

National LGBT Tobacco Control Network  
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Positively Smokefree:  
Helping HIV + Smokers to Quit



THIS PUBLICATION WAS SUPPORTED BY COOPERATIVE  
AGREEMENT NUMBER 5 U1A DP000558-02 FROM THE CENTERS  
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# SHARING OUR LESSONS

ISSUE 03/WINTER 2010

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NATIONAL LGBT  
TOBACCO CONTROL  
NETWORK

## Positively Smokefree:

## Helping HIV + Smokers to Quit

Achievements of a Cessation  
Program

With Sharing our Lessons we hope to highlight activities happening in the field of LGBT tobacco control and share the stories and voices of those fighting the good fight against big tobacco. We believe that a community driven network must be at the core of the movement and that sharing our stories is an important way to keep the community strong. Please contact us if you know of a project that can be featured in future issues of this publication. [lgbttobacco@gmail.com](mailto:lgbttobacco@gmail.com)

## POSITIVELY SMOKEFREE



Filming the Quit Smoking Support Group PSA at the LGBT Center in NYC

### HISTORY

The Lesbian, Gay, Bisexual and Transgender Community Center in New York (the Center) started its LGBT quit smoking program in 1993, mainly in response to how many gay men living with AIDS in our counseling programs were getting sober but still chain smoking cigarettes. Common sense told us that if they were living with AIDS, which is immunosuppressant and still smoking, which was also immunosuppressant, they were seriously increasing their AIDS-related health risks.

However, our quit smoking message was a hard sell. A study published in a prestigious British medical journal, which indicated no significant relationship between smoking cigarettes and a faster progression to AIDS in a small cohort of gay men, was being circulated throughout AIDS service provider networks as a rationale for not addressing smoking. And with so many gay men dying of AIDS in the early nineties, the conventional wisdom among our colleagues in AIDS services was that it was better not to push people with AIDS to quit smoking, and that smoking was a fair trade-off, a lesser evil to

alleviate the intense stress of living with AIDS. Many felt that the stress of quitting smoking might lower precious T-cell counts.

At that time, we had no local or national data on LGBT specific tobacco use or tobacco-related health problems. With Brent Saunders, the openly gay Director for Tobacco Control for the regional office of the American Cancer Society (ACS), we conducted the first survey of tobacco use in the NY LGBT communities using the Center as a venue. Of 300 survey respondents, 33% were active smokers, more than 50% were unsure of the health risks, including HIV-related risks, associated with smoking and over 50% supported opportunities for smoke-free activities in the LGBT community (1). With no money but some help from ACS and community volunteers, we started "Becoming Smoke Free With Pride", the first LGBT specific cessation group in NY, integrating the "stages of change" with the American Cancer Society's Fresh Start. At that time we also ran one hour "workshops" in AIDS services organizations on the benefits of quitting and tips on how to quit for people living with HIV, gay and straight, again with

no designated funding. We were the only community based organization (CBO) in New York addressing HIV and smoking and demand for our workshops exceeded our ability to deliver. It wasn't until we received an American Legacy Foundation grant in 2000 and then a New York State Department of Health grant, that the Center was able to fully establish the LGBT SmokeFree Project. Through a partnership with tobacco research consultant Dr. Jack Burkhalter at Sloan Kettering Memorial Cancer Center, we evaluated the impact and outcomes of our cessation and education interventions for LGBT smokers. In addition, we examined how characteristics of LGBT and HIV positive smokers and the issues they face might apply to developing more effective interventions for them.

### WHY ADDRESSING HIV AND SMOKING IS CRITICAL NOW

Since then there have been many more studies which show that smoking prevalence is indeed significantly higher in LGBT populations and in studies among people living with HIV/AIDS, a staggering 49% to as high as 72% (2). Greg Greenwood at the University of California San Francisco found that 50-60% of gay men who were HIV positive smoked, almost twice the rate found in HIV-negative gay men (3). We also now know that our early "common sense" about HIV and smoking being synergistic in immunosuppression is accurate. Ironically, the success of the newer HIV medications in prolonging life has increased the health risks for HIV-positive smokers because the more years one lives to smoke, the greater the risk of related health consequences. Smoking has been shown to interfere with processing of HIV medications by the liver, worsen liver problems like hepatitis and in some cases diminish the effects of HIV meds on viral suppression. People with HIV who smoke are more likely to suffer complications from HIV medication than those who don't, like nausea and vomiting. Quitting smoking reduces heart attack risk in HIV patients more than other factors such as changes in medications (4). The profound impact of smoking on HIV and health,

and the fact that many people living with HIV are still not aware of all of the effects of smoking including medication interactions and risks, are very compelling reasons to intensify our efforts to reach HIV positive smokers, including our gay men, and help them to quit.



HIV Positive Quit Smoking Program Ad campaign

### CHALLENGES AND BARRIERS

In the short video "Fumigation" made by Christopher Murray, the former LGBT SmokeFree Project Director, and himself an openly HIV-positive gay man and ex-smoker, three well-known HIV-positive activists who are smokers talk about their ongoing struggle to quit. Although they are all different- a white, gay man; a Latina bisexual woman and a straight, African-American man, all three share that for them smoking is their way to cope with daily stress and to feel powerful in the face of HIV, the perception that there is an acceptable culture of smoking amongst HIV+ people- an "I've survived so much already, I will survive smoking" sense of fatality about health. We showed this film many times to our HIV positive smoking groups and it never fails to elicit strong identification and powerful discussion.

From focus groups, evaluations, and just listening to the community, we heard this theme again and again; that for many people living with HIV, smoking is seen as their best bet for stress reduction, dispelling anxiety and coping with depression. The intensity of depressed and anxious feelings accompanying nicotine withdrawal discourages many from trying to quit or trying to quit again. The impact of social stigma and discrimination about HIV and about being LGBT is also a factor. In the National Institute of Health funded study Intentions to Quit Smoking Among LGBT Smokers, the distress and life stress associated with anti-LGBT stigma and oppression, was cited as the number one reason that LGBT persons continued to smoke, using smoking as a primary coping mechanism (5). The fear of losing critical LGBT support networks, consisting of other LGBT smokers, emerged as a major disincentive to quitting.

Additional barriers to accessing cessation that came up frequently among our HIV-positive focus groups and from Center LGBT SmokeFree program participants living with HIV included: not wanting to go to cessation services in hospital-based settings, which for many people living with HIV hold negative connotations associated with illness and death; a preference to use LGBT and HIV community-based support programs and settings for cessation if they were available; lack of money to pay for programs that charged fees; and subsequently lack of knowledge that Medicaid covers nicotine replacement therapy (NRT); and again, concerns about confidentiality, i.e. not wanting to talk about HIV status and stressors, previous drug use, sexual orientation or gender identity issues in an unsafe or non-supportive environment.

### WHAT WORKS AND WHAT IS NEEDED

Clearly any effective quit smoking program targeted to people living with HIV, as well as to LGBT populations, has to take into account the role that smoking plays for many in protecting them from stressors like living with HIV and dealing with the impact of stigma and discrimination in their lives and on their communities. The Center's LGBT



Photo of "Quincy Quitter" from NY Center PSA

SmokeFree Project had developed two interventions for LGBT

smokers, a workshop called "Not Quite Ready to Quit," (NQR<sup>2</sup>Q) targeted to LGBT smokers thinking about quitting that is delivered as a one-shot, three hour, self-contained workshop; and Commit To Quit (C<sup>2</sup>Q), a 6 session series targeted to LGBT smokers in the preparation/action stage. In both groups, in addition to emphasizing the benefits of quitting and consequences of smoking for people with HIV, we focus on the pros of smoking, what smoking does to help each participant to cope, and the subsequent fears about what they may lose if they stop. This enables them to identify personally meaningful and effective alternatives and to plan for potential roadblocks ahead before they make the next quit attempt. It also decreases the shame, anxiety and sense of failure that many feel about still smoking in the face of HIV and/or other health risks.

Offering this service in an established and trusted LGBT CBO with trained staff, many of whom are peers sharing characteristics of the participants in terms of race, ethnicity, gender identity, sexual orientation and as ex-smokers, makes a difference in enrollment. For outreach, we created low cost digital videos that were broadcast on cable TV and on our website with

humorous and culturally diverse images of LGBT and HIV-positive smokers in different stages of change in the quitting process, and accessing help through our program. We also mixed up the presentation style, with less "PowerPoint" and more video and exercises, call and respond, and facilitated discussion in the HIV-specific NQR<sup>2</sup>Q and we condensed it into shorter sessions. Attendance increased when we brought the NQR<sup>2</sup>Q workshop to the AIDS services organizations (ASOs) and CBOs where HIV smokers were already enrolled.

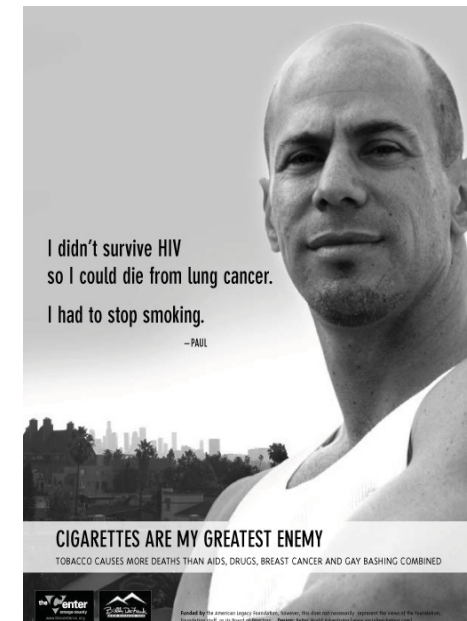
### A WORD ABOUT INCENTIVES...

As an experiment, we added "contingency management" to the HIV-specific groups, which is the use of incentives in the form of small tokens, cash or gifts for attending and completing a behavioral health intervention. For coming to the first two groups, each got a free movie ticket worth about 12 dollars. For graduating -another movie pass and for and quitting, confirmed by carbon monoxide (CO) monitoring, a 50 dollar gift card. Offering incentives were most effective in increasing recruitment. It Pays to Quit Smoking So Get Paid to Quit was a print media campaign we used fairly successfully to enroll HIV-positive smokers but realized that high priced incentives are not cost effective in the long run. Interestingly, our evaluation found that although an incentive like a movie ticket and a free metro card helped get some of the smokers there in the first place, it was the positive group experience that kept many in the group. Quite a few of our program graduates offered to turn back their 50\$ gift cards to the Center as a "donation" in gratitude for helping them to quit. This is clearly an area where more research is needed!

### FINDINGS

Our pre-to-post NQR<sup>2</sup>Q evaluation data showed that motivation to quit smoking increased significantly for all participants as did confidence in ability to quit (quitting self-efficacy). In addition, 82% of all participants

felt that attending an LGBT-specific program, as opposed to a program for the general public, was an important factor in choosing to and following through on attending the workshop. The majority of participants



LGBT Anti-Smoking Ad from Campaign Run in California, Produced by Better World Advertising for the Billy DeFrank LGBT Community Center and The Center Orange County.

indicated that the desire for increased social support for quitting was also motivation to engage in this LGBT community-based group intervention (6)

We were surprised to find how many HIV smokers had misconceptions about the use of NRT as harmful because they were HIV positive, so we needed to provide information to dispel those myths, and to help them to access and appropriately use NRT. New York City gave us free nicotine patches for anyone enrolled in our program and Medicaid recipients are covered for NRT.

We also found that the rate of relapse post-

specific groups than among those in the LGBT group program. This conforms to research on HIV and smoking cessation, and our future programs need to add relapse prevention components or use a more continuous care model rather than a limited session series.

A last point to really emphasize is the most critical factor; using group level and peer-delivered interventions, within an LGBT and HIV affirmative setting, enables increased and enhanced social support, a factor that has been shown to be highly effective in helping isolated or marginalized populations to change behaviors. It has the added advantage of serving as a doorway that swings in both directions. Many participants were motivated to quit because the Center, a place they used and trusted, was offering the services. Many SmokeFree attendees reported coming to the Center for the first time for cessation and then staying involved. This makes ASOs, LGBT community centers and other LGBT/HIV CBO's ideal places to co-locate cessation services.

However running cessation groups does require funding and specially trained staff. This is labor intensive and currently not insurance or Medicaid reimbursable. And not everyone will go to a group. With a comprehensive counseling and support services program, including a licensed substance abuse treatment services program, the Center, and CBOs like us, need to make an ongoing commitment to fully integrating tobacco education and cessation promotion into existing services and activities. The Center developed briefer motivational interventions that were integrated into support groups in variety of settings that are accessed by LGBT and HIV smokers. We added universal tobacco screening to all our counseling programs with referrals for anyone tobacco- positive. We trained all services staff in brief motivational interventions with individual clients who smoke and how to help clients to take incremental, do-able steps to address their smoking. We included resources for tobacco education and cessation, with materials targeted to HIV positive and LGBT smokers, at all inside and off site wellness fairs, events, and activities. Other next steps would

be adding more self-directed quitting tools to the web site and more effectively using the new technology; Podcasting, Twitter, Facebook, etc.

LGBT organizations are at the cutting edge of many innovative behavioral health interventions, in part because the challenge of HIV/AIDS in our communities necessitated that we be on the forefront of insuring the survival of so many in our communities; and because all of the health disparities that gay men, lesbians, bisexuals, trans persons and LGBT families of all backgrounds have endured and still face demand our ongoing best efforts. Continuing to promote equitable access to effective and culturally competent cessation for all HIV smokers puts us again at the forefront of addressing a critical health issue that is affecting so many.



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## TOP FOUR THINGS A LESS RESOURCED LGBT CBO OR ASO CAN DO TO MAKE A DIFFERENCE.:

- 1) Collaborate with local, regional and national organizations like the National LGBT Tobacco Control Network, to leverage information, resources and funding for education and cessation.
- 2) Adding content to existing web sites, publications and outreach materials about the health risks of smoking and HIV, about steps that HIV-positive smokers can take to reduce or eliminate tobacco use, about access to NRT through Medicaid; and links to other resources for quitting like local cessation programs and state quit lines
- 3) Adding tobacco screening, education and referrals to existing individual health and behavioral health services or groups
- 4) Starting a low threshold drop-in support and discussion group for LGBT/ HIV-positive smokers trying to quit and/or stay quit