

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



- Patient Support Program Updates
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**June 18 – July 17**

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

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

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

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

**16,202**

Number of members

**26,878**

Number of subscribers

**30.5%**

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

**8.3%**

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

## Top Conditions:



**30%**

Rheumatoid Arthritis



**19%**

Lung Disease



**13%**

Psoriatic Arthritis or Psoriasis



**10%**

Heart Disease



**10%**

Migraine



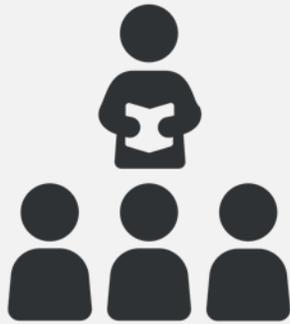
**9%**

Diabetes



**7%**

Inflammatory Bowel Disease



# Patient Support Program Community Poll: Re- Opening and Engaging in Activities

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

## When would you feel comfortable doing the following activities while following guidelines for mask wearing and maintaining social distance when possible?

\*Scores range from 1-4, with a **lower rating** indicating members are more likely to participate in the activity now or in the next two months and a **higher rating** indicating members are more likely to participate in the activity when the threat of coronavirus is much lower or completely gone.

Getting takeout from curbside pickup or delivery	1.56
Going grocery shopping at the grocery store (rather than delivery or curbside pickup)	1.89
Going for a walk, run, hike, bike ride with others	2.00
Picking up takeout from inside a restaurant	2.35
Shopping in-person at a small business	2.47
Going to a salon, such as a hair salon/barber or nail salon	2.64
Going camping	2.66
Eating outside at a restaurant	2.75
Attending an outdoor gathering of 10-20 people	2.85

Going to the beach	2.86
Playing contactless sports, such as tennis or golf	2.90
Going to a library or museum	3.13
Swimming in an outdoor pool	3.13
Staying in a hotel	3.19
Going to a shopping mall	3.20
Attending an indoor gathering of 10-20 people	3.28
Eating inside at a restaurant	3.30
Attending an outdoor gathering of more than 20 people	3.32

Going to a religious service	3.40
Getting on an airplane or train	3.57
Swimming in an indoor pool	3.58
Attending an indoor gathering of more than 20 people	3.64
Going to the movie theaters	3.65
Taking public transportation, such as a bus or subway	3.66
Going to an indoor gym	3.66
Going to a bar	3.74
Playing high-contact sports, such as basketball or soccer	3.77

# Re-Opening and Engaging in Activities: What Our Members Are Saying

“

*I feel pressured to return to my job as an elementary school teacher in August. This makes me really nervous.*

“

*I am concerned that my insurance company is no longer going to cover telemedicine appointments.*

“

*Taking it slow. Protecting myself. Not judging others. Listening to the facts.*

“

*I'd like to see and hug my grandchildren. I'm waiting for that!*

“

*My wife and I are obsessing. We don't touch anything without gloves that has been touched by anyone else. We wear masks anywhere people are: curbside grocery pickup, gas station (pay at the pump only), doctor's office. We don't go anywhere or do anything that isn't absolutely necessary.*

“

*I am trying to still keep in mind that because things are opening up, it still has not changed the COVID situation.*

“

*We need human contact despite being high risk. I will go to see friends outside or hiking.*

# Patient Support Program Community Poll: Vaccinations

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

**Do you plan to get a flu (influenza) vaccine this fall/winter season and do you plan to get a coronavirus (COVID-19) vaccine when/if it becomes available?**

**85%** said yes, they plan to get a flu vaccine this fall/winter season

**67%** said yes, they plan to get a coronavirus vaccine if/when it becomes available

**Where do you typically go to get a vaccination?**

**70%** said they go to their doctor or provider's office

**40%** said they go to a pharmacy

**3%** said they go to an urgent care clinic

**Have you had any scheduled vaccinations in the past four months that you skipped or delayed?**

**8%** said yes, they have skipped or delayed a scheduled vaccination

**92%** said no, they have not skipped or delayed a scheduled vaccination

**If yes, why? Respondents could select all that apply.**

**31%** said they didn't want to get a vaccination due to coronavirus concerns

**20%** said they didn't want to go to an in-office visit due to coronavirus concerns

**16%** said their doctor or provider appointment was cancelled due to the coronavirus pandemic

**15%** said their doctor or provider suggested they delay the vaccination due to coronavirus concerns

**15%** said they have been sick and didn't want to get a vaccination

**36%** said 'Other'

# Vaccinations: What Our Members Are Saying

“

*My pharmacy is not giving routine vaccinations during the pandemic, so I could not get the Shingrix vaccination.*

“

*Anxiety to even leave the house.*

“

*The shingles vaccine was not being given at the pharmacy because of COVID-19.*

“

*Doctors office hasn't been helpful with navigating insurance.*

“

*I delayed second shot for Shingles vaccine due to surge.*

“

*I have a preexisting condition and was afraid to go to the doctor or pharmacy because of the coronavirus.*

# Top New Resources

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

Over the past couple of weeks, we launched a very popular and engaging series called “Is It Safe?” Based on data we collected from our Patient Support Program community polls, these articles examine common reopening activities and feature interviews with top medical experts to help patients decide whether certain activities are safe for them. Here are some recent examples.



**[Is It Safe to Get a Manicure or Pedicure if You're at High Risk for COVID-19?](#)**



**[Is It Safe to Go to the Gym If You're at High Risk for COVID-19?](#)**



**[Is It Safe to Eat at a Restaurant If You're at High Risk for COVID-19?](#)**



**[Is It Safe to Go to a Hair Salon If You're at High Risk for COVID-19?](#)**

# Social Media Outreach

Top social media in terms of engagement and reach centered around covid19 symptoms and lifestyle adjustments (mask wearing and engaging in everyday activities).

**CreakyJoints.org** @CreakyJoints · Jul 3  
When did you last get a hair cut or go to a salon/barber? [creakyjoints.org/living-with-ar...](#) #covid19 #coronavirus #spoonies #spoonie



Is It Safe to Go to a Hair Salon If You're at High Risk for COVID-19?  
Learn more about what safety precautions to take when you go to a hair salon during the COVID-19 pandemic and are at high risk.  
[creakyjoints.org](#)

11 9 23

**CreakyJoints.org** @CreakyJoints · Jul 11  
Knowledge is power but it can also be nerve-wracking. Besides fever, many other #coronavirus symptoms are vague and/or common, such as headaches or nausea. Also, so many — too many — are similar to #rheumatoidarthritis symptoms: [creakyjoints.org/living-with-ar...](#) #spoonies #COVID19



Is It Corona or My Rheumatoid Arthritis? How a Paranoid Patient Is Maki...  
Learn more about how rheumatoid arthritis patient Dibs Baer is paying attention to her body because of overlap between RA and coronavirus ...  
[creakyjoints.org](#)

3 15 27

**CreakyJoints**  
Published by Joseph Coe [?] · June 20 at 4:11 PM · 🌐

The difference may be patients' prolonged exposure to anti-malarial drugs, new research suggests.  
Read to learn more:



CREAKYJOINTS.ORG  
**Eye Damage from Hydroxychloroquine More Common in Lupus than Other Rheumatic Conditions**

**CreakyJoints**  
Published by Joseph Coe [?] · June 19 at 3:44 PM · 🌐

These regulations have helped slow the spread of coronavirus, which has important implications for managing the pandemic going forward.



CREAKYJOINTS.ORG  
**Mandating Face Masks in Public Lead to a Drop in COVID-19 Growth Rate and May Prevented Hundreds of Thousands of...**



The Global Healthy Living Foundation and its CreakyJoints arthritis community are supporting Stop Hate For Profit's "Hit The Pause on Hate Campaign", which is calling on businesses to pause advertising on Facebook until they create policies and procedures that make Facebook a safer and more positive environment.

As a nonprofit we feel that is our responsibility to continue to publish credible and fact-based information to our community on social media. However, we have ceased all Facebook advertising and will continue to post only organic, free, content to communicate our strong objection to Facebook, as well as healthcare issues.

Learn more: <https://www.stophateforprofit.org/>

In addition, until this issue is settled, GHLF, for the first time, is accepting advertising in order to sustain communications continuity to patients.

## Patient Leadership Council Insights: On Our Minds

We spoke with our Patient Leadership Council and discussed the concerns and issues they are seeing in their respective disease communities:

### Telehealth vs. In-person Doctor's Visit

*"Doctors are on time [for telehealth]. If they say 3:15pm, they're there at 3:15pm. I feel more in control of the visit. I feel empowered."*

*"With the exception of blood tests, once they are able to hook that up to a computer, I see this as the future of medicine. I also don't have to drive an hour and a half for my appointment."*

*"I don't have to leave my house and for someone living with anxiety, it's amazing. I like not having to commute. For someone with RA it's amazing, as sometimes you're exhausted and forget things by the time your appointment happens."*

*"I feel like I'm more of an equal in the meeting because the video format sort of forces us to listen to each other. I feel less pain and have more energy because I don't have to go wait in a waiting room, so I feel better prepared."*

*"You can view your chart results ahead of time. By the time my appointment comes up, I have my questions in advance and I don't feel rushed or pressured."*

*"As someone living in a rural area, with doctors 2-3 hours away and waiting lists 6 months long, this is a game changer. Sometimes I can't even make it to the car, much less drive over state lines. I am able to have more frequent visits and appointments when I need them."*

# Patient Leadership Council Insights: On Our Minds (cont'd)

## Telemedicine and Health Disparities

*"As a disabled person from a high-risk group, it's made a huge difference in my care."*

*"Geography is big. I live in the middle of nowhere and have had to wait 6 months to start seeing doctors."*

*"Ethnicity and language are concerns, so other patients can understand their care and help them navigate the healthcare system."*

*"Telehealth can lead to less time off work and can help patients get by when finances are an issue."*

*"I like that telehealth can help with disparities. Advocacy must address each aspect of the moving parts so that patients don't fall through the cracks."*

*"There are less than 600 migraine specialists for the entire country, so I think it makes a huge impact on people being able to get help."*

## Reopening and Surging of Cases

*"Our governor refuses to implement a mask rule, and 1 in 7 people are wearing masks. If we open down the road, there will need to be a lot of regulations put in place. I just don't see how we'll be able to do that effectively."*

*"I live in the epicenter in our country and probably around the world. There was a huge outbreak and it's now moving filling in the middle of the state. There is open hostility between residents and the state. One person went screaming at the governor demanding a resignation. We are on the precipitous now where violence is imminent."*

*"We are going through different levels of reopening because people are refusing to wear a mask. You can't just walk up and tell them to wear one without a confrontation. You can't get it through people's heads that it's mandatory and we have to close down again because the spread is coming back."*

# Spanish-Language Update

We continue to:

1. Research and write Spanish-language articles about COVID-19 and chronic disease management on CreakyJoints Español properties



2. Recruit patients into our Spanish-language Patient Support Program



3. Produce at-home physiotherapy videos for our Hispanic rheumatic community

4. Recruit patients into our [Spanish-language COVID-19 Research Registry](#)



# Research Update: Our Autoimmune COVID-19 Study

GHLF’s research team has developed an IRB-approved longitudinal patient-powered study called the Arthritis & Rheumatic Disease COVID-19 Project of the Autoimmune Research Collaborative (ARC) to understand the concerns and behaviors of patients with autoimmune, rheumatic, and related conditions during the COVID-19 pandemic.

In line with patient centered research, we regularly share learnings with our patient community to promote greater awareness and to encourage patient participation in research. Below are some preliminary results of a supplemental survey on telemedicine, which we have disseminated to our network of participants so far:

The Arthritis and Rheumatic Disease COVID-19 Project:

## TELEMEDICINE SURVEY

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### PARTICIPANT OVERVIEW

<b>607</b> Individuals participated in the survey	<b>73%</b> Reported that their providers are offering telemedicine visits	<b>69%</b> Of those who were offered a telemedicine visit have had one
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### SURVEY RESULTS

Participants were asked to rank their telemedicine visit on a scale from 0 to 10, 0 being their worst visit and 10 being their best visit



**7** Was the average rating participants gave their telemedicine visit



**70%** Of participants ranked their telemedicine visit between a 7 and 10

To learn more about how to make the most of your telemedicine appointment click [here](#).



# Research Update: Our Autoimmune COVID-19 Study

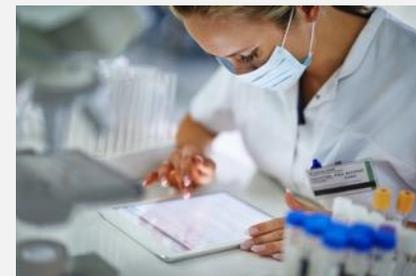
- **Total Numbers:** Since study launch on March 28, 2020, more than 24,000 patients have enrolled in the [Autoimmune COVID-19 Project](#). For the [Arthritis and Rheumatic Disease COVID-19](#) subset of this project, a total of 2,678 patient participants have enrolled. We have fielded the survey in both English and Spanish.
- **Follow Up Surveys:** The study is longitudinal; we recently fielded week 12 of the follow-up survey. Our next follow up survey is at week 16 and then at every 4 weeks until week 28 when we will re-visit the timeline going forward. We intend to close baseline recruitment on Thursday, July 30.
- **Telemedicine Survey:** In order to learn more about telehealth utilization during the pandemic, we invited participants to complete a short, added survey on this topic. To date, more than 600 patients have completed the telehealth survey.
- **Press Coverage and Media:** Since project inception, we have received some press coverage about this initiative:



[Interview: Autoimmune COVID-19 Project Assesses Long-term Impact of COVID-19 on Patients with MS, Arthritis, and more](#)



[Doctors Are Pooling Data to Help Understand Covid-19](#)  
Published in DocWire News



[The Autoimmune COVID-19 Project: A Patient-Centered Initiative](#)  
Published in Rheumatology Advisor

# ArthritisPower PCORI Funding and COVID-19



The Patient Centered Outcomes Research Institute (PCORI) is developing a blog about tools to help with engagement efforts during the era of COVID-19 and social distancing. The Engagement Awards team selected three tools in the PCORI Engagement Repository as examples of virtual engagement, and GHLF's [\*Social Media and Research Toolkit \(SMART\)\*](#) was among the three selected. The [\*blog post\*](#), titled 'Engagement Tools Offer Tips for Engaging Virtually', provides insight on ways to boost virtual engagement.

# Advocacy Update: Legislative Outreach

As part of an ongoing effort to have more direct communication with local and federal elected officials, we have been individually contacting legislators through our direct email campaign to promote GHLF's COVID-19 Patient Support Program. We are pleased to announce we have conducted direct outreach to every state legislator across **all 50 states**. Through our outreach efforts, GHLF's patient-centered resources have reached reaching **over 7,000 elected officials** across the country.

Additionally, GHLF continues to submit letters to policymakers around the country to ensure patients have access to care without obstacles. Related to COVID-19 concerns, GHLF has recently submitted comment to Centers for Medicare & Medicaid Services (CMS) detailing our support for the expansion of telehealth services.

- [Comments to CMS about Additional Policy and Regulatory Revisions in Response to COVID-19](#)

## Advocacy Update: Virtual Advocacy

GHLF has initiated virtual meetings with state legislators to share ongoing issues that our patient community is facing and how they can better support their constituents. Members of our advocacy team recently met with **New York State Senator Brad Hoylman** to advocate for patient-centered policies.

The pandemic has illuminated many policy concerns that impact our patient community. Some of the key issues we are discussing in virtual advocacy meetings include:

- Returning to work and life: supporting high-risk individuals
- Vaccinations: expanding pharmacists vaccine authority
- COVID-19 vaccination access and information
- Promoting at home infusion services
- Promoting telehealth expansion



***New York State Senator  
Brad Hoylman***

# Patient Leaders in Our Patient Support Group



## From left:

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

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

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

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