

Global Healthy Living Foundation COVID-19 Patient Impact & Insights



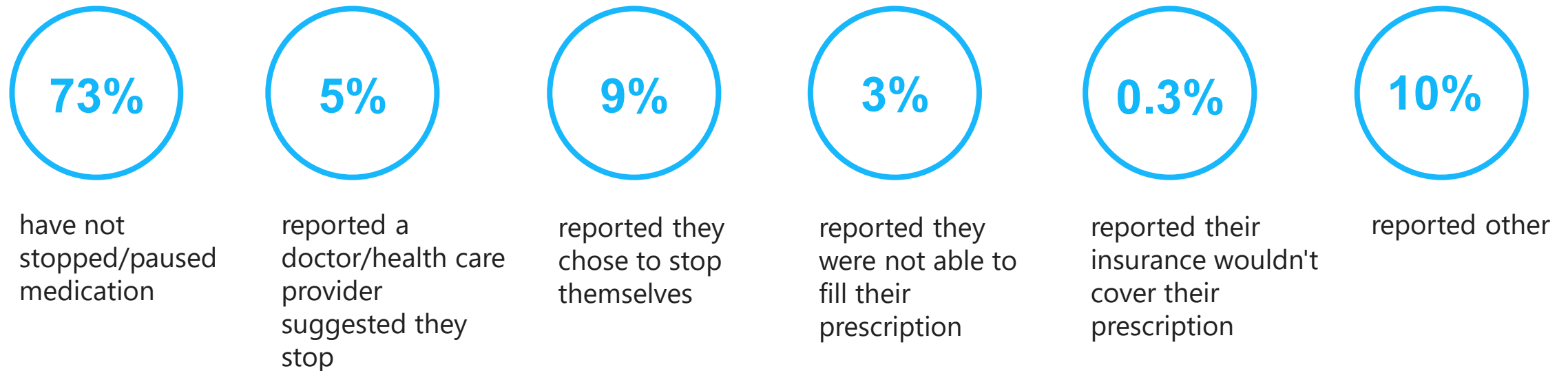
- Patient Support Program with personalized email newsletters
- Education across GHLF.org + CreakyJoints.org
- Support across Facebook, Twitter, Instagram
- Patient Leadership Council insights
- Research via The Arthritis & Rheumatic Disease COVID-19 Project
- Spanish-language resources

Week of April 13, 2020

Patient Support Program Community Poll

Have you stopped or temporarily paused any of your medications because of having COVID-19 or concerns around coronavirus?

718 Responses:



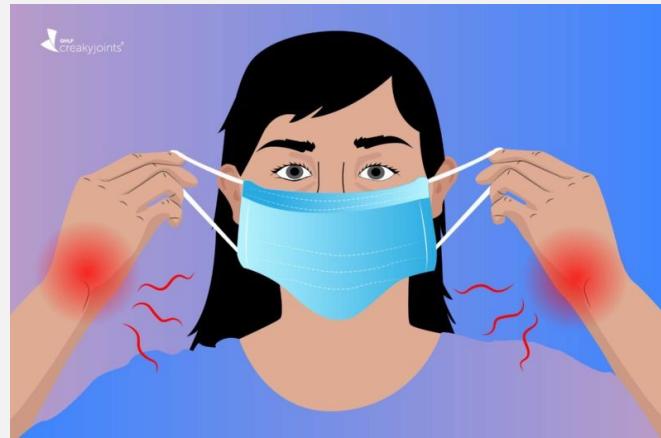
Top New Resources This Week

1.



Botox for Migraine During COVID-19: What If You Can't Get Botox to Prevent Migraine Attacks?

2.



Rheumatoid Arthritis and Coronavirus: What RA Patients Should Know About Managing COVID-19 Risk

3.



20+ Gentle Stretches for Arthritis You Can Do Every Day at Home

Top Content on Social Media

Facebook

 **CreakyJoints**
April 15 at 3:51 PM · 🌐

"Two weeks. Two agonizing weeks during which I weighed the pros and cons of receiving my monthly infusion amidst the coronavirus pandemic." Can you relate?



CREAKYJOINTS.ORG

I Was Dreading My Biologic Infusion Because of COVID-19 Fears. Instead, It Made Me the Most Grateful I'd Felt in Weeks.

👍❤️ 93 27 Comments 25 Shares

Twitter

 **CreakyJoints.org** @CreakyJoints · Apr 14


People with [#rheumatoidarthritis](#) are considered in a higher-risk group for potential [#COVID19](#) complications. Follow this guidance to stay safe and healthy through the pandemic: [creakyjoints.org/living-with-ar...](https://creakyjoints.org/living-with-arthritis) [#HighRiskCovid19](#)




Rheumatoid Arthritis and Coronavirus: What RA Patients Should Kno...
Learn more about why people with RA have a higher potential risk of COVID-19 complications and what to do to protect yourself.
creakyjoints.org

💬 7 ↻ 41 ❤️ 69 ↗

Instagram

 creaky_joints • Follow



50+ People Share What It's Like to Have an Arthritis Flare During the Coronavirus Pandemic

❤️ 💬 📌

135 likes

The Conditions Our Patient Leadership Council Represents

The COVID-19 Patient Leadership Council is a group of 18 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**

Patient Leadership Council Insights

How do you think the people in your disease communities are feeling in terms of their own levels of anxiety?

58%

much more
anxious than usual

33%

slightly more
anxious than usual

8%

slightly less
anxious than
usual

How do you think the people in your disease communities are feeling in terms of their own levels of depression?

33%

much more
depressed than
usual

50%

slightly more
depressed than
usual

17%

slightly less
depressed than
usual

Have you heard about any of the following access issues among patients in your disease community?

92%

Issues with access to
medication(s) (such as
problems getting
medication(s) or problems
with insurance coverage)

67%

Difficulties seeing a
health care provider for
routine visits

67%

Difficulties paying for
rent and/or living
expenses

58%

Issues with access to in-
office treatment (such as
infusions)

58%

Issues with access to
groceries or other
household staples

33%

Difficulties seeing a
health care provider
for urgent or
emergency visits

Have you heard in your disease community that people are stopping treatment?

50%

No

42%

Yes, stopped by
choice

17%

Yes, stopped by
health care provider

17%

Yes, stopped by
pharmacy or
insurance provider

The Most Pressing Issues Right Now



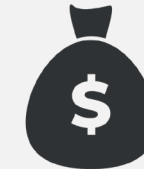
Access to medication



Inability to see health care providers



Changing medications without a face-to-face meeting with a doctor



Difficulties with living expenses



Getting cut off from Plaquenil/hydroxychloroquine or fighting to keep getting it



Getting groceries (people don't have enough money, can't get delivery, or worry about getting infected)



Botox for migraine appointments are being cancelled

On Our Minds

How will re-opening the economy impact the #HighRiskCovid19 community?

COVID-19 Cases in Chronic Illness Communities

Are you hearing of COVID-19 cases in your disease community? If so, how are they being addressed?

“

I see reports from people on Facebook about being COVID-positive. Their posts get hundreds and hundreds of comments from others who are either giving well wishes or wanting to know about symptoms/what treatments they were already on, how they are treating COVID, and more. I have seen some medical professionals in those groups (who live with ankylosing spondylitis) comment asking that other patients (who don't have COVID) talk to their rheumatologists before changing meds.

“

People are having trouble getting access to testing. They fear going to the hospital to be tested and being turned away, but then contracting the disease when they go for other things. Surgeries they told were essential are being postponed in areas like NYC that are hit the hardest.

“

I have heard of cases in the HIV community and, no, they have not been addressed.

“

In my Facebook group we have had some people who were faking for attention. Unfortunate. A few people have said they were being tested, but I have not heard about any positive cases. The reactions have been a mix of sympathy and people trying to sell snake oil to cure it.”

The Arthritis & Rheumatic Disease COVID-19 Project

GHLF's research team has developed an IRB-approved, patient-powered study to understand the concerns and behaviors of patients with autoimmune, rheumatic, and related conditions during the COVID-19 pandemic. This includes Crohn's and colitis, multiple sclerosis, and vasculitis groups that, along with CreakyJoints, are part of the PCORI-funded Patient-Powered Research Network. It is the only longitudinal study available for patients to join directly. It is designed so academic partners can also easily gain IRB approval and participate. Unique surveys will ask patients about their respiratory illness symptoms, experiences of COVID-19 testing, modified doctor visits using telehealth, concerns and choices regarding immunosuppressive therapy, and preferred sources of information about COVID-19.

Since the soft launch on March 29, 2020, we've heard from more than 2,200 people living with arthritis and rheumatic disease in the United States and Canada. The official launch will include GHLF's extensive social and conventional media outreach. Insights to date include:

14 %
**showed
respiratory
illness**

3%
**got tested for
COVID-19**

1%
**diagnosed with
COVID-19**

29%
**accessed
telehealth**



Spanish-Language Programming

In early March, a CreakyJoints survey revealed different COVID-19 educational needs among U.S. English and Spanish speakers:

Just **28%** of English-language survey respondents said they were not self-isolating

But **90%** of Spanish-language survey respondents said they were not self-isolating

From the very beginning, we made coronavirus resources available in Spanish-language versions. This includes:

- Patient Support Program (Recursos Importantes Sobre El Coronavirus Para Pacientes Con Condiciones Crónicas)
- CreakyJoints Spanish-language Instagram posts
- COVID-19 articles on creakyjoints.org.es
- Surveys and polls available in Spanish
- Arthritis & Rheumatic Disease COVID-19 Project research registry available in Spanish

