

Global Healthy Living Foundation COVID-19 Patient Impact & Insights



Weeks of April 20 and April 27, 2020

- Patient Support Program with personalized email newsletters
- Education across GHLF.org + CreakyJoints.org
- Support across Facebook, Twitter, Instagram
- Patient Leadership Council insights
- Research Dissemination via a National Briefing with the CDC
- Promotion of Spanish-Language Research Registry

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

13,043
Number of members

42%
Email open rate
(health industry average = 22%*)

14%
Email click rate
(health industry average = 2.5%*)

Top Conditions:



32%

Rheumatoid Arthritis



16%

Lung Disease



14%

Psoriatic Arthritis or Psoriasis



9%

Diabetes



9%

Migraine



8%

Heart Disease



8%

Inflammatory Bowel Disease

Patient Support Program Community Poll

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

Have you experienced changes to your doctor or health care provider visits in the past 6 weeks?

52% Have visited with their provider over the phone or video call

25% Have had routine visits rescheduled

9% Have had treatment visits rescheduled

3% Have not been able to schedule urgent or emergency visits

15% Have had routine visits cancelled

6% Have had treatment visits cancelled

18% Have not had changes to their scheduled visits



Health Care Provider Visits: What Our Members Are Saying

“

I give myself weekly Zarxio shots now after two years of receiving them at the office.

“

Putting off my hip surgery.

“

My blood tests are now every three months instead of every month which I am not happy about.

“

I have been told [I] will not get B12 injections ... it's not considered important, which is crazy. I need these every 8 weeks.

“

I have not been able to complete testing to receive a proper diagnosis and further treatment.

“

I am supposed to have a blood test every two months and I doubt I will be able to keep that schedule. I am not sure if the lab is open, but I do know my senior taxi service is on hold so I wouldn't be able to get there anyway.

“

I can't get hold of anyone at all.

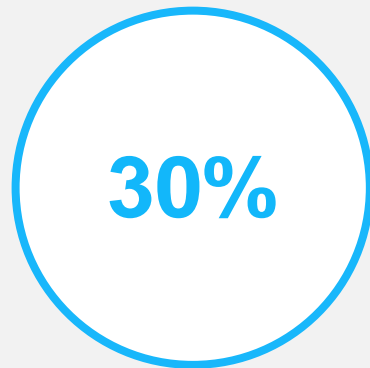
“

Quick phone call, doctor seemed rushed.

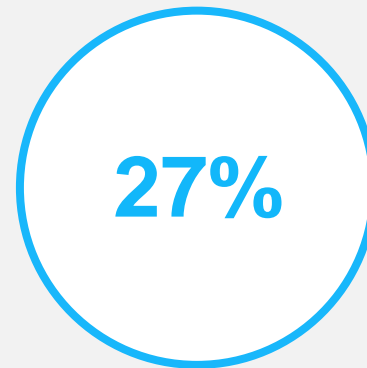
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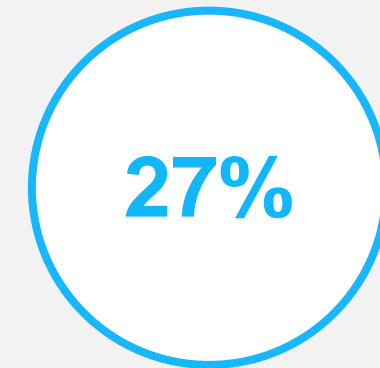
In the past month, how do you believe your eating habits have changed?



Have eaten a little to a lot more **junk** food than usual



Have eaten a little to a lot more **healthy** foods than usual



Have **not changed** their eating habits

Eating Habits: What Our Members Are Saying

"I am having trouble paying for groceries and therefore I have to eat only what I can afford to buy."

"Stress Eating."

"Depends on my pain level."

"I have learned to cook with non-fresh food."

"My eating disorder was triggered more."



Top New Resources This Week

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



[I'm a 35-Year-Old Mother with Stage 4 Colon Cancer. The Coronavirus Pandemic Has Postponed the Clinical Trial That Could Save My Life](#)



[What Your Myers-Briggs Personality Type Reveals About How You're Coping with the Coronavirus Pandemic](#)

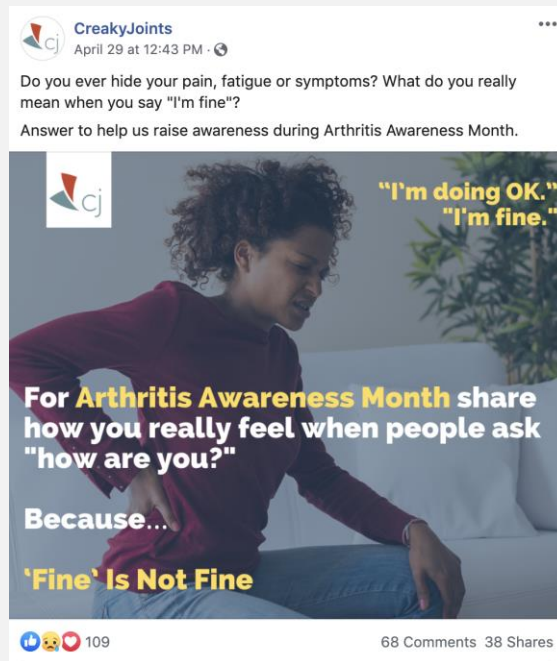


[You're High Risk and Your Partner Has to Work Outside the Home: 7 Coronavirus Precautions to Take](#)

Top Content on Social Media

These are the top resources from our social media channels over the past two weeks, according to engagement on social media platforms and internal traffic and engagement data.


Facebook



CreakyJoints
April 29 at 12:43 PM · 🌐

Do you ever hide your pain, fatigue or symptoms? What do you really mean when you say "I'm fine"?

Answer to help us raise awareness during Arthritis Awareness Month.



**"I'm doing OK."
"I'm fine."**

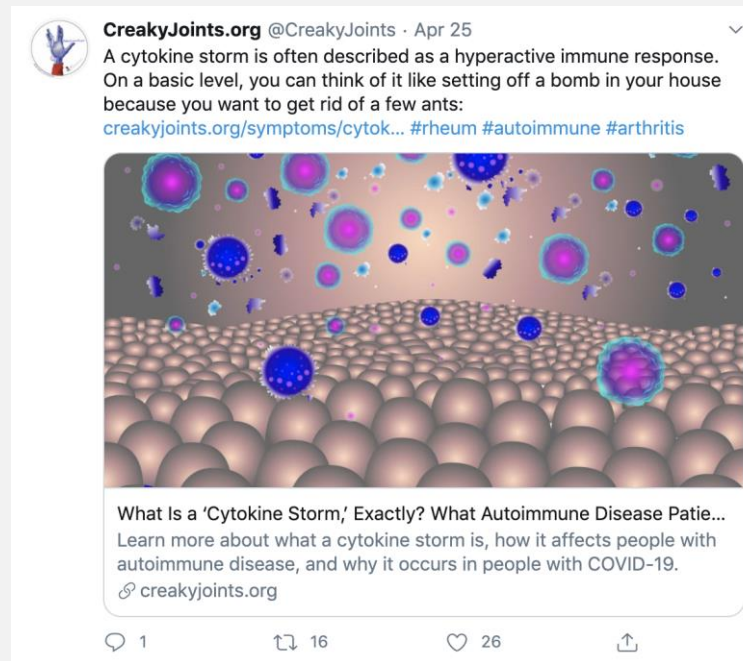
For Arthritis Awareness Month share how you really feel when people ask "how are you?"

Because...

'Fine' Is Not Fine

👍👎🗨️ 109 68 Comments 38 Shares

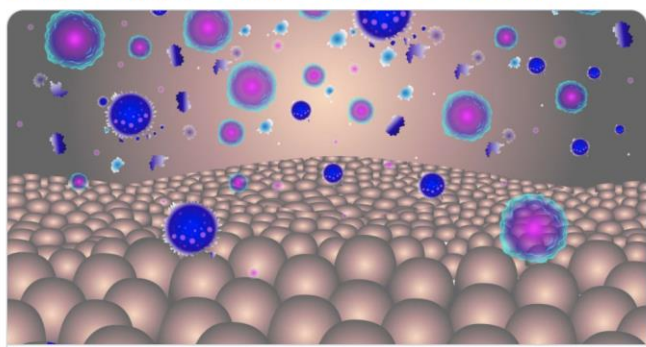
Twitter



CreakyJoints.org @CreakyJoints · Apr 25

A cytokine storm is often described as a hyperactive immune response. On a basic level, you can think of it like setting off a bomb in your house because you want to get rid of a few ants:

creakyjoints.org/symptoms/cytok... #rheum #autoimmune #arthritis



What Is a 'Cytokine Storm,' Exactly? What Autoimmune Disease Patie...
Learn more about what a cytokine storm is, how it affects people with autoimmune disease, and why it occurs in people with COVID-19.

creakyjoints.org

🗨️ 1 ↻ 16 ❤️ 26 ↗

Instagram



creaky_joints • Follow



"I Wanted So Badly to Skip My Biologic Infusion for Rheumatoid Arthritis. It Was Oddly Normal and Reassuring." -Dibs

👍🗨️🚩

126 likes

3 DAYS AGO



#CreakyChats Twitter Chat

Our April 22 #CreakyChats was co-led by our Patient Council leaders who started the #HighRiskCovid19 movement on Twitter.

7.8M

Impressions

801

Tweets

110

**Participant
s**

Topics discussed:

- Self-care is important, especially in stressful times. What are you doing to take care of yourself?
- At this moment, what is your biggest concern regarding the COVID-19 pandemic?
- Last night patient leaders started a hashtag called #OpenAtMyHighRisk. What would opening the economy, without adequate safeguards, feel like for you?
- Have you missed or had to cancel scheduled health care visits or treatments because of the pandemic? If so, how are you managing?
- More health care providers are moving to telemedicine. Have you tried it? If so, what were some of the pros and cons?
- Our parent org @GHLForg started a COVID-19 support program for people who are at higher risk for COVID complications. Where are you finding support?



Patients Are Talking About...Telemedicine

“

Had a telehealth visit with my rheumatologist today. Although glad this is available, it's just not the same. Intermittent audio and camera issues and the fact that the visit had to be conducted by what's on his computer screen made it go less smoothly. No wait time though!

— Laura T.

“

It was a great experience. Also with a new rheumatologist, first-time meeting. Used my laptop and camera so I could show her my feet, knees, hands. Great experience. I hope I continue appointments this way.

— Val M.

“

I had a phone appointment today. It was fast and easy. The one thing I would recommend: Make a list of any questions or concerns beforehand so you don't forget. It's easy to forget on the phone.

— Alison B.

“

Being able to still speak with my therapist was greatly appreciated but my rheumatology appointment felt rushed compared to an in-person visit.

— Kealie M.

“

I don't like them. At least half of medicine is observation. And this isn't good observation at all.

— Kelly C.

“

I don't have internet access at home. Telehealth does not work for me or others that are on the low end of the socioeconomic scale.

— Maureen H.

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.

These patient influencers 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**

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

Patient Leadership Council Insights

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

73%

reported slightly to much more anxious than usual

9%

reported slightly to much less anxious than usual

18%

reported no change

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

73%

reported slightly to much more depressed than usual

9%

reported slightly to much less depressed than usual

18%

reported no change

Patient Leadership Council: On Our Minds

“

I am hearing of more and more people who have had [COVID] ... If they get through it, then it knocks them down and they have worse symptoms than before and/or new symptoms.

“

Less importance placed on the risk of contracting COVID; the emphasis is changing to public demand for everything to reopen.

“

Some [COVID] deaths within the HIV community have shaken up folks.

“

People who can't make it to the doctor and/or people who are worried that if they have an emergency they will have to expose themselves.

“

Chronic illness patients are more fearful of going out now than before, with many states relaxing restrictions despite increases in case numbers.

“

I think everyone is finally exhausted. And also, politics are getting hectic within chronic communities. I've still seen some playing down the severity of COVID so we can reopen. Frankly, that's terrifying to see.

“

More people have a shortage of [hydroxychloroquine].

“

Pain levels and symptoms are up across the board. This is indicative of the stress levels people are feeling.



GHLF Teams Up with CDC on a National Briefing

The CDC, Johns Hopkins University, and University of California, Davis presented a national briefing for the chronic disease community that GHLF organized and co-hosted with the Chronic Care Policy Alliance and the Allergy and Asthma Network on April 29, 2020.

More than 60 chronic disease partner organizations who helped co-sponsor the briefing helped publicize the event. More than 1,000 people joined the [webinar](#).

Expert speakers on the panel included:

Georgina Peacock

MD, MPH, FAAP, Director, Division of Human Development and Disability, National Center on Birth Defects and Developmental Disabilities (NCBDDD), Centers for Disease Control and Prevention (CDC)

Vikram Tejwani

MD, Pulmonary and Critical Care Fellow, Johns Hopkins Pulmonary Critical Care

William Bommer

MD, FACP, FACC, American College of Cardiology, CA Chapter; Professor of Cardiovascular Medicine and Director, Noninvasive Services, UC Davis Health



GHLF Teams Up with CDC on a National Briefing (cont'd)

TOPICS INCLUDED:

- What makes an individual high-risk for coronavirus complications?
- Why are people with certain chronic conditions more severely affected than others?
- What are some of the things people living with chronic conditions can do to protect themselves against this virus?
- What are some of the treatment options for people living with chronic conditions?
- What to do and be aware of if a high-risk individual contract the virus
- What it means to safely resume everyday routines once “stay at home” orders begin to lift
- The status of testing for COVID-19 infection and antibodies

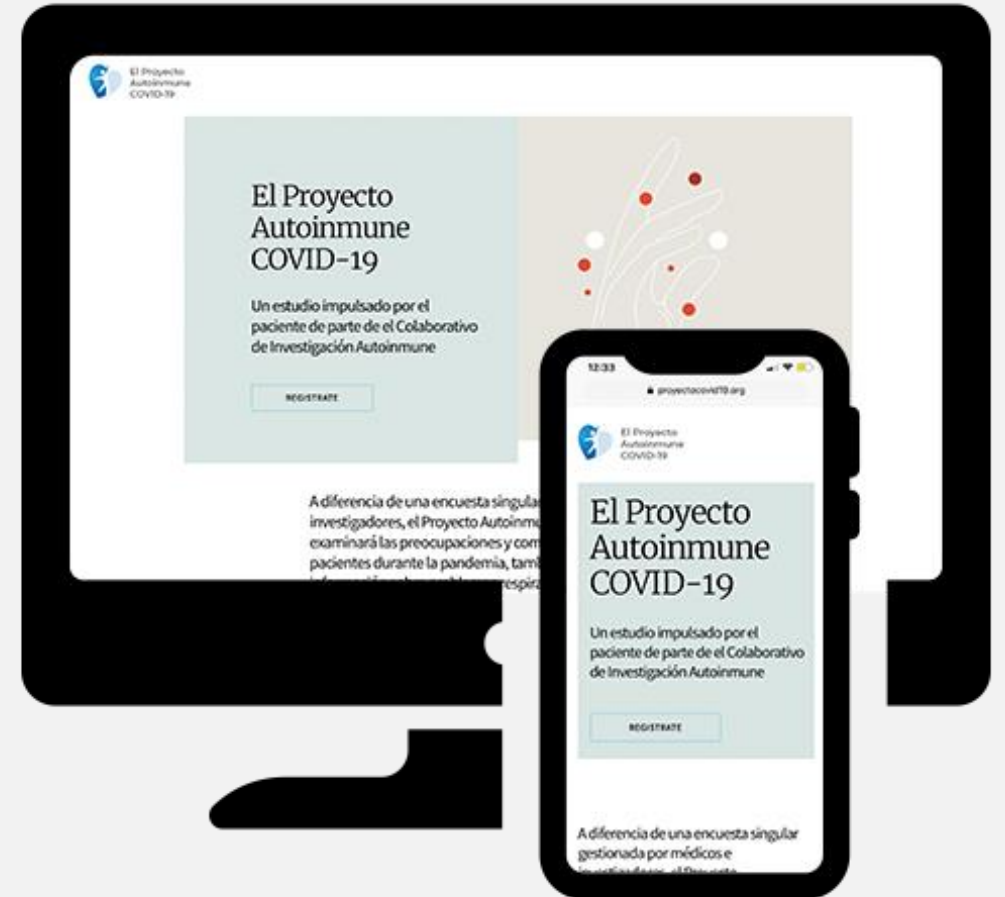
Spanish-Language Programming

We have launched and are actively promoting the Spanish-language version of our COVID-19 patient research registry, ProyectoCovid19.org.

We invited partners and key opinion leaders to encourage their patient communities to participate.

Notable Opportunity:

GHLF's Daniel Hernandez, MD, Director of Medical Affairs and Hispanic Outreach, appeared on the radio program *Hablemos de Reumatología* to speak about our COVID-19 longitudinal survey and to invite the Hispanic community to participate. This is broadcast through Radio Isla, a Puerto Rican radio station that also broadcasts outside of Puerto Rico through their Radio Isla TV platform and Facebook Live.



Advocacy Updates: Legislative Outreach

The coronavirus pandemic has swiftly and significantly impacted the lives of the chronically ill patients whom GHLF serves.

Our organization has responded urgently to the many advocacy issues related to access to health care providers and critical medications, drug shortages, and more concerns that affect our community.

Overview of our recent activities:

Legislative Outreach:

- Shared resources with the Congressional Arthritis Caucus, the Congressional Hispanic Caucus, and the National Hispanic Caucus of State Legislators
- Individually contacted and shared resources with the entire state legislature of 14 states:
 - California
 - Connecticut
 - Florida
 - Georgia
 - Illinois
 - Louisiana
 - Maryland
 - Massachusetts
 - Michigan
 - New York
 - New Jersey
 - Ohio
 - Pennsylvania
 - Texas
- Individually contacted and shared resources in Spanish with the Puerto Rico legislature
- Additional outreach to, and sharing resources with 160 members of local city councils from largest U.S. cities

Advocacy Updates: Advocacy Alerts

GHLF issues Advocacy Alerts to share important information with our patient community and encourage members to join our 50-State Network to find ways to raise their voices as patient advocates. This is a sample of recent Alerts:



Autoimmune Patients at Risk: Global Healthy Living Foundation



Protect Access to Prescription Medication During the Coronavirus Pandemic



Coronavirus Drug Shortages and Threats to the Health Care Supply Chain: What You Must Know



Fighting Against Step Therapy and Prior Authorization Requirements During the Coronavirus Pandemic

GHLF's Patient Leadership Council:



From left:

Top row: Jovana Gonzalez Placido, Daniel Garza, Tinu Abayomi-Paul, Molly Schreiber, Terrance Hill, Peter Morley

Middle row: Jed Finley, Jamie Holland, Charis Hill, Beth Madison, Jennifer Walker

Bottom row: Ebby Isbill, Catherine Charrett-Dykes, Dawn Gibson, Roxanne Watson, Diane Talbert, Ray Bouchard, Eileen Davidson

For questions or comments about this report, please contact [Lauren Gelman \(LGELMAN@GHLF.ORG\)](mailto:LGELMAN@GHLF.ORG)