




national
lgbt
cancer
network

ADVOCATING FOR HEALTH EQUALITY

2021
Annual Report

Table of Contents

1. Executive Summary
 2. Mission + Values
 3. Financial Snapshot
 4. Cancer Research & Support
 5. Community Education
& Support
 6. Health Systems Change
 7. Looking Ahead
 8. Ways to Give
- 

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Message from our Executive Director

April 2022

As a public health researcher and long time health equity advocate, I don't think there has ever been a time when the work of The National LGBT Cancer Network has been more important. More than a year and a half into the COVID-19 pandemic, we've seen how members of the LGBTQ+ community on their cancer journey have struggled with care delays, staggering isolation, and overwhelmed hospitals in addition to the routine challenges of accessing welcoming and knowledgeable care. All of these issues are especially poignant for Black, Indigenous, and People of Color (BIPOC) who identify as LGBTQ+, people who are too often systematically segregated, underserved, and disenfranchised when it comes to receiving equitable care.

As a trans man, I know all too well that the fear of not being treated well is a powerful health deterrent. For some of us, the pandemic became one more excuse to avoid screenings. The estimated backlog of over 10 million missed cancer screenings is predicted to lead to a wave of advanced cancer diagnoses. How quickly will the LGBTQ+ communities get back to care when our connection to care is strained already? We think one of the best ways to facilitate this is to make care visibly LGBTQ+ welcoming - something the *Out Survey* showed was extremely uncommon. As we live through a historic wave of anti-trans legislation, the issue of knowing where we are welcome becomes even more critical. We are heartened by how many cancer and tobacco control entities reached out to us this year to start new work together. Because of all the issues laid out above, we tried to say yes to as many as possible. This was at times a herculean effort, one that would not have been possible without the dedicated efforts of an amazing staff team going above and beyond in our quest to level the playing field for LGBTQ+ people's health.

As I approach my second full year as Executive Director, I am proud to reflect on the accomplishments of the Network. In 2021 we increased the number of programs and services we provide, gave more "live" trainings than ever before, doubled the number of full-time employees working for The Network, and began developing *Welcoming Spaces* - our updated and expanded LGBTQ+ cultural humility online training designed specifically for healthcare workers. All of this while the nation experienced unprecedented stress.

The National LGBT Cancer Network met 2021 with determination and resolve. And with the continued support of our strategic funders and community stakeholders, we are poised to address the continued historic challenges staged to unfold in 2022.



Scout, PhD
Executive Director



Mission

The mission of the National LGBT Cancer Network is to improve the lives of LGBTQ+ cancer survivors and those at risk by:



Educating the LGBTQ+ community about our increased cancer risks and the importance of screening and early detection.



Training health care providers to offer more culturally-competent, safe and welcoming care.



Advocating for LGBTQ+ survivors in mainstream cancer organizations, the media and research.

Values

Compassion & Empathy

By intentionally leading with kindness, we seek to cultivate and prioritize the health and well-being of ourselves and our communities.

Trust

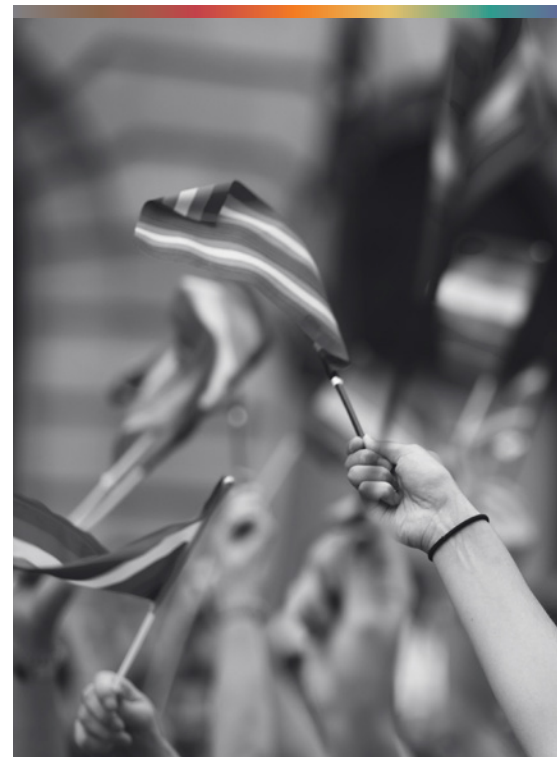
Within our team and board, we build a culture of trust through accountability, integrity, transparency, and evidence-based decision making that extends to our external partners and community stakeholders.

Unapologetic

Queer lives are inherently politicized, particularly trans lives. It is our responsibility to be outspoken and disruptive in order to serve and care for our LGBTQ+ communities.

Justice

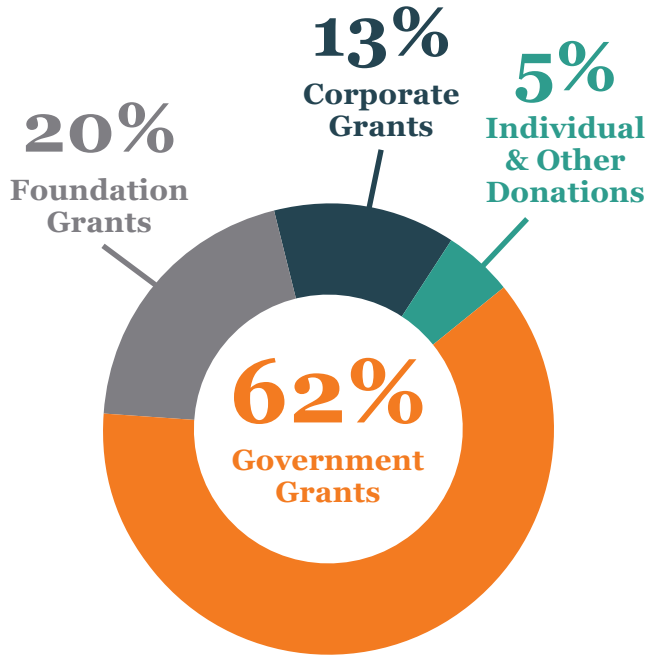
Everything we do is with an intersectional lens rooted in racial justice. We know the only way towards a just future for all is through dismantling harmful systems of power and oppression.



Financial Snapshot

Revenue Breakout 2021 (pre-audit)

\$937,000



In 2021, we joined over 20,000 charities worldwide, becoming a part of the Combined Federal Campaign (CFC). The CFC allows Federal civilian, postal and military personnel to support eligible non-profit organizations that provide health and human service benefits throughout the world. During the campaign season you can visit the CFC website and search for our Charity #12565.



Cancer Research & Support

We believe the only thing a cancer survivor should have to worry about is getting better. No one should feel scared about being treated differently because of who's holding their hand as they wait for the doctor to arrive. In 2020, we launched [OUT: The National Cancer Survey](#) - one of the largest-ever studies of LGBTQ+ people with cancer.

In 2021, we closed the survey and began analyzing the data from the over 2,700 respondents. Over the course of the year we released two reports on the survey data, accompanied by online launch events where we shared that data with our communities. The first report was a summary of the overall survey findings, while the second report focused specifically on the experiences of transgender and gender-nonconforming respondents. We are grateful to the many people living with cancer who shared their stories with us at these launch events and in the survey.

Out: The National Cancer Survey

Reported on the experiences of over 2,700 LGBTQ+ people on cancer journey



Gender Expansive Participants Report

First report to document experiences of gender expansive people with a cancer diagnosis.



“

Surgeon said he had good news and bad news. Bad news: you have cancer. Good news: you don't have much hair to lose.



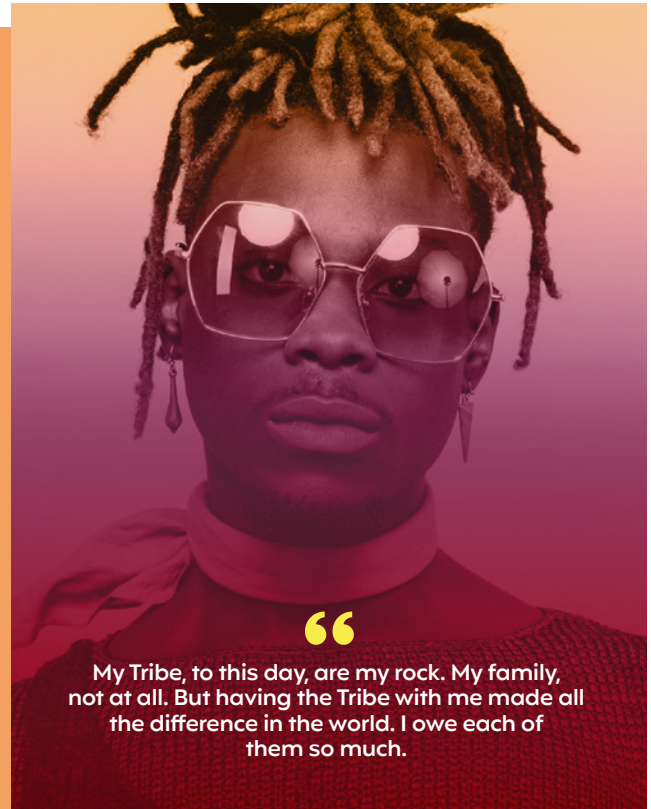
“

I'm TIRED of reading articles about having sex after chemo induced menopause that are all about "overcoming your lack of libido to please your sex-starved husband after he's been your caretaker for months"-- NO! What if I need to understand how to navigate a post-cancer sex life WITH NO DICKS INVOLVED??



“

My Tribe, to this day, are my rock. My family, not at all. But having the Tribe with me made all the difference in the world. I owe each of them so much.



Support Groups

In 2021, we launched our first-ever, virtual LGBTQ+ cancer peer support groups. We know that many LGBTQ+ cancer patients and survivors often do not feel welcome or understood in mainstream support groups, and transgender survivors are especially excluded. Individuals who live further from major metropolitan areas are also unlikely to find one at all. **OUT: The National Cancer Survey** demonstrated the urgent need for tailored support groups. In response, we offer support groups that meet multiple times each week, free of charge, and are professionally-facilitated by a licensed social worker.



Looking for Support as an LGBTQ+ Cancer Survivor or Patient?



Scan to learn more

We offer national peer support groups via Zoom. The groups are free to participants and professionally facilitated. Contact us at info@cancer-network.org



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“

I am absolutely impressed with everything about this organization. I'm impressed with the staff. I'm impressed with the Support Groups and the folks that facilitate them. I have lived with incurable cancer for over 12 years now. It is so comforting and satisfying to be in an all LGBT support group. And the fact that it is a National group, enhances the experience even more. I am so grateful for the experience that the National LGBT Cancer Network provides. Thank you.

- Alina H., Support Group Attendee 10/19/2021

Tobacco and Cancer

At the Network, we focus on tobacco policy change across different jurisdictions in the United States. Much of this work is focused on supporting the regulation of flavored tobacco and menthol. Unfortunately, tobacco use remains an issue that disproportionately affects LGBTQ+ individuals.



“

...There are many disparities that the LGBT community faces, and adequate care from health professionals who understand and can empathize is high on that list. I thank the National LGBT Cancer Network for this education and advocacy work to make health space more safe for those in our community. Maybe, if we feel like we can receive the care we deserve, we may actually seek it out. The National LGBT Cancer Network understands this, personally and professionally.

- Client Served, 10/18/2021

PROTECT OUR YOUTH

LGB MIDDLE SCHOOLERS WERE
3 TIMES MORE LIKELY
TO USE TOBACCO PRODUCTS THAN
THEIR NON-LGB PEERS.

4 OUT OF 10
LGB YOUTH USED TOBACCO
PRODUCTS IN THE LAST YEAR.

FOR ADDITIONAL INFO VISIT:
cancer-network.org

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At the Network, we are committed to addressing the root causes of systemic health disparities. We do this by advocating for and conducting research into cancer-related health disparities among LGBTQ+ populations, engaging in tobacco control work across the country, and providing technical assistance on best practices for LGBTQ+ data collection and policy development and implementation. Our work to address disparities across health systems includes the following initiatives:

Networking 2 Save (N2S)

The National LGBTQ Cancer Network is 1 of 8 Centers for Disease Control (CDC) funded national networks and, as such, works to reduce tobacco and cancer-related disparities in LGBTQ+ communities.

- Data collection
- Evaluation
- Community-based interventions
- LGBTQ+ cultural humility
- Mass media strategy development



Technical Assistance

The N2S team provides customized training and technical assistance opportunities through our webinars, trainings, and educational opportunities.

Toolkits and Resources

The network also provides resource guides, toolkits, and best practices that promote provider and public health education on issues impacting LGBTQ+ communities and tobacco and cancer control.



Training Reach

In 2021 we conducted 26 cancer-focused trainings and 31 tobacco-focused trainings for a total of 57 trainings.



Cancer-Focused

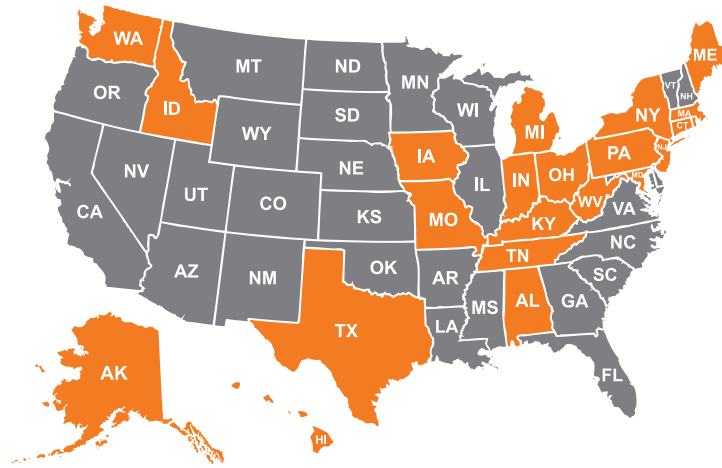
26

Tobacco-Focused

31

All 2021 Trainings

57



Technical Assistance to States

In 2021 we provided ongoing cancer-focused Technical Assistance to 5 states: **West Virginia, Kentucky, Massachusetts, Maine, and Iowa**

In 2021, we provided ongoing tobacco-focused Technical Assistance to 19 states: **West Virginia, Hawaii, Missouri, Rhode Island, Ohio, Michigan, Idaho, Texas, Connecticut, Indiana, Maine, New Jersey, Tennessee, New York, Alabama, Maryland, Alaska, Pennsylvania, and Washington**

“

My experience with the National LGBT Cancer Network has been outstanding. We were fortunate to have a member spend a great informational session with our group of administrators and it was incredibly helpful as we are working to establish our own support group in our area. Can't recommend them enough - knowledgeable, engaging, compassionate and thoroughly professional.

- Client Served, 10/18/2021

Federal Systems Change

The Network serves in an advisory capacity on various federal committees that aim to accelerate queer engagement in mainstream cancer and tobacco control work. The Network is often key in advising on the best, most up-to-date practices for data collection on LGBTQ+ populations. In 2021, the Network worked in collaboration with other national organizations to accomplish:

- Led a successful [community drive](#) in support of the appointment of Admiral Levine, the country's first transgender Assistant Secretary of Health for Health and Human Services (HHS)
- Presented the Biden Administration [joint community policy priorities](#)
- Presented the Biden Administration and Congress our first [organizational policy priorities](#)
- Developed and released our [Big Pride Data Letter](#)
- Urged the adoption of the first ever Sexual Orientation Gender Identity (SOGI) data marker on a census survey, the [Household Pulse Survey](#)

Other advisory groups we are active in include:

- Member of the National Institutes of Health (NIH): [Council of Councils](#)
- Co-chair of National Institutes of Health (NIH): [Sexual and Gender Minority Research Office Work Group](#)
- Member of the National Institutes of Health (NIH): [All of Us Research Advisory Panel](#)
- National Cancer Institute (NCI) Consortium [Sexual and Gender Minority \(SGM\) Special Interest Group](#)
- American Cancer Society (ACS): [Accelerating Cancer Screening National Roundtable](#)
- Centers for Disease Control (CDC): [Menthol Advisory Group](#)
- [Louisiana Campaign for Tobacco Free Living Scientific Advisory Board](#)
- American College of Obstetricians and Gynecologists (ACOG): [Ovarian Cancer Evidence Review Conference](#)
- LUNGeivity [Health Equity Council](#)

“

National LGBT Cancer Network has been an invaluable resource to me and my team. The training, technical assistance, and resources like presentation slides and infographics are thoughtful, evidence-based, and accessible to those working to eliminate LGBTQ+ tobacco disparities. I cannot thank them enough for the work they do!

- Christina G, 10/18/2021

Evaluating our Work

We measure the impact of our tobacco and cancer control work by evaluating state programs three times over the course of the 5-year project. Evaluating states at baseline, midterm and endpoint gives us a comprehensive look into how all state programs are reaching and engaging LGBTQ communities with messaging and interventions around tobacco and cancer control. The evaluation is based on our [Best and Promising Practices](#), a set of standards which has formed the basis for our technical assistance for years. The results of the 2021 assessments can also be viewed on our website using an interactive map.



Best & Promising Practices

This list was originally compiled by over 30 LGBTQ public health professionals in 2007; it has been updated and undergone expert review several times since. These practices have formed the basis for our technical assistance for years. They also are the backbone of our own program evaluation; we are successful as a project if we spur better performance on these measures.

1

Promote LGBTQ professional safety and leadership in public health.

The first resource for LGBTQ expertise is your own staff. Are LGBTQ staff valued? Have you formed an internal advisory group to assist with agency engagement?

2

Include LGBTQ community members in policy planning steps.

The second resource for LGBTQ expertise is local community leadership. Do you routinely make sure we are represented on advisory bodies and review groups? Do you ask the same of grantees?

3

Monitor impact of tobacco/cancer on LGBTQ populations.

In the past two years, 35 states have included LGBTQ measures on their Behavioral Risk Factor Surveillance Survey; including these measures as key demographic variables is becoming routine. Have you asked your state BRFSS to collect these data? Have you fielded community surveys? Do you ask grantees to report LGBTQ measures in program data? Do you urge clinicians to collect these data in health records?

4

Establish cultural competency standards for agency and agency-funded programs.

Do LGBTQ persons know that your program is welcoming? How would we find this out? If it is not clear, we can presume a program is not welcoming.

5

Fund community-based programs.

Local community-based organizations are the best experts in behavior change in this population; funding these organizations directly consistently achieves the greatest level of community engagement.

6

Routinely integrate LGBTQ tailored materials into larger campaigns.

Do your full population campaigns routinely integrate LGBTQ-welcoming materials and practices? Do you ask grantees to do the same?

7

Disseminate findings and lessons learned.

Google "Hawai'i LGBTQ data" to find an excellent example of a state disseminating findings from their own data collection. Be sure to disseminate lessons learned as well; ask us how we can write up a case study of lessons learned and put it on our resource library. Your lessons help others move faster.

Tobacco Policy Change Project

Out, Proud, Free is our tobacco policy change initiative. Historically, tobacco companies have heavily targeted the LGBTQ+ community with their products, including menthol (mint flavored) products, hosting LGBTQ+ nights at bars, sponsoring pride festivals, and targeted advertising. Due to the extensive marketing directed at our communities, LGBTQ+ people have disproportionately high rates of tobacco use, and higher rates of menthol-flavored tobacco use. In recent years, e-cigarettes have hooked a new generation of our youth on nicotine through enticing offerings including candy and fruit flavored nicotine products.

In 2021, we were involved in successful tobacco control policy campaigns in: [San Jose, California](#) and [Portland, Maine](#)



“
I struggled with quitting smoking for eight years. After failing many times, I picked a date to smoke my last cigarette but more importantly, chose not to harm myself anymore.

—
Kyoung



No level of tobacco use is safe.



“
9 out of 10 lung cancers deaths are caused by smoking cigarettes or secondhand smoke exposure.

U.S. Department of Health and Human Services, The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General, Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health, 2014. (2010 January 27)



No level of tobacco use is safe.



“
Smoking as little as 1 cigarette a day over your lifetime increases your risk of early death.

Issaie, Choi, Li, Linn, LM, Bayar, Guzman, C, Hongo, J, Caporaso, N, Freedman, ND, Association of Lung, Liver, Low Intensity Smoking With All-Cause and Cause-Specific Mortality in the National Institutes of Health-NIAHSP (Sex and Health Study). JAMA Intern Med. 2017;177(8):87-95. doi:10.1001/jamainternmed.2016.7511



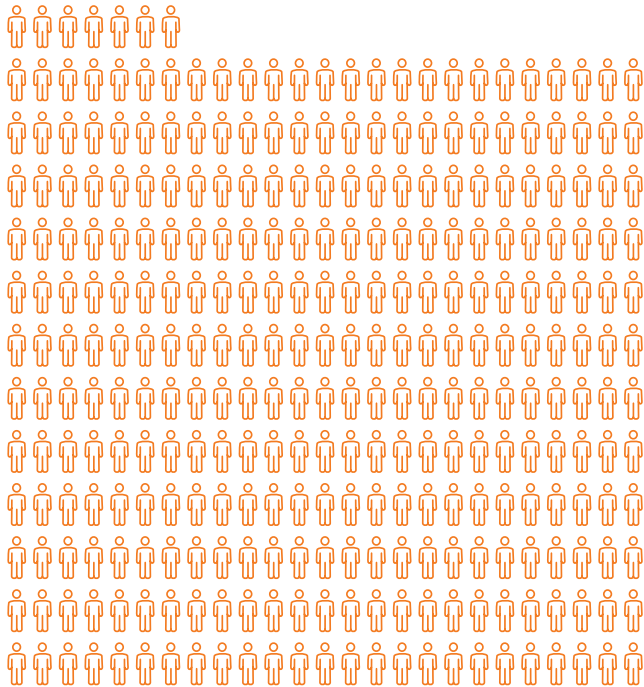
“
I grew up with an uncle who had been smoking since childhood. He developed lung cancer, and had to get a hole in his neck and a feeding tube. I don't want to see queer family members die like that.

—
Stephanie



Network Members

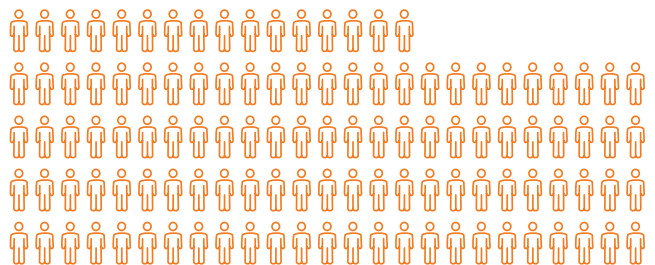
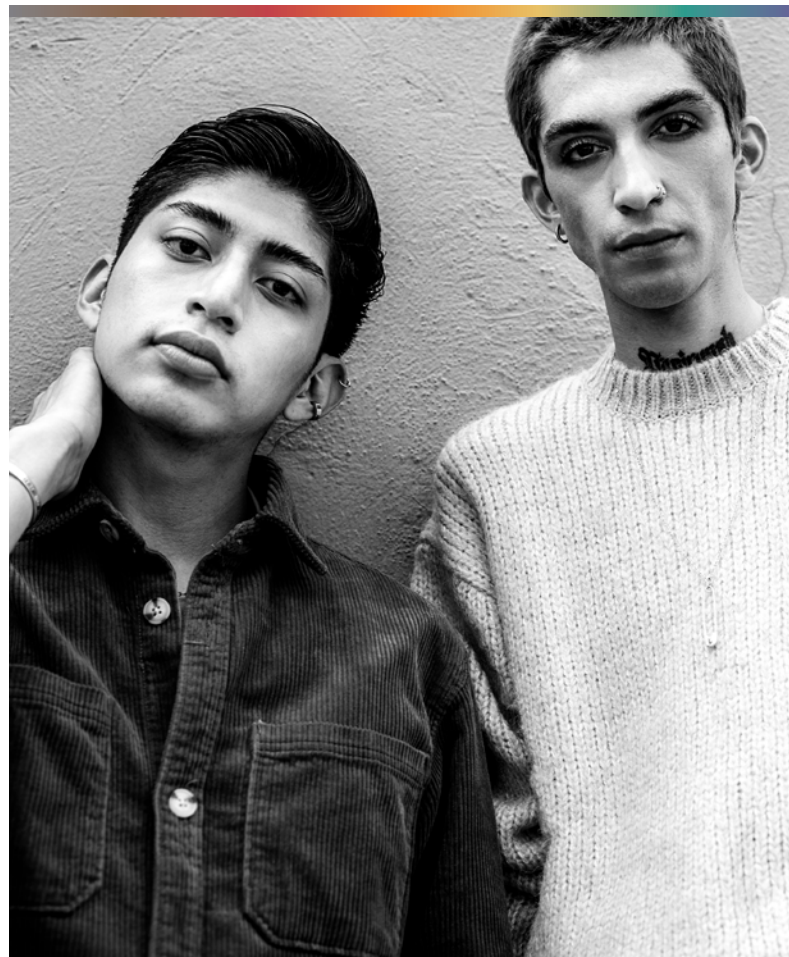
In 2021, 114 new organizational members joined our national network, bringing our **total membership to 307**. Our member network is composed of a variety of local, state and national organizations committed to engaging with LGBTQ+ populations and sharing lessons learned from this engagement. Organizational members receive early access to customizable images, our monthly newsletter and are eligible for personalized technical assistance from us.



April 2021: 307



April 2020: 193



April 2019: 116

Healthcare Provider Trainings

During 2021, we took steps to transition our foundational, in-person training, known as the Cultural Competency Coordination (C3) to an online platform. In partnership with the Society for Gynecologic Oncology (SGO), we developed **Welcoming Spaces**, a nine-part online training series.

Welcoming Spaces is an updated and expanded online version of our previous LGBTQ+ cultural competency training that provides a special lens on cancer by focusing on terminology, pronouns, the root causes of LGBTQ+ health disparities, and creating a welcoming environment. The last 3 modules were created specifically for providers and cover cancer information and screening guidance for transgender and gender non-conforming folks.

Welcoming Spaces launched in April 2022 and is free to all trainees for the duration of 2022. We are already getting great interest from a wide variety of entities as it will be **the most comprehensive training available anywhere**.

Providers can receive Continuing Education credits for the course. It will also be accredited by the Human Rights Campaign to be part of their Healthcare Equality Index rankings.



Frankly

Sex and sexuality are a big part of who the LGBTQ+ community is. Sexual dysfunction due to cancer can be uniquely detrimental to physical, emotional and mental health. Frankly is a project on a mission to break the myth that queer people on the cancer journey are just happy to be alive. Frankly is a space for LGBTQ+ folks to share stories about their sexual desires and dysfunctions, the challenges disabilities can have on relationships and breakthrough discoveries about how to reclaim intimacy and gain sexual satisfaction. We'll feature profiles of physicians who know the importance of communicating the impact their treatment will have on the the sexual activities of their patients. Sex experts will give tips on how folks with chronic illness can reclaim intimacy with their partner and get creative with self-love. Frankly is here to give hope to LGBTQ+ folks, who experience sexual dysfunction, chronic pain or emotional challenges with their partners, and confidence they should and can be sexual beings.

Outlast Tobacco

Outlast Tobacco was launched in 2021 as an online portal designed to encourage LGBTQ+ individuals to quit tobacco as an act of self-love. The portal highlights the effects of the tobacco industry's targeting of the LGBTQ+ community and shares stories of LGBTQ+ folks providing their tips and motivations for quitting tobacco. Our approach is non-judgmental and reminds LGBTQ+ people that one of the best cessation resources at their disposal is the quitline. Outlast Tobacco encourages LGBTQ+ people to reclaim their narratives and create a better world where we can live the long, healthy, and joyous lives we deserve.



LGBT adults spend over **2.6 billion** on cigarettes per year



More than 36% of LGBT smokers report that they usually smoke menthols, which are easier to use and harder to quit.



About **1 in 5** LGBT adults smoke cigarettes

For more than 20 years, the tobacco industry has targeted the LGBT market through direct advertisements, sponsorships and promotional events. Source: TOBACCO USE IN LESBIAN, GAY, BISEXUAL AND TRANSGENDER (LGBT) COMMUNITIES. (2021, March 29). Campaign for Tobacco Free Kids, <https://www.tobaccofreekids.org/assets/factsheets/0415.pdf>

More than 36% of LGBT smokers report that they usually smoke menthols, which are easier to use and harder to quit. Source: Menthol Toolkit. (n.d.Tobwis) <https://tobwis.org/toolkits/menthol-toolkit/#heading-targeting-and-disparities>

About 1 in 5 LGB adults smoke cigarettes. Source: <https://www.cdc.gov/tobacco/disparities/lgbt/index.htm>

35.5% of transgender adults report currently using cigarettes. Source: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5478444/>

About 16.7% of heterosexual/straight adults smoke. <https://www.cdc.gov/tobacco/disparities/lgbt/index.htm>

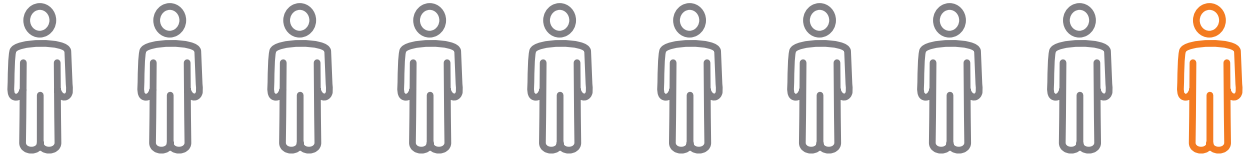
TRANSforming Cancer Site

There are many transgender people across the country who have a cancer story. This site aims to highlight the stories from transgender people from all walks of life that all have the common experience of navigating cancer-related healthcare. We hope to bring to light the shared experiences and of transgender people diagnosed with cancer in hopes of bringing awareness to the many barriers faced and how to best advocate for oneself throughout the process.



Colorectal Cancer Resources

Colorectal cancer is the second leading cancer killer in the United States, but it doesn't have to be. Colorectal cancer screening saves lives by helping detect cancer at early stages when treatment works best. **About nine out of every 10 people whose colorectal cancers are found early and treated appropriately are still alive five years later⁴.** The Colorectal Cancer site project aims to provide comprehensive education and resources for LGBTQ+ community members who have colorectal cancer so they can feel seen and heard.



⁴Centers for Disease Control and Prevention. "Basic Information about Colorectal Cancer." Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, 17 Feb. 2022, https://www.cdc.gov/cancer/colorectal/basic_info/index.htm.

TRANS ELDERS TO THE FRONT!
CANCER SCREENING IN THE BACK

If you're 45 or older, there is a new kind of booty call you should DEFINITELY answer.

People of all genders should be screened for colorectal cancer.

With regular screening, doctors can prevent colon cancer.

Show the people how it's done, preventative medicine is an act of self love.

Get the safe and welcoming screening you deserve. To learn more about the signs for colorectal cancer and screening options visit: StandUpToCancer.org/ColonCancer

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DIGNITY & JUSTICE TO THE FRONT!
CANCER SCREENING IN THE BACK

If you're 45 or older, there is a new kind of booty call you should DEFINITELY answer.

People of all genders should be screened for colorectal cancer.

With regular screening, doctors can prevent colon cancer.

Listen to your gut! Colorectal cancer is a leading cause of death among Asian Americans, Native Hawaiians, and Pacific Islanders.

Get the safe and welcoming screening you deserve. To learn more about the signs for colorectal cancer and screening options visit: StandUpToCancer.org/ColonCancer

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BLACK LOVE TO THE FRONT!
CANCER SCREENING IN THE BACK

If you're 45 or older, there is a new kind of booty call you should DEFINITELY answer.

People of all genders should be screened for colorectal cancer.

With regular screening, doctors can prevent colon cancer.

Listen to your gut! Black folk are more likely to get and die from colon cancer.

Get the safe and welcoming screening you deserve. To learn more about the signs for colorectal cancer and screening options visit: StandUpToCancer.org/ColonCancer

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Ways to Give



MAKE AN ANNUAL GIFT

easily and safely online:
cancer-network.org/donate

or mail a check to:
11 South Angell Street #377
Providence, RI 02906



BECOME A SUSTAINING DONOR

with a monthly gift to sustain our ongoing programs and events throughout the year.



LEAVE A LEGACY

with a deferred gift in your will, or by naming the National LGBT Cancer Network as a beneficiary in your planned giving.