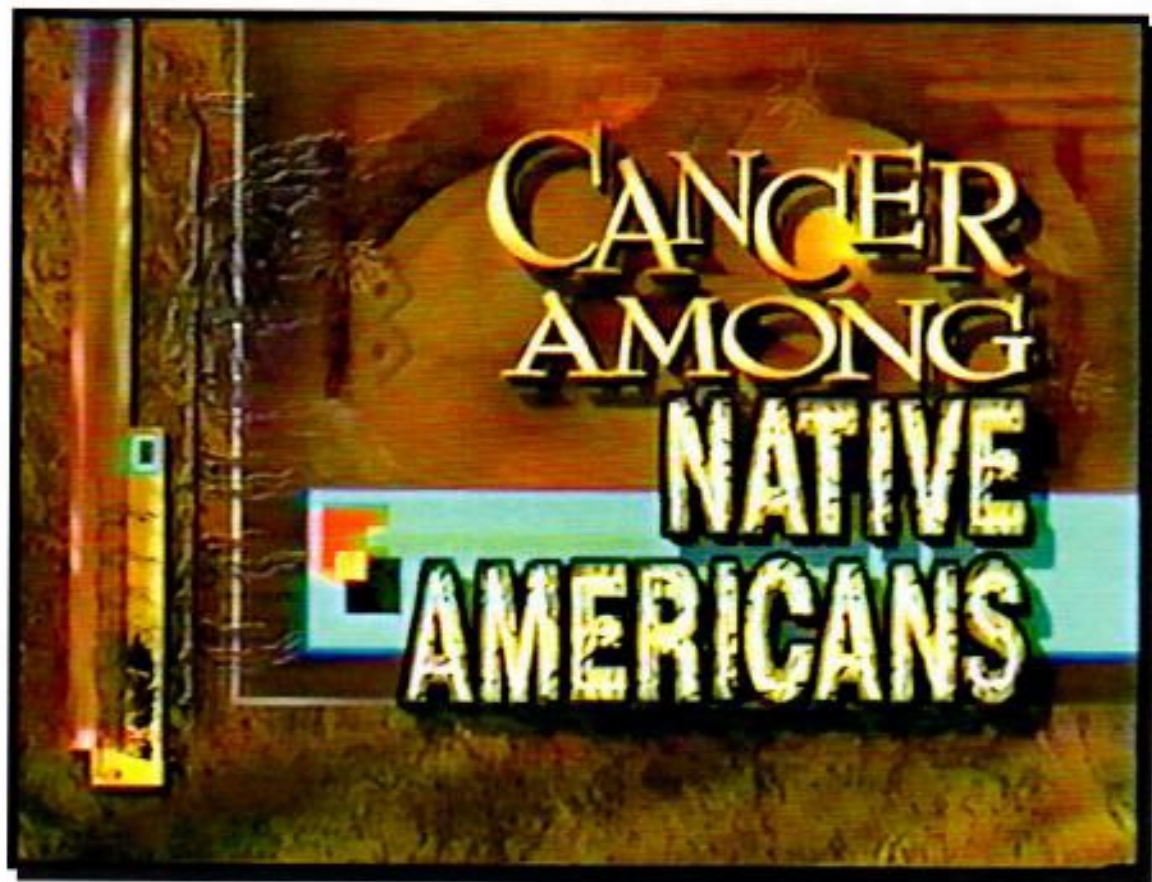


**Native American Breast Cancer
Survivors:
*Stories of Our Symptoms***



Native American Interviewers:

Mary Helen Deer Smith (Kiowa)
Judith S. Kaur (Choctaw/Cherokee)
Mary P. Lovato (Santo Domingo Pueblo)
Angela Russell (Crow)
Barbara J. Stillwater (Yurok/Inuit)
Don Thornton (Western Cherokee)

**Special thanks to our Native American "patients" for sharing their stories
to help others through this experience.**

Katherine Big Hail (Crow)
Mary Lou Calabaza (Santo Domingo Pueblo)
Mary Lou Davis (Caddo/Cherokee)
Georgianna D. (Fort Bend)
Ruth Demit (Athabaskan-Tanacross)
Eloise D. (Standing Rock Sioux)
Patricia Horse Johnson (Kiowa)
Jennie Joe (Navajo)
Frances Johnson (Fish River Inupiaq/Yupik)
Candi Miller (Haida)
Martha Red Willow (Oglala Sioux)
Dominga Rosetta (Santo Domingo Pueblo)
Angela Russell (Crow)
Carolyn Shubert (Fish River Inupiaq)
Carolyn Spotted Horse (Crow)
Norma Staples (Mandan/Sioux)
Gloria Suazo (Taos Pueblo)
Cyndi Thornton (Western Cherokee)
Evelyn Trujillo (Yaqui)
Esther ("Bunny") Venes (Inupiaq/Yupik)
Annie Williams (Yupik)

PURPOSE:

The purpose of this booklet is to share stories of strength from Native women who have been diagnosed with breast cancer. The intended audience for this booklet is others who are going through a similar experience, and for their loved ones. Although we have made videotapes of these stories, for many Native families, print materials are easier to use. We have prepared these materials to help prevent anyone from going through this experience alone. Many Native American cultures discourage discussing personal health problems. But with a disease like cancer that is surrounded with so much misinformation (such as a cancer diagnosis means a death sentence), we need to help one another through the experience. By sharing such information for this booklet, the Native women wanted others to learn from their stories so that they would seek diagnostic services and if cancer is present, that it be diagnosed and treated in early stage of growth (while it is still curable). These women shared their stories to help others through this experience.

Our program had many delays in developing these materials. We experienced severe budget cuts and without the help of our current supporters (see the back panel of this booklet), we would not have been able to produce these materials.

It has been an honor to learn from these women.

Dr. Linda Sekonsetijano

Symptoms



Martha Red Willow
[Oglala Sioux]

My first discovery of [a lump] was in 1987 . . . , I never did any self examination . . . , and I was not aware of any type of cancer in our family. I was in my sleep and I rolled over and my hand accidentally hit me and I felt this burning sensation, it was not a normal feeling. And because of . . . family problems... I put my illness on the back burner, I didn't really do anything about it until I would say the end of 1988, then . . . , I went to see a doctor. I went to a clinic here in town for a breast examination and the normal thing was, "you're too young so we really don't think you have it."

I had symptoms . . . for about a year and a half to two years before the actual diagnosis. I . . . noticed some changes in my breast probably around Spring of 1985 and . . . I went to the doctor later that summer. . . . She noticed that there were some changes in my breast and I remember she said something like, "that's interesting, . . . we'll just have to watch it". But never ever gave me any kind of recommendation about coming back in three months or six months and let's take a look at it, never any kind of . . . requirement to do anything beyond sort of what we normally do in a physical exam.



Angela Russell
[Crow]

WHAT ARE COMMON BREAST CANCER SYMPTOMS?



A lump or thickening in the breast or under the arm.

Most women's breasts become lumpy as they grow older ... if you practice Breast Self Exam(BSE), you know what your breasts normally feel like and would recognize an unusual lump or thickness.



A change in the size or shape of the breast.

Sometimes women notice that one breast is becoming larger or bulges where there weren't bulges before.



Discharge from the nipple.

The nipple drains some type of liquid. The liquid or discharge may be clear, or yellowish.



A change in the color or feel of the skin of the breast or the skin around the nipple; this may be dimpling, puckering or scaliness of the skin. *The skin feels differently than it used to ... the "dimples" look like dimples that some people have on their faces when they smile, but they appear on the breast.*



Other changes in skin color or texture, such as "orange peel" skin. *The skin itself feels rougher and scallier.*



Swelling, redness or feeling of heat in the breast.

The swollen area feels hot to the touch.

Note to the reader: If you notice any of these changes, don't panic (and don't be upset) but do have your breast(s) checked by your health care provider as soon as possible.

I really didn't think that much of it cause I've had other lumps before . . . And that was removed three different times, you know; just go to the doctors office and have them removed no problem, you know. So when I discovered this lump I thought no big deal. . . It was close to Christmas time last year around this time...and I just thought to myself I'll just put it off. After all this is over, Christmas is over, [I'll] just go and get it checked out. And it went on, and on and I never did have it checked out. And then one day I, I just, you know, you just feel like. . .something is wrong and it's just not [quite] right. . . . I just had this funny feeling even though I had [lumps removed] before. This some how. . .felt different. And, also the lump was getting bigger . . . Finally, one day I told my husband, 'You know I have this lump, this lump on my breast.' And right away he told me 'Make an appointment tomorrow you need to get this . . . checked out.' So if I hadn't told him, I wouldn't have gotten anything done.



Gloria Suazo
[Taos Pueblo]



Frances Johnson
[Fish River Inupiaq]

I went into the bathroom, nothing ached. . .I want to get back to Alaska. I [looked] in the mirror. They have [a] big mirror by [the] washroom. [I looked] at myself when I lift my breast, pull them hard and see big dimple just like [it pulled] from inside. I never seen that before so I got a little scared [to] think about breast cancer. I put them down then I feel around, sure enough, I feel a lump, close to the bone.

I had a little pain in one of my breasts and I was doing my own breast examination and I felt a lump. . . I called my doctor and I told him . . . I wasn't due to come in for my physical for about another month or so but, . . . I'm feeling a lump and so he said "well maybe we can move it up" He said "why don't you come in next week?" . . . I went in, and I . . . had a mammogram, probably about four months before this time so . . . I thought it might be a cyst or something. . . . When I went to see the doctor, they asked to have a biopsy done. . . . I was referred to a surgeon who did the biopsy, and he told me to come back in a couple of days. I went back in and he proceeded to tell me that it was positive.



Jennie Joe
[Navajo]



Mary Lou Calabaza [Santo Domingo Pueblo]

I was in Albuquerque with my son and I was playing around, you know wrestling playing and the girl just grabbed my breast and . . . next morning, I went to bed, I didn't feel nothing. Early I woke up and I had a bruise on my breast and so I call my son and I asked my son I say "what's happen to me? . . . look at my breast it's blue", [and] he said "what happened?", and so I said "it's hurting", so he took me to doctor in Albuquerque at the Indian hospital. He took me there and . . . they gave me some medicine to take, they thought it was just a bruise, so I went back home.

Few days later, my nipple started dripping so I [got] scared. My son took me back to the hospital and the doctor in Albuquerque told me to go up to Santa Fe and have it x-rayed, so I got scared again cause he told me it might be cancer. . . . I didn't accept it. So, I hid [it] from my brothers again you know, I hid it. I didn't want to tell them, I didn't want to scare them, cause I was scared myself.

(daughter's translation) And then she knew about [the cancer diagnosis] a year before and she never told us, you know she had it for over a year before she let us know about it . . .



Katherine Big Hail
[Crow]



Annie Williams
[Yupik]

I find out I had the cancer, I was losing weight every time I going down the hospital when they weigh me. I lost all the time and I was wondering how come I'm . . . losing weight, even I'm not sick and I eat, sometimes I don't get hungry, I don't feel like eating and . . . one year later it start, sometimes it just like stinging or pain like burning, do that not for a long time it stopped, that's why I don't check it. Sometimes I feel it, I don't feel nothing one time it was sometimes they pain three or four times a day I keep wondering I

wonder why my breasts get so pain sometimes and I don't say nothing. And then one time I go to bed. I lay down just before I sleep really sharp pain and I hold it. Then when it stop paining I fall asleep and the next morning I wasn't real sick, nothing. And I get up next morning take my gown off and bend down and take my gown off I was thinking, I wonder why my breast so pain last night and I look at them and my skin was look like they stuck in and after I take my gown off and put my dress on and have coffee and I told myself I should go to the hospital. So I went down to the hospital that day. The doctor ask me what's wrong and I say . . . when I [got] up this morning I saw my breast and my skin goes in, look like a dimple and he look at them and he said he feel it. I feel it too for first the time I feel it too, it's kind of big, hard and they think its . . . cancer.

I was diagnosed with breast cancer in March of 1995 at the age of 31. . . When I went in for the mammogram, I already knew there was something going on because I could not only feel the lump, I could see the lump as I looked down at my chest.



Alisa Rodulfo-Gilbert
[Tewa Pueblo]



Evelyn Trujillo
[Yaqui]

I was laying in bed one night in October and I had this little . . . I thought was a growth, you know, that was sticking out that was just like skin, you know, just like a little extra. And I was laying in bed and as I was feeling for it, I felt a lump on my breast that was as big as my thumb.

I had a little pain in one of my breasts and I was doing my own breast examination and I felt a lump and . . . I called my doctor.



Jennie Joe
[Navajo]

Delaying Diagnosis

A year before I seen a doctor I found a lump on my breast while showering. . . . I got worried about it but I didn't want to see a doctor right away. I [kept] putting it off . . . so it took like a year to finally go to see a doctor about it . . . It was a women doctor and, I went in and I didn't know how to tell her. So I said I had a sore throat and she examined my throat and there was nothing wrong with my throat. And then I said my ears. So then she examined my ears and there was nothing wrong. . . . That's when . . . she picked up on it that there was something wrong, but I didn't want to tell her. Finally she [kept] asking me questions, and finally I told her, "Oh, I have this lump on my breast." So she examined it and then she sent me down right away for a mammogram.



Eloise D.
[Standing Rock
Sioux]



Katherine Big Hail
[Crow]

(translated by daughter) on the way to the clinic with my granddaughter, I told her about the pain in my breast... That there was so much pain [!] ... couldn't take it anymore.



Esther Venes
[Inupiaq/Yupik]

It was about 10 years ago when I was diagnosed with breast cancer . . . I kind of had a feeling that that's what I had before I even came up here to the hospital. . . . I was afraid and so I didn't want to come and find out for sure and so I waited about six months, which was almost too long but I did. I finally did decide to come up and I saw the doctor. That very same day they sent me into Anchorage and, then it was a couple of days later they did the biopsy and I knew for sure. But I just want [to] let people know, that please don't wait, it's harder on you and it's harder on your family if you do wait because it works on your mind and it can just about drive you crazy wondering. . . . It's best to go to the doctor as soon as you do find a lump and find out right away.

I really didn't have time to research it [breast cancer] because I procrastinated so long and that's one of my major downfalls, that the minute you think you have something unusual a little lump or whatever and it may be minor or something, but get attention right away, because it does not go away.



Martha Red Willow
[Oglala Sioux]

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In Honor & Memory of *Katherine Big Hail* [Crow]