



**GLOBAL  
HEALTHY  
LIVING  
FOUNDATION**

january  
**2021**

**COVID - 19**  
Patient Impact & Insights

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

PHONE/EMAIL:  
845 348.0400  
[advocacy@ghlf.org](mailto:advocacy@ghlf.org)

ADDRESS:  
515 N. Midland Avenue  
Upper Nyack, NY 10960

# COVID-19 PATIENT IMPACT & INSIGHTS



Patient Support Program Updates  
Autoimmune COVID-19 Study Updates  
Education and Support Across GHLF.org + CreakyJoints  
Social Media Outreach

Patient Council Insights  
Spanish Language Update  
Advocacy Policy Updates



## GHLF COVID-19 PATIENT SUPPORT PROGRAM FOR CHRONIC ILLNESS PATIENTS

In mid-March 2020, 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 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



19%

LUNG DISEASE



13%

PSORIATIC ARTHRITIS + PSORIASIS



14%

FIBROMYALGIA



12%

HEART DISEASE



11%

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.

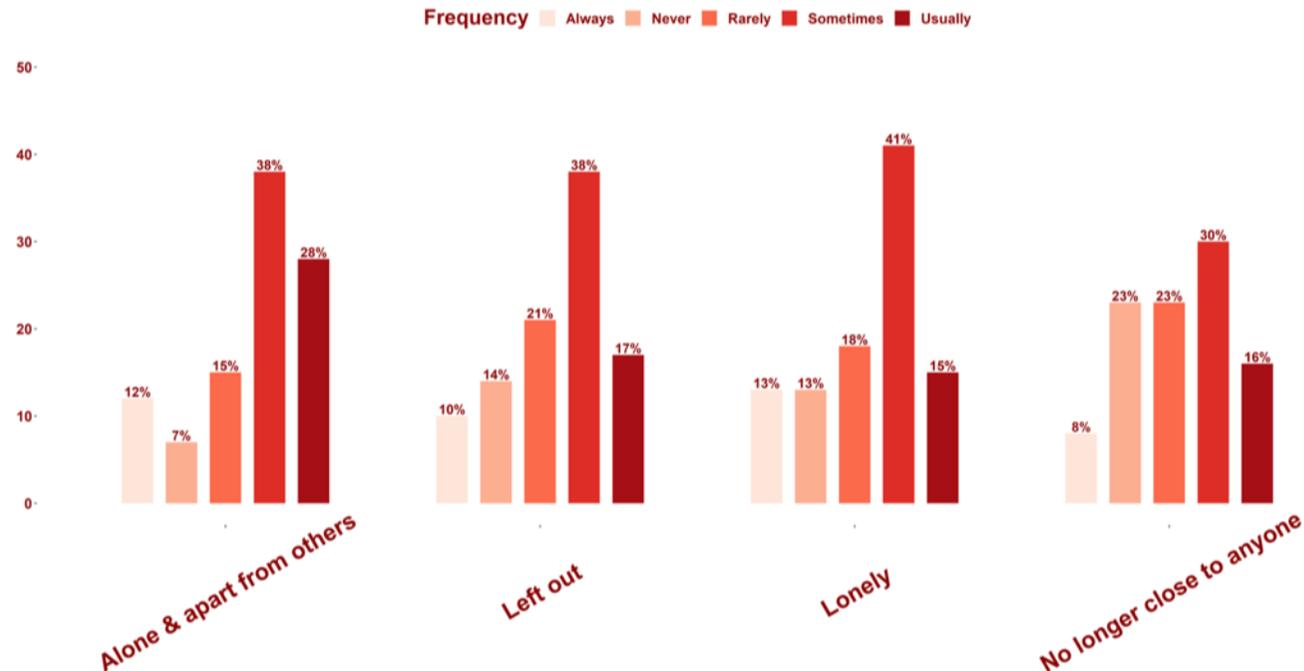
# LONELINESS AND COPING POLL

## A TOTAL OF 330

Patient Support Program subscribers responded to our December quick poll on how they have been coping during the pandemic.

We asked respondents to share how often they have felt the following feelings: Alone and apart from others, Left out, No longer or close to anyone, Lonely. Here are the results

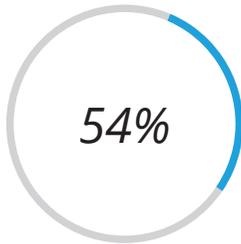
### In the Past Month, Please Describe How Often You Have Felt the Following Due to the Coronavirus (COVID-19) Pandemic



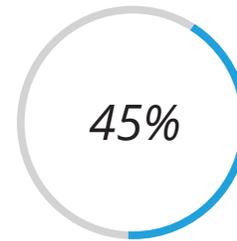
We also asked our members what they did to cope when they are feeling lonely.

## 88% OF RESPONDENTS

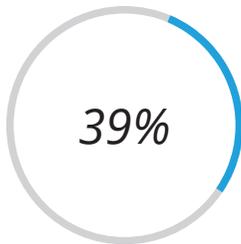
said they prefer to distract or occupy themselves. There were many other popular coping strategies as well.



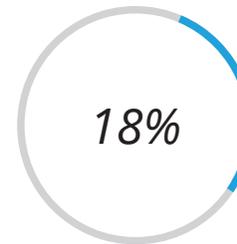
REACHING OUT TO MY SOCIAL SUPPORT NETWORK (CALL FAMILY AND FRIENDS, FACETIME, OR ZOOM WITH FRIENDS, PLAY ONLINE VIRTUAL GAMES)



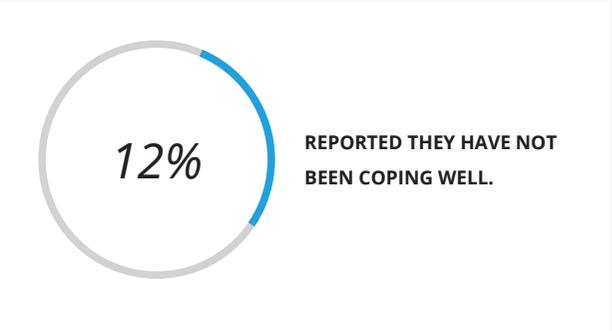
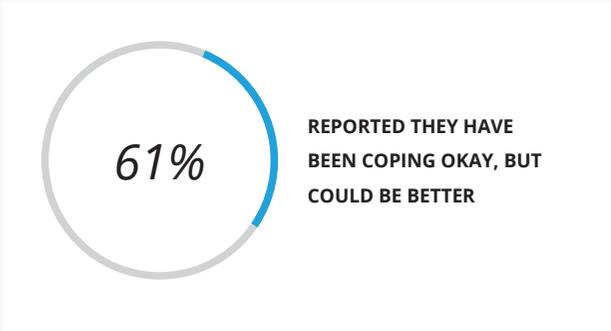
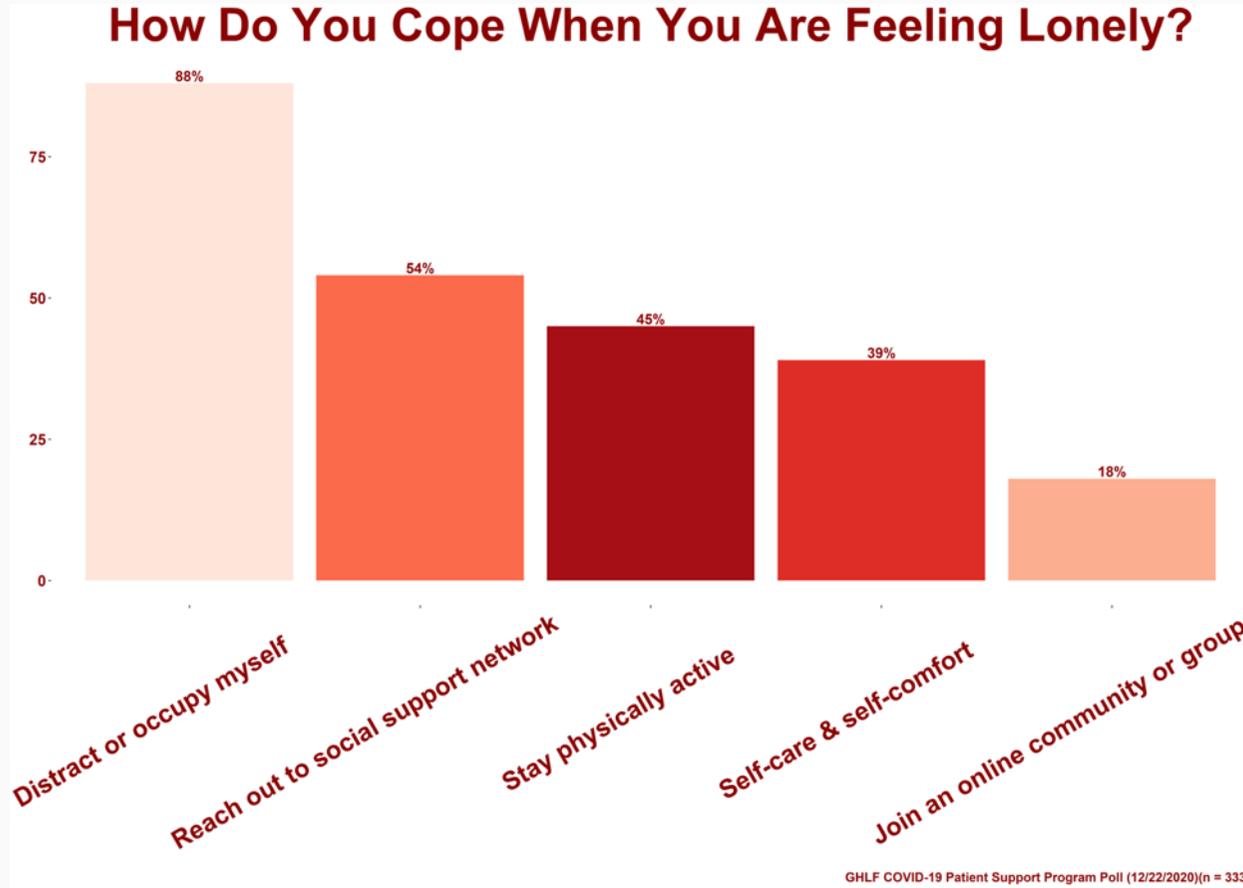
STAYING PHYSICALLY ACTIVE (EXERCISE, WALK, YOGA, HIKE, MAINTAIN MY GARDEN OR FOLIAGE)



SELF-CARE AND SELF-COMFORT (MEDITATE, TAKE A BATH, HAVE A SELF-SPA DAY)



JOINING AN ONLINE COMMUNITY OR GROUP (SUPPORT GROUPS/COMMUNITIES, ENROLL IN AN ONLINE COURSE)



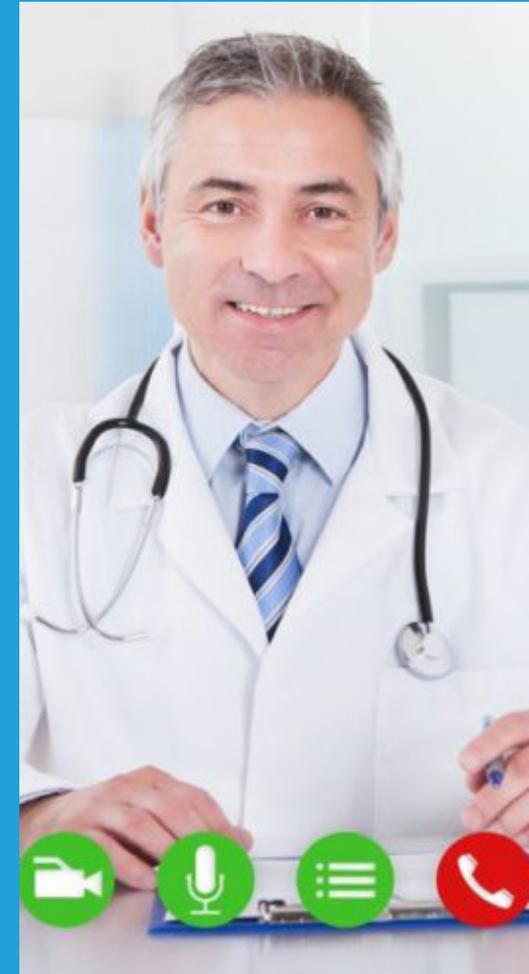
## LONELINESS AND COPING: WHAT RESPONDENTS ARE SAYING

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:

**“ I have come to truly appreciate the Zoom technology. The ability to ‘get together’ and ‘see’ my friends has been a wonderful boost during this difficult time.**

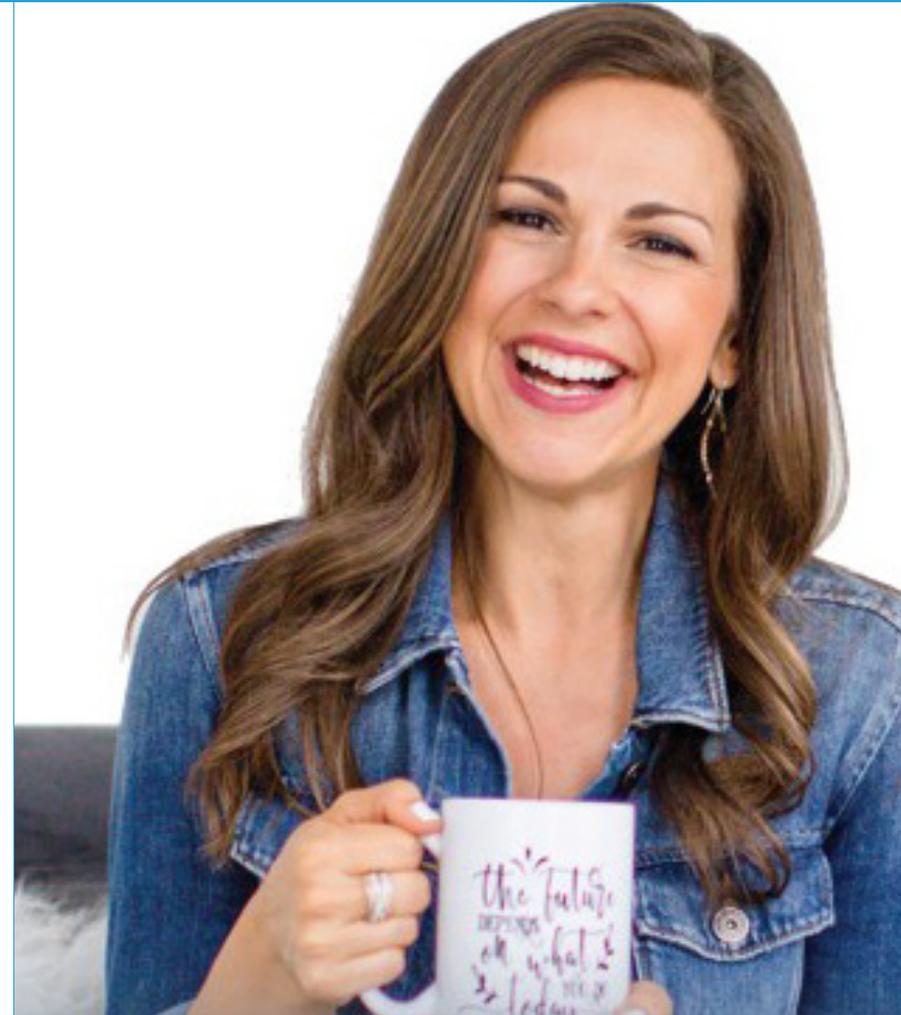
**I utilize my doctor appointments as occasions to dress up and socialize. Sometimes, when extreme cabin fever hits, I drive my SUV to a shopping center parking lot and sit in the sun, read a book, listen to great 60s rock n roll, and maybe, just a little, “dance” in my set. However, I really miss being with people. Ten months is a long time without social interaction and a bit of fun.**

**”**



“

**Play the ‘Glad Game’ I’ve played this all my life, and it just means that whatever is wrong or bad about things, you can always find something to be glad about. It might be something small, like the sun’s shining or an unexpected phone call, but it helps. It’s a state of mind to get into, and soon you’ll do it without even thinking about it. I’ve not been out of my flat since March 9th, and I’m doing fine. Hope this helps.**

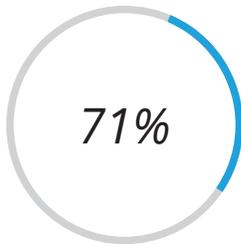


# COVID-19 VACCINE VIEWS POLL

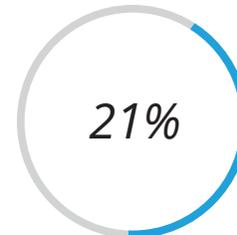
## A TOTAL OF 520

Patient Support Program subscribers responded to our January quick poll on whether their views about getting a COVID19- vaccine have changed since the emergency use authorizations.

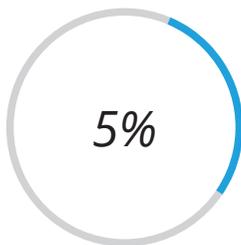
Many of our members have wanted more information on how the COVID19- vaccine relates to those with autoimmune conditions or who are immunocompromised. GHLF and CreakyJoints have consulted with experts in the field to provide educational resources about the vaccine to better empower patients to make a well-informed decision. We wanted to know how this content has affected their decision to get the vaccine and if their views changed after the FDA's authorization of multiple vaccines. They plan on getting the vaccine at the following rates:



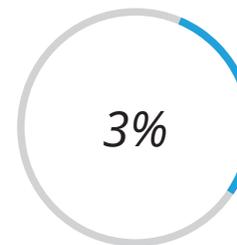
WILL GET VACCINE AS SOON AS THEY ARE ELIGIBLE



ARE INTERESTED BUT WOULD LIKE TO LEARN MORE ABOUT THE VACCINE BEFORE GETTING IT

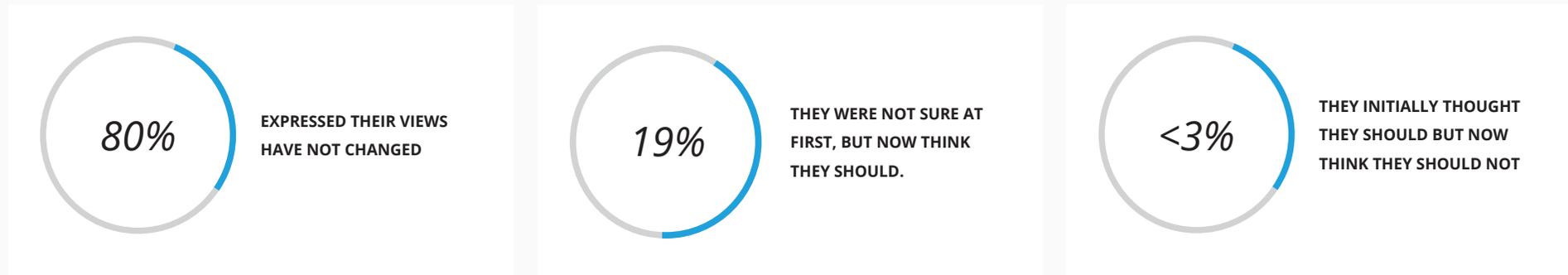


ALREADY RECEIVED AT LEAST THE FIRST DOSE OF THE COVID19- VACCINE



ARE NOT INTERESTED IN GETTING THE VACCINE WHEN ELIGIBLE

The emergency use authorization had little effect on our members' views.



As a follow-up to these questions, we asked if our content on how the vaccine relates to autoimmune patients has influenced their plans to get the vaccine. Here are the results:



## COVID-19 VACCINE VIEWS: WHAT OUR MEMBERS ARE SAYING

---

“

I have already received the first Moderna shot on 30/12. I have 4 different autoimmune diseases and experienced some side effects, they were tolerable. There should be a test for antibodies for immunocompromised people like myself after the second shot (I am currently on remicade would like to know if I mount antibodies).

Thank you for putting out the information for those of us with RA. It's difficult to find otherwise!

”



“

**I am not concerned about getting the vaccine. I am concerned about efficacy – that vaccine effectiveness could be compromised/minimized for people with autoimmune disorders.”**



**The best thing lupus patients can do is get valid reliable information to make an informed decision. I had no adverse effects so I'm interested in knowing whether there will be follow up for immunocompromised patients to determine the effectiveness of the vaccine in our population, as I've had to have the Hep B series 4 times because of my insufficient immunity response.”**

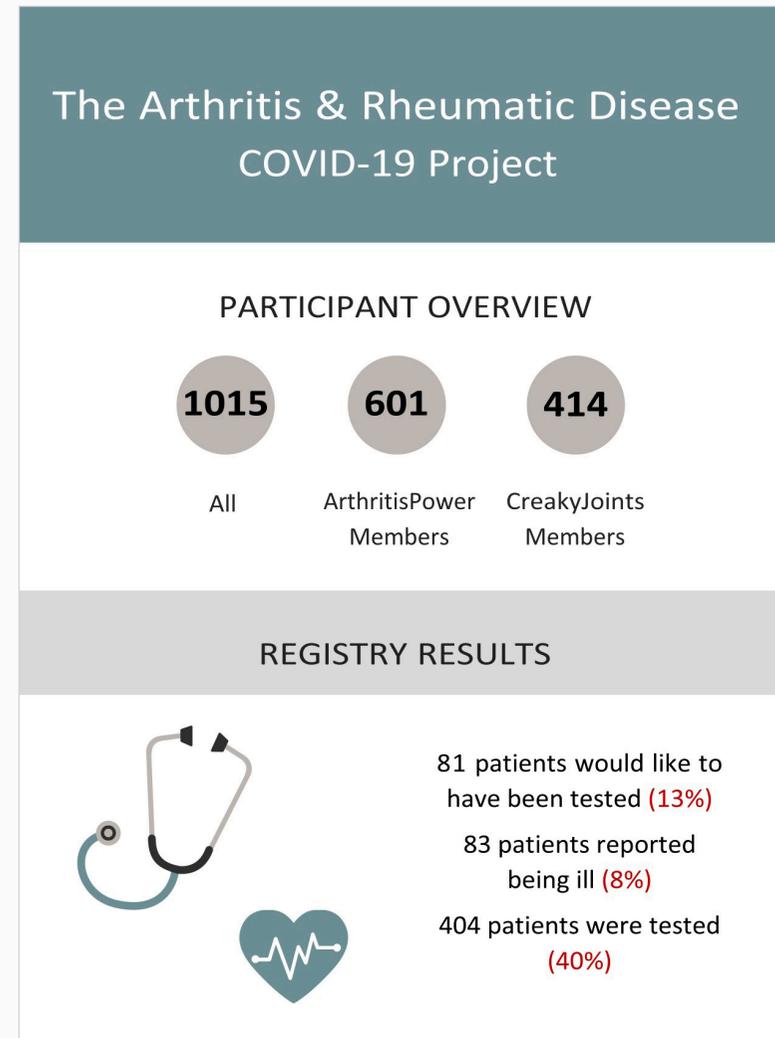
”

# RESEARCH UPDATE: OUR AUTOIMMUNE COVID-19 STUDY



Our mission with patient centered research is to share 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. Participants were asked to take follow-up surveys every 2 weeks for the first 2 months and every 4 weeks up to the 6-month mark, and will take additional surveys at 9 months and 12 months. The following infographic is an overview of the participants' experiences with coronavirus (COVID-19) testing at the 6-month mark. While many of the patients were tested for the virus, many others were not. To better grasp the barriers to testing for patients, we asked patients to provide why they were not tested. Here are the results:



# SOCIAL MEDIA



**CreakyJoints**  
January 4 at 3:32 PM · 🌐

Although people who are on immunosuppressant medications were included in clinical trials for the vaccines, we're going to have more insights soon about how patients with inflammatory and autoimmune conditions fare after being vaccinated against COVID-19.

**Autoimmune and Immunocompromised Patients**

CREAKYJOINTS.ORG  
**Researchers Are Starting to Study the COVID-19 Vaccine Autoimmune and Immunocompromised Patients**

👍👎🗨️ 98      83 Comments 64 Shares

Share

**CreakyJoints**  
January 2 · 🌐

"The bottom line: I trust science," she says. "Being on a biologic medication that's helped to control my symptoms for almost 20 years taught me this. I did my research."

CREAKYJOINTS.ORG  
**I Have Rheumatoid Arthritis, Take a Biologic, and Just Got My Moderna COVID-19 Vaccine — Here's How I'm Doing**

👍👎🗨️ 150      37 Comments 2 Shares

Share

**CreakyJoints**  
January 11 at 11:40 AM · 🌐

Kristen Schlichting, 38, has had a number of close calls with COVID-19 since the pandemic began. But now that she is vaccinated, she hopes she can keep doing her job as an eye surgery nurse with a lot more reassurance.

CREAKYJOINTS.ORG  
**I Have Ankylosing Spondylitis, Take Remicade, and Got the Pfizer COVID-19 Vaccine — Here's How I'm Doing**

👍👎🗨️ 99      19 Comments 10 Shares

Share

## COVID19- Vaccines: A Conversation with the Chronic Disease Community

Special Guests: Healthy Women, Medical Student/Patient Advocate Sarah Islam, and GHLF Director of Medical Affairs and Hispanic Outreach Daniel Hernandez, MD.

Join our community

# #CreakyChats

**COVID-19 Vaccines: A Conversation with the Chronic Disease Community**

Monday, January 18, 2021 7PM ET

Hosted by

@CreakyJoints #CreakyChats      @HealthyWomen      @sarah\_islam25 Patient Advocate      @dihernandezmd Medical Director Hispanic Outreach

### Top 10 Influential

-  [@CreakyJoints](#) 100
-  [@sarah\\_islam25](#) 81
-  [@dihernandezmd](#) 78
-  [@HealthyWomen](#) 75
-  [@JediMaster941](#) 66
-  [@BeingCharisBlog](#) 66
-  [@mollyschreiber](#) 64
-  [@RaBionic](#) 64
-  [@Tinu](#) 59
-  [@DawnMGibson](#) 58

### The Numbers

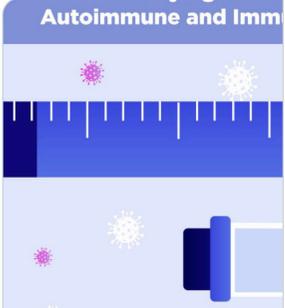
4.637M Impressions

627 Tweets



**CreakyJoints.org**  
@CreakyJoints

!!! Although people who are on immunosuppressant medications were not included in clinical trials for the vaccines, we're going to have more insights soon:  
[creakyjoints.org/living-with-autoimmune](#) [#autoimmune](#) [#COVID19v](#) [#Covid19](#)



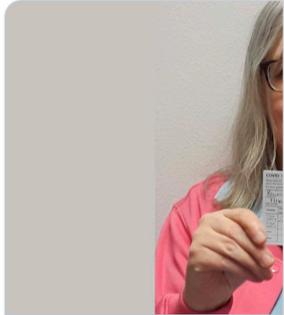
Autoimmune and Imm

Researchers Are Starting to Study the  
Learn more about research studies th  
safety of COVID-19 vaccines in peopl  
[creakyjoints.org](#)

2:46 PM · Dec 31, 2020 · Twitter Web /

**CreakyJoints.org**  
@CreakyJoints

"The bottom line: I trust science," she says. "Being on a biologic medication that's helped to control my symptoms for almost 20 years has taught me this. I did my research." [creakyjoints.org](#)  
[#Spoonie](#) [#Spoonies](#) [#CO](#)  
[#COVID19Vaccination](#) [#C](#)



I Have Rheumatoid Arthritis, Take a Bi  
Learn more about what it was like for  
to get the Moderna COVID-19 vaccin  
[creakyjoints.org](#)

2:27 PM · Jan 2, 2021 · Twitter Web Ap

**CreakyJoints.org**  
@CreakyJoints

Kristen Schlichting, 38, has had a number of close calls with [#COVID19](#) since the pandemic began. But now that she is vaccinated, she hopes she can keep doing her job as an eye surgery nurse with a lot more reassurance.



I Have Ankylosing Spondylitis, Take Remicade, and Got the Pfizer COVID-19 V...  
Learn more about what it was like for an ankylosing spondylitis patient on Remicade to get the Pfizer COVID-19 vaccine.  
[creakyjoints.org](#)

2:41 PM · Jan 11, 2021 · Twitter Web App

# COVID-19 VACCINE EDUCATION

---



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

We continue to reach tens of thousands of rheumatic and inflammatory disease patients each day with information about COVID-19 vaccines that is targeted to them. New resources published over the past four weeks include:

Over the last month, top content has focused on COVID-19 vaccines. 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.

---

[Researchers Are Starting to Study the COVID19- Vaccine in Autoimmune and Immunocompromised Patients](#)

[Rituximab and the COVID19- Vaccine: Should You Get Vaccinated If You Take Rituxan?](#)

[Should You Get the COVID19- Vaccine If You Have a History of Allergic Reactions to Infused or Injectable Medications?](#)

[What to Do After Getting a COVID19- Vaccine If You're Immunocompromised or Have an Autoimmune Condition](#)

## COVID-19 VACCINES: THE PATIENT PERSPECTIVE

As the vaccines started to roll out last month, it became clear that rheumatic and inflammatory disease patients valued hearing about the experiences of other patients (at that point, namely eligible health care workers) who had received the vaccine.

What was their decision process to get the vaccine like? What did it feel like afterward? By sharing stories of patients with underlying health issues who take immunosuppressant medications, we hope to increase comfort and decrease vaccine hesitancy among this at-risk patient population.

Here is a sampling of the patient stories we've shared so far.



[I Have Ankylosing Spondylitis, Take Remicade, and Got the Pfizer COVID19- Vaccine — Here's How I'm Doing](#)



[I Have Rheumatoid Arthritis, Take a Biologic, and Just Got the Moderna COVID19- Vaccine — Here's How I'm Doing](#)



[I'm a Student with Non-Radiographic Axial Spondyloarthritis and Just Got the Pfizer COVID19- Vaccine — Here's How I'm Doing](#)



[I Have Lupus, Take Immunosuppressants, and Just Got the Pfizer COVID19- Vaccine — Here's How I'm Doing](#)

# CREAKYKITCHEN

---



## CreakyKitchen Episode 3: A Healthy Start to the New Year

---

In the spirit of starting off 2021 with a healthy mindset even while COVID-19 rages on, we hosted a virtual CreakyKitchen event to celebrate the new year together as a chronic illness community and learn how to make nutritious quarantine snacks and meals.

CreakyKitchen Guest Chef, patient Chantelle Marcial, gave a virtual class on how to spruce up a salad recipe with common kitchen staples. We were also joined by Brooke Levine, RD, CDN, and head of weight management private practice at [Brooke's Mission](#), who shared her expert advice for incorporating foods with anti-inflammatory properties into our routine.

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

# SPANISH-LANGUAGE UPDATE

## SPANISH-LANGUAGE TELEMEDICINE SUPPORT



We are happy to announce that our [telemedicine support tool](#) is available to our Hispanic community. Through a culturally appropriate translation, this tool offers telemedicine information in patient-friendly language. eRheum defines telehealth and how rheumatologists utilize it, provides patients with access to different video conferencing portals to try with their physician, and explains how to make the most of your limited face-to-face time with your physician during the appointment itself.

We continue to provide up-to date information during the COVID-19 pandemic, focused on addressing doctor-patient relationships, vaccine information, and wellness through our CreakyJoints Español properties:



## PATIENT UPDATE

---

### “Questions About Getting a COVID-19 Vaccine?”

With COVID-19 vaccines from Pfizer and Moderna rolling out in countries around the world many questions have arisen about whether people who take immunosuppressant medications can receive a vaccine. To assess the opinions, experiences, questions, and concerns of our patients, an inquiry was sent to the COVID-19 Leadership Council and CreakyJoints Patient Council, our community leaders, via email. This information was also used to help inform and develop questions for a #CreakyChats Twitter Event, “COVID-19 Vaccines: A Discussion with the Chronic Disease Community,” on January 18, 2021 at 7:00pm EST.

Here are the responses:

---

“

“I wonder if the manufacturer of Rituxan has any advice? Rituxan seems to be a special case.”

-Rick P.

---

“I am waiting to hear back from rheumatologist on the go ahead to get the vaccine, but my only concern is having to go to a doctor office or public place to receive it and thus have possible exposure in this. Thus, my question is how effective is it from the beginning?”

-Beth M.

”

“

“(1) Community questions have come up regarding anaphylactic reaction to Remicade (no other food or drug allergies mentioned), and if that puts you on the no list for an mRNA COVID19-vaccine, (2) Other questions are regarding food allergies, one cannot find concise guidance for those with food allergies to items such as shellfish or dairy. The CDC guidance seems vague.”  
-Jamie H.

“Here are the questions that are getting asked the most in my group: (1) Is it safe to get the COVID-19 vaccine if we are on immunosuppressants?, (2) Do Biologics lessen the effectiveness of the vaccine?, and (3) Can I still catch and transmit the virus if I received the vaccine?”  
-Jed F.

“I have a few questions: (1) How effective is it?, (2) Will citizens need to take a booster shot?, (3) Will this vaccination be implemented like the flu shots?, and (4) Is it safe for patients who have received transplants to take (question for my doctor)?”  
-Terrance H.

”

---

“My RA doctor told me I had to stop my Kevzara for a month to take the COVID-19 vaccine. Has anybody else been told they need to stop their injections? I can't find the answer to this question most people are told to take the vaccine, and nothing is said about our RA medications.”

- Denise M.

“Side effects.”

-Aberdeen A.

“Medication interactions with vaccination.”

- Chantelle M.

“

“(1) I have had an autoimmune disease for over 30 years. My immune system is shot, and I have had a sinus infection for 3 years that persists. Would it be wise of me to get the vaccine?  
(2) Can they make me take the vaccine if I don't want to?, and  
(3) Why can't I just wear my mask and be left alone?”

- Diane T.

“I had my telehealth appointment on Monday with my rheumatologist. We talked about it in length. She is also a researcher and a member of the ACR and follows their guidelines. Which is to get it for RA patients.”

- Deb C.

## ADVOCACY AND POLICY UPDATE



### Congressional Briefing on Non-Opioid Pain Management for Chronically Ill Patients

We fostered an important discussion around pain management for those living with chronic conditions – an issue of critical importance during COVID-19 as patients suffering in pain are seeking alternatives to opioids.

Access to innovative pain treatments continues to be a challenge for patients and providers, especially as the COVID-19 pandemic has upended many aspects of our nation's health care system. On January 26, we hosted a virtual Congressional briefing where issue area experts and directly impacted patients discussed how we can seek out innovative (non-opioid) solutions for pain management. The event featured Representative Brad Wenstrup (R-OH-2nd), and the audience included key health staff from multiple Congressional offices.

Additionally, GHLF signed onto [a coalition letter to President-elect Biden on Human Fetal Tissue Research](#) (Every Life Foundation Sign-On).



## 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)

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

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

ADDRESS:  
515 N. Midland Avenue  
Upper Nyack, NY 10960

january  
**2021**

**COVID - 19**  
Patient Impact & Insights

