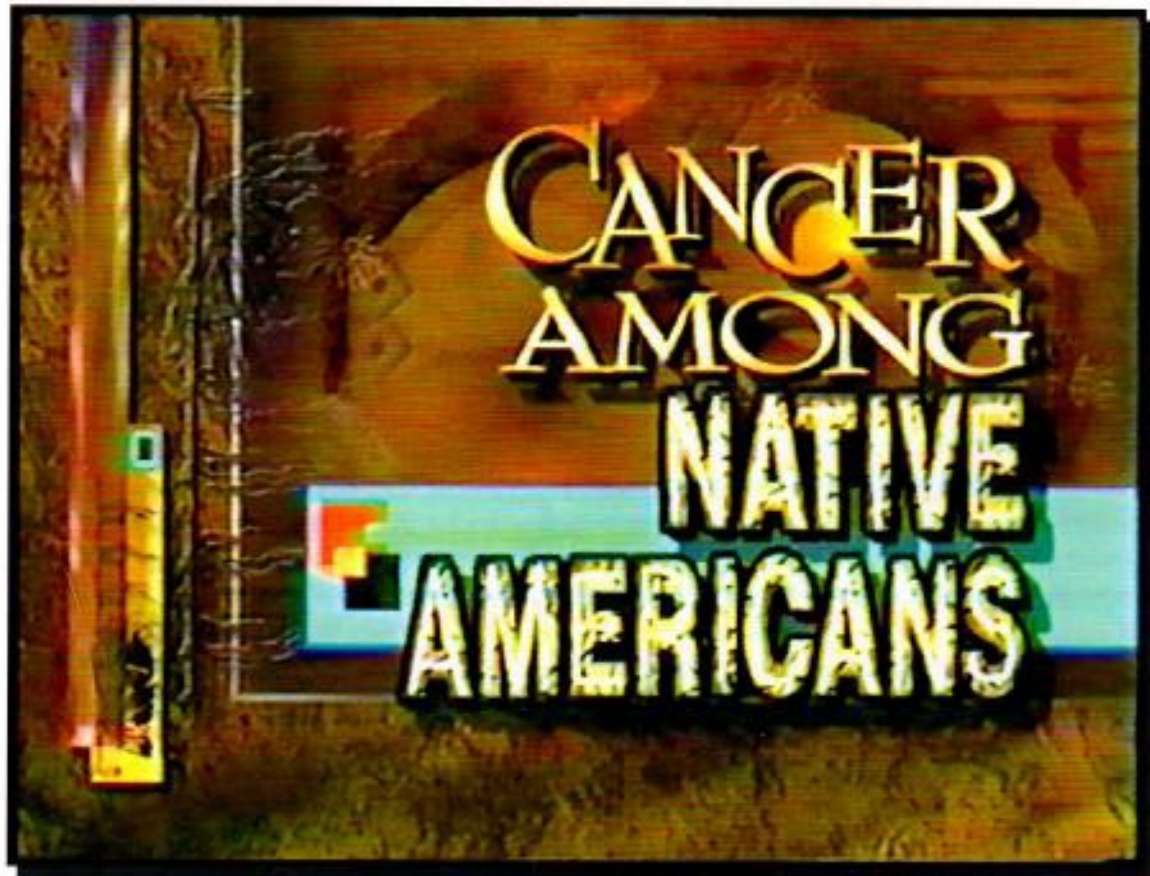


**Native American Breast Cancer
Survivors:**

Family's Reaction to 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. Lydia Bunkaetjanov

FAMILY'S REACTION TO DIAGNOSIS

Partner/husband



Eloise D.

[Standing Rock Sioux]

There was nobody to help me, to talk to me, . . . Not even my husband, he didn't even try to hug me . . . He said he was scared he was going to hurt me.

I had my doctor call my husband, I couldn't tell him, I couldn't handle it; I wanted him to break it to him. And so the doctor called him at work and told him . . . when he came home from work . . . , we talked about it and it was devastating. He just, he didn't know what to do or say. . . . I have three girls And we talked about it. We talked and we talked. And, . . . they were very, very supportive . . . But, . . . they accepted it and, . . . you know, they just learned to live with it now. You know what my daughter told me the other day, my 10 year old, she told me, "I think we're getting our [real] mommy back". You know, . . . she's not sick anymore".



Gloria Suazo

[Taos Pueblo]



Evelyn Trujillo
[Yaqui]

And my husband was very supportive and everything we did, we did it together, we did it as one person . . . Um, my husband went with me and when I did the chemo he would stand behind me, you know, with his hands on my shoulders. And it was really neat because I got sick and he got sick at the same time. Um, when I started losing my hair, he lost his hair too. And everything I went through when I'd go in to get my chemo, I guess it was just like the smell of the . . . alcohol that they [use to] . . . clean before they start your chemo. . . . My husband, would get sick as soon as we went in. He would turn gray, his face would turn gray and ah, but he stayed there. And the doctor would say, "Mr. Trujillo you don't need to stand there behind her, you know." And he would say, "I know I don't have to, I want to." So I had a lot of support, and . . . , it was good to know that so many people loved me and that were behind me and that were pulling for me.

Jerry he helped me get through it . . . he said there are no options, . . . you have to get it done; you have to watch your son play tee-ball and you have to be there for your son. . . . are definite [things] to live for; Jerry provides me that strength. He's like my silent partner too, because I'm the one that does all the talking and he just sits and shakes his head, "yes." But he's . . . definitely there when I need him.



Cindy Thornton
[Western Cherokee]



Candi Miller
[Haida]

My husband was in shock I think, . . . he really didn't know what to do, I mean he was there and . . . he babied me a lot and . . . talked to me a lot, and . . . didn't leave me alone or . . . when I felt like being alone, he would give me that space . . . He took more of . . . [the] stress, he took the burdens that I normally would have dealt with; the everyday household things, . . . he'd make sure the groceries were taken care of, the bills were taken care of, the

kids were taken care of, so you know that I could concentrate on myself and made sure that all arrangements were all made . . . for me in the process of having to do my travel [for treatment] and that sort of thing. And contacting the insurance company, that was very helpful because when you're going . . . being diagnosed with cancer I found that there were so many things that needed to be done and it was very difficult to do those things myself . . . it was real helpful to have my husband there for that.

Children

At the time that I was diagnosed as having cancer . . . , I was upset, my family was upset you know but . . . , my family my oldest daughter . . . , stayed with me and she took care of my youngest daughter while I was taking radiation and they . . . , kept in close telephone contact with my [mom] out in California and my [brother] out in Seattle . . . I think . . . , my oldest daughter is the one that really helped out. She stuck right beside me all . . . the way.



Ruth Demit
[Athabaskan]

. . . except for the oldest, he, . . . took it hard, he thought I was going to die. And we almost had to take him for counseling because what he knows of cancer is that when you have it, you're going to die. And when he thought he was losing his mother, he had a tough time in school, and . . . well counseling, . . . local friends like pastors and stuff and they helped him and he got through it.



Carolyn Spotted Horse [Crow]



Hans [is] my 15 year old. Hans was up in Nome . . . And so I said, 'Hans I've been diagnosed with cancer. I'm going to have to have surgery at some point. Do you what to stay up there or do you what to come home?' He said, 'No, I'm coming home.'

Caroline Shubert [Eskimo]

nieces and nephews [helped me survive]. When they'd see me starting to get in a sad mood or starting to get depressed, and . . . or I'd go to their place and play with the kids . . . I don't want to . . . forget this, I want to be here, I want to watch them grow up. . . . I was always happier around the little kids, and it was, . . . good to be around family cause they . . . were there in case I needed someone to lean on and they always tried to keep me busy. And of course my favorite pass-time was eating (laughter) so, my sisters always had . . . baked good around and of course I loved to eat Native foods. . . . [my sister], my little niece, all three of us would



Esther Venes [Inupiaq/Yupik]

sit around and eat and then I'd take a nap with my niece and that was . . . when I was really the happiest, when I was around the little kids so I spent more time with them.

Family



Katherine Big Hail
[Crow]

(translated by her daughter) Well, she didn't want to hurt us and I think she was afraid and there was fear there too, you know, before she let us know about it. . . . And then that night we sat around, the family all sat around, and then, it was a shock, . . . because it had gotten to . . . her lung and liver and part of her spine. And then what scared me was when it got to the liver, I thought that was it, you know. And then so we sat around and my daughters one of my daughters was crying and we all cried and then she got up. She got up real strong and then she said,

"well, where's your faith?" She said if you want me healed, she said [believe] with me, you know the whole family, [believe] with me. And then right away I said well we'll stand with you, we'll [believe] with you, we'll be praying for you. And . . . that very next day, they sent her to Billings clinic here and that's when they scheduled her for the operation, the surgery.

I think it scared them more than it did me.

Jennie Joe [Navajo]



. . . they felt hurt inside . . . One of my daughters called me and they gave me a Bible verse to read. Psalms 1:21 was the verse. Um, the other kids were saying mom, "We'll pray for you," you know.

Evelyn Trujillo [Yaqui]



Well the rest of my family was a little bit frightened I think . . . they all hovered around and thought, . . . you say, "cancer" and you think, "boy, that's the end of time." And it really isn't, you know, there is treatment now, and so they were very supportive though, but they were very scared.

Mary Lou Davis [Caddo/Cherokee]

And that evening family members were coming, but . . . they acted like they were scared of me. Nobody hugged me and they were all . . . , sitting there looking at me. And like I don't know what . . . And that's when I started to feel different.

Eloise D. [Standing Rock Sioux]



Well my sister and my mother did not know until after I had already had the operation and I knew I was going to make it. That's when I told them. Of course they were all mad at me because I didn't tell them

Esther Venes [Inupiaq/Yupik]

before. But, ever since I was a kid, it seemed like my mother was always the one to make my decisions and so this was one time I was going to make a decision on my own and I was going to try to do it on my own and see if I could and I did. . . . Then I told my mother, my sisters. . . . I decided then that if I can survive this I can do anything, and so I did.

My . . . uncle . . . thought he had to keep his distance so that he would not get . . . the cancer . . . He didn't say it, but I could sense it. . . .

Ruth Demit [Athabaskan]



Annie Williams
[Yupik]

I got no family . . . I got cousins, my aunt's daughters and sons she's the one she raised me . . . I had two kids, Johnny and Theresa. When . . . my husband drowned in Aleknay (sp?) when they were small and I take care of them. They grow up and we still live in Aleknay, Johnny he was 20 years old grow up and he start hunting for me, . . . he drowned when he was 20 years old. And I only got one left, Theresa and then Theresa finished the high school and we moved here and she went to school down Astoria Oregon . . . She got killed there.

. . . so they operate on me and my brothers and my sisters come and my sons they come and talk to me all the time.

Mary Lou Calabaza [Santo Domingo Pueblo]



So then . . . , we went into his office and had a consultation, my whole family and I went, and he explained everything to us to the point where we could understand everything.

Gloria Suazo [Taos Pueblo]



Caroline Shubert
[Eskimo]

After having been released from the hospital and I came home. My 11 year old grandson Brian came and stayed with me and took care of me. My children stopped in and would bring some food to eat . . . Brian and I would take walks in the neighborhood. My granddaughter Jessica, she's 11, and she came over spent a couple of nights with us. And the 3 of us would go for walks in the neighborhood . . . my family provided emotional support. . . Your family members tend to become more attentive to you and your needs because they realize your mortality.

my family had . . . just kind of sat and waited to see how I was going to react before they would react themselves . . . if I show fear, they're going to be frightened, . . . and I'm a very strong willed person so I did try to keep myself in check, . . . they were able to deal with it as long as I did and . . . you know it was hard for them, very difficult, nobody likes to see someone you love suffer and I think that was the way that they felt.



Candi Miller
[Haida]

The hard part is my son, in the beginning it was very difficult for him to understand and accept my illness, he thought maybe because of my marriage and having problems with my husband . . . , that he might have injured me in some way and that's how I had gotten it. But I had him you know feel the wound and so forth and explain to him there's so many ways of getting breast cancer, and there's no one answer.



Martha Red Willow
[Oglala Sioux]



I called my husband and I told him and there was this dead silence at the other end. . . . I was going to have my surgery at Minot and my family had a fit and they said go to Bismarck you know, and so that's how I met you. [Dr. Judith Kaur] I think my niece contacted [you].

Georgianna D. [Fort Bend]

They were strong, they understood, and we have the meeting I told [Mary P. Lovato] that I was going to tell my parents, my brothers and my sisters too. I didn't want to accept it so they kept on talking to me so we prayed and . . . I know my baby brother, he's the one that got really hurt and my son. They all say, "why you? Since you got home, you got sick, why?" So my daddy told me, be careful, what you do, each step you take, be strong in body and soul. We got our own beliefs so that's what I do everyday, I take one at a time . . . they understand, they don't want me to do a lot of work, they want to do the work and they want to suffer the pains that I've suffer. And I tell them, I say, you can't do that, I got will power. I . . . Especially my son, "Mamma are you all-right, mamma are you all-right" that's what he always tell me. He come up there sometimes every weekend and see me.



Mary Lou Calabaza
[Santo Domingo Pueblo]

Parents



**Carolyn Spotted
Horse**
[Crow]

my father was [diagnosed with cancer before me] . . . we never did talk about it. I mean we live together and we ate together and everything but we just never talked about it. It just happened to us and we just went on with our lives. We just never talked about it . . . we didn't pity each other or anything, we just expected each other to get through with what we're going through, because he was going through radiation too.

My mother has instilled . . . , Indian messages and . . . different Indian beliefs in us children . . . we grew up in an Indian church and . . . my family is still active in it. And anytime we have a problem, . . . or anytime we need prayer, we just pick up the phone or else go over there [Indian Church] and we're covered.



Cindy Thornton
[Western Cherokee]



Norma Staples
[Mandan]

. . . and then I told my mom. And she was all upset about it. . . like my oldest daughter she was really upset about it you know, and even now she said, 'mom are you sure you're all right 'cause I'm not ready for you to die.' I said 'I'm too ornery to die,' you know . . .

FRIEND'S REACTION TO DIAGNOSIS



I think the things that have helped me survive is . . . wasn't just family, but it was friends I didn't even know or think about. People were praying from Boston to CA, you know, and all in between. And I think that has been the, . . . answer, you know, their prayers. So, I think it is very important.

Evelyn Trujillo [Yaqui]

My friends have not changed. My co-workers did not change. They were extremely supportive, send letters of encouragement, people called. People said 'Hey, you know, we're just glad you're alive . . . [My friends said] We're just glad yours was found in an early enough stage to where your life is not in danger'. In my situation, my cancer was found so early and, . . . I did not require . . . any chemotherapy or radiation.



Caroline Shubert
[Eskimo]



And . . . also a friend of mine came in and he says just cause I talk to you and come see you can I get it too? And I says no. . . . I call my cousin right away you know cause I told a couple people from Northway area that I had cancer and boy something

Ruth Demit [Athabaskan]

like that would spread like wildfire right down the highway. By the time it reaches my aunt and uncle and my cousins, I'm dead, right? . . . what I did is I called my cousin and said "don't get shook up, I want you to listen to me", she says, "what?" I said I've been diagnosed as having breast cancer, malignant, I have to have radiation and chemo. And there's a long silence on the phone now. And I says . . . I want to tell you I will keep in touch with you and I says if you hear any wild rumors down there I says, you have any questions, you call me. I says you get the facts from me, you know. So that was fine and then I was able to make a trip down there in the summertime and my cousin . . . talked to me and she says you know Ruth, she says you can go to our graveyard and pick out a place where you want to be. I says ok, I will do that but I says, "I'm taking my time getting there." That was so funny you know and she just kind of smiled at me and said Ruth!



Evelyn Trujillo
[Yaqui]

And . . . , my friends as they found out, they called and everybody had a remedy for me. And I did everything. . . . I did it because I felt that they cared enough to go out of their way and find things for me. One of my girl friends went to her nutritionist and told her everything about me. And her nutritionist gave her soups, teas, herbs for me to use, and so,

it was beautiful the way that everyone supported me, . . . and was behind me. And the people at church were all praying for me, . . . and they were like my cheering team- "Come on, we know you can do it." . . . I can't say it was a beautiful experience, but it was an experience that was good, you know.

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