Providing Hope and Affirmation to LGBT People With Cancer

The founder of the National LGBT Cancer Project discusses the community's unique challenges—and how to overcome them.

June 18, 2019 By Trent Straube

June is a time to celebrate LGBT Pride, and 2019 marks the 50th anniversary of the Stonewall uprising, widely regarded as having sparked the modern gay rights movement. What better time, then, to highlight the National LGBT Cancer Project? If you visit the group's website at LGBTcancer.org and the related Malecare.org, you'll find a wealth of resources tailored to this community, including a list of treatment centers and clinical trials, articles and first-person stories with headlines such as: "We Hold Each Other's Hands in Front of Our Doctors. We're Fighting Cancer, Together." Cancer Health emailed Darryl Mitteldorf, LCSW, the founder and director of the organization, to learn more about the project's work and mission.

Darryl Mitteldorf, LCSW, founder and director of the National LGBT Cancer Project Courtesy of Darryl Mitteldorf

Your organization’s stated goal is to eliminate cancer as a major health problem in the LGBT community. How do you work to accomplish this?

We are the major driver of LGBT inclusion in clinical trials and federally funded health-related research. Without research and validated studies, we simply do not know what will or will not be effective treatments for our community. Notably, we, alongside our parent nonprofit, Malecare, have produced many peer- reviewed articles, abstracts and presentations of original research. Our staff has also contributed chapters to four major books, including the recently published Gay and Lesbian Medical Association’s The GLMA Handbook on LGBT Health and the highly regarded cancer quality of life mobile app Cancergraph. Malecare is currently in partnership with the University of Minnesota in conducting a national clinical trial regarding gay men and prostate cancer. In short, the National LGBT Cancer Project takes pride in initiating original research and in supporting our allies in their research.

What are some unique cancer risks within the LGBT community?

Our community has a high prevalence of obesity and tobacco abuse. These two factors alone lead to cancer incidence disparities. Fear of the health care system and demotion of our concerns and psychosexual needs by health care providers discourages many LGBT people from accessing

services such as cancer screenings. The efficacy of treatments has not been investigated regarding transgender people.

It's impossible to accurately state if there are cancer types that are more prevalent because gender and identity data is relatively rare to come by outside of large urban hospitals. I think most people will say that anal and oral cancer has a higher incidence among men who have sex with men than among heterosexual men. Statistics without evidence can be used in horrible, self-serving ways, often by activists that have high profiles.

Do LGBT people face unique challenges when it comes to cancer?

Many of us have doctors who don't have a clue who we are and what we want out of life. Coming out to our doctors regarding who we are is critical. Cancer treatments impact sexuality and our capacity for expressing our identity and enjoying our lives. We don't know if treatments are truly affective for LGBT people, since there is no evidence-based research that investigates our community against treatments and therapies. People keep pushing the myth that cancer affects all of us, physically, in the same way. We don't know if that's true or not.

Are there characteristics of the LGBT community that can be beneficial to cancer survivorship?

Our community has a multi-decade history of health care activism. Our advocacy regarding affordable care for HIV/AIDS has given birth to many vital and energized health activists, several of whom volunteer with the National LGBT Cancer Project.

Who makes up the National LGBT Cancer Project?

We have a three-person full-time staff and another six to 12 people who have been at the ready as volunteers. We are all psychologists or social workers. I am an oncology social worker. Almost everyone here is also diagnosed with cancer or, like me, has lost all of his blood relatives to cancer. For me, this work is revenge against cancer killing people I love.

What element or program at the LGBT National Cancer Project are you especially excited about? And what do people who use your services respond to best?

Cancergraph is a mobile app that was developed collaboratively with Malecare. It's helping thousands of LGBT cancer survivors worldwide tell their doctors, in real time, how their treatments are impacting their quality of life. Cancergraph is now available in English, Italian, Spanish and Chinese. We are presently testing an Arab language version.

People love that we exist. We started our work in 2005. We were the very first national nonprofit to focus on the needs of LGBT people diagnosed with cancer. Our mere existence, not to mention the hard work of our advocacy, provides everyone with affirmation and hope.

Tell us more about the Out With Cancer online support group.

Out With Cancer was a 10-years-long support group system open to all LGBT people. As more and more people navigated to online groups, we ended Out With Cancer as a support group network. The National LGBT Cancer Project now works with hospitals to help them make their support groups either LGBT appropriate or help them create LGBT groups of their own. Malecare produces online and in-person support groups for gay, bisexual and trans people diagnosed with cancer. All the in-person groups are 90-minute-long peer-to-peer discussions.

People who visit OutWithCancer.org may be surprised to find themselves directed to Malecare.org. Malecare also frequently appears on your social media platforms. What's the relationship between these two groups?

Malecare began in 1998 as—what we believe—the world's first nonprofit of any kind to focus on gay men with cancer. The National LGBT Cancer Project was born from Malecare's work on intersectionality, as we wondered if there were cancer-related patient advocacy issues common to all LGBT people. Malecare and the National LGBT Cancer Project share office space and resources.

Can you tell us about some of the research and clinical trials the LGBT Cancer Project is involved with and how people can participate?

Gay men with prostate cancer can learn more about the RESTORE clinical trial at https://malecare.org/restore. In October, we begin a new project to investigate whether the gender of the health care provider has any significance to LGBT cancer patients.

Finally, if someone is dealing with a cancer diagnosis, what general advice would you like to give them? If you are reading this, you are still alive. Cancer doesn't kill love and community. Keep enjoying life.

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