



**GLOBAL
HEALTHY
LIVING
FOUNDATION**



fall
2021

COVID-19
Patient Impact & Insights

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COVID-19 PATIENT IMPACT & INSIGHTS



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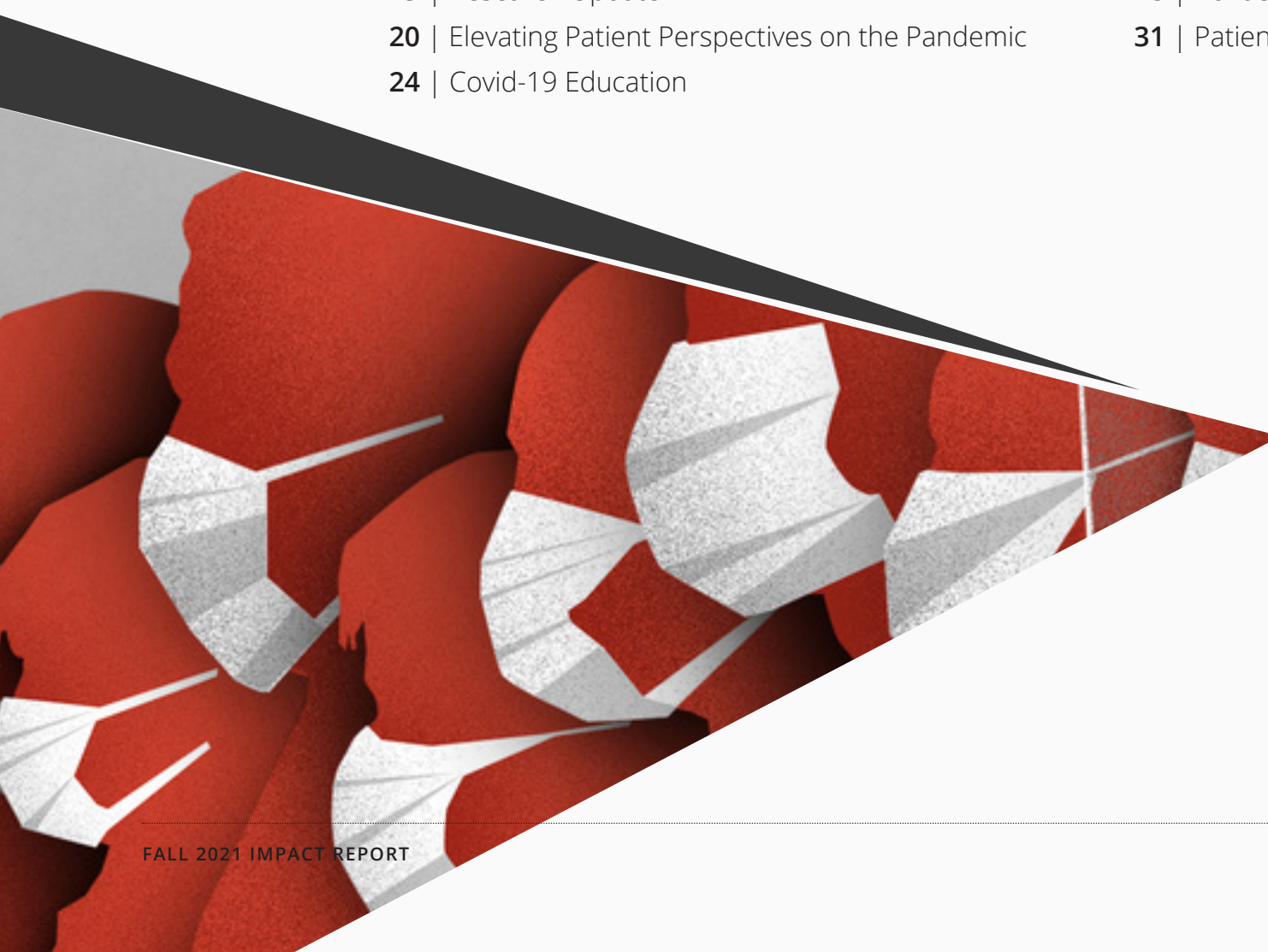
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Creating Positive Spaces on Social Media: A Special #CreakyChats with Walgreens, AIDS United, Susan Komen, The Leukemia and Lymphoma Society and the Children's Organ Transplant Association.

In November we organized major health care leaders and facilitated a #CreakyChats twitter discussion on the importance of vaccines for chronic disease/ immunocompromised patients resulting in more than 10 million impressions.

During this chat we highlighted the unique needs chronic disease/immunocompromised patients face when accessing vaccines and how we can build a society that supports science and keeps all safe.



Join our community

#CreakyChats

Vaccines Save Lives: A #CreakyChats with Health Care Leaders

Thursday, November 11th 7 P.M. ET

Hosted by



Walgreens

@CreakyJoints
#CreakyChats



@AIDS_United
AIDS United



@SusanGKomen
Susan G Komen



@LLSusa
The Leukemia & Lymphoma Society



@COTA_ORG
Children's Organ Transplant Association

PATIENT SUPPORT PROGRAM COMMUNITY POLLS

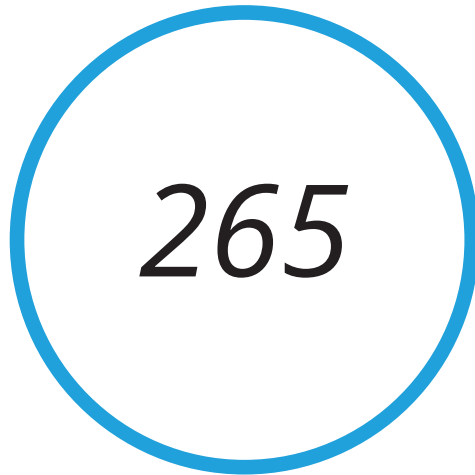


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We are surveying our Patient Support Program members regularly about important issues in health care and other topics.

CHILD COVID-19 VACCINES POLL

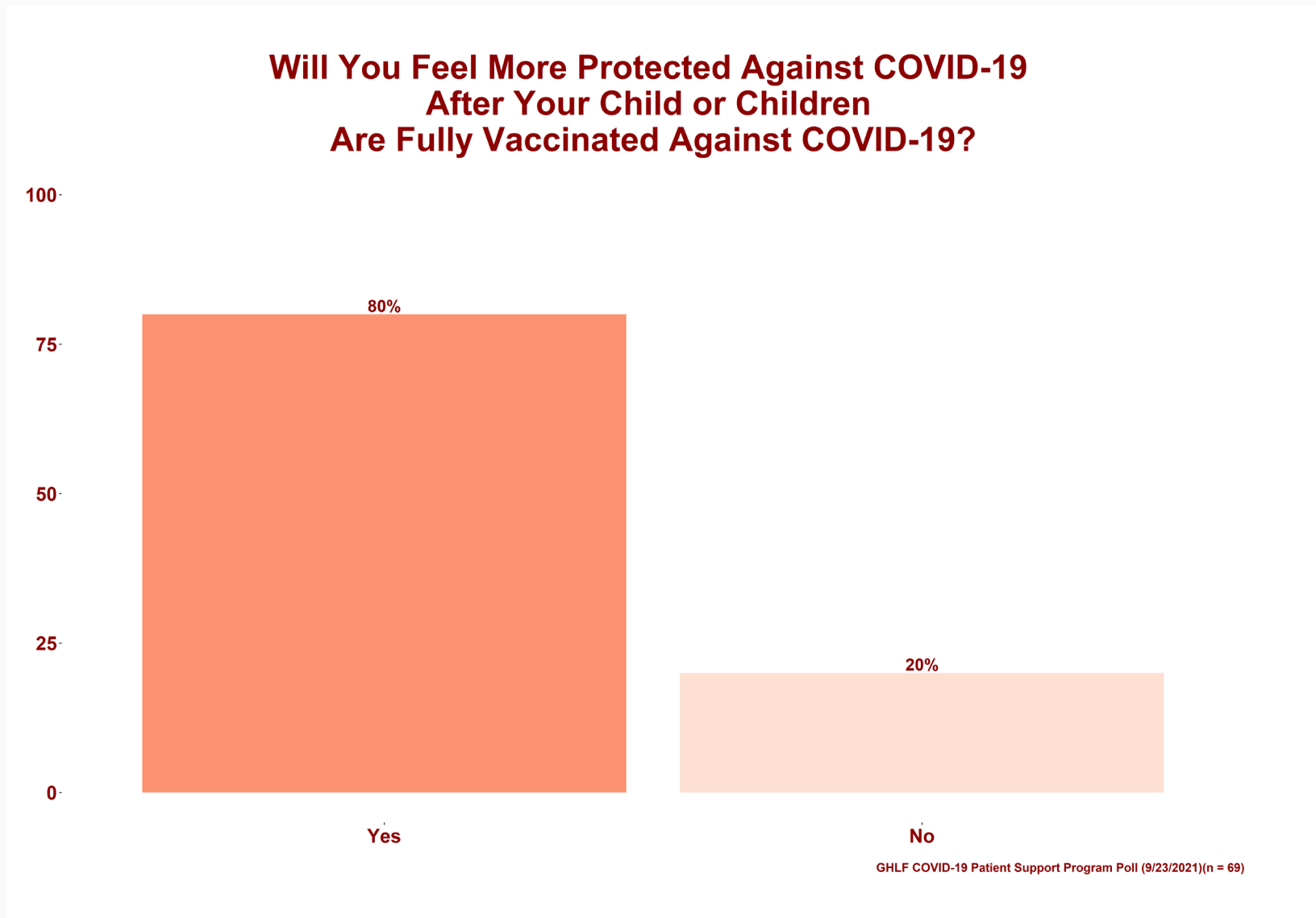
A TOTAL OF 749

Patient Support Program subscribers responded to our September quick poll on COVID-19 vaccines for children.

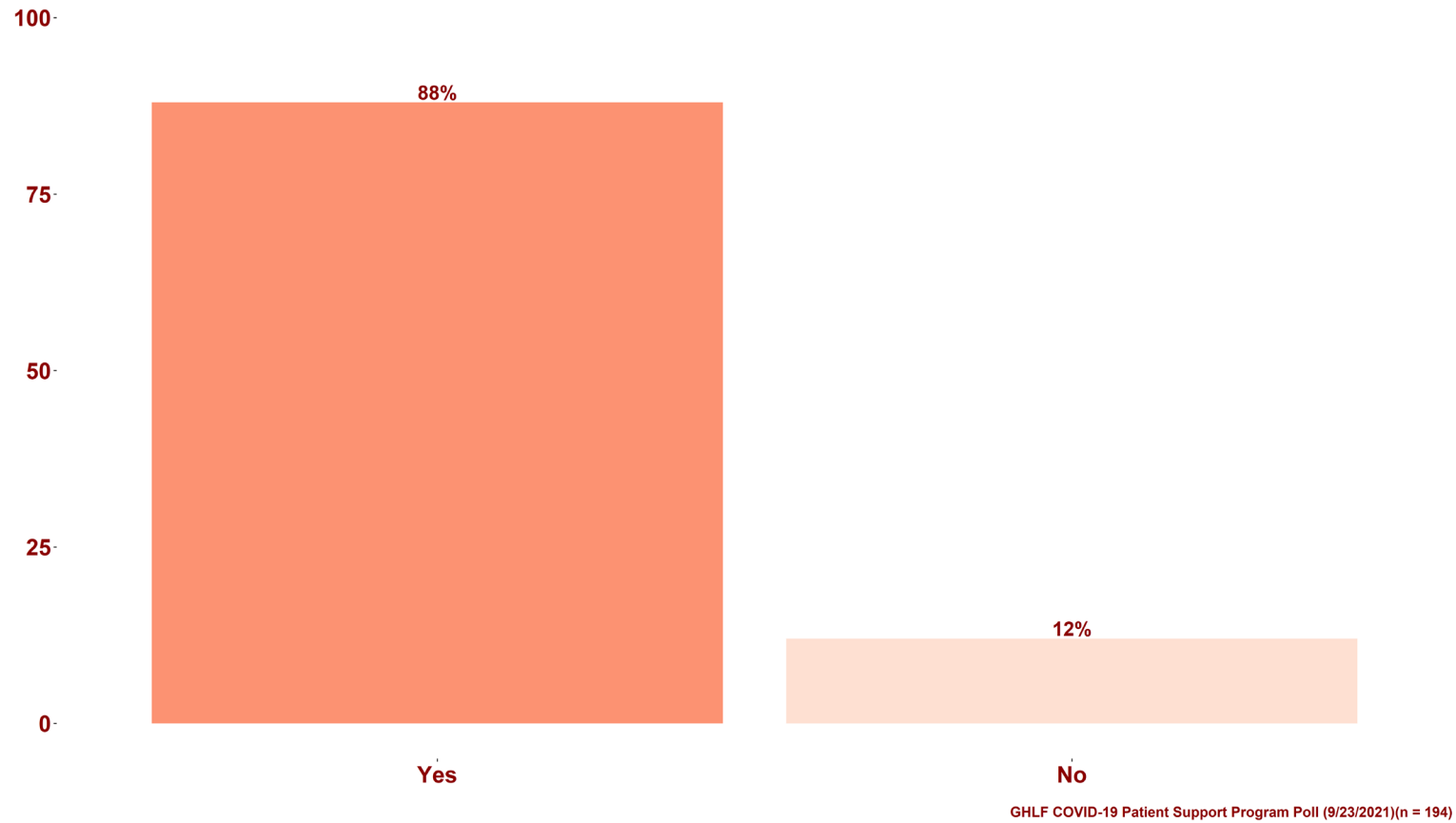


RESPONDENTS HAVE CHILDREN OR ARE AROUND CHILDREN MULTIPLE TIMES A WEEK.

We asked those with children in their lives whether they would feel more protected if those children were vaccinated against COVID-19. Here are the responses:



Will You Feel More Protected Against COVID-19 After the Other People's Children You Are Around Are Fully Vaccinated Against COVID-19?



CHILD COVID-19 VACCINES POLL WHAT OUR RESPONDENTS ARE SAYING

“ I want very badly to be able to be more involved in my grandchildren’s lives and if they are vaccinated, I will feel much safer around them as an immunocompromised person.

Being a teacher who is immunocompromised I fear everyday working with kids who can’t wear their mask properly.

”

“ I think vaccinating children is a crucial step in making the threat of this virus manageable.”

I am relieved that this age group will hopefully be able to be protected against serious disease sooner than expected, but I am still concerned that this announcement will result in even lower mitigation enforcement in schools and businesses, and at the state and federal levels.

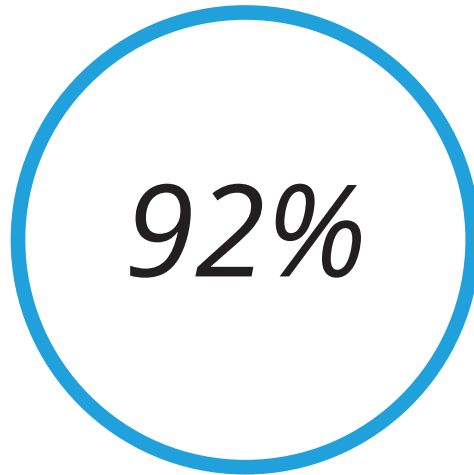
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FLU SHOTS COMMUNITY POLL

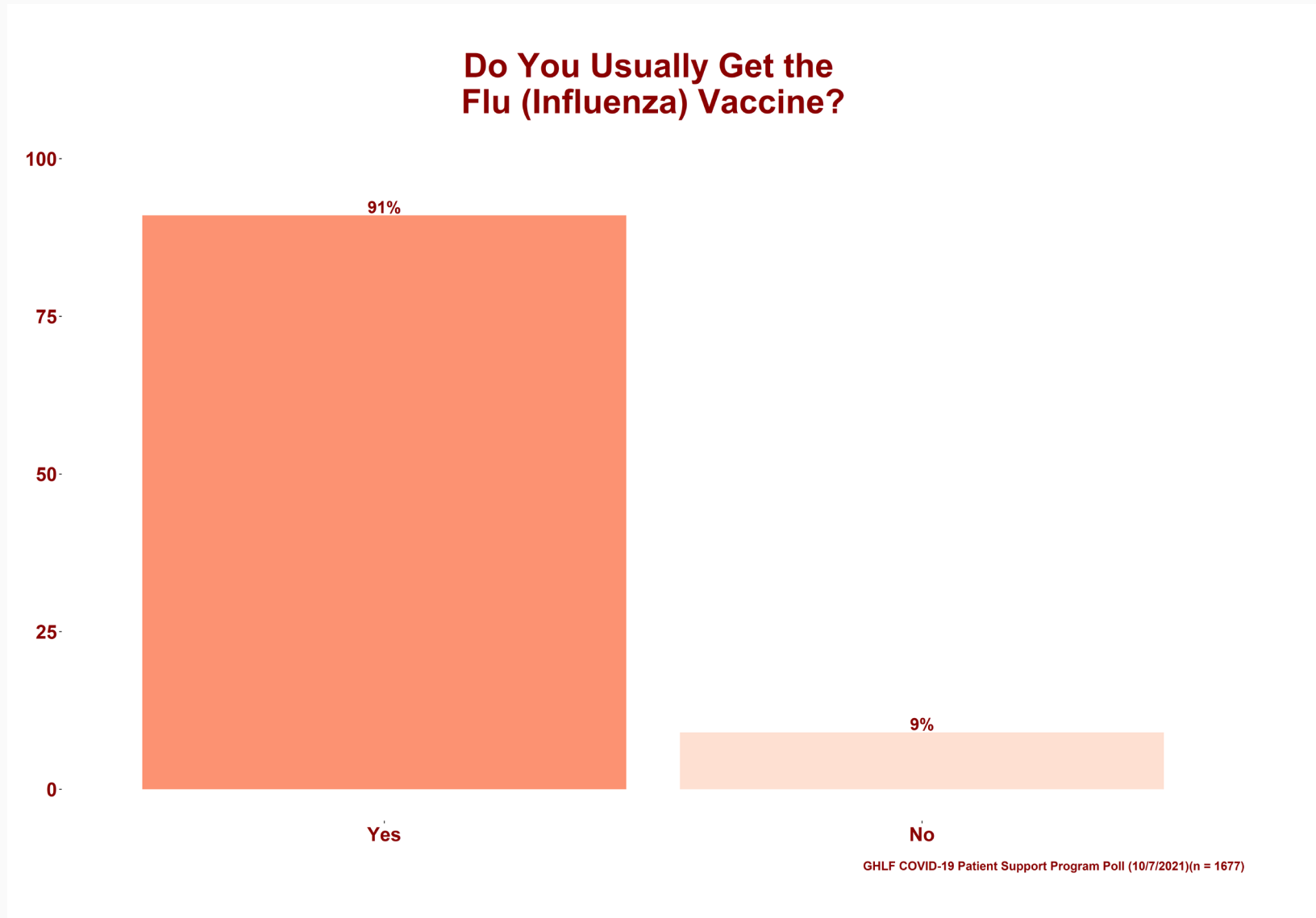
A TOTAL OF 1,677

Patient Support Program subscribers responded to our early October quick poll on the flu shot.



**RESPONDENTS PLAN TO
OR ALREADY GOT THE
FLU SHOT.**

We also asked respondents whether they usually get the flu shot or not. Here are the responses:



FLU SHOTS: WHAT OUR RESPONDENTS ARE SAYING

“

I always get the flu vaccine, [but] I think it's more important than ever for this season because of COVID.

I'm definitely getting the flu shot, as a couple friends got the flu already and they were miserable.

”

“

Flu season last year was mild because of masking. This year we are seeing less masking which to me means a worse flu season, so having any protection will be extremely helpful.



HOLIDAY PLANS COMMUNITY POLL

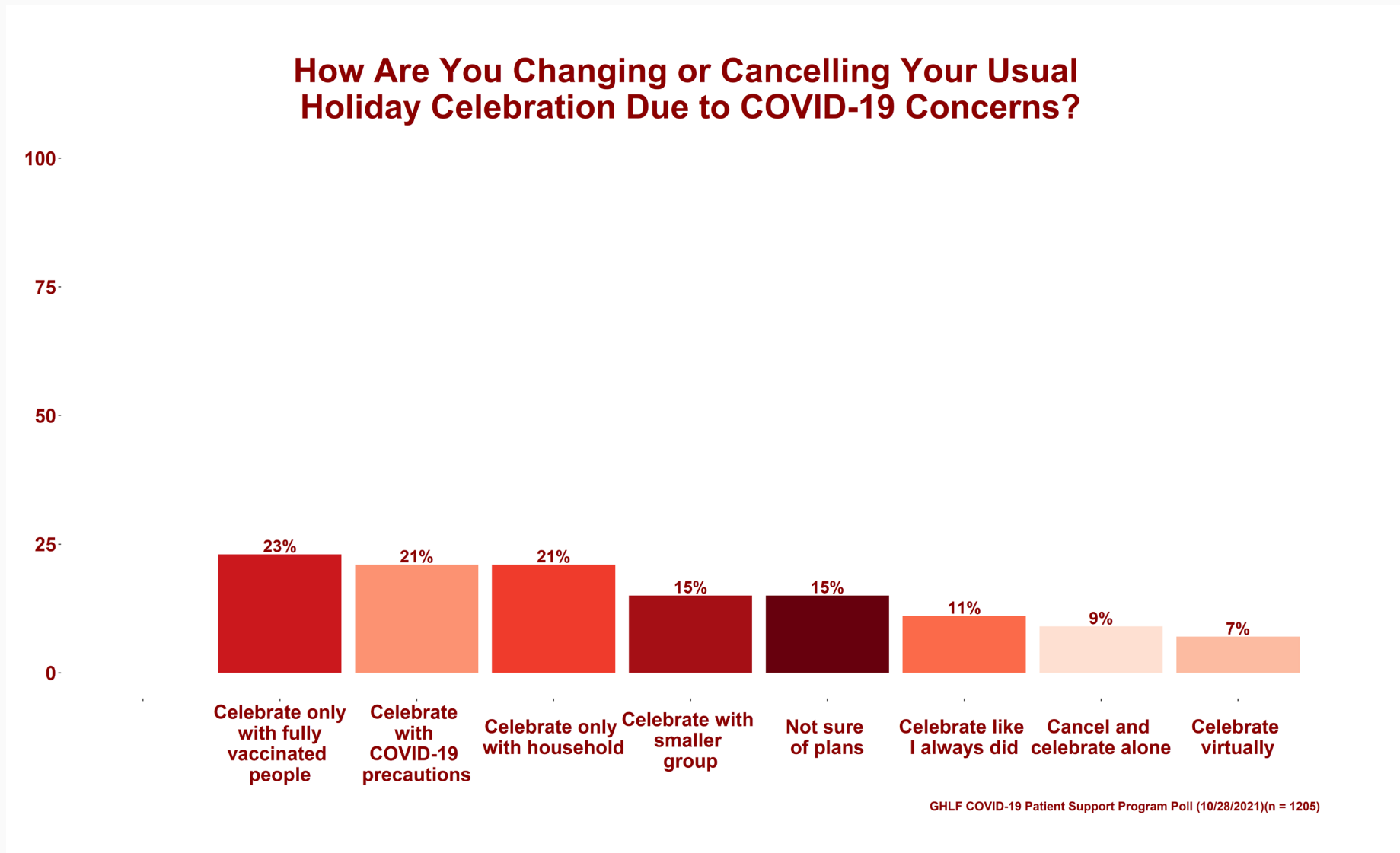
A TOTAL OF 1,227

Patient Support Program subscribers responded to our late October quick poll on plans for the holiday seasons.



PLAN ON TRAVELING AT ALL FOR THE HOLIDAYS.

We also asked whether respondents planned on changing their usual plans due to COVID-19 concerns. Here are the responses:



HOLIDAY PLANS: WHAT OUR RESPONDENTS ARE SAYING

“ All family members have been fully vaccinated, so I feel comfortable to be with them

Everyone attending, except two small grandchildren are fully vaccinated. But we will still have everyone get tested within 72 hours of the family dinner”

“ My small family will be coming off an airplane the day before Thanksgiving and we will celebrate on Sunday after everyone has taken a COVID test and is negative. I’m too old to miss a possible last holiday with my family.”

Because I take two highly immunosuppressive medications, my doctors have advised me to continue limiting indoor contact with even vaccinated family & friends.”

”

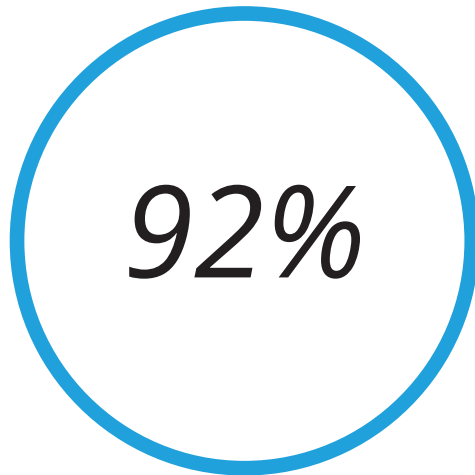
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SATISFACTION WITH SOCIALIZING POLL

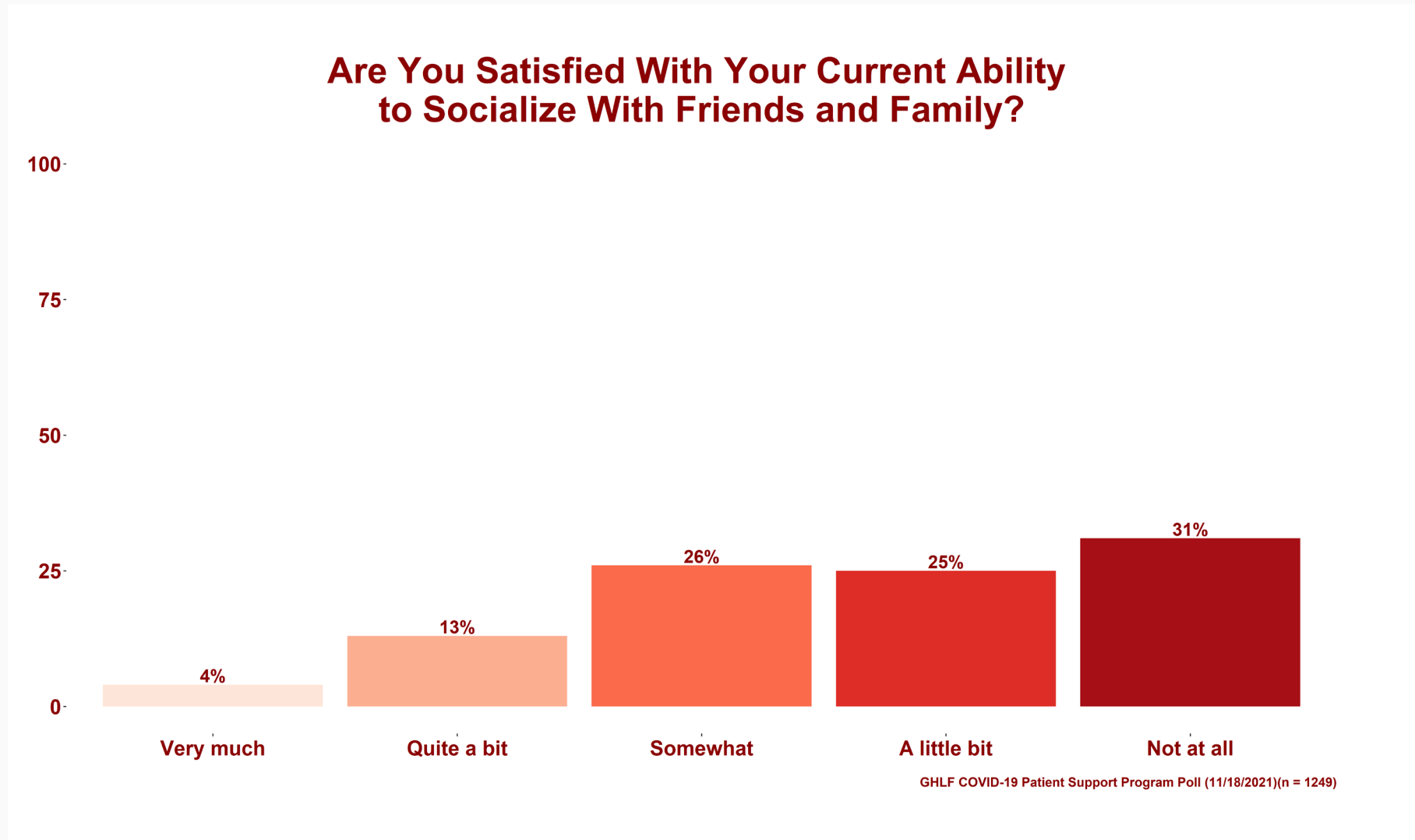
A TOTAL OF 1,249

Patient Support Program subscribers responded to our November quick poll on socializing during this stage of the pandemic.

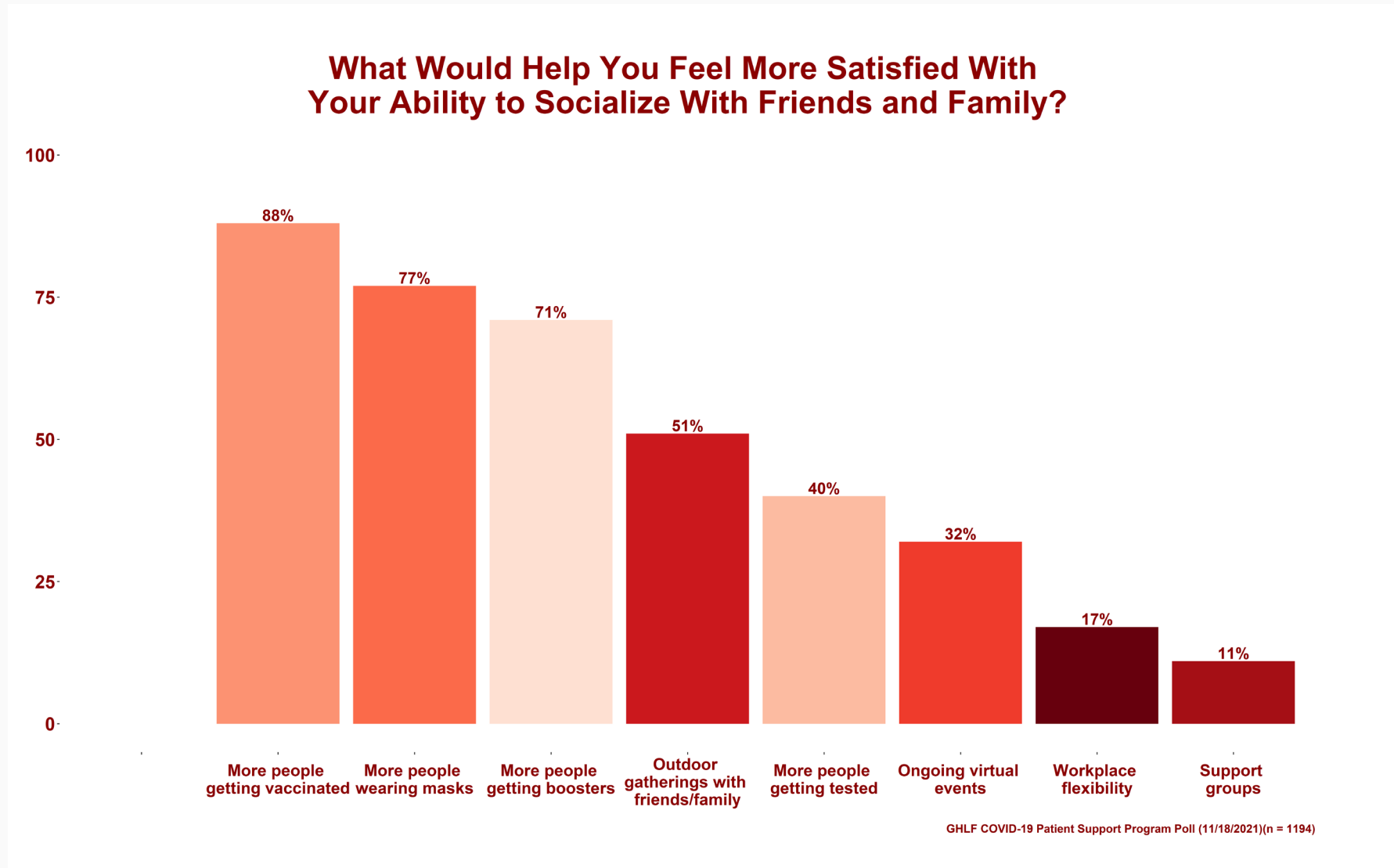


SAID THEY WERE IMMUNE-COMPROMISED BECAUSE OF THEIR CONDITION(S) OR MEDICATION(S) THEY TAKE.

We asked respondents whether they were satisfied with their ability to socialize with their friends and family. Here are the responses.



We also asked respondents what would help them feel more satisfied with their ability to socialize with friends and family. Here are the responses:



SATISFACTION WITH SOCIALIZING: WHAT OUR RESPONDENTS ARE SAYING

“

This year is almost harder than last: A year ago, everyone who took COVID seriously was masked and adhered to guidelines for gathering. Now, most healthy vaccinated people have «moved on» leaving someone like myself who is immunocompromised to be left out of gatherings. So I actually feel more isolated than a year ago.”

I don't worry as much when outside. I am concerned about indoors. I won't know who is or isn't vaccinated for Covid-19. Being in a confined space is of more concern. It's the not knowing that causes me to worry.

”

“

I feel immunocompromised people have been forgotten. Everyone has moved on, or didn't take it seriously to begin with, and we are left out and dismissed. It makes me very angry and sad that people refuse to be vaccinated or wear masks.



RESEARCH UPDATE: FALL 2021 PUBLICATIONS



Global Healthy Living Foundation has continued to publish work using the digital tool, the 35,000-patient ArthritisPower® Research Registry. This work ranges from tracking specific PROs to better understand disease management to understanding relationships between biologic disease modifying antirheumatic drugs (bDMARDs) and treatment

One of GHLF’s recent publications focused on rheumatology patients and what patient reported outcomes they find most important for managing their diseases.

[Which patient-reported outcomes do rheumatology patients find important to track digitally? A real-world longitudinal study in ArthritisPower](#)

W. Benjamin Nowell, Kelly Gavigan, Carol L. Kannowski, Zhihong Cai, Theresa Hunter, Shilpa Venkatachalam, Julie Birt, Jennifer Workman & Jeffrey R. Curtis

Another recent publication explored treatment satisfaction and decision-making for axSpA patients based on data from ArthritisPower survey data.

[Treatment Satisfaction and Decision-making from the Patient Perspective in Axial Spondyloarthritis: Real-World Data from a Descriptive Cross-sectional Survey Study from the ArthritisPower Registry](#)

W. Benjamin Nowell, Kelly Gavigan, Theresa Hunter, William N. Malatestinic, Rebecca J. Bolce, Jeffrey R. Lisse, Carol Himelein, Jeffrey R. Curtis, Jessica A. Walsh

GHLF also supported an ArthritisPower study which explored medication decision-making for pregnant women with inflammatory arthritis.

[Tough Choices: Exploring Medication Decision-Making During Pregnancy and Lactation Among Women with Inflammatory Arthritis](#)

Mehret Birru Talabi, Amanda M. Eudy, Malithi Jayasundara, Tayseer Haroun, W. Benjamin Nowell, Jeffrey R. Curtis, Rachelle Crow-Hercher, Whitney White, Seth Ginsberg, Megan E. B. Clowse



ELEVATING PATIENT PERSPECTIVES ON THE PANDEMIC



CreakyJoints and the Global Healthy Living Foundation were proud to help four different immune-compromised COVID-19 -susceptible patients share posters in the Patient Perspectives track at the American College of Rheumatology meeting.

The posters in this track address ways that patients make changes to improve their care. Each of the CreakyJoints members shared different outlooks about how working with our organization has helped them stay informed about COVID-19, combat loneliness, and take better care of their rheumatic condition:

[From 'Disengaged' to Fighting for Change: The Research Project That Pushed Rheumatoid Arthritis Patient Guadalupe Torres to Become an Advocate](#)

[How CreakyKitchen, a Virtual Cooking Show, Helped Rheumatoid Arthritis Patient Chantelle Marcial Build a Community During COVID-19](#)

[For Wigna Cruz, Spanish-Language Resources Have Made a Huge Difference in Her Rheumatoid Arthritis Journey](#)

[How Rheumatoid Arthritis Patient Deen Allen Went from Fearing the COVID-19 Vaccine to Encouraging Others to Get Theirs](#)

FALL 2021 MEDIA



Having become aware of our Patient Support Program, a reporter with Slate.com reached out to Global Healthy Living Foundation to secure expert perspective on how people who are immunocompromised feel about the ongoing pandemic and vaccination. Titled, [“What Exactly Is the Plan for Us?”](#)

The article pointed out that, “if the immunocompromised were a state, it would be the fifth largest in the nation—about the size of Pennsylvania. If they all worked in the same industry, they’d be the size of the hospitality labor force.” The article summarized some of our quick poll data collected to better understand our community’s concerns about the Delta variant, reporting, “Before delta, some members were cautiously resuming their favorite activities for the first time in over a year, such as going to restaurants or socializing indoors. But when delta arrived, they had to dial those activities back again. In the survey, multiple members reported feeling “sad” and “angry” that people won’t get vaccinated. The relentlessness of the virus is taking a toll on them—and not just physically.”



Shilpa Venkatachalam, PhD, Associate Director of Patient-Centered Research at GHLF said in the article, “People living with these conditions have been isolated because that’s the way they can keep themselves safe... And that isolation then has mental health impacts.” She also commented on the ongoing need for flexible work environments, saying, “During COVID, there were work accommodations for many people...A long-term concern for our community is, will there continue to be flexibility by employers for people living with autoimmune inflammatory conditions?”

In November, the reporter reached out again, this time speaking to our CreakyJoints member Chantelle M. to understand how people living with autoimmune conditions might feel about the country opening up again and people getting together for the holidays when she feels that precautions must continue given that she is immunocompromised.

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 the more than 1 million patients per month with chronic conditions navigate the COVID-19

Top recent content has focused on reporting the latest COVID-19 scientific research from the annual meeting of the American College of Rheumatology. We read through hundreds of abstracts and curated the most important research for patients into these comprehensive guides:

Fall 2021 Update: 8 Things We Now Know About COVID-19 in Rheumatic Disease Patients



<https://creakyjoints.org/living-with-arthritis/coronavirus/fall-2021-update-covid-19-rheumatic-disease>

Fall 2021 Update: 7 Things We Now Know About COVID-19 Vaccines in Rheumatic Disease



<https://creakyjoints.org/living-with-arthritis/coronavirus/covid-19-vaccines/fall-2021-update-covid-19-vaccine-rheumatic-disease>

CREAKYKITCHEN



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.



CreakyKitchen Holiday Specials

In Episode 9, Chef Chantelle taught us a seasonal recipe for Butternut Squash Soup with a spooky balsamic web topping. We were also joined by Fitness and Nutrition Coach, Lauren Scholl. Lauren shared tips for how to stay on track with healthy eating during the holidays, along with suggestions on how to avoid trigger foods in some of our favorite holiday meals.

In Episode 10, Chef Chantelle taught us recipes for delicious Thanksgiving side dishes like her famous mac and cheese and sweet potatoes. Just like our Friendsgiving last year, we heard from members of our community who shared favorite holiday memories and recipes.

SPANISH-LANGUAGE UPDATE

CreakyJoints Español Outreach Hispanic Heritage Month

From September 15 to October 15, America celebrates American citizens' histories, cultures, and contributions whose ancestors came from Spain, Mexico, the Caribbean, and Central and South America.

The rampant misinformation around rheumatic conditions has increased during COVID-19, especially within this community. This year, we address myths and dispel misinformation during Hispanic Heritage Month about alternative therapies by highlighting some valid scientifically-backed data about alternative therapies and the importance of speaking to a rheumatologist and continuing conventional treatment.



Hispanic Patient Voices at ACR around COVID-19 education

One of CreakyJoints Español's patient representatives, Wigna Cruz, shares [her story](#) at the ACR conference about how [Spanish-Language Resources Have Made a Huge Difference in Her Rheumatoid Arthritis Journey](#).



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 have been focused on protecting patient access to medication and raising the voice of patients living with chronic disease.

Take a look at the comment letters:

- [Taking action to address out-of-pocket costs in Medicare Part D](#)
- [Supporting step therapy protections](#)
- [Addressing patient community concerns with drug pricing proposals](#)
- [Discussing the FY22 appropriations process](#)
- [Supporting New York S.4111/A.4668 - prohibiting formulary changes during an enrollment year](#)
- [Supporting Michigan HB.4353 - against copay accumulators](#)
- [Read the letter opposing Ohio HB 435 restricting COVID-19 vaccine requirements](#)
- [Addressing FDA Acting Commissioner Woodcock regarding JAK Inhibitor Warnings](#)
- [Discussing and opposing HHS accumulator adjustor policies](#)

We're excited to announce two new podcasts focused on health advocacy and policy that are part of the Global Healthy Living Foundation Podcast Network. Join us by listening to [The Health Advocates](#) where we break down major health news of the week to help people living with chronic disease make sense of it all. Also tune in to Healthcare Matters for a simplified rundown of not-so-simple matters in healthcare policy.

After the relaunch of The Health Advocates podcast, hosts Zoe Rothblatt and Steven Newmark talked weekly about the impact of the ongoing pandemic on autoimmune patients. They spoke on topics such as changes in local regulations, boosters, and the new Omicron variant – all through a lens of how this impacts our high-risk community.



*Steven Newmark and
Zoe Rothblatt*





PATIENT LEADERS IN OUR PATIENT SUPPORT PROGRAM

From left:

Top row: Jovana Gonzalez Placido (Scleroderma), Daniel Garza (HIV/AIDS), Susan Herley (Gout), Tina Hill (Sickle Cell Disease), Peter Morley (Lupus)

Middle row: Jed Finley (Ankylosing Spondylitis), Jamie Holland (Crohn's Disease), [Name obscured] (Asthma)

Bottom row: Ebby Isbill (Multiple Sclerosis), Catherine Talbert (Psoriasis & Psoriatic Arthritis), Ray B...

GHLF COVID-19 PATIENT SUPPORT PROGRAM FOR CHRONIC ILLNESS PATIENTS

In mid-March 2020, -- 21 months ago -- 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 continues to grow and meet underserved needs of high-risk and chronic illness patients.

Go to www.GHLF.org to learn more

29,158

NUMBER OF MEMBERS

45,895

NUMBER OF SUBSCRIBERS

23.9%

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

6.4%

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



16%

FIBROMYALGIA



14%

HEART DISEASE



11%

MIGRAINE



9%

DIABETES



7%

INFLAMMATORY BOWEL DISEASE

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