STAYING THE COURSE

GHLF and CreakyJoints Resolutely Supports the Chronic Disease Community with Evidence-Based COVID-19 Education

During the fourth quarter, we all felt encouraged by the promise of COVID-19 vaccines, even though we know that their approval doesn’t mean a quick end to the pandemic. With this in mind, CreakyJoints® and the Global Healthy Living Foundation (GHLF) remain committed to being a leader in providing science-based information, support, and advice for people living with chronic disease and their families. During the fall, we continued to grow our COVID-19 Patient Support Program and deepen engagement with our patient communities.

The goal of the 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 includes 20,693 diverse members and 33,552 subscribers (as of December 31, 2020). This was a 12 percent increase from November 1, 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:

- Rheumatoid Arthritis: 29%
- Lung Disease: 19%
- Psoriasis or Psoriatic Arthritis: 13%
- Fibromyalgia: 12%
- Heart Disease: 12%
- Migraine: 11%
- Diabetes: 9%
- Inflammatory Bowel Disease: 7%
ROBUST CONTENT

Our members have questions about managing their health conditions and everyday lives during the pandemic. As COVID-19 vaccines began to receive FDA authorization and as the “third wave” of COVID-19 started to sweep the U.S. in November, our members developed new sets of concerns. We interview leading experts in rheumatology, infectious disease, public health, and other specialties to seek answers, curating the most important medical research about COVID-19 for people with chronic medical conditions. We also continue to share personal essays from CreakyJoints and GHLF members to amplify their voices and share the perspective of the chronic disease community. Impactful content from the quarter included:

• Don’t Stop Taking ‘Immunosuppressive’ Medication During the COVID-19 Pandemic: A Plea from Doctors Who Are Studying COVID-19 in Inflammatory Diseases
• How to Have a Low-Risk Thanksgiving During COVID-19: 5 Tips for People with Chronic Illness
• How to Move More at Home When You’re Stuck Inside During COVID-19
• Exactly What to Do If You Get COVID-19 and You’re Immunocompromised
• 11 Extra Steps Chronic Illness Patients Should Take to Stay Safe from COVID-19 This Winter
• How I’m Coping with COVID-19 Deniers, Covidiots, and Anyone Not Taking the Pandemic Seriously

From October through December, 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 CreakyJoints Español website and its Instagram page.
An important area of patient education that launched in the third quarter and continued into the fourth quarter was about COVID-19 vaccinations. Patients in the Global Healthy Living Foundation and CreakyJoints communities had many questions specific to their health conditions and medications. There was a huge dearth of information — and plenty of misinformation — regarding COVID-19 vaccines for people who are immunocompromised, take immunosuppressant medication, and have autoimmune conditions. We developed content specifically to address these issues and, also, to share the experiences of patients receiving the vaccine.

Content included:
- **Getting a COVID-19 Vaccine: What to Know If You’re Immunocompromised**
- **Can You Get the Pfizer COVID-19 Vaccine If You’re Immunocompromised or Have an Autoimmune Condition?**
- **Can You Get the Moderna COVID-19 Vaccine If You’re Immunocompromised or Have an Autoimmune Condition?**
- **What Major Medical Organizations Are Saying About Getting an mRNA COVID-19 Vaccine If You’re Immunocompromised**
- **I Have Lupus, Take Immunosuppressants, and Just Got the Pfizer COVID-19 Vaccine — Here’s How I’m Doing**

As a result of our efforts and authority in this space, many of our resources received top ranking in Google search results and led to record traffic to the CreakyJoints.org website.

We have received a very positive response to our vaccine coverage from the professional and patient community. Patients, health care providers, and other advocacy groups alike have been thanking us for proactively following this issue and creating patient-friendly, informative resources that can guide shared decision-making.
IN TOUCH WITH OUR COMMUNITIES

Our efforts to understand and directly interact with our COVID-19 Patient Support Program members continue through the initiation of regular polls and dissemination of results. Poll questions are informed by social listening and insights from our COVID-19 Patient Leadership Council. Below are results from recent polls:

Poll Topic: Holiday Plans (October 27, 2020)
With the holiday season approaching (Thanksgiving, Kwanzaa, Hanukkah, Christmas, Diwali, etc.), do you plan on changing or canceling your usual holiday celebration plans due to coronavirus (COVID-19) concerns? (Respondents could select from multiple answers.)

- **15%** of poll respondents planned to change their traditional plans.
- **44%** planned to celebrate only with those in their immediate household, but 18% also planned a virtual celebration with extended family and friends.
- **5%** indicated they would celebrate without changing their traditional plans.

Our members said:

"My three adult daughters definitely keep me and my health #1 in regard to holiday gatherings. They feel very bad that I cannot see my little grandsons, but we do our best to do virtual calls and send little cards and gifts through the mail."

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 live in New Orleans, so we’re doing Thanksgiving outside, but I’m not sure if the temps will allow for Hanukkah or Christmas or New Year’s outside."

Depending on where you live, you may be experiencing a stay-at-home order or there may soon be the potential for one to combat the spread of the coronavirus (COVID-19) locally and regionally. What are your thoughts on a regional or local stay-at-home order to slow the spread of the coronavirus (COVID-19) where you live? (Respondents could select from multiple answers.)

- **65%** of poll respondents said they were fully supportive of a stay-at-home order if it is what we need to combat the coronavirus.
- **43%** said they were okay with a stay-at-home order if local businesses and unemployed and furloughed workers receive a stimulus to compensate for economic losses.
- **11%** said they prefer a stay-at-home order that allows schools and day cares to remain open.
- **16%** preferred a hybrid of closing restaurants and other businesses before a full stay-at-home order.
- **9%** did not prefer a new stay-at-home order.

Poll Topic: COVID-19 Vaccination (November 24, 2020)

Would you get a coronavirus vaccine now that there is more than one vaccine that may soon get emergency-use authorization from the FDA and become more widely available later next year? During this polling period (before two vaccines were FDA approved):

- **5%** had no interest in vaccination.
- **24%** wanted to learn a lot more about vaccination before getting the vaccine when it is available.
- **15%** were interested in vaccination, but hesitant to get the vaccine when it is available.
- **6%** would get the vaccine as soon as it is available and health authorities advise getting it.

- **56%** worries about how the vaccine could impact their chronic condition.
- **51%** side effects from the vaccine.
- **56%** worries about how the vaccine could impact their chronic condition.
In November, CreakyJoints launched CreakyKitchen, a series of virtual cooking classes to bring our community together during the ongoing pandemic. The first event celebrated “Friendsgiving” and was hosted by one of our CreakyJoints members, Chantelle M. As she demonstrated how to cook one of her family recipes, various participants shared stories from past Thanksgivings, fostering laughter, good memories, and many positive connections among community members.

In December, CreakyKitchen celebrated the holiday season with host Chantelle baking a sweet treat as well as CreakyJoints member and occupational therapist Cheryl C. sharing “kitchen hacks” to make cooking and baking easier for people living with arthritis and chronic pain. More than 100 people attended each event, spanning the continent from New York and New Jersey in the east to Washington and Hawaii in the west, and to countries near (Canada) and far (Australia).

Do you have an idea for a virtual event? Email us at zrothblatt@ghlf.org.
Four research abstracts related to the CreakyJoints-led Arthritis and Rheumatic Disease COVID-19 Project were presented as oral or poster presentations in November during the American College of Rheumatology’s annual meeting, ACR Convergence 2020. In addition, the study titled “Concerns, healthcare use, and treatment interruptions in patients with common autoimmune rheumatic diseases during the COVID-19 pandemic,” published in The Journal of Rheumatology in November, reported that “in the early months of the COVID-19 pandemic, patients with RA, PsA, AS, and SLE frequently avoided office visits and laboratory testing. DMARD interruptions commonly occurred without the advice of a physician and were associated with socioeconomic status, office visits, and telehealth availability, highlighting the need for adequate healthcare access and attention to vulnerable populations during the pandemic.” This study was covered by Healio in late December. A second study on vasculitis (referenced lower in this report) was also published. A number of other manuscripts are being submitted to peer-reviewed medical journals to report early research results.

Our research team launched this project in March 2020 as part of the Autoimmune COVID-19 Project, a longitudinal study for patients with multiple sclerosis, arthritis, Crohn’s and colitis, or vasculitis, and will track the evolving impact of the COVID-19 pandemic on patients living with these conditions. The project is implemented through CreakyJoints’ 29,000-member ArthritisPower® Research Registry in partnership with three other patient research networks: IBD Partners, iConquerMS™, and the Vasculitis Patient-Powered Research Network. All four, including ArthritisPower, are known collectively as the Autoimmune Research Collaborative (ARC), a group initially convened with funding support from the Patient-Centered Outcomes Research Institute (PCORI), a long-term CreakyJoints research funding source.
Our efforts to provide evidence-based education to our members continued in the fourth quarter.

In October, GHLF hosted a live, one-hour webinar titled “The Flu Vaccine and COVID-19: What People with Chronic Illness Need to Know.” Nationally recognized infectious disease and chronic disease health care providers contributed their perspective and answered questions about why getting vaccinated against the flu is a priority this year, particularly for those living with chronic conditions such as inflammatory arthritis. The expert panelists debunked common myths about the flu shot and shared information about where and how to safely get the flu vaccine. Panelists included:

**IRIS NAVARRO-MILLÁN, MD**

rheumatologist and Assistant Attending Physician, Hospital for Special Surgery; Assistant Professor of Medicine, Weill Cornell Medicine; and rheumatologist, NewYork-Presbyterian/Weill Cornell Medical Center. Dr. Navarro-Millan was recently featured in the New York Times article [How Covid Sends Some Bodies to War With Themselves](https://www.nytimes.com/2020/11/24/health/covid-fight-body.html).

**WILLIAM SCHAFFNER, MD**

Medical Director of the National Foundation for Infectious Diseases (NFID) and Professor of Preventive Medicine and Infectious Diseases at Vanderbilt University.

**TASHA POLSTER, RPH**

Vice President of Pharmacy Quality, Compliance and Patient Safety, for Walgreens.
Dr. Schaffner said in the press release, “Unfortunately, it’s likely that both the flu and COVID-19 virus will spread as fall and winter advances. Getting a flu vaccine during the 2020–2021 flu season is critical because even if the vaccine doesn’t prevent flu entirely, it can reduce a person’s risk for serious complications and possibly death.”

During this webinar, experts explained why the flu vaccination is important in general every year to bolster an individual’s immunity while supporting the public’s health, but particularly for the 2020–2021 flu season and in the face of a infectious disease pandemic.

Also in October, we hosted a webinar titled “Staying Safe During COVID-19: What People with Chronic Illness Need to Know.” The webinar featured Lauren Gelman, MS, Director of Editorial Services, Global Healthy Living Foundation, and Michael George, MD, MS, MPH, Assistant Professor of Medicine, University of Pennsylvania. More than 400 people registered for the event, with nearly 150 attending live.

Our webinar library can be found at creakyjoints.org/category/webinar.
GHLF URGES PATIENTS TO 86 MIGRAINE

In November, the Global Healthy Living Foundation launched 86 Migraine, an educational campaign that encourages people living with migraine to discard, or “86,” what they think they know about migraine. Migraine is a disabling neurological disease that impacts more than 37 million Americans. Of those, four million experience chronic migraine, which means experiencing debilitating attacks more than 15 days a month. Unfortunately, fewer than 50 percent of people who meet the criteria of the illness have ever been diagnosed. The 86 Migraine campaign includes educational articles, quizzes, and four new videos that depict the experience of migraine. For example, one of the videos rejects the idea that male migraine patients should power through their pain and, instead, encourages them to seek support. As a result of our media outreach to promote this resource, three people living with migraine will be featured in an upcoming issue of Brain & Life, an official publication of the American Academy of Neurology. The campaign was already covered by Practical Neurology.

Is Migraine Disrupting Your Career?
We also continued our efforts to raise awareness of the impact of migraine via media outreach. As a result of us sharing our “Migraine in the Workplace” report, during the third and fourth quarter, we worked with in partnership with HealthCentral to publish an article on the impact of migraine on a person’s ability to work and their career. HealthCentral spoke with Joseph Coe, MPA, Director of Education and Digital Strategy at GHLF, about our report. “We need to create a culture where people are believed, where we trust the people we work with, and we provide and leverage our resources to make the best care possible,” Coe said in the article. “Employers have tremendous power and opportunity to negotiate insurance contracts, and to really push the positive agenda of making sure people are taken care of.” The article also features several patients sharing their positive and negative experiences with migraine in the workplace. As well, it directs people to the 86 Migraine campaign for additional resources and support. You can read the full article at healthcentral.com/article/impact-migraine-on-career.
In the fourth quarter, GHLF announced the launch of eRheum.org, a new digital destination to help rheumatology patients get the most from telehealth visits. We saw early on during the pandemic that telehealth visits were going to permanently transform how rheumatology care is delivered, but patients needed help and support navigating this new care model — from technology challenges to doctor-patient communication. The project was developed based on such data insights as those presented at the 2020 ACR Convergence by CreakyJoints from our Autoimmune COVID-19 Project, which showed that as the pandemic ramped up during the spring of 2020, return-patient appointments dropped and telehealth visits increased, but not enough to overcome the frequency of missed/canceled in-person appointments. This is a problem because disruptions in rheumatology care slow the rate at which patients can be diagnosed and treated, which can adversely affect health outcomes and chronic disease management. We firmly believe that optimizing the availability and effectiveness of telehealth appointments for all rheumatology patients will help with continuity of care.
Written in patient-friendly language, eRheum defines telehealth and how rheumatologists utilize it, provides explanations of how to use different common conferencing portals (e.g., Zoom, Skype, Doximity, Microsoft Teams, and others), and gives tips and support for how to make the most of your limited face-to-face time with your physician during the appointment itself. In addition to the main portal, eRheum has been adopted and cobranded by the Association of Women in Rheumatology (AWIR) and the Rheumatology Nurses Society™ (RNS).

Simultaneously, CreakyJoints announced that it is collaborating with the University of Alabama at Birmingham, Attune Health in Los Angeles, and Cedars-Sinai Medical Center on a telehealth delivery research study funded by a two-year, $400,000 grant from the American College of Rheumatology’s Rheumatology Research Foundation. The Telehealth-delivered Healthcare to Improve Care (THRIVE) project’s primary investigator, Swamy Venuturupalli, MD, the founder of Attune Health, is the recipient of this year’s ACR’s Norman B. Gaylis, MD, Clinical Research Award, and the study is slated to begin in January 2021.

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 rheumatoid arthritis (RA) patients how to perform a joint self-assessment and compare its accuracy with an in-person clinician joint exam (the gold standard). Notably, Dr. Venuturupalli and Ben Nowell, PhD, Director of Patient-Centered Research at the Global Healthy Living Foundation, recorded a podcast about THRIVE for Rheumatology Consultant, which will publish in Q1 2021.
ARTHRITISPOWER RESEARCH CONTINUES

Current ArthritisPower statistics as of December 31, 2020:

- Total patients: **30,758**
- % increase in membership from 12/31/19: **22%**
- Top Conditions:
  - Osteoarthritis: 17,156 (56%)
  - Rheumatoid Arthritis: 13,632 (44%)
  - Fibromyalgia: 11,303 (37%)
  - Psoriasis/Psoriatic Arthritis: 5,445 (18%)
  - Osteoporosis: 4,659 (15%)
  - IBD: 4,013 (13%)
  - Lupus: 1,762 (6%)
- PROMIS Measures, mean (SD)
  - Pain Interference: 64.2 (7.3)
  - Fatigue: 63.4 (9.1)
  - 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 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. 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.
ARHTITISPOWER MAKES BIG IMPACT AT ACR CONVERGENCE 2020

At the virtual ACR Convergence 2020, the American College of Rheumatology’s annual meeting, CreakyJoints presented data collected during the COVID-19 pandemic that spotlights its impact on people living with chronic rheumatic diseases, reporting in part that many patients stopped their immunosuppressive medications without a recommendation from their doctor. The availability and integration of digital research tools, such as the ArthritisPower Research Registry, combined with access to complementary physician and patient networks, resulted in CreakyJoints presenting more data at ACR Convergence 2020 than at previous annual meetings, with two oral presentations and eight additional poster presentations. Studies included:

- **Concerns and Behaviors of Patients with Common Autoimmune Rheumatic Diseases in the United States Early in the COVID-19 Pandemic**, Abstract 1144 (poster)
- **Concerns and Health-Related Behaviors During the COVID-19 Pandemic in Patients with or Without Autoimmune Rheumatic Disease in a Large Physician Network**, Abstract 0468 (oral presentation)
- **Impact of COVID-19 on Missed/Cancelled Rheumatology Office Visits and Parenteral Immunosuppressive Medication**, Abstract 0017 (poster)
- **Effects of the COVID-19 Pandemic on Patients Living with Vasculitis**, Abstract 1416 (poster)
- **Participant Engagement and Adherence in an ArthritisPower Real-World Study to Capture Smartwatch and Patient-Reported Outcome Data Among Rheumatoid Arthritis Patients**, Abstract 1979 (oral presentation)
- **Treatment Decision Making Among Axial Spondyloarthritis Patients: Real-World Data from the ArthritisPower Registry**, Abstract 0154 (poster)
- **Changes in Patient-Reported Outcome (PRO) Scores for Nausea and Fatigue Following Weekly Methotrexate Dose in a Real-World Sample of RA and PsA Patients in the ArthritisPower Registry**, Abstract 0155 (poster)
- **Patient Perceptions of Fibromyalgia Symptoms and the Overlap with Axial Spondyloarthritis**, Abstract 1316 (poster)
- **Stepping Up for Inflammatory Arthritis (SUFIA): A Pilot Trial to Test Behavioral Economics Strategy to Increase Physical Activity in Inflammatory Arthritis**, Abstract 0546 (poster)
- **Implementation of Web-Based Patient-Reported Outcome Measures (PROMs) in SLE Clinical Care: A Multi-Center Prospective Cohort Study**, Abstract 1145 (poster)

As a result of our media outreach to share data presented at the meeting, the Autoimmune Learning Network published four videos featuring Michael George, MD, MCSE, Assistant Professor of Medicine and Assistant Professor of Epidemiology in Biostatistics and Epidemiology at the Hospital of the University of Pennsylvania, describing the impact of the COVID-19 pandemic on patients.
Ben Nowell, PhD, Director of Patient-Centered Research at the Global Healthy Living Foundation and CreakyJoints patient community, and Principal Investigator of the ArthritisPower Research Registry, also had an opportunity to participate in two video interviews with DocWire News. The first discussed a study about patient engagement in studies that use a smartwatch to capture data. He explained, “In ArthritisPower, we employed [a] user-centered design where we worked with patient partners to design the workflow, make sure that it was patient-friendly, that it was usable, [and] the user interface was good so that patients could easily follow along [with] what they were supposed to do.” The second described a pilot trial to test a behavioral economic strategy known as “loss aversion” to increase physical activity in patients with inflammatory arthritis.

Rheumatology Network and Healio also covered CreakyJoints’ ACR data.

In addition, guidelines for the management of RA, led by principal investigator Liana Fraenkel, MD, MPH, Professor Adjunct in the Division of Rheumatology, Allergy and Immunology at Yale University School of Medicine and Berkshire Medical Center, was announced at ACR Convergence 2020. ACR’s guideline-development process has included the input of patients as well as clinicians and researchers, and this year, a former GHLF patient governor and current researcher collaborator, Kristine Kranadang, and GHLF’s Associate Director of Patient-Centered Research, Shilpa Venkatachalam, PhD, served as patient representatives on the voting panel. The manuscript is expected to be published shortly.

**ArthritisPower studies in progress include:**

- **WEARable Activity Tracker Study Exploring Rheumatoid Arthritis Patients’ Disease Activity using ArthritisPower Registry Patient Reported Outcome Measures and Biometric Sensor Data (the WEAR 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, and the protocol was recently approved by AbbVie’s Protocol Review Committee and Advarra IRB. RA patients on upadacitinib or adalimumab will be recruited from participating rheumatology clinic sites across the U.S. starting in Q1 of 2021.

- **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 Health Economics and Outcomes Research (HEOR) group at AbbVie US. The patient survey was recently pilot tested, and the research team is now reviewing patient feedback. Recruitment will continue in Q1 2021. Register at ArthritisPower.org to be notified when the study opens.

- **Patient Outcomes: Real World Evidence in Rheumatoid Arthritis (the POWER study):** The POWER study is being conducted in partnership with the Corrona® RA Registry. Approximately 500 RA patient participants will be recruited at Corrona 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 Health Economics and Outcomes Research group at AbbVie US. The study launched in September and already has more than 70 participants from Corrona sites across the country. Participants can enroll if their doctor is part of the Corrona RA Registry.

- **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 currently analyzing the quantitative data.

- **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 began during Q4 2020 and will continue through Q1 2021. To reach ethnically diverse and underrepresented patient populations, recruitment for this project will involve identifying and building partnerships with clinics and physicians who cater to diverse populations and community clinics, community health centers, and research partners working with minority groups. For more information, email research@arthritispower.org.

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. This survey study was conducted as part of the Autoimmune COVID-19 Project. Manuscripts are being submitted to peer-reviewed medical journals to report research results.
Several peer-reviewed journals published ArthritisPower data during the fourth quarter, including:


Key findings (as described earlier in this report):

“In the early months of the COVID-19 pandemic, patients with RA, PsA, AS, and SLE frequently avoided office visits and laboratory testing. DMARD interruptions commonly occurred without the advice of a physician and were associated with socioeconomic status, office visits, and telehealth availability, highlighting the need for adequate healthcare access and attention to vulnerable populations during the pandemic.


Key findings:

“During the COVID-19 pandemic, patients with vasculitis have high levels of concern and exhibit potentially harmful health-related behaviors. Health care use varies across different demographic groups and geographic regions. Specific strategies are warranted to facilitate engagement of these patients with the health care system during the pandemic.”
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.

Key findings:

The results indicate the following patient communication considerations: patients have diverse and varied preferences; the tone is important but challenging; and patients want information on security, identifiers, and final disposition of information. The findings of this study provide insights into what research-related information is useful to patients and how researchers can communicate such information. These findings align with the current understanding of health literacy and its challenges. Communication is essential to transparency and ethical data use, yet it is exceedingly challenging. Developing FAQ template language to accompany a complex software may enable researchers to provide greater transparency when informed consent is not possible.
In October, CreakyJoints Español announced that the Bristol Myers Squibb Foundation has funded the RA Hispanic Outreach Program, a $1 million, two-year grant to improve relationships between Hispanic/Latinx people living with rheumatoid arthritis and rheumatologists. The grant includes creation and dissemination of evidence-based education about RA, developed in patient-friendly formats and language. The project includes assembling an advisory council of Hispanic/Latinx patients with RA and Spanish-speaking rheumatologists to collaboratively develop and evaluate educational materials to achieve culturally sensitive and patient-friendly interventions that can become part of established care.

What’s more, the RA Hispanic Outreach Program will develop and test patient-centered outcomes and create educational materials that are culturally appropriate and patient-friendly. Materials will be developed, then disseminated digitally and in partnership with rheumatology pilot sites, Hispanic/Latinx community organizations, and key opinion leaders. Part of the goal is to use findings to train clinicians to deliver culturally competent care and patient education to develop stronger more-trusting relationships.
CreakyJoints Español is becoming more accessible!

We are happy to announce that the simple-to-type URL cjes.org now directs Spanish-speaking patients to the full CreakyJoints Español website, versus the longer URL CreakyJoints.org.es.

Partnerships

On November 29, 2020, the Pan American Network of Associations of Rheumatic Patients (ASOPAN) hosted their first patient conference for Spanish-speaking rheumatic patients with the support of CreakyJoints Español. This online patient conference was streamed through YouTube Live and featured a series of Spanish-language panel discussions, Q&A sessions with patients and rheumatologists, and a wide variety of information on living with rheumatic conditions through the COVID-19 pandemic.

CreakyJoints Español continues to grow

CreakyJoints Español continued to grow its online presence by 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. Some of the most popular articles were:
CreakyJoints Australia (CJA) launched the inaugural edition of *A Patient’s Guide to Living with Axial Spondyloarthritis* in Australia as a free download from their website to coincide with World Arthritis Day on October 12.

This 60-page publication is the first of its type to be written by patients specifically for Australians living with axial spondyloarthritis (axSpA), including its subcategories ankylosing spondylitis (AS) and non-radiographic axial spondyloarthritis (nr-axSpA). Renowned rheumatologist and professor Paul Bird, Medical Director of Optimus Clinical Research in Sydney and a medical adviser to CreakyJoints Australia, reviewed these patient guidelines prior to publication. Professor Bird says, “This wonderful resource is accurate and comprehensive. The lack of jargon gives it a simplicity that allows the patient to move through the concepts with ease.”

To support the launch of the patient guidelines, a feature article was written for Rheumatology Republic’s final issue of the year (print only). The article’s focus was on how doctors can use the guidelines effectively with their patients.
VISIT CREAKYJOINTS AUSTRALIA ONLINE

CreakyJoints Australia continues to publish locally relevant articles for members, many of which are specific to COVID-19:

- COVID-19 Vaccine Implications for Australians with Autoimmune Conditions
- Ixekizumab Now Available for Australians with Ankylosing Spondylitis
- Share Your Chronic Pain Story via the #MyPainJourney Awareness Campaign
- My Life with Chronic Illness During Melbourne’s Second Lockdown: Part 1 – August
- My Life with Chronic Illness During Melbourne’s Second Lockdown: Part 2 – September
- Australian Patients Speak Up to Help Shape Healthcare During COVID-19
- The Unsung Centrelink Allowance That Helps Lead to Other Benefits (Update)

UPPING THE VOLUME OF PATIENT VOICES

This quarter, a new dedicated page for patient stories launched on the CJA website. This page is devoted to patients’ personal stories so they can read about other people’s experiences and learn from them. We hope the stories will help patients feel less isolated and that they will validate their feelings and concerns. Visit creakyjoints.org.au/patientstories.

PBAC

CreakyJoints Australia sent in a number of submissions for the Pharmaceutical Benefits Advisory Committee (PBAC) November meeting. The PBAC is an independent expert body appointed by the Australian government. Members include doctors and other health professionals, health economists, and consumer representatives. Its primary role is to recommend new medicines for listing on the Pharmaceutical Benefits Scheme (PBS).

The PBAC encourages and welcomes consumer input at these meetings, and CJA has a respected history of bringing the patient voice to the table. On behalf of the CJA patient community, supporting comments were submitted for these medicines/indications: filgotinib for severe RA and Tremfya for severe PsA.

PATIENT COUNCIL MEETS

In December, the CreakyJoints Australia Patient Council met for a final Zoom meeting to recap the year and to celebrate the achievements of 2020. The group will be working on a number of exciting projects in 2021 and hopes to expand their numbers to include some male patients.

SETH IN OZ

The CJA team is very excited to have CreakyJoints President and Cofounder Seth Ginsberg and his family now residing in Australia. With no time zone logistics to hinder activities, we have been enjoying the ease of communication and direct nature of having Seth down under. With Seth at the helm, 2021 promises to be a big year for the organization. Seth’s Australia assignment, lasting through 2021, extends to Oceania and focuses on Japan. GHLF PTY LTD has been the Australian nonprofit umbrella of CreakyJoints Australia since 2015.
SPEAKING WITH AND FOR THE CHRONIC DISEASE COMMUNITY

As the nation focused on the presidential election and aftermath in the fourth quarter, legislative efforts slowed down. However, while legislators were directing their attention elsewhere, GHLF has kept our eyes and ears out for any issues impacting our patient communities.

We focused on stopping the continued growth of copay accumulator adjuster programs and have joined related letters to advocate on behalf of patients. We are concerned that the expansion of such programs will negatively impact patients’ ability to afford their medications, especially amid the COVID-19 pandemic and the resulting economic recession.

To ensure patients around the country have access to care without obstacles, GHLF continues to submit letters to policy makers. Recent comments include:

3 Nov
Letter to WEA Trust opposing their implementation of copay accumulator adjustors

4 Dec
Letter to support step therapy reform federally (Federal Step Therapy Coalition sign-on)

22 Dec
Patient and provider groups oppose most favored nations rule (Part B Access for Seniors and Physicians (ASP) Coalition sign-on)

28 Dec
GHLF comments on 2022 Notice of Benefit and Payment Parameters

Coalition comments on 2022 Notice of Benefit and Payment Parameters (All Copays Count Coalition sign-on)

29 Dec

Specific to COVID-19, our comments during the third quarter included:

23 Nov
Letter to support step therapy reform in Massachusetts (American Cancer Society – Cancer Action Network sign-on)
THE MEDICAID TSUNAMI IS HERE

In November, Steven Newmark, JD, MPA, Director of Policy and General Counsel of the Global Healthy Living Foundation, contributed an opinion piece to The Doctor Weighs In that explained why opposing forces of the pandemic-related economic downturn and related diminished tax income versus an increased demand by many unemployed Americans newly eligible for Medicaid would cause an economic crisis for state legislatures. He urged states, “For the sake of your residents, for the sake of our country, and, yes, for the long-term sake of your state budgets, please be sure to fully fund Medicaid in your upcoming budgets,” to protect the long-term health outcomes of residents, particularly those with chronic diseases.

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:

- 07 Oct: Columbia Narrative Medicine: October Virtual Narrative Medicine Rounds with Writer Eula Biss
- 15 Oct: Telehealth’s Future: How Rosy Is the Picture Post-Pandemic?
- 22 Oct: Connecticut Step Therapy Roundtable
- 04 Nov: Brookings Election 2020: Results and Implications
- 12 Nov: HLTH Matters: Digital Health Investments
- 16 Nov: Digestive Disease National Coalition’s webinar “Patient Access to Care and Treatments in the Cost-Shifting Era”
- 20 Nov: Prescription Drug User Fee Act (PDUFA) VII Stakeholder Meeting with FDA
- 02 Dec: Columbia Narrative Medicine December Virtual Narrative Medicine Rounds with Alex Vitale
- 04 Dec: Columbia Business School: Social Enterprise Conference
- 10 Dec: Biosimilars 101 – Patient Benefits, Policies, and Opportunities in New York
- 11 Dec: Prescription Drug User Fee Act (PDUFA) VII Stakeholder Meeting with FDA
ADAPTING TO VIRTUAL ADVOCACY

In September, GHLF introduced a training session on the basics of teleadvocacy conducted by GHLF Patient Advocates and Community Outreach Managers Conner Mertens and Zoe Rothblatt. Topics covered included: scheduling meetings, on-call etiquette, technical support, effective storytelling, making the most of meetings, and ways to follow up. Trainings continued into October as we strive to empower patients to be their own best advocates. The CreakyJoints’ patient council received training on October 7, GHLF partnered with the Headache and Migraine Policy Forum to train migraine patients on October 13, and trainings were held for GHLF’s Covid-19 Leadership Council October 20.

ADVOCACY ON SOCIAL MEDIA

GHLF and CreakyJoints have been advocating for years against “fail first” policies that require patients to first “fail” a cheaper medication before they are put on a more expensive (and potentially more effective) one. We released a TikTok and Instagram video depicting the struggle patients go through when they are forced to fail first. The “Expectations versus reality: Medication version” video had over 100,000 views on Instagram and 140,000 views on TikTok.

The U.S. Supreme Court heard another lawsuit against the Affordable Care Act (ACA) that could have major implications for patients with chronic conditions. While the outcome of this case (California v. Texas) is important for all Americans, it’s particularly important for our community members, who has preexisting conditions. We put together the article “5 Things Chronic Illness Patients Should Know About California v. Texas.”

In the first week of December, GHLF participated in Crohn’s and Colitis Awareness Week through social media. Each day we highlighted an inflammatory bowel disease patient who described what they wish everyone understood about living with IBD.
In December, CreakyJoints launched *The Gout Show*, a new podcast series and digital destination to raise awareness of one of the most misunderstood and misdiagnosed forms of arthritis: gout. Hosted by Steve Clisby, a professional musician who was recently diagnosed with gout, the five-episode series features experts and fellow patients defining gout, debunking common myths, and sharing useful tips to help other patients take control of their health. In addition to the podcast, there are three bonus patient audio guides about gout diagnosis, risk factors, and the treatment landscape. The Gout Show section of the CreakyJoints website (creakyjoints.org/thegoutshow) includes a quiz about uncontrolled gout, and robust educational and support articles specific to gout. The podcast and patient audio guides are available everywhere podcasts are downloaded.

As a result of sharing The Gout Show with select media, one of the expert contributors, Theodore R. Fields, MD, a rheumatologist at the Hospital for Special Surgery and Professor of Clinical Medicine at Weill Cornell Medical College in New York City, had the opportunity to develop a case study and quiz about gout published on *Rheumatology Consultant* in early January 2021.
Starting this summer and continuing into the fourth quarter (and beyond), CreakyJoints and Bergenstages, the theater department at Bergen Community College in Paramus, New Jersey, have collaborated to turn our members into famous radio stars. (Famous is a loose term.) We’ve been producing a series of radio shows from the 1930s and ’40s — complete with sound effects — to provide people who are feeling restless after months of social isolation with some much needed engagement and fun. It also gives our community members with the acting bug a chance to flex their artistic and creative muscles. The program is directed and produced by Jim Bumgardner, GHLF’s Director, Arts Education, who is also an Associate Theater Professor at Bergen Community College.

The most recent production was October’s “The Man Who Thought of Everything,” starring CreakyJoints members Laura Gardner as Irene, Heather Schick as Phyllis, and Jed Finley as Ernest. When this show was written in 1939, it involved climbing up ivy and down a rope ladder with a Cadillac in waiting and a Ford for a backup. This short comedy written by E. N. Taylor is a double take on marriage with no detail left to chance. Listen to the episode and several others at creakyjoints.org/support/radio-theater.
During the fourth quarter, there were 38 earned media placements featuring CreakyJoints members or leadership, generating nearly 88 million media impressions. The biggest news driver was data stemming from the 2020 ACR Convergence.

For the entire 2020 calendar year, earned media outreach generated over 1 billion media impressions, thanks to high-profile placements in outlets such as USA Today, Public Radio International, Business Insider, WebMD, Everyday Health, HealthCentral, Good Housekeeping (print only), and hundreds of other original placements reaching consumer and physician audiences.

In the fourth 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 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). Audience age data is not collected for visitors under 18.
• 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 continue to 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 include:
  o  The 4 Stages of Rheumatoid Arthritis Progression
  o  How Arthritis Strikes Your Feet and 11 Ways to Heal Your Foot Pain
  o  Fibromyalgia Tender Points: What and Where Are They?
  o  Arthritis in Your Neck: Signs of Neck Arthritis, and What to Do About It

The Stages of Rheumatoid Arthritis

STAGE 1
The body mistakenly attacks its own joint tissue.

STAGE 2
The body makes the antibodies and the joints start swelling up.

STAGE 3
The joints start becoming bent and deformed, the fingers become crooked. These misshapen joints can press on the nerves and can cause nerve pain as well.

STAGE 4
If not treated, the disease will progress to the last stage, in which there’s no joint remaining at all and the joint is essentially fused.
SOCIAL MEDIA

In the fourth quarter, we sustained nearly 120,000+ fans on Facebook and grew to 15,700+ followers on Twitter. Our Facebook page generated over one million organic impressions, and our Twitter handle generated over 30 million impressions in the last 90 days.

In addition to our sustained Facebook and Twitter presence, during this quarter GHLF focused 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.

Examples include generating a viral video about chronic disease comments from friends on TikTok (viewed approx. 145,000 times), publishing a viral step therapy advocacy video on Instagram that was viewed over 350,000 times, and increasing our LinkedIn presence by regularly sharing GHLF updates. We also continued producing digital events such as CreakyKitchen and CreakyJoints Radio Theater.

In addition, CreakyJoints continued our tradition of being the top nonprofit social media influencer at ACR Convergence, making sure we reach both providers and patients with important updates. During ACR Convergence 2020, our estimated impressions were 9.4 million, vastly higher than even the ACR itself at just 2.4 million impressions.

Notably, our articles about what people need to know about COVID-19 vaccination generated as much social media engagement as our educational articles at the start of the pandemic. The tweet below was the third most “liked” all year.

CreakyJoints.org @CreakyJoints · Dec 20, 2020

“i know the #vaccine was not tested in people w/ my health conditions/taking my medications but i wanted to get it partly to show other people like me that you can get it & still be OK,”
creakyjoints.org/living-with-ar... #lupus #autoimmune #COVID19Vaccine #Pfizervaccine #spoonie #spoonies

I Have Lupus, Take Immunosuppressants, and Just Got the Pfizer CO...
Learn more about what it was like for a health care worker with lupus and on immunosuppressant medication to get the Pfizer COVID-19 ...
creakyjoints.org

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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®
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® (ArthritisPower.org), 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
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 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_aus, @creakyjoints_esp
TikTok: globalhealthylivingfnd
LinkedIn: linkedin.com/company/ghlf