



**GLOBAL
HEALTHY
LIVING
FOUNDATION**

may
2021

COVID-19
Patient Impact & Insights

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COVID-19 PATIENT IMPACT & INSIGHTS



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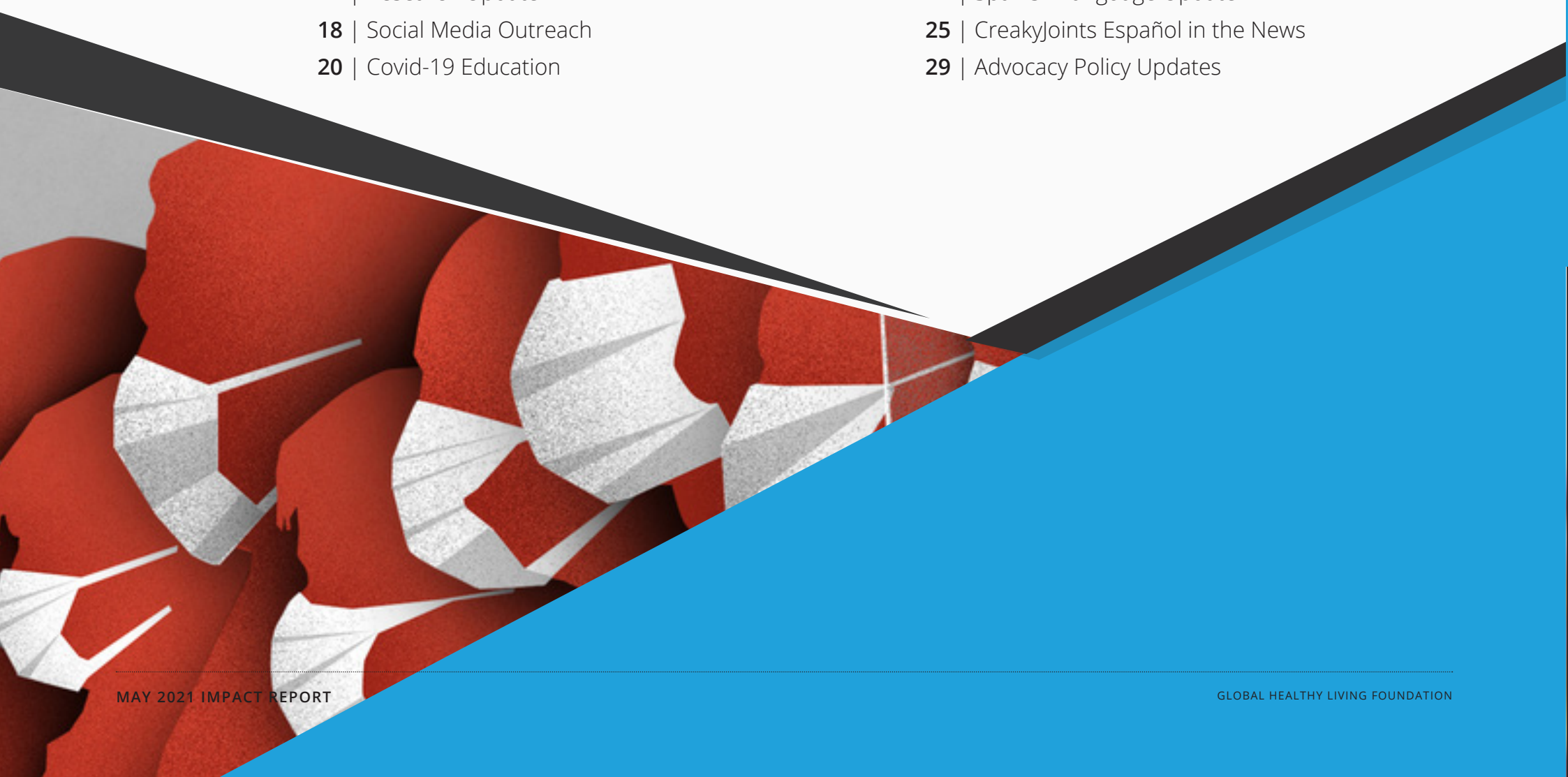
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GHLF COVID-19 PATIENT SUPPORT PROGRAM FOR CHRONIC ILLNESS PATIENTS

In mid-March 2020, 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.**

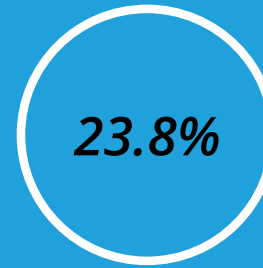
Informed by our COVID-19 Patient Leadership Council, the program is growing rapidly and meeting underserved needs of high-risk and chronic illness patients. [Go to www.GHLF.org](http://www.GHLF.org) to learn more



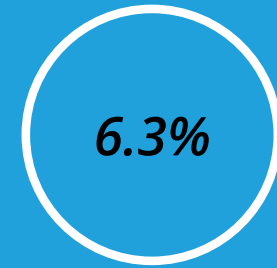
NUMBER OF MEMBERS



NUMBER OF SUBSCRIBERS



EMAIL OPEN RATE
(HEALTH INDUSTRY AVERAGE = %22*)



EMAIL CLICK RATE
(HEALTH INDUSTRY AVERAGE = %2.5*)

Source: Mailchimp Email Marketing Benchmarks

TOP CONDITIONS



31%

RHEUMATOID ARTHRITIS



19%

LUNG DISEASE



13%

PSORIATIC ARTHRITIS + PSORIASIS



15%

FIBROMYALGIA



13%

HEART DISEASE



11%

MIGRAINE



9%

DIABETES



7%

INFLAMMATORY BOWEL DISEASE

PATIENT SUPPORT PROGRAM COMMUNITY POLLS

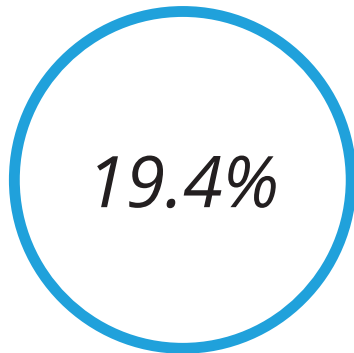


We are surveying our Patient Support Program members regularly about important issues in health care and other topics.

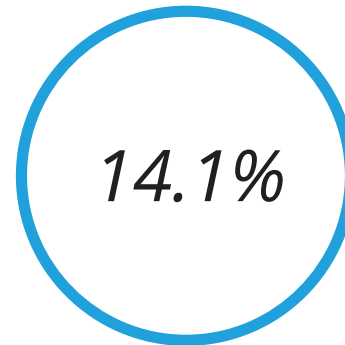
CAREGIVER MORE LIKELY TO ACCOMPANY PATIENT TO DOCTOR VISIT

A TOTAL OF 1,289

Patient Support Program subscribers responded to our April quick poll on whether they have brought a caregiver to a doctor's appointment (telehealth or in-person).

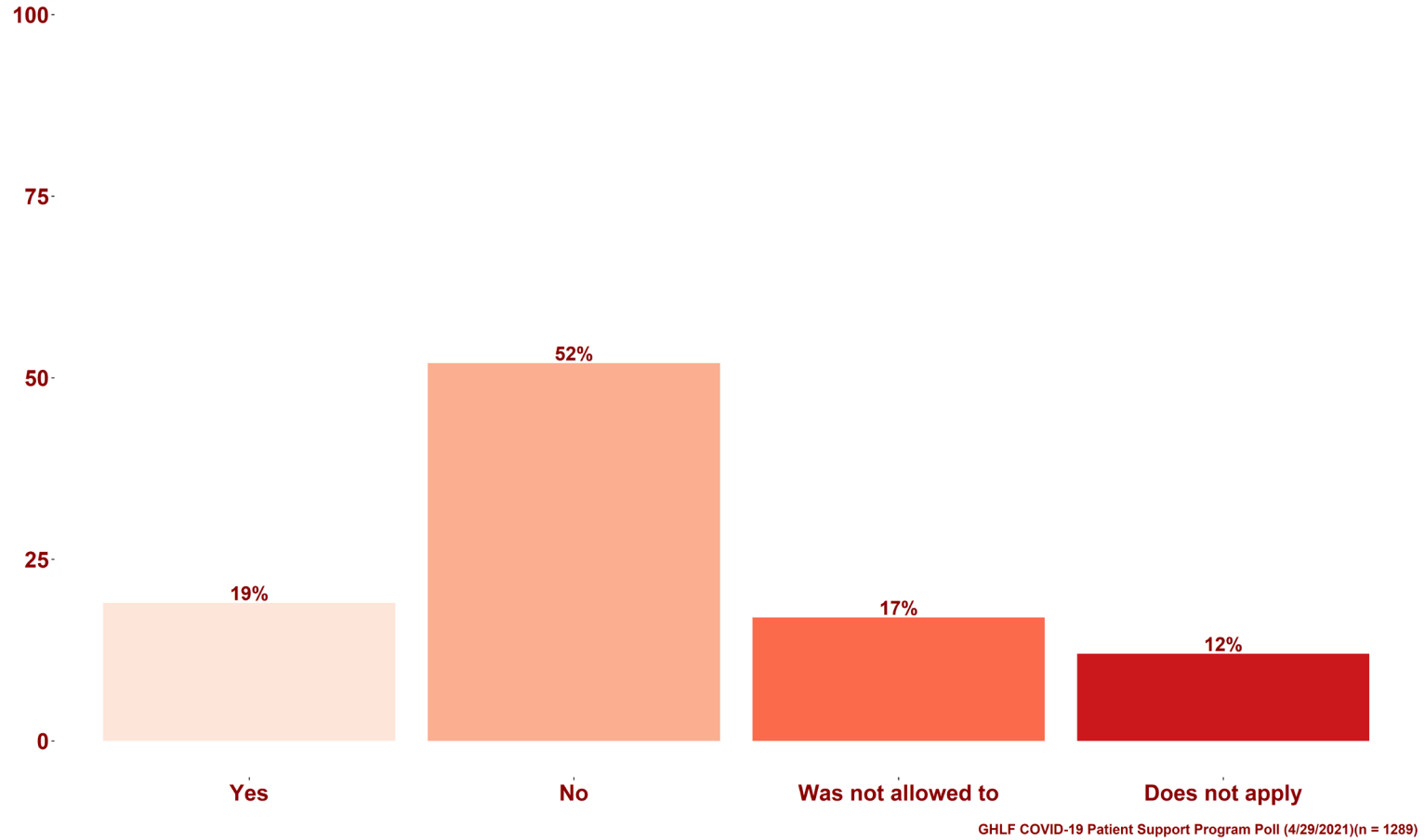


OF PATIENTS BROUGHT A CAREGIVER TO THEIR IN-PERSON APPOINTMENT,

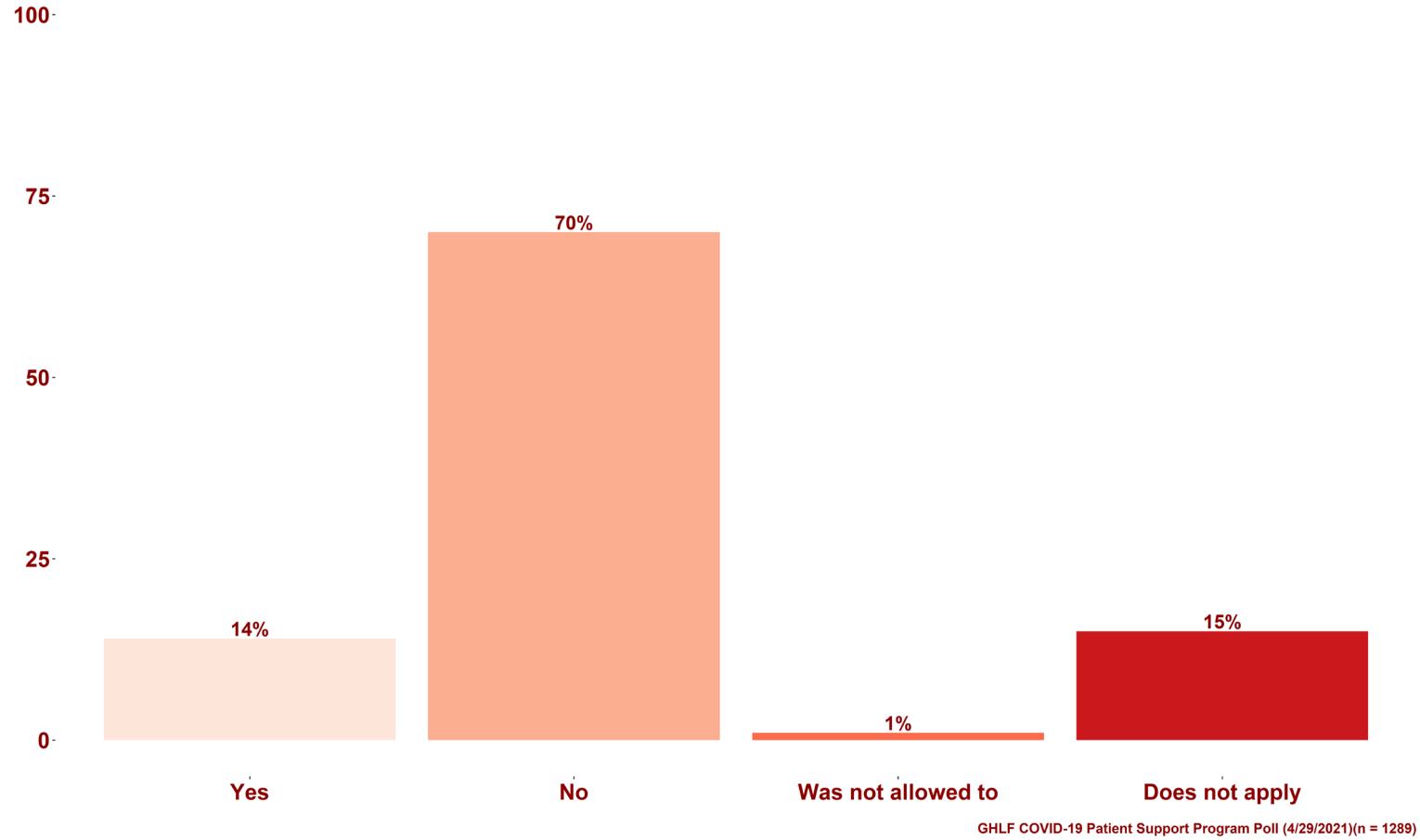


OF PATIENTS BROUGHT A CAREGIVER TO THEIR TELEHEALTH APPOINTMENT.

Since the COVID-19 pandemic began, have you brought a caregiver to an in-person appointment with your health care provider?



Since the COVID-19 pandemic began, has a caregiver joined you on a telehealth appointment with your health care provider?



When we asked respondents if they wanted to bring a caregiver to their in-person or telehealth appointment, they said YES respectively.

21.8% IN PERSON

6.4% TELEHEALTH

We also asked respondents how their health care providers felt about their caregivers joining their appointments. Here are the responses.

IN PERSON APPOINTMENT

23.3%

VERY HAPPY

24.9%

HAPPY

26.6%

NEUTRAL

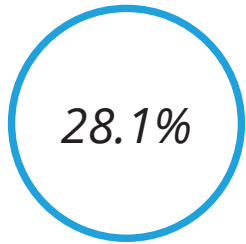
4.4%

UNHAPPY

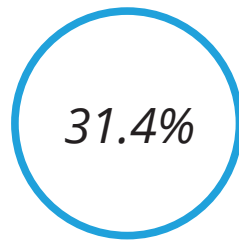
0.8%

VERY UNHAPPY

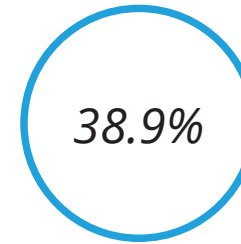
TELEHEALTH APPOINTMENT



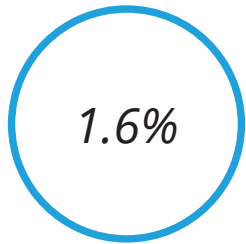
VERY HAPPY



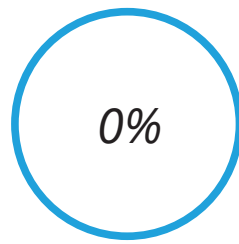
HAPPY



NEUTRAL



UNHAPPY



VERY UNHAPPY

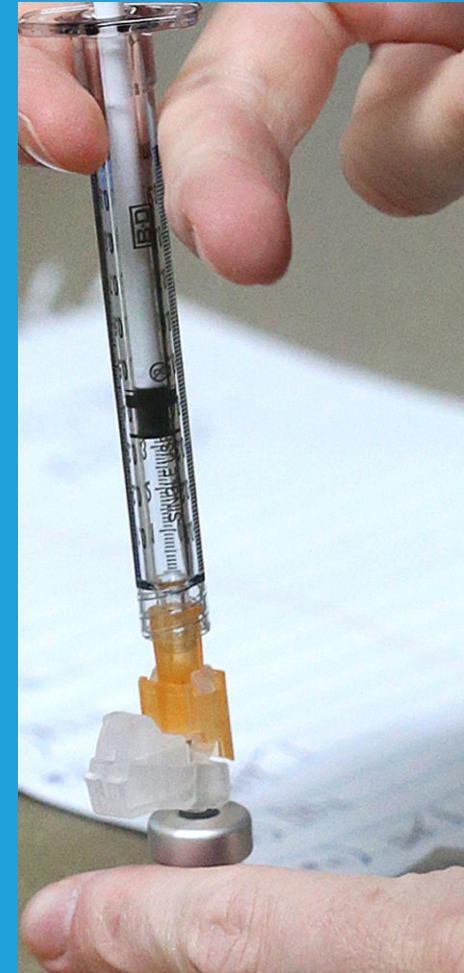
PATIENT CAREGIVERS: WHAT OUR RESPONDENTS ARE SAYING

“ A caregiver can add important information when you have an in person appointment. When this is not allowed, there are many gaps in the appointment that are so vital.

Having a caregiver present as a second set of ears is invaluable. ”

“ I am very glad that I have my advocate with me for in-person appointments with my health care provider because she takes notes to refer to later as needed, and I can just focus on my conversation with the health care provider during the appointment.

I have brain fog and difficulty keeping things straight at times. My husband helps fill in gaps if needed and more importantly he writes down notes and plan from the appointment. That way I do not have to worry about forgetting something. ”



ALTHOUGH MOST AUTOIMMUNE PATIENTS ARE VACCINATED THEY ARE STILL CAUTIOUS ABOUT SUMMER PLANS

A TOTAL OF 1,292

Patient Support Program subscribers responded to our May quick poll about what they plan to do this summer compared to last (2020).

We asked questions about accessibility to events during and after the pandemic.



75.9%

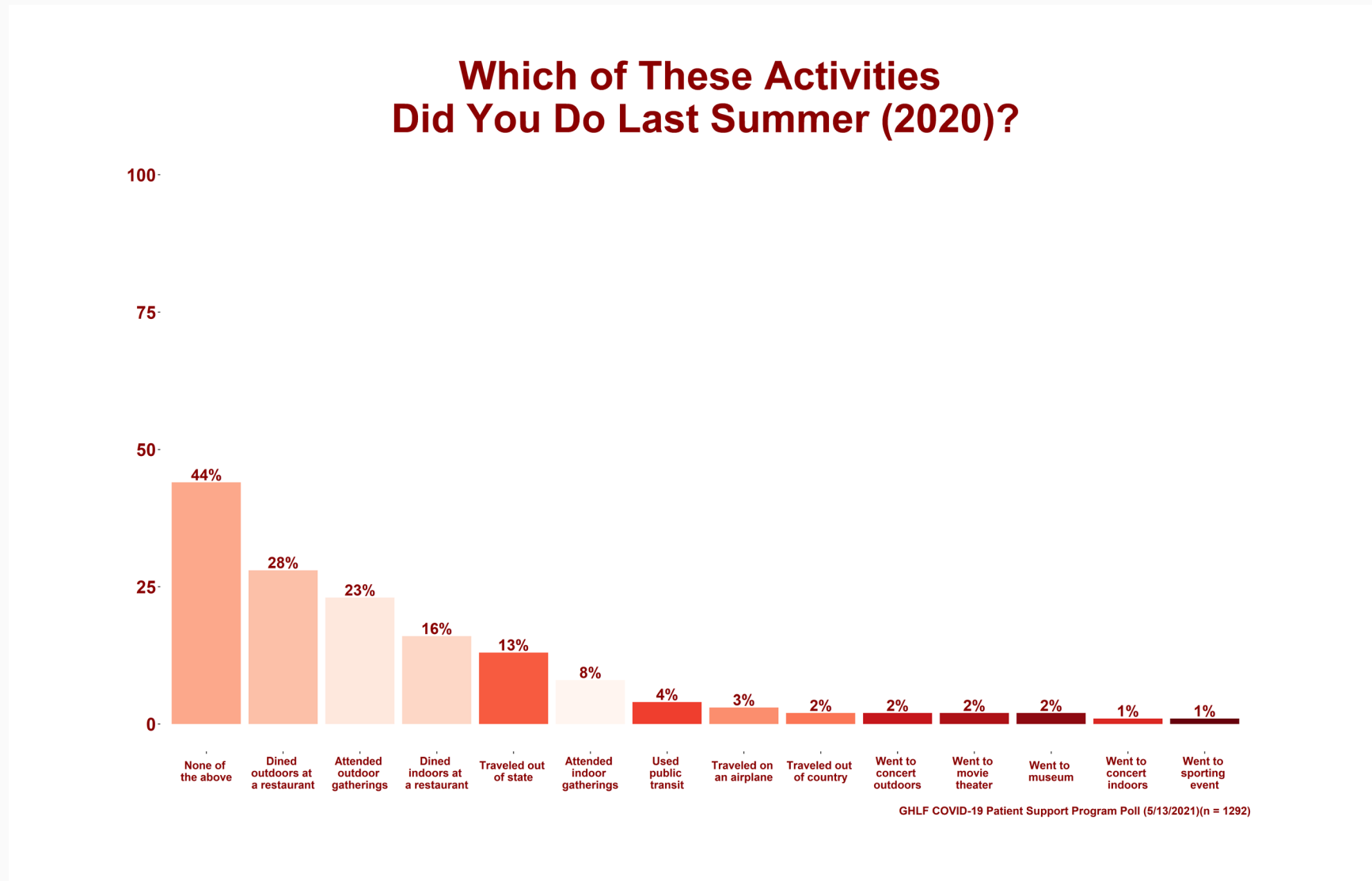
RESPONDED THEY ARE FULLY VACCINATED



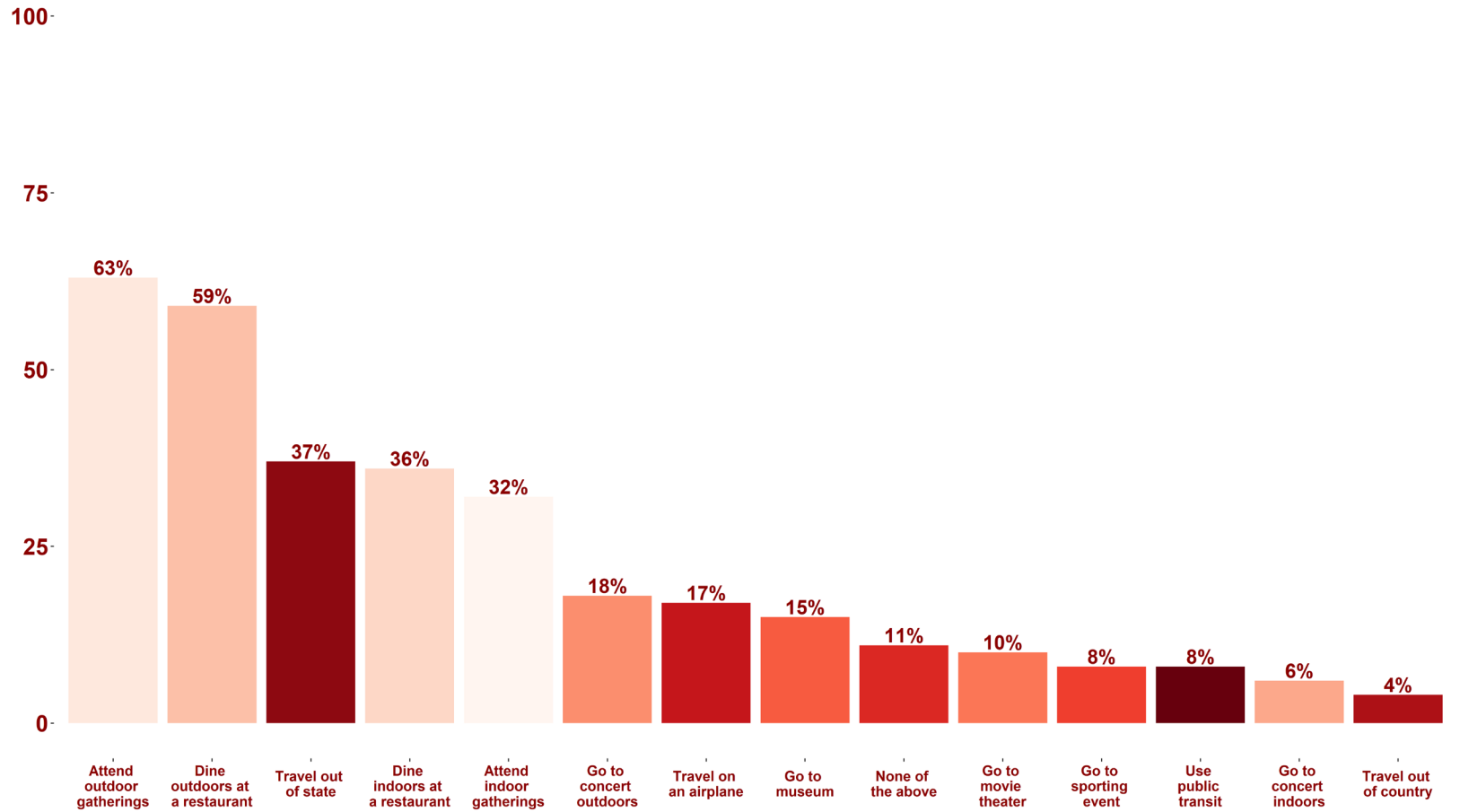
8.5%

SAID THEY WOULD BE BY JUNE

We also asked respondents to tell us activities they participated in last Summer, and what they plan to participate in this Summer. Here are the responses:



Which of These Activities Do You Plan to Do This Summer (2021)?



GHLF COVID-19 Patient Support Program Poll (5/13/2021)(n = 1292)

Relative to last Summer



SUMMER PLANS POLL: WHAT RESPONDENTS ARE SAYING

We also provided respondents the opportunity to share their thoughts or feelings about what it will be like entering the new normal as a chronic disease patient. Here is a sample of responses.

“ Being vaccinated only ensures that I won’t end up in the hospital or on a ventilator. It doesn’t mean that I can’t catch COVID! Having RA ALWAYS makes me careful and as long as COVID is around I need to maintain my vigilance.

Due to being immunocompromised and having no response to the J&J vaccine the only activity my immunologist has approved for me to do is camping as long as extreme precautions are taken. Now that restrictions are being lifted I think I am more scared now than I was just a few months ago, still so many unknowns for someone like me.”

”



“

I may feel safer with people I know who are vaccinated, but not with others. Because I am long term prednisone I do not have confidence that the vaccine will protect me personally, so need to rely on others and continue social distancing.

I am cautiously optimistic things will become more normal again. I still will avoid crowds and mask up indoors.

”

“

My family & close friends are all vaccinated so I feel safer spending time with them. We have 2 local eateries we feel safe at. Going to our parks & walking trails will be a welcome joy. We will not be taking a vacation. The rest we are playing by ear.”

“THE PATIENT,” A RESEARCH JOURNAL, ANNOUNCES GHLF’S PCORI-FUNDED VACCINE UPTAKE STUDY AWARD AMONG IMMUNE COMPROMISED PATIENTS



The GHLF-led Autoimmune Research Collaborative (ARC) is [described in “The Patient,”](#) an official journal of the International Academy of Health Preference Research

The research will present a model for the shared capacities and challenges of the Patient-Powered Research Network (PPRN). The PPRN collaborates across autoimmune conditions to design, conduct, and disseminate patient-centered outcomes research.

The study will cover autoimmune and immune-mediated conditions that make up the Autoimmune Research Collaborative. They are: ArthritisPower (rheumatoid arthritis, spondyloarthritis, and other rheumatic and musculoskeletal diseases), IBD Partners (inflammatory bowel disease), iConquerMS (multiple sclerosis), and the Vasculitis PPRN (vasculitis).



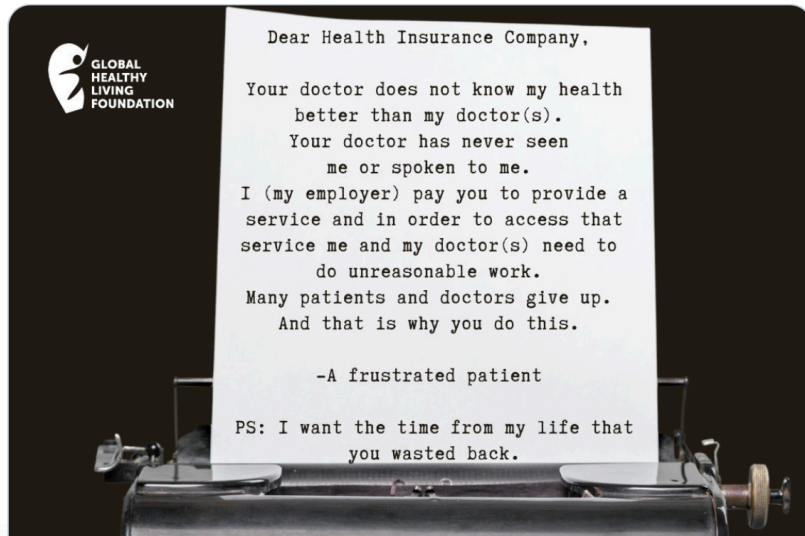
SOCIAL MEDIA

Dear health insurance company that denied my medication,

Your doctor does not know my health better than my doctor(s). Your doctor has never seen me or spoken to me.

Love,
A frustrated patient

PS: I want the time from my life that you wasted back.



CreakyJoints.org @CreakyJoints · May 18

Are you changing how/when you wear a mask based on new @CDCgov guidance?

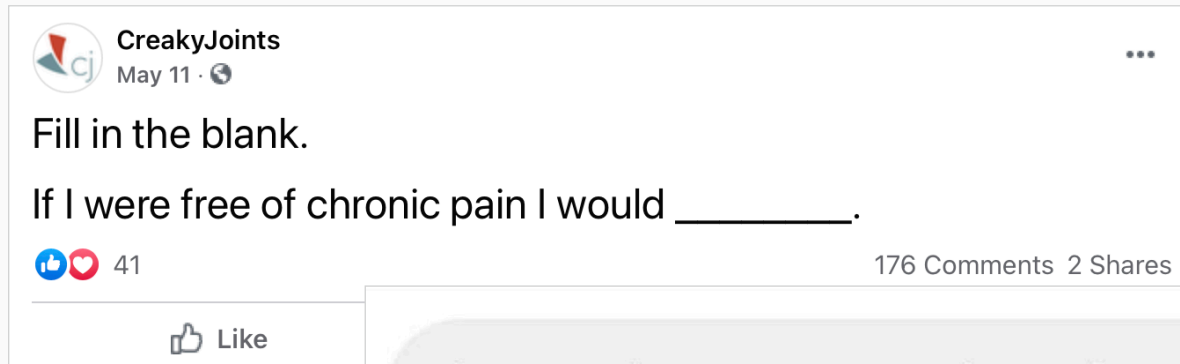
"Fully vaccinated people can resume activities without wearing a mask / physically distancing, except where required by federal, state, local, tribal, or territorial laws, rules, and regulations..."

18

8

22

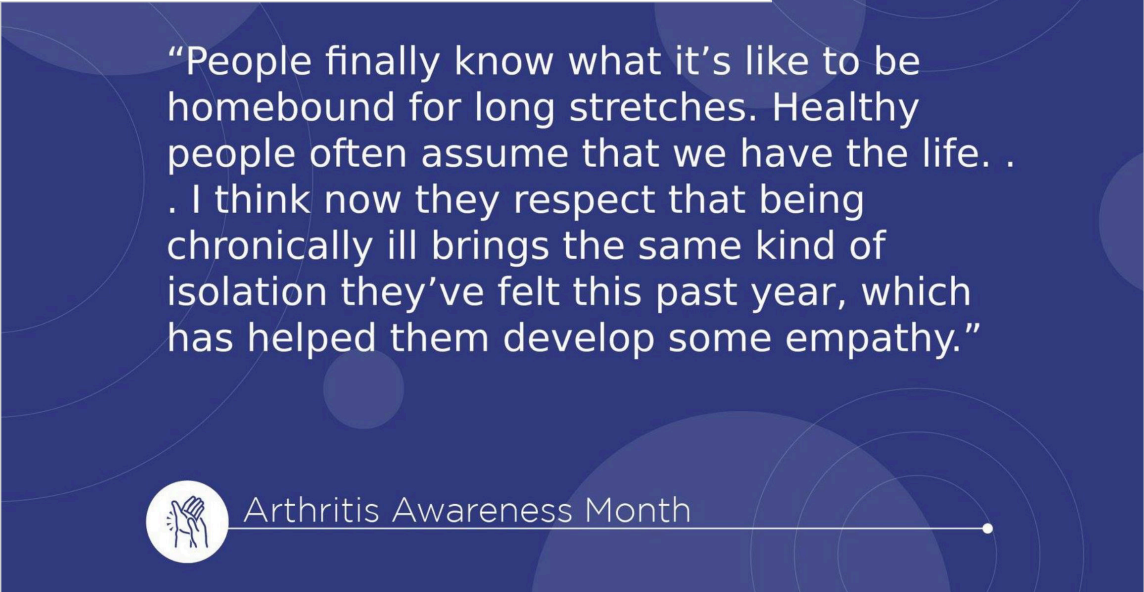




A screenshot of a Facebook post from the page 'CreakyJoints', dated May 11. The post text reads: 'Fill in the blank. If I were free of chronic pain I would _____.' Below the text, it shows 41 likes and 176 comments. A 'Like' button is visible at the bottom left of the post area.



Are others experiencing inability to get sulfasalazine???



A dark blue banner for Arthritis Awareness Month. It features a quote: "People finally know what it's like to be homebound for long stretches. Healthy people often assume that we have the life. . . I think now they respect that being chronically ill brings the same kind of isolation they've felt this past year, which has helped them develop some empathy." The banner includes the Global Healthy Living Foundation logo in the top right and an Arthritis Awareness Month logo in the bottom left.

COVID-19 EDUCATION: HELPING PATIENTS WITH THE PANDEMIC'S NEXT CHAPTER



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

Over the last month, top content has shifted to help our immunocompromised community adapt to the ever-changing pandemic landscape; specifically, changes in mask-wearing and reopening guidance. As guidance loosens and much of the country and the world continues to “return to normal,” our community has concerns, including the effectiveness of the COVID-19 vaccine among those on immunosuppressant medication.

We are reaching many thousands of rheumatic and inflammatory disease patients each day with information about COVID-19 that is targeted to them. New resources published over the past four weeks include:

[Should You Attend Weddings If You're Fully Vaccinated and Immunocompromised?](#)

[What to Know About Going Back to the Office If You're Fully Vaccinated and Immunocompromised](#)

[What Immunocompromised People Should Know About the CDC Recommendations for Outdoor Mask Use](#)

[Monoclonal Antibody Treatments for COVID-19: What Immunocompromised and Chronic Illness Patients Should Know](#)

COVID-19 VACCINE EDUCATION: ONGOING MESSAGING MEETS THE COMMUNITY'S NEEDS



CreakyJoints and the Global Healthy Living Foundation continue to regularly publish new resources about the COVID-19 vaccine specifically for the chronic illness and immunocompromised community.

We are reaching many thousands of rheumatic and inflammatory disease patients each day with information about the COVID-19 vaccine that is targeted to them. New resources published over the past four weeks include:

[Some Patients on Methotrexate May Have a Less Robust Response to the COVID-19 Vaccine](#)

[How to Talk to Vaccine Hesitant Loved Ones About the COVID-19 Vaccine If You're Immunocompromised](#)

[Juvenile Arthritis and the Pfizer COVID-19 Vaccine: What Parents Need to Know](#)

[Biologics Don't Interfere with COVID-19 Vaccine in Inflammatory Bowel Disease Patients, Study Finds](#)

[Biologics Don't Interfere with COVID-19 Vaccine in Inflammatory Bowel Disease Patients, Study Finds](#)

[Some Autoimmune Inflammatory Rheumatic Disease Patients Developed Shingles After the Pfizer COVID-19 Vaccine](#)

GHLF IN THE NEWS

[People Who Got COVID Vaccine Had These Side Effects Most](#)



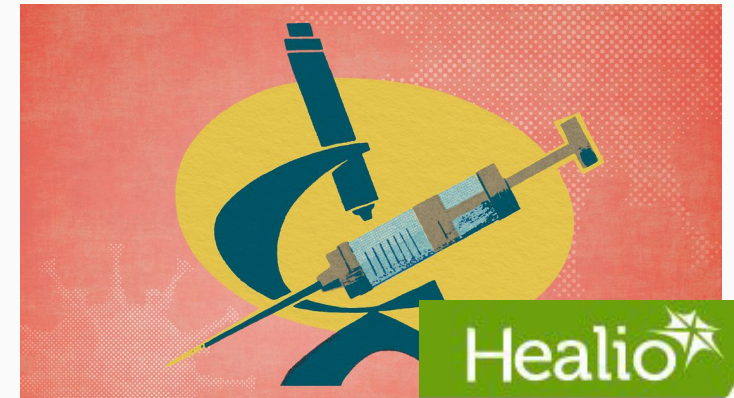
Eat This, Not That!

[Going viral: Squaring off against social media's medical misinformation 'infodemic'](#)



EVERYDAY HEALTH

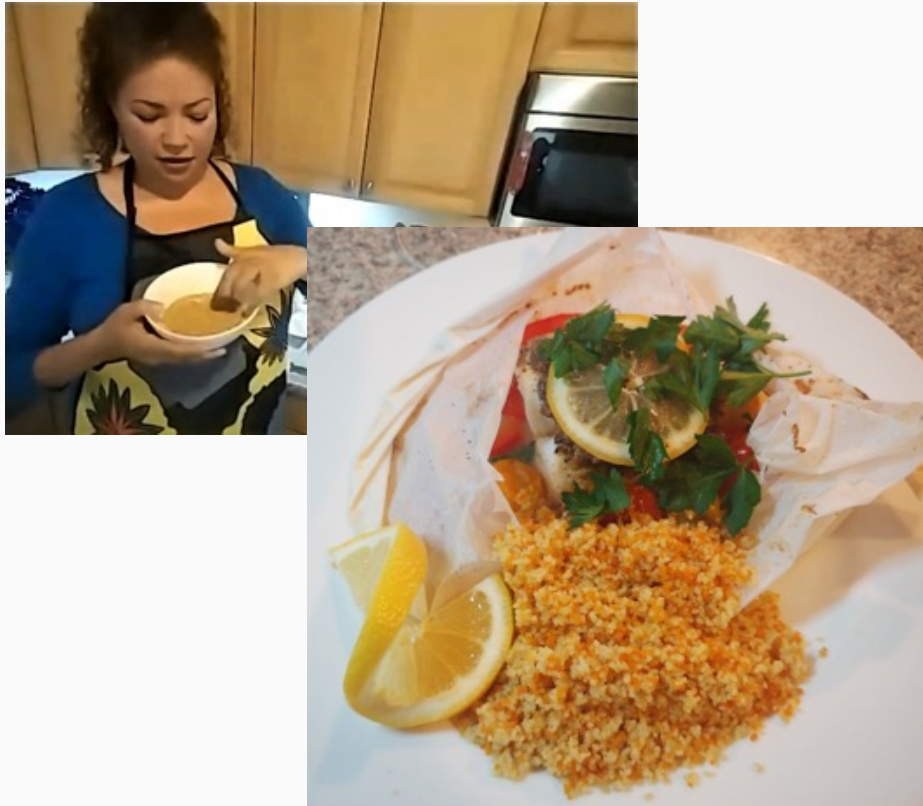
[Study Finds People on Methotrexate Mount a Weaker Immune Response to a COVID-19 Vaccine](#)



Healio

Rheumatology

CREAKYKITCHEN



CreakyKitchen Episode 7: CreakyKitchen Celebrates Arthritis Awareness Month

We continue to provide much needed entertainment during the COVID-19 pandemic. CreakyKitchen provides a way for our community to join together in a fun and stress-free environment to share strength and experience when it comes to cooking and nutrition.

In Episode 7, Chef Chantelle taught us her recipe for Fish en Papillote, an easy oven ready and tasty fish entrée. In the spirit of Arthritis Awareness Month, we were joined by @mad4minnie, @the_eds_baker, and @grabaspoonwellness who discussed how they use their social media to share posts about food and cooking while managing chronic illness.

SPANISH LANGUAGE UPDATE

CreakyJoints Español launched new social media platforms and ArthritisPower Español, continuing its mission to improve access to credible health information for Spanish-speaking people living with all forms of arthritis and their families.

ArthritisPower Español invites Spanish speakers, many of whom self-identify as Hispanic, to proactively participate in their disease management and contribute to better understanding of people living with arthritis and other inflammatory disease.

“

Part of our mission is to provide patients with opportunities to amplify their voice and feel heard.



CREAKYJOINTS ESPAÑOL IN THE NEWS

CreakyJoints Español Addresses Health Disparities Through Innovative Communication Portals

In May 2021, Outreach to reporters, combined with controlled media vehicles, delivered key messages in print, online, and broadcast to Hispanic communities across the U.S. in English and Spanish. GHLF's Director of Medical Affairs and Hispanic Outreach, Daniel Hernandez, MD, and Angel Tapia, Hispanic Patient Advocate, Community Outreach Manager, along with our Hispanic medical advisors were the primary spokespeople.



EFE America is the 4th largest news agency wire service in the world and the largest providing Spanish-language content to media outlets around the world. Featuring interviews with Daniel Hernandez, MD, Director of Medical Affairs and Hispanic Outreach, and CreakyJoints member Yaideliz Acevedo, EFE America's story ran in the top Hispanic outlets in the United States, including in print in La Opinion (Los Angeles), the largest US daily paper in Spanish.



Millones de latinos padecen artritis

Hay limitada información de ayuda en español sobre esta enfermedad

La artritis reumatoide se suma a las condiciones de salud donde los hispanos en Estados Unidos se encuentran en desventaja. Con más de 4.4 millones de hispanos diagnosticados con algún tipo de artritis, el acceso a información en español para educar a los pacientes es limitada.

Según Hernández, a través para pacientes y cuidadores, ha con condiciones reumáticas en y "La mayoría de la información prometen curar tu condición si condiciones no tienen una cura especialista", dijo.

Por ello recomendó visitar la Power, un registro de investi con condiciones articulares, óse Este tipo de herramientas di gran ayuda para Yaideliz Acevedo Nueva Jersey, quien se enfrentó de edad y en medio de un embi "Tenía 38 semanas de emba muy fuerte en mis manos. Estal era parte normal del embarazo" "El dolor en mis manos emp primeros días en casa con él, hu fuertes que ni tan siquiera podi Según Acevedo, fue su insie laboratorios y dieran con el cau: Ella jamás pensaba que un c persona joven y en el proceso d navegar por diferentes páginas "Lo primero que uno hace es

Lunes 17 de mayo de 2021 Con la comunidad hispana cada día \$1

La Opinión
laopinion.com

ALTA 68° | BAJA 57°

BELLEZA MEXICANA
Andrea Meza gana la corona de Miss Universo en un concurso marcado por la promoción de

Solo 7% de los alumnos de secundaria han regresado a las clases presenciales en LA por miedo al covid P. 2

Residentes de Boyle Heights inician huelga de hambre contra el proyecto de una torre de comunicaciones de 5G P. 2

La crisis en el Medio Oriente toma desprevenido a Biden P. 8

Pacuca elimina al América y

Broadcast Results:

- 1,432 airings from 17 interviews (volume related to 4 nationally syndicated placements; three tour interviews pending)
- 11.8M estimated media impressions
- Additional live radio interview

Highlighting Health Disparities Across the Country and with Rheumatologists



Overcoming Health Disparities by Reaching Patients With Arthritis in Their Preferred Language

Daniel Hernandez, MD

[f](#) [t](#) [in](#) [v](#) [h](#) [e](#)

The COVID-19 pandemic has highlighted significant health disparities in the Hispanic community. Although these disparities are more apparent now, inequalities, including adequate access to health care and information, among Spanish-speaking communities pre-date the current pandemic. Hispanic individuals are also underrepresented in medical research.¹

During the COVID-19 pandemic, Richardae Araojo, the US Food and Drug Administration (FDA) associate commissioner for Minority Health and the director of the Office of Minority Health & Health Equity, agreed with the premise described in a recent CenterWatch article that, "Clinical trial researchers should include input from patients before the trial design and consent process even



Daniel Hernandez, MD, is Outreach at the Global Health CreakyJoints/CreakyJoints International Medical Group National Hispanic Medical



CreakyJoints Espanol Strives to Close the Gap in Healthcare Disparities

May 25, 2021
Lana Dykes

[f](#) [t](#) [in](#) [v](#) [h](#) [e](#)



Rheumatology Network sat down with Daniel Hernandez, MD, and Shilpa Venkatachalam, PhD, MPH, of CreakyJoints to highlight health disparities in marginalized communities and introduce their exciting new venture, CreakyJoints Espanol.



Shilpa Venkatachalam, PhD, MPH
CreakyJoints/Global Healthy Living Foundation/Arthritis Power



SPANISH EDUCATION AND SUPPORT

We continue to provide up-to date information during the COVID-19 pandemic, focused on addressing health equity, doctor-patient relationships, vaccine information, and wellness through our CreakyJoints Español properties and partnerships:



REGISTRATE: Vacunas contra el Covid-19 y Artritis Inflamatoria: Una Discusión con una Reumatóloga

GHLF creakyjoints® ESPAÑOL **lunes, 17 de mayo** **HSS**

Desigualdades en La Salud Hispana en EE.UU. - A Través de La Perspectiva del Paciente:

Presentado por Global Healthy Living Foundation

ADVOCACY AND POLICY UPDATE

GHLF continues to submit letters to policymakers around the country to ensure patients have access to care without obstacles, especially now during COVID-19. We have been focused on protecting patient access to medication and raising the voice of patients living with chronic disease.

The op-ed entitled [“California Is Last When It Comes to Protecting Patients’ Rights”](#) by Morgan Fitzgerald, 50-State Network patient advocate, was published in The Coast News. Morgan shares her story in support of reforming step therapy legislation to protect Californian’s access to medications.

Here are May’s comment letter to legislators:

[Letter in Support of Rhode Island Bill S0859](#)

[Letter About North Carolina Gout Medication Coverage Policies](#)

[Letter About South Carolina Gout Medication Coverage Policies](#)

[Letter to Speaker Pelosi about H.R.3](#)





PATIENT LEADERS IN OUR PATIENT SUPPORT PROGRAM

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)

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april
2021

COVID-19

Patient Impact & Insights

