

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



- Patient Support Program Updates
- Education and Support Across GHLF.org + CreakyJoints
- Social Media Outreach
- Patient Council Insights
- Autoimmune COVID-19 Study Updates
- Spanish Language Update
- Bingo!
- Advocacy Policy Updates

**August 20 – September 19**

# 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**

**17,710**  
Number of members

**29,133**  
Number of subscribers

**27.9%**  
Email open rate  
(health industry average = 22%\*)

**7.6%**  
Email click rate  
(health industry average = 2.5%\*)

## Top Conditions:



**29%**

Rheumatoid Arthritis



**20%**

Lung Disease



**13%**

Psoriatic Arthritis + Psoriasis



**12%**

Fibromyalgia



**11%**

Heart Disease



**10%**

Migraine



**9%**

Diabetes



**7%**

Inflammatory Bowel Disease



## Patient Support Program Community Poll: Medication Access

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

# Patient Support Program Community Poll: Medication Access

**A total of 368 Patient Support Program subscribers responded to our August quick poll on medication access.**

**27%** of poll respondents have had difficulty accessing their medication(s), for any reason, since the coronavirus (COVID-19) pandemic began.

**58%** of poll respondents have had a telehealth appointment with their provider since the beginning of the pandemic to discuss their medication(s). The most common reasons for the appointments were:

- To discuss switching medication(s): **15%**
- To discuss starting medication(s): **12%**
- To discuss lowering the dosage of medication(s): **8%**

**19%** of the poll respondents take a medication that is administered through infusion

- **67%** felt protected from coronavirus while receiving their infusion medication in-office due to the precautions the staff took
- **13%** reported not feeling protected from coronavirus while receiving their infusion medication in-office
- As much as **20%** have not received their infusion medication in-office since the pandemic began

## Medication Access: What Our Members Are Saying

*This is a sample of free responses to the community poll on medication access:*

“

*Due to a national shortage of enteric coated sulfasalazine, **I could not get it.** I was offered regular Sulfasalazine. I am unable to take the regular due to GI problems.*

“

*Primary Care **refuses** to give me a new script until sees me. Have been on this medication for several years by former Primary Care doctor.*

“

*Difficulty in getting lab work done to continue medicine.*

“

*I was told that if I get symptoms, I cannot get my infusion. **There is no back up plan.***

“

*I **stopped** my meds when Covid started.*

## Patient Support Program Community Poll: Loneliness and Social Interaction

**A total of 333 Patient Support Program subscribers responded to our August quick poll on loneliness and social interaction.**

**Participants were asked to report how often they felt loneliness and other related emotions due to the coronavirus (COVID-19) pandemic throughout the prior month:**

- **78%** sometimes to always felt alone and apart from others
- **66%** sometimes to always felt left out
- **65%** sometimes to always felt lonely
- **54%** sometimes to always felt no longer close to anyone

**In terms of how the coronavirus (COVID-19) pandemic has changed the way participants interact with family members, friends, and/or acquaintances:**

- **59%** reported having to avoid making plans
- **59%** reported interacting with people over the phone more
- **52%** reported having to cancel plans
- **42%** reported missing out on big events

# Loneliness and Social Interaction: 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:*

“

*I miss **going anywhere, whenever I want to, as I did in the past.** I was very social and very involved in a variety of activities at Church and in my community. Would like things back the way they were and am looking forward to freedom.*

“

*I wish I could get on a plane and **go visit my parents but I don't feel safe on a plane.** That means I would have to drive which would take me two days.*

“

*I miss seeing my family and friends, **being able to hug them and spend time together.** I look forward to family dinners, going out to eat, shopping just because.*

“

*Enjoying a meal with immediate family **inside my home.***

“

*I have not seen my baby granddaughter who lives on the opposite coast in six months. How awful is that? **It is a nightmare.***

## Patient Support Program Community Poll: Voting in the US Presidential Election

**A total of 470 Patient Support Program subscribers responded to our September quick poll on voting in the US presidential election.**

**63%** reported that they plan to vote by mail-in or absentee ballot in the upcoming election

- This is compared to 39% of participants who voted by mail-in or absentee ballot in the last election in which they participated

**15%** reported that they plan vote in-person on Election Day in the upcoming election

- This is compared to 35% of participants who voted in-person on Election Day in the last election in which they participated

# Voting in the US Presidential Election: What Our Members Are Saying

*This is a sample of free responses to the community poll on voting in the US presidential election:*

“

*I wanted to vote early at City Hall, but the hours kept changing that you could do this, and then in early August the voter registration in city hall closed until further notice. I will have a change of address this year so I have to present my proof of residency piece of mail and I am probably going to have to do this on election day, at the polls. **Not my preferred way of voting, but budget cuts are making it hard for everyone.***

“

*It is less crowded for early voting. **I prefer to vote in person as I do not trust the mail in ballot system for everyone.** It should be limited to those who are homebound, or in a nursing home or are out of the country.*

“

***I prefer to vote in person,** always have and as long as I am able will do so. If I become unable to go in person I always have the absentee ballot option.*

“

***Mail ballots are the law of the land in the State of Colorado,** so I feel confident that I won't be a disenfranchised voter with a paper ballot instead of the poor souls who are forced to use voting machines.*

“

*I am at high risk for bad outcome if I contract COVID-19. I have been isolating since March. I do not intend to expose myself unnecessarily to potentially contracting this virus. However **it is of the utmost importance that I am able to cast my vote.** I have already requested an absentee ballot and I intend on filling it out asap.*



# Social Media: COVID 19 Social Content

## Top Tweets:

**CreakyJoints.org**  
@CreakyJoints

True for you? "The researchers found that 46 percent of patients with [#rheumatoidarthritis](#), [#ankylosingspondylitis](#), or [#psoriaticarthritis](#) adhered to strict isolation measures, compared to just 29 percent of healthy controls." [creakyjoints.org/living-with-ar...](https://creakyjoints.org/living-with-ar...) [#Covid19](#) [#spoonie](#) [#spoonies](#)



Rheumatic Disease Patients Are Isolating More Strictly Than the General Public D...  
Learn more about research that shows people with arthritis and other rheumatic conditions are isolating and quarantining more strictly.  
[creakyjoints.org](https://creakyjoints.org)

1:00 PM · Sep 6, 2020 · Twitter Web App

<https://twitter.com/CreakyJoints/status/1302652907402276866?s=20>

**CreakyJoints.org**  
@CreakyJoints

"Between my chronic illnesses, COVID-19, and fires burning all around me in Sacramento, I feel trapped." - [@BeingCharisBlog](#): [creakyjoints.org/living-with-ar...](https://creakyjoints.org/living-with-ar...) [#COVID19](#) [#HighRiskCOVID19](#)



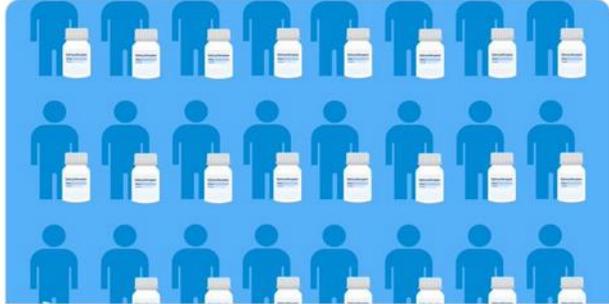
I'm Chronically Ill, COVID-19 Is Everywhere, and My Whole State Is on Fire  
Learn more about how ankylosing spondylitis patient Charis Hill is navigating underlying illness, the COVID-19 pandemic and California wildfires.  
[creakyjoints.org](https://creakyjoints.org)

3:25 PM · Sep 14, 2020 · Twitter Web App

<https://twitter.com/CreakyJoints/status/1305588407549276162?s=20>

**CreakyJoints.org**  
@CreakyJoints

[#Hydroxychloroquine](#) and [#chloroquine](#) update. New research shows the true extent of just how much more these two drugs, commonly used for rheumatologic conditions such as [#lupus](#) and [#rheumatoidarthritis](#), have been prescribed in 2020: [creakyjoints.org/living-with-ar...](https://creakyjoints.org/living-with-ar...) [#covid19](#) [#coronavirus](#)



Prescriptions for Hydroxychloroquine and Chloroquine Increased 80-Fold This Ye...  
Learn more about why the increase in prescriptions for hydroxychloroquine and chloroquine came from doctors who don't usually prescribe them.  
[creakyjoints.org](https://creakyjoints.org)

11:10 AM · Sep 11, 2020 · Twitter Web App

<https://twitter.com/CreakyJoints/status/1304437156765720581?s=20>



# Social Media: COVID 19 Social Content

## Top Facebook Posts:

Is this true for you?  
Researchers found that 46 percent of patients with rheumatoid arthritis, ankylosing spondylitis, or psoriatic arthritis adhered to strict isolation measures, compared to just 29 percent of healthy controls.



CREAKYJOINTS.ORG

**Rheumatic Disease Patients Are Isolating More Strictly Than the General Public During COVID-19**

<https://bit.ly/32VTnGH>

Are you going out to eat?



CREAKYJOINTS.ORG

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

<https://bit.ly/33Stela>

"The coronavirus pandemic has obviously caused the entire world a tremendous amount of grief and hardship. Much of the time, it feels impossible to find silver linings, but for the sake of my mental health, I am forcing myself to try to look on the bright side."



CREAKYJOINTS.ORG

**The 13 Silver Linings I Found in the Coronavirus Pandemic as Someone with Chronic Illness**

<https://bit.ly/3mLcXgB>

# Top New Resources

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

Over the last month, top content has included sharing patient perspectives from CreakyJoints members who are struggling with back-to-school decisions and living through the West Coast fires. We also began re-educating about the importance of getting flu vaccines for the chronic illness community (we do this every flu season, but this year it is of utmost importance).



[I'm a Teacher with Chronic Illness: After One Week Back in School, I Don't Feel Safe](#)



[Keeping My Son Home From School This Fall Is a No-Brainer Choice, Says One Mom with Chronic Illness — But It Still Breaks My Heart](#)



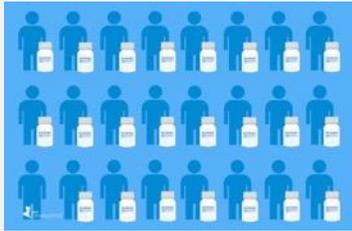
[I'm Chronically Ill, COVID-19 Is Everywhere, and My Whole State Is on Fire](#)



[The Flu Vaccine, Inflammatory Arthritis, and COVID-19: What You Need to Know](#)

# Covering COVID-19 Research Through a Lens of Rheumatic Conditions and Chronic Illness

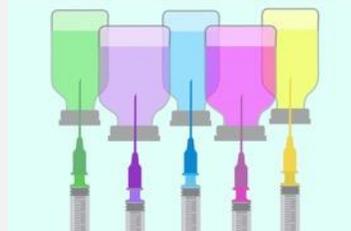
Six months into the pandemic, information fatigue is real. We hear from our patient community that many are feeling burned out and overwhelmed. At the same time, medical research about COVID-19 (symptoms, risk factors, transmission, testing, etc.) continues to proliferate. Our mission is to help the community be aware of research that could directly impact them because it is especially relevant to those with rheumatic, inflammatory, or other underlying chronic conditions. Here is sample of the medical research news have recently published:



[Prescriptions for Hydroxychloroquine and Chloroquine Increased 80-Fold This Year \(and Mostly from Doctors Who Don't Normally Prescribe Them\)](#)



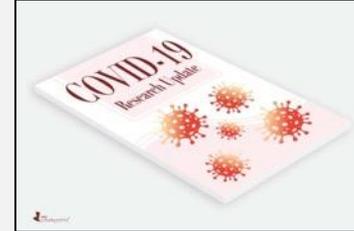
[Rheumatic Disease Patients Are Isolating More Strictly Than the General Public During COVID-19](#)



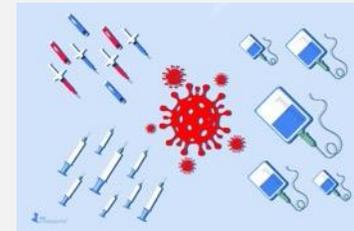
[Will People with Underlying Health Conditions Be Prioritized for a COVID-19 Vaccine?](#)



[New Study: Autoimmune Patients Don't Seem More Likely to Get COVID-19, But Those Who Do May Have More Complications](#)



[Having High Levels of Inflammatory Proteins \(Like TNF and IL-6\) Could Indicate More Serious Course of COVID-19](#)



[Here's Why Rheumatologists Are Calling for Trials to Study TNF Biologics to Treat COVID-19](#)



[Having 'Metabolic Syndrome' Could Triple the Risk of Dying From COVID-19](#)



[New Research Shows Young Kids \\*Are\\* Catching COVID-19 — and Spreading It to Their Families](#)

# Pain Awareness for Rheumatoid Arthritis

In conjunction with September's Pain Awareness Month, we launched a new resource called [A Patient's Guide to Understanding Rheumatoid Arthritis Pain](#). This comprehensive guide helps RA patients understand what may be causing their pain, the role of comorbid conditions in RA pain, when a treatment change may be recommended, and how to talk to their providers about RA pain as part of shared decision making (especially in a COVID/telehealth world).

## The resource includes the following original articles, checklists, and tools:

- Special ArthritisPower invitation to track pain-related patient-reported outcomes
- Article: [Rheumatoid Arthritis Pain and Flare-Ups: What to Know and Do](#)
- Article: [6 Causes of Rheumatoid Arthritis Pain Aside from Inflammation](#)
- Article: [Rheumatoid Arthritis Pain: When to Consider a Medication Change](#)
- Article: [How to Discuss Your Rheumatoid Arthritis Pain During a Telehealth Visit](#)
- Article: [Rheumatoid Arthritis Pain: 7 Things You Should Tell Your Rheumatologist](#)



The screenshot shows a webpage titled "A Patient's Guide to Understanding Rheumatoid Arthritis Pain" from GHLF creakyjoints. It features a logo, a hand illustration with red spots indicating pain, and a "TRACK YOUR PAIN >" button. Below the illustration is a section titled "Why Is Rheumatoid Arthritis (RA) Painful?" with text explaining the immune system's role and joint damage. It also includes a "KEEP READING >" button and a list of related articles.

**GHLF creakyjoints**

## A Patient's Guide to Understanding Rheumatoid Arthritis Pain

Living with RA doesn't have to mean living with pain. Learn more about RA pain and start tracking your symptoms today.

[TRACK YOUR PAIN >](#)

### Why Is Rheumatoid Arthritis (RA) Painful?

When you have RA, your immune system, which is supposed to protect against germs and foreign invaders, turns against the body and starts attacking the joints — and that hurts.

"Inflammation is the root cause of RA pain," says Elizabeth Schulman, MD, a rheumatologist at Hospital for Special Surgery in New York City. "The joint lining can get inflamed, thickened, and irritated, which causes pain and swelling and stiffness in the joints."

RA pain can also be caused by joint erosion and damage or could be due to co-occurring conditions that also cause pain. If you delay treatment, or your medication isn't working well enough, and RA inflammation persists, it can cause permanent damage to the joints, explains rheumatologist Angus Worthing, MD, a clinical assistant professor of medicine at Georgetown University Medical Center in Washington, D.C. "Once a joint is damaged, even if the inflammation is controlled, it's uncommon for that damage to repair and the pain might persist long-term," he adds.

Keep reading to learn more about:

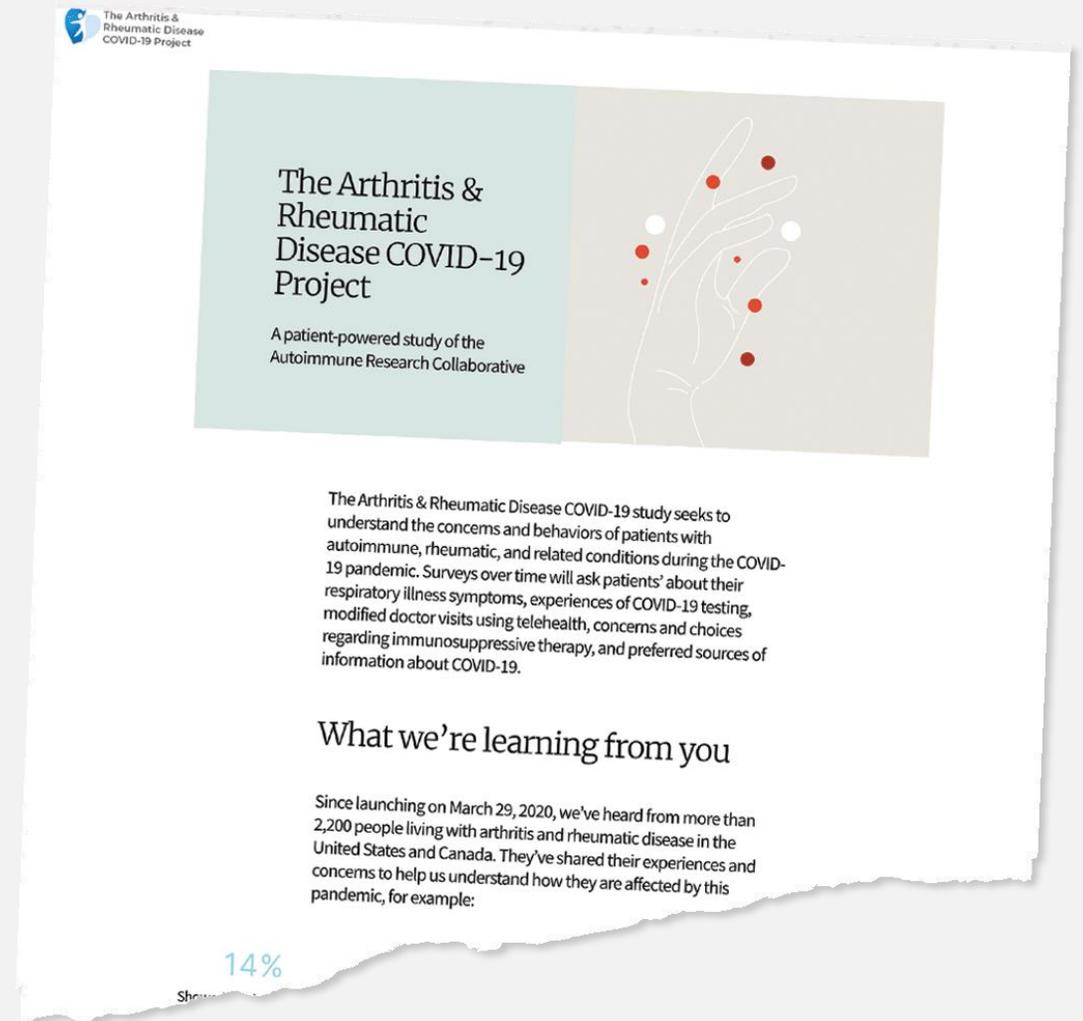
- The Difference Between Rheumatoid Arthritis Pain and a Rheumatoid Arthritis Flare
- Monitoring and Discussing Rheumatoid Arthritis Pain
- How Rheumatoid Arthritis Medications Treat Pain

[KEEP READING >](#)

# Live Patient Education and Engagement Webinars

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 have organized a 2-part webinar dissemination series.

The webinar was hosted by GHLF and featured expert panelists including Michael George, MD, MSCE, assistant professor of medicine at the Hospital of the University of Pennsylvania, Jeffrey Curtis, MD, MS, MPH, professor of medicine at the University of Alabama at Birmingham and Maria I. Danila, MD, MSc, MSPH associate professor of medicine at the University of Alabama at Birmingham. We also shared a link to the recorded webinar for patients and other stakeholders unable to attend live scheduled webinars. We have conducted more than a dozen webinars so far on a variety of topics. All webinars can be found on the CreakyJoints webpage at <https://www.creakyjoints.org/category/webinar/>.



# Research Update: Our Autoimmune COVID-19 Study

**ACR:** The American College of Rheumatology's (ACR) annual meeting titled [ACR Convergence 2020](#) will be held online this year from November 5–9. We submitted a number of abstracts highlighting ArthritisPower research, 8 of which were accepted for poster presentation and two of which were invited as oral presentations. Of these, three highlight findings from the Autoimmune COVID-19 project.

**PCORI Conference:** GHLF/ArthritisPower staff members and patients attended The Patient-Centered Outcomes Research Institute's (PCORI) 2020 annual meeting titled "Accelerating Impact on Care and Patient-Centered Outcomes". The sixth (and inaugural virtual) annual meeting took place September 16-17. PCORI's new Executive Director Nakela Cook, MD, MPH, provided opening remarks. There was special attention this year during the breakout and plenary sessions highlighting and discussing PCORI-funded COVID-19 research and health and health care disparities, among other timely topics.

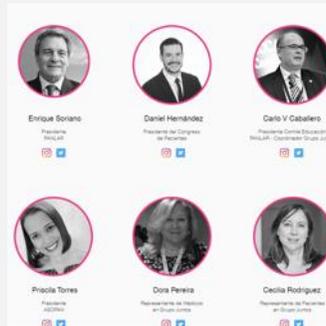
**COVID-19 Qualitative Study:** We will be launching a qualitative research study titled, *The COVID-19 Pandemic – Perspectives from People Living with Rheumatic Diseases*, in collaboration with patient researchers. This study will gain insight via diverse perspectives about living with an autoimmune (rheumatic or musculoskeletal) condition during the COVID-19 pandemic. As part of this research study, one-hour interviews will be conducted with patients to learn more about the experiences of people with rheumatic conditions during the COVID-19 pandemic. We will ask about changes to day-to-day routines and emotions, access to care, and how these have impacted rheumatic disease management.

# Spanish-Language Update



## ReumaExpo

On August 22, 2020, the [Puerto Rican Foundation for Rheumatic Diseases](#) (FER) and [Global Healthy Living Foundation](#) through [CreakyJoints Español](#) hosted the first digital-version of ReumaExpo. This online patient conference was streamed through [YouTube Live](#), and [Facebook Live](#) and featured a series of Spanish-language live Q&A sessions with patients and rheumatologists, and a wide variety of information on rheumatic conditions such as arthritis, lupus, gout, osteoarthritis, and others.



## PANLAR – 3<sup>rd</sup> Pan American Congress of Patients with Rheumatic Diseases

On September 16, 2020, [CreakyJoints® Español](#), the digital patient community for people with all forms of arthritis and part of the [Global Healthy Living Foundation](#), in partnership with the [Pan-American League of Rheumatology Associations](#) (PANLAR), hosted the [3rd Pan American Congress of Patients with Rheumatic Diseases](#) for Spanish-speaking people in the United States and Latin America who live with rheumatic diseases such as rheumatoid arthritis, osteoarthritis, lupus, juvenile idiopathic arthritis, and more. The all virtual conference featured an international panel of physicians to provide advice on disease management strategies, particularly during the COVID-19 pandemic. Daniel Hernandez, MD, Director of Medical Affairs and Hispanic Outreach, [CreakyJoints](#), was named President of this event.

# Spanish-Language Update: Media

A number of prominent Spanish-language newspapers reported on PANLAR, RheumaExpo and CreakyJoints Español's involvement. Notably, La Opinión, the largest Spanish-language circulated newspaper, reported on the FER conference as well as provided education about CreakyJoints Español's educational resources for the Hispanic community.



[La Opinion](#)



[El Diario NY](#)



[El Menu Local](#)



[La Raza](#)



World Today News  
[World Today News](#)



[Deporticos](#)



[Medicines Salud Publica](#)

# Hispanic Heritage Month (Sep 15 – Oct 15)



## We're celebrating National Hispanic Heritage Month!

The Hispanic population amounts to almost 60 million Americans, but there are still very limited resources in Spanish for specific diseases and great need. There is much to do and together we will achieve it.

Since 1968 the United States government honors the achievements of Hispanics (people who speak Spanish) every year from September 15 to October 15. We may come from different places, but the language unites us (and much more!)



En un nuevo estudio los estados que exigían el uso obligatorio de las mascarillas en público tenían una mayor disminución en las tasas de casos diarios del COVID-19 a comparación los estados sin mandatos.



## We also continue to...

- Research and write Spanish-language articles about COVID-19 and chronic disease management on CreakyJoints Español properties
- Recruit patients into our [Spanish-language COVID-19 Research Registry](#)

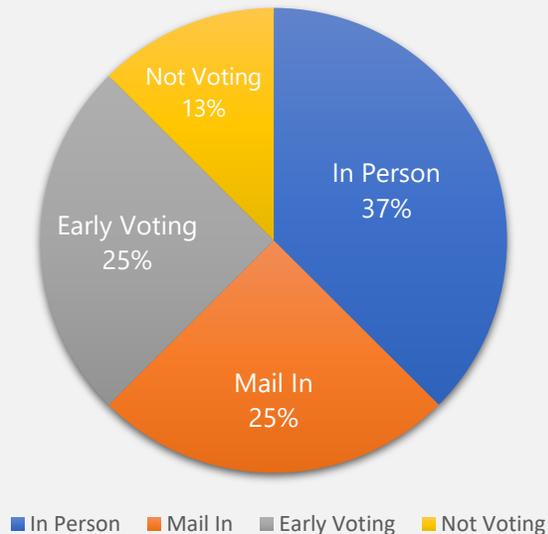


# Patient Update: Teleconference Format

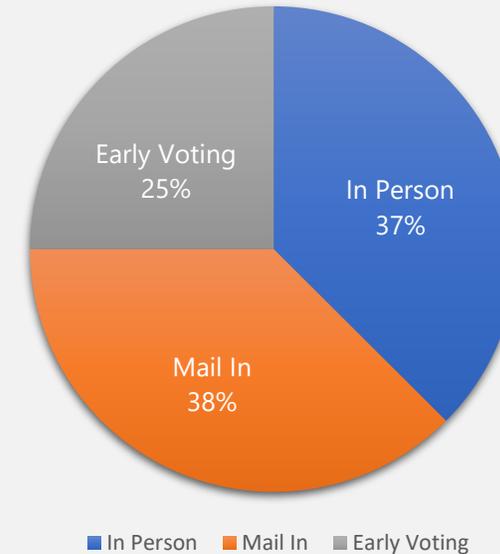
The COVID-19 Leadership Council teleconference was conducted online to allowing participants to see one another using video and chat to both respond to questions by the moderator and engage each other during the meeting.

## Leadership Council Quick Poll: Voting During and Before COVID-19

**This Election: How Are You Voting?**



**Last Election: How Did You Vote?**



# Patient Update: Teleconference Format

## Why are you voting using this method (in person, mail in, etc.)?



*I am voting in person. I really enjoy voting as a tradition. I would hate to miss out on that due to a disease (COVID-19). Besides, in Missouri, you have to vote by mail, and I don't want to pay a notary for that. – Jed F.*

## What should patients know about cold and flu season?



*What it's like to go to the emergency room for an unrelated thing (non-respiratory) if you have a chronic condition. - Charis H.*



*It is important when distinguishing between COVID-19 symptomology and chronic illness symptoms which could overlap (as in a RA or lupus flare with fever and fatigue, etc.). - Beth M.*

## What can the GHLF do to better support your emotional wellbeing and mental health?



*Online events work great for what we can do now. Bringing everyone together. Bingo was great. - Eileen D.*



*More game nights would be fun. - Charis H.*

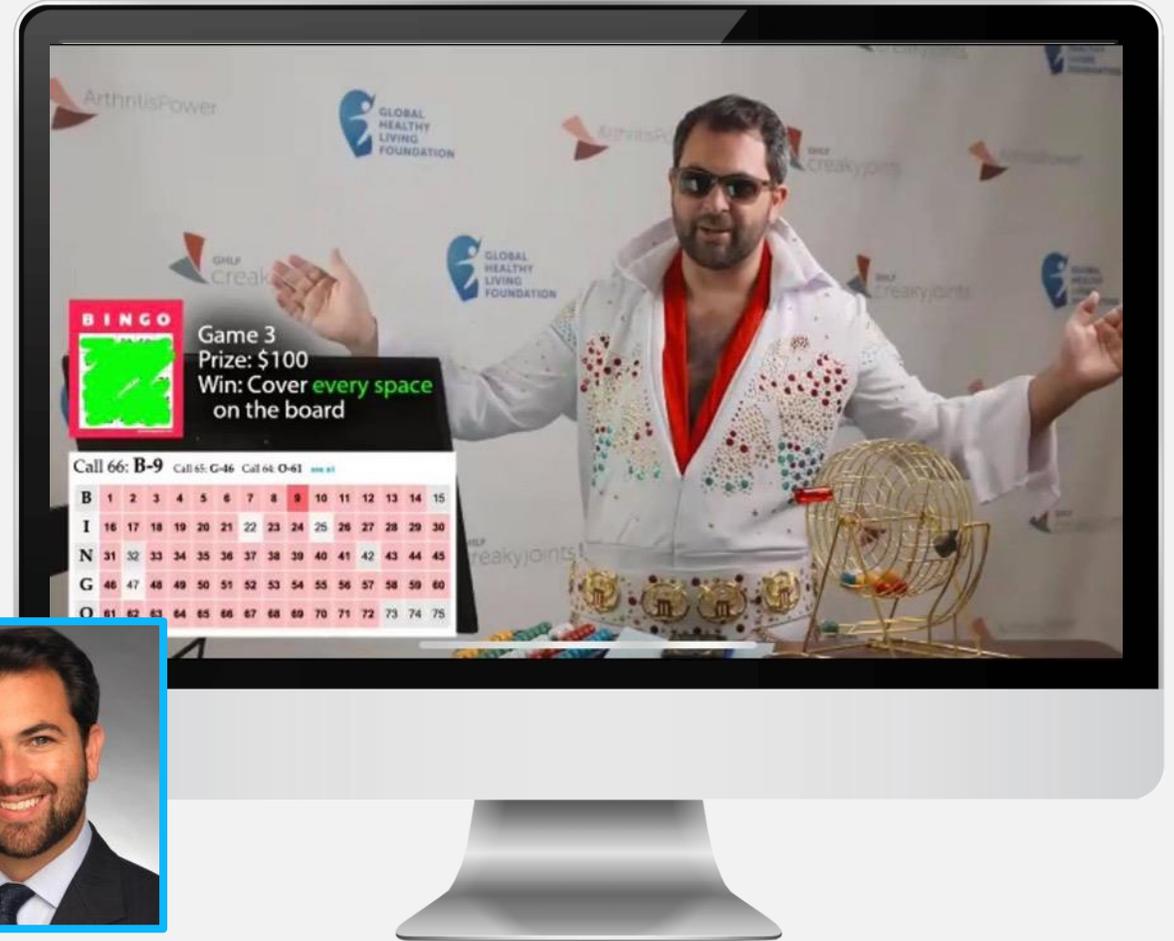


*Social events like bingo where there was an opportunity for people to connect with others. - Jennifer W.*

# B-I-N-G-O!

## GHLF Hosted Our First Ever Virtual Bingo Tournament

We brought together patients for an evening of fun and prizes to find a bright spot in these difficult times. Patients seemed to love it, but not as much as our host – GHLF Co-Founder Seth Ginsberg.



# Advocacy and Policy Update: Legislative Outreach

GHLF is conducting virtual meetings with state legislators to share our support related to Covid-influenced vaccine access, telehealth expansion, as well as promoting access to at home infusion services. We have recently advocated for patient-centered policies through meetings with:



Representative  
Garnet Coleman (D  
Texas 147<sup>th</sup>)

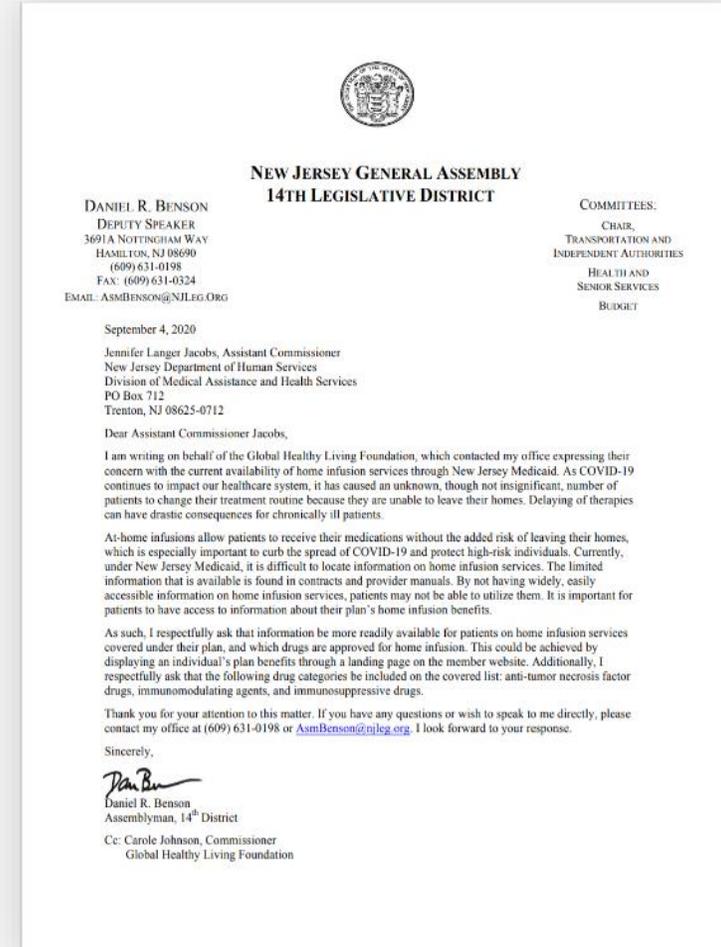


Assemblyman  
Daniel Benson (D  
New Jersey 14<sup>th</sup>)



Senator Laura  
Murphy (D  
Illinois 28<sup>th</sup>)

Additionally, GHLF worked closely with Assemblymember Benson on a letter to the New Jersey Department of Human Services raising concerns about Medicaid beneficiary access to home infusion, a critical service during the pandemic.



# 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))