



**GLOBAL
HEALTHY
LIVING
FOUNDATION**

summer
2021

COVID-19
Patient Impact & Insights

WEB:
www.ghlf.org

PHONE/EMAIL:
845 348.0400
advocacy@ghlf.org

ADDRESS:
515 N. Midland Avenue
Upper Nyack, NY 10960

COVID-19 PATIENT IMPACT & INSIGHTS



03 | Patient Support Program Updates

04 | Patient Support Program Community Polls

17 | Research Update

18 | Social Media Outreach

20 | Covid-19 Education

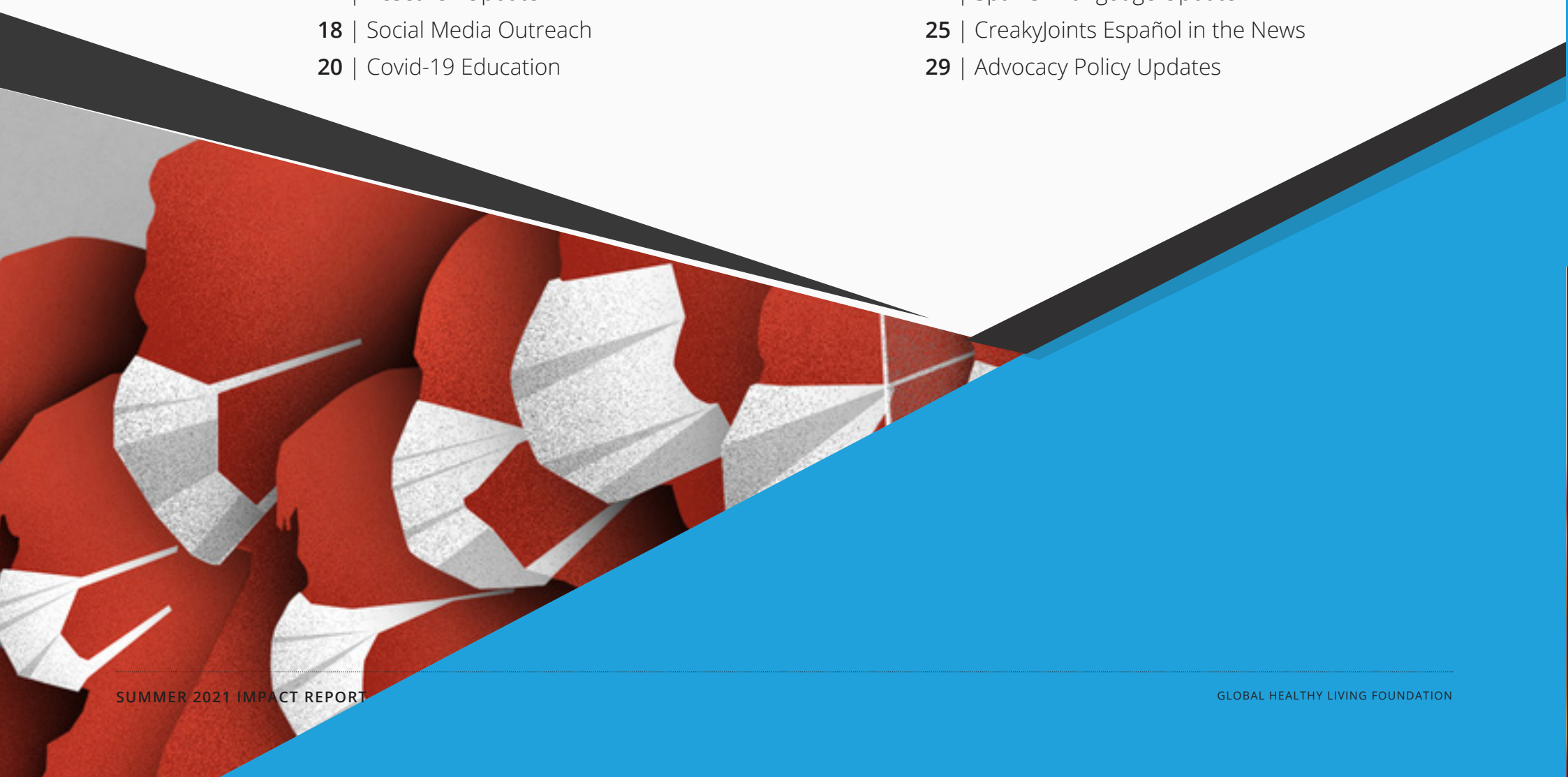
22 | GHLF in the News

23 | CreakyKitchen

24 | Spanish Language Update

25 | CreakyJoints Español in the News

29 | Advocacy Policy Updates



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.**

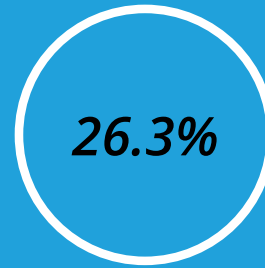
Informed by our COVID-19 Patient Leadership Council, the program is growing rapidly and meeting underserved needs of high-risk and chronic illness patients. [Go to www.GHLF.org to learn more](http://www.GHLF.org)



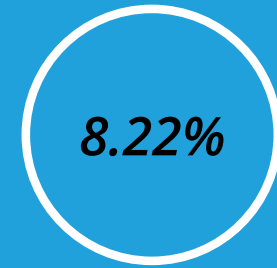
NUMBER OF MEMBERS



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



18%

LUNG DISEASE



13%

PSORIATIC ARTHRITIS + PSORIASIS



15%

FIBROMYALGIA



14%

HEART DISEASE



11%

MIGRAINE



9%

DIABETES



7%

INFLAMMATORY BOWEL DISEASE

PATIENT SUPPORT PROGRAM COMMUNITY POLLS

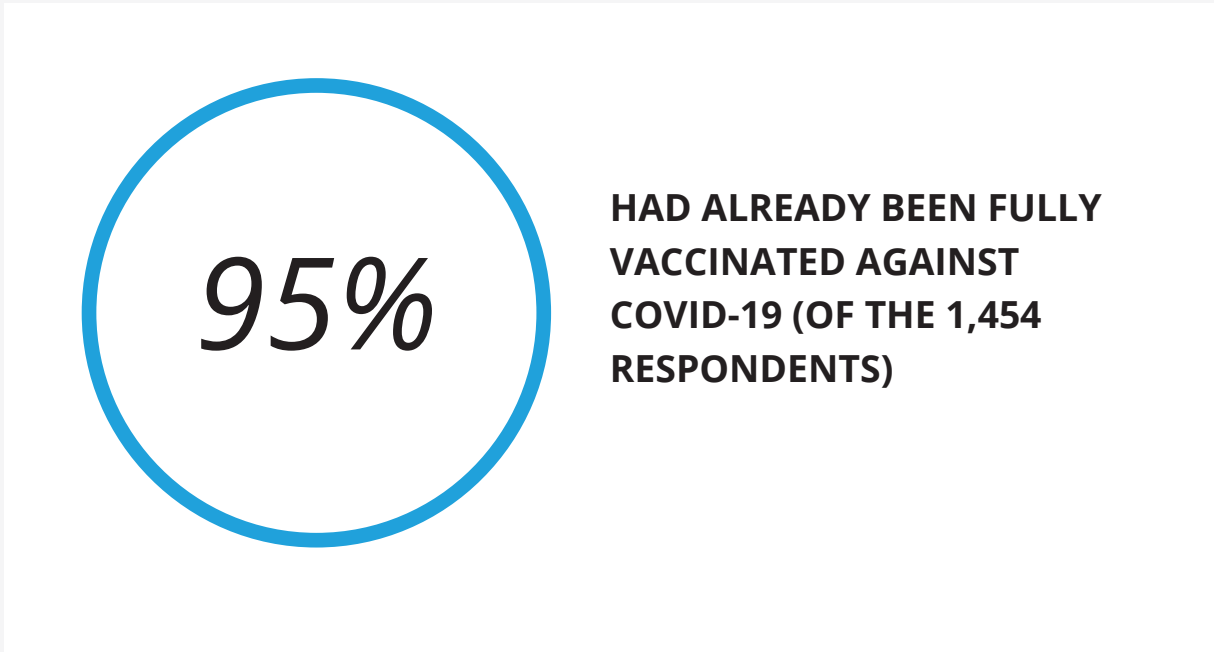


We are surveying our Patient Support Program members regularly about important issues in health care and other topics.

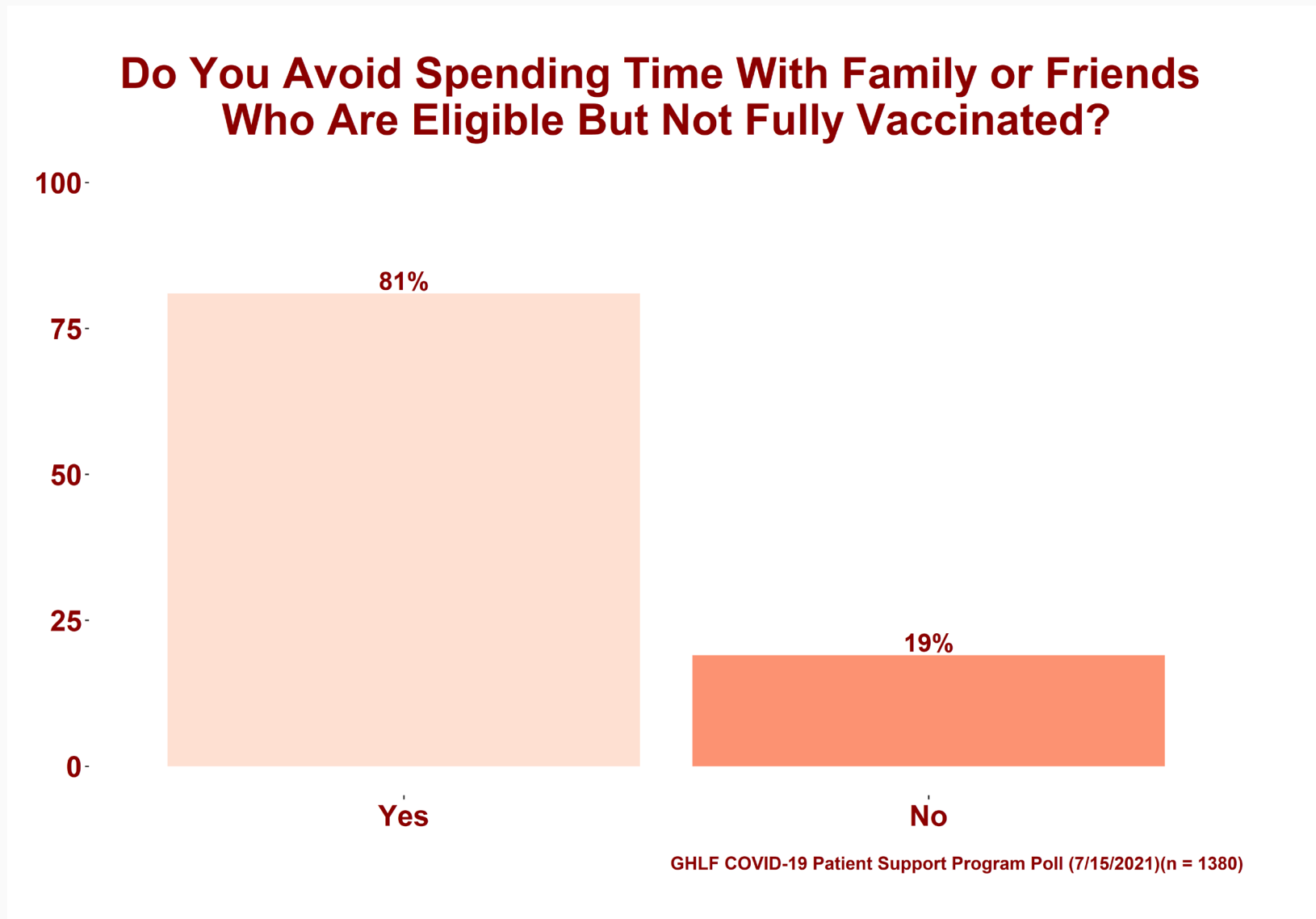
FRIENDS AND FAMILY VACCINATION STATUS POLL

A TOTAL OF 1,454

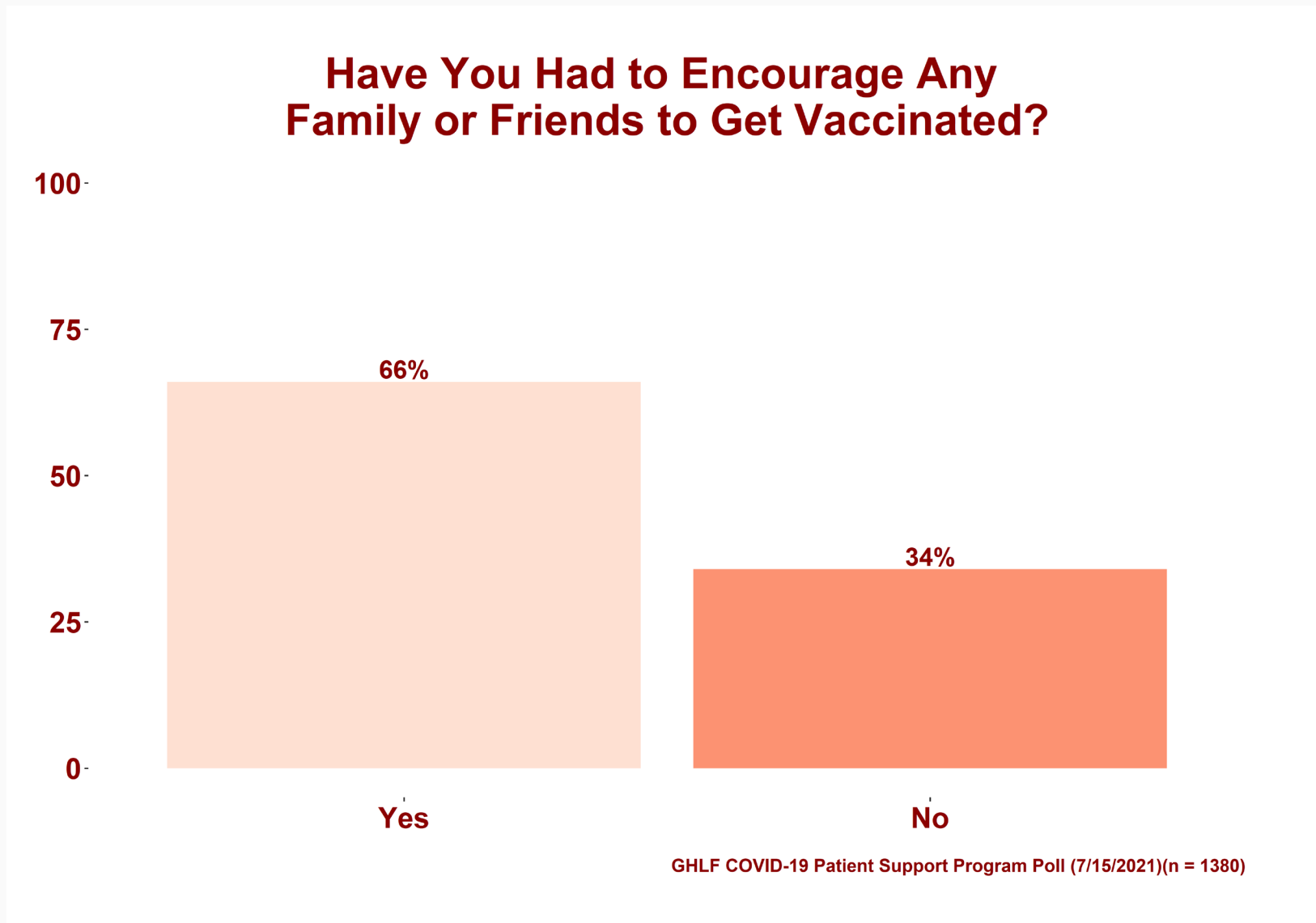
Patient Support Program subscribers responded to our July quick poll on the vaccination status of their family and friends.



We asked all fully vaccinated respondents if they avoided spending time with family and friends who are eligible but not fully vaccinated. Here are the responses:



We also asked those respondents if they have had to convince any family or friends to get vaccinated. Here are the responses:



FRIENDS AND FAMILY VACCINATION STATUS: WHAT OUR RESPONDENTS ARE SAYING

“I am still in isolation, regardless of what my friends and family are doing. Being around others is simply too risky at this time, which is depressing and frustrating.”

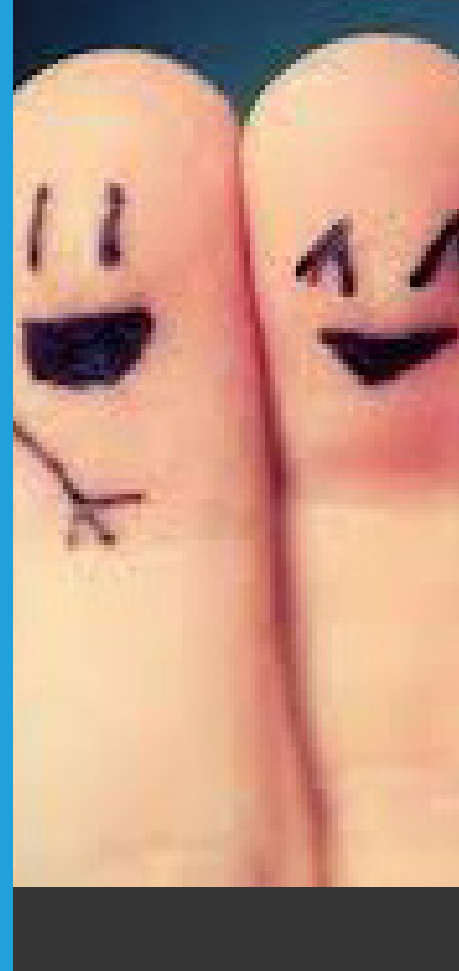
“I have four adult children and one doesn't believe in the vaccine. I also have one sister who won't get vaccinated. This situation has caused a divide in my family.”

“Being immunocompromised has me in a difficult position. Because I wear a mask and am vaccinated, I am seen as a sell-out by family members.”

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.

”

”



THE DELTA VARIANT POLL

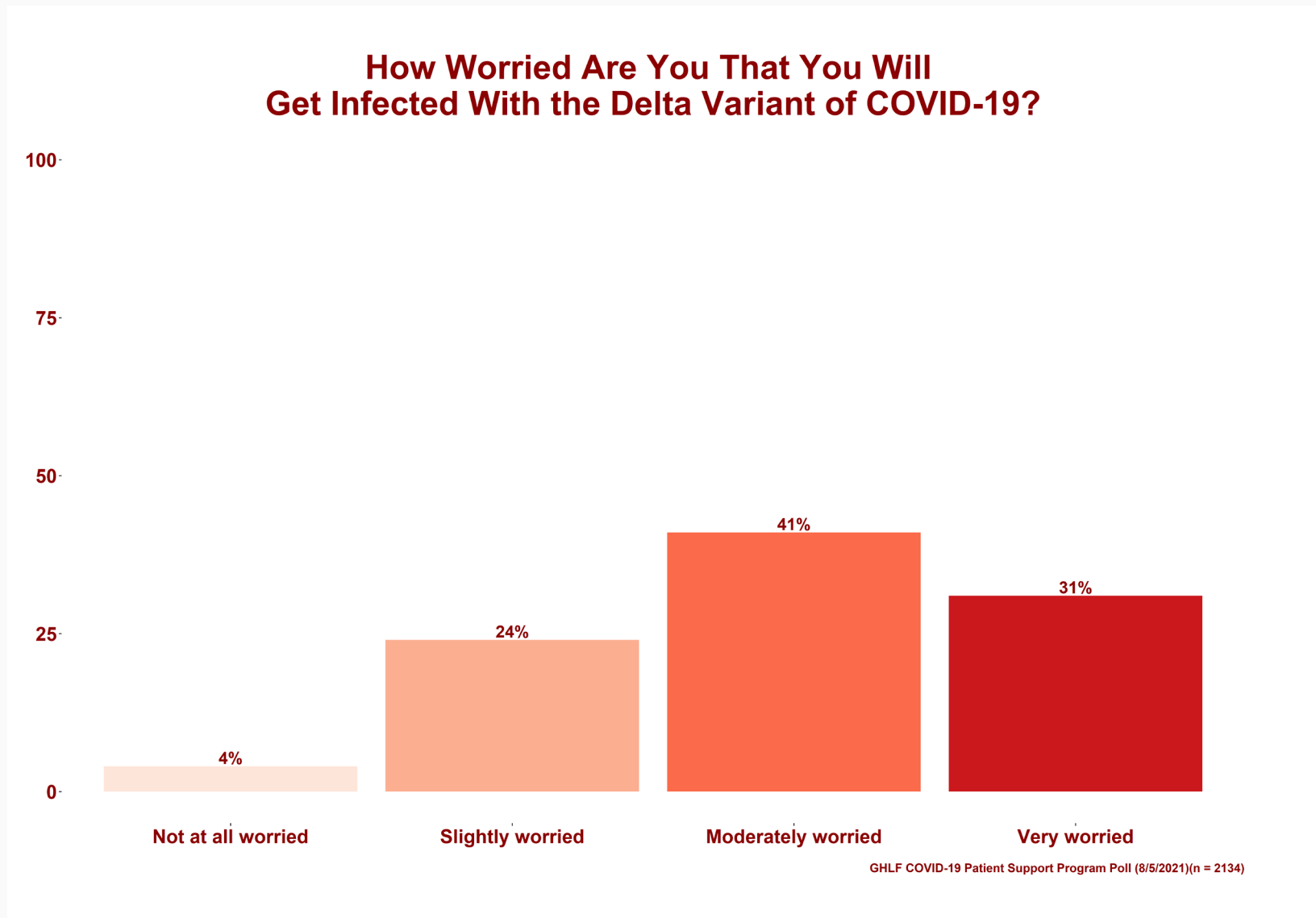
A TOTAL OF 2,137

Patient Support Program Subscribers responded to our early August quick poll on their concerns with the Delta variant.



**OF RESPONDENTS SAID
THEY WERE AWARE OF THE
COVID-19 DELTA VARIANT.**

We asked respondents how worried they were that they would get infected with the Delta variant. Here are the responses:



THE DELTA VARIANT: WHAT OUR RESPONDENTS ARE SAYING

“

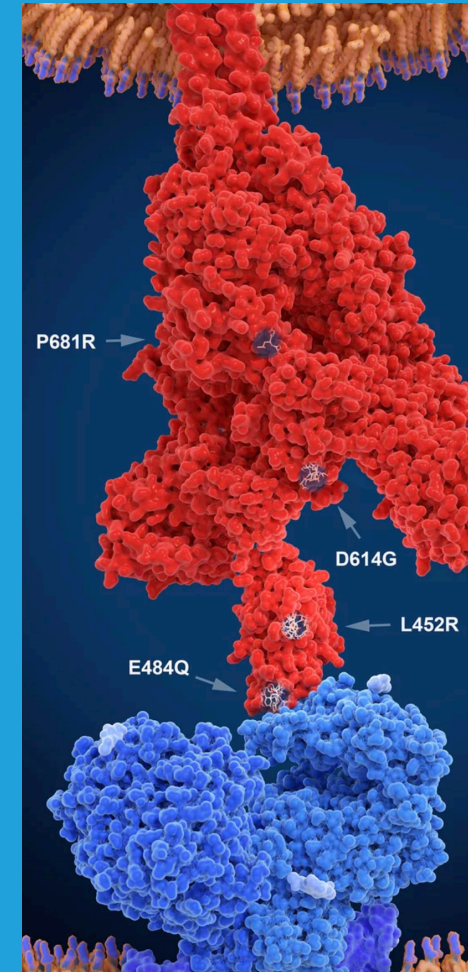
As someone with an autoimmune disease, I never stopped wearing a mask and now with Delta, I feel stuck at home again.”

I was so happy when vaccines came out and cases went way down that I ventured out of my home, and even went to Hawaii. Now, I'm scared to leave my house. I feel like I will never have a life again.”

”

“

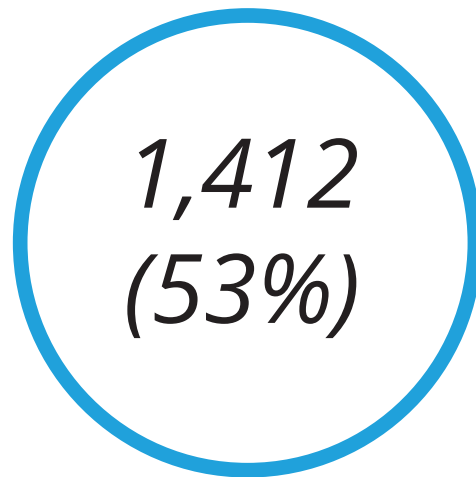
It feels impossible to do the daily calculations to figure out what is reasonable safe with masks and what is not. It's bad enough being chronically ill without having to constantly assess risk and then justify my conclusions to everyone else I interact with, most of whom are vaccinated people not following Delta as closely or taking it as seriously because they believe they protected.”



THE THIRD DOSE POLL

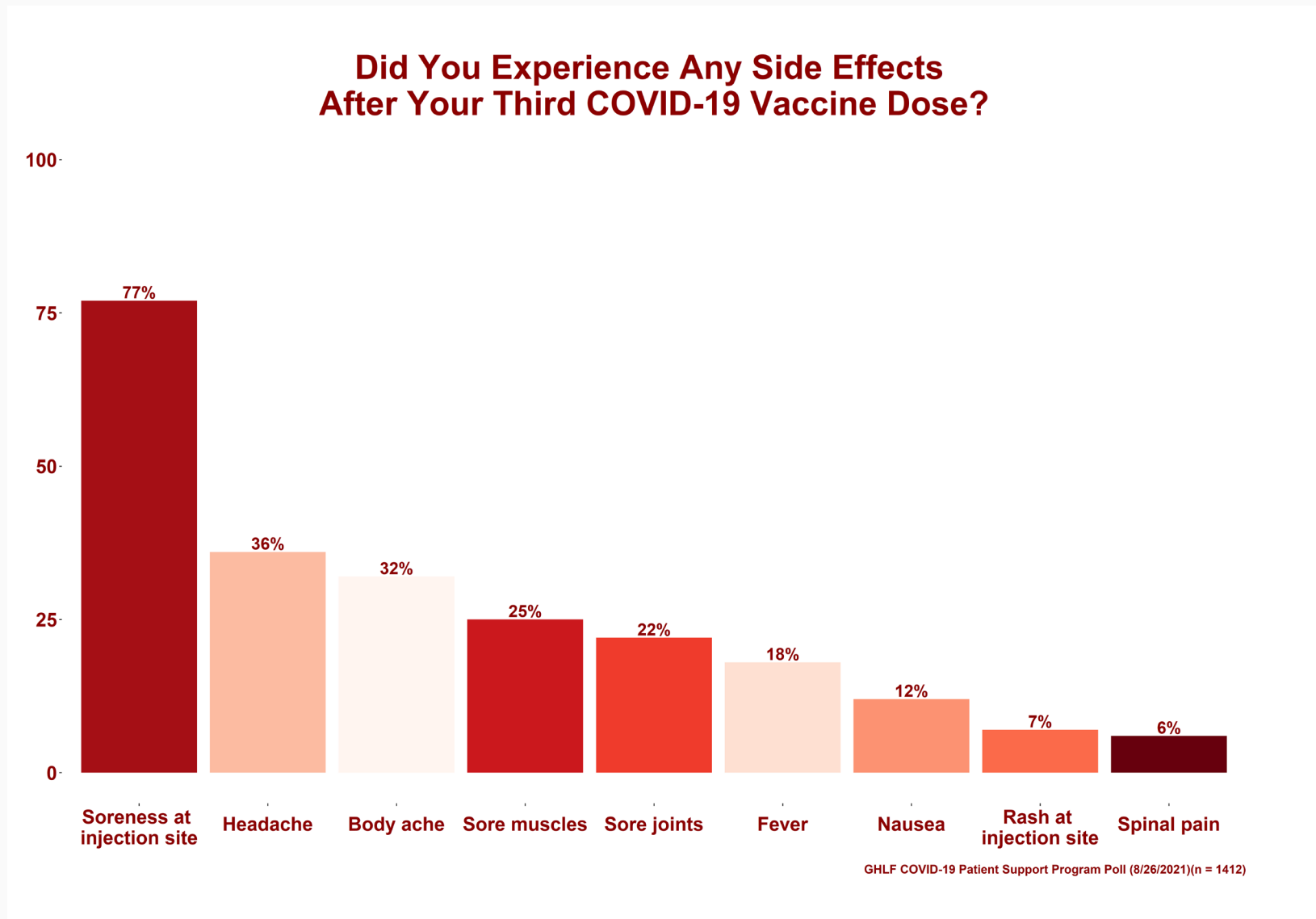
A TOTAL OF 2,738

Patient Support Program Subscribers responded to our late August quick poll on their thoughts about the CDC's recommendation of a third COVID-19 vaccine dose for immunocompromised people.

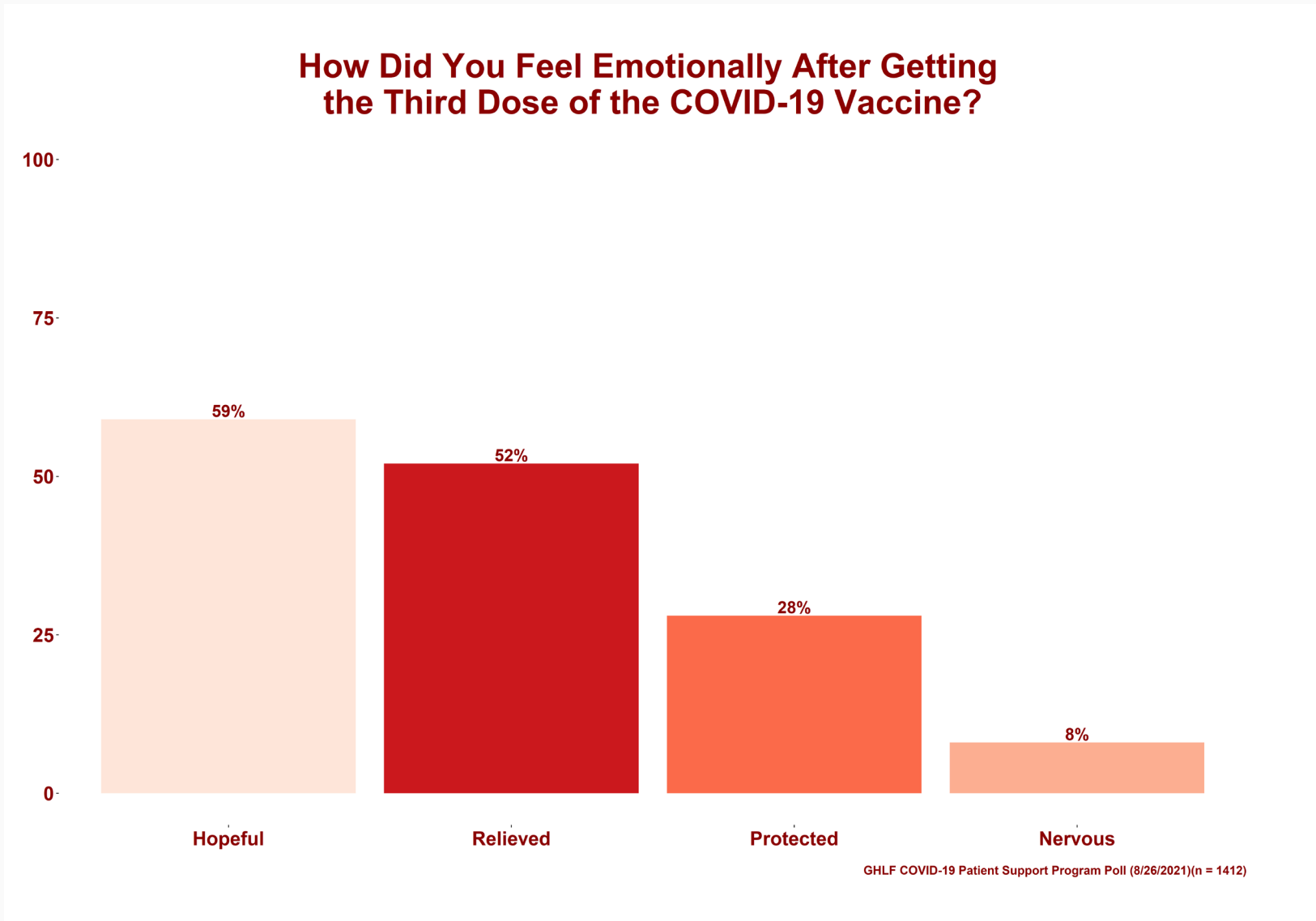


**HAD ALREADY RECEIVED
A THIRD DOSE OF THE
COVID-19 VACCINE
(OF THE 97% OF
FULLY VACCINATED
RESPONDENTS**

10% of those who received the third dose had done so before the CDC's recommendation. We asked them what side effects they experienced after getting the third dose. Here are the responses:



We also asked how those who have received the third dose how they felt emotionally afterwards. Here are the responses:



THE THIRD DOSE: WHAT OUR RESPONDENTS ARE SAYING

“ I got a bad rheumatoid arthritis flareup four days after the second vaccination and it has gotten worse. I’m afraid the third vaccination would make arthritis even worse.

The first 2 shots gave me zero reactions and one test showed no immunity this time a reaction which meant my body was finally getting the protection it needed, hopefully.

“ I plan to wait to learn of positives or negatives of the third shot.

While I am hopeful I will finally mount an immune response after the third shot it won’t make any difference in my behavior since the vaccinated people who are getting sick enough to be hospitalized or die are primarily immunocompromised.

”

”



RESEARCH UPDATE: EIGHT ABSTRACTS ACCEPTED AT THE AMERICAN COLLEGE OF RHEUMATOLOGY (ACR)



Every single abstract submitted to the ACR Annual Meeting 2021 by Global Healthy Living Foundation was accepted. That includes all COVID-19 related abstracts (both scientific and patient perspectives). Here are the abstracts related to COVID-19 and their information for the ACR 2021 meeting.

SCIENTIFIC PROGRAM

1. Perceptions about COVID-19 Vaccination Among Patients with Rheumatic Diseases Enrolled in a National Patient Registry (POSTER, Tue 11/9 @ 8:30-10:30 a.m.)

a. Maria I. Danila, Kelly Gavigan, Esteban Rivera, Michael D. George, Jeffrey R. Curtis, W. Benjamin Nowell, Shilpa Venkatachalam

2. Trends in Medication Interruptions and Associations with Disease Flares During a Public Health Crisis: Longitudinal Data from Patients With Autoimmune Rheumatic Diseases During the COVID-19 Pandemic (POSTER, Tue 11/9 @ 8:30-10:30 a.m.)

a. Tiffany Dharia, Michael D. George, Shilpa Venkatachalam, Joshua F. Baker, Shubhasree Banerjee, David Curtis, Maria I.

3. Impact of the COVID-19 Pandemic on the Quality of Life of Patients with Rheumatic Conditions: A Qualitative Analysis of Perceived Risk and Decision Making (POSTER, Tue 11/9 @ 8:30-10:30 a.m.)

a. Courtney Wells, Guadalupe Torres, William Benjamin Nowell, Shilpa Venkatachalam, Laura Stradford, Kelly Gavigan, Barbara Boyd-Floering, Maria Danila, Kristine Carandang

4. Changes in Patient-Reported Outcome Scores During the COVID-19 Pandemic: Data from the ArthritisPower Research Registry (POSTER, Tue 11/9 @ 8:30-10:30 a.m.)

a. Kelly Gavigan, Esteban Rivera, Jeffrey R Curtis, Shilpa Venkatachalam, Laura Stradford, David Curtis, W. Benjamin Nowell

5. Changes in Telemedicine for Rheumatologic Care during the COVID-19 Pandemic: Patient Perceptions and Preferences (POSTER, Tue 11/9 @ 8:30-10:30 a.m.)

a. Maria I. Danila, Kelly Gavigan, Esteban Rivera, W. Benjamin Nowell, Michael D. George, Jeffrey R. Curtis, Lisa Cristopher-Stine, Shubhasree Banerjee, Peter A. Merkel, Kalen Young, Dianne G. Shaw, Jennifer Gordon, Shilpa Venkatachalam

PATIENT PERSPECTIVES POSTER PROGRAM

1. How Online Spanish-Language Resources Got Me and My RA Through the COVID-19 Pandemic (POSTER, date/time TBD)

a. Wigna Cruz

2. Fighting for the Care We Deserve: My Experience as a Latina Patient-Researcher During the COVID-19 Pandemic (ORAL PRESENTATION, date/time TBD)

a. Guadalupe Torres, Kristine Carandang, Courtney Wells

3. Should I Get the COVID-19 Vaccine With My RA? Using Evidence-Based Resources for Decision-Making (POSTER, date/time TBD)

a. Aberdeen (“Deen”) Allen, Jr.

MEDIA: ABC RADIO, YAHOO NEWS & GHLF GO INDEPTH ON MASKING

Mask shaming ignores COVID-19 fears of immunocompromised people

The delta variant has many with autoimmune and other diseases on edge.

By **Kiara Alfonseca**

July 14, 2021, 6:09 AM • 8 min read



“This is my new normal,” Morley said. “You don’t know who the person behind the mask really is. You can’t know someone and their story and their struggles.”



Courtesy Peter Morley

Peter Morley and Anjelika are pictured in an undated handout photo.

During the summer months, the Global Healthy Living Foundation continues to be an important resource for reporters seeking the real-life perspectives of how the pandemic impacts people living with chronic disease.

In July, [ABCNews.com](https://abcnews.com) interviewed GHLF member Peter Morley, a person living with lupus, about how mask-shaming ignores the fears of people who are immunocompromised. In the article, Peter described how at a New York City parade a local photojournalist got frustrated when he refused to remove his mask for a picture. After Morley declined, the photographer responded by saying, «COVID is over. Get on with your life.» GHLF’s Laurie J. Ferguson, PhD, Director, Educational Development, also contributed to the article, explaining why people wearing masks trigger responses, saying, «Anybody wearing a mask is kind of symbolizing the fear and the concern. It’s like, «why can’t we all just be normal? Why can’t we go back to what was?»» After reporting that some of her clients have also been harassed or bullied about wearing masks, she said «It’s not a moral issue, it’s not a political issue. It’s a health issue...Unfortunately, it’s going to come down to the situation where, again, it’s on the shoulders of the vulnerable to have to carry this and do a lot of the communication.» This article was picked up by [YahooNews!](https://www.yahoo.com/news) and syndicated on [ABC Audio](https://www.abc.com.au/audio), which produces online stories for ABC-affiliated news radio stations across the country, resulting in significant additional pick-up of the story.

COVID-19 EDUCATION: HELPING PATIENTS STAY HEALTHY AS THE PANDEMIC CONTINUES



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

We are reaching many thousands of rheumatic and inflammatory disease patients each day with information about COVID-19 that is targeted to them.

Top recent content has focused on helping our patient community understand the latest news about the COVID-19 vaccine (including third doses for the immunocompromised), updates in guidance from the American College of Rheumatology, the risk of breakthrough infections, navigating medication shortages, and more.

[COVID-19 Vaccine Third Dose vs. Booster: Will Immunocompromised People Need Both?](#)

[Breakthrough COVID-19 Infections: What to Know If You're Immunocompromised](#)

[Actemra Shortage: What to Do If You Have Issues Accessing This Biologic Because of COVID-19](#)

[What It's Like Getting the Third COVID-19 Vaccine Dose: Immunocompromised Patients Report Back](#)

[Immunocompromised Patients Can Now Be Treated with Monoclonal Antibodies to Prevent COVID-19 After Exposure](#)

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.

Here are additional new resources published over the past four weeks:

[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](#)

SOCIAL MEDIA



Join our community

#CreakyChats

Is the Pandemic Over? A #CreakyChats Discussion on What It Means to 'Reopen'

Wednesday, June 2, 2021 at 7 p.m. ET

Hosted by



Special Guest

@CreakyJoints
#CreakyChats

[#CreakyChats: Is the Pandemic Over?](#)


Join our community

#CreakyChats

COVID Vaccine Myth Bustin'

Monday, August 30th, 2021 7PM ET

Hosted by



@CreakyJoints
#CreakyChats

[#CreakyChats: COVID Vax Myth Busting](#)

CREAKYKITCHEN



CreakyKitchen Episode 8: CreakyKitchen Swap Meat

We continue to provide much needed entertainment during the COVID-19 pandemic. CreakyKitchen events provide 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 8, we focused on food swaps that can be made to make favorite dishes healthier. CreakyKitchen Chef, Chantelle Marcial, shared her recipe for [Chicken Meatballs in a Curry Sauce with Zoodles](#).

We were also joined by Carol Finkelstein who shared her substitutes for common ingredients like onions, garlic and tomatoes. Carol also shared advice and tips for getting started with food swaps.

GHLF, REUMAEXPO SUMMIT & PANLAR CONGRESS REACH HISPANICS

CreakyJoints Español Outreach

CreakyJoints Español participated in ReumaExpo's 2021 summit with a group of Hispanic Rheumatologists and patient advocates to discuss the importance of research within the Hispanic Rheumatology community.

The 4th Pan American Congress of Patients with Rheumatic Diseases was a full-day event that focused on the patient experience of rheumatic disease. CreakyJoints Español covered DMARDs for rheumatic conditions. Mindful of the ongoing global impact of the COVID-19 pandemic, CreakyJoints Español also reviewed special risks and considerations for people living with rheumatic conditions as well as how to prepare for telemedicine appointments.



Highlighting Misinformation in Spanish-Language Rheumatoid Content


Findings were presented at the 23rd Pan-American Conference of Rheumatology (PANLAR) 2021, which ran from August 12-15.

CreakyJoints Espanol: Factual vs Misinformation YouTube Spanish-Language Rheumatoid Arthritis Videos

August 17, 2021
Lana Dykes

Facebook Twitter YouTube LinkedIn

Daniel Hernandez, MD, and Esteban Rivera discuss the study, "Social Listening: Factual vs. Misinformation YouTube Spanish Arthritis Videos," presented at the 23rd Pan-American Conference of Rheumatology (PANLAR) 2021.




Esteban Rivera
Global Healthy Living Foundation

NEWS

Study: Health misinformation rampant in Hispanic communities

The report, from arthritis advocacy org CreakyJoints Español, found that inaccurate videos are viewed more frequently than credible ones.

Lecia Bushak | August 17, 2021 | 5:00 AM



SOURCE: GETTY

MM+M MEDICAL MARKETING AND MEDIA

PRWeek

SmartBrief

Emphasizing Health Equity, Vaccines, Wellness and Relationships To Bring Education and

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:

LOS BROTES RELACIONADOS CON LA VACUNA CONTRA EL COVID-19 SON POCO FRECUENTES EN PACIENTES CON ENFERMEDAD REUMÁTICA

Qué debes saber sobre la nueva guía de la CDC sobre COVID-19 si estás completamente vacunado e inmunodeprimido



COVID-19 ADVOCACY AND POLICY CONTINUE WITH DIGITAL

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, stopping vaccine disinformation, and raising the voice of patients living with chronic disease.

Take a look at the comment letters:

- [Letter to Stop Vaccine Disinformation](#)
- [Comments to Senate HELP Committee about Medications in Emergencies](#)
- [FTC Pharmaceutical Task Force Comments](#)
- [Coalition Statement in Support of Research Using Human Fetal Tissue](#)
- [Comments to Federal Departments on Reporting on Benefits and Drug Costs](#)
- [Comments to Congressional Leadership on Patient Centered Drug Pricing](#)
- [Improving Patient Drug Affordability through Standardized Benefit Plans](#)

We continue to focus on stopping the growth of copay accumulator adjuster programs and have met with legislators to advocate on behalf of patients. We are concerned that the expansion of such a program will negatively impact patients' ability to afford their medications, especially amidst the COVID-19 pandemic and the resulting economic recession. We recently advocated in support of Massachusetts bill H.1053 / S.644 and Pennsylvania bill S.196 through virtual legislative meetings.





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)

WEB:
www.ghlf.org

PHONE/EMAIL:
845.348.0400
advocacy@ghlf.org

ADDRESS:
515 N. Midland Avenue
Upper Nyack, NY 10960

CONTACT:
Steven Newmark, Chief Legal Officer, Policy Director
SNEWMARK@GHLF.ORG

summer
2021

COVID-19
Patient Impact & Insights

