

Global Healthy Living Foundation COVID-19 Patient Impact & Insights



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October 21 – November 24

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 to learn more



18,338

Number of members

30,129

Number of subscribers

27.1%

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

7.1%

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: Holiday Plans

A total of 492 Patient Support Program subscribers responded to our October quick poll on their plans for the holiday season.

44% of poll 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):

17%

Celebrating virtually with family and/or friends

15%

Cancelling plans and celebrating alone

12%

Celebrating with a smaller group than usual

7%

Celebrating with the same people with appropriate coronavirus (COVID-19) precautions

5%

Not changing any plans

4%

Changing the day of celebration to ensure appropriate coronavirus (COVID-19) precautions

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 medication access:

“

*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.***

Patient Support Program Community Poll: The Pandemic's Third Wave

A total of 474 Patient Support Program subscribers responded to our November quick poll on the Third Wave of the Coronavirus (COVID-19) Pandemic.

Respondents from the United States were asked to report on their behavior in response to the third wave of the coronavirus (COVID-19) sweeping the nation.

60% of respondents expressed they never stopped taking all appropriate precautions throughout the pandemic. Below are other most common precautions reported (not mutually exclusive):

32%

Staying home more

23%

Practicing more social distancing

16%

No longer attending social gatherings

16%

Stopped going to local businesses

10%

Opting for curbside pickup for groceries and other essential items

Respondents from outside of the US (85 respondents), were asked to report on their comfort with how their country is handling the pandemic:

36%

are cautiously comfortable with their country's handling of the pandemic

24%

are moderately comfortable with their country's handling of the pandemic

15%

are not at all comfortable with their country's handling of the pandemic

14%

are comfortable with their country's handling of the pandemic

11%

are confident with their country's handling of the pandemic

Lastly, we asked the pool of respondents to report on their level of concern about the state of the pandemic: 58% reported they were extremely concerned.

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 Covid-19. 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 with it. 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 (which I really try not to think about).*

COVID-somnia: What Our Respondents Are Saying

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**.*



Social Media



CreakyJoints
October 21 at 10:03 PM

Care about someone with a compromised immune system? Get your flu shot. Take action and wear a mask. Flu Vaccine and COVID-19: What People with Chronic Illness Need to Know <https://register.gotowebinar.com/regi.../7638779378985209615>

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.

Help protect me by getting a flu vaccine.

PRESENTED BY THE GLOBAL HEALTHY LIVING FEDERATION www.GHLF.org

10 Comments 42 Shares

CreakyJoints
October 18

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

88

48 Comments 22 Shares

CreakyJoints
October 29 at 4:24 PM

The CDC recommends that people get a flu vaccine by the end of October. Flu Vaccine and COVID-19: What People with Chronic Illness Need to Know <https://register.gotowebinar.com/regi.../7638779378985209615>

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.

PROTECT YOURSELF - PROTECT OTHERS

PRESENTED BY THE GLOBAL HEALTHY LIVING FEDERATION www.GHLF.org

9 Comments 13 Shares

CreakyJoints.org @CreakyJoints · Oct 19

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

3 7 27

CreakyJoints.org @CreakyJoints · Oct 20

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... #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

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... #spoonie #spoonies

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 COVID-19 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 COVID-19 Pandemic: A Plea from Doctors](#)



[How to Have a Low-Risk Thanksgiving During COVID-19: 5 Tips for People with Chronic Illness](#)



[How to Avoid Getting COVID-19: 9 Key Reminders for People with Chronic Illness](#)



[How to Move More at Home When You're Stuck Inside During COVID-19](#)

New COVID-19 Research at ACR

This year's American College of Rheumatology meeting was filled with hundreds of abstracts about COVID-19. 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 slide 17, you can learn more about GHLF's own COVID-19 research presented at ACR. This slide is focused on disseminating research findings from other sources.

- [Are Inflammatory Arthritis and Rheumatic Disease Patients More at Risk for COVID-19 Complications?](#)
- [How Is COVID-19 Affecting the Mental Health of Rheumatic Disease Patients?](#)
- [Children with Rheumatic Diseases May Not Be at High Risk of COVID-19 — or Serious Outcomes](#)
- [Black and Hispanic/Latinx Rheumatic Disease Patients Have More COVID-19 Hospitalizations and Complications](#)
- [Telemedicine Helps Rheumatology Patients Stick to Their Routine Appointments](#)

New COVID-19 Research at ACR

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.](#)

Introducing CreakyKitchen

GHLF Hosted Our First Ever Cooking Event: A Virtual Friendsgiving Feast

This year our holiday season is looking quite different because of COVID-19. With folks still isolating and being away from family this Thanksgiving, GHLF brought our family into patients' homes as we gathered virtually to kick off the holiday season with a night of fun, food, and community.

A member of our community, Chantelle Marcial, gave a virtual class on how to make Spinach Stuffed Mushrooms Topped with Breadcrumbs and Parmesan, along with other cooking tips for people to use to prepare for the holidays this year.

We also heard from patients in our community who shared their own favorite Thanksgiving meals, cooking tips, and how they are adjusting holiday plans during the pandemic.



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 COVID-19: 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:

<https://creakyjoints.org/education/webinar/webinar-flu-vaccine-and-covid-19-chronic-illness/>

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)

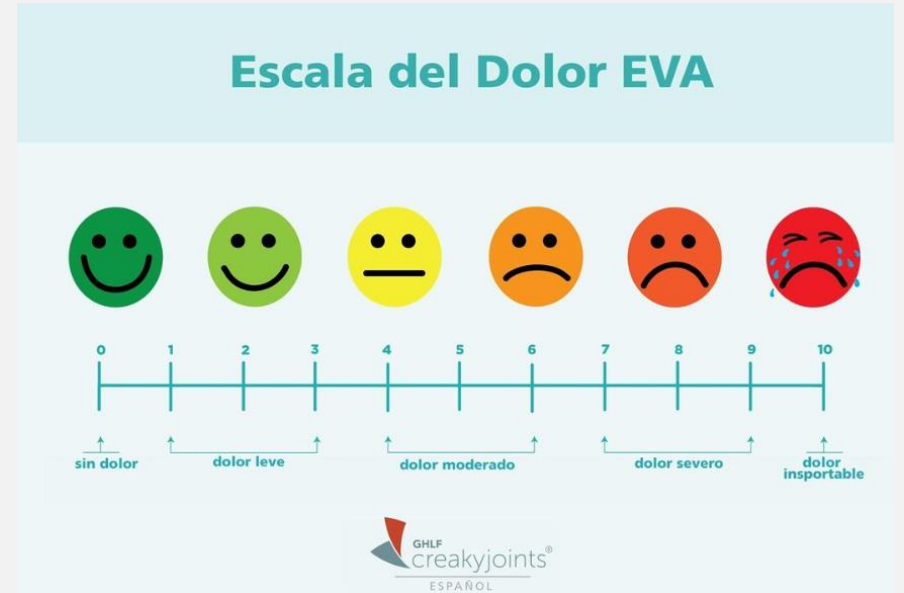
Spanish-Language Update

CreakyJoins Español is becoming more accessible!

We are happy to announce that the simple to type url: CJES.ORG will direct Hispanic patients to our site.

We continue to:

- Research and write Spanish-language articles about COVID-19 and chronic disease management on 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

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

“

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.

“

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.

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

As the nation has been focused on the presidential election these past few weeks, legislative efforts slowed down. However, while legislators were directing their attention elsewhere, GHLF has kept our eyes and ears out for any issues impacting our patient communities.

We have 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 to WEA Trust opposing their implementation of copay accumulator adjusters.](#)

We've also been concerned with state's response to COVID-19. We issued an advocacy alert to draw attention to North Dakota's coronavirus response and encourage residents to contact their legislators.



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)