

## **What do we know about lesbians and breast cancer? Not enough!**

By Liz Margolies

So far, the information we have on breast cancer in lesbians has been both limited and contradictory. The large national cancer registries and surveys of cancer incidence have not collected data about sexual orientation, leaving lesbians embedded and invisible among this vast wealth of information. Other ethnic, geographic, and racial groups have been able to use the data gleaned from these statistics to develop programs to erode the health disparities they face. They know precisely how prevalent cancer is in their communities. Lesbians don't.

A handful of studies have specifically addressed lesbian cancer risks and experiences, but their findings have been inconsistent. Furthermore, the sample sizes have been too small for us to draw reliable conclusions. To overcome these problems, we need more organizations like the Lesbian Health Research Center at the University of California San Francisco and the major financial backing that will allow researchers to conduct the large studies that will give us insights into cancer risk and incidence among lesbians.

Some researchers have theorized that lesbians may have an increased risk of developing breast cancer. This is not due to any physiological or genetic differences between lesbians and heterosexual women. Instead, it's because of a theory often referred to as the "cluster of risk factors." Studies have found that certain cancer risk factors are higher among lesbians. It's also been noted that these risk factors are linked to behaviors that stem from the stress and stigma of living with homophobia and discrimination.

We know that most women who get breast cancer don't have any of the known risk factors. We also know that many people with known risk factors never develop cancer. But what does it mean when a population has a "cluster of risk factors?" Will they have an increased risk? Nobody knows. That's why we need more research!

The four most-cited cancer risk factors in the research on lesbians and breast cancer risk are:  
**Cigarette smoking**—Data suggests that lesbians smoke cigarettes at a substantially higher rate than heterosexual women.

**Alcohol use**—Some studies have reported higher rates of heavy drinking among lesbians than among heterosexual women

**Obesity**—Some studies report that lesbians are more likely to be overweight or have a BMI over 25.

**Pregnancy**—Lesbians are less likely to have biological children before the age of 30, and early pregnancy is known to decrease breast cancer risk.

The research on lesbian cancer screening rates is disturbingly consistent, but not surprising. In every location surveyed, lesbians reported lower rates of mammography, colonoscopy, and Pap smears than their heterosexual counterparts. Part of the problem is that lesbians are less likely to have adequate health insurance coverage than heterosexual women, as most employers do not offer coverage for unmarried domestic partners. However, even when cost is not a factor, previous or feared negative responses from health care providers frequently keep too many lesbians from seeking routine screenings.

If you are heterosexual, imagine, for a moment, that you enter a waiting room where all the forms are designed for lesbians and all the magazines are lesbian-related. Then imagine that the doctor assumes your partner is female and you have to correct them and point out that he's male. More than likely, you'd feel uncomfortable and unwelcome. That's what it's like for most lesbians in most doctors' offices, all the time. And that's why until health care facilities and providers become knowledgeable about and respectful of lesbians, even free screening services will continue to be underutilized and lesbians will continue to be at higher risk of having their cancer detected at a later stage, when it is often more difficult to treat.

I live in New York City and do not have cancer. Sometimes, I imagine a lesbian who is living in a small town in Utah or Iowa who has just been diagnosed with cancer. I wonder if it is safe for her to be out to her oncologist. Will she go to a support group that is comprised of heterosexual women? Will she feel safe being out there? What about her partner? And do we really think she will be comfortable in a caregiver's support group talking about the effects chemo is having on their sex life in a roomful of men?

I picture the two of them using the Internet to learn more about breast cancer and survivorship. More than anything, I want them to be able to easily find the information they need. That's why whenever I visit a website, I pretend I am this couple and type the word "lesbian" into the search box. More often than not, though, we're invisible and the search comes up empty.

I founded **The National LGBT Cancer Network** [[www.cancer-network.org/](http://www.cancer-network.org/)] because I want to end this invisibility. As part of my work, I've been contacting all the national cancer organizations and offering to write articles for their websites about lesbians and cancer. In turn, I ask that they, at the very least, provide links to websites that are dedicated to addressing our risks, needs, and experiences.

**The National LGBT Cancer Network** also helps health care facilities and cancer organizations implement culturally-sensitive care and advocates for the funding necessary for us to get answers about lesbians and cancer. Thankfully, I am not alone in my work. There are many, many committed activists and organizations working on these issues right now. It will take all of us to make a difference.

Liz Margolies, LCSW, is the founder and executive director of **The National LGBT Cancer Network** [[www.cancer-network.org/](http://www.cancer-network.org/)] the country's first program addressing the needs of all LGBT people with cancer and those at risk. You can reach her at [liz@cancer-network.org](mailto:liz@cancer-network.org).