in report), the advocacy team has worked with patients and in partnership with other organizations to address access issues such as non-medical switching, copay accumulator programs, and step therapy, which are all payer and PBM protocols that put cost savings ahead of the patient-provider relationship.

## Recently submitted comments and letters submitted to policy makers include:

7 JAN	Coalition letter to President-elect Biden on human fetal tissue research (Every Life Foundation for Rare Diseases sign-on)
5 FEB	Letter to Congress to include the Community Immunity During COVID-19 Act in the next relief package (American Academy of Pediatrics sign-on)
5 FEB	New Mexico House Bill 129A, copay accumulator adjustor ban
12 FEB	Comments on proposed rule regarding research involving human fetal tissue (Every Life Foundation for Rare Diseases sign-on)
12 FEB	Letter to HHS secretary about copay accumulator adjustors (All Copays Count Coalition sign-on)
2 MAR	Rhode Island House Bill 5438, coalition testimony in support of banning copay accumulator adjustors
9 MAR	Connecticut Senate Bill 1003, banning copay accumulator adjustors
15 MAR	South Carolina House Bill 3956, Rare Disease Advisory Council
25 MAR	Letter to Senator Amy Klobuchar to support her efforts to study rebate walls (GHLF sign-on)

Patient advocate Denise Marksberry testified at a recent joint meeting of the Arthritis Advisory Committee (AAC) and the Drug Safety and Risk Management Advisory Committee (DSaRM). She said,



Patients did not feel they have enough information to make important decisions of surgeon, device type, surgical approach, facility, or timing, for their total knee arthroplasty. Although further research is needed to generalize these findings, physicians should consider these questions during shared decision making with patients considering total knee arthroplasty.

### **■ NEW VOICE AT GHLF: ROBERT POPOVIAN**

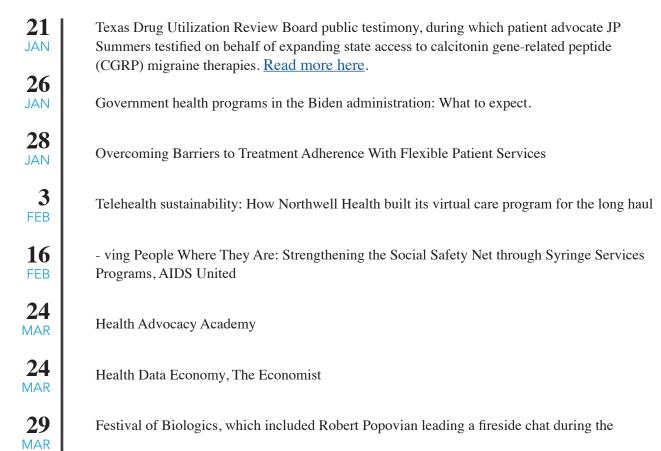
Robert Popovian, PharmD, MS, recently joined the Global Healthy Living Foundation as Chief Science Policy Officer after spending 13 years with Pfizer working in U.S. government relations. A trained pharmacist and health-science expert, Popovian's mandate is to raise the voices of patients through the contribution of opinion pieces highlighting access and research issues. Already, his work has been published in:

- InsideSources: We Need Greater Transparency to Improve the U.S. Healthcare System (3/24)
- Washington Examiner: The Pandemic Will End at Your Local Pharmacy If We Let It (3/24)

Steven Newmark, JD, MPA, Director of Policy and Chief Legal Officer of the Global Healthy Living Foundation, has also been tapped by media in the first quarter, contributing perspective to a forthcoming print and online article in Managed Healthcare Executive on the impact of drug inclusions and exclusions on patients. He also was interviewed for a <u>Dermatology Digest</u> podcast, which published in early April on a similar subject.

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

Virtual meetings continue to be the norm as the pandemic interrupts normal business practices. Recently, GHLF attended or participated in the following virtual meetings:



We joined the Digestive Disease National Coalition's 31st Annual Public Policy Forum to advocate for digestive disease research and improved patient care. In virtual meetings with Capitol Hill congressional offices, we shared our support for the Safe Step Act.

We recently met with:



Congressman Sean Maloney



Congressman Thomas Suozzi



Senator Chuck Schumer



Congressman Paul Tonko



Senator Kirsten Gillibrand



Congresswoman Yvette Clarke

## CREAKYJOINTS AND THE GLOBAL HEALTHY LIVING FOUNDATION IN THE NEWS

During the first quarter, there were 64 earned media placements featuring CreakyJoints members or leadership, generating more than 340 million media impressions. In addition to trade outlets covering two ArthritisPower studies, we generated significant consumer/patient-facing coverage in outlets such as <a href="Everyday Health">Everyday Health</a>, <a href="Women's Health">Women's Health</a> (picked up by <a href="Yahoo!Life">Yahoo!Life</a>), and <a href="WebMD">WebMD</a> that spoke to the experience of living with rheumatoid arthritis. <a href="Notably">Notably</a>, HealthCentral published six videos featuring CreakyJoints member Deen Allen, who spoke about what it's like to get diagnosed and live with rheumatoid arthritis. In the second quarter, HealthCentral will interview another member about living with ankylosing spondylitis for a second video series.



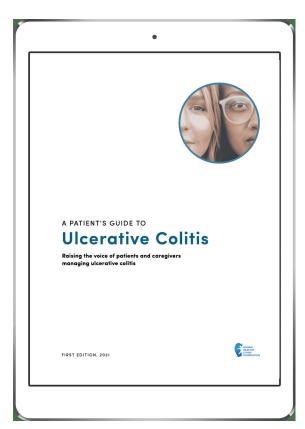
In the first quarter, nearly 2.5 million people visited CreakyJoints.org to consume its information and support content about rheumatic diseases. The metrics below illustrate the quality of traffic coming to CreakyJoints.org, the diversity of visitors, and the rheumatic topics they're interested in.

- The average site visit is four minutes, 58 seconds (far longer than 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 10 percent.
- Also, despite the COVID-19 pandemic, 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 It's Like to Have Both Rheumatoid Arthritis and Osteoarthritis at Age 35
  - o Symptoms of Non-Radiographic Axial Spondyloarthritis: Could You Have This Inflammatory Back Pain?
  - o How Rheumatoid Arthritis Affects Your Hands, and 7 Ways to Keep Them Healthy
  - o Finding Myself in an Ableist World: The Advocacy Issue I Didn't Know I Needed to Fight For
  - o Psoriatic Arthritis Rash: Symptoms, Treatment, and Pictures

### **■ NEW GUIDELINES PUBLISH**

In the first quarter, we published two new patient guidelines for people living with inflammatory bowel diseases (IBD), specifically ulcerative colitis and Crohn's disease. We created these resources as trusted guides to help people with IBD become informed about managing daily life with ulcerative colitis and Crohn's disease. Read more here:

ghlf.org/ulcerative-colitis-patient-guidelines ghlf.org/crohns-disease-patient-guidelines



### SOCIAL MEDIA

In the first quarter, we sustained 120,000+ fans on Facebook, grew to 16,000+ followers on Twitter, and grew to over 9,000 followers on Instagram. Our Facebook pages generated a half million organic impressions, and our Twitter handles generated over 20 million impressions during the quarter. In addition to engaging directly with patients, we're also coordinating our social media to promote important organization projects, such as our recent Racism in Health Care webinar. The tweet below generated more engagement than any other in the previous six months, demonstrating how the topic is of interest to many of our members and other stakeholders.



In addition to our sustained Facebook and Twitter presence, we continued to focus on other platforms to continue our strong social media engagement strategy. This is in keeping with our mission of meeting chronic disease patients where they are. On Instagram we continue to publish content through images, stories, and Instagram Lives.

On TikTok our arthritis "life hack" content continues to resonate. This TikTok on how to put on compression socks received almost 50,000 views: <a href="https://vm.tiktok.com/ZMemeOw51/">https://vm.tiktok.com/ZMemeOw51/</a>





#### #CREAKYCHATS KEEPS THE CONVERSATION GOING

On January 18 we hosted a #CreakyChats titled "COVID-19 Vaccines: A Conversation with the Chronic Disease Community" with special guest HealthyWomen and featuring patient advocate Sarah Islam and Daniel Hernandez, MD, Director of Medical Affairs and Hispanic Outreach at CreakyJoints. We generated over 4.9 million impressions during the discussion. This chat mirrored our efforts on the website and on Facebook to share evidence-based information on the different vaccines to encourage thoughtful decision-making about getting vaccinated. (We're hoping everyone gets vaccinated!)

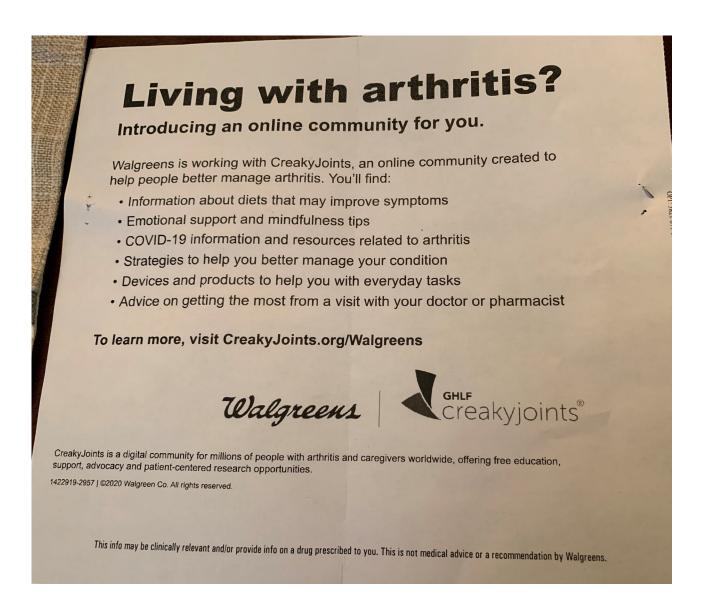
On February 23 we hosted a #CreakyChats titled "Health Care Topics to Watch," featuring Corey Greenblatt, MPH, GHLF's Manager, Policy and Advocacy; Zoe Rothblatt, MPH, GHLF's Patient Advocate, Community Outreach Manager; and Dawn Gibson, a patient advocate and the founder of #SpoonieChat on Twitter. This chat explored critical topics including non-medical switching, step therapy, biosimilars, health disparities, and telehealth. The chat generated over 11 million organic impressions.

On March 31 we hosted a #CreakyChats titled "Women, Wellness, and Chronic Illness" with special guests Tien Sydnor-Campbell, an author and medically retired, body-centered psychotherapist; Cristina Montoya, a registered dietitian; and Leah Rocketto, the new Manager of Editorial Services for the Global Healthy Living Foundation. During the chat, participants talked about how their body image changed in light of their chronic illness and how they coped with how they felt about their body image. We earned over 2.8 million organic impressions during this chat.



### **■ WALGREENS AND CREAKYJOINTS CONTINUE COLLABORATION**

If you receive a prescription for one of the over 100 drugs that help treat arthritis and its symptoms from Walgreens, make sure you check the back of your prescription pamphlet for an important health resource panel. Through the end of May, Walgreens is directing its arthritis patients to learn more about CreakyJoints by visiting <u>creakyjoints.org/walgreens</u>.



## 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® (ArthritisPower.org) 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®**

<u>CreakyJoints</u> 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 <u>50-State Network</u>, which includes more than 1,600 trained volunteer patient, caregiver, and health care activists.

Part of the <u>Global Healthy Living Foundation</u>, CreakyJoints also has a patient-reported outcomes registry called <u>ArthritisPower®</u> (<u>ArthritisPower.org</u>), 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 <u>"Raising the Voice of Patients"</u> 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



#### **Global Healthy Living Foundation**

515 N Midland Ave, Upper Nyack, NY. 10960 www.ghlf.org | 845-348-0400

#### **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 <u>50-State Network</u> is the grassroots advocacy arm of the <u>Global Healthy Living Foundation</u>. 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 <u>50StateNetwork.org</u>.



#### **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 <u>CreakyJoints</u>, <u>eRheum.org</u> 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, <u>eRheum.org</u>.



#### Find us online

CreakyJoints: <u>CreakyJoints.org</u> CreakyJoints Español: <u>CJES.org</u>

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

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

Twitter: @GHLForg, @CreakyJoints, #CreakyChats

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

TikTok: globalhealthylivingfnd

LinkedIn: linkedin.com/company/ghlf











