



**GLOBAL
HEALTHY
LIVING
FOUNDATION**

winter
2022

COVID-19
Patient Impact & Insights

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COVID-19 PATIENT IMPACT & INSIGHTS



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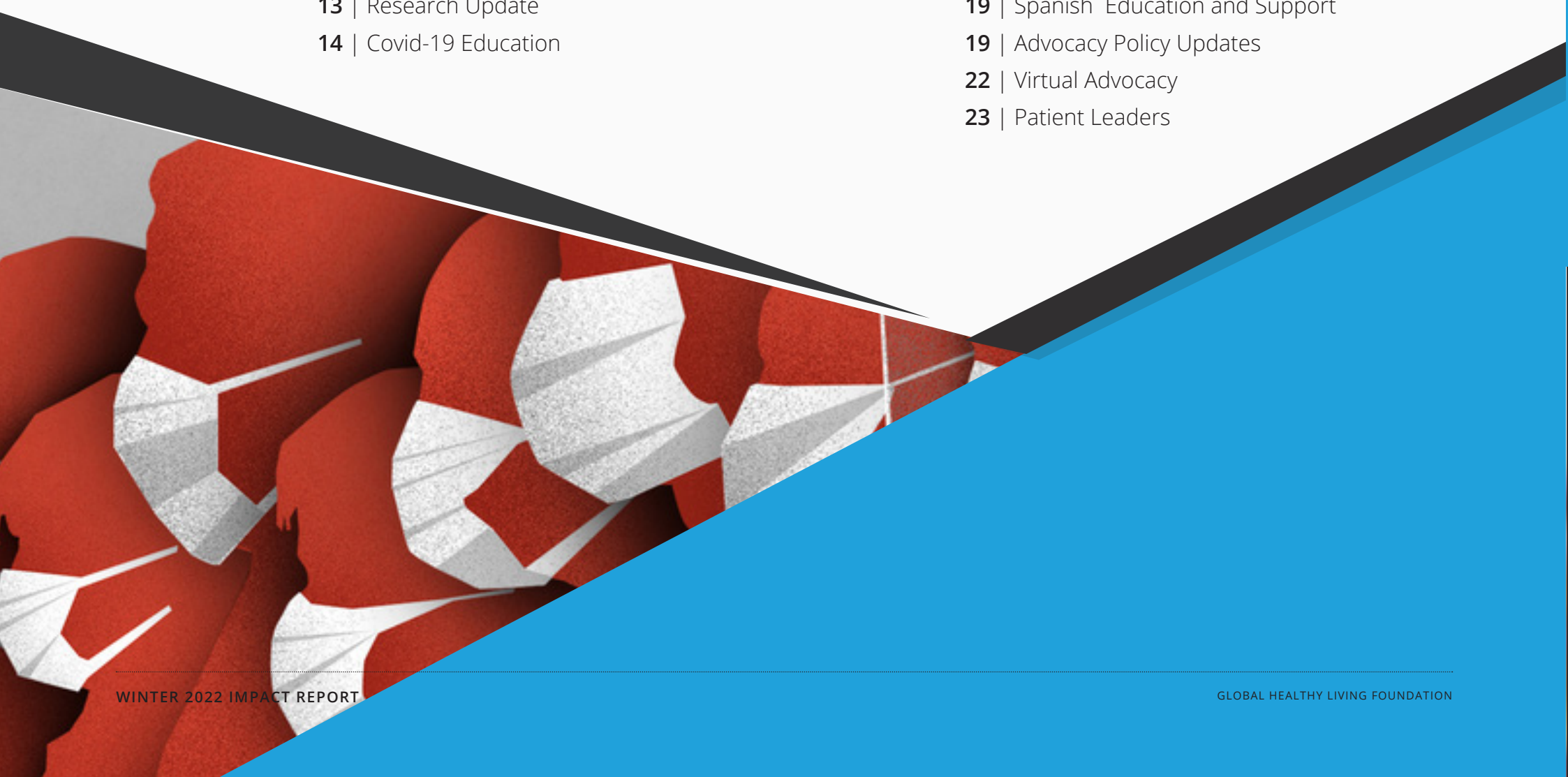
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GHLF COVID-19 PATIENT SUPPORT PROGRAM FOR CHRONIC ILLNESS PATIENTS

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.**

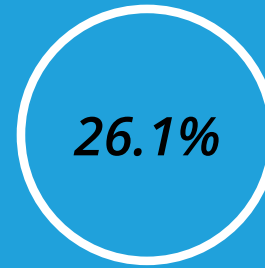
Informed by our COVID-19 Patient Leadership Council, the program is growing rapidly and meeting underserved needs of high-risk and chronic illness patients. [Go to www.GHLF.org to learn more](http://www.GHLF.org)



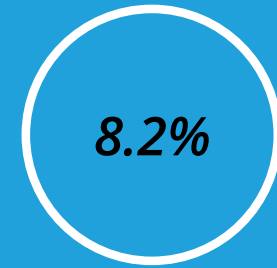
NUMBER OF MEMBERS



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

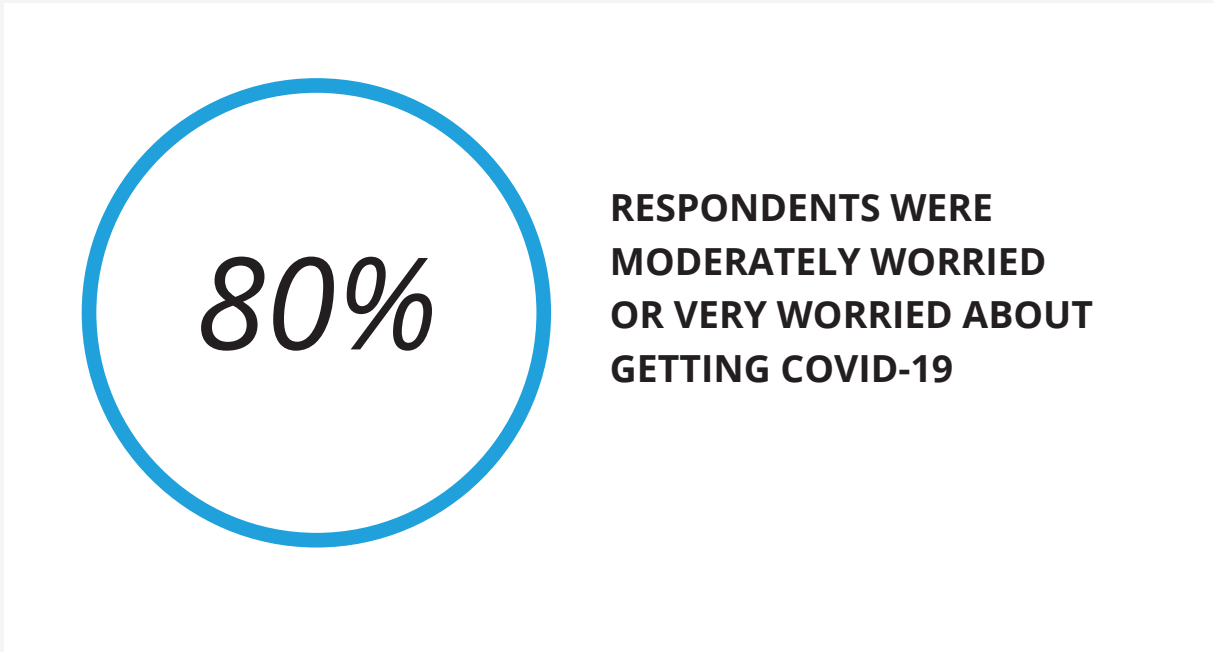


We are surveying our Patient Support Program members regularly about important issues in health care and other topics.

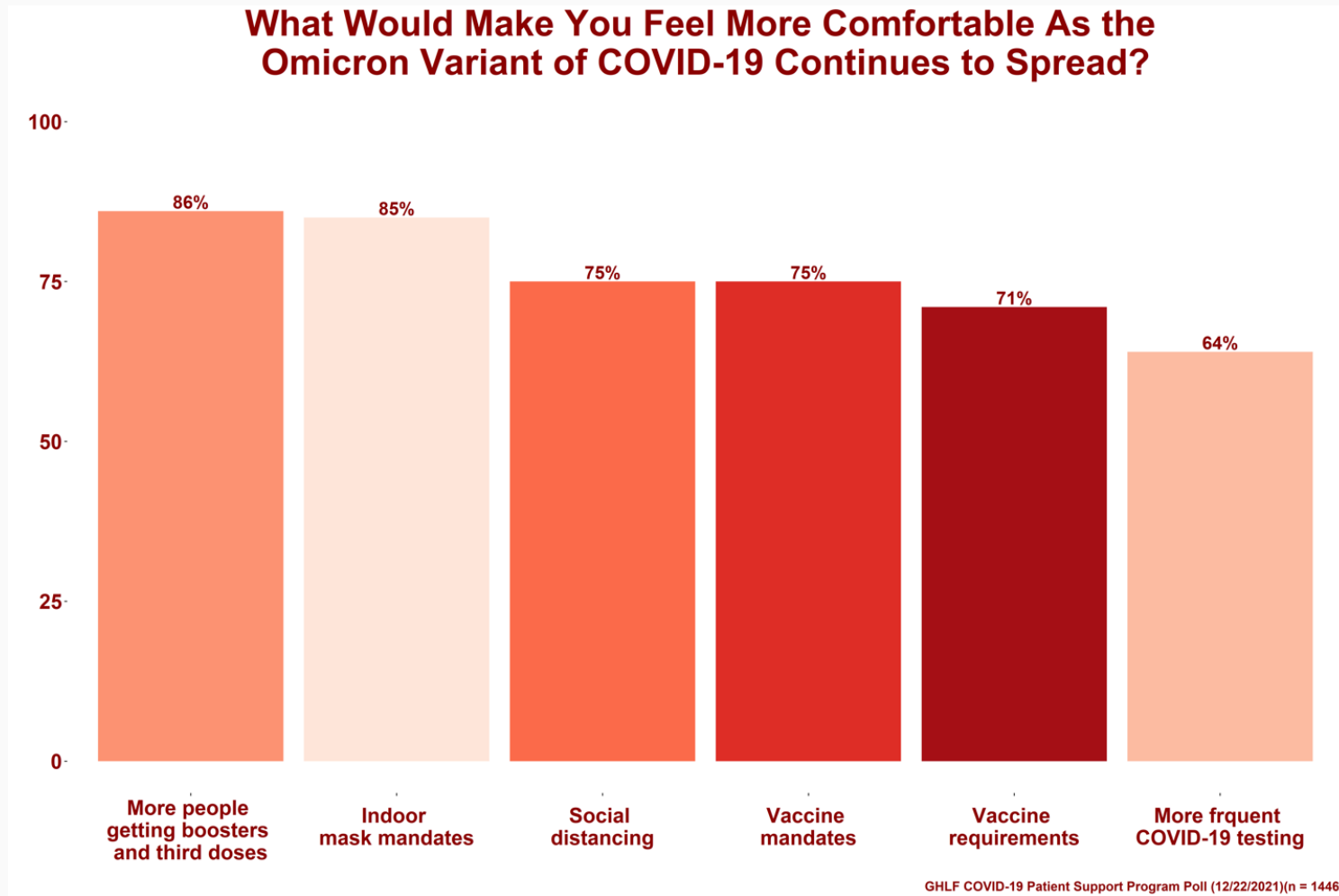
OMICRON VARIANT POLL

A TOTAL OF 1,149

Patient Support Program subscribers responded to our December quick poll on the Omicron variant.



We also asked respondents what would make them feel more comfortable as the Omicron variant of COVID19- was spreading. Here are the responses:



OMICRON VARIANT POLL

WHAT OUR RESPONDENTS ARE SAYING

“ Would like to know about a booster or fourth shot for immune compromised people ... Not comfortable because I don't understand.

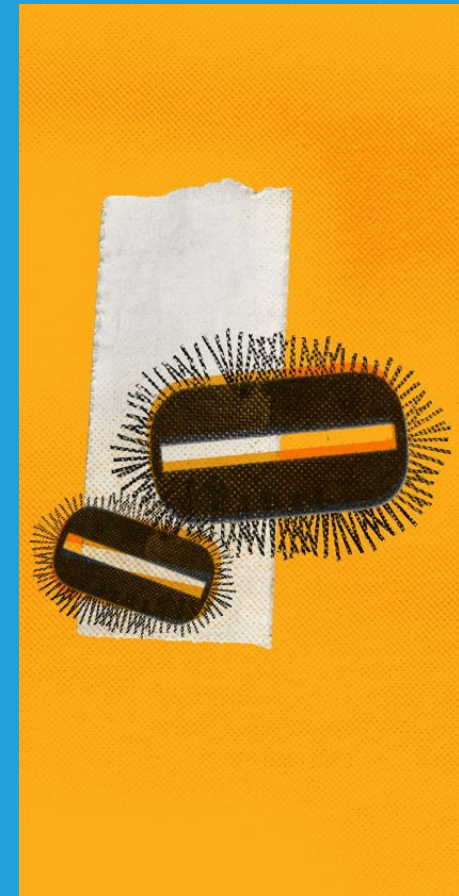
So tired of missing everything with my family and friends. Even though I am vaccinated and boosted, my life is still the same as 2020.

“ With a compromised immune system this is even scarier than before, and I feel more trapped and unsure. Early on it was easier to do nothing outside my home — now I am confused and afraid.

With the Omicron variant now with us, it is enforcing the fears of many that this pandemic is far from over. My depression is worsening.

”

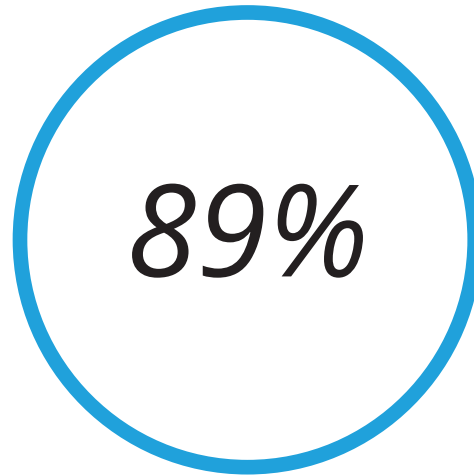
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HIGH-RISK PEOPLE NAVIGATING OMICRON POLL

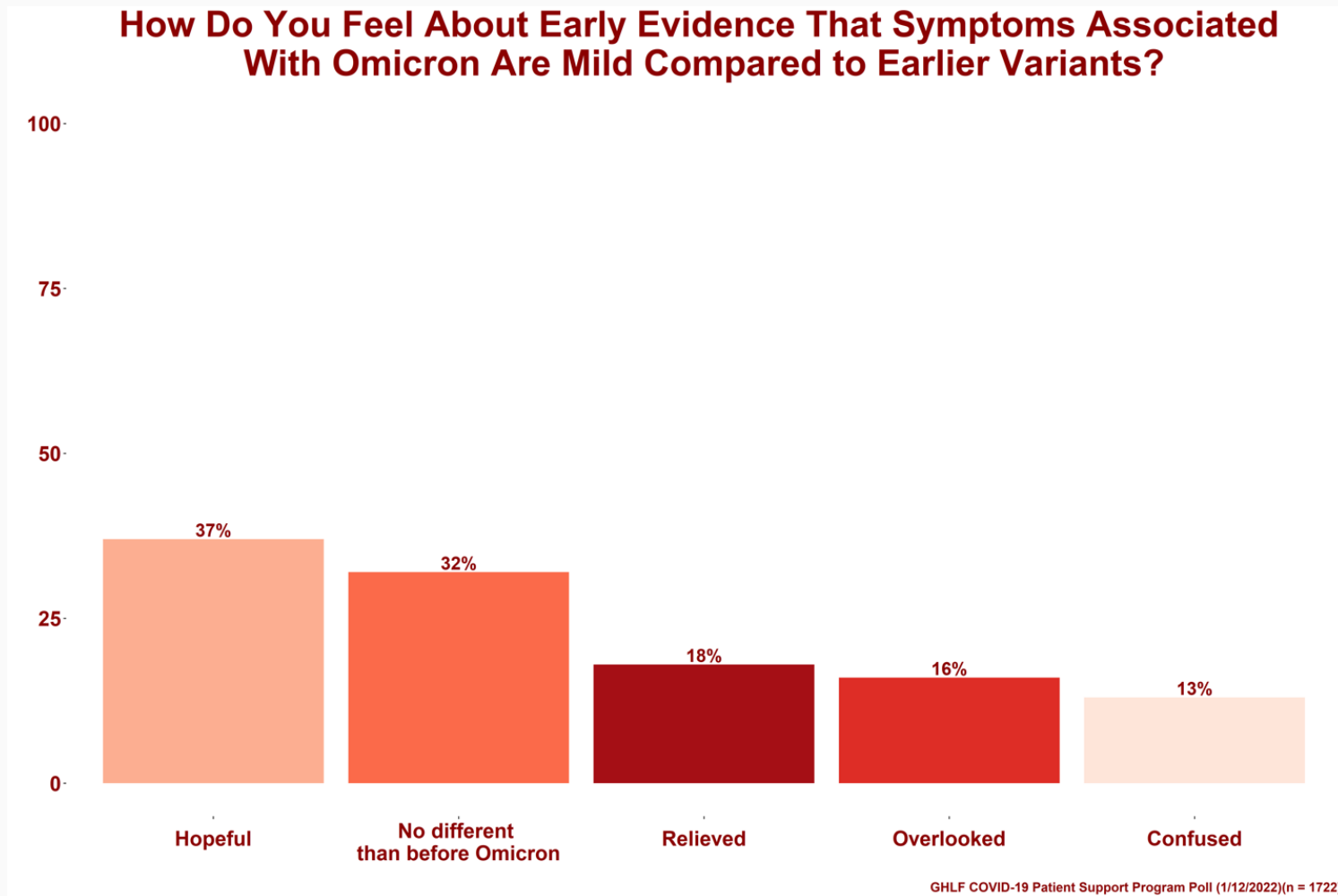
A TOTAL OF 1,722

Patient Support Program Subscribers responded to our early January quick poll on navigating the Omicron variant as a high-risk person.



RESPONDENTS IDENTIFIED AS BEING AT HIGHER RISK FOR SEVERE CORONAVIRUS (COVID-19) ILLNESS.

We asked respondents how they felt about the perception of Omicron symptoms being mild compared to earlier variants. Here are the responses:



HIGH-RISK PEOPLE NAVIGATING OMICRON POLL WHAT OUR RESPONDENTS ARE SAYING

We also provided respondents the opportunity to share their thoughts or feelings about being a high-risk person at this time.

“ Symptoms may be mild but there’s no guarantee that symptoms will be mild for me.

I hope they’re correct but there is still limited data on immunocompromised people who get COVID.

”

“ Mild is relative, and even ‘mild’ viruses and other infections can be debilitating to me because my immune system is unreliable at best.

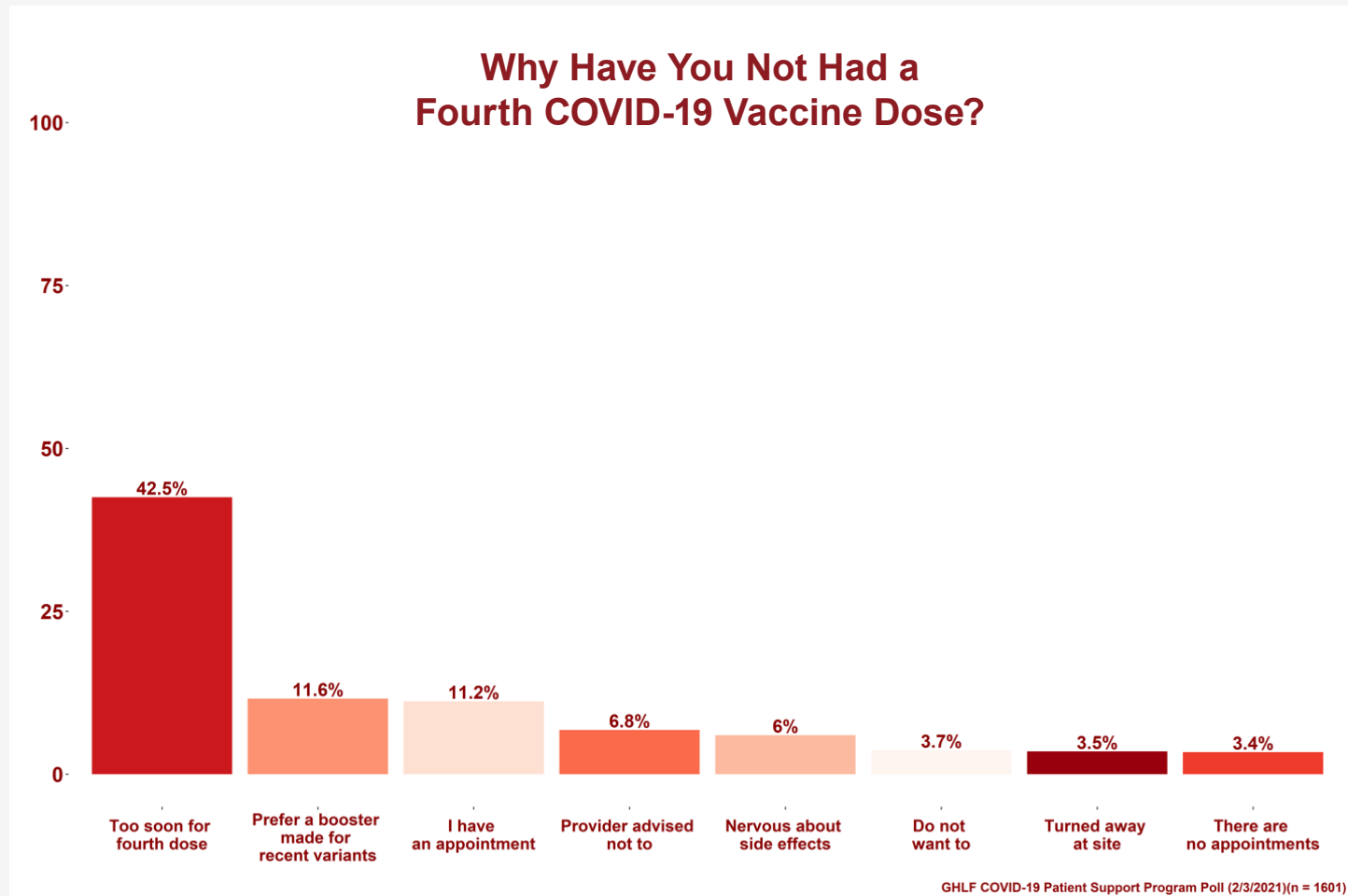


THE FOURTH DOSE POLL

A TOTAL OF 2,384

Patient Support Program Subscribers responded to our February quick poll on the fourth dose of the COVID-19 vaccine.

We asked respondents who did not receive the fourth dose yet why they have not. Here are the responses:



THE FOURTH DOSE POLL

WHAT OUR RESPONDENTS ARE SAYING

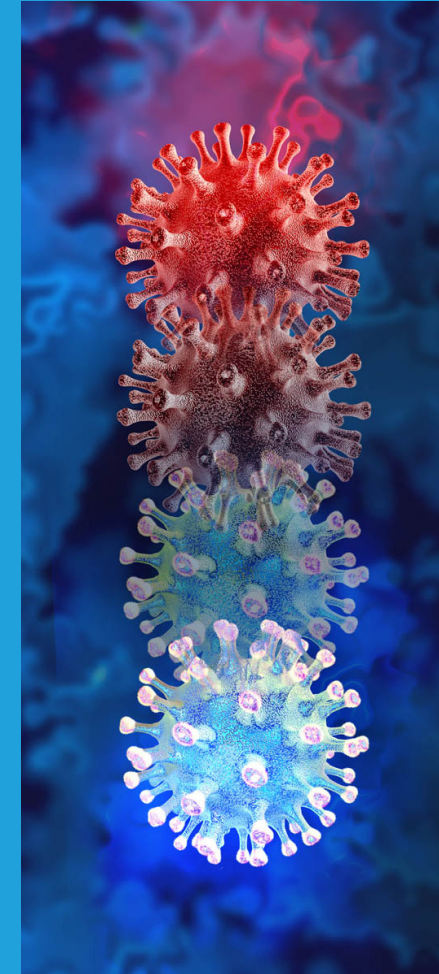
We provided respondents the opportunity to share thoughts or feelings they had about the fourth dose. Here is a sample of the responses:

“ I am concerned about getting so many vaccines in such a short time. I have six autoimmune conditions and several other chronic conditions that are flaring about a week after each vaccine. More info and reassurance along these lines would be so helpful.

I am a believer in and a staunch advocate for the vaccine, but I must admit, finding out that the efficacy only lasts for a few months in my group — the immunocompromised — is disconcerting.

”

“ Grateful that I have access to a fourth dose when many people throughout the world are still awaiting primary/booster doses.



RESEARCH UPDATE: WINTER 2022 PUBLICATIONS



The Global Healthy Living Foundation has continued to publish work using the digital tool, the ArthritisPower® Research Registry. This Covid-19 work ranges from tracking preferences for telemedicine, medication interruptions and flares, to vaccine hesitancy.

[COVID-19 Vaccine Uptake and Vaccine Hesitancy in Rheumatology Patients Receiving Immunomodulatory Therapies Treated In Community Practice Settings](#)

Stephanie S Ledbetter 1 , Fenglong Xie 1 , Patrick Stewart 2 , Gary Cutter 1 , Michael George 3 , Kenneth G Saag 1 , William Benjamin Nowell 4 , Ted Mikuls 5 , Lesley Jackson 1 , Maria I Danila 1 , Kevin Winthrop 6 , Jeffrey R Curtis 1

[Medication Interruptions and Subsequent Disease Flares During the COVID-19 Pandemic: A Longitudinal Online Study of Patients With Rheumatic Disease](#)

Tiffany Dharia 1 , Shilpa Venkatachalam 2 , Joshua F Baker 1 , Shubhasree Banerjee 1 , David Curtis 2 , Maria I Danila 3 , Kelly Gavigan 2 , Jennifer Gordon 4 , Peter A Merkel 1 , Dianne G Shaw 5 , Kalen Young 5 , Jeffrey R Curtis 3 , William B Nowell 2 , Michael D George 1

[Patient Perceptions and Preferences Regarding Telemedicine for Autoimmune Rheumatic Diseases Care During the COVID-19 Pandemic](#)

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

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 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 patients get through the Omicron wave, encouraging getting a fourth vaccine dose, and more. Here are some examples of recent popular content:

[Omicron and the Immunocompromised: A Guide for Those at High Risk for COVID-19](#)

[Getting a 4th 'Booster' Dose of the COVID-19 Vaccine for Immunocompromised Patients](#)

[How to Find N95 Masks If You're Immunocompromised](#)

[At-Home COVID Tests: What Immunocompromised People Need to Know](#)

ELEVATING PATIENT PERSPECTIVES ON THE PANDEMIC



#HighRiskCOVID19:
A Public Service Announcement

“
**Immunocompromised folks
are the most effective
incubators of new strains of
COVID. Failure to protect
us basically means
weaponizing us.**

— Charis H., who lives with ankylosing spondylitis


CreakyJoints and the Global Healthy Living Foundation continue to give the immunocompromised patient community a voice. This is especially important now as much of the world is resuming “normal” life and COVID-19 safety rules are being rolled back. It is easy for society to forget that vulnerable patients are being left behind, and we play a critical role in representing patients who are still high-risk and must continue to follow COVID-19 prevention practices to protect their health.

[You Need to Hear This COVID-19 Public Service Announcement from Immunocompromised Patients](#)

[What It’s Like Having COVID When You’re Immunocompromised — and What I’m Still Worried About](#)

SOCIAL MEDIA

← Tweet

 **Tinu :Empress of Twerk, Thirst of My Line** ✓
@Tinu

Immunocompromised Patients: COVID-19 Public Service Announcement creakyjoints.org/living-with-ar... from @creakyjoints

<p>“ Immunocompromised folks are the most effective incubators of new strains of COVID. Failure to protect us basically means weaponizing us. — Charis H., who lives with ankylosing spondylitis</p>	<p>“ If you would wear a ribbon for cancer, you should wear a mask for the immunocompromised. — Tinu A., who lives with arthritis, fibromyalgia, and</p>
<p>“ Don't hesitate and get vaccinated because COVID-19 and its variants can lead to our demise. — Terrance H., who lives with sickle cell trait</p>	<p>“ With chronic illness, every day is a battle to keep things on an even keel. For us COVID-19 is an elephant, standing on the edge of that ship, in already bad weather. — Cat C., who lives with chronic migraine and depression</p>

[You Need to Hear This COVID-19 Public Service Announcement from Immunocompromised Patients](#)



Join our community

#CreakyChats

Finding Community in Isolation
Monday, February 28th, 2022, 7:00 pm ET

Hosted by  @CreakyJoints #CreakyChats

Cohost by  @ACICommunity Autoimmune Community Institute

[#CreakyChats: Finding Community in Isolation. Co-hosted by the Autoimmune Community Institute](#)

CREAKYKITCHEN



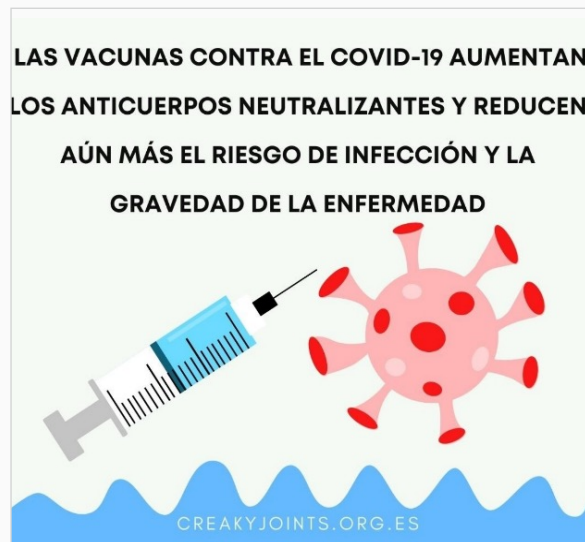
CreakyKitchen's Holiday Celebration

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 11, we hosted a virtual holiday celebration. Chef Chantelle showed us a raisin bar recipe from her mom, for a little sweet treat this holiday season. We were also joined by writer and patient advocate, Lene Andersen, who shared tips on managing the holidays with chronic illness.

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:



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're also excited to announce that **Season 3 of The Health Advocates** is here! Season three has focused on the impact of COVID on our chronic disease community. We've discussed dealing with an excess of selfishness during Omicron, how to get free COVID tests, getting the most protective masks, living with a COVID endemic, and the future of mRNA technology. As mask mandates are rolled back, and there is increased worry in our community, co-hosts Steven Newmark, Chief Legal Officer and Policy Director and Zoe Rothblatt, Patient Advocate Community Outreach Manager, dedicated an episode to calculating COVID-19 risk, and how we can find comfort in the numbers.



Feedback from our listeners:

- ***“Great and informative material I can relate to as a chronically ill patient”*** – writergal5404
- ***“Great podcast, engaging hosts, and timely topics. Highly recommend”*** – corecore9222
- ***“Too often we only think about healthcare when we urgently need it, when we may lose it, or when our politicians are fighting about it. This podcast is raising important topics in public health and healthy living that don’t get enough airtime elsewhere. More please!”*** – tunezoon
- ***“This podcast was super interesting and just the right length. I was able to quickly get clear and concise answers to the many questions I had about vaccines, boosters, and antibody tests.”*** – Lyn1911

GHLF’s Chief Science Policy Officer, Robert Popovian co-hosts our [Healthcare Matters](#) podcast with Conner Mertens, Patient Advocate Community Outreach Manager. In the first quarter they covered COVID-19 issues in the following episodes:

S1, E1: Trusting the Vaccines, [Apple Podcasts](#) or [Spotify](#)

S2, E2: A Deep Dive Into COVID-19 Vaccines, [Apple Podcasts](#) or [Spotify](#)

S2, E3: Status of COVID Treatments, [Apple Podcasts](#) or [Spotify](#)



Robert focused on COVID-19 during the first quarter with speaking engagements, too:

- **Oct 26, 2021** – He moderated a panel for University of Southern California entitled, Town Hall: COVID-19 Pandemic, Vaccine Clinical and Public Policy Discussion – panelists were Dr. Richard Dang, University of Southern California and Lisa Coen, Head of US Vaccines Public Affairs, Pfizer Inc. GHLF’s Chief Science Policy Officer, Robert Popovian
- **Dec 2, 2021** – He moderated a panel at World of Vaccine and Immunotherapy Congress entitled, US Immunization Policy – what have we learned that could better prepare us for the next public health crisis – panelists included Dr. Denise Foster, Chief Nursing Officer at County of San Diego; Abby Bownas, AVAC (Adult Vaccine Action Coalition); Rekha Lakshmanan, Immunization Action Partnership and Kathryn Hashey, GSK
- **March 30, 2021** – He was a panelist on Vaccine Virtual Days an event hosted by GSK where he discussed policy issues related to COVID-19 vaccine access in the U.S.
- **April 4, 2021** – He was a guest on the podcast – The Business of Pharmacy: Evolving After the Pandemic - where he discussed policy issues related to COVID-19 vaccines and therapies in the U.S.
- **April 21, 2021** – He was a guest on the podcast – House Calls, Be Your Own Advocate – where he discussed policy issues related to Covid-19 vaccines and therapies in the U.S.

VIRTUAL ADVOCACY

Each year, the Alliance for Headache Disorders Advocacy (AHDA) unites health professionals, migraine and cluster headache advocates and patients to present our requests or “asks” of Congress during the annual advocacy event Headache on the Hill. These asks are typically focused on improving awareness about the impact of headache disorders and the need for research funding. Because of Covid, Sarah Shaw, GHLF’s BIPOC Patient Advocate and Community Outreach Manager, joined the NJ Headache on the Hill team. The team met virtually with six different congressional offices to request funding to establish Indian Health Service (IHS) Headache Disorders Centers of Excellences (IHS HCoE). They met with staffers in the following offices:

- Senator Robert Menendez
- Senator Corey Booker
- Congresswoman Bonnie Watson Coleman
- Congressman William Pascrell
- Congressman Chris Smith





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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