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Nurse's Own 'Gay Cancer' Story

"I WILL SURVIVE!"

by Bobbi Campbell, R.N.

I'm Bobbi Campbell, and I have "gay cancer". Although I say that, I also want to say that I'm the luckiest man in the world. Let me hasten to add that I'm not lucky because I have Kaposi's Sarcoma. I'm lucky, and happy, because in my time of crisis, I've found out who my real friends are. I'm surrounded by people who love me, who care about me, who follow my progress with interest, and who want me to get well soon.

Let me tell you something about myself. I'm a 29-year-old, white, gay man who's lived in the City for six years. I work as a Registered Nurse at Ralph K. Davies Medical Center, and I'm studying at the University of California at San Francisco (UCSF) for a Master's Degree in Nursing as an Adult Health Nurse Practitioner. When UCSF's Graduate Division asked me what my focus of study would be, I wrote that I was most interested in specializing in gay health care.

My argument was that lesbians and gay men are often ill-treated by

the straight health care establishment and that we constitute a population at risk for certain health problems, such as substance abuse, mental health concerns over being gay in a homophobic culture, sexually transmitted diseases among sexually active gay men, etc. The school loved my rap, and now I'm in graduate school studying to be a gay health Nurse Practitioner.

In September, my lover Ron and I went on a honeymoon car trip down the coast to Monterey, Big Sur, San Simeon, and the Pinnacles National Monument. When we returned, I took off my hiking boots and, surprise! On the soles of both feet I noticed purple, painless spots, about an inch in diameter. Since Ron and I had been hiking through some rough territory, I assumed that they were blood blisters and didn't pay any more attention to them.

Three weeks later, the lesions were still there. ("Lesion" is a broad medical term referring to any tissue breakdown or loss of function.) About that time, I was reading in the straight media about

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DANIEL GENERA and ROSA AGUILAR of Teatro Flamenco danced at the Gay Latino Alliance (GALA) sixth anniversary celebration at the American Indian Center on December 5.

Larkin Liquor License Still Unchallenged

by Jack Nichols

Neither the San Francisco Police Department nor the Alcoholic Beverage Control Board has yet determined which store reportedly sold liquor to two increasingly belligerent men tagged as suspects in the November 21 slaying of a gay man on Larkin Street. Witnesses reported that the duo made repeated trips to a liquor store before they wounded two men and killed a third in a series of knife attacks.

"Theoretically," said Mayor Diane Feinstein, shortly after the

he found out about the liquor store forays from witnesses and "assumed" they meant a store across the street from the apartment where the suspects were arrested. But he wasn't sure either.

Police spokesperson Sgt. Mike Pera said, "At this point there is no direct information linking any particular store to inappropriate conduct." There was some "vagueness," he reported, on the part of the witnesses.

Pera said that when investigators pursue liquor store owners, the owners say "Hev. listen. what am

State-Funded Television

OBLEDO DELAYS DECISION ON SPOTS

by Sue Zemel

State Secretary of Health and Welfare Mario Obledo on December 7 delayed his decision whether to reinstate the Lesbian/Gay Mental Wellness Project and promised to meet on December 14* with the eleven-member work group to discuss the future of the controversial project.

In late November, Obledo notified the five other special population groups participating in the state-funded Mental Wellness Promotion Program that they could proceed with their plans to air public service announcements. Obledo, however, declined to give the Lesbian/Gay project the go-ahead, expressing his concern that the proposed television spots bordered on "advocacy."

Obledo offered no guidelines or definitions of what constituted advocacy, according to Pat Norman, coordinator of the Lesbian/Gay work group. Norman also pointed out that Obledo's new set of criteria for the projects, issued on October 22nd disqualified five of the six work projects ten months after they were approved.

The Hispanic project was the only one that didn't violate Obledo's *post hoc* criteria. Obledo is Hispanic.

B.T. Collins, Governor Brown's chief of Staff, subsequently scrapped the entire Mental Wellness Project. When Al Loeb, director of the state Department of Mental Health, resigned on December 1, he stated that Collins's decision was one of the factors that led to his resignation.

Subsequently, Mario Obledo reinstated five of the six projects.

draw the line at government activities that might advocate a gay lifestyle.

Obledo was unavailable for comment.

The stated objective of the Lesbian/Gay Mental Wellness Project, approved last December by the state department of Mental Health, is "to promote wellness in the lesbian/gay community through the development of multi-media materials that emphasize a positive self-image, question irrational stereotypes, and encourage mutual aid and social support systems."

The Lesbian/Gay project is part of a larger campaign sponsored by the Office of Prevention in Sacramento. Norman said the campaign, called "Friends Can Be Good Medicine," came under scrutiny early on because of its underlying concept of preventative healthcare.

However, the Department of Mental Health went ahead and approved the general campaign, providing \$100,000 grants to five minority "special population" groups. These groups were the Asian, Hispanic, Black, Native American, and Lesbian/Gay communities.

In December of 1981, the Lesbian/Gay Project work group received word that funds were being held up because the elderly had not been included as a special population group.

At that time, Obledo suggested that this group replace the Lesbian/Gay group. Gay men, lesbians, and their friends successfully lobbied state officials to retain funding for the Lesbian/Gay project. The state decided instead to deduct \$15,000 from each existing group in order to form a sixth group for

"I Will Survive"

(Continued from front page)

"gay cancer"—rare diseases that were mainly afflicting homosexual males. When my lover, who is a chiropractor, told me that Kaposi's Sarcoma usually occurred on the feet, I started to worry.

Could I, a relatively healthy 29-year-old man, have cancer? Ridiculous. Still, my lesions didn't go away. When I mentioned these concerns to my therapist, he urged me to go to see a gay doctor to have the lesions evaluated by someone who has seen this thing before. "You're worth the money it'll cost, aren't you?" he asked.

Well, I am worth the money, but since I'm a student at UCSF, I can get free medical treatment there for most problems. The doctor at the student health service had never seen Kaposi's Sarcoma, so she referred me to Marcus A Conant, M.D., the dermatologist who is co-ordinating the Kaposi's Sarcoma task force in the City.

Dr. Conant took a medical history, did a physical examination, and biopsied one of my foot lesions. (A biopsy is the removal of a piece of living tissue for microscopic examination.)

The next week, accompanied by my best friend Maggie, I was back in Dr. Conant's office for the stunning diagnosis: the purple spots on my feet didn't hurt or itch or anything—were Kaposi's Sarcoma. I had "gay cancer." Dr. Conant was kind enough to take an hour off to explain the disease to me.

Basically, there has been a recent increase in reported cases of rare diseases in young, otherwise healthy gay men in San Francisco, Los Angeles, and New York City. One of these diseases is Kaposi's Sarcoma (KS), which is essentially a tumor of blood vessel walls, another is cancer of the tongue, and another is Pneumocystis Carinii Pneumonia (PCP), which is an infestation of lung tissue by a one-celled organism called a protozoa. The doctors do not yet know why gay men, and not other people, are getting KS, PCP, and other illnesses. The Center for Disease Control (CDC) in Atlanta, the same folks who solved the clinical problems of Legionnaire's Disease and Toxic Shock Syndrome, are researching this one, too.

This is serious business: in August, 1981, the CDC reported that out of 108 reported cases of KS, PCP, or both, 43, or 40%, had died. Ninety-six of these 108 reported cases, or 89%, were homosexual men.

Well, I'm not going to die—not yet at least. I am lucky because my cancer was detected early and is treatable. I have an excellent prognosis. Extensive diagnostic tests showed that my cancer had not spread to internal organs. Extensive blood tests showed that my immune system, which is how the body fights off invaders, was relatively intact. I didn't have any other infections which would have complicated my cancer treatment. I'm a prime candidate for the administration of Vinblastine, a drug that could get rid of my cancer in a matter of months.

That's the good news. The bad news is: I have cancer. I'm 29. Hey, this is too young for a mortality crisis! I've been a nurse for many cancer patients, but this was a real twist of fate.

Dr. Elizabeth Kübler-Ross, a famous cancer specialist, has suggested that people typically face any loss, especially the loss of life, in five overlapping phases:

- 1) Denial: "The doctor must have made a mistake."
- 2) Anger: "Goddamn, this isn't fair!"

3) Bargaining: "Just let me live until my daughter gets married."

4) Depression: "It's worthless and hopeless. I might as well die now."

5) Finally, for those who can work through the earlier phases comes acceptance: "I've put my affairs in order and I'm content with the life I've lived."

I've already gone through most of these phases in two months. In my denial phase, I didn't actually refuse to admit that I had KS, but I was emotionally disconnected from it. Feigned nonchalance was the key. My friend Michelle asked me in the elevator at work, "What's new?" and I said, "Oh, I have 'gay cancer.'"

In my anger phase, I became irrationally furious with my lover, my doctor, my therapist, my roommates, and others close to me. For bargaining, I tried to figure out how I was going to co-ordinate a cancer treatment with my roles as a part-time nurse and as a full-time student.

In my depression, I coped with grief and anxiety by abusing alcohol and other substances. My lover and I broke up, made up, broke up, and sort of made up, all within a two week period, all revolving around the issue of my self-destructive behavior. "Goddamn it, Kon, this is my mortality crisis and I'll screw it up any way I want to."

I haven't exactly "gone through" these phases because I'm still dealing with each of them. I am simultaneously denying, angry, bargaining, and depressed. I'm getting closer everyday to accepting, the fifth phase, because of the energy I've expended on behalf of myself and my brothers with KS and PCP. Since I'm a professed gay health nurse, I decided that one way for me to help myself deal with this crisis was to be functional. I wanted to find out what needs the KS and PCP patients had that a nurse could address.



Bobbi Campbell, R.N.

What I found out was that the doctors were treating the KS patients beautifully from a medical perspective. However, the men did not know each other, and a support system had not yet been implemented.

"Find the need and fill it," someone once said, and I think I found it. I'm helping to establish a network of brothers (no sisters so far) with KS or PCP. I'm helping Berkeley's Shanti Project establish a support group for all cancer-stricken gay men. I'm writing this column. I'm writing articles for professional journals, and I'm researching the complicated story of "gay cancer" thoroughly.

What is "gay cancer?" "Gay cancer" is a catchy term which inaccurately refers to a complex syndrome of illnesses which include, but is not limited to, cancer itself. Since 1976, these have been reported in increasing numbers in young, white, homosexual men. Formerly these illnesses were seen only in very specific geographic areas, such as Uganda, or in a specific group of patients, such as those whose immune systems had been deliberately suppressed so they would not reject an organ transplant.

The occurrence of these illnesses in the gay male population suggests that our own immune systems are being suppressed to dangerous levels. How, why? The doctors do not yet know.

Factors suggested for this upsurge of disease include 1) exposure to a particular virus, possibly one known as cytomegalovirus (CMV); 2) hereditary predisposition; 3) frequent exposure to sexually transmitted diseases such as gonorrhea and amoebic dysentery; 4) frequent exposure to the drugs that are used to treat these diseases, such as Flagyl, which is itself possibly cancer-causing; and/or 5) frequent use of recreational drugs—marijuana, cocaine, LSD, alcohol, poppers, etc.

The Kaposi's Sarcoma Poster boy

In view of this depressing story, why did I refer to myself as "the luckiest man in the world?" Aside from having the diagnosis which everyone fears, things are going well for me now. I found my lesions early, so it's treatable and I've already seen a response to the therapy.

I have a job that provides disability insurance and a supportive supervisor who said, "Go home, take care of yourself, and I'll pray for you." I have health insurance that covers nearly everything. I have a man I love dearly who loves me. I have a gay therapist whom I've been seeing for months who can help me work out my feelings. I have parents who know I'm gay and who are supporting me magnificently.

I have tremendous respect for the doctors that are treating me, and that's quite a compliment from a nurse! I have more friends than I ever knew, who expressed shock and sympathy and offered their support anytime I needed it, ever. Wow, folks. I've tried to thank you individually, but this is for those of you I might have missed—thank you.

In one very practical moment, it occurred to me that I might be able to use the CDC research to write my master's thesis. Just then, my ex-lover Tom called from Seattle to ask delicately how I was feeling. I answered "Great! I've just figured out how to turn this thing into a master's thesis!" After a few moments of stunned silence, Tom said, "I don't know how you do this."

Tom, I don't know how I do it either. Something in me says I have a choice between curling up and dying, or else getting out in the community and getting this job done. The job is that I'm worried about a man who doesn't exist, exactly. I made him up to illustrate someone who is not so lucky as I am.

Suppose there's a young, white, gay male on Castro Street right now with purple, painless spots on his feet, or arms, or anywhere. This man will not know he has KS—"gay cancer"—for months because he doesn't like doctors or doesn't believe in "gay cancer." When he finally is diagnosed, he'll be wrecked because his job doesn't provide for health or disability insurance, neither his boss nor his parents know that he's gay, he just moved here, and doesn't have a lover or many friends. Sigh.

Remember that I just made up the profile of this man, but it could conceivably be someone you know and love. Sigh, again.

I've become so active in publicizing KS and the other gay illnesses to friends and media that I've taken to referring to myself sardonically as the "Kaposi's Sarcoma Poster Boy." True, I haven't received any offers from movie stars for telethon fundraisers, but I'm still available.

My friend Gary thought that calling myself a "poster boy" showed a macabre sense of humor. Yes, Gary, I can be macabre—but it's my way of adapting. The purpose of a poster child is to raise interest and money in a particular cause, and I do have aspirations of doing that regarding "gay cancer."

In subsequent columns I will discuss both my own subjective feelings as a KS patient and, as a nurse, issues relevant to gay health care, especially "gay cancer."

I'm doing this for me, I'm doing this for you, and I'm doing it for our hypothetical brother standing on Castro Street who has "gay cancer" and doesn't know it. He may also be standing on Christopher Street or Santa Monica Boulevard, and he's probably not hypothetical.

I've taken to wearing a button with the title of Gloria Gaynor's 1979 hit song, "I Will Survive." It seemed an appropriate title for this column. I'm writing because I have a determination to live. You do, too—don't you?

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