



**GLOBAL  
HEALTHY  
LIVING  
FOUNDATION**

december  
**2020**

**COVID - 19**  
Patient Impact & Insights

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# 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



## 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 COVID19- or not.

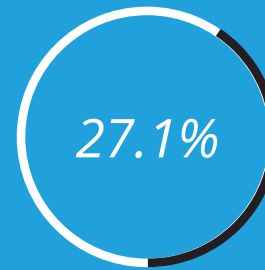
Informed by our COVID-19 Patient Leadership Council, the program is growing rapidly and meeting underserved needs of high-risk and chronic illness patients. [Go to www.GHLF.org](http://www.GHLF.org) to learn more



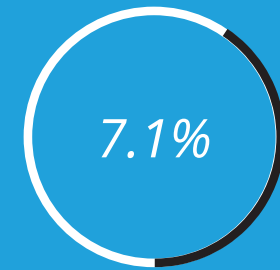
NUMBER OF MEMBERS



NUMBER OF SUBSCRIBERS



EMAIL OPEN RATE  
(HEALTH INDUSTRY AVERAGE = %22\*)



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

# PATIENT SUPPORT PROGRAM COMMUNITY POLLS



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

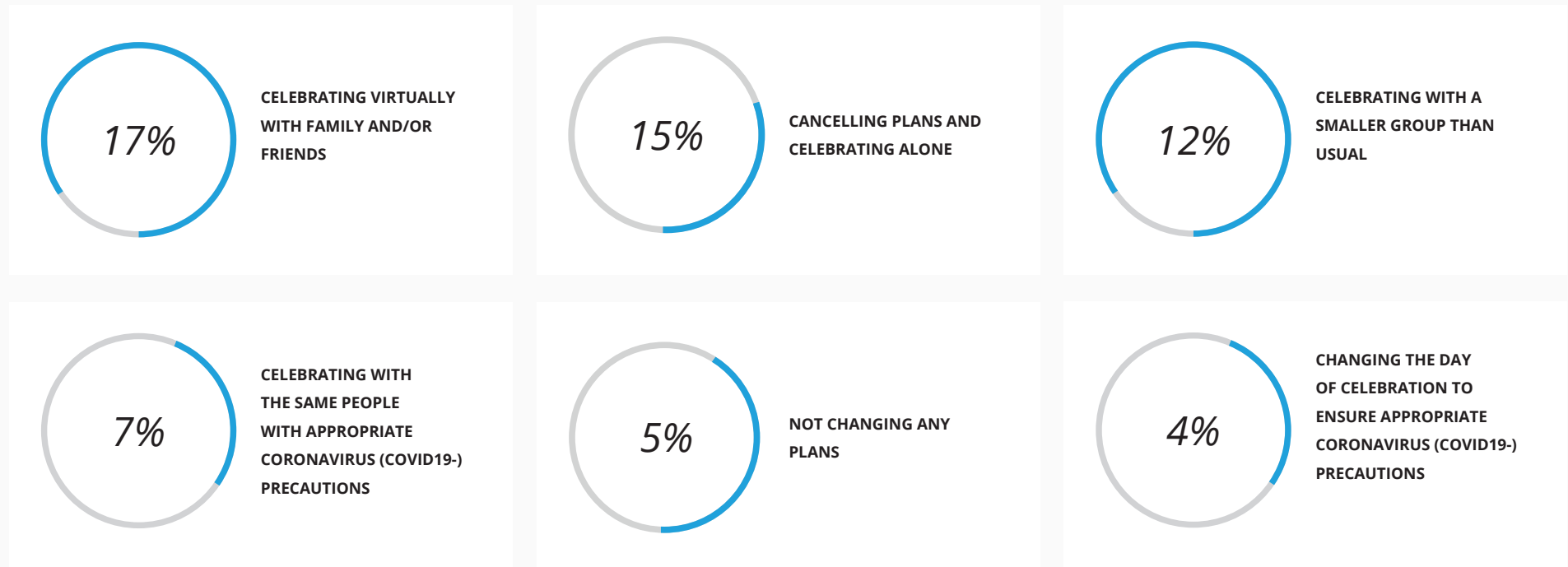
# HOLIDAY PLANS POLL

Patient Support Program subscribers responded to our October quick poll on their plans for the holiday season.

## A TOTAL OF 492

### 44% OF RESPONDENTS

reported that their plan is to celebrate the upcoming holidays with those in their household only. Other plans for the holiday season consisted of the following (responses are not mutually exclusive):



### 94% OF RESPONDENTS

noted that their family and/or friends have been somewhat to very understanding of the need to change or potentially change holiday plans.

## HOLIDAY PLANS: WHAT OUR RESPONDENTS 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:

**“ We are sad not to have family with us but will cook and bake. Then distribute food by packing leftovers like we do on normal times. Different but still share the love so that is most important.**

**My 3 adult daughters definitely keep me and my health 1# in regard to holiday gatherings. They feel very bad that I cannot see my little grandsons but we do our best to do virtual calls and send little cards and gifts through the mail.**

**”**





“

I live in New Orleans, so we're doing Thanksgiving outside, but I'm not sure if the temps will allow for Chanukah or Christmas or New Years outside.



”

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

”

My family has decided that the best way to manage the holidays, or any day, is to be flexible.

# THE PANDEMIC'S THIRD WAVE POLL

Patient Support Program subscribers responded to our November quick poll on the Third Wave of the Coronavirus (COVID19-) Pandemic.

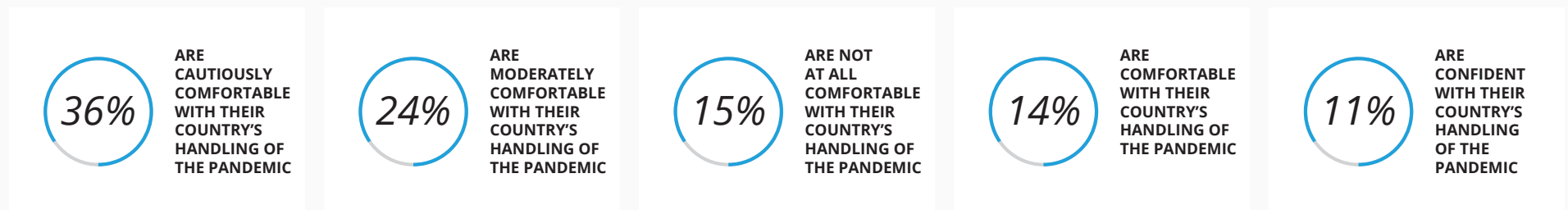
## A TOTAL OF 747

## 60% OF RESPONDENTS

of respondents expressed they never stopped taking all appropriate precautions throughout the pandemic. Below are other most common precautions reported (not mutually exclusive):



Respondents from outside of the US: **85 RESPONDENTS** were asked to report on their comfort with how their country is handling the pandemic:



## 58% OF RESPONDENTS

reported they were extremely concerned when asked to report on their level of concern about the state of the pandemic



## THE PANDEMIC'S THIRD WAVE: — 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:

**“ We have family member in the hospital with Covid19-. They are also our neighbors. The numbers are going up in Ohio. I am being more careful.**

**The medical care in Italy is not very good. The hospital care is not very good. They try, but it's outdated.**

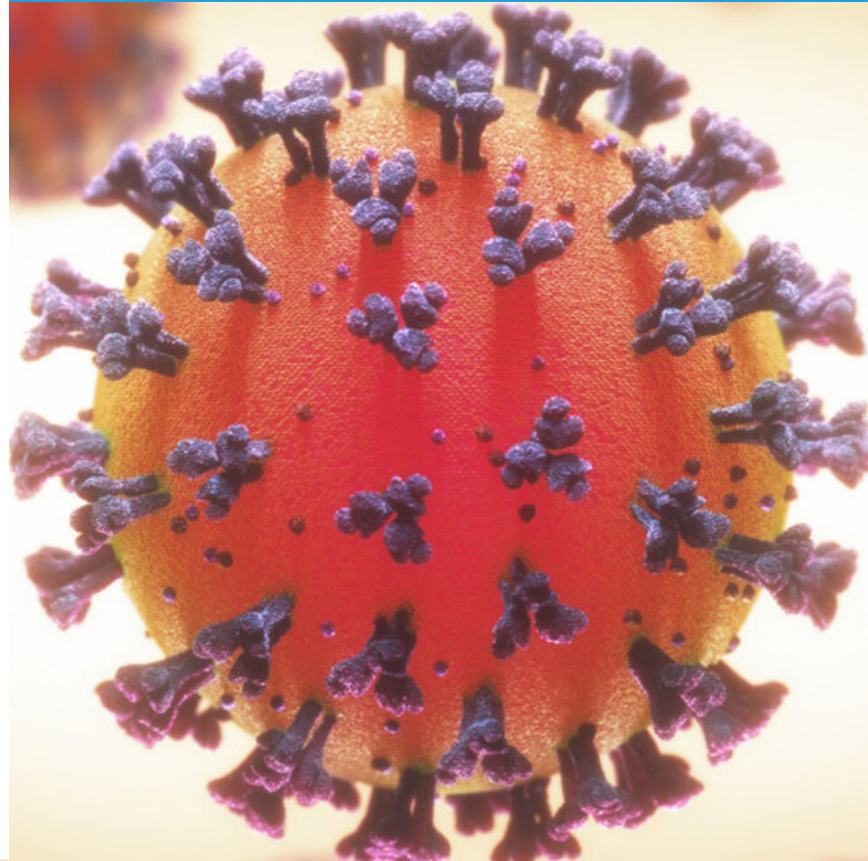
**”**

**“ Fear of lockdown and the financial and mental toll it will have on not just me but my family and friends.**



“

I am concerned because I am a UPS driver coming into our busiest season. I have several risk factors and my daughter also has several.



”

I worry that I will not be able to reintegrate into the outside world for a long time.

”

I am afraid of getting sick. Even if I were to get through it, it is hard to imagine that I wouldn't be left with remnant effects. Even after vaccinations get going, it is a long-term worry for the foreseeable future for people like me (I really try not to think about).

## PARTICIPATION IN ACTIVITIES POLL



### 'SALON'

In September we asked our Patient Support Program subscribers to report on activities they were participating in and compared this to results of a similar poll on reopening activities that we conducted in June.

### 'IN-PERSON SHOPPING'

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While the sentiments didn't change substantially between June and September, activities such as going to a salon, in-person shopping, and eating indoors at a restaurant saw the biggest percent changes in what people have done or were willing to do from June to September.

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### 'EATING INDOORS'



## COVID-SOMNIA: WHAT OUR MEMBERS ARE SAYING

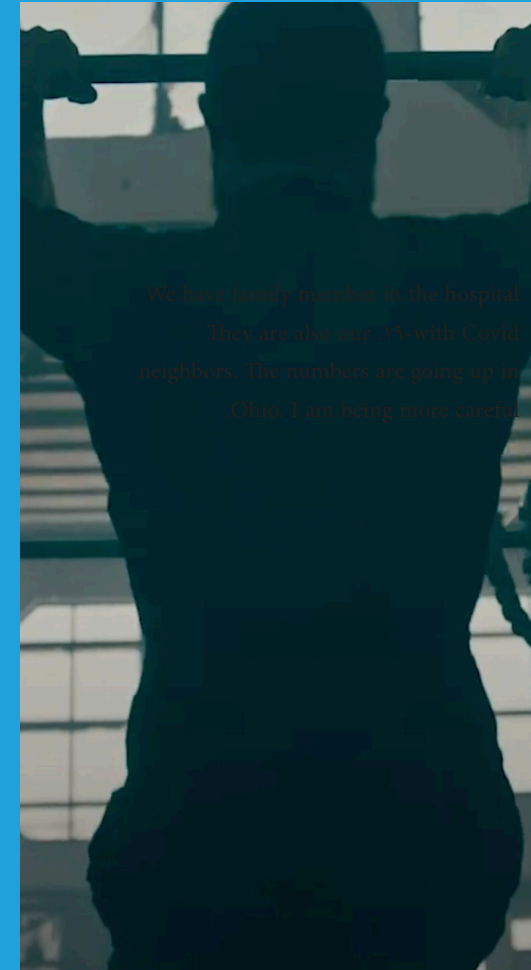
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This is a sample of free responses to the community poll on COVID-somnia:

**“ 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.**

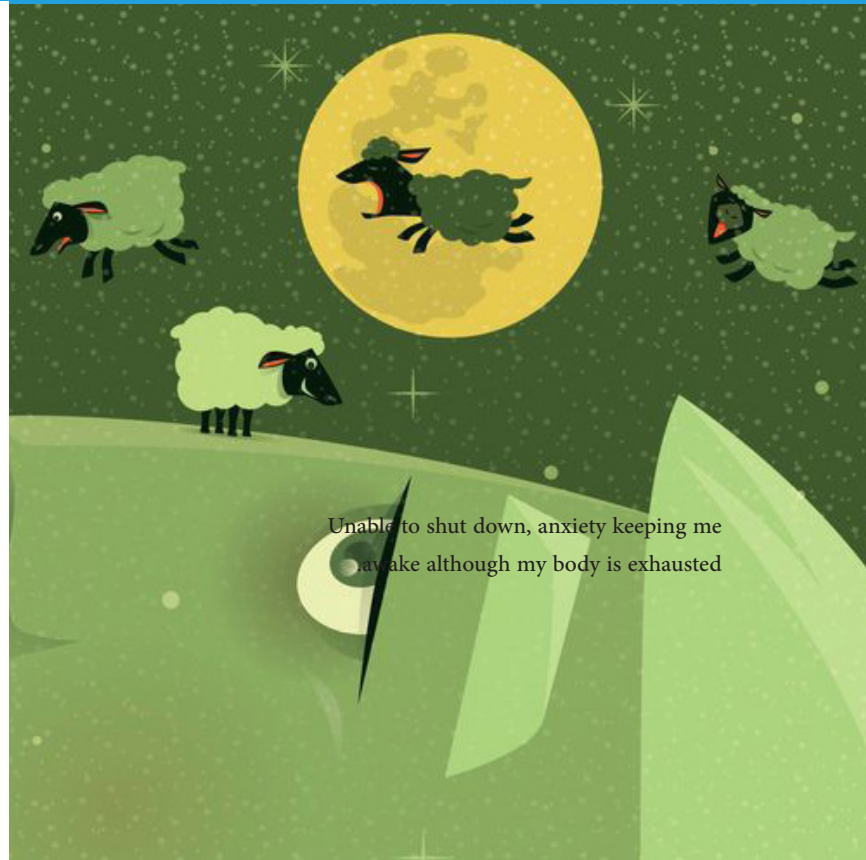
**I’ve found myself staying up later... Watching mindless tv, maybe because I’m bored but also hyper-focusing on nonsense.**

**”**



“

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



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

”

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

”

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



# SOCIAL MEDIA




CreakyJoints  
October 21, 2020 · 🌐

Care about someone with a compromised immune system? Get your flu shot. Take action and learn more.  
Flu Vaccine and COVID-19: What People with Chronic Illness Need to Know  
<https://register.gotowebinar.com/regi.../7638779376985209615>

👍👍👍 93 10 Comments 43 Shares

## CARE ABOUT ME? GET VACCINATED



Community immunity is extremely important for people with chronic disease: Compared to the general population, people living with chronic illness are at a higher risk of getting the flu (and other vaccine-preventable infections) and also at risk of getting more complications and hospitalizations from those infections.

CreakyJoints  
October 18, 2020 · 🌐

File under: "Wear A Mask"



CREAKYJOINTS.ORG

### Face Masks Are Safe and Don't Impair Breathing (Even for People with COPD and Respiratory Conditions), Study Shows

CreakyJoints  
October 21, 2020 · 🌐

Care about someone with a compromised immune system? Get your flu shot. Take action and learn more.  
Flu Vaccine and COVID-19: What People with Chronic Illness Need to Know  
<https://register.gotowebinar.com/regi.../7638779376985209615>

👍👍👍 93 10 Comments 43 Shares

## WHEN SHOULD YOU GET VACCINATED?



The CDC recommends people get their shots before flu starts spreading, ideally by the end of October.

But you can still get the vaccine through the fall, even into January or later. It takes two weeks after vaccination for antibodies that protect against flu to develop in the body.



CreakyJoints.org @CreakyJoints · Oct 19, 2020

When treatment for inflammatory #arthritis escalates, so does the risk of depression and anxiety — and there are many possible explanations for this link.



Starting or Switching a Biologic Is Linked to an Increased Risk of Dep...  
Learn more about why arthritis patients who start or switch a biologic drug are more likely to have anxiety or depression.  
[creakyjoints.org](https://creakyjoints.org)

🗨️ 3 🔄 7 ❤️ 27 📌

CreakyJoints.org @CreakyJoints · Oct 20, 2020

Going barefoot while spending more time at home can further damage arthritic joints. Here's how to avoid foot pain during the pandemic: [creakyjoints.org/living-with-ar...](https://creakyjoints.org/living-with-ar...) #spoonie #spoonies #arthritis



Got More Arthritis Foot Pain Than Usual? The Surprising Way the Pan...  
Learn more about how spending time barefoot at home can increase foot pain, especially in people who have arthritis in their feet.  
[creakyjoints.org](https://creakyjoints.org)

🗨️ 🔄 4 ❤️ 17 📌

CreakyJoints.org @CreakyJoints

The CDC recommends that people get a flu vaccine by the end of October.

#FluVaccine and #COVID19: What People with Chronic Illness Need to Know  
[register.gotowebinar.com/regi.../763877...](https://register.gotowebinar.com/regi.../763877...) #spoonie #spoonies

## WHEN SHOULD YOU GET VACCINATED?



4:30 PM · Oct 25, 2020 · Twitter Web App

8 Retweets 13 Likes



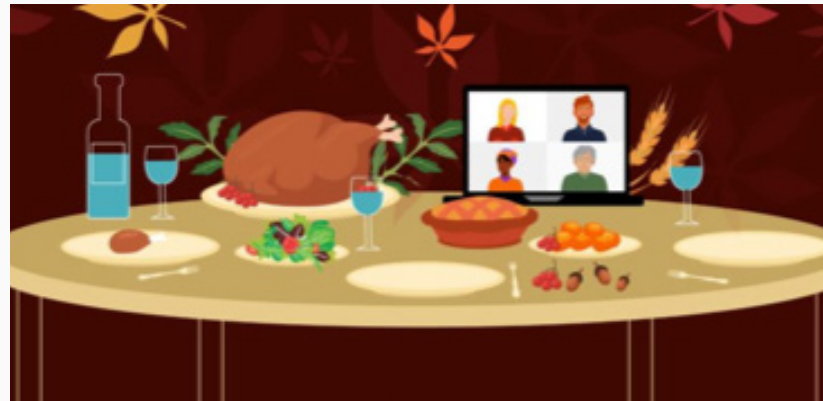
## TOP NEW RESOURCES

CreakyJoints and the Global Healthy Living Foundation continue to regularly publish new resources on a regular basis to help patients with chronic conditions navigate the COVID19- pandemic.

Over the last month, top content has included helping people re-adjust to rapidly rising cases across the U.S. and around the world, including content specifically focused on getting through the holiday season.



**Don't Stop Taking 'Immunosuppressive' Medication During the COVID19- Pandemic: A Plea from Doctors**



**How to Have a Low-Risk Thanksgiving During COVID5 :19- Tips for People with Chronic Illness**



**How to Avoid Getting COVID9 :19- Key Reminders for People with Chronic Illness**



**How to Move More at Home When You're Stuck Inside During COVID19-**

## NEW COVID-19 RESEARCH AT ACR



**This year's American College of Rheumatology meeting was filled with hundreds of abstracts about COVID19-. Our mission: Sift through the research and curate the findings patients need to know about most.**

We focused on curating research into bigger themes to help avoid making patients feel information overload. Here is a sample of our coverage so far, which is still ongoing.

On page 18, you can learn more about GHLF's own COVID-19 research presented at ACR. This page is focused on disseminating research findings from other sources.

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.

**Are Inflammatory Arthritis and Rheumatic Disease Patients More at Risk for COVID19- Complications?**

**How Is COVID19- Affecting the Mental Health of Rheumatic Disease Patients?**

**Children with Rheumatic Diseases May Not Be at High Risk of COVID19- — or Serious Outcomes**

**Black and Hispanic/Latinx Rheumatic Disease Patients Have More COVID19- Hospitalizations and Complications**

**Telemedicine Helps Rheumatology Patients Stick to Their Routine Appointments**

**TNF Biologics and COVID19-: 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.**

# CREAKYKITCHEN

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## GHLF Hosted Our Second Cooking Event: A Night of Tips and Treats

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We hosted a virtual CreakyKitchen celebration to spread holiday cheer during the pandemic. We gathered online to celebrate the holiday season together as a chronic illness community while enjoying a sweet treat and learning kitchen hacks.

A member of our community, Chantelle Marcial, gave a virtual class on baking a dessert for the holidays. We were also joined by Cheryl Crow, occupational therapist, rheumatoid arthritis patient and founder of the educational company Arthritis Life, who shared her best tips and tricks for navigating the kitchen with arthritis.

To learn more about CreakyKitchen, please visit <https://creakyjoints.org/creakykitchen/>

# 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 organized an informational webinar on the flu vaccine.

## Flu Vaccine and COVID19-: What People with Chronic Illness Need to Know

Presented by:



### **IRIS NAVARRO-MILLÁN, MD**

Rheumatologist at Weill Cornell Medicine in New York City with current appointments at the Hospital for Special Surgery (HSS) and New York-Presbyterian Hospital



### **WILLIAM SCHAFFNER, MD**

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



### **TASHA POLSTER, RPH**

Vice President of Pharmacy Quality, Compliance, and Patient Safety for Walgreens, overseeing the Retail Pharmacy Immunization program, Pharmacovigilance Group, and Walgreens Patient Safety Organization

The webinar debunks common myths about the flu vaccine, particularly for people with chronic conditions. Panelists provided important information on the difference between COVID-19 and the flu, including how to tell symptoms apart, what to do if you suspect being infected, and how to get tested for both. To access the webinar, please follow this [link](#).

# RESEARCH UPDATE: ACR CONVERGENCE 2020

**GHLF presented data collected from the Arthritis and Rheumatic Disease COVID-19 Project at the American College of Rheumatology's (ACR) annual meeting, ACR Convergence 2020. We presented these four COVID-related abstracts:**

Concerns and Behaviors of Patients with Common Autoimmune Rheumatic Diseases in the United States Early in the COVID-19 Pandemic, Abstract 1144 (poster)

Concerns and Health-Related Behaviors During the COVID-19 Pandemic in Patients with or without Autoimmune Rheumatic Disease in a Large Physician Network, Abstract 0468 (oral presentation)

Impact of COVID-19 on Missed/Cancelled Rheumatology Office Visits and Parenteral Immunosuppressive Medication, Abstract 0017 (poster)

Effects of the COVID-19 Pandemic on Patients Living with Vasculitis, Abstract 1416 (poster)

# SPANISH-LANGUAGE UPDATE

## PARTNERSHIPS

The [Pan American Network of Associations of Rheumatic Patients](#) (ASOPAN) hosted their first patient conference for Spanish-speaking rheumatic patients with the support of [CreakyJoints Español](#). This online patient conference was streamed through [YouTube Live](#) and featured a series of Spanish-language live panel discussions, Q&A sessions with patients and rheumatologists, and a wide variety of information on rheumatic conditions living through the COVID19- pandemic.

### Education and Support

We continue to provide up-to date information during the COVID-19 pandemic, specifically focused on addressing vaccine hesitancy within the Hispanic community through our [CreakyJoints Español](#) properties

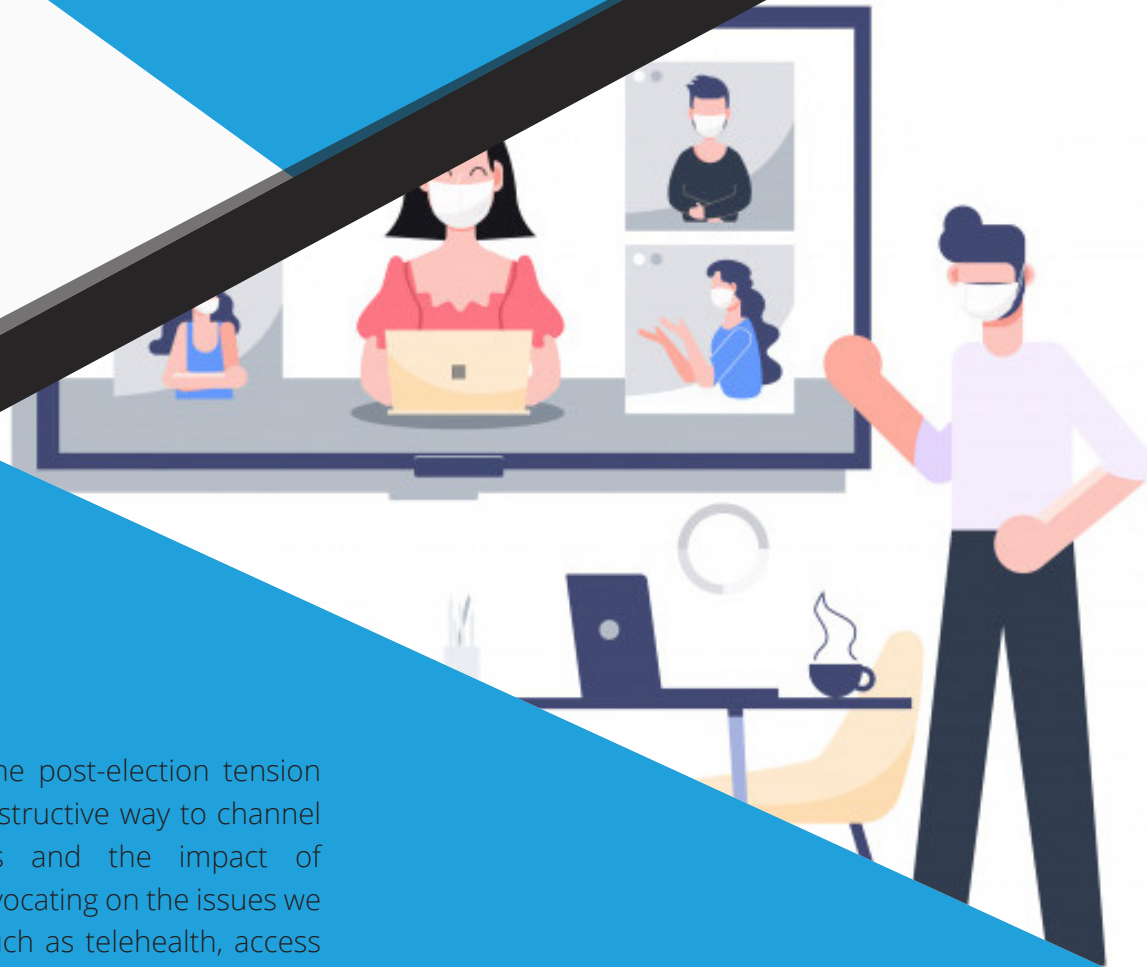


# PATIENT UPDATE

## 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: Post-Election Stress – Turning Pain Into Purpose

While we wait for the post-election tension to clear up, one constructive way to channel post-election stress and the impact of COVID-19 can be advocating on the issues we may face in 2021 such as telehealth, access to care, health disparities, and vaccinations, among others. This teleconference reviewed various coping strategies and advocacy activities patients can engage in and included

discussions around key topics that are most important to the high-risk community.

## TELECONFERENCE TOPIC: POST-ELECTION STRESS – TURNING PAIN INTO PURPOSE

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Since the election results were announced, what have been your fears and concerns or perhaps relief for the high-risk community?

“

**My biggest fear is when the vaccine does come out, because I'm at the 60 plus age and living with a chronic condition, will I even be eligible for it? If I get sick and go to the hospital, what happens? – Diane T.**

---

**With the reopening, we are forced to decide if we want to stay employed or to keep ourselves safe. After Thanksgiving I don't know what's going to happen. – Jed F.**

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What does the 2021 administration need to know about your condition?

”

**“What we stand to lose if the ACA goes away.” – Charis H.**

**“People are letting us die so others can go to barber shops, salons, and parties. We don't feel our lives are valued at all and we don't have trust in being protected anymore.” – Jennifer W.**

## TELECONFERENCE TOPIC: POST-ELECTION STRESS – TURNING PAIN INTO PURPOSE

Access to care and health disparities are very important healthcare issues. What education do you think is needed related to the coronavirus and diversity, equity, and inclusion?

“

**How do you stay safe everyday as a low-income person with a chronic illness and how can we afford the medications to maintain our health with many low-income people losing their jobs. – Diane T.**

**“Minority stress: minorities face a much higher source of rejection in jobs and in healthcare.” – Jennifer W.**

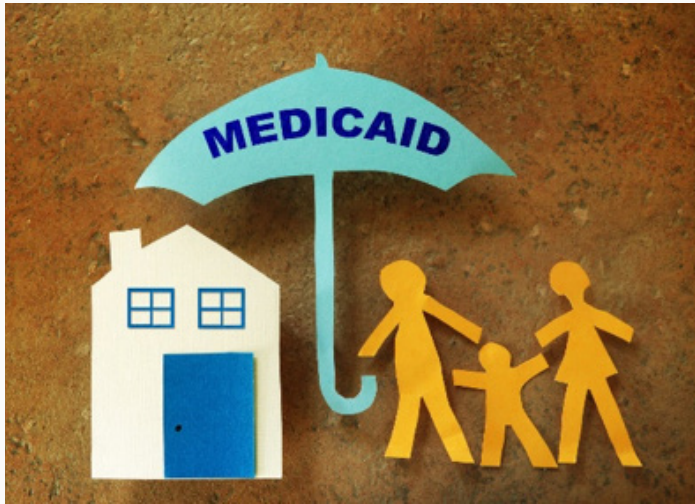
What other healthcare-related education do you think is important now or 2021? What should we focus on?

”

**The is an important year to get your flu vaccine. It's literally vital to keep people out of the hospitals right now. – Charis H.**

**Navigating the CDC website so we can easily find answers to questions like how we quarantine in our homes if living with someone who's been infected and others. – Jennifer W.**

## ADVOCACY AND POLICY UPDATE



**[Read the letter to Congressional leadership](#)**

During the COVID-19 pandemic we have witnessed a dramatic fall in immunization rates across all ages. Concerned by the decrease in immunization, we joined a sign on letter with the American Academy of Pediatrics in support for the Community Immunity for COVID-19 Act and the VACCINES Act. The letter urges Congress to take immediate action to provide much needed funding to state and local public health departments to promote ACIP-recommended vaccinations during the COVID-19 public health emergency and to combat vaccine hesitancy that lowers the immunization rate for both routine vaccines and COVID-19 vaccines.

Many patients in our community continue to isolate strictly to remain safe from the coronavirus. Telehealth helps our community to have continued access to care, which is vital for people living with one or more chronic diseases that require ongoing management. Steven Newmark, Director of Policy at GHLF, contributed an opinion piece to The Doctor Weighs In commenting on the need for ongoing Medicaid funding for telehealth.

Read the op-ed entitled [“In The Face of a Medicaid Tsunami, Telehealth is More Important Than Ever”](#).



## 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)

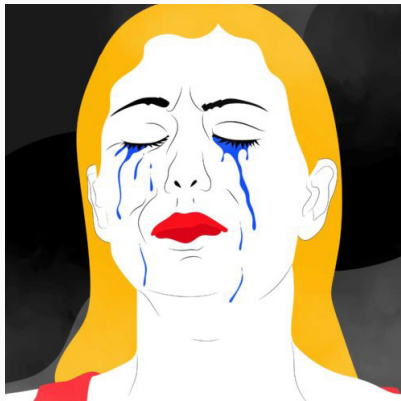
**Bottom row:** Ebby Isbill (Multiple Sclerosis), Catherine Charrett-Dykes (Migraine), Dawn Gibson (Ankylosing Spondylitis), Roxanne Watson (Heart Disease), Diane Talbert (Psoriasis & Psoriatic Arthritis), Ray Bouchard (Rheumatoid Arthritis), Eileen Davidson (Rheumatoid Arthritis)



## MENTAL HEALTH SUPPORT

CreakyJoints and the Global Healthy Living Foundation continue to regularly publish new resources to help patients with chronic conditions navigate the COVID19- pandemic.

We know the holiday season can be emotionally challenging for chronic illness patients to begin with, let alone during a nearly yearlong pandemic filled with depression, anxiety, and loneliness. We have been focused on providing mental health educational resources and support.



**'I'm Scared and Sad': A Health Psychologist's Tip for Coping with These Common Pandemic Feelings**



**The 19 Mental Health Tips Everyone with Chronic Illness Needs to Get Through the COVID19- Holiday Season**



**Chronic Pain and Suicide: Signs You or a Loved One Needs Help, and How to Get It**



**I'm in a 'Groundhog Day' Haze: How a Chronic Illness Patient Started Shaking Things Up When Every Day Feels the Same**



# COVID-19 VACCINE EDUCATION

## **Vaccines continue to be the most popular topic on CreakyJoints and GHLF webpage and in social media.**

The last month, was no different. Top content focused on COVID-19 vaccines specifically. There is a huge dearth of information — and plenty of misinformation — regarding COVID-19 vaccines for people who are immunocompromised, take immunosuppressant medication, and have autoimmune conditions.

To help counteract this misinformation, a widely attended webinar featured expert physicians (right) in autoimmune and vaccine specialties.

### **LEONARD CALABRESE, DO**

Professor of Medicine at the Cleveland Clinic Lerner College of Medicine

### **GRACE LEE, MD**

Professor of Pediatrics at Stanford University School of Medicine and member of the U.S. Advisory Committee on Immunization Practices (ACIP)

### **MARIO CASTRO, MD**

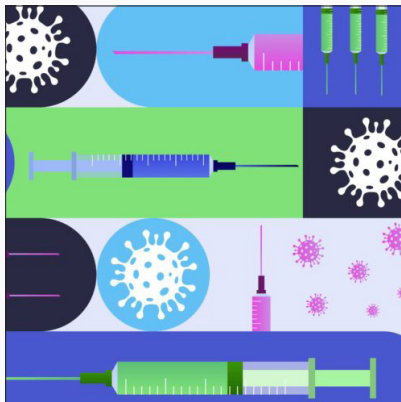
Vice Chair for Clinical and Translational Research in the Department of Internal Medicine and a pulmonologist at the University of Kansas School of Medicine

### **BALA MURUGAN, MD**

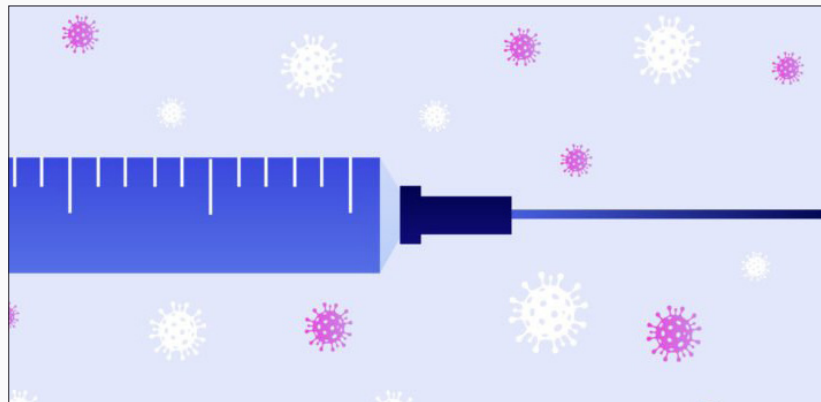
Acting Chief Medical Officer at the Arkansas Department of Health and board member of the National Association of Chronic Disease Directors

# COVID-19 VACCINE EDUCATION

CreakyJoints is also in regular contact with dozens of rheumatologists and other inflammatory disease experts for clinical opinions regarding the COVID19- vaccine in this patient population.



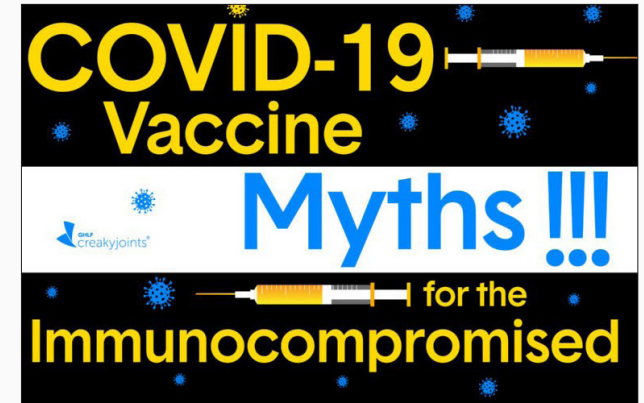
[Getting a COVID19- Vaccine: What to Know If You're Immunocompromised](#)



[Can You Get the Pfizer COVID19- Vaccine If You're Immunocompromised or Have an Autoimmune Condition?](#)



[What Major Medical Organizations Are Saying About Getting an mRNA COVID19- Vaccine If You're Immunocompromised](#)



[4 Fast Facts to Share in Response to These COVID19- Vaccine Myths About Immunocompromised Patients](#)

# COVID-19 VACCINE EDUCATION

## Top Ranking in Google Search Results

CreakyJoints has produced numerous resources on this topic and as a result is currently ranking first in Google search results for phrases around “immunocompromised COVID-19 vaccine” and “immunocompromised Pfizer COVID-19 vaccine.”

## Best Site Traffic Day of the Year

On Tuesday December 15, CreakyJoints had its top traffic day of the year due to our COVID-19 vaccine content. More than 50,000 organic visitors (meaning no paid traffic) visited the site, driving more sign-ups for our Patient Support Program.

The screenshot shows a Google search for "covid-19 vaccine immunocompromised". The search bar is at the top with the Google logo on the left and search controls on the right. Below the search bar, there are navigation tabs for "All", "Shopping", "News", "Images", "Videos", and "More". The search results show "About 3,460,000 results (0.51 seconds)".

**Top stories**

- abc NEWS**: Pregnant? Allergies? Immunocompromised? You are still eligible for COVID-19 vaccine. 1 day ago.
- OTTAWA CITIZEN**: Immunocompromised may have to wait longer for COVID-19 vaccine. 2 hours ago.
- ABC NEWS**: COVID vaccines will be recommended to almost all Australians. But are there people who can't... 18 hours ago.

A "View all" button is located below the top stories.

**Featured snippet:**

**creakyjoints.org** › coronavirus › covid-19-vaccines › c...  
**Getting a COVID-19 Vaccine: What to Know If You're ...**  
 7 days ago — The rapid pace of COVID-19 vaccine news is hard enough for the general population to keep up with. But if you are immunocompromised, ...

**creakyjoints.org** › living-with-arthritis › coronavirus  
**Can You Get the Pfizer COVID-19 Vaccine If You're ...**

## Powerful Community Feedback

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

“

“Shout out to @CreakyJoints for keeping the #autoimmunedisease warriors so informed on everything known on the #covidvaccine for our community. Because immunocompromised ppl cannot be included in early trials, there are a lot of nervous patients out there.”  
— @CAFineberg

“I’ve been worried about getting the vaccine because I have an autoimmune condition and there is literally no data yet on this. A very useful article summarising what we currently know.”  
— @RuthRosselson

“For people who are IMMUNOCOMPROMISED (rheum, onc, etc.) there is [a] resource @CreakyJoints made. I’ve sent it to several rheum attendings. It is easy to read and meant for patient education.”  
— @londyloo



WEB:  
[www.ghlf.org](http://www.ghlf.org)

PHONE/EMAIL:  
845.348.0400  
[advocacy@ghlf.org](mailto:advocacy@ghlf.org)

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december  
**2020**

**COVID - 19**  
Patient Impact & Insights

