

# Global Healthy Living Foundation COVID-19 Patient Impact & Insights



- Patient Support Program Updates
- Education and Support Across GHLF.org + CreakyJoints
- Social Media Outreach
- Patient Council Insights
- Autoimmune COVID-19 Study Updates
- Spanish Language Update
- Advocacy Policy Updates

**September 20 – October 20**

# GHLF COVID-19 Patient Support Program for Chronic Illness Patients

In mid-March, GHLF launched a patient support program for people living with chronic illness to help them navigate the coronavirus pandemic— **whether they have COVID-19 or not.**

Informed by our COVID-19 Patient Leadership Council, the program is growing rapidly and meeting the many underserved needs of high-risk and chronic illness patients.

**Go to [www.GHLF.org](http://www.GHLF.org) to learn more**



**18,028**

Number of members

**29,628**

Number of subscribers

**28.2%**

Email open rate  
(health industry average = 22%\*)

**7.7%**

Email click rate  
(health industry average = 2.5%\*)

## Top Conditions:



**29%**

Rheumatoid Arthritis



**20%**

Lung Disease



**12%**

Psoriatic Arthritis + Psoriasis



**12%**

Fibromyalgia



**11%**

Heart Disease



**10%**

Migraine



**9%**

Diabetes



**7%**

Inflammatory Bowel Disease

\*Source: Mailchimp Email Marketing Benchmarks



## Patient Support Program Community Polls

We are surveying our Patient Support Program members regularly about important issues in health care and other topics.

# Patient Support Program Community Poll: Continuing Coronavirus Precautions

**A total of 649 Patient Support Program members responded to our September quick poll on continuing coronavirus precautions.**

**71% of poll respondents feel that they have people in their life who understand their need to take precautions regarding the pandemic. However, many respondents reported also having people in their life who do the following (not mutually exclusive):**

- Do not understand their need to take precautions regarding the pandemic: **24%**
- Try to get them to participate in activities that they're not comfortable with due to the pandemic: **21%**
- Say or do things that make them feel guilty for not participating in activities with them: **17%**
- Have stopped inviting them to things due to their concerns about the pandemic: **16%**
- Have stopped talking to them due to their concerns about the pandemic: **8%**

**27% of poll respondents have had difficulty accessing their medication(s), for any reason, since the coronavirus (COVID-19) pandemic began.**

**50% of the poll respondents believe that half or less of the people around them (e.g., friends/family, neighbors, coworkers/employer, elected officials) are taking appropriate coronavirus precautions**

- Only **10%** reported that everyone around them is

**50% of respondents believe the people around them are taking fewer appropriate coronavirus (COVID-19) precautions compared to 3-4 months prior.**

# Continuing Coronavirus Precautions: What Our Respondents Are Saying

*This is a sample of free responses to the community poll on medication access:*

“

*A family member suggested that I want to keep my immune system up so I shouldn't be so careful. They said I need a few germs to keep my immune system healthy. **With heart, lung and a multi system immune disease I couldn't disagree more.***

“

*As time goes on and with **inconsistent data coming from our government** and other leaders, many have lost faith and taken the situation with less importance than they should. I think there are many other reasons too, but when society cannot trust or believe what we are being told, naturally society will rebel. **Everyone is entitled to their own opinion, but it will be those who are most at risk who will pay the price for that rebellion.***

“

*I wish everyone would wear a mask **out of respect for me.** It makes me very upset when people look at me as if I am "one of those" people who are afraid or are "liberal" when I am wearing my mask.*

“

*This has created **a sense of loneliness for me, and despair.** Unable to control others beliefs and actions, family dismisses and shames multiple efforts I've taken to ensure my physical and emotional health is important. I have considered moving out of my own home. And, thank you for offering this platform for myself and millions of other health compromised individuals. **It feels both caring and reassuring.***

“

*I get very **frustrated and angry** with people still not taking this virus seriously. No masks, living life with little or no precautions.*

## Patient Support Program Community Poll: Pandemic Fatigue

**A total of 544 Patient Support Program subscribers responded to our September quick poll on pandemic fatigue.**

**Participants were asked to report on their experiences with pandemic fatigue, defined as participating in activities that they may have felt uncomfortable participating in a few weeks or months ago because of a desire for things to feel normal again. Below are the top 10 activities respondents have participated in the prior three months (not mutually exclusive):**

- **69%** have gone grocery shopping at the grocery store (rather than delivery or curbside pickup)
- **61%** have gotten takeout from curbside pickup or delivery
- **43%** have gone to a salon, such as a hair salon/barber or nail salon
- **39%** have gone shopping in-person at a small business
- **33%** have gone for a walk, run or bike ride with others
- **32%** have picked up takeout from inside a restaurant
- **27%** have eaten outside at a restaurant
- **23%** have eaten inside at a restaurant
- **13%** have gone to the beach
- **13%** have attended an outdoor gather of 10-20 people

## Patient Support Program Community Poll: Pandemic Fatigue

**A total of 544 Patient Support Program subscribers responded to our September quick poll on pandemic fatigue.**

**Below are the top reasons respondents have participated in the above activities during the prior three months (not mutually exclusive):**

- **67%** felt the activities were safe to do
- **38%** wanted to do things that made life feel more “normal”
- **26%** felt like they needed in-person interactions
- **19%** felt lonely and isolated
- **17%** didn't want to miss out on those activities anymore

# Pandemic Fatigue: What Our Members Are Saying

*This is a sample of free responses to the community poll on loneliness and social interaction. We asked participants what they miss doing due to pandemic:*

“

*It has been **excruciatingly lonely** at times. I'm tired of wearing a mask everywhere but I will continue until this over. I'm tired of fighting for doctor's appointments. I'm tired of worrying about getting sick every time I go out. **I'm just tired.***

“

*I'm just tired of hearing about it because most of what I hear through media feels like a lie. **I trust Creakyjoints and GHLF, but I wish society knew the truth** and could trust those in power to share the truth in what they know rather than politicizing everything.*

“

*The pandemic feels like it **will never go away** and life will never return to being able to get out of the house safely.*

“

*Pandemic isolation is not much different than isolation during prednisone treatment. You only live your life once **so make the most of it**, not worth wasting time worrying and complaining.*

“

*I find that I no longer care. If I get sick, then the worry will be over. I will either recover or I won't. **I'm tired of being scared.** I am going to Disney World next week. I am flying to get there and will be spending a week in the theme parks and a resort hotel.”*



## Patient Support Program Community Poll: “COVID-somnia”

**A total of 536 Patient Support Program subscribers responded to our October quick poll on “COVID-somnia”, or worsened sleep quality since the coronavirus (COVID-19) pandemic began.**

- **41%** of respondents reported having very poor to poor sleep quality in the prior 7 days
- **41%** of respondents reported having very poor to poor sleep quality in the prior month
- **71%** of respondents reported that their sleep quality had changed since the coronavirus (COVID-19) pandemic began

**Of the participants who reported having poor or worsened sleep quality in any of the three questions on sleep (75%), top contributing reasons are below:**

- Stress due to the uncertain state of things nationally and throughout the world: **72%**
- Stress due to threat of coronavirus (COVID-19): **61%**
- Pain due to condition(s): **55%**
- Lack of socializing due to coronavirus (COVID-19) restrictions: **50%**
- Lack of exercise and/or mobility due to coronavirus (COVID-19) restrictions: **43%**

## “COVID-somnia”: What Our Members Are Saying

*This is a sample of free responses to the community poll on loneliness and social interaction. We asked participants what they miss doing due to pandemic:*

“

*It's **difficult sharing a bed with my partner** because his sleep is as disrupted as mine. Fortunately we have enough bedrooms to sleep in separate rooms but I miss him.*

“

*I've found myself staying up later... Watching mindless TV, maybe because I'm bored but also **hyper-focusing on nonsense**.*

“

*Unable to shut down, **anxiety keeping me awake although my body is exhausted**.*

“

*The stress has caused me to have **stress headaches** often which then turn into migraines.*

“

*Yes I'm tired, but when I go to bed, **I lie awake until 2 AM**.*

# Social Media: World Arthritis Day

Across our digital channels CreakyJoints World Arthritis Time Capsule project reached over 100,000 individuals throughout the world. GHLF activated CreakyJoints Australia and our *Canadian Arthritis Patient Alliance (CAPA)* partner to make this a unique, global patient effort.

People living with chronic disease from the USA, Canada, United Kingdom, Ghana, Chile, New Zealand and Singapore shared what life is like during COVID-19 through a digital time-capsule Q&A.



[Chantelle \(USA\) RA](#)



[Jed \(USA\) AS](#)



[Alice \(New Zealand\) AS](#)



[Eileen \(Canada\) RA](#)



[Padika \(Ghana\) Lupus](#)



[Simon \(UK\) Psoriatic JIA](#)



[Kasey \(Australia\) RA](#)



[Sherly \(Singapore\) RA](#)



[Cecilia \(Chile\) RA](#)



## Fatigue, Flu, and COVID-19 Twitter Chat

On twitter, CreakyJoints co-hosted an important discussion with Everyday Health on managing rheumatic disease during the pandemic.

Questions included addressing emotional/mental health, understanding the difference between COVID-related symptoms and disease progression, and how to stay connected in a more physically distanced world.

**FATIGUE, FLU, AND COVID-19:**  
Managing Rheumatic Disease  
During a Pandemic

Join @EverydayHealth and @CreakyJoints for a Twitter chat on Wednesday, 9/30, at 7pm EDT

#EverydayRheumChat

EVERYDAY HEALTH

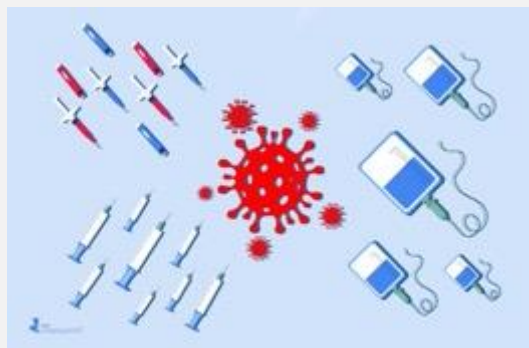
The graphic is a dark teal rectangle with a white border, set against a background of light green and teal geometric shapes. It contains text about a Twitter chat event, including the title, date, time, and hashtag, along with logos for Everyday Health and CreakyJoints.

<https://twitter.com/EverydayHealth/status/1311456031751499776?s=20>

# Top New Resources

CreakyJoints and the Global Healthy Living Foundation continue to regularly publish new resources every day to help patients with chronic conditions navigate the COVID-19 pandemic.

Over the last month, top content has included helping patients navigate arthritis symptoms related to the pandemic (sleep disturbances due to “COVID-somnia” and “painsomnia”) and understand how common medications affect their COVID-19 risk. We are continuing to educate on the importance of getting flu and pneumonia vaccines.



[\*\*TNF Biologics and COVID-19: What Autoimmune Patients Need to Know\*\*](#)



[\*\*‘COVID-somnia’ and ‘Painsomnia’: Why You Can’t Sleep During the Pandemic, and 8 Tips to Help\*\*](#)



[\*\*The Pneumonia Vaccine and Inflammatory Arthritis: What Patients Need to Know\*\*](#)



[\*\*Do You Still Need to Get the Flu Shot If You’re Strictly Isolating? YES.\*\*](#)

## Research Update: Our Autoimmune COVID-19 Study

Our mission with patient centered research is to share back any insights gleaned from the studies we conduct. Earlier this year we launched the [Arthritis and Rheumatic Disease COVID-19 Project](#) to understand how the pandemic has affected patients living with autoimmune diseases, including arthritis and related conditions.

With the aim of sharing what we have learned through this research study with our patient communities and raising awareness of what the latest in research is telling us about coronavirus, we have organized a **2-part webinar dissemination series**.

The webinars were 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.

## Research Update: Our Autoimmune COVID-19 Study

### The informational webinars for patients related to the COVID-19 pandemic were on the following topics:

- The first one titled '**How the COVID-19 Pandemic Affected Patients with Arthritis and Rheumatic Disease**', was conducted on September 17, 2020 during which we shared some early findings of the Arthritis and Rheumatic Disease COVID-19 Project, which studied patients living with arthritis and related conditions from the beginning of the pandemic. The Arthritis and Rheumatic Disease COVID-19 Project is led by researchers at the Global Healthy Living Foundation (GHLF), University of Pennsylvania, and University of Alabama at Birmingham (UAB). The survey asked people living with rheumatic and musculoskeletal conditions questions about their COVID-19 testing, telehealth visits, choices about immunosuppressive treatments, and where they receive information about COVID-19.
- The second webinar titled '**Staying Safe During COVID-19: What People with Chronic Illness Need to Know**', was conducted on Thursday, October 1, during which we shared the latest evidence based information with patients to help dispel dangerous myths about COVID-19 in an effort to help patients make important choices about their safety in this difficult time.

Both webinars are available for viewing and listening and can be accessed on <https://creakyjoints.org/category/webinar/>

# Spanish-Language Update

## CreakyJoints Español Awarded \$1 Million Grant to Promote Health Equity and Improve Health Outcomes Among Hispanics Living with Rheumatoid Arthritis – During and Post-COVID-19



Bristol Myers Squibb Foundation has funded the “RA Hispanic Outreach Program,” a \$1 million, two-year grant to improve relationships between Hispanic people living with rheumatoid arthritis (RA) and rheumatologists. The grant includes creation and dissemination of evidence-based education about RA, developed in patient-friendly formats and language. The project will include assembling an advisory council of Hispanic patients with RA and rheumatologists to collaboratively develop and evaluate educational materials to achieve culturally sensitive and patient friendly interventions that can become part of established care, if found effective.

Read release here in [English](#) or in [Spanish](#)



# Hispanic Heritage Month (Sep 15 – Oct 15)



## We're celebrating National Hispanic Heritage Month!

The Hispanic 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 unites us (and much more!)



## We also continue to...

- Research and write Spanish-language articles about COVID-19 and chronic disease management on CreakyJoints Español properties
- We have finalized recruitment period of patients into our [Spanish-language COVID-19 Research Registry](#)

# Patient Advocacy Update

## Teleconference Format

The COVID-19 Leadership Council and the CreakyJoints Patient Council teleconferences were conducted online via Zoom to allow participants to see one another using the video feature, as well as the chat feature to both respond to questions by the moderator and engage each other during the meeting.

## Teleconference Topic: Teleadvocacy

As the landscape of advocacy adjusts to a virtual world, GHLF aims to give you the essential tools to continue important healthcare advocacy. The purpose of these teleconferences was to share the basics of “teleadvocacy” and how to effectively advocate while practicing social distancing as well as hear the thoughts and experiences of our patient leaders in this new age of virtual communication.

# Patient Advocacy = *Teleadvocacy*

**What key topics have become important to you in the world of advocacy since the pandemic?**

“

*Telehealth! – Beth M.*

“

*Any social media strategies to fight for ACA, opioid access, telehealth coverage, mask mandates, EBT/SNAP delivery options through local/national supermarkets, universal internet access, and work discrimination during for high-risk individuals asking to work from home. – Charis H.*

“

*Medical communities, trust of vaccine, and communities of color. There's a mistrust of the medical community amongst the minority community. - Chantelle M*

**What are some potential pros and cons of in-person vs. virtual meetings?**

“

*Pro: Legislators may have more time and not shuffling in and out, although in person you can get a photo which has more power on social media. – Charis H*

“

*Pro: Those cobble stones are horrible for patients living with a chronic condition. – Cat D.*

“

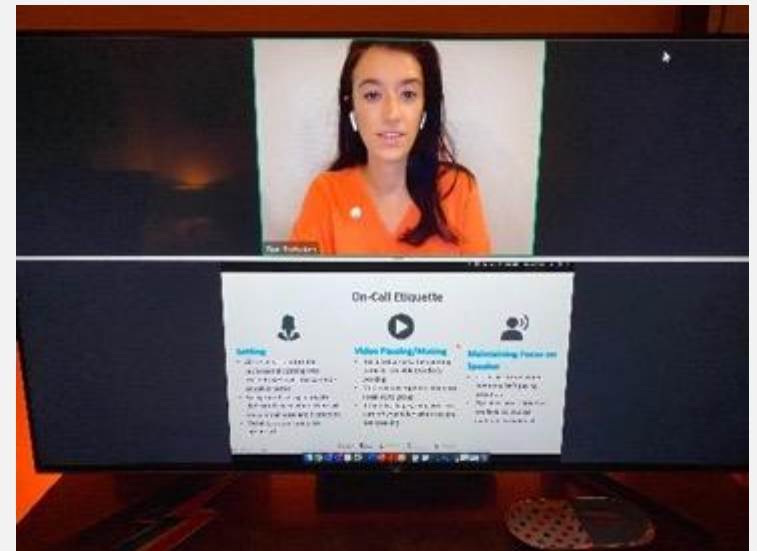
*Con: The lack of visual impact of a disability in person and its impact on daily life - a picture is worth a thousand words in many times. – Beth M*

# Advocacy and Policy Update

GHLF has been hosting virtual training sessions on the basics of “teleadvocacy”. As the landscape of advocacy adjusts to a virtual world due to COVID-19, GHLF aims to give patients the tools to continue important health care advocacy. In these sessions, we’ve shared tips on how to effectively advocate while practicing social distancing.

## Topics covered include:

- Finding your legislators
- Scheduling meetings
- On-call etiquette
- Technical support
- Effective storytelling
- Making the most of meetings
- Ways to follow up



# Patient Leaders in Our Patient Support Group



## From left:

**Top row:** Jovana Gonzalez Placido (*Scleroderma*), Daniel Garza (*HIV/AIDS*), Susan Herley (*Gout*), Tinu Abayomi-Paul (*Cancer*), Molly Schreiber (*Diabetes*), Terrance Hill (*Sickle Cell Disease*), Peter Morley (*Lupus*)

**Middle row:** Jed Finley (*Ankylosing Spondylitis*), Jamie Holland (*Crohn's Disease*), Charis Hill (*Ankylosing Spondylitis*), Beth Madison (*Lupus*), Jennifer Walker (*Asthma*)

**Bottom row:** Ebby Isbill (*Multiple Sclerosis*), Catherine Charrett-Dykes (*Migraine*), Dawn Gibson (*Ankylosing Spondylitis*), Roxanne Watson (*Heart Disease*), Diane Talbert (*Psoriasis & Psoriatic Arthritis*), Ray Bouchard (*Rheumatoid Arthritis*), Eileen Davidson (*Rheumatoid Arthritis*)

For questions or comments please contact Steven Newmark ([SNEWMARK@GHLF.ORG](mailto:SNEWMARK@GHLF.ORG))