

wise words

HPV and HIV

human Papillomavirus (HPV) is the most common sexually transmitted infection in the United States, and most people appear to be exposed to the virus shortly after their first sexual experience. Similar to other gynecological conditions, HPV infection is detected more frequently, is more persistent and is more difficult to treat in women living with HIV compared to HIV-negative women. Regular monitoring is the best way to ensure that any problems are detected and treated as soon as possible. This article will highlight some of what is known about HPV and HIV.

HPV is very easily transmitted from person to person, and condoms cannot prevent HPV transmissions as warts around the genital area may shed virus to skin that is not protected by a condom. In most cases, HPV-related disease (genital warts or a pre-cancerous condition called *dysplasia*) may not develop at all or take years or decades to develop. In addition, the risk of recurrence after treatment is low, suggesting in general that HPV treatment is effective. As with most viruses, however, even when an HPV-related condition isn't present (like when warts respond to treatment and go away), a person still has HPV infection. It's possible that warts or other HPV-related conditions can come back and/or it's possible to transmit HPV to others.

People living with HIV and others with compromised immunity are more at risk for HPV-related complications. Women living with HIV tend to have multiple types of HPV (which is associated with a greater risk of HPV-related disease), are less likely to clear HPV-related conditions (like when warts are more difficult to treat and less likely to go away) and are more likely to progress to HPV-related disease (such as warts progressing to dysplasia.)

One study looking at HPV infection in both HIV-positive and -negative women suggests that HIV may be activating dormant HPV and thus increase the risk of HPV-related disease. Immune suppression decreases the body's ability to keep HPV in check. This link was recognized well before the HIV epidemic. In the case of HIV, as HIV progresses, the ability of the immune system to control HPV infection is reduced. This can result in higher levels of HPV and the development of HPV-related disease.

CD4+ cell count is a marker of immune health, and HIV viral load is an indicator of how active HIV is in the body. Both of these lab tests provide information for people living with HIV to monitor their health. Studies have found links between HPV-related disease, CD4+ cell counts and HIV viral load in women living with HIV. As the CD4+ cell count declines and/or HIV viral load rises above 10,000 copies, women are at higher risk for having abnormal Pap smear results and developing HPV-related disease.

Having high levels of HIV (greater than 10,000 copies) has also been linked with abnormal Pap smears and the development of HPV-related disease. More specifically, high levels of HIV have been linked to high-grade dysplasia and cervical cancer (see article on page 3 for a description of *grades* of HPV-related disease). Taken together, what this

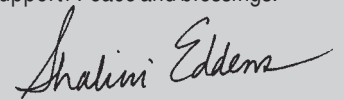
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Greetings Wise Women!!

Welcome to another issue of Wise Words. This issue contains some very helpful information about Human Papillomavirus (HPV). HPV is a major concern for women living with HIV. Consistent and early gynecological screening and treatment are essential in managing your health, and this is particularly true in detecting HPV and HPV-related conditions (anogenital warts, precancerous conditions and cervical and anal cancer). In the Policy Section of Wise Words is information about Medicaid, which is currently under significant stress and pays for the healthcare of many women living with HIV. Finally, a greeting from Project Inform's new Hotline Associate, Kris Star, tells us a little more about the Hotline and information that may be valuable to you and/ or the women you work with.

We hope this issue of Wise Words will be informative and useful. As always, if you have comments, suggestions or questions, please contact me at wise@projecinform.org.

Thank you for your consistent support! Peace and blessings.



Shalini Eddens
Program Manager, Project Wise

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Wise Words
is a program of



HPV and HIV, *continued*

information tells us is that keeping the immune system healthy and HIV under control may be useful in preventing the development of HPV-related disease.

The goal of anti-HIV therapy is to keep the level of HIV as low as possible and increase the CD4+ cell count to at least above 200 and preferably much higher. The data on the impact of anti-HIV therapy on the development and persistence of HPV related disease is conflicting. Some studies have found a regression in HPV related disease, while others have found limited or no regression. The limitation of many of these studies is the time frame of the study and the length of time the participants have been on anti-HIV therapy. One study, called the Women's Inter-agency HIV Study (WIHS), is looking more carefully at the impact of anti-HIV therapy on HPV-related disease and more information is expected in the future.

What we do know is that HIV-positive women may face challenges when they are treated for HPV-related disease. HIV-positive women may respond poorly to the standard treatment for HPV-related disease and as a result may need multiple treatments using different methods.

THE BOTTOM LINE

Work with your doctor in developing a strategy to monitor and manage *both* your HIV and HPV infection. Optimally this will include regular visits—including laboratory monitoring of your CD4+ cell count and HIV levels—with your doctor to monitor and track your immune health as well as routine GYN screening and care from a gynecologist who knows about HIV. Working with your doctor to develop an individualized strategy that suits your lifestyle and needs is the key to living longer and healthier with both HPV and HIV.



For more information about HPV and medical screenings, read Project Inform's publication, *GYN Conditions in Women with HIV*, available toll-free at 1-800-822-7422 or www.projectinform.org.

human papillomavirus: the basics

human Papillomavirus (HPV) is a common sexually transmitted virus that causes abnormal growth of tissue on the feet, hands, vocal cords, mouth, anus and genitals. There are over 70 types (strains) of HPV and it is possible to have more than one strain at one time. In women, HPV can grow on the cervix, vagina, vulva, urethra, and/or anus. Genital and anal HPV can cause two kinds of abnormal tissue growth: genital warts and cervical dysplasia.

GENITAL WARTS (CONDYLOMA ACUMINATA)

When genital warts first appear, they may be small pink or red bumps on the vulva, cervix, or anus or immediately surrounding skin. They are usually painless, but may cause itching, burning or slight bleeding. Genital warts can be found on the urethra, anus, inside the vagina, or on the cervix.

Genital warts can be frustrating to treat, as some will disappear on their own, while others may not, even with treatment. There is no magic treatment for genital warts, and several methods may be tried depending on where, how large and how many warts have been there. Early detection and treatment is important as it makes it easier to get rid of warts. Over-the-counter gels and creams for treating genital warts are generally not recommended.

CERVICAL DYSPLASIA

Dysplasia or lesions refers to abnormal changes in the size, shape or appearance of cells that line the cervix. Changes to the cells can range from mild to severe. Although dysplasia is not cancer, if left untreated it can turn into cancer. Dysplasia is found mostly on the cervix, but can also be on the vagina or vulva and usually there are no symptoms.

DIAGNOSIS AND SCREENINGS

Early diagnosis is important in treating HPV-related conditions, especially since they often do not have obvious signs or symptoms. Therefore, routine screening is critical to getting early treatment. There are several types of screening methods, described below.

PAP SMEAR: This is a test in which a doctor will collect cells from your cervix or anus. A Pap smear can detect any inflammation, and in most cases predict abnormalities in cervical cells. For women living with HIV, if your CD4+ cell count is below 300 or has been dropping, it is suggested that you have a Pap smear every six months. If you have an abnormal Pap smear, further evaluation with a *colposcopy* is suggested.

ANAL PAP SMEAR: An anal Pap smear is like the cervical Pap smear, the cells are collected from the anus. If any abnormal cells are found, an anoscope (similar to a colposcope—see *Colposcopy*) is used to look inside the anal canal.

Many providers have limited or no experience with anal Pap smears. In addition, anal Pap smears are not a routine part of the standard gynecological exam. As a result, anal Pap smears are often not done. Talk with your doctor about a specialist who is able to do an anal Pap smear.

We can advocate for doctors to attend trainings on anal screenings. As positive women are living longer with HIV, consistent and quality healthcare is critical. It is important that we advocate for medical procedures such as anal Pap smears to become routinely available components of HIV care.

COLPOSCOPY: A solution of diluted vinegar is applied to the cervix/ anus to remove the mucus and highlight the abnormal cells. Using a light and an electric microscope (called a colposcope, or anoscope if they're looking at anal tissue), the doctor can look at the tissue closely. The vinegar makes the abnormal cells white and the normal cells appear pink. Lesions, warts and inflammation are usually visible during the colposcopy, however it is difficult to determine if the changes are mild or severe. If abnormal cells are seen a biopsy is usually done.

BIOPSY: A small amount of tissue is taken from the area where abnormal cells are found. A biopsy can tell the difference between a mild lesion and a severe lesion. A biopsy can be uncomfortable and

painful. Some women experience mild bleeding after the procedure. There are several types of biopsies, explained below.

- **Cervical and Anal Biopsy:** This is the standard biopsy. A small pair of forceps is used to remove a sample of the abnormal tissue from the cervix or anus. More than one sample may be taken, depending on the amount of tissue detected by the colposcopy/anoscopy.
- **Endocervical Cutterage:** This procedure is done if a doctor is unable to determine if there is abnormal tissue beyond the cervix. A small spoon shaped instrument called a curette is used to remove the cells. The procedure takes 10–15 minutes and may cause cramping.
- **Dilation and Curettage (D&C):** If abnormal cells are found beyond the cervix, a D&C will be conducted. Abnormal cells from the cervical canal and lining of the uterus are removed. A local anesthesia will be administered and the procedure may cause cramping and spotting.

READING THE PAP SMEAR RESULTS

There are two methods that have been used to read the results from Pap smears. Most labs use the Bethesda System. Results are divided into categories based on the changes in the size and shape of the cells. Some labs may use another system to report the results called the Cervical Intraepithelial Neoplasia (CIN) System. In this system the degree of cell abnormality is assigned a number. Below is a chart explaining what the results for the Bethesda and CIN Systems mean.

Bethesda System	CIN System	What does this mean?
Negative for Squamous Intraepithelial Lesions or Dysplasia	Not Applicable	There are no abnormal cell changes detected.
Atypical (unusual) Squamous Cells of Undetermined Significance (ASCUS) <i>ASC-H is a new category added which means atypical squamous cells and high-grade lesions cannot be ruled out.</i>	Atypia	There may be inflammation in the cervix; however, it cannot be determined if the cells are normal or abnormal. Suggest follow-up with a colposcopy.
Low Grade Squamous Intraepithelial Lesions (LSIL)	CIN I	Mild cell abnormalities (<i>dysplasia</i>) are present on the surface of the cervix. For women living with HIV, treatment is not considered standard; however, careful monitoring is strongly suggested.
High Grade Squamous Intraepithelial Lesions (HSIL)	CIN II/ CIN III	Moderate to severe dysplasia and/ or precancerous lesions. Treatment is recommended.

Treating HPV

The success rate of treating HPV in women living with HIV has been inconsistent. For the treatment of genital warts, there is a higher rate of recurrence after therapy. As a result more frequent and costly treatment and follow-up is required and can be a source of frustration. For treating dysplasia, the effectiveness has been shown to be dependent on the level (high or low grade dysplasia). Low grade dysplasia may or may not progress and can be a chronic condition. However, if a woman has a low CD4+ count and high HIV viral load, she may be at a higher risk for developing high grade dysplasia. So, in this case, a doctor may recommend treatment for low grade dysplasia. For women with high grade dysplasia, treatment is strongly recommended, however may not always be effective.

Screening, monitoring and managing HPV infections are crucial for women living with HIV. While there is a lack of consensus in the medical community for treatment and management of HPV infection, there is an effort to establish guidelines to better serve women living with HIV. The Centers for Disease Control (CDC) recommends HIV-positive women receive two Pap smears a year within the first month of diagnosis. If the results are abnormal, colposcopy or biopsy is suggested.

HUMAN PAPILLOMAVIRUS TREATMENT CHART

Treatment/ procedure	What is it?/ How does it work?/ How to use it?	Used for ...
Podofilox	A solution or gel that chemically damages the warts is applied. Using a cotton swab for the gel or your finger for the solution, apply to the visible warts twice a day for 3 days, followed by 4 days of no therapy. Can be repeated for up to 4 cycles.	Genital warts
Imiquimod	A cream that stimulates immune responses against warts. Apply cream once daily at bedtime, 3 times a week for up to 16 weeks. Wash area with soap and water after 6-10 hours after application.	Genital warts
Podophyllin resin	A brownish and yellowish chemical that is applied directly to the affected area and allowed to air-dry. This chemical will damage the warts.	Genital warts
Trichloroacetic (TAC) or Bichloroacetic acid (BCA)	Chemicals that destroy the warts by burning them. A small amount is applied only to the warts and allowed to dry. The warts will turn a white color, shrink and then disappear. Can be repeated weekly and may require multiple treatments.	Genital or anal warts
Cryotherapy or Cryocauterization	Liquid nitrogen is applied to affected area using an instrument called a cryoprobe. Liquid nitrogen freezes and kills the abnormal cells. Can be repeated every 1-2 weeks. Cryocautery uses an electric probe to burn off the abnormal cells.	Genital or anal warts; cervical or anal dysplasia
Interlesional interferon	Applied as cream or injection. Interferon triggers your immune system to fight infection. Interferon may be applied directly to genital warts as a cream or injected into the warts and the skin surrounding them. May require multiple treatments.	Genital warts
Laser vaporization or ablation	A high intense light stream is used to kill abnormal cells.	Cervical or anal dysplasia
Electrocauterization	LOOP Electrosurgical excision procedure (LEEP) uses a small wire, which has an electric current running through it, to burn or destroy the abnormal tissue.	Genital or anal warts; cervical or anal dysplasia
Cone Biopsy	A cone biopsy is used to both diagnose and remove abnormal tissue. A cone shape tissue sample is removed from the cervix. This is an in-patient procedure; however, a general or spinal anesthesia is usually recommended. The tissue that is removed is sent to the laboratory for examination. If dysplasia is found, no further therapy is needed (assuming that all affected cells have been removed). If cancer is found, additional treatment may be recommended.	Cervical or anal dysplasia

HPV TREATMENT CHART

continued ...

Patient applied/ provider administered?	Special Considerations
Patient applied	Not recommended for use during pregnancy.
Patient applied	Not recommended for use during pregnancy.
Provider administered	May cause a burning sensation as it dries. The solution can be absorbed into the body and can cause side effects. Thus, some providers may thoroughly wash off the solution 1–4 hours after application.
Provider administered	May cause a burning sensation.
Provider administered	May require multiple treatments. May experience some pelvic pressure or menstrual like cramps during the procedure. May cause cervical scarring, which may make the cervix difficult to see during exams. Because of the heavy water loss from this procedure, drink lots of fluids.
Provider administered	Usually used if other treatment methods have failed.
Provider administered	Laser vaporization can cause some cervical scarring although less than cryosurgery. Procedure is done in the hospital under general or local anesthesia.
Provider administered	A local anesthetic may be used and you may experience mild cramping for up to 24 hours after the procedure.
Provider administered	Usually done for high grade dysplasia, recurrent dysplasia, and suspected cancer.

Pregnancy

Genital wart removal is recommended during pregnancy. Specific types of HPV (6 and 11) can be transmitted to infants and children causing respiratory problems.

Please note that Podofilox, Imiquimod and Podophyllin are not recommended for use during pregnancy as they are absorbed by the skin and may cause birth defects in the baby.

Things to keep in mind after surgical procedures:

- You may have a slightly odorous watery and/or bloody discharge for several weeks after procedure. You can wash the labia (vaginal lips) with warm water several times throughout the day and use sanitary pads not tampons.
- Avoid intercourse or douching for at least 3 weeks following the procedure. (Note: douching is generally not recommended, ever, as it can worsen—and may cause—GYN conditions.)
- Can use Tylenol or Advil as needed for pain relief.

Contact the provider if any of these occur:

- Unusual heavy vaginal bleeding
- Bad smelling discharge
- Fever or Chills
- Abdominal Pain

Treatment for Cervical Dysplasia

The treatment for cervical dysplasia depends on several factors including:

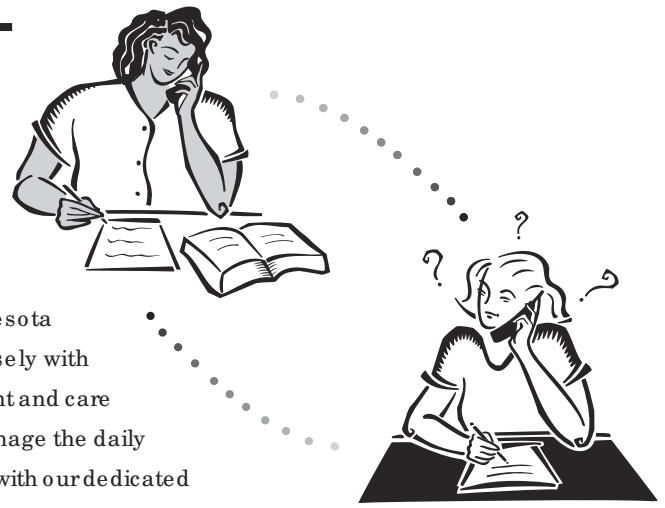
- The severity (mild, moderate, or severe dysplasia)
- the presence of HPV
- Risk factors (including smoking or an untreated sexually transmitted disease)
- Your choice/preference

NOTE: Cervical and anal dysplasia can return after treatment. Recurrence may be more likely if you have higher HIV levels.

Keep in mind that the treatment is to get rid of the abnormal tissue, not the virus. This means that the virus is present in your body and the abnormal cells can come back even after treatment. For women living with HIV, genital warts are more likely to reoccur after treatment.

my name is Kris Starr and I am the Hotline Associate for Project Inform's toll-free National HIV/AIDS Treatment Information Hotline. I arrived in San Francisco in December 2001 and started at Project Inform in May 2002.

Previously, I worked as a Community Educator at the Minnesota AIDS Project in Minneapolis. My job allows me to work closely with numerous hotline volunteers answering people's HIV treatment and care questions. I'm delighted to play a role in this program and manage the daily responsibilities of running a national HIV/AIDS hotline. Along with our dedicated staff, I work hard to keep our highly trained volunteer operators (close to 50 people) updated on HIV treatment- and care-related information and issues.



January 2003 marked the 18th year of Project Inform's commitment to providing free HIV treatment and care information through our national hotline. Sometimes talking to people about your health, especially concerns about HIV, can be challenging. A person may feel intimidated and frustrated when trying to get a doctor or other medical provider to answer her HIV treatment questions. It is not uncommon for people to feel they should already know the answers to their questions or know where to find the answers themselves. Our hotline operators (many of whom are living with HIV themselves) take these feelings and concerns seriously and are committed to empowering callers to take steps to actively participate in their own healthcare.

Through our national Hotline a caller may obtain written treatment information and health charting tools, referrals to HIV care and social services in your area and assistance from a highly trained volunteer or staff member to help you formulate your *own* answers about treating HIV.

What can Project Inform's toll-free Hotline do for you?

Just found out that you're HIV-positive or thinking about HIV treatment for the first time?

- Our volunteers can provide information about HIV disease, when to start treatment and how to choose among the various treatment options. Having this knowledge makes it easier for you to participate in decision-making with your doctor.
- We can also provide discussions with tips on how to develop a relationship with a doctor and how to develop a strategy for managing HIV for the long-term that meets your needs.

Did you hear something on television, or the radio, or read something in the newspaper or a magazine about a new treatment for HIV and you want more information?

- Project Inform provides accurate information and commentary on the latest discoveries in HIV and what they mean (or might not mean) for people living with HIV.

Are you having a difficult time taking the therapies that your doctor prescribed or want more information about them?

- Project Inform provides information and tips to help you improve your adherence to sometimes difficult medication schedules or how to find alternatives that might be easier for you to live with.
- The Hotline can also provide you with information about the possible side effects of therapies you're taking, as well as ways of coping with them.

Regardless of whether you decide to take anti-HIV therapies right now, the first step to making an informed decision about treatments is learning about them. Project Inform is a great resource for you. Perhaps the most important second opinion you can seek about your treatment decisions is your own. Project Inform is here to answer your questions and provide you with information to help you be an active participant in your choices about HIV treatment today and the future.

You can call the Hotline at 1-800-882-7422 and ask questions about living with HIV, request information on HIV treatment options or tools, and learn about the HIV care and services available in your community. The call is free and will not appear on your phone bill.

**Project Inform's toll-free
National HIV/AIDS Treatment Information Hotline**
Monday–Friday: 9am–5pm (P.S.T.)
Saturday: 10am–4pm (P.S.T.)

Understanding anti-HIV treatments is an important part of HIV care. Knowing how to get the best possible healthcare services is equally important, but often difficult and sometimes overlooked. Getting good healthcare starts with understanding your options.

In this article, we will focus on Medicaid because so many (more than 50% of people living with AIDS and 90% of children) rely on it. It is a comprehensive healthcare program, meaning that it offers the majority of important medical benefits. However, it can also be one of the more difficult programs to understand and use.

Medicaid is a federal and state program serving low-income people who qualify through certain categories. Most people with HIV/AIDS qualify through the disability category or linkage with Temporary Aid to Dependent Families (TANF). Although the overall program is administered by the federal government, the states decide most of the specifics, including optional benefits, managed care or fee-for-service, income and eligibility criteria and other important issues. Therefore, qualification and benefits vary state by state. Significantly, with the exception of those living in Massachusetts and New York, people who don't meet the social security definition of disability and who haven't qualified for TANF can't get Medicaid, even if they have HIV disease and meet the income and asset requirements.

Most of the concerns about Medicaid can be summarized by one woman's comment: "It's not enough." Sometimes this is true because your state Medicaid doesn't offer all the benefits you need and sometimes, although the benefits exist, people aren't aware of them or able to easily access them.

Very few people think about their healthcare coverage unless they need to use it. Usually that means you are sick or worried about your health, which may make it even more difficult to figure out your rights and benefits. Consider getting help rather than trying to navigate the system on your own. There are several ways to find help.

If you have a medical provider you trust, she or he may be your best advocate. Many Medicaid providers are experts at getting what their patients need. Others may not have the time or the expertise to help. Talk to



your provider about problems with your healthcare coverage and don't be afraid to ask for assistance.

One of the challenges can be finding a qualified medical provider who takes Medicaid, because the program pays very little for patient care. Currently, the best way to find a good provider is probably word of mouth. If you don't have friends or family members to consult, contact your local AIDS service organization (ASO) or call Project Inform's Hotline. Although most organizations won't give specific referrals, many have lists or websites that can be helpful. The American Academy of HIV Medicine maintains one helpful web site (www.aahivm.org). Some ASOs run support groups focused on care and treatment issues where people often share information about providers.

Benefits counselors and case managers are often a good source of information about your state Medicaid and medical benefits. Check with your local ASO organization and/or Project Inform's Hotline for assistance in locating a benefits counselor or case manager. Finally, talking directly with your state Medicaid can sometimes be helpful. The Access

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Project (212-260-8868, NY state: 800-734-7104 or www.atdn.org) maintains state-by-state listings of Medicaid contacts. Project Inform hotline operators can access this information for you as well.

Your Medicaid benefits and protections are decided by elected and appointed officials in Washington, DC and your state capital. Their decisions can protect, expand or limit access to care and determine who qualifies for the program. Most states and the federal government are experiencing budget problems. It is very likely that Medicaid services will be targeted for cuts. Decision-makers may start instituting co-payments (the amount of money you pay out of pocket) for services, cutting back on certain benefits and mandating that more people enter into managed care. You can make a difference in how these decisions are made. Check with your local ASO to see if they are monitoring the Medicaid program and how you can be involved as an advocate. Since many of the decisions regarding changes to the program are made at the state level, you can write a letter to your state elected representatives stressing the importance of Medicaid to you and/or those you know. For assistance with contact information and letters, email Treatment Action Network (TAN) or call the public policy department at Project Inform (TAN@projectinform.org or 415-558-8669 x224).

Additionally, a proposed federal law called the Early Treatment for HIV Act (ETHA) would make it easier



for states to expand their Medicaid programs to serve low-income people living with HIV who don't currently qualify. It needs co-sponsors in both the House and the Senate, particularly Republican members. If you would like to advocate for this important step forward in improving Medicaid and HIV care, contact Project Inform's TAN at TAN@projectinform.org.

Medicaid is an important healthcare safety net for millions of Americans. It is perhaps most important for low-income people who face chronic or life-threatening diseases like HIV. It is also one of the most vulnerable healthcare programs because there are few politicians who actively work to protect and expand healthcare, particularly for low-income individuals. Your advocacy, whether it is on behalf of your own or a loved one's benefits, or pushing your state to expand Medicaid to serve more people makes a difference. It can go a long way towards ensuring that the program is a strong healthcare provider for those who most need it.

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