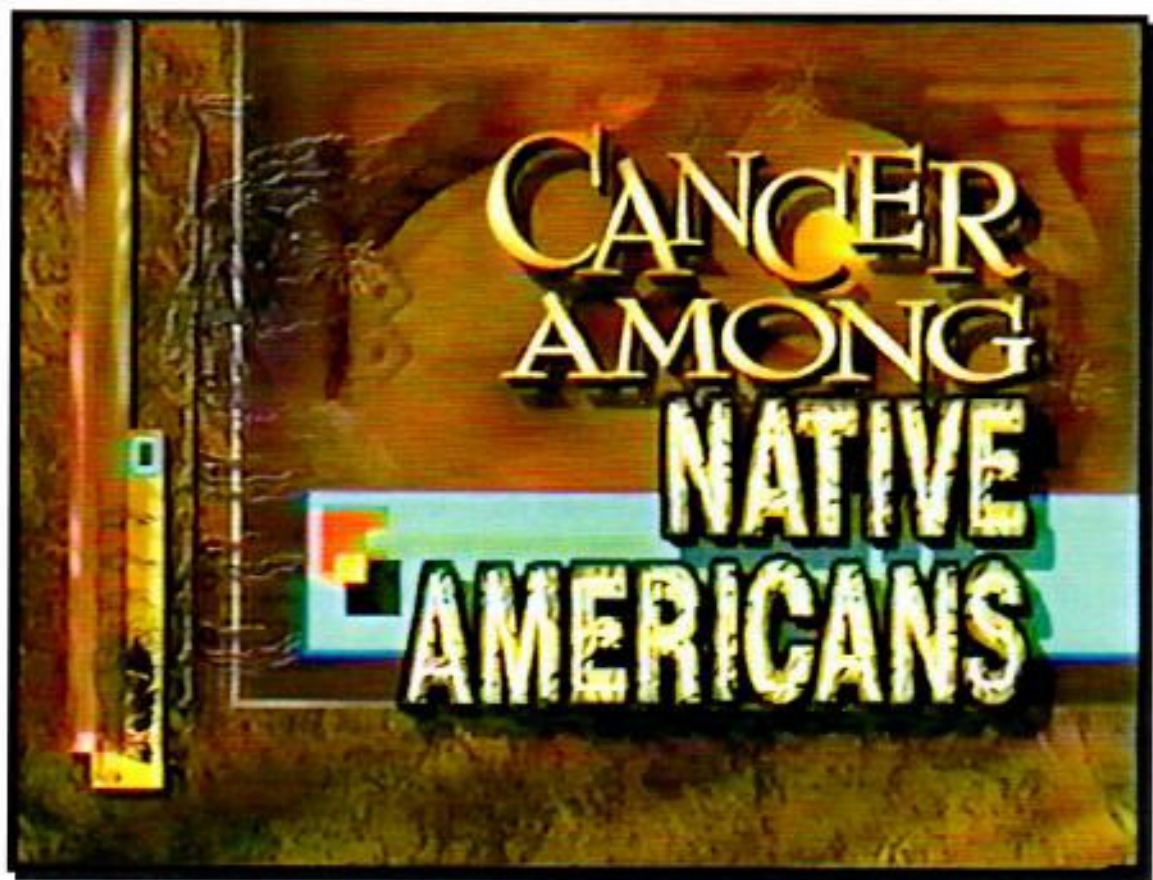


**Native American Breast Cancer
Survivors:**

***Stories of Our Personal Reactions to
Our Breast Cancer Diagnosis***



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 Suckersettjanor

Personal Reactions to a "Breast Cancer" Diagnosis

Why Me?

.. Then I seen all the women and they all looked so happy so healthy and you know I kept wondering, "why me?" And one of the feelings I kept thinking about was what did I do wrong in my life so far that I have to go through this and I kept thinking about it.



Eloise D.
[Standing Rock Sioux]

Shock / Devastated



Alisa Rodulfo-Gilbert
[Tewa Pueblo]

the nurse came in and handed me the instructions of how to handle the biopsy side and with a basket of chocolates. And I was devastated ... I walked out of the office and I just lost it. And I gathered all my energy, and I didn't exactly know how to share this with my friends (pause) because I was, I was so scared.

... it's real hard to describe the feelings that I had ... It was, it was just a big rush nothing. I mean it was like no one existed, it was just a horrible feeling, it was very frightening and very traumatic. I felt very limited with my time.



Candi Miller
[Haida]



Carolyn Spotted Horse
[Crow]

... When I first found out (speaks in native tongue) it really didn't dawn on me, until after ... I've heard about [cancer], but it never was in our family, we'd never dealt with it, so it wasn't anything to me, but I know it was a killer, I just never thought of it ...

I was having considerable pain in my right breast earlier that winter and ... so when I went through the biopsy I just had a really strong faith that I was going to be okay, You hear of cancer but you always think it's going to happen to somebody else and not to each of us personally and so when I got the news from the lab that my test was positive, it was pretty devastating.



Angela Russell
[Crow]



Gloria Suazo
[Taos Pueblo]

We went in there so carefree, you know, no worry in the world, no nothing, ... we [were] just ... going to get the results. And he said, 'Gloria, you know, you have ... cancer.' I thought, oh my goodness ... , that's not true, that's a joke, you know, really I don't believe you.

I don't know what to do, . . . it just really hurt just like somebody you know put me down, really weak, but I didn't say nothing.

Annie Williams
[Yupik]



It was overwhelming . . . I was sort of in a daze . . .

Jennie Joe
[Navajo]

It was just one shock after another! You just barely recover from one shock and you got slapped with another one ...

Alisa Rodulfo-Gilbert
[Tewa Pueblo]



Denial / Not Discuss

At the time . . . Well, when I came home on Wednesday I had not bothered to tell anybody. . . . well except my employer, because I . . . was going to be off for awhile . . . up to that point I hadn't [told] anybody in my family about my situation. I had decided that I knew exactly what I was doing. And, I'm a very private person. I don't like to worry anybody about anything.

And I was comfortable dealing with my own situation, but when [the doctor] mentioned that I would be asleep for 3 to 4 hours if she did bilateral mastectomies, I thought, "holy buckets, you know maybe I'd better tell my kids because if something happens to me, they'll really be upset, then I'd really be in trouble." . . . so, I decided maybe I better tell my kids. So I called all my kids and I asked them to come over. And . . . , told them that I had been diagnosed with cancer and that I was going into a hospital that following Monday. And . . . , that we had no idea how extensive the cancer might be, but . . . I knew I was going to be under the knife for about 4 hours and I thought they should know that. . . . some of them burst out crying, . . .



Carolyn Shubert
[Eskimo]

At the time I was in Nome I didn't tell my mother or my brother or my sister . . . I didn't tell anyone in Nome what was going on with me. Part of the reason for that was my mother's age. Earlier this year . . . she'd gone into cardiac arrest in the state of Washington and she had a pacemaker put in. And she's 84. My brother, Johnny, . . . just had quadruple bypass surgery. And I thought, holy buckets, I mean, that's a lot for her to have to deal with, you know just the fear of the unknown. And, . . . having been diagnosed herself with breast cancer, having undergone a right mastectomy, and having lost her husband to cancer, my dad, . . . she'd had a lot to deal with. And I didn't want her to have to worry about me because I was confident that the procedure would go fine. You know . . . , I probably was going to be real uncomfortable for awhile, but I just didn't want her to worry.

You know, when you're bombarded by all this medical jargon that you don't have a clue and you don't understand. You know, I didn't know, I mean even though the doctor was telling me what was going to happen as the chemo went into my body, and as things started going on. I didn't believe it, I didn't believe it because I didn't think that it was going to be that bad. Cause everybody has that natural instinct that they're indestructible. That mortality will never be questioned.



Alisa Rodulfo-Gilbert
[Tewa Pueblo]



Gloria Suazo
[Taos Pueblo]

So, like I just didn't believe it and my little girl was with me. And, . . . it was just hard . . . , hard to accept. So I went in there feeling pretty comfortable and it was like the whole world was shattered, just like that, you know.

Fear / Crying

Well he (doctor) called me at work and told me, you know that the test came back and that . . . was cancerous. It was really awful for me because when I was at work I started crying. The first thing I thought of was that I was going to die because my great-grandma died of breast cancer. And so I told my . . . my girlfriend. She asked what was wrong and I told her. And she was a lot comfort to me . . .



Norma Staples
[Mandan/Haida]



Esther Venes
[Inupiaq/Yupik]

I was scared, I was hurt because I thought God was punishing me and the one thing I didn't want [is] a [punishment], the people I didn't want to punish were my sisters, my nieces and my daughter . . . you know it was not too much for me . . . , I was thinking of them more. . . . I didn't want [to] die, cause I wanted [to] live and see my nieces and my daughter grow up and get married, it was pretty scary but, . . . you just have to go and try to find out because waiting doesn't help and I almost waited too long.

Well I think having myself checked [because] . . . my mother died from breast cancer and . . . When I found out I had cancer I cried, I just left my room . . . I told my friend that I was going home, that I had cancer and she said, "You're going to be ok". "I know," I said, "I have to be alone." . . . And I think of it--the first time I start crying . . . when I found out but after, . . . I knew I had it . . . I just didn't cry over it cause it's not going to help. And I think that's about all I have to say.



Georgianna D.
[Fort Bend]

Depression

(translated by daughter, Caroline) Ah, mother had a difficult time dealing with and adjusting to her situation. She ended up being hospitalized for depression for three months. For me that was extremely difficult to have to . . . , see her reaction that way because . . . I was certain she understood the procedure before it was done. It became obvious afterwards that she didn't really understand what was going to happen to her and her reaction to that was the depression. . . At one point when the depression was very severe, I went to her and asked her, 'Would it be better for you, to have me see if the doctors would remove my right breast so that you could have it? Would that help?'



Frances Johnson
[Fish River Inupiaq]



Eloise D

[Standing Rock Sioux]

... I went into a depression so bad that I threw all my black clothes away and my shoes and whatever had black, I threw it away. I couldn't read the local newspaper because of the obituaries in there. I couldn't watch TV cause it was all a lot of death ... When I took a shower I couldn't even stand to look at ... , my breast. It was like I ... I don't know. But this went on for a long time ...

[I cried] a lot. The pills that they gave me knocked me out for about six hours at a time, and I lost a lot of weight, couldn't eat, I was depressed ... [I got over it] by going out and doing things, I mean there wasn't anything that I could do. . . Ah, women don't have to go into depression. It's okay to cry, it's okay to get frustrated, but your life does not have to end because of breast cancer. You know you can still have a full life. And if I can help one woman to keep from going into depression, turning to drugs, turning to alcoholism, or just giving up ... you know that's what I want to do.



Carolyn Shubert
[Eskimo]



But, it was like two weeks ... it didn't bother me and then after two weeks I went into a deep depression.

Candi Miller
[Haida]

Acceptance

[The] doctor told me about the cancer. They told me they don't grow fast, they grow . . . really slow so I told myself "I think I'm not going to die" (laughter). That's what I really think, I think I m not going to die today or this winter.



Annie Williams
[Yupik]



Carolyn Spotted Horse
[Crow]

. . . it had already happened. That had to sink in first and when it did, when I accepted it, I dealt with life again. It was embarrassing at first to go out because it seems like people were just staring at you, I mean they probably didn't even know, but it seemed like they did know.

I would like to say that . . . you know the cancer has given me, . . . something that I have not had before . . . it's very difficult to describe, I have this need to do something -- not just for myself but for others . . . I feel like I've been given another chance in life and I appreciate every bit of it more so now than I ever have.



Candi Miller
[Haida]



Martha Red Willow
[Oglala Sioux]

I had two very young children, I believe my daughter was around eight years old and my son was ten or eleven, and that's the first thing that came to my mind was I have to get well, who's going to care for my children, who will take care of them if I'm gone. You don't have time for self-pity, because everybody else will pity you anyway . . .

I appreciate [life], my family more, my friends, and I [don't] take things for granted anymore . . . [now] I enjoy [work] . . . when I think about . . . when I thought I was going to die [and] . . . when, you . . . say "cancer," you naturally think your going to [die], that's it, but now they have radiation and everything you know.



Norma Staples
[Mandan]



Ruth Demit
[Atabascan]

. . . the literature they had given me I had set it aside. It was collecting dust because I didn't want to have nothing to do with it you know, just "leave me alone" period. . . . There was nothing on T.V. so I reached out and picked up this book and started reading . . . it, and it was just like something opened my mind up you know and I was ready to accept it and so I cooperated. And that was shortly before the end of radiation .

When they first told me I don't think it really sunk in. And then . . . , when I realized, . . . what they had told me, I thought, okay Lord whatever is your will use this for your honor and glory and whatever I do and what [ever] I have to go through, let it be able [to] be something that can help someone else that has cancer.



Evelyn Trujillo
[Yaqui]

Humor



Martha Red Willow
[Oglala Sioux]

. . . and your muscles are all achy, so my mother told me she'd give me a back rub and she brought this tube in and she opened it and she started to put it on my back, it was toothpaste. There's a lot of funny stuff that you do.

. . . Yes, I make jokes and stuff, I mean people would ask me and I joke about, I mean how I am, I did that.



Carolyn Spotted Horse
[Crow]

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For further information, Contact

Native American Cancer Research
Corporation

3022 South Nova Road

Pine, CO 80470-7830

Webpage://www.NatAmCancer.org

Layout, Graphics & Photo Enhancements by: Rick Clark
Morning Dew Computer Productions, Pine, CO
(E-Mail: dontdoam@aol.com)

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