

*Native People's*

# wellness

CERVIX HEALTH, CANCER  
PREVENTION, DETECTION,  
AND CARE





## Rosanne Wyman

*diagnosed with cervix cancer in 1987. She passed February 2009 due to complications from her cancer treatment (22 year survivor).*

**R**osanne created “Miles to Go”, a Canadian Aboriginal cancer education and support organization in the 1990s. She lived on both sides of the US/Canada border. She was an active member of Native American Cancer Research Corporation (NACR) “Native American Cancer Education for Survivors” (NACES) program. She was on the cover of CR Magazine in 2007. She was always positive, caring and supportive to others. She is included in video vignettes on the NACES website ([http://www.natamcancer.org/vignettes/vignettes.html#w\\_text](http://www.natamcancer.org/vignettes/vignettes.html#w_text)), both her words and voice. She is the voice for the “communication” leaf on the NACES tree, called “I Messages”.

Rosanne was an advocate for anyone diagnosed with cancer. I recall observing her talking with a young 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, while talking with her 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. ”

# wellness

CERVIX HEALTH, CANCER PREVENTION, DETECTION AND CARE

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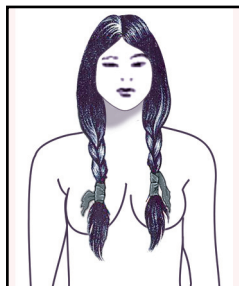
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September 2011



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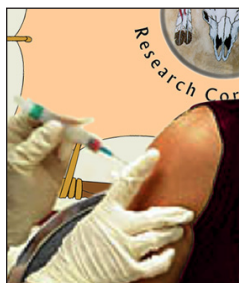
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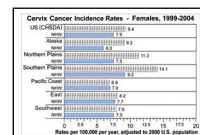


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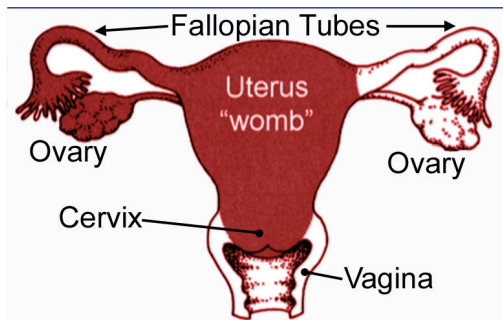
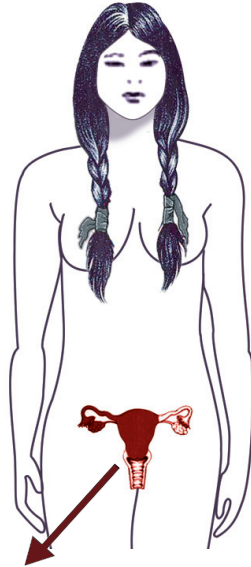
Cervix cancer survivor of 33 years, Maxine Brings-Him-Back Janice Oglala Lakota

# “What is my cervix and why do I care if it’s healthy?”

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.

## Anatomy

- The uterus is located below your stomach.
- The cervix is located in the lower portion of the womb.
- The cervix opens into the vagina which leads to the outside of the body.



## What is cervix 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 cervix or cervical cancer.

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

## What “causes” cervix 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 cervix cancer. (This booklet describes HPV on page zz).

## What are the risks?

“Risk Factors” are behaviors that increase your chances of getting cancer. Exposure to infection or tobacco smoke can also be a risk. Risks that “damage” the shield of health are shown as holes in the shield. Risks for cervix cancer include having HPV infection. If a woman or if her sexual partner has sex with other people, her risks for getting HPV increase. Habitual use of manufactured tobacco is another risk.

## Cancer risks that “damage” her shield of protection include:

1. Early Age At First Intercourse (16 Years Old Or Younger)
2. More Than 5 Different Sexual Partners In Your Whole Life
3. Having Sex With Partners Who Have Had Many Sexual Partners
4. Sexually Transmitted Diseases (HPV -Human Papilloma Virus) Which May Also Cause Genital Warts
5. Herpes Virus
6. HIV Infection
7. Exposure To Cigarette Smoke (Smoking And Second Hand Smoke)
8. Giving Birth To More Than 7 Children
9. Long Term Use Of Oral Contraceptives
10. Diets Low In Carotene, Vitamins C And E
11. Not getting regularly screened with a Pap test
12. Not getting all 3 HPV vaccine shots













# Excuse me. You want me to do **WHAT???** **WHY?**

## 9 things YOU can do to reduce your risk.

- 1 Get the HPV vaccine (all 3 shots in 6 months)
- 2 Delay first intercourse until you are 16 years old or older.
- 3 Have fewer than 5 different sexual partners in your whole life.
- 4 Only have sex with partners who have not had very many sexual partners.
- 5 Avoid sexually transmitted diseases and use condoms:
  - a. HPV (human papilloma virus) may cause genital warts as well as cervix cancer.
  - b. Herpes virus.
  - c. HIV infection.
- 6 Avoid exposure to cigarette smoke (smoking and second hand smoke).
- 7 Give birth to less than 8 children.
- 8 Limit long-term use (5 or more years of use) of oral contraceptives.
- 9 Have a diet high in colorful fruits and vegetables (possibly protective).

Cervix cancer is preventable  
Early detection is important

## Quick Facts about Cervix Cancer

-  In women under 45, cervix cancer is the 2nd most common cancer.
-  American Indian women get cervix cancer more than twice as often as other women.
-  More American Indian women die from cervix cancer than other women.
-  AIAN women are more likely to be diagnosed with later stage disease.<sup>1</sup>
-  AIAN women aged  $\geq 65$  years had more cervix cancer diagnosed in comparison with Non-Hispanic White women (85% higher for elder 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.<sup>2</sup>
-  Regular Pap tests can find changes in the cervix.
-  Rates of invasive cervix 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.<sup>3</sup>
-  Cervix cancer is preventable and curable.
-  No woman should die from cervix cancer.

(1) Becker, Thomas M, Espey, David K, Lawson, Herschel W, et al. Regional Differences in Cervical Cancer Incidence among American Indians and Alaska Natives. Cancer 2008; 113 (5 suppl): 1234-43 DOI 10.1002/cncr.23736, p 1234 (2) Becker, p. 1237 (3) Becker, p. 1238

## What is a Pap test?

The Pap test is an early warning system for cancer in the cervix. Pap tests tell if you have abnormal cells or cervix cancer. Cervix cancer is easy to cure when found early. A trained healthcare provider does a Pap test during a pelvic exam. You can have this test in a health clinic or screening van. 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 plastic 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 outside the clinic. The lab staff sends a report back to your provider. The report explains if the cells are normal or if more tests are needed.

*I always wondered about that ...*

## Can't the doctor see if I have cancer when they do a pelvic exam?

No, a pelvic exam does not test for cancer. The pelvic exam lets the provider look at your cervix and feel your ovaries and uterus (womb). The Pap test is different. A provider does a Pap test during your pelvic exam to check for abnormal cells or cancer. If you're not sure whether your pelvic exam includes a Pap test, ask your doctor or nurse.<sup>1</sup>






## I am so embarrassed to have this test! Is it really THAT important?

### 3 Reasons why it is important to have a Pap test:

1. It can save your life by finding abnormal cells before they become cancer.
2. You can show your daughters how a well woman behaves.
3. It can find HPV (if you request the test) that causes some cervix cancer and genital warts.

## What should I do to get ready for my Pap Test?<sup>2 3</sup>

Having an accurate Pap Test is important. Sometimes a Pap Test may not find abnormal cells even when they are there. You can help make your Pap Test more accurate by not scheduling your Pap Test for when you have your period (moon). In addition, for the two days before your Pap Test, you should **not**:

-  Have sex
-  Use birth control foams, jellies or creams
-  Use any medicines or creams in your vagina (birth canal) unless ordered by your healthcare provider
-  Use a tampon
-  Douche (rinse the vagina) with any type of fluid (even water)

(1)[http://www.ashastd.org/hpv/hpv\\_learn\\_dysplasia.cfm](http://www.ashastd.org/hpv/hpv_learn_dysplasia.cfm) cited on 05-20-2011 (2)The Pap Test. Retrieved from [http://www.acog.org/publications/patient\\_education/bp085.cfm?p...](http://www.acog.org/publications/patient_education/bp085.cfm?p...)  
(3)Cervical Cancer Screening. Retrieved from [http://www.cdc.gov/cancer/cervical/basic\\_info/screening.htm](http://www.cdc.gov/cancer/cervical/basic_info/screening.htm)



## 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.<sup>4</sup> Fewer Natives (78%) have Pap tests as compared to Non-Natives (84%).<sup>5</sup>

## How often should I have a Pap test?

Females need to begin having Pap tests when they become sexually active or by age 21. 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. Older women need Pap tests at least until they are 65. This includes women who have gone through the change of life (menopause [(MEN-uh-pawz)]). Your provider may recommend less frequent tests (every 3 years) if:

You have had 3 “normal” Pap tests in a row within the most recent 5-year period.

You have had a recent HPV test in combination with a Pap test and both are normal.

## 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.

## What if I have had a hysterectomy (hiss-ter-EK-toe-mee)?

Today, most women who have a hysterectomy have their cervix removed during surgery. This was not as common 30 years ago. If you do not know if your cervix was removed when you had a hysterectomy, you will need a pelvic exam to find out. If you do not have a cervix, you do not need a Pap. However, if you had a hysterectomy because of a pre-cancerous or cancer diagnosis, you may still need to have a Pap.

## What does it mean if I have an abnormal Pap test?

This means that the cells removed from your cervix during your Pap test are not normal. This can be due to an infection, cervix cancer or other cause. Your provider may do further tests to find out why the cells are abnormal. These may be a colposcopy, biopsy, or a repeat Pap test. The provider also may suggest you have an HPV-DNA test.<sup>6</sup> 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.

(4)CDC [www.CDC.gov/cancer/cervix/statistics/screening.htm](http://www.CDC.gov/cancer/cervix/statistics/screening.htm) accessed 6-14-2011 (5)ref 2 Steele 2008, p1136 (6)Table modified from <http://www.webmd.com/hw-popup/comparing-classification-systems-for-abnormal-pap-tests> cited on 05-20-2011

**Table 1.**

Classification systems for abnormal Pap test			
World Health Organization Dysplasia System	Cervical Intraepithelial Neoplasia (CIN)	The Bethesda System (commonly used today)	What do I do next?
Normal (benign)	Normal (benign)	Normal (benign)	Routine follow-up (every 1-3 years as recommended by your provider)
Benign with inflammation	Not reported in CIN	Infection and atypical squamous cells (ASC), which includes ASC of undetermined significance (ASC-US) and ASC that cannot exclude high-grade squamous intraepithelial lesions (HSIL) (ASC-H)	If infection, treat and follow-up per provider recommendations; repeat Pap in 1 year. HPV test. If cannot exclude HSIL (ASC-H) – immediate colposcopy
Dysplasia (mild)	CIN 1	Low-grade squamous intraepithelial lesions (LSIL)	Colposcopy
Dysplasia (moderate to severe)	CIN 2, CIN 3	High-grade squamous intraepithelial lesions (HSIL)	Colposcopy within 6 weeks
Invasive cancer	Invasive cancer	Squamous cell cancer (or any of the other types of cervical cancer)	Referral to gynecologic oncologist for further evaluation and treatment depending on age, stage of disease, overall health

## **Maxine Brings-Him-Back Janis**

excerpts from interview June 21, 2011

Oglala Lakota, Born and raised on Pine Ridge reservation in SD

Diagnosed with cervix cancer in situ in 1978; (diagnosed with breast cancer in 2002)



### **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 cervix in situ, the physician gave me the option to have a hysterectomy. Well, I wanted to have another child. I have 2 sons and I wanted another child and I wondered what were the implications..... of this diagnosis. According to the physician I could have a pregnancy and [the baby would] not be affected ... [by] the cancer diagnosis. So I had a pregnancy. So I waited until I delivered a child in 1980...[and] immediately after that I had a hysterectomy ... so I still have my ovaries, but don't have my uterus [or cervix].

So, in answer to the question, how it affected me personally, at the time I was young and I didn't really have the full scope of knowledge of you know 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]

(8) Abnormal Pap Test from <http://www.youngwomenshealth.org/abpap.html> retrieved on July 9, 2011 (9) Understanding cervical changes: A health guide for women. Retrieved from <http://www.cancer.gov/cancertopics/understandingcervicalchanges/page1> retrieved on May 20, 2011



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 as well. 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, which is critical even amongst unwanted health related challenges. I believe healing comes from being engaged with positive people, they can become actual 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.

## Early Menopause

I was told that I would have early menopause and the side effects of early menopause have stayed with me for years ... the hot flashes ... the sweating at night. I don't know when the transition happened from the hysterectomy to the change of life. For me it was ongoing. The triggers were often times stressed related. Then I took Hormone Replacement Therapy, following the hysterectomy ... to try to manage the hormonal rise and fall of being a woman ... until I was diagnosed with breast cancer (2002). The breast cancer could have been caused by HRT ... It was an estrogen positive tumor... so I got off the HRT.

## 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.



There is a relationship between cervix cancer and sexual abuse, but we cannot assume that most young women who are diagnosed with cervix cancer were victims of such abuse. That doesn't apply to everybody. We need to not be so quick to judge one another.



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.



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 handed and just ...easy to say, but take the next path, remember we make our road by walking.



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 ...



Although I place value of Western Medical treatment, I also value the immense role traditional medicine holds for tribal people.

## 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 suspend judgment and just address the issue of HPV and how it affects the cervix and the person. 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. It could be related to the partner. 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.

One of the things that really keeps me grounded is the spirituality piece of who I am. The spirit of who Maxine is related to the Creator. My daily walk is always based on asking myself a question, "Maxine, what is your legacy going to be?" I ask myself that question all the time and I try to live by that in the context of everything I do--even my bad moments even when I am not so pleased with someone. "What is your legacy going to be? How is what you are doing today going to affect you 2 years from now?" and usually it won't ... so I let it go.

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.

# HPV and Cervix Cancer

## What is Human Papillomavirus (HPV)?

HPV is a very contagious virus. It is easily spread by skin-to-skin contact from an infected person during sexual intimacy. There are more than 100 different types of HPV. Only about 15 types cause cervix cancer. Most of the time, HPV goes away by itself within 2 years and does not cause health problems. 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).

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. Only HPV infection that does not go away over many years can lead to cervical cancer.<sup>1 2</sup> In addition to leading to cervix cancer, HPV can cause cancer of the vagina, vulva, penis, anus, mouth and throat.<sup>3</sup>

## What is an HPV test and why does my doctor want to do one?

The HPV-DNA test can tell your provider if you are at risk for cervix cancer. Some types of HPV cause cervix 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.<sup>4</sup>

## Why do providers talk about different types of HPV?

Fifteen of the more than 100 HPV types cause cervix cancer. Most cervix cancer has HPV types 16 and 18. Both of the HPV vaccines include HPV types 16 and 18. About 30% of Northern Plains American Indian women with cervix cancer have HPV, but NOT types 16 and 18. The HPV vaccine can get rid of most cervix cancer, but not all. Females still need to practice good health behaviors to prevent cervix cancer.

## Can HPV infections be treated?

There is currently no 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.

## Can men be screened for HPV?

A provider does physical exam of men to check for sores or warts. There is no specific way to test directly for HPV in men. Researchers are looking for ways to better screen men.<sup>5</sup> 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.

## What about partners?

Most sexually active couples 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.

(1) updated 05-20-2011 from <http://www.cancer.cdc.gov/std/hpv/sdtfact-hpv-and-men.htm> (2) updated 05-20-2011 from <http://www.ashastd.org> (3) <http://www.cancer.cdc.gov/std/hpv/sdtfact-hpv-and-men.htm> cited on 05-20-2011 (4) [ref 4 <http://women.webmd.com/tc/abnormal-pap-test-exams-and-tests>] (5) <http://www.ashastd.org/pdfs/menandHPV.pdf> 05-20-2011

## What if I get a positive HPV test result?

A positive test result means you have HPV. It does not mean you will get cervix 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.

## What about the HPV Vaccine?

### What is the HPV Vaccine?

The HPV vaccine helps to prevent the majority of cervix cancers. To gain the full effect of the vaccine, you need to have 3 shots within 6 months. 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 3 shots cost \$400-\$600. One vaccine (Gardasil) can also prevent up to 90% of genital warts.

### If I have the vaccine, why do I still need a Pap test?

The HPV vaccine is not 100% effective in preventing cervix cancer. HPV is not the only cause of cervix 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.

### Why does my daughter need to have so many shots for the vaccine?

One shot is not enough. To be effective, 3 doses of the vaccine within 6 months are needed.

### What can my daughter do to make the shot less uncomfortable?

The provider will usually give the shot in your child's arm.

Ask your provider about ways to make the shot more comfortable

Three 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. Thirty minutes before the shot, take an over-the-counter pain relievers (aspirin, ibuprofen, acetaminophen, Naprosyn)



## How can I afford to pay for the vaccine?

Vaccines for Children (VFC) pays for this vaccine. VCF includes children younger than 19 years of age and those eligible for Medicaid. American Indians and Alaska Natives without health insurance are also eligible. IHS is not insurance. IHS, Tribal and Urban Indian Programs also may provide free HPV vaccines.<sup>6</sup> When checking with the local programs about VCF support, please note that the cost of giving the injection may not be covered nor will a general office visit (may be free, may not depending on who the provider is/site for obtaining the vaccine series).

(6) [www.cdc.gov/vaccines/programs/vfc](http://www.cdc.gov/vaccines/programs/vfc)

## A Northern Plains HPV Vaccine Project.

In 2009 the American Cancer Society funded a 2-year project to increase HPV vaccine use among Northern Plains American Indians. The project team conducted 4 focus groups with 69 participants to learn their opinions and obtain their guidance. The participants included tribal health providers, Indian Health Service providers, young adult women ages 19-26, and girls (14-18) with a parent. These individuals were also asked to complete a survey, which a total of 60 completed. About 75% of parents and over 90% of young adults had at least heard of HPV, but only 50% of teens had heard of it. Specific knowledge was low in all groups. For example, only 31.3% of parents, 40.9% of young adults, and 14.3% of teens were aware of the connection between HPV and warts. Parents and young adults were more knowledgeable that HPV causes cervical cancer (68.8% of parents and 86.4% of young adults), but only 28.6% of teens knew of this connection. There was also less awareness that HPV is spread by sexual contact; 43.8% of parents, 54.4% of young adults, and 42.9% of teens correctly identifying this connection.

Table 1. Major Focus Group Themes

Parents/Teens Themes	Young Adult Themes
<ul style="list-style-type: none"> <li>⊕ Parents want more information</li> <li>⊕ Some young women have had vaccine</li> <li>⊕ Barriers included concern for side effects and the vaccine causing cancer</li> <li>⊕ State Health Department and Providers play an important role</li> <li>⊕ School-based programs are suggested for increase HPV Vaccination</li> </ul>	<ul style="list-style-type: none"> <li>⊕ Some young women have had vaccine</li> <li>⊕ HPV is familiar but there are misunderstandings and stigma associated with it</li> <li>⊕ Information sources included clinics, providers, mothers, and relatives</li> <li>⊕ School-based programs are suggested for increase HPV Vaccination</li> <li>⊕ Community-wide education and events are suggested to increase HPV Vaccination</li> </ul>
Tribal Health Providers	IHS Providers
<ul style="list-style-type: none"> <li>⊕ Tribal Health Programs are aware but do not fully understand HPV</li> <li>⊕ Tribal Health Programs want more information so they can better educate the community</li> <li>⊕ Parents can be a barrier, including fathers, due to the sexual connotations</li> <li>⊕ School-based programs are suggested for increase HPV Vaccination</li> <li>⊕ Community-wide education and events are suggested to increase HPV Vaccination</li> </ul>	<ul style="list-style-type: none"> <li>⊕ Perception that abnormal Paps and HPV is not at higher rate than general population in their community</li> <li>⊕ Parents can be a barrier, including fathers, due to the sexual connotations</li> <li>⊕ Clinic barriers also exist such as lack of time, provider shortage, etc.</li> <li>⊕ Some activity is being done for HPV Vaccination but not systematically being addressed</li> </ul>

### Recommendations for Interventions Included, but were not limited to:

1. Good Health TV (a TV system in IHS clinic waiting rooms that could play educational videos and promote community events/activities)
2. Eye-catching and culturally specific posters and brochures
3. T-shirts and ribbons about HPV given at health fair to raise awareness
4. School health education
5. CHR and nurses to visit and educate various communities
6. CHR and nurses to visit college dorms to education young adults
7. Create educational materials in Lakota
8. Reaching out to grandparents/elders for opinion leaders
9. Provide information on HPV to parents at school registration
10. Provide vaccination clinic at school
11. Utilize Facebook and other social media for youth awareness/education
12. Provide In-service sessions at clinics for healthcare providers on HPV
13. Providers to provide more counseling on HPV to parents

**For more information** or how to become involved with new HPV vaccine programs, please contact: Delf Schmidt-Grimminger, MD, Associate Professor, Sanford School of Medicine, University of South Dakota, Department of Obstetrics & Gynecology, 1400 West 22nd Street Sioux Falls, SD 57105; Tel 605-357-1526



## ***ON THE MOVE***

*'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.

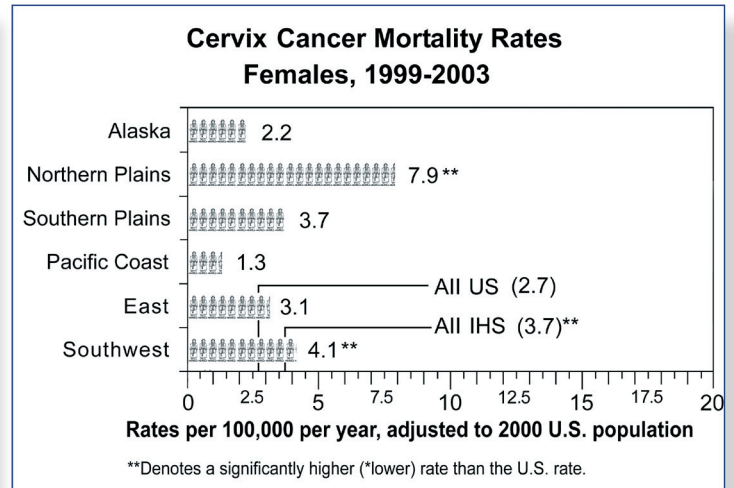
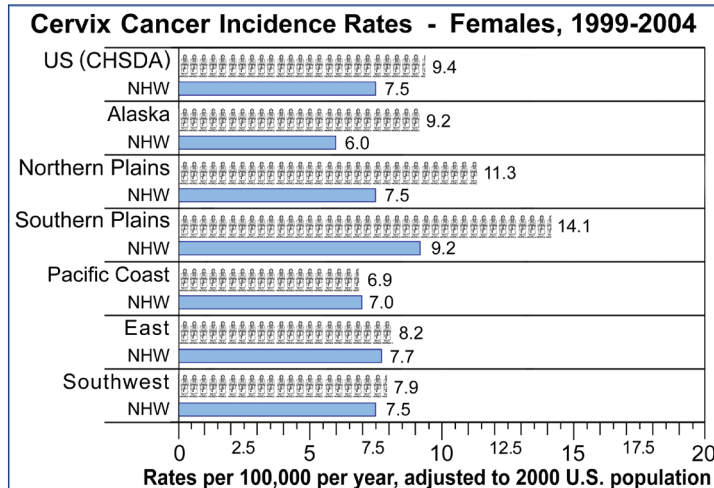


***Physical activity make it part of our daily***

# American Indian / Alaska Native Cervix Cancer Statistics

## 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.



Espey, David K; Xiao-Chen; Swan Judith; Charles; Jim; Melissa A; Ward, Elizabeth; Howe, Holly L.; Ries, Lynn A.G.; Miller, Barry A.; Jemal, Ahmedin; Ahmed, Faruque; Cobb, Nathaniel; Kaur, Judith S.; and Edwards, Brenda K. Annual Report to the Nation on the Status of Cancer, 1975-2004, Featuring Cancer in American Indians and Alaska Natives. Cancer [American Cancer Society]; 2007 [11-15-07]; Volume 110: No. 10. GRAPHS MODIFIED BY: Rick Clark, Native American Cancer Research

Haverkamp D, Espey D, Paisano R, Cobb N. *Cancer Mortality Among American Indians and Alaska Natives: Regional Differences, 1999-2003*. Indian Health Service, Rockville, MD, February 2008. GRAPHS MODIFIED BY: Rick Clark, Native American Cancer Research (note horizontal grid)

## 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?

- Cervix cancer is more common among AIANs than it is within Non-Hispanic White women
- American Indian women from the Southern and Northern Plains have more cervix cancer in comparison with Native women living elsewhere.
- There is little variation in cervix cancer among Non-Hispanic White women regardless of the region where they live
- There is great variability among AIANs by geographic regions (see how few AIs living on the Pacific Coast have cervix cancer as compared to AIs from the Southern Plains)
- AIAN women as a group, are younger at time of diagnosis in comparison with Non-Hispanic White women (mean age for AIANs was 47.3 versus 50.1 years for Non-Hispanic White women).

# Treating Cervix Cancer

Cervix 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 cervix 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 (see Table 1). When cervix cancer is diagnosed early, you are likely to be cured and live a normal life span.

As with all cancers, there are different types of cervix cancer. Each organ (like your breast or your liver) has different types



Sarah S. Allman  
[Oglala Sioux]  
Dx 1970 Cervix

of cells. 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 an area of the cervix called the transformation zone (see Figure XXX, p. xxx – this is the figure we are to get from Paula). Most cervix cancers are found in this area.

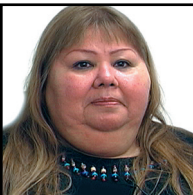
My recommendations for others? go have check-ups. The only reason I went was because I had that bladder infection. [The provider] said you better have your Pap smear test, it's been a year or two. So I did, and I'm thankful. Because I might have waited too long.

## If you have an abnormal Pap Test or symptoms

You may receive a diagnosis of precancerous disease after your Pap test. (See Table XXX, p. xxx) This means that the cells from your cervix do not look normal. These abnormal cells are not cancer. But they could become cancer if not treated. Depending on what the abnormal cells look like, your healthcare team could suggest:

1. A repeat Pap test in 4-6 months.
2. HPV testing
3. Referral for colposcopy. A colposcopy allows a closer look at the cervix.

A biopsy of any abnormal areas may be done at this time. If you are a teenager, pregnant or post-menopausal your health care team may have different suggestions for treatment.



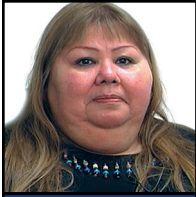
Rosanne Wyman  
[Mohawk]  
Dx 1987 Cervix

I was about 5 months pregnant with my youngest son who's 21 right now; I had my Pap smears and they were suspicious. They said I had precursors to cancer. We went through all the medical stuff. The doctor told me that I was going to have a biopsy. I got right to the point where I was on the table, and then all of a sudden he tells me, well, I'm gonna do this and this and this. This little detail that he forgot to tell me, that you might lose your baby. Well, this was no little detail to me, it had an impact on my life. I figured, ... this was going to be my last one, and I was hoping it was a girl. It was a boy and he's been the light of my life too. So, anyway, the doctor says, you might lose the baby. He says, well the baby is abnormally small anyway, if you lose it, that's ok, you can have another one! I thought, what a cold person! Was I treated like this because I am Native?



Sarah S. Allman  
[Oglala Sioux]  
Dx 1970 Cervix

I didn't have any symptoms ... I didn't know anything about cancer ... I thought it was a killer, you know. I was always so scared of that word "cancer"... I'm not even scared of that word anymore. I'm just thankful for having thirty-four years of cancer free. [paraphrased by LB]



Rosanne Wyman  
[Mohawk]  
Dx 1987 Cervix

I objected, no way, I'm not going to do that. I don't want to lose my baby, and I didn't. He got mad and refused to be my doctor. So, that was it. I had to find another doctor, to have the baby delivered. This abnormally small baby is three hundred pounds today. He weight lifts, he's about 6' tall, and is as healthy as they come. I'm glad I put my life on the line for him. He's certainly made every moment worth while. This was all from basically my spirituality, my strong faith. The belief that the Creator was going guide me in the right direction. He has.

He has guided me today and who knows where else I will end up. Just like talking today and telling you my story of a few little details of my life, hopefully out there, maybe a man, a woman, a grandparent, a child, whatever. Maybe a little phrase will catch on them, or maybe say, well hey, there's hope. She's there, she's talking, she's not a freak of nature. She doesn't look out of sorts. She's got lots of hair. It isn't all about losing your hair, and hopefully they'll take that in. Spread the word, or maybe save someone in their family... I figure I'm going to be here as long as the Creator has something for me to do. When the time comes, I don't believe I will die of cancer. I am hoping I will die of old age. I like to joke with myself saying, I think I am going to die a fat little old lady! And probably I will. My son gets to laughing at me and says, oh mom, you know how people shrink when you get older? I can see you being four by four some day.

Bleeding (not your moon/period but bleeding between moons or after sex) or a discharge can be signs of cervix cancer. If you have bleeding or a discharge and a mass is seen on your cervix during your pelvic exam, you will have a biopsy right away. This is to see if the mass is cancer. A pathologist will look at the tissue to decide. The biopsy can be done in many ways:

- ⊕ Punch biopsy – a small piece of cervix tissue is removed using a tool that looks like a small cookie cutter on a stick.
- ⊕ LEEP (loop electrosurgical excision procedure) – thin slices of the cervix are cut away using a thin wire loop that acts like a surgical knife (scalpel). An electrical current is passed through the wire loop.
- ⊕ Cone biopsy – a cone-shaped piece of your cervix is cut out using a scalpel or laser. A cone biopsy removes both precancerous and cancer cells.

### Staging your cervix cancer



Northern Plains  
female (25 years old)  
anonymous  
Dx cervix cancer 2010

My doctor told me that I probably got cervix 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.

Once a diagnosis of cervix 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 cervix cancer is important. Staging lets your healthcare team make the most informed suggestions about what is the best treatment for you. Before treating your cervix 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. Table 1 provides a brief explanation of staging for cervix cancer. Stage I is the least amount of disease. The cancer is found only in the cervix. Stage IV is the most amount of disease. It has spread to other parts of the body like the lungs or liver.



**Table 2: Cervix Cancer Staging**

Stage	Definition	5 Year Survival*
Stage I	Cancer is found only in the cervix (the staging may be labeled as Stages IA1, IA2 or IB based on local spread and size of tumor)	98% for very early disease (IA1), 75%-95% for larger tumors
Stage II	Cancer has spread to upper part of vagina or tissue around the uterus	65-75%
Stage III	Cancer has spread to the lower part of the vagina or to the pelvic wall. You may have cancer in your lymph nodes.	About 30%
Stage IV	Cancer has spread to other parts of the body and may be found in the bladder, rectum, liver or lungs	5% - 10%

### Treatment for precancerous disease and cervix cancer

Once the stage of your cancer is known, treatment suggestions are made. Your healthcare team will consider the stage of your cancer, your age, your overall health, your lifestyle, and your personal beliefs about treatment to decide what is best for you. You should take part in the discussion so that the best choice is made. Before starting treatment, you may want to get a 2nd opinion about treatment (see below). Also be sure to talk with your healthcare team about any possible side effects of your treatment. Your team can help find ways to manage these side effects.

### Precancerous disease

Treatment of precancerous disease is based on your age, desire for future pregnancies and current health status. Also considered is concern about your cancer coming back. Some women choose to have no further treatment. These women will need frequent (every 6 months or more often) pelvic exams and Pap tests. If treatment is chosen, the abnormal cells can be treated by:

Cryotherapy (also called cryosurgery): kills the abnormal cells by freezing the tissue

LEEP: (see above),

Cone biopsy: (see above)

Laser surgery: removes the abnormal cells by using a laser beam that acts as a scalpel

Simple hysterectomy: removes the cervix and uterus in those who do not want further pregnancies

Discuss these choices with your healthcare team to make the best choice for you.



Southern Plains AI woman, anonymous, dx cervix cancer at age 29

I had to have colposcopy for my cervix cancer. It didn't even hurt. And now I am fine. I get my Pap test every year and tell all of my friends that they need to do this too.


### Cervix Cancer

#### Surgery

Surgery is used for those with early stage cervix cancer. The type of surgery you have depends on many things. Among them are your stage of disease and overall health. Your team will also consider your ability to withstand surgery and your desire for future pregnancy. If you are very overweight, have risk factors like heart disease or are too ill to have anesthesia, you may not be offered surgery.


If your cancer is small and only in the cervix, only the uterus and cervix are removed. For larger tumors, surgery may remove:

1. the lymph nodes in your pelvis
2. your ovaries and fallopian tubes
3. the upper part of your vagina
4. some of the tissues around your uterus (See figure XXX, p. xxx).

	<p>I was so afraid when the provider told me that I had to have surgery to remove part of my cervix. I have not had all of the children I want to have yet. The doctor said they will stitch me up and that I can still get pregnant. When it comes time for my baby's delivery, they will cut the stitches and then after the baby is born, they will put the stitches back in again. Sounds like a lot, but it will be worth it to be able to have a baby.</p>
<p>Northern Plains female (25 years old) anonymous Dx cervix cancer 2010</p>	


**Side effects of Surgery:** All surgery has some side effects. The most common are pain and discomfort. Pain can be treated with medications. Some side effects happen right after your surgery. Some will occur much later (weeks to months). Your healthcare team can help relieve any side effects you have. See Table 2 for side effects of surgery.

**Future pregnancies:** If you have a very small cervix cancer and wish future pregnancies, a cone biopsy may be done. If there is no further sign of cancer, no more treatment is needed. You will need close follow-up. If you have a slightly larger cancer, a radical trachelectomy may be done. This surgery removes the cervix and the pelvic lymph nodes but keeps the uterus. This allows future pregnancies. You should discuss future pregnancies with your healthcare team before deciding on your treatment.

	<p>First I was in the hospital twice with radiation. Four days each time, and then after that five and a half weeks of x-ray treatments.... Later, I drove myself everyday from Longmont to Denver for my treatment. Mondays through Friday for five and a half weeks. A few times I stayed in town, because I was so sick to my stomach. It made me sick to my stomach...[the treatments would last about] one minute. One day I'd lie on my stomach. The next day I'd lie on my back. Every other day it changed.</p>
<p>Sarah S. Allman [Oglala Sioux] Dx 1970 Cervix</p>	

## Radiation Therapy (RT; radiotherapy)

RT is very useful for treating cervical cancer. RT uses high energy x-rays or other types of radiation to kill cancer cells. It can be used in both early and late stage disease. It can treat the entire area of disease, including any lymph nodes that may have cancer in them. RT may be used alone or with surgery or chemotherapy.

	<p>I was diagnosed with cervical cancer, went through the treatments, went through the surgery, went through the radiation, day after day having to go to the cancer clinic having radiation.</p>
<p>Rosanne Wyman [Mohawk] Dx 1987 Cervix</p>	

RT may be given by an external source (external beam RT) or by an internal radioactive source (brachytherapy). Sometimes both are used. External RT is given daily (Monday-Friday) for 6-8 weeks. Each treatment lasts only a few minutes and is painless. You do not have to stay in the hospital. A machine that points the radiation to a specific area of your body is used. In brachytherapy, a small container of a radioactive substance is placed in your vagina near your cervix. This kills the cancer cells nearby. Treatment may be as in a clinic or you may need to stay

in the hospital overnight or for a few days. This depends on the type of treatment you have. The container is removed when the treatment is finished. When you go home, you are not "radioactive." You should discuss which type of RT is best for you with your healthcare team.

**Side Effects of RT:** Side effects of RT depend on the dose of RT you receive and the part of your body that is treated. You can have side effects while you are being treated. They also can occur shortly after treatment is finished or weeks to months following your treatment. Some long term side effects can be prevented. Be sure to talk with your healthcare team about preventing or reducing side effects of RT. See Table 2 for side effects of RT.



Rosanne Wyman  
[Mohawk]  
Dx 1987 Cervix

Cesium insertions are a thing of the past. It caused a lot of problems for the way I am today. It's caused a lot of side effects ...Losing the kidney was due to the fact of having the cesium insertions.

## Chemotherapy



I lost some hair from chemo, but not much.

Sarah S. Allman  
[Oglala Sioux]  
Dx 1970 Cervix

Sometimes even though you had surgery or RT, there is a risk that your cancer may come back. This is because a few cancer cells remain in your body that were not removed or killed by your treatment. Chemotherapy is cancer treatment that uses drugs to stop cancer cells from growing. It may be offered to you to decrease your risk of recurrence. You may receive one or more drugs. The drugs are usually given into a vein (IV, intravenously). You may receive treatment over several weeks to months. The plan suggested for you will consider your tumor stage and any prior treatment. Your current health, lifestyle and personal wishes also will be considered.

**Side Effects of Chemotherapy:** Chemotherapy side effects are common. Some people will have many and others will have a few or none. Side effects may start within hours of your treatment or happen days to weeks later. Some side effects, such as nausea, can be prevented with medications. Most chemotherapy side effects last only a short time and then go away. Others may last a month or more after your treatment is done. Be sure to talk with your healthcare team about how to prevent or lessen these side effects. See Table 2 for side effects of chemotherapy.

**Table 3. Side Effects of Cervical Cancer Treatment**

Side Effect	Surgery		Radiation Therapy		Chemotherapy	
	Early	Late	Early	Late	Early	Late
Nausea/Vomiting	X		X		+/-	
Pain	X					
Fatigue	X		X	X	X	X
Early menopause	X			X		X
Diarrhea			X			
Constipation				X		
Altered fertility	+/-			X		+/-
Lymphedema		X		X		
Vaginal shortening/narrowing		X		X		
Decreased vaginal lubrication			X	X		
Anemia					X	
Easy bleeding/bruising					X	
Increased risk of infection					X	
Skin changes (redness, thickening)			X	X		
Mouth sores					X	
Urinary difficulty/frequency	X	X	X			
Changes in sexual function			X	X	X	+/-

Early = side effect occurs during or right after treatment  
 Late = side effect occur weeks to months after treatment  
 X = side effect is common for this treatment  
 +/- = Side effect may occur; side effect may be prevented

## **Clinical Trials**

Research to find the best treatments for cervix cancer is important. Many cancer centers carry out clinical trials to test new treatments against those used today. These are done to be sure that new treatments are safe and useful for cervix cancer. Clinical trials may look at new ways to do surgery or give RT or test new chemotherapy drugs. Sometimes new combinations of treatments are used. Taking part in a clinical trial may be one of your choices for treatment. You should talk with your healthcare team about whether a clinical trial is right for you.

## **Advanced Disease or Recurrence**

Treatment for advanced disease (Stage IV) or cancer that recurs is more extensive than treatments for earlier stage disease. Advanced disease has spread to other parts of the body. Recurrent disease has come back after treatment. People with advanced disease or recurrence usually are treated with more than one therapy. Surgery or RT is given to manage cancer in the pelvis (called local disease). Chemotherapy will be given to manage disease that has spread to other parts of the body. A clinical trial may be suggested as well.

## **What's New in the Treatment of Cervix Cancer**

Healthcare providers are always looking for new ways to treat cancer. They hope to find treatments that remove less tissue, take less time or have fewer side effects. These new treatments need to still have the same possibility of long term survival. The main treatments for cervix cancer are surgery and RT. Chemotherapy is added for more advanced disease. But new methods of giving these treatments are being evaluated.

New surgical techniques include the use of robots to hold surgical instruments. These instruments bend and turn once inside the body. They have small cameras that let the surgeon see inside without making a large incision. A small incision means less time to heal, less pain and smaller scars. In addition, new surgical tools and improved surgical techniques let your surgeon complete the operation in less time with same quality results.

RT has been improving over the last 10 to 15 years. Treatment planning is better at locating the exact site and extent of your tumor. Then the Radiation Therapist knows right where to focus the beam or place the radiation source. New RT machines focus the radiation beam right where it is needed to kill the tumor. This means that the tumor is killed but normal, healthy tissue is not seriously injured. New treatment called tomotherapy combines CT scanning with RT. Rather than treating one area the same for the whole treatment, the treatment is focused only on remaining tumor. The exact area to be treated changes as the tumor becomes smaller. Treatment length may be less and gastrointestinal (diarrhea and feeling sick to your stomach) and sexual (vaginal dryness and soreness) effects will be less. For brachytherapy, treatment is again combined with the use of CT scanning. Higher doses can be used and treatment is targeted to exactly where it is needed.

Chemotherapy is most often used for women with recurrent disease or those at high risk for recurrence. New drugs are becoming available that target tumor cells and have fewer side effects. In addition, new ways of combining chemotherapy with other treatments are being used to decrease the chance of recurrence (Stages IIA-IVA). Researchers also are looking at treatments that kill HPV-infected cells. These could be used to treat precancerous lesions before they become cervical cancer.

Many clinical trials are being used to find even better ways to treat cervix cancer. These clinical trials test new surgical methods and equipment and new machines and methods to give RT. In addition, they test new chemotherapy drugs and combinations of therapy. The goal is to find the best way to treat your cervix with the least amount of side effects. The next 5 years will have many new advances.

## **Cervix Cancer during Pregnancy**

Some women are diagnosed with cervix changes while pregnant. For most women the diagnosis is precancerous disease. For a small number of women, the diagnosis is cervix cancer. Often the diagnosis is made when the woman goes to her OB/GYN for her 1st pregnancy visit. Others may be diagnosed later in pregnancy. If the Pap test shows abnormal cells, a colposcopy will be done. The results of the colposcopy will decide further treatment. For some women a LEEP can be done and full treatment delayed until after the birth. If you are pregnant, it is important to see your doctor right away and have a Pap test. If you are diagnosed with cancer during your pregnancy, your healthcare team will discuss the options for treatment with you.

## Getting a 2nd Opinion

You might want to get a 2nd opinion from another provider before deciding on treatment. Your provider will not be upset if you decide you want to. Most insurance companies will pay for a 2nd opinion. Be sure to check. During the 2nd opinion, the 2nd provider may agree with your 1st's treatment plan. Or a different plan may be suggested. You will need your medical records and information about your cancer. The delay in starting treatment while you have a 2nd opinion will not usually hurt you. Talk with your healthcare team about any delays and to get the name of a specialist for your 2nd opinion.

## Follow-up appointments and testing

After you finish your cancer treatment, your healthcare team will want to see you regularly. This is to make sure you are feeling well. They also will check on how you are managing any side effects from your treatment. Most importantly, they want to make sure your cancer has not come back. In the beginning you will have frequent (monthly) follow-up appointments. The time between appointments will lengthen the longer you show no signs your cancer has come back. Your follow-up plan will fit your disease and treatment. It is important that you make every appointment and have the tests ordered for you.

## References

1. Cervical cancer. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001895/>
2. Cervical cancer. Retrieved from <http://www.medicinenet.com/script/main/art.asp?articlekey=318>
3. Cervical Cancer Treatment (PDQ®). Retrieved from <http://www.cancer.gov/cancertopics/pdq/treatment/cervical/Patient/page1>
4. Cervical Cancer- Topic Overview. Retrieved from <http://www.webmd.com/cancer/cervical-cancer/cervical-cancer-topic-overview>
5. Cervical Cancer – Surgery. Retrieved from [http://www.emedicinehealth.com/cervical\\_cancer/page9\\_em.htm#Surgery](http://www.emedicinehealth.com/cervical_cancer/page9_em.htm#Surgery)
6. Cervical Cancer- Medical Treatment. Retrieved from [http://www.emedicinehealth.com/cervical\\_cancer/page8\\_em.htm#Medical%20Treatment](http://www.emedicinehealth.com/cervical_cancer/page8_em.htm#Medical%20Treatment)
7. Cervical Cancer Treatment Overview. Retrieved from <http://www.webmd.com/cancer/cervical-cancer/cervical-cancer-treatment-overview>
8. Cervical cancer: The Basics. Retrieved from <http://www.oncolink.org/types/article.cfm?c=6&s=17&ss=129&id=8226&CFID=25127027&CFTOKEN=49484136>
9. Greer, B.E., et.al. (2010) Cervical Cancer: Clinical Practice Guidelines in Oncology. JNCCN, 8, 12, 1388-1416.
10. Krebs, L.U. (2010). Sexual and reproductive dysfunction. In: C.H. Yarbro, D. Wujcik & B. Holmes Gobel (Eds.) Cancer Nursing: Principles and Practice (7th. Ed., pp. 879-911). Boston: Jones & Bartlett.
11. Loop Electrosurgical Excision Procedure. Retrieved from [http://www.acog.org/publications/patient\\_education/bp110.cfm?p](http://www.acog.org/publications/patient_education/bp110.cfm?p)
12. Phelps, C.K. & Peteret, D.G. The role The Role of Transabdominal Ultrasound in Facilitating Successful Brachytherapy Outcomes in Cervical Cancer (in review)
13. Understanding cervical changes: A health guide for women. Retrieved from <http://www.cancer.gov/cancertopics/understandingcervicalchanges/page1>
14. Understand cervical cancer: A woman's guide. Retrieved from <http://www.innovations.ahrq.gov/content.aspx?id=1021>
15. Alcorn, K. HIV drug could lead to new cervical cancer treatment. Retrieved from <http://www.aidsmap.com/HIV-drug-could-lead-to-new-cervical-cancer-treatment/page/1785622/>
16. Downs, L. (2011). Advances in cervical cancer treatment. Gynecologic Oncology, 123:431-433.
17. Monk, B.J. & Willmott, L. 2010. Treatment of early-stage cervical cancer. Retrieved from [http://www.clinicaloptions.com/inPractice/Oncology/Gynecologic\\_Cancer/ch28\\_Gyn-NonOvarian/Pages/Page%202.aspx](http://www.clinicaloptions.com/inPractice/Oncology/Gynecologic_Cancer/ch28_Gyn-NonOvarian/Pages/Page%202.aspx)
18. Monk, B.J. & Willmott, L. 2010. Treatment of locally advanced cervical cancer. Retrieved from [http://www.clinicaloptions.com/inPractice/Oncology/Gynecologic\\_Cancer/ch28\\_Gyn-NonOvarian/Pages/Page%202.aspx](http://www.clinicaloptions.com/inPractice/Oncology/Gynecologic_Cancer/ch28_Gyn-NonOvarian/Pages/Page%202.aspx)
19. Monk, B.J. & Willmott, L. 2010. Treatment of metastatic or recurrent cervical cancer. Retrieved from [http://www.clinicaloptions.com/inPractice/Oncology/Gynecologic\\_Cancer/ch28\\_Gyn-NonOvarian/Pages/Page%202.aspx](http://www.clinicaloptions.com/inPractice/Oncology/Gynecologic_Cancer/ch28_Gyn-NonOvarian/Pages/Page%202.aspx)
20. Klopp, A.H. & Eifel, P.J. (2011). Chemoradiotherapy for 2010. Clin Oncol Rep, 13:77-85.



# Painted Feathers *by Peg Fennimore*

Peg is a sixth generation Eastern Band Cherokee (Tsalagi) and uses her heritage and the spirits of the animals she portrays as the 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 that you like and get good acrylic paints. Acrylic paints can wash off or streak 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 usually 10 layers 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 very 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 is usually dries in a couple of hours.



It is said that, "When you are creating something, is when you are the closest to God."

# Cervix 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-uhl**)) is not the same as cervix 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 the treatment of choice for tumors that have spread or have a high potential of spreading or recurrence.

**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:** 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 determining if the symptoms or evidence of cancer is really cancer.

**Dysplasia (dis-PLAY-zuh):** 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 cervix cancer. HPV may cause other types of cancer (anal, vaginal) as well.

**Human Papillomavirus Vaccine:** A vaccine that helps prevent 70+% of cervix 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.



# Cervix 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.

**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.

**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 Cervix 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.

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## 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.

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## 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.

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## 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 Cervix 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 NNBCPP 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.

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## 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.

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## 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.

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## 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.

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## Winyan Wicozani – Healthy Women

### Cheyenne River Sioux Tribe BCCEDP

PO Box 590 - Field Health Bldg.  
317 Main Street  
Eagle Butte, SD 57625  
Phone - 605-964-8921  
www.sioux.org



**Summary of services:** Breast & Cervical cancer screening services are offered to eligible women ages 18 to 64 residing in Dewey and Ziebach counties. Transportation assistance is available if needed to high risk women ages 30 to 39. Our program is committed to eradicating breast cancer. We advocate early detection, prevention through yearly screenings and offer a variety of educational services to our clients and communities.

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## 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.P.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.

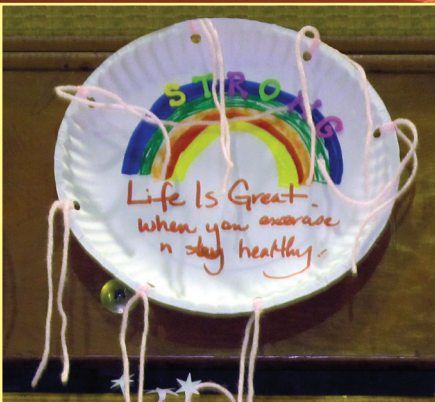
Both men and women wore special pink shirts to celebrate Women's Health Week and their theme, "Empowering Women to Stay Healthy: It's your time." They decorated "masanpi's" or paper plates with messages about what it takes to be healthy. Men decorated headbands with their statements to encourage healthy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



## Hopi Women's Health Program

