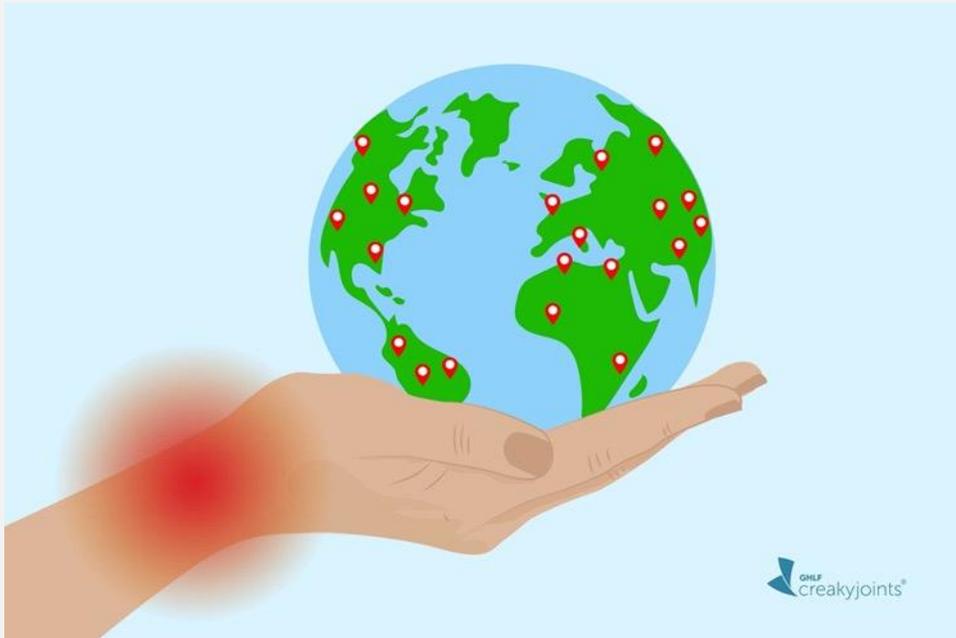


Global Healthy Living Foundation COVID-19 Patient Impact & Insights



May 25 – June 17, 2020

- Patient Support Program Updates
- Education and Support Across GHLF.org + CreakyJoints
- CDC Facebook Live
- Black Lives Matter + Disability
- Arthritis Awareness Month
- Patient Insights
- Autoimmune COVID-19 Study Updates
- 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 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

15,418

Number of members

25,417

Number of subscribers

30.5%

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

8.3%

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

Top Conditions:



19%

Rheumatoid Arthritis



15%

Lung Disease



8%

Psoriatic Arthritis or Psoriasis



5%

Diabetes



6%

Migraine



6%

Heart Disease



5%

Inflammatory Bowel Disease

Patient Support Program Community Poll: Mask Use and Re-Opening

We are surveying our Patient Support Program members regularly about important issues in health care and other topics. *Respondents could select all that apply.*

How often do you wear a mask to protect yourself and others from coronavirus?

- **35%** Wear a mask when they leave their home, no matter where they are going
- **28%** Wear a mask when they are around other people
- **27%** Wear a mask when they are in an enclosed space around people, but not when they are outside
- **7%** Wear a mask depending on how crowded the situation is or when it is required
- **3%** Do not wear a mask

Now that businesses are starting to re-open, what is your approach to social distancing?

- **55%** Of people are not leaving their home unless for an essential item or errand
- **45%** Of people are leaving their homes for these reasons:
 - **63%** To go to work or do other essential tasks like doctor visits or treatment appointments
 - **25%** To socialize with family and/or friends in parks, yards or homes
 - **25%** To engage with local businesses, such as take-out from restaurants and sidewalk shopping
 - **8%** To resume normal activities, such as going to restaurants, bars, salons, and other businesses

Mask Use and Re-Opening: What Our Members Are Saying

“

I try to visit places where masks are required by the business, such as Costco. When walking in my neighborhood, although most people are not wearing masks outside, people watch and step aside when we are going to pass on the sidewalk. We jokingly refer to it as doing the sidewalk dance.

“

People should not bully or shame a person who is not wearing a mask; a person may have a medical condition or physical disability that makes mask wearing problematic.

“

Most people don't handle masks properly in terms of contamination control, such as taking masks on and off without washing hands, sliding masks down and then back up, etc.

“

I am more afraid now than when we were in lockdown. Judging by what I saw when I picked up a curbside order at Target, people are acting like everything is over. The store's parking lot was full and most people were not wearing masks

“

I wear a mask to show that I care about others and their health and mine. Masks are a sign of respect for the whole community.

“

I wouldn't feel right around people for a very long time, like at church.

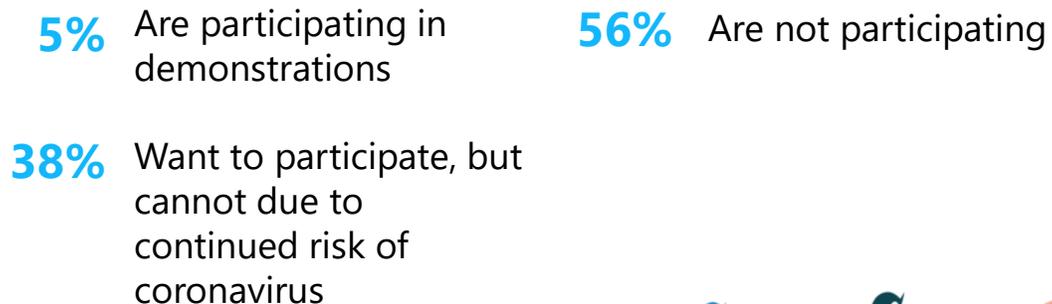
“

Since I have asthma and masks make it difficult to breathe, I try not to be in situations where I need a mask.

Patient Support Program Community Poll: Racial Justice Demonstrations

We are surveying our Patient Support Program members regularly about important issues in health care and other topics. *Respondents could select all that apply*

Have you participated in-person in any of the racial justice demonstrations that have occurred throughout the US and the world in the past week?



[Asked of the people who reported that they are participating in demonstrations]: **What measures are you taking to stay safe from coronavirus while participating in the anti-racism demonstrations?**



Racial Justice Demonstrations: What Our Members Are Saying

“

I would very much like to participate, but I am a senior with health issues. My way to support the movement is by prayer.”

“

My heart, prayers, and support are with our world's individuals that are affected by the unfair treatment and judgement by individuals that are not affected by racism. Our society has let this continue for too long.

“

I am reading and trying to understand the appropriate conversation to have with coworkers and clients. Language is important, and I don't want my empathy to be lost with the incorrect words.

“

I am with them in spirit.

“

I am signing as many online petitions as I can.

“

I have been an activist for social justice for years. Ordinarily, my disabilities make it difficult if not impossible to protest in public spaces. It hurts but I often feel like there's no place in activism spaces for a body and mind like mine. Perhaps we can discuss this as a community some time. There is very little I'm capable of with my physical limitations but I'd love to be able to protest and show up again.

“

I have continued as have generations of my family, to advance the anti-racism movement through peaceful protest, serving on committees, and other forms of community activism.

CDC Facebook Live

CreakyJoints, the CDC, and a community-based rheumatologist from United Rheumatology produced a Facebook live for how chronic disease patients can better control their health during COVID19.

Panelists:

- Dr. Shilpa Venkatachalam, PhD, Associate Director, Patient Centered Research at Global Healthy Living Foundation/CreakyJoints (Moderator)
- Dr. Anne Kimball, MD, MPH, CDC National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention; Division of Sexually Transmitted Disease Prevention
- Dr. Max Hamburger, MD, Founder, Executive Chairman and Chief Medical Officer of United Rheumatology and Managing Partner of Rheumatology Associated of Long Island (RALI)



#ICYMI: Watch CDC experts discuss managing chronic illness during the #COVID19 pandemic in this Facebook Live hosted by @CreakyJoints and the Global Healthy Living Foundation.



CreakyJoints.org @CreakyJoints · Jun 1

Stay in touch with your health care provider if you have any concerns about your underlying health condition or COVID-19: creakyjoints.org/living-with-ar...

4:51 PM · Jun 2, 2020 · Twitter Web App

52 Retweets 104 Likes

We reached over **6,000 people**. A total of 152 questions were received with **2,500 video views**. We had an average of 180 people live at all points throughout the broadcast.

Wrap up link: <https://creakyjoints.org/living-with-arthritis/coronavirus/managing-symptoms/cdc-covid-19-chronic-illness-facebook-live-event/>

Black Lives Matter + Disability

There is a strong connection between the racial justice movement and the disability rights movement. Three leaders hosted an important #CreakyChats twitter discussion centered on black lives matter and disability. A discussion about COVID19 and attending rallies/ demonstrations while being high risk for COVID19 complications was raised.

24.5M

Impressions

3,244

Tweets

920

Participants

19

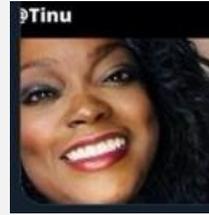
Avg Tweets/Hour

4

Avg Tweets/Participant

Twitter data from the #CreakyChats hashtag from Wed, June 10th 2020, 8:00AM to Wed, June 17th 2020, 10:40AM (America/New_York) - Symplur

Hosts:



Tinu Abayomi-Paul (@Tinu): Tinu Abayomi-Paul is a disability activist and the founder of Everywhere Accessible. She maintains a master list of Twitter chats and patient-facing hashtags to help the community easily find resources and each other. Her e-book on being a spoonie with cancer comes out later this year.



Dawn Gibson (@DawnGibson): Dawn Gibson founded the Twitter support group Spoonie Chat in 2013, which has grown into a thriving community of mutual support, friendship, and solidarity for patients living with chronic illness. Health care providers, health care organizations, and non-profit foundations rely on Spoonie Chat to hear directly from the community about patients' experiences.



Imani Barbarin (@Imani_Barbarin): A graduate of Eastern University with a degree in Creative Writing and a minor in French from the Sorbonne, Imani Barbarin writes from the perspective of a black woman with Cerebral Palsy. She specializes in blogging, science fiction and memoir.

Amplification Through Media Outreach

Our efforts continue to position organizational leadership, medical advisors, and patient leaders as experts to provide perspective to major consumer and trade media.

Since the start of the pandemic, we've generated over 90 original placements, which have published or aired on hundreds of websites and radio stations nationwide. Most recently, we've contributed to perspective on best practices for telemedicine visits, the importance of people with arthritis contributing to research, and been recognized for the quality education we provide our patient communities.

Univision.com



[Artritis y coronavirus: cómo afecta la pandemia a quienes padecen esta dura condición](#)

Everydayhealth.com



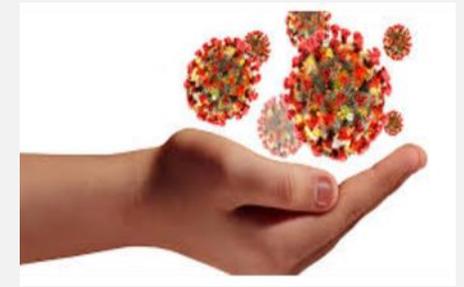
[What Telemedicine Can — and Cannot — Do for People Living With Rheumatoid Arthritis During the Pandemic](#)

RheumatologyAdvisor.com



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

Medscape.com



[Advice on Treating Rheumatic Diseases From a COVID-19 Epicenter](#)

Top New Resources

CreakyJoints and the Global Healthy Living Foundation are publishing 10 to 15 new resources a week for patients across many different chronic conditions. This is a sample of popular new content, according to internal traffic and engagement data.



['COVID Toes' and Rashes: 6 Important Things to Know About Coronavirus Skin Symptoms](#)



[The 5 Main Things We Learned from the Biggest Study on COVID-19 in Rheumatology Patients to Date](#)



[Swimming Pools and COVID-19: Precautions for People with Chronic Illness](#)

Top Content on Social Media

Our most engaging tweets during this period were about our CDC Facebook Live. Here is an example:



Arthritis Awareness Month

Our Arthritis Awareness Month Campaign raised awareness on the importance of not settling for “fine” when it comes to health.

The “**Fine Is Not Fine**” campaign reached over half a million people on Facebook, Instagram and Twitter.



Here is wrap up of what we heard:

<https://creakyjoints.org/living-with-arthritis/why-people-with-chronic-illness-say-they-are-fine/>

The Conditions Our Patient Leadership Council Represents

The COVID-19 Patient Leadership Council is a group of 19 patient leaders with whom we are meeting regularly to inform our educational resources, research initiatives, and advocacy campaigns.

They represent various chronic health conditions that include:

- **Asthma**
- **Axial spondyloarthritis/ankylosing spondylitis**
- **Cancer**
- **Diabetes**
- **Fibromyalgia**
- **Heart disease**
- **HIV/AIDS**
- **Inflammatory bowel disease**
- **Lupus**
- **Migraine**
- **Multiple sclerosis**
- **Osteoarthritis**
- **Psoriasis**
- **Psoriatic arthritis**
- **Rheumatoid arthritis**
- **Scleroderma**
- **Sickle Cell Disease**
- **Gout**

Data on the following slides is from a weekly survey we conduct with our council.

Patient Leadership Council Insights: On Our Minds

For this insights report, we spoke with our Patient Leadership Council and discussed the concerns and issues they are seeing in their respective disease communities:

Racism Is a Pandemic

"I always knew about disparities, and that people of color get half of the care that I get."

Thoughts About the Demonstrations

"Hopefully, these movements will keep going and building."

"It's more than statements that come out from a company, they don't mean much right now, it's more about what they will do 6 months from now."

"It's powerful, and I spent time thinking about it."

"If you hear something you know is wrong, do something about it."

Concerns About the Demonstrations

"The majority of protestors, not social distancing, almost all police not wearing masks, police even removed protestors masks, I don't know if there's anything we can do about this."

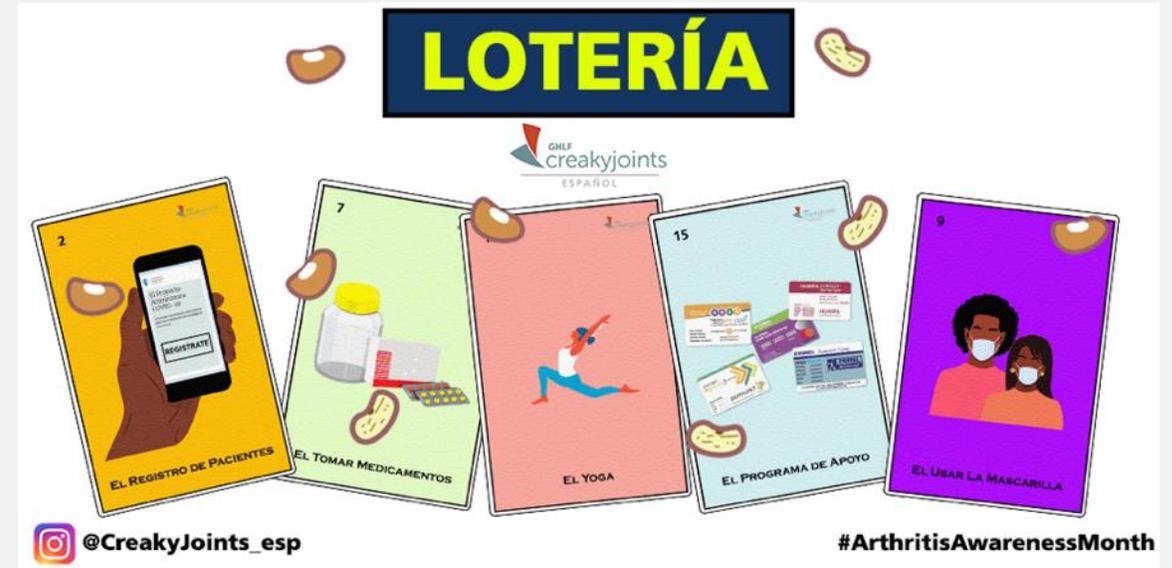
"Sometimes you have to be selfish and take care of yourself."

"We're all entitled to feel guilty and be scared."

Spanish-Language Update

Our mission to address the COVID-19 pandemic to the Hispanic community has involved recruiting key opinion leaders from the Hispanic community. Our Spanish-language content has been shared through national advocacy groups, including:

- Congressional Hispanic Caucus Institute
- National Hispanic Caucus of State Legislators
- Influential Spanish-language media appearances
 - [El Diario](#) newspaper
 - [Radio Isla](#) (Puerto Rico)
 - [Univision](#) television



We also continue to:

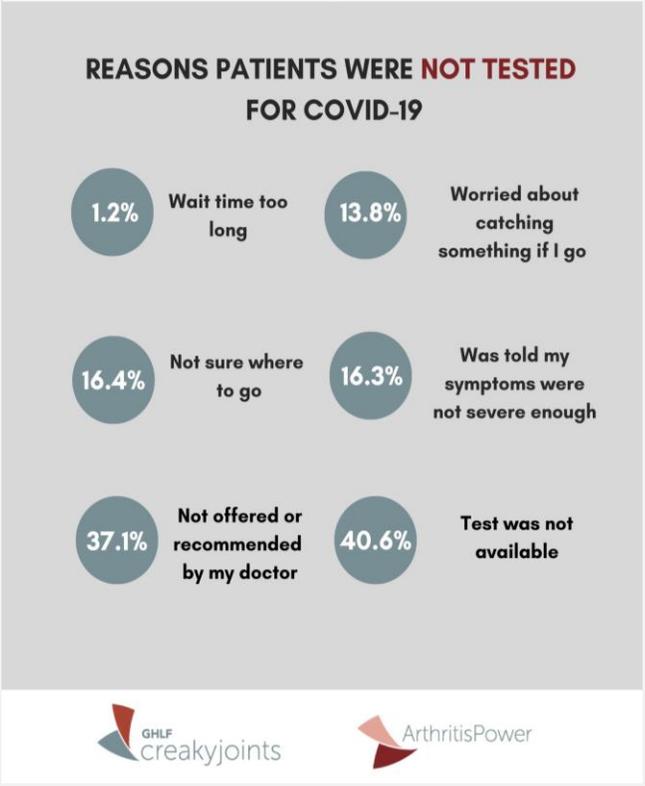
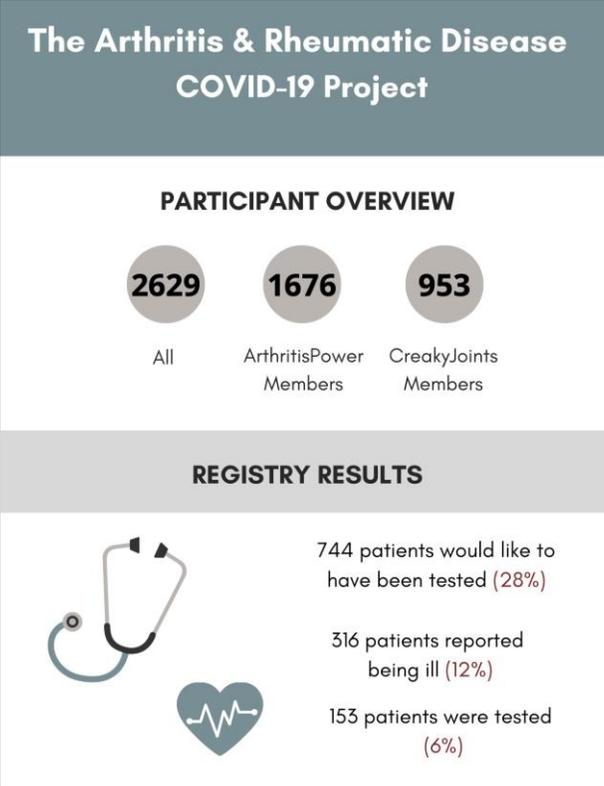
- Research and write Spanish-language articles about COVID-19 and chronic disease management
- Recruit patients into our Spanish-language Patient Support Program
- Recruit patients into our Spanish-language COVID-19 Research Registry

We engaged the community for Arthritis Awareness Month with wellness programming on Instagram with daily cards and information inspired by Mexican Bingo or Lotería.

Research Update: Our Autoimmune COVID-19 Study

GHLF’s research team has developed a 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. This study is on-going and currently has over 20,000 patients participating.

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 which we have disseminated to our network of participants so far:



Research Update: Our Autoimmune COVID-19 Study

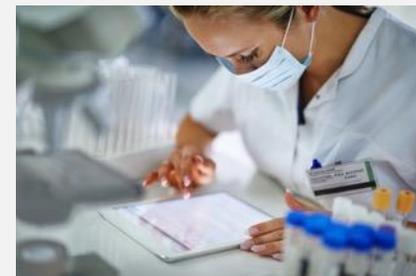
- Study has passed the 8-week follow-up for those who completed baseline assessments at launch. Additional follow-up will take place every four weeks moving forward.
- An additional survey has been designed specifically around telehealth and telemedicine to understand patients' perceptions, behaviors and utilization of this healthcare delivery channel.
- Abstracts with preliminary baseline results submitted to ACR 2020 conference.
- Manuscript submitted to peer-reviewed journal to report early results.



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



[Joint Study to Assess Effects of COVID-19 on Patients with IBD, Other Autoimmune Conditions](#)



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

ArthritisPower PCORI Funding and COVID-19

As part of our Patient Centered Outcomes Research Institute (PCORI) Engagement Award, [Diversifying, Expanding and Tracking Patient Engagement in Arthritis Research](#), GHLF was awarded COVID-19 Enhancement Funding from PCORI to engage eligible patients to participate in the design, programming and fielding of a yearlong, longitudinal project (GHLF's Autoimmune COVID-19 Project) and conducting outreach and recruitment for the COVID-19 project by engaging new patients who are unfamiliar with ArthritisPower (GHLF's PCORI-funded patient-reported outcomes registry). It also includes funding to translate all COVID-19 study materials into Spanish to expand our reach to underrepresented patients in ArthritisPower (i.e. those who primarily speak Spanish and, as appropriate, Latinx stakeholders in the US and territories). GHLF's Director, Medical Affairs and Hispanic Outreach, Daniel Hernandez, MD will lead this effort.

In addition, 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 and its projects will be highlighted in a webinar PCORI is hosting later in June on ways to boost virtual engagement.

Advocacy Update: Legislative Outreach

As part of an ongoing effort to have more direct communication with all 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.

Over the past few months our advocacy team has reached out to **over 6,000** federal, state, and city legislators in **43 of the 50 states**. Many legislators continue to share our Patient Support Program in their constituent updates and on social media.

Since our last report we have reached out each state legislator from:

- Arkansas
- Delaware
- Idaho
- Kentucky
- New Hampshire
- New Mexico
- North Dakota
- Oklahoma
- Oregon
- South Dakota
- Utah
- Washington

Advocacy Update: New Policy Concerns...What Our Members Are Saying

In June, members of the advocacy team joined a CreakyJoints patient council monthly teleconference call to present on policy issues and learn from patients' perspectives. Three key questions were posed to the group and we are using the patient insight to inform our advocacy efforts.

Home Infusions: Would you feel comfortable receiving an infusion in your home?

- *"I previously had received some medications through home infusions and found the experience very good. My current meds do not give me a home infusion option but if coverage was expanded to include them, I would gladly do it."*
- *"I am very comfortable receiving treatment in my home vs going to a doctor's office. I would even be ok for routine blood work taken at home so I can avoid going into labs as well."*

Medicaid Cuts: Will state budget deficits impact (or potentially impact) your care?

- *"Yes, I receive my health care through Medicare and California's Medicaid plan. On top of that, CA Medicaid pays for my Medicare premiums so any reduction in coverage or eligibility could have major impacts on both of my health plans. I am very scared about the potential for cuts to my benefits and what it would mean for my care."*

Vaccinations: Would you feel comfortable going to your pharmacist to receive a vaccine?

- *"Yes! I see no difference in getting a vaccine from one or the other"*
- *"Additionally, giving expanding pharmacists' ability to vaccinate would save significant costs on the administrator (employer) side of the plan so many employers would also likely support this as a way save them money without cutting benefits for their employees."*

Additionally, GHLF continues to submit letters to policymakers around the country to ensure patients have access to care without obstacles. GHLF has recently submitted the following comments and sign-on letters related to COVID-19 policy concerns:

- [Comments to CMS about Policy and Regulatory Revisions in Response to the COVID-19 Public Health Emergency](#)
- [Letter to CMS about Step Therapy concerns during COVID-19](#)
- [Letter to Congressional Leadership about Prior Authorization and COVID-19](#)

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)