

QUARTERLY REPORT

JANUARY – MARCH 2020



GLOBAL
HEALTHY
LIVING
FOUNDATION

GHLF AND CREAKYJOINTS LEAD THE COVID-19 RESPONSE FOR THE CHRONIC DISEASE COMMUNITY

At the start of 2020, no one could have predicted how COVID-19 (novel coronavirus) would impact the daily lives of every single person around the world. But as the pandemic began to spread globally, CreakyJoints and the Global Healthy Living Foundation immediately pivoted from our planned educational and support activities to instead become “digital first responders” for chronic disease patients who may be susceptible to complications from coronavirus, either due to their chronic conditions, comorbidities and age, or medications they use to treat those conditions that can affect immune system function. At the onset of the pandemic, there was little information or support specifically for these patient populations and GHLF was the first and most prominent source of trusted information for the arthritis patient community and well beyond.

Daniel Hernandez, MD, center, GHLF Director, Medical Affairs and Hispanic Outreach, meets with patients and other non-profits.



Recognizing that the coronavirus has rapidly cut through geographic, socioeconomic, political, and other divides, our goal was to develop comprehensive, credible, sympathetic, and actionable resources for the chronic disease community. We specifically targeted our efforts to those high-risk patients who were craving information to understand how to protect themselves and their loved ones from a potentially life-threatening disease.

■ ROBUST CONTENT

Late February through March 31, GHLF published more than 80 pieces of original coronavirus-related content, which generated nearly 1.5 million pageviews. Many of these articles were also published in Spanish and made available on CreakyJoints Español and its associated Instagram page.



Graphic design by Tatiana Ayazo

The most popular articles dealt with general information about what people who may be at higher risk for coronavirus needed to know to protect themselves and their loved ones, stories about how to manage anxiety, and first-person testimonials from leaders of different patient communities. These included:

- [Coronavirus Questions from Immunocompromised Patients](#)
- [Prednisone and Coronavirus: Do Corticosteroids Make You Immunosuppressed and Higher Risk for COVID-19?](#)
- [‘The Cripples Will Save You’: A Critical Coronavirus Message from a Disability Activist](#)
- [‘Expect to Have Shortness of Breath and Wait It Out’: What an Immunocompromised Patient with Coronavirus Is Going Through](#)
- [Are Coronavirus Symptoms Different If You Have an Autoimmune Condition or Chronic Illness?](#)

PATIENT SUPPORT PROGRAM

Seeing the tremendous response from our community to our COVID-19 content, we then created a [digital patient support program](#) to provide members with regular news, resources, and advice about navigating COVID-19 customized to their health condition. Upon signing up for the free program, participants receive information and education in their email inbox that is specific to their disease and interests.

In addition to building support program sign-up pages tailored to 18 chronic diseases, we completely redesigned and relaunched the GHLF homepage to reflect the diversity of the chronic disease community.

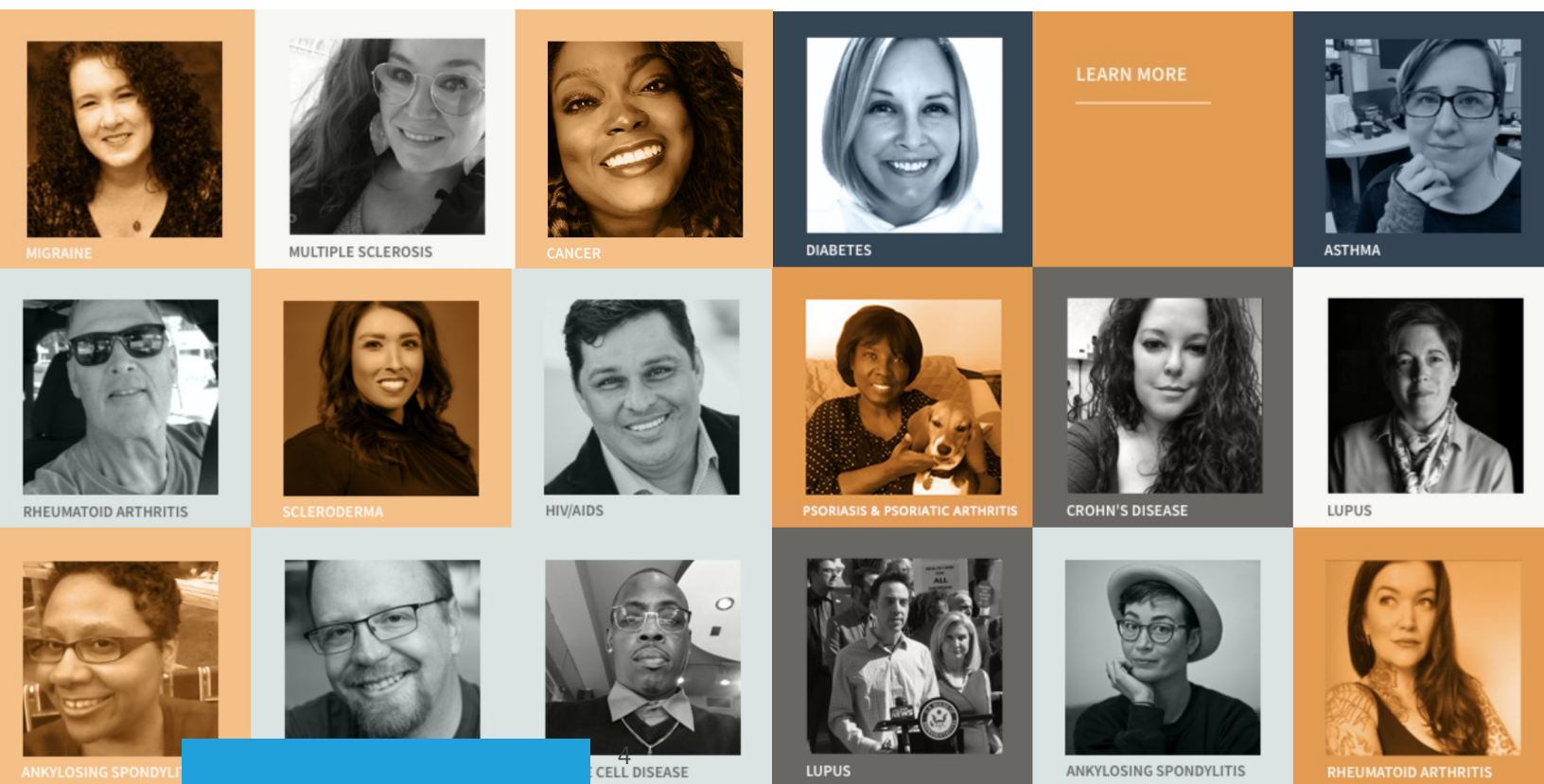
The Patient Support Program was informed from its inception by 18 patient leaders — particularly those with strong influence in their disease communities — to advise on educational resources, unmet patient needs,

advocacy opportunities, and more. They also serve as ambassadors of the program, which help us recruit members and increase engagement with the program.

- Between the program’s launch on March 18, 2020 and March 31, 2020, the program has more than 9,000 members.
- The top five health conditions represented among our members are rheumatoid arthritis, lung disease (asthma, COPD), diabetes, and psoriasis/psoriatic arthritis.

Via social media, conference calls, surveys, and other platforms, we regularly meet with our patient leaders to inform ongoing content and resources as well as elevate their patient voices on key issues.

Visit www.ghlf.org to review our new homepage and sign up for the patient support program



MIGRAINE

MULTIPLE SCLEROSIS

CANCER

DIABETES

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ASTHMA

RHEUMATOID ARTHRITIS

SCLERODERMA

HIV/AIDS

PSORIASIS & PSORIATIC ARTHRITIS

CROHN'S DISEASE

LUPUS

ANKYLOSING SPONDYLITIS

CELL DISEASE

LUPUS

ANKYLOSING SPONDYLITIS

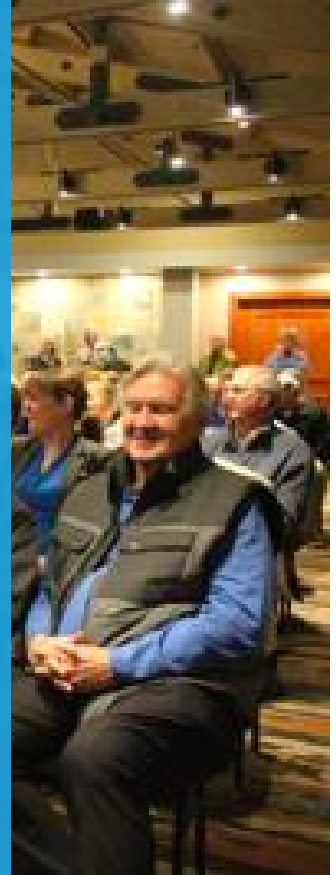
RHEUMATOID ARTHRITIS

■ INVESTED AUDIENCE

Not only are we reaching high-risk patients, our content is resonating with them and helping them make informed decisions to safeguard their health. The average email open rate in the Patient Support Program is 45 percent and the average click-through rate is 15 percent — far surpassing the health care industry average of 22 percent open rate and 2.5 percent click rate.

As of March 30, CreakyJoints/GHLF content ranks among the top 10 search results for 73 coronavirus-related keywords (when we look at keywords with over 1,000 searches since 2/27/20). Among those 73 keywords, here are a select few for which we rank in the top 10 results:

- immunocompromised patients and coronavirus
- rheumatoid arthritis and coronavirus
- psoriasis coronavirus



■ HISPANIC PATIENT OUTREACH AND EDUCATION

As a result of our efforts, our CreakyJoints Español webpage and Instagram page have seen significant growth.

CreakyJoints Español website traffic is growing organically. We doubled our 2019 traffic to the site in the first quarter of 2020 through:

- SEO-optimization – 60 percent of traffic comes from organic search.
- Social media referrals – Instagram, Facebook, WhatsApp and Twitter.

On Instagram, we've seen increased engagements with CreakyJoints Español by offering, quick polls, IGTV wellness videos, and coronavirus stats, resulting in:

- 109 percent Growth Rate
- 18,085 Impressions
- 153 unique visitors average reach
- Targeted audience - majority of followers from United States and Puerto Rico

COVID-19 PATIENT SUPPORT PROGRAM - EN ESPAÑOL

Recursos Importantes Sobre El Coronavirus Para Pacientes Con Condiciones Crónicas

Our dedicated Spanish-language patient support program landing page for US and Puerto Rico patients with relevant links to disease-specific information includes:

- Chronic-disease agnostic articles on COVID-19
- Science-based chronic-disease specific resources
- Regular surveys and “e-check-ins” to ensure the community is receiving the proper information

As a result of our outreach, we confirmed that the Congressional Hispanic Caucus Institute would share the GHLF patient support program with all of their offices.



Moja las manos con agua de la llave



Aplica jabón y frota las palmas de la mano



Extiende la espuma de jabón sobre todas las manos.



Asegúrate de que el jabón lave entre los dedos



Agarra los dedos de cada mano



Asegúrate de limpiar los pulgares



Presiona las yemas de los dedos en la palma de cada mano



Sécate bien con una toalla limpia o una toalla de papel

■ SURVEY: WHAT HIGH-RISK PATIENTS ARE THINKING AND DOING TO PREPARE FOR CORONAVIRUS

In mid-March, to help us better understand our community's behaviors, habits, fears, and needs, we fielded a survey in English and Spanish to patients about how they are coping with the coronavirus pandemic. In just a couple of days we received more than 350 responses, which is an excellent sample size for this type of market research. We learned that:

- High-risk patients have been doing a lot to prepare for self-quarantine but have not done as much asking for help — such as with grocery shopping or getting other essential supplies — from other people.
- High-risk patients have a lot of anxiety due to a lot of different reasons.
- High-risk patients generally feel supported by loved ones and friends. Of those who work, a majority report that their workplace is being supportive.
- High-risk patients are craving more information from their health care providers.
- High-risk patients think their state and local government is managing the outbreak better than the federal government.

The full results can be found here: <https://creakyjoints.org/research/high-risk-patient-coronavirus-survey-results-infographic/>

#HighRiskCovid19

How Immunocompromised Patients Are Coping with Coronavirus



We surveyed 353 CreakyJoints members from March 19-23, 2020:

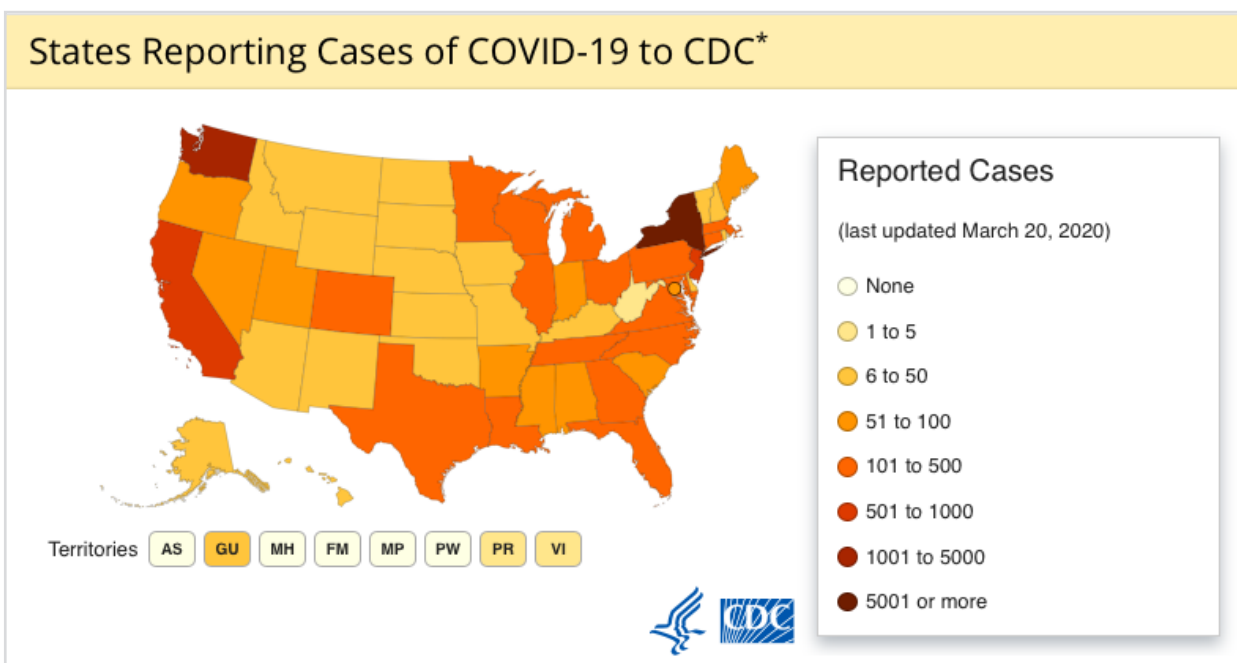
Notably, we also surveyed the Hispanic, Spanish-speaking community and learned:

- The community has less anxiety and seemingly less urgency to act
 - 42 percent said they had high anxiety levels (compared to 70 percent of English-speaking survey takers)
- Nearly two-thirds (64 percent) worried about continuing to take immune-suppressing medications, such as DMARDs and biologics
- Fewer were not self-isolating
 - 90 percent of Spanish language respondents were not insulating (compared to 28.36 percent of respondents in the English-language survey)

SPEAKING WITH AND FOR THE CHRONIC DISEASE COMMUNITY

As the COVID-19 pandemic ramped up and increasingly threatened chronic disease patients' potential access to their doctors and treatments, the advocacy team stepped-up. We issued alerts, spoke with legislators on behalf of high-risk patients, and communicated directly with our patient populations about what they needed to know to advocate for their best care. Some of the issues they addressed included:

- [Urging Senators to allow autoimmune patients on Medicare to get infusion drugs at home during the coronavirus pandemic](#)
- [Compiling a state-by-state public health resource guide for coronavirus information](#)
- [Understanding sick leave options for immunocompromised patients in the coronavirus pandemic: What you need to know](#)
- [Protecting access to prescription medication during the coronavirus pandemic, particularly soliciting for stories related to hydroxychloroquine](#)
- [Fighting against step therapy and prior authorization requirements during the coronavirus pandemic](#)
- [Asking Congressional leadership for increased funding and support to the CDC and NIH during this pandemic](#)
- [Letters to Governors along with the American College of Rheumatology with recommendations for Hydroxychloroquine and Chloroquine usage](#)



■ ENGAGING WITH INFLUENCERS

Our advocacy team shared our COVID-19 Patient Support Program with members of the Congressional Arthritis Caucus, the Congressional Hispanic Caucus Institute, as well as stakeholders at the state level across the country in both English and Spanish. In turn, many of these lawmakers [shared the program](#) with their constituents. Many different patient and provider-facing organizations are including links to GHLF's resources as part of their library of information, such as Global Genes, the Headache and Migraine Policy Forum, the Alliance for Gout Awareness, the National Forum for Heart Disease & Stroke Prevention and Dialysis Patient Citizens.

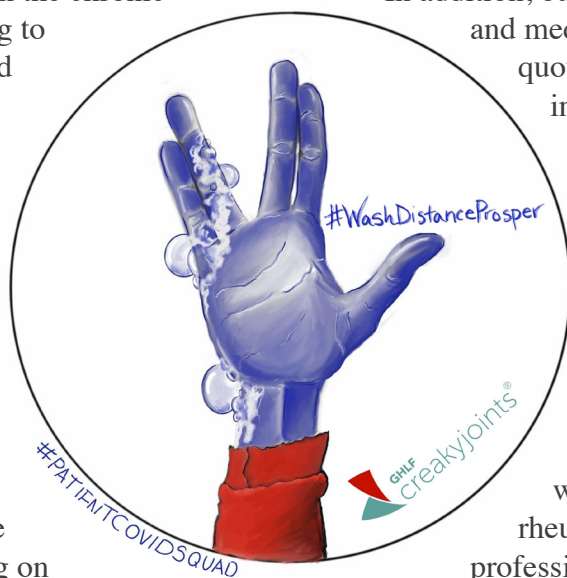
We have also been on the front lines asking chronic disease patients to raise their voices about COVID-19 pandemic management/health policy that could impact their quality of care. We've activated patients by issuing [Advocacy Alerts](#) that generated significant social media engagement and increased enrollment in the 50-State Network, many of whom volunteered to share their story, publicly, if needed. For example, an advocacy alert raising awareness of potential hydroxychloroquine shortages following the Trump administration's suggestion it might be a treatment for COVID-19 resulted in over 40 individuals reaching out with their stories, resulting in two patients being interviewed by USA Today, which published on April 18.

■ PUBLIC AND SOCIAL MEDIA RECOGNITION

Our efforts to raise the voice of chronic disease patients have not gone unnoticed. Our Twitter (@CreakyJoints and @GHLForg) and Facebook pages became “go to” destinations for those in the chronic disease community looking to engage with us directly and share our content with people in their own personal network. In the first quarter, our monthly average impressions were 13.5 million social media engagements, which is significantly higher than normal. Notably, several of our patient influencers came together to create the nationally trending hashtag on Twitter #HighRiskCOVID19. We helped them to coordinate their effort and supported this hashtag via our own handles, which led to even more social media engagement and drove media coverage of the impact of coronavirus on people living with serious

chronic diseases. We've also continued to host #CreakyChats during the COVID-19 pandemic.

In addition, our members, leadership, and medical advisors have been quoted by major media including the [Los Angeles Times](#), [Forbes](#), [CTV](#) (Canada), [HuffPost](#), [Health Magazine](#), [U.S. News & World Report](#), [Vogue](#), and [The Mighty](#) among many other placements (60 as of March 30) that reach people living with chronic disease and rheumatology health care professionals.



Importantly, CreakyJoints member and artist Jennifer Walker contributed impactful art shown above that we used to create a Facebook frame that was used by many people on that platform.

■ GHLF SUBMITS PATIENT-CENTERED COMMENTS TO U.S. FEDERAL AND STATE GOVERNMENTS

In the first quarter GHLF submitted 15 public comments and sign-on letters:

24

JAN

FEDERAL

[Transparency in Coverage Comments to CMS \(ATAP Sign-On\)](#)

3

MAR

[2021 Notice of Benefits and Payment Parameters](#)

3

MAR

[2021 Notice of Benefits and Payment Parameters \(I Am Essential Sign-On\)](#)

3

MAR

[2021 Notice of Benefits and Payment Parameters \(ATAP Sign-On\)](#)

6

MAR

[Safe Step Act Coalition Letter \(Coalition Sign-On\)](#)

STATE

24

JAN

[Ohio House Bill 469, Banning Copay Accumulator Adjustors](#)

13

FEB

[Iowa House File 2089, Relating to Non-Medical Switching](#)

21

FEB

[Indiana Senate Bill 241, Relating to PBM Transparency](#)

21

FEB

[Wisconsin Assembly Bill 114, Relating to PBM Transparency](#)

26

FEB

[Oklahoma HB 3737 – Oklahomans for Patient Access Letter Against Copay Accumulator Adjustors](#)

1

FEB

[Maryland House Bill 1360 / Senate Bill 623, Banning Copay Accumulator Adjustors](#)

COVID-19 RELATED

21

MAR

[Letter to Senate About Expanding Medicare to Cover In-Home Infusions during Coronavirus Pandemic](#)

23

MAR

[Letter to state Governors, Insurance Commissioners, Medicaid Directors, and Executive Directors of State Boards of Pharmacy with regards to the Coronavirus Relief Efforts \(Every Life Foundation Sign-on\)](#)

27

MAR

[Association for Accessible Medicines Sign On Letter to Oppose the “Buy American” Executive Order](#)

31

MAR

[Recommendations for Hydroxychloroquine and Chloroquine Usage \(American College of Rheumatology Sign-on\)](#)

ARIZONA

In Arizona, one of our volunteer advocates published an Op-Ed in the Arizona Republic titled, “First Feel Worse: That’s essentially how my insurer dealt with my illness” to comment on the challenges of step therapy for people living with chronic disease.

OREGON ADVOCACY DAY

On February 6th, Steven Newmark Director of Policy and General Counsel, and Conner Mertens, Patient Advocate, Community Outreach Manager, traveled to the Oregon State Capitol to participate in a utilization management advocacy day. GHLF members met with Democratic and Republican state officials and their staff to advocate on behalf of HB 4102-A; including House Health Committee Vice-Chair Rob Nosse and Senate Majority Leader Ginny Burdick. The bill would later pass the house unanimously.



SETH GINSBERG CLOSES THE COALITION OF STATE RHEUMATOLOGY (CSRO) FELLOWS CONFERENCE

GHLF co-founder and president Seth D. Ginsberg returned to San Francisco in March to be the final speaker at a day-long conference for rheumatology fellows (new doctors) with a presentation titled, “What arthritis patients want the next generation of rheumatologists to know.” The presentation included a top-10 list of thoughts, comments, and feelings that were crowd-sourced from the CreakyJoints community. Chief among them were “don’t judge” and related advice from patients for their doctors – and new doctors – to recognize how invisible illnesses take serious tolls on patients’ minds and bodies.

Ginsberg was introduced to the podium by Dr. Madeline Feldman, MD, president of CSRO, as “every patient’s friend.”

■ GHLF REPRESENTS PATIENTS AT INDUSTRY AND GOVERNMENT MEETINGS

GHLF had the opportunity to attend a variety of meetings with health policy stakeholders including legislators, regulators, insurance commissioners, and physicians. Public meetings (attended by invitation) include:

<p>February 9-11</p>	<p>Joseph Coe, Director of Education and Digital Strategy, participated in Headache on the Hill in Washington, D.C.</p>
<p>March 2-3</p>	<p>Steven Newmark, Director of Policy and General Counsel, Corey Greenblatt, Manager of Policy and Advocacy, Zoe Rothblatt, Advocacy and Policy Fellow, participated in the Digestive Disease National Coalition Spring Policy Forum and Advocacy Day in Washington, D.C.</p>
<p>March 9</p>	<p>Corey Greenblatt spoke to a joint committee of the FDA/ FTC, giving GHLF patient-centered recommendations on the US Biosimilar market. He discussed the lack of growth of the US biosimilar market and how the agencies and organizations like GHLF can join to educate patients and providers about the benefits of biosimilars. Click here to read the full comments.</p>

At the joint committee hearing of the Federal Drug Agency (FDA) and the Federal Trade Commission (FTC) to discuss the biosimilar marketplace, GHLF commented on the potential reasons for the lack of growth of the US biosimilar market and how the agencies and organizations like GHLF can combine to educate patients and providers about the benefits of biosimilars. [Click here](#) to read the full comments that GHLF submitted to the agencies.

GHLF STANDS UP FOR MIGRAINE AND INFLAMMATORY BOWEL DISEASE PATIENTS

In February, Joseph Coe, Director of Education and Digital Strategy, and GHLF advocates met in Washington, D.C. for “Headache on the Hill” an advocacy day for people living with chronic migraine. Several productive meetings occurred, including with Chair of the House Appropriations Committee, U.S. Representative Nita Lowey, GHLF’s Congressperson.

In March, Steven Newmark, Director of Policy and General Counsel, Corey Greenblatt, Manager of Policy and Advocacy, Zoe Rothblatt, Advocacy and Policy Fellow, and GHLF Patient Advocate Elisa C. (TN) travelled to Washington, D.C. for the Digestive Disease National Coalition (DDNC) Spring Policy Forum and advocacy day. The GHLF team met with staff for several Senators and Representatives, including Senate HELP committee Chairman Lamar Alexander (R-TN) to support the Safe Step Act, to reform federal step therapy regulations.



Pictured are Joseph Coe, Director, Education and Digital Strategy (second from left), Congresswoman Nita Lowey, Chair of the U.S. House Appropriations Committee (center) and other Headache On the Hill participants.

COVID-19 PUTS DRESS TO DEPRESS VIDEO ON HOLD

This winter, CreakyJoints prepped a new educational campaign anchored by a new video called *Dress to Depress: An Invisible Illness Guide to Getting Ready for a Doctor's Appointment*, a parody on the lengths some people with invisible illnesses will go to get ready for their next appointment with their health care provider. The video addresses the concerns that people living with chronic disease(s) have about meeting with their physician, including that they won't be taken seriously, get enough time with their doctor, or know the right questions to ask.

In light of the COVID-19 pandemic, this Dress to Depress campaign has not officially launched yet. When it does, the campaign will highlight anecdotal accounts about the extra effort that some in our community report making such as either deliberately 'dressing up' or 'dressing down' — for their doctor's appointments. We wondered if that was a common phenomenon in the community and, therefore, surveyed our membership to learn more.

The survey results and the video will premiere later this summer when CreakyJoints returns to the "normal" activities related to helping people with chronic conditions, like arthritis, advocate for their best care and live their best quality of life.



ARTHRITISPOWER RESEARCH CONTINUES

Current ArthritisPower statistics as of March 31, 2020:

- Total patients: **27,977**
- % increase in membership from 3/31/19: **55%**
- Top 5 Conditions:

Osteoarthritis:	16,064 (57%)
Rheumatoid Arthritis:	12,475 (45%)
Fibromyalgia:	10,556 (38%)
Osteoporosis:	4,378 (16%)
Psoriatic Arthritis:	3,777(14%)
- PROMIS Measures, mean (SD)

Pain Interference	62.4 (7.3)
Fatigue	63.4 (9.1)
Physical Function	37.0 (7.1)

ArthritisPower offers researchers access to a unique, dynamic and robust patient community. There are many opportunities for registry participants to opt into research that will inform our future understanding of arthritis and potentially lead to new management and treatment strategies. If you would like to participate in a study, go to ArthritisPower, sign up 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, Data Scientist at kgavigan@ghlf.org

CREAKYJOINTS DATA FINDS THAT PATIENTS PRIORITIZE THEIR PHYSICIAN'S TREATMENT GOALS

In January, we announced the publication of a new ArthritisPower study that described the barriers people living with rheumatoid arthritis face in modifying their treatment even when experiencing high disease activity, and why they tolerate suboptimal disease control.

Gavigan, K., Nowell, BW, Serna, MS, et al., “Barriers to treatment optimization and achievement of patients’ goals: perspectives from people living with rheumatoid arthritis enrolled in the ArthritisPower registry” *Arthritis Research & Therapy* volume 22, Article number: 4 (2020) <https://doi.org/10.1186/s13075-019-2076-7>

Treatment goals prioritized by participants, irrespective of disease activity, were to reduce joint pain and swelling, minimize fatigue, and improve physical function. But among participants who had high disease activity at baseline, only 38 percent were offered a treatment change by their rheumatologist at their most recent appointment, which the majority (71%) accepted. Physician recommendation was a major reason given by participants for intensifying (42%) or scaling back treatment (60%). The most common reason (66%) for deciding not to change treatment was the participant’s perception of their rheumatologist’s satisfaction with the current therapy. Even when participants were offered a treatment change, some of them decided against the change. The main reason participants did not change their treatment was that their doctor said it was okay not to change (e.g. they were doing ‘well enough’).

In the press release, W. Benjamin Nowell, PhD, Director of Patient-Centered Research, CreakyJoints and ArthritisPower principal investigator, said, “We found that participants seldom changed RA therapies because they failed to reach treatment goals; instead, treatment was more commonly changed due to continued severe, or even worsening, RA symptoms. Yet, even in the face of escalating symptoms, our study showed that patients defer to their physicians’ recommendations regarding whether it is time for a treatment change. Given our findings, we need to find ways to encourage and empower patients to talk to their doctors about how to achieve their treatment goals.”

This study was covered by trade publications such as [Healio.com/rheumatology](https://www.healio.com/rheumatology) and [Docwire](https://www.docwire.com).

NEWLY PUBLISHED ARTHRITISPOWER RESEARCH

In addition to the Arthritis Research & Therapy study reported above, three new studies were published in the first quarter:

- Yun, H., Nowell, WB, Curtis, D., et al., **“Assessing Rheumatoid Arthritis Disease Activity With Patient-Reported Outcomes Measurement Information System Measures Using Digital Technology,”** Arthritis Care & Research, Vol. 72, No. 4, April 2020, pp 553–560. Published online on March 28, 2020. <https://doi.org/10.1002/acr.23888>
- Coleman, KJ, Schlundtz, DG, Bonnetz, KR, et al. **“Understanding the Bariatric Patient Perspective in the National Patient-Centered Clinical Research Network (PCORnet) Bariatric Study,”** Obesity Surgery. Published online January 21, 2020. <https://doi.org/10.1007/s11695-020-04475-7>

The amount of time needed for patients to complete PRO measures in real-world settings and clinical trials may place an excessive burden on patients and lead to respondent fatigue. This burden can result in lower completion rates, poor data quality, diminished patient engagement, and greater loss to follow-up. This study found that there was excellent agreement between the observed RAPID3 and predicted RAPID3 scores estimated using several PROMIS instruments. The Multidimensional Health Assessment Questionnaire and patient global assessment components of RAPID3 may be unnecessary if PROMIS scores are available.

Following nine focus groups conducted in Southern California, Louisiana, Pennsylvania, and Ohio and in a national advocacy conference for patients with obesity, the study reported that the approach to bariatric surgery should be expanded to provide long-term comprehensive care that includes in-depth postoperative lifetime monitoring of emotional and physical health.

- Ogdie A, Nowell, WB, Applegate E., et al. **“Patient perspectives on the pathway to psoriatic arthritis diagnosis: results from a web-based survey of patients in the United States”** BMC Rheumatol. 4, Article number: 2 (2020) Published online January 10, 2020. <https://doi.org/10.1186/s41927-019-0102-7>

This study reported that many people living with PsA faced a winding and long path to arrive at a diagnosis, migrating through various types of healthcare providers prior to the diagnosis. Increased recognition of heterogeneous symptoms associated with PsA, as well as understanding existing diagnostic barriers, may lead to prompt diagnosis and initiation of appropriate treatment that may improve outcomes.



OTHER 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 (RA) from several clinical sites across the US 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.
- 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 and its treatment. This study is being 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. Recruitment will begin this summer.
- 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 custom workflow in the ArthritisPower app. The primary aim of the study is to better understand the experience, disease activity, and symptoms of RA patients treated with janus kinase inhibitors (JAK inhibitors) over time. This study is sponsored by the Health Economics and Outcomes Research (HEOR) group at AbbVie US. The study is expected to launch later this year.
- 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 (RA) when they are contemplating a change in treatment regimen. This study will consist of semi-structured 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”). This study is part of a Rheumatology Research Foundation (RRF) award to Liana Fraenkel, MD, MPH of Berkshire Medical Center. Results from the study will help guide development of materials to assist physicians and their patients to work together in treatment decision making. The study team is currently coding transcripts of patient interviews. The team will then use themes identified in interviews to design a survey that will be fielded to hundreds of patients this summer.
- Understanding the Axial Spondyloarthritis (axSpA) Treatment Journey:** This cross-sectional study of ArthritisPower members reporting a physician diagnosis of ankylosing spondylitis (AS) or axial spondyloarthritis (axSpA) examines the experiences of patients, including the journey to getting diagnosed and treated, and managing different treatment options. The study is sponsored by Eli Lilly and Company. The study team is currently analyzing data and preparing an abstract for ACR 2020.

■ ENGAGEMENT AWARD ON CHRONIC PAIN MANAGEMENT

Our work continues to support the project, “Encouraging Patients to Manage Chronic Pain Using the Latest Evidence from Research,” funded by the Patient Centered Outcomes Research Institute (PCORI).

This project consists of a dedicated team of patients, patient advocates, researchers, and physicians committed to preparing people with arthritis and chronic pain as ambassadors in the dissemination and use of science-based information on effective chronic pain management. There is a lot of information available online regarding medication and non-medication approaches you can use for chronic pain management.

Yet, it is not always easy for patients to determine whether the information is science-based and valid. Through this project we will disseminate high-quality evidence-based research on chronic pain management so that patients can use this information in the management of chronic pain.

In 2020, the project will include a series of 60-minute online sessions about what the latest in what science tells us about chronic pain: what it is, how it works and how to manage it. Sessions are still ongoing and interested participants may click here to learn more and register: <https://creakyjoints.org/chronicpain/>



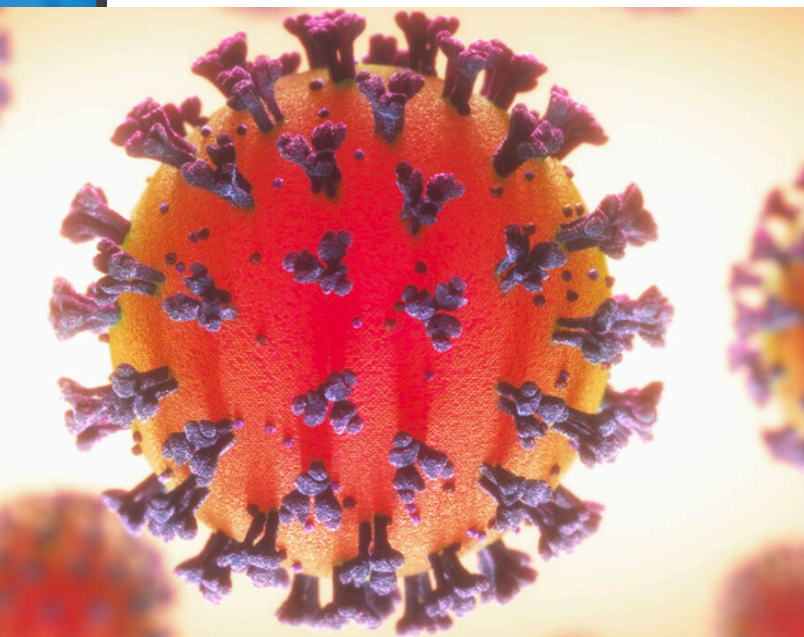
■ DIVING DEEPER TO LEARN MORE ABOUT THE IMPACT OF COVID-19

Building on our experience with patient-powered research infrastructure, our research team prepared to launch the Autoimmune COVID-19 Project. This is a new longitudinal study for patients with multiple sclerosis (MS), arthritis, Crohn's and colitis, and vasculitis and will track the evolving impact of COVID-19 on patients living with these conditions. The Project is being led by CreakyJoints and implemented via its 30,000-member [ArthritisPower® Research Registry](#) in partnership with three other patient groups, [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 formed with funding support from the Patient-Centered Outcomes Research Institute (PCORI).

Over time, the study will examine the concerns and behaviors of patients with autoimmune, rheumatic, and related conditions during the COVID-19 pandemic and collect information from patients about illness and testing. GHLF's component of the project, known as the Arthritis and Rheumatic Disease COVID-19 study, will be conducted in both English and Spanish. The English longitudinal study launched in late March and the Spanish study launched in mid-April.

Study lead Shilpa Venkatachalam, PhD, Associate Director of Patient-Centered Research at CreakyJoints and ArthritisPower explains, "Patient surveys collected at regular intervals will study patients' respiratory illness symptoms, experiences of COVID-19 testing, modified doctor visits using telehealth, concerns and choices regarding immunosuppressive therapy, and preferred sources of information about COVID-19. We need information about the impact of COVID-19 on patients with autoimmune, rheumatic, and related conditions in order to provide support for health decision making, especially given the heightened risks associated with a highly transmissible infection."

GHLF and CreakyJoints were also early supporters of the COVID-19 Global Rheumatology Alliance, which is a physician-reported outcomes research registry. The Alliance has since added a one-time cross-sectional patient survey, distinct from our Autoimmune Research Collaborative COVID-19 project.



CREAKYJOINTS AND THE GLOBAL HEALTHY LIVING FOUNDATION IN THE NEWS

During the first quarter, there were 85 earned media placements featuring CreakyJoints members or leadership, generating more than 400 million media impressions, which is much higher than average due to our dedicated engagement as experts for commentary about COVID-19. In addition to national media placements, several articles were picked-up by high traffic websites including [Yahoo! News](#). Other media opportunities appeared in both print and online ([LA Times](#)) or on TV and online ([CTV](#), [NY1](#)), increasing the reach of our key messages about the concerns of chronic disease people at higher risk for COVID-19.

Beyond COVID-19, [Fresh Toast](#), a publication focused on cannabis, included remarks from W. Benjamin Nowell, Ph.D., Director of Patient-Centered Research and our volunteer advocate, Dawn Gibson, from an older article (published elsewhere) on Painsomnia. This article was picked up by several other cannabis-forward publications.

The Doctor Weighs In published an article by Seth Ginsberg titled, "[Five Reasons You Should Participate in Clinical Trials.](#)" CreakyJoints member, Cheryl Ackerman appeared on her local TV program [Bloom TV](#) to talk about aerial yoga. Conner Mertens, GHLF Patient Advocate, Community Outreach Manager, was profiled as a high achieving alumni by [Willamette University](#).

WHO WE ARE

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 through our popular social media channels, our website www.CreakyJoints.org, and the [50-State Network](#), which includes more than 1,500 trained volunteer patient, caregiver and healthcare activists.



As part of the [Global Healthy Living Foundation](#), CreakyJoints also has a patient-reported outcomes registry called [ArthritisPower®](#) (ArthritisPower.org) with nearly 28,000 consented arthritis patients who track their disease while volunteering to participate in longitudinal and observational research. CreakyJoints also publishes the popular “[Raising the Voice of Patients](#)” series, which are downloadable patient-centered educational and navigational tools for managing chronic illness, and hosts [PainSpot](#) (PainSpot.org), a digital risk assessment tool for musculoskeletal conditions and injuries. For more information and to become a member (for free), visit www.CreakyJoints.org.

About ArthritisPower®

Created by [CreakyJoints®](#), [ArthritisPower®](#) is the first-ever patient-centered research registry for joint, bone, and inflammatory skin conditions. With more than 28,000 consented arthritis patients, the free ArthritisPower mobile and desktop application allows patients to track and share their symptoms and treatments while also participating 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. ArthritisPower’s past participation in PCORnet®, the National Patient-Centered Clinical Research Network, was supported through multiyear, multimillion-dollar Patient-Centered Outcomes Research Institute funding awards [PPRN-1306-04811]. To learn more and join ArthritisPower, visit www.ArthritisPower.org



About Global Healthy Living Foundation

The [Global Healthy Living Foundation](#) is a 501(c)(3) non-profit organization whose mission is to improve the quality of life for people living with chronic illnesses (such as arthritis, osteoporosis, migraine, psoriasis, 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 arthritis community for millions of arthritis patients and caregivers worldwide who seek education, support, activism, and patient-centered research through [ArthritisPower®](#) (ArthritisPower.org), the first-ever patient-centered research registry for joint, bone, and inflammatory skin conditions, and hosts [PainSpot](#) (PainSpot.org), a digital risk assessment tool for musculoskeletal conditions and injuries. Visit www.GHLF.org for more information.



WHO WE ARE

About the 50-State Network

The [50-State Network](#) is the grassroots advocacy arm of the [Global Healthy Living Foundation](#). It is comprised 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 www.50StateNetwork.org.



About PainSpot

PainSpot by CreakyJoints® is an innovative algorithmic-based web site for musculoskeletal disease or injured patients that features an interactive, easy-to-use pain assessment tool using the same validated clinical decision-making tools used by healthcare professionals in a clinical setting. PainSpot aims to educate and empower people to better understand their health, so they can get diagnosed and treated faster. After participating in the assessment tool, the user 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 post-injury. 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 www.PainSpot.org

