

# QUARTERLY REPORT

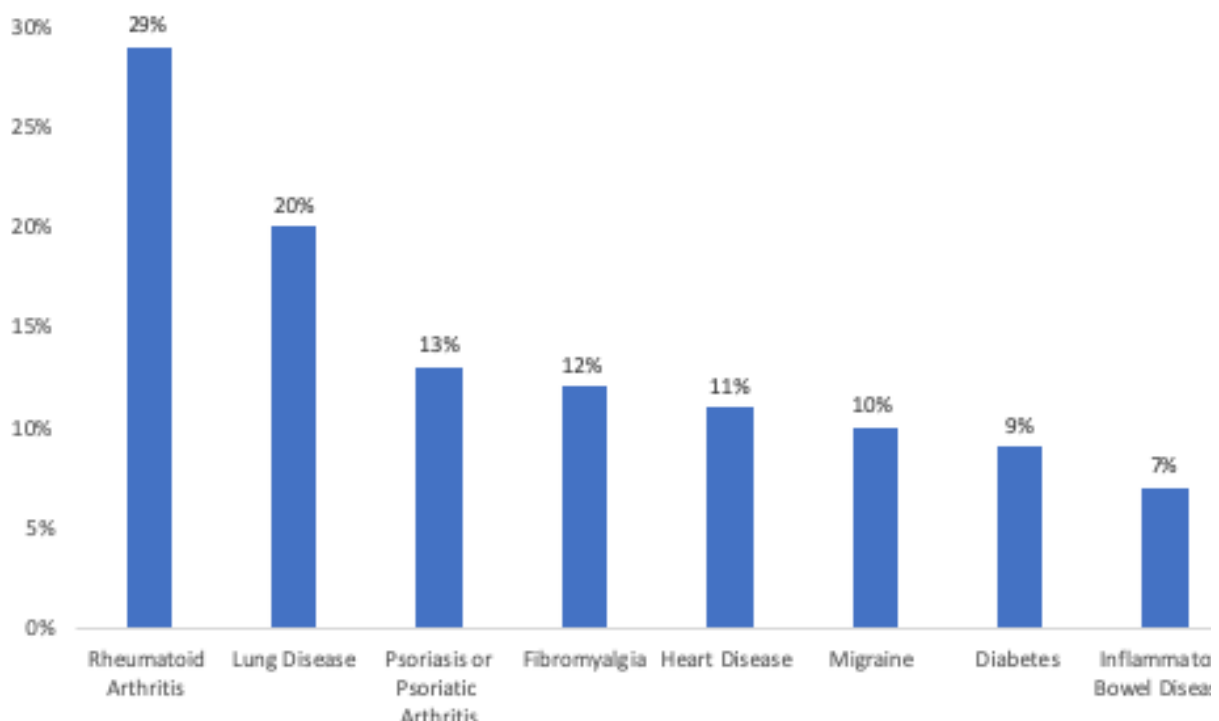
JULY – SEPTEMBER 2020

# STAYING ENGAGED: GHLF AND CREAKYJOINTS CONTINUE ITS COVID-19 RESPONSE FOR THE CHRONIC DISEASE COMMUNITY

As the COVID-19 pandemic continues — with many parts of the U.S. reopening during the summer months only to see cases start to spike again as of this report’s publication — 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. Over the summer, our COVID-19 Patient Support Program continued to grow as we deepened 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 17,758 diverse members and 29,168 subscribers (as of September 30, 2020). Common conditions of members in the program include:**



## ■ ROBUST CONTENT

Our members have questions about managing their health conditions and everyday lives. We seek out the answers, turning to respected physicians and scientists for perspective. We also curate the most important medical research about COVID-19 (ours and others') and its impact on those with underlying conditions, and share personal essays from CreakyJoints and GHLF members.

From July through September, GHLF continued to publish new COVID-19-related content each week, which has generated nearly 750,000 page views. Many of these articles were also published in Spanish and made available on the [CreakyJoints Español website](#) and its [Instagram page](#).



A popular content series called “Is It Safe?” was developed during the third quarter in response to patients’ concerns about whether and how to participate in reopening activities. Content included:

- [Is It Safe to Go to a Movie Theater If You’re at High Risk for COVID-19?](#)
- [Is It Safe to Carpool with Other People’s Kids If You’re at High Risk for COVID-19?](#)
- [Is It Safe to Go to a Hair Salon If You’re at High Risk for COVID-19?](#)
- [Is It Safe to Get a Manicure or Pedicure If You’re at High Risk for COVID-19?](#)
- [Is It Safe to Eat at a Restaurant If You’re at High Risk for COVID-19?](#)

Another important area of patient education launched during the third quarter was around vaccinations — specifically, the importance of getting the pneumonia vaccine and annual flu vaccine. Content included:

- [The Flu Vaccine, Inflammatory Arthritis, and COVID-19: What You Need to Know](#)
- [The Pneumonia Vaccine and Inflammatory Arthritis: What Patients Need to Know](#)

All our content is also shared on our social media platforms, including Twitter, Facebook, and Instagram.



## IN TOUCH WITH OUR COMMUNITIES

Regular polls have become an integral part of our COVID-19 Patient Support Program. Informed by social listening and insights from our COVID-19 Patient Leadership Council, we ask the community timely questions to better understand the perspectives and concerns of chronic disease patients. We use this information to inform new educational resources for the program.

### Poll Topic: Access to Medication

27%

of poll respondents have had difficulty accessing their medication(s), for any reason, since the COVID-19 pandemic began.

58%

of poll respondents have had a telehealth appointment with their provider since the beginning of the pandemic to discuss their medication(s):



To discuss switching medication(s)



To discuss starting medication(s)



To discuss lowering the dosage of medication(s)

19%

of poll respondents who take a medication that is administered through infusion:



felt protected from the coronavirus while receiving their infusion medication in-office because of the precautions the staff took.



reported not feeling protected from the coronavirus while receiving their infusion medication in-office.



have not received their infusion medication in-office since the pandemic began.

Here's what some of our members said:

“ Due to a national shortage of enteric-coated sulfasalazine, **I could not get it.** I was offered regular sulfasalazine. I am unable to take the regular due to GI problems.

I was told that if I get symptoms, I cannot get my infusion. **There is no backup plan.**

“

## IN TOUCH WITH OUR COMMUNITIES

### Poll Topic: Experience with Telehealth

72%

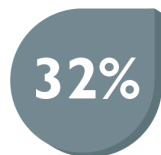
of participants have had a telehealth (video or audio call) visit with a health care provider in the prior three months, and 28 percent have not.

28%

who did not have a telehealth visit, participants had the following reasons for not having a visit (responses are not mutually exclusive):



have not needed to make an appointment with their provider.



have had an in-person appointment with their provider.



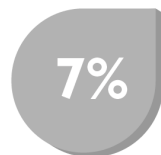
are waiting until they can have an in-person appointment with their provider.



do not have the technology needed for a telehealth visit.



have providers who are not offering telehealth visits.



do not feel comfortable using the technology needed for a telehealth visit.

72%

who had a telehealth visit, participants had the following reasons for the visit (responses are not mutually exclusive):



had a routine or regular visit.



had a follow-up appointment.



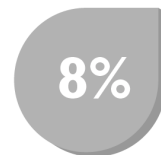
had a visit to address a flare-up or recent problem with their condition.



had a visit to review results of lab work or other tests.



had a visit to discuss a change in medication for their condition.



had a visit to discuss concerns about COVID-19.



had a visit to address side effects from one of their medications.

Here's what some of our members said:

“ When the pandemic is all over, **I'd like to continue**, but maybe alternate or do one in person and two telehealth, depending on how often I see the doctor.

The only issue I have is that every provider seems to use a different app to schedule these visits, so **you have to learn multiple applications**. Some applications work better and are easier than others, so it can be cumbersome. I can do it, but older people or people without computer experience may have trouble.”

“



## LET'S GET TOGETHER! BINGO AND MORE

From our community poll data, we know our patient community is struggling with loneliness and dealing with mental health concerns that have been exacerbated by the pandemic. In response, CreakyJoints began hosting events virtually with the aim of bringing our community together.

In September, we hosted a BINGO event on Zoom, which featured Seth Ginsberg, President and Cofounder of CreakyJoints, pulling numbers LIVE while dressed in an Elvis suit. There was a ton of laughter, and prizes were won by many members!

Later in the month, CreakyJoints also entertained and supported our community when we hosted a virtual fashion show featuring the Tumbler and Topsy® spring/summer 2021 collection, created by CreakyJoints member Michael Kuluva. (More about this later.)

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



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

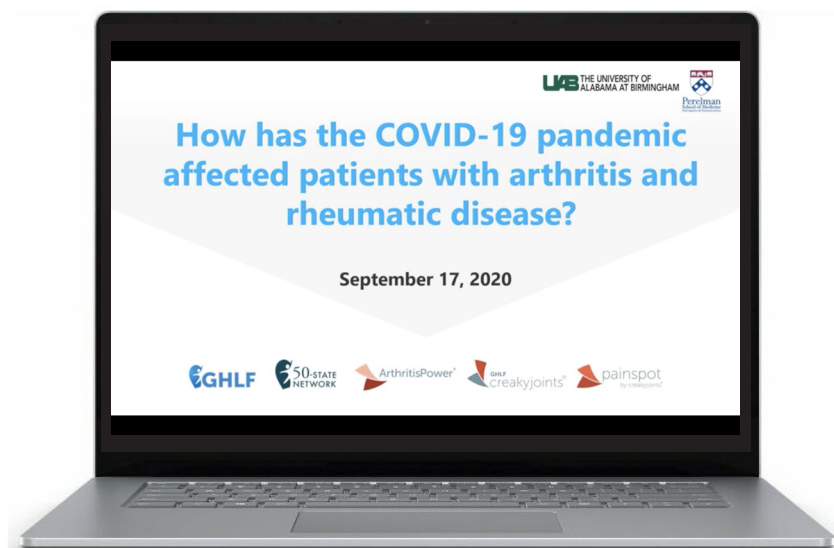
Four research abstracts related to the CreakyJoints-led Arthritis and Rheumatic Disease COVID-19 Project were accepted for oral or poster presentation during the November American College of Rheumatology (ACR) Convergence 2020. In addition, manuscripts have been submitted to peer-reviewed medical journals to report early research results. The project began in the second quarter when our research team launched it 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.

## ■ LIVE PATIENT EDUCATION AND ENGAGEMENT WEBINAR

Our mission with patient-centered research is to share with participants and others insights from the studies we conduct. Following the launch of our Arthritis and Rheumatic Disease COVID-19 Project in April to understand how the pandemic has affected patients living with autoimmune diseases, including arthritis and related conditions, we organized a late-September webinar to discuss findings to date.

The webinar was hosted by GHLF and featured expert panelists including Michael George, MD, MSCE, Assistant Professor of Medicine at the Hospital of the University of Pennsylvania; Jeffrey Curtis, MD, MS, MPH, Professor of Medicine at the University of Alabama at Birmingham; and Maria I. Danila, MD, MSc, MSPH, Associate Professor of Medicine at the University of Alabama at Birmingham. We also shared a link to the recorded webinar for patients and other stakeholders unable to attend live.

Our webinar library can be found on CreakyJoints.org at [creakyjoints.org/category/webinar](https://creakyjoints.org/category/webinar).

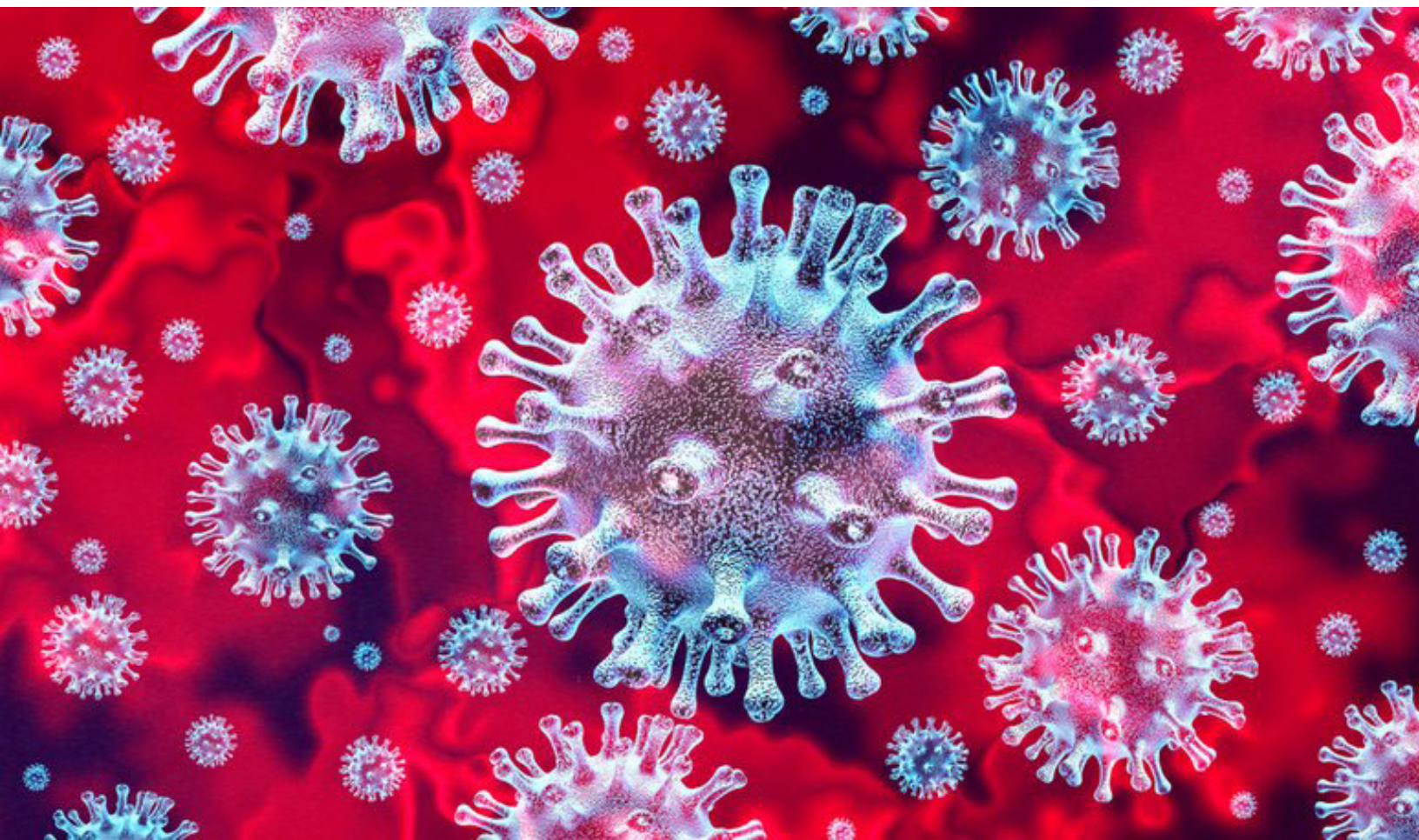


## ■ HELPING HEALTH CARE PROVIDERS PROVIDE BETTER COVID-19 PATIENT EDUCATION

Lauren Gelman, Director of Editorial Services at the Global Healthy Living Foundation, coauthored a peer-reviewed article in the September issue of *Current Opinion in Rheumatology*, which included a special section called Rheumatological Aspects of COVID-19 that was curated and edited by key opinion leaders Leonard H. Calabrese, DO, and Cassandra Calabrese, DO.

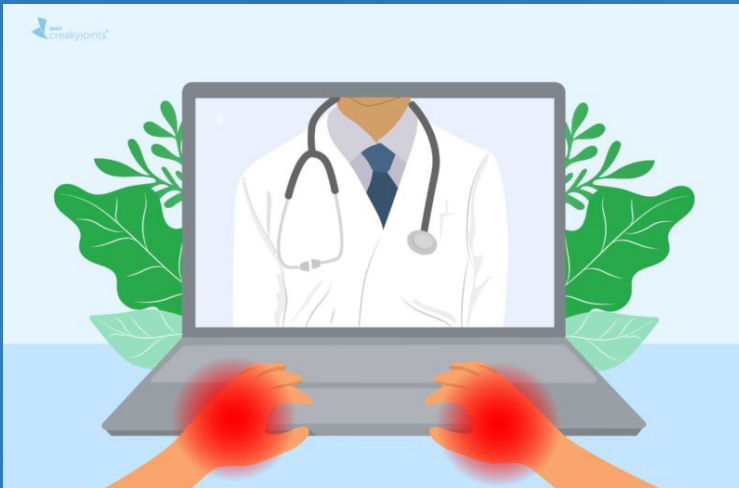
Titled “[Tracking Clinical Resources for Coronavirus Disease 2019](#),” the article spoke about how rheumatologists are drowning in data, with more new studies published on COVID-19 and its impact

on rheumatic disease than they could possibly read. The paper identified specific threats to the validity of the COVID-19 literature and recommended resources for practicing rheumatologists and their patients, specifically that rheumatologists develop a system to acquire high-quality information and offer guiding principles for triaging specific resources, which include relevance, accessibility, credibility, timeliness, and trustworthiness. The same principles can be applied to selecting patient-oriented resources. Specific trustworthy resource are recommended. This study was covered by [DocWire News](#) and [Rheumatology Advisor](#).



# SEPTEMBER WAS PAIN AWARENESS MONTH

In conjunction with September being Pain Awareness Month, we launched a new resource called *A Patient's Guide to Understanding Rheumatoid Arthritis Pain*. This comprehensive guide helps RA patients understand what may be causing their pain, the role of comorbid conditions in RA pain, when a treatment change may be recommended, and how to talk to their providers about RA pain as part of shared decision-making (especially in a COVID-19/telehealth world).



The resource includes the following original articles, checklists, and tools:

- Special ArthritisPower invitation to [track pain-related patient-reported outcomes](#)
- Article: [Rheumatoid Arthritis Pain and Flare-Ups: What to Know and Do](#)
- Article: [6 Causes of Rheumatoid Arthritis Pain Aside from Inflammation](#)
- Article: [Rheumatoid Arthritis Pain: When to Consider a Medication Change](#)
- Article: [How to Discuss Your Rheumatoid Arthritis Pain During a Telehealth Visit](#)
- Article: [Rheumatoid Arthritis Pain: 7 Things You Should Tell Your Rheumatologist](#)

On August 31, right before the start of Pain Awareness Month, CreakyJoints also hosted a #CreakyChats featuring the **U.S. Pain Foundation** (@US\_Pain) and special guest Juliette Kleinman, LCSW, Senior Social Work Manager (@kleinmanlcsw) at the **Hospital for Special Surgery** in New York City. The chat was promoted by media partner **HealthCentral** (@HealthCentral) and covered pain disparities, the stigma associated with chronic pain, and the importance of innovation to help those who live with pain. This discussion generated seven million impressions and had over 100 participants.

## ■ CHRONIC PAIN ONLINE PACKAGE: PAIN EXPLAINED

Understanding that everyone experiences aches and pain, sometimes pain can become chronic and cause major frustration and distress to those who experience it. The medical community defines chronic pain as pain that lasts for more than three months. It may start with an injury or develop because of an underlying disease. To address these concerns, in September we launched a six-part online course about managing chronic pain called [Pain Explained](#).

Through this online package, our goal is to help patients understand what chronic pain is and what causes and influences it, and share with them science-based information about different ways to manage chronic pain. Knowing what information is accurate, trusted, and helpful may help you have better discussions with your doctor regarding your pain-management strategy.

## 'Pain Explained': A 6-Part Online Course About Managing Chronic Pain



# THE NEWEST NORMAL BY MICHAEL KULUVA

For the past four years, [CreakyJoints](#) has presented the spring/summer collection from Tumbler and Tippy by Michael Kuluva, timed to September's New York Fashion Week. In past years, we've invited members and our partners to his always-exciting NYC-based fashion show and shared images on social media and on our website.

However, given this year's pandemic, we knew that we had to adapt our plans to meet the times. Further, as a designer with rheumatoid arthritis and a CreakyJoints member, Michael advocates for social distancing and following local guidelines to stay safe and reduce the spread of the COVID-19 virus. Therefore, we collectively decided to host an event for the Newest Normal collection — filmed in Canada, where Michael is residing during the pandemic — as a virtual presentation, and it [premiered on YouTube](#) on September 16, 2020, at 8 PM ET. As a bonus, we were able to invite our members from around the world to join us for this entertaining, uplifting, and fashion-forward event!



Immediately preceding the premiere, Michael participated in a live #CreakyChats on Twitter to discuss the inspiration behind his collection. After the chat, CreakyJoints and the [Canadian Arthritis Patient Alliance \(CAPA\)](#) hosted an interactive watch party on Zoom, which included a panel featuring Michael, model Nini Amerlise, arthritis patient Emily Sirotich, and special guests from the CreakyJoints community.



As a result of our media outreach, Michael's Newest Normal collection was covered by local media in Canada, including [CBC Ontario Morning](#) (radio), [CTV-Barrie](#), and [Barrie Today](#). Michael's collection was also covered by online fashion media.

“ I’m thrilled to bring my COVID-conscious collection to a global audience because being physically distant does not preclude joint celebrations,” says Michael. “ My new collection was inspired by my desire to inject light, color, and happiness into our world, which may feel smaller as we hunker down to protect each other during the pandemic. When I get dressed in something that looks amazing and feels great, it sets the tone for the rest of my day. I hope my collection inspires self-care.

# ARTHRITISPOWER RESEARCH CONTINUES

## Current ArthritisPower statistics as of September 30, 2020:

- Total patients: **29,392**
- % increase in membership from 9/30/19: **35%**
- Top Conditions:
 

Osteoarthritis:	<b>16,610 (57%)</b>
Rheumatoid Arthritis:	<b>13,095 (45%)</b>
Fibromyalgia:	<b>10,947 (37%)</b>
Psoriasis/Psoriatic Arthritis:	<b>4,997 (17%)</b>
Osteoporosis:	<b>4,511 (15%)</b>
IBD:	<b>3,872 (13%)</b>
Lupus:	<b>1,699 (6%)</b>
- PROMIS Measures, mean (SD)
 

Pain Interference	<b>64.2 (7.3)</b>
Fatigue	<b>63.4 (9.1)</b>
Physical Function	<b>37.0 (7.1)</b>

If you or someone you know would like to participate in an arthritis research study, please sign up at [ArthritisPower.org](https://ArthritisPower.org) and, after you consent to participate in research, your profile will be matched against open studies. You will receive an invitation to participate when a match is made. If you are an ArthritisPower member and think you may qualify for one of the studies below, please reach out to

**Kelly Gavigan, Manager, Research and Data Science at [kgavigan@ghlf.org](mailto:kgavigan@ghlf.org)**



## ■ PCORI ANNUAL MEETING INCLUDES COVID-19 & HEALTH CARE DISPARITIES RESEARCH

ArthritisPower team members and patients attended the Patient-Centered Outcomes Research Institute's 2020 annual meeting, titled Accelerating Impact on Care and Patient-Centered Outcomes. The sixth-annual (and inaugural virtual) meeting took place September 16–17 with PCORI's new Executive Director, Nakela Cook, MD, MPH, providing opening remarks. There was special attention this year during the breakout and plenary sessions to PCORI-funded COVID-19 research and health and health care disparities, among other timely topics.

## ■ ARTHRITISPOWER RESEARCH CONTINUES WITH PCORI & INDUSTRY SUPPORT

- **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. The study protocol was recently approved by AbbVie's Protocol Review Committee. Register at [ArthritisPower.org](https://ArthritisPower.org) to be notified when the study opens in 4Q 2020.
- **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. The patient survey was recently pilot tested, and the research team is now reviewing patient feedback. Recruitment will begin in 4Q 2020. Register at [ArthritisPower.org](https://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](https://ArthritisPower) smartphone app. The primary aim of the study is to better understand the experience, disease activity, and symptoms of RA patients treated with janus kinase inhibitors (JAK inhibitors) over time. This study is sponsored by the Health Economics and Outcomes Research group at AbbVie US. The study launched in September and already has more than 30 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 will consist 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”). 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. A survey, whose development was informed by qualitative interviews with RA patients, was fielded in ArthritisPower and CreakyJoints this summer and has now been completed by more than 600 people living with RA. 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 also 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 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 will begin during 4Q 2020. In order 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](mailto:research@arthritispower.org).

### ■ GHLF INVITED AGAIN TO PRESENT AT ACR CONVERGENCE WITH TWO ORAL AND EIGHT POSTER PRESENTATIONS

In September, the research team confirmed that two abstracts for oral presentations and eight abstracts as poster presentations had been accepted at this year’s virtual ACR Convergence 2020 meeting. 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 this year’s virtual ACR Convergence 2020 than at previous annual meetings.

# HISPANIC/LATINX PATIENT OUTREACH AND EDUCATION

## REUMAEXPO

On August 22, 2020, the Puerto Rican Foundation for Rheumatic Diseases (FER) and CreakyJoints Español hosted the first digital version of ReumaExpo. Streamed via YouTube Live and Facebook Live, this online patient conference featured a series of live Spanish-language Q&A sessions with patients and rheumatologists about a wide variety of rheumatic conditions, such as arthritis, lupus, gout, osteoarthritis, and others. As a result of our media outreach to promote attending this meeting, Daniel Hernandez, MD, Director of Medical Affairs and Hispanic Outreach at GHLF, was interviewed by [La Opinión](#), the largest Spanish-language newspaper in the U.S. It was then picked up by other major Hispanic media, including [El Diario NY](#).

## PANLAR –3RD PAN AMERICAN CONGRESS OF PATIENTS WITH RHEUMATIC DISEASES

At the start of Hispanic Heritage Month, on September 16, 2020, CreakyJoints Español, in partnership with the Pan-American League of Rheumatology Associations (PANLAR), hosted the 3rd Pan American Congress of Patients with Rheumatic Diseases for Spanish-speaking people in the United States and Latin America who live with rheumatic diseases such as rheumatoid arthritis, osteoarthritis, lupus, juvenile idiopathic arthritis, and more. The all-virtual conference featured an international panel of physicians to provide advice on disease-management strategies, particularly during the COVID-19 pandemic. Daniel Hernandez, MD, was named President of this event.



The Hispanic/Latinx population amounts to almost 60 million Americans, but there are still very limited resources in Spanish for specific diseases and great need. There is much to do, and together we will achieve it.

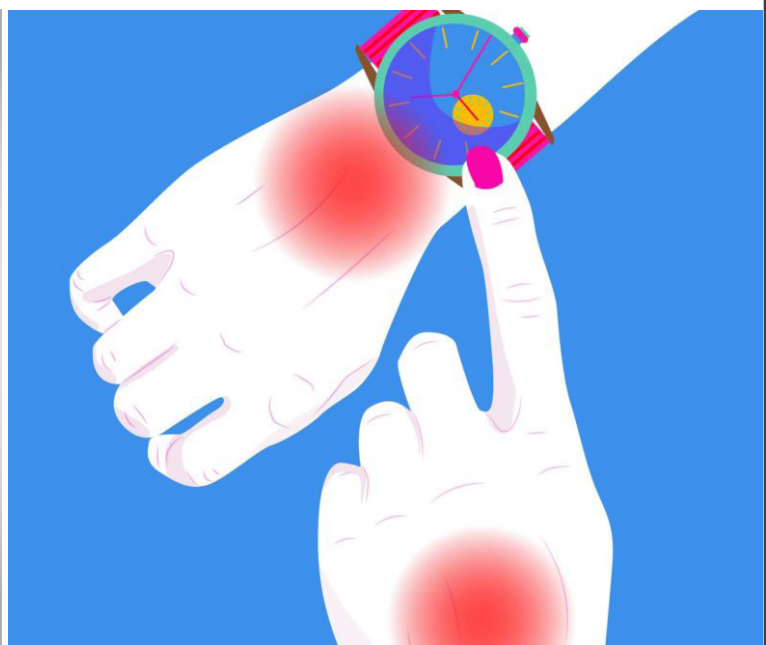
Since 1968, the United States government honors the achievements of Hispanics (people who speak Spanish) every year from September 15 to October 15. We may come

from different places, but the language (and much more) unites us!

CreakyJoints Español continued to grow its online presence by developing and sharing original contextualized Spanish-language content related to the Hispanic experience with arthritis, as well as, more broadly, to the COVID-19 pandemic. Some of the most popular articles were:

- [¿Es seguro ir a una peluquería si tienes un alto riesgo de contraer el COVID-19?](#)
- [¿Cuál es el momento adecuado para tomar tu medicamento para la artritis?](#)
- [¿Es seguro comer en un restaurante si tienes un alto riesgo de contraer el COVID-19?](#)

CreakyJoints Español also continues to support and encourage participation in the Spanish-language version of the Autoimmune COVID-19 Project ([proyectocovid19.org](http://proyectocovid19.org)).



# CJ AUSTRALIA PATIENTS IN RHEUMATOLOGY REPUBLIC

For Rheumatology Republic's September issue, CreakyJoints Australia wrote an article titled "How Patients Want Their Healthcare Team to Communicate." In the article, patients from the CreakyJoints Australia patient council shared their real-life situations and how they would like to better communicate with their health care team. This publication, spearheaded by Australian rheumatologist Irwin Lim, MD, continues to be a great platform for CreakyJoints Australia to share the patient voice and increase awareness about our organization.

Our patient council member Neen Monty recently was interviewed for [a news story in \*The Australian\*](#) about the struggles with the new Australian opioid regulations. Naomi Creek, a consumer representative with Pain Australia and CreakyJoints Australia's National Coordinator, put forward Neen's name as a patient who continues to advocate in this area.



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

- [CreakyJoints Australia Supports the #DontWaitMate COVID-19 Healthcare Campaign](#)
- [New Opioid Regulations – Why I Am Being Force-Tapered Off My Opioid Pain Medications](#)
- [New National Musculoskeletal Consumer Survey Launched in Australia](#)
- [Australia's First Treatment Drug for COVID-19 Just Approved by TGA](#)
- [Coronavirus: All You Need to Know About Getting Tested for COVID-19 \(Updated\)](#)
- [Important Information From the Australian Rheumatology Association About COVID-19 \(Updated\)](#)

## ■ EDUCATIONAL RESOURCES

During the third quarter, CreakyJoints Australia invested time developing their 60-page AxSpA Patient Guidelines in collaboration with Professor Paul Bird and the patient council. The document launched on World Arthritis Day, October 12.

## ■ WELCOME ROBYN

Robyn Lacey joined the patient council in July. Robyn lives in Darwin and has rheumatoid arthritis. She is a strong advocate and will be a valued participant in our group who can share insights into living with arthritis and the health care system in rural Australia.

## ■ ROUNDTABLES

NPS MedicineWise — As part of their Value in Prescribing bDMARDs program, nine health organizations led by NPS MedicineWise and engaged by the Department of Health met for the second time. The goal of the program is to optimize the use of bDMARDs to achieve better health outcomes and support PBS sustainability. Following a comprehensive formative research and program-design process, a list of interventions have been identified for the rheumatology indications of rheumatoid arthritis, psoriatic arthritis, and ankylosing spondylitis. These interventions have been scoped and prioritized depending on interdependencies and development timelines. Development for most of these interventions is well underway, and a phased implementation will commence from September 2020. An update will be provided in the next meeting.



# SPEAKING WITH AND FOR THE CHRONIC DISEASE COMMUNITY

The Global Healthy Living Foundation is conducting virtual meetings with state legislators to share our support related to COVID-19-influenced vaccine access, telehealth expansion, and promoting access to at-home infusion services. We have recently advocated for patient-centered policies through meetings with:

		
Representative Garnet Coleman (D Texas 147 <sup>th</sup> )	Assemblyman Daniel Benson (D New Jersey 14 <sup>th</sup> )	Senator Laura Murphy (D Illinois 28 <sup>th</sup> )
		
Representative Michelle Mussman (D Illinois 56 <sup>th</sup> )	Assemblyman Herb Conaway (D New Jersey 7 <sup>th</sup> )	Senator Arthur Ellis (D Maryland 28 <sup>th</sup> )
		
Delegate Benjamin Brooks (D Maryland 10 <sup>th</sup> )	Senator Jeff Smith (D Wisconsin 93 <sup>rd</sup> )	Representative Padma Kuppa (D Michigan 41 <sup>st</sup> )
		25

Additionally, GHLF worked closely with Assemblymember Benson on a letter to the New Jersey Department of Human Services raising concerns about Medicaid beneficiary access to home infusion, a critical service during the pandemic.

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

<b>1</b> JUL	<a href="#">Letter to Congress asking for legislation to delay the implementation of the 2021 NBPP (Chronic Policy Alliance sign-on)</a>
<b>17</b> JUL	<a href="#">Comments to CMS about proposed changes to Medicaid and copay accumulator adjustors</a>
<b>20</b> JUL	<a href="#">Comments to CMS about proposed changes to Medicaid (ATAP sign-on)</a>
<b>20</b> JUL	<a href="#">Comments to Congressional leadership about concerns regarding the Medicare Part D out-of-pocket cap (Project LOOP sign-on)</a>
<b>28</b> JUL	<a href="#">NIH human fetal tissue research comments</a>
<b>14</b> AUG	<a href="#">Reauthorization of Prescription Drug User Fee Act (PDUFA)</a>
<b>19</b> AUG	<a href="#">Patient group letter to OIG on Medicare Part D copay assistance (AARDA sign-on)</a>
<b>31</b> AUG	<a href="#">Coalition letter to HHS on human fetal tissue research (coalition sign-on)</a>
<b>21</b> SEPT	<a href="#">Making admission or placement determinations based on sex in facilities under community planning and development housing programs</a>

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

<b>2</b> JUL	<a href="#">Comments to CMS about additional policy and regulatory revisions in response to COVID-19</a>
<b>10</b> JUL	<a href="#">Letter to Congressional leadership about policy recommendations to accommodate and protect immunocompromised patients (Immune Deficiency Foundation sign-on)</a>

**We've also continued our efforts to communicate on the state level:**

<b>2</b> JUL	<a href="#">Letter to Massachusetts Health Policy Commission studying copay assistance (New England Hemophilia Association sign-on)</a>
<b>17</b> JUL	<a href="#">California AB-1710, expanding pharmacists ability to vaccinate</a>



## ■ DRUG REBATES: TRUMP ADMINISTRATION EXECUTIVE ORDERS ARE LACKING

In late July, the Trump administration signed a series of executive orders meant to address the escalating price of drugs. However, at the Global Healthy Living Foundation, we didn't feel the one addressing drug rebates went far enough to address the problem. 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](#) which explained the order authorizes Health and Human Services to create new avenues permitting “health plan sponsors, pharmacies, and PBMs to apply [negotiated] discounts at the patient’s point-of-sale in order to lower the patient’s out-of-pocket costs ...” While this is a positive step forward to changing market dynamics to give patients direct benefit from these discounts and help reduce patient spending, it affects only a portion of patients who need to access prescription medications. It does not affect those with private insurance or no insurance. Until this is addressed, secretly negotiated rebates will continue to cost patients rather than save them money.

## ■ 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:

- 6**  
JUL

 Brookings Institution: How Deep Will the COVID-19 Recession Be?
- 7**  
JUL

 Overview: Telehealth Policy and COVID-19
- 8**  
JUL

 UnitedHealthcare COVID-19 Briefing
- 15**  
JUL

 Pfizer’s COVID-19 Vaccine Briefing
- 16**  
JUL

 AIDS United: Relief, Recovery & Resilience: HIV, Aging and COVID-19
- 22**  
JUL

 Think Tank Policy Roundtable: Biopharmaceutical Competitiveness: Ensuring an Enabling Ecosystem for Innovation
- 23**  
JUL

 Advocacy Summit on the Role of Telemedicine: Now and Moving Forward
- 28**  
JUL

 Think Tank Policy Roundtable: COVID-19 Vaccine Development Efforts, Pandemic Preparedness, Domestic and International Regulatory and Policy Trends
- 29**  
JUL

 Inside the Virtual Care Boom: What Happens When the Point of Care Becomes Anywhere?

[continued on next page]

17 AUG	The Planetary Society: Space Policy vs. Health Policy — a Worthwhile Conversation
27 AUG	AIDS United: National Faith HIV/AIDS Awareness Day conversation — How People of Faith Find and Maintain Community amid Pandemics
1 SEPT	Brookings Institution: How the Fed Will Respond to the Covid-19 Recession in an Era of Low Rates and Low Inflation
9 SEPT	Brookings Panel Series: Are US health care prices too high, too low, or some mix of the two?
10 SEPT	Duke Margolis Center for Health Policy: Safe and Effective Coronavirus Vaccination: The Path From Here
17 SEPT	Association for Accessible Medicines: Recommendations to Enhance the U.S. Supply Chain to Secure a Consistent Supply of Critical Medicine
17 SEPT	Association for Accessible Medicines (AAM) Blueprint Briefing for Allies
17 SEPT	Australian Biosimilars Clinical Trial Landscape — How Agilex Biolabs and Nucleus Network Work Together
25 SEPT	Prescription Drug User Fee Act (PDUFA) VII Stakeholder Meeting with FDA

## ■ GHLF TALKS TO JEWISH CHANGEMAKERS AND VICTORY INSTITUTE ABOUT ADVOCACY. AIDS UNITED SHARES THE VICTORY INSTITUTE STAGE

On two occasions this quarter, GHLF's Director of Education and Digital Strategy, Joseph Coe, was invited to speak with the Jewish Changemakers fellows. During these discussions, he shared how GHLF uses digital communications to support the chronic disease community and provided tangible ways for the fellows to become better advocates in a shifting advocacy landscape.

On July 7, 2020, GHLF hosted a health care advocacy training session for the Victory Institute's congressional interns. The Victory Congressional Internship brings together outstanding LGBTQ undergraduate students for an intensive leadership program. This includes a development program to learn about careers in policy making as well as engaging with subject-matter experts across the District of Columbia and across working sectors. GHLF was asked to give a presentation on effective health care advocacy. We asked AIDS United to join us to share their insights into advocacy. Overall, this was a valuable experience for this group of interns, who were able to hear firsthand about real-world advocacy in a health care space.

# MAKING MIGRAINE MATTER

On September 24, 2020, GHLF hosted a training session on the basics of teleadvocacy conducted by GHLF patient advocates 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. Questions asked by 50-State Network members included how to find/approach your elected officials, how many topics should be discussed, and the best platforms for hosting these meetings.

## ■ NURSE PRACTITIONERS: IMPORTANT HEALTH CARE STAKEHOLDERS

GHLF worked with the Nurse Practitioner Association New York State to better understand the extent to which nurse practitioners work with migraine patients and what challenges they face.

An eight-item survey was fielded among nurse practitioners from the Nurse Practitioner Association New York State from mid-August to mid-September 2020.

- 62 percent of participants said they do not understand the way anti-CGRPs (calcitonin gene-related peptide) and gepants work as migraine treatments, and only 22 percent said they would be comfortable prescribing an anti-CGRP or a gepant to their patients.
- 40 percent of participants reported using telehealth (phone or video) to discuss migraine symptoms or treatment with their patients.
- Access to treatment was ranked as the most challenging problem migraine patients face.

## ■ EDUCATING MIGRAINE PATIENTS

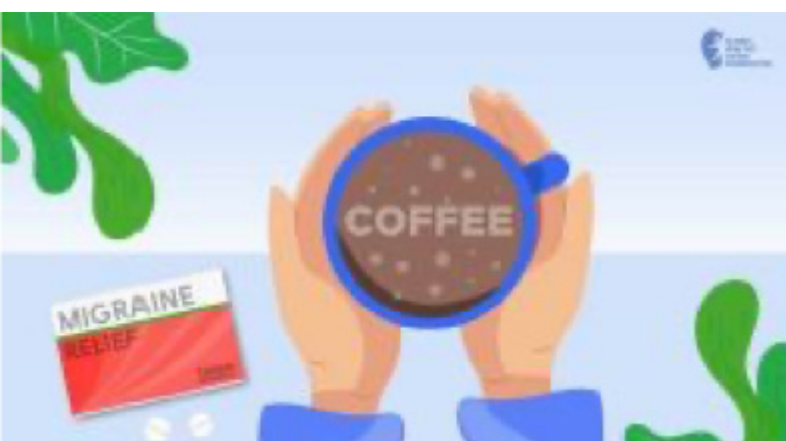
This quarter, GHLF launched a three-part migraine-management series focusing on acute treatment, preventive treatment, and lifestyle changes. Each article includes a uniquely designed graphic to increase engagement.



### [Managing Migraine With Lifestyle Changes](#)



### [Managing Migraine With Medical Treatments: Preventive Treatments to Reduce Migraine Attack Frequency](#)



### [Managing Migraine With Medical Treatments: Acute Treatments to Stop Migraine Attacks When They Happen](#)

# CREAKYJOINTS AND THE GLOBAL HEALTHY LIVING FOUNDATION IN THE NEWS

During the second quarter, there were 55 earned media placements featuring CreakyJoints members or leadership, generating more than 179 million media impressions. The most significant news drivers for the quarter were the FER/CreakyJoints patient event, generating significant coverage in Spanish-language publications, and Michael Kuluva’s online fashion show. Other notable placements included coverage from **The Mighty**, which referenced CreakyJoints member Jennifer Walker’s art, and **Healthline**, which interviewed Jennifer about her experience with medication delays due to United States Postal Service delivery issues. In addition, CreakyJoints member Eddie Applegate contributed a first-person story about his experience with psoriatic arthritis in the September issue of **WebMD: Living with Psoriatic Arthritis**. Two of our media partners, **Health Central** and **Everyday Health**, have also supported our recent #CreakyChats, and we’re working with both outlets to develop content based on awareness months and member stories.

In the third quarter, over 2.1 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.

## Website visitors are highly diverse in terms of age:

18-24:	<b>11% of total traffic</b>
25-34:	<b>22% of total traffic</b>
35-44:	<b>17% of total traffic</b>
45-54:	<b>17% of total traffic</b>
55-64:	<b>17% of total traffic</b>
65+:	<b>16% of total traffic</b>

- The average site visit is four minutes, 52 seconds (far longer than the industry's average of one minute, seven seconds). Audience age data is not collected for visitors under age 18.
- While GHLF's COVID-19 Patient Support Program continued to grow, the CreakyJoints community also continued to grow despite the pandemic. 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:
  - [Exercises to Avoid with Osteoporosis: The Types of Workouts You Probably Shouldn't Do](#)  
= **458% increase in organic Google search traffic**
  - [Does Humidity Make Your Joints Hurt? Here's Why, and What to Do About It](#)  
= **381% increase**
  - [Walking with Arthritis: Benefits, Tips, How to Prevent Pain](#)  
= **226% increase**
  - [Knee Replacement Surgery Recovery: What Doctors and Patients Want You to Know](#)  
= **224% increase**
  - [Does CBD Interact or Interfere with Medication? What Arthritis Patients Must Know Now](#)  
= **215% increase**

## ■ SOCIAL MEDIA PRESENCE GROWS TO OVER 30 MILLION IMPRESSIONS

In the third quarter, we sustained and grew to 120,000+ fans on Facebook and 15,300+ 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. Our influential and engaging monthly Twitter chat, #CreakyChats, is a large driver of impressions.

During the third quarter, we hosted very successful #CreakyChats that were cosponsored by several of our media partners:

- August 30: Pain Awareness Month Kickoff: Pain disparities, stigma, and the need for innovation, organized by CreakyJoints and cohosted by **Health Central**
- September 16: The Newest Normal: Get Ready for Tumbler and Topsy's spring/summer 2021 collection premiere event, organized by CreakyJoints and promoted by **Everyday Health**
- September 30: Fatigue, Flu, and Covid-19: Managing Rheumatic Disease During a Pandemic, organized and cohosted by **Everyday Health**

# 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 websites [www.CreakyJoints.org](http://www.CreakyJoints.org), <https://creakyjoints.org.es/>, [www.creakyjoints.org.au](http://www.creakyjoints.org.au), 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](http://ArthritisPower.org)) with more than 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. It also hosts PainSpot ([PainSpot.org](http://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](http://www.CreakyJoints.org).

Find us on social media:

Facebook: <https://www.facebook.com/creakyjoints> and <https://www.facebook.com/GlobalHealthyLivingFoundation/>

Twitter: @GHLForg, @CreakyJoints, #CreakyChats

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

TikTok: globalhealthylivingfnd

## 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](http://www.ArthritisPower.org)



## Global Healthy Living Foundation

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[www.ghlf.org](http://www.ghlf.org) | 845-348-0400

# WHO WE ARE

## 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.



## 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](#)




 facebook.com/creakyjoints  
facebook.com/globalhealthylivingfoundation

 linkedin.com/company/ghlf

 youtube.com/creakyjoints

 @GHLForg, @CreakyJoints, #CreakyChats

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