



**GLOBAL
HEALTHY
LIVING
FOUNDATION**

february
2021

COVID - 19
Patient Impact & Insights

WEB:
www.ghlf.org

PHONE/EMAIL:
845 348.0400
advocacy@ghlf.org

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

COVID-19 PATIENT IMPACT & INSIGHTS



03 | Patient Support Program Updates

04 | Community Polls

10 | Autoimmune COVID-19 Study Updates

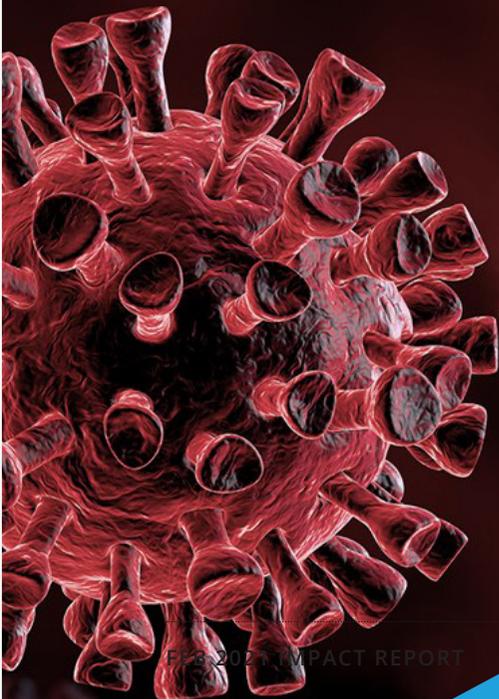
12 | Social Media Outreach

14 | Education and Support Across GHLF.org + CreakyJoints

17 | Spanish Language Update

21 | Advocacy Policy Updates

22 | Patient Council Members



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*)

Source: Mailchimp Email Marketing Benchmarks

TOP CONDITIONS



30%

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.

PATIENT/PROVIDER CONVERSATIONS ABOUT THE COVID-19 VACCINE

A TOTAL OF 655

Patient Support Program subscribers responded to our January quick poll patient and provider conversations about the COVID19- vaccine.

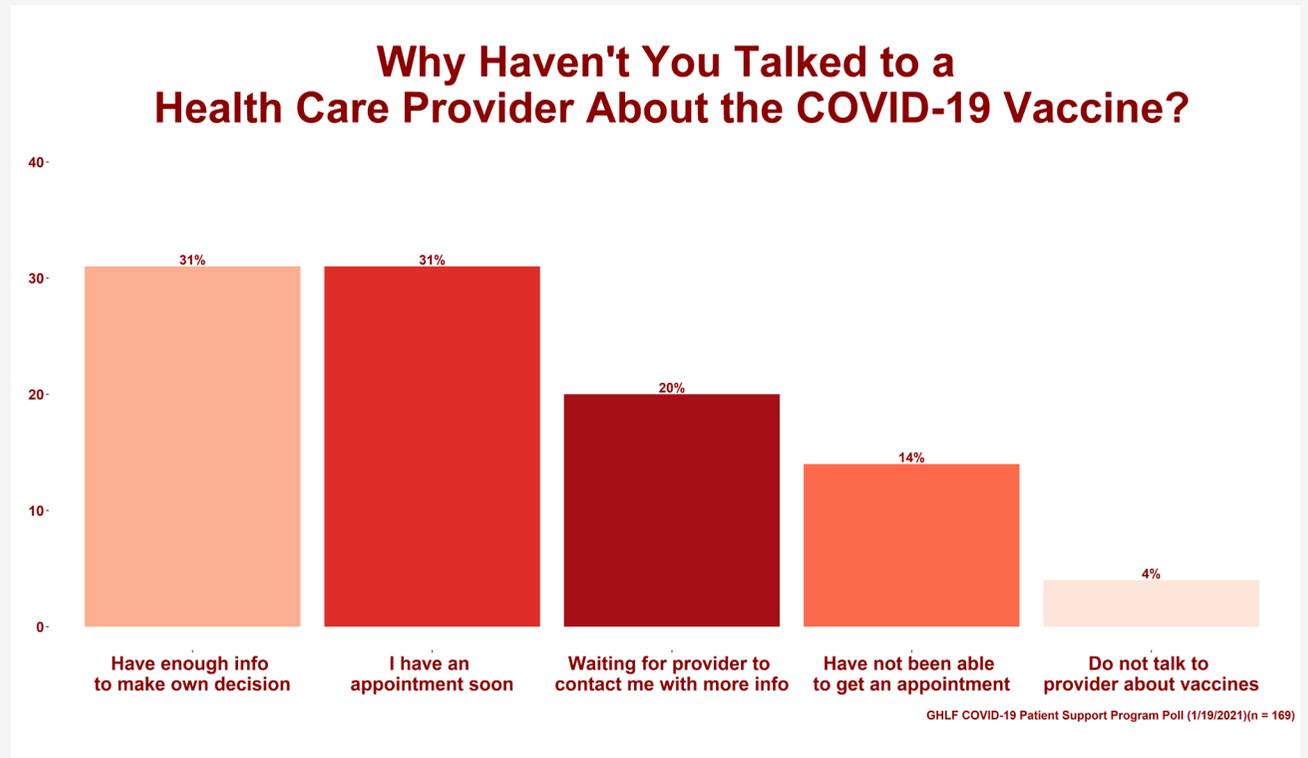
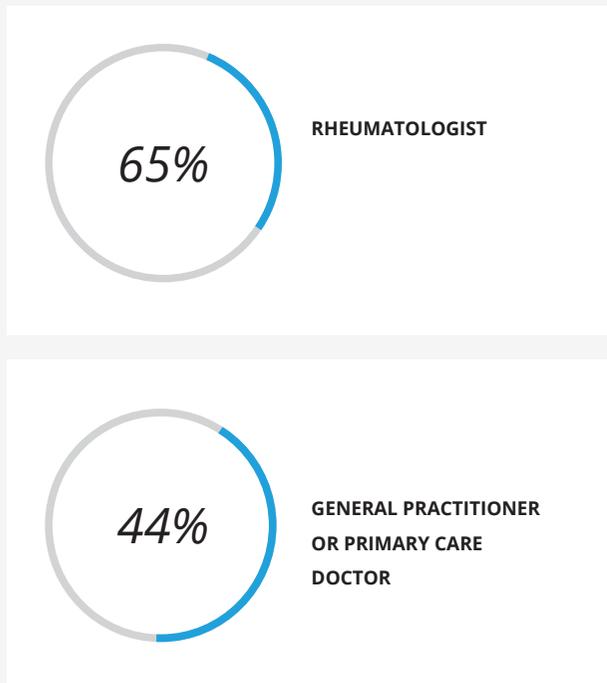
74% OF RESPONDENTS

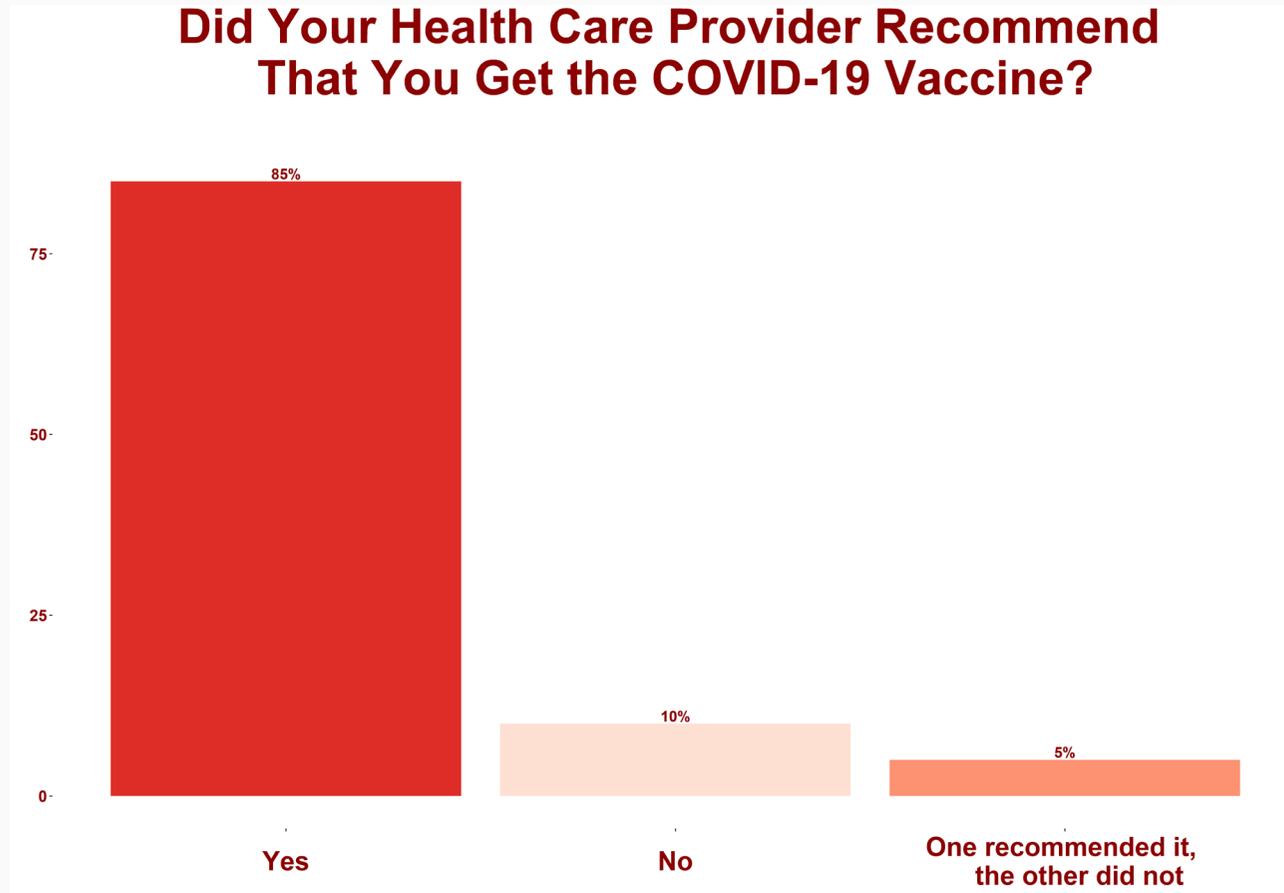
had already spoken to their provider about getting the vaccine

26% OF RESPONDENTS

had not spoken to their provider for various reasons

The most common type of provider was:





80%

OF PATIENTS PLAN TO TAKE THEIR PROVIDER'S RECOMMENDATION TO GET THE VACCINE.

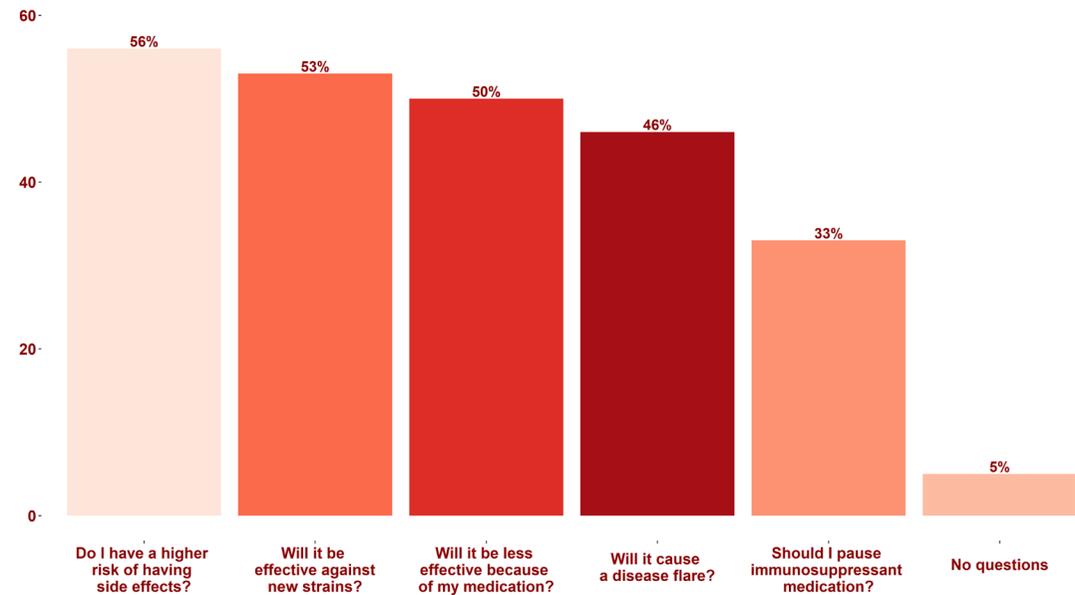
PATIENTS' QUESTIONS AND CONCERNS ABOUT THE COVID-19 VACCINE

A TOTAL OF 679

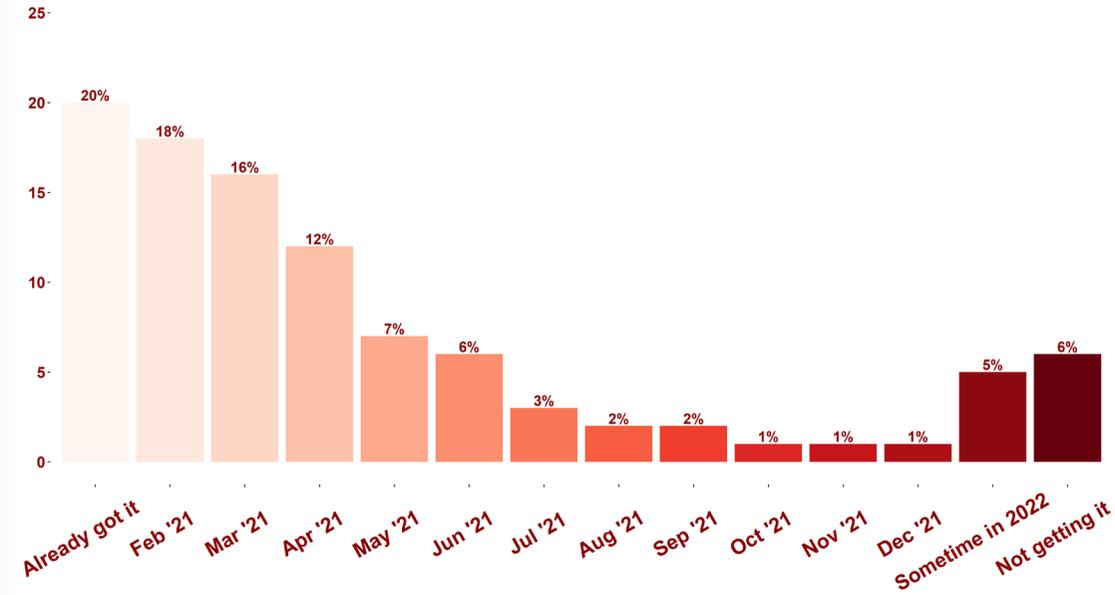
Patient Support Program subscribers responded to our February quick poll on their biggest concerns about the COVID19- vaccine.

We asked participants which outstanding questions about the COVID - 19 vaccine are most important to them, given their current medical condition and treatment, and when they believed they would get the COVID - 19 vaccine.

Which Questions About the COVID-19 Vaccine Are Most Important to You?



When Do You Believe You Will Get the COVID-19 Vaccine?



PATIENTS' QUESTIONS AND CONCERNS ABOUT THE COVID-19 VACCINE: WHAT RESPONDENTS ARE SAYING

Respondents were also given the opportunity to provide their own questions and concerns. The questions ranged from disease-specific to questions about the various types of COVID19-vaccines. Here are some of those questions:

“ How long will immunity to COVID last once you have had the vaccine?

What type of mask is recommended now? I have heard -3ply medical masks are now the expected protection that people wear.

”

“ Will I be able to spread the virus?



“

To what extent do we ‘normalize’ a bit after vaccine, i.e., wear masks but get coffee with a friend less than 6 feet apart?

What trials are going on involving those on biologics and vaccine effectiveness, side effects, and long-term consequences?

”



“

How do I find out when I am eligible to get the vaccine and where can I get it?

RESEARCH UPDATE: RACISM AND HEALTHCARE WEBINAR



Racism has profound effects on the health of black communities, people of color and indigenous communities.

The COVID-19 pandemic has further exposed the realities of racism and the impact of systemic racism on black people and people of color. GHLF conducted a free informational webinar to discuss how racism affects the healthcare and health outcomes of communities of color. This one-hour informational webinar was conducted on Wednesday, January 27 at 5 PM EST and featured an expert panel that included :

IRENE BLANCO, MD, MS

Professor in the Department of Medicine and the Associate Dean for Diversity Enhancement at the Albert Einstein College of Medicine

JILLIAN ROSE, PHD, MPH, LCSW

Assistant Vice President for Community Engagement, Diversity and Research at Hospital for Special Surgery

ASHIRA BLAZER, MD, MSCI

Assistant Professor of Medicine, Division of Rheumatology, at NYU Langone Health.

To demonstrate how racism has far reaching impacts on the healthcare and health outcomes of people of color individually, and on affected communities as a whole, panelists offered definitions and examples and invited discussion and questions on the topic.

RESEARCH UPDATE: PUBLISHED STUDIES ON PATIENT-REPORTED OUTCOMES (PROs)



GHLF's digital research tool, the ArthritisPower® Research Registry, uses patient-reported outcomes to study the effects of rheumatic and musculoskeletal diseases from the patient perspective. This past month, GHLF published a longitudinal study titled:

[Which patient-reported outcomes do rheumatology patients find important to track digitally? A real-world longitudinal study in ArthritisPower](#)

The study examined the patient-reported outcomes (PROs) over a three years that ArthritisPower members considered most important to track. The study examined whether there were differences in the PROs selected across the four timepoints (baseline, month 1, month 2, and month 3), whether the number of selected measures changed as the study went on, and whether there were differences in selected PROs among the conditions studied: ankylosing spondylitis, fibromyalgia syndrome, osteoarthritis, osteoporosis, psoriatic arthritis, rheumatoid arthritis, and systemic lupus erythematosus. The study linked above was published on February 10th in Arthritis Research and Therapy.

In addition, GHLF contributed to a recently published research study titled:

[**OPEX: Development of a novel overall patient experience measure to facilitate interpretation of comparison effectiveness studies**](#)

The purpose of the study was to develop a patient-reported measure that captures the treatment experience, including benefits and harms, for rheumatoid arthritis patients. The study used a trajectory mapping approach to develop the measure, which would be used to improve shared decision-making for RA treatment. The study linked above was published on January 29th in PLoS ONE

SOCIAL MEDIA

ACR Vaccine Guidance Article

CreakyJoints.org @CreakyJoints

!!! UPDATE!

If you have a form of [#autoimmune](#) or inflammatory [#arthritis](#) or take immunosuppressant medication, chances are you've had questions about getting a COVID-19 vaccine. Here are some answers from a new resource from [@ACRrheum](#):



COVID-19 Vaccines for Rheumatic Diseases: Guidance from the American Co. Learn more about guidance for getting a COVID-19 vaccine with autoimmune or inflammatory arthritis, including changes to immunosuppressant ... [creakyjoints.org](#)

3:05 PM · Feb 11, 2021 · Twitter Web App



Vaccine Fairness Poll

CreakyJoints.org @CreakyJoints · Feb 9

Do you feel that the process to get the [#COVID19](#) [#vaccine](#) is fair?

Yes it is fair	30.2%
No it is not fair	69.8%

225 votes · Final results

6 replies · 12 retweets · 9 likes

Racism in HealthCare Webinar

CreakyJoints.org @CreakyJoints · Jan 26

!!! Webinar on [#Racism](#) in [#Healthcare](#).

Wednesday, January 27 at 5 PM EST featuring [@jrose1282](#), [@ashira_md](#), [@IreneBlancoMD](#).

Sign up here: register.gotowebinar.com/register/76038...



3 replies · 67 retweets · 63 likes

TikTok

globalhealthylivingfdn Global Healthy Living Fdn · 2-5

Amazing hack for putting on compression socks when your hands hurt, thanks EquipMeOT on IG for the tip, and [@arthritislife](#) for the demo! [#lifehack](#)

🎵 How You Like That - BLACKPINK



531 likes · 28 comments · 71 shares

Compression Sock Hack

Juggling A Lot



CreakyJoints
January 24 · 🌐

Although more research is needed, experts believe that severely immunocompromised patients may give the SARS-CoV-2 virus a greater chance to mutate.

CREAKYJOINTS.ORG
New Coronavirus Variants and Immunocompromised Patients: What's the Link?

👍👎👀 39 6 Comments 15 Shares

[Although more research is needed, experts believe that severely immunocompromised patients may give the SARS-CoV-2 virus a greater chance to mutate.](#)

ACR Guidance Article

CreakyJoints
February 12 at 11:59 AM · 🌐

The American College of Rheumatology guidance says, "beyond known allergies to vaccine components, there are no known additional contraindications to COVID-19 vaccination." This means that simply having an autoimmune or inflammatory rheumatic disease — or taking immunomodulating medication to treat it — is not a reason to not get a COVID-19 vaccine.

CREAKYJOINTS.ORG
Getting a COVID-19 Vaccine with Autoimmune or Inflammatory Rheumatic Disease: New Guidance from th... of Rheumatology

👍👎👀 58 21 Comments 27 Shares



“

“I had been told by my Rheumatologist in Dec just to wait as there was not significant data or guidelines as we were not included in the trials. When i saw this post i messaged him thru my health portal and got the go ahead and specific RX instructions, understanding that i may not get full benefit as a healthy person may, but some protection is better than none. i am on my pharmacy waitlist. ”

-Bobbi

COVID-19 VACCINE EDUCATION



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 COVID - 19 pandemic.

We are reaching many 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 continued to focus 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.

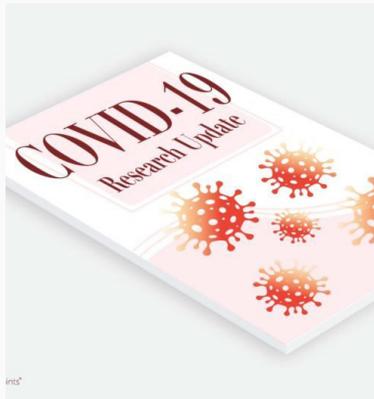
[Getting a COVID-19 Vaccine with Autoimmune or Inflammatory Rheumatic Disease: New Guidance from the American College of Rheumatology](#)

[Methotrexate and the COVID-19 Vaccine: Should You Stop Taking Methotrexate Temporarily After Getting the Shot?](#)

[What to Know About Getting the Second COVID-19 Vaccine Dose If You're Immunocompromised or Have an Autoimmune Condition](#)

INCREASING UNDERSTANDING ABOUT COVID-19 AND AUTOIMMUNE PATIENTS

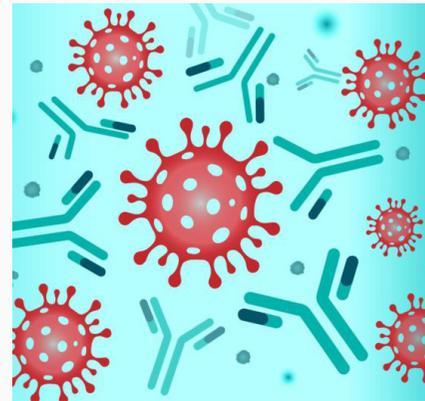
There is so much medical research on COVID - 19 issues that our patient community cares deeply about. We continue to share the most relevant studies with our Patient Support Program:



[Can IL6- Inhibitor Rheumatoid Arthritis Medications Treat Severe COVID - 19?](#)



[The Risk of Severe COVID - 19 Outcomes Appears to Be Improving for Rheumatic Disease Patients](#)



[More Research Suggests That COVID - 19 Can Cause Autoantibodies Linked with Autoimmune Diseases](#)



[Autoimmune Disease Doesn't Lead to More Severe COVID - 19 Outcomes, But Corticosteroids May, New Research Shows](#)



['Long-Hauler' Symptoms Are Common After COVID - 19 — and May Resemble Fatigue Syndrome](#)

CREAKYKITCHEN



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

“

CreakyKitchen is such an important tool to have right now. It is giving us tools and bringing us together.

– Shantana



CreakyKitchen Episode 4: A Jam-Packed Night with CreakyKitchen

We continue to provide much needed entertainment during the COVID-19 pandemic. CreakyKitchen events provide a way for our community to join together in a fun and stress-free environment to share strength and experience when it comes to cooking and nutrition.

In Episode 4 Cristina Montoya, RD, shared cooking tips and an easy-to-make Berry Chia Jam. We also heard from patients in our community who shared their own tips for cooking while coping with a disease-related flare, their favorite recipes that make them feel good, and how their health condition impacts how they prepare foods.

Here's what our members are saying about CreakyKitchen:

I love these events and I hope I can join in a lot of them. It is really nice to see new faces on these zoom calls, too.

– Shelley

”

SPANISH-LANGUAGE UPDATE

SPANISH-LANGUAGE TELEMEDICINE SUPPORT



CreakyJoints Español now has its own Facebook page! Follow us [@CreakyJointsESP](https://www.facebook.com/CreakyJointsESP) for the latest news, tips, and resources for the Hispanic arthritis community.

- CreakyJoints Español continuously aims to tackle misinformation by taking fact-based information to where the Hispanic community is.

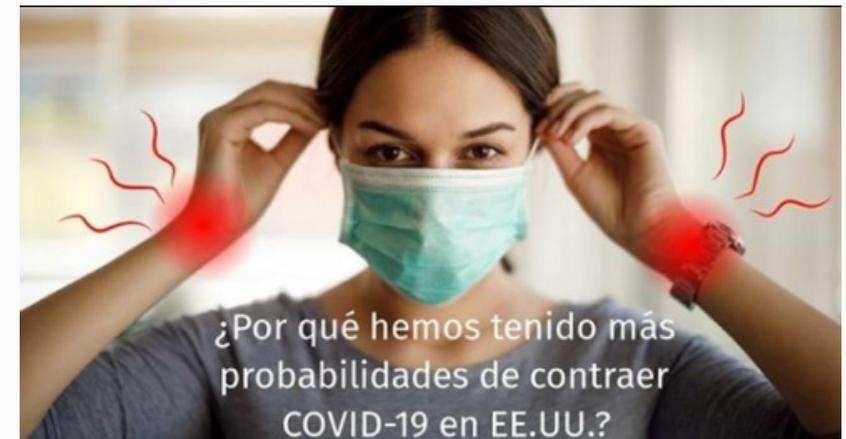
SPANISH-LANGUAGE UPDATE (CONT'D)

The popularity of social networks as primary news source channels - in some cases - tends to be significantly higher among Hispanics compared to other populations.

According to Pew Hispanic Research, 71 percent of Hispanics obtain health information through their social networks, and 79 percent of them act on this information.

But the general health information available for the Hispanic community online heavily leans towards dangerous misinformation, which has led to low levels of diagnosis and a growing knowledge gap.

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



PATIENT UPDATE

“What Makes an Exceptional Doctor?”

With the launch of a new initiative to explore what goes beyond standard treatment protocol to represent exceptional patient-centered medical care, we asked our patient council members and patient governors what measurements would constitute “exceptional care”.

Below are their responses:

“

“Understands tracking apps and open to discussing them (for example, ArthritisPower).”
– Rick P.

“

“Physicians that are engaging. Must include good listener. Listens to your experience and is not grouping you in certain patient categories or groups, individualizes care.” – Brenda K.

“Initiates collaboration with other healthcare professionals. Not have patients doing free labor, where doctors, nurses, etc. are collaborative.”
– Charis H.

”

“Never go to a doctor that does not laugh, not fun not doing it (personality is important).” – Rick P.

“

“Follows up on other details of your life.” -Brenda

“Flexibility for telehealth/ in-person visits. Punctual. Engaging and Listening. Appointments more than 5 minutes long.” – Chantelle M.

“Someone who is familiar with the latest research within the last 5 years.” – Ashley N.

“Acknowledges your emotional health. Open to talking about complementary care.” – Courtney W.

“Someone who is familiar with latest research and willing to give references to the literature.” – Joan W.

“Available. Easy to contact and responds in a timely manner. Professional.” Vanessa K.

“Follow through on referrals. For example, if there are no requirements and when insurance doesn't require it, they let you know when your specialty pharmacy returns prescriptions to you because they aren't your pharmacy anymore.” – Regan R.

“Detailed. My doctor had a list of four patients who had insurance changes and he made sure to check to see if I was on that list.” – Chantelle M.

”

ADVOCACY AND POLICY UPDATE



GHLF joined another sign-on letter urging Congress to include the Community Immunity During COVID-19 Act in the next relief package.

The letter, led by the American Academy of Pediatrics, asks Congress to take immediate action to provide much needed funding to state and local public health departments to promote Advisory Committee on Immunization Practices-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 vaccine alternatives to opioids.

[Read the letter in support of Community Immunity During COVID-19 \(H.R. 736/S. 167\)](#)

We've also been focused on stopping the continued growth of copay accumulator adjuster programs and have joined related letters to advocate on behalf of patients. We are concerned that the expansion of such a program will negatively impact patients' ability to afford their medications, especially amidst the COVID-19 pandemic and the resulting economic recession.

[Read the letter in support of New Mexico House Bill 129A which bans copay accumulator adjusters.](#)



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

PHONE/EMAIL:
845 348.0400
advocacy@ghlf.org

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

CONTACT:
Steven Newmark, Chief Legal Officer, Policy Director
SNEWMARK@GHLF.ORG

february
2021

COVID - 19
Patient Impact & Insights

