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Vivian Stephenson

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## Don't Let Your Disease Define You

VIVIAN STEPHENSON

*Vivian Stephenson directed information technology systems at numerous companies, including Target Corporation, as Executive Vice President and Chief Information Officer, and Williams-Sonoma, as Chief Operating Officer and Chief Information Officer. In 1994, Vivian was a recipient of the “Oscar” of information technology—the Smithsonian Institution and Computerworld Award—for developing the Planned Store Inventory System at Mervyn’s Corporation. Vivian is a former chair of the Board of Trustees at Mills College, from which she received a Doctor of Humane Letters Honorary Degree in 2005 for her “ethical and compassionate leadership” and for serving as “an inspired, unwavering advocate for women and the power of education to transform women’s lives and society as a whole.” Vivian survived two different types of breast cancer, diagnosed in 1980 and 1996. In 2009, she was diagnosed with stage IV ovarian cancer.*

**KEYWORDS** *Vivian Stephenson, information technology, Mills College, lesbian leaders, lesbians fighting disease and disability, lesbians and medical treatment, lesbians coping with illness, lesbian support systems, best medical practices, ovarian cancer*

*N.B. Vivian Stephenson was interviewed for this chapter by Nanette Gartrell.*

### CAREER

I was born and raised in Cuba. I came to the United States in 1960, a year or so after Castro was in power, because it became clear that things would be difficult in terms of freedom and opportunities—especially for lesbian, gay, bisexual, and transgender (LGBT) people. After receiving an MBA from

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the University of Havana, I went to New York University for a degree in mathematics. Nearly my whole career was in information technology. It was a difficult thing for a woman, particularly one from Latin America, to get into leadership positions, and opportunities were very limited. However, I worked hard, and over time moved from management to executive positions at different corporations. For example, at Target Corporation, I became Executive Vice President and Chief Information Officer; I was in charge of all technology for the company. After I retired in 2000, I served as a technology consultant to Ron Johnson at Apple when they were just beginning to think about opening retail stores. I also did leadership consulting because that has always been a passion of mine. While serving as a management consultant to the Chief Executive Officer of Williams Sonoma, he asked me to join the company as Chief Operating Officer—a position I held until I “re-retired” in 2006. I have continued to serve on several boards of directors, including Carmax Inc.; AAA of Northern California, Nevada and Utah; Mills College; and the San Francisco Opera.

## ACTIVISM

I would have to say that my activism began during the AIDS crisis. Since then, my spouse Margarita and I have been very involved in the HIV/AIDS community. In 1990, I joined the San Francisco AIDS Foundation Board, which I chaired for a couple of years. Comparing that experience to my entire professional career, the AIDS Foundation was probably the environment in which I learned the most. It was a time when we profoundly faced the deaths of friends and so many others on a daily basis. I also served on the board of Continuum, another organization that provided services to people with HIV.

We have always had many gay friends throughout our lives. Some were more like brothers to us. When HIV hit, we felt strongly about stepping in to help because these friends were dying. Lesbians were critical allies during that era when the men were too sick to create resources rapidly enough. At the beginning of the pandemic, the lack of resources and the public's lack of a sense of urgency informed my activism in a very major way. A big part of my education during that time was learning to be aware of what's possible, and if something was not possible, figuring out what was needed to make it happen. Margarita and I still have great friends who worked with us during that era, and also gay friends who were lucky enough to survive.

Another great area of interest for me is women's leadership and education. In 2000, I was asked to join the Mills College Board of Trustees. Mills is a liberal arts college founded in 1852 that educates only women at the undergraduate level and primarily women at the graduate level. It was a perfect fit for me. I chaired the Mills Board for seven years. At that time there were no term limits, and I could have made a life-long career of being chair, but I did not think that staying for life was good governance. I stepped

down in 2009 so that somebody else could bring her thoughts and ideas to the position.

## BREAST AND OVARIAN CANCER

Concurrent with the end of my term at Mills, I was diagnosed with Stage IV ovarian cancer. This was my third experience with cancer. In 1980, I was diagnosed with breast cancer and had a mastectomy. There was no node involvement so they gave me what they called “booster shots” of chemotherapy and *a lot* of radiation. Today, most people get a lumpectomy and have radiation treatment that is a lot more benign than it was then. I have had long-term effects of the radiation because it has limited my ability to use my left arm and hand. Since nothing else was required after the radiation, I thought, “I’ve had my turn at this.”

But in 1996, during a regular checkup, they found an unrelated breast cancer on the other side. Again, I had a mastectomy. This time there was no need for chemotherapy because it was a much smaller lesion and there were no node involvements. All treatment after that was based on hormonal therapy.

Then in 2009, after two years of having symptoms that included lower back, abdominal, and intestinal pain that my medical professionals could not figure out, I was diagnosed with Stage IV ovarian cancer. These past four years have been a series of intense medical treatments. I had 3–1/2 years of chemotherapy, trying different protocols. A lot of progress was made with the initial surgical procedure and the chemotherapy that followed it, but there are some spots that are quite resistant to chemotherapy. Recently, after having tried just about everything in the book, my oncologist decided to try eliminating the spots that are left via radiation therapy. I have had radiation therapy during the past eight months.

Before the operation, my CA 125 was close to 1,000 [normal level is 36 U/mL]. After the operation, it dropped to about 500. When we started the chemotherapy, it dropped pretty consistently. The cycle is that you are on a certain chemical. It normally works at the beginning, so the CA125 goes down. Then it plateaus, starts going up again, and at that point, they change to a different chemical. The CA125 is not an absolute marker, but when it starts going up, that’s a sign of increased cancerous activity. Then you want to attack it with something different because it’s a signal that it’s not going to respond to the chemical that you are taking. Right now my CA125 is hovering around 50.

## SUPPORT DURING TREATMENT

I was very fortunate to have friends who are a lesbian couple, both physicians, involved at the beginning, right at the time my ovarian cancer was

diagnosed. Through another prominent lesbian physician, Dr. Patty Robertson, I was connected with a world-class oncologist, Dr. Lee-May Chen at the University of California in San Francisco (UCSF). I cannot even imagine having better luck than that, nor can I imagine better treatment. From UCSF, I have received more care than treatment. I mean, Dr. Chen is on it. She's not a prima donna even though she has all the credentials to be. She's also open to exploring new treatments or protocols if we ask her about one that we have heard of, because she wants to do what is best for me. I feel that I really have a safety net in her care and at UCSF, where if I need anything, if I am feeling something that I do not have an explanation for, I can always call. I know I will be called back in less than half an hour.

In terms of support, it's been very important to me that my wife Margarita and I are seen as a couple by all of our health professionals. I happen to be the one who is undergoing treatment, but Margarita is the decision maker together with me, and at UCSF we are treated as a couple just like any other couple. The professionals at UCSF understand the relationship and accept it. They involve Margarita in all the discussions. This experience speaks to the value of being out as a lesbian, married couple. Also, although there is still considerable discrimination in this country based on race and ethnicity, we have never experienced any racism directed toward us as Latin American women by any health provider.

Without Margarita, I do not think I would be around. And that's not just because of the things she does for me or with me, but because she's really the source of my inspiration. When I think about why I want to live longer, she's at the top of that list by a mile. And so are my close lesbian and gay friends, and of course our family.

Although Margarita inspires me, she does not cut me any slack, which I find frustrating at times. After all, here I am, I am sick, I am not feeling well. She makes me go for a walk or get out to some event. I am sure it's very difficult for her to keep everything as together as she does. But she does, and that gives me the strength that I lack at times.

Margarita also serves as my healthcare ally. She does a lot of the research. She spends hours on the computer looking at what's in the pipeline and what people are saying about new drugs or new treatments. For example, radiation oncology for ovarian cancer has changed a lot in the last four years. Margarita has become kind of an expert in treatment regimens, and she asks Dr. Chen lots of questions about different possible protocols.

In addition to Margarita, my primary care doctor for the past 23 years is a lesbian. Also through friends of ours in the lesbian community I have had the opportunity to meet a lesbian with degrees in pharmacology and microbiology who runs a nonprofit biotech company that provides molecular profiling for ovarian cancer patients to improve their treatment options. She is really doing cutting-edge research. Not only did she develop one of the chemotherapy drugs that is widely used today, but she also happens to be a

survivor of the same kind of ovarian cancer that I have—clear cell carcinoma. I am very fortunate that she has been willing to take a look at my case and advise my oncologist about chemotherapy protocol sequences.

A benefit of my long-term activism in the fight against AIDS is that it empowered me to be attentive to keeping up on the research on ovarian cancer, even though I am fortunate to have great providers whom I trust to do the same. For me, it's important to stay informed about the disease and new developments so that, as much as possible, I can continue normal activities such as my family life, design work, activism, and profession life.

### ADVICE TO OTHERS WHO ARE DIAGNOSED WITH OVARIAN CANCER

What advice do I have to others who are diagnosed with ovarian cancer? Individually one has to make a decision. How are you going to deal with this disease? First of all, you are scared. You are afraid of what the treatment will entail. You are afraid of losing your life and your family and your friends. You have to choose to fight this disease, even though you are feeling very insecure. I know for a fact that eventually this will kill me. But I want “eventually” to take a long time to get here. And the only way to do that is to be on top of it. It requires a very attentive set of professionals around you. You are responsible for making sure that they stay attentive. It's important not to give up. Because what you are trying to do is elongate your life, hopefully, for years. But however long it is, you are responsible for making sure that you are doing what needs to be done. That is a very difficult decision and process to follow. Working through these feelings is very challenging, especially at first.

Dealing with breast cancer was very different for me. Both times it was very bad news. The treatments were not great. But I regarded them as, “It happened, now move on.” Even with the second one, which very much surprised me, I had the same attitude. I treated them as incidents that were taken care of. I did not stop for them, or do anything different relative to my professional life or activism.

The ovarian cancer was different, because it was and is so life-threatening. This time I had to say to myself, “well, this is it.” Fortunately, it's still a question of when “it” is. I had to make a decision that I was able and willing not only to fight it with everything I have, but also to fight it in a way in which I can retain as much as of a normal life as I can. This has at times been very hard to execute, but it has been doable.

Early on, Margarita said to me, “Don't let this disease define you.” For me, that has been the best advice. But I realize that everybody is different. Everyone has different strengths, and therefore will tackle these types of

personal challenges differently. But for me, trying to retain as much of a normal life as possible has meant not letting my ovarian cancer treatment define me.

## ACTIVISM DURING TREATMENT

At the beginning of the treatment for my ovarian cancer, it was very difficult for me to do much of anything because I was so wiped out from the surgery and immediate chemotherapy. I had a photographic exhibit at Mills College that opened during that first chemotherapy. It was an exhibit of black and white photographs of architecturally significant places in Cuba. These 30 photographs were intended to be used as a teaching resource at Mills. I could not go to the opening because I was too weak, and that was a big disappointment. When I finally saw the exhibit, it was very rewarding.

Because I continue as a lifetime trustee at Mills, I stay as involved as I can in working through their strategic plan. Margarita and I also continue to support the San Francisco AIDS Foundation, Horizons Foundation, and the National AIDS Memorial Grove. Margarita chairs the latter.

Opera is another passion of mine. I serve on the San Francisco Opera Association Board. My focus there lately has been on introducing LGBT youth to the opera. LGBT youth are often homeless, because they are thrown out of their homes, they leave because they do not feel safe, or they have drug or mental health issues. Here in San Francisco, Larkin Street Services is a group of professionals who work with these youth, whose ages range from about 12 to 20.

One day it occurred to me that there should be a way to provide the opportunity for some of these homeless LGBT youth to experience opera—something that would be hard for them to know, given their circumstances. I do not necessarily assume that they will become opera lovers, but I wanted to help them understand that in the performing arts world, there are many different careers that do not involve being a great singer or great musician. A lot of these jobs, particularly related to the opera, are really based on technology, which is again, right up my alley. I have really enjoyed exposing these youth to the workings of the opera company. We have invited them to see master classes, the final product, as well as the making of that product.

Another recent project that I am excited about is creating a community of LGBT opera lovers. It's still a mystery to me, in a city like San Francisco, that there was no such community, even though many of the people who love to attend opera performances are LGBT. But there was no community, no sense of belonging, no sense of knowing who is part of this group. So several years ago, we started working on making that happen, by having parties for LGBT opera lovers, and now an LGBT opera series. Bringing

LGBT community to an opera company may not come to mind as a need, but I think it's important for us to be connected because we are everywhere.

## GROWTH EXPERIENCE: A NEW CAREER DURING CHEMOTHERAPY

For over thirty years I have been interested in design, but I have never had the time to focus on it. In the 1980s, I designed a wall sculpture in wood that we still have in our home. People often admired it and asked why I did not do more. Art requires a significant intellectual and time commitment, with continuous processing to get to a design. Right after my surgery, while I had a lot of *uncomfortable* time on my hands, I started thinking about designing again. I began to create new sculptures, and I have worked on these designs almost every day for the last four years.

Mathematics plays a role in my design, in that I design things that are geometric and repetitive in shape. I design wall sculptures and sculptures to be placed on tables and other surfaces. Sometimes I use 3-D printing for the main prototype or the final product. Others are designed with a 3-D software package, and then the fabricators take it from there to build the pieces. Some are constructed in bronze. The wall sculptures range in size from 30 × 30 inches to 50 × 50 inches.

I have remained very committed to this new career. It helps me a lot. It encourages me to continue to think outside the box and it's very rewarding when I see my sculptures come to life. I have been very fortunate that people who have major art collections have purchased some of my pieces. Although I am more interested in the process of producing them than in the process of selling them, it is wonderful to be recognized by people who are art experts.

## CONCLUDING COMMENTS

Health challenges are very personal in terms of how people respond to them. It's never one size fits all. If you have a serious health challenge, the first step requires a decision—how are you going to deal with it? You are not in control of what's going to happen to you, but you are in control of what you do about it, or are willing to do about it, and how far you decide to push it. The first question is, can you fight this? How do you get organized to take the most intelligent path forward? That is very difficult, but you can and will do that. You cannot change your diagnosis, but you can organize to be as proactive as possible, and as courageous as needed, to try the things that have a shot at prolonging your life.