Rosanne Wyman lived on both sides of the US and Canada border. She was always positive, caring and supportive to others. Rosanne was an advocate for anyone diagnosed with cancer and created “Miles to Go”, a Canadian Aboriginal cancer education and support organization in the 1990s. Once while talking with a 20 year old woman diagnosed with breast cancer during the “Young Women with Breast Cancer” annual conference in 2008, she gently held and comforted the young woman. She talked about spiritual strength and the Medicine Wheel. She was a model to all people, not just those diagnosed with this disease. Here are a few of her words:

“[The cancer experience] has been a journey that I wouldn’t change now. If I had the chance to take it all back, I wouldn’t. It’s increased my awareness of other people, it's increased my spirituality. It’s increased the fact of who I am. And I am an Indian woman and proud to be one…I’m happy I got it. It changed me as an individual, I’m walking a different path, I’m walking on a hopefully straight and narrow road and going in the right direction that the Creator intended me to go. I pray. I feel my spirituality is why I am here today. I like to go out and talk, tell my story of my hardships, my good times and my bad times--things that can bring a smile to your face or bring a tear to your eye, or things that maybe somebody else is going through those same feelings that they have suppressed. It is all attributed to my spirituality. The power of prayer, the Indian medicines combined with the western medicines is powerful. I feel that this is the reason I’m here. To walk my walk and talk my talk. And that’s what I do. It’s just something that’s so incredible.”

Rosanne was an active member of Native American Cancer Research’s “Native American Cancer Education for Survivors” (NACES) program. Her voice can be heard in the examples of “I messages” found in the Communication branch of the NACES tree.

Hear and see more of Rosanne at: [www.natamcancer.org/vignettes/vignettes.html#w_text](http://www.natamcancer.org/vignettes/vignettes.html#w_text)

Click on the NACES tree for cancer information for survivors and families at: [www.natamcancer.org](http://www.natamcancer.org)
Acknowledgments

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Editorial Credits

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Disclaimer

This publication should not substitute for professional advice by a health care professional. Readers should always consult a physician or other health care professional for medical screening, treatment and advice. Please note that the phrase, “see your doctor,” refers also to tribal clinic professionals such as a Physician’s Assistant, a Nurse Practitioner and/or Nurse Midwife.

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The Native American Cancer Research Corporation (NACR), is a national non-profit organization “… dedicated to helping improve the lives of Native American cancer patients and survivors. We seek to reduce Native American cancer incidence and mortality, and to increase survival from cancer among Native Americans.”

Please gives us Feedback at:
www.natamcancer.org/booklet_evaluation.html
What is cervical cancer?

Cancer is a term that describes more than 100 different diseases. In cancer, abnormal cells multiply without control. Cancer cells may not know how to die, so they live and grow. The organ located between your uterus (womb) and vagina (birth canal) is called the cervix. Cancer in this organ is called cervical cancer.

NOTE: “Cancer of the womb” (uterus / endometrium [EN-doh-MEE-tree-um]) is not the same as cervical cancer

4 reasons why a healthy cervix is important

1. Healthy cervix has a better immune function to protect against infections
2. The cervix is an opening to your womb. It defends against infections getting to the rest of your body.
3. Sexual intercourse is more comfortable when the cervix is healthy. An unhealthy cervix can cause painful intercourse.
4. The cervix helps to keep your baby in the womb until you are ready to deliver your baby.

What “causes” cervical cancer?

When something “causes” cancer, there is a direct link between a behavior and the cancer. A behavior can be having many different sexual partners or smoking cigarettes. Some types of HPV can also cause cervical cancer. (This booklet describes HPV on page 8).

Quick Facts about Cervical Cancer

In women under 45, cervical cancer is the 2nd most common cancer.

American Indian women get cervical cancer more than twice as often as other women. More American Indian women die from cervical cancer than other women.

AIAN women are more likely to be diagnosed with later stage disease.¹

AIAN women aged ≥65 years had more cervical cancer diagnosed in comparison with Non-Hispanic White women (85% higher for older AIANs). This may be related to a lack of screening in this older age group. NHW women were more likely to be diagnosed between ages 30 and 49.²

Rates of invasive cervical cancer in AIAN women are currently lower than earlier published reports. The decrease is felt to be due, at least in part, to aggressive screening programs.³

How Can I protect myself and be healthy?

**9 THINGS YOU CAN DO TO REDUCE YOUR RISK**

1. Get the HPV vaccine (all 3 shots in 6 months).
2. Do not have intercourse early, especially before the age of 16.
3. Have fewer than 5 different sexual partners in your whole life.
4. Do not have sex with partners who have had many sexual partners.
5. Avoid sexually transmitted diseases and use condoms.
6. Have a diet high in colorful fruits and vegetables (possibly protective).
7. Avoid exposure to cigarette smoke (smoking and second hand smoke).
8. Give birth to less than 8 children.
9. Limit long-term use (5 or more years of use) of oral contraceptives.

**YOU CAN PREVENT CERVICAL CANCER**

**The Shield of Health: Look at your cancer risks**

The cancer risks described above can threaten your health. These behaviors can put holes in your shield of health. To see how these can affect your health go to:

[www.natamcancer.org](http://www.natamcancer.org)

Scroll down to the right and click on “Cervical cancer risk factors”. Here you will see the shield of health. Choose risk factors for you.

Next, scroll up near the top of the webpage. Click on “health factors.” See what happens when you change to healthier behaviors.
All about Pap Testing

The Pap test can be an early warning system for cancer in the cervix.\(^1\) Pap tests tell if you have abnormal cells which could be cervical cancer. Cervical cancer can be curable when found early. You can have this test in a health clinic or screening van. A trained healthcare provider usually does a Pap test during a pelvic exam. The provider does the test by placing a special tool (speculum [SPEK-yoo-lum]) into the vagina. This tool pushes the walls of the vagina apart so that the cervix can be seen. The provider uses a small spatula or a tiny brush to collect cells from the opening of the cervix. The provider puts these cells on a glass slide or in a container with liquid. The provider sends these cells to a lab for processing. The lab staff sends a report to your provider. The report explains if the cells are normal or abnormal. If the cells are abnormal, more tests may be needed.

When should I have a Pap test?

Females need to begin having Pap tests when they become sexually active or by age 21. Older women need Pap tests even after menopause (MEN-uh-pawz) until at least age 65. If you have a new sexual partner, you may consider having pap tests more frequently.

Many American Indian women quit having Pap Tests after their childbearing years or when they quit taking oral contraceptives (the pill). You should NOT stop having Pap tests. You need them to stay healthy and be there for your family! Your provider may recommend less frequent tests (every 3 years) if:

1. You have had 3 “normal” Pap tests in a row within the most recent 5-year period.
2. You have had a recent HPV test in combination with a Pap test and both are normal.

Is it really THAT important?

YES! A few minutes of embarrassment can save your life!

1. A pap test can save your life by finding abnormal cells before they become cancer.
2. It can find HPV that causes some cervical cancer and genital warts.
3. It can keep your body healthy by finding treatable diseases.

Getting ready for a Pap test

Having an accurate Pap Test is important.\(^2\) Sometimes a Pap Test may not find abnormal cells even when they are there. To make your Pap Test more accurate, for the two days before your Pap Test, you should:

- **NOT** Have sex
- **NOT** Use birth control foams, jellies or creams
- **NOT** Use any medicines or creams in your vagina (birth canal) unless ordered by your healthcare provider
- **NOT** Use a tampon. If you are on your moon (menstrual period), you will need to reschedule your exam.
- **NOT** Douche (rinse the vagina) with any type of fluid (even water)

When can I quit having Pap tests?

You should talk with your provider about when it is okay to stop having Pap tests. If you are older than 65 and have had normal results for the last 10 years, you may be able to stop.

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\(^1\)[http://www.ashastd.org/hpv/hpv_learn_dysplasia.cfm cited on 05-20-2011](http://www.ashastd.org/hpv/hpv_learn_dysplasia.cfm)


Abnormal Pap test results

This means that the cells removed from your cervix during your Pap test are not normal. This can be due to an infection, cervical cancer or other cause. Your provider may do further tests to find out why the cells are abnormal. Sometimes the cells appear abnormal but are not (a false positive result). Your provider will make sure the results are correct before suggesting any treatment. For more information about abnormal pap test results, please go to: http://www.cancer.gov/cancertopics/factsheet/detection/Pap-test

If I have had a hysterectomy

Today, most women who have a hysterectomy have their cervix removed. Without a cervix, you do not need a Pap. In the past, surgery may not have included the cervix. If you do not know if your cervix was removed, you will need a pelvic exam to find out. However, if you had a hysterectomy because of a pre-cancerous or cancer diagnosis, you may still need to have a Pap.

Pelvic exams

A pelvic exam does not test for cancer. The pelvic exam lets the health care provider look at your cervix and feel your ovaries and uterus (womb) for any swelling or abnormalities. Your health care provider will let you know if everything is normal.

How do Native Women compare to Non-Natives for getting their Pap tests?

The CDC tracks screening. It looks at Pap Testing over a 3 year period. The CDC reports that Native women had the largest drop (15.4%) in Pap testing since 2003. Fewer Natives (78%) have Pap tests as compared to Non-Natives (84%).

Was my great grandma worried about this disease?

Probably not. Our ancestors lived in healthy ways. They had fewer sexual partners. This made them less likely to get sexually transmitted diseases. That would include HPV. They also saved tobacco for ceremonies. Today many use manufactured tobacco daily. Many women also have more sexual partners or have sex with men who have had multiple partners.

Cervical Cancer Statistics

**Legend**

- CHSDA: IHS Contract Health Service Delivery Area
- NHW: Non-Hispanic White
- Alaska: includes all of Alaska
- Northern Plains: 11 states: IA, IL, IN, MI, MN, MT, NE, ND, SD, WI, WY
- Southern Plains: 3 states: KS, OK, TX
- Pacific Coast: 4 states: CA, ID, OR, WA
- East: 25 states, such as FL, GA, MO, MS, NC, NY, PA, TN
- Southwest: 5 states: AZ, CO, NM, NV, UT

So what does this information in these graphs mean?

- Cervical cancer is more common among American Indian/Alaska Natives (AIAN) than it is within Non-Hispanic White (NHW) women.
- American Indian women from the Southern and Northern Plains have more cervical cancer in comparison with Native women living elsewhere.
- Cervical cancer is different for AIANs living in different geographic regions (see how few AIs living on the Pacific Coast have cervical cancer as compared to AIs from the Southern Plains).
- AIAN women have a higher death rate from cervical cancer compared to all US women.
- The death rate from cervical cancer is higher for AI women living in the Northern Plains than Native women living in other regions.
- No conclusive evidence explains these regional differences but researchers are working to find out.
My Story

At the time [of my diagnosis] in 1978, I was young and I think sometimes ignorance is bliss. So when I was diagnosed with cervical [cancer] in situ, I had the option to have a hysterectomy. I have 2 sons and I wanted another child and I wondered what were the implications … of this diagnosis. The physician said I could have a pregnancy and [the baby would] not be affected … [by] the cancer diagnosis. So I had a pregnancy. After I delivered a child in 1980… I had a hysterectomy. At the time I was young and I didn’t really have the full scope of knowledge of the implications of cancer and the cancer diagnosis … I didn’t tell [anyone about the cancer]. I lost my mother at an early age. I didn’t tell my family. Not that I can recall. … I didn’t share with my family or with my children.

Coping

I was so involved with my children and they were my focus. As Lakota, we are a matriarchal society so I felt that I was in charge of this business of cancer diagnosis and treatment. It was my body. I didn’t need [anyone’s] permission or consent … [paraphrased] [I just wanted to be reassured that [my child] was going to be okay].

The essence of who I am is being spiritual. So I had to give [the cancer] up to the Creator and say this is in your hands. I have done that with my breast cancer. I’ve done that and I’ve let it go. And I’m always reassured that I’m okay. The healing post hysterectomy was very much grounded by spirituality. For me true spirituality is something that is found deep within me, it has become my way of loving, accepting and relating to people around me. I believe healing comes from being engaged with positive people, they can become good medicine for use during healing. During my treatment for breast cancer in 2002 the practice of traditional medicine played a significant role in my management of healing.

HPV

I think …that we should … suspend judgment when we are talking about cervical cancer because there are so many variables associated with it--the human papilloma virus for one. We need to increase health literacy if we are going to address HPV as a health disparity. HPV may not be related to the woman and promiscuous behavior. The message is about raising the health literacy around the human papilloma virus. Lastly, I would recommend the HPV vaccine if I had a daughter under 26.

Clinical Trials

Although in many tribal communities, we resist the notion of participating in clinical trials when we have been diagnosed with cancer, I think that if we are going address the rising cancer disparities in our communities, we do have to participate in clinical trials. As a Native person, it is not for me. Remember, we are doing it for those who follow us. We look to 7 Generations ahead and I think this the way we give back; protecting the 7 Generations to come.

MESSAGES:

🗹 Native women need to know that they are not alone in this journey of diagnosis and treatment. That there are many of us like myself who are available to reach out to in our communities.

🗹 Being diagnosed with cervical cancer is not an indication that you are going to die. But it is an indication that you need to take care of what you have been …

🗹 Keeping yourself busy and go on with your life. This was a diagnosis, a surgery that you’ve had … but for me it was like, okay, that’s done, move on. Remaining hopeful is critical.

🗹 I value Western Medical treatment, but I also value the immense role traditional medicine holds for tribal people.

🗹 You need to be the voice that takes an active role in our health and our wellbeing. We have the power to do that and we need to acknowledge that power to be well and be healthy … with that being said, be active in being healthy and do everything to model for our children--Sending positive messages …
Almost all women and men will have HPV at some point in their lives, but very few women will develop cervical cancer. The immune system of most women will usually suppress or eliminate HPV within 2 years and not have health problems. Only some types of HPV infection that do not go away over many years can lead to cervical cancer. In addition to leading to cervical cancer, some types of HPV can cause cancer of the vagina, vulva, penis, anus, mouth and throat. HPV, HIV and herpes are NOT the same infection.

You can have HPV and not know it because you have no symptoms. But, you can still spread it to someone else. Some types of HPV cause genital warts. If you have genital warts, you have HPV. Most people will get HPV if they have more than 5 sexual partners in their lifetime. You and your sexual partners are likely to share the same HPV type. HPV may be found on skin not covered by a condom (spreading is possible).

HPV-DNA testing can tell your provider if you are at risk for cervical cancer. Some types of HPV cause cervical cancer. The test shows if you have any high-risk types of HPV. Knowing if you have a high-risk type of HPV can help guide your evaluation and treatment choices.

There is no specific way to test directly for HPV in men. A provider can do a physical exam of a man to check for sores or warts. Researchers are looking for ways to better screen men. Anyone with a history of anal sex (including gay men) should speak with a health care provider about having an anal Pap test. Anal cancer is uncommon, but screening can still be an important precaution. Talk to your provider.

Positive HPV test results mean you have one or more types of HPV. It does not mean you will get cervical cancer. However, you may be at higher risk than someone who does not have HPV. You need to follow up with your health care provider.

Fifteen of the more than 100 HPV types cause cervical cancer. Most cervical cancer has HPV types 16 and 18. Both of the HPV vaccines include HPV types 16 and 18. The HPV vaccine can reduce your chances of getting most cervical cancer, but not all. Females still need to practice good health behaviors to prevent cervical cancer.

There is currently no HPV treatment available for the virus itself. Treatments do exist for the diseases HPV can cause, such as cell changes or genital warts. Your health care provider will discuss these treatment options with you.

Most sexually active partners share HPV. People do not pass the virus back and forth. The virus can become inactive. Becoming immune to one HPV type does not protect you from getting another type of HPV.
**Vaccines for HPV**

The HPV vaccine helps to prevent the majority of cervical cancers. To gain the full effect of the vaccine, you need to have 3 shots within 6 months. One vaccine (Gardasil) can also prevent up to 90% of genital warts. The first group who should receive the vaccine is 9-13 year old girls who are not yet sexually active. Others who may receive the vaccine are women (under 27), boys and young men.

The HPV vaccine is not 100% effective in preventing cervical cancer. HPV is not the only cause of cervical cancer. The vaccine does NOT replace the need for Pap tests. Women still need to have Pap tests and pelvic exams on a regular schedule.

The provider will usually give the shot in your child’s arm. Ask your provider about ways to make the shot more comfortable.

**3 things you can do to make it less uncomfortable are:**

1. Before and after the shot ice the arm.
2. After the shot, massage the arm.
3. 30-minutes before the shot take an over-the-counter pain reliever with your provider’s advice (such as: ibuprofen, acetaminophen, naproxen sodium).

There are several ways to help with paying for the HPV vaccine. The 3 shots cost about $400-$600. Vaccines for Children (VFC) may pay for this vaccine if you are eligible. VCF covers children younger than 19 years of age and those eligible for Medicaid. American Indians and Alaska Natives without health insurance are also eligible for VCF. Indian Health Services, Tribal and Urban Indian Programs also may provide free HPV vaccines. Check with your local provider to ask about coverage for the cost of giving the injection and the Native People’s Wellness office visit for all three shots.
Spread the word by:

- Making posters and brochures that are eye-catching and culturally specific, with native languages like Lakota.
- Giving out T-shirts and ribbons at health fairs and other events.
- Posting messages and fact sheets to Facebook and other social media.
- Reach out to the community leaders such as grandparents and elders.
- Have workshops for parents.

Make the vaccine more available by:

- Training Community Health Representatives and health care providers about HPV, the HPV vaccine and side effects.
- Allow more time with patients to discuss HPV and the HPV vaccine.
- Work with schools to better reach students, teachers and parents.
- Provide vaccines at schools and other facilities.

In collaboration with the Northern Plains Area Tribal Chairman’s Health Board, Delf Schmidt-Grimminger works to decrease cervical cancer in Native American communities. As doctor who works with Native American communities, he knows the importance of involving communities in all aspects of research. In a recent project funded by the American Cancer Society, he worked with a Community Advisory Board to better understand why some people do not get the HPV vaccine.

To find out the answer to this question, four groups of people were asked to be in a group discussion. Parents and girls aged 14-18, young adults, and tribal and IHS health care providers talked about HPV, getting the vaccine and better ways to spread the good news about the vaccine.

Parents wanted more information. They were particularly concerned about side effects.

Young adults had a lot of misunderstandings about HPV and talked about the stigma of HPV as a sexually transmitted disease.

Tribal Health Providers wanted more information about HPV, the HPV vaccine and side effects of the vaccine.

IHS providers thought that they needed more time to be with patients and that there were not enough providers.

Everyone had a lot of good ideas for getting the word out about the HPV vaccine.
Kristi Arellano found out about the HPV vaccine by watching a TV commercial. She was glad that her mother was in the room when she watched it. She was glad they saw it together as she might be embarrassed to bring it up. It was good to discuss the vaccine when they had the same information at the same time. “Once we started talking about it, I was like, it would be good to get... to keep yourself safe. She said that her mom is really supportive of what she does. “She [mom] thought it was a good idea and so did I so I got the shot...The shot is just good to have. It prevents a lot of serious disease.”

She didn’t do a lot of reading or research about it. The first time she went to a clinic, the nurse didn’t know about it. Kristi explained the shot to the nurse and that it prevents cancer. The nurse thought it might be a good idea and said she would look into it. They set up another appointment where her mom would also come in.

“When I got the shot it didn’t hurt at all.” She went on to say. “My arm was really sore [later]... because the needle was long. I bruise really easily.” The other two shots were not in the same place and they didn’t really bruise like the first one, she noted. “The first one hurt the most. It wasn’t as bad as I thought it would be.”

She said she would tell her friends, “It would be a really good idea to get it because it helps for in the future that you won’t get sick. It would be really good idea for everyone to have it.”

Kristi did not hear about the vaccine from her friends, school or health care providers. “Nobody ever talks about it but it’s good to have.” “Everybody should get it to stay healthy. Talk to your parents. I’m pretty sure they will understand. . . I have less to worry about compared to other kids so I’m not really worried.”
Cervical Cancer

As with all cancers, there are different types of cervical cancer. The two main cell types in the cervix are stratified squamous and columnar or glandular cells. Squamous cells line the inside of your vagina and the columnar cells line the inside of the uterus (womb). These two cell types meet in a transformation zone of the cervix (see picture below).

Cervical cancer treatment depends on the stage of disease and chance of spread or recurrence. Your healthcare team will make suggestions for treatment based on the latest medical information. Your personal choice for treatment is also very important. The common forms of treatment for cervical cancer are surgery, radiation therapy and chemotherapy. Often more than one treatment will be used. Cure rates are very high when you have early stage disease. When cervical cancer is diagnosed early, you are likely to be cured and live a normal life span.

Staging your Cervical Cancer

Once a diagnosis of cervical cancer is made, your cancer will be “staged.” To “stage” a cancer means that many different tests will be done before suggestions for treatment are made. Staging of cervical cancer is important. Staging lets your healthcare team make the most informed suggestions about what is the best treatment for you. Before treating your cervical cancer, your team will need to know if the cancer is just in the cervix or if it has spread to other places in your body. It is common to have a chest x-ray, lab tests, and a CT scan (or MRI or PET scan). You may have a cystoscopy to look inside your bladder or a proctosigmoidoscopy to look into your rectum and colon. Some women may also have a more thorough pelvic exam under anesthesia. All of these tests are done to show if the disease has spread.

Once these tests are done, your team will know the stage (extent) of your disease. Stage I (one) is the least amount of disease with cancer found only in the cervix and 75-98% of people survive after five years of diagnosis. Stage IV (four) is the most amount of disease spreading to other parts of the body like the lungs or liver with only 5-10% surviving after five years. To see more about cancer staging go to: [www.cancer.org/Cancer/CervicalCancer/DetailedGuide/cervical-cancer-survival](http://www.cancer.org/Cancer/CervicalCancer/DetailedGuide/cervical-cancer-survival)

My doctor told me that I probably got cervical cancer so young because I had been molested as a child. I was only 5. The doctor said that my vagina and cervix tissue were “infantile” and not ready yet for sex. He started doing check-ups on me every 5 years, always with my mother in the room with me. But I got the cancer anyway. It is early stage (in situ) and I should have a normal life and not die from cancer. My traditional Indian healer told me this too, so I believe it! I am happy and I am healthy.
Less Surgery
Especially if caught early, improvements in surgery means smaller cuts, less infection and faster healing. Many surgeries can be done in your doctor’s office!

Robotics!
Some new surgical methods use robotics. This method allows for smaller surgeries and quicker healing times.

Focused Radiation!
New radiation machines put the radiation beam right where it is needed to kill the tumor. Healthy tissue is spared.

Better Combination therapies!
When CAT scanning machines are used with radiation therapy, smaller and smaller areas can be treated with fewer side effects.

New drugs!
New chemotherapy drugs are available that target only tumor cells and have fewer side effects.

More Clinical Trials!
New clinical trials are available that are finding even better ways to treat cervical cancer. Ask your health care provider about whether a clinical trial might be right for you. Trials can be found at: http://clinicaltrials.gov/

For many tribes, the hummingbird is a sign of healing.
The hummingbird below has common methods for treating cervical cancer.

For additional information on cervical cancer treatment and side effects:
Cheyenne River reservation is located in north central South Dakota. This proud reservation has a wonderful website where you can hear running water and singing—just click on the intro at [http://www.sioux.org/](http://www.sioux.org/).

First funded by the CDC in 1994, the Cheyenne River Breast and Cervical Cancer Early Detection program (CR BCCEDP) also known as “Winyan Wicozani” ~ Healthy Women is a leader in reaching Native American women who are rarely or never screened for cancer. According to the CDC website at: [http://www.cdc.gov/cancer/nbccedp/data/summaries/cheyenne_river_sioux.htm](http://www.cdc.gov/cancer/nbccedp/data/summaries/cheyenne_river_sioux.htm), from 2005 to 2010, their program linked 809 women with mammograms and 1,249 who had pap tests annually. Of these women screened, 134 had an abnormal pap test (a 3% age adjusted rate) and 202 had an abnormal mammogram (a 9.2% age adjusted rate). Much of this success has to do sharing and developing model programs. According to Arlene St. John-Black Bird, Program Director/RN-Case Manager for the CRBCCEDP, screening navigators are a best practice. Through funding from the American Cancer Society, the program was able to hire a full-time outreach and education staff person that speaks Lakota fluently. We learned in a research study done in collaboration with CDC and the University of Washington that our rarely to never screened women are more likely to participate in screenings when approached in a more traditional culturally sensitive manner and the screening process is explained to them in our own language. Case management, patient navigation and community education programs are offered to all the women screened through our program including non-Native Americans residing in the two county areas of the Cheyenne River reservation.

In another ACS funded project, their program was able to participate in the “Circle of Life” cancer education curricula for community workshops which are available on the ACS website for all tribes across the nation. Arlene explained that in remote, rural and isolated parts of the country, many people do not know about screening guidelines, the benefits of cancer prevention and early detection. Few know about the progress in cancer treatment that has increased survivorship and care giving at home. There are very few health screening and preventative programs on the reservations to address these issues.

The CR-BCCEDP continues to have challenges in being a very rural and isolated area and is utilizing what they have learned to make the changes necessary to meet the needs of the people that they serve. In the November 2011 the CR-BCCEDP is moving into the new Cheyenne River Health Center which will house all of the local IHS and Tribal Health Programs to provide a more comprehensive health care system. We are working hard to create partnerships to implement lessons learned. “All of our Native communities’ health is at stake more so now than ever. We have known for years what the barriers and access to care issues are and nothing has changed in the last 10 years. The time has come to put into practice what we know will work with what we have. For example, like the contaminated water issues, the research and data is there so why not invest in determining what water filters will work for the given contaminates on the different reservations and invest in the distribution of those water filters.” said Arlene, “We must work together in partnership to act on what we already know by utilizing existing research to build model programs to share and implement what we can instead of waiting for those million dollar projects while the cancer rates continue to increase.”
Idaho’s Comprehensive Cancer Program is hitting cervical cancer and smoking at the same time. They are spreading the word that “Smoking Doubles Your Risk for Cervical Cancer” at events all over the state and through their smoking QuitLine. “These cards are being used several ways. They are distributed at events like rodeos, fairs, races, etc.,” explains Patti Moran, Idaho Comprehensive Cancer Control Program Manager “and through the QuitLine/QuitNet. All contractors for the breast and cervical cancer program (providing mammography and cervical cancer screening) are required to ask clients about their tobacco use. To drive home the message, cervical cancer clients are provided with the QuitLine/QuitNet information or other resources if they smoke, and they are given the “Smoking Doubles Your Risk for Cervical Cancer” information cards. In addition, when any woman calls the QuitLine, they are asked on their intake survey, “Do you know that smoking doubles the risk for cervical cancer (Yes, No, Refuse)?” and, “Have you had a Pap test in the last 3 years (Yes, No, Refuse)?” All QuitLine callers, male and female, are sent the smoking cards with their initial packet of QuitLine materials. “They do not have a system in place to mail packets to female participants only, so the cards go to everyone, which we think is OK since most men will have a women in their life who is important to them and that woman might be a smoker.” Between the QuitLine and the various public events, these little informational cards are making their way across the state to combat smoking and cervical cancer!

For the Idaho QuitNet/QuitLine: [http://idaho.quitnet.com/](http://idaho.quitnet.com/) or 1-800-QUIT NOW (1-800-784-8669)
In 2000, Phyllis Stewart heard that NARA was having a Woman’s Wellness Day and decided to go and find out what was going on. She went and had a pap test and got an appointment for a mammogram. On the day of the mammogram, she knew something was wrong as soon as she saw the face of the radiologist but she was told to go home and that she would get her results later. The very next day the call came telling her to immediately go to the doctor. She had no symptoms and couldn’t even feel the small lump in her breast but it was stage 1 breast cancer. Although she wasn’t surprised because many in her family had cancer including cervical, breast and colon cancer, it was still hard to cope. Going through surgery and radiation were hard but now she is cancer free and working at NARA as the Outpatient Manager. Proud of her Cherokee heritage, she shows it in her art and compassion for NARAs urban Native American clients. “My traditions make me strong so I can be there for others,” she pronounced.

Celebrating their 40th year in 2010, the Native American Rehabilitation Association of the Northwest, In Portland, over 251 different tribal Inc., (NARA) offers a wide range of services targeted for Native Americans living in the Portland metropolitan area as well as the nine tribal nations in Oregon. In Portland, over 251 bands and nations have been served by NARA. To increase awareness of what it means to be from a different tribe, NARA offers cultural competency training regularly to their staff. Although two thirds of NARA staff are Native, all staff benefit from learning more about Native American history and different cultures. “This training brings us together.” Even then, “Asking the patient what they prefer is the best!” said Joan Bacchus, Director of the Women’s Wellness Program.

The NARA Women’s Wellness Program is funded directly from the Centers for Disease Control and Prevention and, like most Breast and Cervical Cancer Early Detection Programs, NARA provides outreach, education and medical testing for women who meet eligibility criteria. NARA is a federally qualified health clinic so they serve women and men of all ages through a range of foundation, state and federal funding including Indian Health Services (IHS). NARA is committed to addressing client issues from a holistic, family perspective.
Susan Anderson, a health care provider at the NARA clinic, talks to parents and teens about HPV and the vaccine. When the vaccine first came out, she notes, a lot of resources were available to promote the vaccine and such resources would be helpful if available today. NARA’s medical chart system tags the files of eligible patients to remind providers to discuss the HPV vaccine at the next patient visit. “Most patients are interested in the vaccine,” she said. “Eventually most patients return for all three shots.” Some parents have asked for the shots for their sons because they do not want their sons giving HPV to their girlfriends. Everyone should be protected!

Despite active outreach activities such as powwows and health fairs over the years, continuing basic health education is necessary and vital. Education for health care providers is also important in order to better serve Native American patients, especially those who have cancer. Often such patients go to the doctor alone and don’t ask any questions. They walk away without really knowing what is going to happen and what they need to do next. The community still has a lot of misconceptions about procedures. Mammograms have a reputation for being painful. If technicians took a few extra steps like warming up the plate and going slowly so that there is less pinching, more patients would recommend health exams over the “moccasin telegraph.” This is why case management and patient navigation are important components of NARA’s services.

Sponsoring events like a Women’s Wellness Day, allows for setting a comfortable pace for health exams and education. On event day, fun activities like arts and crafts makes the community feel at home while waiting for friends and family to complete cancer screenings and other procedures. A taxi company provides transportation to and from Epic Imaging, the mammography center. NARA gives each patient a gift before they leave.

For more information about NARA, visit http://www.naranorthwest.org/homepage_files/Page432.htm
Regional conferences were held in Portland, OR (the Northwest Region) and Omaha, NE (the Northern Plains) as part of Native American Cancer Research Corporation’s (NACR) ongoing CDC cooperative agreement, “Collaborative Partnerships in Cancer Prevention and Control Programs for American Indians” (PI: Seals; 1U57 DP003084). The purpose of the conferences is to strengthen AIAN inclusion in comprehensive cancer control (CCC) efforts and to improve access to cancer screenings and services. Each year, collaborative partnerships are made with American Indian/Alaska Native (AIAN) organizations and communities and with local public health programs. These partnerships plan and implement regional conferences to identify both unique and common issues.

A key feature of the conference is when meeting participants work in groups to create action plans for important issues selected by their group. “The action plans lay the basis for continuing work beyond the conference and many participants were really excited about working with others outside their state,” according to Brenda Seals of NACR. Look at the example that the “green” group created. [note action plan is on the opposite page.]
During the conference, information is presented on cancer data, successful programs and state and local issues. “I think that the networking was really important for conference participants.” said Lisa Harjo of NACR. “Programs in isolated areas do not have information on what is going on in other areas. I’m still getting emails asking for conference information and how to contact other participants and programs.”

My favorite part was the Zumba class that we had in Omaha led by Anne Marie Collingwood, said Brenda Seals. Anne Marie was so enthusiastic that everyone was laughing while exercising and having fun. Some participants came early and stayed late just to do more Zumba. Many reservations have adopted this as a great way to get community members involved in activities.

Dr. Don Warne was my favorite speaker, continued Lisa. “I really learned a lot about health care reform and what applied and did not apply to Indian country.” Take a few minutes to see the video of his talk by going to the NACR CDC conference website.

Find out more about regional conferences in your area at: http://www.natamcancer.org/regional.html
‘We must continue to change the environments that increase food intake and make it hard for people to be active. By doing this, we’re investing in our children and grandchildren.’

In 2002, random community surveys from tribal members of the Fond du Lac Indian Reservation in Northeastern Minnesota indicated little to no exercise, and showed even less knowledge about nutrition. Bonnie LaFromboise, Fond du Lac PHN with assistance from Nate Sandman, Lead Health Educator determined it was essential to increase activity levels and consumption of healthy foods for tribal communities thus, “On the Move!” (OTM) was born. In 2003 the program began with 280 participants and grew to 430 and hosted over 100 presentations one exercise, health and nutrition by 2004.

Today, there are 986 active members! New and exciting exercise classes like the Zumba dance classes, keep the participants coming back for more! While other classes like yoga and water aerobics continue to be the favorites.

Tribal community members sign in at one of the three community center sites; and are encouraged to exercise for 20 minutes which will earn them points to be exchanged for; t-shirts, exercise mats, gym bags, towels and other incentive items once a month.

Movie Review

The beginning was helpful because most everyone has a difficult time pronouncing the virus name and the importance of getting the vaccine. This makes people feel comfortable right away. The Native American music is an attention catcher.

The timing of the slides gave some time to ponder issues. The real stars of the video are those who agreed to be filmed for such a sensitive subject. Everyday teenagers who made the video and the importance of the information come to reality.

Parents need to review the movie first and think about it. If they watch it with their children, they will want to answer questions so it’s best to see it. Some parents may feel that their children are too young to view it.

The education about HPV is sorely needed as many schools do not cover this material. Health care providers may also not bring it up as early as they could.

View it and see what you think! “The health of our nations depends on the sharing of wisdom.”

Video available at:  
http://www.nativeamericanprograms.org/index-circle.html
Painted Feathers by Peg Fennimore

Peg is a sixth generation Eastern Band Cherokee (Tsalagi). The spirits of the animals are inspirations for her unique artwork.

Materials Needed:

Feathers: You can obtain turkey, peacock or other feathers at your local craft store. Feathers that are from some protected species are not legal for general public use. Some tribes have special permissions to use special feathers. If you get feathers from the wild, you may need to treat the feathers prior to use.

Paint: Look for colors you like and get good acrylic paints. Acrylic paints can wash off so you can spray the feather with a clear mat acrylic spray before and after painting.

Hand painting feathers is thought to be an ancient art form to honor the belief among many Native Americans have that the feather is a symbol of communication between people and the Creator. Because feathers do not last, little evidence remains but this art form has been documented back to the early 1800’s.

Painting down the quill (quill painting) takes a steady hand and usually has 6 layers. The detail is then painted on the shape followed by color. Simple shapes have 10 layers of paint with different colors. Full size animals usually have around 40 layers.

I use very small brushes and start by painting the shape in white acrylic paint to fill in the grooves of the feather and put on about 4 or 5 layers.

For a simple design, you can dip a stamp with a pattern into acrylic paint, make sure there are no drips and then lightly press the stamp onto the feather. Practice with paper first!

To hang the feather, you can wrap the top of the quill in cotton thread with a loop at the top. If you use red thread, this represents “The Red Road”. To make the feather fancier you can add a small amount of fur beneath the red thread or attach the feather to a dream catcher. You can use Tacky Glue. It dries in a couple of hours.

Cancer support groups enjoy making feathers for family, friends and as donations to benefit cancer survivors.

It is said that, “When you are creating something, is when you are the closest to God.”
Cervical Health Terms
Definitions of words you may hear from healthcare providers

Biopsy (BY-op-see): A piece of tissue or group of cells is removed from the growth or cyst. These cells are examined by a pathologist. A biopsy is the best way to make a diagnosis.

Brachytherapy (BRAY-kee-THAYR-uh-pee): A type of radiation therapy in which radioactive material is placed right into or near a tumor. The material is sealed in needles, seeds, wires, capsules or catheters. It is also called internal radiation.

Cervical cancer (SER-vih-kul Kan-ser): Cancer (malignant (ma-LIG-nant) cells) that is found in the cervix. The cervix sits between the womb and the vagina (birth canal); NOTE: Cancer of the womb (uterus / endometrium (EN-doh-MEE-tree-ulm) is not the same as cervical cancer.

Cervical biopsy: A cervical biopsy removes a small piece of the cervix so the tissue/cells can be examined under a microscope.

Chemotherapy (KEE-moh-THAYR-uh-pee): Treatment with drugs that kill cancer cells. It is generally used when there is a high risk for the cancer coming back or for those with more advanced disease. Drugs are usually given into a vein (IV; intravenously)

Clinical Trial: Research that tests how well a new method of screening, prevention, diagnosis, treatment, or a supportive/comfort care measure works in people.

Colposcopy (kol-POS-koh-pee): Examination of the vagina and cervix using a lighted magnifying instrument called a colposcope (KOL-poh-SKOPE).

Cone biopsy: Surgery that removes a cone-shaped piece of tissue from the cervix and cervical canal. Cone biopsy may be used to diagnose or treat a cervical condition. Also called conization (kone-ih-ZAY-shun).

Cryosurgery (CRY-o-SER-juh-ree): A procedure performed with an instrument that freezes and destroys abnormal tissues. Liquid nitrogen or liquid carbon dioxide may be used.

CT scan: (Computerized Axial Tomography or CAT Scan) Detailed pictures of the inside of the body. Pictures are created by a computer linked to an x-ray machine. They are taken from different angles. Also called known as computerized tomography (toe-MOG-rah-fee).

Cystoscopy (siss-TOSS-koh-pee): The process of looking into the bladder and urethra with a cystoscope (siss-TOE-skope). A cystoscope is a thin, tube-like instrument. It has a light and a lens for viewing a tool to remove tissue.

Diagnosis (die-egg-NOH-sis): The process of finding if the symptoms or evidence of cancer is really cancer.

Dysplasia (dis-PLAY-zhuh): cells that look abnormal under a microscope but are not cancer.

Human Papillomavirus (HPV): A contagious virus that causes abnormal growths such as genital warts; HPV is spread through sexual and skin-to-skin contact. There are many different types of HPV. Certain types of HPV cause genital warts and cervical cancer. HPV may cause other types of cancer (anal, vaginal) as well.

Human Papillomavirus Vaccine: A vaccine that helps prevent 70+% of cervical cancer. Three doses of the HPV vaccine need to be taken over a 6 month period to complete the vaccine series. It works best before a girl (or boy) is sexually active. It is not a cure-all.
Cervical Health Terms
Definitions of words you may hear from healthcare providers

**In situ (in-SIGH-two):** The cancer cells have not spread to neighboring tissue

**LEEP / LOOP excision (ek-SI-zhun):** Loop electrosurgical excision procedure. A technique that uses electric current passed through a thin wire loop to remove abnormal tissue.

**Metastasis (meh-TAS-ta-sis):** The process by which cancer cells spread from one body part to another or from the primary site to other organs by traveling through the blood vessels or lymph vessels.

**Oncologist (on-KOL-o-jist):** A doctor who specializes in treating cancer. Some oncologists specialize in a particular type of cancer treatment. For example, a radiation oncologist specializes in treating cancer with radiation.

**Pathologist (pa-THOL-o-jist):** A doctor who studies tissues and cells to identify disease.

**Pap Test:** A test done during a pelvic examination by a trained provider. It can be done in a health clinic or medical screening van. It is usually done as part of a pelvic exam. Cells are scraped from the cervix for examination under a microscope. It is used to detect cancer and changes that may lead to cancer. A Pap test can also show noncancerous conditions, such as infection or inflammation.

**Pelvic Exam:** During a pelvic exam the health care provider looks at and feels the organs around your cervix to make sure their shape and size is normal.

**Precancerous (pre-KAN-ser-us):** Cells/tissue that is not yet malignant, but is likely to become malignant over time if left untreated.

**Radiation (ray-dee-AY-shun):** Energy released in the form of particles or electromagnetic waves. Common sources of radiation include radon gas, cosmic rays from outer space, and medical x-rays.

**Radiation Therapy:** May be used for both early and late stage disease or for those who are unable to have surgery. May include an external source (external beam) or an internal radioactive source (brachytherapy).

**Radical trachelectomy (TRAY-kul-ek-toe-me):** Surgery that removes the cervix and the pelvic lymph nodes but keeps the uterus. This allows for future pregnancies. The lower end of the womb is closed with sutures. A c-section is used for childbirth.

**Speculum (SPEK-yoo-lum):** Used to widen a body opening (such as the vagina) to make it easier to look inside.

**Surgery for Cervical Cancer:** Usually used for early stage disease; may include removal of the cervix, uterus, ovaries, fallopian tubes and upper part of the vagina.

**Tumor (TOO-mer):** A mass or growth of cells that multiply more than they should or do not die as they should. These cells form a mass of tissue, called a tumor.

  - A benign (BEE-nine) tumor is not cancer and it does not become cancer. Most (8 out of 10) tumors are not cancer (they are benign)
  - A malignant [ma-LIG-nant] tumor is cancer and can spread to other parts of the body

**Ultrasound (UL-tra-sound):** High-energy sound waves (ultrasound) are bounced off internal tissues or organs and make echoes. The echo patterns are shown on the screen, forming a picture of body tissues called a sonogram. Also called ultrasonography (UL-tra-son-OG-ra-fee).
Tribal and Urban Native Breast and Cervical Program Contacts 2011

Screening For Life, Breast & Cervical Cancer Screening Program

Arctic Slope Native Association
P.O. Box 29; Wellness Center Barrow, Alaska 99723 Phone: 907-852-5881 www.arcticslope.org

Summary of services: Breast and cervical cancer screening is offered in Barrow and five surrounding villages. Air transportation is provided from these rural villages for mammography clinics in Barrow, which are held four to five times a year. A mid-level provider goes to each village two times a year to provide annual exams, including pap smears. Follow-up care and re-screening is done as needed in Barrow or in the Native villages. Colposcopy and diagnostic services are also provided in Barrow.

Cherokee Nation Breast and Cervical Cancer Early Detection Program

Cherokee Nation Health Services
1200 W. 4th Street, Suite C Tahlequah, OK 74465 Phone: 918-458-4491 www.cherokee.org

Summary of services: Appointments are offered for clinical breast exams, mammograms, pap tests and one-on-one patient education on breast and cervical cancer and breast self examination techniques. The program provides breast and cervical cancer screening for uninsured, income-eligible Indian women at ten screening sites throughout and around the 14-county Cherokee Nation Tribal Jurisdictional Service Area in Northeastern Oklahoma.

Hopi Women’s Health Program

Hopi Tribal Complex
P.O. Box 123 Kykotsmovi, AZ 86039 Phone: (928) 734-1150 www.hopi-nsn.gov

Summary of services: Breast and cervical cancer screening services are offered to Native women living on and near the Hopi Indian Reservation at the Hopi Health Care Center and Tuba City Indian Medical Center. The program contracts with Mobile On-site Mammography stationed out of Tempe, Arizona for mammography services, which is offered every other month. Transportation is provided to those who qualify through the program. Other services include one-on-one patient education, community education, recruitment, and support services.

Kaw Nation Women’s Health Program

Kaw Nation
3151 E. River Road Newkirk, OK 74647-0474 Phone: 580-362-1039 x 207 http://kawnation.com/?page_id=2278=

Summary of services: Services are provided to women at five clinics, seven tribes, in a seven county area in North Central Oklahoma. Our staff attends health fairs and other special events in the area to outreach to women that are eligible for the program.

The Native Women’s Wellness Program

South Puget Intertribal Planning Agency (SPIPA)
3104 Old Olympic Highway Shelton, WA 98584 Phone: 360-426-3990 x 3221 www.spipa.org

Summary of services: The program works to reduce breast and cervical cancer mortality among Native American women of the Chehalis, Nisqually, Shoalwater Bay, Skokomish, Quinault and Squaxin Island Tribes through culturally appropriate outreach, education, screening, and diagnostic services. The program provides no-cost mammograms, clinical breast examinations, pelvic exams, and Pap tests to low-income Native American women living in the six tribal communities. The program also offers a variety of educational activities as part of our effort to promote early detection and treatment of breast and cervical cancers.

NARA Indian Health Clinic Women’s Wellness Program

NARA Indian Health Clinic
15 N. Morris Portland, OR 97227 503-230-9875 www.naranorthwest.org

Summary of services: We provide breast and cervical cancer screenings to Native women, residing in and around Portland, OR, who are under-served, uninsured, under-insured, never screened, rarely screened, and at-risk. Native women are treated with respect and cultural sensitivity. Our program is committed to honoring and respecting our families, communities, and Mother Earth. We advocate early detection, prevention, and yearly screenings; honoring diversity, and celebrating life.
Tribal and Urban Native Breast and Cervical Program Contacts 2011

Navajo Nation Breast and Cervical Cancer Prevention Program
P.O. Box 1390
Window Rock, Arizona, 86515
Phone: 928-871-6249; 928-871-6923
www.ihs.gov/medicalprograms

Summary of services: The Navajo Nation Breast and Cervical Cancer Prevention Program provides mammography screening services to older, low income women who are either uninsured or under-insured. Screening women 50-64 for mammogram and 40-64 for cervical cancer and high-risk women per Provider’s approval. The NNBCCPP is also responsible for providing case management for abnormal findings. Other services provided are One-on-One Patient Education/Teaching, Referrals for Mammogram Screening, Contract Health Safe Ride Services, Community Outreach Education, and Community Health Fairs.

Poarch Band of Creek Indians
Women’s Wellness Program
5811 Jack Springs Road
Atmore, Alabama 36502
Phone: 251-368-8630

Summary of services: The program provides a “One-Stop Shopping” concept of women’s health at the tribal health department. Clinical examinations are done by tribal providers. Mammogram screenings are provided by a visiting mobile unit. Referral for diagnosis and/or treatment is done through contracted specialists. Small interactive groups offer health education with each clinic visit.

SouthEast Alaska Regional Health Consortium (SEARHC) Breast and Cervical Health Program
222 Tongass Drive
Sitka, Alaska 99835
Phone: 907-966-8782 / Toll free: 1-888-388-8782
www.searhc.org/womenshealth

Summary of services: Our goal is to increase the education, outreach and breast and cervical cancer screening of Alaska Native women and uninsured/under insured non-Native women living in Southeast Alaska communities, and to find cancer at its earliest and most treatable stage. We have eight screening sites that have either on-site mammography or that receive visits from the mobile mammography unit as well as cervical screening services.

Southcentral Foundation (SCF)
Breast and Cervical Health
4105 Tudor Center Dr. #200
Anchorage, AK 99508
Phone: 907-729-8891
www.southcentralfoundation.com

Summary of services: The program provides screening services (mammograms, clinical breast exams, pap smears) to Native women in Alaska ages 40-64. It offers ongoing one-on-one and group client education, focusing on breast and cervical cancer awareness, risk factors, and the benefits of early screening. It also provides tracking, follow-up and case management services, public education and outreach services, and professional development opportunities. We work closely as part of the Alaska Breast and Cervical Health Partnership with the four other NBCCEDP programs funded in the State of Alaska to provide seamless delivery of services to Alaskan women.

Women’s Health Program
Yukon-Kuskokwim Health Corporation
P.O. Box 287,
Bethel, Alaska, 99559
Phone: 907-543-6696; 543-6296
www.ykhc.org

Summary of Services: Our program offers breast and cervical health screening services for 50 villages throughout the Yukon-Kuskokwim Delta in Southwest Alaska. Our service area spans 20 million acres and is approximately the size of the state of Oregon.
A Night of Dance

Country line dancing, the Electric Slide, Salsa and Macarena dancing kicked off the May 4th, 2011 “Night of Dance” sponsored by H.O.R.I. Cancer Support Services, the Hopi Special Diabetes Program and the Wellness Center. The Power Fitness Night was held in conjunction with the 10th Annual National Women’s Health Week and is part of an ongoing fitness program to improve health and decrease cancer risks.

Both men and women wore special pink shirts to celebrate Women’s Health Week and their theme, “Empowering Women to Stay Healthy: It’s your time.” They decorated “masanpi’s” or paper plates with messages about what it takes to be healthy. Men decorated headbands with their statements to encourage healthy activity.

The event finished with Tewa Yah nee wah Dancing, Hopi style Mexican Dancing, the Cupid Shuffle and the Cha Cha Slide.

Other events included a “Clan Run” and “Women’s Expo.” The one and two-mile walk/run was held in Kykotsmovi. Nada Talayumptewa, Hopi Tribal Council Representative, welcomed the runners. Participants carried clan symbols to recognize special women in their lives. Runners were given carnations to give to the women they were honoring.

The Expo included arts, crafts and educational booths in addition to activities such as a theatrical program and addresses. Susie Vanderlip, CPAE, CSP from the Legacy of Hope presented a show illustrating some of life’s serious concerns and a “De-Stress for Success!” program.