



A Book of Hope



Stories of Healing to Honor Asian American & Pacific Islander Cancer Survivors

Acknowledgements

A Book of Hope: Stories of Healing to Honor Asian American & Pacific Islander Cancer Survivors is dedicated to Asian American and Pacific Islander cancer survivors and their support systems. We would like to thank these individuals and their family members for allowing us into their homes, experiences, and lives: Susan Matsuko Shinagawa, Reverend Frank Chong, Torise F. Saifoloi, Victoria Lin, John Lin, Victor Kaiwi Pang, Alosiana Abner Bejang, Lucianne Latu, Leafa Taumoepeau, Jackie Young, Christopher Pablo, Suzanne Robert, Lora Taylor Falealili, Jina Peiris, and Xiem Mai Tran. Thank you for opening up to the community and sharing your inspirational experiences.

About the Asian & Pacific Islander American Health Forum

The Asian & Pacific Islander American Health Forum (APIAHF) is a national advocacy organization dedicated to promoting policy, program, and research efforts to improve the health and well-being of Asian American and Pacific Islander (AAPI) communities. APIAHF's mission is to enable AAPIs to attain the highest possible level of health and well-being. APIAHF envisions a multicultural society where AAPIs are included and represented in health, political, social and economic areas, and where there is social justice for all.

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Introduction

A Book of Hope: Stories of Healing to Honor Asian American & Pacific Islander Cancer Survivors is primarily intended to educate a broad public audience about coping with the disease of cancer and cancer survivorship. These stories are meant to stir hope of survivability among those affected by the disease and to ease their fears and anxieties. These accounts help to illustrate that cancer is not a ‘death sentence.’ The intent of *A Book of Hope* can assist in dispelling Asian American and Pacific Islander (AAPI) cultural beliefs related to cancer, reducing disparities, and providing hope.

While cancer survivors deal with many challenges, it is possible to thrive with cancer as demonstrated by those individuals highlighted in this book. The fourteen AAPI cancer survivors featured in this publication were asked questions related to their experience of being diagnosed and treated for cancer, what were existing cancer services/programs for AAPIs during that time, what types of cancer services/programs are still needed for AAPIs who have cancer, and what would be their message of hope for AAPIs with cancer.

A Book of Hope’s main intention is to educate and raise awareness about cancer survivorship among AAPIs by representing individual narratives of challenges and successes. One key message that the book conveys is that **people thrive and have happy, fulfilling lives despite the physical and medical challenges imposed by cancer.** The love and support of family members and friends are key elements in coping with cancer for AAPIs. *A Book of Hope* can be used to educate community members and leaders, policy makers, health care institutions, community based organizations, and health care providers about how cancer impacts the patient and their family and what is needed to improve health care delivery and outcomes. This is not only a collection of inspirational stories, but also a community driven and community developed advocacy tool.

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Susan Matsuko Shinagawa

Japanese American Breast Cancer Survivor

In January 1991, I was working as a program administrator at an academic cancer center. A friend was teaching breast self examination (BSE) and asked me to attend her workshop, which I did. I realized there were good reasons why I should do BSE: I started my period early (age 10) and was older than 30 with no kids – two of many risk factors for breast cancer. I started practicing BSE and was diligent about doing it every month, recording what I felt each month on a breast map. That June, a new lump popped up, so I watched it for two months. The lump remained constant and didn't change during my periods.

I was about to take a personal leave of absence to join my (then) husband, who was in Naval flight training in Florida. Knowing I was giving up my personal medical insurance, I had my teeth cleaned, got my eyes checked, and also decided to have the lump checked. In August, an oncologist at the cancer center examined my lump. She wasn't very concerned, but it was palpable, so she sent me across the street to get a mammogram, which was negative. The diagnostic radiologist decided to do a sonogram, which showed my lump was a solid mass, and not cystic. She sent me back to the cancer center to see a surgical oncologist, who reviewed my mammogram, took my family history, examined my breasts, and then told me I had fibrocystic breast disease – lumpy breasts. He told me to take vitamin E tablets and decrease my caffeine intake to resolve the lump. He also said, "You're too young to have cancer, you have no family history of cancer, and, besides, Asian women don't get breast cancer." At the time, that really didn't mean anything to me,

but I knew something wasn't right. I told him, "I don't drink coffee, tea or sodas, won't take aspirin since I hate swallowing pills, and I don't like chocolate, so I don't think caffeine intake has anything to do with my lump." I explained I was about to take a personal leave of absence and give up my medical insurance, and asked him to please biopsy the lump. His response was, "You have to trust me. I see thousands of young women like you every year. You don't have breast cancer, and I absolutely refuse to do a biopsy." When you're 34, that's what you want to hear. So, I went on my leave of absence, and moved to Florida.

Fortunately for me, my lump was painful, which kept it in the forefront on my mind. I finally decided to get a second opinion, and made an appointment at an academic medical center in Mobile, Alabama, 90 minutes from our home. Thankfully, I was within my insurance

"cobra" period, and still covered by medical insurance. I brought my medical records and mammogram with me, and told the second surgeon what happened in San Diego. After reviewing my films, taking my family history and examining me, he agreed with the first surgeon. But I already knew I wasn't going to take "no" for an answer, and demanded a biopsy, which he agreed to do. My biopsy was scheduled at 7 a.m. under local anesthesia. When the surgeon removed the lump, he said it was definitely not breast cancer, since so much fat had grown around it, meaning it had been there for at least 10 years! He told me to go live a happy life, and I was ecstatic.

The next day I was out job hunting and returned home around 5:30 p.m. to a phone message from the surgeon asking me to call, leaving four phone numbers where I could reach him. I knew this was a bad sign, especially on a Friday evening. Reaching him, he said, "I'm sorry, Susan, but you have breast cancer." I thought to myself, "Oh no, I've got breast cancer. I'm going to die," and then I decided I'd better do something about it.

I was 34 years old, and didn't know what to do. I called my boss at the cancer center where I worked in San Diego, but he was in Europe. I spoke with my mom; you have to know Mom – she never worries about anything and is always on an even keel. Much later, she told me she always knew that I'd be okay. Dad was really worried, although I didn't know that till much later. I remembered the cancer center had hired a woman – diagnosed with breast



cancer at a young age – to be their patient ombudsman, representing patients’ interests. I didn’t know her, but asked a friend to have her call me. We talked for an hour, and for the first time since I received my diagnosis I felt, “I can do this. I can do this!”

After talking to doctors and reading lots of books about breast cancer, I decided to have a mastectomy. Losing my breast didn’t bother me or my husband. We just wanted to get rid of the cancer. By then, the only insurance I had was as a military dependent, requiring me to have surgery at the Pensacola Naval Medical Center. I inquired whether anyone there specialized in or had surgical experience with breast cancer, and the answer was “no.” I didn’t know much about breast cancer, but I knew that I didn’t want anyone who was a novice in dealing with breast cancer to touch me, so surgery at the Naval Medical Center was not an option. I suddenly felt as if I was uninsured. It occurred to me, “What do the uninsured do when they have cancer? What do people do when they lack the resources they need or don’t know who to call?”

After exploring numerous options, I called the benefits office at the medical center where I worked in San Diego, and learned that if I went back and worked for one day, I could reinstate my benefits. I called my boss, returned to San Diego and worked for four days at the end of October. It just happened to be breast cancer awareness month, and the same friend whose BSE workshop I attended back in January was teaching another class that week. She asked me to attend, and I was happy to do so, not realizing that local media would be filming. At the end of the workshop, I told the participants about finding my breast lump after taking this class, and would be having surgery the following day. As my friend had hoped, the women understood the importance of BSE, and that was my first appearance on TV news.

I ended up having surgery by the same surgeon who had originally refused to do a biopsy, and amazingly, I continued to see him for a year after my return to San Diego. I did very well with the surgery. I had a modified

radical mastectomy, and 29 clean lymph nodes were removed. I had minimal pain and was discharged the following day, at my request. My parents came down to San Diego for my surgery, and Mom stayed with me until I could return to Florida.

Having read a lot and talking to other young breast cancer survivors, I elected to have adjuvant chemotherapy, wanting to be as aggressive as possible. Doctors said I was paranoid, but this time I refused to accept “no,” having learned to become my own health advocate. I returned to Florida and had the chemo there. Unfortunately, I never got a full dose because my white blood cell count was too low. I later read that if you can’t have 85% of full dose, you might as well not have chemo. I was told to eat fatty foods prior to each treatment, to help me tolerate chemo better. As a result, I gained 15 pounds. When I returned to San Diego, I was concerned not only about my weight gain, but also memory loss, and asked my medical oncologist about these. At the time, there was no research about the effects of chemo on weight or cognition, but things have since changed; “chemo brain” is now a well known side effect of chemotherapy.

After completing treatment, someone asked me about the worse part of my cancer experience. I immediately responded, “Dealing with the medical system,” and my biggest headache was insurance companies. Four years after completing chemo, I was still receiving hospital bills, even though medical insurance fully covered my treatment. I had to seek legal assistance to get the hospital to stop bugging me.

I also had problems dealing with some of the doctors in Florida, since they thought they were god, and expected patients to treat them accordingly. Whenever I had any treatment-related problems, I waited for the three weeks between my chemo appointments to talk with my oncologist. During that time, I was dealing with thrush, experiencing black outs and body rashes. One day when my regular oncologist was out of town, another doctor saw his patients. After having my blood drawn, I waited to talk



with the oncologist about these issues, but the substitute doctor told me that he didn't have time to talk with me. I told him I'd been waiting for three weeks to talk with my doctor, and he told me that I'd have to wait another three weeks until my regular oncologist returned. I became upset and demanded he listen to me. After I explained my problems, he ordered several tests and prescribed medications. I always received a copy of my medical records while in Florida, and when I saw the records for that appointment, I found that the substitute doctor had written that I was "hysterical and in need of psychological counseling." It was difficult dealing with people like that.

Early on, my oncology social worker suggested that I attend a support group. It was open to men and women with all kinds of cancers, along with their families. At first I didn't want to go because I thought I was doing just fine and didn't want to listen to a bunch of complaints. But at my first support group meeting I ended up balling my eyes out. It was cathartic. I found that others could finish my sentences because they understood my experiences. I attended a breast cancer support group at another hospital. Both groups were helpful in different ways.

Eventually I returned to California and together with a good friend, started teaching BSE classes with a comic routine. We wanted women to have fun, but also understand that breast cancer could happen to anyone, regardless of age. I also attended five different breast cancer support groups following my return to San Diego, but none fit my needs. In each group, all the women were White, and there were no women of color. That's when I first starting thinking about support services specifically for Asian and Pacific Islander patients.

One day in late 1992, I was talking with my

cousin, a demographer with the Census Bureau, and learned that in 1990, 65% of Asians in the U.S. were first generation immigrants. At the time, the National Cancer Institute was reporting APIs had among the lowest breast cancer rates. Thinking about these statistics, I realized they



didn't fit. That's when I first started to advocate on behalf of Asian and Pacific Islander cancer survivors. I finally started thinking about my surgeon's statement that, "Asian women don't get breast cancer," which, of course, is a total fallacy. Unfortunately, doctors, researchers, and funders make decisions based on these negative assumptions and data. Since then, my mantra has been to "disaggregate, disaggregate, disaggregate!"

In 1995, I went to my first Biennial Symposium of the Intercultural Cancer Council (ICC), which addresses the unequal burden of cancer in minority and medically underserved communities. That's where I first met Evaon Wong-Kim. I didn't know anyone there,

so I clung to Evaon, who seemed to know everyone. The opening plenary featured diverse cancer survivors, but none were Asian or Pacific Islander. Evaon introduced me to Armin Weinberg, ICC's co-founder, and when I asked why there were no API survivors on the panel, he told me they couldn't find any. When Evaon told him he had just met one, Armin asked me to come on board and get involved, which I did. Four years later I was elected ICC chair. I was also nominated and appointed to be on California's Breast and Cervical Cancer Advisory Council, and the California Breast Cancer Research Council, my entrées into mainstream cancer advocacy.

In the mid-1990's, I met Lucy Young and learned there were Chinese cancer support groups in New York. I later met Lei-Chun Fung and learned about the Chinese women's cancer support group in San Francisco. Lucy's and Lei-Chun's support groups were both enormously successful. But for most other Asian or Pacific Islander cancer survivors, there was no "safe haven" where they could share their experiences. I kept hearing that people wished there were cancer support groups in other Asian or Pacific Island languages.

Later I met Tessie Guillermo and Luella Penserga with the Asian & Pacific Islander American Health Forum. We had just come off the Health Forum's 1997 Voices Conference, where I had co-facilitated a breakout session on involving consumers as advocates. During a 1998 conference call, Tessie asked if there was something I wanted to do with cancer advocacy.

I felt we needed a national Asian & Pacific Islander cancer survivors advocacy and support network. She introduced me to APIAHF Board member, Reverend Frank Chong, and together we co-founded the API National Cancer Survivors Network.

Although it had nothing to do with my cancer, my (then) husband and I were divorced. When

I started dating again, I met Rob Norberg, and we were married in April 1996. In October of that year, I received the University of California, San Diego's Outstanding Staff Employee of the Year Award. Everything was going great, when one day after work, I felt a severe pain in my left hip. It got so bad I couldn't sleep that night, but by the next day, it was gone. I felt the same pain a week later, so I called my primary care doctor. She put me on immediate bed rest, and ordered a whole slew of tests. Within weeks, I had complete left-sided weakness, and was in a wheelchair. It was very painful, and I couldn't move anything on my left side. It didn't occur to me that it would be related to cancer, yet, I was eventually referred to a neuro-oncologist and after even more tests, I was diagnosed with carcinomatous meningitis (CM) – a rare recurrence of my breast cancer in the cerebrospinal fluid. When I asked about my prognosis, very nonchalantly the neuro-oncologist told me I had 10 months to live. He was so arrogant! It was a presumptive, exclusionary diagnosis, which means that there was no definitive cytologic or radiographic evidence of cancer, but all my clinical symptoms fit the diagnosis perfectly. The neuro-oncologist said 50% of CM cases would only be proven at autopsy. I sought nine second opinions, with a four-five split agreeing with my doctor. Yet, the five who disagreed were unable to come up with a differential diagnosis, and all urged me to obtain frequent lumbar punctures and to start treatment immediately if any came back positive.

So, I started treatment in March 1997, beginning with surgery to implant an Ommaya Reservoir in my brain, with a catheter leading to the part of the brain that produces cerebrospinal fluid (CSF). When they tested my CSF flow, a partial blockage in the area of my pain was identified, so I had to have radiation to my lumbar spine to ensure continuous CSF flow. Intrathecal chemo administered through my brain gave me severe headaches, and radiation caused horrendous nausea. Not only did I not want to finish treatment, the severe pain and nausea made my quality of life so poor that I seriously contemplated suicide. I was also

taking high-dose steroids for inflammation and nausea, and had gained more than 80 pounds. It took me 14 months to get rid of the steroids in my body, but the pain and nausea never went away. It was so depressing. My boss kept my job open for me for two years, both of us believing I would eventually be able to return to work, but I was medically discharged from UCSD and went on total disability in March 1998, although I had already been out of work for 16 months. It was only thanks to my husband, Rob, that I was able to get through it all.

I always talked about the importance of regular screening, but in early 2001, my medical oncologist called me at home to scold me for being six months late for my annual mammogram. Turns out I had a cancer in the other breast. This time I elected to go with a modified radical mastectomy plus sentinel node biopsy, because if it wasn't necessary to remove my lymph nodes, it would decrease my risk of lymphedema. I decided against any adjuvant treatment since I was still being treated for chronic pain, which I began in July 1997. I'm still dealing with the pain and continue treatment with opioids to this day, and I've also dealt with clinical depression off and on for the past several years.

I resumed advocacy activities soon after my recurrent diagnosis, even before completing treatment. Life's been challenging, and at times I feel overwhelmed, but so much change still needs to happen, so I'll continue to my advocacy work until we achieve equity.

Message of Hope:

Just remember that you are not alone. So many men and women have had cancer and its associated challenges, and most are more than happy to talk, share, and cry with you. Find somebody to talk with who's "been there, done that," and you'll be able to do it, too. I don't want to give false hope, but I believe if you live the best life you can, when the end comes, you can die with dignity. 

*“It’s not how
much life
you have left, it’s
the quality of life
you live.”*

“Cancer is probably the most dramatic experience that anyone could have.”

Reverend Frank Chong

Chinese Nasopharyngeal Cancer Survivor

When I was in college, I did volunteer work for the American Cancer Society (ACS). I was recruited in 1964, went to all of their events, and took photographs. One of the things that we did with the ACS was a lot of public education about “early warning signs of cancer.” One of the early warning signals is an unusual lump or swelling that doesn’t go away. I found out much later how important it is to keep an eye on those kinds of things.

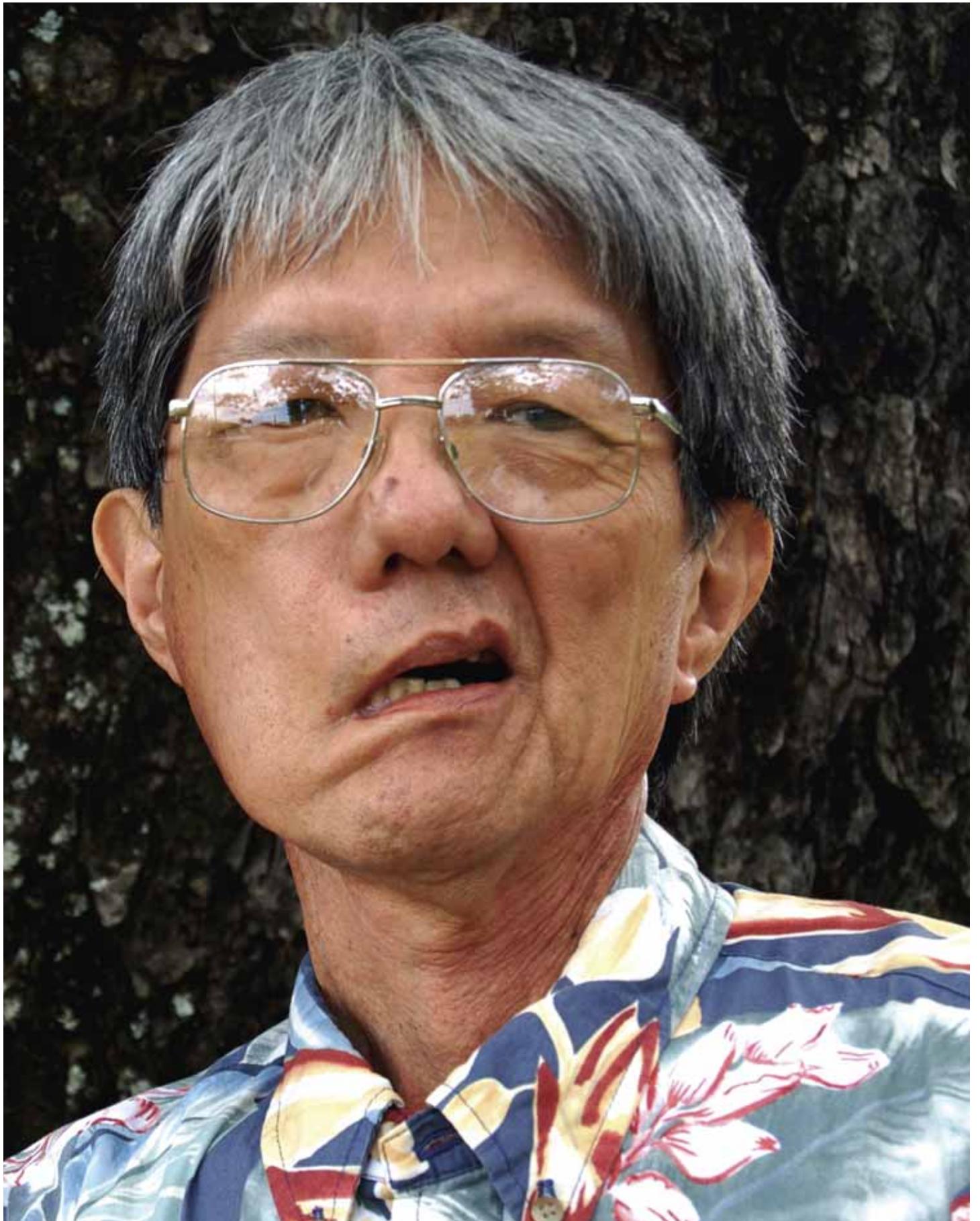
I was diagnosed in 1973. I was 28 years old. My first real job was as the youth minister of a

got larger and swollen. So, at about six months, we did a biopsy. It turned out to be carcinoma of the nasopharynx. Had I not learned about unusual lumps, I would not be here today. I was a Stage 3 or 4 when I was diagnosed, and what they had found inside my neck was actually a metastasized tumor that had already spread. The primary site was at the back of my nose and the neck tumor was the secondary site. Nasopharyngeal cancer can metastasize into the lymph nodes, the eyes, or the brain; so, I was fortunate that it was localized in the head and neck.



local church, which happens to be right across the street from where we are right now. One of the things that I noticed during that time was that I had a lump on the side of my neck that wouldn’t go away. I went to the doctor and asked what it was, but he said he didn’t know and that we should wait. So, I waited, and it

The type of cancer I had is found predominantly in Chinese, so it’s an unusual cancer in that it is ethnic-based. It doesn’t seem to make a difference between generations either, because cancer rates for this particular site are always pretty high for Chinese. I think it is also found in higher rates among Jews.

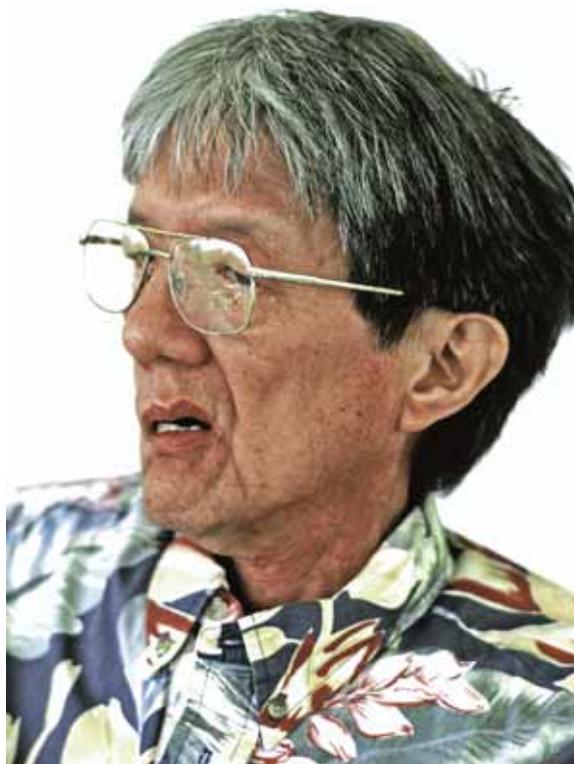


For my treatment, I had the opportunity to go to Houston, Texas. That is where all the major medical centers are, such as MD Anderson, Baylor, Methodist, and a whole bunch of others that specialize in cancer. So, I went to Houston for a church conference, and since my father-in-law was on the Board of Directors for the Colorado American Cancer Society, he arranged for me to consult a doctor at MD Anderson for a second opinion. While there, they proposed a number of treatments for me and said that I could either be treated in Houston or in Honolulu. I decided to come back to Honolulu and I got my treatment at Queen's Medical Center. The most important thing was that I was here with family and friends, as opposed to Texas where I would not have known anybody. Family and friends were critical to my recovery.

First, they surgically removed the second tumor from my neck and then treated the area with radiation therapy for six weeks. I don't believe that they had chemotherapy perfected well enough at that time to use on this particular type of cancer. I think today, if you had this cancer, the usual course of treatment would be surgery, radiation, and chemotherapy. The physicians that treated me here were trained in the mainland at the best places and treatment was superb. I had absolute faith in the doctors and equipment.

I'm an unusual case because I'm a long-term survivor of 33 years. There are things that I'm going through that many others haven't. Some of the long-term survival issues that I've had to deal with have to do with all kinds of complications with my head and neck. The neck is filled with different muscles, nerve endings, and blood vessels. In 1988 through 1990, my carotid arteries started to shut down due to radiation damage, and it was serious. The radiation also badly damaged my neck muscles, and I've had occasional muscular problems such as hardness and cramping in my neck that radiates into my chest. Sometimes, I feel like I'm having a heart attack. Another major issue

has to do with my oral health. Most people who have head/neck radiation have damaged salivary glands, they get dry mouth, and their taste buds are badly damaged. Your teeth disintegrate as well. Recently, I have had to have all of my teeth extracted. Also in the head/neck area is



the thyroid gland and other mechanisms which control your blood pressure. I've occasionally had problems with my thyroid as well as with high and low blood pressure. In the last five years, I've developed Bell's Palsy, which is essentially loss of muscle control on the side of the face. Whether it was related to the radiation or not, no one knows.

Most people in my situation die. Long-term complications are a relatively new phenomenon, so we're starting to look at cancer as more of a chronic disease now. Most doctors don't follow their patients beyond five years, since long-term follow up is usually done not by the doctors but by researchers and cancer support groups, etc.

Let me now mention some of the institutions that were important to me. Because I was a minister actively serving a local church, I

was visible every Sunday. People would see me losing weight and notice the effects of the radiation. I talked about it a lot to my church community, and I really had an extended family in them that was supportive of me. There was no hiding the fact that I was diagnosed with cancer. The church was very important, however, so was the local Catholic hospital where I was initially diagnosed. A number of the nuns there were very supportive and continued to stay with me throughout my treatment period.

Other institutions that were important during my recovery included the American Cancer Society (ACS) and other social groupings. At the time, the role of the local ACS was much less obvious. I know that there are people from the ACS that came to visit my wife, but the ACS wasn't sophisticated enough to have support groups at the time.

In general, there needs to be involvement of cancer survivors in care and policy. Public policy and advocacy can create far more changes than medical technology. For years, we believed that we could conquer cancer one patient at a time, and we put a lot of money into that effort. Now, we need to go upstream and find out what the causes are. That's why there is so much money in tobacco control and the environment. Those are some of the big issues that we're dealing with.

Message of Hope:

Cancer is probably the most dramatic experience that anyone could have. It's dramatic in that it's a turning point in one's life and it's a challenge. Cancer is both physical and metaphysical. It is spiritual and existential because it forces one to find one's place in time and space and to make peace with one's maker.



Torise F. Saifoloi

Samoan Cervical Cancer Survivor

I was first diagnosed with cancer in April 2002. I was the secretary of our Women's Ecumenical Fellowship in American Samoa, where five churches come together. We have always invited people from the hospital, like the teen pregnancy and domestic violence groups. Then I heard about this group, the breast and cervical program in the public health. We invited that group from the breast and cervical cancer program to come to the women's group. One of the nurses and head of that program presented and then came to a conference for the women of the church. They presented and talked about what is breast and cervical cancer. And so they invited us, all of us, to have the appointments at their clinic at four o'clock Tuesday or Thursday, free of charge. You could get a test for pap smear and/or mammogram at that clinic. That's when it started.

I didn't go to the four o'clock clinic, but I went to the OB/GYN clinic at eight o'clock in the morning. They sent me to a Palagi (white) doctor, but she was a specialist from off island working at that time. I remember her name was Dr. Melanson. We had a talk and then I took the pap smear test. And she told me to wait for two weeks because they have to send my test off island. And then I had to wait. At the beginning of June, she called me back to come to the hospital and have a talk with her. My tests had just arrived from Hawaii. I went to the clinic that morning. I was so happy that she told me my results were there. Then she called me inside her office and we had a talk. She asked me, "How are you?" I said, "I'm okay, fine, and happy." She said, "Are you ready?" I said, "Ready for what?" She said, "I got your results. There is bad news and there is good news." I told her to tell me the good news first. She said that the good news is, "You have developed cervical cancer, and the good news



was it was detected at an early stage. It is not as bad as other cases and it has not spread." I then asked what was the bad news. "The bad news is that you have to go through the operation and we don't want that cyst to stay because it will grow bigger and spread." I asked then what was I going to do. She said we'll have all your check ups, like blood tests and physicals.

I then told her if she would wait so I could go and think. Because to me, I know what cancer is. But I didn't have this experience. It's like a cold block of ice hitting my face. I was really scared, but had to have faith. I knew I was going to beat this and that I was going to be cured. I went home and I think I didn't tell my husband or even my kids for a whole two weeks. I just prayed to God to help me and give me strength so that I could have my treatment. Because I knew that I was going to have that operation. The only person that I told was my mom. She said that she would let her prayer meeting group remember me and pray for me.

Dr. Melanson called me back to have a CAT scan to find out the size of the cyst. This was after two weeks. I came and had the CAT scan on my cyst. When I got my results, Dr. Melanson said, "Wow. I think this is a miracle." It was just a small cyst that almost the cat scan didn't detect it. The doctor said that I was lucky. But I asked her if she could hold off for one more week to do the surgery, because the following week was my younger daughter's graduation from high school. I would like to see my daughter graduate and after that, I will go straight to the hospital.

I asked my family to pray for me and don't worry because the doctor said I had two choices: go off island or do it here. I asked the doctor, "Can you do it here in Samoa?" Okay, might as well do it here. My husband is here and my whole family is here, my mother, my kids. I want everybody beside my bed when I came back from the surgery. So that's what I did. By the time I told my husband what happened, it was the Friday night before the surgery. Before he had wanted to know why was I going to the OB/GYN. He asked if there was something wrong. I said don't worry and it was just a female check up, but I told him before my operation. On Sunday, we all went into the hospital and checked me in and slept there overnight before my operation on Monday. It made me so happy when the surgery was done. The doctor said that I only had to stay for five or six days at the hospital and then I could be released. It's finished. No more medical anything, even bills, just if I wanted hormones or pills. Never mind, I didn't like those, just as long as I'm cured. And she said that there's no need to have chemo or radiation or anything else. It was caught early.

That's it. I was so lucky. People kept asking what happened. I said it was just a women's disease. It's funny for them if I told them that

I got cervical cancer. They would respond, “What?” I would say, “Yes, I just finished having my hysterectomy.” They were so surprised. My family was so relieved that it was over. My oldest daughter was at the University of Hawaii. When she found out about my surgery, she took a quarter off to stay with me. After that I was okay and then she went back.

I think it was God’s way to have the breast and cervical cancer group to come to have a talk in my church for the women’s conference. I became even more interested in the health programs after my experience. The breast and cervical cancer program had a kick off event in June. I was the speaker and shared my story for the whole government. I then invited these health program speakers to my village and my church, which is so far from the hospital to share their information. It’s so hard for the women in my area to come to the hospital. Most of the people are from Western Samoa and it’s so expensive for them to go to the hospital to get their check ups. So, that’s what I did. I took the car and I took four women from the church to the hospital because I knew they were sick and complained of stomach pains and back pains, even leg pains. It was good that I did that because two had cervical cancer from my village. Some had the cancer for almost 25 years, a long time. When asked why they didn’t go to the hospital, they said that it was too expensive and it was too far. One of the ladies finished her chemo and radiation from New Zealand. She’s okay now. The other woman had to have a D and C (dilation and curettage) and she’s okay now, too. It is still cheaper for those in Western and American Samoa to go to New Zealand for health care than to go to American Samoa. Western Samoans are not residents.

Besides the breast and cervical cancer program and the comprehensive cancer control program, there is only the cancer foundation in American Samoa. It provides money for student scholarships. The lieutenant governor at the time died of cancer and his children started a foundation to offer scholarships for students. I am unsure if they provide money for cancer patients. I am only aware of the breast, cervical, and mammography screenings at Tafuna Public

Health and Lyndon B. Johnson Hospital, where the women have to go. In the villages, there are only educational presentations done. They just finished the prostate cancer awareness at the Department of Health.

The cancer survivorship group is needed for Samoans. The future plans are to translate the English brochure we developed into Samoan. We really need to reach out to those impacted and affected by cancer, the survivors, family members, and caregivers and get them together. They are stressed. Cancer treatment is so expensive and many cannot afford it financially. It is important to raise funds and even without money to keep the support group going and reach out and give help, not only to the patient, but also to the family and caregivers. We will go and provide support to cancer patients in the hospital so that they can have someone to talk to and pray with.

We really need funds to provide help for these people. I know I am cured, but I really want to have something to share with them. I want to give them hope. Even just to help with medicines is good. We need to provide something back to show you care. We can also provide help in a spiritual way. They cannot afford the financial side of cancer. That’s why we really want to put up this support group. We need to give support even though some may not be able to go through treatment. Some will give up and won’t go to the doctors. That’s when we really need to be there to help, to understand or just sit by them and give advice. Sometimes when the doctors say they have cancer, they feel, “That’s it,” and there’s no hope. It is important to have the education, screening, and raise awareness of the community. Everyone is affected, not just that person.

Message of hope

For those diagnosed with cancer I say don’t give up. Pray to God. God will help in any way. Be faithful and be prayerful. Family is your first support system.





“We really need to reach out to those impacted and affected by cancer, the survivors, family members, and caregivers and get them together.”





Victoria Lin

Chinese Non-Hodgkins Lymphoma Survivor

When I was diagnosed I was a sophomore in high school, doing the regular high school things. It began in February when I started feeling stomach cramps and they just wouldn't go away. Every single day I'd take two Tylenol, and they still wouldn't go away. Also, at that time, I'd start throwing up every Friday. It would be so bad that I would throw up just bile. My parents would send me to the emergency room (ER), and every single time, it would be something else. The doctor at Valley Medical Center would say that I had some parasite, or inflamed bowels, and they'd give me tummy medicine. I would take the medicine, but the episodes would continue. The pain got to be so bad that I'd take the maximum amount of Tylenol every day. One time, they asked me if I was pregnant because the frequency of when the stomach pain would start was very timed.

During a third trip to the ER, my parents said, "Listen. We've been here three times. There is something wrong with her." Finally, the doctors agreed to admit me. After that, there were two weeks of testing and I basically had every single bowel/gastrointestinal (GI) test you could have. They gave me a nasogastric (NG) tube, a barium x-ray, CAT scan, blood tests, and an endoscopy. After each test, they couldn't really find anything, except on the barium test. On that test, they said that when the barium went through, it looked like it went through the small intestines too slowly. They then said there was one last test they could do. They took an NG tube and pumped barium and air through it into the small intestine.

At the end, I remember asking the doctor, "Did you see anything? I'm not lying." Most people didn't believe I was in pain. They thought I just wanted attention. This time, though, they did find something. Unofficially, they had found that there was a narrowing in

my small intestine. That's why when I ate I had cramping and vomiting, because it was hard for the food to go through, causing it to come back up.

Over the weekend, the doctors deliberated over my condition. One doctor said it was a bacterial condition and said I could take antibiotics. The other doctors said it looked like a tumor. After the weekend, they told us that they had determined it was a mass in my small intestine. By this time, it had taken ten days to determine this, and I weighed only 98 pounds. It was decided that I would have surgery during the next day. Because it was intestinal surgery, I had to clean out my bowel. It was difficult because I couldn't eat or drink and I threw up the laxatives. The nurse and my mother finally gave me enemas throughout the whole evening so I ended up going to the bathroom every single hour.

I had surgery in the morning. Three days later, I found out my diagnosis of Non-Hodgkin's Lymphoma. They told me that it was 95% curable with treatment. I remember going back to my room and crying for five or ten minutes. I called up my best friend and we talked. I just remember going to sleep and waking up feeling like it was another day.

I wanted to learn more so I called the American Cancer Society and ordered everything I could. I did research online about the drugs and went to the library. At the library, I couldn't find an updated book about cancer survivors that were under the age of 25. Not to belittle anyone, but they were all outdated and I couldn't relate. I was so scared when I read their stories about their throwing up every day, etc. Luckily, I had Zofram, so I threw up only once. The only good book I read had a lot of stories about those who had a lot of willpower and who were able to beat the odds. The survivors were like,



"Okay, what can I do about this?" That was the person I wanted to be. I didn't feel the constant questioning of "Why me?" was going to help me get better. I wanted to be as normal as I could, and that was my whole focus throughout my journey.

I went through nine weeks of chemotherapy, with chemo rounds every three weeks. I lost all of my hair. Before that all happened, my mom suggested that we go get my hair cut because I had long hair. I wanted to cut it really short because I didn't want it to all fall out, but my mom said no to that because she was afraid it'd be prickly. When it fell out, though, it looked silly, so I asked my dad to shave it off.

“Cancer did affect me in a bad way, if you can say that, but it also taught me a lot. I wouldn’t be who I am today without that experience.”

I didn’t wear a wig. It wasn’t comfortable with it and I didn’t want to be someone who I wasn’t. I wore a baseball hat or different bandannas my mom made me to wear to school. I only went to school part time. I tried to go to a whole day of school during treatment because I wanted to be normal, but I came home and slept the whole night and couldn’t do homework. So I would go to three classes one day and three classes the next.

Another side effect I had was joint pain. It felt like my knees were burning. It was so painful that I couldn’t move them. I also remember being really weak and tired and not being able to do much or go anywhere. I finally had my last chemotherapy treatment on Memorial Day weekend in May. After that, I’d go to Stanford for checkups every six months or so.

During my treatment, and to this day, my mom is my hero. When I was sick and in the hospital, my grandma had been diagnosed with colon cancer and she had just had surgery and was one floor above me. My mom would switch off between us. She would be with me for my rounds, and then be with my grandma during her rounds. I was always amazed at how she did that. When all the nurses found out, they were like, “Oh my gosh, your mom!” I think a lot of people would freeze and not know what to do, but my mother was fine.

Although I am Chinese, my experience of having cancer in the U.S. is different



because I can speak and read English. For my grandmother, though, I wish they had had translators or some doctor that she could’ve identified with and communicated with. What if my mom hadn’t been there to translate? For me, what was often on my mind was the fact that there are so few youth cancer patients/survivors. This was an issue because I wanted to see and learn more about the youth perspective of having cancer. Also, during my treatment, the doctors didn’t talk so much about alternative therapies. They would say that such treatments wouldn’t fully address the problem. However, even though I got better, it would’ve been nice to have a reference of different options.

Message of Hope:

Be who you are. Be very proactive and as positive as you can. Cancer did affect me in a bad way, if you can say that, but it also taught me a lot. I wouldn’t be who I am today without that experience. A lot of the choices I’ve made since then I wouldn’t have made had I not gone through that experience. Don’t be ashamed, even when you are sick. People might not look you in the eye, but don’t be scared. **AP/HE**



John Lin

Chinese Skin and Prostate Cancer Survivor

I had two types of cancers. One was skin cancer and the other was prostate cancer. I found the skin cancer first in 2001. I had a small mole that was a different shape and color than it used to be. I looked on the Internet and I found information saying this is a sign that it might be cancerous. I went to the doctor to get it checked and he said it didn't look bad, and told me to come back and check it next year. Two or three years down the line, the mole started bleeding and it would never heal. I went to the hospital, they took a biopsy, and they diagnosed me with cancer. Even though I had other moles, they said that the cancer hadn't spread and that I wasn't going to die. The mole didn't spread out because it had reached only the second layer of the skin. If it had reached the third layer of the skin, it probably would have spread. Because the mole was also near my eye, I was under the care of an eye doctor and had to have eye and plastic surgery. After the eye surgery, the doctor told me that they were successful in getting out the tumor and I wouldn't have to worry about things anymore.

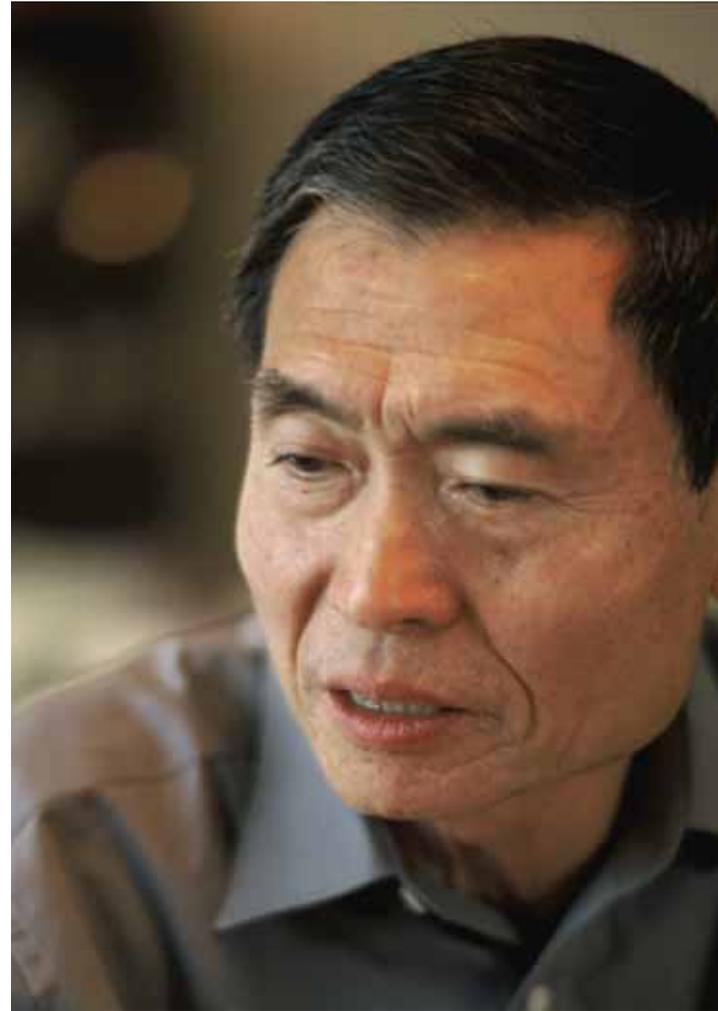
But, in 2002, I developed prostate cancer. At the doctor's office, I had a PSA test every year. At the beginning, before 2002, my PSA was 1.2. It started to increase slowly, but the doctor said it was okay and that he would watch it. In 2002, it increased even more. I also began having symptoms including irritation during urination. When the PSA jumped very quickly, the doctor suspected there was something wrong and took a biopsy. They found that there were cancer cells in my prostate. I said, "You've got to be joking. It cannot be me. I'm pretty healthy." I didn't have any serious health problems, so I thought they must have made some mistake. I was in denial, yet I had to accept the fact, a couple of weeks later. The doctor gave me a month to think about the treatment options. I

could take out the tumor, have chemotherapy, or have some other treatment.

I started to look somewhere for help. The first couple of days were very frustrating. I didn't know where to find help for what I needed. I only had one month to figure out all of the options. I finally got some information from American Cancer Society, but the general literature out there didn't help me too much.

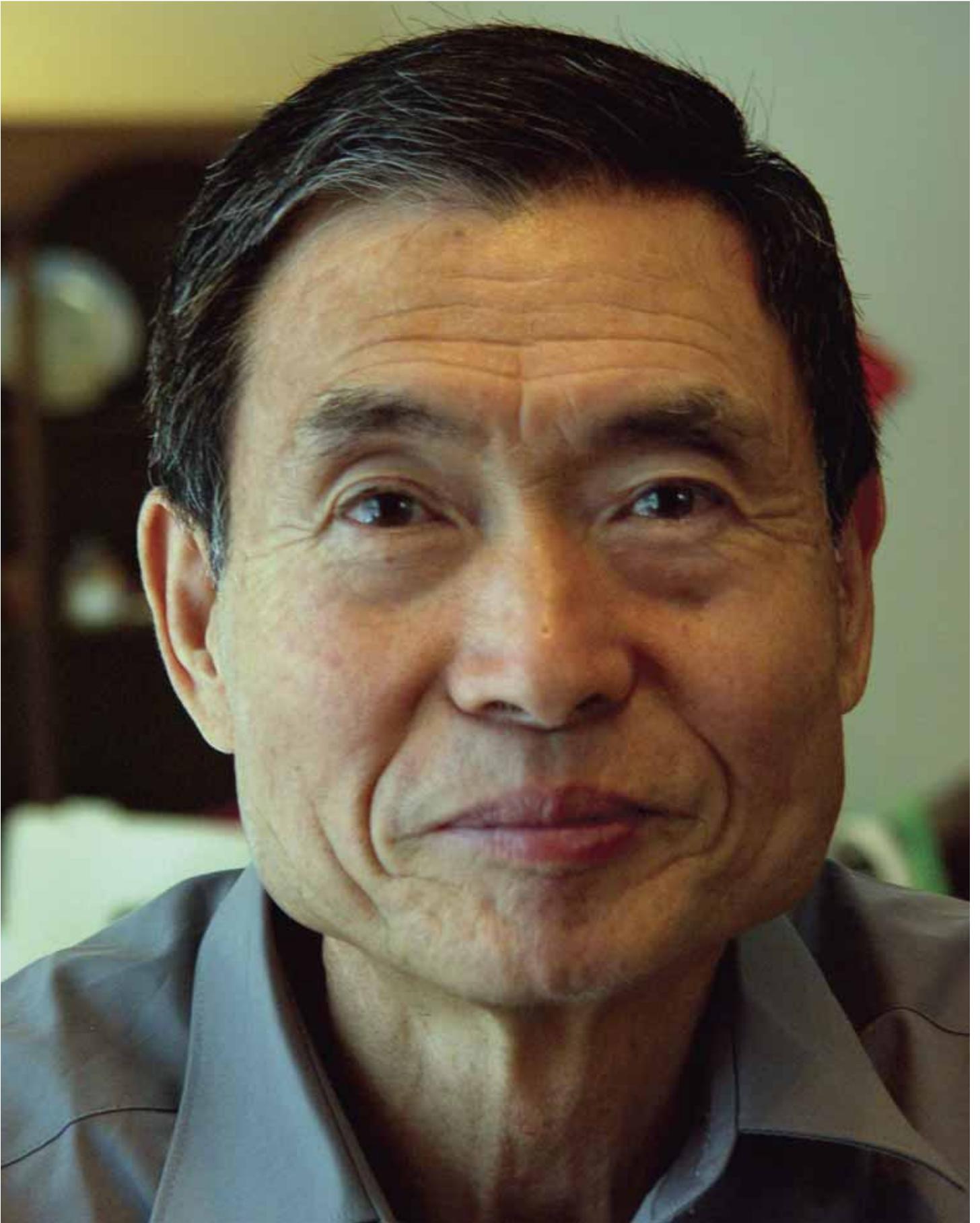
What helped me was a support group. Each group was for a certain cancer. From there, I got opinions about my options. I couldn't find the same information in books because most are not up to date and they were very general. The members of the support groups were able to tell me the good and bad of different treatments. They told me a lot about chemotherapy and other therapies. I went to several groups in the Bay Area and even one in Los Angeles. They were good. They had a lot of people and resources and they were organized. They had tapes that talked about treatments and consequences that were very helpful.

It would have been helpful to have a support group in Mandarin so I could ask more questions and understand more easily. I had to go through a lot to understand what was going on and what I was supposed to do. I was told that there weren't many Chinese support groups in the Bay Area at all.



In the end, I decided to have surgery. Before the surgery, however, I tried Chinese medicine. A month before the surgery, I asked the doctor to draw my blood to see if the alternative medicine had helped my cancer. It didn't, although it did help to relieve some symptoms.

After surgery, they found out the cancer cells were contained and hadn't spread anywhere else. They decided not to give me any additional

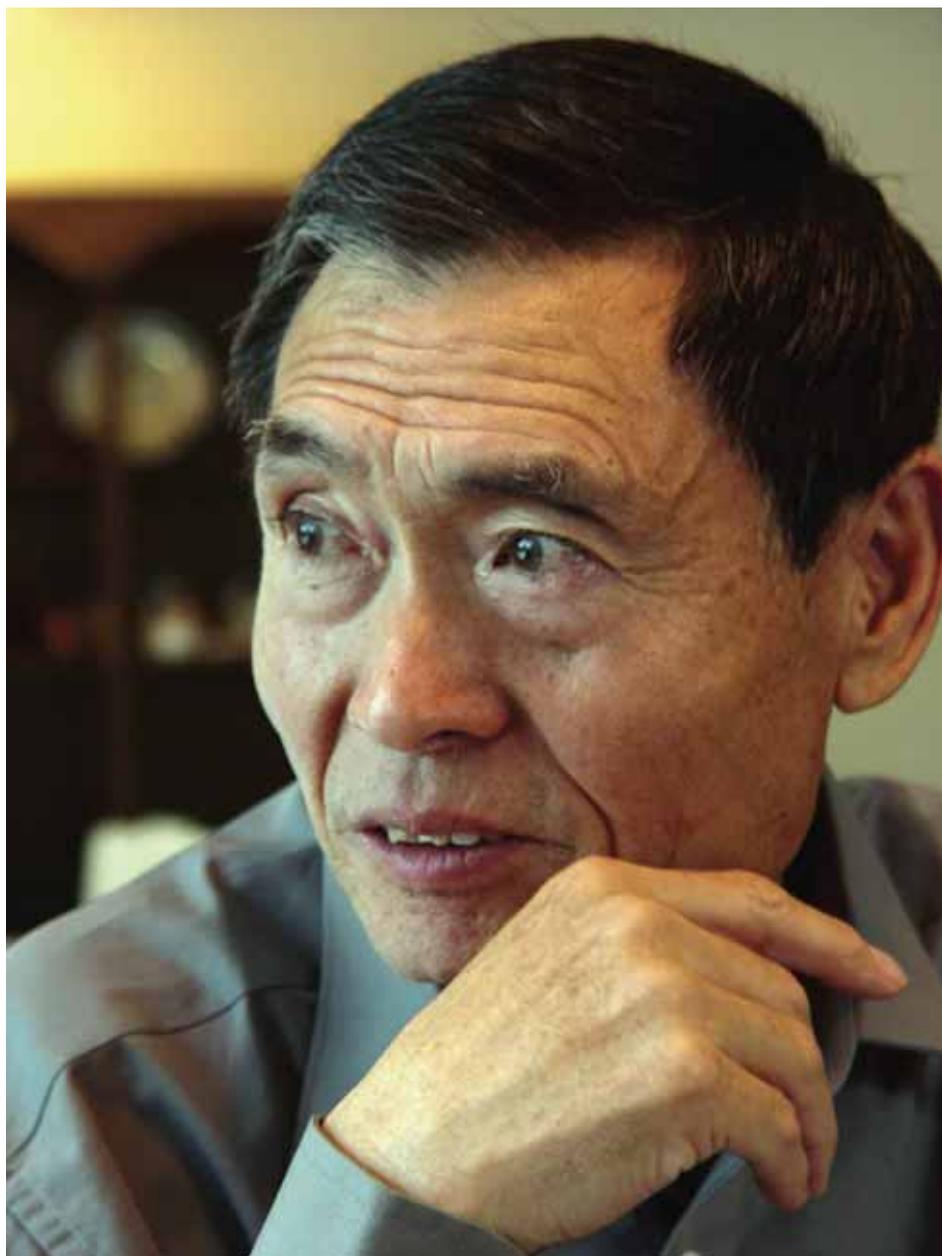


treatments other than check-ups. However, I did have some side effects that were difficult to deal with. I had trouble with urination. It was so frequent, sometimes every two hours. I was lucky, though, because since the tumor was small, it didn't affect my bowel movements.

From this experience, I have learned to take care of my health even better. I have good nutrition and I exercise. When you get cancer, it's a signal that you might have to change things.

Message of Hope:

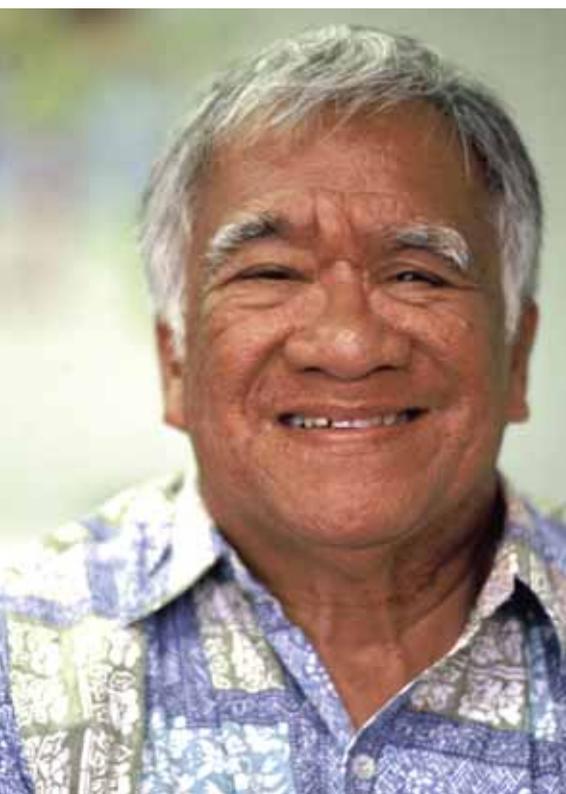
When you get cancer, be more open and talk. It's not just your own problem. Face it and try to get help. Don't be fearful and think that it's your fault that you got cancer. Think about and change your lifestyle. Be positive and have a good attitude. Eat good food and exercise. Try Qi Jong, it has some helpful effects. 



“What helped me was a support group. Each group was for a certain cancer. From there, I got opinions about my options.”

Victor Kaiwi Pang

Native Hawaiian Non-Hodgkins Lymphoma Survivor



In 1990, I was working during the time that I was diagnosed with Non-Hodgkins Lymphoma (NHL). I had found the lymphoma when one day I noticed that one side of my eye was protruding. You know, when you're really little, and you used to give names to everyone. So, I was a little boy and my friends and I used to play with this young guy, and his eyes bulged, so we nicknamed him "bubble eyes." That day that I noticed my eye, I just started laughing. My wife asked me why I was laughing, so I told her the story of the young guy. Now I had the bubble eye!

My eye started itching, and I wanted to find out what it was, so my wife and I went to the doctor and they referred me to an oncologist. The oncologist then referred me to an ophthalmologist, and they discussed my case.

They had found something growing behind the back of my left eye. The oncologist scheduled a surgical biopsy, and it came back negative the first time. They tested my blood, looked at the blood levels, and said I had a certain level that needed more exploration, which they did at a clinic out in Duarte. They said it was cancer. I had to get medical care through the hospital where my ophthalmologist, oncologist, and primary care doctor were, and they suggested the treatment I should go for was radiation. I said okay as long as it wasn't going to affect my eye, to which they said no, it wouldn't. Now there are better techniques and technology that have focused on treating that area of the eye.

I went to get my treatment, but I didn't think it was going to be any different from any other visit, where you go in to see the doctor and that's it. I didn't think it was going to be a long-term treatment. I would often go to work right afterwards and in between the times that I was getting chemotherapy. I didn't know why at the time, but I would sometimes be at my desk and wonder why after lunch I would get so tired. I guess those were the effects of my chemotherapy. But the chemo didn't really affect my lifestyle. I mean, some of my hair started falling off, but I didn't go bald. My effects were minimal. Since I was working, I had to juggle appointments with the doctor and time with work, but that was the only thing I had to worry about. Other than that, I think my treatment went sort of well.

In 2003, I was supposed to go back to Washington for the National Asian and Pacific American Families Against Substance Abuse (NAPAFASA) conference with Ford Kuramoto. We arranged the trip and everything, but the morning before the trip, my wife found me in the bathroom lying down. She asked me what I was doing, but I was in a catatonic state. She tried to lift me back into the bed, but she

couldn't. My oldest son was home, so she went upstairs and got him. But by the time they got downstairs, I had somehow gotten myself back into bed. They called an ambulance, and shortly after, that is when they found another tumor in the front part of my brain. More tests were done, and we thought we had some time. So, the doctors scheduled me to do a laser brain surgery. The surgery didn't happen at that time, though, because I had a seizure. Instead, the surgery was done four months later when I was back in the hospital. The doctor said, "We have to do it now!" They operated on me and removed a tumor the size of an orange. It was benign. I had to go through treatment for three years after that.

I had continued to see a brain surgeon, and he told me that since I hadn't had any recurring seizures, he was going to wean me off my anti-seizure medications. I went on for about a good year, and then I went home to Hawaii and there I suffered another seizure. I was checked out at a hospital there, and we came back home and now I am on anti-seizure medications again.

Then in 2004, I don't know how I got it, but I got a pneumonia infection and they did a cat scan of my lungs. They also did a cat scan of my stomach area, and they found out that there was some NHL there. So, I had to go through treatment for about two years for that. The treatment arrested the NHL in my stomach.

In the meantime, what keeps me going is trying to be an advocate for cancer survivors. I think to myself, if I made it this far, then I am probably going to make it to the end. I'm not gambling, but I am trying to not be fatalistic. My wife and other members of the Hawaiian community here are doing a needs assessment, and they found out that there are a lot of people who believe that if you have cancer, it was "meant to be," and they are very fatalistic. It

shouldn't be that way. With my cancer, what I'm doing is just empowering myself, and it is good that I have a wife who is very understanding and a community that was also understanding and supportive. Then I have three grandchildren, and they keep me up and going.

My family is very supportive. My oldest boy lives in Hawaii now, has a PhD, and works for the feds. Then my youngest son has two engineering degrees and is married, and with my three grandchildren. Originally, when he graduated from college, he was working in Arizona, but he got a job out here, and he decided to take that job. When he moved into the area, he was renting a place ten minutes away from our home in Huntington Beach. I thought he would want a place closer to his work in Long Beach, but when he got a home, it was only three blocks away, and I thought, "Boy, that's too close!" But you know, the girls come over, and they are a joy.

Fortunately, we had good services out here at Hoag Hospital and Newport Beach Hospital. We have this medical plan, where you choose your doctor and your hospital. But most doctors will work out of certain hospitals, and you have to know that. I thought, well, I always liked Hoag Hospital. My doctors- oncologist, radiologist, pulmonologist, and primary care doctor all came out of Hoag Hospital. They are good there. Special considerations during my course of survivorship include: recurrences, multiple incidents while traveling in Hawai'i, working within multi-system referrals, navigational needs with six to seven medical consultants when complications occurred, keeping medication profile in order with frequent changes, possible drug reactions, etc. While on chemo, I suffered critical pneumonia, secondary to chemotherapy depressing autoimmune system, and lung abscess and resultant asthma development despite no smoking for less than 40 years.

The person that supported me most was Jane, my wife, and my family gave me a lot of support. There were a lot of educational brochures about cancer by Papa Ola Lokahi and Joann Tsark that I read. There weren't any real support groups

here at that time.

OAPICA, the Orange County Asian & Pacific Islander Community Alliance, was a resource during that time. They formed a men's health group. We met staff there and they addressed cancer survivorship through diet



and exercise. They provided participants with support and a place for meetings. This group was not just for Native Hawaiians, but also for all Asian and Pacific Islander males, and it provided many services for Asians. There was no Native Hawaiian group, and we had to form our own, but this men's group provided us with a model group. We started inviting a whole bunch of Native Hawaiian men that were survivors and they became part of the men's health group. Native Hawaiian males were part of the men's health support group. It was well received and they wanted to be involved. We didn't meet very often, probably quarterly, but we also formed focus groups. Generally we focused on men's health, but there was a small part of the support group that focused on cancer and survivorship.

One thing that we did we formed was a program called Ohana Retreat. "Ohana" means family. The retreat is where we take

all the generations of the Hawaiian families to University of California, Irvine (UCI), and we immerse everyone in the Hawaiian values, language, song and culture. We have the UCI cater for us in the Hawaiian style food. This year we are having another one, and we

found out that there are Chamorro and Filipino groups at UC Irvine. So we were like, hey, we want adobo!

Part of the Ohana retreat has been to have focus groups, or discussion groups with men and women, sometimes together and some apart. The women will talk about breast and cervical cancers, and men will talk about prostate and other cancers. There was also a group for the children, where we had someone from Kamehameha schools come that is skilled in teaching children and young teens. Then we had an aerobics instructor to teach us exercise, although we call it "hula-cise." The aerobics instructor was also a licensed social worker, and she was going to talk to us about cultural trauma, about why the Native Hawaiians are sick, why the American Natives are sick, and why do we have all of these problems. We have been having these retreats now for about 15 years, and though the faculty may be the same,





the subject matter is always a little different. We also had tobacco education programs, and participants go off campus to smoke. We had signs all over the area, but it was still hard.

In terms of services, there needs to be more advocacy for cancer survivors, especially for Native Hawaiians, as well as other Pacific Islanders. I know a lot of these communities smoke a lot, and since they usually speak only one language, it makes advocacy harder. Fortunately, my group here in Orange County, the Pacific Islander Health Partnership (PIHP), can help to translate and train people to become focus group facilitators. For the males and females, they need to know more about different types of cancers. They could even do a genealogy of the families' health history, and then have someone who is knowledgeable to inform you about whether these cancers are being passed down.

PIHP was thought of and formed to provide services to Native Hawaiians and other Pacific Islanders in the area, like the Micronesians and Marshallese. We are trying to educate ourselves with the new Medicare laws, so we can service the elderly community with that. We also have a project where we work with the food bank to arrange for Pacific Islander families that come to us to be fed, provided they are under the federal poverty level. For example, there was a family from Chuuk that was sent out here from Guam to receive treatment maybe because the medical care is better out here. So, the people who brought them out here approached us and asked if we would be able to feed them.

Message of Hope:

You need to empower yourself to find out all you can about cancer. Become comfortable with your oncologist. Ask him any questions you have and tell your concerns. If you are not comfortable with your doctor, talk to your nurse. Advocate for those in your community going through cancer treatment, and help them though it. Focus groups are important, too.



“The person that supported me most was Jane, my wife, and my family gave me a lot of support.”

Alosiana Abner Bejang

Marshallese Thyroid Cancer Survivor

I was thirteen years old when I felt the lump. I had a lump in my throat for three years before I went to the hospital. I didn't eat and I would vomit. The mass was big and I thought it was fine. My parents took me to the hospital. I was losing weight and feeling sick. When I went to the hospital, I had an x-ray. I was referred to another hospital to have a cat scan. The mass was big and closed up my tube (esophagus). I had to get admitted and got an IV to be fed. I had the cat scan and was told to have this mass removed. The doctors did a biopsy. They felt with their hands that it might be related to the thyroid. So, I took medications they told me to take.

I was supposed to have the surgery on July 1, 1989, but I didn't go through with it since there was no power in the hospital. They can't do procedures when there's no electricity. I had to wait until the next day. The same thing happened again. It was three days before I was operated. So on July 4, 1989, the surgery happened in about two to three hours. After the surgery, I woke up and vomited. I think I was still feeling something from anesthesia because I was making signals to everyone. I rested and then got up again. I heard the doctor talking to my mom that they were not sure if I would speak again. There were some problems in the operating room. When awake,

they checked to see if I still had my voice. So, I woke up and pretended that I didn't speak, but I had overheard the conversation and they didn't know that I was awake. Then they asked if I could talk. I still hurt from the surgery and it was painful to talk. I was thirsty. I spent four months in the hospital after the surgery. The surgeon sent the thyroid mass to Honolulu. I waited for two months for the test results. I was then told that I had thyroid cancer. I was prescribed medications that I had to take every day for the rest of my life. They removed the entire thyroid and so I had to take medications to replace the oils that the thyroid used to produce in the body.

It took me two years to recover from surgery. I still wasn't sure what was wrong with me. I felt that a part of me was gone. In the operating room my mother would cry and asked everyone to please pray for me. Only my parents supported me during this time. My parents had 14 kids altogether. My friends and other family didn't know at the time about my surgery. My classmates made fun of me, but it was better that I had my surgery. I had to go back two times a year to get checked. I was thirteen years old and I didn't know anything or what was out there for my community that was affected by cancer. Back then, I didn't know there were cancer problems. Now I want to know what other cancer survivors are feeling now and in the past and also what types of cancer they have.

Some barriers my family and I faced in order for me to get services were waiting in the waiting room for approval to be seen, and having to pay to be seen. Our family is big, so we did not have much money. So, dad asked his family to borrow money to help us out and they did.





*“Today,
the
kinds of services
and support that
are needed for
Pacific Islanders
who have cancer
are resources
to help detect
cancers early, more
education, and
more physicians.”*

After coping, I realized I had to do whatever it takes to stay healthy. I also asked myself, “How did this happen?” I knew that my grandfather died from thyroid cancer. This might have been around the time when there was nuclear testing in the islands. I knew that there were many Marshallese that had thyroid cancer and leukemia. I didn’t know if there was a connection at the time.

So, I was married when I was 17 years old. I was married for 10 years. I never went to go see the doctor because my husband did not want me to go. He started beating me up two

years into the marriage. So, I had to sneak out to see the doctor and get checked and be seen. My husband knew I was a cancer survivor. My two kids knew I had cancer, too. They would look at my scar and ask, “Did Daddy do that to you?” So, they also knew that their father was hurting me.

My health care provider realized something was wrong. He noticed my bruises. When he asked how that happened, I lied and said that I bumped into something. He knew that my husband might be abusing me. He just said to please tell us when you’re ready, but I

kept hiding it. I was scared. I didn’t want to leave my son, so I stuck around. We had been living in Hawaii and I had to sneak away to Marshall Islands to get my check ups following the cancer. I knew I had to try to go back to the doctor to see how I was doing after the thyroid cancer.

What finally got me to leave my husband was my sense that he was having an affair with another woman. I went to a hotel that I had a feeling he was at and begged the front desk to let me have a key to my husband’s hotel room. I said that I just wanted to see with my own two eyes what he was doing. I got the hotel room key and went to the room. I opened the door and saw my husband there with another woman. That’s when I decided to leave this man and this relationship. Now I am with a good guy who I’m thinking about having a child with and he treats me well. He trusts me and loves me and my kids. I do see my ex-husband once in a while in the Marshall Islands and am glad that he is no longer in my life.

Today, the kinds of services and support that are needed for Pacific Islanders who have cancer are resources to help detect cancers early, more education, and more physicians. We have a difficult time to send people to the States for meetings because of the costs of travel. We need to share that there are thyroid cancers in Republic of the Marshall Islands and other types of cancers in Hawaii. There is better health education than before, but we have to have staff continue on.

Message of Hope:

The advice I would give to other Pacific Islanders with cancer is as soon as you find out something is there and feel it, rush to a doctor right away. Don’t wait. You might lose your life. Even in a bad situation, you can find a way to see a doctor and seek help and anyone that you can trust.



Lucianne Latu

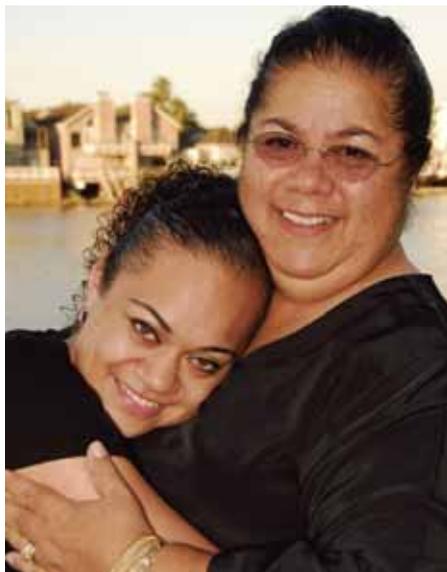
Tongan Osteogenic (Bone) Cancer Survivor

Lucianne “Luci” Latu was thankful that her mom was her advocate during her cancer experience. Her mother, Leafa Taumoepeau, was asked to participate in this interview to provide her experiences as a parent of a cancer survivor.

Luci: It was at the beginning of 1987, and I was eight yrs old. I was definitely the more playful tomboyish type. What led up to us finding the cancer was when my mom noticed I was limping. She asked me all of the usual questions moms ask to try to figure out what happened. Did you fall out of a tree? Did you fall off your bike? Was I horsing around too hard? I said no to all of these questions. She asked how it felt, “Well, does it really hurt?” The way I remember the pain was that it felt like a cramp that I could never stretch out. There were some positions that I could sit in that would make it more comfortable, like having my knee up against my chest, but I would always get in trouble when I would sit like that, especially at the dinner table.

We were back in the islands, back in Tonga at the time, so my mom scheduled an appointment at the hospital. I don’t know how it is now, but back then in Tonga the medical technology wasn’t great. What they were able to do was take an x-ray of my leg and that’s when they found that it was a tumor. But, as far as being able to do a biopsy or figuring out what type of tumor is was, they didn’t have that capability. At the time, there were very limited flights to countries that did have better medical technology. We ended up having to go to New Zealand because there was only one flight a week that left to the U.S. The doctor expressed the urgency of finding out what type of cancer it was, so we left to New Zealand right away.

I was only eight years old, so even after having the biopsy and being told it was cancer,



it didn’t really hit me. I didn’t know what that was or how it would affect me. All I knew was that something was wrong and that I was in the hospital. All it really meant to me was that it was “cramping my style.” I couldn’t go out, and obviously something was happening because I was stuck in a hospital. I couldn’t be a kid.

I think I wasn’t scared because I wasn’t too experienced with life. I wasn’t worried about death. Death had been around me, but the people around me that did die when I was young were all old people, and I knew I was definitely not old. Even the idea of possibly dying didn’t occur to me. My mom would try to have serious talks with me, but I was more concerned about her hurrying up and finishing what she had to say so I could get back to watching TV.

Leafa: I had heard of cancer before, but it was always other people who had cancer. I knew little about it, but the few cases I knew about always were associated with death. Before we boarded the plane, the doctor, who was a family friend, pulled me aside and warned me that Luci might lose her leg. He hoped that it was only an

infection. But this young doctor, he had done his residency in New Zealand, and he had seen cases similar to Luci’s and knew how aggressive bone cancer was.

The main emotion I was feeling at the time was fear- fear of not knowing what we were getting ourselves into. We were not going back to the U.S., and New Zealand was a strange place and very foreign to us. New Zealand has this mutual agreement with Tonga that they can accept difficult medical cases that can’t be handled on Tonga. When the doctors in New Zealand told us it was cancer, I wanted them to tell me honestly what my best options for Luci were. In the end, they decided that amputation was the best way to ensure that the cancer didn’t spread.

Luci: They amputated my leg, and immediately after the amputation, the phantom pains started. It was the most excruciating pain, more than I could ever describe. I felt like my insides were being yanked out. It always amazed me because even though I knew I didn’t have my leg there anymore, I would feel still feel like I had an itch, or I’d feel a heat sensation, or my calf flexing. The phantom pains were really difficult.

I didn’t have radiation, but I did get chemotherapy. I don’t know what made them decide not to give me radiation, because there was a young boy about the same age as me who had the same thing, but he also got radiation after his amputation. The side effects of my chemo included the usual ones, like definitely the scarring of my liver, infections, lower platelet counts, and so on. I always got very, very sick with the chemo and would always be throwing up.

The hardest part for me was staying in the hospital. After a cycle of chemotherapy, the doctors and nurses would hypothetically let me

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leave the hospital to go home. However after a cycle, I often couldn’t leave right afterwards because I would be too sick and weak to leave the hospital or my white blood cell count would be too low. There was always something when the time I had to leave the hospital would be decreased, and by the time I was well enough to leave, I’d have to start another cycle of chemo. This, in particular, was really hard for me. Because of this, I would desperately try to hide my infections, and once it got so bad I had to go into isolation. I remember one time, I tried so hard to cover up the fact that I had a fever and that my throat was completely closed up to the point where I couldn’t even swallow my own saliva. I so desperately wanted just to stay out. I didn’t want to have chemo anymore, and I didn’t want to have to return to the hospital.

It didn’t really work when I was trying to cover up the fact that I had an infection, because we had this whole breakfast spread out in front of me, and I so desperately wanted to eat. I would even try to coax myself into swallowing a piece of egg or something, but it hurt so much when I tried to swallow I just couldn’t do it. I ended up hopping away from the dining room table to the bedroom and just crying because my throat hurt. Mom came in and asked me why I was crying. I didn’t want to tell her and I was trying so hard not to, but finally I just broke down and said, “I can’t swallow!” And that’s when she felt my forehead, and was like, “Oh my gosh, you have a fever. We’ve got to go to the hospital.” And still, I was like, “But I don’t want to go!”

I wasn’t scared. I just really didn’t want to be in the hospital. Even to this day, hospitals have this smell, this scent to them that I can’t stand. The times when I couldn’t leave the hospital for more than a week, my mom would try to give me some type of perk, like just wheeling me outside. They had a pond with ducks there, and it was nice going out to feed the ducks with day old bread just because I was able to step outside of the hospital.

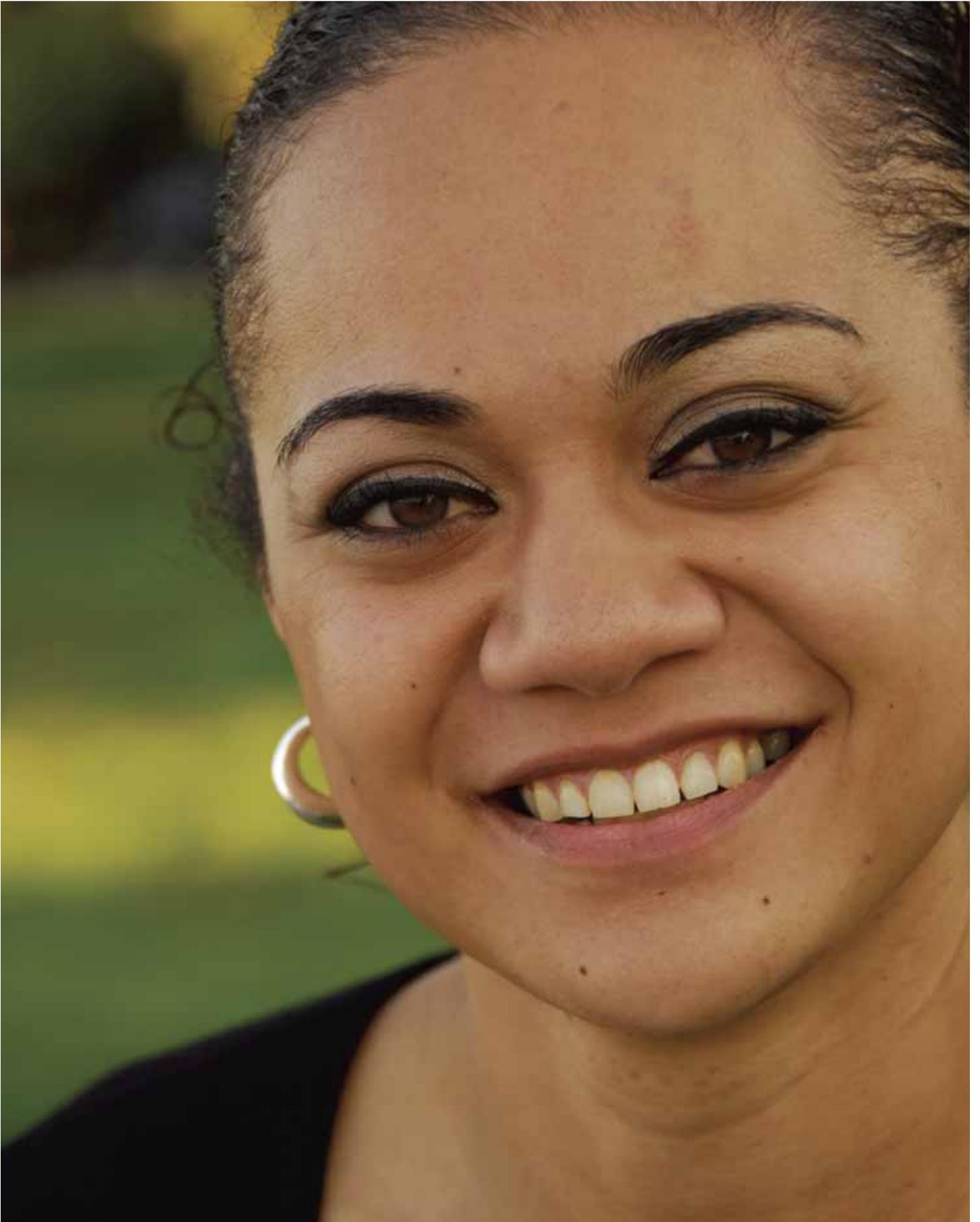
Leafa: In a way I was thankful because God removed the fear from Luci. She didn’t even cry when they amputated her leg. She cried more

when we cut off her hair during chemo. I knew her hair was going to fall off, so I thought it would be less dramatic if her hair were shorter. But with Luci, it was uncontrollable sobbing when we cut her hair.

Luci: Losing my hair was hard. Like my mom said, I didn’t cry when they cut my leg off, but I did cry when they cut off my hair. And then when my hair started falling out, it was hard, but I took it with a smile. In the oncology ward, I was nicknamed “Casper, the friendly ghost.” I was so small and scrawny, just skin and bones, pale, no hair, and nothing to accent anything on my face. It was funny because the nurses would give me the make-up sets, and I would put it on, and even have these obnoxiously large earrings. When I would use them the only accent on my face would be the bright make-up and big earrings. Everything else was completely bald.

I guess the nurses liked me because I was the nicest patient. I was the most agreeable kind, because even if I threw a tantrum, it wasn’t really bad. It was mostly just crying, and whining about taking medicine, but taking it anyway. So, the nurses had gathered money amongst them and bought me a jade bracelet. They convinced me to believe that if the stone turned green, that meant I was getting better and I was healthy, which is all I really wanted because that meant I would get to leave the hospital. If it turned white, it meant I wasn’t taking care of myself, and that I wasn’t being healthy. I really believed it, so I would sit there and wait with all my might for that bracelet to be green just so they could tell me I was better and I could leave the hospital. I still don’t know if the bracelet thing is true, but I really believed it at the time.

The time definitely passed by so slowly. I mean, there are only so many times that a child can watch Mary Poppins and Chitty-Chitty Bang-Bang before I don’t want to watch them anymore. I can’t say that I was the perfect patient, or the perfect daughter, because I did throw tantrums and give attitude when I wasn’t in the mood, and my mom took it all in stride.



Leafa: The time went by so slowly in the hospital. The treatment was good, though. I couldn't have asked for better treatment. Because of the Maori, the indigenous people of New Zealand, the doctors and nurses were pretty sensitive to Pacific Islander cultures.

They hadn't really treated many children cancer patients. Up to that point, there weren't very good treatments for children. Luci was lucky because Dr. Rosen of UCLA had created a new protocol for treating children and they were using this new protocol on Luci. But, because she wasn't strong enough and she was always getting sick, her treatment dragged on for a year.

Luci: Although we were in New Zealand and with all the Western medical care we were getting out there, my mom still tampered with traditional Tongan medicines. I have to say I still haven't forgiven her for that. The concoctions she made me drink were the most disgusting things ever, like milk with fish liver, that I wouldn't wish that on even my worst enemy!

Leafa: That is actually one of my sore points. My relatives in Tonga are still very traditional and believe in traditional medicine. They all encouraged me to keep Luci at home and treat her there since they believed Luci had a Tongan illness. Only my father does not believe in traditional medicine. I decided to stick with Western medicine, but when we went to New Zealand my aunt came with us. On the day Luci started her chemo, my aunt had a heart attack and passed away. I still believe that it had something to do with my choice not to treat Luci in Tonga.

Luci: After my treatment, we came back to the U.S. and I went to UCLA and Stanford for my follow-up. Growing up afterwards, they tried to give me support there to help me deal with my grieving. The type of support they were giving me though felt more like a band-aid over what was really going on, rather than a solution

to a specific issue or feelings I was having. I kind of wish I could have had a heads up as to the types of issues I would be dealing with.

They tried to help me go through the whole grieving period when I was still in New Zealand, but at eight years old, I still didn't know what grieving was. Aside from losing my hair, which



was probably the biggest thing I felt I had lost. They even made me write a goodbye letter to my leg, but I didn't understand what saying goodbye to my leg was, because it wasn't such a big thing to me at the time.

As an eight year old, I didn't know what I needed. Looking back, I don't think I got the type of guidance I needed to get through it as a child. I feel that a lot of things that one learns as a child are the building blocks of learning about life. But I had to grow up quickly and adults always surrounded me. I felt like I was teetering between two mental states of being a child and being an adult. For a whole year I only had my mom with me, she was the only constant, and then when the treatment was over I was thrust into the real world. I remember one time, I still hadn't been fitted for my prosthetic leg and I was on crutches. This little kid came up to me and started shaking my crutches, and I didn't do anything! All I did was stand there and cry. And my mom was like, "Why didn't you just shoo him away or something," but I didn't know what to do. I didn't have the skill sets to stand up for myself. I guess I just wanted that reassurance and reinforcement that what I was going through was normal based on my situation.

Leafa: I didn't know a lot about the grieving process that Luci was talking about either. Looking back, I wish I had. Luci finished elementary school, and it was not too bad. When it came to junior high, Luci was one of those high achievers. The transition into high school was when Luci took a turn for the worse. She went from being an honor student, and then

she took a dive all the way down that by the end of her senior year she almost didn't graduate. And I had no idea that Luci was depressed, she was clinically depressed. And I think that was because there was no preparation for her to know how to stand up for herself, how to face people without her leg. She was pushed into high school where kids are mean and cruel. And if we had to do it again, I would like to focus more on the preparation grieving period. Even I, as her mother, didn't go through the grieving of the loss because

I couldn't afford to. Someone had to be strong, and as her mom, I felt that was my role, because I wasn't with my husband anymore. I wish she had been better prepared to deal with life minus her leg.

After high school, it still continued. Luci got into drinking, and all this I know was to compensate for the loss of her leg. This is how she was dealing with it. She ended up having to do either rehab or jail because she had like three DUIs in a period of three years. She is still sometimes very depressed, but I am hoping that she is now working herself out of it.

Luci: I think the support needed to start in the home, like I wish I had gained support from my mom in being able to talk, and the cultural support that it was okay for me to talk about how I felt. I mean, now I can do it without my mom's permission, but then, culturally I was supposed to have been able to just deal. And to this day, my mom will still say that sometimes, "Just deal with it!" Pacific Islanders, especially Tongans, have a "deal with it" mentality, and they like to keep things like this within the family, and don't like to air out dirty laundry. I just get tired of it, though. I wish there were some way that culturally it would be acceptable to talk about what I was going through, to ask for help, to get

that type of support that other cultures seem to have an easier time obtaining. It would have had to start at home, though. Or even to just have someone who had gone through a similar experience, especially within the Tongan culture, to be supportive in that sense, like “this is how it’s going to be,” or “it’s going to be okay.” But we didn’t have that luxury. And even if we met another family or children who had gone through the same thing, unless they were Tongan or Polynesian, I don’t think my mom would have heard it, or actually given it some thought about whether this might help me or not. Of course, in hindsight, I wish I knew then that I could have done it regardless, but I took a lot of my lead of how I thought I was supposed to be by trying to mirror my mom. I mean, she’s definitely been the rock out of the two of us, and I couldn’t have handled it on my own, but now I know she is different from me.

Leafa: For Luci’s follow-up care here in the U.S. we were lucky that we speak English and could easily communicate with the doctors and nurses. For people who don’t speak English, it would have been very different. A lot of Tongans here die of cancer, especially of breast cancer, because they don’t complete their treatment protocols. You know, they’ll get a few treatments, and then decide, “Okay, I’m going to go to Australia for a funeral, and then I’ll come back and continue.” But you can’t get your treatment that way, because that’s not going to help you. But most of them don’t know that. They need someone to explain things to them, like how treatments work, and the importance of completing them. We have so many fatalities from cancer because of the lack of communication. We need doctors to not only be linguistically competent, but also culturally sensitive people working to gain the trust and connect with the different ethnic minorities, not just Tongans.

There also needs to be better navigation, such as helping people know whom they have to call to get help, or to get insurance. There needs to be culturally sensitive education for ethnic minorities encouraging them to get mammograms and other screenings, and to be comfortable with doing these types of things.

Luci: I wish it were considered okay for Tongans to not necessarily keep it inside all the time and put up the strong, held together front, but instead be able to just let oneself go and ask for help. I mean, I am able to do that now, but I wish it had been okay when I was younger, especially when I was going through high school and all my struggles. I mean, not only was I dealing with being a teenager, but also I was dealing with being a teenager with one leg, which is a huge physical difference from other kids. There was this distorted perception of what was normal, and I didn’t feel like people accepted me for me, and I wasn’t good enough, so therefore I didn’t accept me for me. I compensated for it in other areas, like turning to alcohol. When I was drinking, it was a time when I could put my guard down or not really care what other people had to say. I could be someone else other than just me.

Through the type of work that my mom does, and through me opening up and sharing the struggles that I went through (which in a way is my grieving process), I’m hoping that if I ever meet another person who is going through what I did that they know it’s normal, and that they can make it through to the other end of the tunnel. I hope they realize that everything is going to be okay, and that losing a limb or whatever physical part of your body isn’t the end of the world. I still have my bad days, but I’ve learned to enjoy life a lot more. I think about the times when I wouldn’t do stuff just because I was worried about having to take off my leg, or having to wear shorts, and now it’s like, “forget that!” I use that analogy of the giraffe ended up having to grow a longer neck just so it could reach the leaves in the trees, and that’s what I have to do. I have to adapt my surrounding to what I need. Like even with driving, people told me that I would have to get one of those special vehicles, but I said, “No, I’m not. I’m just going to get a regular vehicle and just cross over my leg and drive.” And DMV seems to think that I can still drive that way, and that’s all that really matters. Even if I can’t run, my way of running is a hop, skip, and a jump, and that’s what I do. Climbing stairs, I may not be able to do one after another, but I’ll do two at a time and be able to get to the top just as fast as you!



Message of Hope:

Leafa: I think I would like cancer patients to stand up and tell the world, “I’m okay!” You know, don’t take it lying down. Make it known you have a voice and make your statement. Get out there. Don’t accept it and don’t be a doormat.

Luci: My message actually comes from something my mom said to me, and it stemmed from having a bad day at work. I had cried because I had gotten yelled at by a customer and it wasn’t even my fault. So my mom sent me some flowers with a card that said, “Good days will outnumber the bad days.” And, what I’ve taken from that (and it’s really become like a mantra for me) is that the good days really will outnumber the bad days, and when you have enough good days, the bad ones will begin to disappear. So, I’m always looking for the good times. Like out of all of yesterday, all I can remember is that I had a total blast playing softball with my co-workers, even when I hit myself in the head with the ball. It made it a good day because I was able to have fun, play softball, and forget about the fact that I have one leg. I was just doing it, and I was out there with all the regular folks. For me, it only takes one great moment to remember to define the whole day as a good day. Before you know it, if you are constantly looking for all the good days, you’ll forget there was a bad day in between. It sounds corny, but I like it and it works for me.

APA HF

“There is hope that cancer will transform from being a deadly disease to more of a chronic disease and there is certainly hope that we can live with cancer.”

Jackie Young

Korean Breast Cancer Survivor



I remember the date I was diagnosed because it was one day before Valentine’s Day, February 13, 1998. It came about because I had missed getting a mammogram for several years. I had called to get a refill for a prescription of my estrogen pills and the doctor wouldn’t give it to me because I hadn’t come in for a mammogram. I was running for office, writing my memoirs, and doing a lot of things. So, getting a mammogram just wasn’t high on my priority list, although it should have been because I was in the age range where I needed to worry about it. So, I begrudgingly went in so I could get my estrogen pills for my hot flashes.

This is when they said that there was something suspicious and that I needed to see a radiologist. I had to get an ultrasound and a biopsy. I wasn’t worried though, because I had confidence that I didn’t have breast cancer. I went to the mainland for a meeting, and when

I came back, I was scheduled for a biopsy. The radiation oncologist, who was a neighbor from down the street, said, “Oh, 95% of these are benign.” He gave me his card saying, “If you don’t hear from me in the next couple of days, just call.”

Well, I heard from the surgeon in a couple of days and I thought to myself, “This is strange. The surgeon is calling me.” I went in by myself and the surgeon asked if I wanted a family member to be with me. My children are all on the mainland, so I called my eldest daughter who I knew happened to be home. She was on the teleconference with me when he told me I had cancer.

The first thought that went through my mind was that this is a legacy that I’m going to leave for my children, and it wasn’t something that I wanted for my daughters. Because I had cancer, this meant that they were now at a higher risk for cancer. I think that the thought runs through a lot of people’s minds, whether they’re Asian or not Asian, that cancer is genetic. I’ve learned since that only 8% is genetic. But, at the time, all I could think was, “It’s in my family now. I’m going to pass it on to my children.”

During that phone conversation, the surgeon explained what the procedure was. It was a Friday and he wanted to operate on the following Monday. I felt a sense of urgency. Because he was a surgeon, and not an oncologist, he was concerned about potential after effects of the operation. He gave me a video on drainage because they were going to take out my axillary lymph nodes. I was still handling the news of my cancer, and there I was, watching a video about a tube that was going to be stuck in my body.

At the time, I happened to have been involved in a political campaign, so my mind was very focused on that. I thought, “Oh well, if I die



on the operating table on Monday, what am I going to do over the weekend?" I began calling up people to put into place a political group that would move the campaign forward in case I didn't recover from the surgery. I spent that whole weekend calling up people to ensure that they would be there to support the campaign.

In the meantime, my daughters were checking on the website of the American Cancer Society and National Cancer Institute for information, and encouraged me to consult a second opinion. I didn't think that I should've gone for a second opinion. I just wanted them to take it out and that would be fine with me. If it was cancer, then take it out. I didn't think there was a need for further explanation. I felt there was an urgency.

On Monday morning, I had my surgery. When I was recovering from that, I had to sign all of these papers. They told me that all they had done was a lumpectomy because the tumor was small enough. The lump they removed from my breast was the size of a lemon. Even though the tumor itself was only 1 centimeter, they had to take the clear margin around it, leaving the dentation in my left breast. They also took out 22 axillary nodes. They said that because of procedures in the past where they had to do mastectomies, they did research on lumpectomies. At the time, I didn't know if there was much of a difference, but I certainly value it now.

Afterwards, they ran some more tests and they found that I am estrogen receptor negative. That meant that I wouldn't respond to some of the new chemotherapy drugs that were out there, such as tamoxifen. It turned out that I had to have the whole regimen of six weeks of radiation and three months of chemotherapy. I began that course of treatment. First came the chemotherapy, during which I lost my hair, and then came the radiation.

Because I was so focused on my political activities, I saw my treatment as a distraction. Even though they told me that I'd throw up and feel ill, I just thought that I'd deal with it as it



comes. When I began to lose my hair, I got a buzz cut. I didn't want it falling out and feeling shaggy in the process. It is a stunning feeling to have your hair fall out in handfuls; you don't even pull it. It comes out without any resistance at all and it was the strangest feeling. My buzz cut did empower me, though. I felt like I had some control over the situation.

Because I was in the limelight politically, the Star-Bulletin, the local paper, had heard I was going through treatment and asked to do a story, I said, "Sure," and I took off my wig. It didn't bother me to take it off because I just thought of it as, "This is the way it is." I was surprised to see that I had made the front page of the newspaper, in color, and with my bald head. I received a lot of calls from women who didn't know that I had cancer and who said I was brave for showing my bald head. The doctors told me my hair would grow back, so I thought it was part of the process and I was okay with the baldness. I got a lot of comments about that and I got faxes and cards.

Many people were praying for me and suggesting a lot of alternative/complementary medicines, from shark oil to flax seed oil, noni juice to chrysanthemum juice and bee pollen. I tried them all. If people sent me something, I

tried it. I also did healing touch in the hospital and learned how to do it myself. It's a way to open up your energy passages by laying out your hands, and I came to really like it. I have a history of doing transcendental meditation and I went back to that. I felt that I needed to heal my body. I tried everything I could knowing that I could get tired while running a political campaign. And I did get tired, but I didn't let that stop me. The political work kept me going. It distracted me from giving in to my treatment and illness.

During that period of time of February through November, I was on television quite a bit and I would sometimes take off my wig. I would talk about my cancer while talking about my political activity. I would use it to tell people, "Don't tell me you're busy and that you don't have time to be involved. I'm going through treatment right now and I still feel like it's important to be out here."

In terms of care, I generally had no problems. As Chief Staff Officer of American Cancer Society-Hawaii, I fully recognize that there are a host of disparities that exist between Pacific Islanders and mainstream populations when it comes to cancer care. This is why I'm excited that the focus for our work has become centered on Native Hawaiians, Filipinos, and Hispanics living on the islands.

We are in an exciting time for cancer treatment and research. There are new drugs and treatments that are less debilitating and we're learning so much about prevention. There is hope that cancer will transform from being a deadly disease to more of a chronic disease and there is certainly hope that we can live long lives with cancer.

Message of Hope:

Know your body and be familiar with what is normal. You can never forget that you have cancer and you'll worry about recurrences, but you can still have a full life.



Christopher Pablo

Filipino Chronic Myelogenous Leukemia Survivor

Let me relate the incident that led to my diagnosis, because of course it's different for everyone. In May 1995, on the Friday evening of Mother's Day weekend, I prepared dinner for my wife. During dinner I bit my tongue, which wasn't particularly unusual; I had bitten my tongue before while eating because I always talk when I eat! The next morning though, there was blood all over the pillow, and I was a little concerned. When the doctors at the Kaiser clinic couldn't stop the bleeding, I was immediately referred to the emergency room, where finally the bleeding was stopped. Clearly there was something wrong. Blood tests showed that my white blood cell count was highly elevated and my platelet count was very low. This called for more tests the following week. Those tests soon revealed that I had chronic myelogenous leukemia or CML. It's a type of cancer which causes the bone marrow to produce more white blood cells than normal and to release the white cells into the blood stream before they are mature. The result of this abnormality is that the body's immune system is compromised.

When the diagnosis was finally confirmed, my wife and I were in the exam room together. The oncologist sat in one corner of the room, and delivered the message to us in a business-like fashion. The test results following the tongue-biting incident prepared us for the bad news. Still, it was pretty shocking to receive such news. I was just numbed by it all. There was a fear of dying and leaving behind my wife and children. I was concerned more about them than I was about myself, because they were the people relying on me.

Thanks to the tongue-biting incident, my cancer had been detected early. The initial symptoms of CML are night sweats and fatigue, which did not give me a clue that there was a problem. Because I'm a lobbyist, I'm

usually exhausted during the first week of May following the adjournment of our legislature. Warmer weather and humidity could explain the night sweats, so I naturally attributed these symptoms to my work and the climate instead of a disease.

In the first two or three weeks after the diagnosis, I was overwhelmed with a sense of calm and serenity. It's not what a person usually feels soon after receiving a diagnosis of cancer. The fear of dying and the question of "why me" is a more common reaction among cancer patients. That didn't happen for me - perhaps it's my spiritual constitution. Things happen for a reason.

The first thing I had to do was start taking a pill regimen to manage the increased production of white blood cells. Eventually, I was put on interferon, which is an injectible drug. Like most guys, I don't do well with needles. I don't



resist them and I don't faint, but nobody likes getting poked. I'll never forget the nurse who showed me how to inject myself. I cried in appreciation for her kind and gentle instruction. I involved my kids in the process from the very beginning. I said, "We're gonna put those soldiers to work to kill the leukemia cells!" They got to pick the spots where I could inject myself. My kids were 3 and 5 at that time,



and I wanted to involve them because I didn't want them to be afraid, so I had to be brave. Engaging them was to make them aware that Dad was taking this on and that he could do this, and they could be a big help to Dad in his fight with leukemia.

Two months after my diagnosis, I was practicing on the driving range of a favorite golf course, and I found an unlikely messenger at the driving range. I picked up a golf ball from the bucket and put it on the mat, preparing to hit it. I don't know what caused me to stop and pick up that ball, but there was a message of hope printed on it. It read, "Beat Leukemia." This eventually became a front-page story in our local media when the reporter who was following my journey wanted to try to find out where the ball had come from. We never did find out. I still cherish it as my good luck charm!



The only cure for leukemia then was a bone marrow transplant. For Filipinos, there are religious implications when it comes to organ donation because they believe one must keep their body whole. This religious myth is a barrier in convincing them to register as organ and tissue donors. Friends who were bilingual put me on Filipino language radio programs where I could speak in English and they would translate in Ilokano. We put out a plea to become bone marrow donors, to explain the purpose of donation, to address the religious myth, and to

educate. This provided an opportunity for me to connect to the Filipino community, especially since a match was more likely between me and someone of my ethnicity.

My donor came from one of the many bone marrow donor registration drives that I was actively engaged in. At the same time that I was critically in need of a donor, there was a movement to register donors for Alana Dung, a two-year old Chinese girl, who needed a bone marrow transplant immediately because of her aggressive form of leukemia. The community was moved by her plight and 33,000 people

registered in a 6-week period. My donor was one of those registrants who wanted to help her.

My colleagues at Kaiser in Northern California also initiated bone marrow donor drives. Kaiser received a corporate award from the National Marrow Donor Program because of their recruitment efforts on my behalf in 1996. Instead of collecting the award themselves, they passed that honor on to me. It was quite a challenge to travel from Honolulu to Minneapolis to attend the awards ceremony in 1997 because it had only been six months since I had returned home from the bone marrow transplant. But, it was worth the trip to stand in front of hundreds of people who recruit life-saving bone marrow donors and thank them for that “second chance” at life.

Let me share a spiritual perspective that I gained. This came after my donor was found and I was preparing to leave for California to have a bone marrow transplant at the City of Hope National Medical Center in November of 1996. Up to that point, the CML was in remission and things were quite “normal.” But, with the bone marrow transplant looming, things were going to change quickly and drastically. I was either going to be cured or I could die from the treatment. One day while I was praying, a deep sense of fear of dying occupied my thoughts. Up to that point, I felt comfortable with the notion that my life was in God’s hands. At least, I could intellectualize it. That day was different because I began to question the notion. I then came to the realization that my life came from God: I was put on this Earth by Him and my exit from this world would be determined by Him. My life was not my own, but His. I said, “Lord, take me home now if that’s your will. Or, leave me here, use me; let me be your messenger.” This conclusion was so liberating because I didn’t have to hold on so tightly to my life. I also came to the realization that finding peace was more important than finding life (i.e., surviving cancer).

The actual bone marrow transplant was quite uneventful. The nurses hung a bag of marrow on a pole and gravity brought the marrow through the IV into my body, much like a blood transfusion. The drama that followed for several months thereafter is what was rough. From the physical standpoint, I felt so unsure about myself, and my body felt so weak because it was undergoing such a struggle. The new marrow and my body underwent a battle before they became one. The struggle manifested itself through high fever and chills as well as other maladies, such as skin peels, mouth sores, lethargy, and all kinds of different neuropathies. Powerful drugs used in the transplant process brought on serious side effects.

My older son and I were estranged. He came to visit me in the hospital in California on the Christmas Eve after my transplant. This visit was engineered by one of my closest friends here in Hawaii, who knew of the pain and the hurt that came from that damaged relationship. I got the call that my son was visiting his uncle in Los Angeles, and it was arranged that we were able to meet and reconcile.

In terms of services and support, what I really wanted was to hear from other patients about what I was going to experience, even the bad stuff. It's important to seek out fellow patients who have gone through this experience. Your doctor and the nurses who provide your care are not likely to have undergone this disease and treatment.

There is a certain reluctance among Asians towards support services. They tend to stay within their own families and friends to get support in dealing with their disease, or to deal with it all alone. The participants in the patient and family support group sponsored by the Leukemia Society that I attended were mostly Caucasian and some African-American. Most were from the mainland and did not have access to extended family or friends for support. There was only one older Japanese man in the group because he didn't want to burden his family. In general, though, I found that it was helpful

to talk to other patients, regardless of their backgrounds. The diversity of their experience is what mattered most to me. What I have also found post-treatment is that patients currently undergoing treatment learn much from and are encouraged by those who have gone through the treatment and are survivors.

I believe in support groups. I believe in the good of patients sharing their stories and getting help for all dimensions: body, mind, spirit, and soul. Merely knowing about the disease, prognosis, and cures is just one dimension. Healing encompasses the whole self, not just the curing of the body from the disease.

This ordeal was a tremendous learning experience, from a spiritual, physical, emotional, and intellectual standpoint. The reasons why I am here as a volunteer is because, as a survivor, I have a responsibility to give back using the skills and talents that I have.

Cancer Hero:

I could not have survived cancer without my wife, Sandra. She is truly the hero in my journey with cancer. She was and continues to be my advocate, caregiver, "worry-wart," and inspiration to fight for life. Every patient needs humor to survive. I will never forget the words she whispered in my ear every day in the transplant unit, "I'll kill you if you die." That's why I survived leukemia and a bone marrow transplant!

Message of Hope:

You will find hope when and where you least expect it. The lessons that you can learn from your cancer experience are priceless. This journey was the biggest blessing in my life, besides my wife and kids. I learned a lot and I was profoundly fortunate that it wasn't a death sentence.



“The reason why I am here as a volunteer is because, as a survivor, you have a responsibility to give back using the skills and talents that you have.”

Suzanne Robert

Chamorro Breast Cancer Survivor

My new life of living with cancer started back in October 1997. I had found a lump in my right breast. Since it was just a little tender, I wasn't sure if it was there just because it was before my period, so I left it alone. But it still stayed in my mind. Then after my period, I realized that the lump didn't go away and I finally went to the doctor. She was alarmed and asked me, "Are you sure you checked it last month?" I always knew about doing my breast self-exams, but I wasn't doing them every single month. At that time, breast cancer was out there, but it wasn't really talked about, it was almost like a "hush-hush." So, my doctor was extremely concerned when I came in. She said, "I want to send you immediately to have your mammogram done." I went by myself because there was no one to go with me.

I met the technician, who was so sweet. She asked if I was alone. I said that my mom had passed away and it was just me. It was breast cancer awareness month, and I didn't even know it. So, she took off her breast cancer awareness pin, she pinned it on me, and hugged me, and said everything was going to be okay. I still have that pin today.

I went back to the doctor and she told me that I would have to see a surgeon. The surgeon wasn't even a specialist on breast cancer, but just a regular general surgeon. She told me that I would have my first surgery done on November 6, 1997. She said to come and see her prior and I said, "Okay, no problem." I was so scared, but I was trying to think positive. Deep down, though, you can feel it when there is something wrong.

Prior to the day I was supposed to have surgery, I went to see her and she wanted to do an ultrasound. That was when I told her, "You



know, there is something in my left breast. I don't know what it is, but I can feel it." So she said when I do the ultrasound she'll go ahead and check it. Well, the order came in just for the right breast, so the ultrasound technician didn't want to check my left breast. I said, "Please, there is something there," but the technician said she couldn't do it because it was not on the order. I insisted she checked it though, and after the ultrasound, the technician agreed that there was something there. I told the doctor and she said she would also do a little biopsy on the left breast to check it.

When I came out of surgery, both breasts were positive. So, on November 11, 1997, I was finally diagnosed with breast cancer. I had to go back for a second surgery to clear up the margin of where the tumors had been. On December 5, 1997, I found another lump on my left breast. At that point, I told my husband

Richard, if these lumps are malignant, I want my breasts removed. I didn't think about saving them, I just wanted it all out of me.

So, I had another surgery on December 9, 1997 and they found that all three lumps were malignant. From there, they didn't know what to do with me. So, I had a case worker assigned to me. She set me up with a consultant at City of Hope. For insurance we had an HMO, and it was difficult dealing with them. The director there knew what to do with me, but the caseworker gave me some problems. Finally they agreed to get a doctor at City of Hope for my consultation. I asked the doctor there if he had done this before. He said yes and that he was experienced and had done a lot of this. This hospital was where the research center was, unlike the other hospital.

I went back to my caseworker, and she gave me so many problems. There was no compassion and empathy from my caseworker. I guess some people like to maintain their distance and not get too close, but still, she was so cold. There was a lot of fighting back and forth, especially among the insurance companies who fought over who would get the money. My husband was the one who fought for me, because when you are sick you need someone to fight for you

In January 1998, I had another major surgery at City of Hope. My children were small and so it was my husband and I traveling from where I lived and he stayed with me. They made arrangements for a little area for him to stay while we were at the hospital. The day of my major surgery, we got up early because I had to be there before seven o'clock. I kissed my children, who were taken care of by friends. Both my mom and dad are gone, and my family is all back home on Guam, but we had friends from a track club that we put together. They helped to check on the kids and bring food for them since my 15-year-old daughter was the one who stayed home with my younger kids.

At the City of Hope, while I was waiting for surgery, I had in my hand a rosary that I put in a little red pouch. It was my mom's from when she passed away. I carry it all the time, even when I was being rolled into surgery. I was clutching it because it gave me hope and comfort. I felt like I couldn't really talk to anyone. I kept thinking of the kids, and asking to please let me live until they can take care of themselves. I know it sounds selfish, but I even told my husband Richie, that if anything happens to me, I don't blame him if he got married again. But I wanted him to know that I

want my children to be the priority. My children were my main concern.

So, I went through a long surgery that was 12 hours and I was scared. They had a hard time getting the entire tumor out, and had difficulties



with the IVs since I've been sick so many times. When I woke up, I could hear the rain. Richie was there. I said, "I'm tired." You know, when you get that feeling where it's just so much. He kissed me and we were both crying. I told him I just wanted to sleep.

At one point I overheard the doctors talking that I still had a chance, but that if my tissue didn't take the implants, I might have to go

back into surgery. So the nurse in the oncology ward was constantly monitoring me, changing my bandages every few minutes, and there was a lot of bleeding. I could feel her lifting me, and she was so strong. I felt like dead weight because I was so weak I couldn't do anything.

I couldn't help them. So that night I think I just went to sleep and told Richie to check on the kids.

The next morning when I woke, I didn't know what was going on. The doctors didn't tell me what was my prognosis. I felt I was in a place that was of death and dying. Your whole reality comes back to you. I said that I don't want to die. I was a difficult patient. Instead of staying the full seven days, I only stayed in the hospital for four days. I walked soon because I wanted to get out of there. The oncologist surgeon didn't want to release me. It was the plastic surgeon that said, "Okay, I'll let you go home." But I was in pain, excruciating pain, especially when I moved, and on the drive home. I was cut from the abdomen area to my breast.

When I got home, I immediately went into my room because I didn't want to tell my kids what was going on, and I didn't want them to see me sick. But they had a feeling something was wrong, so it was Richie who finally told them. At the time I was a little upset because I wanted to be the one to tell them, but

I think I wouldn't have been able to do it because I would have scared them. So, he explained to them what was going on, and he tried to spare me from that because I probably would have broken down and started crying.

Family was my support. We had to depend on each other, but mainly I depended on just Richie, and I don't know how he did it. Together we fought the system, such as the hospital and the insurance. They didn't want to send a home

“What’s also needed is a support group for families, especially for kids and spouses, because your whole family’s life is being affected by the cancer.”

care nurse, but Richie fought for that, called all over and got it, and the insurance finally agreed to it.

Richie was amazing. He made dinner, since none of the kids knew how to cook, and he tried to help out with the kids. Sometimes the soup would have no taste, but he tried. During the time when we didn’t have the home care nurse, he was having some trouble with his job. My husband works for the government, and even though he had leave, they were still giving him a hard time for being absent while caring for me. Then, one night I had a major infection with a fever, and we didn’t know where the infection was. So, we had to go to in the middle of the night to City of Hope. I felt bad because Richie had to work that night, but he needed to drive me to City of Hope and his supervisor was upset. There I was lying in the emergency, and I was so sad because he was going through so much already in our life, and then his job was just one more thing. To this day, I don’t know how he did it.

Richie was my life support, my rock of Gibraltar. He spoke for me when I couldn’t speak. He was my eyes when I couldn’t see. He was my strength when I didn’t have any. Him being an only child, I think it was really hard for him, and he didn’t let me down. I said to him that I would understand if he wanted to leave. In the years after I mourned the loss of my breasts, the only thing I’ve felt is that my own self, my breasts had betrayed me.

But the turning point in my life happened during my second chemotherapy. There was this little girl at the City of Hope on the pediatrics floor, and I saw her wearing her Cinderella dress and her little heels, while pushing her IV pole. She came up to me and said, “Don’t I look beautiful?” I told her, “You are the most beautiful girl I’ve ever seen,” and I hugged her. Here was this little girl that would never have her first kiss, dance, and never experience life. At least I am 34 and my only regret would be leaving my kids. At least I had a full life, and here I was being selfish. From that day on I wanted to change my life. And I remember, one day at home while Richie was

away, I was lying down on the sofa, and I had this feeling of someone breathing on me. I thought it was the cat, but when I stood up she wasn’t around. Anyway, that was my strange encounter. That started my second life of living with cancer, and I began doing advocacy work in the community.

During the time right after I was diagnosed, it was difficult for me to find services I was comfortable with. I went to a support group in Fountain Valley, but the women there couldn’t relate to me due to my age and my culture as a Pacific Islander. It was sad that I really didn’t feel much support, so I didn’t really go after that. Even until today, I haven’t met anyone with breast cancer that was younger than I was because most of the time women are older. There was also a women’s center in Long Beach that called me after my first surgery, but they seemed disorganized.

There were also some problems with the insurance. Because I didn’t completely finish my treatment at the City of Hope, I had to go back to the HMO. I told them that I would not go back to that same first hospital, and that I would rather die. There were so many things that happened at that first hospital. I remember during my second surgery, there were so many people having surgery that it was too crowded. They put me on a gurney in a room with four other people, and someone had put my dirty shoes on me on top of my bed, which was not sanitary or healthy. I also felt so rushed by the nurses at that hospital who kept rushing me to go home. Richie knows that I don’t like hospitals, but I knew I wasn’t ready to leave and that I needed to lie down. But the nurses kept pushing me, trying to get me to walk around, and they would say, “You’ll be much better when you go home.” So I felt like they were trying to push me out of there, even though I felt so weak and sick. It was strange. At the City of Hope, I felt a different kind of atmosphere, and the nurses were actually caring.

So, my HMO asked me if I would like to go to greater Newport, which was the Hoag Hospital, and I said I would rather go there than the first hospital. So, that’s where I am now.



The follow-up care is wonderful there, and up to today I still go every six months.

Before my cancer, Richie had found Guam Communications Network (GCN). We brought over the kids and we met Auntie Lola Sablan-Santos and Uncle Joe Santos. But we live far, and I'm not a good driver, so we lost some contact. But after my cancer experience, we reconnected because of our Track Club. Richie and I had started a Track Club for children, because we wanted to give back to the community. I was the "Team Mom", manager, or whatever you want to call it, and I was the one serving watermelon, drinks, and coordinating registrations and uniforms. I was always out there supporting the kids, even during the times I was going through my chemo. So, I was nominated and selected to carry the torch for the 2002 Winter Olympics in Utah. Richie emailed Lola, and at the time Lou was part of the GCN group. So, Lou came out and was there to support me and cheer me on while I was carrying the torch

During this time that I reconnected with GCN (January 2000-2001), they had the PATH project which included educational outreach to the community. The PATH project was instrumental in getting lay health workers, leaders, and other cancer survivors connected. So, GCN asked me to talk to some Chamorro women in San Diego, and that's where I met Faye, Rose, and Lucy. Then I also met Sala. These ladies became my support group, and since then the group has grown. One time, Lou and GCN asked me to speak at an event, but I had never done that before and I didn't know what I had to say. With pressure from Richie, though, I participated in the speaking engagement at the Carson Community Center. That was the first time, and it was where it all began. I became comfortable speaking at GCN's luncheons and gatherings.

Richie did a lot to get me to this point, so now my part was to get my message out there. I wanted to give hope, to show it's okay to cry. It only takes one person, one voice out there to show that you can live with cancer how you want to live. The PATH project gave me the

opportunity as one of the first Chamorro woman to openly speak about my experiences dealing with cancer. Although some cancer survivors have spoken to me, they haven't felt ready to come out yet and speak. I understand how it is hard for them. For some women it is embarrassing, so I don't push it because I know when they are ready, it will happen.

What is really needed for Pacific Islanders who have cancer, in terms of services, is a "tree" line, or phone line, to talk to someone who can answer questions for cancer patients. People need someone to talk to. I wouldn't mind doing that, because I think it's important to get the information out there. Cancer is something that women, as well as men, should be aware of. People need to know that you can live with cancer if it is found early enough and that the quality of life after cancer can still be good. You just need to be diligent with getting health screenings and doing follow-up.

What's also needed is a support group for families, especially for kids and spouses, because your whole family's life is being affected by the cancer. Many times Richie would come home at ten or eleven o'clock at night, and the kids were home by themselves. He had to help them get ready for school, cook, and clean the house. Jenny, my eldest daughter, tends to be very quiet, and it was difficult for her because there was no one for her to talk to. During my cancer, it would have been helpful if my daughter had some support and someone to talk to about her feelings and how to cope when a parent is going through cancer. It would have been good for my family to get together with other families going through the same thing to cry, to understand what's going on, and to let go of something they had no control over. If they did, at least my kids could've shared their feelings and experiences, and cried when they



wanted to, because my kids didn't show it. They didn't want to burden me, but I knew there was a lot of emotion because I could feel it.

There should also be summits and conferences to educate the community, help them prepare for such a life changing illness, and to ask questions and share concerns about cancer.

Message of Hope:

It's okay to cry and crying is part of healing. You can live. You are not alone. The power of one can make a difference to change the world and others will follow. Someone said something that really hit home and that is, "To the world you may be just one person, but to that one person you may mean the world." Just a simple touch or a hug can show that you care.



Lora Taylor Falealili

Samoaan Breast Cancer Survivor

In 2002, I was 26 years old and I was breastfeeding my second child, who was about a year old. When he was done feeding, you know how your milk glands go away after feeding? I still felt a lump on my left breast. I knew it didn't feel right and it wasn't the milk gland. I knew there was a problem with it because it felt really hard. It started hurting every time I pushed on it. So, I went over to the emergency room (ER) to try to find somebody to look at it and see what it was. I didn't want to go on and not know what it was.

It wasn't that easy to be seen. The transaction at the hospital to find someone to look at me took time. At the hospital when I got there, they did not know who to direct me to. I went the ER. I went to the OB/GYN. I went back to the ER. I went to surgical. And then I was like, "Forget it. I'd just rather see Dr. Williams." Luckily, I knew what he did. It was almost a month until I saw Dr. Williams. But I knew Dr. Williams (also known as Dr. Tofaeono) from Vegas and I went to him. He told me that my claims and worries were correct.

I had a breast ultrasound and that's when he diagnosed me with cancer. He said that I had lumps in my breast. I was supposed to do a lumpectomy, but when I went into surgery, he said that it looked like it was carcinoma. He advised me to go into treatment right off. He though I was going to have a mastectomy, and I thought that I was also going to have one because it was right on top of my breast. There would have been no other way for them to do it. So I had a tissue biopsy. At the time of being diagnosed, I only knew about the hospital and that's where you go. At that time, I didn't know about the Breast and Cervical Cancer Program.



I went to New Zealand for treatment. I had a mastectomy, chemotherapy, and rehab. They just took part of my breast and filled it up with skin as part of the reconstruction. I had to have rehab due to the reconstruction. I was there for almost a whole year. My partner stayed with me, but my kids were here in Samoa with my parents.

After that, I did nothing but stay home, and I didn't go back to work. I kept to myself. I was very, very anti-social. I didn't want to go out. I didn't want to see anybody. I didn't want to work. I had very, very short hair. In fact, my hair was just growing back. So, I was very uncomfortable with the way I looked.

I had to go back within three months for a check up. So, when that was done, it was okay and I came back from New Zealand. Every year since then, my mammograms have been

clear. Now I have four kids. I was the first one that people knew to have kids, much less twins, after cancer.

When I was in New Zealand, I was part of a cancer support group. Even before I went into my surgery, I had nurses come in from the cancer society in New Zealand. They came in and knew that I was there for cancer. So, they would check up on me and help me and ask me if there was anything that I needed. Right after the surgery, I was involved with the Look Good, Feel Good Program and that made me really feel better. I was ineligible for any of the benefits for New Zealand residents could receive because I was a U.S. resident. But it was just being invited to these things that I felt very overwhelmed with how kind they were.

When I came back, I joined the Breast and Cervical Cancer Program clinic. I used to help the staff there. What they use to do was go to the villages and have educational lectures. And I would give my time and volunteer and go speak to the villagers because the majority of the people that would go to these lectures were female. I wanted to tell people my story and let them know that this is realistic and not just folk tales and just a Samoan disease. So, that's what I was doing with them, but it was very limited. They offered these lectures and didn't really need anybody, but I still offered my time. Other than that, I started working again. I still help out any time they ask me to come over. But I was looking for support group to join and just try to help the community.

When they started the cancer coalition in 2003-2004, I wasn't really that motivated because I tried so hard to find somewhere to go and to find people. In fact, it was a friend that told me they were starting this cancer

“I wanted to tell people my story and let them know that this is realistic and not just folk tales and just a Samoan disease.”



group. But I didn't have the time to check it out and see if it was okay. It was last month that I received an invitation for a meeting and I joined the cancer coalition. Every year I would be on TV to help them since 2003, and I would also be on the air on the radio station helping and just telling people my story. I worked with the department of health folks and participated in walk-a-thons. I hoped that the cancer support group will start. I went to the first cancer survivorship meeting. I know that being a survivor is not because I was inflicted with cancer. It's because I actually survived a disease that Samoans consider deadly. And I want to show people that there is life after cancer. This is my story and this is what you can do with it. You don't have to stay home and act like you're sick because people will know that you do have cancer when you act like that. In my experience, they don't believe when I say that I had cancer because of the fact that I'm very active. I still work. I still have a life after cancer and that is a survivor. So, that's why I wanted to join and

that's why I went to that meeting. But it's just nothing but words without action.

I want support groups for Samoans. I actually want the same thing that New Zealand provided to me. I want everybody to have that opportunity that I had when I was there- people coming in to visit you; somebody taking you to your appointments when you don't have a ride or when you can't make it; and somebody there to follow up for those that missed their appointments. The majority of people (not in New Zealand and in the U.S) here on island think it's very difficult when you have cancer. So, it's important to show them that they are not alone. Having something like the Look Good, Feel Good program would help. I want to be able to help them feel better. I wanted to come back and just share what I had learned in New Zealand and what I gained. I'm glad something is getting started with the cancer survivorship group here.

Message of Hope:

I know that being a survivor is not because I was inflicted with cancer. It's because I actually survived a disease that Samoans consider deadly. And I want to show people that there is life after cancer. This is my story and this is what you can do with it. You don't have to stay home and act like you're sick because people will know that you do have cancer when you act like that. In my experience, they don't believe when I say that I had cancer because of the fact that I'm very active. I still work. I still have a life after cancer and that is a survivor. **HPA HF**



Jina Peiris

Sri Lankan Breast Cancer Survivor

I knew about mammograms. I had lumps in my breast in my 20s, but I didn't have any mammograms at that time because it is recommended for women in their 40s. I found my lump in the shower and not through a mammogram. I told my doctor and asked him to do a biopsy and it was done. Three days later I knew it was cancer. When I was diagnosed with cancer, I felt very lonely and scared. I didn't know what to do and whom to reach for advice or help. I didn't know anyone who had breast cancer in my community. I knew that cancer is not something that people would discuss. I wanted to talk to someone. I wanted to know if this was a death sentence. In Sri Lanka, they don't call it cancer. When I was a child, I could remember the elders talking about a "giant disease." I thought that there is no way that this person will survive with this. When I look back, I know now, that they described cancer with the words "giant disease." The attitude is that you should do your best and you will still die. When you come from that community, you accept it and will die too.

I felt I was fortunate enough to have caring doctors around me. All three of my doctors—the surgeon, primary care physician, and anesthesiologist—were South Asian and had sisters that went through breast cancer episodes. Their experience with their own family members helped in some ways, for them and for me to decide the best way to deal with my disease. However, since there was not much

research done in the area of breast cancer, the doctors didn't know exactly how to handle my situation. They only did what they generally did to help a cancer patient.

I was concerned about the surgery, but I wanted to wait and talk to my family. How would my family talk about this? My two sons were in university at that time. I am sure



they must have been devastated to hear about my cancer and thinking that I may die. Also at that time, I was going through a divorce and the court proceedings were in progress. I never know how they felt. I could remember my sons telling me that I would not die of cancer and that I should not worry. I am sure those thoughts must have come to them, only for me to feel better because they were feeling sad about possibly losing their mother. I was the breadwinner of the family since my husband moved out and my sons had no communication with him.

It could have been much better if I could talk to at least one woman who had breast cancer among my circle of friends. Yet, the opposite happened. Even the people, who were close to me before the diagnosis, seemed to be moving away from me. Even though, at that time, I felt very sad for not having anyone to talk to about this cancer. Now, I have a very different point of view about the situation. I understand now why they moved away from me and I have sympathy for them and want to bring more awareness to the community and outreach. They didn't know how to approach me, since as far as they knew, cancer was a deadly disease.

My surgeon wanted me to have a mastectomy, but my primary care physician said no and that he just signed on for me to have a lumpectomy. Unfortunately, I have heard that some patients will have a mastectomy without their physicians getting approval from them. I was told that they should test the tissue and see if the cancer had spread first before going to performing a mastectomy. Even during the morning of my surgery, the mammogram did not show my lump. So, I had a lumpectomy, radiation, and chemotherapy. I was told the consequences of the radiation, but I had to go through it.

At the time, I didn't know there was anything for me. I didn't see anything specifically catered for Asians or other immigrant populations. I really didn't know at that point, about any differences between an Asian and a Caucasian as a cancer patient. Since three of my doctors

were South Asian, I felt very comfortable with them. I didn't know another person with cancer. I only knew about National Cancer Institute (NCI) and American Cancer Society (ACS). As far as I knew, there were no culturally and linguistically appropriate educational materials or support groups. ACS was recommended to me by my surgeon. I called them up and a Reach to Recovery volunteer came to my house to give me some support. This cancer survivor gave me a recommendation for a certain radiation oncologist and I appreciated that. Having a choice is important with cancer. This particular ACS volunteer recommended that I become a Reach to Recovery resource person. I had no problems with ACS because they did provide me with help, such as more information about chemotherapy and radiation. In fact, I shared what my medicinal treatment was with some NCI people. They told me that I should fire my oncologist because the treatment he prescribed would've killed me. How many don't have others to provide this type of advice and support? Many will follow physicians' instructions and not really question them. I took the view of that cancer survivor. If she could survive, I can, too. After I found out what kind of impact that treatment could've have done to me, I decided not to get chemo at the same time as the radiation. My radiation oncologist argued with my chemotherapy oncologist.

When I experienced that two of my doctors were disagreeing, that may have been the point to begin doing my research and went to NCI. NCI told me what types of medication I should be taking for my type of breast cancer. My radiation doctor said the same thing. I think my oncologist may not have been giving me the whole truth.

I have been a breast cancer survivor for 13 years. I think it's okay to go to other people with different expertise and question your doctor. Maybe by that we can save one life. After my treatment, I volunteered for a mammogram unit and that's where I met a friend who asked if I would like to share my story with South Asian community. I said yes and was introduced to the South Asian Network. I assisted them in conducting focus groups on cancer with South

Asian women. I also learned that there was a lack of resources and places to get financial assistance. That's when I joined hands with several others to start SAATH, which is the South Asian Cancer Foundation. I wanted to help develop a patient navigation program for

because of your accent. We need culturally and linguistically appropriate educational materials in different languages. We need interpreters and translation available. We also need information about financial assistance for cancer treatments as well as for the family.



South Asians impacted by cancer. We want to guide the community to collect data, collaborate with other organizations. It is my dream that the community won't lose their livelihood, job, or house over cancer. We want to provide resources and support in different ways- personally, financially, legally, and appropriately. Patient navigation is very important.

The needs of Asian cancer patients are varied. Health care providers need to be trained and educated about different cultural and linguistic environments and aspects. Most doctors are not trained to talk to Asian women. Asian cultures are different. Every country has different ways of looking at things. There are issues with language, insurance, medications, not knowing who to talk to, and being denied

We need support groups. We need to know how to find a good doctor, where we can go for second opinions and other recommendations for treatment, and where to go for support.

Community-based organizations speak English, but we need in language materials. There needs to be translated materials for specific South Asian groups, such as Indians, Sri Lankans, and Bangladeshi and in languages such as Sinhalese, Gujarati, Tamil, and Hindi. I recently got involved with a Muslim women's association and their culture is very different. They are very slow into coming into the mainstream. I went to their meeting and talked about breast cancer. They listened and slowly have come to me after asking permission from their spouse to get screenings. However, they

want to only go to female doctors, which would be okay with their spouses. Support groups are needed to cater to other cultures. This group may want just a Muslim support group and not something broader, like a South Asian support group.

As a role of an advocate for cancer survivors, I have been asked to provide support to anyone Asian who calls ACS. I am the only Asian volunteer and they want to pair me up with any Asian patient. I told them that there are differences between many of the Asian communities and there needs to be a training, a conference, or something about cultural competency for Asians. ACS liked that recommendation and asked me to do it. How could I do this as an individual? It needs to be something, like an organization, that has structure and money. After my cancer, I am now having fibromyalgia and have lots of aches and pains. I can only do so much. I would like to go back to Sri Lanka and help start a bone marrow registry there since many leukemia patients die from the disease. I like to get involved with advocacy programs to reduce cancer deaths in our community. I want to know how we can increase the number of advocates, which is much needed at this time.

Message of Hope:

Talk to someone, whether it be an organization or an individual. Find the survivors and talk to everyone and anyone. I have the hope for life. Get your emotional support from your family. Give encouragement to women who need support. Educate others in the community. Advocacy is so important. Bring hope that people can survive from breast cancer. **APRAHF**





*“It could have
been much
better if I could talk
to at least one woman
who had breast
cancer among my
circle of friends.”*

Xiem “Mai” Tran

Vietnamese Breast Cancer Survivor

I remember very vividly, in May 1999, I went to Walgreen’s to buy some vitamins and the store had a campaign—if people bought a rose, the money would go to cancer research. I thought to myself that if the month of May had 31 days, I should buy 31 flowers. I bought 31 flowers dedicated to this cause, because I was thinking of breast cancer and had hope that no

one would get cancer. I didn’t think that I would be the one that would get cancer.

me for an appointment a week later, but I told someone on the phone that I wanted someone to look at the lump right away because I was very scared. Sure enough, I got an appointment on the same day. When I got there, the breast surgeon looked at it and suggested a biopsy immediately. In my mind, I knew something wasn’t right.

administer another one. I got really scared. I went through the operation, and two days later, the doctor put in an urgent request for results. I got a call at work, but I wasn’t there, so the doctor left me a voicemail. She told me I had cancer. I thought it was not thoughtful and that the doctor should have waited to talk to me in person instead of leaving me that message.

When I got the message, I called back and the doctor asked me to come in and see her the next day. I went in and we had a long conversation about the treatment and other next steps. She gave me a few booklets to read and information about consultation with the radiation specialist. She also let me know that they didn’t get a clear margin on my lump, so I had the choice of having another lumpectomy or a mastectomy. I decided to do a mastectomy right away, even though my lump was very small. I chose it so I could have a clear mind that the cancer was gone.

The mastectomy was done almost a month later. It didn’t take this long because they didn’t have appointments for me. I chose to wait until after the graduation of my youngest daughter to have the surgery. I had no idea at the time that the actual surgery is nothing compared to the treatment. Had I known that, I would’ve done the surgery right away. In my mind, having surgery a month later led me to develop two more positive lymph nodes in my breast. If I were to advise someone else in my position, I would tell them to have the surgery right away, because you never know if the cancer cells will travel through your body, get into your lymph nodes, and get into your bloodstream.

When I scheduled for a mastectomy, I also scheduled for a breast reconstruction. They could not do the reconstruction at the same time as the mastectomy, even though they had scheduled a window of time to do



one would get cancer. I didn’t think that I would be the one that would get cancer.

It was strange. Shortly after, in the shower, I took some time to explore my body. I found a little lump. I had done a little research about breast cancer prior to that, but the reading was casual and I didn’t remember everything that I read. But, when I found that lump, I was shocked. The lump was hard, not painful, and it reminded me very vaguely of a breast cancer lump. When I called the doctor, they scheduled

I opted to have a lumpectomy with local anesthesia. I had a lot of trouble, mainly because I was so skinny. I had lost 15 pounds. I had never paid attention to my weight because I thought it had something to do with the fact that I wore braces and didn’t eat a lot. I never thought it could be a sign of cancer. Because of my weight, they couldn’t use a lot of anesthesia. When they started, I could hear them cutting into my flesh and I screamed and my doctor stopped. My doctor gave me another shot. The second shot was not enough, so they had to



those procedures together. My skin was too thin and I had lost too much weight by that point. The doctor was afraid that I didn't have enough blood vessels to withstand the surgery and help the scars heal. I ended up having a reconstruction a year later.

In terms of treatment, I chose to undergo a clinical trial that lasted 12 weeks. Everyone, family and friends, were against me going into the clinical trial. I still did it. I chose a trial that was in its third stage, plus there weren't a lot of Asian women in the research. I knew that if I participated, I would be very disciplined and it might increase my chance of avoiding a recurrence. The clinical trial involved a different medication that was not that different from the mainstream treatment. Four ounces of adriamycin and four ounces of taxol were originally given to cancer patients. In the clinical trial, I was given four rounds of adriamycin, rested for 15 to 20 minutes, and then given the taxitir injection at the same time the adriamycin was in my system. There were two medications in my body at the same time, even though they were not mixed.

I noticed that I had a lot of side effects, mainly because the clinical trial involved two medications going into my body on the same day. I lost a lot of white cells. My white cell count came down to 700 during my second session of chemotherapy and I got a 102 degree fever. The hospital admitted me right away and I stayed there for five days to boost my white cell count. I got a lot of different tests because they were afraid that I had gotten some sort of infection. I also was given new shots of nuprogin to boost the white blood cells and by the end of my stay, my white cell count had boosted from 700 to 8000.

During the time I was in the hospital, I wasn't able to have any visitors, except for my husband at the time. When he came, he had to wear a mask. I couldn't have any flowers, magazines, or books. My food was like baby's food. It had to be really cooked and very pureed. It was a strange time. I had lost all of my hair and had nothing to do. Every day was spent staring out of the window and having mixed, terrible

thoughts in my mind. One of the things that I told myself, though, was that I had to have confidence in the medication and the medical team caring for me.

I had to do a six month leave to take care



of myself. I had such a terrible "chemo brain," though. The things that I could do in five minutes took me half a day, and it was so frustrating because I felt like I couldn't complete my job. I would even forget my way to work or which building my doctor was in. It was scary. I remember one day where I went to a Christmas party in the neighborhood, which is where I've been for 25 years. After the party, I couldn't even remember my way home. I drove around for almost an hour and finally gave up. I called my sister and told her where I was and asked her to come and get me.

Having experienced that, I went to a lot of classes to get tips and strategies to get my memory back, like getting yellow Post-Its to write down reminders and stick them everywhere. Even then, I would forget what I had written on the notes. Only two to three years later was I able to regain my memory, health, and weight.

When I went to Kaiser, before I decided to have a mastectomy, I got involved in an outreach program. I believe it was a coalition between American Cancer Society (ACS) and Kaiser, because ACS had sent two people to my house.

I remember the person who had had cancer more than 10 years experienced lymphedema. Her condition was a wake-up call and gave me knowledge about what I would be facing. After their visit, I went to the Wellness Community and signed up for a support group. My husband at the time came with me. In terms of other support that I got, my sister in the area called every day and often cooked for me. A very sweet memory is that, when I was in the hospital for low white blood cell counts, it was 11 at night and she brought me soup because I couldn't eat anything in the hospital. The funny thing was, I wasn't allowed to eat food from the outside.

When I was completely done with my chemotherapy, I volunteered for the Wellness Community and ACS. There were no Vietnamese support class at the time and no Asian support class. I had also joined the Asian and Pacific Islander National Cancer Survivors' Network in October 1999. When I went to

the Wellness Community, there were a lot of different people. I was glad that I joined the group because I learned a lot from the others, more than I had learned from my oncologist.

I learned a lot from the support group, especially emotional support. I realize that some other had it worse. There was a young man in his 30s that cried when he saw the rest of us laughing at a meeting. So we talked to him and asked him what was going on with him. He had lost his hair and his daughter thought that he looked like a monster. We gave him a hug and gave him some tips, some ways to talk with his daughter. He was much better the next week. This was just another example of the healing process that each had to go through. In 2002, I was happy to set up a Vietnamese support group for cancer survivors and patients just like the ones I went to in the Wellness Community.

What I recommend for other cancer patients is that they become more educated so that they are not too scared and that they know where to get help and information. I also recommend that they contact an outreach group, because the staff are willing to make follow-up phone calls and home visits. A support group is definitely a must, especially during chemotherapy. It's a place where people can go and feel that they belong. I especially recommend this for Asian patients. Our culture teaches us to share in the joys but not in the sorrows. Asian patients need a place to learn how to open up and get help.

The support of the family is very important, especially for the spouse. Asian men need to be educated. Women need a little gesture, nice words, and a touch to feel support and feel better. I participated in a focus group, where this older woman in her 70s talked about her cancer treatment. Her husband said that he saw how much pain she was in and if he could have had any of her pain, he would. This sharing of her husband's feelings helped her a lot. If an old couple can say that, why not young couples? At the Wellness Community, there were many facilitators and there were two groups, one for cancer patients and survivors and the other for caregivers. At the Vietnamese cancer support group, there are not that many facilitators, so

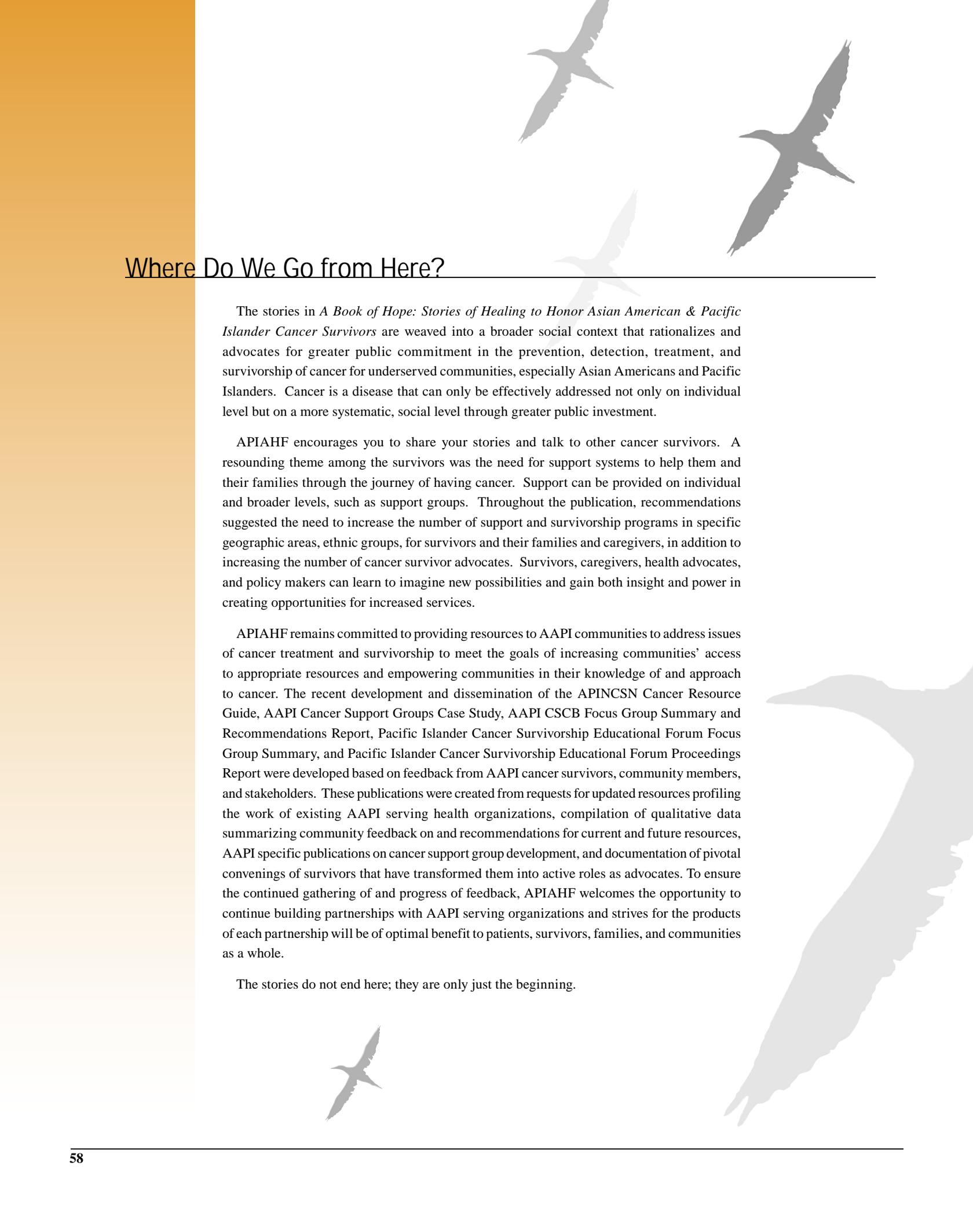
the groups have to mix, but that is not bad. Sometimes there are arguments, but we also get to laugh.

Usually, we take things for granted—our health, love, family, the beauty of nature, and just everything. We forget those things. During the time of my cancer, my mother died, my husband left me for a younger woman, my kids went away to college, and a dog that I had taken care of for many years passed away. I couldn't work, so I took an early retirement. Maybe cancer happened to me during this time to give me strength. Everything looked disintegrated to me, but even though my mom died, her spirit is still around. My dog died, but my cat does a lot of things like him. When you pass through the door of death, there's a second life—a rebirth. Don't sweat the small stuff if you've gone through cancer treatment and survived; you can handle the small stuff. Do anything to express love and to love people.

Message of Hope:

Never lose hope. Hope is there. You have to have total confidence and trust in the medical team that is helping you. You also have to have confidence in the love of your family and friends. You should know that, with the advances of technology, the cure for cancer could be there. Keeping hope is 50% of your treatment; hope is half of the cure. Even if your hope is to live one more day, that one more day means a lot, not just to you, but to your family and friends. Your hope means a lot to other cancer patients. 

“A support group is definitely a must, especially during chemotherapy. It's a place where people can go and feel that they belong.”



Where Do We Go from Here?

The stories in *A Book of Hope: Stories of Healing to Honor Asian American & Pacific Islander Cancer Survivors* are weaved into a broader social context that rationalizes and advocates for greater public commitment in the prevention, detection, treatment, and survivorship of cancer for underserved communities, especially Asian Americans and Pacific Islanders. Cancer is a disease that can only be effectively addressed not only on individual level but on a more systematic, social level through greater public investment.

APIAHF encourages you to share your stories and talk to other cancer survivors. A resounding theme among the survivors was the need for support systems to help them and their families through the journey of having cancer. Support can be provided on individual and broader levels, such as support groups. Throughout the publication, recommendations suggested the need to increase the number of support and survivorship programs in specific geographic areas, ethnic groups, for survivors and their families and caregivers, in addition to increasing the number of cancer survivor advocates. Survivors, caregivers, health advocates, and policy makers can learn to imagine new possibilities and gain both insight and power in creating opportunities for increased services.

APIAHF remains committed to providing resources to AAPI communities to address issues of cancer treatment and survivorship to meet the goals of increasing communities' access to appropriate resources and empowering communities in their knowledge of and approach to cancer. The recent development and dissemination of the APINCSN Cancer Resource Guide, AAPI Cancer Support Groups Case Study, AAPI CSCB Focus Group Summary and Recommendations Report, Pacific Islander Cancer Survivorship Educational Forum Focus Group Summary, and Pacific Islander Cancer Survivorship Educational Forum Proceedings Report were developed based on feedback from AAPI cancer survivors, community members, and stakeholders. These publications were created from requests for updated resources profiling the work of existing AAPI serving health organizations, compilation of qualitative data summarizing community feedback on and recommendations for current and future resources, AAPI specific publications on cancer support group development, and documentation of pivotal convenings of survivors that have transformed them into active roles as advocates. To ensure the continued gathering of and progress of feedback, APIAHF welcomes the opportunity to continue building partnerships with AAPI serving organizations and strives for the products of each partnership will be of optimal benefit to patients, survivors, families, and communities as a whole.

The stories do not end here; they are only just the beginning.



About the Asian American and Pacific Islander Cancer Survivors Capacity Building Project

The Asian American and Pacific Islander Cancer Survivors Capacity Building (AAPI CSCB) Project is a five year project funded by the Centers for Disease Control and Prevention under the program announcement 03050. This project serves the AAPI cancer survivor population through the facilitation of a network of cancer support groups and resources and provides capacity building and trainings to mainstream and AAPI serving organizations. The AAPI CSCB Project Consortium Partners include the Association of Asian Pacific Community Health Organizations, Family Health Center, Inc. of Worcester, MA, and Kalihi-Palama Health Center.

About the Asian & Pacific Islander National Cancer Survivors Network

The Asian & Pacific Islander National Cancer Survivors Network (APINCSN) is national network of cancer survivors, caregivers, advocates, health care providers, researchers, community organizations and cancer programs that are concerned about the issue of cancer in the Asian American and Pacific Islander (AAPI) Community. APINCSN was founded in 1997 by Susan Matsuko Shinagawa and Reverend Frank Chong. APINCSN became a program of the Asian & Pacific Islander American Health Forum (APIAHF), a national health policy and advocacy organization whose mission is to enable AAPIs to attain the highest possible health and well-being. APINCSN is a component of the AAPI CSCB Project and the goal is to increase organizational and individual membership to the Network in order to build a community of AAPI cancer survivors, cancer advocates, and programs.

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